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Evaluating the feasibility and effectiveness of a critical care discharge information pack for patients and their families: a pilot cluster randomised controlled trial

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ABSTRACT

Objectives: To evaluate the feasibility and effectiveness of an information pack, based on self-regulation theory, designed to support patients and their families immediately before, during and after discharge from an intensive care unit (ICU).

Design and setting: Prospective assessor-blinded pilot cluster randomised controlled trial (RCT; in conjunction with a questionnaire survey of trial participants' experience) in 2 ICUs in England.

Participants: Patients (+/− a family member) who had spent at least 72 h in an ICU, declared medically fit for discharge to a general ward.

Randomisation: Cluster randomisation (by day of discharge decision) was used to allocate participants to 1 of 3 study groups.

Intervention: A user-centred critical care discharge information pack (UCCDIP) containing 2 booklets; 1 for the patient (which included a personalised discharge summary) and 1 for the family, given prior to discharge to the ward.

Primary outcome: Psychological well-being measured using Hospital Anxiety and Depression Scores (HADS), assessed at 5±1 days postunit discharge and 28 days/hospital discharge. Statistical significance ($p \leq 0.05$) was determined using χ^2 and Kruskal-Wallis (H).

Results: 158 patients were allocated to: intervention (UCCDIP; n=51), control 1: ad hoc verbal information (n=59), control 2: booklet published by ICUsteps (n=48). There were no statistically significant differences in the primary outcome. The a priori enrolment goal was not reached and attrition was high. Using HADS as a primary outcome measure, an estimated sample size of 286 is required to power a definitive trial.

Conclusions: Findings from this pilot RCT provide important preliminary data regarding the circumstances under which an intervention based on the principles of UCCDIP could be effective, and the sample size required to demonstrate this.

Trial registration number: Current Controlled Trials ISRCTN47262088; results.

Strengths and limitations of this study

- This is one of few randomised controlled trials that have evaluated critical care discharge information resources and the first to evaluate the use of an intervention, which includes a personalised patient discharge summary.
- Results suggest that information based on self-regulation theory is feasible to deliver, may improve patients' understanding of their critical illness and may help optimise critical illness rehabilitation.
- The a priori enrolment goal was not reached and attrition was high.
- The study had insufficient statistical power to determine any outcome benefit.

INTRODUCTION AND BACKGROUND

Providing information is an important element of effective critical illness rehabilitation care,[1 2] yet at the time of discharge from an intensive care unit (ICU) to a general care environment (ward), some patients and relatives report not receiving any information[3 4] or receiving ad hoc verbal information, sometimes accompanied by a leaflet or booklet.[5]

Patient-focused healthcare provision, which promotes shared decision-making, is widely advocated.[6–9] Guidelines from the Department of Health in England (p.16) recommend that acutely ill patients should be "encouraged to actively participate in decisions related to their recovery…"[10]; this, however, requires the provision of appropriate information. To be effective, ICU discharge information needs to take account of the cognitive problems and fatigue apparent in many patients recovering from critical illness.[11] Any written information must also

acknowledge the heightened anxiety experienced by both patients and relatives at this time[11] and reflect the differing information needs of both groups at various time points.[4 5] Our intervention was designed to address all of these elements, in contrast to the interventions described in the few studies which have previously evaluated written ICU discharge information resources.[12–15]

There is currently little evidence to support best practice with regard to ICU discharge information delivery.[5] Data from the few studies, which have evaluated written resources, suggest that it can improve family members' knowledge and satisfaction[13 14] and reduce their anxiety[15] during and after ICU discharge. The results of a multicentre UK randomised controlled trial (RCT) also suggest that written information may help lower patients' levels of depression and symptoms of post-traumatic stress disorder (PTSD), when provided as part of a broader rehabilitation strategy.[12] These limited data justify further investigation of the key elements of ICU discharge information that lead to positive health outcomes.

OBJECTIVES

This paper reports a RCT designed to (1) provide an initial evaluation of a user-centred critical care discharge information pack (UCCDIP), (2) inform decisions regarding its further development and evaluation, and (3) estimate the sample size required to power a definitive trial.

METHODS

Design

We designed an external pilot pragmatic RCT (figure 1) to provide initial data regarding the feasibility and effectiveness of UCCDIP. In accordance with the definition of an external pilot,[16] an assessment of the primary outcome was included. To reduce the chance of between-group contamination, the design also incorporated cluster randomisation, where groups of participants (as opposed to individuals) were allocated to study arms. During the trial, a questionnaire survey was conducted to determine the experiences of trial participants and nursing staff.

In line with best practice,[17 18] a former patient and Trustee of ICUsteps (an ICU patient and relative support charity) was included on the project team. Recruitment took place between 8 August 2011 and 4 May 2012, and informed patient consent was obtained prior to data collection. The trial was registered on The International Standard Randomized Controlled Trial Number (ISRCTN) database (ISRCTN47262088) 5 months after recruitment of the first patient. This delay was due to an administrative problem between trial

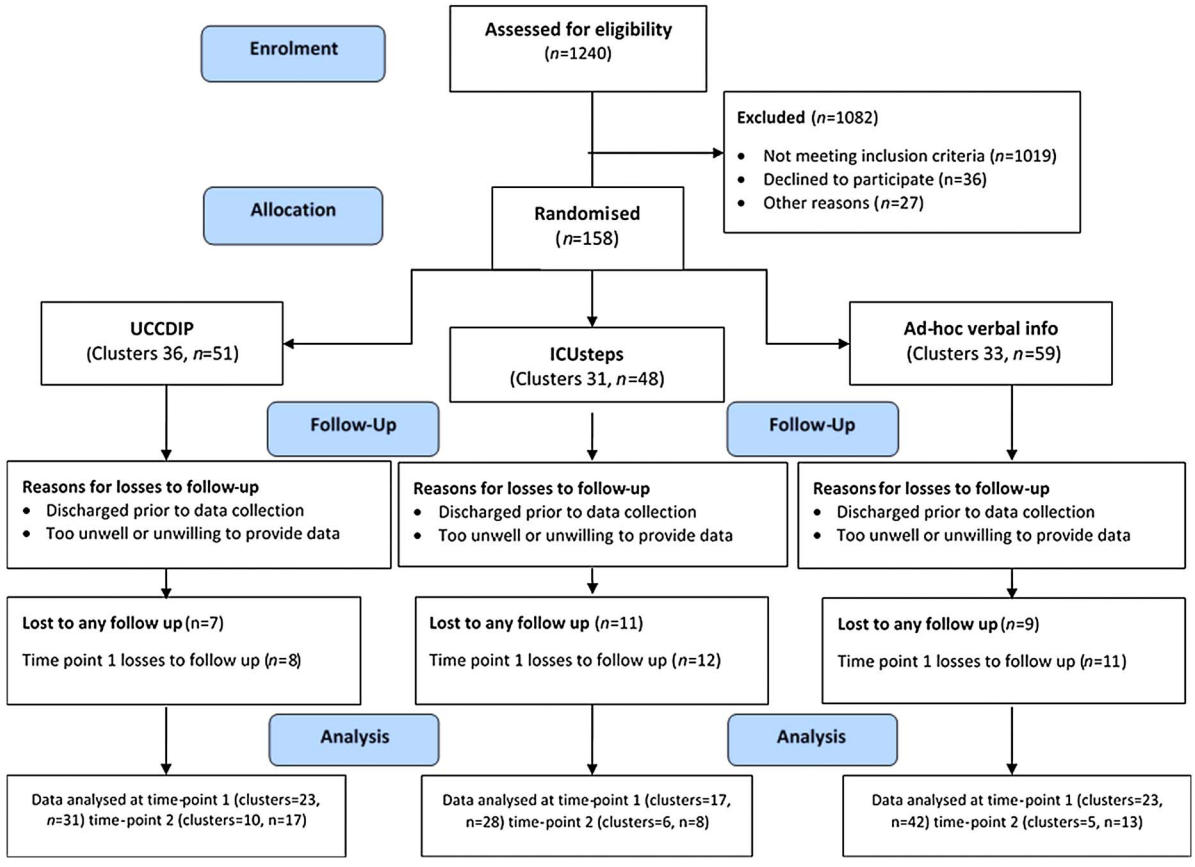

Figure 1 Flow of participants (ICU, intensive care unit; UCCDIP, user-centred critical care discharge information pack).

registry and the funding body. The full trial protocol is available in online supplementary file 1.

Setting and participants

The study took place in two ICUs (medical n=14 beds and surgical n=18 beds) within a single teaching hospital in central London, England; providing care for a mixed medical, surgical and trauma patient population, requiring level 2 (high dependency) or level 3 (intensive) care.[19] Both units functioned as one department; staff rotated between units and patients were allocated to a bed based on availability; regardless of whether they required medical or surgical care. Patients over 18 years were considered for inclusion into a cluster if they had spent at least 72 h in the ICU (table 1). The intention was to recruit all eligible patients, declared medically fit for discharge to a general ward Monday to Friday (08:00–20:00) and a nominated relative. Inclusion criteria were based on best practice guidelines surrounding ICU discharge,[1] with an aim to avoid including overnight stay elective surgical patients whose discharge had been delayed due to the unavailability of a ward bed.

All participants (patients and relatives) were recruited while the patient was in ICU. Potential patient participants were consented the day prior to a formal discharge decision wherever possible. For patients unable to provide informed written consent at the point of ICU discharge, personal consultee declarations,[20] usually from the patient's next of kin, were sought. Informed consent from the patient was then obtained prior to data collection on the ward. The relatives of all recruited patients were given study information when they visited the ICU, or telephoned and invited to participate. Written consent was obtained from relatives who agreed to participate during their next hospital visit. All participants were allocated a trial number. All members of a family unit were given the same number, prefixed by either a P or R (eg, P1 for the patient and R1 for the relative). The assigned trial number was used across all data collection forms, enabling anonymised data from all sources to be matched and comparisons made between patient participants (and their relatives), their characteristics and the outcome data.

Table 1 Inclusion/exclusion criteria for individual participants

Inclusion criteria	▶ Adult patients (>18 years) ▶ Adult family members of eligible patients (>18 years) ▶ Elective or emergency admissions in the ICU ≥72 h ▶ Patients identified for discharge to a general ward setting within the hospital ▶ Elective discharges between 08:00 and 20:00 Monday to Friday
Exclusion criteria	▶ Patients for whom active treatment had been withdrawn ▶ Inability to verbally communicate in or read English ▶ Involvement in a phase I focus group study[4]

ICU, intensive care unit.

Intervention

Drawing on self-regulation theory (SRT),[21 22] our intervention (UCCDIP) was developed using data from a previous focus group study.[4] UCCDIP consists of two booklets, one for the patient and one for the relatives (see online supplementary file 2). The front page of the patient booklet includes an individualised patient discharge summary, written by ICU bedside nurses; trained to use a template designed by the project team (CW, PH). The pack also contains information aimed at preparing the patient/family for ICU discharge and the transition to the ward. It encourages active participation by offering space for expression of individual questions and concerns. It also includes diary pages for both the patient and family to record their thoughts and feelings during the in-hospital recovery period, if they wish. In accordance with SRT, UCCDIP was designed as an information resource, to help users develop revised illness perceptions, more consistent with effective coping.[22 23] The intervention is further described in Bench *et al*.[24]

Participants in all three study arms received usual care, which consisted 'ad hoc' verbal ICU discharge information provided by a variety of healthcare professionals. No guidance was given for this and the quality and quantity of information delivered was totally dependent on each staff member's usual practice. To minimise the risks of additional attention, given to participants in the intervention group having a placebo effect,[25 26] in addition to the 'ad hoc' information given to all participants, a second 'attention control' group received alternative written information in the form of a booklet produced by the ICUsteps charity.[27] In contrast to UCCDIP, the information in the ICUsteps booklet covered the whole trajectory of critical illness from ICU admission to after hospital discharge. In addition, the ICUsteps booklet did not offer opportunities for participants to reflect on their experience or feelings, or prompt them to consider their individual information needs.

Intervention delivery

Immediately after recruitment, patient participants in all clusters were given an identical looking folder containing a covering letter, study information and, where applicable, written discharge information (either UCCDIP or the ICUsteps booklet). These folders accompanied patients when they were discharged to the ward.

For participants randomised to a cluster receiving the intervention, the bedside ICU nurse orientated the patient to the contents of the UCCDIP and the research nurse (KH) checked that the patient discharge summary was completed according to agreed guidelines.[24]

The bedside nurse did not go through the written booklet given to participants in the cluster allocated to receive the ICUsteps booklet.

Recruited relatives were allocated to the same study group as the patient, but it was left up to the patient to pass the information on to their family. Although UCCDIP contained an information book specifically for relatives, they were not included in the discussion between the bedside nurse and the patient, unless they happened to be present on the unit at the time.

Outcomes

The primary outcome was individual patients' sense of psychological well-being (specifically anxiety and depression), measured using the internationally validated Hospital Anxiety and Depression Score (HADS) tool[28] with a threshold ≥8 used to identify possible clinical cases of anxiety and/or depression.[29] Secondary outcomes included individual patients' perceptions of coping, measured using the Brief Coping Orientations to Problems Experienced (BCOPE) tool[30] and relatives' sense of psychological well-being (anxiety, depression and coping assessed using HADS and BCOPE). In addition, patients' perceptions of their ability for self-care were measured using the Patient Enablement Instrument (PEI).[31] A locally designed questionnaire survey described the discharge experiences of all recruited patients and their relatives. The views of the ICU and ward nursing staff about UCCDIP were also explored using the questionnaire survey and have been previously published.[32] Face and content validity of the questionnaire were reviewed by the patient advisory group, but no pilot was undertaken prior to its use. Table 2 details the instruments and measures used to assess both primary and secondary outcomes.

To assess the effects of the intervention on early in-hospital psychological well-being, outcome data from patient and relative participants were collected on the ward on two occasions after ICU discharge: 1 week (defined as 5±1 day) and at hospital discharge or 28 days, whichever was sooner. The questionnaire survey was completed prior to a patient's hospital discharge (participants) or at the end of the trial period (nurses) (table 2).

Data were collected by one researcher (SB), with back-up provided (TD). To maximise the chance of retrieving a full data set, researchers facilitated completion of forms (by reading questions and writing responses) for some of the less able patients. Relatives were asked to complete forms on the ward or at home, and to return them directly to the research team (by email or post) or to leave them for collection at the patient's bedside.

Demographic information, length of ICU stay, ICU readmissions, medical history, Acute Physiology and Chronic Health Evaluation (APACHE) II scores,[33] therapies received and complications pertinent to the critical illness period were retrieved from local databases and medical notes immediately after each patient participant was recruited. At this point, participating relatives were also asked to complete a form detailing their demographics, previous experiences of critical illness and relevant medical history (such as anxiety and/or depression). The number of unit discharges per day during the trial period and other feasibility data, such as comments received from staff and challenges associated with intervention delivery, were also recorded by the research nurse. All completed discharge summaries were photocopied and retained.

Sample

Based on data from a previous RCT by Gammon and Mulholland,[34] which examined the effect of information giving on the HADS of a sample of perioperative patients, the sample size calculation for the present trial was carried out using G*Power V.3.1.2. To detect a moderate effect size of 0.6 (mean difference of 3 units, SD 5) with a power of 80% and α set at 0.05, a minimum of

Table 2 Data collection instruments and measures

Participant	Outcome	Instrument	Measurement
Patient	Anxiety and depression	HADS	1. On ward, 5 (±1) days post-ICU discharge 2. Hospital discharge or 28 days
Patient	Perceptions of coping	BCOPE	1. On ward, 5 (±1) days post-ICU discharge 2. Hospital discharge or 28 days
Patient	Perceptions of self-care ability	PEI	1. On ward, 5 (±1) days post-ICU discharge 2. Hospital discharge or 28 days
Patient	Discharge experience	Questionnaire	Prior to hospital discharge
Relative	Anxiety and depression	HADS	1. On ward, 5 (±1) days postpatient's ICU discharge 2. Patients' hospital discharge or 28 days
Relative	Perceptions of coping	BCOPE	1. On ward, 5 (±1) days postpatient's ICU discharge 2. Patients' hospital discharge or 28 days
Relative	Discharge experience	Questionnaire	Prior to patient's hospital discharge
ICU and ward nurses	Views about UCCDIP	Questionnaire	End of trial period

BCOPE, Brief Coping Orientations to Problems Experienced; HADS, Hospital Anxiety and Depression Scale; ICU, intensive care unit; PEI, Patient Enablement Instrument; UCCDIP, user-centred critical care discharge information pack.

45 participants in each group were required. To account for attrition and the likely variation in ICU discharges in each cluster (discharge day), our accrual target was 50 participants in each of three study arms.

Sample size was not based on an intracluster correlation (ICC) calculation, as insufficient information was available to determine the real extent of any homogeneity between clusters. As only those discharged on weekdays were recruited, it was anticipated that every day would produce a fairly similar and randomly determined clinical case load (local data 2010/2011), thus limiting the likelihood of homogeneity (eg, similar diagnoses) within and heterogeneity (eg, care led by different medical teams) between clusters. The intervention for each cluster was also preallocated on a random basis, thus minimising (although not eradicating) the chance of clusters being homogeneous.

There was no opportunity to influence cluster size, and so to maximise the chance of recruiting the required number of participants, data collection was planned to continue for at least 132 days, providing 44 potential clusters in each of the three study arms, significantly greater than the minimum of five recommended by the UK Medical Research Council.[35]

Randomisation

As described by Hayes and Moulton,[36] this trial used cluster randomisation for pragmatic reasons, with an aim to reduce the risk of cross-contamination between study arms. All patient participants (and their relative where applicable) discharged from either ICU on a particular day (a cluster) were allocated to one of the three study groups (figure 1). Particular days of the week were not allocated to specific arms; instead each day was randomly allocated to a study arm and treated as a distinct cluster, based on the allocation schedule.

To ensure that the sequence of allocation was not predictable, the day on which the intervention, control and attention control was used was randomly assigned using a computer-generated random sequence, prepared by a statistician. This involved simple randomisation with no blocking or stratification for defined variables.

The allocation schedule was prepared by persons independent of the trial and concealed by being wrapped in a blank piece of paper and placed inside sequentially numbered, sealed envelopes. These envelopes were signed across the seal and opened by the research nurse (KH), in the presence of another member of the research team, only after a recruited patient was identified for discharge to the ward on a particular day. The clinical ICU staff only became aware of which study group the patient was allocated to when the bedside nurse was provided with a study pack to give to the patient. Allocation concealment for the whole cluster was revealed after the first envelope was opened on any day.

Blinding

It was not possible to achieve full blinding during this trial as intervention delivery required input by healthcare staff and trial participants. Those collecting and analysing data were, however, blinded by the use of codes, which were not broken until after data analysis. Blinding was compromised if participants revealed their information pack to the data collector. In most instances, however, as all participants received a folder, identical on the outside, data collectors (SB/TD) remained blinded to the allocation.

Statistical methods

Data analysis was based on an 'intention-to-treat' strategy[37] and statistical significance was set at $p \leq 0.05$. Average values for sample characteristics, HADS, BCOPE, PEI scores and questionnaire responses in each of the study groups were compared using χ^2 for categorical data and Kruskal-Wallis (H) for data of at least ordinal level. In addition, Friedman's test (χ^2r) was used to explore associations between the different types of coping. Difference in HADS (the primary outcome) between the three study groups was also tested using the Statistical Analysis System (SAS) V.9.3 (SAS Institute Inc, Cary, North Carolina, USA), Generalised Mixed Models procedure (GLIMMIX) that adjusted for clustering (by fitting a random intercepts model) and recruitment weekday. At time point 2, it was not possible to fit random intercepts because the G-side matrix was always not positive definite. We followed the CONSORT guidance and did not conduct baseline statistical comparisons between study groups.[38]

This paper reports outcome data from the patient participants only, with reference to the demographics and attrition data collected from the sample of relatives.

RESULTS

Two hundred and twenty-one (18%) of the 1240 screened patients met the inclusion criteria and 158 of these were recruited in 100 clusters, each containing 1–5 patients (table 3). The distribution by cluster size was as follows: one patient (n=66), two patients (n=21), three

Table 3 ICU patients discharged and recruited per weekday

Recruitment day	Clusters, n (%)	Patient participants recruited, n (%)	Patients discharged, n (%)
Monday	31 (31)	56 (35)	161 (16)
Tuesday	20 (20)	30 (19)	216 (22)
Wednesday	10 (10)	14 (9)	189 (19)
Thursday	16 (16)	18 (11)	226 (23)
Friday	23 (23)	40 (25)	198 (20)
Totals	100 (100)	158 (100)	990 (100)

ICU, intensive care unit.

patients (n=6), four patients (n=3) and five patients (n=4). Fifty-one (32%) patient participants were allocated to the intervention group (UCCDIP), 59 (37%) to control group 1 (ad hoc verbal information) and 48 (30%) to control group 2 (ICUsteps booklet; figure 1). Eighty relatives of the recruited patient participants also agreed to take part.

Sample demographics

The mean age of patients was 60 (SD 16.04) years (table 4). Participants were predominantly white British/Irish (n=115, 73%) and 82 (52%) were male. Median length of ICU stay was 6 days (range 371). Severity of illness on admission (measured by the APACHE II score) ranged from 4 to 34 (median 17) and on discharge to a ward between 0 and 21 (median 9). Ninety-eight (62%) participants received at least 1 day of level 3 (ICU) care.

For the majority of the sample (n=122, 77%), admission to the ICU was unplanned. Twenty-nine (18%) had experienced previous ICU admissions; 9 of these participants were from the ICUsteps group (n=48, 19%), 10 were from the UCCDIP group (n=51, 20%) and 10 from the ad hoc verbal information group (n=59, 17%). A recorded history of depression with or without anxiety was evident in 14 (9%) of the total patient sample and the presence of delirium while in the ICU was recorded in 11 (7%) participants' medical notes.

Relatives (n=80) were aged between 18 and 94 years (mean 55 years, SD 14.6), predominantly white British/Irish (n=63, 79%) and female (n=52, 65%). Most were spouses or long-term partners (n=37, 46%) of the recruited patient. A history of anxiety and/or depression was reported by 20 (25%) of the sample.

Patient participants in the UCCDIP sample were more frequently admitted from an in-hospital bed and received more days of level 3 care. They also had higher APACHE II scores on both admission and discharge and stayed in the ICU for longer than participants in either of the other two groups, even when outliers with a ICU stay of >100 days were removed (n=2). None of these differences were statistically significant.

Participant follow-up

One hundred and one (64%) patient participants provided primary outcome data at time point 1 (5±1 day post-ICU discharge). Fifty-four (34%) were still in hospital and eligible for data collection at time point 2 (28 days or hospital discharge and at least 7 days after their first data collection point). Of these, 38 (70%) provided some data. A total of 48 (60%) patients' relatives provided at least one set of outcome data.

Twenty-seven (17%) patients and 32 (40%) relatives were lost to any follow-up. By time point 1 (5±1 day), 17 (11%) of the patient sample had already been discharged or transferred from the hospital, and in a further 15 (10%) cases, the patient was either too unwell or unwilling to provide data. In the case of patients' relatives, the most significant follow-up problem was due to a failure to return data collection forms within the protocol timeframe (n=29, 36%).

Hospital anxiety and depression

One week postdischarge (time point 1), median HADS for patients was 7 for anxiety (HADS-A) and 6 for depression (HADS-D). There were no significant differences ($p \geq 0.05$) between study groups (table 5). There was, however, a wide range in individual HADS, with almost half the total patient sample (44%) reaching or exceeding the trigger for disorder (≥8). At time point 1, where it was possible to fit a random intercepts model, the estimated ICCs were all low (HADS-A 0.14, HADS-D 0.00, total HADS 0.07).

Coping and enablement

No significant differences between groups ($p \geq 0.05$) for emotion-focused, problem-focused and dysfunctional

Table 4 Sample characteristics (patients)

Characteristic	Value	ICUSteps	UCCDIP	Verbal	Total	p Value
Age (years)	Mean±SD	59±15.26	60±15.19	61±17.48	60±16.04	0.72
Ethnicity (white British)	n (%)	34 (71)	40 (78)	41 (69)	115 (73)	0.54
Gender (male)	n (%)	25 (52)	26 (51)	31 (53)	82 (52)	0.99
Medical/Surgical ICU	Medical, n (%)	28 (58)	28 (55)	26 (44)	82 (52)	0.30
Admission type (emergency)	n (%)	38 (79)	40 (78)	44 (75)	122 (77)	0.83
APACHE II score	ICU admission Median (range)	17 (24)	18.0 (30)	16.0 (29)	17.0 (30)	0.41
	ICU discharge Median (range)	8.0 (20)	9.5 (20)	9.0 (21)	9.0 (21)	0.66
Length of stay	ICU days Median (range)	6.0 (62)	7.0 (104)	6.0 (371)	6.0 (371)	0.24
	Hospital days Median (range)	16.0 (132)	21.5 (220)	22.0 (166)	21.0 (221)	0.25
Level 3 critical illness	n (%)	29 (60)	35 (69)	34 (58)	98 (62)	0.58
Total number of participants	n (%)	48 (100)	51 (100)	59 (100)	158 (100)	NA

APACHE, Acute Physiology and Chronic Health Evaluation; ICU, intensive care unit; NA, not available; UCCDIP, user-centred critical care discharge information pack.

Table 5 HADS (patient sample)

Outcome	Unit of measurement	Study group				Kruskal-Wallis		Mixed model			
		ICUsteps	UCCDIP	Verbal	Total	χ^2 (2df)	p Value	Intervention	p Value	Intervention adjusted for day of week	
								F (dfn,dfd)		F (dfn,dfd)	p Value
HADS-A: 1*	Median (range)	7.5 (19)	7.0 (17)	6.0 (19)	7.0 (19)	0.98	0.61	0.57 (2,27)	0.57	0.32 (2,27)	0.73
	n	28	31	42	101						
HADS-A: 2†	Median (range)	6.0 (13)	7.0 (18)	5.0 (16)	6.0 (18)	0.08	0.96	0.01‡ (2,35)	0.99	0.00 (2,31)	1.00
	n	8	17	13	38						
HADS-D: 1*	Median (range)	6.5 (18)	6.0 (16)	7.0 (21)	6.0 (21)	0.43	0.80	0.46 (2,24)	0.64	0.41 (2,24)	0.67
	n	28	30	40	98						
HAD-D: 2†	Median (range)	4.5 (16)	6.0 (12)	7.0 (15)	6.5 (16)	0.73	0.70	0.35‡ (2,35)	0.72	0.27‡ (2,31)	0.77
	n	8	17	13	38						
Total HADS: 1*	Median (range)	16.0 (35)	12.5 (32)	14.0 (39)	14.0 (9)	0.44	0.80	0.57 (2,24)	0.57	0.48 (2,24)	0.62
	n	28	30	40	98						
Total HADS: 2†	Median (range)	10.0 (23)	11.0 (27)	12.0 (23)	11.5 (27)	0.41	0.82	0.13‡ (2,35)	0.88	0.10‡ (2,31)	0.90
	n	8	17	13	38						

*5±1 days post-CCU discharge.
†28 days post-CCU discharge or hospital discharge.
‡Model fitted without random intercepts—estimated G matrix not positive definite.
HADS, Hospital Anxiety and Depression Score; HADS-A, HADS for anxiety; HADS-D, HADS for depression; ICU, intensive care unit; UCCDIP, user-centred critical care discharge information pack.

coping categories or PEI scores were identified at either time point. Over time, the median PEI score for the total patient sample did, however, drop from 12 to 10, indicating that patients felt less enabled the longer they stayed in hospital.

Questionnaire findings

Patient participants in the ad hoc verbal information control group reported significantly more chance of worrying a lot (χ^2=11.16 (df 2), p=0.03) than those in either other study group. However, after using GLIMMIX to adjust for clustering, the effect of the intervention on 'worry about leaving the Critical Care Unit (CCU)' was not statistically significant (F (2,39)=0.23, p=0.80). There were no other statistically significant differences in reported feelings or experiences between study groups. However, more participants from the medical as opposed to surgical unit reported that their written information had helped their recovery on the ward, with a result approaching statistical significance (χ^2=3.69 (df 2), p=0.06).

Adverse effects

One patient asked to be withdrawn from the trial after data collection point 1 as she felt that completion of the HADS had triggered deterioration in her mental health status. A note was made in her medical file, and she was referred to her primary medical team. There were no other reports of any adverse effects.

The impact of protocol violations

Twenty-five (16%) patients and 10 (13%) of the patients' relatives had data collected outside of the time period stated by the protocol for time point 1. At time point 2, the mean time from ICU discharge to data collection was 23±6 days for patients and 25±8.36 days for the relatives.

Including these data produced no change in HADS or PEI outcomes compared with the analysis, which excluded them. At the first follow-up point, however, some significant differences in the scores given for individual questions in the emotion and problem-focused coping categories of the BCOPE were identified. UCCDIP sample data reflect significantly less use of religion (question 12; p=0.01), active coping (question 2; p=0.04) and planning (question 9; p=0.01) strategies, than those participants in either of the other two study groups. Analysis of the composite scores for each coping category (emotion, problem and dysfunctional) also revealed that those in the UCCDIP group used significantly fewer problem-focused coping strategies (H=6.49, p=0.04).

DISCUSSION

Despite some limited data from previous research, which suggest that written resources may lower levels of patients' anxiety, depression and symptoms of PTSD,[12]

the health benefits of providing written ICU discharge information remain inconclusive.[5] Our trial did not find sufficient evidence to determine whether UCCDIP improves patients' or relatives' health outcomes or experiences (anxiety, depression, coping, patient enablement) compared with the ICUsteps booklet and/or the delivery of ad hoc verbal information. However, our survey data suggest that those who receive written information may feel less worried about going to a ward than those who receive ad hoc verbal information alone.

The UK Medical Research Council point out that evaluations of draft complex interventions are frequently undermined by numerous practical and methodological problems, and recommend a period of feasibility testing and piloting prior to full scale evaluation.[39] Using these design principles, data collected during our RCT has identified some important future considerations.

Deciding the optimal time to provide ICU discharge information is an important issue for future practice, particularly considering that recovery rates for physical and emotional recovery may differ.[40] We gave our intervention to patients immediately prior to their discharge from the ICU. However, the survey data that we collected alongside the trial indicate that many felt unable to engage with the information at this point or during the early days on the ward, and that some of the patients allocated to UCCDIP or the ICUsteps booklet were unaware of having received any written material.[32] Retention of information is a common problem for ICU patients.[3 4] Having a family member present when UCCDIP was discussed with the patient may have increased participants' awareness of and engagement with the intervention. Where possible, such practice is encouraged, particularly if a patient's cognitive function is compromised.

The intention of this trial was to determine the effect of adding UCCDIP into the usual care provided during discharge; thus, after discharge to the ward, no specific instructions were given to ward nurses or other healthcare staff about their role in facilitating its use. Knowledge of the intervention, obtained due to contamination of the allocation concealment after recruitment of the first patient on any day may, however, have influenced staff members' verbal information delivery, both its quality and quantity. In addition, follow-up personnel, such as discharge coordinators and critical care outreach nurses, have been shown to aid patients' and relatives' interaction with written information.[41] Not providing this support as part of the intervention in this trial may account for some of the problems with engagement that we encountered, particularly for those with English as a second language, poor literacy and/or cognitive impairment. It may also have contributed to the excessive loss to follow-up we experienced, which in turn may have influenced our outcome data. We did not collect data on these participant characteristics and thus are unable to validate these assumptions. These issues are further discussed in Day *et al*.[42]

UCCDIP is a multicomponent intervention, which includes an individualised patient discharge summary written by ICU nurses. Survey data (reported in Bench *et al*[32]) suggest that this element of UCCDIP was of particular value to the patients, relatives and ward nurses who took part in our study. In the protocols for the Scottish RECOVER and RELINQUISH trials,[43 44] discharge summaries, similar to those used in the present trial, but written by doctors are also included as part of the intervention. In addition, 'lay summaries' are now being written by physiotherapists in some parts of the UK (personal communication from Williams N, Edinburgh Critical Care Research Group 6th annual meeting; 26 June 2013). Healthcare professionals' interest in using patient discharge summaries is also evident by the number of 'discharge summary training packs', designed by our project team, being downloaded from the ICUsteps website.[32] Based on these findings, we recommend that reflective opportunities, such as diaries, are included as part of all individualised rehabilitation programmes.

Our results suggest that medical as opposed to surgical patients may value interventions such as UCCDIP more; perhaps because this group have an increased tendency for psychological problems such as PTSD.[45] Elective surgical patients may also be better prepared for an ICU admission and their stay is generally expected to be shorter. In our trial, it must be acknowledged, however, that most admissions to the surgical ICU were unplanned. Further, admission to the medical or surgical unit was not always reflective of a patient's condition as beds were used flexibly to meet demand. Despite this limitation, defining subpopulations of critical care (eg, medical vs surgical, ventilated vs non-ventilated) that may benefit most from such an intervention remains an important future consideration, particularly where resources are limited.

Future research

Evaluating any complex intervention is practically and methodologically difficult.[39] UCCDIP contains a number of different components, making it difficult to isolate those aspects likely to be most effective. Although findings from the questionnaire survey suggest that the patient discharge summary was considered valuable,[32] future research is required to examine its effectiveness as a stand-alone intervention.

In this trial, the patients and relatives in all clusters received ad hoc verbal information as part of usual care practice. Ad hoc information delivery can be inconsistent and its quality can differ between healthcare professionals. As in other studies,[13–15] it was unclear who was delivering the 'ad hoc' verbal information during our trial, what was being said or whether it was actually provided at all. Although challenging, attention to qualifying and quantifying these data is a recommendation for further research.

The high prevalence of anxiety and depression experienced by patients and their families in our study suggests that a higher threshold (≥11) on the HADS tool, as used by other researchers[12 46 47] is required to differentiate the effects of interventions such as UCCDIP on participants. The relationship between emotional status, cognitive appraisal and coping behaviours is complex and individualised. Outcome assessment measures, more closely aligned with the theoretical basis of the intervention (in this case SRT) may, therefore, be better suited to evaluate information interventions in recovering critically ill patients. Development of a validated tool to provide more rigorous data to support the positive views of UCCDIP reported in the locally designed questionnaire survey[32] is also required.

Our data collection points were specifically chosen to identify any early effects of the intervention on psychological well-being that might influence ongoing recovery. However, the effects of our intervention on patients' and relatives' perceived anxiety, depression, coping and enablement may not have been visible during the early stages of recovery.[48] A longer follow-up period would enable both the early and ongoing impact of different methods of ICU discharge information to be better explored. The common problem of delayed discharge from ICU[49] should also be considered. Delays can have both positive (physically stronger) and negative effects (increased dependency) on psychological well-being at the point of ICU discharge, and thus may have important implications for evaluating information provision.

It is widely acknowledged that in complex intervention studies such as this, the risk of follow-up bias is high.[39] Reasons for low follow-up in this study were multifactorial, but key reasons included patients being discharged from hospital earlier than anticipated and relatives failing to return data collection forms. These factors need to be considered in the design of future trials. Including relatives in the evaluation of any critical illness rehabilitation intervention is important, as the family unit often provides substantial support to the patient and close relatives can also be affected by the patient's critical illness.[50 51] Our experience suggests, however, that once a patient leaves ICU, it is very difficult to maintain communication with relatives and that their commitment to completing study requirements is reduced. Alternate methods of data collection, such as individual telephone interviews, may help reduce the level of attrition we experienced in this study.

In line with best practice recommendations, one of the purposes of this pilot RCT was to inform the power calculation for future work.[52] Mean HADS-A and HADS-D was 7 (SD 5) in the patient sample. Based on a power of 95% and 0.05% level of significance, to achieve an effect size of 0.4 (difference of 2), a total sample of 286 (143 in each of two groups) would be required for a definitive trial. The different numbers of participants recruited on each weekday (table 1) should also be accounted for. The recruitment rates we observed suggest that this would require a multicentre study to achieve. Given our attrition, it is difficult to judge if such a study would represent value for money although possible benefits for patients include an improved understanding of their critical illness experience, use of more positive coping strategies and improved psychological well-being during the rehabilitation period. Considering the feasibility challenges we experienced and have previously described,[49] future research could focus on assessing patients' and relatives' perceived usefulness of written information resources and the extent to which specific information deemed important is successfully transmitted and retained.

Limitations

This was a single-centre pilot trial, with a short follow-up period and a high rate of attrition (particularly in the sample of relatives). Only recruiting patients discharged during weekdays and daytime hours may have led to a selection bias, as poorer outcomes are associated with night-time and weekend discharges.[1] Other potential biases may also have influenced our results. There were some pretest differences between study groups which might have attenuated any potential benefits. HADS were skewed and the sample was small at time point 2. This should be borne in mind when interpreting the statistical model; however, the results were consistent whichever approach was used. There was also a failure to maintain allocation concealment after recruitment of the first patient in each cluster and a possible Hawthorne effect, where staff may have provided verbal information differently from normal because they were aware of the nature of the study.

Results must therefore be viewed with caution and may not be generalisable to the wider critical care population. The study has, however, provided important data, which can inform future trials evaluating interventions like UCCDIP, enabling processes to be streamlined and a sample size based on a more accurate power calculation to be used.[52–54]

CONCLUSION

This single-centre pragmatic pilot RCT used cluster randomisation to undertake an initial evaluation of UCCDIP, a discharge information pack designed by the project team. We were unable to prove the effectiveness of UCCDIP, supporting the view that information giving to those recovering from critical illness is a complex intervention. This research has, however, provided important preliminary data regarding how, when and for whom an intervention based on the principles of UCCDIP could be most effective and what it would look like.

To increase the likelihood of similar interventions improving health outcomes, key considerations for future work are: (1) medical as opposed to surgical

critical care patients may be more likely to benefit from such interventions; (2) after discharge to the ward, patients need further input and support to help them engage fully with written information resources; (3) data collection time points should reflect the potential effects on both early and later recovery; and (4) outcome measures more sensitive to the effects of UCCDIP should be used for future evaluations.

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Contributors SB conceived, designed and coordinated the study as part of a PhD, collected and analysed the data and drafted the manuscript. PG was principal investigator, supervised SB and provided critical comment on the drafted manuscript. TD participated in the design and coordination of the study, was second supervisor to SB, assisted with data collection and provided critical comment on the drafted manuscript. KH recruited and consented trial participants, collated baseline data, assisted with intervention delivery and provided critical comment on the drafted manuscript. PH participated in the design and local coordination of the study, co-drafted guidelines for the patient discharge summary and provided critical comment on the drafted manuscript. CW was the service user representative for the project, participated in the design of the study, co-drafted guidelines for the patient discharge summary and assisted with their analysis, and provided critical comment on the drafted manuscript. All authors read and approved the final manuscript.

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King's College Hospital NHS
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KING'S College LONDON

Study Protocol

Title

A user centred critical care discharge information pack (UCCDIP) for adult critical care patients and their families at the point of discharge from critical care to the ward; a pilot study evaluating feasibility and effectiveness.

Investigators

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Funding details

National Institute of Health Care Research

Research for patient benefit

Competition 12

Summary

This study will explore the effectiveness of a user centred critical care discharge information pack (UCCDIP), developed with user involvement, as compared with usual care using a single centre prospective cluster Randomized Controlled Trial (RCT). The primary outcome measure will be sense of psychological well being during early critical illness recovery. Secondary outcome measures will include length of hospital stay, critical care readmission rates, feasibility and user experience.

Background information

Discharge from any critical care facility (High Dependency, Intensive Care or combined facility; as defined by Department of Health, 2000) to a general ward is a difficult time for patients, relatives and healthcare staff. A number of physiological and psycho-social problems, including weakness, feelings of helplessness, anxiety and depression have been identified as compromising critical illness recovery (NICE, 2007; Bench and Day, 2010). These are compounded by the move to a general ward setting. Previous research has indicated that in contrast to the critical care unit where patients feel safe, ward care is seen to be unpredictable and difficult to understand from the patients' perspective (Chaboyer et al, 2005), leading to relocation stress/anxiety (McKinney and Melby, 2002).

Review of relevant literature and justification for study

McKinney and Melby (2002) argue that it is necessary to think creatively about interventions which might enhance the discharge and rehabilitation process. Guidelines for the acutely ill patient in hospital from the National Institute of Health and Clinical Excellence (NICE) recommend that "*patients should be offered information about their condition and encouraged to actively participate in decisions related to their recovery...tailored to individual circumstances*" (NICE, 2007: 16; recommendation 1.2.2.16). This recommendation is based on a review of existing

evidence of patients' experience of care during this transition period, and supports the development of patient focused interventions as stated by Coulter and Ellis that "*recognise the role of participants in the process of securing appropriate, effective, safe and responsive healthcare*" (Coulter and Ellis, 2006: page 7). The importance of providing appropriate, timely and accurate information during critical illness recovery is further endorsed by NICE (2009) in their guidelines for the rehabilitation of patients after critical illness.

Producing health information based on specific research into what patients have identified as being required is of utmost importance in the development of effective interventions (INVOLVE, 2004; Coulter and Ellis, 2006). There is, however, little evidence in the literature of user involvement in the design or evaluation of information strategies for this population group, despite information giving meeting the criteria for being a complex intervention as defined by Campbell et al (2007).

The use of more active information strategies, defined as those requiring user participation, tailored to individual need, builds upon successful approaches to self care developed in community settings (Griffiths, 2005). If feasible within the critical care population, information strategies which encourage self management could enhance perceptions of control and lead to improved psychological and physical recovery. Despite their vulnerability, evidence suggests that some patients are capable of and desire more input and control over their information needs. It is on this premise that the intervention to be evaluated in this study has been developed.

Limited published work has evaluated critical care discharge information strategies, and most previous work has been inconclusive (for example Paul et al, 2004). This may in part be due to a lack of user involvement in decisions related to both information content and delivery methods, and its generalised nature. Jones et al (2003) demonstrated in their RCT that the use of a self help rehabilitation manual was effective in reducing depression in critically ill patients, providing some evidence to support a more participatory approach. Further, Mitchell and Courtney (2004) demonstrated a reduction in families levels of uncertainty with a more individualised information strategy. Systematic reviews from other patient populations also support

the development of information personalized to the individual. For example, a Cochrane review by McDonald et al (2004) examined nine studies to determine whether preoperative education improved postoperative outcomes in patients undergoing hip or knee replacement surgery, concluding that there was some evidence of beneficial effects when preoperative education was tailored according to anxiety and individual need. Such strategies could help patients' regain the sense of empowerment potentially lost during their critical care stay, reducing the psycho-social and physiological complications which prolong recovery from critical illness. Evidence from the review of patient focused interventions by the Health Foundation (Coulter and Ellis, 2006) provides support for this, stating that self management education is about empowering patients to take active control of their illness, including the management of the emotional impact of their illness (Coulter and Ellis, 2006).

A study by Garrod et al (2006) further supports the importance of a focus on psycho-social well-being during rehabilitation. In their study with chronic respiratory patients, those with depression were found to be significantly more likely to drop out of a pulmonary rehabilitation programme than those without depressive symptoms (odds ratio 8.7; confidence interval 2.8-27.1). Evidence such as this, despite being conducted on a chronic respiratory patient population, strongly supports the development of interventions, which improve psycho-social well-being during early critical illness rehabilitation, and suggests that altering psycho-social well-being could impact on physical rehabilitation targets.

Discharge from critical care is a time which presents potential patient safety issues as defined by the National Patient Safety Agency (NPSA, 2004), a view reflected in a number of recent critical care policy documents (DH, 2000; DH, 2005; NICE, 2007; NICE, 2009). Although the association between psychological well being and other outcomes such as length of stay and patient safety has yet to be established with critical care patients, this RCT, which will be conducted in a real clinical environment, has the potential to provide data that could begin to establish the existence of any such links.

Hypothesis

A user centred critical care discharge information pack (UCCDIP) developed with service users, for adult critical care patients and their families, in comparison to usual care, will:

1. Improve the psychological and physical well-being of patients leaving critical care
2. Improve the psychological well-being of relatives when their loved one leaves critical care
3. Improve the critical care discharge experience for patients and relatives
4. Be considered feasible from the perspective of patients, relatives and critical care and ward nurses

Method

This study is the second of two studies focused on the development and evaluation of more effective critical care discharge information strategies, using the Medical Research Council (MRC) framework (MRC 2008) for the development and evaluation of complex interventions as a guide.

A single centre prospective cluster (patients discharged on a single day) RCT will compare outcomes for an intervention group (of patients and relatives) who will receive the user centred critical care discharge information pack (UCCDIP), with a control group who will receive the currently used information strategy (informal ad-hoc verbal information from health care staff). In order to eliminate any effects imposed by an increase in attention alone, a third 'attention control' group will receive the same amount of provider attention and a standard discharge information booklet without the user centred elements. User experience and feasibility data will be collected from patients, relatives and nurses using questionnaires at the end of the trial period. Following the MRC (2008) framework this single centre study will enable initial evaluation of the proposed complex intervention.

The intervention

The intervention to be evaluated is a user centred critical care discharge information pack (UCCDIP), developed using focus groups, a meta-synthesis of the user experience of critical care discharge (Bench and Day 2010) and a review of currently available discharge information strategies (Bench et al 2011). The pack includes the following:

- Patient discharge summary

A "lay" summary of what has happened to the patient since admission, and their current health status completed by critical care bedside nurses.

- Core information on the discharge process and the early days on the ward.

Information about the discharge process, ward organisation and common physical and psychological concerns of critical care patients and their families. Possible self help strategies will also be detailed.

- A self-assessment tool for identification of individual information needs.

Patients and their family members (as appropriate) will use the tool to identify their own information needs at the point of critical care discharge using written prompts. This tool will have separate parts for the patient and the family to complete. Critical care bedside nurses and ward nurses will assist completion where necessary.

- Personalized information

The patient, family and/or health care professionals will document information focused on the identified needs.

- Personal diary

An opportunity for patients and family members to maintain a reflective account of personal feelings, concerns and early rehabilitation experience.

- Support resources

A list of possible information sources, support services and contact details, including health care professionals, internet support sites, and relevant charities and support forums.

The pack is intended to be flexible, and to support and encourage assisted independence. It recognises the different information needs of patients and family members, acknowledges the physical and psychological vulnerability of both the patient and the family member at this point in time, and acknowledges the patients' need to understand what they have been through and have evidence of the progress they have made. The individualised and flexible nature of this information pack makes it suitable for use across a variety of different age groups, levels of illness severity, and for discharge to a range of different in-hospital destinations.

The pack will be given to the patient (and/or family member as appropriate) by the critical care bedside nurse when the decision to discharge to a ward has been made. Ward nurses will then be involved in providing ongoing information support after discharge to the ward (using the new information pack where relevant).

Outcome measures

The primary outcome measure will be sense of psychological well being, measured using the Hospital Anxiety and Depression Scale (HADS) score (Zigmond and Snaith, 1983). Patient perceptions of coping, self-efficacy and sense of empowerment will also be measured in order to determine the factors (upon which the intervention is focused) that might impact on psycho-social wellbeing. Other secondary outcome measures will include length of hospital stay and rates of readmission to critical care in order to provide some insight into whether improvement in psycho-social well being impacts on physical health outcomes. In addition, feasibility from the perspective of patients, family members, critical care and ward nurses will be assessed providing some evidence as to whether the intervention, if effective, is likely to be utilised in real world clinical practice. Finally, the patient and relative experience will be explored in order to allow identification of

previously unknown and/or unconsidered issues of relevance as to whether the intervention is likely to be effective.

Data collection tools

Psychological well-being will be assessed using HADS for both patients and identified family members. HADS is a self-assessment screening tool, designed to detect depression and anxiety (Zigmond and Snaith, 1983), which has been extensively validated (Bjelland et al, 2002). A total score >8 for either depression or anxiety indicates the presence of disorder. In addition, coping, self-efficacy and empowerment assessment tools will be used to further assess psychological well-being.

Questionnaires will be used to assess patients' and relatives' perception of their discharge experience and to determine the feasibility of the intervention from the perpsective of patients, relatives and ward/critical care nurses. Questionnaire items reflect key themes identified from a previous focus group study. User groups (consisting of participants from a phase I focus group study and two user support groups) will be used to test the validity and reliability of questionnaires prior to use.

Hospital databases and medical records will provide access to information related to patient and family demographics, relevant past medical history (including a history of depression or anxiety), admitting diagnosis, patient illness severity, length of critical care stay, therapies received, discharge destination and complications pertinent to the critical illness period.

Sample

The sample will be drawn from a single NHS Trust in Central London. Calculation of sample size is based on the primary outcome measure (sense of psychological well being) using the HADS score. There is currently very little information available to enable precise calculation of the required sample size to determine an effect. In a previous RCT by Gammon et al (1996) examining the effect

of information giving in peri-operative patients using HADS as a primary outcome measure, the mean post intervention score was 4.2 for the intervention group (n=41) and 6.8 (range 0-15) for the control group (n=41) (a difference of about 3 points).

Based on the information available to date, using a power of 80%, a minimum of 45 participants in each group are required in order to detect a difference of 3 points on the HADS score in the intervention group (assuming SD=5). This study aims to recruit 200 patients, with a minimum of 50 patients in each group. The same number of data collection days will be employed for each arm of the study. Data collection will continue until a minimum of n=50 is achieved in all groups. Although the number of critical care discharges vary from day to day leading to a potential difference in the final number of participants in each group, randomisation is likely to ensure that overall numbers are not unduly unbalanced between groups. If groups are unbalanced in size we will ensure that we recruit sufficient individuals so that assumptions of the statistical tests to be used remain robust. As long as the minimum number (n=50) are recruited into each group, analysis of outcomes will not be affected. Records of the daily discharge numbers during the trial period will, however, be used during analysis in order to identify any potential influences on results.

Attrition is likely due to a number of factors including death, lack of opportunity to collect all data or participant drop out. Attrition rates will be assessed as data collection progresses, allowing for necessary adjustments in sample size. With an average of one hundred overall unit discharges per month, and by using an over recruitment strategy, a six month intervention period should enable enrolment of at least the minimum number required.

Inclusion criteria

- Adult patients and family members (>18 years)
- Elective or emergency admissions who have been in critical care for at least 72 hours
- Critical Care patients identified for discharge to a general ward setting

- Elective discharges between 08.00-20.00hrs Monday to Friday

Exclusion criteria

- Patients for whom active treatment has been withdrawn
- Inability to verbally communicate in or read English
- Involvement in the phase I focus group study

All critical care and ward nurses (from wards who have received patients discharged from critical care during the study period) will also be invited to participate in part of the study, in order to determine the feasibility of the intervention in real world practice.

Implementation

Preparation

A series of staff training and information sessions will be provided, and all critical care nurses will be encouraged to attend. Details of the intervention and the attention control will be given and instructions provided as to how they should be utilised. A research assistant will be present throughout the recruitment and intervention period to provide ongoing support and instruction.

Randomisation and recruitment

The statistician will provide a computer generated list of random numbers, which will be used to determine the days on which the intervention, control or 'attention control' methods will be used. A clerical assistant will make up three separate types of sealed information packs labelled with the dates that each is to be used. These packs will be left in the clinical area and their distribution co-ordinated by the research assistant.

The research assistant will screen patients due for discharge from critical care on a daily basis by liaison with the nurse in charge. Those who meet the inclusion criteria will be invited to participate and provided with a participant information form and verbal study information (this will be carried out either by phone or during visiting for

family members). Only one identified family member from each patient will be recruited into the study.

Consent

No less than 4 hours after receipt of the participant information sheet, the research assistant will seek patient consent. Only after consent has been obtained will they be recruited into the study. Capacity to provide informed consent will be determined by the research assistant (who holds a professional healthcare registration) using the MacArthur Competence Assessment tool for clinical research (MacCAT-CR) (Appelbaum and Grisso, 2001). If patients are unable to provide informed consent prior to critical care discharge, advice will be sought from a personal consultee. If a personal consultee is not available, a member of care staff unconnected to the project, who is most likely to know what the individual might have chosen had they retained capacity, will act as the nominated consultee in the event of no personal consultee being available (Code 9 of Mental Capacity Act). Assessment of capacity and consent will be repeated prior to data collection. Any data already collected from those who refuse consent at this point will be discarded.

Delivery of intervention

Recruited participants (patients and relatives) will be clustered by day of patient discharge, with all those identified for discharge on the same day (and their relative) allocated to receive either the intervention (UCCDIP), control (usual information strategy) or 'attention control' (discharge booklet) information delivery method. The research assistant will ensure the appropriate information pack is selected and will assist bedside nurses to use it correctly. The research assistant will also record the number of discharges from the unit on each weekday during the trial period, and any potential cross contamination.

Data collection

The data collector will assist recruited patients and family members to complete the HADS, coping, self efficacy and empowerment assessments after one week on the general ward, and again at one month or on discharge from hospital, whichever is sooner. User experience questionnaire data will also be collected from participants at

the one month/hospital discharge point. The data collector will be blinded to the group into which participants have been randomised. At the end of the trial period, feasibility questionnaires will be placed in the post trays of all nursing staff in critical care and on wards where patients participating in the study have been discharged. A box for posting completed questionnaires will be provided in each area.

The research assistant will access databases and patient notes in order to record relevant retrospective and prospective information throughout the trial period as detailed above.

Withdrawal

All recruited participants who withdraw will be followed up (where possible), and with their consent, reasons for withdrawal and any data collected up to the point of withdrawal will be included in the final analysis.

Data analysis

Objectives 1 and 2:

Groups will be compared in terms of HADS, length of hospital stay after critical care discharge and other similar measures. Techniques used will include Analysis of Variance (ANOVA) with co-variates as necessary, and with possible transformation of the data, for example ranking. For binary measures such as readmission to critical care rates, logistic regression will be considered. A number of concomitant variables, from both patient and relative data, will be drawn from the hospital database, patients' medical records and relative questionnaires and will inform the above analyses.

The goal will be to determine what effects (if any) the intervention has had, and how consistent any effects have been. This data will then inform the power calculation to determine the necessary sample size for a phase III trial. Maintenance of time records will enable checking for any drift over time induced by any of the interventions.

Different group sizes will NOT 'skew' the results. Except in laboratory studies (and not always then) equal sample size is impossible; such a requirement would invalidate most research. We will be comparing averages or typical values and all tests standardise against varying sample size. Sample size does affect the power (or sensitivity) of the test, it is not so much the total sample size that matters but the minimum. We have included in our method a strategy of collecting data until each group has at least 50 to ensure that we will have sufficient power. It is preferable (in terms of effort) and fortunately unlikely that the larger group will be much larger than 50. While equal sample sizes are desirable they are not necessary; the tests will continue to correctly assess the p-value

Records of the daily discharge numbers during the trial period will be used during analysis in order to identify any potential influences on results, and the notes kept by the research assistant detailing any potential cross contamination will also be collated and reported.

Objectives 3 and 4:

Categorical variables, from the feasibility and experience questionnaires, will be examined using cross-tabulation and chi-square, and if necessary log-linear modelling. Qualitative data from the free text section of questionnaires will be collated, coded, categorised and key themes identified. Nvivo7 will be used to assist this process.

Dissemination

A lay summary of study findings will be prepared and sent to all participants before their personal details are destroyed. Information about and consent for this is included in the participant information sheet and on the consent/assent forms.

Findings from this study will be used to refine and amend the intervention being studied before further evaluation using a larger multi-site phase III trial takes place. It will also provide data, which will inform the power calculation to determine the necessary sample size for a phase III trial. This should ensure that such a complex intervention is more likely to be effective at this point.

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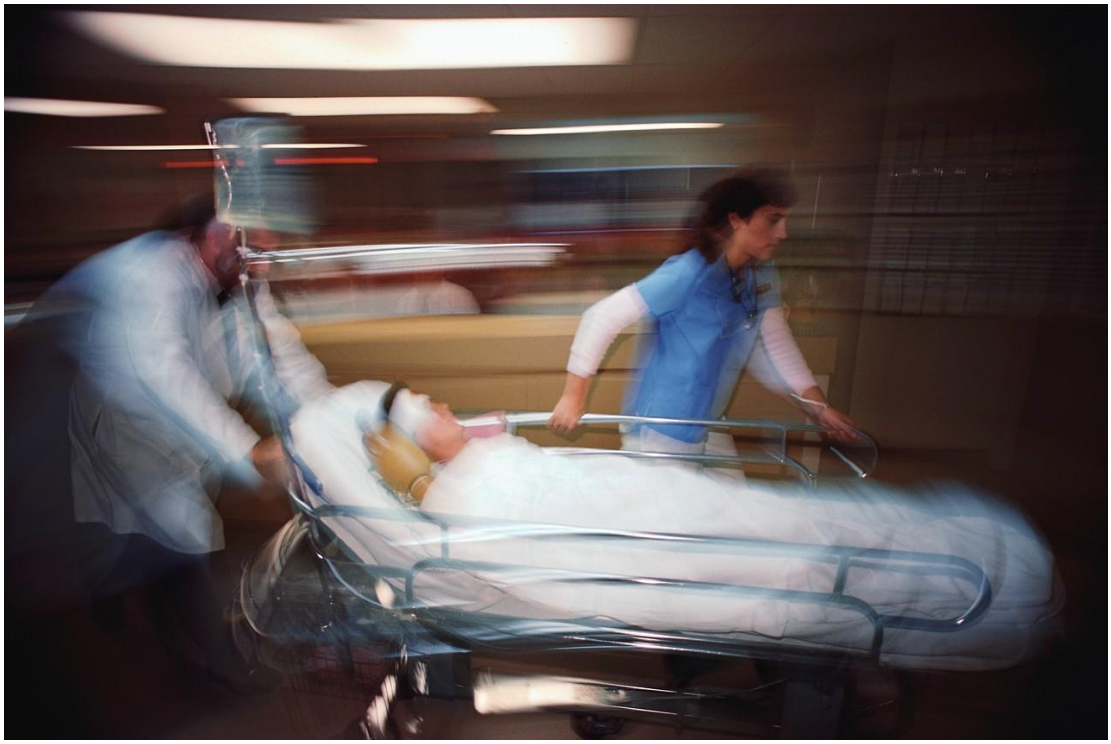
Critical Care Discharge Information



Information for patients and relatives during and immediately after discharge to the ward

KING'S College LONDON

Critical Care Discharge

Information for Patients

Information for Patients

This information has been designed to support you when you move from critical care to a general ward. Everyone is different. This pack will help you to identify your own individual needs and get the information you require to support your recovery whilst on the ward.

Name:.....

Why was I in critical care? What happened to me?

Completed by:.....**(Print name and position)**

Date of discharge from critical care:.....

Ward:.....

Name of Ward sister/Charge Nurse:.....

Ward Tel no:.....

What else do I want to know?

Read through the following pages and write down any questions you have in the sections provided (or ask someone else to). Show this to the nurses, doctors, physiotherapists and other staff looking after you. They will be able to discuss these issues with you in more detail.

You can ask anything you want to know.

NO question is too trivial or too basic.

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Before discharge to the ward

Am I ready for discharge?

Being discharged from critical care is a positive step, but you can feel scared leaving the staff you have got to know and a place which is familiar. You may not feel ready and may still feel very unwell.

An experienced team of doctors, nurses and other health care staff will have made the decision that you no longer require such intensive monitoring and nursing. Ward nurses and doctors will be given a handover from the critical care team to enable them to continue your care.

If you feel concerned about the decision to move you to a general ward, you should tell this to the nurse or doctor who can discuss it with you further.

When will I go to the ward?

You might not be told which ward you are going to until a short time before and things can change quickly. Occasionally discharge to the ward can happen during the night, but this is avoided wherever possible. If there are delays in organising beds on the ward you may be taken off some of the monitoring as you will no longer need such high level observation.

Who will go with me?

A nurse from the critical care unit will help you pack your things, inform your family and will go with you. This is usually your bedside nurse. A porter will also usually come to help. Sometimes a nurse from the ward will also visit you on the unit before your discharge and may accompany you to the ward.

What ward am I going to?

This should be written on the front of this booklet. If you cannot find it please ask the nurse caring for you. Ask what type of ward it is.

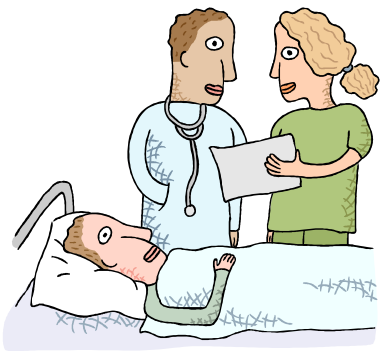
What will it be like on the ward?

Many wards have information booklets explaining who the staff are, visiting times and how the ward works.
Ask for a copy when you get to the ward.

You could be in a bay with up to 8 other people of the same sex as you. The wards also have smaller bays and single bedded rooms. There will be less equipment than in critical care. Other patients may be able to talk to you, but the ward can be noisy and you may find this disturbing at first.

Each ward nurse will be looking after a group of people, assisted by a number of health care support workers. Even though you may not always be able to see a nurse you can contact them by pressing the call bell. Ask the nurse to leave it within your reach and press it if you want any help. You may have to wait for a short time if the nurses are busy with other patients. This can make you feel neglected or deserted. This isn't the case. You are being looked after. It is just that the level of care is different compared to critical care.

Staff on the ward will encourage you to become more independent. It can feel like they are asking too much of you, but it is an important part of your recovery.



The ward staff will be given a handover from the critical care team, but they may also ask you and your family some questions.
This is not because they do not know what is wrong with you, but because they need to get to know you as a person and plan your ongoing care.

Concerns about going to the ward

Use this section to write down any questions or worries you have about going to the ward and show it to your bedside nurse. Record any advice/information given. Ask your family or the nursing staff to help you complete it if you feel unable to do so alone.

Question/Concerns I have
Answers to my questions

On the Ward

Recovery is different for everyone. Information about some of the most common worries can be found on pages 12-18. You might find it useful to read through these. Most worries are temporary and will return to normal with time. **You may have some, all or none of these.** You may also have other worries.

What should I do if I am worried about anything?

The first thing you should do is tell the nurse looking after you and/or the nurse in charge of the ward. You can also tell the doctors or any other health care staff when they come to see you.

Write down any questions or concerns you have on pages 19-25 (or ask someone else to). Show these to your nurse, doctor, physiotherapist or other available health care staff. Ask them if there are some things you can do to help with your worries. Your family could also help with this. Together, you can work out what you can all do to make you feel better.

You can also talk to your relatives/friends if you are concerned about anything and ask them to speak to the nurse in charge and/or doctor on your behalf.

Your recovery from a critical illness

You have been very ill and you need to give your mind and body time to recover. The suggestions below may help your recovery. Do them as and when you feel ready for them.

What can I do to help my recovery on the ward?

1. Recognise the progress you have made

Some people find the following useful:

- *Looking at any pictures of you that may have been taken in critical care. Ask the staff or your family if any were taken*
- *Reading and talking about what happened to you in critical care. Ask the staff or your family if a diary of your time in critical care was kept*
- *Keep a daily diary of your feelings whilst on the ward (page 23)*

2. Set yourself short term, realistic goals

Achieving small things each day will help improve your confidence and morale. Write down your goals on pages 17-18. Ask the staff what their goals for you are, and discuss with them how you are doing.

3. Listen to your body

Remember, you have been seriously ill and recovery will take time. Go at your own pace, guided by the health care staff. Do not judge yourself against how others are doing, as everyone is different and people are in hospital for lots of different reasons. Ask if you have any concerns.

4. Have a positive mental attitude

Each day try and think of one positive thing. If you cannot think of anything ask the staff or your family/friends to help.

5. Talk to family/friends and staff

Don't bottle things up. Share and discuss your feelings and concerns. Use the sections on pages 17-18 to help with this.

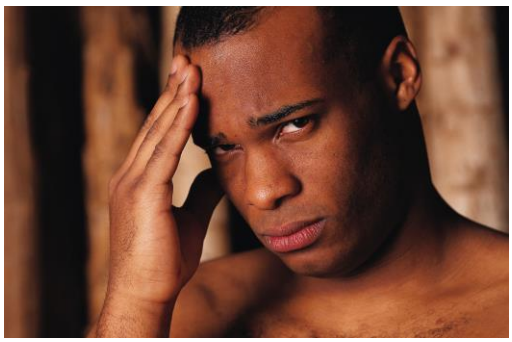
6. Exercises to aid recovery

You could try to do some of the exercises described on page 21. Do as much as you can and rest when you need to.

What common emotional worries might I have?

Feeling scared and anxious/ panic attacks/phobias/ loss of confidence

The first few days and weeks on a ward may not be easy and you may feel frightened, insecure, anxious and stressed (dry mouth, rapid breathing, fast heart beat, cold sweats, butterflies in the stomach).



You might be worried about getting ill again and might feel frightened if you have been told that you nearly died. You might also feel scared about being in an unfamiliar environment and being expected to do more for yourself.

You may have lost your confidence and might try to avoid things that make you feel scared. These are all normal feelings. For most patients, as time progresses your confidence will grow and return to normal.

Difficulty understanding what has happened

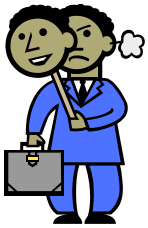
You are not alone. Many people are unable to remember all of their time in critical care. You have been seriously ill and may have been given strong drugs which made you sleepy. Coming to terms with what has happened can take time and you

may never remember everything. Everyone's experience is different and individual to them.

You may find that you cannot concentrate on anything for long and keep forgetting what you have been told. This should get better as you continue to recover.

Mood changes

It is normal for your mood to change often. One moment you may feel good and the next you may feel down or very tearful.



You may feel irritable for no specific reason, and you may feel depressed for some time. You might also feel restless, fidgety, unsatisfied, have racing thoughts or lose your sense of humour. These are normal reactions to being seriously ill. They are not permanent changes in you and will subside with time. You may also feel frustrated if it seems like you are not progressing, but remember you have been very ill and you need time to recover.

If you smoke or normally drink a lot of alcohol then you might also feel irritable due to nicotine or alcohol withdrawal.

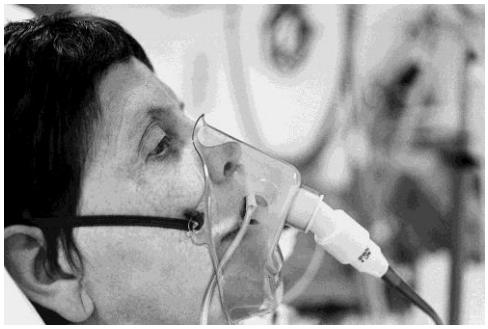
Hallucinations/Flashbacks/Paranoia/Sleeping problems

You may have flashbacks and memories of disturbing or strange experiences. These are often 'unreal', but can be very vivid and frightening. You may also suffer from bad dreams or nightmares. These experiences are common and are related to your illness and the strong drugs you may have been given in critical care. They usually settle after a few days or weeks.

You might also find it difficult to fall asleep or you may wake frequently during the night. This might be because the ward is noisy, but your sleep pattern may also have been disrupted whilst you were in critical care. Being awake at night can be worrying and things easily seem to get out of proportion. Your sleep pattern will improve as you become more active during the daytime, but if you are concerned, talk to the ward staff.

What common physical problems might I have?

Changes in appearance, senses and voice



You may feel worried when you first look in the mirror as your appearance may have changed due to the effects of your illness.

You may look thinner and you may have lots of marks, bruises and scars on your body because of the various tubes, drips and injections used in critical care. The quality of your hair or nails may have changed and you may also experience some hair loss. You might also find that your skin feels itchy and drier than before.

You might also notice changes to your senses. For example, your hearing might be slightly worse or more acute, your vision might be affected and things that touch your skin can feel strange for a while. You might also experience dizzy spells due to an altered sense of balance.

Your throat may be sore if you have had a breathing tube in, and your voice may be weak and sound different. If you still have a tracheostomy tube, you may not be able to speak until it is removed.

These changes are usually temporary and most will disappear over time.

General weakness/Lack of energy/Poor mobility

You will probably have lost weight and your muscles may be weak and your joints stiff from being in bed. You may also have generalised aches and pains, feel exhausted and have no energy. The slightest activity may make you feel very tired. This is normal after a serious illness.

Your muscles have not been working for a while and will need time to build up their strength again.

You may experience difficulty in doing things which require fine movement such as fastening buttons, writing, holding cups etc. This means you are likely to still need some help with personal care such as eating, dressing, washing and walking. This should slowly improve.

Breathing problems

You may feel breathless at times, particularly when you are doing anything. Even talking can make you feel short of breath, and you might need some oxygen which will be given through a mask. You might also find it difficult to cough due to muscle weakness. These problems should improve over time, but may not completely resolve, depending on your condition.

Whilst in critical care you may have had a tube in your throat to help your breathing (a tracheostomy), and you may still have this on the ward. It will usually be

removed after a few days/weeks once you are able to breathe effectively on your own. The hole it leaves will gradually close. There will be a scar which will slowly fade and become less obvious.

Eating and drinking problems

You may be having food through a tube in your nose which goes down to your stomach, or by a drip straight into your vein. This is unlikely to be permanent and will be removed once things return to normal.

Food can taste very salty, sweet or have a metallic taste

You may be given nourishing yoghurts, drinks and food supplements to help build up your strength

When you first start eating and drinking again, food/drinks may taste different until your taste-buds readjust. You may not feel hungry, your mouth may be sore or it might hurt to swallow. These problems can be caused by the strong drugs you may have had. You might also develop a thrush infection (candida) in your mouth (a thick white coat over the roof of your mouth and tongue). This can make your mouth very sore. Your mouth can also feel very dry due to a lack of saliva. If you wear dentures, you may find that they no longer fit well, as your gums may have shrunk.

These problems are rarely permanent.

Going to the toilet

You may still have a tube in your bladder (a catheter) which drains urine from your body into a bag. This is so that staff can check your fluid levels. When the tube is taken out, your muscles may be weak for while so you may find it difficult to control your bladder. Sometimes, the medicines you are on can also change the colour of your urine.

You may develop a urine infection. Symptoms of this include not being able to pass urine, or passing very small amounts frequently. You might also have a burning pain whilst urinating and/or blood in your urine. Any such symptoms should be reported to the nurse or doctor caring for you.

Your bowels might also be upset for a while, but things should gradually return to normal.

You might have bloating, diarrhoea or feel constipated.
You might need some medicines to help you go to the toilet.

Concerns about my recovery

Use the following pages to record any questions or worries you have about your recovery, and any goals you have set or agreed with the staff. Ask your family or the nurses to help you complete it if you feel unable to do so alone.

Week 1 (Date……)

Question/Concern I have
What I can do?

Week 2 (Date……..)

Question/Concern I have

What I can do?

Week 3 (Date……)

Question/Concern I have

What I can do?

Week 4 (Date……)

Question/Concern I have

What I can do?

What support will I get on the ward?

In addition to the ward nurses, health care assistants and doctors, many other health care professionals may contribute to your recovery. They include:

- **Critical care outreach team/Discharge liaison nurses**

  These are nurses from critical care whose role it is to check that recovery is going as planned. Sometimes, they are available to talk to patients about their critical care experience

- **Physiotherapists**

  Physiotherapists help with getting you moving again and increasing your strength. They can also assist with coughing and breathing

- **Speech and Language Therapists**

  They may see you if you have any speech or swallowing problems

- **Dieticians**

  Dieticians can give advice on diet and any necessary food supplements

- **Occupational Therapists**

  Occupational therapists help prepare people for going home. They can provide assistance with improving skills such as dressing, cooking etc

- **Chaplains**

  Support for different faiths is available. If you wish, they can talk to you and help support your religious/spiritual needs

- **Volunteer staff**

  Some areas have volunteers who are available to sit and talk with patients, provide reading materials, and help with simple tasks

- **Specialist support**

  As a result of your illness there may be temporary or permanent changes, which you have to adapt to, which can be difficult. Staff specialising in your condition can offer specific advice on rehabilitation. There may also be a charity for your specific illness or injury which can provide additional information and/or support.

Useful contacts

- Patient Advice and Liaison Service (PALS). They can offer general support and advice about being in hospital. Contact details can be obtained from the ward receptionist
- Chaplaincy: all hospitals have multi-faith support and ward staff can arrange for the appropriate person to be contacted

If you feel well enough, you could ask if there is any access to a computer on the ward or if your family can bring you a laptop. You can then look at some of these useful websites as and when you feel ready:

- ICUSteps website. A charity set up by former intensive care patients and their family members. Includes information such as 'Intensive Care: a guide for patients and relatives', plus experiences of former patients and family members, and links to support groups: www.icusteps.org
- DIPEx-Database of Individual Patient and Relative Experiences: www.healthtalkonline.org
- I-Canuk: A professional and independent national organisation which contains important publications and guidance documents, and links to patient experiences and information support: www.i-canuk.com.

There are also many charities set up for specific injuries and illnesses, which can provide support and information. Ask the nurses about those which might be relevant to you. You could also ask your relatives to look into relevant charities for you, either on the internet or at their local library.

Exercises

These exercises are designed to help you regain the strength that you may have lost during your illness.

- Take a deep breath through your nose and out through your mouth. Repeat 3 times
- Pull your toes up, down and round in a circle. Repeat 10 times
- Keeping your leg straight, pull your toes upwards, count to 5 then relax. Repeat on both legs 10 times
- Bend your knees and put both feet flat on the bed. Roll both knees together to the right keeping your shoulders still. Return your knees to the middle and repeat to the left. Repeat 10 times
- Place a rolled up towel under your left knee. Pull your toes upward and lift your lower leg off the bed. Hold for 5 seconds. Repeat 10 times on both legs.
- Stretch both arms out in front of you. Touch your nose with your outstretched hand, then straighten. Repeat 10 times on both arms
- Turn your head to look over your left shoulder, back to the middle, then turn to look over your right shoulder. Repeat 10 times
- Bend your head and try to touch your ear on your left shoulder, keeping your shoulders still. Repeat on the right. Repeat 10 times
- Take both arms out to the sides with your elbows straight. Circle your arms forward 10 times and backwards 10 times.

Do as much as you can.

Rest when you need to

Acknowledgements

This information pack has been produced by Suzanne Bench of the Florence Nightingale School of Nursing and Midwifery, King's College, London.

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Reflective Diary

This diary can remain private to you or it can be shared with the nurses so they can help with any concerns. Write down how you feel each day. It might help to look back after a few days and see if things are improving.

Day/Date	How do I feel today?

Day/Date	How do I feel today?

Critical Care Discharge

Information for Relatives

Information for Relatives

Who is this booklet for?

This information is designed to support you during and after your relative leaves critical care to go to a ward. Everyone is different. This pack will help you to identify your own individual needs and get the information you require whilst your relative is on the ward.

We realise that close relationships come in many forms and that our closest relationships are not necessarily with someone traditionally classified as a 'relative'. For the sake of simplicity we use the term 'relative' throughout but realise that for many people terms like 'friend', 'partner', 'loved one' would be more appropriate.

What do I want to know?

Read through the following information:

Page 3-6: Before discharge
Page 7-11: Helping recovery on the ward
Page 12-18: Questions and concerns
Page 19-22: Looking after yourself
Page 25-29: Diary pages

Write down any questions, worries or concerns you have in the sections provided. Show this to the staff looking after your relative who will be able to discuss these issues with you in more detail.

You should also read the information pack given to your relative. You might like to read sections of it to your relative as they may be unable to read it themselves.

You can ask anything you want to know.

NO question is too trivial or too basic.

Before discharge

Is my relative ready for discharge?

Having a relative discharged from critical care is a positive step but it can make you feel scared leaving the staff you have got to know and a place where you feel your relative is safe. You may have developed close relationships with the nurses and doctors in critical care, and the technology and monitoring may have made you feel secure. You may not feel that they are ready to leave.

An experienced team of doctors, nurses and other health care staff will have made the decision that they no longer require such intensive monitoring and nursing, but if you feel concerned about the decision, you could speak to the nurse or doctor.

When/Where will my relative go?

Details of the ward your relative is going to can be found on the front of their information pack. We may not know this information until a short time before discharge, and things can change quickly. Sometimes there are delays in organising beds on the ward. This can mean that discharge sometimes happens during the evening or overnight, although this is avoided wherever possible.

The bedside nurse should keep you informed, but sometimes your relative may be discharged more quickly than planned. A full handover of care will always be provided to ward staff both day and night.

Will my relative be looked after on the ward?

There will be nurses and doctors on the ward, but they will be caring for other patients as well, and may not be visible at times.

You may feel neglected or worry how your relative will cope with this change. You should be reassured that your relative has been discharged to the ward because they are getting better and need less support.

Staff on the ward will encourage your relative to become more independent. This is an important part of their recovery plan, but may feel difficult at first.

The ward doctors will be given a handover from the critical care team, but they may also ask you some questions. This is not because they do not know what is wrong with your relative, but because they need to get to know them as a person and plan their ongoing care.

Visiting times in a general ward may not be as flexible as in critical care. Many wards have information booklets which explain who the staff are, visiting times and how the ward works. Ask for a copy on the ward.

On the ward

What can I do to help my relative's recovery?

Read the information together

It may be helpful to read sections of the patient information pack to your relative. It is likely you will need to repeat the information at other times as they may not be able to remember it. Help them complete the sections detailing their worries, concerns and feelings.

People respond differently to a stay in critical care. Some people want a lot of information and some do not want to know anything. You will know your relative best and can help them to get the individual information that they need
Your relative may not understand how ill they were. Talk to them about what happened, and how they are feeling. You may need to tell them about their injury/illness and treatments in stages or when they ask for more information.

They may be unable to remember the last few days/weeks. If they are ready to, help them fill in the gaps and piece together their time in critical care. You may have kept a diary of their stay, which you can discuss with them.

They may still feel very ill, feel they are not getting any better or not understand how ill they have been. Looking back will help them recognise the progress they have made.

Encourage independence

It is natural that you might feel over protective and want to help your relative as much as you can. However, it is important that they now start to regain their own

independence and you should, therefore, encourage them to do as much for themselves as they can.

Help them set realistic short term goals for recovery. Bring in personal items for them that will help them to regain their independence. For example, own clothes, toiletries, glasses, hearing aid, dentures.

A personal music player or laptop with headphones can also be useful and will help them to occupy their time.

Recovery for a critical care patient

Now your relative is in the general ward you may expect them to be happy and relieved that they are getting better and that they survived their illness or accident. However, they may act differently from what you expect.

They may be depressed, anxious, upset, irritable and/or unmotivated. They may still be very confused from all the strong medicines they have taken.

These are all normal reactions, but can be difficult for relatives to deal with. Remember, your relative has been through a huge ordeal, and it can take a long time for them to recover physically and mentally.

You may also find it hard if they cannot understand what you have just experienced as a relative of someone in critical care, and what it was like for you to see them so ill.

Try not to expect too much. It may be useful for you to think back and see that they are making progress, even if it is very slow.

I have questions, where can I get answers?

You might feel like you want to go back to the critical care unit to speak to the nurses and doctors that were looking after your relative. This is natural, but they will not necessarily have an updated knowledge of your relative's condition after discharge as they will have handed care over to another team of doctors.

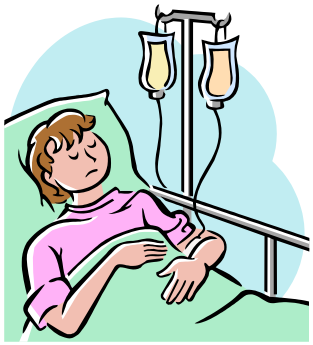
The first thing you should do is read through this information pack, and the information given to your relative. Talk to the nurse looking after your relative and/or the nurse in charge of the ward.

Although the ward nurses may be unable to give detailed ongoing explanations of each change in your relative's condition, they can arrange for you to speak to a doctor for an update if necessary. You can also ask to talk to the doctors or any other health care staff when they come to see your relative.

The ward can be busy. It may not always be possible to speak to a doctor on the same

Write down your questions and concerns on pages 15-17 of this information pack. You can also record here any advice you are given.

What if I am really worried that their condition is getting worse?



If you think your relative is becoming seriously ill, you should ask to speak to someone urgently. If you remain concerned you should ask the ward nurses to contact their seniors, and the doctors, who may not reside on the ward. If possible you should remain with your relative until someone has seen them, and an action plan has been agreed. The Patient Advice and Liaison Service (PALS) may also be able to help. Ask the ward receptionist how to contact them.

Questions/concerns

Question/Concern I have

Advice/What I can do

Question/Concern I have

Advice/What I can do

Looking after yourself

Having a relative who has been critically ill is extremely stressful and you may feel both physically and emotionally exhausted. You may not have been eating or sleeping well, and you may also feel under pressure to support other family members and to maintain a normal life outside of the hospital. If you have young children, they might also be acting differently, and may need more attention than normal. Feelings of guilt, worry or depression are common at this time, particularly if you were afraid that your relative might die or feel that they are still too ill to be going to a ward.

You might also have money worries or concerns about your job

It is important that you share your feelings and devise strategies for coping. Try to ask friends and family to support you at this early stage of recovery–you may need as much or more help now even though your relative is out of critical care.

Use the diary on page 25 to record your thoughts and feelings. Discuss these with family and friends. You might also want to contact your own General Practitioner for further advice and support. Some of the organisations listed on pages 21-22 could also be of help.

Useful contacts

- Patient Advice and Liaison Service (PALS): contact details can be obtained from the ward receptionist
- Chaplaincy: all hospitals have multi-faith support and ward staff can arrange for the appropriate person to be contacted
- ICUSteps website. a charity set up by former intensive care patients and their family members. Includes information such as 'Intensive Care: a guide for patients and relatives', plus experiences of former patients and family members, and links to support groups: www.icusteps.org
- DIPEx: database of individual patient and relative experiences:www.healthtalkonline.org
- I-Canuk: a professional and independent national organisation which contains important publications and guidance documents, and links to patient experiences and information support: www.i-canuk.com.
- UK Debtline: call free on 0800 731 7973. www.national-uk-debtline.co.uk
- Samaritans: provides confidential, unbiased emotional support, 24 hours a day, for people who feel distressed, desperate or suicidal. Helpline: 08457 909090. www.samaritans.org. Email: jo@samaritans.org
- British Association for Counselling and Psychotherapy: for details of counsellors and psychotherapists in your area call: 0870 443 5252. www.bacp.co.uk
- Princess Royal Trust for Carers: the largest provider of support services for carers in the UK: Tel; 0844 800 4361. www.carers.org

There are many different charities set up for specific injuries and illnesses which will be able to provide support and information. You could look for relevant charities on the internet or at your local library.

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Reflective Diary

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Date	How do I feel today?

Date	How do I feel today?

Date	How do I feel today?

If this has been helpful why not start your own diary or continue on the back pages of this pack

Please add any additional information here

Day/Date	How do I feel today?

If this has been helpful, why not start your own diary or continue on the back pages of this information pack

Please add any additional hospital/department specific information here