



It's Not Yet Dark

Simon Fitzmaurice

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In 2008, Simon Fitzmaurice was diagnosed with Motor Neurone Disease (mnd). 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 to ventilate in order to stay alive.

Here, the young filmmaker, a husband and father of five small children draws us deeply into his inner world. Told in simply expressed and beautifully stark prose - in the vein of such memoirs as Jean-Dominique Bauby's *The Diving Bell and the Butterfly* - the result is an astonishing journey into a life which, though brutally compromised, is lived more fully and in the moment than most, revealing at its core the power of love its most potent.

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.

It's Not Yet Dark Details

Date : Published June 5th 2014 by Hachette Books Ireland

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Author : Simon Fitzmaurice

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From Reader Review It's Not Yet Dark for online ebook

Mr Norton says

Simon Fitzmaurice had two of the keystones of a happy life: success in his professional life, love in his personal life. Then he noticed how his foot slapped on the pavement as he walked. Then he got diagnosed with Motor Neurone Disease. Then he had everything taken away from him. Or did he?

'It's Not Yet Dark' is the author's defiant assertion that he is alive and that, like the rest of us, he will live life as fully as he can for as long as he can. Written with obvious courage (not the least example of which being the tenacity to write solely through an eye tracking interface with a computer), the book has many moving moments. To read of the joy felt by Fitzmaurice at the touch of his children in his arms is to become aware of the poverty of our own everyday gripes and groans. And the author doesn't just offer moving personal testimony. He also moves his memoir into the political arena by raising inconvenient opinion about the medical care of people with MND.

However, as Oscar Wilde said, there is no such thing as a moral or immoral book, only a well or badly written one. And, while the book benefits at times from Fitzmaurice's clipped cinematic style, especially early on, this begins to grate and, as a result, the book fails to gain a cumulative power. More successfully, for the last third or so of the narrative, Fitzmaurice switches back to his childhood and adolescence. The dramatic irony of knowing what awaits the adult Fitzmaurice offers a well judged, unsentimental layer of pathos that adds greatly to the book's ending; however, this isn't enough to redeem the middle section's longueurs.

If you enjoy poignant real life stories of the uplifting kind favoured by Oprah Winfrey or The Late Late Show, then this book might be for you.

Marika says

Irish film maker Simon Fitzmaurice was diagnosed with ALS in 2008, and given four years to live. During a medical emergency, against medical advice, he chose to be go on a ventilator, Why? Because even though he was told that it wouldn't be much of a life, he knew that it wasn't his time to die. Exquisitely written, as the author explores what it means to truly "live" and how the term "to live" is a subjective one. Similar to both "The Diving Bell and the Butterfly: and :My Left Foot." Great for book clubs.

This book was a bestseller in Ireland.

I read an advance copy and was not compensated.

Donna says

My daughter recommended this book. I lost one of my dearest friends to Amyotrophic Lateral Sclerosis, so I took the recommendation in hopes that I would understand what he experienced. The author wrote this in a first person narrative, that made for a quick moving read. Fitzmaurice like my friend had a deep love for life, and chose to live life to its fullest rather than to succumb to ALS as the beginning of the end. The author prevailed in many ways...love, family and his profession in cinema. Though it was hard for me to read at times, knowing his suffering experiences were the same that my friend also experienced. Although I had to

put this book down at times, I do recommend the reading of this book not only for further knowledge and understanding of this horrible and debilitating disease, but to see the strength of the author and how he was still able to describe in his words the beauty of life itself.

Anne ? says

It's not Yet Dark is an inspiring memoir by an Irish writer and film director who, at age 34, was diagnosed with Motor Neuron Disease (MND/ALS/Lou Gehrig's) and given a prognosis of 4 years to live. Flash forward nine years to 2017, and Simon had written a memoir, directed a movie, been the subject of a documentary, and had three more children. These accomplishments are all the more commendable when you understand the extent to which the illness reduced his physical capacities. With no muscular control beyond this eyes, he breathed through a mechanical ventilator, moved with a specialty powered wheelchair, ate through his stomach, and communicated through an eye-gaze technology computer. He was reliant on 24hr nurse care, and the support of an amazingly dedicated and loving wife Ruth, and their 5 kids.

The book is short, to the point, and thoughtful. At 165 pages it's a quick and engaging read that's hard to put down. The stories he told of his life both before and after the illness evoke a powerful picture of all that was lost to him, and the courage needed to face the difficult questions of a meaningful life.

"I do not eat or drink or walk or talk the way you do. I don't breathe without a machine helping me day and night. I cannot move my arms or legs. And yet. I'm still man. I've lost so much. And yet. I'm still here. I feel everything. The slightest feather touch anywhere on my body. And my heart is alive. To meaning. To value. To love. Which is all it's ever been about"

At the core of this story lies a fierce determination to live his life as fully as possible, and a deep appreciation for the gifts of life, love, and family. *"We often think we are entitled to a long and fruitful Coca-Cola life. But life is a privilege, not a right. I feel privileged to be alive."*

If you're like me, and find yourself inspired to learn more after reading this book:

- A documentary chronicling his experience living with MND, titled 'It's Not Yet Dark' is available to watch on Netflix
 - The movie he directed while living with MND, titled 'My Name is Emily' can be watched on Amazon Video
 - Ruth Fitzmaurice, Simon's wife, released her own memoir in July 2017, expanding on the impact of Simon's illness on their lives together and their family. It's titled I Found My Tribe
 - And, on a sad end note, if you do search the internet for more info, you will learn that Simon did finally succumb to the disease on 26th of October 2017, at age 43. :(He lived his life fully, and was an inspiration!
-

Taryn says

It's only important that you remember that behind every disease is a person. Remember that and you have everything you need to travel through my country.

3.5 Stars. One month after his film was accepted into the Sundance Film Festival, Irish filmmaker Simon Fitzmaurice's foot started going limp. The sensation passed, but his symptoms continued to escalate until

they couldn't be ignored any longer. At only 34 years old, Simon was diagnosed with ALS (Lou Gehrig's disease/a form of MND). Over the next two years, "the seesaw balance of strength and weakness" quickly began tipping more towards the side of weakness. When the disease took away his ability to breathe on his own, Simon's doctors said it was the end. They began to counsel him on his end-of-life options, but Simon knew it wasn't his time to go. Surrounded by the love of his family and friends, there was so much to live for.

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? Surely only the individual can hope to grasp the meaning of his or her life. If not asked if they want the choice to live, it negates that meaning.

ALS is an unpredictable disease that progressively destroys the nerve cells that control voluntary muscle movement. While the disease takes so much away from a person, there's still an opportunity to lead a full life. Simon advocates for patients to be made aware of all their options and allowed to decide their own fate. There are many technologies that help improve the quality of life of ALS patients: "The disease takes your ability to speak. But it need not take your voice." Simon is still able to control his eye muscles, so he wrote the entire book using an eye-gaze computer.

It's very much a filmmaker's book! This short, evocative memoir is composed of fragments--the memorable scenes that constitute a life and poetic bursts. He doesn't always take a straightforward approach to telling his story. Just when it seems the story is ending, he darts back to his coming-of-age years ("What is man?") and then returns to the present ("I'm still man"). I actually didn't appreciate this section until I went back over it later: "How much spans the divide between Before and After? What is Man? How much can be taken away and what is left?"

I do not eat or drink or walk or talk the way you do. I don't breathe without a machine helping me day and night. I cannot move my arms or legs. And yet. I'm still man. I've lost so much. And yet. I'm still here. I feel everything. The slightest feather touch anywhere on my body. And my heart is alive. To meaning. To value. To love. Which is all it's ever been about.

It's Not Yet Dark is a beautiful testament to the love of family and life. I read this book because I was curious about the medical side of things, but my favorite parts ended up being the Fitzmaurice's love story and his descriptions of the precious moments he spent with his children. Sometimes the quietest moments are the most powerful. Simon Fitzmaurice is an example of the full existence that can be led after all seems lost. When he was diagnosed, he was given a prognosis of three to four years. Defying the odds, he is still watching his children grow up and producing films nine years later. He doesn't deny the daily struggles, both emotional and physical, but the sacrifice is worth it to extract all he can out of this fleeting, fragile life. It may not be the life he would have imagined for himself, but it's still a life.

The emotional trailer for the *It's Not Yet Dark* documentary gives a good sense of the tone of this book. Its release date is August 4, 2017. His wife Ruth's memoir *I Found My Tribe* coming out in Spring 2018. If you like this book, you might also be interested in *The Diving Bell and the Butterfly* by Jean-Dominique Bauby.

Update: Simon Fitzmaurice passed away on October 26, 2017.

LINKS

- [It's not yet dark for filmmaker Simon Fitzmaurice - Simon's story](#)

- How Ruth Fitzmaurice found her tribe in Ladies Cove, Greystones
- My Name is Emily trailer- A film made after his diagnosis. It stars Evanna Lynch, the actress who played Luna Lovegood in the Harry Potter series.
- Breathing and ALS - This handout from the ALS Association Greater Philadelphia Chapter outlines some of the benefits and problems with ventilation for ALS patients.
- Wild and Precious Life by Deborah Ziegler - A few months ago, I read a book about a young woman who made a very different choice when confronted with a terminal diagnosis. Brittany had a very different outlook on life, but there's a very similar issue at the heart of both books: dominion over your own body.
- I'm currently reading Admissions by Henry Marsh, and this quote about the ease of assuming your future state of mind when you're well stuck with me: "When you are feeling fit and well, it is relatively easy to entertain the fantasy of dying with dignity by taking your own life, as death is still remote. If I don't die suddenly, from a stroke or a heart attack, or from being knocked off my bicycle, I cannot predict what I will feel when I know that my life is coming to an end – an end which might well be distressing and degrading. As a doctor, I cannot have any illusions. But it wouldn't entirely surprise me if I started to cling desperately to what little life I had left."

I received this book for free from Netgalley and Houghton Mifflin Harcourt. This does not affect my opinion of the book or the content of my review. It was originally published in 2014. This edition will be available on August 1, 2017.

mindy says

"We often think we are entitled to a long and fruitful Coca-Cola life. But life is a privilege, not a right. I feel privileged to be alive. That's hope"

Guys I don't normally read memoirs. And I definitely don't read sad books. I don't know why I decided to read this arc, but it moves me to tears on every page.

Honestly, if you have time then read a few pages. It's such a powerful reminder of life and love.

Excuse me while I ugly cry. This book is beautiful.

Susanne Strong says

3.25 Stars* (rounded down)

"It's Not Yet Dark" is a memoir written by Simon Fitzmaurice, an Irish Film Maker, who was diagnosed with MND (Motor Neuron Disease a/k/a ALS (Amyotrophic Lateral Sclerosis) a/k/a Lou Gehrig's Disease) at the age of 34. At the time of diagnosis, he was given 4 years to live. Yet he had hope. And he believed in the power of love.

"For me, it is not about how long you live, but about how you live."

"I am not a tragedy. I neither want nor need pity. I am full of hope. The word hope and ALS do not go together in this country. Hope is not about looking for a cure to a disease. Hope is a way of living. We often think we are entitled to a long fruitful Coca-Cola life. But life is a privilege,

not a right. I feel privileged to be alive. That's hope.”

Mr. Fitzmaurice's memoir advocates for a person with this disease to make the choices for themselves; he chose to live. Unfortunately, in each country, the choices a person can make are different. This I know.

“It's Not Yet Dark” is a memoir that tells you what happened to Simon Fitzmaurice, it doesn't show you, nor does it evoke emotion from its reader, in my opinion. I admit that I held off reading this novel for months as I was afraid of the reaction that I would have. However, the writing felt somewhat stilted, cold and unemotional to me and I was expecting the exact opposite and I thought reading it would destroy me.

Sadly, I have lost two relatives to MND/ALS, which is unspeakable: my My Uncle, Edward Lightowlers, who passed away in July of 1998 and my cousin, Les Halpin who passed away in September of 2013. I miss Les very much.

While, I didn't feel the emotions of Mr. Fitzmaurice's plight in this memoir, that in no way diminishes it.

Thank you to NetGalley and Simon Fitzmaurice for an ARC of this novel in exchange for an honest review.

Published on NetGalley, Goodreads and Amazon on 8.13.17.

Justyna says

I have read and am reviewing the Advance Reader's Copy of the book!

With his simple yet raw and beautiful prose, Simon Fitzmaurice pens a memoir about his life with ALS that is hard to put down. Fitzmaurice invites readers into his life and on his journey while, at the same time, discusses the importance of the precious gift of life. If I could, I would give it 10 stars! What a masterpiece!

Michele at A Belle's Tales says

At 165 pages, *It's Not Yet Dark* is a book I read in one short sitting; but it is one that will stay with me forever. Written using an eye-gaze computer, Simon Fitzmaurice's beautifully authored memoir is told simply and honestly. Sharing moments from his meeting of wife Ruth, the births of their children, and his successful career as a filmmaker, Mr. Fitzmaurice gives us these amazing glimpses into his life leading up to the moments when he realized something was very wrong. When he was diagnosed with ALS (Lou Gehrig's disease, or Motor Neurone Disease), it threatened to rob him of his career and, most importantly, his life; but Simon wasn't having it, and the determination and courage he possesses are what transforms this book from heartbreaking to heartwarming. I adore the way he writes about his wife and children, as well as family and friends. It's a beautiful thing when a man can express his love so eloquently and freely.

This is an eye-opening look at an awful disease and the vastly different approaches medical personnel had in treatment as well as non-treatment plans. An absolutely inspiring story about love, determination, and the will to live, *It's Not Yet Dark* is a book I wholly recommend to everyone.

I received a copy of this book in exchange for my honest review.

Review originally posted at A Belle's Tales.

Aoife Lennon says

This book was a punch in the stomach and a punch in the heart all at once. Devastating, heartbreaking, yet powerful and inspiring.

Esil says

"It's not important you know everything about ALS, about the specifics of the disease, about what it's like to have it. It's only important that you remember that behind every disease is a person. Remember that and you have everything you need to travel through my country."

Simon Fitzmaurice is an Irish film maker who was diagnosed with ALS a few years ago. The country he refers to in this quote is his disease. He has written this sparse short memoir using some of the only muscle control he has left -- using technology that allows him to write with eye movements. He has an extraordinary will to get the most out of the life that remains, and so a book that should be horribly depressing ends up feeling powerfully uplifting. Tough topic but well worth reading. Thanks to Netgalley and the publisher for an opportunity to read an advance copy.

Iryna (Book and Sword) says

"I do not eat or drink or walk or talk the way you do. I don't breathe without a machine helping me day and night. I cannot move my arms or legs. And yet. I'm still man. I've lost so much. And yet. I'm still here. I feel everything. The slightest feather touch anywhere on my body. And my heart is alive. To meaning. To value. To love. Which is all it's ever been about"

One of my biggest 2018 reading goals was to read more of different genres, and I am happy to say that I've been doing great with it (at least I think so). This time I ventured out to read some non-fiction, particularly a memoir, which I honestly never read. But I am so happy that I did.

?I am a hypochondriac, so even reading this book made my scalp tingly with worry and self destructive thoughts. But I am pushing my comfort zone this year, and It's not yet dark was totally worth it.

"It's only important that you remember that behind every disease is a person. Remember that and you have everything you need to travel through my country."

It's not yet dark reads like a fiction. Maybe it's the first person narrative. Maybe it's the short, to the gut sentences. Maybe it's just the flow of it, but it does not feel at all as I thought I a memoir would feel. Which I think is absolutely perfect for people who don't read much non-fiction (like me).

?ASL is a terrible disease, and it's so terrible because nobody understands why it happens. Nobody can tell that it might happen till it actually happens, and once it does - there is no cure for it. Person loses their mobility, bit by bit until they are completely motionless and powerless in their body. We ll know the saying **"your body is your temple"**, but what do you do when **"your body becomes your cage"**?

What pulled me into this book was how honest Simon was - he was terrified and he wasn't hiding it. He wanted to live, he was angry, he was desperate and he was real. Death is scary and death was looming over him for many years, taking little bits of him each passing day.

Despite of it all Simon never gave up - he managed to keep dreaming and creating, all made possible with love and devotion of his family. Even when doctors came into his room saying "*why would you choose to keep living like THIS?*". Even when Simon couldn't move anything except his eyes - he was still there, he was a man who loved and was loved in return.

?If you are looking into venturing out into non-fiction I'd definitely recommend *It's not yet dark*. It's a quick ,but very memorable and important read.

My WEBSITE

My INSTAGRAM

My WORDPRESS BLOG

Julie wright says

This is an account of Simon Fitzmaurices strong will to live when facing death or choosing the difficult road of living with ALS. This book hit close to home with my experiences of my husbands health issues dealing with lung disease and being so close to death before receiving the life saving double lung transplant. Many passages throughout the book made me tear up and sometimes just full on cry. You never know how much you appreciate life until you almost lose it. Some quotes that meant a lot to me:

"That's the thing about your death, and the threat of your death: it's not just about you, it pulls in all your loved ones. Everybody's life has stopped." Another one when a neurologist questions why he would want to ventilate and live with such a debilitating illness: "They are there because they have made a decision about my standard of living. To them it is inconceivable that I would want to live. But not for me. For me, it's not about how long you live but about how you live." "ALS is a killer. But so is life. Everybody dies. But just because you will die at some point in the future, does that mean you should kill yourself now?" Most people when faced with this circumstance would have opted to take the sedated approach that eased into death.

I'm so glad I read this book even though it made me cry. Life is a precious gift and a privilege. I have strong feelings that we need to honor this life and fight to live as long as we can. In my eyes, this man is brave and his wife is a strong woman to stay by his side and take care of him and their family. He fought to stay alive for his children and wife and for the sheer love of being alive and experiencing all that life offers even though his mobility is limited and he can only speak with the assistance of technology. I'm so grateful that someone could put into words many of the things that I believe. This is a beautifully written book.

Meg - A Bookish Affair says

"It's Not Yet Dark" is a memoir by Simon Fitzmaurice, a filmmaker, father, and husband, who is struck down in the prime of his life by ALS. Even if we are relatively healthy, there is a chance that something could strike us like that without warning. It is a slim chance (luckily!!!) but there is still a chance. Most of us just don't go around thinking about things like that because it would drive us absolutely nuts. It's the fact that this book is so raw that makes it good and that makes it thought-provoking. This situation could happen to any of us.

Fitzmaurice walks us through his diagnosis and the disbelief that he originally has when he starts having issues. He blames it on his shoes at first because the idea that a healthy person like him could have a medical issue that makes it impossible to fully work his foot seems so strange and then things quickly seem to go from bad to worse.

Told in stark prose, this is a story of heartbreak and how you go on living when everything that is happening to you is fully out of your control. How do you embrace family and friends? How do you adapt and move forward? How do you form a new life when reality is so different than what you had anticipated? This book explores all of these topics and more in a really raw and real way. This book is relatively short but it packs a huge punch!

Caroline says

This was an extraordinary book for me to read. Written by a successful film maker - and a marvellous writer - it was also written by someone almost completely immobilized by motor neurone disease. He wrote the book using a computer that could respond to eye movements.

I am someone who hates having any sort of illness, pain or discomfort. The moment my temperature rises above 97.5°F, I am ready to bundle myself off to Dignitas.... What a shock therefore to read this book, and immerse myself in the soaring joy, celebration of love, wife and family, adoration of film, and pleasure in the beauty of the world around him, that Simon Fitzmaurice experiences. He loves life. He wants to wring out the very last drop of it that he possibly can, and he fights to make this possible.

We learn something of the huge challenges and trials of having advanced motor neurone disease, but mostly Fitzmaurice's imagination leaps, pirouettes and spins over the intense joys of life that he has experienced....and that he is still getting now, mostly via his wife and children, friends and family. Of course he has great fears concerning his illness, but this is always outweighed by his love of life.

One of the most incredible attributes of books generally is that they can enable you to get inside the minds of people who have perspectives completely different to your own.....and this book did this for me in spades. Not only that, but it was beautifully written. A truly marvellous book.
