



# Development of a Protocol to Withdraw Treatment From Low Adherence Patients.

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# The Austin Hospital

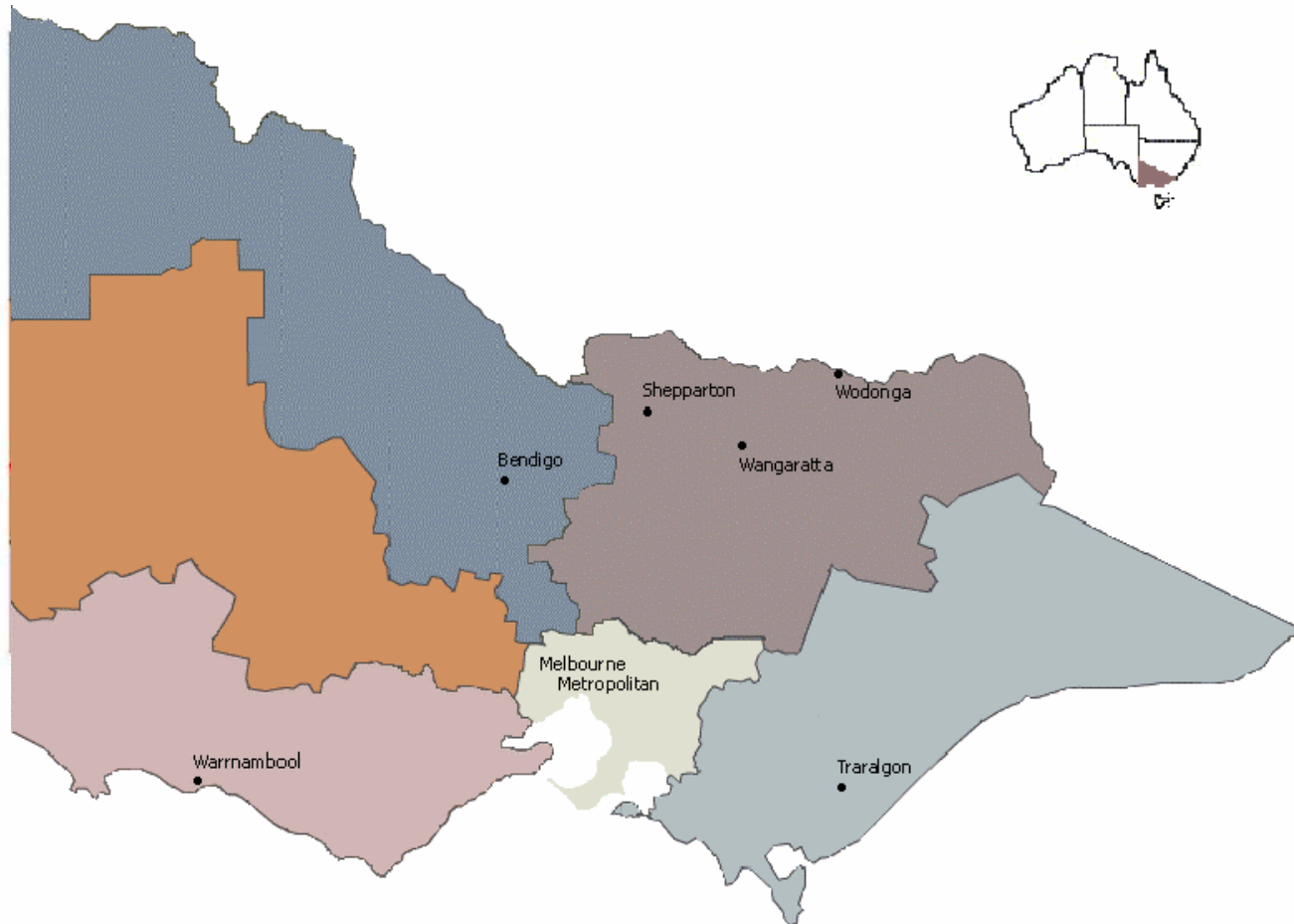
The Austin Hospital Tower opened in May 2005.

There are 400 acute beds, a High-tech Spinal Unit, an expanded Emergency Department, ICU, CCU and two additional operating theatres



# Victoria State-wide Service

12 Metropolitan areas and 10 Rural areas



# Conditions requiring long term ventilation

Central Sleep Apnoea  
COPD/Emphysema  
Cystic Fibrosis  
Kyphoscoliosis  
Marfan's Syndrome  
Motor Neurone Disease  
Guillain Barre' Syndrome  
Muscular Dystrophy

Myotonic Dystrophy  
Obesity Hypoventilation  
Phrenic Nerve Palsy  
Post Polio Syndrome  
Spinal Cord Injury  
Spinal Muscular Atrophy  
Other Neuropathies  
Other Myopathies

# The Victorian Respiratory Support Services Outreach Team

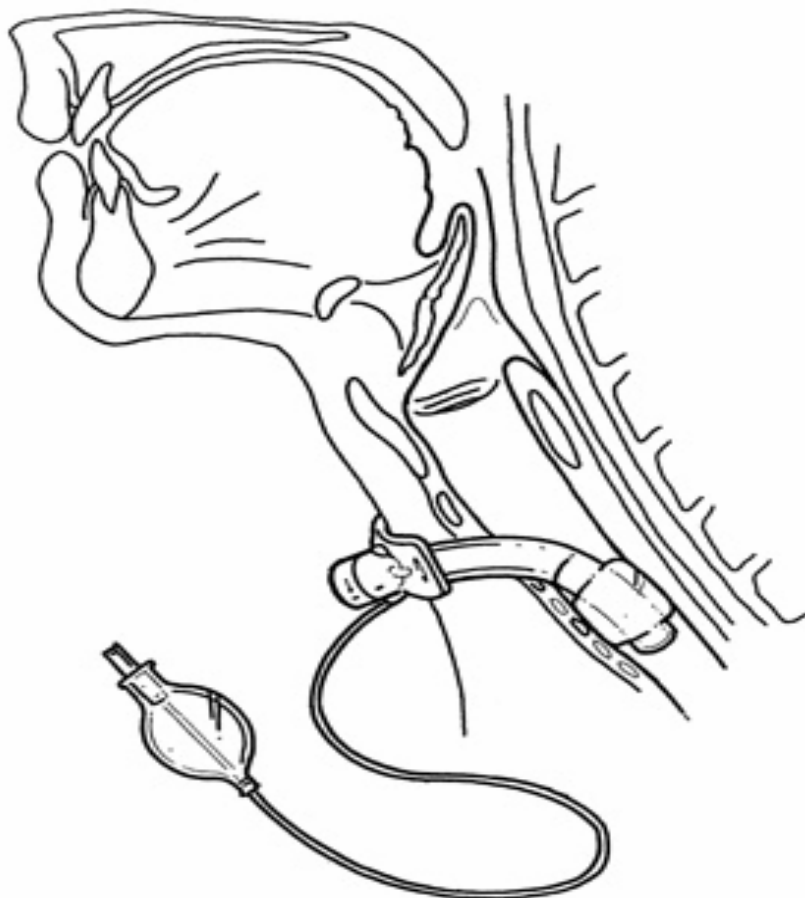


- Works in partnership with the VRSS team in preparing the patient for discharge from hospital
- Provides education and support for the patient, his her family and other carers.
- Manages the purchase and supply of all equipment needed for care in the home.
- Helps the patient stay well at home , and reduce the number admissions to hospital.
- Manages the annual servicing and interim repairs of all ventilators.

# Masks



# Tracheostomy



# Ventilators



# What's this stuff???



# Do I have to do this?



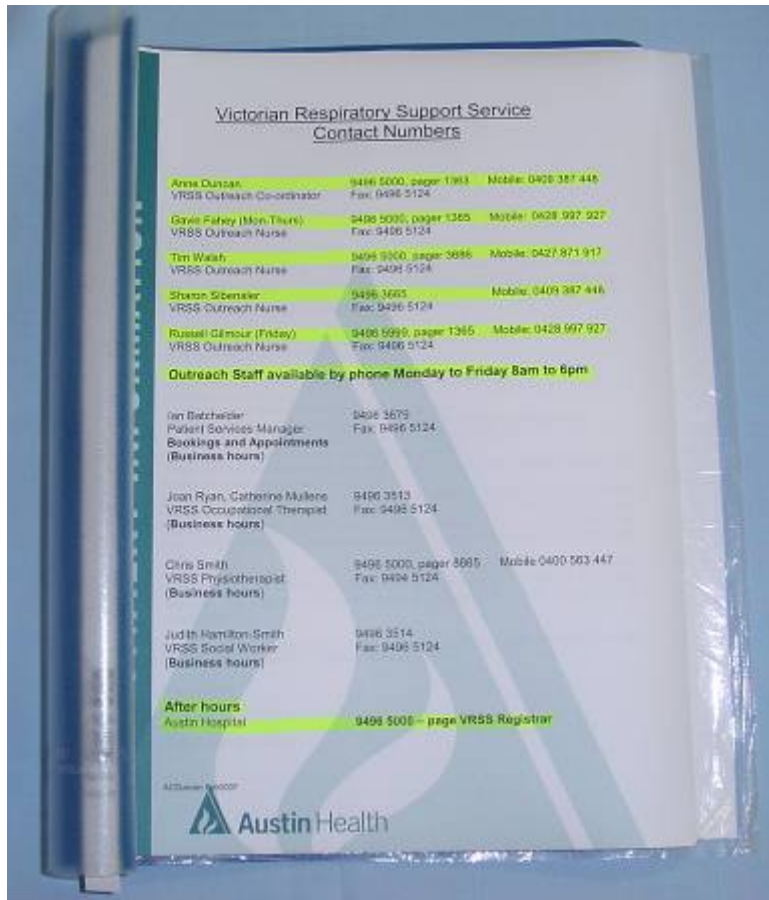
**It Works!!**



# Education



# Education Booklet and Contents



## Contact Numbers

Breakdown letter

Discharge Information & Circuit cleaning advice

Ventilator instruction manual with troubleshooting guide.

Using the ventilator internal battery (Breas & PLV)

Humidifier instruction booklet (if in use)

Circuit diagram (if humidifier in use)

How to apply your mask (Bi-level units)

Mask instruction guidelines

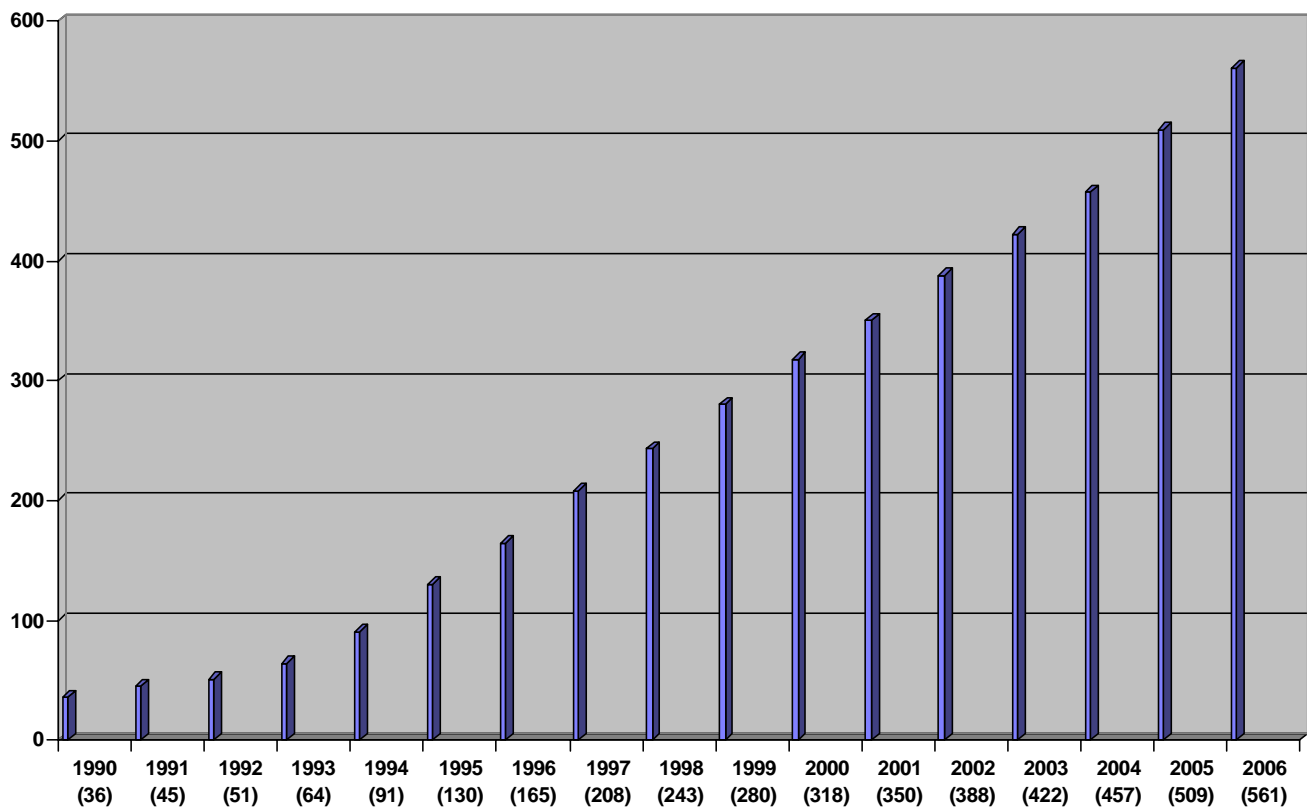
Equipment letter

Equipment list

Order forms.

Life Support Concession application form

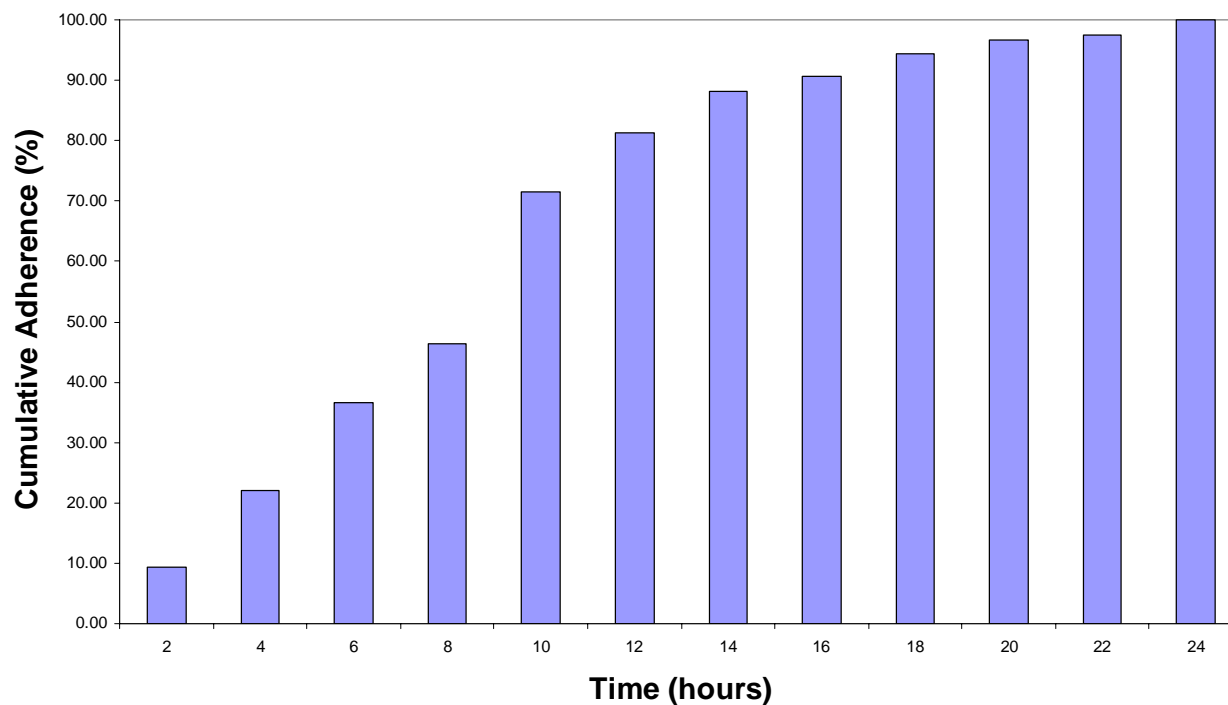
# VRSS growth rate



# Secret Adherence Tracker



# Ventilator Adherence in VRSS Clients



# Stressed?



# Ventilation usage comparison

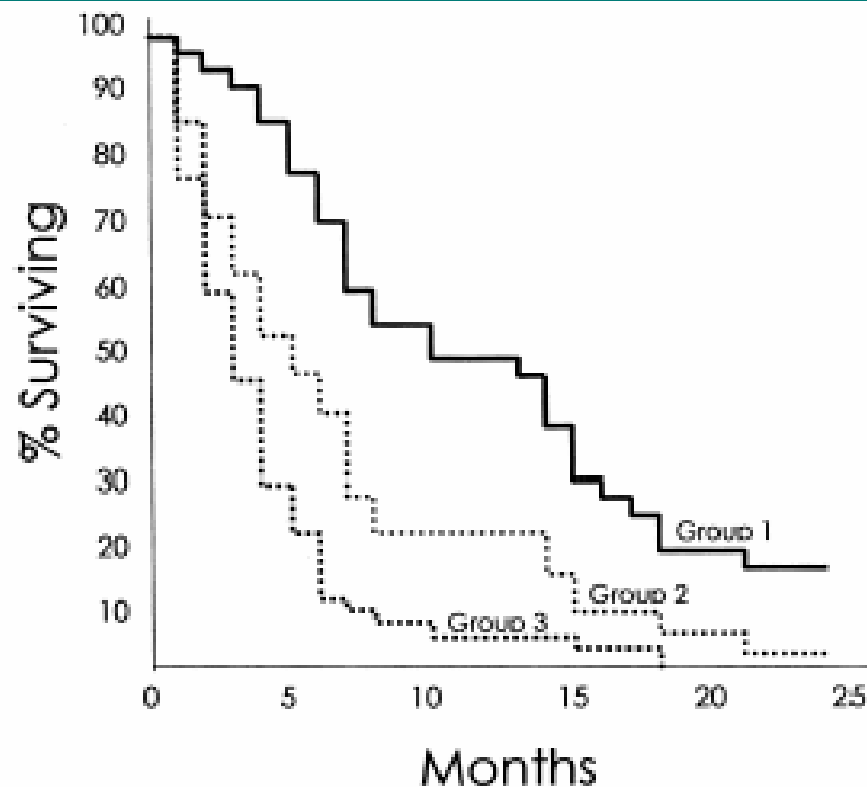


Fig. 3. Kaplan-Meier survival curves for Group 1 (Bipap use >4 h/day,  $n=38$ ), Group 2 (Bipap use <4 h/day,  $n=32$ ) and Group 3 (no Bipap,  $n=52$ ).

# Psychological Principles (Dr Kennedy)

- Various fears - dying, suffocating, etc..
- Realisation of mortality
- Will not be able to get used to the mask
- Claustrophobia
- Attractiveness to partner/future partner
- Sex life issues (having to talk about it)
- Disturbing partner
- Having to sleep in another room

# Physical problems (Dr Kennedy)

- Mask fit (size, type, leaks etc..)
- Noise of machine
- Putting mask on and off during the night
- Physical symptoms (dryness nose and throat, sore eyes etc..)
- Pressure correct

# Question?

**Do we remove the ventilator or not?**

## Reference

- Bipap improves survival and rate of pulmonary function decline in patients with ALS; K.A. Kleopa, M. Sherman, B. Neal, G.J. Romano, T. Heiman-Patterson; Journal of Neurological Sciences, 164, (1999)
- Cognitive Behavioural Therapy & CPAP/NIV Compliance; Dr G Kennedy, Unpublished, (2003)

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