



Government of **Western Australia**
Department of **Health**

Hospital Stay Guidelines

A guide for people with disability,
families, friends and carers





Acknowledgement of Country and People

WA Health acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. It acknowledges the wisdom of Aboriginal Elders both past and present and pays respect to Aboriginal communities of today.

Readers are warned that this document may contain images of people who have deceased since the time of publication.

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Contact information

For further information contact Western Australian Department of Health on (08) 9222 0200 or health.policy@health.wa.gov.au.

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Introduction

Our commitment

The Western Australian (WA) Department of Health is committed to improving health outcomes for people with disability. The Hospital Stay Guidelines acknowledges the United Nations Convention on the Rights of Persons with Disabilities. Visit www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html for more information on the United Nations Convention, including an Easy Read version.

The Disability Health Network

The Disability Health Network helped to write this guide. The aim of the network is to improve health outcomes for people with disability. The network works together with people with disability, families and carers, health professionals, hospitals, health services and staff from the WA Department of Health.



Disability Health Network Co-Leads Stephanie Coates and Jocelyn Franciscus

The network acknowledges the many organisations and individuals that participated and contributed to the revision and co-design to update the Hospital Stay Guidelines:

- Danielle Loizou-Lake (Author)
- Dr Amber Arazi (access consultant)
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- Dr Jacquie Garton-Smith
- Katie Browning (Child and Adolescent Health Service)
- Ready to Go Home Project (National Disability Services and Department of Health WA, Chief Allied Health Office)

Family, friend, carer and paid support person involvement



You can have somebody support you in hospital.

You can choose who is the right person to give you the support you need. This may be a family member, a friend, a carer or a paid support person.

Family members or friends who support you are sometimes called carers. Carers are people who give you support that is not part of a paid work or community work arrangement. A person who is paid to provide you with support is often called a support worker.

If you are a young person (under 18 years old), you will need to have a family member or carer with you at hospital.

It is important that you have your health and disability information ready before you go to hospital so that you and your supporter can show the hospital staff.

People can have National Disability Insurance Agency (NDIS) approved supports attend the hospital with them and stay with them. You can use your NDIS funding to pay your support worker to support you while in hospital if this is 'reasonable and necessary' according to the NDIS.

Examples of 'reasonable and necessary' supports can include if you have communication support needs, or if you experience behaviours described as challenging.

- If you have communication support needs and use a communication partner or support worker to help you with your communication.
- If you have behavioural support needs and a support worker is needed to help you feel safe, regulated and in control. The support worker may also be needed to assist with helping you access information, so you can engage with medical treatments safely.

About the guide

This guide is for people with disability, families, friends and carers. It considers the different reasons why you may go to hospital and helps you to prepare to go to hospital.

The guide has been divided into 4 main parts:

1. Being prepared for hospital
2. Going to hospital
3. At the hospital
4. Preparing to go home



Being prepared for hospital



Your general practitioner or local doctor

Your general practitioner (GP) or local doctor is an important part of your healthcare team and can help you prepare for a hospital procedure. If you don't have a GP, you can find one using the link below or ask someone to help.

Visit www.healthywa.wa.gov.au/Service-search to find a GP.

Seeing your GP regularly is good. They will learn about your needs and support you with your health. Your GP is the first person you should contact if you have a question about your health, you are unwell or need medications. Your GP will be able to link you up with other health providers like physiotherapists, occupational therapists, podiatrists, community nurse, mental health and other specialist doctors.



Health and disability information

Another way to prepare for hospital is to have a record of your health and disability information to share with the hospital staff.

Listed below are different ways you can create a personal health record.

Disability Health Profile



An example Disability Health Profile form has been included at the end of this guide. This form can be filled out before you go into hospital and given to the hospital staff when you arrive. You can include information about your equipment and supports too.

Health passport



Having a health passport may help to improve your health care. There are different types of health passports you can use depending on your health needs and how you would like to communicate.

It is good to fill out the health passport before you go to hospital. You can give it to the hospital staff when you arrive. Examples are at the end of this guide.

My Health Record



My Health Record is a safe and secure way to store your health information online. You can decide who you would like to share your record with, and which healthcare providers can add information. Your record can include a list of your medicines, allergies, tests and scans.

Talk to your GP and/or visit www.digitalhealth.gov.au for more information.

Visit https://www.ideas.org.au/images/resources/blog/My_Health_Record_Plain_English_booklet.pdf for a Plain English booklet.

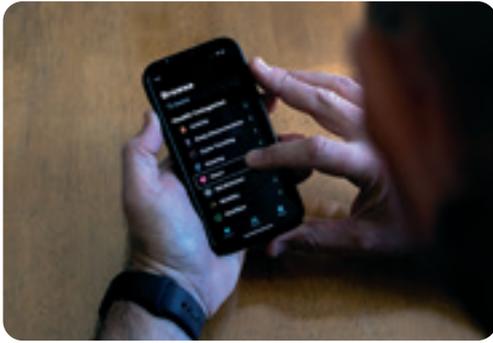
Advance Care Planning



Advance Care Planning is a way to prepare for a time when you may be unable to make decisions due to illness or disability. Your choices about your future health and personal care can go into an Advance Care Planning document. This could be called an Advance Health Directive or a Values and Preferences Form. Contact your GP if you are interested in Advance Care Planning.

Visit www.healthywa.wa.gov.au/advancecareplanning for more information.

Medical ID



You can set up Medical ID so that in an emergency other people can access the information from your mobile phone without a password. This is helpful if you have a condition like epilepsy or severe allergies.

If you have an iPhone, search for Medical ID in your phone settings.

If you have an Android phone, search for and download Medical ID in the Play Store.

Access cards

Some disabilities may be less visible than others. If you have an invisible or hidden disability, an access card can help you to communicate your needs.

National Access Card



The National Access Card and Lanyard includes your photo and important medical and contact information that you can show to hospital staff.

Visit www.invisibledisabilities.com.au for more information.

The Sunflower Lanyard



The Sunflower Lanyard is a lanyard you wear around your neck. The sunflowers show people that you have a hidden disability.

Visit hiddendisabilitiesshop.com.au for more information.

Autism Alert Card



The Autism Alert Card lets hospital staff know that you have autism. It has your photo and name and the contact details of 2 people the hospital staff can call if you need help.

Visit www.autism.org.au/our-services/fact-sheets-autism-2/autism-alert-card for more information.

Going to hospital

You may go to hospital:



In an emergency, to the Emergency Department



For a planned visit or appointment
(as an outpatient)



For a planned visit where you stay for the day
or overnight (as an inpatient)

An emergency visit

In an emergency, you may go to hospital in an ambulance. This will cost you money unless you have health insurance that includes ambulance cover. If you don't have health insurance, you can get ambulance cover from most health insurance companies. Ambulance cover will cost less than the cost of an ambulance trip.

When travelling to hospital by ambulance:

- take your hospital bag if you have one (pre-packed bag with essential items and a change of clothes)
- if you can, tell the paramedics important information about your health and disability. You might also like to have a card with information about your health and disability that you can give to the paramedics
- take your small disability aids with you (for example noise cancelling headphones, walking stick or communication aids)
- take other essential disability equipment with you (for example wheelchair or ventilator)
- a family member, friend, carer or paid support person may go in the ambulance with you. If they do not go with you, they can give their contact details to the paramedics and ask them which hospital you are going to.

A planned visit

Your GP or specialist may organise for you to be admitted to a hospital for a health procedure.



To get ready for this visit:

- use the going to hospital checklist (pages 10–12)
- check the information about your appointment. Set a reminder if you need to stop eating or drinking before your procedure
- plan how you will get to and from the hospital
- you may choose to have a support person with you. This person may be a family member, friend or carer. Your support person can help you to understand medical information. If you want, your support person can help you to make decisions and give consent
- tell the hospital as soon as possible if you need to change the date and time of your appointment.

Travel to the hospital



Plan how you will get to and from the hospital. You may wish to ask someone to take you or book a taxi.

If you live in the country and you have to travel a long distance for your health care, you may be able to use the Patient Assisted Travel Scheme. This scheme can help to cover the cost of travel.

Visit www.wacountry.health.wa.gov.au/our-patients/patient-assisted-travel-scheme-pats for more information.

Going to hospital checklist



The going to hospital checklist includes a list of things to get ready and pack before you leave for the hospital.

Not everything in the list will be relevant to you. This will depend on your individual needs and whether you are going to hospital for an appointment or staying overnight.

If you think you may need to go to hospital at short notice, you can pack a hospital bag in advance.

Information

- Cards – Medicare, concession, private healthcare
- Disability Health Profile
- Health passport
- Advance Health Directive or Values and Preferences Form
- Update your My Health Record
- GP contact details (also paediatrician/specialist doctors)
- Behavioural support plan
- Mental health plan

Medications

- Your medications (these may not be available at the hospital)
- Information on the dose and strength of the medication



Equipment

All equipment must be clearly labelled with name tags.

- Wheelchair, mobility aids
- Orthotics, splints, continence aids
- Feeding, drinking aids
- Other assistance aids, such as assistance dogs (have a plan for the care of these dogs) and respiratory care (such as ventilators)



Communication

- Mobile phone
- Pen and notebook
- Communication tools or boards
- Assistive technology
- Charging equipment



Sensory and comfort

- Items of comfort such as a familiar blanket, pillow, night light
- Fidget toys, comfort toys, sensory aids (music, headphones)
- Books, magazines or activities and craft

For overnight stays

- Comfortable clothes, underwear
- Comfortable shoes, slippers
- Nightwear, pyjamas
- Toiletries

Other

- Money for parking, snacks and phone calls

No smoking



Smoking, including use of e-cigarettes (also known as vaporisers), is not allowed anywhere on hospital grounds. This includes car parks and in cars.

If you smoke cigarettes or use an e-cigarette, let your doctor or nurse know. They can help you to not smoke or vape and be comfortable while you are in hospital.

At the hospital

Your rights

Your rights are protected by the Australian Charter of Healthcare Rights. Visit www.safetyandquality.gov.au/consumers/working-your-healthcare-provider/australian-charter-healthcare-rights for more information.



While it is important for hospital staff to support your rights, it is also important to remember to treat the hospital staff with respect. Good communication helps you and hospital staff to work together.

Visit www.safetyandquality.gov.au/consumers/working-your-healthcare-provider/australian-charter-healthcare-rights/resources-australian-charter-healthcare-rights for an Easy Read version of the Charter.

Visit www.healthywa.wa.gov.au/News/2021/My-Health-in-My-Hands for information for young people.

Communication

It is important that the hospital staff understand your health care needs. You may choose to have a family member, carer or friend assist you in the hospital and speak on your behalf. If you have complex communication access needs or behavioural support needs, a communication partner or support worker may assist while you are in hospital.



You can ask the hospital staff for an interpreter if you communicate in Auslan, Tactile Signing or a language other than English. This is a free service and available at any time of day or night.

For support or advice while you are staying in hospital, you can also speak to a Patient Liaison Officer or Aboriginal Liaison Officer. It is their job to make sure your rights and interests are met.

Assistance animals

There are a range of animals, mainly dogs, who support people with disability.

For example:

- Seeing eye dogs: sed.visionaustralia.org
- Assistance dogs and therapy animals: therapyanimals.com.au
- Guide and assistance dogs: www.guidedogswa.com.au



These animals have been formally trained to assist a person with disability and are allowed in hospitals where the public can go. For example, they are allowed in outpatient clinics and general hospital wards, but they are not allowed into operating theatres.

If the person using an assistance dog must be in a hospital bed, then the dog may need to go and stay with an expert dog handler.

At the emergency department

At the emergency department, the hospital staff will ask you information about how you are feeling.

They will ask for your:

- name
- Medicare number
- GP's name, practice name, address and phone number
- health and disability information.



It is also important to tell the hospital staff about any religious or cultural health care requirements you may have.

People are seen depending on how urgent their health needs are. This means it is possible that a person who came after you is seen before you. You may have to wait a long time to see the nurse or doctor, depending on how serious your condition is.

If you need to stay in the hospital for treatment, you may be admitted.

Tell the hospital staff if you have specific needs or if you need to call a carer or support worker.

CARE Call

If you become very sick while you are waiting in the hospital, you can use the CARE Call.

Aishwarya's CARE Call is a way that you or your family, friends and carers can call for urgent assistance in the hospital.



Worried about a change in your condition or the person you care for?
Tell a hospital staff member that you are worried.



If you are still worried, ask for a senior nurse.
Tell them why you are worried.



If you urgently need assistance, make the CARE Call.
Some hospitals have a phone for Aishwarya's CARE Call in the Emergency Department.
You can also make the CARE Call on your mobile phone.

Supported decision making



At the hospital, you may be asked to make decisions about your health care. You may be asked to sign a form to say that you agree to a medical procedure or operation. This is called giving consent. It is important that you have been given all the information you need to make a decision so that you are giving informed consent.

If you don't want to have the treatment, or you have not

been given enough information about it, you can choose not to give your consent. You can ask for more time or more support to make your decision. You can change your mind and take back the consent you gave.

If you would like support to make decisions, a family member, friend or carer can support you. You can also tell the hospital staff if you use communication tools or pictures to help you understand information.

You can include information about the supports you use in your Disability Health Profile and health passport.

When you are not able to make decisions



Sometimes you may not be able to make decisions about your health care. For example, when you are unconscious. If you have an Advance Health Directive (AHD) and/or Values and Preferences Form, this tells the hospital staff about some of your health care choices but may not include all your decisions for different situations.

You can include the name of a person you would like to

make decisions for you should you become unable to make these decisions yourself.

If you have an Enduring Guardian with authority, they can sign documents for you and make decisions in your best interest. It is important to check what type of guardian you have because only someone with authority can do this for you.

If you do not have an AHD or an Enduring Guardian, the hospital staff will follow the decision makers list below. The Enduring Guardian is the first choice, then it goes down to the next person. This decision maker becomes the person responsible for your health care choices.

Your decision maker must be:

- 18 years of age or older
- of full legal capacity
- available
- willing to make the decision.



Decision maker's list:

Advance Health Directive (AHD)

Decisions must be made in accordance with the AHD unless circumstances have changed or could not have been foreseen by the decision maker.



Enduring guardian with authority



Guardian with authority



Spouse or de facto partner (e.g. husband or wife)



Adult son or daughter (over 18 years old)



Mother or father



Brother or sister



Primary unpaid caregiver



Other person with a close personal relationship

If urgent health care is needed, a doctor can care for you if you don't have an AHD and the staff can't contact your decision maker.

Visit www.wa.gov.au/organisation/department-of-justice/office-of-the-public-advocate/making-treatment-decisions-opa-information for an Easy Read decision makers list.

Preparing to go home

Discharge plan

A discharge plan includes information about your health care after you leave the hospital. You should be involved in this plan and can involve your family, friends, carers and support workers. Your GP is also an important part of your healthcare team.



Manage My Care

When you leave the hospital, your GP should receive a discharge summary. This will tell your GP about any follow up medical appointments. Your GP will be able to connect you with other health providers such as a community nurse, physiotherapist, mental health provider and other specialists.

Manage My Care is a free app you can use to help you manage your public hospital outpatient appointments. Visit www.healthywa.wa.gov.au/managemycare for more information.



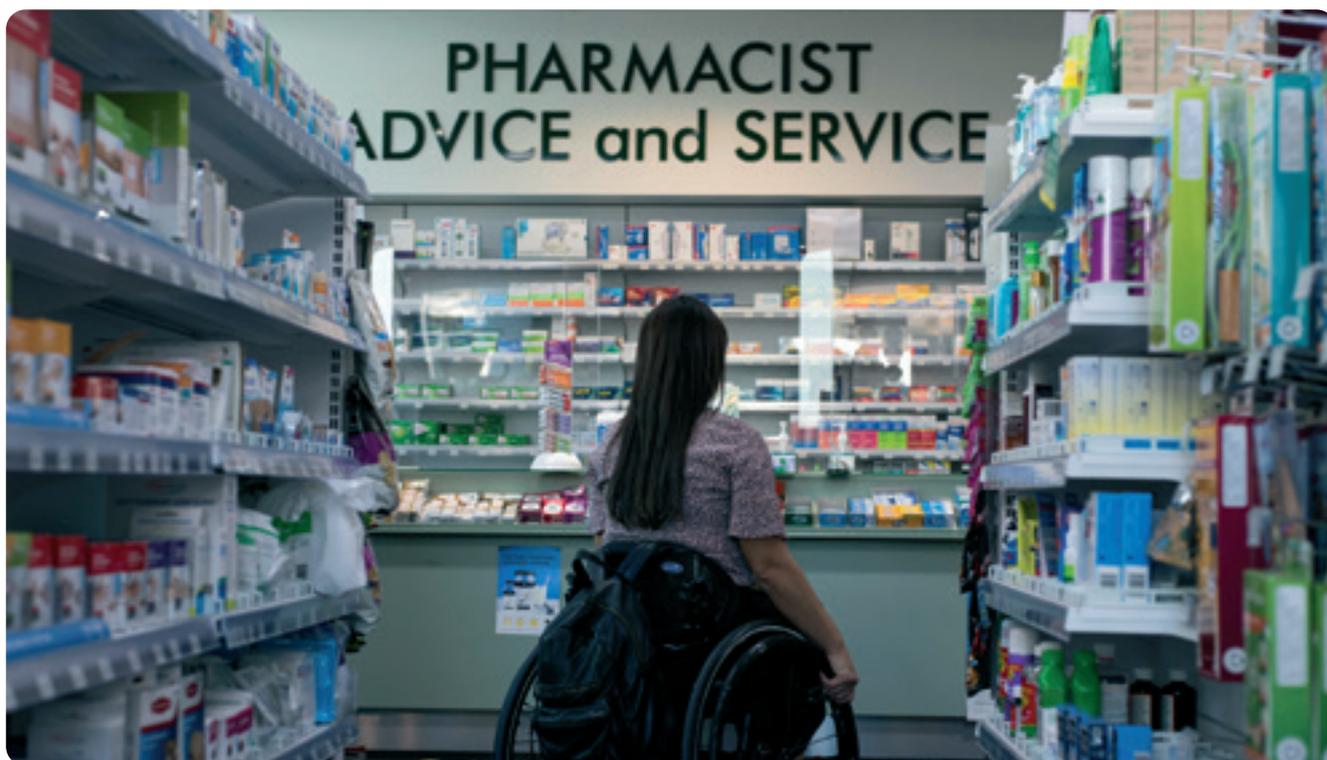
Going home checklist

You can use this checklist to make sure you have everything you need before you leave the hospital.

Information

- Discharge summary
- X-rays and scans
- Other care plans

For example, wound care plan, nursing transfer letter or rehabilitation referral plan.



Medications

- Are your current medications included in your discharge summary?
- Are there any changes to your medications?
- Do you have any specific requirements you should tell the doctor or nurse before you leave the hospital?

For example, you may not be able to swallow large tablets or you may need support to get to the pharmacy.

Medical appointments

- Do you need to see your GP or a specialist after leaving the hospital?
- Do you have support in getting to and from medical appointments, if required?
- Does your council or shire offer assistance to patients to get to and from medical appointments?

Support and training

- Do you require any training in looking after your health after you leave the hospital?
- Do your family, friends, carers or support workers require any training?
- If you need nursing care at home, the hospital can arrange this.
- If you have an NDIS plan and your disability support needs have changed while you are in hospital, the NDIS may work with you to discuss your supports.

Equipment

If equipment is a new requirement following your hospital stay, then the hospital may arrange a short term loan so that you can leave the hospital safely. This equipment may include mobility or communication aids.

- Do you know how to use the equipment? You can ask the hospital staff to show you.
- Check how long you can borrow the equipment for and how long you need it.
- If you have an NDIS plan you might be able to buy or hire equipment.
- Can your NDIS support coordinator arrange this for you?
- If you are not an NDIS participant, can you get the equipment through another source? For example, My Aged Care or the Insurance Commission of WA.



Home modifications

- Do you require basic and essential home modifications before you leave the hospital?
- Can the hospital assist you with basic modifications?
- Can anyone else assist, such as a support coordinator?
- Do you have accommodation options while waiting for home modifications?

If you rent your home, check with the housing owner or agent before making any modifications to your home.



Getting home

- Are you able to get home safely?
- Do you need to arrange for assistance from a family member or carer, friend or support worker?
- Has the doctor arranged for you to be transported home by a patient transport service?
- Are you well enough to travel home by taxi or other public transport?



After you return home

If you start to feel sick again when you have returned home:



Tell your family, carer or support worker



If it is not an emergency, call your GP or after hours doctors



Call Healthdirect on 1800 022 222.
Healthdirect also have an after hours GP helpline



If you start to feel very sick, go to the hospital
Emergency Department or call 000

Information about family, friends and carers

Your family, friends and carers have an important role when they help you in hospital. This role is very important if you are a child or person who has difficulty communicating your needs.

A carer is a person who supports a family member or friend without being paid for it. The person a carer supports could have disability, mental health condition or a chronic condition. They could also have an alcohol or drug dependency, be frail, or be aged and needing support.

A carer does not give support as part of a paid work or community work arrangement. The role of a carer is stated in the *Western Australian Carers Recognition Act 2004*.



Visit www.wa.gov.au/government/publications/carers-recognition-act-fact-sheets for more information.

Family, friends or carers can support you by communicating important information with hospital staff. Your carer will also usually know when something is not 'normal' for you and can let hospital staff know when something is wrong. The partnership between you, your carer (or family or friend) and the hospital staff is important for delivering safe health care.

The role of family, friend or carer

The role of your family, friend or carer includes:

- assisting you in being prepared for the hospital visit
- providing support to prepare and update your disability and health documents
- getting you to and from the hospital safely
- supporting you with your health care and decision-making
- acting as a communication partner to clarify and translate information between you and healthcare staff
- coordinating your care with providers and services for discharge
- communicating with your private health insurers
- assisting with any feedback and complaints you may want to make
- your emotional support.

Your family, friend or carer also has rights when they are supporting you in hospital. The Western Australian Carers Charter (included in the Act) states that:

- carers must be treated with respect and dignity
- carers must be recognised by including them in the assessment, planning, delivery, and review of services that impact on their role
- when decisions are made, the views and needs of carers must be considered along with the views, needs and best interests of the people they care for
- consideration must be given to complaints made by carers about services that affect them.

Carers WA

Carers WA has a Prepare to Care booklet that can help your family, friend and carer to support you during your hospital stay and after you leave the hospital. Visit www.carerswa.asn.au/our-services/prepare-to-care-hospital-program to access the booklet online.

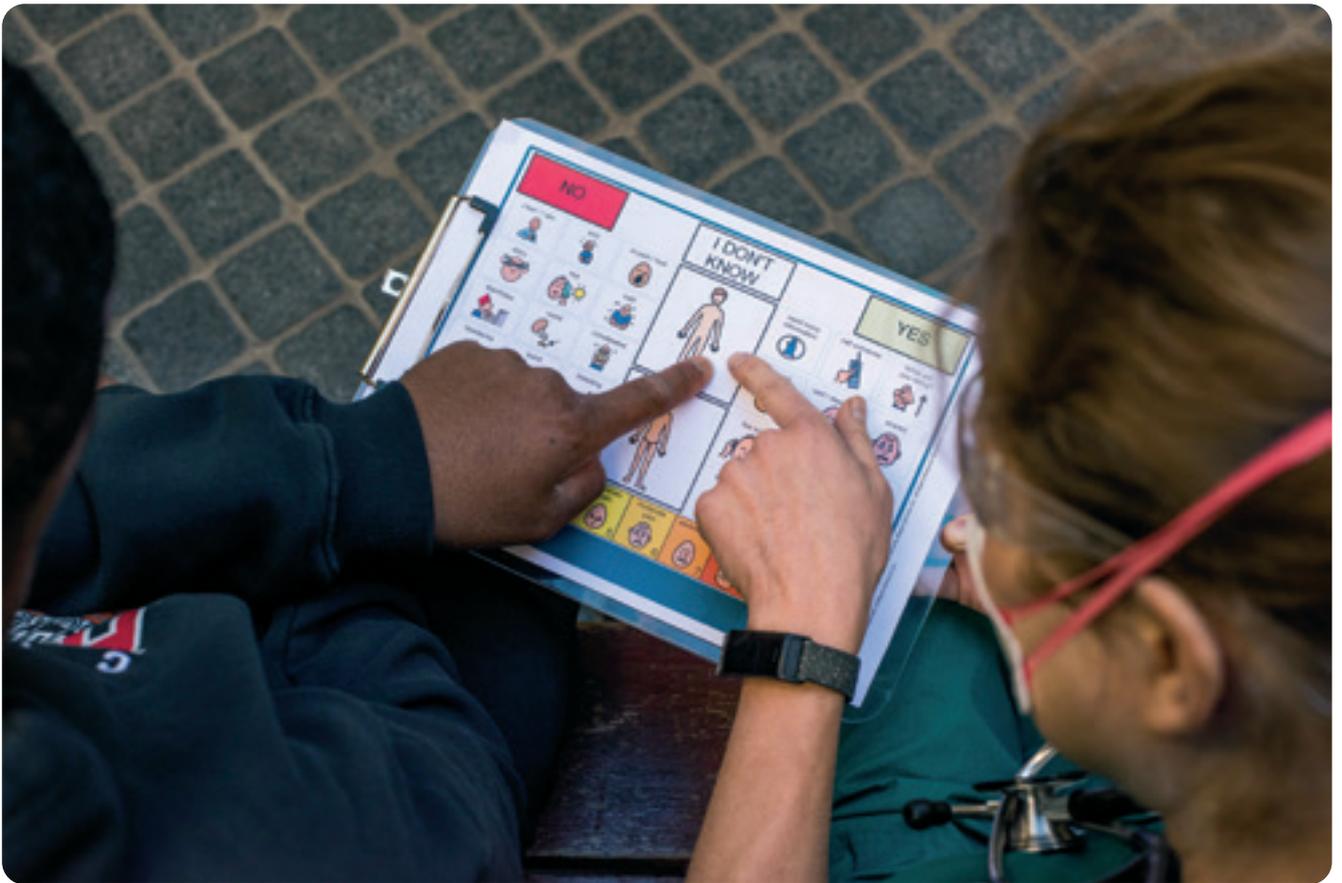
Carers WA can be contacted by email at info@carerswa.asn.au or on 1300 227 377.

Carer Gateway

Carer Gateway is an Australian Government program for your family, friend and carer. It can give them support services and advice. These can be given in person, over the phone and online. These services include peer support, counselling, funding for practical supports or respite for your carer to have some time away from their caring role.

Visit www.carergateway.gov.au for more information.

These services are run in WA by Carers WA. Call the WA Carer Gateway on 1800 422 737. Visit www.carerswa.asn.au/our-services/carers-gateway-services for more information.



Complex communication access needs

At the end of this guide are communication scripts covering different ways your carer can help you communicate if you have complex communication access needs.

The scripts cover:

- pain
- communication
- distress or sensory overload
- understanding procedures
- supported and shared decision-making, and informed consent
- medication requirements
- education and training of support people.

Having your say

During your hospital stay, there may be some things that are worrying you or you may wish to provide some positive feedback. You may also want to provide feedback after your hospital experience.



You can:

- tell the hospital staff about the feedback or complaint
- talk with the Patient Liaison Officer or Aboriginal Liaison Officer
- ask a family member, friend or carer to speak to the hospital staff on your behalf
- ask the hospital staff for a feedback form or more information about their complaints processes.

Care Opinion

You can share your experience on the Care Opinion website. You can share what you think the hospital is doing well and what can be done better. When you share your story, it is sent to the relevant area of the hospital. Visit www.careopinion.org.au/tellyourstory for more information.

Disability advocacy services

You can contact an advocate if you have a complaint that has not been resolved. An advocate can help you to have your say and make sure that your rights and choices are heard.

The Disability Advocacy Finder can help you to find an advocacy service in your area. Some advocacy services also provide self-advocacy training. Self-advocacy is about having your say and speaking up about your rights.

Visit askizzy.org.au/disability-advocacy-finder for more information.

The Health and Disability Services Complaints Office (HaDSCO)

HaDSCO can assist you with making a complaint about a health or disability service.

Phone: 6551 7600 or free call 1800 813 583

Email: mail@hadsco.wa.gov.au

Health Consumers' Council of WA

The Health Consumers' Council of WA can give free advice and can help you to make a complaint about a health service.

Phone: 9221 3422 or 1800 620 780 (Country only)

Email: info@hconc.org.au

Mental Health Advocacy Service

The Mental Health Advocacy Service is a free independent service for people receiving or referred for involuntary mental health treatment.

Phone: 6234 6300 or free call 1800 999 057

Email: contactus@mhas.wa.gov.au

Microboards Australia

Microboards Australia can help you set up your own microboard. A microboard is a small group of people that come together to support you and help you achieve your goals. Your family and friends can be a part of your microboard. Your microboard can help you when you are in hospital.

Visit microboard.org.au for more information.

WA Department of Health

Example Disability Health Profile
(Admission information)

UMRN: _____
Name: _____
Address: _____
Sex: _____ DOB: _____

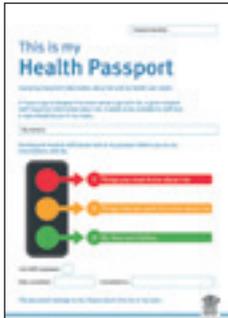
Admission date	NDIS number		
Reason for person attending hospital	NDIS plan in place: <input type="checkbox"/> Yes <input type="checkbox"/> No NDIS plan nominee: <input type="checkbox"/> Yes <input type="checkbox"/> No	Date of next plan review	
Next of kin (NOK) Name and contact details	Support coordinator contact details		
NOK aware of admission <input type="checkbox"/> Yes <input type="checkbox"/> No	Service provider/s: Request copy of care plan for the file		
Is the individual able to make decisions independently? <input type="checkbox"/> Yes <input type="checkbox"/> No If no, who supports them with decision-making? Complete below: <input type="checkbox"/> Enduring Power of Attorney <input type="checkbox"/> Enduring Power of Guardianship <input type="checkbox"/> Administration order <input type="checkbox"/> Guardianship Order <input type="checkbox"/> SAT in progress Hearing date (if known): _____ Other: _____	Funding source	<input type="checkbox"/> NDIS <input type="checkbox"/> MyAgedCare <input type="checkbox"/> ICWA <input type="checkbox"/> Worker's compensation <input type="checkbox"/> CAEP <input type="checkbox"/> Other _____	
Primary language	Interpreter required? <input type="checkbox"/> Yes <input type="checkbox"/> No		
Residential status	<input type="checkbox"/> Own home <input type="checkbox"/> Private rental <input type="checkbox"/> Public rental <input type="checkbox"/> Other _____ <input type="checkbox"/> Lives alone <input type="checkbox"/> Lives with others <input type="checkbox"/> Formal support (paid) <input type="checkbox"/> Informal support (unpaid) Details: _____		
Disability/s	<input type="checkbox"/> Physical <input type="checkbox"/> Sensory <input type="checkbox"/> Neurological <input type="checkbox"/> Neurodivergent <input type="checkbox"/> Intellectual <input type="checkbox"/> Developmental <input type="checkbox"/> Psychosocial Specify: _____		
Behaviour/s of concern	Positive behaviour support plan in place	<input type="checkbox"/> Yes <input type="checkbox"/> No (if yes, request copy for file and PBS practitioner details):	
Cognition	Cognitive impairment: <input type="checkbox"/> Yes <input type="checkbox"/> No Comments: _____		
Mental health	Risk assessment and management plan (RAMP) <input type="checkbox"/> Yes <input type="checkbox"/> No		
Communication	<input type="checkbox"/> Independent <input type="checkbox"/> Assisted (if assisted, details): _____		
Specialised equipment	_____		
	Independent (Tick)	Assisted (Tick)	Comments (Note level of assistance required and equipment needs)
Mobility			
Personal care			
Toileting			
Eating/drinking			
	Continent (Tick)	Incontinent (Tick)	Comments (Note any equipment/consumables required)
Bladder			
Bowel			

Colour strip

Signature	Name	Designation	Phone/pager	Date

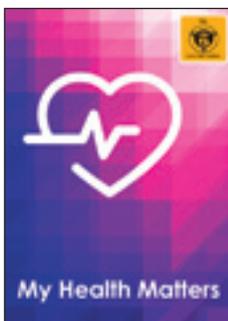
Health passports

Below you can find links to a sample of health and hospital passports.



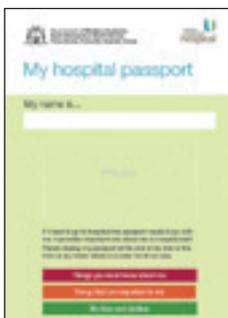
Julian's Key

Visit www.health.qld.gov.au/public-health/groups/disability for more information.



My Health Matters (The Council for Intellectual Disability)

Visit cid.org.au/resource/my-health-matters-folder for more information.



Fiona Stanley Hospital

Visit ddwa.org.au/support-info/health for more information.



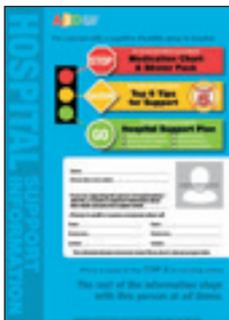
Developmental Disability WA

Visit ddwa.org.au/support-info/health for more information.



Valued Lives

Visit valuedlives.org.au/resources for more information.



Admission2Discharge

Visit a2d.healthcare/resources for more information.



Kalparrin WA Emergency Care Plan

Visit www.kalparrin.org.au/information-resources/resources/?cat=emergency-care-planning for more information.

Hospital booklets

Apps

Visit www.myvoicemyhealth.org.au for more information on My Voice My Health for people with Down Syndrome.

Resources for adults

Visit www.healthywa.wa.gov.au/Articles/F_I/Going-to-hospital for Going to Hospital, Staying Safe in Hospital and Now You Are Home booklets.

Visit www.carerswa.asn.au/our-services/prepare-to-care-hospital-program/carers for a Carers WA Prepare to Care booklet.

Resources for children

Visit ddwa.org.au/resources/theres-no-such-thing-as-a-silly-question for a helpful booklet for parents of children with disabilities on going to hospital.

Visit www.youtube.com/channel/UCKckdFtJzheBpUT7EY-E9Sg/videos for videos for children and health care by the Perth Children's Hospital.

Visit pch.health.wa.gov.au/Our-services/Keeping-Kids-in-No-Distress for more information on the Perth Children's Hospital Keeping Kids in No Distress service.

Easy Read

Visit cid.org.au/resource/going-to-hospital-for-surgery-guide to access the Going to hospital for surgery guide.

Visit www.safetyandquality.gov.au/publications-and-resources/resource-library/find-good-health-information-online-easy-english-booklet for an Easy English booklet on finding good healthcare information online.

Visit cid.org.au/resource/types-of-health-checks-fact-sheet for a Types of Health Checks fact sheet.

Visit www.hconc.org.au/issues/empowering-consumers-with-a-disability for Easy Read resources and information on providing better hospital care for people with disability.

Social stories

Social stories can help you to prepare for going into hospital and when visiting the doctor or GP.

Autism Association WA

Autism Association WA have created social stories for people with autism about health care and dental procedures.

Visit www.autism.org.au/our-services/fact-sheets-autism-2/healthcare for social stories on health care.

Visit www.autism.org.au/our-services/fact-sheets-autism-2/accessing-dental-services for social stories on dental procedures.

Dental Health Services WA

Visit www.dental.wa.gov.au/Publications for more information and resources on going to the dentist for people with autism, including the Maggie goes to the dentist social story.

Perth Children's Hospital

Visit pch.health.wa.gov.au/For-patients-and-visitors/Coming-to-Emergency/Welcome-to-ED for the Welcome to Perth Children's Hospital in multiple different languages.

NSW Government

Visit aci.health.nsw.gov.au/resources/intellectual-disability/hospitalisation/say-less-show-more for more information on health care and dental procedures for people with intellectual disability.

Council for Intellectual Disability

Visit cid.org.au/resource/me-and-my-doctor-guide for more information on things to think about when going to the doctor.

Communication

Communication tools

Visit www.qld.gov.au/_data/assets/pdf_file/0028/58375/medical-signing-board.pdf for an example medical signing board.

Visit www.patientprovidercommunication.org/userfiles/file/1_1MedicalEncounterCommunicationBoard.pdf for an example pictorial medical encounter communication board.

Communication scripts

Using carefully considered, respectful alternatives can change the entire experience of a hospital journey, all the way from admission to discharge. Below are scripts to help communicate needs in a hospital setting.

Pain

Possible staff observation: 'They are not in any pain / they don't seem to be in pain.'

Response: 'He doesn't show pain in the usual way, but we know he's in pain by... (the paleness of his face/clenching of his hands).'

Visit cerebra.org.uk/download/flacc-pain-scale-infographic for an example pain scale.

Understanding

Possible staff observation: 'So she is non-verbal / can't talk / doesn't understand what I am saying?'

Response: 'She is able to understand, she just communicates in other ways, with (Auslan / braille / natural gestures / using her iPad/ visual symbols). If you speak directly to her, I can help explain to her what you mean, or we can use this picture communication symbols board.'

Distress

Possible staff observation: 'You'll have to calm him down/stop this behaviour or take him home/come back another time.'

Response: 'His fear of unfamiliar surroundings is increasing his distress. If we can help him regulate his emotions by doing... (giving him his favourite thing to hold / by distracting him / turning the lights down) he'll be able to co-operate better' or 'We have a positive behaviour support plan that documents strategies to help, I have a copy to share with your team.'

Coping with procedures

Possible staff observation: 'Don't move / stop them moving, I have to insert this canula.'

Response: 'Can I just let her know what is about to happen, and check she is ok with you holding her arm first please?'

Supported shared decision-making and informed consent

Possible staff observation: 'I'll need you to just sign this form for him.'

Response: 'If you can outline the possible risks, I'll explain in a way he can understand, to tell him what we are signing and give him a choice.'

'If you can simplify the language and take a little more time he can decide.'

Visit ddwa.org.au/online-learning-directory/supported-decision-making-course for more information on individualised supported decision-making.

Medication

Possible staff observation: 'I'll just need you to take your tablets now.'

Response: 'We have had a concern in a past admission with a wrong dose / wrong medication / wrong timing. Could I ask if we can cross check before he takes these medications, please.'

Education and training of support people

Possible staff observation: 'If you watch me insert the naso-gastric tube/peg tube a couple of times then you'll be able to do it yourself if it comes out again.'

Response: 'I really feel under prepared to be able to take on a task like this, which needs almost nurse-level training. Can I take a video of how you do it to refer back to later please, and is there someone I can call after discharge to guide me through this?'

Concessions and support

Below are links to information on concessions and supports that may be available.

Parking concession (ACROD)

If you have a walking restriction or are blind, you may be eligible for the Australian Disability Parking Permit (ACROD). Visit www.acrod.org.au/eligibility for more information.

Companion card

If you require support to get around the community, you may be eligible for a companion card. Where the companion card is accepted, you will receive a second ticket for your companion at no extra charge. Companion cards are accepted at many venues including the cinema, leisure centres, sporting and music events, theatres and museums. Visit www.wacompanioncard.org.au/apply-now for more information.

Thermoregulatory Dysfunction Energy Subsidy

If you need to heat or cool your home because of a thermoregulation disability, you may be able to receive a subsidy from the state government. You need a concession card to be eligible. Visit www.wa.gov.au/government/publications/subsidies-thermoregulatory-dysfunction-fs for more information.

Life Support Equipment Electricity Subsidy Scheme

If you need to use life support equipment at home, you may be eligible for this subsidy. You need a concession card to be eligible. Visit www.wa.gov.au/government/publications/subsidies-life-support-fs for more information.

National Disability Insurance Scheme (NDIS)

If you have NDIS funding, you may need to update your plan if your support needs have changed. If you do not have an NDIS plan but think that you would be eligible for a plan, phone 1800 800 110 or visit www.ndis.gov.au to find out more information.

Support for seniors

The Disability Support for Older Australians program supports people over the age of 65.

Visit www.health.gov.au/initiatives-and-programs/disability-support-for-older-australians-dsoa-program for more information.

Visit My Aged Care www.myagedcare.gov.au for more information on other services available for seniors.

Better Access initiative

The Better Access initiative gives Medicare rebates to people living with a diagnosed mental condition. This includes many conditions, such as depression and anxiety.

Support is available from eligible GPs and other medical practitioners, psychologists, social workers and occupational therapists. Eligible people can receive up to 10 individual and up to 10 group allied mental health services each year.

Visit www.health.gov.au/initiatives-and-programs/better-access-initiative#learn-more for more information.

Closing the Gap

Closing the Gap is a plan to reduce disadvantage among Aboriginal and Torres Strait Islander people. If you are Aboriginal or Torres Strait Islander, you may be able to get cheaper healthcare and medications. You can speak with your GP about it.

Visit www.pbs.gov.au/info/publication/factsheets/closing-the-gap-pbs-co-payment-measure for more information.

You can also visit www.servicesaustralia.gov.au/aboriginal-and-torres-strait-islander-health-assessments-and-follow-up-services?context=20 for more information.

Word list

Access card: A card that contains important information about the person, their medical needs and contact details.

Assistive technology: Any products, equipment, aids and systems that enhance learning, working, and daily living for persons with disabilities.

Autism Alert Card: A card that lets emergency services know the person has autism and contains important information about the person and contact details.

Carer: Friends or family who support the person with disability. Carers are people who provide support that is unpaid and not part of a paid work or community work arrangement.

Communication partner: A person who provides communication support. Communication partners may include family, carers and trained disability service workers.

Community participation: The process of assisting the person with disability to participate in the community.

Disability-related health supports: Supports relating to the functional impact of a person's disability, such as respiratory and nutritional supports and podiatry.

Disability service organisation: An organisation that provides support for daily living, support coordination for community participation, therapy services and disability-related health supports.

Disability service provider: A person, business or organisation who delivers disability services. These include support workers, support coordinators and therapists.

Disability supports: Personal assistance and equipment to help a person with disability with their daily living, participate in their community and reach their goals.

Easy Read: Clear, everyday language matched with images. People who use Easy Read may include people with learning or developmental disability, people with low literacy levels and people with English as a second language.

Family: A person or persons who provide support to a family member with disability.

Guardian: A person appointed by the State Administrative Tribunal, under the *Guardianship and Administration Act 1990*, to make decisions for a person with limited decision-making ability. There are different types of Guardianship.

Health Passport: A document used to outline how an individual wants people to communicate with them and support them when using health and disability services.

Informal support: Another name for an unpaid family member, friend or carer.

National Disability Insurance Agency: This is the agency that administers the NDIS.

National Disability Insurance Scheme: The NDIS provide funding for people with disability to access support they need in the community.

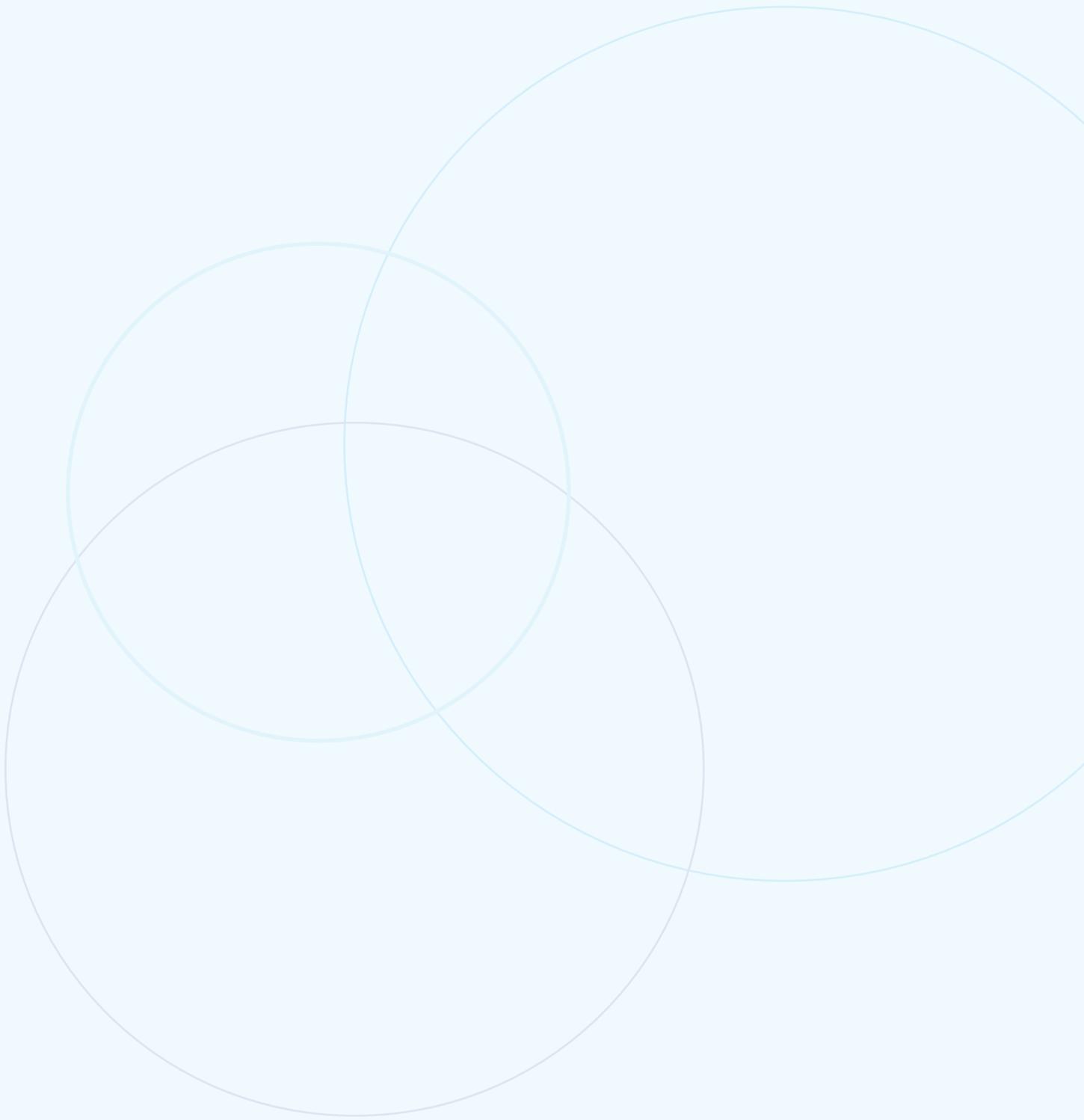
NDIS Quality and Safeguards Commission: Provides registered NDIS services providers with information and education. The commission has regulatory powers for ensuring high quality supports in a safe environment.

Support coordinator: A person funded through an NDIS participant's plan. Their role is to coordinate services and assist the person to build their informal support networks.

Supported accommodation: In-home support for people with high support needs. Examples include supported independent living and specialist disability accommodation.

Support worker: A person employed or otherwise engaged to provide disability supports and services for people with disability.

Therapy: A range of therapeutic services such as physiotherapy, occupational therapy and speech pathology.



This document can be made available in alternative formats on request for a person with disability.

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