

# Background, Clinical Problems, Common Presentation and Treatment Considerations

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Whether present at birth or acquired later in life, a visible disfigurement can have a profound psychological impact on those affected (Rumsey & Harcourt, 2004, 2005; Thompson & Kent, 2001). Difficulties include adverse effects on body image (Newell, 2000), quality of life and self-esteem and shame (Kent & Thompson, 2002; Turner et al., 1997). Macgregor (1990) and others have argued that visible disfigurement comprises a 'social disability', since in addition to impacting on the thoughts, feelings and behaviours of those affected, it also affects the reactions of others. Social encounters can present many challenges, including meeting new people, making new friends, unwelcome attention such as staring, audible comments, teasing and unsolicited questions (Robinson, 1997). Research to date has focused predominantly on the difficulties and distress resulting from disfigurement. Rumsey et al. (2002) reported levels of anxiety, depression, social anxiety, social avoidance and quality of life were unfavourable in a third to a half of a sample of 650 consecutive out-patient adults attending hospitals for treatment of a wide range of disfiguring conditions. However, not all are equally affected. A proportion adapts positively to the demands upon them and either relegates their visible difference to a relatively minor role in life (Rumsey, 2002) or uses it to good advantage (Partridge, 1990).

There is a consensus amongst researchers and practitioners in the field that individual adjustment is affected by a complex interplay of physical, cultural and psychosocial factors (Clarke, 1999; Endriga & Kapp-Simon, 1999; Falvey, 2012; Moss, 1997a; Rumsey & Harcourt, 2004, 2005). However, what is very clear is that people affected by a disfigurement do have to contend with a range of reactions from others, many of which may be subtle and automatic (Grandfield et al., 2005). This is centrally important as the processing of information in people with a visible disfigurement is likely to be primed by the threat posed by the automatic reactions of others and such priming will activate normal bodily threat mechanisms. Awareness of this assists in normalizing the responses. That said, there is a high level of individual variation. Some factors clearly contribute to distress, yet others appear to 'buffer' a person against the stresses and strains of living with a visible difference. Some researchers have developed models of the processes involved (see for example, Kent & Thompson, 2002; Newell, 2000; White 2000). However, in most cases these have been condition specific, based on evidence drawn from small samples, and problem focused. Whilst models may help to organize collective thinking, they have the greatest clinical value where they focus on the identification and clarification of those factors which have the potential to be amenable to change through psychosocial support and intervention – either as an adjunct, or where appropriate, as an alternative to surgical and medical intervention. The Appearance Research Collaboration (ARC, funded by the Healing Foundation) has derived a cognitive model of adjustment based on previous research (see Figure 3.5, section 'The ARC Framework of Adjustment to Disfiguring Conditions', Chapter 3), and further developed it using data from both community and clinical samples (Thompson 2012).

In addition to emphasis on appearance-specific cognitive processes highlighted in the current research programme, previous research has indicated that a range of physical, treatment-related, socio-cultural and some other psychological factors are implicated in adjustment. Readers are referred to Moss (1997a), Clarke (1999), Newell (2000), Kent & Thompson (2002), Rumsey and Harcourt (2004), Moss (2005), Ong et al. (2007), and Thompson (2012). However, a brief resumé of the factors identified in previous research as the 'likely suspects' affecting adjustment is offered below. The findings of the ARC research programme are expanded in Chapter 3 of this guide.

## Physical and Treatment-Related Factors

These include aetiology, the extent, type and severity of the disfiguring condition, and the treatment history of each individual. Contrary to the expectations of the lay public and many health care providers, the bulk of the research, clinical experience and personal accounts written by those affected, demonstrates that the extent, type and severity of a disfigurement are not consistent predictors of adjustment, although the visibility of the condition has been shown in some studies to exacerbate distress (Moss, 2005; Ong et al., 2007; Rumsey & Harcourt, 2004; Thompson & Kent, 2001).

## Socio-Cultural Factors

Socio-cultural factors are particularly important as there is a fundamental human motivation to be connected with one another and the nuances of how these connections operate are dictated by social and cultural conventions. Cultural factors influence the core beliefs that people share about the meaning and consequences of disfiguring conditions. Social and cultural factors therefore provide a context in which adjustment takes place and are often influenced by demographic factors such as age, developmental stage, gender, race, and social class as well as the broader cultural milieu, religion, and parental and peer group influences. Research has also established that the media can play a role in creating and exacerbating the pressures on those distressed by their appearance although the impact of media and other socio-cultural factors varies between individuals (see Halliwell & Diedrichs, 2012; Prichard & Tiggemann, 2012 for review). Early experiences of attachment and of being accepted are likely to be particularly important in sensitizing individuals to the perceived threat posed by a disfigurement (Kent & Thompson, 2002), and this should be fully explored as part of the history and formulation building during therapy.

## Psychological Factors and Processes

Factors included in this category include the structure of a person's self-esteem and self-image (e.g. the weight given to the opinions of others and to broader societal standards), a person's personality/disposition, characteristic attributional style, coping repertoire, perceptions of social support, levels of psychological well-being (e.g. anxiety, depression) and social anxiety, feelings of shame and the perceived noticeability of their visible difference to others (see Moss & Rosser, 2012a, 2012b for review). Again, it is important to consider that such factors are intimately associated with, and shaped by, socio-cultural factors. They can be broadly categorized as affective (relating to feelings), cognitive (relating to thoughts) or behavioural (relating to behaviour), and are, on the whole, more amenable to change than physical, treatment-related or socio-cultural factors.

## Body Image Disturbance

In addition to those people with a disfiguring condition visible to others, there is a second group for whom their concern is related to self-perception, or a perceived problem or deficit in their appearance. Body Dysmorphic Disorder (BDD) is described in the *Diagnostic and Statistical*

*Manual of Mental Disorders, Fourth Edition (DSM-IV-TR, 2000)* under somatoform disorders, and is defined as a preoccupation with an imagined or slight defect in appearance, which cannot be better explained in terms of an eating disorder (such as Anorexia Nervosa) or a disfiguring condition.

Many commentators have expressed concern about a diagnostic category which is dependent on the observation and judgment of an observer rather than the experience of the individual. An experienced plastic surgeon is likely to use a different normative scale from someone who is influenced primarily by the norms of their peer group. The definition also suggests that someone with a very obvious disfiguring condition should be excluded from this diagnosis; yet there are some people in this group for whom the high levels of preoccupation and concern are very characteristic of BDD.

For all these reasons, in our opinion, and contrary to the categorical *DSM-IV-TR* definition, BDD represents the extreme end of a continuum which can arguably be anchored at the opposite pole by a 'normal' preoccupation with appearance, dress and dissatisfaction with appearance. In clinical settings, body image disturbance is often present in disfiguration independent of cause or severity, and may be most evident in the more objectively 'minor' disfiguration group. The perceived mismatch between actual and ideal (how they ought, should or used to look) can result in considerable preoccupation, checking behaviour and anxiety in the absence of actual negative social reactions from other people. (See Price (1990) for discussion of this mismatch in mediating challenge to the integrity of body image.) Indeed, reassurance seeking from others that 'they look okay' serves to maintain anxiety, probably by maintaining focus on the perceived threat (Veale et al., 2009).

The results of the ARC research programme have reinforced the clinical observation that people also present with multiple concerns, or with a specific 'highlighted' problem in the context of other concerns about appearance. For example, excess skin following weight reduction is often described as 'ageing' and it is important to recognize that the 'normative' concern with appearance that is evident in the general population means that there is often a multiplicity of issues underlying appearance cognitions. Further, the ARC study demonstrated that people with a disfigurement might be more concerned about other unaffected areas of their bodies (such as the size of their stomach or buttocks), so it would be inaccurate to assume that the simple anatomical location of the disfigurement may be the prime source of concern.

## **Clinical Problems and Presentation**

All examples are based on real clinical examples referred to people working in psychological therapies, attached to general hospital services, including plastic surgery. Names and identifying details have been altered. In the brief vignettes in the box below, the range and complexity of appearance concerns are illustrated. This is to provide an overview for those new to this area of work and briefly indicate both the similarities of concerns (e.g. the worries about the reactions of others and the impact of unusual appearance on self-esteem), and also the importance of individual differences (e.g. the meaning of the disfigurement for that person). More in-depth examples are provided through the book to demonstrate treatment approaches, with the major treatment focus in Chapter 7.

### **Example 1**

Geraldine has a small skin graft on her nose following treatment for facial cancer. An artist, she finds the change in her appearance devastating although she accepts that it is relatively minor. She is puzzled by her own response to what she can see is a relatively minor change but is seeking revision of surgery to try to achieve symmetry.

### **Example 2**

Jack has a congenital condition which includes an absence of an ear on one side. Although he has undergone ear reconstruction with a good result, he is still anxious about the appearance of his ear and has avoided cutting his hair or going swimming. He continues to wear a hat pulled low over his head.

### **Example 3**

Eve has had surgery to remove facial cancer which has left her with a visible disfigurement, including loss of her nose. She is overcome by this and cannot envisage ever leaving the house again. She confines herself to her bedroom. Her husband seeks help from the doctor and is told that there is nothing that can be done; 'she just has to learn to live with it'.

### **Example 4**

James has an industrial injury and loses his dominant thumb. He hates the appearance of his hand and is fearful of others seeing it. He has very marked episodes of dissociation, flashbacks of the injury and his mood is low. His doctor lectures him about people who learn to use their feet to write and use cutlery. He tells him he is making too much fuss and should get back to work immediately.

Note that James presents with symptoms characteristic of post-traumatic stress disorder (PTSD) as well as appearance concerns. Managing the impact of trauma is the priority at this point. Hand injuries may also cause pain and this can impact on mood and ability to manage the treatment regimen. Again we would recommend pain intervention as a priority.

### **Example 5**

Pauline has small breasts. She feels that these single her out from her peer group and describes herself as a freak. She has identified breast augmentation as a means of improving her self-confidence and allowing her to undertake her hoped for training as a beautician.

Pauline has breasts which objectively fall within the normal range, but which she perceives to be abnormal. Her own experience of her appearance is very similar therefore to someone who is worried by a disfiguring condition, and for whom this perception results in appearance anxiety. Unfortunately she is likely to be perceived as vain and her concerns dismissed as 'purely cosmetic'. She is heavily invested in appearance choosing a career in this field.

### **Example 6**

Mark is a builder who has lost a finger in an accident with a Stanley knife at work. He is very distressed by the appearance of his hand, keeping it in his pocket. He anticipates that he will never get a girlfriend because his hand is off-putting and disgusting. He is very angry both with himself and his employer.

### **Example 7**

John has had surgery for a facial palsy. He had a good result but still has a noticeable palsy when he smiles. He presents with a very low mood, finding it hard to cope at University and feeling that his peers treat him differently and that he is unable to fit in.

### **Example 8**

Peter lost an eye as a child, and the resection means that he is unable to wear an eye patch. He is now at University where he feels that his obvious facial disfigurement limits his opportunity to socialize and in particular to meet girls. He describes himself as 'always the one going home on his own'. He has low self-esteem and self-confidence and perceives his appearance to be limiting his opportunities for the future both socially and for employment. He is becoming increasingly socially avoidant.

### **Example 9**

Lucy has a breast asymmetry. She presents requesting surgery and becoming very upset in the consultation. She feels like a freak, having been for a bra fitting where the assistant has told her: 'you need to see a doctor my dear, you are deformed'.

### **Example 10**

Jenny has burn scarring affecting 80% of her body. In the past, most people with the severity of her injuries would have died, but advances in burn care mean that she and other people like her now survive. She presents with a chaotic lifestyle, drinking and smoking heavily with a low mood and has difficulties managing the physical problems resulting from her original injury. Managing her temperature in the absence of sweat glands is a particular challenge. When she goes out she experiences high levels of staring and comments from other people, including frequent questions about the cause of her scarring.

### **Example 11**

Veronica presents with scarring on both wrists resulting from self harm as a teenager. She wants these scars removed as they are reminders of an unhappy and difficult time in her life, and she finds them difficult to explain when other people ask her about them.

### **Example 12**

Bryony has had a cycling accident resulting in significant scarring and contour changes to her legs. She is unable to look at the scarring, retching and sweating if she catches sight of her appearance during dressing changes.

### **Example 13**

Sean has acne and also a stoma following surgery to treat Crohn's disease, he is depressed and rarely leaves the house except to weight train. He misuses steroids. He sees himself as 'disgusting' and is unable to see how life could be different without reversal of the stoma and treatment of the acne.

### **Example 14**

Gillian is a softly spoken shy 20-year-old, who appears much younger than her age. She has severe psoriasis. She tends to avoid swimming and covers the affected areas of her body. She has not had an intimate relationship and she describes herself as lacking confidence in her job. She has several very close friends, but she has not told any of them about her skin condition or shown them it, for fear that they would see her differently and might not wish to be friends with her.

### **Example 15**

Frank suffered an industrial accident that left him with severe crush injuries to his leg which was eventually amputated. The rehabilitation team report that he is 'de-motivated' and hostile. He has stopped socialising and ended the relationship he had prior to the accident. He says he is furious towards his employer as he believes the accident could have been prevented. He talks of having 'flashbacks' and describes spending hours ruminating on how his appearance has 'changed for the worse' and how they (his employers) have 'finished him'.

Note that whilst Frank describes having 'flashbacks' formal assessment suggests that he is describing intense rumination about the consequences of the accident rather than having dissociative episodes of re-living it, and consequently the primary issue is adjustment following limb loss.

### **Example 16**

Jeff suffered a road traffic accident where he sustained severe damage to his arm resulting in it being stiffened and the muscle wasting. He has returned to work and driving and attempts to socialize as much as he can and is continuing to spend time with his family and children. However, he says that he has to 'bully himself along' and he can't really believe why his wife is sticking with him as he now looks 'old and odd'.

### **Example 17**

Mark has had alopecia since childhood, during which time he was bullied; now in his 40s, he no longer fears teasing or bullying, yet he describes feeling 'different' and is unable to leave home without wearing a hat or a hooded sweatshirt, and he will not answer the door unless he is wearing a hat. He says that people have commented on him wearing a hat but he believes that he 'just can't do without it'. His reliance on wearing a hat or hooded sweatshirt has detrimentally affected his occupational opportunities and in his last job he received a written warning for not adhering to the expected dress code. Following this he described losing his confidence and feeling unable to work.

### **Example 18**

Michele has had cancer of the mouth and had extensive reconstructive surgery. She does have some facial scarring and palsy and she now feels less attractive to her partner and feels unable to continue to associate with her friends who 'always talk about appearance'. She says her mood fluctuates between rage and sadness.

### **Example 19**

Peter has Moebius syndrome and has no facial nerves, meaning that he is unable to smile or use his face to express emotion. He is very frustrated by the behaviour of other people who often treat him as though he has learning disabilities.

## **Common Features in Referral**

### **Visibility of Condition**

The first thing that is clear from the examples above is that all these people locate the source of their difficulties in their appearance, or the change in their appearance, and all have sought or considered medical intervention as a solution. Some have completed their treatment, sometimes for a life-threatening condition, but are still preoccupied and disabled by the appearance change. Objectively, there is a considerable range in degree of visible difference when rated by an observer. For some, the problem may need to be pointed out, whilst others may have features which are habitually concealed by clothing. For some, the appearance difference has been lifelong and for others acquired as a child or adult. For all, the level of preoccupation is high and the 'problem' is perceived as significantly distressing and disabling. This is the core issue that the group have in common, and the reason that they are appropriate for referral and/or treatment of appearance anxiety. Severity does not predict distress (Moss, 2005; Ong et al., 2007), and those with a more minor objective disfigurement may have equal or higher levels of distress than those with greater objective visible difference, although they will very often have been told that their distress is 'out of proportion' to their appearance. Some have more than one disfiguring condition and it is not necessarily the thing that is most obvious to

other people which is the one that causes most concern. Importantly, the lack of a clear relationship between visibility to others and levels of distress is confirmed in the ARC research programme.

Thus, psychological treatment approaches focus on managing the impact of the condition (anxiety, the preoccupation and worry, altered and avoidant behaviour, etc) rather than changing the condition itself, sharing the same goals for treatment as psychological interventions across the range of chronic health conditions.

## Shame

As long ago as 1963, Goffman described shame as central to the experience of stigma and yet the concept of body shame has received less attention than body image. Clinicians widely acknowledge body shame as a commonly occurring issue in some people living with a disfigurement that drives avoidance and safety behaviours (Gilbert & Miles, 2002). A distinction has been drawn between internal and external shame, where external shame describes the experience of perceiving oneself to be ‘disgusting’ or unattractive to other people, whilst internal shame describes perceiving oneself to be shameful (Gilbert & Miles, 2002; Kent & Thompson, 2002). Internal shame may be accompanied by marked parasympathetic response (see below). Whilst internal and external shame tend to occur together, they may occur independently. Thus, individuals may comment that although they know that other people do not notice or respond to their appearance, they have strong feelings of revulsion or disgust about themselves (internal shame), whilst others may feel that although other people have issues about their appearance, personally they are not ashamed of their appearance, but they maybe nevertheless worried by anticipated negative reactions of others. The concepts of internal and external shame are closely related to the idea of felt and enacted stigma and the processes involved with all these concepts may act independently of objective appearance (for a full discussion see Gilbert & Miles, 2002; Thompson, 2011, 2012).

## The Meaning of Visible Difference

Linked with shame, the meaning that people place on unusual appearance is important to understanding its impact. For example, people commonly believe that their disfigurement labels them as ‘deformed, freakish, ugly or unattractive’. Often surgeons are reluctant to carry out procedures which objectively ‘worsen’ appearance; however, even when the objective visibility of a scar is increased, this may sometimes be successful in reducing anxiety when it is the means of altering the meaning and therefore the anticipated stigmatizing from others (see Example 11). This points to the need for careful assessment of motivation for treatment seeking and for being clear about the nature of people’s thoughts about the perceived disfigurement. A psychological intervention may similarly focus on modifying the meaning of scars, for example, as evidence of strength, resilience, and survivorship rather than signs of weakness, or of having had a disease such as cancer.

## The Experience of Loss

Many people describe the impact of visible difference in terms of loss or bereavement. The process of grief for the loss of appearance and for the undamaged self is not dissimilar to the process of mourning

in other kinds of loss. It is important to recognize that this applies equally to those who have acquired disfigurement and to those with a congenital or longstanding condition. Loss of the idealized or never experienced self has as great a potential to impact on the individual as loss of the previous self. Loss also impacts at the level of perceived loss of opportunity; not only loss of appearance but questions about opportunities for the future. 'Will the same life opportunities be there? Will I be able to do the same job? What about relationships? Will other people find me attractive? Will I find a sexual partner? Do I need to compromise because I am not like other people?' Like bereavement in other settings, there may be periods of intense emotion, anger and sadness (Bradbury, 1996). Timing of a structured intervention needs to take account of this emotional response. Evidence for management of distress after trauma supports a model of information provision followed by treatment within the first 4 weeks following trauma (see National Institute for Health and Clinical Excellence (NICE) guidance) using a standardized approach. Although no clear evidence based recommendations can be made for a similar model in managing appearance issues, clinical experience suggests that a period of simple acknowledgement of loss and legitimizing of concerns as a first step before social skills intervention, or further specific focus on managing visible difference (Clarke, 1999).

### Physiological Responses

Whilst the level of preoccupation and concern is usually high, physiological responses vary considerably. Some people dislike the visible difference but can look at and touch it, allowing them to participate in self-care behaviours (Gaind et al., 2011). However, others exhibit considerable physiological arousal including bradycardia, sweating or nausea. This may be because they are repelled or disgusted at the sight or sensation of their own body, and show pronounced disgust responses, or tachycardia because of anxiety. An acquired visible difference may also be a trigger for intrusive recollection of a traumatic event that is likely in turn to result in hyperarousal and avoidance.

### Culture

Appearance is valued differently in different cultures and there may be a particular premium placed on appearance for women. In addition, beliefs about illness are known to be linked to psychosocial adjustment and beliefs about conditions affecting appearance may well vary according to culture and ethnicity. Understanding the meaning of altered appearance and the explanations and beliefs within the relevant culture is essential to formulating the problems and planning treatment. (For a good review of these concepts see Falvey (2012) and Habib and Saul (2012).)

One of the ARC studies examined British Asian women's experience of the depigmenting skin condition, vitiligo (Thompson et al., 2010, and summarized in the Appendix). Like other participants with vitiligo from other ethnic backgrounds, the respondents described feeling different, and reports of stigmatisation were not uncommon. However, the experience of stigmatisation was associated with subtle cultural values related to the role played by appearance in status, and myths linked to the cause of the condition. The condition was perceived as affecting marriage prospects. Cultural nuances as to how stigmatisation operates are also reported in one of the other ARC studies that explored community views of disfigurement (Hughes et al., 2009). Therefore, whilst the original ARC model included consideration of social and cultural factors, the need for further emphasis on this

emerged as a result of the findings of the ARC studies and consequently a fourth element that specifically highlights the role played by social and cultural influences has been recently added to the ARC model and is given consideration in guiding the interventions described in this handbook (see Thompson, 2012).

## Gender

There is a prevailing belief that appearance-related issues have a bigger impact for women. However, this research programme has identified considerable levels of distress in male participants which, for some, results in high levels of hostility and enacted aggressive behaviour. Similarly, in an audit of 300 facially disfigured patients referred to the Royal Free Hospital over a 5-year period (Cordeiro et al., 2010), male patients were significantly distressed by both objective and perceived facial changes, with no evidence that women comprised a less well-adjusted group. Where male concerns about appearance have been framed as related to the muscular ideal, this evidence identifies facial issues as highly relevant in male groups. It may therefore be important to challenge the beliefs of other health professionals or family members that male patients are not appropriate for treatment or 'should not be making so much fuss about things'.

## Age

There is a similar belief that older people are less worried about appearance. The ARC research programme has found supporting evidence for lower levels of distress in older group. However, there is considerable variability in this population; some older people have very high levels of concern about their appearance. Age should not, therefore, be used as a criterion for referral or access to psychological services. Children may have particular problems with teasing and bullying in schools and this is often cited as the reason for surgical intervention at a young age. Unfortunately, this approach anticipates a problem which may not arise, and there is an interesting ethical debate around the question of whether or not it is appropriate to intervene before a child is old enough to consent to significant surgery, on the basis of problems anticipated by parents.

## Expectations of Treatment

Most people with concern about their appearance will present to clinicians with a request for a physical treatment, commonly surgery – increasingly laser or dermatological techniques. Others will present to clinicians following treatment for some other condition that has resulted in an iatrogenic change in appearance (such as following colorectal or breast surgery). The lay understanding of surgical procedures is often very poor and may be driven by commercial marketing. Patients tend to have unrealistic expectations of surgery to ameliorate scars, the appearance of scars after treatment and the fact that scarring is inevitable after surgery. Indeed many people are referred for 'scar removal'. Information is often drawn from reality television shows and magazines. General practitioners in the United Kingdom do not have plastic surgery included in undergraduate training and may often be under the same misapprehension as patients (Charlton et al., 2003). Therefore, despite advice to

discuss plastic and reconstructive procedures with a primary care physician (Department of Health, 2007), these may be a source of misinformation. For this reason, many potential clients can be angry or disappointed since they have identified a solution to their problem that is impossible to provide. Some people also present after surgery that has failed to meet expectations for the same reasons, or that has resulted in unexpected changes in their appearance. There is also emerging evidence from the health psychology literature that procedures that are predominantly sought for quality of life gains have a higher risk for associated postoperative dissatisfaction (Elkadry et al., 2003). This research suggests that whilst clinicians traditionally target reduction of symptoms or functional improvement, patients target secondary lifestyle changes, which may be only indirectly related to the intervention. For example, change in the shape of a feature may be perceived by a surgeon to be correction of asymmetry, but for a patient it may be the opportunity to have a relationship. Where a relationship fails to materialize, dissatisfaction is attributed to the procedure or the surgeon, or both.

### Association of Physical Change with Psychological Outcome

Most people with appearance-related problems associate their well-being, self-confidence and self-esteem with appearance. Expectations of outcome for treatment are commonly phrased in these terms. However, evidence from studies of outcome following cosmetic procedures suggests that higher satisfaction is related to expectations of physical rather than psychological change (Sarwer and Crerand, 2004; Sarwer et al., 2006). For this reason, an early emphasis on identifying exactly what will change physically and how much it will change is important for patients about to undergo physical treatments. Similarly, it is helpful to frame psychological goals in more concrete ways that can be measured and are more evident. Thus 'improve self-confidence' can be described in terms of consequent behaviour change, for example, go out with my friends, remove concealing clothing, change job, etc.

Where there is a very visible difference in appearance, people often report high levels of social intrusion with staring, comments and questioning commonplace (Partridge, 1990). Surgery is often seen as the solution to managing the behaviours of other people driven by the assumption that if the appearance difference is minimized, then social situations will no longer be anxiety provoking. However, as a raft of research literature has indicated, an appearance closer to the social norm does not necessarily make traversing the social world easier, indeed many people with unremarkable appearances find social situations difficult. Viewing appearance changes (rather than cognitive and/or behavioural change) as a means to fix social relationships including problems with intimacy, should be identified as an ineffective solution and be challenged during assessment.

### Fix It Solutions

The myths about medical interventions include a common perception that surgery and medications can 'fix' a problem and that less-than-optimum outcomes are the result of lack of expertise, 'something gone wrong' with a procedure, or rationing of resources. Since patient-centred goals and expectations of outcome are predictive of satisfaction with treatment, preparation for any intervention should include eliciting expectations and helping the patient to modify them where necessary. It is also helpful to elicit expectations of the treatment setting. Many people are unaware that they will see different doctors rather than have continuity of care and that the length of stay will be short

in most hospitals. Paradoxically, very small changes in appearance are often much harder to achieve than significant change, and it can be hard for people to understand that heart transplant is possible whilst scar removal is not.

## **Treatment Considerations**

Clinical health psychologists are familiar with the challenges of framing health-related problems in psychological terms (e.g. in pain management, management of chronic conditions and disability). Formulating an appearance-related problem in psychological terms and making this accessible to the patient has the additional challenge that a patient often presents when the perceived ideal treatment is either unavailable or has failed. Psychological solutions can be seen as second best.

A key goal for an assessment is evidence from the patient that the therapist has listened and has understood the problem. This is described more fully in the section on assessment, where standard techniques of reflecting back, questioning and summarising are used to help frame a psychological formulation. Attempting to reassure by commenting on the objective appearance of the patient is almost always unhelpful. Many people report doctors and other therapists commenting that 'it is not that noticeable'. This is perceived as evidence that the problem has not been understood – or as one patient put it 'they just don't get it'. People with body image issues often ask therapists how noticeable their feature is. Encouraging the patient to examine whether this is a helpful question is a better way of dealing with it than offering an opinion, and is also an early 'taster' of what treatment might entail. Most people accept that there is no answer that is reassuring – either it is very noticeable, or the therapist is perceived to be 'trying to make me feel better'. Framing appearance as unimportant is another potential pitfall, especially with younger people. Sayings such as 'you can't judge a book by its cover' or 'beauty comes from within', 'personality is more important than appearance' are all messages which are contradicted by the social context in which people exist. All the evidence, to which the patient has access and their own experience, is to the contrary. Appearance is actually very important in determining how people appraise each other, and suggesting that it is not makes it harder to work with people for whom appearance has a very high premium. Again, such non-specific and stereotyped attempts at reassurance demonstrate to the patient that the therapist has not understood the nature of their problem.

Later on in treatment, examining the role that appearance plays in people's lives may well form part of therapy in the context of examining components of self-esteem. The role of behaviour in creating a positive impression will also be considered as part of the skill set of someone managing an unusual appearance. But entering an early debate about the value of appearance is not helpful in an assessment.

Formal psychometric assessment using scales such as the Derriford Appearance Scale (DAS24; Carr et al., 2005) is helpful not only for quantifying the level of distress and the associated avoidance behaviour but also for reinforcing the idea that the therapist is trying to understand the problem. It is also very useful in identifying tangible treatment goals. Simple idiosyncratic psychological measurement tools including visual analogue or ordinal scales of noticeability and worry, which can be recorded on a daily basis to provide information about the process of change, are excellent practice-based tools (see section 'Core Clinical Dataset', Chapter 4). High scores on both are predictive of psychological distress. It is also helpful to be able to formulate treatment goals in terms of reducing worry or preoccupation, since most people will accept that it would be helpful for them to be less worried or preoccupied by their condition.

For a psychological intervention to be effective, the patient must be able to identify goals for change that are achievable and perceived to be important. People need to feel ready for change, and goals must be structured so that they are easily understood and agreed to be manageable. Intervention may start by working on these aspects of a client's motivation, readiness for change and perceived self-efficacy in the therapeutic partnership. Formulation of appearance-related problems in terms of psychological management is not intuitive to people outside a psychological setting. Even other health professionals commonly perceive such an intervention to be a non-directive general counselling intervention. The idea that psychology is about changing how a problem is understood and modifying behaviour to reduce disability needs constant rehearsal. For this reason, it is helpful to summarize the formulation and goals for treatment at the beginning of each session – eliciting these from the patient as they become more familiar with the model (see treatment plans in Chapter 7). This is equally important whether working within a systematic CBT framework or simply providing social skills training. It is also useful to ensure that the patient's support network is also familiar with the model of treatment being offered. This will decrease the likelihood of well-meant but ineffective advice, and distracting 'helpful' articles cut out of newspapers about magical new physical and psychological treatments.

Finally, it is important to think about the therapist. To what extent will the appearance of the therapist impact on the course of treatment? Unlike most therapeutic settings where little is known about the therapist, appearance, the central focus of therapy, is immediately apparent. Race, ethnicity, wearing make-up, colouring hair, choice of clothing, visible piercing or body hair, having a visible disfigurement, body shape and size, all have a different meaning in the context of working with body image concerns. This is particularly important because patients may habitually make social comparisons that may in turn trigger self-criticism. For example, someone who is worried about the appearance of a specific feature will tend to make comparisons with the same feature on other people. There is a bias amongst those with visible difference who experience difficulties toward 'upward' comparison (i.e. studying people who have an 'ideal' or 'better' version of that feature) rather than downward comparisons with people who are perceived to have a 'worse' feature (see Halliwell & Diedrichs, 2012). This tends to maintain the idea that the feature is substandard or unacceptable. Sometimes patients may bring these issues up themselves, and when they do it is helpful to explore the processing associated with them. Or this might be covertly addressed by checking how the patient feels about working with the therapist. Occasionally, the therapist may encounter outright resistance stemming from envy associated with perceived differences in appearance.

Similarly, people beginning work in this area should consider the way their own body image or appearance-related concerns may impact in their work with patients. High levels of disgust sensitivity (which can be screened and treated via an exposure programme) can also make it more difficult to work comfortably with people who have significant wounds. Similarly a therapist with a very high investment in their own appearance will need to be aware of the way this impacts for different patients. Addressing the needs of those who experience psychological difficulties leads to consideration of a broad range of factors affecting the individuals themselves and also affecting the general management of the treatment process. These considerations are explored in more detail in the remaining chapters.