CONTROLLED DRUGS NEWSLETTER

SHARING GOOD PRACTICE IN THE SOUTH WEST

NHS South Region South West

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SPECIAL EDITION – FAYE'S STORY

What can happen when things go wrong with prescribing for chronic pain – lessons that must be learned by all healthcare professionals

As told by her parents, Linda and Steve



Faye (right), when she was well

Our daughter Faye injured her back lifting an empty fish tank into a car boot in 2009. Her pain did not resolve, so she was referred for surgery in 2010. This did not go well, and she left hospital still in pain, on oxycodone. As her pain continued, the doses and numbers of medications prescribed increased. Faye put on 7 stone, and developed sleep apnoea, and then in June 2013, she developed diabetes. In September 2013 Faye had a respiratory arrest, and died – she was just 32 years old.

Before Faye injured her back, her life was pretty normal. She worked as deputy manager at a major pet store, and she was planning to get married, and start a family. She and her fiancé both had a horse, and a social life that revolved around this.

Following her operation in May 2010, Faye was taking 80mg oxycodone daily, and by June 2013, she was taking more than 200mg oxycodone daily, along with diazepam, amitriptyline, prochlorperazine, sertraline, diclofenac, esomeprazole and paracetamol. Gabapentin had been tried, and withdrawn. Her symptoms and health problems had become steadily worse as the dose of oxycodone increased, and more medicines were added in to manage the side effects. As well as the pain, she suffered from nausea, sleepiness, fainting, muscle spasms, blistering skin problems and depression. She had become a compulsive home shopper. Despite the prochlorperazine, her nausea was so bad she sometimes could not bear to use the CPAP face mask at night, for her sleep apnoea.

Whilst waiting inpatient rehabilitation (for 20 months), Faye had some sessions of cognitive behaviour therapy from the NHS counselling service, and also started a pain management course. She did show signs of improvement – she managed to lose 3 stone, started to look after her appearance again, and managed to go out for a walk with her Dad. We really thought that

she had turned a corner, and would finally start getting better. Then out of the blue, she had a respiratory arrest and died.

We believe that her death was avoidable, and that there are still a lot of people like Faye receiving unsafe treatment for long term pain, who are, at worst, at risk of dying suddenly, or at least, of leading a twilight life.

What went wrong?

How did our daughter go from having a normal life in July 2009, to dying suddenly in September 2013? Was the treatment she received to blame? The inquest did not supply the answers that we had hoped for, so we set about trying to find out for ourselves. There are several ways that her medicines could have been doing more harm than good;

- Her dose of oxycodone was repeatedly increased, against the advice of the pain clinic, and despite her pain not being effectively managed by it. It was way above the safe limit, now set at 120mg morphine daily equivalent dose (see Opioids Aware http://www.rcoa.ac.uk/faculty-of-pain-medicine/opioids-aware
- She was taking oxycodone with diazepam - opioid and benzodiazepine medications taken together can lead to respiratory depression, and she already had sleep apnoea https://www.fda.gov/Drugs/DrugSafety/InformationbyDrugClass/ucm518110.htm
- Several of her medicines are known to increase the QT interval, especially in combination – long QT syndrome is a leading cause of sudden cardiac death in young, otherwise healthy people
- Diclofenac - there is a small risk of heart attack or stroke in patients taking systemic diclofenac regularly, especially at high doses (150 mg daily) and for long periods
- Erythromycin – just before her death, Faye received a course of erythromycin for infected in-growing toenails. There is a small risk that when taken with amitriptyline or prochlorperazine, erythromycin can increase the risk of an irregular heart rhythm. Although Faye was told to stop taking the amitriptyline and prochlorperazine whilst on the erythromycin, the long half-life of amitriptyline may not have been taken into consideration. On the day she died, Faye had texted a friend to say that the erythromycin was making her feel strange
- Faye may have had an allergic reaction to erythromycin – her face and upper body were very swollen after death

Any or all of the above could have contributed to Faye's death. Also, given that her MRI scan showed nothing clinically significant, should Faye have been offered the operation on her back? That seemed to make things worse too.

Faye's state of mind

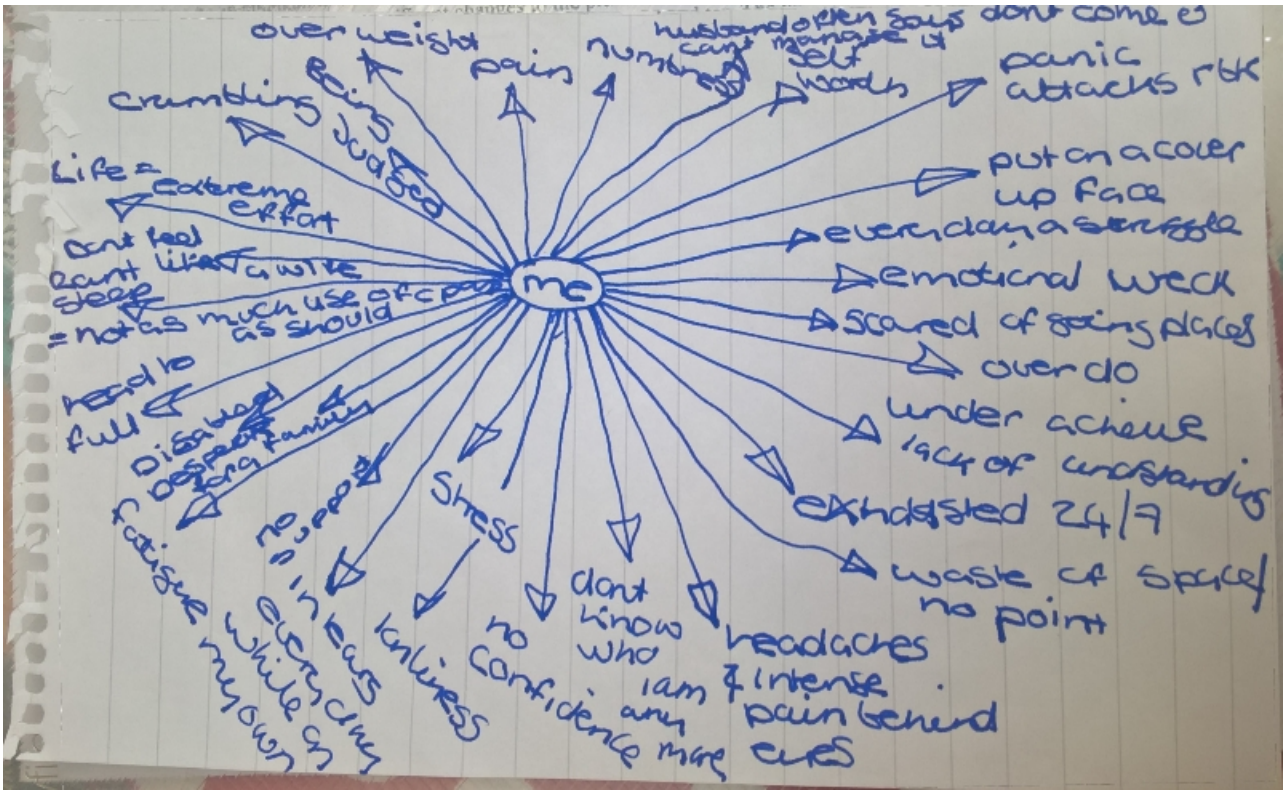
As a nine year old, Faye suffered from a nine month long period of intense pain and illness, which was diagnosed at the time as ME. It left her, as an adult, with a tendency to headaches and joint pains. We don't think that doctors treating her as an adult were aware of this.

Faye put herself under a lot of pressure to succeed in her plans. She was determined and ambitious. Her job was difficult and she worked very long hours. She had to go and look after her horse after work, and got home late most nights.

Faye did not smoke, rarely drank alcohol, and had a real aversion to swallowing tablets. She ended up taking 40-50 tablets a day, using fruit pastilles and grapes to help her swallow them.

When all of this started, if she had been questioned about her mood, and her past experiences of pain, would this have made the doctors think twice about giving her opioids? Or increasing the dose, when they were clearly not working?

Faye's mind map, which was found after she died



What could have been done differently?

Nobody should end up dying of a bad back, especially a young woman like Faye with her whole life ahead of her. Yet we know that there are a lot of people with bad backs, and other sorts of

long term pain. Many are still on high dose opioids, and medicine combinations which may well be doing more harm than good.

We discussed these concerns with the new larger GP practice, which has incorporated Faye's GP practice. They have given this a lot of thought, and have made the following changes, to try to avoid another person like Faye dying unnecessarily.

The GPs at the practice are now focusing on these key learning points:

- Safety issues around opiate prescribing
- The role of oxycodone, and an understanding of the dose equivalence of different opiates
- Alternatives to opiates for managing ongoing pain
- Mechanisms for reducing high doses of medication, e.g. weekly scripts, MDS
- Review of current prescribing in the practice
- Mechanisms for group discussions around difficult to manage cases, including a monthly patient safety meeting to review concerns about medication levels

We have thought about what message we want to send out ourselves, as grieving parents, and we believe that all healthcare professionals in every GP practice in the country should think about these points:

- First, do no harm
- Follow evidence based practice
- You have a duty of care
- Do not authorise prescriptions, even on specialist recommendation, if you don't think they are safe

Guidelines are published, and circulated, and yet change in practice is too slow, in the face of new safety evidence. What should your practice be doing differently, today? How could you spot another person like Faye, struggling and failing on their medicines, and save them?

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We can no longer receive or send faxes.