

Unconditional communication
with most severely handicapped persons
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Mr. T.'s Smile

Basic Communication with Persons with Apallic Syndrome

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Life with Apallic Syndrome

Life for persons with syndrome is radically divided in "before" and "after" - relating to the incident leading into coma and separating present life from the past. We talk about persons who after clinic and rehabilitation have not found back their way to consciously participate in the organization of their life, but have withdrawn (temporarily?) permanently to the innermost core of their vitality. Of course this happened as the consequence of the traumatizing incident - an accident, a failure in anaesthetic, a heart attack, etc. - but at the same time with the background of their life until that point and all the experiences they have made since this incident. Trying a holistic way of empathy for the concrete situation of an individual person may lead to an insight into an underlying context, demanding respect and a restraint from too forced attempts of rehabilitation.

These persons breathe, they have pulse and blood pressure, their muscles are tense or relaxed. They sleep or are awake, their eyes are open or closed. Their facial expression, sometimes even different sounds they produce trigger an emotional reaction in another person present. Often their activity is limited just to these few things, even their food intake mostly happens in a passive way via a tube, their excretion without their active participation via catheter or enema.

In our life there are six basic themes that develop during the first 18 months of non-handicapped life, and which accompany us with different importance all our life and model our personality: To experience *unity* - to secure *survival* - to experience oneself in one's body and in *motion* - to deal with the sensual *effects* of the environment, developing tastes and distastes - to control *contexts* and develop habits - to convey one's *intentions* to others and have them realized (the sensori-motor ways of life - Mall 1997). In life of persons with apallic syndrome the first two themes have become predominant again, compared to infants in their life before and early after birth.

Meeting Mr. T.

Visiting a nursing home for people with brain injuries for one week I get to know Mr. T., with nearly fifty years about my age, from non-European origin, who after an accident has fallen into coma during a visit here. Getting into contact is even more difficult, since besides his native language he probably understands Spanish only, which hardly anybody else around - including me - can speak. His family - wife and children - is not able to visit him. Only a photograph of them, which now is at the ceiling above him, and a video of his home town have been obtained.

The intention of my stay in this home is to get to know people with apallic syndrome, and to find out to which extent experiences of building contact, which I have gathered with severely and multiply handicapped people, help with these persons as well. The approach of Basic Communication I have devel-

oped in that area allows to create situations of communication and mutual exchange without any pre-conditions on the side of the handicapped partner (Mall 1987 u. 1998).

Mr. T. takes up food through a PEG-probe through his abdomen. He frequently seems to suffer from winds, he needs extensive help to empty his bowels. He spends much time in bed, where he periodically is turned to lie on his other side. His legs mostly are abducted, as a consequence of contractions he cannot stretch them out anymore. his hands usually are held folded sideways in a spastic way with arms flexed in front of his chest. He participates in life in the nursing home, taken in his wheelchair to the living room once a day, also taking part in a group where music is made or stories are read loud. When weather is good he sits on the terrace. When sitting in his wheelchair for a longer period, his body posture, facial expression, and sounds he makes lead to the impression that he feels uneasy, in spite of the nurses' attempts to optimise his position. The staff frequently talks to him, include him in their conversation, and in general take care to deal with him in a respectful and good-humoured way. A volunteer regularly comes to take him for a walk in the wheelchair.

In the afternoon of my first day there I meet Mr. T. for the first time. I stay at the right side of his bed, he has his eyes slightly open. I greet him, introduce myself, try to express the situation in my words, no matter how much he understands. I put my hand on his, stroke with my palms from both of his shoulders all the way down his arms beyond his fingertips, create with my hands a slight vibration in his body. Both, the stroking and the vibration, I try to do while he is breathing out, repeating it a few times, then leaving it. I take his arm and try to stretch it with gentle movements, synchronous to his breathing out. His arm becomes softer, he lets me stretch it nearly all the way. His hand remains nearly closed. His breath goes in a slow rhythm, in between he stops or sighs. I take care to behave in a very calm way, as well as to be very aware of myself. I pause now and then, observing Mr. T.'s reactions. While I am with him, his facial expression seems to open up, his lips move slightly. After a while I change to his left side, try to turn his head to this side and then to stretch his left arm also, which does not work out as well. After about 30 minutes I say good-bye.

The next morning I make an attempt on another encounter. After greeting him, I try to find out a way to come to sit behind Mr. T., without causing displeasure and increased tension, which succeeds after my second try. Finally I sit behind him on his bed, his head resting on my belly. For myself I take great care to find a relaxing sitting position as well, supported by the upright head of the bed and some pillows. Now I can concentrate myself on Mr. T. again. I observe every impulse he shows, especially the way he is breathing, this being the most active behaviour he shows. I swing into the rhythm of his breath, my moving abdomen reflecting to him his own breathing out, sometimes underlined by a soft humming or other vocal sound. My hands stroke his arms again, trying to stretch them out, to open up his body posture- Again, Mr. T. is breathing in an even and calm rhythm. Today his left arm can better be relaxed as the day before, he goes along better with my trying to open up the way he holds his arm and hand. In between he shows signs of fright when I set in with a new movement. Later on he suddenly sighs deeply; I understand it as a sign it is enough for him this time, and so I start to withdraw. - This kind of encounter I repeat twice a day over this week, mostly in a similar sequence. I become more trained in finding a good position together with Mr. T. Members of the staff watching me with Mr. T. express that Mr. T. clearly seems to feel well during my encounter with him. After I leave his body posture remains more open than before for quite a while, they tell me.

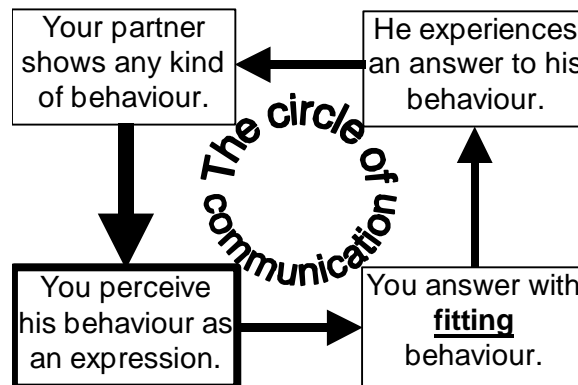
One day I find Mr. T. sitting in his wheelchair on the terrace. After greeting him I stand behind him, take away the neck rest of his wheelchair and let him lean his head against my belly, again reflecting to him the rhythm of his breath by the movement of my abdomen. I stroke over his shoulders and arms down to his hands during our breathing out, transmit humming, other sounds and slight vibration. His neck's tension decreases clearly, he lets me turn his head out of its leftward turned position towards the middle so that finally I can even take away my arm supporting his head.

Later on, after pausing and putting the headrest back into place, I stand in front of him, hold his lower legs trying to stretch his legs. Mr. T. reacts with an increase of tension, so I let go again. It works out better, when I apply counter pressure at his knee and then try to stretch his knee joint a little. Mr. T.'s facial expression shows more awareness, he opens up his eyes. When tension increases in his leg I let go, when it becomes softer I gently try to stretch it again. Later I take his hands, pull a little at his arms - still synchronous with the rhythm of his breath - then place his lower arms and hands on the armrests of his wheelchair. He tolerates this, even lets his arms stay there, when I say good bye to him.

The afternoon of the fourth day, the day before the last, again I sit behind him on his bed. When I have come to see him, Mr. T. has been positioned turned to the right, his eyes are open, arms and hands held in a spastic angle. By now I succeed much easier to find a comfortable position with Mr. T. leaning against me. Soon his breath flows in a fine even rhythm in harmony with mine, he closes his eyes, I can carefully move his right arm away from his body and position it sideways beside my leg. His left arm cannot be stretched as easily, but I can open it up a little, too. A nurse comes into the room. Seeing us she mentions she never had seen Mr. T. in such a relaxed state. After about 30 minutes I notice that he opens up his eyes. His rhythm of breath changes, becomes more varied. I feel a twitch going through his body that makes me think of weeping. Then his breath calms down again, his eyes close. When I withdraw myself after a while I mean to hear him uttering a sound of annoyance, but his body posture remains open. - Afterwards when I re-watch the encounter on video I am overwhelmed: Where I have felt some unrest in Mr. T. a broad open smile crossed his face!

It is all communication!

"It is impossible not to communicate." Watzlawicks statement is commonly accepted by now. It is easily stated, but its consequences are often ignored. There are no persons unable to communicate, everybody expresses himself, exerts influence on his environment. The critical point is if there is somebody who lets himself be influenced, who notices this expression and answers it in a meaningful way, i.e. that his partner feels this answer as matching his behaviour (Mall 1993).



Communication sets on with my decision to perceive (to take as truth is the literal translation of the German word *wahrnehmen*) as an *expression*, to let myself be *impressed* by him, and to answer in a matching way.

Communication begins with my decision to perceive another person's behaviour as *expressive* behaviour, to let myself be *impressed* by it, and to answer it with a *matching* behaviour. The same happens to the newborn infant whose mother naturally perceives his first cry as expressive behaviour and answers it with her voice and body contact. Only the repeated experience that his behaviour meets an answer, that there is somebody who picks it up and reacts on it in a matching way can teach a human being what communication means, that he lives in relationship with others.

A person with apallic syndrome in this sense expresses himself as well, shows behaviour that may change, and which provokes resonance within me. His eyes may be open or closed, his glance pointed

or going astray. His muscle tension may change just as his body posture and facial expression. He shows pulse, blood pressure and body temperature, he has times he sleeps or is awake, his digestion may work in different ways at different days. And above all: He is breathing, and the rhythm of his breath is directly reflecting his soul, telling me something about his way to be in this world. So if I care for getting into communication with a person with apallic syndrome, I will find multiple approaches to begin with, and it is my decision to utilize them. Which precise way will lead to my goal I will find out just by trying, by trial and error.

About Basic Communication

Around 1980 Basic Communication resulted from the necessity to help a non-talking, severely mentally retarded boy, who had been left alone by his mother one day after birth and was completely dominated by fear, to get at least an idea about how trust might be like (Mall 1980). Stimulated by the psycho-somatic approach of "functional relaxation" according to Marianne Fuchs (1989) and other body oriented approaches in psychology (e.g. following Besems' and v. Vugt' Gestalt therapy with retarded persons; see Glar 1997), I discovered the possibility to get involved with my partner so closely that within the limitations of our encounters he could experience a little bit of something like maternal security without preconditions, starting out with relating to the rhythm of his breath.

Since then Basic Communication has become established mainly in the field of assistance and help for persons with severe mental or multiple handicaps or with severe autistic behaviour, who can hardly be addressed by speech or other systems of communication. There were early reports though about experiences with Basic Communication concerning elder people showing symptoms of dementia (Grond 1988, p. 215 f), and so the conclusion was obvious that persons with apallic syndrome might profit from this approach as well (see also Leyendecker 1998, p. 324, 327).

Basic Communication starts out from my partner's rhythm of breath, to which I relate myself in a direct, playful and natural way, adapting my own breathing to this rhythm and integrating my activity like touching, sounding, stroking, vibrating into this common rhythm. Doing this, I keep observing every impulse my partner shows - like a change in his muscle tension, breathing, facial expression, sounds, movements - treat them as expressive behaviour, take them up if possible, mirror them, adapt to them.

How exactly does Basic Communication look like?

Basic Communication demands from me as the "active" partner to be quite conscious of myself and my body in a positive way. I can be aware of my partner only as well as I am able - and allow myself - to be aware of myself. This already starts with taking care for the way I sit/stand/lie while encountering my partner, to notice if I feel well, how I might improve my position. A background of deepened self experience in a body oriented therapy approach may be very helpful.

On the level of immediate sensual perception, if possible in direct physical contact, I let my partner feel my presence, picking up the rhythm of his breath, adapting to it, using it as the basic rhythm of my activities, centred on the phase of breathing out, of letting go. When it is possible to sit behind my partner on a bed or a mat, leaning against my belly he feels very intensively the rocking movement of my/our breathing.

There are other possible ways as well, e.g. to take away the headrest of the wheelchair, stand or sit behind one's partner, tilt the wheelchair towards oneself so that head and upper body lean against one's belly. Even if there is no way to get into broad bodily contact, I can integrate body oriented activities like stroking over parts of the body, stretching, pressing, sounding into our shared breathing out. My intention doing this is not primarily a therapeutic one.

For myself I take care, not to aim at therapeutic goals right away. My primary intention is the experience of concord, of communication. This is why the situation should remain a playful one, without constraints. It does not matter so much what I do in detail, and that everything is "right", as long as I succeed in reaching the other person in a tangible way.

Basic Communication can be used "just like that", to convey contact, comfort, community, relaxation. Situations of encounter, of saying hello or goodbye perhaps can be arranged in a way the person with apallic syndrome can perceive in a direct way. Basic Communication also can be seen as a kind of starting point for specific therapies like physiotherapy, facial-oral stimulation, or Basic Stimulation according to Fröhlich, etc. It guarantees for both sides, therapist and patient, really to be in contact, and to be able to resort to this contact whenever needed, so that any therapeutic approach can be fine tuned appropriately according to the needs of the moment. On short term the repeated experience of Basic Communication can lead to increased calmness, relaxation, well being, as well as to increased readiness to tolerate other approaches. Long term experiences are yet to be gathered. One might imagine that perhaps it could open up a small path to the "inner core" of the partner's personality. Perhaps it might strengthen a notion within him that there might be the possibility to answer actively.

To understand the essentials of Basic Communication one has to experience it. This is done best in a course centred on self experience, where after appropriate preparation the participants feel Basic Communication themselves in both roles - e.g. as the passive partner as well - and can talk about it later.

Limitations

Persons with apallic syndrome fundamentally differ from people who e.g. have grown up with a severe mental retardation from birth on. Their lives may have been quite "normal" until the decisive break of the traumatizing event. Nevertheless their past still is present and has its effects well into the presence of apallic syndrome. This may even become clear in the position this person still keeps in his family system. The situation still is aggravated by the fact that nobody can tell if and how exactly these persons perceive and process incidents in their environment. Even if there is no observable reaction whatsoever, this does not tell anything about what the person himself takes up and what meaning it has for him.

Not getting too close too fast.

After long months in clinic and nursing home, as well as when being nursed at home, persons with apallic syndrome probably have get used to be on their own most of their time. 24 hours are much too much time to be filled with shared activity. One can imagine that they have get used to this situation, and that it could be very irritating if suddenly there is a lot more of attention.

So I shall be very careful at first providing an experience as close as Basic Communication, so not to tear my partner out of the situation he is used to and to expect too much of him. That may mean I shall limit the time being that close to him - maybe once or twice a week up to once or twice a day for about 20 to 30 minutes each time, according to circumstances - and then let him take his time to be alone again. At the same time I shall watch carefully for signs of irritation indicating I am demanding too much of him, and then change my approach accordingly.

Avoiding unrealistic expectations - with me as well as with my partner.

Nursing a person with apallic syndrome is extremely demanding with regard to time, competence, and strength of the people involved. This makes is important for both sides to recognize the framework within the relationship can unfold, even if I feel the impulse, or sense my partner's wish, to engage myself beyond these limitations. An approach like Basic Communication has to respect this framework as well, which is another reason why I shall limit frequency and duration of this kind of attention and carefully watch all short- and long-term changes it may trigger with my partner.

Respecting my partner's autonomy

Facing the impossibility to see the world with another person's eyes leads to respect for his way to live, for his autonomy. The decision what pleases my partner and what does not in the end is not mine. Offering him something like Basic Communication I must be ready to accept his rejection without taking it as an offence. Even if it is me personally, whom my partner rejects, I have to accept this.

Recognizing aroused emotions, dealing with them in a responsible way.

Basic Communication can be a way to get into very direct contact with deep layers of my partner's personality. This may lead to the surfacing of deep emotions which until then might have been hidden under a kind of protective layer, like sorrow, pain, or longing. There is danger that these emotions may even kind of flood my partner and endanger his emotional balance in a massive way. So under this point of view as well I will take care to offer something like Basic Communication in a sensible way, constantly monitoring what it may do with my partner.

Meet my partner in the reality of his everyday life.

To offer Basic Communication I do not need a setting which is designed in a special way, nor any special material, just my partner and me. I do not take him away in a special situation but start right away there where he is, e.g. in his room, perhaps on his bed, just where I can make it comfortable for both of us. What is important is that I am able to concentrate completely on him and myself.

Then I try to be conscious of the fact that meeting him I meet the complete reality of his life, of his history, how he has lived before the traumatizing event, how this event happened, in what subjective circumstances it occurred, what he has experienced since then. I do not let the fact that he lives with apallic syndrome completely dominate my perception, but try as far as possible to see him as a person in a holistic way in its full complexity. Encountering him I enter this complexity, and it is not mine to decide what function this will gain for my partner.

Supplement

Recently a paediatric nurse participating in a training course of mine remembered an incident, after she had experienced Basic Communication in this course herself: Some years ago she was nursing a girl of about 9 who had been in coma for 2 to 3 days already after a bicycle accident. Her mother who had a very intimate relationship to her only child spent night and day beside her bed, sang to her, talked to her about what had happened during the day. Finally the nurse came to see how the mother had laid her head on her daughter's chest, face to face, and had begun to breathe in a very distinct way in her daughter's rhythm. She continued this for about two hours, and then her child woke up. - Of course nobody knows if the child had not woken up anyway at that moment, and there is no clear information about the exact medical circumstances. What impressed me is the mother's intuitive behaviour to pick up the only expression of life that was left with her child and to use this as a path to encounter and answer her.

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