INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO HEALTH AND HOSPITAL SERVICES IN RURAL, REGIONAL AND REMOTE NEW SOUTH WALES

Name: Name suppressed

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Partially Confidential

Dear Members

Health inquiry into and report on health outcomes and access to health and hospital services in rural, regional and remote NSW.

Thank you for undertaking this inquiry.

I gave in-camera evidence at the 2017/18 Inquiry into the Management of Health Care Delivery in NSW (2018 Health Inquiry)

As a result of my evidence, an additional day's expert evidence was heard, which led to two recommendations (recommendations 24 and 25).

I would welcome the opportunity to also give evidence to this inquiry in order to illuminate the patient reality behind the statistics in regional NSW.

Adverse Drug Reactions

Adverse drug reactions are a leading cause of death, disability, and hospital admissions in NSW.

From the outset, I want to make a distinction between drug side-effects and adverse drug reactions.

Throughout this submission I will use the term adverse drug reactions rather than adverse drug events as the later depersonalizes and normalizes their occurrence.

Doctors are well trained in the known side effects of prescription medication that can be 'adverse' but not on how to recognise less obvious or unexpected adverse drug reactions including delirium.

Adverse drug reactions such as the latter can be caused by a wide variety of underlying reasons. This can include genetics, allergies including anaphylaxis, drug to drug interactions, delirium and brain injuries, addictions and difficulty deprescribing, and so on.

Simplistically, an adverse drug reaction can be seen in the case of any medication that acts idiosyncratically. That is not as the drug was intended.

For the record, I take medication, and I am not against medication. I am for better health outcomes for regional NSW through better prescribing practices.

Personal Experience

I have severe life-threatening reactions to certain medications, that has not only disabled me (robbing me of much of my life, community, and my living) and left me with a brain injury and ongoing physical health complications.

When I was having an adverse drug reaction my doctors and even a leading teaching hospital could not recognise an adverse drug reaction, even when I was adamant, and did not know what steps to take when they did.

Now having been successfully deprescribed the medication I personally am being denied essential medical care (and others have no clear pathway to care should they suffer an adverse drug reaction) in my hospital district.

To illustrate the point, the current standard of care provided to me, is as follows:

- (a) being told there is no point running standard preventative screening tests in case they find something, and I need medication,
- (b) failing to advise me of adverse results that required essential medication,
- (c) unnecessarily referring me to specialists in Sydney (with the resultant costs and delays) for basic issues normally handled by a general practitioner,
- (d) being advised that the hospital does not have the skills to deal with adverse drug reactions ("we are just a small hospital you'll have to go to Sydney for that") and
- (e) discharging me peeing blood and in excruciating pain. I drove myself to the John Flynn Hospital in Queensland, where my gallbladder was removed in emergency surgery.

And those are just the considered responses - that is they do not include the responses that were hostile.

Sadly, my situation is not unique.

When I speak locally at functions, approximately 10 percent of the audience, come up to me afterwards with stories of life-threatening adverse drug reactions and the difficulty in getting help.

Northern NSW Local Hospital District (The Hospital District)

The Minister for Health has confirmed that there are no doctors trained in adverse drug reactions in The Hospital District.

2018 Health Inquiry

Far from being "rare" adverse drug reactions are a leading cause of hospital presentations, death and disability in Australia.

Professor Ric Day, an internationally recognized clinical pharmacologist and expert in pharmacotherapy, drug reactions, and interactions, told the 2018 Health Inquiry into healthcare services that the rate of medicine errors in Australia is very high and that in some Australian studies were almost 40 percent of hospital admissions.

Following my evidence, and a day of expert testimony, the 2018 Health Inquiry concluded that adverse drug reactions were a very big problem in NSW.

Health Estimates 2018/2019

Following representations by Dawn Walker the local hospital district held a meeting with myself, and Professor Ric Day, with a view to formulating a pathway to care. The Hospital District failed to follow through or respond to requests following that meeting.

Health Estimates 2019/2020

12 months later, in the 2019/20 Health Estimates Ms Cate Faehrmann asked a follow up question:

"Ms CATE FAEHRMANN: Thank you. I think it was in last year's estimates my former colleague Dawn Walker raised the issue of a woman who suffered an adverse drug reaction and she raised this issue with the Minister at the time. There was a promise by the Minister to hold a meeting, which I understand happened between this woman. , and Professor Ric Day, with a view to pulling together an action plan on the lack of doctors trained in adverse drug reactions and pharmacogenetics in the Northern NSW Local Health District. I will just let you figure out whether or not you are aware of that situation. This was last estimates it was raised. The Minister promised to have a meeting. I understand the meeting [sic] happened and an action plan was promised to pull together. Their understanding is that since that meeting nothing has happened. I am sure you are aware that adverse drug reaction is the single largest cause of avoidable death and disability in Australia. Are you aware of whether that action plan is being progressed? And if not, what is the health department doing in that area?"

MINISTERIAL ANSWER

The Northern NSW Local Health District, Director Clinical Operations met with and Professor Day. The plan following the meeting was to develop a HealthPathway on the management of severe drug allergies. The Pathway will provide advice and management for General Practitioners and Hospital

Specialists. Professor Day is reviewing a HealthPathway that he will assist in adapting for use in the District.

The Minister has been provided with the wrong information.

I can confirm that as of today's date Professor Day has not been sent a HealthPathway to review nor has he or I had any further contact in the two to three years since the initial meeting.

Whose responsibility is it to ensure that there is a pathway to care, for what we know to be a considerable number of people and is arguably the most expensive error being made in regional NSW health today?

Ms Cate Faehrmann then went on to ask a follow up question.

"Okay. What is the health department doing to ensure that there is adequate training for medical staff in adverse drug reactions and pharmacogenetics across NSW Health? Dr CHANT: In terms of vaccination, I can speak to the fact that we fund the National Centre for Immunisation Research and Surveillance, co-located at the Children's Hospital at Westmead in the Westmead precinct, to actually provide expert advice should children or adults get purported adverse reactions to vaccines or if there are gueries around whether the child is able to be vaccinated. In terms of other drug reactions -Ms CATE FAEHRMANN: By the way, I understand I am asking about an adult, not a child. Dr CHANT: I am not across the particular details of the case that you are talking about. I can just talk in general terms that we do have a toxicologist, we do fund a poisons information service, so there is the ability for that specialist input or advice to be sought across the State through that poisons information network. If it was an issue about drug interactions or toxicology or whether a drug would be appropriate, the issue of the genomics-I think you are raising the pharmacodynamics. Ms CATE FAEHRMANN: Yes. Dr CHANT: That is clearly an emerging area where we are understanding the role that genomics might play in prediction. I am peripherally aware that that is an emerging area. I would be happy to take that on notice to look at what services we have in place.

MINISTERIAL ANSWER

Pharmacogenetics is the study of how a person's genetic make-up is used to determine a response or possible side-effects from particular drugs/medication. Future developments in pharmacogenetics may significantly contribute to our decisions about therapy. NSW Health is aware of this and is building capability for this testing as required.

This question has not been answered.

The question was not about vaccinations. It is not about poisons. It's not about testing. It is about adverse drug reactions and the education of doctors.

The fact that Dr Chant was not able to answer the question suggests to me that the NSW Government has limited understanding of the issues related to adverse drug reactions.

This is consistent with the evidence given at the 2018 Health Inquiry where a detailed understanding could only be obtaining through taking expert evidence from a Clinical Pharmacologist and patients who had survived severe adverse drug reactions.

The fact remains that there are no doctors trained in adverse drug reactions in The Hospital District.

Solutions

Adverse drug reactions do not require new science. Actually, they do not even require a lot of funds.

They require better educated doctors in order to improve prescribing practices.

In my experience, doctors training doctors, is the only way to raise the standard of care. I have noticed the enormous benefit of a Clinical Pharmacologist teaching a doctor and that knowledge then spilling over into their practice.

As a minimum each regional health district needs a pathway to care when there is an adverse drug reaction.

That pathway to care needs to lead to access to a Clinical Pharmacologist preferably in each hospital district.

At the moment there is an enormous disparity between Sydney and regional NSW in terms of Clinical Pharmacologists.

Not only does Sydney have access to Clinical Pharmacologists, they also have access to a specialist ward at St Vincent's Hospital (The PANDA unit).

In contrast, the only Clinical Pharmacologist regionally is in Newcastle.

Conclusion

Prescribing errors is one of the leading causes of death and disability in Australia. It is also one of the biggest causes of hospital admissions, and an enormous cost to the Australian taxpayer, to say nothing of the human cost.

Given the seriousness of the problem I would strongly encourage you to seek expert evidence from both Clinical Pharmacologists and patients who have survived adverse drug reactions.

Only through this dialogue, not through statistics, can greater understanding can be achieved.

I would be most grateful for the opportunity to provide further evidence.