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# What information or education should clinicians provide to patients following discharge from hospital after critical illness? A comprehensive review.

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### Summary

***This review aims to describe the content, method of delivery and effectiveness of information or education delivered to patients***

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***and their families or carers following discharge from hospital after critical illness. It provides clinicians with information that may help the development of educational interventions in order to enhance outcomes following discharge from hospital after critical illness.***

### Introduction

The NICE (2009) guidelines categorise the rehabilitation care pathway after critical illness into five key stages and advocate seamless rehabilitation across these:

- (1) during the critical care stay;
- (2) before discharge from critical care;
- (3) during ward-based care;

- (4) before discharge to home or community care;
- (5) 2-3 months after discharge from critical care (home or community).

Patients have identified 'information and education' as one of the key components that should be included in their rehabilitation (Deacon 2012). One section of the NICE (2009) guidelines reviewed evidence for the information needs of patients and their families or carers during and after a period of critical illness. The guidelines provide recommendations that link to the first four stages of the rehabilitation pathway. At stage 5, NICE (2009) recommend that assessment be used to determine if continued support be given if the patient is not recovering as quickly as anticipated. However, there is a lack of guidance for clinicians wishing to address information or education needs specific to this stage.

Recovery from critical illness is associated with physical, mental and cognitive sequelae which may continue for up to five years following hospital discharge (Herridge et al 2011, Cuthbertson et al 2010). The mortality rates of these patients have been reported to be above that of the general population for at least 15 years after discharge (Williams et al 2008). There is also significant negative impact on those who care for survivors of critical illness following their discharge home (Johnston et al 2001). This data highlights the importance of post hospital rehabilitation (stage 5). However, it is unclear what components should be included at this stage and how they should be delivered (O'Neill and McAuley 2011). Studies including exercise-based rehabilitation following hospital discharge are emerging; however few have included education. Investigation into the components of other non-exercise based rehabilitation including education and on-going management has been recommended (Connolly et al 2012).

Many of the recommendations at the earlier

stages of the rehabilitation care pathway refer to issues that may only surface for patients once they leave hospital (NICE 2009). These include, e.g. getting back to everyday routine, managing activities of daily living, information about diet, driving, returning to work, housing and benefits. There is also concern that it may not be appropriate to deliver too much information relating to recovery after discharge too early. Patients have reported wanting to be 'drip-fed' information at different stages in their recovery (Bench et al 2011).

Awareness about the specific content and method of delivery of information or education at stage 5 would enable clinicians to administer educational interventions which could help to improve long-term outcomes following critical illness. This review aims to describe the content, method of delivery and effectiveness of information or education delivered to patients and/or their families or carers following discharge from hospital after critical illness (stage 5).

## Objectives

The objectives of this review are:

- a) To describe the content of information or education delivered to patients and/or their families or carers at stage 5 and to make comparisons to the NICE (2009) guidelines.
- b) To describe the method of delivery of information or education delivered at stage 5.
- c) To examine the effectiveness of information or education delivered at stage 5.

## Methods

An electronic literature search of relevant databases was conducted from inception until January 2013 using key words. The titles and abstracts were screened and those that appeared relevant were selected and the full text was retrieved. Further literature was



obtained by hand searching the reference lists of articles identified in the search. Studies were selected based on the following criteria;

Inclusion criteria:

- Provision of information or education to patients and/or their families or carers at stage 5.
- Description of the content and/or methods of delivery and/or effectiveness of information or education at stage 5.
- Patients aged  $\geq 16$  years with any length of stay in critical care.

Exclusion criteria:

- Follow up consultations where it is not clear that information or education was provided.
- Information or education relating to self-directed exercise or structured exercise programmes alone.
- Information or education relating to the critical care experience alone, e.g., critical care diaries.
- Studies involving specific conditions, e.g. head injury, COPD or cardiac problems where there would be an alternative opportunity for information or education.
- Not available in English.

Where studies included information or education in written format, this was also obtained. Data was extracted relating to the objectives. The research team reviewed the NICE (2009) guidelines on rehabilitation after critical illness and content that was considered primarily pertaining to information or education needs at stage 5 was extracted. The content of the information or education in the included studies was then cross matched to the NICE (2009) content areas to allow comparisons to be made.

## Results

Seven studies met the inclusion criteria: one randomised controlled trial (Jones et al 2003), one cohort study (McWilliams et al 2009), and five studies of descriptive designs (Petersson et al 2011, Peskett and Gibb 2009, Samuelson and Corrigan 2009, Crocker 2003 and Cutler et al 2003).

### ***Content of information or education***

The research team reached consensus on 17 content areas in the NICE (2009) guidelines that primarily pertained to stage 5 of the rehabilitation care pathway (Table 1).

All studies (n=7) described the content of information or education delivered following discharge from hospital after critical illness (stage 5), although specific details were often lacking. In one study access to the written information provided allowed more detailed content to be extracted (Jones et al 2003). This study covered the majority (n=14/17) of the NICE (2009) content areas. Additional content included changes in appearance and smoking cessation. All of the remaining studies describe the content in limited detail only, and covered 6 or less of the 17 NICE (2009) content areas. Although studies stated that information needs were addressed, overall any further detail regarding the content is limited.

Information or education content areas (n=17) (NICE 2009)	Jones et al 2003	McWilliams et al 2009	Petersson et al 2011	Peskett and Gibb 2009	Samuelson and Corrigan 2009	Crocker 2003	Cutler et al 2003
<b>Rehabilitation goals</b>	NR	NR	NR	NR	NR	NR	NR
<b>Physical problems</b> Weakness, mobility, fatigue, pain, breathlessness, swallowing difficulties, incontinence, self care	✓ Mobility, tiredness	✓ Managing breathlessness	NR	NR	NR	NR	✓ Mobility, wound healing
<b>Physical recovery</b>	✓ Importance of exercise, fitness	✓ Benefits of exercise	NR	NR	NR	NR	NR
<b>Sensory problems</b> Vision, hearing, pain, altered sensation	✓ Taste changes, pain from scars/injuries	NR	NR	NR	NR	NR	NR
<b>Communication problems</b> Speaking, language, writing	NR	NR	NR	NR	NR	NR	NR
<b>Social care or equipment needs</b> Mobility aids, transport, housing, benefits, employment, leisure	✓ Getting out and about on your own	NR	NR	NR	NR	NR	NR
<b>Anxiety, depression and post traumatic stress related symptoms</b> Somatic symptoms e.g. palpitations, irritability and sweating, depression, sleeping problems, nightmares, hallucinations, delusions, flashbacks, intrusive memories, panic	✓ Sleeping, nightmares, hallucinations, phobias, mood changes, worrying, anxiety, panic attacks, depression, stress symptoms and causes, anti-stress tactics, relaxation	✓ Anxiety management, relaxation	NR	NR	NR	NR	✓ Sleeping, mood

Table 1 – Content of information or education delivered following discharge from hospital after critical illness (stage 5) compared to the NICE (2009) recommendations

Information or education content areas (n=17) (NICE 2009)	Jones et al 2003	McWilliams et al 2009	Petersson et al 2011	Peskett and Gibb 2009	Samuelson and Corrigan 2009	Crocker 2003	Cutler et al 2003
<b>Behavioural and cognitive problems</b> Memory loss, attention deficits, sequencing and organisational problems, confusion, apathy, disinhibition, insight	✓ Memory loss, scheduling	NR	NR	NR	NR	NR	NR
<b>Other psychological or psychosocial problems</b> Self esteem, self image, body image, relationships	✓ Family and relationships, stress in marriage	NR	NR	NR	NR	NR	✓ Relationships
<b>Diet and nutrition</b>	✓ Nutrition, food, eating normally again, feeling sick, weight loss	NR	NR	NR	NR	NR	✓ Eating
<b>Any other continuing treatment</b>	✓ Medicines and side effects	NR	NR	NR	NR	✓ Current medications, procedures and progression	NR
<b>The rehabilitation care pathway</b>	NR	NR	✓ Current health, illness or injury trajectory	NR	✓ Rehabilitation time and long term health	NR	✓ Advice and help on future recovery
<b>Activities of daily living including self-care and re-engaging with everyday life</b>	✓ Overworking, rushing	NR	NR	NR	NR	NR	NR
<b>Driving, returning to work, housing and benefits</b>	✓ Control of workload	NR	NR	NR	NR	NR	✓ Ability to return to work

Information or education content areas (n=17) (NICE 2009)	Jones et al 2003	McWilliams et al 2009	Petersson et al 2011	Peskett and Gibb 2009	Samuelson and Corrigan 2009	Crocker 2003	Cutler et al 2003
<b>Local statutory and non-statutory support services</b>	✓ Smoking support, who to ask	NR	NR	✓ Reassurance and guidance in raising matters with appropriate professionals	NR	✓ Suggest sources of help	NR
<b>General guidance especially for the family/ carer on what to expect and how to support the patient at home</b>	✓ Coping with setbacks, living alone	NR	NR	NR	NR	NR	NR
<b>Sexual dysfunction</b>	✓	NR	NR	NR	NR	NR	NR
<b>Number of content areas covered</b>	n=14/17	n=3/17	n=1/17	n=1/17	n=1/17	n=2/17	n=6/17
<b>Additional content</b>	Smoking cessation, changes in appearance including hair, skin and nails	Smoking cessation	Review of the critical care stay, individual content	Review of the critical care stay	Review of the critical care stay, identify existing problems	Review of the critical care stay	Review of the critical care stay, discuss perceived problems, facilitate interpretation of complex information, scarring

NR = not reported

### ***Method of delivery of information or education***

All studies (n=7) described the method of delivery of information or education delivered following discharge from hospital after critical illness (stage 5) (Table 2). The majority of interventions were delivered to individual patients (n=5/7): either face-to-face during follow up appointments (n=4), or by incorporating written information as part of self-directed rehabilitation (n=1). Two studies used a group format: formal group education classes incorporated in a 6 week rehabilitation programme (n=1) or informal drop in sessions (n=1). In general the interventions were delivered in a hospital outpatient location (n=5/7). The interventions were generally nurse led (n=5/7) and with multidisciplinary team input (n=5/7) including physiotherapists, occupational therapists, dieticians and physicians. Family members were involved in the majority of studies (n=6/7).

The written information in the study by Jones and colleagues (2003) was divided into weekly sections for six weeks following discharge from hospital, and Cutler et al (2003) delivered information at 3 and 6 months after hospital discharge. The specific timing of the intervention following discharge from hospital is unknown in the remaining studies. In three of these studies the interventions took place at different time points between 2 and 6 months post discharge from critical care. Therefore, the timing after hospital discharge was variable for patients depending on the length of stay in hospital. Generally studies included information or education as a component of other post critical care rehabilitation interventions, i.e. follow up programmes (n=4/7) and exercise-based interventions (n=2/7). Four studies also included information delivery at earlier stages of the rehabilitation pathway. In the remaining studies it is unknown whether patients received earlier education interventions.



Table 2 - Method of delivery of information or education delivered following discharge from hospital after critical illness (stage 5)

Reference and study design	Method of delivery of information or education
<p><b>Jones et al 2003</b></p> <p>Randomised controlled trial</p>	<p><b>Format:</b> Intervention group: Written information in a rehabilitation manual. Included a self directed exercise programme; ward visits; 3 telephone calls at home to reinforce the use of the manual; follow up clinic appointments. (Control group: ward visits, 3 telephone calls at home, follow up clinic appointments.)</p> <p><b>Delivery:</b> Individually delivered. Introduction of the manual took place on the general wards approximately 1 week after critical care discharge. Self directed at home for 6 weeks after hospital discharge.</p> <p><b>HP:</b> Research nurse using a printed training schedule.</p> <p><b>Family involvement:</b> Yes.</p> <p><b>Information or education at earlier stages:</b> No. NB. Manual introduced during ward-based care (stage 3).</p>
<p><b>McWilliams et al 2009</b></p> <p>Cohort study</p>	<p><b>Format:</b> Group education, one hour per week. Component of a 6-week rehabilitation programme that also included a one hour supervised exercise class and two unsupervised exercise sessions per week.</p> <p><b>Delivery:</b> Group based in an outpatient hospital gymnasium.</p> <p><b>HP:</b> Physiotherapy led. Group discussion with a specialist critical care follow up nurse.</p> <p><b>Family involvement:</b> NR</p> <p><b>Information or education at earlier stages:</b> NR</p>
<p><b>Petersson et al 2011</b></p> <p>Descriptive design</p>	<p><b>Format:</b> Follow up consultations. Component of follow up programme that included 3 contacts.</p> <p><b>Delivery:</b> Individually delivered at 2 and 6 months after critical care discharge in a clinic located close to the critical care unit.</p> <p><b>HP:</b> Nurse led. Clinic was run by 4 nurses with critical care experience and special education in therapeutic conversation. Patients were offered a meeting with a physician if requested or had questions concerning medical issues.</p> <p><b>Family involvement:</b> Yes</p> <p><b>Information or education at earlier stages:</b> Yes, during ward-based care (stage 3).</p>
<p><b>Peskett and Gibb 2009</b></p> <p>Descriptive design</p>	<p><b>Format:</b> Informal support group. Drop in sessions held for 2 hours and patients/relatives could come and go during that time.</p> <p><b>Delivery:</b> Group delivered in a community setting.</p> <p><b>HP:</b> Nurse members.</p> <p><b>Family involvement:</b> Yes.</p> <p><b>Information or education at earlier stages:</b> NR</p>
<p><b>Samuelson and Corrigan 2009</b></p> <p>Descriptive design</p>	<p><b>Format:</b> 90 minute follow up consultation as a component of a follow up programme. Also included ward visits; an information pamphlet distributed at the ward visit; an answering machine telephone helpline to the after-care nurse.</p> <p><b>Delivery:</b> Individually delivered 2-3 months following critical care discharge at a hospital clinic.</p> <p><b>HP:</b> Nurse led, with MDT including a physician, psychologist and nurse consultant.</p> <p><b>Information or education at earlier stages:</b> Yes, during ward based care (stage 3).</p>
<p><b>Crocker 2003</b></p> <p>Descriptive design</p>	<p><b>Format:</b> Component of a MDT follow up clinic lasting 60 minutes.</p> <p><b>Delivery:</b> Individually delivered at a hospital clinic 2 and 6 months after discharge from critical care.</p> <p><b>HP:</b> MDT (nurse, intensivist, physiotherapist, occupational therapist).</p> <p><b>Family involvement:</b> Yes.</p> <p><b>Information or education at earlier stages:</b> Yes, during ward-based care (stage 3).</p>
<p><b>Cutler et al 2003</b></p> <p>Descriptive design</p>	<p><b>Format:</b> Component of a follow up service approximately 3 and 6 months after hospital discharge. Written and verbal information.</p> <p><b>Delivery:</b> Individually delivered in a hospital clinic setting.</p> <p><b>HP:</b> Nurse led, with MDT including dietetic, physiotherapy, anaesthetic and pharmacy staff.</p> <p><b>Family involvement:</b> Yes</p> <p><b>Information or education at earlier stages:</b> Yes, during ward-based care (stage 3).</p>

HP = Healthcare professional(s) MDT = Multidisciplinary team NR = Not reported



## Effectiveness of information or education

No studies used objective outcome measures to determine the effectiveness of information or education delivered following discharge from hospital after critical illness. Four studies of descriptive designs used open response questionnaires developed by the authors (n=2/4) or informal discussions (n=2/4) to evaluate the effects of the information or education provided (Table 3). These studies reported positive results relating to the general satisfaction and perceived benefit of the interventions. Patients in a group setting also reported a benefit in sharing experiences with others who had been critically ill.

## Discussion

Information or education is recommended as an important component of rehabilitation after critical illness. This review identified specific content of information or education primarily pertaining to post hospital discharge (NICE 2009) and highlighted that few studies have included this. Delivery of information or education is mostly to individual patients, and this seems appropriate as the content should be based on individual assessment (NICE 2009). No studies used objective outcome measures to determine the effectiveness of information or education provision at this stage of rehabilitation.

Table 3 - Effects of information or education delivered following discharge from hospital after critical illness (stage 5)

Reference	Outcome measure(s) and timing	Effect(s)
<b>Petersson et al 2011</b>	Evaluation questionnaire developed by the authors. Overall impression of follow up and space for own comments.  Following the 6-month contact, patients returned the questionnaire in a pre-paid envelope.	The overall impression of the clinic was good or very good. It is stated that patients appreciated the follow-up, expressed gratitude to the competent and obliging staff. They received information, an opportunity to talk, increased knowledge and re-evaluated memories and experiences.
<b>Peskett and Gibb 2009</b>	Informal discussions.  Timing NR.	Feedback indicated that further support was needed following discharge from hospital. Patients and families found benefit in sharing experiences with others who can empathise, having been through critical illness themselves.
<b>Samuelson and Corrigan 2009</b>	Evaluation questionnaire developed by authors. Visual analogue scale (VAS) for satisfaction (a 10cm line ranging from poor to excellent). Comments were also invited.  At the end of the follow up clinic to complete at home.	The follow up consultation achieved a median VAS rating of 9.8 from both patients and next of kin. No significant differences in VAS ratings between patients and next of kin. It is stated that the written comments were all positive, testifying to the support, care and understanding received.
<b>Cutler et al 2003</b>	Brief semi-structured telephone interviews, open questioning style.  Timing NR.	Patients had their questions answered, were well treated by clinic staff and an almost unanimous lack of suggestions for improving the clinic.

NR = Not reported

Overall the majority of the NICE (2009) recommendations pertaining to stage 5 were not covered in the included studies, however, reporting of specific details was often lacking. Given the heterogeneous critical care population it seems appropriate that the content should be based on an individual assessment (NICE, 2009). A menu driven approach could help clinicians to utilise a range of resources to deliver appropriate information or education based on the results of individual assessment. This would facilitate delivery of an individualised, yet standardised intervention that could be reproduced. For example, when assessment identifies problems with memory loss or flashbacks, then resources could be used to provide specific information or education on these aspects. Menu driven approaches have been recommended in other populations e.g. cardiac disease (BACPR 2012). The 17 content areas highlighted in Table 1 of this review (NICE 2009) may be useful in the development of a menu-driven educational intervention.

Few studies in this review included written information, yet patients have identified the desire for verbal information to be supplemented with written material (Lee et al 2009). This has also been identified in other patient populations (Wilson et al 2007). Jones et al (2003) provides a good example of the delivery of written information including content pertinent to stage 5. Additional information leaflets have been located online (Intensive Care Society 2011, ICUsteps 2010, Society of Critical Care Medicine 2007). These may provide a useful resource for clinicians and could be adapted for use at the different stages of recovery. While written information has been provided at earlier stages of the rehabilitation care pathway in other studies (Bench et al 2011, Paul et al 2004) it may be important to repeat it following hospital discharge focusing on the relevant individualised content.

An awareness of the information delivered at earlier stages of the rehabilitation pathway is important, as this may inform the content to be delivered post hospital discharge.

Communication between healthcare professionals across the stages, in particular stage 5, where a transfer to the community or outpatient setting is required, would help to facilitate seamless delivery.

Current constraints with clinical services may present a challenge for clinicians to deliver comprehensive information or education after discharge, and additional resources may be required to facilitate this. In this review, information at stage 5 was usually delivered in a one-to-one format, often during a follow up clinic. Critical care follow up clinics may provide a platform for the delivery of individualised information or education following discharge from hospital. Alternatively, follow up clinics with a standardised approach could facilitate assessment and onward referral for further specific information or education.

Well established disease specific rehabilitation strategies, including cardiac and pulmonary rehabilitation, include education embedded with physical rehabilitation. A growing number of studies are emerging on the outcome of patients receiving exercise-based rehabilitation following discharge from hospital after critical illness. Education has generally not been included. One exercise-based study in this review (McWilliams et al 2009) delivered group education sessions with topics including breathlessness and smoking cessation. Group education would allow peer support which patients have found beneficial (Peskest and Gibb 2009). However, caution should be used in applying standard education topics to the post-critical illness population due to their heterogeneity (Connolly et al 2012). Rehabilitation programmes that include education sessions should carefully consider how individual information needs can be met and this is an area of further investigation.

It is difficult to determine the outcome measures that should be included to evaluate the effectiveness of information or education at stage 5 from the studies reviewed, as these only briefly explored views about the general



satisfaction and perceived benefit. Satisfaction is central to the success of patient education; however knowledge, understanding and self-efficacy are also key to this success. Ways to assess all of these constructs should be embedded in educational interventions. Additional outcome measures utilised should reflect the goals of the intervention and are likely to differ based on the individual assessment. The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith 1983) is one example of an outcome measure that may be appropriate when the goal is to decrease anxiety and/or depression symptoms.

In the studies that were located, limited specific detail was given, making it difficult to provide direction on the detailed content that may be useful. It is likely that these results are biased by this limited detail due to reporting restrictions for publication. Contacting the authors for a more detailed description, including details of individualised information may have validated the findings. It is important for future studies to provide comprehensive detail on the content, method of delivery, and any information that was provided at other stages. Outcome measures that reflect the specific goals of information or education should also be used. It was beyond the scope of this paper to review information specifically relating to the critical care experience, e.g., critical care diaries (Backman et al 2010). It may be important to incorporate these into menu-driven educational interventions at an appropriate stage of the patients' recovery pathway.

## Conclusion

Few studies have explored the delivery of information or education following discharge from hospital after critical illness. It is important that information or education addresses the patients and their families or carers needs at this stage of recovery. The NICE guidelines on rehabilitation after critical illness (NICE 2009), contain a range of content areas pertaining to post hospital discharge. These content areas

may be useful in the development of a menu-driven educational intervention for patients and their families or carers following discharge from hospital after critical illness. This would facilitate an individualised yet standardised delivery of appropriate information or education. Continuity of care and an awareness of the information delivered at earlier stages are important to facilitate a seamless rehabilitation pathway. Relevant outcome measures should focus on determining whether the aims of education at this stage of rehabilitation are achieved.

## Key Points

- This review identified specific content of information or education primarily pertaining to post hospital discharge (NICE 2009) and highlighted that few studies have delivered this.
- A menu driven approach may facilitate an individualised yet standardised delivery of information or education to patients and their families or carers based on individual assessment.
- Continuity of care and an awareness of the information delivered at earlier stages are important to facilitate seamless rehabilitation.
- Relevant outcome measures should focus on determining whether the aims of education at this stage of rehabilitation are achieved.

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