



Círculo Rojo



# **HOW TO SUPPORT THE HEMATOLOGICAL PATIENT'S CAREGIVERS**



# **How to support the Hematological patient's caregivers**



AGRUPACIÓN ESPAÑOLA DE ENTIDADES DE  
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# PROLOGUE

The publication of this guide is a cause for celebration for all those who are dedicated to hematology. This reflects the vitality and desire of a group of professionals who want to help the people who take care of hematological patients.

This small guide provides concrete information on how to experience different moments of sickness and gives guidance on how to handle possible difficulties.

The clinical experience of those who have written it, in addition to the information from relevant authors, makes this guide a supplementary resource for those who face the hard task of taking care of others. A hard lonely and often poorly recognized and valued work.

*“Helping others is good, but teaching  
them to help themselves is better*

*Anonymous*





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## AT THE TIME OF DIAGNOSIS

*“It was just another Monday, Peter got up as usual to go to work, but this Monday he had to go to get his annual check-up done, like he did every year. He was fine, nothing made me suspect what was coming. At noon we received a call from the doctor’s office, the results of his blood test were confusing and they asked him to go back that same afternoon to repeat them. I accompanied him and we were told right there and then. The doctor sat in front of us, looked us in the eye and told us: I’m not going to beat around the bush, you have leukemia and you need to be admitted immediately. I confess that if he said anything else I wouldn’t know, he tried to make sure I was following the conversation, but my brain had disconnected and all I seemed to hear was the word LEUKEMIA, which was repeated over and over in my head. I didn’t know what to do, how to react, what to say, it was as if the conversation didn’t have anything to do with me. When I left the doctor’s office, I looked at my husband, until that moment I had not done it and I felt guilty for it. That is when I reconnected with reality. We had to move to the hospital, almost 120 km from*

*our house. An ambulance would pick us up in a couple of hours. Yes, a couple of hours... that was all the time I had to arrange everything or rather nothing. Our 14-year-old son was left alone, totally oblivious of what was happening. It lasted a month, the longest month of my life..."*

Leukemia does not appear in just one particular manner; sometimes the patient has already manifested a series of symptoms, but others it appears without warning.



In any case, suspecting that something might be wrong, does not make the news of the diagnosis easier to digest. The impact that occurs when the doctor gives us these news is enormous and each person reacts in a very different way and with different emotional intensity

A mother told me with shame how she yelled at the doctor when she heard the diagnosis - "*I'm not like that, I don't know why I did it!*" -. Others cry or become paralyzed. Our way of reacting is *unpredictable*, we are not prepared for something like this and sometimes we cannot handle the situation; in these cases, the best approach to be able to cope with what is out of our control would be to either *downplay the situation*, just *accept it* or even, in some cases, *deny it*. The emotional overload that a diagnosis produces can lead us to react in many different ways, and doctors know that, or it would be important for them to know. They are normal and adaptive reactions, which will appear depending on the emotional resources of each person and it is good and necessary that they appear for a correct adaptation. The important thing is that these reactions do not prevent us from starting treatment, do not prevent us from taking care of the patient and that they eventually reduce its intensity.

We must bear in mind that the disease will not only affect physical health, but will also cause a wide variety of feelings, both to the patient and to the person who cares for them. These feelings can change every day, every hour or even every minute. *Fear* will appear. Fear of treatment, pain, physical change, death. You *get angry*, you think "it's not fair, we don't deserve it", "why us?". *Sadness* can be made present and you will need to cry. All these feelings are normal and expressing them helps us to know them better and accept them.



At this initial moment, many people are wondering if they should tell the people around them or if it is better to keep it a secret. In this case, the important thing is to receive the necessary social support. Sometimes hiding it from friends, neighbors or colleagues leaves us isolated, in a bubble, without the necessary support to cope with the situation.

Social support helps to reduce the negative impact of the disease, provides affection, trust, security, alternative coping strategies, as well as material or instrumental help in the solution to a problem. On the contrary, lack of support is associated with the appearance of physical (2; 8; 20) and also mental illnesses, such as depression or anxiety (7; 10). A few years ago this disease generated a strong stigma, it is now more accepted, which con-



tributes to the necessary social support. But whether or not to share it with neighbors and friends, or at work, it is still a personal decision. Some prefer to avoid prying questions or morbid curiosity. In any case, the right to keep it a secret, if you will, must also be respected.

For those relatives or caregivers whose sick person has forbidden them to share this situation with their social network, associations present an alternative route with a wide variety of interventions based on social support.

When you decide to share the news, you have to bear in mind that, at first, your entire social environment can be mobilised and, if there is hospitalisation, about fifteen or twenty people may present themselves there.



These will be family members or friends who want to support or know more, but that's not what you usually need at that moment, what you need is an organized network that helps you have moments of calm and that helps you solve specific problems.

Therefore, it is important that when you give the information you explain how they can help you. You should also bear in mind that some of these people, with their best of intentions, may give us the wrong messages. They may tell us “Come on, you have to be strong so the sick person doesn’t sink”. “Don’t cry in front of them”. “You will see that this is nothing!”. Accepting these messages implies that the patient may not feel understood. When the relative hides to cry, the patient will also do , so it is essential that a relationship of trust be established that facilitates emotional relief through the expression of thoughts and emotions, as well as inviting the patient to speak, listening to the facts and their feelings carefully.

Transmitting acceptance and interest in everything that happens and allowing oneself to feel bad, feel sad or want to cry, will reduce the emotional intensity of the patient and also of the person who cares for them, allowing better resolution of the problems.

There are also other problems that aggravate the experience of the disease at this time, these are new situations for which we are not prepared, actions such as relating with the medical staff, moving to places unknown until that moment, such as hospitals and clinics, the separation from family and friends, as well as changes in their social roles and a large increase on the economic burden. This can generate a lot of stress, fear and worry. Many are forced to leave their children in the care of others, sometimes even with people they do not know that well.



I remember the anguish of a mother when she told me that she had left her 4-year-old son in charge of the neighbors. The building had four floors and every week the child rotated and stayed with one of the neighbours.

And despite their interest to take care of the sick person, the caregiver will find their personal plans frustrated, their daily life is altered, their sleeping hours are reduced, they eat worse, etc. In order to be able to face this task, people who care for them must remember that they are an essential part of care: they are the engine of care and must therefore also attend to their own needs and take care of themselves. If they take care of themselves, they can take better care of the patient and this will positively influence the recovery.

For starters, it is important to have the support of different associations and their professionals, of both the psychologist and the social worker, who will help you explore the different coping strategies you have assumed and will help you mobilize the necessary resources.



## THE TREATMENT BEGINS

*“I barely had time to assimilate everything when the treatment started. We were admitted, far from home, away from my son. I was barely aware of where I was until I had to leave the hospital for the first time. Pedro wanted something different to eat and I set out to look for it. Then I realized how lonely and lost I was, but by asking around I got what I was looking for. The phone rang continuously, I could barely answer all the messages from family and friends, at times I wanted to throw it out the window. The nurses kept coming in with fluids, medication, sometimes they would break our sleep and the tiredness was overbearing. At one point I went out into the hallway, looking for a little moment to myself... And I found a perfect place for it, it was the hospital lounge, some volunteers took me in nicely, invited me to a coffee, introduced me to other women who were there. Talking to other caregivers helped me a lot, I learned to take care of myself. I remember that time as an exhausting time, but when I made great friends.”*

In most cases the time between diagnosis and the start of treatment is very short, so the patient and caregivers may feel overwhelmed.



They have hardly had time to take on and process the reality of the disease when they already have to start treatment. A treatment that is sometimes unpleasant because of its side effects.

Treatments come in varied forms, but as a general rule there is a high possibility of having several adverse effects such as diarrhea, nausea, vomiting, skin alterations, fever, hair loss, mucositis, loss of muscle mass, etc.

Some caregivers interpret these symptoms as negative ones, as a sign that the treatment does not work, so being aware of what they are and anticipating them can help you live them with less anxiety.

Looking for this information on the Internet is perhaps not the best option, as the veracity and rigour of this source of information is often quite doubtful. The most appropriate thing is to consult the doctors, without being ashamed of any doubts that you may have.



Any doubt is important and should be resolved as soon as possible. Treatment often involves, in addition to physical repercussions, hospital admission and even isolation.

In other cases, treatments may be given in a day hospital, a place where the patient can be accompanied by his or her caregiver and can then go home.

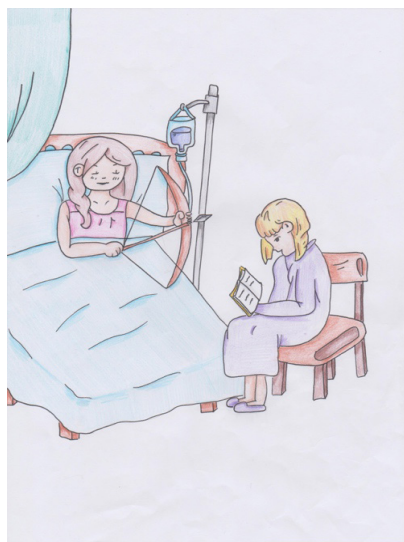
In the hospital context, the days and hours become very long because the possibility of carrying out activities or having contact with other people is very limited, especially when treatment requires stricter isolation, either because their defenses have dropped or because some infection has occurred and isolation is required to prevent it from spreading.

During the period of isolation, the care-taker can accompany the patient by taking, in some cases, a series of simple precautions such as the use of a mask and thoroughly washing their hands, and in other cases, depending on the diagnosis, the measures may be extended to the use of a hat, gloves, dressing gown, etc. The duration of this isolation period can vary from a few days to

several months, so it is very important that the patient feels accompanied, and cared for. The caregiver will be able to go out and take a break, but the patient will have to stay in the hospital, which will cause a loss of direct contact with much of their social environment; this sometimes, especially for the youngest people, is often perceived as abandonment by friends and creates a feeling of disappointment.

Social networks are also companions in the periods of admission, however they can be a double-edged sword because, on the one hand, they can help them maintain contact with the outside world, but on the other hand they generate anger and frustration because the patient can see that life remains the same for everyone but themselves. All this can cause emotions such as sadness, anger, anxiety, etc. They are not negative emotions, but they cause discomfort for the patient and the person who cares for them, so allowing their expression (sometimes through crying, sometimes through shouting or blaming the person who cares for them) will be the best way to help them.





The difficult thing is to take out the received arrow and to give it back to be thrown at you again. Understanding anger as the tale of sadness that lost its clothes and did not want to be naked, can help the caretaker in this difficult situation (Jorge Bucay's story, "La tristeza y la furia")

Due to all the side effects, both physically and psychologically, it is recommended that the patient be accompanied as much as possible, but always respecting their space, avoiding overprotection and leaving them certain moments of intimacy. Overprotecting means doing things for the sick person that they could do for themselves. They will become increasingly dependent and unable to do things on their own, something that will hinder their autonomy and self-esteem, and this will mean an overload for the caretaker. Not overprotecting means putting limits on caring, and not helping

in those tasks that they can do on their own, saying NO in an assertive manner, without either of you feeling bad. In these cases the rejection of an ask must be accompanied by reasons and not by excuses. Excuses can be turned into traps. For example, it's better to say "I know you can do it alone" than to say "I'm busy".

In the event that the patient can count on a large number of companions, something unusual, it is advisable to organize and establish shifts preventing some of them from ending up spending as much time in the hospital as the patient. Usually, at first many family and friends are available, even to go to the hospital, but as time goes by the primary caregiver is usually alone or at best has a person with whom to alternate.



Taking advantage of these shifts to rest or simply to change their environment, is very important. Taking rest does not mean abandoning the patient, it means

taking care of ourselves to be able to develop optimal performance in care-related tasks.

Although the caregiver feels great personal satisfaction with the task they perform, they may also feel exhaustion, sadness, guilt, boredom, irritability, immunosuppression with the associated risk of physical illness, etc.... Some caregivers leave their work, their children, their friends, their hobbies, they leave everything to take care of the patient; they forget their own needs for the benefit of the sick. To prevent that from causing a temporary inability to continue caring, it is important that as a caregiver you take care of yourself.

A first step in the process of learning to take better care of yourself is to “become aware” of the need to take care of yourself. We can mention two reasons: to take care of oneself and to take care of oneself in order to maintain one’s own health. Many caregivers feel guilty attending to their own needs because they think they are acting in a selfish way, taking care of themselves when there is a close person in conditions much more unfavourable than they are and who needs their help to continue living.



They don't realize that taking care of themselves is taking better care of their family member: caregivers with their resting needs, leisure, satisfied emotional support will be able to have more energy and mobilize their physical and psychological resources in the care of the sick much more and better.

If caregivers do not take care of themselves, they will be more likely to become ill or at least to see their physical and mental energies depleted. And, if this happens, who will take care of your dependent relative instead? Or how will this weakness, this exhaustion, this lack of rest in the care of your family member be reflected?

Taking care of yourself will also help you maintain your own health. Many caregivers forget themselves, but the fact is that they are still the same people as before and therefore they still have the same needs. Caring for a close relative does not mean that the caregiver becomes a being who is above and beyond basic human needs and who can pass through life without caring for or satisfying them. Caregivers must come to realize that their life is as dignified and deserving of care and attention as that of their family member.



When caregivers overextend themselves and forget about their personal needs, their own body has “alarm mechanisms” that show them that they are too tired or overcome by some situation and that it is time to start taking better care of themselves...

Caregivers who choose to take care of themselves have learned to listen to these warning signs and to take them as indicators that more attention needs to be paid to themselves. This is what a caregiver does, for example, when they think: “when my head hurts like this, I know it’s time to take a break”.

Below is a list of possible “signs” of exhaustion and stress in caregivers, which you can use as a tool to detect the need to increase taking care of yourself.

### *Possible Warning Signs*

- Sleeping problems (early morning awakening, difficulty falling asleep, too much sleep, etc.)
- Energy loss, chronic fatigue, feeling of continuous tiredness, etc.
- Isolation
- Excessive consumption of caffeinated drinks, alcohol, or tobacco. Excessive consumption of sleeping pills or other medicines.
- Physical problems: palpitations, hand tremor, digestive discomfort
- Memory problems and difficulty concentrating
- Less interest in activities and people who were previously the object of interest
- Increase or decrease in appetite
- Routine repetitive acts such as continuous cleaning
- Getting angry easily
- Giving too much importance to small details
- Frequent mood or mood swings
- Proneness to accidents
- Difficulty overcoming feelings of depression or nervousness
- Lack of recognition of the existence of physical or psychological symptoms that are explained by other causes not related to the caregiving.
- To treat other persons in the family in a less considerate way than usual.

Sometimes, in order to have these breaks, the caregiver needs to ask for help, to share the responsibilities and tensions associated with the situation with others.

Asking for help is not always easy, but the caregiver should not assume that people will help them naturally. If a caregiver doesn't ask for help, they probably won't get it.



Many caregivers don't ask their family and friends for help because they feel it's something that should come out of them, because they don't want to implicate or bother anyone, because they think it's natural for the whole burden of care to fall on them or because they think no one will do it like they themselves do it.

They may also have asked for help on occasions and have not received the desired response. This may be for a number of reasons, but these may include the possibility that the aid has not been properly requested: demanding the help or aggressively asking for it, as if it were obligatory, is not the best way to get the support and collaboration of family or friends. You must ask for help and you must do it properly.

Below is an example of how you can ask for help step by step:

How to ask for help:

1. *Request permission. Make sure you can speak:*  
*Can we talk for just a moment, please?*
2. *Direct and accurate verbalization:*  
*I'd like you to stay Thursday or Friday with Dad at the hospital*
3. *Empathic self-assertion and positive expression of demand:*  
*If you help me with this I will be able to go out for a little while. Lately I'm feeling exhausted.*
4. *Give them the option to get a negative answer:*  
*If you can't, just tell me, I won't be angry.*
5. *Express why it is important for you, your needs:*  
*It's important to me that you stay with Dad on Thursday or Friday so I can rest. It would be very kind of you to stay on Thursday or Friday, I need to rest.*
6. *Manifesting one's own feelings, thoughts or behaviors in the first person:*  
*Lately I'm exhausted and I could really use your help.*
7. *To offer alternatives:*  
*Does it work for you? How about Saturday? Tell me what day you can make it.*
8. *To finish with thanks:*  
*Thank you very much. It's a relief that you help me. Luckily I'm counting on you.*





How **NOT** to ask for help:

1. *Aggressively. Because it causes rejection:*  
*Mary I'm sick of you never coming to see dad and nobody helping me. This is going to end. I'm leaving on Thursday, so it is up to you.*
2. *In an inhibited way. You will be providing arguments for rejection:*  
*Look, I was going to ask you something, but it's not very important... Can you come to the hospital? If you can't I understand, of course.*

Despite all efforts, there may be no one willing to collaborate with you, whether they have their reasons or not. On these occasions, it is important to turn to other people who might do so, for example associations for the care of sick people and their families. There you can find professionals who will provide you with information on different resources for help, guidance, emotional support, resting activities, etc. It is important not to wait until there is a desperate situation to turn to a professional, but to do so before this happens. The activities that these associations carry out inside and outside the

hospital can also help you normalize your stay in this environment, generate a resting routine and put you in contact with other caregivers.

# DAY HOSPITAL

Sometimes treatments can be provided in the Day-Time Hospital without having to be admitted to the plant. In this case waiting times will be long, but the patient and you, as caregiver, can rest at home afterwards. The Day-Time Hospital is a common space where several patients share their treatment, along with them can be a caregiver, therefore, the possibility to establish a link with other patients and caregivers is there, sharing experiences, resources, etc. Carergivers in this context can act as mediators of this possible contact.



In the Day-Time Hospital the spaces are usually small, several nurses intervene simultaneously in the room, dodging chairs and people. The respect on the part of caregivers with the healthcare personnel is fundamental, to facilitate their work and to have as relaxed an atmosphere as possible for all.

Another fundamental aspect in this context is the construction of the reality of sickness. As this is a situation in which the patient does not need to be admitted, many family members or patients are not aware of the impact of treatment or of the necessary precautions that need to be taken against the disease. Not being admitted does not mean that the side effects are not felt with intensity, obviously it will depend on the treatment and tolerance to that treatment of each person. Some patients in this context complain of getting little help when they are at home. Caregivers normalize their life more easily when the patient receives treatment in the Day-Time Hospital and therefore the patient feels that much more is required of them, however we must be aware that, while we cannot overprotect them it's not good for the patient to feel abandoned right now either. In fact, it is increasingly common to find the caretaker's chair empty.

The opposite is also true; caregivers who do not want to leave the chair during treatment, do not want to go out for coffee or to eat if necessary. Caring for yourself does not mean giving up. Not paying attention to your needs can decrease your physical and mental energy. In

fact, I once saw how nurses had to take care of the caregiver instead of the patient in the Day-Time Hospital.





# END OF TREATMENT

Being discharged from the hospital after a long period of hospital admission is a moment of joy, but also of doubts and fears on recovery or the possibility of a relapse.



Although patients and their caregivers assume that the less time in the hospital the better, they are not always ready to leave. If you need more time to finalize home accommodations or complete transfer arrangements, you should inform your doctor

Unfortunately, the suggestion of hospital discharge is sometimes rushed for reasons that have nothing to do with the patient's needs, even if the care process is not complete. It should be borne in mind that, even if the patient requires assistance, he or she can be monitored

without admission, at least in the short term. Sometimes these needs can even be better met on an outpatient basis or in another centre.

Once at home, it is convenient that you carry out a progressive adaptation, favor the patient's self-care and thus reduce their dependence. The patient and their caregiver move from a context where all care is provided to a place where they will both have to cope on their own. Depending on the limitations caused by the disease and the treatments, the adaptation will be more or less easy. It is a time when everyone has to adapt to changes and losses. Keep in mind that the abilities of the patient to perform their personal tasks may have changed.



Their social environment will have been destabilized and their role in the family environment will have taken a turn, for this reason it will be important to identify their capacities and deficits, always involving you in activities that help you overcome their limitations and in making daily decisions.



For a long time these patients feel a loss of control in their life, returning home is an opportunity to regain their autonomy, but on many occasions the caregiver has created such dependence on their role as caregiver that they maintain unnecessary care at this stage which limits the patient's autonomy. The caregiver must consider that the care needed in the most critical stages may not be the same now. I remember a mother taking care of her 42-year-old daughter in the hospital during her treatment. In the periods where she did not need to be at the hospital, she went home to her mother, because her partner and her lived 300 km away. When she finished her treatment, she also went to her mother's house. This woman had been looking after her daughter for almost two years, leaving much of her hobbies and work behind. Actually, when the treatment finished the daughter was fine, but the mother told her that it was better that she stayed at home with her for a while longer. The mother did everything for her: the house, the clothes, the food, the shopping, and the daughter began to fall into a state of depression. What she really needed was to go back to her life, home and with her partner, get her activities back, but she felt bad leaving her mother alone. "What's she going to do now," she said. In these cases it is important that you get out of the role of caregiver and gradually recover your hobbies, call friends you haven't seen in a while, go out with them, exercise...



The fear that the disease will reappear will be especially present before the check-ups, medical checks and also with any pain or physical discomfort.

Both patients and caregivers often display a sense of continued alertness. This sense of uncertainty and fear is understandable and normal. The important thing is not to prevent the patient or caregiver from carrying out their daily routines. Not sleeping the day before a check-up is normal, not sleeping ever would be considered a problem. In that case it is advisable to ask for help.

It will take some time to regain self-confidence and be able to face these situations without so much difficulty. But even after several years, this fear can come back and make you feel bad. There is no shame in these emotions, it is human and natural, you can still be happy while having these emotions and you can lead a totally normal life. It all depends on what you make of this fear. It is most appropriate to accept the fear of possible relapse and try not to let this fear prevent you from focusing on the present.

Sometimes a certain degree of fear can even become an ally. If we have some degree of fear, we will be more aware of possible symptoms that may be indicating a relapse, and that will make us to see a doctor first. Early detection is essential for curing a disease. Also, fear will put in place personal care mechanisms, healthier meals, exercise, etc..., and make us take the necessary precautions to avoid certain contagious diseases.

Expressing your concerns with the surrounding environment will help both the patient and your family to receive support. In order to do so, they must gradually resume their activities and social relations and gradually move away from the role of the sick person or caregiver. A new stage begins and getting back your usual routine, that of which we sometimes complain about, will be your greatest desire.



# RELAPSES OR RECURRENCES

For the patient and close relatives the appearance of a relapse of the disease (recurrence) is a difficult situation, sometimes devastating, since it means having to face again a disease that they thought had been overcome; with all that this entails at a physical, emotional, social and work levels,



Adaptation to recurrence will be more complex the longer the period of remission that preceded it is.

In many cases, existing emotions may resurface at the time of diagnosis and the person may feel more cautious, and less optimistic and may be disappointed with themselves and the medical team.

There may be mixed feelings of anger, sadness and fear, but it is important to bear in mind that this time there is the previous experience of having already gone through it. Treatments may have improved since the first diagnosis, including new medicines or new methods that may help the treatment and to control side effects.

Not everyone has the same emotions and thoughts when the disease comes back, but in most cases people tend to feel angry, sometimes it's the doctor's fault, either for something they think they didn't do correctly or because they didn't follow up more carefully; other times the sick person or relatives feel guilty or feel that they have made a mistake: missing a medical appointment, not eating well, postponing a test, lack of hygiene, etc. But even when everything is done correctly, the disease can come back. Feelings of guilt are often interpreted as something negative by many professionals or friends, however they sometimes offer an explanation, a meaning to what is happening to us, because everyone needs to have a meaning for their experience. Guilt can be better than not feeling anything. In addition, the feeling of guilt offers a sense of control: "*If this happened for something I did not do... if I do it next time, it won't happen again*".



Symptoms of anxiety, sadness may also appear. Relapse may seem more unfair than the first time. Treatment may be different and perhaps more aggressive than the first time.

Fear of death appears. Many patients fear more for their loved ones than for themselves, they are terrified of the prospect of months in hospital. When the patient tries to express the possibility of death, the most frequent answer is: “Don’t talk like that, you’re not going to die!”. Unable to talk about death with those who are most important to them, their fears are not alleviated and can continue to grow.

The fear of death is very natural, not uncommon, either for the patient nor their relatives. Sometimes that fear creates anxiety, the heartbeat speeds up, you may feel a sharp pain in your chest, everything seems out of control, you don’t know what’s going on, but you feel it’s not good. They are anxiety attacks, the first time that it happens you can even fear for your life, it may feel as if you were going to drop dead to the ground, but in reality

it is only a state of uncontrolled anguish. It's not easy to control, but you should try not to think that something bad is going to happen to you. If you don't control it, more symptoms may appear. Find a place to sit down, if it's quiet better, try to control your breathing, slowly catching and releasing air, tightening your lips as if trying to blow a candle can be helpful, and try to remember that these symptoms are a reaction to stress.

Having a person to talk to about these fears helps reduce that anxiety.



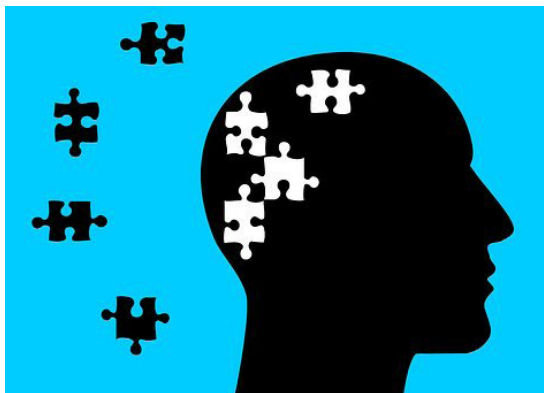
It is important that the caregiver allows the patient to talk about what worries them, and the caregiver will also need to take it out with someone. They can be family, friends or professionals, the important thing is to find a way to express these feelings.

If this is not enough and the situation worsens, you can ask for the help of a psychiatrist who will assess the need for medication. What you should never do is to indulge in self-medication or provide the patient with medication without consulting a professional them first.



# PALLIATIVE CARE AND TERMINAL SITUATION

Palliative care refers to a care approach that improves the quality of life of terminally ill patients and their families. It helps to live the end of life with dignity and the greatest possible well-being, through prevention and relief of suffering through early identification, correct assessment and treatment of pain. All therapeutic decisions must have objectives set with the patient and their family, ensuring freedom of choice and taking into account that palliative care includes physical, emotional, psychological, social and spiritual aspects.



The care of end-of-life patients involves both a physical and an emotional burden with possible negative consequences for the health of the caregiver, so it is necessary to learn how to prevent overload problems.

It is important that caregivers are able to reconcile their own lives with the care of the patient as far as possible. Having time to breathe, going out for a walk, eating well, talking to other people, etc. One of the things that usually happens at this moment is that both professionals and caregivers want to protect the patient and try to avoid their suffering, withholding information about the disease. However, an uninformed person cannot adequately prepare for the final stage of their life, cope with their illness, make their own decisions, resolve outstanding issues and share their last moments with their family. Clear and honest information about the situation gives the patient the opportunity to make decisions about their process in a manner appropriate to their values, beliefs and expectations. In any case, it should be the patient and not the caregiver who decides how much they would like to know. There are patients who don't want to know anything and patients who demand that information, who even openly ask, am I going to die?



Caregivers need to know that when a patient asks a question it is because they are prepared for their answer, otherwise they would not ask.

That doesn't mean that the answer can't affect them it certainly will, but they have enough emotional resources to handle that information. In most cases, it is the caregivers who are not prepared to give that information, trying to maintain an apparent normality, as if nothing had happened. This approach not only denies patients the right to be informed and make their own decisions, but also increases the stress that caregivers suffer. The pretending that everything is ok and the lack of communication will create distance between them, prevent the proper goodbyes and complicate the preparation of the mourning.

One of the most present emotions at the moment is fear. Fear of not receiving adequate care, of the patient's suffering, of speaking of illness, of not taking good care

of them, of not being present at the moment of death, of loneliness after death, etc... While the involvement of several family members in this care is important, some are incapacitated by these fears to provide an adequate response to the patient's multiple demands and needs. Some are not able to express their fear and hide behind other aspects, work, family care, studies, etc.; these are different mechanisms of defense against feelings of incapacity. For the person who stays in charge of the patient's care, this is often difficult to understand, as they feel alone in the task of taking care of the patient and gets angry with those who are not present. But that caretaker will be the best person to handle the grieving, as they will feel that they have done everything in their power to help and provide all the necessary care.

It is important to give everyone their time to face the situation and to use all the resources available to be able to take rest and take care of themselves.





# THE GRIEF

In today's society, no one talks about or deals with the subject of pain, suffering and much less death.



It is a taboo subject that causes great disorientation along the way. While each person faces grief in the best way they can, there are certain aspects that can help crafting it.

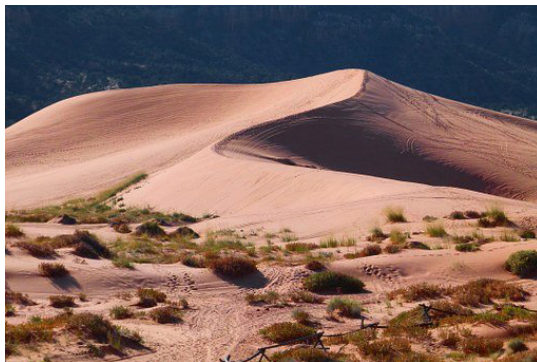
First of all, it must be made clear that mourning is not a disease, it is a normal and adaptive response to the loss of a loved one, which helps the sufferer to accept that loss and to rebuild their daily life and values without the loved one.

The grieving process will depend to a large extent on the resources available to the survivor, both at a personal and

family and social level, as well as on the response reactions to previous intense emotional situations experienced before . Not all bereavement processes are the same or resolved in the same way. The intensity, pace and duration of the mourning will depend on the emotional and dependency relationship with the deceased, the age of the mourner and of the deceased, the circumstances and timing of the loss, the preparation time for the loss, religious beliefs, social and economic problems caused by death, personal, family or social disruption, among other things.

The duration of the bereavement processes varies greatly. Although there are some who consider that the person who has had a significant loss begins to recover after a year, when all four seasons have gone by and they have gone through all significant dates of the relationship without the deceased (birthday, saint-day, anniversaries...)

The manifestations of grief may include both psychological symptoms (pain, grief, sadness, anger, guilt, anxiety, etc.), and somatic symptoms (loss of appetite, insomnia, fatigue, tightness in the chest, etc.).





Sadness and anxiety are the most common manifestations, as if a part of ourselves has been lost and there is no way to carry on.

On many occasions, feelings of guilt may appear, for not having done everything possible to prevent the death, for not having contributed sufficiently to the happiness of the deceased in life, or even for experiencing a feeling of relief after their death (especially after a prolonged illness that has required constant assistance or the thought that death would free the patient from suffering). Many people dream about the deceased, think they see them on the street, treasure their personal belongings; and others avoid reminders of the deceased, they don't want to talk about that person, quickly remove their personal belongings, etc. All these reactions are normal, don't worry.

At first, you may deny the reality of the situation, you may act as if nothing had really happened, because you are not prepared to endure that pain. Afterwards, the reality becomes evident during the day-to-day activity, the pain is so great that feelings of anger and rage arise, even to the point to questioning the meaning of life. But life goes on, and you will restart your projects, you will gradually get used to the loss although the pain may still be alive. You will start being involved in other activities, but it is difficult. There are feelings of sadness, of fear. As time goes by, you begin to understand what happened, you accept it and it gives a meaning to life.

The experience is not forgotten, but the intensity of those emotions will gradually decrease.

Although grieving is a normal process, there may be situations where you need professional help.



This is especially important when the grief does not evolve towards its resolution with time and cannot overcome the loss of the loved one; when emotions can be so intense that it is difficult to continue with your own life, and you reach a feeling of overflowing.

You may also need professional help if you are one of those people who have difficulty expressing their feelings, as there may be more physical manifestations, such as anxiety, pain, insomnia, and even some illnesses. In these cases, associations have professionals who offer their help in these situations. Some have even set up support groups for bereavement situations.

# ANEX 1: SOCIAL RESOURCES

In our environment there are different resources that can be used to support the caregiver. For more information, you can ask the social worker of the corresponding association of your medical centre for help.

Public resources:

- Dependency Act
- Degree of disability
- Legal incapacity
- Social application for home help service
- Application for tele-assistance
- Application for a day centre
- Application for residence
- Technical assistance loan service

Some of these services can also be obtained through private channels, for example telecare, home help and the day centre.

Benefits

- Service-related financial benefit

- Financial benefit for family environment care and support for non-professional carers.
- Financial provision of personal assistance, aids and subsidies for the removal of architectural barriers.
- Contributory pensions, non-contributory pensions and allowances.

Associations:

Volunteering. Accompaniment services.

- Respite services. Accommodation flats.
- Social and Psychological Care.
- Self-help therapeutic groups.
- Self-care workshops.

## ANNEX 2: THE AUTHORS

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## ANNEX 3: GUIDE OF PARTNERSHIPS

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In collaboration with:



