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## **Why is there so much creativity in the study of Alzheimer's disease?**

### ***The Snoezelen approach***

Two years ago in Holland, I had the great pleasure of giving a talk on how we enable older people in France to stay in their own homes. Here I am again today talking to you. In my opinion this is mainly thanks to the creativity of Etienne Robin. Having worked together for almost 15 years in Moulins, him in the hospital and me in town, Etienne often used to say to me that I was a creator of links!...the committee of médecine de la personne have again placed their faith in me and I am going to talk to you about the ability of carers to imagine original and better solutions in the management of patients with Alzheimer's disease.

This new specialty never ceases to research new, non-pharmacological means of managing people faced with diminishing cognitive function.

That amounted to a lot of work: choosing, researching, observing cases. As the French singer, Henri Salvador said; 'To work is to be healthy!' but he then adds: 'Doing nothing maintains your health!' You will see that 'DOING NOTHING' can be a source of creativity.

In order to have a positive outcome in creativity in care, several stages are necessary:

After first having an idea, one must see where it will end, research the means of achieving it, allow space for emotion, investigate whether it is feasible and how much it costs, and finally evaluate whether it will last. The necessary prerequisite to this creative activity has to be **the cohesion at the heart of the group**, its motivating force which arises necessarily by the act of **training the members of the group**. I think of Jesus Christ: 'when he saw the crowd, he climbed the mountain. He sat down and his disciples drew near. He opened his mouth and started to teach them '(Matthew 5, 1-12a).

The cinema director Tony Raglift has said that to be creative is to invite life in. This corresponds to something which a friend who is a teacher of philosophy said to me when I asked him for the opposite of the word 'creativity'; he chose the word 'infertility'. This term is spot on, for we are faced by a so-called sterile situation; the monotony, the passivity, the routine, the rejection, notably seen in Alzheimer's disease. Some even go as far as to say that these are the living dead!

That is the choice which I made as I went regularly for six months to a ward at Moulins hospital which admits patients with dementia whom one is obliged to admit to a secure ward because of their troubled behaviour which include agitation, wandering and aggression.

I knew that Fabrice Nicolas, the manager (supervising nurse) had thought in July 2014 of the possibility of a Snoezelen space in his ward. (I am grateful to him for having allowed me to do this study by taking part in the day to day activities of his team).

I am going to present my talk in two parts :

- Getting to know patients with Alzheimer's better.
- Introducing you to the 'Snoezelen' approach, a new creative tool useful for patients and their carers.

## *1. What Alzheimer's patients can teach us*

According to Professor Louis Ploton, patients with Alzheimer's disease need to teach us alternative methods of communication. The loss of structured verbal communication leads to the phenomenon of 'attacks of thought' which translate into cries, wandering, aggression or delirium. These difficult situations lead to an unconscious distancing from those around them, and the staff who are often poorly trained focus their work on the tasks they need to achieve leaving no place at all for any initiatives the patient might have. It is not easy to react while staying rational so as not to succumb to the emotion of the moment.

This dissatisfaction of professionals is a source of exhaustion and the real cases of 'burn out'. So what are we to do to arrive at an 'emotional connection'? It would be better to mistake what the patient is trying to communicate rather than seeing him as a vegetative being having nothing left to say.

We need to restore that capacity to think in the carers while avoiding the emotional pressure to say: 'He's mad!'

By restoring the legitimacy of 'he is not mad' by 'he frightens the others', it becomes possible to talk to him without discounting him nor attacking his self-esteem. All approaches, all modifications of our point of view lie at the origin of a possible new unlocking of the status quo: the person with symptoms will thereby gain in humanity and dignity.

Louis Ploton is insistent in asking: 'What must we do?' He leaves the space to reply: 'What can we think?'

Re-reading a book published in 1969 by Rodolphe Roelens ('Introduction to psycho-pathology'), I noticed that every time it was necessary to place the patient with Alzheimer's at the centre of a three-part plan with a dramatic approach to mental illness.

Knowing his life history now becomes of prime importance; then we must get to the bottom of their current situation, that inner malaise: the feeling of emptiness, social uselessness and defensive behaviour.

In the second place, the same patients find themselves in a situation of malaise vis a vis their relationships: friends, social contacts have grown estranged. The spouse can fail to cope, just like the children who don't understand the illness. No-one visits any more (except when the family is present and loving, as in the case of Madame O. which we will see on the video). Equally, I have seen doctors who didn't want to treat them anymore, particularly in their own home!

Finally, that inner malaise and the malaise in relationships both contribute to an institutional malaise: social rejection is considerable, their role in life is annihilated and often the patient enters a

specialised unit (his last institution) with a great sense of malaise, avoiding other residents and also in many of our modern facilities almost ignoring the people caring for him.

Let us now enter a specialised ward (so-called secure) for patients with advanced dementia: Nathalie Rigaud, a sociologist, decided to stay several weeks in a ward in Lyon to live with the residents and their carers. Her book which I read in 1998 opened my eyes to this separate world when I started in geriatrics.

She understood from the start that there was one approach which predominated: it was difficult to love the demented patient not only for what he had been but also for what he had become and to take pleasure in being with him. One family said 'he is no longer one of us, he has become like all these others, a poor old thing'.

We need to acknowledge the demented patient as someone who has something to say. The theme which keeps coming back is the anguish of death, the abandonment of their nearest and dearest. Nathalie Rigaud sits one evening next to a man with dementia, who used to be a police inspector. He is thinking about his dog left all alone and says to her, 'I am terribly worried and anxious.' A nursing aide comes past, doesn't want to listen to him and says to Nathalie Rigaud; 'Would you like a herbal tea?' She behaves as though he doesn't exist..., and this gentleman replies; 'Yes please, I'd love a herbal tea!' We must not treat them as though they have no autonomy, even in our everyday dealings with them.

Even when they are no longer capable of thought, there are still their emotions which we can react to. This isn't a sub-human, this is a partner. He still feels his environment, is affected by it and communicates with it. He is aware of other people's facial expressions, both those who value him and those who think he doesn't count for anything.

Taking one example, a simple story about a fork; Nathalie Rigaud sits down next to a lady who can no longer eat mashed up meals alone (she cannot chew). On this occasion, she has a good appetite for her lunch, but eats it with the tip of her lips while glaring at Nathalie and at the spoon which she is using to feed her. Nathalie therefore suggests using a fork and this lady responds with a big smile, saying 'That's good!' Several months later Nathalie Rigaud understood why, when she invited a three year old child round: she gave him a spoon to eat his plate of chopped up spaghetti. Not very happy, the child said to her, 'Only babies eat with spoons!'

We need to talk of temporary breakdown not of loss.

Returning to the herbal tea! Nathalie is still there at 8.30 pm, with a lady who can neither eat nor drink on her own, resistant to the idea of drinking her tea with Nathalie who is gazing at her sympathetically. The nurse arrives who is responsible for putting her to bed and without looking at her says, 'It's time.' Now this lady is flustered and can't finish her herbal tea: she is taken away as though she is an inanimate thing at a time which is convenient for others.

Repeatedly, the residents express in front of her boredom, the feeling of time passing slowly, some keep their gaze fixed on the clock. Boredom saps any desires including the desire to talk or to do anything at all.

Any enjoyment derived from investing in a relationship with another was a pleasure enjoyed together and, already in 1998, it was rewarding for the carer, who said that these moments were 'the pearls of her stay'.

## 2. *The Snoezelen approach*

Before I give you the definition of the word ‘Snoezelen’ which you won’t find in a medical dictionary, allow me to start with a clinical case which will allow you to totally understand the reasoning behind this concept.

An old man had lived all his life in the country-side; he was a peasant, accustomed to a hard life and now he found himself on his own at some distance from his children. His doctor, finding him to be nearing the end of life was obliged to admit him to a retirement home.

This was in the middle of winter with each room kept at a temperature above 22 degrees. It became more and more difficult to communicate with him and he looked more and more unhappy until the day one of his daughters asked that his window be often left open; he needed to smell FRESH air.

The nursing team decided to leave his window open for long periods. In a touching response, he breathed better, seemed calmer...and creativity consisted for his carers of accepting his wishes, adapting without compromising their care, since, in the last days of his life, they pushed the bed closer to the window.

Doing whatever it took to make this man happy is the basis of the Snoezelen type approach.

The term ‘Snoezelen’ is a neologism; it corresponds to the combination of two Dutch words:

- ‘SNUFFELEN’ : sniff, feel, explore, sense
- and ‘DOEZELLEN’: doze, recover, calm down, become peaceful.

‘This word suggests an indefinable sensation of languor, of careful exploration, of calm...’ (Ad VERHEUL and Jan HULSEGGE).

In cases of people affected by Alzheimer’s disease, understanding is difficult and one can resort to stimulating the five senses; a picture, a noise, music, touch, a scent, a taste. We are not taught this at university!!!

We can introduce some humanity by communicating. Often this results in a visible result after each session, so we are told in conferences about the Snoezelen approach. The most important thing is to make the effort to communicate. That’s what makes the difference.

You need to find a calming space (18-25m<sup>2</sup>) such as a bathroom; a secure environment allows a unique relationship. With what equipment? You can have it fixed in the room or buy a mobile trolley which is well equipped with Snoezelen material; optic fibres, equipment to diffuse light, scents, music, different tactile materials...

It is impossible to know in advance how long it will last, the quality of the interaction and the moment when it seems right to stop.

Who should we do this with? Those who are difficult to communicate with verbally or who demonstrate disturbed or depressed behaviour, but also those who are approaching end of life and are suffering physically. You can include families, medical personnel or anyone who wishes to be involved.

The object of the exercise is to get to know the resident better while avoiding moments where they are unhappy; to allow the carers to know the patient as an individual (see them with new eyes), to

give back to the old person their role in life, to retrieve old memories again, thanks to water, scents, colours.

The Snoezelen ethos means that every trained carer continues to develop their creativity whatever the circumstances; even when lacking equipment, they will know how to adapt their strategies when faced with difficult patients.

Why invest so much? We have to acknowledge that it does cost a lot and justify that cost, while assessing quality of life; decreased pain and anxiety, a clear decrease in the prescription of neuroleptic drugs, marked decrease in the need to constantly be with the patient, a new energy imparted to the team's work (motivation, decrease in time off sick, feeling valued because of the training) and in the short or medium term being ready to care for the new generation of older people who will have known relaxation therapies such as sea-water (thalasso-) therapy, thermal cures, massage...

I became convinced during my 6 month attachment of the benefits of the Snoezelen approach both for patients and for the team looking after them.

The final word in terms of the spiritual realm is to tell ourselves that we are all co-creators; God left the world only partly completed and our vocation is to make joy spring forth in order to be happy ourselves.

When daring and courage become a communal approach we avoid selfishness. That is the whole idea of carer-cared for; it releases pleasure.

By creating a real focus of creativity, speech becomes freed, individual talents are put to use (one carer will be more attracted by touch or smell than another...).

If the chief of service is creative and is convinced that the team will be welded together while putting into practice the project, the fruits of this creativity will be recognised in the quality of the caring delivered by the team. As we are in Berlin, I would like to talk to you about Herbert von Karajan. He was the conductor of the Berlin Philharmonic with its 120 musicians and 120 singers. When he accepted the post he asked just one thing; 'I would like to be conductor for life.' He held the post for 24 years. When listening to him on a well-known radio programme ('radioscopy'), I reckon I have found the words for an ideal in creativity:

'For 24 years, I gave all my love, I wanted a collective harmony just like a flock of birds in the sky when they all turn together, perfection. It wasn't down to me, it was thanks to the collective genius. The art of conducting consists in knowing when to stop beating time so as not to get in the way of the orchestra.'

Let us finally think of the many who are not conductors but who have ideas. In their place of work, they need to know that they will often be ill-treated, hassled, thought ill of, for they disturb the status quo. They can't be pigeon-holed, they have to be reined in since we reproach them for working outside procedures and protocols, as said Etienne Robin!

The best approach is always to carry others with you in a new idea or project.  
To know how to propose without imposing.

I am also reminded of Nathalie Nicolas, nurse and trainer in massage. In her study on the ethos of care in the corridors of the emergency department in Moulins hospital, Nathalie plunges us into this world which we can enter in a brutal and unexpected manner; certain people dread it so much that

you hear them say; 'I hope that I won't have a night like the last one.' 'Have you found me a bed?' 'Is that where you left my mother all night?'

How can we reassure people when they are facing a long wait, a lack of facilities?  
The dignity of each human being is affected in the emergency department.

We don't have to prove any more the importance of speech, of gentle words. A bed-ridden old man who is disorientated and withdrawn, is spoken to for no more than 20 seconds per day. 'Who shows any affection to old people these days?' says Marie de Hennezel, psychologist.

Massage creates a link, it opens a non-verbal space for communication, whose quality depends on the availability and the listening skills of the therapist.

Philippe Svandra talks of the 'moral compass' which we need to have when we don't know what to do in certain very difficult cases.

Out of creativity even more creativity can emerge. All through my studies, ideas have come to me gradually, as I discovered new fields of research previously unknown to me. Our five senses are under-used in certain medical situations.

But what about those places deprived of the equipment to provide the Snoezelen approach? I wanted to throw myself in as much as my creativity as a geriatrician was concerned into the care of end of life. To dare, to suggest, to try, to accept refusal, to modify, to retrace my steps.

To create is to start with nothing. For example, an anonymous room in a retirement home with its occupant who had cancer and was nearing the end of life. This patient was despairing, rebelling, folded in on himself. When I arrived in the middle of the day he had chosen to close the blinds three quarters of the way down, we spoke only of pain, of adjusting the morphine...his unhappiness was affecting the whole team. He was becoming disagreeable, demanding, cross, one could even say odious.

One day I decided to speak to him about Snoezelen, in terms of being able to reach moments of well-being through our five senses. He listened, I took my time. The first set-back was music; as a previous music lover, he didn't want to try it, he was absolutely decided. I broached the subject of smell, and there he agreed to speak of his olfactory memories, as being very sensitive, he missed his garden and his roses. Thankfully, at the end of the consultation, he said to me: 'That might interest me'. His companion found him a cheap oil diffuser and bought some essential oils. Each week, he gave me his opinion; already we were speaking less of his pain. He found his solution; not with the diffuser but on his handkerchief. We even ended up talking of the difference between roses...

Later on, seeing that the stimulating effect of smell was becoming less, I broached with him the role of touch. Our exchange that day was amazing, I was able to enter a little into the intimate moments of a person with chronic disease who is in bed 20 hours out of 24; while smiling at me (which was already a triumph!), he said to me: 'look at my arm which is touching that towel!; In one year, I had never observed that having an indwelling urinary catheter often connected to a bag, the piping was covered by a towel; he added: 'it's like a bridge and when I pass my arm and my elbow over it the contact does me good!' smiling more and more and happy to talk to me about what he was feeling, he said to me: 'that towel isn't very good, I'm waiting for the one which is in the wash, which is much softer.'

My Snoezelen approach was immediate: 'I would like to suggest to you a well-being practitioner, Patrick Dalaudière, who can come and see you and give you a massage'. Dumbfounded, he replied; 'I will think about it.'

That encounter took place and he received regular treatments until his death. The therapist was able to be quite personal with him and here is the summary which P. Dalaudière sent me afterwards:

*'André was an intellectual, he wanted to be in control of everything and was very up and down. He knew perfectly well that the inevitable outcome was approaching but he had doubts about his cancer. He would say to me; 'If I had widespread cancer I would have died long ago, the doctors are all liars!!!' The only way to make contact with André was via his hand. I would place my hand on his, we could always talk for about 10 minutes and only after that would his hand become receptive and he would squeeze mine harder and harder. At that moment, I would start to massage one hand, and then the other and then his feet. I had to change and adapt my tactics for getting close to him each time I visited him in order to 'tame' André, which was not at all easy for me. My objective was to arrive at a relationship of 'trust'. I think that it is equally important to accompany the carers (partners) since they also suffer greatly and blame themselves as the end of life approaches'.*

### **Can one imagine creativity without doctors?**

I had never posed myself this question. But in 2015 in France, you may have heard people talk of doctor's strikes in the face of a health law which holds up to ridicule liberal medicine and the general physician.

For more than 20 years, my practice in retirement homes has enriched my life, since the older person's spirit has borne much fruit: our medical meetings have become open to other professionals; nurses, nursing aides, psychologists, directors...

If so much creativity has been able to end by improving the daily life of our older people, it is via a collective work, the project of life, the project which consists in building up...

But one morning, running into trouble with a new system (a change in computing which in our opinion had been introduced too rapidly) the nurse confided in me: 'Doctor, they don't want doctors any more, it's going to be machines which study us.'

I will leave our small groups to tell me if my anxieties are justified.

As a result of this talk, I am even more convinced that patients with Alzheimer's retain their capacity to adapt to a long life. The robustness and the relevance of their emotional functioning allow them to continue a psychological and relational existence even in an institution.

Amongst the new treatments, in the non-pharmacological domain, the Snoezelen approach has become one of the worth-while treatments for the patient and has far-reaching effects on all their carers.

My experience over six months is a lovely example of **collective creativity**. Having chosen to train the nursing aides before the qualified nurses as deliverers of the service, this was to acknowledge their close proximity to the patients, and the result was a much more motivated work-force. It allowed me to see for myself how much this tool changed the way a whole service functioned, even if everything wasn't perfect (difficulties linked to planning the service so that a Snoezelen practitioner was regularly available). One can see very well that we have reached a new horizon.

Put in other terms, Professor Ploton concluded by saying: 'What are the foundations of humanity? Is it necessary to be fully functioning cognitively, to be able to claim Mankind has dignity?'

Between October 2014 and April 2015, the difficult case of Madame O. in the ward of patients with dementia at Moulins will be at the heart of my study, with a care plan based on the Snoezelen approach.

I have known this lady since 1996. She used to be a dress-maker, who is 82 this year and comes to consult me in 2003 for minor depression and problems with her memory. In 2004, I diagnose mild dementia, well compensated in all her activities of daily living. She reassures herself by telling me that she can still perform perfectly well in the productions directed by her children. After 2006, living at home becomes difficult, she gets lost more and more often while doing her shopping, she doesn't see people as much, she doesn't telephone as much. Until 2009, her family manage to compensate for her deficiencies, but in time it gets worse, and her wandering obliges us to place her in this specialist (secure) ward.

In October 2014 when I see her again, she doesn't recognise me, can't hold a conversation and is still mobile. The nursing staff have observed that she has times during the day when she is very agitated and distressed (incessantly rubbing her hands, wandering..) and decide to put into effect a Snoezelen approach.

Here to finish with is a short video which I filmed during a Snoezelen session with Madame O. You will discover the room which allows us to individualise her care. Look at the lights, the optical column and the fibre-optics which change colour. The patient, who used to be a dress-maker is attracted to the fibres and wants to make knots out of them. The carer dims the light, the quality of the video is less good. It is the look, the attitude and the relationship created between patient and carer which is the most important. The session lasts about 30 minutes, of course, I have made cuts; look at the end how relaxed she is when the light is restored, and she even starts to sing.

#### Bibliography :

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#### **Extracts from the letter received from Madame O's daughter:**

*'I want to thank you for your videos. I was very touched to see her like this, it is always more difficult to see her in those moments which are unknown to me. My refusal to view her as ill means that I never cease to try and learn from her...the language of the barely heard...I cling to minuscule signs, that curtain which separates us is always present, but I want to keep her present.*

*I don't want that mountain of incomprehension to rise up between her and me...creating that terrible solitude. I try to invent the language of the moment whenever I am with her.*

*In your videos, the young carer slides herself into that permanent present... She is 'on the look-out'. She is in the 'here present'. A part of a phrase... a fragment of a word... a look... Mother was not silence... a waving of hands... the hands spoke to each other... caressed... calmed... the lights... the music... the zen ambiance.*

*I found Mother very calm... it was a lovely example of the language of that day... a new body language. It was not a passive event... it was a lovely present gift time...*

*I want to sincerely thank you for allowing me to share in this (with my daughter). Even if her gaze wanders... her unexpected laugh, fresh as a caress sprang out from time to time. I want to thank the whole team who accompany her every day in her infinite spiral.'*

**Evelyne**