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"I am still the same person"

An invitation to communicate differently about Alzheimer's disease and related illnesses.



The
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TO HELP
ANTICIPATE
AND LIVE
WITH DEMENTIA


NeF

An invitation to communicate differently on Alzheimer
and similar diseases

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Colophon

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This invitation goes out to everyone who is in contact with people with Alzheimer's disease or related illnesses. It is also addressed to all of those who might speak, write, make reports or develop campaigns about these illnesses.

This invitation is the result of a broader deliberation conducted, along with other activities, by the King Baudouin Foundation. It is based upon the widely-shared conviction regarding the urgency of bringing much more nuance to the manner in which we communicate about these illnesses.

The image currently conveyed regarding Alzheimer's and related conditions does much harm to many people, and first and foremost to those who have the illness. This is unacceptable.



Foreword

EFID – The European Foundations’ Initiative on Dementia- was born of the desire shared by several foundations across Europe to fight the stigmatization around dementia and work towards changing the societal perception of the condition, through an awareness-raising campaign and the support of local projects.

When one of the EFID members, the King Baudouin Foundation, presented its work on the frames and counter frames related to dementia, the group felt it was worthwhile investing in disseminating across the board the learning and recommendations that stemmed from this analysis. Although the research was carried on in Belgium, we are convinced that it can apply to all of Europe.

As the title of this leaflet indicates, we wish to invite everyone to communicate differently about the disease and to do so, we provide new perspectives and propose a shift of mind-set to stay connected with all “citizens with dementia”.

As EFID foundations we stand ready to invest in time to make this shift happen. Throughout Europe we can expect to live longer and the population that will live with the disease will increase, so we need to be able to enhance our care and support for them.

Ken Logue- EFID Chair
Programme Executive, The Atlantic Philanthropies

EFID includes the following partners: The Atlantic Philanthropies, the Fondation Médéric Alzheimer, the King Baudouin Foundation and the Robert Bosch Stiftung

More than an illness

A serious affection...

« It's a shock the first times when you no longer know how to do something: when you can't do up your shoelaces or your buttons... Or when the letter comes from the tax man that you can't understand, the errors you make while driving, or the first time that you lose your way in a familiar place, ... These are the memories that have been traumatically engraved in my failing memory, and which often come to mind.»

An Alzheimer's patient

We must not pull a veil over this: Alzheimer's disease – and related conditions – is a serious and, up to now, irreversible illness that affects the brain. It can cause changes in behaviour and always brings about a decline in intellectual functions: memory loss, problems of orientation in time and space, impairment of judgement, the progressive loss of language and the capacity to carry out everyday jobs, etc. For most of those affected, several years pass by before reaching a stage considered to be 'severe', and then a fatal outcome. It is an illness that affects principally, but not only, the elderly. Given our increasing life expectancy and aging population, the problem posed by these illnesses will only increase. So much for the basic facts...

... but also a social construction...

"The stigmatization, the taboos, the isolation and frustration that result from a feeling of incomprehension are not physical symptoms of Alzheimer's disease, but rather the perception that society has of the illness."

Baldwin Van Gorp and Tom Vercruysse, *Framing and reframing: a different way of communicating about Alzheimer's disease*, King Baudouin Foundation, 2011

Alzheimer's is not only a disease; it is also a social issue. We speak about it among ourselves, we read articles and books about it and we watch reports on Alzheimer's. There are whole Internet sites devoted to it. It provides the dramatic framework for films. Awareness campaigns are launched. In short, more and more is communicated about Alzheimer's disease. Within such communication, however, various choices, opinions and values are hidden.

... with radical consequences

"I wanted to attend an annual conference for carers, but I was refused admission. Because I had dementia. That triggered something in me and I said to myself, 'This is not right! 'And a year later, our working group was set up and I was able to participate in the selfsame congress... as an officially-invited speaker!"

James McKillop, Founder member of the Scottish Dementia Working Group

Society has a certain image of Alzheimer's disease. It is no use denying that this image is horribly negative. Those with the disease are only viewed through the prism of their illness, and this is often reduced to the image of its last and most tragic phases. In reality, however, this illness develops slowly: between the moment when it is diagnosed and the terminal phase, there may be years of development. Moreover, people with the illness only rarely have the opportunity to express their thoughts and feelings about it: there is communication *about* them, but only rarely *with* them. The individual disappears behind the illness.

This unilaterally negative image affects the quality of life of the sufferers and of those close to them. It influences the attitude of all of those with whom they are in contact and this in turn affects their own life. Alzheimer's disease is one that causes great anxiety, unease and taboos. Sociological studies confirm that all of these negative stereotypes end up by being assimilated into the image that the sick person has of him- or herself and his/her own identity: 'Yes, I am going downhill' or 'Yes, I have become a burden to my family'. The sick person then becomes even more difficult to support; the isolation of both the patient and the family is accentuated. The vicious circle has begun.

Negative stereotypes reduce the quality of life

"I'm Sylvia. I was Sylvia before the diagnosis and I'm still Sylvia after the diagnosis. I'm still the same person. Treat me in the same way. Speak to me like you've always done. Include me in conversation like you used to do."

The negative impact of the image of Alzheimer's disease on the quality of life of those with the illness is the main reason behind this invitation to nuance the way in which we communicate regarding this illness.

Here are a few simple examples taken from everyday life:

- *"I asked the oculist if I could take my mother to see him; he asked me if she could still explain what she would see. We then spoke to the team in the home, but they decided it wasn't worth it because she couldn't explain things properly."* A recent study showed that people with Alzheimer's are often visually impaired or have hearing difficulties, because people 'forget' to correct their vision or provide hearing aids for them. They are no longer seen as elderly people with dementia; we forget that they too might simply be suffering from reduced vision or hearing. Sometimes too, real depression may set in which is neither diagnosed nor treated and yet it is not because one is suffering from Alzheimer's that one cannot have other health worries, be they of a physical or a psychological nature.

- Moving into a care home is a difficult decision to take. Often, however, the opinion of those most concerned is not even asked for: *"In any case, he/she wouldn't understand."* A recent study revealed that less than half of the care homes in France worried about providing information for their residents. Yet this is a question of respect for a person's autonomy.

- The exaggeratedly negative image that surrounds Alzheimer's disease and related conditions – *"It's not worthwhile, in any case they forget everything!"* – is such that it discourages those likely to help from the very beginning: *"I should never have told my friends that I had Alzheimer's disease. I thought I'd be able to count on them but, quite to the contrary, they immediately became more and more distant from me."*

Six fundamental values

One does not communicate in a vacuum. There is always a context, a target group, an angle of approach, an objective, values, prejudices and underlying conceptions... Communicating always involves favouring, among a multitude of possibilities, one or the other perspective, one or the other facet of reality. Communicating is about making choices (even if these are sometimes subconscious).

As far as Alzheimer's disease is concerned, the EFID foundations believe that there are six values which are essential to keep in mind when making such choices:

1. Dare to speak about **all aspects of the illness**; re-frame to their correct importance the deficiencies that accompany the illness's development; let people express their feelings of powerlessness, guilt, shame, anger, incomprehension and so on. Speaking enables people to share the burden.
2. **Take into consideration the various phases of the illness** because the accent is all too often placed on the terminal phase. It is from this that the persistent misunderstanding springs, whereby a person with Alzheimer's disease loses, from the very first phases, all of his/her capacities. Instead of painting the illness as a homogenous and unchanging totality, it would be preferable to place the accent on its progressive and developmental nature.
3. Respect **the autonomy of those who are ill** by considering them as active and autonomous individuals – whilst still having an obvious vulnerability related to their illness – rather than dependent patients or incapable citizens. This will lead to more respectful support for the wishes and needs expressed by those with Alzheimer's disease.
4. Put the accent on **continuing to be a real person** despite the decline due to the illness: acknowledge the personality, the identity and the life journey of those with Alzheimer's disease. Consider them as subjects and partners, not objects of care. Refrain from reducing their disconcerting behaviour to manifestations of symptoms and instead patiently analyze their meaning. Quality of life will then become a central element and the illness can become an experience of quality (a quality of living).
5. Consider those with the illness as full citizens, with **rights, responsibilities and a social circle**, and take into account their experience in the light of these various perspectives.
6. Develop **empowerment and social inclusion**. Those with Alzheimer's disease are more than passive and dependent consumers of help and care services. They have resources that should be mobilized. The principle of inclusion implies that society is composed of all its citizens.

These values form the bedrock of a series of recommendations that were formulated in 2009, after two years' deliberation. These recommendations are addressed to people with Alzheimer's disease and their families, to political decision makers at all levels, to scientists, those working in healthcare and in the care of the elderly sector, to lawyers and justices of

the peace, society and all of its citizens. It is of no surprise that the first of these recommendations is to try to build a more nuanced image of Alzheimer’s disease.



How, in practice, can we communicate 'differently' about Alzheimer's disease?

Three Main Principles: Respect – Nuance – Knowledge

Recommendations with a sound basis

The following recommendations have not come out of nowhere. First of all, the King Baudouin Foundation (one of the EFID foundations) commissioned a scientific analysis of how we communicate today regarding Alzheimer's disease. The results of this study (set out in detail further on) were then discussed by a multidisciplinary group of specialists in communication, doctors, journalists and people concerned by the illness. Together they thought about practical ways of putting their observations into practice in the world of communication. An exercise followed by a workshop to which specialists in communication, experts and people in the sector etc. were invited. It is from all of these projects, as well as from the countless contacts and informal exchanges that accompanied them, that the findings outlined below emerged.

"WE ARE OURSELVES"

A profoundly human desire

"The world of medicine, society, culture and history do their best to convince us that we are well and truly this (Alzheimer's disease patients) and nothing else. No, we are ourselves and we must be able to remain so. We are not just people with dementia: we are also people who love, have desire and share the lives of the people who look after us."

Richard Taylor, psychologist with Alzheimer's disease

Here's some good advice: speak with the people who have this illness. Listen to them and discover their profoundly human desire to be recognized and understood. This begins with a more nuanced communication about them. Send back to them an image of themselves that is not so terrifying. Begin with the people themselves.

ALZHEIMER'S? DEMENTIA?

What the words say.

"It's an Alzheimer's", "She's demented"... Such expressions are heard here and there and are part of our everyday language. A more nuanced communication would begin by becoming aware of how we use such language. Why not say instead: "He has Alzheimer's disease" or "She has dementia"? The difference is not so great, but it is so significant!

1. RESPECT

- Letting those with the illness speak

Let those who have the illness speak. It will provide you with one of the most powerful counter-examples in relation to the current dominant image, which often makes the individual disappear behind his/her illness. Reporting what they say has a great impact among the general public.

- Respect!

Let your respect for those with Alzheimer's be obvious in what you have to say. This is an ethical question. A simple little trick: just imagine that it is you who has Alzheimer's disease and that it is you who is being spoken about...

- Not just failures

This illness cannot simply be summed up as losses and failures, as apathy and passivity. Point out also what these people are still capable of doing or what they enjoy doing.

- Biography and personality

Never forget that people with Alzheimer's disease also have their own life story, their own personality and character. Enable these aspects to be expressed too; do not reduce those with the disease to being nothing more than the illness.

- Openness

Give things their proper name. This too is a question of respect.

2. NUANCE

- **Go beyond the clichés**

Be aware of the different stages of the illness, of the nuances in its development, rather than focusing on its most dramatic aspects or the terminal phases. There are moments of happiness and there is a place for humour too! Relationships between parents and their children, for instance, can become deeper and more intense.

- **A multifaceted reality**

Show the reality in all of its dimensions by showing those with the illness in all their diversity. There is no typical Alzheimer's disease patient. Here is just one statistic: 70% of these people live at home.

- **A multicultural population**

Diversity is also societal and multicultural. Alzheimer's disease affects not only those born in this country. Just as it also affects younger people.

- **As a family**

Let people see that those with Alzheimer's disease also have a family circle and enjoy family and social life. Show that relationships and emotions often endure and that there is a place for tenderness. Demonstrate that young children, for example, have fewer prejudices than adults regarding this illness. And in so doing, you will also highlight the role of family carers.

- **The other extreme**

Beware of falling into the other extreme by presenting dementia as a marvellous world where everyone is beautiful and kind... We have to must remain realistic: the illness is still a tragedy.

3. KNOWLEDGE

- **Know what you are speaking about**

In order to communicate about Alzheimer's disease, you need to know a minimum about the subject. Find out about recent discoveries and current statistics before delivering a message. Knowledge about the condition is constantly expanding.

- **Facts rather than dramas**

Anxiety, alarmism and defeatism are the elements that colour discussions about Alzheimer's disease today. Check out the facts, figures and percentages. And give your target the option of finding out more for themselves, of investigating further.

- **Fight prejudice**

If you knowingly communicate, you will soon find out how prejudices persist! You should not hesitate to fight them one at a time!

- **Show where you stand**

One of the ways in which you can show your own position regarding dementia is by being aware of existing frames and counter-frames (see p.10). Be careful about the metaphors and images that you use.

- **Changes are taking place**

It is important to know that, as much in Belgium as at international level, more and more original initiatives are taking shape (in, for instance, MR-MRS, the CPAS, towns and communes), so as to put into practice the basic values for those with dementia, namely retaining their autonomy and being included in society, as well as informing the general public.

And If You Are Still Not Convinced...

1. **Why should I not be able to show elderly people playing childlike games when that is the reality?**

Because with such images you transmit a message about how people with dementia *seem* to be. In reality you are showing a *way of dealing* with those with dementia that is a choice of the outside world. This is not the same thing.

2. **Why can't I show apathetic-looking people in an armchair being fed with a spoon, if that is the reality of the illness?**

Because showing *only* images such as these portrays only a limited aspect of the problem. People who only see this kind of image (or worse, who grow up with such images) have a narrow and frightened image of people with dementia.

3. **Why can't I show people in embarrassing situations when this is the reality?**

Because we all sometimes find ourselves in embarrassing situations. Imagine that this is you (or someone in your family or your parents) and that an image like this is broadcast or printed without your approval... Once more, it is a question of respect.

4. I show dementia in a shocking way to provoke the public to act. To raise awareness of the fact that more resources are needed.

The best thing we can do, working together as citizens, is to break down the taboos surrounding this illness. This is much more important than campaigns and fundraising. Showing shocking images reinforces the taboos by painting such a frightening picture.

5. If you want to gloss over the drama of dementia.

Alzheimer's disease is an incurable illness and a terrible ordeal for the person who has the disease and the family. It causes great distress. This must be known. However, the illness is also a social construction. We must not increase the burden of those who suffer by cultivating taboos and stigmatization that will only serve to increase their frustrations and make their isolation worse.

6. You want to curtail freedom of speech

We want to respect everyone's rights and values. And we believe that the negative stereotypes regarding Alzheimer's disease erode the quality of life of people with the disease. We must be aware of this. This is the message contained in these pages.

BENEFICIAL OUTBURSTS OF ANGER

"In recent years, the context surrounding Alzheimer's disease has changed significantly, thanks firstly to the voice of those who have been diagnosed with the disease and sometimes to their highly beneficial outbursts of anger in the media or on the Internet. Likewise the many initiatives undertaken by professionals who support them on a daily basis and fight the segregation to which they are subjected contribute to the development of ideas and practices in care and support."

Fondation Médéric Alzheimer, *Guide repères*, 2010

How do we communicate about Alzheimer's disease?

Frames and counter-frames

How do we speak today about this reality called 'Alzheimer's disease', of 'people with dementia'? What are the (subconscious) choices set out when we communicate about these subjects? What are our shared views, what is our 'collective conscience' regarding Alzheimer's disease?

We have already mentioned that we always communicate from a particular angle, and against a background of implicit values. We also quite naturally seek to share our perspective with others, so that they adopt the same vision of reality as ours. This is how the *frames* are created, which are a sort of 'framework of thoughts', perspectives that are shared by many within society, usually involuntarily and implicitly. In the field of communication sciences, *frames* are the object of codified research.

In the following pages, we will set out the results of the analysis conducted at the request of the King Baudouin Foundation regarding the **frames** in operation regarding Alzheimer's disease. There are six of them.

For each of the designated frames, the researchers identified a **counter-frame**, an alternative way of considering the same reality.

You can check which frames you most often call upon in your own imagination and most probably transmit in your speech and communication.

An example of framing

GMOs: FRANKENSTEIN MONSTER OR A BETTER WORLD?

As everyone knows, genetically modified organisms are seen very differently. In other words, there are very different frames in relation to the subject:

* Adversaries believe that GMOs represent an irresponsible risk because we do not yet know the possible consequences of their use. Such a position can be likened to the image of Frankenstein, a monster created by man, recklessly playing God.

* The partisans highlight the concept of 'scientific progress', which will enable us to develop more resistant plants and solve the problem of hunger in the world. Seen in this light, GMOs represent a step towards a perfect world.

One can similarly approach any subject from different perspectives, in function of one's basic convictions and the objectives one is seeking to fulfil.



ABSURD?

* For many people, the interpretation of *frames* is somewhat disturbing, absurd. This is linked to the difficulty we all have in observing reality from an angle that is different from the one we habitually use. Yet these frames come from an analysis of our cultural environment. The purpose of the exercise is thus to become aware of the frames we favour and the values that we promote as a result.

* It is also important to understand that frames are not a question of right or wrong. Each frame comprises a part of reality, but none covers all the aspects of a phenomenon such as dementia. Reality always shows the very different course that a discussion can take.

* A last reminder about the *raison d'être* of these pages: the image that we ourselves hold of Alzheimer's disease can exert an influence – positive or negative – on the quality of life of the people who suffer from the disease.

Six frames

1. The loss of what makes us human

In this frame, which is widespread in our society, Alzheimer's disease is seen as a disease that deprives the human being of its spirit and thus of what makes our human essence and identity. This vision of the human being corresponds to the classic dual approach in which body and soul are separate and the soul is superior, a uniquely human characteristic: 'I think, therefore I am'. It is within this vision, that the request for euthanasia as a 'solution' should be seen, the final triumph of the spirit.

As part of this frame, metaphors such as 'a gaping black hole', 'a fatal mental short-circuit', 'a plant' and 'a living dead' are often used.

2. The invader

Here, the illness is seen as an insidious invader who takes possession of a person's life and eats away at the memory. In this instance, one has to fight the invader (the illness).

This frame can be found in all of the warlike metaphors and glorifies the heroic battle against the illness, the fight against Alzheimer's.

3. Faith in all-powerful science

According to this vision, Alzheimer's disease is the result of a biological degeneration of the brain and can be described scientifically and objectively. The patient becomes a 'case' and disappears behind this or her diagnosis. Scientific research must thus find the cause of the illness and develop a preventative treatment. The hoped-for solution will come in the form of a medicine; it is for this reason that research must be supported. Compared to the other dominant frames, this is the only one to set out a future full of hope. (For those who believe in a cause and effect relationship, this frame enables some to believe that people with Alzheimer's disease are 'responsible' for their illness because of their bad lifestyle.)

Examples: 'a new advance' in research, discovering 'new risk factors', and 'how to prevent Alzheimer's disease'.

4. Fear of death

In this frame, the accent is on the end of life and (the anxiety about) death. After the diagnosis of Alzheimer's disease, life is viewed as being at an end, mourning begins and one can only await death with fear and resignation.

Examples of characteristic expression used in this frame are: 'a fatal prognosis', 'condemned to death' after which the 'ordeal' begins, 'a slow death', 'an endless goodbye', a 'long period of mourning'.

5. Role reversal

This frame places the emphasis on communication with those around the sufferer. Alzheimer's disease make those afflicted 'fall back into childhood', which results in the family being faced with situations that are commonly accepted when it is a case of children, but which generate shame when it is a question of adults and especially of one's parents. Those with the disease lose their independence and their autonomy, but they also forget their manners and their responsibilities...

Examples of expressions: 'I'm ashamed of my father', 'a second childhood', 'a process of inversed development'...

6. Giving without reciprocation

Here it is those around the sufferer who are the first victims of the illness: the family is condemned to giving a great deal without receiving anything in exchange. This arouses feelings of excessive self-sacrifice or guilt in the event that this role cannot be fulfilled.

In this frame, we observe expressions evoking burden, exhaustion, endless devotion and despair.

Six counter-frames

1. They are still real people

A person is at the same time a body, a spirit and emotions. None of these has pre-eminence over the others and losing one's intellectual capabilities does not turn us into sub-human creatures. Identity is not diluted as cognitive decline occurs: affection and emotion take over. This frame encourages us to approach those with Alzheimer's disease by exploring other means of communication and it stresses aspects such as warm physical contacts, sensory stimulation and music.

Examples of expressions used include: 'the illness never becomes greater than the person' and 'eyes shining with recognition'.

2. The strange travelling companion

You can learn to cope with Alzheimer's disease. You come upon the disease during life and you have to come to terms with it for the rest of your life. You have to learn how to deal with this invasive companion whilst maintaining as much your autonomy as possible.

This frame is seen through expressions such as 'my friend Alzheimer', 'an adventurer', 'a strange lodger in my house'.

3. Aging as a natural process

In this frame, dementia is a variant of the ageing of the brain. As such, it is not an illness and there are thus no 'patients'. We must move towards care and empathy rather than cure. Alzheimer's is merely an attempt to put a label on people for what is the natural process of aging.'

Some of the expressions used include: the illness seen as an 'inadequate social construction' and 'We must stop this endless search for the elixir of youth'.

4. Carpe diem

For those with dementia, the remainder of their lives can still hold happy moments and it is to these that we must attach importance. The message is therefore to look for happiness in the small things in life. Death is a universal fact of life.

In this frame we find expressions such as 'taking advantage of the little things in life' and 'every day is a new day'.

5. Back to childhood

People with Alzheimer's disease go back to their 'origins' and re-live the happy times of their childhood. They are liberated from the duties and responsibilities that society imposes on adults. Each in his/her turn: children become the parents of their parents.

6. An opportunity to care for people

Some of the expressions used in this counter-frame include: 'In this child, there was still the adult woman' and 'One is born a child and one dies a child.' Dementia provides people with the opportunity to care for someone unconditionally. It is a natural duty, just like that of parents to care for their children. This counter-frame accentuates physical contact, demonstrations of love and it acknowledges the real vulnerability of the person with Alzheimer's disease and the person who looks after him/her.

Here, one often finds expressions such as 'We willingly give each other cuddles', 'I am emotionally close to her' and 'the family has come together around her'.



FRAMING: GOOD TO KNOW

* The frames described here are presented as being distinctive one from the other, but in reality they are often combined. One of the most frequently observed combinations associates, for example, the frames of 'The loss of what makes us human' and 'The invader'.

In this case, Alzheimer is a robber who takes over a person's spirit ('he steals your personality', 'the spirit thief') or his or her 'deepest me'. Alzheimer may also be presented as a curse (The invader, The fear of death), but then highlights, through 'Faith in science' the importance of research.

In the following verbatim, we can see observe a combination of three frames: The invader, Faith in science and The loss of what makes us human: "Those among us who have been on the front line against dementia have never been so close to unmasking this mysterious thief who robs us of what makes us human."

* The research carried out shows that counter-frames are mainly used by those with Alzheimer's disease, their families and by some of the medical and care staff, namely those who are directly concerned by the experience of the illness. Frames, on the other hand, are found above all in the media and in public opinion. This leads to a paradox: those who have the least contact with the illness are the ones who set the tone!

* Frames are culturally determined and are thus extremely persistent. A single campaign will not change the world. Creating a more nuanced image of Alzheimer's disease is a long-term project, which must be organized at different levels: local, regional, national and international.

The scientific analysis of the frames and counter-frames was led by Baldwin van Gorp, Assistant Professor at the Centrum voor Mediacultuur en Communicatietechnologie at the K.U.Leuven, and by Tom Vercauysse.

On the basis of this framing analysis the research team developed a test campaign in collaboration with the communications agency Tramway 21. The campaign was tested among a representative sample of the population in Belgium.

The EFID initiative has been granted a European Commission label for the 'Year of Active Ageing and Solidarity between Generations 2012'.



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