

Volunteering at a hospice

Training

1.

At first it seems to be finding the right words.

Is the person a patient? Resident? Or is it client, when referring to a person in a hospice? And there are substitutions for terms I didn't know to begin with.

A person that has a life-limiting illness must, I'm told, be referred to as having a *potentially* life-limiting illness. Or as having a *life threatening* illness.

How to refer to a person matters.

And then we parse the term palliative. Palliative cannot, I'm told, be exchanged with the term end of life care. The two are often paired, thought the same.

They're not.

Palliative care ought to begin the moment a potentially life threatening illness is diagnosed. Palliative care is to help a person deal with the idea of death.

What really shapes the use of the term palliative is economics.

As it makes the most sense economically to provide palliative care in cases thought to be terminal, the term gets linked with end of life care. It also gets linked with cancer.

I'm told that ninety percent of hospice residents are suffering from cancer. This is because hospices have admission requirements. Usually a prognosis of three months or fewer. And cancer, I'm told, has a trajectory.

2.

She said that her father died of a heart attack. Before that, she was going to go in dentistry. "I was studying to be a dental hygienist, or a dental assistant," she said. She wore a red knit sweater, and glasses with big black frames. She had a cane, too. "My brother was going to be a dentist," she added. "But I didn't have the marks for it." Instead, she went into cardiac nursing.

"I made this promise to myself," she said, "that no one was going to die under my watch. It was silly – probably out of guilt, probably out

of ..." she trailed off. "Because people died, of course. But I remember, my first time in the unit, there is a – there's a machine that, when the heart stops, it makes a sound like beeeeeep."-- "

I nodded.

"When that happens, you can thump on the chest, to make the heart beat again."

I nodded, again.

"Well, I heard that. I slammed the button for a crash cart. I got on top of this guy, I was up there, my uniform hiked-up, straddling this guy, and I went" – she indicates slamming down, her fingers knotted together in a giant fist – "everyone got there, my teacher, the head of nursing, the doctor, and the man I was straddling, looked-up at me ... and," she slowed her words, "he wasn't having a heart attack. The machine that measures his heart beat had come off." She told me that her superiors told her, next time, feel for a pulse.

Retired now, she told me that volunteering allows her to stay connected to "that world," referring to hospitals, I think. Early on, she went on to tell me, there was a specific incident when she wasn't sure if this world was right for her. "I had just started training," she said, "and I was assigned to a man that had surgery; had just had some kidney work done." Her job was to collect a urine sample. The patient went to the bathroom, came back to me with what looked like a urine sample; it turned-out to be the apple juice from beside his bed. "Before he gave me the sample, he drank half of it. 'Don't do that!'," she said, mock shouting. "He told me it was just apple juice after." A pause. "The moment he was drinking it though, I asked myself, 'what am I doing here?'"

3.

What made her bad with conversation, she said, is that she used to work in immigration services. "I am very accustomed," she said, in an implacable accent, "to asking questions of other people. But when someone asks me, a question, I become very shy," her firm tone softening; "I don't know what to say."

Another woman spoke up. "I have a habit of finishing off what a person is saying," she said.

The room laughed.

"My sister will call me out on it. 'Stop doing that!' she says it's very annoying." Then adding, "and I can see how it would be."
Again the room laughed.

After a pause, advice was offered. "There are a hundred ways of saying the word, wow, aren't there?" said a woman sitting at the far end of the room. "'Wow,' she demonstrated, "or 'oh wow,' or 'wwwow,'" or, phrasing it as a low, understatement, "'wow,'" a few in the room laughed. "Sometimes, that's all you need. You don't need to say anything more than that."

What she said next surprised me. "You don't have to relate to a person to let them know you're listening."

A hand shot up. "So even if you do, don't say it?"

"Don't turn the attention to yourself by saying, 'oh yeah,'" mimicking a gregarious reply, "y'know, I went through something similar." She shook her head. "The focus is on you then. And be honest: just because you went through something similar doesn't mean you understand what they're going through."

Another hand. "Isn't that what empathy is?"

"Empathy is knowing another person is in pain, and trying to appreciate it. You want to be empathetic. Definitely, don't say, 'oooooh, you poor baby!' because no one wants to hear that. That's sympathy at its worst. Be empathetic."

4.

She got to the topic of alcohol, after a digression on another drug. "This is not a jail," she later said, flatly. "This is a hospice."

One resident, she recalled from her experience working as a nurse at an innercity hospice, wanted to smoke crack before death. "That was her one wish." Policy does not permit residents to get high on its premises. At the very least, residents must go to the parking lot.

"So," the nurse went on, "it was her sister who bought the crack. We got the resident into a Hoyer lift, into a wheelchair. And she got high." There was a pause.

"Her sister had to blow the smoke into her; inhale and blow it into her mouth," because the resident couldn't take it directly from the pipe. "And it was a beautiful moment," the nurse added. "Her daughter was there. And, the resident was able to speak a few words to her daughter before going. Three hours later, she was gone."

A few hands went-up at the conclusion of this anecdote.

"No," said the nurse, also the admissions coordinator where she works, "none of you will be asked to do anything illegal." The nurse, she wore a striped dress bulging at her mid-section – her second pregnancy she mentioned before taking a seat – went on to state flatly, that some residents bring addictions with them. The policy of the hospice is not to rehabilitate any resident. It is harm reduction.

The topic of alcohol took up a lot of time. "Sometimes, people's relationship with alcohol changes near the end of life." There is no prohibition of alcohol at the hospice. "Some residents want to take a shot of alcohol from time to time. Others, they want a tumbler of alcohol that they can sip on for the afternoon. When they don't have that tumbler they feel very uncomfortable. Sometimes residents need it for comfort."

She went on to say, "sometimes a volunteer might accompany a resident when they go out to buy alcohol. But you never have to. This is where it's most important to reflect on what you feel comfortable with."

5.

Before the nurse who brought in the safe crack kit and the safe injection kit (the former includes a plastic tube with a rubber tip to reduce lip burns, and, a couple of condoms wrapped in a schedule of clinic drop-in times, because "people high on crack are more likely to engage in unprotected sex," and, the latter which includes amongst other items a small container of saline, because "sometimes a user will mix a drug with blood before injecting if no other liquid is available; this is a safe alternative"), we were offered another presentation. This one had neither props nor drug and alcohol use as its subject.

It began with a question.

"I want you to take out a piece of paper," said the rather tall woman standing at the front of the room. "On this piece of paper, and I wish *no harm* on you, but I want you to answer: How would you react if a doctor told you, that you had a terminal illness?"

I looked about, unsure of what to put down on the paper. Others, too, were not writing.

After a few moments, the silence was interrupted. A woman near the front volunteered her answer. "First, I would ask: Is it going to be painful? Then, I'd ask what is going to go first? And, then: Do I need any help as I am deteriorating?" The speaker wore a sharp suit coat. She seemed very sure of herself.

Another person, near the back of the room, much older than the first, lifted her hand. "I wouldn't have half the soundness of *mind* to ask all that! I'd be on the floor crying," she said. "*Begging* for a second opinion," she added, for good measure it seemed.

"Again," intoned the rather tall woman, "I don't wish *any* harm upon you or on your family, when I ask this." Her accent – implacable – had a way of softening and separating her words. "What you must know is that one-in-eleven people is diagnosed with dementia" – there are over ninety different kinds of dementia, she tells us later – "and when a person is over eighty, the number is one-in-three."

This is much higher than cancer or other illnesses. "There is," she said "a very good chance that you will meet a person that has been diagnosed with dementia in your work."

There are reversible, or temporary kinds of dementia, she says. Some brought on by severe depression. After a hand was raised, she replied as though defending the claim, "I had a client that was in her early twenties, with her memory wiped *blank* because of depression. It was recovered after much therapy was given."

Amongst the many things the rather tall woman told us, one thing – it was a metaphor – stuck with me. "Imagine each memory you have, is a sheet of paper. And you stack them on top of one another. "Eventually," she smiled, "you get a stack, soooo high." A pause. "Now, imagine: a fan is turned-on, and blows toward that stack. What will happen?"

Silence.

"The top sheets will begin to blow off. The top sheets are the most recent memories. Then, more blows away ... this is why, you get someone saying, 'Take me to my home in Uganda,' – Uganda is where I am from – when they are living here. They might have moved here thirty years ago. But, to them, they are living in old memories that are real."

6.

Still reeling with feelings of my own insignificance to help, I asked a woman that has long worked with the ill if she has had similar feelings.

There was a silence.

"No," she said. Then, as I sensed her reaching for something to tell me, there was again a silence.

She said that there was once a time when she left the hospice deeply unsettled.

"I got to my car one night, and," she hesitated, "there was a resident that was going to have a catastrophic bleed. I knew it. That day at rounds, the nurses were discussing putting a bleed kit in his room." The resident, she said, had a large tumor on his neck. Often with large tumors like this, they begin to bleed – usually internally, she told me, and sometimes the bleed is external.

A bleed kit is, unlike most things in a hospice environment which are a hygienic white or floral print, full of very dark fabrics. The idea, she said, is that when a resident begins vomiting blood or bleeding-out, they won't be as aware of the quantity of fluid, which is, she added quietly, usually quite large.

This resident, she said, was also a very bitter man. "I didn't like to go near him." She hesitated. "I felt this deep sense of repulsion even though I knew – I could feel as I left that day – he was very near death. I *had to go back*, and tell the staff how I was feeling." She told me that she felt as though she was intentionally neglecting this resident, however, she also wanted to stay away from the room. "What do you do? The resident is going to sense things are going poorly if you're in there with a bleed kit on your lap, just waiting."

What she described, this terrible awareness, and, perhaps, most important to me, a sense of meaningless agency – bearing futile, frightened witness to events happening as expected – brought little consolation. However, she mentioned that this experience, with the resident that had a large tumor, was rare. Usually, she said, death happens with unexpected humor and acceptance, And, at the least expected time.

7.

The next exercise is, a woman with a sweep of thick grey hair addressed us, a loss exercise. "How cheery," the person beside me whispered.

In front of each of us, were five scraps of paper. On them, we were to put down five things, either material things, or relationships, that were important.

After a few moments, the woman with the thick grey hair instructed that each of us must crumple and throw away one scrap of paper.

"Oh, well – this is *novel*," exclaimed a voice in the room with a British accent. "We don't get to litter usually, do we!"

The instruction was repeated; this time each of us was to choose from the four remaining scraps of paper. There was a moment of collective hesitation. There were a few laughs as the paper began to flutter down. "I wish I put down more material things," said one man.

Again, the instructions were repeated. Across from me, I saw a person lay out their scraps, before, with a awkward laugh, addressing one, "Well, goodbye mom." Again, papers fell to the floor all around the room.

When the instructions were again repeated, there was little chatter and no laughter. All of us, it seemed, were staring at the remaining bits of paper. "I'm not giving up mine," said a woman, who appeared – I'd guess – middle-aged, wearing thick-rimmed glasses.

"Whatcha got there?" blurted-out a person that happened to be sitting a couple seats over.

"I got my son, and I got my daughter."

"*Ooh*, you got Sophie's choice."

"I'm not giving up either," she said, curling her arms around the papers.

A few people tossed off papers, covering their eyes.

We didn't make it to another round. There was too much revolt. The woman with the sweep of thick grey hair addressed us. "Now imagine, if you can't let go of a piece of paper, imagine how a person with their

actual loved one feels.”

8.

Crossing her arms, she said, "Well, *philosophically*, I don't agree with that." She shrugged, shaking her head. "I just – can't – agree with that."

I, too, felt resistance.

The blurted objection was to the notion that once a person is a resident in a hospice, when that resident stops eating, concern is *not* warranted. The woman instructing the seminar, her hair in a high coif – a ball of it nearly floating over her head – took a few steps toward the objector, a healthcare worker formerly from Baltimore, wearing glasses that had heavy brown frames.

"We have been conditioned," said the woman with the high coif, "through *life* to associate food and eating with love and comfort. We imagine that by not offering a person we love, food, that we are starving that person. Or causing them discomfort." When a person is dying however, "malnutrition is not a concern. Nutrition," she said, in her big voice, carefully treading over each word, "is to build new cells. Nutrition doesn't keep one *comfortable*."

It seems that the body knows when it is dying. "Death is a desiccating process," the instructor reiterated. "That old saying, dust to dust, whatever your reli –" she cut herself off. "Whatever your belief is, that is true. Our bodies stop taking on water as death approaches. The cravings for solid foods decrease, as the production of saliva decreases." Typically, one produces two liters of saliva a day. "This is a different process than *self-preservation*. If a healthy person is in a disaster, or a war zone, and can't access food, the body slows down the metabolism to preserve itself. When a person is dying, the metabolism actually speeds-up."

She went on later to say that sugars often stabilize. Meaning that diets like, diabetic diets and hypo- or hyper-glycemic diets, no longer have to be followed. "If a person with diabetes wants to eat ice cream all-day, every day, and they're actively dying, they can do *that*. If they want to eat a *whhhhole* birthday cake, they can do that – they probably won't consume very much though."

"Can we eat the rest, if we're in the room?"

The instructor burst into laughter.

Because residents in hospice care do eat, there is a need to take precautions.

"There is a myth around Jell-o," said the instructor. "That it's a good soft food, like stew, or pudding. But it is the easiest thing to act as *plug* in the throat."

The other point that she stressed, is that forcing – for lack of a better term – a resident to eat solid foods can lead to aspiration – when a bit of solid food gets lodged in the lung. The body's response to this is sending fluid to the lodged item. The fluid, in turn, can lead to pneumonia. "And that's not a very comfortable thing," the instructor said, with unusual softness in her voice, "to have as one is near-death, is it.

"Residents will eat, because they want to eat, *not* because they *need* to eat. Because they want to eat," she went on. "That often means tasting comfort foods, which offer pleasure and familiarity."

In many cases, the dying body immediately rejects too much food – a miniscule amount by healthy body standards – vomiting it up or with explosive diarrhea. The result is a decrease in dignity. The notion that we, as compassionate people, insist a person near-death eats in the hope of reversing the condition has to be thrown-away.

Fluid, like water, has associated problems., too.

The dying body does not absorb fluid. What happens is, we are told, what's called, third placing, in which the fluid is stored in other parts of the body. Edema, or swelling, in the feet and hands can occur. Fluid can build up around the belly, which can be a source of pain. "Because that," said the instructor, "pushes up on the diaphragm. Making it harder to breath. If there's too much fluid, the excess is sent to the lungs." She left a pause. "The resident may actually drown in their own fluid if it is forced near death."

9.

"I have this saying," said the doctor standing at the front of the room. "Ah, it's, No brain. No pain." The audience broke into laughs for a couple of moments.

"Ah, and that's because, the brain, while it has no pain nerves – which is why your friend," said the doctor, addressing a woman in the room

who told the story of a young woman dying of meningitis, whom had reported no pain, "said that she felt fine the same day that she died. The brain is the interpretive centre for pain.

"Emotions," he added, "have a *huge* power over how a patient interprets symptoms like nausea, shortness of breath, and pain. This is true in healthy people too. It doesn't just apply to sick people.

"A study was performed, where a person would have their hand in hot water. And if they were engaged with –the pain threshold," said the doctor, interrupting his own words, "the temperature we know generally causes pain in people, went *up*. If they were shown *positive* imagery. The reverse was also true: if a person was shown scary imagery, the threshold for pain went down.

"So, that hour that you're in the room with a resident, that might be an hour when their shortness of breath or pain actually goes down, because you're engaging them in something pleasant. "

The doctor had asked each person in the room to volunteer a question on a death they had experienced. He said he would do his best to answer the question in a medical way.

I volunteered the story of a distant relative. He had died, it seemed, quite mysteriously. One moment he seemed okay. The next he had died. The death certificate, I reported, said that he had died of a pulmonary embolism.

The doctor, a man that appeared in his early thirties, maybe mid-thirties, with short dark hair, and a tinge of a French accent, nodded gently at the assessment.

Was it a pulmonary embolism, or ...

"Well, I'd say the most common cause of sudden death is a pulmonary embolus. This is when," he took a tone of digression, "a clot forms, usually in the thigh, and comes loose. It's carried to the lungs and blocks the flow of blood with oxygen to the rest of the body."

Is this the same thing as suffocating?

The doctor hesitated a moment.

"No, no. Because suffocating involves pressure on nerves that have pain receptors, usually. So there's a discomfort associated to suffocation. With an embolus, the blockage doesn't press any nerves with pain receptors."

So, he had no pain?

"It's a very peaceful way to die," said the doctor.

The soft spoken answers, it seemed, offered many in the room the gentle reassurance, even if oblique, that medically, things had gone well in the death that they had a question about.

An oblique answer, for example, came after a few people reported that, just before death, their loved one had reported seeing divine imagery.

"What I've heard," the doctor was often careful to frame his answers with experience, "and this was something I was told by my uncle, who was a palliative doctor, something like in fifteen-percent of cases, people report hallucinations when they're near death. In my experience, I'd say it's probably higher." He paused. "And the hallucinations can be positive or they can be negative. So, it can be either. It's good to hear they were positive," he added, with a small smile.

One woman spoke of the death of her husband at home. She described a loud gurgle in the final moments. "His son," she said, "was absolutely hysterical. He wanted me to use a turkey baster to suck-out the fluids from his" – her husband's – "throat. I didn't." she added, firmly. "Please tell me I did the right thing!"

"Yes," he said. "You did the right thing. Usually as people are close to death, the muscles in the throat relax. There's a buildup of fluids in the throat that can't be suctioned out, without surgery. It's in an area," he said, shaking his head, "of the throat that we just can't access with suction."

"Why is that?"

The answer was technical. To do with trachea.

"Was he in pain?"

The doctor said that in that area of the throat, there are nerves with few pain receptors. The sound is much louder than one might expect, he said, because that small amount of fluid vibrates a lot.

10.

"I always say, 'it's the dosage, and not the drug,'" the doctor said with a small smile. "Take, for example, botox. Botox is the deadliest substance you can get. " He paused. "You can kill a person with less Botox than with any other toxin. But, in small doses" – people around the room started nodding – "it can be used therapeutically, on the vocal chord, or for the treatment of migraines."

These words were in reply to a question on pain management with opiates. There was concern of addiction.

The doctor told us that, sometimes, family members of a resident will object to a loved one getting a dose of an opiate after they are reporting less pain. "Opiates usually level off in a person after about twenty-four hours. A dose usually lasts between four and five hours. So, to maintain the dose that's in the blood," said the doctor, "new injections are needed." He paused a moment.

"There's this misconception, I think, that what we're trying to do is get their family member high. Or that we're giving too much, and it might lead to an addiction. Pain is like a sponge though –" the room responded with laughter.

"Pain is like a sponge: if a person has real pain, it absorbs the opiate. The chances of getting addicted are very slim. Something like, under two percent of people with high levels of pain become addicted to their medicine."

A hand went up. "What if a person doesn't?"

"Doesn't – ?"

"Don't have a high level of pain."

"The chances of getting addicted are higher. But, studies have shown," words beginning to speed up, "that it takes about two years of use before a person shows signs of an addiction to a drug."

"Much longer than they'll be treated," replied the interlocutor.

The doctor did not reply.

Another hand went up. "Do people ever choose not to have pain management?"

"Well, most people don't – they want it. But, it all comes back to the question of what a good death is," said the doctor. "There's really no such thing as a good death as an objective thing. For some people," he sighed, "to fight, and to struggle to the end, that is a good death."

The doctor, a relatively young man with a slim frame, wore a dark orange top that day. He next screened three video clips in which people died in hospice care.

The first and last of the three were tranquil events. The expressions – those of the actively dying – don't change much, so the focus -- or, at least my focus -- was on the sound of breathing. It speeds up, and

halts for a few moments, then speed-up, and halts for a longer period; and, so on, with longer and longer pauses.

The second death seemed like a struggle for the actively dying man. He looked, to me, very afraid. His breathing was more a gasping. His eyes were glassy and seemed very aware.

11.

"Re-positioning," said one nurse, before demonstrating the practice, "is a big part of what we do." A resident at the hospice is re-positioned every two hours. The consequence of staying in one position too long can be reduction in blood flow and sores. The sores, I was later told, can be difficult to tend to – because a resident's body is often so delicate – and very painful for that person.

This nurse, a very tall man with pronounced arm muscles, chose two people for the demonstration. One to play the role of the resident. The other to assist him in the re-positioning.

The woman playing the resident lay on her side. He did it in just a few swift moves. First, flattening the resident on her back. Then bending one leg – as it turned out, the leg opposite to the side the resident was going to lay on – and then, by the hip and knee, pushing the resident onto their side. After that, it is a matter of propping up the back with a pillow; and, sliding a pillow between the resident's knees.

The person assisting had no role until the next demonstration: changing what's called a soaker.

A "soaker" is a thick pad that goes under a resident's lower back, bum, and upper thighs. The purpose of one, it seemed, was to make sliding a person up the bed easier. Slouching, which can lead to discomfort, happens when the angle of the upper third of the bed is elevated. It's also an unsafe position for eating.

To change a soaker is a matter of folding it while the resident is on their side. Then reaching under to grab the folded material.

"So, we can't just yank it out from under them," one person asked.

The room burst into laughs.

"No, I was serious," the same person added.

The answer was no.

After a couple more demonstrations of how to reposition a resident and change a soaker, we were asked to break into groups; for each

group to gather around one of three beds in the room; and, to practice.

When it was my go to lie in the bed, the first thing that became apparent is how big everyone else seems. The bed didn't seem particularly low when I was assisting others. But, on laying back on the mattress, looking up, everyone seemed towering. It had been mentioned earlier that putting up the bed rails on both sides at the same time is not allowed – technically, I'm told, it's considered restraint; as is putting a tray table over a bed when it is flat -- so, I requested, out of curiosity, to experience this. The narrowness of the mattress very quickly becomes apparent when the rails are up.

While playing the resident, I was surprised by how easily, when a person is familiar with the mechanics of the body, it responds to outside forces.

12.

Because the emphasis is on dignity, every accommodation is made before diapers are used. "When a resident can no longer go to the toilet on their own," said an instructor on personal support, "that's ..." she allowed her words to trail off.

"There's no going back," offered another person in the group.

"No, no," she said, with emphasis on the second iteration, "there isn't. It is a big psychological step." Then, she added, perhaps sensing a dourness to the moment, "but *some* residents, they're like, *yeah*, gimme one of those," her voice taking on a high, perky tone. "I'll put it on myself," she said, imitating a resident.

A volunteer is chosen to lie in the slender bed that has been rolled into the room for the next exercise: aiding a resident from bed. First, the bed as a whole is raised – usually a resident's bed is as near to the ground as possible to reduce the risk of falls.

The volunteer's legs are positioned diagonally in the bed. Then, with a hand across the back, resting on the shoulder, the instructor pushes the volunteer up from the mattress. When the volunteer's feet are dangling over the edge of the bed, the next step – and, this was stressed a couple of times – is to put shoes on the person. This is a safety precaution, to reduce slipping as the resident ambulates.

Laying in the bed myself, playing the role of the resident, and having the process performed is a bit surreal. The urge I had was to move in anticipation of the help. To actually, totally succumb to the helping hands of others takes practice as well.

The instructor brought out a shallow, oval bucket. Aqua marine in color. The top on a gentle angle. This bucket is the option if a resident chooses that they prefer to urinate and defecate into something vaguely like a toilet, and cannot leave the bed.

To demonstrate how this bucket is used, a volunteer is chosen. She is told to lay in the bed. She was rolled on to one side, then the bucket is pressed on to her backside and she was gently returned to a resting position. The bucket is adjusted, the slope of it facing her; then, for privacy, a sheet was pulled-up.

Usually a nurse or personal support worker exits the room for a few minutes, and on returning, the smell can "hit you like a brick," we're told. To counter, some rub Vicks under the nose, or put eucalyptus oil there. There are air fresheners in some rooms. In some, there is litter, which can absorb smells from the room.

The next demonstration is how to put a diaper on another person. To my surprise, the diaper is quite a thin, unobtrusive pad. I was also surprised to learn that the resident has the option of leaving the diaper unfastened, the front of it hanging-down, so that it doesn't feel like a diaper. Rather it's just an H-shaped absorbent pad that's present under the bum and upper thighs.

Working

13.

A white panel truck pulled onto the curb. A big man – big arms, big shoulders, and a solid mid-section – opened its back door, swung a mattress over his shoulder, and approached the front door of the hospice at a tremendous speed.

I was outside with a resident. I called to the man with the mattress, asking if he needed a hand.

"Oh no," he said, keeping the mattress balanced with one hand as the other tapped a button next to the door.

He left the mattress leaning up on a wall in the lobby as he shut the back door of the truck. Then returned. By then I had come in for an unrelated matter.

Is that mattress to replace another?

"It's a special mattress," he said. "It helps heal bed sores."

I asked him how.

He told me to feel the mattress. "It's got nine air pockets on there. That way, it relieves the pressure spots."

This can heal wounds though?

"Well, y'know, once you have less pressure on the skin of a person that's in bed ten-twelve-more hours, then that body can start to heal. At the very least, those bed sores'll shrink."

A woman in the lobby, listening in, said, "you shoulda been here four days ago when she" – referring to a resident, maybe her mother – "needed it."

"I just follow orders ma'am, the OT [occupational therapist] had to order it," he said with a smile.

"She got that sore *four* days ago," the woman repeated.

He asked her to indicate how big the sore was. She made a circle with her index and thumb. "Well," said the man, "I betcha it'll be down to this," holding a nickel between his thumb and forefinger, producing the coin seemingly out of nowhere, as though a magic trick, "in two days."

The woman looked unimpressed. She left the room.

Does that happen a lot?

"What?"

A family member is prickly like that, over the treatment of a loved one.

"Nah; it hardly ever happens. And I get where they're comin' from. That mattress though, that's worth several thousand dollars. It's got to come from an OT's recommendation. And that one," he added, "that model is the least expensive one we rent. There's another that constantly releases air. A fan is constantly going to blow it up again. That's another way the mattress is designed to relieve pressure on the skin. There's another model – the most expensive one – has fluid in it. People think it's gel. But it's fluid." He went on to describe how tricky it is to put a mattress cover and sheets on a mattress that has fluid in its many pockets.

Bedsore are, I'm told, the most insidious problem which affects people in healthcare facilities. Untreated they can lead to serious recovery complications.

"Yeah, I didn't know a thing about mattresses till I took this job. But they're lifesavers for some people," the deliveryman said with a bit of a laugh.

A moment later, a person was down to sign for the mattress, and the man was on his way again.

14.

They came, most often, in couples. Some came alone. And, just once, there was a great horde.

In sunglasses and floppy hats, they crowded around the door of the hospice. I was there on a nearby bench, sitting next to a resident. There was a din of voices, then a firm, loud one as a man broke from the pack.

The man – a guide for a walk of the neighborhood – was tall, and wore khaki-colored pants, with a khaki-colored shirt, and a matching khaki colored hat with a wide brim. In a few sentences he summarized the history of the chapel that was re-purposed as a hospice. He went on to shout out terms like terminal and three-weeks and cancer

Hearing that speech, as I sat beside a resident, was easily one of the most uncomfortable experiences that I have ever had. The resident I got up from the bench and returned inside.

At first I couldn't put my finger on why this was so uncomfortable. There was nothing untrue in the speech, and there is no effort, as far as I'm aware, to elide the facts from residents.

Later it dawned on me that it was the language the guide used, how the event of death, and the time leading immediately up to it, are – or, at least can be – thought of as one and the same. As though there is no distinction between the knowledge of death, the time leading to it, and the event. The suggestion in the language was that this, the hospice, is where one goes to die, as compared to, this is where a person goes to *live* before succumbing to death.

Perhaps the most telling phrase of this forgivable but mistaken

outlook on the purpose of a hospice was the statement, "it's the closest thing to heaven on earth." The guide said this as a conclusion to his remarks. Suggesting that entering the hospice is to reach an end point; heaven as a hospice suggests one has *already* succumbed, when the prognosis, but not the event, has occurred. I know what he meant of course. But, still it said more. Prognosis as an event, as an event nearly equal to the event it predicts.

So, why was that moment the speech was made, as I was sitting next to the resident so uncomfortable? I didn't do any parsing at that moment. I can only describe what I thought. And it was like, when the guide was describing the residents of the hospice, that they were dead already. And suddenly, the person I was sitting beside in the sun, listening to the birds chirp, was already gone.

15.

A few weeks ago, I was told to expect changes in the breathing of a person near death.

When this was described to me, the person describing it drew on observations from her own experience. One of her phrases – "it was like a woman giving birth" – stuck in my mind more than anything else she said on the subject.

In the time that I have had to spend with a person near death, the breathing was neither shallow nor urgent the way I expected from the description.

For the person near death with whom I have been with, when she takes in air, it comes after thirty or forty seconds. Sometimes longer. As she lays there, in those, what feel like very long, intervals between taking in fresh air, her body is without the slightest bit of movement. Her eyes are half open. When a new breath – *finally* – comes, her eyes open wide. After a couple of moments, her eyes usually begin to glisten. They glint light from the window in a way that the grayish white of her half-open eyes did not.

Occasionally after a breath, she adjusts her arms over her head. She is not in a condition, unfortunately, to speak. Though sometimes, the way she moves her head, and arms, and eyes, I have a sense she has something she wants to say.

I have asked others on the phenomenon of this breathing, known as Cheyne-Stokes respiration. There doesn't seem to be much information on why it happens. Though, informally, there is what one nurse calls, the wisdom of the body.

The slowed breathing is said to allow carbon dioxide and moisture to mix together in the lungs, which forms, I'm told, cacid. The acid, in turn, can numb and slow down the body in other areas, easing it toward death.

16.

He tries to adjust himself on the mattress. Before long he is lopsided. Setting him upright takes just a moment. First pulling his shoulders to the middle of the mattress. Then aligning his legs with his shoulders.

A few minutes after crossing out from his room, passing the room again I see that he's – again – lopsided. In slow motion, flailing his arms and legs.

When a nurse attends to this resident a couple minutes later, she observes his catheter tube has become wedged under his thigh. She checks whether the catheter is still properly placed inside of him. Not an enviable beginning to the day for this man.

A few minutes later, I had a tray for him. On the tray was a small bowl of oatmeal and a tiny cup of brown sugar. He barely dips *just* the tip of his spoon into the brown sugar, applying that to his tongue. And then a half-spoonful-at-a-time eats the oatmeal before taking another small portion of brown sugar to his tongue. As he did this, he changed dramatically. From the man who had been flailing and lopsided; he was, it seemed to me, now in control.

I wondered later if this was because he had come to engage in something familiar. With two others, I have also noticed this. With one, it is when she is listening to Mendelssohn.

When she is listening to Mendelssohn, she talks more easily than when the room is silent, or when the younger visitors she has, have left on the television. Mendelssohn is her oatmeal and brown sugar.

For another resident, a cup of decaffeinated coffee in the afternoon brings out nearly another person. And time stands still.

17.

"Just rub the spoon along the lower lip," she says. "There's, like," she shrugs, "an instinct, to open the mouth when the lower lip is rubbed."

I walk back briskly to the room of a resident. A woman.

Her condition had me wondering what to do. "Say her name," a nurse told me. "Say her name; she looks like she's asleep but she's there."

Adding, "she's probably hungry."

I went back with that instruction. I said her name while close to the door to the room. No response. I went into the room, a few paces from the bed. I say her name. No response. I cross to her bed, standing a foot or so from her. I notice in her ear, a dull pink plastic blob. Is her hearing aid? I wonder. I say her name. No response.

What to do.

"Say her name, and rub her arm, as you say it," a nurse tells me. "She's probably hungry." It's breakfast time.

Again I say her name close to the bed. No response. I say her name now, while rubbing her arm. No response. I try once more. One of her eyes opens, partly, just for a second. Her breathing suddenly changes. It went from routine to short gasps. Sounding as though she were having difficulty. The term labored breathing comes to mind. I wonder if this is the Cheyne-Stokes pattern of breathing which has been described to me by one hospice worker as like a woman giving birth.

Unsure of whether to proceed with trying to feed her, this is when I was told about rubbing the spoon under her lower lip.

I try this, taking a spoon with a small portion of applesauce in it, to her lower lip. No response. I try with a spoonful of pureed pancakes. Again, no response. The coarse sound of exertion still accompanies her breathing.

Later I see the resident's bed flattened. I am told that what I saw was extreme exhaustion. The followup is asking a doctor if a low dose of oxygen is necessary.

18.

"The time I remember it really paid-off," she said, "is when a patient had his wife translating. I told him what his diagnosis was, she translated. I asked her, Does he *understand* the diagnosis? Because it was serious. The wife said" – imitating a dismissive tone – "yes." The woman telling this story, a medical student a few days from finishing her residency, cocked her head to the side, mimicking her own expression at the time. "Are you *sure* he understands? And the wife said" – imitating a tone more dismissive than before – "yes."

The student paused.

"I know ." she went on "that it's common for a person not to understand a serious diagnosis the first time they hear it." Another pause.

"I asked," she went on "Does he want chemotherapy as part of his treatment? And his wife said, No." She paused again in her story. "Something didn't feel right though. So I had a translator come in, to explain the options available.

"Well," she said, taking a deep breath, "as it turned-out, he *hadn't* understood his diagnosis. After using the translator, he actually chose to go on a clinical trial of a chemotherapy drug."

Other stories, similar to that of the medical student, followed from around the table. While treating a person who speaks a language other than your own, in a medical or social services context, there's a need for a translator. How does one fill this role?

In some cases family and friends offer to take on the role of translator. The positive to this, is the emotional support they can offer. The trouble can be that "if a family member is acting as a point person, and they don't like something they've heard," said one person at the table, "they may just decide not to tell the person."

A study of hospice residents in Melbourne found that of the over 100 participants in the survey, of those that didn't speak English, only a fraction reported that they understood their diagnosis. Compare that to English speaking residents, of which a vast majority reported that they understood their diagnosis. This study also found that amongst respondents who did not speak English, their reported pain level was *lower* than that of residents who did speak English. What accounts for this discrepancy?

Going around the table, listening to the stories from the nurses, PSW's, and doctors assembled, a few approaches to non-English speaking residents emerged. One PSW, for example, said that she tried to make up for the language deficit by spending longer attending to personal care. "Make something like a bed bath," she said, "the way of communicating with that person." A doctor at the table said that she tried to use a system of emoticons to allow a resident to communicate her level of pain.

The impression I got was that although the Language Link telephone service, which provides translation between medical staff and clients, is useful, for the most part, improvised methods that make the most of face-to-face communication are preferred. Many people at the table reported that a non-verbal language quickly develops between residents and caregivers, which takes the place of a verbal one.

19.

When I first met her, it was mid-morning. She was applying moisturizer to her arms and face. Before, with help, crossing to the restroom to brush her teeth.

Her skin now, as it was then, is supple.

It is as soft as dough. And hers has vaguely the same color as flour. And like paper – tissue paper, not the stuff the printed word appears on – her skin is delicate. It does not stretch like e dough. Her skin, when the slightest strain is applied, tears apart. The tears bleed.

This makes tending to one wound in particular, a scrape on one shin sustained not long before she was admitted to care, a challenge.

Conventionally, a scrape can be treated with a bandage. One changed every couple of days. Sometimes, I have noticed, that a wound will be dressed using clear plastic and tape, so that the healing can be monitored. I'm also under the impression that the latter method is more hygienic. Because there's no bacteria-trapping fabric touching the wound.

In this case, however, the skin is so prone to tearing and bleeding when the adhesive from old dressing is pulled off, that the nurses attending to her have to find a way of covering the healing scrape, while, figuring out a way to minimize the contact of adhesive with her skin.

After going around the room at a meeting, each caregiver pitching an idea, an experimental solution emerges. Apply netting to the skin. The netting will be wrapped around the affected portion of the skin, taped together, then bandages applied over-top the netting to soak-up blood were the scrape to begin bleeding again.

20.

The room was otherwise calm when the little dog began to growl.

"Maybe ghosts?"

A few people in the room nodded.

"Are there –"

"Oh *yeah*," the response was unequivocal. "I'm sure this place is haunted."

The little dog was still growling.

"From before?"

"No, no. Since," another person replied, softly.

"I'm sure it's haunted here. Sometimes, you'll just sense someone behind you in the hall. Or, in the elevator, you'll get the waft of the smell of someone there."

"Taps turn on."

"Taps turn on," nodded another.

"And I'm absolutely sure I can hear the sound of," she then used the name of a past resident "with his cane in the hallway."

The previous night three residents had passed away.

21.

"I don't want to die," she said to me as we sat out in the late morning sunshine. "I love life. I love this." she followed a bird hopping in the garden. "But I am ready to go. If that makes any sense." She propped one of her feet lazily on the oxygen canister in front of her.

Just a week before a computed tomography scan of her chest showed that a massive tumor was pressing on her aorta, in addition to several metastatic lumps – "mets" – on her lungs, tis resident was doing ballet twice a week. A friend had persuaded her to go to a doctor after she was coughing persistently in class. Less than a week after the tumor was discovered, she underwent what was described to her as emergency treatment.

"What I hate," she told me, her sentences often abruptly dipping in volume halfway, for shortness of breath. "Is when people come. And tell me about movies I should see that I will never see. Places they've been that I will never go to. And make it about them. A friend wrote me an email," she said, her tone, for the first time ever, suggesting irritation, "saying, I *want* to ask you about your diagnosis. But I'm sure you don't want to talk about *that*."

"No. No. Sometimes I *do* want to talk about my diagnosis. Sometimes I don't. It depends what type of day I'm having."

My own experiences talking with this resident suggest that, more than anything, it's the terms of discussion which count. When we talk about how far she can walk without using oxygen, for example, she's always delighted. She smiles. She tells me how much farther she can make it without feeling exertion. Refraining, "the oxygen man" – referring to the man who delivers her oxygen canisters – "told me I could *only* go to my," then refers to a place, like the door, "and I made it to," then refers to somewhere well beyond that, like the hallway. This resident has a cautious reverence for the oxygen man. Never pushing too far. Always testing the limits. When she is talking strictly of the tumor – "the big one," she calls it, which pushes on her aorta, and, she reports, seems to be shrinking – she is unerringly pragmatic. "It's still going to kill me," is one refrain. "It's definitely terminal. There's no cure" is another. She swiftly dismisses any possibility of lasting progress. And yet each day this resident seems to be getting better, albeit with some setbacks.

22.

I saw that the room was unusually spare. There was not even a glass for water on the table. He rubbed his belly, gently, when I asked if he wanted water. I thought this was an indication that he was hungry.

"I don't think he can eat," a nurse replied when I reported this for her opinion. "I would hold back on food until the family gets here.

"You can try bringing water," she said. "But it might hurt his tummy." She paused for a moment, to finish a task. "You saw that his stomach is dissented?"

I nodded. The man, his face perfectly round with silver hair on top, had a very large protruding mid-section.

"He has ascites," she continued. "So, he may not want to drink

anything."

The nurse was right. A glass of water that I set on the table, which the resident acknowledged with a wave and smile, as he spoke no English, sat there for the rest of the morning.

Days later, the one time I did see him drink, it was with a pained expression. As though he were pushing down one too many mouthfuls after a large dinner. And this was from just a few sips of water to accompany medicine. He seemed content. Laying on his back, watching television, or sleeping with the window open, his family nearby.

His family was grateful after his death, that the body – his mouth and skin – was thoroughly cleaned.

The cleaning took countless towels, because for reasons that are still unclear, though likely related to a bowel obstruction, just before death, this otherwise tranquil person began to violently vomit a foul smelling substance. About five minutes later, his pores began to emit the same substance. "Before, his skin was a yellow-ish color. I could tell after he passed away that it had changed color," a nurse recalled, quietly. "It was more of a darker, brownish color when we began to wipe down his skin." She said that after they had finished, the deceased looked so much better it was as though "you were looking at a different person."

The way the poison was expelled from the body of this resident, then wiped away, reminded me of a curse, lifting/ Revealing the true person, intact. The different person, as the one nurse put it, that emerged in the end, was, in fact, the man that the family knew best.

23.

A bed alarm is a device that fits onto a resident's mattress, When the resident moves significantly, suggesting that the person may be getting out of bed, an piercing tone begins.

After first thinking that a bed alarm is a bed that rings like an alarm clock, the device sounded just as odd. Authoritarian, really. A device which allows one person to remotely monitor another's movements. Particularly while the latter in bed. Where's the privacy and incumbent dignity if there's something like that in a resident's life?

The crucial thing that I was not told, is that this device only comes into use when two criteria are simultaneously met.

The first is that the resident is at risk for falling, because, say, muscle strength is diminished, or the person has lost a reliable sense of balance. The second is that the resident *forgets* that they have lost muscle strength or has unreliable balance. The latter criteria is key. Because while many residents have reduced strength, most of them are aware of this, and call a nurse or a PSW when attempting to leave the bed.

Attaching the device can be particularly challenging. Especially when a resident has a mattress perpetually inflating and releasing air – a design to minimize the risk of bedsores. Because the surface of such a mattress is constantly changing, the bed alarm has a tendency to slide around.

This is the case for one resident who is suffering from brain cancer. This means he will sleep for long, long periods, making the skin highly susceptible to sores, followed by bursts of relatively high energy. And also means that functions like memory and balance have been distorted. The resident is no longer reliably able to gauge what's safely possible.

In situations like this, where the nurses come together to improvise a solution, I am in the most awe of them. The solution is two-fold. First, to bring in some bandaging tape, and tape down the alarm so that it can't slide on the bed, causing it to misread the movement on the bed. The second is to bring in a one-way radio, and turn it on when the resident is sleeping, to serve as a back-up to the bed alarm.

24.

How is your arm?

She makes a face.

Does it hurt?

"Sometimes," she says. "It's like a knife sticking in" pointing just above her elbow. "My foot too," she says.

Is your foot also swollen?

She pushes off one of her sandals. The foot she has now exposed does not look nearly to the proportions of her arm. The sandal, in fact,

seemed to come off easily with a couple of nudges from her other foot.

I look down at the foot she now draws attention to, and say nothing.

"The whole right side of my body is no good," she says.

I know next to nothing of her case. Just that she speaks in a voice so big that, when she is on the telephone, it fills the hallway, waking other residents. It is, for me, a first. No other resident I have met has a voice anywhere comparable in size.

Is that what's called edema?

"Edema," says the doctor, gently correcting me, "is any swelling. In her case," referring to the resident with the swollen arm, "she had breast cancer. What happens in some cases of breast cancer is it spreads to the lymph system. You have lymph nodes in a few parts of your body, including your throat," says the doctor, indicating to the sides of her throat. "When you get sick they swell, and you can feel them. Swollen. Her cancer moved to affect the lymph nodes under her arm, and the body can't remove fluid that's in her arm."

Is it blocking the blood?

"No. It's not the blood in her arm. It's the fluid in her soft tissue. So, she wears that sleeve, you saw –"

I nod.

"That helps control the swelling, so her arm doesn't continue to get larger." The doctor was referring to a large dark pinkish bandage that the resident wears. The seam on it sticks out a bit, and because the bandage itself is nearly the same color as the resident's skin, at first I mistook the seam as a varicose vein. It looked as though her arm – maybe five or six times larger in width than her other arm. Like an over-filled hot water bottle.

Can you drain the fluid?

"Well, the trouble is, there's no one place where the fluid is. You couldn't take a needle and drain it, because the fluid is suffused into the tissue and muscle.

"But, we've ordered a special machine that will apply pressure up her arm, and milk the fluid away from it. It's not going to remove all the fluid," she added quickly. "But it should help to reduce the swelling and the pain that she feels."

Because, she says she is freezing, the bedclothes – three blankets and a quilt – are pulled right up to her chin.

"Are you ok, then?" a nurse asks.

"Yes," she says, alert, and, I can see, smiling.

"Okay then, have a good sleep."

I'm told by the nurse to check frequently on this room to make sure the resident has not gotten up out of bed. The balance of this resident is gone. Before exiting, rushing off to another room, the nurse calibrates a bed alarm.

I quickly find out the bed alarm is triggered once every few minutes. This due to the unusual surface of the mattress.

So, while it's not completely useless, if for every alarm the nurse came, there would have to be a nurse for only this resident. If, however, family or friends are not in the room with the resident, and a nurse or PSW is not there, the bed alarm must be on.

When I first check, the room is still. Sunlight pours in under a shade on the window. The resident appears to be asleep. "She has energy spikes," I'm told, in reference to the resident. "But she sleeps for most of the time. She's often asleep."

After ten minutes of returning again and again to the stillness, slowly, she begins to push the blankets up in the air, with her arms, and allows them to resettle around her head. Then she begins to bend her knees. Bbegins to kick. The covers slide apart from one another, and make dams of fabric along the bed rails.

After twenty minutes, the bedclothes are strewn apart. The bed has to be re-made. Again the covers are pulled right up to her chin the way she likes them. She smiles with satisfaction when tucked in like this.

"Are you ok, then?" a nurse asks.

"Yes," she says, smiling.

"Okay then, have a good sleep."

This routine is repeated again and again over the course of just a single afternoon. It has to do, I'm told, with the way she is very gradually succumbing to multiple tumors in her brain.

26.

"Back where I am from," she says, referring to the country by name,

"we would have already done palliative euthanasia."

A couple days before, her relative stopped taking food and water. "He had actually" – sharply pronouncing each syllable of the word actually, as with all longer words – "wanted to come to my country. My father, he decided to do palliative euthanasia in February of this year."

A pause.

What is palliative euthanasia?

"This is when there is a high dose of sleeping medication mixed with morphine," she says. "It takes about four hours to work.

"They say after the first hour, you can no longer talk or hear, and you are out of it." Today she is frustrated. Leaning in to tell me earlier, "in this country you give better treatment to *dogs* to die." The day before, the staff was saying that her relative was likely in his final hours. Now, with an unexpected improvement, he may have several days.

"I did research what the law is, whether," she refers to her relative by name, "can come to do palliative euthanasia. You have to be a resident of the country for six months before this is allowed. I said, He doesn't have six months before he will die."

She left to go outside to smoke.

27.

The day before, her husband was drifting the hall. He was not sure whether she was hungry. That morning, she had a few sips of orange juice.

Later that afternoon, her husband sat by the bed. The room quiet; light from the window.

Now, at night, she is up. The way her words come, is as a babble of sounds. Her watery blue eyes are open. The first time I have seen them open. She is gripping the forearm of a nurse tightly and twisting the skin.

Death without agitation is a vaguely reassuring phrase I have heard a couple of times at the hospice. But I had never felt up to asking what the term agitation in the phrase refers to. And, just as significant, whether it was a state of agitation that hastened the decline, or was the agitation the result of the body entering a particular type of

decline.

When I first heard the phrase, I thought it referred to a violent denial of the inevitable. I imagined a person writhing in bed saying, something melodramatic. But, those thoughts had long left my mind, and so the phrase didn't conjure much anymore.

On feeling the squeeze of this resident, her hands twisting the skin on my forearm, and resisting her attempts to pull my arm toward her mouth to bite it, only to have her grab my thumb to bend it backwards with a force that had me wincing, it occurred to me that this might be what the term agitation refers to.

Though neither I nor the nurse can diagnose what causes it, if I had to guess, it'd be a massive amount of pain. Because it's only after a dose of – something – is administered from a small device in a Velcro pouch by the bed, that the resident with the watery blue eyes stops trying to break my thumb.

What is that stuff, I ask the nurse, referring to the medicine.

"Hydrocodone. It's the next step above morphine. Above that is fentanyl. People worry about morphine. But it's nothing," she says in a dismissive tone, "compared to what some of the residents get here."

28.

He bounded up the stairs. And barely seemed to pause punching in the numbers to unlock the door, before slipping into the hallway, and back into the room where his lover once lay. The night before, that man died. Now, a canvas bag in hand, he came to collect a few things in the room.

Later that afternoon, I was asked by a nurse who had attended to the dead man's partner, how he looked on coming back to the room.

I said that he seemed okay.

"Yeah? Good," replied the nurse. "Y'know," she said, in the slow way she says things, "he said to me, that he" – referring to the man who had died – "died with a smile on his face."

I told her that that was a relief, as a relative had been agitating for palliative euthanasia.

"Yeah, yeah," she replied. "I know she said something like that." There was a small pause. "But each person, they have to go in their own time, y'know. She thought that that's what best. But each person

has to go in their own time."

I nodded.

Two of the primary fears that come with foreknowledge of death, that is, the diagnosis of a potentially life limiting illness, is that one is going to lose control, and that one is going to be in pain.

The combined fears, of loss of dignity and existential anguish – "a week in cancer pain can be like a month or two in pain for that person," I was once told – is what palliative euthanasia plays on. Advocates play on fears.

What if those fears were removed? What if it were a genuine possibility to move toward death without realizing either one of those fears? This is the argument, abstractly, for a hospice/ Each person deserves to go at their own time, and, implicitly, not give into the fears that illness may bring about.

On a practical level, the value of the hospice for me is that the man who died the night before was smiling just before he took his last breath. Does anyone smile when they agree to take a high dose of sleeping pills mixed with morphine?

29.

And just like they say you can taste the rain in the air before a cloud breaks, so too, there is something felt just before the last breath. All others in the room go quiet. And before another breath ought to come, there is a very still moment. A very long, still moment. Then there is nothing. The room suddenly feels cold.

The rain begins.

A small elderly woman by the bedside sobs loudly. The emergency call button is rung. And before long, a black stethoscope was brought to the room, to confirm that the heart was not beating.

One of his sons, a wiry man always in a sports jersey which gave off the stink of cigarette smoke, broke into tears. Just a few days before, I remember, he seemed so blasé, when he asked me to show him to the room Pops was in.

30.

When night begins to fall, there is a cacophony in some trees as birds settle. And so, at first, night is not at all quiet.

And just before the last bit of blue fades from the sky, the hospice fills with hushed tones as the sons and daughters of the residents talk in the halls.

Outside one room, I remember there as a priest.

He had been picked up from home across town. Rushed here by the son of a man who'd arrived that day. The latter man, insisting he wanted to get things over with, told his son to get a priest to deliver the last rites. As his father only spoke a slow musical dialect from the south of Italy, the son had to track down a priest who did too. The priest prepared to enter. The son still clutched his car keys.

Not far away, a wife and mother, with her two twenty-something sons, and their girlfriends, stood. In the room they stood outside, was the husband and father. He prefers sleeping sitting upright in a chair near the door. So the bed, I saw, was still perfectly made from the first day he arrived.

I had been called to this room to pass on a note to the nurse regarding sleeping pills. My guess, from experience, is that, at about any given time, about half the residents are actively dying. That is, declining rapidly, with, what's called breakthrough pain, and acute symptoms, like changes in respiration. The other residents are – outwardly – quite well.

For the latter group, there's usually enough time to experiment with sleeping medications. The goal is to allow for a full night's sleep without any side, they don't usually sleep much. At least not sleep as we commonly know it. Though total exhaustion seems more than likely – just trying to adjust in bed can lead to panting for air – the body seems to be so actively changing, that acute attention is required.

As I left that night, many still whispering in the hall to one another, and at one room, a person just arriving to say good night to his closest friend, I saw a few kids gathered in the front room of the hospice. They were watching television.

While their parents were inside, looking after their parents, the youngest children were watching cartoons.

31.

"And he showed some agitation with the sub cu injection," she said.
"But. That may have to do with his earlier life ..."

A pause.

"What do you mean?"

"His occupation," said the nurse.

"What did he do" asked a doctor at the table. "What was his occupation?"

A pause.

"He was a professional burglar," blurted another person at the table.

"Why didn't you *say so!*"

"I was trying to be obtuse about it, but," she sighs. "Yes," suddenly firm. "He *was* a professional burglar."

"He was one of the city's best burglars," added the blurter.

The doctor looked around.

"Was he ever caught?"

"Well, they didn't call him a professional for nothing," came a comment from far down the table.

"He was caught. But the stuff he was caught for was only minor."

"Anyway," said the nurse leading rounds, stoically. "Whst's important here, is when he was in jail, they did some testing on him. And I think it involved sub cu injections, because he won't have them. Can we do his hydromorphone sub lingually?"

32.

"The bumper," says the officer, "is blocking the sidewalk." I say to the officer, wait just a minute. And dash back in.

There's a parking guy out there, I say to a man in a black suit. He's about to write-up a ticket for you. He says the van's blocking the sidewalk.

The engine of the big black van starts. The wheels roll back into the drive.

They just wait, don't they, I say to the man in the black suit.

After she went, and before that black van came, I was told to take down a few wine glasses.

"This is no time to drink," says one man in the kitchen. He is pouring

a second glass. "A sunrise glow is okay," says the man. "But who *drinks* now?"

He and a few others, amongst them a giant man I met on many occasions, who'd sat in the room of a youngish woman who'd just succumbed to – well, it doesn't matter what, really – and was there that moment ten minutes after her last shot of hydromorphone, began what I can only describe as a sorting of who this youngish woman was.

"She believed in God," says another man. "But she wasn't much of an anything." A pause. "She was thrilled to find out her mother was Jewish" – "Her biological mother," interrupts another at the table. "Yes, her-biological-mother. But, y'know, it was superficial. She embraced it, superficially." "She knew the ceremonies," says another. "Yes, and – but, she was really open to everything. She believed in God I'd say though."

The others drink.

"If she held her hand up, a bird would land on it. And then, after a pause, "she had a hard streak, she *did*. And if she wanted you to do something, she wouldn't let go of it."

Hours and hours of this. There is no sugarcoating. There is little nostalgia. Talk and talk and more and more wine.

When the black van arrives, its nose pokes over onto one square of pavement. This means that a wheelchair has trouble passing. And this – "that man in the wheelchair couldn't get past without going on the road" – is what the traffic officer cites as he gets ready to ticket the vehicle.

After the man in the black suit moves the van back, he returns to the hallway. "This is the last chance to see her, if you want to go in," says the giant man.

From behind the door I hear an explosion of sobbing. Like nothing that came out before. Nothing at all like the nippy conversation before. Now it is deep heaving sobs. High pitched crying. One man comes out of the room gasping for air, dabbing his eyes.

The point when I had the most trouble, when I almost broke into tears, is when this youngish woman's friends began to stroke her hair, under the body bag.

"If I know" – then referring to the name of the woman in the blackbag – "I know her, she'd say, 'let's go! Let's see what's next!!!' And those

gathered broke into laughs, as the gurney was rolled in the rain, and into the black van.

33.

On gently taking off the dressing, at first it is like old eggs, breaking open. Like old rubber, burning. And as the nurse takes back more of the dressing, the miasma billows out of the milky goo leaking from a couple of holes in the chest of a resident. I stroke what is left of her hair. The plastic bag of goo, now free of its adhesive to her skin, plops into a garbage, and her gaping pink wounds are to the air. They look to me like wounds from a red-hot poker. I can't shake the feeling that she is burning away on the inside of her body.

What is the milky stuff?

"No one's sure," says the nurse. "It maybe old necrotic cancer cells, getting flushed out."

As holes are punctured into a plastic bag, to be taped over the wounds, the air has not yet cleared. The window is wide open. The air still has a pungency that hangs, and refuses, it seems, to be gotten used to.

I have heard that dogs sometimes sniff out cancer before it is diagnosed. That they rub at the spot where they smell the tumor, and won't give up sniffing at it. I wonder if this is what they smell.

34.

"See," said the nurse, her hands stretching a band of fabric. "We have to improvise. This is actually underwear that's been cut."

The band is to hold in place bandages, none of which can be adhered to the skin of this resident. I am told that her skin is breaking down. To my eyes, it looks like a deep scrape to which her skin is returning to unevenly. There are oases of whitish skin. They are small. And few. Much of the flesh, which is exposed, which humbles me to see, is a shade of pink. In some places, the flesh is bumpy and an angry crimson.

I learned to use the angry like that, from the nurses.

It looks to my untrained eyes like a rash/ As though poison ivy leaves were stuffed into the front of her nightgown.

To cover this weeping landscape of her body, a raft of bandages is

needed. A couple of the bandages are large and hyper absorbent. I'm told these are called abdominal pads or ab pads – "pass me an ab pad." Around the edge of the ab pads, the nurse tapes thinner fabric bandages, which she cuts to match the contours of the pink.

Before the stretchy band of fabric is brought back over the head and chest of this resident, a cream is applied to portions of the chest. And then the nurse asks me to help lean the resident forward. So that the same lotion can be applied to her back. The skin on her back is, I'm told, beginning to break down. Though the skin looks normal. That is, aside from a few blotches that look to me like pimples. When the lotion is on, then the band is put over her head. She wiggles into it with a sense of humor.

The band holds the raft of bandages in the proper place.

Breast cancer, never, at no point to me, evoked rough raw skin like that. Chapped. Almost bleeding.

I had heard of a mastectomy before, but I didn't know about this. But that really is just it. Sometimes cancer surgery is a brutal process of ripping one thing right out of the body.

I was very humbled.

35.

When she first tried to rouse him, she tugged on one of his toes. "Com'on now," she said. "Com'on now, let's go to bingo!" A pause. "Common, let's get off to bingo huh?" She looked down at his toes. "Boy you got curly toes! Are these the toes you walk on? Huh?" She paused. "March likka soldier, with your toes all curled up like that?" He went on sleeping.

It was long the habit of this resident to pace, I was told. The rugs in the home where he stayed had all been worn to threads. A visitor for the man, another visitor than the woman who'd been unable to rouse him with her toe tugging, told me that he used to pace for hours. All in the night. "He'd pace five miles. And he'd turn right on his heels, y'see. So right at the top of the stairs, that's where he'd turn, he'd worn a patch right through the rug. I says to him, you gotta nice place here, all 'cept for the rug and the burns on the floor." His friend took a moment before telling me of a tic that the man, sound asleep, his legs

tangled in his sheets as they often are – he has very restless legs – has. "He'd go like this with all his cigarettes. N' he was a chain smoker. Have one cigarette right after another – five small packs of cigarettes a day. One after 'nother. Before he finished one, he'd have another ready. Because he'd flick 'em, he had a tic. Nice house where he lived, all 'cept the rug and burns, I says. Because the floor was all burned."

Our gaze turned to the man for a few moments.

Bandages are taped over the back of the man's heels. Every few hours they have to be re-taped, because he hates them. He hates the bandages. He moans when they are put on. He rubs his ankles very firmly on the sheets. He hates the bandages. Were they to be left off though, the skin of his heels will break, due to pressure wounds. He *only* sleeps on his back, so there is always pressure on his heels. It always surprises me just how much damage the weight of the body on itself can do.

36.

That gurgle, and it happens again and again now, is the most visceral of sounds. To hear the stringy goop wobble in his throat is nearly to feel it in my own.

When I first passed his door, I thought the way he was breathing, as though a bicycle pump was furiously working up and down, up and down, up and down – the sheets rose and sank at a terrific speed – to fill a tire with a big hole in it, was the result of a vivid dream. He seemed so totally immersed in the experience of something else. And the gurgling, I thought, was just snoring. A bit of harmless congestion.

"When the body begins to shut down," a nurse told me, as the spouse of the sleeping man paced the hall, a hunched wreck, "it stops absorbing its own fluids as much. This is why you get this sound."

We were both quiet for a moment.

Later that afternoon, I pressed my ear frequently to the chest of another resident, as his breath was so faint and infrequent but all I could hear while listening for the air was gurgling from the room down the hall.

"This is why people often die of pneumonia when they're like this," the same nurse tells me, referring to the weak state of that resident. "The body stops absorbing fluid. In the lungs, this means that the lungs fill with fluid." Adding, quickly, "not right away, they don't fill up. But they gradually fill. And there's nowhere for the fluid to drain to."

37.

A uniform pink, the look of it strikes me as a good thing. Progress. No more dark scabs. No more glistening crimson. Pink, like a split salmon.

It takes a few moments to sink in that this color and texture, which seems so clean and simple, is not progress. The resident, who had a mastectomy as part of her treatment, is now dabbing a Kleenex at the middle of her chest, where the ribs meet, to soak up spontaneous bleeding. Though the wound has none of the variegated texture that scabs and a rash have – it is not better this way.

The nurse I am working with shakes her head gently after I catch her eyes when we apply lotion to her – the resident's – back. The hope is that the infection on her chest can be halted.

No one can determine what the infection is.

The next area for attention is this woman's legs. The coloring of them has been of concern to me all day, though I had no time to ask a nurse why they had gone from a whitish-brown to a deep yellowish brown.

"That's just the betadine."

Benzo-dine?

"Beta-dine. It's for cleaning," says the nurse. She applies a damp cloth. The skin returns to its original pigment.

Because the cancer moved to her lymph system, and, this led to swelling in her limbs, which was then controlled by compression, this woman's lower legs now contain much of the interstitial fluid pushed from her arms. The back of one has a roaring rash. Her calves also weep. They weep so much that she wets down cloths fastened around her calves and set under her feet.

38.

Frog's legs?

"Oh *yes*," she licked her lips. "They're my favorite. Can't get 'em no more.

"But I remember, I'd wake up Sunday morning, not wanna go out, and order up frogs legs to my house." Her gaze fell on the man in bed. She had his hand in hers.

"He'd phone up," she went on, "if we were travelling, to see where the best restaurant was in town, always to check to make sure they had 'em for me. He was really good to me. To my aunt too. Took us all over."

A pause.

What did he do, I ask.

"Oh, well ... He made lots of money," she said.

Was he a businessman?

"Oh no," she smiled. "He made it the naughty way."

What's that?

"He," she whispered, "was a safe cracker."

I allowed a pause.

"Never used guns or any of that stuff."

No, I can't imagine.

A pause.

So, was it like the movies; he'd dress up in black and sneak into banks?

"He never did it here. He'd go to another city – that's where he did his work. All across the states. But he never did it around here."

What a man.

"Oh he was. He'd get his hair cut every, day. And he'd get his shoes shined every, day. He'd always look immaculate. He even got hair plugs put when he was sixty-three."

Just to ...

"He was a ladies' man," she laughed. "That's for sure."

That's what the nurses tell me, too, I say.

And, again, our gaze fell on the man dying in bed.

39.

They had been talking to one another with the television on, when it happened. No one noticed at first. Because it was so routine for nothing to happen.

It wasn't until one of the sisters turned her gaze from the weather

forecast. "Wait – *shhh*," she shouts to her sister. "Quiet."
The five day forecast is muted.
"I don't hear it."
The call bell rings.
"Is she breathing?"
The yells begin.

They'd been sitting at that bedside for months.
"I have no answers," a doctor once told me. "I tell them I don't know what to expect, because I don't know how it's possible." He hesitated before adding, "but the body is built for redundancy. So much of what the body has is redundant in size, if you were to look at what the body needs to sustain life."
"We see something function at ten percent or less, and think that's bad. But really, it was the other ninety percent that was built-in redundancy. That ten percent maybe all that was ever needed."

The daughters, after awhile, took it for granted that she would keep on going/ And going. And in an unwatched moment, the woman they were there for took her last breath. They did not see it happen. Perhaps it was too undramatic for them.

40.

In training, again and again, we're told that when a person is dying in hospice that they can have whatever and do whatever they want. Though they, the words, do not change the larger forces in the universe, at least they offer a sense of power. And maybe in that power, a hint at hope.

By power, I mean this more in terms of the will. And the will is, to desire.

Desiring is, well, who knows? But it's not something that can be pointed to as a functioning thing in the body. Nor can hope.

And by hope, I mean the wording hints that a dying person is not going to be restricted nor preoccupied by the condition that they are in.

Is it fair then, to reword that statement. When a person is dying in hospice, they can desire whatever they want, regardless of their own condition.

It sounds too abstract to me. And it sounds too specific, too. Both at

the same time. And it misses something so obvious, which I failed to appreciate before. Here I was, thinking when I first heard this policy that there might be exotic or hedonistic consequences. When, really, the desires of a dying person are almost entirely related to their physical condition. Namely: pain. The desire is to get out of pain.

I say all this as context more than anything though. Because without it, it is hard to express the relief I feel when a resident wants to do something, which is not related to pain relief. Drink chocolate milk, for example. Wear pajamas in the dining room. Or, go to sit in the sun. Those modest desires, which genuinely seem to have less to do with satiating some need of the body than pure pleasure.

41.

When not the sufferer, it is easy to talk of pain. It does not register viscerally.

Symptoms that we don't know directly, are easiest to define I think. And this is because we don't know them directly.

The prosaic stuff though, the all-too-common sources of pain, those can be the tricky ones. There's something almost embarrassing that comes with it. Because when referring to the experience, it may as well be your own. Maybe this is why, in training, there was never a reference to what seems to be a common source of pain for people in hospice care. Constipation.

The language, of course, cannot be too casual. But there is also a need, just a natural human need, to convey sympathy for the condition while talking about it. Medical language seems too distant. The experience can neither be spoken of casually nor exotically. But something in between. The experience is not such an unusual one that one can't try for metaphors that work to describe their personal experience, and apply that to the pain of another.

One of the most memorable metaphors I heard was constipation as a boulder. And before the boulder comes tumbling out, little bits of it break off, giving a sense of a having to go. When – finally – the boulder comes out, the relief is huge. It doesn't take much imagination to appreciate why.

Perhaps ridiculous, but knowing that a person maybe suffering from a

boulder breaking up inside them is helpful. Knowing it is true of any person specifically is unnecessary. But knowing that, like say dementia, it's a possible factor to be considered when a person seems upset does help.

42.

Her face had an exhausted expression.

The night before, she had fallen, slipping on the stuff still running down from the back of one leg. A blister there had ruptured. And crossing to the toilet, she slipped on what was weeping from the sore.

Weeks later – walking again – a nurse tells me that this resident has let herself be taken by the cancer. I didn't know what this was to mean.

She stopped fighting it as much, I'm told.

I went in to her room to assist with bandage dressings.

For the first time I saw this resident actually lying in bed. The others there tell me that she has barely opened her eyes all day. Hiking back the sheet around her feet, pulling it back to just below her knees, I look up. Is she awake now?

Her eyes are shut.

The nurse and I raise her ankles on to pillows, preparing to unwrap the old dressings. There is a slight groan.

"Itz ok, itz ok," says another in the room.

She's not in pain, is she?

"No-no. You keep going, keep-going," says the other, returning to pacing.

Remarkably, the ankles – really, the skin all below the knees, on both the back and front of the leg – are now white. It used to be dark red. I can feel, what I think is wetness on the back of one. To confirm I remove my glove to touch. Another groan.

I take her hand, while telling the nurse that the leg is weeping. Its overall complexion is the best I have seen. When I cite this later, the nurse tells me that the legs had been gradually healing. But that that had no connection to the progression of the illness.

It occurred to me how caught up I had been in the external. The wounds. When, really, the way they healed was not related to the condition which brought her to hospice.

Halfway into re-applying dressings, the woman in bed begins to try to say something. It is far from clear. Then it seems she has increasing difficulty taking in air. As though in just that short period the internal had gotten worse. And, then on testing her oxygen saturation levels, it turned-out – yes – that it had.

Now, for the first time, the woman who I had never seen lying in bed, was going to be hooked-up to oxygen while flat on her back.

43.

Her hand so engorged, her palm totally smooth – shinny, and the lines that crisscross, mostly gone. I touched her hand; happening to rub mine over the spot on the hand where the thumb meets the palm. Usually tender, this spot is hard. Her eyes don't open when I touch her, or call her name after she had begun to groan.

I saw that her wrist, too, had got much larger.

The elastic bandaging she usually wears to control swelling, brought on by her illness, was gone. Her shoulders had swollen, too. To the touch, her skin is hot.

"When I was changing the dressing on her ..." A pause, as the nurse turns to figure-out whether she is going to refer to the left or right leg. "Her *left* leg," she says, "it was just – this."

Groaning.

Is it her leg then, I ask?

"We don't know," she says.

"When I moved her forward," says another nurse, called in to offer her observations. "She was like that when I made contact with her back."

More groaning. As she groans, I see her legs twitching.

I ask if the twitching is from the pain.

"No," says one nurse, "it's a side effect from the opiates. But," she adds, "she's not really retaining much," referring to the pain killers. "So much fluid is coming out of her skin. It's hard to know how much to give her."

On the woman's bed, there is a pouch with a device that has a few over-sized buttons. Every fifteen minutes or so a button on the device

can be pushed. Releasing more opiates in the suffering body.

There is talk of using more powerful drugs. I have seen delivery of these through the skin. Using patches. In the case of one man, for example, the patches were set on the upper thighs, with a bias toward the inside. Were such drugs used here, however it is unlikely a patch would work because of the condition of the skin.

To my touch, her hot, taunt skin feels under tremendous pressure; pressing from inside-out.

44.

"When he coughs too much," says the nurse, reporting her observations from the shift, "this is what happens. His *stomach* comes out," indicating a bulge with her hand.

"It's like nothing I have seen before," adds another, softly.

"Just sort of, it pops out," exclaims the first.

"Like this," indicates the other.

There is a pause.

"And I think it's rotting," the volume of the reporting nurse, falling, "like the *tip* of it, the tip of it is very red – it's definitely necrotic. It doesn't have the soft pinkish look of healthy tissue."

There is a pause.

"And then," says the nurse, "it just goes back in on its own after a few minutes."

That afternoon, a coughing from a resident. I run to the room.

Before long, I am across from a nurse, as we stand on either side of the man's bed. He wants to eat, he says. He needs to take medicine, what's conversationally referred to as a cocktail.

Some nurses are better at concocting cocktails than others. This cocktail is a mixture of something called hedanol, which is a drug name I hear often, a sleeping pill, and something for the cough. Before those are given though, the colostomy bag on the man's side has to be emptied into a plastic tray.

The bag is, to my surprise, small and narrow. My expectation was something like the plastic bags used to collect urine, which are wide and flat. The bile inside the bag is – for lack of a better term – fully

formed. The body still can squeeze it through the intestines. Our task is to open the end of the bag, and gently, with the thumbs and forefingers, move the bile from the bag into the plastic tray.

When the end is opened, the smell, at first, makes my knees weak. I begin gasping. A nurse gives me a look of concern. I say I'm fine. I look over at the resident. His eyes have rolled back. His jaw hangs open. The nurse asks me to open the window.

After the tray is flushed, the nurse rolls up the end of the bag. She tucks it into his briefs. He is very hungry after the process.