Late effects

Although retinoblastoma (Rb) is a cancer of early childhood, some after effects may occur later in life, and for some patients longer term follow-up will be required.

A 'late effect' is a health problem that occurs months or years after a disease such as retinoblastoma is diagnosed or after treatment has ended.

After treatment has finished, and with time, the risk of the retinoblastoma recurring falls. There is then a shift in the focus of long term follow-up, with the emphasis moving towards monitoring for the late effects of treatment including chemotherapy, radiotherapy and surgery. This will optimise long term health, particularly in those patients with heritable / genetic Rb (the form which may be passed from parent to child).

Long term follow-up

The aim of long term follow-up care for retinoblastoma is to ensure that each individual receives high quality, personalised aftercare which will enable them to achieve their full potential in life. As young people reach adulthood their care is likely to move to either a late effects team within adult services or to their GP. The process of transferring care from paediatric (child) to adult services is called transition and will be offered to all patients who need it. The need for ongoing care into adult life is tailored to each individual patient depending on the type of Rb they had and the treatment they received.

What is a Late Effects Team / Clinic?

A late effects clinic or team are there to help patients learn about and plan the follow-up they will require. This includes detecting and managing any problems caused by Rb or the treatment received to ensure the best possible quality of life.

Late effects support does not always mean regular hospital appointments, but patients should have access to a late effects keyworker (main contact), know how to contact the late effects clinic or team if needed, and understand their personal risks in order to make their own lifestyle choices.

Typical long term follow up outcomes following differing treatments for Rb:

Surgery alone and non-heritable Rb:

- Follow-up during childhood.
- Discharge at 16-18 years to GP-led care and self-management.

Chemotherapy and non-heritable Rb:

- Follow-up during childhood.
- Transfer to adult late effects team at 16-18 years.
- Eventual discharge to GP-led care and self-management.

Heritable Rb or treated with radiotherapy:

- Follow-up during childhood.
- Transfer to adult late effects team at 16-18years.
- Remain under supervision with lifelong access to an adult late effects team.

The focus of long term follow-up is:

• **Monitoring for the side effects of chemotherapy:** these are reassuringly low and most patients can expect very few late effects.

However, depending on the chemotherapy used, a small number may develop complications, some of which may occur many years after finishing treatment.

These include:

Carboplatin: possible effect on kidney function and hearing.

Etoposide: very rarely secondary leukaemia can occur, and generally this would be within five years of completing treatment.

Vincristine: possible nerve damage.

• **Monitoring for the side effects of radiotherapy:** Radiotherapy has a number of potentially challenging side effects, and so newer treatments are being developed in order to try and limit its use. However, it is an effective treatment for Rb and was the mainstay of treatment for many years. A significant number of patients have retained their eyes and vision thanks to its use. The focus of follow up is to identify late effects promptly. These can include:

• **Dry eye:** after whole eye radiotherapy damage to the lacrimal glands, which produce tears, can lead to dry eye. A dry eye is more susceptible to infection, to damage from dust and air pollution, and to extremes of temperature. Artificial tears or eye drops can keep the eye moist on a long term basis. This problem is much less evident after "lens-sparing" radiotherapy.

• **Facial asymmetry:** radiotherapy can reduce the growth of the bones around the eye socket which may result in poor fitting of an artificial eye, or lower self-confidence due to alteration in appearance. If the radiotherapy beam has exited through the jaw, dental problems may also occur.

• **Retinal detachment:** very rarely, the retina may become detached some months or possibly years after successful treatment for retinoblastoma. This tends to occur in eyes treated for large tumours and where cryotherapy (a freezing treatment) has been used. Any sudden deterioration in vision should be taken seriously, and people are advised to make an urgent appointment to see an ophthalmologist (hospital-based eye specialist) or attend eye casualty.

• **Second cancer:** although an effective treatment against Rb, a long term effect of radiotherapy includes the small risk of developing a second cancer in the area that received the radiotherapy treatment. If you are worried about this, please speak to your GP or late effects team.

• **Monitoring the side effects of surgery:** some patients may undergo enucleation and will be seen by an orbital prosthetist at the National Artificial Eye Service or private ocularist about their artificial eye.

• **Socket problems:** these may occur in the years following surgery. If problems persist, seek a referral to a local oculoplastic/orbital surgeon via your GP.

At the end of treatment, patients and parents affected by retinoblastoma should be offered an appointment with an oncologist to discuss the treatment they received and the potential consequences of this in the shorter and longer term. If you did not have this opportunity when you finished treatment, discuss this with your GP, or long term follow-up team, who may be able to access this information for you.

How can I get my old Rb treatment records?

The most straightforward way is for your GP to request the information from your treatment hospital. You can also request them yourself, but this can be a more complicated process.

I am not currently registered with a late effects clinic. How do I / my GP do this?

If you had heritable Rb (either bilateral or heritable unilateral), or were treated with radiotherapy, you should be under the care of a late effects team. To do this you should ask your GP for a referral to your local adult late effects clinic. The referral letter should detail the treatment you had as a child – if available. If for any reason they are unable to do so, your GP can contact your local paediatric cancer centre who will be able to give them contact details for your local adults late effects team. If you are not able to contact your local team through either of these routes, or would like our help in doing so, please get in touch with one of the CHECT support workers.

CHECT can provide emotional, pratical and social support for any issues relating to the cancer experience, including treatment, late effects and living with an artificial eye.

Any medical issues related to Rb and follow-up can be directed to the specialist teams at the Royal London Hospital or Birmingham Children's Hospital.

If you have had non-heritable Rb and were not treated with radiotherapy you do not need to be under the care of a late effects team. However, if you observe any unusual symptoms or changes to your health, you should make a GP appointment as soon as possible.

If you would like to find out your genetic status (ie whether your form of Rb is heritable), contact one of the CHECT support team who can help to arrange an appointment with the relevant team.

See also our leaflet on Cancer Risk & Self Care After Retinoblastoma, and the 'My story' section on the CHECT website.

CHECT continues to support adults affected by their previous Rb in many ways, but can also connect you with other support organisations. Contact our support team to find out more on 020 7377 5578 or email support@chect.org.uk

www.chect.org.uk

020 7377 5578 info@chect.org.uk
@ChectUK /CHECTUK

Registered charity no. 327493. A company limited by guarantee, registered in England and Wales no. 2143917. Registered Office The Royal London Hospital, Whitechapel Road, London E1 1FR

Fighting Retinoblastoma Childhood Eye Cancer Trust