



# Next Steps

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## Support groups

Despite the vastly different reasons for admission to critical care, meeting and talking to people like them can make a huge difference to ICU patients and help them realise they're not alone in what they feel and think.

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## The story so far...

Welcome to our first newsletter to update you on recent developments from ICUsteps. To make sure you receive copies of future newsletters, be sure to sign up on our website by visiting <http://icusteps.org/newsletter>

ICUsteps is a patient focused charity set up to help intensive care patients in their recovery after critical illness. We were founded by Mo Peskett, an intensive care follow up nurse, in collaboration with ex-ICU patients and relatives. We knew that more needed to be done to support patients and relatives through critical care treatment and recovery and began by establishing a support group in Milton Keynes in 2005.

Being a patient-led group, we were driven by the desire to repay the debt of gratitude we owe to those who saved our lives, to gain every ounce of positivity from what we've been through and lessen the suffering of those yet to follow us through critical illness. Having seen critical care from the other side of the looking glass, we wanted to help make the experience better for other patients.

### Finishing the job - rehabilitation

The crucial work of the multi-disciplinary team in helping patients back from the brink is only the start of the job. While those

fortunate enough to survive critical illness are forever grateful, survival is not the sole measure of success. Leaving a patient alive, but physically and psychologically scarred, isolated from those like them and devoid of support is not a successful patient outcome.

The need for rehabilitation following critical illness was recognised by the National Institute for Health and Clinical Excellence (NICE) in their 2009 clinical guideline CG83. The views and input of patients and relatives were fully considered in developing the guideline. Both CG83 patient representatives are now ICUsteps trustees.

When patients leave critical care for a general ward, they leave a place where the severity of their condition and the possible issues they might face in their recovery are understood. On the ward, they're unlikely to meet another ICU patient and even the medical staff are often unaware of the issues their patient may be experiencing as a consequence of critical illness leaving them isolated, anxious and feeling like nobody understands what they're going through.

ICUsteps is unique in being an organisation for ICU patients led by ex-ICU patients. Through this, we're able to offer empathy, not just sympathy.

### Coping with life after survival

As well as support groups, we have developed patient information. For many patients and their relatives, going through intensive care is a very traumatic and frightening experience. But that is nothing compared to the distress afterwards trying to

understand and come to terms with what has just happened to them. At ICUsteps we believe that providing information and telling patients what to expect after ICU can make a world of difference. Know that others have experienced similar feelings and learning from the knowledge of those who have been through it, can make an immense difference to patients' quality of life after intensive care treatment.



'Intensive Care: a guide for patients and relatives' - information for patients, written by patients in Plain English.

Since first publication in 2008, ICUsteps information booklet 'Intensive Care: a guide for patients and relatives' has helped thousands of ICU patients with 75,000 copies distributed and ordered by over half of the UK's critical care units.

## THE PATIENT PERSPECTIVE

*Would it be ungrateful to say that saving our lives isn't enough?*

*After all the effort, skill and dedication that's committed to helping critically ill patients back from the brink, all too often the less glamorous but crucially important stage of rehabilitation seems to be treated as a 'nice-to-have' or a luxury extra when in fact this stage can make a world of difference to patient recovery and restoring our quality of life.*

*Rehabilitation bridges the gap between just surviving and returning to a normal life, or as close as we can get to one. Shouldn't that be the aim of treatment from the start?*

*When it comes to healthcare economics, I believe rehabilitation makes even more sense. At the very least, it's protecting the investment that's already been made through critical care treatment. In comparison to critical care treatment at around £1,800 per day, rehabilitation is a snip. Aside from the fact that patients want to get better and be supported through their recovery rather than abandoned on leaving ICU, the reduced likelihood of ICU readmission, repeat visits to their GP and ongoing health issues are all surely going to save more than the rehabilitation costs. If that's not enough then factor in the reduced burden on the benefits system and increased tax revenue through an earlier return to work.*

*So, no. Speaking as a former intensive care patient and as a tax-payer, rehabilitation isn't a luxury or a 'nice-to-have'. Saving our lives is a vital part of the process - and don't get me wrong - I will be forever indebted to the skill and caring of the many, many people who helped ensure my emergence from critical illness, but survival isn't an end product in itself.*

*Rehabilitation and returning patients back to a normal life is the ultimate goal and should be regarded as integral to the process from the very start.*



Peter Gibb - Chief Executive, ICUsteps

## Support groups

*Support groups are commonplace across a vast array of healthcare areas where patients coping with specific conditions or illnesses can draw strength, get support and develop camaraderie from others facing similar issues. Despite the vastly different reasons for critical illness, it can make a huge difference to intensive care patients to meeting and talk to people who truly understand.*

It was while running the ICU follow up clinic at Milton Keynes Hospital that Senior Sister Mo Peskett noted a common desire



from patients and relatives to meet others like them. She arranged a meeting for former patients and their relatives to get together and see what could be done to help other patients recovering from critical illness. The result was the decision to hold drop in sessions for recent patients to come and talk to people who were further down their recovery journey.

This was the beginning of ICUsteps and in November 2005 we held our first drop in. Patients found it a great help to be able to talk to others about what they'd been through and be understood; to realise that they're not alone in what they feel and think and what they've experienced is normal for someone who's been through a period of critical illness.

Having seen the difference that drop ins made to patient recovery, we had to spread the message and seven years on, it has really gathered momentum.

While patients will face problems specific to their own critical illness, many of the issues they have to overcome are common to critical care patients. Being able to talk to other people who truly understand them and no longer feeling isolated by what they've been through is a great relief. Simply talking to others who have similar experiences can provide reassurance and dispel many of their worries, leaving the remaining issues that are particular to them seeming much less daunting.

Mo Peskett and Peter Gibb began work on an article to highlight the benefits of support groups and address the topics that need to be considered when setting up a group. The article, 'Developing and setting up a patient and relatives intensive care support group' was published in the January 2009 edition of Nursing in Critical Care. Since then, dozens of healthcare professionals from across the UK and Europe have visited ICUsteps to

find out more and to see for themselves how a drop in works in helping ex-patients.

As a direct result, ICUsteps branches have been started in London, Liverpool, Bristol, South of Tyne and Poole with more groups in the process starting up too.



We can offer expertise, knowledge and experience to help you set up your own support group. If you'd like to know more, get in touch with us through the website at <http://icusteps.org/contactus> or email us directly at [contact@icusteps.org](mailto:contact@icusteps.org).

## Patient information

*Due to a lack of consistent and comprehensive patient information, we produced our booklet 'Intensive Care - a guide for patients and relatives' in 2008. Patient information in plain English written by those who've been there. This was a great start, but we've not stopped there.*

Following the praise and recognition of patients and healthcare professionals alike, we've gone on to make the vital patient information contained in the guide even more widely accessible beyond the 75,000 copies already distributed.

With booklets costing as little as 32p each, they represent one of the most cost-effective interventions in critical care.

### Booklet prices - 2012

- 32p each for 500 booklets
- 34p each for 375 booklets
- 35p each for 250 booklets
- 45p each for 125 booklets

Costs include delivery and orders can be placed through the website at <http://icusteps.org/booklet>

In addition to the hard copy English language version used in hospitals across the United Kingdom, a print friendly version is also available as a free download on our website.

### Intensive care guide apps

For those who prefer digital content to paper, our booklet is also available free for iPhone and Android.

To get the app, just go to your app store and search for icusteps.

## Intensive care guide translations

In addition to English, we've translated the guide into nine other languages, including Hindi, Urdu, Chinese and German.



These are all available for download in PDF format free of charge from our website to print, photocopy and distribute ensuring patients and their relatives get the vital information they need at such a crucial time.

Find out more at <http://icusteps.org/guide>

## Information supplement sheets

In addition to the intensive care guide, a number of topic supplements are also available. Written by ICUsteps' Catherine White and healthcare professionals specialising in these areas, the supplements provide valuable additional detail on key areas that affect many critical care patients.

So far, supplements on Physiotherapy & rehabilitation and Delirium are available for download on the website. Further work is underway on producing a supplement on head injury in collaboration with Headway and we're also working on a booklet about sepsis with the UK Sepsis Trust.

We also advise other organisations on information produced for intensive care patients. If you'd like our help with your patient information or there are other topics you'd like to see covered by a booklet supplement, let us know by emailing [booklets@icusteps.org](mailto:booklets@icusteps.org).

## Presentations

To highlight the issues faced by patients and their relatives through intensive care treatment and recovery, we've presented at conferences up and down the country and in Europe over the past few years.

As well as training days, learning events

and university lectures, ICUsteps has presented to conferences for the BACCN, the Chartered Society of Physiotherapists, the National Outreach Forum and the European Society of Intensive Care Medicine.

If you're arranging an intensive care related conference and would like us to participate, share the patient experience or see how ICUsteps can help, please get in touch by email to [contact@icusteps.org](mailto:contact@icusteps.org).

## ICUsteps online community

In July 2012, ICUsteps teamed up with HealthUnlocked to create a new online community for ex-patients, relatives and healthcare professionals to connect with like-minded people to talk about the issues that matter to them. While it doesn't provide the more involved support that a follow up clinic or support group can provide, it does give patients another channel of communication to reduce the isolation they can feel through

their critical illness, recovery and long afterwards.

Of course, the lifeblood of any community is people, and that's where you can help. By telling patients and their relatives about the community you open the door for them to meet others who understand what they've gone through.

The community offers participants to read and comment on blog posts or write their own. You can ask a question of the community or respond to existing questions.

The community also has polls to allow participants to cast their vote on questions being discussed and they can even submit their own suggestions for new polls.

Healthcare professionals are welcome to contribute too, along with patients, relatives, volunteers and ICUsteps trustees.

**Help your patients contact other people like them by telling them about ICUsteps and visiting <http://icusteps.healthunlocked.com>.**

## Getting in touch

As ICUsteps is run entirely by volunteers, the best way to get in touch with us is by email or through the website.

To comment on anything we've covered in this newsletter, or anything we haven't, please get in touch with us.

### Website:

[icusteps.org](http://icusteps.org)

### Community:

[icusteps.healthunlocked.com](http://icusteps.healthunlocked.com)

### Email:

[contact@icusteps.org](mailto:contact@icusteps.org)

### Booklet orders:

[booklets@icusteps.org](mailto:booklets@icusteps.org)  
[icusteps.org/booklets](http://icusteps.org/booklets)

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