

Submission  
No 69

**THE PROGRAM OF APPLIANCES FOR DISABLED  
PEOPLE (PADP)**

Name: Ms Christine Hughes

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Partially Confidential

## SUBMISSION BY CHRISTINE HUGHES

### TO THE INQUIRY INTO THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

I forward my submission under the following terms of reference:

Item No. 5. Future departmental responsibility for the PADP

Item No. 6. Any other related matter

I make reference to the Ventilator Dependent Quadriplegic Program and other programs for home ventilation which are administered by EnableNSW and established under the auspice of Health Support.

EnableNSW are responsible for the delivery of **Appliances** to the disabled and in this case I refer to a respiratory ventilator also known as life saving equipment and not to be confused with oxygen dependent therapy. The "Onus of Proof" is with EnableNSW to then provide qualified and trained medical staff to operate the ventilator.

Under the new Ventilator Dependent Quadriplegic Program (VDQP) the mode of care will be changing whereby Registered Nurses and Enrolled Nurses will be dismissed and replaced by personal carers to provide all of the client's direct care. These clients live at home and their lives depend on life support equipment.

Personal carers do not have the level of medical expertise or training required to operate/maintain life support equipment. They are not affiliated with any organisation or Registration Board and have no accountability. Hospital patients on ventilators have Registered Nurses/Enrolled Nurses to attend to them. Home ventilated patients are not afforded the same care therefore, finding themselves in a most inequitable and unfair situation. Their health is not stable as they are at risk of sudden death.

The administrators of this program have failed to include the clients in any discussion or consultation regarding personal carers taking on the role of a Registered Nurse/Enrolled Nurse. This change has been thrust upon clients without their approval forcing them into accepting a personal carer simply because their financial position doesn't allow them to access the private sector to pay for a Registered Nurse to care for them. I particularly make reference to this point and add that this paragraph serves as evidence for any future medical negligence claims including death arising from the employment of personal carers under Ventilator Dependent Quadriplegic Program.

EnableNSW has not considered their Duty of Care when formulating this policy. A Duty of Care is "owed" to ventilated clients. The employment of personal carers will result in an inadequate and potentially unsafe delivery of the VDQP. Clients understand that their quality of care has been greatly reduced and that the possibility of mistakes occurring affecting their health or even death is a possibility. They feel helpless. The way the law of negligence is applied the client and their families are aware of the foreseeable neglect and therefore are responsible for "Contributory Negligence"

This submission supports any future decision by the Committee for a full and transparent Parliamentary Inquiry into EnableNSW.

Thank you for this opportunity to express my concerns and await your further advice regarding appearing before the Committee.



Christine Hughes