



Erasmus+



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„Safeguarding the Human Rights of Older People through an Intergenerational Solidarity and Active Citizenship Approach“

ERASMUS+ Partnerschaft unter Leitung von Sage Advocacy (Irland)

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On the way to age- and dementia-friendly cities, districts and municipalities

"Being human - remaining human - with and despite the diagnosis of dementia.

Waltraud Klein Alzheimer Society Northern Rhineland-Palatinate e.V.

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Thank you for the opportunity to bring you all closer to your ageing; because the elderly of tomorrow - that is you. Take charge of your ageing today; because you will spend the rest of your life in it. Now, what do I mean by that?

- I will remind you of your own impermanence.

- You need to plan your ageing.

- You too may become confused.

- You have to take care of your elderly and at the same time ask yourself: who will take care of me when I am old and confused?

At the same time, each issue has different realities - depending on the perspective of the different actors (institutions, service providers, relatives, experts, etc).

Unknown to all of us so far is the reality of the people affected. The likelihood of experiencing it ourselves at some point is great and so I welcome you to the world of confusion - to the world of forgetfulness. The picture I am about to show you could also be your future; for . . .

Age confusion knows no nationality, no gender, no skin colour, no social affiliation, no age. Whether you are rich or poor, one thing is certain: the probability to live with this diagnosis one day is quite high. Start thinking today about how you would like to be accompanied and cared for. You can still have a say and help shape your future - about later, when you may be affected yourself.

The term "dementia" currently "neurocognitive disorders" in the "Diagnostic and Statistical Guide to Mental Disorders". This corresponds to the current state of medical knowledge. (Recognised) in the medical field - isn't it about time that we also reflect on this and draw our consequences? The term "dementia" scares us. Do you know why? It can affect any one of us - in a very important place for us: the mind and reason. Yet we live in a society that claims: Everything must be perfect. Everything must be self-determined. Everything must be done quickly . . . and forgetfulness does not fit in at all. The fear of dementia becomes a fear of life - of no longer being perceived as a human being - as a person.

The word has tremendous power - pejorative and stigmatising - it causes fear, generates defence. Decades of fear images (helplessness, spiritlessness, loss of dignity and more) are attached to it - in other words, a problematic and outdated term.

The power of words! How do words and texts unconsciously and subliminally affect people with cognitive impairment, their relatives and other people? Phrase-like, pathologising, stigmatising speech patterns and terminology need to be changed. With certain expressions, speakers have the power to consciously or unconsciously degrade the other person or certain groups of people: the demented, the care case, care degree, the care object, the elderly and the infirm. Please ask yourself: What effects do which pieces of information produce? They stand for statements, attitudes, images. Language is never neutral. Remember, medicine has already taken an important step in this direction.

An open and inclusive society needs a language in words and images that does not exclude or belittle any group. Only in this way can the focus shift from caring for the sick, the patient, to caring for the human being. All people deserve an appreciative and inviting language. But images also have power. They often have a stronger impact than the spoken/written word.

A democratic society can only be an inclusive society that offers all people and groups protection, a sense of belonging, opportunities for development and support.

It is inclusive when we no longer use this word. (Source unknown)

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In this context, a question for everyone: Does inclusive society mean - the Alzheimer's dance café, church service for people with dementia or the dementia sports group? Can separate formats, without the togetherness and the meeting of all - mean 'middle'?

Millions of people research, treat, therapise, rehabilitate, design, dance, validate, do gymnastics, sing, paint. A flood of films and books focus on medical and/or nursing aspects. It is often forgotten that confusion and forgetfulness is a very emotional issue for those affected. Therefore, here are a few quotes from people affected by confusion and forgetfulness:

The diagnosis

"From then on, it was all downhill, not so much with myself, but especially with the way everyone treated me and talked to me - or rather, talked about me. My life as a normal person was over. They treated me as if I no longer knew what I was doing, as if I was no longer good for anything". In addition to the hopelessness of being able to do anything about it, there is now also the feeling that the whole world thinks I am crazy. (Author wishes to remain anonymous)

It may be that I forget something, but since the moment of diagnosis, they have forgotten me, the person I once was: the one behind this diagnosis. (Peter Zimmermann)

We remain people like you and me until our last breath. People with feelings and needs, people who want to belong. Because only if we continue to see people will they never disappear (HumanForever).

If you only see people as a group with a diagnosis, you not only ignore everything they stand for as a person - as an individual - no, you also create a distance.

Because dementia means exclusion. Peter Wissmann puts it this way: "We all have to stop stigmatising (care case) and pathologising (dementia) people with support needs. That would be an important step to take away some of the horror of these threats". To do this, we must learn to understand the other world. Erich Schützendorf and Jürgen Datum describe in the book "Anderland entdecken, erleben, begreifen - Ein Reiseführer in die Welt von Menschen mit Demenz" (Discover, experience, understand the other world - a travel guide to the world of people with dementia), among other things, the first steps towards this: understand the other world as a different culture. Embark on a journey where you don't know exactly how it will end. Be amazed and become a guest in the other world and accept that the people who live there cannot be brought back - into our world. Welcome to another world . . . which we have to acknowledge, but which we can hardly grasp empirically, scientifically and also conceptually, and which we cannot empathise with.

We find it difficult to put ourselves in the "other" world. This world is a world crazy of time, space, person and situation. The crazy person becomes a model for us. The environment has to adapt to him - to his individualism. The confused person lives consistently with himself: often no longer knows what he is saying or doing. He goes his own way, he is the norm, he is the rule. He asks clever and unconscionable - sensible and senseless questions. Normality, rules and order are only defined from the point of view of the confused people entrusted to us - not from our understanding.

People in the world of confusion are sociable and difficult, some even quarrelsome. They are lonely and seek companionship. They also seek their money or forget that they have money or insinuate that it has been stolen from them. They tell the truth, but they define for themselves what truth is - and this truth often changes.

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People in the world of confusion have forgotten: who they are and what they have done in life, where they are, what is happening around them, who they are dealing with, what is happening, what will be. They have lost themselves. Loss of self also means no longer knowing whether I can get up now or not - what to drink or not. Confused people look for a place that accepts them in their world. This place is, among other things, the place of crazy self-determination. Otherlanders don't stick to any clock times, they tick differently, shift times, swap, consort and confuse. Times of experience and events prevail. That means: for them, time means what happens in the moment. Many of them are exclusively in the here and now, without past and without future. Therefore, it is absolutely superfluous to confront them with the current time. And we? Well, we rush through our lives with full schedules. We have forgotten the present because we live under the delusion that life consists only of a past that has been worked through and a future that needs to be worked through.

They want to wander, call, eat, laugh, sing, play, cry, but also determine, mourn or work. And they do so whenever they feel like it - regardless of time, situation and space. Now is the time to be afraid and not later . . . the person from normality thinks: no, no, now is not the time for fear, playing or mourning - but time for lunch. There is a fixed schedule for everything - fixed times and I will take care of you, your fear and sadness later. Do you notice anything? Chronological time makes our actions measurable, divisible, plannable and predictable

Otherworld is also a world of embarrassment - there is no etiquette or civilised behaviour here. Inhibition thresholds fall. Here, people say what is important, including embarrassing things. Embarrassment - no reason to blush; because daring acts are no longer taboo: eating with fingers, licking knives, exposing oneself, burping, saying things unfiltered, what they think; because they just feel like it. Even the dress code is different - he wears what he likes. Otherworld is also a world of enjoyment. Here, the world of the senses, tenderness, love, joy and tears dominates. Here, in this crazy, magical world, age confusion is not seen as a loss, but as an invitation to see the world with new, wondering eyes, free from the restrictions of conventional reality. "It is a place where love is the strongest currency, and where every moment, no matter how confusing or chaotic, is an opportunity to celebrate the beauty and wonder of life. So, in the midst of chaos and unpredictability, the people of the Realm of Confusion find joy and laughter, and discover the true magic of life, in a world where anything is possible, and where the craziest dreams can become reality." (Chat GPT).

Otherworld is also a world of wordless language: words are losing more and more meaning. The people here teach us that communication goes far beyond words. They show us that the language of the heart, spoken through gestures, looks and touches, is a universal language that everyone can understand. "In this world, where time has no linear meaning, we can witness the merging of past and present. It is a place where a smile or a touch can build a bridge to a loved one, a bridge stronger than the barriers of forgetting." (Chat GPT)

Otherworld is also a world of meaningful senselessness - for example, a folded napkin turns out to be a newspaper that someone is reading. This realisation requires that we are able to pause and observe - in our hectic tick-tock time.

This world challenges us to let go of our prejudices and expectations and instead accept people as they are, in this moment, with all their uniqueness and dignity.

Is the Otherworld not also a world in which we can learn something? Surely you are now asking yourself . . . well, what? Well here are the answers:

Confusion can remind us how important it is to live in the here and now. Someone who suddenly slows down in our fast world can be a great asset to all those who can't manage to

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slow down on their own. A slowed-down everyday life, a different perspective are not per se a deficit.

Someone who suddenly becomes more playful and emotional offers a decisive hint to all those who try to solve everything with their head and possibly fail. Feelings get priority again and are allowed to play an appropriate role. Reason and rationality only come into play sporadically. Is that so bad?

Can people from the Otherworld be a role model for all those who think they have to direct everything in life? Could it be a world that asks us: How do you actually live? What is your pace like? Always in a hurry? Always late? In the fast lane of life? What was that about proper time?

It is not the confused who are moving away from us, but we are moving further and further away from them.

All-age confusion is one of the many ways in which growing old can find expression. The first priority is not to fight this confusion but to be ready to understand that it can be part of growing old in this world. So always remember: by changing the way we think about ageing confusion, we change the story we tell about our own ageing brains. So confusion, despite its challenges, can also be a source of inspiration, a reminder that life in all its facets is precious and beautiful, and that love and compassion are the most powerful forces in the universe. Dr Manfred Lütz describes this in his book "New lunatics! - We treat the wrong ones, our problem is the normal ones: A cheerful study of the soul. Expanded and based on the latest research" thus: . . . "and at the latest then the view becomes free for this amiable and colourful other world, which is more chaotic but also more imaginative, which is more harrowing but also more existential, more sorrowful but also less cynical - than the smoothly painted generally prevailing normality.

To conclude my remarks, I would like to make a request to all of you: If at some point I find myself standing in front of the supermarket in my underwear with winter boots on my feet and a toothbrush in my hand, I would like to have fellow human beings who do not walk past me shaking their heads in amusement or even call the police.

I want people who will take me by the hand and take me home.

I wish for people who accept me as I am, in this moment, with all my uniqueness and dignity. I would like to address each and every one of you and ask you to stand up for the rights and dignity of those who need our support, give them a voice and please take a stand. Say goodbye to the old way of looking at things and the old prejudices and expectations and instead become ambassadors of a new human way of thinking. Remember: "The head is round so it can change direction".

Thank you.

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