COPING WITH DISFIGUREMENT
1: CAUSES AND EFFECTS

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ABSTRACT Millstone, S. (2008) Coping with disfigurement 1: causes and effects. Nursing Times; 104: 12, 24–25. This is a two-part unit on helping patients to cope with the anxiety and challenges of disfigurement or looking different. Part 1 examines the causes of disfigurement, dispels myths surrounding the issue and offers guidance on understanding the feelings and behaviours of those affected and their families.

INTRODUCTION
There are at least 400,000 people severely affected by disfigurement in the UK, according to a government survey (Office of Population Censuses and Surveys, 1988). In today’s appearance-conscious society in which the way you look has become increasingly important, living with a face or body that is visibly different, whatever the cause, is likely to be difficult.

Many people not only find it challenging to feel good about themselves but also experience psychological distress when having to deal with staring, comments and awkward questions (Lansdown et al, 1997).

This two-part unit aims to examine the psychological and social aspects associated with disfigurement and to explore how healthcare professionals can help patients to cope with the anxiety and challenges associated with this. Nurses have been identified as having the most appropriate skills to fulfil this role (Clarke and Cooper, 2001).

CAUSES OF DISFIGUREMENT
Causes of disfigurements fall into two main categories – congenital and acquired.

Congenital causes include: birthmarks; medical conditions that involve cranio-facial disfigurement, for example Apert’s syndrome, neurofibromatosis, and cleft lip and palate; and skin conditions such as eczema and vitiligo.

Acquired causes include: medical conditions that result in disfigurement, such as head and neck cancer; facial paralysis; development of skin conditions; and traumatic injury, such as burns and scarring.

MYTHS AND ASSUMPTIONS
Assumptions about disfigurement and what life is like for someone with a disfigurement are deeply embedded in our culture and distort views of reality. In fact, these myths are without foundation (Coutinho, 2006).

The perceptions people may have formed about what it means to live with a disfigurement may influence how they themselves deal with their own emotions when they, a member of their family or a friend personally experience a changed appearance. Therefore it is important for both patients and healthcare professionals to be mindful of the reality of living with a visible difference.

Four common myths associated with disfigurement are outlined below.

The myth of surgery
This myth assumes that aesthetic or cosmetic surgery is a magic wand that will ‘fix’ everything. As a result, this can lead to false expectations, not only on the part of patients but also on that of the general public. For, while surgery can certainly help reduce conspicuousness of a disfigurement and improve functioning, it rarely does this without leaving other scars.

The myth of ugliness/evil
This myth assumes that having a disfigurement also means having a damaged personality. It is often perpetuated by the media, films and fairy tales, where ‘bad’ people are frequently portrayed by characters with a disability or disfigurement.

As a result, many people may be afraid of someone with a disfigurement or may feel free to ridicule them.

In reality, of course, a facially disfigured person is in no way intrinsically frightening or ‘evil’, and a disfigurement certainly does not influence moral character or intelligence.

The myth of attractiveness or success
This myth assumes that people have to look good to be successful in life and, again, is often perpetuated by the media.

As a result, this can lead to feelings of failure or uselessness, and may result in the general lowering of expectations by both the person with the disfigurement and other people.

The reality is that many people who have a facial disfigurement live normal, successful lives and enjoy fulfilling relationships and achievements.

The myth of severity
This is, perhaps, the most common myth of all, and assumes that the more severe the disfigurement, the more distress is experienced, and vice versa.

However, research on the psychosocial impact of disfiguring conditions shows that severity of the underlying pathology does not predict distress (Rumsey et al, 2003). Indeed, studies have identified perceived noteworthiness – as opposed to objective noteworthiness – as the important factor.

If a person’s disfigurement is perceived by others as causing less distress because it appears to them to be less severe, this diminishes not only the disfigurement but also the very real need to understand the extent to which that person might be experiencing their visible difference emotionally.

LEARNING OBJECTIVES
1. Be aware of myths and assumptions.
2. Understand the psychological and social effects of disfigurement, and the feelings and behaviours of those affected and their families.
THE REALITY OF DISFIGUREMENT
The reality is that social norms change when a person looks or sounds different (Bradbury, 1993). Here are some examples:

- There is a real sense of being invisible yet at the same time highly visible – people stare;
- Strangers feel they have permission to comment and ask questions about a person’s appearance;
- A person with a disfigurement may feel uncertain of what to expect from others, or what to say in response;
- Many feel they are ‘on duty’ all the time, and have to maintain a near-constant vigilance, which can result in increased self-consciousness;
- Some will feel alone and isolated, and therefore cannot go out, or believe they cannot have intimate relationships;
- Others express feelings of anger, embarrassment and a need to be ‘fixed’;
- Sometimes there is a lack of communication with family and friends;
- Many will feel the social pressures associated with stereotyping and myths linked to disfigurement.

UNDERSTANDING PEOPLE’S FEELINGS
Congenital disfigurement
For a person born with a disfigurement, psychological effects may occur at many stages, from very early childhood through to adulthood. The social and cognitive processes during the early years of a child’s life, in relation to how their family, friends and others around them react to their disfigurement, will affect their self-esteem, their sense of worth and their self-confidence (coping with other people and situations). These may result in low expectations later in life regarding relationships and work.

Children with disfigurement and their parents often show signs of stress, anxiety and depression as well as a sense of social isolation (Bradbury, 1993). Parents of a newborn baby with a disfigurement may feel and react in a variety of ways. Feelings may range between total acceptance, joy, distress, anger, guilt, grief for the ‘perfect’ child, or a need for surgery before attachment. In social situations, behaviour may range from normality to avoidance (unless the disfigurement is concealed), or being defensive.

Another important aspect is the effect of having a baby with a disfigurement may have on the relationships between parents or other family members. This can range from drawing the family closer together to a breakdown of a relationship, immediate adjustment, or long-term difficulty adjusting.

Acquired disfigurement
For people with medical conditions such as head and neck cancer, there is the trauma of diagnosis, followed by rapid medical investigation and treatment. For those who have experienced injury to the face from burns or other scarring, there are a variety of medical challenges related directly and indirectly to the injury and disfigurement.

For many patients, the effects of the disfigurement can actually be more troubling than the medical condition itself, especially after the initial immediacy of the treatment.

Visible difference can have a profound psychological impact, and people with facial disfigurement often have emotional, social and economic difficulties. This is in addition to those associated with the medical treatment. Self-esteem, body image and quality of life can be adversely affected (Rumsey et al, 2003). The psychological and emotional effects of a changed appearance may result in social isolation and a process of bereavement for the loss of a patient’s former face and identity.

A useful framework for understanding this process is the model of the five stages of loss as described by Kubler-Ross (1969):

- Denial and isolation – ‘No, not me. It cannot be true’;
- Anger – ‘Why me?’;
- Bargaining – ‘Yes, me… but’;
- Depression – ‘Yes, me’;
- Acceptance – ‘It’s OK.’

It is important to remember that this is not a linear model – patients can move back and forth according to what may be happening at various points in their lives.

The family and social circle will experience the effects of disfigurement in different ways. Partridge (1990) said they will find it hard to come to terms with the first sight of facial wounds, and even harder to accept that these are bound to leave disfiguring scars.

He added that relatives, especially spouses and partners, will have to make some major adjustments, and some are unable to do so. Reactions may range between commitment to help and support, feelings of sorrow, avoidance, worrying what to say and, sometimes, complete rejection.

Parents of children who have experienced surgery or injury resulting in disfigurement will react in a number of ways, ranging from depression, guilt and distress to anger. Siblings may become overprotective, or may be ashamed of their sibling’s appearance.

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KEY REFERENCES


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