

## A story about **Personal future planning** for people with a short, valuable future...

### Lieve's story

Lieve was an active, vibrant 59 year old woman who loved to read (Dan Brown's books were at the top of her list!) and cook. When her husband was alive and her 2 sons were still at home Lieve spent a lot of time and care making dinner: with vegetables from the garden, plenty of fresh herbs, fresh fish they got at the coast. When the kids left home Lieve and her husband became members of certain organizations where they planned all sorts of excursions with, ... Ever since her husband passed away several years ago Lieve discovered an organization for the elderly where she started as a volunteer: together with a few others she delivered warm meals to the elderly from the neighborhood. Lieve did this with care and devotion. She stuck around with 2 elderly who were alone, so they wouldn't have to eat by themselves.

Aside from that Lieve also often kept in touch with people from her village, she was especially close to her neighbor and her granddaughter Kelly stayed with her 2 days each week, when she had to be nearby for work.

When Lieve started to become unhealthy (she had the feeling that the strength had gone from her hands) she went to a check-up at her doctor... who referred her to someone else and after a while the diagnosis was made: ALS, Amyotrophic Lateral Sclerosis.

Lieve's world stopped. First the idea was: we'll see, it won't progress too quickly, but after several months the setback was so clear that something needed to be done, whether she wanted it to or not!

Through an organization where she was an active volunteer Lieve heard about **PFPP, Personal future planning**, and one day she made an appointment with **NPO P.L.A.N.** to find out more.

### **Personal future planning**

*Personal Future planning or PFP is a way for people who need temporary or prolonged support to, together with their partner, children, friends and/or family, think about what is a "good life" for them, make their own decisions and choices and take action to change things from that point on.*

*Those who are interested in PFP can go to **NPO P.L.A.N.** This organization has years of experience in this line of work.*

*Through a project with the Flemish Users' Consultation for People with Disabilities (FUCPD) NPO P.L.A.N. is capable of supporting PFP processes in all provinces in Flanders on a large scale. Meaning there are no waiting lists, so a process of PFP can be started up at the pace of the person at heart.*

*So don't hesitate to get in touch:*

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During the first meet-up Lieve shared that one of the most difficult about her illness was that she became dependent on others so quickly: she, who had always been so self-reliant, who had managed on her own after her husband's passing, was frightened to give up her freedom of choice: she wanted to remain in control, of both small things and big decisions.

One of Lieve's biggest wishes was to keep living at home for as long as possible, aside from that she wanted to keep reading, cook, ...

Lieve didn't have to think long about who she wanted in her support group: both of her sons, her granddaughter and her neighbor. When they were together they never used the word 'support group': everyone gathered together when necessary, to talk through several things among themselves, assume a point of view, ... Lieve came in contact with many different professionals in a short amount of time who all gave her good advice, but often also contradictory advice...

Lieve experienced the 'get-togethers' as a very big support because that way she had the possibility to calmly think everything through, consider everything and form an opinion, and by doing this she felt stronger afterwards to call certain services, apply for things, ...

When Lieve couldn't call herself anymore at a certain point, the decisions were talked through during the 'get-together' and the neighbor had permission to arrange further appointments.

Lieve's sons do all they can to clear their schedules to gather together: they like being able to talk to their mother in a calm, serene way about how it's going and what needs to happen. Because of the rapid progression everyone is aware of the fact that Lieve's future is very limited, and during the get-togethers a lot of emotional things are shared, which the ones involved will carry with them even after Lieve's passing. By sitting together on a regular basis (near the end they did this in an intimate circle) Lieve remained in charge, of her own life and her goodbye and this in consultation with her loved ones.

**Each PFP process is unique, but there are a few fundamentals you can find in each process:**



*Within each PFP process **desires, wishes, dreams** have a place, even where the future is very frail and valuable.*



*PFP isn't about 'the illness', it's about the person in question: who is this person, what and who are important to him or her, what makes life good, what needs to change, ...*



*PFP is something **you never do by yourself**. In our society self-sufficiency and independence are strongly encouraged, while one of the starting points of PFP is interdependency: the idea that no one stands alone and you need others to expand your life. Bringing together family and friends to look for what makes a good life usually provokes resistance at first, especially in situations where the person is (still) in charge of making decisions. But at some points people will come into a situation where they lose the power to make decisions, sometimes in a very drastic way, sometimes in a more insidious manner but in no way less drastic and then it's nice being 'heard' by your peers, who can help make sure your voice heard.*

Which subjects came up? A glimpse from the many things they talked about:

Lieve wanted to live at home as long as possible. The caretakers who were involved advised Lieve to admit herself, while she was still relatively self-sufficient, but Lieve didn't want to: she didn't feel like living somewhere else yet and create a new 'home': when things really didn't work anymore, she no longer cared where she had to go to. During the day Lieve managed well on her own, but Lieve became more and more afraid of the nights by herself. When she told during a conversation that she was genuinely scared of it, her sons, granddaughter and neighbor told her she could count on them: they would, when Lieve found it necessary, create a rotation schedule and perhaps get volunteers so she could stay home as long as she wanted to. This mean a lot to Lieve: on one hand she was reassured she could keep deciding how to go on, on the other hand her family and neighbor explicitly let her know they were there for her...

Lieve wanted to keep reading, but it became increasingly more difficult to hold a book and turn a page. Granddaughter Kelly therefore recorded several books on a cassette and the neighbor came by in the morning to read the paper to Lieve out loud (there was some arguing about which paper this should be but soon they found a compromise!!).

As mentioned before Lieve loved to cook. After a while this no longer seemed possible: the cooking pots were too heavy, the stove caused trouble, ... She needed to look for a service that delivered meals at home. Lieve was really disappointed about this and didn't look forward to eating food from a catering service. She hated it when they put sauce on everything and found it a shame to see so little fish on the menu. She looked for all sorts of alternatives: instead of a catering service of the public center for social welfare Lieve got meals from a restaurant nearby. But after a few months it always appeared that Lieve's health worsened and new steps needed to be taken: first smaller cut food, then mixed, ... and every time they looked at which way was best out of deep respect for Lieve's love for good food.



*The purpose of the group is to first of all think along and then see as to what is possible. No one in the group has to feel obligated to do something they don't have time for or don't feel like doing. Making time to listen, think along and look for people (whether or not professionals) who can help find an answer to a question is at the core, not the fact that everyone has to assign everything to themselves.*



*There is an optimal use of all possible existing support within a PFP group. Here we start from the principle 'ordinary where possible'*



*PFP is listening most of all to the central person and not immediately wanting to take over and arrange things. Listening is done with care. Care doesn't mean pity, but it does mean recognizing the vulnerability, fears, disappointment, failures that have happened and will happen. Care means having an active interest in the point of view of the person and being prepared to see that what they see or do or say can have meaning to them, even if sometimes it doesn't seem that way to us at first. (That way we could really understand how important food was for Lieve after her story about fresh fish by the sea, her experiences with home-delivered food, ... and this kept her son going to look for ne alternatives time and again.)*

A few months ago Lieve passed away. Even in her last phase Lieve remained in control. Where at the beginning the conversations were led by an employee from NPO P.L.A.N., the family chose to, in the end, have the conversations in a small circle, only with those directly involved.

Personal future planning allowed Lieve the chance to live her own future until the end and gave those directly involved many intense moments and memories to cherish the rest of their lives.



*Each process of personal future planning is **supported by an NPO P.L.A.N. employee.***

*Their assignment is to:*

- *If necessary, look for people to participate and invite them.*
- *Get an idea of who the central person is, what they want. This especially happens by listening to people and asking questions.*

*The employee also makes sure people take action: if the central person's life can be improved they have to look for how this can be done!*



**NPO P.L.A.N.**