Cancer risk and self-care after retinoblastoma

Some people who had retinoblastoma (Rb) as a child will have an increased risk of developing other types of cancer. These are called second primary tumours / cancers.

There are two factors which increase risk.

• Having the heritable form (may be passed from parent to child) of Rb – this includes everyone with bilateral and around 15% of those with unilateral retinoblastoma. If you are not sure what type of Rb you had, genetic counselling and testing is recommended as soon as possible. Your support worker can help you arrange this.

• Those who have undergone radiotherapy.

People in these two groups have an increased risk of developing a kind of cancer called sarcomas. Osteosarcomas can arise in any bone in the body, but most commonly in one of the leg bones or in the bones of the orbit around the eye. Soft tissue sarcomas can occur anywhere.

There is also an increased risk of developing other forms of cancer, such as skin cancer (melanoma) and cancers of the bladder, uterus (womb) and lung. Many of these cancers are associated with the damaging effects of UV light or tobacco.

By understanding these risks and taking action to protect yourself (such as not smoking and limiting exposure to UV light) these risks could be significantly reduced in the future. Patients with heritable Rb, or who were treated with radiotherapy, should remain under the supervision of a late effects team lifelong (see our leaflet on late effects).

Looking after yourself

• Be aware of the signs of cancer* (www.cancerresearchuk.org/about-cancer/cancer-symptoms)

• Seek medical advice from your GP for any unexplained or persistent pain

• Check your skin regularly to monitor for any changes and visit your GP as soon as possible if you notice any lumps, bumps, new moles, or changes to an existing mole.*

• Wear sunscreen and hats, avoid over-exposure to the sun and don't use sunbeds.

• Eat well and maintain a healthy weight

• Do not smoke, and drink alcohol in moderation

• Take regular exercise

• Avoid routine X-rays and CT scans due to their association with extra radiation (see below)

• Remind your GP that you have a higher risk of developing second primary tumours if you had a heritable form of Rb as a child or have had radiotherapy treatment. You can download our retinoblastoma leaflet for GPs from chect.org.uk/gp.

* Please note: We have listed some of the symptoms which may be linked to a second cancer, but the list is not exhaustive. If you notice anything unusual / recurring it is important to discuss this with your GP or late effects nurse.

How do I monitor my skin for any changes?

If you have had heritable Rb or have had radiotherapy treatment it is useful to get into the practice of regularly checking your skin to monitor for any changes. If you are visually impaired or blind, you could ask your partner, a family member or a good friend to check for you. Be aware that any unusual rashes, abnormal skin colouring, lumps or swelling and changes to moles should be taken seriously. If you become aware of any changes or have any concerns, you should always visit your GP as soon as possible.

X-rays and scans

It is important to avoid routine x-rays and CT scans if you have had the heritable form of Rb, or have had radiotherapy treatment, because of the radiation exposure. However, if you are advised to have an x-ray or scan to help diagnose a problem or for treatment purposes, it is important to go ahead. If you are advised to have an x-ray or a scan for diagnostic purposes, it is important to ask if an MRI could be used instead (an MRI may not always be suitable for every investigation). If you have had an enucleation, advise your doctor what kind of implant you have before having an MRI. If the x-ray or scan is not required for treatment or diagnostic purposes (ie routine dental x-rays), they should be avoided.

See also our leaflet on Late Effects, and the 'My story' section on the CHECT website.

It is important to remember that part of our knowledge on cancer risk is based on how retinoblastoma was treated historically. It is hoped that with advancing treatment techniques, more knowledge around the genetics of Rb, and better awareness on healthier lifestyle choices that this risk will be reduced for people in the future.

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

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