

Psychostimulation – dementia
(lecture)
F. Meulmeester

Ladies and gentlemen,

First of all I like to thank Josep Vila and the organizing-committee to invite me here for this meeting to speak about the psychostimulation for people with dementia. I hope I can offer you some new points of view or maybe confirm you on the ideas you already have.

Now, I like to invite you to do a little experiment with me:
please concentrate on yourself and allow yourself some time to reflect on the following questions:

- * what is important for you in your life now?
- * what makes your life worth living for?
- * what gives you joy?

Just take a few moments to think about these questions.

Now imagine that you are ten years from now, that you are ten years older. How would you answer these questions now? Do the answers change or are they still the same?
What is important for you when you are ten years older?

And how would it be twenty years from now?
How do you want your life to be then? What will give you joy, what will give you sense?

How about when you are 80 or 90?
Can you imagine yourself being 80 or 90? What will be important now? What will give you sense now?

Now, just hold on to your answers, keep them somewhere in your mind, while we are looking at this theme of psychostimulation of people with dementia.

Maybe just one more question before I go on: what stimulates you? what gives you energy?
Just think of a situation or moment in which you really felt at the top of the world, that you felt: Woow!!! Como agua para chocolate!

Can you see how this situation or moment looked like? Can you feel this energy again?
Who were there or were you alone? If there were other people, what did they do?

Again, just hold on to your answers. Keep them in mind, while we are talking about psychostimulation of old people with dementia.

Now suppose I would ask you to take the hand of your neighbor and bring both your hands in the air. Up and down and up and down and up and down and up and down.
How would you feel?
Silly, isn't it?

Well let me assure you, it still feels silly when you're 80 or 90 years old.

But after being in a nursing home or a home for the elderly for say some weeks, you start to believe you like it.

At least that is what they are telling you!

Imagine, here I am: Sr. Francesco, 85 years old, living in a nursinghome and here comes this nice looking nurse of twenty years old, saying to me: 'Sr. Francesco, please raise your arms high, it will be good for you.'

And while she is raising my arms, I can see her wonderful shapes right in front of me.

'Oh my God, if I could just lay my hands on them!'

'Oh no, sr. Francesco, we don't want to do that! Raise them higher!'

'Well, maybe you want them higher, but for me they are just in the right position!'

The next day there is this occupational therapist who wants me to make nice paintings.

'It will give you joy and it will do you good.'

I hate paintings, but o.k., this girl is nice looking too and I like to watch her, so I go to her every day, look at her and make very nice paintings of her.

Unfortunately she sees what I am doing and says to me: 'Now sr. Francesco, what are we doing here? Are we a dirty old man?'

'Well, I don't know what I am, but I am very sure, that you are not an old man.!''

And so she brings me to another colleague, who does behaviour-modification.

Actually the message is: 'Please adjust this nasty old man and have him behave 'good'.

But I'm not a nasty old man, I just have my own way of living, I have my own interests.

But these twenty or thirty year old people, who are just starting up their lives, are telling me, an eighty-five year old man, how to live, what my interests should be.

Isn't that strange?

Of course, I did exaggerate a bit and of course I am not against activities with older people.

They can be very helpful and also be very pleasant to people who like to do them.

E.g. my own mother, who is over her eighties, goes to her gym-class, her dance-group, her cart-clubs and many more clubs every week and she enjoys it.

But now we come to an important issue: moving can be pleasant and also usefully when I want to do it. When I have a purpose in doing it. It is unpleasant and maybe even useless, when I am not motivated.

And so are other activities: they too can be pleasant and also usefully when I want to do them. When I have a purpose in doing them. They are boring and maybe even useless, when I don't want to do them.

Let me give you the example of mrs. E.

Every time the physiotherapist or occupational therapist tells mrs. E. to move her arms high, she refuses by saying that it hearts her too much and that she can't do this anymore.

One evening there was a program on t.v. with some kind of popgroup and by accident the sound

was very loud.

Mrs. E. got up out of her chair and started to dance, waving her arms high above her head. What we are talking about here, is the difference between intrinsic and extrinsic motivation.

Intrinsic motivation means that I am motivated from the inside.

It means that I have a purpose in doing this or that, that I have a need to do this.

Extrinsic or outside motivation means that I do something, because you want me to do it. You have a purpose. The motivation comes from the outside.

I am not saying that this is wrong; sometimes we need this outside motivation, but we must be careful with it.

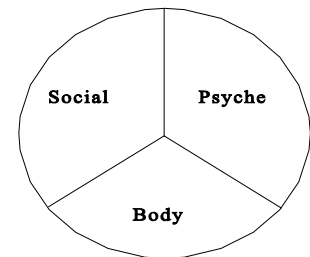
Outside motivation, having people do things, because we think it is good for them, can easily lead to dressure, like with a dog or a horse.

Now I know some people will say: 'But it is good for the health.' Yes I know, stopping smoking is also good for your health.

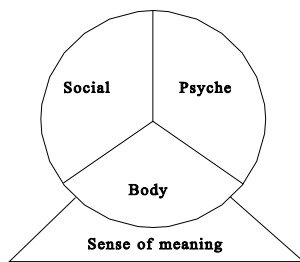
But when the doctor forbid my father to smoke when he was seventy-three years old and was smoking already for more than sixty years, it was not good for his health: he became a nasty old man, who walked away from the hospital.

Some people will say, but our activities are good for the body and for the mind and it will give them nice social contacts. You see, we have a holistic approach.

We are directed to the 'whole' of the person.



But they are not. Not completely.



They forget a very important aspect of the holistic approach. They forget the statue or the base of this tri-unity and that is the *sense of meaning*.

This 'sense of meaning' is a very important aspect: it holds the whole together and at the same time, it is a part of this whole.

Our sense of meaning gives us direction, gives us the spirit to live.

It has to do with the question: 'What makes life worth living for?'

'What makes sense in my life? What gives me joy?'

Do you remember, I asked you these questions at the beginning?

Do you remember your answers? Can you see, that many things that you do in your life, if not all, have a connection with your sense in life, with what is important to you or gives you joy?

And can you see, that when you are involved in activities that have this connection, they cost you less energy, sometimes they even give you energy!

So this is a very important thing: as long as we are involved in activities that gives us joy or that have a meaning, we don't need to be stimulated, we have enough spirit from the inside.

And this is something that also counts for old people. They too want to be involved in activities that give them meaning, that connect to their sense in life. Specially now that they are old and facing illness or facing deterioration or facing the fact that their life is ending.

And we know from people who are in the process of dying or are in a process of ending up their lives:

the less time you have, the more important is the question: What is the meaning of my life?

What purpose does it serve?

When I count my blessings and my sins, how does the scale end? Does my life have had any sense?

It is a matter of looking back and adding up the score.

It is a matter of looking into your own life-story, reading your own novel of life and try to understand the loose ends.

Also the so called 'demented' elderly are involved in this process of reading their own novel of life.

Maybe it is not so clear as with other persons, but they too are involved in a process of looking back and ending up their life.

But I think, at this point, it is important to look at these words 'demented' or 'dementia' now.

The word 'dementia' or 'dementia syndrome', now a days in Holland is used to name a cluster of symptoms that often goes together.

The word is no longer used as the name of a disease, but to name a combination of some specific symptoms.

So the 'dementia syndrome' can be found in different situations, by different causes as a result of different diseases. The moment a person shows some of the specific symptoms, he has the risk of getting the diagnose: 'dementia syndrome'.

This is an injustice!

Because not every person with these symptoms is the same. There is e.g. a big difference between a young Alzheimer patient and an old person of 85 with dementia.

To treat them both as 'demented' is not right!

The problem is the meaning of this word 'demented'.

As you will all probably know, the word 'demented' means 'without a mind'.

So the word suggests, that people who are dealing with dementia have no mind; so what they are doing makes no sense! And that is not true!

It does make sense.

Specially the very old people who we call demented are doing things that make a lot of sense.

They are busy ending up their lives, they are reading their novel of life again and meeting, confronted with old unfinished experiences again. Not always in a conscious way, but they are. They need this confrontation, it is a natural process of ending up our lives. We should not disturb them in this process but rather facilitate or support them.

Therefore it is so important to ask our self: How does our activity fit in the personal sense of meaning for this old person? Does our activity fit in his or her novel of life? Does it make sense for this person? What makes sense for this person?

Let me give you an example again:

'In a nursinghome there was an old woman, who was standing in front of the window, staring outside the whole day long.'

From our point of view we might say: this doesn't make any sense, she is standing and staring, while there actually is nothing interesting to see. She is also getting very tired and she isn't involved in any other useful activity.

We'd better have her to sit down and try to get her involved in some pleasant and useful activities.

So we go there and ask her:

- >Mrs. B., please come and sit down with me.=
- >No thank you son, I want to stay here.=
- >But mrs. B., you are standing there so long and you are so tired. Please sit down.=
- >No, I don't want to and now please go away.=
- >But we're making apple-pie. Don't you want to join us. It will make you feel good.=
- >No, now leave me alone! =

At the end of this conversations we both will be frustrated and maybe even irritated, because we did not reach each other.

But when we look at it from her point of view, when we try to get into her world, than we might say: She is standing there for such a long time. There really must be a very important reason for her, that she is doing this. Something or someone is bothering her.

So we go to this lady and ask her:

- >Excuse me mrs. B., I saw you standing here by the window and was wondering what you were doing? =
- >Oh, I am looking outside my son. =
- >Are you looking for something or someone special? =
- >Yes, I am. My husband should come home. =
- >Your husband should come home? =
- >Yes, he should be here hours ago. =
- >Oh, should he? You must be worried then? =
- >Yes, I am. I just don't understand what has happened. =
- >Are you afraid something has happened? =
- >Yes, I really am very afraid. = and then she starts to cry.

At that time we both stand there for a while, staring outside, sharing her fear and sadness in silence.

After a while she says:

>Thank you for being with me. You know, he never got home again and I did not have a chance to say goodbye.=

Afterwards I hear from a nurse, that her husband was killed in a car-accident on his way home years ago.

In this example it becomes clear that when we are only looking from our point of view, we probably would have tried to stimulate this woman to sit down and participate in one of our activities. We would try to motivate her by telling her that it would do her good.

But to this woman, it would not fit in her mind, in her sense of meaning.

She was waiting for her husband. Actually she was reliving this event day after day. It was her way of dealing with this traumatic, unfinished experience.

So we can not decide, what is important or useful for this old person. We have to dis-cover it, we have to learn it from the old person.

We have to listen to him with all our senses.

This means that any activity or any form of psycho-stimulation with an old person has to start with the will to get in touch with this person, the will to meet this old person.

Meeting means, that we don't try to put the old person in one of our models: the Feil-model, the Henderson-model, the Gordon-model, the DSM-IV-model or whatever model there is, but that we really try to see the person in who he really is, in what is important to him in his life now, in how he sees his world.

So meeting the old person means: I want to see you as you are.

It is like looking at a painting.

When we look at a painting, we can look at it from two perspectives:

1. an *analytical perspective*: then we look at the colours, what colours do we see, how is the balance between the colours, how is the balance between dark and light, what techniques did the painter use, what materials did he use, etc.?
2. There is also a more receiving perspective, a *phenomenological perspective*: then we look how this painting appears to us, how do I perceive it, how does it effect me, etc.?

From the analytical perspective, we keep at a distance: we observe, we take notice.

From the phenomenological perspective, we make contact with the painting, we get involved, we become a part of the relation 'I - painting', 'I - thou'.

Both these ways of looking have their value: we need our analytical perspective, this looking from a distance to see what is actually there, both with the painting as with the old person.

When we want to find out what parts of the person are functioning right or wrong, we have to use our analytical way of looking.

But we also need the phenomenological perspective. Because in this way we no longer keep the

distance, but we make contact and get involved with the person, get in touch with the person. We also learn to see the symbolism in the behaviour of the old person, we can get more sensitive for these symbolic aspects.

The person's novel of life starts to live and we can listen to it, perceive it, experience it and maybe even play a role in it.

Let me give you another example again:

'In another nursing home there was an old man. He worked with horses all his life. He was always busy: He raised them, trained them and sold them. It was difficult for him to get used to a living without working. So, normally he was still busy all the time. E.g. many times he walked with a chair up side down as a wheelbarrow. It gave him the feeling he was still working.

One day the weather was terrible. It rained a lot and there was this huge storm, with thunder and lightning. At that day this man was very restless: he stood in front of the window and just said repeatedly:="Oh my God, my horses. My horses."

When someone went to him, telling him that there were no horses there, he did not listen. He just repeated "Oh, my horses, oh my horses."

From an analytical perspective we might say:="This man is talking about his horses, but they are not there. He is confused and restless. Maybe we have to give him some sedative, to calm him down."

From a phenomenological perspective we might say:="This man is really worried. It looks like he is seeing something outside. Let's go to him and ask him what is going on."

So we go to him saying:

>Mr. K. You look terribly worried, what is going on?="

>Oh, my horses, my horses."

>Your horses?="

>Yes, my horses, they are drowning. They all will be dead."

>Your horses are drowning? But that is terrible for you."

>Yes it is. I will lose them all." and he starts to cry.

At this point we stand together in silence, sharing his feelings and after a while he says:

>I've lost them all, you know. All eighty. Just in that one night. I could do nothing to save them."

And then he tells me about that night in 1953, when there was this huge storm and rain and a part of Holland was drowned by the sea. Many people lost their houses and everything they had. In this night he lost all his horses. And every time there is such a bad weather Mr. K. relives this night.

When we were only using our analytical way of looking with Mr. K., we probably would have tried to stimulate him too, to sit down and participate in one of our activities.

But to this man, it would not fit, it did not make sense. He too is dealing with a traumatic, unfinished experience.

So when I want to make sense to Mrs. B. or to Mr. K., I first have to go into their world and try to

meet them in where they are.

This does not mean that I have to say or pretend that the husband is still alive or that the horses are actually there, because deep inside they may also know that this all happened in the past.

It is like with a patient with cancer, who knows that he has cancer and he maybe will die of this illness. Sometimes these patients also deny their situation, just to be able to handle it.

It has to do with the difference between *facts and feelings*, also between *facts* and *symbols*.

On the level of facts we can say: >Listen, this woman lives in a nursinghome and her husband is dead.= or >There are no horses outside, this man has nothing to worry about.=

On the level of feelings, it is different. On this level we can see:

>These people are reliving old losses, because maybe they were not able to face them before or they were not able to express before.

Something in the here-and-now reminded them of these old unfinished experiences.'

This is the same with symbols: words can be like symbols, with several different meanings.

Lets look at the sentence 'I want to go home now.'

On the level of the facts, we can say: 'You can't go home. You live here.'

On the level of the symbol, this same sentence can have completely different meanings:

< in the beginning it can mean: I don't want to stay here. I don't belong here. I am not crazy!

< in a later phase it can mean: I don't feel comfortable here, I am looking for some warmth and containment like I used to have at home.

< in the proces of dying, it can mean 'I want to die. I want to go to where I came from.'

So you see, just one sentence, but several meanings.

We will not always be able to understand the meaning or the reason behind the words or behind the behaviour of a person.

More important is, that we believe there is a meaning, there is a reason.

We also can=t solve the problems for the people, although we really would like to do. But we can=t.

We can=t bring the husband back or the horses. We can not change the past!

What we can do is influence the present.

What we can do, is help them to express their feelings. One of the basic needs of all of us, is that we can share our feelings. Because when we can't share, we will withdraw and become lonely. And maybe, when these old persons get the possibility of expressing and sharing their feelings

regularly, maybe some day these feelings will bother them less.

When I started to work with demented or dis-oriented people, somewhere in the Seventies, I wrote the following thought:

*Dementia
is
at the end of your life
fighting with your past.
To fight now
what you did not fight then,
to cry out now
what you did not cry out then,
to speak out now
what you did not speak out then.*

*One big psycho-drama
with you in the leading role.*

What I wanted to do, was to meet these people in their struggle, in their joy and in their sadness. I wanted to help them to express what they needed to express.

By listening to them with empathy I noticed I could facilitate their expressing themselves.

They started to speak about their life, about what was bothering them and I discovered that many - if not all - of the things they said made sense.

At the end of the eighties some colleagues from Holland visited America and met a woman over there, who was having the same ideas and more than that she had a lot of practical experience with this way of approaching demented elderly.

She is called Naomi Feil. Naomi worked in a same way and had developed a method on this approach. She calls it the *Validation-method*.

To me and many others in Holland this Validation-method was a confirmation of what we were doing and experiencing.

The power of the Validation-method is its practical use in working with disoriented elderly: it is a way of really meeting the person, a way of helping the person to express what he/she needs to express and at the same time a method to understand what a person tries to express.

At the same time I like to state here that the Validation-method is an American method, based on the American culture and developed in American nursinghomes.

So in Holland we have integrated or transformed the Validation-method into our approaches of demented elderly.

In this way we have enriched our approaches, our attempts of meeting these old persons and have seen some really nice effects.

Let me mention just some basic effects:

1. Establishing contact.

Everybody knows these moments of not being able to make contact with the demented person. We say things or ask things and it seems that we are not getting through.

By getting more in touch with where the person is, helped the workers to make a better contact.

2. More and better contact by better understanding the old person.

Let me illustrate this by the example of Mrs. N.

Every morning Mrs. N. woke up, she was very sad and did not want to get out of her bed to wash herself. It gave a struggle every morning again: the nurses who tried to persuade her at one hand and Mrs. N. - on the other hand - resisting stronger and stronger.

One of the nurses started to change the situation: before asking her to come out of bed, she sat down on the bed and took the time to go into her sadness and helped her to express it.

Mrs. N. told her, that every morning when she was still asleep, she dreamed of her husband and her son that had both died. > ... and you know, for a moment they are with me again and then I wake up and I am all alone again.=

So the nurse helped her to express her feelings of sadness and after say 10 or 15 minutes, Mrs. N. was willing to come out of her bed and was ready to start her day.

From this day on, the nurses have the habit, that the one who is helping Mrs. N. first takes the time to make contact with Mrs. N. and when necessary helps Mrs. N. to express her feelings of grief and when the time is there, she asks Mrs. N. to come out of bed.

3. Establishing feelings of selfworth;

Let's look at me: here I am, in front of a lot of people, getting a lot of attention, the fact that I am invited, to speak here, gives me a great feeling: I must be worth something, otherwise they would not invite me, right?

Suppose I am 85 and I live in one of your homes: who of you knows of my past, of what I did, of how important I was in my country? To you I'm maybe just an old man like all the others. But I don't want to be like all the others, I want to be the old me again, I want to feel worthy again.

So every day when I enter this room where all the people are together, I clap my hands and say:

>Ladies and gentlemen, I thank you for coming to my lecture. If you permit me, I like to start now.= And then the nurses come to me and say:=Come on Sr. Francesco, sit down please. This is not your classroom, you're no longer a teacher. You're in a nursing home now. You can rest now! =

But I don't want to rest.

But then there comes this wonderful nurse, who asks me: >Sr. Francesco, I have heard you used to be a teacher. You must have been a great teacher. Can you tell me about that? =

And then I start to tell, and while I'm telling, I feel myself becoming a teacher again.

I feel my worthy again and for a moment I'm no longer just one of them, but I am >old me = again.

4. Establishing an inner rest or inner peace.

When I can express the feelings that are bothering me and there is someone listening to me, I feel relieved and there is peace inside of me.

We all know this feeling: we are all full of something and we want to tell everybody about it. We tell it a hundred times until we have it >of our chest=. We feel relieved.

Too often we are directed to >outer-peace=: we try to keep some-one on his chair, we try to keep everybody nice and quiet and cosy.

May I give you an example again: during me first day in a nursinghome - some twenty years ago - I went to see a concert with one of the ladies, mrs. K. The concert was outside in the garden.

The moment the music started mrs. K. got up out of her chair. Because I was afraid that she would walk away, get an accident, disturb other people and so on and so on, I tried to keep her on her seat. But mrs. K. resisted to sit and got up again. I was really stressed. What will other people think of me, that I am not able to keep the lady sitting. After a few minutes, I did not know what to do anymore and let her get up. Mrs. K. did not walk away, did not have an accident, did not disturb other people, she just started to dance and enjoyed the music full. It was my fear and my need for outer rest, that almost caused her an unpleasant evening, while now she was having the night of her life.

5. More satisfaction

Many workers go home every day again, with this feeling of guilt, that they could not help mrs. K. or that they did not have the time for mrs. V.

These feelings of not being able to help a person, can be very frustrating.

You did not choose your job just to wash and clean. You wanted to work with people, be of help to people.

We noticed that working in the way I just described gave much more satisfaction.

Of course we still can't solve all the problems and this is hard to accept sometimes, but we all, me and the nurses learned to see, how we can mean something to the old person by being present and available, so that this old person can share his feelings.

It has to do with letting go of the illusion, that we can solve or change the past, or that we should be able to make an eighty five year old woman happy, while she was unhappy all of her life. That is an illusion.

By letting go of these illusions, of these >shoulds=, we can be more open to what is there.

We can learn to meet the person and notice how satisfying, enriching this can be, to both of us.

This reminds me of a saying somewhere in the bible. It says: >Where two people really meet, really are together, I - God - am there too=.

In other words: when two people really have contact, something Devine happens.

So back to the question of psychostimulation for old people with dementia.

I hope, I made clear, that from my point of view all forms of psychostimulation for people with dementia have to start with our wish to really meet the person. Really wanting to see who he/she is, what he/she needs and what he/she has to give.

This asks from us, that we are willing to stand still and hold on to what is happening right here and now.

Not running around with our analyses, our models, our techniques, or our 'it's so good for you' , but willing to let go and be open to what is there to see or hear.

Nothing is more stimulating for a person, than meeting someone with whom you can share your feelings and thoughts.

So I would like to finish my contribution to this meeting by inviting you all to go out and find your own way of meeting the people in your nursinghome.

Try to be present to them with empathy and respect, so that they can share with you, what is important to them. Listen to them with all your heart and discover what makes sense to them.

And when it makes sense to them to express their feelings and thoughts, please be with them and don't overrule them with your ideas or methods.

We're dealing with old people, who have a whole life behind them.

People, demented or not, who have Wisdom, from whom we can learn.

F. Meulmeester.

Reactions are welcome at the address:

Invitation

Mathenesserlaan 185
3014 HA Rotterdam
Holanda

tel.: + 31 10 24 17 358

fax.: + 31 10 24 17 360

e-mail: fjmeul@wxs.nl