



**2024 Guardianship Training Symposium November 6-7**  
 Marc A. Markell Ph.D., CT  
 People with Disabilities: Involvement, Inclusion & Healing  
**Thursday, November 7, 2024**  
**2:30 pm- 3:45 pm**

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**Outline**

- Introduction
- People with Cognitive Disabilities and Unique Grief
- Involving People With Cognitive Disabilities With Funerals/Memorials
- How to Support
- Erma's Angel by Erma Bombeck




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**Reminder: Ways to discuss disabilities**

- Speak to the person first- then the disability
  - A person with a Cognitive Disability
- Identity first
  - Cognitively Disabled people
- I'll switch between the two different terminologies.




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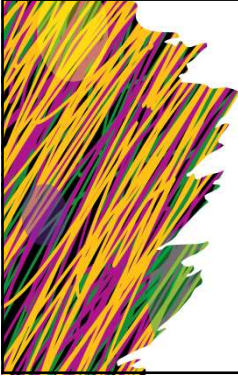
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There is no "cognitive disability grief"  
 There is no "normal grief"  
 Grief is paradoxically individual and universal  
 There are components of grief that may be unique to people with cognitive disabilities  
 The same as there are components of grief unique to Latino/a/x, ASD, LGBTQIA+...

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"Children are the forgotten mourners."(Kubler-Ross )

"Cognitive disabled people are often the ignored mourners."




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Another quick reminder...

- A 40-year-old person with a cognitive disability is not "like a 6-year-old". The person is 40 years old, has 40 years of experience, is physically 40 years old... They are a **40-year-old person who is a concrete thinker**
- Adults with cognitive disabilities are adults, and... they should not be prevented from doing "childish" things they enjoy
  - Color
  - Play with dolls
  - Watch cartoons




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- If someone is capable of love, they are capable of grief (Wolfelt)
- Sometimes grief does not "look" like what others expect
  - Might be obvious such as **sadness, crying, or depression.**
  - Might be the expression of emotions through behaviors such as **irritability, sleep problems, anxiety, or expressions of fear.**




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- When a parent of a person with a cognitive disability dies:
  - It is **not just the loss of someone they love.** It is also the loss of someone who is probably the most familiar with their needs, and with whom they shared a trusting relationship.
  - Many cognitively disabled people are left out of the rituals of mourning.
  - Some people with cognitive disabilities are not even told when a loved one dies.

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- Cognitively disabled people are often confused and frustrated by the disappearance of a significant person
- Care providers don't tell about a death or are not honest to "protect" the person
- Trying to "protect" someone from loss usually results in more problems during the grieving process

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- The more severe the cognitive disability, the more likely the person's grief will go unrecognized
- About 15% of people with moderate to severe cognitive disabilities attend grief rituals (funerals, memorial services) Why?
  - Care providers feel the person with the disability will act out
  - The person with the cognitive disability won't understand death
- If the family/community has gathered for funeral activities, the person with a disability should be given the option to attend
- If a cognitively disabled person is not able to decide, include them in the funeral activities (Hoover, Markell, Wagner, 2005)




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- The person may not want to attend death ceremonies. Being alone or away from the funeral activities may be the right thing for the person – **if they can decide**
- How the person responds to grief is often dependent on the family/community's reaction




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"If we can establish significance, we can move on. If we cannot do so, we tend to stop progressing, and the hurt can become an obsession to us."  
 Doug Manning

If cognitively disabled people are helped to be made aware of how significant the death is, they are likely to move on. If not, it may become an obsession.




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Included People with Cognitive Disabilities in Aspects of Death Surround

(Taken from Doka, 2002; Hollins, 2016; Markell, 2004, 2013; Wolfelt, 2005; Primo, 2013 The Elizabeth M. Boggs Center on Developmental Disabilities and Vanderbilt Kennedy Center)




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**Communicate honestly; include as much as possible**

- Respond as simply and honestly as possible
- Answer questions as directly as possible
- Don't make up information
- If you don't know, tell the person you don't know




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**Include**

If people are excluded from "death surround" (Summer and Witts, 2003), they may have more fear, anxiety, and problem behaviors. They may also have difficulty in the future when they experience loss.



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- Include the person with a cognitive disability as much as possible in the funeral and memorial arrangements.
- Give them some way of contributing (could give two options).
  - Picking out flowers
  - Color of casket or urn
  - Take away
  - Memory cards



The question should always be, "How do we include everyone in the leave-taking rituals?" Not, "How do we exclude someone from the leave-taking rituals?"

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**Include Nonverbal and Concrete Rituals In Funeral If Possible**

- Rituals are symbolic
- People who are more concrete in their thinking, need concrete rituals
  - Nonverbal rituals may be helpful
    - Music
    - Pictures
    - Art
    - Tactile experiences
    - Smells



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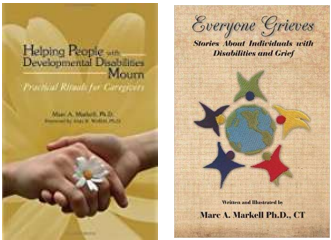
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Rituals




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### Provide Support

- If the person wants to participate in the funeral/memorial
  - Provide suggestions for participation
    - Designing of the program, picture by the casket or urn, insert in the program...
    - Putting valued objects on the casket or by the urn
    - Speaking
    - Singing
    - Writing a poem/statement
  - Provide backup support if needed




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**Poem**

Mike is my best friend. Mike and I played together. He liked trains. One day Mike and I were going to ride a train together. Now we will have to ride a train in heaven. I miss you, Mike. It will be fun to ride the train with you in heaven when I get there.



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**Avoid Euphemisms**

- For example, saying a dead person is "asleep" will not only mislead a person, but may also cause misunderstanding that the dead person might "wake up".
- People can cope with what they know. They cannot cope with what they don't know.
- Use the words dead, dying, died, and explain what they mean. For example: Dead means...**when a person's body stops working. It doesn't see, hear, feel, eat, breathe, etc. anymore. The person can never come back** (Wolfelt).

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**passed away** } In a survey of 3,116 participants from a range of 39 countries  
**passed on** }  
**gone** }  
 lost  
 big sleep  
 gone to be in Abraham's bosom  
 buy the box - coffin  
 buy the farm  
 cross the Great Divide  
**expired**  
 give up the ghost  
 go to meet one's maker  
 kick the bucket  
 negative patient care outcome  
 did not meet full health potential  
 pushing up daisies  
 six feet under  
 take a dirt nap

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**Listen to the person who is grieving**

- Must listen immediately after the death
- Also listen in the weeks and months following
- Understanding the permanence of death can come slowly

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**Make photos and other mementos available**

- Shortly after the loss, it is common to avoid pictures and possessions and places associated with the person who died.
- Later, mementoes may come to be valued




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- People with cognitive disabilities should be helped to choose some mementos
- This choice should be offered again later when some of their emotional pain has subsided.
- Sometimes people make unexpected choices, but these choices should be respected.

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**Minimize change**

- Minimize changes in routine, accommodation, and caregivers as much as possible
- Major changes should be avoided for at least one year
- If you can't avoid change, be creative




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**Provide opportunities for the individual to make connections ... past, present, and future:**

- Look at pictures and share memories
  - Make a book or a memory box about the person who died
- Light a candle in honor of the person
- Visit places they used to go together
- Talk about how much the person who is gone would be happy about a present activity




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**Observe anniversaries**

- Anniversaries can be observed.
- Many religions have formal services a year after someone has died.
- This is especially helpful on the anniversary of an important loss.
- Depending on the person and the loss, the observance could be more frequent than a year (do not need to be formal)




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**Keep connecting with key supportive relationships**

- Keep in touch with people in the person's life. The situation may have changed because of the death, and the relationships with others may still be very important.
- This may be especially important if a house or roommate dies.




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**The concept of death depends on experience and age**

- The ability to understand death is not dependent on IQ, but on chronological age. This suggests the importance of learning through experience.
- If a person has never been allowed to experience loss, attend leave-taking rituals, or learn from loss, they may have a difficult time understanding.

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**Be aware of Burdensome Messages**

- **How a person died may be represented as the person's fault**
  - Cancer (smoking), liver disease (drinking), heart disease (weight/inactivity)...
  - Remind the person with a cognitive disability that everyone dies, and the cause does not take away from grief
- **"The person will be kept alive in your memory"**
  - Fear of forgetting and being responsible for the person's "death"
    - Memory box, write down memory book, record memories...

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- **"God took them because they were finished with what they were here to do."**
  - What about me?
- **"They were so good on earth that God wanted them to be an angel in heaven."**
  - I'm not being good anymore.
- **"They're in a better place." or "Don't be sad, they're in a better place."**
  - I don't care. I want them here!

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**Rituals**



Rituals are actions **that symbolically connect us to something meaningful**. They can be comforting, express feelings, bring about a sense of closure, or keep an important part of the past alive.

◦ <https://www.psychologytoday.com/us/blog/supersurvivors/201909/it-he-power-rituals-heal-grief#:~:text=Rituals%20are%20actions%20that%20symbolically,th e%20person%20they've%20lost>

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People who are Concrete Thinkers and Rituals

When rituals are **symbolic**, individuals who are more concrete thinkers may have a difficult time finding symbolic rituals helpful



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What May Help?

- Make Rituals more concrete.
- Five examples (three with additional stories and two without) from **Helping People with Developmental Disabilities Mourn: Practical Rituals for Caregivers**
- *\*\*person with a cognitive or developmental disability will typically be referred to as "the individual" throughout this presentation.*



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Ritual #1: Use of Pictures in Ritual

Purpose: Show a picture or pictures of the person who has died to the individual and talk.

Materials: a picture or pictures of the person who died.

Directions: You could do the ritual in a place that the individual and the person who died enjoyed.



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Start by having the individual look at the picture and say whatever they are thinking or feeling while looking at the picture. The facilitator can model this behavior.

If the individual is unable or unwilling to speak, the facilitator can "speak for" the individual. The facilitator may say something they remember about an interaction between the individual and the person.

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For example, "I remember when Carlos (the person who died) helped Jose (the individual) learn to ride a bike. I also remember them having such a good time riding together. Jose was a bit scared, and Carlos was right by Jose to make sure he was safe.

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Example: Earl is a 12-year-old whose best friend was Martin. They go to the same school and often spend evenings together. They play video games, watch movies and go for walks. Both Earl and Martin have mild cognitive disabilities and autism. One evening while Earl was reading, his dad received a call from Martin's mother telling him that Martin was walking to a corner store and was hit by a truck while crossing the street and died.

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Earl heard his father said phrases like, "oh no," "when did it happen," and "is there anything we can do?" Earl stopped reading and stood looking at his dad. When the short phone conversation was over, Earl's dad told Earl, "Martin was walking to the corner store. It was very slippery on the roads. Sadly, the truck could not stop, and it hit Martin when he was crossing the street. The ambulance came right away, and they did everything they could. It is so sad, but Martin died."

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Earl stood for a few seconds staring at his dad, and then he ran into his bedroom, took a picture of Martin he had on his dresser, and he started to cry very hard. He laid on his bed and screamed that it couldn't be true, and it wasn't fair that Martin died.

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After Earl and his family attended Martin's visitation and funeral, Earl did not want to look at pictures or go anywhere that reminded him of Martin. Earl's dad knew that Earl's reaction was typical; seeing pictures and going places that reminded him of Martin was very painful. Several weeks after Martin died, Earl's dad asked Earl if he would like to look at some pictures of Martin and talk about how Earl was feeling. At first Earl said no to looking at pictures and talking. His dad told Earl that if he wanted to look at pictures at some other time, to tell his dad and they could look at them together.

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Several days later, Earl told his dad that he would like to look at pictures of Martin and maybe talk. Earl's dad took out some pictures from a drawer. He handed Earl a picture of Martin and Earl at the county fair. They were on a ride, and both were smiling. Earl smiled and then started to cry. "I miss Martin so much dad." he said. "He was such a good friend to you Earl. You both loved going on rides together." Dad responded. "After every ride Martin would always say, 'that was a real mind blower bro.'" Earl and his dad laughed. They continued looking at pictures and talking about Martin. They laughed and cried.



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After about 20 minutes Earl said he was ready to stop. He told his dad that looking at pictures made him feel happy and sad. "Can we do this again in a few weeks. It's good to remember how much fun Martin and I had, and it's okay to feel sad as long as you're near me." Earl's dad assured Earl that they could look at pictures together again.

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Ritual #7: Use of Writing in Ritual M

Purpose: The individual will **write or dictate a letter** to or about the person who died.

Materials: Paper and writing utensil or computer.

Directions: This ritual may be **most appropriate for individuals who are able to write** but can be used with Individuals **who are unable or unwilling to write**. A letter could be written **individually, with assistance from the facilitator**, or **dictated while having the facilitator** write the letter for the individual. Another way of writing the letter is to have an **outline of the letter** with blanks that the individual can complete.



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For example: M

Dear \_\_\_\_\_, I feel \_\_\_\_\_ that you have died.

The times I feel saddest are when I \_\_\_\_\_.

What I miss most about you is \_\_\_\_\_.

One thing I want to tell you is \_\_\_\_\_.

Love, \_\_\_\_\_

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After the **completion of the letter**, the individual could **read the letter to others**. If there are several individuals involved with the letter writing, the individuals **could take turns reading** what they wrote. If an individual is **non-verbal or unable or unwilling** to read the letter orally, an adult could volunteer to read the letter out loud.

If this letter writing is **finished prior to the funeral**, the letter could be **put in the casket** with the body of the person who died or **with the body to be cremated**. The individual may also want to **read the letter in the presence of the body**. If this is something desired by the individual, it could be done **prior to the arrival** of or after the **departure of other mourners** at the funeral home. It could also be done in the **presence of other mourners**. Some other options for the **letter are to have the individual place it at the gravesite**, by the **urn**, or attached it to **helium filled balloon or balloons** (depending on the weight of the letter) and release it into the air.

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Dear Papa, I feel verry sad that you died.

The times I feel saddest are when I go to sleep. What I miss most about you is giving hugs. One thing I want to tell you is \_\_\_\_\_.

I miss you. Love, Ponn

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Ritual #5: Use of Drawing in Ritual M

Purpose: The individual **will draw a picture of the person who died** and have the opportunity to share the picture and memories with others in their life.

Materials: Paper, some tools to create the picture (marker/colored pencils/crayons/paint).

Directions: Provide the individual an opportunity to **draw a picture** of the person who died. The individual may want to draw a picture of an **event they enjoyed** doing with the person who died or **simply a portrait** of the person who died. Even if the **individual** has limited fine motor skills and is unable to draw with much or any reality, **encourage them to draw whatever they remember** (even if it is circles or scribbling). What may appear to be random lines to another person may signify a specific event or portrait to the individual drawing.

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The facilitator can ask the individual to **"tell us about the drawing"**. The individual can talk about what they are drawing as they draw or after the drawing is complete. If there are **several pictures**, from the same or different individuals, all the pictures can be copied and made into a **booklet**. The individual can use the booklet to **look at or show others** to give them more opportunities to talk about their mourning.

A variation of having the individual draw a picture is to **make a light copy of a picture of the person who died** on a copy machine and have the individual either trace or color the picture. This will give the individual **a lot of structure while drawing or coloring**, rather than drawing or coloring freehand.

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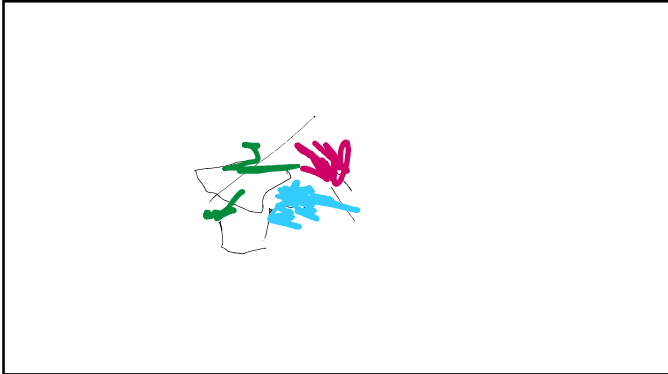
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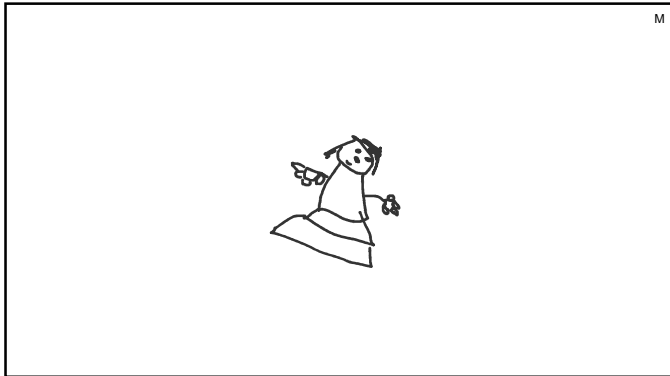
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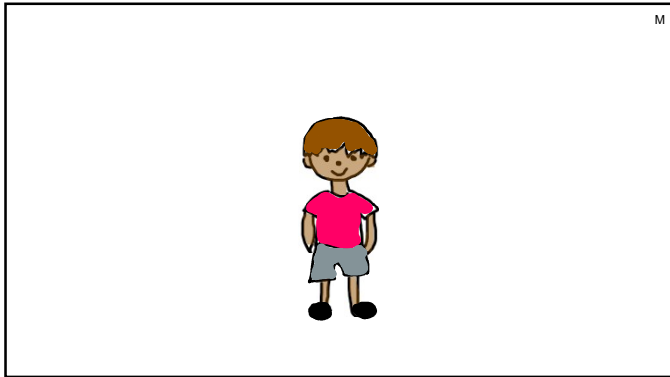
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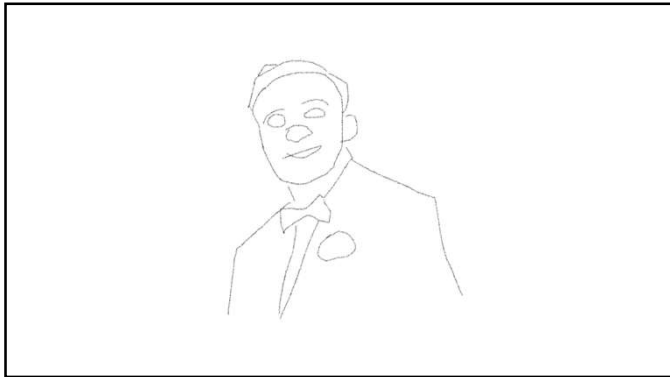
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• Ritual #8: Use of Stones in Ritual

• Purpose: Invite the individual to remember something about the person who has died and place a small stone in a water fountain after they say what they remember (they could also paint the stone or write a word or phrase on the stone).

• Materials: Stones and paint. Water fountain.

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• Directions: Gather or purchase stones – if the stones are going to be painted or written on, it may be most effective to find or purchase smooth stones. You could invite the individual to paint or write something on the stones they remember about the person who died. After the stone dries, the individual can place the stone in the water fountain, the individual can say (or the facilitator “speaks for the individual” who is non-verbal) something they remember about the person who died. The individual or facilitator could invite others with or without disabilities to participate.

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I would have talked less and listened more.  
I would have invited friends over to dinner  
even if the carpet was stained and the sofa  
faded.



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I would have eaten the popcorn in  
the "GOOD" living room and  
worried much less about the dirt  
when someone wanted to light a  
fire in the fireplace.



I would have taken the time to  
listen to my grandfather ramble  
about his youth.

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I would never have insisted the car  
windows be rolled up on a  
summer day because my hair  
had just been teased and  
sprayed.



I would have burned the pink  
candle sculptured like a rose  
before it melted in storage.

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I would have sat on the lawn with my children and not worried about grass stains.  
I would have cried and laughed less while watching television and more while watching life.



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I would have gone to bed when I was sick instead of pretending the earth would go into a holding pattern if I weren't there for the day.  
I would never have bought anything just because it was practical, wouldn't show soil, or was guaranteed to last a lifetime.



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Instead of wishing away nine months of pregnancy, I'd have cherished every moment realizing that the wonderful growing inside me was the only chance in life to assist God in a miracle.  
When my kids kissed me impetuously, I would never have said, "Later. Now go get washed up for dinner."



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There would have been more “I love you’s and more “I’ m sorry’ s”.  
...but mostly, given another shot at life, I would seize every minute... look at it and really see it...live it... and never give it back.



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