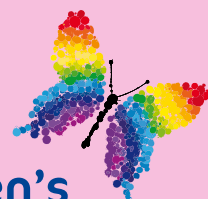




A Toolkit to Support Ventilated Children & Young People in Children's Hospices

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A Toolkit to Support Ventilated Children & Young People in Children's Hospices

Section 1

Foreword – Dame Elizabeth Fradd

I am delighted to have been invited to write the foreword for this document because so many Children’s Hospice Services are now supporting children and young people with life limiting conditions requiring long term ventilation. Hospice services are well placed to do so, but understandably need guidance, training and support to provide such complex care. In 2010, *Children’s Hospices UK* held a national seminar to explore the specific requirements for staff who provide long term ventilation support and a toolkit was proposed by delegates. In response to this event, *Children’s Hospices UK* applied and received a grant from the Department of Health, England’s (“£30 million Children’s Palliative Care Grant Programme”) to develop a toolkit to support those staff who care for children and young people requiring long term ventilation either within a hospice or at home.

I commend this excellent toolkit to care staff working in children’s and young people’s hospice services. Whilst the tool kit has been primarily developed for staff working in children’s hospices I believe it will also be a useful tool for staff working in NHS settings. It should be readily available, as a reference tool, for family members to help them understand complex elements of care provision.

Divided into six sections, the toolkit provides valuable advice and information on a wide range of important issues. Importantly the case studies and views from professionals and young people help provide reality to the text. There is a useful teaching pack as well as helpful signposting to relevant organisations. I therefore very much hope people will use the entirety of the toolkit to support their every day practice in order to; ensure the increasing number of children and young people across the UK receiving Long Term Ventilation, and their families are well supported wherever their care is delivered.



1.2 Introduction

This toolkit has been developed for professionals working throughout the children's hospice sector. Children and young people with life threatening conditions that require ventilation are entitled to the very best care when receiving ventilation support. This may include end-of-life care and bereavement support for both the child/young person and family.

The toolkit is designed to enhance current practice. It offers a range of ideas and information. It is not a workbook or programme to complete from beginning to end, nor is it an exhaustive list of ideas or subjects. It aims to help staff to support children and young people (and their families) who require ventilation. It provides practice examples, together with information about some of the ethical challenges, duties of staff, competencies and training requirements. It also includes teaching packs to support learning.

1.3 Background

Over the last ten years there has been a steady increase in the numbers of children and young people who require long term ventilation (LTV). The greatest increase in use of non-invasive LTV was due to obstructive sleep apnoea (OSA), with obesity being a key factor. The majority of these children/young people, however, would not be eligible for children's hospice care. Research has shown that the number of children and young people under 17 years who receive LTV rose from a total of 141 in 1998 to 933 in 2008 (Wallis *et al* 2010). Of the children and young people for whom data was provided, 88 received 24-hour ventilation compared with 33 in 1998. A further 658 were ventilated only when asleep, while 136 were ventilated both at night and intermittently during the daytime.

Most ventilated children and young people are supported with non invasive ventilation: In 2008, 704 were ventilated via a face mask, compared with 206 who were supported via a tracheostomy. The underlying conditions that lead to the initiation of ventilation have not changed significantly in the past decade, although the steepest increase has been in those who have neuromuscular conditions such as Duchenne Muscular Dystrophy (DMD). The average age of introduction of LTV for this group of young people is 16 years.

Children and young people with complex needs are increasingly being supported at home by their parents (especially Mothers) with the expectation that parents will also take financial responsibility for this care. Noyes *et al* (2006) found that care at home was mostly, but not always, cheaper. Nevertheless a package of care for a ventilator dependent child or young person will create additional demand on statutory budgets and meeting the needs of this group of children and young people is expensive. But

cost is not the only factor when planning care for children and young people who are technology dependent. Other vital considerations, for example, are the right of children and young people to be cared for in an environment that is most suited to their needs, and the right to respect for private and family life, home and correspondence (United Nations Convention on the Rights of the Child 1989).

What are the issues for children, young people and families?

The impact of LTV for children, young people and families will vary according to the child or young person's underlying condition and the level of support that he or she requires/receives. There may also be a discrepancy between level of need and level of provision: information from children's hospice services and from the responses of children/young people/parents or carers to service evaluation is detailed in Section 5 of this document. This information suggests that there is not always equity in the level of support available to ventilated children and young people with similar needs.

For some LTV may be initiated as an acute intervention from birth, or following a neurological insult or injury. For others the introduction of LTV is part of a wider process during the course of a chronic, long-term condition and can signify a significant milestone in the child or young person's palliative care journey (Wallis *et al* 2010).

For those for whom ventilation is a life enhancing intervention, the use of LTV may be an inconvenience: it can be challenging to manage if the child or young person becomes distressed or non-compliant due to discomfort or dislike of the ventilator. But there may be little further impact on family life as a whole.

On the other hand, children and young people who require a life-sustaining level of ventilation may receive a substantial package of care. This may involve professional carers being in the house for many hours per day, up to seven days each week.

For some, this may be a package of care that is reduced over time as the child grows and develops and is weaned off the ventilator. For example, a baby with Central Hypoventilation Syndrome will require support for several hours each day and throughout the night while they are asleep. As the child gets older and sleeps for shorter periods, however, this need will reduce until he or she requires only overnight ventilation. Other children, who are less stable will require unpredictable levels of support when unwell in addition to the care they require when asleep.

It is important that parents and families are made aware of the increased risks involved in managing a ventilator-dependent child or young person at home (or in the hospice environment), compared to supporting the same individual in an acute hospital setting. Leaving hospital will inevitably increase some risk factors: it will significantly reduce access to skilled medical support and emergency treatment, for example. But this is balanced by the delivery of one-to-one care by people who know the child/young person well.

Managing the sometimes conflicting issues of risk and quality of life is fundamentally important. For both families and professionals there is a need for open and honest discussion based around the best interests of the child/ young person and their family. The threshold of acceptable risk will differ in each case.

There are often significant financial and social implications for families caring for a child or young person who receives LTV. A study of 15 families by Margolan *et al* (2004) found that nine mothers had given up work to care for their child. Whilst none of the fathers had given up work completely, eight had taken time off. In addition, 12 homes had been adapted and a further five were awaiting adaptations. Access to a social life is also difficult (Noyes 2007). The child or young person may need to have a competent carer with them at all times which could be very restrictive, and careful planning will be required when visiting new places to ensure that adequate levels of ventilation can be maintained.

Large packages of care that involve a lot of support by professionals can have a big impact on the wider family. Families may feel a lack of privacy when there are carers working in the home for long periods of time each day. This can place great strain on family life as there is often very little short break or respite care available due to the high level of clinical expertise required to care for the child or young person's needs. Yet a breakdown in the care package will often lead to inappropriate hospital admission (Selby 2008).

What are the issues for children's hospice services?

There are a number of challenges facing children's hospice services in supporting children and young people who are ventilated. Anecdotal evidence suggests that in many cases awareness has evolved slowly over time as increasing numbers of young people arrive at the hospice for a short break with a newly prescribed ventilator to support breathing overnight. This equipment may be for life enhancement rather than for sustaining life, and there is often little acknowledgment of the significance of this new intervention - or the issues that could arise.

Until recently families were often not asked to provide the child or young person's ventilation prescription. Typically, there was little or no appreciation among staff of the parameters for ventilation and the risks associated with incorrect settings, regardless of the level of ventilation required.

The philosophy of the children's hospice movement has always been to care for the child in the same way as they are cared for at home. The young person, or their parents might simply show staff how to set up the ventilator and this aspect of care could simply be incorporated into the young person's care plan without providing additional advice or training for staff who would be caring for that individual.

A number of anecdotal reports suggest, however, that children's hospice services have

not fully acknowledged that these young people are all ventilated, and staff may not be aware of the potential changes that could occur in their level of dependency. Some children's hospice services do not feel able to support children and young people who cannot breathe without the aid of their ventilator, whilst others care for these children and young people by requiring their home ventilation team to support them within the hospice. In many cases the home ventilation team is staffed by competent carers/health care assistants, rather than nurses, and there is a need for clear understanding of where clinical and welfare responsibilities lie. In such circumstances qualified nurses working on shift will be clinically responsible for the child or young person's welfare, yet may have no additional training in this field and little understanding of the process of ventilation.

The significant increase in the number of children and young people who receive LTV brings further challenges for children's hospice services in examining the criteria for acceptance. Those who are ventilator dependent for any period of time will be at significant risk of harm should their ventilator become disconnected or ineffective. In such circumstances it could be argued that any child who is unable to cope for long periods of time without their ventilator should be eligible to access children's hospice services, regardless of their underlying condition. Some children's hospice services already acknowledge this and have extended their acceptance criteria to reflect such need. It is likely that this issue will have impact on both acceptance criteria and the wider decision making process for children's hospice services across the UK in the future.

End of life care planning/resuscitation

Ideally children and young people who receive LTV will have an end-of-life care plan that details any actions to be taken in the event of sudden deterioration in their condition, or the care needed if the decision is made to withdraw treatment.

In the event of a sudden deterioration in their condition many ventilated children and young people will require active resuscitation. It is important that children's hospice services have a clear understanding of their resuscitation status and the method of resuscitation they require. They will often require resuscitation by bag and mask or trache-valve and staff must be trained to respond appropriately in an emergency situation. It is also important to ensure that there is good liaison with the local ambulance service and the child or young person's tertiary centre.

Holistic care and support

It is clear that there is a need for more information and guidance to support children's hospice services in caring for the increasing numbers of children and young people who require LTV as part of their palliative care package. Nevertheless children's hospice services can provide a range of health, social and spiritual services that may be difficult to access in the hospital environment (Blackburn 2010). Many of these children and young people have high levels of dependency and complex care

needs which can have profound impact on a number of issues. These include risk management, staffing levels, training and development, accountability, legal and ethical challenges, culture and diversity, and funding.

1.4 Context

LTV is a relatively new but realistic treatment option for increasing numbers of children and young people who have life limiting or life threatening conditions (Wallis *et al* 2010). In such cases ventilatory support can significantly enhance quality of life. While it may not provide a cure for the child or young person's condition, LTV may increasingly become a life sustaining intervention as that condition progresses.

Many of the children and young people who are now ventilated as a part of their daily care have additional palliative care needs that are recognised and meet the criteria for children's hospice support under one of the four categories defined by ACT (2009) below. A proportion of these may already be known to their local children's hospice.

Children's palliative care

Palliative care for children and young people is defined as:

"...an active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement." (The Association for Children's Palliative Care (ACT 2009 p.7)

Because of changes in prognosis for some children's conditions ACT is currently using the following four categories of children's palliative care conditions:

Category 1: Life-threatening conditions for which curative treatment may be feasible but can fail. *Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services.*

Examples: cancer, irreversible organ failures of heart, liver, kidney.

Category 2: Conditions where premature death is inevitable, *where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.*

Examples: Cystic Fibrosis, Duchenne Muscular Dystrophy.

Category 3: Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.

Examples: *Battens Disease, Mucopolysaccharidoses.*

Category 4: Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death.

Examples: *severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode.*

(ACT 2009, p.8)

These categories are regularly reviewed and may be redefined again in the future.

Children's hospice services, including hospice at home, have traditionally supported any child or young person with a life-limiting or life-shortening condition who is not expected to survive beyond 19 years of age. As medical interventions improve many young people with complex and palliative care needs are living much longer. Some children's hospice services are now able to continue to support young people through their transition into early adulthood and beyond.

The nature and remit of children's hospice care can change over time. Some young people gradually cease to meet the criteria for support. Others, who might previously have died soon after diagnosis, are now able to survive for months or years with technological support and are now being cared for within children's hospice services (*Children's Hospices UK 2010*).

LTV

LTV is defined as: *"Any child who, when medically stable, continues to require a mechanical aid for breathing, after an acknowledged failure to wean, or are slow to wean, three months after the institution of ventilation."* (Jardine & Wallis 1998)

Advances in LTV have given rise to a whole new group of children and young people who may be eligible to use children's hospice services. There is now a cohort of children and young people who require LTV as part of a package of care for previously untreatable conditions, or as a result of intervention following an acute neurological insult or injury (Wallis *et al* 2010). Therefore any child or young person who requires life sustaining ventilation (level 3 as outlined below) could also meet the criteria for children's hospice care under the fourth ACT category above.

Some children or young people may eventually be able to be weaned from their

ventilator. But they could still meet the criteria for children's hospice care during the time that they require level 3 ventilation.

Levels of ventilation

One of the key issues for children's hospices supporting children and young people who are ventilated is understanding the importance of recognising *the level of ventilation they require*, rather than focussing solely on the method of ventilation. While it is important to understand the differing needs of those who require invasive ventilation (via tracheostomy) and non-invasive ventilation (via face mask or nasal cannulae), the critical issue lies in knowing whether the child or young person can breathe without the aid of the ventilator, and for how long, and knowing the factors that affect this - such as being asleep or unwell.

Defining the levels

The following levels of ventilation are defined according to the level of need identified within the decision support tool outlined by the National Framework for Children and Young People's Continuing Care (2010):

Level 1

The child/young person is able to breathe unaided but needs to go onto a ventilator for *supportive* ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm. Ventilation is 'life enhancing' not 'life sustaining'.

Level 2

The child/young person requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support.

Level 3

The child/young person is unable to breathe independently and requires permanent mechanical ventilation or has no respiratory drive when asleep or unconscious and requires ventilation and one-to-one support while asleep (as disconnection would be fatal).

The decision about whether to accept LTV as part of a long-term package of care for children and young people who have a long-term palliative care condition can be a very difficult issue for many children, young people and their families. Some may not feel that they wish to pursue this option.

1.5 Short breaks as part of a care package

The need for short-break care and holidays for families of children who require LTV is outlined in the National Service Framework for Children, Young People and Families Long-Term Ventilation Exemplar (Department of Health [DH] 2005). But the availability of short-break care for children and young people who require LTV varies considerably.

There is little information that demonstrates the true cost of this burden of care for families and this area would benefit from further study (Margolan *et al* 2004; Wallis *et al* 2010). Nevertheless it is evident that all parents and full time carers are dependent on adequate short breaks in order to continue to care for their child in the long term (Ludvigsen and Morrison [PRIU] 2003). In addition, home care services provided for ventilator-dependent children and young people do not necessarily enhance their lives in ways that they desire, such as enabling an active social life outside of the home (Noyes 2007) Short breaks/respice care should be an essential component of any care package, to ensure that the family remains fully supported. While children and young people may receive support, including short-break care at home, this does not give respite from the intrusive nature of the package itself.

Children's hospices can provide specialist residential care for the child or young person either with or without their family, as part of a bigger package of community based care. This means that parents can spend quality time alone together or with siblings at home while their sick child or young person is staying at the hospice, or have the flexibility to spend time together as a family within the hospice environment.

Children's hospices can also provide support to siblings whose lives are affected by the additional needs of a brother or sister who is technology dependent and requires LTV.

1.6 Transition from hospital to home

Some children's hospice services are now working in partnership with local health and children's social care services to ensure a smoother transfer of children and young people from hospital to home. In some cases, children and young people who are ventilator-dependent receive a large package of care, well in excess of the routine short-break provision offered by the children's hospice service (*Children's Hospices UK* 2010).

It is well documented that prolonged hospitalisation is not an acceptable option for children and young people who have the right to be cared for in an environment that is most suited to their needs (United Nations Convention on the Rights of the Child 1989). It can be difficult to organise care packages to support timely discharge home (Margolan *et al* 2004).

Children's hospice services at their best provide an excellent 'home from home' environment that enables the whole family to spend time together as a family unit. They can also support the training of carers (both professional health care assistants and family members) and the development of care packages. Children's hospice services are able to work in partnership with other professional organisations to ensure continuity of care for the child or young person who is moving from hospital to home (*Children's Hospices UK 2010*)

1.7 Withdrawal of treatment in a children's hospice

Many of the children and young people who use the services of children's hospices have chronic degenerative conditions that will progress and deteriorate over time. For this reason end-of-life care planning and decisions to withhold or withdraw treatment are not unusual in the children's hospice setting.

Any decisions to withdraw treatment, which may include withdrawal of ventilation and extubation, or decannulation of the tracheostomy, should be made in partnership with the child, the young person and/or their parents or carers, their consultant paediatrician and the wider multidisciplinary team. It should always be led by the desire to act in the best interests of that child or young person.

Parents' perceptions of what is in their child's best interests may differ from those of professionals. Discussions about end-of-life decision-making may often be reached together as part of the on-going relationship between hospice staff and the family that develops over many weeks, months and even years as the child or young person's condition progresses.

Some parents may have difficulty in recognising their child's changing and developing levels of autonomy and the impact this can have on the extent to which it is appropriate for the child/young person to be involved in his or her own decision-making. In such situations the unique position of children's hospices can enable staff to play a key role in supporting all family members.

There may be an increase in requests for children's hospice services to take on a greater role in supporting extubation as LTV becomes more commonplace for children and young people with palliative care conditions.

The ACT care pathway for supporting extubation within a children's palliative care framework (ACT 2011) provides clear and detailed guidance in this area.

Section 2

2.1 Legal issues

Children and young people who require LTV will be managed and supported by their own consultant paediatrician and respiratory team. Children's hospice services that support children and young people requiring ventilation have a legal duty of care, whether this care is delivered at home or within the hospice setting. Nurses and doctors also have both a legal and a professional duty to care appropriately, and must act in a manner consistent with a reasonable standard of care. Professionally, the Nursing and Midwifery Council's (NMC) Conduct and Competence Committee or the General Medical Council (GMC) Fitness to Practice Panel could find them guilty of misconduct and impose sanctions (NMC, 2008; GMC, 2011).

On legal consideration for children's hospice services caring for children and young people who are ventilated concerns the capacity and consent to accept or refuse treatment (some children/young people may be non-compliant with ventilation). Another concerns responsibility for the actions of unqualified carers who are not directly employed by the children's hospice service.

The information detailed below applies to children's hospice services in England. The situation may be different for services in Scotland [www.scotland.gov.uk], Wales [www.wales.nhs.uk] or Northern Ireland [<http://www.dhsspsni.gov.uk/index/hss.htm>]

Parents or people with parental responsibility have moral and legal responsibilities for the care and well-being of their child. They are able to care for their child according to their own beliefs and values until that child is deemed competent to take this responsibility for him/herself, provided they act in their child's best interests.

Doctors and nurses, on the other hand, must act in accordance with their code of practice. They are accountable to their employer and their professional body for their actions.

Competence/consent

Children under 16 have a legal right to confidentiality. Wherever possible, however, parents or those with parental responsibility should be involved in decisions about their care. There may be situations where a child under 16 wishes or needs to give consent for him or herself. In such cases the child or young person must be deemed 'Gillick competent' (NSPCC 2009). In other words, he or she must be able to understand, process and retain information relating to that treatment. The young person must

understand the consequences of both giving and refusing consent, and they must be able to communicate their wishes.

Children and young people's level of competence may be affected by a number of factors: These include age, cognitive awareness, ability to communicate and life experiences. Life experiences may mean that a child or young person with a long term, palliative care condition may be more able to engage in decisions about their treatment options than someone of a similar age that has not experienced life with a chronic illness or disability.

Children under 16 who are deemed competent to consent to treatment may not have a corresponding right to refuse treatment. It should be noted that competent 16- and 17- year-olds may also not have a corresponding right to refuse treatment. Nevertheless, Gillick competent children and young people often succeed in refusing treatment in the clinical setting (British Medical Association [BMA] 2000).

Mental Capacity Act 2005

The Mental Capacity Act 2005 for England and Wales came into force in 2007. It provides a framework to protect people aged 16 and over who may be unable to make some decisions for themselves. It is underpinned by 5 key principles:

- There must be a presumption of capacity – every person has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise;
- Individuals must be supported to make their own decisions
- If a person makes what might be seen as an unwise decision it does not mean that he or she is lacking capacity to make that decision
- Any act done or decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests
- Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

The Act defines who can take decisions in which situations, and how they should go about this. It also allows people to plan ahead for a time when they may lack capacity.

Vicarious liability

Children's hospice service managers should recognise their corporate responsibility and accountability for the care delivered by their service. Legal liability for this care ultimately rests with the employer who will be deemed to have vicarious liability for the actions of employees.

Some children's hospice services support children and young people who are ventilated by working in partnership with their community children's nursing service or home ventilation team. For those services caring for a child/young person in a residential hospice building this may mean that named carers employed by an agency, PCT or local authority will come with them to give care when they are staying at the hospice.

Situations will differ but it is important that children's hospice services establish who will take legal responsibility for the actions of such carers. It is also important to be mindful of the legal and professional accountability of nurses employed within the hospice. In addition children's hospice services should be mindful of the vicarious accountability of the employing hospice: it will retain responsibility for the welfare of the child or young person, even when his or her carers are employed elsewhere.

Honorary contracts

Carers who are employed by agencies outside of the hospice service may require an honorary contract in order to care for a child or young person on the hospice premises. This will vary as some community-based services may have a contract that enables them to care for the child/young person wherever they are. The purpose of such a contract is to allow the children's hospice service to discharge its duty to the individual as an honorary employee, taking responsibility for ensuring competence and ensuring that the individual can be held to account for their duty of care.

Practising privileges

Medical professionals such as the child/young person's own consultant or GP may require Practising Privileges to carry out clinical assessments or support care of the child/young person when he or she is staying at a children's hospice.

Confidentiality

Confidential information can be defined as:

- Private or sensitive personal information
- Information that is not already lawfully available to the wider public or readily available from another public source
- Information that has been shared in circumstances where the person giving the information could reasonably expect that it would not be shared with others.

(Department for Children, Schools and Families and for Communities and Local Government 2008)

Respect for confidentiality is an important component of the Data Protection Act (2005) and is a key consideration for health care professionals. Children, young

people and families should feel confident that their personal information is being kept safe and their privacy maintained. However the Data Protection Act should not be a barrier to sharing information. There are situations where sharing of information is essential to good practice and the provision of well-co-ordinated services (Department of Education, Schools and Families 2008).

2.2 Accountability

Many home ventilation teams that care for children and young people consist of a team of competent health care assistants who are trained and supported by qualified nurses. Competent health care assistants may be alone with the family, supporting the child by following strict protocols, but without the autonomy or authority to make decisions outside of identified parameters.

In this situation, health care assistants will only be accountable for following the procedures and protocols provided by their training. They will not be expected to act outside of these limitations. There may not be a trained nurse on the premises, and in such situations support is provided by a robust nurse-led 'on-call' service. In contrast to this, residential children's hospice services will always have nurses on the premises when caring for children and young people.

The Nursing and Midwifery Code (NMC), published in 2008, states that any decision to delegate is either made by the nurse or midwife or by the employer. The person who decides to delegate remains accountable in this situation. Children's hospice services are predominantly nurse-led and they have a duty of care for all qualified and unqualified staff that requires them to provide appropriate training and supervision for those caring for children and young people. They must ensure that nurses taking responsibility for the care of children and young people have the necessary training and skills to do so.

Health care assistants have legal accountability for their actions. But when nurses are on duty those nurses are accountable for the supervision and support of health care assistants who perform aspects of care normally within the nurse's scope of practice. The professional accountability of the nurse will stand regardless of whether the health care assistant is employed by the hospice or is part of the child or young person's home ventilation team working within the hospice.

The code states:

"You must establish that anyone you delegate to is able to carry out your instructions."

"You must confirm that the outcome of any delegated task meets the required standards."

"You must make sure that everyone you are responsible for is supervised and supported."

Where a nurse or midwife has authority to delegate tasks to another, they will retain responsibility and accountability for that delegation.

(NMC 2008)

Nurses must be able to justify the decisions they make. They should only delegate an aspect of care to someone whom they believe to be competent to perform the task. It is therefore essential that the nurse has the knowledge, skills and ability to recognise and understand whether the person to whom they have delegated a task is competent to carry out that task safely and effectively. The nurse must be able to assess and reassess the condition of the child or young person at appropriate intervals to ensure that their condition remains stable and predictable. They must also be able to recognise the need, and respond should the circumstances within which the task has been delegated change and delegation is no longer appropriate. It is not acceptable for a nurse to delegate responsibility for a child or young person's care if that nurse does not have the skill and expertise to recognise when the care given is unsafe or inappropriate.

It is equally important that children's hospice service managers, particularly those with clinical responsibility, recognise their responsibilities. Those responsibilities include ensuring that staff employed by the service, or working within the hospice environment, are competent to provide the care required. Managers should ensure that all staff receive appropriate training and support to enable them to carry out their duties effectively.

2.3 Ethical issues

There have been a number of recent high profile ethical debates regarding the appropriateness of LTV for some groups of children and young people. Medical opinion on the appropriateness of LTV may differ (Wallis, *et al* 2010). However awareness of the need for guidance is growing, for example, a consensus statement for the standard of care for infants with severe type 1 Spinal Muscular Atrophy (SMA) was developed in 2009. This acknowledges the value of non invasive ventilation for some, less severely affected individuals but states that long term invasive ventilation would not be appropriate for this group (Roper and Quinlivan 2009).

LTV has continued to evolve as a treatment option for many children and young people and it is essential that any decision to ventilate must be in the best interests of that individual. Decisions should be made by the consultant paediatrician and multidisciplinary team in partnership with that child or young person (if possible) and with their parents/carers.

Each child/young person is unique and specific ethical dilemmas or challenges

may rise at any time. Such issues should initially be raised with the hospice clinical governance committee but may also need to be taken for discussion at a higher level within the hospice service's local ethics committee.

Most children's hospice services already offer one-to-one care for all children and young people. But those who are ventilated may require more frequent access to the service to enable staff to retain skills. The ventilated child or young person may require the support of more than one nurse or carer. They will also require support from nurses and carers who have a higher-level skill set than is required to support others who use the service.

This additional need should be acknowledged when considering the impact on others using the hospice of supporting children and young people who are ventilated. But it is equally important to balance this against the impact of LTV on the accessibility of other services for this group. Many short-break care facilities are simply not equipped to manage children on LTV, and this means that the options for these children and young people will be more limited than those available to other children and young people with complex needs.

2.4 Culture and diversity

We are all subject to cultural factors and values that influence our choices and the acceptability of the decisions we make. Emotional, psychological and spiritual concerns will all underpin the way in which we cope with difficult situations.

The impact of LTV can raise significant issues for many families and it is important to understand the way in which culture and diversity affect the way in which families react to the challenges they face. While it is vital to have an understanding of how factors such as culture and religion can influence the ability to engage in care, it is important to avoid stereotyping and carry out individual needs assessment.

It may be helpful to appoint a named key worker. In addition, peer support and the involvement of the wider family or community may be helpful. Providing access to interpreters or translation services, if appropriate, will help to reduce a sense of isolation. Staff should always ensure that they are able to communicate effectively with families in order to be able to understand their expectations around faith and culturally appropriate care.

2.5 Risk management

Risk assessment can be defined as “... a careful examination of what could cause harm to people, the environment and the organisation...” (Lewis and Noyes 2005)

Risk assessment and risk management are key factors in supporting children and young people who require LTV. Those caring for them need to identify risks and develop strategies that will reduce these to an acceptable level.

When supporting children and young people to live outside of hospital it is important to recognise the element of risk involved. Risk assessment and careful planning should enable children’s hospice services to identify the key issues and develop training and policies that will reduce the risk of harm, without undermining the choices that are important for each child/young person and family. Furthermore, children’s hospice services should acknowledge their responsibility for raising awareness about risk factors and risk management among the children, young people and families in their care. Open and honest discussion will enable each family to make informed choices about their care within the children’s hospice environment.

Risk can be mitigated in a number of ways:

Assessing the risk in the context of the child/young person

The risk should be removed wherever possible. This can be done by ensuring that there is always access to a fully charged battery and a back-up ventilator, or by ensuring that a suction machine is always charged and readily available.

Risk assessment

Assessing risk factors for children and young people who require LTV can be a complex business. For example, child A may achieve huge benefit and enjoyment from being able to access hydrotherapy, despite requiring level 3 invasive ventilation, whereas child B would not gain anything from this activity. In this situation what might be an acceptable risk for child A would not even be worth considering for child B.

It is also important to recognise the level of autonomy that children/young people and their families have in risk taking if they are making choices that are appropriate for them. Hospice staff need to understand that it may not be acceptable for professionals to make similar decisions on their behalf.

Parents may choose to sleep while their child is ventilated overnight, managing risk by assuming that the ventilator or a monitor alarm will wake them. There is always scope for human error, however, in setting parameters for monitors. And an alarm may not be triggered in time to act. In addition, some oxygen saturation monitors can automatically switch off without alarming if the external power supply becomes disconnected and there is no battery back-up, or if the battery runs out. Because

of this it would not be acceptable for professionals to rely solely on an alarm when caring for a child or young person who is unable to breathe without a ventilator.

Training/retraining

It is essential that any professional involved in caring for children and young people who require LTV should be competent to support them. Nurses may be expected to have a higher level of skill and decision-making ability than health care assistants. Nevertheless, anyone who accepts delegation of a nursing task must ensure that they are competent and have the skill to carry out that task. Maintenance of this competency will require regular exposure to the task and regular review and re-training. Monitoring and supervision are also key factors in ensuring that skills are maintained.

Staffing levels

Risk assessment will enable children's hospice services to identify how many staff will be needed to support each child or young person in their care who requires LTV. This will vary according to the level of ventilation involved and depending on factors such as the stability of the child's condition or other clinical needs. A young person with Duchenne Muscular Dystrophy who is ventilated at level 1 may only require hourly monitoring when asleep but, a child whose condition is unpredictable may require the support of two health care assistants or a qualified nurse at all times when the ventilator is in situ. As most children's hospice services are nurse led units it is important to ensure that there is at least one nurse on duty at all times who is familiar with each child's needs and competent to manage care accordingly.

On-call support

Access to 24-hour support is important when caring for children and young people who require LTV. This should include maintenance of equipment and may include liaison with the home ventilation team and/or tertiary centre.

Protocols and procedures

Children's hospice services should have robust strategies and protocols in place for managing LTV. Protocols may be slightly different depending on the level of ventilation required. Each child or young person will have individual needs that should be clearly documented in their care plan.

Step Down from nurse to health care assistant

Many LTV care packages involve the delegation of nursing roles to competent health care assistants. Risk assessment should acknowledge the accountability issues that arise in such situations and identify whether the child or young person's condition is stable and predictable enough for their care to be delegated. In some cases it may be essential for all care to be delivered by a qualified nurse, or additional measures may need to be introduced - such as the need to have two health care assistants with dedicated roles working together as a team with access to nursing support if required.

Environmental control

Risk assessment involves careful consideration of environmental factors. These include ensuring that there is always access to a power supply in an emergency situation and identifying factors that might trigger the need for ventilation. Environmental issues will vary as the child or young person moves around the hospice building or leaves the premises. It is therefore important to assess each location separately to ensure no assumptions have been made that could place them at risk of harm.

The key risk-related issue when supporting children and young people who require LTV lies in understanding what level of ventilation they need, rather than whether or not ventilation is invasive or non-invasive. A child/young person who is ventilated at level 3 would not survive if their ventilator failed, regardless of whether ventilation is delivered via a tracheostomy or face mask. Some examples of risk assessments for children and young people requiring each level of ventilation are given in appendices 5.3 – 5.6.

2.6 Financial implications

The number of children and young people who are ventilator dependent has increased dramatically over the past ten years. In 1998 68% were managed at home but by 2008, this applied to 91% (Wallis *et al* 2010). Information about the support of ventilated children and young people by children's hospice services is now being collated through the *Children's Hospices UK* annual data collection.

The number of ventilator –dependent children and young people is likely to continue to increase as non-invasive LTV becomes more widely accepted as a long-term care option for those with chronic neurodegenerative conditions such as Duchenne Muscular Dystrophy (DMD). DMD causes respiratory muscle weakness that leads to sleep hypoventilation.

Until the 1990's the onset of sleep hypoventilation meant imminent death unless invasive ventilation via tracheostomy was introduced, and this raised significant ethical questions about the appropriateness of invasive ventilation for people with incapacitating incurable disease. Today, however, the increasing availability of non-invasive ventilation at home for this group of young people has proven effective in both relieving symptoms and in increasing life expectancy (Manzur *et al* 2008).

There is little recent data regarding the financial cost of supporting children and young people who require LTV. It is clear, however, that the cost will vary according to the level of ventilation required. The cost will be significantly higher for those who require invasive ventilation or ventilation at level 3, regardless of whether this is invasive or non-invasive.

Noyes *et al* (2006) examined care packages for 35 ventilator dependent children and young people aged between one and 19 years from the caseloads of 11 consultants across England and Scotland. Some were supported in hospital, some at home and some were in the care of their local authority. The researchers found that caring for ventilator dependent children and young people at home is usually, but not always, cheaper than supporting them in hospital or long stay units, with the majority of the cost being picked up by the NHS.

Noyes *et al* found that the total cost of supporting 35 ventilator dependent children and young people over a 12-month period was over £6.2 million (based on 2002 prices). Of this sum, 92% was borne by the NHS, 3.2% by education authorities and 1% by social services. The annual cost per child ranged from £10,000 to £633,700, excluding the cost of informal care.

Home care costs included medical equipment, pharmaceutical products, and professional care. This included qualified nurses, nursery nurses and unqualified carers. Some teams were made up of a combination of skilled and unskilled staff and some parents or health care assistants were supported at a distance by qualified nurses.

Packages of care ranged from night or day time only to 24 hour support. The average annual cost of care at home for a ventilator-dependent child or young person was £104,352 but costs could be as high as £239,855 for 24-hour care. The cost per child ranged from £10,000 to £633,700 per child, excluding the cost of informal care. This compared with an average annual cost of £155,158 for care on a children's ward, £301,888 in a LTV unit and £630,388 in a children's intensive care unit.

This data is supported by Murphy (2008) who found that the average cost of caring for a child in a paediatric intensive care unit was £2,067 per day, equating to £754,455 annually, in contrast with £100,000 - £250,000 for a community package.

Both Noyes *et al* and Murphy identified additional issues to consider when caring in a hospital setting for children and young people who are medically fit for discharge. Important areas to consider include emotional, social and psychological implications for the children/young people and families and the impact of blocking an acute bed that could be required urgently by another patient.

Evidence shows that as the financial cost of supporting children and young people who require LTV escalates, parents, especially mothers, are increasingly expected to be actively involved in the care of their disabled child (Noyes *et al* 2006). They will often be the principle carers, learning complex nursing skills and assuming 24-hour responsibility in order to keep their child at home (Sidey *et al* 2006).

A study of families who received home care support for a ventilator-dependent child

found that the quantity of support varied from none at all to 168 hours per week (Margolan *et al* 2004). Where available, support was generally provided by home-based health care assistants and funded by the NHS. While the majority of parents were happy with their care, some were concerned about a lack of privacy and the stress caused through having carers in the home.

The study also found that it was often difficult for professionals to cover annual leave or sickness, especially at short notice, and parents often had to step in at these times. Most of the families received some respite but the majority found that planned respite was inadequate. Parents were usually highly dependent on formal respite because extended family or friends were not able to help without comprehensive training, which was rarely provided. Margolan *et al* identified the need for joint funding between health and social care to enable adequate short-break respite to be provided.

The need for more joint working to support children and young people and their families is well documented (Craft & Killen 2007); Kennedy (2010); DH (2010); Hughes-Hallett & Craft (2010). The NHS, Social Care, and other agencies should work in partnership with families to ensure high quality, well co-ordinated care. In addition, there is growing emphasis on the need to keep children and young people and their families at the heart of decision-making. To facilitate this, there is government commitment that shared decision-making will become the norm, with a strong emphasis on an approach that reflects the concept of “no decision about me without me” (DH 2010).

The government is also committed to ensuring that improved outcomes for children and young people will be the driver for delivery of services (DH 2010). The development of a ‘payment by results’ system means that increasingly funding is set to follow the patient. This provides a real incentive for trusts to deliver high-quality services that meet the needs of all children, young people and their families (DH 2010).

Children’s hospice services provide holistic, child/young person centred care that is highly valued by those who access this support. The philosophy of one-to-one care and competency-based practice ensures that highly dependent children and young people, including those who require LTV, are able to receive care that meets their needs. This gives the whole family an opportunity to benefit from short breaks, offering respite from an intrusive package of care at home.

Despite these benefits government funding for children’s hospices only covers an average of 15% of running costs. This proportion would be even lower but for a programme of emergency funding by the DH through Section 64 (Hughes-Hallett and Craft 2010).

2.7 Staffing

Children's hospice services have a philosophy of offering a ratio of one-to-one care as a minimum. It is important to fully assess the needs of the individual when planning care as some children and young people with complex needs - including some who are ventilated - need a higher ratio of care at certain times. In addition, staff may need to acquire specific skills to care for these children and young people, and this should be taken into account when considering service provision and planning off-duty. Families may also benefit from the support of a link worker or named nurse who can liaise between the hospice, family and other professionals involved in their care, including the home ventilation team and acute hospital services.

Section 3

The following case studies illustrate different levels of ventilation. Names have been changed to preserve the anonymity of those involved but all have given their consent for the following information to be used in this toolkit.

3.1 Case study 1 – Mikael: level 1 ventilation

Mikael was born with Duchene Muscular Dystrophy. At the age of 14 he began to suffer with headaches on waking and generalised fatigue throughout the day. During this period he also developed acute pneumonia and was admitted to his local paediatric intensive care unit where he was ventilated for several days. Following his recovery from this illness and during his subsequent care on a children's respiratory ward, investigations found that he would benefit from overnight non-invasive BIPAP ventilation via a face mask. He was discharged home with a Nippy 3+ ventilator.

Mikael can breathe easily without his ventilator during the day and initially struggled to accept that it was of any benefit to him. He dislikes wearing the face mask and for several months he would only use the ventilator for short periods at night if coerced by his mum. Over time, however he has come to realise that his quality of life is much better on the days after he has used the ventilator. He has gradually started to use it for several hours every night. Mikael does not require additional support when using the ventilator and does not have an overnight care package.

3.2 Case study 2 - Maria: level 2 ventilation

Maria is 17. She was born with severe cerebral palsy. Her condition has deteriorated over recent years. Because of severe scoliosis she now requires level 2 intermittent positive pressure ventilation (IPPV) using a Nippy 3+ ventilator via nasal prongs, for up to 24 hours a day. She is able to breathe without her ventilator but would become very unwell and require hospital admission if she were without it for any significant length of time. She uses the ventilator most of the time; she is only without it for short periods during the day to reduce the risk of tissue damage around the nasal prongs. She lives at home with her mum and visits her local children's hospice for day care every week. Maria does not have any additional care at home overnight. She is often anxious about her condition and has initiated several conversations with hospice staff, talking openly about her hopes and fears. She enjoys visiting the hospice and also feels that her mum benefits from the break.

3.3 Case study 3 – Ameera: level 3 ventilation

Ameera is six years old. At the age of two she developed acquired central hypoventilation syndrome caused by brain stem lesions of unknown origin. A further complication of her condition led to her requiring a tracheostomy to support her breathing. Following an acute exacerbation of her condition she is now unable to breathe without the support of her ventilator when she is tired, asleep or unwell. She is fully ventilated overnight via a LTV 950 ventilator. Her difficulties are compounded by complex seizures that regularly lead to respiratory arrest leading to a need for resuscitation via bag-valve to her tracheostomy.

Ameera has an extensive care package to support her needs. At home, she has overnight support every night from her local Community Children’s Nursing Service plus care either at school or at home for five days per week. She also has care for two evenings per week, and every six weeks she has two full days of respite. When she stays at the children’s hospice she is cared for by nurses who have been trained to manage her ventilator. There she receives one-to-one support both day and night. Her parents value the break this provides as when Ameera is at home it is difficult for them to have quality time together: They have very little opportunity to spend time alone, especially at night, as she needs to have nurses or health care assistants with her at all times, or one of her parents has to stay with her to monitor her ventilation.

3.4 Case study 4 – Stuart: withdrawal of treatment/extubation

Stuart died at the age of four after being born with an undiagnosed neuro-degenerative condition. When he was 12 months old he was admitted to PICU following a respiratory arrest during an acute illness. Numerous attempts to wean him from the ventilator failed, and he became dependent on invasive ventilation via a Nippy Junior ventilator. Despite a successful transition home his condition was found to be progressive and he required frequent readmissions to hospital, eventually becoming so unstable that it was unsafe to care for him at home.

The progression of Stuart’s condition meant that he became unable to respond or communicate with those around him. Investigations found, however, that he had a normal EEG, was able to see shadows and could hear well. It became clear that he was ‘locked in’, with no hope of recovery. After numerous multi-agency meetings his parents took the decision, with his medical team, to withdraw all treatment including ventilation.

Stuart had previously been referred to his local children’s hospice and his parents asked if he could be transferred to the hospice for the extubation to take place there.

The family had been able to spend little quality time together in the last few months of Stuart's life. They wanted to have some time to be a family, outside of the hospital environment before he died. This was agreed and arrangements were made for Stuart to be transferred to the hospice. Throughout this process, and during his short stay at the hospice Stuart's family were able to discuss their wishes around his death and were given support to plan and arrange his funeral.

Stuart was extubated in his bedroom 48 hours after arriving at the hospice with his parents and consultant at his side. He died peacefully within a few minutes of being extubated. His family were supported throughout the whole process by a named key worker within the hospice and this support has continued following bereavement.

Section 4: Service evaluation

This section has been contributed by Alison Cooke from Rainbows Hospice for Children and Young People and Tracy Ruthven of National Clinical Audit Support.

4.1 Questions for children's hospice services relating to care of children and young people who are ventilated

As part of the development of this toolkit it was important to gain information from children's hospice services about the numbers of children and young people who are ventilated and the level of ventilation they require.

Methodology

A short questionnaire (appendix 6.2.1) was considered the most appropriate and cost effective methodology to enable all children's hospice services contribute easily to this aspect of the project. The questionnaire developed by the project team included sections to capture information about the levels of need, as outlined in the National Framework for Children and Young People's Continuing Care (2010), and about the ventilators used. Most questions included an option to categorise answers straightforwardly but hospice staff were also given the opportunity to expand on their answers and comment further on the care they provided. Hospice services have been anonymised for the purposes of this analysis.

Response

Fifteen out of 44 children's hospice services responded to this questionnaire equating to a response rate of 34%. One children's hospice service with multiple sites provided a response from each site. The project team asked for responses to be returned by the end of January 2011.

Results

For each question we have summarised the quantitative data collected and the qualitative answers given. The quantitative data is displayed using simple frequency and percentage calculations. The qualitative data is grouped where practicable or provided alongside the quantitative data to give additional detail.

The following classifications are based on the levels of need outlined in the National Framework for Children and Young People's Continuing Care (2010):

Level 1

Is able to breathe unaided but needs to go onto a ventilator for **supportive** ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm. Ventilation is 'life enhancing' not 'life sustaining'

Level 2

Requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support

Level 3

Unable to breathe independently. Requires permanent mechanical ventilation or has no respiratory drive when asleep or unconscious, requiring ventilation and one-to-one support while asleep because disconnection would be fatal

In total information relating to 157 children and young people was provided by children's hospice services that responded to the questionnaire.

Number and percentage of children/young people supported by:

Invasive ventilation (via tracheostomy)	40 (25%)
Non-invasive ventilation (via facemask or nasal cannulae/nasal pillows)	117 (75%)

Number and percentage of children/young people supported at each level in relation to the total number identified as ventilated (n=157)

Level 1	51 (33%)
Level 2	62 (39%)
Level 3	44 (28%)

The following information provides a breakdown of children supported at each of the identified three levels of support.

Number of children/young people supported at level 1:

Invasive ventilation (via tracheostomy)	0
Non-invasive ventilation (via facemask or nasal cannulae/nasal pillows)	51

Do you provide any additional support for this group of children and young people?

Children's hospice service	Comments
1	Short breaks, hydrotherapy, physiotherapy
2	Nothing specific, although all staff are knowledgeable of supportive ventilation and are able to provide advice and support as needed
3	Occasional home care

Number of children/young people supported at Level 2:

Invasive ventilation (via tracheostomy)	3
Non invasive ventilation (via facemask or nasal cannulae/nasal pillows)	59

Do you provide any additional support for this group of children and young people?

Children's hospice service	Comments
1	4 have overnight SATS monitoring 1 has regular Nebulisers Some have a camera on overnight
2	Extra member of staff provided overnight to ensure specialist on-to-one care is provided and a safe environment is maintained
3	Occasional home care
4	3: CPAP 6: BIPAP

Number of children/young people supported at level 3:

Invasive ventilation (via tracheostomy)	37
Non invasive ventilation (via facemask or nasal cannulae/nasal pillows)	7

Do you provide any additional support for this group of children and young people?

Children's hospice service	Comments
1	One young person uses face mask at night and nasal cannulae during day
2	Hydrotherapy, chest physio, short breaks
3	Nursing care is provided either in the hospice and/or in the family home according to the wishes of the child, or young person, and their family. The children and their families are invited to take part in a range of social and fun activities throughout the year
4	These children are cared for on a one to one basis 24 hours a day, when ventilated by qualified nurses who have experience caring for long term ventilated children. Staff have gained experience by working on a high dependency ward and have completed competency training
5	One child is fully ventilated
6	We would put an extra member of staff on the night shift depending on the dependency levels of the other children staying
7	Home care more common. Useful for familiarising staff with children and young people as well as providing support
8	[Hospice] allocates two members of staff to care for ventilated children/young people if they are the primary carers. 'By this I mean carers from home do not come with the family. We have three children who visit where this is the case. Two young people wish for their carer to look after them for the 24 hours, so that's great and we provide accommodation. For Two children at present we are working alongside home carers during the day and at night but we hope to take over night-time care during 2011. By allocating two staff (one always a nurse with additional ventilator training) and a carer it allows the children to go out on trips/shopping/movies etc'

Please identify the numbers of children using the following modes of ventilation used by children and young people who use your services:

157 children/ young people were identified by services that responded as being ventilated. The mode of ventilation was identified for 121 (77%) of these children/ young people.

Number and percentage of children/young people using identified modes of ventilation (n=121)	
CPAP	26 (21%)
BIPAP	67 (55%)
Pressure Support	9 (7%)
Volume Control	9 (7%)
Other – PSIMV (Pressure Synchronized Mandatory Ventilation)	1 (1%)
Other – IPPV (Intermittent Positive Pressure Ventilation)	3 (3%)
Other – Pressure Control	5 (5%)
Other – SIMV and Pressure Control overnight	1 (1%)

One hospice identified usage of VIVO 40 but did not provide information about numbers of children/ young people.

One hospice didn't know which ventilators children/ young people use but has subsequently started to collect this data.

Please identify the types of ventilator used by children and young people who use your services:

The following types of ventilator were identified by children's hospice services as being used by children/ young people who access their service.

BREAS Legendair LTV 950 Nippy Nippy II	Nippy 3+ Nippy Junior Nippy Junior Plus Nippy Junior 3 Nippy S+	REMstar M series Resmed Elisee Respironics Synchrony Resmed VPAP III SMARTAR + (Airox)
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If you are not able to identify the levels or modes of ventilation please would you provide the number of children and young people who are ventilated at any level/mode:

One children's hospice service identified that they support children/ young people who use seven different combinations of ventilators/modes of ventilation.

One children's hospice identified that they didn't know the levels or modes of ventilation required by children/ young people using their service.

4.2 Questions for children and young people who are ventilated in children's hospices

It was also felt important, in the development of this toolkit, to gain information about the experiences of those ventilated children and young people who already visit children's hospices.

Methodology

A short questionnaire (appendix 6.2.2) was considered the most appropriate and cost-effective methodology to enable all children's hospice services to reach children and young people who are currently ventilated and use their service.

The questionnaire developed by the project team consisted of ten questions and a section for other comments. Most questions invited respondents to categorise their answers but there was also plenty of scope for children and young people to comment further. Those who responded to the questionnaire were not asked to identify themselves or the service they access.

Response

It is impossible to determine a response rate for this questionnaire, this is because the questionnaire was circulated by email to all children's hospice services and individual services were then able to distribute to children and young people (who are ventilated) as appropriate. Individual hospice services were not asked to record how many children and young people they distributed the questionnaire to.

The project team asked for responses to be returned by the end of January 2011. At this point 31 children/ young people had responded. Children and young people who responded accessed a total of seven different children's hospice services.

Results

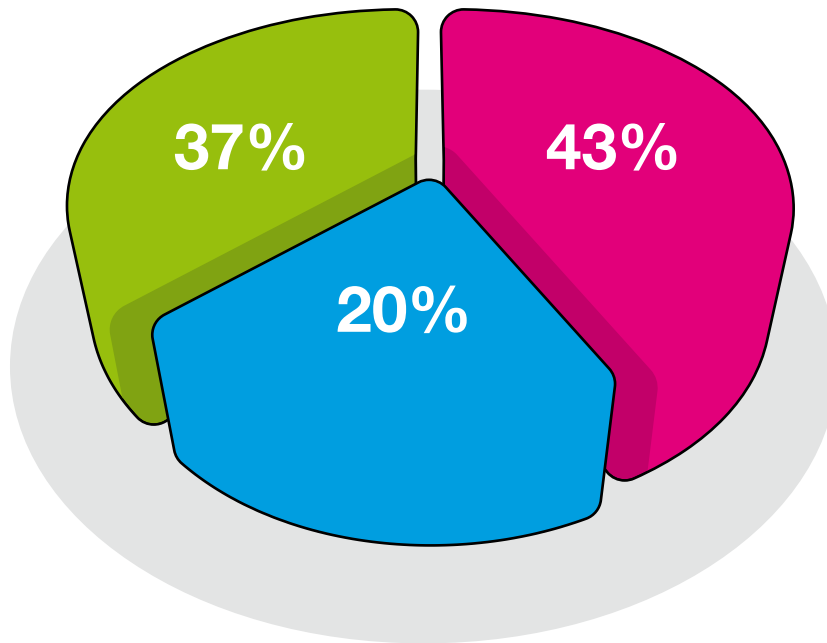
For each question we have collated and set out both the quantitative data and the additional comments of the children and young people who responded. The quantitative data is displayed using simple frequency and percentage calculations. The additional comments are grouped where practicable or provided alongside the quantitative data to give additional detail.

Question 1: Are you able to breathe without your ventilator?

Response	Frequency	Percentage
Never	4	13
Comment made by one respondent who provided a 'never' response: One who said <i>'Only when changing from one ventilator to another'</i>		
Sometimes	9	29
Comments made by five respondents who provided a 'sometimes' response: <ul style="list-style-type: none"> • <i>'Only need it overnight'</i> • <i>'I have my ventilator as I have a chronic high CO₂ and have unexplained apnoea episodes'</i> • <i>'I like to try to breathe without my ventilator. I do try but I can stay only for a few minutes'</i> • <i>'I can breathe normally but I get very breathless after meals, so I have to use my ventilator after I eat. However I could not breathe when I am sleeping without my ventilator'</i> • <i>'Must always use it when sleeping'</i> 		
Always (it is there for extra support only)	18	58
Comments made by four respondents who provided an 'Always' response: <ul style="list-style-type: none"> • <i>'[child]'s ventilation is for support only. He uses his ventilator every night, he uses one which is fitted to his wheelchair as and when he feels the need, [Child] will use his ventilator more if he feels unwell and has a bad chest, he is very aware of when he needs extra support'</i> • <i>'If I didn't use the ventilator at night I would wake up with a headache'</i> • <i>1 who said 'I use nippy +3 = non-invasive positive pressure ventilation'</i> • <i>1 said 'VPAP and oxygen required only when sleeping unless suffering from chest infection when there may be day time requirement'.</i> 		
Total	31	100

Question 2: Do you use your ventilator:

■ All the time ■ When you are tired or unwell ■ Just at night



- Six respondents (20%) identified that they use their ventilator 'all the time'
- 11 (37%) use it 'When they are tired or unwell'
- 13 (43%) use it 'Just at night'

Additional information provided for Question 2

Respondents who use their ventilator when they are tired or unwell made five comments:

- *'Every night and daytime when I am asleep and all the time when I am poorly'*
- *'Also at night – every night'*
- *'I do wear it every night BUT not when I first had to use it'*
- *1 who said 'I use my ventilator more if I have a cold or chest infection'*
- *'When well, two hrs in the day and all night. When unwell, most of the day/night'*

One respondent who uses a ventilator just at night said they would need day-time support if unwell in answer to Q1.

Question 2a: If you only use your ventilator at night, do you use it every night? (If not, why not?)

Sixteen children/ young people answered 'Yes' to this question. It should be noted

that in Question 2 there were 13 children/ young people who said they only used their ventilator 'just at night'. In reviewing the data we are aware that some children/ young people who use their ventilator at other times of the day responded to and commented on this question. All of the comments are helpful and have therefore been included.

Additional information provided for Question 2a

Six respondents provided additional information when answering this question:

- *'I use my BiPAP every night, all night. I also use it if I have a chest infection before and after physio, to give me a rest, or when I am tired after school. I think that my BiPAP has made a huge change to my life as I can get up in the morning without a sore head and eat breakfast and I'm not as tired during the day. Before BiPAP I used to have nightmares and sweat a lot at night but that has nearly stopped now'*
- *One commented that they have the ventilator on every night from 4am until they wake*
- *Another commented that they also use it when tired or unwell*
- *'Every night and when I am unwell and if I go to sleep in the day'*
- *'Do not like it'*
- *'Every night; when tired or unwell or even for a short nap'*

One respondent did not answer this question, even though they had ticked the box to say they only use the ventilator at night and had also said that the child can't ever breathe without a ventilator.

Question 3: Do you bring your ventilator with you every time you come to stay? (If not, why not?)

Thirty one respondents (100%) identified that they brought their ventilator each time they came to stay at a children's hospice.

Additional information provided by one respondent:

- *'Yes because otherwise I wouldn't have a good night's sleep and I'd wake up tired. I have not slept without my ventilator for a year now. I feel it is very helpful to me. I have less headaches, more energy and am able to think more and concentrate. I would be scared to go to sleep without the ventilator now.'*

Question 4: Do you have a back up ventilator and if so, do you always bring both ventilators with you?

Part 1: Do you have a back-up ventilator?

Response	Frequency	Percentage
Yes	13	43
No	17	57

No response 1

Additional information provided by two respondents for Question 4 – Part 1:

- *‘No, I don’t have a back up. I would like to have one as I feel like I couldn’t have a good night’s sleep without one but I could get by when well’*
- *1 respondent has a spare battery but not a spare ventilator.*

Part 2: If so, do you always bring both ventilators with you?

Response	Frequency	Percentage
Yes	8	62
No	5	38

Additional information provided by six respondents for Question 4 – Part 2:

One child/young person who has a back-up ventilator and brings their back-up ventilator with them to the hospice said ‘my back-up ventilator is a different type of ventilator’.

Five individual comments were made by individuals who have a back-up ventilator but don’t bring the back-up when they stay:

- *One has another ventilator on the ward*
- *One said ‘I don’t always bring the commented ventilator to the hospice’*
- *One said ‘I have a commented battery and a commented ventilator but only bring 1 ventilator to the hospice’*
- *One said ‘I just bring normal 1’*
- *One said yes ‘but don’t always bring it as you [hospice] have generators’*

Question 5 – Part 1: Do you have someone with you all of the time when you are using the ventilator?

Response	Frequency	Percentage
Yes	19	63
No	11	37

No response 1

Eleven respondents answered ‘no’ to Question 5, indicating that that they don’t have somebody with them all the time while using a ventilator

Two additional comments were made:

- *‘No, I get turned during night so whoever does that will make adjustments to the straps to make it more comfy’*
- *‘No – because I am asleep when I use it, but I can call my mum if I need help, she has an alarm in her room so she can hear me every night’*

Question 5 - Part 2: If so, who?

The comments below were made by 18 of the 19 respondents who identified that they do have somebody with them all of the time while using their ventilators. Their comments describe what support they receive.

Response	Frequency	Percentage
Yes – parent/s only	10	56
Yes – parent/s and trained carers/ nursing team	8	44

No response 1

- *Four said ‘Mum, only at night’. These included two who said ‘Mum does not sleep in same room’.*
- *One has parents or a carer but they don’t stay in the same room*
- *Two said parents care for them at home*
- *One said Their support came from mum and dad or respite carer/outreach staff from their hospital during the school day and every night*
- *One identified mum and trained nurses, both in the daytime and at night*
- *Three said Mum/carers at home*
- *‘Mum sleeps right above me’*
- *‘Parents when at home although not required to be in the same room’.*

- Yes – trained nurse
- Yes – NHS carer or parents (24 hours)
- Yes while awake but frequently checked when asleep – parents/carer
- ‘mum’s always in the house and we have an alarm system so I can call her.’

Question note

A review of all of the comments made in response to this question indicates that the question was interpreted differently by some children/ young people.

The two children/ young people who indicated that they don’t have somebody with them all the time while using their ventilator provided comments similar to some children/ young people who indicated that they do have somebody with them all the time e.g. mum being available at any time via an alarm system

Question 6: Who looks after you when you are using your ventilator here (at the hospice)?

Your home ventilation team nurses

Your own ventilation team carers

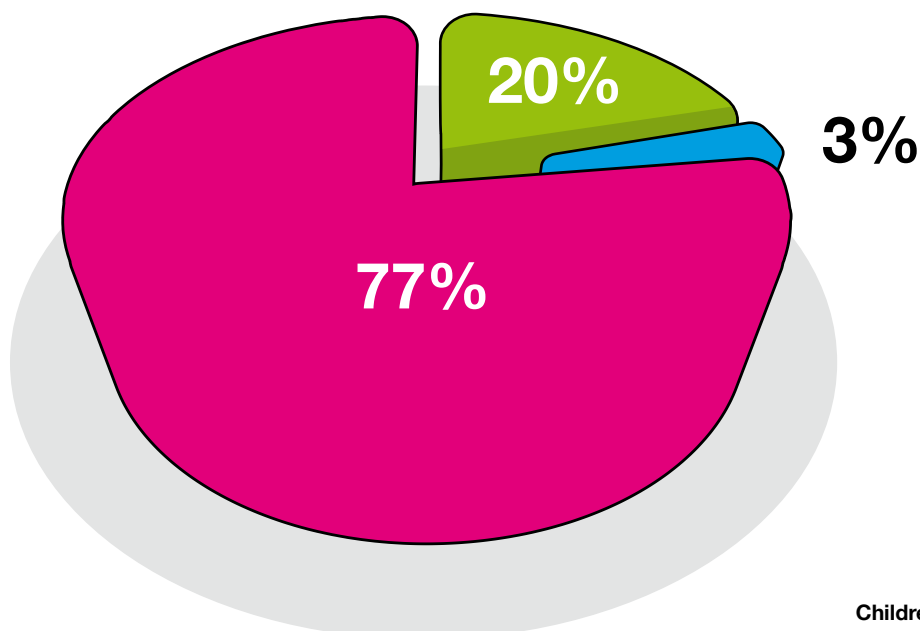
Your parents

Hospice staff

A combination (please specify)

There were 31 responses to this question. None of these indicated that home ventilation team nurses or their own ventilation team carers provided all of their care when they were using their ventilator in the hospice. One respondent identified ‘carer’ but did not specify whether this was a home carer or hospice staff, so this response has been omitted from the pie chart.

■ Hospice staff ■ Your parents ■ A combination



- One respondent (3%) identified that their parents looked after them when they were using their ventilator at the hospice
- 23 respondents (77%) identified that hospice staff looked after them when they were using their ventilator at the hospice
- Six respondents (20%) identified that a combination of people looked after them when they were using their ventilator at the hospice

Additional information provided for Question 6 – where the response to the question was ‘a combination’

- *One identified trained nurses from my team and hospice staff*
- *Three said parents and hospice staff*
- *One parent said ‘due to [child’s] complex needs my daughter requires two people to care for her most of the time. The plan is for her own nurse to work with the hospice staff but at present the NHS outreach service are not allowing her staff to do shifts at [hospice service] so we do not use [named hospice]’*
- *One said they use a combination of all and commented ‘I plan to use my own ventilation team carers because NHS & Social work and Education do not able to work together. Too many problems.’*

Question 7 - Part 1, Do the hospice staff look after you in the same way as your carers do at home when you are using your ventilator here?

Response	Frequency	Percentage
Yes	24	86
Don’t know	1	3
Other responses	3	11

No response 1

Not applicable (my mum and carer look after it) 1

Parent/ carer answering on behalf of child so unable to reply 1

Additional information provided for Question 7 – where the response to the question was ‘yes’:

- *‘They look after me the same. I think that the hospice staff should know the young people’s settings as some young people need them changed when they take sick. I know what mine should be increased to and know that they could ring my mum but it could be helpful for other young people. Hospice staff should be aware about how to protect the young people’s skin from breaking with the pressure of the mask’*
- *‘I don’t have carers at home and my mum has shown the nurses how to use it. I*

think they have had someone to speak to them too'

- *'No carers at home. Mum gets up in the night if the ventilator alarm goes off'*
- *'Yes. They were told by the same people who told my home carer'*
- *'My mother looks after me at home'*
- *'More or less the same'*
- *'Most of it'.*

Question 7 – Part 2: If not, what is different, and would you like us to try to change things?

One respondent indicated that they 'didn't know' and made the following additional comment:

- *'Not had chance to use hospice more than once'.*

Three respondents indicated 'other responses' and made the following comments:

- *'Okay'*
- *'Yes and no, depending on which staff are working'. I would like the staff to wash my mask with soap and water each morning when I've used it because it becomes dirty with mucous. My mum washes it and lets it dry on the radiator so I am able to use it that night.*
- *'Overall, yes. Most of the staff have experience of dealing with ventilator users. However if any staff have not, I instruct them'.*

Question 8 - Do you have confidence in the hospice staff looking after your ventilator?

Response	Frequency	Percentage
Yes	27	90
No	3	10

1 response not applicable as parents look after child's ventilator when staying at the hospice

Additional information provided for Question 8 – where the response to the question was 'yes'

- *'Yes, I know that the staff always listen to what I say and will ring my mum if we are both unsure'*
- *'Respiratory nurse is based at the hospital which is close to the hospice'*
- *'Yes but I do find putting my nasal prong mask on a bit tricky. It also depends on who is putting my mask on. Some staff are better than others. I try to be*

confident with the staff but I do get stressed thinking about it. This does put me off coming to stay at [hospice] because if the mask is not put on right I get a sore nose and it hurts the next night’.

Additional information provided for Question 8 – where the response to the question was ‘No’:

- *‘Not sure they would be up to date with daughter’s full care rather than the ventilator itself’ (parent)*
- *‘Not at the moment’*
- *‘50% we had issues over connections with filters and entailed oxygen. We have solved this now. Addressing the matter with staff who took photos for future admissions. We still have issues over ‘bad packing’ – i.e. not disconnecting the mask from the tubing leaving the mask at risk from squashing and breaking’.*

Question 9 - Do you feel differently when you are looked after by your own home ventilation team? (Please give details)

Response	Frequency	Percentage
Yes	4	25
No	8	50
Other responses	4	25

Not applicable 14

No response 1

It should be noted that 14 respondents felt that this question wasn’t applicable to their situation. One respondent within the ‘not applicable’ category also made the following comment:

- *‘My carers at home know how to make it really comfy because they do it more often but [hospice] staff will listen to me before they put it on and during the night if I am uncomfortable.’*

Additional information provided for Question 9 – where the response to the question was ‘yes’:

- *‘Yes in a way because my mum has more expertise, however I am willing to learn to trust the members of staff’*
- *‘Yes – my home team know me better as I am totally paralysed’*
- *‘Yes – I am more used to them’*
- *‘I feel my daughter is so complex she needs her own team at all times who are up to date with her changing health needs and equipment’ (parent)*

Additional information provided for Question 9 – where the response to the question was ‘other’:

- *‘Just the same, although I like to have some of my family with me to explain any little things I like done’*
- *‘There is no team. We as parents look after [child] on the ventilator with three nights overnight per month supported by carers/nurses paid by direct payment (employed and chosen by us)’*
- *‘My home ventilation team is my mum and dad! The ventilation team are at [hospital] where I go for regular respiratory check-ups’ (nb: This young person previously said they need their ventilator after meals and couldn’t breathe at night without it)*
- *‘Don’t know what you mean by home ventilation team – I have carers at home’.*

Question 10: Would you prefer your own team to come with you or would you prefer a complete break?

Response	Frequency	Percentage
Yes	3	23.5
No	9	53
Other responses	4	23.5

Not applicable 11

No response 3

It should be noted that 11 respondents felt this question wasn’t applicable to their situation. Three of these respondents identified that they prefer a complete break from home.

Additional information provided for Question 10 – where the response to the question was ‘yes’:

- *‘My Mum and Dad prefer my own team to come into the hospice to look after me’*
- *‘My own team’*
- *‘Yes – would want own team as I do not feel I could relax knowing staff at the hospice do not know her well enough, which defeats the whole purpose of going for us’ (parent).*

Additional information provided for Question 10 – where the response to the question was ‘no’:

- *‘Happy for hospice staff to care for child at hospice as he would say if something was wrong’ (parent/carer)*

- *'No – complete break'*
- *'No, I would like to be independent, given a choice. I feel less stressed if my mum puts the mask on. Also I have a spit cloth which is positioned under my mouth so it absorbs the mucous and it is thrown away'*
- *1 said 'Happy with the way things are with the hospice staff'*
- *1 said 'I don't have a home ventilation team but when I come to [hospice] I like to get a complete break from my parents'.*

Additional information provided for Question 10 – where the response to the question was 'other':

- *'No funding, not feasible, distances also would prohibit – needs to be staffed by hospice'*
- *'I prefer to have my parents or my sister with me'*
- *'I don't have a team at home – just parents'*
- *'Not relevant – I need 24-hour care – I cannot move at all.'*

Please add any other comments that you feel would be helpful in telling us about your experiences

Compliments to hospice staff

- *'Very happy no problems'*
- *'I am fine with no complaints'*
- *'I think that [hospice] staff are great when it comes to my BiPAP as they don't make a fuss about it because it's just another part of me J'*
- *'The one time we did visit [hospice] with our staff we found it a very friendly and relaxing experience. Our second visit was cancelled as NHS were taking our staff away for that visit so we did not go.'* (parent)

Comments about ventilators:

- *Three commented on 24 hours on-call ventilation team for support re: problems with ventilator*
- *'[Hospice] use Nippy 3 ventilator'*
- *'I go to [hospice] and have done so since 1998 (I am now aged 25). The ventilator I use is a nippy 3+'*
- *'[child] uses [hospice] and a BiPAP Ventilator'*
- *[hospice]Ventilators – Resmed Elisee 150/Resmed Ultra VS.*

Other comments

- *'I don't like myself or anyone calling my BiPAP a ventilator as I think it makes it sound scary and something more than it is! The bridge of my nose used to get really sore, but we have discovered that using Tesco's own brand or micropore*

tape helps preventing the redness. We use it because it's not too sticky to pull of in the morning'

- *'It is quite difficult to get a good seal between mask and [young person's] face, too loose causes leaks, too high causes leaks, too tight causes sore nose. This works at home because we do it daily ([young person] has asymmetrical face). Last year [young person] had 11 nights over the year so ventilation could be difficult. We do not know the young adult team to whom [young person] has now transferred {at the hospice}.'*

Section 5

5.1 Teaching pack for ventilation

This section is intended to provide information to support the delivery of training for those caring for children and young people who require assisted ventilation. It should be used in conjunction with other teaching packages to support the holistic care of children and young people. Useful resources that support teaching of ventilation, including PowerPoint presentations and workbooks are available on the ACT website (www.act.org.uk). Following the link to help for professionals.

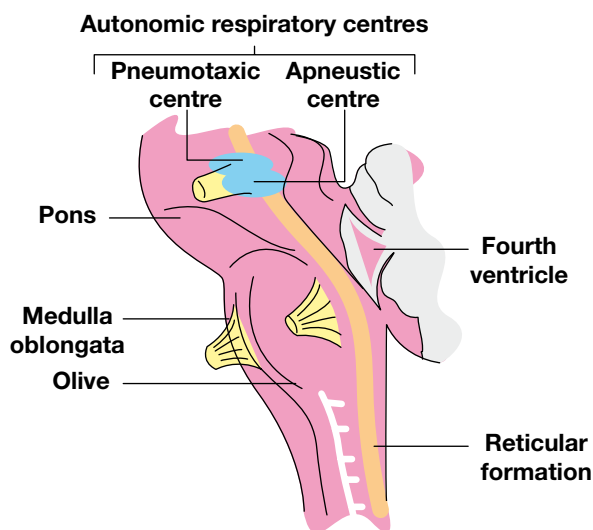
5.1.1 How do we breathe?

(This section has been contributed by Sam Harris of Acorns Children's Hospices/ Warwickshire PCT)

When we breathe we expel carbon dioxide (CO₂) – a waste product from cellular activity – and take in oxygen, which every cell in the body needs to produce energy. Cells produce energy through an aerobic process, known as cellular respiration. This is where glucose reacts with oxygen to release the stored energy. If oxygen were not present then the cells would be unable to maximise the release of energy.

Breathing can be split into three processes:

- 1 Inspiration
- 2 Gas exchange
- 3 Expiration



Inspiration

We breathe in using negative pressure. To do this the body goes through a number of processes that are triggered by a message sent to the brain. This message is first prompted by an increase of CO₂ and a lower pH level. Chemoreceptors located near the respiratory centre (**primary chemoreceptors**) are responsible for detecting these changes, known as acid-base balance in the cerebral spinal fluid. This increase in CO₂ is the cause of 'normal' respiration.

There are **secondary chemoreceptors** located in the carotid artery. These will only detect hypoxia, and when this occurs, the person affected will start to gasp for breath. Secondary chemoreceptors only detect large drops in oxygen levels and are not as sensitive as the primary receptors.

The **respiratory centre** is located in the **medulla oblongata**, which is situated in the brain stem. The Brain stem is the lower extension of the brain, where it connects to the spinal cord. It is made up of the **pons**, **midbrain** and the **medulla oblongata**. The **medulla oblongata** is the **inspiration** and **expiration centre**. The **pons** controls gasping, and this is where the **pneumotaxic centre** can be found.

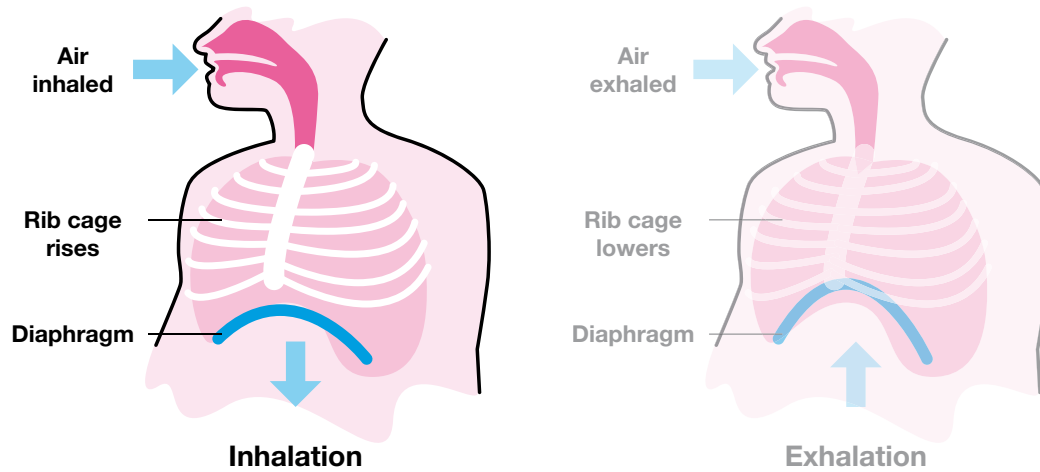
The **pneumotaxic centre** regulates the amount of air taken in with each breath. If we need to take a bigger breath or breathe faster, this centre will communicate it to the medulla.

The **apneustic centre** activates inspiration under normal resting conditions. It helps to control the depth of breath and kick starts the inspiratory centre if too long is left between breaths. It could be said that the **pons** gives all the information necessary for the **medulla oblongata** to produce the most effective breathing pattern.

Once the message has been received, a number of changes take place. The pressure in the lungs and thorax must be lower than atmospheric pressure for **inspiration** (breathing in) to occur. Air will naturally flow from where there is a high pressure to where the pressure is lower.

The **diaphragm** is the main muscle used in breathing. To create the pressure required, the **diaphragm** moves down (inverts). This is done by stimulation from the **phrenic nerve**.

The rib cage moves up and out, thanks mainly to the operation of external intercostal muscles. This results in an increase in the size of the thorax and therefore reduced pressure: a large empty space is created. Air is naturally drawn in, and inspiration has taken place. Once inspiration has occurred the body exchanges CO₂ for oxygen.

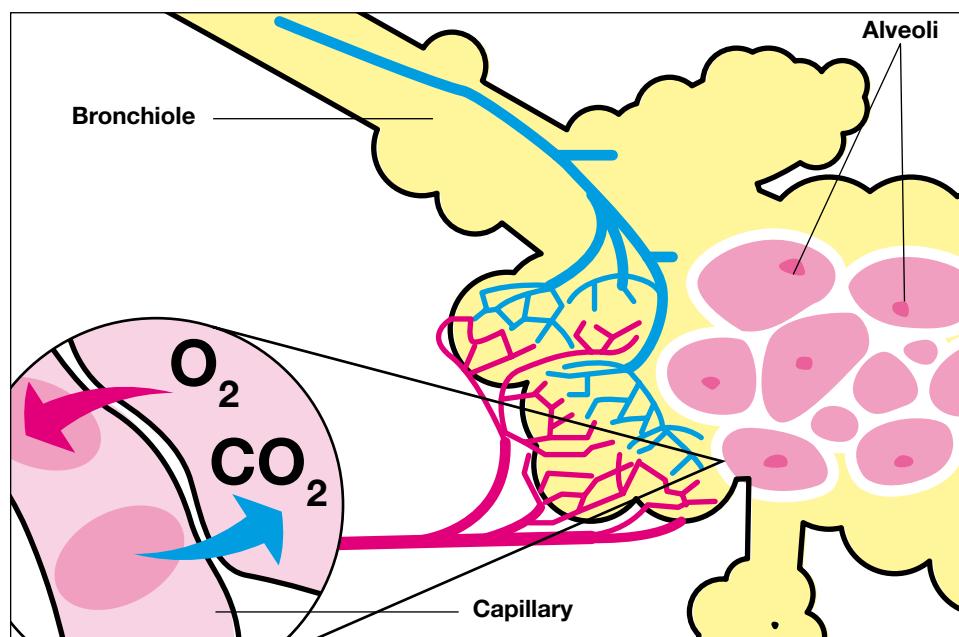


Gas exchange

Gas exchange takes place in the alveoli - tiny air sack (0.2mm when inflated) that are situated at the end of the terminal bronchioles and around the outer rim of the lungs. When the oxygenated air reaches the alveoli it is dissolved in the fluid that lines these sacks. It then passes into the blood stream through diffusion.

Diffusion

Diffusion is when particles move from a high concentration to low concentration. The oxygen binds with the haemoglobin and the CO_2 is given up. The CO_2 diffuses out of the blood plasma and enters the alveolus ready for expiration. Gaseous exchange will continue to take place while the concentration of oxygen in the lungs is greater than in the blood.



Expiration

Expiration (breathing out) is more of a passive movement than inspiration. The diaphragm rises, and there is relaxation of the rib cage, and the internal intercostal muscles. The lungs relax, squeezing the air out due to the elastic recoil of the lung muscle. Exhalation takes place under positive pressure.

Gas	% in inhaled air	% in exhaled air
Oxygen	21	16
Carbon dioxide	0.04	4
Nitrogen	79	79

[These figures are approximate]

Normal breath rates by age:

Under one year	25-35 breaths per minute
1-5 years	20-30 breaths per minute
5-12 years	20-25 breaths per minute
12 years and older	15-25 breaths per minute

References:

Human Physiology web pages - see
<http://people.eku.edu/ritchisong/301notes6.htm>

National Heart, Lung and Blood Institute website (United States) – see
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Roberts, Fred (2000). *Respiratory Physiology*. Article 11, Issue 12. pp 1-3.

Contributions:

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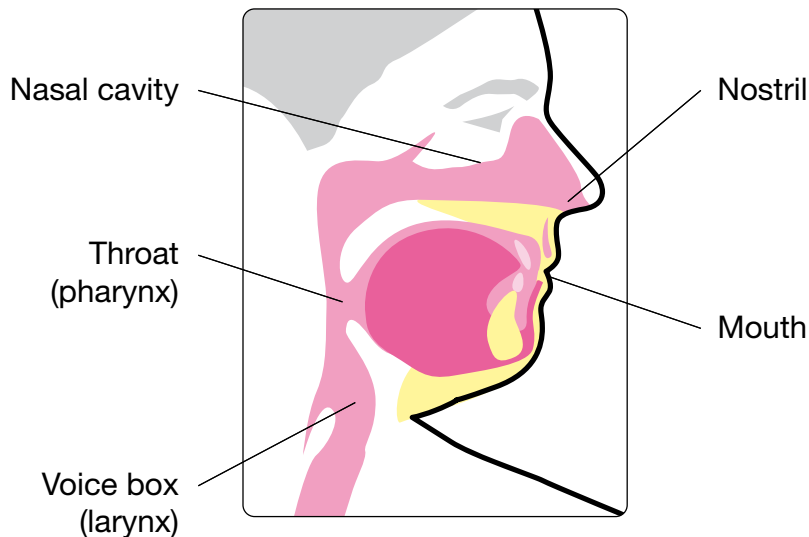
5.1.2 Anatomy of the respiratory system.

The respiratory system is made up of many structures, from the nose to the diaphragm. Each piece of the system has a unique and important role to play in helping oxygen (O₂) to enter the body and in removing harmful carbon dioxide (CO₂).

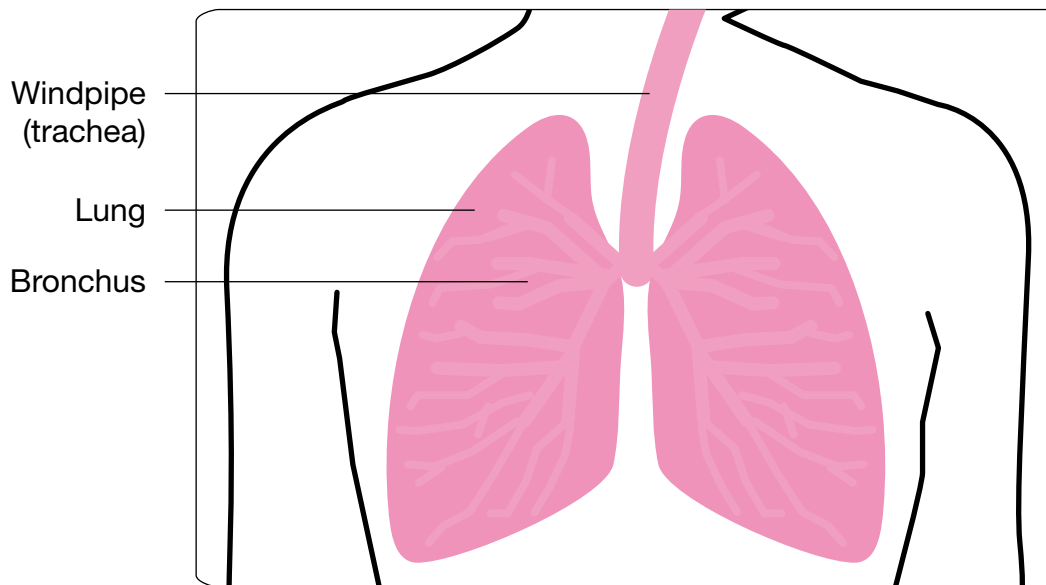
Oxygen is required so that cellular respiration can take place. This is something that happens in every cell in the body and occurs when oxygen reacts with glucose to release its' energy in a chemical form. This process also produces carbon dioxide as a waste product.

The respiratory system is normally split into two:

The upper respiratory area consists of the nose, nasal cavity, pharynx (made up of the back of the nose and mouth, ending at the larynx) and larynx (voice box).



The lower respiratory area consists of the trachea, lungs, main bronchus, secondary bronchus, tertiary bronchus, bronchioles and alveoli. When air enters the body it passes through all of these structures.



Air enters the body mainly through the nose, and sometimes the mouth. In the nose it is filtered by the hairs that are situated just inside the entrance to the nose. Particles are then trapped by the sticky mucus membrane that coats the inside of nose. The air is also warmed, and some moisture is added as it travels to the **nasopharynx**.

Beyond the **nasopharynx** air passes the **epiglottis**, the cartilage flap that covers the **larynx** during swallowing to prevent any food and fluids entering the trachea. It then passes through the larynx, a short tube joining the **pharynx** with the **trachea**. The **larynx** is a cartilaginous tube whose main functions are to protect the upper part of the trachea and to produce sound (it houses the **vocal folds (cords)** and helps manipulate the various muscles for sound production).

The **vocal folds** play a vital role not only in the production of sound but also in protecting the lungs from foreign bodies. This is achieved by the **vocal folds** shutting when swallowing occurs, ensuring that food and liquid do not enter the **trachea** during eating and drinking. Air enters the **trachea** after it has passed through the **larynx** and voice box.

The **adult trachea** is approximately 10 – 11cm long and 1.5 - 2cm wide. A **child's trachea** can be significantly smaller. In the neonate the **trachea** can be as small as 3.1cm long. Until the age of one it is no more than 4mm in diameter, while in later childhood its size is related in mm to the age of the child. It is also more mobile in children than in adults.

The **trachea** can rapidly alter its length during a deep breath. Its main function is simply to join the **larynx** to the **bronchi**. It consists of incomplete **cartilage rings** that create a C shape, with a flat muscular wall to the back. There are between 16 and 20 of these rings, giving structure to the tube and keeping it open during breathing.

The first and last rings differ from the others in thickness and shape. The last ring curves around the **trachea** and then has a hook (the **carina**) which goes under the trachea where it splits to the right and left.

On leaving the trachea air continues in the left and right main bronchi. The right bronchus is wider, shorter and more vertical than the left. This is why foreign bodies are more prone to entering the right bronchus before the left. From the main bronchus the air will travel through the **secondary** and **tertiary** bronchus, into the **bronchioles** and then into the **alveoli**. Here **gas exchange** will take place.

The right and left lungs differ in shape. The right lung has three lobes and is slightly larger, accounting for 55-60% of the total lung volume. The left lung only has two lobes to make room for the heart.

When talking about the respiratory system it is important to remember that the diaphragm is a major part. It is the main muscle of breathing and is responsible for approximately two thirds of quiet breathing.

The other important structure is the pleural membrane. This is made up of two thin membrane layers. One of the membranes excretes fluid between the pair allowing them to slide smoothly when breathing. The pleural membranes encase both lungs.

References:

BBC bite size: <http://www.bbc.co.uk/schools/gcsebitesize/science/add.aqa/cells/cell3.shtml>

Hull and Johnstone (1999). Cited in *Developing Practical Nursing Skills (2nd Edition)*. Hodder Arnold, 2005.

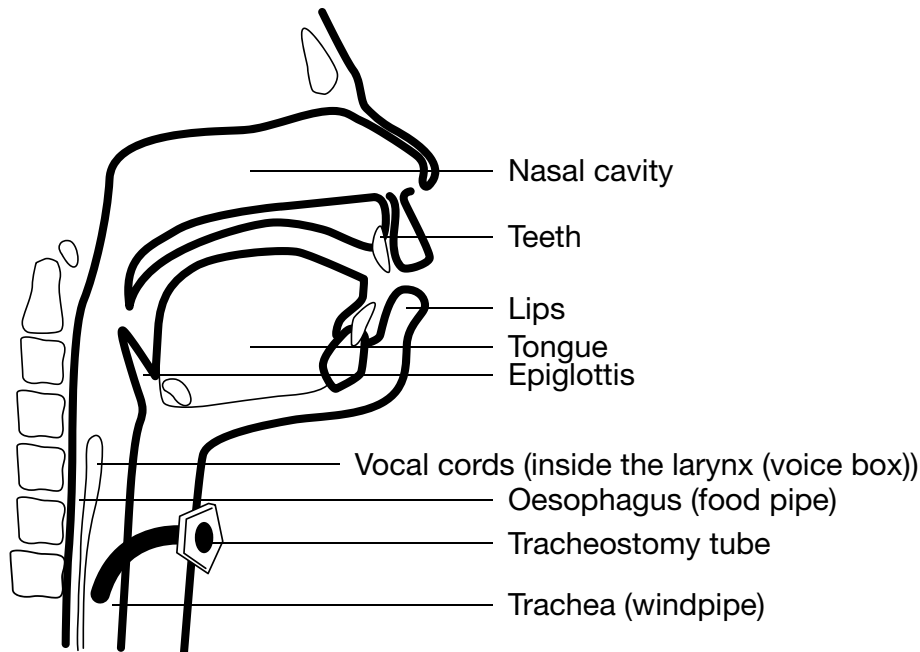
Standing, S (2008) *Gray's Anatomy. The Anatomical Basis of Clinical Practice. 40th Edition*. Churchill Livingstone, pp1000, 1005.

The Human Body Book. DK, 2007, pp 132 – 137.

5.1.3 Tracheostomy

This section was contributed by Sam Harris of Acorns Children's Hospices/ Warwickshire PCT

A tracheostomy is a surgical opening through the neck into the trachea. The opening is made between the second and fourth tracheal rings, below the level of the voice box. A tube is inserted into the opening (stoma) to keep the airway open.



Tracheostomies are created for a number of reasons:

Reasons for a Tracheostomy.	
Congenital Abnormalities	These include vocal fold palsy, trachea-oesophageal abnormalities, choanal atresia, laryngeal insults, tumours, sleep disorders, poor muscle tone
Trauma	Road traffic accident, head and neck injuries, brain stem liaisons, neurological insults, burns, long-term ventilation
Infection	Croup, epiglottitis
Foreign body	Damage due to a foreign body.

(Source: Reproduced with permission from a presentation by Annika Shepard)

Historically tracheostomies were mainly performed in children to treat infections. Today, however, they are used primarily in children that have a fixed airway lesion or a neurological impairment. The most common reason for a child/young person who requires LTV to have a tracheostomy is to facilitate ventilation (Wallis *et al* 2010).

Tracheostomies are sometimes referred to as tracheotomies but these slightly different words refer to two different procedures. A tracheostomy is a permanent stoma created via surgical procedure between the trachea and the cervical skin. A tracheotomy is a non-permanent opening and is strictly a temporary procedure. Both provide an effective channel for respiration when it is impossible to breathe via the nose or mouth, and for the removal of secretions. A temporary tracheotomy is in situ for less than six months. A tracheostomy is in situ for longer than six months.

How is a tracheostomy tube chosen?

The tube size, type and make are a clinician's decision. There are several to choose from. The decision taken is based on the child's presenting upper airway, anatomy, physiological requirements and body size.

Different types of tracheostomy tube

There are a number of different types of tracheostomy tube, including cuffed, uncuffed and fenestrated. Many of the smaller plastic tracheostomy tubes do not have an inner tube. They are called single-cannula tubes. For infants and small children, the tracheostomy tube is usually a single-cannula plastic tube and is generally not cuffed (even if mechanical ventilation is required) – see www.tracheostomy.com/faq/types.htm

Cuffed tube

A cuff is a soft balloon around the distal (far) end of the tube. It can be inflated to support mechanical ventilation in some children and young people who are ventilated.

The cuffs are inflated with air, foam or sterile water. There are several types of cuffs and these may be high volume or low volume. A low-volume cuff is similar to a balloon, whereas a high-volume cuff is barrel-shaped.

The high volume cuff spreads out the pressure rather than pushing against one spot in the airway. It can be more effective in avoiding complications such as stenosis. When the balloon is deflated, the tube allows air around tube so that the child can speak. In small children, cuffed tubes may not be needed. In older children a low-pressure cuff may be needed to achieve an adequate seal.

For children who are not ventilator-dependent, the tracheostomy tube should allow some airflow around the tube. This helps to avoid damage to the tracheal wall and to enable the child or young person to speak. (www.tracheostomy.com/faq/types.htm)

Fenestrated tubes

Fenestrated tubes have an opening in the tube that enables the child/young person to speak through the upper airway when the external opening is blocked, even if the tube is too big to allow airflow around the outer cannula. Fenestrated tubes are not recommended for small children, because they can obstruct the opening with

Granulation tissue. The opening of the hole must be at a correct angle to prevent problems. Also, in an emergency, a solid inner cannula must be inserted in order to ventilate the child through the tracheostomy (www.tracheostomy.com/faq/types.htm).

The most common makes of tracheostomy tubes are Shiley, Arcadia, and Bivona. Some examples are shown below:

Complications of a tracheostomy

There are a number of complications linked with a tracheostomy.

Immediate

- Haemorrhage, eg from thyroid isthmus
- Hypoxia
- Trauma to recurrent laryngeal nerve
- Damage to oesophagus
- Pneumothorax
- Infection (this can be infection of the stoma or the respiratory system)
- Subcutaneous emphysema
- Decrease in verbal communication.

Early

- Tube obstruction (most commonly caused by secretions; can be due to an increase in secretions, thickness of secretions, dryness, infection)
- Displacement
- Aspiration
- Bleeding from tracheostomy site
- Infection
- Decrease in verbal communication

Late

- Airway obstruction with aspiration
- Damage to larynx, e.g. stenosis
- Pressure necrosis (death of tissue due to continuous pressure)
- Tracheal stenosis (damage to the trachea from the tube leading to a narrowing of the trachea)
- Tracheomalacia
- Aspiration and pneumonia

- Fistula formation, e.g. tracheo-cutaneous or tracheo-oesophageal
- Granuloma (tumour composed of granulation tissue) usually caused by a foreign body or chronic infection
- Bleeding, due to trauma or infection
- Decrease in verbal communication

Most of the listed complications can be detected and/or prevented through good observation and high level care.

How does a tracheostomy affect the respiratory system?

Humidification

Humidity is water vapour in a gas. It is expressed in three terms:

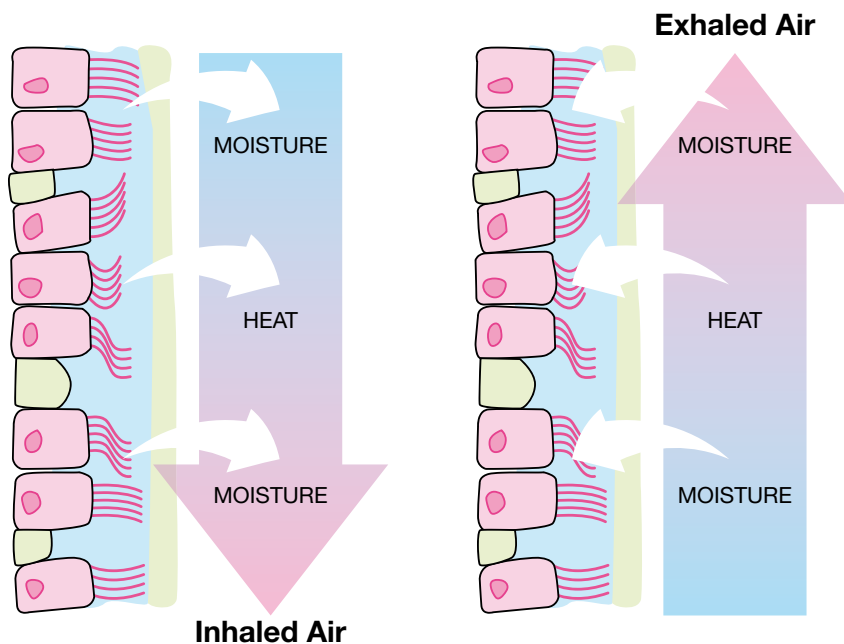
- Absolute humidity, measured in mg/l, is the amount of water vapour per litre of gas
- Relative humidity, measured as a percentage, is the actual amount of vapour in a gas compared to the maximum that gas can hold at that temperature
- The dew point - the temperature at which a gas reaches 100% relative humidity. If the gas cools, some of the water vapour is lost as condensation

Humidity values			
	Medical gases	Room air	Lungs
Temperature	15°C	20°C	37°C
Relative humidity	2%	50%	100%
Absolute humidity	0.3mg/l	9mg/l	44mg/l

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Normal Humidification

The nose and mouth are responsible in part for the warming, moistening (humidifying) and filtering of the air we breathe in (inspired). Inspired air warmed to core body temperature and is saturated to 100% Relative humidity. The upper airways only take about 25% of the heat and moisture during inspiration, the majority is taken on board during exhalation (breathing out).



The moisture is obtained by the air condensing as it hits the cooled mucosa.

We breathe in through our nose and mouth, where air is warmed, filtered and humidified. It is such a well-designed system that through nasal breathing the air is warmed to approximately 36 degrees and has about 80-90% relative humidity by the time it reaches the carina. Mouth breathing reduces the relative humidity to 60-70%. The humidified air then travels from the nose or mouth through the oral-pharyngeal space, through the larynx, into the trachea and finally into the lungs.

When a tracheostomy is formed it is sited below the larynx. The most obvious change this makes is that air is drawn in and breathed out through the tracheostomy tube rather than the nose and mouth. The placement of the tube means that the inspired air is no longer warmed, humidified or filtered. Cold gases can now enter the respiratory system and 100% relative humidity can no longer be achieved, resulting in the lower structures having to humidify and heat. Having a tracheostomy reduces the dead space in the respiratory system by 30-50%. This results in impairment of humidification, warming and filtration of the inspired air.

Mucus/sputum

Mucus is 95% water. Its function is to waterproof, to protect the epithelium and to humidify the air we breathe. It contains some white blood cells which give it a vague protection from infection role. The mucus membrane of the nose is made up of mucus coated hair and plays an important role in the filtering and trapping of dust, small particles, pollen and so on. The mucus membrane of the respiratory tract is made up of cilia.

The body clears mucus through:

- 1 Mucociliary action: the movement of mucus up through the respiratory system by a wave motion of tiny hairs. In order for this to be effective there needs to be optimum heat (37 degrees) and 100% relative humidity
- 2 Effective cough
- 3 Patent or stable airway: in other words free from infection, swelling, trauma and so on.

When a tracheostomy is in situ this can result in a drying of the tracheal and bronchial epithelium, damage to the structure of the cilia, and therefore less effective wave motion. This can then lead to pooling of mucus in the airways and inflammation and ulceration of the mucosa. The body reacts to this by increasing the production of mucus.

Having a tracheostomy leads to a thickening and encrusting of secretions because of a decrease in relative humidity in the respiratory system and a degree of compromise to the clearance system. This increases the risk of blockage to the tracheostomy. It also reduces airway patency and lung compliance, increasing the resistance to gas flows, and making it harder work to breathe.

Ineffective cough

Tracheostomies make coughing ineffective because the body relies on closure of the glottis so that a forced expiration can be produced against it. Closing the glottis increases intrathoracic pressure and helps to create an explosive force that dislodges mucus. As the tracheostomy is placed below the larynx, it prevents complete closure of the glottis. Children with a tracheostomy still have a cough reflex but it is not of sufficient power to completely clear secretion.

Poor swallow

The placement of a tracheostomy can cause pressure on the posterior tracheal wall and oesophagus. It also impedes laryngeal elevation, which is needed to ensure complete closure of the epiglottis during swallowing. This may lead to aspiration and regurgitation. A poor swallow with a tracheostomy can mean that upper airway secretions migrate to the lower airway via aspiration around the tracheostomy tube.

Points to consider

Children's airways are narrower and floppy in comparison to those of adults, while their lungs are less compliant. This creates a risk of secretions remaining within the airways, leading in some cases to blocked airways and collapse.

The insertion of a tracheostomy bypasses the vocal folds. The folds are crucial for speech and they also help break the breath as it comes out of the lungs, maintaining some pressure inside the lungs (PEEP). This pressure ensures that the next breath is easier to take and reduces the work of breathing.

Because of the reduction of pressure in the lungs at the end of each breath, a child with a tracheostomy has to work harder to breathe. This increases the amount of calories burned just in the work of breathing. A child's metabolic and ventilator requirements are two to three times that of an adult.

How do we help prevent these complications?

Many of the complications mentioned can be reduced and/or managed by good observation, and the application of appropriate knowledge and skills.

Positioning

Correct positioning of the child is imperative to help with adequate ventilation and secretion clearance. It is essential if the child is unable to change their own position. When children are lying on their side they will ventilate better on the upper lung. But perfusion and gaseous exchange are better on the lower (dependent) lung. This means that there is a ventilation/perfusion mismatch, so it is important to reposition ventilated children regularly. Repositioning also helps children breathe with different areas of their lungs, helping them to clear secretions from these areas. It is worth noting that if the child has any areas of collapse or consolidation as you move them their oxygen saturations will change because the gaseous exchange will be significantly reduced in the affected areas. It is therefore worth listening to the child's chest on a daily basis to ascertain if there are any quiet areas.

Humidification

Humidification can be increased and/or maintained in a number of ways:

Heat moisture exchanges (HME):

These trap the warmth and moisture of the expired breath so that the air breathed in can be warmed and humidified (taking over the job of the nose). They also act as a filter. There are many different types of HMEs and you need to ensure that the correct type and size is in use.

HMEs tend to be weight or tidal volume dependent. They are normally built into dry ventilation circuits. Incorrect use can lead to increased airway resistance, poor humidification and carbon dioxide retention. HMEs need to be changed daily, and should also be changed when contaminated with secretions or if dropped on the floor. Do not use HMEs if the child is dehydrated or has thick secretions.

HMEs can also help break the expiratory part of the breath and so maintain some natural PEEP.

They are called a number of things: T-piece, nose, coil, Swedish nose, cork and they may be given personal names by the children! This can be confusing at times. Sometimes when you ask a tracheostomy patient where their nose is they point to their HME.

HMEs	Tidal Volume of child	Weight of child	Self-Ventilating Child	Ventilator Dry Circuit	Oxygen delivery (Flow rate)
Swedish Nose	>70ml	> 10kg	Yes	No	< 2litres/min
Humid-Vent Mini	15-50ml	< 10kg	Yes	Yes	Only when used in a ventilator circuit
Humid-Vent	50-600ml	n/a	No	Yes	Only when used in a ventilator circuit
Trachphone	50-1000ml	no minimum weight	Yes	No	< 2litres/min

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Nebulisers

A nebuliser works by converting the prescribed liquid into particles that are small enough to breathe in. It does this by forcing gas through the liquid. This gas can be compressed air or oxygen. The aim of using a nebuliser to target secretions is to reduce the secretions' viscosity, thus making it easier to remove them through coughing or suction. It is a short term humidification.

The nebulised solution can be delivered via a tracheal mask or through the ventilation circuit.

There tends to be an increased need for nebulisation when the weather is hot or very cold, as both have a drying effect, or when the child has a chest infection. In terms of ventilation a nebuliser is more likely to be needed when the child is beginning to spend increased time on a dry circuit, or has just been weaned from the ventilator.

Saline

Many adverse effects are associated with the use of saline solution on ventilated patients, so its use should be carefully considered.

The main reasons for using saline are:

- To loosen and mobilise secretions that are sticky and difficult to dislodge through suction. The saline helps by stimulating a cough
- To reduce the possibility of a tracheostomy tube blockage
- To cut down on the amount of suctioning required, by making suction work more effectively
- To dilute secretions so that it is easier for them to be mobilised

Saline should not be routinely instilled prior to suction. When it is used, its use should be accompanied by chest clearance techniques, ie chest physiotherapy.

While there are many advantages in using saline, the disadvantages need to be considered. These are:

- Patient discomfort
- An increased risk of infection – you are at risk of pushing infected material further down the respiratory system and introducing infection to the lower respiratory system
- Irritation to the airway that can lead to bronchospasm and/or stridor
- Reduced oxygen saturation levels
- Cardiovascular instability. Incorrect instilling of saline can affect the child's blood pressure and heart rate.

When using saline you need to ensure that the correct amount for the age and size of the child is being used. The amounts advised are a guideline only, and the child's physiotherapist should be consulted.

Neonates 0.1 -0.5 ml total of 1ml (warmed so as to decrease their body temperature)

0-4years 0.5-1 ml total of 5ml

5-12 years 0.5-2ml total 10ml

12-18years 0.5-2ml total 20ml

Oxygen

Some children need to have oxygen delivered so that they can maintain their oxygen saturation levels. Ideally this oxygen should be humidified but it is not always appropriate for a child to stay in one place so that this can occur. There are many different ways of delivering oxygen via a tracheostomy. For children that are ventilated oxygen can be added directly into either their circuit or their ventilator.

Method	Maximum % O ₂ delivered	Flow rate range (litres/min)
Nasal cannula	≈ 28	< 2
Humidified aerosol mask	80	5 – 15
High concentration mask with reservoir bag	> 95	12 – 15
Head box for infant < 5kgs	90	5 – 15
Simple or aerosol face mask	40 – 60	4 – 8
Tracheostomy mask	80	5 – 15

Method	Maximum % O ₂ delivered	Flow rate range (litres/min)
Tracheostomy with HME	≈ 28	< 2
Bag valve mask (resuscitation only)	90	15

(Reference: Reproduced with permission from a presentation by Annika Shepard)

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Contributions:

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5.1.4 Ventilation

This section was contributed by Sam Harris of, Warwickshire PCT/Acorns Children's Hospices

What is mechanical ventilation?

Mechanical ventilation is the use of a programmed machine to take over active breathing, controlling the flow of gas into the lungs. This may involve the whole breathing process (inspiration and expiration), support of a portion of a breath, or supporting the patient when they breathe. It may be needed all the time, or as a form of support for set periods of the day. In some cases, the child or young person will initially receive 24 hour ventilation but will later work through a 'weaning off' period in which they spend increasing periods of time off their ventilator. At such times careful observation will be required.

The need to ventilate can be for a number of reasons:

- Brain injury
- Phrenic nerve damage
- Congenital central hypoventilation syndrome (CCHS)
- Acquired CCHS, obtained through injury/insult to the brain
- Damaged lungs
- Degenerative diseases
- Poor muscle tone
- Anatomical reasons

A ventilator works by taking air from the room, reducing it to a prescribed level and then delivering it to the child via a prescribed mode.

Ventilation can either be Pressure specific and volume variable or volume specific and pressure variable.

Types of ventilation:

Positive pressure ventilation

Positive pressure ventilation works by increasing airway pressure in the lungs. The pressure allows air to flow into the lungs until the ventilator breath is terminated. The airway pressure then returns to zero the diaphragm. At this point, the lungs and rib cage relax and the breath (tidal volume) is pushed out passively.

Negative pressure ventilation

The most well-known version of negative pressure ventilation is the Iron Lung. A large chamber that encases the patient up to their neck is used. A vacuum is then created in the chamber, creating negative pressure that leads to the expansion of the lung. It is not a type of ventilation used in the community.

Type of breath delivered:

Pressure Controlled

The ventilator will deliver a breath to a predetermined pressure and rate. The tidal volume (amount per breath) is determined by a pre-set pressure limit (PEAK). In pressure control the time taken to facilitate breathing in (inspiration) is also predetermined. In this type of breath the pressure that the ventilator reaches will always be the same. The volume will vary depending on how quickly the pressure is reached. It is also dependent on lung compliance and the presence of secretions.

Pressure control tends to be used in children that have well lungs, as the lungs are compliant.

Volume Controlled

The ventilator will deliver a breath to a predetermined volume. In this type of breath the ventilator will be programmed with an I:E ratio. The amount of time allowed to breathe in (I) in relation to the amount of time to breathe out (E). The breath rate is also set. For example, if the ventilator is programmed to give **15 breaths per minute**, that means that each breath cycle (inspiration and expiration) is **4 seconds**, (60/15). If the ventilator is programmed to give the inspiration over **1 second (I)**, then the expiration time is **3 seconds (E)**. So the child's I:E in this case is 1:3. The expiration part of the breath is still passive.

The ventilator will deliver the breath at whatever pressure is required to get the volume in; there is a risk, however, of causing barotraumas in the lungs of small children as a result of the increased pressure which may be generated.

Volume control tends to be used in children that have damaged lungs or are paralysed and sedated; this is because the breath is more refined.

Modes of ventilation:

Pressure Support

This mode will support the child's spontaneous breathing. The ventilator can be programmed to support either breathing in only or breathing in and out. The patient will trigger a supported breath from the ventilator. The ventilator will then support that breath up to a prescribed pressure limit. The role of pressure support is to decrease the work of breathing for the child. In this mode the child's breath rate and tidal volumes will vary as they would in normal breathing.

On some models the pressure-support setting implies BiPAP

Synchronized Intermittent Mandatory Ventilation (SIMV)

In this mode the ventilator will deliver a pre-set number of breaths per minute, each either pressure or volume. When the setting is 15 bpm, each breath cycle will take around 4 seconds. Within each cycle the ventilator will wait for the patient to initiate

or trigger a breath. It does this by using pressure or flow sensors. If the ventilator detects a triggered breath then it will deliver the pre-set ventilator breath. If no trigger is detected then it will deliver the pre-set ventilator breath at the pre-set time. If the next breath is also a triggered breath then the ventilator will give a pressure support breath with PEEP. Again if the following breath is also triggered, the ventilator will only deliver a PEEP supported breath. By employing this method the ventilator encourages the child to breathe spontaneously without causing them to work too hard. If at any point the ventilator does not sense a trigger it will revert to the pre-set breaths.

Volume Control/Assist

In this mode the ventilator will deliver a triggered breath that is identical to the pre-set mandatory breaths. It will deliver a volume rather than a pressure. It is not as sophisticated as SIMV, and patients tend to hypo ventilate. In the assist setting it works in a similar way to the pressure support, but it will deliver a volume rather than a pressure. The drawback with this setting is that it can take some 'playing' to find the most appropriate level of volume for patient demand.

Continuous Positive Airway Pressure (CPAP)

In this mode a continuous level of pressure is maintained through the child's ventilation circuit. The aim is to reduce the work of breathing for the child. In this mode children have to initiate all of their own breaths. No support will be given above the CPAP. CPAP can be used with the pressure support mode.

Bi-Level Positive Airway Pressure (BiPAP)

The ventilator will alternate pressure between the inspired positive airway pressure (IPAP) and the expiratory positive airway pressure (EPAP). This is instigated by the patient and requires them to be able to generate a negative pressure to trigger inspiration. The difference between BiPAP and CPAP is that this mode can have a back-up rate set so that IPAP will be delivered if the patient fails to initiate a breath.

Positive End Expiratory Pressure (PEEP)

PEEP is the residual volume of gas left in the lungs at the end of expiration. It prevents the lungs from collapsing. Everyone has natural PEEP. PEEP is used in ventilation to ensure that the airways are kept above atmospheric pressure. The presence of PEEP helps collapsed or unstable alveoli to remain open, thus increasing the surface area for gas exchange. PEEP also decreases the work of breathing because it improves the compliance of the lungs. The higher the compliance the more easily the lungs will inflate.

PEEP has a number of implications for the body. It decreases the venous return to the right side of the heart and decreases right ventricular function, thus decreasing cardiac output. PEEP can also increase intracranial pressure and induce changes in neurological status. This tends to occur in PEEP exceeding 10-11cmH₂O.

How do we measure pressure?

When talking about pressure in ventilation it is always measured in cm of water (cmH₂O).

This describes how much pressure x cmH₂O exerts.

Tidal Volume

Tidal volume in children is calculated as 8-10 mls/kg.

Plateau Pressure

This relates to the ventilator simulating the holding of a breath, just before we breathe out. This is used in positive pressure and volume ventilation to reduce to possible damage to the lungs by ventilation and over stretching of the alveoli. In pressure ventilation this simulated holding of the breath is referred to as the plateau. In volume ventilation it is the peak airway pressure.

5.1.5 Oxygen Saturation Monitoring

This section was contributed by Helen Kenny of Rainbows Hospice for Children and Young People.

Some children and young people will require oxygen saturation monitoring. This applies, particularly but not only to those who are ventilated at level 3, and those who require supplementary oxygen. Oxygen saturation monitoring will provide a back-up alert system if there is any risk that the child or young person would come to harm in the event of the ventilator being accidentally disconnected for a period of time. If required it is prescribed by the child or young person's Respiratory Consultant or Paediatrician.

Oxygen saturation monitoring is a non-invasive way to reliably evaluate oxygenation. Adequate tissue oxygenation depends on a balance between oxygen supply and delivery, and the tissue demand for oxygen. Normally an increase in oxygen demand is met by an increase in supply and delivery. When oxygen demand exceeds supply, hypoxia occurs.

Adequate oxygenation requires adequate blood oxygen, adequate haemoglobin content to carry oxygen, adequate cardiac output to transport saturated haemoglobin to tissues and appropriate tissue utilisation of oxygen to meet individual organ needs. Cyanosis is a late symptom of hypoxia and should not be relied on as an indicator of hypoxia.

Oxygen transportation

Arterial blood transports oxygen in two ways.

- 1 Dissolved in plasma. Only 1-2% of oxygen is carried this way
- 2 Bound to haemoglobin. Haemoglobin molecules are capable of carrying 98-99% of all oxygen present in the blood.
- 3 Haemoglobin is a protein molecule normally contained in red blood cells. Chemically it is composed of a 'globin' protein and four iron atoms, enclosed in a 'heme' group.

Oxygen molecules bind to the iron atoms. Once one joins, three more quickly follow: it is all or nothing. They are bound together in a loose connection which allows haemoglobin to pick up oxygen where it is in excess, in the lungs, and deposit where there is a need for oxygen around the body.

Haemoglobin with oxygen attached is called oxyhaemoglobin or saturated haemoglobin.

Haemoglobin without oxygen attached is called deoxyhaemoglobin or desaturated haemoglobin.

Technology

Pulse oximetry provides non-invasive and continuous information about the percentage of oxygen combined with haemoglobin. 'SpO₂' is commonly used when referring to oxygen saturation readings obtained from a pulse oximeter. Light absorption technology is used to reproduce wave-forms that are produced by pulsing blood. Changes that occur in the absorption of light due to vascular bed changes are reproduced by the pulse oximeter.

Pulse oximeters use two light-emitting diodes (LEDs), one with red light and one with infra-red light. A photodetector is placed opposite to the LEDs, across an arterial vascular bed (a finger, toe or earlobe, for example), and used to measure the intensity of the light transmitted. The difference in the intensity of the transmitted light at each wavelength is caused by the difference in the absorption of light by oxygenated and deoxygenated haemoglobin.

Oxyhaemoglobin absorbs little red light and absorbs more infra-red light.

Deoxyhaemoglobin absorbs more red light but absorbs little infra-red light.

Arterial haemoglobin oxygen saturation is computed by the pulse oximeter from the ratio of red light and infra-red light transmitted to the photodetector from the LEDs.

To ensure an accurate and reliable pulse oximetry reading it is essential to choose the correct size of sensor. The sensor needs to be appropriate for the child/young person's size, available application site, activity level and expected duration of monitoring.

The LEDs and photodetector should be positioned opposite each other, making good skin contact. The sensor should be protected from environmental light sources and venous pulsation.

Clinical and technical issues

Motion

Motion at the sensor site results in light absorption changes that mimic pulse activity. The photodetector may be unable to differentiate between pulsations that are due to motion and those that are truly arterial. This means that where there is movement during a pulse oximetry reading, the pulse rate and SpO₂ values may not be accurate.

Low perfusion

In circumstances of low perfusion, only a small amount of arterial blood may flow into the arterial bed. Weak pulse activity may result in little or no increase in light absorption. When the oximeter has difficulty in detecting and identifying the arterial pulse, this may result in there being no SpO₂ reading and display 'pulse search' being displayed.

Treating the causes of low perfusion, such as hypothermia or hypovolaemia, will improve the detection of SpO₂. Keeping the sensor site warm with towels or blankets may improve the flow of blood to the area.

Venous pulsation

Venous blood is usually considered non-pulsing. But in conditions of elevated venous pressure - such as right sided heart failure, a tightly applied sensor or the presence of a tourniquet - venous blood in the periphery may pulsate. As the oximeter detects all pulse signals, the SpO₂ value may be lower than the true arterial oxygen saturation.

To avoid venous pulsation apply sensors following the manufacturer's guidelines; do not apply additional tape to the sensor. Sensors placed on extremities should be positioned at heart level. When sitting in a chair use fingers rather than toes. It is important to be aware that children or young people who have high levels of positive end expiratory pressure (PEEP) may give inaccurate saturation readings.

Optical Interference

Ambient light sources - such as sunlight, infrared lights and bright fluorescent lights can interfere with pulse oximetry. In the presence of significant ambient light, the photodetector may detect these incoming optical signals in addition to those it receives from the LEDs across the vascular bed. The SpO₂ and pulse reading may be affected by both these light sources and may be affected. Sensors should be shielded from ambient light sources.

Another problem to guard against is optical shunting, which occurs when some light from the LEDs reaches the photodetector without passing through the vascular bed. This happens when an incorrect sensor is used – one that is too large or has not been attached correctly - or if there is excessive movement.

You should also be aware of optical cross-talk, which may occur if two sensors are placed close together. Light from one sensor may be picked up by the photodetector on the other sensor.

Oedema

Light from the LEDs may scatter through oedematous tissue before reaching the photodetector, possibly resulting in an inaccurate reading.

Anaemia

To ensure an accurate oxygen saturation reading there must be adequate haemoglobin in the blood. If the value is less than 5gm/dl the pulse oximeter may be unable to provide a reliable reading for oxygen saturation.

Carbon monoxide (CO)

Carbon monoxide is a colourless, odourless and tasteless gas generated by incomplete

combustion. It has a 200-250 times greater affinity for haemoglobin molecules than oxygen, and binds to the same site. When carbon monoxide is present in the blood in sufficient concentration, some haemoglobin molecules become unavailable to bind with oxygen. It does not require much exposure to carbon monoxide to prevent haemoglobin molecules from picking up oxygen. This can quickly result in tissue hypoxia.

Nail polish

Certain colours of nail polish - especially blue, green, black and brown-red - interfere with the accuracy of saturation readings. It is advisable to remove nail polish to ensure accurate pulse oximetry.

Reasons for saturation monitoring

- 1 The child or young person is ventilated (mainly those who are ventilated at level 2 or 3)
- 2 The child or young person requires supplemental oxygen
- 3 Sleep assessment/apnoeas
- 4 Spot check for intermittent assessment of oxygenation
- 5 To determine the effectiveness of treatments such as bronchodilators, positioning and suctioning
- 6 To assess children or young people following seizure activity

Sensor site

Sensors should be moved to another site every four hours to preserve skin integrity. Sometimes this is not appropriate overnight because of the disturbance caused, so moving a child's sensors is an issue that should always be discussed with the child/young person and/or their parents when planning care. If sensors are not moved, however, the lights can become warm and may result in a burn at the site. A written record should be kept of sensor site checks and changes. Additional tape should not be applied to sensors, as this can make them too tight and act as a tourniquet.

Alarm settings

Alarm settings should be checked every time the monitor is turned on and set to the child's/young person's individual parameters. Some saturation monitors will default back to the factory settings for alarm limits when the monitors are turned off.

References

<http://www.ebme.co.uk/arts/nellcor3.htm>

www.pulseox.info

5.1.6 Competency for Positive Pressure Ventilation via Tracheostomy (Invasive Ventilation)

(Coventry and Warwickshire competency adapted for hospice use by Helen Kenny at Rainbows Hospice for Children and Young People)

- 1 Initial training
- 2 Practical training
- 3 Competent to practise* (maximum level for carer)
- 4 Competent to teach**(maximum level for nurse)

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required			
		1	2	3	4
1 To understand the normal respiratory system	<p>Demonstrate an awareness of:-</p> <ul style="list-style-type: none"> • The anatomy and physiology of the upper respiratory tract Q • The anatomy and physiology of the lower respiratory tract Q • Show an understanding of normal gaseous exchange Q 				
2 To understand the reasons why a child / young person requires ventilation	<ul style="list-style-type: none"> • To be able to give a simple explanation of the variety of conditions which may require ventilation Q • To show an awareness of the implications ventilation may have on a child/young person and their family Q/D • To understand the consequences for a child/young person if they do not receive ventilation Q 				

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required		
<p>3 To understand the reasons why a child or young person is ventilated via a tracheostomy, and to understand the safety issues related to this.</p>	<ul style="list-style-type: none"> • To be able to explain why children/young people requires ventilation via a tracheostomy Q/D • To be able to identify the safety measures required to care for a child/young person who is ventilated via a tracheostomy Q/D • To demonstrate the preparation of the equipment required to safely care for a child who is ventilated via a tracheostomy Q/D • To be able to demonstrate the safe bagging of a child/young person, if required, with a self-filling bag valve Ambu bag D 			
<p>4 To understand the psychological implications of the child/young person's Condition.</p>	<ul style="list-style-type: none"> • To have an awareness of the concerns of : <ul style="list-style-type: none"> a) Child/young person Q/D b) Parents/carers Q/D c) Siblings Q/D d) Other professionals involved in the child/young person's care Q • To demonstrate an age appropriate approach to the child/young person 			

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required		
<p>5 To demonstrate safe preparation for ventilation.</p>	<p>To be able to :-</p> <ul style="list-style-type: none"> • Demonstrate knowledge of a variety of machines. Q/D • Demonstrate the safe storage of equipment Q/D • Find the current settings for individual children/ young people Q/D • Recognise the control panel D • Identify all the functions on the display Q/D • Recognise alarm warning lights D • Understand the term locked and explain why locking occurs Q/D • Describe a safe place for the ventilator Q • Demonstrate how to test the alarms Q/D • Know where to find the back-up system Q/D • Understand the normal power supply Q/D • Understand the auxiliary power supply Q/D • Demonstrate setting up the machine safely D • Demonstrate setting up the ventilator using the auxiliary power supply D 			

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required
<p>6 To understand the health and safety issues related to ventilation.</p>	<ul style="list-style-type: none"> • To have an understanding of the health and safety issues in relation to moving and handling Q • To be aware of other equipment that may disrupt ventilation Q • To be able to recognise other equipment that is essential during ventilation and to be proficient in using it Q/D • To have an awareness of how extreme temperatures can affect the ventilator Q • To have an awareness of where spares and supplies can be found Q • To have an understanding of the risks with regard to: <ul style="list-style-type: none"> a) Missed alarms Q b) Audibility of alarms Q c) Silencing of alarms Q 	<div style="background-color: #cccccc; height: 100%;"></div>

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required		
7 To demonstrate the safe fitting of the ventilator tubing to the tracheostomy and understand the safety reasons.	<ul style="list-style-type: none"> To demonstrate fitting the ventilator tubing to the tracheostomy of the child/young person D To demonstrate the correct positioning of the ventilator tubing once it is connected to the tracheostomy D To have an understanding of the actions to be taken if there is a problem with the connection between the ventilator and the tracheostomy Q 			
8 To be able to undertake a respiratory assessment.	<ul style="list-style-type: none"> Colour Q Respiratory rate Q Oxygen saturations Q Chest movement Q Identify signs of respiratory distress Q To be able to recognise that these may be different in the individual child/young person Q To be able to identify specific signs of respiratory difficulty in a ventilated child/young person Q 			

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required		
<p>9 To be able to identify common reasons for poor ventilation</p>	<ul style="list-style-type: none"> • Child/young person restless Q • Airway obstructed Q • A leak in the ventilator circuit Q/D • An ill-fitting connection Q/D • Child/young person is in a poor position Q/D • Loss of ventilator pressure Q/D • To demonstrate aspects of trouble shooting Q/D • To be aware of when to seek assistance Q/D • To be aware of the dangers of ill-fitting electrical connections from the plug to the ventilator Q/D 			
<p>10 To identify the priorities in case of a fire.</p>	<ul style="list-style-type: none"> • Identify fire procedures Q/D • Recognise that these may change depending on where the child/young person is Q/D • Know where to find the fire exits Q/D • Know the plan to relocate the child/young person Q • Understand the implications if oxygen is in use Q 			

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required	
11 Understand the need for observation during ventilation.	<ul style="list-style-type: none"> • To be able to identify where to find the normal ventilator settings for the child/young person Q/D • Demonstrate the correct recording of the ventilator settings present during ventilation Q/D • To recognise the importance of recording ventilator settings Q/D • Identify what actions need to be taken if there is a discrepancy between the prescribed and recorded settings Q/D • Identify signs of poor ventilation Q/D • Identify ways in which to improve ventilation Q/D • Identify the normal sleep pattern of the child/young person Q/D • Identify ways to promote sleep and improve ventilation Q/D 		

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required		
12 To show the importance of record keeping and reporting.	<ul style="list-style-type: none"> • Demonstrate appropriate communication skills with the child/young person Q/D • Identify who to contact for assistance and how to do so Q/D • Will speak to parents/carers appropriately, handing on significant information accurately Q/D • Ensure all recorded information is accurately documented, signed and dated Q/D • Demonstrate knowledge of the criteria for referral to hospital Q/D 			
13 To show awareness of the need for privacy and dignity	<ul style="list-style-type: none"> • Demonstrate confidentiality with regard to children/young people and their families Q/D • Be aware of the child/young person's wishes and how they express them Q/D • Prepare the child/young person for ventilation whilst recognising their right to privacy and dignity Q/D • Recognise the parents' 'parent expert' role Q/D 			

Level of competency: _____ **Competency completed by:** _____

Individual levels assessed by:

Name: _____ **Signature:** _____ **Professional qualification(s):** _____ **Date:** _____
I certify that the person named on this document is competent to carry out the procedure detailed above and that I have current NMC registration.

Either:

Carer trainee

I the above named carer certify that I am happy to carry out the above procedure within the competencies detailed above. I understand the scope of these competencies. I will only use this training in respect of the child specifically named on the front of this form. I will not carry out procedures that are contrary to or not covered by this training.

I will seek further training if I have any concerns about my competency. In any event six weeks before the expiry date on the front of this form I will renew my training. Upon the date of expiry of this competency, if my training has not been renewed, or if I have concerns about my competency, I will discontinue undertaking the procedure detailed in this document and seek appropriate advice from a suitably qualified clinician and or my employer. In all other respects I will seek all necessary advice, guidance and further training needed from time to time in order for me to continue to operate within these competencies.

Name: _____ **Signature:** _____ **Date:** _____

OR:

Nurse trainee

I am professionally happy with the training I have received and my skill level. I deem myself skilled to deliver the care described in this document. I understand my responsibilities under sections 6.1, 6.2 and 6.3 of the code of conduct NMC

Name: _____ **Signature:** _____ **Professional qualification(s):** _____ **Date:** _____

5.1.7 Competency for Positive Pressure Ventilation via Face Mask (Non Invasive Ventilation)

(Coventry and Warwickshire competency adapted for hospice use by Helen Kenny at Rainbows Hospice for Children and Young People)

- 1 Initial training
- 2 Practical training
- 3 Competent to practise* (maximum level for carer)
- 4 Competent to teach**(maximum level for nurse)

Area of concern	Required skills and knowledge Q = assessed by questioning d = assessed by demonstration	Level required			
		1	2	3	4
1 To understand the normal respiratory system.	<p>Demonstrate an awareness of:</p> <ul style="list-style-type: none"> • Anatomy and physiology of upper respiratory tract Q • Anatomy and physiology of lower respiratory tract Q • Show an understanding of normal gaseous exchange Q 				
2 To understand the reasons why a child/young person requires ventilation.	<ul style="list-style-type: none"> • To give a simple explanation of a variety of conditions which may require ventilation Q • To show an awareness of the consequences this may have on a child/young person and their family Q/D • To be able to recognise the consequences of not receiving ventilation Q 				

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required		
3 To understand the psychological implications of the child /young person's condition.	<p>To have an awareness of concerns of: -</p> <ul style="list-style-type: none"> • The child/ young person Q • Parents/carers Q/D • Siblings Q/D • Professionals involved in child/young person's care Q • Demonstrate an age appropriate approach to child/ young person D 			
4 To demonstrate safe preparation for ventilation.	<p>To be able to demonstrate: -</p> <ul style="list-style-type: none"> • A knowledge of a variety of ventilation machines Q • The safe storage of equipment Q/D • Where to find the current settings Q/D • Knowledge of the control panel of the ventilator D • The identification of the functions on the display Q/D • Recognition of alarm warning lights D • An understanding of the term locked and why locking occurs Q/D • Describing a safe place for the ventilator Q • How to test the alarms Q/ D • Where to find the back-up system Q/D • An understanding of the normal power supply Q/D • An understanding of the auxiliary power supply Q/D • Setting up a machine correctly D • Demonstrate setting up the ventilator using the auxiliary power supply D 			

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required		
4 To demonstrate safe preparation for ventilation continued...	<ul style="list-style-type: none"> • Know how to change the battery and recognise the running times of the batteries Q /D • Demonstrate how to use and maintain the batteries D • Demonstrate how to set up the ventilator circuits D • Demonstrate which parts of the circuit are re-useable and which parts are disposable D/Q • Describe the maintenance and servicing of machine, including the changing of filters Q/D • What is the protocol for power failure? Q • Describe the limitations of the alarm system used on the ventilator Q/D • Demonstrate the safe disposal of the circuit following the infection control policy Q/D 			

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required			
5 To understand health and safety issues related to ventilation.	<ul style="list-style-type: none"> • Understand the health and safety issues in relation to moving and handling of the child/young person and their equipment Q • Be aware of other equipment that may disrupt ventilation Q • Recognise other equipment that is essential during ventilation and be proficient in using it Q/D • Show an awareness of how extreme temperature can affect the ventilator Q • Have knowledge of where spares and supplies can be found Q • Show an understanding of the risks to ventilation in regard to: Q <ul style="list-style-type: none"> a) missed alarms b) audibility of alarms c) silencing of alarms 				
6 To demonstrate the safe fitting of the mask and understand the safety issues around face/nasal ventilation.	<ul style="list-style-type: none"> • Demonstrate the safe fitting of the mask on the child/young person D • Be aware of the long term side effects of prolonged use of face mask ventilation Q • Recognise how these risks can be minimised Q/D 				

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required			
7 To be able to do a basic respiratory assessment.	<ul style="list-style-type: none"> • Colour Q • Respiratory rate Q • Chest movement Q • Identify respiratory distress Q • To be able to recognise that these may be different in the individual children/young people. Q • To be able to identify the specific signs of respiratory difficulty in ventilated children/young people. Q 				
8 To be able to identify common reasons for poor ventilation.	<ul style="list-style-type: none"> • To be able to identify why these factors may affect ventilation: • Child/young person is restless Q • Airway appears blocked Q • Circuit has developed a leak Q/D • Ill-fitting connections Q/D • Child /young person is in a poor position Q/D • Loss of ventilator pressure Q/D • To demonstrate some aspects of trouble shooting Q/D • To be aware when to seek assistance Q/D • To be aware of the dangers of ill-fitting electrical connections from the plug to the machine Q/D 				

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required		
9 To identify priorities in case of fire.	<ul style="list-style-type: none"> • Identify the hospice fire procedure Q/D • Recognise that this may change, depending where the child/young person is being cared for Q/D • Identify where to find the fire exits Q/D • Know the plan to relocate the child/young person • Identify what your responsibilities are if oxygen is in use Q 			
10 To show an understanding of the need for observation during ventilation.	<ul style="list-style-type: none"> • To be able to identify where to find the normal ventilator settings for the child/young person Q/D • Demonstrate the correct recording of the ventilator settings present during ventilation Q/D • To recognise the importance of recording ventilator settings Q/D • Identify what actions need to be taken if there is a discrepancy between the prescribed and recorded settings Q/D • Identify signs of poor ventilation Q/D • Identify ways in which to improve ventilation Q/D • Identify the normal sleep pattern of the child/young person Q/D • Identify ways to promote sleep and improve ventilation Q/D 			

Area of concern	Required skills and knowledge Q = assessed by questioning D = assessed by demonstration	Level required			
11 To show the importance of record keeping and reporting.	<ul style="list-style-type: none"> • Demonstrate the importance of accurate, appropriate documentation Q/D • Identify the point of contact if there are issues with regard to ventilation or the child/young person's condition Q/D • Demonstrate knowledge of child/young person's criteria for hospital admission Q • Identify when to contact named nurse on call/parent Q • Will speak to children/ young person appropriately Q/D 				
12 To show awareness of privacy and dignity.	<ul style="list-style-type: none"> • Demonstrate confidentiality with regard to the children/young people and their families Q/D • Be aware of the child/young person's wishes and how they express the. Q/D • Prepare the child/young person for ventilation whilst recognizing their right to privacy and dignity Q/D 				

Level of competency: _____ Competency completed by: _____

Individual levels assessed by:

Name: _____ Signature: _____ Professional qualification(s): _____ Date: _____
I certify that the person named on this document is competent to carry out the procedure detailed above and that I have current NMC registration.

Either:

Carer trainee

I the above named carer certify that I am happy to carry out the above procedure within the competencies detailed above. I understand the scope of these competencies. I will only use this training in respect of the child specifically named on the front of this form. I will not carry out procedures that are contrary to or not covered by this training.

I will seek further training if I have any concerns about my competency. In any event six weeks before the expiry date on the front of this form I will renew my training. Upon the date of expiry of this competency, if my training has not been renewed, or if I have concerns about my competency, I will discontinue undertaking the procedure detailed in this document and seek appropriate advice from a suitably qualified clinician and or my employer. In all other respects I will seek all necessary advice, guidance and further training needed from time to time in order for me to continue to operate within these competencies.

Name: _____ Signature: _____ Date: _____

OR:

Nurse trainee

I am professionally happy with the training I have received and my skill level. I deem myself skilled to deliver the care described in this document. I understand my responsibilities under sections 6.1, 6.2 and 6.3 of the code of conduct NMC

Name: _____ Signature: _____ Professional qualification(s): _____ Date: _____

5.2 Pack for supporting day to day care of ventilated children/young people

5.2.1 Assessment and plan for children receiving long term ventilation

(Provided by Andrea Cockett, Shooting Star Children's Hospice and adapted for toolkit by Alison Cooke, Rainbows Hospice for Children and Young People)

Child's name

DOB

Primary diagnosis

Reason for ventilation

Level of ventilation

Date of assessment

Parents/carers assessment undertaken with

Name and signature of practitioner undertaking assessment

Respiratory and ventilation needs	
Invasive or non-invasive ventilation?	
Invasive ventilation	
Make and size of tracheostomy	
Type of tapes and changing frequency	
Tube-changing routine (normal day, procedure)	
Non-invasive ventilation	
Make/model and size of mask	
All children/young people	
When does the child/young person go onto the ventilator?	
If 24hour ventilation is currently in place, is the child/young person being weaned off the ventilator?	Yes (record how often/when child/young person is taken off the ventilator) No
Make and model of ventilator	
Who owns ventilator?	
Emergency contact number in case of ventilator failure	
Back-up ventilator available?	
Internal/external batteries and life of batteries	

Mode of ventilation				
Ventilator settings	CPAP	Peak press/ IPAP	PEEP/EPAP	RR
Extra settings	Trigger		Plateau	
Level of dependency	Day(hours)	Night(hours)	Continuous	
Alarm limits	CPAP	Peak pressure	PEEP	
Humidification	Make and model			
	Day: dry/wet	Night: dry/wet		
Procedure for filling wet humidification. Record how often unit is filled, water bag changed and system used.				
Oxygen requirement	Yes (record amount and how it is connected to circuit) Cylinder/concentrator		No	
Suction pressures				
Frequency of suctioning if well				
Monitoring	Saturation	HR	ETCO ₂	RR
Make and models of monitoring equipment				
Child's normal parameters if well	HR	RR	SaO ₂	ETCO ₂

Child's normal respiratory status (ie Do they normally have some recession, colour, extra noises etc)	
Ventilator circuit tubing changes: record how often, normal day undertaken and how procedure is undertaken.	
Are there filters in the circuit? What is their position?	
Filter changes: record how often, normal day undertaken and how procedure is undertaken.	
What medications is the child receiving? Do they use nebulisers? Document how these are administered.	
What care package does the child normally have? Record hours, day or night, staff providing care, respite in place already	
What care would the family like? (Tick all that apply) Day care Outreach Overnight stays	
Record competencies completed by the parents.	
Is there an action plan in case of respiratory deterioration?	Yes
Record agreed action plan. Record if there is a patient specific ambulance plan.	No
How is equipment moved around with the child?	

Photograph of wet/dry circuits

Photograph of nebuliser administration

Photograph of oxygen administration

Photograph of mask fitting

Feeding needs				
Method of feeding	Oral	NG	Gastrostomy	
Type of feed				
Instructions for making feed				
Current feed regime				
Feeding tube changes: document last tube change and when next is due.				
Are there any ventilator-related feeding issues? (decompression needs)				

5.2.2 Observation chart

(Source: Helen Kenny, Rainbows Hospice for Children and Young People)

Name: _____ DOB: _____

DATE	TIME	Heart Rate	Resp rate	Temp C	Oxygen sats	Oxygen litres	Signature	Print name

5.2.3 Day to day checklist

(Source: Andrea Cockett, Shooting Star Children's Hospice)

Week commencing Sunday: _____

To do list	Sun.	Mon.	Tues.	Wed.	Thurs.	Fri.	Sat.
Tape changes (daily)							
Clean suction machine & change tubing (daily)							
Tracheostomy tube change (weekly)							
Wet circuit change (..... night)							
Dry circuit change (..... night)							
Clean ventilator filter. (..... night)							
Check gastrostomy balloon – water 5mls (weekly)							
Check emergency alarm (daily)							
Clean / wipe down wheelchair (daily)							
Change Mickey extension (Sunday night)							

PLEASE TICK AND SIGN YOUR NAME WHEN YOU HAVE CARRIED OUT THE ABOVE TASKS

IF UNABLE TO COMPLETE TASKS SCHEDULED ON A CERTAIN DAY/NIGHT, PLEASE LEAVE THIS SHEET IN THE COMMUNICATION BOOK TOGETHER WITH A NOTE, SO IT CAN BE COMPLETED BY ANOTHER MEMBER OF STAFF. THANK YOU.

5.2.4 Hourly Ventilation Observations

(Helen Kenny, Rainbows Hospice for Children & Young People)

NB: Children/young people who are ventilated at level 1 may not require hourly ventilation observations overnight. Individual risk assessment should be carried out to determine whether this is appropriate. In addition, it may not be necessary to carry out hourly observations on children/young people who are ventilated at level 2 or 3 when he/she is awake and supported by a nurse or carer.

Name: _____ DOB: _____ Date: _____

	08.00	09.00	10.00	11.00	12.00	13.00	14.00	15.00	16.00	17.00	18.00	19.00
Vent mode												
Back-up power												
IPAP/PIP												
EPAP/PEEP												
TI												
Asleep/awake												
Resps												
SPO2												
SPO2 probe site (move 4 hourly)												
Humidifier temp												
Humidifier water level												
Signature												

	20.00	21.00	22.00	23.00	24.00	1.00	2.00	3.00	4.00	5.00	6.00	7.00
Vent mode												
Back-up power												
IPAP/PIP												
EPAP/PEEP												
TI												
Asleep/awake												
Resps												
SPO2												
SPO2 probe site (move 4 hourly)												
Humidifier temp												
Humidifier water level												
Signature												

5.2.5 Tracheostomy handover check

(Source: Coventry and Warwickshire CCN Services. Adapted for hospice use by Helen Kenny Rainbows Hospice for Children and Young People)

Name: _____ DOB: _____

Tracheostomy type/size: _____ Date and time: _____

CHECKS										
Emergency box:										
Spare tube - size []										
Smaller tube – size []										
Tapes or velcro										
T-vent or bib										
Scissors										
Gloves										
Suction machine										
Charged and working										
Plugged into red plug										
Minimum of 15 catheters available size []										
Suction unit clean and empty										
Suction water available										
Oxygen										
Oxygen available and patent (if required) Delivered at [] litres per minute										
General										
Tapes secure and skin intact Changed daily/as required										
SpO2 monitor working to agreed parameters with patent probe										
Inner tube (if applicable) patent and clean as required										

5.2.6 Ventilator handover checklist

(Source: Helen Kenny, Rainbows Hospice for Children & Young People)

Name: _____ DOB: _____ Tracheostomy type/size: _____ Date and time: _____

Ventilator type _____ Prescription: _____ Mode _____ Pressures IPAP _____ EPAP _____

Rate _____ Inps.Time _____ Upper/lower alarms _____ Sats monitor settings _____ Pulse _____ / _____ SaO2 _____ / _____

Mask type/tracheostomy and fittings _____ On-call ventilator support tel number _____

Date and time			
SpO2: Monitor working to agreed parameters with appropriately sized patient probe Alarm limits set at SPO2 ___ / ___ Pulse ___ / ___ Spare batteries available			
Oxygen: Spare cylinders/tubing available with adequate volume a) In use/connected b) Switched off			
	Humidification: In use (below level of child) a) Self filling b) Manual - water level checked		

5.2.7 Use of Oxygen

(Source: Andrea Cockett, Shooting Star Children's Hospice)

Name: _____ DOB: _____

Reason for use	
Frequency	
Amount required and parameters	
Cylinder or concentrator(s)	
HOOF form required? Y/N	
Is oxygen humidified? Y/N	
Where is equipment stored?	
Is saturation monitor used? Y/N If Yes: When used Probe site(s) Frequency of site change Parameters Oxygen saturation Heart rate	
Any other useful information	
Date	
Parent/young person's signature	
Nurse's signature	

5.2.8 Use of suction

(Source: Andrea Cockett, Shooting Star Children's Hospice)

Name: _____ DOB: _____

Indication for use	
Own suction unit available? Y/N	
Where is equipment stored?	
Pressure required	
Size and type of catheter	
Is oxygen humidified? Y/N	
Type of suction required Y/N Oral Nasal Tracheostomy	
Suction measurement (for tracheostomy suction only)	
Any other useful information	
Date	
Parent/young person's signature	
Nurse's signature	

5.2.9 Care plan for child/young person on invasive ventilation using hydrotherapy pool

(Source: Helen Kenny, Rainbows Hospice for Children and Young People)

Name: _____ DOB: _____

Date:
Problem:
Child/young person has a tracheostomy and is ventilated. Requires special care when using the hydrotherapy pool.
Goal:
That child/young person is able to use the hydrotherapy pool safely.
Actions:
<ol style="list-style-type: none"> 1 Ensure that child/young person is appropriately dressed to use the hydrotherapy pool. 2 Ensure that there are at least two people in the pool with child/young person, one to support position in the water (keeping airway clear of the water) and the other one to provide activities. One of these should have completed the pool training. 3 One member of staff is available on the side of the pool to provide assistance and perform suction if required. 4 Check that child/young person's tracheostomy tube is securely fixed and tapes are not too loose. 5 Ensure that child/young person's emergency tracheostomy bag is present and fully stocked and that all emergency equipment is available, including a bagging circuit connected to an oxygen supply. 6 Perform suctioning of tracheostomy if required. 7 Check the suction machine is fully charged with sufficient suction catheters and gloves. Do not have it plugged in to the mains supply. 8 Ensure that ventilator has a long dry circuit in situ and that the ventilator is positioned on a dry surface away from the edge of the pool. The ventilator should be running on batteries that are fully charged Check batteries for cracks, chips or breaks that will mean they are not waterproof. 9 Check that the ventilator tubing is fitted securely to the tracheostomy and will not fall into the water.

- 10 Child/young person should be transferred to the poolside on a trolley in preparation for hoisting into the pool. At least two members of staff need to be ready to receive child/young person into the pool. One member of staff who remains at the side of the pool is responsible for guiding the ventilator tubing, which should not become too wet.
- 11 One member of staff should have a clear view of the child/young person at all times to ensure that they are not lowered too far into the pool, preventing water from entering the tracheostomy. This staff member must inform the staff in the pool immediately if the child/young person's position becomes too low, so that he/she can be raised.
- 12 If child/young person's ventilator becomes disconnected from the tracheostomy but does not fall into the water, the bagging circuit should be attached to the tracheostomy and manual bagging performed. The child/young person should be removed from the water and the ventilator reconnected once they are out of the water.
- 13 If water enters child/young person's tracheostomy, this is an emergency situation and the emergency alarm should be activated at the poolside. Child/young person should be immediately removed from the pool and placed on the trolley. Suction should be applied to the tracheostomy to remove any water present. Hand bagging with 100% oxygen should be initiated. An ambulance should be called to arrange immediate transfer to hospital. Wet clothing should be removed and warm dry towels used to keep child/young person warm.
- 14 While child/young person is in the water, constant observation should be made of colour, chest movement and any indication of respiratory compromise. If these occur child/young person should be immediately removed from the water.
- 15 Initially limit child/young person's time in the pool to approximately 15 minutes building up to a maximum of 30 minutes as he/she tolerates it.
- 16 Do not take child/young person into the pool if secretions are particularly loose and he/she is requiring frequent suctioning episodes as this will increase the likelihood of water entering his/her tracheostomy.
- 17 Do not take child/young person into the pool if they appear unwell or secretions are copious and thick. The increased humidity and movement will increase the likelihood of a secretion plug blocking his tracheostomy which will require an emergency tracheostomy change.
- 18 At the end of the hydrotherapy session child/young person should be removed from the pool and dried promptly, wet clothing removed and dry clothing applied. Tracheostomy tapes should be changed and dressing applied if used.

Name: _____ Signed: _____

Review date: _____

Section 6

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6.2: Appendices

6.2.1: Questionnaire sent to children's hospice services

(Source: Alison Cooke and the *Children's Hospices UK* Reference Group)

Questionnaire request

We are collating data to inform the development of the CHUK Ventilation Toolkit. There is no recent data regarding the numbers of children and young people in the UK who are ventilated and the level of ventilation they require.

We would be very grateful if you would complete the following questionnaire to help identify the current needs of children and young people who are ventilated and accessing children's hospices.

The following classifications are based on the levels of need outlined within the National Framework for Children and Young People's Continuing Care (2010):

Level 1

I.E: Is able to breathe unaided but needs to go onto a ventilator for **supportive** ventilation. The ventilation can be discontinued for up to 24hrs without clinical harm. Ventilation is 'life enhancing' not 'life sustaining'.

Number of children/young people supported at this level by:

Invasive ventilation (via tracheostomy) _____

Non invasive ventilation (via facemask or nasal cannulae/nasal pillows) _____

Do you provide any additional support for this group of children and young people (please explain – use a separate sheet if necessary)?

Level 2

IE: Requires ventilation at night for very poor respiratory function; has respiratory drive and would survive accidental disconnection, but would be unwell and may require hospital support

Number of children/young people supported at this level by:

Invasive ventilation (via tracheostomy) _____

Non invasive ventilation (via facemask or nasal cannulae/nasal pillows) _____

Do you provide any additional support for this group of children and young people (please explain – use a separate sheet if necessary)?

Level 3

IE: Unable to breathe independently and requires permanent mechanical ventilation or has no respiratory drive when asleep or unconscious and requires ventilation and 1:1 support whilst asleep as disconnection would be fatal.

Number of children/young people supported at this level by:

Invasive ventilation (via tracheostomy) _____

Non invasive ventilation (via facemask or nasal cannulae/nasal pillows) _____

Do you provide any additional support for this group of children and young people (please explain – use a separate sheet if necessary)?

Please would you identify the numbers of children using the following modes of ventilation used by children and young people who use your services:

CPAP _____

BIPAP _____

Pressure Support _____

Volume control _____

Other (please identify) _____

Please would you identify the types of ventilator used by children and young people who use your services:

Nippy Junior _____

Nippy Junior Plus	_____
Nippy Junior 3	_____
Nippy S+	_____
Resmed VPAP III	_____
BREAS	_____
LTV 950	_____
LTV (any other model – please identify)	_____ _____
Resmed Elisee	_____
Respironics Synchrony	_____
Other (please identify)	_____ _____

If you are not able to identify the levels or modes of ventilation please would you provide the number of children and young people who are ventilated at any level/mode.

Thank you for completing this questionnaire.

6.2.2: Questionnaire given to children and young people supported by Children's hospice services:

Children's Hospices UK are developing a toolkit to give help and advice to those who care for children and young people who are ventilated. It would be really useful to gain some information about the experiences of those ventilated children and young people who already visit children's hospices and we would like to ask your views. All information will be treated confidentially.

1 Are you able to breathe without your ventilator (✓)?

- Never
- Sometimes
- Always – it is there for extra support only

Please give comments

2 Do you use your ventilator (✓)?

- All the time
- When you are tired or unwell
- Just at night

If you only use your ventilator at night, do you use it every night? (If not, why not?)

3 Do you bring your ventilator with you every time you come to stay? (If not, why not?)

4 Do you have a backup ventilator and if so, do you always bring both ventilators with you?

5 Do you have someone with you all of the time when you are using your ventilator? (if so, who?)

6 Who looks after you when you are using your ventilator here (✓)?

- Your home ventilation team nurses
- Your own ventilation team carers
- Your parents
- Hospice staff
- A combination (please specify) _____

7 Do the hospice staff look after you in the same way as your carers do at home when you are using your ventilator here? (If not, what is different, and would you like us to try to change things?)

8 Do you have confidence in the hospice staff looking after your ventilator?

9 Do you feel differently when you are looked after by your own home ventilation team? (Please give details)

10 Would you prefer your own team to come with you or would you prefer a complete break?

11 Please add any other comments that you feel would be helpful in telling us about your experiences.

Thank you for completing this questionnaire.

6.2.3 Example risk assessment for level 1 ventilation

(where appropriate, use in conjunction with tracheostomy risk assessment)

Name: _____ DOB: _____ Date: _____ Assessor's signature: _____

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
<p>Child/young person is ventilated at Level 1 ie:</p> <p>Child/young person is able to breathe unaided but needs supportive ventilation.</p> <p>Child/young person is able to tolerate disconnection from their ventilator for up to 24 hours without clinical harm.</p>	<p>Ventilator may stop working/ malfunction.</p>	<p>L</p>	<p>Follow ventilator prescription which has been signed by clinician and checked by 2 nurses.</p> <p>Use handover check list to ensure ventilator patency.</p> <p>Ensure emergency ventilator support contact details are available.</p> <p>Ensure that ventilator filter is not obstructed to prevent overheating. Change weekly or as required.</p> <p>A manual bagging device is available to use if the ventilator fails to function and the child/ young person is not able to breathe independently. This should be clearly labelled with their name.</p>

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
	Child/young person's condition may deteriorate/change.	L	<p>Ensure child/young person is cared for by a nurse/health care assistant who has had training in ventilation and is familiar with their needs, including resuscitation status and method of resuscitation if appropriate.</p> <p>Complete base line observations and identify normal parameters for child/young person.</p> <p>Ensure that saturation monitor is present and working, with alarm limits set to child/young person's parameters.</p> <p>Use hourly observations chart to record child/young person's condition.</p> <p>Increase observations if condition deteriorates. Liaise with medical team as required.</p> <p>Ensure oxygen and suction are patent and available.</p>

Review date: _____ Date reviewed: _____ Nurse's signature: _____

6.2.4 Example risk assessment for level 2 ventilation

(where appropriate, use in conjunction with tracheostomy risk assessment)

Name: _____ DOB: _____ Date: _____ Assessor's signature: _____

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
Child/young person is ventilated at Level 2 ie: Child/young person requires ventilation for poor respiratory function. Child/young person has a respiratory drive and would tolerate an accidental disconnection. Child/young person would become unwell and require hospital admission if ventilation discontinued for a significant length of time.	Ventilator may stop working/ malfunction and child/ young person would require additional support of a hospital admission to maintain safety.	M	Follow ventilator prescription that has been signed by clinician and checked by 2 nurses. Use handover check list to ensure ventilator patency. Ensure emergency ventilator support contact details are available. Ensure that ventilator filter is not obstructed to prevent overheating. Change weekly or as required. A manual bagging device is available to use if the ventilator fails to function and the child/ young person is not able to breathe independently. This should be clearly labelled with their name.

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
	Child/young person's condition may deteriorate/change.	M	<p>Ensure child/young person is cared for by a nurse/health care assistant who has had training in ventilation and is familiar with their needs, including resuscitation status and method of resuscitation if appropriate.</p> <p>Complete base line observations and identify normal parameters for child/young person.</p> <p>Ensure that saturation monitor is present and working, with alarm limits set to child/young person's parameters.</p> <p>Use hourly observations chart to record child/young person's condition.</p> <p>Increase observations if condition deteriorates. Liaise with medical team as required.</p> <p>Ensure oxygen and suction are patent and available.</p>

Review date: _____ Date reviewed: _____ Nurse's signature: _____

6.2.5 Example risk assessment for level 3 ventilation

(where appropriate, use in conjunction with tracheostomy risk assessment)

Child/young person's name: : _____ DOB: _____ Date: _____

Assessor's signature: _____

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
<p>Child/Young person is ventilated at Level 3 ie:</p> <p>Child/young person is unable to breathe independently and requires permanent mechanical ventilation and 1:1 support.</p> <p>Or</p> <p>Child/young person has no respiratory drive when asleep/ unconscious and requires full ventilation and 1:1 support.</p>	<p>Ventilator may stop working/ malfunction and child/ young person would require immediate intervention to support breathing.</p>	<p>M</p>	<p>Follow ventilator prescription that has been signed by clinician and checked by 2 nurses.</p> <p>Use handover check list to ensure ventilator patency.</p> <p>Ensure emergency ventilator support contact details are available.</p> <p>Ensure that ventilator filter is not obstructed to prevent overheating. Change weekly or as required.</p> <p>A manual bagging device is available to use if the ventilator fails to function and the child/ young person is not able to breathe independently. This should be clearly labelled with their name.</p>

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
			<p>Ensure that second ventilator is kept in a working condition, fully charged and set up ready to use.</p> <p>Transfer to hospital if unable to resume ventilation.</p>

Review date: _____ Date reviewed: _____ Nurse's signature: _____

6.2.6 Example generic risk assessment for child/young person who has a tracheostomy

Child/young person's name: _____ DOB: _____ Date: _____

Assessor's signature: _____

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
Child/Young Person has a tracheostomy Tube in situ to aid breathing	Tracheostomy could become blocked or dislodged	M	<p>Ensure child/young person is cared for by a nurse/health care assistant who has had training in tracheostomy management and is familiar with their specific needs.</p> <p>Ensure emergency tracheostomy set is at hand and is checked at each hand over of care.</p> <p>Ensure oxygen and suction are checked at each hand over of care and are patent and available at all times.</p>

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
	Child/young person's condition may deteriorate/change		<p>Ensure child/young person is cared for by a nurse/health care assistant who has had training in ventilation and is familiar with their needs, including resuscitation status and method of resuscitation if appropriate.</p> <p>Complete base line observations and identify normal parameters for child/young person.</p> <p>Ensure that saturation monitor is present and working if required, with alarm limits set to child/young person's parameters.</p> <p>Increase observations if condition deteriorates. Liaise with medical team as required.</p> <p>Ensure oxygen and suction is checked at each hand over of care and are patent and available at all times.</p>

Review date: _____ Date reviewed: _____ Nurse's signature: _____

6.2.7 Example risk assessment –child/young person on invasive ventilation using hydrotherapy pool

Assessor's name: _____ Job title: _____ Date: _____

Assessor's signature: _____

Counter assessor's name: _____ Job title: _____ Date: _____

Countersignature: _____

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
Child/young person has a tracheostomy and is ventilated. Requires special care when using the hydrotherapy pool.	That child/ young person inhales water via tracheostomy	H	<p>There are at least 2 people in the pool with child/young person, one to support position in the water keeping airway clear of the water, the other to provide activities. One of these should have completed the pool training.</p> <p>One member of staff is available on the pool side to provide assistance and perform suction if required.</p> <p>Check that child/young person's tracheostomy tube is securely fixed and tapes are not too loose.</p> <p>Ensure that child/young person's emergency tracheostomy bag is present and fully stocked and that all emergency equipment is available, including a bagging circuit connected to an oxygen supply.</p>

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
			<p>Perform suctioning of tracheostomy if required.</p> <p>Check the suction machine is fully charged with sufficient suction catheters and gloves. Do not have it plugged in to the mains supply.</p> <p>One member of staff should have a clear view of the child/young person at all times to ensure that he/she is not lowered too far into the pool, as this would allow water to enter his/her tracheostomy. The staff member must inform the staff in the pool immediately if the child/young person's position is too low so he/she can be raised.</p> <p>If water enters child/young person's tracheostomy, this is an emergency situation and the emergency alarm should be activated at the poolside. The child/young person should be immediately removed from the pool and placed on the trolley. Suction should be applied to the tracheostomy to remove any water present. Hand bagging with 100% oxygen should be initiated. An ambulance should be called to arrange immediate transfer to hospital. Wet clothing should be removed and warm dry towels used to keep child/young person warm.</p>

Behaviour/ extra needs	Hazards/ potential for harm	Risk L M H	Control measure/ planned action
	That child/ young person ventilator becomes disconnected resulting in a respiratory emergency.	H	<p>Ensure that the ventilator has a long dry circuit in situ and that it is positioned on a dry surface away from the edge of the pool. The ventilator should be running on batteries that are fully charged.</p> <p>Check batteries for cracks, chips or breaks that will mean they are not waterproof.</p> <p>Check that the ventilator tubing is fitted securely to the tracheostomy and will not fall into the water.</p> <p>If child/young person's ventilator tubing becomes disconnected from the tracheostomy but it does not fall into the water, the bagging circuit should be attached to the tracheostomy and manual bagging performed. The child/young person should be removed from the pool and the ventilator reconnected once they are out of the water</p> <p>While child/young person is in the water, constant observation should be made of colour, chest movement and any indication of respiratory compromise. If these occur child/young person should be immediately removed from the water.</p>

Review date: _____ Date reviewed: _____

Manager/Health and safety officer's signature: _____

6.3 Glossary of terms

Care pathway/journey

ACT's description of a 'care pathway' approach to working with children who have life-limiting or life-threatening conditions is a way of engaging with a child and their family's needs, which can be used to ensure that everything is in place so that families have access to the appropriate support at the appropriate time.

Children's palliative care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (ACT, 2009).

Care of the dying

Care of the dying is the care of the patient and family in the last days and hours of life. It incorporates four main types of care: physical, psychological, social and spiritual, and supports the family at that time and into bereavement.

Children's hospice services

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services aim to meet the needs of both child and family - physical, emotional, social and spiritual - through a range of services.

These include:

- 24 hour end of life care.
- Support for the entire family (including siblings, grandparents and the extended family).
- Bereavement support.
- 24 hour access to emergency care.
- Specialist short break care.
- 24 hour telephone support.
- Practical help, advice and information.
- Provision of specialist therapies, including physiotherapy as well as play and music therapy.
- Provision of information, support, education and training where needed to carers.

Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose built building.

Complex care/continuing care

Complex care, sometimes known as continuing care, is an individualised package of care beyond what is available through standard health services. It is provided to children with highly complex health care needs or intense nursing care needs.

Community services

Community services refer to a service that an individual or organisation performs within the local community. This might include community children's nurses (CCNs) who deliver nursing care and support within the local community including visiting a patient's home. Community services may also include some of the services delivered by the local council.

End of life

The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health or social care team, but it is often the child/young person or their family who first recognises its beginning.

End of life care

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition, this includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and their family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement. This is not confined to specialist services but includes those services provided by any health or social care professional in any setting.

Family

The term 'family' includes parents, other family members involved in the child's care, or other carers who are acting in the role of parents. Family includes informal carers and all those who matter to the child/young person.

Hospice at home

Hospice at home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment. Hospice at home works in partnership with parents, families and other carers.

Key working

Key working or care co-ordination is a service, involving two or more co-ordinated

agencies. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and their family. (Care Co-ordination Network UK, 2006).

Life-limiting/life-shortening conditions

Life-limiting conditions, sometimes known as life-shortening conditions, are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be possible but can fail, such as children with cancer. Children in long-term remission or following successful curative treatment are not included.

Needs-led

Need-led is the term used to describe services provided on the basis of the needs of the patient and family, rather than as a result of assessing the resources that are available.

Neonate

A baby in the first 28 days of life.

Parents

The term 'parents' is used to mean any carer for a child whether that is a married or unmarried couple, a single parent, guardian or foster parent.

Supportive care

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to improve the quality of life for people with life-threatening conditions. It recognises that people need some forms of care that are not directed towards cure from the time that the possibility of a life-threatening condition is raised.

6.4 Useful organisations

ACT

ACT is the only organisation working across the UK to achieve the best possible quality of life and care for every life-limited child and their family.

Tel: 0117 916 6422
Email info@act.org.uk
www.act.org.uk

Bliss

Bliss is the special care baby charity which provides vital support and care to premature and sick babies across the UK. Bliss offers guidance and information, funds ground-breaking research and campaigns for babies to receive the best possible level of care regardless of when and where they are born. www.bliss.org.uk

Tel: 020 7378 1122
Helpline: 0500 618140
Email: information@bliss.org.uk

The Child Bereavement Charity

The Child Bereavement Charity supports families and educates professionals both when a child is dying or has died, and when a child is bereaved of someone important in their life.

www.childbereavement.org.uk
Tel: 01494 568900
Email: enquiries@childbereavement.org.uk

Contact a Family

Contact a Family are a national charity providing advice, information and support for any family with a disabled child, whatever the child's condition. Their helpline staff can answer queries on all aspects of raising a disabled child, from providing medical information about a diagnosis, giving advice about benefits and services, through to schooling and assessments and statements of special educational needs.

www.cafamily.org.uk
Free helpline: 0808 808 3555
Email: info@cafamily.org.uk

Cystic Fibrosis Trust

The Cystic Fibrosis Trust is the UK's only national charity dealing with all aspects of Cystic Fibrosis (CF). It funds research to treat and cure CF and aims to ensure appropriate clinical care and support for people with Cystic Fibrosis.

www.cftrust.org.uk

Helpline: 0845 859 1000

Email: enquiries@cftrust.org.uk

Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign is a UK charity dedicated to improving the lives of children and adults affected by muscle disease. It provides free care and support, funds world-class research to find treatments and cures, campaigns to bring about change and awards grants towards the cost of equipment such as wheelchairs.

www.muscular-dystrophy.org

Information Line: 0800 652 6352 (freephone)

Email: info@muscular-dystrophy.org

Sibs

Sibs supports siblings who are growing up with or who have grown up with a brother or sister with any disability, long term chronic illness, or life limiting condition. They can provide parents with phone support on talking to siblings about diagnosis, as well as activities for explaining disability or illness to siblings.

www.sibs.org.uk

Tel: 01535 645453

Email: info@sibs.org.uk

Winston's Wish

Winston's Wish is a childhood bereavement charity and provider of services to bereaved children, young people and their families.

www.winstonswish.org.uk

Helpline: 0845 20 30 40 5

Email: info@winstonswish.org.uk



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