



# Life and Breath

Worry Free Breathing During  
Power Failure



## Life and Breath

When you rely on vital medical equipment, having a plan for emergency situations such as a power failure could save your life.

This factsheet contains a variety of information and strategies, from adults with Duchenne and similar types of muscular dystrophy, who use respiratory equipment (e.g. positive pressure machines/ventilators, cough assistance, nebulizers).

We hope you find it useful in making your own power failure safety plans.

### Why we produced this fact sheet.

There are occasions where power failure has led to loss of life. Whilst we don't wish to comment on individual cases, the importance of a robust power failure safety plan is essential for people using ventilation.

The purpose of this fact sheet is to share information and offer guidance on ventilator use in the event of power failure.

- Facebook members have together offered their power failure plans and we have compiled these in this Factsheet about managing ventilation in such an event.
- Our facebook group offers the voice of lived experience – talk to adults with DMD and similar conditions, find out how they manage these situations.

- Become a powerful self-advocate – take action and insist that your ventilator provider gives you appropriate battery back-up (many hospitals do not provide back up batteries routinely if you are not almost totally dependent on your ventilator).
- If you live in a care/nursing home or supported accommodation – ensure you are confident that they have suitable generators, manual resuscitation bag/masks or emergency plans to ensure prompt support with varying levels of fail safes.

## Power failure can occur in many ways:

- In your own home through blowing a fuse by overloading electrical sockets.
- Through damage to the main power grid for wide areas e.g. storm damage
- Through damage to your local areas e.g. repairs in your street or someone accidentally digging through underground cables or pulling down overhead power lines.
- Gas leaks where residents will be told to turn all power off quickly.
- Generator failure, low fuel.

A good plan should cover what to do if the power goes off for a few hours, days or maybe even weeks. During the UK floods in 2013/14 some homes lost power for weeks. Your plan might involve what to do if you had to leave your home in an emergency or live somewhere else for a short time.

## Here are some ways that people prepare for power-cut emergencies



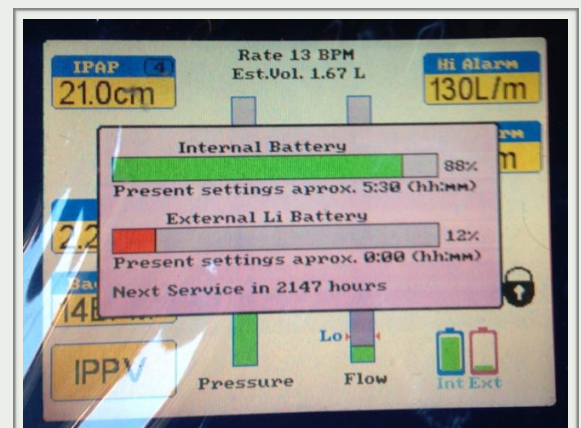
•Ventilator equipment with it's own batteries (automatically switching to battery back up if the mains power goes off).

Insist on a battery back up if you can't breathe unaided at night. A battery might last a few hours or as much as ten - depending on whether the battery is fully charged and what your pressure settings are. The higher your pressure settings, the shorter the battery life.

You might want to find out how much battery power is left as time goes on - so make sure people know how to check this. Some ventilators only show a bar graph but will often have a 'hidden' menu which will tell you a more accurate percentage estimate.

Some ventilators are able to power and interface with nurse/carer systems.

You might also want to consider purchasing a power generator or plan to use your car battery in an emergency. If you want to run your ventilator from inside your car you will need an inverter as Daniel describes below.



“I have battery back up for my vents, I also have a small generator outside for mega emergencies, then there's handy mains which can plug in to a car lighter socket to power a ventilator, last port of call would be an ambulance to get to a hospital which should have generators. I have thought and worried a lot about power failures, luckily in this country they aren't that frequent, going on holiday abroad does worry me though.”

*[Daniel Baker, UK]*



**An inverter to power equipment in the car.**

- **How will personal assistants / carers be alerted to the power going off?**

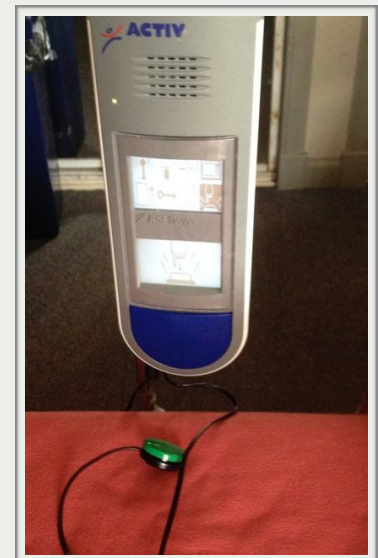
Even if your battery takes over - alarms may need to be switched off or you might need help after losing power to your bed / mattress or other medical equipment. It's also reassuring to know someone knows the power has gone out and how this can impact on your well being.

“I have 3 battery packs which I keep as fully charged as possible. I have a wireless doorbell push that I use to alert my carers if it's in the night.

*[Sarah Rose, UK]*

“My husband sleeps in the same room to hear my vent alarms and I also use a wireless door bell to alert assistants during the day. They are also trained in how to respond and what to listen out for. I can also ‘frog breathe’ a bit in a dire emergency.”

*[Louise Watch, UK]*



- **Keep mobile phones charged and take them with you if you have to leave your home - a torch will also be essential.**

“We have a torch and there's always my phone App torch to fall back on. I like to keep my mobile as charged up as possible so I can contact the power company to ascertain how long it's likely to be off and I can run the vent off the car using an inverter.”

*[Sarah Rose, UK]*

- **Many people have a multi layered plan depending on the severity of the emergency.**

You may need to consider powering other devices or having a second ventilator. Some techniques may be able to be done manually in an emergency so training people and refreshing their skills is important. You might be able to use a car inverter to also power these if

## Alternatives

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**Ventilator** - replace with a bag and mask device like e.g an Ambu Bag. Assistants can attach the bag to a mask and squeeze to breathe for you.

**Cough Assist / Clearway** - replace with assisted coughing (your respiratory specialist can show someone - family or assistants how to do this).

**Suction machine** - replace with manual suction techniques using equipment.

**Pulse Oximeter** - often internally powered or switch to handheld/finger device.

**Humidifier** - find out if you lose your humidification when on battery back up.

**Nebuliser** - as above.

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I'm ventilator dependent 24/7, I have a very good backup system. In case I have a powercut I have the following protocol:

- A Gas operated Generator which is regularly checked by my local authority
- A back battery which can be attached to my ventilator
- A second fully charged ventilator

*[John Ahsby, UK]*

**A back up power station can be useful.**





**David Skinner describes his 4 layer plan:**

Layer 1

“Everything on my vent table except the humidifier is plugged into an APC SmartUPS 1400 (\$250 investment I wouldn't go without). So even during a breathing treatment my IPV (ventilator), Cough Assist, and Pulse-Ox all stay powered (lasts over an hour with just vent & pulse-ox) the moment the power goes off, and it starts alarming. I have an analog and a digital baby monitor, plus a wireless mic around my head, all plugged into the UPS and 2 of them also have internal batteries. Equally important, all three receivers in mom's room have internal batteries.”

Layer 2 - back up generators.

“Within 30 seconds the Generac Standby Generator in the backyard starts and takes over my room and most of the house. If its hot out, my window A/C takes over cooling my room.”

Layer 3 - if the generator doesn't work.

“Vent gets plugged into wheelchair batteries (12hr run time) and extension cord gets run to the inverter in my bus/van (engine running). My Dad gets a call to bring the gasoline generator & troubleshoot the Generac. If its hot out, we start a breathing treatment in-case I need to get up to get in the bus for air conditioning.”

Layer 4 - David has a converted RV his can live in that is fully equipped.

- **Plan how to use battery power, if this is limited, and ensure assistants/carers are aware of what to do to make the best use of remaining power.**

“For the first six months my hospital didn't provide me with a battery even though I can't breathe unaided when lying down. I had to push for one. My battery lasts 7 hrs (My husband make sure it's charged and connected each night) and I have a car inverter. I sleep with my hands by the bed controls so I can do an emergency sit up. My bed has just enough battery power to do this so I can breathe if I am upright and the mask is taken off my face.

I also have to be aware of using my hoist - as I can only get into my sling from a sitting position. If I use the remaining power in my bed battery to alter my sleeping position, I might not be left with enough to sit up with by the morning!”

[Louise Watch, UK]

- **Register with your power supplier.**

Your electricity network operator looks after the safety and security of your electricity supply in the UK.

There will be a power supply register for people who need extra support in a power cut. In the UK it doesn't mean you get priority for having electricity restored though, which is a common myth. However, they do help with being able to give you more frequent updates, advice and can link you in with the British Red Cross and emergency services.

It is important to check with your supplier about the level of support that is available and keep their emergency phone numbers handy.

"I have two battery packs the last around 4 hours each and both of my vents have an internal battery that last 3 hours each. I can also run my vent off the car using an inverter. If I have to I will go to the hospital but that is the last resort. Also the power company that services my area has a program where if you use a vent and your power goes out they will come to your neighborhood before anybody else's."

*[Joey weber, US]*



## Check List for ventilator users.

- Do I have battery back-up?
- If I don't have a battery - will generators automatically start to keep my equipment powered - and if they fail, do people know how to use a bag and mask to enable you to breathe (or if you have to evacuate)?
- Will my battery automatically take over when the power fails?
- How long will my battery last?
- Can you alert a personal assistant/carer to your needs using a battery powered alarm?
- Do personal assistants/carers know what to do when the power goes?
- Consider what you will do if your power goes off for longer than your battery might last.
- Use battery power wisely - prioritise if you need power for other equipment.
- An inverter can allow you to run medical equipment from inside your car.
- Keep your mobile phone charged and have emergency contact numbers to hand.
- Contact your power supplier to go on their register to be kept updated.
- A torch will be invaluable - have you got one to hand?