

A guide to communicating successfully when you have a disfigurement affecting your eye(s)

1 INTRODUCTION

The appearance of your eye(s) may be different for a number of reasons including facial palsy, cancer, an accident, a congenital condition or a stroke. You may have scarring around your eye, the eyelid may droop or the eye muscles may have lost tone. One of your eyes may have been removed or both eyes may protrude as a result of thyroid eye disease.

Aside from enabling us to see, our eyes play an important role in communication and self expression. They also form an important part of our self-image or the way we feel about ourselves. It is therefore natural to be just as concerned about the way you look and your ability to communicate or express yourself effectively as about the possible change or loss of function.

This guide explains the role of the eyes in communication and how you may feel if your eye(s) looks different. It also includes some tried and tested suggestions which aim to help you feel confident about handling other people's reactions to your eye(s) and managing everyday social situations.

2 UNDERSTANDING YOUR FEELINGS

People often feel anxious when they have a disfigurement especially in social encounters. If you feel self-conscious about your eye(s) you may also feel less confident about making eye contact, which, in turn, can make you feel more anxious because, without making eye contact, it can be difficult to 'connect' with other people.

If the appearance and/or function of your eye(s) has changed, it can take time to adjust. It is very normal to grieve for a loss of function, for the loss of your previous 'looks' and the way you have seen yourself, and even the loss of how other people have perceived you until now. Isolation, denial, anger, sadness, and depression, are just some of the feelings which you may experience.

As with any sort of bereavement or loss, grieving takes time and you may find it helpful to express these feelings with a person you trust. This person may be a family member, a friend, or a professional counsellor. You can also get in touch with *Changing Faces* and speak to one of our adult specialists.

3 WHEN THINGS GO WRONG IN COMMUNICATION

Your face is the focus when you communicate with someone. We all look at people during a conversation to show when we are speaking and listening. Most of our attention is directed at the central triangle formed by the eyes, nose and mouth, as we gather information about the person from their constantly changing expression. Whether or not they smile, look at us directly, or glance away frequently can tell us as much about someone as the words they speak.

Eye contact is an important aspect of this process and we tend to maintain more eye contact when we listen than when we speak. It can feel very uncomfortable in communication when this eye contact is interrupted or blocked in some way.

It is very natural to avoid making or maintaining eye contact when you have a visible difference which affects your eye(s) perhaps because you are anxious about how people are going to respond to the appearance of your eye(s). But people may find it difficult to communicate with you or think you just aren't interested if you continually avoid eye contact or your eye contact is obstructed in some way.

Think about how you have felt when speaking to someone wearing dark sunglasses or someone who is looking at the ground or over your shoulder. You may have wondered: What are they looking at? Do they want to speak with me? Are they listening?

It is also important to remember that you won't be the only person feeling anxious. The other person may deliberately avoid eye contact because they feel awkward and embarrassed about not knowing how to respond to your visible difference. Most people are used to making eye contact with two eyes and if one eye looks unusual, they may not know which eye to look at or whether to look away for fear of being seen to be staring. Instead of risking 'getting it wrong', they may prefer to avoid contact all together. You may interpret their behaviour as a lack of interest in getting to know you which then increases your own anxiety levels and may have the unintended effect of widening the communication gap between you both.

4 DEVELOPING YOUR CONFIDENCE TO COMMUNICATE SUCCESSFULLY

Good social and communication skills are two of the determining factors in the success of a social encounter when one of you has a disfigurement. Appearance can undoubtedly have an effect on social interactions but research shows that the way you behave is MORE influential. If you can adopt the following suggestions, you can literally change the way that other people respond to you – with very positive results.

Make eye contact

It is easier to make eye contact with some people than others. So, start by making a list of all the people that you need to make eye contact with on a daily basis putting people that you know and trust at the top of the list e.g. a family member, friend, close work colleague. Practise with these people first.

The aim is to gradually build up the length of time you make eye contact to about four seconds when it is very natural behaviour to glance away and then refocus on their face.

When you feel comfortable making eye contact with these people, start to practise with people you find more challenging e.g. clients at work, parents at the school gate, people in the queue at the supermarket check out, other guests at a party.

If it feels too difficult to make eye contact at first, focus on the bridge of the other person's nose instead because it has exactly the same effect.

Gradually building up your eye contact skills will also keep any anxiety you may feel at a manageable level.

Help others to help you

Being assertive about your eye(s) can help put others at ease and allow them to communicate more easily. Remember you are the expert here, and you cannot expect others to guess your needs. They might need reassurance that you can see them with both eyes, or that they should direct their attention to your sighted eye or perhaps they need to know that you cannot see them clearly. By taking charge and raising the subject of your appearance yourself, you will feel more in control and less anxious.

Consider the following situations:

You find yourself at a dinner party and the person you really want to talk to is sitting on the 'wrong side' of you. You are unable to see him/her clearly without turning your head completely which will eventually give you a neck ache.

Instead of turning your head and feeling anxious and distracted by your discomfort, which may also distract the person you wish to talk to, you could simply say, "Let me sit on the other side of you so I can see you better."

The elements, especially wind and sun can have an adverse effect on some people's eyes, causing irritation, weeping, redness or inflammation.

Instead of suffering in silence, you could say, "Do you mind if we go inside? The wind is really irritating my eyes."

You and your friends are getting ready to go out for the evening. Everyone's putting on their eye make-up except you and you are feeling awkward because you can't join in.

You could hang on to your feeling of being 'left out' and not tell them anything but doing this means that they are not able to show that they understand and offer you some reassurance. Or you could say, "I wish I could wear eye make-up, but my eyes are too sensitive because of my condition, but perhaps I'll try some lipstick."

You've been invited to play football with your colleagues after work in the park. You've just joined the company so you don't want to look like you are not a good sport but your doctor has recommended you avoid contact sports because of your eye.

You could leave work early muttering an excuse about having to go to the dentist and feeling angry at yourself and your condition. Or you could say, "That sounds great. Thanks for asking but I can't risk aggravating my eye condition. How about I join you in the pub afterwards for a few beers?"

Have an explanation ready

If the unusual appearance of your eye(s) is noticeable, people will probably ask you about it. Remember that other people are usually curious or concerned, not hostile. How you reply is up to you. You may not feel like answering at all or you may feel like giving all the details. This will probably depend on how you feel at the time, who's asking and what situation you are in. The most important thing here is to be prepared with some kind of response. This takes practice and most people find that their anxiety is greatly decreased by having answers prepared in their mind.

Here are three situations that might require three very different responses.

1. *A child asks you "Why does your left eye look all funny?"*

"I had an operation on my eye but I'm ok now."

This simple, clear statement will satisfy the child's curiosity and closes the subject down.

2. *You are at a job interview and the interviewer asks, "What happened to your eye?"*

"I was born with a condition which affected the appearance of my eye, but it does not affect my sight. In fact, I find it has helped me acquire really useful communication skills which I've found very helpful in my previous roles...."

OR

"The advantage of an unusual appearance is that people always remember you."

This shows you are comfortable with your appearance and suggests that they should be too. It also turns things around to your advantage.

3. *You are going out with your new partner and s/he asks what happened to your eye.*

"I find it quite difficult to talk about but would like to share it with you at some point. Perhaps we could talk about it another time."

Although it can be upsetting when a new partner asks about your difference, it is unlikely that they are thinking of it in a negative way. Sharing personal details about yourself will bring you closer but you also need to feel that you can trust the other person and this can take time. This response shows that you are open to talking about it but when you are ready.

"I'm really glad you brought it up. I don't like to tell everyone the details but I've been wanting to tell you what happened to my eye for a while now."

This response reassures your partner that it is ok for them to ask and suggests you trust them with your experience.

Handling staring and comments

Unfortunately we also need to be prepared at times for unwanted attention or comments. Having assertive responses ready for these will help you feel empowered in what can be very distressing situations.

If somebody is staring or you sense that someone is talking about your eye, you might try smiling first which can usually break the ice, but if you feel someone is being persistent in their rude behaviour you could say:

"Does my eye bother you? Because it doesn't bother me!"

Firm confronting statements like this clearly express your feelings and turn the attention to the other person.

"I would rather you didn't stare at me!"

This is simple and assertive and tells the other person you are confident.

“How original!” or “Very imaginative!”

Said in a dismissive tone, this will turn the attention back to the speaker and allow you to stroll away with confidence.

For more examples and details on developing your responses in different situations, take a look at *Changing Faces'* booklet, *Handling Other People's Reactions*.

Wearing an eye patch, prosthesis, glasses etc

You may be required to wear a prosthesis, eye patch or glasses as a result of your eye condition or following an injury. It will naturally take time to adjust to any new 'aid' and may feel unfamiliar and uncomfortable for a while. These aids may also attract attention so preparing for questions and comments about them is the best way to manage someone's reaction. For example:

My eye patch helps protect my eye, that's all.

This is a prosthetic eye. The doctors have done a great job matching it to my other eye!

This is a prosthetic eye. I can't see through it but I'm pleased with how it looks.

Whilst some aids are necessary to protect or maintain the health of your eye and/or orbit and surrounding skin, others, like glasses or hats or wearing a particular hairstyle, may be an optional choice.

It is worth monitoring how you feel when you do/don't wear an aid, particularly if it is not for health reasons. If you are finding that you will only go out or meet people if you are wearing glasses, an eye patch, hats or with your hair 'just so', these aids can actually have the longer term effect of increasing your anxiety around social situations.

If you are finding it hard to go out without an 'aid' or you feel yourself becoming increasingly anxious you might like to talk to someone like your doctor or a family member about this. Alternatively you can contact one of the adult specialists at *Changing Faces*.

5 GAINING INFORMATION AND SUPPORT FROM CHANGING FACES

If you have a disfigurement of the eye (s) or are close to someone who does and you would like further information, support or advice, please contact *Changing Faces* on 0845 4500 275 and ask to speak to one of our adult specialists or email info@changingfaces.org.uk.

Changing Faces runs a number of workshops every year which help people to develop new communication and social skills, address issues around intimacy and relationships, and look at how we present ourselves through our appearance. If you are interested in attending a workshop or finding out more, please contact us using the details given above, or have a look on our website for forthcoming dates.

Changing Faces also publishes a range of guides and self-help booklets which provide advice and suggestions for increasing your confidence when you have a disfigurement in a range of situations. For more information, please contact us on the number given above.

6. FINDING FURTHER SUPPORT

Moorfields Eye Hospital
www.moorfields.nhs.uk

Cancer Backup
0808 800 1234
www.cancerbackup.org.uk

RNIB
0845 766 9999
www.rnib.org.uk