

Significant safety issues for kids on long term ventilation at home

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There are significant safety issues for children who receive long term mechanical assistance with breathing at home (ventilation), finds an analysis of officially reported safety incidents associated with provision, and published online in the *Archives of Disease in Childhood*.

In nearly half of such cases (41%) reported over 5 years, the child had come to harm, often as a result of faulty/damaged equipment or inadequately trained staff/carers.

The findings prompt the researchers to call for substantial improvements to be made to service provision, particularly in light of the rapid increase in the number of [children](#) cared for in this way, and the fact that reported incidents "likely represent the tip of the iceberg."

There has been a shift towards caring for people with complex medical needs at home, rather than in hospital, in the UK. Long term ventilation, which provides mechanical assistance with breathing, via a face mask or tube inserted into a hole in the neck (tracheostomy), may be used in these cases.

The number of children on long term ventilation in the UK has risen from 844 in 2008 to an estimated 1500 in 2015.

While there are many advantages to this type of home care for the child and family, there are also significant risks, which need to be carefully managed, point out the researchers.

To try and gauge the extent of these, they reviewed all the safety incidents associated with the long term ventilation of children in England and Wales, and reported to the National Reporting and Learning System database, over five years (2013-17).

During this period, there were 220 incidents relating to ventilator or tracheostomy care given to children at home across the age span.

While there were few in babies (1%), around one in four (22%) occurred in those aged 1 to 12 months and around one in five in 2-4 year olds (26%) and in 5-11 year olds (28%). Some 17% of incidents occurred in 12-17 year olds.

The most [common problems](#) arising during the processes of care were faulty or unavailable equipment (99); factors associated with procedures and treatment, such as the wrong size tracheostomy tube fitted (91); and concerns around staff availability and competency (27).

There were also 18 communication issues and 16 relating to the information, support and training needs of families.

The child came to harm in 89 (41%) incidents, resulting, variously, in the need for cardiopulmonary resuscitation (CPR), emergency tracheostomy, transfer to hospital, and substantial distress/pain.

The researchers identified 50 contributory factors, which they classified as: family carer, such as pressure and anxiety; equipment, such as design and instructions; organisational, such as out of hours care or staff shortages; patient, such as challenging behaviour or distress; and staff performance, such as gaps in knowledge; and environmental factors, such as the child being on a flight.

The researchers make a raft of recommendations, including the need to

improve the knowledge and training of staff and carers, who include relatives, nurses, paid carers, school and nursery staff, and respite workers.

"High risk emergencies can happen at any time...Some of the incidents in our study highlight lack of training for staff supporting children on long term ventilation," they write.

"The importance of good quality training and ongoing monitoring of skills for all staff that support these children is paramount for such high risk care," they emphasise. And that includes relatives.

Other "key areas of concern" include the reliability and availability of equipment, the significant stress placed on families, as well as the coordination of services, they note.

While the data they analysed reveal the types of incidents being reported, they don't indicate how often these arise, and they are unlikely to cover all the sectors in which safety problems can occur, emphasise the researchers.

"It is important to note that these incidents likely represent the tip of the iceberg," they conclude.

More information: Analysis of paediatric long-term ventilation incidents in the community, *Archives of Disease in Childhood* (2019). [DOI: 10.1136/archdischild-2019-317965](https://doi.org/10.1136/archdischild-2019-317965)

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