

Veno-venous (VV) extracorporeal membrane oxygenation (ECMO) post-procedure information

The aim of this leaflet is to help answer some of the questions you may have about what happened to you during and after your intensive care stay. You have had serious problems with breathing and were treated with a therapy called ECMO. If you have any questions and concerns, please do not hesitate to speak to the doctor or nurse caring for you.

What is ECMO and why did I need it?

ECMO is a temporary life support system used for people whose lungs have stopped working properly. You needed ECMO because you were seriously ill with breathing problems that could not be managed by other methods of breathing support, such as ventilators. Severe lung failure can be caused by a number of things, such as very severe infections resulting in a condition called acute respiratory distress syndrome (ARDS).

The ECMO machine did the work of the lungs. A tube carried blood from the right side of your heart and pumped it through an artificial lung where it picked up oxygen and dropped off carbon dioxide. The oxygen-rich blood was then passed back into your blood, near your heart.

What happened while I was on ECMO?

While you were on ECMO, the staff from the intensive care unit looked after you. You were given powerful pain relief and sedatives, so you may not remember all of the events during this time.

What problems may occur during or following ECMO?

Unfortunately, as with any treatment when you are very sick, ECMO does have complications. This section lists some of the more common problems, but if you have concerns about any aspect of your health following ECMO you can speak with your GP or call the Guy's and St Thomas' ECMO team, details are at the end of this leaflet.

Respiratory difficulties

Following an episode of severe respiratory failure, your breathing may take more than a year to return to normal. It is likely that you will feel breathless with exercise (even walking or other light exercise) and you may have a persistent cough. These should improve with time. Because you required a breathing tube, either through your mouth or the front of your throat (tracheostomy), you may have a hoarse voice or problems with

breathing due to a narrowing of the trachea (wind pipe). Problems such as hoarseness may settle with time, however if you have persistent problems, your GP should arrange for an ear nose and throat surgeon to see you.

Scarring

You will have scars over your groin or neck. These are the cannula sites, where tubes were used to allow your blood to be put through the ECMO machine. For most people, the scars become less obvious with time, but if the scar is unsightly and shows little sign of improvement, your GP can arrange for a plastic surgeon to revise the scar. Some people develop lumps with a pulse in them – pseudoaneurysms – and need to be seen urgently by a vascular surgeon (contact your GP for details). This is more likely if you had a cannula in an artery.

Bleeding

ECMO requires powerful blood thinning medications to allow your blood to run through the machine. It is possible that you bled as a result of this and probably had a blood transfusion. Blood transfusion in the UK is very safe and it is unlikely that you will have any permanent problems. The bleeding will have been controlled by staff and it is unlikely that it would happen again. If you bled into your brain, you may have features of a stroke, such as weakness on one side of your body. This may, or may not, improve with time.

Psychological wellbeing

Because patients on ECMO have been so unwell, psychological problems, such as depression, are very common. It is also not unusual for people to have flashbacks that may be distressing – this is called post traumatic stress disorder. Please speak to your GP if you are experiencing problems with your psychological wellbeing.

Other problems

When you were on ECMO you remained in bed for a very long time and although you were on a special bed, it is possible that you will have pressure sores. Although many pressure sores will require special dressings, they will usually heal with time. Sometimes, patients need to have an operation to help with them.

It is also likely that you will need rehabilitation due to muscle weakness. This is very common and may take years to improve.

Other problems, such as changes in your ability to taste, are common following critical illness and will usually improve with time.

Will I have a follow-up?

Approximately three to six months after you leave hospital, we will contact you to see how you are. We will send you questionnaires asking about any problems you have been having, and also asking you and your family to tell us what you thought about the care you received. Your GP will co-ordinate your follow-up and ongoing care, but you are welcome to come back and speak with the ECMO team at any point. Please call us for an appointment.

Contact us

If you have any questions or concerns about anything you have read in this leaflet or the care your relative is receiving, please contact the ECMO nurse in charge.

For anything else, please contact the Intensive Care Team on 020 7188 3038, Monday to Friday, 9am to 5pm.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

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