

# FACTSHEET

This fact sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: [www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form](http://www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form).

## The Oncology Long Term Follow Up Clinic: Information for patients and families

Congratulations on your graduation to The Oncology Long Term Follow Up Clinic!

It is now over 5 years since you finished your cancer treatment and your Oncologist has referred you to the Oncology Long Term Follow Up Clinic (LTFU).

Treatment for childhood cancer is often complicated and may include chemotherapy, radiotherapy, surgery or a combination of therapies.

Sometimes there can be long term consequences of childhood cancer and treatment. We know that some late effects may not present for many years after the end of treatment. It is therefore important that you look after yourself and monitor your health for the rest of your life.

The Oncology Long Term Follow Up Clinic has three main goals:

1. Health Monitoring
2. Education
3. Working together

### Monitoring your health

About 12 months after your last visit with your Oncologist, we will contact you to invite you to attend your first Oncology Long Term Follow Up Clinic (LTFU).

The clinics are held twice a month in the Oncology Treatment Centre (Level 2). Clinics are staffed by the Doctor in charge of LTFU, Clinical Nurse Consultants (CNC), a Secretary, Psychologist and Social Worker, as well as a team of doctors specialising in paediatric and adult endocrinology, andrology (male fertility), gynaecology/ obstetrics and radiation oncology.

Prior to the clinic, you will receive a letter outlining the location and timing for all your appointments. **You must have a GP referral to attend the clinic.** You will also receive an SMS reminder the week prior to the LTFU clinic.

You will need to attend the hospital for most of the day:

1. Firstly all patients will have an appointment with the psychologist/social worker in the morning.
2. Investigations: Depending on your diagnosis and the treatment that you received, a range of tests will be organised for you. Tests commonly ordered include a blood test (full blood count, electrolytes, thyroid function and hormones) and an echocardiogram. Some patients may need a thyroid ultrasound, a lung function test, an eye review or a hearing test. It may not be possible to organise all the investigations on the day of the clinic. Some tests may need to be done before or after the clinic.
3. You will be reviewed by various members of the long term follow up team in the afternoon in the oncology treatment centre.

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We will try to complete your appointments as quickly as possible. Sometimes this can take some time so we recommend that you set aside the majority of the day.

Your first clinic experience may be a little overwhelming, while you get used to how things work, meet new people and are given new information. We suggest that you bring a support person, parent or partner with you.

Depending on your age you may also be seen on your own by the doctor or specialist. You may also be referred to other specialists at a later date if additional follow up is needed.

All available results will be discussed with you on the day. After your clinic appointment a letter will be sent to you and your nominated GP. This will include a summary of your clinic visit, test results and a list of 'required actions' that need to be completed by you. We will also tell you when you will be seen again in LTFU.

A copy will also be sent to your oncologist and other relevant specialists detailing the outcomes of the clinic visit.

## Education

On clinic day the nurses and doctors will speak with you about your understanding of your cancer and cancer treatment, as well as your understanding of why you have been asked to attend the long term follow up clinic.

A treatment summary will have been prepared for you. This is a document that summarises the details of the treatment that you have received as part of your cancer treatment and includes recommendations for your long term follow up. It is an important document and we will discuss it in detail.

You will also receive written information about the potential long term complications you are at risk of developing. These are known as 'health links'. They include information about healthy living after treatment for childhood cancer as well as the tests required to identify any early changes to your health.

## Working together

### General Practitioners

Treatment for childhood cancer is intense and it is not unusual for patients and families to lose contact with their GPs during this time as you may be attending hospital regularly and having regular check-ups with your oncologist.

We recommend that if you do not already have a good GP, one who you can work with in managing your follow up, NOW is the time to find one.

Once you have nominated your GP the LTFU Clinic can look after and support both you and your GP while you learn everything there is to know about being a childhood cancer survivor and the sort of follow up that may be needed throughout your life.

Even while you are being seen in the LTFU Clinic, we recommend a yearly check up with your GP and there may be some tests that need to be attended annually.

### Transition

Transition is the planned and coordinated move from paediatric care to the adult health system for those young people who need ongoing medical care. You may already be aware of the services of the Transition coordinators who are employed within both paediatric and adult hospitals. More information is available in the "Growing Up and Moving On: Transition Planning Information" fact sheet, found at: [The Sydney Children's Hospital Network website](#).

As you get older, some of your tests will be booked at Westmead Hospital or through other local adult services. You may need to transfer your care from a paediatric specialist to an adult specialist or you may need a new referral to an adult specialist. The LTFU Clinic will help you with aspects of your ongoing follow up such as this.

### How long will I be seen in the LTFU clinic?

Just how often you will be seen in the LTFU clinic depends very much on the individual. Usually patients will be seen every 2-3 years for 3-4 visits; however this is a very flexible arrangement and is completely dependent on your needs.

Our aim is to make sure that you are well educated and confident about all aspects of your medical history and the recommendations for long term follow up, that you have a good working relationship with a GP and that you are well linked in with any specialist services that you may need.

Eventually, you will be discharged from the care of the LTFU clinic at which time you and your GP will be responsible for your follow up. Even when you are discharged you or your GP can always call with questions or for advice.

### Remember:

**If you have any questions about the Oncology Long Term Follow Up clinic please don't hesitate to contact us on 9845 2141.**