

Long-term follow-up (LTFU) clinic (oncology and haematology)

Information for children, families and carers

This factsheet explains what the long-term follow-up (LTFU) clinic is and what will happen at your child's appointments, so you know what to expect. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

What is the long-term follow-up (LTFU) clinic?

The LTFU clinic is a specialist clinic held at University Hospital Southampton NHS Foundation Trust that provides long-term follow-up care for children and young adults who have had treatment for cancer. This includes all types of cancer (for example, cancers of the blood, brain and other organs).

It offers ongoing and regular check-ups to monitor any health concerns that may have been caused by your child's cancer or their treatment for cancer.

Your child's consultant (specialist doctor) will refer your child to the LTFU clinic approximately three to five years from the end of their treatment.

Why does my child need long-term follow-up care?

Chemotherapy, radiotherapy and surgery are important treatments for a number of cancerous and non-cancerous childhood conditions and many children's lives are saved as a result of them. However, these treatments can sometimes cause problems in the future. These problems (also known as 'late effects') can develop years after the original treatment was given.

By having regular appointments in the LTFU clinic, we are able to detect and treat any problems as early as possible.

Who are the LTFU team?

Our LTFU team is made up of a number of specialist healthcare professionals, including:

- a consultant (this may be the consultant who was previously treating your child, or it may be a different consultant)
- a late effects clinical nurse specialist (CNS). Your child's CNS will be your main point of contact. They will arrange any necessary tests for your child and will answer any questions you may have outside of clinic appointments.

The following specialists may also be involved in your child's care:

- an oncology consultant
- a clinical psychologist
- an endocrine consultant (a doctor who specialises in diagnosing and treating disorders of the endocrine system)
- a teenage and young adult lead nurse

How will the LTFU clinic support my child?

During your child's clinic appointments, we will provide you with information and advice about:

- your child's initial diagnosis
- the treatment your child received (for example, surgery, chemotherapy, radiotherapy or a combination of treatments)
- the possible late effects your child may experience
- how to lead a healthy lifestyle

Regular LTFU clinic appointments will help your child:

- become more independent
- be more knowledgeable about their treatment journey
- understand why they need long-term follow-up and the importance of attending appointments
- prepare to move from yearly follow-up appointments to patient initiated follow-up (PIFU)

Where will the appointments be held?

Your child's first LTFU clinic appointment will be held on the Piam Brown ward at Southampton Children's Hospital. After this, your child's clinic appointments may be face to face at Southampton Children's Hospital (or your child's local hospital if appropriate) or held via video or telephone. Please see your child's appointment letter for more details.

How should I prepare my child for their appointment?

We will contact you a month before each of your child's appointments to arrange any necessary tests. It is important that we have up-to-date contact details for you, including your mobile number, email address and home address. **Please update us if anything changes.**

What will happen during the appointment?

At the start of the appointment, we will measure your child's height and weight and take their blood pressure. We may also ask for a urine (wee) sample.

We will then carry out a holistic needs assessment (HNA) called 'the worry memory thermometer'. This assessment is age-specific and involves answering a number of short questions by ticking the relevant answer boxes. The questions relate to how you and your child have been feeling in the weeks leading up to their appointment. It is a way for us to see how you and your child are coping with everything that is happening. It also gives us a chance to discuss any challenges you may be experiencing or any worries you may have.

If your child is between 11 and 12 years old

Between the ages of 11 and 12, your child will start transitioning (moving over) to adult services. We understand that moving from the children's service to the adult service can be scary for some young people. To help support your child with the move, we will use the 'Ready Steady Go' and 'Hello to adult services' transition programmes which are designed to help young people feel ready to take more of a lead on their health and the management of it by the time they reach the adult service. We will send you more information about this before your child's appointment so that you can start to think about any questions you or your child may have. For more information about these transition programmes, please see the 'Useful links' section at the end of this factsheet.

During your child's appointment, we will help them complete the first part of the Ready Steady Go programme (this is the part titled 'Ready'). To help your child become more independent, we will offer them the opportunity to come into the clinic room on their own. This will also give them a chance to ask any questions that they may have.

How often will the appointments be?

LTFU clinic appointments are usually once a year.

If you have any issues outside of your child's clinic appointments, contact your child's CNS using the details at the end of this factsheet.

What will happen when my child turns 16 years old?

If your child still needs LTFU care when they turn 16 years old, their LTFU clinical team will remain the same, but their appointments will be held in a young adult clinic in the adult oncology outpatient department. Sometimes it may be more appropriate for the appointments to be held every second year rather than every year. We will send you an appointment letter with more information.

Please note that when your child turns 16 years old, we will address their appointment letters to them, rather than to you as the parent or carer. It is important that your child contacts us if their address or telephone number changes.

If your child needs any investigations, these will also be performed in an adult department. The department carrying out the investigations will contact your child by letter or telephone to arrange a suitable time and date. If your child cannot make an appointment due to work or study, they should contact us as soon as possible to rearrange their appointment.

Before your child's appointment, we will contact them and ask them to complete the 'Hello to adult services' programme. This programme includes questions about careers and wellbeing. We will also ask them to fill in a '16 plus' worry memory thermometer.

Contact us

If you have any **non-urgent** questions or concerns between your child's appointments, please contact us.

Late effects clinical nurse specialist (CNS)

Mobile: **07771 344400** (Monday, Tuesday, Wednesday and Friday, 9am to 5pm, Thursday, 9am to 6pm)

Email: Pblongtermfollowup@uhs.nhs.uk

If we are unable to answer your call, please leave a voicemail with your name, your child's name and hospital number, and a short message about your reason for calling. We will aim to return your call within 24 hours or within the next one to two working days if the message is left on a weekend.

If you have an **urgent** concern, contact your general practitioner (GP) or NHS **111** for advice. In an emergency, go to your nearest emergency department.

Useful links

'Ready Steady Go' and 'Hello to adult services' transition programmes

www.readysteadygo.net

The Children & Young People's Cancer Association (CCLG)

www.cclg.org.uk

Teenage Cancer Trust

www.teenagecancertrust.org

Macmillan Cancer Support

www.macmillan.org.uk

Young Lives vs Cancer

www.younglivesvscancer.org.uk

Teens Unite Fighting Cancer

www.teensunite.org

Ellen MacArthur Cancer Trust

www.ellenmacarthurcancertrust.org

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