

**Trust Board Meeting in Public: Wednesday 13 January 2016**  
**TB2016.04**

<b>Title</b>	<b>Ms P - Patient Story</b>
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<b>Status</b>	For information
<b>History</b>	Patient stories are regularly presented to Trust Board and Quality Committee

<b>Board Lead(s)</b>	<b>Ms Catherine Stoddart, Chief Nurse</b>			
<b>Key purpose</b>	<b>Strategy</b>	Assurance	Policy	Performance

**Executive Summary**

1. This paper gives an overview of the story of Ms P, who was treated at OUH from 2008-2014 for chronic, uncontrolled pelvic pain following an unplanned hysterectomy at another trust in 2004.
2. Ms P experience highlights the positive and life changing impact of excellent care and compassion on patients.
3. It shows the importance of an Opioid Management Clinic which can treat and support patients holistically as they reduce long term opioid use.
4. This story was co-produced with involvement from the patient the Anaesthesia and Pain Management consultant and the Patient Experience Team.
5. **Recommendation**  
The Trust Board is asked to note the contents of the report.

## Patient Story

### 1. Purpose

- 1.1. The purpose of this paper is to tell the story of Ms P who was treated at OUH from 2008-2014 in the Gynaecology Department and the Opioid Management Clinic for chronic, uncontrolled pelvic pain following an unplanned hysterectomy at another trust in 2004.

### 2. Background

- 2.1. Ms P was invited to participate in a patient story by the Opioid Management Clinic after giving positive feedback to a clinic's patient survey. The story was discussed during a telephone call with a member of the Patient Experience Team. Subsequently the Anaesthetics and Pain Management Consultant provided staff perspective whilst discussing the patient story with the Public Engagement Manager.
- 2.2. This story portrays the importance of compassionate, person-centred care. It highlights that an understanding of the psychological aspects of an individual's condition is essential to successful recovery. It also highlights the value of clinicians and patients working collaboratively for recovery.
- 2.3. Throughout the six years that she was treated at OUH, Ms P only had one negative experience. That experience, though isolated, highlights the importance of clinicians understanding the impact of pain on patients and responding appropriately and holistically. This experience is outlined below.
- 2.4. The presentation of patient stories gives an opportunity to represent real life positive examples of the Trust's values in action and gives Trust staff an opportunity to reflect on clinical work with patients; and the critical role we all play in supporting healthcare to run smoothly.

### 3. Ms P's Story

#### Background and treatment at the OUH Gynaecology Clinic

- 3.1. Ms P had an unplanned hysterectomy in 2004 at another trust resulting in uncontrolled, chronic pain. The hysterectomy was followed by further surgery which aimed to reduce or eliminate the pain. However, Ms P continued to be in constant pain. Over time, this affected her life in a number of ways including her work where she had taken lengthy sick leave, had been downgraded and had reduced her hours to part time.
- 3.2. In 2008 she was referred to OUH and seen by the Gynaecology consultant. Ms P said from that first appointment her *"life changed"*.

*"(Consultant name) is the best person I have ever met in my entire life. The first appointment was over an hour and I cried for most of it. (Consultant name) immediately started putting into place actions and she gave me hope that my life could and would get better"* (Ms P)

- 3.3. At every point she was treated, she felt that action was taken swiftly. For example, on one occasion her mother phoned to say that the family could not cope because Ms P was in so much pain. The consultant immediately asked them to come into the hospital that afternoon.

*“She said “can you get in for 2pm and we’ll find you a bed?”. I got there and they saw me and reassured me but couldn’t find a bed. However, she said we will get you a bed by Friday 8am. So I returned on Friday and a bed was available. I didn’t mind waiting because I knew everyone was trying to do the very best for me” (Ms P)*

Another time she saw a consultant in the Urology clinic who had told her that she needed more surgery but there wasn’t a surgeon available in OUH. However, the consultant found a surgeon in Milton Keynes who could do the surgery.

*“The whole department worked together – they always actioned what they said they would do and always followed up”*

- 3.4. She was overwhelmed by the compassion she experienced.

*“I was made to feel by everyone that I was important, that I was a whole person, that my parents were important people. (The consultant) said that I needed to take as much pain relief as I needed. She never made me feel that my pain wasn’t real” (Ms P)*

Another example of this was the way she was treated by the anaesthetist. When she had her initial surgery for the hysterectomy she had been under the care of a *“very arrogant anaesthetist”*. Afterwards she was so traumatised by this experience that she refused surgery. She explained this to the consultant who relayed the message to the anaesthetist who made every effort to reassure her.

*“Before surgery, the anaesthetist came to see me, walked me to theatre, reassuring me all the time.” (Ms P)*

Another example of care that had a huge positive impact on her life was following her operation she had problems passing urine, had been catheterised<sup>1</sup> and had been given large catheter tubing to use. While she was being treated at OUH, a nurse noticed these and said *“you don’t need those”* and replaced the large tubing with much smaller, discreet tubing which could fit into a little handbag. The tubing was also very quiet so if you were in a public toilet, you could not be overheard opening them which Ms P had found embarrassing. This transformed her life and made her much more confident to go out.

- 3.5. At the time of her original treatment she was given opioids<sup>2</sup> to manage the pain<sup>3</sup>. By 2014, she had been on opioids for 10 years and it had impacted every

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<sup>1</sup> Urinary catheters are hollow, partially flexible tubes that collect urine from the bladder.

<sup>2</sup> Opioids are medications that relieve pain. They reduce the intensity of pain signals reaching the brain and affect those brain areas controlling emotion, which diminishes the effects of a painful stimulus. They are most effective for acute

area of her life. She suffered from daytime sedation, poor concentration, impaired memory and night-time insomnia. Her quality of life was very poor. She had tried decreasing her opioids herself but had suffered intolerable withdrawal symptoms so felt unable to move forward. At this point she was referred to the Opioid Management Clinic with a view to supporting her to manage her pain without opioids.

- 3.6. Ms P outlined just one negative experience when she was undergoing surgery and had spoken to her consultant about her concerns that the pain would be managed. The consultant said to Ms P that she should ask for an epidural and if the surgeon/anaesthetist had any questions that they should call her (the consultant). However, when it came to the surgery, she was refused an epidural and the doctors would not phone the consultant, despite Ms P recommending that they did. This resulted in Ms P having a very distressing time and her pain post-surgery being uncontrollable.
- 3.7. Although a negative experience, Ms P noted how the doctors involved quickly realised their mistake and were very apologetic afterwards. This episode highlights the importance of everyone understanding the nature of chronic, uncontrolled pain and tailoring their patient's treatment to their needs.

### Treatment at the Opioid Management Clinic

- 3.8. In 2014 Ms P felt that her pain was improving. She was also aware that she was on high doses of opioids which were affecting her quality of life and making it impossible for her to work full time. Through a combination of fentanyl patches and oxycodone<sup>4</sup>, her total morphine equivalent dose was 540mg per day. This is nearly 5 times the limit recommended by the British Pain Society<sup>5</sup> and costed £4700 per annum<sup>6</sup>.
- 3.9. The Opioid Management Clinic is held within the Pain Relief Unit<sup>7</sup> at the Churchill hospital (<http://www.ouh.nhs.uk/services/departments/pain-management/default.aspx>). The Clinic started in June 2014 after the emergence of new evidence in 2009 regarding the dangers of opioids in treating long term chronic pain and the deleterious effects on mood, immunity and hormones. This is in addition to the already known opioid effects of sedation, constipation and the risk of respiratory depression. A survey of GPs in

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pain after surgery or trauma. Medications that fall within this class include morphine (eg oramorph, MST), fentanyl, oxycodone (eg OxyContin, OxyNorm), codeine, and related drugs.

<sup>3</sup> It was common practice at this time to give opioids up to levels that provided sufficient pain relief. In 2009 evidence started emerging of the dangers of long term opioid use for people with chronic pain.

<sup>4</sup> She was on fentanyl patches and oxycodone (similar to morphine but fewer side effects and more expensive) liquid,

<sup>5</sup> [The British Pain Society](http://www.britishpainsociety.org) is the largest multidisciplinary professional organisation in the field of pain within the UK and membership comprises medical pain specialists, nurses, physiotherapists, scientists, psychologists, psychiatrists, general practitioners, occupational therapists and other healthcare professionals actively engaged in the diagnosis and treatment of pain and in pain research for the benefit of patients.

<sup>6</sup> The clinic treats around 20 patients a year who are taking varying amounts of opioids costing in total around 100K per annum.

<sup>7</sup> Currently called the Pain Relief Unit – the name is being changed to the Pain Management Centre to reflect the emphasis on us supporting patients in managing and living with their pain, rather than the old name of the Pain Relief Unit, which implies that we can provide relief from pain, which is often an unrealistic goal.

Oxfordshire in 2014 found that they would value a clinic to support patients with problem opioid use.

- 3.10. Prior to this new evidence, patients who experienced chronic uncontrolled pain were given large doses of opioids as it was thought that the presence of pain protected individuals from becoming addicted to the drugs. It is now clear that this is not the case in chronic pain. It was found that when patients tried to reduce their opioid doses they suffered classic withdrawal symptoms<sup>8</sup> which were difficult to manage, and it was also found that, contrary to expectation, they showed increasing sensitivity to pain.<sup>9</sup>
- 3.11. The Opioid Clinic is currently not a commissioned service. It is run by the Anaesthetics and Pain Management Consultant and the Lead nurse for Pain as an extra clinic to meet a previously unmet need.
- 3.12. A key part of the support, provided to Ms P, was counselling to help with anxiety that might have been masked by opioid use. Currently there are two part time psychologists available to the clinic which may mean there is a long wait for an appointment. This can be extremely difficult for patients who need this support while they are coming off the drugs. The clinic requires dedicated psychology input to support patients with anxiety that is commonly unmasked during the opioid reduction.
- 3.13. The Anaesthetics and Pain Management Consultant treated Ms P from June 2014 to May 2015 by which time she had completely stopped taking any opioids. This was achieved through the treatment being patient led and the patient taking full responsibility for withdrawal with the clinic providing emotional, practical and psychological support.
- 3.14. The treatment that Ms P received was a combination of managed withdrawal, tools for managing the symptoms and counselling. Ms P said of the consultant and the team:
- “(Consultant name) was brilliant. The team put me in charge of my own destiny but knowing they were there to support me. They gave me the confidence and tools to get control back” (Ms P)*
- The consultant ensured that Ms P wasn't rushed and encouraged her to take the withdrawal at a gradual pace that was manageable. She praised Ms P for her “intelligence, perseverance and determination”.
- 3.15. The first withdrawal took place and Ms P was encouraged to observe the affects which were likely to start around 2 days after the patch strength was reduced. The team gave Ms P ideas for distraction e.g. watching a television programme but not for too long as concentration span is quite short during withdrawal. After the first reduction and with the support and advice of the clinic, Ms P decided to

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<sup>8</sup> Opioid withdrawal symptoms are: sweating, diarrhoea, runny nose, teary eyes, hot and cold sweats, goose bumps, muscle aches and pains, abdominal cramping, nausea, vomiting, diarrhoea.

take annual leave for the few days after each reduction. Ms P finally came off the opioids when she was going to Madeira.

She met up with friends who she sees every year on holiday and she said *“nobody could believe I had done it and they commented how well I looked”*.

3.16. Ms P is now back at work full time with a far higher quality of life than when on opioids and now feels able to control her pain without drugs:

*“Many, many thanks. Without this support I would still be on opioids and living a very different life”* (Ms P)

#### 4. Conclusion

- 4.1. Ms P’s story celebrates excellent care and the life changing impact it can have. It also shows the importance of whole person care and the equal importance of psychological and physical treatment.
- 4.2. There is very little provision across the country for patients with opioid painkiller dependence, so this is already an innovative service. By holding the clinic within the Pain Management Centre, rather than in addiction services, this takes away the stigma for this very different group of patients stuck on long term opioids.
- 4.3. Many pain patients on high dose opioids are frequent attenders at GP surgeries and emergency departments, and their management is often difficult for a GP to undertake alone without specialist help.
- 4.4. Consideration on how to seek ongoing funding for the Opioid Management Clinic with dedicated doctors and psychological support needs to be explored. The involvement of an addiction psychiatrist would also enable us to support complex pain patients with psychiatric comorbidities who have developed more classic addiction to their opioid pain medication.
- 4.5. The benefit of supporting these patients includes savings on drug costs, GP consultations and ED attendances, as well as wider cost implications on the patient’s family and work life.

#### 6. Recommendation

- 5.1 The Trust Board is asked to note the contents of the story.

**Catherine Stoddart**  
**Chief Nurse**

**January 2015**

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