



Dear Blue Badge Team,

As Chair of **CCHS UK**, I am writing in support of this application for a Blue Badge. CCHS UK is a UK charity supporting people affected by **Congenital Central Hypoventilation Syndrome (CCHS)** by connecting families, providing education, and funding research.

CCHS is a **severe, life-threatening disorder of the autonomic nervous system** that impairs the body's ability to regulate vital automatic functions. The most critically affected system is **respiratory control**. Individuals with CCHS do not reliably detect a build-up of carbon dioxide (CO₂) in the blood, which normally stimulates breathing. As a result, breathing can become **dangerously shallow or stop completely without warning**. All individuals with CCHS require **mechanical ventilation to survive**, either invasively or non-invasively.

CCHS **does not improve with age or treatment**; while ventilation technology may evolve, the underlying condition remains **lifelong**, and the level of dependency is **unchanged**.

Because of the severity of the condition, every person with CCHS must always have immediate access to their prescribed medical equipment. This applies regardless of age, as there is **no cure or alternative therapy** currently available.

The medical equipment required is **substantial and heavy**. A typical list includes ventilator(s), masks or interfaces, monitoring equipment, suction and emergency oxygen supply. In addition, **backup equipment** is required in case of power failure or medical emergency, including a large oxygen cylinder, AMBU bag, and other essential emergency kit items. This equipment must always travel with the person and cannot be carried long distances or easily lifted.

People with CCHS also **fatigue easily** due to CO₂ build-up during physical activity. Even mild illness or infection can cause their autonomic function to deteriorate, leading to **rapid exhaustion, dizziness, and risk of collapse**. There is also a risk of “**breath-holding**” **episodes**, where the drive to breathe stops completely in response to fear, pain, or distress.

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These can be **life-threatening emergencies** requiring **immediate intervention** with medical equipment.

Any delay in reaching their equipment or vehicle can result in **respiratory compromise or arrest**. **Walking long distances or being far from a vehicle can therefore present a direct and serious risk to health and safety**. Proximity to their vehicle and medical equipment is not a matter of convenience, but of **immediate survival**.

A **Blue Badge is essential** to ensure safe mobility and equal participation in daily life. Without accessible parking close to destinations, individuals with CCHS are often **unable to undertake necessary daily activities** such as attending school, college or work, medical appointments, or community activities. This can result in **social isolation and increased health risk**.

The Gov.UK guidance lists the following criteria for Blue Badge eligibility:

- you cannot walk without help from someone else*
- you find walking very difficult due to pain, breathlessness, or the time it takes
- walking is dangerous to your health and safety
- you have a child under the age of 3 with a medical condition that means the child always needs to be accompanied by bulky medical equipment**
- you have a child under the age of 3 with a medical condition that means the child must always be kept near a vehicle in case they need emergency medical treatment**
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All of these criteria are directly relevant to individuals with CCHS:

* children and adults alike cannot safely manage or carry their own medical equipment and **fatigue easily when walking**;

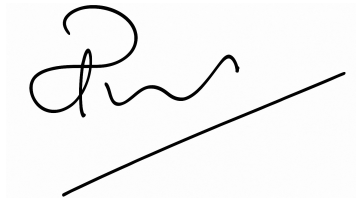
** while written for children under 3, these points remain applicable to anyone with CCHS, as the **need for equipment and proximity to a vehicle is lifelong and medically essential**.

This position is supported by **clinicians across the UK CCHS network**, who routinely advise that individuals with CCHS must remain within **immediate reach of their medical equipment and vehicle** to avoid potentially fatal complications.

I hope this letter clarifies the **severe and ongoing mobility limitations, medical risks, and safety concerns** associated with CCHS, and demonstrates the **vital importance of a Blue Badge** to enable safe and equitable mobility.

Please do not hesitate to contact me if you require further information.

With best wishes,

A handwritten signature in black ink, appearing to read 'Amanda', with a long horizontal line extending from the bottom right of the signature.

Amanda Yardley
Chair of CCHS UK

Typical prescribed equipment list

Ventilator x 2
Dry circuit x 2
Ventilation mask x 2
Headgear
Car charger
Battery inverter
Ambu bag and circuit
Oxygen cylinders (2 large)
Oxygen cylinder (portable)
Ventilator mains lead
CO2 monitor mains lead
Pulse oximeter monitor mains lead
Ventilator external battery
AA batteries for pulse oximeter monitor x 8
Saturation probes x 2
Multi-site attachment rings for CO2 monitor x 1 box
Gas canister for CO2 monitor
Membrane changer for CO2 monitor
Changer inserts for CO2 monitor
Humidifier chamber (necessary for overnight stays)

The total weight of these items required in the vehicle would be between 25-30kg. The weight of the items required to accompany the CCHS patient at all times (carried on foot) would be between 10-15kg.