



Elaine St. Helen looks ahead to a bright future

Putting on a brave face

About 400,000 people in Britain have a disfigurement to their face, hands or body. Their imperfections could be the result of any number of conditions – from birthmarks and burns to a cleft lip or skin conditions. Some people were born with their disfigurements. Others developed them following an accident or cancer treatment. Whatever the reason, these people may suffer crippling psychological and social. Marissa Charles investigates.

When she looks in the mirror, Elaine St Helen sees an image that is slightly out of proportion. The left side of her face is swollen. The jaw-line is heavy. It is the sort of puffiness you would expect after returning from the dentist, following the removal of your wisdom teeth. In truth, Elaine has had some teeth removed. She lost all those that sat on that side of her mouth.

It makes sense really, because the whole of the lower jaw on the left-hand side of Elaine's face has been removed. Remarkably, there are only a few telltale signs of the procedure that she underwent. There is the strip of hair that has been shaved from her head (roughly two centimetres wide and stretching from her crown to above her left ear), which marks the surgeons' point of entry. They had to peel her face back to remove that side of her jaw.

The other clue that Elaine is recovering from an extensive operation is the 30-centimetre scar that stretches along her lower left leg. That is where the surgeons had to remove her fibula bone. They removed it and put it where her jaw once was. They split the bone into three parts, so that it

could conform to the right shape. Then they fine-tuned it, carving it so that it sat securely in its new home.

Stitches have now re-sealed the skin on her leg. Staples were applied to the wound in her head. For a few weeks Elaine will have to walk on crutches. She will also find it painful to speak. It will be hard for people to decipher what she is saying. Her tongue feels heavy. Until she receives dental implants, she will maintain a soft-food diet. And, when she does eat, it will be painful to swallow. But despite all these hardships, Elaine St Helen is overjoyed. She feels as though she has got her life back for the first time in years. She no longer feels suicidal or depressed – just relieved.

Before her operation, Elaine had an ameloblastoma. A rare disorder, it is a benign tumour of the jawbone. Occasionally the growth can be malignant. Most of the time it just eats away at the jaw. Elaine discovered something was wrong when she was 20. "My jaw felt heavy. It was swollen. I noticed because I could feel a lump in my face." Thinking something was wrong with her teeth, she went to the dentist, who diagnosed her disorder. She was told that surgeons could go into her mouth and scrape the tumour out from inside, but it would come back.



The scars still leave their marks



Elaine shows where the doctors removed a bone to use in her jaw

She would have to have surgery at yearly intervals for the rest of her life. As the tumour grew more noticeable and wreaked havoc in her mouth (some of her teeth just rotted away and fell out), Elaine felt more self-conscious. She felt embarrassed around people when she had to explain what was wrong with her. "I used to comb my hair on that side to try to hide it. People would ask if I had a toothache or if I was taking care of my mouth. I used to cry. I bawled when my teeth fell out. I would sleep badly, eat badly... I used to have nightmares about my mouth falling out."

Today, post-surgery, it is a different story. The 27-year-old mother of two feels like a stronger person. Her confidence has soared. "I will be able to speak up for myself more. I was very quiet before." Elaine's post-operative positive reaction is not unusual to her surgeon Iain Hutchison. The consultant in oral and maxillofacial surgery is also the research director of The Facial Surgery Research Foundation: Saving Faces. Launched in 2000, the charity aims to share information among surgeons in the UK about the best treatments for facial disfigurements brought on by benign tumours, malignant cancers or facial injuries. When Mr Hutchison restructures faces, he frequently finds that, along the way, he has helped to transform the self-esteem and thus the lives of his patients. "There are people that I've operated on who were garage mechanics before I operated on them and afterwards they end up owning a fleet of garages," he says. "Like a flowering bud, when you first see them they are all closed up. After the operation, voom! they blossom – they open up."

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What Hutchison acknowledges is that the face and appearance can be inextricably linked, not only to a person's self-confidence, but to how they perform in society. Some people who suffer from disfigurement feel awkward in social situations, shying away from meeting new people or forming romantic attachments. Many face discrimination. They find it difficult to find a job or avoid going out in public, tired of being constantly stared at in the street.

Surgery or medication can be used to correct or improve some imperfections, but other strategies can also be useful. For



Maxine Whilton is now at ease with her improving vitiligo

decades Maxine Whilton, a retired academic librarian in her early 60s, found that make-up was her coping mechanism. Since the age of 12 Maxine has had vitiligo – a skin condition that depletes the skin's pigmentation. The disease developed when she was in Jamaica. As children do, she fell over and scraped her knee. The wound healed, but the colour did not return properly in that area. There was a little patch of white skin surrounded by her mahogany hue. At the hospital Maxine was diagnosed with vitiligo. Neither she nor her parents had heard of the condition. And it wasn't until she came to England at 18 that she saw another person with it.

At first the vitiligo did not concern Maxine. But as she hit her mid-teens, white patches started to appear on her face. They surrounded her eyes giving her a reversed panda-like look. It removed the colour from her lips and around them, making her appear like a black-and-white minstrel. Although she was popular at school and had plenty of friends, Maxine admits that vitiligo affected her. "I felt isolated, like I was a freak or something. I didn't think I would ever get a boyfriend, get married or have children."

Maxine was wrong. She did get married and went on to have two children. For many years make-up restored her confidence. When she arrived in Britain, her GP gave her some make-up on prescription that could even out her skin tone. "I just slapped it on. A bit round my eyes and on my lips before I put lipstick

on and I would pretend that I had nothing." She would never dream of leaving her house without her security blanket. And, as the vitiligo spread to her arms, hands and legs, Maxine took further steps to hide it. She always wore long-sleeved shirts, even in the summer. And going swimming in the sea or in a pool was out of the question. She tried it once or twice, but was too embarrassed by the patches of white that were revealed.

It was not until Maxine hit her 40s that she realized that her coping mechanism was no longer working. She was going through the menopause. Her children were leaving home. Her father had a heart condition and Alzheimer's. And her vitiligo was getting worse. Despite all the concerns she faced, Maxine focused mostly on her skin. Her appearance was changing rapidly and she was distressed. She says: "It was this feeling of lack of control, that something was taking over my body."

Encouraged by her husband, Maxine visited a counsellor. It was the turning point in her life. Her counsellor had a cleft lip and palate, so he knew what it felt like to have a facial disfigurement. Over nine months he encouraged Maxine to look in the mirror each day without make-up. Instead of telling herself that she was revolting, she had to notice the positive things about herself – from her beautiful smile to her curly eyelashes. The counselling worked and eventually Maxine was able to make short trips outside barefaced.



Maxine can now afford to smile

Nevertheless her first trip across London without make-up was a harrowing experience. It happened four years ago, long after the counselling. She had to travel from her home in Essex to St Thomas's Hospital to participate in a trial to restore her skin's pigmentation. She went on the Tube, wearing dark glasses, and shielded from the outside world with a broadsheet. No one said anything to Maxine. And, although she burst into tears when she arrived at the hospital, she was elated that she had left the confines of her local area, for the first time in 30 years, without make-up. Now she does so on a regular basis without giving it the slightest thought.

Today, like Elaine, Maxine is a more confident person. But acceptance of her vitiligo has been a journey. The counselling helped her. So, too, did becoming a member (and later the chairman) of the Vitiligo Society, which provided her with support and information. The experimental trial, which involved exposure to ultraviolet B light, is not widely available, but it has restored the majority of pigmentation to her face.

Dr James Partridge, a friend and colleague of Maxine, agrees. Dr Partridge, himself a burns victim, is the chief executive of Changing Faces, a charity that helps people with facial disfigurements come to terms with their imperfections. The organization gives patients social and psychological tools to deal with situations that can cause them anxiety. Surgery, he insists, though often helpful and necessary, is not the cure-all it is perceived to be. The surgeon's knife cannot remove physical scars. But cognitive behavioural therapy (CBT) can smooth away psychological ones. CBT involves looking at how a person thinks and behaves and revising that thought process and behaviour. Paul Farrand, a senior lecturer in psychology at the University of Plymouth, explains how CBT works. "You can do role rehearsal with a patient who finds it hard to cope when people stop and stare at them. Someone may say something rude and the patient can use a simple statement to deal with it."

But even when the facially disfigured are armed with such tools, constantly dealing with the ignorance of others can be difficult. Forty-year-old John Corion has had a port-wine stain covering half of his face and the top of his chest since his birth. He is used to looking "different" and uses humour to put people at ease when he first meets them. But humour cannot always shield him from stares and impertinent questions. A Bedford resident, John says the Caribbean is the worst place to go if you have a facial disfigurement. He tells of one experience of many. While on holiday in Carriacou, a small island off the coast of Grenada, his father introduced him to an old friend. John held out his hand. The woman pulled hers away. "What's the matter with your face?" she asked. John was incensed. "I felt like saying, 'My name is John. What's yours?'"

Over time, the counsellor encouraged Maxine to look in the mirror each day without make-up. She had to notice the positive things about herself: her beautiful smile or her curly eyelashes.

It is this reaction to people with facial disfigurements that Changing Faces is working to change. Dr Partridge believes that educating the public is as important as empowering those who look different. So the charity has started an advertising campaign advising people on how to react when meeting a person who is facially disfigured. Here is his tactic: "Don't look away. At the appropriate time you might want to ask about the disfigurement. Don't do it in the first few seconds. Instead, look the person in the eyes and shake their hand." It is simple and effective, and it just might work. And when it does, something remarkable happens to the person that is not disfigured. John says: "They start talking to me as though I am anybody else." What more could a person ask for? ☐

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