The Right Thing

I wasn't supposed to be working the clinic that day. Six weeks shy of retirement, I had reduced my hours to two days a week, doing mostly administrative work, preparing to transition the program I'd run for twenty years to a younger nurse practitioner. But Rebecca had a family matter to attend to, so I said: sure, I'll do clinic on Thursday.

And Mary wasn't initially on the schedule. But she'd called – or rather her caregiver had called, as Mary herself was no longer able to speak – to request a same-day appointment. I agreed to squeeze her in. I'd known Mary for over ten years. She was now in her early fifties,

with end-stage ALS. She'd been unable to walk ever since I met her, but she now couldn't move her hands or swallow or talk. Fully alert, she communicated with eye movements.

A year earlier, Mary had suffered a bout of pneumonia and her brother Daniel had sent out an email saying this was the end and Mary wanted to wish everyone farewell. But she'd bounced back and was still hanging in there. Her needs were now too complex to be managed at home so she was in a skilled nursing facility, but her family continued to pay for her long-term attendant to supplement the care provided by the staff at the institution.

At my clinic, we managed an implanted pump that contained medication Mary used to control some of her symptoms. When she was initially implanted many years ago, I had met her brother who lived locally, and her parents who'd flown out from the East Coast. I'd had to advocate on her behalf when there was some kerfuffle about accommodating her nighttime BiPAP machine on the regular nursing unit. But all had gone well, and she obtained tremendous relief from the spasms and tightness in her legs. She and Sam, her attendant, were very appreciative of the care we provided. She always had a smile, remaining amazingly upbeat in spite of her increasing disability. I came to learn a bit about her life before her disease, when she'd travelled extensively and pursued a successful career in banking. After the dose titration period, she remained stable and we now saw her only twice a year to refill the pump. She wasn't due to come in for another two weeks, but the message I received from the front desk stated that she felt she need an

adjustment in the dose of the medication.

It was a busy day. I was running behind, and Sam called to say they were stuck in bad traffic, so I saw two patients originally scheduled after her before finally getting to Mary, my last patient of the day. She was seated as usual in her power wheelchair with her head supported by a neck pillow; a large woman, she filled the chair, in spite of the sixty pounds she had lost since I first met her. She looked hot and fatigued, but she smiled and used her eyes up motion to signify yes when I asked if she was okay. Sam apologized for being late, saying there had been a terrible accident on the bridge. I said not to worry, and I told Mary, as I had in the past, that there was now a clinic closer to her home that could manage her pump so she wouldn't have to travel so far.

"She likes to come here," Sam said. "She has a lot of trust in you."

I hadn't yet told her I was about to retire.

I examined her. She seemed drowsy but otherwise okay. I saw no indication that her medication dose needed to be adjusted. "I think you're fine at this dose," I said.

But as she had made the long journey I decided to refill her pump then instead of making her return in a couple of weeks. I left the exam room to get the medication and everything else I would need for the procedure.

When I returned a few minutes later, however, Mary looked very pale and her breathing was shallow. She was less responsive. I could no longer get her to open her eyes. I called her name and rubbed her sternum. Her eyelids flickered but nothing more.

"Have you seen her like this before?" I asked Sam.

"No, not really." He was big and strong, but gentle like a giant teddy-bear, always very devoted to her.

"Mary! Mary!" he shouted in a crescendo of panic.

I looked through the papers the nursing home had sent with her. I saw she was now on morphine, but her last dose was several hours ago.

"How long has she been on the morphine?" I asked.

"A few weeks."

"She's been tolerating it okay?"

"Yes. Mary! Mary! Wake up."

But she was not waking up. Her breathing was increasingly shallow,

her pulse weak and thready. She was very pale now, white, with blue around the lips. I looked through the papers again.

"Doesn't she have a POLST?" I said.

The POLST (Physician Orders for Life-Sustaining Treatment) form is legally recognized in California as a way to make sure that a patient's wishes for end-of-life care are honored across all healthcare settings. I knew Mary's ALS doctor would have ensured that she had completed a POLST. I had followed many of Dr. L's patients through the terminal stages of their disease, and I knew she would have had the discussion, that Mary and her family would have agreed Mary

would receive no benefit from CPR in the event of a cardiac or respiratory arrest. I knew she would not want to be placed on a ventilator, with no hope of being weaned off.

But here she was in my clinic, unresponsive, going into respiratory arrest. We were situated in a hospital, but one without any acute care services. The protocol would be for me to call a code; to summon a team of well-intentioned first responders who would pound on her chest and insert a tube down her throat and cart her off to the big house – the main hospital a mile down the street – and place her on a ventilator in the ICU.

"Where is the POLST?"

"Yes, she has one, but I don't know where it is," Sam said.

"Call Daniel on his cell." Mary's brother Daniel was in a meeting but he picked up right away. I explained Mary's condition. He confirmed that Mary did not want any resuscitation: no chest compressions, no mechanical ventilation.

I looked at Mary again. Her head was slumped to the side. I could barely feel her pulse. She was quietly slipping away.

"I have to have that in writing Dan," I said. "I need a copy of the POLST."

He didn't have a copy with him. I called through to my front desk and asked them to have the nursing home fax it over immediately. I held Mary's hand and tried to comfort Sam who was weeping in distress. We waited.

The receptionist knocked on the door and handed me a piece of paper received from the nursing home. But it was not the POLST. It was

a handwritten order from the doctor there saying "DNAR" – for Do Not Attempt Resuscitation – but unlike the POLST, this would not be valid outside of that institution. I called Daniel again.

"I need the POLST."

He had left his meeting and was on his way. "I'll call my wife," he said. "I think she's home. We have a copy there.

Mary now had the unmistakable yellow hue of death. I could not feel a pulse. Her skin was cooling.

I went to the front desk. The fax machine whirled into action again. This time it was the right piece of paper.

"Call a code," I said to the receptionist, waving the POLST in the air.

Daniel arrived at the same time as the paramedics. "She's DNAR," I said and Daniel confirmed this, and we had the paper to prove it.

They performed an EKG and pronounced her dead.

We ended up staying hours together in the clinic that night: me and Daniel and Sam and my receptionist, who for once did not scurry home the moment her shift was over. A young chaplaincy intern joined us. I thought the paramedics would remove Mary's body to the morgue at the main hospital, but apparently not, as she was a "No Code". They said the police would come, and they did and they completed a report, but they said the coroner would remove the body. But no, it turned out Daniel had to call a funeral home for that. So we set him up at the office computer for him to search online and make calls, and then waited for hours for the mortuary van to navigate rush hour traffic. We ordered Chinese take-out for Daniel and Sam. We covered Mary's body, still seated in her wheelchair, and we talked about her life and her courage in the face of her illness, and Daniel's relief that the end had been so peaceful, without the pain or the air-hunger they had feared. We wondered what it was that had made her want to come to the clinic that day.

"She wanted to be here," Daniel and Sam agreed. "She felt safe with you."

It was odd. I had no way to understand it. But I was glad she had gone so peacefully. And that we had done the right thing.

In my written report, I had to fudge the timeline. I had to make it sound as if I had the POLST form in my hand all along.

Sometimes you got to do wrong to do right.

Barbara Ridley was born in England but has lived in California for over 30 years. She has recently retired after 40 years in nursing. Her work has appeared in journals such as *Clockhouse Review, Writers Workshop Review, Ars Medica, BLYNKT* and *The Copperfield Review*. Her debut novel *When It's Over* will be published by She Writes Press in September 2017. She can be followed at www.barbararidley.com