Submission No 19

# THE PROGRAM OF APPLIANCES FOR DISABLED PEOPLE (PADP)

Name:

Mrs Gail Martin

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Legislative Council
General Purpose Standing Committee No 2

Inquiry into the Program of Appliances for Disabled people [PADP]

6. Any other related matter.

Submission.

Alex has been dependant on State Government funding since January 12, 2005.

He is a man who has worked hard, paid tax, stayed fit, who has never smoked, taken drugs, or willingly caused his own ill health.

He had a freak accident doing the quintessentially Australian thing that has rendered him totally reliant on the health system and government funding for his existence, as he is now a Ventilator Dependent Quadriplegic.

He was not a heavy drinker, heavy smoker or obese.

He didn't willingly cause his ill health as most in these groups are felt to do.

However they are grouped together and will rely on the health system and the government for their existence.

Ventilator Dependant Quadriplegic Program provides the funding for all Alex's care needs.

Alex requires High Risk Equipment.

He is a client with complex equipment needs.

We are a family of four and have been reduced to one income.

My role is to be a wife, mother, household manager, business woman and a support person for my husband and a support person for our children.

We have all suffered from the momentous emotional, physical and financial adjustments needed to be made since Alex's catastrophic accident and resulting injury.

We have had significant increases in costs, which are not funded, in order to provide for Alex at home.

Our family has provided the funding to modify our house, which has meant a huge drawdown on the family resources.

The modifications the family have funded were prescribed by the spinal team and include the supply and installation of a lift, air conditioning, new floor surfaces in the bedroom and new bathroom fit out, new front path, hoist and ECU's.

The PADP are unclear about what they deem essential equipment for Complex clients.

Alex's equipment requirements encompass a momentous range. They are designed for the best healthcare outcome for Alex's ongoing care.

We are therefore puzzled as to whether the provision of a lift, air conditioning, ramped front path, bedroom and bathroom renovations, ceiling hoist and ECU's are part of the PADP's area of responsibility.

Without these modifications Alex could not return home.

We have no guidelines indicating what the PADP provides.

The list of equipment below is what we believe Alex needs for his safe return home.

## Equipment for complete spinal cord injury:

- .Motorised height adjustable bed with features including:
- sip/puff controls,bolsters,footboard,trendelenburg, head and foot raise,side/grab rails,linked to ECU or voice activation system
- .Alternating air pressure mattress
- .Overnight drinking system accessible from bed
- .Foam overlay mattress for portable/emergency use
- .Power wheelchair with features that include:

head rest, head/ chin / breath control, postural support devices, power recline, tilt in space, and leg raise. including attendant control system, ECU system and drinking system.

- .Battery charger
- .2 pressure relief wheel chair cushions
- .Manual wheelchair with tilt in space component
- .Electric ceiling hoist with chargers with two batteries, 2 sets slings, wet and dry
- .Portable electric hoist with chargers with two batteries, 2 sets slings, wet and dry
- .Shower commode chair with high back, tilt and custom seat
- .Hand held shower and hose
- .Over bed table height adjustable
- .Set of 2 lightweight portable ramps
- .Sliding board
- .Vehicle modification for attendant -operated accessible wheel-in, including lifts, automatic tie downs air conditioning
- .Head and postural support during travelling
- .Voice activated and independently activated ECU, intercom or call buzzer
- Reverse cycle air conditioning, covering living area and bedroom at a minimum.
- .Computer with mouth stick and voice activated access including software and hardware
- .Adjustable computer desk
- .Physiotherapy equipment to maintain / increase muscle strength and fitness in a home program.
- .Hand splints custom made
- .Mobile phone with hands free feature and accessories
- .Home landline phone with voice activation and speaker phone
- .2 ventilators and batteries
- .Pulmonetic system automotive power cord

- .Battery packs for emergencies
- .3 dry ventilator circuits
- .3 wet ventilator circuits
- .Portable ventilator for use in shower and as back up in emergency
- .13m hosing
- .Air viva resuscitator
- .Mains operated suction unit
- .Portable suction unit, battery operated
- .Cuff pressure gauge
- Nurse's stethoscope
- .Portable sphygmomanometer hand held
- .Oral thermometer
- .Sheepskin booties
- .Abdominal binders
- .Anti-embolic stockings
- .Oedema gloves
- .Slide sheets
- .Egg crate overlay mattress
- .Adaptive leisure equipment
- .Additional equipment for social participation, recreation and leisure pursuits
- .Towel Dispense
- .Glove Dispenser
- .Carer's Desk, chair and lamp
- .Stainless Steel Dressing Trolley
- .Including all disposable items

#### The importance of a complete equipment inventory.

Alex will need an inventory of all equipment supplied indicating servicing dates, replacement dates and warranty details to help prevent risk to Alex's healthcare outcome.

We are most concerned that there is no information that we can find outlining how Alex's equipment will be assessed, maintained and / or replaced and managed when he is in the community.

## The importance of the Multidisciplinary team.

The Multidisciplinary team is required to prescribe for Alex as his needs change.

The Multidisciplinary team is the only way to manage Alex's ongoing requirements once in the community to prevent risk to his healthcare outcome and ensure his quality of life.

## The Multidisciplinary team includes:

Occupational Therapist
Registered Nurse
Physiotherapist
Nurse practitioner
Clinical Nurse Consultant IDC
Clinical Nurse Specialist IDC
Respiratory Specialist Consultant
ENT Specialist Consultant
Rehabilitation Specialist Consultant
Neurology Specialist Consultant
Rheumatology Specialist Consultant
Podiatrist
Speech Pathologist
Sleep Physician with FRACP accreditation

#### Timeframe for repairs and replacements.

Once the equipment is assessed and evaluated with request for funding approved, it is essential we have a schedule and timetable to identify completion dates to prevent any risk to his healthcare outcome.

We need to be provided with a Tracking System for this process, regularly updating its progress, so nothing is left to guesswork.

#### The Process includes:

- assessment
- request
- prescription
- approval
- order
- repair or replace

#### New guidelines.

We hope the new guidelines will improve Alex's quality of life, help prevent risk to his healthcare outcome and meet Alex's complex needs.