

Patient Perspectives

The process of medicines optimisation places patients at the heart of the process. It seems only right, then, to seek the views of patients about their experiences with medicines, their medical condition in general and their contacts with health professionals. Understanding what it is really like for a patient to live with a particular clinical condition will hopefully assist healthcare professionals to become more effective with their interactions and communications with patients and improve the healthcare services provided.

This has been done by providing patients identified through healthcare contacts with a template of questions to be completed anonymously by the patient on the basis that no individual be named or identifiable from the content. What some people have to cope with and the way they do it will amaze you.

Trigeminal neuralgia

Abstract

A patient's experience of living with Trigeminal Neuralgia is outlined. The way contacts with healthcare professionals could have been better are described. The medicines that are being taken, the elements of service provision that have been found to be most helpful and the steps needed to improve the ongoing management of the condition are identified. Key messages for healthcare professionals that have arisen from the patient experience are indicated.

Keywords: medical condition, medicines, dentist, pain, carbamazepine.

About your medical condition

What is the medical condition that is most important to you and is being presented here?

Trigeminal neuralgia

Can you please explain the problems you experience with this medical condition?

Frequent and recurring spikes of severe pain in both upper and lower left jaw brought on by eating, draught, pressure, etc. There are brief periods of respite but, at its worst, it results in a dread of eating, cleaning teeth, going out or engaging in social activity. This leads to tension and makes the condition worse.

It can be both depressing and debilitating, especially when sleep is disturbed and it is difficult to find a pillow that gives support while being soft enough to cradle the affected area - memory foam is far too hard.

It affects confidence as it is impossible to hide the effect of a spike of excruciating pain and this means that social interaction is avoided.

Can you please say how the medical condition was first diagnosed?

The dentist instructed me to seek pain relief from my GP.

Can you please say when the medical condition was first diagnosed?

April 2016.

If you look back, what would you have liked to have been different in terms of contact with health professionals, etc?

With hindsight, I should have been more assertive in demanding attention for the condition. I raised my problems with my dentist at the time at virtually every visit, thinking it must be a dental issue. He merely kept asking which tooth was causing the problem, which was impossible to answer as it was the whole area. Some advice from him about pain control would have been beneficial. I had numerous X-rays which failed to show any problem and, because I do have periods of respite from it, thought it had perhaps settled down and followed his advice to

use Sensodyne toothpaste and take a pain killer. No mention of neuralgia was ever made and I was given the impression that I just had sensitive teeth. There was no indication given that it could be a medical, rather than a dental, condition.

When the paracetamol failed to provide any relief I consulted the pharmacist who suggested a different type of painkiller but at that time I had no diagnosis so I was seeking help for sensitive teeth.

With a change of dentist came a recognition that this was something that needed to be pursued as he informed me that there was treatment specifically for this condition, which I had not been told before. I followed his advice to see my GP but was just told to take paracetamol.

A particularly acute and lengthy bout forced me to seek advice from a different GP who prescribed a treatment regime and informed me of the nature of the condition, the long-term outlook and alternative forms of treatment if the prescribed course was not effective or didn't suit me. I now understand how the current treatment can be modified and feel able to consult the GP as and when needed. This GP took time to explain the condition and the alternative forms of treatment, the fact that it is one that can be managed but not cured and how we can work together to reach a point where I am happy with the outcome. This results in a very different and positive attitude towards the problem.

When I had a prescription for carbamazepine the pharmacist explained what it was for, how to take it and was (and is) happy to answer any questions.

I should have pursued this more energetically but as frequent X-rays didn't identify any problem I accepted the advice that it was sensitivity and followed the regime suggested until it reached the point where it was becoming unbearable.

The pharmacist I use couldn't have been more helpful but didn't have sufficient information to make a difference. Many people don't like to feel they are wasting the doctor's time and if told something tend to accept and put up with it. This must be difficult for health workers to identify but if someone raises the same issues time and again then it should be investigated.

The most profound change for me has been a dentist and GP who recognised this wasn't some minor issue, who shared their knowledge, involved me in the process and made it clear I wasn't wasting their time.

I do not suffer as severely with this as some people. I think this was part of the problem as the periods of respite give the illusion that the problem has gone, which of course it hasn't. Now, through talking to the GP, I understand that the treatment regime should continue during the periods of respite as it will recur.

About your medicines

Please list the medicines you taking for your medical condition.

- Carbamazepine (low dose of 100mg night and morning to be monitored and increased until pain level controlled).
- Ibuprofen.

Have you had any particularly bad experiences with regard to your medicines? If so, please explain and indicate how this could be avoided in future.

Restless nights and disorientation in the day. If the dosage needs to be increased but the side effects continue then referral to a specialist for alternative medication will be needed.

Have you had any particularly good experiences with regard to your medicines? If so, please explain.

Although the pain isn't controlled, the severe spike doesn't reach the same excruciating level as previously. This provides hope that the condition can be controlled.

About the services you received

What have you found to be most helpful to you in terms of the services you have received?

A dentist and a GP who listened, recognised the problem, provided information, provided medication and continued to monitor progress. This, in turn, enables control to be taken of the condition with confidence that professional support is on hand.

To what extent have the health professionals you have come in contact with appreciated what it was like from your position as a patient?

Initially not at all. However, there is now a willingness to listen and provide help to return to normal life.

To what extent was the information you were given about your medical condition sufficient for you?

The GP discussed the condition at length, gave printed information and is monitoring closely so any concerns can be addressed on a regular basis.

To what extent did the health professionals you came in contact with communicate effectively with you?

Initially not at all, now very effectively.

What have been the best experiences you have had with the services you have received?

Professionals who listen, appreciate the devastating effect this condition has and encourage consultation with them.

About other medical conditions

Do you have other medical conditions and how do they make life problematic for you?

Torn ligament right knee: limitations to mobility.

Carpal tunnel syndrome: pins and needles sensation in hands and forearms, burning sensation in fingers.

About going forward

What would you like to happen at this stage that would make living with your condition easier for you?

Getting the pain management right and having a period of respite.

If you could give a brief message to healthcare professionals, what would it be?

Adopt an holistic approach, listen to the patient and recognise that just because a person isn't making a fuss their condition is nonetheless distressing.

Please add any other comments or observations that would be helpful to health professionals who are responsible for providing services for you.

There needs to be greater communication and exchange of information between healthcare professionals.

What are the three most important things that health professionals should learn from your experiences?

- 1) Missed and delayed diagnosis leads to a reluctance to seek further help.
- 2) An opportunity should be afforded to patients to be proactive in their treatment - but they are not professionals and need advice and guidance.
- 3) Listen to patients.

Declaration of interests

In the spirit of being open and transparent, would you please disclose any payments, interests or activities that could be perceived as influencing what you have written.

A fee was offered by Pharmacy Management to complete this questionnaire within a defined timescale. I have no other interests to declare.

KEY LEARNING POINTS FOR HEALTH PROFESSIONALS IDENTIFIED AT THE EDITING/PEER REVIEW STAGES

- The importance of listening to the salient points made by the patient and recording in the notes.
- Taking a 'whole person' approach to understanding and solving the problem.
- Realising that a health situation can change quite rapidly and the changes therefore need to be identified and considered.