

Council for Intellectual Disability



HEALTHIER  
LIVES

# Health Fact Sheets

On health and people with intellectual disability



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My name is Michael Sullivan and I am a board member at CID.

I would like to introduce you to our health fact sheets.

Every person in Australia, including people with intellectual disability, has the right to good health care.

But at the moment there are many barriers to people with intellectual disability getting access to health care and this means that there are terrible health inequalities.

CID has written these health fact sheets aimed at the people who support people with intellectual disability such as family members, health professionals, advocates, support people and disability workers, to try to address some of these inequalities.

We invite you to read these fact sheets and learn more about the health of people with intellectual disability and to start breaking down the barriers to good health care.

The health and lifestyle of people with intellectual disability can improve, if they receive the support they need to have regular health checks and to communicate with health professionals.

**Michael Sullivan**

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# Diagnosis and assessment of a disability

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Diagnosis and assessment is the process of working out the nature and cause of a disability and providing advice about the person's needs and available services.

Diagnosis and assessment services in NSW Health also assist with complex health needs of some children and young people.

## When can diagnosis and assessment help?

Diagnosis and assessment usually occurs in early childhood, but can also be useful in adolescence or adulthood. Diagnosis and assessment is particularly important for a person with complex or challenging needs. By learning more about a condition or symptom a person has, we can better help them live their healthiest and best life.

## How to get diagnosis and assessment

If you suspect that a child has an intellectual disability, there are a number of services that can help.

NSW Health encourages parents to have their child undergo regular health checks, from birth to age 4, done by a nurse or doctor. This is explained in My personal health record which is given to all parents of newborns. These checks help to detect any delay in a child's development or learning – two areas that may suggest an intellectual disability.

Seeing your GP is a good first point of contact. They are likely to know what other services are available in your area. Your GP can check to see if there are other conditions that are causing the person's difficulties, such as a hearing problem or a deficiency in nutrition. The GP can identify and treat general health conditions. They can also refer your child to a paediatrician or child health service.

A paediatrician can say whether a significant problem is likely and link your child with intervention services. The paediatrician may do some tests to try to find a cause for the disability.

School counsellors and psychologists can also do assessments to identify intellectual disability.

However, it is often best to go to a diagnosis and assessment service that is a multidisciplinary team. These teams have a number of different kinds of health professionals working together.

## About diagnosis and assessment services

Diagnostic and assessment services are usually multidisciplinary teams of health professionals with expertise in intellectual disability such as paediatricians, psychologists, speech pathologists, occupational therapists, physiotherapists, nurses and social workers.

The main roles of diagnosis and assessment services are:

- Assessment of the extent and cause of the disability.
- Assessment of the person's strengths, difficulties and potential.
- Recommendations for ways to help the person achieve their potential.
- Support to receive and work with other services, for example NDIS, early intervention.
- Health assessment and referral, for complex health needs.
- Information, counselling and support for families.
- Case reviews at key stages in the person's life, for example starting or leaving school, when complex health and medical needs are suspected, or when a sudden change occurs in the person's health or abilities.

## How do I find a diagnosis and assessment service?

See the contact details below of NSW diagnosis and assessment services. These services are multidisciplinary teams. They vary in who they see and what they can offer.

There may be other local services that provide some diagnosis and assessment.

## Other intellectual disability health services for children

Apart from diagnosis and assessment services, there are various other specialised intellectual disability health services in NSW for children and young people. See the **Specialised intellectual disability health services** fact sheet.

### For more information

My personal health record [www.health.nsw.gov.au](http://www.health.nsw.gov.au)

You might be interested in these fact sheets

- **Causes of intellectual disability and health care**
- **Children - what kinds of health services are there?**
- **Specialised intellectual disability health services**

This fact sheet was updated in **2019**.

The fact sheet contains general information only and does not take into account individual circumstances. It should not be relied on for medical advice. We encourage you to look at the information in this fact sheet carefully with your health professional to decide whether the information is right for you.

### NSW Diagnosis and Assessment services

Name of D&A Service	Area covered	Phone (02)	Age
Child and Family Health Developmental Assessment Team	Gosford & Wyong area	4328 7900	0-12
Child Development Service <a href="mailto:nslhd-cds@health.nsw.gov.au">nslhd-cds@health.nsw.gov.au</a>	Northern Sydney, Hornsby, Northern Beaches, Ryde, Pennant Hills	9462 9288	0-6
Kogarah Developmental Assessment Service  Includes Illawarra Shoalhaven Diagnostic Service (ISDAS)	St George & Sutherland area	8566 1222	All ages
Tumbatin Clinic, Randwick <a href="http://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/autism-spectrum-disorder/sch">www.schn.health.nsw.gov.au/find-a-service/health-medical-services/autism-spectrum-disorder/sch</a>	South and East Sydney LHD and rural remote where no services available	9382 8189 9382 8191	0-5

Name of D&A Service	Area covered	Phone (02)	Age
Disability Specialist Unit, Croydon Community Health Centre <a href="mailto:Intake@health.nsw.gov.au">Intake@health.nsw.gov.au</a>	Ashfield, Burwood, Canada Bay, Canterbury, Leichhardt, Marrickville & Strathfield Council areas	9378 1100	0-16
Child Assessment Team, Macarthur (now part of Liverpool LHD) Central Intake: <a href="http://www.swslhd.health.nsw.gov.au">www.swslhd.health.nsw.gov.au</a>	Campbelltown, Camden, Wollondilly area	4634 3553	0-12
Rainbow Cottage (Liverpool Hospital)	Liverpool and surrounding areas	9616 4405	0-18
Developmental Assessment Clinic, Nepean Hospital	Penrith, Hawkesbury, Blue Mountains	4734 3166	2-16
Parramatta Early Childhood Assessment Team (PECAT), Parramatta <a href="http://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/developmental-delay-and-intellectual-disability/chw">www.schn.health.nsw.gov.au/ find-a-service/health-medical- services/developmental-delay- and-intellectual-disability/chw</a>	Auburn, Baulkham Hills, Castle Hill, Holroyd, Parramatta, Blacktown, Penrith, Hawkesbury & Blue Mountains areas	9891 7200	0-6
Blue Mountains Child & Adolescent Development Unit <a href="http://www.nbmlhd.health.nsw.gov.au">www.nbmlhd.health.nsw.gov. au</a>	Blue Mountains, Penrith, Lithgow	4784 6671	0-18

Name of D&A Service	Area covered	Phone (02)	Age
Auburn Child Development Assessment Team (Children's ward)	Auburn, Berala, Chester Hill, Regents Park, Lidcombe	8759 3225	0-5+
Child, Infant and Family Tertiary Service (CIFTS), Goulburn	Goulburn, Queanbeyan, Cooma, Yass, Southern NSW LHD	4827 3950	0-18
Bathurst Child Development Clinic	Bathurst, Mudgee, Cowra	6330 5363	0-18
Child and Family Health Team, Wallsend <a href="http://www.hnekidshealth.nsw.gov.au">www.hnekidshealth.nsw.gov.au</a>	Newcastle, Hunter, Lake Macquarie	4924 6400 4924 6190	2-12
Royal Far West, Centre for Country Kids, Manly <a href="http://www.royalfarwest.org.au">www.royalfarwest.org.au</a>	Rural and remote, must be 100km outside of Sydney	8966 8500	0-12
Child Development Unit, Westmead <a href="http://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/developmental-delay-and-intellectual-disability/chw">www.schn.health.nsw.gov.au/find-a-service/health-medical-services/developmental-delay-and-intellectual-disability/chw</a>	Statewide	9845 2395	0-16
NSW Centre for Effective Reading <a href="http://www.cer.education.nsw.gov.au">www.cer.education.nsw.gov.au</a>	Dubbo, Manly, Wagga Wagga, Westmead	9687 0377	5-12
Illawarra Child Development Centre	Wollongong, Illawarra Area	4224 2900	2-12



# Children – signs of illness

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Children and adolescents with intellectual disability can have the same health problems as anyone else. They often have more health problems. Many people with intellectual disability find it hard to explain their symptoms.

It is really important to have regular health checks and watch out for signs of health problems.

## Common signs that a person is unwell

If a person finds it hard to say they are feeling sick, you need to watch out for signs that may point to a health problem. For example, the person:

- seems sad.
- has lost interest in a hobby or things they used to enjoy.
- doesn't want to eat.
- has challenging behaviour.

Some of the signs seem obvious when you read them. But when carers are busy or stressed it can be easy to miss that a person might be sick.

## Watch out for common health problems

- **Hearing problems** – Does he seem to ignore you? Does he want the TV very loud?
- **Vision problems** – Does she seem hesitant on stairs? Does she have trouble finding things that are nearby?
- **Tooth or gum disease** – Is he holding his jaw, or refusing food? Do his gums bleed when his teeth are being cleaned? Does he have bad breath? Does he brush his teeth at least daily?
- **Gastric problems** – Is she choking or coughing during meals? Is she vomiting? Does she seem in pain after eating?
- **Swallowing problems** – Does he take a long time to eat or does food fall out of his mouth? Does he cough or choke when eating or drinking?
- **Poor nutrition** – Does she lack energy? Is she underweight or overweight? Is she developing pressure areas?
- **Chest infections** – Watch very carefully for this if the person is immobile. Can you hear a rattle or wheezing sound in his chest when he breathes? Is he breathing fast? Does he have a cough or a temperature? Does his skin have a bluish tinge especially around the mouth and finger tips?
- **Muscle and joint problems** – Is she holding a part of her body, or having trouble moving? If she is immobile, look for any redness or swelling and if there is any discomfort when you move her.
- **Skin disease** – Is there a skin rash? Is he scratching or picking at his skin?
- **Epilepsy** – Does she seem to be in a day dream? Does she have seizures or muscle spasms? Has she forgotten something he would normally remember? Does she have unexplained periods of drowsiness?
- **Sexual development** – Is she having difficulty with sexual changes in adolescence, for example managing periods?
- **Mental illness** – Does he not want to do things he was previously interested in? Does he seem depressed or anxious? Is he hurting himself or other people? Is there a change in behaviour?
- **Grief** – Is she tearful? Is she having trouble concentrating?
- **Reactions to medication** – Has her behaviour changed? Has she got a rash, swelling, vomiting or diarrhoea? Is she falling over?

If a person with intellectual disability is showing these sorts of symptoms, it is important to get the doctor to check if there is a medical problem that can be treated.

Some other common problems that can arise in early childhood:

- Problems with posture, correct seating and need for modified cutlery – an occupational therapist can help.
- Muscle development and posture, swallowing, dribbling, choking and breathing issues – a physiotherapist can help.
- Walking on the toes – a physiotherapist or an orthopaedic specialist can help.

## Organise regular health checks

No matter how alert you are to signs that a person is unwell, there might be health problems that you and the doctor are not aware of. You can ask the GP to do an annual Medicare health check and get a dental check every six months. If the person has complex health needs, it may be better for a health check to be done by a paediatrician.

## You might be interested in these fact sheets

- Annual health assessments
- Causes of intellectual disability and health care
- Children – what kinds of health services are there?
- Dental care
- Diagnosis and assessment of a disability
- Mental health

This fact sheet was updated in **2018**.

The fact sheet contains general information only and does not take into account individual circumstances. It should not be relied on for medical advice. We encourage you to look at the information in this fact sheet carefully with your health professional to decide whether the information is right for you and your child.

# Children – what kinds of health services are there?

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

The health system is complex, and it can be hard to find the help you need. This fact sheet tries to help you through this maze by explaining what health services there are for children and young people.

## Who provides health care?

Usually, the GP is the starting point for health care. If the problem is complicated, the GP can refer you to a paediatrician or another specialist doctor and to allied health care providers, for example physiotherapists or speech pathologists. Specialist doctors and allied health care providers work in government services and their own practices.

## Community health services

Some local health districts provide allied health and medical services for young children including those with developmental delay or disability.

## Paediatricians

Paediatricians are specialist doctors for children and young people. If a child or young person has ongoing health problems, they may see a paediatrician regularly until adulthood.

Paediatricians can also make referrals to other specialist health services, including developmental paediatricians, who have expertise in disability issues.

## Diagnosis and assessment services

These services work out if a child has a disability and provide families with advice about meeting the child's needs. These services may also assist with complex health problems. See the **Diagnosis and assessment of a disability** fact sheet.

## Allied health services

Allied health services can include, speech pathologists, psychologists and occupational therapists. Some of these services are available for free in community health centres, hospital, and in some disability services. A person's NDIS plan may provide funding.

For children aged under 6, there are early intervention services. You can find out about these by ringing the Early Childhood Intervention Infoline.

Other allied health professionals work privately and charge a fee. Sometimes Medicare can help with the payment where a GP makes the referral. See the **Getting the most out of Medicare** fact sheet.

Allied health services include:

- **Dieticians** – advise about diet, including healthy food choices.
- **Occupational therapists** – advise on equipment like wheel chairs and rails in bathrooms.
- **Speech pathologists** – help with communication and swallowing problems.
- **Exercise physiologists** – advise about exercise and sport.
- **Podiatrists** – treat foot and toenail problems and can recommend footwear.
- **Optometrists** – check vision and provide glasses. Eye examinations by optometrists are covered by Medicare.
- **Audiologists** – test hearing and provide hearing aids. Australian Hearing provides free hearing assessments and hearing aids for children.
- **Drug and alcohol services**
- **Aboriginal health services**
- **Multicultural health services** – help people from non-English speaking backgrounds. They provide some health services and help people to use other health services.
- **Women's health services** – specialist health services, for example menstruation problems.

- **School counsellors** – assist in identifying a disability, and provide information about health and other services.
- Alternative treatment providers such as **osteopaths, naturopaths and chiropractors**. If the person is using these treatments, you should let the GP know to check it will not conflict with the doctor's treatment.

## Pharmacies

It is a good idea to have a regular pharmacy. They can recommend basic treatment for common illnesses and package prescription medications in blister packs to make it easy to ensure the correct daily medication dose is given.

## Dental services

Most dentists work privately but some work in Public Oral Health Services provided by the NSW Government.

## 24 hour phone advice line

You can phone healthdirect Australia at any time and obtain free health information and advice from a nurse.  
**1800 022 222**

## Ambulances

The Ambulance Service provides emergency treatment and takes injured people to a nearby hospital. Call **000** and ask the operator for an ambulance. If you are not sure how serious the situation is, it is okay to call anyway. In some cases, the ambulance service will also transport people to medical appointments. There may be a cost for some services.

## Transition to adult health services

Planned transition is recommended for young people as they approach age 18 years. This may start as early as age 14 and should address health needs from a holistic perspective. The role of the GP often becomes more important through this period so it is important to keep the GP involved throughout childhood.

The young person may have other specialists who only work with children, for example a paediatrician, a neurologist for epilepsy and a child psychiatrist. These doctors should work together during the transition to adult specialists.

It is best not to wait until the person is nearly 18 to start the transition process. It is better to get to know the adult medical team when the young person is well rather than when there is a medical crisis.



Transition Co-ordinators in some major hospitals can assist with organising transition.  
A specialist health service for adults with intellectual disability can help with complex health issues.

## What will it cost?

Some health services are provided free by government agencies including public hospitals and community health centres. Other health care providers charge for their services.

Medicare provides a payment for visits to the doctor and some other health services. However, this will only cover the full charge if the health professional bulk bills. If a person has private health insurance, this also helps with some health costs, for example private hospital admissions. But, the insurance may not cover the full charge.

It is very important to talk to the health professional about costs before treatment starts, so that you know how much it will be and can talk about options. For hospital treatment, there is often a choice of waiting a long time for free treatment in a public hospital or paying for a private hospital.

## For more information

Aboriginal health services  
[www.healthinfolnet.ecu.edu.au](http://www.healthinfolnet.ecu.edu.au)  
**(08) 9370 6336**

Australian Hearing  
[www.hearing.com.au](http://www.hearing.com.au)  
**1300 412 512**

Community health centres and public hospitals  
[www.healthdirect.gov.au/australian-health-services](http://www.healthdirect.gov.au/australian-health-services)

Early Childhood Intervention Infoline  
**1300 656 865**

healthdirect Australia  
[www.healthdirect.gov.au](http://www.healthdirect.gov.au)  
**1800 022 222**

If you have a speech or hearing impairment, call the National Relay Service on 1800 555 677 and ask to be transferred to healthdirect.

If you require phone interpreting, call TIS National on 131 450 and ask to be transferred to healthdirect.

Transition Care Network

Information for young people with chronic health problems and disabilities to facilitate their effective transition to adult health services

[www.aci.health.nsw.gov.au](http://www.aci.health.nsw.gov.au)

(02) 9464 4666

## You might be interested in these fact sheets

- **Children – signs of illness**
- **Diagnosis and assessment of a disability**
- **Finding the right doctor**
- **Getting the most out of Medicare**
- **Going to the dentist**
- **Mental health**
- **Specialised intellectual disability health services**

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# Adults – signs of illness

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

People with intellectual disability can have the same health problems as anyone else. They often have more health problems. Many people with intellectual disability find it hard to explain their symptoms.

It is really important to have regular health checks and watch out for signs of health problems.

## Common signs that a person is unwell

If a person finds it hard to say they are feeling sick, you need to watch out for signs that may point to a health problem. For example, the person:

- seems sad.
- is reluctant to do normal things.
- doesn't want to eat.
- has challenging behaviour.
- looks tired and has no energy.
- has unexplained bleeding, for example from the anus or vagina.

Some of the signs seem obvious when you read them. But, when carers are busy or stressed, it can be easy to miss that a person might be sick.

## Watch out for common health problems

- **Hearing problems** – Does he seem to ignore you? Does he want the TV very loud?
- **Vision problems** – Does she seem hesitant on stairs? Does she have trouble finding things that are nearby?
- **Tooth or gum disease** – Is he holding his jaw, or refusing food? Do his gums bleed when his teeth are being cleaned? Does he have bad breath? Does he brush his teeth at least daily?
- **Gastric problems** – Is she choking or coughing during meals? Is she vomiting? Does she seem in pain after eating?
- **Swallowing problems** – Does he take a long time to eat or does food fall out of his mouth? Does he cough or choke when eating or drinking?
- **Poor nutrition** – Does she lack energy? Is she underweight or overweight? Is she developing pressure areas?
- **Bowel problems** – Does he seem to have pain in the abdomen, or when opening his bowels?
- **Chest infections** – Watch very carefully for this if she is immobile. Can you hear a rattle or wheezing sound in her chest when he breathes? Is she breathing fast? Does she have a cough or a temperature? Does her skin have a bluish tinge especially around the mouth and finger tips?
- **Muscle and joint problems** – Is he holding a part of his body, or having trouble moving? If he is immobile, look for any redness or swelling and if there is any discomfort when you move him.
- **Arthritis** – Does she have trouble using small items, for example a knife and fork? Does she seem uncomfortable when moving around? Does she have swollen joints?
- **Diabetes** – Excessive thirst, frequent urination, tiredness and frequent infections may point to diabetes. Being overweight and not having enough exercise increase the risk of diabetes. Is there a family history of diabetes?
- **Skin disease** – Is there a skin rash? Is he scratching or picking at his skin? Is the skin dry and scaly?
- **Epilepsy** – Does she seem to be in a daydream? Does she have seizures or muscle spasms? Has she forgotten something she would normally remember? Does she have unexplained periods of drowsiness?
- **Mental illness** – Does he not want to do things he was previously interested in? Does he seem depressed or anxious? Is he hurting himself or other people? Is there a change in behaviour?
- **Grief** – Is she tearful? Is she having trouble concentrating?
- **Dementia** – Is he becoming forgetful? Does he seem lost in familiar places? Is he losing everyday skills?
- **Reactions to medication** – Has her behaviour changed? Has she got a rash, swelling, vomiting or diarrhoea? Is she falling over or very sleepy?
- **Sleep apnoea** – Does he snore? Is he restless at night? Does he seem tired when he wakes in the morning? Does he seem drowsy in the daytime? Does he have trouble concentrating or seem irritable?

If a person with intellectual disability is showing these sorts of symptoms, it is important to get the doctor to check if there is a medical problem that can be treated.

## Organise regular health checks

No matter how alert you are to signs that a person is unwell, there might be health problems that you and the doctor are not aware of. You can ask the GP to do an annual Medicare health check and get a dental check every six months.

## You might be interested in these fact sheets

- **Annual health assessments**
- **Adults - what kinds of health services are there?**
- **Causes of intellectual disability and health care**
- **Dental care**
- **Mental health**

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# Adults – what kinds of health services are there?

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

The health system is complex, and it can be hard to find the help a person with intellectual disability needs. This fact sheet tries to help you through this maze by explaining what health services there are.

## Who provides health care?

A GP is the starting point for health care. If the problem is complicated, GPs can refer you to:

- specialist doctors like psychiatrists, rehabilitation physicians and neurologists.
- allied health care providers, for example physiotherapists and speech pathologists.

Specialist doctors and allied health care providers work in government services and their own practices.

## What will it cost?

Some health services are provided free by government agencies including public hospitals and community health centres. Other health care providers charge for their services.

Medicare provides a payment for visits to the doctor and some other health services. However, this will only cover the full price if the health professional bulk bills.

If a person has private health insurance, this also helps with some health costs, for example private hospital admissions. But the insurance may not cover the full charge.

It is very important to talk to the health professional about costs before treatment starts, so that you know how much it will be and can talk about options. For hospital treatment, there is often a choice of waiting a long time for free treatment in a public hospital or paying for a private hospital.

## Allied health services

Some allied health services are available for free in community health centres, hospitals and in some disability services. Other allied health professionals work privately and charge a fee. Sometimes Medicare can help with this where a GP makes the referral. A person's NDIS plan may provide funding.

Allied health services include:

- **Dieticians** – advise about diet including healthy food choices. This is important if the person has a weight or swallowing problem, or has diabetes.
- **Occupational therapists** – advise on equipment like wheel chairs and rails in bathrooms.
- **Exercise physiologists** – advise about exercise and sport.
- **Podiatrists** – treat foot and toenail problems, and can recommend footwear.
- **Speech pathologists** – help with communication and swallowing problems.
- **Optometrists** – check vision and provide glasses. Eye examinations by optometrists are covered by Medicare.
- **Audiologists** – test hearing and provide hearing aids. Australian Hearing provides free hearing assessments for pensioners.
- **Drug and alcohol services**
- **Aboriginal health services**
- **Multicultural health services** – these help people from non-English speaking backgrounds. They provide some health services and help people to use ordinary health services.
- **Women's health services** – for women's health issues eg menstruation problems.
- **Screening services** – check people for some health risks, eg breast cancer and bowel cancer.
- **Alternative treatment providers such as osteopaths, naturopaths and chiropractors.** If the person uses these treatments, you should let the GP know to check they will not conflict with the doctor's treatment.

## Chronic disease management

Chronic diseases are medical conditions that tend to be long lasting and persistent in their symptoms or development. For example, chronic heart and respiratory diseases and diabetes.

NSW Health has some chronic disease programs:

- Chronic Disease Management Program – This program provides coordinated health care and self-management support to help people manage their condition, access services, prevent complications and reduce the need for hospitalisation.
- Hospital in the Home – This program provides clinical care that reduces the length of stay in hospital or in some instances can avoid an admission altogether.

The NSW Ombudsman has seen many examples of these programs not being provided to people with disabilities. So, ask the doctor or hospital about these programs if you think they might be relevant to a person's needs.

## Pharmacies

It is a good idea to have a regular chemist. They can recommend basic treatment for common illnesses and package prescription medications in blister packs to make sure the correct daily medication dose is given.

## Dental services

Most dentists work privately but some work in Public Oral Health Services provided by the NSW Government.

## Specialised health services for people with intellectual disability

Some health services specialise in complex health problems of people with intellectual disability. These exist to backup and advise GPs and hospitals, not to take over medical care from mainstream health services.

## 24 hour phone advice line

You can phone healthdirect Australia at any time and obtain free health information and advice from a nurse. Phone **1800 022 222**

## Ambulance service

The Ambulance Service provides emergency treatment and takes injured people to a nearby hospital. Call **000** and ask the operator for an ambulance. If you are not sure how serious the situation is, it is okay to call anyway. In some cases, the ambulance service will transport people to medical appointments. There may be a cost for some services.

## For more information

Aboriginal health services  
[www.healthinfonet.ecu.edu.au](http://www.healthinfonet.ecu.edu.au)  
(08) 9370 6336

Ambulance Service NSW  
[www.ambulance.nsw.gov.au](http://www.ambulance.nsw.gov.au)

Australian Hearing  
[www.hearing.com.au/home](http://www.hearing.com.au/home)  
Phone **1300 412 512** or **(02) 9412 6800** or TTY **(02) 9412 6802**

Community health centres and public hospitals  
[www.healthdirect.gov.au/australian-health-services](http://www.healthdirect.gov.au/australian-health-services)

healthdirect Australia  
[www.healthdirect.gov.au](http://www.healthdirect.gov.au)  
Phone **1800 022 222** or

If you have a speech or hearing impairment, call the [National Relay Service](#) on **1800 555 677** and ask to be transferred to healthdirect.

If you require phone interpreting, call [TIS National](#) on 131 450 and ask to be transferred to healthdirect.

## You might be interested in these fact sheets

- **Adults - signs of illness**
- **Alcohol and other drugs**
- **Finding the right doctor**
- **Getting the most out of Medicare**
- **Going to the dentist**
- **Mental health**
- **Specialised intellectual disability health services**

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# Ageing and health

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Older people with intellectual disability have the same range of health problems as all older people, and many develop age-related problems at a much earlier age. You should watch for any signs that a person's health is deteriorating.

Like all people who are growing older, the person with a disability should have a full health assessment every year.

The fact sheet **Adults – signs of illness** lists signs that a person with intellectual disability may have some common health conditions. You should watch out for these in older people and remember that, as people age, they often find it harder to recover from illness.

This fact sheet talks about some conditions that are more common as people age.

## Common health problems as people age

- Reactions to medication – Some medications have serious side effects especially if they have been taken for many years. Some medications may not be needed any more. Older people are also more likely than younger people to have reactions to new medications. Regular medication reviews are important! Some



medications used for managing mental health conditions, menstruation (periods) or epilepsy can affect weight gain, bone strength and diabetes risk.

- Contractures – A contracture is the shortening of a muscle or body tissue so that a joint becomes deformed. If a person already has contractures, eg because of cerebral palsy, they can get worse and more painful with age. Is the person showing signs of increased pain?
- Thyroid and bowel problems – Some causes of intellectual disability, eg Down syndrome, make people more likely to have early deterioration in their thyroid and their bowel function. Medication can make a big difference if the problem is detected early.
- Dementia – This occurs earlier in some people with intellectual disability. The person also may develop depression or seizures that can be mistaken for dementia.
- Lack of exercise and obesity – Older adults with intellectual disability need support to avoid and manage these problems. Otherwise, they can lead to constipation, incontinence, arthritis, diabetes, high blood pressure and heart disease.
- Nutrition – This remains important as people age. In particular, vitamin D and calcium helps keep bones and joints healthy.
- Arthritis – Older people with intellectual disability may not be able to demonstrate their pain.
- Vision and hearing – These may deteriorate as people age.
- Skin deterioration – Older people's skin becomes thinner and paler, so they feel colder, wounds take longer to heal, and they are at risk of sun burn. They need to drink plenty of fluids in warm weather and use sunscreen. If the person spends most of the time in bed or a chair, they may develop pressure sores - they need to move regularly and have correct seating options.
- Neurological deterioration – People with intellectual disability may develop neurological disabilities at a younger age than other people. In a person's fifties or sixties, they may develop cataracts (eyes), hearing loss and decline in balance, gait and/or co-ordination.
- Depression – You need to be alert to this in all older people.

## Where to get help

The GP is the best starting point for advice and treatment. Where an older person has complex health problems, the GP may refer the person to:

- A geriatrician (a doctor who specialises in the health problems of ageing people).
- A specialised health service for people with intellectual disability. Two of these have specialist ageing clinics. See the Specialised intellectual disability health services.

## Chronic disease management

Chronic diseases are medical conditions that tend to be long lasting and persistent in their symptoms or development. For example, heart and respiratory diseases and diabetes.

NSW Health has some chronic disease programs:

- **Chronic Disease Management Program** – This program provides coordinated health care and self-management support to help people manage their condition, access services, prevent complications and reduce the need for hospitalisation.
- **Hospital in the Home** – This program provides clinical care that reduces the length of stay in hospital or in some instances can avoid a hospital admission altogether.

The NSW Ombudsman has seen many examples of these programs not being provided to people with disabilities. So, if you think they might be helpful, ask the doctor or hospital about them.

## You might be interested in these fact sheets

- **Adults – signs of illness**
- **Adults – what kinds of health services are there?**
- **Annual health assessments**
- **Causes of intellectual disability and health care**
- **End of life care**
- **Mental health**

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# End of life care

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

A disability is no reason to withhold medical treatment to a person, including treatment needed to keep the person alive. Sometimes, medical treatment is not offered to people with intellectual disability because of doctors' views about their quality of life. Family and support workers may need to be educators and strong advocates in these situations.

However, death comes to all people and it is wise to prepare for it. This includes thinking about what treatment will be in a person's interests when they have a health condition that may limit their lifespan. It also includes how to make the end of a person's life as positive an experience as it can be.

## We all die sometime

As people age, the end of life becomes closer. Also, some people have health conditions that may shorten their lives, for example chronic lung disease. In either case, it is sensible to start thinking about how the person wants to live the rest of their life and about issues that may arise when they are dying. This can be done through discussion between the person with intellectual disability, family, any other advocate, disability support workers and health professionals. Sometimes, an individual plan meeting is a good time to do this. These issues need to be discussed in a way that is very sensitive to people's fears and emotions but also allows people to express their views freely.

A person's culture may affect who should be involved in discussions and how they should proceed. For example, in Aboriginal communities, it is common for the extended family and community to participate in decision making.

Discussion of end of life issues becomes very important when a person has a terminal illness - an illness that will lead to the person's death. There should be a meeting with a palliative care service. GPs and hospitals can link patients to palliative care services.

The person with intellectual disability should be supported to have maximum involvement in all these processes. The person's views and values should be at the core. If the person understands the nature and effect of decisions, their decisions should be respected. Plans should be worked out by discussions involving the person, family and other relevant people - the discussions should aim for a consensus about what plans are in the person's best interests.

The **Talking End of Life** with people with intellectual disability (TEL) toolkit gives family members and professionals the skills and resources to help people with intellectual disability understand and make plans for the end of life.

## Issues to think about

The issues to think about will vary with the individual and the situation. Some common questions are:

- Would I be surprised if the person died in the next 12 months? This may help to decide whether a discussion about end of life should be initiated.
- How can the person's quality of life be maximised as their life comes towards an end? For example, it is usually good for the person to stay in their home for as long as possible - are home modifications, extra equipment and extra support needed? What support will help the person to keep doing their usual activities? If the person has trouble eating and drinking normally, how can their diet be modified?
- Are there particular hospitals and treatments that the person does or does not like?
- How can pain be managed?
- Would some treatments be of little benefit and possibly add to the person's suffering?
- If the person has a terminal condition, should they be resuscitated if their heart stops beating? A hospital will sometimes suggest placing a "not for resuscitation" ("No-CPR" or "DNR") endorsement on a person's file. This issue needs to be approached very carefully. If a "not for resuscitation" endorsement is made, there should be very regular reviews of both the person's condition and the endorsement. All other treatments that will benefit the person should still be provided.
- If the person has a terminal condition and reaches the point where they cannot eat or drink normally, should they be tube fed?
- Does the person have religious, spiritual or cultural needs to be met when dying?
- What sort of funeral would the person want?
- Does the person have a will? If the person wants to make a will, it will be important for a lawyer to see the person and prepare it. The lawyer will need to carefully check that the person has the understanding needed to make a will.

- What support do family, close friends, co-residents and support workers need to deal with a person's terminal illness and death?

The interests of the person with intellectual disability must be paramount in considering these issues.

All end of life plans should be regularly reviewed. The person's condition may change, treatment advances can occur and people can change their minds.

## Ways to put plans in writing

Sometimes, future care planning can be included in a person's individual plan.

In other cases, a more specific plan may be better. The names given to these plans vary with the circumstances in which they are prepared. **An advance care plan** spells out how to deal with situations that are likely to arise at the end of a person's life. It can spell out a person's wishes about things like what treatment they want or do not want. Advance care planning often occurs when a person has an illness that may shorten their life.

A **palliative care plan** focuses on the coordinated care which will be provided for a person who is terminally ill. It can include pain relief, diet advice, physiotherapy and how to keep the person active. It can also cover grief and bereavement support for the person and others close to them.

All these plans are guiding documents. They are not legally binding. Consent is still needed when a particular treatment arises and consultation is still needed if a doctor is considering withholding treatment.

Sometimes, people also make legally binding **Advance Care Directives**. These spell out treatment that the person does not want in particular circumstances, for example some people sign directives saying that, if they are terminally ill, they do not want to be resuscitated or tube fed. These directives come into play if the person becomes unable to make decisions, for example due to being in a coma. Doctors must follow Advance Care Directives if they clearly cover the situation that arises and if the person understood the directive when they made it.

If a person with intellectual disability wants to make a directive, they should be provided with support to understand the decision they are making and a person like a clinical psychologist should assess their understanding.

No one else can make an Advance Care Directive on behalf of a person with intellectual disability.

Another option is to make an **appointment of enduring guardian** – a person appoints their own guardian to make decisions about things like medical treatment if they lose capacity to make their own decisions. An intellectual disability may prevent a person from having the understanding to make an appointment of enduring guardian. The person's understanding should be assessed and they would need legal advice.

## The law and end of life decisions

If an adult understands their condition and proposed treatment, it is up to them to decide whether to have the treatment. Wherever possible, a person with intellectual disability should be supported to make their own decisions.

For adults who cannot understand their condition and the proposed treatment, their views should still be taken into account. NSW law says:

- Providing treatment requires consent from a “person responsible” (usually a close family member or guardian) or the Guardianship Division of the NSW Civil and Administrative Tribunal.
- In an emergency, the doctor can treat without consent.
- Decisions about withholding or withdrawing life sustaining treatment for someone who is dying are generally made by consensus. This includes “no CPR” decisions. However, if there is a guardian with authority to make health care decisions, they decide. The law does not assume that a person’s best interests are always served by extending life.
- If there is a dispute about what should occur, you can consider applying to the Guardianship Division for consent to treatment or appointment of a guardian. Only the Supreme Court can force a doctor to treat. Usually, people should try to talk through a dispute before going to the Guardianship Division or Supreme Court.

For children with intellectual disability, similar rules apply as for adults with guardians. Parents usually decide about treatment issues.

## Resolving disputes

The approach described in this fact sheet is along the lines of what NSW Health expects doctors to do.

If possible, it is best to work through disagreements by discussion and negotiation, as long as the final decision is in the interests of the person. The person with intellectual disability will often need time and support to think through information that doctors give them. Sometimes, a second opinion from another doctor may help, especially if that doctor is experienced with people with intellectual disability. You could try to get advice from a specialised intellectual disability health service. You can also consult a disability advocacy group. Sometimes, a skilled facilitator can be brought in to help you and the health professionals talk the situation through.

You can also consider approaching a formal complaints body. See the **Rights and complaints** fact sheet.

## A last word

We all would want the end of our life to be as dignified and comfortable as it can be. Good communication between the person involved, family, doctors and others should achieve this aim for people with intellectual disability.

## For more information

**Talking End of Life** ...with people with intellectual disability toolkit

[www.caresearch.com.au/caresearch/tabid/4778/Default.aspx](http://www.caresearch.com.au/caresearch/tabid/4778/Default.aspx)

Advance Care Planning

[www.health.nsw.gov.au/patients](http://www.health.nsw.gov.au/patients)

End of Life Decisions, the Law and Clinical Practice

[www.healthlaw.planningaheadtools.com.au](http://www.healthlaw.planningaheadtools.com.au)

Responding to Needs of People with a Disability during Hospitalisation, NSW Health

[www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017\\_001.pdf](http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017_001.pdf)

The Guardianship Division of the NSW Civil and Administrative Tribunal has more detailed information on guardianship and medical consent.

Phone (02) 9556 7600 or 100 006 228 National Relay Service 1300 555 727

[www.ncat.nsw.gov.au](http://www.ncat.nsw.gov.au)

In other parts of Australia, the law is different to NSW. Contact your local Public Advocate or Guardianship Tribunal. Find the relevant information at the Australian Guardianship and Administration Council

[www.agac.org.au](http://www.agac.org.au)

## You might be interested in these fact sheets

- **Ageing and health**
- **Consent to medical treatment**
- **Rights and complaints**

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# Healthy lifestyles

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

A healthy lifestyle includes a good diet, regular exercise and rest. People with intellectual disability have higher rates of obesity and get less exercise than the general population.

An intellectual disability makes it harder for someone to understand about a healthy lifestyle. Health promotion campaigns often do not get to people with intellectual disability and often healthy lifestyle issues are overlooked by support staff and carers.

Families, advocates and support workers can do lots of things to help people with intellectual disability to lead healthy lifestyles.

## Nutrition

Encouraging someone to eat healthy food can be a challenge. It requires patience and practice. You may have to balance people's right to make their own choices against the importance of having a healthy diet.



There is a lot of information available about healthy eating. Eating food that contains too much energy (calories), fat or sugar can lead to being overweight. This can cause illnesses like heart disease, diabetes, high blood pressure, stroke and some cancers.

Many people with intellectual disability are overweight. Some, particularly people with high support needs, are underweight.

If someone is overweight or underweight, you should get advice from a health professional. A dietitian can recommend a suitable diet. Sometimes, the GP can arrange for Medicare to pay for this.

## Exercise and rest

Many people with intellectual disability do not get enough exercise. Respecting people's right to make their own lifestyle choices is important but physical activity makes people feel better, builds skills and helps prevent obesity and lifestyle diseases. Try to find something the person enjoys and then build it into their weekly routine.

Any type of exercise is good – dancing to music or walking to the shops. However, for people to lose weight, they need to work up a bit of a sweat.

Sometimes, a person should see a doctor before starting vigorous exercise – for example, if the person is ageing, has been inactive, has major health problems or has heart disease in the family.

Getting enough rest is also important. Doctors recommend that adults have 7 to 8 hours sleep a night.

## Smoking and drinking

Smoking and drinking too much alcohol cause serious health problems. The *I can quit* program helps people with intellectual disability to stop smoking.

## Barriers to healthy lifestyles

People with intellectual disability can miss out on health information online, in magazines, brochures and books. On the other hand, they may be easily influenced. If people feel well they can find it hard to understand the importance of healthy life style choices.

In the past, there was not much focus on nutrition and exercise in disability accommodation services. People were often excluded from mainstream leisure activities.

So, it is important to help people with intellectual disability learn about healthy lifestyles and provide opportunities for exercise.

## For more information

### Australian dietary guidelines

[www.nhmrc.gov.au](http://www.nhmrc.gov.au)

### Disability - Managing underweight fact sheet

[www.betterhealth.vic.gov.au/health/HealthyLiving/disability-managing-underweight](http://www.betterhealth.vic.gov.au/health/HealthyLiving/disability-managing-underweight)

### National physical activity guidelines

[www.health.gov.au/internet](http://www.health.gov.au/internet)

### I can quit manual

[www.icanquit.com.au](http://www.icanquit.com.au)

## You might be interested in these fact sheets

- Alcohol and other drugs
- Getting the most out of Medicare

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# Annual health assessments

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

People with intellectual disability often find it hard to explain if they are in pain or feeling sick.

People often suffer in silence, or their behaviour changes and other people do not know why. So, it is important for a person with intellectual disability to have a thorough health assessment each year. Medicare pays for these assessments which can show up health problems that no one knew about, for example sight and hearing problems, reflux, side effects from medications and major diseases.

## Medicare health assessments

Medicare pays for GPs to do annual health assessments of adults and children with intellectual disability. Medicare item 701 is for a brief assessment (up to 30 minutes), 703 standard (up to 45 minutes), 705 long (up to 60 minutes) and 707 for a prolonged assessment. Medicare says that a person with intellectual disability may need a long or prolonged assessment because of the communication barriers between doctor and patient.

## Organising the assessment

- Make an appointment for the person with the GP. Say you want an assessment under Medicare and ask for a long appointment. See if the doctor has a practice nurse who can help with the assessment. Check that the doctor bulk bills.
- If the person agrees, someone who knows them well should go with them to the appointment. For people in supported accommodation, workers should discuss this with their family or advocate. It can make sense for both a family member and a support worker to attend.
- Take the person's health records, personal profile and current medications to the appointment.
- If it will be hard for the doctor to assess the person in the clinic, you can ask the doctor to come to the person's home.

At the appointment the GP will check things like the person's teeth, hearing, eye sight, nutrition, any swallowing problems, immunisations and so on. And then, the GP will advise on preventative health care, treatment and any other medical tests that are needed.

If the person has a chronic medical condition and complex care needs, the GP may decide to follow up with Chronic Disease Management Medicare items. These can allow other health professionals to be paid for by Medicare, for example speech pathologists, physiotherapists and occupational therapists.

## Using the CHAP tool

The CHAP is a tool that can be used to carry out the annual health assessment. CHAP stands for Comprehensive Health Assessment Program. There is a questionnaire for the family, advocate or support worker to fill in with the person. This gives the doctor lots of information about the person's health. The doctor then fills in the second part of the CHAP at the appointment and works out a health action plan with the person and other people present.

## Health action plan

It is important that the actions recommended by the doctor are followed up. One person should take responsibility for supporting the person with disability through the necessary actions – for example arranging blood tests and making appointments with specialists and therapists. If you have trouble with this follow through, contact the GP for advice.

The annual assessment can also feed into an individual health care plan.

The plan covers things like a healthy lifestyle, follow through on annual assessments and ongoing support with health problems.

## Follow up

Ask the GP about a follow up appointment to talk about the results of any tests and other assessments. The doctor may use these results to give more advice about treatment or monitoring.

## For more information

### Medicare Benefits Schedule

Health assessment for people with intellectual disability:

### Fact sheet

[www.health.gov.au](http://www.health.gov.au)

### Question and Answer Sheet

[www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-qandaintelldisability](http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-qandaintelldisability)

### CHAP tool

[www.qcidd.centre.uq.edu.au/resources/chap](http://www.qcidd.centre.uq.edu.au/resources/chap)

## You might be interested in these fact sheets

- **Going to the doctor – tips and tricks**
- **Personal health records**
- **Helping the doctor understand the person**
- **Getting the most out of Medicare**

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# Preventive Health

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Preventive health strategies aim to prevent illness or diagnose and treat it early for example immunisation and regular health checks. People with intellectual disability should receive the same preventive health care as the rest of the community. But this does not always happen.

Many people with intellectual disability cannot explain their symptoms or say if they feel unwell, so regular health checks are crucial. Also, the cause of a person's disability can make them more likely to get a particular disease. For example, heart defects are more common in people with Down syndrome.

Families and support workers should make sure with the GP that people with intellectual disability are getting appropriate preventive health care.

## How often should people have checks and screening?

Adults and children with intellectual disability can have an annual health assessment with a GP that is paid for by Medicare. The doctor will check general health and things like medications, height and weight, diet and exercise.

Most people with an intellectual disability will have required medication that can make their bones more fragile. A bone mineral density screen can be helpful to check for Osteoporosis, especially as people get closer to middle age.

Hearing and vision should be assessed every 3 to 5 years and people should have a dental check every 6 months.

People's skin should be checked every year for sun spots or cancers. Some people with intellectual disability will need support to protect them from sun damage that could lead to skin cancer.

GPs can organise screening for bowel cancer. This is recommended for all people over 50 and earlier for some people with a family history of bowel cancer.

## Immunisation

All people with intellectual disability should be vaccinated on the same schedule as other people. Also, Hepatitis A vaccine is recommended for people with intellectual disability, and the combined Hepatitis A and B immunisations should be considered.

The shingles vaccination can help prevent painful skin condition shingles and should be given to all people 70 years and older. Booster immunisation for Whooping cough is needed from 50 years of age or for those in regular contact with very young babies.

Many people with intellectual disability die from respiratory disease. Consult the GP about an annual flu injection. This is an option for everyone. Flu injections are very important for people who are over 65 or with some health conditions or who live in congregate care.

People aged over 65 or who have heart, liver or congenital disease, should also have the pneumococcal vaccine – this protects against one type of pneumonia.



## Women's health

All women need regular breast examinations and women over 50 should have mammograms every 2 years.

All women should be familiar with the normal look and feel of their breasts, this may be difficult for those with an intellectual disability. A regular breast examination by their GP is recommended. All women aged 50-74 are encouraged to have a free mammogram every two years.

Women 25-74 years old should have the Cervical Screening Test, every five years or earlier if the woman has the HPV virus. It is similar to the old 'Pap smear' and should be done two years after their last Pap smear.

Families and support workers will often need to help a woman with intellectual disability understand these procedures and reassure her during the appointment.

## Men's health

Some conditions are more common in males with intellectual disability. Some boys have hormone deficiencies that impede puberty. The genitals may not grow normally, hair may not grow, face and muscles may not develop. This condition is treatable. Some men's testicles do not descend, rates of testicular cancer are higher for this group and men with an intellectual disability. The doctor should check their genitals for signs of cancer at least yearly.

Prostate cancer occurs more commonly in men aged over 50. The blood test 'PSA level' can be helpful in detection. The digital rectal examination is no longer a routine test. Families and support workers will often need to help a man with intellectual disability understand these procedures and reassure him during the appointment.

## Medical history

An accurate record of a person's medical history makes it easier for a doctor to know what preventive health is needed. This should be part of the Personal Health Record and eHealth record of each person with intellectual

eHealth is an electronic medical record system that connects doctors, nurses, and other professionals to provide high-quality health care and enable people to better manage their care at home. A person's information is available to clinical staff at the point of care when and where they need it. Through the Health eNet System, clinical staff have access to a person's records from all New South Wales Hospitals.



## For more information

eHealth NSW

[www.ehealth.nsw.gov.au](http://www.ehealth.nsw.gov.au)

Pap test: the plain facts, a booklet for people with intellectual disability

[www.papscreen.org.au/downloads/resources/brochures/Pap\\_tests\\_the\\_plain\\_facts.pdf](http://www.papscreen.org.au/downloads/resources/brochures/Pap_tests_the_plain_facts.pdf)

Preventative women's health care for women with intellectual disabilities

Being a healthy woman - An educational resource for women with intellectual disability, their families, health care providers, carers and support workers

[www.health.nsw.gov.au/disability/Pages/being-a-healthy-woman.aspx](http://www.health.nsw.gov.au/disability/Pages/being-a-healthy-woman.aspx)

## You might be interested in these fact sheets

- **Annual health assessments**
- **Causes of intellectual disability and health care**
- **Healthy lifestyles**
- **Personal health records**

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# Dental care

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

People with intellectual disability are at high risk of dental disease. This can be due to poor dental care and poor mouth hygiene, which can lead to other health problems.

People with intellectual disability should be taught and encouraged to brush their own teeth and gums. Families and support workers need training on how to support people with dental care.

For some people, you may need to brush their teeth. This can be difficult and you may need advice on how to brush a person's teeth.

## Dental care at home

A healthy diet is a good start to dental care. Sugar free drinks and snacks are a good idea. Also, people should drink water after meals.

All people with intellectual disability need to be shown how to brush their teeth and gums correctly. Some people will need lots of training and to be reminded to brush their teeth regularly. People with limited fine motor skills may need brushes with adapted handles. Incorrect brushing can cause gum disease. This is painful and the person may then resist having their teeth and gums brushed.

Some people will need family or support workers to brush their teeth and gums. Cleaning someone else's teeth is quite complex and intrusive. You should get professional advice on how to do it. Making a video of a dentist demonstrating how to brush someone's teeth can be helpful.

Westmead Centre for Oral Health has hygienists to train carers, educators and staff in oral hygiene techniques. The Sydney Dental Hospital has a special outreach program to help some disadvantaged groups with their dental care. Unfortunately, these supports will not always be available. But, here are some key tips on how to keep a person's mouth healthy:

- Have the person in a reclining position when brushing their teeth - turn their head to the side if they are likely to choke.
- Brush the teeth and gums twice a day - morning and night. If only once a day is possible, it should be at night, after eating.
- Use an electric tooth brush if the person will accept it - it is easier to use and cleans better.
- Use a three-sided tooth brush.
- Brush in small circles along the gum line where the gums and teeth meet.
- Use a pea-sized amount of a high fluoride tooth paste - this strengthens the teeth.
- Use dental floss or interdental brushes.
- Use mouth wash or gel with Chlorhexidine one hour after toothpaste. This reduces the bacteria that causes dental decay.
- If necessary, use props to keep the person's mouth open.
- Clean dentures after each meal and leave them in water overnight.

## Preventive care at the dentist

Regular check-ups are essential to good dental health. Dentists recommend that people have check-ups every 3 - 6 months. The dentist should provide preventive treatment like cleaning off plaque and tartar and applying fluoride, as well as filling any cavities.

It is important for dentists to have an accurate dental and medical history. This can be documented in a person's health record.

## Special problems for some people

- If people have problems with swallowing, food can stay around the teeth and cause decay. Also, people can breathe food into their lungs which can lead to pneumonia.
- Saliva helps protect the teeth from decay. Some people have a dry mouth from medication. They can be given saliva substitutes. Some people have gastric reflux and acid from the stomach gets on their teeth. The tooth enamel will wear away leaving the person with hypersensitive teeth. This problem needs to be identified early as it is complex and expensive to repair.
- Some people have a malocclusion (protruding lower or upper teeth) and ordinary braces will not always be appropriate. The dentist needs to monitor this.
- Some people grind their teeth. The dentist will need to monitor this.
- People with Down syndrome are at risk of gum disease.
- People who have a heightened gag reflex can be sensitive to the taste of toothpaste or the froth it produces. You can try a toothpaste with low froth or no flavour.

## For more information

Special Care Dentistry Unit at Westmead (02) 8890 7424 or 8890 7423

[www.wslhd.health.nsw.gov.au/Westmead-Centre-for-Oral-Health/Departments-and-Clinics/Special-Care-Dentistry](http://www.wslhd.health.nsw.gov.au/Westmead-Centre-for-Oral-Health/Departments-and-Clinics/Special-Care-Dentistry)

Sydney Dental Hospital Special Care Dentistry Department (02) 9293 3333

[www.slhd.nsw.gov.au/carers/help\\_dental.html](http://www.slhd.nsw.gov.au/carers/help_dental.html)

Promoting oral health within disability services

[www.dhsv.org.au/oral-health-programs/disability](http://www.dhsv.org.au/oral-health-programs/disability)

Good oral hygiene for adults by Chris Daly

[www.nps.org.au/australian-prescriber/articles/prescribing-good-oral-hygiene-for-adults](http://www.nps.org.au/australian-prescriber/articles/prescribing-good-oral-hygiene-for-adults)

## You might be interested in these fact sheets

- **Going to the dentist - information on finding a dentist and how to make visits to the dentist go well.**
- **Personal health records**

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# Challenging behaviour and health

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Challenging behaviour means that something is not right for the person. There can be many causes like health problems - the person may be sick or in pain or have a mental health problem. When a person has challenging behaviour, family and support workers will want to find and try to fix the causes. A behaviour support practitioner can help with this. It is also important for the person's doctor to check for any health problems causing the behaviour.

## Challenging behaviour and its causes

A person's behaviour is challenging if it causes serious risk to the person or other people or prevents the person having normal access to the community.

Challenging behaviour can have many different causes. For example, if the person:

- Wants something but cannot explain it.
- Is bored.
- Does not like something that is happening.
- Is unsettled by a change in his or her life.
- Is grieving the loss of someone close.
- Is in pain.
- Has a mental health issue, for example anxiety or depression.

## **What to do when a person's behaviour is challenging**

Family and support workers can do two things:

1. Get the person's doctor to check for any medical cause of the behaviour.
2. Seek help from a behaviour support practitioner.

These should be pursued at the same time.

## **Behaviour support**

Where a person has challenging behaviour, family and support workers need help from a behaviour support practitioner like a psychologist.

The behaviour practitioner should assess the possible reasons for the behaviour and what function the behaviour has for the person. For example, the reason might be that the person is unsettled by a change in routine and the function might be to express anxiety about this. The practitioner should work with the person, family, advocate or disability workers to find strategies to minimise the challenging behaviour. The practitioner may also arrange other assessments such as a communication assessment by a speech pathologist.

The behaviour support strategies should include:

- Ways to prevent the behaviour occurring.
- Changes to the person's environment and lifestyle addressing reasons for the behaviour.
- Teaching the person skills so that he or she does not need to use the behaviour.
- What to do when the challenging behaviour happens

The behaviour practitioner should show family and support workers how to carry out the strategies. The practitioner should write down the strategies in a behaviour support plan. The practitioner should regularly check if the strategies are being used, if they are working and if they need to be changed.

## Checking for medical causes

As well as considering behaviour support, the person's doctor should check for any medical problem that may be causing challenging behaviour. This is very important if the person has limited communication and is not able to explain symptoms of illnesses. The challenging behaviour may be the way the person is expressing pain. The doctor should do a full medical review just like the person's annual health assessment.

For example, the doctor may find:

- The person is in pain from a tooth abscess, constipation or a broken bone.
- A urinary tract infection, a thyroid disorder or diabetes.
- A woman has painful periods.
- Medications the person is taking are having side effects or not working well together.
- A person in their 50's, who has become less cooperative, may have early dementia.

The doctor may find that the person has a mental health problem that is contributing to the behaviour. See the **Mental health** fact sheet for information on diagnosis and treatment of mental health issue, including the use of psychotropic medication.

A GP may refer the person to see a medical specialist, for example a neurologist if the GP suspects that the person has epilepsy or a psychiatrist for a mental health issue.

## You might be interested in these fact sheets

- **Adults - signs of illness**
- **Ageing and health**
- **Annual health assessments**
- **Children - signs of illness**
- **Mental health**

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# Mental health

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Like anyone, people with intellectual disability can have mental health issues. People with intellectual disability have a higher rate of these problems than in society as a whole. However, treatment is available for most mental health issues.

It can be difficult to diagnose a mental health issue in a person with intellectual disability, especially if the person has limited verbal communication. Families, support workers and disability professionals need to be alert for signs of mental health issues and then seek advice from appropriate health professionals.

## Types of mental health issues

Some of the common types are:

- Anxiety disorders – the person feels very anxious or panicky in particular situations or most of the time. One type of anxiety disorder is obsessive compulsive disorder – the person has very anxious thoughts which are only relieved when they do particular activities, for example hand washing.
- Mood disorders – the person with depression may feel ongoing and overwhelming sadness that affects things like sleep, appetite and energy levels. Bipolar disorder can involve both highs and lows. In highs, the person may be excessively energetic, talk very fast and appear overly confident. In the lows, the person may seem depressed.

- Psychosis – the person hears or sees things that are not there (hallucinations) or believes things that are not true (delusions).

## Signs that a person might have a mental health issues

If a person's normal behaviour changes, for example, the person:

- Does not want to do normal things.
- Seems to be losing skills.
- Seems anxious or down or very elated.
- Is hurting himself or other people.
- Appears to be talking to herself.
- Has big changes in sleeping or eating patterns or in weight.
- Starts to have challenging behaviour or it gets worse.
- The person's behaviour seems to go in cycles, for example there are periods of normal behaviour but also periods where the person seems high and is hurting other people.

## What to do if you see these signs

Where a person's behaviour deteriorates, two things should be done:

1. Ask the doctor to check for any medical cause for the behaviour. Maybe the person is in pain but cannot explain it. Alternatively, the doctor may suspect that the person has a mental health issue.
2. A behaviour support practitioner should look into the reasons for the behaviour change, for example is the person bored, or frustrated by something? The practitioner can then design behaviour support strategies that address the cause of the behaviour.

See the **Challenging behaviour and health care** fact sheet for more detail.

In extreme situations, for example the person seems suicidal, you may need to get help from the local mental health crisis team or police.

## Who treats mental health issues?

Sometimes GPs treat mental health issues. Sometimes, they refer the person to a psychiatrist.

GPs should be cautious about treating mental health issues in people with intellectual disability. They should consider whether to seek advice from a psychiatrist. Diagnosing the condition is often very hard with a person who has difficulty describing their thoughts and feelings. Also, mental health issues sometimes have different symptoms for people with intellectual disability than they have for other people. Sometimes, a psychiatrist will base treatment on a judgment about what is likely to be the person's problem, and the person's response to the treatment helps clarify the diagnosis.

Paediatricians sometimes treat mental health issues in children with intellectual disability. However, they will also want the advice of a psychiatrist in some complex situations or if they are not experienced with a condition.

## Finding a suitable psychiatrist

It is best to go to a psychiatrist who has a good understanding of intellectual disability mental health issues. The number of these psychiatrists is limited and so they cannot see all patients with intellectual disability. However, if a GP or general psychiatrist needs expert advice, they can seek it from a mental health professional who has experience with intellectual disability.

To find a suitable psychiatrist in NSW, you could phone one of the services in the **Specialised intellectual disability health services** fact sheet and, for children, also the **Diagnosis and assessment of a disability** fact sheet. Some of those services have a psychiatrist. Otherwise, they might be able to give contact details for one. Also, see the ideas in the **Finding the right doctor** fact sheet.

For people with intellectual disability and very complex mental health needs, there are statewide services who can advise the person's treating health professionals.

For people from culturally and linguistically diverse backgrounds, the NSW Transcultural Mental Health Centre can act as a consultant to other health services. This can include help with assessment of a person's mental condition and development of culturally appropriate treatment plans.

## The visit to the psychiatrist

Some people with intellectual disability will need someone to accompany them to a psychiatrist. It should be someone who gets on well with the person and knows them well. If an accommodation worker is making the appointment, they should check if a family member or advocate wants to go too. Also, if there is a behaviour support practitioner involved, that person should attend or at least write a report for the psychiatrist.

You should take the person's Personal Health Record, My Health Matters document and behaviour records, assessments and plans.

## Treatment for mental health issues

Most mental health issues can be successfully treated, using medication and/or psychological treatments. The appropriate treatments will depend on the nature of the problem, what triggers it and the ability of the person to use different treatments.

Some people may benefit from cognitive behaviour therapy – where a therapist helps a person to change their thinking and behaviour that is causing inappropriate emotions. Counselling can also be important, for example grief counselling. People with anxiety disorders may benefit from strategies like set routines in their day. Music therapy, relaxation therapy and massage can also help some people.

A psychiatrist can do some of these treatments or work with a person's behaviour support practitioner to implement them. Also, the GP can refer the person to a psychologist for mental health care, and Medicare may pay for this.

## Psychotropic medication, consent and authorisation

The doctor may recommend that the person takes medication. Because it can be hard to know exactly what is wrong with the person, the doctor might need to try a number of medications to be sure if the medication is a good idea and which one is best. The doctor may say the person should take medication each day or on a "PRN" basis – that is, only when the person shows specified symptoms.

The doctor needs consent to give medication and needs to provide information about things like alternative treatments and any risks and side effects of medications. The person with intellectual disability makes the decision about taking the medication if they understand it. Otherwise, NSW law says that the consent of a "person responsible" is needed. The doctor has to satisfy the person responsible that it is in the person's interests to take the medication.

Sometimes, it is in the interests of a person with challenging behaviour to have psychotropic medication even where a psychiatrist is not sure of a mental health diagnosis. There also needs to be a behaviour support plan and a system for recording symptoms. Medication should never be used as an easy option for managing a person's behaviour. It can only be used for the benefit of the person taking it.

If the person does start medication, ask the doctor what records you should keep so that the doctor can see if the medication works and whether it is having any side effects.

The doctor should regularly review the use of psychotropic medication. Just because medication is needed for a while does not mean it is needed indefinitely.

If an NDIS service provider uses medication as a chemical restraint, the provider must provide reports to the NDIS Quality and Safeguards Commission and comply with the NSW Government's restrictive practices authorisation system.

Chemical restraint is the use of medication to influence a person's behaviour rather than to treat a mental health issue.

## Mental health and disability professionals working together

The behaviour support practitioner and the doctor need to work together. They will have important information for each other. And the behaviour support plan and any medication need to fit in with each other.

## The role of mental health services

Sometimes a person with intellectual disability will have a case worker from the local Community Mental Health Service. Family or supported accommodation staff may need this backup, especially at times when the person is mentally unwell.

Sometimes, a person with a mental health issue needs treatment in a psychiatric hospital – a mental health facility. This can only occur on an involuntary basis where:

- The person has a mental health issue that leads to serious risks to the person or others, and
- Appropriate care cannot be provided outside hospital.

An intellectual disability is not a mental illness. A person with intellectual disability would only be required to go to a mental health facility if they also have a major mental health issue.

## For more information

Department of Developmental Disability Neuropsychiatry (3DN), UNSW 3DN has lots of resources including elearning modules on mental health and intellectual disability for carers and professionals.

[www.3dn.unsw.edu.au/content/carers](http://www.3dn.unsw.edu.au/content/carers)

Mental health, Health NSW

[www.health.nsw.gov.au/mentalhealth/pages/default.aspx](http://www.health.nsw.gov.au/mentalhealth/pages/default.aspx)

**Phone (02) 9391 9000**

Mental Health Line, a 24-hour mental health telephone access service.

**1800 011 511**

WayAhead Mental Health Information Line, provides information, telephone support and referral on issues relating to mental health generally

**1300 794 991**

WayAhead Anxiety Disorders Information Line, focuses more specifically on anxiety disorders

**1300 794 992**

Mental Health Advocacy Service, provides legal advice and information on mental health law.

[www.legalaids.nsw.gov.au/what-we-do/civil-law/mental-health-advice](http://www.legalaids.nsw.gov.au/what-we-do/civil-law/mental-health-advice)

**Phone (02) 9745 4277**

NSW Transcultural Mental Health Centre

[www.dhi.health.nsw.gov.au/tmhc/default.aspx](http://www.dhi.health.nsw.gov.au/tmhc/default.aspx)

Depression in Adults with Intellectual Disability Checklist (for Carers)

[www.cddh.monashhealth.org/index.php/depression-in-adults-with-intellectual-disability-checklist/](http://www.cddh.monashhealth.org/index.php/depression-in-adults-with-intellectual-disability-checklist/)

## You might be interested in these fact sheets

- **Alcohol and other drugs**
- **Challenging behaviour and health**
- **Consent to medical treatment**
- **Finding the right doctor**
- **Getting the most out of Medicare**
- **Going to the doctor - tips and tricks**
- **Helping the doctor understand the person**
- **Personal health records**
- **Specialised intellectual disability health services**

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# Alcohol and other drugs

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

People with intellectual disability can have trouble with alcohol and other drugs. These are often people who lead fairly independent lives and do not have strong support from families and support services.

It can be very hard for these people to get the help that they need for their drug problems. They may not recognise the problem and it can be hard to find appropriate services.

However, there is support available to help people with intellectual disability who have drug problems.

## People with intellectual disability and drugs

The most common drugs that people with intellectual disability have trouble with are alcohol and cannabis. Other drugs include ecstasy, cocaine, heroin and prescription medication.

Overuse of alcohol has many bad effects on health. Health experts say that consuming more than two drinks a day increases the long term risk of death from illness and injury. Other drugs are illegal and also have bad effects on health, including mental health issues.

Misuse of alcohol and other drugs reduces self control which can lead to accidents, being exploited and getting into trouble with the law.



## Helping the person to seek help

The first step is for the person to recognise they have a problem. People are often reluctant to accept they have a drug problem. An intellectual disability can make it even harder for the person to understand the problem and seek help.

If you are trying to help a person see that they need help:

- Choose the moment to talk. You will have a much better chance if the person is sober and you are both calm.
- Try to have open discussions where the person tells you about their drug use in ordinary conversation. Do lots of listening and show your concern. Discuss the pros and cons of drug use.
- Understand the drug – get the latest information on the drug and its effects.

Sometimes it will be a criminal charge that leads to a focus on a person's drug problem. There are some drug programs linked to the Local Court. Also, lawyers will often want to get their client into drug treatment to reduce the chances of a heavy sentence.

## Treatments for drug problems

Treatments for alcohol and other drug problems include:

- Case management.
- Individual and group counselling.
- Self help groups like Alcoholics and Narcotics Anonymous and SMART Recovery.
- Going to stay in a drug-free setting for a period of rehabilitation.
- Detoxification in a supervised setting
- Opioid Treatment Programs such as methadone and buprenorphine.

Often a person needs a combination of treatments. Successful treatment can take a number of attempts and a long time.

## How do I find a drug service?

If a person has taken drugs and suddenly becomes ill, dial 000 and ask for an ambulance.

Otherwise, you can access a local public drug and alcohol service by contacting your Local Health District or ring the Alcohol and Other Drugs Information Service (ADIS). See 'For more information'.

Lawyers and case managers often find it hard to get alcohol and other drug services for their clients with intellectual disability. Drug treatment services may say that their programs will not work for people with intellectual disability. But anti-discrimination law says that health services need to make reasonable adjustments to meet the needs of clients with a disability. You can expect drug treatment services to do this. You can offer them help to make these adjustments.

## Helping the drug service work with the person

A person with intellectual disability may find it hard to understand the language and concepts a drug worker is used to. The worker may need to communicate more simply with the person. A disability case manager, advocate or family member might be able to help the drug worker to adjust their usual approach. And they might be able to help the person understand what the drug worker has said and apply it day to day.

Also, the drug treatment will usually need to be part of an individual plan to meet the overall lifestyle and behaviour support needs of the person. The person will usually need a worker from disability services to develop this plan.

People with intellectual disability who use drugs often lack self esteem, positive relationships and activities. They are vulnerable to peer pressure. Drug services and disability services need to address these problems.

Some people with drug problems also have mental health issues. It may be very hard to treat the drug problem if the person is not receiving mental health treatment too.

## What if the drug treatment services say “No”?

If you feel that a drug treatment service has unfairly refused to assist a person with intellectual disability, try talking to the service manager. If that does not work, you can go to a complaints body. See the Rights and Complaints fact sheet.

## For more information

Alcohol and Other Drugs Information Service (ADIS)

A 24 hour 7 days a week confidential telephone counselling, support, referrals and information for those affected by alcohol or other drugs.

(02) 9361 8000 or Toll free 1800 422 599 (for people outside Sydney)

Complex Needs Capable, a practice resource for drug and alcohol services

[www.complexneeds capable.org.au](http://www.complexneeds capable.org.au)

Drug and alcohol service intake, NSW Health

Contact numbers for area intake services, consumer publications and information other drug programs.

[www.health.nsw.gov.au/aod/Pages/contact-service.aspx](http://www.health.nsw.gov.au/aod/Pages/contact-service.aspx)

Mental Health, Health NSW

[www.health.nsw.gov.au/mentalhealth/pages/default.aspx](http://www.health.nsw.gov.au/mentalhealth/pages/default.aspx)

Your Room, for facts about alcohol and other drugs

[www.yourroom.health.nsw.gov.au/Pages/home.aspx](http://www.yourroom.health.nsw.gov.au/Pages/home.aspx)

## You might be interested in these fact sheets

- **Helping the doctor understand the person**
- **Mental health**
- **Rights and complaints**

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# Causes of intellectual disability and health care

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Families and disability workers may be interested to know what causes an intellectual disability. Knowing the cause can help professionals advise how the person will develop and how to meet the person's needs.

Intellectual disability is not a disease or mental illness. But some causes of intellectual disability can make a person more likely to get particular health conditions.

In many cases doctors cannot identify what causes an intellectual disability. In other cases they can work out the cause. There can be many causes, including:

- genetic conditions
- problems during pregnancy
- problems at birth
- health problems in childhood

Paediatricians may be able to tell you the cause of intellectual disability. In some cases, the paediatrician will refer you to a specialist diagnosis and assessment service.

## Genetic conditions

One of the most common causes of intellectual disability is abnormal genes. Sometimes these are inherited from parents. Examples of genetic conditions are syndromes like Down syndrome, fragile X syndrome and Prader-Willi syndrome.

## Problems during pregnancy

There can be problems with the way the cells divide as a baby grows. Alcohol or drug consumption during pregnancy can be a cause. If a woman gets an infection like rubella (German measles) during pregnancy, then the baby may have intellectual disability.

## Problems at birth

Intellectual disability may occur if a baby does not get enough oxygen during labour or birth, or if a baby is born very premature.

## Health problems during childhood

Diseases like whooping cough, measles, or meningitis can cause intellectual disability. Intellectual disability can also be caused by extreme malnutrition, lack of good medical care, or being exposed to poisons like lead or mercury.

## Some syndromes and health conditions

Overall, people with intellectual disability are more likely than other people to have problems with hearing, vision, teeth, epilepsy, heart disease and thyroid function.

People with a specific syndrome may be more likely to get a particular disease or condition than other people. Here are some examples:

- People with Down syndrome may be born with heart defects.
- People with Prader-Willi syndrome may have Type 2 diabetes or delayed puberty.
- People with fragile X syndrome may have attention deficit hyperactivity disorder (ADHD).
- People with Angelmann syndrome may have severe epilepsy.
- Women with Rett Syndrome may break their bones more easily because they can have low bone density.

Some GPs may not be aware of the health conditions that affect people with specific syndromes. And so it is important to get advice from a paediatrician or another doctor who has specialised knowledge about intellectual disability.

## For more information

Down syndrome - Better Health Channel, Victoria

[www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/down-syndrome](http://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/down-syndrome)

In Health Care for People with Intellectual Disabilities – Guidelines for general practitioners, there is a list of health conditions that can occur with different syndromes

[www.aci.health.nsw.gov.au](http://www.aci.health.nsw.gov.au)

## You might be interested in this fact sheet

- **Diagnosis and assessment of a disability**

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A photograph of a young couple standing outdoors, seen from the waist down. They are both wearing jeans and plaid shirts. The person on the left is wearing a light-colored sweater over their plaid shirt. They have their hands clasped behind their backs. The background is a dense green hedge.

# Sexuality

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

All people have the right to make choices about relationships. Many people with intellectual disability have boyfriends, girlfriends, partners or spouses. People with intellectual disability have sexual feelings just like other people. They have the same choices to make about their sexuality.

People with intellectual disability often need information and support to help them make decisions about these issues.

## Education about relationships and sexuality

Education helps each person to think about and feel comfortable with their sexuality. It helps to make safe choices and protects them from abuse.

Education for a young person should start with topics like friendships, feelings, public and private, ok and not ok behaviours, parts of the body and the law. As people go through their teenage years, education moves on to subjects like menstruation, masturbation, consent, intercourse, safe sex, and heterosexual and same sex relationships.



Formal education is particularly important for people with intellectual disability. They are less likely to informally learn about sexuality from movies, the internet, magazines and talking to friends. They also find it harder to learn what is ok and not ok sexual behaviour.

The teacher should be a person who has been trained to run sexuality programs for people with intellectual disability. However support staff and family can help by being willing to talk, answering questions and reinforcing education.

## Privacy

All people need privacy and to respect other people's privacy. One important role of privacy is that it gives a person the opportunity to be sexual. This can mean masturbation. Or it can mean developing a relationship – kissing and cuddling and moving to a sexual relationship if the two people want that.

## The role of support workers and families

Workers and families have an important role in supporting a person with their sexuality. They can also be role models by doing things like:

- Using daily opportunities to talk about what is ok and not ok.
- Using a person's favourite TV show to talk about things like relationships.
- Knocking on a person's door and waiting for a response before entering.

Sometimes, support workers and families don't feel comfortable talking about sexuality. Then, it is important to help the person find someone else to talk to.

## Consent

People with intellectual disability have the right to decide if they want to be sexual but they can be vulnerable to exploitation.

For a person to consent to sexual touching, they need to understand that the other person is going to touch them in a sexual way. They have to be happy about what is happening and know they can say yes or no. It can be difficult to know whether a person is able to give consent. You can consult a professional like a psychologist if you are unsure.

NSW also has laws to protect people with intellectual disability from sexual exploitation. It is a crime for a disability worker to have sex with a person with intellectual disability. And it is a crime for anyone to take advantage of a person's intellectual disability to get them to have sex. Consent is no excuse for these crimes.

## Sexual health

Education needs to cover the risks of sexually transmissible infections (STIs). People need to learn about their own bodies including the importance of seeing a doctor if they see changes in their breasts and testes. Also, women 25-74 years old should have a Cervical Screening Test, every five years or earlier if the woman has the HPV virus.

Some people with intellectual disability have very delayed puberty. A doctor can investigate the cause of this.

## For more information

Family Planning NSW has:

- Education resources for people with intellectual disability and education programs for disability workers.
- Clinics where people can see a doctor or nurse for advice.
- A telephone advice line staffed by nurses: **1300 658 886**
- Website [www.fpnsw.org.au](http://www.fpnsw.org.au)

There is information on Family Planning Associations in other parts of Australia at [www.familyplanningallianceaustralia.org.au/services](http://www.familyplanningallianceaustralia.org.au/services)

The Intellectual Disability Rights Service provides legal advice and information.

Phone **(02) 9318 0144** or freecall **1800 666 611**

[www.idrs.org.au](http://www.idrs.org.au)

Being a healthy woman is a book for women with intellectual disability, their families and disability workers.

[www.health.nsw.gov.au/disability/Pages/being-a-healthy-woman.aspx](http://www.health.nsw.gov.au/disability/Pages/being-a-healthy-woman.aspx)

## You might be interested in these fact sheets

- Contraception
- Managing menstruation
- Preventive health

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# Contraception

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

People with intellectual disability have the same choices about contraception as other people. But, they will often need clear information and support to make choices.

## Types of contraception

There are lots of types of contraception to choose from. Some common ones are:

**Condoms** – If condoms are used properly, they are a very reliable contraceptive. They should always be used with a water based lubricant. Condoms are the only contraceptive that help to stop the spread of sexually transmissible infections (STIs). A person may need to be taught how to use condoms just like teaching any other skill. The teacher can use pictures and help the person practise on an object shaped like a penis.

**The pill** – The contraceptive pill is a reliable contraceptive as long as the woman remembers to take it every day. The pill may not work if the woman has vomiting or diarrhoea or is taking particular medications (including some anti-epileptic medication). The pharmacist can put the pill into a blister pack or dosette box.

**Contraceptive injection (eg Depo-Provera)** – This is an injection that is given to a woman every three months.

**Hormone implants (eg Implanon)** – This is a small rod that is put under the woman’s skin. It can stay in place for up to three years. It needs to be inserted and removed by a doctor.

**IUD** – An Intra Uterine Device is put into a woman’s uterus by a specially trained doctor. The doctor can also remove it. IUDs and implants are very reliable.

## Deciding on contraceptive options

People with intellectual disability are more likely to understand about contraceptive options if they are clearly explained with the help of pictures.

Most contraceptives are medical treatments and so the doctor needs consent from the person. Adults can consent for themselves if they understand the general nature and effect of the contraceptive, for example it is a pill that will stop you getting pregnant if you have sex. If the person cannot consent, NSW law says that the doctor needs consent from a “person responsible” (usually a guardian or close family member).

## Personal choice

Each person has the right to make contraceptive choices. People consider personal factors when deciding about contraception:

- Religious and cultural beliefs – Some religions say that preventing pregnancy is wrong and that people should avoid having sex altogether if they do not want to have a baby.
- Personal beliefs – For example, a person might be influenced by their own past experiences or the contraception being used by close family or friends.
- Relationships – For example, if a person is not in a long term relationship they may choose to use condoms.
- What suits the person – Sometimes people try a few different types before they find the right one for them and their partner. Sometimes the best choice of contraception may change as the woman gets older.

## Sterilisation operations

Some operations are intended to make sure a person does not become a parent. A woman can have her tubes tied or blocked (sometimes called a tubal ligation) or a hysterectomy where her uterus is removed. A man can have a vasectomy.

Because these operations have such a big effect on a person’s life, they need to be approached very cautiously. The doctor should make sure that the person has thought about the operation very carefully and can consent. The person needs a higher level of understanding than for a simple treatment.

In NSW, if an adult does not understand a sterilisation operation, it requires the consent of the Guardianship Division of NSW Civil and Administrative Tribunal. The Tribunal can only give consent if the operation is needed to prevent serious damage to the person’s health. A child can only be sterilised with the consent of the Guardianship Division or the consent of the Family Court

## Role of professionals

A person's GP is the best place to start for information and to talk about which contraception is best for the particular person. Think about booking a longer consultation so there is enough time to ask questions.

Support workers and family have an important role in supporting the person with intellectual disability in this area of their life. Some carers feel uncomfortable discussing things like contraception. If so, you can contact Family Planning for advice or education.

## For more information

See the places to get information and advice at the end of the **Sexuality** fact sheet.

Family Planning NSW [www.fpnsw.org.au](http://www.fpnsw.org.au)

## You might be interested in these fact sheets

- Consent to medical treatment
- Managing menstruation
- Sexuality

This fact sheet was updated in **2018**.

The fact sheet contains general information only and does not take into account individual circumstances. It should not be relied on for medical advice. We encourage you to look at the information in this fact sheet carefully with your health professional to decide whether the information is right for you.

# Managing menstruation

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Periods are a normal part of being a woman. Women with intellectual disability have the same choices as other women. Managing periods is not a problem for most women with intellectual disability. But for some, it can be complicated.

Women with intellectual disability often need clear information and support to make choices about their periods.

## Assisting women to manage their periods

All women should be given the opportunity to manage their own periods. They might need:

- Teaching - Women should be taught to manage their periods as independently as possible. Some women learn quickly. Some need formal teaching programs and regular refreshers of their knowledge.
- Support - Some women need someone to change their pads and underwear. Some need reminders to change pads or someone in the background prompting them through the process.

If you are helping a woman with her periods, you should be respectful of her dignity and privacy. Let the



women choose who supports her with this personal task. Many women would be uncomfortable being supported by a man. Also, people's religious and cultural beliefs can affect how they manage their periods.

When supporting any person with personal care, remember the basics of good hygiene.

## Problems with periods

Families and support workers should watch out for:

- Painful periods - ordinary pain relief medication may help.
- Heavy periods need close monitoring. It may be a woman's normal period but new heavy bleeding may need further review and she should see a doctor.
- Some women do not have regular periods. Keep notes of the dates and changed amounts to help the doctor.
- Pre-menstrual syndrome (PMS) - can include tender breasts, headaches, mood swings and crying. PMS occurs before a period starts.
- Sometimes, epilepsy can be harder to control around the time of a woman's period.

If any of these problems is having an impact on a woman's life, a visit to the doctor is necessary.

Also, a woman should see a doctor if her periods stop. This could mean pregnancy, menopause or other conditions. Sometimes, a woman may not even start to have periods. Ask the doctor to investigate why this is so.

## Role of the general practitioner

A GP may do some tests to understand what is happening. These might include a physical examination, a blood test, an ultrasound or the Cervical Screening Test. This can be frightening and the woman may need lots of support from someone she trusts. Sometimes, the GP will refer on to a specialist women's doctor - a gynaecologist.

## Treatments for problem periods

If a woman is having major problems with her periods, the doctor might suggest a treatment to control or even stop the periods. These include the contraceptive pill, or implanted devices- like 'Implanon' (put in the upper arm for two years) or 'Mirena' (put in the uterus for five years).

All medications can have side effects. Ask the doctor what to watch out for. It may take time to find the treatment that best suits the woman.

The woman may need support to understand and decide about these treatments. If she understands it is her choice and decision. If she does not understand, NSW law says that the doctor needs consent from a "person responsible" (usually a guardian or close family member) or the Guardianship Division of the NSW Civil and Administrative Tribunal.



Decisions about treatment for problem periods must be based on what is best for the woman. Periods should not be stopped just to make life easier for carers.

## Operations to stop periods

Occasionally, major health problems lead a woman to consider an operation which will stop her periods permanently. This could be a hysterectomy or an endometrial ablation. This is the same for women with or without a disability. Special legal rules apply to these operations since they result in sterilisation of the woman so that she can never have children. See the **Contraception** fact sheet for information about the legal consent required for these operations.

## For more information

See the places to get information and advice at the end of the **Sexuality** fact sheet.

There are resources on managing menstruation on the following websites

Centre for Developmental Disability Health (Victoria)

[www.cddh.monash.org](http://www.cddh.monash.org)

Queensland Centre for Intellectual and Developmental Disability

[www.qcidd.centre.uq.edu.au](http://www.qcidd.centre.uq.edu.au)

Family Planning NSW

[www.fpnsw.org.au](http://www.fpnsw.org.au)

## You might be interested in these fact sheets

- **Consent to medical treatment**
- **Contraception**
- **Sexuality**

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# Finding the right doctor

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

We all need a good GP who we feel comfortable with. This is even more important for a person with intellectual disability who may not be able to explain symptoms and may feel anxious about visits to the doctor.

Some doctors are really good at communicating with a person with intellectual disability, taking extra time in getting the person relaxed. But, how do you find the right doctor?

Once you have found a doctor that suits the person, you should try to see that doctor every time. They will get to know the person's health, and the person will feel more comfortable with someone they know.

## Tips for finding the right GP

- Talk to the person with intellectual disability or think about what will suit them. Is the person more comfortable with women or men? With older people or younger?
- Talk to other families and disability workers. Is there a doctor they can recommend?
- Phone a specialised health service for people with intellectual disability and see if they have any suggestions.

- Phone the local Primary Health Network, and ask if they have contact details of doctors who have an interest in people with an intellectual disability.
- Check if the doctor bulk bills. Is the doctor happy to do an annual Medicare health assessment? And then to coordinate any follow up with allied health professionals and specialist doctors.
- Ask the doctor if they have experience with people with intellectual disability. If not, is the doctor keen to know more? Would they like you to provide some written information?
- Is the doctor happy to talk with disability professionals, for example about a coordinated response to challenging behaviour or a weight problem?
- If the person has limited mobility, does the doctor have a height adjustable examination bed (as required by the Standards of the Royal Australian College of General Practitioners, 5<sup>th</sup> Ed).
- Establish a relationship with the doctor by arranging the first visit when the person is well. The doctor can see what the person is like when they are not sick.

## Finding other health professionals

Sometimes the person with intellectual disability will need to see a specialist doctor or an allied health professional like a physiotherapist. The GP may have someone to refer you to. However, it is often a good idea to look around for someone who will suit the person, just like finding a GP.

You might also be able to find allied health professionals through:

- Your local disability services.
- The local community health centre of NSW Health.
- Professional associations, for example the Dietitians Association of Australia.
- Primary Health Networks.

If a person has complex health problems, sometimes they may need to see a health service that specialises in health care of people with intellectual disability.

Some of the other fact sheets have information about how to find particular kinds of health professionals.

## For more information

Choosing a GP, CHOICE Australia fact sheet

[www.choice.com.au](http://www.choice.com.au)

Contact details for Primary Health Networks

[www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Home](http://www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Home)

Allied Health Professions Australia

[www.ahpa.com.au](http://www.ahpa.com.au)

Hospitals/Health Services

[www.health.nsw.gov.au/hospitals/pages/default.aspx](http://www.health.nsw.gov.au/hospitals/pages/default.aspx)

Find a Health Service

[www.healthdirect.gov.au/australian-health-services](http://www.healthdirect.gov.au/australian-health-services)

**1800 022 222** – for 24 hour health advice and information

## You might be interested in these fact sheets

- **Alcohol and other drugs**
- **Annual health assessments**
- **Going to the doctor – tips and tricks**
- **Helping the doctor understand the person**
- **Mental health**
- **Specialised intellectual disability health services**

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# Going to the dentist

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

People with intellectual disability should go to the dentist at least every six months. Many people find it hard to tell the dentist that they have a toothache or sore gums. They may be anxious about what is going to happen at the dentist.

A lot of dentists are not trained to meet the needs of people with intellectual disability. It is important to try to find one who does have these skills.

## Finding the right dentist

### Public dental clinics

Most people with intellectual disability go to public dental clinics. These are located around NSW and do not charge. However, they usually have long waiting lists and the dentists are not always skilled in working with people with specific communication needs.

To go to a public dental clinic you need to phone for an appointment. The clinic will ask you questions to work out what priority to give to the person requiring dental care. A person with intellectual disability may have to wait for as long as six months for an appointment, and so it is very important to speak up if that is too long. If the person seems to be in pain they should get an appointment within 10 days. You should also explain if the person may need sedation or a general anaesthetic when they have treatment.

If you feel that the dental clinic staff member you are talking to would benefit from specialist advice, you can suggest they ring the Special Care Dentistry units at Westmead or Sydney Dental Hospital.

### **Specialist public clinics**

There are two specialist dental services for people with intellectual disability and other complex needs:

- The Special Care Dentistry Unit at Westmead Centre for Oral Health
- The Sydney Dental Hospital Special Care Dentistry Department

Some people with intellectual disability need to get their dental treatment at these services. Your doctor or dentist can refer the person by a letter which must include the person's name, address, telephone, medical history, type of disability and Medicare number. You will get a letter saying the referral has been received.

### **Private dentists**

Some private dentists are experienced with people with intellectual disability but they do charge fees. If you have private health insurance this may cover part of the fees.

Medicare covers some dental fees if a person's dental problems are likely to affect their general health, for example some people with respiratory illness. However, this does not apply if the person needs a general anaesthetic for the dental treatment.

If you are looking for a private dentist, ask around your network. Other families, disability services or your GP may know a dentist with the right skills. Think about what kind of people the person with intellectual disability is relaxed with. For example, is the person more comfortable with men or women? See the **Finding the right doctor** fact sheet for some more ideas.

The Special Care Dentistry Unit at Westmead may also be able to refer you to a suitable dentist.

## **Being prepared**

Some people with intellectual disability go to the dentist alone and can communicate well with the dentist. Others will need varying levels of support.

Who will go with the person to the dentist? It should be someone who gets on well with the person and knows them well. If an accommodation worker is making the appointment, they should check if a family member or advocate wants to go too.

If a person is likely to be anxious at the dentist, it may help to prepare them by explaining what will happen and showing them pictures of a dentist. It can help to make the first visit a social visit so that the person can see the surgery and meet the dentist. Bring something that will help the person with anxiety, for example portable music.

See **Your Dental Health: A Guide for People with a Disability, Their Family Carers, Friends and Advocates** for online videos and information for people with intellectual disability about dental care and what to expect during a visit to the dentist. The guide also includes information for dentists about working with people with intellectual disability.

You should write down a list of signs that indicate the person has dental problems. For example:

- Does the person seem uncomfortable or in pain when eating or drinking items that are hot or cold, sweet or acidic?
- Is the person resisting having their teeth brushed? Do the gums bleed?
- Does the person have bad breath?
- Sudden or unusual behaviour changes may indicate that a person is in pain.

When you go to the dentist, take the person's health records and a personal profile for the dentist to look at. See the fact sheets on **Personal health records** and **Helping the doctor understand the person**.

If the person has limited mobility, make sure that the dental clinic and equipment is accessible.

Tell the receptionist if the person will have trouble with waiting or if an interpreter is needed. They can phone Translating and Interpreting Service (TIS) National on **131 450**.

## During the visit

- Make sure the dentist explains what is happening and what they are going to do. Encourage the dentist to speak directly to the person with intellectual disability rather than the support person. See the **Helping the doctor understand the person** fact sheet for other ways to help the dentist communicate with the person.
- Make sure the person or support person gets all the information needed to decide about treatment options. Remember that the dentist needs consent from the person or a "person responsible" – usually a family member.
- Ask the dentist to do normal preventive care, for example removal of plaque, as well as doing any fillings.
- Ask the dentist if there is more that can be done at home to prevent dental problems.
- Some people will be anxious during dental examinations and treatment. It may help if the dentist uses the person's own toothbrush to examine their mouth. People who are very anxious or have involuntary body movements may need sedation or a general anaesthetic.

## After the visit

If there are further appointments or follow up needed, make sure you explain this clearly to the person with intellectual disability and check that they understand.

If there are things to do at home, for example rinsing for a day with a mouth wash, make sure the dentist explains or demonstrates this to the person. And, if the person has more than one carer, make sure they all know what to do.



## For more information

**Your Dental Health:** A Guide for People with a Disability, Their Family Carers, Friends and Advocates.  
[www.inclusiondesignlab.org.au/what-weve-learnt/dental/](http://www.inclusiondesignlab.org.au/what-weve-learnt/dental/)

To locate your local public dental clinic, call your Local Health District oral health service call centre as listed on [www.health.nsw.gov.au/oralhealth/pages/call-centre-search.aspx](http://www.health.nsw.gov.au/oralhealth/pages/call-centre-search.aspx) or call NSW Health (02) 9391 9000 or TTY (02) 9391 9900

Special Care Dentistry Unit at Westmead Centre for Oral Health  
[www.wslhd.health.nsw.gov.au/Westmead-Centre-for-Oral-Health/Departments-and-Clinics/Special-Care-Dentistry](http://www.wslhd.health.nsw.gov.au/Westmead-Centre-for-Oral-Health/Departments-and-Clinics/Special-Care-Dentistry)

Phone (02) 8890 7424 or 8890 7423

For Emergency Treatment Phone (02) 8890 6766

(Provides emergency treatment for the management of dental pain and acute dental problems for patients over 15 years of age).

Sydney Dental Hospital Special Care Dentistry Department  
[www.slhd.nsw.gov.au/carers/help\\_dental.html](http://www.slhd.nsw.gov.au/carers/help_dental.html)

Phone (02) 9293 3333

## You might be interested in these fact sheets

- **Dental care** - information about kinds of dental problems, good dental care at home and what the dentist can do to prevent dental problems.
- **Consent to medical treatment**
- **Getting the most out of Medicare**
- **Going to the doctor - tips and tricks**
- **Helping the doctor understand the person**
- **Personal health records**

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# Specialised intellectual disability health services

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

When you have a health problem you usually go to a GP first. Sometimes, the GP refers you on to a specialist doctor or an allied health professional like a physiotherapist. Children with intellectual disability and complex health conditions will often have a paediatrician to help with their health care.

But sometimes, GPs and other mainstream health professionals struggle to diagnose and treat people with intellectual disability. A health service that specialises in working with people with intellectual disability may need to be approached as suggested in this health factsheet.

Following increased funding in the 2018 NSW budget, there will be more services in NSW that specialise in people with intellectual disability.

At the time of updating this fact sheet, contact details for the new services were not available and the impact of those services on some existing services was not clear. We will update this fact sheet with a full list of services and contact details as soon as possible.

## Services existing prior to 2019

These included:

- Disability Assessment and Rehabilitation Team for Young People (DARTYP) at Concord Hospital.
- Disability Health Team – Fairfield.
- Kogarah Developmental Assessment Services and Metro-Regional Intellectual Disability Network.
- NSW Developmental Disability Health Unit – Ryde.
- Northern Sydney Intellectual Disability Health Team.
- Westmead Hospital specialised services.
- 3DN Clinic, Prince of Wales Hospital (complex psychiatry second opinions).
- Psychiatric Clinic, Concord Hospital.
- A small number of private psychiatrists who specialise in working with people with intellectual disability.

These services usually require a referral from a GP or another specialist doctor.

## For children

Diagnosis and Assessment Services can help with complex health conditions of children with intellectual disability.

Diagnosis and Assessment Services often have a developmental paediatrician. This is a paediatrician who specialises in working with children with intellectual and other developmental disabilities. A general paediatrician can refer a patient to a developmental paediatrician.

See the **Diagnosis and assessment of a disability** fact sheet.

## New statewide network of intellectual disability health services

From mid 2019 there will be a specialised intellectual disability health team in six Local Health Districts (LHDs) and a specialist health worker in the other Districts.

The LHDs with teams will be:

- Sydney
- Northern Sydney
- South Eastern Sydney
- South Western Sydney
- Hunter New England
- Western NSW

Each of the teams will provide outreach services to one or two of the other LHDs.

The teams are focussed on people of all ages and will include a physician, a psychiatrist, a nurse, a social worker and other health professionals.

The new services' roles are to provide:

- Comprehensive health assessments and health care plans for people with complex health needs.
- Advice and skill development for GPs, hospitals and other health services.

The services will provide advice and support to a person's usual doctor rather than taking over from the usual doctor.

## New mental health centres

There are two new statewide tertiary mental health services being set up at:

- The Children's Hospital at Westmead for children and young people.
- Concord Hospital for adults.

These services will provide short term assessment and advice for people with intellectual disability and complex mental health needs including advice to the person's usual doctor.

## For more information

See **Going to the dentist** for information about specialised dental services.

See **More information** for specialised centres in Victoria, Queensland and South Australia.

Maps of the NSW Local Health Districts [www.health.nsw.gov.au/lhd](http://www.health.nsw.gov.au/lhd)

- **You might be interested in these fact sheets**
- **Adults - what kinds of health services are there?**
- **Alcohol and other drugs**

# Getting the most out of Medicare

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

For many people, Medicare covers much more than just going to the doctor when they are sick.

If you think that items in this fact sheet might be useful for a person with intellectual disability, take this fact sheet with you when you go to the doctor.

## The Healthy Kids Check

Every four year old child can have a free health check by a GP. The doctor can identify signs of a disability and provide advice on healthy lifestyles.

## GP Management Plans and Team Care Arrangements

For people with a chronic or terminal medical condition, a GP can write a "Chronic disease GP Management Plan" to help with treatment. Chronic conditions include ones like diabetes, asthma, and heart disease.

If the chronic or terminal condition requires ongoing treatment from a multidisciplinary team (nurse, other doctors, allied health therapists) then the GP can also create a "Team Care Arrangement".

## Allied health services

Medicare covers allied health services for a person who has a Team Care Arrangement up to 5 visits each year. Allied health services include dietitians, physiotherapists, speech pathologists, audiologists, psychologists, occupational therapists and Aboriginal health workers.

## Early intervention for children

Better Start for Children with Disability has provided funding for early intervention and allied health services for children under 6 years old with conditions such as Cerebral Palsy and Down syndrome. The Helping Children with Autism (HCWA) package has provided similar funding for children with autism.

This funding is being phased out with implementation of the NDIS.

Better Start and HCWA also have special Medicare items that allow a paediatrician or psychiatrist to diagnose, review and manage a child and make referrals to allied health services. A management plan needs to be prepared by the child's 13th birthday and up to 20 therapy sessions used by their 15th birthday. These Medicare payments may continue to be available after NDIS implementation.

## Group services for people with type 2 diabetes

If a person has a GP Management Plan, the GP can refer the person for group sessions to help manage their diabetes.

## Mental health care

The GP Mental Health Treatment Plan and Review services are suitable for people with a mental health issue, the issue must significantly interfere with their social, emotional or cognitive abilities. The GP may use this plan to suggest strategies, such as seeing a psychologist, at a discounted rate. Psychiatrists can also do an assessment and management plan and refer the person to allied health professionals.

## Dental services

For adults with a health care card or pension concession card, public dental services are provided free of charge. An 'Oral Health Specialist Referral' form can be completed by your doctor. Two sites are available for adults - Sydney Dental Hospital and Westmead Centre for Oral Health.



## Specialist physicians

These include paediatricians, adult physicians, neurologists and psychiatrists, among others. As well as standard consultations, Medicare has special items for a physician:

- Assessing and preparing a treatment plan for a person with intellectual disability and a complex health problem.
- Organising or attending a case conference with a team of health and care workers.

## Will Medicare cover the whole bill?

Medicare only covers the full fee if the health professional bulk bills. However, Medicare keeps an eye on costs and once your costs reach the Medicare Safety Net threshold, further Medicare refunds will be at a higher rate (the Extended Medicare Safety Net).

Private health insurance may also allow some costs to be refunded.

Remember that Medicare is for payment of private health professionals. There are also some free health services provided by government.

## Language/hearing barriers

For people who are deaf, Auslan interpreters are available for no cost at medical appointments. Bookings need to be arranged in advance. (Phone 1800 246 945)

The Translating and Interpreting Service is for people who do not speak English. Phone interpreting is available 24 hours a day, seven days a week by phoning 131 450.

## For more information:

Better Start for Children with Disability [www.betterstart.net.au](http://www.betterstart.net.au)

Helping Children with Autism [www.dss.gov.au](http://www.dss.gov.au)

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# Going to the doctor – tips and tricks

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

It can be hard for a doctor to work out what illness a person with intellectual disability has, especially if the person has limited verbal communication. Most doctors are very busy and try to keep appointments as short as possible. So it is very important to be well prepared to make the most of a visit to the doctor.

## Making an appointment

If the person with disability finds waiting difficult, you can try to book the first appointment of the day, or the first after the doctor's lunch break. Or the receptionist might be able to phone you to say you are next to see the doctor. It is always worth building a relationship with the receptionist and explaining any special needs the person has. If you have a lot to ask the doctor about, try to book a double appointment.

Who will go with the person to the doctor? It should be someone who gets on well with them and knows them well. If an accommodation worker is making the appointment, they should check if a family member or advocate wants to go too.

## If an interpreter is needed

Tell the receptionist if you need an interpreter. The interpreter might come to the appointment or be available by phone. Interpreters for NSW health services are available free for people who are deaf or not fluent in English. GPs can use the Doctors Priority Line **1300 655 820**. Or phone Translating and Interpreting Service (TIS) National on **131 450**.

## Be prepared

- Be clear about the reason for the visit. Write down any symptoms and questions you want to ask.
- Help the person to be ready for the visit. Explain why you are going and reassure them if they are anxious. What questions do they have for the doctor?
- Is there a disability professional the doctor should talk to, for example a psychologist who has assessed the person's behaviour? Maybe, they could attend, write a report or be available for the doctor to ring.
- Take the person's medical records, current medications and My Health Matters folder or a one page profile of the person which includes how they communicate.
- Is there other important information to take? For example, an article about intellectual disability that might help the doctor.
- Take a notebook and pen so you can write down what the doctor says.
- Make sure you and the person are dressed well. People make unconscious judgments about others based on their appearance.

## During the visit

- Be aware that doctors don't always think about common problems when treating people with intellectual disability, for example hearing and obesity. Ask about anything that you or the person are worried about. Ask how to prevent health problems. Ask the doctor to do a comprehensive health assessment each year.
- Encourage the doctor to talk directly to the person with disability. For example the doctor should explain if they want to examine the person and check the person is okay with this. Suggest an icebreaker for conversation. Show the doctor how to talk to the person about health issues. Check if the person wants to ask any questions.
- Make sure the person (or you) gets all the information needed to decide about treatment options. Remember that the doctor needs consent from the person or a "person responsible" – usually a family member.
- If new medication is prescribed, ask about side effects to watch out for.
- Ask the doctor to write down an action plan and to explain difficult words.
- Trust your instincts and ask questions. There is nothing wrong with asking for a second opinion or a referral to a specialist.

## After the visit

Following up is important.

- Check that the person understood what happened and what the doctor said.
- Make sure there is a system in place to carry out the action plan that you worked out with the doctor. Think about who needs to know about the action required and things to watch out for.
- Does any other professional need to know what the doctor said? For example, a psychologist who is helping with the person's behaviour or a speech pathologist who is helping with swallowing problems.
- If you are not clear on what the doctor recommended, ring the clinic. Also, some doctors are happy to clarify things by email.
- Plan when the person should go back to the doctor for review.

## For more information

Questions to ask your doctor

[www.healthinsite.gov.au/topics/Questions\\_to\\_Ask\\_Your\\_Health\\_Professional](http://www.healthinsite.gov.au/topics/Questions_to_Ask_Your_Health_Professional)

For ways to help a person be ready for health checks like blood tests and x rays, see

Desensitisation programs at

[www.qcidd.centre.uq.edu.au/resources/desensitisation-programs](http://www.qcidd.centre.uq.edu.au/resources/desensitisation-programs)

## You might be interested in these fact sheets

- **Annual health assessments**
- **Consent to medical treatment**
- **Finding the right doctor**
- **Helping the doctor understand the person**
- **Personal health records**

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# Helping the doctor understand the person

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

You are the only person who can fully explain your symptoms to the doctor. But doctors are often not experienced in communicating with people with intellectual disability and may not know how a particular person communicates. So it is important to help the doctor communicate with the person. This will help the doctor get information and explain the problem to the person, and help the person relax and participate in treatment decisions.

Also, the doctor needs to know what the person is like when they are well. Otherwise, the doctor might assume that some symptoms are just part of the disability. For example, if the person is unusually lethargic, the doctor needs to know how active they usually are.

## General tips for communication

There are lots of ways to help the doctor communicate with patients with disability. Consider these ideas.

- Try to see a doctor the person is comfortable with and try to see the same doctor every time.
- Introduce the person to the doctor first before introducing yourself.
- If the doctor starts by asking you questions, repeat them to the person for them to answer. Or ask the person if it is okay for you to talk about their health problem.

- Explain to the doctor how the person communicates.
- Ask the doctor to speak slowly and clearly, and to explain difficult ideas in simple words. Sometimes, you may need to repeat what the doctor has said using easier language.
- Check that the person understands, for example by getting them to tell you what the doctor has said. See if the person has questions for the doctor.
- Ask the doctor to show the person diagrams, testing equipment or tablets.
- If an interpreter is used, tell them beforehand about the best way to communicate with the person.
- If the doctor is rushed or the health problem is complicated, offer to come back when the doctor has more time.

If available, refer to the person's 'My Health Matters' folder. If this hasn't been completed, fill out the Top 5 section which is the 5 most important things people need to know about the person. This could be about their disability, health, behaviour or communication.

Some people do not use many words, but have other ways to express themselves. Some people use sign language or pictures. Other people may have hand and facial gestures that have clear meaning. It is important that you understand the person's way of communicating, and explain it to the doctor – so that they can talk directly with the person as much as possible.

## Preparation

You can help the person be ready to talk with the doctor. Explain to them what will happen at the visit. Help them to think about what they want to tell the doctor and questions to ask.

If the doctor wants to examine the person or take a blood sample, make sure they explain this to them and get their okay.

You may be able to relax the person during an examination by reassuring them and by using physical contact, such as holding their hand.

## Making a personal profile

A profile of the person can help the doctor communicate with the person and understand what they are like when well. You can use the My Health Matters folder to create a detailed profile of the person. Family, support workers and advocates are important partners with the person in putting together a personal profile. You should explain to the person why the record is being developed and check they are okay about the information that is included.

The profile should cover:

- What the person is like when well – things they are good at and favourite activities. Is the person usually happy and active? Include a recent photo.
- How the person communicates. For people who do not use many words, cover other ways they communicate, for example signs used, how they show pain and contentment, how they express Yes and No.



- Suggestions for conversation starters, for example favourite football team or TV show.
- Strategies to help the person stay calm and cooperate with medical procedures.
- Any relevant religious or cultural practices - for example dietary restrictions or fasting periods, alternative therapies or herbal supplements.

The profile should usually be just one page. Include it in the person's personal health record.

## How the personal profile is used

Always take the profile with you when visiting a health professional. Show it to them at the start of the visit.

Personal profiles should be regularly updated with input from the person, family, advocates and support workers.

## For more information

Working with people with intellectual disabilities in healthcare settings Fact Sheet (Centre for Development Disability Health Victoria)

[www.cddh.monashhealth.org/wp-content/uploads/2016/11/2016-working-with-people-with-intellectual-disabilities.pdf](http://www.cddh.monashhealth.org/wp-content/uploads/2016/11/2016-working-with-people-with-intellectual-disabilities.pdf)

## You might be interested in these fact sheets

- **Going to the doctor - tips and tricks**
- **Personal health records**

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# Personal health records

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

People with intellectual disability often find it hard to tell the doctor about their medical history. And often doctors are not experienced in treating people with intellectual disability. So it is very important for a person with intellectual disability to have a health record that provides their doctor with information about them and their medical history.

## Collecting information

Usually, family, support workers and advocates are important partners with the person in putting the health record together and checking it is accurate and up to date. They may all have vital information to include. It is very important that the person with intellectual disability is involved. You should explain why the record is being developed and check the person is okay about the information that is included.

Find all the person's health related documents, for example medical and psychology reports, test results, X-Rays and medication charts. You may need to dig out old service files to find some important information.

If the person has complex health needs or has recently moved to Australia, consider getting a comprehensive health assessment done at a specialist clinic for people with intellectual disability. This is a good baseline for everyone.

## How to organise a personal health record

A good starting point is using CID's My Health Matters folder [www.cid.org.au/mh](http://www.cid.org.au/mh)

Within the folder can be recorded a personal profile, preferred communication methods, health and behaviour information. Additional important information should also be added to the folder.

If you are unable to access a My Health Matters folder, use a ring binder to make your own.

All personal health records should contain:

1. A clear plastic sleeve for the person's Medicare card and Health Care card.
2. A one page summary of basic health details:
  - The person's full name, date of birth, address and language spoken.
  - Current medication, dosages and how it is administered.
  - Height, weight, blood group, allergies.
  - Medicare and pension numbers.
  - Contact details of general practitioner and other health professionals.
  - Contact details of guardian, person responsible and case manager (if relevant).
  - Any special swallowing or nutrition needs.
  - Any emergency information.
3. The person's current health care plan if there is one.
4. A running sheet listing significant conditions that have been diagnosed (for example diabetes, asthma) and procedures or operations (for example tonsils taken out).

These important things could be:

- If the person has a serious medical issue, what is it and what do people need to know about it?
  - If the person has communication barriers, what are the important signs they use to let people know what they need or want?
5. A list of medications the person has used and their effects.
  6. Lists of immunisations and allergies.
  7. Major health conditions that family members have had.
  8. A running sheet of each visit to a health professional, including the health issue, any medical tests or medications, and instructions from the professional.
  9. All annual health reviews and other health assessments, reports and charts.
  10. Any other material relevant to the person's health care, such as contact details of useful organisations.

## How to use the personal health record

Take the health record every time the person goes to a health professional. Show them the folder at the start of the visit, especially the first summary page. Be sure you know what is in the folder so you can speak up if there is something relevant the doctor should know.

Keep updating the running sheets and other parts of the health record.

If the person spends time away from home, they should take a copy of important information.

## My Health Record (eHealth)

The My Health Record (MHR) is an electronic health summary that has been set up by the Australian Government. Unless they have opted out of MHR, everyone now has one that includes some basic information.

An MHR will eventually contain key health information drawn from the existing electronic records of multiple healthcare providers involved in a person's care. MHR will include details like allergies, medical conditions and treatments, medications, and test or scan results.

Healthcare providers like doctors, specialists and hospital staff may be able to see the person's MHR online at any time if they need to, such as in an accident or emergency

The person can control what information goes into MHR and which organisations have access to their record.

If an adult with intellectual disability cannot be supported to make their own MHR decisions, another person like a family member can become authorised representative for the person. Parents can also be authorised representatives for their children.

See the link below to find out more about My Health Record. There is a fact sheet for people with limited literacy skills.

## For more information

My Health Matters  
[www.cid.org.au/mhm](http://www.cid.org.au/mhm)

My Health Record – information on the electronic health summary established by the Australian Government.  
[www.myhealthrecord.gov.au](http://www.myhealthrecord.gov.au)

## You might be interested in these fact sheets

- Annual health assessments
- Consent to medical treatment
- Going to the doctor - tips and tricks
- Helping the doctor understand the person
- Specialised intellectual disability health services

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# Going to hospital

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

A stay in hospital can be stressful and confusing for a person with intellectual disability. If you plan the visit carefully with the hospital, the stay should go as smoothly as possible.

People with intellectual disability should receive the same quality of care in a hospital as anyone else. Sometimes, families, advocates and support workers need to speak up to make sure this happens.

## Preparation and planning

Most hospitals will do pre-admission planning. You can raise all the issues that need to be worked out to make the hospital visit go smoothly. You should support the person with intellectual disability to be involved in this process. If a disability service has a nurse on its staff, involve the nurse in pre-admission planning.

Be ready to provide the hospital with these documents:

- A personal profile including information about how the person communicates
- Up to date information about the person's health
- Details of who can consent to any treatment that the person does not understand.



You should already have these documents in the person's health record, My Health Matters folder or an online My Health Record.

See the Personal health records fact sheet. The pre-admission plan should also include:

- How to make the hospital stay as stress free as possible. If the person is likely to need behaviour support, you may need to involve a psychologist.
- Providing information about the person's personal care needs such as feeding and bathing. How will these needs be met in hospital? Hospital staff may request families or support workers to help with this.
- If available, provide the 'My Health Matters' folder. If this hasn't been completed, fill out the Top 5 section, which is the 5 most important things people need to know about the person. This could be about their disability, health, behaviour or communication.

Important information about the person with intellectual disability could be:

- If they have a serious medical issue, what is it and what do people need know about it?
- If they have a communication barrier, what are the important signs do they use to let people know what they want or don't want?
- How to make sure the person does not lose skills while in hospital.
- What arrangements need to be planned for discharge from hospital?

Emergency admissions cannot be planned for but it is useful to always have at hand a brief document that lists the person's medications, allergies, communication needs, swallowing and nutrition needs, etc. You should already have this information in the front of the person's health record. Also, take the person's current medications to hospital.

## Supporting the person

Before the hospital stay, it may help the person to look at pictures of hospitals and health professionals or even visit the hospital. If the person will need things like crutches or a cast, try to explain this in advance or show them to the person.

It may help to take to hospital some personal items, such as photographs and games. Also try to organise visits from friends, workmates and housemates.

Hospital social workers and patient liaison officers can also support the patient and their family.

## Hospital staff

Hospital staff have a duty to adapt their services to meet the individual needs of a person with disability. This happens better in some hospitals than others. You may need to speak up for the person to make sure they get the support and health care they need. Wherever possible, do this in a cooperative and non-threatening way.

Demonstrate to staff how the person communicates. This will help the person let staff know if they are in pain or want something. Encourage medical staff to speak directly to the person and fully involve them in decisions.

## Hospital environment

Hospitals are busy places 24 hours a day. Bright lights, buzzers and regular observations can be disturbing and can cause challenging behaviours. Try to work with staff to minimise the negative impact of the hospital routine.

## Discharge and follow up

Careful discharge planning and follow up will reduce the risk of problems with the person's recovery. Make sure that you get clear information about:

- Any wound care or new medication.
- Any extra support needs that the person has when they leave hospital.
- What follow up treatment is needed.

Work out with the person and hospital staff how these needs will be met. If the person lives in supported accommodation, their manager or case manager needs to be involved in this process.

## For more information

My Health Matters

[www.cid.org.au/resource/my-health-matters-folder](http://www.cid.org.au/resource/my-health-matters-folder)

People with disabilities: responding to their needs during hospitalisation, NSW Health policy

[www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017\\_001.pdf](http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017_001.pdf)

The hospital communication book – a resource for patients, families and hospital staff

[www.surreyhealthaction.org/downloads/Hospital%20Communication%20Book%20-%20version%202%20-%20web.pdf](http://www.surreyhealthaction.org/downloads/Hospital%20Communication%20Book%20-%20version%202%20-%20web.pdf)

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- **Consent to medical treatment**
- **Helping the doctor understand the person**
- **Personal health records**

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# Health issues for families and support workers

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Families and support workers often have high levels of stress. Meeting the needs of a person with intellectual disability can be very challenging.

Parents can find it emotionally painful to tell their story again and again to different services. Parents often face pressures from lack of sleep, financial issues and the needs of their other children.

Stress can have a bad effect on your health, both physically and mentally. But there are many ways you can reduce stress and stay healthy. Remember this: you can better care for others if you take care of yourself.

## Stress and health

When we are stressed for a long time we can develop illnesses like heart disease, high blood pressure, anxiety or depression. Our immune systems can weaken and we can get more frequent colds.

Parents of a person with intellectual disability often neglect their own health issues because they are focusing on the needs of the person.

## Managing stress and staying well

- Keep life as simple as possible.
- Eat well, get enough rest and exercise regularly.
- Be gentle with yourself. Be realistic about what you can do and don't be hard on yourself if you can't do everything. Find time to do something for you!
- Try to keep a positive outlook. Make a list of the good things in your life.
- Think about how you have dealt with other challenges you have faced and see if you can apply any of those strategies to disability related challenges.
- Have regular health checks. Talk to your doctor or a counsellor if you are finding things hard.
- Speak up about the needs of the person you are supporting. You may find it helpful to ask a friend, family member or trained advocate to help with this.

## Maintaining social networks

Look after the relationships you have with your partner, children, extended family and friends. Many families become socially isolated. It is important for your health to stay connected with the people you care about, and who care about you. Many people find the new friendships they make through support groups very helpful. Others prefer to spend time with existing friends and family.

Accept offers of help. Most people like to help others when they can.

Parents, especially mothers, often take the role of primary caregiver, and many give up their careers. Others feel that it is worth paying for support workers so they can stay connected with work and the social interaction that comes with it.

## Where to go for help and support

Support groups can be great places to share experiences, information and tips. Disability advocacy and information services also provide useful advice and support. GPs can help with advice, referrals to specialists and therapists, and can write letters of support for you to get services and equipment.

With more information and experience, families learn to trust their instincts and feel more confident to deal with issues as they arise.

## Issues for support workers and disability managers

The work of a disability support worker is very important but often unappreciated by people who don't understand it.

Value the work you do! It helps to value the people you support, get to know them and celebrate their achievements. Support your colleagues and encourage each other to keep on learning and improving the way you work. Be proud of the difference you make every day to the lives of others.

Managers should develop a supportive team centred around each person with intellectual disability. Encourage your staff to support each other, and make sure they know signs of stress and where to get help.

## For more information

You can get information about disability services and advocacy groups from Council for Intellectual Disability and other disability information services.

Carers NSW website  
[www.carersnsw.org.au](http://www.carersnsw.org.au)

Stress, Better Health Victoria  
[www.betterhealth.vic.gov.au/health/healthyliving/stress](http://www.betterhealth.vic.gov.au/health/healthyliving/stress)

Stress management website  
[www.stressmanagement.com.au](http://www.stressmanagement.com.au)

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# Consent to medical treatment

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

Doctors and dentists usually need to get consent before they carry out treatment. No-one can do things to your body unless you agree! But what happens if a person with intellectual disability does not understand the treatment?

## If possible, the person should decide!

For people over 14, doctors should get consent from the patient whenever possible. They should do their best to explain the problem and the treatment to a person with intellectual disability. Families, advocates and support workers can help the person understand.

Here are some tips for helping the person understand and make their own decision:

- Involve someone who the person likes talking to.
- Talk about the treatment somewhere that is quiet and where the person feels relaxed.
- Try to use words the person knows. If you have to use difficult words, try to explain them simply.
- If the person has an alternative communication system, use that.
- Use pictures that show the problem and the proposed treatment.



- Stick to the basic information. Do not overload the person with detail.
- Give the person time to think about the information and then have another talk.

## What if the person cannot consent?

For children under 16 parents can give consent.

If the person is over 16 and does not understand the problem and the treatment, then the NSW Guardianship Act spells out who can give consent. Usually, it is a “person responsible”.

## The person responsible

There is a list of people who can be a person responsible:

1. The person’s guardian.
2. A spouse.
3. An unpaid carer, eg a parent. And, if the person moves into supported accommodation, the previous carer continues to be the person responsible.
4. A close friend or relative who is actively involved in the person’s life.

The person responsible is the first one on the above list that the person has access to. For example, if the person does not have a guardian or spouse, but has a carer, then the carer is person responsible.

The doctor needs to give the person responsible information about the health problem and treatment options. The person responsible can ask questions and also ask for a second opinion.

They should not give consent unless they are satisfied that the treatment is a good idea and in the interests of the person.

If there is no person responsible available, consent can be obtained from the Guardianship Division of the NSW Civil and Administrative Tribunal.

## Are there treatments that a person responsible cannot consent to?

A person responsible can consent to most treatments. But they cannot consent to “special treatments” under the Guardianship Act. These are sensitive treatments like sterilisations, abortions, experimental treatments and medication to reduce sexual urges.

Also, if the patient is objecting to treatment, a person responsible usually cannot consent.

Where a person responsible cannot consent, the doctor needs to get consent from the Guardianship Division.

## Consent is not always needed

In an emergency, the doctor can go ahead without getting consent.

Also, the doctor can go ahead with necessary minor treatments if there is no person responsible available and the person is not objecting. The Guardianship Act and Regulation spells out what are minor treatments. They are treatments that are not contentious or risky.

## For more information

The Guardianship Division has more detailed information on medical consent.

Phone **(02) 9556 7600** Toll free **1800 463 928** TTY **(02)9556 7634**

[www.ncat.nsw.gov.au/Pages/guardianship/g](http://www.ncat.nsw.gov.au/Pages/guardianship/g)

In other parts of Australia, the law is different to NSW. Contact your local Public Advocate or guardianship tribunal.

[www.agac.org.au](http://www.agac.org.au)

The Capacity toolkit has practical information about supporting a person to make their own decisions and assessing if they have the understanding to do this.

[www.justice.nsw.gov.au/diversityservices/Documents/capacity\\_toolkit0609.pdf](http://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf)

You might be interested in this fact sheet

- **Rights and complaints**

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# Rights and complaints

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

If a person with intellectual disability does not get a fair deal from the health system, it is okay to make a complaint. And if the person suffers from inadequate health care, they might be able to seek compensation.

There are independent complaints bodies you can go to. But usually it is best to try to sort the problem out with the service first.

## A right to good health care

Under the UN Convention on the Rights of Persons with Disabilities, people with disability have a right to good health care. You cannot take health professionals to court for breaching this right, but you can expect the service to take a complaint seriously.

The NSW Patient Safety and Clinical Quality Program spells out what any person, including people with intellectual disability, can reasonably expect from health professionals, including good quality care, to be treated with respect, and clear complaints procedures.

## General tips for making a complaint

- It is usually best to raise a concern as soon as the problem arises. Before deciding whether to make a complaint it may be useful to ask a health professional to explain why they acted as they did.
- It may be quickest to sort out the concern face-to-face or by a phone call. And, if that does not work, write a letter or email.
- Stick to the facts and try to be calm and clear.
- Be ready to listen to the service provider's point of view.
- Tell the person what you need from them. Is it an explanation or an apology? Do you want them to do something?
- Politely tell them what you will do if the concern is not resolved.
- Keep records of the health problem and what was done about it.
- Be persistent and try again if they do not get a response.

The main ways to make a complaint are:

- Talk to the service provider directly. Sometimes, this is enough to solve the problem informally.
- Contact the provider's supervisor. This may be a more senior doctor, manager or head of the organisation.
- Contact a formal complaint organisation, (see below). Often, these organisations can look at the health service's records and say whether they did the wrong thing.

## Complaint handling organisations

### NSW Health

The NSW Department of Health handles complaints about services that it runs, including community health centres and public hospitals. You can complain to the service or to the head office of the Department.

### Health Care Complaints Commission

An independent body that handles complaints about health services and individual professionals. The Commission can help you prepare your complaint. If you want a language interpreter, you can contact the Commission through the Telephone Interpreter Service (TIS) on 131 450.

### Discrimination complaints

Under anti-discrimination law, it is unlawful for health services to discriminate on the basis of disability. For example, by refusing to offer heart surgery because a person has Down syndrome. Also, health services must make reasonable adjustments to their services to meet the needs of a person with a disability. If you think these rights are breached, contact the Australian Centre for Disability Law or the Intellectual Disability Rights Service for advice. They might suggest you complain to the Anti-Discrimination Board NSW or the Australian Human Rights Commission. These bodies can investigate and conciliate complaints. In some cases, complaints lead to compensation or orders for services to comply with the person's rights.

## Suing for damages

If a person is badly injured or suffers great pain or distress because of the negligence of a health professional, you can consider suing for damages in court. You would need to talk to a solicitor who has experience in negligence law.

## Ombudsman NSW

The Ombudsmen reviews deaths of people with disability who lived in supported accommodation.

## Where to get help

Anti-Discrimination Board NSW (02) 9268 5555 <a href="http://www.lawlink.nsw.gov.au/ADB">www.lawlink.nsw.gov.au/ADB</a>	Australian Human Rights Commission (02) 9284 9600 Complaints: 1300 656 419 <a href="mailto:complaints@humanrights.gov.au">complaints@humanrights.gov.au</a> <a href="http://www.humanrights.gov.au">www.humanrights.gov.au</a>
Australian Centre for Disability Law 1800 800 708 (NSW only) <a href="http://www.disabilitylaw.org.au">www.disabilitylaw.org.au</a>	Health Care Complaints Commission (02) 9219 7444 Free call: 1800 043 159 <a href="mailto:hccc@hccc.nsw.gov.au">hccc@hccc.nsw.gov.au</a> <a href="http://www.hccc.nsw.gov.au">www.hccc.nsw.gov.au</a>
NSW Health (02) 9391 9000 <a href="mailto:nswhealth@doh.health.nsw.gov.au">nswhealth@doh.health.nsw.gov.au</a> <a href="http://www.health.nsw.gov.au">www.health.nsw.gov.au</a>	Intellectual Disability Rights Service (02) 9318 0144 Free call 1800 666 611 <a href="mailto:info@idrs.org.au">info@idrs.org.au</a> <a href="http://www.idrs.org.au">www.idrs.org.au</a>
Ombudsman NSW (02) 9286 1000 Free Call 1800 451 524 <a href="mailto:nswombo@ombo.nsw.gov.au">nswombo@ombo.nsw.gov.au</a> <a href="http://www.ombo.nsw.gov.au">www.ombo.nsw.gov.au</a>	

## For more information

Patient Safety and Clinical Quality Program - NSW Health

[www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2005\\_608.pdf](http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2005_608.pdf)

Tips for making complaints

[www.ombo.nsw.gov.au/\\_data/assets/pdf\\_file/0012/1227/BR\\_TipsMakingComplaint\\_Mar10.pdf](http://www.ombo.nsw.gov.au/_data/assets/pdf_file/0012/1227/BR_TipsMakingComplaint_Mar10.pdf)

UN Convention on the Rights of Persons with Disabilities

[www.humanrights.gov.au/disability\\_rights/convention.htm](http://www.humanrights.gov.au/disability_rights/convention.htm)

## You might be interested in this fact sheet

- **Consent to medical treatment**

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# More information

People with intellectual disability should be involved in all decisions about their health and wellbeing.

Some people can make decisions alone and some people will need support. It is critical that supporters know the person's will and preferences to make sure the right support is provided and the right decision is made.

## Key contacts in other states

These fact sheets contain a lot of information that will be useful to readers in all parts of Australia. They will be most useful for people in NSW because they talk about NSW services.

In Adelaide, Melbourne and Brisbane, there are intellectual disability health centres. These are which are good starting points for local information as well as for general information on health of people with intellectual and developmental disability

### Melbourne

Centre for Developmental Disability Health, Monash Health

[www.cddh.monashhealth.org](http://www.cddh.monashhealth.org)

Phone (03) 9792 7888

### Brisbane

Queensland Centre for Intellectual and Developmental Disability

[www.qcidd.centre.uq.edu.au](http://www.qcidd.centre.uq.edu.au)

Phone (07) 3163 2412

## **Adelaide**

Centre for Disability Health  
Phone (08) 8397 8100

### **General information on health issues**

Better Health Channel  
Plain English fact sheets on a very wide range of health conditions and issues.  
[www.betterhealth.vic.gov.au](http://www.betterhealth.vic.gov.au)

Health Direct  
Free health information and advice  
[www.healthdirect.gov.au](http://www.healthdirect.gov.au)  
Phone 1800 022 222

Child health – Raising children  
Information for parents on health and other issues.  
[www.raisingchildren.net.au](http://www.raisingchildren.net.au)

The Sydney Children's Hospitals Network  
Fact sheets for parents on health issues - includes some in community languages  
[www.schn.health.nsw.gov.au/fact-sheets](http://www.schn.health.nsw.gov.au/fact-sheets)

Australian Indigenous Health InfoNet  
[www.healthinfonet.ecu.edu.au](http://www.healthinfonet.ecu.edu.au)

National Rural Health Alliance  
Fact sheets and other information on health in rural and remote areas  
[www.nrha.ruralhealth.org.au](http://www.nrha.ruralhealth.org.au)

### **Key references for health professionals**

Management Guidelines, Developmental Disability  
A practical text for health professionals.  
[www.tg.org.au](http://www.tg.org.au)

Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities, David Dossetor, Donna White and Lesley Watson (editors), IP Communications 2011.

Department of Developmental Disability Neuropsychiatry (3DN) UNSW Sydney  
3DN has a range of information and elearning resources especially on mental health and cardiometabolic health.  
[www.3dn.unsw.edu.au](http://www.3dn.unsw.edu.au)