Communication can be a difficult process with ICU patients. Patience is required by all involved and it is common to use a variety of methods. Please ask staff on the Unit for help and guidance.

Sometimes, patients can be confused and forgetful, and it is necessary to repeat information for them again and again. (Please see *Hallucinations* and *Delirium* leaflets or ask a staff member for more information.)

Points that are common from patient feedback are:

- Where am I?
- Why am I here?
- Why can't I talk?
- Why can't I eat and drink?
- What are all the alarms for?
- What are the tubes for?
- I'm uncomfortable
- I want to watch TV/listen to music etc.
- What time is it?
- When will I get better?
- I want to go home
- Why are you leaving me here? Why can't I go with you?

If you are concerned about communicating with your relative, please tell a member of staff who may consider a referral to Speech and Language Therapy.

Recovery after Critical Illness Level 3 South Block T: 0118 322 7248 E: RaCl@royalberkshire.nhs.uk

Contact the Recovery after Critical Illness team if you have any concerns regarding your relative's altered mental state. (Leave a message if it is out of office hours.) The team will visit the patient when they go the ward as part of the normal rehabilitation process for continued observation if there are any concerns.

This leaflet has been produced as a result of nationally funded research (NIHR) in which patients, relatives and staff worked collaboratively, sharing their experiences of being involved in critical illness.

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ICU support webpage – www.readingicusupport.co.uk



To find out more about our Trust visit <u>www.royalberkshire.nhs.uk</u>

Please ask if you need this information in another language or format.

RBFT ICU Reviewed: December 2023 Next review due: December 2025



Voiceless – why can't the patient talk?

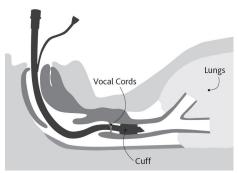
Information for patients, relatives and carers

Some patients in ICU cannot talk mainly due to having a 'breathing tube' in place.

The patient will be on a ventilator (breathing machine). This might be through a tube in the mouth or in the throat (trachesostomy). Both of these tubes go into the windpipe and through the vocal cords. Each of these tubes has a 'cuff'. When it is inflated, this helps the breathing machine deliver all the support needed and helps keep the tube in place. When the cuff is inflated, no air can pass up to the vocal cords. It is the air flowing over the vocal cords that helps the vocal cords that helps the vocal cords vibrate, creating the sound that is your voice.

Cuff up = No voice

It also may not be possible for the patient to drink or eat at this time.



The patient might believe at this time that they can speak, and from patient experience, believe they can hear themselves talk.

Patient experience

"Having been on a ventilator for a long period of time through a tracheostomy the frustration and fear you feel at not being able to speak, is overwhelming. I was not aware at the time I was attached to a ventilator; you can't feel it and you can't see it. I believed I was speaking guite clearly to people. I even believed I could hear my own words. It is hard to describe the feeling of loneliness you get when you desperately want someone to understand you. Only afterwards do you also realise the frustration others feel when they want nothing more than to understand you. Despite the frustrations, I never forget, the ventilator kept me alive. Seeing a simple drawing which was done for me of how a tracheostomy prevents you from speaking made such a difference to me, I felt relieved and educated that I now knew why".

Jason Boyes

Once the patient is well enough not to need the breathing machine all the time, and if the patient has a tracheostomy, the cuff can be deflated. If the patient is not 'distressed' by this (e.g. finding breathing more difficult, oxygen levels falling, coughing continuously), a 'one-way valve' can be tried on the end of a tracheostomy. The healthcare professionals will decide when this is appropriate. The one-way valve is not guaranteed to work. Patients often do not manage this, as they may be too weak. The patient will not speak with their normal voice even with the one-way valve in place. When a patient is on a breathing machine, they might be "suctioned" – that is secretions removed from the chest that they cannot always clear themselves. Feedback from patients is that being told why this is being done is important to them, as it can be an uncomfortable procedure and this explanation needs to be given more than once.

Other ways of communicating

- 1. The patient may mouth words. This may be a very frustrating time for all involved. While this works for some people, lip-reading can be very difficult. Encouraging patients to speak slowly, over-articulate sounds and use one word at a time may help.
- 2. The patient might try to write for you. Some assessment of the patient is involved before attempting this, as they might not have the strength and coordination. Again, the patient might believe what they have written is clear and makes sense.
- Alphabet/picture boards the patient uses their fingers or eye gaze to point to a picture or a letter to spell a word.
- We have other aids to help with communication, such as iPads and an eye gaze, which we may trial, if appropriate.