



Follow Up

A GUIDE FOR PARENTS



This leaflet explains some of the possible follow up tests that may be necessary to check on any long term side effects.

LONG TERM MONITORING

There has been very significant progress in treating children with cancer and survivors can expect to live a normal life span, so why do we keep seeing your child in clinic after their treatment is finished? Most people think it is to check that the cancer is not coming back. This is true at the beginning but as time passes the focus of the visits changes from checking for recurrence to thinking about any possible long term problems that may have been caused by the treatment.

When a child is first diagnosed with cancer or leukaemia a lot of time is spent with the doctors and nurses talking about the treatment they will have. At some stage of these discussions the side effects of the cancer treatment are mentioned. Parents remember the immediate side effects, such as sickness and hair falling out, but often don't remember any longer term side effects being mentioned.



THE MAJORITY OF CHILDREN WON'T HAVE ANY LONG TERM PROBLEMS

After a few years have passed, your child will probably only need to come back to the clinic once a year for a check up. This leaflet explains some of the possible follow up tests that may be necessary to check on any long term side effects.

Although any problems may not be obvious now, it is important for all survivors and their parents to have enough information about the treatment they received and to understand how this might affect them in the future. These may include problems with growth and development, heart, lung and kidney function and fertility.

What causes long term problems?

These happen because of the damage cancer treatment can cause to healthy cells in the body. These effects can occur as a result of surgery, radiotherapy, some chemotherapy drugs and bone marrow transplants. Most problems result from chemotherapy or radiotherapy. They depend on four things:

- the type of treatment
- the site of treatment
- the dose of treatment
- your child's age during treatment.

Growth

At the clinic your child will be regularly weighed and measured to check that they are growing normally. Decreased growth during treatment is common. There is usually a period of “catch up” growth when treatment finishes. Radiotherapy may have important effects on growth and development. It may affect growing bones, e.g. radiotherapy to the spine can mean your child will not grow as tall as expected or, if given to an arm, it might be shorter than expected.

Radiotherapy to the brain may affect the pituitary gland which produces many hormones, including growth hormone. If your child does not produce enough growth hormone they will not grow properly and may need to have some special tests. If there is a problem they will be referred to an Endocrinologist (specialist in growth and development). Sometimes a daily injection of man-made growth hormone is needed to help your child grow. Sometimes other hormones are affected, for example thyroid hormone and cortisol. These can be replaced with tablets.

Puberty (sexual development)

Certain treatments may affect your child’s sexual development (puberty). These include

- Radiotherapy to the brain
- Radiotherapy to the lower abdomen or pelvis, including the ovaries and testicles
- Total body irradiation (TBI) for a bone marrow transplant
- Certain chemotherapy drugs
- Surgery to the ovaries, womb or testicles

All children are monitored carefully at the follow up clinic for signs of puberty, especially if they had any of the treatments mentioned

above. If there appears to be any delay going into puberty some investigations will be done. Sometimes sex hormone therapy may be needed to help to start sexual development. If there are problems they will be referred to an Endocrinologist.

Heart and lungs

Some chemotherapy drugs and radiotherapy can affect the heart and lungs. If your child had these they will have had heart ultrasound scans (echocardiograms) during treatment and these will continue occasionally, about every 3 to 5 years, after treatment ends. Careful monitoring is important because there are often no symptoms. Your child will be referred to a Cardiologist (heart specialist) if any problems are found.

Sometimes it is necessary to do special tests on the lungs (lung function tests). This is usually following radiotherapy to the lungs or total body irradiation (TBI). These tests involve measuring lung volumes and are easy for a child to do.

Kidney tests

Removal of one kidney does not usually cause any long term problems, as the remaining kidney can cope alone. Certain drugs can cause kidney problems and if your child received these they will have had special kidney tests during treatment. Kidney function will be checked occasionally at follow up visits, either by a urine sample or a blood test, or both. It is important to have their blood pressure checked; this is usually done routinely at the clinic visit. If your child’s kidneys are working well at the end of treatment they should not develop problems in the future.

Fertility

After treatment is finished and your child recovers there will be time to think about their future and growing up. This may lead you to think about them having a family of their own. There is a common belief that any cancer treatment causes infertility. This is NOT true. Many children treated for cancer go on to have their own families. All types of cancer and leukaemia are treated differently and it depends on which treatment each child had how it will affect their fertility. You will be able to discuss this in more detail with the doctor or nurse specialist in the follow up clinic.

Second cancer

A very small number of children who are cured of cancer can go on to develop another, different, cancer later on in life. There are two main reasons for this. Firstly, some cancer treatments can increase the risk of developing another cancer. Secondly, some families have a special risk of developing certain cancers. This is very rare. Your doctor or nurse specialist will be able to discuss any worries you have about this.

TRANSITION – follow up after 16

It is very natural to want to protect your child from worrying about their past illness. Many children may have been too young to remember and not really understand why they have to come to the hospital. There is a CCLG booklet about this called “What’s the point of coming to clinic?” It tries to explain to your child the reason for follow up visits. A diagnosis of cancer has lifetime implications so it is very important for your child to understand all that happened and

what this will mean for them as an adult. If they understand why they need to be followed up they can develop the necessary independence in their future health care. The process of them becoming independent is called “**transition**”. Your child may attend a follow up Transition clinic before moving to follow up in the adult health system. If your child has no risk of long term problems they may be discharged from follow up.



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