

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.

Cervical Osteoarthritis (Spondylosis)

Abstract

Title

Patient Perspective: Cervical Osteoarthritis (Spondylosis)

Summary

A patient's experience of living with Cervical Osteoarthritis (Spondylosis) 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, locked up.

About your medical condition

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

Cervical Osteoarthritis (Spondylosis) is my main medical condition.

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

- Muscle spasms in my legs.
- Problems moving my arms and legs.
- 'Locking up' so that it is difficult to move at all.
- The feeling throughout my body from the bottom lip down has progressively gone.
- I have been having operations on my right leg to shorten my tendons - four operations to date. I was told recently that they cannot do anything more for it. The same

problem is appearing on the left leg but the surgeons are a little frightened to operate again.

- I am now losing height, having lost over 2 inches in the last 2 years.

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

It was diagnosed in 1996 after I broke both my wrists following a fall when I put both my arms out to save myself only to find that they were under me when I landed and had both broken. My local hospital was unable to find a way to straighten them so I was in plaster from under my arms to my fingers for three months.

When I eventually decided to go privately to an orthopaedic surgeon I had both wrists plated and pinned straight. It was then that the surgeon suggested that I go and have a MRI scan and see a neurologist. He told me I had some osteoarthritis in my spine. The only suggestion to help this was to change my

pillows so that I could rest my neck at a right angle to the bed.

In falls before and since, I have also broken my knee cap, an ankle and a finger.

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

In 2006, while travelling for my employer, I was in a traffic collision. This led to my complaining about my neck, arms and legs. When I went to see a specialist neurologist in 2008, I was told that I had the spine of an 80 year old, although I was only 40 years old. I would complain of pain down my spine, which led to my 'locking up' so that it was difficult to move at all and problems moving my arms and legs.

During the years that have past I have been diagnosed with muscle spasms in my legs causing me to have trial medications to help my problems. I have had Botox in the calf muscles of one leg and an anaesthetic injection in the other leg, which shows no improvement.

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

Looking back over the years I have had the spondylosis I wish I could have been diagnosed quicker and perhaps this would not have led to my having been taken to hospitals where they thought I had been suffering TIAs down my left side and cramping sensations in my arms and legs causing such pain.

About your medicines

Please list the medicines you taking for your medical condition.

Before the car accident I simply took 1 x 2.5mg Ramipril tablet for my blood pressure.

Since the car accident in 2006 I now take up to 20 tablets a day (3 antibiotics and 6 steroid tablets when required for my asthma as well as the 11 tablets for things like blood thinners, muscle relaxants, blood pressure, ramipril 1 x 5mg, reflux medication, anti-depressant, quinine tablet and sleeping tablets).

These, together with fentanyl patches 25mg and 12mg over three days which, on occasions, has been increased to 50mg over 3 days and two asthma inhalers.

I also need to take very high doses of antihistamine to stop irritation caused by the patches.

I also use Oromorph on a regular basis to top up the pain relief.

Have you had any particularly bad experiences with regard to your medication? If so, explain and indicate how this could have been avoided in the future.

My GP has prescribed anti-inflammatory tablets for me but they had the effect of making my stomach bleed. When an injection of anti-inflammatory was tried I had an anaphylactic shock, which required me to be ambulanced to the local Accident and Emergency department where I drained the local hospital of adrenaline. I believe that if I had been allergic to the tablets then maybe the injection should not have been tried.

Have you any good experiences of your medications? If so, please explain.

Trying different tablets to be used on a regular basis throughout the day, and sometimes being on up to 20 tablets per day, led to me constantly have to get them from the pharmacy. Changing to the fentanyl patches cut down my intake of tablets and meant that I could just attach them and forget about them for 3 days at a time, which improved my life.

About the services you received

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

I am pleased that my GP is not beyond trying different medications and has tried his best to understand my condition, reading up about it so that he could help me to understand what can and cannot be done for it. I have found losing my job stressful and have been given an antidepressant and, because of the possibility of TIAs, I am on a blood thinner.

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

I am sorry to say that the best diagnosis I have received has been when I have paid to go to local and a national specialist hospitals. My neurologist at the private specialist hospital explained to me how surgery advances had made it possible to replace almost all of the joints in the human body except the spine and as such, apart from pain relief, nothing further could be done for my osteoarthritis.

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

I have a surgery of mostly very helpful GPs who have found very helpful consultants who have tried different treatments on me to improve the 'side effects' of my osteoarthritis, such as my calf muscles being in constant spasm. They have tried anaesthetic injections and Botox injections to release the spasms in the calf muscles.

I have been to a number of physiotherapists but this has not resulted in very much change in symptoms. My GP also sent me to a physiotherapist-led light exercise class twice a week for six weeks but I found that I 'locked up'. I did carry on to try the local gym but had to make sure that a member of my family came with me and the staff knew what to do in my 'locked up' state to release me.

About other medical conditions

Do you have any other medical conditions that make life problematic for you? If so, please list them and explain the main problems you experience with each one:

Dystonia: severe pain in joints and 'locking up'.
Asthma: I have spent time in hospital due to this.

Possible TIAs: face, arm and leg on left side drooping and speaking difficult. Can last between 2 minutes and 6 weeks.

Depression: since losing my employment due to the car accident in 2006.

About going forward

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

I wish I could have found a nurse who deals with osteoarthritis in my area. There seems to be a lot of help for those suffering with rheumatoid arthritis but no one specialising in osteoarthritis. It seems that as osteoarthritis is a condition of the elderly but no one wants to know about it from a patient perspective. Those with the condition are of an age that they do not explain about how they feel.

I use a stick although I have at times used double crutches, a zimmer frame and an electronic wheelchair. I do try to do without help I have but I have 'flare ups'. I did not know about the possibility of 'flare ups' and have liked these to have been explained to me by my doctors.

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

If I had asked medical professionals about my condition when I was first diagnosed I would have known what to expect and what could happen as the condition progresses but then the depression I suffer might have been far worse. So, I guess it is a little like life - if you knew what was in the future you would not want to live it but perhaps you would try to avoid doing things that might make it worse, such as not eating properly when a child.

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

I have been on my way to visit my GP but 'locked up' on my way into the surgery. Due to time constraints for GPs, who only get 10 minutes at most to see people, I had to be placed in a room to wait for my son to come and 'release' my neck. This involves putting one hand under my chin and the other at the back of my head and gently pulling as in traction until movement comes back. This may not seem scientifically correct but seems to work.

Unfortunately, since my accident my feeling throughout my body from the bottom lip down has progressively gone. Meaning that I have been able to have a bottom tooth filled without anaesthetic, and neurologists have tried with pins to find the sensations.

I would have liked my health professionals to know more about my condition and been able to help me more as I deteriorated. Knowing that I may 'lock up' and how to 'release' me would be good as would knowing why my feeling sensation has gone and if it will ever return.

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

- Because a patient does not keep returning to the surgery does not mean they feel better. It may be due to depression caused by feeling worse.
- Because osteoarthritis is a part of growing older it does not mean that the person with it just requires pain relief and nothing else.
- A named GP should be assigned to those people with a long term health condition. It should be this GP who sees them regularly.

Declaration of interests

You will have been offered a fee for your contribution to be submitted within a specific timescale. In the spirit of being open and transparent, would you please disclose any other payments, interests or activities that could be perceived as influencing what you have written or state 'none'.

None. I shall be giving the fee split between four different local charities.

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

- Early diagnosis is very important.
- Patients wish to learn more about their conditions, understand their symptoms and what to expect as their condition progresses. They look to healthcare professionals as a source of information so healthcare professionals need to be up-to-date to offer advice.
- Medicines can have a great impact (positive or negative) so getting the type, dose and use correct can affect someone's quality of life for the better against a backdrop of coping with a condition they can do little to improve.