



...your voice in health

Getting the Healthcare you need:

An advocacy toolkit for people using the healthcare system in Queensland

Health Consumers Queensland

Tomorrow's Queensland:
strong, green, smart, healthy and fair

Toward 
Tomorrow's Queensland

 **Queensland**
Government

Acknowledgements/Thanks

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Health Consumers Queensland sees consumers as **people who use or are potential users of health services**, including their families and carers. Consumers may participate as individuals, groups, organisations of consumers, consumer representatives or communities.

Health Consumers Queensland (HCQ) contributes to the continued development and reform of health systems and services in Queensland. It provides the Minister for Health with information and advice from a consumer (patient) perspective and supports and promotes consumer engagement and advocacy.

HCQ aims to strengthen the consumer perspective in health services policy, systems and service reform and improvement. In acting as your voice in health, HCQ supports consumer, community and patient involvement in all aspects and stages of their individual and collective healthcare journey.

Health Consumers Queensland sees advocacy as **speaking, acting or writing with minimal conflict of interest to support a health consumer or group's wellbeing, and to promote, protect and defend their right to accessible, safe, quality healthcare.**

Health advocacy can be undertaken by the consumer themselves, or by an advocate representing the individual or group's perceived interests.

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1

Introduction

What is this kit about?

This kit is about advocacy. Many of the things we do when we use a health service, or any other service, are advocacy – we just call them other names: standing up for yourself, standing up for another person or a group, and standing alongside a person. It's also helping someone know what choices they have, and what the impact of those choices may be. And importantly, it's about enabling a person to have control over their life but taking up issues on their behalf if they want you to.

Who is this kit for?

This toolkit is designed to support you, as a health consumer, to receive the best health outcomes possible. This can be through speaking up, acting or writing (advocating) on your own behalf or on behalf of another person within the health system. It can also be by advocating on behalf of a group or groups to change the system itself. This kit has information, ideas and tips for making informed decisions in order to take charge of your own healthcare, or to advocate on someone else's behalf. The kit may also be useful for community organisations, health professional bodies and other agencies to assist them in their work.

Advocacy can involve:

- Standing alongside a person
- Standing up for a person or group
- Listening and trying to understand a person's point of view
- Finding out what makes a person feel valued
- Understanding their situation and what might be stopping them from getting what they want
- Offering support to tell other people what they want
- Helping someone know what choices they have and what the impact of those choices may be
- Enabling a person to have control over their life but taking up issues on their behalf if they want you to



2 Your healthcare rights

Everyone who uses the Australian health system has certain rights. These rights are outlined in the Australian Charter of Healthcare Rights.

These rights let you know what you should expect from health services and the people working there. This kit can help you understand how these rights work in practice. It gives you some ideas about what you can do to help yourself, or someone you support, get the best healthcare possible.

Patients, families, carers and services can work together if they understand these rights.

What your healthcare rights are

1. You have the right to healthcare.

This means you have the right to healthcare when you need it, and healthcare that looks after your needs properly. Sometimes this means you may be referred to a different service to the one you first attend. You can ask for a second opinion at any time.

2. You have a right to receive safe and high quality healthcare.

If you are unsure what is happening to you or you think you are not getting the care you need, tell your healthcare service. Telling them what is happening helps to protect your safety.

3. You have the right to be shown respect, dignity and consideration.

This means you have the right to receive healthcare in a way that respects your culture, beliefs and values, age and gender.

4. You have a right to be informed about services, treatment, options and costs in a clear and open way.

Healthcare services need to tell you about the treatment you are getting and help you understand what is happening to you.

You can ask questions if you need more information or if you need the information communicated in a different way.

You can ask for an interpreter if English is not your first language. Confidential interpreter services are free in public hospitals.

5. You have a right to make decisions and choices about your care.

You have a right to be provided with the information you need to make informed decisions about your care. You can ask questions if you are unsure about what is happening to you. Ask someone to support you if this makes you feel more comfortable.

You have the right to ask for a second opinion to make decisions in your own best interests. The final decision rests with you. You also have the right to refuse treatment if this is your decision.

6. You have a right to privacy and confidentiality of your personal information.

You have the right to see your records and to ask for any information regarding your health. Sometimes your health information will need to be shared with other health services and you will be asked to allow this to happen.

7. You have the right to comment on your care and to have your concerns addressed.

You can give feedback, both positive and negative, about your healthcare. You can also make a complaint and expect that healthcare services will deal with your concerns quickly.

Notes



3 **Advocating for yourself in the health system**

Every time you ask to have your needs met, you are using self advocacy skills.

Most of the time these skills work for us. We overcome our lack of confidence or shyness or insecurity to keep control over our lives. When you use a health service you continue to use these skills. This is just another time when you can call on your own resources to work for you.



Self advocacy : *Self advocacy is speaking, acting or writing on your own behalf and in your own interests. Most of us do this without even realising it.*

Understanding how to communicate in the health system can help you to have your needs met. It can also improve the healthcare you get. The way in which people providing health services communicate can be confusing. They often use medical words and statements that have no meaning for us. Knowing that you have the right to information, in a way that you can understand, can help you to speak up and help you to receive safe, quality healthcare. When you speak up you can influence how health services are provided for yourself and for others in the community.

When you use a health service it is very important that you understand the information you've been told. Although it is your right to get good information, sometimes it doesn't happen. Health workers can sometimes be very busy, they may talk very quickly and/or they may not find out if you understand what they're saying.

Tips for communicating about your health

1. Concerned that you haven't covered everything in your appointment

Tip: Take a list of the medications you take with you to the appointment, as well as copies of your most recent tests and any questions you'd like to ask or issues you would like to discuss. This will help to make sure that everything is covered during your appointment.

2. Confused by the medical words used

Tip: Ask the person to give you information in words you can understand. Also ask to have the words written down for you. This means you can ask someone to explain the words to you later, or you can find out more information on your own. You can also ask for the person to draw you a picture or diagram to help you understand. If English is not your first language you have a right to ask for an interpreter, either in person or over the phone.

3. Feeling that you are not being heard

Tip: This makes it very hard to remain confident. If you don't feel you are being heard you can quickly forget the questions you wanted to ask or the reason for your visit. If you feel like this, tell the person. You could say 'Sorry but I don't think you heard me.....'

4. Not talking openly

Tip: Talking openly is important. It will lead to better understanding of your situation and give you an opportunity to talk about your needs and concerns. Health workers do not always understand your special situation. Learning to speak up for yourself, or finding someone you trust who can support you to speak up gives you more control. It means that you have more information to help you to make informed choices about your healthcare.

5. Not having enough time to ask questions

Tip: If you find that you need more time to ask questions, think about making a longer appointment time. You are then more likely to have a good discussion about your health needs.

6. Not knowing what questions to ask

Tip: The best way to work out your questions is to spend some time before your visit thinking about your most important issues. There is a checklist in this kit to help you think about questions to ask. By giving yourself this time you'll have a better chance of having your needs met. Sometimes it helps to take another person with you, someone you trust or a person who can speak up for you if you need them to.

7. Lacking confidence to speak up

Tip: Many people talk about lacking the confidence to speak up in order to have their health needs met. This is a common problem and is not made any easier by the way health information is communicated. If you want to have the information you need to make choices, it is important to ask questions. You may find it easier to speak up for someone else than for yourself. If this is an issue for you, try to imagine what you would do if supporting someone you love. You are worth speaking up for. If it's still too hard for you, ask someone you trust to help you speak up for yourself. Use this kit to think about ideas for speaking up.

When you are sick or not feeling well, communicating can be hard. Your confidence can be low. Being afraid, embarrassed or angry can make you forgetful. If you have pain or tiredness you might not be able to communicate the way you normally would. If the way you are feeling is making your visit difficult, try to honestly tell this to the health worker. Ask for a moment, count to 10 and breathe slowly and deeply. Begin again if you can or wait for another time.

Brian is 45 years old and has been newly diagnosed with motor neurone disease. He attended a health service to find ways to manage his illness and to strengthen his body with exercise. The physiotherapist he saw spoke very quickly and talked about issues he would face in the future. She told him about things that might happen in medical words he had never heard before. He became very anxious and left feeling worried and depressed. He felt too upset to ask her to explain.

At his next visit he took a friend, Larry, with him who helped him ask questions. Larry was able to ask the physiotherapist to slow down and asked her to explain the meaning of words. Brian was much less worried when he understood what she was telling him.

8. Not remembering what is said to you

Tip: Sometimes people think they know what is going to happen next without asking. For example, thinking your test results will be normal unless you are called back could be a mistake. Always follow up with your doctor for test results rather than waiting for your next visit. Ask questions to find out how things are going to happen. Ask the person to slow down. Repeat any instructions you get and write everything down if you can. Take your list of questions with you. Take someone else with you if that will help.

If you feel confused or uncomfortable at any stage of the appointment it's important to say so. Here are some things you could say:

'I know you're busy, but I'm feeling rushed. I need to be sure that I understand what you're saying.'

'I'm confused with how fast you're talking. I need you to slow down and help me understand please.'

By practising some of these things you may find it easier to communicate about your health and to have your needs met.

Notes

This image shows a single sheet of white paper with horizontal blue lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

4

Working with your doctor and other health professionals

In this part of the kit we are going to talk about some ideas to help you get the service you need at your health appointment. It includes what to think about before your appointment, what to think about during your visit and some ideas for making sure you get the information you need to make choices about your health.

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Who is a health professional? A health professional is a person who uses skills and knowledge to treat people and work towards them getting well in a clinic situation. Some examples: a doctor, physiotherapist, dentist, counsellor, nurse.

Your relationship with your health professional is a very personal one. It is built on communication and trust. Trust allows you to share important and sensitive information confidently and freely. You must be able to talk honestly about your health issues, including all your symptoms. The person should listen to you, give you options based on facts, and have your best interests in mind.

Sometimes, because of cultural and other beliefs, it is important for a person to see a doctor or other health professional of the same gender. If this is the case make sure you ask about this when making your appointment. Usually health services will do their best to support you. If it's not possible they can provide you with information about other services that can better meet your needs.

The fact that a person can tell their doctor, for example, anything in confidence is the basis of the trust that's needed in a patient-doctor relationship. There are rules for doctors about confidentiality. These rules are there to help and protect patients. A doctor can't talk about a patient's medical history, even to their closest family members, without asking the patient, no matter how much they might want to.

The rules of confidentiality are there to protect people, so there are times when a doctor has to break the confidentiality rule. It does

not happen often, but it can happen. The law says a doctor must tell someone if a person's actions are putting themselves or others at risk; for example, when someone keeps driving a car even though they suffer blackouts, or if a person talks about harming themselves when they are mentally unwell. Another example is child protection issues, where the needs of the child are put before those of the adult.

Working with teams of health professionals

Sometimes a team of people are involved in caring for you in a healthcare centre, hospital or in the community. This means a lot of conversations about your medical condition and how you're feeling. You may need to tell your story a number of times. Each person you meet has their own way of communicating, so it's really important there is good communication between all members of the health team. It is a good idea to ask for regular meetings to bring together all team members. Then everyone is on the same page with regards to your treatment plan.

Try to find someone you communicate with well and ask them if they're prepared to act as the main contact for the healthcare team. This could be your doctor, another health professional or someone from a community-based support service. Also let health professionals know who they can and can't share your information with, and make sure they are able to communicate with your main contact person.

How you communicate can work against you getting your needs met. The things that are not helpful are to be threatening or aggressive. It is better to find someone else to support you to speak up than to disrespect the rights of staff.

You could ask a family member or a friend to speak for you. Tell one of your health team if someone is to act on your behalf. Make sure that if you are speaking for someone, the person who is sick has asked you to do this. Ask to fill out any forms or paperwork you need to in order to be able to speak up for someone.

Many health professionals find it helpful when the people they see:

- Are prepared for their visit.
- Tell them their concerns clearly and honestly.
- Give them a complete description of their medical condition.
- Ask questions about their illness and its treatment.
- Come with a list of prescription, over the counter and herbal medications.
- Talk about their concerns or problems with medicines and treatments.
- Let them know of any cultural or other support needs before the visit so that your needs can be accommodated.

Tips for making an appointment

- Make sure enough time is set aside for your needs. Be as open and honest as possible about the reason for your visit.
- Most times when you make a doctor's appointment you're given a short time. If you're worried it won't be enough time, ask for a long appointment. For example, you might do this the first time you see a new doctor.
- If you're concerned about how long you might wait, try making your appointment for the first time slot in the morning, or the first time slot after lunch.

Tips for preparing for your appointment

- **Think about what you want to get out of your visit.** For example, do you want to talk about new symptoms? Do you need a letter to a specialist?
- **Write down your symptoms and concerns** so you can talk about these clearly.
- **Make a list of questions.** Be sure to list the most important ones first.
- **Think about your medical history.** Sometimes it helps to write your history down to give to a new doctor. It can save time.
- **Write a list of medications** you're taking and how much you take. Tell your doctor if you take over-the-counter medications, vitamins and herbs.
- **Take your most recent tests.** Always ask for copies of your test results so you can have them.
- **Write down any allergies you have.**

What to take to your appointment

- Medicare card
- Pension card or healthcare card if you have one
- Notes or a list of questions you would like to ask
- A letter from another doctor if you have one
- A person to support you if you want one

At your appointment

Remember to take your lists! If you forget, ask the person at the front desk for paper and start writing while you wait.

Sometimes it can be frustrating if you have to wait a long time.

Ask how long the expected wait is, and find out if you can take a walk or come back later.

If there is not enough time to cover everything during your appointment **ask for any handouts and leaflets for more information**. Then make another appointment with more time.

Health professionals don't read minds! Most of the information a person needs to find out what is wrong with you comes from what you say. The rest of the information comes from an examination of your body and from tests.

The information you give from what you say — known as your 'history' — is important. There are two ways to find out this information:

- your answers to questions
- what you tell the person yourself.

Give your health professional as much information as you can. Doctors don't always look back through your file so remind them if you've had similar symptoms before. If there's anything you think they need to know - that you're taking vitamins or over-the-counter medication, for example - then say so. They may forget to ask certain things.

You may feel nervous about speaking up in these situations. Sometimes it helps to take a friend or support person with you. You may have to make some decisions while you're there. You might need to have some tests, for example, a blood test; you may need to take some medication or you may need a referral letter for getting some more help.

If you are not sure about what choices to make, ask for some more information or some more time. You may need a longer appointment. Then talk it over with someone you trust.

Tips for getting your needs met at your appointment

- **Make sure you talk about the most important thing first.** It can be a good idea to give a copy of your list to the person. Keep a copy for yourself so you remember what to ask. It's best to ask questions as soon as you think of them.
- **Ask the person to explain again** and repeat back to them what you've heard. Ask them to say it again if you're not sure.
- **Ask questions,** for example: How will this help me? What will happen if I don't do this? When you say to get more exercise, what kind of exercise and how often? What do you mean by 'come back if you are not better'? When and how much better? How much will this cost? How much will I have to pay and how much is paid by Medicare or my health fund?
- **Find out what choices you have,** if any. It's also OK to think about your decision or change your mind. Don't be scared into doing something before you're sure of your decision. Unless it is a life-threatening emergency, there is always time to think things through.
- **Take a notebook** if you want to take notes or bring a support person with you to help you remember the information.
- **Speak up for yourself** or have a friend or family member speak up for you if you don't get the help you need.

Sometimes people feel worried or shy if they don't understand something. They don't want to seem stupid. But if you don't understand something, it's important to ask. It shows that you care about getting all the information. Also, you are more likely to remember what you are told.

Ask your doctor to spell medical words, draw a picture, or write down information for you. Remember it is your right to have all the information given to you in a way you can understand.

Ella had been very sad since her partner died suddenly six months before. Every time she went to see her doctor she became too upset to talk about the way her body was feeling, and left the office without dealing with her health problems. Her appointment with the doctor was over before she could calm down.

She realised that being upset stopped her from getting the help she needed. So Ella decided for her next visit she would make a longer appointment. She decided to write down all the symptoms she was having and take the list with her.

At her appointment she gave her doctor the list. She had time to talk about her problems. When she got upset her doctor had time to wait for her to calm down. The doctor could reassure her that her symptoms were part of her grief and let her know she would slowly get better. It helped her to understand what was happening to her. It took away some of her worry.

Tips for getting answers

If you have any health issues relating to your culture or beliefs talk to your doctor about it. If you have any difficulties in communication, you have the right to ask for an interpreter. The more openly you talk to your doctor, the more likely you are to get a good health outcome.

By planning some things to say before you have your appointment, you might be able to get better information.

For example:

I understand you're busy, but I want to make sure you understand. I want to learn everything I can about my condition.

These are the medications I'm taking and these are the herbs and vitamins I take... is it a problem to take them together?

Laila is a Somalian woman. She went to the doctor as she felt tired and had no energy. Laila is taking herbal medication that she used to have back home.

The doctor asked Laila a few questions but found it hard to communicate with her. Laila wanted to ask her about the herbal medication she was taking and its effect on her current health, but because of the language barrier, she couldn't discuss her issues with the doctor.

The doctor asked her to have a blood test and said for the next visit she would arrange an interpreter for her. Laila refused as she was concerned about her confidentiality. There was a chance the interpreter could be from her own community. She tried hard to explain how she felt. The doctor understood and offered another option. She could have an interpreter over the phone from another state. Laila was very happy with this option.

At the following appointment, Laila talked about different cultural issues, the herbal medication she was taking and other health issues. She was happy to talk about those issues openly through the phone interpreter. The doctor learnt a lot about Laila's culture and beliefs. This information helped them to build a trusting relationship which supported Laila to get the best health outcome possible.

Be as clear as you can. Instead of simply saying 'my leg hurts', you might also talk about the problems you have climbing stairs, bending down and lifting children.

Other questions you could ask:

Can you please explain that in another way? I'm having trouble understanding.

How much do I have to pay for the tests you are ordering?

Do I have to prepare for the tests?

What do these medicines do?

What are the side effects?

Is there a cheaper medicine?

Will this condition affect the things I can do? If so, how?

How long will I have to follow the treatment?

Where can I find more information about it?

Are there support groups? If so, how do I find them?

Questions about tests or procedures

If tests or procedures (e.g., an x-ray, a CAT scan) are ordered:

Why do I need the test? What will it tell us?

Are there any risks in doing the test?

What does the test/procedure involve? For example:

Will it be painful?

How long does it take?

Will I be awake or asleep?

Do I need to bring someone with me?

Does it matter what I eat or drink?

Do I need to stop taking medications?

How is it done, what steps are involved?

Where is it done? Is there a place close to where I live?

Questions about medication

If the doctor gives you a prescription for medicine ask:

What is it for?

What will it do?

What the side effects could be?

How long do I need to take it?

What time of day should I take it?

Should I take it with food or on an empty stomach? Why?

Remember to talk to the doctor about any other medication you take including herbal medicine.

Also talk about any allergies that you have. Some doctors may forget you are allergic to certain drugs, for example: penicillin.

Try to go to the same chemist each time you need medication. Ask the chemist questions if you are unsure about your medication. They may be able to provide you with extra information to help you understand your prescription, over-the-counter or herbal medicines.

If you have problems with treatment prescribed by the doctor:

- Don't change the treatment; including stopping medication until you speak to a doctor, other health professional or chemist. Stopping or changing your treatment or medication may cause problems for you.
- Tell your doctor if you have stopped following the treatment and why.
- Tell your doctor you want to work together to find a treatment that works better for you.

Your Medical Records

You have the right to look at your own medical records. This means that you can look over your records or have a copy of them. Also you can have someone explain them to you. There may be a fee to pay if you want to take a copy of your records away.

There are a few situations where you may not be able to have your records. To find out more about this you can ask Queensland Health or the Office of the Privacy Commission for information. You will find their contact details at the back of the kit in 'Resources and Referrals'.

In your medical records it is important to have current information on all tests and procedures you have had. It's important for your doctor to know about any emergency hospital or medical treatment you may have received.

Tips for finding a new doctor

It helps to stay with the same doctor. You develop a relationship and they know your health issues. If you change doctors you are always starting at the beginning. However, if you're not happy with the way you are treated or if you're not able to communicate your needs, find another doctor. If you would like to get your medical records to take to your new doctor, you can ask for a copy of them. Most doctors are happy to give you a copy of your records but they keep the originals.

Greg went to the doctor to ask for medication to help him lose weight. After examining him, Greg's doctor told him to change his diet and join a gym. He wouldn't talk about other options. Although Greg tried to explain his home situation to the doctor, he felt rushed. He didn't feel the doctor had listened to his situation when he refused to talk about medication that might help him.

Greg knew this plan would not work for him. He's a single parent and looks after his son who has a disability. He doesn't have the time or money to attend the gym, and his pension would not cover the cost of the different foods the doctor suggested.

Greg went back a couple of weeks later and the doctor again told him to exercise and eat better, saying that 'everyone can find that extra hour in the day if they really want to!' At this point Greg decided to find a new doctor – someone who would take more time to understand Greg's situation and help him to come up with solutions that suited his needs.

If you do need to find a new doctor here are some questions to think about:

- What friends can I ask for information to help me find a new doctor? Often friends or other family members can recommend a doctor who they know.
- Do I want a male or female doctor?
- Do I want a doctor who bulk bills?
- Do I need to think about where the doctor is located, for example, near buses or trains?
- Do I want a doctor who speaks my language and understands my culture or my life situation?

- What do I need to take when I go? (This may include your Medicare card, health benefits or pension card, any health records you have, a letter from your old doctor if you have one and a list of questions you want to ask).

If you have trouble finding a new doctor there is a 24 hour telephone service called Health Direct. A registered nurse gives you advice if you need to talk to someone about your symptoms. They also give advice if you cannot get an appointment with a doctor when you need it. The contact number is in Resources and Referrals at the back of this kit.



There is a legal document called an Advance Health Directive that enables you to give instructions about your healthcare for future situations when you are no longer able to make decisions. It allows you to give written instructions about the care and/or treatment you want and under what circumstances. You can find out more information about this and about making decisions on another person's behalf in the booklet 'Advance Care Planning'. This booklet is available through Queensland Health or the Guardianship section of the Department of Justice and Attorney General. Their contact details and websites are in the back of this kit.

Notes

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Advocating for yourself in a hospital or healthcare centre

Many people do not know that they have rights when they go into hospital or use a healthcare centre. Because it can be hard to keep control over what is happening to you in a large health system, understanding your rights can give you confidence to speak up for yourself or someone else your support.

Your rights

- If you have a Medicare card you get free hospital and community-based services as a public patient. This does not include adult dental services.
- You may also use private healthcare centres and other community-based services that bulk-bill. If they don't, check what you will need to pay.
- To be treated with respect, dignity and consideration in relation to your age, gender, sexual preference, religion and culture.
- To be provided with a free interpreter if needed.
- To get information so you can choose to be a public or private patient.
- To get treatment based on how sick you are.
- To make decisions about your healthcare.
- To have information that is easy to understand about your treatment, including risks and choices.
- To give your permission before being treated, if you are able.
- To get a second opinion from another doctor.
- To give a compliment or make a complaint.
- To have your personal information kept private and confidential.
- To ask to see your medical records.
- To decide if you want to take part in medical research and clinical training.

When you go into hospital or use a healthcare centre, there are certain things expected of you:

- You need to be open and honest with information so you can get the best healthcare possible. For example, letting staff know about medicines or drugs you take, or if you're having any problems with the treatment.
- You need to treat people with respect and be aware of the needs of others as well as your own if you are able. This includes respecting the privacy and confidentiality of others.
- You need to be prepared to ask questions and to let the staff know if you don't understand an explanation you're given. You also need to let staff know if you want to talk to your family before making decisions.

By taking responsibility for these things, or letting someone know if you need support to do these things, you have much more personal control over your situation.

There are many ways in which people can access hospital services. Some hospital visits are planned. Others are unexpected, such as through an emergency department. Sometimes people can visit the hospital as outpatients for clinic visits and simple treatments. Other situations and health issues require a stay in hospital.

In most cases a visit to hospital comes from first visiting your doctor who then refers you to a specialist. The rest of this chapter talks about some of the issues you might face in preparing for a hospital visit. There are tips for speaking up about your healthcare needs. You can also use these tips when visiting any other health service.

Specialist appointment before going into hospital

When you go to your appointment with the specialist, you can use the same tips as in 'going to your doctor' or 'communicating your health needs' in this toolkit.

If you're told you need treatment in hospital, find out:

- why you need the treatment,
- the benefits and the risks of having the treatment,
- what could happen if you do nothing and
- what your other options are.

Ask if you are unsure about any treatment or have any questions. It's important you fully understand what is happening to you. **You could ask:**

Why do I need it?

What is the treatment or surgery like?

How is it done?

What are the risks?

What could I do instead?

Ask about the costs of the treatment and how you can pay. Ask how much you pay yourself and how much Medicare or your health fund pays. You may have to wait for non-emergency healthcare or to go into hospital.

A doctor usually decides how serious your problem is and how quickly it needs attention. Ask the doctor what the risks are of waiting for the treatment and what your out-of-pocket expenses could be.

If you are on a waiting list for treatment, find out who to talk to so you can keep informed of where you are on the list. If your condition changes or gets worse while you are on a waiting list, make sure you let your doctor know. They will be able to inform the hospital and your position on the waiting list may be reassessed.

Pre-admission clinic visit

Before you go into hospital you may need to visit the pre-admission clinic. This could be a few weeks or a few days before going into hospital.

You need to take these things with you to the pre-admission appointment:

- Medicare card
- Pension or healthcare card if you have one
- Letters/referrals from your doctor
- Forms the hospital sent you to fill out
- A list of the medications you take
- Any health records you keep (your health history and family health history)
- A person to support you if you want one
- A list of questions if you have one – for example, you might like to ask ‘What happens in hospital if I need assistance?’

Consent to treatment

You will be asked for your consent before any treatment, and sometimes given a consent form to read. You may want to talk to the doctor about the information on the form. You may also talk about the information on the form with other people, for example, family members. You can do this before you give your consent. Ask about any risks there are with your treatment. Ask for an explanation of these risks until you understand them. When you fully understand the treatment and any risks there may be, you’ll be asked to sign the consent form.

Make sure when you are asked for consent to treatment that you remember the **BRAN** acronym and are fully informed about:

- **Benefits** – what will the treatment achieve?
- **Risks** - how likely the risks are to occur – what is the success rate of the procedure?,
- **Alternatives** – are there any other options for treatment
- **Nothing** – what will happen if you don't do anything or delay the treatment?
- **Side effects** – what are the possible side effects and how long will it take to get over them?

Can I have a family member or friend with me during treatment?

Usually family and friends have to wait for you in the waiting room at the hospital. However, sometimes they can stay with you except during the surgery. For example, if the person is a child, if you don't speak English or if you have special needs.

Roz has a learning difficulty. She sometimes has trouble understanding what someone says to her, particularly when she is scared or upset. When she had to go into hospital for an operation she was very worried. Her mother talked to the staff to help them understand how scared she was. They let her mother stay with her while she was given her anaesthetic to put her to sleep. It helped her to feel safe.

Tips to help you get your needs met in hospital

- Introduce yourself to a staff member.
- Remember it's OK to ask for what you need. When you're sick it is hard to understand information. You may need someone else to speak up for you.

- Let the staff know that you understand they are busy. You could say, *'I can see that you're really busy and I am grateful for your help. Could you please....?'*
- When you're in hospital the doctor usually writes notes on the chart in your room. If you are not sure about what the notes say, ask the nurse to explain what the doctor has written. This will help you know what to expect. If necessary, find a person to support you to get the information you want.
- Ask what the machines in your room are for. Then you can understand any strange noises or the numbers changing on the screen.
- If you are a support person, find out what time the doctor usually visits and then try to be there at that time. Write a list of questions to ask with the person you are supporting. Sometimes for privacy, visitors are asked to wait outside when a doctor visits. Ask the person if they would like you to stay and if so, make it clear to the staff.
- When possible have a family member, close friend or support person present throughout much of your hospital stay. Some people find that having someone to support them means their needs are better met. Healthcare workers may also see them as a willing part of your healthcare team.
- Don't be afraid to ask for the nurse manager when you're worried about something that is happening.

You may be afraid that if you ask to speak to someone else or a manager, staff will get angry and make your stay in hospital difficult. Sometimes this means that you stay quiet rather than speaking up. If this happens, it's a good idea to ask someone to support you to talk about your concerns.

Planning to go home from hospital

After your treatment a doctor or nurse will talk to you about any care you need. They'll tell you when you can go home and tell you when to see a doctor again.

This is called **continuity of care** or **discharge planning**. It's very important that you go home from hospital with all the information you need. If you are worried or unclear about the information ask to speak to a social worker for support.

Usually a discharge plan has the following steps:

- a check up by healthcare staff to make sure you're ready to go home
- a talk with you and/or your support person about how you might feel at home
- planning what you need if going home or to another service
- helping you find support if you need it
- arranging follow up appointments or tests

Before you leave, make sure that you:

- understand the treatment you were given and what care you need
- know what medicines you need to take and why
- know when you need to see a doctor again and who to see (your doctor, the specialist or outpatient clinic)
- ask if you need a medical certificate, a letter for your doctor or WorkCover (workers' compensation) information
- have someone to care for you at home or stay with you if you need it
- have the contact details for any service to which you are referred.



6

**Advocating on behalf of
another person to get
their health needs met
(or having someone advocate for you)**

i

What is advocacy?

‘Where a person has their own voice, advocacy means making sure that person is heard’

‘Where a person has difficulty speaking up, it means providing help’

‘Where a person has no voice, it means speaking up for that person’

Sometimes speaking up with health professionals raises difficult issues. We’ve talked about some of these already in the toolkit. For example, if you’re not being listened to by your doctor, you can try some different ways of saying things. You can also take a list to your doctor of the things you want to talk about.

However, in very hard times, for example, where you have a child in hospital who is seriously injured, you can be so upset that you place a lot of trust in the staff who are looking after the person you love or support. In these hard times, an advocate is someone who can support you to get the best health service you can. They can support you to make hard decisions and to have your rights respected.

Many people don’t think about asking someone for support when they’re using a health service. They feel they can speak up for themselves. However there are certain times you might like some extra support:

1. You are too sick to ask questions, listen to complicated information, or to stand up for your own rights.
2. You are having difficulty getting the information you need.
3. You feel confused because there is just so much information to take in.

4. You feel that no one is taking any notice of what you say or ask.
5. There is a problem with someone in the system or with the system itself.
6. You are very upset or angry at what is happening and don't feel you can speak calmly about the issues.

Who to ask for support?

Someone who:

- Respects you and you can trust
- Lets you keep control of decisions
- Helps you understand your choices
- Supports you to speak up for yourself
- Speaks up for you when you ask them to
- Respects the decisions you make

Tips: Questions to ask myself

1. Who do I know who is willing to listen? In particular, who is willing to listen to what my needs are and what would I like them to support me with? I don't want someone who is going to take over and to think they know what is best for me.
2. Who do I know who would be willing to learn about my health issues so they can better support me with my health needs?
3. Who do I know who is happy to ask questions when the going gets tough for me and I cannot ask them for myself? And who is willing to keep on asking questions until we understand all my choices?
4. Who do I know who is willing to work with others to find answers that we need? Who is a good 'people person'?

5. Who do I know who can take on the people in charge, if necessary, without isolating me from their support?
6. Who do I know who has the strength to keep going and pushing through barriers to get the outcome I need?
7. Who do I know who speaks the same language and has the same beliefs as me? Can this person help my understanding and communication?

Jack needed some painful tests done at day surgery. He felt he needed someone with him as he was very nervous about the tests and the results. He thought he would take his wife with him as she is his best friend. He thought about whether or not she would be the best person to support him and realised that if the going got tough she would get very upset as she broke down easily if he was upset.

Jack discussed this with his wife and then decided he would ask his sister. They had a great friendship and he knew she was used to dealing with health professionals as she was a nurse unit manager before she retired. Jack's sister agreed to pass on information to his wife throughout the day so that she wouldn't worry and would be fully informed about how Jack was going.

Different kinds of support you can get

1. **Informal advocacy** means that you or a person you trust speaks up on your behalf. It can also mean that you speak up for another person. Informal advocacy focuses on changing the situation of one person – to protect his or her rights. This is the most common kind of advocacy for people who are using the health system.

2. **Formal advocacy** is when staff or volunteers from services support a person when they need it. The person who is being supported and the advocate reach an agreement about how the support will be given. They agree what issues the advocate will support the person with and for how long the support will be given. Some services have agreements for people to sign so that both the person and the advocate understand how the support will work. It is important to understand exactly what the agreement says before signing it. Ask questions if you need more information, or ask someone you trust to talk it over with you before you sign.

Tips: When you are the support person

1. **Get to know the person you are supporting.**

The job of the advocate is to walk beside the person. It is not to put your own views and beliefs onto their situation. Sometimes if you are supporting a person in your family you might think you know what the person wants, but this is not always true. It is important to spend time getting to know the goals, values, hopes and wishes of the person.

2. **Be clear about the issue or problem.**

Develop a clear understanding of the person's health problem. This will help you focus on actions that help find a solution. It's not always easy to get to the heart of the issue when personal feelings are involved. An advocate can help a person to look at the key issues so their health outcomes are met.

3. **Be clear about what the person wants to happen**

It's important that the person you are supporting has enough information to make an informed choice. Does the person want help with something that will improve their health? Or are they more concerned with setting something right in communication? You may need to use different strategies to achieve the outcome the person would like. Begin with the most important need for the person.

4. Develop strategies

Find out who you need to connect with in the health system to support the person with their health issue. It may be the GP, the specialist, the Adult Guardian, the registrar at the hospital, the nurse manager, the community nurse, or other support staff. It may be only one or two health workers.

Still, it is important to identify who these people are. If the health issue is a one-off situation, then the response of the support person can be straight forward, for example the doctor speaking rudely to the person in the waiting room, or, a meeting could be set up with the doctor so the person can talk about their concerns.

In more complicated situations you might need to arrange larger meetings, or write formal letters. For example, if a person is not having the right care in a long term health centre; it may take more effort to sort things out.

5. Keep records, take notes

Having a record of what is said at meetings or appointments can be important. Writing things down can help you to remember details of dates and meetings. It's a great way to communicate to others what has been happening. As a support person you can provide a lot of help by taking notes of all the information from meetings.

One of the most important roles of a support person is to help someone understand their choices concerning their health issues and treatment. The important thing to remember is that the more information you have the greater your ability to make decisions in the best interests of the person you support.

If you are supporting a person with high support needs who is not legally able to make their own decisions, you have a responsibility to make sure the person is involved to the greatest extent possible in decision-making about their healthcare. This involves seeking the adult's views and wishes and taking them into account.

It is your role to give the person as much information about their health and treatment as you can. This information needs to be in a form that they can understand. Find out the best way of communicating the information. Use pictures, diagrams or signs if they help the person to understand.

It's very important to know the person's needs, wishes, views and desires to the greatest extent possible before you advocate on their behalf. In some cases it may not be possible to find out this information from the person themselves. If that is the case, you can ask other people who have a close relationship with the person what their views and wishes might have been.

Kath has dementia and can no longer speak up to make her wishes known or take part in her health treatment plans.

When she was first diagnosed with early-onset dementia, Kath decided to plan her future healthcare. She talked with her four children. They agreed that Kath's daughter was to act as her healthcare decision-maker when she was no longer able to make decisions, and this was recorded in an Advance Health Directive.

Twelve months later Kath hurt her leg and because Kath was unable, due to her dementia, to make decisions for herself her daughter took her to the doctor. Her daughter talked with him about the importance of giving Kath exercises to get her moving again, as her mother has always loved walking and still enjoys it. Her mother had always talked about wanting to keep walking as one of her main activities.

As Kath's daughter was appointed as her attorney in Kath's Advance Health Directive, Kath's daughter was able to speak directly about Kath's health condition and healthcare with Kath's doctor.

Tips: What advocacy is and isn't

Advocacy **is**:

- Standing alongside a person
- Standing up for a person or group
- Listening and trying to understand a person's point of view
- Finding out what makes a person feel valued
- Understanding their situation and what might be stopping them from getting what they want
- Offering support to tell other people what they want
- Helping someone know what choices they have and what the impact of those choices may be by encouraging them to ask questions
- Enabling a person to have control over their life by taking up issues on their behalf if they want you to
- Understanding a person's culture and values and how this impacts on their life situation

Advocacy **isn't**:

- Making decisions for someone
- Mediating
- Counselling
- Telling a person what you think they should do
- Solving all someone's problems for them
- Filling all the gaps in someone's life
- Acting to benefit others more than the person you are advocating for
- Agreeing with everything a person says and doing anything they ask you to do

7

Working together to change the system – systems advocacy

When people work to change what happens for a whole group or community of people, it is called systems advocacy. Health systems advocacy aims to make positive changes to attitudes, policies, systems and laws in the health area. Its focus is on the rights and interests of health consumers.

Many of the groups that lobby for change have been created by people who have experienced issues and barriers within the health system. They have worked successfully to achieve change and improvements that make the system work better for anyone who uses it.

People working together around similar issues have a stronger voice which is more likely to be heard and lead to reforms that benefit many people.

People working together can:

- help the community and its leaders to understand health issues and needs
- assist people to have a say and put their views and interests forward
- influence decision-makers to develop legislation which provides consumer-centred, safe, quality health services
- generate changes to policy and procedures so consumers have better services
- help people to get more resources
- help consumers to exercise their healthcare rights
- help consumers to have choice and control over their treatment and services
- help consumers to get culturally appropriate services delivered in ways that respect their beliefs and values

In 2010, the Birth Centre of a major hospital was closed without warning, leaving many local women without their expected model of maternity care. Upon hearing what had happened, local consumer organisations joined forces to support the centre and protest its closure. Through a combination of text messaging, emails and social networking websites, hundreds of people were notified of the centre's closure within hours. Media estimated 300 - 500 people attended a rally outside the hospital the next morning, supporting access for women to birth centre care.

As a result of the rally and negotiations with consumer representatives, midwifery representatives and Government, the hospital decided to immediately re-open the Birth Centre while an independent review of maternity services led by a committee of doctors, midwives and consumers took place.

Tips for working to change the system

- Be prepared to keep at it for a period of time, even if you get some knock-backs – change doesn't happen overnight!
- Make sure you take care of yourself so you don't burn out
- Develop an understanding of how systems and services work
- Learn how advocacy works and approaches you can use
- Be committed to the issue
- Stay positive and focused
- Take and make opportunities to get the message to others
- Speak up in the community to get support for your cause.

Tips to help you get started

1. Understand your issue

What strategies have other people and groups used that worked well, and what has worked less well?

This involves doing research and gathering information about the issue. You can talk to other people, groups and organisations with similar issues to draw from their experiences. You can find out what has happened in the past and what may be planned for the future. Also find out from people what their needs are about the same issue.

2. Gather support

Who are your friends?

Find out whether other people or groups have similar issues and interests and whether they are willing to work with and/or support you. It is good to look for and create partnerships with other people, services or groups who have the same desire to achieve change. It is also useful to find out who has different views and why, as they may oppose your efforts and you will need to be prepared and able to respond.

Some months after a patient had poor treatment in hospital, she was contacted by several other people who were also unhappy about the treatment they had received.

Together, they formed a support group, and began to lobby the Health Department and the Government for change. Their actions, in combination with the efforts of others, contributed to two Commissions of Inquiry and a major review of the health system. As a result, large scale reform and extra funding to the system has been obtained.

3. Develop a common goal

In addition to identifying people, groups and organisations with similar issues, it is essential to reach agreement on a common goal. While people may have issues in common, there may be differing opinions on what needs to be achieved. Unless all parties agree on a common goal there will be conflict around the steps to take and the people and organisations to be involved.

4. Put together a strategy

Once you have a common goal, you need an advocacy strategy or campaign to achieve it! The strategies will vary depending upon the issue. It is essential to plan the activities you will undertake and who will undertake them. You may need to agree on a leader/s to act as a spokesperson/s for the group. You also need to identify your key messages about your cause and what you want to achieve, and who you will approach about the issue.

Strategies may include meeting with or writing to decision-makers; holding community meetings/forums to gather public opinion and support; producing publications (including fliers, leaflets) to promote your issue; speaking or writing to your local Councillor or Member of Parliament; or using the media (radio, TV, newspapers) to raise awareness about the issue and goal.

If you do not have the time to form your own strategy or campaign to tackle the issue, supporting existing networks to champion the issue is another way to work towards the changes you seek. Networks are valuable in bringing people together who share common goals.

Some systems advocacy is quite simple, for example, a group of neighbours getting together to prevent a new mobile phone tower being put up in their area. Other situations are more complex, for example, setting up an injecting drug room for illegal drug users. Most however, fall somewhere in between these two examples.

The State Government proposed to redevelop a hospital in a regional area and a redevelopment plan was developed.

A local health consumer group saw the plan and noted that it included only 15 hospital beds, and no private rooms or palliative care beds.

During the consultation process the group had several meetings with the Project Management Team and voiced their concerns about the inadequate number of hospital beds to service the local region; the absence of private rooms for patients with private healthcare; and the failure to accommodate patients in need of palliative care. The health consumer group undertook research and presented statistical evidence to the Project Management Team justifying consumer/patient need for more beds, private rooms, and palliative care beds, and engaged in ongoing discussions and negotiations about these issues.

As a result of the health consumer group's systemic advocacy, further funding was allocated to the hospital redevelopment project, which enabled 32 hospital beds including six private rooms and two palliative care rooms to be built. The government also amended its Health Service Planning Policy to include consideration of local community needs in relation to palliative care and private rooms in the development of new services across the State.

If you have an issue that you feel passionate about, don't be afraid to have a go at systems advocacy. If you want to work with a friend, neighbour or colleague to make a change consider 'taking the bull by the horns' and look at some of the ideas in this kit. In the resource section you will find names of services that may be able to advise you.

8

Making a complaint

If you're like most people you probably don't like to complain. It's even more difficult to complain if you are upset, busy or think it won't make a difference.

Complaints are an important source of feedback as they help healthcare services to improve the quality of their service. They also reduce the likelihood of a problem happening again for someone else.

If you have concerns about your healthcare, talk with your health service as soon as possible. Often this is the quickest and most effective way to resolve your issues. Many health services have staff who manage complaints about their service. Find out who is the best person to talk to.

Anyone can make a complaint about a health service that causes them concern. If you are complaining on behalf of another person, make sure you talk it through with them first and understand the issues clearly.

Think about how you are going to talk about your issue in a clear way and consider what you would like to happen, for example, an explanation, an apology, or a change in process or policy. Writing down your concerns and talking them through with another person before you talk to the service can help you be clear.

Make an appointment so there is time to talk things through.

As it can be difficult to talk about problems, think about taking someone with you for support. Ask someone who you trust who understands your issues. Make notes of any phone calls or discussions in meetings to keep a record of your complaint.

Give the Health Quality and Complaints Commission a call if you are unhappy about the response of the service, or feel too uncomfortable to talk to the service directly. The number is at the back of this kit.

You can find more information about making a complaint in the Fact Sheet on the HCQ website.

9

Referrals and resources

General Health Contacts

Health Direct

If you are unable to see a local doctor, you can contact Healthdirect Australia. This is a 24 hour health advice line. You can speak to a Registered Nurse who can give you expert health advice.

Telephone: 1800 022 022

www.healthdirect.org.au

HealthInsite

Up-to-date reliable information that talks about your health and wellbeing.

www.healthinsite.gov.au

Government Contacts

Queensland Health Website

This website provides general information about Queensland Health's services. It also provides information on planning for the future through doing Advance Care Planning.

Phone (07) 3234 0111

<http://apps.health.qld.gov.au/acp/HOME.aspx>

Office of the Privacy Commissioner

If you need further information on privacy, confidentiality and medical records this website might help.

www.privacy.gov.au

Guardianship – Department of Justice and Attorney General

This website provides information on Advance Care Planning, Advance Health Directives, Power of Attorney and substitute decision-making.

<http://www.justice.qld.gov.au/justice-services/guardianship>

General Information and Advocacy Contacts

Health Consumers Queensland

To find useful information on advocating for your health go to their website.

www.health.qld.gov.au/hcq

National Aged Care Advocacy line

Telephone: 1800 700 600

For information on issues relating to aged care you can phone this advocacy line.

Please note this number is not available from mobile phones and in some capital cities. For alternative contact details phone the Department of Health and Ageing Aged Care Information Line on 1800 500 853.

Council on the Ageing, Queensland

The Council provides information for Queensland seniors on activities and services, including health services.

Telephone: 1300-738-348

<http://www.cotaq.org.au>

Queensland Aged Care and Disability Advocacy Inc

This is an advocacy service funded to provide information, education, support and representation to enable older people and people with a disability to understand and exercise their rights and their responsibilities.

Their services are free and confidential.

Telephone: 1800 818 338

<http://www.qada.org.au>

Carer's Queensland

Contact this service for referrals to advocacy services and practical written information for carers or support people.

Telephone: 1800 242 636

www.carersqld.asn.au

Queensland Association of Healthy Communities

This association promotes the health and well-being of lesbian, gay, bisexual and transgender Queenslanders.

Telephone: (07) 3017 1777

<http://www.qahc.org.au>

Family Planning Queensland

Family Planning Queensland (FPQ) offers clinical, education, and information services through its nine regional centres. FPQ also provides clinical training in all aspects of sexual and reproductive health, and has a comprehensive resource catalogue to support teachers, parents and young people.

Telephone: (07) 3250 0240

<http://www.fpq.com.au>

Multicultural Development Association

This organisation promotes multiculturalism and empowers people from culturally and linguistically diverse backgrounds through advocacy, community and multicultural sector development, and the delivery of client services.

Telephone: (07) 3337 5400

<http://www/mdainc.org.au>

Ethnic Communities Council of Queensland

This Council works to ensure people from diverse cultural and linguistic backgrounds have equal access to services and can fully participate in the community through advocacy; community development initiatives; state-wide health programs; support groups; cross cultural training; multicultural policy development and research and a resource and reference library.

Telephone: (07) 3844 9166

<http://www.eccq.com.au>

Maternity Coalition

A national umbrella consumer advocacy organisation committed to the advancement of best-practice maternity care for all Australian women and their families. The Maternity Coalition brings together support groups and individuals for effective lobbying, information sharing, networking and support in maternity services.

<http://www.maternitycoalition.org.au>

Systems Advocacy

The following website is a comprehensive resource if you are interested in learning more about systems advocacy. It includes step-by-step guides on all stages of the process as well as case studies.

<http://www.thechangeagency.org>

Complaints**The Health Quality and Complaints Commission**

The Commission is Queensland's independent health watchdog and can be contacted to learn more about filing a complaint. The website has useful information and tips for making complaints.

Telephone – 1800 077 308

www.hqcc.qld.gov.au

Notes



Notes

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