

Rb into adulthood: patient aftercare

As a result of treatment success, there is a growing population of more than 2,000 survivors of retinoblastoma (Rb) in the UK. Their “after care,” along with that of other survivors of childhood cancer, has become a priority area within the NHS. This article will highlight the purpose of follow-up and outline what patients and families can expect.

On finishing treatment...

Children with Rb will initially be followed up by their Rb team. Feelings of relief and pleasure can be mixed with uncertainty and worry and a detailed summary of the treatment received with a clear plan of the care to expect over the coming months and years can help lessen some of these worries. If you are not offered an end-of-treatment summary and care plan then ask your team to provide one. Immediately after treatment has finished the focus of follow-up is:

- To check for Rb coming back in previously treated areas within the eye.
- To check for signs of new tumours developing in the eye.
- To ensure there is no evidence of the disease having spread outside of the eye.

During these early months off-treatment you will have access to your Rb keyworker who should be available to answer queries and provide support.

Dr HELEN JENKINSON, Consultant Paediatric Oncologist at Birmingham Children’s Hospital, looks at what happens to Rb patients when their treatment comes to an end...



Dr Helen Jenkinson

In the longer term...

With time, the risk of the tumour recurring falls and there is a shift in the focus of long term follow-up with the emphasis moving towards monitoring for the late effects of treatment and ensuring good health in the future.

During this period, your care is likely to transfer from the RB team to a Late Effects team who are based in your local paediatric oncology centre. This may happen from as early as one year from finishing treatment up to 16 years, depending upon local arrangements. The focus of long term follow-up is:

1. Monitoring for the side effects of chemotherapy. Chemo drugs used to treat Rb have a range of side effects, some of which may occur many years after finishing treatment. There are

national recommendations for investigating these long term side effects which include:

- Carboplatin: effect on kidney function and hearing
- Etoposide: secondary leukaemia
- Vincristine: effect on nerve function

2. Monitoring for the side effects of radiotherapy. Radiotherapy has a number of potentially challenging long term side effects. Because of this, newer treatments are being developed in order to try and limit its use. However, it is an effective treatment for Rb and a significant number of patients have retained their eyes and vision thanks to its use.

Long term complications can be cosmetic, hormonal or related to second cancers and the focus of follow-up is to identify and treat these promptly.

3. Lifestyle advice and health promotion. A priority for long term follow-up is to encourage young people to be aware of their own health risks and to minimise these through a healthy approach to life. Patients who are known to have the heritable form of retinoblastoma carry an alteration in the Rb gene which predisposes them to other

cancers later in life. This is not the case for patients with non-heritable or non-genetic Rb. Although this can be a difficult issue to face, it is important to remember current knowledge is based upon patients treated many years ago. We hope that through patient education, newer treatments and healthy lifestyle choices it may be a very different story in another 40 years.

A recent paper studied second cancers in patients treated in Britain since 1951. This paper confirms the risk for patients with heritable Rb - particularly bone and soft tissue tumours, melanoma, and cancers of the bladder, uterus and lung. Many of these cancers are associated with UV-light or tobacco. By raising awareness in young people, encouraging them to avoid smoking and use high SPF sunscreen these risks could be



Caroline Aherne had heritable Rb and has been treated for bladder and lung cancer

significantly reduced. For this reason, patients with heritable Rb should remain under the supervision of a Late Effects team lifelong. This may not mean regular hospital appointment but patients should have access to

a Late Effects keyworker, know how to contact the Late Effects team and understand the risks to make their own lifestyle choices.

On reaching adulthood...

As young people achieve adulthood their care is likely to move to a Late Effects team within adult services. The process of transferring care from paediatric to adult services is called transition and will be offered to all patients who need it. The need for on-going care depends on their genetic status and the treatment received.

Summary...

There has been a welcome shift in the provision of long term follow-up care for Rb and teams have the challenge of ensuring that each survivor receives high quality, individualised aftercare which will enable them to achieve their full potential in life.