are at greatest risk and thereby ameliorate at least some of the patient-specific damages of air pollution.

Dr. Dockery reports receiving a stipend from Industrial Economics for participation in an expert-opinion study. No other potential conflict of interest relevant to this article was reported.

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The Healing Power of Listening in the ICU

Craig M. Lilly, M.D., and Barbara J. Daly, Ph.D, R.N.

Critical care services are highly valued because they can often restore function in patients with acute life-threatening illnesses. In this context, advances in medical science have led to increased expectations for favorable outcomes of episodes of critical illness, even when the patient has severe coexisting chronic disease. The growing demand for critical care has led both to increased numbers of patients who survived with desirable functional outcomes and to increased numbers of patients who die in the intensive care unit (ICU). Today, many deaths in the ICU occur after a decision has been made to discontinue or forgo advanced supportive technology.1 Decisions to shift from apparently ineffective technology to a treatment plan that focuses primarily on the patient's comfort are usually made in discussions between caregivers and family members.² These discussions involve complex conversations and are important to families. Communication processes that have been shown to improve the well-being of patients and family members include proactive, multidisciplinary sessions that provide patients (when they are able to communicate) and family members with the opportunity to ask questions, articulate the patient's values, express painful emotions, discuss concerns, and obtain help with managing feelings of guilt.³

A clinical course that runs counter to the family's hopes and expectations is extraordinarily stressful and is an important contributor to ICUrelated post-traumatic stress disorder (PTSD) among families.4 A better understanding of how intensive care clinicians can support families as they make the transition from a goal of cure to one of comfort and acceptance of death is clearly needed. Recognition of the relationship between satisfaction, on the one hand, and expectations, perceptions, and prognosis, on the other hand, can lead to communication processes that synchronize the perceptions of family members with those of providers and close gaps between reality and expectations. Curtis and colleagues have described some of the components of a system of communication that is being increasingly recognized as an effective means of promoting harmony between critical care providers and families.5 This five-part system, known by the mnemonic VALUE, includes the following elements: valuing and appreciating what the family mem-

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bers communicate, acknowledging their emotions by using reflective summary statements, listening to family members, understanding who the patient is as a person by asking open-ended questions and listening carefully to the responses, and eliciting questions from the family more effectively than by simply asking, "Any questions?" A key skill is listening more and talking less.6 Structured, proactive, multidisciplinary communication processes7 that are supported by ethics consultation⁸ and palliative care teams⁹ and include bereavement conferences that encourage providers to use a structured approach (such as the VALUE system) for guiding effective communication during critical care¹⁰ are the foundations for improving end-of-life care for patients and interactions with their families.11

The importance of understanding how to use effective communication to improve end-of-life care is increasingly supported by randomized intervention studies - such as the study by Lautrette and colleagues reported in this issue of the Journal¹² — that meet most of the accepted standards of good clinical science. Lautrette et al. found that formal bereavement meetings held at the time that the senior physician had concluded that death was inevitable improved the well-being of family members, as measured by validated instruments. This study is groundbreaking in its demonstration of a statistically and clinically significant improvement in symptoms of anxiety, depression, and PTSD among family members, and it shows that expanding the focus of critical care to include family-centered outcomes is appropriate and desirable. In reporting these advances in the peer-reviewed literature, it is often difficult for authors to fully explain the core of their interventions, in part because of the complex, diverse, and emotion-laden nature of these multidimensional conversations.

Although the amount of time spent listening in an individual case will be driven primarily by the medical facts and the needs of the persons facing loss, the study by Lautrette and colleagues¹² suggests that spending an average of 30 minutes (or 10 minutes longer than typical practice) with the patient's family members leads to a significant improvement in their well-being in the months after their loss. Since there is substantial variation in the frequency of deaths, depending on the size of the ICU and the mortality rate of the population served, the fraction of time caregivers spend to help families manage the critical illness and death of a loved one will vary. On the basis of our research, we propose that the time clinicians working in adult ICUs spend supporting family members in shared decision making should roughly correspond to the mortality rate of the ICU patient population. For example, a full-time clinician serving a surgical ICU with a mortality rate of 2% would spend about 2 hours a week supporting patients and families. The same clinician would spend about 2 hours per day supporting families when serving a medical ICU with a mortality rate of 20%.13 When used effectively, this time can translate into considerable savings in costs by reducing the number of days a patient spends in the ICU before death¹³; the time spent with families thus deserves support for compelling economic as well as humanistic reasons.

Recommendations to improve care for patients dying in ICUs are rooted in both observational and interventional studies. Observational studies confirm our own practical experience that nearly every American family will be affected by the loss of a loved one in an ICU and that the effect of this loss can be mitigated by high-quality care. The field has been advanced by interventional studies showing that proactive communication processes, including intensive communication¹³ as well as ethics8 and palliative care9 consultations, improve outcomes. Evidence that proactive multidisciplinary conferences in which care providers and family members address bereavement, with the provision of printed materials, is another important advance in the field of end-oflife care in the ICU. All providers of critical care should receive training that will allow them to offer the kind of support that they would want if they had a family member who was facing death in an ICU.

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Pay for Performance at the Tipping Point

Arnold M. Epstein, M.D.

It is hard to dispute the rationale behind realigning payment incentives in health care to encourage higher quality and more efficient care. Indeed, across the country and beyond, the number of "pay for performance" programs, as such realignment is called, has reached a tipping point. In the United States, more than half the health maintenance organizations (HMOs) in the private sector have now initiated such programs, covering more than 80% of the country's HMO enrollees.¹ Congress has mandated that the Center for Medicare and Medicaid Services (CMS) develop plans to introduce a pay-for-performance program into Medicare.² The British have gone a league further, introducing their own version of pay for performance that puts 25 to 30% of the income of family practitioners at stake.3

Because the rationale behind pay for performance is so compelling, it may seem surprising that the evidence base linking such programs to a better quality of care is thin (at least, according to two recent review articles^{4,5}). Most previous studies have looked at incentives to physicians and medical groups. The data showing efficacy are inconsistent, and some studies have revealed unintended effects, such as improvement in documentation without much change in the underlying quality of care.⁶ Only one previous study examined cost-effectiveness.⁷

Given this dearth of solid evidence, it seems apt to compare our adoption of pay for performance with our adoption of new surgical procedures or medical therapies. Many of my clinical colleagues would insist on hard evidence documenting efficacy before endorsing a new therapeutic approach. They cite sobering stories of what can happen when we introduce new approaches prematurely. Consider, for example, the numerous surgical procedures or medical therapies including radical mastectomy for women with early-stage breast cancer and hormone-replacement therapy for postmenopausal women ---that were diffused widely before solid evidence of their relative efficacy was available, only for us to learn later that they were, at best, no more effective than alternative therapies or, at worst, harmful.8-10 If pay for performance were a therapy, its rapid diffusion thus far would have to be considered premature.

The study by Lindenauer et al.¹¹ in this issue of the *Journal* begins to address this information gap on pay for performance. The authors report the initial results of a 3-year program in which more than 200 hospitals participating in a quality-benchmarking database maintained by Premier volunteered for a Medicare demonstration in which payments would be allocated partially on the basis of quality performance. Hospitals performing in the top decile received a 2% increment in Medicare payments, whereas hospitals in the second decile received a 1% increment. Hospitals that underperformed by failing to exceed the performance of hospitals in the lowest two deciles (as established during the program's first

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ORIGINAL ARTICLE

A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU

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ABSTRACT

BACKGROUND

There is a need for close communication with relatives of patients dying in the intensive care unit (ICU). We evaluated a format that included a proactive end-of-life conference and a brochure to see whether it could lessen the effects of bereavement.

METHODS

Family members of 126 patients dying in 22 ICUs in France were randomly assigned to the intervention format or to the customary end-of-life conference. Participants were interviewed by telephone 90 days after the death with the use of the Impact of Event Scale (IES; scores range from 0, indicating no symptoms, to 75, indicating severe symptoms related to post-traumatic stress disorder [PTSD]) and the Hospital Anxiety and Depression Scale (HADS; subscale scores range from 0, indicating no distress, to 21, indicating maximum distress).

RESULTS

Participants in the intervention group had longer conferences than those in the control group (median, 30 minutes [interquartile range, 19 to 45] vs. 20 minutes [interquartile range, 15 to 30]; P<0.001) and spent more of the time talking (median, 14 minutes [interquartile range, 8 to 20] vs. 5 minutes [interquartile range, 5 to 10]). On day 90, the 56 participants in the intervention group who responded to the telephone interview had a significantly lower median IES score than the 52 participants in the control group (27 vs. 39, P=0.02) and a lower prevalence of PTSD-related symptoms (45% vs. 69%, P=0.01). The median HADS score was also lower in the intervention group (11, vs. 17 in the control group; P=0.004), and symptoms of both anxiety and depression were less prevalent (anxiety, 45% vs. 67%; P=0.02; depression, 29% vs. 56%; P=0.003).

CONCLUSIONS

Providing relatives of patients who are dying in the ICU with a brochure on bereavement and using a proactive communication strategy that includes longer conferences and more time for family members to talk may lessen the burden of bereavement. (ClinicalTrials.gov number, NCT00331877.)

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HAVING A LOVED ONE DIE IN THE INtensive care unit (ICU) is an extraordinarily stressful event.¹ The patient is usually unable to communicate with the family or with ICU staff. Qualitative and quantitative studies of families in this situation² have identified effective communication between caregivers and families and support from caregivers throughout the decision-making process as important to family members.³⁻⁹

In many ICUs, an end-of-life family conference, which is rooted in findings from epidemiologic and interventional studies on communicating with families of dying patients, is an important part of ICU practice.¹⁰ In these conferences, family members and ICU staff discuss the patient's situation in a quiet room. Ideally, family members are given opportunities to ask questions, express concerns, and confront painful emotions with the help of caring, compassionate professionals.^{11,12}

Although the conference is important, the effect of its structure on bereaved family members has not been evaluated in a randomized trial. We

conducted a multicenter, randomized, controlled study to evaluate the effect of a proactive communication strategy that consisted of an end-oflife family conference conducted according to specific guidelines and that concluded with the provision of a brochure on bereavement. We hypothesized that this intervention, as compared with the customary end-of-life conference, would decrease stress-related symptoms and symptoms of anxiety and depression in family members 90 days after the patient's death.

METHODS

We conducted a prospective, randomized, controlled trial in 22 ICUs (Table 1) in France from May 2005 to October 2005. The study was approved by the institutional review board of the French Society for Critical Care, and oral informed consent was obtained from the participating families. At each ICU, one investigator was responsible for the study, which included six consecutive patients and their surrogates. On day 90, one mem-

Table 1. Characteristics of the 22 ICUs in the Study.	
Characteristic	Value
Teaching hospital — no. (%)	15 (68)
Type of ICU — no. (%)	
Medical	10 (45)
Surgical	3 (14)
Medical and surgical	9 (41)
No. of attending physicians — median (interquartile range)	6 (5–6)
No. of residents — median (interquartile range)	3 (3–4)
No. of patients per nurse — median (interquartile range)	3 (3–3)
No. of beds — median (interquartile range)	16 (12–21)
Rooms with more than two beds — no. (%)	10 (45)
Regular (at least weekly) nurse-physician meetings — no. (%)	19 (86)
Availability of bereavement brochure before study began — no.	0
Research group on end-of-life family care — no. (%)*	8 (36)
End-of-life family conferences held before study began — no.	0
Routine involvement of family members in daily care — no. (%)	8 (36)
Routine involvement of family members in decisions — no. (%)	8 (36)
No. of family-staff conflicts in 2004 — median (interquartile range)	25 (12–41)
No. of visiting hours per day — median (interquartile range)	4 (2–8)
Unrestricted visiting hours — no. (%)	5 (23)
Psychologist present in ICU — no.(%)	5 (23)

* The research groups consisted of nurses and doctors who met weekly to discuss how to improve the quality of care.

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Table 2. Characteristics of Patients and Enrolled Family Members at Time of ICU Admission.					
Characteristic	Control Group (N = 63)	Intervention Group (N=63)	P Value		
Patients					
Age — yr			0.10		
Median	68	74			
Interquartile range	56–76	56–80			
Male sex — no. (%)	37 (59)	33 (52)	0.47		
French descent — no. (%)	56 (89)	58 (92)	0.60		
Unmarried — no. (%)	15 (24)	21 (33)	0.23		
Direct admission to ICU — no. (%)	34 (54)	37 (59)	0.77		
Coexisting conditions — no. (%)					
Chronic obstructive pulmonary disease	13 (21)	13 (21)	0.99		
Chronic heart failure	10 (16)	14 (22)	0.36		
Cancer	21 (33)	12 (19)	0.10		
Cirrhosis	2 (3)	5 (8)	0.24		
Poor performance status — no. (%)	28 (44)	27 (43)	0.61		
Reason for ICU admission — no. (%)					
Acute respiratory failure	28 (44)	27 (43)	0.85		
Coma	27 (43)	25 (40)	0.71		
Shock	21 (33)	24 (38)	0.57		
Acute renal failure	11 (18)	14 (22)	0.50		
Cardiac arrest	14 (22)	16 (25)	0.67		
Simplified Acute Physiology Score — median (interquartile range)†	64 (52–76)	59 (52–81)	0.85		
Treatment needed at end of life — no. (%)					
Mechanical ventilation	56 (89)	58 (92)	0.54		
Vasopressors	42 (67)	49 (78)	0.23		
Dialysis	16 (25)	14 (22)	0.67		
Sedation	47 (75)	49 (78)	0.83		
Family members;					
Male sex — no. (%)	12 (23)	17 (30)	0.39		
Age — yr			0.48		
Median	54	54			
Interquartile range	46–64	47–58			
French descent — no. (%)	46 (88)	48 (86)	0.35		
Catholic — no. (%)	35 (67)	35 (63)	0.78		
Married — no. (%)	24 (46)	22 (39)	0.57		
Relationship to patient — no. (%)			0.45		
Spouse	22 (42)	20 (36)			
Child	22 (42)	30 (54)			
Parent	5 (10)	2 (4)			
Other	3 (6)	4 (7)			

* Indicates that the participants and their parents were born in France.

† Scores range from 0 to 163, with higher scores indicating more severe illness.

⁺ Data are for the 52 family members in the control group and the 56 family members in the intervention group who were interviewed at 90 days.

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ber of each family — either the patient's designated surrogate or the person who ranked highest in the hierarchy for surrogate decision making — was interviewed.¹³ Additional methodologic details are presented in the Supplementary Appendix, available with the full text of this article at www.nejm.org.

PARTICIPANT SELECTION AND STUDY PROCEDURES

The only criterion for inclusion in the study was the belief by the physician in charge that the patient would die within a few days. Patients young-

Interquartile range Clinicians' observations — no. (%) Family expressed guilt

Family reported successful expression of emotions

Family reported conflicts with ICU staff

Family believed that patient's symptoms were controlled

er than 18 years of age were excluded from the study, as were family members who had insufficient knowledge of French for a telephone interview. Table 2 lists characteristics of the patients and family members. Surrogates were assigned at random to the intervention or control group. In the control group, interactions between the family and the ICU staff, including the end-oflife conference, occurred according to the usual practice at each center. In the intervention group, the end-of-life family conference was held in accordance with detailed guidelines developed by

Table 3. Implementation of the Intervention and End-of-Life Care, Including Decisions to Forgo Life-Sustaining Treatments.* Control Intervention D Group Group Variable (N = 63) (N = 63)Value Implementation of intervention Family informed of decision to forgo life-sustaining treatment - no. (%) 0.99 61 (97) 63 (100) More than one family member informed of decision - no. (%) 55 (87) 58 (92) 0.55 Involvement of family in decision - no. (%) No involvement 2 (3) 0 0.15 Family members expressed patient's wishes 34 (54) 44 (70) 0.04 Family members expressed their own wishes 53 (84) 44 (70) 0.05 End-of-life conference No. of family members present 0.07 Median 3 2 2–3 2–3 Interquartile range 51 (81) 0.03 Nurse present — no. (%) 38 (60) No. of ICU physicians present 0.05 Median 2 1 Interquartile range 1-2 1-2 Duration of conference - min < 0.001 Median 20 30 Interguartile range 15-30 19-45 Total time that family members spoke - min < 0.001 13.5 Median 5 5–10 Interquartile range 8-20 0.006 Total time that nurse spoke — min Median 1 3

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0-3

13 (21)

47 (75)

61 (97)

1 (2)

0.5-5

7 (11)

60 (95)

61 (97)

1 (2)

0.01

0.03

0.99

0.95

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one of the authors at the University of Washington.^{10,14,15} Families were given a brochure on bereavement (see the Supplementary Appendix for the original French version and a version translated into English by the authors). The end-of-life conference used in the intervention group had five objectives for the caregivers, summarized by the mnemonic VALUE^{10,14,15}: to value and appreciate what the family members said, to acknowledge the family members' emotions, to listen, to ask questions that would allow the caregiver to understand who the patient was as a person, and to elicit questions from the family members. Each investigator received a detailed description of the conference procedure.¹⁰ Randomization was performed centrally in blocks of six, stratified according to the ICU, with group assignments sent in sealed envelopes to the study centers (for details see the Supplementary Appendix).

OUTCOME MEASURES

One family member per patient was interviewed over the telephone 90 days after the patient's death; the interviews took place between August 2005 and January 2006. The primary outcome measure was the score on the Impact of Event Scale

Table 3. (Continued.)			
Variable	Control Group (N = 63)	Intervention Group (N = 63)	P Value
End-of-life care			
Decision to forgo life-sustaining treatments — no. (%)	63 (100)	63 (100)	1.00
No. of days from ICU admission to decision			0.38
Median	5	2	
Interquartile range	2–10	2–14	
Nonbeneficial interventions after end-of-life conference — no. (%)			
Mechanical ventilation	47 (75)	41 (65)	0.30
Vasopressors	23 (37)	17 (27)	0.33
Dialysis	1 (2)	0	0.99
Other†	35 (56)	28 (44)	0.16
No. of nonbeneficial interventions provided after decision to forgo life-sustaining treatments			0.04
Median	3	2	
Interquartile range	2–3	2–3	
Life-sustaining treatments withdrawn — no. (%)			
Mechanical ventilation	9 (14)	17 (27)	0.03
Vasopressors	19 (30)	32 (51)	0.01
Dialysis	15 (24)	14 (22)	0.78
Other data			
No. of days from decision to forgo life-sustaining treatments to death			0.16
Median	2	1	
Interquartile range	1-3	1–2	
No. of days in ICU			0.54
Median	9	7	
Interquartile range	5–20	4–14	
Conflicts with family members reported by ICU staff — no. (%)	4 (6)	8 (13)	0.36
Patients who survived and were discharged — no. (%)	2 (3)	1 (2)	0.30

* The intervention began on the day that the end-of-life family conference was held.

† Other treatments were blood transfusions, antibiotics, and vitamins.

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(IES), which assesses symptoms related to posttraumatic stress disorder (PTSD); scores range from 0 (no PTSD-related symptoms) to 75 (severe PTSD-related symptoms).^{5,16-18} We classified patients as having low or high IES scores, using 30 as the cutoff, in agreement with previous reports.^{5,18} Secondary outcome measures were symptoms of anxiety and depression, which we assessed using the Hospital Anxiety and Depression Scale (HADS); subscale scores range from 0 (no distress) to 21 (severe distress).^{19,20} HADS subscale scores above 8 were considered to indicate clinically significant symptoms of anxiety or depression.¹⁹

DATA COLLECTION

Investigators recorded ICU and patient characteristics on standardized forms. The data elements included in Table 3 were gathered in a prospective fashion. In addition, a specific form was used to collect data describing the end-of-life family conference, and investigators were asked to clock family conference times. Primary-outcome data were collected by the interviewer 90 days after the patient's death.

STATISTICAL ANALYSIS

On the basis of data from our previous study,⁵ we hypothesized that the intervention would decrease the risk of PTSD-related symptoms by 30%. To detect a significant difference between the two groups with a type I error of 0.05 and a power of 0.90, 100 families had to be recruited, 50 in each group. We decided to include 132 family members (66 in each group) to allow for families lost to follow-up on day 90 (up to 25%).5 Continuous variables were reported as medians and interquartile ranges, and categorical variables as proportions. Comparisons of continuous variables between the two randomized groups were performed with the Wilcoxon rank-sum test, whereas comparisons of categorical variables were performed with the Pearson chi-square test or Fisher's exact test, as appropriate. All tests were two-sided, and P values of less than 0.05 were considered to indicate statistical significance. Statistical tests were performed with the SAS software package, version 9.1 (SAS Institute).

RESULTS

Of the 132 eligible family members, 126 were randomly assigned to a study group, and 108 (86%) were interviewed 3 months after the patient's death (range, 90 to 104 days) (Fig. 1). Of the 22 ICUs in the study, 15 were in teaching hospitals, and 7 in general hospitals. In all the ICUs, nurses and physicians held regular meetings about end-of-life issues; however, only three ICUs had written procedures for delivering information to families of dying patients, and only five ICUs had unrestricted visiting hours. Before the study, none of the ICUs provided family members with written information about bereavement, and none were aware of the VALUE-based guidelines for end-oflife conferences. The characteristics of the patients at enrollment did not differ significantly between the two study groups. A decision to forgo life-sustaining treatment was made for all the study patients; at the time that the decision was implemented, 114 patients (90%) were receiving mechanical ventilation and 96 (76%) were deeply sedated, precluding meaningful communication between the patient and family.

A comparison of the characteristics of the end-of-life conferences in the two study groups provides a measure of the implementation of the intervention. The significant differences in the conduct of the conferences, shown in Table 3, suggest that the guidelines for the intervention conferences were followed.^{2,21}

Regarding the prespecified process-of-care measures listed in Table 3, although the length of stay in the ICU and in the hospital did not differ significantly between the intervention and control groups, there were fewer nonbeneficial interventions (continued life support after a decision to withhold or withdraw life-sustaining treatments) in the intervention group (see Fig. 1 of the Supplementary Appendix), and withdrawal of mechanical ventilation and vasopressors was more common in this group than in the control group. Among the relatives who initially disagreed with the ICU clinicians regarding decisions to forgo life-sustaining treatments, those in the intervention group were more likely to agree with the decisions eventually (six relatives in the intervention group vs. none in the control group, P=0.02). Among the family members in both groups, 96 (89%) reported that the amount of time spent providing information was sufficient, and 97 (90%) felt that the information was clear; 41 (38%) reported a desire for additional information that was not provided (Table 4). The proportions of family members who reported a desire

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for additional information, who received newly prescribed psychotropic drugs, and who expressed feelings of guilt were lower in the intervention group than in the control group. In addition, 95% of family members in the intervention group said they were able to express their emotions to the ICU team, as compared with only 75% of family members in the control group.

Regarding the prespecified main outcome variables recorded 90 days after the death of the patient (Table 4), the IES scores in the intervention group were lower than those in the control group (median score, 27 [interquartile range, 18 to 42] vs. 39 [interquartile range, 25 to 48]; P=0.02), indicating that 25 family members in the intervention group (45%) were at risk for PTSD as compared with 36 (69%) in the control group. Similarly, family members in the intervention group had significantly lower HADS scores than those in the control group (median score, 11 [interquartile range, 8 to 18] vs. 17 [interquartile range, 11 to 25]; P=0.004), with 25 family members (45%) reporting clinically significant symptoms of anxiety and 16 (29%) reporting clinically significant symptoms of depression, as compared with 35 (67%) and 29 (56%) in the control group, respectively (P=0.02 and P=0.003, respectively) (Fig. 2).

DISCUSSION

Over the past decade, epidemiologic studies have identified the specific needs of family members of dying patients,3-7 thereby allowing the development of proactive interventions that have improved communication with family members.^{22,23} End-of-life family conferences are rooted in the evidence provided by this literature, their main goals being to improve communication between ICU staff and family members and to assist families when difficult decisions need to be made.10,11,14 In our multicenter, randomized study, we compared two end-of-life conference formats, one reflecting a proactive approach to communication and ending with the provision of a brochure on bereavement, and the other reflecting the typical approach used by each center. The proactive communication strategy decreased PTSD-related symptoms and symptoms of anxiety and depression among family members.

In the intervention group, ICU clinicians were

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Table 4. Outcomes Assessed on Day 90.					
Variable	Control Group (N=52)	Intervention Group (N=56)	P Value		
IES score			0.02		
Median	39	27			
Interquartile range	25–48	18–42			
Presence of PTSD-related symptoms (IES score >30) — no. (%)	36 (69)	25 (45)	0.01		
HADS score			0.004		
Median	17	11			
Interquartile range	11–25	8-18			
Symptoms of anxiety — no. (%)	35 (67)	25 (45)	0.02		
Symptoms of depression — no. (%)	29 (56)	16 (29)	0.003		
Saw a psychologist after death of patient — no. (%)	6 (12)	4 (7)	0.41		
Received newly prescribed psychotropic drugs after death of patient — no. (%)	12 (23)	6 (11)	0.05		
Effectiveness of overall information provided — no. (%)					
Time allotted to provide information was sufficient	45 (87)	51 (91)	0.45		
Information was clear	45 (87)	52 (93)	0.34		
Additional information requested	24 (46)	17 (30)	0.05		

asked to follow detailed published guidelines14,15 to ensure a uniform and effective change in their approach to communication. As compared with the control conferences, the intervention conferences were attended by a larger number of relatives and were associated with longer times spent delivering information and listening to relatives. The intervention conferences also provided family members with more opportunities to discuss the patient's wishes, to express emotions, to alleviate feelings of guilt, and to understand the goals of care. Our finding that patients in the intervention group received fewer nonbeneficial treatments concurs with evidence of the efficacy of proactive strategies such as ethics consultation²⁴ and early palliative-care consultation for dying patients in the ICU.25

A bereavement brochure was given to the family at the end of the intervention conference. Previous studies by our research group showed that comprehension was markedly improved by simply delivering standardized written information for families.²³ This experience prompted us to include a brochure in our proactive communication strategy. Furthermore, prior research suggests that multifaceted interventions are necessary to effect changes in clinicians' behavior.²⁶

Our study has several limitations. First, it was performed in France, where the patient-physician

relationship is perceived as more paternalistic than elsewhere,27 with physicians having final authority in decisions to forgo life-sustaining treatments.⁵ Nonetheless, the intervention used in our study was rooted in the international literature and is relevant to other countries.² It might be argued that the gap between the intervention and the control groups was larger as a result of paternalistic attitudes in the control group, since this group replicated usual practice; if this view is correct, the magnitude of the beneficial effect of the intervention in France would be greater than could be expected in countries where shared decision making with family members is more firmly established. A strong argument against this view, however, is the fact that interactions with family members in the control group were similar to those reported in other European countries and in North America.14,15 Furthermore, the results of our intervention were consistent with those in earlier studies of proactive interventions.^{22,24,25} In addition, 22 centers participated in our study, further enhancing the generalizability of our findings.

Second, our only criterion for inclusion in the study was the belief on the part of the physician in charge that death was inevitable and that a decision to forgo life-sustaining treatment was in order. In some cases, however, patients in such

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The median HADS score was 11 (range, 8 to 18) in the intervention group versus 17 (range, 11 to 25) in the control group (P=0.004). With a cutoff of 8 for each of the subscales, symptoms of anxiety and depression were less common in the intervention group (anxiety, 25 patients [45%], vs. 35 [67%] in the control group; P=0.02; depression, 16 [29%] vs. 29 [56%]; P=0.003).

circumstances survive.^{28,29} Conceivably, our intervention might have a negative effect on the family members of patients who survive, a situation that transpired only once in this study. Nevertheless, the possible negative effects of such an event must be compared with the negative effects of suboptimal communication on the much larger number of families whose relatives die.

Third, we did not determine how many families read the bereavement brochure or how those who did reacted to it. The multicenter design of the study and the fact that each ICU physician held only three intervention conferences did not allow us to evaluate the physicians' learning curve. Previous work has shown that even a brief course of training may improve communication skills.³⁰ A study over time would be useful to determine whether benefits to the families increase as ICU physicians improve their communication skills. There is a need to develop a process for evaluating and improving end-of-life conferences in ICUs. Also, to make sure that the interviewer was unaware of the group assignments, we did not ask questions about the intervention itself during the telephone interview.

Fourth, because we did not assess the HADS toms and symptoms of anxiety an score before the critical illness or at the time of 3 months after the patient's death.

the patient's death, we cannot be sure that the two groups of family members were not different at baseline. However, in a recent noninterventional study, we recorded the HADS score for family members 90 days after the patient's discharge or death.⁵ The median score was 17 (interquartile range, 10 to 22), suggesting not only that symptoms of anxiety and depression were common and lasting but also that the proactive communication strategy we tested in the current study had positive effects.

Fifth, although the interviewer and the analyst were unaware of the group assignments, blinding of family members and ICU clinicians was not feasible. Consequently, we cannot exclude the possibility that the investigators believed strongly in the effectiveness of the intervention and that this may have influenced other interactions with family members.

Finally, the positive results of the current study might in theory indicate that in the control group, communication was less personalized and interactive than the norm. However, we believe that the characteristics of the control conferences (reported in Table 3) — notably, their longer duration, as compared with that in earlier work by our group (20 minutes vs. 10 minutes) - show that communication with families was as good as, or better than, the norm. In addition, the proportion of relatives who were satisfied with the information they received and the proportion who requested additional information indicate that the standard of care for providing information was met.^{5,23,31} The fact that the IES and HADS scores in the control group were similar to those in our previous studies argues against the possibility that the control conferences were substandard, as does the extensive experience acquired over the years by the ICU physicians in our study group.5,19,23,31-34

In summary, a proactive strategy for routine end-of-life family conferences that included provision of a brochure on bereavement, as compared with customary practice, resulted in longer meetings in which families had more opportunities to speak and to express emotions, felt more supported in making difficult decisions, experienced more relief from guilt, and were more likely to accept realistic goals of care. The result of this strategy was a decrease in PTSD-related symptoms and symptoms of anxiety and depression 3 months after the patient's death.

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Supplementary Appendix

This appendix has been provided by the authors to give readers additional information about their work.

Supplement to: Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. N Engl J Med 2007;356:469-78.

Appendix for web-only publication

A Proactive Communication Strategy for Family Members of Patients Dying in the ICU: A Multicenter Randomized Controlled Trial

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Patients and Methods

This prospective randomized multicenter controlled trial was conducted in 22 ICUs in France, from May 2005 to October 2005. The study was approved by the institutional review board of the French Society for Critical Care in January 2005. In each ICU, a local investigator was responsible for the study and agreed to include the surrogate decision-maker of six consecutive patients who were expected to die within a few days. The surrogate decision-maker was either the surrogate designated by the patient or, when there was no surrogate, the person who ranked highest in the hierarchy for surrogate decision-making according to French law (spouse>parents/children>others) (1). Thus, in each family a single person was included.

The potentially eligible relative in each family was informed that a study on family needs was ongoing in several ICUs in France to compare two communication strategies (standard end-of-life communication and a new proactive communication strategy plus a leaflet) and that group assignment would occur at random. If the family member agreed to participate, he or she was asked to provide at least one telephone number for an interview 90 days after the death of the patient, aimed at assessing the emotional burden generated by the ICU experience.

The only inclusion criterion was that the physician in charge believed the patient would die within the next few days. Physicians were asked to identify eligible patients based on their own clinical judgment. This inclusion method was chosen to make the inclusion criterion generalizable to other critical-care settings. Exclusion criteria were patient age younger than 18 years and surrogate decision-maker having insufficient knowledge of French for a telephone interview. No interview was done if the patient was alive on day 90. Family members (one per patient) were allocated at random to the intervention or control group. As detailed below, in the control group the end-of-life conference occurred according to usual

practice in each center; whereas in the intervention group it was conducted according to specific guidelines and ended with a bereavement information leaflet being handed to the surrogate decision-maker.

Randomization procedure

The study biostatistics department generated a randomization list stratified on the ICUs, using permutation blocks of six. Sealed consecutively numbered envelopes containing the name of the assigned group were sent to each ICU, with bereavement information leaflets. The leaflets were not in the sealed envelopes, so that the blind design was not broken. In each ICU, surrogate decision-makers who consented to the study were assigned a study number, and the investigator opened the envelope bearing that number to determine group assignment.

Description of routine family meetings occurring before end-of-life conferences

The 22 ICUs that participated in the study were members of our research group FAMIREA (the study group aimed at improving communication with relatives in French ICUs), which has been working on family care in the ICU for 10 years. The intensivists in the FAMIREA have built up strong experience with studies of family care.(2-9) In all FAMIREA ICUs, practices are homogeneous regarding family care.

In FAMIREA ICUs, three early formal information meetings are held for all families. In our study, these three meetings occurred prior to randomization (that is, before the attending physician could determine that the patient would die) and were therefore identical in the two study groups. First, information is provided within 12 hours after ICU admission by the senior or junior physician on duty to provide general information on the diagnosis, prognosis, and treatments in the patient. This meeting is held with the relative or relatives who are present at ICU admission. A previously evaluated family information leaflet is given to the family at the end of this meeting.(2, 4) The second meeting is held within 48 hours after ICU admission, led by the senior intensivist in charge of the patient and attended by all family members who want to and can attend. Nurses and junior physicians (residents) may participate in this meeting, which is intended to confirm the information provided at ICU admission, to provide additional information based on the course in the ICU, to answer the family's questions, and to check that the family understands the situation. The third meeting, which takes place between day 3 and day 5, is conducted by the senior intensivist in charge of the patient. All ICU staff members involved in care of the patient participate in this meeting. The patient's surrogate (or, when there is no surrogate, the person ranking highest for surrogate decision-making) attends the meeting, as well as other family members at the surrogate's request. The patient's history, acute disease, and treatments are detailed to the family, and the prognosis is explained. Questions by the family are answered by the intensivists and nurses.

For each patient, all meetings but the first are held by the same physician, who is the senior intensivist in charge of the patient. The first meeting is held by the intensivist on duty, who may or may not be the intensivist in charge of subsequently managing that patient. The primary care physician is not involved in these meetings but can attend them should the family so request; the family physician can provide additional information to family members in the ICU. In addition to these three formal meetings, information is provided to the family members by the nurses when they come to visit. On rare occasions, information is given to family members over the phone.

After these three meetings, if the patient is expected to die within the next few days, i.e., if a shift from curative care to palliative care (withdrawal or withholding of life support) is in order, an end-of-life conference is held, as described below. The intervention in our study consisted in changing the modalities of this end-of-life conference.

Description of routine end-of-life conferences in France

In our study, the control group received end-of-life conferences as conducted routinely in each study center. In agreement with French legislation on end-of-life practices (1) and recommendations by the French Society for Critical Care, relatives of patients dying in the ICU are informed at least once a day of the patient's medical condition and of treatmentlimitation decisions. An end-of-life conference is held to inform the family that death is imminent and to describe treatment-limitation decisions and their consequences; family members are free to share in decisions if they so wish, but treatment-limitation decisions in France are under the authority of the physicians and are made collegially by the ICU team.(6, 7) The end-of-life conference is not scheduled in advance but instead is held when the need becomes apparent, and when at least one relative happens to be in the ICU.

The nurses may or may not attend. The conference is led by the senior physician in charge of the patient. In some cases, but not always, the conference is held in a separate room. In earlier studies done by FAMIREA, mean end-of-life conference duration was 10 minutes.(2). In the current study, the investigator in each center attended all three usual-care (control) end-of-life conferences to ensure homogeneity in the conference format, completing a form on each conference. If the patient was still alive and in the ICU 3 days after the conference, a second conference was held according to usual practice.

Description of the proactive communication strategy tested in this study

The intervention consisted in replacing the routine end-of-life conference described above by a conference conducted according to specific guidelines and ending with the delivery of a bereavement information leaflet. The intervention end-of-life conference was planned several hours in advance by the ICU staff members involved in caring for the patient. The participants included senior and junior physicians, nurses, a psychologist, other health professionals, and an unrestricted number of family members and friends; a social worker and a spiritual representative were invited to the conference if requested by the family. The conference always occurred in a quiet room where seats were available for everyone; beepers and cell phones were off.

In each ICU, the investigator was given specific guidelines for conducting family conferences. These guidelines were developed by the director of the research group at the University of Washington (JRC), who conducted extensive qualitative evaluations.(10-12) A detailed conference procedure was provided to each investigator.(10) During the conference, the investigator provided information on the diagnosis, prognosis, and treatment in the patient and discussed the appropriateness of treatment limitation with the family members. While conducting the conference, the intensivist sought to achieve five objectives described in the guidelines and summarized by the mnemonic VALUE:(10-12) Value and appreciate things family said, Acknowledge emotions, Listen, ask questions that allow you to Understand who the patient is as a person, and Elicit questions from the family.

To prepare for the study, the investigators attended a meeting about the study intervention. Each investigator was given a copy of the VALUE guidelines and of five published research articles reporting the description and evaluation of family conferences.(10-14) Subsequently, one of us (AL) traveled to each center to discuss the VALUE guidelines with the investigator and to check that the difference between the intervention end-of-life conference and the usual-practice (control) end-of-life conference was clearly understood. In each center, the investigator then worked with the other intensivists to explain the VALUE guidelines. Nurses were not made aware of the guidelines. The investigator attended all three intervention end-of-life conferences, to ensure homogeneity of the conference format, completing a form on each conference. If the patient was still alive and in the ICU 3 days after the conference a second conference was held.

At the end of the intervention end-of-life conference, the family member who was included in the study was handed a bereavement information leaflet, whose content was explained orally. The 15-page leaflet describes and explains end-of-life care, possible reactions after the death of a family member, how to communicate with other family members or children, and where to find assistance. This leaflet has been used for several years in pediatric ICUs in France.(15) For the current study, the leaflet was modified in two ways: it was adapted for adult ICUs, and the explanations were provided in a way that emphasized the seven points previously suggested to optimize end-of-life care.(14) To prepare for the study, the investigators read the leaflet and made suggestions about improving it. The final leaflet was then printed.

Telephone interview 90 days after the patient's death

One family member per patient was interviewed over the telephone 90 days after the patient's death, between August 2005 and January 2006. All phone calls were made by the same person (AL), who was not an investigator in any of the participating ICUs and who was blinded to group assignment. The first phone call was made exactly 90 days after the patient's death. Family members who did not answer the first call were called again, two to three times a day. After 15 unsuccessful attempts, the family member was considered lost to follow-up. The interviewer was trained by the sociologist of our research group (NKB), who has extensive experience with interviewing family members of ICU patients.(7) After introducing

himself, the interviewer reminded the family member of the study design and that the interview would last 15 to 30 minutes. Our primary outcome measure was the Impact of Event Scale (IES) score, which assesses symptoms related to posttraumatic stress disorder (PTSD).(7, 16-18) Our secondary outcome measures were symptoms of anxiety and depression as assessed using the Hospital Anxiety and Depression Scale (HADS).(9, 19) French versions of both the IES and the HADS have been validated in family members of critically ill patients.(7, 9) The IES has been widely used for many years(18) and found reliable for many traumatic events, including bereavement.(17) It can be easily completed during a telephone interview.(7, 20) Each of the 15 IES items is scored from 0 to 5, so that the total score can range from 0 to 75, with higher scores indicating greater severity of PTSD-related symptoms.(21, 22) We classified patients as having low or high IES scores using 30 as the cutoff, in agreement with previous reports.(7, 18) The HADS consists of two subscales that evaluate symptoms of anxiety (7 items) and symptoms of depression (7 items). Subscale scores range from 0 (no distress) to 21 (maximum distress). A score above 8 on the two subscales was taken to indicate significant symptoms of anxiety or depression.(9)

Data collection

Investigators recorded ICU and patient characteristics (Tables 1 through 3) on standardized forms. Continuing life-sustaining treatments after a decision has been made to withhold or withdraw other life-sustaining treatments in patients who ultimately die in the hospital indicates failure to achieve a fundamental goal of medicine and provides no benefit to patients; therefore we defined "nonbeneficial treatments" as non-palliative treatments used after a decision to forgo life support.(23, 24) ICU patients with decisions to forgo life support are not transferred to wards in France. Assessment of family participation in the end-of-life decision-making process was recorded as previously reported.(6, 7) A specific form was used to collect data describing the end-of-life family conference. Investigators were also asked to

clock family conference times. Data in table 4 were collected by the interviewer 90 days after the patient's death.

Statistical analysis

Because PTSD-related symptoms are common in family members of ICU patients, particularly those of patients who die in the ICU, we selected the IES score as our primary outcome measure.(7) Based on data from our previous study,(7) we hypothesized that the proactive communication strategy (end-of-life family conference and bereavement information leaflet) would decrease the risk of PTSD-related symptoms by 30% compared to usual practice. To detect a significant difference between the two groups with a type I error of 0.05 and a power of 0.90, 100 families had to be recruited, 50 in each group. We included 132 family members (66 in each group) to allow for families lost to follow-up on day 90 (up to 25%).(7) Symptoms of anxiety and depression as measured by the HADS were secondary outcome measures. Continuous variables were reported as medians and interquartile ranges (IQR), and categorical variables as proportions. Comparisons of continuous variables between the two randomized groups were performed using the Wilcoxon rank-sum test, whereas comparisons of categorical variables were with the Pearson chi-square test, or the Fisher's exact test where appropriate. All tests were two-sided, and P values less than 0.05 were considered statistically significant. Statistical tests were performed using the SAS software package (SAS 9.1 Institute, Cary Inc. CA).

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Figure 1 of the supplemental appendix



Figure 1 - Supplemental Appendix



Bereavement Support Leaflet

Medical Intensive Care Unit, Saint-Louis Teaching Hospital ORGANIZATION CHART

Head of the unit : Assistant head: Full-time hospital physicians :

<u>Clinical fellows</u>:

Head nurse:

<u>Secretary:</u>

<u>Social worker</u>:

<u>Members of the clergy</u>: for each religion

Volunteers:

You have come to see a loved one in the intensive care unit. The doctor has just told you that none of the treatments can prevent your loved one from dying.

This leaflet was written for you. We hope that it will help us support you as you work through this personal tragedy.

Most people say that losing a loved one is the worst ordeal they have ever experienced. Although this leaflet cannot lessen your pain, we hope it will help you understand your feelings. Family members of patients who have died in the intensive care unit have told us that understanding their feelings helped them to cope.

This leaflet supplies practical information about things you will need to do in the next few days for yourself and your family. It also discusses the feelings you or your family may experience over time in response to your loss.

Please read it as often as you need to, according to the way your feelings change over time. Give it to your family members so that they can read it also. Some of the sections will be useful now and others later on. If you cannot read it now, keep it and read it later.

This leaflet is not intended as a substitute for a personal caring relationship between you and us. On the opposite, it is an invitation to develop with us the kind of relationship that will help you.

We will gladly meet with you and answer your questions. Please feel free to ask to see us, now or later on, whenever you feel the need.

We care deeply about your sorrow.

Who can you ask?

We are available for answering any questions you may have. Please feel free to ask us.

- Regular meetings with the doctor will help you understand how your loved one's situation is evolving.

- The nurses and head nurses can provide you with guidance about administrative procedures, such as registering the death and contacting a funeral home.

- A social worker can meet with you to help work out solutions to financial or social problems.

- A psychologist will meet with you at your request.
- A member of the clergy can be contacted at your request.

- If you have a family doctor that has not yet been in contact with us, feel free to ask your doctor to call us.

The first section of this leaflet explains the care your loved one will receive now in our unit. We hope this information will help you understand what the doctors and nurses are doing for your loved one and how the unit works. We are extremely attentive to detecting pain and any other symptoms your loved one may experience, and we are doing everything we can to keep your loved one comfortable, free of pain and distress.

Organization of care for patients at the end of life in the intensive care unit

- The nurses provide care to your loved one continuously. There is always a doctor in the unit, 24 hours a day and 7 days a week. The doctor and nurses take the necessary steps to make sure your loved one remains free of pain, distress, or suffering.

- The hospital has a Family Home with rooms for family members who live far away. If you would like to know whether rooms are available, please ask us to call the Family Home.

- In our unit, care at the end of life is planned by the ICU team according to each patient's needs and is delivered in the same way during the day and at night. You may have special requests, for instance about being notified if your loved one dies, about calling a member of the clergy, or about allowing a family member coming from far away to enter the room outside visiting hours. Please let us know: we will write your requests in the unit log, which will ensure that they are honored at all times.

- The nurses and doctors deliver care to the patients regularly. Each doctor and each nurse is responsible for several patients. In our unit, you are free to visit at any time during the day or at night. However, during some patient care routines you may be asked to go to the waiting room, in order to protect the confidentiality, privacy, and dignity of your loved one. We will do our utmost to let you spend as much time with your loved one as possible. You may want to participate in some of the aspects of your loved one's care, such as washing, massaging, or feeding: if so, please let us know.

- You have met with the doctor in charge of the medical care to your loved one. Feel free to ask for another meeting if you wish to have additional information. The terms used by intensive care doctors may be difficult to understand. Please ask them to explain if needed. The nurses can also give explanations. There is a glossary in this leaflet.

- Your usual family doctor can ask for explanations and review the medical records of your loved one. It is important to share information with people who can help you to understand.

Glossary to help you understand the care given to your loved one

Sedation: Sedation is the use of relaxing medicines to induce a deep sleep. Sedation prevents pain and agitation and lets the patient be more comfortable with the breathing machine.

Catheter: A catheter is a slender tube made of soft plastic that is inserted into a large vein at the neck or leg. Analgesics, other medicines, fluids, and nutrients (liquid food) can be given rapidly and efficiently through the catheter.

Gastric tube: A gastric tube is a soft plastic tube that is inserted into the stomach and used to remove secretions or to give food.

Hydration: Hydration is the administration of fluids, sugar, and salt to cover the patient's needs, so that dehydration does not occur.

Pain management: Pain can be physical or psychological. We treat physical pain by giving powerful analgesics. For psychological pain, which is a mixture of anxiety and depression, we use effective anti-anxiety medications. In both cases, the medications are administered through a catheter into the bloodstream.

End-of-life care: When a patient is admitted, our goal is to provide care that will allow the patient to get better. However, when none of the treatments that exist today is capable of achieving this objective, our goal is to accompany the patient through the final stages of life, in order to avoid suffering and to make sure that the patient is free of physical pain and psychological distress at all times.

Palliative care (Comfort care): Palliative care differs from curative care (which seeks to achieve recovery). Palliative care is designed to provide comfort and repose, psychological well-being, and freedom from pain.

Appropriate level of care: For each patient in the ICU, we continuously evaluate the plan of care to determine the benefits and possible drawbacks of each component of the plan. We determine the appropriate level of care based on these benefits and drawbacks. We stop components of the plan of care that are not working and that cause suffering.

Listening/Giving information: Every day, the nurses and doctors will listen to you and inform you about your loved one's condition. Feel free to make appointments with the doctor. You should feel that you have all the information you need and that you have said what you wanted to say, on your own behalf or on behalf of the patient. You can make an appointment with the head of the ICU.

After the death of your loved one...

The rest of this leaflet will help you prepare as best as possible for your loss. Some pages will be useful to you, and others will be less helpful.

After the death of your loved one

We suggest that you spend time with the body in quiet remembrance, in the ICU room then in the hospital mortuary room. Family members may not be ready or willing to see the body at the same time. Feel free to talk to us about this.

The nurse and nursing assistant who cared for your loved one will prepare the body. Some family members have very personal wishes, such as holding the body in their arms, helping to prepare and dress the body, or reading a passage out loud. We will do our best to help you realize your wishes.

A member of the clergy can be called at your request.

Paperwork

The hospital will notify the registrar's office at the Town Hall (.....adequate address for each center.....) within 24 hours of the death.

You will need to contact a funeral home to make arrangements (burial, cremation, or shipment of the body to another country). The funeral home can take care of obtaining the death certificate from the town hall; you will need to lend the appropriate ID documents for this purpose.

Information on the required paperwork is available at the hospital's vital records office. If you are unable and unwilling to visit the vital records office, a member of your family can go instead.

What will happen to the body?

You will decide about funeral arrangements and what will happen to the body.

At the hospital, the body will be taken from the ICU to the mortuary room. By law, the body can stay in the ICU no longer than 10 hours. You will decide whether the body is taken from the mortuary room to the place of burial, to your home or your loved one's home, or to a funeral home.

It is very important that you give enough thought to the funeral arrangements. You need time to decide what you want regarding the burial or cremation.

The mortuary room attendants will place the body in a casket. The funeral home arranges the transportation of the body and the burial or cremation. The family must pay for the cost of the funeral. The social worker at the hospital can inform you about the financial help that is available for families with limited financial resources.

If you decide to have the body cremated, you will need to decide where you want the urn containing the ashes to be placed (for instance, in the ground, in a tomb, or in a columbarium). Experience has shown that keeping the urn at home is not a good choice, for you or your family. It is probably best to choose a specific place for the urn where you will be able to go and reflect about your loved one. You may also decide to have the ashes scattered either at a scattering garden or in an outdoor setting of your choosing.

The mortuary room

The mortuary room is a department in the hospital where the bodies of deceased patients are harbored to give families the time they need to make funeral arrangements.

You and your family can visit the mortuary room to reflect near your loved one's body as often as you want to. Ask about mortuary-room opening hours.

The mortuary room staff is available to meet your needs and to help you through the steps that lead to the funeral. Feel free to ask them for advice. They will answer your questions and requests.

You can give them clothes to dress the body in and you can help to prepare the body.

At your request, the mortuary room staff will give you a list of funeral homes. The mortuary room is designed so that all religious and cultural customs can be honored. Contact information for members of the clergy is available at the mortuary room.

Funeral rites

Funeral rites are extremely important to help you honor your loved one as you take the body to its final resting place. The rites fulfill a need, and experience shows that they provide comfort. You will probably choose the rites for your loved one's funeral according to your religious beliefs, your culture, and your family traditions.

You will need to make the arrangements for the funeral, together with the funeral home and members of the clergy if you so wish.

The funeral ceremony, which may or may not be religious in nature, is designed for you and your family. It can help to symbolize your loss, which you share with the other family members and friends. You will cherish the memories of the ceremony all your life. These memories will be important in helping you work through your grief.

If you have no religious beliefs, you can choose non-religious rites, which will serve the same purpose as religious rites. Give yourself enough time to explore all the options.

The autopsy

The doctor may already have explained how important it is, in some specific cases, to perform an autopsy in order to clarify the cause of death. By law, consent to the autopsy must be obtained from the family. If you refuse, no autopsy will be performed, except by judicial decision in specific situations.

The autopsy is performed at the hospital. An autopsy is a medical procedure that is performed by specialized doctors, in a way that respects your loved one's body.

The hospital doctor or your usual family doctor will give you a copy of the autopsy report and will discuss the results with you.

Remember that several months may be needed to obtain some of the autopsy results.

The next pages were written based on the accounts of families who lost a loved one. They told us that receiving at least partial explanations about the grieving process helped them work through the pain of their loss. Grieving is a complex and exhausting process, but by working through it you will eventually recover. Please let us know about any special requests you may have, about your feelings and about how you believe we can support you.

Landmarks on your journey through grief

The moment of death

Even when there has been plenty of time to prepare, the moment of death comes as a shock that is felt almost more as a physical jolt than as an emotional experience, a sort of violent inner renting.

Your loved one is dead and you are there, unable to understand what happened to you. People have told us they felt numb, stunned, in a state of deep emotional shock that prevented them from reacting. You may experience regrets and guilt: please share these natural but painful feelings with us or your usual doctor. Guilt about the death of a loved one is common and can be lessened by explanations about the exact causes and circumstances of the death.

The death of a loved one is a major life crisis that turns our world upside-down. Time seems to stand still.

The funeral

The funeral is a time of strong emotions. It may seem unbearably painful because it signifies permanent loss. However, the funeral is also a time for saying good-bye and for finding comfort in sharing your sorrow with others.

Give enough thought to what is important to you and to what you want for your loved one's funeral, in accordance with your beliefs and wishes. The funeral will allow you to share your pain with those who are close to you and who join you in bidding a final farewell to your loved one. You may want to make a speech or to ask other family members or friends to make one.

Do, or have others do, what your feelings tell you should be done. You may want to obtain help from those who are close to you: share your thoughts with them.

Remember that it is never too late to honor the memory of your loved one. If you were not able to at the moment of death, you can choose another time that works for you.

The grieving process is an intensely personal journey during which you will work through inner upheavals and painful feelings. At some of the stages in this long journey you will experience terrible suffering, while at others you will feel relief.

Grief is a succession of feelings and overlapping stages that vary according to personal and cultural factors. You will need time and an enormous amount of energy to go through the grieving process.

Along your journey, sharing your feelings with other people is very important. You must find people you can talk to. However, you will also need to protect yourself. Some people will be of help, but others will not. Close family ties do not always translate into effective support.

Helplessness

You may experience a sense of emptiness, of being drained. You may feel you are going through the motions of everyday life like a robot and that you are only hanging on out of habit.

Denial

Sometimes, a member of the family tries to deny the tragedy. This person may behave as though your loved one were still alive. This sense of disbelief is usually a brief phase that provides a reprieve before confronting the terrible loss. Some people are surprised by this reaction of disbelief, which may be a barrier to communication with family and friends.

Physical symptoms

Your physical and emotional pain may settle in your body. Your entire body may be painful. You may experience a vague feeling of ill-being, difficulty sleeping, stomach pain, headaches, loss of appetite, or other symptoms. Your whole body may reflect your suffering. You may feel that your thoughts and movements are slowed down, as your energy is turned inward. All your thoughts are for your loved one. Or perhaps on the contrary you will feel a need to be extremely active in all the areas of your life. There is no reason to feel ashamed or afraid of these feelings.

Anger and rebellion

Feelings and questions may force themselves on you: you may want to protest at the unfairness of your loss or to find someone to blame, for instance. Incomprehension may lead to a search for meaning, for explanations. You may ask yourself and others: "Why?", over and over again ...

Guilt

As you strive to understand what happened, you may experience feelings of guilt related to things you did or did not do. Many people believe that feelings of guilt contribute much of the suffering, last longest, and are particularly complex. Talk about your feelings of guilt to those who are close to you and to us here in the intensive care unit.

The suffering woven into everyday life

Everyday life is full of small events that will rekindle your suffering and remind you that your loved one is gone. Being in places that are permeated with memories of your loved one, seeing a happy family, attending family reunions: all these events may reawaken your suffering.

It is important to share your pain with those who are close to you, your family, your friends. Allow yourself to cry and let people take care of you. You may feel your behavior is babyish: that's OK.

Acknowledge that sharing memories just doesn't work with some people. People may be clumsy and their words may hurt you.

Little by little, set yourself day-to-day goals (prepare a meal, run an errand, read a newspaper article ...)

Loneliness and despair

Intense inner suffering may lead to feelings of despair and depression. You may feel that you don't care about anything anymore. Getting through each day may seem unbearably burdensome. You may feel that you are losing your mind or that you want to die. All these feelings attest to the intensity of your pain and distress. Sharing them with other people is extremely important. However, it may be difficult to talk about you pain with people you know. You may find it useful to talk with a counselor, a psychologist, or a psychiatrist.

Coping with the absence of your loved one

Learning to live without your loved one is a long and difficult task. Give yourself enough time and be forgiving toward yourself and toward others, as you will make progress at times but also seem to lose ground at other times. There will be hurdles to clear and turning points to negotiate.

Grieving is not the same as forgetting. Grieving means accepting that life has changed forever and that you can be happy and fulfilled while carrying the scar left by the loss of your loved one. The relationship you had with your loved one must change in order to incorporate your loss.

Your relationship with your partner

Bereavement can strain your relationship with your partner. The strong emotions that may arise because of your loss may seem to pull you together or push you apart. You and your partner will not necessarily experience the same emotions at the same time. Sometimes, this difference helps. At other times, the differences in your emotions may seem to harm your relationship by making it more difficult to share your feelings with each other.

For many men, sharing feelings of pain is difficult or even impossible. In our society, men rarely allow themselves to express their suffering. Accepting to talk about your feelings is important, and your partner may be able to help you.

However, remember that you are both different and that each of you must make his or her own journey through the grieving process.

Telling the children

Children need to know the truth, told simply, with words that are easy to understand. It is best to tell them about the death rather than to wait until they understand on their own. Many children neither cry nor even seem to pay much attention. Getting back to what they were doing before your conversation may appear to be their main concern. Nevertheless, your words do get through to them.

Let them know it is OK to talk about it and to share their feelings when they are ready to. Children also must work through their grief. Their suffering may show in many ways, for instance as sadness, anxiety, anger, loss of appetite, difficulty sleeping, aggressiveness, withdrawal, and also denial or apparent indifference...

Children's conception of death varies with their developmental stage, and therefore they handle grief differently according to their age. You can state clearly that everyone dies. Do not compare death to sleep or to a long trip, as the child may then develop a fear of falling asleep or traveling. You might want to say that when people die they do not move, breathe, or feel any more.

Reassure your children that death is not a punishment or an act of retaliation and that they are not responsible for the death, although they may feel guilty.

A huge amount of effort will be needed on your part to be your usual self for your children, and at first you may feel that you are not behaving naturally. Remember, your efforts to keep yourself together and to appear upbeat when your children are there is your first step toward embracing life again.

Some of your family members and friends may feel uncomfortable about your personal tragedy. They may choose not to talk about it, instead acting as if nothing has changed or as if they no longer dare to broach the subject. You may be deeply hurt by this response.

Protect yourself. Talk about your loss only with people you feel are capable of listening to you. You will need to give hints to your family and friends. You want to talk about your loved one and to discuss memories about good times spent together? Let them know! You don't want to talk about the past, you prefer to think of other things, to make new plans, to look toward the future? Again, let them know! They cannot guess your feelings ...

Your loved one is dead. How can you go on living?

- Allow yourself to feel pain, to show your sadness, and to cry. You are not weak, and neither are you abnormal. You are grieving.

- Accept to do less than usual. Grieving requires a huge amount of energy, and you often feel tired. Exhaustion is normal.

- See other people: withdrawing does not help. Let your family and friends know whether you want to talk about your loved one or instead turn your thoughts toward other things

- Take care of yourself. If you do not usually pay attention to your own needs or take care of your body, now is the time to develop self-care routines: they are indispensable to people who are grieving.

- Learn to identify the people and activities that are good for you. Spend time with the people and schedule the activities.

- Set goals that are simple and within easy reach. Setting the bar too high is unhelpful. Realistic goals may be to prepare a real dinner, to walk down to the park, or to swim for an hour. Deciding that you "must get over it" is not realistic. Each small victory over sadness is a step toward enjoying life again.

- If you feel guilty about the death of your loved one, talk about it. Otherwise, you may get stuck in your feelings of guilt, which will stop you from getting back to enjoying life again. You are a human being, and no one is perfect. If you acknowledge this, you will be able to see your guilt merely as a sign that you must accept yourself as a human being.

- At times, you may be unwilling to talk about your loved one, and you may want to go to a place where no one knows what happened to you. These wishes are normal. You may at times experience a fleeting sense of happiness. Don't feel guilty. You can be happy again without betraying your loved one.

- Your family and friends may give you a plentiful supply of advice, in an effort to support you. Some pieces of advice will help but others will not. Remember, you are the only person who knows what is best for you. There is no reason to let others tell you what to do.

- Wait a while before making life-changing decisions such as changing jobs, moving, divorcing, or relocating abroad. Acknowledge that now is not the time to make decisions you might regret later on.

- Some people find that the grieving process is harder than they thought or that they are not getting enough support. If such is the case for you, professionals can help you.

- Ask your usual doctor to help. Your doctor will decide whether you need medications (antidepressants or sleeping pills).

- Feel free to see a psychiatrist, a psychologist, or a counselor. You are not crazy or inept. A need for professional help is normal in people who have lost a loved one. Because they are not personally involved in your loss, professionals are in a good position to help you.

Where can you find help?

- Here, in the ICU, from the doctors, head nurses, nurses, psychiatrist, psychologist ...

You can ask for help now or later on, according to your needs.

- At bereavement organizations.

Feel free to obtain information from one or more bereavement organizations. An exhaustive list of bereavement organizations can be found in the book: *Vivre le deuil* (Living through Grief) by Emmanuel Moreau, Ed. Jacob Duvernet / guide France Info, 2001.

Further reading

Here are a few books that may help you in your personal journey.

Aimer, perdre, grandir, assumer les difficultés et les deuils de la vie Loving, losing, growing up, coping with the challenges and grief that are part of life Jean Monbourquette, Bayard / Centurion, 1995 This book is designed to serve as a companion. It is not a treatise or an essay. It is a guide that focuses on the emotions.

Le deuil. Comment y faire face? Comment le surmonter? Bereavement. How to cope? How to get on? Nadine Beautheac, Seuil, 2001 The concrete ideas and information supplied in this h

The concrete ideas and information supplied in this book will help you understand the importance of journeying through this period of bereavement according to your own specific wishes.

Quand le deuil survient. 80 questions et réponses. When bereavement happens. 80 questions and answers.

Roger Régnier et Line Saint-Pierre, Sciences et culture, Montréal, 2000 In this book, the authors answer frequently asked questions, in order to provide information, support, and comfort to bereaved people.

Vivre le deuil au jour le jour : réapprendre à vivre après la mort d'un proche Living through bereavement from day to day: learning to live again after losing a loved one Dr Christophe Faure, J'ai lu, 2001

This book helps to understand bereavement and the feelings it generates, and it also helps to provide support to people who suffer. This is a psychological guide for bereaved people and for those who are close to them.

Parler de la mort

Let's talk about death

Françoise Dolto, Mercure de France, 1998

This is a conference that discusses talking about death with people who are dying, who no longer want to live, or who have lost a loved one. It also discusses talking to children about death.

Glossary

Burial, interment, inhumation

The practice of placing the body of the deceased person in the ground.

Casket

A special receptacle in which the body is placed for burial (or sometimes for cremation).

Columbarium

A place in a cemetery designed to harbor urns that hold cremated remains.

Cremation, incineration

The practice of burning the body of the deceased person. The ashes are then placed in an urn.

Departure ceremony

Moment when the family gathers one last time around the body of the deceased. The body is then placed in a casket and taken from the hospital or home.

Funeral, funeral service

Ceremonies held in connection with a burial or cremation.

Funeral rites

Set of practices that have a religious or symbolic character and that help people say their final farewell to a deceased loved one.

Garden of Memories

Flowered lawn in a cemetery where the ashes of the deceased person may be scattered, if such was the deceased person's wish.

Memorial ceremony

Ceremony designed to remember a person or an event.

Morgue, mortuary, mortuary room, funeral home

Place in a hospital or specialized establishment that is specifically designed to harbor the body of a deceased person and to allow viewing or visitation by family and friends before the funeral.

Place of burial

The final resting place of the body after interment, that is, the ground or burial vault.

Sepulture

The act of placing the body of the deceased person in the ground or in a burial vault, with the attendant formalities and ceremonies.

Preparing the body

Cleaning and clothing the body in the mortuary room before the departure ceremony.

Viewing, visitation

A time during which family and friends pay their respects to the deceased person by visiting the body, which may be in an open or closed casket, in a special room at the hospital or funeral home.