



HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

Making it easy to put the **Code into Action**

A practical guide to the Code of Health and Disability
Services Consumers' Rights for aged care and disability
support workers

Contents

The Health and Disability Commissioner's Office 3

Commissioner's Greeting 4

Consumer Rights

Right to be Treated with *Respect* 5

Right to *Fair Treatment* 6

Right to *Dignity and Independence* 7

Right to *Services of an Appropriate Standard* 8

Right to *Effective Communication* 9

Right to *Full Information* 10

Right to *Informed Choice and Informed Consent* 11

Right to *Support* 12

Rights in respect of *Teaching or Research* 13

Right to *Complain* 14

The Health and Disability Commissioner's Office

Our Vision

Our vision is “Champions of consumers’ rights”. This reflects the aim of the Health and Disability Commissioner legislation “to promote and protect the rights of consumers”.

HDC champions consumer-centered health and disability services for all New Zealanders. We believe this country should lead the world in promoting and protecting health and disability services consumers’ rights.

Our Mission

Our mission echoes our organisational goals: resolution of complaints; protection of individuals and the public; learning from complaints to improve all health and disability services.

We “speak up” in three key areas: partnership (making consumers true partners in their own care); participation (ensuring consumers are heard at every level of the health and disability systems); protection (ensuring the safety and quality of all health and disability services).

What We Do

The Health and Disability Commissioner is an independent agency set up to:

- promote and protect the rights of consumers who use health and disability services;
- help resolve problems between consumers and providers of health and disability services; and
- improve the quality of health care and disability services.

The Code of Health and Disability Services Consumers’ Rights became law on 1 July 1996 as a regulation under the Health and Disability Commissioner Act.

Consumers have Rights and Providers have Duties:

1. Every consumer has the rights in this Code.
2. Every provider is subject to the duties in this Code.
3. Every provider must take action to:
 - (a) inform consumers of their rights; and
 - (b) enable consumers to exercise their rights.

Ngā mihi mahana ki a koutou katoa

Warm greetings to you all



As support workers of aged care and/or disability services consumers, it is important that you have a clear understanding of consumers' rights and the role you can play in assisting consumers to exercise these rights. Our brochure entitled "Code of Health and Disability Services Consumers' Rights" explains the ten rights that all health and disability service users are entitled to. This guide, however, is designed specifically to enhance your understanding of the practical implications of those rights and gives concrete examples of actions that you can take in your day-to-day work to respect and uphold consumer rights.

Please note that, in line with the Code, the term "consumers" is used throughout this document to refer to people you support. We, however, acknowledge that in your organisation, you may be using some other terms such as clients, members, or service users.

If you need any further information, please contact your employer, or you can contact us directly toll free 0800 11 22 33, fax 09 373 1061, email hdc@hdc.org.nz, or visit our website: www.hdc.org.nz.

I trust that you will find this resource useful and that it will make it easier for you to put the Code of Rights into action.

Nāku noa, nā

Anthony Hill

Health and Disability Commissioner

Right 1

• Right to be treated with respect

Consumers have a right to be treated with respect. This means they have the right to be listened to, to be treated kindly by people, to have their beliefs and ideas respected, and to have their privacy respected.

Things you can do to treat consumers with respect:

1. Knock on the door before entering a consumer's home or room, and greet consumers before carrying on with your work. Remember that even in a rest home or residential situation, it is the consumer's home that you are entering.
2. Ask consumers what they would like you to help with on a given day. It is important to do this even though you might be a regular support worker in their home.
3. If a consumer wants to tell you something, please listen to him or her patiently — do not ask consumers to hurry up or shout at them.
4. Always treat consumers in an age-appropriate manner. Do not talk to them like children and avoid excessive hugging, patting, and kissing.
5. Always speak to consumers politely and in a gentle voice. If a consumer is being disrespectful to you, talk to him or her politely about how you feel and how you would like to be treated. If there is a problem, talk to your manager.
6. Give consumers enough privacy to talk to their visitors or to talk to their friends or family members over the phone.
7. Encourage consumers to open their own mail. If they need your support, open the mail in front of them.
8. Take time to learn about every consumer's cultural, religious, social, and ethnic needs and beliefs — be aware of things like removing your shoes before entering someone's home, or not cooking food that consumers don't eat for religious reasons.
9. Always respect consumers' beliefs about religion, sexuality, and morality. Do not try to force your beliefs and values on consumers.
10. If you are not getting on with a consumer or are finding it difficult to work with a consumer — talk to your manager — the sooner the better.

Right 2

- **Right to freedom from discrimination, coercion, harassment, and exploitation**

Consumers have a right to freedom from discrimination, coercion, harassment, and exploitation. This means they have a right to be treated in the same way as other people. They should not be forced to do things they don't want to, and no one should abuse them or take financial, sexual or any other form of advantage of their situation.

Things you can do to treat consumers fairly:

1. Always treat consumers in the same respectful manner as you would treat other people. Do not treat them differently based on their age or ability.
2. It is inappropriate to pass any insulting or offensive comment about what consumers can or cannot do.
3. Remember that over-praising consumers for little day-to-day activities can come across as patronising.
4. It is unacceptable to force consumers to do things they don't want to. If it is a matter of their health or safety, please contact your manager.
5. It is unacceptable to threaten consumers.
6. Verbal or physical abuse of consumers is never acceptable under any circumstances.
7. It is inappropriate to use someone's belongings without their permission, or manipulate them to give permission for something they don't fully understand.
8. It is unacceptable to take any money from consumers' accounts or to make them spend money on you, including on food, or to use their (personal/home) phone to make toll calls.
9. It is unacceptable to force consumers to talk about or read or view any material of a sexual nature; or to have any physical contact with consumers of a sexual nature.
10. If in doubt, talk to your manager, and he or she should be able to give guidance about your professional boundaries with consumers.

Right 3

• Right to dignity and independence

Consumers have a right to dignity and independence. This means they have a right to receive support in a manner that does not put them in awkward or embarrassing situations, and allows them to do as much for themselves as they possibly can within the limits of their impairment.

Things you can do to promote consumers' dignity and independence:

1. It is inappropriate to do or say anything that will place consumers in an embarrassing situation.
2. When providing personal care, ensure a consumer's privacy by closing the door, drawing the curtains, using a towel during transfers from bathroom to bedroom, etc.
3. If providing support with dressing, ensure that consumers are always dressed neatly and appropriately for the occasion.
4. Ensure that consumers' belongings and equipment are always clean and tidy — for example, wheelchairs, communication devices, walking aids, etc.
5. Always ask before offering support to consumers — they may be able to manage without your support.
6. Encourage consumers to do as much as they can on their own and offer support only as and when required.
7. Do not underestimate consumers' abilities, especially severely disabled people with very high needs. Be creative and find out what they can do on their own.
8. Encourage consumers, where possible, to take part in household chores, including cleaning, cooking, gardening, etc.
9. When visiting health practitioners or other professionals, encourage consumers to do most of the talking and intervene only if required.
10. If in doubt about how much consumers can do on their own, ask them directly or talk to your manager. *Do not assume people's capability based on their disability.*

Right 4

• **Right to services of an appropriate standard**

Consumers have a right to services of an appropriate standard. This means they have a right to receive support that is right for them; to have services provided with care and skill; to have services provided according to applicable legal, professional, and ethical standards; and to have professionals working together to provide quality and consistent service.

Things you can do to provide services of an appropriate standard:

1. Provide all services to consumers with great care and skill using the correct techniques and appropriate equipment.
2. Ask your manager to provide you with more training if you are not confident or are unsure of the correct method of supporting a particular consumer.
3. Always complete all the documentation requirements of your job in a timely and appropriate way — for example, completing house diary or care notes.
4. Follow all your organisation's policy and procedures correctly; if unsure, talk to your manager for clarification.
5. If you observe any changes in a consumer's health status or mental well-being, immediately report it to your manager.
6. Always make sure that the support you are providing is appropriate for the consumer — for example, make sure that you are giving correct medication to the right person.
7. Provide services to consumers based on their individual needs and preferences according to their care plans, if any. Pay special attention to people's cultural needs.
8. Take all the necessary precautions to avoid and/or minimise any potential harm or risk to consumers. Report all accidents, incidents, hazards, or potential infection risks.
9. Do not try to provide professional services that you are not qualified for — for example, medical advice, counselling, or therapeutic services. Consult the professionals.
10. If in doubt, talk to your manager — he or she should be able to give you information on the best possible ways to support consumers.

Right 5

• Right to effective communication

Consumers have a right to effective communication. This means they have a right to be told things in a way they understand, and the right to an environment that allows them to communicate openly and honestly.

Things you can do to communicate effectively with consumers:

1. Use different forms of communication as appropriate — for example, oral, written, pictures or symbols, body language and gestures, New Zealand sign language, or communication aids.
2. When communicating with elderly people, be patient and give them enough time to talk. Do not ask them to hurry up or interrupt them if they are taking a long time.
3. When communicating with people using wheelchairs, go down to their eye level, whenever possible, while talking to them.
4. When communicating with visually impaired people, always let them know before you leave the room so that they do not continue talking.
5. When communicating with hearing impaired people, always maintain eye contact and talk in a normal pace and tone. Do not shout or speak more slowly or faster than usual.
6. When communicating with intellectually impaired people, speak slowly and clearly. You may need to repeat yourself several times before they can understand you.
7. Always check with consumers that they have understood you.
8. If you do not understand what a consumer says, ask him or her to repeat, rephrase or write it down for you. Do not pretend that you understand.
9. Create a fear-free environment where consumers can talk to you openly, honestly and privately, if required.
10. If you have difficulties communicating effectively with consumers, ask your manager to provide you with more training, or ask for an interpreter or seek support from someone who knows the consumer well.

Right 6

- **Right to be fully informed**

Consumers have a right to be fully informed. This means they have a right to have correct information about their health or disability, to be informed of available options, and to be told what is being done to them and why.

This right mainly impacts on the work of health practitioners when a consumer needs a medical check-up, treatment or surgery. However, there are some things that support workers can do to provide information to consumers.

Things you can do to make sure that consumers are always fully informed:

1. Inform consumers about exactly what you are going to do when providing personal care or other support. Give step-by-step explanations such as “now I will transfer you from your bed to your chair” or “now I am going to hoist you up”, etc.
2. If going out with the consumers, inform them in advance about the programme for the day — for example, where you are going, what you will be doing there, what time you are likely to return.
3. If going out with consumers for an activity, also give full information about how much it will cost to attend the activity, including transport costs.
4. If you are involved in preparing care plans for consumers, consult them and give them full information about what is covered in their plan.
5. Give truthful answers to questions asked by consumers. If unsure, talk to your manager, but never give any information that is not correct or that you are unsure of.
6. If a consumer is unable to understand the information you are providing, consult his or her family/whānau with the support of your manager.
7. If you are concerned about privacy and confidentiality issues of any information that a consumer is asking for, check with your manager first.
8. If you are supporting a consumer in visiting a health practitioner, make sure that the consumer has all the information he or she may need about the proposed treatment, including its side effects, benefits, costs, etc.
9. Ensure that all information is provided in a format that is suitable for the consumer to understand.
10. If in doubt, talk to your manager, who should be able to assist you to provide full and appropriate information to consumers.

Right 7

• Right to make an informed choice and give informed consent

Consumers have a right to make an informed choice and give informed consent. This means they have a right to be consulted on every decision that affects them, to be given explanations so they can make choices, and to refuse services or change their mind about receiving services.

Things you can do to assist consumers to make informed choices and give informed consent:

1. Always ask for and respect consumers' choices about what service or support they would like, including how to deliver the support.
2. If consumers are not able to make a choice on their own, wherever possible offer different options and encourage them to make a choice. For people with high needs, it could be simple choices like what colour shirt to wear or what fruit to eat.
3. When assisting consumers with options around health issues, for example, "stay longer in hospital" or "go home", explain the advantages and disadvantages of each option so that the consumer can make an informed choice. In some cases, consultation with family/whānau may be required in addition to appropriate professional guidance.
4. It is inappropriate to manipulate consumers to do something that you prefer.
5. If you are unsure of a consumer's likes and dislikes or what a consumer would choose in a given situation, ask the consumer directly, refer to the consumer's care plan, or talk to your manager. Check your organisation's policy before contacting family directly.
6. When making a choice on behalf of a consumer, it is your responsibility to ensure that your choice does not put the consumer in a potentially harmful or dangerous situation.+
7. Always seek appropriate permission before discussing any consumer-related information (personal or medical) or sharing consumers' photographs with anyone.
8. When asking for permission from consumers, provide a full explanation of exactly what you propose to do or exactly how you are likely to use the information requested, so that consumers know what they are agreeing to and can give *informed consent*.
9. It is inappropriate to manipulate consumers to give consent for something that they don't fully understand.
10. If in doubt, read your organisation's policy on informed choice and informed consent, or talk to your manager.

Right 8

• Right to support

Consumers have a right to support. This means they are allowed to have someone with them when they receive care and support.

Things you can do to provide consumers with appropriate support:

1. Consumers have a right to have a support person of their choice with them when they receive any health or disability service. Always ask them who they would prefer as their support person/s.
2. Try your best to organise the support person of the consumer's choice for any activity or outing. If required, talk to your manager to get the right person.
3. The right to support also includes a consumer's choice not to have a particular person as his or her support person, or to have no support person at all.
4. If a consumer refuses your support in a situation that could be potentially unsafe or harmful, talk to your manager immediately. For example, if you are the only support person on site and a consumer refuses to take medication from you or does not allow you to provide necessary first-aid, contact your manager immediately.
5. If you accompany a consumer to a health practice as a support person and the health professional refuses to allow you to be present during the consultation, encourage the consumer to talk to the professional about his or her right to have you present.
6. When supporting a consumer during a meeting, empower the consumer to do most of the talking and also encourage the other people or professionals to talk directly to the consumer.
7. If you are responsible for, or part of, a team preparing a care plan for a consumer, ask the consumer if he or she would like to have any friends or family members present for the planning meeting.
8. Support is different for everyone — treat people as individuals.
9. Being supportive means being alongside the consumer, not in front. Allow the consumer to take a lead.
10. If in doubt, talk to your manager about your role and responsibilities as a support person.

Right 9

• Rights in respect of teaching or research

Consumers have rights in respect of teaching or research. This means they have a right to be fully informed about the nature of their involvement in the research, and to choose to refuse to be part of teaching or research.

Things you can do to support consumers with their right in respect of teaching or research:

1. If you are a trainee support worker, ask consumers if they are OK to be a part of your training.
2. If you have been asked to train a new support worker, introduce the new worker to consumers and ask if they are OK to be a part of his or her training.
3. When trying a new method of working with consumers, always explain the method in detail and ask for their permission before trying it out.
4. If a consumer denies permission for participating in training, or is not comfortable participating, report the consumer's choice to your manager and wait for further instructions.
5. If consumers are asked to be a part of any external teaching — for example, teaching of a junior doctor when at a medical centre, explain to them that they have a right to refuse to be part of such teaching if they are not comfortable with it.
6. If consumers are asked to be a part of any research — for example, they have been asked to complete a questionnaire or attend a focus group — ensure that they have understood the purpose of the research, what their involvement in the research will be, how much time they will have to give, how their information will be used, any risks associated with taking part in the research, etc. All the information should be available on the “information sheet” that researchers are obliged to give.
7. Explain to consumers that they have a right to refuse to be part of any research or to withdraw participation at any time.
8. If you witness a situation where consumers are forced to take part in any training, teaching or research, report it immediately to your manager.
9. Before using any information about a consumer, or any other material that may identify a consumer in any studies (for example, National Certificate Unit Standards) or research that you are doing, ensure that you have obtained informed consent from the consumer.
10. If in doubt, contact your manager for appropriate guidance.

Right 10

• Right to complain

Consumers have a right to complain. This means they have a right to complain about the care and support they receive, a right to have their concerns and worries listened to, to know the complaints procedure, and to be told how and when their complaint will be dealt with. If a consumer makes a complaint, he or she still has a right to receive care and support that complies with the Code.

Things you can do to support consumers with their right to complain:

1. Inform consumers that they have a right to complain if they are unhappy with the care and support they receive or if they think that any of their rights under the Code have been breached.
2. If consumers complain to you directly about any aspect of support that you provide, you must listen to their concerns carefully and provide them with a full explanation of what you did and why you did it in such a way. If there are any unresolved concerns, you must encourage the consumer to talk to your manager, and you too should do so.
3. Explain your organisation's complaints policy to consumers, including how to make a complaint and who to make the complaint to.
4. Explain to consumers what happens once they submit a complaint, including how and when they are likely to know the outcome.
5. If you witness any breach of a consumer's right when supporting someone who is unable to speak for himself or herself, talk to your manager immediately.
6. If a consumer asks you to assist in making a complaint, check with your manager whether it is OK for you to get involved. If the complaint is about a colleague of yours, or your supervisor, it may be better to ask the consumer to get support from a manager or a friend or family member to lodge the complaint.
7. If you are involved in any complaint, whether against you or not, always give the factual information. Say exactly what happened and not what you think might have happened.
8. Inform consumers that if they are not happy with the outcome of their complaint lodged to the service provider, they have a right to complain directly to the Health and Disability Commissioner.
9. Inform consumers about the Nationwide Health and Disability Advocacy Service and encourage them to call a local advocate for support.
10. If in doubt, refer to your organisation's complaints procedure or refer to the Code of Health and Disability Services Consumers' Rights brochure for more information.

For further information and help:

The Nationwide Advocacy Service

Free Phone: 0800 555 050

Free Fax: 0800 2 SUPPORT / 0800 2787 7678

Email: advocacy@hdc.org.nz

The Health and Disability Commissioner

PO BOX 1791, Auckland - 1140

Auckland: (09) 373 1060

Wellington: (04) 494 7900

Other areas: 0800 11 22 33

Email: hdc@hdc.org.nz

Website: www.hdc.org.nz



HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA