

Monographs of  
the Víctor Grífols 19  
i Lucas Foundation

# The person as the subject of medicine

*Eric Cassell*

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18/07/10

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**Eric Cassell**

ISBN 978-84-692-0780-2  
Edita: Fundació Víctor Grífols i Lucas. c/ Jesús i Maria, 6 - 08022 Barcelona  
fundacio.grifols@grifols.com www.fundaciogrifols.org

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## CONTENTS

Page

Presentation	
<i>Ramón Bayés</i> .....	7
What is a person? .....	11
What is a Sick Person? .....	25
What is Autonomy in Sick Patients? .....	39
About the autor: Eric Cassell.....	51
Publications .....	52

## PRESENTATION

In October 2007, the Victor Grifols i Lucas Foundation inaugurated the Josep Egozcue Lectures with a presentation by Daniel Callahan, International Program Director at the Hastings Center in New York. A year later, Eric Cassell, Professor of Public Health at the Faculty of Medicine at Cornell University, kept up the high standards set in the previous year's lectures.

Several years ago, as part of an Oncology Workshop organized by the College of Doctors of Barcelona, I was part of a panel which also included an oncologist from the Hospital de San Pablo, Carmen Alonso, who mentioned a piece by Eric Cassell which had appeared a short while before in the *New England Journal of Medicine*. This was the first time I had heard his name, and I was so impressed by Dr. Alonso's contribution that I asked her for the details. A few days later, I received a copy of the full article by post –this was back in the days when computers and the internet were still a thing of the future<sup>1</sup>.

From that moment on, Eric Cassell has been a constant source of inspiration for me. I have followed his publications closely and he has had a major influence on much of my subsequent work in the field of health. If anyone wants to explore his line of thinking, I would recommend that they read:

- a) The groundbreaking lecture<sup>2</sup> given by another famous doctor, Francis Peabody, in 1927 at the Harvard Medical School: «*What is spoken of as a 'clinical picture' is not just a photograph of a man sick in bed; it is an impressionistic painting of the patient surrounded by his home, his work, his relations, his friends, his joys, sorrows, hopes and fears.*»
- b) Twenty pages of a book by Laín Entralgo<sup>3</sup>.
- c) «*The goals of medicine*», often referred to as the Hastings Report, which is available in Spanish and Catalan translation on the Foundation's website<sup>4</sup>.
- d) The article by David Callahan, «*Death and the research imperative*»<sup>5</sup>.
- e) The second extended edition of Cassell's book, *The nature of suffering and the goals of medicine*<sup>6</sup>.

If one had to sum up the essence of Eric Cassell's work, it would be hard to do better than to quote the author's own thought-provoking observation: «Bodies do not suffer; persons do.»

Now 80 years of age, Eric Cassell continues to play an active role in life. Like David Callahan, like the centenarians Moisés Broggi and Rita Levi-Montalcini, he is walking proof that in many cases the rule of «retirement at 65» is nothing more than an expression of administrative rigidity, age discrimination and social impoverishment<sup>7</sup>.

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**What is a person?**

## Introduction: The Sufi Parable about the blind men and the elephant

Remember the parable of the blind men and the elephant. One feels its side and thinks an elephant is a wall, another, its trunk and thinks an elephant is a snake, yet another felt its tusk and thought it a mighty spear-like animal, and so forth. They all ran to the city to tell people what an elephant was. We rarely hear about the last man to go to the elephant, an old man, also blind. He took his time going around and around, studying the elephant in every detail. Then he returned to the city to find that everyone had taken sides and was arguing about what an elephant was. He laughed and laughed, remembering how foolish he had been when young thinking he knew something when he only knew a part of it. He laughed hardest, however, when he realized that he was the only one who didn't know what an elephant was.

I, of course, I am an old man who has spent a lifetime working with, studying, and thinking about what persons are. This isn't so funny, however, because I have to give a lecture on the subject. I think the old blind man, when he got to his home would have reflected and realized that an elephant is a very complicated thing. Maybe it is a good idea to think of elephants (or persons) one way or another depending on what you want to do with the knowledge.

I don't know anything about elephants, but I do know about persons and I think it is reasonable to say first why the subject has come up. Probably from the first doctors have known that it makes a difference who the patient is.

In the era of high mortality rates and acute diseases –maybe until after World War I– these differences in persons may not have had a big impact on the outcome of care. In our era most people die of chronic diseases, and disability rather than only death is the dreaded outcome of sickness. For our diseases the nature of the person has a major effect on the origin, diagnosis, course, treatment and outcome of the disease.

Because of this knowledge, for fifty or so years medicine has been trying unsuccessfully to put the person rather than the disease as the central con-

cern of medicine and of physicians. This has culminated in the present call for patient-centered medicine.

There have been notable steps along the way:

- In 1951 Carl Rogers, a psychologist, wrote about client-centered therapy.
- In 1970 Michael Balint, a psychiatrist, wrote about patient-centered medicine and the name caught on.
- In 1977 Ralph Engel wrote a famous paper describing biopsychosocial medicine which aroused great interest but did not change practice.

During these decades there have been marked social changes in the US so that previously peripheral groups came into the mainstream of personhood –the civil rights movement, the reemergence of the women's movement, people with disabilities, and most recently gays have achieved full personhood.

As part of this, patients also became persons. The emergence of bioethics as a force in medicine with its emphasis on respect for persons and autonomy played a part in these changes. So at this time, the flag of person-centered medicine flies from the top of most American medical schools and hospitals, but the medicine practiced on their floors remains disease centered.

It seems reasonable –though quite unusual– to stop to answer the question, «What is a person?» You would think that because of its intrinsic interest –after all we are all persons– the literature would be littered with in depth explorations –but it isn't.

In medicine when we consider something –the liver or genes– we are very careful to define what we mean by the terms. Person seems to be an exception to that. Perhaps because the subject is daunting –«Where do you start and where will it end».

On the other hand because we are all persons, what a person is seems self-evident –and it is until you actually start trying to write it down. The subject is of more immediate interest to medicine because, there are changes in the nature of persons when they are sick.

Changes that have an impact on how the sick are to be treated, on ethical issues such as autonomy that cannot be avoided. Sickness and its effects on the person can only be understood with the background of knowledge about everyday personhood.

## Is the subject of this talk the Self or the Person?

For centuries philosophers, and for more than a century social scientists have used the word *Self* as the generic term, rather than *person*. How strange, person seems a good and common word.

The word «self» seems to have come from the word soul and to denote much the same idea. In the split world view of Descartes, we understand the problem with the word «person» –persons have both minds AND bodies and that would not have fit.

The dictionary of Philosophy in 1979 said of self «An obsolescent term for person, but a person thought of as incorporeal and essentially conscious.» Considering current usage, it is not so obsolete for philosophers or psychologists.

In the beginning of the 20<sup>th</sup> C George Herbert Mead, a sociologist said that a self was created out of language and the language interaction. We know what he meant because we often define ourselves by words and language. But if a self has a body, you cannot create it out of language.

By the 1960s antihumanism, antiindividualism stance of primarily the French philosophers cast doubt on the authenticity of the person and individuality itself. This was followed by the postmodern assumption that persons are not simply diverse or fragmented but fundamentally incoherent. I do not believe the self is incoherent but there are in most of us if not all, more than one self.

People sometimes behave one way in a given set of circumstances and in other circumstances another way. These behaviors and meanings, however,

are internally cohesive and coherent. Thus each person may be more than one self. For example, when people return to their family home, even after they have become adults, they may find themselves behaving as they did when they were children. Then there is the social out-in-the-world and in-the-office self: the home-with-the-family private self, the bedroom-*very*-private self, and so on. These different presentations to different worlds are example of the fundamental social rule –one must get along– of this, more later.

These selves are not the equivalent of persons. When I, Eric Cassell, return home, I shed the doctor self and return to the at home self. Does that mean I am hopelessly incoherent? I think not. Each self of mine is housed in the same body, wearing the same glasses, answering to the same name, living at the same address as the person of that name.

I find the word and the concept of the self insufficiently inclusive –it is simply not big enough to contain everything– including the body –that makes up a person.

It is another example of the depersonalization of persons that we find everywhere. Depersonalized medicine, depersonalized psychiatry, depersonalized social and biological sciences... All of these specialties whether they use the word self (most often) or not are not talking about living breathing persons. You cannot find yourself in their idea of persons. Depersonalization here as elsewhere keeps us from understanding persons– and especially sick persons.

## «What is a person» – the short form

A person is an embodied, purposeful, thinking, feeling, emotional, reflective, relational, human individual who does things. Virtually all of whose actions –volitional, habitual, instinctual, or automatic– are based on meanings. A person lives at all times in a context of relationships with others and with self. These are never gone.



All persons have a past and a future and that is part of the person today. All persons are marked by the ability to love from the least to the greatest degree. All persons have a spiritual life –a transcendent dimension that reaches beyond them. Sometimes that is only expressed in religion. But spirituality is also expressed in the love of others. Love of things larger than the person like country and profession. Spirituality is present in all relationships. All persons have one or more public, private and sometimes secret lives and they are different and distinct to a greater or lesser degree. All persons die.

## All persons have a body

The body can do some things but not others. To the body's enormous range of capacities and inabilities persons become habituated. These capacities become accepted as part of the person. This view of persons has been partly hidden by the cultural importance of and attention to individuality developed over the past number of centuries in Western European and American societies. Individuals as though there were no bodies.

A truth about bodies is that things happen to them –they can be injured or get sick. Bodies sometimes bleed, smell bad, make embarrassing sounds, have embarrassing functions, create desires, sometimes look bad, get old and slow, and sometimes ugly.

Accepting the body as it is, is vitally important in understanding functional impairment and disability. And increasingly persons with disabilities are no longer hidden from view –they are part of our lives.

Persons are always in relationship to other persons, institutions, and society. You will *never* see just-a-person, an isolated-in-a-vacuum-person because there is no such thing. The atomistic person is as much a myth as the atomistic fact of positivism.

The extended web of durable human relationships and the rules that guide them are called family, society, and culture. Society is an enduring and cooperating social group with organized patterns of relationships –a com-

munity, nation, or broad grouping of people having common traditions, institutions, and collective activities and interests (Mirriam-Webster Online).

Culture is «a historically transmitted pattern of meanings embodied in symbols, a system of inherited conceptions expressed in symbolic forms by means of which men communicate, perpetuate, and develop their knowledge about and attitudes toward life» Geertz, C (1973 p. 89).

The relationships to others dominate life at all ages starting with infants and establish persons' place in society and culture. They determine a person's roles and responsibilities in society. Bruner has called the impact of these things on the mental life «folk psychology.» (1990 p33ff)

We are too often fooled about these things and think there really are truly completely independent individuals. Look at me standing here. Where is my family, New York City and American culture. Where is the culture of medicine in which I grew up? All inside me and out of sight –except that these are in my walk and my speech and mannerisms. Most of all these other people are fixed in my meanings.

Persons are always in relationship to themselves. As the relationships of persons to others are guided by lasting rules and meanings that are spread outward. Persons' behavior and thoughts in relation to themselves are spread inward in the sense that some rules are readily apparent, known, and acknowledged by the person, but others with the same power to control behavior are unapparent, unknown, and unacknowledged residing out of consciousness.

Persons know themselves by beliefs they hold. I am a man, a doctor, a husband, a father, a friend, an American, a liberal Democrat, and everyone of those and more has an influence on every aspect of my ideas, thoughts, and behaviors. Persons know themselves by what they can do; their aptitudes, skills, accomplishments. Their ability to make things, do things, write things... Hegel was correct that when persons create something –a piece of furniture, a cake, a lecture, or a song– they also create themselves.

Persons re-create themselves every day –what they did yesterday or last week is not sufficient– what they can do today is as important. They also know themselves by their thoughts, by what their hands and feet can do, by what they see when they look in the mirror, by the sounds of their voice.

Self-regard and vanity is the place where relationships with the body, others, and ones-self interact. Everyone wants to be valued by others and by themselves. Everyone wants to be admired or liked by others and themselves. Everyone wants to be like those they admire. Vanity to a lesser or greater extent is present in all and a part of the relationship of persons to others and to self.

## Meaning

Let us go back and look more closely at all these aspects of person and start with the general statements. «A person is an embodied, thinking, feeling, emotional, reflective, acting human individual. All of whose actions –volitional, habitual, instinctual, or automatic– are based on meanings.

The key word is meaning. We think we sense –see, hear, feel, taste smell– the world around us and act on those sensations. But that is not literally true. Between us and the world around is an invisible web of meaning and it is on the basis of those meanings that we act. Look out and see a tree –the word tree is the meaning of what you see– all you actually see is brown and grey with green things upright thing, a blur of color and structure. *Not the things themselves, but their meaning. You taste something divine and want more until you know it is poisonous. You see something beautiful and want to possess it until you know it is stolen. Do you still want to possess its beauty yes, but the experience is changed?* Why, the beauty is the beauty. Yes, but it is tainted.

You hear a noise and wonder what it is-what it means. A twinge of pain in your abdomen demands a meaning. Nothing exists without meaning. Why is this especially important to us in the context of medicine –because the world and its objects may be fixed and unchangeable, but meanings are changeable and can be changed.

Why don't we all know this? That between us and everything in our world there is a screen of meanings influencing our every response and action. Because in the 20<sup>th</sup> C when the Anglo-American philosophers first got involved in the subject of meaning they wanted nothing to do with the complications introduced by humans and the human mind. So meaning, for them, was about written words.

But we all know that everything has meaning, not just words. Not just symbols, but everything. What the philosophers did not want to deal with put off true in depth comprehension of the subject of meaning. Mentality is the problem –it is very confusing. But persons without mentality are not persons.

Forgive this brief tangent. This is not my subject, but the problem of meaning reaches to the most primitive animals. The fundamental characteristic of animals is that they can move –they can attack or flee. There must be some reason why they attack that and flee this –those things must have some very primitive version of meaning for the animal.

That is really obvious but we don't know it because since Descartes in the 17<sup>th</sup> C animals are only machines and machines don't think. Even though every pet owner knows that is not true and must have known from forever. The subject of meaning is often hidden behind terms like instinct.

For example Pavlov dogs who learned that the ringing bell meant food are the example of conditioned reflex. What the dogs did is learn that the meaning of a ringing bell changed. Because they had a physiologic response to the bell it was called a conditioned reflex. There are always physiologic responses to meaning (see below).

People are too often quick to dismiss philosophers and philosophy but they have more impact on your life and for a longer time than you can even imagine. Another thing about persons and meanings stems from the fact that nothing happens to one part of a person that does not happen to every other part. Like a stone cast in a lake the ripples of meaning go everywhere.

A meaning is not just a definition of a word –what is in the dictionary– the denotative meaning. A meaning is not merely its connotative meaning

–the associations and values inherent in the word's meaning. Meaning is not merely a cognitive in the mind thing. *All* meaning has an emotional dimension –there are emotions or emotional feelings associated with it. And emotional feelings are just that –you *feel* emotions in your body.

*All* meaning has a physical dimension –it acts on the body from the molecular upwards. *All* meaning has a spiritual, a transcendent dimension. To say that everything humans do is based on meanings is to say that everything that persons do –volitional, habitual, instinctual, or automatic– is based on meanings is to say that everything involves all of a person –thinking, emotional feeling, acting, spirituality– resonates through the whole person including the body!

An important fact about meaning is that it can change and when meanings change so do all the things associated with it. Which is why learning is so difficult –real learning is not merely adding new knowledge but about changing and that is never easy.

## The flow of thought and emotion

### Persons reason

People are able to reason clearly and logically about objects, events, relationships and persons. They can think about concrete things and about abstractions like, e.g., health, love, beauty, or evil. They can think about things from their own perspective or they can take the perspective of another person and see things from that viewpoint as well.

Reasoning draws on a well of knowing and the knowing is generally adequate to the thinking in progress –when knowledge is clearly inadequate the person usually avoids the subject. Between reasoning and knowledge, human thinking is able to construct ideas and abstract concepts that are new to the person.

### Persons feel emotionally

In addition to thinking about things, people have emotional responses to them as experience flows by. This pleases them, that is annoying, the other feels good. These emotional reactions occur as fast or faster than thought. The ancients saw reason and emotion –which they called the passions– as in conflict.

The emotions, they believed, got in the way of clear thinking –in fact that can happen. In everyday life it is very difficult to keep them apart. Emotions serve an evaluative function –they tell you how you feel about things faster than lightning– or as we now say, in real time.

## The stream of thought

There is a stream of thought running through our heads about ever changing subjects. The subject of this stream is personal –it is related to each of us as a person and not shared in the thoughts of others at the same time or about the same subjects.

Even in persons who have trained themselves not to be aware of the «noise in their heads,» the stream of thought is continuous. If the subject of thought is fed by worry or anxiety, the person cannot change the subject at will. They can, however, choose the subject to actively think about. When the chosen subject stops the stream resumes. If a person awakens in the middle of the night the flow starts again. The person can choose from among the subjects of the stream and continue thinking about one aspect for awhile and then the stream starts again. The stream of thought quickly makes it clear we are not of one mind –the criticizing voice of the conscience may appear and cannot be banished for awhile even if the person wishes it to be gone.

A negative voice may appear that disagrees with the dominant voice and as with the conscience it takes its place in the stream of thought. With these thoughts may come unpleasant emotions certainly not wished for by the person.

If you ask psychologists where all these voices come from they may say it is the unconscious –but, it is not clear what that means. Is it the unconscious of which Freud spoke or something else. Put another way, the stream of thought tells us that there is much that we do not know about our mental life.

## The person in his or her world

People attempt to live in an world of *security* not racked by uncertainties and irresolvable fears and worries. And when such uncertainties occur, people who are worriers chew on the problems like a dog on bone. Look carefully at the worry and you will see that is constructed of but not the same as the problem in reality –the current economic crisis provides examples.

Others with the same uncertainties banish their fears behind a wall of denial. People are not usually lonely nor kept among others not of their choosing. People have and maintain their privacy. They have *meaningful* human interactions of their choice. They have a community of choice and they can *depend on* others in that community. They are *not* purposeless, hopeless, and lost.

They have purposes. Realistic hopes and desires. Goals and intentions. Realistic expectations. They are aware that they can do things and make things happen, they do not feel useless or helpless. What matters to them is not beyond possibility. Their world is *orderly and coherent* and they know what things mean. They have a *realistic desire* to be like others and to be admired. They have a *sense of self-worth* and do not feel persistently worthless. They have *identity* and they know it. *Anomie* is not their fate. They have a *sufficiency* and they do not feel persistently deprived.

Keep in mind the brief statement of the characteristics of persons as we go on the nature of sick persons. «A person is an embodied, purposeful, thinking, feeling, emotional, reflective, relational, and acting human individual».

And very complicated!

**What is a Sick Person?**

## Introduction

Let me start with a typical proud doctor story: A long time ago, maybe 1970, three sisters asked me to see their elderly aunt because she was so weak she couldn't get out of bed. I went to her home and the patient was so anemic that she was literally as white as her bed sheets. But she did not have other symptoms, she didn't seem sick otherwise. I made the diagnosis of pernicious anemia and admitted her to the hospital where the diagnosis was proven. Treatment with Vitamin B12 cured her. The diagnosis of pernicious anemia made on a house call and I was pleased with myself.

This typical story is about the event –the diagnosis of an uncommon disease on a house call. But that is not the whole story. How did I get to that house. I had taken care of the three sisters whom I knew well for almost ten years all of whom lived in the same big apartment. So when I saw the aunt I was not a stranger.

Because of that the aunt –who was very modest– allowed me to examine her and went to the hospital without much resistance and I took care of her until she died years later. The aunt saw me as a trusted physician in the traditional role of kindly doctor who diagnoses and treats disease and wards off death. How does a doctor learn about how to behave and how to evaluate and relate to patients? They learn in medical school and in their postgraduate training. Medical educators call this the «informal curriculum» because it is not actively taught –as though these things are not considered important.

Understanding patients may have been considered not important in 1970s but it is now vital to good medical care because the diseases have changed and so has the nature of medical care.

The lady of the story could be cured with an injection of Vitamin B12 once a month but contemporary diseases are rarely like that our burden of diseases consists of chronic diseases like cancer, heart failure, HIV-AIDS, arthritis, chronic lung diseases, dementia, diseases of aging and more.

Chronic diseases are not primarily taken care of by doctors, but by patients themselves, family and other caregivers with the advice of physicians. Many

of the people with these diseases make many trips to the hospital over the years and end their lives there. Knowing who they are as persons and how sickness changes their personhood improves their care.

## What is Sickness

We think that people are sick because of their disease –their cancer, liver disease, or heart failure- and that comes from our definition of a sick person as someone who has a disease. I want you consider another definition of sickness that is more useful and more importantly related to what it is like to be and feel sick. Patients are sick when because of impairments of function they cannot pursue their purposes and goals.

The response of physicians to what the patients tell them, what their examination reveals, and all the technical data that physicians discover, is to make a diagnosis and decide on treatment. You must remember that the diagnosis is not the thing itself, it is a name for an abstraction.

It is a very useful abstraction, the disease name and what it stands for, because with that name one can find out many things about the disease that are the result of decades of experience, laboratory research, and the accumulated wisdom about the disease.

What sickness is, independent of any assigned name or meaning is «a derangement or abnormality of function». The sickness is *larger than* the disease that the name stands for, and *larger than* the patients' experience of illness, because it includes things that neither patients nor doctors are aware of.

For example if patients' thinking is affected by sickness, or their expression of emotion, or their ability to maintain relationships but they are not aware of this and neither are their doctors aware, then these things will not be included in the definitions of the disease. Their sickness is more encompassing than symptoms and patients' experience.

There are, therefore, three different «entities» that describe what is wrong with the patient.

- The sickness: A characteristic of the patient that is made up of all the disturbances or derangements of function that actually exist.
- The illness: The patient's subjective attribution or imputation of a name for, a description of, or a belief about the manifestations of the disorder as the patient experiences them.
- The disease: The name or pathologic process to which the physician or the diagnostic process is attributing the patient's disorder.

Sickness, illness, and disease? Is this just dividing up the person the way, for example, mind and body, person and body –the famous dichotomies– divide up the person? No. There is only the sick person who has the disorders of function that actually exists in that person. It is as if the disorders of function, the sickness, is a text about which the patient makes one reading and the physician another.

None of these is quite what we mean when want to know about sickness so we can describe a sick person. If you look at function differently, however, you will realize that impairments of function are found in all sick persons.

What is function? Human function is the overriding, all encompassing set of activities that includes the entire range from the cellular to the spiritual –eating is a function, thinking is a function, loving is a function among a thousand others. A hierarchy of functions from the molecular to the social and the spiritual is involved in the achievement of purposes aspirations, and goals.

There is *no* boundary between the body and other parts of the person in regard to functions and the purposes they support. Sickness is made up of the entire phenomenon –the personal, emotional, social, physical, spiritual things– that happen to sick persons.

Remember the only real thing is the sick person who is the amalgam of all the characteristics of both the disease –what the doctor sees– and the illness –what the patient experiences. As an example, cancer of the breast is not just the characteristic lump and the pathology of breast tissue. Breast cancer is the whole spectrum for that person of all the physical, psychological, social, and personal things that have become associated with and initiated by the abnor-

mal breast tissue –including the treatment: the surgery and its effects, the radiation, the chemotherapy, disfigurement (if present), fear, embarrassment, anger, emotional conflicts known and unknown... All of these and more is breast cancer for that woman (or man).

## Stages of sickness

The hallmark of sickness is symptoms –from a running nose to agonizing pain. All symptoms result from alterations of function.

Persons may have mild symptoms or really annoying symptoms for a relatively short time –runny nose, sore throat, sneezing, and cough– but they generally don't consider themselves to be sick. Symptoms like cough, bringing up phlegm or even intermittent wheezing may go on for weeks or months but people just accept them or attribute them to some everyday thing like smoking and not consider themselves sick.

Sometimes the burden of symptoms can be considerable –pains, difficulties in everyday life because of joint stiffness, trouble walking, and mild shortness of breath, abdominal distress, bowel difficulties and similar things– but persons will adapt to these, change everyday behaviors, develop rationalizations and excuses for the symptoms and not consider themselves sick.

Person will sometimes go to amazing lengths to avoid recognizing that there is something wrong or that they should see a physician. Some unusual people with very serious or even life threatening disease being taken care of by physicians, heavily burdened by symptoms go about their lives which they have adapted to their sickness without considering themselves sick. They do what is important to them and live their lives as though they were not ill.

Then something qualitatively different happens and the illness becomes the center of the patient's life –this a *state of illness*.

## State of illness

The essential characteristic of the state is a redirection of all of the people thoughts and actions to focus on the state:

- On the hopelessness in a state of hopelessness.
- On the grief in a state of grief.
- On the object of the love in a state of love.
- On the sickness in a state of sickness.

The impact of a state of illness on the person is widespread, from the social to the molecular. What is happening to the patient is made up of the entire phenomenon –the personal, emotional, social, physical, spiritual things– that happens to sick people.

This is the personal experience that is often obscured by the clinician's focus on the characteristics and the phenomenon of disease. It is this personal experience –decrepit, fragile, weak, no energy, feeble– even more than (e.g.) the cough and loss of appetite –that makes patients know they are really ill– even sick.

## The Sick Person

Now we are in a place to begin to describe sick persons and compare them to everyday persons. We had to get rid of every understanding of sickness as being what patients experience who have a disease. We had to get rid of everyday notions of diseases as though they were the real things. We had to understand that the concept of a sick person is much larger than merely someone who is ill –even seriously ill.

We had to understand that the concept of a sick person is much larger than merely someone who has a disease –even a serious disease. Most often sick persons have symptoms that are prominent and seem to be the whole illness. The experience of the symptoms stands out –especially and above all *pain*. But also nausea and vomiting, dyspnea, or maybe any symptom if it is severe

enough to dominate the patient's experience. Fear and uncertainty. These and all the other manifestations of illness take central place in patients' lives and in the actions of their clinicians. The patient as a person seems to move to the periphery.

There are certain characteristics that are present in all *serious* illness –it doesn't matter what the disease is or where the patients are. The ill are disconnected from the well and from their world. In health we know we are alive by our connectedness to the world. By touch, hearing, sight, and the other senses; by our interest in things around us, our relationships with people and our daily intercourse with others. In illness however slight, some of these connections are lost.

When illness deepens or becomes the state of being, patients' connectedness diminishes still further; made worse through isolation in special places like hospitals. Or through loss of interest and a narrowing perceptual field.

The ill lose the normal feeling of being indestructible (in psychology often called omniscience). Why it is silly to say, «but anybody could die any minute» to someone who has just been told that with their disease death is possible. That person now *knows it*.

When the sense of indestructibility is really lost, the world becomes a dangerous place. The sick person focuses on the fears, dangers, threats, peril, risk, and fragility. The ill lose omniscience –the completeness of reason. When people are well, they think they know about the body, diseases, doctors, treatments etc. Knowledge may seem quite complete. And nowadays everybody knows everything. When illness happens, the knowledge is suddenly incomplete. Whatever is known isn't enough –especially in the light of all the uncertainties.

And combined with the loss of interest it is difficult to think straight. Sickness brings cognitive impairment, when persons are bed bound and require regular care, their thinking literally becomes impaired. They cannot take the perspective of another. They cannot handle abstractions –they are concrete. They just don't think straight. *This is often called regression, as though it was a characteristic of this particular person –it is illness!*



Sickness brings emotional impairment –the sick may feel distant from their emotions or not feel them at all– especially love and affection. The ill become helpless and lose control –often the most frightening aspect of sickness. Healer should acknowledge the possibility that the patient feels helpless or without control.

Illness has symptoms: the perception, feeling, or awareness of something being wrong, a change or loss of function or impairment of function, an abnormal sensation like pain, these symptoms are given meaning by the sick person and become the focus of attention. Everything in the circle of the patients world of sickness becomes the center of attention.

These symptoms and the other facts of the illness become the focus of the sick person's attention. Everything is searched for clues to what is happening or will happen to the patient. The behavior of the staff –even their expressions; are they smiling or frowning– everything is searched for clues to what is happening to the sick person.

Events and circumstances in the outside world that were once important to the patient, fade in significance in comparison to the patient's world of sickness. The doctors, nurses, and the other staff can seem to become more important than even the family –after all, they seem to hold the keys to survival.

Someone who visits every day, or who is there «all the time» and especially attentive can become the increasingly important to the patient out of all proportion to their actual importance. (Which is why wills are sometimes altered in the hospital naming such people as the new beneficiary).

Illness involves a change in purpose. In every waking moment life is filled with purpose –all the myriad functions of the body and person are in the service of those purposes and goals. Purposes and goals exist in a pyramid.

Smaller purposes, such as getting the automobile ready, serve larger purposes such as driving to work, which serve larger purposes such as getting ahead or advancing at work, which serve even larger purposes, all of which end up server the central purpose which is being oneself.

With the exception of the lowest purposes in the pyramid, the fulfillment of purposes requires others. While we can make many things happen by ourselves, one can rarely accomplish even the tasks of everyday life by oneself. Postal service employees, shopkeepers, operators of computer servers, one's employees or comrades at work, family members, and many more are necessary to carry out tasks, make things happen, and bring to completion one's goals.

In sickness, purposes narrows and become focused on the preservation of oneself in a much narrower manner than in the healthy. Here it is the relief of distress, carrying out simple but necessary bodily functions, being in the presence of others and accomplishing the most simple of social functions. Still, unless severe distress or suffering are present, central purpose –the being of oneself remains most important.

## Suffering

Suffering is a special state of being and a unique form of distress that may be found among the sick because the best recognized sources of suffering are often those precipitated by physical illness.

Even when suffering is caused by illness, suffering is not the illness, it is suffering. When the source of suffering is pain, suffering is not the pain, suffering is suffering. When pain is present and suffering starts, the awful distress is no longer the pain, it is the suffering.

Suffering occurs when a source of distress is so threatening or is so severe that the person loses his or her sense of intactness or integrity as a person and it continues until the distress or its threat are gone, or integrity or intactness of the person has been restored in some other fashion.

Suffering has a number of unique characteristics:

- Suffering is personal –suffering always involves the future– what will happen if, for example, the pain keeps on going even though the pain is not so bad this moment. Suffering always involves not just the dis-

ness itself, but its meaning. Bodies have no sense of future and bodies do not create meaning, only persons do. Suffering is something that happens to persons not to bodies. Bodies do not suffer, only persons do.

- Suffering is always individual. What is a source of suffering in one person may not cause suffering in another. Even when more than one person suffers from the same stimulus –for example, a certain kind of pain such as a dissecting thoracic aneurysm– the characteristics of the suffering in each person will be different because the persons are different.
- Suffering always involves self-conflict. As a simple example, a person may want to give in or succumb to pain while another part of the person wants to fight the pain and to survive and the conflict itself adds to the distress that is suffering. In the suffering that occurs in chronic illness, the person may want to be and try to be like everyone else, but because of the impairments of function that occur in the illness that is impossible. Conflict occurs between the desire to be like others and the part that wants to hold back because of impairments of function.
- Suffering always involves the loss of central purpose. When suffering supervenes, purpose narrows its focus to the source of suffering. Ideas of oneself in the largest sense characteristic of the healthy disappear.
- Suffering is always lonely. Suffering is lonely because it is always has its source within the individual and not shared with others. And it is lonely because of the loss of central purpose.

## Comparing the sick to the well – some simple statements

This section compares the sick and well. The features of sickness are most pronounced in «a state of sickness» but the impairments of function that characterize sickness are found to a variable degree in all sick persons.

Persons who are in bed with a long standing illness, but seem in all other ways just like the well, will have relational, cognitive, and emotional impairments characteristic of the sick. In the opposite extreme, people who are suddenly and forcefully propelled into a world of sickness, for example by an accident, will begin immediately to show characteristics of illness –for instance, they will enter immediately into a therapeutic relationship marked by trust and obedience with a treating physician who is a complete stranger.

Remember that I summarized what a person is by the statement, «A person is an embodied, purposeful, thinking, feeling, emotional, reflective, relational, and acting human individual». When we consider the sick person we see that while the sick person is still a human individual, every other term in that short definition has changed.

Yes, the sick person is embodied, but the body has changed and the person's relationship to the body has changed. Sick persons are purposeful, but the focus of the purpose has shifted to themselves. If they are also suffering, focus has narrowed even further and is directed to the source of suffering.

Sick people think, but their cognitive function is impaired and their focus of attention has narrowed to themselves and little else. I do not know how to characterize the stream of thought of the sick because to my knowledge it has not been studied. Emotional function has also changed. While emotionality is present and may serve the evaluative function of emotions, emotion as a mode of being (as in being loving) is changed in the sick and become distanced from its objects.

The world of the sick is one of immediate existence –the impaired world of here and now. When the past is considered it is in terms of what was then and is no longer now. The future is seen as the impaired present stretching out into the future. Like the healthy, sick persons live in a web of relationships. Their relationships are different. Where they may have been the dominant figure before –like a husband, an older brother, or even the boss, now they are seen as weaker and more dependent. In acute illness, other persons will help and support them and their personal importance continues with an expectation that they will be themselves soon again.

In chronic illness which is marked by impaired function that lasts over a long time, their personal power is one of the impaired functions. Depending on the kind of illness –for example, chronic kidney disease where dialysis is required– the medical people become very important and family members are of less importance.

In the same way the sick person is now in a new important web of relationships and the doctors and nurse are of increasing importance. Every decision we make of any importance always involves others –usually informally– especially because we can always and usually do take the perspective of others as well as ourselves whenever we make decisions.

One of the impairments of thought as sick persons is that they *cannot* take the perspective of others. They cannot see things the way others see them. Any decision they make will primarily be in terms of themselves and not others.

Human beings can act, do things, make things and make things happen. Not so the sick. When Aleksandr Solzhenitsyn wants to sharply characterize what has happened to the doctor in The Cancer Ward who develops cancer he has him taken off to have X-rays. In fact, at that point we are not sure that he has cancer, but it is no matter. He is sick and the sick do not do, they are done to.

None of these characteristics of sick persons are a surprise. While some sick persons will have more of one and less of another, this is the way serious sickness is. There are good reasons people do not want to be sick. What is a surprise is how all of these characteristics of the sick seem to have gone into hiding as far as the world of bioethics is concerned. Before this era, before patients became persons, no one, I believe, would have had to be reminded of the nature of sick persons. Somehow, when personhood was bestowed on sick persons in the era after the Second World War, it was as if we expected that sick persons are just like the rest of us. They are not. The real change has been the change in the status of the sick.

Until the World War II, the sick have been treated differently than the well. To be sick was to lose full status as a person in society. Like the disabled, the infirm elderly, and the very poor, the sick did not share in the personal free-

dom of the well. Even though these categories of person might officially be recognized as persons, they did not share in the social status of the well. This is sometimes difficult for us in West in the 21<sup>st</sup> century to understand. But there are still societies where the sick fall from full social status.

**What is Autonomy  
in Sick Patients?**

## Introduction

From the time of Hippocratic medicine until the start of the bioethics era the moral basis of medicine was benevolence and the avoidance of harm. The Hippocratic author of Book 1 of *Epidemics* says the physician should: «Declare the past, diagnose the present, and foretell the future; practice these acts. As to diseases, make a habit of two things –to help, or at least to do no harm. The art has three factors, the disease, the patient, the physician. The physician is the servant of the art. The patient must cooperate with the physician in combating the disease.» (Hippocrates. *Epidemics 1*. trans WHS Jones. Loeb Classical Library. Harvard Univ Press. Vol I p165).

In 1979, Professor Pedro Lain Entralgo the wonderful Spanish historian of medicine, in a lecture about what is a good patient, and following the Hippocratic lead, suggested that a patient had a responsibility to work to get better; that good patients had a duty to aid in their treatment. James Childress, commenting on Lain Entralgo's lecture, disagreed strongly.

Childress stressed the paternalistic nature of such a statement. Speaking of the good patient in those terms left out the person who was the patient. A person who might not want to get better. Who might wish to refuse treatment. And all of these on a rational basis. The implication of their difference of opinion was that at least prior to 1979 and perhaps in other countries a patient and a person were not the same thing.

## The Idea of the Patient as a Person

Prior to the 1950s the word person was not part of medicine. Respect for patients was a part of medicine –in fact, to reiterate, benevolence toward patients was the fundamental ethical precept of medicine. Do good and avoid harm –benevolence and non-malificence in contemporary terms.

Patients were not persons. In the late 1960s, Arthur K, the president of a large corporation responsible for many employees and many millions of dollars,

was admitted to the hospital with pneumonia. After being settled in his bed and told what was going to happen, the doctor and the man's wife went into the hallway where the doctor told her all about his disease and what was expected –he was not told, his wife was told– something that would never happen today.

These things were not shared with the patient –he was no longer treated like a powerful man of responsibility, he was treated like a patient! Starting in the 1950s the phrase, «Treat the Patient as a Person,» became common. It literally meant, «Treat a patient *as if* a patient were a person.»

In 1970 the book, *The Patient as Person*, by Paul Ramsey, a Christian theologian was published and achieved considerable acclaim. It was my introduction to modern bioethics because I was invited in January 1971 to the Hastings Center –then just starting– to discuss a chapter in that book called, «On (Only) Caring for the Dying.» I was there as a practicing physician.

I had never read anything like that before. Paul Ramsey was suggesting that dying patients be just cared for –not treated for disease like every other patient, but since cure was impossible, simply cared for. Their affliction was that they were dying and because their disease could not be treated successfully, their treatment should be about caring for a dying *person*! That was an extraordinary idea at the time.

Paul Ramsey's book was one manifestation of the growing influence of the bioethics movement. And with bioethics the concept of person had entered medicine. In fact, patients became persons about the same time as the American Civil Rights movements of the late 50s and the 60s started changing the status of large groups in American society that been marginalized previously. African-Americans and other minorities, women in public, and more recently gays and persons with disabilities.

Another step forward in the march of individualism that has marked American and other Western societies for centuries. Not political individualism present since the 17<sup>th</sup> and 18<sup>th</sup> C. Not individualism of effort –the Horatio Alger story– the American version as the rugged individualist. Not individualism of the interior self –starting with Freud and widely accepted–

that we all have a unique inner life. This time it was been the individualism of diversity.

That may seem funny –after all isn't individualism all about being different– well, actually, *no* until recently. This is the step in the march of freedom and individualism where full social status is conferred on groups and people who were previously beyond the pale –outside the boundaries of full acceptance in society. Why spell this out? Because it has to do with how we treat patients ... more later.

Bioethics rapidly increased its influence and effects on medicine and medical research. In 1979 the Belmont report, introduced by the President's Commission (Jimmy Carter) for the Protection of Human Subjects of Biomedical and Behavioral Research, suggested three moral principle that should guide research (quickly extended to practice):

- Respect for persons.
- Beneficence.
- Justice.

Beneficence –benevolence– was already part of medicine. Respect for persons quickly became transformed into patient's rights although persons are much more than bearers of rights. Now patients had all the rights of other persons in society. Suddenly –and it happened very quickly– a long history of medicine and the relationship of doctors and patients got swept aside as irrelevant. Suddenly what mattered were rights!

Patients had the right to refuse treatment. Patients had the right to decide on their treatment. If the doctors wanted to stop a particular treatment many believed that if the patient wanted the treatment anyway, they had a right to continue the treatment.

Suddenly, it was if the doctor was the patient's enemy. In New York State signs were put up in every hospital in prominent places (near the elevator) that outlined patient's rights and made it appear as if physicians (and the hospital) were the adversary of patients. As if doctors who treated patients were primarily intent not on the welfare of patients but on robbing them of their rights.

In relation to bioethics a sick person was considered the same as a well person except that the sick person had a sickness. As though the sickness was like a backpack on their back. Sick persons in this view were like the well –independent, atomistic objects spinning in their own orbits.

Autonomy became the pre-eminent principle of clinical bioethics (and paternalism in doctors its enemy). Autonomy soon got translated into *freedom of choice* even though as we shall see, autonomy is much more than freedom of choice.

This is the version of autonomy that most clinicians know and use. It has been translated into: present the patients with the current and correct information about their clinical situation and offer them the options from which they must choose. Allow the patient to choose.

There were even some ethicists who believed that autonomy should be mandatory: Haavi Morreim is an example. She said: «In matters of health, and of health care, it is time to expect competent patients to assume substantially greater responsibility. In the first place they should generally make their own decisions. Not only is the patient entitled to decide these issues that effect his life so fundamentally; he has a preemptive obligation to do so.» Or «On the most basic level, the failure to treat a competent patient as being responsible to make his own decisions and be accountable to them is a profound moral insult.» (Haavi Morreim Balancing Act: *The New Medical Ethics* 1995 Georgetown Univ Press).

I could find quote after quote from bioethicists, physicians and others to the same effect. It is common it is to find physicians or other caregivers seeing their role as only providers of information –not active participants with the patient in decision-making. Stepping back, as it were, to let the patients make their own decisions. Their role becoming dispassionate to the point of being like a web site on the Net.

Carl Schneider in his book, (*The Practice of Autonomy: Patients, Doctors, and Medical Decisions*. 1998 Oxford) discusses these ideas in detail. In this perspective, the problem is not that the patient is too independent but rather does not exercise sufficient choice.

Here are the patients who only want their physicians to provide information so that they the patients can make decisions. It is not too surprising to see that in a world where patients are encouraged to make their own independent choices and even choose whatever they wish as an exercise of their autonomy. And doctors believe their role to be a provider of information.

On the other hand doctors really believe that they know what would be the best thing for the patient. There will be frequent conflicts –for example in questions of discontinuing life support.

## What Happened to Sickness – a digression

This discussion of autonomy in medicine must seem a little bit strange and unreal. What happened to sickness? It is as if no one is sick. What we know about sickness –not as doctors– not even what we heard in the previous lecture –but merely the everyday knowledge of sickness. Because if people are really sick, with everything that goes with sickness can they really make the best decisions about their care the way I have described?

In the United States it is somewhat as if sickness has disappeared –the really messy kind of sickness where daily living is difficult and people have a hard time and sometimes die. Advertisements for Managed Care organizations –the kind people have to join so that will receive medical care in the United States –never show sick people. They show only healthy people.

Drugs that are given to very sick people can be advertised on TV, but when they are the facts of sickness are never shown. In my small town there are advertisements for MRI scanners that show a woman in a lovely night gown in odalisque position. And another advertisement for MRI and CT scans says that the doctor is «The Michelangelo of imaging!». Those machines are for diagnosing sickness and sick people.

It is not as though disease has disappeared, special disease oriented organizations are advertised and so are hospitals, but that this is all about sickness is not mentioned.

Pornography is sex without feelings, murder and death on TV is about death without grief, so maybe we have discovered a way to hide sickness so we can have disease without sadness or pain! And most of all, sickness without impairment!

We seem to have hidden the most important fact about the loss of autonomy by whatever definition. The biggest thief of autonomy is sickness itself!

## More about Autonomy

Strangely, ideas about autonomy in medicine have not changed very much in the last *decades*! From the point of view of bioethics you would think that the definition of a person is someone who has rights. Although it should be clear that persons are more than just bearers of rights.

Autonomy as meaning freedom of choice has also lasted and lasted. Autonomy as Freedom of choice is primarily a legal view of the meaning. Autonomy is an important concept in medicine and elsewhere and we shouldn't leave it in that stunted, abbreviated form.

Generally we think of an autonomous person as one who has the capacity, someone who is able, to make choices and to act. The person is rational –that is, he or she can acquire and understand the information on which decisions are based.

Here is a patient saying the same things in her own way. She is a palliative care physician in her fifties who has multiple myeloma. She is refusing aggressive chemotherapy but consenting to a different regimen. «I reviewed the literature and I am as knowledgeable as all but a few doctors, and I know my own body, which they don't –even if they know about myeloma.» Other patients who are not physician says the same kind of thing.

This doctor is considered independent, that is one of her personality characteristics. But, is independence as a personality characteristic what is important to autonomy or is there more to it. I generally mean by independent that there are no influences on the person that would interfere with the persons

capacity to act or rationality. If that is the case than she is not so independent.

Of course she has influences that might interfere with her ability to make clear and rational decisions –she has multiple myeloma. The fact that she has the disease –that so much is involved in her decision aside from just the facts makes us wonder if she is as independent as she thinks she is.

This woman is going to make her own decision no matter what anyone says –that is who she is. But is that our ideal of autonomy? Close maybe but not quite. Let's go back and look at autonomy again –from the beginning, so to speak.

One requirement of autonomy is that autonomous persons are authentically themselves. In their presentation to the world, their behavior, how they look and act, what they say and the way they think we recognize that person. Why is authenticity important? Because all decisions are made in a world of others –when autonomy is usually thought of as freedom of choice that doesn't seem important. But picture yourself as someone making a decision surrounded by people who know who you are and whom you trust and whose opinions you trust. Now picture yourself surrounded by people that do not know you, who you do not trust and whose opinions you do not trust. Do you believe your decisions will be as authentic and autonomous in the bad untrusting environment as in the trusting environment?

No, I think we know that. And if you are not authentically yourself, you will not be as autonomous either. Let's keep going. You also need to be independent –as I said before– meaning by independent that there are no influences on the person that would interfere with the person's capacity to think rationally. You also require all the information that bears on the choice that must be made. If you do not have the necessary information you cannot be independent. Then, you must understand the information and be able to think about it rationally.

Finally, you must be able to act on your decision or cause others to act on your behalf because if you cannot act of what value was your decision? We have moved quite far from autonomy being simply freedom of choice, but I believe we have moved in the direction of clinical reality.

## Back to Sickness

Brief restatement of the characteristics of the sick:

- Persons who are in bed with a long standing illness, but seem in all other ways just like the well, will have relational, cognitive, and emotional impairments characteristic of the sick.
- Persons who find themselves in a world of sickness, for example by an accident, will begin immediately to show characteristics of illness.
- The sick person's body has changed and the person's relationship to the body has changed.
- Sick persons are purposeful, but the focus of the purpose has shifted to themselves.
- Sick people think, but their cognitive function is impaired and their focus of attention has narrowed to themselves and little else.
- Emotional function changes with sickness.
- The world of the sick is one of immediate existence – the impaired world of here and now.
- Sick persons live in a web of relationships that are different. Relative strangers –doctors and nurses– assume great importance.
- In both chronic and acute illness the personal power of the sick is impaired.
- Every decision we make of any importance involves taking the perspective of others as well as ourselves but sick persons are unable to the perspective of others.
- Human beings can act, do things, make things and make things happen. The sick cannot act like the well.

These are only some of the things about the effect of sickness on sick people that we know. There is so much more that we do not know and do not seem interested in discovering.

Is it not amazing that if a patient is in the hospital sick with liver disease, doctors know about the problems of the liver in detail down to level of molecules? But doctors do not know, because it has never been studied, about that patient's impairments of emotion and its expression. If you wonder why that



is important to the patient's care or to autonomy, I will change the story slightly so that the patient is dying of the liver disease. Who thinks that those problems of emotion are not important to dying patients? Or to the expression of emotion!

Why is that the doctor's problem? Maybe not in 1908, but in 2008! Decisions have to be made by the patient who will be presumed to be autonomous. Whose problem is it (apart from the patient and the family)? If so, why has it not been systematically studied?

Recent research by neurophysiologists wanted to find out whether «Chemobrain» was real; the effect of chemotherapy on their thinking about which woman complained who received chemotherapy for cancer of the breast. But the researchers never thought to find out whether just being sick with breast cancer had an effect on thinking or emotions or on autonomy (by any definition).

## Back to Autonomy

I have no question that the characteristics of sickness prevent sick persons from thinking and acting autonomously. These are not new facts. The evidence of impairment of thinking in the sick has been known for at least thirty years and has been known systematically for almost a decade.

Everybody who takes care of sick persons knows most of the effects of sickness that I have described so why do we continue to act as though autonomy is simply freedom of choice? We continue to act as though sick persons who pass simple tests to see if they are «rational» –that is, are not confused, know where they are, and can do other simple tasks– can be counted as autonomous and their decisions as truly representing themselves.

I believe that the conclusion is correct that a central principle of contemporary bioethics that sick people –for example, people who require care in bed– can be considered autonomous, is wrong. The next question is what do we do about it? We cannot go back to the days when doctors made all the decisions

–the days of paternalism. For one thing, most patients are *not* sick and they are autonomous.

Another, vitally important reason we cannot go back to the old days is the fact that almost all medical decisions –in fact, almost all personal decisions– involve questions of value. What is important to the person, what does the person think is of most personal importance. These questions of value are as important as questions of fact or technical knowledge.

Nobody else but the persons whose decisions they are, truly knows what matters to them. Thus, nobody else except that person who may be impaired by sickness can make these vitally important decisions. What kind of a conclusion is this, «They are not capable of making the decisions, but they *must* make the decisions?»

To answer that contradiction we have to first question another, largely unspoken, principle of contemporary bioethics that people exist independently. That people really are atomistic; existing in their lives, in their thinking, and their actions largely independent of one another.

That idea, probably a child of Anglo-American philosophy of the 20<sup>th</sup> C, is incorrect I believe. It is true that adult persons should be independent –largely self-governing– and individual –existing as separate and distinct from other persons.

On the other hand, all thoughts and actions of any importance are originated or influenced in the context of the thoughts and actions of (usually important) others and the social milieu. To understand how persons arrive at decisions as important as those in medicine where we believe autonomy is key, one must understand the relationships and forces that influence the decisions. Remembering always that it is the values of the person making the decisions that should be their central determinant.

For bioethics this means that the nature and dynamics of relationships in general and certain relationships in particular –for example, the family and the doctor-patient relationship– should be a central focus of interest and study.

It also implies, I believe, that to obtain an autonomous decision from a sick person requires the help of others to find out what that person believes is in his or her best interests as he or she would know those interests when well. Best suited to that task is the physician or other clinician who because of familiarity with sickness and its effects can know the person as authentically themselves no matter what the inroads of sickness.

Who can find through inquiry, insight, and intuition the answers to the questions posed by the situation. And who can continue to probe to make sure that the answers obtained are truly authentic and representative of the patients beliefs, desires, and concerns. Hopefully, gone will be the days when the medical or surgical care «team» confronts the sick person thrusting the question at them that demands an answer *now*.

Finding out what someone desires, believes, or cares about is as much a part of caring for the patient as other more direct aspects of medical care. There lies the larger issue. When patients became persons they arrived at a status is much more than autonomous bearers of rights. They are human beings, persons just as we are, but wounded. Their change of status and our caring, joined to them co-equal, will ultimately transform medicine.

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He is the author of a number of scientific and educational articles, and has paid particular attention to the issues of suffering and of the training of doctors. His books include *The nature of suffering and the goals of Medicine*, 2nd ed. New York: Oxford University Press; 2004. This book significantly expands on the contents of an article of the same title, published in the *New England Journal of Medicine* (1982), which is probably one of the most frequently cited articles in medical journals worldwide of recent years.

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- Cassell EJ. *Doctoring: The Nature of Primary Care Medicine*. Oxford, UK: Oxford University Press/Milbank Memorial Fund; 1997.
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- Author's website: [www.ericcassell.com](http://www.ericcassell.com)

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### Bioethics Monographs:

19. *The person as the subject of medicine*
18. *Waiting lists. Can we improve them?*
17. *Individual Good and Common Good in Bioethics*
16. *Autonomy and Dependency in Old Age*
15. *Informed consent and cultural diversity*
14. *The issue of patient competence*
13. *Health information and the active participation of users*
12. *The management of nursing care*
11. *Los fines de la medicina (The Goals of Medicine)*
10. *Corresponsabilidad empresarial en el desarrollo sostenible (Corporate responsibility in sustainable development)*
9. *Ethics and sedation at the end of life*
8. *El uso racional de los medicamentos. Aspectos éticos (The rational use of medication: ethical aspects)*
7. *La gestión de los errores médicos (The management of medical errors)*
6. *The Ethics of medical communication*
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