

Book

Love in the face of death

According to literary legend, Ernest Hemingway was once challenged to write a short story using only six words. The resulting miniature masterpiece read: "For sale. Baby shoes. Never worn." Medicine, I believe, has its own combination of words unparalleled for fusing sorrow with brevity. They describe a particular medical specialty: paediatric palliative care. For the death of a child is inescapably freighted with a wrongness that feels monumental, that violates the way the world should be. For this reason—and many more besides—the health-care assistants, physiotherapists, doctors, nurses, play specialists, and other skilled professionals who choose to work with dying children are often remarkable people. They elect to occupy a realm of suffering from which most of us instinctively recoil. But parents have no say in the matter. To be told that your child is going to die—that there is nothing any doctor, any surgery, any medical technology can do to save them—is an entirely different order of awfulness.

The acclaimed US writer and comedian Rob Delaney is one such parent, dragged by force into hell. His son Henry was almost 1 year old when he was diagnosed with an incurable brain tumour in 2016. *A Heart That Works* is Delaney's astonishing memoir about the period from Henry's birth to his death from cancer when he was 2 years old. The book reduced me to laughter almost as often as it wrenched my guts with sobs. I am not sure I have ever read anything so hilariously, horribly, beautifully, obscenely, candidly brilliant about death and grief.

At the memoir's core is a fundamental question. How does a human heart keep working—keep on beating, keep on loving—after a terminal illness such as cancer claims,

in remorseless steps, your beloved child? Delaney is desperate to tell you. What he has learned in his grief

"Delaney needs you to understand precisely how ugly and savage grief can be. Not for him the awkward discomfort and polite timidity with which people often tiptoe around death and dying. His candour about rage is especially liberating."

is too important, too vital, not to share: "I genuinely believe, whether it's true or not, that if people felt a fraction of what my family felt and still feels, they would know what this life and this world are really about." In unflinching detail, he describes it all. Henry's weeks of vomiting before his diagnosis. The gruelling attempts at curative surgery. The tracheostomy, the sepsis, the ever more tortuous cycles of chemotherapy. The removal of Henry's body, cold and lifeless, from the family lounge in a body bag.

But Henry is never reduced to his illness. "In between Henry's birth and death was, of course, his life. That's my favourite part. Henry led a hell of a life", writes Delaney. He describes the "impossibly sweet and calm" son who smiles and babbles at his two older brothers and "was just generally a delightful and smooth little nugget we all loved to kiss and squeeze". He paints a radiant picture of Henry dancing to Justin Bieber, rummaging through a giant bowl of lentils for toy dinosaurs, mischievously pinching the nurses' pens, and smiling so wildly at a pet therapy dog it is as though "the amount of sheer joy was slightly too much for a human face to safely express".

Delaney needs you to understand precisely how ugly and savage grief

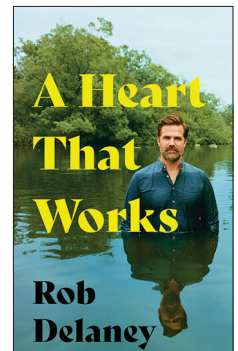
can be. Not for him the awkward discomfort and polite timidity with which people often tiptoe around death and dying. His candour about rage is especially liberating. There is an awesome rant when someone responds to the news of Henry's diagnosis by telling Delaney that his grandfather also had a brain tumour and, happily, survived. "Are you f***** kidding me?" is Delaney's unvoiced response. "I wouldn't care if your ninety-year-old grandfather got hit by three buses and fell in a meat grinder! Grandfathers are supposed to get tumours and die! That's their job! ... Grandparent deaths are like practice deaths, a step above pet deaths, to help you have the barest preparation for a truly painful death. And that guy's grandfather didn't even have the decency to die!"

Ultimately this magnificent book is about loving in the face of dying. Delaney may be enraged, impotent, fractured, and heartbroken—a "decaying disused train station while freight train after freight train overloaded with pain roars through"—but it is the innumerable acts of kindness from friends, health professionals, volunteers, and family that knit him back together. Even as Delaney, his wife, Leah, and Henry's two older brothers wait, in agony, for the inevitable to happen, they discover they are united by and immersed in love in its purest and most tenacious form. "We were in hell and we were loving each other", he says simply. Delaney wants the world to know that when everything else has been stripped away, love is all there is and all that matters. What a profound and beautiful message.

Rachel Clarke

@doctor_oxford

Rachel Clarke is the author of *Breathtaking: Inside the NHS in a Time of Pandemic* (Little, Brown, 2021).



A Heart That Works
Rob Delaney
Coronet, 2022
pp 192, £16.99
ISBN 9781399710848