

Case 200501938: A GP Practice in the Lothian NHS Board area

Introduction

1. On 14 October 2005 the Ombudsman received a complaint from a man referred to in this report as Mr C about the care and treatment provided by his general practitioner (GP 1).

2. Mr C suffers from loin pain haematuria syndrome. Mr C said that this causes him constant severe pain. In the past he had been given opiates in the form of morphine liquid and pethidine and occasionally morphine injections to control the pain. He became dependant on these drugs and they were stopped and replaced by Methadone. Mr C stopped taking Methadone in about October 2004. Mr C said that GP 1 refused to provide him with any pain killers because of the risk of him becoming dependant again. The complaint from Mr C which I investigated was that GP 1 had not provided Mr C with adequate pain relief for his condition.

3. Following the investigation of this complaint I did not uphold the complaint (see paragraph 11).

Investigation and findings of fact

Background to the complaint

4. In August 2005 Mr C complained to NHS Lothian, Primary and Community Division about the care and treatment provided for him by GP 1.

5. On 1 September 2005 GP 1 replied as follows:

‘... I have been [Mr C]’s GP for over 2 years now. I have seen him regularly over that time and liaised with consultants, psychologists, CDPS [Community Drug Problem Service] and CPN’s [community psychiatric nurses] regarding his treatment.

... loin pain haematuria syndrome is a rare but documented condition. It involves loin pain and blood in the urine. It never leads to kidney damage, there is no known cause, patients are usually young adults, and patients often end up addicted to opiate medication. The condition seems to disappear in later life. Patients with the condition often have

concomitant mental health issues as in [Mr C]'s case.

[Mr C] was on Methadone at a dose of 180mg daily via the CDPS for a long time, even when on this dose [Mr C] would ask for additional pain relief (although this was usually declined he was occasionally given additional opiates by doctors that did not know him). This was a very large dose that could have been potentially fatal if misused. [Mr C] attends all his appointments at the surgery and seldom displays outward signs of pain, although on asking he always describes his pain as severe.

Soon after [Mr C] stopped his Methadone he disclosed a history of severe childhood abuse including torture and sexual abuse. I have been trying to persuade [Mr C] to re-engage with his old psychologist ... who saw [Mr C] regularly for several years. [Mr C] has yet to take up this offer despite being provided with 2 appointments. I have also provided him with counselling numbers for places that deal with survivors of childhood abuse.

I think that [Mr C]'s pain syndrome is related to the abuse he experienced and that he will need to deal with this before being able to move on. I'm sure [Mr C] however would disagree with this. [Mr C] is considering having his other kidney removed in order to solve his problems, this would leave him on dialysis for the rest of his life and something I think the surgeons would be VERY reluctant to do.

... [Mr C] has done exceptionally well to come off his opiate analgesia and I see this as a hugely positive step towards his recovery. I am therefore reluctant to restart opiates and feel that this would not be in [Mr C]'s best interest. He is intolerant to anti-inflammatory medication and is not responsive to anything except opiates. ...'

Mr C's complaint to the Ombudsman

6. Following receipt of Mr C's complaint by this office, I examined the background correspondence provided by Mr C. I also obtained a copy of his GP medical records and obtained advice from one of the Ombudsman's clinical advisers, an experienced GP. Mr C and the Practice have been given the opportunity to comment on this report.

7. Mr C wrote to this office that loin pain haematuria causes him severe chronic pain on a daily basis. He had a kidney transplant about five years ago but that did not help so he had the left kidney removed. Since then he has had no pain on the left side. However, the syndrome affects the remaining kidney. He passes a lot of blood in his urine. He used to take a lot of analgesia in the form of oral morphine liquid, pethidine and occasionally morphine injections. It was decided to take him off these medications. He was prescribed Methadone 180mg daily instead. Mr C said that the methadone did not help him as much as the oral morphine and so he stopped taking it.

8. Mr C said that the pain is so severe that it keeps him awake and affects his appetite. However, GP 1 would not give him any pain killers. Morphine was the only analgesic that worked well for him and he had shown that he could come off it if necessary. Mr C felt that the only reason GP 1 had refused to prescribe opiates was the fear that he would become addicted again. Mr C said that GP 1 did not understand how bad his pain was. He had had the condition for about 14 years and it was getting worse. He wanted his remaining kidney removed because without opiate pain killers he did not feel able to cope. He had been told that removing his remaining kidney would not guarantee the pain would go away and he would be on dialysis for the rest of his life. Nevertheless, he said that he could not go on as he was and wanted the kidney removed. He had also been to pain management clinics and had tried a TENS machine but nothing helped.

9. Mr C described abuse that he suffered as a child which had caused severe mental health problems from which he still suffers. He said that GP 1 felt that his childhood trauma and mental health problems were causing the pain from his kidney illness. Mr C disagreed. His understanding was that the cause of loin pain haematuria syndrome was unknown and although it can resolve for no apparent reason, people have had this condition for 40 years. Mr C said that he gets on with GP 1 but did not feel that GP 1 had done all he could to help. Previous doctors had given him whatever medication he needed. He questioned why some doctors would help him but others would not.

Adviser's comments

10. The adviser explained that loin pain haematuria syndrome causes pain and that the level of pain is variable and can be severe. In Mr C's case there appeared to be little objective evidence of severe pain exhibited by Mr C. Control of the pain expressed by Mr C was attempted by prescription of opiates

and paracetamol up to 2004. There is evidence that Mr C was addicted to the opiate medication. The adviser considered that the Practice and, in particular, GP 1 took appropriate care of Mr C. He felt that they had also done their best to ensure that when Mr C came off methadone he was not placed in a position to cause further addiction which, the adviser agreed, was appropriate action. He said that the cause of loin pain haematuria syndrome is at present poorly understood. Whether Mr C's suffering is due to the trauma he suffered as a child would, therefore, be uncertain, but not impossible. Treatment is in essence that of relieving the pain the patient experiences, but it is known that long term use of powerful pain killers leads to tolerance and thus they do not get rid of the pain. It is also known that the taking of narcotics, such as morphine, in chronic pain tends to have the paradoxical effect of maintaining the pain at an abnormally high level, as well as keeping the patient mentally dull and with increased irritability. The adviser considered that GP 1 had taken all reasonable action to provide Mr C with adequate pain relief.

Conclusion

11. While I sympathise with Mr C's situation, GP 1's clinical opinion was that further prescription of opiate medication would not be in the best interests of Mr C. The adviser agrees with that opinion and considers that GP 1 has taken all reasonable action to provide Mr C with adequate pain relief. I, therefore, do not uphold the complaint.

30 May 2006

Explanation of abbreviations used

CDPS	Community Drug Problem Unit
CPN	Community Psychiatric Nurse
GP 1	Mr C's general practitioner
Mr C	The complainant
The Practice	GP Practice in the NHS Lothian Health Board Region
TENS machine	Transcutaneous electrical nerve stimulation machine which delivers small electrical pulses to the body via electrodes placed on the skin and is thought to help ease pain