

Caring Through the End Final Stage of Chronic Kidney Disease



TIME REQUIRED

45 minutes

(55 minutes if optional pre-test and post-test are conducted)



PREPARATION/MATERIALS NEEDED

- Set up training space. The training room can be set up in many different ways. The recommended arrangement is a circle or a U shape so that participants can see and interact with one another.
- Pens, pencils, paper for participants.
- Name tags.
- Copies of your facility's guidelines (See additional preparation note below).
- Blank flip chart for taking group notes. If no flip chart is available, then use blank 8 ½ x 11 inch paper or a dry erase board.
- Prepare and post the following information well before the participants enter the room (see diagram below):
 - ◆ Module title
 - ◆ Purpose of training
 - ◆ Learning activities, including definitions, benefits to staff and patients, and group discussions

**Caring
Through the End**

Purpose of training:
Provide you with an opportunity to gain a greater understanding of how end-of-life issues may arise in our facility.

Learning Activities

Benefits:
How does the patient benefit if they are allowed to talk about end of life?

How does the staff benefit?

Learning Activities

Group discussions

- ❑ Optional: Photocopy pre/post-tests; 2 copies per participant.

ADDITIONAL PREPARATION FOR THIS MODULE

Before the in-service, consider pulling real samples of policy language or procedures from your unit. Try to find an example or sample of each kind of policy and procedure to inform discussions on how your specific unit deals with each of these issues. For example, have available:

1. A copy of policies, procedures or processes on palliative care.
2. A copy of the unit's policies, procedures or processes regarding medical directives. A sample medical directive for John Doe or Jane Doe (*not an actual patient*) should be made available at the training.
3. A copy of the policies, procedures or processes regarding "do not resuscitate" (DNR) orders should be made available in the training. A sample DNR order for a John Doe or Jane Doe (*not an actual patient*) should be made available.

If your unit has information about end-of-life support and resources, make this information available so that participants can be aware of resources to share with their patients.

Welcome and Statement of Purpose

(5 minutes)

Trainer states out loud:

*Welcome to the training on **Caring Through the End**. You'll see here that I've written the purpose of today's training on the flip chart.*

Trainer notes printed in italics

The purpose of the training is to provide you with an opportunity to gain a greater understanding of how end-of-life issues may arise in our facility. If they do arise, you'll want to know how to respond—appropriately, respectfully and honestly. We'll talk about how to discuss these issues with patients as well as families.

We'll also talk about the degree to which our dialysis care facility is integrating palliative care into their treatment plans.

We'll discuss, as a group, what end-of-life issues mean to those of us working in dialysis care, an area of health care where dying and death occur more often than other areas of health care. The mortality rate among people with end stage renal disease is 20 to 23 percent. That's almost a fourth of our patients.

Considering this mortality rate, we really can't pretend that we don't have to think about these issues. That's just not very realistic. It's also important to think about how we can help each other in managing our own grief and stress from patient deaths. So we'll take a few minutes to share with each other what we have done as individuals to cope with our own grief and how we've supported co-workers who were grieving.

Finally, we'll look at some related issues that come with end of life, like advance directives and orders called DNR (do not resuscitate) orders. So let's move on and define what we mean by palliative care.

Defining Palliative Care

(5 minutes)

Trainer states out loud:

What do we mean when we say palliative care?



Give a chance for anyone to answer, and then proceed.

Trainer states out loud:

Right. Your definition covers some of it. For the purpose of this in-service, the definition we're going to use is from the Renal Physicians Association (RPA) and American Society of Nephrology. In their Clinical Practice Guideline called "Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis," they define palliative care this way:

↳ *Active total treatment of the patient whose disease is not responsive to curative treatment. It affirms life and regards dying as a normal process. It neither hastens nor postpones death. It includes relief from pain and other distressing physical symptoms, integrates the psychological and spiritual aspects of patient care, and offers a support system to help the*

family cope during the patient's illness and in their own bereavement. Palliative care should be provided to ESRD patients throughout their course of care.

Another definition is:

↪ *Palliative care is special, end-of-life care that focuses on treating the whole person; body, mind and spirit. Palliative care works aggressively to relieve pain and other physical symptoms. Patients (and often members of their family) have a very active, independent role in deciding what care options are best for them.*

Will this In-service Make Me an Expert on End of Life?

Group discussion: 15 minutes

Trainer states out loud:

So are we saying that this training will make you a grief counselor? No! It is not the specific job of front-line dialysis treatment staff to discuss end-of-life issues with patients. But this training will better prepare you to provide supportive listening when a patient wants to talk about the end of his or her life.

How many of you have ever been with a patient who brought up the topic of dying, death or discontinuing treatment?



Take 5 minutes to allow the participants to tell their stories. If no one offers a story, you should be prepared to share one of your own. Then continue with the discussion.

Trainer states out loud:

Hearing your stories and how you handled some of them was very interesting.

It's true that attending a short in-service on end-of-life issues will not make any of us a grief counselor or an expert on death and dying. But it can prepare us as a staff member to listen and respond to patients' concerns regarding end-of-life issues.

In fact, it's not always a therapist or an expert that the patient wants or needs. Often staff can simply help by identifying the palliative care resources available. Knowing how to direct a patient or family member to services (especially peer programs, where patients are supporting other patients) will help the patient get what he or she need.

Let's take another five minutes to think about other services we could direct our patients to. I'll post your answers on the flip chart.

NOTE TO THE TRAINER



Many of the services mentioned will be specific to your specific unit and community. In general, listen for, and post, answers such as:

- ✓ Support groups, including peer support. Support groups can take the form of renal dialysis support groups, end-of-life support groups or other peer support groups.
- ✓ The clinic's social worker
- ✓ Hospice services
- ✓ Articles on patient's involvement in palliative care
- ✓ Brochures or pamphlets on specific services, including locations and time of services
- ✓ Web sites on renal disease, palliative care or end-of-life issues
- ✓ Any other specific services that the participants, or the trainer, know about

Discussing Palliative Care and End-of-Life Issues Can Benefit Staff and Patients

Group Discussion: 10 minutes

Trainer states out loud:

It's hard to believe that there can be anything positive about talking about the end of life. It all seems so sad and depressing, doesn't it? But being equipped to listen to patients, to be supportive and to inform the patient about resources can be very beneficial to staff. For example:

- ↳ *We can know that we are improving the quality of life of patients who are dealing with emotional end-of-life issues. We can offer treatments to help with pain management and improve patients' comfort and emotional, social and spiritual well-being.*

- ↪ *We can improve our skills for communicating with patients and their support persons about end-of-life issues.*
- ↪ *We can increase our knowledge about what palliative care is and how it might be integrated into our approach with our patients.*
- ↪ *Being aware of end-of-life issues helps ensure that we have the resources we need to deal with our own grief. We also can increase our own skills for positive self-management of stress and depression from working in an environment with chronic deaths.*
- ↪ *Dealing with end-of-life issues, including our own grief, helps to decrease staff burnout and turnover.*

Let's take a few minutes to answer this question: What are other ways staff can benefit from listening to our patients about end-of-life issues?



Add any other staff benefits to the flip chart, and then continue.

Trainer states out loud:

At the same time, it's hard to imagine that a patient would want to talk about his or her end of life. Why dwell on the end of life? Don't we want to help our patients focus on their dialysis treatment and staying alive? Isn't that the right approach to dialysis care?

Well, not always. It's only one approach. But believe it or not, giving patients the space to talk about end-of-life issues can bring them peace and relief. Here are some of the ways patients benefit from addressing end-of-life issues:

- ↪ *The more comfortable and accepting we are about end-of-life issues, the better it will be for patients who need resources, support or someone just to listen to them*
- ↪ *Because staff are better able to discuss this issue and/or make referrals to support networks and other services, the patient is less apprehensive about end of life*
- ↪ *Comfort and security from having a knowledgeable, caring staff*
- ↪ *Appreciation that people are being honest and open with them*

↪ *With palliative care, patients are offered treatments to help with pain management and increase their comfort and their emotional, social and spiritual well-being.*

From writing advance directives, living wills, health care powers of attorney and do not resuscitate orders (DNRs), to just sharing feelings, worries or concerns – all of this can be very therapeutic for the patient. What other benefits to the patient can you imagine?



Add any other patient benefits to the flip chart, and then continue.

Trainer states out loud:

We mentioned in the list of benefits that the idea of talking about end-of-life issues with our patients also gives us permission to talk to other staff members about our own grief. We know that the better we deal with our own sadness about the loss of a patient, the less chance we have of burning out and quitting our jobs.

Talking about grief and loss is very personal and, for some, very private. So I won't write any of it down on the flip chart. Let's just take a few minutes to share with one another. I have two questions:

- ↪ *How have you dealt with your own grief after patients die?*
- ↪ *How can we support (or how have we supported) co-workers when they are really sad?*

NOTE TO THE TRAINER



It's important not to rush this process. People may be hesitant to share their feelings, though they may really want to. It's important for you as the trainer to be still and quiet so people can get in touch with how they want to answer these two questions. Count silently and slowly to 50. If no one has opened up by the time you get to 50, then you should be prepared to share an experience that you have had; one of being sad or one of receiving/giving support. After the discussion, thank participants for sharing their experiences with the group and continue the training.

So How Do We Address End-of-Life Issues in Our Unit?

(10 minutes)

Trainer states out loud:

We know that no two dialysis units are alike and no two units address end-of-life issues in the same way. It's important for us to know what the policies and procedures are in this particular dialysis unit.

*So using the handouts that I've given you, let's take **10 minutes** to discuss the following questions:*

- ↪ *What are our policies, procedures or processes on palliative care?*
- ↪ *If we support palliative care in this unit, what's our procedure for talking to patients about their care options?*

NOTE TO THE TRAINER



Many involved in palliative care say that patients should be given all of their options to deal with end-of-life issues at the *beginning of their treatment*. Waiting until patients and family are in crisis is usually too late. This includes discussing the fact that refusing treatment, or discontinuing treatment, are also options. If your unit's policy and procedures are different, you should let participants know.

A copy of policies, procedures or processes on palliative care should be made available to each participant so that it informs the group discussion.

Trainer states out loud:

*What are our facility's policies, procedures or processes on **medical directives, including DNR orders**?*

NOTE TO THE TRAINER



A copy of the unit's policies, procedures or processes regarding medical directives and DNRs should be made available so that it informs the group discussion. A sample medical directive and DNR order for John Doe or Jane Doe (***not an actual patient***) also should be made available.

Trainer states out loud:

What are the clinic's resources in terms of peer support for our patients? Is there a patient-to-patient support group? Where is it located? Has anyone told our patients about these resources? How has the social worker been involved?

NOTE TO THE TRAINER



If the unit has **information about end-of-life support and resources** make that information available on a handout so participants will be aware of resources to share with their patients.

Resources/Wrap-up/Questions

(5 minutes)

Trainer states out loud:

You all did a great job in the discussion. I know a lot of this information isn't easy to think about or talk about, so I want to thank you for participating in this in-service.

Do you have any questions or comments about this in-service on palliative care and end-of-life issues?



Answer any questions or acknowledge comments.

Trainer states out loud:

I want to thank you all for coming to the training today. You did a great job.

I'm also passing out some more information on palliative care that you can take with you.



Additional resources that you can copy before your in-service are at the back of this module.

Optional: Post-Test

(5 minutes)

Hand out 1 post-test sheet per participant. Allow participants to work for a few minutes. Collect all sheets.

Want More Information?

Here are some resources to help you adapt this training module to your facility's circumstances or to share with your staff.

Articles

- ♦ Renal Physicians Association and American Society of Nephrology, *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, RPA Clinical Practice Guideline Number 2, Washington, D.C., February 2000.
- ♦ Campbell, Margaret, and French, Ellen, Eds, "Forgoing Life-Sustaining Therapy: How to Care for the Patient Who Is Near Death." American Association of Critical Care Nurses, August 1998, page 140.
- ♦ Perry, Erica and others, "Palliative Care in Chronic Kidney Disease: Peer Mentoring Program Personalizes Advance Directives Discussion." *Nephrology News & Issues*, July 2003, pages 28–31.

Web sites

- ♦ www.promotingexcellence.org
Promoting Excellence in End-of-Life Care, a national program of the Robert Wood Johnson Foundation, aims to foster long-term changes in health care institutions to substantially improve care for dying persons and their families.
- ♦ www.lastacts.org
Last Acts Palliative Care Resource Center provides practical information and tools on palliative care.
- ♦ www.growthhouse.org
Growth House is an international gateway to resources on life-threatening illnesses and end-of-life care.

Video

- ♦ *Dying in America—On Our Own Terms*
Investigative reporter Bill Moyers' four-part television series about illness and choices in dying. Viewer's guide and additional information from www.pbs.org/wnet/onourown/terms/. Order from 1-800-257-5126.

Additional Resources

- ♦ *Local Hospice Unit*
Contact your local hospice unit to discuss issues or questions regarding palliative care, end of life, etc.

Pre/Post-Test

Name:

Title:

Today's date:

Today's session: **Caring Through the End**

Goal:

This module defines palliative care and helps participants identify end-of-life issues that might arise in the facility as well as possible solutions and support.

Objectives:

- Describe, through group discussion, how to be a supportive listener when a patient wants to talk about the end of his or her life.
- Describe, through shared, personal storytelling, what kind of experiences technicians have had listening to patients and addressing their concerns about end of life.
- Demonstrate, through group discussion, familiarity with various support services, both on the unit and in the community, that patients could be directed to when they have end-of-life concerns.
- Define “do not resuscitate” (DNR) orders and the clinic’s DNR policy
- Describe, through group discussion, benefits to addressing end-of-life issues—both for the patient as well as the staff.

Directions: Please circle your responses, there is one correct answer for each question.

Questions:

1. When a patient brings up an issue related to dying or death, it's best to listen first, and then respond in some way. The response from the patient care provider should be:

- a. Appropriate
 - b. Respectful
 - c. Reassuring, even if it's dishonest
 - d. Quick
 - e. a and b
 - f. a, b and c
2. Palliative care is different from other kinds of care because it:
- a. Is provided when the patient's disease is no longer responsive to treatment
 - b. Speeds up death
 - c. Includes relief from pain and other distressing physical symptoms
 - d. Pays attention to the physical, psychological and spiritual needs of the patient
 - e. Offers support to the patient only, not the family
 - f. b and e
 - g. a, c, and d
3. One of the best ways to encourage and support a patient with end-of-life issues is to direct them to services, like support groups, peer support, a social worker, a hospice service, etc.
- a. True
 - b. False
4. Examples of the benefits to discussing end-of-life issues include:
- a. The patient becomes more secure knowing that they are surrounded by a caring, knowledgeable staff
 - b. The patient may feel more comfortable with writing advance directives or a DNR
 - c. The staff has the opportunity to improve their skills for communicating with patients and their families about end of life
 - d. Increasing knowledge about palliative care helps lead to its use with patients in the dialysis facility/clinic
 - e. All of the above
5. The best way to learn the facility/clinic's policies, procedures and processes on DNRs is to:

- a. Ask the patient
- b. Ask the patient's doctor
- c. Ask my supervisor
- d. Ask a co-worker

Developed by Mid-Atlantic Renal Coalition (contract number 500-03-NW05) and Academy for Educational Development
with funding from the Centers for Medicare & Medicaid Services
June 2004

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Available on-line at <http://www.esrdnet5.org/in-service.asp>