

Last Dance

By Ellen LaPointe

Prologue

In our last year we danced. An intimate dance, choreographed delicately. Small moves, subtle cues. It was a dance of speaking and not speaking, holding but not clinging, preparing but not pushing, hoping but not fooling ourselves.

The dance of our last year was frozen in time even as it blurred and melted into itself, and then inevitably and irrepressibly slipped through our grasp.

It was a year of coming as close together as we could in order to say goodbye.

July 2006

Our last year begins in California. You arrive on the first day of July. The moment I see you I know things are very wrong. Your skin is like tissue. Your muscles seem to have melted. Sores expose your insides to the air. And I can see from the gaps in the light in your eyes that you are hurting from a deep place. But I say nothing about this. Instead I pull you into an embrace and breathe in the sweet smell of your skin. Your smile comes big now. *Hello!* we say together. And then you say *This trip is going to be so short!* The first thing out of your mouth, every time.

We laugh. I am reminded again that your body and your spirit don't match. Our visit has officially begun.

Rheumatoid arthritis. An insidious, insulting affliction in which the body eats itself alive. Inflammation. Sharp pain. Fatigue. Depression. And all the while, the body slowly replaces its own synovial tissue and tendons with a thick tangle of fibrous, calcified cords that knot

into frozen, grotesque sculptures. Invisible to the world at first, then slowly more revealed, until one day you are painted brightly with the shameful labeling of distorted joints, halting gait, and mottled skin.

And that's just part of the story. The drugs - that abate the swelling, that tamp the debilitating bonfires of pain that conflagrate you without warning, that hack bluntly at the army of cells that have been brainwashed to kill their own - are themselves a poisoning. A toxic river flowing through you, ravaging the shores of healthy cells through which they pass on their way to battle, slowly rendering everything inside a sickened sludge.

You are sixty-two now, and have lived in this prison of pain and self-destruction since you were twenty-five. And now it seems we are beginning to move into a new stage. Turns out we could call this phase of your illness "penultimate," but we don't know that on this first day of the last week you will ever spend with us in California.

We try to have a normal visit, but it is not. For the first time, you do not cook meals while I am away at work. This is in stark contrast to past visits, when I would return home at the end of the day to find the house infused with the dinner smells of my childhood: stuffed cabbage, homemade meat sauce, chicken stew – and you in the kitchen with the apron you had brought from home, humming while you set the table. It appears that will not be happening again.

Each night I help you change the dressing on a pernicious, two-inch black and red-stained sore on your shin. You tell me you've had it since the spring. I take you to church down the street; drive you right up to the door and then help you make your way up the stairs (nine of them!) so you can go pray. I wonder what you are praying for these days, but I don't ask.

Watching you during this visit brings a new sensation: electric jolts shocking my chest, sparked by terror. I am terrified we are suddenly on a path that is leading us inexorably to merciless suffering, boundless sorrow, and our goodbye. Leading "us." Somewhere during your California visit in our last year "you" and "I" become an "us" as never before. When I put you on a plane at the end of the week I know I will see you again soon. I don't say this out loud, but I am sure of it on the inside. *Don't worry Mama, I think. This will be a together journey.*

October 2006

The first call.

I have cirrhosis. The doctor says I have to stop taking my arthritis drugs..

I know you are capable of processing your own medical information, but this seems like way too general a statement to be true. Later that afternoon I place a call myself.

What's happening? I ask your doctor.

Her liver is severely damaged. The drugs she takes to slow her arthritis progression and keep symptoms in check are liver-toxic, and they have finally taken their toll. The consequences of taking the drugs now outweigh the benefits.

So what is the next course of treatment? I ask.

There is none, he says.

I pause to take that in for a moment. I am suddenly breathless.

I push. *What about all of the new biotherapeutics?*

I am afraid not. His voice is gentle. *She is too advanced and many of the new compounds are also liver-toxic. There simply are no more drugs for her to take.*

I pause again, longer this time. *Thank you,* is all I say. But he is not finished.

I care a lot about your mother. I am so sorry it is coming to this. This is so hard. I am sorry. I am moved by his emotion, but I end the call so he can stop apologizing.

So there it is. The calamitous, mercenary drugs that also save you will no longer be there to stave off the insistent, debris-infested tsunami that is your arthritis. And your doctor, who has been by your side for over twenty years, has just bowed out of the fight as well.

This is a point of no return.

Your feet are your tormenters. The arteries responsible for carrying blood to your feet barely function; the walls are corroded to the point where they are now collapsing on themselves.

As a result, your lower legs and feet are no longer receiving what they need to live. They are cold to the touch. Their red-purple surfaces are dappled with sores that no longer heal. And the pain in them upends you. The paradox of our days is that we spend much of our energy making sure blankets and sheets never touch you, as the fabric itself can cause your

disintegrated, molecule- thin skin to burst open and form sores that may never heal. So the cold never stops. (Dying flesh can never be warmed anyway.)

We visit your surgeon. He's been in your body more times than a lover: re-tethering and fusing and replacing the parts of you (three toes, two shoulders, a wrist, four knuckles on your left hand, a thumb) that, in a perverse rheumatoid way, have dropped off the edge of the disassembly line your immune system has become.

On this day he says what we know to be true (me from what my eyes tell me, you from the wholesale, relentless sensory squall that swirls through you): you need surgery. Femoral Artery Bypass surgery, to be exact.

I look over at you. Your gaze is fixed on a vague spot in the room.

How big a deal is this procedure? I ask.

This is not a procedure. It's major surgery. We make an incision along the inside of her thigh to about her knee and graft a porcine (a medically obfuscating word for pig) artery at your hip and knee.

Why isn't he talking to you?

How painful?

Quite. Pain management is a major part of the early recovery process. What are the risks?

Oh you know, the usual for this kind of thing. Cardiac arrhythmia, hemorrhage, sepsis, edema, thrombosis, pulmonary edema, restenosis, graft occlusion, cerebral vascular accident. The usual. To his yes-these-are-big-scary-words-I'm-not-telling-you-what-they-mean-that'll-teach-you-not-to-ask-questions list of risks I silently add several of my own: [Catachysm](#). [Diaschiasis](#). [Perfidy](#). [Misery](#). [Annihilation](#). [Catastrophe](#). [Wreckage](#). [Vanquishment](#). [Fucked](#).

The usual.

He is still looking at me.

Will this fix the circulation problem?

It's the only chance for that to happen. But with your mother the improvement is only going to be incremental. She will need months of rehabilitation. Also the fail rate is 50 per cent. And of course the surgery itself could kill her.

Again I look over at you. Your eyes are still focused on a floating, mid-air space. Your mouth pulls into a thin, small line.

I finally give up on any pretense that you are part of this discussion.

So what happens if she doesn't do this? She'll lose her legs.

Oh my fuck.

When?

Can't say. Could be a year from now, could be next week. Depends on when that blood finally stops moving. By the looks of things, that's coming up quick. And in that case we'll be doing an emergency amputation. So much trauma to the body in it's unlikely she'd survive.

I stand. For the briefest moment I tower over him. Imagine driving him through the floor using my fist as a hammer.

Oh one more thing, he adds as he stands, unfolding his tall frame to its full height. He looks down at me. *She needs this on both legs. We'll only be able to do one at a time, so we really need to get moving.*

Get moving. He actually said that. No expression of irony on his face. No expression at all, in fact. He seems not to have a shred of feeling about this, nor does he acknowledge that we might. But then I find myself forgiving him, imagining (as if this matters) that he must deliver bad news like this a lot in his work. Also I want him to like us, because he has the knives. I thank him and tell him we'll talk it over. He admonishes us to decide soon so you can "get on his calendar." Like he has invited you to lunch or something.

We bundle up against the bitter January cold. Say nothing as we slowly navigate the long walk to the parking lot. Inside the car you fall asleep immediately. This time I know it's not the drugs that are taking you there. I'd seek refuge in sleep too if I could. I remove my right glove and burrow my fingers under the soft hair at the base of your warm neck. Drive all the way home using only my left hand.

Two weeks later we are in Boston. I have been able to get us a squeezed-in appointment for a second opinion with a surgeon at the Lahey Clinic. When I tell you this you say you are grateful. *Grateful. Lucky.* I try to breathe these words in, but they are stopped short at the dam of dread and helplessness that clogs my throat. Only one of us is graceful right now.

We are sent to a waiting area that is also for plastic surgery consults. The intake person looks at you and then at me and asks me what time my appointment is scheduled. Your laugh comes first: sudden and high and sweet, a loud surprise bursting out of your small body.

Then I am laughing too, and we can't stop. People stare. In that moment I revel in your smiling eyes that I have not seen in months.

No more laughing when it's time to go in. We are again silent and stiff as we are ushered into a small room where we will meet with the doctor.

A man opens the door. The doctor. He looks at you. *Hello. I am Michael. You must be Gilda. So nice to meet you.* He extends his hand in greeting. You push your arm out stiffly into the middle space and he grasps your crackled hand in both of his.

Hello I say. *I am Gilda's daughter. We brought her charts.* I thrust the heavy, suddenly-disheveled-seeming pile in his direction. But he just smiles at me briefly and then turns his attention back to you. *Where shall I put these?* I ask. He shakes his head gently. *I'll review those later,* he says, still looking at you. *Now let's have a look at those legs.*

For the next several minutes he touches your legs and feet, asking you a series of quiet questions as he does. I can barely hear him. I fade to the edge of the room and sink onto a stool. I see that the edges of your body are softening, and your eyes are looking open and wide at his face. I recognize your look is one of trust, which I rarely see in your face. Now the gratitude is here for me, washing through my body and pushing up into my throat. I turn my head to the wall as the low murmur of your voices becomes a song for my tears.

He never does look at the papers, or the pictures, or the charts, or the files. No need, it seems. *I agree with your surgeon* he tells you. *Without these surgeries you will lose your legs. You need to do this, and soon. I am sorry.*

We have learned two essential things today: there is no way around this for you but through, and even the nicest of messengers cannot change the message.

The night before the surgery I slip the big stuff in interstitially. *Mama?* I ask during dinner. *What should we do if (I don't say "when") you can't make medical decisions for yourself?*

You put down your fork and look up to meet me eyes. I hope my face looks calm, and like this is routine dinner conversation happening at countless tables just like this one.

Do what you think is best.

I pick up the salt and shake it over my plate, appearing to concentrate. *How we will know if (not when) it's time to let you go?*

I don't see your face because I can't look up.

If there is no hope I want to go.

I pick up my fork and look at you again. You are right there with me.

What should we play at your funeral?

Ave Maria. I am the Bread of Life. And whatever else you like.

Later I ask you whether we should have an open casket viewing and where we should bury you. With this you come over to me and wrap your arms around me. I rest my head on you, facing inward. Your skin has the sweet smell I remember from when I was little.

Are you scared, I ask into your neck.

Oh Ellie I am scared, you say. I don't want to die. And then, into the room with air that is sorrow-heavy you offer this: *I am so grateful, Ellie. I am one of the luckiest people I know to have you.*

We have just spoken about the when of you being gone and you are choosing gratitude in this moment. You are an absolute miracle.

We leave for the hospital in the cold, pre-dawn, black dark. We have little to say in this indescribably dreadful and uncertain moment, and so we are quiet.

Everything moves very quickly once we arrive. It feels like only seconds before they have you gowned and gurneyed. The nurse comes into the small space where we are waiting.

Her hands are instantly busy with purpose.

I'll give you something now to help you relax. Then we will go in.

She readies the medication as she speaks, and then pushes it into your veins. Your eyes soften; your eyelids go low. Suddenly I am frantic to say everything.

I love you, Mama. I am right here. You are going to be OK.

Your eyes are closed. I fall silent. I move aside so the nurse can wheel you away.

I sit in this place where you just were until someone gently touches my arm and suggests I find a more comfortable place to wait. As if there is a comfortable place to wait to learn whether my mother will live through the day.

The surgery was successful.

I jerk my head up. Mid-afternoon light. Your surgeon looms over me.

She made it through fine.

Where is she?

In recovery. She'll be there awhile and then they'll take her up to a med-surg. unit.

Is she OK?

There were no surprises. The rest is up to her.

Up to you. Like, if you just practice your piano enough now the recital will be a success. And if you don't, well, don't even think about blaming the teacher when it all goes south on the stage in front of God and everyone.

Pretty sure that's what he just said.

I am astonished by the force of my momentary hatred of the man who has saved your legs.

The next day is one of the longest of my life. The pain you were experiencing before - that you once thought was the most excruciating you would ever have to bear - has been supplanted by a pummeling, pulverizing horror current that sucks your breath away as it courses along the electric rail incision carved along the entire length of your inner thigh. The tears move in a near constant stream down your cheeks.

All I can do is witness. The nurses give me wide berth. They don't ask me to leave when visiting hours end. Late in the evening one of them rolls a cot in. She makes the bed silently and rests a hand on my arm before she departs. I am overcome with gratitude by her generosity. And then I see it: she too is a daughter. All of us women here are daughters, witnesses to each other.

June 19.

I am home again and so are you. My cell phone rings while I am driving to work. I recognize the hospital phone number in Portland. I signal to get into the right lane so I can pull over.

Hello?

I am at the hospital Ellie.

What happened?

I had terrible stomach pain last night and they called the ambulance. It's the bleeding again.

How is your pain now?

Which pain?

Your stomach.

Better. But they want me to have an endoscopy later.

OK. *Well hopefully you'll be out later today or tomorrow. I'll try you later this afternoon, OK?*

OK, Ellie. *Talk to you then.*

I put the car in drive and ease back onto the highway. Here we go again.

June 24.

I fly to Toronto for business. I land at 7pm after a four-hour flight and turn on my phone.

There are seven voice mails.

Ellen call the hospital please. It's important.

Ellen, please call as soon as you land.

Ellen you should get here soon if you can.

(click)

(click)

(click)

(click)

I race to the ticket counter.

I need to get to Portland Maine tonight.

I am sorry, Ma'am. No flights until tomorrow.

Please. My mother is dying...

These words reach over the counter and pull up the chin of the agent. Her eyes meet mine.

She nods and looks at her screen again.

Only flight to the States tonight is to Newark in an hour. Gets in at 10pm. One seat left. You want it?

Yes.

I land in Newark. Rent a car. Am on the highway headed north by 11pm.

The phone rings at 2am.

She can't breathe. They are intubating her.

We are losing you.

I scream.

And cry.

And pray.

And beat my hands on the steering wheel.

I drive as fast as I can to you, through this impossibly dark, terrifying, most-alone-ever night of my life.

June 25.

All of your family comes. Goodbyes are said. We believe we will lose you at any moment. And then – most amazingly – we don't. You have stabilized again, they tell us. This strikes me as an extraordinary fabrication, given that you are only breathing because there is technology pushing air into and out of you.

Sometime that evening they tell us they are transferring you to the Intensive Care Unit. They wheel you quickly down the hall and we hurry behind, plastic hospital bags filled with your belongings banging against my legs. It is hard to imagine you will ever need anything in them ever again.

June 26.

You are continuously unconscious. There is a tube coming out of you that drains your stomach contents. One of the jobs of the nurses is to take note of the color, consistency, and volume of the brackish, thick substance that drips steadily into the clear plastic container that hangs next to your head. Remarkable really – this would be wretched, unspeakable to behold in any other context, But here – inside our ICU vault – it is utterly normal. Comforting, even. One more way to measure direction. A “benchmark.”

A catheter tube dangles below your hospital gown, snaking down the side of the bed in a surprisingly-elegant *sin* curve. It ends in a plastic container with black lines and numbers on the side of it. The liquid accumulating there combines with these numbers and lines to provide clues to your inner-workings. As long as it continues to drip, the doctors are satisfied. I sometimes watch it for several minutes on end, willing another drip offering to spill into this amber pool that represents your life.

I sleep beside you, watching a machine expand your lungs in the half-dark. I devour other signs of life – the warmth of your skin, the rhythm of the breathing machine, the numbers that mark your heart rate and blood pressure, the urine that drips slowly into a bag, the faint pulse of the little veins on your face and neck.

July 1.

The nurse and I are chatting about our kids. She is looking at the accoutrements that protrude from your body. Her face darkens as she picks up something near your abdomen. The hair on the back of my neck awakens.

What is it?

She holds up the container. There is a two-inch deep pile of black sludge on the bottom.

That's abdominal blood. I need to call the doctors.

A resident arrives. Carlene shows him the sludge.

This is obviously not good, he says right into my eyes.

Thank God the doctor's here. How else would we have known this?

What will you do? I ask.

Nothing now, he says. *We'll see whether or not the abdominal blood continues to accumulate.*

And if it doesn't stop?

She will need surgery if it keeps up this way.

I nod.

I don't know if she can survive another surgery. Let's hope we don't get there. He turns and walks out of the room.

I look at you for a moment and feel a settling in my chest. It makes me heavier and lighter all at the same time. I leave you and locate the doctor in the hall.

Can I talk to you?

Sure.

It's time to create a Do Not Reecessitate order for my mother. How do I do that?

He looks at me for a moment and then fishes a form out of a desk drawer.

Fill this in and sign it. Give it to one of the nurses when you are done.

OK you probably won't answer this question but I am going to ask you anyway. Is this what you would do if it was your mother?

He doesn't hesitate. *Absolutely.*

Thank you for that.

He nods and turns to his charts.

I fill out the form and bring it over to the nurse. She takes it without a word, but squeezes my arm.

We are now through the second-to-last gate on this goodbye road we are on.

I return to the room. Move to your side and try to absorb the feeling and smell of your skin into my own hands. I stay there for the rest of the day.

Our good friend Elaine has come to see you. Elaine is our former neighbor; she has become a hospice minister in her second career. She is an angel. She whispers to you and I give thanks for the words she is providing us:

It's OK, Gilda.

It's OK, Mama.

They have what they need.

We have what we need.

They'll be OK.

We'll be OK.

It's OK for you to go.

It's OK for you to go. (*Please don't leave me Mama!*)

July 3. (9:00am)

We talk with your personal doctor. We trust her, and know you do too. And we know she adores you. She tells us there is no more hope. We review your advance directive together and it becomes clear what we must do. So that's what we will do tonight.

July 3. (10:00am)

We return to your room. Tell the nurse what we have decided. She nods, squeezes my arm, and leaves.

And then it happens. After nine days of unconsciousness, you open your eyes and smile.

Mama you are awake and you are smiling! You are silent, of course – the tube in your throat renders you voiceless – but the look on your face is peaceful and open and even a little happy.

Here is what your eyes tell me:

I am ready.

It is time.

You are doing the right thing.

Don't be afraid.

I love you.

You stay awake and smiling for nearly two hours. During this time Father Paul comes from your church to give you Last Rites. You look into his eyes as he recites the prayers that have given you solace your whole life. He leaves. We look at each other some more. And then your eyes drift closed.

This may be the single biggest gift you have given me since you gave me life.

July 3. (12:45pm)

I am sitting next to you. You are sleeping. The day is cool and brilliantly sunny. This room is quiet and comfortable. It's been our home for nine days. I say the same thing over and over and over:

It's OK for you to go now, Mama. We have what we need. We'll be OK.

July 3. (7:00pm)

Michael and I gather near you. The sweet nurse called Delina sedates you deeply. I touch your legs. And then one of the nurses removes the tube from your throat.

It's done.

It's OK for you to go now, Mama. We have what we need. We'll be OK.

Now we will sit with you and wait.

Delina turns off the respirator and monitors. This surprises me at first; then I realize they are no longer necessary.

You continue to breathe quietly.

Delina tells us you may linger for several minutes, hours, or even longer. She turns the lights down and leaves the room. For the first time in nine days she closes the door. I settle in next to you, touching your arm. All is quiet.

July 4. (1:00am)

I jolt awake. Can't believe I dozed off during this impossible time. Your body is motionless. Your breathing is slow and raspy. You are still here. The world is gone. All there is is us here now.

July 4, 2007. (5:30am)

The nurse's hands are on you when your heart stops. "I think she just passed," she says. I sit up and peer into her eyes in this unfathomable, never-again moment of my life.

In the months of despair and the final agonizing days leading up to your death I had a lot of time to think about what it would be like to lose you. Never once did I anticipate what actually happened in those initial moments after your heart stopped, which was that my body welled up with gratitude. For the clarity you gave us at the end, for the opportunity to see your eyes and your smile a final time (!) for the privilege of being by your side during your final hours, and for the grace and peace of your passing.

Later that morning a doctor walks tentatively into the room. She is small and young, her red hair pulled away from her face with barrettes. She will be the one to make it official that you are gone. I would never have predicted that this is what omnipotence looks like.

We face each other on either side of your body. She is gentle, placing the stethoscope against your chest bones for a moment. Looking at your face. Turning on the monitors one last time, as if it might somehow be possible that they could still be bouncing and beeping with the rhythms of your living heart.

And then a stunning moment of candor: *I don't know what to list as the cause of death*, she says to me.

My momentary surprise is quickly replaced by compassion, and then with authority. *You should write that complications from rheumatoid arthritis killed her*, I tell the young doctor. *Because it did*. She says nothing, nods her head. (Weeks later I see that the certificate of death says you died of heart failure. An image of that young redheaded doctor flashes. *Well, yes, doctor. Isn't that what kills us all?*)

The moment before I leave this room for the last time is absurd. Once I am gone from this room I will never lay eyes on your face again. I will never smell you. I will never feel your skin. You will be gone from my life. How to come to terms with that? How to make my legs move? How to cope with this, the ultimate parting? How in the fuck am I supposed to leave you?

An endless, instantaneous moment as I gaze at you for the last time. And then, somehow, I manage to leave the room. But I back out, keeping my eyes on you until you are gone.

Ellen LaPointe is a Maine native and current Californian who works in the health care sector. In addition to narrative nonfiction, she also writes short fiction and poetry.