The Geese and the Peanut Butter Chocolate Ice Cream:

The Grieving Gifts to the Lexington Street Community

A Resource to Help Individuals with Developmental Disabilities and People Who Support Them Grieve the Death of Loved Ones

Written by Melody A. Steinman

Illustrated by Pat Schosser

December 2006
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Suggested Citation:

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# Table of Contents

Preface  
Introduction  
The Story  

- Chapter 1: Getting To Know The Neighborhood  
- Chapter 2: Remembering The Details Of The Death  
- Chapter 3: Sharing About The Death  
- Chapter 4: Letting The Neighbors Know About The Death  
- Chapter 5: Visiting At The Funeral Home  
- Chapter 6: Attending The Funeral  
- Chapter 7: Coping Without The Loved One  
- Chapter 8: Nurturing A Community Of Acceptance And Support By Remembering The Loved One  

Reflection and/or Discussion Questions  
Practical Strategies For Dealing With Loss, Death and Grief  
Activity Book  
Game  
Reviewing the Characters  
Bibliography  
What Others Are Saying About This Resource  
About Melody A. Steinman and Pat Schosser
Preface

A time to be born and a time to die….
A time to weep and a time to laugh,
A time to mourn and a time to dance.
(Ecclesiastes 3: 2 &4)

My first experience involving the death of a person with a developmental disability was as a chaplain intern at an acute care medical center in North Carolina when a young man with Down Syndrome died of a heart defect. I had gotten to know him a little, listened to the family, and had the honor of being asked to participate in the funeral. Little did I know that my words, reworking what I heard from the family about the wonderful character of their son, would be the only words in the ceremony that focused on his gifts and their real loss.

My next one was as a chaplain of a large residential institution in 1976. At one of the first deaths after my arrival, I led the service in the basement chapel. Five other people came. Four residents serving as pall bearers (It was one of the best paying jobs on the campus) and one staff person sent from his living unit. Funerals are for the living and someone’s community. This one made no sense, but in my frustration, I made sure we did it with dignity.

Scroll forward close to thirty years, and at an international conference related to developmental disabilities in Montpelier, France, in 2004, there were close to thirty papers presented on dealing with grief, loss, and death for people with intellectual disabilities. Most of them, though, were not from the USA. Until recently, and the excellent work done by the Last Passages Project and some new initiatives by the AAMR (soon to be AAIDD), there has been little formal focus on end of life caregiving and even fewer resources.

But that is changing rapidly as service systems everywhere are dealing with people with developmental disabilities who are aging like everyone else, dying like everyone else, and grieving like everyone else. You may have your stories about the ways that real grief often gets compounded, when, for example, someone does not want to tell a person with a developmental disability that someone died or does not want them to come to the funeral of their father, mother, or family member. For a system of services based on developing every known potential, encouraging growth, and overcoming obstacles, it is not easy to shift gears to loss, leaving, and saying “Goodbye.” In a system with huge demands for services, it is also hard to pause and take time to recognize, celebrate and deal with the depth of connections and relationships between and among people with intellectual disabilities, their families, and their professional caregivers. The pressure to fill the program slot and move someone else in adds to frustrations that people are replaceable cogs and that feelings are not important. A time of death can indeed be a tough loss, one that is not easy to handle, but it can also be a time of recognizing gifts: the qualities of someone’s life, the way their lives have touched many, the depth of care and commitment by family and staff, and many more.

The Elizabeth M. Boggs Center on Developmental Disabilities
UMDNJ – Robert Wood Johnson Medical School
Melody Steinman has developed this resource out of her work and ministry with adults with developmental disabilities, their families, and caregivers as just such a resource, one that will provide and support ways for everyone to take time to weep, laugh, mourn, dance, remember and celebrate. Just as grief happens in all kinds of ways, with all kinds of feelings, there are multiple ways you can use this resource. It is a fictional story about a person and a home, for death and loss happen to real people. It is for individual reflection and group discussion. It is a resource guide. It can be used on a home by home, team by team basis, to help people think through: What happens when this happens to us? (Not “if” it happens to us…it will!) It is a guidebook. It can be used by staff and families with people with intellectual and developmental disabilities. The simple line drawing pictures helps it come alive. Readers may find ways to use it in ways that Melody Steinman had not even anticipated.

The Boggs Center is very grateful for Melody’s work here as a trainee. She is one of a growing number of people who feel called and led to address the spirituals needs and gifts of people with intellectual and developmental disabilities and those who work with them. Through her faith community, the Mennonite and Anabaptist networks, Melody found Pat Schosser as she was looking for a potential illustrator. Pat contributed her time and talents as an artist. Pat is headed toward seminary in the fall of 2006 in response to her growing sense of call. We are grateful to both of them, not least of all for the fact that their concern and hope was that this resource should be made available for anyone to use. With the help of our very able Communications Manager, Robyn Carroll and the helpful editing and suggestions from Deborah Spitalnik, Ph.D., the Executive Director of The Boggs Center, those dreams came true.

All we ask is that you let Melody Steinman know how this resource served as a gift in your caregiving and in your journey with people with intellectual and developmental disabilities. Thank you for sharing your gifts with them, and for taking the time to recognize and remember that their gifts, like everyone’s, perhaps become most evident when we lose them. That is when grieving becomes giving, for it calls us to remember and share from the depths of who we are and what we believe is most important.

Take the time. Blessings as you do so.

Bill Gaventa, M.Div.
Associate Professor, Department of Pediatrics
Director, Community and Congregational Supports
Co-Editor, Journal of Religion, Disability and Health
Introduction

All people rely on relationships to add meaning to their lives and to carry out their day-to-day activities. As much as their meaning and enjoyment become a part of these relationships, losses or changes are inevitable. These changes can take the shape of loss from physical deaths, geographical moves, changes in employment, etc. People with developmental disabilities are not exempt from these losses. They encounter a significantly high number of losses in their lives which are often not recognized. The reactions and feelings of people with developmental disabilities are typical grief responses of all people. People with developmental disabilities tend to want to talk about them especially losses that come from death. As many people with developmental disabilities do not have the same inhibitions as other people, death becomes a frequent piece in their choice of conversations because they actively seek out opportunities to process their feelings and experiences. These opportunities often are not granted because of the discomfort in our society to talk about death and the tendency to want to protect people with developmental disabilities. This desire to protect people comes from the false belief that people with developmental disabilities would not know the difference, would not understand or they should not have to bear additional pain. It is not doing anyone any favors by withholding the death loss from people with developmental disabilities. Even people who do not talk need to hear stories and memories of people who have died. People with developmental disabilities can often sense that something is wrong and often find out anyway. Their need to talk can be gifts. The debatable issue is not if we are going to talk with people with developmental disabilities but how the conversations occur.

Caregivers, then, have a critical role to play. Most likely, family, staff and friends will be the ones informing the individuals of the loss because they know the people with developmental disabilities the best. They will be the ones providing ongoing support of listening to and helping to work through feelings. Generally, the more comfortable that caregivers are with talking about their own losses and experiences of death, the more equipped they will be to help people with developmental disabilities.

The Geese and the Chocolate Peanut Ice Cream: the Grieving Gifts to the Lexington Street Community has many uses. It is primarily intended to help people deal with death, loss and the process of grief even though it demonstrates how support and community can occur, both at the time of death and other times as well. Although it was originally designed for family members and people who support individuals with developmental disabilities, anyone can use it. Agencies can use parts of it for their staff trainings. Clergy, social workers and other professionals can use it to talk about grief issues among themselves and with their clients. Family members and friends can identify their own feelings and responses and find ways to deal with them. Anyone can sit down informally one on one with a person with a developmental disability and talk about the individuals in the story and how the situations might apply to that person’s life. This interaction can also occur in a formal group setting as well. The resource is designed to be flexible to the needs and desires of its user.
The Geese and the Peanut Butter Chocolate Ice Cream: the Grieving Gifts to the Lexington Street Community resource contains six main sections. Just like they can be used by a variety of people, they can be used as one complete package or individual sections. The sections are The Story; Reflection and / or Discussion Questions; Practical Strategies for Dealing with Loss, Death and Grief; an Activity Book; a Game; and Bibliography.

THE STORY

The resource centers around the story, “The Geese and the Peanut Butter Chocolate Ice Cream: The Grieving Gifts to the Lexington Street Community”. The story describes the responses of staff, family, neighbors and individuals in a group home after a sudden death of an individual with a developmental disability. It can be used by family members, friends and individuals with developmental disabilities as well as social workers, clergy and other professionals. It can be read leisurely by oneself or used in group trainings and in-services as a discussion starter.

THE REFLECTION AND / OR DISCUSSION QUESTIONS

The questions are intended for individual reflection and group discussion. There are no right or wrong answers. People can choose which questions are relevant for them and adaptations, of course, can be made whenever necessary.

PRACTICAL STRATEGIES FOR DEALING WITH LOSS, DEATH AND GRIEF

This section follows the format of the story and contains practical strategies that people can be supportive and sensitive to other people as they grieve. Tips are provided to make the telling of the death, the visitation, funeral and time after the funeral run more smoothly so healing can occur. People can read the story first and then focus on these practical strategies or they can go directly to this section. It can be used in staff trainings and in-services or as a quick resource when facing the death of an individual. This section is beneficial for family members, friends, social workers, clergy and other people who want to know how to respond to other people as they cope with the death of another individual.

ACTIVITY BOOK

The activity book contains pictures from the story. Individuals can sit with people with developmental disabilities and talk about what is happening in the picture. People can also talk about their feelings that come from looking at each picture. It is also possible to select to specific pictures that address specific experiences of individuals. They can sketch themselves into the pictures as well as color them. Children would also find the activity book helpful.
GAME

Anyone can play the non-competitive game. It is designed to give all people, regardless of verbal skills, the opportunities to participate and to work through their grief. People can choose to draw on the experiences of the characters in the story or their own personal experiences with death and grief. People draw from cards in the following categories: feelings, behaviors/actions, insights and personal reflections. Further instructions on constructing and playing the game are listed in the following pages.

BIBLIOGRAPHY

An annotated bibliography about grief and loss makes up the final section. Although it is not comprehensive, it provides a place for people to begin to delve deeper into the issues. Public libraries contain good children’s books on death and dying that can be adapted to the needs of the individuals that you support. Internet sites that contain helpful information are also provided.
THE STORY

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Chapter 1: Getting To Know The Neighborhood

Priscilla had been the manager of the 1424 Lexington Street group home for five years. She was always concerned about people on the fringes getting the life that they deserved. She was good at what she did and she enjoyed her work. She knew that it gave her a sense of purpose in life. It was more than a job for her. Priscilla also knew that she could not do it alone. She contributed her longevity to her valuable staff. They worked together to make 1424 Lexington Street truly a home for the five people who lived there. The values of the team had meshed into a common vision and had built a viable residential program.

In a sense, the staff and residents had formed their own community of support. Marco and Larry, two of Priscilla’s full-time staff, had gained many things from knowing Sylvia, Rachel, Robyn, Reuben and Bruce. Likewise, these residents felt their support and encouragement. Each person made significant contributions. Their circle of acceptance and support grew as they welcomed other members to their team over the years.
Other people lived in the neighborhood of Lexington Street. Mrs. Kipfer and Mr. O’Reilly lived there when the group home opened up. Mrs. Kipfer lived in the red brick house two doors down. Not only could she be counted on in emergencies, she also made her presence known in the day-to-day. As she wanted to be a support, she made frequent visits. Another neighbor, Mr. O’Reilly, always kept his blinds closed as he was a private person. Mr. O’Reilly lived next to Geetha and Suresh Patel, a family who had moved into the neighborhood last week. Mrs. Kipfer reported to Priscilla that the Patels were friendly. Within the year, these neighbors, and even Mr. O’Reilly, would evolve into a community of friends.

The work and position for Priscilla was rewarding and had a lot of responsibilities to juggle. She cared deeply for all of the residents. She knew too that she needed to care for herself if she was going to continue to do challenging work. Priscilla loved being in the outdoors and tried to spend as much time as possible outside. She always felt renewed by nature. She was especially drawn to the Canadian geese when they flew by in the spring and fall. She admired their beauty, strength and freedom.
Lately the thought of them had become bittersweet. She kept thinking about how she had been woken up early that late October morning by the sounds of the geese. Their honking came just a few minutes before she received “the official call” from Rachel’s mother, Mrs. Brie.

Chapter 2: Remembering The Details Of The Death

Mrs. Brie was having a difficult night. Although she tried to sleep, she just tossed and turned and thought about the details of her daughter’s death. Mrs. Brie knew that she would feel better after talking to Priscilla. Priscilla had been her confidante throughout the last four years that Rachel had lived at the group home. Having such a caring person involved in her daughter’s life helped to ease the guilt of relinquishing the care of Rachel to others. Mrs. Brie always believed that family was supposed to care for each other, regardless of personal cost but as Rachel grew older, her mother realized Rachel needed more freedom. Even though Rachel lived at the group home that Priscilla managed, she returned to her mother’s house for a weekend visit each month.

That morning, Mrs. Brie’s fingers jittered as she punched in Priscilla’s telephone number. She knew her body was still responding to the tragic events of the night before. Mrs. Brie had never been so direct in a conversation with Priscilla. After a quick hello, she blurted out, “I can’t believe it. Rachel is dead.” Priscilla felt too stunned to take in the words. “She died suddenly last night from a massive heart attack,” Mrs. Brie continued as Priscilla began to wake up to the reality of what she was being told.

Priscilla threw back the covers and sat up straight. She desperately tried to assimilate the news about Rachel. She was recalling a collage of details about Rachel. Rachel’s favorite colors were purple and yellow. Rachel put all of the silverware to the left of the plates when she set the table. She was passionate about so many things, especially chocolate peanut butter ice cream. It was
The Bries’ custom to eat peanut butter chocolate ice cream whenever they celebrated a family member’s birthday. Rachel had brought this tradition with her when she moved to the 1424 Lexington Street residence.

The retelling of the story to Priscilla helped Rachel’s mother to absorb what had happened. The previous day, Rachel had complained of tightness in her chest. She said it felt like someone was stretching an elastic band around it. Mrs. Brie was concerned but certainly did not think it was as serious as it turned out to be. Rachel’s mother remembered similar sensations a few years ago and thought that Rachel’s gall bladder might be acting up. After all, they had eaten bacon and eggs for breakfast that morning. Mrs. Brie tried to limit Rachel’s intake over the years but Rachel did not seem to listen. Besides, Rachel was an adult now and had to make her own lifestyle choices.

Rachel’s words from yesterday echoed through Mrs. Brie’s mind now as she told Priscilla the story. Rachel mentioned her pain again several times throughout the day. Mrs. Brie only made a mental note to herself to remind Priscilla of this health concern and suggest that she make a doctor’s appointment to get it checked out.

In the evening, the situation had gotten worse. Mrs. Brie’s concern grew when Rachel went to bed without taking her shower. Her concern intensified when Rachel went to bed before she watched the Elvis Presley move, “Jail House Rock.” This indeed was not the way that Rachel normally acted. When Mrs. Brie checked on her later, she knew she had to call 911 at once.

The rest of the details were more of a blur. “Could this really be true?” Priscilla wondered to herself. The reality of the story was becoming real as she listened further. Mrs. Brie remembered that the doctor said that it was extremely unusual for someone with no history of heart problems to die from a heart attack at a young age of 26. Heidi, the on-call chaplain at the hospital, tried to comfort her by encouraging her not to blame herself for what happened. No one would have expected such ominous results. Together, Mrs. Brie and Heidi called Mrs. Brie’s pastor and two other daughters, Erin and Alison. They came at once.

Before they arrived, Mr. Larson, the coroner, had arrived to pick up the body. An autopsy was required because Rachel died at such a young age. Before he took Rachel’s body, the family was able to spend sometime with her. It seemed sacred for the family to be able to touch the body of their family member. They commented that the joints around the knees and elbows were still warm while
her toes and fingers were already getting cool. During this time, Mrs. Brie went over with them the details of the day. After a time of prayer, Mrs. Brie left the hospital. Her daughter, Alison, drove her home with plans to stay the night. Priscilla was now up to date on the details of the previous night.

Chapter 3: Sharing About The Death

Before going to the group home where she worked, Priscilla shed some tears with Mrs. Brie on the phone. As Priscilla drove by the riverbank at the edge of town, she glanced out the car window and breathed deeply. She could not help but notice a dozen geese that had made their reassuring presence in the sky. “Give me courage,” she prayed to them. “I need wisdom to know what to do.”

As Priscilla pulled up into the driveway, Marco, who worked overnights, was still mopping the kitchen floor to clean up Robyn’s wheelchair tracks. Robyn did not have time to clean up the mess before the bus came. Robyn was Rachel’s housemate and best friend. Priscilla invited him to sit down. “I received some news today that might upset you. Rachel’s mother phoned to tell me that Rachel died last night.” Previously, Marco did not think anything of Rachel not being there in the morning because Mrs. Brie always dropped her off at work when they spent the weekend together. As she continued, Priscilla explained what Mrs. Brie had told her. Then, she let him speak. Marco shared how he chose to stay at the computer firm where he worked at the time instead of going back to Brazil for his grandmother’s funeral. Although he always felt guilty for this decision, he rationalized to himself that he could not afford the trip as he had too many student loans to pay off. After this time of processing his own response to the news of Rachel’s death, Marco admitted that he did not know how he would deal with Rachel’s death let alone help the residents. Priscilla gave him a warm hug.
Priscilla surprised herself at how composed she was. She could truly listen to Marco’s concerns but she doubted how she would do at telling the others. What would she say? How could she help staff juggle their personal feelings and professional responsibilities? Would the residents understand? How would they respond? How would they all together manage to cope with the unknowns in the upcoming days? How would everyone handle the stress of the funeral? What would life be like without Rachel afterwards? How could they all best support each other? After calling her supervisor for advice, she knew that she had to act quickly. Her supervisor helped her to see that the group needed to create a safe place for people to deal with their feelings. They could be supportive of each other more naturally if they were told together instead of individually. She was appreciative of his guidance and encouragement to be herself. Priscilla prepared to tell the group that afternoon as soon as they returned from their work and day programs.

Priscilla was grateful that she was able to reach all of the staff on the phone on the first try and that they could be at the group home by 3:30. As she wanted to make their time together special, she quickly drove to the store to pick up some specialty coffee and fresh fruit. She also pulled out a dozen of Mrs. Kipfer’s chocolate chip banana muffins from the freezer. Now that the physical environment was taken care of, Priscilla needed to prepare herself. It was important that Priscilla take time to collect her thoughts and think about how she felt. She wanted to be present emotionally to the group.

The staff arrived at the group home before the residents. Although Priscilla was unsure about waiting to tell the staff before the residents arrived, she decided to tell everyone together. The staff could see that she was upset. Priscilla wanted everyone to have refreshments as well because she thought that they might be too upset to eat after they found out the news.

Priscilla had not held very many house meetings and wished that she had done more of them. She thought it would make this setting more natural. In thinking about her approach, she decided to be as honest and direct as possible. She wondered how others had faced the issue. She was grateful that each member of the team could be present.
Priscilla was concerned about how everyone would take the news. She gently put her hand on Sylvia’s shoulder to communicate compassion. Priscilla could also sense her own uneasiness as she could not decide if she wanted to sit or stand. She decided to pull up a chair so they would be at eye level with one another. Priscilla initially was going to say something about the van driver who liked to tease Sylvia but then stopped because she did not see its relevance to the news that she had to share. She did not know how much Sylvia would understand nor was she certain how Sylvia would respond. Even though Sylvia would not have words to vocalize her feelings, Priscilla knew she still could express them and that they deserved attention and recognition.

“I am glad everyone can make it here today. I have some bad news for you” said Priscilla as she cleared her throat. “Rachel will not be coming back to live here.” Priscilla spoke slowly and clearly to avoid any unnecessary confusion. “My friends, Rachel died last night.” Priscilla noticed that Sylvia started to fidget with her hands and decided that this was enough information for Sylvia to take in. Priscilla could only hope that that Sylvia understood even though Sylvia moved her chair to her usual spot by the window.

“You are safe and loved here.” Priscilla said with reassurance. She went on to explain to the group what had happened. She, then, set up some important ground rules about their time together by telling people that they could express how they felt and ask whatever questions they had. No one would make fun or laugh at others. Their comments would be accepted. It was important that they spend this time together. It was a lot of information to absorb.
Although Bruce had known Rachel for only three weeks, he was the quickest to respond verbally. He had just moved into the group home from the State institution where he had lived for many years. He did not know Rachel that well but he still felt her loss. Priscilla knew that loss was no stranger to him. At the State institution, he encountered the death of many other residents as well as the loss of many staff through its continual turnover. The staff at the State institution refused to tell him what happened to others that he had grown attached to. He just knew something was different when his roommates or staff disappeared and did not return. He learned that these were issues that he was not to question. Although Bruce acted as though he was used to losses in his life, he had not. He had many questions that he never felt comfortable asking at the State institution. At the table though, Bruce wondered what happened after a person died and what it was like to die. With these questions, it was evident that Bruce was learning to trust and even to blossom in his new environment. He wondered why so many of his staff over the years were so afraid to talk about death. Bruce also wondered why some people died at a young age and why others lived to be very old. Priscilla let him ask questions, even those without simple answers.

Bruce also wanted to know if someone else would be moving into Rachel’s room. Priscilla knew of the practical reality of getting another resident but did not want to face it herself let alone address it with the group. “Yes, someone will be moving in but not for a while.” She redirected the conversation and said, “Let’s think about what we feel about Rachel dying first.” She hoped that she was not setting him up as she knew that she needed to talk to her supervisor tomorrow about possible placement. An uncomfortable silence entered the room.

Then Larry spoke up. Larry expressed his concerns because he had dealt with some significant deaths in his life previously. He shared how he remembered crying and being deeply comforted by his mother when his dog, Buddy, had disappeared many years ago. He was able to tell his father that he loved him and say goodbye before he died of cancer seven years ago. Larry was not afraid of what feelings would surface within him in the process of being with the residents. Marco, on the other hand, already had time to debrief with Priscilla earlier that day. He was more focused on the needs of Rachel’s housemates.

Priscilla knew that Rachel’s death would change Robyn’s life the most. These two women had shared their lives together for four years. During this time, they shared the same bedroom and bathroom. “She was my friend. Now she is gone.” Robyn repeated this phrase over and over again. It was true. They were more than roommates. Priscilla thought about the dynamics of their relationship. It definitely had its kinks but
it was solid. Throughout their life together, Robyn frequently complained about the
toothpaste that Rachel left in the sink. She also didn’t like that she needed to watch for
the puddles of water on the bathroom floor in the evening after Rachel took her shower
because Rachel did not pull the shower curtain against the wall. More often that not,
Robyn was usually left to clean up the mess.

Even though
these things about Rachel
bothered Robyn, they
shared a mutual love for
Elvis Presley. Each of
their hearts would beat a
little faster when he sang,
“Love me tender love me
ture….“ Priscilla knew
their friendship ran deep
and they had truly cared
for each other. Now
Robyn’s words remained
constant, “She was my
friend. Now she is
gone.” Robyn was
feeling the hole in her life
left by her friend.

Reuben was a quiet man and seldom spoke. He often rocked back and forth. His
rocking became more intense and agitated when Larry asked him if he wanted to attend
the visitation. Three years before his brother, Levi, died of pneumonia. At that time, he
felt happy because he knew that he would no longer have his hair pulled by Levi or be
called nasty names. Larry remembered how his rocking increased in greater frequency
after his brother’s death and volunteered to stay at home with him.
The group reminisced about Rachel and comforted each other for about an hour. As Priscilla was emotionally exhausted herself, Priscilla sensed that this might be enough processing time for now. She knew that the group needed to know about what would be happening over the next couple of days as well. There would be a visitation at the funeral home, followed by the funeral at Rachel’s church the next day. Each person would be given the choice to attend the visitation or funeral or not. The visitation was a time at the funeral home when they could express their support and sympathy to Rachel’s family and receive support themselves from others. Rachel’s body would be there. It would be in a coffin, which looked like a box. Although it might look like Rachel was sleeping, she was really dead. Only her body remained. Sylvia indicated that she wanted to go to the visitation and funeral even though she was scared.
Chapter 4: Letting The Neighbors Know About The Death

Priscilla was grateful for their neighbor, Mrs. Kipfer. As usual that evening, she was generous with her time and food. She had been over at the group home earlier in the day and dropped off a tuna casserole for supper. Tuna casserole was Rachel’s favorite meal and she always put lots of ketchup on it. Priscilla had decided to tell Mrs. Kipfer about Rachel’s death before the others got home. Rachel knew that Mrs. Kipfer would be hurt if she found out from another source. Besides, Priscilla reasoned, they would be told that night.
After her tuna casserole delivery, the kind-hearted and helpful neighbor, wandered over to the home of Geetha and Suresh Patel. Even though they had only moved three days before, Mrs. Kipfer already had made a pot of homemade chicken noodle soup and chocolate chip banana muffins just in case they needed some food as they unpacked their boxes. Mrs. Kipfer thought that they might be new to North America because they had an accent when they spoke. She wanted them to feel welcome. True to her character, Mrs. Kipfer freely told them the details about Rachel. They listened graciously.

Although the Patels had not met Rachel, they wanted to reach out to their new neighbors. As they wrote down the address and directions to the funeral home and church, they decided that they would make an effort to attend the service. They were a bit uneasy about attending because they followed the Hindu religion and were not sure what to expect. Yet they remembered how supportive people had been to them when Geetha’s sister died two years ago. They recalled the service that was held in her honor by their faith community and how their friends had supported them. They wanted to pass along the same care and love that they had received from their neighbors. They knew instinctively that attending the funeral would be a good step to help them become good neighbors even though the funeral ritual would be different from what they practiced. They hoped that their support would be a first step in making new friends.

Mrs. Kipfer debated telling the news to Mr. O’Reilly, the longest resident on Lexington Street. After weighing the pros and cons in her mind, Mrs. Kipfer did not see its value. She did not think that Mr. O’Reilly would be interested in knowing because he never showed any interest in the lives of anyone who lived on the street. She did not think that he would start now even though he had lived on the street for over thirty years. She believed he would not be interested so she decided not to tell him the information.

Despite her avoidance, Mr. O’Reilly still found out. He saw the obituary in the local newspaper. As Mr. O’Reilly read the write-up, memories of the deaths of his own his wife and 10-year-old daughter, Valerie, flooded once again into his consciousness. A truck driver did not see their car and had sideswiped them. It had happened 25 years ago, but a day did not pass that he did not think of them.
Chapter 5: Visiting At The Funeral Home

The household ate their meal quietly that evening. Afterwards, they got ready for the visitation. After supper, Priscilla reminded them again what to expect and reviewing together what happens at a visitation. Then, they drove silently to the funeral home. After parking their vehicle, Priscilla heard again the honking of the geese. She walked towards the funeral home with courage. Robyn, Rachel’s housemate, said over and over again, “She was my friend. And now she is gone.” Sylvia gave no indication of what she was thinking or feeling even though she was scared to attend.

At the entrance to the viewing room, pictures of Rachel were out on display. They included photos of Rachel with her mom and sisters. There was also a picture of Rachel with her dad, who died when she was a little girl. But, Robyn knew that Rachel’s most cherished picture was one with her nieces and nephews that she put under her pillow each night. A close second was the one that Mrs. Brie picked up at 1424 Lexington Street earlier that morning when she picked up the dress for Rachel. Fortunately, Priscilla had arranged to have a group photo taken two weeks prior and each member of the household was present. Rachel’s sisters, Alison and Erin, enjoyed pointing out Rachel’s housemates to their relatives almost as much as the residences were proud to have their picture out on display. When Robyn saw the photos, she cried. “She was my friend. Now she is gone.” Priscilla knew that it was important that Robyn be allowed to express her grief through her tears.
Each person was allowed to experience the visitation in whatever way made sense for them. When Bruce entered the room, he headed straight for the coffin. He had never seen a dead body before and Rachel had never been so still. Priscilla was quick to notice Bruce's interest. She feared that he would want to touch the body and try to pry open her eyes and maybe even her mouth. Priscilla realized again that she needed to help Bruce understand more about the death. Nervously, she took a deep breath. Priscilla explained that Rachel was not sleeping but that she was dead. Priscilla explained that her heart, lungs, and other organs had stopped working and that it was just her body that remained in the coffin. Her spirit, which was the important part of who Rachel was, had left. She was not in any pain. Priscilla asked Bruce if he had any questions. He did not respond, as he still seemed fascinated with her body.
After another nervous breath, Priscilla asked him if he would like to touch Rachel’s hands. After he nodded, Priscilla noticed how fast her heart was beating. She had never touched a body before herself but she had heard that the body would be cold and hard. She thought she better warn Bruce as well. With apprehension, she took Bruce’s hand and placed their hands on Rachel’s. Bruce was gentle and respectful. She felt relief that Bruce was responding well in the circumstance that was new to the both of them. They stood together in silence.

When they were standing in front of the coffin, Jason, a friend from the sheltered workshop where Rachel and Bruce worked, joined them. Jason compassionately stood between them and put his arms gently around their waists. With conviction, he whispered, “Jesus loved Rachel.” Then he continued to stand with them in silence.

Bruce was not sure what to believe, as he needed more time to decide for himself. Although he still had questions, he did not ask them. He just knew that Rachel was gone like many others before her and this was ok for now. Priscilla had her own questions. Robyn on the other hand just wanted to cry. She did not want to come close to the coffin.
As the evening progressed Bruce felt something shift within himself. He felt lighter on the inside. It seemed like something was connecting for him. He also noticed that people were giving money to the funeral staff. Bruce came close to witness the transaction. After Gary, the funeral home director, finished with the couple, he explained to Bruce that they were giving money to help other people who were affected by heart attacks. Bruce wanted to do the same and he pulled out his wallet and emptied it on the table. Coins fell everywhere. With pride, Bruce gathered them up and gave them to Gary with the baseball card and candy wrapper that he also found. Gary graciously accepted. Bruce gave all that he had to honor his housemate.

Although it totaled only $7.43 of monetary value, it was worth far more.

After many tears, Robyn moved towards Rachel’s mother. She gave Mrs. Brie a big hug. It felt safe and reassuring for both of them. Together they went over to look at Rachel’s body. “She was my friend. Now she is gone” shuddered Robyn. “Yes, Robyn, Rachel was your friend. But she can still be your friend. And yes, she is gone” said Mrs. Brie as she wiped her nose and tears from her own eyes and reached for another tissue for Robyn. “We both will miss her.” Robyn then showed Mrs. Brie a postcard of Elvis Presley. As Mrs. Brie knew of their common love for Elvis, she asked Robyn if she wanted to leave his picture with Rachel. Robyn eagerly stretched out of her chair enough to place the postcard by Rachel’s hands and stated emphatically, “She was my friend. And now she is gone.” Robyn and Mrs. Brie embraced again.
Soon it was time to go home. It was important that they try to stay with their routine as much as possible. Everyone needed to get lots of rest because the next day was the funeral.

**Chapter 6: Attending The Funeral**

As with the visitation the night before, Priscilla reminded Rachel’s housemates of their choice to attend the funeral or not. She had learned from the night before that it was helpful to explain to everyone what was going to happen. Priscilla was grateful for Larry’s willingness to describe the practical details this time. People would have one more time to see Rachel’s body before Gary Larson, the funeral home director, closed the coffin. Then the coffin would be ushered up to the front of the sanctuary of the church. At this point, the residents would then enter behind Rachel’s family. A special place at the front was reserved for them. Their spot was close to Mrs. Brie, Erin and Alison as well as Rachel’s nieces and nephews. They were also considered to be Rachel’s extended family.

During the service, the congregation would sings songs, someone would read from the Bible and the pastor would preach a message and say some prayers. It was a lot like church on Sunday morning only it would be different because they would be saying goodbye to Rachel. After the service, they would follow the coffin out to the cemetery behind the church for more prayers from the pastor. There probably would be food served in the church afterwards. They were assured that their attendance or lack of attendance did not determine how they would treat each other in the future. It was up to each person to decide what he or she wanted to do.

Everyone decided to attend the service. Priscilla knew that she as well as the others had felt and learned so much in the past 24 hours. Despite, the uncertainty that she felt she knew that could trust herself, staff and the residents to know what they needed to do. They could cope effectively and she would just need to be attuned to them and let them guide each other. Although she looked at them with concern, she was pleasantly surprised to find for the moment at least that they were holding their own. Priscilla knew them well enough to know that their coping was genuine. They did not distinguish between what they were experiencing on the inside and what others saw on the outside. Not only could Priscilla see that they were able to care for themselves, she could tend to what was happening inside of herself.
Priscilla was struck by the content of the message taken from Psalm 121. Its final phrase, “The Lord will keep your going out and your coming in from this time on and forevermore” stuck with her and gave her confidence and assurance. The pastor then explained how God is with us always even in the difficult times. Priscilla’s thoughts turned towards the geese. She was beginning to feel that they were connected to God. She realized then that this God was truly mindful of all of the circumstances in life. God was available to her especially during the difficult times.

Larry was grateful for the presence and support that he felt from others who attended the funeral. He expressed his appreciation to Geetha and Suresh on behalf of the entire group. He recognized that they were new to the neighborhood and had probably never been to a Christian funeral before.

After the service but before they began the procession to the cemetery, Marco noticed that the pastor did not sprinkle incense over the coffin. In his culture, this was a significant part of a funeral. The incense represents the prayers of the people that ascend to God. Even with the absence of this ritual, Marco felt that he could pray. He also allowed the tears to flow down his cheeks as he expressed his sadness about missing his grandmother’s funeral and the unfairness of Rachel’s death when she was so young. After Marco cried, he felt more equipped to be present to others.
At the gravesite, it started to rain. Priscilla felt its refreshment on her face. Initially, the rain disappointed her because she saw no geese but the thought came to her that God who made the geese was also present in the rain. She felt that this creative God was crying tears of sadness along with Rachel’s family and friends. As the group continued to gather around the grave in silence, Priscilla whispered this idea to Robyn as words of comfort. Instead Robyn laughed. She just laughed and laughed and laughed until she was crying. At first, Priscilla felt embarrassment at Robyn’s laughter and she wished that she had not said anything to her. She wondered what their neighbor, Mrs. Kipfer would be thinking if she heard her and how she would retell that part of the day.

As these feelings stirred within her, she heard a kind response from Rachel’s mother that broke the silence. “It is so good to hear Robyn’s laughter and to see her tears of joy.” “It is easier to let my daughter go” she said in between her own tears of sadness, “because I know that good memories of Rachel will continue to live on in the lives of others who cared so much about her.” Priscilla found comfort in Mrs. Brie’s words. Relief followed which helped Priscilla to remember that the important thing was that they were there to support the residents and Rachel’s family. Mrs. Kipfer’s possible comments were secondary.
After everyone had gathered, the pastor read more scriptures and said a brief prayer that released Rachel’s body back to the earth. Then Gary Larson, the funeral home director, dismantled two flower bouquets of red and white carnations. He gave the flowers to Rachel’s nieces and nephews who then gave each person a flower to put on the coffin as a final expression of respect and goodbye for Rachel. It gave everybody something to do and they did it together.

Mr. O’Reilly was at home during the funeral. Even though he could not bring himself to attend the service, he stopped what he was doing when the service began. Throughout the next hour, he found himself humming, the hymn “Amazing Grace” which had been sung at the funeral service of his wife and daughter. He wondered how the time at Rachel’s funeral had gone and how his neighbors were dealing with their loss. Although Mr. O’Reilly felt things very deeply, he had always kept his feelings in check. At the start of the afternoon rain though, he wept. He was surprised at the depth of his feelings. He was surprised at his deep expression of grief. He realized that he was mourning the death of his family and he had kept so many feelings bottled up inside of him for so long.
After the funeral, life soon fell into a routine. Staff were careful that the residents received additional support through the initial transition. Marvin, the day program supervisor where Robyn and Reuben worked, was extra sensitive to their feelings and actions. Priscilla called Sylvia’s sister, Sharon, to tell her about Rachel’s death. They decided that Sharon would phone Sylvia every other week instead of every month even though Sylvia was nonverbal. Mrs. Brie made a point of coming over to the group home. Although Bruce had no family, he took an interest in Mrs. Brie when she came over. She even picked him up occasionally to go to church with her. He was developing a relationship with Gary Larson, from the funeral home. Robyn enjoyed Mrs. Brie’s visits too because she would often bring her photo albums of Rachel when she was lonely. Sylvia did not like the photos and was quick to leave the room.
After a couple of months, it was time to celebrate Sylvia’s birthday. The group home was planning to have veggie burgers and Sylvia’s favorite flavor of ice cream for dessert. When they were waiting for Larry to finish cooking the burgers, Robyn broke out in tears as their aroma made her think of Rachel. “She was my friend. And now she is gone” she protested. Her sense of loss was compounded, as she knew that Rachel’s birthday was coming. Bruce piped in. “It’s no fair. I just do not like it” said Robyn as she started to cry again. “Robyn and Bruce you are absolutely right” affirmed Priscilla even though they had voiced similar comments many times since Rachel’s death. “I miss Rachel too and I wish that we could have her back” said Priscilla. “I can see that you are still upset and that is ok.” “She was my friend. And now she is gone” sobbed Robyn through the tears. Reuben just rocked back and forth as Sylvia stared out the window at the stark trees.

Priscilla had been wondering how to commemorate Rachel’s birthday in a couple of weeks. She anticipated this landmark would be difficult for everyone. She was going to talk to Larry, Marco and the other staff at their meeting in two days about what to do. Before she had opportunity, she suddenly got an idea. She blurted with excitement. “Let’s have a party in honor of Rachel. After all it’s her 27th birthday on the 27th.” Robyn said again but this time with hints of happiness breaking her sadness. “She was my friend. And now she is gone.” They all liked the idea of having a party. It was time to celebrate Rachel’s life for a change. At that moment, the atmosphere in the group home shifted.
Chapter 8: Nurturing A Community Of Acceptance And Support By Remembering The Loved One

After some convincing from Marco, the residents decided to continue the celebrations for Sylvia’s birthday that night. They would plan for Rachel’s celebration the next night. The next night as they gathered to plan the party they decided to serve Rachel’s favorite food: peanut butter chocolate ice cream and tuna casserole and to invite the neighbors to join them. It was a given that they would even ask Mrs. Kipfer to make the tuna casserole. “Ketchup,” said Reuben as he rocked with less intensity. “Wow! And the fact Reuben is talking again is truly another reason to celebrated,” she thought. Priscilla leaned over to him and gave him a big hug. Reuben grinned with excitement.

Geetha and Suresh Patel were the first on their list of invited guests. It had not taken long for the bonds between the two households. Rachel’s death helped to bring them together.

Even Mr. O’Reilly was invited and much to everyone’s surprise, he accepted. Although he was quiet and reserved, he actually showed up. He even came with some peanut butter chocolate ice cream. As it took all the energy that he could muster to come, he did not even think of sharing that he had a daughter who loved to put peanut butter and chocolate sauce on her ice cream. As the group gathered and celebrated the life of Rachel from the group home, Geetha and Suresh shared that they were going to have a baby.

By the time little Priya Patel was born, the neighborhood had gotten together a few times. The birth was a definite reason to gather. It was an occasion that had mixed blessings though. Although they were celebrating the addition to the neighborhood, Larry also announced to the community of friends on Lexington Street that he would be leaving for another position in another town. It was here when they realized just how special the bonds they had created.
Larry had been concerned about the residents’ reaction to his news so he told them early. He knew that this would be another significant loss for them. He wanted them to know that he would always care about them even though he would not see them regularly. They would always hold a place in his heart. With the help of Priscilla, they decided that they wanted a physical reminder of people who had left them. In talking about what to do, the folks at the group home decided to create a memory wall. It would be the dining wall next to the window to the backyard. They would put pictures of members of their group to remember the times that they had shared together.

The evening gave the group an opportunity to honor Rachel. They laughed and cried about their shared experiences and memories of her. Marco told the story how Rachel always wanted to get chips and ice cream when they went grocery shopping. She would tell him that she would start her diet tomorrow. Priscilla remembered how she folded her laundry only during the television commercials. Mrs. Kipfer commented on Rachel’s warm reception when she came over for a visit. She noticed that she was especially welcoming when she had food. Larry remembered how one Saturday it took her two hours to clean up after lunch because she did not want to go bowling with her friends from work. It came out later that she had arranged to go shopping with her friends from church. Bruce knew that he would have loved her as they others had.

The evening was emotional for another reason. When everyone in the room was silent, the moment was right for Mr. O’Reilly to speak. He finally gathered courage to share his personal heartache about his wife and daughter. As he shared his story, Mrs. Kipfer saw a different man than she thought she knew. Mrs. Kipfer just sat in silence and wept. She had no idea that this tragedy was part of his past. Bruce, who was sitting beside her, reached into his pocket to give her a tissue to wipe her nose and eyes. He also took one out and gave it to Mrs. Kipfer. Priscilla looked around at the dear people who had become friends. As she scooped up a spoonful of ice cream, she looked out the window, saw the geese flying in the distance and smiled.
THE REFLECTION AND/OR DISCUSSION QUESTIONS

The questions are intended for individual reflection and group discussion. There are no right or wrong answers. People can choose which questions are relevant for them and adaptations, of course, can be made whenever necessary.
Reflection and Discussion Questions

Who do you identify with in this story?

How did Priscilla prepare to tell the group about the death? How would you?

What are the advantages and disadvantages of telling staff and individuals with developmental disabilities together about a death?

What were the various responses to Rachel’s death at the visitation and funeral?

What similar responses have you seen from people? What other responses have you seen?

In your experience, what glimpses do you have of how people’s personal loss history affected their experience of other recent losses?

What are the unresolved grief issues of the individuals in this story? What unresolved grief issues have you seen in others and/or yourself?

What are strategies for dealing with these grief issues?

What role does one’s culture have in the funeral rites and grieving process?

What role does spirituality and religion have in the understanding of death and grieving process?

If you were Priscilla, what would you have done differently?

What do you think about Mrs. Kipfer’s decision not to tell Mr. O’Reilly about Rachel’s death?

What is your experience of neighbors responding after someone died?

What do you think is the role of family and staff in providing support to people with developmental disabilities in the mourning and grief process?

What can staff do if they know individuals want to attend the funeral and family members do not want them too?

What are ways that your agency could support people in your group home?

What recommendations would you have for your home and/or agency?
PRACTICAL STRATEGIES FOR DEALING WITH LOSS, DEATH AND GRIEF

This section follows the format of the story and contains practical tips for people to be supportive and sensitive to others as they grieve. Tips make the telling of the death of the individual, the visitation, funeral and time after the funeral run more smoothly so healing can occur. People can read the story first and then focus on these practical strategies or they can go directly to the strategies. The strategies can be used in staff trainings and in-services or as a quick resource when facing the death of an individual. They are beneficial for family members, friends, social workers, clergy and other people who want to know how to respond to other people as they cope with the death of another individual.
Practical Strategies For Dealing With Loss, Death and Grief

Strategy 1: Getting To Know The Neighborhood

For the purposes of this resource, the neighborhood is more than the geographical area where people live. It refers to the community of support for people. It is also known as a “circle of support” or “network”. Creating a well-established neighborhood takes intentional and diligent work. These relationships work the best if they are centered on common passions and interests instead of the disability of the people. Developing a well-established neighborhood can benefit all people as all people have the need to belong and to contribute. When developing neighborhoods with people with developmental disabilities, think broadly. Think about the types of people that you know and have relationships with and try to build similar-type relationships. Include people from the faith community if people are interested in religion. People who live in the same geographical area are viable possibilities too. Even though it takes hard work, it is worth the effort. Having a neighborhood enriches the lives of people presently and can provide ongoing support at the time of death.

Strategy 2: Remembering The Details Of The Death

Regardless if people with disabilities have been present when the person died and/or was taken away in the ambulance or hearse, never underestimate the importance of talking about the death and the surrounding circumstances. These traumatic events compound the actual loss. People need to feel free to talk about the death as a means of not only sharing the news but as a way of helping the reality of the death sink in. Many staff and family members have not had any formal training about death and many agencies do not have policies. Thus, learning about what to do and how to support people often comes at the time of the death. It is natural to feel overwhelmed, inadequate and unprepared for the road ahead. Trust yourself to know that you are capable. Even though this time is stressful, remember that people, including those with developmental disabilities, often know
what is best for them. Practice active listening by repeating and clarifying what people are saying. Be sensitive to the needs of each person. It is ok to need and rely on others. Work together as a team. Do not become too busy with the many details and needs of others without taking care of yourself.

During this time, many people look to God or a higher power for comfort, strength and direction. If you have a Bible, Psalm 23, Psalm 121 and the Lord’s Prayer in Matthew 6 can provide comfort. Other people turn to their favorite music. Religious and spiritual beliefs and practices should never be forced on people. Remember that your presence makes a huge impact.

**Strategy 3: Sharing About The Death**

Before you tell people about the death, spend time centering your thoughts and identifying your own feelings. Think about what you are going to say. Tell both staff and people with disabilities about the death of the individual as soon as possible. Use your discretion whether to tell staff when you call them or if wait until the group is gathered. It is helpful to have other staff present when you tell the individuals with disabilities about the news of the death. A plan for the next couple of days can more easily be established when everyone is together.

Convey the news in a simple fashion. Euphemisms like ‘passed’, ‘expired’, ‘gone to sleep’, ‘gone to heaven’, ‘gone to be with Jesus’ are not recommended. Simply inform people that you have some bad news, and, then, tell them that the individual has died. Speak clearly and loudly. Be careful to give enough information without overloading people. Be attentive to their body language and listen to what they say and do not say. Answer the questions that people have and respond to them. If you do not know the answers, acknowledge that you do not know. It is ok not to have all of the answers. Be sure to communicate that the individuals are safe, loved and they will not die right away too as they will feel vulnerable.

Below are basic facts that help to explain death. The brain, heart, lungs and other body parts stop working. The person will not be coming back. The person does not feel hungry or thirsty. Being angry with a person does not make a person die. A dead person looks like he is sleeping. People with developmental disabilities understand a lot more than they are often given credit for. They can sense the mood of what is happening even if they are not included in or told about a situation.

All people need assistance in processing death and loss. People with disabilities can help ease the difficult situation. They can help by providing comfort and/or humor. It is ok to laugh. Relax and remember you do not have to have it all together. Be real with your own feelings. Remember that you are grieving and might still be in shock like those around you. Your own caring and sensitivity is more important than being composed. When the news is shared with everyone together, the group learns to care for each other.
Each person will process the news of the death differently. Encourage people to express how their feel about the death and to share memories, either good or bad, about the person as a means of talking about the person who died. It is healthy and necessary to talk about the person instead of suppressing memories and feelings. Let people express their feelings in a way that is natural for them provided that they do not hurt themselves or others. Even people who do not talk benefit from hearing memories. It is common to feel a variety of feelings ranging from guilt, sadness, anger etc. Be prepared for anything. It is acceptable and healthy for staff to cry. Have tissues readily accessible for anyone who needs them. Handing people tissues may communicate that they are to stop crying.

Consider helping people express their grief by making a card or a poem to offer the family of the individual. If there is a death in one group home in your agency, the individuals from your group home might want to show support by making a meal to share. It is important to offer choices. During this difficult time, the appetite is affected. While some people eat more, others eat less. Offer choices about what and how much to eat.

**Strategy 4: Letting The Neighbors Know About The Death**

Death often occurs when it is not expected. When someone dies, telling people who know the individual becomes one of the primary initial tasks. If a family member dies, work out with the family who will tell the person with the disability. If a person with a disability dies, the checklist below provides a way to keep track of people who need to know and any other information that might be helpful in order to avoid overlooking anyone. As people work out their grief in different ways, one staff might want to make the phone calls while another may find it to be extremely difficult.
The Geese and the Peanut Butter Chocolate Ice Cream: the Grieving Gifts to the Lexington Street Community

<table>
<thead>
<tr>
<th>Person to Contact</th>
<th>Date Contacted</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jillian Pound, Day Program Supervisor</td>
<td>March 31, 2006 morning</td>
<td>Message left with staff member, Joe Gold. Jillian to call back for details of funeral.</td>
</tr>
</tbody>
</table>

___Parent(s)

___Sibling(s)

___Guardian

___Supervisor at your agency

___Staff at your agency

___Doctor

___Case worker

___Local religious leader i.e. rabbi, pastor or priest

___Friend(s) from Faith Community

___Employer/Job Coach/Day Program Supervisor

___Friend(s)

___Other

Funeral Home & Address: ______________________________________________________

Funeral Location & Address: ________________________________________________

When you give out information, speak slowly and clearly when you tell people about the death. Think ahead of time what you are going to say. You will want to include at least the following information. Do not get bogged down with too many details. Be sure to ask if the person has any questions.

➤ your name.
➤ your agency’s name and phone number.
➤ name of individual who died.
➤ how and when individual died.
➤ how and when individual died.
➤ day, time and place of visitation, if known.
➤ day, time and place of funeral, if known.
You may want to say something like the following, "Hello this is [your name] from [relationship with individual] where [name of individual who lived] is calling with some sad news. [Name of person] died from a means of death i.e. car accident, heart attack etc. when (for example, last night). Visitation will be from [X date and time] at [Funeral Home]. The funeral is on [X date and time] at [X location]. Feel free to phone me, [contact name], at [phone number] if you have additional questions."

When a person dies, it is natural for people to remember other people in their lives who have died. These memories might bring about feelings and issues connected with the past losses especially if they have not been dealt with. Feelings of sadness, anger and guilt might be felt with a greater depth later. The death of another person may bring about these intense feelings. If issues are not processed in the past, they will not go away by pretending that they do not exist. Grief has no timeline. Each person’s experience of grief is unique.

Grief has physical and emotional symptoms. It is normal to either sleep a lot or not much. Expect to be drained of energy and maybe even numb. Do not expect yourself and others to get over it right away. It can take months and even years to heal. Some people never get over the death of others. Grief expresses itself in behavior as well. Sometimes, people regress and no longer do things that they once did. Do not place judgment on how others grieve as there are no right and wrong ways.

**Strategy 5: Visiting At The Funeral Home**

Visiting at the funeral home is one way to offer closure. Individuals with developmental disabilities need to know what to expect at the visitation at the funeral home and, then, to be given the choice if they want to attend. Explain that the visitation is an opportunity for people to express their care for each other and to see the body of the person who died. Let them know what you expect of them. Prompt people about what to say to others. “I’m sorry” or “I offer my sympathy” are simple and effective phrases. Handshakes and/or gentle hugs to family members and friends are also appropriate. Depending on the individual, you might want to spend time role-playing these gestures so that you and the individuals are comfortable.

Be specific with what they will find. Explain that they will probably see the person laying in an open casket or coffin. The person may not look like herself, as the funeral director has put makeup on her face. Although people with developmental disabilities often do better during this time than expected, be prepared for their direct and honest comments.

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It might be necessary to wait in line to greet the people and to see the body. If you think that there will be a long receiving line at the funeral home, you might want to see if you can arrange a private viewing. This way individuals will not feel rushed and can spend the time that they need with the body. Remember in some cases that the individual who died has become like a family member to those who remain and this time will be emotionally and physically charged.

Provide adequate staff support to the individuals when you go to the funeral home. Ideally, a one-to-one ratio is best, as it is difficult to know how people, including staff, will respond. Sometimes people want to touch the body to confirm the reality of the death. If this is known, gently touch the hands of the person with the individual. Before you do so, warn the individual that the body will be cold.

Funeral homes are public places. If you are unsure of the norms of the family regarding interaction with others and whether it is ok to touch of the body, ask the funeral home director. Follow the cues and responses from the family as well. People notice the actions of others. Do not let this threaten you. Instead, trust in the relationship that you have developed with the individuals and use the opportunity to model positive ways of being with people with disabilities.

**Strategy 6: Attending The Funeral**

Again, let people know what is expected of them at the funeral and let them choose if they want to attend. Encourage everyone to go to the bathroom before the service. During the service, follow the example of others who are present if you are unsure what to do. Describe as fully as possible to those with you what they are to do and what will happen. Encourage them before entering the place of the funeral to sing and stand when others do. When the priest, rabbi, pastor or another person is talking, it is important to be quiet. If you know how long the service will be, let it be known. As the funeral is the last time that people will get to see the person who died, it is ok to cry and express their sadness. Since other people will be watching, remember that you are modeling how to be with people with developmental disabilities. Again, if possible, have one-to-one ratios.

Some traditions have a fellowship meal after the service. Listen to the instructions of what is expected to happen. If in doubt, ask. In some circles, people are welcome to share memories or attributes of the person who died. Ask if the person(s) that you are supporting is interested in talking. It would be a way to help them grieve while making a meaningful contribution.
Strategy 7: Coping Without The Loved One

Continue to talk about the person who died in the weeks, months and years after the funeral. If people need to repeat the same story about the person who died, listen. Their talking about the death is necessary grief work, which leads to healing. Do not be afraid of your feelings and those of others. Your honesty and caring speaks volumes. You do not have to have it all together. Try not to feel guilty as you have probably done all that you could have. Remember that you are grieving too. It is normal to feel that people have become a part of you. It is ok to cry and to experience whatever feelings surface. They do not have to be logical. The intensity of the feelings may come and go. Smells and objects may serve as reminders of the person. If you think of the person, express it with other staff and individuals. All people need to hear stories and talk about the person who died in order to grieve healthily. Make it a point to discuss with others what you have learned from the situation and what you would do differently and the same if and when faced with the next death. Give family members and other staff opportunities to support and encourage individuals and the group. It takes many people caring and working together to come through the losses. Even though it is natural to be depressed, if depression lingers for more than three weeks, seeking professional help maybe beneficial.

Strategy 8: Nurturing A Community Of Acceptance And Support By Remembering The Loved One

Expect birthdays and holidays to be difficult. You may want to check what people want to do ahead of time. You might want to light a candle or do something else to honor the memory of the person. Some people never get over the death of a person that they care about. Planting a tree in the person’s honor can become a meaningful remembrance. You might want to designate an area that contains objects that serve as reminders of the person. Before you put out a photograph of the person in a public area of the house, check with all those involved as some people will be comforted by the picture and for others it might stir up too much pain. Consider making a memory wall or scrap book for pictures of people who are no longer actively involved in the lives of people. It is ok to do happy things that people enjoy doing without feeling guilty.

Everyone handles grief differently. Some people gain comfort by talking while others may process their grief internally. It is the responsibility of support staff to allow opportunities to talk or be silent as the need arises. Suppressed grief will surface in other ways. It can be demonstrated physically, emotionally, and/or behaviorally. How you and staff and/or family members handle your grief will greatly affect how people with developmental disabilities handle theirs. People with developmental disabilities understand more than we often give them credit for. Death is a natural and normal part of life. Dealing with loss and death as well as their accompanying pains of grief help all people to live more full and abundant lives.
ACTIVITY BOOK

The activity book contains pictures from the story. Individuals can sit with people with developmental disabilities and talk about what is happening in the picture. People can talk about their feelings that come from looking at each picture. It is also possible to select specific pictures that address specific experiences of individuals with developmental disabilities. They can sketch themselves into the pictures as well as color them. Children would also find the activity book helpful.
The Elizabeth M. Boggs Center on Developmental Disabilities
UMDNJ – Robert Wood Johnson Medical School
The Geese and the Peanut Butter Chocolate Ice Cream: the Grieving Gifts to the Lexington Street Community

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GAME

Anyone can play the non-competitive game. It is designed to give all people, regardless of verbal skills, the opportunities to participate and to work through their grief. People can choose to draw on the experiences of the characters in the story or their own personal experiences with death and grief. People draw from cards in the following categories: feelings, behaviors/actions, insights and personal reflections. Further instructions on constructing and playing the game are listed in the following pages.
The Lexington Street Community Game

If you have read the story, this game is one way that you can talk about it. The game encourages people to talk about their own experiences.

**Story Summary:** Rachel dies suddenly when she is visiting her mother, Mrs. Brie. Priscilla, the group home manager where Rachel lives, must tell others about her death. Rachel’s death brings about various responses of the staff (Marco and Larry), residents (Sylvia, Robyn, Bruce and Reuben) and neighbors (Mrs. Kipfer, Mr. O’Reilly as well as Geetha and Suresh Patel). Memories of past deaths surface for them. Priscilla guides the individuals through the visitation and funeral. Together they form a community that care deeply for one another.

**Objectives:**
- Each person takes their turn at choosing a card from each of the four categories. Categories include: Feelings, Actions/Behaviors, Insights and Personal Reflections. The card is read, discussed, and then placed on the person from the game board. For example, Person A draws the card, “Mrs. Brie had difficulty sleeping” from the Action/Behavior pile. After Person A reads the card, he is given the choice to share with others a similar experience from his past. Then, Person A puts the card on the spot for Mrs. Brie on the game board. Person B, Person C etc each take their turn until all of the cards are drawn. Each person is given opportunity to talk about their grief experiences through the cards.

**How to Assemble:**
- Enlarge and cut out the table scene and pictures of the faces from the Profiles of Lexington Street file. Label each face with the appropriate name. Glue unto Bristol board. Cut three circles out of aluminum foil (mirror effect) to personalize places. Laminate the board for protection.

- Print and cut out response cards and glue onto colored pieces of Bristol board. Feeling cards are red, Action/Behavior cards are blue, Insight cards are yellow, and Personal Reflection cards are green. Print, cut out and glue faces of characters on back of appropriate card. Cut out circle out of aluminum foil (mirror effect) and glue on back of the Personal Reflection cards.
Response Cards: cut out and glue on Bristol board with profile of character on front.

<table>
<thead>
<tr>
<th>Action/Behavior:</th>
<th>Action/Behavior:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reuben showed his feelings by quietly rocked back and forth.</td>
<td>Mrs. Brie had difficulty sleeping.</td>
</tr>
<tr>
<td><strong>Insight:</strong></td>
<td><strong>Personal Reflection:</strong></td>
</tr>
<tr>
<td>It takes a long time to grieve the death of significant people in our lives.</td>
<td>I __________________________when ____ ____________________.</td>
</tr>
<tr>
<td>Action/Behavior:</td>
<td></td>
</tr>
<tr>
<td>Priscilla cried with Mrs. Brie.</td>
<td></td>
</tr>
<tr>
<td><strong>Feeling:</strong></td>
<td></td>
</tr>
<tr>
<td>Reuben did not want to go to the visitation.</td>
<td></td>
</tr>
<tr>
<td>Action/Behavior:</td>
<td></td>
</tr>
<tr>
<td>Robyn talked a lot about how much she missed her friend.</td>
<td></td>
</tr>
<tr>
<td><strong>Feeling:</strong></td>
<td></td>
</tr>
<tr>
<td>When Robyn was standing by the gravesite, she remembered something funny that had happened with Rachel &amp; laughed out loud. Her response helped Mrs. Brie feel better.</td>
<td></td>
</tr>
<tr>
<td>Action/Behavior:</td>
<td></td>
</tr>
<tr>
<td>During the funeral, Mr. O’Reilly wept. This helped him let out feelings about the deaths of his wife and daughter that he had to keep to himself for a long time.</td>
<td></td>
</tr>
<tr>
<td><strong>Insight:</strong></td>
<td></td>
</tr>
<tr>
<td>Rachel’s death brought the people closer together.</td>
<td></td>
</tr>
<tr>
<td>** Feeling:**</td>
<td></td>
</tr>
<tr>
<td>Priscilla was shocked when she heard Rachel died.</td>
<td></td>
</tr>
<tr>
<td><strong>Feeling:</strong></td>
<td></td>
</tr>
<tr>
<td>Priscilla remembered many details about Rachel.</td>
<td></td>
</tr>
<tr>
<td><strong>Feeling:</strong></td>
<td></td>
</tr>
<tr>
<td>Priscilla looked inside herself and discovered the things that helped her find peace and rest.</td>
<td></td>
</tr>
<tr>
<td><strong>Action/Behavior:</strong></td>
<td></td>
</tr>
<tr>
<td>Priscilla gathered the staff and individuals with developmental disabilities together to tell them that Rachel had died.</td>
<td></td>
</tr>
<tr>
<td><strong>Action/Behavior:</strong></td>
<td></td>
</tr>
<tr>
<td>Bruce asked many questions about the death and what would happen at the visitation and funeral.</td>
<td></td>
</tr>
<tr>
<td><strong>Feeling:</strong></td>
<td></td>
</tr>
<tr>
<td>Bruce wanted to stand close to the body at the funeral home.</td>
<td></td>
</tr>
<tr>
<td><strong>Action/Behavior:</strong></td>
<td></td>
</tr>
<tr>
<td>Robyn and Mrs. Brie supported each other with a big, long hug.</td>
<td></td>
</tr>
<tr>
<td><strong>Feeling:</strong></td>
<td></td>
</tr>
<tr>
<td>The burgers reminded Robyn of Rachel.</td>
<td></td>
</tr>
<tr>
<td>Feeling:</td>
<td>Feeling:</td>
</tr>
<tr>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>The food that Mrs. Kipfer bought over was a big help to the people at the group home.</td>
<td>The Patels did not know what would happen at the funeral but they wanted to go to show that they cared.</td>
</tr>
<tr>
<td>Feeling:</td>
<td>Feeling:</td>
</tr>
<tr>
<td>Having other people at the funeral who truly cared about Rachel helped Mrs. Brie get through the day.</td>
<td>Reuben needed to keep to his schedule.</td>
</tr>
<tr>
<td>Feeling:</td>
<td>Feeling:</td>
</tr>
<tr>
<td>Larry felt comfortable talking about death, in part because he had experienced his own father dying.</td>
<td>Priscilla needed to rest and center her thoughts often.</td>
</tr>
<tr>
<td>Feeling:</td>
<td>Feeling:</td>
</tr>
<tr>
<td>Mrs. Brie had to be told that she did not need to feel guilty and that she did all that she could.</td>
<td>When Marco heard that Rachel died, his guilt about not attending his grandmother’s funeral returned.</td>
</tr>
<tr>
<td>Feeling:</td>
<td>Feeling:</td>
</tr>
<tr>
<td>Marco did not know how he would support the individuals with disabilities.</td>
<td>Mrs. Brie felt assurance when she heard Robyn laugh.</td>
</tr>
<tr>
<td>Feeling:</td>
<td>Insight:</td>
</tr>
<tr>
<td>Sylvia felt numb at the funeral service.</td>
<td>Priscilla knew she had to be honest and direct about Rachel’s death.</td>
</tr>
<tr>
<td>Insight:</td>
<td>Insight:</td>
</tr>
<tr>
<td>Mr. O’Reilly realized that the funeral helped him to express his grief from the death of his wife &amp; daughter.</td>
<td>It takes a long time to grieve the death of significant people in our lives.</td>
</tr>
<tr>
<td>Personal Reflection:</td>
<td>Personal Reflection:</td>
</tr>
<tr>
<td>I felt ___________ when_________ ________________________________ .</td>
<td>I learned ___________ when_______ ________________________________ .</td>
</tr>
<tr>
<td>Personal Reflection:</td>
<td>Personal Reflection:</td>
</tr>
<tr>
<td>I _______________ when ____ ________________ .</td>
<td>I did ______________________ when ____ ______________________ .</td>
</tr>
</tbody>
</table>
The Geese and the Peanut Butter Chocolate Ice Cream: the Grieving Gifts to the Lexington Street Community

<table>
<thead>
<tr>
<th>Personal Reflection:</th>
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</tr>
</thead>
<tbody>
<tr>
<td>I felt ____________ when_________ __________________________.</td>
<td>I learned ____________ when_________ __________________________.</td>
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<td>I did ______________________ when ____ _____________________________.</td>
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<tr>
<td>I __________________________when ____ _____________________________.</td>
<td>I learned ____________ when_________ __________________________.</td>
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</thead>
<tbody>
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<td>I __________________________when ____ _____________________________.</td>
</tr>
<tr>
<td>Personal Reflection:</td>
<td>Personal Reflection:</td>
</tr>
<tr>
<td>---------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>People at my group home __________ when __________________________.</td>
<td>People at my group home __________ when __________________________.</td>
</tr>
<tr>
<td>Personal Reflection:</td>
<td>Personal Reflection:</td>
</tr>
<tr>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feeling:</th>
<th>Feeling:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Robyn needed to talk about Rachel after she died.</td>
<td>Robyn often told the same story about Rachel.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feeling:</th>
<th>Insight:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sylvia got nervous when she heard about Rachel’s death.</td>
<td>Larry cared about the people with disabilities and let them talk about their feelings when he told them that he was leaving.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insight:</th>
<th>Action/Behavior:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Priscilla knew that the anniversary of Rachel’s birthday would be difficult for everyone.</td>
<td>Bruce provided support to Mr. O’Reilly by listening to Mr. O’Reilly’s story about the death of his wife and daughter.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feeling:</th>
<th>Feeling:</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Patels showed that they cared about their neighbors by attending the funeral.</td>
<td>The individuals with developmental disabilities and staff felt loved and cared for when they found out about Rachel’s death.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Action/Behavior:</th>
<th>Feeling:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Larry had talked about the death of his dog and father, which helped him to deal with the death of Rachel.</td>
<td>Everyone was shocked that Rachel died. They did not understand why it happened.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insight:</th>
<th>Feeling:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some people needed to know that they would not die suddenly like Rachel did.</td>
<td>The community had people who loved and cared for them.</td>
</tr>
<tr>
<td>Action/Behavior:</td>
<td>Insight:</td>
</tr>
<tr>
<td>------------------</td>
<td>----------</td>
</tr>
<tr>
<td>People did not continually think about Rachel’s death but they were able to continue to do the activities that enjoyed doing.</td>
<td>Although Rachel’s death was disruptive, the individuals coped well with the change.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feeling:</th>
<th>Insight:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Robyn’s hug made Mrs. Brie feel better. It was more powerful than any words.</td>
<td>When a person dies, their brain, heart and lungs stops working.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insight:</th>
</tr>
</thead>
<tbody>
<tr>
<td>When a person dies, the person is not in pain.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insight:</th>
<th>Feeling:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making a card, preparing a snack or offering some other expression of support help people feel less sad.</td>
<td>People respected each others feelings during the visitation and funeral.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Insight:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death is a normal and natural part of life.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Action/Behavior:</th>
</tr>
</thead>
<tbody>
<tr>
<td>The individuals talked openly about their feelings &amp; memories with staff. It was a good experience to be together.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feeling:</th>
<th>Personal Reflection</th>
</tr>
</thead>
<tbody>
<tr>
<td>People respected each others feelings during the visitation and funeral.</td>
<td></td>
</tr>
</tbody>
</table>

-Cut out names and glue on game board below profile. Add, three circles of aluminum foil to personalize places.

<table>
<thead>
<tr>
<th>Larry</th>
<th>Mr. Larson</th>
<th>Priscilla</th>
</tr>
</thead>
<tbody>
<tr>
<td>Robyn</td>
<td>The Community</td>
<td>Mrs. Kipfer</td>
</tr>
<tr>
<td>Mrs. Brie</td>
<td>Rachel</td>
<td>Patels</td>
</tr>
<tr>
<td>Reuben</td>
<td>Sylvia</td>
<td>Marco</td>
</tr>
<tr>
<td>Bruce</td>
<td>Mr. O’Reilly</td>
<td></td>
</tr>
</tbody>
</table>
Profiles of Lexington Street Community

-Cut out profiles and glue onto Bristol board with names in a circle. See Game board for sample.
Reviewing the Characters

Alison
- sister of Rachel who died.
- mother of children who distributed flowers at gravesite.

Bruce
- housemate of Rachel.
- lived in State institution for many years.
- curious about death.

Erin
- sister of Rachel.

Gary Larson
- funeral home director.

Geetha & Suresh Patel
- couple who move into the Lexington Street neighborhood.
- parents of Priya.
- open to new experiences.

Jason
- friend of Robyn and Bruce.
Larry
• group home staff.
• talks easily about his experiences about death.
• leaves the community for a new position at another agency.

Marco
• group home staff.
• expresses discomfort & guilt over death of his grandmother.

Mrs. Brie
• mother of Rachel.
• loving and protective mother.

Mrs. Kipfer
• long time resident of the Lexington Street neighborhood.
• enjoys sharing her cooking and baking with others.
• loves to be around people & share the news with others.

Mr. O’Reilly
• long time resident of Lexington Street.
• private man who is grieving the death of his family.
Priscilla
- group home manager.
- dedicated.
- finds hope and renewal in nature especially geese.

Rachel
- woman who dies.
- lively.
- loves to eat.
- Elvis Presley fan.

Robyn
- roommate of Rachel.
- Elvis Presley fan.
- quiet.

Sylvia
- housemate of Rachel.
- easily sensitive.
- connects with the stark trees.

Rueben
- housemate of Rachel.
- has Down’s syndrome.
- rocks back and forth for comfort.
BIBLIOGRAPHY

The annotated bibliography about grief and loss makes up the final section. Although it is not comprehensive, it provides a place for people to begin to delve deeper into the issues of death and grief. Public libraries contain good children’s books on death and dying that can be adapted to the needs of the individuals that you support. The bibliography also lists internet sites that contain helpful information.
Bibliography


This book contains simple prayers that express various feelings connected with the death of a pet. They can easily be adapted for the loss of an individual.


In this children’s book, Mattie’s mother tells her how she stole the key of winter to prevent the death of her grandmother. By doing so, spring could not come and life could not continue until she accepted the impeding death of her grandmother.


In this children’s book, the value of grandparents for and the impact of their death on children are explored. Nuggets of helpful exercises can be found.


Freddie the Leaf looks to his friend, Daniel, to explain to him their life experiences. Although Freddie freely accepts and values spring and summer, Daniel helps Freddie to see that he must accept fall, which ultimately leads to his death as winter. Although Freddie is initially resistant to this reality, he eventually embraces it and receives comfort.


This resource booklet provides an excellent overview of the types and symptoms of grief as well as the theories of healthy grief work. It describes ways to support people with developmental disabilities through their grief and to prepare for their own death. It also provides insight into the grief of caregivers. Contact Candace at Candace.Cassin@state.ma.us for a copy.


Betsy works through the sudden death of her friend, Peter, by receiving comfort by her parents, remembering past experiences with Peter, drawing a picture of the two of them, and sharing the picture with her schoolmates. This book also addresses some frequently asked questions about the grieving process and understanding of children.
Throughout the various stages of childhood and adulthood, a daughter dances with and for her father. As her final dance for him is on his death bed, he promises that he will continue to watch her dance forever even after he dies.

After a tree rejoices in discovering its new growth from surviving the winter, it becomes outraged that this growth results from facing its difficulties by itself. After grieving, it is able to embrace more fully its complete journey.

A series of articles and responses that deal with ethical and practical considerations for people who are disabled interwoven with some personal reflections.

A wordless picture book that tells the story of a father dying and the response of the grieving family.

A wordless picture book that tells the story of a mother dying and the response of the grieving family.

Case studies provide examples to the psychological explanations and theories of the emotional and behavioral responses of grief for people with developmental disabilities. The book also provides concrete ideas of what to include in grief/loss trainings for agencies that provide services for people with disabilities.

Following definitions of the types of developmental disabilities, issues that impact individuals with these conditions are explored. They include: overprotection, disenfranchisement, limited supports etc. The article also contains a section that describes ways that caregivers can help in the grieving process.

The grief process for people with and without mental retardation is described. The book also contains a detailed listing of practical strategies of providing support and enabling people to address and work with their grief issues.
A simplified version of Charlene’s book listed above.

The Nigerian funeral rite and mourning traditions are told through the eyes of a child whose great grandmother has just died.

As each water bug leaves the water and enter the world above, those remaining wonder what happens to them.  While one promises to return to tell them, he finds he cannot as the world is too beautiful and is comforted because he knows the others will understand when they reach this part of their journey as well.

This book weaves together practical suggestions to accompany people who are dying and stories with care and sensitivity.  Spiritual needs are at the fore front.

Van Dyke teaches that death is part of the natural life cycles and uses stories that address various situations that deal with death issues.  With each chapter then, she presents practical rituals and activities that can bring healing.  Finally, she outlines a 6-week model of grief counseling.

Through the use of stories, the article provides practical strategies for helping people deal with the death of others.

Internet Sites of Books and Resources
Bethesda Lutheran Homes and Services.  Watertown, WI.  
This workbook helps individuals work through the stages of grief from a Christian perspective. It includes scripture passages and places for people to draw.  It can be downloaded from  
http://www.blhs.org/resources/spiritualResources/griefLoss.asp  

Down’s Syndrome Scotland,  
This workbook describes death and funeral rituals using simple language.  It also contains photographs.  It can be downloaded from  
http://www.dsscotland.org.uk/ageing/bereavement/
King, Angela. “Last Passages Sharing Information and Promising Practices to Enhance End-of-Life-Care for Person with Developmental Disabilities.”

Holmes, Michael, RN. “Crossing the Creek A Practical Guide to Understanding Death and the Process of Dying. Care Alternatives.”
  This resource describes the physical and psychological responses that occur in the dying process. Highlights include the importance of resolving issues from one’s life and a discussion on pain. Information available at <crossingthecreek.com>.

Other Internet Sites
www.compassionbooks.org
www.SacredDying.org
www.willowgreen.com
www.woodbinehouse.com
What Others Are Saying About This Resource?

It has often been very hard for staff in group homes and other residential settings to imagine themselves dealing with the death of one of the persons they support. It is not something people want to think about or plan for. But it happens, and as people age, it will happen more frequently. Melody Steinman has written a story and resource that has multiple possible uses. First, the story helps people imagine and think about what might happen in a setting where they work or live. Second, with the sections of discussion questions and practical strategies, managers and staff can think about what they might want to do when someone dies. Hopefully, this is the kind of thinking and imagining that agencies will do before a death happens, so it does not become a crisis that is compounded by the lack of plans and potential sources of support. Finally, it is a resource that could be used with adults with developmental disabilities, in grief support groups and other discussions, and includes a way to make a game that promotes discussion. Throughout the sections, Melody is making a fundamental assertion that everyone grieves, and that a community that comes together in times of grief to talk and share, even when it is hard, is one that honors everyone's humanity and memory.

Bill Gaventa, M.Div., Associate Professor
Director, Community and Congregational Supports
The Elizabeth M. Boggs Center on Developmental Disabilities
UMDNJ-Robert Wood Johnson Medical School

“The Geese and the Peanut Butter Chocolate Ice Cream: the Grieving Gifts to the Lexington Community” is a simple, straight forward story about a difficult topic—death, grieving and people with intellectual disabilities. It provides helpful insights. The descriptions of how the four individuals with intellectual disabilities react to the death of their housemate are very realistic. So are the responses of the people working at the home and the neighbors. Overall it provides a good overview of some "normal" but varied reactions to grieve. The package also includes some practical strategies that will be helpful to those working in the field of intellectual disabilities. A useful resource for use both in preparation for and in responding to a death of someone with an intellectual disabilities.

Jane Powell, Long Term L’Arche Assistant, Toronto, Ontario, Canada.

Melody Steinman's "The Geese and the Peanut Butter Chocolate Ice Cream: the Grieving Gifts to the Lexington Street Community" is a welcome resource for helping persons with developmental disabilities deal with the death of someone close to them. Written with a practical sensitivity to the many issues surrounding this subject, the story of how a group home manager guides both individuals with developmental disabilities and staff through the process of grieving over the death of an individual provides many helpful insights, not only through the story itself, but also through additional sections which offer practical strategies, discussion questions, and activities. Managers and staff will find this particularly valuable in preparing themselves for the inevitable losses in the group home setting, but parents, teachers, pastors, and social workers will also find this resource helpful.

Paul Leichty, Anabaptist Disability Network Director, Goshen, Indiana.
About Melody A. Steinman and Pat Schosser

**Melody A. Steinman** graduated from the Associated Mennonite Biblical Seminary in Indiana with her Master of Divinity and Master of Arts in Christian Formation and a certificate in Spiritual Formation from Eastern Mennonite Seminary in Virginia. She draws on her relationships with people with developmental disabilities when she worked as a counselor in a day program in Manitoba, a group home in Ontario, where she originates, as well as a pastoral intern in New Jersey. She plans to create more resources in the area of grief support, spirituality and general lifestyle choices for people with disabilities and people who support them. She can be reached at masteinman@gmail.com.

**Pat Schosser** and her husband and their 2 out of their 5 children moved to Burnsville, NC (Yancey County) from Pennsylvania. They designed and built their house, where they raised 5 children and a variety of animals: cow goats chickens and ducks. She has written and illustrated some stories about these animals and children. She enjoys a variety of activities, which include needle work, gardening, cooking and being around horses. In the past, she has worked as an LPN, substitute teacher, and in a Group home. Currently, she works with a child with a developmental disability, and once a week, as a Hospice volunteer.

We hope that you find this resource helpful in addressing your loss and grief needs. In many it is just a beginning to start talking about the impact of loss and death. Feel free to drop Melody a line if you have used this resource and/or you other ideas and subjects that you would like to see developed. She can be reached at masteinman@gmail.com.