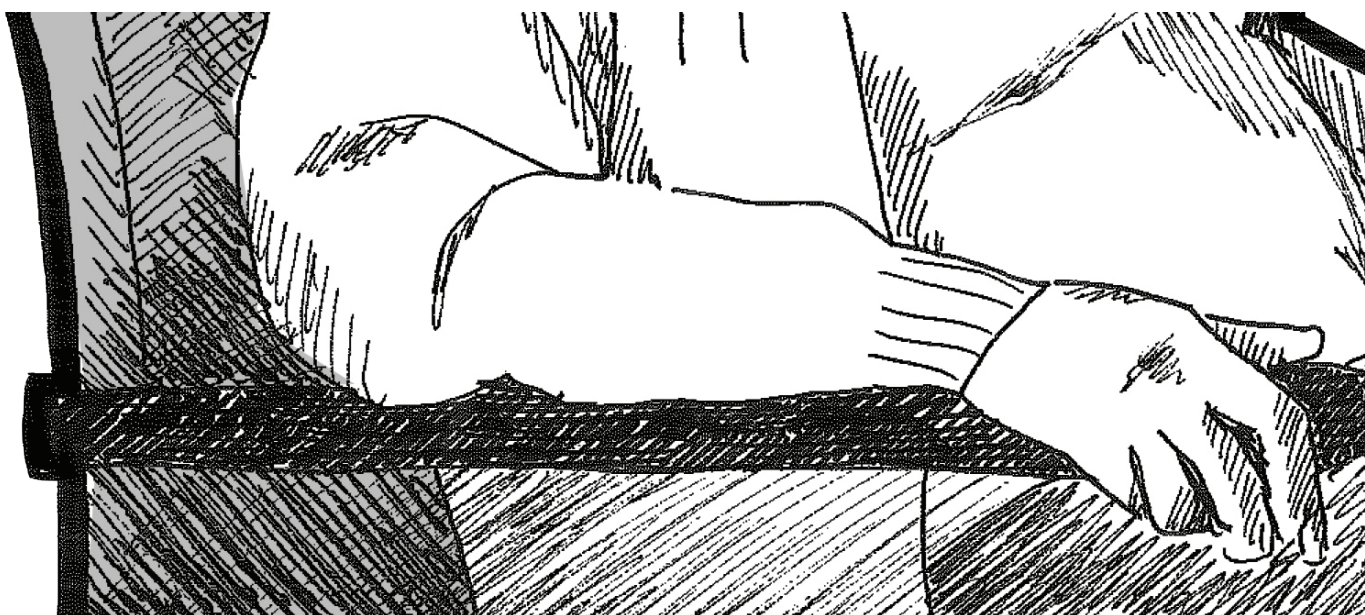


Real-life care stories



10 portraits



waag society

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The names of the persons involved in this publication are fictitious for privacy reasons.

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Foreword

When does an innovation really meet user needs? Can technical applications be as simple to use as a toothbrush or a bicycle, things which – perhaps after some small adjustments – we can all adopt? Can elderly people understand technology, and do we really understand elderly people? Naturally, this last question holds the secret of successful innovation; development is something you do, not for the project, or for science, not for compliments, however well-earned they might be, not for the show or for the design, but for the user. Innovative applications can only be successfully developed together with their users.

The Health-Lab within which AMSTA works together with scientists, designers, educational institutions and instigators employs a creative process in which the knowledge that benefits care is acquired by care clients, and the residents of care institutes take an active part in this process. In fact, they live in the middle of it.

Products and services can only be made to meet people's needs if you listen to users impartially. Don't decide for them what they can or cannot do; watch carefully, and let them speak.

Leo Versteeg
AMSTA

*What works on paper and what
happens in practice*

Introduction

“They’re people, after all.” This comment by a care provider about her clients might seem self-evident, but in practice we often lose sight of the people we are devising solutions *for*. Despite the best intentions – we all know, after all, about rising levels of care demand and the impending shortage of capable care staff – most decisions still appear to be out of touch with users’ actual living situations. While everyone talks about ‘user-oriented design’, instances of actual user involvement are often hard to find.

If products and services are to be developed which are a good fit with users’ perception of their environment and needs, then these users have to be given a central role within the development process. And not just at the end of a project, to test finished concepts, but from the very beginning, in an iterative process that makes space for inspiration, new discoveries, and new lines of thought. This kind of open and reciprocal process yields important insights into users’ perceptions of their environment – such as the gentleman who was very willing to take part in the research project, but who also wanted to keep his privacy intact, and therefore only wanted sensors in his house if he could also switch them on and off; the care provider who explained that the world of her care home clients had become so small that they could easily be overwhelmed by anything new; and the old Surinamese woman who spoke so little Dutch that all communications had to go through her daughters.

While working as a design researcher and a concept developer, both specialized in user-centred design, we have regularly come up against the fact that what looks good on paper does not always work in practice. Even though the Health-Lab is in principle a user-centred design organization, in practice we would find that situations and choices had not been adequately attuned to actual users. We would arrive at an address only to find that the resident, to whom we had written to announce our visit, could not read; interminable, inflexible health questionnaires had to be presented to seriously ill people; or multiple power sockets had to be installed before a wheelchair-bound resident could switch the interactive lamps he was testing off and on himself. We started citing such experiences to demonstrate to our project partners and the wider world how important it is that you know enough about your real-life users. When it became clear that these anecdotes were having an impact, we decided to compile them so that they could be shared more widely. We hope that these accounts encourage others to involve users in the decisions that affect them, to develop more empathic research methods, and ultimately, to generate better applications for end users. ‘End users’ are people, after all, each with their own story and their own desires.

The human stories related here are based on interviews with the residents of a number of different AMSTA care homes. The names have been changed to protect their privacy. For the same reason, the portraits are a collage of drawing and photography, so that they reflect reality without being too recognisable. All the people mentioned in the stories gave their permission for the material to be used. We hope that these stories serve to inspire designers, policy-makers, project developers, and all those developing care products and services.

Miriam Reitenbach and Marise Schot
Waag Society



Freek

“I prefer to manage my own affairs.”

Freek is a middle-aged man of sturdy build. His home is filled with gadgets; he has a laptop, a flatscreen TV, a digital camera and – his most recent acquisition – a smartphone. He has been working out how to link these devices together, and has just succeeded in viewing his holiday photos on the large TV screen.

His busy programme leaves little time for contact with other residents. In the mornings he is usually at his desk, or in his words ‘the office’, dealing with ‘business’. He arranges everything via his computer: his holidays, appointments with friends, and his role in the Client Council. He stays up to date by reading magazines and newspapers. He goes out once a week to attend a radio broadcast. He has a drink with friends regularly – sometimes, by his own account, one or two too many. Right now he’s researching into the possibilities of doing a Spanish language course, because he likes going to Spain on holiday.

Friends often visit, but sometimes he needs a day off to rest. He also has to lie down at some point during the day, and keeps a schedule to make sure he gets the rest he needs. Sometimes he will fall asleep, but if that doesn’t happen he listens to the radio or watches television. Three times a week he goes to a physiotherapist in the care centre where he lives.

He is a straightforward man who speaks his mind. If he doesn’t like something, or there’s something wrong, he will say so. And he’s not too proud to ask for help, if it means he can become more independent. For every problem there’s a solution. He frequently travels on public transport, for instance, and if the doorway step is too high, he will just ask a couple of strong-looking lads to grab his wheelchair and lift him in or out. He often does his own shopping, and he arranges a Christmas tree for himself by asking the seller to tie the tree to the back of the wheelchair.

In the morning someone always drops in to make a cup of tea and turn the heating on. But he looks after his own medicines; he likes it better that way. He always wakes early, and watches a film. In the mornings he uses his small wheelchair so that he can wash himself and get onto the toilet. Then the carer arrives to lift him off the toilet and into his electric wheelchair. That’s when his day really begins, because the electric wheelchair gives him the freedom to go where he pleases. He needs a bit of help with cooking, because the pans are too heavy, but he can make his own coffee and snacks. Not long ago he made a buttered sandwich that fell onto the ground; he just left it there, much to the carer’s amusement when she saw it later. Sometimes friends bring something to eat. He enjoys the change of diet, but Freek likes doing as much as possible for himself. If his curtains were electric curtains, he says, I could draw them myself too.

Freek enjoys taking part in research projects, but he expects his privacy to be respected. He doesn’t want to give out too much information, as this might affect his privacy.



Ton

“I do nothing all day.”

Ton is usually in his room watching television. He takes no initiative to get something started; if the care staff didn't get him out of bed in the mornings, he'd be there all day.

He is not curious at all about technology; the care staff turns on his television. He has no contact with his fellow residents and no interest in doing anything with them. Sometimes the staff move him to the corridor so that he can join their care meeting. He likes that well enough, but quickly bores of it and wants to go back to his own room. Once a week his son, his only visitor, drops in for a chat. He does not go anywhere himself.

His only activity is occupational therapy, which he enjoys. Ton doesn't care for games, but does enjoy watching films on TV. He likes the old comedy TV series *Toen Was Geluk Heel Gewoon*. Others do his shopping for him, but he takes almost no notice. His carer explains that they go through the shopping list once a week.

He comes across as a grumpy old man, but after a while you notice that he rather likes company and attention. If a carer walks by he will always react, usually with a shout. Usually nothing is the matter, he just wants a bit of attention. Sometimes he will start the day off by cursing. “What else can I do?” he asks. Sometimes, halfway through a sentence, he will forget what he wanted to say. It looks as if he is thinking until you realize that he is waiting for a question.

He has no sense of the day progressing and does not know when he ought to be doing something, or what. The care staff try to structure his day somewhat through routine daily activities like eating and washing, but if you ask him what he does he says: “I do nothing all day.”

If something happened too long ago, Ton will have forgotten all about it. Personal letters and meetings are forgotten after only a few weeks. It is unclear whether he fully appreciates the researchers' visits; on one occasion he will happily cooperate with all research, and on another he will refuse to have anything to do with it.



Karin

“It’s good to stay in touch with others through Facebook.”

Karin is a woman in whom one can see the evidence of a stroke but also traces of the high-spirited, beautiful woman she used to be. Since the stroke she has had difficulty walking and talking, so she goes to a speech therapist and a physiotherapist a few times a week. She has made great progress since living in this care centre. She practices assiduously and recently succeeded in walking a short distance unaided, calling over the care staff so she could proudly show them the progress she was making.

She gets several visits every week. From her sister, for example, with whom she window-shops for clothes on the H&M website. She often Skypes with her son or with friends, and she is very active on Facebook, where she keenly follows the Jewish Broadcaster page.

She often talks of her ‘little boys’, by whom she means her grandchildren, twin boys. She likes showing photographs of them and loves getting cards from them.

She has no contact with her fellow residents; she prefers to either be alone with her cat, or to receive visitors – colleagues from her old workplace, for instance. And she often talks with the doctor. She enjoys reading and has lots of books.

The care staff help her shower, get dressed, and have breakfast in bed. In the evening they heat up a ‘steam meal’ from the supermarket for her. She usually goes to bed around 7.30pm. She watches the evening news and then, ideally, a travel programme. She might telephone someone, perhaps her aunt. Before she goes to sleep at around 10pm, the care staff call in to do a bladder scan. She has been recently trying to control her own urination again, and they have to check that her bladder is completely empty; otherwise they have to catheterize. She suffers from urinary infections frequently.

Karin’s stroke suddenly made her world a lot smaller. Learning to walk again, to talk, to use the toilet – it’s a lot to deal with at once. Not being able to oversee the consequences, for instance of participating in research, makes her anxious. Will her grandchildren still be able to visit? For reasons of self-preservation, the family decides not to embark on any new technologies.



Desiree

“You going away already?”

Desiree is usually in her room. She is from Suriname and speaks only a few phrases of Dutch. Her daughters blame themselves; they always spoke Surinamese with her. This language barrier means she has little contact with her fellow residents, but she is also hard of hearing. She enjoys, however, getting in touch with her own family frequently; they visit almost every day. Her daughters come on weekdays, and the grandchildren and great-grandchildren usually come at weekends. They bring her food. On the days her family cannot make it, care staff heat something for her to eat. Her daughters have decorated the room attractively. The windows are too high; she cannot see outside from her wheelchair.

Desiree has a picture-button phone. She cannot read or write, but she has learned to sign her name. She grew up in the interior of Suriname where there were no schools for her to go to. Still, her daughters emphasize, she is very sharp.

Desiree is very creative. Before her stroke she often took part in daytime activities, making beautiful sculptures. She was very proud when her work was shown in a magazine.

Desiree is a fighter, too. She has made good progress since her stroke; her daughters encourage her to practice her walking, which she does, every day, in the corridor. She proudly shows everyone how she can now walk a short distance unaided.

Communication with Desiree goes mainly through her daughters. The daughters are open to taking part in research involving new technologies; after all, they say, it's their future too.



Hubert

“If it helps others, then I want to be in the research.”

Every morning after Hubert gets up he spends 20 minutes doing exercises on the floor next to his bed. Hubert often wakes early; he is a kidney patient and the medicines give him insomnia. Sleeping pills determine how long he sleeps. Three times a week he goes to the hospital for kidney dialysis. On those days he tries to lie in bed a bit longer. Then he has a shower and gets ready until the bus comes to pick him up. On Sundays the bus is always late.

Hubert has made numerous acquaintances at the hospital and is warmly welcomed as he goes in. During the dialysis he either talks with people he knows there or he reads a book.

On non-hospital days he devotes the morning to Bible study. Once a week someone visits in order to study the Bible with him. The church has given him some music. They have also told him that watching a lot of TV is not good for him, so he only watches the news. Sometimes one of the care staff gives him a freesheet newspaper, the Spits or the Metro. He doesn't often sit in the shared corridor; it's only got a lounge suite. In the last home things were much better, it was much more lively. Everyone sat together at a big table there. Nothing much happens here. There is one other resident he can talk to about books; he knows a lot.

In the mornings one of the care staff drops in to check everything's all right. Hubert prefers to do as much as possible for himself. He likes working. He can't do much, but he is keen to do whatever little he's capable of. Hubert can make up his own bed, and he washes his own dishes in the kitchen. And he is able to do a little cleaning; he sweeps his own room.

The carers order his food shopping from the supermarket, but sometimes he goes to the shops himself. He cooks all his own food and eats it in his room. The cooker doesn't work that well, so he usually eats something ready-made, often a 'steam meal'. He takes care to watch his weight, and eats lots of salad, pasta and now also vegetarian food, which he has discovered is delicious. If there were a restaurant close by he would certainly go there, he says; he loves good food. He doesn't eat bread in the evening, but he does sometimes eat crackers; you don't put on weight with crackers.

Hubert telephones his wife every day, and his daughter on occasion. He is also in touch with his daughter via internet. In his last nursing home he took an internet course given by his occupational therapist. He also has a book that explains how to get onto the internet. Hubert would be interested in an overview of how physically active he is; that way, his family could see that he's living here for a good reason.

Hubert thinks it important that others can learn from his experience. Whether it concerns his living expenses, medicines, visits to the toilet and the shower – people can ask him whatever they like as long as they can learn something. He has no secrets.



Frans

“Oh, that was then!”

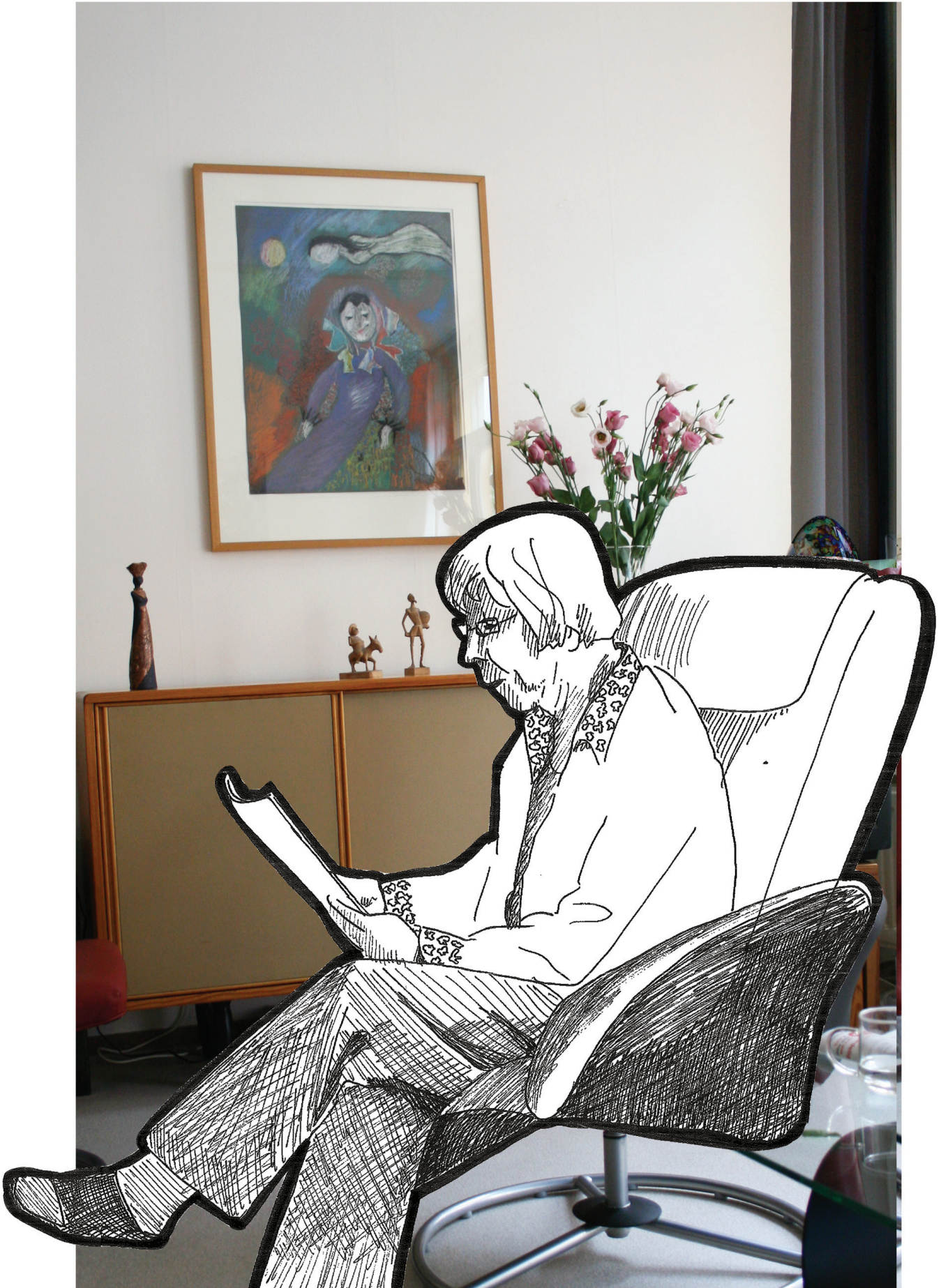
Frans is hard of hearing, but has no trouble expressing himself verbally. He walks with difficulty, explaining that he has a disorder that affects his sense of balance. Other residents say that his main disorder is his drinking problem. Who knows; it might just be gossip. The others usually avoid his company or point their finger. His own view is clear: he seeks no social contact and feels no desire at all to join their group activities.

Secretly, though, he enjoys visits and getting the chance to talk. He has no children, but once a week a friend of his drops in. He hardly dares go out any more; it's tricky enough just getting around indoors. He grasps the furniture to steady himself as he crosses from one side of his room to the other. His room is heavily furnished. Frans is terrified of falling, but he refuses to wear his alarm pendant; just thinking about an emergency is more than he can bear. The pendant lies on the table.

He used to read a great deal, but his eyes are getting worse and now he just watches television. Watching television is what he does most of the time; the TV is his favourite domestic appliance. He will stay up till 3am in order to watch certain detective programmes. He regards watching television as a moment of rest and a moment to himself.

Frans grumbles a lot. He talks at length about his ailments and all the things he can no longer do. He has no interest at all in new things or activities, but he acknowledges a need for attention, for someone to share his thoughts with or talk something through.

With regard to something like fall detection, Frans says that what he appreciates most is probably the fact that it's a preventive device that he doesn't have to think about at all. He's fine with the sensors registering his every move; the higher aim is so important that he's not concerned with what happens to the data. "I'm not the kind of bloke who says 'What business is that of yours?'. I'm just not that bothered about it."



Liesbeth

“I want to stay a part of the world.”

Liesbeth is not one to give up. She is determined to live independently as long as possible. She often goes out for a stroll, using her walking frame to hold the bottle that supplies fresh oxygen, via a slender tube, to her nose. When she gets home she plugs the tube into a special apparatus that allows her to walk around the house freely. The tube can easily get tangled up with furniture, however, so she has chairs but no sofa, leaving more room to manoeuvre.

She lives in a care location in the centre of a large city. This was a conscious choice; in a city there's always something going on, something to see. She loves being able to look out of her window and see the activity. The curtains are sometimes drawn shut, however. She attaches great importance to privacy and rest; whenever she needs peace and quiet she wants to be able to retreat to her own room, where no one will disturb her.

She thinks it important to keep up with the times. She knows exactly what she wants and is not afraid to give her opinion. She leads an active social life, but takes part only in those activities that she finds really interesting. Liesbeth can still do everything she wants, and never needs to be pushed into action.

She would, however, like to have a clearer idea of what is being organised around her. She always wants to know what's going on, so that she can get involved with the activities she finds most interesting. But she does not want to use a computer for this purpose. She's reluctant to begin, for fear of discovering what she is no longer able to do. If a technology could help her to be more independent, however, she would definitely embrace it.

Liesbeth is an enterprising woman who is in charge of her life. She is interested in participating in different research projects and is keen to learn. Although she refused to look at a computer, she agreed to join the iPad research project.



Gideon

"I turn the TV on in the morning, and it stays on."

Gideon is wheelchair-bound and has some difficulty speaking. He came from a large family and now he has his own large family. He has a deep love for his relatives, especially his grandchildren. They visit several times a week and this keeps him happy. He would like to be even more involved with them if that were possible, especially with his grandson.

Alone at home, he likes to watch television. He has absolutely no desire to join in with his fellow residents' activities. He attaches great importance to peace and quiet and to his own space. Though he loves to be visited, it also exhausts him, so he prefers to receive family in the care home's restaurant. He has felt lonely on occasion since his wife died. He turns on the TV in the morning and it stays on all day. Noise in the house makes him feel less alone.

Gideon would like it best if he could decide for himself how to spend the day, when to get up and what to do. But he would want the care staff to know when he woke up, so that they could come and help him get out of bed and into his wheelchair. He is very independent, although he does occasionally forget things, such as turning off the tap.

Gideon has only a few pieces of furniture in his home because wheelchairs need space to move around. His wife, now passed away, put the decorations around his home. It was she who decided what should go where, and he wants to keep everything just as it is.

Gideon would also like it best if he lived close to his family members. It would then make no difference to him if he were in the city or not; after all, he doesn't go out alone – only with relatives. He is happy for them to decide where to go. Just as long as they keep him company.

What matters most to Gideon is his family. He would like to communicate more with his grandson, including through technology. But the system should not exhaust him. He wants to receive information, not send it, so the system should be as simple as possible.



Truus

"I worry too much."

Truus used to be a ship's captain. She's still a good walker, does her own organic food shopping and goes for strolls around the park. She would like to have more contact with her fellow residents, but she's not sure how to go about it. She often joins group activities at the care centre but she needs a bit of encouragement to do so. Truus is rather shy and modest.

Truus is always ready to lend a helping hand. She attaches great importance to etiquette. She often worries about what others think of her. She tries to prepare well for everything; this keeps her from worrying.

She's not keen on visiting the doctor, because she only hears what's wrong. She knows that her health will inevitably decline; she just doesn't want to have to consciously deal with it. So she constantly thinks up new excuses for not going.

Truus is deeply attached to her own space, where she can feel at home amongst her things and where other people don't come – if they did, they might interfere with her things. For her, a sense of cosiness and warmth in her own room is very important. Her room has six standard lamps and lots of accessories in red. She doesn't want technology in her home; she wants objects that exude warmth and conviviality. She had a mobile phone, but she got rid of it; it was too much trouble and gave her stress.

Truus likes her room to be cosy. She's open to having a technological novelty in her home, but is often put off by its appearance: "So cold, it does nothing for me, it doesn't appeal to me." And she knows very well what she does like: "It should be warm, nice, and it should feel cosy."



Joke

“You have to keep on stimulating them.”

Joke used to be a nurse and now she is an activity coordinator in a care facility.

Joke works hard to activate the residents in her group and stimulate them to do things for themselves. Even if they arrive in a wheelchair, she tries to set in them motion by making them walk as much as possible and use ordinary chairs. When people start using a wheelchair their muscles quickly weaken and it becomes increasingly difficult to get them to walk. When Joke goes on a week's holiday the other carers tend to go through less trouble, and the residents sit around in wheelchairs again.

The members of the group talk very little amongst themselves and usually employ the carer as an intermediary. If the carer leaves the room, conversations usually stop and the residents go into a sort of sleep. Joke says that while some of them look as though there's no life left in them, if you talk to them directly you can often have a very good conversation. Over-medication can be one reason they are so drowsy.

Stimulating people stops them fading away. In the mornings she does this by starting conversations and involving the whole group. It's vital to keep things lively. Partners of group members, even of residents who are no longer in the group, drop by every day. Joke keeps busy the whole time, keeping everything upbeat, but she always takes care to follow the conversations. By keeping in contact with people, even while she's making the coffee, she helps them to feel safe. With Joke they feel heard. In the afternoon she often trains their memory, using questions or pictures. She can see the benefits, even in people with Alzheimer's.

Joke tries to offer people a clear structure. In the mornings they sit together in their social room, the 'soos', and after lunch she guides them back to their rooms to enjoy a rest, a walk, or a cigarette. This brings more variety into their day. Joke has had to stand up for her soos at several occasions. It's there to offer quality time, and she uses it to provide structure. It's not a coffee room, that's what the restaurant is for. She has to protect her own group. If she doesn't, the more assertive residents will get all the attention, her own group will fade into the background and would gradually fade away altogether. After lunch she helps them to their room or to another area. They all want to go first. Nobody wants to be last.

Besides providing activation and structure, to Joke 'quality' also means fetching fresh bread from the market every day. Every resident has their own place at the table. Each of them eats one or two sandwiches every afternoon. And they all get brown bread. Teeth or no teeth, they even finish the crusts. Chewing is good for them, it stimulates the brain.

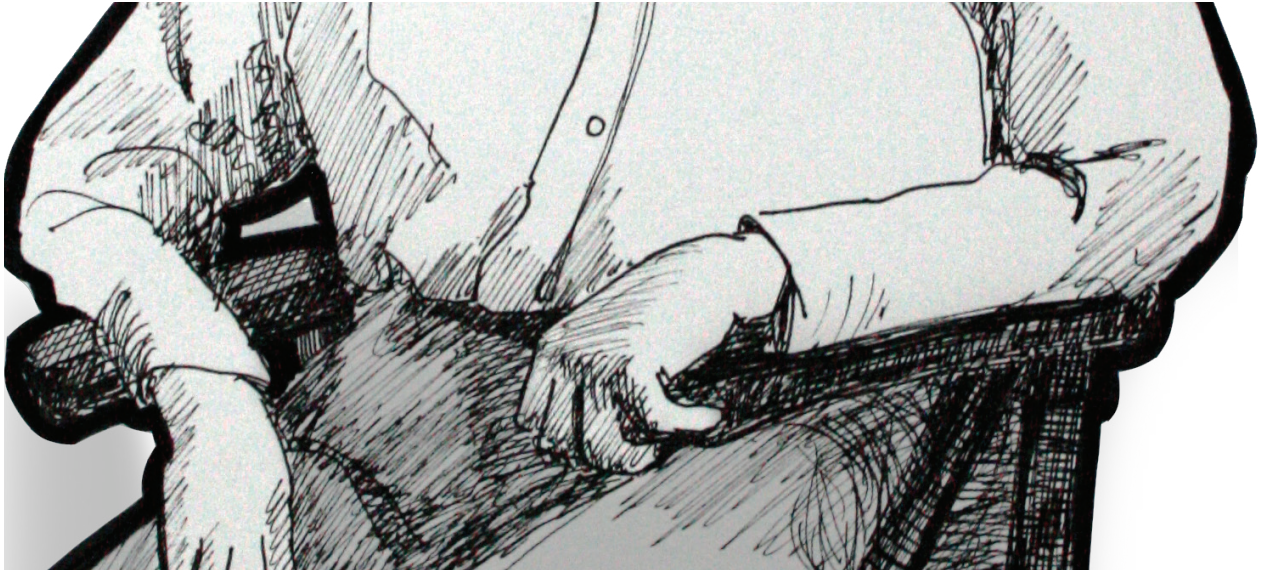
Joke treats all the residents politely and as adults; she doesn't want them to feel patronized or to be treated as children. The soos is furnished as one would a cosy living room: with plants, soft lighting, a cabinet, and net curtains at the windows. It's important to her that it doesn't look frumpy. And there's no bingo here, only activities that she enjoys and considers appropriate for adults.

She explains that it occasionally feels more like a re-education centre. Sometimes people have lived their whole lives in a certain way, and they make all sorts of demands; you have to break that pattern. She sees this as an important task. She has to set her limits. Because Joke sees these residents every day, she gets to know them much better than the daily changing

care staff, for instance. Her contact with them is much more intensive and long-term. So she can get to grips with them. She dismisses demands for negative attention; positive reinforcement is more her style. Joke admits that there are also people who spend all day lying in bed and don't want to do anything any more. That's just how some people are. It can't be changed. They're people, after all.

One of the group members, a 98-year-old woman, constantly shouts something unintelligible; her sounds are almost animal. Joke explains that this woman misses her home and is deeply unhappy. She doesn't feel at home here, whether in the soos or in her own room. She feels comfortable only when her children are around. She is now being given medication that will stop her shouting so much. Joke had reported that it would be impossible to go on otherwise.

Joke begins every day by switching on the lights and the music. In her view it is important to do this, even if the music is not to everybody's taste. She stops to chat with different residents, not just those in her own group, and she always uses the kind of language they use themselves. She would never say "What a nice suit you're wearing today"; it would probably sound more like "Well, well, look who's back and in his best suit!"



Real-life care stories

This booklet contains portraits of people. Of real people. These are the stories of nine inhabitants and a member of the care staff of of rest homes run by AMSTA. The stories are based on interviews, researchers accompanying care staff for several days and short tests that were carried out within the Health-Lab project. This project aims to develop products and services that help elderly people to live independently for longer. This intensive contact with care home residents enabled a clear view of their day-to-day lives which yielded valuable insights. With this publication we would like to share these insights.

The Health-Lab project is a joined effort of Waag Society, AMSTA, Amsterdam University of Applied Sciences, the University of Amsterdam, VU University Amsterdam, and Amsterdam Innovation Motor.