

I am the chief

About my life with personal assistance

Monika Rauchberger, first published in: Zeitschrift Behinderte Menschen 06/2012



I have already had personal assistants for 4 years. They assist me in my own apartment.

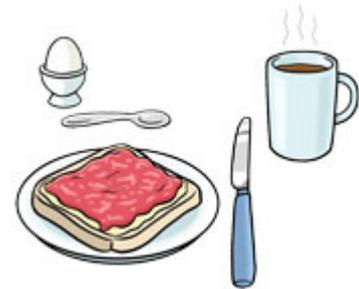
Before I moved into this apartment, I could practice this kind of support with an assistant. For instance, I went to different furniture shops with the assistant in order to look at many things for my apartment. I looked at some double beds for me and my boy-friend: which double bed I found nice and if there was some space for it in my bedroom.

At that time, I was able to instruct the assistants a bit, because I had learnt that at my work at Wibs¹. Then I moved from the group home into my new accessible apartment. I started off there with personal assistants from the beginning.



¹ Wibs is a peer-counselling centre for persons with learning difficulties and self-advocates. Wibs is part of the People 1st movement. More information (in German) <https://www.wibs-tirol.at/>

During the week, one of my 6 assistants comes to my place in the morning at 7 a.m. Most of the time, I tell her right after her arrival what I want to drink or eat. Some assistants already ask me while entering the apartment. The assistant prepares breakfast for me. Afterwards, she does my hair and binds them together with a scrunchy. The assistant prepares my medical pills on a towel, so that I only have to take them from the towel and put them into my mouth.



While I am eating breakfast, she opens the door of the bedroom's balcony. She shakes the blanket out and arranges it in a way I only need to cover me up in the evening.

Then, my assistant prepares my lunch for work. By now, I don't need to tell it to the assistants anymore since they know I need a lunch. They only ask me what meal they must cook and they put it into my backpack.



When I turned on the full washing machine in the morning at 6 a.m., the assistant hangs up the clothes right after 8 a.m. on the clothes horse.

In the evening, I tell them to fill up the washing machine with colour wash, with laundry that can be boiled or woolens. I also tell them which washing powder and which softener they must put into the washing machine.



When there is time left in the morning, I ask the assistant to sweep the floor.

In the morning, the assistants work 1 or 2 hours at my place and in the evening they stay 3 to 4 hours. I always instruct the assistants.



Week-end

On the week-end, I usually have 3,5 hours of assistance from 11 a.m to 2:30 p.m. I don't want to get up too early on the week-end.

From time to time, I have more or less hours of assistance on the week-end. For instance, when I have a competition of boccia, then I need much more assistance time. We always look how much time does the competition of boccia last, and then the assistant writes her working hours.



Every month, I need 115 hours of assistance. I can decide myself what I use the hours of assistance for. Sometimes I need less hours of assistance: for instance when I go out with a friend who helps me. If there are hours left in the end of the month, I can take them to the next month and use them later.

	MO	DI	MI	DO	FR	SA	SO
Früh							
Spät							
Nacht							

In the beginning, it was really not easy for me to tell the assistants what they had to do in my own apartment. You need high mutual patience to put it in place.

Nobody can learn to instruct personal assistants overnight. Some people with learning difficulties need more time to learn instructing.

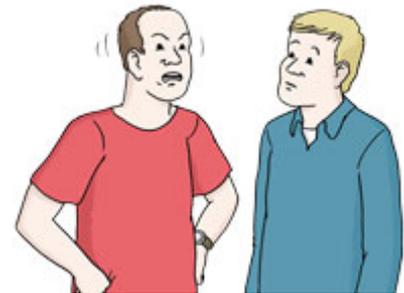
	Montag	Dienstag	Mittwoch	Donnerstag	Freitag
Klaus					
Inga					
Maria					

Resolve conflicts

Sometimes I have conflicts with the assistants. For instance when they do something not in the way I want it. Or just when they open the balcony door without asking me while I am still putting my clothes on. Or when they begin working before I gave them a task.



In the beginning, the assistants often did not ask me what I wanted to drink for breakfast. Sometimes, it happens that assistants tidy up the table without asking me.



Then I always get angry. It is not easy to talk about the conflicts. By now I do it this way: when something bothers me, I tell the assistant right away what I don't like. When an assistant comes to my place, I say immediately what there is to do, even if it is sometimes difficult for me.



2 coordinators and one assistant from the Centre for independent Living Innsbruck helped me to move in my own accessible apartment.

A coordinator sorted building issues out with me, so that everything is accessible and adapted for me in the apartment. That is to say for instance: all the light switches must be at the same level, so that I can reach them from my wheelchair. Or that the front door opens automatically, then I can come in and go out without help.



The other worker of the Centre for Independent Living Innsbruck supports me with the



assistants. She gives me the names and the telephone numbers of people wanting to work as assistants. Then I write a message on my mobile phone and I introduce myself briefly. I ask when they have time for an interview and I make a proposal for an appointment. Most of the time, I receive an answer immediately.



I always do an interview before someone works at my place regularly. At first, I introduce myself. I have a text on my computer, in which I wrote the most important things about me. The candidates read on the computer and they can ask me questions as well.

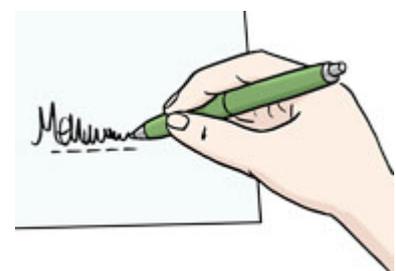


Then they introduce themselves to me. I prepared questions on the computer about what I want to know. I generally ask very precise questions.

I did the first interviews with the coordinator from the Centre for Independent Living Innsbruck. I used the letter board to speak. It was often very exhausting for me because it took a long time. That is why I decided after a while to write the text about me and the questions for the assistants.

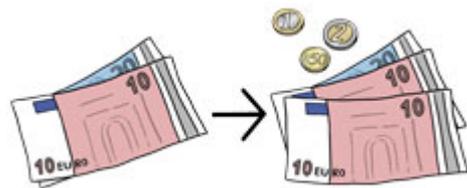


The assistants receive their money from the Centre for Independent Living Innsbruck. I have got empty time sheets. The assistants write their working hours on the time sheets.



At the end of the month, I pass the assistance time sheets with my signature to the Centre for Independent Living.

Then I get a bill from the accounting every month. I only have to pay a certain contribution. The Province of Tyrol pays for the major part.



I already know well how it works, but I still receive support from the Centre for Independent Living. For example, when an assistant stops working at my place. Then I write an email to my responsible coordinator. I write from when the assistant will not do work at my place anymore. Then the coordinator knows she has to delete the name of this assistant.



I also write an email when I need a new assistant. Then the coordinator sends me names and telephone numbers of new candidates.



Holidays

I can go on holidays with my assistants as well.

I already went on holidays with an assistant and two of my friends. I payed for the bus trip, the hotel and the food of my assistant.

I planned almost everything before going. For instance if I need the assistant all the time and if the assistant has free time. She had free time in between. We arranged it on site. Then I did something by myself with my two friends with learning difficulties. We got along well with each other.



Since I've lived in my own accessible apartment, I know the difference between personal assistance and care. Before that, I



lived for a very long time in institutions and group homes. In these places, there was only attendance and no personal assistance.

The attendants at the institutions and at the group homes decide about the schedule. They tell the people with disabilities what they have to do.



The attendants keep their eyes glued on the people with disabilities because they are very afraid that something happens to the disabled persons in the institution.

People with disabilities have to be back on time to the institution, for example for the mealtimes.



The personal assistants come to me at the time I agreed on with them. That is to say that I tell them what time they must come to my apartment or to some other place. Then I tell them what they must do for me and how they must do it. The assistants are not worried about me.



The organisation and the instruction is often not easy. You both have to work on yourselves and be patient.

Source of pictures: Lebenshilfe für Menschen mit geistiger Behinderung Bremen e.V., Illustrator Stefan Albers, Atelier Fleetinsel, 2013.

