

THE THREADS OF MEMORY



HOW THIS STORY WAS WRITTEN

DESCRIPTION OF THE CONTEXT
AND PROCESS OF CREATING THE
EXHIBITION.

DESCRIPTION

THE PIECE WAS DESIGNED TO INTRODUCE AND CONTEXTUALIZE THE EXHIBITION.

IN THE PIECE, THE PILLARS OF THE INECO FOUNDATION FRAMING THE EXHIBITION ARE DESCRIBED, ALONG WITH THE OBJECTIVE OF THE SHOW AND ITS CREATION PROCESS. IT INTRODUCES THE THEME ADDRESSED BY THE EXHIBITION: ALZHEIMER'S DISEASE.

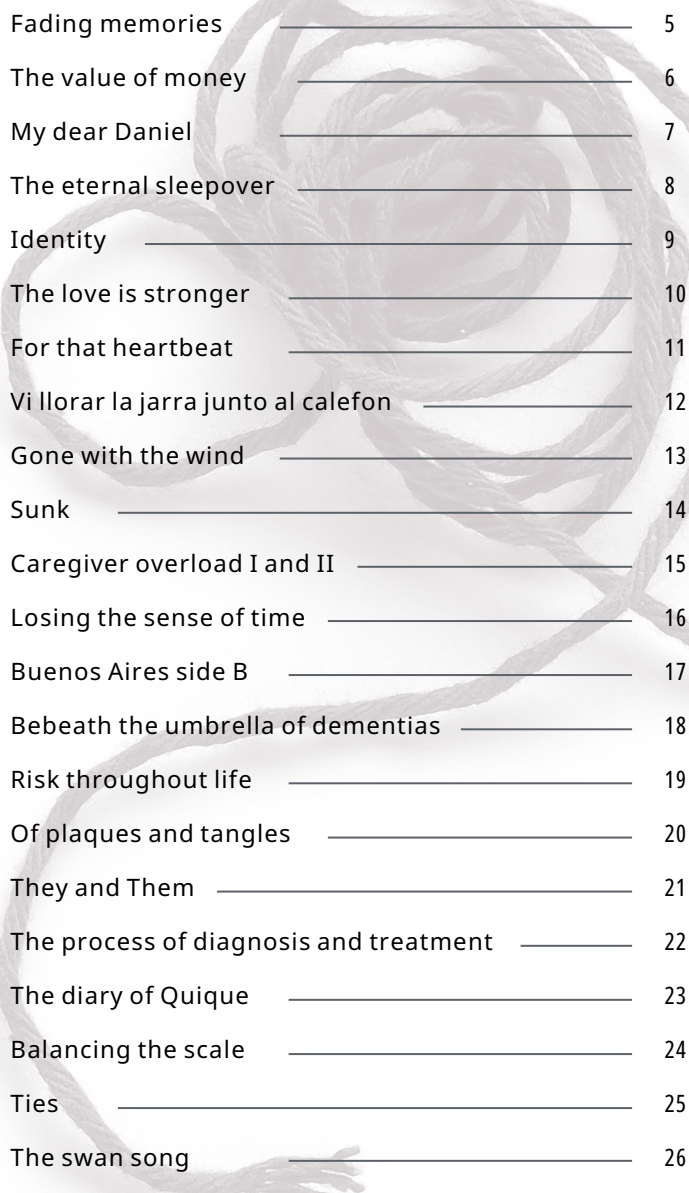


WEAVING MEMORIES

In this space, you can also see the bodily poetry that opens and closes this exhibition. It was performed by the artist Aku Menditeguy, who also wrote the text in collaboration with Felicitas Martínez Vivot.

While each object in the exhibition has been curated academically and scientifically, their purpose is to convey information by appealing to emotion and the individuality of the observer. In order not to hinder the clear and impactful transmission of the intended message, some objects may involve minor academic inaccuracies that seep in the quest to transcend words and speak directly to the heart.

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FADING MEMORIES

Temporal Pattern of Memory Loss: First, the most recent memories fade away.

Description

Forgetting and memory problems are often the initial symptoms of Alzheimer's disease. Difficulties usually first appear in generating new memories and storing the most recent ones. Thus, the degradation of memory follows a specific temporal pattern: first, the most recent memories are lost while older memories persist. That's why we sometimes feel that the person is living in the past since they can remember distant information and forget more recent matters. They may forget the names of their children or grandchildren or even call them by the names of their parents or siblings.

This piece attempts to highlight this temporal pattern of memory loss. In this family photo, the faces of the younger members of the clan begin to disappear, showing how the people from our recent past fade from our memory, initially preserving those we knew longer, whether or not they are more significant.

Difficulties in recent memory can also occur as part of normal aging, without constituting a symptom of a disease. How do you know if forgetfulness is to be expected or if it's something to worry about? When forgetfulness affects details but not the complete memory of the event, it is usually an indicator that the forgetfulness is within the expected range for normal aging. When forgetfulness extends to the entirety of a conversation or a lived event, that indicates it's time to consult. Similarly, if forgetfulness does not prevent the person from efficiently carrying out activities, there may be no cause for concern. When they become an obstacle, when mistakes start to happen, when productivity decreases, it is an indicator that something may be wrong.

THE VALUE OF MONEY

Confusion with Calculation and Difficulties in Handling Money

Description

Simultaneously with cognitive impairment, there is an observed decline in the person's functionality, gradually losing their independence. They begin to need assistance, first with complex activities (such as managing their finances and money) but later also with simpler ones (performing household activities). As the impact on functionality progresses, there will be an observed impairment in more basic activities of daily living, such as feeding or bathing independently.

This piece seeks to connect us with the confusions that patients may experience with money. This requires them to seek assistance with their purchases, paying bills, or managing their finances.

Assisting individuals with what they need without going beyond is always good advice. Not limiting their independence in simpler activities due to errors in more complex ones. The person may not be able to perform complicated calculations but can handle reasonable amounts of money for their daily purchases. Opening accounts for them or leaving prepaid amounts at the local businesses they frequent, such as the neighborhood café or the small store where they make minor purchases, can also be helpful. Assessing what the person can still do at each moment and emphasizing that helps maintain the patient's functionality and delays deterioration.

MY DEAR DANIEL

The importance of the support network and affection for both the patient and the caregiver

Description

As the disease progresses, the patient's dependence on others for carrying out daily activities increases. Their support and care rely on a network of affections and disciplines that work together in the battle against the progression of the illness.

In that network, there are key pieces that must be protected and valued, especially the primary caregiver.

This piece was designed from objects shared by the wife of a patient who emphasized the crucial point of conveying the importance of the support network for both the patient and the primary caregiver throughout the course of the disease.

The treatment of Alzheimer's disease, as well as other dementias, is based on the collaborative efforts of various disciplines, including medicine, occupational therapy, neuropsychology, speech therapy, and arts-based therapies, among others. Each discipline may play a different role in various stages of the disease, but their interaction is only possible through the work and coordination of the patient's social network and their primary caregiver. Taking care of those who care is a fundamental aspect of dementia patient treatment.

THE ETERNAL SLEEPOVER

Temporal confusion and managing behavioral issues

Description

It was 9 in the evening. After a day of outings, songs, brief conversations, some silences, and many hugs, I prepared to put Mom to bed, as she no longer went to bed alone. Just as she had done with me many years ago in that same house, it was now my turn to accompany her and tuck her in every night.

Suddenly, as I wished her goodnight, her smile disappeared, replaced by a look of deep concern.

-What? I can't stay overnight here! My mom and my siblings must be waiting for me. I have to leave; I can't sleep away from home!

-Don't worry. I already called your mom, and she said you can stay here tonight with me.

-Really? Did she say that? Can I stay?

-Yes, dear, because she knows you're with me.

And so, that night, after tucking her in once more, Mom fell asleep, peaceful.

This piece was designed by the daughter of an Alzheimer's patient and the therapist she worked with for years. Through the narrative, the therapist proposed this work composed of a photo of her own mother sleeping on the beach, wrapped in a blanket.

The narrative is a written piece by Mónica Marinakis, the daughter of our dear Ana.

When individuals suffering from the disease are already disoriented in such basic matters, their emotions and behaviors become challenging to contain. There is no solution in confronting them with the fact that the reality they live in no longer exists; that only adds more confusion and distress. It doesn't help to tell them that they no longer live with their parents, that their parents have passed away, or that they haven't worked for years. Gently bringing the person from their reality to the new one with calmness and affection is the way.

IDENTITY

Impact of memory loss on the sense of identity

Description

This piece aims to describe how as the disease progresses and memories fade, the patient may begin to feel a certain disintegration of their identity. They are no longer the successful doctor or the uncle everyone turned to for advice. Now, they need assistance for most things they want to tackle. This awareness, when it exists, causes a lot of distress and dismay in both patients and their families.

A passport that has lost some of its information on the journey is the metaphor professionals and patients have found to illustrate this sensitive stage of the disease.

Supporting from understanding is fundamental. Guiding the patient's mind to a safe place where recognition exists is crucial. Using a song or a memory that still holds, accompanying their journey to the past through reminiscence, and then safely bringing them back to the present are strategies employed to support the patient when this disintegration of their identity emerges.

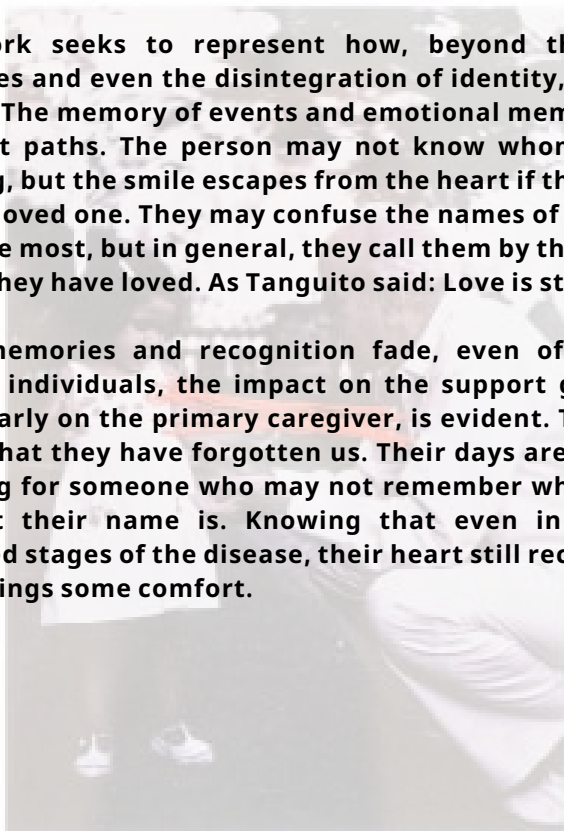
THE LOVE IS STRONGER

The persistence of affection and emotion

Description

This work seeks to represent how, beyond the loss of memories and even the disintegration of identity, affections endure. The memory of events and emotional memory follow different paths. The person may not know whom they are greeting, but the smile escapes from the heart if the one they see is a loved one. They may confuse the names of the people they love most, but in general, they call them by the names of others they have loved. As Tanguito said: Love is stronger.

When memories and recognition fade, even of the most beloved individuals, the impact on the support group, and particularly on the primary caregiver, is evident. The feeling can be that they have forgotten us. Their days are dedicated to caring for someone who may not remember who they are or what their name is. Knowing that even in the most advanced stages of the disease, their heart still recognizes us often brings some comfort.



FOR THAT HEARTBEAT

Impact on functionality and risk assessment

Description

This piece aims to illustrate another type of behavior or issue that patients may experience. A hot iron burning right where our heart is symbolizes the emotional pain that family members may feel as they witness the disease progressing, affecting the stability of the family. A shirt may be lost, but what hurts is the heart

Calculation error

Description

The functional difficulties faced by people with Alzheimer's disease are related to cognitive changes. For example, problems that may arise in calculations can affect their financial capabilities or money management, limiting their independence early on.

In this piece, created by a relative of a patient with cognitive impairment, the aim is to illustrate how even those who have expertise in a subject can make mistakes. A calculator designed for calculations shows an error."

Real objects

A cellphone from a patient with this difficulty is displayed, in which his wife programmed it so he could call her without any issue. She identified the speed-dial number with a color associated with the action. This strategy allowed the patient to maintain independent mobility for a longer period.

The third piece in the series is the information the patient carried with him in case he became disoriented on the way from where the transportation dropped him off to the care center.

VI LLORAR LA JARRA JUNTO AL CALEFÓN

Disruption of functionality and independence

Description

As the disease progresses, difficulties in carrying out everyday activities impact simpler tasks, potentially putting the person undergoing the illness at risk. It is at this moment that closer supervision is needed, often extending to caregivers during both day and night.

This piece is an object contributed by the family of a patient who placed an electric kettle on a toaster and then placed it over an open flame. Threads were added to simulate flames, but the rest of the object is real and remains in the state it was left in after the incident.

It is important to consider, throughout the different stages of the illness, what type of assistance and supervision the person needs. While preserving autonomy and functionality for as long as possible is crucial, the risk to oneself and others must be frequently assessed. It is important for the family to consult with professionals regarding the type of care and assistance the patient requires. Additionally, it is crucial that the individual feels supported in difficult decisions, such as the inclusion of a caregiver or potential institutionalization.

GONE WITH THE WIND

Difficulties in finding words: anomia

Description

As the disease progresses, other areas of the brain begin to be affected, along with various skills and functions. Even in the early stages of the disease, difficulties in finding words, known as "anomia," may become evident. Anomia often first affects words that are not frequently used such as "stethoscope" before impacting more everyday words (for example, "pencil" or "watch")

There is typically also a noticeable difficulty in recalling people's names, initially affecting the ability to bring to mind less familiar names (such as names of actors or public figures) before hindering access to the names of those closer to us.

A group of patients from INECO participated in creating this piece, under the coordination of the Speech Therapy Department. Some words identified by the patients as challenging are crossed out, attempting to illustrate the difficulty in accessing these words as identified by the patients.

Difficulty in finding words can also occur in non-pathological aging. While in normal aging, it does not impede effective communication, in Alzheimer's disease and other dementias, the difficulty becomes more pronounced, affecting the communicative function of language. There are assessments and tests that can determine whether a person's anomias exceed what is expected for their age.

If you live with someone facing this issue, you can try giving them the first syllable of the word. This phonological assistance can resolve the moment without causing the frustration that comes from providing the complete word while also stimulating the search mechanisms in our brain.

SUNK

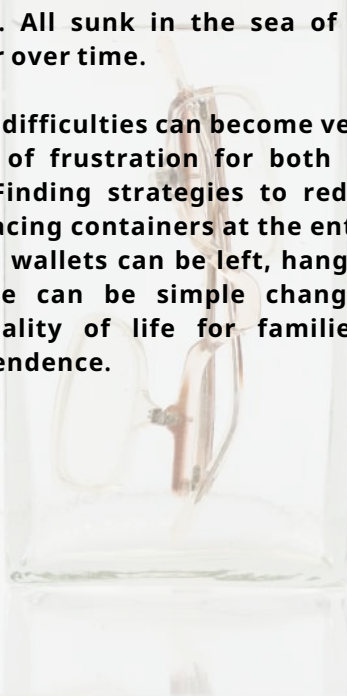
Memory Loss as the First Symptom

Description

Memory failures impact the everyday life of people suffering from the disease, initially mildly but increasingly significantly. Thus, individuals with Alzheimer's disease may start repeating the same questions, making the same comments, or losing everyday objects.

This piece was designed collaboratively by professionals and family members of Alzheimer's patients in an effort to illustrate the loss of everyday objects that patients often experience, which also affects their families. Glasses, keys, phones, money. All sunk in the sea of forgetfulness that becomes deeper over time.

These everyday difficulties can become very bothersome and generate a lot of frustration for both patients and their surroundings. Finding strategies to reduce them is often very helpful. Placing containers at the entrance of the house where keys and wallets can be left, hanging glasses around the neck—these can be simple changes that positively impact the quality of life for families, preserving the patient's independence.



CAREGIVER OVERLOAD I AND II

Caring for the Caregivers and the Economic Impact of the Disease on Families Description

In Argentina, as in many parts of the world, the care and assistance for patients with Alzheimer's disease and other dementias fall upon a family member. In most cases, it is a spouse, and in other cases, it may be the children.

Caregivers of dementia patients are predominantly women who progressively take on more responsibilities in caregiving. In many cases, what is called burnout syndrome emerges, characterized by physical and emotional exhaustion. This exhaustion can manifest as persistent fatigue, sleep problems, social isolation, and even irritability. It may also lead to the abandonment of personal interests or elevated levels of anxiety.

This piece aims to depict the burden carried by the caregiver who, beyond evident exhaustion, continues to bear their load with love and responsibility, unwilling to let go.

This piece is a tribute to all those who care for individuals with Alzheimer's disease on a daily basis. With this piece and this exhibition, we say to them, "You are not alone in this struggle."

The burden is not only emotional but also economic, and that is what the second piece of this pair aims to illustrate. The annual global cost of dementia is over 1.3 trillion dollars, and 50% of it is related to informal care.

The hours of informal care for people with dementia amount to 133 billion hours annually, equivalent to the work of 67 million full-time workers.

It is important for the caregiver to have their own support network to turn to for help. Knowing and having someone to talk to about the disease is crucial because it allows us to prepare for its different stages. Taking care of oneself and dedicating time to personal well-being is central. It is the only way to effectively care for others.

LOSING THE SENSE OF TIME

Temporal disorientation as a symptom of the illness

Description

As the disease progresses, there can be confusion regarding the time of day being experienced whether it's morning, afternoon, lunchtime, or dinner, and whether it's daytime or nighttime. All of this creates significant confusion in individuals, who may feel frustrated due to their inability to comprehend their surroundings. Behavioral issues can worsen, and aggression or isolation may even emerge.

This piece aims to illustrate the mental confusion of patients regarding time, which often extends to not knowing the exact date. Initially, they may confuse the days of the week and the months, but eventually, individuals may not be aware of the current year or the events occurring in the present.

Understanding the origins of people's reactions and the confusion they feel is the first step in providing assistance. Bringing calmness, explaining in a gentle tone, and diverting attention to things that provide comfort are often behaviors that can be beneficial.

BUENOS AIRES SIDE B

Reduplicative Paramnesia: The sensation that one's home is not their home

Description

This piece was designed by the exhibition director and a family member of a person with Alzheimer's disease. It aims to describe the belief that patients sometimes have that their home is not their home, but that they are in a house identical to theirs but located elsewhere. Academically, this condition is called "reduplicative paramnesia.

At times, something similar happens with loved ones. Patients insist that the person beside them is not their spouse but has been replaced by an imposter (Capgras syndrome).

The piece is accompanied by a real audio provided by the family of a patient who suffered from this condition. The voice has been distorted to prevent recognition, and it can be accessed through the QR code.

If you are a family member of a person with dementia exhibiting any of these symptoms, remember that it is important not to confront them. Try to redirect their attention to something else and provide reassurance.



Real audio of a patient with cognitive impairment.

BENEATH THE UMBRELLA OF DEMENTIAS

Difference between the terms Alzheimer's, dementia, senile dementia and atherosclerosis

Description

The piece was designed with the aim of clarifying certain confusions that exist around the term "dementia." This word refers to a set of diverse diseases that share the common feature of the onset of cognitive decline that progresses, eventually affecting two or more cognitive functions, impacting the individual's functional performance.

There are different types of dementias, including Alzheimer's disease, Vascular Dementia, Lewy Body Dementia, and Frontotemporal Dementia, among others. Alzheimer's disease is the most common form of dementia.

Dementias are represented in this piece under an umbrella where elements carry weight, and while they share common characteristics, they retain their distinctiveness.

A special mention in this confusion deserves the term "atherosclerosis" It is a term that refers to a condition in which a plaque composed of calcium, fat, and cholesterol accumulates in the arteries of our body. Over time, this plaque grows and hardens, narrowing the arteries and impeding the proper flow of blood. While this term was previously used incorrectly to refer to dementias, currently, those dementias resulting from this mechanism of action are termed Vascular Dementia or Mixed Dementia. Similarly, what was previously erroneously called "Senile Dementia" is now referred to as Alzheimer's Disease.

Words carry weight. The way we speak shapes the way we think. It's important that if we have doubts about the terms we use, we consult sources that help clarify them. It's also important not to use these words in derogatory colloquial language. Statements like "Are you insane?" or "Are you atherosclerotic?" may be uttered casually, but they carry significant weight for patients, their families, and all those battling against these illnesses.

RISK THROUGHOUT LIFE

Age is the primary risk factor for developing this disease



Description

This artwork, composed of three objects, aims to illustrate how the risk of developing Alzheimer's disease increases with advancing age. The burnt matches represent the number of people affected by the disease. The first piece depicts the age range from 65 to 74 years, the second from 75 to 84 years, and the third from 85 and above. We aim to emphasize how age is the most significant risk factor for developing this disease.

Just as there are risk factors that cannot be modified, there are others that can be. Adopting a healthy lifestyle, engaging in physical exercise, maintaining a balanced diet, staying socially and intellectually active, and nurturing our relationships are things we can do to reduce the risk of developing the disease.



OF PLAQUES AND TANGLES

What happens in the brain in this disease

Description

Senile plaques and neurofibrillary tangles are the neuropathological hallmarks of Alzheimer's disease.

As we age, a protein called Beta Amyloid begins to accumulate in our brains, which in turn stimulates the accumulation of another protein called Tau. For some reason still unknown, in people with Alzheimer's disease, this protein accumulates excessively, giving rise to the so-called senile plaques and neurofibrillary tangles, which are the characteristic elements in the brain discovered by Alois Alzheimer. These plaques and tangles deposit in different areas of the brain, causing neurons to die, leading to the loss of abilities related to the affected brain area. The initially affected areas are the medial temporal lobes where the hippocampi are located, structures shaped like seahorses that are responsible for the consolidation of new learning and memories.

As the disease progresses, other areas of the brain are affected, such as the parietal cortex and the frontal cortex, impacting other functions, such as language or orientation in time or space. This progressive deterioration of cognitive functions causes the person to begin losing functionality: they can no longer do things in their daily life, first complex tasks and then simpler ones.

This piece displays different cross-sections of the brain. In it, Dr. Blas Couto, a neurologist from the INECO team, highlighted the areas of the brain where the characteristic plaques and neurofibrillary tangles of Alzheimer's disease initially settle.

At present, the diagnosis of Alzheimer's disease uses neuroimaging studies that can show the degree of brain atrophy and its location. While there are studies that allow us to detect plaques and tangles in a person's brain, they are used only in specific cases. If you have doubts about the usefulness of any study, consult with a professional.

THEY AND THEM

Gender as a Risk Factor: Women Suffer from Alzheimer's Disease More Than Men

Description

This piece, composed of two objects, aims to illustrate the higher prevalence of Alzheimer's disease in women compared to men. Data shows that for every man with Alzheimer's, there are two women who suffer from it. This pattern is not observed in other dementias. The reasons for this gender difference in Alzheimer's disease are not entirely determined. Possible explanations include women living longer, hormonal, immunological, and experiential factors.

Not only do women experience Alzheimer's disease more frequently, but they also tend to be the primary caregivers for others with the condition. Easing this burden, once again placed on the shoulders of women, is the responsibility of everyone.

THE PROCESS OF DIAGNOSIS AND TREATMENT

Interdisciplinarity in Diagnosis and Treatment

Description

The process of diagnosing and treating Alzheimer's disease involves various healthcare professionals working together.

To reach a diagnosis, we rely on medical consultations and various complementary studies that can help us make an accurate diagnosis. These include neuropsychological assessments that objectively identify difficulties in memory, nuclear magnetic resonance that shows whether there are particularly affected areas in the brain, and blood tests. All these studies are interpreted by the treating physician in the context of the patient's symptoms and complement the information obtained in the interview with the patient and those around them.

The treatment of Alzheimer's disease includes both pharmacological and non-pharmacological strategies. The latter encompass occupational therapy, cognitive rehabilitation, speech therapy, and arts-based therapies.

On this desk, there is a brain nuclear magnetic resonance (MRI), a cognitive evaluation, and a requisition for a blood study. These are arranged alongside the exercise folder of a patient who suffered from an atypical form of Alzheimer's disease.

If you have concerns about your cognitive functioning or that of someone in your environment, it's important to know that there are professionals who can determine whether the changes you notice are typical or if they require a more complex diagnostic process. The sooner you seek consultation, the earlier a diagnosis can be reached, and treatment can begin, improving the prognosis of the condition.

THE DIARY OF QUIQUE

The actual diary of a patient with cognitive decline created by their family.

Description

This diary is a real object created by the family of a patient suffering from dementia. His sons and daughters created this diary to cherish their affections and memories so that he could turn to them whenever needed. As the disease progressed, his family would go through its pages with him.

Beyond therapeutic teams, the role of the network of connections in the treatment of the disease is fundamental. Family, friends, active caregivers who struggle alongside the patient make a difference, sustaining functionality for a longer time and improving the patient's quality of life.

BALANCING THE SCALE

Modifiable Risk Factors: What Can We Do to Reduce the Risk of Developing This Disease

Description

To develop Alzheimer's disease, there are non-modifiable risk factors, including age, gender (women have a higher risk), and genetics. However, these factors are accompanied by other modifiable protective factors. These include engaging in physical activity, maintaining a healthy diet, leading an intellectually and socially active life, and cultivating overall well-being.

This artwork was created in the neuropsychology department with the special collaboration of the group of patients with cognitive impairment at INECO in their Temperley headquarters. In it, a scale attempts to illustrate how there are variables that can help us prevent Alzheimer's disease by compensating for the impact of those risk factors that cannot be modified. The accumulation of small actions and behaviors can balance the scale and make a difference.

Taking care of our brain shouldn't be something we exclusively worry about in adulthood; on the contrary, the care of our mind and brain should be central throughout our entire lives. Teaching children to adopt healthy habits and sustain them over time is a variable that can help us change the future statistics of this disease.

T I E S

Love prevails over deterioration

Description

This set of 4 photos was provided by the family of a dementia patient. They aim to illustrate how bonds persist and affection sustains what would otherwise be unsustainable.

“I always knew that beyond wherever your mind was, this joining of hands connected us: your being - my being, your essence - my essence. There, you returned to being in harmony with what you always were, and that moment brought us closer, allowed us to remember, to look at each other, and to find each other in complicity. A healthy, deep, and eternal gaze. That connection was pure love, and so, without more, being together, forever together...”

Matías Ruarte - Hijo de Quique

THE SWAN SONG

Piece by the daughter of a patient depicting the evolution of the disease in her father, with her mother as the primary caregiver

Description

The Swan's Song" is a book of photographs by the photographer Flavia Schuster. Flavia is the daughter of Silvio Schuster, a patient who suffered for years from an atypical variant of Alzheimer's disease. In it, Flavia tells the love story of her parents that began in 1966 and reached 2019 when she felt he was fading away. In the midst of this love story is the tale of his care from a personal and emotional perspective.

The entire book can be viewed in the office located on this same floor.

This book was awarded by the Bob and Diane Fund and can be purchased at Potenza Libros.

<https://www.instagram.com/potenzalibros/>

TREADS OF MEMORY

Memories are etched into the body through music and art

Description

To close this exhibition, we appeal to that which withstands all the onslaughts of this disease: emotion, music... art.

In this final piece, we invite the viewer to cease being just that a viewer. We encourage them to leave something of themselves in this struggle, something they wish to tie to the threads of memory. We cannot promise that this memory won't be erased from the list of lived events, but we assure you that it will remain tied to your heart through that enduring memory, through the connection, through the emotion.

And if we, too, find ourselves lost in the sea of forgetfulness. How will we return to that footprint? Through music, through art. These not only transcend words but also resist any degradation. A song, a poem, a piece of art appeals to emotional memories that are etched into our bodies and cannot be erased.

The musical memory is preserved even in advanced stages of the disease. Songs are threaded with milestones of life, moments, people, places of belonging, that when heard again in the present, trigger a series of deeply personal emotions and memories.

The music playing on an old recorder brings memories to this space, memories that persist strongly in those who don't want to forget. The recorder was adapted by the son of a patient with cognitive decline and was a gift to a professional who attended to her. The songs playing were chosen by a group of Alzheimer's patients under the guidance of the music therapy team. The threads hanging for you to tie your memories (phrases, photos, objects you don't want to forget) were designed and constructed by our dear Pecky, the daughter of a patient who also suffered from the disease. Thank you.

It closes with what was opened. Like a circle. Memories build us, and memories sustain us. Some are lost, but others persist. You just have to know how to find the way to them, following the threads left by our memory.

NUESTRO EQUIPO



María Roca

Exhibition Director

Ph.D. in Psychology specializing in
the diagnosis and treatment of
dementias

Teresa Torralva

President of the INECO Foundation

Ph.D. in Neuroscience,
specializing in the diagnosis and
treatment of dementias

Mariana Ruarte

Psychopedagogue

Family Member of a patient with
dementia

The exhibition was also coordinated by the entire team
from the Memory Clinic at INECO

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