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.

Personal Space: Support workers in your home

Having someone provide care and support in your own home can be a very close and intimate experience. So that you and your personal assistant both feel comfortable about it being your home, it may be a good idea to talk about how you want to receive support in your home from the outset. Talking about how you would like things to work is important — even small things can turn into big annoyances over time if you don't speak up.



Personal Space: Support workers in your home

What are the 'house rules' where you live?

- Do you want people to take off their shoes when they come into your home?
- Can people eat or drink anywhere in the house, or is that inappropriate in some areas?
- Do you have a non-smoking house?
- Would you like your support worker or personal assistant to answer the phone?
- Do you like listening to certain types of music, and do you mind people changing the channel on the radio without checking with you first?
- If you have pets, how would each of you like your personal assistant or support worker to interact with them?

Have a talk about whether there are any 'no go' areas in the house.

- You may live with other people who would not want your personal assistant in their space.
- You may want to keep some spaces private and just for yourself.
- It may be a good idea to talk to your personal assistant or support worker about the important people in your life: your partner, child(ren), family members or close friends. How should your personal assistant interact with them?
 - If your partner asks your personal assistant to do things on your behalf, should your personal assistant check with you first? Or should your personal assistant assume that these requests come from you?
 - How would you like your personal assistant to answer if they are asked a question about you by a family member?



Kim's story

Kim gets on really well with his personal assistants, and is also very fond of his housemates. Once a month, Kim organises a meeting with his housemates and personal assistants about the support he is being provided, to make sure that everyone is happy and knows what is going on. All the housemates and personal assistants take turns leading the meeting, and they check to see whether anyone is having problems, or anyone has any news or ideas to discuss. At the latest meeting, Kim's personal assistant, Dave, raised a good point: even though smartphones and laptops mean that some people are contactable all of the time, it's important to have time when you're 'off duty'. Kim and his personal assistants agreed that, unless it was an emergency, they wouldn't call or text each other before 8am or after 8pm,and wouldn't expect a reply to emails during that period.

Things to think about:

- Be aware that personal assistants will have their own boundaries, and they need to feel comfortable to provide you with the care and support you require.
- It can be hard not to get frustrated sometimes or feel defensive when people raise issues. Getting feedback and being able to raise issues about the services you are receiving is really important it's also a good idea to let people know when they are providing great care or support.
- **Think about how you phrase things:** you and your personal assistant or support worker may come from very different backgrounds and contexts, or cultures. Try to use clear language, and don't assume that people will have the same ideas that you do about personal space.

Kate's story

Kate's personal assistant, Peggy, supported her to do a range of activities throughout the day, including bathing every morning. Although Peggy was always pleasant, professional and appropriate while assisting Kate with bathing, Peggy would sometimes forget about other aspects of Kate's privacy. Peggy would sometimes enter Kate's bedroom without knocking or asking for permission, even when the door was shut.

Kate was a little embarrassed to have to point out to Peggy that she had a right to have privacy in her own home, but she made the effort to speak up. Peggy apologised and admitted that she was also embarrassed and a little uncertain about Kate's private spaces and times — Peggy agreed that she would be much more careful to wait for permission from Kate in the future.

Things to think about:

• **Everyone has their own ideas** about personal space and privacy—talking about what you consider appropriate will help you have your privacy respected by your personal assistant or support worker.

DON'T FORGET — YOU HAVE RIGHTS

Right 1: Right to Respect — you have the right to physical privacy when receiving services from personal assistants or support workers in your home. It is important that everyone understands your right, and what privacy means for you.

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 set boundaries.

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 support worker or personal assistant 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.

In an emergency or in situations of abuse — if you think you are in immediate danger, call or text **111** — otherwise contact your local police station: www.police.govt.nz/contact-us/stations.

