

The Etiquette of Illness: What to Say When You Can't Find the Words

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What should I say when I hear that my friend has cancer? How can I help but not get in the way? How do I let my loved ones know what I need?

The Etiquette of Illness is a wise, encouraging, and essential guide to navigating the complex terrain of illness. This collection of anecdotes and insights will help those who feel awkward and unsure about responding to a friend, colleague, or relative who is suffering. The book is also for people who are ill and want to engage with their loved ones effectively. We read about a range of people who are dealing with chronic illness, doctor-patient communications, and end-of-life issues-and who are striving to find their way with awareness and compassion.

Drawing on her years of counseling people with serious illness, as well as her own experiences with cancer, Susan Halpern presents an insightful book of the utmost relevance for patients, their caregivers, and their family and friends - a group which will, at some point, include all of us.

Susan P. Halpern is a social worker and psychotherapist. She is the founder of the New York Cancer Help Program and a staff associate at the Commonwealth Cancer Help Program. She lives with her husband, near their children and grandchildren in Berkeley, California. This is her first book.

The Etiquette of Illness is a finalist for the Books for a Better Life award.

The Etiquette of Illness is an Amazon "Editor's Pick" for Best Book of the Year (2004).

The Etiquette of Illness: What to Say When You Can't Find the Words Details

Date : Published April 17th 2004 by Bloomsbury USA (first published 2004)


ISBN : 9781582343839

Author : Susan P. Halpern

Format : Hardcover 256 pages

Genre : Nonfiction, Health, Self Help

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Lici says

This is a nice book. Each chapter addresses a unique issue within the topic of illness. It is written not only for those who are well and are wondering how to approach someone with illness but also for those who are ill and not sure how to deal with others around them. There are no grand revelations or rules given in this book. She uses story after story of people in these circumstances to nudge the reader into seeing how life looks through the lens of illness (and that it is different for everyone.) I would recommend this book to anyone who is dealing with illness or death for the first time or having anxiety about what to say or do for a friend facing illness or death. It's a generous and gentle approach for overcoming your shortcomings and being the most compassionate person you can be for the people you care about.

Jc says

This book does exactly what it sets out to do. I couldn't ask for more. I think that it is necessary for a book of this sort that is built on such personal experience to be flawed in its presentation because people are flawed. I was happy to read of the many errors and triumphs the real people become involved on. I recommend this book to anyone who is dealing with illness and feels even a little befuddled by the whole process.

Dee Renee Chesnut says

The Etiquette of Illness was recommended to me when I read *The End of Your Life Book Club*. It also had the recommendation of Dawn, a www.goodreads.com reviewer who recommends it to all readers of a certain age.

I knew I needed to read this book because I tend to give too much advice that begins with the phrase, "What you ought to do..." or I avoid people with illness or people who are grieving. I have been taught avoidance by the best, and it is high time I learned better ways. I still found myself arguing with the book when the author's suggestions are not something I felt I could do.

The book gets 4 stars for discussing the topics in its 7 chapters.

Krista Stevens says

This edition was published in 2004, there is a more current one and I am curious how it has been updated. With today's social media, I think the book would be very different. Email is barely mentioned.

Because I am already been well-acquainted with both dying and death, this book did not offer me any fresh perspectives. However, for those who are uncomfortable with their own and other's illnesses and pending deaths, this might be a great book. Lots of short anecdotes, though a little too saccharine for my liking. The advice of what to say, how to say things, what not to say, how to help, how to tell children are clear and concise.

Annette Reynolds says

This is a well-written, easy-to-read book on what to do to help yourself and people you know/love in the face of severe illness or imminent death.

Written in the first person using the author's own experiences with her cancer diagnosis, she also adds many other stories from other people who have gone through it all and what made them feel better, what helped, what didn't help when it came to friends wanting to do the right thing.

The book is a good guide for anyone - sick or not - because the author tells ways to ask for help as well as how to ask HOW to help.

The author's style is compassionate and kind, and the book doesn't read like a how-to manual.

My only complaint: the book is poorly formatted (lines aren't justified, making the book look jumbled and messy), and there are quite a few typos or missing punctuation marks throughout.

Camie says

3.5 stars. Because I have worked as a registered nurse and worked with lots of very ill people , I didn't feel like this book provided me with too much new information although I 'm sure many people will find it very helpful. It has many stories with great examples of how to best deal with different people and the circumstances of their different needs during illness. Because I have a chronic illness I found the chapter pertaining to it most interesting , having experienced in my case that most people simply ignore the fact that I am ill. I understand that many people just indeed do not know what to say or how to help. My favorite line in the book was on page 3." The simple phrase , I don't know what to say , can be the catalyst, and everything can flow from there ." I think this is something that could be helpful in many situations not just with those who are ill , but anyone who we wish to help in time of need , or even just reconnect with , or apologize to. How many times have we thought of someone and let that moment go by because " we don't know what to say . " Overall a good read.

Laura Siegel says

I read this book over about a six-month period-not because it is slow but because it is one to savor. It is divided into short sections and I enjoyed reading a bit each day. The book deals with people who are ill, have disabilities or are caregivers. It covers how to communicate, ask for what you want and don't want, how to respect each persons individual needs. The author herself has dealt with lymphoma. I found it very helpful in navigating all kinds of personal situations.

Cyndie says

What do you say to someone you care about who is dealing with illness, disfigurement, or the possibility of death? I'm sure I'm not alone in not knowing what to say or how to handle the situation in a way that is compassionate and caring. What do you say? Is it more polite to say something or not say something? This book gets at the heart of these challenges and gives specific tips but also general advice about how to continue to show needed love and caring while being respectful of the other person's needs. Fantastic. Should be required reading for every human being. Great insights for doctors as well.

Shirley Freeman says

A friend lent me this book after it was recommended in "The End of Your Life Book Club" by Will Schwalbe. I plan to get a copy as a reference. The author has survived lymphoma and has interviewed many patients, former patients and family and caregivers to find out best practices for responding to people who are ill - chronically, terminally or temporarily. There are some specific suggestions for things to say and do and things Not to say and do but most of the advice is more situational. Some people want to be asked about their illness, some people don't, some change their minds depending on various parameters. The key seems to be to use common sense, forgive yourself and others, check in with the person who is ill and simply ask, "do you want me to ask how you are feeling today?" Our responses should be in proportion to the already established relationship - i.e. different etiquette for your best friend vs. an acquaintance. Most of us need a dose of common sense in times of stress - this book will help.

Bdalton says

I read about this book in The End of Your Life Book Club by Will Schwalbe. There is a tremendous need for a book that addresses how to best support people with serious illnesses. In addition to providing valuable phrases (the "what to say when you can't find the words" of the title), Susan Halpern provides the stories of many caregivers and people dealing with a variety of illnesses. These stories may provide comfort and confidence to those seeking the words to ask for what they need.

Halpern does not provide a succinct rules of etiquette. Instead, advice is found throughout the point. Here is a small list of the do's and don'ts found in the book:

1. "It is tempting with illness, to quickly pass on what we know. But it's important to check carefully each time to learn whether the person with the diagnosis wants it known. Why do we violate the privacy of others so freely with illness? it is not our place to relieve our discomfort by intruding on someone else's privacy." Allowing people to share their own story with whom they want when they are ready preserves dignity. If someone was raped or assaulted, would people share that story so freely? Or, would they be protective of the attacked individual's privacy during a difficult time? The same ethical considerations apply.
2. "In the arena of helping, it is important to gauge your giving. ...I am a strong advocate for doing something when you hear a friend is ill, I would add that it is important to keep your assistance in line with what's possible for you and respectful of your sick friend's ability and desire to care for himself or herself, as well as congruent with your relationship."
3. "Family and friends, out of their own desire to fix, cure, and be helpful, often give advice...This directives arise from the best of intentions, but they are not respectful of the needs of the diagnosed person."

4. "To ask, "How did you get this?" is not appropriate. ...There are few of us who know what caused our cancer or chronic illnesses. Whatever we did, millions of other people do without getting sick."
5. "Let the wishes of the person who is ill be the guide, not your agenda. Over time, a person who is ill has changing needs and the ability to help changes. From time to time, ask the question, "What can I do?" again."

Halpern's basic advice is to be honest, kind, caring, and respectful of the ill person's wishes. If you or someone you know is not behaving in a manner that is in keeping with these principles, then you are behaving in a hurtful manner to someone who is already struggling. If you are sharing information about a person's illness without their consent and asking others to hide this revelation from the sick person, then you are asking others to join you in treating the ill individual disrespectfully and in a manner that will foster distrust. If you are the person receiving the information, you can always tell the "sharer" that you will let the person know that the "sharer" has told you about the illness. In that way, you need not participate in gossip or a request that compromises your integrity. Halpern says that if you are worried that you have made a mistake, you can always try again.

One out of every two Americans will have a chronic or life-threatening illness in their life. Learning how to ask others to treat us when our turn comes, is incredibly important. Improving our ability to respond politely and compassionately is important both professionally and personally. Everyone can benefit from reading *The Etiquette of Illness: What to Say When You Can't Find the Words*.

Cagne says

Somebody told me books like this are possibly a waste of time, but there is no end to how awkward I can feel. Overall it's a collection of single episodes, experiences, arranged by themes, to give you a bit of an idea of human interaction when one of the people is sick. Starting from the idea of prepping myself, I was surprised upon reading the parts from the point of view of the person with an illness, but they are equally useful.

Things I found interesting/useful:

- the warnings against trying to help too much, against making the receiver feel more uncomfortable with their condition.
- the importance of exposure of kids to death.
- dealing with people crying, specially the list of the appropriate/unappropriate things to say.

In the end, the book might not reveal to you anything you don't already assume or know, but it's still a needed immersion into the description of an experience, to get your bearings and feel less out of place in... hurt.

It's also a beautiful looking book. Size, cover, text... The note about the font, Adobe Caslon, made me take a step into e-readers and fonts.

Elyse Walters says

Update:

This is not a book about Cancer!

This is not a book about treatments!

This book is useful in be speaking appropriately to a person who is sick.

This book is for a person who 'is' sick to support 'asking' for what they need from others.

This book has great little examples of things not to say -not to do -
what do do -when to do -

This book has several stories for readers to connect with -think about -and relate to.

I give this book as a gift 'with' a couple of other books (as a package) when looking for gifts for those who are sick.

As another Goodreads member, (Hikerdee), has posted ---She also first heard of this book when she read "The End of Your Life Book Club" (A FANTASTIC-FANTASTIC BOOK).....by Will Schwalbe.

When I read the 2,000 +++ reviews on Amazon about 'THIS' book, "The Etiquette of Illness", with an average of 5 stars, I knew I not only needed to read it-own it--but also call our local "Center For Spiritual Living" book store and tell them to order 'tons' of copies for 'their' book store. (I knew they did not carry this book). They've ordered it!

This is a book which makes a difference! (for people who ARE sick ---and for people who have friends and family members who have an illness)

Last year, *two* friends had Cancer of the pancreas. (both are now doing well).

This year (within the last few weeks) ---*two* friends have told me they each have Cancer. Patty has bone Cancer.

I know her from taking workshops together at "The Center for Spiritual Living"

Ofrit (a close friend), from Israel, has Breast Cancer ---which as come back from last year. I will be going through the long journey with her during her 4 months of Chemo. (plus twice a week we will walk together).

I'm at the age (60) where I feel its my responsibility to read this book. If I had not read this book 'before'....the time sure has come!

Rosemary says

I have intended to read this book as it came into my consciousness over the years. I finally got it out from the library. If you are now, or ever think you might be, dealing with loss or death in your life or in a friends' life, or a family members' life, this is a wonderful resource teaching how to be in such times. What questions to ask. How to hold open the ambiguity. Letting the person who is ill or dying decide what particular conversation makes sense. Whether it's a deep and soulful accounting, or a trashy discussion of the latest tv drama. I am glad I read it. I hope I am a better friend/family member/confidant/confessor because of this book.

Mary says

A wonderful read for caregivers, hospice workers, and people with chronic/terminal illness. As a caregiver, I found all of the chapters worthwhile. However, I would recommend specific chapters - talking to children, death and dying, what to say, etc for specific people. Some clients will want/need to read the whole book, others would be helped with specific chapters. Still others may want to read the book over a period of months or years.

Having read this book over the weekend, I found myself using it with 4 clients today. Wow! This text encouraged me to have frank conversations about chronic illness and death/dying with several clients.

I think that the most important thesis from this book is to take the risk to say what is in your heart. Susan Halpern encourages us to act or speak if you have the inclination. Whether it is reaching out with a card, word, or action - she reminds us to be our best (and bravest) selves and reach toward our friends and relatives.

Thank you Susan - for an easily readable text that takes the terror, uncertainty, discomfort, and fear out of difficult conversations and gives the reader the courage (and some prompts) to speak to those who are ill among us.

Jeannette M. Hartman says

This is a helpful, handy book for those times when someone you care about is facing a serious diagnosis, a difficult chronic condition or a terminal condition. Author Susan P. Halpern, a psychotherapist who has led or founded a number of cancer support groups and has herself been treated for lymphoma, is clear that there's no rote prescription that can cover all circumstances. Her many anecdotes demonstrate a variety of approaches, some that worked and some that didn't. Ultimately, this book shows that it is better to reach out than not and that we have more options than we might realize to support someone who is ill.
