

**INQUIRY INTO OFF-PROTOCOL PRESCRIBING OF
CHEMOTHERAPY IN NSW**

Name: Name suppressed

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Partially
Confidential

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The Chairman, Deputy Chairman and Committee Members
Select Committee on Off-Protocol Prescribing of Chemotherapy in NSW
Parliament House,
Macquarie Street
Sydney. NSW 2000

Dear Select Committee Members

Re: Inquiry into off-protocol of chemotherapy in New South Wales

In regard to the Parliamentary Inquiry Terms of Reference, I feel, as a patient, that I can only comment on the following: -

(a) the efficacy of electronic prescribing systems, and their capacity to stop or limit off-protocol prescribing of chemotherapy,

I do not see that as medicine becomes more & more specific to individuals that you have a right to stop or limit off-protocol prescribing of chemotherapy – every patient is individual both physically and mentally/emotionally – and this should be taken into account when prescribing treatment.

(b) the value of a potential new patient information sheet on dose adjustment for patients and caregivers information,

Any information given to patients and their caregivers is vital – being fully informed as to treatments including dosage, side effects, etc. is paramount if the patient/caregivers so desire – it enables patients to feel more in control of their own treatment. I believe it is critical to recovery.

I do, however, understand that some patients do not want this information and that is entirely their choice. But for myself I want as much information as there is. I would definitely appreciate being given full and total information.

This information should be provided freely to those who wish to be so informed.

(d) the capacity of the NSW Health system to have all notifiable cancer patients in New South Wales overseen by a Multidisciplinary Cancer Care Team, and if this may prevent off-protocol prescribing,

I can see that a Multidisciplinary Cancer Care Team could be a buffer for all patients' safety in treatment but I don't agree with total protocol prescribing as a set definite system – patients are individual and treatment should reflect this. Treatment should be tailored to suit each patient after consultation with that patient.

(f) the NSW Health Code of Conduct and specific programmes within NSW Health in relation to staff raising concerns about the practice of clinicians, and other breaches of the Code of Conduct.

This is the major point of reference for me -

I will address the impact of the poor system in place at present, if in fact this concern was raised & dealt with by a Current Code of Conduct. This process has taken many months – there must be a better Protocol put in place to handle such matters in the future so that patients are not impacted so heavily and for so long.

I would ask why suspension is immediate ??

Criminals who commit heinous crimes are 'innocent until proven guilty' !!!

Please make sure patient education and support is paramount in future investigations.

My story: -

I was diagnosed with Mantle Cell Lymphoma in August 2014 at stage 3 to 4.

I saw Dr Phadke & very soon after blood test, bone biopsy & pet-CT scan, was having chemotherapy at Sutherland Hospital.

I was informed by telephone, then by letter on August 1, 2016 that 'concerns have been raised about the management of some patients at Sutherland & St George Hospitals, of which your case is one'. Naturally, my first response was 'oh no, I don't want to go through treatment again, enough is enough'. And then when I thought about it I tried to tell myself constantly that all would be good because I have faith and trust in Dr Phadke.

However, having said that, naturally I still had a little niggle in the back of my mind 'what if'. Understandably I have been very anxious about it to the detriment of my health.

I believe that Dr Phadke chose the best treatment for me and I had a very good response to the chemo.

Along the way my family and I have discussed other treatments with Dr Phadke and we agree that quality of life is paramount. We have researched treatments and so far are satisfied that I had the best treatment for me at the time.

I was due to see Dr Phadke again for a 6-month check-up in August this year and it was very distressing not being able to do so. My anxiety level rose immensely and I have struggled physically & mentally without his ongoing support.

I would also like to note here that our grandma is now in hospital – if she had seen Dr Phadke as scheduled and had a blood transfusion she would not be so sick now. The scope & impact of his absence is horrendous.

Although I realise it takes time to review cases such as these, I find it very unfair that more information was not given to individuals whose cases were being investigated. The length of time this review has taken has adversely affected many people. You continually try & come up with a reason your case is being investigated, had I known what I know now I could have done my own research & satisfied myself that I had the appropriate treatment for me.

Having a cancer diagnosis is enough for anyone to deal with, without pressures such as this investigation has added. I would ask again why suspension is immediate ??

Several patients would be far healthier now without the stress of the investigation and for not being able to continue seeing Dr Kiran Phadke for their checkups & continued reassurance.

I am not sure I have faith in the hospital system to correctly treat patients safely without bias or political agenda.

I also note that the 1800 Number given as a helpline did not answer!!

I sincerely hope that Dr Phadke is vindicated and that he returns to practice helping myself, my grandma and all his other patients.

I also hope that the media is as quick to tell everyone that Dr Phadke has been vindicated – as quick as they were to persecute him at the beginning of this fiasco.

I wish everyone touched by this review & investigation can move forward smiling and live a happy & healthy life.

I wish for you, the Select Committee, that you do your very best to ensure improvement and stability in the health system so that patients can feel confident in their treatment & recovery without further undue stress. I wish you all good health & happiness.

Yours sincerely