



Changing
the way you face
disfigurement

Moebius Syndrome Foundation, Washington DC, July 2014

Looking imperfect in a look- perfect world: insights and challenges

James Partridge OBE, DSc (Hon), FRCSEd (Hon)
Founder and Chief Executive, Changing Faces





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'Disfigurement'

- a collective word referring to the effect that any trauma or medical condition or their treatment can have on the appearance or function of a face or body, making it look different, unusual, scarred or asymmetrical
- covers all the different causes of unusual-looking faces (1 in 111 people) and bodies (1 in 45) such as:
 - birthmarks, clefts and cranio-facial syndromes
 - scarring from accidents, burns, self-harm, warfare
 - cancer and its treatment
 - eye or skin conditions
 - facial paralysis
- used in the UK's Equality Act 2010 protecting people with disfigurements from discrimination
- not the word to be used to describe an individual's condition or visible/facial condition – name it!



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About Changing Faces

Mission:

To create and work for a better and fairer future for people of all ages with face and body disfigurements from any cause

Organisation:

- set up in 1992, underpinned by user views and research
- raises £1.4m pa primarily from voluntary donations
- has 30 full-time posts (18 f-t, 19 p-t) in London with Regional/National Managers in the English Regions, Wales, Scotland and N Ireland
- manages the Skin Camouflage Service with 200 trained volunteers in 140+ monthly NHS clinics and community centres

Programmes:

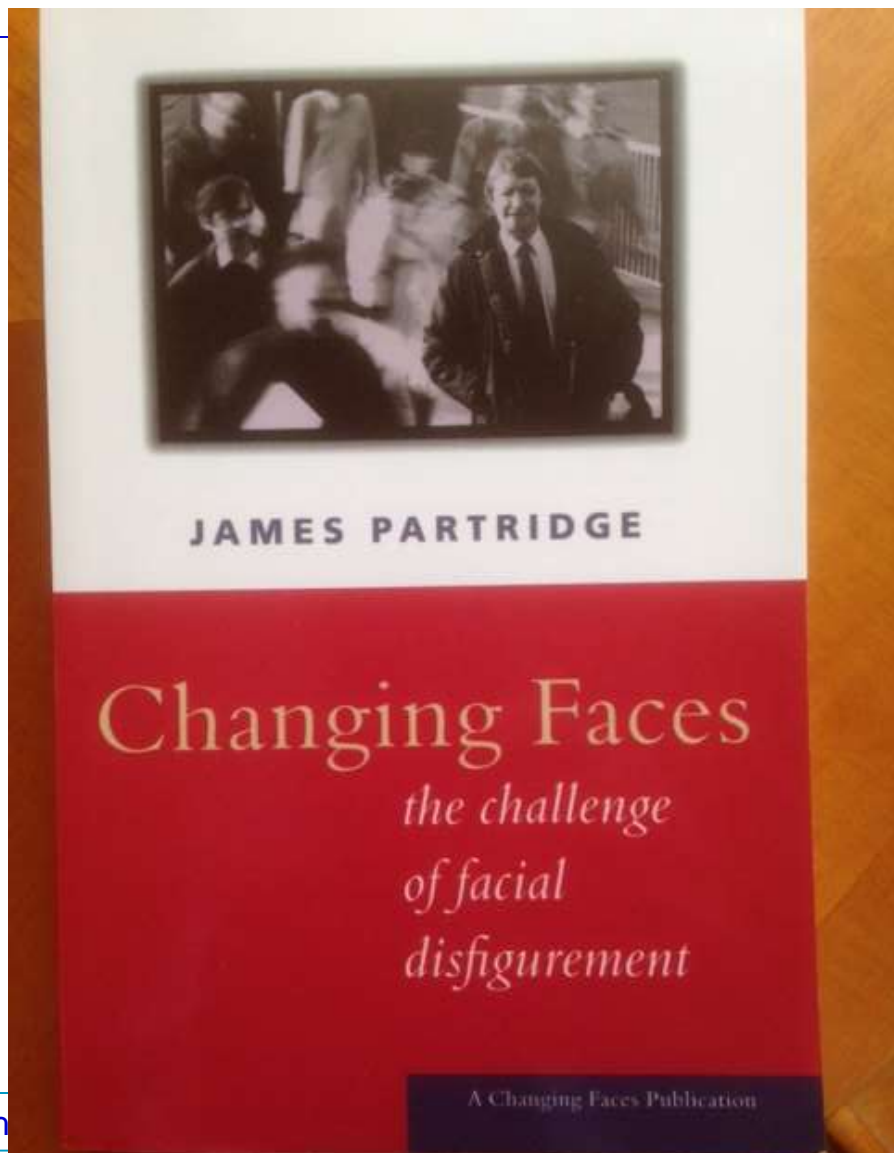
- **Changing Lives:** to build self-esteem and confidence of individuals and families and to advocate for better psycho-social care/services
- **Changing Minds:** to promote 'face equality' for all whatever their face or body looks like, free of prejudice and discrimination





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My book, published by Penguin in 1990



Ch

A Changing Faces Publication

gfaces.org.uk



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Insights from earlier research

Frances Cooke Macgregor wrote in 1990:

- “In their attempts to go about their daily business, people with (facial) disfigurements are subjected to visual and verbal assaults, and a level of familiarity from strangers not otherwise dared: naked stares, startled reactions, double-takes, whispering remarks, furtive looks, curiosity, personal questions, advice, manifestations of pity or aversion, laughter, ridicule and outright avoidance.”

Erving Goffman (Stigma 1963) wrote;

- the moments when stigmatised and normal are in the same social situation... [are] one of the primal scenes of sociology... [a moment] when the causes and effects of stigma must be directly confronted by both sides... The stigmatised individual may find that he[/she feels unsure of how we normals will identify and receive him[/her]. He is likely to feel ‘on show’ having to be self-conscious and calculating about the impression he is making... Even when he achieves something creditable, he is likely to feel that others view these as ‘remarkable in the circumstances’.



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Living with a disfigurement: everyone is vulnerable to:

- 1. INTRA-PERSONAL:** low self-esteem in 'look-perfect' culture
- 2. INTER-PERSONAL:** self-confidence challenged in dealing with other people's reactions; many problems can be traced back to social interaction difficulties...
Macgregor: People experience a loss of "civil inattention that most people take or granted" and yet also a sense of isolation
- 3. MEDICAL ISSUES:** unresolved questions about medical and surgical choices/access + complex information + **LACK OF PSYCHO-SOCIAL HELP**



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What Changing Faces does

We try to tackle 'both sides of the coin':

- **Changing Lives:** to build self-esteem and confidence of individuals and families and to advocate for better psycho-social care/services
- **Changing Minds:** to promote 'face equality' for all whatever their face or body looks like, free of prejudice and discrimination



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CHANGING LIVES: The FACES Package

Successful adjustment to a disfigurement involves an individual and family having access to help (and/or social support) that enables them to gain the **life-skills** to manage it.

The FACES package involves:

- F FINDING OUT** about their condition and its treatment
- A** Getting '**ATTITUDE**', a positive outlook/belief about future
- C COPING** with feelings (anxiety, anger, loss, intimacy etc)
- E EXCHANGING** experiences with others
- S SOCIAL SKILLS** training to manage others' reactions

FACES can

- be delivered by Changing Faces Practitioners and suitably-trained health care professionals
- be accessed in self-help format from our website and via FACE IT and be facilitated by support groups



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CHANGING LIVES: Skin Camouflage

- The Skin Camouflage Service is delivered by 200 trained volunteer Practitioners
- Gives advice on how to self-apply camouflage creams that are on the NHS prescription list
- Main beneficiaries are people with vitiligo, rosacea, scars (including after self-harming) and birthmarks
- We operate 140 clinics monthly across the NHS
- Referrals come mainly from dermatologists, plastic surgeons and GPs



, Registered Charity 1011222,



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IN MORE DETAIL...



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F FINDING OUT

Why? In order...

- To be more in control of one's life and treatment
- To be able to explain it to others... and educate

What is involved?

- Getting fully informed about the condition
- Understanding the range and risks/benefits of different interventions
- Being able to ask and discuss different treatment options, timings etc



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A 'ATTITUDE'

Why? In order...

- To develop resilience and positive beliefs in our look-perfect society – family and friends too

What is involved?

- Gaining positive stories about how others/role-models who have coped/adjusted well can help – see Cole and Spalding's book 'The Invisible Smile', for example
- Self-talk and conditioning often need re-scripting/programming – 'debunking the myths'



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C COPING with feelings

Why? In order...

- To deal with loss, grief, anger, distress, isolation, intimacy and relationships

What is involved?

- Being able to articulate one's feelings in a safe and confidential setting
- Finding patient-centred, empathetic psychological support/counselling can be invaluable



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E EXCHANGING EXPERIENCES

Why? In order...

- To realise that you are not alone and to find solidarity with others

What is involved?

- Meeting or connecting with others who have been through or are going through similar experiences
- Peer-to-peer support programmes/groups often need to be mediated by professionals in order to ensure positive outcomes



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S SOCIAL SKILLS TRAINING

Why? In order...

- To manage the reactions of other people with more confidence and thereby gain better reactions from other people – and so self-esteem starts to rise

What is involved?

- Acquiring an analysis of what is liable to happen in many social encounters (SCARED syndrome)
- Learning new ways to handle all sorts of interactions including ones like such as being in public places, staring, meeting new people and children, etc
- Can be done in groups, 1-1 or in self-help format



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Analysis of social interaction problems

The SCARED Syndrome – an analytical tool

An individual with a disfigurement may feel and act

- S Self-conscious, Shy
- C Conspicuous, Cavalier
- A Angry, Awkward
- R Rejected, Retreating
- E Embarrassed, Evasive
- D “Different”, Defensive

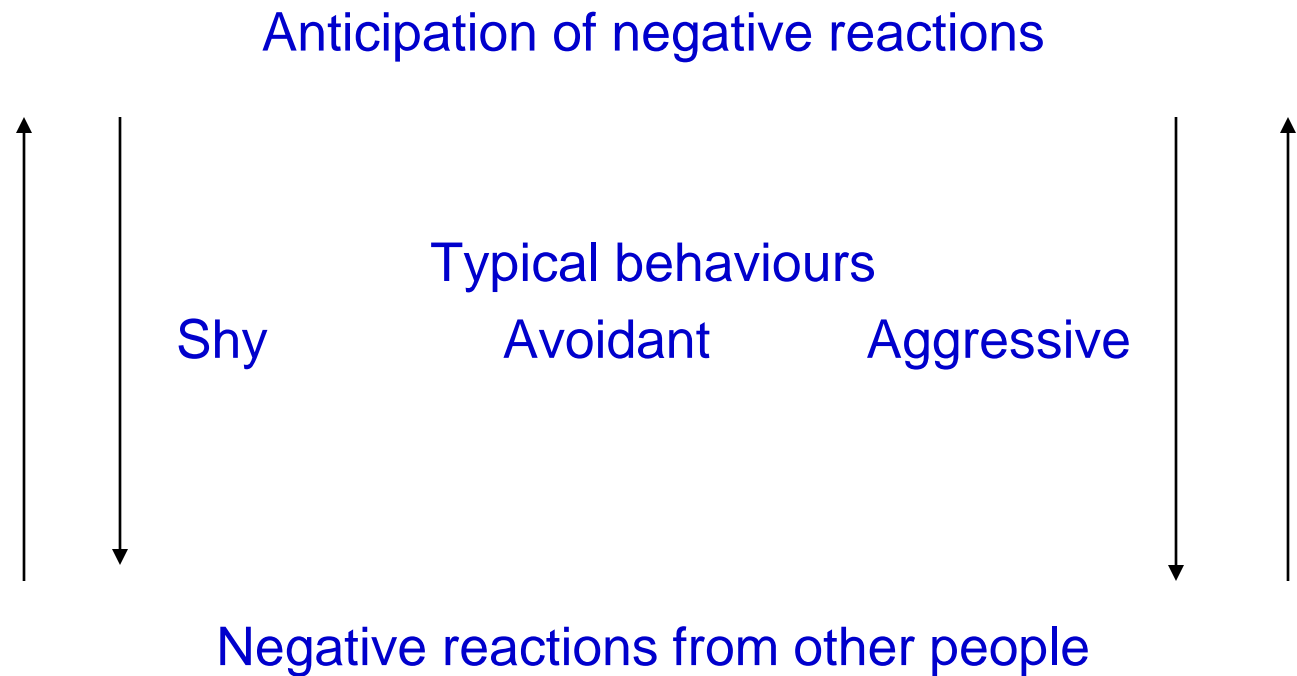
People meeting him/her may feel and act

- S Sorry, **Staring**
- C **Curious**, Clumsy
- A Anxious, **Anguish**
- R **Recoil**, Rude
- E **Embarrassed**, Evasive
- D Distressed, **Dread**



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Negative feedback loop





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A tool-kit of useful social skills

REACH OUT – a toolkit of communication strategies for taking the initiative and thereby influencing how you are received by other people

R **Reassurance**

E **Energy**

A **Assertiveness**

C **Courage**

H **Humour**

O **Over there!... ‘other-consciousness’**

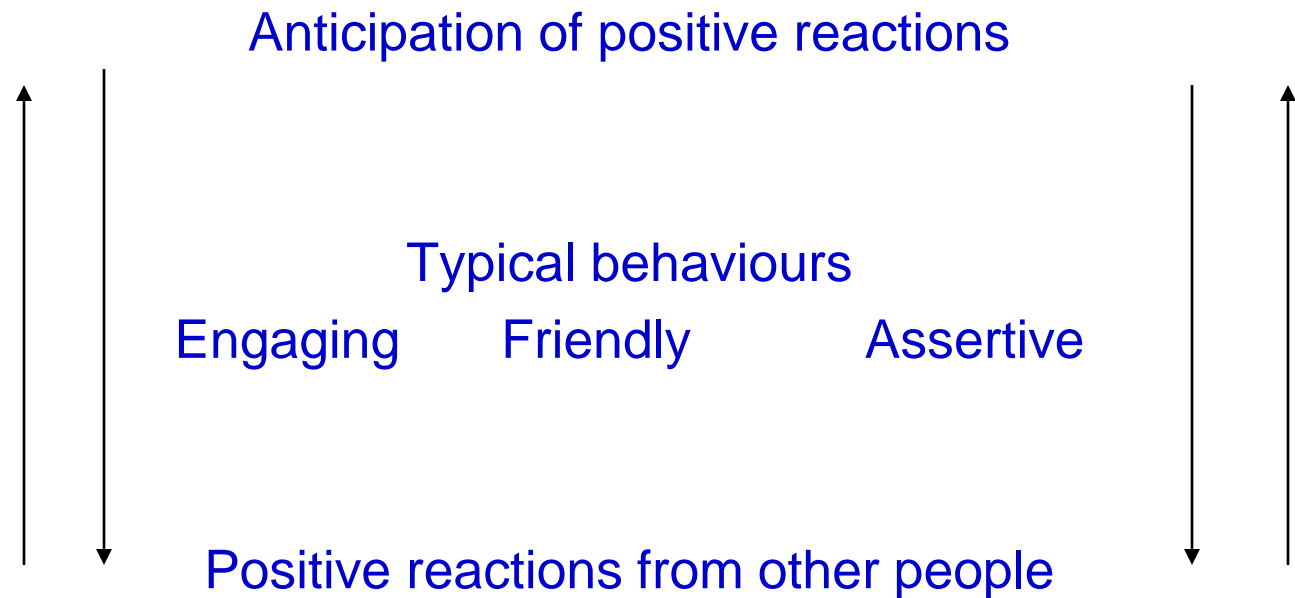
U **Understanding**

T **Tenacity**



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Positive feedback loop





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Self-help guides for adults

The following guides are available to read online or download as a PDF.

- Living with confidence
- Communicating with confidence
Part 1: Join the conversation
- Communicating with confidence
Part 2: Handling other people's reactions
- Intimacy, love and relationships
Part 1: Taking the first steps
- Intimacy, love and relationships
Part 2: Getting closer

<https://www.changingfaces.org.uk/Supporting-You/Self-help-guides>



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Self-help guides for young people and parents

For young people:

- Building confidence
- Looking different
- Feeling different
- Finding out
- When teasing becomes bullying

For parents:

- You and your Baby
- You and your Child
- Talking with your Child
- Preparing for School
- Preparing for Hospital
- Communicating with Confidence

<https://www.changingfaces.org.uk/Children-and-Families>



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CHANGING LIVES: Training and advocacy

- Training health (and other) professionals about the psycho-social aspects of disfigurements
 - Study Days
 - Master-classes
 - Training and induction of CFPs

- Advocacy for improved psycho-social care
 - Patient pathway guidelines of NICE and CRGs
 - Commissioning
 - Training/curricula of NHS consultants, nurses etc



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THE BIG NEXT CHALLENGE

**HOW TO GET THIS ADVICE AND HELP
EMBEDDED INTO ROUTINE PATIENT CARE?**

NB: Online versions may be very cost-effective



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What about the other side of the coin?

How other people think and behave towards people who
unusual faces or bodies...

Why are they SCARED?



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UNCONSCIOUS ‘facial discrimination’

Facial discrimination is often unwitting and unintentional – it can be seen in the behaviours of the public, professionals and institutions (eg: the media) and can be institutional discrimination.

Examples include:

- uncontrolled staring
- name-calling and bullying
- ridicule and pointed jokes
- patronisation (eg: ‘so brave’)
- avoidance of contact and eye contact
- ostracism and discounting
- half-hearted support/lip service
- low expectations
- pity and excessive sympathy
- loaded job descriptions



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UNCONSCIOUS 'facial prejudices'

- 1. The prejudice of the sad and second-rate**
- 2. The prejudice of the 'scary'**
- 3. The prejudice of a medical/surgical fix**



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Campaigning for face equality

Cinema portrayal

- See the Leo film:

<https://www.changingfaces.org.uk/Face-Equality>

- The Lone Ranger – see our response:

<https://www.changingfaces.org.uk/show/feature/preview/hp-lone-ranger-2013>

Challenging public ridicule

- Jeremy Clarkson on BBC's Top Gear re 'elephant car'
- Moshi Monsters: the Glumps Family

<https://www.changingfaces.org.uk/show/feature/preview/Moshi-dont-call-me-a-freakface>

To anyone who looked
at me and thought I'd
never achieve anything
look at me now



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See why Louis
chose to star in
our face equality
campaign at
www.changingfaces.org.uk

To anyone who
looked at me and
thought I'd never have
the confidence to
do anything
look at me now



Changing
faces
the way you see
disability

See why Mia
chose to star in
our face equality
campaign at
www.changingfaces.org.uk

To anyone who looked
at me and thought
I'd never have anything
to smile about
look at me now



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faces
the way you see
disability

See why Henry
chose to star in
our face equality
campaign at
www.changingfaces.org.uk

Are you only
comfortable
looking here?



Stand out.
Show your support for face equality.
www.changingfaces.org.uk

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eyeliner?

Stand out.
Show your support for face equality.

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Are you
the
kind
of
person
who
doesn't
know
where
to
look?

Stand out.
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FIVE NEWS



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What Success Looks Like

- New campaign to transform the expectations and confidence in the workplace of people with disfigurements and employers
 - Successful role models
 - Guidance
- See www.whatsuccesslookslike.org.uk
- #faceequalityworks
- @FaceEquality



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Conveying realistic expectations

Changing Faces has been at the forefront of public debate about the pros and cons, benefits and risks of:

- Reconstructive surgery
- Face transplantation
- Cosmetic surgery and other aesthetic interventions



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THE BIG NEXT CHALLENGE

**HOW TO GET THIS FACE EQUALITY THINKING TO
BECOME PART OF PUBLIC CONSCIOUSNESS?**





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How to contact Changing Faces

Changing Faces
The Squire Centre
33-37 University Street
London WC1E 6JN

Tel: 0845 450 0275

Fax: 0845 450 0276

Email: info@changingfaces.org.uk

Website: www.changingfaces.org.uk

We rely entirely on voluntary donations and gifts...

James Partridge: james.partridge@changingfaces.org.uk