

Patient discharge pack

Research from Kings College has led to development of a patient discharge summary staff training pack, available as a free download.

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Success story

Five years after its launch, our patient focused ICU guide is now the leading source of intensive care patient information with the 100,000th copy due to ship soon.

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Can you help us?

To continue our work and better represent the patient voice of critical illness, ICUsteps is looking for volunteers who are willing and able to help.

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The patient perspective

Turning a negative into a positive. Peter Gibb shares his reflections on patient and public involvement after critical illness.

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Research priorities

The launch of a new project with the James Lind Alliance is set to put issues that matter most to patients at the top of the research agenda.

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Getting in touch

How you can get in touch with ICUsteps.

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Study finds patient support lacking after discharge

For patients and relatives, it will come as no surprise but now a new study has confirmed the anecdotal evidence that critical care survivors face on-going issues after intensive care and hospital discharge. The study highlights the financial impact following critical illness as well as reduced employment for both patients and their family members, many of whom have no choice but to take on the role of primary caregiver for an extended period. On-going health issues result in the majority of patients seeking help from their family doctor but still leaves the majority suffering from moderate to severe pain and almost a half from significant anxiety or depression a year after leaving ICU.

In the last issue of Next Steps, Peter Gibb's editorial on 'The patient perspective' covered many of the issues raised in the report. Peter said "It's good that there is solid scientific evidence to support what patients have been saying for years. Perhaps now it will be understood that survival to discharge isn't the sole measure of success and that rehabilitation is not an optional extra."

You can read the full report on the Critical Care Forum website.

<http://ccforum.com/content/17/3/R100>

Critical Care 2013, 17:R100 doi:10.1186/cc12745

ICUsteps conference

We've been running a patient and relative support group in Milton Keynes since 2005. In 2009, Mo Peskett and Peter Gibb published an article on the topic in Nursing in Critical Care, and since then our group has been visited by health professionals from across the UK and Europe leading to over a dozen other local support groups being set up.

To build on our work with the Intensive Care Society in establishing guidance on setting up and running local support groups, we're delighted to announce our conference in Milton Keynes this November to share this knowledge further.

There will be sessions covering the need for support, how support groups can help and what you need to do to set up a group and keep it running. Considerations such as a structure, location and funding will all be covered by speakers with first hand experience.

If you'd like to know more, register your interest at <http://icusteps.org/conference>.

This no-obligation pre-registration will ensure we let you know more details as they become available.

New sepsis booklet now available

We are also delighted to announce a new booklet called 'Sepsis: a guide for patients and relatives' produced in collaboration with the UK Sepsis Trust.

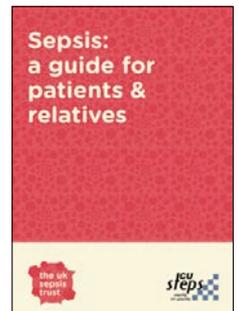
Latest figures show that that 100,000 people a year suffer from serious sepsis in the UK and that worldwide 18 million people are affected, which is 3 in a 1000 people, every year.

Catherine White, ICUsteps' Booklet & Information Manager was delighted to work with the UK Sepsis Trust to produce the booklet:

"I had severe sepsis in 2008 and it is a devastating illness. It can happen extremely fast, so you can be in good health to fighting for your life in a matter of days. The speed of the illness means it can be very hard for patients and relatives to come to terms with what has happened to them, and it is vital that clear and comprehensive information is given to help explain the illness and what to expect through the long recovery period. It was a pleasure to work with Dr. Ron Daniels and Libby Kain from the UK Sepsis Trust to produce this booklet and we hope it will make a real difference to sepsis patients and their families."

For a short time only, the first order from each hospital is at the cost of postage only (£11.95 for 125 booklets) and can be ordered from the UK Sepsis Trust by emailing: info@sepsistrust.org

The booklet can be viewed on the UK Sepsis Trust website, <http://sepsistrust.org>



New free resource - a patient discharge summary staff training pack

Any intensive care patient will tell you, one of the hardest aspects is not understanding what has just happened to you. A recent research project led by Suzanne Bench of Kings College London found that 54% of patients had little or no understanding of their time in intensive care. The research focused on producing a User Centred Critical Care Discharge Information Pack (UCCDIP) to help the difficult transition between ICU and the general ward, and an important element was the patient discharge summary – and we now have a training pack available to help staff write them.

ICUsteps' own Catherine White, who worked with the research team to produce the training pack, said "I know a summary would have been a great help to me and my family when I left intensive care. One of the main problems facing patients who have just left intensive care is that they are often confused about what happened to them in ICU, and that can be very frightening. A clear explanation, written in easy to understand language, can help to orientate the patient and be the first step in helping them understand their ICU

experience. It takes less than fifteen minutes for staff to do, but may make a huge difference to patients and their recovery."

The training pack gives guidance on what needs to be covered by the summary, such as how long a patient was in ICU, why were they admitted, and what treatments were required. It also gives a list of conditions with translations into lay language to help staff save time.

The staff training pack is available as a free resource from our website at <http://icusteps.org/professionals>

Success story

Since launching our information booklet 'Intensive Care: a guide for patients and relatives' in 2008, nearly 100,000 copies have been shipped to hospitals across the UK and it has been translated into 10 other languages. It has even been adapted for use in German critical care units. Peter Gibb, ICUsteps Chief Executive said "We decided to produce our own booklet because the information being given to patients and relatives wasn't meeting their needs. As ICU survivors ourselves, we knew what patients needed to know to support them through treatment and recovery. I'm grateful to all the health professionals who recognised the value in this patient-

led initiative and who've helped us establish it as the leading source of information for intensive care patients and relatives. At as little as 32p a copy, it has to be one of the most cost-effective interventions you can get in critical care."

To order your booklets online, go to <http://icusteps.org/booklet>

To download free PDF translations, visit <http://icusteps.org/guide>

Can you help us?

ICUsteps is a patient led organisation, but partnership with healthcare professionals is at the heart of what we do.

In order to continue improving patient rehabilitation, expanding our involvement with research and helping healthcare professionals appreciate the patient perspective we'd like to hear from professionals, patients and relatives willing to volunteer to help with our vital work.

Whether it's contributing to our online community, helping grow our network of local support groups or getting involved with our other work, there's plenty you can do to assist. If you'd like to help, let us know by registering at <http://icusteps.org/volunteers>

THE PATIENT PERSPECTIVE

Using our experiences to make a difference

Mo Peskett, co-founder of ICUsteps once said to me 'the more you do, the more you do'. She doesn't remember telling me that, but I do. My experience of patient and public involvement is best described as a domino effect.

The first event was a follow-up conference, then the BACCN conference and it just snowballed from there. Next month will be my 41st speaking engagement giving the opening keynote to the European Academy of Nursing Science in the Netherlands on the topic of the importance of patient and public involvement. Being a patient representative on NICE CG50 and CG83 were keystones along the way and any thought I might have had about PPI being a box-ticking exercise were swiftly dismissed. I feel proud of these

involvements and honoured to have been given the opportunity.

Critical illness makes you reassess your priorities; the things that matter in life. The people who work in intensive care have my profound respect. Helping build ICUsteps, helping patients through our support groups, helping doctors, nurses, physiotherapists and so many more understand about the issues patients face during recovery and rehabilitation has been a privilege and a duty I've been more than happy to take on – to turn my experience into something positive.

Looking forward, local support groups in the UK are really starting to gather momentum, so we want to help nurture and support that. There's also interest in ICUsteps from a number of countries in Europe. They've adapted our booklet for use in Germany, support groups based on our model are starting in the Netherlands and in November I'll be giving a talk to health professionals in Sweden so we hope our ideas will take off in Scandinavia as well. Back in the UK, I'll be serving as a patient rep on the adult critical

care Clinical Reference Group for the NHS Commissioning Board which will be exciting and I hope will see another step forward in ICU patient care and rehabilitation, building on CG83.

With ICUsteps being run entirely by volunteers, it certainly keeps us busy, but as the network of support groups grow, so will the network of other ex-patients who have a similar desire to turn their experience of critical illness into a positive.

Looking back to 2005 when we started, we had no idea things would develop as they have but it's fantastic to be able to help make a difference. Mo was so right about doing more and those dominos continue to gather pace.



Peter Gibb - Chief Executive, ICUsteps

Patient focused intensive care research project

ICUsteps is working with the Intensive Care Foundation, the James Lind Alliance, health care professionals and patient representatives to form the James Lind Alliance Intensive Care Research Priority Setting Partnership Steering Group. This new project aims to ensure that research prioritises the issues which matter most to critical care patients and their relatives.

Over the next 18 months, the Partnership aims to identify unanswered questions about adult intensive care and prioritise those that patients, their families and the health professionals who care for them agree are the most important. This will enable us to find the 'top 10' intensive care research priorities which can then be used to encourage researchers and funders to investigate the issues that are most important to those receiving and providing intensive care.

The Partnership is being launched this month with a survey to generate suggestions for later prioritisation. This is a valuable opportunity for clinical staff that do not usually set the research agenda to have their say and to find out what patients and relatives feel is important.

This project is likely to shape subsequent direction for National Institute for Health Research (NIHR) funding into intensive care research and Intensive Care Foundation awards.

Please take the time to participate, share this information with others and encourage them to take part as well.

You can complete the survey online at <http://surveymonkey.com/s/intensivecarepsp> or downloaded and print it from the Partnership website http://ics.ac.uk/foundation_home_james_lind_alliance

Intensive Care Research Priority Setting Project

Imperial College
London



intensive care
foundation
science saving life

Help us set research priorities for Intensive Care!

Do you have a suggestion about any aspect of care or treatment that you feel should be considered by researchers?

What do we need to find out to be able to improve life during or after critical illness?

This is your chance to make your views known!

The Intensive Care Foundation is leading a project to put people affected by critical illness at the centre of setting research priorities.

It is crucial that intensive care research answers the questions that matter most to people who have been critically ill, their friends and relatives, and the health professionals who care for them.

This project aims to find the 'top 10' research priorities in intensive care.

If you have a question, or are uncertain about any aspect of intensive care and you think it needs to be answered by new research, we want to know about it!

Please tell us your ideas online at:

www.surveymonkey.com/s/intensivecarepsp

Or contact us for a printed copy of the survey which can be returned by freepost

For more information about this project go to www.ics.ac.uk/foundation_home/james_lind_alliance or contact us (see details below)



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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.

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