

## A Patient Perspective: Renal Pain

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.

### About your medical condition

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

Pain caused by my renal sludge and sometimes renal colic from gravel and stones. I have raised calcium and raised oxalate in my urine.

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

With my renal pain, I experience different types of pain. I can have full flank, excruciating pain and need paramedics with morphine, gas and air. At other times I just need some paracetamol and to manage the mild discomfort. I also carry dihydrocodeine and Oramorph but use the latter very rarely. I also carry Buscopan and that can be helpful when my pain becomes spasmodic. The biggest problem is not knowing when the pain will strike; it can and does happen at any time and has no sense of timing. I have had bad pain at almost any time of the day, in the middle of funerals and on flights on my way on holiday. Living with that uncertainty is very hard. Living with renal pain most of the time is also emotionally and physically demanding - it affects every part of my life.

From time to time I get scared - usually if the pain is extra intense or different in some way. It is at these times that I present at A&E. I go there for reassurance and to have my pain managed. I have had very variable care in A&E, mostly relating to the time it takes to get my pain under control. The issue is that, after more than 20 years, I manage to hold it together well most of the time so the staff, I believe, don't think I am a priority as opposed to someone who is shouting and crying. So there are times when, in A&E, I have to 'act up' to get the care I need. At other times, by the time I get to A&E I am too exhausted and can just about hold myself together.

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

Over 20 years ago, I went to my GP with white urine. I was sent to the GU Clinic and they treated me for NSU. I was then sent

to a pathologist and he then sent me on to a renal consultant. It all took a long time and it is only in recent years that the doctors have realised that I do drink enough fluid and this is a chronic condition.

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

I think I went to my GP for the first time in 1990 but the diagnosis took about 20 years to evolve into something which my GP and consultant understood.

#### If you look back, what would you say would be the main things you would have liked to have been different in terms of contact with health professionals, etc?

There are many examples.

The feeling of not being believed was awful for many, many years. From the doctor who accused me of being a drug addict to the consultant who made me feel like a failed experiment.

Having very good treatment in A&E and then, the next time, having to wait ages to get pain relief while all the time being in awful pain.

From the GP who scared me by shouting at me because I went to an emergency clinic as I needed more pain medicines to the wonderful GP who always genuinely asked me how I was and then went on to tell me how he admired me for coping so well.

The experience in A&E where they told me to take my own dihydrocodeine and tramadol, then gave me a script for Oramorph but, in the next breath, told me that the pharmacy was closed and I would have to return in the morning. Then they said that my local DGH would have Oramorph when the pharmacy opened at 9am but when I went it was closed all day (Sunday). I went to the Out-of-Hours GP service at the hospital and they exchanged my prescription for me.

## About your medicines

### Please list the medicines you taking for your medical condition:

- Paracetamol
- Buscopan
- Buccastem
- Dihydrocodine
- Tramadol
- Oramorph

### Have the experiences you have had with your medicines been positive?

Please tick: No ✓ Yes

#### If you ticked 'No', please say how things could have been better:

As listed above, the process of getting Oramorph when I was in great distress with pain could have been better. The A&E must have had a duty pharmacist to call on but instead they wanted me to 'get through the night' on what I had.

No one should be expected to wait for pain medication, it is inhuman. The Out-of-Hours GP was wonderful and phoned the duty pharmacy to check they had Oramorph, they did and the pharmacist was very kind and talked me through how to take it. This was the first time in over 20 years that I had been given Oramorph to take home.

### What have you found to be most helpful to you in terms of helping you take your medicines as intended?

Just the care and concern that the GP and the Pharmacist showed. The care in talking me thought how to take my medicine.

## About the services you received

### Have you had any negative experiences with the services you have received?

Please tick: No Yes ✓

#### If you ticked 'Yes', please say how things could have been better:

Another example was when I was in very bad pain with my spine in Manchester, the Out-of-Hours doctor called the Pharmacy to ask them if they would deliver tramadol to me. I could hardly move off the bed.

The pharmacy agreed and then later phoned to say they got the hotels mixed up and that they had thought that I was in a hotel very close to them. They refused to come across the city centre to my hotel and told me that I would have to pay £20 for taxis. They were aggressive and uncaring, it was all about the money; I paid as I had no choice.

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

One time in hospital, a hospital pharmacist spent about 40 minutes with me going through my medication. It turned into a medicine use review but I learnt a great deal about my medicines. I was in for heart problems and it took my mind of what else was happening to me. The pharmacist was exceptionally kind and patient with me.

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

There are great doctors, nurses and pharmacists out there but, regularly, I have to be quite assertive. I do this in a very nice way to get what I need and to explain what I think is happening, the reassurance I am looking for and how they can do that.

I think the other big issue is that, other than my GP, all my consultants are just dealing with their area. I have the following consultants: renal, cardiology, respiratory, endocrinology and ophthalmic. Then there are the medicines and how they interact!

### Was the information you were given about your medical condition sufficient for you?

In the beginning 'no'. I spent years feeling not believed. How can someone have stones, gravel and sludge most of the time? It doesn't make sense, so he must be exaggerating. Even now, I sometimes get the feeling that, outside of my consultants, people don't quite believe I can have so much wrong at 44 yrs old.

### Did the health professionals you came in contact with communicate effectively with you?

My experience over the years has been very variable.

There was the pain consultant who did some procedure with needles a foot long and a CT scanner (unpleasant even with sedation) and who, after, asked me 'Are you still in pain'. I said, 'yes' and he then said, 'well it didn't work then' and promptly walked away. I was in tears!

There was also the Occupational Therapist, who said 'no one can tell you that you are not in pain' - she was so kind and her words and genuine concern and care meant a great deal to me.

Then there was the lovely GP locum who showed a human side and was the first doctor ever to say 'I just don't know.' He showed me humility and a human side. He then said 'but let's find out together'. I really loved that GP and hated it when I moved home and had to find a new GP. I have a great GP now by the way!

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

My current renal doctor is totally wonderful and very, very kind. He spends the time with me that I need. He explains things to me, even if he did the same last time. He has empathy and I hate the thought that he is in his 50s and will retire one day. He is 'A1'.

My GP is my rock, he shares all the attributes that my renal doctor has and he knows me well. The last time I went to see him, I went in with my little list (yes, I am organised). We worked through my list but there was something that came up that took some more time. At the end I apologised for taking so long and that I should have booked a double appointment. He smiled and said it was no problem, he saw I was on the list and gave me a double anyway! I roared with laughter and he said 'With all you are going through at the moment, I knew we would need a little longer'. I can't quite put into words what that meant to me but it meant a lot!

## About other medical conditions

**Do you have just one medical condition that make life problematic for you?**

**Please tick:** No ✓ Yes

**If you ticked 'No', please list the other medical conditions and explain the main problems you experience with each one:**

<b>Medical condition</b>	<b>Main problem experienced</b>
Osteoporosis	Bone Fractures (3 in one fall in 2014)
Paroxysmal atrial fibrillation	Feeling faint, unwell, palpitations
Costochondritis	Very sore ribs
Early onset osteoarthritis	Painful joints all over my body
Asthma	Shortness of breath
Sleep apnoea	Sleep with CPAP
Gout	Part of my stone problem
GERD from taking Voltarol	Acid reflux
Chronic migraines	Feeling drunk, pain and jaw pain
Hearing Loss	Having to wear hearing aids
Constant tinnitus	Psychologically hard to adjust too

## About going forward

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

Easier access back to see my consultants when I need to see them. My GP can help by writing but it would be so much better if I could just phone or email their secretaries to get questions answered or to get back to see them in clinic.

My local hospital has been having huge problems in this area and it can take 6 months to get to see someone even when you are in the system.

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

Show you are human, show you care, be humble, be reassuring, ask what the patient needs from you, be kind.

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

Patients on the whole do know that you are busy, that you see many people in a day and that can be stressful. If you can do one thing it is, as I said before, be human. Show you care - the vast majority of people came into medicine because they wanted to help people. If you came in to just make money, then it is time to re-examine your motives.

## 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.**

I don't think I have any but I am a judge for the Grunenthal Pain Awards and did receive a payment to cover my lost earnings during judging. I was also offered a fee by Pharmacy Management to complete this questionnaire within a defined timescale.