

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

Name: Mrs Lois Aspin
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Partially
Confidential

Lois Aspin

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Submission for Inquiry into off-protocol prescribing of chemotherapy in New South Wales

My Personal Account: Lois Aspin

In 1998 I was diagnosed with Transitional Cell Carcinoma in the ureter. I underwent surgery to remove my ureter, right kidney and tumour followed with two cycles of radiation therapy in 1998 and 1999. This did not stop the cancer metastasising. Following scans In 1999 I was referred back to Dr Kiran Phadke for chemotherapy. Chemotherapy was the last option for treatment of metastatic transitional cell carcinoma.

At the time of my diagnosis (April 1999) for metastatic transitional cell carcinoma Dr Phadke was overseas. My first round of chemotherapy commenced under the supervision of another oncologist from St George Private Hospital. While I was informed of the toxic side effects of the drugs I could never have envisaged how toxic, severe and permanent the effects of the chemotherapy drugs would be. Dr Phadke returned to Australia while I was still in hospital and could observe the very significant side effects the initial round of chemotherapy had on my body. (My chemotherapy was undertaken at Kareena Private Hospital.)

For the second round of chemotherapy Dr Phadke explained he would reduce the amount of the primary drug – Cisplatin. I also was administered Vinblastine and Methotrexate. At every consultation Dr Phadke clearly explained how important it was to balance the amount of the very toxic cisplatin drug with the expected and most likely permanent side effects and to recognise that such cancers will become resistant to chemotherapy drugs with prolonged use. To maintain quality of life it was made clear the aim was to destroy the cancer without killing or incapacitating the patient. From the first cycle of chemotherapy it was evident that if I survived the cancer and the treatment I would be left with permanent peripheral neuropathy and loss of hearing. The side effects of the platinum chemotherapy drugs are so toxic and severe and not easy to endure.

At the time Dr Phadke informed me that the recommended regimen was 6 cycles of Cisplatin combined with other drugs. He also informed me that if I completed all cycles I would most likely be confined to a wheel chair. If I had completed all six cycles of the recommended regimen at the time with the recommended dose I would not be able to walk now. I completed four cycles of the drug treatment and as a CT scan indicated no evidence

of cancer, chemotherapy was not continued. The effects of the chemotherapy drugs on my white cell count were such that I was rarely able to have all the drugs delivered at the times and intervals recommended. Blood transfusions were required to assist in improving the integrity of the blood so chemotherapy could proceed. Dr Phadke continued to monitor my cancer status for the next five years. At all times during my chemotherapy oncology I was informed by Dr Phadke and felt confident of his medical expertise and treatment plan.

The damage to my peripheral nerves is significant and the effects are exacerbated with ageing. A significant long term effect has been the damage to nerves in my legs, feet, arms and hands. Chemotherapy has a profound effect on the integrity of the bone.

This treatment afforded me ten years of complete remission which is far more than was believed possible in 1999. While my cancer returned seven years ago it is localised and managed by Dr [redacted] (Urologist) and his team.