

"True Happiness?"

by
Nicky Porter

Nicky grew up believing she was born unlucky and would never find true happiness....

As Nicky Porter talks to her husband, Stuart, one of their young children reaches up and tries to grab Nicky's hair. Catching his hand she gently scolds him. Nothing out of the ordinary in that, except that she isn't worried about her hairstyle - just that what's underneath might be revealed. Despite being just 20 years old (21 in July) Nicky wears a wig to hide baldness and ugly scars on her scalp.

She suffers from a rare condition called Ectodermal Dysplasia and has worn a wig, a hearing aid and dentures since she was a child. "I don't mind so much now because I'm used to it, but as a child I hated being different to everyone else," she says. "I spent so much time in hospital that it became almost my second home."

Although ED is a genetic condition neither of her parents had shown any sign of it and Nicky wasn't diagnosed herself until she underwent an operation to correct a cleft palate when she was a toddler. As a baby, she'd suffered severe cradle cap and developed an infection on her scalp. The infection was scraped off and the hair on the top of her head never grew back. "My GP sent me to have plastic surgery on my scalp," says Nicky. "I had countless tissue expansion operations to try and make my hair grow back, but it never worked and my scalp was left covered in scars."

By the time she started school Nicky also had a scar behind her left ear after failed operations to fix her hearing impairment and her teeth were badly misshaped and had little enamel so they were removed.

"I didn't know I had ED because by the time my parents thought I was old enough to understand I had two younger sisters and a brother - all free from ED - and there was never a quiet moment to sit down and talk to me about it. I just thought I'd been born unlucky because I had so many health problems and looked different to everyone else."

That changed when Nicky started high school when, for the first time, she was teased and bullied by other pupils because of her appearance. The problem was made worse when at the age of 12, Nicky turned up for school wearing her first NHS wig. "The previous day I'd gone to school with my usual patchy, pale, brittle hair and scarred scalp and then the next day, I turned up with a full head of perfect hair," she says. "I was called 'wiggy' and the subject of everyone's jokes."

When she was 14 Nicky demanded that something was done about the bullying. Instead of addressing the bullying the school brought in a Counsellor to help Nicky deal with it. It was the Counsellor who told Nicky she was suffering from ED and put her in contact with the ED Support Group. "It was fantastic knowing, at last, that I was different for a reason," she says. "I hadn't just been born unlucky. But knowing why I was different didn't stop the bullying."

She spent much of her time writing poetry and stories often starring herself, but as a beautiful girl with long permed hair who grew up to marry and have children - something Nicky was convinced could never happen to her.

"I believed my looks meant no one could ever fall in love with me and I'd spent so much time in hospital, I convinced myself my family would be better off without me," says Nicky.

At school, a few days before her 15th birthday Nicky swallowed a packet of paracetamol tablets. Luckily a friend suspected something was wrong and searching Nicky's bag discovered the empty paracetamol packet and alerted their teacher. She was rushed to hospital where her stomach was pumped and the reaction from her family and friends proved to Nicky how much she was loved and cared about.

After leaving school at 17 Nicky started a one-year health and social care course at her local college. She and her friends used to communicate with other students using an internal computer mailing network and one day Nicky starting chatting online with a student called Stuart. After several computer chats and a quick glimpse of each other in a corridor Stuart asked Nicky on a date.

"I was really excited because despite having seen me he was still interested, but I was terrified of being rejected once he'd found out about ED," she says.

A few weeks later and Nicky's opinions on her future had changed radically. She says: "I was really falling for Stuart and he told me he felt the same way. For the first time I actually believed that it could be possible for me to have a normal relationship and even perhaps marriage."

Three months after they'd begun dating Nicky still hadn't told Stuart about her condition and it was obvious to him that something was on her mind. He told her she shouldn't be scared to tell him so she told him a little about her ED. Her rejection fears proved totally unfounded.

"It didn't bother me in the slightest. I liked Nicky for who she was not whether she had her own hair," remembers Stuart, a supermarket canteen supervisor. "She'd never let me touch her hair so I'd had a few suspicions anyway."

The following month Nicky was shocked to discover she was pregnant. "I'd always assumed I wouldn't be able to have children because of my health problems and although a Geneticist revealed our baby would have a 50 per

cent chance of inheriting ED, we were overjoyed at the thought of becoming parents," she says.

The couple moved into a council flat together and while she was pregnant, Stuart once again proved his love and commitment to Nicky when they met up after a dentist appointment. "I told Stuart I needed a new set and he asked 'a new set of what?' He'd never realised I wore false teeth and it'd never occurred to me to tell him. But even my dentures didn't faze him!"

She sailed through her pregnancy and Michael was born in December 1998 and was immediately diagnosed with ED. "I was a little anxious," says Nicky. "My ED hadn't bothered Stuart but now I'd given birth to his son who'd inherited my condition. But again, it just wasn't a problem for him."

Nine months later Nicky and Stuart, who were both 19, shared their perfect wedding and within months they began discussing the possibility of extending their family. Nicky quickly fell pregnant again and at her first scan they were told they were expecting twins.

"Having coped with ED myself I knew I'd be able to help Michael understand his condition and although we didn't want the twins to have ED too, if they did then we could deal with it."

Rebecca and Sophie were born last November and were free of ED. Since then the family have moved into their own five-bedroom house, which they are renovating.

"I'm still insecure about my looks and probably always will be," says Nicky. "Stuart hasn't seen me without my wig or a headscarf on. I know it wouldn't change the way he feels about me, but I'm worried it might change the way I view our relationship.

"Growing up, I just wanted to look normal because I thought only normal looking people could find happiness - but thanks to Stuart I've proved that it doesn't matter what you look like - there's love and happiness out there for everyone."

Some names and locations have been changed in order to preserve confidentiality.

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