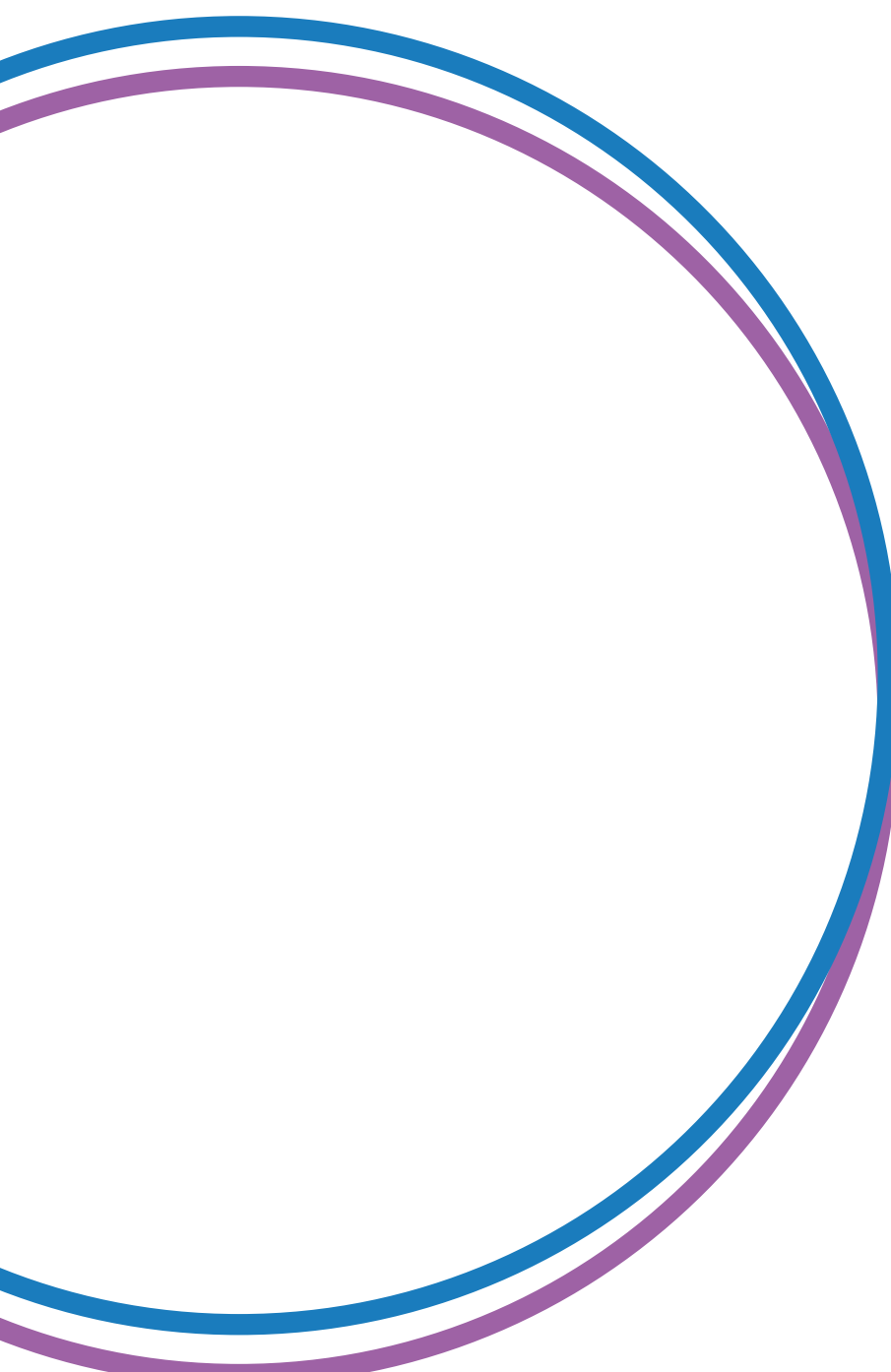


Facial Palsy

Advice for carers, friends, family and partners



An introduction to advice for carers, friends, family and partners

Facial palsy can have a significant impact on many aspects of a person's life, including their ability to eat, hear, drink and/or speak, as well as changing their appearance. These difficulties can in turn affect relationships, employment and quality of life. These can lead someone with facial palsy to feel anxious, low in mood or low in confidence.

This guide has been written for people supporting somebody with facial palsy. Although it focuses on the partners of people with facial palsy, this guide is still relevant to you if you are supporting another member of your family, a friend or neighbour.

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Offering support

Support can take lots of different forms, including:

- going along to hospital appointments
- offering emotional support
- helping with chores (e.g. cooking and cleaning)
- looking after finances
- managing tricky social situations (e.g. people staring or asking questions).

Taking on some of these roles can have an impact on your relationship with the person with facial palsy, as well as on your own wellbeing. This guide discusses the various challenges that you might face when supporting someone with facial palsy. It also introduces ways to look after yourself, provides advice for how to manage any changes in your relationship and gives tips for how to best support the person with facial palsy.

Challenges you might face

Supporting someone else can often be challenging. It is not uncommon for it to feel quite overwhelming and you might notice that this can have an impact on your mood, stress levels and relationship.

Your independence

Some people with facial palsy can find being out in public quite anxiety-provoking. They might worry about people judging their appearance or not being able to understand their speech. If your partner is experiencing anxiety, this may have an impact on how confident they feel about being alone or independent. This may result in you spending more time supporting your partner and less time doing things independently.

Some people say that they feel guilty at times when they are not offering support, and as a result they spend less time looking after themselves.

Socialising

Having facial palsy can often have a big impact on someone's ability to chew food and/or keep food in their mouth. It might also lead to too much or not enough saliva being produced, making it difficult to chew. Food can get trapped in the mouth and some people find it trickier to drink out of certain cups or glasses. On top of this, people with facial palsy might feel self-conscious about their appearance and this may make them feel less confident about going out for a meal or a drink in public.

You might notice that facial palsy has changed the way you socialise with each other, as well as with other friends or couples. You may find you are now spending more time supporting the person to cope with these situations. As a result it may be hard to find time to socialise in a way that you would like, or continue with your own hobbies. This can leave people feeling isolated from friends and means that life can feel less fun.

Stress, worry and mood

Supporting someone with facial palsy may leave you with less time to look after yourself. You may also find that you spend a lot of time worrying about their facial palsy and how this has changed life for you both. These things can result in you feeling more stressed than usual and can have an effect on your mood, as well as your sleep and appetite.

You might find yourself feeling very frustrated about having to give up parts of your life in order to support them. You may also want to put your partner first, and as a result start to think that you are not worthy of care and attention yourself. If you start to miss out on things you previously enjoyed, this can have an impact on your confidence.

Finances

As there are a limited number of hospitals in the UK that offer treatment for facial palsy, you might find that you are spending lots of money on travel costs. The person you are supporting may have also had to take some time off work, which can put additional strain on finances. You might have had to take on additional work or cut back on certain things, such as holidays or trips out. These can all add to the stress of the situation.

Take some time to think about some of the challenges that you face when supporting somebody with facial palsy.

How has life changed?

Looking after yourself

It can often feel challenging to find time to look after yourself. You may even feel guilty about not dedicating all of your time to looking after your the person with facial palsy. It is important to remind yourself that you will be able to provide better support if you are also taking time to look after yourself. By focusing on your own physical and emotional needs you will be less likely to feel tired, stressed or overwhelmed. You can't pour tea from an empty teapot!

Your physical wellbeing

It is really important to create time in your daily routine to look after your physical health. This can include:

- getting enough sleep and rest
- exercising, going for a walk
- eating healthily
- taking a break if you are feeling unwell.

Things I can do to look after my physical well-being:

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Your emotional wellbeing

Just as it is important to take a break if you are feeling tired or unwell, it is also helpful to take a break if you have noticed that you are feeling stressed, anxious or low in mood. Try to plan regular enjoyable activities into your routine. This could include meeting up with friends, making time for hobbies or planning a weekend away.

It can be helpful to think of a list of activities or things that you could do to 'take a break'. Think of fun and/or fulfilling things that you can do with your partner, as well as things you can do on your own or with other friends or family members.

Taking a break

Write down some things that you could do to take a break. Try to come up with a mixture of things (e.g. those you could do daily, weekly and monthly).

Daily (e.g. drawing, going for a walk, doing a mindfulness exercise)

Weekly (e.g. going to a gym class, going for coffee with a friend)

Monthly (e.g. going to the cinema, spending the day shopping with friends, playing golf)

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Getting support from others

Although it can be very useful to ask for support from others, people often feel anxious or embarrassed about asking other people for help. They might feel vulnerable sharing their concerns with others, or worry about 'making a fuss over nothing'. Other people may feel uncomfortable asking for support, as their more usual role is giving rather than receiving support from other people.

If you find yourself worrying about reaching out for help, it can be helpful to ask yourself the following questions:

- What would I say to a friend who needed some support? Would I tell them to cope on their own or to talk to someone?
- How do I feel if a friend asks me for help or support?
- If a friend was struggling but didn't tell me, how would I feel?
- What is the worst thing that could happen by asking for help?
- Have there been times in the past when asking for support has helped me to feel better?

If you are worried about how to talk about your feelings with other people, you might find it helpful to start small and just share a little bit of information, then share more as you feel more comfortable.

Try to think about whether you have a family member, member of your community or a friend who is particularly helpful to talk to. You might find that certain people are good at providing practical advice, while others are better at providing emotional support, making you laugh or offering a distraction.

Helpful people to talk to:

For practical advice:

.....

For emotional support:

.....

To have a laugh/joke with:

.....

Having enough information

Supporting someone with facial palsy can sometimes feel more challenging if you do not know much about their condition. As everybody is different, doctors and facial therapists cannot always be 100% certain about how your partner will recover. However, despite this, it can be helpful to find out relevant information about facial palsy.

While finding out about facial palsy is important, you might notice that spending too much time reading about facial palsy online can have a negative impact on your mood. Remember, not all information online is accurate. We recommend that you use the NHS team caring for your partner of as your primary source of information.

If you do want to look for information online, it is helpful to only look at reliable websites, such as Facial Palsy UK (www.facialpalsy.org.uk), or the website of your local NHS facial palsy service.

Some people find it very helpful to access online support groups, but it is important to note that you cannot always guarantee that the information provided on these groups will be accurate, as everyone has different experiences of facial palsy.

Problem solving

Supporting someone with any type of health condition can be challenging. Some partners of people with facial palsy describe often having worries about their partner's condition, such as 'what if it never improves?' or 'why did this happen to us?'.

When our mind is full of negative thoughts we can sometime feel overwhelmed and this makes it harder to solve problems. Decisions which previously may have felt straightforward can feel harder and when you are feeling low in mood problems can seem bigger than they really are.

Taking a step-by-step approach can help to make problem-solving more simple:

- Write down the problem.
- List as many potential solutions as you can, however helpful or unhelpful they seem! It can sometimes be useful to think about the advice you would give to a friend in a similar situation.
- List the advantages and disadvantages of these different solutions.
- Choose the best solution.
- Think about the steps you need to take to put this solution into action.
- Review whether the solution was helpful; often testing a solution out can provide useful information to feed back into the problem solving.

Steven, aged 37

Steven's wife Samantha developed Bell's palsy 10 months ago. He was offered a job interview, but was due to join Samantha for her appointment with her facial palsy team at the same time as the interview. He started to feel anxious about this and found himself spending lots of time worrying about what to do. He used the problem solving approach to help him with his situation.

Steven's problem: Job interview and Samantha's hospital appointment at the same time

Potential solutions	Advantages of this solution	Disadvantages of this solution	Rank in order of probable usefulness	What do you need to do to put this solution into action?
<i>I could ask Samantha's mum to take her to the appointment</i>	<i>Samantha's mum might be able to take and support her</i>	<i>Samantha might feel upset that I am not taking her</i>	1	<i>I can talk to Samantha to see if she is happy with this and then give my mother-in-law a call</i>
<i>I could ask if any of our friends are free to take her to the appointment</i>	<i>High chance that someone will be free to take her</i>	<i>Samantha might want to keep her appointment private from her friends</i>	3	
<i>I could call the employer and ask if they could change the interview time</i>	<i>It might be possible to move and then I could go to the appointment</i>	<i>It might not look good to the new employer</i>	2	

Steven, revisited

Samantha was happy for her mother to take her to the appointment, but unfortunately her mother was not free to take her. She said that she would have been able to do so if she'd had a bit more notice. Steven shared his other two potential solutions with Samantha. She told him that she would feel happy asking a friend to take her to her appointment, so Steven called a few friends to see if they were free. One of them was, so Steven was able to go to his job interview.

Now it's your turn!

What problem(s) do you currently have? What solutions might there be?

What is the problem?

Potential solutions	Advantages of this solution	Disadvantages of this solution	Rank in order of probable usefulness	What do you need to do to put this solution into action?

After you have tested out your solution, review whether it has been helpful. If the solution was not helpful, repeat the problem solving process until you find an effective solution.

Managing changes in relationships

Tina (aged 53) and John (aged 55)

Tina and John have been married for 25 years. They have two grown up children, who are both currently at university. Six months ago John developed Ramsay Hunt syndrome. This causes him problems closing his mouth when eating and he needs a straw to drink. He also has difficulties closing his left eye, which means it can become very sore if the air temperature is too hot or too cold.

John's confidence has really dropped over the past few months, and he now relies on Tina to help him with many different things. He finds being in busy public areas, such as supermarkets, particularly anxiety-provoking, as he often worries about what people think of his appearance. As a result, he will rarely go out of the house without Tina's support.

Tina has noticed she is having less time to herself and is starting to feel frustrated that John isn't being more independent. They are both missing meeting up with friends for meals out and drinks together and are feeling sad that they are socialising less than they used to.

You, like Tina, might have noticed a change in your relationship and that you are taking on the role of carer, as well as partner, friend or relative. This might be a big or a small change, depending on the extent to which the person is affected by facial palsy.

If it is your partner who has facial palsy, you might find that more and more time in your relationship is spent thinking or talking about facial palsy. Many couples report feeling very close to each other. However, living with a health condition such as facial palsy can feel stressful and you might notice that there are times when you and your partner become more distant or frustrated.

The following tips may help to reduce the impact of facial palsy on your relationship:

- Make a list of activities you and your partner used to enjoy doing together, before they had facial palsy. You might be surprised what has stopped or become less frequent since the facial palsy occurred. Are there things you could start doing again?
- Try to make time for enjoyable activities and shared interests together
- Accept help from other people
- Try not to think of yourself as purely their carer, but also their partner
- Work together to make a plan for how you can strengthen your relationship
- Focus on (and try to encourage your partner to take part in) their interests and hobbies.

Are there any positive aspects of caring for your partner? It can help to write a list of these and look at them if you ever feel frustrated or stressed.

Three positive things about caring for the person with facial palsy:

1.
2.
3.

Helping the person with facial palsy to feel more independent

Many people with facial palsy describe feeling frustrated about being more reliant on their partner than before the development of facial palsy. People with facial palsy often have certain goals they want to work towards to regain their independence, but find their anxiety or lack of confidence can hold them back. In the earlier example, John wanted to start going to the supermarket on his own, but found that his anxiety about the reactions of others held him back from achieving his goal.

Talk to the person with facial palsy about whether they have any goals you can work on together. Invite them to choose a goal (e.g. your partner going to the supermarket on their own) and come up with a plan for how you can help them to meet their goal (e.g. start by going to the supermarket together, and then gradually spending less and less time together when in the supermarket until they feel comfortable and safe to go on their own).

It may be helpful for the person with facial palsy to 'test out' their anxiety first by facing their feared situation together (e.g. observing whether people make unkind comments about their appearance in the supermarket).

People with facial palsy may find our **Facial palsy: Managing your anxiety** guide useful if they are experiencing anxiety. By working with your friend, partner or family member, you can help them to gradually face their feared situation. This will slowly help them feel able to tolerate that situation, as their body gets used to the feeling of anxiety or as they realise their fears aren't as bad as they expected.

Over time, you may find the person is able to gradually spend more time facing their feared situation alone. Encourage them to reflect on whether the feared situation was as bad as they had predicted and whether any of their negative predictions about the situations came true. You could help them to fill in the following record.

John's example

The activity I want to feel more independent with is:

Going to the supermarket

My negative prediction:

People will say unkind things about my appearance

Situation	Anxiety rating (%)			Any comments? Did the negative prediction come true?
	Before	During	After	
<i>Going to supermarket together</i>	70%	85%	40%	<i>This was more challenging than I thought it would be, but nobody said anything linked to me.</i>
<i>Going to supermarket together for the second time</i>	70%	85%	40%	<i>This felt better than last time. One child was staring at me, but it didn't really bother me.</i>
<i>Going to supermarket together, but spending half the time in a different part of the shop</i>	75%	50%	30%	<i>I felt anxious at first, but it actually felt good to be coping on my own. The person at the checkout asked if I had facial palsy, because their cousin had it too. I felt ok talking to her about it.</i>
<i>Driving to the supermarket together, but partner waiting in the car (second time)</i>	60%	50%	20%	<i>I coped really well, even though a couple of people seemed to be staring at me. I reminded myself that they had probably never seen some with facial palsy before and were just curious.</i>
<i>Driving to the supermarket alone</i>	60%	40%	20%	<i>I found it easy and even had a coffee in the café afterwards.</i>

Tina and John, revisited

Tina followed some of the tips we've mentioned. John decided that he was going to start playing golf again. Although at first he wanted Tina to stay with him while he was at the driving range, they agreed she would go for a walk while he was playing golf, so he could get used to being on his own. John soon got used to being on his own and noticed that if he focused on his golf technique he was able to gradually forget his worries about what other people would think of his appearance.

Tina wrote a list of the positive aspects of supporting John. Her list included:

'We have been able to spend lots of time together; it is nice to have someone completely trust me; it feels good to help John and I have met some really nice people through the local Facial Palsy UK support group.'

Tina and John also talked about finding time each day to make sure they had fun together. They used to love playing board games and so agreed that they would make time to start doing this again.

Sharing your feelings with each other

We often find that people with facial palsy and their partners can worry about the other person. This can make both partners reluctant to share their concerns with each other, because they do not want to risk hurting the other person's feelings.

Although most people try to be open and honest in their relationship, changes or stresses can make it feel harder to say how we truly feel or be 'emotionally honest'.

This can be for lots of reasons, including:

- trying to protect the other person's feelings, not wanting to hurt them or add to their distress
- worry about how the other person will react to what we say or share
- not wanting to have a confrontation or create conflict
- feeling vulnerable when sharing emotions or not feeling confident about how to do it
- worries about feeling embarrassed when being honest about emotions
- finding it hard to see people we love in pain.

Even the most honest of people can find themselves not sharing their emotions with a partner, because they are concerned about their reaction or that it will have a negative impact on their relationship. Unfortunately, by not sharing our emotions, it can be really tricky for our partner to know how we are feeling. This is shown in the example of Graham and David below.

Graham (aged 43) and David (aged 46)

Graham and David have been married for two years. Six months ago, David developed Ramsay Hunt syndrome, which has resulted in him experiencing pain in his face and head, as well as lacking energy. David has been relying on Graham to do more of the household chores.

Although Graham is very happy to help, he is starting to feeling tired, stressed and short-tempered, as he is particularly busy at work and having to provide a lot of support for David. Graham is worried about telling David, because he doesn't want to 'cause a fuss' or for David to feel guilty. Instead, Graham stays quiet about how he has been feeling.

Unfortunately, this means that David does not know how Graham has been feeling and is confused when Graham 'snaps' at him. This often leads to arguments and both Graham and David feeling unhappy.

By becoming more emotionally honest we can avoid misunderstandings in our relationships and learn how best to support one another. One of the first steps towards sharing your feelings is to learn to recognise how we are feeling and why.

If your partner has facial palsy, take time each day to 'check in' with how you are feeling. Ask yourself 'What am I feeling right now?'. We often spend much of our time living our lives on 'auto-pilot' and not paying attention to how we feel. However, by taking the time to regularly notice how we are feeling, it becomes much easier to recognise our true feelings.

Once you are aware of how you are feeling, it can be helpful to share this with your partner. As we have seen earlier, this can feel uncomfortable for many different reasons. It can be helpful to start small, by sharing your some of your feelings with your partner, but perhaps not sharing your deepest feelings.

After you've spoken to your partner about the way you feel, you might want to think about how the conversation went. Did your partner become upset? Did it lead to an argument? Did you feel embarrassed? Or did your partner respond positively and did you feel heard and understood?

People often find that when they understand how their partner is feeling, it can become easier to solve problems together and work as a team. By sharing small feelings at first, you may notice that it becomes easier to share deeper feelings over time.

Fact – Emotion – Need

The Fact-Emotion-Need approach is a technique you can use to let other people know how you are feeling and what they can do to help you.

In this approach, you let the other person know a **fact**, for example *"A customer shouted at me at work today"*.

You then tell the other person about the feeling or **emotion** you felt, for example *"I felt really sad"*.

Finally, you can offer the other person some advice about how they can support you or meet your **needs**, for example *"I could really do with a cup of tea and a chance to talk about my day"*.

Fact – What has happened?

Emotion – How did it make you feel?

Need – What do you need to happen to help you feel better?

Graham and David (revisited)

Graham made the decision to share with David how he had been feeling. He made sure not to blame David for how he was feeling, but instead was open about the difficulties he was having, saying "Work has been busy lately and I am not having much time to relax." (fact). He was able to tell David that he had been feeling tired and stressed (emotion) and asked David if they could make a plan for relaxing activities they could take part in at home in the evenings after work (need).

Have a go yourself. Reflect on what has happened, how you are feeling and what will help you feel better:

Fact:

Emotion:

Need:

Managing other people's reactions

You and the person with facial palsy might sometimes get asked questions about their appearance. The main 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 “Does your partner know that he is dribbling?”

These questions can be very frustrating and upsetting for both you and the person with facial palsy. Talk to them about how they would like to manage these questions. Perhaps they feel confident replying themselves, or perhaps they would prefer you to respond on their behalf.

Below are some tips for you, if the person with facial palsy finds it helpful for you to explain their facial palsy on their behalf.

Many people have found it helpful to briefly **explain** that their partner has facial palsy and **reassure** the person asking the question that their partner is ok.

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. It can help to reassure them:

- **My boyfriend was born with facial palsy. It can sometimes affect his speech a little bit, it is ok to ask him to repeat himself if you don't understand what he is saying.**
- **Muscles in my wife's face sometimes move without her wanting them to. This is because of how some of her nerves have mis-wired after developing facial palsy. It's called synkinesis. It's OK, Botox helps to stop the muscles being so active.**
- **Her facial palsy makes it hard for my wife to close her eye; she uses eye drops to help with the discomfort.**
- **He has something called Bell's palsy. It caused damage to the facial nerve, although no one knows for certain why it happened. He is having facial therapy to keep his facial muscles healthy.**

My explain and reassure answer to questions about their facial palsy:

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There will be some situations where you don't want to go into too much detail about facial palsy and how it affects your friend, family member or partner. In these situations, it can be helpful to give a shorter explanation and to then change the subject. Asking a question about the other person can be a good way of moving the conversation on to a different topic.

Offering different types of support

Research has shown that there are three different types of support that people with facial palsy find helpful.

Helpful feedback about their facial palsy

One way that you can support the person with facial palsy is by talking to them about their facial palsy. In particular, it can be helpful to give feedback about any improvements in their appearance or the way that their face is working, for example saying "I can notice you're able to move your face more.". Have a discussion with your partner about the type of feedback they find helpful.

If the person you are supporting is feeling low in mood, they may find it harder to focus on the positive aspects of their recovery, focusing instead on their remaining difficulties. Be sensitive of this, while at the same time gently reminding them of any progress they have made since developing facial palsy. For example, you might remind them that they are now able to close their eye, drink without spilling anything or they have clearer speech and are easier to understand when talking on the phone.

It can also be helpful to give your partner, friend or family member feedback on their emotional progress, for example if you have noticed that they are coping better with their facial palsy.

Helpful feedback to give about their facial palsy and emotional progress:

Emotional support

People with facial palsy have said they find it helpful when people treat them as if they are the same person as before the onset of facial palsy. Though while doing this, it is important to also bear in mind any additional emotional needs that they now have. Talk to them about the support they would like from you if they are feeling stressed, anxious or upset.

- Do they prefer being distracted, rather than focusing on their worries?
- Is there anything that you can do to make it easier for them to talk about how they are feeling?
- Is there a certain joint activity you can do together that they will enjoy?

If they share some of their thoughts and feelings with you, it can be helpful to let them know that you understand. **You can let them know you understand by:**

- Giving verbal responses to show you are listening. Say things like “uh-huh”, “I see” and “ok” to help them to feel heard.
- Reflect on what they have said and help them feel heard and understood’. Try saying things like: “That sounds really hard.”, “You seem really upset by that.”, “So you’re frustrated that your smile is not improving?”.
- Although well meant, reassurance such as “It’s not that bad.” or “I’m sure you’ll be ok.” doesn’t tend to be helpful and can feel a bit ‘dismissive’ of very real concerns.

Ways I can provide emotional support:

Practical support

Even small things, such as driving your partner to hospital for appointments, can help them to feel supported and reduce their own stress levels. You might also talk to them about the kind of support they want when you are out socialising.

- Do they want your help answering any questions about their appearance, or would they prefer to do this themselves?
- What information would they like you to share (or not share) with mutual friends?
- Can you come up with a plan together for how you can gradually support them to be more independent?

Practical ways I can provide support:

Summary

Facial palsy can have a big impact, not only on the person with facial palsy, but also on their friends and family. Remember:

- Take time to make sure you are looking after yourself; you will be more able to provide helpful support.
- Focus on planning activities into your own routine which focus on your physical, emotional and social wellbeing.
- Gather information about facial palsy from reliable sources.
- Plan enjoyable activities with the person with facial palsy
- Spend time with talking with the person with facial palsy about the types of support they find most helpful.
- Think about how friends or your local support groups might be able to help.
- Design a plan with the person with facial palsy for how you can support them to gradually regain their independence.
- Talk to the person with facial palsy about how they would like you to respond to comments or questions from others about their facial palsy.

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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