

63th International Meeting of the Medicine for the Whole Person

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## The Person of the Disabled Child

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### **1. Introduction**

At this point, I would like to express my heartfelt thanks for the invitation to speak within the framework of your *Medicine of the Person* assembly.

I have the privilege of supervising children and adolescents together with occupational therapists, physiotherapists, speech therapists, neuropsychologists, specialists in neurophysiology, doctors and a large administration in a large interdisciplinary team at the East-Swiss Children's Hospital of St. Gallen. We comprehensively supervise children with paralyses, muscular illnesses, epilepsies, and head pains, but also with development disorders, partial-performance deficits, problems at school and behavioural abnormalities.

### **2. What did reading the book '*Medicine of the Person*' trigger in me?**

What made me hesitate to accept this request for a talk was the fact that I had never previously grappled more closely with Paul Tournier. My wife had heard him in the context of a talk in Zurich in the early eighties, though at that time I was unfortunately prevented. During my reading, I said to myself on several occasions, if only I'd taken more time at the outset of my professional activity for the examination of an holistic medicine of the person on the basis of a Christian persuasion and value. I am certain it would have significantly influenced my professional conduct. From these remarks it is not difficult to guess: The reading has exerted a great and hopefully also lasting influence on me. As I now stand before you, I feel myself as a newcomer, as one inexperienced, wishing to share something with you who are conversant with the medicine of the person – what presumptuousness! On the other hand, it is precisely this existential concern with the central message of Christ that Paul Tournier has translated into our medical profession. With numerous personal case-studies from experiences with patients, he demonstrates how he has experienced this rehabilitating, liberating message as effective, life-changing and -transforming.

If I now highlight some salient points from *Medicine of the Person*, I beg all those to forgive me for whom these are all too familiar. Paul Tournier begins his book with a young girl, to whom he gives the name Theresa, and whom he treated as a young doctor in the Children's Hospital because of a spondylitis. He saw her again as an adult woman accompanied by her mother. She was totally exhausted. He was asked to sign her off sick from work because she had had to work

too much at the office. Upon his remarking that overwork is not always the only cause of great tiredness, Theresa breaks down in tears and pours out to him a part of her life story. With this example, Paul Tournier makes it clear to the reader that it is not sufficient to rescue a patient health-wise and support him in his physical recovery process, but rather he should provide him with a means by which he can overcome problems that appear later on. He further makes it clear that many illnesses do not appear suddenly. They are prepared over a period of years due to our maladjusted way of life, which slowly diminishes the person's life force.

Paul Tournier comes directly to the central statement of his book, namely that close relationships exist between our life problems and our health. That God has a plan for our life and our world and that the world and people are sick today because they do not obey God's laws and do not live according to His plan. Hippocrates taught us: Treat the sick man – not the sickness. Paul Tournier follows this request closely, in that he investigates her life problems, listens closely to the sick woman and questions her about her way of life, her moral conduct and her behaviour in the family. He clearly names the life problems such as over-indulgences in the diet, overwork due to jealousy or greed, an overly comfortable life that diminishes the bodily and spiritual endurance, sexual excesses and passions, and lastly everything that gnaws at the heart: anxiety, rebellion, guilt conscience. He demonstrates in numerous examples how closely “my physical life, my mental and spiritual lives depend directly on my obedience to God, on the full dominion of Christ over my body, my thought world and my psychic life<sup>1</sup>.” Paul Tournier impressively describes the significance of the silent gathering, in which patient and doctor listen for God's inspiration, and how, in the personal encounter with Jesus Christ, a miraculous transformation of the heart occurs. The natural consequence is the confession of one's own sin and the experience of a hitherto unimagined calmness, of assurance and a liberating power, which breaks through all hitherto encountered rules. In numerous examples Paul Tournier demonstrates how he experiences this turn-around in the silent gathering with his patient, often when he himself no longer knows the way forward, and the sick person recognises God's plan for him and receives the miraculous power that he needs to obey Him<sup>2</sup>. He goes on to say: “Words of advice only work from the outside. The spiritual revolution works from the inside.” And “the source of every spiritual renewal consists in a personal encounter with God”<sup>3</sup>. One final important insight: “I have experienced that one helps everyone to whom one gives oneself. And to give oneself means quite simply to speak of one's own experiences, one's suffering, one's mistakes and one's triumphs.”<sup>4</sup> The nurturing of the doctor's personal relationship with God is central. Paul Tournier dedicated at least one hour daily to being with God, reading the Bible, listening to His voice, praying for the day ahead, and individual encounters with people. In order to accommodate this, he had, in comparison with his earlier work method – he describes this as “always in a hurry, always rushed” - to give up certain activities, which he had formerly considered mandatory. For these, he was able to gain more happiness and better achievement in his work. In his book, Paul Tournier demonstrates an holistic medicine, that is to say, a medicine of the person, which takes the whole person seriously. A medicine that is strongly characterised by faith in the divine reality in our life and the life of sick people whom we look

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<sup>1</sup> Paul Tournier, *Sickness and Life Problems (Médecine de la personne)*, 9th Edition, 1984, p. 21  
<sup>2</sup> Paul Tournier, *Sickness and Life Problems (Médecine de la personne)*, 9th Edition, 1984, p. 215  
<sup>3</sup> Paul Tournier, *Sickness and Life Problems (Médecine de la personne)*, 9th Edition, 1984, p. 216  
<sup>4</sup> Paul Tournier, *Sickness and Life Problems (Médecine de la personne)*, 9th Edition, 1984, p. 217

after. I will gladly also say something at this point about what this reading triggers in me in the way of further steps.

Concerning the child, Paul Tournier makes interesting assertions (following Caron, Thooris and Mac Auliffe): During babyhood, the child is little more than a digestive duct, insensible to the things of the outer world. It is concerned with the age of digestion. This is followed by the age of breathing, which in turn is followed by the adolescent's age of muscle, which at last concludes with the age of the brain, with completed brain development and social expansion. During the corresponding development ages, the individual is primarily subject to illnesses of the dominant organs. He classifies each development age according to one of Hippocrates' four main character types: P, S, C and M, which would increasingly suffer from the corresponding afflictions of the chief organ.

### ***3. How was I appointed to the accompaniment of disabled children and their parents?***

At the age of eleven years, my brother Marcus who was one year younger than me suffered a traumatic brain injury, when he was hit by a nearby overtaking car and hurled to the ground. We were together out and about on our bicycles. Marcus rode behind me. During three long months he was at the children's hospital and, following a 3 week comatose period, developed a marked transition syndrome. During this long time, we his siblings were not allowed to visit him. When he came home, he was restless, impulsive, emotionally unstable, had forgotten all his school abilities, displayed a hemiparalysis, a severe difficulty in finding words and an epilepsy. We were largely left to our own resources. There was as yet no such thing as an established post-traumatic rehabilitation. My parents were furthermore in the process of getting a divorce at this time, as for a long time they had already become increasingly estranged in their marriage. I was plagued by guilt feelings as to why it had affected him and not me. For me, there followed an existentially very challenging time as the eldest at my mother's side, fearing and daring to hope. In the context of an evangelisation establishment, I consciously turned to Christ. He became the centre of my life. I could now share with him my deep grief about our situation without a father and with a disabled brother.

After approximately half a year, Marcus could be schooled on an hourly basis. At home we very intensively practised the most fundamental skills, such as involvement of the affected hand, keeping within limits, or expressing simple requests, but school stuff also had to be recapitulated. I experienced how I and my brother were stared at on the street, and how people talked about us behind our backs. Marcus now claimed most of the time in our family life, and my younger sister and I came second. After a year of certain progress, it was decided that Marcus should go to the rehabilitation centre for children in Affoltern-am-Albis for comprehensive support. The pain of the weekly parting with tears at the rehabilitation centre on Sunday evenings remains in my memory. We spent every Wednesday afternoon there, learning and playing with my brother. In the three years of his stay, the desire grew in me to become a children's doctor specialising in neuro-rehabilitation, together with educators and therapists to accompany and support disabled children and their parents.

Subsequently, due to the combined efforts of us all, Marcus was actually able to pass an apprenticeship as a seller of foodstuffs. Sadly he was not able – as he wished, and as I was able – to start a family. He still lives at home with my mother, now already over eighty, and has been without work for eight years. Three years ago, he developed a depressive behavioural disorder

with autistic traits. He would run away or not let himself be induced towards anything. He no longer wanted to look after himself, for a time also he hardly ate anything. For lengthy periods, he no longer spoke and often also avoided eye contact. He had to be repeatedly hospitalised, on one occasion also psychiatrically, because he was plagued by delusional imaginings. The doctors in the institutions were overwhelmed, because they were unaccustomed to dealing with people with a disability. Sadly, my aged mother has after a short time broken off the support of a psychiatrist who is an expert in accompanying mentally handicapped people. She lives very secludedly and in isolation with her son. She does not allow him to search for a way of life in a life partnership living together that would correspond more with him, because she would be lonely without him.

I lost my brother when he was eleven years old, and since then I have been on the trail of discovering what moves my brother, what he loves, what he wants. Despite his disability, in his thoughts, his prayers, his singing he is always very close to God his Creator. In recent times, since he has worsened emotionally, he no longer allows me to see into his soul. For my sister, who lives with her family in Canada, and for myself, it is hard to bear, be forced to watch, and not be able to help.

Despite my greatest ambitions to pursue a career in engineering, I felt the desire to study medicine. Through my father who was a doctor, I was able to receive great support in pursuing further training in paediatrics and was also sent by him to England for two years for further training in paediatric rehabilitation. There I learned a lot about an holistic care for people with a disability and was also presented with the value judgement of seeing each child firstly as a child and not as a patient. The Children's Charter of Rights from Chailey Heritage expresses this. Back in Switzerland, after my completion of the further training, I worked in neuro-paediatrics at the rehabilitation centre in Affoltem-am-Albis, which I had come to know during my brother's stay. During the last 12 years, I could be in charge of the department for rehabilitation and development at the East-Swiss Children's Hospital. Since the 1<sup>st</sup> of August, we have joined forces with the department for children's neurology, with the goal of committing ourselves even more comprehensively and more effectively to the children and their parents, who are looked after in these strongly complementary departments. I deliberately hand over the leadership to a younger colleague, and now as a Teamleader of doctors I have more time for the patients and their parents.

#### [Children's Charter of Rights<sup>5</sup>](#)

All children and adolescents at Chailey Heritage<sup>6</sup>, wherever they are, whoever they are, and whatever they do, have the following basic rights while in our care:

- to be esteemed as an individual
- to be treated with dignity and respect
- to be loved and treated first and foremost as a child
- to be safe

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<sup>5</sup> <http://www.sussexcommunity.nhs.uk/index.cfm?request=b1004186>

<sup>6</sup> School and rehabilitation centre for physically disabled children, West Sussex, England.

### *Casestudies of physically disabled Adolescents*

I've known R. for 12 years. She was born in 1997 as the 4<sup>th</sup> child of a Turkish family, with severe physical disabilities of Roberts syndrome, with a hypoplasia of the right leg, with hexadactyly, a missing left thigh and a rotation disorder of the left leg, a sacral agenesis and a hypoplasia of the left iliac bone, as well as a Pierre Robin Syndrome (cleft palate retrognathia) and a dysmelia of the left arm. The parents have lived for many years in Switzerland though speak poor Turkish. They are not practising Muslims.

R. attends senior classes at a school for physically disabled children and is independent as regards mobility, through crawling on the floor, lying on a skateboard, in a special manual wheelchair increasingly also on steeper footpaths, and in an electric wheelchair outside. She manages all transfers on her own. R. presents a decompensated sitting posture and when seated she has to support herself with her left forearm. Dressing the top half of her body is no problem for her, dressing the lower half is difficult, though possible with great effort. She cannot cut hard and chewy foodstuffs. At home she does not yet go the toilet on her own, though at school she does so with the aid of a wooden stool. Looking after her body in the lower extremities is still restricted (cutting her toe nails). She writes with all the fingers of her right hand on the keyboard, and with her left index- and ring-finger. Cognitively, she displays a speech development disorder with limited speech comprehension, further complicated by the bilingualism, and a hyper-nasality and hence a resulting weakened articulation. Her concentration and stamina remain limited, as does her problem solving behaviour.

Only recently a great breakthrough was achieved. After a long period of searching, the family received a wheelchair-accessible apartment, reachable by lift, which R. can also use herself. The rent cost is borne entirely by the social welfare department.

### *How is R. doing as a person? What keeps her busy?*

Emotionally, R. increasingly detaches herself from home. One night a week she spends in the school's residential group, where after some initial resistance she would willingly stay more often. She is very targetedly encouraged in her independence there. R. struggles with her body and its shortcomings in the context of her puberty. She feels shame when she is examined by me. R. has discovered her sexuality and raves about boys. She wants to spend her free time independently from her parents and keeps herself distanced from their cares and problems. Questions of her own identity occupy her: Who am I? What do I want, what do I feel? Such questions she discusses with the psychologist.

### *The Grieving Process*

R. increasingly realises her limitations, seeks social distraction and is time and again frustrated that she is excluded, in that she cannot participate in many things that others of the same age do.

The parents grieve in their life phase for their children, all of whom they should let go, though all of them display their life problems.

The eldest daughter who is 28 years old is newly divorced and should according to her custom and her values belong at home, if she is no longer married. The second daughter who is 25 years old has a severe epilepsy, was able to complete an 4<sup>th</sup> apprenticeship certificate, lives far away and is engaged; the 23-year-old brother has no professional training, is afflicted with a leukaemia and jobless, and due to the regulations of the social welfare department, which finances the family's apartment, he was not allowed to live at home.

### ***Partner Relationship / Parenthood***

The mother has suffered with diabetes since her pregnancy with R., is bad tempered and depressive. She blames her diabetes on R. R., with her disability, was never accepted by her mother. The father is depressive and only recently was psychiatrically hospitalised. Time and again he displays aggressive outbursts at home. Since R.'s early childhood, he has a close and affectionate relationship with her. He finds it extremely difficult to accept that she now wants to become more and more independent. For the parents, the numerous processes of change are great challenges, because their value system, based on a closed, stiff, rigid worldview has been shaken.

### ***Cognitive Assessment Processes***

The parents are overwhelmed by R.'s disability, see no meaning therein and have no future prospects. The parents feel themselves powerless, at the mercy of the situation without a possibility of being able to influence it.

### ***Coping***

It is increasingly impossible for the parents to actively mould their situation. The father can scarcely any more fulfil his role of providing for the family because of his health. He commands no future prospects, both parents lack a positive worldview, flexibility and a network of relationships and cooperations.

Their daughter R. by contrast behaves more and more actively and flexibly towards the outside world. With increasing frequency it gets to the point of conflicts with her, as she increasingly wants to implement her own perspectives and ideas.

### ***Surroundings/Living Situation***

R. sees the school and residential community positively. Increasingly, she experiences family life, which originally gave her much security, as fraught with problems. She receives from her parents an ascription of her function in that she has become the meaning of their life.

The parents experience financial independence through the social welfare department, and live increasingly in isolation, largely lacking support from the family. They suffer from the living conditions: no incomes, no possibility of self-formation, and their own health as a catastrophe without hope of improvement. They do not live in their homeland, speak the German language poorly, suffer from the above-mentioned manifold stresses and are involved with a large carer-system, which itself in its turn is a stress-factor.

Mrs Gabi Gmür, former physiotherapist, who after her early retirement still offers a systematic training in psychological accompaniment for children and families with disabilities, has been accompanying the family and R. for several years. She conducts regular interdisciplinary help-

sessions. Through her, I found out about the difficult situation of R.'s family and their lack of coping strategies.

### ***My Open Questions***

How can I, as the case-leading doctor, accompany the family in their grief- and coping-process, in their illnesses and life problems, and with them as Muslims stand by them as a companion in the readjustment of their living conditions? Should I delegate this work of the psychologist, who has great insight on the systematic coherencies yet designates the family's situation and also the partnership as hopeless?

### ***Casestudy of a Severely Multiply-Disabled Toddler***

A. is an almost 4-year-old girl with an incompletely diagnosed deformity syndrome, from Czech parents. External abnormalities are a cleft palate that was closed up at 18 months, retrognathia, hypertelorism, low positioned ears, a sacral recess, a hypoplasia of the first pair of ribs and a hypertrophic cardiomyopathy without obstruction of the ventricular outflow tract. She has a central vision disorder with pendular nystagmus. Brain imaging shows the non-specific discovery of a corpus callosum hypoplasia as an expression of a reduction of the white substance. She displays a severe psychomotor development retardation, an axial muscular hypotonia and dystonic joint malalignments of the extremities. Additionally, she has a severe oral sensomotor disorder with an initially much limited respiration-swallowing coordination, i.e. she could scarcely swallow her own saliva and choked on her own saliva with recurrent pneumonia. She is nourished via a PEG (parenteral gastronomy) tube on a high calorie nutrient solution and even then is prone to being underweight. The mother administers some nourishment orally according to corresponding advice from A.'s speech therapist, in which it is more of a case of exploration. The PEG tube itself was frequently a cause of localised irritation, was leaky or caused interference (critical ballooning of the stomach). Together with the at first marked sleep regulation disorder, this brought her parents, most of all her mother, to their wit's end. The dose of melatonin brought rapid relief through sleep rhythmisation. She suffered from pains, which were also the cause of increased screaming, because she displayed a strong tendency towards constipation. The introduction of an osmotically active intestinal regulator in addition to an osmotically active babyfood helped, in that the stool became more fluid and the constipation was thereby corrected. Regular gastro-enterological and nutritional-advisory consultations are indispensable in order to adapt the nourishment to the constantly changing needs, so that her digestion is guaranteed. Emotional and organisational challenges included a dental treatment under narcosis to remove tartar, and the first PEG tube replacement. In the same narcosis, her central hearing ability was reviewed with AEPs (acoustically evoked potentials) with a normal result.

Clear progress could be made in her communicative, motoric and homeostatic behaviour: she shows happiness more clearly, is slightly less over-sensitive to touch; nevertheless she still needs a lengthy acclimatisation period when the physiotherapist wants to work with her. Indeed, just as before, A. gets extremely agitated about the medical examination.

Once every week, she receives the therapy-educational early-intervention therapist at home, physiotherapy, and speech therapy; A. is also seen at longer intervals by the vision-educator and the occupational therapist, the latter being responsible for the evaluation and adjustment of help-resources. A. currently has at her disposal a highchair for sitting at the table at home, a

bath-seat, a wheeled zimmer-frame, and soon also a standing-frame. A wheelchair is currently out of the question for her parents.

Thanks to the Kinder Spitex with 20 hours per week, A. can be nursed and therapied and supported at home according to the goals of the two therapists, without the parents, most of all the mother, becoming over-challenged.

I have prescribed a psychological accompaniment, prescribed because the mother was overwhelmed by A.'s initially very challenging regulation-behaviour and the unstable health situation with numerous infections, but also because of the numerous offers of support and opinions. She lived in constant fear that A. would die.

With this example, I want to look at the greatest stresses and the help-resources of a young family with a disabled child and what my role as the case-leading doctor is, who has previously concerned himself in the care-network almost exclusively with the health aspects and recommended and introduced the various supporting measures.

### ***Surroundings/Living Situation***

Dealing with the care-system is the greatest stressor: Discrepancies between one's own values and expectations and those of the carers, who also have different views among themselves. For the mother it signifies a great challenge to gauge anew in each specific situation what the best thing for A. is. Support and offers of help are often experienced as stressors. Forms of communication and modes of expression in the care-system that go over the mother's head (e.g. accusations) lead her to feel overlooked, not taken seriously, or misunderstood. Often these assessments are not clarified, so that they may be affirmed or refuted and assessments or condemnations may be corrected.

Bad coordination of measures, insufficient agreements on points of focus and priorities (example: weight gain, contracture prophylaxis).

The parents' lack of time for all therapy measures, but also the professional carers' lack of time for sufficient communication, for hearing the parents' concerns.

Increasingly restrictive authoritative practice of IV for reasons of cost efficiency with refusal of requests for funding for help-resources.

What the mother and the parents need are offers of help and unburdening, and dialogue partners with technical competencies to accompany and advise them in case of uncertainties and new health- or nursing-related questions of therapies and help-resources.

### ***Example: Help-Resources as Stressors***

Help-resources are willingly offered by us carers, yet often the reason for their importance is insufficiently explained. Either they are a help, for the facilitation of a function such as playing or eating, or they work preventatively (e.g. to avoid the increase of Wiener Spectrum distortion, or contracture). These purposes could not be made clear enough to the mother to convince her that these help-resources were essential. Therefore she did accept a highchair, but not a standing-frame, because on the grounds of her perceptual disorder, A. at first struggles against everything new and cries at the same time. The other grounds for arguing against help-resources are that help-resources externally mark a child out as disabled. When the parents use a rehabilitation help-resource, the world confronts them with the fact that their child is abnormal. This hurts and makes them sad. The mother, for whom outward appearance is very important, could as yet not warm to the idea of a rehab-buggy, even though A. would be much better supported therein

while sitting. The accompanying psychologist, who also leads the half-yearly carer-sessions, assesses the parents' situation as follows: the gradual acceptance of the disability itself along with the entire grief and rebellion; the acceptance of help-resources also happens in this way. This succeeds to the extent that the mother is gradually more and more confronted with the externally increasingly visible effects. In so doing, we health-professionals must encourage those affected in their grieving process and supportively accompany them. In particular we should encourage them also to voice their feelings. This means also at some point to be able to take anger, uproar and accusations, in the knowledge that these don't count for me as the person, nor do they call my professional competence into question, but rather it is precisely for this reason that I stand at their side, in that moment in which they are once again overwhelmed in the inevitable confrontation with the whole fate. We should accompany them in dealing with their own reaction and the often cruel reactions of the outer world, and give them courage also to take new steps along this path.

In such critical phases, guidance and therapy should be competently, thoroughly and cautiously given. With lack of understanding, with pressure or even coercion on the part of the health-professionals, this will sooner effect the reverse: not only will the mother not be able to accept the recommended help-resource or the therapeutic proposal, but rather she furthermore persists in her condition of (partial) denial of the seriousness of the disability and closes her eye to the increasing discrepancy with the 'Norm' for her age group and remains therefore trapped in her grieving process, which after all is also unhelpful for the child.

This family's greatest resources are the partnership of the Czech parents and their supportive family of origin with good economic circumstances, allowing them to live in their own spacious and for A. well equipped apartment. They were in the process of being able to understand the causes, the seriousness of the disability and their daughter's needs, and recognising the significance of the previous therapeutic measures and help-resources.

As types they demonstrate a great flexibility concerning their life goals, a positive attitude to life and confidence about the future, and a healthy measure of self-care.

### ***My Open Questions***

How can I as the case-leading doctor find out more from the family of that which really occupies them, where they stand in their grieving process, learn from them how things really are with them, [discuss] with them the wider perspective of the significance of their daughter's disability, but also anxiety about the future (will she die early?). When the mother comes to me, she is constantly occupied with A., and has a hundred concerns. Often there are also one or more persons in attendance (father, physiotherapist, occupational therapist) and we have exactly one hour's time to examine A., assess her help-resources and answer the numerous questions. The mother does not want additional appointments, as she already has to observe many appointments and for a time always used to cancel appointments at short notice or "forget".

### ***Casestudy of a severely disabled Adolescent with unexplained screaming***

I got to know I. when he was 11 years old, when he travelled from Kosovo to Switzerland in the context of a family reunion with his mother and his two brothers (one of them two years older, the other five years younger). I. was born spontaneously in the 38<sup>th</sup> week of pregnancy and showed a good primary adaptation. An umbilical infection when he was 3 days old made a 12 day stationary antibiotic treatment essential. Apparently cerebral attacks occurred in the neonatal

period, due to which he had to be treated with Phenobarbital. From this initial period, we have no data, as the parents lost everything in the war.

At the first examination, I encountered an eleven year old boy, who had spent the whole of his life so far in the lap of his mother, grandmother or aunt. He could not himself sit, seemed not to see, as he could not focus, though he heard subtle noises, in that he would flinch at surprising sounds. He was underweight, very pale, and did not command sufficient strength to stabilise his body. Additionally he displayed contractures in the elbows and both hip and knee joints, as well as a hip subluxation on the right. When swallowing milk and bread that were given to him as nourishment, he very often choked. He communicated his current feelings with mimicry and noises. He recognised people familiar to him, possibly also everyday situations.

I met also a family who had already experienced a lot of hardship. Father and mother, having their origins in the same village, each having 3 or 4 siblings, had both lost their home in the Yugoslav war. I was unable to determine anything more precisely. The father married his present wife, who was chosen for him from the family, when he was able to travel to Kosovo again for the first time after working for 3 years on a farm in Switzerland. As an 18-year-old, he had to flee from the country because of the military, since he did not wish to be shot dead in military service like other people. He took his young wife with him to Switzerland. However, she was unhappy in a foreign country, the language of which she could not speak, and felt totally isolated. So he took her back to Kosovo, where she bore him three sons. During the war, the mother spent 3 months with the three-year-old I. and his five-year-old brother alone on the run in a refugee camp in a forest in Albania. The whole village was burned down. Everything was again rebuilt. A post-traumatic disorder is highly probable, above all in the mother. The father lived all these years alone and frugally in a single room, worked hard, and saved as much money as he could every month to support his family and also to build a new house again in Kosovo. When possible, he would spend a few weeks five times in a year in Kosovo with his family. In 2006, he decided that the whole family should come to Switzerland. Now we return to the starting point of our first encounter.

At that point in time, I could not yet guess at what challenges would face the family and also ourselves. Full of zest for action, we supplied I. with a corset, a lower-leg brace, a wheelchair, treated his severe anaemia, introduced a regular physiotherapy and an early intervention, and registered him at an ophthalmological council for a hearing examination, which confirmed our suspicion of a severe central vision impairment. Additionally, we enrolled him for schooling at the special needs education school.

Two months later, I. began to scream more and more. We took him to carry out various examinations, such as a swallowing examination in suspicion of a gastro-oesophageal reflux, a nutritional consultation because of malnutrition, a swallowing examination in suspicion of recurrent aspirations, and a teeth restoration.

The school, the parents, the therapists and we the doctors sat down together to discuss what the reason for his increased screaming could be: hunger (despite high-calorie intake, he does not gain weight), pains originating from the reflux-oesophagitis, constipation, subluxated hips, epilepsy-equivalents, being carried around less? We corrected all possible causes of pains, administered a stomach acid blocker, and pain killers in increasingly high dosage. I. still screamed on and on and at the same time sweated profusely. We gave him various muscle relaxant drugs in increasing dosage and injected Botox into the shortened, cramped up muscles. All of this, together with the administering of Risperdal effected no improvement. Only with sedatives could

I. be calmed down for a short period. Because of the reflux, we conducted a fundoplication of the mouth of the stomach. The gastro-oesophageal reflux could be corrected thereby, but I. still screamed. Then we discovered a chronic otitis media, which was resolved, without leading to any reduction of the screaming. How strong his conditions of tension were during the screaming phases is shown by the right femoral shaft fracture with osteopenia, which I. suffers and which was treated with an external fixture. This experience was perceived as very drastic by the parents. Following brief improvements in the context of the measures concerned, it always returns to exacerbation. As we were increasingly uncertain and increasingly proceeded on the assumption of a multi-factorial origin of the screaming, we appointed, in accordance with our psychosomaticist, an interdisciplinary behavioural observation circle, in which all concerned observed I.'s behavioural conditions, noting his own reaction and resulting behaviour. This circle was interdisciplinarily analysed: According to assessment from our psychosomaticist, I. reacts mostly with mimic/gestural stereotypes, both in aversive and also primarily emotionally positive situations. This means that his behaviour may be misunderstood and even the parents are occasionally uncertain. As a rule, even when a situation turns out positively, I. would need at least five minutes to regulate himself emotionally and motorically. In general, it is an effort for I. to deal with new situations. This could have to do with repeated traumatic experiences. In September 2009, it came to the point of emergency hospitalisation because of almost unstoppable screaming linked with severe cramps in the region of the entire body. A sacral block led to a clear relief. An intrathecal baclofen pump was evaluated and then implanted. Complications arose and the catheter tip was twice repositioned, unfortunately also on one occasion linked with a catheter infection after which the catheter had to be removed so that the treatment could be carried out. Since Christmas 2010, I. now has a pump, which leads to clear tonal reduction. He is sleeping better, can now be positioned in the wheelchair and even carrying orthoses has become possible. We all breathed again, because I. is clearly more relaxed, content once more, and smiles again often. At night, however, the father still mostly gets up three times. I. now has comprehensible pains in his dislocated hip, which cause him to become tense anew. The fear of pain leads to tensions when moving the hip. After the summer holidays, he will need firstly a spondylodesis-straightening of the spinal column, and later on unfortunately also a hip reconstruction. The parents are anxious about the operations. Nevertheless, they take the great challenges extremely calmly. They ascribe to me a great competence: 'You are the doctor. We will do what you recommend us to do.' Meanwhile, I have frequently made it clear to them that I also often do not know what the correct solution is. A fit of cramping at the beginning of July terrifies the parents anew. They fear they will lose I. in his seizure. We are adjusting the dose of Phenobarbital, which up till now had been administered in a very small dose.

The parents feel well supported. They have seen over the course of the past year a significant improvement in I.'s condition: fewer phases of pain and anxiety, fewer attacks of sweating, less spasticity. Admittedly, they are continually uncertain in that it is difficult for them as it is for us to differentiate between I.'s anxiety and pain. It still happens that I., especially in the morning, becomes severely tensed before being seated in the wheelchair. One has to regularly clasp him in one's arms and wait until he is able to gradually calm himself down.

For a long time, we proceeded on the assumption of a disorder concept, that the pump in the wheelchair interferes (mechanically) and that I. has a variable trigger for shunning the wheelchair. In connection with the refusal of the wheelchair, they cannot recall any associated trauma in respect of a life-event, which might have had the consequence of an avoidance

behaviour. Familiar aversive triggers concerning the wheelchair are the morning's transition following a restless night. However, this would not happen regularly. Additional aversive (generalisable) triggers are his hyperacusis and high frequency of irritation in transitional and unfamiliar situations, most especially under time pressure and in the morning, but also when visiting the children's hospital.

On the subject of the summer holidays, the parents describe a harmonious picture. I. really enjoys the time in Kosovo. It is for him a familiar atmosphere, and as a rule he is more relaxed there than at home, without being free of symptoms.

Recommendation: regular, predictable and continuous structures, in order to be able to contain familiarity (stabilisation), continually to make the setting clear and thereby to create security. It is difficult to find out anything about the parents' psychical traumas, which they have experienced in connection with the war, but also in witnessing the various crises. The problems in this regard are the mother's very meagre skills in German, and that the father is unaccustomed to speaking about his emotions. On being asked what the parents want for themselves, the father only replies: 'We both wish that it would go better for I., that he could develop and no longer have pains.' Joyfully, they show me the wheelchair-accessible apartment, newly refurbished 15 months ago, which is very clean and conveniently equipped. Their two other sons also greet me very politely. Everyone is looking forward to the upcoming holidays in their old homeland in Kosovo for 3 months in the summer vacation.

#### *Grieving Process*

I ask myself how the parents cope with their fate. They always treat I. very lovingly, are both always present and concerned with I.'s well-being. For the above-mentioned reasons, it is difficult to speak with the mother, indeed also with the father, about their coping with grief in regards to their middle son.

#### *Partnership / Parenthood / Cognitive Assessment Processes / Coping*

The parents seem not to say much to each other about I., leastways not in our presence, though they deal lovingly, engagedly and affectionately. The two brothers also have a very positive relationship with their brother. The father has frequently made it clear that I.'s disability is part of their purpose in life.

#### *My Open questions*

How can I as the case-leading doctor relieve the family more of that which really occupies them, and accompany them in their grieving and coping processes? Should I seek to converse with the mother with the aid of an interpreter? To be sure, the fathers who in such families mostly do not have better German skills, do not want this, because from their point of view they can easily take over the role of translator. The future prospects, including life expectancy and the limiting of intensively medical measures after large operations (straightening of the spinal column-spondylodesis), should also be addressed.

### ***The handicapped child in the Bible***

- In the Bible, we find that the unborn child can already feel and express the presence of God. John the Baptist quivered in his mother's womb when Elisabeth came into contact with Jesus' mother, who was also pregnant. Certain children in the Bible, such as Moses, Samuel and Jesus, are quoted as having specific vocations and a particular destiny.

- Jesus credits these children with both dignity and esteem. His attitude stands out when compared to the standards and the predominant attitude of the period toward children because he blesses them.
- Jesus places a child in the midst of his disciples when discussing the question of who would be considered the greatest in the heavenly kingdom. He encourages them to convert and to become "as little children." In this way, He makes the child appear to be an independent creature who places unconditional confidence in his father and mother.
- In addition, Jesus takes the suffering of children seriously and heals an epileptic adolescent and a young, dying girl, who was considered dead until Jesus arrives to heal her.
- As a teenager, Jesus felt a great need to be close to God, His Father, and to oppose the role of God presented in the Torah.

### ***Conclusion.***

I should like to conclude my thoughts concerning the handicapped child with a quote from Henri Nouwen. In his book on Adam, I found a profound respect for the handicapped person who, from a developmental point of view, remains a child throughout life. It is this respect which permeates my accompaniment of profoundly handicapped children and their parents. He discovers and describes Adam, a child with Down's syndrome whom he met in the latter part of his life at the Community of the Arch, « Daybreak, » as a friend, a master and a companion on life's road: an unusual friend since he couldn't express the affection and love he felt as others could; an unusual master since he was unable to debate ideas and concepts; and an unusual companion because he couldn't give him directions or counsel.

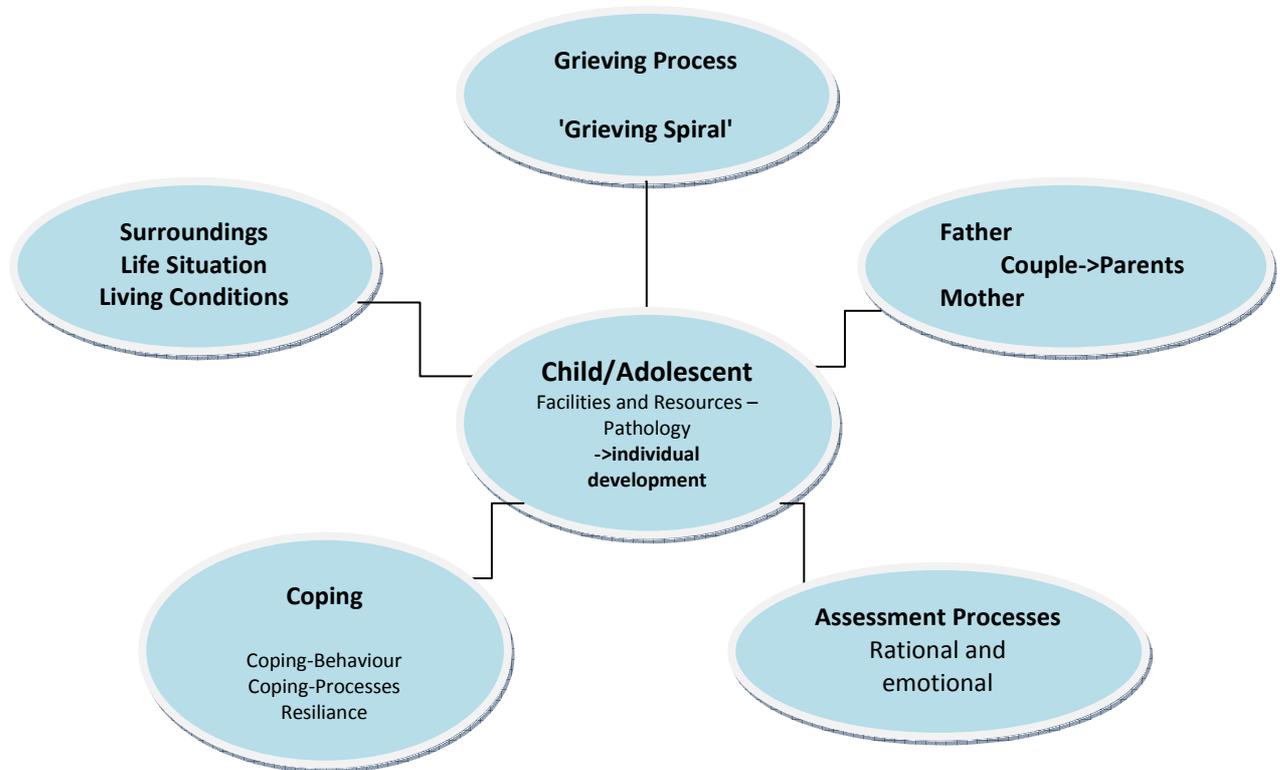
I will end with the following quote: "On Adam's tomb, I suddenly understood the secret of this man's life and death. My heart was struck as if by lightening with an understanding that this very handicapped man was deeply loved by God for all eternity and that he had been sent into the world by Him with the specific mission to heal and that now his mission was accomplished. I realized that there were many parallels between the story of Jesus and Adam's life. I also knew something else; I knew deep down that for me, Adam had become in some mysterious way, an image of the living Christ, just as Jesus had, during his life on earth, been a friend, a master and a companion for his disciples.

Thanks to Adam I have found a truly new understanding of these relationships with Jesus. They existed a long time ago, but they should also be relived today in the spirit of Jesus by me and by all of us with those who are weaker than we, yet who are the most wonderful of creatures. In truth, I not only learned more about God through my accompaniment of Adam, but also that Adam's life helped me discover and rediscover the living spirit of Jesus in the poverty of my own poor spirit. Jesus lived long ago, but Adam lived in my time. Jesus was physically present with his disciples; Adam was physically present for me. Jesus was an Emmanuel, God with us. For me, Adam became a person blessed by God, a saint, an image of the living God."

## Appendix

(based on slides from G. Gmür, psychologist for the accompaniment of children and their families)

The following interacting spheres should in each case systematically be looked at more closely:



Possibilities of support during accompaniment are

- To reduce stressors, or
- To seek, facilitate and develop resources.

The current topic, the current problem or need is multi-faceted and variable. In the case of accompaniment there is always yet another decision to be made, whether a subject should be handled in depth, or whether, as regards a personally important subject, a need-oriented alleviation should be sought.

As an accompanying person, it is important to be noticeable, trustworthy and reliable. A long-term accompaniment is advantageous. Personal engagement such as home-visits or asking for more details are important and one's own flexibility and capacity to cope with stress are a good qualification.

The role of the doctor himself, as children's neurologist and/or development-paediatrician, is often that of someone medically responsible for a particular case, one who recognises the needs of the child and parents on the physical and psychic-emotional levels, and works together in a network with educators, psychologists, social-workers, medicinal therapists, and doctors of other specialist fields, especially orthopedists, gastro-enterologists, neurosurgeons, pneumologists, eye doctors, throat-, nose- and ear-doctors, nutritional advisers, Kinder Spitex nurses, orthopedic

technicians and help-resource specialists. With this large number of carers, a case management through one of those affiliated with nursing, psychology or the social services is important. Regular carer-sessions with complex children or those who are being integrated in the mainstream school are enormously helpful, clarifying, supportive and time-saving.

*Insights on the Accompaniment of Families with disabled Children or chronically ill Children and Adolescents:*

- The diagnosis of a child's chronic illness or disability always affects every person of the entire family system.
- All spheres of their individual and communal life, actions and feeling will be touched and changed by it.
- This is true not only in the present but also in the future to come.
- Correspondingly diverse and changing are those who accompany parents and the disabled child.
- The subjects and areas of life that have been brought up.
- The current stressors and resources, which in turn are all closely linked with one another and interact.

*Important Insights on the Accompaniment of Children with a Disability and their Parents*

- The child's conflict with its own disability and the current constraints in its own life constantly arises anew, with age and growing-up as far as puberty and adult life, and again more than ever in old age (premature degeneration, arthrosis, pains, post-operative afflictions...)
- The grieving processes of parents and affected children run asynchronously. At the first hurdle of the diagnosis, the children do not yet have their own share of understanding!
- The diagnosis itself and its significance is often not really so clear for parents and children as we as health-professionals assume: "But surely you've known this since birth" is not necessarily always correct! Who has ever really explained all of this? Who knows what they have understood and what that means for children and parents? Do we as professionals know in any case what they as the afflicted are thinking, what they "have"?
- In particular they do not know all the things (logical for us professionals) that can be consecutive symptoms of the primary illness (e.g. worsened postural control due to length growth inconsistencies, scoliosis and backache, new essential help-resources that were not needed previously...) and then they find that no one ever told them that all these things would get even worse, despite all the many therapies that they've been through.

*Ever-recurring Questions and Subject Matters in the Accompaniment of the Families of disabled or chronically ill Children and Adolescents:*

- Parent(Mother)-Child bonding corresponding to development and health. It concerns an acceptance of the child as a child with or despite a disability or disformity. This can lead to the child being hurt, to allocation of blame, to failure and denial. Possible themes: symbiosis (I'm feeling as well as my child currently feels, I understand every sign), over-protection (I am always there for my child, I owe that to him...), being able/having to let go, recognising the child's needs, interpreting, being to react thereto.
- Working on the child's point of view: self-acceptance ('I'm ok', as opposed to 'I am a total failure'), which must be corrected with therapies, operations or 'help-resources'.

- Upbringing: Setting up barriers despite so many limitations? Accompaniment of the child's striving for autonomy.
- Grieving Process: Detachment from ideas, life-plans, hope (replaced by therapy, miracles...) or resignation
- Guilt feelings (one's own or those of others) and follow-up treatments; essential medicinal measures.
- Questions of Meaning (Meaning of life, of the illness, of a life with illness/disability)
- Understanding illness, disability, behavioural symptoms: Translation assistance, clarification about normal development
- Questions about the future for the afflicted: what personality development is possible in any case, what is 'normal' in these circumstances, what freedom is there for an autonomous way of life?
- Parents' and siblings' questions about the future: Who will provide for my/our child when we are no longer here, when we no longer want to?
- Living with continual uncertainty and vigilance: no stable state of affairs, no end.
- Restriction of the individual way of life and quality of life (freedom)
- Limited time and energy: setting priorities, striking compromises; someone/something always misses out.
- Siblings: Impacts on their development, their behaviour, their psychic health. Recognising, understanding and accepting their needs – how to behave as parents?
- Problems with and within the carer system; parents' role as post-messenger.
- Finiteness of life, death and dying (prematurely)
- Particular: acute adjustment phase, shock