

The 10 things you need to know about Squamous Cell Carcinoma (SCC) if you have Epidermolysis Bullosa (EB)

1. What is an SCC?

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

2. Who gets it?

In the general population an SCC can occur due to sun exposure and accounts for 20% (or 1 in 5) 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 Kindlers syndrome, although everyone should be vigilant.

3. 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, however it is not unheard of for children and teenagers with RDEB to be affected.

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

4. How do I check my skin?

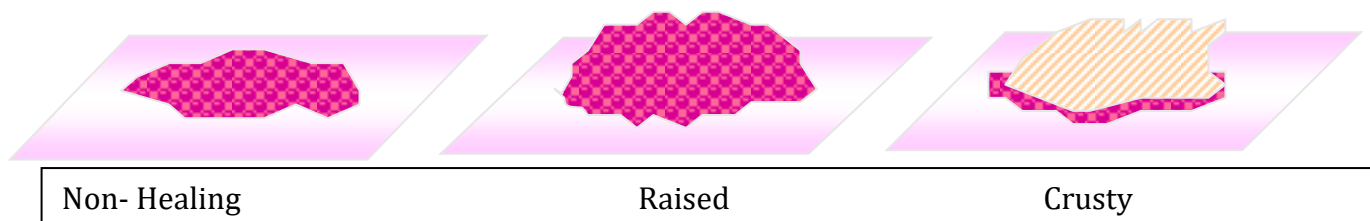
It is very important that your skin is checked regularly including areas that you are not able to see yourself. Either you or your carer should be aware of any changes in your skin that are different for you. In addition, if you have severe EB your EB nurse should

visit you at least every six months to undertake a whole body skin inspection. If you have any concerns please contact your EB nurse.

5. 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



6. 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.

7. 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 small samples (a biopsy) 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, after which 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 before they are available and someone from the EB team will contact you with the results.

8. 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.

9. Will I get another SCC?

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

10. Patient experiences

What made you become concerned about the area where the SCC was found?

"The area started off as a normal wound but after two weeks, which is my normal healing time, I noticed the wound was scabbing over with a hard crust but not healing underneath. I eventually peeled the scab off to see and this is when I noticed it wasn't healing underneath. It looked like overgranulation which I have had before so I tried steroid cream on it for a week and it didn't do anything. The wound was also raised from the skin and not flat. This is when I decided to contact the EB clinic."

"Each of the 6 SCCs were abnormal scabs that were not able to be removed. Having used the usual creams we normally use, each scab remained and at times parts of the scab would come away but immediately grow back."

"I became concerned about the area where the SCC was found because the wound looked 'different', with a lump growing that didn't look right. It didn't actually feel that different; it wasn't more painful. It just felt harder and more solid."

How did it feel in relation to the rest of your skin?

"No different to any other wound, it didn't hurt, it wasn't particularly sore, it's just that it wasn't healing within normal time periods for me."

"The one on the foot and 2 of 3 on the back of the neck were very itchy, but nothing else. No pain or burning."

What advice would you give to other people with EB?

"I would just say that if something looks different, or isn't healing as it normally would, or feels different ask for it to be biopsied to be sure. It's best to be safe and have a negative result than leave it and have it turn into something worse. Talking with other people who have been through it also made a huge difference and helped with any worries or uncertainties I had."

"If something looks different to what you're used to seeing, call your EB nurse ASAP. If you have a biopsy and it comes back as an SCC, the team will support you throughout it all. The word cancer is scary but it's better to know quickly and begin the process of surgery and healing."

“If someone gets an SCC, I have to be honest, it’s a horrible thing to hear, wherever it is and however old you are. The healthcare professionals that will be there are second to none; they will do everything in their power to help you through it from the physical health side of things. Psychologically, everyone’s different, but the reality of going through this could resonate for months and years. Seeking psychological support and not bottling it up is vital.”

What was your experience of the whole process from first contacting your EB nurse to recovery after your surgery?

“Overall the whole process was very quick, from having my biopsy I had the results that it was an SCC within 7 days and my surgery to remove it was 3 weeks after that, so within 1 month I had the diagnosis and removal of the cancer.”

“Every SCC has been different in terms of size of the areas, surgery, my recovery and getting back to ‘normal’. But each has been a quick process from calling the EB team, to having biopsies, confirmation and then surgery, with lots of support, reassurance and explanation of plans, the type of SCC and what it means in the future.”

“As far as my experience, it was hard. My EB nurse saw the suspicious area on a visit and a biopsy was taken soon after. Finding out that I had cancer was a shock. The worst bit was the week of scans - CT and MRI - to see the extent of the tumour, as I didn’t know how bad it was at that point. I then found out that it hadn’t gone too deep, so I just needed surgery to remove the SCC. The medical procedures went well, and everyone was very helpful. The pain was mostly kept under control, but the trauma of having something like a tumour taken out of you, along with some of the surrounding area, is bigger than you expect.”

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

The EB service works in collaboration with DEBRA

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/ **t:** 01344 771961

Contact us

Always include contact details for relevant services with opening hours. Include useful helplines and websites – the KIC can help you with this. Provide details of who to contact if the patient is worried about anything, or if something goes wrong.

Ensure that the patient is given a location for the service if they are going to need to travel there themselves.

[CORE TEXT]: For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit 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 9am to 5pm, Monday to Friday

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

t: 020 7188 3514 (complaints) **e:** 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

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

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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