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Technology Dependent Children

Dr Sadasivam Suresh
Paediatric respiratory & Sleep Physician
Queensland Childrens Hospital
Brisbane Australia



Great state. Great opportunity.



20 years ago

Tanner 1998,53:762-767

Core guidelines for the discharge home of the child on long term assisted ventilation in the United Kingdom

Elisbeth Jardine, Colin Wallis

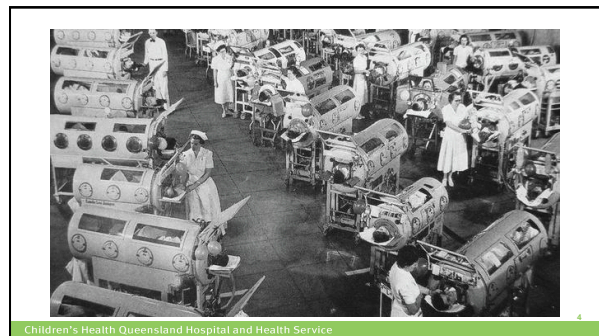
- Paediatric home ventilation is a feasible option and can be successful in a wide range of conditions and ages. Advances in ventilator technology and an ethos of optimism for home care has increased the possibilities for discharging chronically ventilated children from intensive care units and acute medical beds.

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Roadmap

- History
- Recent evolution
- Is it all worth it?
- Literature
- Premise that home is the best place for the child
- Increasing use of NIV
- Technological advances
- Position statement
- Funding issues

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Goal

Home is the best place for the child

Is it all worth It?

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Literature

Thomax 1998;53:702-707

Core guidelines for the discharge home of the child on long term assisted ventilation in the United Kingdom

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- Address a group of children who
 - Are Medically stable
 - Have a safe airway
 - Are dependent on external support for management of their ongoing respiratory condition
 - Nutritional intake is adequate
 - No other associated medical conditions that needs further investigations or management
 - Home environment is deemed suitable for this to be provided

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Different Groups

- Invasive ventilation via tracheostomy
 - Spinal cord injury
 - Central hypoventilation – congenital or acquired
- Non invasive ventilation – bilevel ventilatory support
 - Respiratory failure
 - Neuromuscular
 - Restrictive lung disease
 - Obesity hypoventilation
- Non invasive ventilation – Continuous Positive Airway Pressure [CPAP]
 - Obstructive sleep apnoea
 - Upper airway lesion
 - Malacia

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UK Trends

Year of survey	Total
1990	35
1994	44
1995	90
1997	136
2000	241
2008	933

Wallis 2010

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The Thoracic Society of Australia and New Zealand

Ventilatory Support at Home for Children. A Consensus Statement from the Australasian Paediatric Respiratory Group

February 2008

Journal of Paediatrics and Child Health

doi:10.1111/jpc.12040

VIEWPOINT

Paediatric home ventilatory support: Changing milieu, proactive solutions

Elizabeth Anne Edwards¹ and Gillian M Nixon² on behalf of the Australasian Paediatric Respiratory Group Working Party on Home Ventilation

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Australia & New Zealand

Table 2 Non-invasive ventilatory support

Respiratory support	NIV		CPAP		Total NIV	
	1997-1998	2007-2008	1997-2008	2007-2008	1997-1998	2007-2008
Victoria	2 (0.2)	21 (2.2)	10 (1.1)	69 (7.3)	12 (1.3)	90 (9.5)
Queensland	15 (2.2)	35 (4.3)	42 (6.1)	46 (5.7)	57 (8.2)	81 (10.0)
New South Wales (Includes ACT)	7 (0.6)	81 (6.1)	20 (1.6)	163 (12.2)	27 (2.2)	244 (18.3)
Western Australia	10 (2.7)	28 (7.1)	5 (1.4)	33 (8.3)	15 (4.1)	61 (15.4)
South Australia	5 (1.8)	37 (13.2)	4 (1.4)	25 (8.9)	9 (3.2)	62 (22.1)
Total Australia	39 (1.1)	202 (5.1)	81 (2.2)	336 (8.5)	120 (3.3)	538 (13.7)
Total New Zealand	3 (0.4)	48 (5.2)	5 (0.6)	80 (8.6)	8 (1.0)	128 (13.7)

Estimates from a national survey of paediatric respiratory physicians of children actively managed on home ventilatory support in Australian and New Zealand centres compared with 10 years ago. Absolute numbers are given, with population estimates per 100 000 in parentheses. Population estimates for children aged under 15 years were estimated using 2006 census data (Australian Bureau of Statistics (<http://www.abs.gov.au>) and Statistics New Zealand (<http://www.stats.govt.nz/>)). ACT, Australian Capital Territory; CPAP, continuous positive airway pressure support via mask interface; NIV, non-invasive ventilation.

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Shifting clinical Paradigm

- Technological advances
- Multispecialty advances
- Changing expectations of the society
- Ethical challenges
- 'Can do - Should do' situations

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Time to Home is improving

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Processes

- Individualised management plan
- Specialist setup
- Co-coordinating multidisciplinary team
- Interdisciplinary including society stakeholder
- Parents key role in developing the process and when suitable drive the process
- Check lists – KidVent list Canada [Amin 2017]

Domain	Number of items	Mandatory/optional
Normal anatomy and physiology of the respiratory system	6	Mandatory
Infection control	13	Mandatory
Humidity	8	Mandatory
Secretions/suctioning	25	Mandatory
Stoma care	11	Mandatory
Tracheostomy management	30	Mandatory
Ventilator	33	Mandatory
Manual ventilation	10	Mandatory
Cardiopulmonary resuscitation	4	Mandatory
Feeding and nutrition	9	Mandatory
Medications, vaccinations, and allergies	14	Mandatory
Community living	22	Mandatory
Emergency planning	5	Mandatory
School readiness	6	Mandatory
Communication adjuncts	12	Optional
Oxygen	15	Optional
Calimeter	12	Optional
Pulmonary treatments	12	Optional
Diaphragmatic pacing	6	Optional

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Conditions needing NIV

Case of ventilation	Major subgroups	No.
Central nervous system (n=188)	Congenital central hypoventilation syndrome	658
	Spinal injury	136
	Birth injury/cerebral palsy	88
	Acquired central hypoventilation syndrome	36
	Other central causes	15
Musculoskeletal (n=402)	Duchenne muscular dystrophy	Not completed
	Congenital myopathy	Mask
	Other myopathy	Method of ventilatory support (n=933)
	Other dystrophy	Tracheostomy
	Kyphoscoliosis	Not completed
	Spinal muscular atrophy type 1	Phrenic nerve pacing with tracheostomy
	Spinal muscular atrophy (I/II)	Negative pressure
	Myoepiphyseal dysplasia	Current location of child (n=933)
	Other musculoskeletal	Home
	Respiratory (n=343)	Acute hospital setting
Chronic lung disease (prematurity)	Rehab/transitional care	
Airway malacia	Not completed	
Prader-Willi/sickle cell syndromes	Intensive care	
Upper airway obstruction	Community setting	
Cystic fibrosis/primary ciliary dyskinesia	High dependency unit	
Other respiratory		

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Conditions needing NIV

- Increasing cohort
- Not just respiratory
- Reduces hospital stay
- Obesity
- Technological advances in terms of mask and machine interface
- Palliative

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Emergency Management Plan

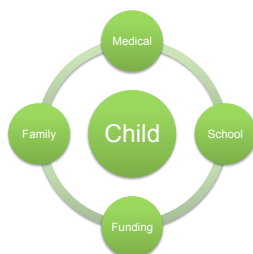
- Tracheostomy education
- Acute respiratory illness
- Respite support
- Carer education
- Dynamic and flexible resources

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Governance Structure

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Varying Models



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Win - Win situation

- Feasible
- Simple processes
- Adaptive flexible feedback
- Changing growth needs
- Cost effective in terms of overall healthcare costs

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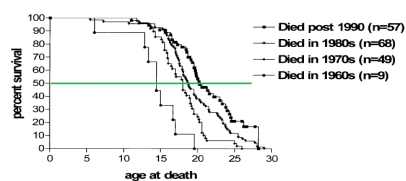


Fig. 1. Survival curves (Kaplan Meier), showing comparison in percentage survival decade on decade from the 1960s to 2002. The post-1990s cohort includes all boys, ventilated or not. If the ventilated group is removed from the post-1990s cohort, the 1980s and 1990s cohorts are not significantly different as shown in Fig. 2 ($P = 0.82$, log rank test, data not shown). Legend: Log rank tests for successive decades: 1960s vs. 1970s, $P = 0.002$; 1970s vs. 1980s, $P = 0.007$; 1980s vs. 1990s, $P = 0.03$.

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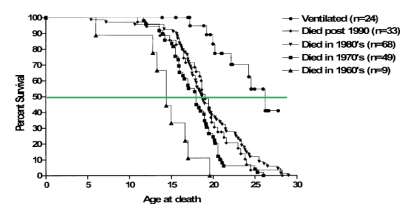


Fig. 2. Survival curves (Kaplan Meier) showing percentage survival of ventilated versus non-ventilated patients, 1967-2002. (Includes live patients censored on 28th February 2002.) Legend: Log rank test for non-ventilated vs. ventilated patients post-1990 ($P = 0.0001$).

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Funding

- Poorly funded across the world
- Advocacy is most needed
- Patient groups
- Channelise the energy of social media
- Political will

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Summary

- The number of children who receive long term ventilatory support is increasing.
- Long term hospitalisation is inappropriate for the developing child.
- Home care of children requiring long term ventilatory support is feasible and should be a priority of the health care team.
- Dedicated government funding is needed for children who require long term respiratory support in the home.
- Increased resources are required to provide psychological support for children requiring long term ventilatory support and their families to improve quality of life and emotional wellbeing.

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