***Airing Pain* Programme 131 - Face Pain, Treatment & Management**

What causes different types of face pain and what treatments are available?

In collaboration with UCLH Royal National ENT and Eastman Dental Hospitals.

In this episode of ***Airing Pain*** we cover facial pain in many forms, what treatments are available and how to cope better with your pain.

The way our face feels and how we move it is a massive part of our identity. Feeling pain in the face, or not being able to use your face the way you want to, is not only a physical burden on the person suffering, but a heavy psychological load to cope with as well.

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Issues covered in this programme include: mental health, Trigeminal Neuralgia, self-management, intermittent pain, neuropathic pain, nerve injury, secondary care, neurosurgery, Temporomandibular Disorders, post-surgical pain, physiotherapy, acceptance and commitment therapy (ACT)

Paul Evans:

This is ***Airing Pain***, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for those who care for us. I'm Paul Evans, and this edition of airing pain is supported with a grant from the Hospital Saturday Fund.

Dr Joanna Zakrzewska:

It’s recorded that up to 20% of patients may have unnecessary dental treatment. So, I mean, if you've taken out a tooth, that's it. You've lost a tooth.

Roddy McMillan:

There’s, very often, not any outwardly visible signs so that somebody can look at somebody and say ‘oh they've got chronic pain of the face’. The amount of negative impact that facial pain can have on patients can be extremely high.

Susie Holder:

We could probably manage to get by if we weren't using one arm or one hand or something. You know there's no way round it, you can't really get by without being able to eat. It's difficult to express yourself. I suppose it's difficult to be who you are if you can't use your face.

Rachel Stovell:

I'm not going to promise people, and I'm not going to set up expectations that I can't actually meet. But what I can say to them is that extra level of suffering that comes on top of dealing with those symptoms, that is somewhere that I can have some impact on.

Evans:

Our face is the portal, if you like, to our world: eating, talking, smiling, kissing, breathing and much more. In this edition of ***Airing Pain***, we'll be looking at conditions that cause facial pain, and management techniques and strategies that will help us live with it. Trigeminal Neuralgia is not a common condition, but it is debilitating. Professor Joanna Zakrzewska is a consultant in facial pain at the Royal National ENT and Eastman Dental Hospitals in London, and she is internationally recognized as one of the world's leading experts in Trigeminal Neuralgia.

Zakrzewska:

Trigeminal Neuralgia is a facial pain, a very severe one-sided excruciating pain that comes in bursts. A single burst can last just for a few seconds to two minutes, or you can have a burst that lasts quite long because there's so many of them, a series of stabs that you actually think that it's lasting much longer, and that can sometimes go on for several hours. But then you have a break, and that's very, very important, and the break can be for anything from just minutes to hours. You may only get two or three attacks a day, you may get no attacks and then you can go into periods of what are called remission, when there is no pain at all.

Then there are other periods [that] we call the relapse period [when] the pain is brought on. It's an electric shock like pain brought on by light touch. So, it's just gently touching your face, trying to shave, trying to wash your face, and it's made worse obviously by eating, drinking, talking, and it is mostly, except in 3% of patients, one side of the face only. Lower part of the face most commonly, least likely in the top of the face, but it can be all three divisions of what's

called the Trigeminal Nerve, and initially it often feels like a toothache because it often presents around the mouth and the natural thing is to think I've got toothache and therefore start your journey on this condition by going to see your dentist.

The first thing the dentist will do is examine all the teeth to check whether there is potentially a dental cause. They will often do X-rays as well to check that there isn't an abscess forming or some other decay under a tooth. Now this is the difficulty, some dentists will then be in a dilemma because they can see that there is potentially a dental problem, but they're not quite sure, some will go ahead and do dental work. That is, they may do root canal work, or they may even take the tooth out. And yet after those procedures, the pain doesn't settle and it's very difficult for dentists to actually recognize that it is Trigeminal Neuralgia, because it is rare, and it's about teaching dentists to ask the right questions. Four or five questions could be helpful to try and diagnose that, so again, the onus is also on the patient to try and record a history as carefully as possible.

But it is this paroxysmal nature, that is the intermittent nature of the pain that is often a pointer to the fact that it isn't a dental pain because dental pain tends to be constant and there the whole time, and particularly if you touch a particular tooth, it is likely to set off a dental pain. Whereas in a patient with Trigeminal Neuralgia, just touching the gum around the teeth or the cheek area can set off an attack, and therefore that doesn't come from the teeth, but it is very difficult because the Trigeminal nerve supplies all our teeth, and every single tooth has a piece of Trigeminal nerve in it. So that's why it gets very confusing and sometimes the dentists have to hold off and wait a moment before they do anything drastic, because it's recorded that up to 20% of patients may have unnecessary dental treatment and the problem is that this dental treatment is often irreversible. So, I mean, if you've taken out a tooth, that's it, you've lost a tooth. Whereas if patients go to their GP, they might be given various drugs, but at least you can take the drugs off and start again. So, a dentist has a big onus and we're now trying also to develop a short questionnaire, a screening questionnaire, that dentists could ask their patients to try and see whether they can diagnose Trigeminal Neuralgia, as opposed to a dental problem.

Evans:

So Trigeminal Neuralgia has been diagnosed by the dentist. What's the treatment then?

Zakrzewska:

So, the first treatment is Carbamazepine, a drug that has been recommended by the NICE guidelines, by our guidelines and is taught everywhere. Now dentists can actually prescribe Carbamazepine, but it's a very, as we call it, a black drug in the States and it's a dangerous drug to use, difficult to use. So, if you're not used to using [Carbamazepine], it's much better that the GP prescribes it first. So, what happens in good communities is that the dentist will write to the GP and say 'I think this is Trigeminal Neuralgia, I think the treatment is Carbamazepine,' and leave it to the GP to start the first dosages. And the NICE guidelines say use Carbamazepine. If Carbamazepine fails, either because [the patient] doesn't respond, which is unusual, or [because] they have severe side effects, then they should be referred to the secondary care sector. The big dilemma is who to and how to do that referral. But in the first instance, Carbamazepine can act as a diagnostic drug, and only a small dose of it is sufficient to really turn that pain off in those first few weeks or months of the pain. So, we often call it a diagnostic drug.

Evans:

So, basically, if the Carbamazepine works, it's Trigeminal Neuralgia, if it doesn't work, it's something else. What else could it be?

Zakrzewska:

It could be some other form of neuropathic pain, nerve injury pain, possibly related to having had dental treatment, or an infection post-shingles or due to trauma to the face. So, one has to then start looking at other causes for it, and what we do encourage is that if you can't find a cause, then do refer [the patient] to the secondary sector. If you refer to dental schools, then we can get an opinion from oral physicians who are well skilled to recognize Trigeminal Neuralgia and other types of facial pain. We also have the back-up that we have restorative dentists who are skilled in reviewing for rare causes of dental pain, because the one that's most

difficult to differentiate is, in fact, what we call cracked tooth - where the tooth has a crack in it- and every time you bite on it, you get pain. But here, the pain occurs on release of the tooth from biting. So, in Trigeminal Neuralgia it's that very first touch that sets off the pain, and that's a difficult one to diagnose. Some dentists in primary care may not find that because it's quite subtle. So, if in doubt, we suggest referral in for second opinions.

Evans:

Is Trigeminal Neuralgia curable or is it just manageable?

Zakrzewska:

That's a very difficult question to [answer], whether it's curable or not. Some patients will feel that it is curable, but I think in general it's a long-term condition that can be managed very effectively. So, when we have just done a long-term cohort study, that is, we've followed patients up for a minimum of six years, what we found was that just under 50% had undergone neurosurgery in order to get pain relief, the others had remained on medication. And at the time of the survey, 80% of patients were saying that they were in a good place and that they were relatively pain free. Although quite a large percentage of them had to be on drugs, so I would say it is a long-term condition, but it is manageable and probably more manageable than other chronic pains and some patients who undergo major neurosurgery can be totally pain free, off all medication and no need to see us anymore.

Evans:

OK, you brought up neurosurgery. Where in the treatment path would that come?

Zakrzewska:

So, neurosurgery is obviously a complex set of procedures, and patients need to be prepared for it. Now what we suggest in our unit and in our guidelines, is that all patients, once they've been diagnosed, we're sure about the diagnosis and we call this phenotyping, and we have done an MRI scan because every patient with Trigeminal Neuralgia should have a scan. Once we have both of these, we do a joint clinic. That is, I am present, plus a neurosurgeon and

together with the patient and their spouse or their significant other, we discuss the treatment, so we will look at the scans. The surgeons will propose what potential surgeries are available given the medical history as well, because that will influence the choice, and what drugs are available. At that consultation, patients can either decide 'I want surgery' and which type of surgery, and can be immediately put on waiting lists or even have surgery fairly quickly if they're in desperate pain, or they can opt to stay on medication.

But the door is always open, so the moment they get more severe pain and they decide they can't cope with the drugs anymore because either the drugs are no longer working or the side effects are intolerable, they can opt to have surgery because they're known to the neurosurgeons and they can have their surgery fairly quickly. So, the deciding factors are lack of efficacy of a variety of drugs, because I will have tried several drugs, and tolerability. Tolerability is a major, major problem, patients [can] feel cognitively impaired, they can't think properly, they can't find their words, they have memory loss. They get very tired [and] fall asleep at the drop of a hat. They can get unsteady on their feet, they can have double vision, they can start to fall over, so those are side effects that we recognize in all these patients, and again, we've shown this by having patients doing computer programs and tests. This is an indicator for neurosurgery.

So, neurosurgery is done, mostly now by neurosurgeons, who are particularly skilled in working in what we call the posterior fossa, that is, in the head rather than, say, on the spine. So, the most effective procedure is a *Microvascular Decompression*, which is a big neurosurgical procedure because the neurosurgeons have to enter the skull. They do a small incision behind the ear, and they get right inside the skull, not into the brain, and they look for the vessel. There's a big blood vessel that presses on the nerve, and that therefore causes the loss of insulation between different type of fibers and allows for this crosstalk, between light touch and sharp pain. And so, they move this vessel out of the way, and maybe several vessels, there may be veins, but often it's a very big large artery which they have to do very delicately, because if you touch that one, you've got a stroke or even death. Then close everything up very

tightly, so everything is sealed again, and the cerebrospinal fluid (CSF), the CSF, is contained again within the brain. Now that gives the best option, 70% of patients will be totally pain free at ten years and off their medications. But there is still this 30%, side effects are obviously [a risk], there is always a risk of death, but it is very low indeed, 0.1%, and the main [risk] is this leak of CSF fluid, but that can be mended. There can sometimes be loss of hearing, which is often a temporary loss of hearing, not permanent, but it is a big procedure. Patients stay in the hospital for three days and it takes up to six weeks to recover.

Now patients who are not fit enough to have the operation or feel reluctant to have a big operation can have smaller procedures done, which are done under a short-acting general anesthetic where a needle is passed through the cheek into what's called the Gasserian Ganglion. This is a point at which all the three major branches of the Trigeminal nerve congregate together. They put the needle in, they do X-rays to check that the needle is in the Ganglion, and then they can do a variety of three different things and it depends which one the surgeon chooses. They can heat it by putting an electrical current through it, or they can fill that Ganglion with glycerol, a toxic substance. Or they can actually compress it with a little balloon; and all those three therefore cause destruction, so the patient will feel sensory change, that is, that side of the face might be numb, and it's unpredictable. So, you don't know when it's going to be numb and how much numbness. It can be just one little area of the face, or it can be the whole side of the face, and that doesn't give as good a result. We're talking about 50% of patients having relief for five years, up to five years. These procedures can be repeated time and time again, but the risk of causing permanent sensory loss increases and you can get what we call *Anesthesia Dolorosa*.

The final treatment is the Gamma knife, or what is more generally known as *Stereotactic Radiosurgery.* Gamma Knife is the trade name and this is the least invasive, because all you have to have is four pins put under local anesthetic just to stabilize a helmet that is put on the head. And then you're in [something] similar to a scanner, and radiation is projected onto the nerve in the place where we think the main source of the pain is. Now this treatment can take one month up to six months to work, so it's not an immediate result. With the other procedures you wake up from your anesthetic and you're pain free, so this one takes a little bit longer to

do, but is available to every single patient. There's virtually-except if you've got a pacemaker or some metal within you, when you can't put somebody into a scanner, that one is available to everybody.

So, there are a lot of surgical options which can be repeated and patients are warned that they can have this procedure again because the big problem with Trigeminal Neuralgia is its total unpredictability, and that's what patients live with, the fear of pain [returning], and often isolation because they're on their own. They haven't met anybody with it and that's why we also run a psychology program specifically for these patients. We have a pain management program with our psychologists and our physiotherapists, and we teach and make patients aware of how to manage flare-ups, how to meet each other and how they can use things like meditation, mindfulness. The first thing we do is recommend that they go to websites to help them with that such as *www.my.livewellwithpain.co.uk*, a very useful website for them to have.

Evans:

Isn't it strange how a printer would choose to do its maintenance tasks just when you least expect it. That was Professor Joanna Zakrzewska and I'll give you the address of the *my.livewellwithpain.co.uk* website at the end of this edition of ***Airing Pain***. Susie Holder is a clinical psychologist working within that facial pain team at the Royal National ENT and Eastman Dental Hospitals in London.

Holder:

The psychologist role in the facial pain team is about recognizing and acknowledging the impact that facial pain has on people. Facial pain can feel really threatening because it impacts on your vital functions, the things that you need to be doing every day, like communicating, eating, intimacy, and it's really important that we get to grips with what the impact is on them and also think about what they can be doing differently. Learning to manage and learn skills to be able to manage more effectively on a day-to-day basis.

Evans:

For a patient, it must be a fairly difficult thing to get your head around: [that you're] going to a doctor to have your pain cured. Yet you'll get to see a psychologist: a head doctor.

Holder:

You're right, and that's really difficult, isn't it, and a lot of patients can feel really distressed by that, and it is the way in which it's introduced that's really important. So, one of the things that our team - our medicine team - and facial pain team are really good at doing - the doctor or dentist that they see on the team - what they're really good at doing is actually suggesting that this is really hard to live with. This is really difficult. We understand the impact that this is having on you. So it's not that we're suggesting that this is made up in any way, that this is a fictional problem. But this is really looking at how hard this is and one of the things that we know, just like with other chronic pain conditions, is that people can experience things like anxiety [and] depression as a result of living with a long-term persistent condition. And that's true of any long-term condition, not just facial pain. But [we understand] that it brings difficulty and the skills that we have to manage those [symptoms] may not be working for them, and [the skills] might need looking at. [The skills] might need broadening out, and [patients] might need to learn different skills to help to manage that impact better on a day-to-day basis.

Evans:

We'll explore some of those skills a little later. Now, we've been focusing so far on Trigeminal Neuralgia, but not all facial pain is Trigeminal Neuralgia. In fact, compared to other conditions, it's not very common at all. Doctor Roddy McMillan is a consultant in oral medicine and facial pain at the Royal National ENT and Eastman Dental Hospitals in London.

McMillan:

The most common one, by quite some way, is the *Temporomandibular Disorders,* or TMD as we call it for short, which is basically pain around the jaw joint and the muscles that are associated with the jaw. So, that tends to be on the sides of the face but can radiate elsewhere, including into the ears and side of the neck, for instance, as well as presenting with pain inside the mouth. The other conditions that we tend to manage are mostly related to some form of nerve

wear and tear or nerve damage. One of the most common ones that we see is called *Burning Mouth Syndrome*, which presents generally towards the front part of the mouth. For instance, the tongue and the inside of the lips and the gums, and that is to do with wear and tear of the nerves, that's what we call a neuropathic pain condition, and that's probably one of the more common ones that we will tend to see. We also see quite a mixture of nerve damage related pains or neuropathic pains, particularly affecting the teeth, and around that sort of area we have a condition that we see not uncommonly called *Persistent Idiopathic Facial Pain*. It used to be called *Atypical Facial Pain*, and that's actually pretty common, particularly following dental treatments. Even relatively innocuous dental treatments such as root canal treatment. We know that around about 5%, at least 5% of people who have had a perfectly good root canal treatment conducted by their dentist will have persistent discomfort in and around the tooth following that procedure. More obvious types of neuropathic pain includes those related to trauma damage such as people who've had surgery for cancer or any other types of surgery in and around the face or the mouth. Procedures such as extractions of teeth, particularly lower wisdom teeth, is an example that can directly lead to nerve damage, which can cause continuous or persistent pain following the procedure.

Evans:

How would somebody know that it wasn't just pain from having the tooth out?

McMillan:

If we're dealing with pain following a dental extraction, if there's direct nerve injury associated with that, such as in the case of a lower third molar wisdom tooth, then quite often the area supplied by the nerve in question may be tingling or numb following the procedure. You would normally expect it to be quite numb immediately following the procedure if you've had local anesthetic there, but the numbness of the tingling can persist. That doesn't always happen, but that certainly would be a suggestion that there's been some - at least - bruising, not damage to the nerve itself. Following a dental extraction people expect it to be a bit sore for a few days or a couple of weeks afterwards, and generally as a rule of thumb, people that have nerve damage pain relating to dental extractions, despite the fact that area is healed up, they would have

persistent numbness and tingling potentially. In the case of people with neuropathic pain, we would tend to expect discomfort to persist in that area following the healing process. So as a rule of thumb, the figure of three months is used, in reality most of these people will be aware of persistent discomfort much sooner than that. So, these patients may have a combination of numbness or altered sensation, such as when they touch their face or their lip or their tongue it's perhaps tingly combined with this persistent discomfort or pain on top of that, it can present without numbness or tingling, and in the case of the Idiopathic facial pain that we mentioned previously. They don't always have numbness or tingling or altered sensation in that region afterwards. They may just have discomfort, which is persistent. So, it's either there all the time or it tends to be present most of the time.

Evans:

What is the treatment for that?

McMillan:

As a rule of thumb, most of the conditions in facial pain are neuropathic or related to some form of nerve damage or nerve injury, with the exception of Temporomandibular disorders, which tend to be more musculoskeletal, joint related or muscle related. The management of the neuropathic pain conditions affecting the face tend to be quite similar. The exception of course is Trigeminal Neuralgia, which has quite a unique set of medication options, but in terms of the other neuropathic conditions that we deal with, such as persistent idiopathic facial pain or trigeminal neuropathic pain, which is the one that we tend to see following surgical damage to the nerves for instance, [they are quite similar].

The main part of the initial consultation that we tend to do is take your history. The important thing is listening to the patient's story, the patient's- what we call the patient's narrative, so actually finding out from the patient what has happened. Listening to how they're describing their pain, also actually quite importantly, listening to what they think may be causing the pain as well, because very often the assumptions from clinicians may be one thing, but the patient's beliefs, and indeed their expectations, can be completely different, so that's an important point. So, part of the process may be that we will send patients for scans; most of the time we

don't need to send them for X-rays, so things like dental X-rays have usually been conducted by the referring clinician, whether that be a dentist, an oral surgeon, or a neurologist, or whoever it may be. It's important to note that scans don't actually diagnose these pain conditions, they just help to rule out other potential causes for the symptoms.

In the case of the pandemic, for several months actually, we were not able to see patients face-to-face for facial pain conditions, and we found that the accuracy of our diagnosis using videoconference or telephone was actually extremely good. The important thing to get across to patients is that even though we can see no disease process as-such, like an inflammation or an infection, or a fracture or dental problem or whatever it may be, that doesn't mean to say the pain isn't real. And [it] is certainly well recognized that in the majority of the conditions that we treat in the face, we can't find an underlying identifiable focus of a problem that will account for the pain. The history alone is the important feature here in terms of trying to get an accurate diagnosis, and really listening to the patient's story is absolutely crucial in this situation.

Evans:

Now you mentioned Temporomandibular disorder. That's not a nerve pain.

McMillan:

It's a collection of different conditions which effectively result in dysfunction or impaired function of the jaw, the jaw joints and the jaw muscles and or pain of the jaw, joint, and jaw muscles. The majority of these patients do not have an underlying arthritic process with the jaw, that can happen, and we do see that from time to time, but it's relatively rare for patients to develop arthritic-related TMDs, we call it temporomandibular disorder. Those patients will tend to present more with functional problems such as they say 'I can't open my mouth wide enough to eat my dinner or open my mouth, and it jams open and I have to wiggle it back into position or [there's] a clicking of the joints,' etc. The majority of patients that we see [who don't] have a significant underlying arthritic process or mechanical problem with the jaw, will tend to be in more pain, affecting the jaw joints and the jaw muscles.

The research would suggest about 1/3 of people develop this pain condition during their lifetime and the consensus would tend to suggest that for the majority of those patients it will not be related to traumatic events such as dental treatment or bash to the face or whatever it may be. It tends to come on fairly insidiously and be associated very strongly with stressful periods in life, and as we mentioned earlier, this is not considered to be a neuropathic pain condition. It's actually a lot more complicated than that, so it's what we would call a *Central Sensitization Pain Syndrome*. To try to explain that in reasonably simple terms, in the areas of the brain that process pain, there's a number of different areas that often overlap with other features in the brain, such as the areas that would deal with stress, anxiety, depression, these kind of negative emotional aspects of things. What we suspect happens with TMD and at least in the musculoskeletal or the muscle related pain condition, is that when people become stressed or anxious, it sensitizes the pain centers in the brain, and then signals will come down the nerves into the muscles and joints of the face and release chemicals in those areas which lead to the muscles and joints becoming tight, sore, sensitive [and] painful. For 80% of those patients the problem will not last for a huge amount of time. It may last for a few days or a few weeks, then it will usually settle down.

The 20% of people who have what we call chronic TMD or long-term issues with the pain where it's either there all the time or it comes and goes very regularly and is more of a problem. Those patients, by and large, not always but usually, will have other risk factors in the background: reasons why this sensitization process hasn't switched off. Top of the list are conditions that are painful chronic pains elsewhere in the body. One condition which is at least physiologically almost the same as TMD is Fibromyalgia, which is quite common, a widespread musculoskeletal central sensitization pain syndrome, other conditions we know are associated are things like anxiety, depression, sleeping problems which often come as a package together and last but not least, would be headache conditions, particularly tension type headache and migraines, which are again regarded as central sensitization pain syndrome. So, it's a very complicated condition, and if somebody has chronic TMD, it's not a condition [for which] we can say we'll give you a treatment which will definitely make this disappear or go away, and that's true of more or less all of the conditions that we see, but certainly in terms of the management of

these patients, then that kind of discussion is really crucial. One of the areas that we do tend to focus on is the role of regular exercise and physical relaxation activities in the management of chronic pain. We're not very prescriptive in our service about what we recommend patients do, but if you speak to the physiotherapist, they will often say 'I don't care what you do as long as you move every day, and enjoy what you're doing,' and that's really crucial.

Evans:

Doctor Roddy McMillan, Consultant in oral medicine and facial pain at the Royal National ENT and Eastman Dental Hospitals in London. Well, Rachel Stovell is a specialist physiotherapist in the facial pain team.

Rachel Stovell:

We do spend time explaining pain, explaining how pain works, explaining some of the neuroscience behind pain, just to help people to appreciate that pain is a bit more complicated than 'if I find the bit that's broken and fix it, it will all go away.' Doesn't quite work like that with chronic pain, and also then helping them to - alongside our psychologists - recognize how we might need to work with normal behaviors and body parts and gain activity. But do it in a way that is recognising this sensitivity, but recognising everything else that influences [the pain]. So alongside them we will work with perhaps movement and exercise, exercise - in this instance - of the face and then restoring their functional ability. It's all very well to exercise your face, to open and close and things, but that's not helpful if it doesn't mean that you're able to talk more, eat more and be intimate again. You know, those are the things we want to do, but you might have to start somebody off with gentle exposure to just moving that part of the body in a really simple way before you do the complex behaviors of eat, chew and talk.

Evans:

It seems to me that if I have pain in my mouth or my jaw, if I'm eating or chewing something hard, that will make it hurt more. So, I stopped doing that. I start drinking soup instead of chewing things, but that is not addressing the problem.

Stovell:

It's not, but I suppose with persistent pain conditions, it's difficult to address the problem because we haven't found a way of being able to get that nervous system to not be sensitive. But what we know with all of these conditions is that if we adapt the way that we use our body part that's painful in such a way that we're not doing what it's designed for, then we might have the problem of getting other issues. The area becomes weak, it becomes stiffer, it becomes out of condition and on top of already having pain and sensitivity, that's not helpful and it probably maintains some of that sensitivity because we're not perhaps exposing the area to normal stimuli and therefore we're going to get perhaps a bigger response to something than we would do normally, because [that body part is] now being avoided. So, yeah, one of the things that we promote and encourage in our work is this idea of exploring and working with that body part, particularly the face in facial pain to allow for us to do what's normal in the presence of pain. With the understanding that you're not harming yourself, that you're not actually creating damage or harm, that you're using muscles, joints, ligaments, bones normally and that actually they need to do that to stay healthy.

Evans:

That's Rachel Stovall, specialist physiotherapist in the facial pain team at the Royal National ENT and Eastman Dental hospitals in London. Earlier we heard from her colleague psychologist Susie Holder that skills can be learned to help the patient self-manage their pain. The therapy comes under the acronym ACT and it's suitable for people with all kinds of chronic pain, not just facial pain.

Holder:

ACT is acceptance and commitment therapy. It comes out of cognitive behavior therapy, so lots of people have heard about CBT, but it's a slightly different approach, and it incorporates a number of different important mechanisms that we use when we're working with patients, either in a group or in individual. So, those sorts of things that include things like acceptance- actually it's quite difficult word, *acceptance*... yeah. People find that a difficult thing to digest. Often a doctor will say ‘you know you need to learn to accept this condition’ and that's a hard thing. A difficult message for people to hear. I actually prefer the word *willingness*: ‘can I

willingly live with these symptoms?' One of the problems is that [when] living with any sort of long-term condition, you've got the symptoms that you're experiencing, and that might be pain. Or it might be something else for another condition, but on top of that comes a huge amount of discomfort, distress. The suffering that comes on top.

What we say to patients as psychologists is 'what I can't do is I can't cure.' I can't take away that pain and that's really hard to digest, isn't it? That's really hard to accept, that really they've come to our service because they're hoping that we're going to get rid of their condition, to cure it. But the reality is, they're going to need to learn to live with it. How could they live in a better way, in the presence of those symptoms? So, I can't get rid of those symptoms. I'm not going to promise people, and I'm not going to set up expectations that I can't actually meet. But what I can say to them is that extra level of suffering that comes on top of dealing with those symptoms, *that* is somewhere that I can have some impact on. You may not want those symptoms of course, you don't want those symptoms, but actually, could we approach it slightly differently? Could you come on a journey with me and I could help you to learn some skills to help you to manage it in a different way on a day-to-day basis?

Evans:

Some people say that you need to stop looking for that magic cure, that golden bullet if you like. And I'm speaking to somebody who said 'actually I don't have a pain condition anymore, the pain is there, but this is me.'

Holder:

One thing that can happen living with any sort of long-term condition is that life can narrow. We can spend so much time and energy, caught up in looking for those cures. What can happen is that we stop doing the things that are important to us and that over time people can find that life can get very narrow. So yeah, can we learn to live alongside pain? 'Yes, pain's there. I don't really want it to be there. I don't like it. I'd love to get rid of it, but it probably isn't going to happen. So can I find a way of living with it, but still doing the things moving towards the values, doing the things that are really important to me in the presence of pain?'

Evans:

That, I guess, is the acceptance bit. Now it's commitment, that I struggle with.

Holder:

ACT is really all about changing behavior and doing things differently and not being pushed around by our thoughts and feelings and our pain as well. The things that get in the way of us doing the things that are important to us. Part of the passage of this sort of treatment is recognizing what our goals are, but setting up steps towards goals, so small sustainable goals, that are in line with our values and so it's really all about changing our behaviors, doing the things that are important to us. You know, it might be that you want to socialize more, so your goal might be to go to a coffee shop and meet somebody, COVID permitting. So, we're asking people to commit to goals. OK, now we also know that commitment is really difficult. Yeah, if you ever try to change a behavior, we all know how difficult that can be. It can take weeks, months to actually put a behavior in place that actually becomes automatic that we don't have to think about anymore, and sometimes people commit to something and then it falls off, and what we need to think about is how can we recommit. 'It's OK that I've stopped doing it. Can I recommit again and again and again and again to doing the behaviors that are moving towards the goals that I have, and are in line with the values that I have?' That's what's important to me going forward.

Evans:

It's avoiding a blame game if you like, 'well, I failed, I failed again.'

Holder:

Absolutely, so one of the big elements is also working on those thoughts and feelings, so we all have a tendency to judge and criticise ourselves, that is a normal part of being a human being. That's what we do all the time. But if we get caught up in those feelings, then what tends to happen is that impacts on what we do, or 'I'm not going to do that because I'm not going to do that well. I'm not going to do that Pain Concern podcast, because it's just not going to work out for me.' You know, I could have called you, couldn't I? And said 'actually, I don't think I [can] do

this,' but I chose to recognise [the] anxiety that it provokes, [which] shows that despite that anxiety I'm going to do it anyway. So, one of the important things we do is recognise that criticising - that tendency to criticise and judge ourselves - and learn techniques to unhook from that.

So, we use various different ideas to help people take a step back from what they're thinking rather than getting involved with it and caught up with it. Worrying about what we've done in the past or worrying about what could be in the future, or beliefs that we have about ourselves and learn to unhook from those ideas, and that's one of the key skills that psychologists have for working with people; and we're looking at opening up life again, engaging with things, whilst recognising that there's stuff that comes up that gets in the way and we need to be aware of that. We need to observe that we may need to use that information to help us to overcome some of the obstacles that get in the way.

Evans:

Clinical psychologist Susie Holder. Well before we go on, I just need to remind you that whilst we in Pain Concern believe information and opinions on ***Airing Pain*** are accurate and sound based on the best judgments available, you should always consult your health professional on any matter relating to your health and well-being. They are the only people who know you and your circumstances and therefore the appropriate action to take on your behalf. Do check out Pain Concern's website at *painconcern.org.uk* where you can download all editions of ***Airing Pain*** and find a wealth of support and information material about living with and managing chronic pain and there you can find details of how to order edition number 77 of our ***Pain Matters Magazine***, which is guest edited by the facial pain team at the Eastman Dental Hospital in London who are featured in this edition of ***Airing Pain***. The 'my live well with pain' website recommended by Professor Zakrzewski can be found at: my.livewellwithpain.co.uk., that's: my.livewellwithpain.co.uk, and if you or someone you know has Trigeminal Neuralgia, the Trigeminal Neuralgia Association UK website is: tna.org.uk.

Well to end this edition of ***Airing Pain***, Susie Holder was talking about obstacles to living better with pain. As we record this edition of ***Airing Pain*** just before Christmas 2021, there couldn't be

a better time to talk about obstacles, as the Omicron variant of the Coronavirus is scuppering any chance of returning to what we used to call a normal way of life.

Holder:

Obviously, we did all our work face-to-face prior to COVID and we've had to change very quickly the way in which we work. It's been great that we've been able to offer people telephone consultations, but also video consultations. So, it's really changed the way that we work. What I've found is that, in a sense, what's happening is I'm actually [virtually] going into somebody's house in a sense. That when I make a phone call [or] when I make a video call, I'm in their own environment. It has some advantages [because] they're making changes or thinking about making changes in their own environment. But I'm also picking up on lots of things that, you know, somebody is not just dealing with facial pain, but they're also dealing with the difficulty, or perhaps loneliness or being on their own for many people, or feeling cut off from other people with similar sorts of conditions as well.

We run an about face pain management program for facial pain that's been really helpful as an online platform. At least you'll be able to have that interaction with other people who've got similar conditions to you, so that's been helpful as well, but yeah. If you think about it, you know you're dealing with facial pain, but you're also dealing with a very threatening, fearful situation. I do wonder whether that level of threat and fear can also have an impact on the whole system and how we manage our facial pain. But there's so much you can do on a daily basis. There's so much you can do in the present moment, we can enjoy making ourselves a nice cup of tea, but we can actually experience it. We can actually be in the present moment with it. We can use some of those mindfulness skills that we've learned together, to be in the present moment and actually enjoy everyday activities. Something as simple as putting hand cream on. We can all do that. Something very simple. ‘What's that like? What's the feeling like of that cream on my hand? What does it feel like when I spread it out? What does it smell like? What's the texture?’ All of that actually being in the present moment rather than getting caught up with the worries about the past, or perhaps fears about the future, and a lot of the skills that we talk about in psychology are transferable to lots of different types of situations as well.

Evans:

If you had just one tip to give somebody, not just with facial pain, [but] with chronic pain, to get them through however long this COVID period lasts, just to help them get through, what would you say?

Holder:

One of the things that I keep hanging onto is 'this will pass, this will pass.' We will learn to live with it. We will have learned a lot about ourselves in the process. I think that we need to show ourselves self-compassion and look after ourselves as well within this and recognise 'yeah, this is difficult. This is hard, but how can I best look after myself within this?'

END

Transcribed by Owen Elias, edited by Georgia Gaffney

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- Dr Roddy McMillan, consultant in oral medicine and facial pain at the Royal ENT and Eastman Dental Hospitals, UCLH NHS Foundation Trust.