

INQUIRY INTO OFF-PROTOCOL PRESCRIBING OF CHEMOTHERAPY IN NSW

Name: Name suppressed

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Partially
Confidential

please find attached some questions that we would like answers to.

- Why wasn't medication reviewed and changed given the lack of adverse health affects from the under dosage?
- was reviewed in early November and was told by Dr Grygiel; "That they had reached the end of this course of treatment, so go home and enjoy Christmas and I will see you in January". never made the next appointment as she had passed away.
My questions are;
 - Why were no further tests carried out in November?
 - Why no review of treatment and dosage was done in November?
 - Why wasn't given more information in relation to her expected life expectancy time frame and the possible outcomes (success or failure) of the current treatment, so that she could get her life in order?
- was on 50 % dosage (that is 50% under dosage) up until the meeting in early November, if she was as sick as we all know she was, why was her dosage not increased to the maximum (also considering that there were no ill affects on her health at the 50% dosage level?
This may have given some relief and could have extended her life expectancy to spend time with loved ones, and to sort out her affairs out?
- first dosage in early 2004 was at 50% and was never increased or decreased, Why?
- In Dr. Grygiel notes' there is no mention of why he hadn't increasing her dosage to the maximum percentage or indeed why he had chosen an initial under dosage of 50%?
- Patients pay for service and take the information given to them in good faith and on face value, after all Dr Grygiel and the Health System recognised this Dr. as an expert in Oncology. Where were the fail-safe or quality assurance systems?
- Given was reviewed by the "expert" Dr Grygiel who did not prescribe other dosage levels can you advise what other treatment options were available and what their success outcomes would have been? There is no mention of other options considered in Dr. Grygiels' notes! Is this usual practice?
- What we, as family members, want to see come out of this, is that better treatment plans are adopted for all patients so that they have as much information as possible, and when making decisions, patients and or their carers are fully aware of what may or may not happen while receiving treatment.
- I believe that a second opinion should have been sought in order to ensure that the best course of treatment has been prescribed for the patient, whatever the outcome may have been.
- Ultimately it is the patient's decision to make and they need to be given sound information so that they can make the best informed decision for them and their family.
- There are no clear notes between the doctor and that shows had a clear understanding of her treatment and prognosis was. In my opinion this is one of the most important things that a doctor can do. You can never ever have too many notes and from what I can see there are very minimal if any taken. Is this normal practice? What are the standards in place for note taking and consultation?

- We believe that _____ was not given sufficient information to make informed decisions which has robbed her valuable time with her family notwithstanding any possibility of extending her life expectancy.
- The medical fraternity really need to learn from this, as these are people lives we are dealing with. The domino effect on the greater family and community is enormous.
- It's important that we get this correct going forward and that a review is under taken to ensure something like this never happens again and that other families and the wider community don't have to go through what we are dealing with at moment.
- Finally the politicisation and damage control spin emanation from the government of the day does nothing to remediate the problem or console affected families. I urge the Government and the Political Fraternity to undertake a statistical correlation on life expectancy of cancer patients under dosed by Dr Grygiel and those correctly dosed by other Doctors.