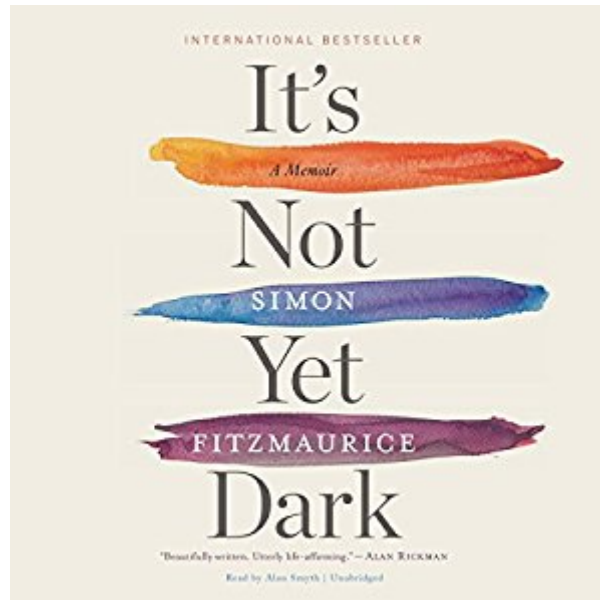




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# It's Not Yet Dark



## Synopsis

In 2008, Simon Fitzmaurice was diagnosed with Lou Gehrig's disease. He was given four years to live. In 2010, in a state of lung-function collapse, Simon knew with crystal clarity that now was not his time to die. Against all prevailing medical opinion, he chose life. Despite the loss of almost all motor function, thanks to miraculous technology he has continued to work, help raise his children, and write this astonishing, life-affirming memoir. Fitzmaurice, a husband and father of five, draws us deeply into his inner world. Told in simply expressed and beautifully stark prose, it is a journey into a life that, though brutally compromised, is lived more fully than most, revealing the potent power of love, of art, and of the human spirit. Written using an eye-gaze computer, *It's Not Yet Dark* is an unforgettable book about relationships and family, about what connects and separates us as people, and, ultimately, about what it means to be alive.

## Book Information

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## Customer Reviews

The thing I most value, and have the most regret about, is the time with my wife, who had ALS. I don't usually seek out material about the disease anymore, but this book is different--not about dying with ALS but living with it. Simon Fitzmaurice (SF) is living with ALS in defiance of medical wisdom, perhaps partly by accident, because of love. An eventual effect of ALS is respiratory failure. Some time after diagnosis SF was in a local hospital in Ireland being treated for pneumonia (a common problem with ALS) and fainted after complaining of breathing difficulty. He was connected to a ventilator on an emergency basis to revive him, and has been on one ever since. It has kept

him alive. Soon after he was hooked up he was told by doctors that ventilation isn't recommended for ALS in Ireland and was pressured, as he describes it, to be disconnected. He refused. He believes if it hadn't been an emergency at a small hospital, he might not have had the option of a ventilator because of his ALS. And he would be dead. The vast majority of those with ALS choose not to use a ventilator, they die from respiratory failure. The disease doesn't cause physical pain (in any direct way). It causes "skeletal" muscles, including all voluntary muscles, even the smallest ones, to gradually fail and waste away. It's confining; one must eventually be hooked up to the ventilator (thankfully portable) and rely on a wheelchair for movement. It makes communication increasingly labored, and eventually requires assistive technology that makes it slow to express any developed thought. And it's costly. It is and does these things to the point that most people, including most who suffer with it, feel it would be better to die. Having a tube through your throat (tracheostomy or "trach" tube) to do your breathing via a machine is particularly unappealing to most, so when that becomes necessary to live, most say no. So why does SF choose to live that way? He exhibits a healthy degree of defiance and stubbornness, but the fundamental answer for him is, as he puts it, "True love." It's a quote he draws from the movie *The Princess Bride*. He refers first to his love for his wife, children, friends and family. Then, "Love for life in general. My love is undimmed, unbowed, unbroken. I want to live. Is that wrong? What gives a life meaning? What constitutes a meaningful life? What gives one life more value than another?" Movies are a big part of his life. *Dead Poets Society* is the film that changed his life when he was young. *Blade Runner* is mentioned more than any other film, once as his favorite. *Wings of Desire* is singled out. Apart from *Princess Bride*, he doesn't spell out how the films might relate to his choice, but if you've seen them, it's not hard to guess. SF's own first feature film, *My Name Is Emily*, was recently released to positive reviews. He wanted to make "a beautiful Irish film." Not about ALS at all, it's about a 16-year-old girl, about redemption. He wrote and directed it the way he wrote this book, via a computer controlled by tracking his eye movements. (This book was written a few years ago for publication in Ireland, so it doesn't cover making the film, but you can read about it elsewhere and watch a documentary also called *It's Not Yet Dark* about the making of the movie.) "This life is the harshest of opposites: Death and Love," SF says. Love is his reason to live and what makes it possible. Those he loves love him, love life, and sustain him. Their support is crucially both material and spiritual. "I don't know how other people handle ALS but sometimes it lays me so low that I don't know how I will go on. I feel like I'm being tortured, a thousand little jabs ... Someone I love not understanding me. One of the boys telling me about something I will never do again with them. The hundreds of urges that I have to do simple human things but cannot do ... I think I'm doing fine, then

realize I'm holding myself together with I don't know what. Something unbreakable that pain keeps trying to break. And then my boys pass the doorway on their scooters. Dot. Dot. Dash. ... Or one simply stands in the doorway, looks at me and says, Hi, Dadda. And I remember. And I write. Writing is my fighting."SF doesn't criticize or question those with ALS who make the usual choice. It's their choice. He does offer a remarkably mild reproach for those who should know better who encourage that choice without acknowledging and making room for the choice to live with ALS. Some of the book is familiar to me, and likely is to many who have been close to ALS. The early signs, the heartrending diagnosis, questioning whether it was caused by something he did, desperate efforts to find another explanation or cure, including all manner of health aids, treatments, and healers, none of which work, some of which imply it's the fault of those afflicted, and most of which cost money. The mixture of glorious moments of happiness with advancing theft of ability to control one's body. Doctors, nurses, family, friends, strangers, mostly helpful, some not. The book is short, 165 pages of moderately large type. The style is mostly fragmentary, as the author points out, episodic, some poetic, not always polished, not always immediately transparent. Narrative arc is sometimes there, sometimes not. SF doesn't dwell much on the details or mechanics of the disease. He covers early life to several years into his illness, with reflections on his choice and the meaning of his life.\*That's the end of the main part of this review. For those interested in more detail and illustrations from the book, I give some below along with some personal observations. The brave That's the title of the first chapter, and the last line of that chapter is the quote in the title of my review. He's not talking about himself or others with ALS. Like most brave people, he doesn't feel brave, he feels afraid (page 70). (My wife grew to hate being called courageous, which is something of a cliché about the disabled. Though I think she secretly appreciated it in some corner of her soul.)SF is talking about those who overcome, or lack as many children do, the natural aversion to people who are made strangers, different from us, by disability. Those who approach and interact, they are the brave. The combination of altered appearance, stunted behavior and difficulty of communication makes it hard not to feel isolated, locked into a prison that most of humanity prefer not to or cannot see into. "Everyone notices but no one sees," SF says on page 1. When my wife could no longer speak above a bare whisper I took her to her book club, which included some of her dearest friends, the best of people, for a Christmas gathering. They all sat around a table, she at one end. No one could hear her, she felt left out, and it looked like there was discomfort from her friends at her worsened condition. All completely natural, but crushing. None of us knew what to do, or had the courage to try something anyway. Love can make us brave, but it may also require creativity, learning, and special effort. Usually effort is appreciated even if there is some

fumbling. What is man? That's the title of the shortest chapter in the book. Here's most of it: "A life. Now glimpsed in photographs and memory, of Simon as he was. Walking, talking, eating, drinking. Breathing. Simon. How much is left of him? How much spans the divide between Before and After? What is Man? How much can be taken away and what is left?" These are questions bound to cross the mind of someone with a disease that takes so much. The chapter doesn't offer answers. The book is an answer, in a broad way. A more direct answer is near the end in the chapter titled "I'm still man." It's more affirmation than philosophy. Much of it's about choosing to live. That may seem to be a different topic, but there's a connection: when most people think you'd be better off dead, there's an (unintended) way in which it devalues your present life to the point that you may wonder if you're still human, if others still see you as fully human. Such an idea never occurred to me before my wife introduced me to a publication called The Disability Rag, which gave arguments from disability rights activists against assisted suicide on the basis that it devalues the lives of the disabled, and adds pressure on them to just get on with dying. SF doesn't make such an argument, and may not even agree, but you can see the logic of it in his experience. Is ALS fatal? SF doesn't refer to ALS as fatal, and seems uncertain about whether it will end his life. According to most sources ALS is a fatal disease, "100% fatal" according to the ALS Association website. But this may be more a value judgment than a fact of science. With a ventilator, it isn't clear that ALS is any more deadly than some other conditions, such as spinal injury, that require a ventilator and aren't referred to as fatal. The Emory University ALS Center website says, "Some ALS patients choose to have a tracheostomy and go on a ventilator. This choice will prolong someone's life indefinitely and death eventually comes from infection, heart attack/failure, blood clots, or a similar problem." None of those is a direct effect of ALS. So why is ALS treated as fatal while some other conditions requiring a ventilator to live aren't? It appears to depend on common expectations of whether those with the condition should choose life or death. Time, team and place SF says, "ALS does not let you rest. It does not let you adapt. It does not give you space. ALS takes and keeps taking." My wife had to stop using brushes and learned to use a mouse to do her artwork in Photoshop. She learned to use a mouth stick to type. A few months later she couldn't do that anymore, so she learned to use a modified Morse code with very slight finger movements to write. Eye-tracking was just being created then, so it wasn't practical, but it would have been next for both typing and art. If that failed, which can happen eventually, more direct brain-computer interfaces are being developed that don't require any muscle movement at all. But each stage requires new equipment, new expertise, and relearning. And it's not one thing but several: nourishment, bathroom functions, and other daily aspects of life that are changing at an accelerated pace. The progressive

nature of the disease complicates the ordinary demands of a severe medical condition. It's a lot for a person with ALS to keep up with, and in many situations it's attempted with only one main caregiver. By the time ventilation is called for, everyone involved is worn down. SF has succeeded in part because when he got out of the hospital with the ventilator, he also started receiving 24-hour nursing care at home. He doesn't say who pays for that--quite possibly it's publicly funded in Ireland--but it's expensive. Living with ALS requires a team. SF talks about how family and friends have helped, and have become experts on various aspects of ALS. He also points out the help received from the motor neuron disease association in Ireland, which has counterparts in other countries. Without others pitching in, in an organized, predictable way, living with ALS is probably not practical. And place matters. My wife and I lived in a beautiful pioneer home out in ranch country, a special project of hers, which was great, but the isolation limited much-needed support from friends, a mistake in retrospect. After they married, SF and his wife bought a beautiful country cottage that they improved and made their own. But as the disease progressed, they realized they needed to be closer to resources, so they moved back to the town where family and friends lived. Not easy, but necessary.

**Locked-in condition** One reason given for not recommending ventilation for those with ALS has been that if all voluntary muscles fail someone might become unable to communicate her desires while hooked up and may end up continuing to be ventilated against her will. SF argues that this doesn't happen suddenly, that people can communicate their intentions before it does. Technological advances are making this concern less of an issue, as there are now ways to read people's intentions without them being able to use any muscles.

**Painful EMG?** A note about a peculiarity of this book that might unnecessarily scare people who need an EMG. SF describes an EMG test he had as inserting needles into his nerves and as "the most pain I have ever experienced." Actually an EMG inserts thin needles into muscles, not nerves, and for most people causes no more discomfort than intramuscular shots for injections. SF was under a lot of stress and, for reasons explained in the book (36-8), he actually hoped the procedure would hurt him. So it did! But that's not how it normally works.

There is no more life-affirming book than this. The stark beauty and wisdom within will make you shiver, cry and cheer. Fitzmaurice has created an awe-inspiring masterpiece that is profound, yet deceptively simple. Quiet passages will grab you by the throat, and shake the reader from the stupor of complacency. Fitzmaurice has ALS, but knows more about the intrinsic value of life than most of the people I've met. His ferocious will to live and unwavering insistence on being a participant can teach us all what it means to be truly alive. Fitzmaurice chooses life in all its glory,

pain, difficulty and joy, because he has love and an undaunted desire to create. He chooses to witness, to interpret, to think and to partake in all that life has to offer. I shudder to think of those in the medical community who abhorrently attempted to suggest that his life should be abbreviated, surrendered and extinguished. No one has the right to determine the value and length of another person's existence. Fitzmaurice has the enduring devotion of a loving wife, the joy watching his children thrive and the ability to render lyrical prose from extremely challenging circumstances. Without trying to be, Fitzmaurice is the very embodiment of what it means to be resilient. This is a small, but utterly exquisite book. The author's deep appreciation for life shines throughout. Fitzmaurice drinks it in like a banquet, refusing to let go. I applaud and admire the sheer tenacity to meet life on his own terms, defiant, unapologetic and grateful. Mr. Fitzmaurice, may the powerful life force that propels you forward continue to burn brightly for as long as you wish. Stunning book. Highly recommended.

I rated it five stars because it's gripping, powerful, heartfelt and happy all at once! The gift of the moment & taking it all in! A must read for all those affected by ALS & anyone afflicted with a debilitating disease

I want everyone I care about to read it. Enlightening and powerful. An amazing account of facing certain death with brutal honesty yet optimism and appreciation of life.

This is the first time that I have heard the name Simon Fitzmaurice. Although, after finishing this book, I can guarantee you that it will not be the last time. In fact, I am more intrigued now to check out Mr. Fitzmaurice's film and other work. What I loved the best about this book is the simplicity of it. Sometimes simple is best. It is even better when it is done right. Mr. Fitzmaurice's wife, Ruth is an angel. I don't know her but I feel like I have a good idea of what a kind hearted person she is from this book. Mr. Fitzmaurice gave me a good insight into ALS. Additionally, he showed that you don't have to be a victim to the disease. You can be a fighter and live your life. For example, Mr. Fitzmaurice may no longer have the function of his hands but he was able to still write this book using an eye gaze computer. Mr. Fitzmaurice is a good spokesperson for ALS. There is a passage in the book that I really liked: "Tell me your secrets. In the deepest depths of night, whisper them to me. Tell me your desires, if you can. Tell me your fears. Tell me what you like to eat. And how you like to eat it. Tell me details, as if you're half awake, half asleep. We are humans. I'm listening. Tell me with your body. Tell me with your mouth. Tell me something I can keep. Without thinking, tell me

something in the shape of you. Your skin prickles in the breeze tell me, I'm obsessed with you."

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