



KNOW YOUR RIGHTS

**A GUIDE FOR PEOPLE WITH DISABILITY TO GET THE
HOSPITAL CARE THEY NEED DURING COVID-19**

FUNDED BY:



A GUIDE TO HELP PEOPLE WITH DISABILITY TO MAKE A PLAN, KNOW THEIR RIGHTS, AND GET THE SUPPORT THEY NEED WHEN ACCESSING THE HOSPITAL SYSTEM DURING THE COVID-19 PANDEMIC.

This guide has been developed by **Queenslanders with Disability Network (QDN)** and **Health Consumers Queensland (HCQ)** and co-designed with people living with disability and family and carers with lived experience of Queensland's health system. This guide is proudly funded by Queensland Health.

Thank you to the following individuals for their input into this guide:

Sharon Boyce
Jane Britt
Grant Higham
Noel Muller
Keren Pointon
Wilfred Prince
Peter Tully

Contractor:

Jane Geltch, Purpose Partners

We acknowledge Aboriginal and Torres Strait Islander peoples as the original inhabitants of Australia and recognises these unique cultures as part of the cultural heritage of all Australians. We pay our respects to the Elders of this land; past, present and future.

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INTRODUCTION

People with disability need to access hospital care during the COVID-19 pandemic, both if they get sick with COVID-19 or if they need essential healthcare. It is a right for people with disability and their families and carers to have equitable access to healthcare during the COVID-19 outbreak.

The following information provides some key things to think about and help you understand your rights and what you can expect in this changing environment as a patient with disability.

This guide can help you if you become sick with COVID-19 or need other essential healthcare in hospital during the pandemic. Equitable access means having access to healthcare that meets your needs, and responds to any adjustments you may require due to your disability and cultural needs.

This guide is here to help you and your supporters think about how you can get the right care, in the right place, at the right time.

WHAT IS IN THIS GUIDE?

In this document you will find information about:

1	 HEALTHCARE AND COVID-19
2	 KNOW YOUR RIGHTS: HEALTHCARE DURING COVID-19
3	 GET PREPARED: BEFORE HOSPITAL AND WHAT TO TAKE WITH YOU
4	 ADVOCACY AND SUPPORT
5	 MORE RESOURCES



HEALTHCARE AND COVID-19

COVID-19 is a respiratory illness caused by a new virus. Symptoms include fever, coughing, a sore throat and shortness of breath. The virus can spread from person to person. There is no current treatment that cures or prevents COVID-19. Some people who contract the virus may become so ill that they need to be admitted to hospital and may need intensive care for a long period.

People with disability are at higher risk if they contract COVID-19 and are more likely to go to hospital for treatment. It is important to understand how COVID-19 may affect you, and what to expect if you need to go to hospital during this time.

INFORMATION ABOUT COVID-19

- ⇒ More information about COVID-19, including how to protect yourself, the symptoms of COVID-19, and where to get tested, can be found on [page 26](#) of this resource.
- ⇒ You can also find detailed information about COVID-19 on the Queensland Health [website](#), including current health directives.
- ⇒ Look at the 'More Resources' list for links to accessible and other resources about COVID-19. You can find these on [page 24](#) of this guide.

CHANGES TO CARE IN HOSPITAL AND HEALTH SERVICES

During the pandemic there have been changes to the way hospitals are providing care. For people with disability who might need additional supports to get to and in hospital, it is important to know what these changes are so you can think about what it means for you and your specific needs.

Any changes to the way hospitals provide care may be unsettling for some people, and it is important to remember that they are there for your safety and protection.



"I'd go back again now I've seen how they're operating. It made me feel safe that they had measures in place"

Jane





The way you go into the hospital may be different:

- There may be a different path for hospital entry and exit and markers on the ground to follow to maintain physical distancing.
- There may be people stationed at the entry to meet you when you arrive.
- You may be asked to sanitise your hands with sanitiser.
- Your temperature may be taken.
- You may be asked questions about potential exposure to the virus e.g. *have you travelled interstate or overseas recently or been in contact with someone who has been confirmed to have COVID-19* and about potential symptoms e.g. *have you had a fever, cough, sore throat recently?* It is important to answer truthfully. These questions are to help health workers keep people safe, and you will not be punished for answering yes to any of these questions.
- You will be treated with courtesy and with consideration for your safety and the safety of others. If people arrive who are showing symptoms of COVID-19, protective measures, such as placing people in isolation away from other patients may happen.



Ahmed recently had to have a day procedure at the major hospital in his region. He was worried about this as he has an auto-immune disorder which puts him at extra risk from COVID-19 and did not want to be exposed to the virus while he was in the hospital.

He talked to friends who had visited hospital recently to understand what might happen and read as much as he could about what might happen during his visit. He asked the case manager he had been assigned at the pre-admission clinic some questions also. He was reassured that everyone was screened as they entered, that all COVID-19 patients were isolated away from other patients, that he would be able to keep distance from other people in waiting rooms and lifts, and that cleaning and other infection control protocols had been increased during the COVID-19 pandemic.

Ahmed felt reassured by this and even more reassured when he saw that it was all true – everyone was treated well at the hospital and all the measures to keep people safe were in place.



The places you get your treatment and care from may be different:

Hospitals may have rearranged the units or wards in which care is delivered. Those who experience regular hospitalisations and respond well to familiar places and routines may be unsettled by these changes.

If you are coming into health services for an appointment or test you may notice that waiting rooms have changed and the seats have been physically distanced. The appointment and waiting process might also have changed to reduce the time that people wait together – this will be different at each service.



The way the doctors, nurses and health professionals are providing your care may be different:

Hospital workers:

Hospital staff now may wear personal protective equipment (PPE), including gowns, masks, face shields and gloves. This may make it difficult for some people to recognise members of their care team, or to understand what is being said to them. It may be challenging for some people to see people in masks or face shields, but this is important to keep people safe from the virus and follow the rules. Health services will continue to provide interpreters if you speak Auslan or a language other than English.

Social distancing practices mean that health professionals may need to be physically further away than usual while talking with patients, families, and supporters. This may also be confusing or challenging for some people.

Patients

Patients and their families and supporters who are visiting may also need to wear PPE. Wearing PPE may not be possible for some people with disability due to fear, distress or breathing difficulties. If this is the case, please talk about this with the health service to ask for guidance.



Emma is 12 and has autism and multiple health issues – she is often an inpatient at the Children’s Hospital. Emma and her Mum have routines that help Emma stay calm and comfortable in the hospital – she is well known by the staff in the ward she is usually in and knows where everything is. She also has a regular nurse navigator to help support her interactions with the hospital system.



Emma’s usual ward has been repurposed as a COVID-19 isolation ward and so her most recent admission was to an unfamiliar ward, where Emma was assigned a bed in a shared room. Some of the staff were different too as some had been moved to COVID-19 testing duties. Emma was upset by these changes and became agitated and unco-operative with her care. The staff did not know Emma well enough to support her well and didn’t seem to be listening to Emma’s Mum about what was needed for Emma to help her manage the unfamiliar situation. Emma’s support worker was not allowed in the ward as visitors were restricted to one person at a time.

Emma’s Mum requested the nurses contact the nurse navigator, who attended quickly and worked with the ward staff to understand Emma’s needs, transfer Emma to a private room, ensure she could have familiar nursing staff whenever possible and helped Emma’s Mum to display Emma’s vital how-to-care-for-me information posters where everyone could see and use them. She also confirmed that Emma’s favourite support worker could be with her and not counted in the visitor limits. Emma quickly settled with this support.

WHY WOULD I NEED TO GO TO HOSPITAL?

During the pandemic, you may need to go to hospital if you:

- Contract COVID-19 and are too sick to be cared for at home
- Have a serious injury
- Need surgery
- Become sick with another condition that requires hospitalisation
- Need essential regular care in a hospital
- Have regular treatment and reviews as part of your health condition or disability

OTHER WAYS OF ACCESSING HEALTHCARE DURING COVID-19

Patients have been receiving healthcare in other ways during COVID-19 for treatment and appointments with General Practitioners, therapists, nurses or specialists. This includes:



- **Telehealth** – where your appointment with the healthcare provider happens on videoconference on the computer or by telephone



- **Virtual wards** – where you wear monitors that send information about your condition to healthcare providers in the hospital and they make decisions about treatment from this information



- **Hospital in the home** – where some types of hospital care is provided by community-based healthcare providers in your own home. This is a program that provides short term home-based acute care, and is being used by some parts of the hospital system. You can talk to your healthcare team about the suitability and availability of this program for you if you require hospital care.

If you are a National Disability Insurance Scheme (NDIS) participant, you may be able to access some of your funding to purchase a low cost device.

Patients who have received their care in these ways during COVID-19 have said it has helped:

- Protect them from being around lots of people
- Save time in waiting around hospital, and transport to and from hospital
- Reduce the stress of getting to appointments

If you are unable to receive care in the way that is being offered, you may need to advocate for a different approach, change providers if you are able to do so, or accept that you will need to receive care differently for the time being.

You **may** be able to have a choice about how you access your healthcare but it will depend on your situation. You will need to discuss this with your healthcare practitioner. The rules for this will change throughout the COVID-19 pandemic so always check first with your healthcare provider about what is available and how your appointment will happen.



"I prefer seeing people because I lip read versus on the phone where I am relying only on audio. Of course, in some cases I've had no choice but to use phone such as when telehealth failed last week for an appointment, so we had to revert to phone"

Jim



MAINTAINING HEALTHCARE DURING COVID-19

It is very important that you continue to have your regular healthcare needs met. While there may be some changes to when and how your care is delivered, it is important for your ongoing health and wellbeing that you continue to get the care that is essential for you.



If you have a regular and confirmed appointment with the hospital or GP it is important that you attend the appointment so that you are getting the healthcare you need.

Some hospital care, such as non-urgent surgery, has been slowed down or stopped during the pandemic if it is not "essential". It is important to know that 'not essential' doesn't actually mean that it doesn't have to happen, it means that it is not critical that it happens right this moment.

You may have longer waiting times for outpatient appointments, non-urgent surgery, oral health and other services. However, if your healthcare need is urgent or will have a critical impact on your ongoing health if not attended to, it should be addressed. If you are unsure or have concerns, your GP is often your best support, or you can call the service directly.

Don't stay away from hospitals or healthcare providers because of COVID-19 – if you need healthcare, it is important that you receive it, and that you know you may have choices about how to receive it.

If you are facing an emergency or are very unwell, call 000.

If you are feeling very unwell but are unsure whether you need to come to hospital, contact your GP or call 13 HEALTH for clinical advice.





KNOW YOUR RIGHTS - HEALTHCARE DURING COVID-19

It is important to know how your healthcare rights are protected in Australia, so that you have good information to support you if you need to assert those rights.

Your rights in healthcare are protected by human rights instruments, agreements and law, including the United Nations Conventions on the Rights of Persons with Disabilities, the Rights of the Child, and against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, and the Disability Discrimination Act (Cth) 1992.

These help to ensure that:

- o people with disability receive the same level of healthcare as other persons
- o that healthcare workers promote the dignity and autonomy of people with disability, including their freedom to make their own choices, and
- o that healthcare services are free from bias and /or discrimination.

Australia also has a Patient Charter of Healthcare Rights which include these rights for everyone:

Access

- Healthcare services and treatment that meets my needs

Safety

- Receive safe and high quality healthcare that meets national standards
- Be cared for in an environment that is safe and makes me feel safe

Respect

- Be treated as an individual, and with dignity and respect
- Have my culture, identity, beliefs and choices recognised and respected

Partnership

- Ask questions and be involved in open and honest communication
- Make decisions with my healthcare provider, to the extent that I choose and am able to
- Include the people that I want in planning and decision-making

My healthcare rights

This is the second edition of the Australian Charter of Healthcare Rights.

These rights apply to all people in all places where health care is provided in Australia.

The Charter describes what you, or someone you care for, can expect when receiving health care.

I have a right to:

Access

- Healthcare services and treatment that meets my needs

Safety

- Receive safe and high quality health care that meets national standards
- Be cared for in an environment that makes me feel safe

Respect

- Be treated as an individual, and with dignity and respect
- Have my culture, identity, beliefs and choices recognised and respected

Partnership

- Ask questions and be involved in open and honest communication
- Make decisions with my healthcare provider, to the extent that I choose and am able to
- Include the people that I want in planning and decision-making

Information

- Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent
- Receive information about services, waiting times and costs
- Be given assistance, when I need it, to help me to understand and use health information
- Request access to my health information
- Be told if something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe

Privacy

- Have my personal privacy respected
- Have information about me and my health kept secure and confidential

Give feedback

- Provide feedback or make a complaint without it affecting the way that I am treated
- Have my concerns addressed in a transparent and timely way
- Share my experience and participate to improve the quality of care and health services



AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

For more information,
ask a member of staff or visit
safetyandquality.gov.au/your-rights

Information

- Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent
- Receive information about services, waiting times and costs
- Be given assistance, when I need it, to help me to understand and use health information
- Access my health information
- Be told if something has gone wrong during my healthcare, how it happened, how it may affect me and what is being done to make care safe

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Give feedback

- Provide feedback or make a complaint without it affecting the way that I am treated
- Have my concerns addressed in a transparent and timely way
- Share my experience and participate to improve the quality of care and health services
- The Patient Charter of Healthcare Rights is available [here](#) for download
- The Patient Charter of Healthcare Rights is displayed in every hospital in Queensland. You may like to print out a copy for your reference in hospital and to remind people of your rights when they are caring for you.



In Queensland, your rights are also protected by **The Human Rights Act (Qld)**.

Section 37 of the Human Rights Act 2019 says that:

1. Every person has the right to access health services without discrimination.
2. A person must not be refused emergency medical treatment that is immediately necessary to save the person's life or to prevent serious impairment to the person.

[Guidelines on the rights of people with disability in health and disability care during COVID-19](#) have been developed by the Australian Human Rights Commission to support the Advisory Committee for the COVID-19 Response for People with Disability Management and Operational Plan for People with Disability. The Guidelines provide practical guidance for health and disability care workers on a human rights-based approach to decision making during COVID-19.

In Queensland, there is also a provision in the healthcare system called [Ryan's Rule](#), which serves as added protection for all healthcare consumers. Ryan's Rule is a three step process to support patients of any age, their families and carers, to raise concerns if a patient's health condition is getting worse or not improving as well as expected, and you do not feel your concerns are being acted upon in a timely manner. Ryan's Rule applies to all patients admitted to any Queensland Health public hospital and in some Hospital in the Home services.

As part of the Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19), the Australian Government has developed the [Management and Operational Plan for People with Disability](#). This plan can give valuable guidance in negotiating with healthcare providers if needed.

YOUR RIGHTS IN HOSPITAL DURING COVID-19

It is important to understand that you and your support team understand your rights in hospital during COVID-19, and that you can have open and effective communication between consumers and clinicians in the delivery of patient centred care.



GET PREPARED: BEFORE HOSPITAL, AND WHAT TO TAKE WITH YOU

It is important to take the time to think about what you would need with you if you have to go to hospital. If you have a Person-Centred Emergency Preparedness (P-CEP) COVID-19 Plan in place, you may have already thought through some of this. For more information and link to the P-CEP COVID-19 Planning Tool can be accessed [here](#).

When planning to go to hospital, it is important to think about:

- What are my needs and directions for my care?
- What information can I share with people so they know about me, what I need, and my directions for my care? What else do I need?
- What are the resources and tools that can help me?

GET PREPARED: INFORMATION ABOUT ME AND MY SUPPORT NEEDS



There are a variety of different ways that people with disability may collect and share information about their health and disability support needs. Some of this information may be more formal and completed by a health practitioner, a clinician or on record with disability providers. Other information you may have developed yourself or with your support network. There is no one size fits all, and there is no one format that is going to work for everyone.

Some examples may include:

- COVID-19 Hospital Companion
- Health Passport
- My connection kit or my key instructions
- Individual Healthcare Plan developed by your doctor
- A healthcare plan developed by yourself or your supporters (family or providers)
- My Health Record

You may have some or all these documents or plans (see below) in place. If not, they may be helpful to you in hospital and you may like to consider developing them now.

Think about the key people in your life and your healthcare - family, carers, friends, supporters, GP, specialists - and who can help you with this if you need it.

If you have any of these documents prepared, display copies in a prominent place in your home where first responders who may be caring for and transporting you to hospital can see them. Near your bed or on your fridge could be useful places to display them. It is also a good idea to share these documents with key people in your life.

Click on the links below for more information. You can also ask your GP or other healthcare professional for more information.



COVID-19 COMPANION
Assisting frontline workers to understand my needs

I'm a person with disability. Here's some information about me:

My name is: _____

Date of birth: ____/____/____

My cultural background and/or spiritual beliefs are: _____

I am an NDIS participant: ☐ YES ☐ NO

My Medicare number is: * _____

My next of kin is: _____

My key support people are:

Name:	Relationship:	Phone Number:
_____	_____	_____
_____	_____	_____

I best communicate by: _____
(eg spoken English, Auslan, Braille, other communication aids, writing etc.)

This companion document is a draft.
* The National Health Commission will be signing off this form with disability.
Do not include this information on your NDIS plan.

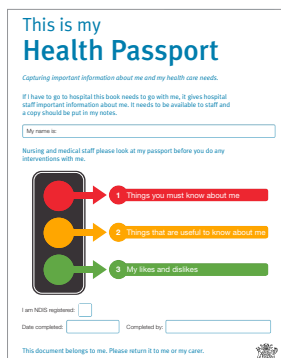
COVID-19 Hospital Companion

The [COVID-19 Hospital Companion](#) is a document for people with disability that helps you communicate important personal information to healthcare professionals and front line workers to understand your needs.

Health Passport

[Julian's Key](#) is an example of a health 'passport' that contains lots of information that health professionals need to know about you.

Julian's Key is a patient/carer-controlled communication tool designed to improve communication and empower people with disability, their families and carers to be more involved in their healthcare. It includes key information in order of importance in a format that can be shared quickly and easily with carers and health staff. It is available as a mobile application, an editable PDF and a paper-based form.



This is my Health Passport
Capturing important information about me and my health care needs.

If I have to go to hospital this book needs to go with me, it gives hospital staff important information about me. It needs to be available to staff and a copy should be put in my notes.

My name is: _____

Nursing and medical staff please look at my passport before you do any interventions with me.

1 Things you must know about me

2 Things that are useful to know about me

3 My likes and dislikes

I am NDIS registered: ☐

Date completed: _____ Completed by: _____

This document belongs to me. Please return it to me or my carer.

Connections Kit and/or Key Instructions

A **Connection Kit** is a document that includes photographs that help you connect to people providing you with healthcare services. This document can be helpful in making sure health professionals provide you with equal quality healthcare, and contains information about who you are as a person, your daily life, and your loved ones. This may be particularly helpful if at any time you are unable to communicate or advocate for yourself.

Key Instructions is a one-page document that can be displayed, and contains essential information that anyone interacting with you should know. This could be about any personal or disability specific needs e.g. visual impairment, deafness, communication needs, or specific triggers to avoid - any critical information that in times of stress you might be unable to recall or communicate.



Individual Healthcare Plan (Developed by your GP or health professional)

An individual healthcare plan outlines the things that need to be considered for you to maintain good health. If you don't have one, or your plan needs updating to take COVID-19 into account, talk to your support worker, carer, GP or other health professional to help you develop a plan. This will help first responders and hospital staff to meet your needs.

People with intellectual disability may choose to access the Comprehensive Health Assessment Program (CHAP) tool, which enables improved identification and documentation of the health needs of adults with an intellectual disability. There is a dedicated Medicare item number associated with GPs conducting CHAP assessments. The CHAP is available [here](#).



Individual Healthcare Plan (Developed by you or your supporters)

You may already have some or all of your health information in one place.

This is information about you that you or someone who supports or cares for you has prepared. It would include things like your Medicare number, name of GP, next of kin, any healthcare directives, your needs for communication, diet, allergies, immunisations, assistance you need with personal care, eating, medications, positive behaviour support plans etc.

If you do not have this, and it is something you would like to put together, see '[Appendix 2: Going to hospital: Checklists](#)' to help you think through the information you may need to include.

My Health Record

This is an electronic health record system which has an online summary of your key health information. You will need to set it up for it to be useful to you and to health professionals treating you. Participation is completely voluntary. You will also need a MyGov account to access the record.

More information about My Health Record can be found [here](#). And more information about MyGov can be found [here](#).



MY HEALTH DECISIONS AND HEALTHCARE DIRECTIONS

There are a range of legal documents that help communicate your healthcare decisions and directions for your care if you are unable to do so, or don't have capacity to make your own healthcare decisions.

For some people with disability, you may have someone appointed or acting as your decision maker for your health decisions.

The following information provides a summary of some of the key documents in Queensland.

Enduring Power of Attorney

An [Enduring Power of Attorney](#) (short form) legally appoints one attorney/substitute decision-maker for personal matters (including healthcare) and/or financial matters, including allowing them consent to withdrawing or withholding life-sustaining treatment.

An Enduring Power of Attorney (long form) legally appoints more than one attorney/substitute decision-maker, such as an attorney(s) for personal matters, including healthcare, and a different attorney(s) for financial matters, including allowing them consent to withdrawing or withholding life-sustaining treatment.

Statutory health attorney

A [statutory health attorney](#) is someone with automatic authority to make healthcare decisions for you if you become unable to make them because of illness or incapacity.

You do not need to formally appoint a statutory health attorney – this person automatically acts in this role when the need arises because of their relationship with you.

In fact, a statutory health attorney is only necessary:

- if the Queensland Civil and Administrative Tribunal has not appointed you a guardian for healthcare matters or
 - if you have not appointed an enduring power of attorney or
 - if you have not provided direction about your medical treatment in an Advance Health Directive.
-

Advance Health Directive

An [Advance Health Directive](#) states your wishes or directions regarding your future healthcare for various medical conditions. It comes into effect only if you are unable to make your own decisions.

To make medical decisions, you must have decision-making capacity. If illness or serious injury (temporary or permanent) prevents you from making decisions about your healthcare, advance care planning makes sure that your values, beliefs and preferences for treatment and care are understood and respected. A completed and accessible Advance Health Directive allows you to be heard and is important to your treating team and others in their decision-making.

Statement of Choices

A [Statement of Choices](#) allows you to record your personal values and preferences for healthcare - helping family and healthcare professionals decide on medical care when you are unable to make or communicate decisions. Although the Statement of Choices is not legally binding (as an Advance Health Directive is) the content can still give guidance to substitute decision-makers and clinicians

There is a form for those who are able to make decisions about healthcare (Form A), and those who are unable to make decisions about their healthcare and need support to do so (Form B).

Acute Resuscitation Plan

An [Acute Resuscitation Plan](#) is a form that your doctor completes after they have had discussions with you or your substitute decision-maker(s) about your preferences for emergency treatment including resuscitation planning. It outlines what the emergency teams should do if you suddenly deteriorate and become critically unwell.

Adult Guardianship

Queensland's [guardianship system](#) assumes that a person has the capacity to make a decision until it can be shown that they do not. The guardianship system gives someone the legal authority to make decisions for an adult who doesn't have the capacity to make such decisions.

Adults with impaired capacity have the right to:

- the greatest possible degree of autonomy in decision-making
- adequate and appropriate support for decision-making.

In Queensland, the guardianship system protects the rights and interests of adults who have an impaired capacity to make their own decisions.

The Queensland Civil and Administrative Tribunal (QCAT) can appoint a guardian on behalf of an adult with impaired decision-making capacity. The appointed guardian can make certain personal and healthcare decisions on the adult's behalf, which protects their rights and interests. Sometimes QCAT may decide that there is no one suitable in the person's life to take on this role, so the Public Guardian may be appointed as last resort for personal and/or health decisions. More information can be found [here](#).

Information about the Office of the Public Guardian can be found [here](#).

Your Will

[Wills](#) are end of life documents that provide instructions about your wishes and where you want your property to go. If you die without these documents, the people making decisions might not be the people you want. The [link](#) will give you some guidance on how to go about making your will.

WHAT TO TAKE WITH YOU TO HOSPITAL



Support Person

Someone who knows you and your wishes well, and can advocate for you or alongside you. Each Health and Hospital Service may have a different policy about visitors and supporters.

It is important to know that even if there are limits on visitors, a support person for a person with a disability may be formal or voluntary, and are not considered a visitor, and must NOT be counted in the number of visitors you are allowed.

A support person is someone whose presence at the hospital is necessary to provide health, medical, pharmaceutical goods or services to you. This also includes people who are supporting your care or treatment including patient advocates, social workers, therapists, sighted guides or translators.

Support people may only be excluded from entering or remaining at the hospital if they have any symptoms of COVID-19.

Some people to ask for or contact if you are having issues around who can be with you are:

- Patient Liaison Officer
- Hospital Social Worker
- Nurse Navigator
- Case Manager – if you have one. Sometimes these are assigned to you in an outpatients clinic



Ron is a young man who is blind, he uses a cane to navigate. He has arrived at the hospital for pre-planned surgery, along with his regular support worker and his partner.

When they arrive at the hospital, they are asked some questions by staff, to understand if any of the group are showing symptoms of COVID-19. No-one in their group has any symptoms.

The staff explain to the group that the policy at the hospital is to allow only one visitor per patient. Ron and his partner explain to the staff that the other person with them is Ron's support worker, who is there as his sighted guide, and should not be counted within this limit.

The staff allow Ron, his partner and his support worker to go through to the waiting room.



Important documents

Two copies of any of the documents in the above section which you have. Make sure they are protected in plastic and are prominently displayed where health professionals can see them, or know they are there - at home for first responders, and in hospital for health professionals.



Medications

A list of all the medications you take, including over the counter medications. Hospitals don't generally allow you to take your own medicine, however some people may feel more comfortable having their medicines with them, for example to show exactly what they are taking, or because there may be exceptions made due to medication unavailability.



Connection Kit

Information about you to give to your healthcare team so they know who you are and how to support you.



Communication and Advocacy Tools

- Phone and phone charger
- Contact numbers
- Things that provide you with confidence and comfort and ease anxiety - music, reading material, objects etc.



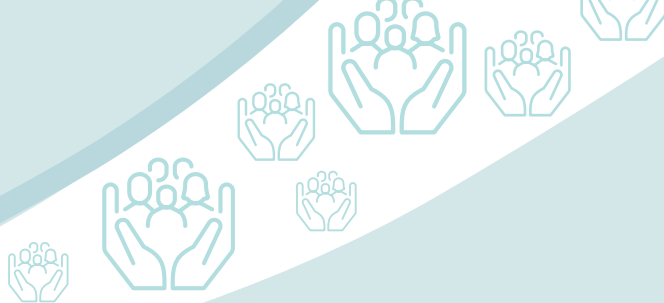
Personal Protective Equipment

If you have it and wish to use it e.g. masks and gloves - hospitals may have some shortages or limits on patient use.

Checklist for hospital admission

See **Appendix 2: Going to hospital: Checklists for more information**

- Be sure to inform key people that you are being admitted to hospital
- Consider how your assistive equipment or assistance animals can be delivered to you in hospital (e.g. Ambulances won't transport your wheelchair – who can bring it to you?)
- It is important to know that in hospital, you will be asked repeatedly to state your name and date of birth and sometimes your address, phone number, next of kin, allergies and to name a procedure you may be having. This protocol is for patient safety – it will help protect you from medical mistakes and you (or your support person if you can't) will need to supply this information when asked.



ADVOCACY AND SUPPORT

WHEN YOU ARE IN THE HOSPITAL

Advocacy supports help people with disability:

- understand their rights to equitable treatment, free of discrimination
- address discrimination and unfair treatment
- understand and make decisions
- build capacity to advocate for themselves

Your best frontline advocates are yourself and those who care about you. Ask questions, show interest, ask for what you need, be alert to potential discrimination based on your disability. And if this is not enough to get the healthcare you need, or if you are refused care, ask for professional support – from both within the hospital system, and outside from advocacy organisations.

You can also get more information about specific health advocacy from the [Health Consumers Queensland Health Advocacy Toolkit](#)

ADVOCACY



Planning first

The more planning you do, the more easily you can advocate for what you need and want from your healthcare providers. Thinking through with significant others your advance health directive, individual care plans etc. will support you to know and clearly communicate your wishes and needs to your healthcare providers.



Get to know your healthcare team

It is important to build a relationship where possible with the people caring for you. Get to know their names, their roles and who makes treatment decisions and how. Let them know something about you, be interested, make a connection, build relationships. Empathise with the additional stress healthcare staff may be facing because of COVID-19.



Know Your Rights

Get to know and have with you the Patient Charter of Healthcare Rights.

Get to know the directives for COVID-19 that are in place for the healthcare service you are in. If they interfere with your healthcare rights, you are entitled to challenge them and should consider doing this.

You can find the most up to date COVID-19 public health directions on the Queensland Health website [here](#).



Ask Questions

Ask questions about what is important to you in having your rights respected. Some examples are below. You might like to think in advance about what questions you might need to ask, or how to assert your rights in a hospital setting.



If a treatment decision concerns you, you could think about or ask:

How are decisions being made about who gets what treatment? Is my disability a factor in your decision-making? What judgments are you making about my quality of life?

I am not comfortable with this decision. Who can I speak to about this decision?

Do you know that you can address me directly? Please include me in your conversations about my health and decisions being made.

Do you know that this is not normal for me? I am acutely unwell and this is not how I usually am. Can you see past my disability to see how unwell I am?

If you are vision impaired: How is my privacy being respected when you are speaking about my health information? Who can hear? How can I have more privacy?

Collect information



Take notes, get names and information about you and your care. If you are unable to do this, ask your healthcare nurse, support worker, carer or family member to do this for you. There may be a whiteboard near your hospital bedside for you or your healthcare nurse or support worker to add key questions for your healthcare team when they next come. Handover is a good time to listen for information and ask questions – you have a right to be part of any handover between shifts/teams, so make sure you and / or your support worker / carer or family member are included in handover.



Ask for help

If you feel at any time that you are not getting the care you need, or if you are refused care, ask for help in advocating for yourself.

Some sources of support in hospital (and in virtual hospital settings such as Hospital in the Home) include:

- Patient Liaison Officer (including, in some hospitals, specialist liaison officers for Aboriginal and Torres Strait Islander people and people from Culturally and Linguistically Diverse backgrounds)



- Hospital Social Worker
- Nurse Navigator
- Mental Health Independent Patient Rights Advisers
- Case Manager – if you have one. Sometimes these are assigned to you in an outpatients clinic
- Interpreters

Ask everyone you can for access to these people – they are there to help you and you have a right to access them when you need them.

It is also important to keep in touch with anyone who acts as an advocate for you – key people in your life who can support you if you can't advocate for yourself. Make sure appointed decision makers and other supporters and advocates know you are in hospital and are kept informed of any issues that arise. If they cannot be with you in hospital, ask for them to be available to you by video or phone.

Make your wishes and plans known

Prominently display your key instructions, advance care plans, connection kit, whatever you have that can help people know your needs and wishes.

You may choose to write your key instructions e.g. 'see advance health directive' or 'please resuscitate' and your advocate/decision-maker's name and telephone number on your body in texta in case you are unable to communicate while unwell.

Ryan's Rule

Are you concerned that your or your loved one's health condition is getting worse and you feel you are not being heard?

We acknowledge that you know your loved one better than anyone. You may feel your health concerns is not being acted upon.

If you have these concerns about your or your loved one's health condition, you are encouraged to seek assistance by following the steps inside this leaflet.

Ryan's Rule is not for General Complaints

For more information, speak with your nurse. Developed by the Patient Safety & Quality Improvement Service with clinicians and consumers. This patient information leaflet aims to assist a number of the National Safety and Quality Health Service Standards including: Partnering with Consumers, Consumer and/or carer provided feedback on this leaflet.

Recognising and Responding to Clinical Deterioration in Acute Health Care

Enabling patients, families and carers to invoke an escalation of care response.

This leaflet has been adapted with permission under a Creative Commons Attribution-NonCommercial-ShareAlike license from the National Safety and Quality Health Service (NSQHS) Standard for Patient Safety and Quality, Standard 13: Responding to Clinical Deterioration in Acute Health Care.

© Ryan's Rule has been developed to provide patients of any age, families and carers with another way to get help.

Remember Ryan's Rule

If your health condition is getting worse or not improving as well as expected, and you do not feel your concerns are being acted upon in a timely manner, you can invoke [Ryan's Rule](#). You can say "I am invoking Ryan's Rule. I would like someone else to review my case".

Sharon is a person with a mild intellectual disability and complex healthcare needs. She had surgery four days ago and had been experiencing increasing pain in her legs, that she was not expecting. She had spoken with the nurse on duty and did not feel as though her pain was been acted on quickly enough. Sharon was becoming more distressed, as her pain was increasing.

When the doctor came on his rounds, Sharon asked to telephone in her family member so that they could also be part of the conversation. Sharon, along with the support of her family member, spoke up about her pain to the doctor and made sure her concerns were heard.

INDIVIDUAL ADVOCACY SUPPORTS

If you need more formal support and advocacy to make decisions or resolve issues, you can contact an individual advocacy service.

- ⇒ The [Combined Advocacy Groups of Queensland](#) are 12 independent advocacy services in different locations across Queensland who can provide people with disability access to independent advocacy and a range of specialist advocacy.
- ⇒ [Aged and Disability Advocacy Australia Ltd.](#) also provide a range of advocacy services across different regions.

MAKING A COMPLAINT

If you are not satisfied with a service provided by a health service provider, or you are concerned with the health, conduct or performance of a registered or unregistered health practitioner, then it is your right to make a complaint.

Before making a complaint, try talking with your health service provider—this is often the quickest and easiest way to address your concerns or fix a problem. Raising issues that you are having may also be helpful for other people in the future.

You can provide feedback in the way that suits you – this could be talking to someone, writing it down, or with an interpreter.

In Queensland, if you're not satisfied with the response, or feel uncomfortable talking with the provider directly, you can contact the Office of the Health Ombudsman online at <https://www.oho.qld.gov.au/> or by telephone on 133 646



MORE RESOURCES

Here you can find a list of further information resources, including those referenced in this guide.

COVID-19 information and resources

- **Queensland Health** provides up to date information about the COVID-19 situation in Queensland, as well as up to date health directives, and easy read resources. This information can be found [here](#).
- **The Disability Information Helpline** provides information and referrals to people with disability who need help because of COVID-19. Call 1800 643 787
- **Australian Government Department of Social Services** provides COVID-19 information, including Easy Read and audio information, for people with disability and carers, it can be accessed [here](#).
- **Queenslanders with Disability Network:** Accessible COVID-19 information and resources can be accessed [here](#).
- **Australian Government Department of Health – COVID-19 resources for Aboriginal and Torres Strait Islander people** can be accessed [here](#).
- **Blind Citizens Australia** - Accessible information for people with vision impairment can be accessed [here](#).
- **Council for Intellectual Disability** – easy read information and resources can be accessed [here](#).
- **National Disability Insurance Scheme (NDIS)** – Accessible Coronavirus (COVID-19) information and support can be found [here](#).
- **Queensland Human Rights Commission:** [Locked environments and COVID-19: fact sheet](#)
- **Disability Royal Commission:** Statement of concern – the response to the COVID-19 pandemic for people with disability can be accessed [here](#).

Know your rights

- **Patient Charter of Healthcare Rights** can be accessed [here](#).
- **Queensland Human Rights Commission:** Information on human rights and COVID-19 can be accessed [here](#).
- **Office of the Public Guardian (OPG):** Information update for ‘When do I need to contact OPG for COVID-19 related decisions for clients under the guardianship of the Public Guardian?’ can be accessed [here](#).
- **Queensland Health – Ryan’s Rule:** Information about Ryan’s Rule can be accessed [here](#).
- **Australian Government Department of Health ‘Management and Operational Plan for People with Disability’** can be accessed [here](#).
- **Australian Human Rights Commission:** Guidelines on the rights of people with disability in health and disability care during COVID-19 can be accessed [here](#).

Get Prepared

- **Person Centred Emergency Preparedness COVID-19 Planning** tool can be accessed [here](#).
- **Australian Government – COVID-19 hospital companion** can be accessed [here](#).
- **Australian Government ‘My Health Record’** information can be accessed [here](#).
- **Queensland Health – My health passport, ‘Julian’s Key’** – can be accessed [here](#).
- **Advanced care planning** – information and documents relating to ‘Enduring Power of Attorney’, ‘Advanced Health Directive’ and ‘Statement of Choices’ and can be accessed [here](#).
- **Council for Intellectual Disability** – ‘My Health Matters’ folder – resource for documenting health information in easy English can be accessed [here](#).
- **Queensland Health** – Acute resuscitation plan factsheet can be accessed [here](#).
- **Adult Guardianship** information for Queensland can be accessed [here](#).
- **Your Will** – information on making a Will can be accessed [here](#).
- **United States - “Know Your Rights” toolkit** that covers rights and strategies for people facing potential triage discrimination based on disability or weight, alone or in combination with other characteristics, during the COVID-19 pandemic in the United States and can be accessed [here](#).

APPENDIX 1: MORE INFORMATION ABOUT COVID-19, SYMPTOMS AND TESTING

People with disability may be more vulnerable to COVID-19 especially if they:

- have a compromised immune system
- are aged 70 years and over
- are a First Nations person aged 50 years or over
- are living in supported accommodation or group residential settings.

Some people with disability may be at an increased risk because they:

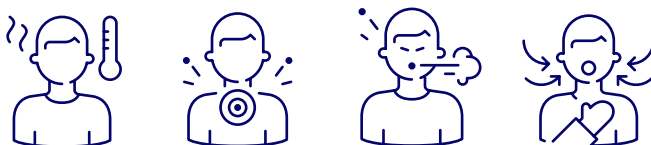
- have high support needs and higher rates of pre-existing health conditions
- live in group residential settings, increasing their risk of catching the disease
- may face barriers in accessing healthcare and information. As well as disruptions to regular medication and services.

These factors may make people with disability more susceptible to contracting the virus. They can also experience more severe symptoms, which may lead to a higher chance of fatality.

More information for people with disability and carers can be found on the Queensland Health website [here](#).

SYMPTOMS OF COVID-19

Some common symptoms of COVID-19 include:



- **High temperature**
- **Sore throat**
- **Tiredness**
- **Cough**
- **Runny Nose**
- **Shortness of breath**

People may also experience other symptoms that are different to what is shown above, such as headache, loss of smell, loss of taste, nausea or vomiting, muscle pain, joint pain, diarrhoea, or a loss of appetite. Symptoms can vary depending on each case.

Queensland Health has a [quiz](#) you can use to assess your symptoms.

There are 5 ways that we can all help stop the spread of viruses:



- Clean your hands regularly with soap and water or alcohol-based hand rubs

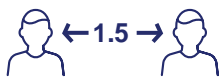
This [link](#) has a poster that shows good handwashing technique.



- Cover your nose and mouth with a tissue or bent elbow when coughing or sneezing.

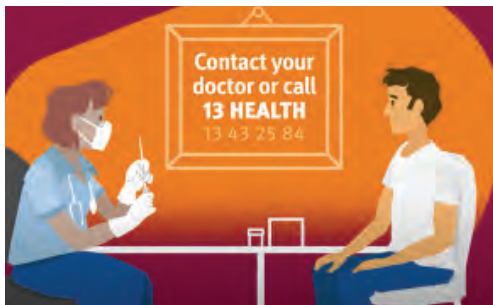


- Avoid touching your face, nose and mouth. Do not shake hands.
- Stay home if you are unwell.



- Practice social distancing, which includes staying 1.5 meters away (or two arms length).

TESTING – WHERE TO GET TESTED AND WHAT HAPPENS NEXT



It is important to get tested if you become unwell with any of these symptoms of COVID-19, even if the symptoms are only mild. This will help public health officials keep track of the illness in the community and have a clear picture of how the virus is spreading.

WHERE TO GET TESTED

If you have any symptoms of COVID-19, you can visit:

Your local doctor



Before your appointment, please call ahead and tell them about your symptoms so they can prepare for your visit.

Fever clinics



Fever clinics are clinics managed by Queensland Health to test people to see if they are infected with COVID-19. These clinics help to keep people who may be contagious away from other areas of hospitals and health centres. This helps to reduce the spread of the virus and keeps the emergency department available for emergencies.



Check the [Queensland Fever Clinic & Respiratory Clinics list here](#) to find your closest location, or contact your [local hospital](#). Not all of these clinics may be able to accommodate your access needs. Before travelling to a clinic, call them first and let them know about your unique access needs. The service will then let you know if they are able to assist.



You can also call **13HEALTH (13 43 25 84)**.

This testing is free for everyone, even if you are not covered by insurance or eligible for Medicare.

What happens when you get tested for COVID-19?

Testing for COVID-19 involves collecting nasal (inside your nose) or throat swabs, and/or sputum (mucus coughed up). These samples are then transferred to the nearest laboratory that is set up to test for COVID-19.

These testing methods may be distressing or painful for some people. If you need special consideration to be tested comfortably, please discuss this with your doctor or the clinic – there may be alternative methods of testing available if you need this due to the impact of your disability.



If you are tested for COVID-19

- But are not really sick - you may be sent home to self-isolate while you wait for the test results. This may take several days.
- If you are very sick - you may be admitted to hospital for treatment.
- If you become sicker while you are waiting for results, please contact your doctor or call an ambulance. Make sure you let them know you are waiting for test results for COVID-19.

Self-isolate: You are advised not to leave your home, residence, hotel or accommodation except to seek or receive medical care. If you do need to leave your home for a medical appointment, wear a face mask and do not use public transport. Private transport is the preferred transport option.



If your test for COVID-19 is positive:

- You will receive a call from a public health doctor or nurse who will tell you what to do next.
- If you are well enough to take care of yourself, you will need to stay at home in self-isolation until you recover.
- If you get sicker, you may be admitted to hospital in an isolation area. An isolation area is a room or space that is separate to regular wards. It is used to make sure you come into contact with less people, to help keep yourself and others safe.



If your test for COVID-19 is negative:

- Your doctor or the clinic that tested you will let you know. Depending on where you got tested, you may just receive an automated SMS.
- If you have been issued with a notice telling you to self-quarantine, you must stay in self-quarantine until the end date written on the notice, even if you get a negative result. This is because you may still develop COVID-19 infection.



If you are waiting on a test result, the people you live with and other close contacts do not need to be in self-quarantine unless the local public health unit tells them to. If you are sick, they should stay away from you as much as possible. Your formal or informal support people or carers should wear personal protective equipment (PPE), and everybody should make sure they wash their hands regularly. If the test result is positive, they may be assessed as a close contact and will then need to be in quarantine.

If you are unable to get to a COVID-19 fever clinic for testing, due to issues relating to your disability, your GP may be able to organise your local pathology clinic to arrange a home visit.

FUNDED BY:



APPENDIX 2: GOING TO HOSPITAL: CHECKLISTS



CHECKLIST – INFORMATION ABOUT ME TO TAKE TO HOSPITAL

You may have a range of specific needs that it is important that your doctors, nurses and healthcare team know about you. It is good to keep all of this information with you and you may like to have it all together in a folder. The following is a checklist of a range of information about you and your needs to consider.

- ☐ Medicare number
- ☐ My Health Record Identifier
- ☐ Name of GP and phone number
- ☐ Next of kin details such as names and contact numbers
- ☐ Advance Health Directive/Resuscitation Plan/Statement of Choices/Power of Attorney
- ☐ Medical history summary
- ☐ Communication needs
- ☐ Medications (including any assistance needed, administration, storage, side effects)
- ☐ Medication assistance required (e.g. with food, syringe drivers)
- ☐ Positive Behaviour Support Plans
- ☐ Allergies
- ☐ Immunisation/vaccination records
- ☐ Eating/Swallowing (e.g. support needed, PEG/NG tube)
- ☐ Fluid intake/restrictions
- ☐ Special diet
- ☐ Equipment needs
- ☐ Sterilisation Care (e.g. wounds, catheter, ostomy)
- ☐ Skin/Hair/Nail Care
- ☐ Continence aids
- ☐ CPAP/oxygen
- ☐ Central line (e.g. port, catheter) - management
- ☐ Other bodily functions (e.g. tracheostomy)
- ☐ Sleeping
- ☐ Behavioural supports needed



CHECKLIST FOR DOCUMENTS TO TAKE WITH YOU TO HOSPITAL ADMISSION

The following is a checklist of the different documents you might like to take with you to hospital. You may not have all of these documents and that is ok. This information is a guide to help you think through which ones might be relevant to you.

- ☐ Identification documents (Medicare card, licence, Centrelink concession card)
- ☐ Private health insurance documents
- ☐ Medication list/medications
- ☐ Registered for MyGov / Registered for My Health Record
- ☐ Key Instructions sheet
- ☐ Individual Healthcare Plan
- ☐ Connection Kit
- ☐ Health Passport
- ☐ Comprehensive Health Assessment Program document
- ☐ Advance Health Directive
- ☐ Statement of Choices
- ☐ Resuscitation Plan
- ☐ Enduring Power of Attorney
- ☐ Guardianship documents
- ☐ Will
- ☐ Positive Behaviour Support Plan
- ☐ Communication tools
- ☐ Advocacy Supports
- ☐ Things that provide comfort and confidence
- ☐ Personal Protective Equipment

FUNDED BY:



ABOUT QDN AND HCQ



Queenslanders with Disability Network

Queenslanders with Disability Network (QDN) is a state-wide organisation by and for people with disability. QDN's work is centred around a strong network of people with disability across Queensland to inform, connect, lead and influence change to deliver an inclusive Queensland community.

Our motto is "nothing about us without us."

Please find more information on our website:

Website: qdn.org.au

Telephone: 1300 363 783

Email: qdn@qdn.org.au



HEALTH
CONSUMERS
QUEENSLAND

Health Consumers Queensland

Health Consumers Queensland is the peak organisation representing the interests of health consumers and carers in the state. Health Consumers Queensland is a not-for-profit organisation and a registered health promotion charity, and we believe in improving health outcomes for people in Queensland.

Our priority focus is on consumer engagement that influences and leads improvements and delivers better health outcomes for all Queenslanders. We achieve this through our Queensland-wide health consumer network, tailored training and skills development programs, and maximising opportunities for consumer representation at all levels of the health system.

Please find more information on our website:

Website: hcq.org.au

Telephone: 07 3012 9090

Email: info@hcq.org.au
