



Carers

Information to help people providing support to a family member or friend because of disability, terminal illness, chronic illness, mental health concerns and/or ageing



WORKING TOGETHER FOR A CARER FRIENDLY HEALTH SERVICE

Illawarra Shoalhaven Local Health District values carers as partners in health care and supports the NSW Carers Recognition Act (2010)



Health
Illawarra Shoalhaven
Local Health District



This information
has been tested
with Consumers

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Acknowledgement

Illawarra Shoalhaven Local Health District acknowledges the people of the many traditional countries and language groups of our District. It acknowledges the wisdom of Elders both past and present and pays respect to Aboriginal communities of today.

The Aboriginal artwork is by Robyn Stewart, a descendent of the Yuin Nation. The meaning of the artwork - *The trees and the people represent the spirits of our ancestors who are still with us and looking after us.*

Thank you to Aunty Lindy Lawler and Aunty Eileen Jenner for permission to use their photos in this booklet.

Aboriginal and Torres Strait Islander people are advised that this publication may contain images or names of people who have since passed away.

This booklet has been developed by the **Carer Program, Illawarra Shoalhaven Local Health District** (ISLHD), islhd.health.nsw.gov.au/services-clinics/carers-program

To contact a Carer Program Coordinator please phone:
Illawarra: 4253 4558 or 0421 099 005 Shoalhaven: 4424 6342 or 0422 004 119

Please note that in this period of Aged Care and Disability Services reforms, some of the information in this booklet is likely to change. The information in the booklet is current as of April 2024.

The NSW Carers (Recognition) Act 2010

About one in ten people in New South Wales are carers. All levels of government and the community needs to support carers. The NSW Carers (Recognition) Act 2010 is a law that recognises the important role that carers play in our community. It includes a Carers Charter that describes how staff in our government departments should interact with carers. The Charter has four main sections:

1. Carers make a valuable social and economic contribution to the community.

They should have the same rights, choices and opportunities as other Australians.

We need to respect the knowledge and experience of carers, and the relationship they have with the people they care for.

2. Carers' health and well-being is important.

We need to support carers to have good health and well-being and be able to take part in family, social and community life.

We need to support carers to balance their caring role with other roles, such as working or studying.

3. Carers come from many different backgrounds and have individual needs. These needs can be related to their role as a carer, or to other roles they might have outside of caring.

We need to consider the individual needs of carers in policies, programs and in the way we deliver services. We also need to acknowledge and respect differences in culture, language, age, disability, religion, economic status, where carers live, and their gender and sexual orientation.

We need to respect and value Aboriginal and Torres Strait Islander cultural concepts of caring.

We need to recognise that some carers may face extra challenges, such as living in rural and remote areas. Children and young carers may need extra support to reach their full potential.

4. Carers are partners in care.

We need to consider the individual choices, ideas and needs of carers when we are planning and delivering services for the people they care for. We need to help carers access services and supports when they need it.

Who is a Carer?

You are a carer if you provide ongoing help to someone who needs it. They may have a disability, a mental health concern, or be sick for a long time. They may be getting old or have dementia. They may have drug and alcohol problems. You can be a relative, friend or neighbour who provides this help.

The caring role can be challenging for carers. You may see caring as a normal part of family and community life and may not think of yourself as a carer. This can make it harder to accept help. If you are a young carer you may find it harder to finish your education and get involved in social activities.



"We all share this country either as neighbours, friends or kin and sometimes become the carer for one another. Are you a Carer?"

Caring for someone can involve:

- cooking and sometimes helping to feed the person you care for
- helping the person you look after to shower, go to the toilet and groom themselves
- helping with their medicines and organising medical appointments
- giving medicines to the person you care for
- shopping, cleaning the house and washing clothes
- providing transport
- arranging social activities
- making health and financial decisions for the person you care for
- using equipment and aids to help the person
- arranging services to help
- meeting cultural and religious needs of the person. For example, going to church or community activities

Feelings

You may not feel like you had a choice in being a carer. It may be a family responsibility. Maybe you feel you can provide better care than others. Carers often feel a duty to care. You can become a carer suddenly or gradually. Over time you find you are doing more and more for the person. You may feel satisfaction about being a carer. You may feel overwhelmed, resentful or angry. These emotions can be difficult, but they are normal for carers.

Some of the feelings you might have are:

Shock about:

- the diagnosis, illness or disability
- the changes this will bring to your life
- what it means to you and your family

Guilt about:

- not wanting to be a carer
- thinking it is your fault
- missing out and resenting it
- losing your temper
- needing to have a break from caring
- placing the person you care for into residential care
- cultural idea of blame
- feeling shame

Fear about:

- what will happen if you get sick or die
- what will happen if you can't cope
- what will happen to children you care for
- being judged by others
- getting old yourself



Sadness and depression about:

- loss of a relationship
- loss of the life you used to have
- loss of plans for the future
- how the person you care for has changed

Angry about:

- why the caring role has fallen on your shoulders
- why doesn't the family or community help more
- not having time for yourself
- giving up social activities, education or work

Counsellors can help you to deal with these feelings. Information and Counselling Services can be found on page 9 of this booklet.

Looking After Yourself

Caring can be stressful. Carers often forget about their own health and wellbeing. Looking after someone can be hard work. You can get very tired and worn out. You may be at higher risk of illness or injury. Signs of stress include:

- sleeping too much or too little
- putting on or losing a lot of weight
- feeling tired most of the time
- losing interest in activities you used to enjoy
- getting easily upset or angry
- feeling worried or sad a lot of the time
- drinking alcohol or smoking more than usual
- forgetting things more easily
- not being able to concentrate
- shouting at people

Stress

Worries about money, the health of the person you care for, the future and family life can make you feel stressed. When you are busy looking after someone else it can be hard to look after your own health. It can seem impossible to get a good night's sleep or eat well or do exercise. Eating well and doing exercise will help you cope and improve your mood. Getting enough sleep will give you more energy.

Ideas to manage stress

- Be kind to yourself. No one is perfect. You are doing your best.
- Try to have 10 minutes a day to do something for yourself - even just to read a magazine.
- Share your feelings with friends and family especially if you are feeling angry or frustrated.
- Ask for and accept help. This can be difficult. Friends and family sometimes want to help but don't know what to do and need ideas. Give family directions such as sit and talk with the person you care for while you go for a walk or cook a meal.
- Speak to a counsellor.
- Accept that it may not be possible to do everything you want to do.
- Try not to eat too much junk food.



Looking After Yourself

Carer Gateway

Carer Gateway is the Commonwealth Government service providing support to carers across Australia. The services that are provided are:

- Emergency Respite – can help to organise care for your person, if you have an urgent or unplanned event that means that you are not able to provide care for them for a short time – see Page 18 Taking a Break for further information.
- Counselling – either on the phone or in person
- Coaching – to help you improve your skills in your caring role
- Peer support – connecting with other carers in person or online to share stories, knowledge and experience.
- Financial packages – one-off to buy a small item or to buy support services over a 12 month period to help in your caring role.

You will need to register with Carer Gateway to receive a service. You can do this by phoning [1800 422 737](tel:1800422737). Visit carergateway.gov.au for further information.

Emergency Relaxation Technique

Sometimes taking a deep breath can help calm you down. Try this next time you are feeling stressed

- breathe in and hold your breath for a moment. Do not hold your breath for more than two or three seconds
- breathe out slowly and as you do so, relax your shoulders and hands
- pause for a moment and then breathe in again
- as you breathe out slowly this time, relax your forehead, face and jaw
- stay quiet for a few seconds, then go on with whatever you were doing but move slowly

Relationships

Feeling a lot of stress can be hard on relationships. For example, caring for an elderly parent can place strain on a marriage because of the continual stress experienced by the carer. You may feel like you are not supported by your partner.

Long-term illness or disability can have a big impact on relationships. It can feel like an emotional rollercoaster of anger, guilt, sadness, loss and frustration. For couples it can be very hard. It is important to talk about how you both feel and the changes, including intimacy. Counsellors can help with relationship advice.

Information and Counselling Services

Counselling means talking to someone who listens and understands. Someone who will work with you to support you to improve your situation. There are services you can contact for information and support:

Carer Gateway for counselling and information. **1800 422 737** or visit carergateway.gov.au

Lifeline Crisis Support Line 13 11 14.

Lifeline Text **0477 13 11 14.**

Lifeline Chat lifeline.org.au

Available 24/7.

13 92 76 (24/7) to talk with an Aboriginal or Torres Strait Islander Crisis Supporter.

GriefLine provides free counselling for anyone experiencing grief.

1300 845 745 or visit griefline.org.au

The Disability Gateway has information on service and supports for people with disability. **1800 643 787** or visit disabilitygateway.gov.au

Talk to your **General Practitioner (GP)** about counselling through a **Mental Health Care Plan**

Mental Health Line for information and advice about mental health issues. **1800 011 511** (24/7)

One Door Mental Health ARAFMI Illawarra for support for carers on **0419 513 684** or contact arafmi.carers@onedoor.org.au

STRIDE Family & Carer Program 4229 7254 (Wollongong) or **4422 1547** (Nowra) or visit stride.com.au/who-we-help/family-mental-health-support-services

Mental Health Carers NSW Carer Connections Helpline connects carers of someone with a mental health condition to services and support. **1300 554 660**

Autism Connect is a free, autism helpline. **1300 308 699** or visit amaze.org.au/autismconnect

Dementia Helpline 1800 100 500 24/7 or visit dementia.org.au

Dementia Behaviour Advisory Service (DBMASS) 1800 699 799 (24/7) for managing behaviours in people with dementia or visit dementia.com.au

Parkinsons NSW Infoline 1800 644 189

ISLHD Drug and Alcohol Helpline 1300 652 226 or visit islhd.health.nsw.gov.au/services-clinics/drug-alcohol-service

Men Care Too visit mencaretoo.org

Mensline 1300 789 978 or visit mensline.org.au

Open Arms for counselling to anyone who has served in the Australian Defence force, and their families. Phone **1800 011 046** (24/7) or visit openarms.gov.au

ISLHD Multicultural Health and Refugee Health Service 4221 6770 or islhd.health.nsw.gov.au/services-clinics/multicultural-health

The Translating and Interpreting Service (TIS) can help you connect to services if you speak a language other than English. Contact TIS on **13 14 50**

1800RESPECT National Domestic Family and Sexual Violence Counselling Service, **1800 737 732** (24/7) or visit 1800respect.org.au

Gay & Lesbian Counselling Service of NSW QLife Helpline **1800 184 527** 3pm to 12am.

Young Carers. Visit carersnsw.org.au/services-and-support/programs-services/young-carers or youngcarersnetwork.com.au for information on support and services for young carers

Well Mob. Social, emotional and cultural wellbeing online resources for Aboriginal and Torres Strait Islander People. Visit wellmob.org.au

Eating Disorders Family Australia (EDFA) provides support, education, advocacy, and counselling for carers and families. **1300 195 626** or visit edfa.org.au

Money Matters



Caring can affect your finances. You may have to give up work or reduce your hours. There may be extra costs, for example, medication, equipment, specialist appointments.

Financial help for carers is available through Centrelink (Services Australia).

- For the Carers, Sickness and Disability Information Line call [132 717](tel:132717)
- an Indigenous Service Officer can give you and your community information about government payments and services. Contact the Indigenous Call Centre on [1800 136 380](tel:1800136380)
- to speak to someone at Centrelink in another language call [131 202](tel:131202)
- Hearing and Speech Assistance TTY FreeCALL [1800 810 586](tel:1800810586)

Financial Information Service

A free service that can inform and educate you about financial matters. To speak to an officer over the phone or to make an appointment phone [132 300](tel:132300).

Aged Care Specialist Officer

A free service to help with information and making referrals to aged care services and providing financial information on aged care services. To book an appointment call [1800 227 475](tel:1800227475).

Types of financial help through Centrelink:

servicesaustralia.gov.au

Carer Allowance

To receive this income supplement, you and your partner's combined taxable income has to be under \$250,000 each financial year. This is paid on top of Carer Payment or any other income you earn. If you care for a child under 16 years and get a Carer Payment you will get the Carer Allowance too. You don't have to live with the person to get this allowance.

Carer Payment

Is an income support payment for carers who can't work while caring for an adult or child. This payment has an income and assets test. You are able to work up to 25 hours per week and still receive some carer payment.

Disability Support Pension

For people who can't work fulltime for at least two years because of a disability.

Concession cards

The Pensioner Concession Card and Health Care Cards. You or the person you care for may be entitled to a card. These cards can get you a discount on car registration, transport, medicines and power bills.

Rent Assistance

For people who pay rent for private accommodation, or some social housing and also receive payments from Centrelink.

Carer Gateway

Carer Directed Financial Support - Financial Packages can be directed towards a range of practical supports to assist you in your caring role. Contact Carer Gateway on [1800 422 737](tel:1800422737).



Advocacy

If you need general information and advice about your financial entitlements or wish to appeal a decision you can contact the:

- Welfare Rights Centre [1800 226 028](tel:1800226028) or visit welfarerightscentre.org.au
- The Illawarra Legal Centre Welfare Rights Service covers the Illawarra and Shoalhaven [4276 1939](tel:42761939) or visit illawarralegalcentre.org.au
- Legal Aid provides a range of specialist services including the Social Security Service, Mortgage Hardship Service, and the Work and Development Order Service Wollongong [4228 8299](tel:42288299) Nowra [4422 4351](tel:44224351) legalaidnsw.gov.au
- Law Access [1300 888 529](tel:1300888529) for legal information, help you plan your next step and connect you with services that can help you. Visit legalaid.nsw.gov.au

Other Financial Help:

NSW Companion Card

For people with a lifelong disability who need a carer to come with them to events. The Companion Card gives free entry to the Carer to many places. Call [1800 893 044](tel:1800893044) to apply or visit nsw.gov.au/community-services/companion-card

Saver Plus Program

Can help you with education costs for your children. Phone [1300 610 355](tel:1300610355) or visit thesmithfamily.com.au/programs/financial/saver-plus

Energy Rebates

For information on Energy Rebates visit energy.nsw.gov.au/households/rebates-grants-and-schemes/find-energy-rebate

Services NSW Ph: 13 77 88

Savings Finder Service

A service to help you find and apply for rebates, vouchers and discounts that you may be eligible for. To book an appointment go to service.nsw.gov.au/transaction/book-a-savings-finder-appointment or you can visit a Service NSW Centre.

Transport Concessions

There are a number of rebates and concessions related to travel and transport. Go to service.nsw.gov.au/guide/carers#travel-concessions or visit a Service NSW Centre.

Continence Payment

The Continence Aids Payment Scheme (CAPS) can help pay for continence products. People need to have permanent and severe incontinence. You can call the CAPS Team on [1800 239 309](tel:1800239309) or visit health.gov.au/initiatives-and-programs/continence-aids-payment-scheme-caps. Call the National Continence Helpline on [1800 33 00 66](tel:1800330066) for information and advice about continence issues.

Department of Veteran Affairs (DVA)

Provides financial help and services to veterans, war widow(ers), their families and carers. Call DVA on [1800 838 372](tel:1800838372) or visit dva.gov.au

Special Disability Trusts

A trust can be set up for people with a severe disability for their future care. You may need to seek legal and financial advice as the rules are complex. Contact the Services Australia Special Disability Trust Team on [132 717](tel:132717) or visit servicesaustralia.gov.au/special-disability-trusts

Young Carer Bursary Program

Provides a 12 month scholarship for young carers aged between 12 and 25 years to help them stay in education. Applications open in July each year. Further information can be found by contacting: youngcarersnetwork.com.au/young-carer-bursary

Planning Ahead

When caring for someone planning ahead is important. This means making plans for your future in case you can't make decisions for yourself about your belongings, money, where you live and health care. You can also have a say about medical treatment near the end of life. This is also important when you are looking after someone so you can follow their wishes when they can't communicate them to you. Refer to page 25 for further information.

4 Ways to Plan ahead – you can make a:

1. Will – Who will get my things when I die?

2. Power of Attorney – Who will make decisions about money if I can't?

3. Enduring Guardian – Who will make decisions about my health and where I live if I can't?

4. Advance Care Planning – What medical treatment and care do I want in the future?

1. Making a Will

A will is a legal document that says who you want your things (your money, property and belongings) to go to after you die. You have to be over 18 years to make a will. If you don't have a will it can cause delays and problems. It is a good idea to keep your will up to date. If there are changes in your life, such as getting married, divorced or having children, you should think about doing a new will.



2. Power of Attorney

A Power of Attorney is a legal document that you sign that gives another person (called your attorney) the power to look after your money (financial affairs) and property if you can't do it yourself. It needs to be someone you trust who will act in your best interest.

It is best to make your Power of Attorney an **Enduring Power of Attorney**. This means the person you appoint will be able to make decisions for you even when you have lost the ability to make your own decisions. This is called 'losing capacity'.

3. Enduring Guardianship

An Enduring Guardian is someone you choose to make medical, personal or lifestyle decisions on your behalf when you are not able to do so. For example, where you live, what health care or support services you receive.

Wills, Power of Attorney and Guardianship papers can be done with a solicitor. It is a good idea to ring around as prices can vary. You can also get your own documents and the Enduring Power of Attorney and Guardianship forms can be witnessed and signed by a Registrar of a local court for free. You will need to ring your local court and make an appointment and complete the form before you go.

The NSW Trustee and Guardian will prepare the above documents for free for people eligible for a full Centrelink Age Pension.

4. Advance Care Planning

An Advance Care Directive states your wishes for health care and treatment in the future when you are not able to communicate or can no longer make the decision yourself. It helps doctors and health staff know what your wishes are.



It is important to think about and talk with people close to you about how you would like to be treated in the future if you cannot speak for yourself at the time. This may happen if you have a progressive condition like dementia or become too ill to communicate. Talking early with your family helps you raise sensitive issues about your future care. Give copies to your GP and to anyone who may be called on to make decisions on your behalf in the future. You can bring a copy with you if you have to go to hospital. This can go in your medical record.

My Health Record is an Australian government secure online summary of your health information and it can include your Advance Care Plan.

Where to go for information:

- NSW Trustee and Guardian
1300 364 103 tag.nsw.gov.au
- Illawarra Legal Centre 4276 1939
- Shoalcoast Community Legal Centre (Shoalhaven) 1800 229 529
- Legal Aid legalaidnsw.gov.au
Wollongong 4228 8299
Nowra 4422 4351
- Law Access
1300 888 529 legalaid.nsw.gov.au
- Carer Gateway
1800 422 737 carergateway.gov.au
- My Health Record digitalhealth.gov.au/initiatives-and-programs/my-health-record or phone 1800 723 471
- National Advance Care Planning Support Service 1300 208 582
- Advance Care Planning Australia
www.advancecareplanning.org.au
- For a copy of the NSW Health Making an Advance Care Directive booklet
health.nsw.gov.au/patients/acp/Publications/acd-info-form-book.pdf
- For Aboriginal Planning Ahead resources visit tag.nsw.gov.au/wills/make-will/wills-aboriginal-people

Help at Home and in the Community

You and the person you care for can get help at home and in the community. There are many different types of services. As a carer you may need to speak with different services to get the help you and the person you care for need. When you first start looking for help it can be overwhelming. Many of the services use words that sound like a whole new language. Ask lots of questions.

Sometimes it is hard to take the first step and ask for help. It is a good idea to think about the sort of help you need.

Getting help when you are aged over 65 years or over 50 years for Aboriginal and Torres Strait Islander people

My Aged Care is a one stop shop for aged care services and information. You can find out about these types of services and how to get them. This includes services in the community and residential aged care.

To receive a government subsidised service, you must contact **My Aged Care** to register your details. You will then be contacted by a local assessment agency. An assessor will make a time to speak to you about the types of help you and the person you care for need to live safely and well at home. They may assess you as needing one or two services (Commonwealth Home Support Program – CHSP) or needing a package of services (Home Care Package – HCP).

Some people need extra help to access aged care services or other supports. This could be because of language, or they don't have family to help them. They may be able to get a free government service called Care Finders to help them. More information can be found at myagedcare.gov.au/help-care-finder.

Carer Gateway

The Carer Gateway is a national service for all carers. It provides information and access to services for people caring for another person. They offer online education, coaching, peer support, counselling, emergency respite, and limited financial support packages. They have practical advice and health information. You can get help to find local support services.

Call **1800 422 737** from Monday to Friday 8.00am to 5.00pm or visit carergateway.gov.au

Carers NSW

Carers NSW is the peak body for carers in NSW. They support all carers. They provide information, education and support. It is free to join if you are a carer and you will get a newsletter to keep you up to date with new services and programs.

You can call on **9280 4744** Monday to Friday 9.00am to 5.00pm or visit carersnsw.org.au

My Aged Care can be contacted on **1800 200 422** Monday to Friday from 8am to 8pm and Saturday from 10am to 2pm or visit myagedcare.gov.au





Home Care Packages includes a wide range of services and supports. For example, dressing, meals, cleaning, shopping, equipment, and home modifications. Also clinical services like nursing, and physiotherapy.

When you speak to an assessor or service provider be clear in telling them what your situation is. Don't pretend things are easy if they are not. They make decisions on what you tell them. Tell it like it is and be prepared to be insistent.

Costs – It is important to ask how much a service will cost. Some of the costs can be paid by the government. You can ask if the cost can be reduced if you believe you can't pay. Information on service costs can be found at myagedcare.gov.au

Short-Term Restorative Care (STRC) Program provides a package of services and therapy for up to 8 weeks. It is for older people living at home.

From 1 July 2025, a new program called **Support at Home** will replace the Home Care Packages (HCP) Program and Short-Term Restorative Care (STRC) Program. The Commonwealth Home Support Programme (CHSP) will move to the Support at Home Program in July 2027. Further information can be found at health.gov.au/our-work/support-at-home

Department of Veterans' Affairs (DVA)

If you are a Gold Card or White Card holder, DVA provides a variety of Aged and community care programs

Phone [1800 838 372](tel:1800838372) or visit dva.gov.au

Getting help when you are aged under 65 years

The Disability Gateway has information and services to help people with disability, their family, friends and carers, to find the support they need in Australia. Call [1800 643 787](tel:1800643787)

Mon to Fri, 8am to 8pm or visit

disabilitygateway.gov.au



The National Disability Insurance Scheme (NDIS)

provides support for people with disability aged under 65 years. To get help under the NDIS the person must:

- have a permanent impairment that significantly affects their ability to take part in everyday activities, or have a developmental delay
- be aged less than 65 when they first apply to enter the NDIS
- be an Australian citizen, hold a permanent visa or a Protected Special Category visa

For more information on the NDIS and to see if the person will be eligible for any services contact the NDIS on [1800 800 110](tel:1800800110) or visit ndis.gov.au

If eligible for the NDIS, a Local Area Coordinator (LAC) can help you develop a plan for funding. They can also help to connect you to other services if you are not eligible for the NDIS. Contact Uniting on [4253 6580](tel:42536580) (Wollongong), [8833 0561](tel:88330561) (Shellharbour) or [4488 1600](tel:44881600) (Nowra) or visit lac.uniting.org/home

Help at Home and in the Community

Early Childhood Approach (0-8 years)

For carers of young children aged under 9 years the NDIS provides support through the early childhood approach.

The early childhood approach supports children who have a developmental delay or disability and their families/carers.

The early childhood approach supports families to help children develop the skills they need to take part in daily activities and find the right supports to enable them to have the best possible start in life.

For more information contact the NDIS on [1800 800 110](tel:1800800110) or visit [ndis.gov.au/understanding/families-and-carers/early-childhood-approach-children-younger-9](https://www.ndis.gov.au/understanding/families-and-carers/early-childhood-approach-children-younger-9)

Safe and Supported at Home (SASH) Program

provides clinical and non-clinical supports up to 6 weeks at a time for people between 18-64 years of age with functional impairment who are not eligible for the NDIS. Local Health District Outpatient clinics and community services can refer you to this program.

Advocacy

If you have a problem with a service you receive or are not happy with any of the decisions made you may be able to get help to sort out your concern. The following services may help you:

NSW Ageing and Disability Commission

To get information or make a report about the abuse, neglect and exploitation of adults with disability and older people living in their home and in the community call the Helpline [1800 628 221](tel:1800628221) Mon to Fri 9am to 4pm or visit ageingdisabilitycommission.nsw.gov.au

Commonwealth Ombudsman

If an Australian Government agency has treated you unfairly or unreasonably, the Ombudsman may help you find a solution. The service is free and independent. Call [1300 362 072](tel:1300362072) Mon to Fri 10am to 4pm or visit ombudsman.gov.au

Disability

Illawarra Advocacy – phone [4229 4999](tel:42294999) or visit illawarraadvocacy.org.au

People with Disability – phone [1800 422 015](tel:1800422015) or visit pwd.org.au

NDIS Quality and Safeguards Commission – phone [1800 035 544](tel:1800035544) Monday to Friday 9am to 5pm or visit ndiscommission.gov.au

Council for Intellectual Disability – phone [1800 424 065](tel:1800424065) Monday to Friday 9am to 5pm or visit cid.org.au

Multicultural Disability Advocacy Association – phone [1800 629 072](tel:1800629072) or visit mdaa.org.au

Intellectual Disability Rights Service (IDRS) – phone [9265 6300](tel:92656300) or visit idrs.org.au

Synapse – Advocacy for people directly impacted by brain injury or disability. Phone [1800 673 074](tel:1800673074) or visit synapse.org.au/our-services/support-services/advocacy

Spinal Cord Injuries Australia – Advocacy for people who have a spinal cord injury or other disability. Phone [1800 819 775](tel:1800819775) or visit scia.org.au/advocacy-policy

Shoalhaven area only, The A.C.T Disability, Aged and Carer Advocacy Service (ADACAS) can be contacted on [02 6242 5060](tel:0262425060) or visit adacus.org.au

Aged Care

Seniors Rights Service – free legal advice and aged care advocacy for people using, or intending to use, in-home and residential aged care services. Phone [1800 424 079](tel:1800424079) or visit seniorsrightsservice.org.au

Aged Care Quality and Safety Commission – phone [1800 951 822](tel:1800951822) Monday to Friday 9am to 5pm or visit agedcarequality.gov.au

Shoalhaven area only ADACAS – see Disability above.



NSW Fair Trading

Provides free information about rights and responsibilities when buying goods and services through a NDIS or Home Care package. They can help with resolving complaints with a trader.

Contact NSW Fair Trading on 13 32 20 Monday to Friday 8.30am to 5.00pm or visit fairtrading.nsw.gov.au

Equipment and Assistive Technology

National Equipment Database (NED) has information on aids and equipment and assistive technology to help people remain independent. Items can be purchased from the site. Visit askned.com.au or phone 1300 885 886, 9.30am to 2.30pm Mon to Fri.

The Aids and Equipment Program provides help with equipment such as wheelchairs, consumable products, ventilators and prosthetic limbs to eligible people. Phone ENABLE NSW on 1800 362 253 or visit enable.health.nsw.gov.au

Funding for aids and equipment may also be available through programs such as My Aged Care – for Goods, Equipment and Assistive Technology (GEAT) and Home Care Packages, or the NDIS. Assessment and recommendations will be needed from an Allied Health Professional such as an Occupational Therapist.

Living Connected helps older people use digital technology to stay connected. They provide help and support in getting, learning about and using IT systems. Phone 0409 753 808 or visit livingconnected.org.au

Transport

The Taxi Transport Subsidy Scheme provides half price taxi vouchers for over school aged people who can't use public transport because of a severe & permanent disability. Phone 13 77 88 or visit service.nsw.gov.au/transaction/apply-taxi-transport-subsidy-scheme

Isolated Patients Transport and Accommodation Assistance Scheme (IPTAAS)

This can help with the cost of travel and accommodation when a patient needs to travel more than 100km or 200km combined per week for specialist medical treatment. Phone 1800 478 227 or visit iptaas.health.nsw.gov.au

Transport for Health – pending availability, provides transport to medical appointments in the Illawarra for people who cannot use public transport and can't afford taxi transport. Phone 4223 8504

Mobility Parking Scheme provides special parking conditions for people with a mobility disability. You can apply at a Service NSW Centre. Phone 13 77 88 or visit service.nsw.gov.au/transaction/apply-for-replace-or-renew-a-mobility-parking-scheme-permit-individual

Community Transport provides affordable and reliable community transport to eligible people in the Wollongong, Shellharbour and Shoalhaven areas who find it hard to use public or private transport. Transport can be individual, group or taxi vouchers.

Phone 1300 987 422 for Wollongong and Shellharbour LGAs or visit ctws.com.au. Phone 1300 411 345 for the Shoalhaven or visit cccs.org.au

Working Carers

Information on working and caring can be found at the Carer Gateway. Visit carergateway.gov.au/working-while-caring

Also visit carersnsw.org.au/services-and-support/advice-for-carers/paid-work or contact Carers NSW on 9280 4744

Taking a Break

Caring can be exhausting. Taking a regular break can help to manage stress. These breaks are called respite. You can get respite from your family and friends helping you and the person you care for. There are also services that can give you respite. Breaks can be good for the person you care for. They meet other people and have some social time.

It is a good idea to have regular breaks from caring. There are different types of respite services that help you have a break. This could be for a few hours a week or for a few days. If you are looking after an older person some of the local Residential Aged Care Facilities provide respite for up to nine weeks a year.

Respite does not always mean being away from the person you care for. Some services can support you to do an activity with the person you care for.

You might have your own ideas about the type of respite you would like or the type of help that will reduce your stress. Some services are for people from particular language groups or cultures.

It is important to plan ahead so you have the best chance to get the service at a time that suits you. Don't wait until you can no longer cope. You might want to plan a regular break or just have one-off support. It is good to find out about the different services to find one that suits you.

To access respite care, for people aged over 65 years or over 50 years for Aboriginal and Torres Strait Islander people, you will need to contact My Aged Care (MAC) on [1800 200 422](tel:1800200422). For people under Department of Veteran Affairs respite may be available under DVA. Phone [1300 550 450](tel:1300550450) or visit dva.gov.au/get-support/health-support/care-home-or-aged-care/services-support-you-home/respice-care

A person under the NDIS might use funding in their plan to include respite.

To find out about respite options contact the Carer Gateway. They can give you information about the respite options in your local area.

Help in Emergencies

Sometimes emergencies can happen with carers which means you need urgent help with supporting the person you care for. You might get sick or there is a death in the family. Emergency respite to look after the person you care for can be arranged through the Carer Gateway. This usually just for a short time.

If you are caring for someone, it makes sense to plan for an emergency. An emergency care plan records all the important information in one place, making it easier for someone to take over from you in a hurry.

Contact the Carer Gateway on [1800 422 737](tel:1800422737) or visit carergateway.gov.au for help with respite or emergency plans.

For a person under the NDIS, this might mean:

- joining a new community group.
- having a short stay out of home to try new things, make new friends or develop new skills.
- temporary periods of extra personal supports so that the participant can remain at home when families and/or carers are not available.
- support to participate in community activities, resulting in a break for carers.

Carers' Guide to the Hospital and Community Health Services

NSW Health is now recording the carer details in the patients' medical record.

How can Carers help health staff?

- Tell staff you are the Carer
- Provide your contact details to health staff and make sure they are included and correct in the patient's medical record.
- You can do this at admission, in the emergency department or on the ward or outpatient service.
- If you are admitted as a patient, you should let staff know you are a carer and if you need help to arrange emergency respite for your person.
- Check the patient's wishes about sharing their information with the Carer is noted in the medical record.
- Providing the name and contact details of other people involved in making decisions about the patient, such as, the guardian, spouse or partner when the patient can't provide the details themselves.

Important

It is important that patients, families or carers let Health staff know if you get help from the NDIS or Aged Care Services when you come to Emergency or other Health Services. This will help Health staff plan your health care and discharge planning.

Handy Tip

If you or the person you care for need an Interpreter, please let our staff know. They can book one in your preferred language or help communicate with a deaf person. It is health policy that we don't use family or friends to interpret.



Are you worried about a change in the condition of the person you care for when in hospital? REACH out in 3 easy steps:

1. Talk to the nurse looking after them.
2. Ask to speak to the nurse in charge and request a "Clinical review".
3. If there is no response in 30 minutes or you are still concerned, call the emergency number using the ward phone and say "This is a REACH call" then say the patient name and ward they are on. The emergency number will be listed on the wall or phone near the bed.

You can ask staff for more information about the REACH program

Carers' Guide to the Hospital and Community Health Services

In the Emergency Department (ED)

When you first come into the Emergency Department (ED) a nurse will assess the medical condition of the person you care for. This is called triage. They will give them a triage number. In ED the sickest people are always seen first. If you are worried about anything or need an interpreter please let the triage nurse know.

- It is important to tell staff that you are the carer.
- Let the ED staff know any important information about the person you care for. For example, medical history, medications, behaviour issues.
- Bring all the medications they are taking, with you to hospital. It is a good idea to have a current list of medications which you can get from the local doctor or chemist.
- If you are sick and going to ED for yourself let the nurse know that you are a carer. If the person you care for can't be left alone they can call someone to help with organising emergency respite.

On the Ward

If the person you care for needs to stay in hospital, introduce yourself as their carer to the nursing and medical staff.

As the carer you will need to talk with the staff to give and receive information about the person you care for. Staff will usually check this is OK with the person you care for first. If the patient can't give their OK (they may have dementia or another condition that affects their ability to make decisions) the staff will need to work with you to understand and support the person you care for.

Some of the ways you can communicate with staff:

- Ask to speak to the nurse in charge of the room. They can help you contact the doctor who looks after the person you care for.

- Ask when bedside rounds happen. This is when the treating team (doctor, physiotherapist etc) visit each patient's bed to talk about their plan of care. You can be there to hear this or give information.
- Ask when the nursing shifts change. This is when the nurses hand over information about each patient to the next shift. You can be there to listen or give information.
- Ask to speak to the social worker. They can give you practical help and personal support and speak on your behalf if needed.
- Ask if you can have a family conference with the team treating the person you care for to talk about their care. Sometimes this is arranged before the patient goes home.
- If you do not understand something, ask staff to explain it to you.
- You can use the Patient My Care Board located near each bed to communicate with staff.

Who's Who in the Hospital

Carers can meet many staff in hospital and outpatient clinics. Each of these staff have special skills. You as the carer also have important knowledge and skills in caring for your person.





Doctors

- Patients are admitted to hospital under the care of a specialist.
- Doctors training to be specialists are called registrars. They supervise the junior doctors (residents and interns) who do the day to day work of the treatment plan which is developed by the specialist.
- The registrar is usually the one to speak to about the patient's treatment plan.
- The person you care for may be asked for their permission to have student doctors and nurses present when the doctor is doing their check-up. If they can't give it, the carer should be asked.

Nurses

Nurses can help explain the illness and teach patients and carers how to follow treatments at home. There is a team of nurses who provide the day to day care and treatment of the patient.

- The Nurse Unit Manager (NUM) is the nurse in charge of the ward and overall patient care. They can help with any questions you have about the person you care for. They are the best person to talk to if you have any patient related worries.
- The Registered Nurse (RN) is the senior nurse in charge of the patient's room. They can follow up your questions and make referrals to other staff.
- The Discharge Planner is a nurse specialist who helps to plan the patient's return home. They can refer to community services if needed.

Allied Health Staff

- **Social Workers** can give you information and practical and personal support. They also speak on your behalf when needed. They are a good contact to help you understand what is happening and connect with the rest of the treating team.

Checklist for Carers

Asking questions can help you get the information you need:

- ✓ What is the cause of the illness or condition?
- ✓ How will they treat the condition?
- ✓ What is the likely progression of the illness or condition?
- ✓ What medicine do they need to take?
- ✓ Do they need to have more appointments?
- ✓ What ongoing care is needed?
- ✓ Who will provide this care?
- ✓ When will they leave hospital?
- ✓ Will transport be provided?
- ✓ Is any equipment or change to the home needed?
- ✓ What support services are there in the community?
- ✓ Who do I contact if I need follow up advice or support?
- ✓ How do I access an interpreter?

- **Occupational Therapists (OT)** focus on improving the way patients can manage their day to day activities. This includes returning to work, using equipment and adapting the home if changes to the home are needed.
- **Physiotherapists** work on improving patient's movement, balance and muscle strength.
- **Dieticians** advise on diet and nutrition.
- **Speech Pathologists** work with patients who have speech or swallowing problems.
- **Pharmacists** help with understanding and managing medications in hospital and the home.
- **Podiatrists** treat conditions of the feet and lower legs.
- **Psychologists** can assess the patient's memory and thinking. They can also help them and their families with adjusting to the illness, anxiety and depression.

Carers' Guide to the Hospital and Community Health Services

Other Staff

- **Chaplains** are there to provide spiritual support to people in times of crisis, anxiety, suffering, grief, loss and death. You can ask to see a Chaplain or spiritual support person from your religion.

- **Principal Aboriginal Health Workers (PAHW)** provide support to Aboriginal and Torres Strait Islander patients and their families in our hospitals in the Local Health District.

A Principal Aboriginal Health Worker can be contacted by phoning the Social Work Department at

Wollongong Hospital on [4253 4501](tel:42534501)

Shoalhaven Hospital on [4428 7624](tel:44287624)

or you can let ward staff know you would like to speak to the Principal Aboriginal Health Worker.

An Aboriginal Family Room is located at Wollongong Hospital, on Level 7, Block C West. The Aboriginal Family Room provides a culturally safe space for families to gather and have a break. There are tea and coffee facilities, microwave, fridge and TV. You can get information about health care and local Aboriginal community services.

Going Home from Hospital (Discharge)

It is important to be involved in the care plans for going home from hospital. This is called **discharge planning or transfer of care**.

- Find out as soon as possible, how long the person you care for is expected to be in hospital. Then you too can plan.
- Ask what care they will need after they come home. You can then prepare your home or other accommodation for them.
- Let nursing staff know if the person you care for is getting services at home. Ask staff to let the services know when the person is ready to go home.
- If the person needs help at home they may be able to get a short term package of care.



Ask about this **before** they leave hospital.

- **ComPacks** – up to 6 weeks of services to help people after they come home from a public hospital.
- **Transitional Aged Care** – up to 12 weeks of therapy and services for people aged over 65 years or over 50 years for Aboriginal and Torres Strait Islander people. This is also available from private hospitals.
- If the person you care for is going to a hospital in another area social workers can contact the other hospital and let them know what the person you care for needs.

Community Health Services

There are a number of health services in the community. For example Asthma Service, Cardiac Rehabilitation, Community Nursing, Women's Health and Child and Family services.

There are Aboriginal Health Workers located in community health centres across the area.

The Aboriginal Chronic Care Unit (ACCU)

helps Aboriginal people with, or at risk of, developing chronic health conditions. If you have a long-term health condition and have been in hospital you will receive a phone call from a health worker with 2 days. This is called "48 Hour Follow Up service".

The Virtually Enhanced Community Care (VeCC)

team supports people with life-limiting chronic illness, including providing end of life care. This service helps people to stay healthy and comfortable at home. VeCC is a free service and includes both face-to-face and virtual care. The team includes Nursing and Allied Health staff.

To contact a community health service (including VeCC) call the Illawarra Shoalhaven Access and Referral Centre (ARC) on [1300 792 755](tel:1300792755). For more information on community health services visit isldh.health.nsw.gov.au/services-clinics/community-health-services

Grand Pacific Health has an Integrated Team Care Program for people from Aboriginal and Torres Strait Islander background. It can help people living with one or more chronic illnesses. Contact [1800 879 096](tel:1800879096) or [4448 2203](tel:44482203).

Grand Pacific Health also provides a number of other community health services. Visit gph.org.au for further details.

You may be able to access **Allied Health Services** via your general practitioner (GP) under a Chronic Disease or Mental Health Care Plan.

There is also the **Multicultural and Refugee Health Service** who have workers that speak various languages. Visit isldh.health.nsw.gov.au/services-clinics/multicultural-health.

The **Health Care Interpreter Service (HCIS)** can provide interpreters for health appointments. The HCIS can be contacted on [1800 247 272](tel:1800247272).

The **NSW Health Pathology Service** provides a Home Collection Service if you need blood tests done. Contact [1300 788 944](tel:1300788944).

If you have private health insurance, check what your insurance covers. You may be able to get help in the community.

Transition Care Service

Young people (14-25 years) with chronic health conditions who need complex case coordination to transition to adult specialist health services. Visit aci.health.nsw.gov.au/networks/transition-care/service for information.

Community Mental Health Services

A number of mental health services are located in the community providing assessment and treatment for people with mental health issues. To be directed to the right service contact the Mental Health Line on [1800 011 511](tel:1800011511).

Palliative Care Services

When an illness cannot be cured, Palliative Care is available to help manage symptoms and provide support to patients, their carers and families. Palliative care services are here to support you at every stage of your illness. This is from the moment of diagnosis, through the changes in your condition, to the final days of life and beyond to the bereavement support for your carers and family.

Palliative Care teams include doctors, nurses, allied health staff, volunteers and support staff. They provide free services to people in hospital and at home.

The ISLHD Community Palliative Care Service can be contacted on [1300 068 458](tel:1300068458). Community Palliative Care nurses are available from 6am to 11pm, 7 days a week. Between 11pm and 6am you will be given an option to leave a message if you would like one of our nurses to contact you after 6am or you can speak to someone from Healthdirect.

For more information on ISLHD Palliative Care Services go to isldh.health.nsw.gov.au/services-clinics/palliative-care-service

CarerHelp supports carers to learn what to expect, communicate, plan ahead, and make shared decisions when caring for a relative or friend at the end of their life. Further information can be found at carerhelp.com.au

Voluntary Assisted Dying - Voluntary assisted dying means an eligible person can ask for medical assistance to end their life. They must also be experiencing pain and suffering that they find unbearable. Further information can be found at health.nsw.gov.au/voluntary-assisted-dying/Pages/default.aspx

Patient Information and Privacy

When can health staff share information with a Carer?

Information the health service has about a patient's health care is covered by privacy laws. A patient's right to privacy is very important and is protected by these laws.

Health staff may need to talk to the Carer about the patient in order to know how best to help them. Talk with the person you care for about sharing health information. It is important to know what their wishes are and that they understand why health staff may need to talk to you.

A patient can tell health staff it's OK to speak to you. The staff member should make a note in the patients' medical record. Health staff can talk to the Carer about the patients' health information if it's to do with their ongoing care and treatment.

Health staff need permission from the patient to be able to speak to the Carer on matters that do not directly relate to the patients care and treatment. For example, for information to be given to the Carer for making an insurance claim or to ask the Carer to pass on information about the patient to an employer, relatives or friends.

If a patient says it's not OK, information can't be given except in special situations. For example under the Mental Health Act or where sharing the information is needed to stop a serious threat to the health or safety of the patient, the Carer or another person.

Sometimes when a patient has more than one Carer, health staff may speak with all Carers about the patients' health unless the patient has said that's not OK. Staff and Carers can work together to help the patient in hospital and when they return home. If the patient and/or Carer has a specific request about the role of the Carer, you can ask for this to be included in the patient's medical record.

What if the patient can't give permission?

Some patients can't say it's OK for staff to share information. They may be too sick, or are unconscious. They may have a severe intellectual disability or dementia.

If the patient is not able to make decisions about their own health care, staff can share the patient's health information with a Carer if it is related to the patient's care and treatment and does not go against what the patient wants.

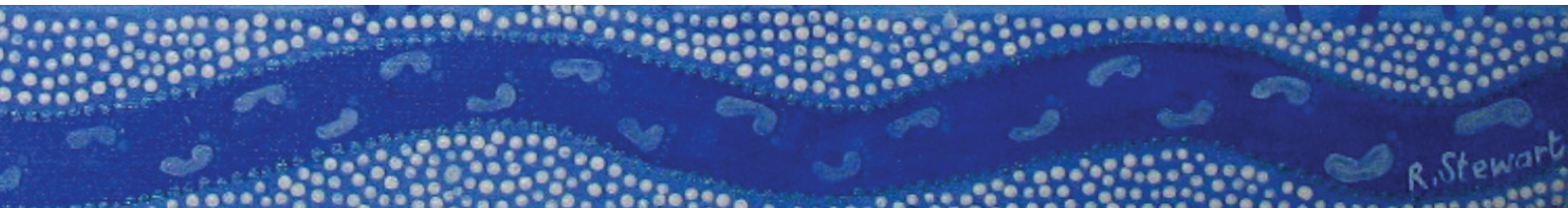
Health staff can't share information with the Carer for other reasons unless the Carer is the "Authorised Representative" or permission is given by the patients' Authorised Representative.

An Authorised Representative can make decisions about who can have health information about the patient when they can't do it themselves. An Authorised Representative can be:

- The patient's spouse, or partner
- Enduring Guardian
- Legal Guardian

If there is no spouse, partner or legal guardian, the Carer may be the patient's Authorised Representative. If you are not sure if you can act as the Authorised Representative, talk to the patient's treating clinician.

Carers can get help from a Social Worker, the ISLHD Privacy Officer, Aboriginal Health Worker, the NSW Civil and Administration Tribunal, who can appoint a legal guardian (who may also be the Carer) or the Ageing and Disability Commissioner.



What about children and young people?

Usually, the Carer of a child or young person under the age of 16 years will be their parent or legal guardian. Most of the time, health staff will be able to share information about the child or young person with the parent or legal guardian.

Sometimes a young person aged 14 to 16 years does not want to share information with their Carer even if they are their parent or guardian. Health staff have to consider a young person's right to privacy. This is a sensitive matter and you may need to talk to health staff and the Privacy Contact Officer.

What about young Carers?

Children and young people may be Carers and may also get information about the patient from health staff.

Health staff will need to consider if the information they are giving, and how they give it, is right for the age of the Carer.

Visit www.carersnsw.org.au/services-and-support/programs-services/young-carers for further information.

What if the patient has a mental illness?

The Mental Health Act (2007) provides special laws about patient privacy and providing information to Carers and family of people with mental illness.

For a Mental Health Act Information sheet for consumers and carers visit health.nsw.gov.au/mentalhealth/resources/pages/carers.aspx

What if the patient can't make decisions about their own health care and treatment?

Sometimes patients can't make their own health care decisions. They may be too sick, or unconscious. They may have severe intellectual disability or dementia. Under a law called the Guardianship Act 1987, a "Person Responsible" can make health care decisions for the patient.

A Person Responsible is one of the following people:

1. Guardian – An appointed guardian (or enduring guardian) who has been given the right to consent to medical and dental treatments, or
2. Spouse or partner – If there is no guardian, a spouse, de-facto spouse or partner where there is a close continuing relationship, or
3. Carer – If there is no spouse or partner, an unpaid carer who provides or arranges for domestic support on a regular basis, or
4. Relative or friend – If there is no carer, a friend or relative who has a close personal relationship, frequent personal contact and a personal interest in the person's welfare, on an unpaid basis.

Who should Carers ask for more help?

If you are finding it hard to give or get information about the person you care for, ask to speak to the Nurse Unit Manager (NUM), Social Worker or ISLHD Privacy Officer.

Health Services and staff are busy and it is important to be patient but persistent in getting the help you need.

The ISLHD Privacy Contact Officer (PCO) can be contacted by email: ISLHD-PrivacyContactOfficer@health.nsw.gov.au.

Feedback

The Illawarra Shoalhaven Local Health District welcomes your feedback about your health experience.

If you are happy with the care you have been given

- you can talk to the Manager or staff or
- you can send an email to ISLHD-Compliments@health.nsw.gov.au or
- you can write a letter and send to ISLHD Compliments, PO Box 239, Port Kembla, NSW 2505 or

- you can phone the Manager of the Hospital or Service

Facility contact details can be found on the ISLHD website: www.islhd.health.nsw.gov.au

If you are unhappy with the care you have been given or would like to suggest an improvement

- you can speak to the staff person caring for you or
- you can speak to the Manager
- you can phone the service you would like to make a complaint about
- you can contact the Consumer Feedback Manager by phoning [4221 6811](tel:42216811) or email: ISLHD-Complaints@health.nsw.gov.au
- you can write a letter to ISLHD Consumer Feedback Manager, PO Box 239, Port Kembla, NSW, 2505
- you can write a letter to the ISLHD Chief Executive, PO Box 239, Port Kembla, 2505 or email ISLHD-CEOffice@health.nsw.gov.au
- you can contact the Health Care Complaints Commission (HCCC) if you do not feel happy to talk to our staff. You can do this by Phone: [9219 7444](tel:92197444) or make a free call: [1800 043 159](tel:1800043159)
Mail: Locked Mail Bag 18, Strawberry Hills, NSW, 2012 Email: hccc@hccc.nsw.gov.au

If you need to speak to someone in your own language you can ring the Health Care Interpreter Service on [1800 247 272](tel:1800247272) Monday to Friday 8.30am to 5.00pm

When you make a complaint

We will:

- treat you with respect
- reply to your complaint
- tell you when we will reply to you
- say sorry when needed

You can:

- have someone make the complaint for you
- have someone come with you to any meeting
- make your complaint in any language

Useful Contacts

Illawarra Shoalhaven Local Health District (ISLHD)

islhd.health.nsw.gov.au

Carers

Carer Gateway

carergateway.gov.au

1800 422 737

Carers NSW

carersnsw.org.au

9280 4744

Young Carers Program

youngcarersnsw.org.au or
youngcarersnetwork.com.au

9280 4744

Centrelink – Services Australia

servicesaustralia.gov.au/caring-for-someone

132 717

Services NSW

service.nsw.gov.au/guide/carers

13 77 88

Older People

My Aged Care

myagedcare.gov.au

1800 200 422

The Seniors Rights Service

seniorsrightsservice.org.au

1800 424 079

Dementia Australia

dementia.org.au

1800 100 500

Dementia Illawarra Shoalhaven

dementiaillawarra.com

Aged Care Quality and Safety Commission

agedcarequality.gov.au

1800 951 822

NSW Civil and Administrative Tribunal – Guardianship Division

ncat.nsw.gov.au

1300 006 228

Department of Veteran Affairs

dva.gov.au

1800 838 372

Ageing and Disability Abuse Helpline

ageingdisabilitycommission.nsw.gov.au

1800 628 221

Disability

Disability Gateway has information and services to help people with disability, their family, friends and carers, to find the support they need in Australia.

disabilitygateway.gov.au

1800 643 787

National Disability Insurance Scheme (NDIS)

ndis.gov.au 1800 800 110

NDIS Quality and Safeguards Commission

1800 035 544 ndiscommission.gov.au

Uniting – NDIS Local Area Coordinators (LACs)

lac.uniting.org/home

02 4253 6580

Illawarra Advocacy

illawarraadvocacy.org.au 4229 4999

IDEAS (Information on Disability and Education Awareness Services)

ideas.org.au 6947 3377

People with Disability - Disability Advocacy

pwd.org.au 1800 422 015

NSW Ageing and Disability Abuse Helpline

ageingdisabilitycommission.nsw.gov.au

1800 628 221

Council for Intellectual Disability

cid.org.au

1800 424 065

Autism Connect

amaze.org.au/autismconnect

1300 308 699

Mental Health

Mental Health Line

1800 011 511

Mental Health Carers ARAFMI Illawarra

onedoor.org.au/our-services/carers-supports/arafmi-illawarra

0419 513 684

1300 554 660 (Information and support line)

Stride Family and Carer Program

stride.com.au

4229 7254 (Wollongong)

4422 1547 (Nowra)

Head to Health (H2H)

headtohealth.gov.au

1800 595 212

Useful Contacts

Aboriginal Services

ISLHD Aboriginal Health Services

islhd.health.nsw.gov.au/services-clinics/aboriginal-health

IAMS (Illawarra Aboriginal Medical Service)

illawarraams.com.au

☎ 4229 9495 (Wollongong)

Illawarra Aboriginal Corporation

iac.org.au

☎ 4228 1585

Australian Unity Home Services (Weja)

australianunity.com.au/assisted-living/aboriginal-home-care

☎ 1800 997 330

SCMSAC (South Coast Medical Service Aboriginal Corporation)

southcoastams.org.au

☎ 1800 215 099 or 4448 0200

Waminda (South Coast Womens Health and Welfare Aboriginal Corporation)

waminda.org.au

☎ 4421 7400

Aboriginal Legal Service

see under Legal p28

Transport Services

see page 17

Multicultural Services

Multicultural Health Service

islhd.health.nsw.gov.au/services-clinics/multicultural-health

☎ 4221 6770

Multicultural Disability

Advocacy Association – Wollongong

mdaa.org.au

☎ 1800 629 072

Multicultural Communities Council Illawarra

mcci.org.au

☎ 4229 7566

ITSOWEL (Italian Social Welfare)

itsowel.com.au

☎ 4228 8222

Macedonian Welfare Association

www.mwainc.org

☎ 4275 2266

Spanish and Latin American Community Organisation

salco.org.au

☎ 4225 2128

GWC Community Services (Greek)

gwccservices.org

☎ 4228 1609

Illawarra Multicultural Services

ims.org.au

☎ 4229 6855

Translated Resources

There are fact sheets in different languages on the NSW Multicultural Health Communication Service website

mhcs.health.nsw.gov.au

Legal

Illawarra Legal Centre

illawarralegalcentre.org.au

☎ 4276 1939

Shoalcoast Community Legal Centre

shoalcoast.org.au

☎ 1800 229 529 or 4422 9529

Legal Aid

legalaidnsw.gov.au

☎ 4228 8299 (Wollongong) 4422 4351 (Nowra)

☎ **Law Access** 1300 888 529

Aboriginal Legal Service

alsnswact.org.au

☎ 4276 7100 (Wollongong) 4424 8900 (Nowra)
1800 765 767 (Sydney)

The National Public Toilet Map

Is part of the National Continence Program. The toilet map provides information on over 23,000 public toilets available across Australia, including accessibility, opening hours and facilities. Download App or visit toiletmap.gov.au

The **Master Locksmiths Access Key (MLAK)** enables people with disabilities to gain 24/7 access to a network of public facilities, including public toilets. Obtain a key by searching masterlocksmiths.com.au or contact them on 1800 810 698.

Glossary

Advance Care Directive/Plan states your wishes for health care when you cannot communicate or can no longer make the decision for yourself (Page 13).

Advocacy is speaking on behalf or in support of another person (Pages 11 & 16).

Allied Health are health professionals who are not doctors, dentists or nurses. Page 21 provides a description of some of these health professionals (Pages 21 & 22).

ARC – Access and Referral Centre for Community Services in the Illawarra Shoalhaven Local Health District (ISLHD) (Page 23).

Assessment Service conducts assessments of older people for access to My Aged Care Services for support in the home or Residential Aged Care (p14).

Authorised Representative is a person who can make decisions about who can have health information about the patient when they can't do it themselves (Page 24).

Carer – Carers provide ongoing unpaid support to family members or friends who need help because of disability, terminal, chronic or mental illness or ageing.

Carer Gateway provides information and access to services for all carers. They offer online education, coaching, peer support, counselling, emergency respite, and limited financial support packages (Pages 9 & 14 & 18).

CHSP – Commonwealth Home Support Programme provides a range of basic support services for older people living at home. Contact My Aged Care (MAC) who will arrange for a local assessment service to assess or review your service needs (page 14).

ComPacks provides up to 6 weeks of community services to help people after they come home from a public hospital (Page 22).

Continence is being able to control bladder and bowel activity (Page 11).

Counselling is talking to someone who listens and understands, and will work with you to improve your situation (Pages 6, 8, 9 & 14).

Disability is when a person has a physical or mental limitation (Pages 9, 10, 11, 15, 16 & 27).

Discharge plan is developed by the hospital together with the patient, carer and community service providers to make sure the right care continues after leaving the hospital (Page 22).

DVA – Department of Veterans' Affairs provides a variety of aged and community care programs to current and former serving Australian Defence Force personnel (Pages 15 & 27).

Early Childhood Approach through the National Disability Insurance Scheme (NDIS) support children aged 9 years who have a disability or developmental delay (p15&16).

GP – General Practitioner is a local medical doctor (Pages 9, 13 & 23).

HCP – Home Care Packages from Level 1 basic care to Level 4 which provides support for older people with higher level care needs to remain living at home (Pages 14 & 15).

Interpreter is a professionally trained person who translates what a person is saying into another language (Pages 9, 19, 23).

IPTAAS – Isolated Patients Transport and Accommodation Assistance Scheme can help with the cost of travel and accommodation when travelling more than 100km or 200km combined per week for specialist medical treatment (Page 17).

ISLHD – Illawarra Shoalhaven Local Health District covers 4 Local Government areas: Wollongong, Shellharbour, Kiama and Shoalhaven and includes the following hospitals – Coledale, Bulli, Wollongong, Shellharbour, Kiama Ward in (Shellharbour Private), David Berry, Shoalhaven and Milton (Page 26).

Glossary

LAC – Local Area Coordinators assist people with a disability to access the National Disability Insurance Scheme (NDIS) and help them to identify their goals and prepare their NDIS plan (Pages 15 & 27).

MAC – My Aged Care is a telephone and online service providing information on and access to services according to the assessed needs of older people (Pages 14, 15 & 27).

Multicultural is the presence of several cultural groups within a society (Pages 9, 23 & 28).

NDIS – National Disability Insurance Scheme provides support for people aged under 65 years with a significant, permanent disability (Page 15, 16, 18, 19 & 27).

Nominee is a person who can act on behalf of another person to conduct business, represent interests and receive correspondence from most Australian Government departments. Only one person can be registered as a person's nominee, and nominee arrangements are not shared between government agencies.

Palliative Care aims to achieve the best quality of life for the person with a life-limiting illness and provide support for their family and carers (Page 23).

Person Responsible is a person who can make health care decisions for the patient when they can't do it themselves (Pages 24 & 25).

Respite is having a break, meaning a time of rest or relief (Pages 15, 18).

SASH – Safe and Supported at Home Program provides clinical and non-clinical supports up to 6 weeks at a time for people between 18-64 years of age with functional impairment who are not eligible for the NDIS (Page 16).

SRS - Seniors Rights Service is a community legal and advocacy service for older people (Pages 16 and 27).

STRC – Short-Term Restorative Care provides a package of services up to 8 weeks for older people living at home or in a residential setting following approval by the Aged Care Assessment Team (ACAT (Page 15).

Transitional Aged Care provides up to 12 weeks of home therapy and services for people aged over 65 years or over 50 years for Aboriginal and Torres Strait Islander people discharged from public or private hospitals following approval by the Aged Care Assessment Team (ACAT) (Page 22). The Illawarra Shoalhaven Local Health District (ISLHD) has the Illawarra Transitional Aged Care Service (ITACS) and the Shoalhaven Transitional Aged Care Service (STACS).

Notes

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