

An unexpected beauty?  
Quality of life? what are we  
speaking about?



On the photo of the cover of my book we see a 10 year old girl sitting on a terrace in the park. It is probably spring.

She seems intelligent, happy and relaxed and is looking through the camera with love at the photographer. She must love him or is it 'her'? Nothing in the picture shows the story behind this smile. The photographer certainly wanted to catch her smile, her love, this precious moment of that particular day.

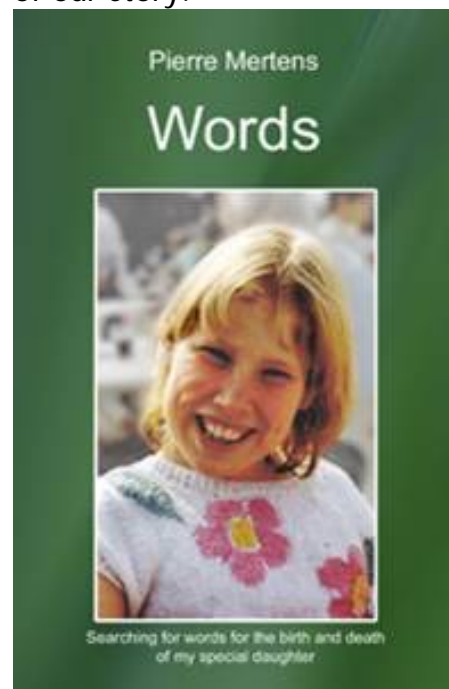
The girl is my daughter Liesje. Next day she went to the hairdresser. She wanted to be pretty to give flowers to the minister at the opening session of

the world conference for spina bifida her daddy was organising.

One week later she died due to a medical mistake.

The photo does not show the wheelchair she is sitting in, not even her proud parents at the same table and not what happened to her one week later.

It is the happy photo I wanted on the cover of the book of our story.



Photography is a lie, probably a bigger lie than words, because it seems to relate to reality.



The second photo shows a man fishing with 3 kids.  
An ordinary holiday picture of a family.

The girl on dad's lap is Liesje.  
She has some difficulties in finding her balance when holding the line.  
Her dad is proudly enjoying the normality of this simple moment.  
The proud dad is me.

Giving words to these images,  
I provide a frame to understand,  
to see more than an ordinary photo.

But these pictures are only one second  
of the lifetime of the four of us,  
not showing my wife Mol who took the photo.  
Not telling what happened before  
and after that wonderful moment.

This limited view on reality  
can be dangerous and subjective.



This is photography;  
it is a personal cut of reality  
made by the photographer,  
probably telling more about him  
than about the person in the  
picture.



To understand we have to see  
the larger picture,  
All photographs  
have to be seen in the larger  
context  
we often don't know.



Who is this lady with her dog  
taking a photograph of herself  
How would I photograph her?  
How would you do it?  
... And how would look the  
portrait,  
the radiography,  
her doctor made from her?



In other words  
'how and in what context are we  
looking at the other?'  
As a patient,  
a disabled person,  
a refugee,  
as an opportunity or a risk...

These questions are crucial when  
looking at other human beings.  
Who is the other?

How can I keep an open view on  
him,  
how can I avoid that my view is  
determined by reduction.  
Reducing him to how he defers  
from me  
reducing him to his medical  
deficit,  
his origin, his sexual preferences,  
his religion?

That is not easy.  
The only way to achieve this  
is to sit down and talk to him.  
Listen to his story,  
his dreams, his hope, his context.

When Liesje was born the doctor  
said that she was not viable.  
That she would die soon.  
He showed me the following  
picture

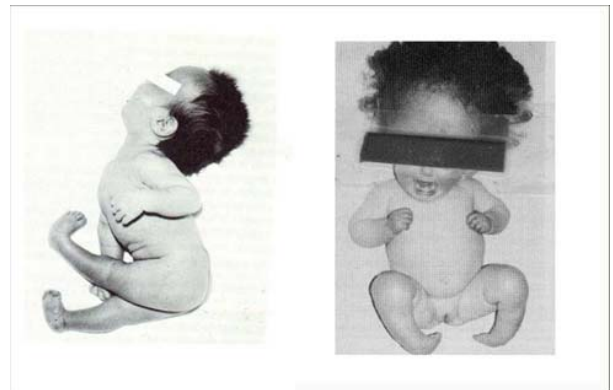


explaining me that it was clear  
that she had no brain anymore.

That she would never speak nor  
recognise me,  
that it was better as well for her  
as for us, parents, to leave her  
and not to destroy my life and that  
of my wife and other future  
children.

The only thing I could see on the  
photo was the skull of my child.  
A skull of a death's head.

But in the incubator  
there was lying my daughter  
she looked so normal, so  
venerable, so cute.



He showed me photo's of children  
with the same disability.  
Black and white photo's with the  
eyes covered like accused  
criminals in the newspaper.  
"No, you can not want this for  
your child. If you let the child be  
treated you will only prolong her  
suffering. This would be selfish  
and egoistic. She will die anyway.

The doctor presumed an impassion  
without hope and it made us  
passive and down;  
The doctor gave us an image of  
her disability with the aim to  
destroy the love, the natural love  
we as parents felt for our newborn  
child

The love so needed as a couple  
to survive this difficult period,

the love we needed  
to comfort and support our child.

It was my wife, who from the very start did not believe the picture the doctor showed us. Her Liesje, the cute girl in the incubator was different.



She looked with love at her child and saw her daughter and not only her disabilities...

This made that the words of the doctor paralysed me more than her. She was a mother. And mothers are strong.

It took us 3 months to get the correct information that led to the available treatment. To come out of this paralysing hopeless impaction.

Liesje was operated on much too late and that made her disabilities worse than at birth.



But she became a happy girl, full of life, she was loved and clever, went to an ordinary school and youth movement. She probably was the happiest child of the whole family.

I learned from Willy, father of a boy with a severe cerebral palsy to change my perception on disability. He spoke with so much love and proud about his son that I saw his beauty too.

I understood, speaking proudly about Liesje would help to overcome people's fear to coop with her. Because .... It's all about perception.



The destructive image the first doctor gave us was replaced by stories of other persons having the same disability. Stories of persons with spina bifida doing sports, enjoying life,

It gave us hope, and hope is needed, because education in a long term project.

Who spoils the child will create dependent and complaining adults. Who spoils parental hope pulls down the future of the child.

In these self-help groups I understood that the information the doctor gave us was only one view on her disability.

All the persons below have the same disability as Liesje, all have severe forms of Spina bifida.



Olga is a psychologist and a medical doctor from the Netherlands.



Sara, Italian, is a medical doctor too



Guro became a political minister in Norway,



Vicky married last year and is a Guatemalan lawyer. She was on Skype last week and told me she became mother of a healthy boy.



Jeffery is a world famous conductor working now for the opera of Napels



And Albert living in Belgium is 87 years old and is determined to go on in his nineties

These are the Barack Obama's of the spina bifida movement. Of course you do not have to become a doctor or a minister to have a valuable life. But for me as a parent it helped to have full life expectations to fight for a decent life of my daughter.

On the following picture I show you the difference in view.

The only difference is the photographer.



Left is the medical view, reducing a human being to its medical deficit, on the right side is the parents view focused on happiness and love.

It's all about a vision on quality of life.

What is quality of life?

When you sit down and listen to persons with a disability you will see that they are more alike you than they defer.

The quality of life depends on meaningful work, on love, on friendship, maybe on a good book, on music or art.

Just like for you and me.



Also the refugees have more similarities than differences with us, but what we first see are the differences. You see probably more your own fear than that you see the human being on the photos.

Liesje was lucky; It was only because she survived the first 3 months of her life -without any treatment- that we could correct the medical image that was given to us

With prenatal selection we would not have had the time to correct this wrong information.

Liesje was well accepted in her class.



She had many friends and her younger sister and brother were so proud of her.

After some time we noticed Liesje's talent to console, her humour, her fighting spirit and most of all her love.

All of these made her impairments of secondary importance.

Liesjes had the ability to console. She comforted us as well as other children.

Comforting means to me 'not walking away',

it means staying with someone even if it's unbearably difficult.

Liesje did not leave. She stayed. She taught me to stay at the crucial moment. She often helped us get through the most difficult periods, just by not running away.



Her life became a gift to us and to the whole family

The poor expected 'Quality of life' is used in the last decades to promote prenatal screening.



Prevention is the catchword in medicine today. The chances of bearing a child with Spina Bifida can be reduced by 75% by taking 0.4 mg of Folic Acid daily, from four weeks before conception and during the first 2 months of pregnancy.

That is prevention. The same child is born, but without the impairment.

Ladies, if you want to have baby, you have to take yet another pill, called Folic Acid.

If we had done that then Lies probably wouldn't have been born disabled and would by now be 30 years old.

Her life and mine would have been completely different. Yet I don't have any regrets. Her short life is the best thing that's ever happened to me.



These days babies are diagnosed not at birth anymore but during pregnancy, in the darkness of the womb.

Pregnancy is handled like a dangerous disease.

Whilst the parents marvel at the tiny nose and ears, on the ultrasound the doctor measures the circumference of the head and scrutinizes the back for abnormalities.

If an impairment is identified, the gynaecologist very often proposes aborting straight away.

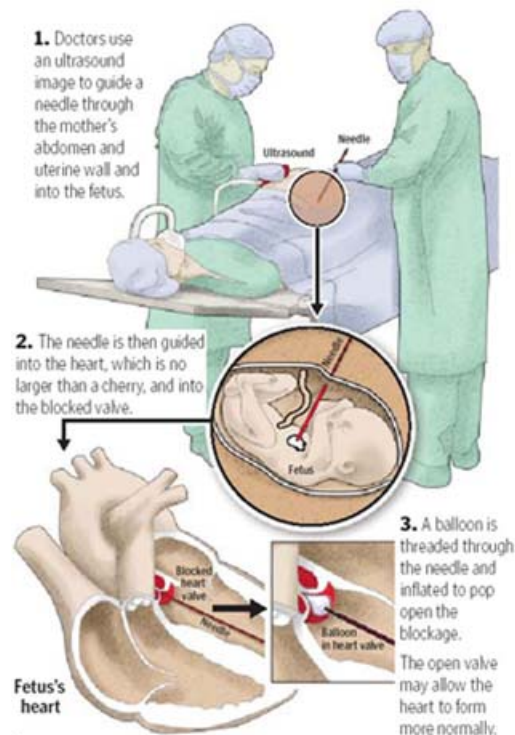
Because of the prenatal screening this information moved forwards in time and is not given anymore by a paediatrician but by the

gynaecologist who often never saw a child with a disability.

He knows Spina bifida from outdated medical journals. If the pregnancy is in an advanced stage, the child could survive out of the womb. To ensure that this does not happen a lethal injection is administered via the stomach of the mother into the baby's heart.

This happens even in the eighth or ninth month of the pregnancy. The procedure is clearly described in medical journals and the actual debate in Spain, the Netherlands and Belgium wants to legalise this practice

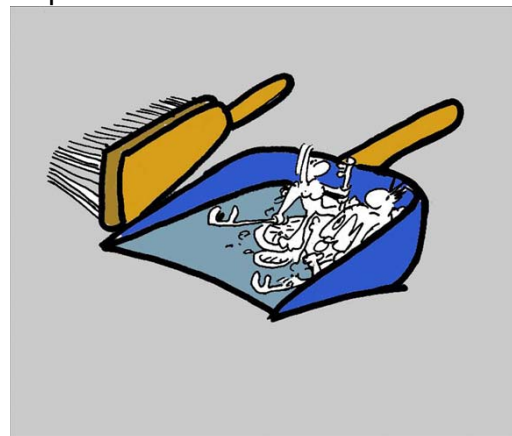
The incorrect one sided negative prognosis about the unborn child as given to us reducing the human being to his medical deficit can not questioned by a cute baby in the incubator. All is done in the darkness of the womb.



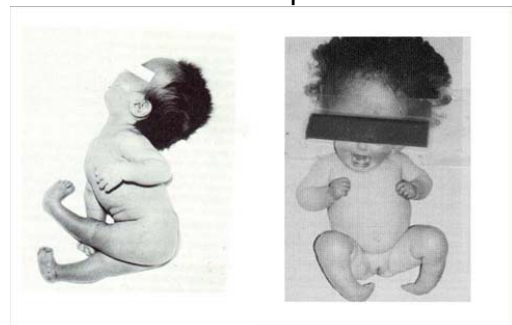
The parents are in a state of shock having just heard that their child

will be impaired. At that venerable moment the doctor suggests killing the child, with the argument that a life with Spina Bifida isn't worth living. The 'result' of the pregnancy is not viable.

Due to the fact that neonates with Spina Bifida are not dying as such, a group of physicians in Groningen in the Netherlands, are pleading to legalize active euthanasia in the case of Spina Bifida. They documented, in the so-called Groningen protocol, 22 children with Spina Bifida who were killed shortly after they were born with the consent of the Justice Department.



They feel backed by the legislation concerning euthanasia. By expanding this legislation to people who are unable to decide for themselves, they are preparing new legislation which permits the killing of children with an impairment.



To support this position the doctors sometimes show the photographs that the doctor showed us when Lies was born. Archive pictures of children with untreated Hydrocephalus with a black strip over their eyes, like criminals in the newspaper.



All religions agree with me, but this has no influence on the actual medical practice. All this I am telling you as a loving father and from a human rights' perspective.



The doctor's suggestion is called secondary prevention. But it isn't real prevention, it is murder.

The right to life in all your differences is the first and most essential human right. All international treaties and conventions underline this right and mention the right of all available treatment that can improve the life conditions of the individual.

I apologise for being bitter. But the systematic elimination of unborn children with a disability is probably as inhuman as any other war.



Euth

Together with Spina Bifida, other congenital anomalies of unborn and newborn children are detected and eliminated: down syndrome, cleft lip, heart diseases...

anasia advocates pretend that euthanasia and prenatal selection are ways of handling pain and they say they do it out of compassion.

Do you think a world without children with down syndrome is a better world?  
I doubt it.

But their compassion is often too much inspired by THEIR OWN fear

fear for everybody that differs from themselves



My daughter Liesje died  
But she was most of all a lucky girl full of life and love but her disabilities are seen, by many professionals as an extreme case where they think there is no discussion about prenatal selection.



They are wrong because their view is limited to the medical deficit focusing on the disabilities and not on the abilities and ignoring the human value of the person.



Lies' life was sometimes difficult but offered me so much.

The book is a tribute to my wife Mol

and to all mothers of disabled children world wide.

As I said, mothers are strong

When a mother from New York meets a mother from Nairobi, one will notice the similarities rather than the differences between them .



They recognize the issues which bind them because their conversations are based on their aspirations and dreams and also because they can share their mutual fears. Often they exchange very simple solutions for complex problems.

Social, cultural or religious distinctions hardly matter in these deep humane contacts. The feelings both of hope and despair are very similar all over the world

In this I agree with Barak Obama' speech in Egypt.

Let's focus on what binds us

Let's underline our similarities and not enlarge these minor differences



I became President too of a smaller country as US I presume of the size of Belgium. We estimate that there are worldwide 10 million people with spina bifida and hydrocephalus .

IF, became the international network of knowledge about Liesje's disabilities, and started projects in developing countries for children like her.

The alliance resulted in an efficient solidarity between persons with Spina Bifida of the North and the South. Between devoted professionals

and parents and persons with the condition.



In some parts of Africa the incidence of spina bifida is higher than here.

A disability combined with extreme poverty is far from easy as you can imagine.

Developing total care for spina bifida in the African context made us experts in what is really needed. We have no money to spoil on useless investigations and treatments

We only do what is really needed, but what we do we try to do better.

Something we here in the North with the immense economic crisis we can learn from.

If we make the right choices we can do better with less.



The last decades we've seen medicine in the North evolving to an overactive high technology and this new knowledge has to be translated urgently into real help and efficient care.

This is not easy because healthcare is organized by a long chain of people and institutions, starting with Obama, his ministers, health economists, insurance companies, sick funds, hospitals, the pharmaceutical industry, specialists, physicians and nurses.

Each link has its own focus, agenda, interests and responsibilities and often approaches, that very one issue he is focusing on, with a kind of tunnel vision.

The medical specialist often enlarges only one detail and may lose sight of the total picture.

In the north this results in an unaffordable overactive and splintered healthcare.

The patient becomes visible only at the end of the chain, exactly in the place where real care should have started.

Especially persons suffering from a chronic disease, those who can not be cured they need care and a holistic approach putting the total person and his family into the picture

Unfortunately doctors are mainly trained to heal. When cure is not possible many of them run away and care is not provided.

That's why Spina Bifida teams with good coordinated care

started 30 40 years ago but some of them are closing their activities



Budget cuts are done by hospital managers  
They calculate the commercial value of each service.

Coordinating and holistic care need time to sit down and listen to the person. Counseling is time consuming and time is money.

When this working time is not rewarded financially, health managers will cut in these services.

Coordinated care has proved to result in better medicine,  
These cuts will lead to more health consuming and less quality of care

From our own practical life experience we have a say in what really helps and what not.

We do not want investigations or treatments if they do not contribute to the improvement of our life-quality.



I believe that in the care of chronically diseases selected professionals and selected parents and patient organisation should work hand in hand

Under the 'motto': 'beginning at the end of the chain'. IF helps yearly hundreds of children with spina bifida in six African countries.

The cooperation between persons with the condition and selected devoted professionals showed to be successful.

Together with other NGO's like the American Cure and Bethany Kids, the Italian AVSI we have developed top neurosurgery and have more that 6000 children in neurosurgical follow up.

Let me share with you two of our successes



What you see here on this slide is top medicine.

The lady washing her hands is Hidaya she is the mother of Amina a 10 years old girl with Spina Bifida.

Hidaya is training in Dar Es Salaam other mothers to perform CIC, Clean intermittent catheterization

With CIC in combination with intravesical Oxibutynine we get all

children with the neurogenic bladder dry and infection free

The urodynamic investigation is done with a feeding tube and a measure tape kidneys controlled by Ultrasound

With this early treatment we avoid all urologic surgeries and kidney damage



Amina did the CIC herself from the age of 4. Her story motivates the other parents.

For bowel management she is performing a bowel washout every second day and also her incontinence for the bowel is under control.

We where able to publish our results and method in an invited article in Paediatric Nephrology



All this is done at low cost with local produced technical aids. and with counselling and training.

Only when a mother understands why she has to do 4- 5 times a day CIC and only when she sees results for her child she will motivated to do it.

Have a look at this photo



These kids have no parent to care for them. The little boy has Spina Bifida and is treated by our projects. The 12 years old sister is taking care of the CIC of her brother.

Do you see the blue point?  
That's the catheter.  
You can imagine to have this tool available and the management done in the context of the slums in Kampala it is a challenge but for the boy it makes all difference between smelling and being excluded or inclusion in the society.

In Africa we use one catheter of 25 cents per child per each 3 months here we use 5 catheters of 1 USD a day 25 cent compared to 5 USD 90 times is 450 USD  
And we have not more infections that in the North.



And other example of cheaper treatment is the shunt.  
IF introduced the Indian made Chhabra shunt, for treatment of hydrocephalus, the price of 30 USD a piece, The drain used in the North that costs more than 1000.USD

IF made these drains available, free of charge, but many Latin American and African surgeons refused to use them.

They only wanted to work with the same material as that in the North. They blamed all possible complications on the cheap drain.

The complications had only to do with their operating technique and insufficient sterility.

That's why IF set up a comparative study in Uganda between the Indian Chhabra and an American shunt. The researcher didn't find any relevant difference between both drains.

Only after publication of the results in the Journal of Paediatric neurosurgery, we were able to force our partners in the South to use the cheap drain.

In 75 % of the children in Uganda and Zambia we operated the hydrocephalus, without placing a shunt but by an endoscopic intervention, to make an opening in the floor of the third ventricle.



In this way a natural bypass is created without a drain. This solution means a considerable economy in expenses and avoids all possible complications related to implanting a shunt.

These results too have been published in the Journal of Pediatric Neurosurgery which, at the same time,

are influencing and improving the care of children with hydrocephalus in the North



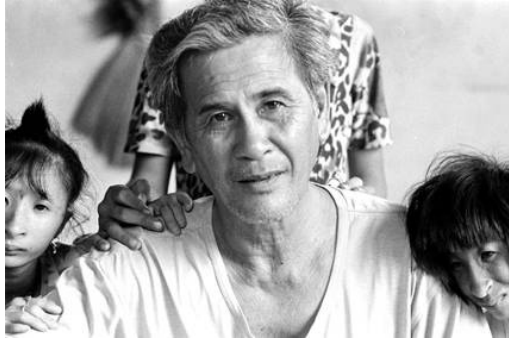
And for me it all started with Lies. And each time I think about it, I wink at the painting I did of her and say: 'Liesje, we did it all together, you and me.' Just an image, but for me it makes all the difference.



I believe that special people play an important role in contemporary society where everybody is competing to have an ideal weight, colour and career.

Disabled persons are questioning the common lie that all pain and suffering can be solved or prevented.

Before I conclude I want to share with you some pictures made by Mr Minh in Vietnam



These are all children with congenital disabilities probably caused by Agent Orange during the Vietnam war.

In collaboration with Handicap International IF started projects for them too. I like the position of the photographer who focused on the love of the caregiver.



In a first stage the image of the child is frightening, but focusing on the mother the image becomes an image of love.



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To conclude: do not trust the photographer, even not the photographer in yourself, who often takes a simple image underlining difference.

But listen to the other. sit down look with him, over his shoulder, in his direction, and you will find the answer unexpectedly.

Maybe you will find an unexpected beauty like Liesje certainly was for me.

Pierre Mertens  
President IF  
[www.ifglobal.org](http://www.ifglobal.org)