Hallowed Eve

A short story

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The cradle rocks above an abyss, and common sense tells us that our existence is but a brief crack of light between two eternities of darkness.

— VLADIMIR NABOKOV

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INTRODUCTION

This story was originally a chapter in my novel *Montpelier Tomorrow*. The novel is about a middle-aged mom—Colleen Gallagher—who expects to have a decade to do all the creative things she's always wanted to do. Colleen lives in Evanston, Illinois, and in her "real life," she teaches kindergarten.

Instead of having a decade of time for herself, she must take a leave from her job and move back to Washington, DC to help her daughter Sandy and her son-in-law Tony, a young man stricken with ALS, also known as Lou Gehrig's disease.

As so often happens in novels, this chapter had to be sacrificed in order to get the novel down to a manageable length. However, it has always been one of my viii Introduction

favorite pieces of writing because it provides a poignant snapshot of the relationship between the caregivers and the dying man. I hope you enjoy it.

> Marylee MacDonald Tempe, Arizona

If you'd like to read the novel in its entirety, click on the image of the book cover, and choose your favorite online bookstore. "An affecting, deeply honest novel; at the same time, a lacerating indictment of our modern health care system."—KIRKUS REVIEWS

MONTPELIER TOMORROW

A Novel

Marylee MacDonald

HALLOWED EVE

Next to a plastic pumpkin filled with candy sat a jacko'-lantern the boy in the house had carved. It was dusk, but the early trick-or-treaters hadn't yet ventured up the zigzagging wooden wheelchair ramp.

With the slate-roofed facades and postage-stamp lawns, the neighborhood resembled an English village, the sort of place where neighbors could hear each other through the walls and where my daughter had anticipated block parties and babysitting coops. That was why my daughter had bought in, never imagining that Tony's diagnosis would put an end to her hopes and dreams.

I lived upstairs, and we were all on top of each other. ALS—Lou Gehrig's disease—had consigned my son-inlaw Tony to the main floor. The new room addition at the back of the house had a handicapped bath, but the room itself felt cramped—barely enough space for a trundle bed, computer table, and Tony's wheelchair. Tony—with his basset hound eyes and withered hands—spent the day at his computer, coming into the dining room for meals, five or six hours of small bites and careful swallowing, for which I had to be on hand. This was why I had moved back here. Tony could not feed himself or do much of anything else.

What I wanted on this particular night—Halloween—was simply an hour alone, an hour when I did not have to slap him on the back to dislodge a bit of food, an hour when I did not have to lift him onto the toilet or brush his teeth or cook dinner or give the children a bath. One hour. Was that too much to ask?

If Sandy was so eager to take the kids, well, let her. I wanted to stay home. Tony and I could sit on the porch and pass out candy. If trick-or-treaters saw two adults calling out admiring comments about their costumes, then maybe they would brave the scary wheelchair ramp. Tony would feel included in the festivities, and it would be a lot easier to care for him at home than to haul his ass over to the party.

Was I feeling a little burnt out? Rhetorical question. Of course, I was. But it wasn't just that.

I knew the house where the party was being held. We'd never get Tony's wheelchair up the stairs. Plus, there'd be a bunch of screaming kids on sugar highs—that's what I foresaw.

"Do you enjoy parties like this?" I asked my son-in-law.

"The coop's party is the highlight of the year," he said, looking away from his computer.

I was sitting with my legs crossed on his bed. Where I often sat. You could never tell when he'd choke on his own saliva. Tonight, his breathing sounded clear.

"I enjoy any party," Tony said, "but this one in particular."

"Not to be a wet blanket," I said, "but isn't it hard for you to talk to people in a crowd? If there's a lot of conversation, it's going to be loud, and no one will be able to understand you."

"I know," he said. "But you can translate. This is the last Halloween I'll be alive."

I groaned and covered my face. A lead weight settled on my shoulders.

Tony's life had become a series of lasts. He was dying, sure, but not very fast. The ordeal of caring for him sixteen hours a day ground on and on. My life had become all about caring for a dying man—who wasn't even my son, for heaven's sakes. And, now, it looked

like I couldn't even wriggle out of my responsibilities for an hour.

"You know I love kids," I said, "or else I wouldn't have taught kindergarten for thirty years, but it's hard to step back into the chaos of young children who are gobbling down trick-or-treat candy."

"Don't go then," Tony said.

"That's not what I meant," I said, although, of course, I did mean exactly that, but I wasn't just talking about him letting me off the hook. "You go through a phase in your life when this stuff is important, the young married stuff and young parent stuff, and then you get beyond it, and it's hard to go back."

"I don't want you to do anything you don't want," he said.

"If I didn't want to, I wouldn't go," I said, which was somewhat true, although lately I'd been doing a lot of things I didn't particularly want to do. However, my daughter Sandy could not manage this event without me. And, as Tony said, this might very well be his last Halloween so, of course, my daughter would go, if only for a chance to connect with the other neighborhood parents. If she went, I should go, too.

And yet, to be honest, when I moved back here to help, I hadn't reckoned with the part of me that hated doing anything with the word "should" attached. The word "should" brought with it guilt and martyrdom, and I did not want to head down that path. Everyone in life feels coerced at some time or another. A therapist once told me, Either change your situation or reframe your response. Okay, maybe it was time to chuck my aversion to the "shoulds."

I'd go, and no more kvetching or second-guessing.



At five, Sandy came home to dress Ben—sixteen months; walking but not yet talking—in the costume his other grandmother had sent down: a miniature Yankee's uniform, complete with baseball cap hooked under his chin by an elastic band. Snapped into his Yankee pinstripes and already in his stroller, he held a blue, rubber bat.

It was my job to get Tony ready. I pulled Bermuda shorts over his running shorts, put on a clean shirt and threaded one crooked arm at a time through his sleeves. Then I found his Birkenstocks and pushed them onto his bloated feet, brushed his teeth, gave his chin a quick scrape with the razor, buckled his seatbelt, located his glasses, and gathered up the wheelchair's footrests from the van.

We were on the move at last, with four-year-old Josh

walking hand in hand with his mother, a lawyer who'd taken to dabbing cover-stick beneath her eyes.

Tony motored forward, taking a route where the sidewalk's corners had wheelchair inclines, and baby Ben sat in his stroller, jabbering, "Doodle-o, doodle-o, doodle-o."

One more child-centered event. One more night of chaos. At least with teaching, I could go home at the end of the day and put my feet up. But who knew when I could ever return to my so called normal life?

For the past ten months, I'd had so little time to myself that my own life felt eclipsed, snuffed out by the needs of the family, and as I approached the party house, I felt as if I were standing ten feet apart from the tall, gray-haired grandma pushing the stroller.

The thud of my winter boots echoed down the street. My jaw ached from grinding my teeth, and I wished I could stop at the next corner and scream out at the neighborhood, "Don't all you people realize we need help?"





By the time we arrived, the party was in full swing. Tony wheeled around to a back gate. To clear a path for the wheelchair, the men of the neighborhood shifted cars. Sandy removed the wheelchair's batteries, I lifted Tony into a ballroom dancing position, and two men carried up the chair to the backyard. Sandy took the batteries one at a time, and then the men walked and dragged Tony up the steps. They draped him like a rag doll across the split-rail fence.

Sandy reassembled the wheelchair, and the men dropped Tony into it. I carried up the stroller and unloaded Ben.

As I guessed she'd want to do, Sandy turned her back to Tony and showed off Josh, the older boy, to the other moms. He was wearing his Tigger costume.

One of the men pushed Tony's chair to the steep stairs that led up to a deck just off the kitchen.

The men vanished without anyone telling me what I was supposed to do next. Were they going to return and carry the chair up those steps? Probably not.



Sandy placed Tony's water bottle on the back steps. "Watch the kids, Mom," she said, smiling. "I'm going to

leave them down here in the yard until it's time for the parade."

My mouth opened. My brow furrowed. So that meant I was supposed to watch Tony *and* the kids?

She turned and scampered up the stairs. She must have decided that Tony would stay at the bottom of the stairs, rather than be carried up. Meanwhile, she went to join the party going on inside.

This couldn't be what Tony had imagined, I thought, and anyhow, this was his dinner time. Where was the Tony-friendly food?

Above us and shining down on the elevated deck, a blinding outdoor spotlight illuminated a round table and potluck snacks. I went up to see if there was anything Tony could eat and brought down a paper plate of hummus and pita bread. I put it on his lap and pushed a Flexi-straw into the bottle of bubbly water in his cup holder. Tony leaned to the left to reach it with his lips. Tony and I were part of a ballet in which the dancers knew their parts.

Then in knee-jerk grandma fashion—because I could never just take care of Tony; I had to mind the children, too—I scanned the yard. A children's plastic picnic table and two wooden garden benches stood on a paved patio. Ben opened the door of a plastic pedal-car and climbed in. The car inched forward.

Tony wanted to eat. I gave him a bite of pita and hummus. He tossed his head back and chewed. Please don't choke, I thought.

A little girl dressed as a green dinosaur appeared. Her cloth costume had a long tail that trailed in the dirt, and the girl picked it up as if it were a bridal veil.

A boy dressed in aluminum baking pans, his arms and legs encased in flexible aluminum duct, wore an automotive oil funnel on his head. Wielding a sword, he chased over to the bamboo and began to whack it. Where were his parents?

The child of the hosts had dressed as a Day-Glo skeleton. He followed the robot back toward the bamboo, then turned to pick up a toy Superhero from the dirt. The skeleton took off his mask and threw it on the ground.

Up above, the hostess opened the kitchen door and called out, "It's time for the parade." From inside came the song "The Monster Mash." The dinosaur, robot, and unmasked skeleton ran up the steps.

Sandy came down to get Josh. She plucked Ben from the car. Almost as an afterthought, she bent to give Tony a kiss. "How you are doing, Sweetie?" she said. "You need more water?"

"Sure," he said.

Sandy took another seltzer bottle from her purse.

"Why do you want more when you haven't finished the first one?" I said.

"I guess it's a matter of whether the cup is half empty or half full," Sandy said.

"Not these days," Tony said. "The cup is always half full. That's how I have to look at it."

Moments like this were so poignant, I almost couldn't bear it, and I thought of the e-mail he'd sent a day or two earlier. Sandy had left it on the counter.

Dear Sandy. Another bad dream in this topsy-turvy existence, and then I woke up to my beautiful wife and children and felt thankful for my life.

—Love, Tony

Sandy squatted and looked into Tony's eyes. "Do you mind if I go back up?"

"Not at all," he said. "I'm just waiting for trick-ortreat."

"Did you get enough to eat?" Sandy said.

"I ate a little," he said.

"Can you handle this, Mom?" Sandy said.

"I handle it every day," I said.

"I want pictures of the parade." Sandy pulled an instant camera from her pocket, and then she took the stairs two at a time. On the bottom step, a white sipper

cup with a purple lid stood, illuminated by the spotlight, like the final prop on an empty stage.



Tony hadn't eaten much. On the appetizer table above us, I found a slice of pizza and brought it down. "You want to try pizza?"

He nodded.

I knew he shouldn't be eating this—he could choke—but it was his call.

Tony opened his mouth, clamped down, and twisted the piece sideways. It ripped like cardboard. Then he tilted his head back and massaged the pizza against the roof of his mouth. His chewing muscles had begun to atrophy, and if a piece of food went down the wrong pipe, he had lost the ability to cough it up.

Music blasted out the second-story windows. *It's a graveyard smash!* Parents cried "form a line" and "Wait, I want a picture." Tony took another bite.

The back door slapped open. Costumed children clomped downstairs. A husky woman in jeans and a flannel shirt leaned over the railing. "How's it going, buddy?"

"All right," said Tony.

"I miss our babysitting nights," she said.

"Me, too," said Tony, looking up.

The woman's child was a short-haired, school-age girl with a tool belt, measuring tape, and work cap that said ANNIE'S PLUMBING. "Let's go, Mommy."

"My partner Sandra's working late," the woman said, following her daughter down the stairs. "I'm doing Halloween alone."

Tony nodded.

She gave Tony's shoulder a squeeze. "Stay out of trouble."

"I will," he said.

Another of those moments that just killed me.

Parents divvied up strollers and retrieved abandoned costume parts. Sandy removed the wheelchair's batteries, and while I stood Tony up and held him around the waist, the same two men carried his chair down to the driveway. They came back for him and carried him down. Sandy dealt with the children, and I reassembled the chair.



It was a perfect fall night, almost warmer than the day. On the front stoops of houses, parents with babies chatted with neighbors.

Ben, missing his bat, but with his costume other-

wise intact, rocked side to side in the stroller. Sandy pushed.

Josh skipped ahead, his goodie bag open, the Tigger mask tilted back.

The lawyers and politicians, academics and brokers, as well as the reporters and stay-at-home moms called out, "Hi! How are you! We should get together." False promises. In the ten months I'd been living here, only one or two neighbors had dropped in to offer help. And, of course, I understood. People were busy with their own lives. Plus, just seeing a vigorous, athletic young father being gradually whittled down by ALS was just more than they could bear. I couldn't bear it either.

Looking up at the moon, I stopped on the sidewalk and stared up at the sky. The moon's craters were faintly visible. Orange as a pumpkin, full and bright, it hung like a setting sun above the trees' naked silhouettes.

When I looked around for the others, I found myself alone; but thinking of my daughter having to deal with Tony and the children, I hurried home, only to find Sandy distributing candy to trick-or-treaters. In the harsh, yellow porchlight, I saw, with such clarity that it took my breath away, my daughter's lean jaw and deepset eyes, neither happy nor sad, just determined to endure.

"Sorry," I called out, "I lost you a couple blocks back."

"That's because Josh wanted to take a shortcut down the alley," Sandy said. "Could you hand out candy and get Tony ready for bed while I give the kids a bath?"

She ought to wear a cape and have an "S" embroidered on her teeshirt. I picked up the candy bowl and blew out the jack-o'-lantern's candle. I thought of Nabokov's words. "The cradle rocks above an abyss, and common sense tells us that our existence is but a brief crack of light between two eternities of darkness."

Of all the exhausting parts of my day, going about my business with a constant awareness of death wearied me the most. The only time I could put this awareness aside and return to a state of obliviousness was when I dropped into a fitful sleep. But then, of course, the next day I'd have to wake up and death would be staring me in the face.

AFTERWORD

This is an excerpt from my novel, *Montpelier Tomorrow*, and not one of the lighter moments in this family saga of a young man's decline.

As with any novel and many movies, there are chapters that wind up on the cutting room floor. "Hallowed Eve" was one of them. In reshaping the scene, I added enough context so that readers wouldn't feel lost, but I couldn't tell the entire story. If you're dying to see what happens to this family, I can promise you a harrowing ride.

Here are the opening lines of *Montpelier Tomorrow*.

Time robs us of chances for reconciliation. Time makes us liars. I wanted to save my daughter, and

even now, I don't know what made me think I could keep her from going through what I had gone through, widowed and pregnant, all at the same time. The scars from her father's death had never fully healed, but if not for Tony's illness, Sandy would have sailed into her future, and I would have gone on trying to save the world, one kindergartner at a time.

Of all the writing I've done, I think this novel speaks the most honestly about caregiving and about parents' desire to shield even their grown children from harm.

If you'd like to read *Montpelier Tomorrow* in its entirety, click the book cover and that will open buylinks to online bookstores.

"An affecting, deeply honest novel; at the same time, a lacerating indictment of our modern health care system."—KIRKUS REVIEWS

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ABOUT THE AUTHOR



Marylee MacDonald is the author of Montpelier Tomorrow, Body Language, Bonds of Love and Blood, The Rug Bazaar, and The Big Book of Small Presses and Independent Publishers. For more info about her writing, please visit her website:

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