Oxford University Hospitals
NHS Foundation Trust

Facial Palsy

COPING WITH COMMENTS, QUESTIONS AND STARING

Oxford Facial
Palsy Service

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AN INTRODUCTION TO COPING WITH COMMENTS, QUESTIONS AND STARING

You might sometimes be asked questions about your appearance or why you're having difficulties doing certain things, such as eating or drinking.

It may feel like people are staring or you may receive rude comments from others.

Regularly receiving comments, questions or being stared at can be challenging. It is common, and understandable, for these things to make some people with facial palsy feel:

- **upset** that people have noticed their facial palsy
- **worried** that people are looking at them and/or judging them for their appearance or difficulties with moving their face
- **low in confidence**
- **angry** or **embarrassed** that people are staring them
- **worried** about how to explain facial palsy to others.

This guide is designed to give you some ideas for how to manage comments, questions and staring.

The experience of facial palsy is different for everyone. In this guide we will think about some common situations which are described by people with facial palsy. You can adjust the responses suggested in this guide to fit with your personal situation.

If you were born with facial palsy or have had facial palsy for a long time, you might find that you already have your own ways of managing comments, questions and starting in an effective way. If that is the case, we hope that this guide can provide you with a few new ideas, to add to your current strategies.

Below are three people with a diagnosis of facial palsy who are affected by comments, questions and staring in different ways:

Mark, aged 52

Mark developed Ramsay Hunt Syndrome 12 months ago. Before his symptoms started, he used to enjoy visiting the pub on Saturday evenings with his wife. The symptoms of Mark's condition include difficulties drinking, especially from pint glasses (or any glass without a curved lip). He still goes to the pub each week, but is becoming increasingly frustrated that people are staring at him while he is drinking. He normally manages this by facing the wall and avoiding talking to people. He is preoccupied with worry about whether or not people are staring at him.

Steven, aged 33

Steven was born with Moebius syndrome. He is normally quite confident talking about his condition with other people, but finds himself feeling very anxious about how to respond to the comments, questions and staring from children when he picks his 8 year-old son up from school.

Layla, aged 36

Layla developed Bell's palsy 6 months ago. She often finds it easy to talk to new people, who she has met for the first time. However, when it comes to meeting old friends that she has not seen since before the onset of Bell's palsy, she finds it hard to know how much to tell people and often worries that she has shared too much information about herself.

WHY PEOPLE STARE, MAKE COMMENTS AND ASK QUESTIONS

As babies develop, they have to learn about the world and try to make sense of their experiences. It is helpful for them to be able to look at people or objects to **work out what is similar and what is different** to their usual experience. This is because normal or more familiar images (such as the face of their mother) are typically safe, while something new, novel or different (such as the face of a stranger) may be a warning of danger.

Learning to sort their experiences into categories is essential for a baby, as it helps them to understand the world around them. Because of this, the **human brain is designed to be very good at noticing things that are new**, or out of the ordinary.

The human brain's preference to focus on objects or faces that are 'different' does not stop in childhood. It continues right throughout our lives. As psychologists, we call this preference an **Attentional Bias**.

Attentional Biases partly explain why we stare at people who look different. The brain has an **in-built mechanism for looking at new information** (e.g. someone whose face looks different due to facial palsy). As the information is new, it takes longer for the brain to process that information.

In 2015, researchers at the John Hopkins School of Medicine in the USA found that when volunteers in an experiment looked at photos of people with facial palsy, they **spent a longer time looking at the parts of the face that were affected by facial palsy**, rather the parts that were unaffected. This tells us that it takes longer for the brain to process these new or different images (e.g. faces with facial palsy) rather than typical images (e.g. faces without facial palsy) and explains why people look or stare for longer at people with facial palsy. **It is often out of curiosity and a need for the brain to understand new information, rather than judgement**.

Much of the time, the reason why people might ask questions is because **they have not seen somebody with facial palsy before and do not know how to react in a sensitive way**. This can often lead to unhelpful questions like:

"Have you had a stroke?" *or* ***"Why are you eating like that?"***

These questions can be very frustrating and upsetting. This guide is designed to help you manage these (sometimes tricky) situations.

HOW TO MANAGE QUESTIONS ABOUT YOUR FACIAL PALSY

Think about a time when you were asked a difficult question about your facial palsy. What did you get asked, how did you answer, and how did this make you feel?

I was asked: ....

I said: ....

Afterwards I felt: ....

Below are some suggestions for how to respond to questions about your facial palsy. It is important to remember that **it is up you to decide how much information you give to people**. There might be some situations where you are happy to give lots of information, while in other situations you might just want to change the subject. This might depend on **how you are feeling** or **who you are talking to**.

You will notice that the following answers vary with regards to the amount of information that is given, starting with offering a small amount of information, through to opening up a conversation about facial palsy.

Explain and Reassure

Many people have found it helpful to respond to comments and questions by briefly **explaining** that they developed, or were born with, facial palsy. Offering **reassurance** can teach the other person about facial palsy and help them to better understand how your feel about it.

People may say things that can feel patronising or frustrating, even though they mean well. This is because they don't understand the situation or aren't sure what to say.

If you are talking to a stranger or not feeling in the mood to talk about your facial palsy, you might want to give a short answer:

- ***I was born with facial palsy; it's not a big deal.***
- ***I have facial palsy. It can affect how I drink. I'm ok if I use a cup with a lip.***
- ***I developed facial palsy a few months ago. Its ok, it's gradually getting better.***

It can be helpful to prepare and rehearse your answer in advance:

My short Explain and Reassure answer:

....

....

Sometimes it is helpful to give a little bit more information, such as how you manage your condition:

- I was born with facial palsy. It can sometimes affect my speech a little bit, but it is ok to ask me to repeat myself if you don't understand what I say.
- Muscles in my face sometimes move without me wanting them to. This is because of how some of my nerves have re-wired after developing facial palsy. It's called synkinesis. Its ok, Botox helps to stop the muscles being so active.
- My facial palsy makes it hard for me to close my eye. I use eye drops to help with the discomfort.
- I have something called Bell's palsy. It was caused by damage to the nerves in my face, although no one knows for certain why it happened. I am having physiotherapy to keep my facial muscles healthy.

Remember Layla from the start of the module?

She was finding it difficult to work out how much information about her facial palsy she should give to people. She used the **Explain and Reassure** method to come up with an answer that she felt comfortable with:

"I see that you have noticed my facial palsy. It started 6 months ago, although no one knows why. It is gradually improving and I do facial exercises which seem to really help!"

Sometimes you might feel comfortable to provide more personal details about how facial palsy affects you and the treatment that you are having. **Remember**, most people only need a very short explanation to help manage their curiosity or interest, so only provide lots of information if you feel comfortable to do so.

My longer Explain and Reassure answer:

....

....

....

....

Explain and Change the Subject

There will be some situations where you don't want to go into too much detail about your facial palsy. In these situations, it can be helpful to give a short explanation and to then change the subject.

This is a good way of getting to know the other person and telling them about your own interests:

- ***It's just my face muscles. Did you see the football yesterday?***
- ***My eye is watering because I have facial palsy. This is a lovely area, have you lived here long?***
- ***I developed facial palsy a few months ago. Have you ever met anyone else with facial palsy?***

Can you think of 3 ways that you could Explain and Change the Subject?

1) ....

2) ....

3) ....

Being Assertive and Deflecting unwanted questions

Sometimes people ask questions which might feel rude or don't take into account your feelings. In these situations, it can be helpful to give an **assertive** and firm response:

- ***Please don't ask personal questions.***
- ***I found that question rude.***
- ***I have something called facial palsy.***
- ***I don't want to talk about it, because I get bored of people asking me.***

If you don't feel like talking about your facial palsy, you can try to **deflect** the question:

- ***I'm fine thank you.***
- ***I don't want to talk about it at the moment.***
- ***I'm in a bit of a rush, so I don't want to go into it all right now.***

Think about a time when someone made a rude comment about your facial palsy.

What did they say?

....

What did you do?

....

How did you feel afterwards?

....

Can you think of 3 ways that you could deflected *the comment or* given an assertive response?

1) ....

2) ....

3) ....

Remember, it is entirely up to you to decide which type of answer you feel most comfortable giving and how much information that you want to provide. Providing an assertive response can often be easier if you are feeling confident. Please see our guides ***Facial Palsy: Communicating with confidence*** and ***Facial Palsy: Building your self-esteem*** for further information and advice.

Body language

It can be helpful to combine all of the above answers with confident body language.

This includes:

- good eye contact
- holding your head up
- standing tall
- walking away.

For further information about confident body language, please see the ***Facial Palsy: Confident communication*** guide.

Humour

Some people find it helpful to respond to comments and questions with humour. This can be a very effective way of managing these situations, but **only if it is something that you feel comfortable doing**. If you don't want or feel able to make light of your facial palsy, then don't put yourself under pressure to come up with a funny joke. Humour can also be tricky if you're feeling a bit anxious or uncomfortable.

Examples of **humorous** responses include:

- *I seem to have something in my eye! (in response to a comment about your eye watering)*
- *I'm loving all this attention that I seem to be getting!*
- *I have something called facial palsy. I don't think I'm looking my best today!*

HOW TO MANAGE STARING

As mentioned earlier on in this module, people may have never met someone with symptoms of facial palsy. This may make them **curious and they might stare**. Often, they do not know that they are doing this and they are not trying to upset you. Despite this, being stared at can feel very uncomfortable; often a simple comment or action can make it clear that you do not want them to continue.

You may choose to **ignore** them by walking away, looking away or turning your body away.

You can also **let them know you have seen them** by looking back with a smile or a nod and **holding their gaze** for a couple of seconds. This often stops people from staring.

If they continue to stare you could say:

- *I'd prefer it if you did not stare at me.*
- *Please can you not stare at me.*
- *Do you realise that you are staring?*
- *Your staring is unhelpful.*

If they look friendly and you decide to talk to them, think of their staring as an 'unasked question' and respond to it:

- *I guess you are interested in why I am finding it difficult to eat. I have a condition which affects my facial nerve. I do exercises to try and help improve it.*
- *You're right, my smile is a bit unusual. I have facial palsy, so the nerve doesn't work on one side of my face.*

Often starting a conversation with the person staring can help you to feel more in control of the situation and can help educate people about facial palsy. Responding to staring can feel hard at first, especially if you are not feeling very confident. Sometimes it can feel easier if you are with a friend or family member. With practice it should get easier!

For some people, staring, comments and questions can be so upsetting that they find they avoid social situations. If you worry a lot about social situations, you may find our ***Facial palsy: Managing anxiety*** guide helpful.

Remember Mark, who we met earlier in the guide?

He was feeling frustrated that people in his local pub would stare at him when he was drinking. He decided to come up with a humorous response to people staring at him and the next time it happened he said to the person staring,

"You seem concerned that I will spill my pint, don't worry, I'm wearing a good rain jacket!"

This actually led the person who was staring to apologise and gave Mark an opportunity to explain about his facial palsy.

HOW TO TALK TO YOUNG CHILDREN ABOUT YOUR FACIAL PALSY

As we mentioned before, **younger children are often curious about the world around them** and particularly things that are new or different. This means that when they ask questions or make comments they are being curious, rather than deliberately hurtful or rude.

With children you don't know and are unlikely to see again, all the previous advice about how to respond to comments and questions still applies.

In some circumstances you might need to explain your facial palsy to a child in a bit more detail. **Children understand information about what they can see or what they can feel.**

For example:

"You've noticed my smile looks a bit wonky. I have facial palsy, which means the muscles on this side of my face don't work so well, but it doesn't hurt."

You might then want to distract the child by changing the topic to something they might be interested in, such as school, computer games or football.

Children under the age of 10 are still developing their understanding of how illnesses are spread, **so you may need to reassure them that facial palsy is not something you can catch or pass on**.

Talking to children in your own family

For children within your own family, it can be helpful to provide a bit more detailed explanation about your facial palsy. **It can be helpful to reassure them that your facial palsy was not caused by what anyone did or said, and is not something they can catch from cuddles or touching**.

Ask children how much they want to know; some may want lots of information, others relatively little. Going at child's own pace allows them to request further information as and when they need it.

Children might find it helpful to have more information about your facial palsy as they grow older. It can also be helpful to think with your own children about how they might talk about your facial palsy with other children at school.

It is ok to acknowledge your own feelings about your facial palsy, for example acknowledging your fear about how other people might react to your appearance, as well as talking about the ways that you cope with this.

For example:

"I remember that I'm still the same Mummy on the inside, even if I look a bit different on the outside."

"I do feel a bit embarrassed when I think people are staring, but then I think about all the fun we're going to have at the park this weekend and that makes me feel happy again."

Talking to children about procedures that might affect your appearance

If you are having surgery or Botox treatment which will affect your appearance, it can be helpful to talk with children about this in advance. When children are not given information or explanations they **try to make sense of what they see and hear around them, which can often be more frightening than the reality**.

Very young children will probably notice your absence around the time of an operation more than your change in appearance. From the age of around 3 or 4 years, we would recommend talking to your children about the procedure 2-3 days before coming into hospital. As children get older, and have a better understanding of time, they can benefit from having longer to prepare for your operation and talking through what will happen or who will look after them while you are in hospital. Your child will benefit from more days' notice before the procedure, the older they are.

Explain what will look different about your appearance in the short, medium and long term. Reassure them that the doctors and nurses will be caring for you and making sure you have medicine, so that the operation doesn't hurt. It can also be helpful to offer reassurance about what won't change.

For example, you might say:

"My face might look puffy and a bit bruised, but I'll still be able to read your bedtime story while I'm getting better."

If you are not anticipating an immediate change after surgery, for example if you are having a nerve graft which might take a longer time to change your appearance, explain the timescale to children using relatable time points in the year, such as their birthday or Christmas.

For example:

"My smile might start to look a bit different by the summer holidays."

THE IMPORTANCE OF PREPARATION AND PRACTICE

Whether you will be talking to an adult or a child, it can be really helpful to **prepare your answers and responses in advance**. It is important to think about what responses you feel most comfortable with and in which situations you will give a certain response.

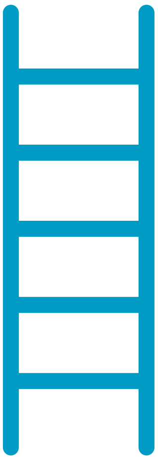
Practicing talking about facial palsy can help you to feel more confident and less anxious about people making comments or asking questions, as well as helping you feel in control of the situation.

Once you have decided what information you are comfortable to share about your facial palsy symptoms, it can be useful to **practice your answers in a graded way**. This means starting to practice your responses in an easy situation (e.g. alone in front of the mirror) and then moving on to more and more challenging situations, such as talking to family members and then strangers.

It might be helpful to think of this as climbing a ladder, with the easiest situation being the bottom rung and the hardest scenario being the top rung.

Steven, who we met at the beginning of the guide, designed the ladder below to help him feel more comfortable talking about his facial palsy with the children at his son's school:

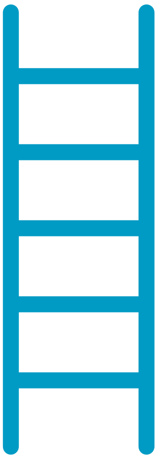
Situation



- Responding to comments, questions and staring from children at the school pick-up.
- Responding to comments, questions and staring from parents at the school pick-up.
- Talking to a friend about my facial palsy.
- Talking about my facial palsy with my son.
- Practicing answering questions with my wife.
- Practicing answering questions in front of the mirror.

Now it is your turn.

What would your ladder look like?



- ……………………………………………………………………
- ……………………………………………………………………
- ……………………………………………………………………
- ……………………………………………………………………
- ……………………………………………………………………
- ……………………………………………………………………

LOOKING AFTER YOURSELF IN CHALLENGING SITUATIONS

Many of the situations we have talked about earlier in this guide can feel very difficult and challenging. It is helpful to remember to **look after yourself** in these situations. There are several ways you can do this.

Positive self-talk

When people ask you upsetting questions about the symptoms of your facial palsy it can be helpful to **say positive things to yourself**:

- Having facial palsy is just a small part of who I am.
- It is ok to look different.
- I am fine, I have lots of people who love me.
- They are being impolite. They are the person with the problem, not me.
- I have lots of great qualities, which people see when they get to know me.

My top 5 qualities

1) ....

2) ....

3) ....

4) ....

5) ....

Understanding

It can be helpful to try and **understand** why people stare or make comments.
You could remind yourself why people do this:

- People are curious and don't know about facial palsy. They want to know more about me.
- Most of the time people are not meaning to be unkind or hurt my feelings.

A phrase I can say to myself about why people are staring or asking questions:

....

....

....

Distraction

The strategies below can be very helpful for when you notice that people are staring at you, particularly in busy or crowded social situations.

Techniques that can be helpful include:

- counting in 7s
- planning your evening
- thinking about everyone who you know whose name begins with 's'
- visualising a recent time when you were having fun
- the *"5 things"* exercise.

5 things exercise

Try to focus on:

5 things that you can see

4 things that you can hear

3 things that you can feel or touch

2 things that you can smell

1 thing that you can taste

SUMMARY

We hope that you have found this guide helpful. If you would like to get more help with how you feel during social situations, you might like to read our guide on Facial palsy: Managing anxiety, which focuses on ways of managing anxiety in social situations.

Our ***Facial Palsy: Communicating with confidence*** guide may also be helpful if you want to read more about how both verbal and non-verbal communication (body language) can help you to feel more comfortable in social situations.

It is important to think about which techniques in this guide have worked for you and which ones did not work. The diary below will help you to keep a record of this:

What happened? (e.g. being stared at, being asked a question)	**What I said/did:**	**What went well?**	**What I might say next time:**
I was asked "What happened to your face?"	*I said "I have something called Bell's palsy. It affects some of the nerves in my face."*	*The person said their cousin also had Bell's palsy. This helped me to feel less alone with it.*	*I'd say the same thing!*

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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March 2025
Review: March 2028
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

The development of this booklet was funded by a grant from the VTCT Foundation

Leaflet reference number: OMI 111275