



Next Steps

NEWSLETTER NO 3

AUTUMN / WINTER 2013

ICUsteps conference

Due to overwhelming demand we've made more places available for the ICUsteps Conference on 13 November which promises to be a fantastic event with a compelling programme.

Page 1

JICS article

October's edition of the Journal of the Intensive Care Society will feature an article on the patient experience from our own Catherine White.

Page 1

Support group guide

ICUsteps and the Intensive Care Society publish joint guidance for healthcare professionals seeking to set up an intensive care support groups for patients and relatives.

Page 1

ICUsteps AGM update

This year's annual general meeting saw continued growth for ICUsteps and the arrival of new trustees setting the stage for continued success in the coming year.

Page 2

Communication survey

It's not too late for patients and relatives to help improve communication in critical care. The ICS survey closes on Friday 11 October but there's still time to contribute to this important work.

Page 2

Medicine & Me event

Register your interest in a joint event being organised by The Royal Society of Medicine, The London Clinic and ICUsteps on 31 March 2014.

Page 2

ICUsteps conference

Since the last edition of Next Steps where we announced the inaugural ICUsteps conference, scheduled for 13th November, we've been delighted by the response from healthcare professionals, ex-patients and carers.

As soon as bookings opened, ticket orders started to come in. Within a couple of weeks it became clear that demand was going to exceed the number of places we had available, but thankfully we've been able to secure a larger room at the same venue. The original capacity has been nearly doubled with places now available for 180 delegates.

Despite adding these extra places, it still looks like the event will sell out so if you haven't already booked tickets, please hurry to secure your place. Ticket prices have been subsidised to keep them as affordable as possible with tickets for healthcare professionals at only £45 and for patients and relatives just £25. BACCN CPD accreditation has also been applied for.

The key theme of the day is rehabilitation following critical illness and setting up patient and relative support groups. Speakers include no less than four of the guideline development group that worked with NICE to develop critical illness rehabilitation guideline CG83.

Sessions include a keynote address by Dr Stephen Brett from Imperial College who was Chief Investigator on the recent study by Griffith et al that highlighted many of the issues commonly faced by intensive care patients after they leave hospital.

Other sessions include patient experiences, guidance on setting up patient and relative support groups, as well as talks by Dr. Christina Jones on the impact of patient diaries and from Suzanne Bench and Catherine White on lay summary discharge information. There is also a breakout session where delegates can choose between sessions on rehabilitation with David McWilliams, the psychological impact of critical care with Laura Barnett and a more in-depth session on setting up support groups with Mo Peskett and Peter Gibb.

You can view the full conference programme and book your tickets online at <http://icusteps.org/conference>.

Journal of the Intensive Care Society

Look out for an article about the ICU patient experience in October's Journal of the Intensive Care Society by Catherine White, a former ICU patient and our Booklet & Information Manager.

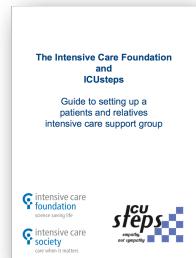
Catherine says 'While in ICU you don't have a voice – you can't speak, you can be very confused and it is difficult to communicate – so it is really important that we share what it is like to be a patient in ICU. Other former ICU patients kindly let me include their experiences too so I hope the article will be a useful summary of the problems ICU patients face and what hospitals can do to help them.'



Patient and relative support group guidance published

We're delighted to announce that ICUsteps and the Intensive Care Society have now published a joint guideline on setting up patient and relative intensive care support groups.

Since 2012, we've been working with the Intensive Care Society's patients and relative committee to produce a joint guideline to advise healthcare professionals on how to set up support groups for ex-intensive care patients and their relatives.



The core of the guidance surrounds *The Five Step Plan* which provides a checklist of items that you'll need to consider in order to establish a support group.

Central to the approach is establishing a core group of healthcare professionals, ex-patients and relatives who bond and form a partnership to become the care-givers to more recent patients and relatives who attend the support group's drop in events. The guideline also includes steps around defining a group structure, agreeing your support method, funding and the practicalities of arranging a drop in.

You can download the guideline from <http://icusteps.org/supportgroupguide> or from the Intensive Care Society website <http://www.ics.ac.uk>.

ICUsteps AGM update

The ICUsteps annual general meeting took place in September where the 2013 annual report and accounts were presented. It was another positive and successful year of growth and the work of ICUsteps has continued to make a difference for recovering intensive care patients and their relatives. The board of ICUsteps would like to thank our many supporters, and particularly the healthcare professionals who support our work and echo our calls for better patient support after critical illness - thank you.

We are also delighted to have five new trustees who joined us at the AGM, who all bring many talents to our trustee board and most of whom are also involved with local support groups. Dr. Christina Jones may already be known to many of you as a champion of ICU patient support who has made a significant and lasting contribution to critical care rehabilitation. She is a Nurse Consultant in Critical Care Rehabilitation at Whiston Hospital and an Honorary Reader at the University of Liverpool. Dr. Kate Regan also joins us as a trustee. Kate is a Consultant in Intensive Care Medicine at the Royal Sussex County Hospital and a co-founder of ICUsteps Brighton.

Our other three new trustees are critical care survivors. Bill Ridley has established and runs a support group in Hastings and has given many presentations on the patient experience of critical illness to raise awareness among healthcare professionals; Phil Smith, a Finance Manager with the Metropolitan Police, joins us and has kindly agreed to be our Treasurer as well as a trustee; and Anthony Vollmer is also now a trustee. Following a period of critical illness in 2010, earlier this year Anthony took on the Blenheim Triathlon with three friends raising an incredible amount of money and awareness in support of our work.

We very much look forward to working with our new trustees.

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.

Patient communication survey feedback needed

The first round of a survey aiming to improve communication in intensive care units ends this Friday, 11th October but patients and relatives still have the chance to participate.

The Patient and Relatives Group of the Intensive Care Society are conducting the survey and aim to survey to devise a list of 10 key points that all staff can use to improve communication with patients and relatives.

The survey is for anyone who has either visited someone in intensive care or has been a patient themselves and involves writing a list of communication *do's and don'ts* that you feel are important during a stay or visit in the intensive care unit. You can list up to ten, but even one would be helpful.

Examples might be:

- Don't talk over patients as if we aren't there
- Don't trivialise any procedure about to be carried out
- Do phone when you say you will
- Do explain things in a way that could be understood

The survey can be completed online. You will be asked for your name and email address so you can be contacted for the next round of the survey but it has been designed so that the suggestions themselves are captured anonymously.

The first stage of the project ends on Friday 11th October so please let patients and relatives know so their input can be part of the project.

The next step will be to pool all of the suggestions that have been submitted into a long list of ideas. This list will then be circulated back to the contributors for them to rank the suggestions in order of what they feel is most important to them.

This ranking procedure will happen twice. This method is a well recognised way of gathering a lot of opinions and creating a generally agreed list at the end of it.

The survey can be accessed online at: <http://tinyurl.com/icucomms>

If you have any questions, you can email the organisers at comsproject@ics.ac.uk.

Royal Society of Medicine - Medicine & Me

ICUsteps, The London Clinic and the Royal Society of Medicine (RSM) are working together on a critical care event as part of the RSM's series of 'Medicine and Me' conferences.

Medicine and Me provides an interactive forum in which the patient's voice is given top priority. The meetings provide an opportunity for healthcare professionals to hear first hand from patients and their families about their experiences and concerns and for patients to hear about the latest treatment and research by questioning the experts in an informal environment.

The programme for the event is already being put together with an engaging range of talks from leading intensive care professionals, patients and their relatives.

Medicine and Me sessions are aimed at an audience of healthcare professionals, patients and relatives so whether you work in critical care or have been a patient or relative in intensive care, you'll be welcome to attend.

The critical care event is scheduled for Monday 31 March 2014 and will take place at the Royal Society of Medicine in London.

If you're interested in attending or would like to find out more, sign up to be notified at <http://icusteps.org/rsm>

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icusteps.org

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