

LA BONA MORT / THE GOOD DEATH

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With advances in public health, living conditions and life expectancy, it is increasingly said that those living in developed countries have lost the familiarity with death and the process of dying that previous generations had. The loss of strong religious and spiritual beliefs may have also removed the language and framework with which we can speak easily of death. Indeed, death is so far from the daily experience that it's easy to deny it, or be surprised when it arrives. Medicine is also responsible for promoting the opinion that death is a failure, rather than a normal part of life that will happen to us all at some point.

Talking about it, thinking about it and considering it, on the one hand, makes me anxious. I'm a practical person, and analysing it like this, well it makes me suffer, and makes me uncomfortable. It even overwhelms me, I can't deal with it. Although I know that death exists, and you have to consider it when talking about your health, about life and about your death, they're realities that we're not used to, and it scares me, and makes me anxious and uncomfortable talking about it.

People who are dying are among the most vulnerable and the quality of care they receive must be one mark of society's humanity as a whole.

INTRODUCTION

In December 2018, I met with Dr. Anna Soldevila, who conveyed her concern for not knowing how to reverse the habits of her students, developed in residences aimed at people with different degrees of dementia, which in many cases consisted of colouring in Disney characters or mandalas.

Given the little enthusiasm either of us would have for such proposals if we were the residents, we wondered what practices from contemporary art could help turn these activities upside down for those who are still students, practices which they would surely develop in their daily routine when they enter the world of work.

With that in mind, I contacted the artist Albert Potrony, who I met in January 2019 at a conference organised by the educational artist Jordi Ferreiro, and proposed that we carry out a project of collaborative artistic practices at a nursing home in Lleida.

After competing against three hundred other proposals for the 2019 Art for Change grant from "la Caixa" Foundation, and winning it, talks began with the team at the Balàfia II residence, led by doctor Conxa Tous, to develop a project focused on creating networks between caregivers and care receivers, and seeking to give agency to the residents.

We knew it was a challenge, but by no means could we imagine how the elderly, institutionalised in residences would fare during the course of this year.

COVID has forced us to rethink the project, and it has allowed us to redesign it to fit the new reality and, thanks to journalist Patrícia Horrillo's advice, share the process, visualise the challenges and possible paths which won't be developed in this project, but which can serve as a basis for the cultivation of other projects in socio-health contexts. And it has been recalibrated so much that it has even moved us to address another area, that of palliative care, after having met the psychologist Vanesa Aresté at a virtual conference.

In her book 'Illness as Metaphor', Susan Sontag states that we refer to diseases such as cancer, tuberculosis or AIDS through euphemisms, as shelters from facing our fears.

We can look for metaphors in art to understand our present and especially to show what we want to hide, such as illness or death, the latter of which has become the biggest of taboos, as Philippe Ariès points out in 'Western Attitudes toward Death'.

Artists like Félix González-Torres took on this challenge to share loss and grief, inviting us to take a sweet from a pile that had been left in the corner of a room. The mountain of sweets weighed exactly the same as his partner who had died from AIDS; he created a new ritual, in which he shared his love, sweet as candy, with each of the spectators, until the mountain was reduced to nothing.

In this book, designed by the artist Albert Potrony and designer Alex Gifreu, Potrony references the medieval *ars moriendi* (*'the art of dying'*), the name of two interrelated texts, written in Latin, which contain tips on protocols and procedures for a good death and how to 'die well', according to the Christian precepts of the late Middle Ages.

We live in a society that seems to be evolving more and more towards secularism, and becoming more and more detached from the rituals accompanying death and loss, as we have seen more than ever in 2020. If we do not want to dehumanise death, we must consciously prepare for the last stretch of life and death, in order to face the need to give meaning to absence and nothingness.

Roser Sanjuan

THE GOOD DEATH/LIFE AT THE END OF LIFE

Towards a statement of principles?

Sometimes I feel that I don't want to carry on contributing to the filling of galleries and museums, too often for the enjoyment of a very small percentage of the population. I want my artistic output to have a tangible connection with the society of which I am a part, with its everyday reality and its problems.

I have talked many times with Roser Sanjuan about how important it is for any social and participatory artistic project to have a "utility" for the people and groups involved, a utility that goes beyond the experience of participating. It is also necessary to leave something behind, no matter how small, as a reference for those who have not been part of the experience. Perhaps now I would like to appropriate the old concept of the 'applied arts', but applied to the needs and concerns of our contemporaries.

"The Good Death" is the result of a journey and a metamorphosis.

It is a continuation of a project that had to be abandoned, "Geography and Memory", that was later transformed into this project, "The Good Death". The two projects are different, but share one common nexus: care and the importance of caring and accompanying, as a revulsive aspect within a society in which the processes of ageing and death are hidden, underestimated or simply taboo.

Care, the accompaniment of another person, as a tool to imagine a society organised around more humane structures and values, and therefore more universal and more shared than the ones we have had to live with.

Like the best road movies, the long process of recalibration and transformation of the initial project, derailed by the carnage of the pandemic in care homes, has become a kind of journey. A journey in which we've found or collected a group of people from very diverse professions, but who share a common trait: being deeply involved in their work, while open, with curiosity and generosity, to sharing knowledge and experiences that help us imagine the possibility of interdisciplinary collaborations for a more integrated future. A future where networking and communication between disciplines are prioritised above individualism and compartmentation. A future in which collaborative artistic practices are, as Fernando Hernández-Hernández says:

"[...] An event that bursts into established discourse and practice, to distort and question them from other points of view (partial, not fixed and multiplied many times). All this in order to provoke fissures and failures in curricular, disciplinary, cultural and socially dominant narratives, to destabilise them and open up to other ways of knowing, imagining and being. "

From this slow recalibration process, an intergenerational and interdisciplinary working group of fifteen people has emerged; from the world of palliative care, mourning groups, social workers and artists from various disciplines (performing arts, sound and visual arts), with a common interest in exploring care, the process of the end of life, and death as preparation for living a good life.

The publication you have in your hands is one of the results of this research and group work, and is vaguely organised in a series of topics related to death and palliative care that we have been collecting throughout the journey: accompaniment, fears, the good death, euthanasia, mourning, legacy...

Of a polyphonic and mixed nature, it can be read as a conversation between fragments, like an introductory letter, like the opening of a door that helps us talk about death and the fundamental role which it has in our lives.

Albert Potrony

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Living and dying together

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Palliate

Make less severe (An illness, pain, the consequences of something, without curing it).

Palliative care is an important public health issue. It is concerned with the suffering, the dignity, the care needs and the quality of life of people at the end of their lives. It is also concerned with the care and support of their families and friends. This is by and large a neglected topic in Europe, but is one that is relevant to everybody in the Region.

Is there always consciousness? Will I know what's happening? Or does morphine soothe everything? To what extent do we have control over ourselves? I think, above all, about rapid disease processes in which the last will has not been made. How do I write a will? Where do I have to go to do it? Can it be done there? How can we make sure that the last will is carried out if the family doesn't want to do what the person asks?

Death is part of life. On the other hand, as members of society, death is a taboo in certain circumstances. But inwardly we all know that it is part of life, and we must come to value in its' true measure what it means to help people to die well. Another risk is seeing death as one more trivial event, without any emotional charge. That is also ignoring it and becomes part of bad practice. Without suffering, the professional must be able to feel, to be able to continue working and to interact with patients and their families near the end of life. You should be able to give exquisite treatment and care.

Palliative care begins from the understanding that every patient has his or her own story, relationships and culture, and is worthy of respect as a unique individual.

Good care is not enough. Humanity and empathy are essential in any health care. That is why the words *health* and *social* have become inseparable in recent times.

Assisting in the best possible death is as rewarding and enriching on a personal and professional level as healing.

My Letter of Introduction

Vanesa Aresté

This is usually the case when it comes to introducing yourself in social contexts, aside from giving your name, and then in the introductory conversation, indicating what you do. I have found all kinds of reactions while doing this: in my case, just by commenting that I am a psychologist, the trap of the Freudian myth "so now you must be psychoanalysing me, right?" it inevitably happens! But if, in addition, you add that you are dedicated to palliative care and therefore to accompanying sick people in an end-of-life situation..., then any reaction in the collective imagination is possible!

When I was younger, in certain settings and at certain times, when announcing my profession, I would always be surprised by the other person's gaze, straddling the deepest bewilderment ("how can someone like doing work like that...") and an expression of compassion ("uh, god forbid... it must be so hard!"), but the most frequent reaction was from those who could not even avoid looking crossed eyed!

Thankfully, my position in this regard has evolved over the years. I went from saying it out of the corner of my mouth and fearing any flight or brazen change of subject, to proudly announcing loud and clear, doing palliative corporatism, the fruit of years of militancy, vocation and conviction!

A few months ago, I went to the dentist. While I was lying under that imposing light and before getting to work on my teeth, the dentist and his helper asked me what I did. I was only able to announce that I accompany people who were dying... I then found myself with my mouth wide open, with a dental suction and all sorts of surgical instruments rummaging through my teeth, I couldn't say anything more!

It was then, taking advantage of my inability to articulate anything and as if I weren't there, that they both started to speculate on death, on the harshness of this kind of work, what to say and what to do when someone was dying, etc. All opinions were allowed and I had to listen to some nonsense! I assure you I felt deeply impotent for not being able to challenge them and, finally, I thought the best thing was to keep out of it (thank goodness dental pieces have no emotions!).

On another occasion, I went to the beauty salon to have my nails done! Between nail files and coloured polish, the professional, who was face to face with me (keeping a safe distance) didn't stop talking about covid-19! When I was given the opportunity, I mentioned my work, and she fell silent as if the cat had got her tongue. The rest of the manicure went ahead in silence! I think she took me for a kind of psycho-killer!

The truth is that I love my job and, on a daily basis, I appreciate the gift of being able to face death from the point of view of life and to do so through all of those people and their relatives that I accompany. The kindness of palliative care is to make it possible to live life until the last moment.

Love lets us overcome the fear of death

Amadeu Bonet i Boldú

Walking along the streets of Sant Celoni, this piece of graffiti caught my eye for two reasons. The first, because it makes the subject of death in our society public, and the fear that, whether we recognise it or not, it provokes us.

The second, because it gives a possible solution to allay this fear of death: love as an antidote to fear. Love that is present, that accompanies, that holds hands, that listens silently, forgivingly, which is appreciated at those moments when someone senses the immediacy of the end of their life.

How different would death have been for so many people who have suffered loneliness in their last moments if they had felt the warmth of someone's love?

FEARS

Accepting the challenge of suffering is fundamental to a satisfactory life. There are ways to integrate death into life: reflection on death is reflection about life; learn to celebrate grief and to say goodbye. Dare to live; be capable of living in solitude.

During my life, I have thought many times about death. When I was little, I thought about it very often at night, and when I did, I entered a kind of void. It was like falling into the abyss of unbearable pain. And how did I get over it? Well, praying. It's the solution my mum gave me when I went to her to explain what was happening to me.

If we can occasionally laugh at fear, the fear decreases.

My 93-year-old grandmother told me one day, at an inopportune moment, that she wanted to die because she was tired of living, that everything was tiring. At the time, I didn't pay much attention to her... How could she say she was tired of living? I was young and eager to take on the world. As an adult, with work, family and social obligations, anxious, tired, overwhelmed, exhausted and not wanting to exist, I saw death as peace, as a life saver at that moment. And I understood Grandma's words, that one gets tired of living and everything it involves (good or bad), but I also realised I still didn't want it in the same way as Grandma had.

Worse than fear itself is not being able to share it with anyone; being afraid and not being able to talk about it.

Chanquete has died

Anna Soldevila Benet

I belong to the "Chanquete ha muerto" generation. It was one of the first collective discussions about death. It wasn't at school, at high school, or at home, but through a television series. Adults wanted to protect us from what could make us feel vulnerable and fragile. We were denied the right to handle it with uncertainty and pain. No need, thank you! Now I know that to speak of death is to stand in front of a mirror which asks you: how do you want to live life?, how do you want to be remembered ?, what do you want to be your legacy?

At the age of twenty-three I became a mother and then buried my own mother four months later. They don't prepare you for either events. Life and death sometimes intertwine. And over time I have learned that the memory is not erased, you don't forget who truly loves you. Images can be blurred, but the feelings linger. We love while we are alive, It's okay to say: I love you!

My professional challenge appeared when I started to teach a subject about ageing. That was two decades ago. I confess publicly that I dodged the end-of-life issue for a few years. The subject was put at the end of the syllabus; it was never reached, and no one complained that it had not been mentioned. The first step was to explore personal grief, put bandages on the soul, because everything hurt, the scars were tender. Where could you train if it was a taboo subject? Today, there is specific training and grief support groups. Then, you learnt through experience and personal therapy.

Almost twenty years later, students find it natural to talk about it. We have normalised it. It's the first time that they reflect in a classroom of such awkward certainty, and I'm talking about young university students. Have they not coexisted with death before?

And remember that we will not come out of life alive. And if death were a new birth? Now it's up to you to continue the story...

The first fear is pain ... Everything else is selfishness or anger for not being there ...

Although there are huge cultural differences, the fear of death is deeply rooted in Western societies.

I'm afraid of not showing enough to the others, not showing that I love them. It also scares me that I won't have lived what I would like to live, that I will still have things to do, even though I know not everything can be done.

Humans are social beings, and it is our interactions with other humans that complete our existence and give our lives meaning.

What scares me the most is dying in solitude, without a loved one by my side.

Multiple factors have contributed to the development of the fear that confronting death generates: the loss of meaning of transcendence and of beliefs that help to give meaning to the suffering, pain, life and death; the culture of doing rather than being in the moment; that the moribund is no longer useful; the current experience of death as an experience of annihilation rather than continuity.

Fear of growing up, fear of maturing, fear of ageing, fear of dying: everything is fear, fear of living, but none of these things is out of the ordinary.

The most common view that runs through the history of thought on death is that the fear of death is innate, that all of life tends to avoid death, and that the underlying terror of death is what drives most human endeavour. The anthropological, philosophical, and psychoanalytic perspectives offer evidence and rationales that the fear of death is a natural response, given all the attempts of biological organisms to preserve life.

I am convinced that there is life after physical death. That life continues, and that everything we have loved has continuity, although I don't know how. I believe that LOVE is stronger than death and that death does not have the last word.

Life and death are closely linked. To expect death is to give weight and structure to life. In order to relate positively with life, we must confront our fear of death.

Over the years, I've come to realise that death is a process that begins with my last sigh and ends when no one remembers me. And how and when will this last breath be? Will I be conscious? Until it comes, I won't know.

Death euphemisms (English)

HOW TO ACCOMPANY**Listening to myself to accompany others****Communication**

Death is the least shared universal experience in the world. You can't reach the end, because in death there is always one that stays and another that leaves. Accompanying and caring for the terminally ill is a tough task, because it puts us face to face with our own death. The daily work with pain, suffering, decrepitude and death can end up being emotionally exhausting. And yet it can also be extraordinarily rewarding. The sick give us the opportunity, if we are attentive, to learn many important things.

Communication is a process and not a single act.

Nonverbal communication is vital to show the patient we are by their side.

It is essential not to hide anything from them, and to answer all of their questions, to be aware of their situation whenever they want.

Many times, good intentions end up being counterproductive.

Don't make false promises like "everything will be ok", listen actively when the patient wants to tell us something and, above all, give importance to non-verbal communication to make them feel that you are with them.

In short, we must accompany by placing ourselves at the person's side, follow their rhythm, ensure our presence and preserve their dignity and wishes.

In the end, the most important thing is for the other person to know that no matter what happens, you will be by their side.

Is this the moment?

Annie Etherington

It was a vigil, a witnessing but more than that, it was a kind of midwifing into dying. We had spent a lifetime missing each other, never quite connecting. This wasn't a time for revisiting our past but for something simpler, just being there. Days and days leaning against the high rails around your bed because sitting felt too inattentive, too remote. So many hours that our breathing synchronised, with those odd moments when yours faltered and mine became suspended — is this the moment, or this, or this? Words were almost redundant, reduced to describing for you the view from the window — sky, trees, hills, sweeping grass until the external was no longer relevant and instead the inner world flooded the common land between us. The dark river you sailed with a gossamer veil between here and there. Eliot wrote: 'I had seen birth and death, but had thought they were different'... the difference was barely visible here, just less pushing and more letting go. I didn't hold your hand fearing the weight of mine would pin you down, instead I placed mine under yours to lift, maybe to carry. I brought flowers with a fragrance and placed them near you, your eyes seemed sightless but smell is such an early sense, played music you had loved and, finally, sang to you — 'will ye go, lassie, go?', somewhere acknowledging the Scottish home you had found for yourself. I like to believe we found some sort of quiet, still meeting place — occasionally disturbed by the practical, bustling, care team who would turn, tuck, stroke and fill the room with a sudden light and laughter. You seemed to like these moments, your eyes would suddenly open until they left, as quickly as they arrived. Later I would recite the names of those you had loved who had gone before, as if to suggest there would be a warmth and loving welcome on the other side of life, I suppose to try to make the path less solitary. With a perfect symmetry you died on my birthday, exactly 52 years after giving birth to me, connecting in death in a way we didn't quite manage in life.

A CONSPIRACY OF SILENCE

An implicit or explicit agreement to alter patient information by the family, friends and / or health professionals, with the goal of hiding the diagnosis, prognosis and / or severity of the situation, regardless of their wishes about the information.

One of the most frequent ethical conflicts that we still find today is the conspiracy of silence. A conspiracy of silence is when the conscious adult does not know they are going to die, and their whole family knows it, the professionals know it, but they do not communicate it to protect them. This is a much more frequent ethical conflict than euthanasia, because it occurs in a very high percentage. Instead, the law says that we should inform the patient. I think there is a lot to do at the end of life. Should a society that is not capable of facing death, which is not capable of speaking about death consider a euthanasia law? We're going at very different speeds.

Memento moris

Khadija Bouiri

This flower, *Lycoris radiata* or Red spider Lily, represents death and the path to the afterlife in Japanese culture. Whenever I see it, I have a nice feeling of nostalgia and melancholy. It is not a flower that I can afford to have, but I always have it as a screen background. It's a *memento mori*.

THE GOOD DEATH

Death as an experience of annihilation

If I could choose how to die... then ideally I would like to die during a nap ... As in “the son of a bitch left without saying anything... “. Okay, but I've had enough time to tell you that I love you, and if I leave without warning, well, you should know I love you a lot. But that's it, something simple, like... He died in his sleep, not as spectacular as dying fucking or from an overdose. To die like... “I've had enough”, as we would say here, I'm done, and I'm moving on to the next phase. I'm sorry but I'm done, for me it's over, I fell asleep, I left, I love you, I'll see you in the next life my dears. Sleeping would be a good death for me.

I wouldn't want to die alone. The feeling of having been able to stand by and feel the last breaths of my daughter and my mother has been the most intense experience that I could ever have.

Dying does not necessarily have to be an unfortunate fact. Even though our cultural conditionings are strong, it is possible to learn to receive death with serenity and without so much fear. Dying in peace can be hard to define, but easy to detect when a person ends their life in circumstances such as the following: to die without the frantic roar of technology designed to give the dying person a few extra hours of biological life; to die without excruciating pains that monopolise all the energy and consciousness of the dying; to die in an environment worthy of a human being and proper to what could be their most beautiful living hour; being able to say goodbye to family and friends who allow them to leave; not to die alone; to die with simple and enriching human contact with loved ones; to die as a conscious act; die with your eyes open, bravely showing your face and accepting what's coming; to die with an open mind, accepting that many questions that life has opened remain unanswered; to die with an open heart, that is, with concern for the well-being of those who remain alive; to die thinking of the possibility that your experience may be helping others; to die with a clear conscience; to die with human and serene nostalgia for those we leave behind (people and things).

If I could choose my death, I would want it to be on a sunny day. I imagine myself in a rocking chair, with white hair, soft wrinkled skin, feeling the heat of the sun on my skin and a light breeze that gives me a lot of pleasure. From time to time, I smell the lavender that I planted in the spring. I hear kids laughing far away and feel a very great peace within me. My breathing slows down until it stops, like the song of a stork that flies further and further away.

I don't want to die! I always think of the concept of the last gaze, what the eyes see before they die... I always think a lot, a lot about what my last image is going to be, and what the last thing I'm going to hear will be, the last thing to be touched by my senses.

QUICK DYING, SLOW DYING

The ars moriendi of the Middle Ages, in which dying people made their peace with their Maker, presumed that the person concerned would die in a matter of days. Now, however, modern medicine can diagnose early, but rarely cure definitely, major killers such as cancer, heart disease, dementia, and HIV infection. A lot of us are walking around knowing that we, or one we love, have a life threatening illness; and we may have to live with this knowledge for decades. (...) So the question about how to die well today is how to live for months, or even years, knowing that we are dying.

I always think about this in relation to my grandfather Jaumet, beyond his health problems, I think the guy consciously decided to die, he was a grafter and even worked to leave, to leave quickly without causing suffering and without himself suffering much.

Doctors have been trained to prioritise a biomedical view of dying, in which “fighting back” at death, rather than acceptance, may be valued by professionals.

Well ... an unexpected death, but let me explain. I would like to be able to go out one day to walk through the forest and suddenly, yes, feel tired, know that my moment has come, to be able to sit and die. Quietly and peacefully. That would be a good death for me.

Death is inevitable, but dying well is not. Despite the role of medical professionals as overseers of dying in contemporary society, there is comparatively little discourse among doctors about the constituents of a good death.

As a biologist, I believe that death is the loss of a living being’s biological functions. It’s the end of an organism’s life. As a Christian, I believe in the existence of the soul and another life after death, but I find it very complicated (like Thomas Aquinas) to justify existence and immortality without a body.

Although doctors are often the overseers of dying in the West, studies suggest that they may misunderstand the real wishes of the dying while focusing on the physiological aspects of death.

One popular understanding of the good death in the 21st century is one in which a person dies at home surrounded by family and their community at the end of a long and fulfilling life. Far from detaching from family and friends, the good death is often one in which the person remains connected to family through the time of dying.

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Death as an experience of continuity

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**'Making' a death
good or bad is an
active process in
which both dying
people and those
around them participate.**

Questionnaire: "What would help you die in peace?"

WHAT WOULD HELP YOU DIE IN PEACE?

A: Being able to feel close to, communicate with, and strengthen affectionate bonds with my loved ones.

B: Feeling that my life has made sense.

- Thinking that doctors can control my pain and other discomfort-generating symptoms.

- Thinking that my death will not be an unbearable burden for my loved ones.

C: Thinking that I will be able to control my thoughts and physiological functions to the end.

D: Thinking that my life will not be artificially prolonged.

- Thinking that my death process will be short.

- Thinking that I can get help to die quickly.

- Not feeling guilty.

E: Belief in another life after death.

- Thinking that I may die at home.

Survey: Aspects that would help Spanish health professionals to die in peace, 2020

The life line

In Western societies, life expectancy for women is 86 years.

Life expectancy for men is 80 years.

If this straight line were your lifespan, where the left end represents your birth and the other extreme (right) represents your death, mark where you would be on this line today.

With a tape measure, ruler or the palm of your hand, measure how much life you have left. Why don't you make a list of the things you don't want to leave undone before you die?

EUTHANASIA

I want to die alone

Jaume Ramon Torné Giralt

I want to die alone having said goodbye to the people I appreciate and/or love; I don't want to see how they suffer. I would like to decide when I die. I want to die in silence.

As has been demonstrated in the contemporary euthanasia debate, autonomy and control over one's destiny are, for some, integral to the good death.

Although palliative care is publicly against active, voluntary euthanasia, the two actually have one thing in common. Both find support in individualistic societies that promote personal autonomy—the right of individuals to make their own choices about how they should live and die. For advocates of both palliative care and euthanasia, the good death is one in which I make my own choices about my last days and months. In individualistic societies, the bad death is that of the person with no autonomy: the patient with a stroke or Alzheimer's disease, who cannot communicate his or her wishes or whose brain has so deteriorated that there are no wishes left.

A very powerful medication is administered intravenously that induces a deep sleep. After two or three minutes the products stop the breathing and the heart, and in ten or fifteen minutes the person leaves in a very calm manner. No pain, no aggression, no violence.

It's an act of love

I tended to retreat to the corner of the room while relatives talked to each other and hugged each other up to the point when the patient died. They are very emotional moments. Clearly there is sadness, however at the same time a sensation of care, of serenity, of rest. It's a very sweet and quiet death, very human.

GRIEF

We all carry death on our shoulders.

Lately I've been finding everything a little harder than at the beginning, I guess that I am now going beyond shock and disbelief, to acceptance and the sorrow it entails. I strive to feel anchored in the world as I feel pretty empty and alone with my grief most of the time.

Death is a basic ingredient of life from the moment we are born and say goodbye to the protection and warmth that we find in the womb. However, this loss of protection provides autonomous breathing (freedom) and an accelerated development of the senses. The same happens in other phases of development: during weaning we use a pacifier as a defence against the pain generated by the absence of the mother, but this pain makes it easier for the baby to fixate on other faces and expand its emotional and intellectual world. That is why living with autonomy is essential to processing grief.

The loss of a loved one is as traumatic psychologically as severely injuring or burning yourself is on a physiological level.

No one ever told me that grief felt so much like fear. I am not afraid, but the sensation is like being afraid. The same fluttering in the stomach, the same restlessness, the yawning. I keep on swallowing. At other times it feels like being mildly drunk, or concussed. There is a sort of invisible blanket between the world and me. I find it hard to take in what anyone says. Or perhaps, hard to want to take it in. It is so uninteresting. Yet I want the others to be about me. I dread the moments when the house is empty. If only they would talk to one another and not to me.

I'd like to speak about my father

Anna Maria Agustí Farreny

Do children who have lost a significant person suffer?
Do they miss them? Do they know what the family is going through?
I'll try to explain it differently.

I meet Maria, whose husband died two years ago. She has two small children. Happy to meet, she excitedly explains that her 7-year-old son thinks about his father:

"You know, the other day when the kids met online, they talked about a number of things and wished each other happy holidays. At the end, the monitor ask if they wanted to make any more contributions. My little one answered quickly: "I'd like to talk about my father."

The mother explained that there was an unbroken silence.

What did little Daniel need? He wanted to let his classmates know that he had had a father and now, as he had died, he couldn't hug him, he could not caress him, nor could he be with him, let alone play ball games with him. He wanted to be like the other children, and rushed to tell them how he remembered his father: tall, handsome, someone who knew everything and someone who had solutions for everything. Daniel needed to put into words what he felt in his heart. Words that express longing, fears, anxieties, the nights of insomnia, and also everything that, when he spoke about it with his mother, involved seeing tears well up in her eyes, and of course he didn't want to disturb her. So much suffering! His and that of his mother, and, on top of that, he couldn't say anything because the grown ups didn't talk. This made him think that it is better to be silent, because talking about it makes people uncomfortable.

This is how we are transmitting the taboo of death and all that it entails. What have we done with what Shakespeare said? "Give sorrow words; the grief that does not speak knits up the o-er wrought heart and bids it break."

Mourning is the loss of a part of ourselves.

AND SUDDENLY, EVERYTHING TURNS GREY

Natàlia Ramos Pla

It was sunny this morning and I just wanted to put on that light sleeveless dress, tie the laces of my sandals around my ankles and go for a walk to savour the smell of spring.

I had woken up happy. I could feel my heart pumping with colourful happiness. There are days when that happiness is absent, grey. But today was special, magical. I have to say that, since that November, no day is the same. My happiness is unstable, intermittent.

Suddenly, everything has changed. The colours have started to fade, the sunny morning has become a stormy morning and I have had to change the dress and sandals for a woollen jacket and closed shoes that warm me up and protect me from the cold.

It was you, yes, you. It's was seeing you and remembering the pain again which I felt when I had to put you here to gather dust. I remember how excited we were to buy you. We would never have imagined that we would also have one. When we had you at home, we looked at you and wondered if we could walk with you. You are so big! You gave us unforgettable moments.

But now, looking at you hurts me. Having you here with us means she isn't anymore. Seeing you here means we had to change you for a smaller one. Putting you away here forever was one of the most painful moments of my life.

I remember the first morning that we couldn't take you out anymore. Everything was grey. Walking without you broke my soul because it meant that she would never come back, that we could never take her for a walk again. Not having you in the hall when we went out for a walk meant that she had died.

I look at you and tears trickle down between my fingers, which touch every corner of you. For many it would only be a simple twin stroller, one more piece of junk from the storage room. But to me, you're a little piece of magic, full of stories between sisters, a space of trust and fights.

Maybe tomorrow I'll be a little happier again. I will be able to put on the sleeveless dress and tie my sandals around my ankles, go for a walk and savour the smell of spring.

Or maybe I'll be down again, because I'll see you again or someone will ask me how many kids I have or simply because, instead of putting six plates on the table, I have to put five.

The stages of mourning

Denial - Avoidance; Confusion; Elation; Shock; Fear

Anger - Frustration; Irritation; Anxiety

Depression - Being overwhelmed; Impotence; Hostility; Escape

Negotiation - Struggling to find sense; Approaching others; Explaining the story

Acceptance - Exploration of options; Establishment of a new plan; Progression moving forward.

Stages of mourning according to Elisabeth Kübler-Ross, who was a pioneering psychiatrist in studies about death and author of the book, *On Death and Dying* (1969), where she spoke for the first time about her theory of the five stages of mourning, also known as the "Kübler-Ross Model". This model has been questioned as being perhaps too rigid.

Euphemisms about death (Spanish)

THE LEGACY

Go through life with your duties fulfilled

Having an illness that allows you to tie up loose ends is, in a way, a gift, because there are people to whom death comes abruptly. That's why you have to go through life with your duties fulfilled, give thanks to who we should, know how to forgive, talk to people we have stopped talking to without remembering why, forgive our own mistakes, know how to say goodbye, know how to say "I love you", know how to say "You've been important in my life," to whom you should.

A person does not die as long as they are remembered

Aida Lesan Griñó

I've thought about this phrase many times and it seems ephemeral to me, because the memory fades. His face, his smell, his touch, end up being rather fuzzy. How does the memory end up? Where is it present? I remember him through photographs and it is because I have them that his memory is alive, because in my head he is no longer there. Sometimes I feel his touch, but I don't know anymore if it's my imagination that still wants to remember everything.

So, for me, memories are also volatile. Can memories last forever? Will I always remember him? How? What will keep him present? I think of what my grandmother was like from a photograph in my parents' dining room and now I remember her like that, always in that lilac dress. I think of my grandfather and I also see him as he was in the photograph on my grandmother's bedside table, wearing the waistcoat from "the suit".

I've thought a lot about memory. In fact, at home, my grandmother keeps a lock of her grandmother's hair inside a black box lined on the inside with red velvet. That always impacted me. But now, I find it wonderful. She proudly said she had long, black hair, without a single white hair. And when she died, they cut a lock of it and kept what made her so unique, her hair. And there it is, inside the box. I always tell my grandmother that I want that box; me, who doesn't even know what my great-grandmother was like, I haven't seen any pictures of her, but I think it's a beautiful touch to keep a small piece of my ancestors, like a relic.

I think it would be nice to be able to save memories in a vacuum, to save smells, which are so characteristic of people; to be able to remember the touch; the warmth of their presence. I also like the act of preserving something material related to them: a piece of fabric from the shirt they always wore, their lipstick, the knife they used to go mushroom picking... Sometimes I wonder what identifies me and what I would like to be kept, if anyone wants to keep something of mine once I die.

How do we want to be remembered?

Aida Lesan Griñó

There is also a question I ask myself often. Will they remember me for everything I did Or for how I made them feel? Will they remember the softness of my skin? The tone of my voice? I think it's nice to be remembered. How should we remember?

There are people who, for example, are places. My partner is a mountain, a specific place, the Pla de la Font, in the Pallars Sobirà. He is this place. My grandmother was countryside, she was effort and work, a well-kept orchard, a land worked. I think I am sea. So, I think we all have a space within us, a territory. I like to imagine people as landscapes. Landscapes that shape us and make us singular.

GOOD BYE**Art saves man**

Oriol Moragas Maragall in conversation with Vanesa Aresté Vilanova

Vanesa

What would you tell us about art and the processes of disease? How have you experienced art during this confinement? What power does art have?

Oriol

That's the key question, right? Art has tremendous power, whether it's with people who aren't well —Especially with them— or with those who are. Art, I always said... and I say, is salvation from the harsh reality, the repetitive reality, and I think it is very important to understand that art is not just something beautiful. It is more than that when it's well done. It is the whole person gathered in an instant, I do not know how to tell you, in such a way that that person lives by art; art is used for many things and heals man's... not physical illnesses, but... man, in fact, is ill and art is what saves him. Art saves man.

Vanesa

And what has art allowed you to do?

oriol

Express myself. Express myself as I want to and whatever happens, that's a constant.

Vanesa

And in this time of confinement could you give us some example of how art has allowed you to express yourself? For example, with Sissi, right?

Oriol

Okay, that too, yes...

Vanesa**Music...**

Oriol

God, music! The music... We were lucky that she and I have a musician in common, Johann Sebastian Bach, and we both recognise that Bach certainly is art, because it feels and plays, not to look good; so much so, that in those times when Bach played the organ and made the choir sing, some chaplains, the Church, warned him "These things are somewhat dissonant, and not very religious." Bach said, "If God isn't dissonant, I don't think he's worth it". And that's really how it is, right? Art is what comes out of your soul at that moment, whatever the consequences.

Vanesa

Earlier you were telling me about the transformative role of art.

Oriol

It's massively important. Look, I'll give you an example about art theory. Nietzsche said that there were sublime realities that couldn't be of this world; to give art the importance it had, he said that it had to be of a hidden God, and he was an atheist! And it really isn't of this world. I think that is it very, very important. "Art is not a mirror where reality is reflected, but rather a hammer that transforms reality".

Vanesa

Who says that?

Oriol

Ah, that's exactly what Bertolt Brecht says.

A communist.

The core group and working group behind "The good death"

Bibliography

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