

## Patient information factsheet

# Welcome to the adult home ventilation service

We have given you this factsheet because you will soon be moving from the children's long-term ventilation (LTV) service to the adult home ventilation service.

This factsheet introduces the adult home ventilation service and explains what will happen as you move across to this service, so you know what to expect. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

### Moving to the adult service

We understand that moving from the children's service to the adult service can be daunting for some young people, as the teams you know and are used to will change. We will work closely with the children's LTV team to help make the move as smooth as possible for you and your family.

To help support you with the move, the children's LTV team will discuss the Ready Steady Go transition programme with you (a programme designed to help young people feel ready to take more of a lead on their health and the management of it by the time they reach the adult service). A member of our adult home ventilation team will also:

- come along to your last one or two children's service appointments so that you can get to know us before you formally move to the adult service.
- explain the different ways that our team can support you.

### What is the adult home ventilation service?

The adult home ventilation service cares for and supports adults who are either being monitored for or are using bilevel positive airway pressure (BiPAP) devices (a type of non-invasive ventilation (NIV) or breathing support). The service also cares for some adults who use continuous positive airway pressure (CPAP) devices (another type of NIV or breathing support) if it is not suitable for them to be under the care of the adult sleep service.

The service covers the Wessex region (Hampshire, Dorset, Wiltshire, and the Isle of Wight), and occasionally areas outside of the Wessex region if you are already under the care of other specialities at University Hospital Southampton NHS Foundation Trust.

### Our team

The adult home ventilation service is a specialist team made up of several healthcare professionals, including:

- consultants
- specialist physiotherapists

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- clinical nurse specialists
- healthcare assistants (HCAs)
- administration team

## Appointments

The adult home ventilation service is an outpatient-based service. This means all your appointments will take place during the day and you won't need to stay in hospital overnight.

Appointments will usually be face-to-face appointments and will be held in our clinic in the outpatient department in The Respiratory Centre on D level, West Wing at Southampton General Hospital. However, we may occasionally arrange for you to have a telephone appointment if we want to check on your progress but don't need to see you in person. We will let you know in advance if this is the case.

## Transition clinic appointment

Your first appointment with our team will be a transition clinic appointment. The transition clinic is a special clinic for those who are moving to the adult service for the first time. A member of the children's LTV team (a nurse and/or a consultant) will come along to this appointment too, so you will have a familiar face there. This appointment will last approximately one hour.

At this appointment, you will have the opportunity to get to know our team and for our team to get to know you. You will also be able to ask any questions or discuss any concerns you may have about moving from the children's service to the adult service.

From this appointment onwards, you will officially be under the care of the adult home ventilation service.

## Follow-up appointments

After we have seen you at your transition clinic appointment, we will make the decision as to how often we need to see you for follow-up appointments. This may be different to the timescales you have been used to and may vary depending on the outcome of each of your follow-up appointments.

Your follow-up appointments will usually be on a Wednesday afternoon or on a Friday morning (unless you have a separate appointment with one of our physiotherapists or specialist nurses).

At your follow-up appointments, we will:

- ask you questions about how you are getting on and any symptoms you have been experiencing
- take your observations (for example, your oxygen levels and blood pressure)
- assess your respiratory health (for example, we may ask you to do a sniff pressure test so we can measure your respiratory muscle strength or we may ask you to cough into a mask so we can measure your cough strength)
- review your NIV equipment and download any data from it (if applicable)
- review any additional equipment that you use to help clear secretions (for example, a Vest<sup>®</sup> airway clearance system or a cough assist machine)
- take a blood sample from either an artery in your wrist (ABG) or from your earlobe (CBG)
- provide any necessary replacement equipment
- service your BiPAP or CPAP device (if necessary)

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## Home sleep studies

We do not perform inpatient sleep studies or evaluation of a transcutaneous carbon dioxide monitor (TOSCA), but we can arrange home sleep studies if necessary. We will discuss these with you if appropriate.

## Differences between the children's service and the adult service

### Care

While you have been under the care of the children's service, one team has looked after all your respiratory needs, including your BiPAP device, oxygen use and general lung health. When you move to the adult service, your respiratory needs will be looked after by separate teams, such as the adult home ventilation team, the adult home oxygen team and a general respiratory consultant. All the separate teams involved in your care will work closely together and we will do our best to support you with this change.

### Independence

You will notice when you move to the adult service that we start to direct more of the questions to you during your follow-up appointments and less to your parent or guardian (where possible). This is to help you to feel confident that you have the skills to manage your condition more independently.

### Equipment

When you move to the adult service, we will replace your current BiPAP or CPAP device with a new device that is managed by our team (we will aim to give you the same device but if this is not possible, we will teach you how to use the new device). We may also suggest trying a different face mask if your needs change.

We will aim to service your device every one or two years (depending on the device you have), and we will give you an alternate device to use while yours is being serviced.

If you need spare or replacement equipment, we can give you this at your face-to-face appointments, or we can leave the equipment for you to collect at The Respiratory Centre reception desk, or we can post it to you, if necessary.

## Contact us

If you have any questions or concerns about moving to the adult home ventilation service, please don't hesitate to contact us.

Adult home ventilation service

Telephone: **023 8120 4416** (Monday to Friday, 8am to 4pm)

Email: [homenivclinician@uhs.nhs.uk](mailto:homenivclinician@uhs.nhs.uk)

If we are unable to answer your call, please leave a message with your name, phone number and a brief reason for your call and we will get back to you as soon as possible.

If you wish to change or cancel your appointment, contact our administration team.

Administration team

Telephone: **023 8120 2617** (Monday to Friday, 8am to 4pm)

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## Useful links

[www.readysteadygo.net/rsg-hello-to-adult-services.html](http://www.readysteadygo.net/rsg-hello-to-adult-services.html)

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**

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