Health & Disability
Advocacy Service
Ngā Kaitautoko

Self-Advocacy in Healthcare

ihc
IN YOUR COMMUNITY

Self-Advocacy

You can learn **self-advocacy** skills.

Self-advocacy means speaking up for yourself. It means telling people what you want, what you need, and what is important to you.

Self-advocacy means:

- You say what you want
- You say what you do not want
- You tell people your rights
- You ask questions
- You get help to speak up if you need it
- You are in charge of your life and your decisions.

Self-Advocacy in Healthcare

Going to the doctor or hospital can be hard.

Many health services are not designed with disabled people in mind.

Here are some things that can help you speak up and get the support you need.

You can bring someone who knows you well to your healthcare appointments, like:

- Family
- Friend
- Support worker

They can speak up for you if you want them or need them to.

Getting ready for appointments

You can take a written list of your questions or things you want to talk about.

You can read from the list or give it to the doctor if reading or talking is hard.

Your rights when you use a health or disability service

You have the right to:

- be treated with respect
- be treated fairly
- dignity and independence
- have good care and support that fits your needs
- be told things in a way you understand
- be told everything you need to know about your care and support
- make choices about your care and support
- have support
- decide if you want to be part of training and research or not take part
- make a complaint

If you are not happy with the support you receive, you can:

Talk to the person you are not happy with

Ask a family member or friend to help you make a complaint

Call **0800 55 50 50** and ask for a Health and Disability Advocate or email **advocacy@advocacy.org.nz**

Call **0800 11 22 33** or email **hdc@hdc.org.nz** to make a complaint with HDC

Know your rights. You have the right to get information in a way you can understand.

Working with health professionals

Try to choose health workers who listen to you and work with you.

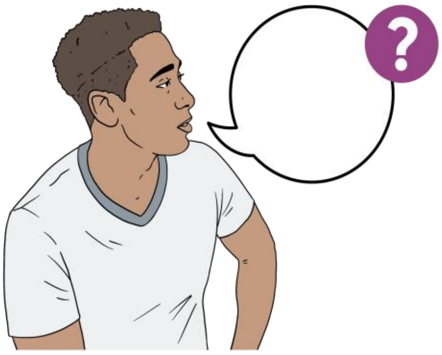
You must be part of decisions about your health.

It is okay to stop seeing a health worker for any reason.

Some reasons could be if they:

- Do not listen
- Do not believe you
- Are not willing to learn or understand.

Asking questions



You are allowed to ask as many questions as you need.

Asking questions helps you understand what is happening and helps you be in charge.

You have the right to get answers in a way that is easy for you to understand.

Speak up if something feels wrong

Tell someone if something does not feel right.

If it is too hard to speak up in the moment, you can still ask for help later.

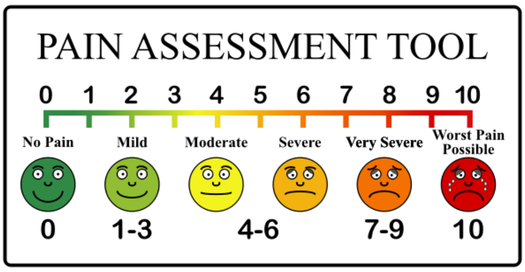
Talking about pain

Sometimes it is hard to show pain through body language or numbers on a **pain scale**.

A **pain scale** is a tool doctors use to understand your pain.

It often has numbers from 0 to 10 or pictures of faces showing different levels of pain.

You choose the number or face that matches how you feel.



You can explain pain by talking about:

- If it makes it hard to fall asleep or wakes you up.

- If it makes you have a low mood where you feel sad, grumpy or frustrated during the day.
- If it makes it hard to do your normal daily activities.

- How much pain medication you take each day.

Helpful documents to bring

You can keep a short “about me” note on your phone to use when you are stressed.

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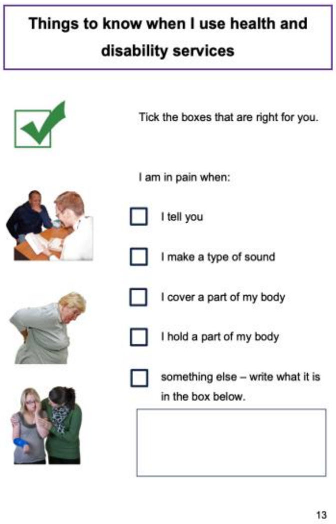
Easy Read

My Health Passport

Please make sure I take
My Health Passport with me
when I leave

You can also have a **Health Passport** with more information about your needs.



Things to know when I use health and disability services

Tick the boxes that are right for you.

I am in pain when:

☐ I tell you
☐ I make a type of sound
☐ I cover a part of my body
☐ I hold a part of my body
☐ something else – write what it is in the box below.

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A **Health Passport** is a small booklet that tells health staff important things about you. It tells them what helps you feel safe and comfortable.

Access and Communication Needs

You can ask services to write down your **access needs** and **communication needs** in your file.

Access needs are things you need to take part safely and comfortably.

For example:

- ramps or lifts
- quiet spaces
- support people
- extra time
- help to understand information
- seating, lighting, or sensory supports.

Communication needs are things that help you understand and share information.

For example:

- using Easy Read
- extra time to think and speak
- writing things down
- using email instead of phone
- speaking clearly and slowly
- using pictures, symbols, or gestures
- having a support person help you communicate

This helps other people understand how to help you.

Using different ways to communicate

Phone calls may be hard for some people.

It is okay to ask for another way of getting and giving information.

You can talk to your health worker about the best ways for them to communicate with you.

Feeling comfortable

You may be able to:

- Wait in a quiet area
- Ask for lights to be dimmed
- Ask for the radio or TV to be turned down.

You might like to use tinted glasses or ear plugs to feel more comfortable.

Sunflower lanyard

You can wear a **sunflower lanyard** to show you have invisible disabilities.

A **sunflower lanyard**:

- is worn around your neck
- has a bright sunflower design
- shows you have a disability that people cannot see
- helps staff know you may need help or changes that make things easier.

Some staff may not understand what the sunflower lanyard means yet, but this is improving.

Everyone is different

What works for one person may not work for another.

We all need different support.

Self-advocacy is important so that health systems can learn from your feedback.

This document was translated from part of *Active Coping and Self-advocacy Strategies* by Luella Wheeler for Altogether Autism. https://www.altogetherautism.org.nz/active-coping-and-self-advocacy-strategies/

Jessica Goodman translated this information into Easy Read at IHC.

David Corner checked this information to make sure it was easy to read at IHC.

Health and Disability Commissioner
Te Toihau Hauora, Hauātanga

This Easy Read uses images of the Health Passport from HDC, accessed on 27/11/2025 at https://shop.hdc.org.nz/category/my-health-passport/