

# MY RIGHTS AND HOSPITAL CARE DURING COVID-19 FOR PEOPLE WITH DISABILITY

PEOPLE WITH DISABILITY MAY NEED TO ACCESS HOSPITAL CARE DURING THE COVID-19 PANDEMIC, BOTH IF THEY GET SICK WITH COVID-19 OR NEED TO GET 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
- Information to help you understand your rights; and
- What you can expect in this changing environment as a patient with disability.

It is important that people with disability can get the right care, in the right place, at the right time, in a way that upholds your rights to equitable access to healthcare.

You can find more detailed information about everything in this document in the full guide at <a href="https://www.qdn.org.au/knowyourrightscovid19">www.qdn.org.au/knowyourrightscovid19</a> - 'Know your rights: A guide for people with disability to get the hospital care they need during COVID-19'.



**FUNDED BY:** 







# In the **Know Your Rights** guide you will find information to help you:

GET PREPARED: Before you go to hospital
Get information about COVID-19 Understand how hospitals are running during COVID-19 Know about your rights to healthcare in hospital during COVID-19 Prepare information about your needs
Get ready and pack what you need to take with you if you have to go to hospital  BE PREPARED: At / in hospital
Have your documents / information about you and your needs and display it so people can see it easily  Give a copy to your healthcare team
Know your rights and have a copy of the Patient Charter of Healthcare Rights on hand
Have a support person with you (as long as it is safe) – they can be with you in person and follow the hospital rules or they could be on the phone
Speak up, and ask for help if you need it – there are staff in the hospital who can help you too as well as advocacy organisations
Make your wishes and your healthcare decisions known
Remember Ryan's Rule – if you don't feel your concerns are being acted upon in a timely manner

# **COVID-19 AND OUR QUEENSLAND HOSPITALS**

The COVID-19 pandemic presents a significant risk to the health and wellbeing of all Australians, but particularly people with disability. Almost 1 Million Queenslanders have disability. It is important that people with disability and their families have factual information about COVID-19 and what you can do to protect yourself, what you need to do to prepare if you have to go to hospital during this time, and your rights to care and treatment.

You can find more information about COVID-19, symptoms and getting tested in the **Know your Rights** guide at <a href="https://www.qdn.org.au/knowyourrightscovid19">www.qdn.org.au/knowyourrightscovid19</a>

During the pandemic there have been many changes to the way hospitals are providing care and 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 disability needs.



The changes include the way

- you go into the hospital and what happens at the front door
- doctors, nurses and health professionals are providing your care
- you are getting your healthcare that may include things like telehealth, and care in other places like your home

You can find more information about these changes in the Know your Rights guide at www.qdn.org.au/knowyourrightscovid19

#### MY RIGHTS TO 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 and guided by human rights instruments, agreements and law, charters, frameworks and guidelines. There are a range of different documents that guide and govern the delivery of your healthcare, You can find more information about these documents in the **Know your Rights** guide at www.gdn.org.au/knowyourrightscovid19

These help to ensure that:

- o people with disability receive equitable access to 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.

# WHY IS IT IMPORTANT TO UNDERSTAND MY RIGHTS DURING COVID-19?

It is important to understand that in a pandemic, resources are stretched and potentially overwhelmed.

During COVID-19, many hospitals have different rules about who can visit to keep people safe and help stop the spread of COVID-19.



**ACTION:** Take some time now to understand your healthcare rights during COVID-19

# YOUR DISABILITY AND YOUR NEEDS IN THE HOSPITAL



# Support Person/Support Workers

People with disability each have different needs and need different accommodations to make their healthcare accessible. Some people need to have a support person with them when they go to hospital. 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 essential supports to you that you need to be able to access health, medical, or other services. 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.



# What can I do now to get prepared if I need to go to hospital?

# Start to get together information about you and your support needs

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

If you don't have this information together in one place, you could take some time now to get this ready in case you do need to go to hospital so you can be prepared.

Some examples may include:

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



**ACTION:** Find the information that you already have about your health and your support needs and put it all in a folder. We suggest you label the folder with your name and then 'My Healthcare'. You can find more information in the Know your Rights guide at <a href="https://www.qdn.org.au/knowyourrightscovid19">www.qdn.org.au/knowyourrightscovid19</a>

## MY HEALTH DECISIONS AND HEALTHCARE DIRECTIONS



There are a range of legal documents that help other people understand your healthcare decisions and directions for your care if you are unable to do so yourself, or if you 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. It is important that you have this information with you so that your healthcare team can understand who that is.

You can find more information about these documents in the **Know your Rights** guide at <a href="https://www.qdn.org.au/knowyourrightscovid19">www.qdn.org.au/knowyourrightscovid19</a>



**ACTION:** If you have a legal document that includes your care decisions and directions for your care find it now and put it in the folder with your other information.

## SUPPORT, ADVOCACY AND SPEAKING UP

When you are in hospital, there may be times when you need to get support, advocacy or to speak up to be able to get the right care, in the right place, in the right way that is equitable.

It is important that you:

- know your rights
- ask questions if you can
- have your support person with you if you can
- · collect information about your care
- be part of any handover between shifts/teams



## Is it OK to ask for help?

Yes it is. It is also important that you can ask for help and there are some people who work in the hospital that can assist and support you, as well as advocacy organisations, advocates or your appointed decision makers. The folder of information that you have prepared will assist in helping everyone to understand your needs.

Make your wishes and your healthcare plans known to your team. You can do this by making sure your key instructions, connection kit, COVID-19 companion information or key things that are essential for your healthcare team to know about you are displayed where people can see them and they get people's attention. Your support person can help you ask for help too.



**ACTION:** Print out the checklist in the Know your Rights guide at <a href="www.qdn">www.qdn</a>. <a href="www.qdn">org.au/knowyourrightscovid19</a>. Go through each item one by one and decide which items you need in your folder – just in case you need to go to hospital.





**ACTION:** Visit <a href="www.qdn.org.au/knowyourrightscovid19">www.qdn.org.au/knowyourrightscovid19</a> to access 'Know your Rights: A guide for people with disability to get the hospital care they need during COVID-19' and find out more information.

#### ABOUT ODN AND HCO



#### **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 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: <a href="https://doi.org.au">https://doi.org.au</a> Telephone: 07 3012 9090 Email: <a href="mailto:info@hcq.org.au">info@hcq.org.au</a>







You can contact QDN on 1300 363 783 and HCQ on 07 3012 9090

This information is available online at www.qdn.org.au/knowyourrightscovid19