



Disease: When Life takes an Unexpected Turn

Hans M. Hirschi

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Alzheimer's is a disease affecting the patient's loved ones as much, if not more, than the patient themselves. In Hunter's case, that's his partner Ethan and their five-year-old daughter Amy. How will they react to, and deal with, Hunter's changing behavior, his memory lapses, and the consequences for their everyday lives?

Disease is a story of Alzheimer's, seen through the eyes of one affected family.

Disease: When Life takes an Unexpected Turn Details

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Teresa says

Title: Disease

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Reviewer: Teresa Fallen Angel

Blurb:

When journalist Hunter MacIntyre is diagnosed with early-onset Alzheimer's, he realizes that his life is about to change, not to mention that he's been handed a certain death sentence.

Alzheimer's is a disease affecting the patient's loved ones as much, if not more, than the patient themselves. In Hunter's case, that's his partner Ethan and their five-year-old daughter Amy. How will they react to, and deal with, Hunter's changing behavior, his memory lapses, and the consequences for their everyday lives?

Disease is a story of Alzheimer's, seen through the eyes of one affected family.

Total Score: 5/5

Summary:

Received for an honest review.

This story was an amazing look into one man's journey as his life was altered and eventually ended by Alzheimers. For those who are not familiar with the disease it slowly degrades an individual's memories until nothing is left. No one knows for sure how it is caused, but it devastates not only the victim, but their entire family. Hunter was a strong and loving man whose life was cut short, but even with that he left a diary which allowed the reader insight into what he felt as he got slowly sicker. The difference between good and bad days was as telling and the notes his partner Ethan added relating what really happened to show how Hunter was slowly slipping away.

This inspiring and revealing story should be a must read by anyone who cares for individuals dealing with memory loss to help them cope with what they and their loved one is going through.

Norma says

"Words carry the power to make something tangible..."

Simply and beautifully written, Disease takes the format of a diary, found and published two years after the death of a talented journalist, Hunter, beginning when he was first diagnosed with around onset Alzheimer's. Interested between some of the entries are comments by his surviving life partner, Ethan, with his own memories of that particular time and the emotions it aroused.

Hunter knew what to expect: his mother had died from the same illness, and this made his diagnoses all the more poignant. And with a very young daughter of his own, Hunter's fears seeds not only for himself but also the family he loved so dearly. The book charts his emotions, his decline as slowly his memories are washed away. Remarkably, though, this is not a simple story of misery, it is also an affirmation of life, love and all that it means to be human.

Recommended.

G.L.O says

I enjoy a book most when I am drawn into it and forget it is fiction. A book that will pull my emotions to the point I have to stop and take a breath. This book does just that. To say this is a book about a gay couple dealing with the diagnosis of Alzheimer's is not enough. In addition to this diagnosis, the couple must deal with it at a time when gay couples had no rights. No right to stay with your partner in his hospital room if his family family objected. No right to make medical decisions. No legal rights at all. We can feel Hunter's pain and anguish as he struggles to keep his memories and worries for the future of his daughter and partner. The book is so well written it is easy to lose yourself in it and feel as if Hunter and Ethan are speaking to you as a friend as they share their concerns and pain. If you have never had to deal with a loved one with Alzheimer's disease, this book gives you a glimpse into its total devastation. I received an ARC edition in return for an honest review and that is what I have tried to do. Don't let this book pass you by. It is full of heart, soul and tears.

Olga Miret says

An emotional journey into a disintegrating mind and its effects I have read quite a few books by Hans Hirschi (not all, but I might get there given time) and have enjoyed them, no matter what the genre. The author is not somebody who writes thinking about the market or the latest trend. He writes stories he cares about, and beyond interesting plots and fully-fledged characters, he always pushes us to think about some of the big questions: prejudice, ecology, poverty, child abuse, families, laws, gender, identity... If all of his stories are personal, however fictional, this novel is perhaps even more personal than the rest.

As a psychiatrist, I've diagnosed patients with dementia (Alzheimer's disease or other types), I've assessed and looked after patients with dementia in hospital, and I have seen, second-hand, what the illness does to the relatives and friends, and also to the patients, but as an observer, from outside. I've known some people who have suffered from the condition but not close enough to be able to give a personal account.

The novel tries to do something quite difficult: to give us the insight into what somebody suffering from Alzheimer's feels, what they think, and how they experience the process of losing their own memories and themselves. The book is written in a diary format, in the first person, by Hunter, a man in his forties who, after some episodes of forgetfulness, goes to the doctors and is diagnosed with early Alzheimer's. He writes articles for a living, is married to Ethan, who is a high-school teacher, and they have a five-year-old daughter, Amy (born of a surrogate mother, and Ethan's biological daughter). They live in Michigan, where they moved to from California, and therefore they are not legally married, as that was not an option at the time. To the worry of his illness and how this will affect him (Hunter's mother also died of the condition, so he is fully aware of its effects on its sufferers), are added the worries about practicalities, about Amy's care, about financial stability, about his own care, as they are not a couple with equal rights in the eyes of the law. Hunter's diary is framed by Ethan's narration. Ethan finds the file of the diary a couple of years after

Hunter's passing and decides to publish it, mostly letting Hunter's words speak for themselves, but at times he clarifies if something Hunter narrates truly happened or not, or gives us his own version of events (for instance, when Hunter gets lost). Although the story is mostly written by Hunter and told from the point of view of the sufferer, Ethan's brief contributions are poignant and heart-wrenching, precisely because we do get the sense that he is trying so hard to be strong, fair, and to focus on his daughter. He accepts things as they are and is not bitter, but the heavy toll the illness has taken is clear.

The novel ends with a letter written by Amy. Although brief, we get another perspective on how the illness affects families, and through her eyes we get to know more about how Ethan is truly feeling. A deeply moving letter that rings true.

The characters are well drawn, and even when the progression of the illness means that some of the episodes Hunter describes might not be true, they still give us a good insight into his thoughts, his illusions, and his worries. He writes compellingly and beautifully (although there is evidence of paranoia, ramblings, and some disconnected writing towards the end), and the fact that his writing remains articulate (although the gaps between entries increase as the book progresses and he even stops writing when he misplaces the file) fit in with research about preservation of those skills we have used the most and are more ingrained. Hunter pours into his diary his thoughts and experiences, some that he has never shared in detail with anybody (like being trapped at a hotel in Mumbai during a terrorist attack), and others that seem to be flights of fancy or wishful thinking. He shares his own opinions (his dislike of nursing homes, his horror at the thought of being looked after by somebody he doesn't know, his worries about the future, his memories of the past...) and is at times humorous, at times nasty, at others indignant and righteous. He is not a cardboard cut-out, and neither are any of the other characters.

Apart from the personal story of the characters, we have intrusions of the real world, including news, court decisions, that ground the events in the here and now, however universal they might be, but wherever you live and whoever you are, it is impossible not to put yourself in the place of the characters and wonder what you would do, and how much more difficult things are for them because they are not a "normal" family.

This is an extraordinary book, a book that made me think about patients I had known with similar diagnosis, about the difficulties they and their families face (there are not that many nursing homes that accommodate early dementia, and most of those for elderly patients are not suited to the needs of younger patients), about end of life care, and about what I would do faced with a similar situation. The book does not shy away from asking the difficult questions, and although it is impossible to read it and not feel emotional, it tells the story with the same dignity it affords its main character.

Although there is a certain degree of intrigue from the beginning (we do not find the exact circumstances of Hunter's death until very close to the end) that will, perhaps, contribute to reading it even faster, this book is for readers who are interested in dementia and Alzheimer's (although it is not an easy read), who love well-drawn characters, deep psychological portrayals, and stories about families and their ties. A great and important book I thoroughly recommend and another first-rate addition to Mr. Hirschi's oeuvre.

I received an ARC copy of this book and I freely decided to review it. Thanks to the author and the publisher for this opportunity.

Debbie McGowan says

Editor's Review:

This is my editor's review of *Disease* - a novel by Hans M Hirschi, released today: 26th October, 2017. I'm stating that now, in case what follows doesn't read as a review. Indeed, it is a personal account - my qualifications, if you will - for recommending this novel to everyone, including those involved in the care and support of people with terminal prognoses and their families. What we say and do are often not what we

think and feel behind the facade of survival. Note: this novel may cut too close to the bone for patients and families themselves, although perhaps there is some solace to be had from shared experience.

Disease is a truly brilliant novel, and an important one.

I doubt I'm the only person who frets from time to time (more often as I get older) about receiving a terminal prognosis. There are so many potential candidates, and some have already come dangerously close to my life and the lives of those I hold dear. I've lost friends and family; I've waited for the all-clear.

Even without those personal experiences, it's safe to say campaigns to raise awareness of cancer, dementia, heart disease, the danger of strokes etc. have been effective in giving these conditions a higher profile. Sometimes they feed our fear by shoving our mortality in our faces, but mostly they offer hope, in the form of advice on reducing risk, or telling us about the clever people engaged in the search for cures, or of those gifted with the emotional strength to do so who offer compassionate, dignified end-of-life care.

Crucial as all of that is, unless you've been close to it, it's distant and impersonal.

There was a conversation at some point last year, after Nige received his cancer diagnosis. It's vague, only half committed to memory. I don't recall the when or the how, but I do remember him snapping at me, "I'm the one who's got cancer." Whatever I'd said was about my struggle to cope, which was the truth. Who do you turn to for support when the one person who supports you, always and unconditionally, is incapable of doing so? Sure, there are support networks - formal and informal - but that is not who you want, and the petulant child inside stamps its feet and shrieks at the injustice.

I recall seeing an image (no idea where - I read a lot) of concentric circles, with the patient at the centre, immediate family in the next circle, extended family and friends in the next, and so on, with each circle representing greater emotional distance from the patient. The rule is, wherever you fall in the circle, you can only seek the support from those further out than you are.

Needless to say, I didn't mention my own woes to Nige again until after the surgeon gave him the all-clear. Never mind that it was the second time he'd put me through the wringer (his recollection of the first - a dissecting aortic aneurysm - is scant, to say the least). I realise this reads as if I'm blaming him...because I am. Or I do sometimes. I know, on a rational level, it's beyond his control, but rationality comes a poor second to the fear, grief and pain of losing - or believing you are going to lose - someone you love.

It's about the loss of trust as much as anything; you trusted them to love you and not hurt you, to be there at your side, offering strength and support, and the time when you both need it the most, neither of you is capable of offering it. There's a whole lot of acting goes on, and it's Oscar-worthy, but you know each other far too well to fall for it.

He was so upset. He tried to cover it up for me, tried hard not to let me feel just how devastated he is by this latest development. Because it is, in a way, a step toward the end of our relationship, the end of our marriage, our family, a step toward death.

~ Hans M Hirschi: *Disease*

It is for books like *Disease* that I do what I do: for the stories that must be told; the voices that need to be heard. True, *Disease* is a work of fiction, but it is realist fiction grounded in lived experience - a beautiful story with a hopeful ending and an insight for professionals engaged in palliative care and those in the

outermost circles.

I'll leave you with Hans' own words:

Hunter's journey is based on my own experiences with loved ones and reading books about Alzheimer's. I always felt there was something missing from those tales: the voice of the affected. While fiction, I hope to have given those who are affected by the disease the most, a voice.

Cee Brown says

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(٠.★*~.٠.٠★*~) This book is definitely going in my hall of fame.٠★*~.٠.٠*~*~★

I have never cried as much as I did while reading this book. I thought I could survive the emotions, but Hans M. Hirschi have made a liar out of me. I always say I will avoid these types of books, then OMFG, I walk into it eyes wide open.

"I'm dying... A slow death..." ~Hunter

"How do you explain Alzheimer's to someone who doesn't have it? It's really impossible. One moment, you're just like everyone else—talking, having fun, being part of a conversation—and then boom! You forget something, a word, a face, a memory, something that belongs right there, in that conversation. You stand there, in that circle of people, and that which you have forgotten becomes the elephant in the room, with everyone staring at you, waiting for you to remember. And you panic, you get stressed, and yeah, at that point, you'll never remember it anyway."

I have to admit, this paragraph had me in full blown tears. I thought about putting it away and never reading despite my promise to the author. Death is not something anyone runs to, and the thought of it slowly eroding the life of one so young and vibrant. I. Just. Couldn't.

I hurt for Ethan, losing the love of his life. I cried just a little bit harder for Hunter, knowing his life was forever changed. And I bawled for that precious little girl who had to suffer with little to no knowledge of why her Papa was changing.

It is hard thinking about your own mortality and when I think of death and loss, it places a stronghold on my being and I stop and take a few moments to remember and pray. Disease is a difficult book to read. It forces the reader to learn and accept, to become involved and remember. Because it is not just the mind that is affected, it is the body, it is the sense of family withering away, it is losing aspect of life and not even knowing when or how.

Disease is the story of writer/journalist Hunter whose life took a path he never expected and his grief and fears of ending up with a life like that of his mother. It was his struggles and journey to not only remember when the disease took away that part of his life, but a way of chronicling his thoughts and words even when it made no sense. **Disease** was the story of Ethan, Hunter's lifelong partner and his reaction to reading Hunter's words, understanding the role he sometimes played in the man's ever changing world. He shared his

struggles and his pain and sorrow of how Alzheimer's affects not only the victim, but the family and friends as well.

As a medical professional, I have encountered this illness. I have been caregiver to one particular patient and it is heartwrenching and not the best feeling. It makes one examine their own mortality and question: *How brave will I be if this were me?*

I voluntarily and honestly reviewed this book without bias or persuasion from the author.

Tracy Willoughby says

Ever read a book that had you facing a fear you never even knew you had? Hans Hirschi brought this beautiful yet informative story to life about a couple whose normal happy family is about to be turned upside down by a tragic diagnosis that will really have you understanding just how unfair life can be. This book gives a glimpse into the perspective of a couple of events as Hunter deals with his rapidly changing mind that's both heartwarming and heartbreaking. There are a few times that this book had me thinking a little differently on viewpoints I once had. Everyone knows I love Hans Hirschi's book *Spanish Bay* and that it's my favorite book but *Disease* has now taken a spot next to it. The characters in *Disease* broke my heart because I knew somewhere there is a family walking down the same road and facing the same hard decisions as Hunter and Ethan did. I really believe this is a book that needs to be read because it highlights the point that Alzheimer's doesn't care who you are or how old you are and that it's a heartless disease that blows in like a bad storm and leaves a trail of tears and destruction behind it.

A.M. Leibowitz says

I read this book over the course of two days. For me, it was a drop-everything-and-read kind of story. Deeply moving and personal, it is the kind of book that requires focused attention and reflection.

There are plenty of books available that address death and dying, usually from a surviving loved one's point of view. There are also books about being given a fatal diagnosis, often glossing over or never reaching the end, and books from an insider's perspective on living with conditions affecting the brain. However, I'm not aware of many (if there are any) which show dementia from inside the sufferer's head. Certainly none that also address the unique issues facing the LGBTQ+ community when a partner or non-legal parent has Alzheimer's.

The author has a particular knack for storytelling which invites the reader in to experience life deeply through the characters' eyes. So, too, with bringing an almost animate quality to non-living parts of the story. This time, Hunter's Alzheimer's is simultaneously something within him and yet also almost its own being.

It is heartbreaking to watch Hunter's progression from the frustrating brief forgetfulness to his increasingly disjointed patterns of thought. Even though he tells us his story on "good" days, there is still an obvious downward slide as his thoughts become tangled. Ethan's interspersed commentary gives us a much-needed breather and some realism. This plays well into the sense of push-pull between Hunter's desperation in hanging onto his faculties and his losing battle.

The story unfolds journal style, with Hunter providing us as much detail as he can about his worsening condition. He often interjects his existential musings as well, which feels only natural for a dying man. Sprinkled throughout is the repetition of his question on what makes us human. He wonders if it is our brain's wiring, our ability to think in complex ways. This comes up often as he feels himself losing that ability. Yet even as he tells us his views, what he shows us is another story. The thing that makes us most human is our capacity for love. Hunter never loses his, not even in the last stages of his battle.

This is not a story with a traditional happy ending, but neither is it a story devoid of hope. What is evident, even through Hunter's growing paranoia and memory loss, is his deep love for his family. Ethan's gentleness and Amy's sweetness both reflect the kind of man Hunter is at his core. The feelings Ethan expresses at the end are devastatingly real, although I suspect some readers may find themselves shocked by his candid expression.

This book is a must-read for anyone who wants to understand the complexities of living with, and dying from, an illness that slowly robs a person's mind. It is finely crafted in a way that feels respectful toward the depth of emotions.

For a heart-wrenching story, achingly real characters and situations, and a glimmer of hope, this gets 5 stars.

Daniela Steiner says

Once again Hans M. Hirschi succeeds in translating feelings into words and pictures which makes me as a reader participating in the history and fate of the protagonists in a very personal and touching way. Among others I very much liked the way the story is structured which gives the reader the possibility to experience Alzheimer both from the perspective of the directly affected Alzheimer patient and the perspective from the closest relatives and friends.

Hans, thank you very much, that you gave me the chance to read this really beautiful story which made me both crying and smiling.

Paul says

I knew going in that this would not be an easy read. Am I sorry I jumped in with both feet? No!

This is a magnificent book that deals with the very difficult subject of caring for someone with a deteriorating/debilitating disease. Were there moments in the book that brought up painful past memories of my own? Yes. But, I wasn't willing to give up. I needed to finish, for me it was about doing something that I needed to do.

Hunter, Ethan and Amy's story is important. The author does a masterful job of telling their story. This story grabs you and doesn't let go. I don't do spoilers or retell the story, the blurb tells you what you're getting into. Gird your loins and go for it.

If you're looking for a light, fluffy story, this is not it. If you're looking for a story that just might change how you look at the world around you, this may be the story for you.

Dawn Sister says

I received an ARC of this book in exchange for an honest review.

Hans Hirschi's *Disease* is a brilliant and highly emotional journey into a horrible illness, told from the point of view of the sufferer, with snippets of comments added by his husband and daughter.

Hunter is a writer and when he is diagnosed with early onset Alzheimer's he begins to record his life, his daily struggle with his diagnosis, prognosis, the symptoms and how he feels about losing the world and the loved ones around him. His husband, Ethan, finds the diary after Hunter's death, and adds notes to explain some of the difficulties from his point of view, along with some shocking revelations that truly caught me off guard.

Despite what seems like a dire story line with a predictably sad ending, this does not feel like a tragic story. The diagnosis is tragic, of course it is, and knowing that there is no cure, and that Hunter will lose everything before he loses the battle is also tragic, but amidst all the sadness there is a glimpse of a life lived and a soul that loves and is loved in return. It is horrifically sad, but Hans does an incredible job to keep the balance just right.

I cried, oh yes, I cried more than once, and at times had to put the book down and walk away because it upset me so much. I defy anyone who has watched a loved one disappear before their eyes because of this horrible disease not to find this book a challenge to read, but at the same time, it is such an important story because it is told from the point of view of the sufferer. This is something we, as onlookers, never see. We see what is lost to us, yes, but never what is going on in that slowly disappearing mind. *Disease* lets us see this from Hunter's unique perspective, and tells how he feels on a day to day basis. He tells how his world is being slowly stolen away from him and replaced by something no one understands, not even his closest loved ones and least of all, him.

I knew this book would be an emotional roller coaster from the very beginning. There is no massive shock reveal. We know Hunter is going to die. He tells it how it is. It begins with him describing his initial diagnosis and the build up to why he sought help. We then follow him through his ups and many downs. It doesn't bear thinking about just how awful it must be for him to know that he won't see his daughter grow up, or that he will be leaving his husband to raise her on his own. All of these subjects are explored with feeling and a stark reality that is touching and beautiful.

Hans handles all the legal issues of a same sex couple trying to make sure their family stay together and are provided for after a death, with a calm acceptance that is heartbreaking. It isn't enough that they have to cope with Hunter's disease, they also have the legal struggles faced by most same sex couples in this world. Our society needs a kick up the backside when it comes to basic human rights and if you didn't know that already, you need to read this book. This is just one family's struggle.

Hans is a brilliant writer and this book should be on everyone's shelf.

Pauline says

Having lost a friend to Alzheimers this year I approached this with a little trepidation and curiosity. It took me a little while to settle into the format, the sufferer trying with increasing difficulty to document his life as his disease take hold of his mind and his partner who is commenting on the file he has found containing these insights into a deteriorating mind. It can be shocking at times. Just when you are enjoying Hunter's reminiscences you are brought back to reality with a thump. You realise that his wonderful memories will be gone before he is. So many aspects of his life are affected by his dwindling ability to remember. This book introduces us to the hardships of being gay in a society which doesn't rate your love equal to that of a heterosexual's. My friend died before she had completely forgotten who her friends and family were. Hunter is not so fortunate and the change in his relationship with Ethan is particularly hard to witness. How can Ethan be intimate with a man who thinks Ethan is his father? Yet Hunter misses the intimacy in his lucid moments, on a good day. Add into this equation a young daughter who he eventually no longer recognises and you will be wise to have hankies at the ready. I think the ending gives the reader some respite even if it is such a shock for Ethan. My friend died in her sleep before her ability to speak had finally gone. It was a blessing.

This book was given to me in return for an honest review.

Ana says

This book was magnificent. It is very hard for me to find words that could describe why I loved this book so much. I don't think there are enough words to make justice to such amazing book, but I guess I could give it a try.

It was beautifully written. I loved the way it was structured. It alternates Ethan and Hunter's points of view. Ethan's explaining about what Hunter have written. It also was alternates moments in time helping the reader to understand Hunter's experiences growing up and adapting to Alzheimer.

It was a very difficult book to read. It was really painful. When I choose a book to read, I seek for one that will make me connect emotions with the main characters and that will make me live experiences I, possibly, will never live. On that terms, this book made a brilliant job. There were moments when I feel I was there. I got so involved in the story so quickly. I could feel the love, the hurt, and the hopelessness. I could feel every single emotion portray by the author. That's what make it so hard to read, because I could feel the greatest love coming for little actions like lying to Hunter so he doesn't realized he forgot something. I don't think there's another book that made me cry as much as this one.

Another thing that I loved about it was how accurate it was. What is so great about this particular part, is that we are used to see the disease, or at least I am, from the point of view of an outsider. As something affecting others and never us or our family, in the better cases. The book make the reader see things from the person living with Alzheimer's point of view and his family. What it means to get the disease, what it means for his family and the pain they will live, how it will affect the way people will see him, how will affect the ability to be who he is. It was very enlightening.

It was so sad for me to realize that, when the book was a little advance, I was expecting Ethan's response to Hunter's comments every time he write something, to see if it was true. It was fantastic to see how things were gradually changing, but I realized I mirrored the response he got from the doctors when he talk about

how they react to his and Ethan's presence. It make me wonder if I do the same with people I meet with Alzheimer and I hope it'll help me be more human and more self-conscious about the way I treat them.

I don't think there was a thing about the book I didn't like, sure it was full of angst, but it was also full of love. I think, beside the disease itself, the most important subject show the book was the love.

The cover artist made a great job to capture the essence of the book. I loved it. I know there are readers who don't like books with angst and I understand it. But I highly recommend it to anyone, not because of the angst that might have, but because of the human elements it has. It was truly a beautifully written book.

Kenneth Larsen says

I'll let you read the book's blurb for yourself rather than try to recreate a synopsis. Also, I received a copy of Disease for an honest review.

Alzheimer's is an insidious disease. Almost in defiance, Hirschi drops the reader into the story at the moment of diagnosis and never blinks or shrinks from what is going on in Hunter and Ethan's lives from that point forward. Still, there are no lies.

I initially held the book at arms length due to the subject matter, but I needn't have. Yes, it's a difficult book if you think about it, but it's not insensitive or unrelenting. We know from the start what we're in for and Hirschi knows just when to give us a break.

The love, care, and compassion comes not just from Hunter's family, but from Hirschi himself to his readers. "Disease" is a brave book and I definitely recommend it.

Dara Nelson says

Heres the thing. Going into a book that has no HEA, that only hints at intimacy, that deals with a devastating disease, was intimidating, to say the least. In all actuality I was scared sh&\$less to read this. Not only for the content but also because I was afraid I wouldn't like it. I was wrong on so many levels. Was this book hard? Absolutely. One of the hardest books I've ever read. But it was also so damned enlightening that I feel lucky to have read it. Yes, this was a book about a horrible disease, yes, it was about death, yes it was about losing who you are and yes, there wasn't any sex. But, you know what? All of that was secondary to the beautiful, amazing love that was weaved throughout this story like a golden thread in a complex tapestry. You couldn't not see it. You couldn't not feel it. Take a chance. Let yourself try something different. Your heart will thank you in the end. I voluntarily reviewed an advanced copy.
