

Know Your Rights

Disability support is changing and evolving and, although the way we receive support may change, our rights remain the same. Everyone who receives a health or disability service has the same rights. These rights apply when we go to the doctor, when we get our eyes checked for example and also when we get support to live independently in our own home. These rights are set out in the Code of Health and Disability Services Consumers' Rights (the Code).

The Know Your Rights resources have been produced by the Health and Disability Commissioner and Enabling Good Lives Christchurch for people who manage their own disability support funding and who receive support from personal assistants or support workers in their own home.

The information in these resources is intended to provide general guidance in relation to your rights as a health and disability services consumer, and does not constitute legal advice. If you have concerns about the employment relationship with your personal assistant or support worker, you should seek independent legal advice.



Starting Off Right: Setting up a good relationship with your support workers

The most important way you can establish and continue to have a good relationship with a personal assistant or support worker, and receive support that works for you, is through good communication and being clear about what you want from the outset. It is your right to receive services that meet your needs.



To help you get the right support, you may want to:

- **Think about your needs, values and beliefs, and how they might affect the way you would like to receive support:**
 - Do you want support that is flexible, or do you prefer to stick to a routine?
 - Do you want a support worker or personal assistant who is chatty and you can joke around with? Or would you prefer a quieter personal assistant or support worker?
 - Are you religious or do you hold firm moral beliefs?
- **You might want to put together your own information** package for your support worker or personal assistant, for example including a list of house rules (shoes off inside, no hats on tables or benches, no go areas, no swearing).
- **Write down some notes or a plan** about what support you need and how that is going to be provided; these can prevent issues and give you both something to refer back to.
- **People often find regular catch-ups to be very helpful**, and they can give you an opportunity to start difficult discussions about your care and support.
- **Although it may take some work** at the beginning of your relationship, talking things out may prevent future difficulties. It is also a lot of work and potentially distressing to be handling problems down the line.
- **Make sure** your support worker or personal assistant understands that they are a service provider and have certain obligations that must be met under the Code.

It is a good idea to be clear with your personal assistant or support worker about what information is private, and what they can share with other people, such as family members. People often talk to those close to them about their day at work, but it is also completely reasonable if you specifically request some things be kept private.¹

¹ To learn more about information privacy when receiving health and disability services, see the Health Information Privacy Code. This Code is administered by the Privacy Commissioner, and is available at www.privacy.org.nz.

David's story

When David was looking for a personal assistant, he made it clear that he was looking for assistance and support in a range of environments and at different times: he wanted someone who could provide assistance regularly during the day, but would also be happy to provide additional assistance occasionally, so that he could go out at night.

David also made it clear that he liked heavy metal music and often played it while he was at home receiving assistance. When David told potential personal assistants that he was looking for someone who would be happy to assist him occasionally at concerts, he was also careful to tell them that the music venues he went to had loud music, alcohol, and sometimes large crowds. It took David a while to find a personal assistant who could provide him with the kind of support he required, but eventually he found Karl, who also loved going to concerts.



Things to think about:

- **Because having a personal assistant or support worker** can involve many different situations, it is worth thinking about the kind of assistance or support you expect to be provided.
- **You may want to discuss** what a few different 'typical' days would look like for you and your personal assistant or support worker — a quiet day, a busy day, a social day — so that they understand the kinds of assistance or support they are expected to provide.

Jessica's story

When Jessica was looking for a new personal assistant, she took the opportunity of their first meeting to have a discussion about boundaries. Jessica had got on well with all of her previous personal assistants, but knew that it was important to receive assistance from someone who knew when to have a laugh and a gossip, and when to get down to work. Jessica also worked from home, so her personal assistant would need to help her get ready for work promptly, and then be able to carry on providing support independently while Jessica was working. Jessica made sure to explain that although a personal assistant would need to assist her in her work area occasionally, when Jessica was working she preferred not to be disturbed, and her files were confidential.



Things to think about:

- **It can be easy to seem 'available'** if you are at home while a personal assistant or support worker is providing support, but you can put boundaries around when you can be interrupted.
- **Remember, it is important to have boundaries** with personal assistants and support workers, but it is also important to be fair to them. They will have their own boundaries, and you should respect those.
- **People are different!** While some people will develop a close relationship and friendship with their personal assistant or support worker, others may not. Some people will be comfortable hugging hello and goodbye, while others will not. Talking about boundaries can prevent problems now and in the future.

DON'T FORGET — YOU HAVE RIGHTS

Right 3: Right to Dignity and Independence — you have the right to have services provided in a way that enables you to maintain your dignity and independence — you can make your own choices.

Right 4: Right to Services of an Appropriate Standard — you have the right to receive services that are consistent with **your** individual needs, that optimise **your** quality of life, and that are provided with reasonable care and skill.

Right 5: Right to Effective Communication — you have the right to open, honest and effective communication with your personal assistant or support worker about the services being provided to you.



For more information:

Health and Disability Commissioner — if you would like to make a complaint about a health or disability service, or the person providing that service, call **0800 11 22 33**, go to www.hdc.org.nz, or email hdc@hdc.org.nz.

Nationwide Health and Disability Advocacy Service — if you would like to talk to an advocate, call **0800 555 050** or email advocacy@hdc.org.nz.