

'Don't worry... it's the inside that counts'

James Partridge and Adam Pearson give personal perspectives on visible difference, and outline a view of the way ahead

Many people who experience disfigurement will have been given the 'Don't worry, it's the inside that counts' treatment. It's what people, with the best intentions, frequently say. But they're wrong. No one doubts the inside counts but outsiders matter too – don't discount faces just because they look different! But liking and living with 'different' outsides can be very challenging.

JAMES As soon as I venture out, my face is what people look at. It's a cliché, but appearances do matter. Faces matter very much indeed, especially in first meetings. When I first took my face out in public – scars, distortion and all – I had to sanction people looking at it. I tried to make people come to admire it – even like it – just as I had to learn to do, as the embodiment of me.

ADAM As a member of the so-called 'Generation X', I learned quickly and harshly that the outside is thought to be very significant in today's society. Growing up, I was teased anyway, but between the ages of 14 and 17, people seem to prioritise appearance and image above everything else. It was not the teasing that bothered me though, because I learned ways of coping, but I still get frustrated with the judgements about me based on my outside without

finding out about the inside me – and they judge that I am slow or stupid.

Life can be challenging for anyone who has a disfigurement. Medicine and surgery are vital in saving lives and can often substantially reconstruct a face's aesthetic appearance and improve its function, but they can rarely remove a disfigurement completely.

Cranio-facial, plastic and maxillo-facial surgery specialties combined with laser

treatments, prosthetics and orthodontics now have sophisticated techniques to reconstruct faces and improve aesthetics. But the results are still

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some way short of the miracle that Hollywood and the cosmetic surgery industry would have us believe. Scars cannot be removed; complexions can rarely be smoothed, asymmetry is very hard to correct. The latest prospective technique in the surgeon's armoury, face transplantation, offers another approach but it involves many potential complications, risks and uncertainties (see Morris et al., 2006: available from tinyurl.com/ypd26y).

In today's society, any disfigurement threatens a person's self-esteem and self-confidence – and it is often associated with low expectations (see Cole, 1997; Grealy,

1994; Partridge, 2006). As other articles in this special issue highlight, severity does not predict how distressing a disfigurement will be. The socio-economic effects can be significant and the demands on health/social services can be costly and preventable.

Research and the charity Changing Faces' experience of helping people with these concerns since 1992 (e.g. Clarke, 1999; Kish & Lansdown, 2000; Partridge, 2006) indicate that the psychosocial problems have two main, interrelated roots:

- I Interpersonal: Many difficulties can be traced back to social encounters: dealing with other people's reactions like being stared at, avoided, ignored, asked curious questions, ridiculed, and refused or given inadequate services. If these encounters go badly, a person can become withdrawn, reclusive and isolated. This can lead to problems at school, in making friends and gaining employment.
- I Intrapersonal: Living in a society that prizes 'good looks' highly makes people with disfigurements vulnerable to feelings of inferiority and inadequacy from which low self-esteem stems; if the equation between looks and success is not effectively debunked, a person's morale can plummet; anxiety, depression and, in extremis, suicide can follow.

The combination is potentially devastating – but it needn't be like this. With the right support and social climate, it is perfectly possible to lead a successful and fulfilled life with a disfigurement. Changing Faces' efforts have all aimed to foster that empowering support and promote that inclusive culture.

JAMES My toughest time was probably when I faced the nasty triple whammy of discovering the limits of surgery, starting to live on my own and failing to get a relationship going with someone I cared for a lot. I was angry, sad, isolated, demoralised all at once – and my face seemed definitely to blame.

ADAM Secondary school, in a word, sucked. My generation, so addicted to glamour magazines, gave me five years of aggravation and bullying. However, on reflection, it has made me a stronger person. I can now handle those situations with dignity and class instead of

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being hostile and a little childish. It forced me to grow up quicker, and without that experience I wouldn't be half the man I am today.

There are more stories from young people on our new website, www.iface.org.uk, which the Changing Faces Young People's Council helped to create.

How can you adjust?

The twin processes involved in adjusting to a disfigurement – developing self-confidence (the ability to project oneself in social situations) and building self-esteem (the inner sense of self-worth) – are seriously challenging.

Self-confidence grows from learning that, by your behaviour, you can influence how other people respond to you, especially in the first crucial moments of a meeting (Blakeney et al., 2005; Kleve et al., 2002; Robinson et al., 1996).

JAMES I experimented with different levels of eye-contact, handshake, verbal energy and body language, and found out and eventually mastered the skills to deal with the scared-ness I met – 'scared' being an acronym for staring, curiosity, anguish, recoil, embarrassment and dread. These skills mediated the effect of my outside and boosted my inside too.

ADAM I discovered too how to control a social situation – just going up to someone who is staring or acting funny and saying 'Hi' is a really good way of breaking the ice and showing your human side. Having just been through the university system I have had to meet hundreds of new people so unless I had been able to introduce myself in a confident (and slightly cocky) way, I doubt I would have found the experience anywhere near as fulfilling as I did.

Building inner self-esteem means finding a way to like your face with all its quirks, in a society that does not. To do that, you have to challenge the validity of the prevailing value judgements about appearance.

JAMES I had to disabuse the negative cultural value placed by my conditioning on scars (as in 'scar on the landscape') and the 'not pretty' judgements made about imperfect complexions. I had to become counter-cultural in the extreme, almost revolutionary. Since setting up Changing Faces, I have encouraged many people to be revolutionaries too!

ADAM The first step was getting to like myself. No one else will like you or believe



James

One evening in late 1970 I contrived, as a newly qualified driver, aged just 18, to turn a Land Rover over on a sharp corner in Wales – and it exploded in flames. In a trice, my life changed. My face and 40 per cent of my body were severely burned. I spent a gap year in a burns unit and the next five years undergoing extensive and brilliant plastic surgery. But I had lost my 'good looks' that I had so prized, for ever. My face is a patchwork quilt of scars, skin grafts and unusual (outstanding) features.

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your confidence until you do yourself. People expect me, and other people with disfigurements, to be quiet and reserved. I am at the complete opposite. I have the attitude that, because of the way I look, people are bound to stare regardless of what I am doing. I think I would be conning them if I didn't give them something to watch.

And of course it is not just individuals themselves who have to adjust – parents, siblings and partners do too (Kish & Lansdown, 2000).

What Changing Faces does, and wants to see happen

Changing Faces has developed a sensitive, empowering service which hundreds of people with disfigurements and their families access each year and that enables them to acquire the 'disfigurement life-skills' they need.

The Changing Faces package involves helping people with any sort of disfiguring condition to ensure that their outside is valued and their inside is open and interesting:

- I Finding out – gaining realistic information about their condition and its treatment;
- I Attitude-building – developing a positive set of beliefs about their future (eg: by challenging false misconceptions and meeting positive role models);
- I Counselling –

receiving emotional support, face-to-face, by e-mail and on the phone;

- I Exchanging – sharing experiences with others in similar situations, through workshops or by connecting with the many condition-specific support groups that now exist;
- I Social skills training – learning new strategies for handling other people's reactions to their looks in any social situation.

We believe everyone should have access to psychosocial help through the NHS – and teachers, schools (see Frances, 2003) and employers too have a major role to play. Delivered under the supervision of psychologists, it can complement the skills of surgeons and other therapists and promote sustainable self-esteem and self-confidence.

Adam

My visible difference is a genetic condition. I have always had it and didn't have to make lifestyle adjustments suddenly. It's called Type 1 neurofibromatosis (Nf1). This means that excess tissue grows on nerve endings causing growths, or fibromas, to grow all over the body. In my case, a majority of the growths are in my face and head. Whilst it is impossible to get rid of the fibromas completely, you can have them surgically debulked so they are less apparent. I have had 24 of these procedures up until this point – I am 22 years old.

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