

'My skin peels off'

Alex Hood is an average teenager with problem skin – but unlike her friends, her flesh peels off in clumps

Head bowed, I shuffled along the pavement. Each step hurt, but I was determined to keep going. The corner shop wasn't far and I wanted to get there as quickly as possible.

But then I saw them – a group of local kids. And they saw me.

'Freak girl,' one boy jeered.

Another shied away from me. 'Yuck! Mummy Girl is here... Zombie...'

Trying not to cry, I ran for home. I should have been used to the jibes by now. But I wasn't. I *did* look different.

I'd been born with a rare skin condition known as dystrophic Epidermolysis Bullosa (EB).

My skin was as delicate as a butterfly's wings – the slightest touch made it flake off.

It meant my life was a round of hospital appointments, steroid creams, bandages and dressings.

Back home, I hid my tears from my family. There was no point getting upset every day. This was my life. There was no cure – I just had to get on with it.

As a little girl, I'd been left out of normal children's games.

'Play on the climbing frame with us, Alex,' my friends shouted, their excited voices echoing around our local park.

'I can't,' I said, as tears for frustration stung my eyes.

'I might get bumped.'

Few babies with EB survive childhood. Doctors hadn't expected me to live past the age of two, but I'd already proved them wrong.

Mum helped me change my dressings every day, and specialist nurses came round four times a week to treat my red-raw skin.

Cruel comments

My dad started supporting a charity, the Dystrophic Epidermolysis Bullosa Research Association (DEBRA), to help me and others with EB.

He organised events to raise money and awareness. And I met lots of famous people. Mike Tyson, Frank Bruno and Mohammed Al Fayed – they all came to the fundraising dinners and events.

As I grew older, people would whisper when I walked down the street. 'Urgh, look at that freak,' I'd hear them hiss.

I knew I looked awful – a walking mummy, covered in bandages, leaving a trail of crusty white skin behind me.

School was even harder. Cruel taunts followed me everywhere. If anyone shoved past me in the corridors, scabby skin showered the floor.

One day, I tripped over a chair and a massive layer of skin ripped off my back. 'Oww,' I cried, writhing in pain.

My family and friends are so supportive, and over



the years, I've learned to cope with the treatment for my super-sensitive skin. I spend hours every day covering myself in bandages and creams.

Shopping trips are still a tricky experience. I dread trying on clothes and spraying the counter with dry skin as I pay. But I'm determined to act like a normal teenager.

Relationships are hard, too. I don't feel attractive in manky bandages, and physical contact leaves my skin red and sore.

I've never had a boyfriend. What's the point if you can't kiss and cuddle properly?

Living my life

Hopefully, one day, I'll find a guy who'll understand my condition and treat me with kid gloves. But for now, I'm happy being single.

My skin doesn't stop me going out with mates. I just make sure I avoid packed bars and jump away if people try to hug me.

I occasionally get a cuddle from my family or close friends, but they have

to touch me very carefully or it's really painful.

I'm currently studying to be an interior designer, and I'm getting on with my life.

There's no cure for EB yet, but scientists are making progress all the time.

Some days I get upset, but everyone has things they don't like about themselves.

Instead of hating my boobs, or my bum, I hate my skin. But I'm happy, healthy and loving the life I've got.

Alex Hood, 18, Leamington Spa, Warwickshire

Epidermolysis Bullosa (EB): The Facts

EB is a group of blistering skin conditions. Sufferers' skin is so fragile, even minor rubbing may cause blistering. In severe EB, blisters can develop in the lining of the mouth, stomach, oesophagus, intestines, upper airway, bladder and the genitals.

It's said to affect two to four people out of every 100,000.

There are three types of EB – simplex, dystrophic and the most severe, junctional, which can be fatal in infancy.

Visit www.debra.org for more information.