



## St John's Institute of Dermatology

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# Squamous cell carcinoma (SCC) and epidermolysis bullosa (EB)

### What is an SCC?

An SCC is a type of skin cancer. Squamous cells are found in the outermost layer of skin. Very occasionally in patients with EB, an SCC can develop in the mouth.

### Who gets it?

In the general population an SCC can occur due to sun exposure and accounts for 1 in 5 (20%) of all skin cancers. Developing an SCC is more common in the severe forms of EB (recessive dystrophic EB (RDEB) and generalised intermediate junctional EB (JEB-I)) but is also found in people with dominant dystrophic EB and Kindler syndrome, although everyone with EB should be aware of SCCs.

### What is the risk of me getting an SCC?

If you have EB simplex your risk of developing an SCC is no greater than in the general population.

We know that the risk of developing an SCC in RDEB is much higher than other forms of EB. The risk increases with age, but it is possible for children and teenagers with RDEB to be affected.

If you are concerned about skin cancer please speak to your EB nurse.

### How do I check my skin?

It is very important that your skin is checked regularly, including areas that you are not able to see yourself. Either you or your carer should be aware of any changes in your skin that are different for you. In addition, if you have severe EB, your EB nurse should visit you at least every six months to undertake a whole-body skin inspection. If you have any concerns please contact your EB nurse.

## What do I look for?

SCCs can develop anywhere but are more commonly found in areas where the skin is frequently damaged, such as ankles, knees, backs of hands and wrists and on sites of chronic blistering, wounds and scarring. SCCs can present in a number of ways and this will be different for each person. It's difficult to give an absolute description but the following advice about what to look for is important to remember:

- any areas that are unusual for you
- wounds that don't heal as they would normally
- a rapidly growing wound, especially if it is raised or "cauliflower like"
- a deep wound, especially if it has raised or rolled edges
- any thick, raised, crusty areas
- a wound with altered sensation different to your normal EB wounds. This may be a feeling such as tingling, increased pain or no pain at all



## What to do if you have concerns

If you are at all worried, you should contact your EB nurse as soon as possible and send some well-focused and well-lit photographs of the area taken from different angles.

Your EB nurse may then visit you at home or they will arrange for you to be seen in the hospital for a review.

## How will my SCC be diagnosed?

It can be very difficult to tell if an area is cancerous just by looking at it, so it is our practice to take a biopsy (small sample) of any suspicious areas. A few biopsies of the area will be taken following an injection of local anaesthetic. This procedure can be uncomfortable but should not be too painful. We will apply a dressing over the site which will stay in place for a few days, then you can continue with your normal dressings. The area may bleed a little but should soon settle.

Very rarely a biopsy may need to be taken under a general anaesthetic. If this is necessary it will be discussed with you.

The biopsy results can take up to two weeks to be available and someone from the EB team will contact you with the results.

## What happens if I have an SCC confirmed?

Current treatment is surgical removal of the cancer. You will have the opportunity to discuss the results and the surgery with your EB doctors. The surgery will usually take place in the operating theatre within a few weeks of the cancer being confirmed. An EB nurse will be able to support you through this procedure. You will be required to stay in hospital overnight or for a few days. Your relative or carer will be able to stay on site during this time.

If cancer is diagnosed, further investigations (MRI and/or PET CT scan) may be necessary depending on the size and location of the cancer. You will be advised by your doctor if these tests are required.

## Will I get another SCC?

Currently there are no certainties, as EB and EB cancers are rare and everyone's EB behaves differently. The evidence suggests that at some point the cancer will be likely to come back. What you can do is be vigilant and aware of your skin. While we advise you to look out for new areas of concern, it is also important that you are able to get on with your life.

Remember: your EB nurse is here to support you and would like to check your skin on a regular basis.

### DEBRA

The EB service at St Thomas' Hospital runs in collaboration with the charity DEBRA – the national charity supporting those directly affected by, and working with, EB.

**w:** [www.debra.org.uk](http://www.debra.org.uk) **t:** 01344 771961

### Contact us

If you have any questions, please contact us. Adult EB clinical nurse specialist team (contact via EB administrator) **t:** 020 7188 0843, Monday to Friday, 8am-6pm.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)

### Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline. **t:** 020 7188 8748, Monday to Friday, 9am-5pm

### Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS) **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints) **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

### Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. **t:** 020 7188 8815 **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

### NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day. **t:** 111 **w:** [111.nhs.uk](http://111.nhs.uk)

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