

## CHAPTER 9

# Legacy and Memory: When We Are Facing Our Final Chapter

**THIS CHAPTER FOCUSES** on considerations of legacy and memory. How can considering the legacies that we will leave behind help us to face our own mortality? How can “spiritual wills” assist us when we are facing our “final chapter” here on earth? And how can letters to loved ones provide comfort if we are concerned that as we age we may no longer be able to remember who we are?

### **Death and Dying: Living on in the Lives of Others**

When we are facing death, either because we are growing old or because of illness or injury,\* it is a time to consider what will be carried on from our lives. While our bodies are sure to die, our spirits are sure to live on in the memories, lives, and conversations of others. In many cultures, this is honored and clearly recognized:

[In some cultures a] distinction is drawn around the death of the body and the survival of the personhood of the deceased

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\* Please note that this chapter has not been written for people who are affected by suicidal thoughts. If you are considering suicide or are affected by suicidal thoughts, I'd suggest you speak about this with someone, be it a friend, community leader, and/or professional.

. . . At a particular point in time after the ritualized goodbye to the dead body, the relatives of the bereaved assemble again, this time to take on the virtues of the deceased, or if you like, the spirit of the deceased. Perhaps we could say that the spirit of the deceased is regained. (David Epston in White & Epston, 1991, pp. 28–29)

And so, as we are approaching death, we can ask ourselves, “What piece of my life will survive physical death?” What legacies will we be leaving behind on earth? These legacies may not be grand, and they may be hard to think of at first, particularly if our lives have been lived outside the mainstream.

When two of Cheryl White’s dear friends were dying of AIDS in the early 1990s, she asked David Epston and Michael White to collaborate to come up with ways of working with those who are dying, particularly those who have been marginalized by the dominant culture, like gay men. In their collaborations, they discovered that it made a difference if the dying person was thought of as a benefactor who could invite certain people to be the beneficiaries of their legacies. If we include certain virtues or values that we have carried in our lives as part of the legacy that we wish to leave, it can broaden our view of life and death.

There may be more than one legacy that we wish to leave. Ted, for instance, was determined to leave behind a beautiful garden that he had created. He was also determined “never to be a bother to anyone ever again.” Ted was HIV positive and took part in a narrative gathering in the 1990s in Adelaide. When we inquired about the histories of these two legacies that he wished to leave, we were told a story about “Aunty Nature.”<sup>1</sup>

## Aunty Nature

### Spirituality of the Garden

by Ted

*When I was diagnosed with HIV, I joined the euthanasia society and distributed leaflets to doctors, to family, and to friends. I prepaid and planned my own funeral. Throughout my life people have always told me that I was a bother to them. I am determined that I will never be a bother to anyone ever again—especially in death.*

*I do not have trust in human beings. This was removed long ago. I was sold by my family when I was only three years old. When, many years later, I came to Australia, I was a foreigner, then a gay foreigner, and then an HIV-positive gay foreigner. I have learned that at the end of the day you are by yourself; you're on your own.*

*But to be honest, I do not believe this completely, because I am with my garden, the trees, the flowers and butterflies. This is my spirituality, to spend time with nature. Some people call nature Mother Nature, but I call her Aunty Nature. When trust is gone, you can turn to her and to the trees—they do not hit you; they offer only comfort, not violence. To spend time in my garden brings me great joy and peacefulness. There is a serenity there and simple beauty.*

*When you ask me why I call her Aunty Nature, well, there is a story I can tell about that. It begins when I was small child shortly after WW2. We were very poor at home, in the mountains of what used to be Yugoslavia—it is now Slovenia, an independent country. There were ten of us children, and there was very little food.*

*I don't have any idea where it came from, but I vaguely remember my Auntie having a hessian [burlap] bag. She would throw this hessian [burlap] bag over her shoulder and would set off walking from village to village. She was a professional beggar. When she would come back home, she would always empty the bag upside down, and things would fall out. Bread, fruit, and I do remember that once there was a salami or sausage. I thought, gosh, aunties are wonderful. And so if there is anything wonderful, I always think of my auntie with her bag of surprises. Nature also has many surprises, and that is why I call her Auntie Nature.*

*What I learned from my aunt became very important later. As I mentioned before, I was sold at the age of three to go and work on a farm. Anyone who was old enough to hold a tool of some kind was given away or sold or adopted. When I couldn't cope anymore at the farm to which I had been sold, I ran away. I had, over the years, become used to hiding in the forest for many days at a time. Trees had been a comfort for me then, a place to run away to. But this time I had decided that I would not go back to the farm. There are many other horrible stories about what happened on this farm, and I am very lucky to be alive. So this time I hid in the forest for three months. I thought to myself, if my auntie could beg (she wasn't alive anymore), then why couldn't I? And so I took up my auntie's profession.*

*I went from house to house, from village to village, begging for food. That was how I survived. Of course, before too long the weather became very cold. Living under the tree wasn't much fun in autumn when the rain and snow started to come, so I had to go back to the farm. Fortunately, though, that was when the social security came and took me away. They placed*

*me in an orphanage—and that was wonderful. I enjoyed my time in the orphanage. This was in the early 1960s. In that part of the world people were still very poor in those days. Being up in the mountains with goats, civilization was very different there than what we know here today.*

*I have plans for what I am going to do when I am ninety, but I have life and my death organized, prepared for. I will never be a bother to anyone ever again. And I will continue to delight in the butterflies, the trees in my garden.*

Think for a moment about what virtues or values you would like to leave others. In considering this, it then becomes possible to create a special sort of document—a secondary will of our legacies, learnings, and virtues. While wills usually have to do with physical property, these secondary wills relate to what could be called “spiritual property.”<sup>2</sup> Here is an example, as told by narrative therapist David Epston:

I was working with a woman who was terminally ill. Shortly before her death she made me the agent of her will and testament. As part of my duties as agent, it was my responsibility to distribute, to appropriate persons, copies of a very important document. This document included a testimony to the sexual abuse that she experienced as a young person, some thoughts about how others might free themselves from the long-term effects of such abuse, and a message of hope. (David Epston in White & Epston, 1991, p. 31)

### **Creating a Secondary Will**

If you know someone who is facing their own death because of old age or illness, perhaps you can assist them in

creating a secondary will in relation to learnings or values that they would like to pass on to others. Alternatively, you might consider the legacies that you wish to leave to others, as well as how you are trying to carry on the legacies that have been bequeathed to you. These may be small, such as a love of gardening, or an interest in sports, or a sense of humor, or an appreciation of beauty, or courage.

Here is an example of a secondary will. Jacinta<sup>3</sup> had been diagnosed with cancer, and while she was optimistic that she might be able to overcome this, she decided it was an important time to consider her life and legacies.

### **Will and Testament of Legacy, Learnings, and Virtues**

I, Jacinta, residing at 1500 Campbell Avenue, New Orleans, being of sound mind, hereby declare this to be my Will and Testament of legacy, learning, and virtues.

1. I acknowledge that the following virtues and values were passed down to me (either from people I met in the course of my life, or from people I did not meet personally but heard about, read about, or listened to, and who were significant to me):
  - *Love of nature* from *my grandmother who loved the morning bird song*
  - *Reading to learn* from *my fifth-grade teacher, Mrs. Simons, who believed in me when no one else did*
  - *Kindness* from *Dusty, my cat, who cuddles with me when I need her*
2. I acknowledge that I have learned the following things during the course of this lifetime, including learnings that have come from difficult times:

- *Determination from the time I left home at 15 and traveled interstate to Grandma's place*
- *That you have to laugh from the time when it was just me and my friend Rose, and we'd gotten ourselves lost and just had to wait till morning light. We laughed our way through the night because we knew we wouldn't sleep.*

3. I propose that the following virtues, values, and learnings that were passed down to me be distributed to the following people and pets, who I think could make most use of them:

- *Reading to learn*      to my niece Georgina
- *Love of nature*      to our neighborhood environmental group, the Waterwatchers
- *Kindness*              to strangers

These are some of the ways I have already tried to share these virtues and values that were passed on to me, and the learnings that I have accumulated over time:

- *I read to Georgina, and we make up stories together.*
- *Each week I meet with the Waterwatchers, and together we are trying to clean the waterways.*
- *The kindness that Dusty has shown to me, I try to show to strangers—people I meet in the supermarket or when walking.*

4. I direct that the following characteristics *not* be passed on to any of my dear ones, and that they end with me:

- *The shakes and sorrows that I sometimes feel*
- *The voice of abuse that makes me doubt myself*

I would like others to understand that I don't want these passed on because . . .

*No one deserves to be abused.*

5. I wish to pass on this message of hope:

*Georgina, you are only four, so it may be a while before you can read this. Perhaps I will ask your mom to read you these words from Aunt Jacinta. I want you to know what you have brought to my life and to the life of your mom. I have loved our story times together. You are a great listener, and stories and characters seem to come alive when we are together. Your imagination helps mine. I also really appreciate how kind you are to Dusty. Dusty has been very important to me in my life, and I know that if anything was to happen to me you would take good care of her. Thank you for being such a kind person, Georgie.*

Dated this 15th day of May 2013

I will update this Will and Testament of legacy, learnings, and virtues every three months.

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Signed by: Jacinta

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Witnessed by: Dusty

If you would like to create your own secondary will or assist someone else in doing so, you may like to use Jacinta's template:

### **Will and Testament of Legacy, Learnings, and Virtues**

I, \_\_\_\_\_, residing at \_\_\_\_\_,  
being of sound mind, hereby declare this to be my Will and  
Testament of legacy, learning, and virtues.



1. I acknowledge that the following virtues and values were passed down to me (either from people I met in the course of my life, or from people I did not meet personally but heard about, read about, or listened to, and who were significant to me):\*

- \_\_\_\_\_ from \_\_\_\_\_
- \_\_\_\_\_ from \_\_\_\_\_
- \_\_\_\_\_ from \_\_\_\_\_
- \_\_\_\_\_ from \_\_\_\_\_
- \_\_\_\_\_ from \_\_\_\_\_

2. I acknowledge that I have learned the following things during the course of this lifetime, including learnings that came from difficult times:

- \_\_\_\_\_ from the time when \_\_\_\_\_
- \_\_\_\_\_ from the time when \_\_\_\_\_
- \_\_\_\_\_ from the time when \_\_\_\_\_

3. I propose that the following virtues, values, and learnings that were passed down to me be distributed to the following people and pets, who I think could make most use of them:

- \_\_\_\_\_ to \_\_\_\_\_
- \_\_\_\_\_ to \_\_\_\_\_
- \_\_\_\_\_ to \_\_\_\_\_

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\*This list can also include virtues inherited from people who have passed away, pets, and invisible friends.

These are some of the ways I have already tried to share these virtues and values that were passed on to me, and the learnings that I have accumulated over time:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

4. I direct that the following characteristics *not* be passed on to any of my dear ones and that they end with me:

- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_

I would like others to understand that I don't want these passed on because . . .

\_\_\_\_\_

5. I wish to pass on a message of hope to someone I have noticed making a contribution to the lives of others, or to those who have been through experiences similar to my own. This is the message I wish to convey:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Dated this \_\_\_\_\_ day of \_\_\_\_\_ 20\_\_

I will next update this Will and Testament of legacy, learnings,  
and virtues on the \_\_\_\_\_ day of \_\_\_\_\_ 20\_\_

\_\_\_\_\_  
Signed by:

\_\_\_\_\_  
Witnessed by:

Name:

Address:

### **Shared Memory**

It is not only when we are facing death that we may think about legacy, but also if we are faced with the loss of memory. Recently I had the pleasure to work alongside people with early-onset dementia and their family members. This was in relation to a theater production that I was writing in collaboration with my sister, who is a dancer and director.<sup>4</sup> My role was to meet with people with early-onset dementia and their family members, gather together their words and stories, and craft these stories into a theater production that would do justice to their lives and experiences.

Prior to my involvement in this show, the word *dementia* evoked only a sense of lurking dread. My grandmother experienced dementia, and my memories of this are depressing—it's as if the times I visited her in the nursing home are cast without color. My first community forum with people with early-onset dementia and those who love them somehow opened a window and brought new light. Together we heard of so many ways in which these couples and families are protecting what is important to them. While we heard stories of

loss, sorrow, and frustration, we also laughed together and learned how people are finding ways to share memory, distribute among themselves what could otherwise be burdens, and continue to delight in love and life. This has been highly significant to me. While the word *dementia* still evokes sorrow and grief, it now also evokes stories of kindnesses and acts of grace and dignity. My experiences with people with early-onset dementia and their families have somehow changed my relationship to memory and even to my own history.

To convey this, it's necessary for me to introduce you to the world and words of people with early-onset dementia and those who love them:

Imagine this. It is becoming increasingly difficult to discern the difference between the present and the past, between what is familiar and what is foreign. Events that took place just minutes ago are being constantly erased, while memories that you have been able to keep at bay for decades now come rushing toward you. Despite the explorations of poets, novelists, doctors, scientists, and philosophers, the realm of memory remains a great mystery. If a loved one starts to lose their memories, what role can we play in holding onto them? And if our parent is no longer the person we know, how can we care for them in the present and also honor their memory?

The following stories convey both the effects of dementia and the ways in which people with dementia and those who care about them respond to these situations:<sup>5</sup>

### **Loss**

*The person with dementia has to let go of the things that they used to do. And this means so many different sorts of losses. My mom was a professional portrait artist. Watching her art-*

*istry change and deteriorate was a source of profound sadness to me. I could feel what was going on inside her mind.*

### **The Last Two Years Were the Best Two Years**

*My father was brought up in a rigid household during the depression and world war. In some ways, the last two years of his life were the best two years of my relationship with him. Somehow the Alzheimer's released the rigidity of his childhood, and this was a gift to me. He told me that he loved me for the first time. He told me that he trusted me. And this was so different to the memories that I had of my childhood years, of the leather strap on my backside. What's more, in his last years, touch became so much more significant between us. Tactile communication became all important. Sometimes he became too tactile! But still, there were times of kind physical contact that meant a lot to me. It was as though these years balanced the memories of my life. During this time it was like I was weighing up different memories. I couldn't have asked for anything better.*

### **A Shift in the Balance of the Relationship**

*In my childhood, my mother looked after me in every way. Now things have turned around completely. I was born dependent on her, and she will die dependent on me. There is a symmetry about this, a poetry almost. It is not always easy, but it makes a difference to remember this balance.*

### **Fantasy**

*Sometimes fantasy worlds develop and can bring great joy. He used to tell us with great excitement stories about the times he was the captain of the rowing team and the football team. But he never had been—these were stories from his father's life! He*

*also used to tell us about managing Elvis and Frank Sinatra. They were great stories, elaborate fantasies!*

• • •

*That reminds me of how my father kept telling us about the conversations he would have in the mornings with the man in the room next to him. He'd tell us all about these chats and how much he enjoyed them. And then one day, we realized that the person in the room next to him could not speak! Only then did we realize that my father was actually referring to conversations he was having with his own image in the mirror when he was shaving!*

### **The Longest Farewell**

*On first hearing the diagnosis, a common reaction is to realize that you will lose a friend (in my case a wife of forty-nine years). So at first I did panic a bit to tap her memory for stories of her childhood, to take overseas trips to say good-bye to relatives and friends, etc. But then the situation seemed to change only slowly. So it's like a farewell, but one that stretches on and on and on—the longest farewell of all.*

### **Longer-Term Memories**

*Alzheimer's is not about losing all memories. While short-term memories may disappear, longer-term memories can become all the more vivid. I remember when my mother suddenly started to tell me things that I had never known. She told me that when she was pregnant with me, her doctor had suggested that she have an abortion. My mother was forty-six at the time, my father was seventy, and the doctor was concerned about*

*complications for my mother and for the baby. My mother told me, however, "I wasn't going to do that with you." It was a profound conversation, like a jewel. Somehow, due to the disease, I learned a little more about aspects of my own history.*

*That was true for my father also. The older memories become even stronger, indelible. My father had served during the war in PNG and he had never told us about this. One day, we were sitting in the garden in the nursing home, and the bushes were moving with a breeze in a way that seemed to stir up a memory. He asked, "Has the battalion been fed?" and then, "Have you got the pistol and rifle?"*

*Dad started to lose his words though. And as he lost his words he replaced them with numbers. He was a Chartered Accountant and he used to say, "18, 19, 20." One day in the nursing home, I was sitting beside Dad. As he appeared to be sleeping, one of the nurses asked me, "What sort of work did your father do?" When I said, "He was an accountant," my dad didn't even open up his eyes; he just said, "Chartered Accountant." That still makes me smile.*

*Later, at the Christmas party in the same nursing home, they had a man playing the guitar, and when he sang "It's a Long Way to Tipperary," my dad joined in. At this stage, I hadn't heard Dad speak for months, so when he sang, I had to leave the room. I went into another room and cried. When speaking is gone, it seems that singing sometimes takes its place.*

• • •

*When this was mentioned in the group, one person with younger-onset Alzheimer's said, "God, I hope not!" And the room erupted in laughter.*

### **Memory Loss**

*When the person you love no longer remembers what you have said, it has a lot of implications. On the positive side, you can crack the same joke time and again and get a laugh! But on the other hand, if there is a death of someone they love, then they relive this loss time and again, and this can be devastating.*

### **Traveling through Time**

*My father thought I was his wife. He thought he was forty and tried to propose to me. We did a book of his life so that I could try to use it to explain who I was. Even so, he would say, "Yes, yes, yes, but I've still got to ask you to marry me."*

• • •

*I would touch my mother's hand and hold it and she would say, "Oh I like that. Except that you're a girl, you could be Jack." And this was the opening to hear stories of her earlier life and the man she had loved but never married. Whenever I held her hand she always went back to Jack. They were very moving conversations. And she would find solace in telling me that she "would never have made a good farmer's wife."*

• • •

*In one aged care facility I worked, the staff would say, "Ask Harold what year it is." And he would always answer 1942. And so we would travel with him back to 1942. We would go with the flow. It is the only way to be with somebody if they are living the past.*

### **It Affects Everyone**

*When someone in a family is affected by Alzheimer's, it's like the family has the diagnosis, not just the individual. Some-*



*times a family can collapse overnight; the relationships can break down and this can be very difficult. Sometimes daughters are pressured by their brothers to care for parents. Sometimes gay men having been rejected by their family years earlier are suddenly expected to come back and care for their parent because they do not have their own children. Alzheimer's affects everyone. And if it is your parent who receives the diagnosis, then you've also got the thought in the back of your mind, "Will my own memory be affected one day?"*

*What seems really important is that care for people with Alzheimer's is shared, not left to any one person. Sometimes family members leave it all to one person in the family (often a woman), and this makes things very difficult. But sometimes a carer might also choose to become the central and "special" carer in a person's life and then they get burnt out, and this is also a hazard. It seems important that care is shared.*

### **Conversation**

*Conversation can be difficult when Alzheimer's is around. I had to realize that the conversation I was having with my mother was not the same conversation she was having with me. I remember she used to say to me, "Jesus, you're a shocking conversationalist." Eventually, when things were stuck in the conversation and my mother was frustrated with my response, I learned to say, "I don't know. What do you want me to say?" She would then tell me what to say, I would give that answer, and we could continue!*

### **Keeping What We Could the Same**

*Right to the very end, there were some things that he could still enjoy. He had been a great sportsman, and he would continue to watch golf and football on television. We had always loved*

*to dance. And right up to the time when he could no longer walk, we would dance together: put the jazz on and dance in the kitchen. Looking back, I feel that we all did the very best that we could. He kept his dignity. Despite everything that changed, we found a way for him to remain the person he always was.*

### **A Wonderful Old Fur Coat**

*I remember a particular woman who I used to work with [in a care facility for the elderly]. She had been there for five years, and by the time I arrived she never spoke. I had to immediately move into her reality, which was entirely nonverbal. I learned that she used to be a dancer and a patron of the arts. When she became confined to her chair, she remained highly tactile. We would use massage to soothe her and to help her to sleep. She would also love listening to music. And there was a wonderful old fur coat that we would wrap around her. It was like we were wrapping her past around her. As soon as she was encircled in it, she would become calm. I've always remembered that wonderful old coat.*

### **Shared Humor**

*In the early stages, shared humor can make all the difference. And remembering the stories years later seems significant too. My mother used to insist that I was her sister, not her daughter. When I would try to insist that she was my mother, she would say, "Jeez, one of us looks good for our age." It was very funny.*

### **Two-Way Caring**

*It's important to realize that especially in the early times, there is a two-way caring. I remember one day tears had come. It had been a really hard time and he couldn't talk*

*about it, but he simply put his arms around me. He knew I was upset, and while there weren't words, there was loving touch. It made a huge difference to me.*



*During the early times, there are so many difficult preparations to be made, like wills and arrangements. And some of this is so difficult to do. It is so painful to face. But my husband went through all of this, and I knew these were acts of great care for me. There was one day in particular where we had had to go through awful practical preparations. At the end of this, we had endured too much and he said, "Let's go and have tea at the Windsor." We went there and it was totally booked out, but the look on our faces must have told a story and they quickly set us up a special table. This was an important ritual for us. There are many different examples of this sort of two-way caring.*

### **Children**

*Sometimes children will respond to the person with dementia in different ways than us adults. For instance, I remember we told our son that "Gran forgets things," so when he next saw her, he said, "Grandma, what do you forget?" There's something about how kids go straight to the point that is very refreshing. Also, our children will remember their grandparent in different ways than we will. They will remember the games they played together, the fun they had with each other. These are important memories to keep alive.*

### **Living for the Moment**

*The changes in short-term memory create unexpected dilemmas. For example, we recently gave my wife a terrific seventieth*

*birthday party; the house was full of relatives and friends, balloons, numerous humorous speeches (she even made a speech herself). But the next morning she could not remember a thing about the party. It had been a huge effort on the part of her family. So you start to wonder if it was all worth it. But then you realize that a person with dementia lives only for the moment, almost literally. You can't stop giving someone a full life just because they will not remember it.*

### **A Book of Memories**

*If a loved one is losing the memory of who they used to be, sometimes it's up to us to hold their memory for them. My mother made a book for Dad containing stories, photographs, and mementos from his life. This also helped the nurses and staff who looked after him. Dad used to go through the book with them, and while he couldn't always answer their questions, he liked to look at the pictures. This book contained photos from his childhood, of his teachers, of where they had holidays, pictures from his school days, and from when he was overseas where he met my mother. It also included their wedding invitation and photos and then the story of us as a family. It was very comforting for both us his family and for Dad to look through this book and retell all the stories. We also made a few large photo boards of Dad and his family for when he was in the nursing home. It was important to us that the staff in the nursing home could see what a loving and loved man he was and the sort of life he lived before he got Alzheimer's.*

### **In It Together**

*A number of us regularly meet together. We are couples in which one partner has Alzheimer's. It makes it so much easier*

*to have others to talk with who understand what is going on. We found that the carers really needed help. They felt that they were carrying the weight on their own and as if they were the only ones suffering. They didn't realize that others were doing the same thing and that the experience could be shared. And we (people with Alzheimer's) realized things too—including that it's important for us to be nice to the people who are looking after us! We've learned that it's good to do things together—to go for a meal or to a hotel or down at the beach. We also stay in touch on the phone. We call every now and again. We've learned a lot. Next week the carers are going to get together just on their own, so they will whine a bit and then get things back together! We also sometimes attend Memory Lane Café, which is run by Alzheimer's Australia. It's hard to convey just how important this has been to us. This group that we are a part of represents perhaps the most important thing that we have ever done in our lives. We're not the only ones.*

### **A Letter to Our Dear Ones**

I find these stories profoundly moving, particularly regarding the care that these people are taking in relation to preparations for the future. They have thought so much about the loss, the sharing, and the transmission of memory. What can we all learn from their hard-won knowledge? How can we apply this to our own lives? One way might be to write a letter to those who are dear to us—now, while we can still remember what's important to us.

From the words and stories shared above, the theater production *Sundowner* was created.<sup>6</sup> The main character is a woman with early-onset dementia, who throughout the show crafts a letter to leave to her children (one of whom is preg-

nant with the next generation). Here is the letter that she writes:

*My Dear Ones,*

*It's the strangest thing, no longer being able to tell what is the past and what is the present. It seems that events that took place only minutes ago are now being erased, while memories I have been able to hold at bay for decades suddenly come rushing towards me.*

*No doubt it is only going to get worse. At times, now, I am no longer able to tell what is familiar and what is foreign. And that is why I am writing to you today.*

*When it comes to pass that I can no longer hold the memory of who I used to be, will you hold it for me?*

*I don't want this to be a burden, but if you could remember me perhaps just once a day in the evening light . . . that was always my favorite time. Hold my memory in the evening light, my dear ones.*

*I don't mean any old, dusty memory of me. I don't mean a time when I was crabby or tired—let others remember those times, or better yet, let them slide into oblivion. No, I'd like you to remember something particular, something luminous.*

*I guess you should have some say in it, but if I get to choose, how about you remember that day we spent at Rosebud?*

*It was hot that day. Our feet had to dance across the sand to avoid being scorched. And we plunged into the sea together. The others were laughing at us—with us, I recall.*

*We'd all been through so much that summer, and somehow we'd found our way through together. Yes, remember me then, if you would.*

*I wish I could promise to always remember you, but that's a promise I can no longer make.*

*I have loved you the very best that I could for all the years that have been.*

*Your devoted mother*

*P.S. There is just one more thing, while I remember! When you are with child, treasure the memories you make together. That child of yours will live with those memories for a lifetime.*

A narrative therapist in Hong Kong is now supporting people with early-onset dementia in writing such a letter to *their* “dear ones.” In these letters, the writers acknowledge what their loved ones have contributed to them, reveal any regrets they may have about how they have treated their loved ones, and highlight particular memories they hope others will carry into the future.

Perhaps there will come a day when we can no longer recall who we are. Writing such a letter to “our dear ones” now might make all the difference down the road.

*Exercise One: Write a Letter to Your Dear Ones*

Take a pen and paper (just for old time's sake), or open a new document on your tablet or laptop, and begin to craft a letter to a loved one. This loved one may be older or younger than you. They may be someone you see regularly or not at

all these days. They may be a friend, a colleague, a sibling or another family member, an invisible friend, or a pet. Within this letter you could include:

- Specific ways in which this loved one has made a contribution to your life
- Any regrets that you may have about how you have treated this loved one
- Two particularly good memories that you shared with this loved one. Try to describe these in vivid detail, evoking all the different senses associated with each memory. What did it look like that day? What did it smell like, feel like, taste like?
- An explanation of what these memories mean to you
- An invitation to your loved one to hold these memories and honor them for you both

*Exercise Two: Recording the Memories of Others*

Alternatively, you might like to take the advice of a caretaker of someone with early-onset dementia:

I would really suggest that you take notes of things that your loved ones say. Note down the family stories, even the ones you think you will never forget, in fact, especially the ones you think you will never forget.<sup>7</sup>

Is there someone whose life you appreciate? If so, perhaps you can make time next week to sit with them and write down (with their permission) some of your favorite stories about them. It doesn't matter what age this person is; they might be younger than you. All that matters is that there are stories associated with them that you would like not to be forgotten.



Perhaps you can also ask this person about some of their favorite memories:

- Ask them questions so that they can describe these memories in vivid detail, evoking all the different senses associated with each memory. What did it look like that day? What did it smell like, feel like, taste like?
- Ask them to describe what these memories mean to them.

As you converse with your loved one, you might like to let them know what these memories and stories mean to you. Find some way of conveying that you will hold, honor, and care for these memories and stories.

### **Looking Back, Looking Forward**

This chapter has focused on considerations of legacy and memory. I have invited you to think about the legacies of values, virtues, and learning that you would like to leave to others. To do so, and to create a secondary or “spiritual” will, can sometimes alter not only how we face our deaths, but also how we live our lives.

Considerations of memory can also be significant. The day will come when it will be up to others to hold our memories for us. We can prepare for this day and I hope the ideas in this chapter of writing letters to loved ones and recording the memories of others can assist in this.

Recognizing the legacies and memories that we will leave behind us places our lives in a broader context. The final chapter of this book focuses on where our story fits in the bigger picture.

## Notes

1. Ted's story was first published in the Dulwich Centre, 2000, and is republished here with permission.
2. David Epston discussed these ideas of "spiritual property" and alternative wills in White & Epston, 1991.
3. Jacinta is a composite character.
4. This theater production, *Sundowner*, was produced by KAGE ([www.kage.com.au](http://www.kage.com.au)). Jack Sach, Jill Linklater, Shirley Rutherford, and Christine Bolt from Alzheimer's Australia (Vic) played significant roles in enabling *Sundowner* to become a reality.
5. The quotations from people with early-onset Alzheimer's and their caretakers are from the article "Special Knowledge and Stories about Dementia" (Alzheimer's Australia Vic Community Advisory Group & Denborough, 2011). The following people contributed their stories: Fiona Beale, Rachelle Better-Johnston, Liz Brady, Robyn Carmichael, Liz Fenwick, Pamela Hore, Carol Liavas, Megan Major, Kim Martin, Carmel McGrath, Rob McGrath, Kris Samuel, Dennis Tonks, Margaret Tonks, Tom Valenta, Tony Walsh, Paul Wenn, and Judith Wheaton.
6. The written resource most helpful to the creative team in developing *Sundowner* was the book *Contented Dementia* by Oliver James (Vermilion, London, 2009).
7. This quotation is from Alzheimer's Australia Vic Community Advisory Group & Denborough, 2011, p. 68.