

# A Fly on the wall...



## ...In Hell.

*I am in my 82nd year, and I am a witness to what goes on in residential “aged care” facilities.*

*My beloved husband died last year after spending time in three different facilities. I am a reliable witness because I stayed with him almost all day, every day, in order to protect him.*

*I became a fly on the wall, part of the background, listening and watching... and wondering.*

*My story would make a compelling film, if we could reconstruct the scenes that I will describe.*

*(Note: all names have been changed.)*

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*Note: all names of accounts of three Australian aged-care facilities have been changed:*

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**"Compassion Place"** is a non-profit organisation. It accepts people who are in need of very high care, and people of limited means. It is based on a Christian ethos of love and respect for the most disadvantaged. The name, **Compassion**, comforted us and gave us hope.

## **Section 2: "The Lodge" ..... page 25**

**"The Lodge"** is an up-market for-profit facility that does not take public patients except for limited periods of respite. The driveway sweeps up grandly to the main portico. As you enter, you are struck by the elegance of the gigantic chandelier above a massive round lounge that takes up most of the large foyer. Huge bouquets of fresh flowers placed on antique sideboards are reflected in ornate gilt-edged mirrors. *Looks can be deceiving.* But, as in **"Compassion Place"**, there is no one in sight. The atmosphere is sterile, claustrophobic.

## **Section 3: "WXYZ" ..... page 27**

**"WXYZ"** will stand for the acronym of this for-profit organisation. It is housed in a dilapidated old school building, surrounded by a gritty parking lot. The venue has had many incarnations as a nursing home, noted over the decades for the fact that the neediest high care residents are accepted there.

# 1. “Compassion Place”

My husband, Art, was assessed in the hospital section of “*Compassion Place*”. I was called in for a session with the physiotherapist and a young nurse. They informed me that because of Art’s dementia, incontinence and infirmity, it would be best if he were placed in residential care, as they considered I could no longer look after him.

They further informed me that there happened to be an empty bed in the residential care section of their establishment, but that I would have to make the decision that very afternoon.

I wept.

Much as I did not want to believe them, I had to concede that, after caring for my husband for the past eleven years, with constant crises and emergency runs to the hospital, I no longer had the physical stamina to meet his needs. The young nurse put it this way:

“Let someone else do the hard yards. You go back to being his wife instead of his nurse.” So, sadly, our daughter Allie and I agreed for Art to be admitted as a resident in “*Compassion Place*”.

“*Compassion Place*” is a non-profit organisation. It accepts people who are in need of very high care, and people of limited means. It is based on a Christian ethos of love and respect for the most disadvantaged.

The name, **Compassion**, comforted us and gave us hope.

## *First impressions*

Art was wheeled across into the residential section by the physiotherapist and we followed.

No one received us. The wide halls were empty. We passed a large room where we could see several elderly people sitting alone, slumped in their chairs. Our hearts constricted at the sight.

Silently, we were led to the far end of one of the corridors to a vacant room. We were left there. We put Art to bed, then took our leave. I was resolved to come back next day.

I arrived next morning in time for the monthly church service, which I knew Art would want to attend. He wasn’t in the chapel, so I went looking for him. I found him in his room, sitting on the edge of the bed in his pyjamas, with a puddle of urine on the floor at his feet.

Devastated, I thought, “Why is he here?” Weeping, I proceeded to clean and dress him. When I led him into the hallway, a young *dwhqgdqwxvkhg xs wr xv1*

“He wouldn’t let me shower him,” she exclaimed breathlessly.

That didn't explain the puddle on the floor. A cold feeling of disquiet set in, though I wanted to withhold judgement.

## *Life at "Compassion Place"*

But as time went on, our daughter and I began to notice other incidents and practices that were unsettling:

- overhearing two attendants loudly referring to a resident as "the squawky lady";
- a heavy office door slammed in the face of a resident asking for help;
- evening meals consisting of three party pies or three greasy sausage rolls or three tough-skinned cocktail frankfurts;
- residents ignored or spoken to like naughty children;
- a lot of shouting over their heads;
- residents roaming the halls looking for a way out;
- residents left for hours unattended and with no members of staff in sight.

The place looked abandoned, as if no one was in charge.

Art's arrival at "*Compassion Place*" coincided with the start of a six-month blitz by management to cut costs, hours and staff numbers.

We expected to hear details at the next Residents and Carers Meeting. Some of the relatives had taken off work to attend. However, neither the Director nor any of the nursing staff was present. None of our questions could be answered. We requested a meeting at which the Director would be present.

Our daughter, Allie, noticed a large bruise on Art's left buttock.

I asked Wayne, the nurse in charge, if the bruise was recorded. He checked and found that it was not. In the next few days, Allie asked different attendants if her Dad had had a fall. No one knew anything about it. Eventually, Allie spoke with one who said, "Oh, he falls all the time. He had a bad fall the other night."

Allie and I had a meeting with the Director to ask what the policy is about falls. He began by saying that no one else had expressed any concerns to him. He then assured us that, legally, any fall must be recorded and reported to the next of kin. He did not promise to look into the matter.

Some days later, one of the nurses went up to Allie and said,

"Tell your mother that the bruise was not due to a fall, but to the medication he is taking."

Allie repeated what the attendant, Sarah, had told her about the frequent falls.

The nurse said, "I'll check on that."

She returned, saying, "Sarah says she never told you that."

*I began to keep a journal, documenting the delivery of care.*

## July 15:

I arrived at noon to accompany Art at lunch and saw that he was not in the lunchroom. I found him sitting in his room, in his pyjamas, unwashed. His covered lunch had been left where he could not reach it. I cleaned him, helped him to eat, and put him to bed for a nap.

That evening, Allie found her father still in bed, in the same pyjamas, which were now soaking wet. There was a large puddle of urine on the floor. Allie helped her father get up and was cleaning him when two attendants came in and remonstrated,

"You're not getting him up again!" They left.

*Allie observed that there was no sign of dinner.*

*There was no one to ask if he'd eaten. Allie made a formal complaint to the Director, to which she did not receive a reply.*

## July 17:

A nurse came up to me and said, "It's not neglect when residents are not washed. It's lack of cooperation on their part. We don't have time to get back to them every few minutes."

*I could only wonder at this as she walked away.*

## July 25:

After lunch each day, Art needs to go to the bathroom, but there is no one to call on, so I take him, clean him, and put him to bed.

Once I called out to a passing attendant:

"My husband needs to go to the bathroom."

"I'll be right back," she said over her shoulder.

I heard her mutter, "He'll probably forget." She did not return.

After lunch, I often see the residents left in the dining room for a long time, waiting to be taken back to their rooms. I have begun to befriend some of the residents. One day, I asked one of them if she wanted me to summon someone for her. She shook her head.

“They get cranky if we ask,” she said. “We cannot argue with our superiors.”

*Superiors! The attendants and nurses are there to serve the residents, who are paying for the service. This is a measure of the intimidation of residents that I have begun to notice.*

## July 31:

In preparation for the Meeting of Residents and Carers, I typed up the questions we had been wishing to bring up at the previous meeting.

I left a copy to the Director before the meeting. He sent for me and said that he felt “sandbagged” by my action.

While speaking with him, I took the opportunity to relate to him that one Sunday afternoon, I had sat in the lounge room with Art for two hours while one resident kept jumping up, bumping into walls, furniture, and the other residents. Art started out of his chair, alarmed, and tried to stop this person. In all that time, there was no supervision and everyone was at risk.

The Director huffed, “What you should have done, you should have found the nurse in charge and told her to circulate!”

I replied, “I did look for someone, but there was no one in sight. Besides, it is not my place to tell the nurse to circulate.”

The Director did not answer our questions at the meeting.

## August 2:

During the evening meal in the small dining room, the nurse shouted to an attendant in the corridor. “I’VE GOT FIVE FEEDS HERE!”

**It sounded chillingly like a zoo.**

The nurse shoved heaping spoonfuls of mush into the mouths of two persons at once, not waiting for them to swallow.

*This is a practice I’ve observed many times, though there are some attendants who are very kind while helping people to eat.*

Another time, Barbara pushed aside the party pies.

"I can't eat those," she said. "They give me indigestion."

There was no other food available.

Felicity waited from 5.30 until 7.30 in the dining room to be taken to the bathroom. "Oh, help! Is there anyone to help?" she cried weakly.

*All of us who are also waiting are affected by her plight.*

*I can only listen and observe...and grieve.*

## August 5:

Various volunteer groups come in periodically and sing and play for an hour or so. Some of the performers are older than the residents!

It's touching to see the response of the residents to live music: nodding, feet tapping, fingers keeping time, mouthing the lyrics of the familiar songs.

Art wakes up when he hears "Oh Danny Boy" and joins in.

*A drawback: the attendants invariably leave during the concerts, so that when one of the residents needs attention, it falls on visitors like me to go and try to find them.*

## August 8:

Ariel is a tiny woman who looks like sugar and spice and everything nice. She sits in the corridor in her wheel chair all day, waylaying people passing by. "Helpmehelpmehelpmehelpme," she whimpers continually, and as they scuttle past, she calls out to them, "YOU DIRTY BITCH! YOU FILTHY SLUT! YOU BIG BASTARD! I HOPE YOU FALL DOWN AND BREAK YOUR NECK BEFORE YOU GET THERE!" Occasionally, she erupts into "HE-E-ELP! ME-E-E-E!"

One of the attendants, fresh from her holidays, shudders at hearing Ariel bellowing in the distance. "This is why I hate coming back here," she mutters to no one in particular.

At first, I go around a different corridor to avoid being accosted by Ariel. But one day, I stop and greet her.

"Helpmehelpmehelpmehelpme," she says.

"Good morning, Ariel. I like your pink cardigan."

"They left me here on my own."

"It's pretty scary for you, isn't it?"

"Yes. I didn't do anything."

"You feel like you're being punished."

"Yes. *And I didn't do anything.*"

"It's not your fault, Ariel. You know you didn't do anything wrong."

*Ariel sniffs. "Thank you for talking to me."*

"Thank you, Ariel, for talking to me."

**Another day.** *"Helpmehelpmehelpmehelpme."*

"Hello, Ariel, it's good to see you!"

*"I want to go home."*

I take her hand. "You will surely be going home one day." We chat for a few moments.

*"Do you have to go now?"*

"Yes, I'm going to see my husband."

*"Well, goodbye, then."*

**Another day.** Ariel can be heard all over. *"HE-E-E-LP ME-E-E-E!"*

"Good afternoon, Ariel. It's good to see you."

*"You're the one who talks to me! I love you!"*

"I like your nail polish. Did you always wear red nail polish?"

*(With a chuckle) "Na-a-ah."*

*Ariel does not associate with anyone. She's always kept to her room because she's too disruptive.*

## August 14:

Leanne is a young woman living with elderly people because there is nowhere else for her to go. She is partially paralysed and is kept under constant restraint by way of a brake on the back of her wheel chair.

After waiting a long time in the lounge room, she asked me to release the brake. "I have to go," she said. I was new. I should not have released the brake, as I quickly learned. Moments later, an attendant brought Leanne back into the lounge room.

"Leanne! Apologise to this lady for asking her to release your brake," she demanded fiercely.



"I'm sorry," Leanne said robotically, "for asking you to release my brake."

Leanne was humiliated, and so was I.

The attendants treat Leanne with disdain.

*"Will you please take me to the bathroom?" she asks politely.*

"NOPE!" they declare, as they sweep past her.

They accuse her publicly of pilfering food from the other residents.

Once, when Leanne complained that one of the residents was pestering her while she was trying to read, an attendant announced loudly, "She can't read, anyway!"

For some time, Leanne had been telling Allie and me that her teen-aged daughter, whom she had not seen for two years, was coming to visit. *"In two weeks...in one week...tomorrow...today!"*

The day arrived when she was going out for dinner with her daughter. I was in the lounge room when Leanne asked an attendant to be taken to the bathroom.

"I'm going out for dinner," she said with a smile.

"SEZ WHO?" shouted the attendant indignantly. "No one told us!" "It's been arranged," Leanne replied patiently. "It's written on the board in my room."

*Sez who? It's Leanne who says. That should be enough.*

*What a lost opportunity for the attendants to be pleased for Leanne, to help her look glamorous for the great event, to welcome her daughter, and to celebrate with them.*

## August 21:

One of the attendants informed me that about 2.45 today, a visitor had found Art on the floor of his room. Later, another nurse came up to me and said brightly, *"Oh, Art had a little tumble today."*

*No mention of his being found by a visitor. I didn't query her about this, though I should have. I'm afraid of making waves.*

## August 22:

I signed permission for Art to have a seatbelt on his wheelchair.

## August 25:

On my way to tell Art that his sister had died this morning, I met Judy and Amanda, two attendants, and told them about my errand. “Oh, how sad!” they exclaimed. Judy offered to go with me as I told Art. She held his hand while I spoke with him. I was very touched by their kind act, and reported it to the head nurse.

## September 1:

Harriet is always lost. She goes up and down the corridors, crying, “*Where am I supposed to be?*”

Thelma, suitcase in hand, is always trying to find her way out. “*How do I get out of here?*”

Henry pushes his trolley into every doorway. “*HENRY! STOP THAT! GO BACK TO YOUR CHAIR!*”

When I guided Harriet back to her shared room one day, I noticed that there wasn’t a single personal possession or decoration around her bed. I mentioned it to one of the kind nurses, and she said,

“That has been right under our noses, and we never noticed.”

I bought a small bouquet of artificial flowers and asked an attendant to place it by Harriet’s bed with a card, “From a Friend.”

Harriet was thrilled and talked about it for the rest of the day.

*The Mission Statement at “Compassion Place” specifies the importance of personal possessions.*

## Scenario in corridor today, at end of shift:

Thelma: “*How do I get out of here?*”

Attendant, on way out of door: “**You can’t! I can!**”

Thelma, turning to me: “*Did you hear that? How rude!*”

Another attendant passes by on her way out.

Thelma: “*How do I get out of here?*”

Attendant, breezing past without looking at Thelma: “*You can’t!*”

Thelma: “*Why not?*”

Attendant, calling back over her shoulder: “*Because it’s Friday!*”

Thelma, turning to me: “*Is today Friday?*”

“Yes.”

“Does that mean I sleep here tonight?”

“Yes.”

“Oh.”

*Security is a prime concern for people with dementia.*

## The illusion of “choice” - overheard one evening:

Thelma, for the umpteenth time: “Why do I have to stay here?”

Nurse: **“BECAUSE YOU HAVE NO CHOICE!”**

### September 16:

Art is not in the dining room for lunch. I find him lying on his back, crosswise on his bed, his head and feet unsupported. He is not dressed. An attendant comes.

“He wanted a lazy day today,” she says.

I speak to Art. “Art, it’s lunch time,”

“Oh, is it that time already?” he asks, struggling to get up.

I ask him: “Do you want to go to the lunchroom?”

“Yes,” he replies, preparing to get dressed.

The attendant interrupts: “But you said no when I asked you!”

**Note:** *I have learned that people with dementia often say “no” at first, perhaps because the information is too much to take in at once, and they need to process it. But later they consent, as if on their own terms.*

### September 24:

There are several sympathetic nurses and attendants who do their best to cheer up the residents.

Debbie, a young student nurse, took flowers to Leanne, who is in hospital.

Karina, an attendant, sat and talked with Harriet at lunch today because Harriet is very depressed.

Julie, an older worker, circulates around the lunchroom chatting with all the residents and relatives.

These workers, however, are seldom on duty.

Sharon tells me that she loves the work, but that she doesn't get enough hours to make it viable for her to stay.

I begin to notice that, in contrast, the bullies have all the best hours and are on every day.

Everyone is glad when Sharon is on duty. "She's a nice girl," a resident commented to me.

*The residents may be deaf, mute, blind or paralysed, but they're not stupid. They know who is good to them and who is not.*

## September 30:

The nurse organising medications is distracted by residents constantly appealing to her for help.

There is no one else for them to go to.

## October 2:

Anne has entered the Home recently. I've known her for over 25 years, and so was delighted to see her. She is 98 years old, can see, hear and talk, and her mind is clear. She is a gracious woman, a teacher. Chatting with her, she tells me how disconsolate she is to be in "**Compassion Place**". Calmly, not complainingly, she says,

"They told me that I was brought here because I would get better care than at the hostel. But I received better care at the hostel. There, everyone loved me. Here, there is *not one smidgeon* of love."

Sometime later, Anne summoned me over to her chair.

"That attendant over there," she said, pointing to Hetty, "asked me the other day what you and I were talking about. And she told me not to talk to you because she says you're dangerous. I froze."

"But we're friends!" I protested. "We can talk to each other!"

*(The Charter of Residents' Rights stipulates that residents may speak to whomever they wish.) I'm troubled. Why am I dangerous?*

A few days later, Hetty was in the large dining room during lunch.

She and another attendant were serving the meal to 60 residents.

Art told me he had to go to the bathroom. I asked the second attendant, who was nearby, to come over.

"Where is the gent's?" Art asked her.

She called out to Hetty across the room: “**ART WANTS TO GO TO THE TOILET!**”

Hetty yelled back in exasperation, over the heads of everyone:

**“WE JUST TOOK HIM! WE TOOK HIM BEFORE LUNCH!”**

Hetty scurried over to Art. She put her face close to his. “You just went!” she said sharply.

“I have to go again,” he replied, looking down.

“No, you have to wait! We are **FEEDING** the **RESIDENTS**.”

“You can charge it to me,” said my husband, clinging to his dignity.

“NO!” she persisted loudly, “You have to LEARN to WAIT!”

*Of course, with his type of dementia, it is impossible for Art to form new memories. Doesn't she know this?*

She turned to me and said mockingly. “We took him and he just did this tiny little bit,” holding up her thumb and index finger to indicate a small space.

“Sorry,” said Art, “I’ll put it in writing.”

“Put what in writing?”

“My apology.”

“I don’t want your apology.” And she flounced off.

*What were the feelings of this good man, my husband?*

***These were my feelings:*** shock, dismay, disbelief, embarrassment, indignation, sorrow, fear, helplessness.

***What were the feelings of all within earshot?*** Everyone, I’m sure, was equally cowed, equally distressed, adding to the feeling of hopelessness at having to live in this place.

*Why did I not stand up and protest? Why did I not report Hetty? I was rendered as powerless as the residents. By not speaking up,*

*I gave Hetty permission to speak to my husband like that in future.*

***This is my anguish, compounded every day.***

True enough, a couple of days later, Hetty passed by our table at lunchtime. She saw that Art had left part of his meal on his plate and was eating dessert.

She said to him, "You have to eat more than that!"

"I've had enough," Art said.

Hetty took his dessert spoon away from him, filled it with left-overs and rammed it into his mouth, not asking his permission and ignoring me, his wife.

After one spoonful, she took off. Art was left trying to swallow it.

*What was the point of this stand-over tactic? Certainly, it was not out of concern for my husband's nourishment.*

That night, I watched *The Shawshank Redemption* on TV.

There is a scene where a new arrival asks, "When do we eat?"

The prison warden punches him in the stomach with a truncheon and shouts:

**"YOU EAT WHEN WE TELL YOU TO EAT. .... AND YOU SHIT WHEN WE TELL YOU TO SHIT!"**

*How is this different from what goes on in "Compassion Place"?*

## October 10:

**When I gave permission for a seat belt for Art's wheel chair, I didn't envision that he would be trussed up tightly around his legs and body, the one in the middle biting deeply into him.**

I expected it to be used only when he was in transit. I had been told that he would not be left strapped down all day, but every time I went to see him, at different times every day, he was strapped down.

*It looked like staff at each new shift just left him as they found him. This made it very hard for me to take him to the bathroom, or for him to eat at table. He had no exercise, and his mobility was affected. He was constantly agitated, asking me and others to set him free.*

*Today, I signed a paper rescinding permission for restraints.*

## October 13:

Many times, when Art indicates he needs to go to the bathroom, he is told to “just go in your pad.” This is an attempt to change the habits of a lifetime, and he doesn’t understand.

**I thought the pad was for incontinence, not as a substitute for the toilet.**

*It’s a constant refrain in this place: Every resident, all the time, all day long and into the night, calls out or signals in some way that they need to go to the bathroom.*

*I hear them all around me as I sit with Art, holding his hand.*

## October 14:

I note that very few relatives visit. On certain occasions, like a birthday, they might come in with a balloon and presents, look around and say effusively,

“This is such a wonderful place! The care is excellent!”

Or they might come in for a few minutes and quickly disappear.

There are some relatives who are constant. Fred, for instance, stays all day with his wife Felicity, who is quite emaciated. He tells me, “She’s my girl. She’s always been my girl.” He sits with her in the day room, reading his paper. From time to time he speaks to her gently or gets a drink for her. He helps her to eat. Once, at a concert, he pushed her wheel chair around the large room in a slow waltz. I found out that they had been champion dancers. I’m sure that in their mind and heart, they still are.

## October 20:

I’m told that Art wanders at night, alarming the new woman next door. They’re considering moving him to another room. “But I don’t think that’s right,” says the attendant who informed me, “because he was here first.”

I go to speak to the head nurse about it. She tells me not to worry, that no action has been decided as yet. I ask her about the buzzer to alert the nurses that Art has gotten out of bed. She replies, “*The nurses are busy elsewhere and cannot respond. We have limited resources. We do what we can. The residents are cleaned. They’re fed.*” She looks me in the eye and adds, “*It’s not one-to-one, you know.*”

*As if I were asking for special treatment.*

## October 26:

I asked the diversional therapist if the residents were taken on field trips. She replied that they didn't have enough staff. Programmed activities were bingo and carpet bowls conducted by volunteers.

The residents are never taken out to the patio to get some fresh air, unless a relative takes them out. *What about Vitamin D?*

I take Art out under the trees. It's good to get away from the TV in the lounge room blaring all day long. I sing to Art, and a little bird joins in. Art laughs.

*These are the moments that keep us going.*

## November 4:

So that Art can have the opportunity to walk, I have requested that his walker be left where he can have access to it. But it rarely is.

Today when I arrived, he was in a lounge chair, half sliding out of it.

"I'm waiting for someone to fix this," he said. I helped him to straighten himself in the chair, a difficult task for me.

I have never observed any physical therapy taking place. But the other day, an agency nurse took the time to walk with Art up and down the corridor, urging him on from one point to the next and encouraging him all the way. He made good progress, and was pleased with himself.

Another time, an agency nurse offered to take Art to the bathroom after lunch. One of the bullies stopped us and told the agency nurse peremptorily that it was time for her to go off duty.

"Where are you taking him?" she asked the nurse, ignoring me.

"I'm going to prepare this gentleman for his nap," replied the nurse. The bully grimaced, then stalked off, calling out over her shoulder, "You! Leave!"

I thanked the nurse, who continued accompanying us to Art's room.

*I observe that agency nurses, who are called in as substitutes, are often more attentive than some of the regulars.*



When Art stands up, he usually has to go the bathroom. I ring for help. If someone comes, I'm usually told, "I'm the only one here."

Or, "I'm leaving in five minutes." And then, as I do most days, I take him to the bathroom, clean him and put him to bed.

*I'm beginning to wonder why he is here if I am still doing the 'hard yards'...*

However, some attendants do proceed to help. Once, when there was an accident with incontinence, I asked Michelle if she had time. "We make time!" she replied forcefully. I thank the staff profusely whenever I get help.

When I put Art to bed after lunch for a nap, I often wait an hour and a half or so, to see if anyone looks in to check on him. No one does.

I leave, knowing that Art cannot remember how to summon help.

*I worry about what will happen to him on his own.*

*What happens to all those residents who have no relatives to look in on them?*

*This is very anxiety producing, to see our loved ones and other residents abandoned for long periods of time. This is what weighs on me: not only Art's welfare, but also that of the 60 others, all equally needful. And I can do nothing...*

## November 10:

Jeannette is very retiring, with a sad white face that looks like a mask. Nothing seems to catch her attention as she stares ahead all day long. The other day, as I sat in the lounge room with Art, I started to sing softly in his ear, and Art began to sing with me in a whisper—he who used to fill the church with his tenor voice.

When we stopped, I was surprised to see Jeannette clapping.

I went over to her and remarked. "You like music."

"Yes," she nodded shyly, with a little smile.

Later I found out that her son is a prominent musician.

The next time I saw Jeannette, I greeted her and she asked in a hushed, halting voice, "Where is your man?"

"He's taking a nap," I replied.

Now I notice that whenever I enter the room, Jeanette's eyes follow me until I go over and greet her.

Today, when I greeted her, she said, "You're looking smart today."

"Oh!" I said. "So are you!"

## November 15:

I've begun to see that certain nurses and attendants are bullies.

They lord it over the residents, the other workers and even the relatives. Today I rang for a nurse when Art was in the lounge room sliding out of his chair. Eventually, one of the bullies—we'll call her Jan—came in and demanded of me:

"Did you ring that bell, or did Art lean against it?"

"I rang it—"

"Well, don't!" she snapped, and went away.

*What is the buzzer for?*

In the lunchroom, Hetty yelled at Sharon across the dining room:

"DID YOU GIVE DELPHINE A CUP OF TEA JUST THEN?"

Sharon called back, "Yes."

"WELL, DON'T! SHE HAS TO LEARN TO WAIT!"

Sharon said, "It was no trouble. The tea trolley was right there."

Hetty hurried over to Sharon and continued berating her.

We all ducked our heads, chagrined.

*In addition to all the shouting, every day during lunch there is loud vacuuming in the area adjacent to the dining room, making it impossible to establish a pleasant dining atmosphere.*

## November 18:

Jack, who eats at our table, was missing today. I asked Leanne, his Scrabble partner, where he was.

“He’s in hospital,” she said sadly.

Jack is a big man who has both legs amputated. Every day he regales us with anecdotes about his football career.

“I could kick fifty yards with my right foot, and sixty yards with my left foot!” he says with a loud laugh.

After lunch, he always asks me to wheel him out to the patio where he spends most of his time, smoking.

“Another cigarette, another nail in the coffin!” he says, laughing and coughing. He adds ruefully, “The sooner to die.”

He did not return from hospital.

## November 19:

Thelma stopped me and asked where she could buy some summer dresses. It’s getting warmer, so it was a reasonable request. One of the bullies was passing by. She looked at us reproachfully.

Smiling, I told her about Thelma’s wish. She bristled.

“Her family attends to that!” she spat out and sped off.

*(They are always cutting you off, without giving you a chance to explain.)*

*I wasn’t asking her to do anything about it. I was just acknowledging what Thelma had said, as I thought it was quite endearing. Once again, I felt rebuked.*

## November 20: This scenario in the lunchroom

I go round to my friends at various tables. Ordinarily, they sit with eyes cast down and eat in silence. But gradually, they have begun to smile and respond when I greet them. At one table today, they comment on what I am wearing.

“From the Op-Shop,” I tell them, preening a bit.

Gloria says, “You’ve done well.”

Lily says, “I like the colour.”

Helen turns to Lily and says, “That’s a pretty colour,” referring to Lily’s blouse.

Leanne is at the table, too, and enters into the animated conversation.

“Ladies,” I say. “This is a happy table! Enjoy your lunch!”

Halfway through the meal, one of the attendants notices something at their table, and calls out, “Leanne!”

From the far side of the room, Jan comes striding. “LEANNE!” she roars, striking fear in all within hearing. “WHAT ARE YOU UP TO?”

She rushes up to the table and starts fussing and scolding Leanne, stabbing at the food on her plate. “EAT THAT PUMPKIN! EAT THIS! EAT THAT! DON’T DO THIS! DON’T DO THAT!”

When she leaves, I look over at their table. All four women are looking down at their plates, back to their self-protective isolation.

*Heartbreaking. All that camaraderie undone. How nourishing was that pumpkin for Leanne? How crushing was it for the others at the table? For all of us? What had Jan accomplished? To what purpose?*

## November 21:

Hetty sidles up to our table at lunch. She stands with one arm akimbo and announces merrily: “*We passed our accreditation with flying colours! As I knew we would!*”

*Strange: during the accreditation, there were a dozen attendants at lunchtime to serve the meals. Usually there are only two – and on occasion, only one, when the cook has to come out and help serve.*

At about this time, Fred, Felicity’s husband, tells me that Hetty has warned him not to talk to me, because I am a trouble-maker.

*What is this? I’m baffled and disturbed. Should I challenge Hetty?  
I hesitate to do so, afraid of the fall-out.*

## November 31:

**Residents and Carers Meeting.** Once again, the nurse who was chairperson couldn’t give us any information. Halfway through the meeting, she got up and left and didn’t come back. We sat there, looking at one another. Spontaneously, we all said, “Well, let’s hold our own meeting.” So we decided on a venue and a date. There were about a dozen of us.

When we met, one of our number brought information about the purpose of the Residents and Carers Meeting, to the effect that it should actually be run by the residents and carers, not by the staff.

We started by saying that we wanted our approach to be positive: "Let's make a list of things that are going well." There was a long, long pause. No one could think of anything. However, we did manage to cobble a few points together.

Then we got down to the business of listing our concerns. We filled nine pages. Everyone signed the submission, standing united so that the Director would not be able to shoot us down one by one.

We decided to present our submission to the Director at the next Residents and Carers Meeting.

### December 3:

In the meantime, I decide to speak with Hetty about her slanderous accusations against me. I gather my courage, go up to her and ask to speak with her.

"What about?" she asks suspiciously.

"I'll tell you when we can speak," I reply.

"Right!" she says. "I'll get a witness."

I'm glad to have a witness, but I had wanted to speak with Hetty on her own, as I didn't wish to report her.

After making me wait a few minutes, Hetty takes me into the nurses' station in the wing opposite to Art's.

Neither Art nor I have ever had dealings with the nurse at this station. Let's say her name is Marian.

Jan comes in and joins us. I don't know why.

Speaking calmly, I address Hetty.

"Hetty, it has come to my attention that you are telling people not to talk to me, saying that I am a 'trouble-maker'. I would like to know: in what way am I trouble-maker? Have I ever made trouble for you or anyone else?"

"Who told you that?"

"I cannot give you their names."

"I never said that! I never talk to the residents like that!"

And Hetty takes off.

I'm left with Marian and Jan.

They ask me again, "Who told you that?" I decline to give names.

Marian: "You have to understand. Patients with dementia don't know what they are saying."

I explain: "One of the informants is a resident who does not have dementia, and the other is a relative who does not have dementia."

Jan: "Complainants should come directly to us. They shouldn't take on issues that don't pertain to them. It's better for them to speak about things that pertain only to their own family member. They shouldn't be talking to the residents or to the other relatives."

*Wait a minute, I think to myself. The issue here is about Hetty.*

*Why is this turning against me?*

I reply: "No. According to the Charter for the Rights of Residents, family members have a right to speak with one another, and residents may speak to whomever they wish."

Jan changes tactics. "Relatives often feel guilty about having their family members in care, and so they project their guilt onto staff by criticising them."

*But I am always courteous to staff. What is she saying?*

Jan continues: "You may not know it, but residents can be very abusive, swearing and hitting out."

*This was not the subject at hand. Where are we going?*

Jan: "Your husband may be very mild when he is with you. But residents can make it very hard on the attendants."

"Are you telling me," I ask, appalled, "that my husband is abusive?"

Jan and Marian nod knowingly.

*So the issue of Hetty's contravening the rights of residents to freedom of association and freedom of speech has turned, first, to lecturing me about proper procedures, and then to blaming Art and making him the scapegoat.*

*He, the innocent one, knows nothing about any of this. But he cannot defend himself. I'm the only one who will defend him.*

## December 4:

Following advise to inform the head nurse of my interactions with Hetty, Jan and Marian, I write a letter to her, with excerpts from this journal.

A few days later, the head nurse passed me in the corridor, paused, and told me:

“I’ve spoken with staff about the matter you raised. They say it didn’t happen that way.” She walked away.

And that was that.

So it’s my word against theirs.

*There’s no recourse.*

## December 10: My conclusion:

I am withdrawing my husband from “*Compassion Place*”.

I came to this place with my beloved husband, ready to cooperate.

I brought an open mind and open eyes and ears, a conscience and a heart.

I cannot let Art die here. People need to die in comfort and at peace. Their family members, too, should be able to be at peace about the care of their loved ones in their last days.

When I informed the head nurse that I was withdrawing my husband, her only words were:

“You understand that he’ll go to the bottom of the waiting list.”

### **What price compassion?**

*Postscript: Without our knowing it, somehow a copy of the submission reached the CEO of the organisation. There was immediate action: a general meeting with the CEO was called, which was packed to the rafters. The Director was dismissed and a new one appointed. By this time, Art and I were no longer there.*

# Interim: I have Art at home

The next eight months with my husband at home were a time of richness and great peace. At first, he spent ten days in the hospital repairing the physical deterioration he had undergone at the aged care facility. He was dehydrated and had several infections.

The EACH program (Extended Aged Care at Home) then provided extensive personal care, home care, home modifications and equipment. The carers who came into the home were uniformly competent and kind. I found I could care for my husband more easily than ever before.

Art blossomed by being back at home in his familiar surroundings.

He could walk better. We could hold conversations. We had many good friends gathering with us as before.

But then, one dark night, I found him slumped over his walker.

He had had another severe stroke, and he was very sick. He spent six weeks in hospital, close to death. After six weeks, the hospital could no longer keep him. As he was totally immobilised, I could no longer care for him at home.

Then the desperate search began for a permanent placement. Aged care facilities in one of several far-off towns seemed to be the only option, but in that event I could not possibly be with him every day.

At my age, I was fearful of driving long distances on country roads.

Eventually, to our relief, Art was accepted for respite at “*The Lodge*”, an aged care facility in our town. The EACH program subsidised the cost. But, again, the time limit at “*The Lodge*” was six weeks. We would have to find a permanent place before the time was up.



## 2. “The Lodge”

“*The Lodge*” is an up-market for-profit facility that does not take public patients except for limited periods of respite.

### First impressions

“*The Lodge*” is an imposing two-storey building in a sylvan setting.

The driveway sweeps up grandly to the main portico. As you enter, you are struck by the elegance of the gigantic chandelier above a massive round lounge that takes up most of the large foyer. Huge bouquets of fresh flowers placed on antique sideboards are reflected in ornate gilt-edged mirrors. But, as in “*Compassion Place*”, there is no one in sight. The atmosphere is sterile, claustrophobic.

Art is transported by ambulance from the hospital. We wait in the foyer. Suddenly, two attendants swoop in on us and begin taking Art’s temperature. They test the use of his hands, his arms and legs.

They try sitting him up. Without a word to Allie and me, they take him upstairs to a private room that looks like it belongs in a five-star hotel. They put him to bed and leave us.

We look around. There is a flat-screen TV mounted on the wall, a fridge, a microwave and an electric kettle. The bed and windows are shrouded in heavy brocade. The easy chair is plush. There is a balcony with a view, a spacious closet and a private bathroom.

It’s all very expensive-looking. The view, we learn, costs five dollars a day extra. But Art can use none of it. This is the high-care section and I doubt that any of the residents can fully utilise the amenities, though they are paying for them. In fact, the microwave and kettle could be a hazard for people with dementia.

There is no shouting. Everything is hushed, except for the call bells that ring continuously. We wait with Art until he falls asleep and then go home.

### Life at “The Lodge”

We return at teatime to find Art sitting up at table in the dining room. There are linen tablecloths and flowers on all the tables. Serving dinner is an interminable process because members of staff go around to all the residents asking them to pick from a varied menu, but most have no idea what they’re talking about. The food, when it comes, is bland. Down the track while we are there, we encounter a few party pies, sausage rolls and cocktail frankfurts.

Roger, at our dining table, tells us that he had to sell all his assets, including his home, to finance his admission to “*The Lodge*” and his on-going care.

The residents do not look as debilitated as the ones at “**Compassion Place**”. Most are dressed well, with jewellery and coiffed hair. After each meal, the residents are ranged in chairs around the TV where they are treated to Ellen De Generis and Co. The whole time we are at “**The Lodge**”, there is no live entertainment. Once a week there are church services, but only downstairs, in the low-care section.

High-care residents are deemed not able to relate to spiritual care.

*In my experience, they are the ones who need it most.*

Every day, we arrive to find Art placed by himself looking out a window at the view, often sliding out of his chair. We have to wait until someone passes by to straighten him up. As always, we feel like we are imposing, interfering, a nuisance.

As we accompany Art throughout the day, we observe that, in effect, there is no more supervision at “**The Lodge**” than there was at “**Compassion Place**”, despite the luxury. The staff/resident ratio is about the same: not nearly enough. The workers, mostly Filipino, have a heavy load.

As the six weeks draw to a close, we do not know what to do if a permanent place is not found. “**The Lodge**” does not accept public patients. We are back to square one, a fearful uncertainty yawning before us.

Almost at the last minute, I get a call from “**WXYZ**”, an aged care facility that is just around the corner from home. There is a vacancy for Art.

### 3. “WXYZ”

“WXYZ” will stand for the acronym of this for-profit organisation. It is housed in a dilapidated old school building, surrounded by a gritty parking lot. The venue has had many incarnations as a nursing home, noted over the decades for the fact that the neediest high care residents are accepted there.

Recently, “WXYZ” had taken over, with the promise of new state-of-the-art premises to be built within three years.

When the manager first spoke to me on the phone, she said, “I want you to know that we are here for your husband’s benefit.

But we are also here for your benefit.” It sounded reassuring.

#### *First impressions*

When we first visited “WXYZ”, it appeared dark, crowded and forbidding. A woman’s voice could be heard barking loudly. People were ranged along the corridors, some of them hanging halfway out of their chairs. The rooms were small, with four beds closely packed in each. There was one toilet block with four toilets and showers to serve thirty people in one ward. Another ward housed thirty more.

There was no sign of any personnel. We entered a small, cramped day room where more people were slumped in chairs along the walls. A TV was blaring with the ever-present commercials dominating the scene. It all looked bleak and soulless.

We could hardly contain our dismay.

When we brought Art to be admitted, however, we were met at the door by a large motherly woman who introduced herself:

“Hello! I’m Hannah, and I’m your carer for the day.”

An attendant we had met at “*The Lodge*” rushed up to greet us.

“I work here, too,” she said cheerfully, “and I’ll keep an eye on Art. He’s a sweetheart.”

Hannah led us to his room. His bed was closest to the door.

Above the bed was a sign: “WELCOME, ART!”

Things were looking up.

I had a long conference with the head of nursing. She outlined the kind of care Art would be receiving. She explained that the health of residents was monitored at regular periods. Also, I was told that they were checked throughout the night at thirty-minute intervals.

I was impressed by her professionalism and courtesy.

The diversional therapist, Sarah, asked for details and photographs of Art's life in order to make up a 'life board' that would inform staff members and visitors about his past interests and achievements. She took me into several rooms to see the life boards above the beds. Two women in one of the rooms, visiting their husbands, welcomed me.

We were invited to a special dinner organised for our family. The table was decorated with flowers and candles. Sarah served the meal with wine, dessert, and a box of chocolates for me. She took photographs. We were made to feel like we belonged.

## *Life at "WXYZ"*

Soon, the inner realities of life at "WXYZ" began to emerge.

### September 15:

This Saturday morning, I was with Art to help him with his lunch.

The small day room is transformed into a dining room by setting up tables. There is hardly any space to move between them. Trays are brought in with food and drink in plastic dinnerware.

The TV is on a commercial station. A resident in the corner, Ruby, is making loud grunting noises. Stanley's ventilator drones at a high pitch. Moira, a nurse, is shouting at Jim.

"JIM! GO TO THE TABLE FOR LUNCH! JIM! GO TO THE TABLE!"

Jim sits by the wall. "JIM! GO TO THE TABLE FOR LUNCH!"

Jim continues to sit there. "I SAID, GO TO THE TABLE!"

Moira takes Jim to the table. "NOW, EAT!"

Jim says, "I don't want to eat!"

"EAT! EAT!"

"I won't!"

"YOU HAVE TO EAT!"

Jim ducks his head down, "I WON'T! I CAN'T!"

Moira grabs Jim's spoon, wrestling with him.

“I WILL MAKE YOU EAT!”

Jim: “NO! NO! NO! NO!”

Moira and Jim get louder and louder.

Ruby’s grunts get louder and louder.

The TV blares.

Stanley’s ventilator drones.

Adolf starts shouting:

“SHUT UP! SHUT UP!”

The other residents are waiting for their lunch.

*I groan inwardly. “Oh, no, not this again.”*

## September 30:

We befriend the residents at lunchtime. June and her husband, Arnie, are in care here together. Arnie has advanced dementia. June still has her mental faculties but cannot walk. They used to be in the Army and June still talks about Army life. They have four children who visit regularly. One of the grandchildren doesn’t want to come in.

“It’s scary,” he says.

Iris spends her time in the day room reading novels. She is a triple-certificate nurse, acclaimed in her time for her competence in a big city hospital. Iris was an orphan and has no family. Her husband left her when their baby died. During lunch, Marge, an attendant, calls out from across the room:

**“IRIS! YOU’RE EATING LIKE A PIG!”**

Iris glares at Marge and stirs her food into a pile of mush.

## October 5:

One of the men in Art’s room bellows at me when I walk in. He does the same with Art, I am told, during the night when Art cries out.

## October 10:

Mikayla comes to my assistance when I cannot help Art to straighten himself in his seat. Mikayla is gentle and attentive to Art and to me.

## October 12:

I sit in the day room every afternoon with Art as all the residents doze, in spite of the noise of the TV and the perpetual drone of Stanley's ventilator. Occasionally, an attendant puts some old-time music on the ancient CD player, which skips tracks, making a jumble of the songs. Usually, though, it's just the TV on all day.

## October 15:

There's a new resident, Myrtle. She screams all day, in a yodelling voice: **"O-o-o-o-h m-y-y G-a-W-D! WHY AM I HERE?"**

Add this to the sound of the TV, Stanley's ventilator, attendants shouting at the residents, and residents calling for help.

I sing in Art's ear to drown out the frightening noises.

Edward, a resident from the other wing, comes into the day room and demands, "Who's in charge here? Is there anyone in charge?"

When Allie and I speak with Myrtle and hold her hand, she calms down, no longer screaming. Her words tumble out in an incoherent stream, but here and there, we discern clear messages:

"Don't leave me. Don't run away. Oh, thank you. What would I do without you? Thank you. Thank you."

People stop visiting their relatives for many reasons. One of them is that they are discouraged because their loved one no longer recognises them. "What's the point? She doesn't know who I am."

*I have learned that though people with dementia may not be able to respond, or even remember, the warmth of our touch stays with them and continues to nurture them and give them hope. Otherwise, they face their last days alone, often in anguish, angry and afraid. I think this makes it harder for them to let go, to die in peace because there is no peace.*

## October 20:

Hour after hour, no one comes in to check on the residents in the day room. Three times so far I've had to go in search of a nurse to report a dangerous situation:

Once, a resident from the other wing wandered in and put her finger on Stanley's ventilator. Stanley lashed out and left long ugly scratches on her arm. I rushed out looking for a nurse and found an attendant talking to the receptionist in the doorway to her office. The receptionist's office and the nurses' station are out of sight, around the corner from the day room.

Another time, I watched as Arnie slipped further and further out of his chair. I went looking for someone to help him, but before I did, he had already fallen to the floor.

This happened also with Syd. I find these incidents traumatic—for the residents, of course, and for me as well.

June says, “It’s not right that we are left without supervision. It’s as if we don’t matter.”

After each of these incidents, I was told to make a report on the official forms that are at the entrance, which I did.

I decide to speak with the manager about the fact that the day room is out of sight of staff, that the residents are left for long periods without supervision, and that I have had to find someone to help people in dangerous situations. She replies that this problem has always existed and that nothing can be done about it.

*She does, however, proceed to make a new arrangement for all those residents who keep sliding out of their chairs: they are to be lined up in the corridors where staff can see them as they pass by.*

## October 25:

During Seniors’ Week, Art and several residents are taken out to a concert and a special dinner. Sarah organises field trips regularly for a few residents at a time. Earlier this year, we went on a picnic near the river.

## October 31:

As I walk into the day room, I hear Marge shouting,

“ADOLF! I KNOW YOU HAVE DEMENTIA, BUT FOR HEAVEN’S SAKE!”

## November 8:

When I arrive each day, I can hear Art softly calling, “Help. Help.”

He has never done this before. He stops it when he sees me.

“Here I am!” I always say.

“You went away six times.”

“But I always come back.”

I try to explain that if he doesn’t see me, I’m not far, sweeping or washing the dishes. (This is true, as our home is near.)

“You shouldn’t have to,” he says mildly, probably thinking that there are staff here to do that. So I can’t fool him!

### November 16:

Harry comes every lunchtime and helps his wife, Marilyn, to eat. Marilyn is almost totally paralysed. She looks at Harry with adoration as he bends over her and says softly, over and over,

“I love you, Marilyn.”

### November 24:

Brenda sits at lunch with her head thrust back, eyes unseeing.

Moira tries to get her to eat.

“Oh, she won’t even open her mouth!” Moira says with exasperation. “She keeps clamping her teeth together.”

Brenda clamps her teeth more tightly together. Moira leaves.

One day, Brenda is gone.

People just disappear when they die. The residents feel this.

“She was my friend,” lamented Stanley.

### November 27:

The Filipino attendants are invariably soft-spoken, kind and respectful to everyone. They tell us that in their culture, they respect the elderly. “I think of my mother when I see the old people,” one of them told me. They dare not contradict the bullies.

“Right away! No problem!” they reply when ordered to do something. Their work is very difficult and their pay is very low. And there aren’t enough workers to cover the need, so they’re always on the run.

### November 31:

I can see that the morale of staff is extremely low. I see workers with red faces and red eyes. No wonder this rebounds on their treatment of the residents.

It’s also becoming evident that the manager openly criticises the workers. For some reason, she picks on Sarah a lot. From what I can see, Sarah does a great job, better than most.

One more thing that doesn’t make sense here.



Mikayla confides that she is leaving because the manager swore at her. I will be sorry to see her go.

*There is a constant turnover in staff. All are working on slave wages. There are never enough on duty. The best ones can't afford to stay. The worst ones stay and accrue more power.*

## December 5:

Every time Art sees me, he goes into transports of delight, even if I have just moved from one side of his chair to the other.

“Oh! You came! How wonderful!”

I am learning to live in the present moment with him, as that is all he has. It's liberating. It makes the “now” come alive and helps us to savour the reality of what we have within our grasp.

## December 12:

At Activities Time, we play Bingo. Art is not interested, so I play on his behalf. He keeps his eyes closed, but occasionally squints at the board, points to a number, then closes his eyes again. He always picks the correct number! If we win, Art gets a little box of M & Ms. He opens it and distributes the prize to those around.

***Another activity another day:** stringing popcorn to hang in the birdcage. Art eats the popcorn. Others toss it around.*

## December 16:

Sarah takes Art to the Mall to do some Christmas shopping. It's all a big secret.

## December 22:

A Christmas party with Santa, carols, and presents for everyone.

Art gives me an elaborately wrapped package. Sarah has asked Allie what to get me and Allie has suggested a book that she knew I wanted. One more example of Sarah's thoughtfulness.

## December 25:

Some families take their loved ones out for the day. We have Christmas dinner in a small anteroom at “WXYZ”.

By the way, if at any time we want to have dinner here, the price has gone up from \$5 to \$12, not including dessert.

## January 10:

The TV dies. A new one is bought and attached high on the wall at one end of the day room. The residents sit at right angles to the TV, so it's hard for them to see it. If they want to. Some do. Most don't.

## January 15:

I have befriended two women who visit their husbands regularly.

We can laugh together and sometimes shed a tear together.

It helps us to keep going.

## January 22:

Some time ago, I noticed that Art and Arnie, who was sitting at our table at teatime, were having trouble eating their spaghetti. It kept sliding off their plate. I saw that some residents had plates with a rim. I suggested to the attendant that in future, a plate with a rim would be helpful for Art and Arnie. She agreed, but it didn't happen.

Similarly, last year a nurse came round asking the relatives for suggestions. I suggested that music during lunch would be preferable to the TV. She agreed, but it didn't happen.

So I decided to write a note to the manager making the two suggestions. I was careful to put it tactfully and somewhat light-heartedly.

But I made the mistake of writing it on the official form available at the entrance. I thought it was a way to communicate with the manager who stayed sequestered in her office most of the time. Subsequently, she sent word that she wanted to see me.

I went to her office. She looked at me grimly.

"I ask myself," she said, "how can I make this woman happy?"

I was astounded. "What do you mean?" I asked.

"You have done nothing but criticise since you came here. You have no right to make suggestions about what other residents might or might not need. And if you want music at lunch, put it on yourself."

I was trying to understand this when she added, "You keep putting in official notices. Now I have to explain this official notice to head office. They're going to wonder what on earth is going on here."

"Oh, I'm sorry, I'll rescind my request."

"It's too late. The forms are numbered, and I have to explain each one."

I couldn't see how asking for a plate with a rim and for music at lunch was so damning, but I said nothing more and left, considerably unsettled.

*After this, Art was removed from his table at lunchtime and placed in a corner by himself. When I came in and saw this, I stood there, puzzled. June leaned over and whispered, "They said he couldn't eat with us any more because he interferes with the other residents at the table."*

***I cried inside.***

## **March 5:**

It's increasingly difficult to go in every day and face people who are judging me and taking it out on my husband.

For example, as I help Art to eat, Marge will call out,

"Let him eat by himself! He has to learn to eat by himself!"

Another day, in complete contradiction, Moira will take the spoon out of his hand, fill it and shove it into his mouth.

*I feel like I'm being drawn and quartered. My heart aches for Art.*

But the harder it gets, the more something wonderful is happening.

The love Art and I have for each other is growing exponentially.

The weaker he gets, the stronger his spirit, and the closer we are to one another. His hand holds mine firmly as I sing in his ear. Everything is rapidly coming to a conclusion.

## **April 21:**

Jim is a gentleman. He always greets everyone with courtesy.

One day I said to him, "Jim, you're a real gentleman."

He bowed and said, "And you are a lady."

I learn that he used to be a builder and that all around town are fifty houses that he built in his lifetime.

But his troubles with eating are increasing. He cannot swallow and his food runs down over his chin and onto his chest.

"Ugh!" says Moira, and tells one of the Filipino attendants to clean him up.

“SWALLOW!” the nurses and attendants call out to him repeatedly as he tries to eat.

***What follows is a verbatim account, with no exaggeration.***

***Indeed, it is difficult to convey in words the true extent of what occurred:***

Today, Moira and Marge, who are both tall women, stood over Jim.

Jim was sitting backed against the wall, his tray if front of him, looking up at the two of them.

“SWALLOW!” they both cried in unison.

The food flowed down his chest.

“**SWALLOW!**” they shouted together.

He looked up at them with pleading in his eyes.

“**SWALLOW!**”

He looked up at them despairingly, shrinking into himself.

Moira and Marge seemed possessed.

“**SWALLOW!**” they both screamed, even more vehemently.

Jim looked like he was crucified. The more he panicked, the more incensed they became.

Finally, they shrieked at the top of their voices, still in unison:

“**SWALL-O-O-O-OW-W-W-W!**”

I bowed my head. “Oh, God! The poor man!” I prayed silently.

*How to make sense of this? Is this an insane asylum?*

I did not report Moira and Marge. What would be the use?

Soon after, mercifully, Jim died.

 **May 1:**

June says to me, "I've lost my faith, religion, God, everything.

I've decided I'm in hell. This is hell."

 **June 10:**

Art is taken to hospital with another stroke. This time, there is no return.

The hospital gives him a private room and palliative care begins. The nurses are quietly attentive, alert to our every need.

We are able to spend days and nights with Art in peace.

We play his music, pray with him, speak to him softly. Friends come and go gently, remarking on the aura of peace and love in the room.

Art's last words are, "I love you."

He dies with a light in his face and a tiny smile on his lips.

He looks young, like he did when I first met him.

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# Epilogue

Let me tell you about “*WXYZ*”. I Googled it and found out that it is a large organisation with many aged care facilities. I have seen advertising and glossy brochures promoting its commitment to health care.

It gets a subsidy from the government to run its facilities, and yet, like many in the industry, readily complains about profits.

On the other hand, more and more state-of-the-art residential aged care facilities are being built, often doubling the number of residents. “*WXYZ*” plans to do the same. It will cost at least \$400,000 (or more) to be admitted.

Aged care has become a business, not a service. It’s a business in which the people to be served are not considered. Despite flash amenities, the personhood of the residents is not attended to.

At best, there is nothing in place to nurture their spirit, to prepare them for a peaceful end.

At worst, they are neglected, antagonised and frightened until they die.

The residents move on silently and no more is heard of them.

There are plenty where they came from, in an unending stream.

The relatives are glad to be quit of the place and never go back or say anything of what they have experienced.

**There is no aftermath, no feedback, and no accountability.**

My husband and I spent our lives working for social justice on three continents. Exposing this industry that runs on scab labour, that exploits its clients at the most vulnerable time of their lives, may be our last effort.

*It takes a fly on the wall in hell to tell it like it is*

