EB: My Story













Young people talk

EB: My Story
Young people talk

EB stands for Epidermolysis Bullosa. People with EB have fragile skin. Most people with EB get blisters and sores on their skin, and need to wear dressings on their hands, feet, arms or legs. In this booklet you will meet children and young people with different types of EB.

EB is a rare skin fragility condition. Living with EB can often be a real challenge. Children and their families can feel tired, sad and sometimes lonely. Regular dressing changes can be painful and very time-consuming. Sometimes playing, going to school and even eating can be difficult.

There are many different types of EB that can affect people differently. EB can be inherited, so more than one person may be affected in any one family. When you have a rare condition, it is hard to imagine that anybody else might be feeling just the same as you. Those of us who work with children and adults with EB, and other skin fragility conditions, know just how frustrating it can be to spend time having your dressings changed instead of having fun with your friends. We know how you have the same dreams and aspirations as any other young person, and how there is so much more to you than your EB.

Despite these challenges, children and young people with EB get on with life and enjoy themselves in all sorts of ways – playing football, playing the guitar, swimming, cooking and even dancing! In this booklet they share their stories and their advice for dealing with day to day struggles but, more importantly, they share their achievements and their hopes for the future.

We hope that through this booklet, children and families with EB will be inspired and encouraged, and will know that they are not alone.

Dr Fiona Browne
Consultant Dermatologist

Jasmine

Jasmine (left) with her big sister Amelia

Jasmine is two. Jasmine has dystrophic EB. She was a bit late to start walking but now her favourite thing is going to Tappy Toes dance class with her daddy, Ian. Big sister Amelia explains, 'Jasmine has delicate skin, so we have to be careful of her if she falls.' Amelia has helped to look after Jasmine since she was a baby. She passes bandages and keeps Jasmine entertained while her dressings are changed. Before Jasmine started at nursery, her mum Anna went with the EB nurse to check their bibs, bedding and cot bumpers. Anna taught the nursery staff how to patch up Jasmine's bandages if they come loose. 'I've only been called in once,' says Anna proudly. Currently Jasmine is being assessed for a one-to-one carer when she starts at school.

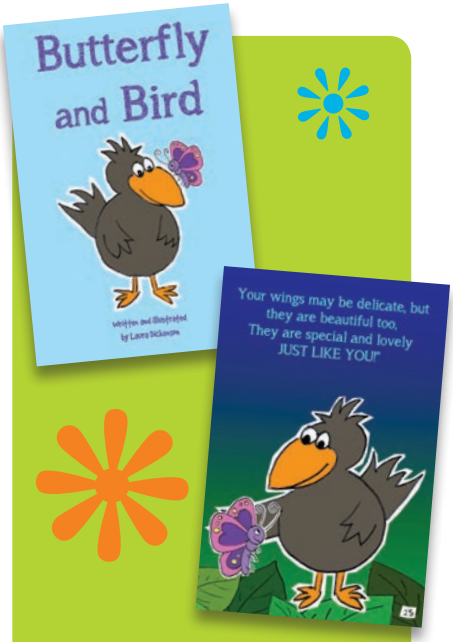
Jasmine knows her own limits,

Jasmine has a bath every other day, with salt water which seems to sooth her skin – a tip Anna picked up from the EB Facebook lounge.

'Jasmine is quite a character,' says Anna. 'She has made friends at nursery. She's aware of her personal space, and she'll find a safe route through a group. She knows her limits, and she stands up for herself.'

Jasmine is a busy girl and she enjoys playing outdoors

and she stands up for herself



Jasmine's Auntie Laura has written a children's book called Butterfly and Bird to explain about EB and to raise funds for DEBRA

Jasmine's mum, Anna says:

Jasmine was born at home, as planned. The midwives found a blister on her knee. They couldn't diagnose what it was, but they told us to take Jasmine into hospital. In the car on the way, she kicked the skin off her feet.

At the hospital, still unsure of a diagnosis, Jasmine was put in an incubator. Treatment with cannula and plasters made her worse and worse. At last the EB nurse arrived. 'Out of the incubator!' she said. 'It's too warm!' It took a while for treatment to get back on track.

Nowadays we have good days and bad days. Jasmine's mouth is severely affected, and she hates having her teeth brushed.

Jasmine recently had an operation to widen her oesophagus (food pipe from mouth to stomach), as she was having difficulty swallowing and eating. We were petrified, but the doctors talked us through it carefully. The EB nurse stayed throughout the operation to help avoid any procedures which might damage her skin.

The consultant passed a very thin wire with a deflated balloon through her oesophagus, then inflated the balloon to stretch out the scar tissue. Half an hour later, she was awake again, a little hoarse, and very hungry! Soon she was shovelling down her dinner. We nearly cried.

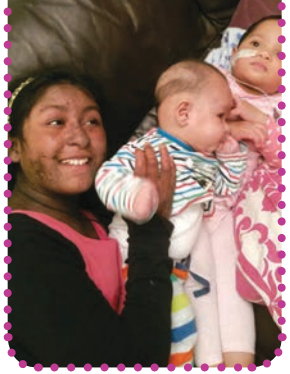
She will probably have to have this procedure again, but next time we'll know what to expect. We won't be half as scared.

Aniqa

11-year-old Aniqa has EB simplex. Nowadays, her skin is very much better than when she was younger.

'It's important to moisturise my skin,' she says. 'I can do it myself, apart from my back.' Parvin, Aniqa's mum, adds, 'You have to take the time to do it carefully, especially if there is an infection. Then you can help the skin to get better.'

'My mum is like a spy!' says Aniqa. 'She is always looking for tiny blisters!'



Aniqa enjoys helping her mum to look after her baby sister and brother

'Because they will grow bigger,' says Parvin, 'and then they get worse. You have to be disciplined. Don't leave them! Always deal with blisters straightaway.'

Aniqa had some hurtful comments from children at her primary school. Some children were worried about touching her skin in case they caught EB. This is something the school can help with, educating other children.

Aniqa has visited relatives in Bangladesh twice, but she didn't like the heat. 'And it was difficult to take all the bandages and needles and medicines we needed,' adds Parvin.

Now Aniqa is settling happily into secondary school. She enjoys hanging out with her friends, chatting and learning to make fishtail braids and other hairstyles. Aniqa wants to be a chef when she grows up. 'I can make pancakes and I've started baking cakes,' she smiles.

Always deal with blisters straightaway

Ruardhrí

3-year-old Ruardhrí has EB simplex – and so does his mum, Amanda, and her four sisters, and lots of cousins too.

But Amanda and her sisters were never diagnosed. It was only when Ruardhrí was born and his condition was recognised that Amanda realised her skin condition had a name.

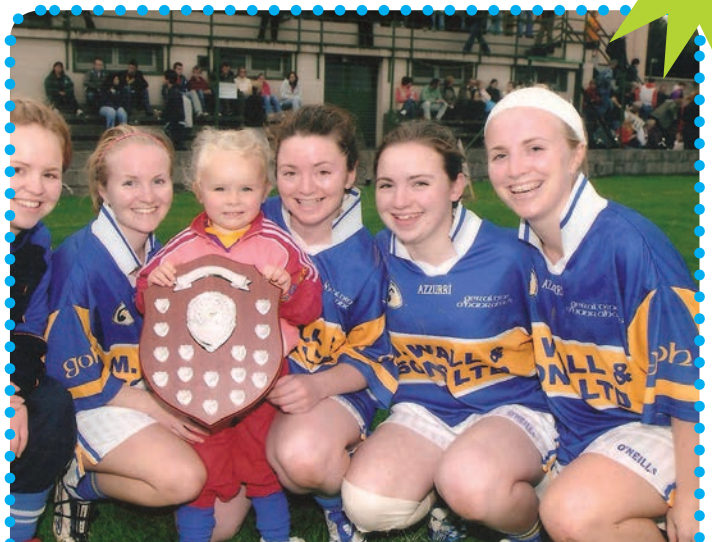
'My sisters and I played Gaelic football all our lives, all five of us in the same women's team,' says Amanda. 'We'd wear two pairs of socks over our bandages, and squeeze our feet into our boots – then we wouldn't feel any pain till after the game. Afterwards we'd come home and burst the blisters.'

Ruardhrí's free to play like any other three-year-old

Ruardhrí hates having his blisters burst, so Amanda tries to do it while he's sleeping. But now he's used to the bandaging each morning, and he's pleased when he sees blisters healing up.

Ruardhrí walked at 10 months. 'I didn't want him to crawl,' says Amanda, 'because I knew it would damage the skin on his knees and hands. But it was upsetting to see him getting blisters on his feet, which made walking painful for him.'

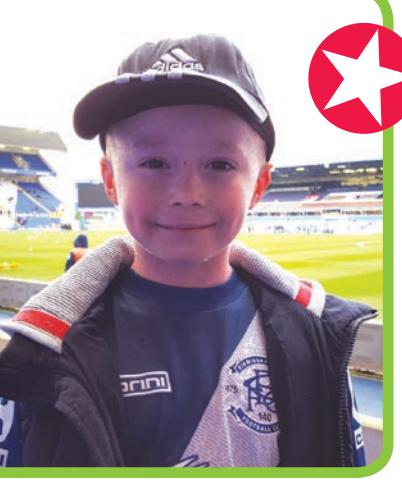
Ruardhrí and his cousin Essie playing outdoors



Even so, Amanda is keen not to restrict Ruardhrí's play. 'It's easier for me, because I know exactly what he's going through,' says Amanda. 'As you grow up, you learn your limits. So I have a good sense of how much to let him do, and when to stop him.

'Ruardhrí's a trickster, he's inquisitive and he's always laughing. He loves to ride his bike – and we make sure he's free to play like any other three-year-old!'

Gaelic footballers Amanda (second right) and her sisters with their trophy



Cody and Harvey

Cody (left, at Birmingham City ground) and Harvey (opposite) are both 8 years old. Both boys have rare forms of EB.

8-year-old Cody is a sporty boy, and he loves playing football, though he needs to put his feet up afterwards. 'It's worth it, even if I'm tired the next day!' says Cody. A treat every couple of months is to go with his dad to see their team, Birmingham City, play a match.

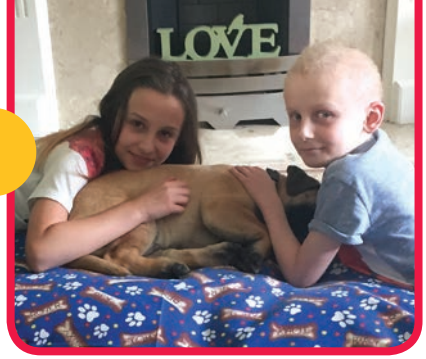
Cody has BIE (epidermolytic ichthyosis), which means his skin is dry as well as blistering. Sometimes Cody's skin flares up when he's feeling stressed or worried, for instance when there's a new teacher or a change in routine. And sometimes he gets tired and snappy when he's hungry.

'So we give him plenty for lunch and extra snacks!' says Cody's mum Jane.

At breakfast every day, Cody draws a face in his bowl of porridge with golden syrup, to tell his mum what kind of mood he's in. Recently, he has been looking after himself a bit more. 'It's good for him to be in charge of himself,' Jane says.

'We take it one day at a time,' she adds. 'Don't try to do it on your own. It helps to have family members involved. Cody's Nan knows what he needs. And we go along to family events for kids with EB. It's helpful to see the stalls, find out about new dressings, new creams – we're always open to try something new. And it's good to know we're not on our own.'

Playing football is worth it, even if I'm tired the next day!



Harvey with his sister Brooke and their new puppy

Harvey has an even rarer skin and hair condition caused by a genetic deficiency in a protein called desmoplakin.

Harvey's condition affects his feet mainly. 'When it's bad, it feels as though I'm stepping on spikes,' says Harvey. So Harvey and his family do everything they can to make sure his feet are comfortable. Harvey uses a wheelchair to get to and from school – so he can spend more time during the day on his feet with his friends.

Every morning, his mum checks his feet and puts cream and dressings on while he's still half asleep. Sometimes she puts his dressings and socks in the fridge – or the freezer! – to help cool him down.

The skin on Harvey's feet grows very fast, so every couple of days his mum trims it with a scalpel so it doesn't get too hard – while Harvey plays on his Xbox.

At school, Harvey is good at maths and art. He loves swimming, wearing diver's shoes to protect his feet. The school has learned what Harvey needs, so he can learn and have fun. A teacher from a nearby special school has helped, bringing PE ideas for Harvey to do with his class.

Now the school is getting more geared up. Recently they invited parents of pupils with disabilities to bring ideas and suggestions, and they promise to do what they can.

Put your dressings and socks in the fridge or the freezer to cool your feet down!

Liam is a keen Liverpool fan

Liam

Liam has recessive dystrophic EB. He is 8 years old, and he's looking forward to his first communion with the rest of his class in a few days' time, now he's back from a recent stay in hospital. 'It'll be a big day, and a bit of a boost,' says his Nanny Kathleen, who lives with the family.

Once a year, Liam spends a few days in hospital, so the doctors can assess his treatment and nutrition. 'You don't need to worry about staying in hospital,' says Liam. 'The nurses are very kind, and my mum can sleep there with me.' This time the doctors have adjusted his nutrition, and Liam is feeling better and stronger as a result – just in time for his communion.

You don't need to worry

Liam loves going to school, and a bus collects him every day. His school is very supportive, and they make sure that Liam has everything he needs, including his own toilet, and first aid when he needs it. 'I don't like missing school when I go to hospital,' Liam admits.

Liam's mum Grainne keeps in touch with other mums of children with EB. 'Social media is great,' she says. 'It makes it easy to communicate, and we can help each other – and learn from each other too.'

Grainne says that the doctors are learning more all the time how to treat children with EB. 'They learn from each child,' she says. Liam had dental treatment a while back. The dentists used what they learned to help a young child with EB who needed assistance with her teeth.

Liam is keen to go outdoors and kick a ball around on the long summer evenings. 'It's too cold and dark in the winter, but it's good for him to play outdoors when he can,' smiles Grainne.

Liam with Deirdre, family support worker for DEBRA Ireland

about staying in hospital. The nurses are very kind.

Salma

Salma is 10 and she has dystrophic EB. Salma knows a lot about how to look after herself – and she knows her own mind!

She knows it's really important that she gets used to cleaning her teeth herself. 'I clean my teeth using an electric toothbrush at the front and a soft baby brush to reach the back teeth. And sometimes I use minty mouthwash, even though it tickles my skin,' she says.

Salma avoids going out at playtime especially when the boys are playing football. She thinks schools should make sure everyone has some time to enjoy being in the playground.

Salma has had an operation on her throat a few times now. 'The hard part is fasting beforehand,' she says. 'When it's time for the operation they put a mask over your face to make you go to sleep, so you don't feel anything.

'Then when you wake up, you eat something cool and smooth, like ice cream or yoghurt. It hurts a bit the next day, but it makes it easier to eat afterwards.'

In the next few months, Salma is going to have another operation to insert a feeding tube in her tummy, called a gastrostomy. 'It will be easier for me,' she says. 'Sometimes I don't feel like eating, plus it takes too long.'

I'm stubborn! I like doing things my way

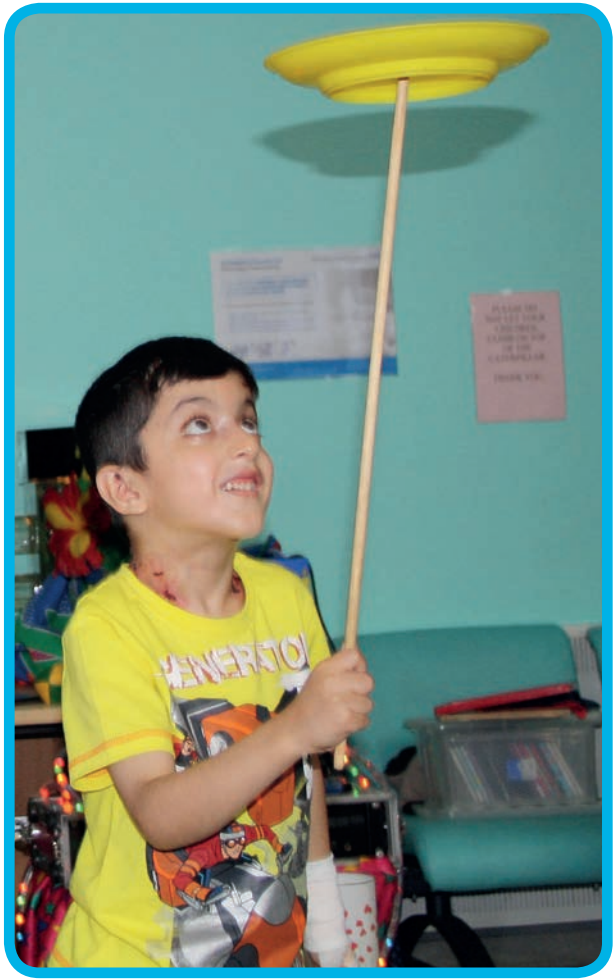
With the tube, Salma looks forward to being able to eat just the things she wants, while the tube will make sure she's getting enough nourishment to help her grow.

Salma's dad, Abdul, has this advice for other children with EB: 'Listen to your parents! They want to help you.'

Salma speaks up for herself. 'But I'm stubborn! And I like doing things my way,' she says. 'Sometimes I do a deal with my dad. If I'm good, and I take my medicine, then he gives me a treat or a little prize.'

Recently Salma has started going for short respite stays at Acorns Children's Hospice with other children with varied conditions. At first, her family came too, but now she goes on her own. She stays for two or three days. 'It's fun! We play games like hide and seek, and we do baking and swimming,' says Salma. 'I've made some good friends there.'

Salma at Birmingham Children's Hospital



Ahyaan

Ten-year-old Ahyaan has dystrophic EB (or CBeebies, as his younger brother Moiz calls it!) At school, Ahyaan enjoys PE. 'Dodgeball is my favourite game,' he says.

Ahyaan is learning to play the guitar along with the rest of his class at school. 'I like playing the guitar,' grins Ahyaan, 'but I don't sing.'

Ahyaan's mum, Afshan, had been worried that strumming the guitar's strings would cause too much friction, and damage his fingers. But his teacher found some fingertip protectors called 'Gorilla Tips'. So now he can play safely and join in with everyone else.

Afshan is naturally protective of her son. 'But the school has been great,' she says. 'They encourage Ahyaan to join in as much as he can, with PE and everything else.

I like playing the guitar...

They've convinced me to let him try.' As Ahyaan grows older, the doctor's advice is to let him decide for himself what is safe for him to do. He is using his wheelchair less than he used to.

Ahyaan has good friends in his class who look out for him. They understand about his EB, and they are protective if people from other classes says anything rude to him.

A one-to-one teaching assistant has worked with Ahyaan for several years now. She knows when he is feeling uncomfortable.

Nowadays, Ahyaan has a bath in the mornings and then they change his dressings, before he gets dressed – instead of doing it at bedtime. 'Sometimes I don't want to get up early to do the dressings,' frowns Ahyaan. 'But it means I have more time to do things I enjoy in the evenings.'

One of Ahyaan's favourite treats is a day out to Warwick Castle to see the knights jousting and the birds of prey. Last time they visited, the family were treated as special guests. They parked right next to the castle, and they were able to walk straight past all the long queues. Ahyaan's friend Leo was amazed and delighted. 'We had a great day!' grins Ahyaan.

'There are some perks!' laughs mum Afshan. 'We try to laugh about them. We would rather Ahyaan didn't have this horrible condition, and then we would happily give up the perks. But since he has it, we make the most of the perks!'

but I don't sing!

Ahyaan's mum, Afshan says:

I've come to realise that it's good to accept help and advice that's available. DEBRA, the EB charity, has helped us a lot, for instance with an appeal about a support worker at school. They provided a new washing machine when ours broke down. The EB nurses offer fantastic support, and now we are exploring respite care for Ahyaan, and some sibling support. Having a bit of extra support has really helped our family.

Tynan

Tynan is 9 and he has the severe type of EB simplex. When he was born, his skin was quite badly damaged. His mum, Carly, remembers as a baby he was bandaged almost from head to toe. 'It was a tough first year,' she says. But now Tynan's skin is much more settled, and he's increasingly independent. Mostly, these days, he deals with his own blisters and bandages. And then he gets busy doing the things he enjoys.

'I like building things with Lego,' says Tynan, 'and I love the story of the Titanic – I watch the film nearly every week!' And he kicks a ball around with his uncle in the back garden whenever he can, though the weather and the temperature do affect him.

Look after any scrapes, so your skin can heal

Now I've learned to let Tynan deal with things his own way

Tynan has learned to deal with people's responses. If they ask about his skin, he just gives them a brief answer. 'I have EB, a very rare skin condition,' he says. 'My skin blisters.'

Tynan's advice to others with EB is straightforward. 'Burst your blister with a needle. Then clean it, powder it or put a bandage on. Sometimes it hurts, but you've got to do it.'

Mum Carly nods in agreement. 'If you fall,' Tynan continues, 'your hands and knees can get very sore. You need to look after any scrapes, and get rid of any dirt or bacteria, so your skin can heal.'

'I guess I was a bit too protective,' says Carly. 'I've learned to let Tynan deal with things his own way.' And in the meantime, Tynan gets back to doing the things he enjoys!

Tynan with Santa and an elf at a Christmas family day at DEBRA Ireland

Dan and Corey

Dan (right) is 22. His brother Corey (opposite page) is 17. They both have the severe type of EB simplex – and so does their dad, and their nan, and other relations.

'We used to play-fight, just like any brothers,' says Dan. 'We'd just suffer a bit longer afterwards!'

'We're both missing a layer of skin,' explains Corey. 'We have no fingerprints where we had no skin when we were born. We could get away with murder! You have to have a sense of humour.'

As boys, both the brothers were in and out of hospital, sometimes for a few weeks at a time. 'Hospital was a place of comfort,' says Dan. 'The nurses and doctors knew the condition, and we helped medical students learning to diagnose skin conditions. We were treated like royalty!'

Corey explains it's important to look after your skin, especially face, hands and feet. 'You must sort out blisters straightaway,' he says. 'It's the first thing I do, as soon as I get back home.' 'If you do too much one day, you'll pay for it the next day,' he says. But the treatments are improving all the time, with cooling sprays and dressings that draw out infection. Loose clothing helps them to stay more comfortable too. 'I buy shirts a collar-size too big,' adds Dan.

Corey is at college, studying radio presenting. He is getting experience of presenting on college radio and at the local commercial station.

You need to make your own mistakes

I know what's good for me and my skin

Meanwhile Dan is an actor and a performer. He was bullied when he was younger, but acting has built his confidence. Sometimes he has to find a way round a problem – for instance in dance, he knew that he couldn't lift his partner. So he worked with the choreographer to adapt that part of the piece. Dan studied drama at Salford University, and is now doing a teaching degree. One day he aims to open a drama school.

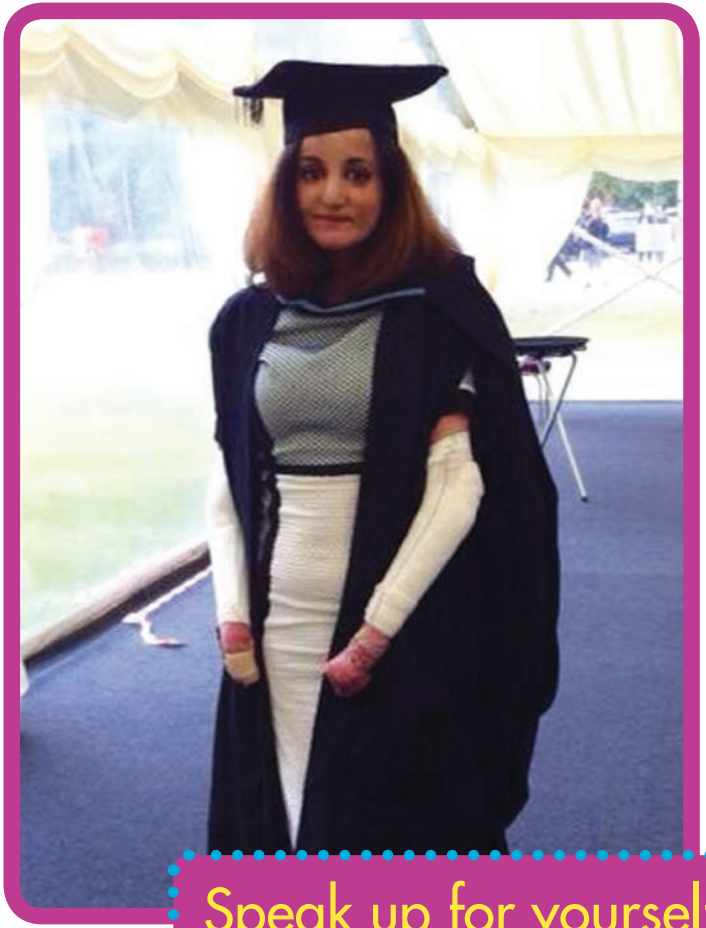
Both Dan and Corey are registered disabled. The process of getting registered can be tricky, because EB is a variable condition. The EB charity DEBRA can advise on matters like these. The brothers agree that DEBRA offers helpful practical support. However they are keen to get across the idea that not all EB is the same, and that you should get on with everything you want to do in life.

'You have to know your limits,' says Dan. 'Your family can be over-protective, and teachers and nurses too. But you need to make your own mistakes.'

'The teen years are the hardest,' nods Corey. 'But I know best what's good for me and my skin.'

What advice do Dan and Corey have for young people with EB? 'Always do what you want,' says Dan. 'The only person who will ever stop you is yourself. Love the skin you're in. Embrace being different! And don't let anyone put you down.'

Corey has advice too for parents of children with EB: 'Don't be scared. Don't limit your children. Let them graze their knee. It's like putting your hand in the fire. You learn!'



Myra

Myra has recessive dystrophic EB. She went to mainstream school, where she would come out of each class five minutes early, to avoid the rush and crush. Her proudest achievement is completing her history degree. 'It took me longer because I became ill, but I was determined not to drop out. I had support from my parents and from the EB team. I persevered.'

Now Myra works as an interpreter in the NHS and in the legal sector, and she volunteers on the burns unit, for DEBRA and Changing Faces. Myra speaks to trainee doctors about how best to discuss cousin marriage, an important issue within the Asian community. 'If there is illness in the family,' says Myra, 'then we should be advising against cousin marriage.'

Speak up for yourself. You need to be a bit feisty!

Don't let your condition keep you down. Aim high!

Myra's advice to young people with EB? 'Don't let EB become bigger than it is. Try at everything. Parents can be protective, understandably, but kids should push!'

Myra knows it's important to be confident, and ready to make the first move to make friends. Other people may feel shy, or unsure if it's okay to ask about EB, in case it might offend. So Myra has always tried to reach out to people in order to get to know them, and she welcomes questions.

Myra advises parents, too, not to assume a child is limited by their condition. 'Even people with really severe EB have achieved a lot. Don't mollycoddle your child! They need to be able to make independent decisions,' she says. 'Our parents always pushed us to get our education and to get on in life. You need to work harder to get past the barriers.'

Myra's younger brother, Qassim, also has EB. Qassim is ambitious. He is currently studying for A Levels, and wants to go into law or banking. He says, 'My faith gives me a sense of higher purpose. It gives meaning to my condition. If people ask, I say I have a condition which makes my skin sensitive to friction. But my identity is not my condition. I deliberately keep information to a minimum, unless people ask for more.'

Qassim's advice? 'Don't let your condition keep you down. Aim high!'

Myra nods in agreement. 'It's just a skin condition,' she says. 'Speak up for yourself. Make sure the doctor talks to you, not to your parent. You need to be a bit feisty,' she smiles.

My identity is not my condition

Amy

Amy is 30 and works for an accountancy company. She is studying part time for a law degree as well. She and her boyfriend, Richard, have travelled far and wide, including to Florida, Switzerland and a cruise to the Canary Islands. They've just bought a house together.

Amy has recessive dystrophic EB. From the age of six until she was 17, she had a gastrostomy (a feeding tube in her stomach). 'Some people prefer it because they don't have to worry about eating enough,' she says. 'But I hated it right from the beginning. So by 15 or 16 I was trying to eat properly. It was difficult at first, but I'm glad I don't have to use the tube now.'

Amy found careers advice at school discouraging. She started office work for a few years, but then later chose to go to university hundreds of miles from home.

Amy on holiday in Rome

'It was harder for Mum than for me – but she'd brought me up to believe there wasn't anything I couldn't do!' At first Amy lived in an adapted room in the student village, but by her final year she had moved into mainstream accommodation.

Amy has had 10 hand surgeries, as well as oesophageal widening. 'Surgical techniques are improving all the time,' she says. 'Now with nerve block and sedation, instead of general anaesthetic, you recover more quickly. As a child, I was sicker for longer after surgery. Now I'm less afraid, more proactive about surgery.'

Amy has been considering genetic counselling and the possibility of having children. She does Pilates to help stop her joints seizing up, and to maintain her core stability – and her independence.

Now Amy is a trustee for the EB charity, DEBRA. She lives independently, dressing herself, doing the washing up, and the cooking. 'Though I did get out of the washing up for a bit, after my recent hand surgery!' she laughs. 'I definitely feel a bond with people who have a similar condition. But EB isn't the main thing in my life.'

I feel a bond with people with EB – but it isn't the main thing in my life

More information and support

DEBRA UK and **DEBRA Ireland** are charities providing an enhanced EB Healthcare Service, in partnership with the NHS / HSE, to deliver optimal healthcare to children and adults living with EB. DEBRA's community support staff work directly with individuals and families, offering practical and emotional support, financial help, respite breaks, and information on different aspects of living with the condition. DEBRA also funds pioneering research to find effective treatments for EB, and ultimately a cure.

DEBRA UK
Website: **www.debra.org.uk**
Telephone: 01344 771961
DEBRA UK's free membership scheme is open to everyone living or working with EB in the UK:
www.debra.org.uk/membership
Email the EB Community Support team directly:
membership@debra.org.uk

DEBRA Ireland
Website: **www.debraireland.org**
Telephone: 0353-1-412-6924
Email family support worker directly:
info@debraireland.org

Childline offers advice and support to children.
Website: **www.childline.org.uk**
Telephone: 0800 1111

Changing Faces supports people who have any condition or injury that affects their appearance
Website: **www.changingfaces.org.uk**

Birmingham Children's Hospital provides a service for children with EB.
Website: **www.bch.nhs.uk/story/epidermolysis-bullosa**
Telephone: 0121 333 8224

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Young people with EB can feel very alone. It is good to know that someone else shares your experience and understands. This booklet is a collection of true stories and photos of real people with EB, so you can read about how they cope with it.

Introduction by Fiona Browne, Consultant Dermatologist

Written by Mandy Ross. Designed by Heather Blackham

Original series conceived by Professor Celia Moss, Birmingham Children's Hospital, and Mandy Ross, developed by BCH Charity and designed by Anne Matthews

Published in memory of Heather Blackham, and also of Liam.

Birmingham Children's Hospital Charity

debra for people whose skin doesn't work we do

DEBRA Ireland

ciste na gcuntas díomhaoin the dormant accounts fund

This project was approved by Government with support from the Dormant Accounts Fund

Further copies of this booklet can be obtained from Debra UK, Debra Ireland or BCH Charity www.bch.org.uk