Living well alongside persistent mouth / face pain and other unpleasant sensations

This leaflet is about living with ongoing or persistent sensations related to the mouth, jaw and face. If you have any further questions or concerns, please speak to one of the team caring for you.

Introduction

We understand it can be challenging living with persistent mouth / face pain or other unpleasant sensations (such as burning or numbness). It may affect your enjoyment in activities or your confidence. Your condition might be ongoing, despite you and your doctors’ best efforts to solve it. The sensations may be different from day to day, making it hard to make plans. You may feel worried about what has caused the sensations and uncertain about the future.

The information in this leaflet will introduce you to some new ideas that you can use alongside medical management. These ideas will not take away the sensations, but might help you feel less worried by them and help you to have a better quality of life. You will find some information and things to try, as well as some links you can follow for resources. If you would like to follow the links, you may find it easier to use the online version of this leaflet. To find it, go to the Guy’s and St Thomas’ website and type the title of this leaflet into the search box. We suggest taking your time to go through the leaflet, perhaps focusing on one section at a time.

You may also find it helpful to look at our other leaflet on common issues (such as stress, sleep problems and fatigue) faced by people with mouth / face conditions. It is called ‘More than a mouth: Caring for the whole person’.

What do we mean by persistent pain and other sensations?

Pain is a normal response when your brain judges an experience to be threatening. Pain is designed as a warning system to grab our attention and make us move to protect ourselves. This can work well when tissues are damaged, such as when you have a broken leg. However, in people with persistent pain the pain signalling system has become over-excitable. In these cases, the pain is more related to the nervous system (including the nerves, spinal cord and brain) than it is to a problem in structure of the face or mouth. We call this sensitisation of the nervous system. The pain is very real but it is not a helpful warning system. For example, you may feel pain when someone gives you a kiss, or when it is cold outside.
Persistent pain is generally defined as pain that lasts for longer than three months and refers to pain that is related to the nervous system being sensitised. Some people experience other unpleasant sensations such as burning, numbness or tingling that are also related to sensitisation of the nervous system.

Imagine a burglar alarm goes off when there is no burglar. If this keeps happening, it is more likely that the settings on the alarm are oversensitive rather than there being a burglar. Keeping hunting for the burglar is probably not likely to get you very far. Rather, it is more helpful to understand that the alarm is going off because it is over-sensitive. The following video called ‘Understanding pain in under than five minutes’ gives a helpful explanation of persistent pain and sensitisation of the nervous system: [https://www.nhsaaa.net/pain-management-service/patient-information-videos/](https://www.nhsaaa.net/pain-management-service/patient-information-videos/)

In the UK today, we are used to going to the doctor, having a test, getting a prescription for some medication, and feeling better again. Unfortunately, for some conditions, there is not a simple test. The sensations do not show up on scans or X-rays and the mouth or face may look completely normal. Your doctor will have checked that the sensations are not a sign of something that needs further investigation. Some medications can help but unfortunately there is not always a medical solution to relieve the sensations permanently. Trying to find a reason for the sensations, and a solution, can be a stressful experience. Many people have felt disbelieved and frustrated that a cause for their sensations has not been identified and that there is not a clear solution.

In addition to these challenges, some people find that persistent pain or other unpleasant sensations have affected important activities such as:

- seeing friends
- eating food they enjoy
- working
- doing hobbies
- exercising

The impact of the sensations on these areas of life can add to the distress of living with the condition.
What steps can I take, now?

When we are faced with unpleasant sensations, it is natural to seek a solution. In fact, you might be finding that life is ‘on hold’ until the sensations get better. For example, you might find yourself saying no to social invitations, or stopping exercising. Unfortunately, this can mean life can be put on hold for a long time. You may find you are spending more time trying to solve the issue, and less on things that are important to you in your life. If this is not getting you very far and is getting in the way of living your life, what might it be like to shift your focus to the things that matter most to you?

Consider these questions and note down your answers:

Deep down inside, what really matters to me in life? ________________________________________
____________________________________________________________________________

What do I want to stand for? ________________________________________________________
____________________________________________________________________________

What kind of person do I want to be? ________________________________________________
____________________________________________________________________________

How do I want to be in my relationships with others? __________________________________
____________________________________________________________________________

Now note down one action you can do today, without anything else (including the sensations) changing. This action should be consistent with what is important to you in your life. It does not matter how small this action is, as small actions can lead to big changes. Commit to a time and place to do it.

Action: ______________________________________________________________________
Time and place: _______________________________________________________________

Dropping the struggle

It is normal to struggle against uncomfortable emotions and sensations, to want them not to be there. It’s normal to try to get rid of them or avoid having them in the first place. While it’s normal to do this, it can contribute to a life focused on avoiding pain and other sensations, rather than focused on the things in your life that matter most to you. Dropping the struggle with sensations can help reduce suffering.

Imagine you come across some quicksand. You start to sink. It is natural to struggle against it, with the hope that doing so will get you out of there. But you just sink further; the more you struggle, the deeper you sink. With quicksand, the way to be free is actually to do the opposite. To spread the weight of your body over it, maximising contact with it. To stop struggling.

Willingness

This different approach is something we call ‘willingness’ and can be helpful when we are faced with unpleasant emotions and sensations. Willingness is a deliberate choice to say ‘yes’ to what life is offering in any given moment. To give difficult emotions and sensations permission to be there, as they are. To drop the struggle with them. It does not mean liking them or giving up. In fact, if we can find a way to allow the uncomfortable emotions and sensations to be there and still take action, then we can build a richer life.

This video called ‘the unwelcome party guest’ illustrates willingness. You can find it here: https://www.nhsaaa.net/pain-management-service/patient-information-videos/
It is important to say that this does not mean you should not seek medical treatment when you need it or that you should stop taking medication that is working well for you. Visit your GP if your sensations change and become unusual for you. It is also not saying that you should give up hope of the sensations changing in future. Rather, it is about acknowledging them, as they are, at this moment in time.

**Mindfulness**

Mindfulness meditation is a way to develop willingness skills. It involves accepting that these sensations are part of your experience at this moment in time. Dropping the struggle with them. Observing experiences (such as pain or other unpleasant sensations), without trying to change them. Noticing judgements and letting them go. Noticing when your attention drifts (e.g. to worries about the future) and bringing it back to the present.

Mindfulness can help you shift your focus and energy to living a rich life. This doesn’t mean that the sensations have gone away, rather that you have dropped the struggle with them so you can focus on other things that matter to you. Developing these skills can help you have more choice in how you respond to flare-ups of sensations, or to difficult thoughts and emotions.

This is a brief mindfulness exercise you can try. Practise it regularly. Doing so will help you to engage more fully with the environment and help you develop a different relationship with your thoughts, emotions and sensations:

1. Pause for a moment.
2. Look around and notice five things that you can see.
3. Listen carefully and notice five things that you can hear.
4. Notice five things that you can feel in contact with your body (for example, your watch against your wrist, your trousers against your legs, the air on your face, your feet upon the floor, your back against the chair).
5. Finally, do all of the above at the same time. Notice that as well as the sensations, these other parts of experience are present.

Here is another one called the three step breathing space.

1. **Awareness.** Bring yourself into the present moment by deliberately adopting an erect and dignified posture. If possible, close your eyes. Then ask: What is my experience right now…. in thoughts… in feelings… and in bodily sensations? Acknowledge and register your experiences, even if they are unwanted, not trying to change them in any way.
2. **Gathering.** Then, gently redirect the attention to a narrow ‘spotlight’ on breathing, to each in-breath and to each out-breath as they follow, one after the other. Your breath can function as an anchor to bring you into the present and help you tune into a state of awareness and stillness.
3. **Expanding.** Expand the field of your awareness around your breathing, so that it includes a sense of the body as a whole, your posture and facial expression. If you become aware of any sensations of discomfort or tension, bring your focus of attention in to the intensity by imagining that the breath could move into and around the sensations.

Set aside a regular time to practise these skills. Like going to the gym, regular practise will build up your skills so that they are available to you when you need them most.
You are more than your sensations
This might sound obvious, but it is not always easy to appreciate when we are overwhelmed by our experiences, especially unpleasant ones. Notice that there is a part of you able to observe your experiences. A part of you that is the ‘container’ where your sensations, thoughts and emotions arise. Mindfulness helps you to connect with this part of you. From this perspective, you can make more skilful choices about how you respond at difficult times.

Putting it into practise
If you have found life has gone on hold while you have been struggling with the sensations, identifying some small steps can be a way forward. Start by identifying some goals. Some actions you would like to do more of, not less of. For example, seeing friends, exercising regularly or becoming more involved in your community.
You are most likely to achieve your goals if they have the following qualities:
- **Specific** (precise)
- **Measurable** (include a way you can identify when your goal has been reached)
- **Attainable** (consider breaking a goal down into smaller steps that you can start now)
- **Relevant** (make sure the goal is important to you)
- **Time-specific** (include a deadline).

For each goal, consider:
- What experiences will you be willing to make room for as you approach this goal? Experiences may include pain, other unpleasant sensations, doubt or uncertainty.
- When will you do each step?
- Consider telling someone about this commitment you have made.
- Start with the first step.
- Practise using willingness and mindfulness skills as you approach your goals.

Further resources
The following sources of information have been reviewed by the psychologists working in the department. Other sources of information are available.

Your local library may be able to order one of these books for you:
- Living with the Enemy by Dr Ray Owen
- Mindfulness for Health by Vidyamala Burch and Danny Penman
- Mindfulness: A practical guide to finding peace in a frantic world by Mark Williams and Danny Penman
- Living Beyond Your Pain by Joanne Dahl

Websites
- This site includes several mindfulness audios you can try free of charge: [https://imparts.org/resources-self-help/](https://imparts.org/resources-self-help/)
- This site gives more detail on mouth / face pain and psychological methods for coping with it: [https://imparts179219473.files.wordpress.com/2019/03/living-with-orofacial-pain.pdf](https://imparts179219473.files.wordpress.com/2019/03/living-with-orofacial-pain.pdf)
- This site has various exercises to help cope with persistent pain: [https://www.paintoolkit.org/](https://www.paintoolkit.org/)
If you need more help

You can ask your doctor or dentist to refer you to the Dental Psychology Service for an assessment appointment. At this appointment, you will be given the opportunity to speak more about how persistent pain or other unpleasant sensations affect you and how psychological approaches may be able to help you.

If your difficulties are not related to your mouth / face condition, you can ask your GP about local Improving Access to Psychological Therapies (IAPT) or counselling services. Many such services also accept self-referrals. You can find details of your local IAPT service here: https://www.nhs.uk/service-search/find-a-psychological-therapies-service/

If you are in crisis and concerned about harming yourself you can request an urgent appointment with your GP, or go to your nearest emergency department (A&E).

This leaflet has further information about how you can manage suicidal thoughts, and details of organisations you can contact: https://www.guysandstthomas.nhs.uk/resources/patient-information/therapies/psychology/keeping-safe-managing-suicidal-thoughts.pdf

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline. t: 020 7188 8748, Monday to Friday, 9am-5pm

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS)  e: pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) e: complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. t: 020 7188 8815  e: languagesupport@gstt.nhs.uk

NHS 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

 t: 111  w: www.111.nhs.uk

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing. w: www.nhs.uk