

Fact Sheet

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.

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 regular, life long health monitoring is established

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

1. Health Monitoring
2. Education
3. Working together

Monitoring Your Health

Approximately 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.

The clinics are held each month from 09.00am and are located in the Clinical Resource Rooms located on Level 1 next to the Book Bunker. Clinics are staffed by the Doctor in charge of LTFU, a Clinical Nurse Consultant (CNC), a Registered Nurse (RN), a Secretary and a Social Worker, as well as a team of doctors specialising in paediatric and adult endocrinology, andrology (male hormones), gynaecology / obstetrics, radiation oncology and dentistry.

Depending on your diagnosis and the treatment that you received, a series 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 require a thyroid ultrasound, a lung function test, an eye

review or a hearing test. Most tests will be attended on the clinic day however some tests cannot be booked for clinic day and will need to be attended at a later date. On Clinic day, whilst we endeavour to have you seen by our team and complete your appointments as quickly as possible, we recommend that you set aside from 8.00am – 2.00pm.

First clinic experiences in particular, can sometimes be a little overwhelming, while you get used to how things work, meet new people and are given new information. We suggest that you may find it helpful to bring a support person, parent or partner with you.

On Clinic day, the nurses will meet and greet you. They will coordinate your appointment and test schedule and arrange for you to see the appropriate specialists. You may also be referred to other specialists at a later date if additional follow up is required.

A “results” letter will be sent to you following the clinic. This will include your results, outstanding appointments and instructions. It will also tell you when you will be seen again in LTFU.

A report will be sent to your GP (plus copied to your oncologist and other relevant specialists) detailing the outcomes of the clinic visit.

Education

On clinic day the nurses 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.

We will also discuss the importance of locating a good GP.



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Working Together

General Practitioners

Treatment for childhood cancer is intense and it is not unusual for patients and families to lose contact with their GP's during this time as you may be attending hospital regularly or 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.

NOW is the time when 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 required 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 will require 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 Children's Hospital at Westmead - Parents - Growing Up and Moving On: Transition Planning Information](#)

The LTFU clinic is currently working with the CHW Transition coordinator and Westmead Hospital to organise links

between both hospitals. 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 assist 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 dependant on the patient's needs.

Our aim is to ensure that you are well educated on 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 require.

Eventually, you will be discharged from the care of the LTFU clinic at which time you will be responsible for your own follow up. This will not occur however, until you are ready.

Remember

If you have any questions about the Oncology Long Term Follow Up Clinic please don't hesitate to contact us on 9845 2146.

This fact sheet is for education purposes only.
Please consult with your doctor or other health professional to make sure this information is right for your child.

This document was reviewed on Tuesday 18th March 2008.

the
children's
hospital at Westmead

www.chw.edu.au