

Growing up using a Ventilator

A booklet for young people and young adults

This booklet has been written for young people / young adults that use a ventilator to support their breathing. There may be questions that are not addressed in this booklet, so please use the section at the back of the book to write down anything else you would like to ask your specialist ventilation team.



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Why do I need to use a ventilator to support my breathing?

The reasons you are using a ventilator will vary depending on your diagnosis and you should discuss your individual needs with your consultant or long-term ventilation team. Some people use Non-Invasive Ventilation (NIV) using a mask and some may use Invasive Ventilation (IV), where tubing is attached to a tracheostomy which is an opening created at the front of the neck so a tube can be inserted into the windpipe (trachea) to help you breathe.

Do I need to use my ventilator every day?

This will depend on your underlying needs and diagnosis. You should discuss this with your ventilation team to ensure that you are aware of the risks of having nights off and we can ensure you are kept safe and well.

Who will look after my ventilator care when I am too old to come to the children's hospital?

Once you have your care transferred to adult services, your ventilator and ventilator equipment will be looked after by an adult ventilation team. The adult team will continue to provide support for you and your ventilation equipment in the same way as children's services did.

Do I have a choice about which sort of ventilator, mask etc I can use?

Your choice of ventilator depends on the type of ventilator your department uses and the best device to suit your breathing needs. However, there are a range of face and nasal masks you can choose from depending on preference and comfort. You may need to try a few before you decide which is best for you and how it supports your breathing. For example, if you are a mouth breather, a nose mask will not work as well for you. Your children's community nurse may also be able to offer a few more options than we currently have in hospital, such as masks with better pressure support and memory foam. They can be explored with the community nurses to enhance your comfort. Once you are in adult services you can discuss your mask options with the adult ventilation service.



Can I exercise or go to the gym whilst using a ventilator?

Yes, you can exercise with your ventilator on. You may wish to apply your ventilator before or after exercise. If you feel breathless whilst exercising you can have the ventilator on at the same time. Having the ventilator on will allow you to train at higher intensities and will help relieve shortness of breath and increase your exercise capacity. Please contact your ventilation team to discuss your individual needs or to get further advice about exercise.

If you are attending a gym or enclosed space, please check they are happy for you to use your ventilator before attending. This is because invasive ventilation is an aerosol generating procedure (AGP) and this can increase the risk of spreading respiratory infections. If you wish to participate in water sports or extreme activities, please contact your ventilation team to discuss your individual needs.

Are there any social activities I cannot do whilst using my ventilator, e.g trips to the cinema, to the pub / restaurant?

You can undertake most activities, however, if you are visiting an enclosed, small space you may wish to contact the venue to ensure they are able to safely accommodate your needs and equipment.

What should I tell my friends about using a ventilator?

You can tell your friends as much or as little as you want. If you choose to tell your friends about your ventilator, it can be helpful to tell them how the ventilator supports your breathing. You might want to tell your friends how using the ventilator overnight supports you to do the things you want to do with your friends when you are awake.

Your friends may think of questions about your ventilator that you haven't thought of. This is okay, you don't have to have all the answers. You can let your friends know their question was something you hadn't thought of, but that you can ask your ventilation team. Your teams are here to support you and will help you find answers to your questions.

Sometimes people compare their ventilator to a fighter pilot mask or an astronaut breathing equipment. Although both these things work in different ways to your ventilator, it can be a light-hearted way of talking about the ventilator with friends.

I want to go to a friend's house for a sleepover. How do I manage this? Can I have a night off?

The best thing to do would be to explain to your friend beforehand about your ventilator and how it helps your breathing overnight whilst you sleep, so you need to take your ventilator with you. If you feel you are unable to use your ventilator in a certain situation when away from home, please contact your ventilation team to discuss ways we may be able to support you.

What if I want to go out clubbing? Will it be harmful to me if I am out all night?

Of course, you can go out to party and enjoy yourself. Just be sure that when you get home and into bed that you apply your ventilator. If you don't manage to use your ventilator for your prescribed hours, then aim to wear your ventilator for a couple of hours the following day so that you meet your prescription regime. If you choose to drink alcohol or are feeling nauseous following your night out, you should not use a full-face mask in case you vomit, so please ask your ventilation team for advice.

Is there anything I shouldn't do whilst using my ventilator, e.g How will smoking or taking drugs and alcohol affect me?

Drinking alcohol or participating in drug taking can slow your breathing down and make your breathing worse. We would not advise excessive alcohol consumption and discourage the use of recreational drugs. If you choose to drink alcohol or are feeling nauseous following your night out, you should not use a full-face mask in case you vomit, so please ask your ventilation team for advice. We also discourage smoking or the use of vaping devices.



How do I tell my partner / girlfriend / boyfriend that I use a ventilator at night? What if they want to stay overnight?

Having a ventilator overnight is nothing to feel embarrassed about. When it comes to telling your partner that you have a ventilator, it can understandably make you feel anxious and nervous. But there is nothing to stop you sharing a bed with your partner. It is useful to explain beforehand what the ventilator is for and how it helps you. If you would like support or advice about talking to your partner about your ventilation, your ventilation team would be happy to help you with this.

What about sex and intimacy? How do I navigate this if I use a ventilator all the time?

Your ventilator can be used during sex if required and should be used afterwards if you feel breathless and need to rest. You should find a position which is most comfortable and restful for you.

Please speak to your ventilation team if you would like to discuss your individual needs or have further questions. Your team are here to help you and we want to assure you that there is no need to feel embarrassed asking us these questions.

Can I still get pregnant / have children if I use a ventilator?

It may be that your underlying condition rather than using a ventilator may impact your ability to conceive or carry children. Please check this with your specialist team.

We would advise that if you are sexually active that you take suitable precautions to avoid unplanned pregnancy and sexually transmitted diseases. Should you wish to conceive we would strongly advise that you discuss this with the consultant in charge of your care. Certain genetic conditions can be passed on through pregnancy and you may require pre-conception counselling.

Pregnancy can also place stress on the respiratory system, and it is important that you inform your ventilation team should you wish to get pregnant so that they can support and monitor you early and throughout your pregnancy and delivery.

Travel



Can I learn to drive if I use a ventilator?

This will depend on your individual condition. You should discuss this directly with your ventilation team or the specialist clinical team in charge of your care.

Can I use public transport with a ventilator?

In the UK, all public transport must by law be “accessible” to allow disabled passengers to use it. If you’re planning to use public transport and are unsure if you can use your ventilator, it is worth getting in touch with the transport provider before travelling to ensure they can prepare to help you in whatever way you need.

If you receive Disability Living Allowance or Personal Independence Payments, you may be entitled to a reduction in fares. Please check the GOV.UK for the most up to date information on using public transport. You may also be entitled to a Blue Badge for your parent / carer or your own car, which means you can park in a disabled parking space.

What do I need to take with me if I travel abroad?

Prior to travelling you should speak with your ventilation or specialist team to make sure you are safe to travel. You may need a flight assessment if you are planning on taking a flight.

When planning your holiday, it is sensible to consider whether your destination has suitable healthcare if you were to become unwell. You should always ensure that you have travel insurance in place. Apply for a UK Global Health Insurance Card (GHIC) or UK European Health Insurance Card (new UK EHIC) before you travel from the GOV.UK website. Both cards give you access to state provided healthcare while staying in an EU country for things like emergency treatment and visits to A&E.

You should inform your airline if you need to use your ventilator during the flight. This should be done prior to booking your flight to check that this is allowed. All ventilation equipment should be carried in your hand luggage and again must be declared to the airline before flying.

Please ensure that you obtain a customs letter from your ventilation team. This describes your condition and any equipment and medication required during travel prior to leaving the UK.

You should ensure that you have the correct equipment before you travel, whether in the UK or abroad. You should speak with your ventilation team to discuss what equipment you would require to support you to travel safely. This may include additional devices or batteries.

I want to go to a festival with my friends. Is this possible?

Yes! Please speak to your ventilation team to ensure you have the appropriate equipment such as a spare device and batteries.

Planning ahead is the key to staying safe and healthy during your festival. Before you go, find out about any accessible and medical facilities available onsite. First aid charities such as the Festival Medical Services and St John Ambulance are present at most of the big festivals. They have volunteer medics providing 24-hour medical assistance. You should know where the nearest Accident and Emergency department is situated, just in case!

Camping may be part of the music festival experience but for some people with disabilities, it's not the most comfortable option. Staying offsite at a hotel could be a better option. You should also think about practical things such as making sure your ventilator doesn't get wet if it rains etc.



Can I move away from home to go to university?

If you wish to move away from your local area, you should speak directly to your ventilation team. Your ventilation team will try to arrange your routine hospital appointments during holidays. They may arrange for shared care with a ventilation service closer to your university during term time to support you in an emergency. If you require equipment whilst at university, please contact your ventilation team as they may be able to post equipment to your term time address.

The UCAS website has a wealth of information for students with physical, mental health conditions and learning difficulties and have guides that help to ensure you have all the support you need for your chosen course. In most instances, the provider's website will be your information starting point. This may include information about learning and assessment methods, support provided, and the contact details of the disability, mental health, and/or wellbeing support teams. If you cannot find the information you need, contact student support services at your chosen university, who will be able to help.

Do I need to tell my employer that I use a ventilator?

It is up to you whether you choose to disclose that you use a ventilator. You are protected under the Equality Act. You should consider disclosing your condition so that your employer can support you and make reasonable adjustments so that you can do your job. If you choose not to disclose, you should consider the need to take time off for medical appointments or if you become unwell.





How should I feel about having a ventilator?

There is no right or wrong way to feel. We all feel different things at different times. Sometimes you may feel happy and thankful to have a ventilator, sometimes you may feel frustrated or sad to have a ventilator. However, we know it is very common for health conditions to affect how you feel. It is also common for your mood to affect your health condition.

We know that many people can experience worries, for example, worries about adjusting to a condition, living with symptoms, managing treatments, or how a condition or treatment might impact on your social life.

How do people cope?

There are different approaches to coping. We might use different approaches at different times. Sometimes people approach the problem. This often involves strategies such as: gathering more information, seeking out support, trying to problem solve the difficulty, trying to find helpful ways to express emotions. This approach may be trying to cope with a difficulty or may be coping with the emotions a situation brings up.

Sometimes people avoid the problem. This involves strategies such as: wishing things could be different, pretending the situation isn't happening, stop attending appointments, blocking worries or emotions. This approach may be trying to avoid a difficulty, or it might be trying to avoid the emotions a situation brings up. It is very understandable to want to avoid things that worry us or that we find unpleasant. Although coping by avoiding can put off the difficulty, which gives a short-term relief, it doesn't solve the difficulty. It also doesn't give you the chance to build up coping or confidence. It also doesn't allow others to help you. Coping in this way over time can increase difficulties. So, avoiding is often not a helpful strategy in the long term.

Different ways of coping will be helpful at different times, being flexible in how we cope is important. The style of coping can affect how involved we are with the tasks of looking after our health and wellbeing. If you can be involved in looking after your health, it will help you make choices and have more control in managing your condition and the treatment. Keeping focused on the things you can do and choices that you can make are important ways of coping.

What can help me to cope?

Understanding your condition. This is the first step in coming to terms with the condition and treatment. Reading the information in this booklet may help you feel more knowledgeable about your ventilator and more in control. Having knowledge and having choice and control are important factors in coping.

It is important to keep in contact with your ventilation team, so that you can share any concerns and feel listened to. When you have chance to talk with the team you can gain answers and make plans together.

The specialist staff from the children and adult services have knowledge and expertise. They are here for you to talk with during the transition from children to adult services.

When you move to adult services, you will be able to get to know the adult team and you can contact the team for support. If you are feeling sad or fed-up about your condition or your ventilator you can talk to your ventilation team. You can think together to find solutions to any worries and find support that might be helpful. Some adult services have a psychology service that can offer support. If you would like to know more about the psychology support, please talk to your ventilation team and they will arrange this for you. There is also likely to be support from psychology services in your local area.





Learning how to manage your long-term health condition and treatment can help you cope. There are several things that you can do:

- Have information about your condition, symptoms and what your treatment options are.
- Learn how you can monitor your symptoms and ways you can manage symptoms.
- Taking medicine and treatments as they are prescribed and talking to your ventilation team if you have any concerns or want to make any changes.
- Find ways that help you cope with the impact of your condition and treatment.
- Finding ways to relax.
- Having good relationships with your care teams.
- Having connections and support.
- Doing activities that help you to stay healthy / having a healthy lifestyle.

Think about what might be helpful to you:

I can get information from: _____

I can talk to: _____ about my health condition.

I can talk to: _____ about my wellbeing and emotions.

Things that help me feel calm / relaxed are:

Things that I am interested in that I like to do are:

Where to find further support:

- You can talk to your GP or ventilation team about your health and your ventilator.
- There are many different reasons why people need breathing support from a ventilator. Talk to your ventilation team to find out if there are any services or charities about your condition. Finding a trusted place to get advice and support is important.
- Having someone to talk to about how you are feeling or how you are coping can be helpful.
- You might find talking therapy helpful. You can talk to your GP or ventilation team about what is available in your local area.
- You can also talk to your school, college, or university, they often have emotional support for students.

If you are struggling with emotions or worries, there are helplines for support:

Childline: Tel: 0800 11 11.

Childline is here to help anyone under 19 in the UK with any issue they're going through.

NHS-Go: Web link: <https://nhsgo.uk>

NHS Go is a confidential health advice and information service for 16-25 year olds.

The Mix: Tel: 0808 808 4994 / text service 85258, text THEMIX/ themix.org.uk

Support and advice for under 25s, including a helpline, crisis messenger service and webchat.

Samaritans: Tel: 116 123 / email: jo@samaritans.org

Samaritans are open 24 hours a day, 365 days a year for anyone who needs to talk. All emails are answered usually within 24 hours.

Patron: The Duke of Sussex



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