

*“You should not only design products,
you must also design your life.”*

B.

The Story of an Engineer with a Disability

This portrait of Bart is a result of the cooperation between
Bart and Matthijs Van Trigt,
commissioned and supervised by SIHO

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Introduction

The portrait

Bart is an engineer who mainly works on prototyping and 3D printing. For the past year, we have been working together on a portrait of him. This resulted in a written story, photos and a spatial work, connected by the story of Bart.

To show who Bart is, a written story would be insufficient. A big part of his life revolves around making objects. Also, images can sometimes say more than a thousand words.

Short facts about Bart

Bart is a male engineer, who is appointed as a project worker in higher education. He is particularly concerned with prototyping and 3D printing. Bart is 31 years old and has a 6 year old daughter and a 3 year old son.

He is someone who sees work as a ‘way of life’.

Lieven, a colleague and friend of Bart, characterizes him as follows:

*“I think that Bart is greatly intertwined with his work.
[...] I think he is someone who lives on targeted
projects of which he quickly sees results.” (L.)*

Bart told in one of our conversations how he had learned to love the world of design and prototyping:

*“In primary and secondary school I was one of those students who did his best
for good grades and sat in front in the classroom. [...] When I went to college ... I chose a
direction where I could make things and where I could create things, that’s what appealed to me.*

*Suddenly you begin to notice
[...] that who is teaching you has a great influence on you and
shows you that design is a way of life.
You should not only design products, you must also design your life.
And then you get slapped in your face quite a few times. Yes, it's true, how will I do that?
And you start to think ... [...]
I think that's personal, a state of mind. That you feel like: "Yeah, I'm in a good direction." (B.)*

In his spare time, Bart works on remote controlled cars, is busy making things for friends and working on his house. Bart is also someone who likes eating. He is, according to Lieven, always the one who sends invitations to eat out in the afternoon. He also likes to go to rock, metal and gothic performances, although nowadays he's not going to many concerts anymore. Now he must devote more time to his children.

In conversations with Bart he seemed very open, but only to a certain level. For example, I only came to know after several interviews that he has children.

This was also something Lieven remarked in our interview:

*“In communication on work, Bart is very direct.
But when it comes to personal, emotional matters, he has more difficulties to express them
[...]
[Bart] also uses humor as a shield. By making a joke about it,
you sometimes laugh it away. I don't think that Bart is someone who will communicate about his
feelings in a very open way.” (L.)*

Besides his dysmelia (a physical disability characterized by deformity or absence of one or more limbs (Encyclo MMX, 2012)), he has an assertive and problem solving attitude. He is someone who seeks solutions for arising problems. Perhaps this is a general characteristic of engineering:

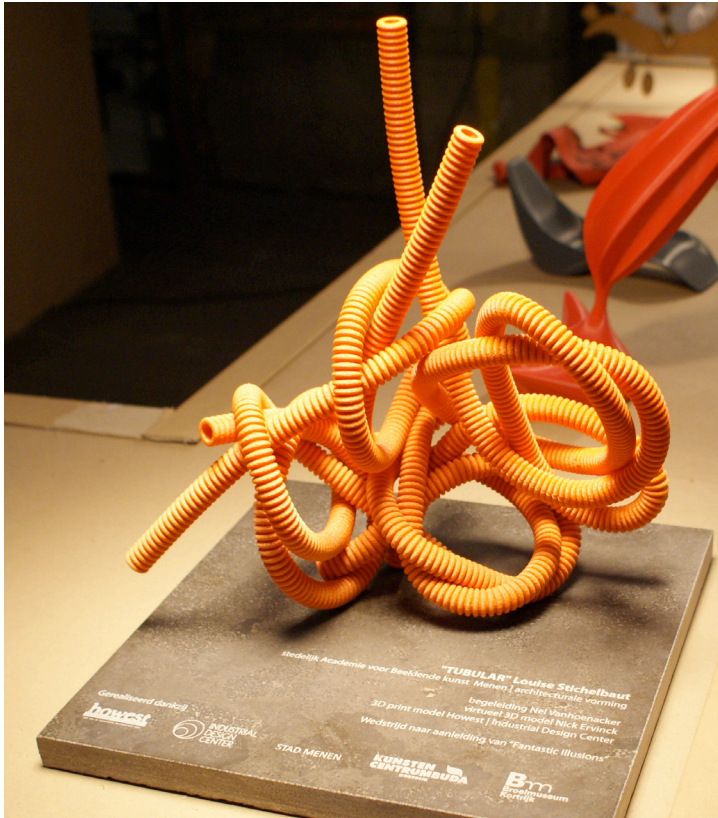


Figure 1

This 3D printing is very complex. It seems almost impossible to draw on the computer and then print it. This can be an assumption with studying and/or working with a disability. However, this is no excuse not to do it.

Note: The original artwork doesn't have this meaning, but is used here as a metaphor. The work is the product of a collaboration between students of secondary education, B. and an artist.

Taking life in your own hands

The road

Bart describes independence as a road he has traveled. From the small adjustments that were arranged for him in his youth to taking the necessary adjustments in his own hands today.

“Both in the kindergarten and primary school there were friends.”

[...] A number of friends who help you, your bosom friends, who you play with the most.

That was important I think. Those who help you cutting paper if you are unable to cut those things... Those things I remember. Or those who help you get in the bus if there is a trip to Bellewaerde [an amusement park in Belgium], etc.

I think it's important that you have a number of people who believe in you and who are present. [...]

In primary education, I came to school with a bike.

It wasn't easy to put the bike in the bicycle storage. Because I couldn't reach it very well, there was another place where I could do that, where there was a ramp installed. The carpenter, the boyfriend of someone at school, had made a ramp of wood. These things are only normal and there are few schools or contexts that would have refused to do such things.” (B.)

Bart says that, before secondary school, he never thought about the fact that there are many obstacles possible in a life with a disability. He only noticed that when he transferred to secondary school:

*“I’ve never really stopped to think that it could be a problem,
but once you go from primary to secondary school ...
You do different schools, you are going to open days etc.
That was the first time I noticed ‘tiens’*
the one is less open for that than the other. When I went to one school,
it was clear: “Yes... Look... you can come here...
We can’t refuse ... but you must not ask too much of us. “
While there was another one that immediately admitted me...
Which gives a very different feeling. That was the first time,
showing that there are people who are not open to it [a person with a disability, MvT],
while I totally was not used to that[...]*

* ‘Tiens’ is an expression of being stunned or astonished in the Flemish dialect.
Its origin lays in the French, meaning: like that.

In secondary school, for instance, the director talked with me [about supportive measures] and then I actually got a minimum of things to help me, which perhaps... Were they necessary or not, that's not the point, but simply: "Look here you have a place in the parking lot, so your mom can bring you closer to the entrance".

When I had a bike that I used to move between the buildings, there was a space where I could put it. There was also a lift in a particular building, which was only accessible with a key from the staff. I also got a key. [...]

I think it's important to not have constant assistance, like: "everything alright, do you need help?" that is not necessary.

On the contrary, it has a counter-effect. But knowing that there are some things ... In college it was far less... Everyone assumes that those who come to college are already mature. [...]

But if you need anything, report it." (B.)

Bart chose prototyping, a part of the industrial engineering course as a designer where working with machines and making models are more important. This is not an obvious choice, but illustrates the assertiveness and perseverance of Bart.

“Of course it is expected from the school that you can do that many things, but there are always sideways if you can’t do things for one reason or another. Then you can do something else or you can focus more on the computer drawing for example. I’ve never had that case, I think.” (B.)

The training was a bridge to independence for Bart:

“Should I not have had higher education, I would probably have more problems now. (B.)”

Bart considers it very important that he could count on the basic support of others in order to grow.

“I think you can achieve much if you can count on a minimum of support. [...]”

*I once chatted with someone, who was a bit in the same situation and then you hear:
“Oops, he has that and had that problem and I actually didn’t have those problems, how can that be? Ah, thanks to people that I knew, who helped me with the ‘basic’ things.
When you then hear of stories ... Oops, they have problems with those basic things, either at school or in a different context... Because they didn’t get those few little things, which I received as aid or as a gift.” (B.)*

Bart articulates the help here as a gift. He is also very grateful for the support of his parents. Especially now that he has children, he realizes how much work his parents had in his upbringing. Bart had to have more exercise when he was young. His doctors recommended him to go swimming.

“It’s not so obvious to learn such a child to swim of course.”

[...]

My mom said she got her driver’s license especially for me, to be able to go to the hospital [...]

I must be honest, I don’t know if I myself would muster so much. [...].To get such things done.

For example swimming lessons, going several evenings each week and

going to the physiotherapist [...].

And going to that hospital for research...

Many of these things were in Ghent or Brussels, at that time that was a huge distance. [...]

As for the swimming it was more like: “Look, I’ll take you there, but you have to do it yourself “. [...] I have not much patience, I like it when things progress fast. If you hear afterwards that it took years before I could swim, probably...” (B.)

Assertiveness and expertise as means for taking control of life

Bart considers it very important that you tackle problems yourself:

*“It’s not because you have a disability, you have a reason not to do things
[...]*

*If you don’t get anywhere, it is not that the world is against you, but rather that you ruined it
yourself... usually [...].*

You usually have the possibility to do something, if only something small.”(B.)

Bart believes that the disability should be subordinate to what you want in life,
although he also corrects:

“Try to do something that you enjoy doing.”

Whether you have a disability or not, actually that’s secondary.[...]

*If someone had to come sit next to me, for example, 90% paralyzed, he would probably have
a different opinion. Like: “Yeah, for you it’s easy to talk, I mean if I don’t have an elevator, I can’t
get where I should be. I depend on someone”. That is something completely different. [...] I see it as
purely personal, my situation and my opinion is also subject to change.” (B.)*

According to Lieven, *“Bart is the living proof that with the right attitude, you can achieve anything in life.”* (L.)

To reach your goals, you have to demand your place in the world. According to Bart to do this, in addition to a strong personality you also need expertise.

“The outside doesn’t really matter, it’s about what you can offer, who you are.” (B.)

He sees expertise as a means to minimize the role of his disability in his work and life.

“I feel that if your expertise on another field exceeds the disability, actually nobody looks at your disability.

I mean that it isn’t even an ‘issue’ anymore than. Except that one time that people will ask out of politeness: “Do we need to provide something special for you?” (B.)

Practical tools

Bart is an engineer and his job is to develop solutions. He has practical tools that support him in his daily life and his work. These are mainly tools for transport. He has a custom bike in front of his office for when he has to go to another building. He also has a custom car.



Figure 2



Figure 3



It's easier for Bart to have a parking space close to the door, an elevator in the building and handrails on both sides of the stairs. He emphasizes that he finds it important to search for solutions for himself and not to wait for solutions of the employer.

Figure 4

Expert

Association for thalidomide victims

After the birth of Bart, his parents have been affiliated to an association for parents of children who, by the use of thalidomide during pregnancy, developed physical disabilities.

This association was started in the sixties, after the consequences of the use of thalidomide during pregnancy became known. Although no more new victims are born (thalidomide disappeared in Belgium in 1963 completely from the shelves of pharmacies (Anicki, 2009)), Bart is still active in the association.

*“Obviously there are no more victims of the same cause,
still there are people with similar conditions, namely on the limbs.*

[...]

There is still no way to exclude such things apparently.” (B.)

Bart tells me that he sees himself primarily as an experienced expert who can help others. His life also develops and changes can bring new obstacles for him and his network. For example he is father of a daughter and a son for several years now. When he experiences difficulties, he consults with the members of the association.

Bart himself says that he doesn't really stops to think why he is still active in the association. The reasons he gave in the interview however appear to be valuable. The association combines the possibility to learn, to get information and especially the possibility to return your own knowledge to others. Next to that, it is also a place where his children can see that Bart is not the only one with this disability.

Project 'Design for (every)one'*.

Bart is someone who often puts things in motion. This is an important facet of his job. He works as a project worker and must always start up new projects to extend his contract with the college where he works.

Bart has been working for 4 years on a project that makes support tools tailored to people with disabilities. Again Bart puts in his knowledge and experience to help others. Bart is careful to say that the reason that he is interested in support tools is really because of the fact that he has a disability of his own.

* For more info see: <http://designforeveryone.howest.be/>

“As a designer, you should not make the mistake to take yourself as a reference”

[...]

It is of course a different approach because I myself am an experienced expert. It's nice when you suddenly see two things come together, you notice: “Wow, in my professional environment, it's meaningful”. That helps, it's an additional motivation or it's a different approach, I think. I try... I'm not going to say really to draw limits... But I try to keep seeing things a bit apart. If I hadn't had this handicap, I think I would probably have the same interest. I mean there are a number of colleagues in the process, who do not have disabilities and are also very much committed to the subject. I think it's a bit separate from it. Maybe the only thing is that sometimes I can empathize more in it. Maybe that has a little bit influence, probably more than that I think, but it's not that I think about it a lot.” (B.)

It struck me that Bart didn't really let it shine through that he was one of the founders and driving forces of the project, something I came to learn later in an interview with Lieven, a colleague and friend of Bart.

“Design for (every)one was actually created out of a teaching assignment.”

There was a need at [the college where Bart and Lieven work, MvT] for a teaching assignment in which rapid prototyping research, that which Bart is also doing at this moment, is integrated into a teaching assignment. Then Bart began to look interdisciplinary at occupational therapy. Then one basically has been given a one-off design assignment. The responses to this design project were very positive and everyone had a gut feeling: “There is much more in this project“. [...] Design for (every)one has actually grown to this day as more than just a teaching assignment. It has become a line of research integrated into education.” (L.)

Prejudices

Searching for the field of tension

Bart is a designer who according to Lieven can find and break the tension in prejudices about his disability in a very personal way. Lieven told about his first meeting with Bart:

*“**F**or many people, when they meet Bart for the first time, you notice that they are a bit out of their comfort zone, they feel a little uncomfortable. Bart is someone who immediately kicks that door open and makes a practical joke or a very striking remark. What you actually totally wouldn’t expect. Making you automatically feel at ease very quickly.” (L.)*

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Bart himself also tells about how he sees prejudices and how he deals with them:

*“I think it’s the same as if you would meet someone
crammed with piercings and tattoos. [...] You’ll think that he or she will be a bit of a marginal, although he can also be a R & D manager
from a company who just chooses to look like
a punk on weekends. I find that interesting to play with. [...] I also never
wear a suit [...]. At exhibitions or
meetings that’s especially fun sometimes.” (B.)*

Bart can also point out pitfalls around prejudices about people with
limitation his colleagues, because he himself has experience and “*is not afraid to kick the sacred
cows*” (L.). Lieven remembers a conversation with Bart about stigma:

*“Recently we were working on stigma and Bart said also:
“You shouldn’t eliminate stigma, a little stigma won’t hurt.”*

Sometimes we think: “Everyone should be fully integrated...” But sometimes people, at certain times in their lives, want others to see their disability because in that way they don’t have to ask for help, but receive it automatically.” (L.)

Experiences with prejudice

In our conversations Bart told me about some events from his life that touched me as a researcher. They were examples of how Bart addresses bias.

“If you need to convince someone that you aren’t a pushover, usually I won’t even bother to talk to that person.

[...]

*Once I took a walk in the neighborhood where I lived. In the village there was a very large institution for people with mental disabilities [...]
You know... in such a village, where people come out and the neighbors chatter rather quickly.*

*Until someone brave enough came to me:
“Are you lost little boy, are you escaped from the walls of the institution, do we need to bring you
back?” Then it’s like: “No fuck you!” [...] and that’s funny then [...] That’s just because they know you from that context.
[...]*

*When they are so very friendly, like: “Oh little boy
and how are you... and ah, you are from here and you work in the
sheltered workshop probably then? “[...] Then it’s: “Actually no. I’m an
engineer [...]. At those times you must prove yourself because their first
impression won’t go away directly...” (B.)*

Lieven also spoke about how at the first contact with Bart, he had some concerns about whether Bart was in the right place in the course for engineer.

“In this drawing lesson, the first day, I thought like: ”

‘Gosh, are we going to have to help? ‘

You have automatically something like ... it’s not really a stigma, but a bit of a motherly aspect ... if you see someone with a disability

But really the only thing that had to happen was helping to stick his paper to the drawing board and ‘that’s it’. And it became even more impressive. Bart traveled throughout the training focused on prototyping. What we did half as good with two arms, he did excellent with one arm. In retrospect, this was for me a very meaningful experience. Studying and working together with Bart has shown me that my image and attitude towards people with disabilities was completely wrong.” (L.)

Working as an engineer

An image of a colleague

Bart has a very direct way of dealing with people. In the interview with Lieven he tried to explain what is so special in the way Bart works with people:

*“Bart is someone who immediately kicks that door open
and makes a practical joke or a very striking remark. What you actually totally wouldn’t expect.
Automatically making you feel at ease very quickly.
In this way he manages to let people collaborate and communicate in a totally different way and
gets things done. When I take Bart with me to a meeting you’ll notice a totally different
dynamic. [...] Sometimes it’s in the little things. If we arrive somewhere and there is
no elevator for instance or no stairs, people are quite often embarrassed. He makes
a certain remark about, but in a positive way,
making people feel at ease.
[...]*

What I also like about Bart that he dares to go that little bit further, verbally, than other people would dare, because he knows that he can.[...] It's not that he wants to hurt people. If something is not right [...] then he'll say it directly. Then he makes a comment, a bit sarcastically, with a cynical undertone. Not that he does that in the professional context from day one. But rather in a work or student environment [...] and you see that some people are perplexed, you wouldn't expect that. But over time it changes, and then people will shout back sometimes and in that way you have a real fast integration.” (L.)

According to Lieven, Bart had always been one of the best in prototyping. This manifests itself today in the fact that he's a bit the leader of the workshop.

*“**W**hat we could with both hands, he did four times better with one hand. [...] Bart is also a practical man. In his prototyping he's always very practical in the sense of, it should work and it should be achievable. [...]*

*He is very focused on result [...] He is very practical yet he sometimes loses the overview. Sometimes he may be a bit lost on the practical side. Then he can be so focused on such a detail that I sometimes think:
“Now wait a moment, let’s go back two steps and let us first consider if it’s worth to work on that detail.” (L.)*

Bart is also accustomed, from his prototyping vision, to work in the form of ‘trial and error’. Lieven noticed that it’s important to have a good planning when you work like that. Bart is very good in the planning of projects:

*“**B**ecause Bart takes enough time and because he also knows that it will always go wrong. He always calculates a buffer. [...] His technique is: “Even though I don’t know, I’m just going to do it, I have time enough to mess it up early enough and still be on time to go in other directions.”
[...]*

We [the colleagues] do not see him as someone with a disability, he goes along on teambuilding, he does everything. Usually we find a way for Bart to participate.” (L.)



Figure 5 (left)

Figure 6 (right)

Work and disability

Bart has a very versatile job. Part of it is the organization of exhibitions. About this he told me an anecdote in which the tension between his disability and his expertise was exposed by his recognizability. He says he is frequently recognized. He suspects that others remember him mainly on basis of his disability, but that people then continue to remember him because of his technical knowledge. His expertise and disability strengthen the extent to which people remember him. That's his advantage according to Bart in terms of networking:

“Then that’s so... yeah... that person didn’t recognize me just now because I have a friendly smile. It is probably that he remembers: “It’s that guy of [the city where Bart lives, MvT], the curious guy”. Then I think that plays in my favor. That can be a nice sometimes. First, they recognize you by your disability and if they see you again they remember you by your expertise.” (B.)

Bart believes that you should take your life in your own hands. However, he says that he had to grow in this assertive attitude.

Bart thinks that employers shouldn't be afraid of a disability.

He believes that having a disability should not be the main reason whether or not you can be recruited. An employer should consider the capabilities of a person rather than the things which he or she believes would constitute an insurmountable problem.

Bart gives an example in which a former employer used him as a sign for the “goodness” of the company. This struck me as an orthopedagogician, as someone who is concerned with the life, rights and possibilities of people with disabilities. This was also one of the reasons why he had left the company. But for him it was a particular problem that this vision of the employer overshadowed his skills as an engineer.

Diversity and variety of work is important

The work of Bart is, according to him rather a ‘way of life’:

*“Actually, that’s also my hobby... why not, it’s not that it’s a heavy burden.
[...]
I’ve always had the freedom to do what I like, to be a little proactive...” (B.)*

He does a lot of different things and that fits him well. According to Lieven this is also a result of his job as a project assistant.

*“He has developed a kind of strategy, especially here at school
[and not in his personal life, MvT]. He jumps on a lot of things coming his way, because he hopes
that somewhere something will come out of it later.
And [the project around support tools for people with disabilities,
MvT] has also been something like that. [...] He is also a project worker, he is deemed to recoup
himself [...] He has to plan his own projects, he must ensure
that each year he has a project [...]
And so you see that he actually jumps on the initiatives on
offer. What we have tried to do is to synchronize those things now.
So that they fit within the ‘bigger picture’. [...] For example, now, when we get a
project [...] then we say, “Hmmm,
we can use it for Design for (every)one? “. So you actually thicken your story
and not always work on short term projects, complete... and
stop there.” (L.)*

Bart likes the alternation, because that makes the work mentally and physically easier. A whole day at the computer is nothing for him:

*“**D**oing both the PR side and coming out,
but also having the technical knowledge so you can always answer questions properly. (B.)”*

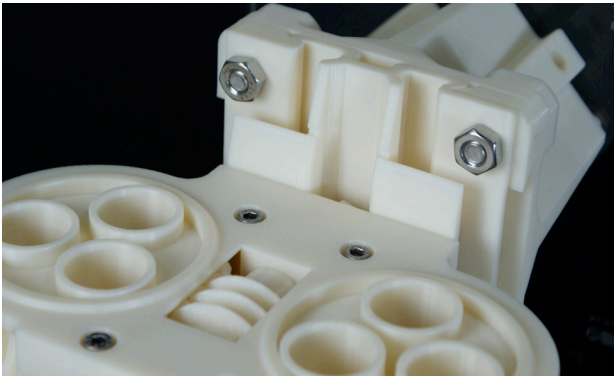
The basis of his job is the service, working with companies. This includes making prototypes and models and designing. He often works on a part of the project. That’s why there is a lot of variety in his work.



Figure 7
Workshop (top left)

Figure 8
Detail of work (bottom left)

Figure 9
Scale model of an elevator (bottom right)



The office of Bart is located just next to the workshop of the college where he works. He helps students where necessary with the operation of machines and technical questions. He is a technical counselor. If he sees motivation in the students he goes for it, but if they don't want to make any effort, he won't either.



Figure 10
Giving a workshop.

Bart is also a research associate. Additionally, he helps organize seminars and exhibitions. This means that he is responsible for the content (invite speakers, explain things, ...) and the organization (delivery of machines, provide food and drinks,).

Bart organizes an annual summer school for young engineers with his colleagues. This is an intensive course where the participants can explore some topics of engineering and design in a more profound way. Bart likes the initiative, especially since it has grown ‘bottom up’.

“*F*un to do.”

[...] Not so easy for me to sleep in a tent, it's not necessary, but actually I do it just because it's fun.” (B.)

Figure 10
Summerschool.



*“**F**or me, Bart is the living proof “
that you can create many new opportunities
from your limitations.”*

L.

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