Title of Course: Death and Dying: The “Butterflies are Free” Program

CE Credit: 2 Hours

Learning Level: Introductory

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Abstract:

Dying isn’t a subject that Americans like to think about. Our national character is vibrant, optimistic, life-affirming. These qualities have been a great advantage to us as a people, but they have a down side. They make us less inclined to think about the inevitable sad events such as death. Consequently, we are often less prepared for it, psychologically and otherwise, than people in other cultures. The “Butterflies are Free” program was designed by the Staff Associates at Life Care Center in Sarasota, Florida to help overcome this problem and to enable healthcare workers and come to prepare for an ill person’s passing. This course presents a case study which reveals how the Life Care Center created and implemented an effective End-of-Life program for their residents. The purpose of this course is to introduce the history, ideals, and practices behind the program in the hopes that it may be adopted in other nursing home facilities.

Learning Objectives:

1. Identify the five issues that became the basis for the “Butterflies are Free” program
2. List the eight objectives developed to attain program goals
3. Name the characteristics of each of Elisabeth Kübler-Ross’s five stages of grieving
4. Identify the tasks to be accomplished in each of the three stages of the Butterfly program
5. Summarize the seven focus points of the Butterflies program
Death and Dying: The “Butterflies are Free” Program

Topic 1: What is the “Butterflies are Free” program?

Introduction

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The “Butterflies are Free” program was designed by the Staff Associates at Life Care Center in Sarasota, Florida to help overcome this problem and to enable healthcare workers and come to prepare for an ill person’s passing. The following course presents a case study which reveals how the Life Care Center created and implemented an effective End-of-Life program for their residents.

In this, the first part of the course, the origins and foundations of the program are described. When you are finished reading this topic section, you will be able to describe how the Butterflies Program began and what it is meant to accomplish.

Case Study: How Butterflies Came About

In the summer of 2002 an article was published in the New York Times quoting physicians from the American Medical Association as saying that “nursing homes are the worst place to die.” The article was read by Staff Associates at Life Care Center in Sarasota, Florida. While they did not accept the sweeping generalizations made by the writer of the article, the associates at Life Care Center were concerned enough to conduct a review of their own practices.

They quickly realized that what they provided for the dying resident wasn’t any different from what they provided for the non-dying. So on September 17, 2002, the Life Care Center began a continuous quality improvement (CQI) project to develop a quality end-of-life program. They named the program “Butterflies are Free” (the butterfly reference signifying “moving from one life to another”). This CQI project continued for nearly two years until July 20, 2004. Although the project is no longer active as a CQI exercise, the Life Care Center continues to make improvements to it. The Butterflies are Free program has become integrated into their facility and is a major part of their culture of caring.

The Problem

After concluding that improvements could be made in the way they approached end-of-life issues, the Life Care Center began tapping into every resource they could find. The Executive Director attended an end-of-life seminar at the Florida Health Care Association’s annual conference. The Director of Nursing began meeting with the local Hospice. The Social Worker began looking online for end-of-life resources. The Life Care Center found the End-of-Life Nursing Education Consortium (ELNEC) Web site www.aacn.nche.edu/elnec, the California Coalition for Compassionate Care (CCCC) www.finalchoices.calhealth.org, and Elisabeth Kübler-Ross’s “stages of grieving” to be particularly helpful. Using the CCCC’s “Assessing Your Facility’s Policy and Practice of End-of-Life,” the Life Care Center completed a facility self-assessment to determine how they felt about providing good end-of-life practices. The Life Care Center identified strengths, weaknesses, and opportunities for improvement, and established baseline data with which they would measure their progress.
The Life Care Center also began to review the needs of their residents, the residents’ families, and their associates to determine what services were needed at the end of life. Initial issues identified were:

- **Resident Comfort**: Residents and families had major concerns regarding residents’ comfort at the end of life.

- **Lack of Knowledge**: Families didn’t know what to expect from the dying process and therefore were reluctant to accept their loved ones’ approaching deaths.

- **Sudden Changes**: At the Life Care Center concerns were expressed about new faces and new philosophies being introduced to residents at the end of life when Hospice staff arrived to provide care. The Life Care Center is fully staffed, with no agency personnel, and this staff on a permanent assignment basis. Because the Life Care Center staff and residents know each other so well, this has created a family culture in their facility—and new faces are new faces.

- **Money Issues**: Financial strain on residents and their families were posed by end-of-life programs already operating in the community.

- **Death and Dying Acceptance**: The Life Care Center associates felt just as uncomfortable with the dying process as the families because of a lack of education and experience.

The Life Care Center assembled an interdisciplinary team, including the Executive Director, Director of Nursing, Social Services Director, Financial Director, Activity Director, and volunteer representatives from nursing, dietary, and housekeeping. Three family members, representing various faiths, were also involved in the early planning stages.

**Planning**

Based on the above information, the team developed the following goals: “Establish an end-of-life program that maintains comfort and dignity for the resident, involving the family, residents, and staff in the plan of care at their personal level of comfort. The end-of-life program should put no financial strain on the family.” The team established the following eight objectives to meet the goals:

1. The resident will be pain- and anxiety-free during the dying process.
2. The family will be actively involved in the end-of-life care and dying process.
3. All associates involved will be aware of the end-of-life care plan.
4. The goal for out-of-pocket expense for the resident and family will be from $0 up to the Medicare co-pay.
5. The resident’s Medicare benefit will be appropriately maximized.
6. The resident and family will be part of the team.
7. The resident and family will assist in developing the care plan.
8. The resident and family will feel/trust that their needs are being met.

The team determined that data would be collected for the following indicators:

- use of pain medication prior to death
- time and shift of death
- witnessed versus unwitnessed deaths
- out-of-pocket expenses for families and residents family concerns

**Education Team**

Teams were developed to initiate different components of the program:
They consisted of the Executive Director, Director of Nursing, Staff Development Coordinator, Social Workers, Hospice, and family members.

- The Staff Development Coordinator secured training resources from Hospice, ELNEC, Long-Term Care Network, CCC, the works of Kübler-Ross, and other providers specializing in death and dying. All associates received training on death and dying. Orientation (for new associates) and competency training on death and dying (including the Butterfly program) were added to the annual requirements for associates.

- Hospice provided information on pain management. Additional training resources were obtained to assist families in their understanding of the dying process. The Life Care Center also determined ways that they could partner with Hospice, as the services it provides to families have a long-reaching impact.

- The Executive Director and volunteer family members purchased books that helped loved ones cope, deal with loss, etc. Many of these were children’s books that tackled the subject of death in a way that anyone would feel comfortable understanding.

- The Social Worker prepared a handout to provide the families with ideas of things to do for the dying resident or things to talk about.

Members of the nursing team developed the stages of the program to use as a teaching tool for residents and families.

**Clinical Needs Team**

The Clinical Needs Team consists of the Director of Nursing, Assistant Director of Nursing, unit managers, nurses, Pharmacist, nursing assistants, and Hospice. This team performed the following:

- Identified a process for early identification of residents who might need the Butterfly program. This is called the “Butterfly Watch,” and several options exist for identifying these residents.

- Developed three stages of the Butterfly program to identify residents’ clinical, nutritional, psychosocial, medicinal, and emotional needs.

- Developed a consent form for the program.

- Developed a focus charting form, which highlights areas of specific interest to the dying resident that the nurse will want to make sure to chart.

- Developed a way to identify the room and chart of a Butterfly resident (butterfly sticker on the spine of a chart and a butterfly cutout placed next to the resident nameplate next to his/her door).

- Developed an end-of-life care plan.

- Developed a checklist for residents’ needs.

- Using the daily bed management form, the team developed a process to identify Butterfly residents, their current stage in the program, and the status of their advance directives.

**Psychosocial Needs Team**

This team was composed of the Executive Director, Social Workers, Central Supply Coordinator, unit managers, nurses, nursing assistants, dietary associates, and housekeepers. Their duties were as follows:
• Developed a Spiritual Assessment.

• Identified Kübler-Ross’s five stages of grieving as a tool for families.

• Filled a mobile cart with items that the team felt would bring comfort to the resident. This cart is rolled into residents’ rooms when they are ready for it and stays there until residents pass away. A butterfly night-light is placed on the resident’s bedside dresser.

• A Butterfly Journal is placed in the resident’s room so that the associates can write messages to the resident or family members. These often include wonderful messages about their love for the resident, the special bond between them, a favorite memory, or a spiritual invitation to the eternal journey that lies ahead. Messages of love and appreciation are written to the families to let them know how much they mean to everyone in the facility. The journal fills two very important needs: First, it lets the family know just how much their resident is loved; second, it shows them how often associates came to visit their loved ones. The journal is perhaps one of the most important parts of the program.

• Sandwiches, coffee, snacks, or other comfort foods are provided to the family as the resident’s death nears.

Resident Participants

Various residents volunteered to do special tasks, such as praying with families or with other residents who were dying, or sitting with a dying resident when the family is not available.

Mission Statement

A mission statement was also developed: “To provide comfort through palliative care and individualized attention for those residents who are at or near the end of their life.”

Learning Activity 1:

Scenario: As supervisor, it is your job to oversee associates working in your organization’s Butterfly Program. Emily, one of your subordinates is overseeing the training of a new associate, Glenn. During a routine meeting, Emily lists the actions she has taken to further Glenn’s training. Based on what you have learned about the Butterfly program, write a critique of Emily’s training approach. Then look below to see the answer.

• Emily allowed Glenn to shadow her while she worked with Mr. Wesley, a resident who had been in the Butterfly program for two weeks.
• Emily demonstrated how to tend to Mr. Wesley’s personal comfort and how to communicate with family members.
• Emily stressed to Glenn how money issues can be a source of stress to the resident’s families.
• Because Glenn was formerly an E.R. nurse, Emily believes he can be brought into the Butterfly Program right away.

Answer to Learning Activity 1:

It probably was not a wise move to bring Glenn into an ongoing Butterfly treatment. New faces can be jarring to residents in the new program as well as to family who are dealing with the imminent death of a loved one. On the other hand, Emily did well to demonstrate methods of communication with residents and family and by emphasizing to Glenn that end-of-life issues cause financial strains for family members.
However she is wrong to assume that Glenn’s E.R. experience perfectly prepares him for working in a Butterfly program. E.R. nurses often see patients for short, intense periods. Typically, they never get to know their patients as people. Healthcare workers in an end of life program get to know residents over time. A personal connection is often created, making the passing of the resident difficult for the associate. Everyone who participates in a Butterfly program should receive training on coping with the emotional distress that comes after a resident passes.

Learning Activity 2:

Consider what items you think you should be placed in a Butterfly cart. Write down your response and then look below to see a list of the items that Lifecare used in their Butterfly carts.

Answer to Learning Activity 2: Butterfly Cart Contents

1) Music: CD/cassette players and hundreds of CDs to choose from. Music to suit the resident’s taste is placed in the bottom drawer of the cart so that the resident can have his/her favorite music at any time. For example, by providing the CD/cassette player and stressing the importance of music, the Life Care Center gave the daughters of a dying gentleman who was an Irish immigrant the idea to bring in cassette recordings of him singing Irish songs he had recorded 30 years earlier. It was abundantly clear to everyone that this music not only comforted the resident but also the family.

2) Books and inspirational information: The Chicken Soup for the Soul line of books, children’s books about death and dying, reminiscence books, books of poetry, and books that offer a line of questions to ask to record a person’s legacy. Bibles, prayer books, and other spiritual journey materials are included in the cart’s middle drawer, as are laminated instructional sheets and laminated copies of the Lord’s Prayer and the Hail Mary.

3) Hygiene Products: The top drawer contains comfort-related products such as tissues, toothettes, softly scented lotion for hand massages (if appropriate), talcum powder for back rubs (if appropriate), baby wipes for cleansing, and bed/bath items if necessary.

Topic 2: Practices and Procedures of the Butterfly Program

Introduction

Anyone who has performed even cursory research into the subject of the dying process is familiar with the name of Elisabeth Kübler Ross, the Swiss-born American psychiatrist who is credited with making the world aware of the special needs of dying people. Dr. Kübler Ross is best known for identifying five stages of the dying process. Knowledge of the stages was used in shaping the Butterflies are Free program.

In the following topic section, you will learn about Dr. Kübler Ross’s ideas and the procedures used in the Butterflies are Free program. At the conclusion of this topic you will be able to implement the practices used in the Butterflies are Free program in your own healthcare facility.

The Five Stages of Grieving

According to Kübler-Ross, once fatally ill people learn that death is imminent, they (and people close to them) pass through the following stages:

1) Denial and Isolation - The dying person or his/her loved ones are in disbelief. They withdraw; keep to themselves, denying that the problem exists. Although it is hard for others to understand, this stage can give the caregivers a time to help prepare the grieving person for what is to come.
2) **Anger** - Rage is expressed at whoever is nearby. Often, the person grieving can be unpleasant to be around and takes his/her frustration out on others.

3) **Bargaining** - This stage of grieving is an “attempt to postpone” the impending grief or death. Often, the grieving person attempts to make ‘deals’ with God, such as “if you let him/her live, I promise I will ………”

4) **Depression** - Deep sadness is felt over the loss (or impending loss) of a loved one. Encouragement and support are needed to help those who are depressed move into the next phase.

5) **Acceptance** - Death has occurred and the loved one is at peace. The grieving person is finally able to acknowledge that his/her loved one has died and is able to function normally in life’s daily tasks.

### The Butterfly Watch Process

Once residents are identified as potential Butterfly Watch by the management team, the resident is reviewed during the “Resident at Risk” weekly meeting.

If a resident has two or more “indicators” (as listed below), the resident may be placed on a 14-day observation period and added to the Butterfly Watch.

- Weight loss
- Decubitus ulcer
- Falls
- Infections
- Change in mental status
- Change in level of function
- Continence status change

After completion of the 14-day observation, a determination will be made for a “Significant Change” or an admission to the “Butterflies are Free” program.

The Admissions Office is concerning the resident’s status. This information will be added to the daily census report that is available to the management team each morning.

Once a resident is admitted to the program, a Care plan meeting is scheduled with resident and family. A Butterfly designation is placed on the door so that all the staff members are aware of the resident’s new status. While all medications and therapies are continued, refusals are allowable. The therapy is paced to the resident’s tolerance.

The staff monitor the resident’s pain daily and medicate as indicated (lab orders are continued). Given the terminal diagnosis, a liberalization of diet is allowed. Family may bring in favorite foods and beverages. In addition a DNR (do not resuscitate), CTI (certificate of terminal illness, which is a Florida regulation), and a “do not hospitalize” order are obtained. Advance directives are discussed and clarified by the healthcare surrogate/proxy with resident and/or family.

### Implementation

The resident is identified for end-of-life care through the Butterfly Watch process, i.e.:

- Change in two or more indicators, e.g., weight loss, decubiti, falls, infections, mental status, level of function, or continence status.
- After completion of a 14-day observation period (based on the above criteria), a determination is made for a significant change in status or admission into the Butterflies are Free program.
If the resident has a sudden decline in condition, he/she can be admitted into the program. The resident and family are notified of the program, and education is provided on the program's stages and what to expect in the dying process. In addition a hospice consult is offered.

The resident or his/her legal decision maker provides signed consent to participate in the program. Social Services complete the spiritual assessment, ensuring that end-of-life wishes are known and opportunities for unresolved issues are available. Next Kübler-Ross's five stages of grieving are reviewed with families to help them cope with feelings of loss.

The resident's name and stage in the program are listed on the daily bed management form. Residents in the Butterfly program are reviewed daily if changes are noted. A butterfly is placed above or below the nameplate at the door of the resident’s room to identify that the resident is in the Butterfly program. A butterfly sticker is also placed on the spine of the resident’s chart to alert the nurses that the resident is in the program.

An end-of-life care plan is developed with the resident and family. This plan will change and need to be updated as the resident progresses through the dying process. The three stages of the program are again reviewed with the resident and family. (Just as each resident ages differently, residents die differently, and not every stage will apply equally to each resident.) Discussions are held regarding medications, lab tests, and diet and consistency of food, as well as psychosocial and spiritual needs.

A Focus Charting alert is placed in the resident’s chart so that nurses will know to chart on the areas that are highlighted. The highlighted items come from the care-planning process.

If desired, a Butterfly Cart is wheeled into the resident’s room. The cart is a three-drawer, heavy, plastic cart on rollers that can be purchased at any discount or office supply store. In the cart are items the team believes will bring comfort to the resident and the family (see “Butterfly Cart Contents” later in the course document). Also, a butterfly night-light and Butterfly Journal are placed on the bedside table.

An Activity Department representative will interview the resident or the family to determine a favorite hobby or travel destination that the resident has enjoyed. Every effort is made to decorate the resident’s room so that he/she will remember the hobby, activity, or favorite travel destination.

Associates make several visits to the resident. Some associates stop to pray; others read to the resident; and yet others just stop by to ensure that the resident is comfortable or to tell him/her that he/she is loved. Everyone writes in the resident’s journal. If desired, music is played and softly scented lotion is applied to the resident’s hands and arms, if appropriate. Other attempts are made to soothe and comfort the resident.

Residents are invited to come and visit with other Butterfly residents, and often they do sit and hold a hand. Other times they pray together. Families are invited to participate in the resident’s care at their own level of comfort. For example, if a family member wants to participate in the pain-management program, training is given on how to monitor for signs and symptoms of anxiety and pain. When the family member sees these signs and symptoms, he/she will alert the nurse so that medication can be given.

As the resident moves through the dying process, the care plan is constantly updated. Making changes to the texture of food is important, and comfort foods are added as desired. (Oreo cookies and ice cream are the number one requested comfort food, and associates are quick to fill those requests.) Routine medications are normally discontinued, and pain medications are monitored for effectiveness. Labs and x-rays are discontinued unless they address an acute situation, relief of which might enhance the resident’s comfort.

A checklist is given to the nurse manager of the resident’s unit to ensure that the facility has not overlooked any opportunity to bring comfort to the resident (see appendix).
Dietary staff routinely check with the family to see if snacks or soft drinks are needed. Spiritual comfort is provided as per the resident’s preference. In addition, every effort is made to have associates in the room with the resident at the time of death.

A stuffed bear (similar to a Beanie Baby) with a butterfly embroidered on its stomach is given to the family as a keepsake. When a family has small children, the Life Care Center often gives each child a Butterfly Bear.

Following the resident’s death, a book called Beyond This Day, with stories and devotionals geared toward helping the family cope with the death of a loved one, is mailed to the family, along with a cedar keepsake box and the Butterfly Journal.

Associates are encouraged to attend funeral services for the deceased resident and may be asked to speak at the funeral. Memorial services are also held at the facility.

**The Stages of the “Butterflies are Free” Program**

Although the progression of the specific steps for the Butterfly program may vary by resident, it is often helpful when explaining the Butterfly program to use definable stages. Below is a breakdown of 3 stages of the Butterfly program that advance as the health of resident deteriorates. You may find this structure useful when developing your own approach to the Butterfly program.

**Stage I:** This stage is initiated when the family/resident approaches the facility staff about end-of-life options. There is some uncertainty if this is really the end-of-life even though a sudden decline is observed. The family may have some concerns over the comfort of their loved one.

**Stage II:** At this point the Butterfly Cart is placed in room. A review of all medications with the family is undertaken and all non-comfort medications are discontinued. Laboratory orders are continued to obtain a better assessment. The staff discusses the goals of therapy and an order for “as needed” pain medication is obtained.

Nursing pain assessment is conducted every eight hours. Weights are discontinued while routine showers proceed (with aggressive mouth care initiated). Also staff assess whether a microair/specialty bed is needed. An arrangement for spiritual support is made. Pet therapy can also be obtained. The clinical leadership team visits every three days and weekly care plan meetings with family are arranged if needed.

In Stage II the resident shows signs of progression of disease or verbalizes readiness to die exemplified by:

- Wounds
- Appetite decline
- Weight loss
- Decrease in activity
- Increased pain
- Guarding

Also, residents may be unable to swallow medications or unwilling to do so.

Family is made aware of the end-of-life, and focus is on comfort and quality of life (Family involvement in Life Care Center end-of-life program is welcomed.)

**Stage III:** By now all initiatives under stages I and II are completed and maintained.

Social Services assess the need for clergy and, if clergy are needed, initiate the call. Clinical signs and symptoms are monitored every four to eight hours. Laboratory work, weights, and therapy are discontinued. Medications are reviewed. As many as possible are discontinued.
Pain should be assessed every two hours and medication provided if assessment warrants. The family is encouraged to be present at bedside. The Leadership team should make contact with resident/family daily. Also, the dietary manager should provide snacks and drinks once per shift for the family or on request.

As death becomes imminent, move the resident to a private room if possible and arrange Care plan meetings with family as necessary. In Stage III, the resident is in the active stage of dying. Bed mobility is poor, and there is high risk for wound development. Motivation is very low. This can be demonstrated by refusal of oral intake and/or becoming incontinent. There can be periods of decreased awareness/arousal or loss of consciousness.

**Learning Activity 3:**

**Scenario:** Anna, one of the Butterfly associates, has put together a list of adult, full length novels that deal with End-of-Life issues. In addition she has taken away the children’s books such as “The Fall of Freddy the Leaf” since she thinks they are too simple and childish to give to an adult.

Write a critique of Anna’s actions and look below for the answer.

**Answer to Learning Activity 3:**

While adult novels may deal with issues like life and death with greater nuance and insight than children’s books, Anna should realize that the mental capacities of the dying resident are probably diminished, thus making them incapable of reading a full length novel or non-fiction book. By comparison, well written stories about death and dying written at a very simple level can be appreciated by residents as well as their families.

Anna’s list, however, may be useful reading for a Butterfly resident’s family members and Butterfly associates.

**Learning Activity 4:**

**Scenario:** Emily is concerned about Mr. Sanders, one of the regular residents. Lately he has seemed confused. He also has experienced a weight loss. She approaches you and recommends that he be immediately admitted to the Butterfly program.

How should you respond? Write down what you think the appropriate response is and then look below for the answer.

**Answer to Learning Activity 4:**

The symptoms displayed by Mr. Sanders suggest that he should be placed under observation. However, they are not so extreme that they warrant immediate admission to the Butterfly program. Unless there is a significant change in his condition, two weeks observation is recommended before a decision is made.

**Topic 3: Improving the Effectiveness of the “Butterflies are Free Program**

**Introduction**

Quality assurance and evaluation are essential in any organizational practice. However, they take on a special urgency when applied to practices that are intended to help dying people and their families cope with the inevitable. The same standards of quality that are observed when we first come into the world should be applied when we are preparing to leave it.
The following topic section presents a case study detailing how the Life Care Center solved a dilemma which is probably common to end of life programs—dealing with the level of pain medication needed for dying people. Reading through this topic section should encourage you to think about such problems. When you are done reading, you should be able to anticipate and resolve problems unique to end of life programs.

Data Collection

Data collection for Life Care Center was focused on the goals the established at the beginning of the project. The deaths that occurred in 2002 were used as the control group and compared with the deaths that occurred in 2003 to see if the program made a difference. The goals that the team selected for 2004 were based on the 2003 data, and included:

- increase the number of witnessed deaths
- have earlier identification of residents in the end stages of their lives
- continue use of the pain medication Roxanol and the anti-anxiety agent Ativan for comfort
- identify residents willing to become members of the Butterfly comfort team

Addressing Problems

During the initiation of the Butterfly program the Life Care Center identified some conflict between the rehabilitation staff (physical and occupational therapists) and the nursing associates concerning the Butterfly residents who continued to receive therapy. The conflict focused on the administration of a narcotic analgesic, Roxanol (morphine sulfate), before therapy sessions. For some residents this meant they were too sedated to participate in therapy. Therapists, accustomed to an aggressive therapy approach, felt that the analgesic was interfering with therapy. On the other hand, some nursing associates were reluctant to administer analgesics at doses high enough to achieve comfort, fearing that their dose would be the “last dose” given before death. Apprehension was high among both groups.

To combat these fears the Life Care Center took the following actions: Hospice was requested to provide additional training for all disciplines on the use of Roxanol and anti-anxiety medication to maximize comfort and improve quality of life toward the end-of-life. The consultant pharmacist was asked to review residents’ medical records to verify that the nursing associates were adequately assessing the residents’ comfort level before administering analgesics. He was able to document that an increase in Roxanol use occurred after a decline in a resident’s condition and was not the cause of that decline.

The additional training and discussion among disciplines at ethics meetings served to give associates a greater level of comfort with the use of an analgesic. (A review of pain assessment and management at the end-of-life is now part of the Life Care Center annual continuing education program for licensed nursing staff.)

The Life Care Center kept detailed statistics on those residents who received Roxanol, with the goal of determining how early identification of the Butterfly residents affected pain management. The Life Care Center found that the average time between identifying the resident as qualified for the program and the subsequent initiation of Roxanol was six days. The decline in the percentage of deaths within six days of starting Roxanol from 78% in 2003 to 50% in 2004 demonstrated an improvement in earlier identification of the Butterfly candidates, thus satisfying one of their major goals. Deaths within two days of starting Roxanol remained virtually the same in the first six months of 2004 as it was in 2003. This lack of improvement may represent those residents who appear to be fine one day and take a dramatic turn the next, not allowing time for the use of Roxanol. Another factor in this seemed to be that the resident did not appear to be in pain at this late stage and/or had already been given other sufficient pain medications.
Positive Outcomes

One of the biggest improvements was the reaction from families of residents who were in the Butterfly program. The Life Care Center received thank-you cards and letters from many of them, which let them know just how much families appreciated the extra-special things that were done for their loved ones during their Butterfly journey. It became clear to the Life Care Center that the music, reading, hand massages, and every visit, no matter how short or how long, were touching lives in a very special way. Families often cry when they read the expressions of love written in the Butterfly Journals. Many, especially those family members who lived out of town, told the Life Care Center associates that the journal gave them a sense of peace, knowing that their loved one was so well loved and was visited so often during his/her final days.

Another unexpected outcome was detected in the community at large. The Life Care Center began receiving direct referrals from Hospice, family members, and physicians in the community who had heard about their program. This has strengthened their reputation and has provided them a specialty role to perform in the community. In fact, the Life Care Center is now sharing their program with their local competitors.

Overview

In brief, the focus of a “Butterflies are Free” program should be:

1. early identification of Butterfly residents
2. continued comfort measures for residents
3. effective pain control
4. resident involvement
5. family comfort
6. reduced family expense
7. staff comfort

The Butterflies are Free program, when embraced as a part of a culture of caring, can become the expected approach to caring for all end-of-life residents. The cost is minimal, and the improvement in the end-of-life experience for both residents and families can be dramatic. The comfort level of staff with the dying process can improve immeasurably.

All or parts of this program can be implemented easily in any nursing home or assisted living facility. It is the sincere hope of the Life Care Center associates that this program will have a positive affect on residents all across the nation.

For more information, contact Nina Willingham, CNHA, Senior Executive Director, at (941) 360-6411. For more information on the OPTIMA Awards, visit www.nursinghomesmagazine.com. To send comments to the editors, please e-mail optima0905@nursinghomesmagazine.com. To order reprints in quantities of 100 or more, call (866) 377-6454.

Learning Activity 5:

Scenario: After two weeks, it was decided that Mr. Sanders should be admitted to the Butterfly program.

Emma is working with him. She has seen to it that he has a Butterfly cart and a journal by his bedside. She routinely communicates with Mr. Sander’s family. She also keeps other residents away so that they will not be depressed by Mr. Sanders decline.

Mr. Sander’s died three weeks after being admitted to the program. Emma decided not to attend the funeral since she thought it would be better to focus her energies on positive activities like working for new residents in the program.

Write a critique of Emma’s performance and then turn to the next page for the answer.
Answer to Learning Activity 5:

It was good of Emma to be mindful about the Butterfly cart and the Butterfly Journal. Those are essential tools, especially the journal. However, she does not yet understand that part of the Butterfly philosophy is confronting death. Discouraging healthy residents from visiting a terminally ill friend in the Butterfly program does no service to either the healthy residents or the dying residents. Moreover, while going or not going to a funeral service is her choice, Emma should consider that attending the service is a valuable way to say goodbye to someone with whom she had formed an emotional bond.

Butterfly Resources

Special Papers:

- Butterfly Instruction sheet – “Patchwork Spring” Paperframes by Paper Direct, Item HF3143
- Butterfly Prayer Cards – “Butterflies” jumbo postcard by Paper Direct, Item HP619

Books – sampling

- The Memory Box by Tammy L. Pitre (order through corporate shipping)
- I Remember Grandpa by Tammy L. Pitre (corporate shipping)
- The Fall of Freddie the Leaf by Leo Buscaglia, Ph.D. (excellent book)
- A Cup of Comfort for Inspiration by Colleen Sell
- Chicken Soup for the Caregivers Soul by Jack Canfield, Mark Hansen and Leann Thieman
- A Cup of Comfort for Mothers and Daughters by Colleen Sell
- Dear Mom, Thank You for Everything by Bradeley Trevor Grieive
- Consider the Butterfly by Carol Lynn Pearson
- Hugs for Grandma by Chrys Howard
- The Mothers Guide to the Meaning of Life by Amy Krouse Rosenthal
- The World According to Mister Rogers by Fred Rogers
- P.S. I Love You by Will Bullas
- My Grandfathers Blessings by Rachel L. Naomi Remen, M.D.

Music – sample of those found in carts

- Whatever type of music the resident would like to hear, we seek to find it!

Butterfly Carts (additional contents)

- Butterfly Bear – “Eternity Bear” by Holy Bears; www.holybears.com
- Small talcum powder
- Toothettes
- Small scented lotion (lavender is popular)
- Kleenex
- Blistex
- CD player
Other Butterfly items

- Butterfly night light – various sources
- Butterfly door designation – various school supply stores; butterfly die cuts; or outlines of butterflies simply traced and cut by hand
- Butterflies to hang from the ceiling
- Posters, photos, etc that bring comfort to the resident. “We may ask a resident, if you could go anywhere you wanted to go, where would it be?” If the answer were “Italy”, we would try to find things that reminded the resident of Italy, such as posters, pictures, music, food, etc that would bring comfort to the resident.

Butterflies are Free Program Consent Form

I have reviewed the End-of-life – “Butterflies Are Free” Program. I have had the opportunity to ask questions and understand the answers given me. I understand there is no fee for this program. I choose to participate in this program.

The goals of this program are:

- To ensure that residents receive medical care consistent with their choices
- To provide human and spiritual support to residents during the dying process
- To enable the dying resident to be as free from pain as possible
- To support the resident & family during the dying process

I acknowledge that I may rescind my consent to participate in this program at any time.

__________________________________    __________
Resident Signature                                            Date

__________________________________
HealthCare Surrogate/Proxy
Sample End of Life Care Plan

Date Initiated:

Review Date:

Problems & Strengths:
  • Is in the End of Life stage

Goals:
  • Resident will not undergo unnecessary medical interventions or transfers. Resident’s comfort will be considered with each intervention to ensure he/she remains as comfortable as possible. (e.g. labs, weights, vital signs, etc.)

Approaches:
  □ Review Advance Directives
  □ Continue to review resident preferences
  □ Review effectiveness of current treatment plan
  □ Provide options and choices
  □ Attempt to provide symptom management on site
  □ Eliminate unnecessary treatments per resident wishes
  □ Report any change in condition

Disc:
  • Nursing
  • Social Services

Goal Analysis:

RESIDENT _______________________________________________________

ROOM NUMBER _________

DATE OF ADMISSION _____________________________________________

PHYSICIAN _____________
Checklist: Butterfly Resident

Resident Name: _______________________ is on the Butterfly Program. Please document every shift on the following:

| Pain interventions (include pain scale, medication administration & outcomes) | 
| Activities of Daily Living (level of assist) | 
| Food and Fluid intake | 
| Bowel and Bladder function | 
| Skin Integrity | 
| Mood and/or Behavior | 
| Cognition | 
| New Orders (Medications/Labs) | 
| Significant changes | 

NOTES:

Checklist: Advanced Directives and Review of Program

Resident Name _______________________________

Complete this checklist by indicating the actions that are appropriate to meet the patients’ wishes. Not all areas will be appropriate for all patients / residents.

<table>
<thead>
<tr>
<th>Advanced Directives</th>
<th>Date Effective</th>
<th>Stage</th>
<th>Initiated / Comments / Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certificate of Terminal Illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do Not Resuscitate Order</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living Will</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Care Surrogate or proxy information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do not Hospitalize order</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospice consult</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family conference with Hospice</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Counseling for resident</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resident or surrogate goals and values for life-prolonging interventions</td>
<td></td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Review of Program</th>
<th>Date Effective</th>
<th>Stage</th>
<th>Initiated / Comments / Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Butterfly program reviewed with resident</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resident options and choices obtained</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Butterfly consent form signed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>End of Life care plan implemented</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Butterfly Assessment including psychosocial and spiritual information completed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Butterfly Cart initiated</td>
<td></td>
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</tbody>
</table>
### Social, Emotional and Spiritual Needs

<table>
<thead>
<tr>
<th>Date Effective</th>
<th>Stage</th>
<th>Implemented/Comments/Status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

- Therapeutic conversation implemented
- Opportunities for completion of personal affairs
- Clergy involvement as indicated by personal preferences
- Spiritual needs addressed
- Funeral service and funeral home wishes discussed
- Opportunities for resident and/or family to maintain a sense of control presented
- Involvement in choices and decision making offered and implemented
- Hospice involvement related to counseling for family and resident
- Prayer and meditation support offered by associates
- Bedside activities (per the resident’s patience and tolerance) offered which comfort the resident, e.g. music, aroma therapy, message, pet therapy, etc. (see care plan)
- Humor therapy offered
- Private time for relationships offered while minimizing resident and family isolation
- Residents and family offered extra chairs, snacks, sodas, coffee, etc (Stage III especially)
- Private room offered as death becomes imminent (if available)
- Counseling offered
- Family or associates at bedside – Stage III

### Education

<table>
<thead>
<tr>
<th>Date Effective</th>
<th>Stage</th>
<th>Implemented/Comments/Status</th>
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</thead>
<tbody>
<tr>
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</table>

- Resident understands the dying process; knows what to expect as death grows closer
- Family understands the dying process; knows what to expect as death grows closer
- Resident and family understand the role of pain management in the dying process
- Resident and family understand the changes in body metabolism; understand there is less need for food or fluid as the body moves toward death

### Labs, X-Rays, Therapies, Medications, etc

<table>
<thead>
<tr>
<th>Date Effective</th>
<th>Stage</th>
<th>Implemented/Comments/Status</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

- Lab orders
- X Ray orders
- Routine Medications
- Pain Medications, including PRN
- Anti-biotic use
| **Dialysis** |  |
| **Therapy** |  |
| **Micro-air or specialty beds** |  |
| **Weights** |  |
| **Blood transfusions** |  |
| **Oxygen** |  |
| **Outside medical appointments** |  |

<table>
<thead>
<tr>
<th><strong>Skin Integrity / ADL’s</strong></th>
<th>Date Effective</th>
<th>Stage</th>
<th>Implemented/Comments/Status</th>
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</thead>
<tbody>
<tr>
<td>Precautions for skin breakdown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Turning every two hours</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positioning</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monitoring</td>
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<td></td>
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<tr>
<td>ADL’s</td>
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<td></td>
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<tr>
<td>Transfers</td>
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<tr>
<td>Meals</td>
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<td></td>
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<tr>
<td>Mobility</td>
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<td></td>
<td></td>
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<tr>
<td>Oral Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peri Care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Toileting</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Food / Diet / Hydration</strong></th>
<th>Date Effective</th>
<th>Stage</th>
<th>Implemented/Comments/Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet orders, including consistency</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resident preferences for food identified</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pleasure foods vs risk of aspiration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tube feedings</td>
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<td></td>
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<tr>
<td>IV’s</td>
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<td>Hydration</td>
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<table>
<thead>
<tr>
<th><strong>Pain</strong></th>
<th>Date Effective</th>
<th>Stage</th>
<th>Implemented/Comments/Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-verbal signs and symptoms of pain being monitored</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anti-anxiety medication effectiveness monitored</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Resident involved in pain management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family involved in pain management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency of pain monitoring</td>
<td></td>
<td></td>
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</tbody>
</table>
Handout for Families: What They Can Do for Dying Residents

Dear family members and friends,

Our facility established a special program entitled “Butterflies are Free,” for our residents who are at or nearing the end of their lives. The sole purpose of this program is to provide comfort and dignity to those residents so that their end-of-life experience is pain-free, is as comfortable as possible, and honors the wishes of the resident.

This cart is filled with items that can be used as therapeutic interventions for your loved one. Please refer to the information provided below. Additionally, if we can assist you in any way, please make us aware. Your needs are important to us also.

It is thought that hearing is the last of the five senses to fail as a person is dying. We encourage speaking or reading to a loved one, even if you don’t think he/she can hear you.

Reading to someone is often a very soothing experience. Feel free to read stories or poems to your loved one. Some books provide questions to ask that invoke pleasant memories. For example, ask your loved one, “Do you remember the time when...?” or “I remember when I was a little girl [boy], you used to...”. Regardless of the response, the conversation is thought to be soothing and can be beneficial to both the resident and the person speaking.

Talk about pleasant memories from the past. If your loved one had a favorite hobby or favorite vacation spot, take him/her there in your conversation. For example, you might ask, “If you could be anywhere in the world right now, where would you like to be?” If the response is, “I would like to be ballroom dancing,” you could play waltz or tango music that brings back special memories. Talk him/her through the dance, helping him/her experience the memories. If the answer is, “I would like to be back in Kentucky,” you might talk about the beautiful countryside, the horse farms, the lakes, or any other characteristic of Kentucky that you know he/she loved.

Allow your loved one to express any unresolved spiritual issues. Bibles and prayer books are available. If desired, members of the clergy can be called. There are also many persons in the facility that would be willing to pray with your loved one at any time.

Music has been described as medicine for the soul. The cart is furnished with a CD player and CDs for the resident’s pleasure. We have a very large collection of CDs with music to please almost any taste. In our collection, we have southern and contemporary gospel music, hymns, big band music, music from various countries, music from every decade since the 1920s, favorite singers, Hawaiian music, country music, classical music, and many others. Feel free to play soft background music to comfort the resident. Please check with our Social Services department for specific requests. We will do our best to find the type of music your loved one would enjoy.

A softly scented lotion is provided for gentle hand massages. Gently rub the lotion on the hands of the resident. If your loved one has paper-thin skin, you will want to check with the nurse to see if a hand massage is appropriate.

Powder may be used for a gentle back rub. If your loved one is unable to turn on his/her side or sit up on his/her own, ask for assistance from the nursing staff. Please do not try to move the resident on your own.

Lip balm or ChapStick may be gently rubbed on the lips to prevent the lips from chapping. In addition, remove the Toohette from the wrapper and gently moisten the inside of the mouth, including the teeth.

If you have any concerns or suggestions to convey to the staff, please feel free to speak with us at any time. We want this time to be comforting and stress-free for everyone involved.

Sincerely,

The Butterflies are Free Committee
Butterfly Assessment Social Services / Spiritual Needs

Resident______________________________________ Date____________________________________

These are a few of my favorite things!

Favorite music: ________________________________________________________________

Favorite reading material: ________________________________________________________

Special song: _________________________________________________________________

Favorite way to relax: _____________________________________________________________

Favorite food: _________________________________________________________________

Favorite holiday: _______________________________________________________________

Favorite fragrance: ______________________________________________________________

Favorite color: _________________________________________________________________

Favorite flower: ________________________________________________________________

Best remembered things: _________________________________________________________

Do you have any special wishes? __________________________________________________

What would you like us to do to help you and your family and/or friends during your journey?

_______________________________________________________________________________

_______________________________________________________________________________

Please share your special accomplishments/hobbies/interests with us:

_______________________________________________________________________________

_______________________________________________________________________________

What are your spiritual beliefs?

_______________________________________________________________________________

_______________________________________________________________________________
Would you have any beliefs that would impact how we care for you?
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

Do you like pets?
__________________________________________________________________________________________________

What kind of work did you do?
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

Did you ever speak a different language?
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

Do you have a favorite passage from the Bible or special book?
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________

Please include any special information that you would like us to know:
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________
__________________________________________________________________________________________________
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__________________________________________________________________________________________________
__________________________________________________________________________________________________
Sample Butterfly Program Bed Management Table

<table>
<thead>
<tr>
<th>PATIENT</th>
<th>ROOM</th>
<th>STAGE 1</th>
<th>STAGE 2</th>
<th>STAGE 3</th>
<th>ADV DIR</th>
<th>CARE PLAN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doe, Sam</td>
<td>105A</td>
<td>X</td>
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<tr>
<td>Smith, Marie</td>
<td>121B</td>
<td>X</td>
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<tr>
<td>Bush, Martha</td>
<td>116A</td>
<td></td>
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<td>X</td>
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<tr>
<td>Cheney, George</td>
<td>222B</td>
<td></td>
<td>X</td>
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<td></td>
<td>Securing 8/17/04</td>
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<tr>
<td>Powell, Beatrice</td>
<td>302P</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td>EOL CP only per family request</td>
</tr>
<tr>
<td>Graham, Roberta</td>
<td>206P</td>
<td>X</td>
<td></td>
<td></td>
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</tbody>
</table>

About the Authors:

Staff Associates at Life Care Center of Sarasota (Sarasota, FL)

Certified by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) since 2002, LCCS provides skilled nursing care; inpatient and outpatient rehabilitation, including orthopedic and stroke rehabilitation; IV, anodyne and oxygen therapy; wound management and respite services. LCCS is best known for its end-of-life care program, “Butterflies Are Free,” designed to provide peace and hope for hospice patients and their families. This program attracted much attention and won the facility the 2005 Nursing Homes Magazine OPTIMA Award.

The program was developed by combining the work of a number of specialty teams in the facility: an Education Team, comprised of the Executive Director, Director of Nursing, Staff Development Coordinator, Social Workers, Hospice, and family members; a Clinical Needs Team, comprised of the Director of Nursing, Assistant Director of Nursing, unit managers, nurses, Pharmacist, nursing assistants, and Hospice; a Psychosocial Needs Team, which was composed of the Executive Director, Social Workers, Central Supply Coordinator, unit managers, nurses, nursing assistants, dietary associates, and housekeepers; and various resident participants.