

# **Creating a personal assistance network**





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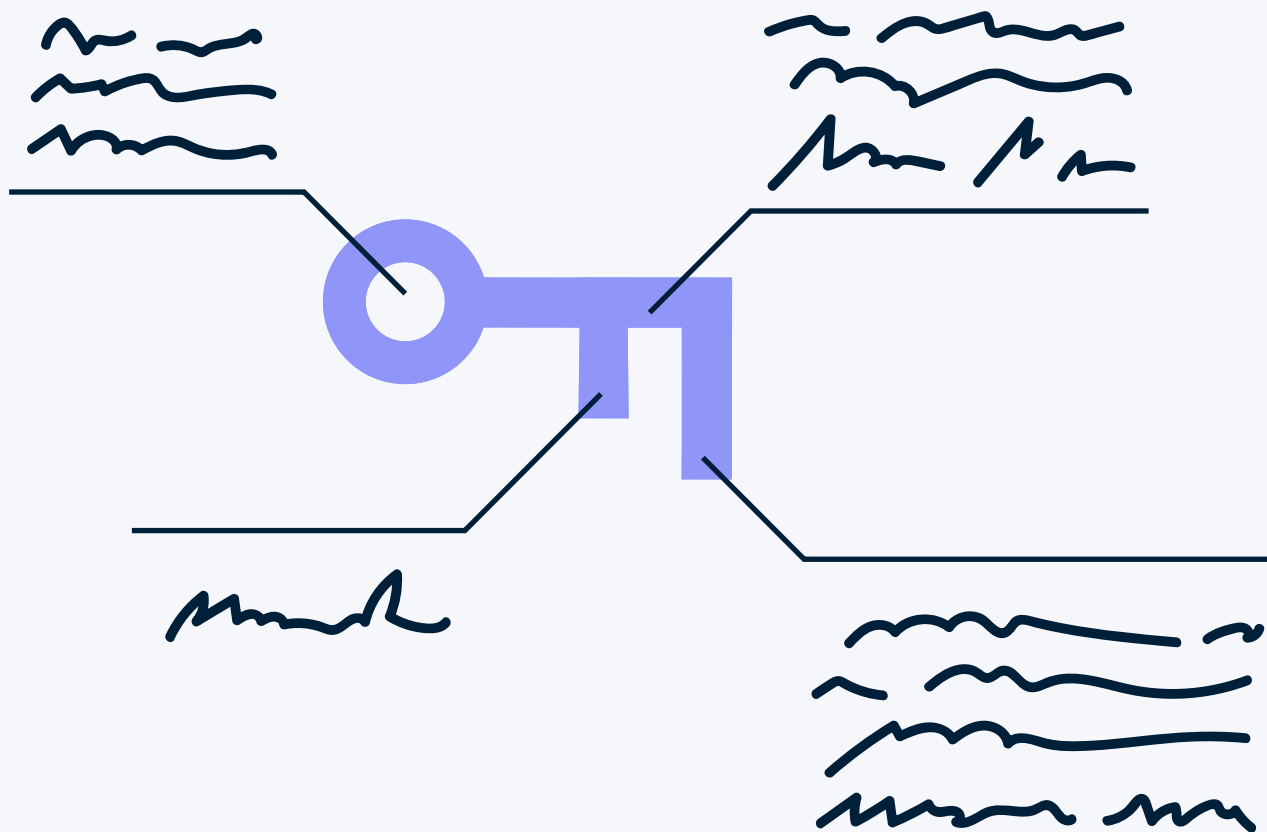
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# BASICS





## What is self-determination?

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In life, we all give and receive help. Help is a natural part and parcel of our everyday life – at the shop, at work, at home.

Each of our experiences is different, leading to different ways of living.

We need help in various activities – some of us more, others less.

Personal assistance usually involves a service for those who need at least several hours a day of support in order to lead a life based on self-determination.

That life can be considered self-determined when we make decisions concerning our own way of living.

“A personal assistant is not required to take care of me, or because I need a friend, but because I can be myself.”

## What is personal assistance?

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Personal assistance is a service where people cooperate with another person for a specific period and receive remuneration, involving something that the user cannot do alone to achieve independence. Conditions of cooperation are laid down in a contract based on mutual agreement.

The contract provides for material, time and legal aspects of employment, as well as the activities and responsibilities involved.

Due to the complexity of the cooperation, in many cases, it is impossible to define certain exact details. These are determined during continuous and mutual communication between the user and the assistant, and they can change over time.

“The assistant helps me with eating, cleaning, and catheterizing to make my standard of living good. Trying to set down everything in the work description is impossible since my life is too spontaneous for me to be able to describe the activities I am going to do in the following 1-2 years covering every detail. On the other hand, the way a job should be done cannot be entirely covered in the work description. The 'how' is as important as the 'what'. “



The user of personal assistance (hereinafter: user, employer) is a person who employs the assisting person (hereinafter: assistant).

The personal assistant (hereinafter: personal assistant/assistant) is an employee chosen, contracted, trained, and employed by the user. This job does not require specific qualifications.

Cultivating successful personal assistance requires the active participation of both parties.

Active participation involves personal assistance on a two-way street, requiring the active contribution of both parties. During the process of personal assistance, the user and the assistant depend on each other.

“This assistance I wouldn’t call assistance, I’d rather call it cooperation. For me, it is extremely important that no one wants to solve problems for me or make decisions over my head, but we have to cooperate in everything as partners.”

It is not optimal if the personal assistant is a family member or a friend, since these relationships are often over-burdened, someone being a mother and an assistant at the same time, for example. If a relative or a close friend becomes an assistant, in many cases it may reduce the independence of the user and may overwhelm the assisting person.

“I might ask my assistant up to five times to adjust my leg in the chair because it is uncomfortable – my mother I won’t ask more than twice. And on certain occasions of my private life such as entertainment or dating, I wouldn’t like my mother to be there. And she wouldn’t, either.”

Ideally, there are several personal assistants making up a user’s network of assistants working in predetermined shifts, taking turns.

Working hours are subject to mutual agreement – they may range from 4 to 48 hours. If someone requires ongoing assistance, it is not optimal to work with the same assistant for longer than 2-3 days in a single shift. That is why it is important for the network to consist of several persons.

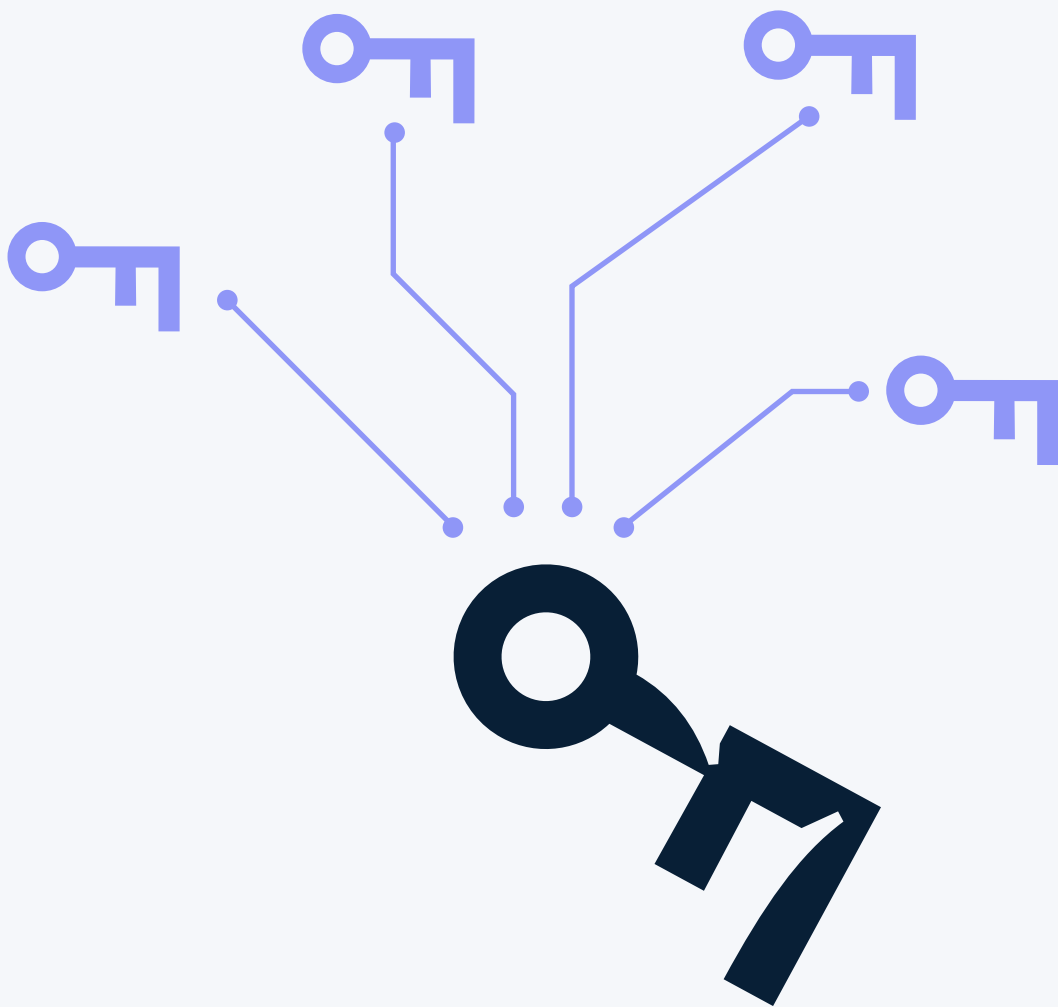
The amount, aim and form of assistance are mainly determined by the user.

This document offers details on the knowledge and abilities you will need to become a self-determined user of personal assistance. Though learning is a life-long process, don’t let inexperience bar you from employing personal assistants.



# CREATING A NETWORK OF PERSONAL ASSISTANTS

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## **What is your lifestyle?**

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The questions above can be answered in many ways. Regarding personal assistance, consider the following factors:

- I live with my parents.
- I live in an institution.
- I live with my family.
- I live alone with a supporting service, with the help of volunteers.
- I live alone without any help.

Consider whether you are satisfied with your answer, or whether you would change the situation if you could.

## **What are your needs? What help do you need?**

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Think over which of your life activities require the cooperation of another person. Make a list of activities where you need assistance. Some examples:

- self-hygiene,
- dressing,
- eating, drinking,
- using the lavatory,
- working,
- entertainment.

## **How can you decide whether you need a personal assistant?**

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The questions above have helped you clarify where you need support. Think over who helps you with carrying out these tasks now.

If any of the sentences below apply to you, perhaps a personal assistant could make your life easier:

- It is time-consuming for me to organize always having an assistant.
- I can't leave home/ the institution.
- I'm tired of my family helping me with everything.
- I don't feel independent.



- I would like to live a self-determined life, independent of my family.
- The assistance I receive is inadequate, not the quality I would like.
- I would like a relationship, I would like to work, I would like to have a child.
- I would like to participate in a community.

## **How to select the right assistant**

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It is important for you to choose your own assistant. Don't let anyone else choose for you. Don't expect "anyone to give you an assistant", as you know best who you can cooperate within the most effective way.

The personal traits of good assistants:

- reliable,
- patient,
- precise,
- open,
- down-to-earth,
- flexible,
- they prioritize your needs; they don't judge your decisions,
- they don't avoid asking something several times,
- they won't make decisions for you,
- they can adjust to your pace, your personalities are compatible,
- you can be yourself with them.

You will need some knowledge of human nature, not only to recognise prospective good assistants but also to detect inadequate candidates or people with bad intentions. Though hopefully, you will not come across people with bad intentions, you have to be prepared. It is important for you to insert safety filters in the process of recruiting assistants, e. g. discussing with common acquaintances, visiting their Facebook site, contacting their previous employers, getting a certificate of a criminal record.



# HOW TO FIND AN ASSISTANT

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Finding a new assistant may seem daunting at first, but if you develop your system, it is not so difficult.

## 1. You should know the kind of person you want

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Before you start searching, make up your mind whether you want a male or a female, for what schedule and time frame, for what tasks, or whether you would like an old or a young assistant, if such factors are important to you.

“I don’t have preconceptions about whether male or female assistants are better, I got on much better with boys, concerning that here at home the oestrogen is in overwhelming majority as there are only girls, even the dog and the cat, so a little counterpoint was refreshing. Another thing that makes me tend slightly towards males is that – and it is terrible to say because I am absolutely a feminist, but these are facts – that they are better at physical work! And despite anything, I can imagine situations that a woman cannot solve if we are all alone.”

## 2. Placing an advertisement

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The advertisement will greatly affect who and how many people will apply. What is a good advertisement like? The clearer and simpler it is, the more potential assistants will apply for the job. It is important for your ad not to evoke pity, but to offer an opportunity. To some extent, you can do this by avoiding medical reports about yourself, stressing your functional needs instead.

Some tips for writing a good advertisement:

- Attach a typical self-photo.
- Write a few details about yourself that you would tell a stranger when you first meet (e. g. age, profession, qualifications, leisure activities).
- Describe where you live (no address needed, just the town/district/part of the town).
- Detail what kind of assistance you need (duration, how often, what activities etc.). It’s vital for you to write about your requirements in a way clear to everyone.
- Be careful not to write too much. The ad should contain the necessary information – it will be explained in detail later when you speak.
- Describe what is important for you in an assistant (gender, age etc). Remember, our experiences have shown that no specific qualifications are neces-



sary for an assistant; you're the one who can explain what you need best.

- Write that it's a paid job, you are not looking for volunteers. (You will agree on exact remuneration in private discussion.)
- Any other information you would like to share.

Where should you advertise?

Freekey works on an interface where assistants are looking for jobs, but at present, this is not enough. However, it is advisable to advertise here initially. If anyone wants to advertise there, first they should visit the Facebook page of Freekey, where they can send a message to us. The administrator of the group will admit them.

Experience shows that if you already have an assistant, you can possibly ask him/her to post the ad on his/her Facebook profile so that his/her acquaintances may see and share. Below, you can read a successful advert which was written by a personal assistant at the request of his/her employer to find an additional assistant.

<https://www.facebook.com/photo?fbid=4208775559158139&set=a.689815584387505>

“One of my main resources is the circle of friends of my reliable assistants and their acquaintances. I ask them to post a photo of us on their own Facebook site with a caption saying that they work with me, describing what they do and that I am looking for another person and those who apply on their site, and they have references.”

Other than your initial ad seeking an assistant, it is not advisable to post the ad many times on your own Facebook profile. After a while, your friends will be overloaded, and fewer people will apply for the job.

It is worth posting in Facebook groups, but as assistance is not nursing, it is preferable to avoid groups of health care workers. Be creative instead and try to address open-minded people who have not heard of assistance yet, but who would consider trying it. Artists, graphic artists, catering workers and university students can be interested.

If none of the above-mentioned methods turns out, consider websites of payable job ads like jofogas.hu. However, it is important to note that these are the people who you can check out the least.



### **3. Selecting and communicating with applicants**

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Keep in mind, good assistance is based on human relationships. You should find an assistant who you are willing to admit to your private life, who you trust, and you can count on etc. Establishing a good relationship requires time, based on adequate selection and communication.

### **4. From first contact to training**

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Initial applicants will respond to your advert in writing. If it comes through Facebook, for example, it is worth checking the applicant's profile. Sometimes you will find content that rules out that person immediately.

After you get the applicant's phone number, follow up with a short conversation. The aim of that first conversation is to find out if it's worth meeting. It may be useful to summarize what assistance you need, how long, where, and how much you can pay. Additionally, it may be useful to try to find out what type of work the applicant is looking for, what their living conditions are like etc. During the conversation, note whether the applicant approaches with pity or offers to volunteer (which may sound promising at first, but it is incompatible with the basic rule of assistance), their ability or inability to listen attentively etc. If you find someone who appears compatible, the next step is making an appointment.

Consider making the venue of the first personal meeting not at your home, but at a neutral place such as a quiet café. Your goal is to get a first-hand feel for the person, to get an overall impression, to look into their eyes and to let them talk about themselves. If the applicant is still compatible, the next meeting may take place at your home, where they can see the tasks to be done. Discuss what is going to happen at the next meeting (e. g. they can try how comfortable it is for them to lift you, they can observe how catheterization is done etc.)

The first home meeting allows applicants to see what tasks they may expect, what the atmosphere is like, how you communicate your requests etc. If you already have an assistant, show them how they can cooperate. It may be helpful to show them potential health care tasks so that the applicants can see them, even though they haven't done such tasks before. They should be invited at a time of day when in 1-2 hours you can show them all the 'spectacular' tasks. After the first session, ask for some feedback about their experiences so that you can decide on whether you can move forward with your cooperation. If the feedback is positive, make another



appointment when the applicant can try some of the tasks. Positive feedback may go along with fears or confusion – it facilitates the process if you mention that it is natural when you happen to see them feel embarrassed in a situation.

“There’s nothing to be afraid of, but it will be strange because it is the first time you have ever done it, but they say that after the third time you have cleaned someone’s behind, it becomes natural, only the first time will people say that they have never done such a thing.”

At the second home meeting, it may be useful to give the applicant an opportunity to try the tasks. This time it is important for everyone to feel comfortable and safe, therefore if it is possible, an experienced (other) assistant or relative should also be present on this occasion. Aiming at the highest level of self-determination possible, the processes should be explained to the person concerned. If it is not possible, or if that particular task at hand requires it, the other assistant can also explain the processes. It is recommended to elicit feedback from the applicants, and also to give your own feedback.

“Others will take you, in some ways others will control your body because you give yourself over to someone merely by being helped out of bed by them, and it requires a degree of trust that must be earned. You must trust the assistant to carry out the catheterization in a way that it won’t cause you any injury or infection, as you are not just a piece of meat for them. It is a two-sided thing: on the one hand, self-agency is badly needed, that is, you must know what is happening to your body and you must give the other person the information they need. On the other hand, control must be relinquished, since it is another person who will catheterize you or dress you.”

Everyone has a different pace and needs a different length of time to be trained. There are some who need just one trial to do everything, and there are others who need several tries. Once you both decide to start your cooperation, it is recommended to draw up “house rules” and to sign an employment contract. This document will serve as a safeguard for both parties, reflecting the earlier agreement concluded orally.

“My two-hour long morning preparation includes all the health care tasks, too. With me one is handling the stool, the other is catheterization. I always tell them, since they have never done it before, these things can be learnt and done by anyone, they don’t require a college degree, it is only



a matter of attitude. Once they observe, they think “OK, after all, if I learn these things, I can do it!”, then we usually agree they should come back as soon as possible so what they saw is still with them and I do a morning preparation with them when they do the processes on their own while I give them instructions how and what to do. Obviously, there must be someone else in case there is some hitch, or some technique must be demonstrated. It’s more difficult to explain than demonstrate. Then it’s good to have them there, but even then, I’m careful not to let one guy teach the other how to do it. I need to be the one who gives explanations all the time and they should ask me.”

## **5. What to do when there are several suitable applicants, but you only need one person**

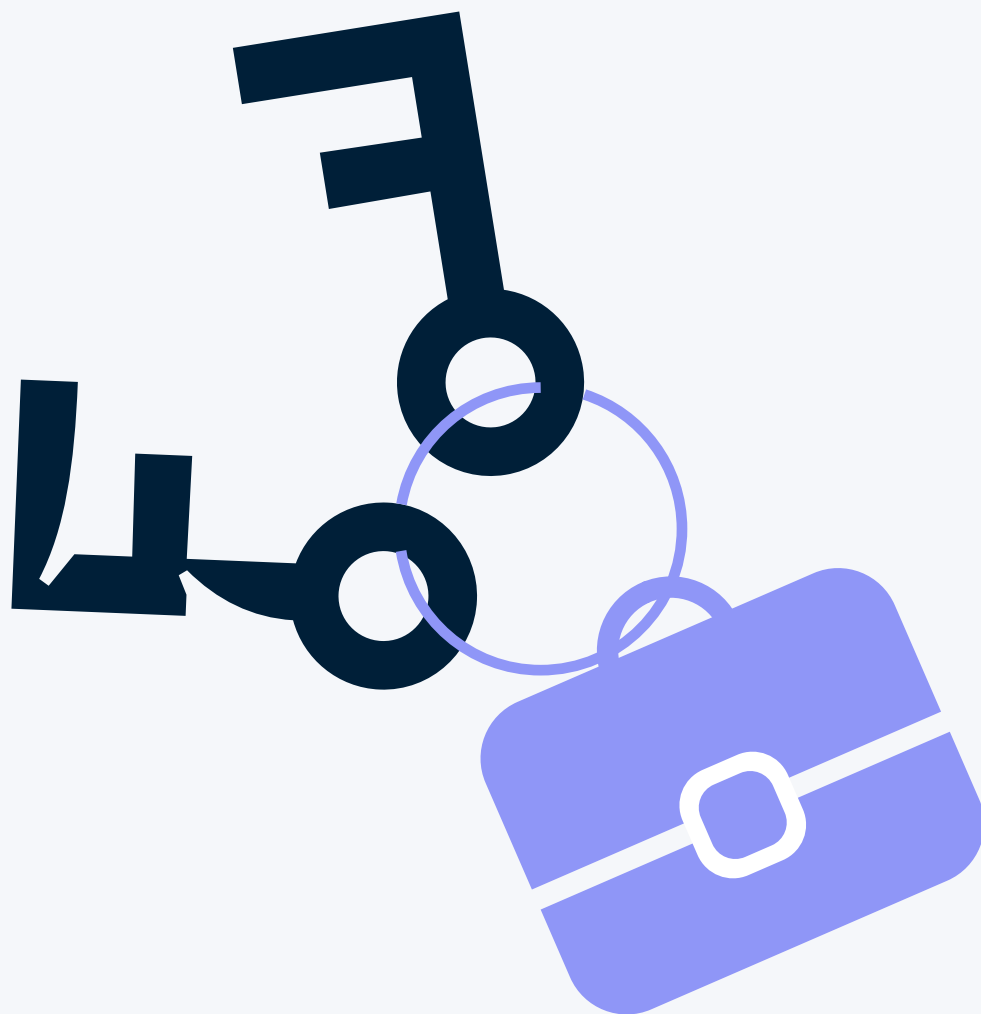
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After the initial contact, it may take several months to find out who you can cooperate within the long term. Therefore, if there are several applicants who seem to be suitable for the job, it may be worthwhile to try various applicants and not to start with only one person. To make the best decision, the following points should be taken into consideration:

- In the beginning, you should learn about the living conditions of the applicant and about how urgent it is for them to find a job. We should clarify with everyone that there are other applicants too and we should strive to give trial opportunities to several people at the same time.
- If you feel that you have found a suitable person, but you cannot employ him/her at the moment or you cannot provide them with enough hours/days to earn their monthly income, write a message on the following website: <https://www.facebook.com/freekey8>. We will help contact them with other people seeking assistants. You don’t need to be afraid of losing the assistant because of this, on the contrary, this way you can ensure the sustainability of your relationship. Since it’s rare to be able to pay an assistant enough to earn their living, it may be advantageous for you if you support them by connecting them with other employers.
- The more people you are in touch with who work as assistants, the better your chances of finding a substitute if someone is unable to work.



# **PROVIDING ADEQUATE WORKING CONDITIONS**





## How can you become a self-determined user of personal assistance?

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To be able to employ personal assistants independently, you should think over the following things.

You can employ personal assistants independently if:

- You know where you need help; what kind of help you need; you can communicate it to the assistant clearly; you regularly allow opportunities to discuss any problems or conflicts.
- You are aware that for operating your personal assistance network, you need some special knowledge and skills in employment, finance, and law. This implies that you consider your assistant as an employee.

**“So, I can say without pathos and fear or without sorrow that someone helps because he/she decided to do this job for some reason.”**

- You know where to gather information and experiences on the operation of the network of personal assistance (e. g. from other users or experienced assistants or from the networks connecting them).
- You know how to train your assistants. This is also important because you take mutual responsibility for each other, and you must provide safety for both parties.

**“It won’t work if you feel that your employer or your assistant is not a good person. We are interdependent, loving and caring for each other. An employment relationship can remain healthy if both parties are attentive to the other.”**

- You know that each assistant has different abilities and capacity so each and every cooperation is different, and you try to create policies with this in mind. It is also important to know what you can and cannot expect of an assistant.

**“In the beginning you have to sit down and lay down frameworks, defining the boundaries of this assistance and where you would like and not like help.”**

## How to create adequate conditions for cooperation

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For successful cooperation, it is important to pay a sustainable and reasonable salary for your personal assistant. Take into account the following financial, employment, communication, and taxation aspects:



## Financial and employment aspects:

- You should agree on the legal framework where you intend to cooperate, at what intervals and how much you will pay them.
- You must know how much you can pay the personal assistant, taking into account a reasonable hourly rate.
- If you employ someone for a complete 24 hours, you can pay a lower hourly rate than someone you employ for two hours. The shorter period of time is spent on continuous, intensive work, without stand-by time, whereas in a 24-hours shift, a few hours must be considered standby time.
- You should clarify the system of payment (weekly/monthly, cash/transfer).
- If a person works with you on a 24-hour shift, you should agree on whether you contribute to the cost of their meals, and if so, how much.
- You don't need to pay the same amount for all your assistants. You may pay more for the more experienced people, who have been working with you for longer.
- It is worth rewarding a person when they must substitute for another assistant unexpectedly who cancelled his/her appointment for any reason.
- It must always be clarified who pays the costs of the assistant at a lunch at a restaurant, on a holiday or a visit to a theatre.
- You should agree on whether you pay any contribution to the assistant's transportation costs.
- Provide reliable and comfortable working conditions for your assistant. You can only cooperate in the long run if your relationship becomes stable and you can rely on each other.
- In a 24-hour shift, you need to provide some time for your assistant to rest. If it is possible, you should provide them with some private space where they can have a rest, e. g. a separate room.

## Taxation aspects

- It is important for you to know that if your assistant is officially registered as a household employee, they are responsible for their own health care insurance and other contributions. Their wages do not include any contribution to their pension fund.

## Communication aspects

- Be patient. Prepare assistants that they will also need a lot of patience.
- Always inform assistants when you would like them to be present and when you would prefer to be alone.



- It is important to keep the possibility of spontaneity in your daily schedule, but it is also important to inform your personal assistant what to expect, such as something different from the usual (e. g.: travelling). It is important to be flexible, but keep in mind that everybody likes certain regularity.
- It is important that both of you should know that it takes time for your cooperation to become smooth. You will cooperate in intimate situations, which at first can be embarrassing for both of you. You should prepare for these situations together, indicate when to expect these occasions, and that it is normal if you both are embarrassed.
- You must be capable to cooperate during the working hours of your assistant (e. g. both you and your assistant should consume alcohol responsibly)
- Your personal assistant must know that You are his/her employer, therefore it is your requests and not those of your family or friends or acquaintances that he/she must pay attention to.

## **How many hours should your personal assistant work?**

This always depends on the needs of the user. You should agree on how many hours of help you need at one time. This may range from a few hours to 24 hours. Even if you agree on 24 hours, this does not mean 24-hour continuous assistance, since the assistant's active help is not always needed, and they also have to relax. However, it is important for them to be available and on-call.

Sometimes you won't need the personal assistant for a few hours. On those occasions, you should plan ahead concerning what tasks they should do so that you can stay on your own for a few hours without calling them back every 10 minutes.

It is also important to draw up a timetable (shifts for individual assistants) in a way that everyone can plan their other activities, and no one makes changes to the duty schedule after it is finalized.

However, sometimes, inevitably, someone calls off, thus affecting the daily schedule for others. If someone falls ill and thus cannot come, then they should warn you as soon as possible. You should compile a prioritized list of who you will call if something comes up last-minute.

“After my accident, it was clear that I would need help practically in everything. While I lived with my mum, I only had an assistant for 8-10 hours a day. But later when I moved out, I started to employ several people over 24 hours. It doesn't mean that they have to do tasks for me all day



long. Most tasks can be done by day in one block, but I didn't want my nightlife to be curbed because my assistant leaves at 6. Just like anyone else I go to bed at around 10-11 and get up at around 7-8, but this way, I have the possibility to do something else."

## **How many personal assistants should be employed?**

Everyone decides on the number of assistants they would like to work with depending on their own needs and personality. There should be a colleague available who takes his/her turn when the other has a day off, or when the other is sick. For some people, it is best when 3-5 personal assistants take turns per a monthly schedule agreed on ahead of time.

It is good to have a 'substitute person' in case someone calls off hours on short notice. Usually, this substitute person has some (paid) fixed days in a month to keep the contact ongoing.

"Currently I have 3 steady people and 1 substitute. I draw up the timetable one month ahead of time with them. The three persons come for 15, 10 and 5 days respectively and if there's a day when no one can come, I call the substitute."

## **What can and cannot be required of a personal assistant?**

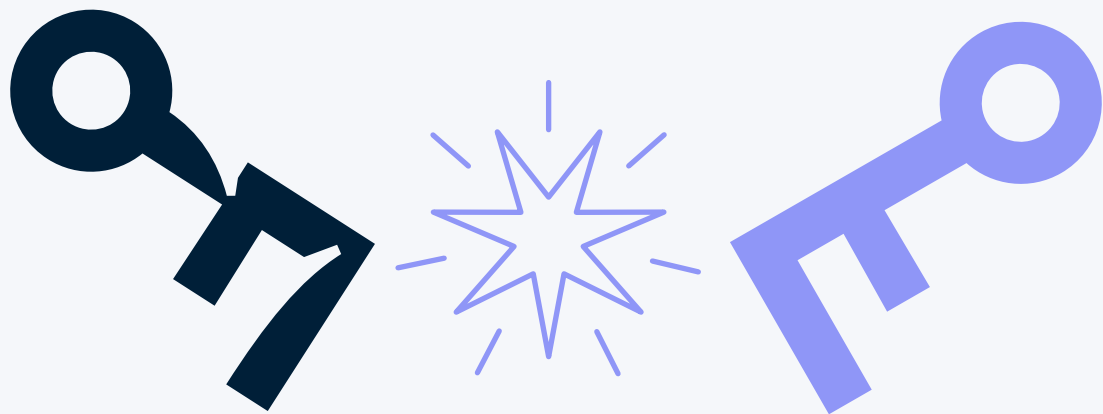
While you should give the personal assistant tasks within their comfort zone, you should clearly express what you require. They need to do what is essential for your life (such as catheterization) if they have agreed to do the job. It is also important for them to express their needs. In cases, if something is uncomfortable or in violation of an assistant's moral code and they won't do that task, it is best to have another assistant who you can rely on.

"I try to have the same expectations of everyone, but it is not always practicable. For example, I ask someone who is dexterous to cut my nails, not the one who has it done by his girlfriend even at home."



# CONFLICT MANAGEMENT, CLOSING THE COOPERATION

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## Warning signs for problematic issues

The personal assistance service is a complex, intimate relationship that requires a certain level of adaptation and flexibility from both parties. However, if you feel that in this relationship you cannot be yourself, the service fails to achieve its goal.

This intimate cooperation can strain both parties, and it doesn't work out successfully in all cases. While sometimes getting used to each other is only a matter of time, after the first few occasions it's sometimes clear that a relationship will not work out.

What can be the signs?

- There are certain things you don't dare ask or do in front of your personal assistant.
- Instead of yourself, it's your assistant who decides on how to do things you would like to do in a different way.
- He/she doesn't keep the rules you agreed on together.
- There is tension/you feel uncomfortable when you are together.
- There are certain conflicts that you simply cannot discuss.
- You don't like each other.
- He/she does things that you cannot tolerate.
- Your assistant is impatient, passive, or aggressive.
- He/she hurts you in any way.

It definitely takes time for cooperation to become successful, but if you feel that you are hurt in this relationship, it should be ended as soon as possible.

## **Oppressive help**

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You must never forget that you, as the user of personal assistance, are the employer of the assistant. It is his/her task to help you in the best possible way per your instructions, which requires continuous communication and practice.

Sometimes your assistant does not understand the basic principles of personal assistance and tries to help you, while actually oppressing you. Let's call it oppressive help. For instance, this arises if he/she often makes decisions instead of you, does things without consulting with you, or helps in a way he/she sees suitable.



In this case, you are fully justified to feel that you are not in charge of the situation, which you can mention to your assistant in a discussion. If he/she doesn't understand this, or there is no change in the person's actions, then this person will probably not be suitable as your assistant.

## **Possible solutions**

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As stated earlier, a successful personal assistance service requires continuous communication, practice, openness, and attention from both parties.

Problems should be discussed as soon as possible to avoid deep conflicts that you can no longer even discuss. Feel free to indicate anything dissatisfactory and encourage your assistant to ask you if they don't know something since you know best what you need. You should make the conversation formal, selecting a low-stress timeframe to talk. Try to create a safe atmosphere where the other person is capable of accepting and listening to criticism. You can facilitate this by instead of saying something like "the problem with you is...", explaining that "in certain situations, I don't feel comfortable...".

It is useful to maintain relationships with several assistants so that an assistant does not prove suitable for you, there is still a person you can call on. This will prevent situations when you spend too much time with any single assistant, which can lead to conflicts in any human relationship.

## **Closing a relationship**

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Sooner or later all relationships come to an end; we should prepare for this as well as we can. Someday even the best person will leave because things change in everyone's life. While certain problems can be addressed with time and adequate cooperation, others cannot be resolved. As in other fields of life, in personal assistance, sometimes two people cannot work together. It is natural.

If you have made up your mind not to continue working with your assistant, you should inform them. In this case, you must discuss how long you will continue your work relationship (which can be that particular day or month). This also depends on the conflict; it's up to you to judge how long you can carry on cooperating with your assistant without negative results.



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