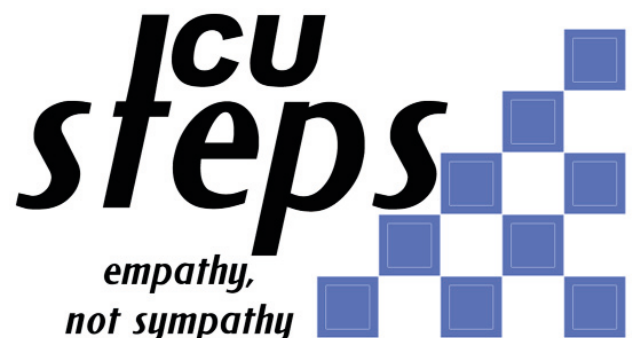


The Intensive Care Foundation and ICUsteps

Guide to setting up a
patients and relatives
intensive care support group



Introduction

Admission to the ICU (whether elective or emergency) can be considered one of the most traumatic/stressful events in life. The period of recovery and rehabilitation after discharge can be protracted and often impacts on the patient's and their family's way of life. Dealing with such changes and adapting to facilitate day to day activities can be tough. Patient Support Groups can help with the transition by providing advice, support and lessening the load.

The Patients' and Relatives' Committee of the Intensive Care Society carried out a survey of all intensive care units in England during 2012 to gauge the level of provision of patient support groups, and of interest in those units without such groups to develop them. The findings showed that there is a high level of support for these groups and indeed there are already a small number of groups up and down the country, largely generated by the sterling work done by ICUsteps and two very local initiatives in Reading and Slough.

Patient Support Groups are vital for providing continuing support for patients and relatives but do not necessarily receive funding or support from ICUs.

To help address this and raise awareness of the benefits of Patient Support Groups, the Patients' & Relatives' Committee of the Intensive Care Society has joined forces with ICUsteps to produce the following guidance to intensive care units/hospitals wishing to set up or support Patient Support Groups.

There does not appear to be one model which meets all needs so what has emerged is guidance on a range of common components or elements that can assist in the establishment of a Support Group but which can be tailored to meet local circumstances and needs.

Some support groups have found that there are specific advantages to being directly supported by a "Mother Trust" which can provide the professional, administrative and clinical support required to run an effective support network. Being attached to a Trust would also negate insurance and other support costs as well as provide a possible income stream from the hospital's charitable donations. It would also provide professional support in the area of fundraising and in addressing any clinical or operational questions that may arise.

Some support groups have, on the other hand, found it more advantageous to be completely independent of the hospital and prefer to run the group with its own volunteers and administrative support.

The following guidance is therefore based on the extensive experience of ICUsteps, the experience of Reading and Slough and the feedback from the questionnaire.

Guidance for setting up patients and relatives support groups

Support Groups require two critical elements to be in place to ensure they are created and managed in a way that benefits both ICU professionals and the patient and relatives they have cared for:

- first, the active involvement of dedicated critical care staff, most frequently from the nursing staff, and
- second, a group of ex patients and their relatives able to help run the group and share their experiences.

The members of this group, the steering/core group, must be prepared to give their time in actively supporting the Support Group. The whole ethos of support groups is to help others by the sharing of experiences and the provision of moral support.

It is beneficial, although not vital, if the intensive care unit operates a follow up service. This appears to be the most effective way of making patients and their relatives aware of the group's activities. A follow up or out patient service is widely recognised as having clinical advantages for many patients but is not available everywhere and is not appropriate for every patient.

A five step plan

1. *Establish steering/core group*

- Patients and relatives who've been out of ICU for 6 - 24 months and healthcare professionals
- Need to agree the objectives which could include some, although not necessarily all, of the following:
 - Provide support for all patients and relatives during and after the patient's time in ICU
 - Referrals from other hospitals will also be accepted.
 - Both hospitals and General Practitioners within the catchment area as well as adjoining areas will be allowed direct access to the Group's activities.
 - Provide 'one to one' and telephone and email support where practical.
 - Provide an environment where patients and relatives can share their experience in confidence.
 - The group will receive professional support and would be underpinned by Intensive Care trained professionals at all times
 - How to publicise the group and make it known to other organisations such as GP surgeries
 - Healthcare professionals, patients and their relatives need to meet at least 3-4 times to build rapport and establish the group's structure before launching. This is also the forum for patients

and relatives to talk about their experiences to each other before they offer that service to more recent patients.

2. Define group structure

- It must be a partnership between patients, relatives and healthcare professionals
- Agree individual members' responsibilities, eg chairman, secretary etc
- Could be independent from the hospital so that it is not seen as a hospital service OR liaise with the hospital's administrative support staff to assist in the start up.
- Agree the legal entity, i.e. is it to be:
 - a charity (can't if the income is less than £5K p.a.)
 - an unincorporated organization such as a voluntary group with charitable aims
 - Need to set up a bank account
 - Contact local CVO (Council for Voluntary Organisations) for funding advice and organisational support

3. Agree support method

- Experience shows that "drop in" support is the best and most helpful.
- Consider alternative options if drop in not feasible e.g. telephone, buddy system, online
- Ensure there is professional support at all meetings

4. Drop in

- If possible meetings should be held outside the confines of the hospital but at a location with good access to public transport, disabled access and parking. Experience shows that meeting off site reduces anxiety and helps foster core group partnership, i.e. all are service providers, not just healthcare professionals. HOWEVER, it might be easier at the beginning to keep costs down and to ensure the group is supported by the professional staff to hold meetings on the hospital site in a suitable venue which is not near to the intensive care unit.
- Frequency - Recommended 6 weekly
- Duration - Recommended 2 hours
- Timing - Recommended weekday evenings so working relatives and patients who have returned to work can also participate
- Publicity - Has to come from the hospital - continuity of care from ICU / HDU / outreach / follow up to tell patients and relatives about the available support at the relevant period and provide information on how to get it. Leaflets of drop in details to patients and relatives at ICU discharge and follow-up, and in relatives' room.
- Supplies - tea, coffee, biscuits
- Roles - healthcare professionals provide triage and familiarity for new visitors and pass patients onto the most relevant core group peers
- Insurance - Most venues will have public liability insurance but you need to check this. Groups

may want to consider having their own public liability insurance to provide cover against possible legal action over things said at group (PLI for a charity up to £2,000,000 can cost as little as £160 p.a.)

- Format - informal, individual tables with clusters of chairs rather than boardroom or theatre. Organic discussion. Suggested group members begin by talking about themselves and their own experiences to put visitors at their ease and let them identify with the group members through shared experiences.

5. Funding

- Minimal funding requirements (less than £500 p.a. for venue and supplies)
- Core group – free – healthcare professional attendance may need hospital agreement
- Contact CVO for funding options
- Consider sponsored events (one event could cover costs for an entire year)
- Consider approaching the various medical supply companies



The Intensive Care Foundation aims to save lives by funding research into new treatments for all critically ill patients. We are the research arm of the Intensive Care Society a professional body for all intensive care professionals and a registered UK charity.

There are two main reasons for supporting research in this area - one to save lives, the other is to improve the quality of life of patients who survive intensive care. Symptoms of survivors can include; post traumatic stress disorder, chronic pain and the social and emotional problems that can result in loss of jobs, depression, and stress on families.

What we do:

Develop new clinical research focused on direct patient benefit and supported by the intensive care community.

Support important pilot studies with funds and ICS members support.

Develop and refine new research ideas.

Support young intensive care professionals through grants and research support.

Over time, the Foundation expects to have a significant impact on the critically ill, saving more lives and enabling a higher quality of life after care.

How we do it:

Set priorities for clinical research.

Undertake national audits and surveys of practice to inform clinical trials.

Award research funds for pilot projects.

Make and assist with applications to grant awarding bodies.

Support post graduate training in clinical trials.

How you can help

- Make a donation via just giving www.justgiving.com/intensivecaresociety
- Participate in one of our many fundraising events
- Organise your own fundraising event for the Intensive Care Foundation

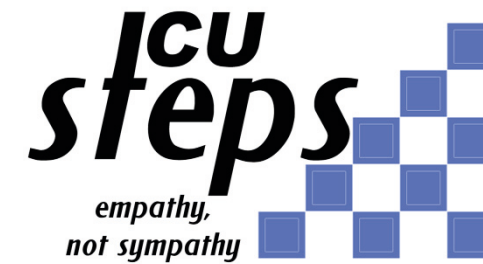
www.intensivecarefoundation.org



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ICUsteps is a charity set up by former intensive care patients and their family members in partnership with healthcare professionals. We understand the impact critical illness has on patients and relatives because we have been there.

Our aims are to:

- support patients and relatives affected by critical illness,
- promote recognition of the physical and psychological consequences of critical illness through education of the medical profession and the general public, and
- encourage research into the treatment and the prevention of these issues.

What can we offer you?

- The patient and relative perspective
- Expertise and advice about how to set up a support group for former intensive care patients and relatives, and membership of the support group network to share ideas and best practice
- Essential information written by patients, relatives and clinicians. As well as our booklet 'Intensive Care: a guide for patients and relatives', we have factsheets and translations of our booklet into numerous languages which are free to download
- Advice on your hospital's patient and relative literature
- Free staff training pack on how to write patient summaries to help patients understand what happened to them in ICU, and
- Advice about ICU research projects.

www.icusteps.org



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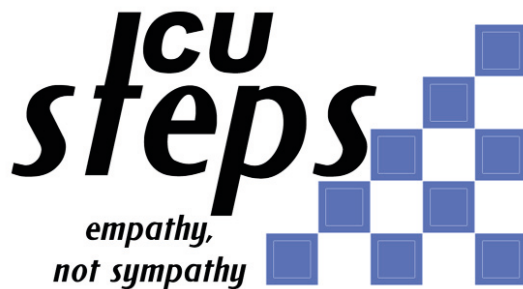
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