

THE RENAL PALLIATIVE CARE INITIATIVE

A Program Funded by the Robert Wood Johnson Foundation

THE RPCI MEMORIAL SERVICE MANUAL

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INTRODUCTION

This manual will describe how to institute a renal and transplantation memorial service at your facility. We firmly believe that these services of remembrance have tremendous value for patients, families, and loved ones; they also clearly benefit participating staff, and they help renal programs come to a greater appreciation of end-of-life issues. We think that such services can change the actual culture of nephrology, and make it more sensitive to the palliative medical needs of its patients.

In 1999, the Renal Palliative Care Initiative (RPCI) was started with the assistance of the Providing Excellence in End-of-Life Care Program of the Robert Wood Johnson Foundation. Financial and other support was provided by Baystate Health Systems, Fresenius Medical Care, Inc., and the Western New England Renal and Transplantation Associates. The RPCI involved a hospital-based dialysis unit and 8 free standing dialysis facilities in the Connecticut River Valley Region of New England. The Initiative was organized to develop a number of different interventions to integrate palliative medicine into the care of patients with end-stage renal disease.

The Renal and Transplantation Memorial Services have been the best received and most meaningful of these interventions. In 1995, Deborah Hayes, LICSW, of the Franklin Medical Center Dialysis Clinic, a Baystate Health Systems renal facility located in Greenfield Massachusetts, organized an annual memorial service for patients who died during the previous year. The RPCI took advantage of her experience to institute two separate, annual services for our patients. Anne Woods, LICSW, chaired an interdisciplinary organizing committee that has been conducting the services in Springfield, and her experience has been condensed in this manual and that accompanying video. These teaching materials have been produced with the aid of a communication grant from the Robert Wood Johnson Foundation.

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DESCRIPTION

The Renal Palliative Care Initiative Memorial Service

Introduction

The Service of Remembrance is an annual non-denominational program designed to remember the patients who have died during the year. It unites members of the renal community: family members, doctors, nurses, social workers, dietitians, technicians, van drivers, fellow patients and others impacted by the death. It is a collaborative effort to meet the bereavement needs of all. Remembrance can be simple or elaborate. It can be confined to one unit or area or cover a broader area. It should be designed in whatever format thought to be appropriate for the needs of the bereaved community.

The following describes the Service of Remembrance that is held in the Greater Springfield area and includes participation of both hospital and freestanding treatment centers. It is intended to be an avenue of support for all who attend. Diversity of culture, ethnicity, religious belief, professional identity, age, and connectedness to the deceased is taken into consideration in developing the program. It is intended to be inclusive and welcoming.

Beginning

Once the participating facilities have been defined, committees can be formed and program planning can begin. An effort was made to include committee members representing each of the participating facilities. This inclusiveness allows for each facility to feel a sense of “ownership” and participation. The Committee Chairs attempted to recruit patients, family members, and professionals. This group identified key contacts to make the program a success. These contacts were then given information, asked if they would like to be involved and what their level of participation would be. They formed a core group that enhanced community contribution to the program.

Administrative staff assured the commitment and support of each institution. Each person was asked to participate when and where needed. For example, the entire group participated in binding and preparing programs, stamping envelopes for invitations, designing invitations, room set up and clean up among other tasks.

Forming a Multidisciplinary Team

For the program to be a success, all members of the renal community need to feel a part of the process. Ownership leads to more participation, attendance and support for future programs. Each committee member must consider commitment to the success of the program and its goals. Time lines must be identified. Toward the event, there are always last minute tasks. Having the major work completed allows ample time to deal with smaller but important details. A program of this nature requires a significant contribution of time over several months.

It is also necessary at this point to consider resources. A budget is needed. Be creative in looking for donations or discounted items. They may come from the renal community itself or from larger community organizations. They may be financial gifts or contribution of goods and services. Our contributions were acknowledged in the program and by thank you notes.

Committee Decisions: Planning the Event

Once a committee is formed, there are a number of decisions that are best made by the committee as a whole. First the population needs to be determined. It may make sense to include all of the dialysis and transplant units in a geographic area. This gives more resources to draw upon because it encompasses more people. It may be better to something on a small scale with just one or two units. Including a transplant team or a hospital based dialysis unit increases access to the hospital resources. These considerations will help them to determine how many attendees are expected.

Location is another major consideration. The facility needs to be large enough to accommodate the potential number of attendees, including loved ones, staff and patients. If a choice is made for the program to be non-sectarian, this will be a factor in the choice of location. This may omit churches from the list. It may also increase facility rental cost. Availability is critical. The committee needs to consider multiple dates. The facility needs to be assessable in terms of handicapped accommodations, access to public transportation and adequate free parking.

With a few locations that meet these criteria, further details are useful to explore. Services available on site will vary as will cost. Useful services include catering, security, set-up assistance, audiovisual capacity and support staff. There may be restrictions that make some facilities less desirable. Some will not allow the lighting of candles. Others may have additional services available and require their use, increasing cost. For example, refreshments that are donated may not be allowed or may have to be served by that facility's staff.

The final committee decision before breaking up into smaller task groups involves the consideration of symbols that touch upon remembrance. Some examples are candles, roses, rosemary and bittersweet. Making decisions about these at this point makes it easier to weave these themes into the program design, ambiance of the room etc.

Before planning the event there are some important tasks that need to be initiated early in the process that involve communication. Lists of patients to be remembered need to be obtained from whatever facilities are involved. The invitation needs to be drafted so it can be printed and mailed in a timely fashion. RSVP arrangements are an important part of the invitation and must be clear. Return cards add expense, but phone responses are not possible in all situations. Printing arrangements for the programs need to be considered. Finally, evaluations and their stamped, addressed envelopes need to be prepared.

The Service

Program Committee decisions will be key in establishing the tone and content of the remembrance service. Major decisions are brought to the full committee for discussion and final decision before implementation. The membership represents a microcosm of the talents and specialties of the entire planning committee. Previous exposure, either through personal experience or through literature is a useful component of member qualifications. Inclusion of pastoral care, social work, administrative and nursing disciplines provide a balanced cross section of education and work experiences to contribute diversity of included elements. Drawing upon the various religious, ethnic and racial backgrounds of members establishes the basis of a program with meaning to all participants and invitees.

Consensus regarding the length of the program is a key starting point. Audience age and physical limitations must be considered as must the event proceeding and following the service. Setting approximate time frames for each event during the development phase will provide a starting point for further refinement as the whole begins to take shape. Approximate numbers of guests expected based on numbers of patients to be remembered will be an important guideline for decisions regarding roles and numbers of volunteers needed to fulfill each function.

Room Set Up

The room designated for the service should be media equipped if large enough to require microphones for speakers and musicians. Chairs should be placed with aisles wide enough to accommodate wheelchairs at each end. Small boxes of tissues on every other chair will be helpful to guests.

Equipment

Podiums are helpful for the readers so that they may have a place to put script to maximize eye contact with the audience. If two podiums are used to facilitate flow of the program they may be placed at opposite side of the front. If floral arrangements and candles are to be part of the service, tables in the center, front may be used for placement. Table coverings, candleholders for large tapers, matches, candle lighter and snuffer will be needed.

Service Participants

All service participants should arrive approximately 1½ hours before the scheduled time of the service. Participants will have their rehearsal during this time period. At the same time the Set-Up Committee will ensure that the facility is prepared and all areas supplied with the necessary resources. A captain to circulate assessing readiness of the rooms and check on participants will provide a point person to make adjustments in staff or provide sufficient numbers to perform each duty. Committee members not participating in the service should be acquainted with all roles so that they are able to fill

in where needed. A group will also be needed to ensure that resources are collected and the facility is secure, neat and clean after the event.

Welcome

As guests enter the facility greeters and escorts should be available. The hospitality greeters' welcome will help to put guests at ease and set the tone for participants. If family members have a photograph for the Collage of Loved Ones, greeters take the photograph at this time. A quick check to make sure the name of the loved one is on the back of the picture will ensure it's safe return. Family members are encouraged to retrieve their pictures at the close of the service. The guests may then be directed or assisted to the "Welcome Table" to sign the guest books. Guests requiring assistance can then be seated in the main room by a hospitality greeter. An ample number of greeters for the expected number of guests insures that people are transitioned smoothly.

Those at the Welcome Table may again extend greetings, handshakes and words of encouragement. Some of the guests will be in need of more support than others. Participants need to recognize and respond to individual cues. A loose bound guest book will allow for pages to be separated so that multiple guests may sign in at the same time. A number of pens will be needed for the guest book and for pictures need to be labeled.

Program Greeters at the entrance to the main room provide guests with a program, and some welcoming words. Greeters should remain at the doors after the service begins to welcome and assist late arrivals.

The Collage Helpers will be stationed at a table in the front of the room. Framed pictures can be arranged on the table while loose photos will be placed on the collage. A good supply of poster tacks or a magnetic photo board that would not harm the pictures is helpful.

Background music playing during the assembly of the guests adds to the atmosphere and may be provided by taped or live music.

The welcoming speech that begins the service is an important mechanism to bring together participants and guests by highlighting the role of the remembered loved ones in uniting the group. The person chosen to deliver the welcome should have name recognition to the audience and should embody the level of commitment of the participants.

Music will be a key piece of the service. Committee members, friends, facility workers, and families may provide sources of talent for the program. Musical instruments, soloists and vocal groups should be representative of the locality of the service. Musical selections reflecting the religions and ethnicity of the audience will provide a sense of identity and comfort to the guests.

Readings such as scripture, prayer, poetry, and quotations may be interspersed with the musical selections to vary the tempo of the service. A litany of remembrance with

audience responses increases a sense of community. Readings, and musical selections included in the printed program should list author and composer. Service participants' names and titles also form part of the printed program along with song lyrics, scripture text and acknowledgment of all financial sponsors and donors of goods and services.

Lighting candles as names of loved ones remembered are read provides a powerful symbol of love and hope. Votive candles may be most acceptable to local fire codes but use of candles may not be permitted. Issues may exist regarding the reading or publication of names. If names are read aloud, each should be read slowly and clearly. Proper pronunciation of names should be provided to name readers. If names may not be read aloud, the audience may be asked to reflect on their loved one as the appropriate number of candles are lit. The process seems to run smoothly if two candle lighters, placed on either side of the table, alternate lighting their candles.

At the conclusion of the service, program greeters are again stationed at exit doors to provide each family with an evaluation form in a self-addressed stamped return envelope. Greeters direct families to the area where resources and refreshments are available.

The Resource table requires staff to assist families in selecting the materials most helpful for them. Staff should take the initiative, offering their support and assistance in the selection process and thanking families for attending the service. (see appendix for sample)

Refreshments would optimally be located in the same area as resources so that families are able to gather and meet. Seating areas should be grouped with service participants circulating to speak with families and assess needs. Staff will be needed for the refreshment area to greet and serve guests. Guests should again be thanked for attending and hope that the service was helpful.

As guests prepare to leave, staff should be available near exits to provide evaluations as needed and to give families the chosen symbols of remembrance. Guests should again be thanked for their participation as they depart.

Families may be reminded to retrieve photos and provided assistance as needed.

Discussion

The first Service of Remembrance for dialysis and transplantation patients in Springfield took place on October 24, 1999. The responses of significant others who attended are attached. Some of their words follow:

"It was meaningful to be able to connect with staff who had been so much a part of our everyday life."

"The lighting of the candles and the reading of names were most meaningful."

"Being a present patient, it made me feel good to know that I will be remembered."

"It meant so much to be able to chat with staff...At the time, (of death) good-byes were too hard."

A man who drove many people to dialysis for a van company said that he felt honored to be able to participate and be present. A physician was overwhelmed by the number of names on the list of those to be remembered, he mentioned how moved he was by the comfort and caring shared without barriers, freely and sincerely given. Others present felt comforted by knowing how much their acts of kindness meant. Some, who attended with misgivings or trepidation, were grateful to have been a part of the day and continued to talk about their experience long after the event.

All of the above factors influence the strength of the treatment team and ability to provide care for the total person. The process of coming together to develop the service and the act of participation in the events strengthen inter-professional relationships and connection with the families. The continuum of inclusion broadens team cohesiveness and understanding.

Prior to this there was no organized way for the community to join in honoring those who had died. The frequent treatments needed for renal failure with dialysis or transplantation requires regular contact with doctors, nurses, social worker, dietitians, technicians, secretaries, van drivers and members of community agencies. Long-standing and meaningful relationships, often of several years' duration, develop. When the patient dies, the family suffers not only the loss of their loved one, but also the connection with the renal support network.

Our committee faced challenges and obstacles. As we worked on the remembrance we encountered resistance to the importance of addressing death, dying and aftercare. Many people went into health care to help people recover or heal. We had to acknowledge our feelings about the large numbers of people who die each year and improve our willingness to view renal disease as a terminal illness. Opportunities for discussion of loss and feelings were brought into the workplace. Bereavement needs of caregivers were acknowledged. Resistance was sometimes expressed as reluctance to attend the service.

Another challenge was the time commitment required to plan and implement this type of service. The experience of the service and comments of loved ones provided a reward that clarified the importance of our efforts and motivated continued participation. In facing these challenges, it was crucial to be mindful of our purpose: to honor those who are remembered and to provide a pathway of support and caring for those who grieve.

This narrative was composed primarily by Anne Woods, LICSW, with the help of our organizing committee. 3/08/02