

Promoting independence for children on long-term ventilation

Sue Lawrence outlines the challenges faced by individuals, families and carers and looks at the preparation needed for one young person's trip to France

Abstract

It is the responsibility of children's nurses to enable children and young people who are on long-term ventilation (LTV) to live independent and varied lives. This article considers the common challenges faced by such children and reflects on personal experience in planning and undertaking a respite week for a young person on LTV with Duchenne's muscular dystrophy without his parents.

Keywords

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A CHILD is considered to be on long-term ventilation (LTV) when, although medically stable, he or she continues to need a mechanical aid for breathing which may be acknowledged after a failure to wean, three months after the institution of ventilation (Jardine and Wallis 1998).

The number of children receiving LTV at home is increasing. In 1990 there were 24 LTV children in the UK with the figure rising to a recent conservative estimate of 150 (Murphy 2008, Gasper *et al* 2010). Perhaps this can be attributed to technological advances in medicine but it raises issues for community care provision about how to maintain an optimum quality of life for these children (Margolan *et al* 2004).

Ludvigsen and Morrison (2003) report that the commonly highlighted issues affecting children on LTV include:

- Barriers to discharge resulting in prolonged hospitalisation, in particular delayed transfer from intensive care, and increased risk of infection.
- Negative impact on quality of life, in particular privacy and dignity and effect on independence.
- Lack of consistency in short break respite provision.

Families of children on LTV face the prolonged discharge process from acute care to the home.

This process is often prolonged because of delays in securing funding, housing and equipment requirements and the co-ordination of multiple services (Margolan *et al* 2004).

A major factor in this process is the provision of an adequately trained care team. Recruitment, training and retention of carers are continual challenges for community teams (Noyes and Lewis 2005). Thorough training packages need to be delivered for all carers with a robust assessment of competency and regular reassessment of continual fitness for practice. In this way parents and children can be confident in their carer's knowledge base and effectiveness as a practitioner.

Once a child is successfully discharged into the community with a care package there are still many aspects to consider. Continual carer presence, commonly of the opposite sex which can be embarrassing for some, can inhibit children and young people from forming and maintaining normal childhood relationships (Noyes 1999). In addition to this social isolation, children and young people on LTV often cope with a lack of privacy carrying out daily functions, such as toileting, washing and dressing. It is integral to a carer's training that he or she is able to manage this responsibility with professionalism and maintain the dignity of the child.

As Ludvigsen and Morrison (2003) report, when families are able to live at home with their child on ventilation their need for respite is clear. However inconsistency and inequity in its provision are commonly reported problems for parents (Department of Health (DH) (Noyes 1999, Mencap 2003, (DH) 2004).

Nurses have the power and responsibility to alleviate barriers to independence and ensure the sentiments of DH (2008) are supported. These sentiments are that palliative care begins at diagnosis and the lives of children and young people diagnosed

with life-limiting and life-threatening conditions should be improved. This follows a declaration from the United Nations (1989), and guidance (DH 2004), which advocate enabling children with disabilities to lead full and independent lives with appropriate care and support.

The trip

In 2006, a school for children with physical and learning disabilities planned to take a group of students on a five-day trip to France. Alex Lewis, one of the young people, was fully dependent on positive pressure LTV via a tracheostomy due to Duchenne's muscular dystrophy. This congenital condition is described by Hockenberry and Wilson (2007) as: 'A gradual, progressive degeneration of muscle fibres characterised by progressive weakness and wasting of symmetric groups of skeletal muscles, with increasing disability and deformity.'

It was planned that the author (Alex's community children's nurse) would lead a 24-hour care package for Alex supported by one of his trained carers and an on-call service based in England. The trip was to provide respite for Alex's parents and his sibling who had not had any respite provision for a number of years and, it was anticipated, would give Alex an equality of opportunity to live among his peers and to have some independence (Department for Education and Skills (DfES) 2007).

In preparation for the trip risk assessments and care planning were extensive. Areas of risk identified included Alex's physical deterioration, tracheostomy blockage and equipment failure. Issues of consent were raised and debated. Alex, aged 15 years, might have been allowed to consent to treatment, if clinically able, but would not have been legally allowed to refuse. He would certainly have been deemed as 'Gillick competent' with: 'Sufficient understanding and intelligence to enable him to understand fully what is involved in a proposed intervention' (DH 2009).

Alex's parents would be unavailable to consent or refuse treatment on Alex's behalf. Alex and his parents said that if his condition deteriorated while away all resuscitation attempts should be made. Risk assessments took this into account. All documentation, care and contingency plans were agreed and signed by Alex and his parents in advance. A proactive approach to risk management was required to ensure inclusion in activities whenever possible while considering Alex's safety (Noyes and Lewis 2005).

Department for Children, Schools and Families (DCSF) (2009) says there should be partnership between parents, children and statutory agencies

to improve service provision and quality of life for children with disabilities and their families. Interprofessional team working is vital to ensure a child's needs are met, in any setting.

In preparation for Alex's French experience, interprofessional team meetings took place involving his GP, respiratory consultant, community nurses, physiotherapist, and school teaching staff to plan for all eventualities. Medical information describing Alex's condition, his general health needs and a treatment plan in case of deterioration were supplied and translated into French. Antibiotics were prescribed to be started if Alex became clinically unwell and a physiotherapy treatment regimen was formulated. Liaison with hosts in France allowed the interprofessional team to plan how emergency services, a GP and the nearest suitable hospital with adequate intensive care facilities could be accessed.

There were practical considerations of ensuring Alex's carer was confident and competent enough in Alex's care, to share a heavy workload throughout the week. In spite of this Alex and his family were fully aware that, if the lead professional became unwell, Alex would be transferred to the nearest suitable hospital with his carer until his parents could attend.

In line with current practice and the recommendations of Noyes and Lewis (2005), emergency and tracheostomy changing equipment were carried at all times. The NHS (2010) advocates a spare of all electrical items must also be available. These included suction machines, power cables and adapters, as well as Alex's ventilator. Consumables from two different batches, in case of batch fault, were ordered and twice the projected amount that would be needed taken. An account was arranged with an international delivery firm that could collect and deliver any extra equipment. It was important to ensure equipment would be guaranteed in France and that a local ventilator representative would be available to repair a ventilator urgently if needed. A cigarette charger for the ventilator and suction machine would mean that, even if the house he was staying in lost power and batteries failed, Alex's life-sustaining equipment could be used in the minibus while he travelled to an alternative power source (Gasper *et al* 2010).

The logistics of planning a week abroad for a ventilated child should not be underestimated. A considerable investment of time and resources is needed. Pre-empting problems without visiting Alex's accommodation and the surrounding area in advance was complex and required much liaison and risk assessment on arrival. By reward, however,

the author gained an in-depth understanding of how Alex lived his life. Ultimately, the visit was a success.

Implications for practice

Noyes (1999) stated: 'Young people and families said they needed to be placed at the centre of decision making and be in charge of their own lives. This will require a change of mind set by most professionals.' Young people who are dependent on ventilators will continue to be discriminated against and suffer injustices unless their stories are told and people who can make a difference listen and act.

It would be a missed opportunity not to use the lessons learned from Alex's experience to inform nursing practice and improve the experiences of other children and young people on LTV.

The community nursing team believed this and helped inform a second school trip for another child on LTV. To ease the pressure on the immediate care team there were a greater number of staff and multiple trips to the venue were organised so all risk assessments and activities were fully informed. The experience gave a second child and family the chance for respite and socialisation.

Recognising the difficulty of arranging respite provision outside of his home, while acknowledging this desperate need, Alex's community nursing team began to provide regular respite weekends for Alex and his family in their own home. The DH (2004) advocates that respite provision should include home and community-based breaks, not solely residential care to cater for a child's particular need. Other opportunities have included attending a music festival and several concerts.

Noyes (1999) reported that care teams often created unnecessary boundaries with their healthcare provision in the name of risk assessment that young people feel is unnecessary and destructive.

While this is almost certainly undertaken with the aim of minimising risk and ensuring the safety of a

Alex Lewis



Sadly, Alex died in December 2009 aged 18. Before his death, he had left home and enrolled in a residential college to study music and information computer technology. He enjoyed his new found independence. In his short life Alex fought against many barriers and constantly strove to achieve. He did not allow his disability to prevent him from doing many things. He gave his permission to the author to use his real name in this article. His photo is reproduced with parental consent.

child and family it could be argued that it is limiting the child's potential. As outlined in *Every Child Matters* (HM Treasury 2003), the five key outcomes for wellbeing are: being healthy, staying safe, enjoying and achieving, making a positive contribution and achieving economic wellbeing. It could be argued that all these outcomes are achievable if care teams enable children and young people to aspire to them.

As the number of ventilated children grows as predicted there will be more opportunity to provide holistic care that breaks down these barriers but raises the expectations of children and families. Nurses working within the philosophy of child health care will place the child or young person at the centre of the family and appreciate the family's commitment to the child's health and happiness.

Conclusion

If community care is to grow and develop it would be valuable to consider lessons to be learned from the successes of Alex and his family. Opportunities can be arranged, respite provision delivered and a family caring for a life-limited child can feel valued and respected. A child on LTV can be independent and free to choose what they want to achieve. They can make a positive contribution and one that breaks new ground.

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Conflict of interest

None declared

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