



**Changing** faces  
*the way you face  
disfigurement*

## Living with a Disfigurement

*managing the challenge*

## Why this booklet?

Disfigurement can affect anyone, at any time, at any age, from any ethnic group. Some people are born with medical conditions that cause disfigurement. Others might acquire their disfigurement in childhood or later in life, perhaps through trauma or injury.

There are over 1.3 million people who have significant disfigurements to their face and body in the UK – that's one in 45.

540,000 people have a significant facial disfigurement – one in 111.

- 92,000: congenital/birth conditions like birthmarks, cleft lips/palates
- 66,000: accidents such as burns and facial scars
- 40,000: cancer-related disfigurements, from surgery for skin cancer
- 25,000: disfigurements to or around the eye
- 100,000: facial paralysis including from stroke
- 220,000: skin conditions like psoriasis, vitiligo and acne.

In a year, 415,000 people in the UK are born with or acquire a disfiguring condition to their face, hands or body, some of which will be temporary.

It is difficult to define a 'disfigurement' precisely – and some people do not like to be thought of as having one.

Disfigurement is in the eye of the beholder – and the person themselves. It is well-recognised in psychological research literature that the extent or severity of a disfigurement is not linked with the amount of distress it causes. What may appear to be a 'minor' disfigurement, especially if it appears on what is called

the 'communications triangle' on the human face – that is, the area that includes the eyes, nose and mouth where people focus their gaze and attention – can be the cause of considerable self-esteem and self-confidence problems. People who have disfigurements on their body – hidden by clothing – can also experience such difficulties.

Whilst medical and surgical interventions can help to make a disfigurement less noticeable, this depends on the nature of your condition and it is rarely possible to remove it completely.

Having a good understanding of common issues associated with disfigurement and finding ways to feel good about yourself and manage other people's reactions to your appearance can help you to manage the challenges of disfigurement successfully.

### This booklet is designed to

- give you an overview of some of the common experiences and challenges faced by men and women who have a disfigurement
- help you to increase your understanding and awareness of the issues and personal challenges associated with disfigurement
- allow you to consider your options in managing these challenges
- offer some strategies that you can use.

For more detailed guides and fact-sheets on specific issues please contact *Changing Faces* or go to our website:

[www.changingfaces.org.uk](http://www.changingfaces.org.uk)

# **Living with a Disfigurement**

**managing the challenge**

Harriet Griffey & Bernadette Castle

## Living with a disfigurement – managing the challenge

### A note on the language

The word 'disfigurement' is used in this booklet to describe the aesthetic effects of a mark, scar, asymmetry or paralysis to the face or body. *Changing Faces* uses the word as a noun, (for example, 'a child who has a disfigurement'), but avoids its use as an adjective, (for example, not 'a disfigured child' but 'a child with/who has a disfigurement'; not 'a disfigured face' but instead, 'a facial disfigurement').

We recognise that the word 'disfigurement' is not particularly positive and some people may not want to use it to describe their condition or appearance, preferring other words like 'visible difference', 'unusual appearance' or the actual name of their condition. These words are used on occasion.

*Changing Faces* encourages the real cause of a person's disfigurement to be spelled out, (for example, a person with/who has a cleft lip, Bell's Palsy, burn injuries, cancer, acne, etc.) because this is an informative way of describing a person's medical condition.

The charity continues to use the word 'disfigurement' as it is a succinct, generic term widely understood by the general public and enshrined in British law in the Disability Discrimination Act (DDA) 1995, which legally protects people who have disfigurements against discrimination.

## 1. The challenge of living with a disfigurement

### 1 Unwanted attention

Having a visible disfigurement can attract unwanted attention, such as staring, double-takes, unsolicited comments, and even discrimination or abuse. This can leave you feeling angry and depressed which in turn can influence your social encounters and impact on your relationships, your sense of your identity and on your self-confidence.

For the most part, other people's reactions are based on human curiosity and uncertainty. Not everyone will have met someone with your condition or disfigurement before, and as social beings, we seek to understand our environments and the people who live within them.

Taking the attitude that people do not mean to be unkind can be more helpful than assuming people are always going to be hostile and gives you more energy to be able to deal with other people's reactions. It can help to think about occasions when you might have been shocked or surprised by someone else's appearance and perhaps you too behaved in a curious manner.

That is not to say that some people aren't thoughtless by staring excessively, moving away or saying something inappropriate –



*People might be curious, or just uncomfortable, or unsure. We live in a world where people feel easier being similar. People don't know how they're supposed to react to people who look a bit different – they might just be uninformed or ill-equipped.*



and a few will be very unkind. At these times, there are a variety of coping strategies that you can draw on. These include finding ways to soothe yourself and seeking the support of others. Our booklet, *Handling Other People's Reactions* gives you more information about what happens when other people meet someone with a disfigurement for the first time and vice versa.

### 2 Body image

In today's society we are exposed to many images and messages which link good looks to success or emphasise physical 'perfection'. These can affect our body image. By body image, we mean the internal image that we have about our physical appearance as opposed to other people's view of us. It is important to make this distinction because, whilst other people's opinions matter and our view of ourselves is largely informed by other people, it is our own perception of our self that really matters to how we experience the world.

Maintaining a positive body image is harder if you have encountered negative reactions to your disfigurement, such as teasing or bullying. This may have led you to believe that your appearance is unacceptable, or even something of which to be ashamed.

Challenging such beliefs takes time and effort, and it may help to talk to a professional counsellor or psychologist about such experiences. It can also help to consider how your beliefs around your appearance were formed. This is discussed further on page eleven.

Attractiveness and beauty are socially constructed ideals that have evolved over time and are influenced by a variety of factors. In today's society, our fascination with celebrity and physical 'perfection' has a considerable effect on narrowing our definitions of what is considered beautiful and attractive.

You have a choice about how much to comply with such definitions and the myths associated with them. Embracing a more rounded and realistic perspective of attractiveness and working positively to enhance your own body image, can be very empowering. Although we rarely see people with disfigurements



*I had to reject the negative cultural values placed on scars – I had to become counter-cultural.*



in adverts relating to fashion and beauty, this doesn't mean you can't enjoy clothes, accessories and make-up.

For some people, it can be helpful to take a more counter-cultural view to appearance and researching literature that enables you to do that can be helpful.

It is important to know that taking such a view may mean going against the strongly-held view of others. Only you can make the decision about how far you want to go. However, the basis for such decisions is to enable you to live more positively with your disfigurement rather than relying on other people's definitions.

### 3 Your self-esteem and sense of identity

Our self-esteem refers to how we think and feel about ourselves and is closely linked to our sense of identity. Do you feel good about your self? Your achievements? How you look?

Our identities are made up of lots of different parts, and include our internal characteristics (for example – intelligence, morals, beliefs, sense of humour, etc.) and external qualities (for example – physical body, abilities, style, stature, etc.)

Our sense of identity is informed by our earliest relationships and evolves as it is influenced by our interactions with others and our life experiences. If you felt loved and valued and accepted in your life, you will tend to have positive self-esteem and a good sense of your identity. If, however, you have felt unaccepted, rejected, or less valuable this can have

a negative effect on your sense of self and you may struggle with low self-esteem.

If you have a disfigurement, your self-esteem can be informed by various factors such as when you acquired your disfigurement or whether you see your disfigurement as something which defines you or as only one part of your experience.

If you were born with a disfigurement or acquired one very early in your life, how people reacted to or talked about your disfigurement will have had an influence on how you now think and feel about it and on how much it forms your sense of identity.

If your appearance was talked about openly and honestly and you learned ways to manage other people's reactions, you will hopefully feel comfortable and even very positive about your appearance and about yourself in general. If, on the other hand, you encountered teasing or discrimination and did not have the support to manage these, you may feel negatively about your appearance and have low self-esteem.


If you acquired your disfigurement later in life whether through accident or disease, you will already have developed a sense of your identity based on how you felt about your previous appearance. You will undergo a period of loss for your old appearance and readjustment to your new appearance.

Our faces, like our voices and our other qualities, are linked to our identity. If one or more of these qualities change, the loss experienced and adjustment required can be considerable.

If your appearance has always been essential to your self-esteem and/or you have been admired greatly for your looks, acquiring a disfigurement can bring about a crisis of identity. This needs careful exploration and review by a trained counsellor or psychologist.

### 4 The experience of loss or bereavement

The experience of loss comes in many forms – the death of someone close to you, the loss of something you value, such as a job or your home, or the loss of your health or your looks.

A close-up photograph of a woman with dark hair, smiling warmly as she hugs a young girl. The girl has light-colored hair with pink bows and a visible red, raised lesion (haemangioma) on her forehead. She is wearing a white shirt and a pink jacket. The woman is wearing a white t-shirt and a silver watch. They are outdoors with green foliage in the background.

Hannah has a haemangioma. She is four years old and wants to be ballet dancer when she is older.

## Acquiring a disfigurement

If you acquire a disfigurement, you will feel the loss of your previous appearance and are likely to undergo a process that can feel very similar to bereavement. You may encounter feelings such as shock, denial, anger and depression. Recognising these feelings as a normal process and not a permanent state of affairs can help you to adjust.

As well as the loss of your appearance you may need to deal with other associated losses. These may be the loss of function and/or general health, and in some cases, the loss of employment. You might also face changes in relationships as family and friends adjust to changes in you.

It is common for people to be shocked by their new image when they see themselves for the first time, and for some time after. Your external appearance is temporarily at odds with your internal self-view, and you might find it hard to believe that you will ever feel okay about your new looks. This is where the grieving process plays its role, as your mind assists you to adjust slowly until eventually you reach a time when you have integrated your new image with your old self. It's quite normal for this to take a number of years, and some people find it helpful to talk with a counsellor about their experience to assist this process.



*The first step was getting to like myself. People expect me, and other people with disfigurements, to be quiet and reserved. I am 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.*



Depending on how you acquired your disfigurement; you may also experience some degree of trauma, which will potentially extend the period of adjustment. Trauma is common when someone has been involved in an accident, been attacked, or perhaps been through very radical surgical treatment.

If you are encountering difficulties sleeping, having repeated flashbacks of the accident or event, you are struggling to concentrate and perhaps feel especially sensitive, you may have post-traumatic stress disorder (PTSD), and it would be advisable to talk with your GP about this. Specialist help is available for this, and receiving a referral to a suitable professional as early as possible is advisable.

## Congenital or early acquired disfigurement

There can also be a sense of loss if you were born with a disfigurement, or acquired it in early life. This sense of loss is slightly different in its nature, and refers more to a feeling of loss for how you imagine life might have been if you didn't have a disfigurement.

Some people imagine that life would have been much easier or they would have been more successful without a disfigurement. You may find yourself blaming your disfigurement for things in your life that go wrong, or you are unhappy about. Such loss is usually encountered at times of change or crisis. Many people experience it when they face a new medical intervention, or perhaps are having difficulties in their relationships. The resulting feelings are similar to those described before, and it can be useful to review your current beliefs and coping strategies when this happens.

## 5 Handling relationships

### Meeting new people and managing intimate relationships

As social beings, our relationships are important to us and learning about relationships begins at birth, when we first bond with our parents and families. How we experience these first relationships will have a bearing on how we approach relationships in later life.

Some of the most common difficulties you experience will occur in social situations – particularly when you meet people for the first time and in intimate relationships.

If your efforts at relating were met with warmth and approval, you will probably feel more confident about future encounters. If your earliest relationships were unsatisfactory, and/or you have experienced a lot of negative reactions from other people, then you may be more cautious, lack confidence, avoid social interactions or find it difficult to trust other people. These factors will inevitably influence your behaviour and social encounters.

### Meeting new people

It is normal to feel anxious when meeting someone for the first time. We naturally want to be accepted by others. If you have a disfigurement people may react to you with surprise and curiosity or avoid you altogether. Once you are more engaged in a conversation however, you will find they are more likely to focus on what is being said than your disfigurement.

People also notice behaviour. If you are self-conscious about your disfigurement, this may show in your behaviour. For example, you may avoid eye contact or display nervous body language. Such behaviour can make the other person feel awkward and less inclined to want to know you. This type of process is called ‘the negative feedback loop’ and you can read more about it in our booklet, *Handling Other People’s Reactions*.

By adopting more positive body language and communication skills you can change these encounters to benefit you. We will look at some of the ways to do this on page twelve.

### Managing intimate relationships

If you have a disfigurement, you may find it hard to believe that someone else will find you attractive. However, your appearance should not exclude you from intimate relationships and many people with disfigurements enjoy very successful relationships.

Understandably, if have been hurt or rejected in the past you may want to avoid more of the same. As a result, you might adopt strategies that prevent you getting close to someone or avoid opportunities where you might meet a future partner.

Employing such avoidance strategies can be counterproductive however, because whilst this may mean you avoid potential pain, you also rule out the possibility of positive encounters.

Any social encounter involves the coming together of two people with their own past experiences, beliefs and assumptions but assumptions can be wrong. Transferring old negative assumptions and behaviour onto your current encounter is more likely to create the very experience that you are trying to avoid! Taking risks requires courage, but can bring untold reward.

*Changing Faces* has produced a guide to intimacy and relationships that offers advice about how to manage some of the most common concerns in this area. The guide can be downloaded from [www.changingfaces.org.uk](http://www.changingfaces.org.uk)

## 6 Managing expectations

Your personal expectations will play a major part in your ability to live positively with a disfigurement. Your expectations will have been influenced by the expectations and reactions of other people. How you experienced these, how they were managed, and what their impact was may continue to inform how you feel about your abilities and future prospects.

Because of your disfigurement, your family, with the best of intentions – because they wanted to protect you from hurt and disappointment – may have over-protected you. This may result in you having less belief in your own abilities and capabilities. If, however, your family instilled the belief that you were just as capable as the next person, you are likely to have a positive belief in your abilities and future.

Unfortunately, if you have developed the belief that others are going to react negatively to you because of your disfigurement, your behaviour may be more defensive. Whilst such a coping strategy will have been developed for a reason and may have served you well in the past, it can be helpful to review if it is still relevant now. You may find that your assumptions are outdated and only serving to limit your life. By giving yourself the chance to experience people differently, you have a chance to disprove unhelpful beliefs and expand your personal expectations.



Monica has Bell's Palsy. She is a writer, a keen photographer, and has exhibited her work widely.

Of course, some people may make negative assumptions based on your appearance. They may assume that you are less intelligent, less likely to be successful or have a relationship, or to enjoy life. Such expectations of you, particularly if they include your family and friends, can inform your own beliefs.

To counter this, adopt behaviour that lets others know that there is more to you than your disfigurement and that it doesn't define you as a person. Engaging in conversation, sharing topics of interest, and letting other people get to know more about you can go a long way to dispelling any myths or misconceptions.

## 2. How to manage the challenges

Some of the key factors that enable individuals and families to face the challenges of disfigurement include:

- 1 Having accurate and realistic information about your condition and treatment options
- 2 Having good quality social support – from family, friends and professionals
- 3 Having a positive attitude and self belief – about your appearance and your future
- 4 Employing a range of effective communication and social skills.

Let's look at these in more detail.

### 1 Having accurate and realistic information about your condition

Being well-informed about your condition and the treatment options available can give you a sense of control and authority. This means you need to take active steps in getting accurate information rather than just allowing others to make decisions for you.



*People do make assumptions about who you are from what you look like. You have to accept that people do make comments, it's the way some have been brought up, it's the way we are constantly bombarded with the message that you have to look good. It used to be hurtful, but not anymore. I see new encounters as an opportunity to let people know that I am actually a quite nice person if you get to know me, so give yourself permission to do that.*



There are lots of ways of obtaining information about your condition. These include talking with 'expert' medical professionals, contacting condition-specific support groups and organisations, and researching medical literature and reputable websites.

Being well-informed can help you to manage other people's questions, and to dispel any myths and misconceptions that others may hold about your disfigurement. It can also help you to be realistic about the outcome of treatment available to you and make informed choices regarding these treatments.

It is natural to explore treatment options that may bring physical relief, enhance functioning or perhaps bring aesthetic changes that you desire. It is, however, dangerous to undergo medical or surgical interventions without knowing all the facts – including the risks and limitations of such interventions.

Holding unrealistic expectations of the outcomes of treatment can lead to considerable distress and disappointment, and for some people, depression when these expectations aren't met. It can also be dangerous to hold on to the belief that the solution to difficulties in your life lies in the surgical 'removal' of your



*I am happy with the way I look and any surgery I choose to have is to make me feel physically more comfortable rather than to fit in with someone else's accepted norm.*



disfigurement. Not only is this unrealistic, as it is rare that a disfigurement can be removed completely, but it is unlikely that surgery will resolve any social or emotional problems.

Having unrealistic expectations about treatment options can also delay the process of adapting to and accepting your disfigurement. If you are constantly holding on to the belief that surgery will solve everything, you are likely to avoid ever accepting yourself fully and this will affect your emotional well-being. Family and friends can sometimes fall prey to this way of thinking, perhaps in an attempt to be positive, but they too need to review their expectations.

When considering treatment options, you might find it helpful to think about the following questions, and use the answers to guide your enquiries with health professionals:

- 1 What makes this the right option for me at this time?
- 2 Am I doing this for myself, or trying to please others?
- 3 What difference will the treatment make to my life? What will it enable me to do that I don't currently do? How will this show? Be realistic.
- 4 Do I know and understand all of the risks as well as the benefits?
- 5 Do I know what to expect from the treatment/surgery? What will I look like after? How long will the recovery process take?
- 6 What alternatives, if any, exist?
- 7 Would it be helpful to speak with other people who have undergone similar treatment?

Our booklet *Talking to Health Professionals about Disfigurement* can give you more guidance on this.

The time may come when you want to stop treatment, or when your medical professional tells you that no more can be done. Depending on whether this is your choice or not, you may experience either relief or find this very difficult to accept.

Some people go through a process similar to loss when this happens, as they finally begin to adjust to accepting their current appearance. You might find it helpful to seek support at this time.

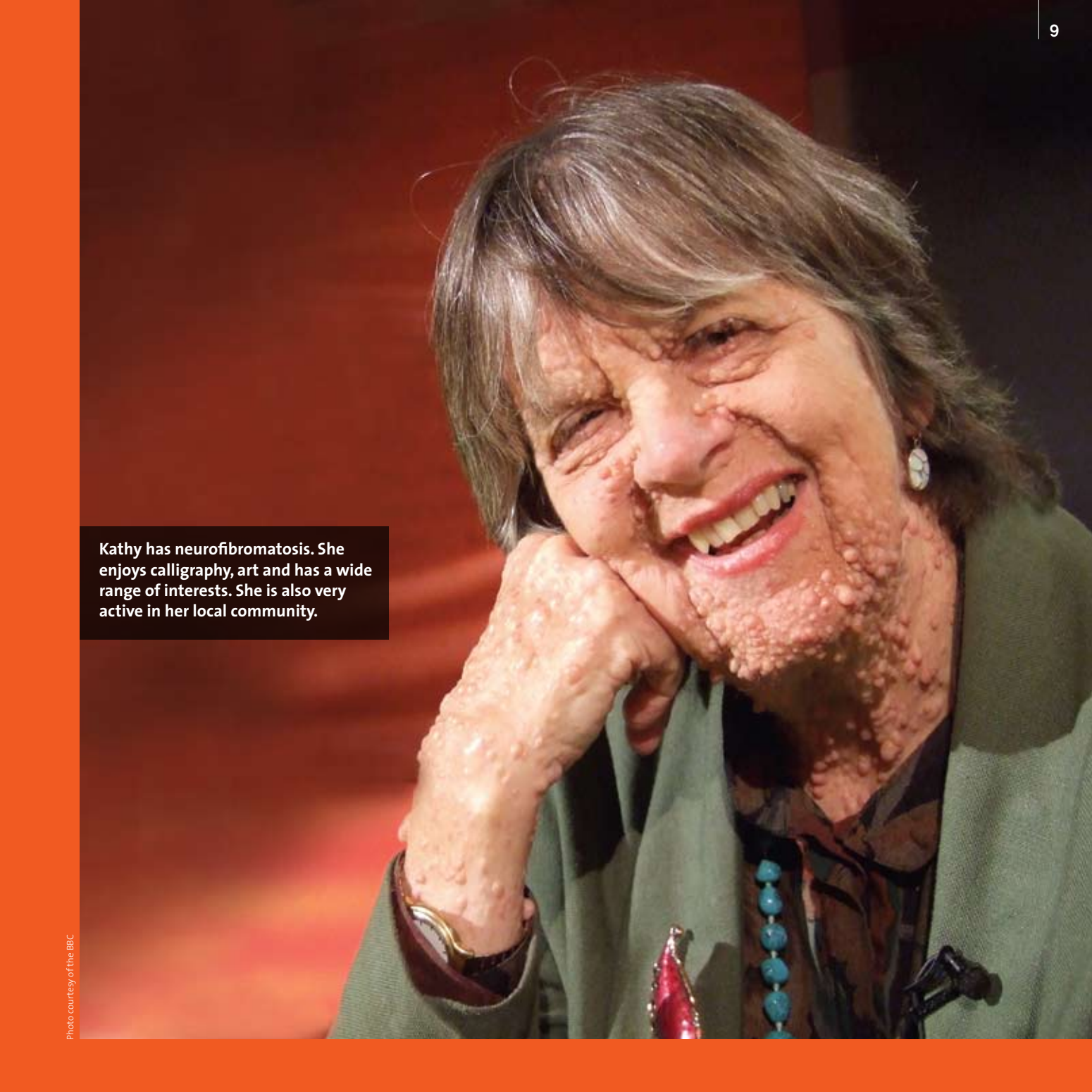
## 2 Having good quality social support

We all need good support in our lives. Knowing we are loved, valued and respected by those we love, value and respect and to whom we can turn to share good and bad news without fear of rejection, acts as a buffer to the negative experiences in life. Our immediate families often provide the starting point for this. For those who don't have immediate family close by or who feel they cannot rely on their families, it is important to create a network of support through friends, work colleagues and others.

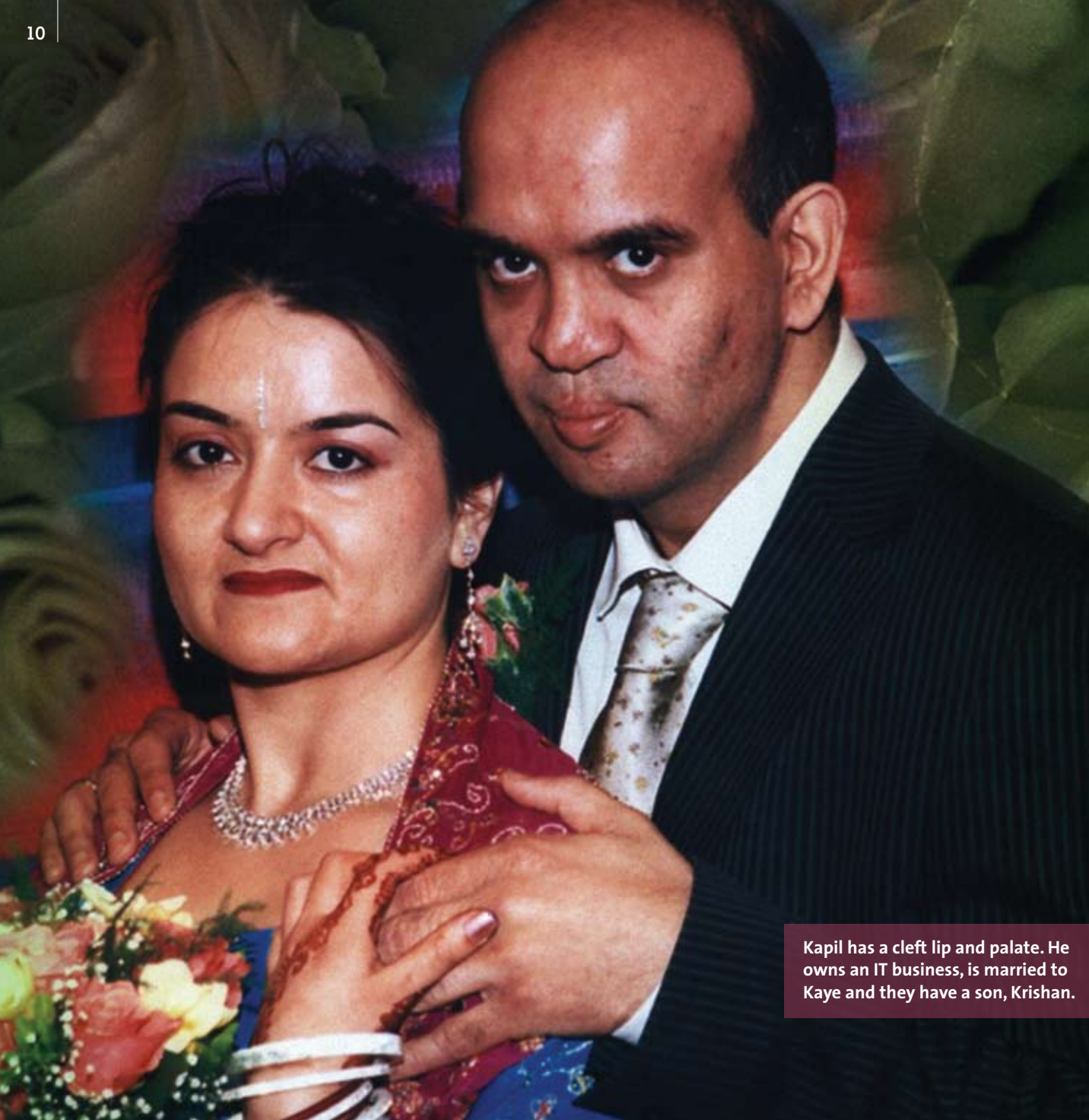
If you have a disfigurement, creating a network that you can rely on supports the experience of belonging and being accepted for who you are. This will have a positive impact on your self-esteem and sense of identity.

Consider how you can extend your support network in a way that makes you feel good about yourself. It can be easier to think about what sets you apart from others, rather than what you have in common, but if you really want to sing in a choir, go rock climbing, or learn a new language, you will be guaranteed to meet those with similar interests. And if you step outside your comfort zone, you may surprise yourself and develop untapped skills, greater confidence and new friends along the way!

You can find out about different social groups, courses and events in your local paper, at your local library, and through the internet. You don't need to spend a lot of money and many activities are free so don't let this be a barrier to looking around!



Kathy has neurofibromatosis. She enjoys calligraphy, art and has a wide range of interests. She is also very active in her local community.



Kapil has a cleft lip and palate. He owns an IT business, is married to Kaye and they have a son, Krishan.

### 3 Having a positive attitude and self-belief

Our thoughts and beliefs are informed by our past relationships and general life experience and are central to how we experience ourselves and other people.

It is our thoughts and beliefs that usually inform our feelings about a situation and, in turn, can influence our behaviour. This interplay of thoughts, feelings and behaviour can be a useful framework for understanding yourself and how you can consider change.

Our ways of thinking tend to be automatic, and often outside of our conscious control.

Although we can't stop thoughts automatically coming to mind, it is possible to learn to recognise them, question their relevance and usefulness, and if they are unhelpful or limiting, then to reject them. Through this process, you can choose to replace your thoughts with something more helpful. For example, if you find yourself automatically thinking that no one will be interested in what you have to say, you can remind yourself that you have lots in common that could be of interest.

It's normal for people to adopt fixed patterns of thinking, and hence behaving, based on a set of assumptions about life. These assumptions may be based on past negative experiences which may no longer be relevant and may interfere with present behaviour.

Adopting a more positive attitude may sound over-simplistic when your life feels like an ongoing battle and in many ways you're right! Widening your thinking about yourself, your disfigurement, and other people – in other words breaking fixed patterns of thinking and trying to think in a different way – especially if you have encountered a lot of difficulties, will not be simple but will take time and hard work. You might find it easier to explore your ways of thinking and how they are impacting on your present life with a trained counsellor or psychologist.

Having a more positive attitude, however, can make a huge difference to how you handle relationships and the various situations in your life. Other people respond more positively to those that hold positive beliefs and adopt positive behaviour,



irrespective of whether they have a disfigurement or not.

One of the most important questions that you need to ask is: 'What beliefs do I hold about my disfigurement?' The answer to this question may not be easy to face, and might take some unravelling, but it will also bring with it a new awareness of how your thoughts might be influencing your feelings and behaviour, and whether or not you need/want to review them.

If, for example, you have developed the belief that your disfigurement has limited your life, this belief may continue to influence your life in a negative way. Perhaps you don't assert yourself with others, at work or with your family? Perhaps you assume that your efforts will be met with resistance, so you choose not to try. Reviewing this belief so that you think something more positive and realistic can open up a completely new way of thinking. For example, how would it be to think the following: 'My disfigurement poses challenges, but I have the same abilities and potential as anyone else, and I'm worthy of success too.'

Adopting a new thought such as the above may give you more courage to take the risk of doing something different. For example, it might help you to consider that you might be capable of getting the promotion you never thought you could get.

Reviewing behaviour is also important because if the outcome of your behaviour proves positive, it will help to change unhelpful fixed ways of thinking. In relation to a promotion, your first step might be to write down all the reasons why you think you deserve a promotion. Secondly, you could write down the position you feel you are ready for. You could then re-write your CV. The next step could be to ask for an informal discussion with



*I discovered 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 way, I doubt I would have found the experience anywhere near as fulfilling as I did.*



your boss to consider what he/she might be looking for. Finally, you could prepare with a friend how you wish to handle the interview for a promotion. This ‘graded approach’ is discussed later on page 16 – ‘building blocks to increase confidence’.

#### **4 Employing effective communication and social skills**

Whilst appearance matters in our society, it is behaviour that has the greatest impact on other people. Being able to communicate effectively, both verbally and non-verbally, is one of the most effective ways to improve your social interactions and your self-confidence.

Verbal communication refers to the spoken word, how and what we say. Interestingly, people respond more to how we say things than the content of our speech. Hence, the tone, pitch, and speed of our delivery are very important. If you introduce yourself in a whisper, other people may not only struggle to hear you, but they may also assume that you lack confidence and may feel uncomfortable speaking with you.

Non-verbal communication, often called body language, refers

to how we use the other parts of our selves to communicate our feelings and needs. This can include the way you walk, your posture, eye contact, how you use your hands, the way you cross your legs. It is this non-verbal communication that is perhaps our most powerful tool, and the one that tends to portray our true feelings. If you observe a confident person enter a room, they might walk with their head up, shoulders back, look other people in the eye, smile accordingly, and then extend their hand when they introduce themselves.

Good communication and social skills can be learned through simple strategies like preparation, thinking about what to say, being more assertive, and using building blocks of behaviour (see page 16).

#### **Being prepared**

Other people’s reactions to your appearance can be exhausting and upsetting. While you may not be able to prevent people’s reactions to you, how you manage them can have a positive effect on your self-confidence.

Other people may also feel uncertain about how to respond to you because they are not used to seeing someone with a disfigurement.

By thinking about new situations in advance, and preparing for them with a positive frame of mind, you can reduce any anxiety you may have, improve your self-confidence, and help others to feel more at ease. For example, if you are going to an event where you will be meeting new people, think about how you might introduce yourself. Bear in mind that the tone, speed and strength of your voice will convey your level of confidence, so practice how you might do this.

Think about your body language. Practise walking with your head up, making good eye contact, smiling, and extending your hand to shake theirs. When you do this, people are more likely to look at and acknowledge you and, by initiating the contact, you are taking control (this will also have an effect on your thinking: a positive experience will register in your mind, and is likely to create a frame of mind which will then be open to new ways of thinking in the future).

Adam, who has neurofibromatosis, celebrates achieving a BA in Business Management, with a friend.





Debbie has a port wine stain. She is a speech and language therapist and has two daughters.

You may then want to have some initial responses or a conversation-opener ready. Think about the context in which you're meeting these new people, so that you can be prepared with common topics of discussion. If it is a work-related event you can talk about your work and enquire about the other person's area of experience. If you're at a party, you might want to ask how the person knows the host. Taking the initiative in the situation puts you in the driving seat, and the other person at ease.

It may feel it's hard and unfair that you need to make the effort and take the initiative in social encounters. It's understandable that you may want to avoid situations that make you feel anxious. If however you do this all the time, you will limit your freedom and lifestyle. By not facing challenging situations, you will only increase your anxiety about them because you never allow for the possibility of disproving your fears – and this will undermine your confidence further.

### What to say or do

If you have a noticeable disfigurement you are probably used to receiving a lot of unwanted attention. Having something to say in response to staring, comments or inappropriate questions is one of the most effective ways to manage such situations. Our booklet, *Handling Other People's Reactions*, offers plenty of advice in these areas. Here are some scenarios for you to consider – in the case of all of them your response might depend on how you are feeling at the time, who is asking, and where you are.

### Dealing with questions

If someone asks 'What happened to your face?' you could consider the following responses:

- 'I'd rather not answer that. I'm sure you can understand'. Declining to answer this question is perfectly reasonable if you don't feel it is appropriate, such as when you are asked by a stranger or are in a public place. Providing a short but firm reply is all that is necessary.
- Provide a brief, simple response and then move onto another subject. For example 'It's just my birthmark. I like your shirt – can you tell me where you got it?' This also has the effect of

distracting the person from asking you about your appearance.

- Provide a more in-depth reply and leave it open for further discussion. For example, 'It's just my birthmark. I've had it all my life. It doesn't cause me any problems although I have to take extra care in the sun.'

### Dealing with staring

- Look back, smile and hold the other person's gaze momentarily. They will hopefully smile back at you and then look away.
- For the more persistent observer, look back and hold their gaze whilst raising your eyebrows as an acknowledgement that you've noticed their staring.
- Ask, 'Can I help you? Do I know you from somewhere?' This will potentially deter the observer from continuing to look, and make them aware of their behaviour.
- If the person continues to look, 'Can you please stop staring at me. It's very rude.'

### Dealing with comments and name-calling

It is important to know when it is best just to walk away from a situation and not assert yourself. When faced with a group of people, or someone who appears aggressive, it may be safer to leave the situation. It can also serve to preserve your energy. Talk to someone about the experience for support and reassurance on such occasions.

Only if suitable, having a reply that disarms the person making the comment can be very useful. For example, if someone makes an unkind comment about your disfigurement, and you feel assertive enough, and feel safe enough, the following reply might be useful: 'Is that the best you've got?' or 'Gosh, how long did that take you to think up?' You could then pre-empt a comeback by offering all the other possible comments/names that you probably know only too well. For example: 'What about... (insert as appropriate).' This kind of response tends to show up the other person, so you may only wish to use it if you feel there are no other options available to you. Depending on your tone you can make your response sound more humorous than humiliating for the other person.

### *Building blocks to increase confidence: a graded approach*

If you feel self-conscious about your disfigurement, or find certain situations difficult, it might feel easier just to avoid them. As explained earlier, this type of coping style can be counterproductive because it prevents you from ever disproving your fears, maintains your anxiety about the situation and undermines your self-confidence.

A useful strategy is to use the graded approach. Identify the area of concern in a clear and tangible way, and then break it down into manageable steps – starting with what you can manage to do and then building on that.

For example, if you find travelling on public transport impossible, go with a friend and during off-peak times when there are less people around.

If there's an activity you want to do, like swimming at the local pool, find out the quieter times or whether there are same-gender or adult-only sessions where you might feel more comfortable.

You could ask a friend to go with you to the pool. You could also visit the health centre at the chosen time, but only go for a coffee and not go swimming on that occasion.

The next time, you could go swimming for just 15 minutes, and over time, build this up. You might also consider talking with the manager of the health centre about your concerns. If you know that your disfigurement will attract attention, it might be useful for staff to know a bit more about your condition so that they can answer any questions from other members accurately.

You can read more about communication skills in our booklet, *Handling Other People's Reactions*, and also in our *Guide to Intimacy and Relationships*. To find out more about these go to [www.changingfaces.org.uk](http://www.changingfaces.org.uk) or contact our offices.



## 3 Living positively with a disfigurement

Gaining the confidence to live positively with a disfigurement requires resilience and a positive attitude. This may feel hard to acquire if you have to deal every day with the sort of unwanted attention that makes you feel 'on duty' all the time.

Whether you were born with a disfigurement or acquired one later on in life, living with an unusual or different appearance will influence how you see yourself, how you see the world and, inevitably, how the world sees you. But, it is important to remember that what you look like is only part of who you are.

For some people, it's possible to transform how they look into a positive, rather than a negative, aspect of themselves. By learning the skills they need to cope with their disfigurement, they can feel stronger and be more consciously aware of the choices they make and direction they take in their lives.

But this isn't true for everyone, and some people struggle their whole lives coping with the unwanted attention. However, for those who are able to adopt a positive attitude and who learn the social skills they need, this is less of a struggle and life becomes infinitely more manageable, more positive and happier.

There are many people who live positively with a disfigurement even though they still encounter unwanted attention. They are able to accept the reality that fundamentally it is not who they are that gives rise to such reactions but only their unusual appearance. Their sense of self is so strong that they see other people's behaviour as a lack of understanding and they avoid seeing this behaviour as a reflection of who they are.

Many people with disfigurements learn to adjust completely to their unusual appearance and go on to lead very fulfilled lives. Their self-acceptance and self-confidence radiates to those around them and results that they are welcomed and well-received. They are not inhibited by their looks.

For further information go to [www.changingfaces.org.uk](http://www.changingfaces.org.uk) or contact our offices.

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