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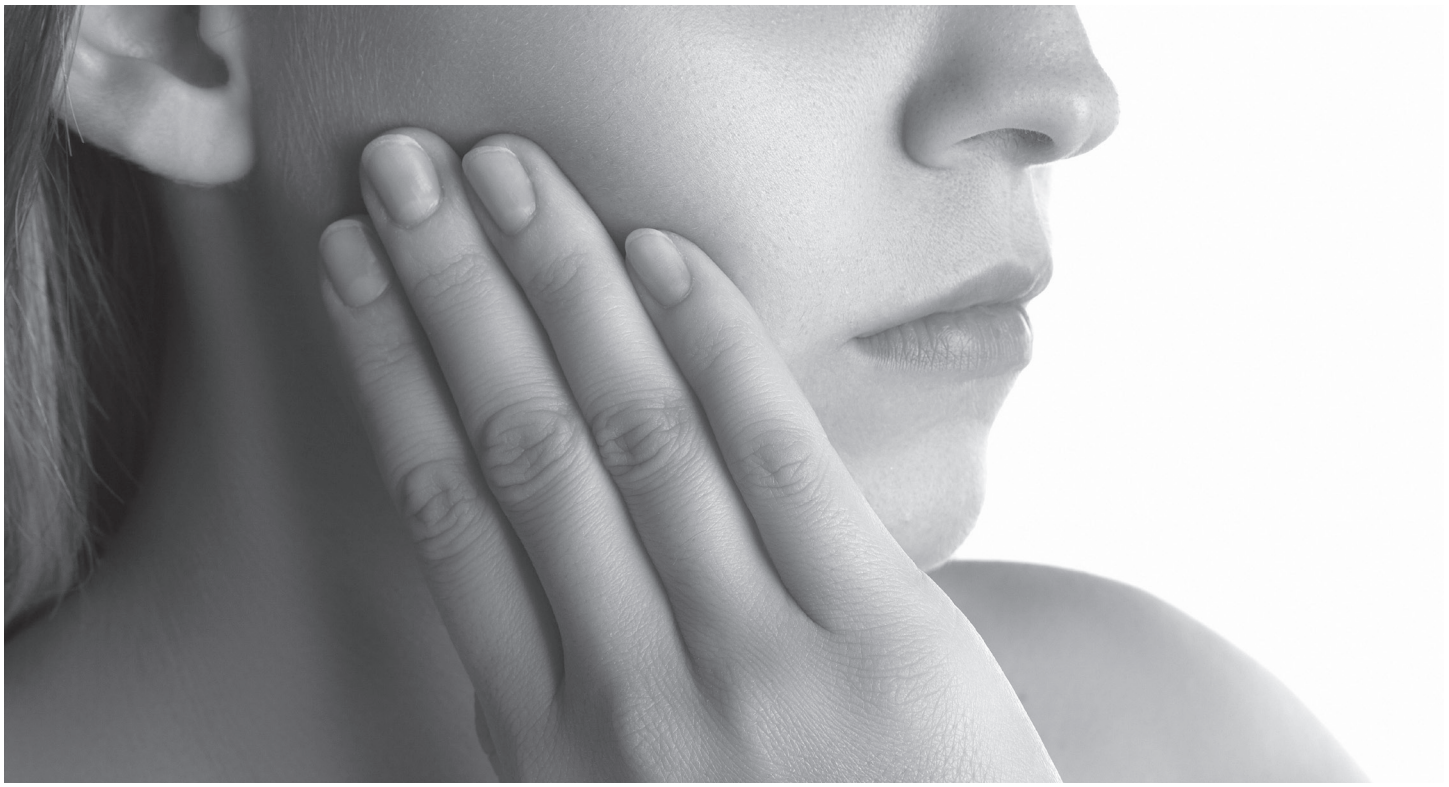
Integrating Mental & Physical healthcare:
Research, Training & Services

King's College Hospital NHS
NHS Foundation Trust

Living with Orofacial Pain

This leaflet is for people who have been diagnosed with a chronic orofacial pain condition, who are currently receiving or have received medical treatment. Orofacial pain refers to pain in the head, neck and mouth region and is a common affliction. As well as the physical effects of orofacial pain, some people find that the experience of this condition can have an emotional impact.

This leaflet provides some information about the ways you may be affected, some strategies that may help, and what further support is available. There is a lot of information in this booklet and it may be helpful to read it several times, in small chunks, or with a friend or family member to get the most from it. You might wish to read part of it for now, and then come back to it at a later stage, whenever you feel ready to do so.



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Introduction

What is Orofacial Pain?

Orofacial pain is a common affliction, affecting up to 26% of the population. Acute pain is pain that can be instant and acts as a protective reflex, or can signal damage or inflammation to a specific area (like toothache or dentine sensitivity). If the pain persists beyond the healing phase (usually up to 3 months) it is known as chronic pain or neuropathic pain. If chronic pain develops it is thought that a large proportion of this type of pain is due to subtle changes in the peripheral and central nervous system that mean the pain sensing nerves (nociceptors) process normal and painful information differently.

The trigeminal nerves are the largest nerves inside the head. There are two trigeminal nerves, one on each side of the face. Each nerve has three branches, supplying feeling and sensation to the forehead, upper and lower jaws. The facial region contains structures vital for living: eyes for sight, mouth for breathing, communicating and eating, and ears for hearing. In addition, the brain is in close proximity. It should be of no surprise, therefore, that any threat of damage to this region is likely to trigger primitive survival instincts and this may amplify the psychological and physiological consequences of pain in this region. This coupled to the level of sensory supply to the face probably helps explain the highly distressing nature of pain in this region.

Throughout this leaflet the term 'orofacial pain' will refer to chronic (rather than acute) orofacial pain where the pain has persisted past the initially healing phase of 3 months. This means the pain no longer serves to protect the area that may have initially been damaged. Both episodic orofacial conditions,

where the pain experienced is intermittent and often unpredictable, and continuous orofacial conditions, where the pain is persistent and often unrelenting, will be considered.

For a comprehensive guide to assessment, classification and medical management of acute and chronic orofacial conditions see the **Orofacial Pain: Demystifying chronic pain in the head, face and mouth** website at www.orofacialpain.org.uk

What are the most common types of orofacial pain conditions and how are they treated?

Episodic spontaneous painful (on and off pain without a stimulus) Orofacial Conditions:

Trigeminal nerve injuries (TNIs)
These are nerve injuries often resulting from dental surgery, injections, implants and root canal treatments. When sensory nerves are damaged, they often fail to heal and as a result chronic pain affects most patients. This results in severe pain that is often intermittent with elicited (caused) by eating, drinking, speaking, kissing and outdoor activity. Sometimes the pain can be constant with or without intermittent episodes. For more information, please visit www.trigeminalnerve.org.uk

Trigeminal autonomic cephalalgias (TACs)
TACs include Cluster Headaches, SUNCT (sudden onsent, unilateral, neuralgiform, conjunctival irritation and tearing), Hemicranial Continua and Paroxysmal Hemicrania, are conditions that frequently mimic toothache, trigeminal neuralgia and other conditions that dentists are less familiar with. They cause severe, intermittent intense pain around the eye with signs including;

- Reddening and tearing of the eye
- A runny or blocked nostril
- Droopy eyelid
- Constriction of the pupil
- Flushing and facial sweating

For more information see Organisation for Understanding Cluster Headaches (OUCH) at www.ouchuk.org/home

Episodic Migraines – Migraines are perhaps the most studied of the headache syndromes. This is due in part to the high incidence and significant loss of productivity and limitation on quality of life suffered by those with the syndrome. It is estimated that 17% of women and 6% of men have migraine headaches. Onset is usually in the 20s or 30s. Migraines are characterised by five or more lifetime headache attacks lasting 4–72 hours each and symptom-free between attacks, moderate to severe pain. The pain has a throbbing quality and feels as if it is associated with a pulse. Photophobia (extreme sensitivity to light), phonophobia (aversion to loud sounds), nausea and osmophobia (hypersensitivity to odours) are features of migraine, as is nausea. The pain worsens with exertion and improves with sleep.

Trigeminal Neuralgia (TN) – Typical trigeminal neuralgia is characterised by sudden, stabbing electric shock-like, or burning bursts (<2min) of severe pain in one or more branches of the trigeminal nerve. Between attacks the patient is completely without symptoms. The pain may be triggered by certain daily activities such as eating, talking, washing the face or brushing the teeth. The syndrome is most common in patients over 50. The course may fluctuate over many years. Remissions of months or years are not uncommon. TN is a very rare condition (1 in 100,000) but the problem with TN is that in the initial stages it often mimics toothache misleading both the patient and dentists.

Continuous Orofacial Pain Conditions

Temporomandibular Disorders (TMDs) – Temporomandibular disorders are the most common orofacial pain conditions affecting adults during periods of stress; for example, during examination periods and life crises. They present with ear pain worsened by opening their mouth wide, eating hard food stuffs and when applying finger pressure over the joint. TMD pain is best managed with reassurance and analgesics (painkiller) medication. Dysfunctional conditions include frequent clicking, crepitus (grating sound or sensation of friction between bone and cartilage) or locking of the temporomandibular joint (TMJ). These symptoms relate to the bones not moving smoothly together. Surgery is only indicated if the joint locks repeatedly. Arthromyalgic pain may be one or more of temporalis, masseteric or pterygoid muscle pain. Such pain is usually related to chronic clenching or grinding of the teeth, known as bruxism. Conservative (dental) management, involving oral splints (bite guards), reassurance and analgesics (painkillers) medications are most effective for these conditions (for more information Orofacialpain.org.uk).

Trigeminal nerve injuries (TNIs) as mentioned above, is a pain condition that results from nerve injury after surgery. For more information please visit Trigeminalnerve.org.uk.

TAC Hemicrania Continua is a very rare condition that is a TAC (see above) and causes constant pain in one side of the face.

Burning Mouth Syndrome – Burning mouth syndrome (BMS) is defined as chronic pain or discomfort in the lining of the mouth of unknown cause, in which other possible causes have been excluded. The condition is more common amongst women in the menopausal to post-menopausal age group. Afflicted patients report a constant burning sensation, typically in the front portion of the tongue, although the front portion of the hard palate and the inside lining of lips region are other common sites (for more information Orofacialpain.org.uk).

Persistent dento-alveolar pain (PDAP) Neuropathic pain (Non odontogenic dentolalveolar pain, phantom tooth pain, atypical odontalgia or primary PDAP), is often difficult to diagnose because it is poorly understood. Even defining and categorizing such persistent pain is challenging. Non-odontogenic pain is not an uncommon outcome after root canal therapy and may represent half of all cases of persistent tooth pain.

Post herpetic neuralgia – Skin lesions that break out on the face can be caused by the reactivation of latent varicella-zoster virus in the sensory nerves. Associated neuropathic, possibly severe pain that persists two or more months after the acute skin eruption is known as post-herpetic neuralgia. Post herpetic neuralgia usually occurs after an episode of the shingles and rarely affects the orofacial region.

There are various interventions for orofacial pain including: surgical, medical and psychological

Psychological therapies are the mainstay of treating chronic pain, alongside other therapies

The surgical interventions available include injections, implants, 'nerve ablation' where an electrical current is used to heat up a small nerve area to decrease the pain and 'decompression' where a surgical opening is made to release compression of a nerve. Unfortunately neuropathic or chronic pain responds very poorly, or worsens in relation to surgery in most cases. There are rare indications to operate soon after nerve injuries.

Medical treatments for orofacial pain There are a wide range of medical interventions designed to treat the causes and symptoms of orofacial pain. The medications that may be offered are usually antidepressant, antiepileptic, analgesic or opioid many with side effects. It is important that you speak to your medical team about the different medical intervention options available to you.

The effects of orofacial pain

Physical effects

As explained above, the precise characteristics of orofacial pain may vary from condition to condition and person to person, but what is very certain is that the main physical effect is the experience of pain. The physical effects of orofacial pain should be addressed by your medical team.

Functional effects of the face and mouth are significantly compromised by continuous or elicited pain. This can compound the psychological impact for the patient.

Emotional effects

We recognize that the ongoing pain and discomfort that is central to orofacial pain conditions can have a significant impact on your emotional wellbeing. Initially, when you receive the diagnosis, you may experience a sense of relief since the problem has been recognised and named. However, we also know that you may experience a number of difficult emotions whilst living with orofacial pain. We have described some of the common ones below –

Anger and irritability: You may feel angry about having an orofacial pain condition, about the length of time it has taken to be diagnosed, and about the limitations it puts on your daily life. It may not always be clear what the long-term prognosis of your condition might be and what your chances of making a full recovery are. This can lead to frustration when you are trying to manage a high level of uncertainty and possible unpredictability of your condition.

Low mood or depression: Living with a chronic health condition can increase the likelihood of experiencing low mood or depression. This can mean experiencing a variety of symptoms such as feeling sad or numb, hopeless about the future, having negative thoughts about yourself, other people or the world, feeling lonely, or as though you are carrying the burden of the condition without support.

If you think you are experiencing depression and have had thoughts that your life is not worth living, it is important to tell a healthcare professional, visit your GP or attend A&E, particularly if you think you might act on these thoughts.

Worry and anxiety: You may be concerned, worried or frightened about what the condition means for you future. Many patients find their mind constantly circling with questions such as "is there permanent damage?" "will this go away?" and "will I ever feel better and the pain stop?", to which is it difficult to get definitive answers for following a diagnosis. These thoughts may lead to a preoccupation that prevents you from engaging in certain activities is addressed in more detail later in this leaflet.

All of these feelings are very normal and it is natural to experience some or all of these feelings at different stages of illness as you continue to process new information. It is possible that they will come and go over time and that many will go away by themselves as you begin to come to terms with your condition. However, if they persist then there are a number of different things you can try which may help.

The effect of orofacial pain on your thinking

The way we make sense of our experiences depends a lot on how we think about them. We can have positive 'glass half full' thoughts which may be really helpful and allow us to get through difficult times. However, often in times of stress, our minds come up with scare stories instead, which can be less helpful. Often there is a noticeable pattern to these negative thoughts which are known as 'unhelpful thinking styles'. Everyone can fall into these patterns at times, and they are often so automatic, that they happen beyond our awareness. Thoughts can also be balanced or unbalanced and do not necessarily appear wholly positive or wholly negative. Sometimes just being able to notice and recognise these thinking patterns can be useful. Some examples of such thinking styles are set out below:

Thinking Style	Examples commonly associated with feeling of anger or irritability
Mind-reading	"The doctors think I'm exaggerating about how much pain I am in"
Black and white thinking	"The doctors can't give me any guarantees, that was a complete waste of time"

Thinking Style	Examples commonly associated with feeling anxious or worried
Self-criticism and labelling	"I cannot seem to snap out of this low mood and stay positive. I am a failure"
Self-reassuring language ('shoulds, oughts, musts')	"I should be able to cope with this and I ought to be able to continue living a normal life. I must get on top of this"
Black and white thinking	"Nothing is improving, I may as well give up"

Thinking Style	Examples commonly associated with feeling anxious or worried
Thinking the worst	"I won't ever feel better"
Predicting the future	"What if I have to take too much time off work and I lose my job?"

You might identify with some or all of these, or be able to think of your own individual examples.

The effect of orofacial pain on your actions

Some things you do will have a positive effect on how you feel physically and emotionally, including maintaining a good diet, exercising, a good sleep routine that refreshes and making time for activities you enjoy such as hobbies and socialising. Other things like smoking, using illicit drugs, drinking too much alcohol, or spending a lot of time playing video games or watching TV can seem to offer immediate relief, but make you feel worse in the long-term if they serve to avoid doing other activities that might improve wellbeing.

You may find that you start avoiding things because of feeling anxious, low in mood or physically uncomfortable, for example you may put off seeing your medical appointments or stop doing things you used to enjoy. This can make life seem easier in the short term because you do not have to face the situation you fear, overcome the feeling that you 'can't be bothered' or tolerate the unpleasant physical symptoms. However, this can be unhelpful in the long term and lead you to feeling stuck. For example, putting off your hospital visit due to fear can lead to more anxiety because you never find out if your

fears come true. Similarly, cancelling plans with friends because you feel low can make things worse because you do not get the chance to experience fun, pleasure and a sense of achievement.

Vicious cycles' and 'virtuous cycles'

The sections above describe the ways that your body, thoughts, feelings and behaviours can be affected by orofacial pain. You may have noticed how these things are all closely linked, which means a change in one area can have a knock-on effect in another area. For example, the thoughts we have about a situation can affect how we feel physically and emotionally, as well as what we choose to do. This relationship can be understood in the form of a cycle and whilst some cycles can interact in positive and helpful ways ('virtuous cycles'), others can interact in negative and unhelpful ways ('vicious cycles'). Below are two examples of a vicious cycle:

Episodic orofacial pain example:

Keith was diagnosed with typical trigeminal neuralgia and was finding the unpredictability of his pain difficult to manage. He felt incredibly anxious cleaning his teeth in the morning and evening, and whenever he ate food, fearful that it might trigger an intense episode of pain. Keith developed a routine of getting ready and eating that took him hours longer than it previously did in the hope of avoiding a trigeminal neuralgia episode. When he did get invited out with friends, Keith thought to himself "well there's no way I will have time with everything else I have to do". This meant he did not ever go out with friends and felt lonely, was constantly feeling on edge and was unable to get anything else done in the day that he wanted to.

Continuous orofacial pain example:

Sarah was diagnosed with post herpetic neuralgia and was finding the constant uncomfortable pain irritating so she did not leave the house unless it was an emergency. Sarah soon felt bored, hopeless and isolated. After a few weeks when she did try and go out to visit friends she felt anxious and her experience of her pain increased. She thought to herself "if it's just going to feel worse when I go out, there really is no point". This meant Sarah did not go out again and felt more lonely and depressed.

Coping with orofacial pain

It is important to remember that while it might not be possible to be free from pain and discomfort when living with an orofacial pain condition, you can find ways of coping with it, getting on with your life, and feeling better.

Tackling unhelpful thoughts

Thoughts enter our minds constantly throughout the day, and can be pleasant, unpleasant or neutral. You could think of the mind as like a storyteller or narrator which is constantly commenting on what is happening around us. Often the mind comments in helpful ways, drawing our attention to interesting or pleasant things, reminding us of happy memories from the past or reminding us of things we have planned in the future. However, sometimes during times of stress, the mind can be less helpful and instead, might draw our attention to unpleasant things, remind us of negative memories from the past or make scary predictions about the future. Although it can seem as though these thoughts represent reality and are 100% truthful, this is not always the case. It can be hard to remember that thoughts are just thoughts, and not facts, which is why we can get into difficulties.

The first step in tackling unhelpful thoughts is to notice what they are, perhaps by trying to pay attention to what your mind is saying (or 'narrating').

The next step is to step back from your thoughts and question them, since they are often based on the wrong assumptions. You could ask yourself the following questions:

- What makes me think this thought is true?
- Is there anything to suggest this thought may not be true?
- Is there another way of looking at this?
- Based on the evidence for and against this thought being true, what is the most logical or balanced alternative perspective?
- If a friend who I cared deeply about had this thought about themselves or their situation, what would I say to them?
- What are the costs and benefits of thinking this way?

While challenging thoughts in this way may not stop them coming into your mind, it could help you feel less upset or distressed by them.

Here is an example of how this method could be applied to Keith and Sarah's situation:

Keith's routine of getting ready and eating took him a long time as he tried to avoid a trigeminal neuralgia episode and therefore didn't do much else. He thought to himself "I just don't have time to go out by the time I have brushed my teeth and eaten breakfast. I can't speed it up because if I have an attack of pain my day will be ruined". However, he was able to notice that this was an unhelpful thought and so decided to question how true it was. He asked himself what he would say to a friend in this situation and thought he might say "I know taking a little less time to do your morning routine might result in an attack of pain that will feel terrible but it is not guaranteed that this will happen. Maybe try and speed things up and go out if you are not in pain. That way you still have a chance to enjoy yourself. If you are in pain the worst of it will pass in a few minutes and you can focus on recovering at home". This helped Keith to construct an alternative, more balanced and helpful thought, which lead to a plan to try a different behaviour (going out to see friends). Gradually he began to go out more and more and only declined invitations when he has recently experienced an attack of trigeminal neuralgia pain. This in turn helped him to feel less hopeless and anxious.

Sarah was in pain so she decided to stay at home. She soon felt bored, hopeless and isolated. After a few weeks when she did try and go out to visit friends she felt anxious and her experience of her pain increased. She thought to herself "if it's just going to feel worse when I go out, there really is no point". However, she was able to notice that this was an unhelpful thought and so decided to question how true it was. She asked herself what she would say to a friend in this situation and thought she might say "I know you are in pain and this is distressing for you but you might have a chance of feeling a bit better if you get out and see the people who you enjoy spending time with. Perhaps you should try and go out for an hour at first and see how you get on. You could then build it up over time and gradually build up your confidence". This helped Sarah to construct an alternative, more balanced and helpful thought, which lead to a plan to try a different behaviour (going out to see friends). Gradually she began to go out more and more and gain a better understanding of her ability to manage the pain when away from the house. This in turn helped her to feel less hopeless and low in mood.

Using a mindful approach

If the above strategy does not work for you, or you are finding it hard to name your thoughts, another method you could try is to apply a mindful approach. This is a way of becoming more aware of our mind

and body right now, and can help us detect certain feelings, unhelpful thoughts or images. Often we can get caught up in reacting to thoughts or feelings automatically, without a successful outcome. Instead, mindfulness encourages us to take a curious stance towards our experiences, including thoughts, feelings and sensations. It teaches us to simply notice them without judgement or trying to change them. To start with, you could try following these simple steps:

First notice the thought that has popped into your mind

Try not to judge the thought as good or bad, just notice it

You could thank your mind, the storyteller, for its contribution to your day

Then ask yourself, is this thought a helpful one? If so, then perhaps pay attention to it and act on it

If it is not helpful, and your experience tells you that these thoughts make you feel bad and keep you stuck, just observe the thought instead of reacting or responding

You could try seeing the thought in your mind's eye being a headline on a newspaper that tends to print exaggerated stories

Then let the thought drift away, like leaves on a stream, or cars passing by outside your window

Being mindful of your experiences is a very different way to our usual way of paying attention and can take practise. There are many good books, CDs and apps for mindfulness if you think this approach might be helpful for you.

You can also find some mindfulness recordings at:
http://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Self-help-materials.aspx

If you are interested in the above mindful approach you may also find Acceptance and Commitment Therapy (ACT) of interest. There is a short clip on YouTube called Passenger on a Bus that uses a bus metaphor to explain ACT in more detail.

Tackling unhelpful behaviours

Sometimes it can feel too difficult to notice and challenge our thoughts and you may find it easier to work on tackling unhelpful behaviours to start with instead. You may have received lots of advice about eating a balanced diet, establishing a good sleep pattern, exercising regularly, avoiding drugs and alcohol, and taking medications as prescribed. Often it can be easier to start doing new, more helpful behaviours, than to try and stop doing unhelpful ones.

To do this, try to ask yourself what is important to you and what your values are (e.g., family, friendships, your health, your work or your hobbies). Then try to do something most days that keeps you moving in the direction of what matters to you most. You may need to try out new approaches if your old strategies don't work.

Do things you enjoy and that bring you fun, pleasure and laughter. This could mean meeting a friend who makes you laugh, watching a repeat of a comedy show or making time for things you relish such as watching sport or soaking in the bath. Also, try to do things that you get a sense of achievement from.

If you want to make a change, such as taking steps to quit smoking or lose weight, try to set a specific goal, write it down and reward yourself once you have achieved it. If you have a setback, do not give yourself a hard time but remind yourself that setbacks are normal and remain curious about what went wrong so you can think about what do differently next time. If you think it was unrealistic, reset your goal and re-commit to it, rather than giving up. If you have several barriers which you struggle to overcome, try using a 'problem-solving' approach (see **IMPARTS** leaflet, *'Problem Solving for People Living with Health Conditions'*).

Dealing with anger and irritability

We all feel angry at times but it can become a problem if it is too extreme, occurs at inappropriate times or lasts too long. The feeling of anger exists on a spectrum, from a simple irritation with something to intense fury and rage. We often feel angry when we feel let down in some way, or denied of something that we feel entitled towards. The feeling of anger can also mean behaving in certain ways, for example shouting, becoming violent or running away. These angry behaviours can have a negative impact on our relationships and our work, and can change the way we feel about ourselves.

As with all emotion, the experience of anger is accompanied by a number of strong physical sensations in the body. This is due to our body's instinctive and automatic 'fight or 'flight' response to a threat, which means adrenalin is released to energise the body to either confront the danger, or run away from it. Some of the physical sensations you may notice include heart racing or pounding (enabling good blood supply around the body), breathing quickly (allowing more oxygen around the body), tense muscles (in a state of readiness to fight or flee), shaking, sweating, light-headed, stomach churning or butterflies, fist or teeth clenching.

In the context of living with orofacial pain, you may feel angry about the treatment you have received, about the way things have been communicated, or about how others are reacting towards your situation. You may also find yourself feeling angry about what has happened to you. Sometimes anger is directed at the illness, and sometimes people report feeling anger towards the healthcare team or the hospital. However, there are ways you can learn to deal with anger, by applying some of the techniques already discussed.

Challenging angry thoughts

Try to recognise the content of your angry thoughts e.g., "I cannot handle this incompetency" or "no one else is helping me".

Try using some of the questions outlined above to challenge your unhelpful thought e.g., "how important is this really?" or "what are the costs and benefits of thinking this way?"

You can then try to come up with a more balanced or rational view e.g., "although it feels as though no one is helping me, several members of my family have offered me support and most of the nurses I have met have seemed friendly and competent. Perhaps I can tell them how I feel and ask them for other sources of support."

Learning new ways to respond

Use a relaxation technique such as mindful or calming breathing which can help you to slow down your breathing and reduce the intensity of the immediate physical sensations. For example; sit in a comfortable position, then work out a stable breathing rhythm such as breathing in for 2 seconds, and out for 3 seconds. It can be helpful to count as you do this. You may need to practise this several times when not feeling angry, so that it becomes easy to start when you do feel anger building.

If you can, excuse yourself from the situation in which you feel anger rising and leave to go into a different space or room, then return once you feel calmer.

Channel your body's energy into a different activity, such as a walk, run or cycle, or maybe some gardening or housework, until you notice the symptoms becoming less intense.

Try to take a 'time out' or a pause and ask yourself "what would be the consequences of responding angrily?", "is there another way of dealing with this?" or "what would be the most helpful and effective action to take for me, the situation or for the other person?"

You could try visualising yourself dealing with the situation in a calm, non-aggressive but assertive way.

Use calming self-statements such as 'calm down', 'take a deep breath' and 'there is no point in getting angry'.

Managing stress

Identify triggers for your anger and avoid them where you can e.g., rushing to work, traffic jams, shopping during busy periods, or perhaps times of day when you are likely to get angrier, such as at night.

Build relaxation into your daily routine so that you make time to relax every day. This could be doing something you enjoy, or just being by yourself. Some examples might be reading a book, having a bath, doing something creative, or visiting a friend.

You could also try practising mindfulness meditation every day, for example the exercise outlined above, or listening to an audio guide.

Dealing with low mood and depression

Feeling low in mood or depressed is common when you have been experiencing pain, particularly if the pain has kept you away from things you usually enjoy.

When you are depressed, you may believe that you are helpless and alone in the world; you often blame yourself for all the shortcomings that you think you have. At the bottom of this, you feel negative about yourself, about the world and about the future, which means you tend to lose interest on what is going on around you and do not get any satisfaction out of the things you used to enjoy. It can become harder to make decisions or carry out simple tasks as you did before. You also may not be sleeping or eating well. Fortunately, once again there are a number of things you can try out which have been shown to help people when they feel depressed.

Challenging gloomy thoughts

As described earlier, it can be helpful to recognise the unhelpful thoughts you are having about yourself, others or the world e.g., "I am useless", "no one is caring" or "the world is a horrible place". Everyone has these thoughts from time to time, but for people who are depressed, they tend to be around a lot more of the time.

Try to remember that these thoughts are automatic and are often not rooted in any logic or reason. They therefore serve no purpose than to make you feel bad since they are unreasonable and unrealistic.

When people are feeling low they can become trapped in patterns of distorted thinking such as over-

generalising, mind-reading, black-and-white thinking or discounting the positive. Ask yourself whether any of these are around for you.

- You could try writing down your negative automatic thoughts and opposite each one, write a more balanced, positive thought, for example:

Negative automatic thought	Balanced thought
"Living with constant orofacial pain means I can no longer enjoy life".	"Although I am in pain and this may make this is less enjoyable than if I was completely pain free, there are still lots of things I can get some sense of please and achievement from."
"I can't risk an episode of pain while I'm out so there's no point in doing anything".	"Although an episode of pain would be very unpleasant while I am out, there is no guarantee I will have one. If I did have an episode I could take time out to recover. That way I still have chance to enjoy things."

Often people who are depressed tend to forget important details and think in more general statements such as, "I have never been good at anything". Try and train yourself to remember specific details so that good times and experiences are easier to recall. A daily diary can help with this, or you could list past achievements or memories of pleasant experiences.

Changing what you do

Research tells us that gradually increasing activity over time can be helpful for overcoming depression. This could mean making a list of things to do, mixing with other people, joining in activities, taking exercise, or simply doing anything you enjoy.

Make a plan or a schedule of your activities for the week, starting by filling in the things you have to do, such as work, making appointments, doing housework or preparing meals, and then plan other activities in the time you have free.

Try to find a balance between activities of pleasure (e.g., seeing a friend, having a bath, reading, watching a film), and those of mastery or achievement (e.g., exercise, shopping, decorating, gardening, paying bills, writing a journal). With regards to exercise, you may find it easier to build this up gradually, starting with small steps, especially following an operation, as muscles take time to heal up. Also, with tasks you have been putting off, try breaking them down into smaller stages and tackling them one by one.

Take care of yourself physically, this means paying attention to your sleeping and eating patterns. If your mind is busy, it could be having an impact on your sleep.

Unhelpful coping behaviours can include drinking alcohol, taking drugs or drinking too much caffeine (such as coffee, tea, cola and energy drinks). Try to avoid doing any of these if you can (speak to someone if you have a problem giving up).

Think about what really matters to you, i.e., your values. Try to do something most days that keeps you moving in the direction of these values.

Dealing with worry and anxiety

We all experience anxiety from time to time, since it is a normal response to situations that we see as threatening, such as a near miss with a car in the street. A certain level of anxiety can even be helpful, for example if we want to perform well or cope with an emergency. As a result of having a chronic illness, it is natural to feel anxious about your recovery, your future health, work, family life or maybe other things. However, it can become a problem if it stays around for a long time since it can make physical symptoms worse, or stop you doing things you usually would enjoy.

The physical sensations associated with anxiety are very similar to those of anger, since it is also a result of the body's instinctive 'fight or flight' response, mentioned earlier in this leaflet. These symptoms include a racing heart, increased breathing rate, a dry mouth, sweating, tingling and feeling dizzy. The list of tips below could help you to cope with both the thoughts accompanying your anxiety, and with the physical sensations. Remember that anxiety itself is not dangerous or harmful, it is just a feeling.

Coping with anxious thoughts

Again, the first step towards tackling unhelpful anxious thoughts is to recognise what these are. You might want to keep a diary of the times you are feeling anxious and what types of thoughts are running through your mind (these can be difficult to pinpoint since they are often very fleeting and automatic).

If it is a realistic worry or problem that is causing you anxiety, try to problem solve it by defining what the worry problem is (or what the main problem is first), then ask yourself if there is something you can do about it, or not. If there is something you can do about the worry or problem, you can write a list of all the possible solutions. You can then ask yourself if there is anything you can do about it right now or not. If there is something you can do about it now, then get on and do it. If there is not something you can do about it right away then make a plan of when you can do something about it and make sure you have a reminder to implement the plan (see **IMPARTs** leaflet, '*Problem Solving for People Living with Health Conditions*' for more detail).

If the worry is about something you cannot control, you might wish to try using mindfulness (see section above) to help you to tolerate the anxiety, and let it fade away, or you could use some of the tips outlined in the next section below.

If the worry is in relation to your illness, it might be something you want to get checked out straight away (e.g., a change in your bodily symptoms), or make a note of to ask at your next appointment.

If your anxious thought is about what your physical symptoms mean (e.g., "I am dizzy which means I will faint"), try to ask yourself whether this thought is realistic, and come up with a more balanced thought (e.g., "I have felt dizzy many times before and not fainted. When I fainted, it felt different"). This may take some practise but it will get easier with time!

Be kind to yourself and try not to block out the worries but accept they are present. Do not criticise yourself for having these worries but try to be kinder to yourself. You could ask yourself "what would I say to someone who I cared deeply about who was going through this?"

Do something different

Try to be mindful of unhelpful behaviours that you might be doing to cope with anxiety, for example; avoiding others or activities, or drinking excessive amounts of alcohol, or using drugs. If you are avoiding certain things because of anxiety, try to tackle these fears in a graded way.

If you are afraid of a certain situation, try to stay in that situation and wait for the anxiety to subside. It usually will come down after a few minutes. For example, if you are anxious about going out, a walk to the shops might be a first step. Although you might feel anxious, if you walk to the shop and stay there for a few minutes the anxiety will usually subside. This can then be extended to another shop a few minutes further away. Eventually you should learn that the situation is not to be feared and you will not have the same anxious reaction as you have in the past. Even if you do start to feel anxious in a new situation, you will have learnt that the feeling of anxiety will subside within a few minutes.

In order to reduce physical symptoms of tension or anxiety, you might want to try relaxation techniques such as controlled breathing, or mindfulness. Controlled breathing is a method of taking normal breaths that are not deeper than usual, using the lower chest whilst keeping the upper chest and shoulders relaxed at the same time.

An example of a controlled breathing exercise:

1. Place your hand lightly on your upper chest and the other on your abdomen just below where the ribs divide.
2. Take a normal breath in through your nose and feel the hand on your abdomen rise up and out.
3. Now breathe out quietly through your mouth and feel the hand on your abdomen sink down and in. The hand on your upper chest should hardly move.
4. Breathe at a rate that is comfortable for you.
5. Now, when breathing, try to make your breathing out last twice as long as when you are breathing in (it will help to count slowly as you breathe in and out).

Some people can relax using other methods such as exercise, listening to music or reading a book, or you might want to find a relaxation or yoga class to try (ask your nurse or doctor for recommendations or search online).

Distraction can also help you take your mind off your symptoms, or keep your mind occupied whilst your anxiety symptoms begin to fade (you will need to distract yourself for at least 3 minutes before this happens). Try focussing on things around you, study your surroundings in detail or listen to other people's conversations. This can help re-focus your mind off your worries. You could also try doing another activity which you find pleasurable or masterful, in order to distract yourself from worrying.

Dealing with sleep difficulties

If your sleep is being affected by the symptoms of orofacial pain, or negative or anxious thoughts associated with it, here are some suggestions you could try to help you sleep better (also see **IMPARTS** leaflet, '*Overcoming Sleep Problems*', for more detailed information):

Do not go to bed unless you are sleepy.

If you are not sleepy at bedtime, then do something else. Read a book, listen to soft music or browse through a magazine. Find something relaxing, but not stimulating, to take your mind off of worries about sleep. This will relax your body and distract your mind.

If you are not asleep after 20 minutes, then get out of the bed.

Find something else to do that will make you feel relaxed. If you can, do this in another room. Your bedroom should be where you go to sleep. It is not a place to go when you are bored. Once you feel sleepy again, go back to bed.

Begin rituals that help you relax each night before bed.
This can include such things as a warm bath, light snack or a few minutes of reading.

Try to get up at the same time every morning.
This can be difficult, but a consistent waking time, even on weekends and holidays, can be really helpful.

Get a full night's sleep on a regular basis.
Get enough sleep so that you feel well-rested nearly every day.

Avoid taking naps if you can.
If you must take a nap, try to keep it short (less than one hour). Never take a nap after 3 p.m.
Keep a regular schedule. Regular times for meals, medications, chores, and other activities help keep the inner body clock running smoothly.

Avoid doing anything else in bed apart from sleeping and having sex.

This includes reading, eating, watching TV, talking on the phone, playing games or surfing the internet.

Avoid caffeine, alcohol, cigarettes or strenuous exercise within six hours of your bedtime.

Do not go to bed hungry, but don't eat a big meal near bedtime either.

Avoid sleeping pills, or use them cautiously.
Most doctors do not prescribe sleeping pills for periods of more than three weeks. Do not drink alcohol while taking sleeping pills.

Exercise regularly, if you can
See the next section of this leaflet for where to find out more information about this.

Make your bedroom quiet, dark, and a little bit cool.
An easy way to remember this: it should remind you of a cave. Also make sure your bedding is comfortable.

If you think that worrying is keeping you awake, try some of the tips in the section 'Dealing with worry and anxiety' above.

For example, you could try writing down your main worries in list form, and making a plan or 'to-do' list for those you can do something about.

Learn to relax

You could try some relaxation or mindfulness exercises before bed, or whilst you are in bed and trying to sleep.

Using mind-body link to your advantage link to your advantage

The brain and the body are constantly sending messages to each other. These messages tell the brain and body to make changes and adjustments to the way they are working. For example, if your eyes told your brain a car was travelling towards you at speed, it would send a very fast message to the body to step back out of harm's way. Similarly, if your stomach was empty and your body needed fuel, your brain would listen to that message and send you in search of food. So, the mind and the body are in constant communication to keep you healthy.

An example of this close relationship between the mind and body already mentioned in this leaflet is the 'Fight or Flight' mechanism. This alarm system developed to keep us safe from danger, like the threat of predators for example. It is triggered when you feel threatened and it makes your body get ready for a fight or for running away (e.g. by making your heart beat faster and your muscles tense up).These physical symptoms are the result of the release of stress hormones in the body, such as cortisol and adrenaline. This worked really well when there were predators around. Unfortunately, it is less helpful for modern day threats. Things like money worries or fears about the future can trigger this 'fight or flight' response, even if it is not that helpful for solving the problem.

The mind-body link does not only have bad effects on our physical and emotional state, it can also have good effects. You may recognise some of the examples below.

Relaxation

When you get a chance to relax, such as having a bath, sitting in the sun, listening to a calming piece of music or practising meditation, you may notice changes in your emotional state such as feeling less tense and more at ease. There are also changes that happen in your body such as your heart beating slower, your breathing slowing down and you blood pressure going down.

We have a selection on mindful mediation exercises available to download on the **IMPARTs** website at: www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Self-help-materials.aspx

Exercise

Many runners and other athletes talk about feelings of physical and emotional well-being during and after exercise. You can feel this after lots of other activities as well, such as walking, going up the stairs or going to exercise classes. It is thought that chemicals called endorphins, which your body produces when you exercise, are what make you feel happier.

For a comprehensive guide to the recommended levels of exercise for adults see the NHS website: www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-adults.aspx

Positive events, pleasure and achievement

When positive things happen such as getting good news, laughing with friends or being meeting with friends or family after a time apart, you usually feel happier and more at ease. During these times, you may also feel more physically alert and active rather than sleepy and sluggish. The same can happen when you do activities you enjoy or something that gives you a sense of achievement. These examples show the powerful effect of positive experiences on both your mind and body.

Where to find more support and information

Orofacial pain – Demystifying chronic pain in the head, face and mouth
www.orofacialpain.org.uk

Trigeminal Foundation – Nerve injuries
www.trigeminalnerve.org.uk

Trigeminal Neuralgia Associate UK – Facing pain together
www.tna.org.uk

British Pain Society
www.britishpainsociety.org

OUCH UK (Organisation for the Understanding of Cluster Headache)
www.ouchuk.org

Written by Dr Amy-Kate Hurrell (clinical psychologist)

With special thanks to Dr Tara Renton (Professor of Oral Surgery, King's College Hospital) and Dr Sarah Barker (Consultant Clinical Psychologist, King's College Hospital) for consulting on this leaflet with their professional knowledge.

King's Patient Advice and Liaison Service (PALS)
This is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleden Wing, near the main entrance on Bessemer - staff will be happy to direct you.

Tel: **020 3299 3601**
Email: **kch-tr.pals@nhs.net**

The full range of IMPARTS booklets can be found at:
www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Self-help-materials.aspx

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