

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

**Name:** Name suppressed

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Partially  
Confidential

My tumour was 26 mm in length, a high Grade 3 ( 9 out of 9 points according to the pathology report) and I had 2 positive lymph nodes. With no previous experience of cancer treatment I did not question my treatment regime. In the subsequent two or three years as I met more women with breast cancer, first as a participant in an after-breast cancer program and then as a Facilitator of the same program, I found that most of them had had six cycles. When I expressed some surprise at this, the reply was always " Oh yes, I had to have six cycles as I had a Grade 3 tumour". As well, my Co-Facilitator of the afore-mentioned program had a 7 mm Grade 2 tumour with one positive node, and received the same treatment regime as I did.

I decided to raise my concerns with Dr. Grygiel at one of my check-ups. He became, what I can only describe as, evasive, and said "Maybe we were just trying to be kind to you". I found this comment strange, to say the least as I had dealt very well with the chemotherapy. I was never ill or even nauseous and it would seem that my blood tests never returned an adverse result, as I never had to have any of my doses postponed. I have known women who have had to be admitted to hospital between doses as they have been dehydrated from constant vomiting or have developed infections. The above comment was all that Dr. Grygiel would say. If there was some other reason why I could not have been given six doses I should have been told.

This highlights another problem which exists with many (certainly not all ) medical specialists, and that is a patronising attitude of "Don't you worry about it. We know best". There seems to be a reluctance to discuss and explain what the drugs are, how they work, why they were prescribed and what can be expected.

I have often wondered if the reason I was never ill was because I was under-dosed.

Thank you for reading this submission