

INFORMATION SHEET

SELF-ADVOCACY AND HEALTH ISSUES

5 August 2021



WHAT IS SELF-ADVOCACY?

Self-advocacy is the ability to speak up for yourself, about the things that are important to you. It's about being able to ask for what you need and want. Self-advocacy is making choices and decisions that affect your life and carrying out a plan to help you get there.

WHY IS SELF-ADVOCACY IMPORTANT?

Self-advocacy allows you to achieve the things you want from life. Being a self-advocate means you will:

- improve your self-confidence and self esteem
- gain dignity and self-respect
- have the strength to guard against exploitation and abuse
- have power as an individual with rights

Self-advocacy helps to empower you, to speak up for yourself and make decisions about your life. When you have good self-advocacy skills you can have more control and make the life decisions that are best for you. It can be fundamental to both asserting yourself and exploring yourself. This is important because it is directly linked to building confidence and self-esteem.

HOW DO YOU SELF-ADVOCATE?

1. BELIEVE IN YOURSELF

You are worth the effort it takes to advocate for yourself and protect your rights. You have the authority to be the expert on your life and nobody else knows how you feel or what you think.

2. KNOW YOUR RIGHTS

Your local health district health board or the Health and Disability Commissioner will have information on your rights. You can find information on their websites but you may still have to make a few phone calls to get the exact information that suits your unique needs.

3. DECIDE WHAT YOU WANT

Think about what you want and need, set yourself goals that will help you be clear to others about what it is that you want and need for yourself.

4. GET THE FACTS

Quality information is important to your self-advocacy, to expect to spend time gathering information and facts, to ensure you are confident about what you are talking about or asking for. While the internet can be a useful source of information, make sure you are looking at reputable websites. You can also check with people who have expertise in what you are

considering, ask others who have been in a similar situation to you, check references in the library and contact reputable organisations for information and support.

5. PLAN YOUR STRATEGY

Use the information you have gathered and plan a strategy that you feel will work to get what you need and want for yourself. Think of several ways to address the problem. It may be helpful to ask those you trust for suggestions and for feedback on your ideas.

6. GATHER SUPPORT

In advocating for yourself it is helpful to have support from whānau, friends and others in a similar situation. You can also gain support from advocacy organisations.

BEFORE YOU MAKE YOUR FIRST CALL

- Write down a description of your problem or need. A short paragraph will help you organise your thoughts.
- Gather background and personal information such as your clinic number or national health number, insurance details, Community Services Card number etc. so you're prepared to answer questions.
- Target your efforts. Identify and talk with the person who can assist you. It may take a few calls to discover which organisation can help or who is in charge, but it is worth the effort. Keep trying until you find the right person.

WRITING TIPS

- You can write to ask for service, to request information, to present facts or to express your opinion.
- Keep the message short and simple - under two pages if possible.
- Its fine to hand-write your message - just make sure it is readable.
- Be clear, specific and to the point about what you want.
- Send copies of your letter to your advocacy agency, or others you want to inform. Put "cc" (copies circulated) at the bottom of the letter. Include a list of those to whom you are sending copies.
- Keep a copy for your records.
- Be sure to follow up with a phone call or another letter.
- Create a file of your letters and responses in date order.

MAKING YOUR CALLS

- State your name, problem and what you need. Be brief with your initial comments. If the first person you talk to cannot help you, ask who can. Ask for the name and position of each person you talk to.
- Phone manner can make a difference. Express yourself clearly. Be brief. State your concern and how you want things changed.

- Assert yourself calmly. Stay cool. Speak out, but also remember to listen. Respect others' rights, but do not let them disrespect you.
- If necessary, ask when you can expect the person to call you back or when you can expect the situation to be resolved.
- If needed, make a follow-up call if you haven't heard back or the situation is not resolved as promised.
- Keep a list of the dates, times, names and positions of the people you spoke to and the result of each call. This information will be valuable if follow-up advocacy is needed.

FACE-TO-FACE MEETINGS

- Plan what you are going to say, then practice. Friends, tape recorders or mirrors can help.
- Bring someone you trust to support your self-advocacy. Having a trusted person with you can provide support, help you stay focused and can possibly assist later if you have trouble remembering something that was said in the meeting.
- Dress neatly. Be on time.
- Look people in the eye and shake hands firmly when you greet them.
- Call the person by name.
- Use positive body language. How you say something often makes a greater impression than what you say.
- Speak loudly enough to be heard without shouting.
- State your message clearly and simply.
- Listen to what the other person is saying. If you do not understand, ask questions to clarify.
- Thank people for their time.
- Follow up.

IF YOU ARE UNSATISFIED WITH THE RESULT OF A CALL OR MEETING

- Ask why the person cannot help you. Write down the answer.
- Ask for another person or agency that may be able to help you.
- If you have been treated unfairly, take action to defend your rights:
 - Address the issue directly with the person who has treated you unfairly.
 - If necessary, talk to the person's immediate supervisor. Your complaint will seem more credible if you appeal one level at a time.
 - Stay calm and respectful and focus on the problem.

Remember you have the authority to be the expert on your life. Nobody else knows how you feel or what you think; you need to tell people if you are not happy or you want something to change. If you are not happy with the way something is done then it is up to you to help change it.

For further information:

- Insight Endometriosis: Endo 101 Factsheet
- Insight Endometriosis: Endometriosis Symptoms Factsheet
- Insight Endometriosis: Diagnosing Endometriosis Factsheet
- Insight Endometriosis Code of Health Services Consumer's Rights Information Sheet
- Insight Endometriosis: Effective Communication Information Sheet

References:

- Effective health behaviour change in long term conditions - A review of New Zealand and international evidence 2012 <https://www.health.govt.nz/system/files/documents/publications/effective-health-behaviour-change-long-term-conditions.pdf>
- Code of Health and Disability Services Consumers' Rights: <https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/>
- Active Listening: <https://www.verywellmind.com/what-is-active-listening-3024343>

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