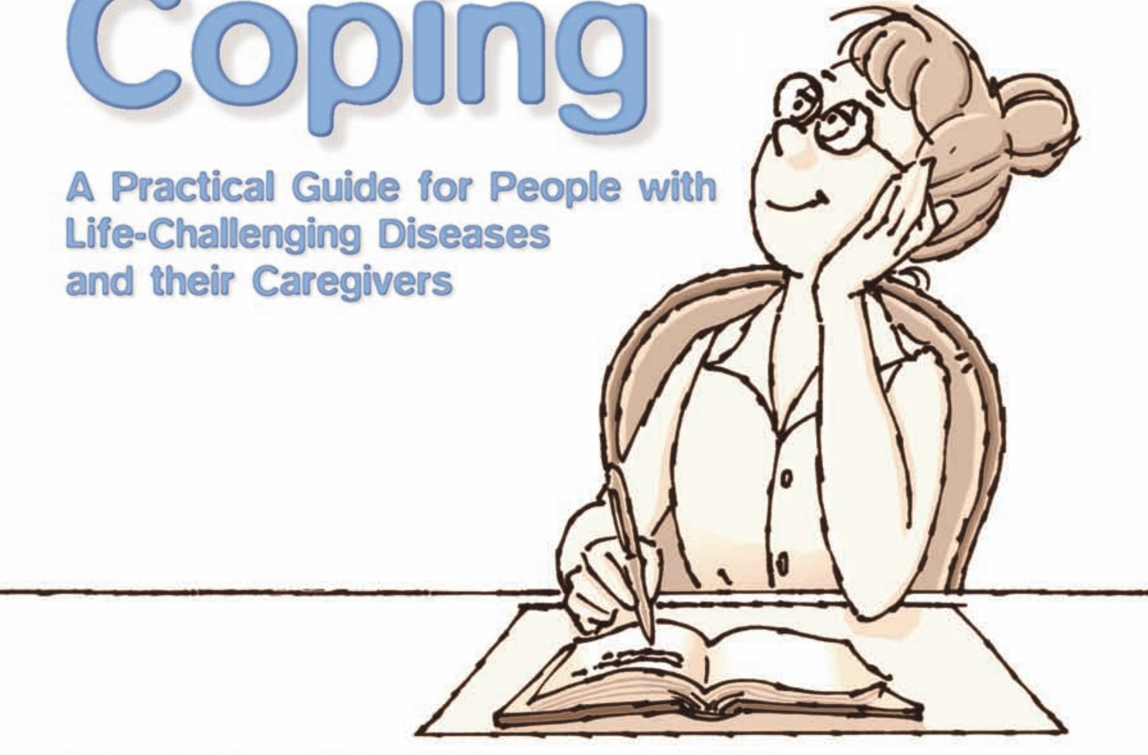
Coping

A Practical Guide for People with Life-Challenging Diseases and their Caregivers



Rubin Battino, M.S.

Foreword by Carl Hammerschlag, M.D.

"An excellent source of information and wisdom."

Bernie Siegel, M.D., author of
Love, Medicine & Miracles **and** *Prescriptions for Living.*

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Preface

At last night's meeting of our exceptional patient support group there were three new members: a man in his late sixties with a recent diagnosis of cancer, his wife of over forty years, and one of his sons. Attending the support group was just one of the many things Sam (not his real name) and his family are doing. They are seeking second and third opinions at major cancer centers, and they have begun the arduous search for information on his particular cancer. What else can Sam and his wife and family do? Fortunately, at this stage, Sam's attitude is upbeat and hopeful. Feeling hopeful enhances the body's capacity to fight disease. Feeling hopeless and helpless and out of control diminishes this capacity. This book is a compendium of the many ways you can cope (rhymes with hope!) with a diagnosis of, living with, and fighting a life-challenging disease. There are many things that Sam and his caregivers can do to face this challenge. The Viennese psychiatrist Viktor E. Frankl has pointed out that we have no control over what challenges life may present us, but we always have the choice of *how* we will respond. This book is also about choice.

The introductory chapter covers some material about the words we use, like useful distinctions between disease and illness, and also between curing and healing. The scientific evidence for attitude being helpful, as manifested in David Spiegel's work on support groups, provides the basis for recommending the many varieties of coping discussed later in the book. Relaxation has been shown to enhance the body's defenses—Chapter Two is about several relaxation methods. This chapter ends with a few scripts for relaxation. (A recording of these scripts by the author is available.) Support groups are described and discussed in Chapter Three. Groups come in many styles and formats—you are urged to find one that feels comfortable to you.

Chapter Four contains the beginning of activities that are helpful for coping. These include journaling or writing in a diary, several structured writing instruments that are designed to organize your thinking, the use of videotaping and autobiographies, art therapy, and rituals and ceremonies. Some of these activities you would do alone, whilst others require organizing with other people.

The heart of this book is Chapter Five where many varieties of coping are discussed, some in much detail. How do you survive in a hospital, cope with insurance companies, communicate with family and friends and medical personnel, set up a support network, and live and die well? In the Alice-in-Wonderland world of a serious disease, many things change in your life. These are not only the physical manifestations of the disease, but also relationships with others and, most importantly, your sense of self. Chapter Five provides guidance in dealing with these matters.

Nutrition is always important. The knowledge and experience of H. Ira Fritz, Ph.D. in this area is a plus. There are many appendices with helpful information including: a sample living will, a sample durable power of attorney for health care, and websites and phone numbers of resources.

Mario Uribe's illustrations provide a pleasant punctuation of the many themes in this book. Mario and I talked about this project over fifteen years ago, and it is wonderful to have him 'illuminate' the text.

Members of the Charlie Brown Exceptional Patient Support Group of Dayton have been helpful in reading some portions of the material, but mainly in their love and support of me as a person. Jane Brown has read the book in its entirety and her comments were helpful. Bernie Siegel supplied a number of useful suggestions. K'Anna Burton's sharing of her surgery story is appreciated. I owe special thanks to my friend Carol E. Dixon. Her comments, based on her experience in helping establish and administer hospice of Dayton, shaped the style and content of this book. Almost every page bears the mark of her suggestions.

Your comments are always welcome. My e-mail address is: rubin.battino@wright.edu.

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Yellow Springs, Ohio

Chapter Three
Support Groups

3.1 Introduction

Everyone's needs are different. The group must *feel right* to you on some personal level before you make any commitments about attendance. Most hospitals offer support groups and/or services to people who have cancer or other serious diseases. These hospital-based groups may be solely for the patient, solely for those who support the patient, or for both. These groups are generally free of charge.

There are many support groups organized around a particular disease like emphysema, cancer, colorectal cancer, asthma, etc. These groups are generally associated with a national organization, e.g., The American Cancer Society. Usually there are no fees. Typically, the specialized support group meetings are heavily oriented towards information about the disease and coping with it. Support groups may be classified by the amount of time spent on information and lectures versus the amount of time spent on emotional or psychological support. This is why it is so important to check out support groups, and be open to going to groups with different styles as your own needs change. Above all, it is important to recognize that seeking help and support is an indicator of *strength* on your part, and is one area under your control. Although the members of a particular group may be quite ill indeed, the atmosphere is generally that of hope and courage—they are brave people who have gone through or are going through whatever is your specific disease. You learn from each other's experience. These are generally not 'downer' groups, and there is a surprising amount of humor present—this 'in' group can share jokes or so-called 'black' humor which they would find to be uncomfortable in the presence of healthy people. This is an important point, since a person with a disease frequently feels isolated and different and even stigmatized with respect to 'healthy' people. There is a sense of unreality, of separateness, of estrangement. On some core level they do not recognize themselves—the disease has transformed them into a different and strange person. It is not so long ago that these people were ostracized, isolated, and driven out of their communities. Recall the history of the way that people with leprosy and tuberculosis were treated. Echoes of these old behaviors and fears still reverberate.

There are a number of psychotherapists and social workers and other helping professionals who offer fee-for-service assistance for people who have life-challenging diseases and those who support them. Sometimes this is ‘straight’ psychotherapy for the individual or their family. Sometimes they offer programs for grieving, and sometimes there are privately run support groups. These groups may reflect the particular orientation of the provider in terms of affiliation, nutrition, body work, and alternatives to conventional medicine. Always remember that you are in control and that the choice to use or stay with a particular practitioner is yours. Michael Lerner′s book (1996) is the essential guide to evaluating complementary practices for cancer. As far as I know, there is nothing like Lerner′s guide for other diseases.

In this chapter, several specific support groups or styles will be described.

3.2 David Spiegel’s Breast Cancer Support Groups

Spiegel et al.’s support group (1989) for women with metastatic breast cancer is a classic psychotherapy-based group. (Spiegel et al.′s research is described in Section 1.4.) Such a psychotherapy group is run by a trained psychiatrist, psychologist, counselor, or social worker with typically two leaders working with a group of 10 to 12 participants. Meetings are weekly or biweekly and run for a fixed time period of 10 or 12 sessions, or from three to 12 months. Participants make a commitment to attend all of the sessions. Once a group has started, new members are rarely admitted, since the group quickly establishes an identity and a strong group loyalty. In a disease-based group (versus a psychotherapy-based group), the members are encouraged to be in contact with each other outside of the meetings.

The Spiegel groups met for 90 minutes. Although other groups may meet for longer times, up to three hours per session, it is rare that a group would meet for less than 90 minutes. One reality constraint is that 90 minutes may be as long as a person with an active disease can comfortably attend a meeting. In the Spiegel groups, an extra measure of rapport was attained by having one of the leaders be a person who had breast cancer in remission.

The following quote from the 1989 paper describes the nature of Spiegel et al.'s group interventions:

> The groups were structured to encourage discussion of how to cope with cancer, but at no time were patients led to believe that participation would affect the course of the disease. Group therapy patients were encouraged to come regularly and express their feelings about the illness and its effects on their lives. Physical problems ,including side-effects of chemotherapy or radiotherapy, were discussed and a self-hypnosis strategy, was taught for pain control (Spiegel, 1985). Social isolation was countered by developing strong relations among members. Members encouraged one another to be more assertive with doctors. Patients focused on how to extract meaning from tragedy by using their experience to help other patients and their families. One major function of the leaders was to keep the group directed toward facing the grieving losses.

This is a succinct statement of the way these groups functioned. As pointed out in Section 1.4, the results were remarkable—which establishes the effectiveness of psychotherapy-based support groups for working with cancer patients. The Spiegel support groups were run by trained psychotherapists. Although it is not necessary, the inclusion of group leaders who were models of healing, in that they were in remission from the same disease, must have been an important contributory factor.

3.3 Exceptional Cancer Patient (ECaP) Groups

ECaP was started by Bernie Siegel in 1978. His initial motivation came from a patient who said, "I need to know how to live between office visits." Initially, ECaP was financed by Bernie (who prefers to

Chapter Five
Varieties of Coping

5.1 Introduction

When a person is diagnosed with a life-challenging disease, he enters a whole new world from his normal everyday existence. There are new priorities and demands, which seemingly cannot be postponed or scheduled for his convenience. Appointments for visiting doctors and getting treatments and being tested have to be made and kept. All other day-to-day tasks must be re-scheduled around the appointments. If a surgery or surgeries are involved, then there are hospital stays and recuperation periods. There are changed and changing relationships with family and friends. There are the hard realities of finance and insurance and employment. There may be things like a changing body identity to adjust to in the case of mastectomies or colostomies or amputations, or just a decreased capacity to do everyday things like walking, going up and down stairs, playing sports, taking a shower, or going to the toilet. And most important are the emotional ups and downs, the fears, the anxieties, the hopelessness and helplessness, the depression, the threat of death, the endless ‘why’ questions, and the sense of unreality that seems to preclude everything else. You have just been forced to step through the looking glass into a dream world that operates with its own strange rules. How do you cope? How do your family and friends cope?

This chapter is a collection of many things about coping. It is written both for patients and caregivers. Patients and caregivers will find many practical ways to cope.

For your guidance this paragraph lists a number of sources on the subject of coping. LeShan’s 1989 book contains an excellent chapter (pp. 80–100) on dealing with hospitals and the medical establishment. This is summarized in the next section. The American Cancer Society and the National Cancer Institute of the NIH have free pamphlets on coping, as do support groups for other diseases.

Appendix B lists a number of websites and contains useful phone numbers. Milstein's book (1994), *Giving Comfort, What You Can Do When Someone You Love Is Ill*, is an excellent compendium of practical coping ideas. In fact, there are over three hundred numbered suggestions in various categories. Unfortunately, this great book is out of print. Some of her suggestions are given in Section 5.3. Doka (1993) has written a comprehensive and resource-full book whose title is descriptive: *Living With Life-Threatening Illness: A Guide for Patients, Their Families & Caregivers*. At the end of this chapter (Section 5.28) is Doka's list of the phases of a life-challenging disease—you may find this to be a useful guide. Doka has written (1993, p. 11), "Life-threatening illness is inevitably family illness, for the life of everyone within the family is changed when one member of a family experiences disease."

5.2 LeShan on How to Survive in a Hospital

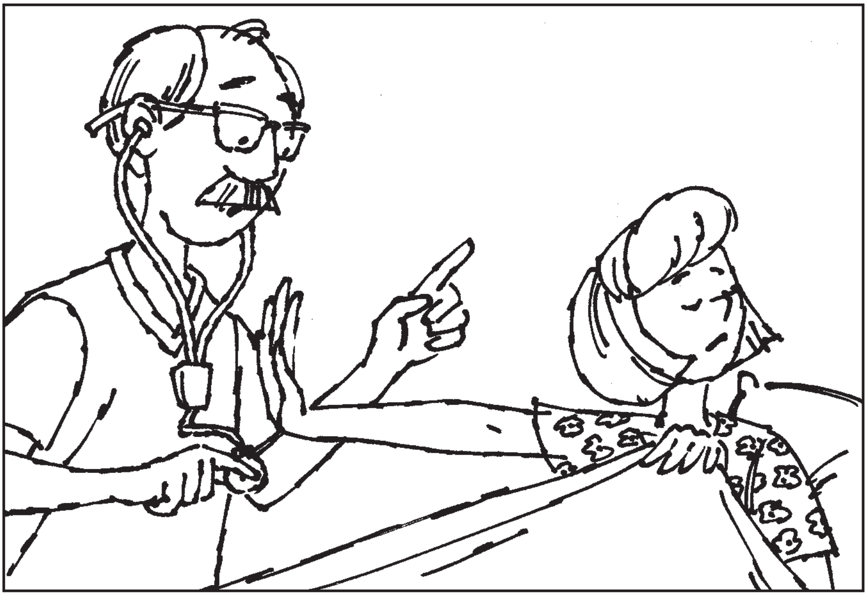
Based on his many years of working as a psychologist with the terminally ill in hospital settings, LeShan (1989, pp. 80–100) has much helpful advice to give on how to survive in a hospital. This is summarized in what follows as a series of bulleted items.

- [with respect to hospital philosophy] They define a *good* patient as one who accepts their statements and actions uncritically and unquestioningly. A *bad* patient is one who asks questions to which they do not have the answers, raises problems with which they are uncomfortable, and does not accept hospital procedures as necessarily wise, useful, or intelligent. There is a tremendous pressure on the staff to regard the institution's rules as correct and the individual patient who objects to them as wrong. (p. 81)
- … if possible have a friend or a relative who can be your advocate. (p. 87)
- Before you enter the hospital, there are certain facts you should have and certain questions you should ask. 1. Who is the physician who has the overall responsibility for your care? 2. What is the diagnosis, and how certain of it is your physician? 3. What is the usual course of the disease, both with and without therapy? 4. What are the side effects of the therapy? 5. What alternatives exist? … Will the physician's course of action

change depending on the results of the test? *If not, there is no reason to take it*.… Remember that the hospital is in the business of selling services, and these include diagnostic tests.… The search for a diagnosis may acquire a life of its own … The more tests that are performed, the more likely the results of at least one looking unusual. (pp. 88–90)

- When you are speaking to a physician about an illness, keep checking to make sure that you are hearing each other.… Do not let yourself be ignored if there is something that the physician should know or should be paying attention to. The word *no* is powerful.… You must also control the number of people who will give you physical examinations. The resident on service needs to examine you because if anything goes wrong he or she has to make quick decisions and so must know your body from direct examination. Ask your personal physician if there are any other physicians who *must* do this. (pp. 91–92)
- On the pad of paper on your bedside table, have your physician list all of the medications you are supposed to get, at what times you get each, and what each looks like. (p. 92)
- Find out what diet you will be on and whether you can have food brought in from the outside. (p. 92)

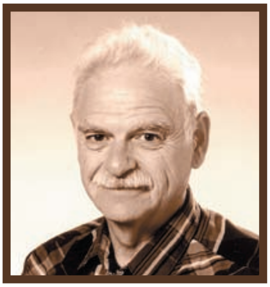
Figure 5.1: I'm sorry—you can't examine me.



Coping is a practical guide for those living with or dealing with life-challenging diseases. Detailing the many effective coping strategies that Professor Rubin Battino has encountered during his extensive professional experience—from friends and support groups, from research and from practice—the book features a wide range of techniques, methods and exercises that have proved to have a healing influence. These include:

- Guided imagery
- Alternative medicine
- Support groups
- Art therapy
- Nutrition
- Meditation
- Structured writing
- Acupuncture
- Relaxation methods, including Jacobson's Progressive Relaxation technique and Benson's Relaxation Response Method.

Packed with invaluable advice on practical subjects such as communicating with medical personnel, and concluding with an extensive appendix of useful contacts, ***Coping*** is simply an invaluable reference and companion for everyone dealing with a life-challenging disease. A complete guide to facing serious illness with resourcefulness.



Rubin Battino, M.S. has a private practice specializing in very brief therapy in Yellow Springs, Ohio. He teaches courses in The Department of Human Services as an adjunct professor at Wright State University, and is president of The Milton H. Erickson Society at Dayton. Rubin serves as a facilitator of The Charlie Brown Exceptional Patient Support Group at Dayton, Ohio. His other books published by Crown House Publishing include ***Ericksonian Approaches*** and ***Guided Imagery.***

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