# CLOWNING FOR PEOPLE WITH DEMENTIA AND CHILDREN WITH AUTISM

Most Significant Changes
In the Words and Pictures of Carers and Artists



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#### **LETTER TO THE READER**

"ClowNexus - Clowning Connects Us" was a project funded through the Creative Europe Programme and implemented between 2020-2023 by nine Healthcare Clowning Organisations and networks in Austria, Spain, Croatia, Hungary, Lithuania, Finland and the Netherlands. The project aimed to facilitate access to art for people with dementia and children with autism while enhancing the expertise of the European healthcare clowning sector. In ClowNexus, artists learned from experts and from each other and used the artistic tools of healthcare clowning to connect and engage with children with autism and people with dementia.

As a team of three external consultants performing the project's endline evaluation, we were privileged to be invited to trace the learning journey of all those involved, and try to uncover what changes occurred along the way, in particular for the wellbeing of children with autism and people with dementia, but also for their families, carers, and for the artists themselves.

In our own journey of discovery over several months, the more we listened, watched and discovered about ClowNexus, the more we wanted to show the impact of the project on those involved through their own words and emotions, which the analytical evaluation report could not fully capture.

While observing first hand the clown visits for people with dementia and children with autism in five countries, we collected Most Significant Change stories from carers in the institutions visited. We later added some first-person accounts from people we couldn't meet, but who shared their views of the changes brought by ClowNexus through other mediums. The stories in this publication solely reflect the opinions of those directly involved in ClowNexus. We have edited some stories for clarity, but we have not altered their meaning or tone. Quotes accompanying the stories were collected during evaluation and are presented verbatim.

We thank everyone who welcomed us with openness and sincerity into their world. Observing healthcare clowning's impact was a real privilege.

Irina, Ioana and Diana

Federal Ministry
Republic of Austria
Arts, Culture,
Civil Service and Sport



# CLOWNING FOR PEOPLE WITH DEMENTIA

### Taking time to listen

People with dementia understand what is happening to them and it makes them sad or angry. This is where the role of the clown doctors is so important, because it focuses them away from their disease. When the clowns come, I see that the people focus more on their jokes than on anything else they do during the whole day. They enjoy the individual attention they get from the clowns, because we as staff don't always have the time to listen to each story they would like to tell, but the clowns are very empathetic and soft and they listen to each person.

After the clowns leave, the people have a need to talk about the visitors they just had. They remember for a while what they did with the clowns and they talk about it with the staff.

(Social worker in dementia care home, Croatia)



### Finding the key

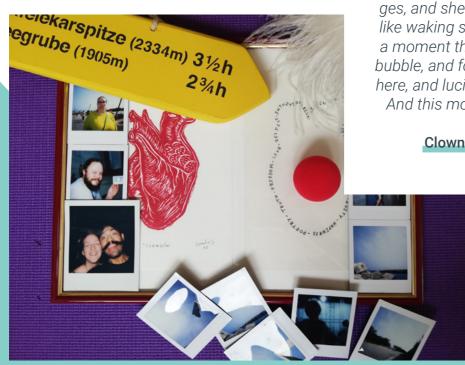
The clown doctors came extremely well prepared to the dementia ward. They knew people's biographies and this helped them a lot to connect with each person faster and to create a better relationship. One example is the event that happened on the first clown visit at the department. An older woman suffering from dementia who had been an English teacher began to experience behavioural changes. She became quiet, self-deprecating, she communicated less and less with the people around her, and she was especially distrustful of new people. During their visit, she did not pay too much attention to the people and events around her. One of the clowns came up to her and started walking with her around the ward. She spoke to her in English because she knew her biography and that turned out to be extremely good because the woman started talking to her.

During the conversation, she often laughed and at the end hugged and kissed the clown on the cheek. It was strange for us to see because she was really shy and closed with the staff.

(Occupational therapist in dementia care home, Croatia)

"This woman wasn't reacting at all, and then because I knew that she was a dean of humanities and she had a doctorate in Edgar Allan Poe, and then I came with a huge book by Poe and I started reading, and she started to touch the pages, and she said Yes. And it was like waking something up, like for a moment they come out of their bubble, and for a moment they are here, and lucid, and they are them. And this moment is important."

Clown artist, CROATIA



Franz, a resident, is supposed to put a juggling cloth back into the clown's bag. Instead of doing this, he plucks a second cloth out of his pocket with a mischievous smile. Big laughter. Franz seems happy about this reaction. Rudolf, another resident, catches a juggling cloth and instead of holding it in his hands, he puts it on his head and smiles innocently. Another great laughter.

Diary about a dementia care home visit in AUSTRIA



### Still have some fun

One of the most significant changes was that many of the older people who previously were only "present" in a very passive way, became more active when the clowns came, they sang, hummed, and joined in the activity. And when the families joined them for the clown's visit, they had so much fun together, and they watched each other have fun! Those moments were very beautiful and touching.

It gives nice experiences to the relatives too, because the relatives had very big difficulties before at home, caring for these people. If we involve them they can see more closely that there are also friendships between women, or that they feel good, that they have nice things happening with them.

(Social worker in retirement home, Hungary)

### Washing clothes all day

There are a lot of other programs to involve the elderly, but in the higher stage of dementia, only the clowns can really do something. Because it's harder to involve people in activities, but the clowns can still connect to them immediately.

There was this one activity when the clowns pretended they were washing clothes together with the residents, and then they were hanging the clothes on a rope. It was really nice for them that so many memories were coming back, from their childhood or from their motherhood with this regular activity. The next day, one of the women was telling her son who came to visit: "I have been washing clothes all day, I am so tired", but she was looking very proud too.

(Mental care worker in retirement home, Hungary)

"We have some kind of long term connection with them, which is not story based, I mean it's not based on the common memories, what happened, but based on emotional memories. That when we come in they immediately realize, even if they don't know who we are, they see us, the clown, they immediately put it together that this has happened before and it was so good. Immediately they have strong reactions like saying 'I love you, I love you'."



### Wide eyes

The most important is the connection they share, the emotions our residents experience. They are so involved in the moment, they smile so intensively, their faces light up, their eyes widen, there is so much laughter and so much love. I think our people have something there. We don't know what it is. We believe in the "feel memory" and it is something that I think clowns trigger.

The connection with our residents is so intensive, the clowns get new reactions from the residents that we didn't see before. I remember a situation where a woman who didn't speak anything at all, she said one word, two words. And the next time she didn't say anything and remained silent, it was just that single profound, magical moment between her and the clown.

(Manager of retirement home, Finland)

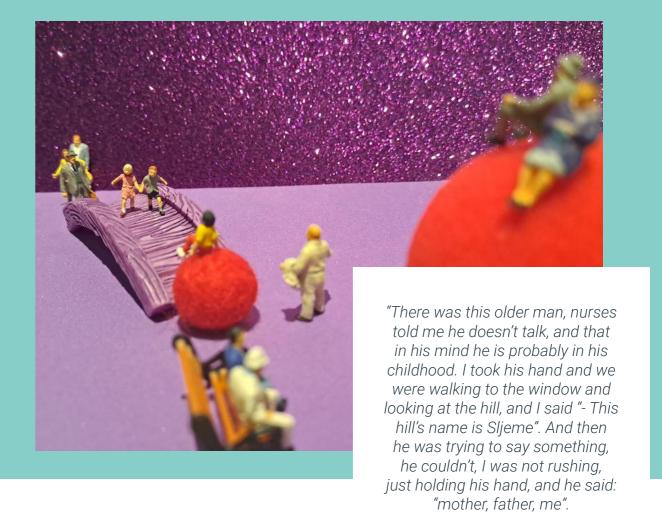
"The moment there is contact between the clown and the elderly people, something happens. There is lots of laughing and lots of love. They feel they are seen and in a safe atmosphere. Contact is very important. The elderly people don't remember my clown name and they don't remember me, but their eyes are opening when they see clowns. There is something familiar with clowns. I feel that when I have the connection, it somehow supports me".

Clown artist, FINLAND



play, an older woman with dementia stood up from the table and started to dance slowly, while her hands were still holding on to the table. She danced for about a minute, then sat back down."

Direct observation of clown visit in dementia care home in HUNGARY



Clown artist, CROATIA

### Moved by music

We had one older man in the ward who was a college teacher, and he liked to play an instrument. So when the clowns played some musical instruments, the man started to dance. But at the same time he has real problems with motorical skills, sometimes he even needs help with walking. And it was really nice for us to see that he was so relaxed and started to dance.

They have such good reactions to the clowns. Sometimes some of them don't recognize them after a while, but that is to be expected with dementia, and I think that giving them the joy in this moment is so much more important.

(Occupational therapist in dementia care home, Croatia)

### **Emotion is not lost**

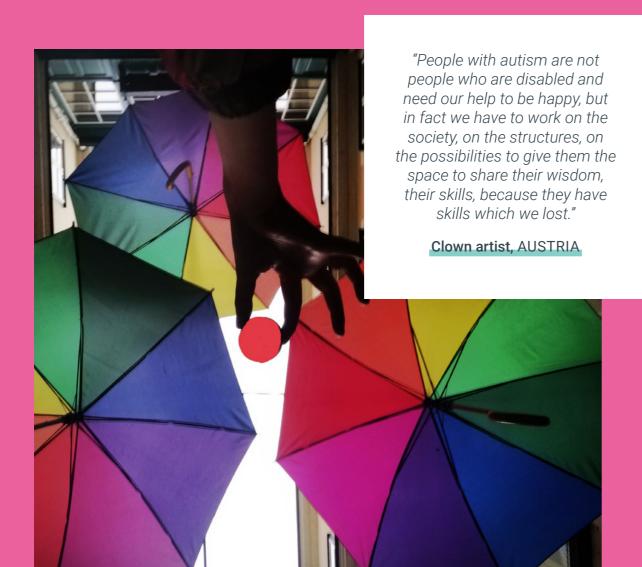
In the institution, the clowns generate a more human, cheerful, spontaneous, creative atmosphere and manage to bring us together, creating cohesion. They help us have a different vision, to prioritise other things.

There's a lot of emotion when clowns visit, and with people with dementia, the emotion is not lost. Memory is lost, language is lost, motor skills are lost, but the emotion is not lost. And clowns can connect with that emotion in a way that we, other therapists, cannot connect so easily.

We learnt from the clowns that we should laugh more. The moment you laugh, you can achieve more. Also, we learnt that if you connect through emotion and wait - no so much "go and go" and "do and do" - you can get better contact. And that helps us be better at our jobs.

(Manager of retirement home, Spain)

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# CLOWNING FOR CHILDREN WITH AUTISM



### The child can succeed

The biggest gain is that in the hospital the meeting with the clown is the only situation in which the child can succeed. In all other cases, the situation is created for us and it is stressful for them - we assess, evaluate, push them to their limits and get information out of them. Interacting with the clowns is the one thing they can genuinely enjoy during their stay here. Without the clowns, it would be too clinical, and the child would only be an object of our observation.

When I witness a clown and child coming together, it makes me so happy to know that the child gets to experience this in the world. Also, it is so important for their parents too. Because they can see their child in the best environment they can be in. The world would never change to better fit the neuro-atypical people, but it is a lot even to know that it can be a little bit different and these kinds of moments also exist for their child.

(Autism Diagnosis Nurse, Finland)

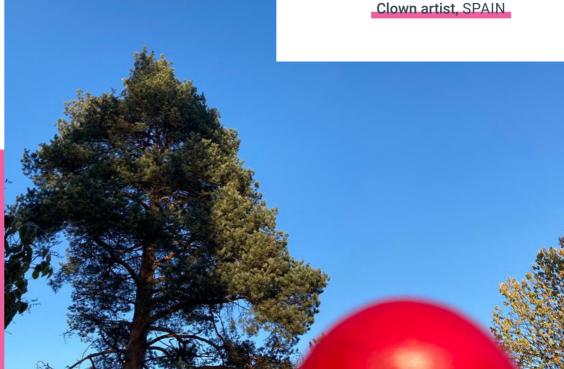
### Relief for the parents

Clowns know how to tactfully find even a small connection with a child with limited interaction abilities. This connection acts like a reset button with our patients, it helps them calm down. And this helps everyone involved: children, their parents and us, the medical staff. We can continue our examinations and observations and the children's parents can become more present in a place that can otherwise be very scary for the parents.

A very common example of these encounters: An autistic child wanders and prefers to go to the corridors rather than the playrooms. The parent follows, watching the child's movements, because the child does not react to his name, nor to the parent's voice or call. The child is not interested in the toys on offer. Although the parents try to entice the child to get to know new toys, the child seems to only enjoy aimless movement and easily gets nervous if the parent tries to limit and calm him down. In a foreign environment, this child's atypical behaviour is more emphasised than in a familiar home environment, and parents may find these situations very unpleasant and stressful. Then the hospital clown arrives in his calm probing way, giving the child a lot of space. The clown's non-verbal actions, gestures and sounds and movements may gradually attract the child's attention. Soap bubbles, music, sound toys and silk scarves often act as pleasant lures. The parents are allowed to remain on the sidelines in the role of followers and see the child gradually reacting to the clown's initiative, in which case the parents may see a delicate successful momentary encounter between the child and an adult they are not familiar with. The parents start to relax and become interested instead of concerned.

(Autism Diagnosis Nurse, Finland)

"One day, in this place where we go to the surgery room, a mother was very nervous, and she was crying because her child was slamming on the floor, screaming, and crying. And, at one point, because of us, the mother became calmer, hugged us, and we calmed her down. It's an example, but sometimes it is very important for the family."



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# **Enjoying and being enjoyed**

Watching the children play with the clowns helps us assess them. But the best thing is to be able to share what I see with the parents. That's why they're here - they want to know about their child's autistic features and development. And observing the clown interactions is a very good place to explain what I mean when I talk about autistic traits. Also, it is a very good place to share the positives.

I remember when there was only one kid with the clown and I sat with the father watching. It was their first assessment. That child had very, very limited interaction skills. But with the clown... it was amazing that he even noticed the clown that quickly - less than 5 minutes... The clown gently played the ukulele and after a few times the child started imitating the clown. The father had tears in his eyes. "I've never seen him do anything like that", he said. I had just explained to him many things about his child that were autistic traits, and it was so nice to share with him that his son was also doing something amazing.

And now the father knows that we just have to make the environment different and easier for his child. His son or her daughter is not only a project or something that we have to change, but a child who enjoys something. And that someone is enjoying the presence of the child. I think it is one of the most healing things the hospital can give to these parents, to have more strength to continue this for the rest of their lives.

(Autism Diagnosis Nurse, Finland)



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"I remember, it was really amazing to be with one child and with one family for three days. There was this little girl, during a normal examination day, but they noticed she had this rash, itching and she needed to be only in a specific room, no other room. The doctors and everybody came in there to do the tests and I was with her the whole day. I was playing with them the whole day, with the same family. It was an amazing journey. The child really liked me. We were like friends all day and the doctors and the parents were amazed as she usually was biting everything and climbing everywhere, but when I was with her I kept her engaged and she did not eat anything or climb anything. All the staff was amazed I helped in everything. It was something really special, I don't know anything like that in the hospital. There were no pauses, launches and everything was in the same room. Of course, it is extreme and once in a lifetime, but it tells how special it is to participate in family life like this. Because it is a special life having a child with autism."

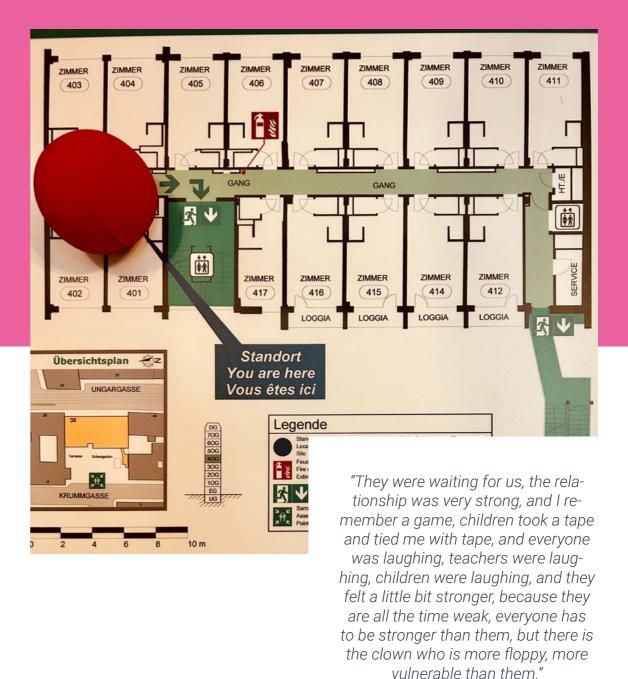
Clown artist, FINLAND

### What room to unlock?

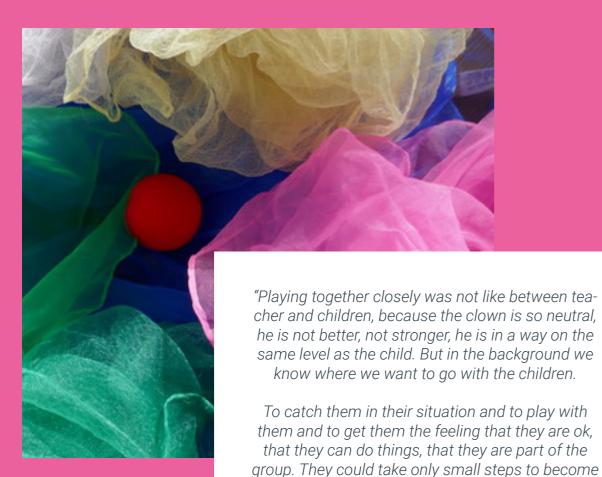
My daughter speaks very little and expresses herself mostly through facial expressions and gestures. She likes to shut herself up. And what I noticed when she started working with the clowns is that she became more alive and there are more moments when she tries to say some words. It is a great joy to hear each word in its own time! I feel very grateful because she has become more vibrant and can express her feelings and say words.

We are really grateful for all these efforts because the future will depend on how much contact we can find with her. I think any way to find that contact is important. It is like the story of Pinocchio, where there was a golden key to a room that contained some kind of treasure. It always seems to me that my daughter is like that. What room to unlock?

(Father of a girl with Autism, Lithuania)



Clown artist, LITHUANIA



Clown artist, AUSTRIA

part of a group. To have fun together and to get the feeling there's someone who sees me."

### Self-expression can shine

The most important thing about children spending time with the clowns is that a child can be whoever he or she wants to be by being here and now, in this moment. When I saw how the children instantly connected with the clown, I began to wonder what it is that clowns do that is so miraculous. I understood that clowns approach each child openly, and when the child shows the clown a certain facial expression, the clown responds similarly, showing acceptance and willingness to communicate. I started to do the same and I realised how important it is to communicate with a child as they understand it, as they are in the mood, as they are experiencing it and feeling it.

This is what impressed me the most. Working with children, art and creativity are important because they allow children to be free. Their self-expression can shine.

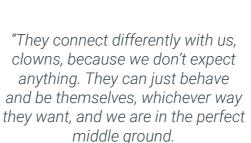
(Special education teacher, Lithuania)

### Cohesion

My group consists mostly of better-ability children. There are also two highly functioning autistic children in the class, and in their case the vocabulary expanded, the understanding of irony and humour developed, and the knowledge of forms of connection with people expanded.

Looking at the group globally, a cohesion emerged during the sessions, which is generally very difficult to achieve in other cases. In autism, social play, cooperation, listening to each other can all be affected areas, difficulties in everyday life, and these visits helped them to improve in these areas.

(Special education teacher, Hungary)



They see the mischievousness in our eyes. Still adults, but we are always ready to play, even if it's just 10 seconds of playing. And we are not just ready, but we pay attention to signs of playing. We see the opportunities and we grab them."

Clown artist, HUNGARY

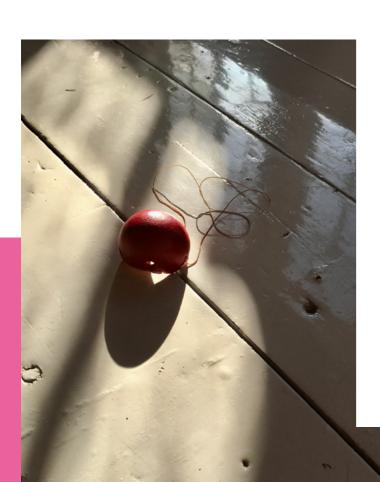


# Simple things into extraordinary ones

Clowns freed the children's emotions, as a result of which they began to communicate more with each other. The most significant thing was that the clowns were able to see each child and their peculiarities and found access to each one personally. Children became creators as the clowns created dances, songs and games with just one movement. All the children reacted and sent feedback by answering them with facial expressions, gestures or body language.

I learned to "turn" simple things into extraordinary ones, in other words, I use a lot of simple things in educational activities (scarf, ball, canister, toy, pieces of paper, etc.), I learned to present them to children in ways they understand, using as many facial expressions, gestures and body language as possible. It is becoming easier to focus students' attention and keep it longer.

(Special education teacher, Lithuania)



"From the first class I remember one boy, he was very silent, no talking, just gestures. We had about 8-10 visits to this class. At the first visit he was sitting under the table and when we tried to reach him, he made these specific movements to suggest to be left alone. So we decided to leave him under the table, in his safe space. Everytime we were coming, in our heads we had a focus on him, but physically we left him be. And with each visit he was coming little by little out from under the table, little by little smiling, and at the end of our visits, he was sitting on the table, giving high fives for the clowns."

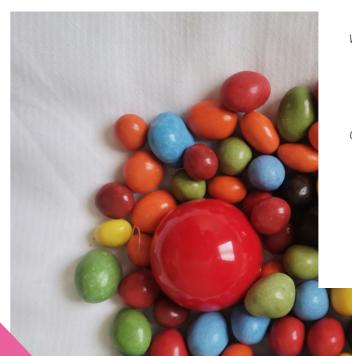
Clown artist, LITHUANIA

## Ready for new adventures

During the first visits, the children were generally more withdrawn and interacted less. They were more in the function of observers than active participants, but after a while they couldn't wait for the clowns to come visit us. The fear of the unknown decreased significantly and they were more ready for new adventures that came with the clowns.

With each visit, the clowns would remind me of how little it takes to get children to interact and how little it takes to entertain them. When you're a rehabilitator who sometimes focuses too much on goals, they come as a perfect reminder that the main goal is to have happy children in the group, and our children were certainly happy, while the clowns were running around the room. I think that an experience like this would be very valuable for the parents of children with disabilities if they could also see how little is needed for interaction.

(Special education teacher, Croatia)



"Oftentimes, when we go more than once, you can see changes - for instance this girl who was wearing noise cancelling headphones, and she was disconnected, and after a while we were together under a fabric and she was blowing us kisses. Making these connections and that they remember us when we come back, and opening up. It's interesting for me to find the code for each child, to get to them."

Clown artist, CROATIA

The endline evaluation was commissioned by RED NOSES International and undertaken by Irina Pop, Ioana Popa and Diana Buluga on behalf of Triskuel Research, between July-November 2023.

The photos were taken by the clown artists involved in the project as part of a visual storytelling component of the evaluation.

December, 2023.



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