



TAKE CARE OF ME LIKE THIS!

DECALOGUE FOR DYING WELL

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Prologue

In a famous paragraph of his *“Theory of Moral Sentiments”*, Adam Smith pointed out that if a distant country were to experience a terrible earthquake resulting into thousands of deaths, a single citizen, after expressing solidarity and pointing out philosophically the uncertainty of the human condition, would go on with his business or pleasures and rest or enjoy, with the same tranquility as if nothing had happened.

And he continues with irony: *“If (the same person) were to lose his little finger, he could not sleep tonight; but he will snore with the most profound serenity over the ruin of a hundred million brothers, when they are strangers to him”*.¹

It may not sound nice, but the reflection aptly describes our human condition. There is a big difference in how we think, feel, and react when we are directly affected by a tragedy as opposed to what happens to others.

This book is written by someone who has been directly affected. It has been written from a place of *“affection”* towards a human reality that ordinarily generates denial and rejection: death itself. Above all, the affection arises from Dr. Jacinto Bátiz’s long professional career as a specialist in palliative care, having witnessed many deaths and tried to accompany so many people in *“dying well”*. But also, and this is certainly striking, the book is written with an unusual degree of personal concern: not written to advise others, but as preparation for one’s own end.

¹ The Theory of Moral Sentiments, Part III, Chapter III: Of the Influence and Authority of Conscience

We have here the uncommon case of a doctor who faces his own death, that is, who confronts it head-on, overcoming professional routine and thus relativizing its profound human significance. This is not a technical or distant reflection, but one that is committed to the point of projecting, based on what he has experienced in relation to others, a personal desire: how he would like to be cared for in that final moment. And this is concretized in 10 rules formulated as wishes for the time of great weakness.

Dealing with death is, although we may not realize it, is an enormous, peculiarity in our culture. There has never been a people or a social context that experiences it as we do. It has been widely discussed that it constitutes one of the strongest taboos in “*developed*” societies. Death terrifies many, is recognized as inevitable, but is perceived as a potentially horrible experience that only generates silence and paralysis. Death is rarely mentioned and it seems tasteless to talk about the subject. If the issue arises in some way, there will always be someone who, sooner rather than later, encourages changing the subject to something “*more cheerful*”. The norm is not to discuss it, and if it comes up, most people prefer to dust off some version of the classic “*carpe diem*”.

Mario Vargas Llosa encouraged us in an interview to “*live as if we were immortal; so that death surprises you when you are working or making plans... Then you have really taken advantage of life until the end*”. Apparently, those of us who do not share this view do not know how to live well. I mention this as an example, illustrating many other references that could be collected.

In this topic, in just a few generations, the change in social perceptions has been very marked. Still in the 1960s, the sick person died at home, surrounded by loved ones. Neither children nor older people were afraid to touch them physically, to hold their hand to pray... In short, the end of life was accompanied naturally. This has been the case for thousands of years and still in many parts of world. But not here. In Europe, we do everything to hide this dimension of life. Funeral services “*take care of everything*”. avoiding that close people suffer the discomfort of having to deal with “*the corpse*”. This, according to frequent comments we hear, has nothing to do with the full-of-life person we want to remember.

It is a curious time in which, on the one hand, the material and pleasurable nature of human life and sexuality is reaffirmed, and on the other, the old or sick body has become something uncomfortable that we do not know what to do with. The denial of death reaches such a point that some “*prophets*” begin to proclaim the more or less imminent coming of a “*creature*,” or whatever it may be, that, definitively liberated from the slavery of its corporeality, may finally become “*immortal*”.

“While we wait for that great day, and given that nothing will prevent the living from having to face their own death sooner or later, we do what we can: we exorcise it so that it becomes invisible, taking special care to avoid children and young people being exposed to “*such a terrible thing*”.

Another peculiarity of the author, which is becoming less common in our environment, is his religious conviction. The book does not argue from faith, but it says something that is worth listening to in this secular society: the experience of dealing with seriously sick people confirms time and time again, even in those who are not religious or are opposed to established religions, that attention to the spiritual and transcendent dimension is very important in this phase of life. In the Diocese of Bilbao, the work of the pastoral health team in our hospitals demonstrates this over and over again. When we approach the sick person with the necessary respect and sensitivity, listening to their story, allowing them to communicate their situation and needs, the result is always positive in all dimensions, including the physical one. The idea is simple: instead of us saying things, let the person speak to us, tell us, and explain what is important to them at that moment.

The book also makes relevant considerations about those who have been trained as healthcare professionals. It points out a great paradox: while knowledge and techniques for treating the body have had enormous development, training to treat the “*person*” of the patient has been barely taken care of. Medicine continues to focus on the material, physiological, chemical, and organic dimensions of the patient, on the physical dimension of illness. Professionals, increasingly specialized, are perfectly prepared to treat this or that aspect of physical illness, this or that specific organ, but they have serious deficiencies in accompanying the person.

In this, medicine only reflects the general tendency of scientific knowledge, which is moving towards increasing fragmentation and technification and, for that reason, runs the risk of becoming increasingly dehumanized.

As the same author says, sometimes we seem to be more interested in the illness than in the person who suffers from it. The attention of specialists cannot be solely focused on cure. When physical healing becomes impossible and improbable, there is still much to be done, and this book helps us to concretize that program.

“Death is sweet; but its antechamber, cruel,” said Camilo José Cela. There are places in the world where, because one suffers greatly in life and because there is no doubt about a more beautiful future life, people are not afraid to die. But even though they don’t have that fear, they may have another: they fear dying badly. The alternative? To die well. Without unnecessary pain, accompanied by loved ones, or, if they are absent, by a compassionate human being. It is perfectly legitimate to desire this. It is something that is owed to us if, as we say, human dignity exists.

Relief from pain, companionship, listening, emotional support, and adaptation to the specific spiritual needs of the patient. This spiritual care is the poor sister of hospital service, although healthcare professionals, even skeptics, can attest that the real demand exists and is considerable. Let us acknowledge that this is an essential dimension of the person. To deny it is to disrespect the dignity of the sick based on prejudices. Just as throughout life, we need companions on the journey at the time of death.

I am grateful to Dr. Bátiz for this necessary work, written with affection and the experience of having sympathized, that is, *“suffered with”* all the people he has accompanied to a good death. Thank you for helping us prepare for the *“good death,”* which can come without warning and peacefully, or become an occasion for human encounter, difficult but beautiful, traversing the final desert.

Mons. Joseba Segura Etxezarraga
Obispo de Bilbao

Introduction

On one occasion, during an interview with a journalist, he once asked me for a recipe in the form of a decalogue for dying well so that I could give a guide my fellow doctors. I told him that I didn't feel capable of giving any recipe, nor would I dare to create a decalogue for others. However, based on my experience of accompanying many patients in the dying process, from whom I had learned a great deal, I would share my ten wishes to those who would care for me when my time comes.

After sharing my experiences on these topics with postgraduate students and explaining this decalogue to them, I realized that it could be very helpful, both to professionals dedicated to end-of-life care and to the patients themselves, so that they would not hesitate to request how they wish to be cared for in their final moments. Patients have shown me that when these ten wishes are fulfilled, one dies well.

Perhaps we are not afraid of death because sometimes we even await it or desire it to end our suffering, but we do fear dying badly. We must consider that dying is inevitable, but dying badly should not be. Palliative care aims to bring quality to the remaining life of the terminally ill person and help them die well when the time comes. Palliative care does not seek to unnecessarily prolong life but to expand it. This should be our endeavor: to prevent patients from dying badly and to live without suffering until their death arrives.

Perhaps, before continuing to read the following pages of this book, we should approach some answers to the question of what constitutes a good death. While reading the book "El límite",¹ I found an answer that convinced me.

1 Gaona JM (2015). El límite. La Esfera. Pág. 265

A good death is when the dying person passes away in the way they desired. This helped me to choose the title “*Care for Me Like This!*”

I hope that reading this book can help the reader to plan their care when their time comes. Putting in writing how we wish to be cared for at the end of our lives, in case we are unable to express it personally to those who will care for us at that moment, is an attitude that should be normalized among us. For this purpose, we have what is called an “*Advance Directive,*” “*Living Will,*” or colloquially known as a “*healthcare directive*”. Let us bear in mind that, at one moment or another, we will all find ourselves at the threshold of exiting this life.

I have written “*Care for Me Like This!*” in the first person because that is how I want to be cared for. If this book can give ideas to others to express their wishes, I will feel satisfied, as well as if it can serve as a guide for maintaining an open dialogue with their doctors or for completing a more detailed advanced directive or living will. I have aimed to provide arguments for each of the ten wishes that I consider to be my *decalogue for dying well*.

With this book, I do not intend to dogmatize about palliative care. What I intend to do is to share how I desire these cares to be when I need them, based on what I learned during many years I accompanied terminally patients. They taught me what you, dear reader, are about to read in the following pages of this book.

1. Treat me as a person

Treat me as a human being until the moment of my death. Do not see me solely as a biological structure, but also consider my emotional, social, and spiritual dimensions.

I wish for you to alleviate my pain and any other symptom that causes me suffering. I desire emotional support in the face of my fears, doubts, and anxieties. I want to be accompanied; I do not want to die alone. I want my spiritual needs to be met and for you to help me find meaning in my life.

Fulfilling these wishes would be treating me as a person, as a human being. However, I believe that there is much progress to be made in order to meet these desires. Perhaps, when planning the care for these patients from a healthcare management perspective, the focus is often solely on their physical needs, the ones that can be measured, visualized on monitors. But there are other important aspects for the patient, their family, their emotions, fears, affections, work matters, their family's concerns for which they hold responsibility but can no longer address, their sense of life, and the future of their family after they pass away. All of these are needs that we must attend to and resolve. Therefore, a comprehensive approach to the patient is needed, without forgetting the person who takes care of and loves them—their family, who also suffers and needs our support. That is why I also wish for you to care for my family in their suffering.

When a person is sick, it is not just an organ that is affected by pathogens, degenerative mechanisms, or trauma; the entire person is involved, from their body to their capacity to think and reason, influenced by pain or limitations imposed by the illness.

In the Faculty of Medicine, we were taught from the first year to understand our bodies in the Anatomy lab. As we progressed through the program, we learned how each organ functions, what diseases they can suffer from, and how each disease can be treated. But upon completing our medical degree and obtaining our license to practice medicine, we were undoubtedly experts in understanding the structure of our bodies, but perhaps we lacked the necessary knowledge to help those who were suffering from illness, the individuals who owned the affected organs. I believe we were well-trained to treat diseases but had many deficiencies in treating sick individuals.

Human beings cannot be understood by reductionist scientific methods that may be successful in other circumstances because when they are broken down into their parts, they cease to exist as individuals. The anatomical pathologist¹ only intervenes through his/her diagnosis of the tissue sent to him/her after a biopsy or surgical intervention; their function is crucial even though they do not interact with the patient.

I would like to share a personal experience that illustrates what I just stated. I remember that in the *Basic and Clinical Oncology Master's program at the University of the Basque Country*, where I teach Palliative Care for cancer patients, there was a biologist researcher enrolled who requested to do an internship in our Palliative Care Unit. Curious about her interest in learning about our work, when she finished her internship, I asked her if it had been helpful. She responded unequivocally, "*from now on, when I study cells through the microscope, I will keep in mind that those cells belong to a person*".

The patient has a name, a story, customs, and an environment that go beyond symptoms, a diagnosis, and a room number. It is all too common to hear expressions like, "*how is the cirrhosis in Room 214?*" This demonstrates a lack of respect and dehumanization in our care towards the sick persons when we have objectified them, reducing them to their diseased liver and the place where they are located.

Calling someone by their name is the minimum we should do to show them our respect. If all we care about is the illness, forgetting about the person who is suffering from it, we will be missing something crucial to do it properly. Of course, we must know their illness in detail in order to combat it, but when the disease becomes incurable, the patient needs us to also care about them, the ones who are experiencing it. This must be kept in mind not only when facing an incurable disease but at any moment when we provide our professional attention to patients.

When caring for the human being from an integral perspective, we need to provide not only biological relief but also the biographical relief that encompasses human suffering, both for the patients and their family. It is true that when we are further removed from the patient because we dedicate ourselves to researching the disease, its control, and possible treatments, we may not fully understand the human aspects of the disease. However, as professionals and family members responsible for their care, we understand other aspects that can help cope with the illness because the patient is a person.

Those of us who work in palliative care, attending to incurable patients and accompanying the dying, are often praised for our work, but at the same time, people feel sorry for us for being so close to the sadness of the end of life. We appreciate the praise but we do not share their pity because we learn a lot when we are alongside these individuals who measure the remaining time of their lives in hours or days, no more; we learn to value our time, of which we often are not aware, measuring it in years without giving importance to each day.

For them, the most important thing is the company of their loved ones and the availability of professionals to help them avoid suffering; we often isolate ourselves and do not sufficiently value the company of others. When we realize that the peace they desire comes from resolving unfinished matters and finding meaning in the life they have lived, we begin to understand the importance of the messages conveyed by the sick individuals.

Being in the front row and witnessing this profound teaching from the sick helps us distinguish the profound from the superficial. It teaches us to better seize life, to be supportive, and to reflect more deeply than we usually do.

Reflection on the everyday doesn't seem to be common nowadays. However, if we were to spend a few minutes each day reflecting, perhaps we would modify some of our attitudes.

But what does a patient need at the end of their life? It is important for us to understand that when we have to care for patients in the terminal phase of an illness, we must adopt a comprehensive approach to their care. In addition to controlling physical symptoms, we must consider the emotional, social, and spiritual aspects. Physical care must obviously be of excellent quality, but this is not enough; a person cannot be reduced to a mere biological entity. Palliative care also encompasses psychological, social, and spiritual aspects.

Patients approaching the end of their lives have four fundamental needs that professionals must be able to identify and meet. By fulfilling these needs, we will help them live with dignity until their death. They need relief from their pain and any other distressing symptoms; they have the right to have these symptoms alleviated to minimize physical suffering. They need emotional support; they have the right to receive psychological assistance. They need to be accompanied; they have the right not to die alone. They need to satisfy their spiritual needs; they have the right to receive the spiritual support they desire.

Throughout my experience with patients in their final stages of life, I have found that the sick people, especially when they are nearing the end of their life, is when they need us the most. They need us to alleviate their pain and any other symptoms that cause them physical suffering, to support them emotionally in their fears and worries, to accompany them so that they do not suffer from loneliness in the face of death, they also need us to provide spiritual support. If we do not approach their care in this four-dimensional manner, we will not be doing it completely right.

I want to emphasize that the spiritual aspect may be the least understood part of the medical discipline, yet it is the spiritual support that patients demand the most in their final days. Therefore, any caregiver, whether a professional or not, must know how to provide spiritual accompaniment.

The Professor Diego Gracia¹ states the following: *“Palliative care must control the patient’s pain but also address their spiritual needs, understood beyond religiosity”*.

I will address spiritual accompaniment in detail because it is the type of support that patients in their terminal phase demand the most. First of all, we must understand their spiritual needs, and to do that, we need to consider the questions that are part of a person’s spiritual life: “Why me? What is the point of continuing to struggle? What is the meaning of my life now that I am unwell? What is God’s role in all of this? Why doesn’t He do anything to stop this illness? Is there anything after death? What will become of me? Does suffering have any meaning? Can one find meaning in life, even while suffering? How can I reconcile with myself, or with others, or with the God in whom one may believe? What can help me when I feel alone? Why does my faith falter?”

As we can see, there are many answers that a sick person needs in those difficult and unique moments for them, when they are nearing death. We must be able to respond to these profound questions that also cause them suffering. Spiritual suffering also requires relief. That is why we need to provide spiritual support when accompanying individuals in their end-of-life suffering. However, in order to offer this type of care to the persons at the end of their life, we must consider spirituality as our essential nature, something that is inherent to us as human beings and aspires to give meaning to our lives.

The experience of suffering is universal and tends to intensify at the borders of life’s end. Its existence becomes a technical challenge and a moral imperative for professionals, which demands that we do not turn a blind eye. I believe that spirituality is also a universal human trait, and denying our spiritual nature in clinical work becomes a clear factor of dehumanization. We must consider that the majority of the suffering that occurs at the end of life, apart from physical pain, is related to other emotional, social, and spiritual issues, as well as their own inability to resolve life’s deepest questions.

The spiritual aspect may indeed be the least understood part of medicine, but it is the one that patients demand the most in their final days; this is something we confirm every day in our practice.

1 Diego Gracia Guillén (Madrid, 1941). Médico escritor y filósofo. Especialista en Psicología y Psiquiatría. Se le considera un experto en Bioética a nivel nacional e internacional.

Human beings have the capacity to confront the experience of their death, albeit with difficulties, approaching it through denial, resignation, or anger, but also through accepting trust that leads to a new space of consciousness transcending reality.

I believe that attending to spiritual resources and needs is not exclusive to palliative care, although it should be particularly emphasized in areas where the experience of suffering is significant, as well as in all contexts of fragility, dependency, chronicity, loss, and the close experience of death. We must embrace a broad and pluralistic vision of spirituality that allows the presence of philosophical, existential, axiological, religious, or any other perspective that respects different convictions and the right to hold them.

Palliative care professionals are aware that we do not own the final process of people's lives; we are simply companions on their journey. What does spiritual accompaniment that we can offer entail? It means being able to recognize, embrace, and provide space for the inner dialogue of the person who is suffering, so that they can give voice to their questions and bring their answers to life. It means helping to awaken or bring to light the longing, the inner search that every person may have.

What are the spiritual needs of people at the end of life? The need to be recognized as persons; the need to reexamine their life; the need to find meaning in their life; the need to free themselves from guilt; the need for self-forgiveness; the need for reconciliation; the need to feel forgiven; the need to place their life in something beyond themselves; the need for continuity; the need for genuine hope, not false illusions; the need to express religious feelings and experiences.

The sick people find it difficult to accept that their body is cared for by a medical team, their personality entrusted to a psychologist, and their spiritual being, *in extremis*, entrusted to the hospital chaplain. It is necessary to care for people at the end of their lives from a spiritual perspective, but in a comprehensive manner. They also need this care in order to die in peace.

TAKE CARE OF ME LIKE THIS!



2. Allow me to express my feelings

It is going to be very important for me to express my own feelings and emotions about my approach to death. When I accompanied those who were dying, I came to understand how important it was for them to express their feelings and emotions. That gave them peace. It is that same peace that I also desire for myself when my time comes.

However, throughout my experience in accompanying many individuals in those moments of dying, I have learned that living with a mindful awareness of death awakens us to life. It encourages us to fully enjoy all that is offered to us here and now, to not postpone what we can do in the present, to not hide what we feel, and to strive for the utmost beauty in our relationships.

Living with a mindful awareness of death requires that we become more responsible. It motivates us to pay attention to the quality of our words and actions. Ultimately, it allows us to give unique value to each moment we live.

When persons are facing death, they need us to provide emotional space to them so that they may express their feelings about the proximity of their end. They often feel fear about how their moment of death will be, they fear suffering, they feel sadness about leaving their beloved forever, and they are uncertain about what will happen after their death. They need to share these feelings and emotions with those who are accompanying them in order to ease the suffering they may cause.

I confess that I am not afraid of dying, but I am afraid of suffering. Above all, I feel sorrow because at some point I will have to leave my beloved ones forever.

Facing one's own death is not the same as facing the death of others. But when we have to care for people who are facing death, we realize that fear of death is one of the most deeply rooted emotions in a person. Despite the fact that death is an everyday occurrence, we often, more or less deliberately and out of a false sense of immortality, tend to forget about it by constantly denying it.¹

The way we approach death has evolved over time. It is necessary for us to integrate death into life and to stop considering medicine solely as something that prevents people from dying. For many centuries, people died in a fairly similar manner, without significant changes, until about four or five decades ago when it suddenly began to change drastically. Previously, it was a known, peaceful, and familiar death. Now it is considered a forbidden, unacceptable, and dirty death. I have witnessed this evolution myself.

I remember when one of my grandparents passed away at home, in their bed, surrounded by their loved ones – their spouse, children, grandchildren, and siblings. We all understood that their life was coming to a natural end. But over the years, especially throughout my medical career, I witnessed very different scenarios of death: sometimes tragic and violent, some occasions undignified due to unrelieved suffering or unaccompanied loneliness, and so on. This motivated me as a physician to strive for a death more similar to that of my grandparent.

When I read an article titled “*Between Inevitable Death and the Quest for Immortality*”² in a professional journal, it made me reflect on our determination to view death as a stage of life that we can avoid and our insistence on the pursuit of immortality. It is then that we must ask ourselves, “*Where are we?*” and “*Where are we heading?*” Because while we are preoccupied with the daily demands of our practice, a new medical conception of life and death is taking shape in certain minds.

The question of the meaning of one's own life is usually not raised when everything is going well. But when an illusion is shattered, when something unexpected happens, when expectations are frustrated, when we fail, when we fall sick, we do ask ourselves about

1 Bátiz J. (2019) Ante la muerte ¿cómo cuidar a las personas? Revista Iberoamericana de Bioética. Núm. 11/01-14.

2 Sans-Sabrafen J. (2002). Entre la muerte inevitable y la búsqueda de la inmortalidad. Medicina Clínica, 2002; 119(3): 99-102.

the meaning of our efforts. And when we perceive the proximity of death, the question of the meaning of life becomes more pressing than ever before.

Those who live each day as if it were their last experience it in a special way because they know that everything they do will never be repeated. It's true that we never know for certain when our last day will be, just as we are not aware of the first day we began to live. But we know there will be a last day, a last evening, a last night. That is why those who live knowing that there is an end, live the present moment with intensity.

In a normal life, it is known, of course, that one is loved. What is not known is how much one is loved, because daily tasks seem to hide the depth of affection. It can only be glimpsed and felt on crucial occasions such as in the face of a serious illness and the proximity of death.

To provide a good end-of-life care, good communication is necessary to better understand the patient's problems and desires. We must listen to them because attentive listening shows our respect and support, helping them better face these difficult and unique moments. By listening, we can appreciate their attitude towards the illness and their emotions. I learned to listen to my patients, which allowed me to understand their desires, fears, sorrows, and more. I hope that when my time comes, you will also listen to me.

It is very important that the patients can speak without interruptions and express their thoughts. Sometimes, what the patient needs is for us to be by their side in silence, attending to them, and embracing what they express. We should not change the subject until they do, nor should we give advice hastily because they no longer need it at this stage. The relationship will be more satisfying if we facilitate the patient's own journey to their own conclusions.

We must answer their questions and address their doubts, but with realistic answers, allowing the patient to fully express themselves so that they can find solutions. We should let them vent whenever they want.

Good communication helps a better control of pain, anxiety, and depression. If the patients feel carefully listened to, they may require fewer doses of painkillers or antidepressants. And, something difficult

but possible, we must put ourselves in the shoes of the suffering persons to seek their greatest physical, mental, and spiritual comfort. Always keeping in mind that suffering is what the patient says it is, what the patient describes, and not what others think it should be.

I also want to reflect on what death means for the doctor. Aristotle³ said that the pride of a doctor is the worst of diseases. It is a pride we demonstrate when we believe we can fight death and have complete power over it, but throughout the accompaniment of the dying, we become less prideful because we realize we cannot defeat it; we can only occasionally delay it, but nothing more.

On the other hand, Albert Camus⁴ said *that as a human being and as a doctor, he could never get used to seeing his fellow human beings die*. He was absolutely right because when we witness the death of our patients, we, as doctors, still cannot get used to it, let alone as individuals. It was Elisabeth Kübler-Ross⁵ who proposed, as a prerequisite for helping terminally ill patients, the need to confront our own death. In order to help someone who is dying and whose death is approaching, we must do so from an acceptance of death as a natural stage of life, even if it is the final stage. It was also the same doctor who said, and we have read it in her writings, that the most important thing is our own attitude and our ability to face mortal illness and death. If this is a great problem in our lives, and we see death as a taboo, terrifying, and horrible subject, we will never be able to help a patient to face it calmly.

If we cannot face death with equanimity, how can we be useful to our patients? We beat around the bush and talk about trivialities, or the wonderful weather outside. Dr. Carlos Cristos⁵ answered the question, *“Where do you find the strength to maintain your vigor in the face of adversity?”* with this response: Well, from having been a doctor for so many years.

3 Aristóteles. (384 a.C. Grecia). Philosopher who was born in the city of Stagira, in northern Ancient Greece. He is considered, along with Plato, the father of Western philosophy. His ideas have exerted an enormous influence on the intellectual history of the West for more than two millennia.

4 Albert Camus (1913-1960). French novelist, essayist, playwright, philosopher and journalist, born in Algeria. His thought developed under the influence of the philosophical reasoning of Schopenhauer, Nietzsche and German existentialism.

5 Carlos Cristos (1956-2008). Doctor from Vigo, affected by a terminal illness (multiple systemic atrophy) who captured his fight for life in the documentary “The Wings of Life”.

When you accompany your first dying patient or sign your first death certificate, it may seem like an exceptional situation, but when this is repeated over and over again, you realize that dying is common place. Death encompasses our entire attitude as doctors towards the patient. It is a daily and pressing problem, while also being a deep philosophical consideration, undoubtedly the most important one for mankind. It is very difficult for a doctor to maintain a mature and serene attitude towards death because in addition to being doctors, we are also individuals who have fear and anguish when it comes to our own death.

The death of our patients reminds us, through resonance, of our own mortality as physicians. Sometimes, we confront it with a certain sense of immortality. Confronting the death of a patient forces us to face the reality, often denied, of our own death. The predictable and imminent death of the patient confronts us with our own destiny, reminding us of our transience. Physicians are almost the only ones in our community to whom immortality and omnipotence are attributed, although the truth is very different. Perhaps doctors are more afraid of death than the patients themselves.

When we are being trained as physicians, we need to see that, death, sooner or later, reaches the patients, it reaches all of us, and, as my friend Dr. Marcos Gómez Sancho⁶ says, the transition towards it is surely through the door of aging and chronic illnesses.

Only when we are able to accept it as something natural and, sooner or later, inevitable, will we dedicate ourselves to caring for the patients until the end, without a sense of failure. Fear of death is one of the most deeply rooted emotions in the human psyche. This anxiety about death and everything surrounding it influences the therapeutic relationship between the healthcare professional and the patients or their family. If we provide close and sincere support to our patients, there is much we can learn from the process of dying before we ourselves find ourselves in the same place they are.

⁶ Dr. Marcos Gómez Sancho. <http://www.mgomezsancho.com/esp/index.php>

TAKE CARE OF ME LIKE THIS!



3. Allow me to participate in the decisions about my care

I would like you to let me participate in the decisions related to my care and to consider my opinion, not because I am a doctor, but because in this case, I am a suffering patient who is dying. I would prefer that you don't exercise the paternalism of the past with me, but also not to fall into obstinate autonomy. I know I have the right to autonomy, but if you truly want to help me, deliberate with me about the decisions that will be made. In other words, I want you to genuinely assist me with shared autonomy.

For a long time, doctors were the ones who decided what they considered best for their patients. However, starting from 2002, through the Law on Patient Autonomy¹, the right to make decisions about important matters such as our care and medical treatment was recognized.

Sometimes, when the patients become older, healthcare professionals may think that they won't understand and instead turn to their families, who then accept making decisions that should be made by the patients themselves. Juan was 90 years old, but he was mentally sharp and engaged in interesting conversations with the professionals who attended him. When the attending physician had to propose a diagnostic test to adjust his care, he directly approached Juan's family, informing them of the purpose and nature of the test. Once the family authorized it, the physician instructed the nursing staff to carry out the diagnostic test. Juan went along without knowing where or why. When the attending physician presented the test results and the proposed care plan for Juan during the daily clinical session with the team, as the head of the unit, I asked if Juan was aware of the test they were going to perform and its purpose.

¹ Law 41/2002, of 14 November, basic law regulating patient autonomy and the rights and obligations regarding clinical information and documentation.

The attending physician responded that he had already explained everything to the family and believed that was sufficient. To correct this situation, we asked the attending physician to first apologize to Juan for informing his family instead of him, and to explain to Juan why they had performed that test and its implications. Furthermore, they were to consult with Juan about whether he agreed to receive the planned care considering the test results. Juan understood the apology and the rest of the explanations.

We learned a lot from this case. We shouldn't assume that elderly patients won't understand our explanations. We must first try to adapt to their capacity to comprehend. We must not forget that, one of the social discrimination to the elders is our lack of patience and understanding in our interactions with them.

Another example serves to illustrate that we must consider and respect the wishes of the patients first and foremost. In our unit, we witnessed the family's decision to admit a patient to a Geriatric Residence. This patient had been admitted to our hospital following the request of her family for rehabilitative treatment due to the sequelae of a stroke. During her hospital stay, representatives from the Provincial Council of Bizkaia came to assess the patient for admission to the Residence requested by her family. Despite her dysphasia², the patient managed to ask for what those people were there for, and when they said it was for her admission to a Residence, she refused to be examined, and her crying became a daily occurrence from that day on. The family, puzzled by her behavior, asked us if the reason was because she "*had no blood flow*". We explained to them that the reason was that they were deciding for her without even consulting her.

The older we get or when we are in a vulnerable situation, we have an urgent need to be heard and for our ideas, both cultural and religious, to be taken into account.

In these circumstances, we have a need to be respected as free beings who should make our own decisions and not be treated as minors. We are not children.

² Dysphasia: is the disorder or anomaly of oral language that consists of a lack of coordination of words and is caused by a brain injury.

It is of utmost importance to keep the terminally ill patients informed about the nature and progression of their illness in order to have their collaboration in the development of their care. This is especially crucial in the case of elderly patients because, on one hand, obtaining their collaboration is often more challenging, and on the other hand, physicians tend to avoid it, reasoning that it requires more time and attention or due to difficulties in communicating with the patient.

Often, physicians try to avoid direct interaction with the patient, employing various excuses such as quick visits, not addressing the patient directly but instead speaking to the nurse or accompanying individuals to inquire about about the patient's condition, responding with monosyllabic or stereotypical phrases, maintaining excessive distance, or not engaging in conversation with the patient by citing their hearing impairment. In our society, we tend to relegate the elderly individuals to an essentially passive role and decide for them, applying paternalistic criteria that are deemed inappropriate for oneself.

So that our opinions may be considered, it is necessary for us to express in terms of writings how we wish to be cared for at the end of our lives, in case we are unable to express it personally to those who will be providing care at that time. This attitude should be normalized among us. We must not forget that at one point or another, we will all find ourselves at the threshold of departing from this life. To write down our wishes, we have what is known as an Advance Directive, Living Will, or what we colloquially refer to as a *"healthcare proxy"*.

A properly completed and duly registered document of this nature is legally binding. Furthermore, it represents a deontological imperative for the attending physician to respect and fulfill it, as stated in Article 38.3 of our Medical Code of Ethics³ (2022): *"When the patient's clinical situation does not allow them to make decisions, the physician must respect advance instructions or anticipatory wills, and in the absence thereof, the patient's previously expressed and known opinion, as well as the opinion expressed by their representatives"*.

The patients need us to assist them and to be able to *"hear their voice"* during such a momentous time as the end of their life. To

³ The Code of Medical Ethics contains the rules to be followed by physicians in the practice of their profession.

properly fulfill what the patient needs and desires, and what the physician offers, frank deliberation based on dialogue and respect between the physician and the patient is advised. This should be far removed from the routine imposition of the past or the uncritical application of current protocols in the name of good professional practice. Patients need us to talk more with them, to listen to them, and to share with them the decisions that will be made during those difficult and unique moments at the end of their lives.

Knowing the patients' last wishes or final instructions is of great importance in order to respect their autonomy and avoid paternalistic medical practices. However, we should not fall into a legalistic and defensive obsession, thinking that a written document will be clearer than a dialogue maintained with the patient. The Advance Directive can serve as a starting point for continuing a dialogue about their life's project in their final days.

The patients' last wishes are not only to be known through a written document that may have been signed under different conditions than those close to their death. Therefore, despite the existence of such a document, we must maintain ongoing dialogue with the patient, who may be in an advanced or terminal illness stage where death may be imminent, in order to understand their final wishes. This is something we often do in Palliative Care because when we are by the patients' side throughout the final stage of their illness, we can come to know their last wishes, their final intentions, and even their changes of mind.

The Advance Directive is a valuable and necessary tool when caring for an unconscious patient. It allows the expression of vital principles and criteria that should guide decisions in the healthcare field, such as personal values and preferences regarding the final moments of life or other situations of severe physical or mental limitation, the choice of where they wish to receive end-of-life care, and the desire to be an organ donor. Specific healthcare situations in which the patient wants their acceptance or rejection of certain treatments or care to be taken into account can also be expressed. Instructions and limits regarding medical actions in anticipated situations, in other words, what the patient would or would not want in terms of treatments and care in cases of temporary or permanent incapacity, can also be included.

Designating a representative to act as a valid interlocutor with the healthcare team in the event that the patients cannot express their wishes, and to act on their behalf in interpreting and fulfilling the instructions, should also be reflected in this document. However, one cannot request anything that goes against current law or against good medical practice.

TAKE CARE OF ME LIKE THIS!



4. Don't let me die alone

As neuroscientist Mariano Sigman¹ says in his book *The Power of Words*, true loneliness is not having anyone to talk to. Without good conversations, basic pillars of health are deregulated, from the immune system to a whole range of metabolic processes that include even the expression of our genes. It also degrades the cognitive control system by which we govern our ideas and emotions. Loneliness turns out to be one of the most harmful and overlooked risk factors for physical and mental health.

I do not want to die alone, abandoned by my loved ones, nor by my friends, nor by professionals, since I have been able to verify with the dying that dying alone is one of the greatest sufferings of a person. On the contrary, the company of their loved ones and caregivers is a great help and the best treatment to combat loneliness at the end of life. No one wants to die alone.

Every human being, by nature, wishes to die accompanied, cared for by the people he or she loves. In such circumstances, strengthening bonds is fundamental, but the dying patient knows that he must personally face the challenge of death and that no one can do it for him.

What is essential in the process of accompaniment is not to leave alone those who do not wish to be alone. It is of the utmost importance that the dying don't feel abandoned; in other words, that they feel that they are being cared for by others, even if they are aware that they have no cure. I wish you to respect my sought-after solitude and to free me from a forced solitude.

¹ Sigman, M. (2022). *El poder de las palabras. Cómo cambiar tu cerebro (y tu vida) conversando*. Debate. Barcelona.

We must also bear in mind that loneliness is an existential possibility of the human being, but it is not only a possibility, but sometimes it can become a necessity. The human being needs solitude to develop and grow.

On our planet Earth there are very lonely places, but there are also places that are overpopulated where the human density per square meter is enormous. Loneliness does not have a merely geographic or demographic sense, since one can feel lonely in the densest place in the world, because loneliness, in the human sphere, is not a physical space, but an environment of a psychic type. A person can be in the loneliest place on the planet and not have the sensation of being alone because this requires a certain mental predisposition.

There is a double risk in human beings: the risk of living permanently outside oneself and, on the other hand, the risk of isolating oneself from the affective world and enclosing oneself in the shell of solitude. Human beings need others to build themselves, but they also need solitude to discover themselves. Miguel de Unamuno², in his essay on “*Solitude*”, considers that the exercise of solitude, isolation and personal recollection, are fundamental for getting to know other people and for delving more intensely into one’s innermost self.

The sick suffer loneliness, but they also need solitude. The *solitude sought* is a vital need of man and constitutes the foundation of his personal identity, while forced solitude is imposed from outside and means the denial of the affective world, as the philosopher Francesc Torralba³ states in his book “*Antropología del cuidar*” (Anthropology of caring). Therefore, it can be said that the solitude desired from the inside is beautiful and the forced solitude from the outside is painful. Human beings need inner solitude in order to develop integrally, but they also need protection from painful solitude in order to be able to develop in a balanced way. Based on these two concepts of loneliness, I would like to make some practical reflections on how to care for the sick, especially at the end of life.

2 Miguel de Unamuno (1864-1936). Writer and philosopher born in Bilbao and a member of the Generation of ‘98. In his work he cultivated a wide variety of literary genres such as novels, essays, plays and poetry.

3 Francesc Torralba (Barcelona, 1967). Philosopher and Theologian. Professor of Ethics at Ramón Llull University. His thought revolves around the central elements of human existence.

Feeling safe, being accompanied and being aware of this is fundamental to withstand physical loneliness. However, when we are witnessing an inescapable fact in our society, which is the atomisation of individuals, this very often leads to the experience of forced loneliness, of forced solitude. This is the loneliness of so many elderly people who live alone in a decrepit home. This is the loneliness of the orphan. This is the loneliness of the widow. This is the loneliness of the homeless person sleeping in the street. When we have to care for a sick person, the question of loneliness is fundamental, because caring for a human being is first of all to be with him, not to abandon him to painful loneliness. When human beings suffer from pain or illness, they feel a compelling desire for the affectivity of others, they feel the need to develop their affective world. It is precisely then that the experience of forced solitude, the experience of abandonment, is particularly negative and has very serious effects on the patient's state of mind.

The dying persons need to feel that they are not abandoned by the health care providers, their family or their friends. They have had occasions in their terminal phase to want to be alone with themselves, but now, when the time comes, they do not want to die alone. They want to feel accompanied, they need to feel loved. Our way of caring for them is to offer them our company; even when they want to be silent or they are unconscious, they continue to feel our company. In this way they are not alone, they are also accompanied.

To illustrate the loneliness in which, at the end of life, the sick person often finds himself, I would like to recall a passage from *The Death of Ivan Ilyich* written by Leo Tolstoy⁴ in 1886. When Ivan returned home after his consultation with his doctor, Leo Tolstoy describes the following:

“He came home and began to tell his wife what had happened (his doctor had informed him that he was suffering from a dangerous, fatal disease). She listened to him, but in the middle of the story the daughter came in with her hat on, ready to go out with her mother. The girl reluctantly sat down to listen to the tiresome story, but she

4 León Tolstoi (1828-1910). Russian novelist considered one of the most important writers in world literature. His most famous works are *War and Peace* and *Anna Karenina*. For palliativists a landmark novel is *The Death of Ivan Ilyich*, a very short novel that explores the life of Ivan, a lawyer who strives to maintain a social status, a family accustomed to an affluent lifestyle, a successful career and an active social life until he begins to suffer from a strange illness.

didn't hold out for long. Nor did her mother listened to her until the end.

- Well, I am very glad," said the woman. Now be very careful to take your medicine regularly. Give me the prescription, and I'll send Gerasim (he was her faithful servant, who was always with her) to the apothecary's shop," and she went to dress herself for going out.

- Well," said Ivan Illich, "maybe it's nothing after all.

As can be seen from this fragment, his wife and daughter cared little or nothing for the fate of Ivan Ilyich, husband and father. And he, in deep loneliness, could not even speak of his fears.⁵ The only one he had with him was his faithful servant.

In the final stage of life, it is common for the patient to have a desire to strengthen emotional bonds with the family and the loved ones in order to reconcile with everyone and say their goodbyes. All of us who are close to the patient and their family should facilitate this process.

I remember a patient who was sad day after day, and when we asked him why he was sad, he confessed to us that he was filled with sorrow because he knew he was going to die very soon, and for many years, he had not spoken to one of his sons. His greatest desire was to make amends with him before he passed away. We asked for his permission to facilitate their meeting, and he granted it, although he didn't have much hope that his last wish could be fulfilled. We managed to locate his son and explain his father's pain to him. The son came to the hospital. The embrace between father and son resolved the father's sadness caused by the feeling of abandonment. On that very day, he said to us, "*Doctor, now I can die peacefully*". A few days later, he passed away.

In addition to the fear of experiencing physical pain, the patient also has a greater fear of dying alone and abandoned. After many years of experience in assisting patients at the end of their lives, we can affirm that the most important thing for the dying individuals is to feel accompanied in the final moments of their life by those who shared it with them. The human connection and presence of companionship bring comfort to the person who is dying, while loneliness intensifies the pain of bidding farewell to life without anyone by his or her side.

⁵ Ortiz Quesada F (2006). *El acto de morir*. Editores de Textos Mexicanos.

The patients need to alleviate their suffering. They require assistance in understanding and adapting to the process of their illness. They need to be informed to make informed decisions. They need support in their sadness. They should not feel abandoned by healthcare professionals, being transferred from one level of care to another without a sense of coordination but rather a sense of “*passing the problem along*”. They need bureaucratic barriers to not hinder their access to appropriate treatment and social assistance so that their family can provide the best care for them. They need to be close to their loved ones, preferably in their own home, with the necessary professional support. If they have to be in the hospital, at least it should not be so far away as to hinder their family’s daily access to accompany them in their final days.

For a patient in the final stage of life, family is everything. However, we sometimes turn it into a mechanical and depersonalized stage, inadvertently causing the family to leave the patient alone in large hospital complexes that have been designed without considering the real needs of these patients. The barriers that prevent families from staying with their loved ones in these situations contribute to the feelings of loneliness and distress.

Undoubtedly, as a doctor, I am not the most qualified person to write about the importance of family in terminally ill patients. Psychologists, social workers, those who work directly with families, would be better suited to do so. However, as healthcare professionals who are with the patients, we observe the different attitudes of families towards the patients, and above all, we witness how these attitudes influence the final phase of life. Sometimes these influences are positive, but often they can be negative. It is important not to overlook the fact that when facing the end-of-life, families experience a range of needs that can turn into anxieties and potentially lead to conflicts among family members. These conflicts can directly impact the care the patients receive from their own family if they are not identified and resolved in a timely manner. I have identified three common needs among families when they have a loved one admitted in the terminal phase:⁶

1. *Family reorganization during the time of caring for the sick individual is crucial.* Each family member has their own job and their own

6 Bátiz, J. (2016). *Aportaciones socio-sanitarias del Hospital San Juan de Dios de Santurce desde 1924 a 2014*. (Tesis doctoral). Hospital San Juan de Dios de Santurtzi. Pág. 193.

family responsibilities, so they need to come to an agreement among themselves to attend to the patient. This involves taking turns and potentially temporarily adjusting work schedules or responsibilities towards their own families. Even organizing this can be challenging, but imagine the additional difficulties if the distance between home and the hospital is significant.

2. *Time to manage all the resources. Time to care for and accompany the patient without rushing. Time to communicate with healthcare professionals and share doubts and fears.*
3. *Money is one of the main concerns for the family. A family with limited financial resources may need to spend their money, for example, on travel expenses to be present with their sick family member during their final moments.*

All the needs I have described throughout these pages cannot be met by medical and nursing professionals alone. It is essential for other professionals, such as psychologists, social workers, representatives from different religious beliefs, and volunteers, to get involved.

When one senses the end of life approaching, they transcend to other thoughts and questions whose answers are crucial for the patient to find meaning in their life. Therefore, we must also fulfill this spiritual need. We must not forget that in this terminal stage, the family is not an inconvenience but a necessity; we must see them as indispensable collaborators in providing appropriate care.

These needs cannot be met if professional caregivers are not adequately trained in communication skills, bioethics, and teamwork.

In this final stage of life, the person feels more vulnerable, withdrawn, physically and emotionally isolated. When the patients sense their impending death, they oscillate between moments of hope for their recovery and the pain of seeing their death approaching. On one hand, they hope for a remedy to be discovered for their illness, and on the other hand, they come to realize that this remedy will not come in time because their life is coming to an end.

However, in this situation, we tend to avoid approaching the patients because we don't know what to say. But it is at this moment that they need us to dedicate our time to understand their concerns and help organize their thoughts. We need to be by their side, listen to them, visit them frequently, and show them respect and understanding,

making it clear that we are ready to support them through whatever may happen.

Our presence will be the best medicine we can offer to the patient at that moment, considering that it is a medication without contradictions or side effects. So, let's dedicate our time to them. Let's not let them die alone.

The first ethical imperative in palliative care is not to abandon the patient. When we encounter a patient in a terminal clinical situation, the exclamation "*There's nothing more we can do!*" is not acceptable. Unfortunately, sometimes the family hears this exclamation from the professionals caring for their sick relative. But what is even more unforgivable is when the patients themselves hear it. Feeling abandoned by professionals is a symptom that adds to the suffering accompanying their fatal illness.

Not only do we abandon the sick persons by saying that there is nothing more to be done, but we also abandon them when professionals fail to educate themselves in palliative care to accompany them in the final stage of their life. In other instances, they are abandoned out of fear or a sense of professional failure. I will emphasize the ways in which we abandon the patient to ensure that we do not do so because we know that, even in that final stage, there is still much to be done

Abandonment due to lack of training. Traditionally, academic training in Medicine has focused on healing as the primary objective. This has often resulted in professionals lacking clinical and personal tools to deal with situations where curing the patient is not possible. This lack of training in Palliative Medicine typically leads to three types of attitudes that contribute to patient abandonment.

Those who believe they are facing a complex situation and choose to avoid it, leaving the sick people and their family to evolve freely through the process, understanding that palliative care should only be applied in the terminal stages.

Those who consider the situation trivial and of little complexity, which can be easily managed with their technical knowledge for controlling physical symptoms.

Those who, driven by fear and reluctance to accept the situation, adopt more interventionist attitudes. They avoid communication and uncomfortable encounters with the patients and their family.

Abandonment due to fear or a sense of professional failure. Our patients already know that we are not gods. Their desire is that we don't abandon them when they need us the most. What they need from us is offering our human connection to help them with all their needs. They understand that technology is no longer useful in curing their illness, but they still need people, their family, their friends, and their doctors. They need us to explain what will happen to them, they need us not to deceive them, but all of this must be done with exquisite sensitivity to help them understand what they need in those difficult and unique moments of their life.

Paternalistic abandonment and autonomous abandonment. Until the enactment of Law 41/2002, the basic law regulating patient autonomy, the paternalism practiced by physicians towards patients and their families was a way of “*not involving them,*” of not taking them into account, of abandoning them. Our own judgment prevailed. Once this Law came into effect, conflicts can arise when we understand the doctor-patient relationship in excessively “*autonomous*” terms. Therefore, we must not abandon the patient by invoking the Autonomy Law. When can autonomous abandonment occur? For example, when, after properly informing the patient and their family about treatment alternatives and their consequences, the patient asks:

- *Doctor, what do you advise me?*

And the doctor responds:

- *I have already provided you with information, but the decision is ultimately yours to make.*

This is also considered abandoning the patient. At that moment, they need our assistance in making an informed decision. This is the moment when we should reasonably exercise the patient's autonomy, which can be referred to as “*shared autonomy*”. To do so, we must take their autonomy seriously and do everything necessary to ensure that their decisions are as well-considered, prudent, and reasonable as possible.

We can achieve this by providing comprehensible information about the benefits, risks, or discomforts involved. To fulfill this primary ethical imperative of not abandoning the patient, we must be sensitive in assisting them to make decisions.

The simple contractual relationship between doctor and patient is not the only alternative to the paternalism that has been rejected in medical practice. However, this relationship alone is not sufficient assistance, especially when facing difficult situations, as the patient requires more personalization and consideration towards his personal world. Defensive or distant attitudes can be perceived as cruel. This occurs, for example, when written or excessively explicit consent is demanded for an obvious request, or when the family is made to decide on the withdrawal of futile treatment.

The alternative that citizens request is a more comprehensive and compassionate relationship, based on hospitality. This means showing interest in the personal world of the patient, allowing them to express fears, articulate desires, and discover preferences. It involves facilitating shared decision-making based on mutual trust.⁷

“Therapeutic abandonment”. When our medical intervention is insufficient, we can say that we are engaging in therapeutic abandonment.⁸ We abandon patients when we fail to adjust the necessary doses for effective pain management out of fear of *“going too far”*. We abandon them when we don’t prevent constipation when prescribing opioids. We also abandon them when we fail to utilize sedation when it is indicated. In essence, we abandon patients when we do not address any symptom that causes them suffering.

We abandon them when they seek our listening ear, and we don’t dedicate time to them. We abandon them when we don’t provide them with adequate information. We abandon them when we strive for success by controlling metastases without considering the unnecessary suffering that such treatment may impose on the patient.

7 Comité de Bioética de Cataluña (2010). *Recomendaciones a los profesionales sanitarios para la atención a los enfermos al final de la vida*. Fundación Grifols Cataluña.

8 Requena P (2017). ¡Doctor, no haga todo lo posible! De la limitación a la prudencia terapéutica. Editorial COMARES. Granada. Pág. 22

Medical technology has made extraordinary advancements in recent years, as has molecular biology, which has perhaps led us to know more about the disease and less about the person who experiences it. As a result, healthcare professionals have developed an almost exclusive focus on the concept of “*curing*,” to the detriment and even forgetting of what was the primary goal of medicine in its beginnings: “*caring*”. Consequently, when we cannot cure, sometimes we stop caring and abandon the person during a stage of life when they need the most assistance, in difficult circumstances and with numerous unrelieved symptoms.

Our culture rejects death, and it is often seen as a medical failure rather than something inherent to the human condition. In this regard, we often maintain a contradictory relationship with medical technology. When we are sick, we want to have faith in the exaggerated promises of technological intervention. However, at the same time, many of us fear a high-tech death, with tubes inserted into every natural orifice of our bodies.

Abandonment and therapeutic obstinacy⁹ are two extremes of medical malpractice in end-of-life care that constitute a serious violation of the Medical Code of Ethics.

9 Therapeutic obstinacy consists of the implementation of non-indicated, disproportionate or extraordinary measures, with the intention of avoiding death in a patient in need of palliative treatment. It constitutes medical malpractice and deontological misconduct. The causes of obstinacy may include, among others, difficulties in accepting the process of dying, the curative environment, lack of training or the demands of the patient or family. (Definition according to the Working Group “Medical Care at the end of life of the WTO and SECPAL. Gaceta Médica de Bilbao. 2015;112(4):216-218).



5. When I ask you, do not deceive me

The importance of the patient being well-informed was taught to me by my friend Joaquín. I am not violating professional confidentiality by mentioning his name. I mention him because he himself requested to openly discuss all of this in the media; he agreed to an interview in a widely circulated newspaper in Vizcaya. He knew he was dying but wanted to recommend patience. He learned of his kidney cancer diagnosis and understood that he would turn fifty-seven that year and would not live to see fifty-eight; his only wish was for the people who loved him not to suffer. He didn't fall apart, although as he said, *"I didn't start jumping for joy, but you have to know how to deal with cancer"*. He accepted what was happening to him and what he expected to happen. He would later learn that he had metastasis throughout the peritoneum.¹

Before continuing to explain the positive aspects of the information that Joaquín had about his illness and how it helped him cope in his final months, I would like to share something that will help you to understand the following paragraphs. From the beginning of our doctor-patient relationship, I promised Joaquín that I would never deceive him. Even before I knew the results of the cytology of the ascitic fluid² that had been extracted to alleviate his discomfort, he found the report that his family had prepared to give me. Joaquín read it and called my mobile phone, through which we had continuous communication when we couldn't see each other. The question he asked left me stunned:

¹ *Peritoneum*. Membrane that covers the inner surface of the abdomen and forms several folds that envelop the viscera.

² *Ascitic fluid*. Accumulation of fluid in the space between the peritoneum and the abdominal viscera..

Jacinto, when am I going to die? Just a moment ago, I found out that I have peritoneal metastases.

It only happened to me to respond with the words that François Mitterrand, the former President of the French Republic, said shortly before he died:

Joaquín, we are all flying aboard a plane that will one day crash into a mountain. While most people have forgotten about it, you, on the other hand, are thinking about it now because perhaps you have already started to see the mountain through the window.

Then I said to him, “Even if I can do nothing to cure you, I give you my word that I will not abandon you.

Neither did he, like the rest of the sick when they learn of his fatal diagnosis, believe it, as he had not noticed any pain, any discomfort, nothing at all. He wanted to know what was wrong. When someone asked him if he would have preferred not to know, he answered:

¡No way! If something has to come, let it come. Illness has helped me to know where I am.

Joachim did not want to disturb those who loved him. During his illness he was concerned about others. I don't know if I helped him at all, but he certainly helped me. He gave me the gift of his friendship and made me reflect on the importance of family, friends and knowing the truth. Also in his last moments, when I asked him if his situation had reinforced his religious convictions, he said:

Rather than reinforcing them, it has attracted them, because it had very few, if any.

Despite his immediate fatal future, he had a sense of humor and when in his last days he had to move around his house in his wheelchair he said that it was the most useful convertible car he had ever seen in his life. Joaquín told his family that he would love them very much while he was alive because when he died they would not believe it.

Before he died, he also wanted to give a lesson to terminally ill patients who, like him, were going to die. A lesson that he did not need to prepare with any bibliography. These were his masterly words:

I am not the one to give lessons on anything, but I recommend to anyone who is in the same situation as mine, and who can, to try to keep their patience, and if they lose it, to regain it.

For people who were about to die, he recommended that:

Don't be fooled, although those who say they don't think about death, are lying through their teeth. Instinctively it comes to your mind.

All these messages that Joachim gave us were externalized because he was informed about what was happening to him and he knew what was going to happen to him. The information he possessed about his illness allowed him in the last days of his life to decide about it.

The sick person asks us to tell him the truth, not to deceive him, but to be gentle enough to tell him the truth if we have to give him bad news. In other words, he asks us to tell him the truth, but “*quietly*” so that we do not frighten him, as a humorist in our country used to say.

Many patients sense the seriousness of their illness and ask for their doubts to be confirmed; they want to know the truth, to know if they are going to die soon. That is why it is important to respond to all the doubts they raise, but respecting the moment when the patients ask for it, when they ask for it, and always taking into account that the communication of the truth should be through the person they want it to be.

The truth must be communicated in a way that it can be accepted and understood, starting from what the patient already knows about his illness. We will explain in a simple and gradual way, when the patient asks for it, but, above all, without lying. If the patient discovers a certain falsehood in our response, we will have succeeded in making him lose confidence in the person who is telling him the bad news, even if he is someone very close to him. And, furthermore, we will have caused the patient to isolate themselves emotionally at a time when what they most need is to open up, express their feelings and put everything in order.

We cannot ignore that the persons, even though they are ill, has the right to know what is happening to them, has the right to make decisions, and has the right for their dignity to be respected. They are still alive, which means they still have rights. Without a doubt, they will be able to face better their future and that of their loved ones if they know the truth about their situation. Furthermore, most patients are aware of their condition because they can perceive the deterioration of their body, which will make them feel the poor prognosis of their illness.

It is crucial that those closest to the patients discover the benefits of communication so that they can work together with them and resolve any pending matters, making the final stage more peaceful. Whatever can bring happiness to the patient should be done or said now, while they are still conscious and alive.

When the patient asks, “*What’s wrong with me, doctor?*” He is expressing his desire to know the diagnosis and prognosis of his illness. He wants to know what is happening to him... And we have the duty to explain it to him in a way he can understand.

Perhaps the patient are hesitant to ask the doctor about the severity of their condition and their prognosis because they believe the doctor will not be honest with them, or simply because the doctor does not encourage them to ask questions about their doubts. It is at that moment when the patients try to “*investigate on their own*”: they review health encyclopedias, popular magazines... And that’s when they become more confused because they attribute everything they read to their illness, without being able to have a dialogue with anyone. The magazine and the encyclopedia cannot provide a specific answer to their question. Their doctor, on the other hand, could answer them because they know the patient very well and also know “*their illness,*” but the patients are afraid to ask.

As doctors, we must understand what the patients wants to know, how much they want us to tell them the truth about their illness and prognosis. Let’s not forget that they have the right to be properly informed so that they can make the appropriate decision. It is crucial that we employ suitable strategies to inform them of the truth in a way that our delivery does not add further suffering. However, we should never deceive them because if they discover the deception, they will no longer trust us and will isolate themselves.

The patients want to know what is happening to them, but they want us to explain it to them in their own language, in a way they can understand.

We have lived in an environment of paternalism from professionals and family members, where both parties preferred to hide the patients' situation, thinking that it was best for them. It is very common for family members to approach this problem assuming that the patients are unaware that they have an incurable and poor prognosis illness, and that we must prevent them from finding out in any way.

Giving good news usually doesn't pose difficulties in delivering it well. However, delivering bad news is more complicated and requires certain communication skills. In order to do so, we should take into account some considerations that can help us deliver bad news effectively.

Each professional should communicate bad news in their own style, as there are no rigid formulas or protocols for it. However, what we must do is to provide information while balancing the truth of the news with the sensitivity of how it is conveyed. Furthermore, we should do it in an appropriate environment, without interruptions, where the patients can express their emotions. We should assess how much information they may already have about their illness and try to understand what they want to know while also respecting their possible desire not to know the truth.

Aurelio was a patient who was admitted to our unit from the referral hospital. We knew he had a terminal oncological illness and was referred to our unit for palliative care. It seemed that he was unaware of his actual situation. When we went to greet him upon his admission, the first thing he asked me was:

- *Doctor, what do I have?*

We knew what he had and what his prognosis was, but we thought that we should not start our first conversation by answering this question. We approached the conversation in the following way:

Aurelio, we haven't had the chance to review your detailed medical records that were provided when you arrived. However,

we would like to hear from you what the doctor who referred you to our hospital has told you about your condition.

He told us:

He told me that I have a small stomach ulcer and that here I will be cured. It was then when we realized that Aurelio didn't know the truth about his illness.

From this “*white lie*” that was told to him, we would have to work towards gradually and honestly answering all the questions he would ask us. It wouldn't be necessary to tell him the whole truth, but whatever we told him must be true. We would undoubtedly respond to everything he wanted to know about his illness, his care, his progress, and his prognosis. He would indicate to us when and how much information he desired. “*I wish for you to tell me the truth when I ask so that I can make my own decisions*”.

While it is inevitable to establish prognoses regarding life expectancy, we should avoid being too definitive (such as stating “*six months,*” a response often given to the question “*how much time do I have?*”). However, we should keep the patient informed about the progression of his illness, and if requested by the patient, we can provide a more realistic assessment, for example, by saying “*it's getting worse*” or “*I believe the time is approaching*”.

We should always leave room for hope, even for individuals with a limited life prognosis, by using expressions such as “*you will be able to meet your new grandchild who will be born in the coming days*” or “*you will be able to hug your son whom you haven't embraced in a long time*”.

When delivering bad news, it is necessary to be attentive to the patient's psychological reaction. Let's not forget that the doctor-patient relationship is greatly strengthened when the information has been delivered appropriately. We will remain close to the patient and convey our commitment to helping them and their family throughout the process.

It is important to remember that we should also be equally delicate when conveying information to the patient's family. Sometimes, the family asks us not to inform the patient and requests our participation in what is known as the “*conspiracy of silence*.”³ In

³ Conspiracy of silence: this refers to the implicit or explicit agreement, on the part of rel-

such cases, we must remember that our ethical and professional obligation is to the patient and not the family. However, we should make an effort to communicate with the family to involve them in the patient's information.

I remember that on one occasion, when my team member and I were about to greet a patient who had just been admitted to our unit, the patient's daughters were waiting for us outside the room to tell us not to inform their father about the illness he had. They told us that he was unaware of the serious illness he was suffering from because that was the family's decision. I asked them the following question:

If you were in your father's situation, with full capacity to understand what is explained to you, would you prefer us not to tell you the truth?

Like a spring, they both said:

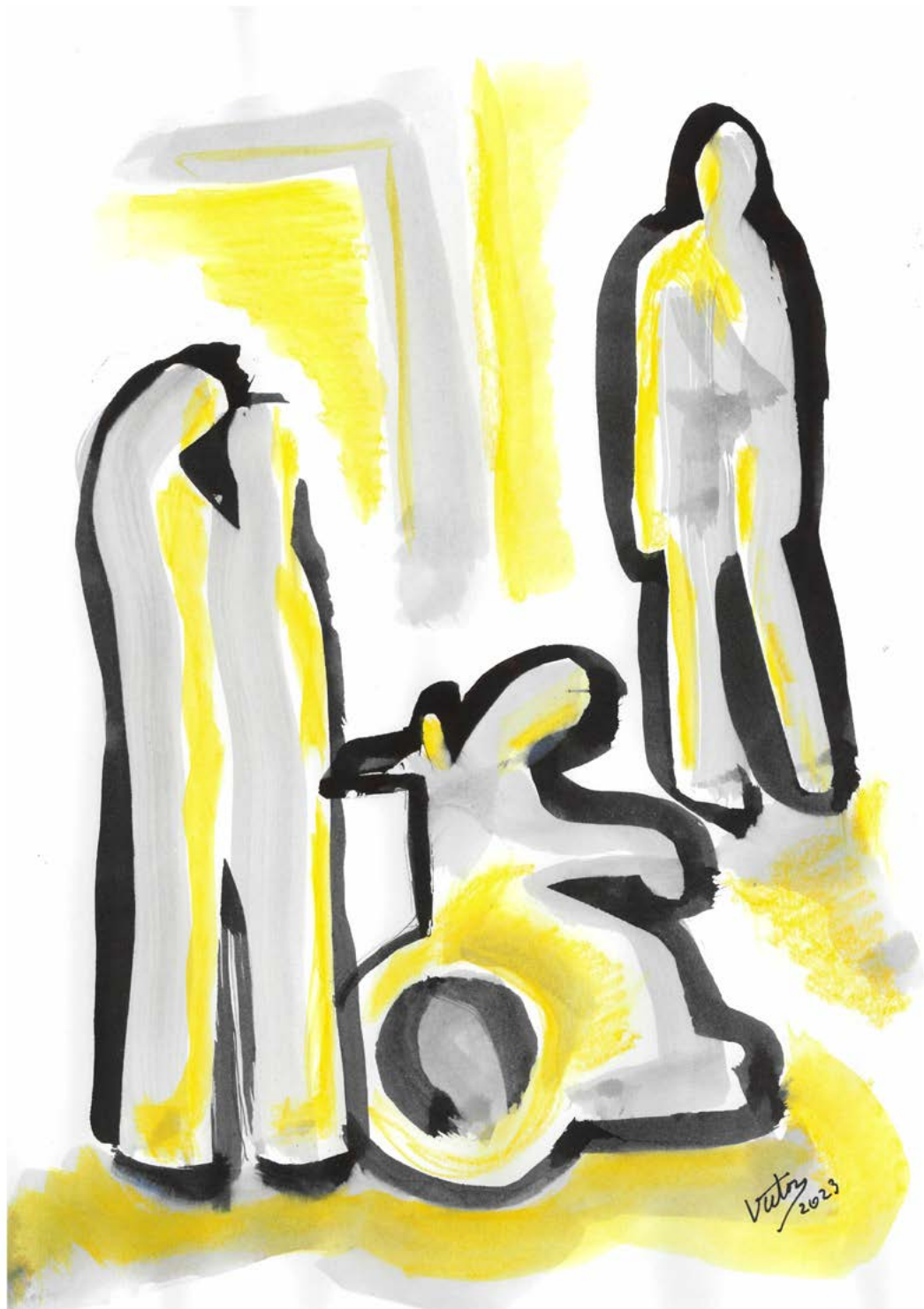
Absolutely not, we would want to be told the truth, we wouldn't want to be lied to.

So, you don't wish for your father what you wish for yourselves?

It was then when they realized that they were responding with overwhelmed feelings of sorrow rather than with reason. It was then when I explained to them to trust us that if their father asked us any questions regarding this matter, we would respond according to his capacity to understand the answer and we would do it delicately so as not to cause him any further suffering. I asked them to assist us in this process of information. From that moment on, they understood what would be best for their father, and their collaboration was decisive in ensuring that their father did not suffer because of this issue.

If we manage to deliver bad news in a way that the patient does not solely remember the news, then we have likely learned how to deliver bad news effectively. We should not inform the patients of their diagnosis and prognosis solely because the law obliges us to do so, but rather because it is an ethical and human professional commitment of the doctor.

atives, friends, professionals, to alter the information given to the patient in order to hide the diagnosis, the prognosis and the seriousness of the situation.



6. Do not judge me

I ask that you respect my individuality and refrain from judging me for my decisions, even if they are contrary to your own. Often, we tend to instruct the patient on how they should behave, what they should do or change so that everything can go well. However, in the context of terminal illness, we must accept the person as an individual with unique and irreplaceable value. We should never judge him.

When I began writing this section, I contemplated the following question regarding spiritual support for a persons who request such assistance but also the desire to help in hastening their death, considering the right granted by the recent euthanasia law approved in our country in March 2021.

How should our spiritual support be for those who wish to hasten their death? Even if some patients request our spiritual support wishing to expedite their death, and their desire goes against our beliefs, they still deserve our presence during the difficult transition at the end of their life. This support should not come with conditions; we must be by their side and listen to them.

When the patients are in a terminal clinical situation, they do not need our advice; they need our company and our listening ear. Under no circumstances should our support aim to change their mind. If they change their mind, it should be because the patients have decided so. We must respect their individuality and refrain from judging them for their decisions, even if they differ from our own perspectives.

We should not abandon the patient because his wishes for us is to continue accompanying him. However, we should withdraw when the euthanasia act is about to take place, based on the believers' reliance on what the Magisterium of the Church states in the document *Samaritanus Bonus*.¹ It would not be acceptable for those who provide spiritual assistance to these patients to engage in any outward gesture that could be interpreted as approval of the euthanasia action, such as being present at the moment of its execution. This presence could only be interpreted as complicity.

Our objective, when caring for patients in the terminal phase, is to preserve their dignity as they approach death and to achieve a dignified death. However, we must ask ourselves, what does dignity mean to them? How do they wish to be cared for based on their own concept of dignity?

On one occasion, I was conducting a training activity on palliative care, and after it ended, one of the attendees approached me and said:

- *Doctor, what you have conveyed about caring for those who suffer to ensure they have a dignified life may sound idealistic, but what exactly is dignity? What defines a dignified life?*

I didn't know how to answer him at that moment because I was certain that my response would also be very theoretical. I promised to reflect on his questions and let him know when I had a solid and well-argued answer. This is what motivated my reflection expressed in this book.

The word "*dignity*" may have become an empty term, as philosopher Francesc Torralba asks. When we care for patients in the terminal phase, we ask ourselves, what does it mean to live with dignity? And what does it mean to die with dignity?

The Spanish Medical Council (OMC) and the Spanish Society of Palliative Care (SECPAL) defined the concept of dying with dignity in a document titled "*Medical Care at the End of Life: Concepts and Definitions*," published in 2015. They defined it as follows: dying with dignity means living with dignity until the very last moment. This requires considering the patients as human being until the moment

¹ Letter *Samaritanus Bonus* of the Congregation for the Doctrine of the Faith on the care of persons in the critical and terminal phases of life. V.11. 22.09.2020.

of their death, respecting their beliefs and values, and involving them in decision-making through a close and honest relationship with the healthcare team. Dying with dignity is associated with the absence of suffering. Other human factors, such as the presence of the loved ones and creating a supportive environment, should also be taken into account.

I believe that defining the dignity of someone experiencing a terminal illness would be audacious, unless the person experiencing the illness defines it himself. However, we can approach it from the lived experience alongside our patients, learning through their own expressions during the dying process what dignity means to them in their final days and what dying with dignity would mean to them. I would like to understand the dignity of the person who is suffering during his final stage of life, so that once understood, it can be preserved.

Our attitude and behavior can recognize their dignity in order to maintain it in difficult situations for them. Sometimes we have to perform uncomfortable and intrusive examinations for the patients, but if we explain to them in advance what the procedure entails and ask for their permission, the patients will undoubtedly realize that we care, respect, and preserve their dignity. Dialogue will help us to know the patient as a person, understand his concerns, and his desires. If we create an environment where they feel comfortable sharing these with us, it will be a recognition of their dignity and help in preserving it until the end. By choosing our words carefully and accompanying them with our gaze and smile, we can demonstrate a compassionate attitude to guarantee their dignity.

Listening to the patients will be essential in understanding how they perceive their illness, prognosis, and end-of-life process. We need to know how they wish to be cared for so that their dignity is not compromised by us, their caregivers. The owner of their dignity is the patients, not us. It is their responsibility to help us understand it so that we can respond to their expectations of dignity and not act solely based on our own criteria of dignity in their situation.

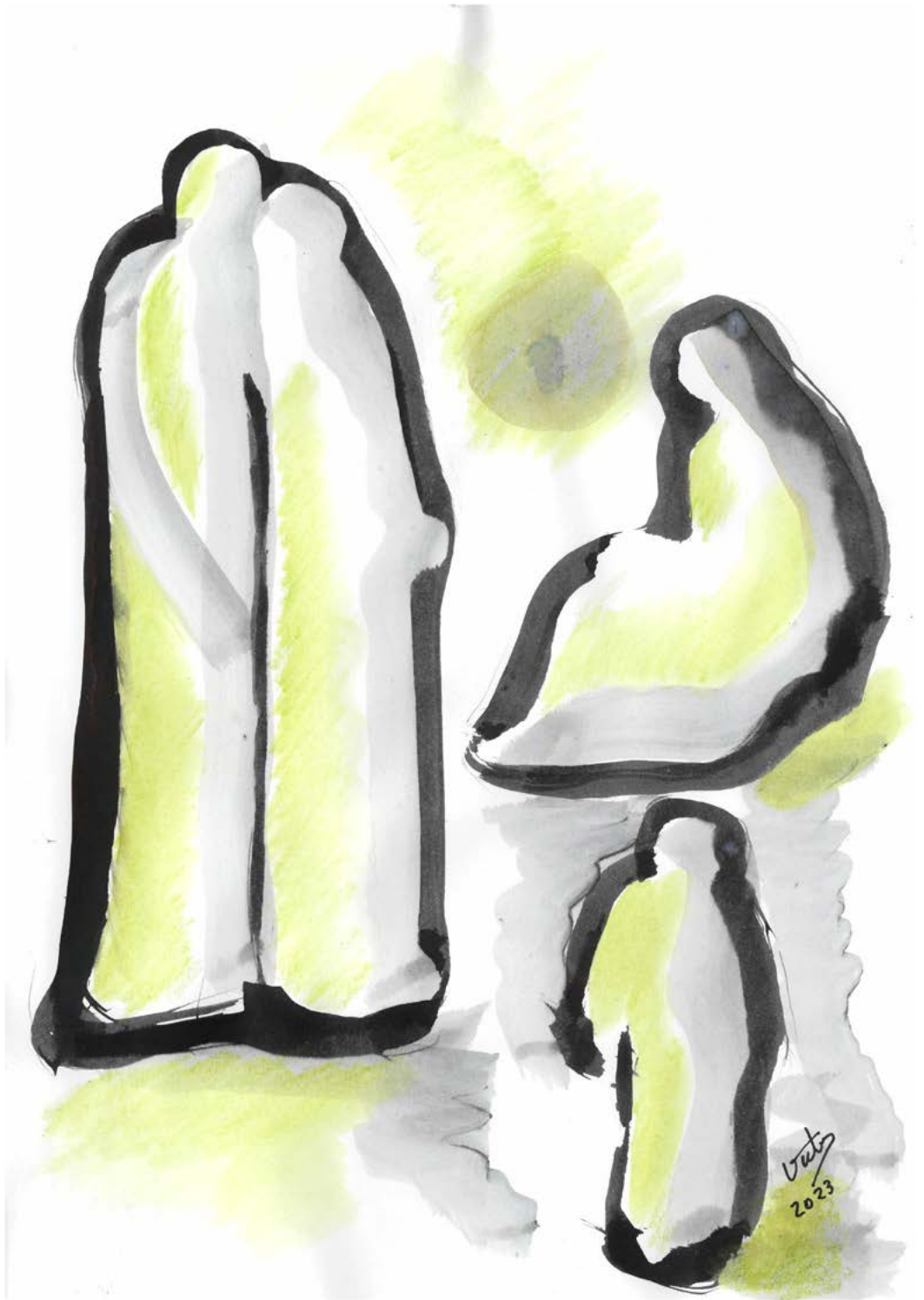
In situations where the patients have not been able to share their concept of dignity and how they would like to be cared for, it is when we can engage in reflective thinking by asking ourselves, *“How would I like to be cared for?”*

Seeking the maximum benefit for the patient remains the fundamental driving force of medical practice, but the will of the patient should determine the right direction and the limits of our medical attention. As physicians, we contribute scientific knowledge and assess the situation, which we translate into therapeutic indications. However, it is the patients who bring their value system, their vision of the future, their unique concept of health and quality of life, as well as their concept of dignity. They weigh the medical indications and make the decision to accept or reject them. Rejecting a medical recommendation, fully aware of the consequences, because they have been adequately informed, is the right of the patients, and it is the ethical duty of the physician to respect it.

Our responsibility as medical professionals is to preserve the patients' dignity throughout their entire process, so that they are not compelled to seek death as a solution to an undignified dying process. If, despite our efforts, they still desire to hasten their death, our attitude should be one of deep respect for their wishes. However, under no circumstances should inadequate or even negligent care on our part in preserving their dignity during the dying process become the cause of a request for hastening their death.

The dignity of the patients is what they perceive as their dignity, not what we believe it to be. Our assistance should be aimed at preserving their dignity according to their own criteria, not ours. In this way, the medical profession will provide good medical care by respecting the patient's autonomy.

TAKE CARE OF ME LIKE THIS!



7. Understand me and help me to face my death

I would like to start this section by saying that I would not wish to be cared for by certain professionals with harmful profiles for palliative care, as expressed by a palliative care colleague on Twitter:

- *“The Palliosaurus”*. That professional who attended a course many years ago and, as they coincided with some pioneers of palliative care, believes they have done more than enough. This type of professional detests those who try to innovate. Their motto is usually *“it has always been done this way”*.
- *The Pallimpostor*. He is the professional who claims to provide palliative care, although he sees it as a *“necessary evil”* and believes that *“not much is needed”*. He solely focuses on physical symptoms and, when the time comes, *“sedates with morphine”*.
- *The Palliodiator*. He is the professional who may not openly acknowledge it, but deeply despises what he considers the discipline of *“morphine and patting on the back”*. He considers himself to have studied to *“save lives”*. He is the prototype of the *“dog in the manger,”* neither doing nor allowing others to do.
- *The Palinsensitive*. I would not want to be cared for in a health centre where the manager only sees numbers, results and short-term profitability. For this reason, palliative care is often seen as an inefficient activity, which must be made profitable by reducing costs, preferably in terms of personnel.

Now is the time to recall how my late friend and renowned palliative care specialist, José Enrique Núñez, defined the role of a physician in his book *“Junto a ellos”*:

*“To be a physician is something else; it is to feel close to those who suffer and to put all our knowledge at their disposal [...] to make every effort to preserve the patient’s autonomy in decision-making aimed at their well-being [...] an open door to a medicine centered around the sole protagonist in our work: the sick individual [...] to turn away from all-powerful technology and rediscover our human dimension, the only path to becoming truly useful, efficient, and effective as professionals”.*¹

Do not allow me to find myself in the situation of the sick person described by Dr. Kübler-Ross in her book *On Death and Dying*:

*“He may cry out for rest, peace and dignity, but he only gets infusions, transfusions... He may want a single person to stop for a minute to ask him a question, but he will find a dozen people watching the clock, all concerned about his heart rate, his pulse, his lung functions, his secretions or excretions, but not about him as a human being”.*²

I hope that those who care for me are not only professionally competent, but also close to my needs, capable of knowing, understanding and satisfying them in order to help me to face my death. I have been very pleased to have been able to help many people to face their own death. I wish that those who will care for me would feel the same way.

Although it is slowly changing, palliative care has traditionally not been high on the agenda of general education and training for health professionals. This may explain why healthcare professionals often acknowledge that they do not feel well trained in the areas of breaking bad news, assessing prognosis, managing symptom control or helping patients make difficult decisions.

Traditionally, academic training in medicine has focused on cure as an objective; this has meant that in many cases we as professionals have lacked the clinical and personal tools to deal with situations in which it is not possible to cure the patient. We doctors should perhaps bear in mind the words of the philosopher Francesc Torralba³: Today,

1 Núñez, J.E. (2007). *Junto a ellos. Reflexiones de un médico junto al enfermo incurable*. Janssen-Cilag. Madrid. Pág. 53 y 56.

2 Kübler-Ross, E. (1993). *Sobre la muerte y los moribundos*. Grijalbo, S.A. Barcelona, pág. 23

3 Francesc Torralba (Barcelona, 1967). Philosopher and theologian.

there are still incurable diseases, but not uncurable patients. We as health professionals must learn to care for the incurably ill. The lack of training in care tends to result in three types of attitudes that occur in reality, in our profession, as I described in Chapter 4.

Isabel is a young doctor who has recently completed her residency in oncology and is now an assistant in the oncology department of a major hospital. A patient has been admitted to her department with a very advanced oncological process with no alternative curative treatment and who could only be helped with palliative care. When she assessed the patient, she considered that she was faced with a complex situation and decided to avoid it and leave the patient and his family to the free evolution of his process, also understanding that palliative care should only be applied in the agonizing phase. The young doctor was unaware that palliative care can be offered from the first moment of diagnosis of the fatal illness and that it can be combined with curative treatments, and as these treatments prove ineffective, palliative care is intensified.

In no case should palliative medicine be applied until the agonizing phase. His lack of training in palliative care led him to abandon the patient and his family in the face of the suffering caused by his advanced oncological illness.

Another attitude derived from a lack of training is that of Roberto, a very prestigious specialist doctor with many years of experience in health care, but who had no training in palliative care, who was asked to care for a patient with an advanced respiratory disease who did not respond to any treatment. The patient was very afraid of suffocating from lack of air, he was afraid of dying; moreover, he did not want to go to hospital so as not to be far from his family and loved ones. Roberto considered that he was dealing with an insignificant situation of little complexity and that it could be easily managed by him with a minimum of technical knowledge and attention to the physical symptoms. This self-sufficiency on the part of the doctor led him to disregard other needs of his patient for which he should also have been trained, such as help with the fear of dying and his ability to make decisions together with the patient when he refused to be admitted to hospital.

Juan is an internist who was noted for his diagnostic successes. In this case, he was faced with an elderly patient in the terminal phase of dementia and a family who wanted to take her home so that she could die peacefully with them. However, the doctor, faced with fear and reluctance to accept his patient's terminal condition, took a more interventionist approach to hydrate and nourish her, avoiding communication and uncomfortable encounters with the patient's family.

These three attitudes, abandonment, self-sufficiency and fear, can cause and do, in fact, the person at the end of life and their family to suffer a lack of comprehensive care for the dying process, a lack of home support and a shortage of continued care. However, there is encouraging evidence that these attitudes can be avoided with the knowledge and skills acquired during academic training.

Our San Juan de Dios Hospital in Santurce formed an alliance with the Faculty of Medicine of the University of the Basque Country in 2011 and with the Family Doctors' Teaching Unit in order to share our experience in Palliative Care with undergraduate medical students, with students of the Postgraduate Medical Degree in Integrated Care in Palliative Care and with Family Resident Doctors (R4). The aim of the internship in our unit was to know the reality of the care of people suffering from advanced incurable diseases and terminal illnesses, as well as their families, both in hospital admissions and in home care. After rotating in our unit for a month, the added value of the palliative care training was expressed to me in these words in their e-mails as a tutor for their rotations:

"I have once again observed the importance of an unhurried presence, without any other goals initially than to listen, allowing patients to express themselves and thus share their experiences, fears, and desires".

"I was struck by the tranquility they conveyed to everyone. There were no time constraints, only the time needed by the patient and their family".

"I was impressed by the affection shown. I loved seeing all the staff and volunteers treating the patients with absolute delicacy".

"In visiting the ward, I highlight the work of the healthcare team who accompany them every day, their commitment to love,

compassion, and the courage to show tenderness towards these deteriorated bodies, showing us the joy of living, not the illness”.

“Undoubtedly, I believe that contact with suffering and death teaches us to live in a more conscious and intense way”.

“I would have never thought that a place with these types of patients could be a place where there is so much life and where the humanity of each individual is discovered, reaching the core of human beings”.

“When I accompanied you to the patients’ homes, I experienced the different tasks undertaken to meet the physical, emotional, social, and spiritual needs of the patients and their families. I understood how important comprehensive care is”.

“I have been able to confirm that if one has enough time from the diagnosis of a fatal illness until death arrives, one comes to accept their fate with more tranquility than we can imagine. Personally, this gives me a lot of peace, knowing that if you have time, you come to terms with your destiny and do not die with anger”.

“It is interesting that among the medical community, so much value is placed on scientific knowledge (which is essential, of course), but so little effort is put into treating the patient in an integrated way, conveying information correctly... when it is for them that we work. It is to them that we owe ourselves”.

I am fully convinced that training in palliative care is necessary to provide better care. However, as Brother José Sánchez from the Order of St. John of God states in his book *“Lights and Theological Content in the Palliative Care Movement,”* charisma is also required for this purpose. Caregivers who tend to the sick often possess a high level of humanity, accompanied by their generous interest and warm concern for a service-oriented approach to medicine.

These professionals form what we could call a humanistic insurrection movement in favor of improving the care provided to patients in terminal phases, who are often forgotten. Personally,

4 Sánchez Martínez J (2004). Luces y contenidos teológicos en el movimiento de cuidados paliativos. Archivo-Museo San Juan de Dios “Casa de los Pisa”. Granada, pág. 18-19.

TAKE CARE OF ME LIKE THIS!

I desire to be cared for by professionals who are well-trained in palliative medicine, but who also possess charisma.



8. Care for me as you would like to be cared for

During my clinical practice as a physician, I always made it a point to provide the patients with the care that I would have desired for myself, unless they expressed a different preference. I believe that caring in this manner, especially towards the end of life, is consistent with our philosophy of providing care. I sincerely hope that you will do so.

“I believe these words spoken by Thomas Sydenham:¹ *“No one has been treated by me in any way different from how I would wish to be treated if I were afflicted with the same illness”*, These should be the essence of good medical practice. If we consider them in our clinical care every day, our patients would undoubtedly receive excellent attention, and we would be greatly satisfied for having treated them as we would want to be treated if we were in their shoes.

When I go for shopping at a store, deal with bureaucratic procedures at a public institution (such as a municipality or county), or accompany a family member to a medical center, I often observe that the treatment we receive from the staff is not appropriate. It is during these moments that I reflect on the following: Would they like to be treated that way? I am certain their answer would be no. Therefore, when we find ourselves in a vulnerable situation, such as when we are sick, we become more sensitive to inappropriate treatment, lack of empathy, and a lack of compassionate attitude.

One morning, while conducting rounds visiting patients at the hospital, I noticed two nursing assistants attending to a patient who was in a coma. They were providing exquisite care, but I overheard

¹ Thomas Sydenham, English physician (1624-1689). He studied at Oxford. He practised as a physician in London. He was highly regarded as the foremost representative of English medicine and was nicknamed the English Hippocrates. His work was characterised by the fact that he was always in close contact with the patient.

them exchanging their weekend experiences while performing the task. I found this to be inappropriate. After they finished tending to the patient, ensuring their comfort and cleanliness, I called both nursing assistants into my office. Firstly, I commended them for providing physical comfort to the patient through their care. Then, I asked them:

“If either of you were the patient, would you have wished for the caregivers to talk amongst themselves about how enjoyable their weekend was while they were attending to you?”

By the expressions on their faces, I understood their answers; they were not satisfied with how they had acted. I took that opportunity to express that even though the patient was in a coma, he deserved our respect. The appropriate attitude would have been to direct their conversation towards the patient, explaining to them while attending to their needs that it was done to ensure their comfort and well-being. I concluded by saying:

“If one day I find myself in the same situation as that patient, I would hope that you would care for me during my hygiene routine in the same way you would like to be cared for yourselves”..

We could go through each of our professional activities in caring for patients and ask ourselves: “Are we doing it as we would want it to be done to us in the same situation?” If the answer is yes, it will be a great indicator of the quality of care we provide.

It is clear that a single person alone would be incapable of handling the necessary care for terminally ill patients. This care needs to be provided by an interdisciplinary team consisting of various professionals, each contributing their own expertise, all working towards a common goal: the well-being of the patient.² As long as I can remain at home, I have no doubt that my loved ones will take care of me with all their love, which will be my best medicine during that time. However, if my condition deteriorates, I would prefer to be admitted to a palliative care unit, so that my family can be with me whenever possible, without the burden of responsibility for the care I would require in that situation.

² Bátiz, J (2019). Cuidar a las personas en el proceso de morir. Fundación San Juan de Dios. Madrid. Pág. 38.

In those moments, I will need nursing staff to provide me with wound care, assist me with personal hygiene, change the sheets, and make my bedridden experience more comfortable. I will rely on them to administer the necessary medication to alleviate distressing symptoms. I will also depend on the cleaning staff to ensure that my room, where I will spend my last days, is comfortable. The psychologist will help me address any unresolved issues and come to terms with my illness using my own resources, while also providing support to my family. The social worker will assist both my family and me in organizing bureaucratic matters and managing any socio-healthcare resources I may need. The priests and their pastoral team will attend to my spiritual and religious needs, offering comfort during this significant moment for me. Of course, the doctor will lead this team of individuals, ensuring that they provide me with the necessary care based on their professional expertise and compassionate qualities.

I don't want to forget anyone who may be involved in my care, such as the orderlies who will also have tasks related to my well-being, or the administrative staff who will make bureaucratic procedures easier for me and my family. I will also appreciate the company of volunteers who can provide comfort during moments when I may feel lonely and wish not to be alone.

All of you are so important in ensuring that the patient feels well cared for! I have learned this during my many years leading the great Palliative Care Team at the San Juan de Dios Hospital in Santurtzi.

Please take care of me in this way!

TAKE CARE OF ME LIKE THIS!



9. Please do not intentionally hasten my death

I am not afraid of death; I am afraid of suffering. Although I do not wish to die, I understand that it is inevitable. However, it is possible to avoid unnecessary suffering. I do not desire for my death to be intentionally hastened, but I also do not want my agony to be prolonged with futile treatments in this terminal clinical situation. I hope that you will be capable of not initiating or withdrawing disproportionate treatments. Instead, I ask that you be proactive and decisive in controlling any symptoms that cause me suffering. If that cannot be achieved, please utilize palliative sedation to ensure that I do not suffer during the approach of my death.

To alleviate my suffering until my death arrives, I request that you effectively manage any symptoms that cause me distress using the available treatments. If it is necessary to increase the dosage to relieve my pain, do not be afraid if it unintentionally shortens my life. It was Pope Pius XII in 1957, in a speech to the 9th International Congress of the Italian Society of Anesthesiology, who affirmed that it is lawful to resort to analgesics for the treatment of pain in seriously ill or terminally ill patients, even if it may potentially shorten the patient's life.¹

When I tell you that I am in pain, please alleviate it. Patients have the right to have their pain relieved, and it is the physician's duty to provide relief. The alleviation of pain should not be considered optional but rather an ethical imperative. No one should be allowed to suffer pains due to ignorance of how to treat it, fear of providing sufficient doses of medication, or misguided beliefs. As physicians involved in pain management, we must recognize that inadequate

¹ *Sembradores de esperanza. Acoger, proteger y acompañar en la etapa final de esta vida.* Conferencia Episcopal Española. Madrid, 2019, pág. 34

treatment of pain, when we have the knowledge and means to address it, is not only an ethical failure but also negligence.

To fulfill the patients' right to receive treatment for the pain they are experiencing, it is crucial to understand that if a patient says they are in pain, it means they are in pain. We must avoid the belief that our own pain is unbearable while dismissing others' pain as exaggerated. Furthermore, we need to identify the type of pain the patient is experiencing in order to provide appropriate treatment. An essential ethical requirement is to study and learn as much as possible about our work, including having a good understanding of the medications we use in pain management.

We must also consider that we should employ the appropriate treatment for the specific pain the patient is experiencing. Let us not forget that the patients themselves will indicate the effectiveness of the analgesia when they say, "Doctor, I am no longer in pain".

Those who treat my pain should prioritize my well-being, offering me the best possible analgesia using the most effective and least risky methods. And let us remember the words of Gregorio Marañón²: "A pain cured justifies a doctor's entire life".³

If you alleviate my pain, you will be helping me avoid suffering. However, I also want to ask you to adapt your diagnostic and therapeutic efforts with me. If I have a poor prognosis for survival or a predicted low quality of life, please reconsider how you approach my care to avoid diagnostic and therapeutic obstinacy. Let my diagnosis and the progression of my condition over time guide you in determining when to initiate the appropriate adjustment of treatment efforts. Keep in mind that a medical intervention may be beneficial in certain situations but not beneficial in many others.

Please remember that a diagnostic or therapeutic procedure may be inappropriate in the following circumstances: if it is unnecessary, meaning that the desired goal can be achieved through simpler means (do not administer medication intravenously if I can still swallow it); if it is futile because the patient is in an advanced stage and unlikely to respond to treatment (do not perform a blood transfusion if I am already in an agonizing phase); if it is unsafe

² Gregorio Marañón (Madrid, 1887-1960). Medical internist, scientist, historian, writer and thinker.

³ Marañón G. (1968). Obras completas. Espasa-Calpe. Madrid. Vol. 1. Pág. 372.

because the potential complications outweigh the possible benefits (do not administer any treatment that would cause me more suffering than the illness itself); if it is cruel because the quality of life offered is not sufficiently good to justify the intervention (do not initiate or maintain any treatment that does not improve my quality of life); and if it is imprudent because it consumes resources that could be more beneficial elsewhere (do not waste treatments on me that are no longer useful but could be beneficial for others).

I remind you that you are not obligated to continue a treatment once its inefficacy has been established, even though often its ineffectiveness is only discovered after it has been initiated. It is then that the possibility of discontinuing the biomedical machinery, once it has been set in motion and deemed not beneficial for the patient, should be considered.

I want to make it clear that adjusting the therapeutic effort is not a form of euthanasia but rather good medical practice, even though we understand that it is easier said than done. It is true that the technical advances in medicine offer us many possibilities that should not be employed arbitrarily but rather carefully evaluated to determine if they will benefit the patient.

As physicians, we are trained to heal, and it is often difficult for us to accept that medicine has its limits. Those who care for me at the end of my life, do not forget that, as important as it is to fight for a cure, it is now crucial to know when to stop it following that cure is impossible.

If, despite employing appropriate treatments to control the symptoms causing me suffering and adjusting your therapeutic efforts to help me to avoid suffering, you find that I am still suffering, please use palliative sedation to decrease my awareness with the minimum necessary dose of medication to prevent me from perceiving the refractory symptom.⁴ However, do not use it deliberately to hasten my death by administering lethal doses of medication to end my suffering. I wish for you to alleviate my suffering, not to eliminate me.

⁴ Refractory symptom. This is the symptom that cannot be adequately controlled with available treatments, applied by expert physicians, within a reasonable period of time.

Palliative sedation should be considered today as an appropriate treatment for those patients who experience intolerable suffering and have not responded to palliative interventions, even the most vigorous attempts to relieve them. The acceptability or reproach of such sedation is determined by its purpose and the circumstances in which it is applied. Keep in mind that if you sedate me according to ethical and clinical criteria, you will be preventing my suffering while I die and ensuring a peaceful death, thus performing good medical practice.

Alleviating a person's suffering should not involve eliminating the one who suffering. Do not be tempted by euthanasia as a hasty solution when someone seeks your assistance in dying. You may see it as a solution to your anguish because you wish to end the patient's suffering, considering it intolerable and believing that you have nothing more to offer. If you believe that euthanasia is necessary to eliminate people's suffering, do not hesitate to train in palliative care. Helping to hasten the death of someone who is suffering does not demonstrate care for the sufferer but rather eliminating their life to eliminate their suffering.



10. Please take care of my family to alleviate their grief

Taking care of the family and the loved ones of the person who is sick is a fundamental part of the patient's final stage of life. Their support helps the person endure the final transition. Sometimes, those who are dying suffer because they don't want to cause pain to those they leave behind. The patients I have encountered have taught me the importance of caring for their families after their passing. That's why I wish to share this final request.

The best way to alleviate the sorrow of my loved ones is for them to have witnessed that I was cared for according to my expressed wishes in the previous points and that I passed away with the dignity I have always conveyed throughout my life, a dignity they also shared. After my death, I desire that the professionals who attended to me continue to support them and provide them with the assistance they need. Knowing that this will be the case will also help me die in peace.

The death of a loved one is perhaps the most heart-wrenching experience in most people's lives. I have personally experienced this when I lost my own loved ones (my father, my mother...). The loss of those around us, whom we love, inevitably triggers a reaction of pain and absence, which brings about a range of adaptive phenomena in our body and mind.

This is what we call grief, a natural mechanism through which we channel the suffering we feel. It is also a necessary process for us to adapt to the loss we have experienced. During this process, we can assimilate the negative emotions that have been caused by the traumatic experience of losing a loved one, eventually filling the void left by their absence.

Grief is a process of change because with death, a life ends but not a relationship. It is a relationship that is altered: it transitions from a relationship of presence to a relationship of absence, as the loss of someone we love does not require us to forget. As the Colombian psychologist Paulo Daniel Acero would say,¹ *“The process of grief is not a process of forgetting, but of learning to remember without pain”*.

When attending to my loved ones who may still be children at that time, please consider some important aspects of how children experience the loss of a loved one so that they can adapt to it. Children are sensitive to the reactions and tears of adults; they can sense that something is happening. Therefore, our attitude towards them should not be to shield them from the reality they are experiencing. Although it may be very painful and difficult, it is better to inform them of what has happened as soon as possible, choosing the right moment and place. We should explain to them in simple and sincere words what has occurred. Regardless of the cause of death, it serves no purpose to hide it from them because sooner or later they will find out from someone outside the family. When my children were still young, the brother of one of my daughter’s friends died by suicide. She found out about it at school, not from her parents, and for many years, this girl was tormented by her brother’s death. It is better to explain how it happened and answer their questions, but we must never lie to them! We should encourage them to express their feelings because children experience intense emotions when they lose a loved one. If their family accepts these feelings, they will express them more easily, and this will help them better navigate the loss.

If you have to attend to elderly individuals, you must consider that they are a vulnerable population. An elderly person also experiences grief; just because they are older does not mean they do not grieve. When they have lost their partner, they likely have gone through a series of experienced grief, which may help them understand their own process. They may feel a greater sense of loneliness due to the gradual loss of family members and friends. Therefore, it is important to offer them companionship to help alleviate their sorrow.

¹ Paulo Daniel Acero. He is a specialist in grief management and is a member of the Colombian College of Psychologists. He is a researcher on soil, trauma, resilience and post-traumatic growth. Writer, Scientific Director of the Grief Management Unit. Los Olivos. Bogotá.

Be alert to ensure that the mourning of my loved ones does not turn into pathological grief. Grief is a process with a beginning and an end; when that end takes too long to arrive, it becomes unhealthy, which is what we call pathological grief. If you notice that, after a while, almost every day or in a very intense and prolonged way, they think about me so much that it's even difficult for them to perform the tasks they usually did; if they remember my absence with immense and profound sadness, thinking that I will return; if they search for me everywhere and almost all the time; if they feel guilty for being alive or believe that it is unfair to continue living while I am dead. If all of this happens daily, and even several times a day, or if it is causing their family, social, and work relationships to deteriorate, it can be affirmed that my loss is turning into pathological grief for them, and they need help.

Grief prepares us to live without the physical presence of our loved ones and maintains an emotional connection in a way that is compatible with the current reality. When all of this has been achieved, the memory will no longer be painful. As the Argentine writer René Trossero,² says, “when we have finished accepting that our dead have died, we will stop mourning them. And we will reclaim them in our memories so that they continue to accompany us with the joy of everything we experienced”.

The Benedictine monk and Argentinian writer, Mamerto Menapace³, wrote a phrase that may alleviate the grief of my loved ones when I am no longer here: “The one who dies cannot take anything they have achieved, but they surely take everything they have given”.

How can we help the family to prevent pathological grief? The family will be able to cope with the loss of their loved one when they have witnessed that their loved one passed away peacefully, without any pain or suffering. This will be the best preventive measure we can offer to the family because if the family experiences a tormenting process of their loved one's dying due to unrelieved pain and suffering, they will undergo pathological grief. Avoiding this will be within our control.

² René Trossero. Argentinian writer and educator.

³ Mamerto Menapace (Argentina, 1942). Benedictine monk and writer.

In the early years of working in our Palliative Care Unit, we encountered situations like this: Matilde had spent days and nights by her father's side in the hospital room, never wanting to leave him alone for a moment. Several days passed, and her siblings insisted that she has to go home to rest so she could continue caring for their father. She resisted, but eventually agreed to go home and rest.

After a few hours of rest, one of her siblings called her to inform her that their father had passed away. Matilde couldn't contain her anger and the pain of not being able to be with him in that moment. This caused her much suffering for many months, constantly remembering that after not leaving her father's side for a moment, he passed away when she was gone. It took her a long time to forgive herself for not being there with him at that moment.

The psychologist on our team, who supported her during the grieving process, shared with the rest of the team that in situations like this, which were not isolated incidents but rather quite common, we needed to do something to prevent this type of grief. He suggested that when we anticipated the end was near, we should advise the family members that every time they had to leave, even if it was just to get a cup of coffee, they should say goodbye to their loved one as if it was the last time they were saying goodbye, so that at least they would feel that way "inside" when they kissed them or gave them a gentle touch. In this way, if their loved one passed away during their absence, they could find solace in knowing that they had already said goodbye. However, when we began implementing this practice, it didn't always turn out as we had hoped. Some family members would say to us, "Yes, I said goodbye, but they passed away when I wasn't there".

That's when the psychologist provided us with another resource to help those who were suffering in this way. In such cases, we would tell them: "They knew that if they passed away in your presence, you would suffer greatly. That's why they chose to pass away when you weren't there". We found that this softened their anger to some extent. Based on this experience, we started using this preventive strategy for more distressing grief.

Another way to prevent painful grief is when family members realize that their loved one passed away with dignity. We observed this in the family caregivers of Alzheimer's patients. We must not forget that

this disease also has an end, a conclusion where there is still much to be done for the patient and their family. But, like any patient in the terminal phase, has the right to die peacefully and with dignity. This disease has two main protagonists, the patient and their family. Throughout the different stages of the illness, the care provided by the family should not end with an undignified death for both the patient and the caregivers.

The Parliamentary Assembly of the Council of Europe, in its Recommendation 1418 adopted on June 25, 1999, reminds us that the obligation to respect and protect the dignity of these individuals stems from the inviolability of human dignity at all stages of life. Respect and protection find their expression in providing suitable means that allow a human being to die with dignity. The concept of dying with dignity implies dying while feeling like a person, dying with humanity, being surrounded by the support and affection of loved ones, minimizing pain and suffering as much as possible, avoiding unnecessary medical interventions, accepting death serenely, receiving the necessary healthcare assistance, and having spiritual support if desired. Dying at home is synonymous with dying well, peacefully, naturally, surrounded by the comfort that life and the people we have shared it with have provided us.

A dignified death is much more than a particular style of dying; it is a broad concept, a philosophy of dying based on respect for the dignity of the human being until their final hour. Palliative care can be included in the category of dignified death. These care practices, as a professional approach in the final phase of the disease, do not aim to “stop doing” but rather seek to modify the way the dying process occurs, promoting a process that happens without suffering.

To provide proper end-of-life care for these patients, we must consider that the patients have the right to be relieved of their pain, even if as a side effect, this may cause drowsiness or decreased alertness, or even unintentionally accelerate death. They also have the right not to experience any other distressing symptoms. Nutrition no longer makes sense at this stage. During the dying process, what they need is someone to moisten their lips and trickle a few drops of water between them. Continuing medication that is no longer useful at this stage of the illness which is not aimed at controlling distressing symptoms also becomes unnecessary.

From the philosophy of palliative care, the consideration of the dignity of a terminally ill patient is defended as a value independent of the decline in their quality of life. When colloquially speaking of undignified living conditions, it is the conditions or behaviors of those who allow them that are undignified, not the life of the patient. It is within this compassionate line of thinking, where medical science is placed at the service of patients who can no longer be cured, that the philosophical tradition of palliative care takes root and develops. In other words, it is about providing the technical and human attention that terminally ill patients need, with the best possible quality and striving for professional excellence precisely because they have dignity.

Dying with dignity, as García-Sabell⁴ puts it, simply means leaving this life not in the sterile solitude of a hospital, intubated, injected, infused, and submerged in a maze of cold apparatus, but at home, among loved ones, surrounded by affection and the soothing care of family and friends.

⁴ Domingo García-Sabell (Santiago de Compostela, 1909), doctor and essayist. Author of the book *Paseo alrededor de la muerte*.

TAKE CARE OF ME LIKE THIS!



Epilogue

I would not like to give the impression that this will be the last book I write. I hope to continue writing some more to share everything I have learned during my professional practice and what my patients, their families, and the members of the multidisciplinary team that I had the honor to lead in the Palliative Care Unit of the San Juan de Dios Hospital in Santurce (Vizcaya) have taught me.

To conclude the book, I would like to remind you in a summarized manner how I wish to be cared for when my time comes:

I wish for my dignity as a person to be respected. I wish for my right to be informed with the truth about what is happening and will happen to me to be respected. I wish for a companionship in my solitude. I wish for competence and interest in my care to be demonstrated. I wish to be able to express my feelings and emotions in the face of my approaching death. I wish not to be judged. I wish for my decisions to be listened to and respected. I wish for my family to be accompanied during my illness and after my death.

I wish for my values and beliefs to be respected. I wish for those who care for me to do so as they would like to be cared for. I wish for my agony not to be unnecessarily prolonged and for my suffering not to be allowed, but rather relieved if necessary with palliative sedation, without intentionally hastening my death.

I wish to be cared for by a friendly hand that does not insist on holding me back and preventing me from leaving when my time comes, nor has the temptation to push me to leave before it is time. The friendly hand I need is the one that will be by my side to help me with anything I need to alleviate my suffering as I die. If I am cared for in this way, I am certain that I will have a good death.

Recommended Readings

In this final section, I would like to recommend some readings that I consider of interest to those readers who wish to learn more about the topics I have addressed in this book. I have taken the liberty of including a brief comment to pique your interest in each of the recommended readings.

SOME PUBLICATIONS BY THE AUTHOR

- ***Aspectos éticos de la analgesia en cuidados paliativos.*** Jacinto Bátiz. Mexican Journal of Algology. Volume 6. No. 1. Pp. 8-16. Mexico, 2009.

In this article, I address the aspects from bioethics that healthcare professionals must consider when dealing with pain, especially in the final stage of life. Important aspects such as the understanding that pain management is not an optional matter but an ethical imperative for the physician. It is the patient's right to receive effective pain treatment, and it is the physician's duty to provide it.

- ***Adecuación del esfuerzo diagnóstico y terapéutico en cuidados paliativos.*** Jacinto Bátiz. Gaceta Médica de Bilbao. 2014;111(3):57-62.

In this article, I tackle one of the core principles of palliative care, which is to perform diagnostic and therapeutic actions that align with the patient's present condition. Appropriateness of effort entails refraining from utilizing or discontinuing certain diagnostic or therapeutic measures when there is a perceived imbalance between the desired outcomes and the available resources, in order to avoid falling into diagnostic or therapeutic obstinacy.

- ***Mi vida al final de su vida. Cómo cuidar a un enfermo al final de su vida.*** Jacinto Bátiz, Inés Becerra, Íñigo Santisteban, Julio Gómez. 2nd edition. Hospital San Juan de Dios de Santurtzi, Bizkaia, 2015.

This book was written from the Palliative Care Unit of the San Juan de Dios Hospital in Santurtzi, capturing the experiences of the individuals who work there, as well as the lives of the terminally ill patients and their families. It is a fictionalized book in which the protagonist, Ana, shares her own experiences, emotions, and a series of practical advice while caring for her father at the end of his life. As authors, our intention was to create an easily readable and comprehensible guide for caregivers of terminally ill patients.

- ***Cómo cuidar a las personas en el proceso de morir.*** Jacinto Bátiz. Fundación San Juan de Dios. Madrid, 2019.

It is a small book because it has few pages, where it summarizes some of the strategies that anyone can implement to care for another person who is in the process of dying: providing companionship, listening, offering tender care, responding to their questions, and so on.

- ***Ante la muerte ¿cómo cuidar a las personas?*** Jacinto Bátiz. Revista Iberoamericana de Bioética. N° 11/01-14. 2019.

The care provided to individuals in the final stages of their lives requires a combination of human, technical, and ethical characteristics. The person facing death requires not only the professional competence but also the human connection from those who care for them. In this article, I address how to provide care in a way that the transition from life to death is not a traumatic experience for the dying person and their loved ones who accompany them in the process. It is important that the dying person perceives the presence of compassionate, sensitive, and understanding caregivers who strive to comprehend their needs.

- ***Reflexiones desde los cuidados a enfermos de alzhéimer.*** Jacinto Bátiz. Fundación San Juan de Dios. Madrid, 2020.

It is also a small book in terms of its number of pages, but it is filled with lived experiences alongside individuals suffering from this illness and their caregivers. These experiences have provided me with valuable insights and inspiration to continue providing care with a human touch.

- ***Mientras llega la muerte.*** Jacinto Bátiz. Fundación San Juan de Dios. Madrid, 2021.

In this book, you will find a compilation of the articles and opinion pieces I have published in mainstream media over the course of more than 20 years. It can be considered a collection of written reflections on important topics such as person-centered care, fragility, the proximity of death, palliative care as a means of alleviating suffering, the significance of communication, the need to care for caregivers, the crucial role of volunteers who provide companionship and care, and the support provided to families who have experienced the loss of a loved one, among other subjects.

- ***Cuestiones sobre la eutanasia. Principios para cuidar la vida de quien sufre.*** Jacinto Bátiz. Nueva Eva. Madrid, 2021.

I wrote this book motivated by the approval of the Euthanasia Law. In it, I address ten questions about euthanasia in order to redirect how we care for the lives of those who suffer, without resorting to eliminating the one who is suffering. One of the important messages I aim to convey in this book is that doctors should be prepared to listen to more than just a request to die. Those of us involved in palliative care know that we can accompany our patients through their suffering to alleviate it. When we apply appropriate therapeutic measures, avoiding diagnostic and therapeutic obstinacy, abandonment, unnecessary prolongation, and deliberate shortening, we are practicing good medicine: helping to ensure a good death.

- ***Bioética y cuidados paliativos.*** Jacinto Bátiz. Comillas Pontifical University. San Pablo. Madrid, 2021.

The aim of this book is to approach palliative care from a bioethical perspective or the application of bioethics in palliative care. It seeks to disseminate what palliative care is and how it should be carried out, based on bioethical principles, for individuals in need of alleviating their suffering. Additionally, it aims to help understand the importance of bioethics in clinical practice within palliative care, as it assists in providing better care for individuals in the process of dying. Through a bioethical lens, I reflect on how to care for individuals at the end of life and avoid wasting time engaging in fruitless debates about when one should die.

- ***La sedación paliativa como último recurso ante sufrimiento refractario.*** Jacinto Bátiz. Revista Labor Hospitalaria. Núm. 331. September, October, November, December. 3/2021. Pages: 103-111

In this article, I address the suffering experienced during the final stages of life, emphasizing that it is not necessarily related solely to physical pain. I discuss the concept of total suffering, which encompasses physical, emotional, social, and spiritual dimensions. To effectively help those who are suffering, we must first accept this total suffering for what it is. If the suffering becomes refractory to treatment, palliative sedation should be considered to reduce consciousness in the person experiencing it and ensure a peaceful death. Within the pages of this article, readers will find an explanation of what palliative sedation entails, how it is carried out, and when it is indicated. I also delve into the topic of palliative sedation for psychosocial or spiritual suffering. I believe that palliative sedation is a therapeutic resource and a valid clinical practice, although it is not without clinical and ethical controversies.

- ***Hacia una cultura paliativa.*** Jacinto Bátiz. Fundación Pía Aguirreche. Madrid, 2022.

This book aims to guide anyone who wishes to understand what palliative care is, how to attend to someone with an incurable, advanced, or terminal illness in all dimensions of their being, and the role that both family members and healthcare professionals

play in the natural process of death. Within its pages, readers will discover why I believe that providing companionship is also a form of care, that compassion is a valuable tool for caregiving, and that those who are dying can teach us how to live, among other topics related to palliative medicine.

OTHER PUBLICATIONS OF INTEREST

- ***Luces y contenidos teológicos en el movimiento de cuidados paliativos.*** Javier Sánchez, OH. Archivo-Museo San Juan de Dios “Casa de los Pisa”. Granada, 2004. Págs. 18-19.

In this book, the author reflects on the implications of studying and embracing medical and nursing care in the light of theological truth. It represents the challenge presented by the Pontifical Council with its “letter to healthcare workers” (its doctrinal introduction is included in the documentary appendix of Javier Sánchez’s book). It is a challenge rooted in faith for the Christian professional, but also for the theologian who must delve into and mature these truths in order to demonstrate to all the immense significance that the Church recognizes in healthcare activity. It is worth reading; it has shed a great deal of light on me.

- ***Humanizar el proceso de morir. Sobre la ética de la asistencia en el morir.*** Comisión Interprovincial de la Orden Hospitalaria de San Juan de Dios. Fundación Juan Ciudad. Madrid, 2007.

With this publication, the Interprovincial Commission of the Order of St. John of God aims to share its experience in the process of humanizing illness and the end-of-life journey. This experience is contributed by the various centers affiliated with the Order of St. John of God in Spain, spanning different healthcare specialties, including Internal Medicine, Geriatrics, Palliative Care, Intensive Care Units for both adults and pediatrics, Nursing, Psychology, and more. In this experience, particular emphasis has been placed on the ethical issues present in these areas of care, involving a team of professionals with expertise in Bioethics.

- ***Velad conmigo. Inspiración para una vida en cuidados paliativos.*** C. Saunders. Fundación Pía Aguirreche. Madrid, 2023.

This book is a fundamental text for palliative care due to the depth and quality of its observations, which enrich and provide profound meaning to this practice. It starts with a respectful consideration of the dignity of the terminally ill patient and understands the dying process as an opportunity for closure in one's own life story. Additionally, it takes into account the person with their resources and capacity for transcendence, recognizing them as someone who needs to navigate their own path. The book also emphasizes the expectation that professionals approach their work with respect, bravery, and a sincere effort to understand.

- ***Sembradores de esperanza. Acoger, proteger y acompañar en la etapa final de esta vida.*** Subcomisión Episcopal para la Familia y la Defensa de la Vida. Conferencia Episcopal Española. Madrid, 2019.

This document aims to provide simple guidance in searching for the meaning of suffering, accompanying and comforting the patients in the final stage of their earthly life, instilling hope in the moment of death, embracing and supporting their family and loved ones, and shedding light on the task of healthcare professionals. It presents a hopeful perspective on the moments that mark the end of our earthly journey, amidst the ongoing debate surrounding human life, euthanasia, and assisted suicide. The chosen format for this document is a question-and-answer style to facilitate better understanding of its content. Additionally, technical language has been avoided to ensure comprehension by those without specialized knowledge, while maintaining depth and rigor of thought.

- ***Carta Samaritanus Bonus.*** Congregación para la Doctrina de la Fe. Roma, 2020.

In this important document, we can find the teachings of the Church regarding the care of individuals in critical and terminal stages of life. While the Church's teaching on this topic is clear and contained in well-known documents of the Magisterium, such as the Encyclical Letter *Evangelium vitae* by St. John

Paul II (March 25, 1995), the Declaration *Iura et bona* by the Congregation for the Doctrine of the Faith (May 5, 1980), the New Charter for Health Care Workers (2016) by the former Pontifical Council for Health Care Workers, and numerous speeches and interventions by recent Popes, it seemed appropriate and necessary for the Holy See to issue a new comprehensive statement on the care of individuals in critical and terminal stages of life, considering the current situation characterized by an increasingly permissive international civil legislative context regarding euthanasia, assisted suicide, and end-of-life provisions, and the need for a new and more effective approach.

- ***Hablar de la muerte para vivir y morir mejor. Cómo evitar dolor y sufrimiento añadido al final de la vida.*** Montse Esquerda. Alienta Editorial. Barcelona, 2022.

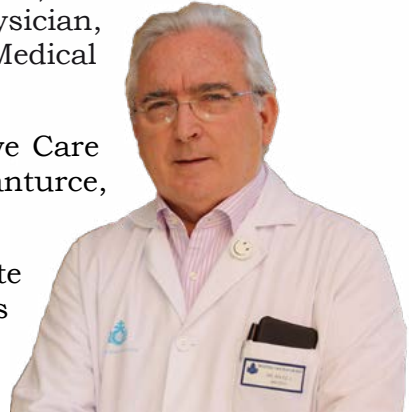
In this book, the author examines how our relationship with death has evolved over time, drawing on historical data, articles from psychologists, psychiatrists, bioethicists, and philosophers, as well as excerpts from novels, songs, and movies. From a medical perspective but above all a human one, she addresses another uncomfortable topic: medicine has focused on curing, forgetting that one of its primary objectives should be facilitating a peaceful death and alleviating the accompanying suffering. This book reminds us of the importance of acknowledging our own mortality. The absence of conversations about death in daily life or when a family member faces a serious illness, the disappearance of children from farewell rituals, and the lack of preparation all contribute to increased stress when faced with the inevitable experience of death.

About the author

Jacinto Bádiz Cantera (Sestao, Vizcaya, 1948) is a Doctor of Medicine and Surgery, a family physician, Master in Palliative Care, and an expert in Medical Ethics and Deontology.

From 1993 to 2017, he directed the Palliative Care Unit at the Hospital San Juan de Dios in Santurce, Vizcaya.

Since 2017, he has been leading the Institute for Better Care at the same hospital. He serves as a trustee of the Pía Aguirreche Foundation for Palliative Care and is the President of the Palliative Care Section of the Academy of Medical Sciences of Bilbao. He is responsible for the Bioethics Working Group of the Spanish Society of General and Family Medicine (SEMG) and is a member of the Observatory on End-of-Life Medical Care of the Medical College Organization of Spain (OMC). He has been a visiting professor at the University of the Basque Country, University of Deusto, Pontifical University of Comillas, and Autonomous University of Madrid, teaching postgraduate courses on Palliative Care. He is an opinion columnist on end-of-life medical care and the author of several books, including *“Mi vida al final de vida”* (2004), *“Aportaciones Sociosanitarias del Hospital San Juan de Dios de Santurce desde 1924 hasta 2014”* (2016), *“Cuidar a las personas en el proceso de morir”* (2019), *“Reflexiones desde los cuidados a enfermos de Alzheimer”* (2020), *“Mientras llega la muerte”* (2021), *“Cuestiones sobre la eutanasia. Principios para cuidar la vida de quien sufre”* (2021), *“Bioética y Cuidados Paliativos”* (2021), and *“Hacia una cultura paliativa”* (2022).



He has received several distinctions, including the National Award for *“Opinion Reflections in Healthcare”* for the article *“Cuidar con Caricias”* published in *El Correo* (2009), the *“Gazte Role Model Saria”* Award from the Begoñazpi Ikastola in Bilbao for comprehensive care for patients and their families to make the transition from life to death a less traumatic experience (2010), the title of National Ambassador of Spanish Medicine by *Diario Médico* (2018), and the European Kate Granger Award for Compassionate Care (2018).



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