

Understanding Chronic Illness

The Medical and
Psychosocial Dimensions
of Nine Diseases

Toba Schwaber Kerson, D.S.W.
with Lawrence A. Kerson, M.D.

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This book is in memory of **Joseph Schwaber Jr.**, who fought the good fight with great dignity and with trust in God and his doctors; and for **Jennie Kerson**, who still believes that Daddy, the doctor, can heal any hurt.

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Introduction

CHRONIC DISEASES ARE long-lasting; they affect and even disrupt the lives of the ill individual and those around her.* The word “chronic” has nothing but negative connotations. People are described not as chronically happy or healthy but as chronically depressed or ill. Caused by nonreversible pathological alterations in the body, chronic diseases generally require long periods of supervision, observation, care, and rehabilitation. Most are characterized by periods of recurrence and remission. Because there are rarely cures, the goal of treatment for these illnesses becomes control of the progression of the disease, which means its tendency to involve and damage increasing amounts of body tissue. Chronic illness is often marked by a loss of physical or mental ability, which curtails a person’s capacity to look after her needs. Each disease disables differently, so much of the impact a chronic illness has on the life of an individual and her family members is inextricably bound to the facts of the particular disease.

Understanding Chronic Illness is written for people who face decisions affecting others who are chronically ill: those dispensing medical care, those in positions of authority in the community, and those who seek to be better informed in their relationship with the chronically ill. A social worker who has to decide whether a child can continue to live with her grandmother who has had a stroke; a manager who must decide whether

*Because no single word exists for he/she or her/his, and the use of those solutions seems heavy-handed, I will generally alternate, using “her” and “she” as representative of both sexes in some chapters and “he” and “him” in others. This introduction will use “her” and “she” as the general terms. The pronoun used has no bearing on the incidence of the disease discussed among males or females.

to permit someone who has cancer or heart disease to return to work; a teacher who must decide how to explain a student's seizures to the rest of the class; or a minister who must counsel a despondent congregant about her husband's emphysema are examples of readers who should find help here.

The book describes the medical, social, and psychological aspects of nine chronic diseases: arthritis, cancer, dementia, diabetes, epilepsy, heart disease, respiratory illness, stroke, and substance abuse. These illnesses were chosen because they are among the most devastating of the chronic diseases with greatest prevalence. Each affects several million people in the United States. Sinusitis, the chronic condition with the greatest prevalence in the United States (about 31 million), is not usually devastating, so it was not included. Multiple sclerosis can be devastating, but the Multiple Sclerosis Society estimates its prevalence at less than 250,000, and the National Center for Health Statistics at less than 100,000, so it also is not included. End stage renal disease (about 60,000) and sickle cell anemia (about 50,000) are not included for the same reason.

Some of the included diseases rank high among causes of death in the United States. In 1982 the National Center for Health Statistics reported the ten leading causes of death as heart diseases, 38.2 percent; malignant neoplasms (cancer), 21.9 percent; cerebrovascular diseases (stroke), 8 percent; accidents, 4.8 percent; chronic obstructive pulmonary diseases and allied conditions (respiratory illness), 3 percent; pneumonia and influenza, 2.5 percent; diabetes mellitus, 1.7 percent; suicide, 1.4 percent; chronic liver disease and cirrhosis, 1.4 percent; and arteriosclerosis, 1.3 percent. Although some of the diseases included in this book are not on this list, suffering from one of them can place a person at greater risk for these high-mortality diseases. Diabetes puts one at greater risk for heart disease and stroke, for example, and alcoholism increases the risk for several of these illnesses, including liver disease. In March 1983 the Department of Health and Human Services announced that Alzheimer's disease and its complications cause 100,000 deaths a year. Although the mortality statistics for such illnesses as epilepsy and arthritis are not high, the degree of disability and the impact on the life of an affected individual are great.

Framework for Understanding Chronic Disease

Each chapter loosely follows the following outline as a guide for presenting information on the medical, social, and psychological aspects of a chronic illness:

- I. Medical Information
 - A. Description of the disease
 - 1. Definition

2. Classification
 3. Etiology
 4. Prevalence and incidence
 5. Populations at risk for the illness
 6. Association with other diseases
 7. Prognosis
 - B. Natural history
 1. Stages
 2. Symptoms
 - C. Diagnostic procedures
 1. History
 2. Physical examination
 3. Laboratory tests
 - D. Treatment
 1. Drugs
 2. Surgery
 3. Radiography
 4. Other
 - E. Anticipated course of the treated disease
- II. Psychosocial Information
- A. Modifications in life-style
 1. Diet
 2. Exercise
 3. Restraint from activity
 4. Restriction from activity
 5. Sleep or rest patterns
 6. Relaxation techniques
 7. Daily schedule
 8. Other
 - B. Impact of the disease on social life
 1. Legal aspects
 - a. Restrictions
 - (1) Driving
 - (2) Marriage
 - (3) Training or work
 - (4) Other
 - b. Protection
 - (1) Right to work
 - (2) Right to retraining
 - (3) Guardianship
 2. Social aspects
 - a. Insurance
 - (1) Medical
 - (2) Life
 - (3) Automobile
 - (4) Social Security disability
 - b. Relationships with others
 - (1) Family members

- (2) Strangers
 - (3) Increased dependence
 - (4) Increased confinement
 - (5) Isolation
- c. Work
- d. Diet
- e. Recreational activity
- f. Daily schedule
- 3. Psychological aspects
 - a. Self-concept
 - b. Particular psychological responses
 - c. Stages of psychological response
 - d. Sexual response
 - e. Changes in appearance
 - f. Changes in mood and affect
 - g. Other

III. How to Be Helpful to Someone Who Has the Illness

The first part of each chapter presents medical information, with an emphasis on clarifying the decision-making processes of the medical team. The disease is defined, and information about mortality, progression, and predictability is presented. The classification involves a breakdown of the broad term into specific types. For example, diabetes can be classified as insulin-dependent or non-insulin-dependent, and cancer can be assorted into more than one hundred categories based on anatomic site and type of tumor. Both prognosis and treatment plan depend on classification.

Etiology or cause of the disease is discussed, although often little is understood about causation. The prevalence and incidence of each disease and its main categories are also described. Prevalence means the number of people who have the particular disease or type at a specified time, and incidence refers to the number of new cases of a disease in a given year. Unless otherwise stated, reported statistics are for the United States, and the source for almost all of them is the National Center for Health Statistics. Particular populations who are at risk for contracting the disease are described as well. For example, women whose mothers or sisters have a history of breast cancer have a greater chance of contracting breast cancer than women without a family history. Smokers have a far greater chance of contracting lung cancer than nonsmokers, and people with uncontrolled hypertension are at greater risk of a stroke than those with normal blood pressure. Next, the prognosis or forecast of the probable course of the disease is presented.

The natural history, the course the disease would take if left untreated, is described in terms of stages and symptoms. Particularly addressed are the frequency and duration of pain, sensory loss, inability to control bodily functions, behavioral changes, mood changes, changes in thought processes, fatigue, and weakness.

The means used to arrive at a diagnosis are described: the symptoms the physician looks for in history-taking, the particular findings the physician looks for in the physical examination, and the tests used to support or rule out the diagnosis. Possible complications resulting from tests are also noted.

The discussion of treatment touches on measures directed at both decreasing the likelihood of a recurrence or progress of the disease and preventing or controlling symptoms. Drug, surgical, and radiographic therapies relevant to specific diseases are discussed. The means presented for diagnosis and treatment represent the standard of medical practice in relation to each illness. The final topic of the medical section is the anticipated course of the treated disease.

The second section of each chapter discusses the social and psychological aspects of the disease. First addressed are the kinds of changes one must make in life-style to adapt to the illness. Diet, exercise, climate change, restraint from or restriction of certain activities, sleep or rest patterns, recreational activities, and daily schedule are among the areas where changes may occur. Examples of life-style changes are the special attention to diet demanded by diabetes and the importance of a specific kind of exercise program for someone with rheumatoid arthritis.

Federal legislation affects the rights and entitlements of many people who are chronically ill. Especially important are the several titles of the Social Security Act relating to aid for the chronically ill such as Medicare (for those over sixty-five), Medicaid (for the indigent), Crippled Children's Programs (for certain handicapping conditions), and Disability Insurance (for those whose severely disabling conditions prevent them from working). Although most individuals are covered by health insurance through the workplace until retirement, the likelihood of contracting one or more chronic diseases rises with age, so many of the chronically ill, being elderly, are insured through Medicare. Medicaid covers the poorest segments of society, especially impoverished dependent children and those (most often elderly people) needing custodial care. Medicare, Medicaid, Crippled Children's Programs, and Social Security Disability Insurance will now be explained briefly in general terms.

Federal Medical Insurance Programs

In 1966 Congress passed Titles 18 and 19 of the Social Security Act. Title 18 called for the establishment of Medicare, and Title 19 the establishment of Medicaid. The Health Care Financing Administration, under the Department of the Health and Human Services, is responsible for the Medicare program, federal participation in the Medicaid program, and other health care programs. Both Medicare and Medicaid are important for those

who are chronically ill, Medicare because the likelihood of chronic illness increases with age, and Medicaid because it is for the poor. It is not uncommon for a person who has become severely disabled as a result of a chronic illness to become poor because of the expense of her care, her inability to earn income, and sometimes her caretaker's loss of income.

Medicare

Medicare is a federally administered health insurance program in which money from trust funds pays medical bills for insured people who are sixty-five or older and for some disabled people under sixty-five. Almost every citizen of the United States who is sixty-five or over is eligible for Medicare. Those who have sufficient work credits under Social Security automatically have hospital insurance when they reach sixty-five. They may purchase medical insurance by signing up during the three months immediately before or after they reach sixty-five or during the first three months of any year thereafter. The medical insurance part of Medicare requires a monthly payment, which is increased by a percentage for every year in which one could have been but was not enrolled. People who have received Social Security Disability benefits for two years or who have chronic renal disease requiring dialysis or transplant are also eligible for Medicare. Total Medicare expenditures were more than \$35.7 billion in 1980. In July 1981, 29 million aged or disabled people were enrolled in the Medicare program.

Medicare has two parts: hospital insurance and medical insurance. Both parts will pay only for services specifically covered, and both require some degree of co-payment or deductible, so that the ill person is sharing the expenses. Hospital insurance helps pay for inpatient hospital care and for posthospital care in a skilled nursing facility or at home. In regard to inpatient hospital care, it covers room and board in a semiprivate room in an approved hospital for the first sixty-day period except for a substantial deductible, and for the next thirty days in each benefit period except for a per diem co-payment. Sixty additional lifetime "reserve days" can be used in case hospitalization extends beyond ninety days in a benefit period. The "reserve days" pay all covered expenses except a per diem co-payment and are not replaced once they are used.

Also covered are laboratory and x-ray services, regular hospital nursing services, drugs used in inpatient treatment, blood and packed red blood cells after the third pint in a calendar year (the first three pints must be bought or replaced through donation), use of operating room and recovery room, intensive care and coronary care units, medical supplies such as surgical dressings or casts, use of appliances such as stretchers or wheelchairs, and rehabilitation services such as physical, speech, and occupa-

tional therapy. Services specifically not covered are the extra cost of a private room unless it is required for medical reasons, private duty nursing, items like telephone and TV that are requested by the patient for personal convenience, physicians' services except at some teaching hospitals (these may be covered under medical insurance), and room and board in a psychiatric hospital beyond a lifetime total of 190 days.

Inpatient care in a skilled nursing facility is also covered for up to one hundred days per benefit period following a hospital stay of at least three days within the last thirty days. To be eligible for a skilled nursing facility, the patient must require skilled nursing or skilled rehabilitation services. Patients who require custodial care but not skilled nursing or rehabilitation services are ineligible for this coverage.

Home health care pays for prescribed part-time skilled nursing care, physical therapy, and speech therapy if one is confined to her home. The home treatment plan must be set up within fourteen days of the patient's discharge from a hospital or skilled nursing facility. Drugs, full-time nursing, and care that is mainly custodial are not covered.

Medical insurance helps pay for doctors' services, outpatient hospital services, and some other services and supplies not covered under hospital insurance. Specifically, it covers physicians' medical and surgical services, including those in the hospital, the physician's office, the patient's home, or anywhere in the United States. Also covered are dentists' services when they are of the kind covered when furnished by physicians; supplies and services relating to diagnosis or treatment such as x-rays and electrocardiograms; and prosthetic devices such as artificial limbs. Medicare will pay for the rental of durable medical equipment for home use such as hospital beds and oxygen; outpatient physical and speech therapy when prescribed by a physician; rehabilitation services from an approved center; ambulance service to the nearest appropriate facility when other modes of transportation would be unsafe; blood and packed blood beginning with the fourth pint in a calendar year; and home health visits by an approved agency. Not covered are routine physical examinations, cosmetic surgery unless needed to correct malfunction or because of injury, optometrists' services except for prosthetic lenses, podiatrist's services for routine foot care, payments for mental illness in excess of \$250 annually, most immunizations, false teeth, eyeglasses except for prosthetic use, hearing aids, orthopedic shoes, drugs, and full-time nursing and custodial care.

Recently legislation was enacted in response to the explosive costs of Medicare, which have created a crisis for reimbursement. The crisis has occurred primarily for two reasons: The number of elderly has grown more rapidly than the rest of the population, and changes in per capita health expenditures have been greater for those over sixty-five years old than for others. Since the enactment of Medicare, life expectancy at age sixty-five has jumped from 14.6 to 16.4. Expenditures rise generally with age, not

because of age *per se*, but because the proportion of people near death increases with age. Expenditures are particularly large in the last year of life. In 1976 the average Medicare reimbursement for those in the last year of life was 6.6 times as high as for those who survived. The United States is spending about 1 percent of its GNP on health care for the elderly in the last year of life. In 1982 Medicare accounted for 7 percent of all federal outlays. That is the crisis to which the legislation was a response.

TEFRA (TAX EQUITY AND FISCAL RESPONSIBILITY ACT)

The first piece of legislation is the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). TEFRA changed Medicare's hospital reimbursement methods in several ways. It made the basis for reimbursement the case (the disease category of the patient) rather than the cost to the hospital or providing daily care for the patient. It incorporated case-mix, that is, the kinds of patients in that particular hospital in the payment system, and it limited the rate at which the costs could be increased per case. In addition TEFRA mandated that the Secretary of Health and Human Services develop a prospective payment plan.

MEDICARE PROSPECTIVE PAYMENT SYSTEM

The Medicare Prospective Payment system established a patient classification system of 468 diagnosis-related groups (DRGs). Hospitals are no longer reimbursed according to a per diem figure based on what it costs them to take care of the patient. Rather, they are now paid according to the diagnosis of the patient. Payments per DRG are to be a function of urban or rural location, area wages, and the number of full-time interns and residents on the staff of the particular hospital. Capital costs and direct education are to be separate from DRGs for the present. The three-year phase-in period for the program is to be completed by 1987.

One concern about the prospective payment system is whether it accounts sufficiently for severity of illness. For example, people who are admitted to the hospital for cataract surgery will usually be discharged very quickly. The course in hospital for those admitted because of the progression of a systemic illness such as cancer or diabetes will often be less predictable. Acute episodes of chronic illnesses are of special concern.

HOSPICE

Section 122 of TEFRA is the Hospice Bill. In effect in November 1983, the bill extended Medicare coverage of both inpatient and home care to Medicare-eligible patients with a six-months-or-less terminal diagnosis. It is thought that the bill was passed because the Congressional Budget Office reported that the hospice legislation would save Medicare \$109 mil-