

**INTELLECTUAL DISABILITY  
MENTAL HEALTH FIRST AID MANUAL**





## Intellectual Disability Mental Health First Aid Manual

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with the kind permission of the authors:  
Kitchener BA & Jorm AF (2002), *Mental Health First Aid Manual*.  
ORYGEN Research Centre. University of Melbourne



## About This Manual

The Intellectual Disability Version of the Mental Health First Aid Manual came about as a result of 2 major factors.

The first was attendance by some staff from the Statewide Behaviour Intervention Service (SBIS), at the Adult Mental Health First Aid Training Course. SBIS is a service within the Office of the Senior Practitioner, NSW Department of Ageing Disability and Homecare (OSP DADHC)

During the course and after completion they felt that those working in the field of intellectual disability could benefit significantly if the content of the manual was adapted for intellectual disability.

The second was the increase in clients with a mild intellectual disability and mental health problems being referred to SBIS and the accompanying requests for simple strategies that direct care staff could use to support those clients they were working with.

Ruth Pappas and Michelle Henwood then approached the authors of the Mental Health First Aid manual to discuss how they could make this happen. Many thanks to both Betty and Tony for their permission and support.

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## Acknowledgements

This manual has taken a significant amount of time to produce and was very much a collaborative effort.

The authors would like to acknowledge the significant contributions by the following people

**John Wagner:** Statewide Behaviour Intervention Service, (OSP DADHC), for his editorial aid and continuous encouragement.

**Michelle Henwood,** Criminal Justice Program (OSP DADHC) for helping to initiate & establish this project.

**Ms Larissa Marks,** Bathurst, for her deeply personal and touching artwork.

In addition the authors would like to thank the following people for their timely, informative and much valued feedback and review.

**Dr. Sophie Kavanagh,** Consultant Psychiatrist. Sydney South West Area Health

**Norma Cloonan,** Clinical Nurse Consultant, Intellectual Disability Mental Health Consultation Team, Sydney South West Area Health Service

**Dr. Meredith Martin,** Martin & Associates and

**Gaye (Punya) Robertson** Mental Health First Aid (Adult) Instructor

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CHAPTER 1  
MENTAL HEALTH FIRST AID



## 1 MENTAL HEALTH FIRST AID

**First Aid** is the help given to an injured person before medical treatment can be obtained. The aims of any first aid course are to:

1. preserve life
2. prevent deterioration of an injury or an illness
3. promote healing
4. provide comfort to the ill or injured.

**Mental Health First Aid** is the help provided to a person developing a mental health problem or in a mental health crisis. The first aid is given until appropriate professional treatment is received or until the crisis resolves. The aims of Mental Health First Aid are to:

1. preserve life where a person may be a danger to themselves or others
2. provide help to prevent the mental health problem developing into a more serious state
3. promote recovery of good mental health
4. provide comfort to a person suffering a mental illness.

Mental Health First Aid does **not** teach people to be therapists. Rather, it teaches how to recognise symptoms of mental health problems, how to provide initial help and how to go about guiding a person towards appropriate professional help.

### Why Mental Health First Aid?

There are many reasons why people need training in Mental Health First Aid:

- ◆ **Mental health problems are common**, especially depression, anxiety, and misuse of alcohol and other drugs.<sup>1</sup> Throughout the course of any person's life, it is highly likely that they will either develop a mental health problem themselves or have close contact with someone who does.
- ◆ **There is a stigma associated with mental health problems.** This may hinder people with such problems from seeking help.<sup>2</sup> People are often ashamed to discuss mental health problems with family, friends and work colleagues. They may also be reluctant to seek professional help for mental health problems because of their concerns about what others will think of them.

- ◆ **Many people are not well informed** about how to recognise mental health problems and what effective treatments are available.<sup>3</sup> They may not seek help at all, or may seek the wrong sort of help. With greater community awareness about mental health problems, people will be able to recognise their problems and feel more comfortable about seeking professional help, such as talking to their general practitioner (GP).
- ◆ There are professional people (GPs, counsellors, psychologists and psychiatrists) who can help people with their mental health problems. However, just as with accidents and other medical emergencies, **professional help is not always on hand** when a mental health problem first arises. This is when members of the public can offer immediate aid and assist the person to get appropriate professional help.
- ◆ Some mental health problems cloud a sufferer's clear thinking and rational decision making. Such a **person may not realise that they need help or that effective help is available for them.**
- ◆ When faced with an accident, **members of the general public often do not know how to respond** unless they are trained in first aid. A person wishing to give assistance at an accident may be reluctant to help for fear of doing the wrong thing or the person may actually do something which makes the problem worse through not knowing the correct thing to do, e.g. unnecessarily move a patient with spinal injuries. Similarly, in a mental health crisis situation, **the helper's actions may determine how quickly the person with the problem gets help and/or recovers.**

### The MHFA action plan

In any first aid course, participants learn how to help someone who is injured or ill. An action plan is taught to help the person giving first aid to remain calm and confident, and to respond in an appropriate way to give the best help.

The action plan for Mental Health First Aid has five basic steps. Chapters 4,5,6 and 7 explain how these steps can be applied to the mental health problems of depression, anxiety disorders, psychosis and substance use disorders.

Although the action of assessing the risk of suicide or harm is the highest priority, other actions listed may need to occur first. Hence they are called actions instead of steps. The helper has to use judgement about the order of the actions. Assessing the risk of suicide may be the immediate task. However, in other situations, it is only after listening to the person that the risk of harm may become apparent.



## Mental Health First Aid

1. Assess risk of suicide or harm
2. Listen non-judgementally
3. Give reassurance and information
4. Encourage the person to get appropriate professional help
5. Encourage self-help strategies

As in any provision of first aid, the first aider must first check there is no danger to themselves or others. In a mental illness crisis, usually the unwell person is only a threat to themselves.

**Listening to the person is a very important step.** Most people who are experiencing distressing emotions and thought want to be listened to empathically before being told what may help them.

CHAPTER 2  
MENTAL HEALTH PROBLEMS IN AUSTRALIA



## 2 Mental health problems in Australia

### What are mental health problems?

A variety of terms are used to describe mental health problems: mental disorder, mental ill-health, mental illness, nervous exhaustion, mental breakdown, nervous breakdown, burnout, cracked up, psycho.

These terms do not give much information about what is really wrong with the person.

**A mental disorder** is a diagnosable illness which causes major changes in a person's thinking, emotional state and behaviour, and disrupts the person's ability to work and carry on their usual personal relationships.

There are different types of mental disorders some of which are common, such as depression and anxiety disorders, and some not so common, such as schizophrenia and bipolar disorder. However, all mental health problems cause a lot of disability to the sufferer – a point often not appreciated by people who have never suffered from a mental disorder.

**A mental health problem** is a broader term including both mental disorders and symptoms of mental disorders which may not be severe enough to warrant the diagnosis of a mental disorder.

Mental health problems are common in the Australian community. The National Survey of Mental Health and Wellbeing, a community survey of 10,6000 adults carried out in 1997, found that close to one in five (17.7%) Australian adults have a common mental disorder (depressive, anxiety or substance use disorder) at some time during the 12 months before the survey.<sup>1</sup>

This means that about **one in five Australian adults will suffer from some form of common mental health problem in any year.**

These three groups of mental health problems often occur in combination. For example, it is not unusual for a person with an anxiety disorder to also develop depression, or for a person who is depressed to misuse alcohol or other drugs.

Another 0.4-0.7% of Australian adults will suffer from a psychotic disorder, such as schizophrenia or bipolar disorder, in any one year.<sup>4</sup>

Given that mental health problems are so common, it is not surprising that they are a major reason for consulting GPs. It has been estimated that a GP who sees 40 patients a day can expect that 8-10 (20-25%) of these patients will require support or treatment for anxiety or depression – and that's not counting those whose disorders go unrecognised.<sup>5</sup>

Many people with mental health problems do not seek any professional help. The National Survey of Mental Health and Wellbeing found that professional help is received by only 60% of people with depressive disorders, 45% with anxiety disorders and 28% with substance use disorders.<sup>1</sup> People with the less common mental disorders, such as schizophrenia and bipolar disorder, will generally get professional help, but it can sometimes take years before they are diagnosed and correctly treated.

### Percentage of Australian adults who suffer from a common mental health problem in any year<sup>1</sup>

Type of problem	Males	Females	Adults
Depressive disorder	4.2%	7.4%	5.8%
Anxiety disorder	7.1%	12.0%	9.7%
Substance use disorder	11.1%	4.5%	7.7%
<b>Any common mental disorder</b>	<b>17.4%</b>	<b>18.0%</b>	<b>17.7%</b>

## Disability caused by mental health problems

Mental health problems can be more disabling for the sufferer than many chronic physical illnesses. 'Disability' refers to the amount of disruption that a health problem causes to a person's ability to work, look after themselves and carry on their relationships with family and friends. Research in the Netherlands has looked at the amount of disability caused by a large number of both physical and mental health problems.<sup>6</sup> It helps to understand the amount of disability that mental health problems can cause by comparing them to physical health problems that cause the same amount of disability. Here are some examples:

- ✦ the disability caused by *moderate depression* is similar to the disability from relapsing multiple sclerosis, severe asthma, chronic hepatitis B or deafness
- ✦ the disability from severe *post-traumatic stress disorder* is comparable to the disability from paraplegia
- ✦ the disability from *severe schizophrenia* is comparable to the disability from quadriplegia.

Only in recent years has it been recognised that mental health is a major issue in Australia. Although mental health problems are not major killers, they are major causes of long-term disability.

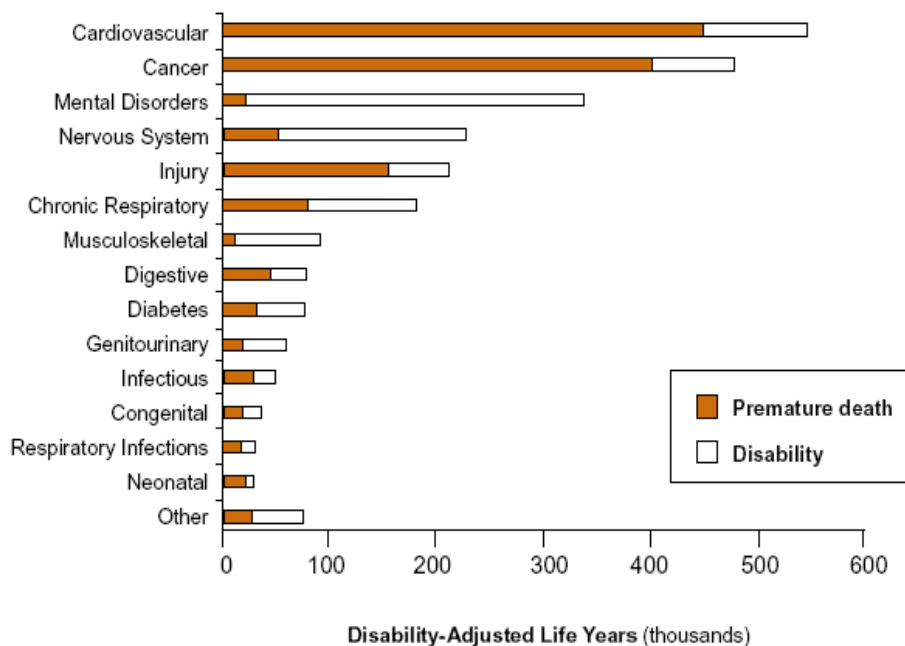
The Australian Institute of Health and Welfare has concluded that **mental health problems rank as the third biggest health problem** in Australia after heart disease and cancer.<sup>7</sup> Of the different mental health problems, depression is the biggest single cause of disease burden. ('Disease burden' refers to the effects of premature death, disability, illness and injury on a 'healthy life'. The burden of disease on the health of Australia's population is measured by 'disability-adjusted life years', or years of health life lost through premature death or living with disability.)

The graph below shows the burden of disease in Australia caused by various categories of disease.<sup>7</sup> Each bar of the graph has two colours: the first shows the portion of disease burden due to premature death and the second the portion due to disability.

Mental disorders rank as the largest source of disability in Australia.

There is all too often additional suffering caused by attitudes of rejection and stigma towards people with a mental disorder. The World Health Organization stresses that approaches to mental ill-health should be fundamentally the same as approaches to physical ill health.<sup>8</sup> People suffering from mental health problems need our respect and assistance.

Burden of disease in Australia, 1996



## Helpful resources

### Prevalence of mental disorders in Australia

<http://www.health.gov.au/mentalhealth>

This website reports findings from the National Survey of Mental Health and Wellbeing which was funded by the Commonwealth Department of Health and Aged Care, and carried out by the Australian Bureau of Statistics in 1997. It gathered information about the one-year prevalence of mental illness in the Australian population, the amount of associated disability, and the use of health and other services by people with mental health problems. This national survey had three components: a household survey in which 10,600 adult Australians aged 18-99 years were interviewed; a household survey of 4,500 children and adolescents aged 4-17 years; and a study of 3,800 people who were diagnosed with psychoses, in the age range 18-64 years. Downloadable reports from the survey can be found under 'publications and resources' at this website.

### Disability of mental illness

<http://www.who.int/healthinfo/bodproject/en/>

This site contains information on the global burden of disease in various parts of the world, including burden due to various mental health problems. It also gives projections into future years when the burden from mental health problems is expected to increase greatly.

CHAPTER 3  
MENTAL HEALTH AND INTELLECTUAL DISABILITY



### 3 Mental health and intellectual disability

#### Why an intellectual disability edition of the manual?

This manual is for people working in human services who are aware of the generic Mental Health First Aid training and those working in or associated with disability services.

The purpose of this manual is to provide guidance on how to support people with an Intellectual Disability who are experiencing difficulties associated with mental health problems. There is also information in the manual that will help those with little or no experience interacting with someone who has an intellectual disability.

This edition builds on the advice given in the Mental Health First Aid Manual, specifically taking into account the difficulties and needs of the person with an intellectual disability. This revision builds on the work done in the original manual, thereby making the Mental Health First Aid approach available to those who work with and encounter a person with intellectual disability.

#### What is intellectual disability?

Intellectual disability (also referred to as mental retardation, developmental disability) is a condition which shows itself as limitations in the person's ability to learn about and solve the problems of day to day life and to be independent in the activities required for daily living.

Intellectual disability occurs along a spectrum and is present in some form in about 3% of the population. It is often present from a person's early years of life and generally speaking is permanent.

#### How does intellectual disability affect a person?

Intellectual disability affects many aspects of the person's day to day life. People with intellectual disability usually:

- ◆ have trouble communicating
- ◆ find it hard to remember things
- ◆ have trouble understanding social rules
- ◆ have trouble understanding cause and effect for everyday events
- ◆ have difficulty solving problems and thinking logically
- ◆ react and interact in ways that aren't characteristic for their age.

#### Recognising people with an intellectual disability

It is not always obvious that someone has an intellectual disability. Sometimes they are recognisable due to physical characteristics of a particular syndrome such as Down's syndrome, but this is not always the case. The following box gives areas that you could ask the person about to help identify whether they have an intellectual disability.

Possible indicators of an intellectual disability		
Activities	Remember	Life Experience
Can they: <ul style="list-style-type: none"> <li>• read</li> <li>• write</li> <li>• manage money</li> <li>• look after their personal care</li> <li>• tell the time</li> <li>• cook</li> <li>• do they have difficulty in communicating with other people?</li> </ul>	Can they remember: <ul style="list-style-type: none"> <li>• significant things about themselves (e.g. birthday)</li> <li>• significant things about their environment (e.g. where they live)</li> <li>• when to do things (get up, what time dinner is)</li> <li>• what you have said?</li> </ul>	Have/do they: <ul style="list-style-type: none"> <li>• attend a special school or class within a mainstream school</li> <li>• attend a day centre</li> <li>• live(d) in an institution or intellectual disability service</li> <li>• have people who support them (e.g. care worker, advocate etc)</li> <li>• manage in social situations?</li> </ul>

Adapted from: Hardy S., Chaplin E.<sup>9</sup>

## Factors contributing to mental health problems in people with intellectual disability

It is only recently that there has been recognition that people with intellectual disability can develop the same mental health problems as the general population and that prevalence rates of mental health problems are higher for intellectual disability.

As for the general population a combination of biological, psychological and social factors can lead to the development of mental health problems. People with an intellectual disability tend to be more vulnerable to these factors as outlined in the box below.

<b>Factors contributing to mental health problems for people with intellectual disability</b> 9, 15, 16		
<b>Biological</b>	<b>Psychological</b>	<b>Social</b>
<p><b>Brain damage</b> Not all people with intellectual disability have brain damage. For those who do, this can cause structural &amp; psychological changes to the way the brain functions, increasing vulnerability.</p>	<p><b>Self-worth</b> Society values achievements such as high social status, independence, employment, relationships &amp; family. People with intellectual disability may have difficulty attaining these, which may affect their self esteem.</p>	<p><b>Living in inappropriate environments</b> People with intellectual disabilities often live in accommodation where they are isolated from their families &amp; community. In such settings they may have little choice &amp; control over their lives. Such environments may provide too little or too much activity or stimulation.</p>
<p><b>Sensory Impairments</b> Sensory impairment can create a barrier to social integration &amp; lead to disablement and problems with self-image.</p>	<p><b>Self-image</b> People with intellectual disability may feel they are different to other people due to either their cognitive or physical disabilities or may feel inferior to others because of their reliance on the support of others. Poor self-image can contribute to mental health problems.</p>	<p><b>Exposure to adverse life events</b> People with intellectual disability are more likely to have been exposed to abuse, trauma, rejection, harassment &amp; exploitation. They are often unaware of or do not understand their rights.</p>
<p><b>Genetic conditions</b> People with intellectual disability are at a significantly higher risk of mental health problems associated with a number of syndromes e.g. Prader-Willi Syndrome, Rett Syndrome, William's Syndrome.</p>	<p><b>Poor coping mechanisms</b> People with intellectual disability find it more difficult to plan ahead, consider the consequences of their behaviour or tolerate/manage their frustration &amp; anger. This can result in greater discrimination by others.</p>	<p><b>Expectations of others</b> Low expectations by others of people with intellectual disability can lead to reduced opportunities for participation &amp; the chance to develop skills and confidence.</p>
<p><b>Medication</b> Side effects of psychotropic medication, particularly when the person is receiving two or more, need to be considered, as these can contribute to mental health problems.</p>	<p><b>Bereavement &amp; loss</b> People with intellectual disability often do not receive the support they require to cope with these stressors. They may not even be told about what has happened. Loss can include siblings leaving home, staff leaving or other clients moving on.</p>	<p><b>Family</b> Some family members can be over-protective, reducing opportunities and leading to over-dependence. Caring for a person with a disability may also put increased pressure on a family leading to increased stress which can affect the family's relationship with the person.</p>
<p><b>Epilepsy</b> Approximately a third of people with intellectual disability have epilepsy, which for some may be associated with mental health problems. Epilepsy can provoke anxiety in a person, which may lead to them avoiding going out &amp; becoming isolated.</p>	<p><b>Difficulty expressing emotions</b> People with intellectual disability often have trouble expressing their inner thoughts &amp; feelings. They find it difficult to put subtle &amp; abstract emotions into words.</p>	<p><b>Reduced social networks</b> People with intellectual disability often have smaller friendship groups. They may lack the skills required to develop relationships &amp; broaden social networks. Others may develop abusive relationships or mix with inappropriate peers in an attempt to fit in.</p>

**Factors contributing to mental health problems for people with intellectual disability cont.**

Biological	Psychological	Social
	<p><b>History &amp; expectation of failing.</b> People with intellectual disability are often not given opportunities to achieve, so they develop low expectations. Frequent failure may lead them to develop learned helplessness, which can lead to a lack of motivation &amp; poor goal setting.</p>	<p><b>Economic disadvantage.</b> Financial and related disadvantages common for people with intellectual disability can contribute to the person's vulnerability to mental health problems.</p>
	<p><b>Dependence on others</b> The reliance on others by a person with an intellectual disability can lead to overdependence, a lack of self-determination &amp; poor problem solving skills.</p>	<p><b>Transitions</b> Movement between services are often poorly managed. Poor communication between services and bad or no planning adds to the problem. The individual may feel they have little control or influence over what happens to them at this time.</p>
		<p><b>Discrimination</b> Discrimination by the wider society can leave people with intellectual disability stigmatised and impact on their self-esteem and self-image.</p>
		<p><b>Legal disadvantage</b> People with intellectual disability may not be aware of their rights &amp; have to rely on the support of others to be advocates for their needs.</p>

**The relationship between intellectual disability & mental health problems**

In the past, the difference between intellectual disability and mental illness was not well understood. People with intellectual disability were accommodated in the same institutions as those with serious mental health problems. We now understand that the two are quite separate conditions. It is however possible for a person with intellectual disability to have mental health problems as well.

People with intellectual disability (as is true for most of us) can experience emotional crises because of mental health problems or as learned ways of coping with situations they find difficult (challenging behaviour). Challenging behaviour and mental health problems may exist at the same time. Individuals may also continue to display their usual challenging behaviour in addition to other behaviour indicative of a mental illness.<sup>10</sup>

**Difficulties of diagnosis**

Assessment of mental illness in those with a mild intellectual disability may be similar to the general population: however there may be greater reliance on others for information.<sup>68</sup>

The presence of intellectual disability poses particular difficulties when it comes to diagnosing a mental health problem. There are several reasons for this;<sup>10,11,12</sup>

- ◆ the person with intellectual disability is often unable to express symptoms that a clinician looks for when diagnosing a mental health problem
- ◆ mental health workers may attribute all forms of behaviour difficulties to the person's intellectual disability and fail to consider that the behaviours may be a symptom of mental health problems
- ◆ unusual or infrequent presentation of symptoms in the intellectually disabled population
- ◆ medications being taken for physical or behavioural issues may mask the presence of mental health symptoms
- ◆ historical information which may deal with previous diagnoses is sometimes inconsistent or missing. This may make it difficult to determine if there has been a change over time.

## Prevalence of mental health problems in intellectual disability

People with an intellectual disability suffer from the same types of mental health problems as those without such disabilities. Prevalence rates of mental health problems are generally higher for people with intellectual disability than for the general population, suggesting that they are a particularly vulnerable group. Some disorders may be more or less likely and may also present in a different way than in the general population. Prevalence rates for people with intellectual disability and mental health problems have been placed between 10% and 74%<sup>13,14,68</sup>. This large variance is a result of the different ways studies have been conducted.

## Presentation of mental health problems in intellectual disability

Presentation of mental health problems in the intellectual disability population will be influenced by factors such as;

- ◆ the cause of the intellectual disability
- ◆ level of disability and functioning (communication, social & physical)
- ◆ personality
- ◆ usual behavioural repertoire
- ◆ cultural background
- ◆ environmental factors

It is generally agreed that those with mild intellectual disability and/or sufficient verbal communication will have a similar presentation of symptoms to the general population. Those with a more significant degree of intellectual disability and inadequate verbal communication are more likely to display their mental health problems through changes in behaviour and behaviour problems (challenging behaviour).<sup>17,18</sup>

For convenience, throughout this manual the term "behaviour" is used to describe potential signs and symptoms of a mental health problem, which may include thoughts and feelings.

It may be useful to consider the following if you suspect that a person with intellectual disability may have a co-existing mental health problem.<sup>10,17</sup>

- ◆ is the person behaving in ways that are different to their usual behaviour? e.g. changes to sleeping and eating patterns, posture and movement
- ◆ are these changes in behaviour occurring across the majority of settings?
- ◆ does the person seem to be experiencing emotional reactions such as anxiety or elation that are out of keeping with the situation?

- ◆ do they talk or interact with someone who is not there or is there anything that suggests that the person is being influenced by unseen forces?
- ◆ has there been a reduction or change in the person's abilities (eg. social, daily living, and work related skills) leisure activities or preferred routines?
- ◆ has there been a reduction or increase in the person's mood or level of motivation?
- ◆ is the person acting in a way that is dangerous to themselves or others?

There are many possible causes for these and other changes. It is important to first rule out a medical or physical condition which may be triggering the behaviours of concern. Bowel conditions and ear infections are two of the most common physical ailments that may trigger behaviours that can be mistaken for symptoms of a mental health condition.

## General tips when working with those with intellectual disability and mental health problems

The following are ways of interacting with a person who has intellectual disability in a situation where Mental Health First Aid may be needed.<sup>12,17,19</sup>

- ◆ use **appropriate language**
  - speak clearly and slowly
  - use simple, short statements or questions
  - avoid using abstract ideas and jargon
  - be specific
  - use a normal tone, don't shout or raise your voice
  - use non-threatening language (including body language)
- ◆ ask **one question** or make **one request at a time**
- ◆ **avoid using leading questions.** People with intellectual disability are often suggestible and will tell you what they think you want to hear or what they think is the 'right' answer
- ◆ **use open questions** where possible, eg "how are you feeling?" or "tell me about". Closed questions may be useful to clarify something; however be careful they are not leading questions
- ◆ stop from time to time and **check the person's understanding.** If you are not sure that they have understood ask them to explain to you in their own words what you have just asked or told them

- ◆ **don't assume** that the person's ability to express themselves is an indication of how much they understand or vice versa. Give the person **time to respond**
- ◆ **don't pretend to understand if you don't.** Use checking questions or paraphrasing to assist your understanding. Ask them to repeat what they have said in another way if they can
- ◆ ask the person or their carer/support person if they have a preferred or **augmentative method of communicating**. Use **visual aids** when appropriate if possible. The use of drawings, pictures, etc can help you to give information in a way the person may be more likely to understand
- ◆ be prepared to **repeat the information** more than once if necessary.
- ◆ **listen** to the person. **Don't be judgemental, critical or flippant** in your response
- ◆ appear **calm, relaxed and confident**
- ◆ **reassure** the person
- ◆ **do not make any promises that can't be kept**
- ◆ ensure the **privacy, respect and dignity** of the person
- ◆ if the person is alone **ask whether they have family or a support worker that you can contact**. They may have contact details for these people in their wallet/purse.
- ◆ a range of disciplines should contribute to the management of mental health problems. These might include psychiatrists, behaviour intervention clinicians, counsellors, GPs
- ◆ these professionals will require good information about the person with an intellectual disability. It is important that a support person knows the client well
- ◆ there should be a plan for managing the issues that arise out of the person's mental health problems. This should include procedures for handling difficult situations such as angry outbursts, withdrawal, threats of self harm, and for the use of emergency medication (PRN)
- ◆ medication should be acknowledged as having a part to play in treatment of mental health problems, although it's not always required. When used it must be monitored and reviewed regularly, preferably by a specialist.

## Comprehensive management of mental health problems in people with intellectual disability

This manual is about providing First Aid to the person with an intellectual disability who is experiencing an emotional crisis due to a mental health problem. However it is also useful to understand the bigger picture in meeting their needs. Long term and lasting help can only be achieved when they receive comprehensive services by individuals and services supporting them. For this to occur:

- ◆ management of mental health problems needs to be part of a broader service plan for the person. e.g. an Individual Plan (IP)

## Mental Health First Aid for people with an Intellectual Disability

1. **Assess risk of suicide or harm**
2. **Listen non-judgementally**
3. **Give reassurance and information**
4. **Encourage and support the person to get appropriate professional help. *The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered***
5. **Encourage the person to use any self-help strategies they may have. *The person with an intellectual disability may need support to do this***



***When administering Mental Health First Aid to people with an intellectual disability keep the following suggestions in mind.***

- ❖ ***Speak in a calm quiet voice***
- ❖ ***Focus on one topic at a time. Because the person may be confused, keep your conversation simple.***
- ❖ ***Be patient and wait for responses.***
- ❖ ***Keep an upbeat attitude and let the person know that you are available and supportive.***

## Treatment options and interventions

Modification to the first aid model for people with intellectual disability occurs in steps 4 and 5 where prompts are given in relation to extra support that they may require.

Part of comprehensive management of the person's mental health problems may involve participation in a consultation with a specialist such as a disability service and/or the person's GP. These may often lead to referral for some form of treatment or therapy. There are a wide range of treatment options available to the general public: however their availability to people with an intellectual disability may be limited because of:

- ◆ assumptions that people with an intellectual disability aren't able to benefit from the same interventions and treatments
- ◆ lack of awareness about services offered by mental health and other providers of treatment and
- ◆ lack of mental health staff trained and experienced in working with people with an intellectual disability.

Fortunately, there is growing recognition that, within limits, established treatments can be adapted to the circumstances of the person with an intellectual disability.

The following are some of the more commonly used approaches.<sup>13</sup>

### **Counselling and psychotherapy approaches**

Cover a range of approaches and involve a trained therapist. Traditionally these types of therapy were thought to be inappropriate for people with an intellectual disability. Recent research, however, is showing that these are appropriate and successful approaches.

- ◆ CBT (Cognitive Behaviour Therapy) uses a range of methods to change thoughts and behaviours that may be causing or maintaining inappropriate emotions.<sup>20</sup> Methods include relaxation training, problem solving, self-instructional training and cognitive restructuring.
- ◆ Emotional awareness training involves helping people to recognise emotions within themselves and others, as well as the links between their thoughts and emotions.<sup>20</sup>

### **Positive Behaviour Support**

This comprehensive approach encompasses learning principles and environmental interventions.

Interventions based on learning principles make the assumption that behaviour is learned, therefore it can be unlearned or re-learned. Approaches may include specific skills training (e.g. relaxation, problem solving, anger management, and assertiveness), reinforcement/reward programs, systematic desensitisation and self-regulation/management approaches.

Lifestyle or environmental interventions focus on making adjustments to the person's lifestyle or environment. e.g. daily routines, increased or, decreased stimulation, exercise and diet.

### **Arts therapies**

These therapies use art, music, dance or drama as a means for the expression of emotion and to teach solutions to emotional difficulties. They can help a person with ID to raise their self-esteem, acquire new skills and positive experiences, reduce anxiety and improve self-expression.<sup>10</sup>

### **Medication**

Medication has a role to play in intervention; however it should be used in conjunction with other interventions that provide the person with skills or life opportunities to manage their mental health problem. Medications should be frequently reviewed by a GP or Psychiatrist.

## Helpful resources

### Websites

#### **Government Disability Department Websites.**

The following are the websites for government disability services in each state or territory.

#### **NSW Department of Ageing Disability and Homecare**

<http://www.dadhc.nsw.gov.au>

#### **Disability South Australia**

<http://www.disability.sa.gov.au>

#### **Disability WA**

<http://www.disability.wa.gov.au>

#### **Tasmanian Dept of Health & Human Services**

<http://www.dhhs.tas.gov.au>

#### **Northern Territory Dept of Health & Families**

<http://www.health.nt.gov.au>

#### **Victorian Dept of Human Services**

<http://www.dhs.vic.gov.au>

#### **ACT Dept of Disability, Housing & Community Services**

<http://www.dhcs.act.gov.au>

#### **Disability Services QLD**

<http://www.disability.qld.gov.au>

#### **Queensland Centre for Intellectual and Developmental Disabilities.**

<http://www.som.uq.edu.au/research/qcidd/default.asp>

QCIDD supports people with intellectual disability through research, teaching and clinical activities. Formerly known as DDU (Developmental Disability Unit), it is part of the School of Medicine at the University of Queensland. It is located at the Mater Misericordiae Public Hospitals in South Brisbane. Joint funding by the Department of Disability Services Queensland and Queensland Health makes QCIDD possible.

#### **Centre for Developmental Disability Health**

<http://www.cddh.monash.org/>

An academic unit established by the Victorian State Government to improve health outcomes for people with developmental disabilities through a range of educational, research and clinical activities. Provides some excellent resources and links regarding intellectual disability and health/mental health.

#### **Australian Psychological Society**

<http://www.psychology.org.au/>

A website which provides general information on many mental health areas as well as a find a psychologist tool by area and speciality.

#### **The National Association for the Dually Diagnosed (NADD)**

<http://www.thenadd.org>

NADD is the leading North American expert in providing professionals, educators, policy makers, and families with education, training, and information on mental health issues relating to persons with intellectual or developmental disabilities. The mission of NADD is to advance mental wellness for persons with developmental disabilities through the promotion of excellence in mental health care.

#### **Commonwealth Carelink Centres**

<http://www9.health.gov.au/ccsd/>

In some states services have been set up to provide respite specifically for families or carers involved with a person who has intellectual disability and mental health problems. The Commonwealth Government website provides access to contacts for local respite services, some of which may offer such a service.

#### **Mental Health Net Directory**

[www.mentalhelp.net](http://www.mentalhelp.net)

An American based website with general information on vast array of mental health issues, with links to many countries.

#### **Foundation for people with learning disabilities.**

<http://www.learningdisabilities.org.uk/>

A British organisation that is part of the Mental Health Foundation, a national charity. The Foundation for People with Learning Disabilities produces a range of publications, including reports, briefings and information booklets. Most of these can be downloaded free of charge from this site.

#### **British Institute of Learning Disabilities. (BILD)**

<http://www.bild.org.uk/index.html>

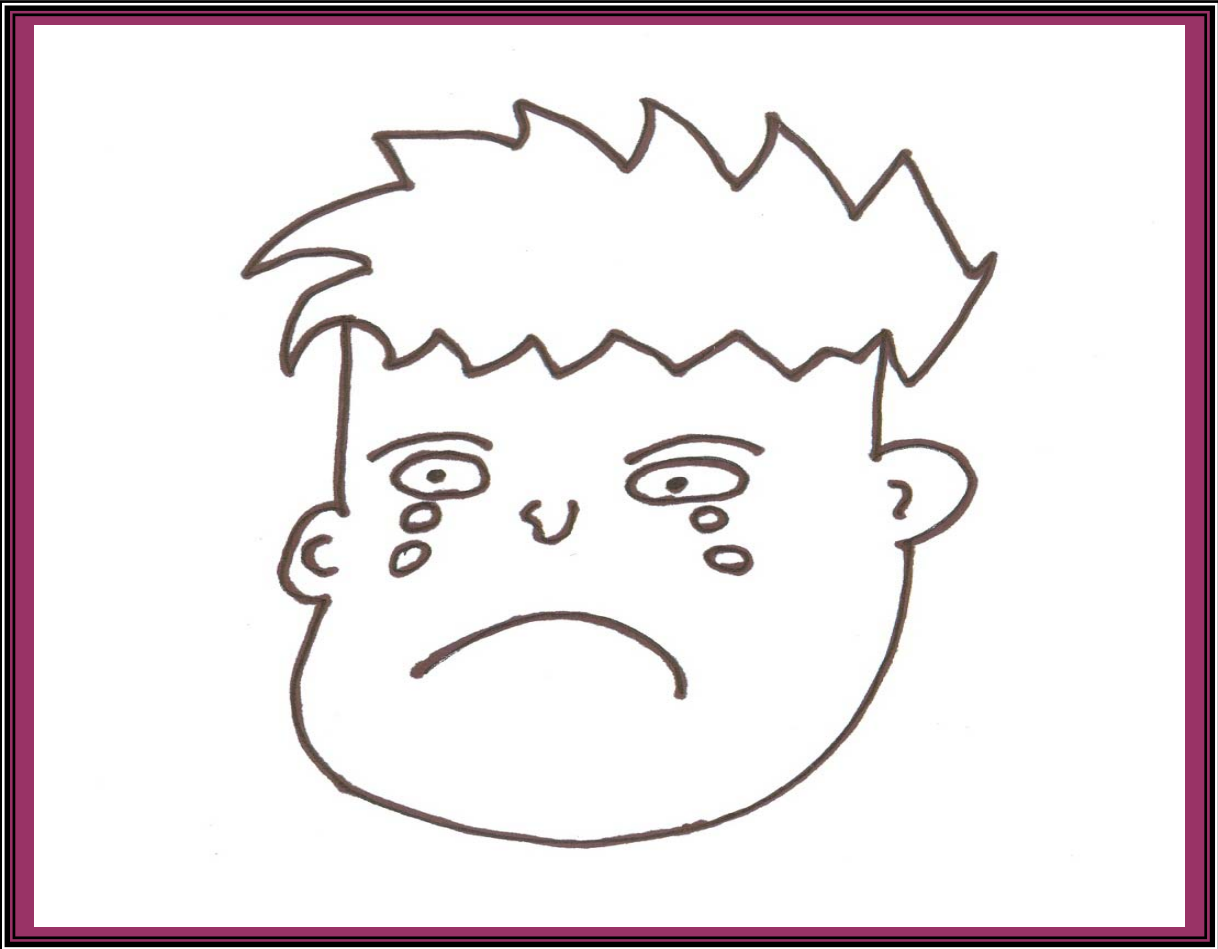
This organisation is involved in policy development and research and provides learning services and publications (books, journals, training materials).

#### **Learning about Intellectual Disabilities and Health**

<http://www.intellectualdisability.info/home/about.html>.

This is an English web-based learning resource for medical and health care students and practitioners. It provides a range of resources and links and has a specific section on mental health.

**CHAPTER 4**  
**DEPRESSION**



## 4 Depression

### What is depression?

The word “depression is used in many different ways. Everyone can feel sad or blue when bad things happen. However, everyday ‘blues’ or sadness is not depression. People with the ‘blues’ may have a short-term depressed mood, but they can manage to cope and soon recover without treatment. The depression we are talking about is ‘clinical depression’, which lasts for at least two weeks and affects a person’s ability to carry out their work or to have satisfying personal relationships. Clinical depression is a common but serious illness and is often recurrent (that is, people recover but develop another episode later on). It affects around 6% of Australian adults in any year. Of this 6% of people with depression, more than 50% also have either an anxiety disorder or substance abuse disorder.<sup>1</sup>

Depression is the most common mental disorder experienced by people with intellectual disability.<sup>12</sup> Prevalence rates between 1.3 and 3.7% have been reported.<sup>12</sup> It has been argued that these rates are underestimates because of the problems involved in diagnosing depression in a population who commonly have communication deficits. Rates are likely to be much higher than in the general population. Some suggest it is as high as 40-50% of people with an intellectual disability. There is a higher prevalence of depression in those with Down syndrome.<sup>21</sup>

The box below shows the symptoms of depression.

### Symptoms of depression

If a person is clinically depressed they would have at least two of the following symptoms for a least two weeks.<sup>9</sup>

- ◆ an unusually sad mood that does not go away
- ◆ loss of enjoyment and interest in activities that used to be enjoyable
- ◆ lack of energy and tiredness.

As well, people who are depressed have other symptoms such as:

- ◆ loss of confidence in themselves or poor self-esteem
- ◆ feeling guilty when they are not really at fault
- ◆ wishing they were dead
- ◆ difficulty concentrating or making decisions
- ◆ moving more slowly or, sometimes, becoming agitated and unstable to settle
- ◆ having sleeping difficulties or, sometimes, sleeping too much
- ◆ loss of interest in food or, sometimes, eating too much. Changes in eating habits may lead to either loss of weight or putting on weight.
- ◆ increase in tearfulness
- ◆ deterioration in social and self help skills.

The following are indicative of more severe signs and symptoms in those with an intellectual disability.<sup>19,23</sup>

- ◆ irritability instead of sadness
- ◆ aggression and self injurious behaviour
- ◆ property damage  
(The more severe the level of disability the more likely the first four are to be expressed due to a decreased ability to verbally communicate thoughts and feelings.)
- ◆ decreased appetite and weight loss
- ◆ severe sleep disturbance
- ◆ weight loss
- ◆ total social withdrawal
- ◆ unwillingness to use speech
- ◆ slowness in thought and movement

Hallucinations or delusions may occur more frequently in people with an ID who are depressed.

Not every person who is depressed has all these symptoms. People who are more severely depressed will have more symptoms than those who are mildly depressed. Here is a guide to severity of depression:

**Mild depression** – 4 of the 10 symptoms over the past two weeks.

**Moderate depression** – 6 of the 10 symptoms over the past two weeks.

**Severe depression** - 8 of the 10 symptoms over the past two weeks.

For the person with intellectual disability there may be gradual or sudden changes in behaviour patterns and or presentation. Some of the symptoms of depression experienced by the general population may actually be a part of the 'usual' presentation of a person with an intellectual disability. This doesn't mean, however, that they aren't symptomatic of depression. The person may have been depressed for quite some time, but it may have been undetected. It is important therefore not to make assumptions, for example, "oh that's just him", "she always looks like that".

It can also be helpful to try and identify whether the person has undergone any negative life experiences in recent times. People who have depression and intellectual disability often have one or more significant traumas in their lives, e.g. loss of significant people, abuse, medical illness, being moved.<sup>19</sup> It is important to understand how significant seemingly minor changes can be for a person with an intellectual disability.

It is also helpful to consider the possible side effects of any medication.

People with ID may not be able to easily communicate their feelings in words. Some may not realise they are depressed, especially if they have been feeling that way for a long time.<sup>17</sup> In those with a moderate or mild intellectual disability, the person may be able to describe the symptoms. Observation of behavioural changes and third party reports from family and direct care providers may need to be more heavily relied upon, especially for those with more severe disability.

The following table outlines the signs and symptoms for a major depressive episode used for the general population and the equivalent for people with an intellectual disability.<sup>10,19,23</sup> Mental health problems may be suspected when the features below represent a change from the person's usual presentation.

Signs and Symptoms in the general population	Intellectual Disability Equivalents
1. Depressed or irritable mood	Apathetic, sad or angry facial expression; lack of emotional reactivity; upset; crying; tantrums; verbal and physical aggression, that don't match the situation.
2. Markedly diminished interest or pleasure in most activities	Withdrawal; loss of interest in usual reinforcers; refusal to participate in favoured leisure activities or work; change in ability to watch TV or listen to music.
3. Significant weight loss; decrease or increase in appetite	Tantrums at meals; refusal to eat or lack of interest in food, stealing food; refusing activities; hoarding food in room
4. Difficulty sleeping or sleeping too much	May or may not be able to self-report sleep problems; if living with others or in a staffed situation, others/staff may report going to bed quite late; any change in sleeping habits; difficulty going to sleep; being up during the night; difficulty waking or waking very early; frequent day time napping; tantrums or activity during sleeping hours; noted sleeping or napping during the day
5. Rapid or slowed thought and movement	Pacing, hyperactivity, restlessness or being fidgety, decreased energy, passivity; development of obsessional slowness in activities of daily living; increase or decrease in vocalizations or speech, muteness; whispering; monosyllables; increase in self-injurious behaviour or aggression, that don't match the situation.

Clinical Criteria	Intellectual Disability Equivalents
6. Fatigue or loss of energy	Appears tired, tiring quickly; refuses leisure activities or work, withdraws to room; loss of daily living skills; refusal to perform personal care tasks; incontinence due to <i>lack</i> of energy/motivation to go to the bathroom; work production decrease; disinterest in joining activities; just watches TV; sitting for long periods of time.
7. Feelings of worthlessness	Statements such as "I'm stupid" or "I'm bad" or "I'm not normal", "nobody likes me". Seeming to seek punishment, blaming themselves. If someone is nonverbal or has difficulty communicating verbally to express their displeasure, frustration or depression they are left with little else but to express this through often aggressive or self harm behaviours. <sup>19</sup>
8. Diminished ability to think or concentrate	Poor performance at work; change in leisure habits and hobbies; appearing distracted, decrease in completion of tasks; needing more instruction or support to complete tasks; loss of previously mastered skills; decrease in IQ upon testing
9. Recurrent thoughts of death; suicidal behaviour or statements	Preoccupation with the deaths of family members and friends; preoccupation with funerals; fascination with violent TV shows/movies; spontaneous comments about death; talking about committing suicide;
	Other symptoms may include excessive need for reassurance, unresponsiveness to preferred staff, complaints of unspecific aches and pains.

### Summary of how a depressed person may appear.

A depressed person is usually slow in moving and thinking, although agitation can occur. Even speech can be slow and monotonous. There can be a lack of interest and attention to personal hygiene and grooming. The person usually looks sad and depressed, and often anxious, irritable and easily moved to tears (although in severe depression the person often describes being emotionally blunted and 'beyond tears'). The thought content often has themes of hopelessness and helplessness, with a negative view of self ('I'm a failure', 'It's all my fault', 'Nothing good ever happens to me', 'I'm worthless', 'No-one loves me'), the world ('Life is not worth living', 'There is nothing good out there') and the future ('things will always be bad')

### The difference between depression & grief

It is important not to confuse grief with mental illness.

Grief is a normal response to loss. The length of time someone grieves and the way in which they do so is very individual.

Unresolved grief and multiples losses over time may increase the risk of someone becoming depressed.

People with an intellectual disability do experience grief and loss, even though they may not understand the concept of death. It is important to remember that due to their cognitive and communicative deficits:

- ◆ they may express grief differently to those without a disability and
- ◆ the mourning process may take longer.

This may lead to the behavioural expression of grief being misdiagnosed as challenging behaviour or depression.

### Bipolar Disorder: a special type of depression

Many people who become depressed will experience subsequent episodes of depression during their life. However, there are some people who experience depression on some occasions and mania on others. Mania is like the opposite of depression. A person experiencing mania will be overconfident and full of energy. They might be very talkative, full of ideas, have less need for sleep, and take risks they normally wouldn't. Although mania may sound like fun, it often gets people into difficult situations. They may lose touch with reality (that is, become psychotic). People who experience mania at some periods of their life and depression at others suffer from bipolar disorder or 'manic-depressive disorder'. Bipolar depression is less common than ordinary depression and requires medical treatment. Bipolar disorder is discussed in Chapter 6.

## What causes depression?

Depression has no single cause and often involves the interaction of many diverse biological, psychological and social factors.<sup>24</sup>

People with an intellectual disability have little control over their lives and often don't have a choice about where they live, the people they live with, activities they participate in, who provides them with care, what they eat, what they wear etc, which can lead to depression.

The risks of developing depression and mood disorders are likely to be higher for people with an intellectual disability due to additional difficulties such as brain damage, higher rates of physical illness, communication impairment, poor social and coping skills and less social support.<sup>12</sup>

People may become depressed when something very distressing has happened to them and they cannot do anything to control the situation, such as:

- ✦ a break-up or loss of a relationship For people with an intellectual disability relationships could also include those at day/work placements, with support workers, carers, therapists, pets
- ✦ living in conflict. Many people with an intellectual disability live in group care. They often have little choice about their placement and as a result the potential for living in conflict is much higher
- ✦ placement changes.(eg, accommodation, day options, vocational)
- ✦ having a baby (10—15% of women suffer depression shortly after childbirth)
- ✦ loss of a job and difficulty finding a new one
- ✦ having an accident which results in long-term disability
- ✦ being a victim of crime
- ✦ developing a long-term physical illness

Depression can also result from:

- ✦ some medical conditions: eg. stroke, dementia, hypothyroidism, Cushing's disease, Addison's disease, Parkinson's disease
- ✦ the side effects of certain medications or drugs. People with intellectual disability are often on medication
- ✦ the stress of having another mental disorder, such as schizophrenia, severe anxiety, alcohol abuse or drug abuse

- ✦ pre-menstrual changes in hormone levels
- ✦ lack of exposure to bright light in the winter months
- ✦ low self esteem and a lack of social skills necessary to obtain positive reinforcement<sup>19</sup>
- ✦ depression is linked to some syndromes associated with intellectual disability, such as Prader-Willi syndrome.

Some people will develop depression in a distressing situation, whereas others in the same situation may not. Those most prone to develop depression are:

- ✦ people who have depression running in their family
- ✦ people who have previously suffered from depression
- ✦ people with a more sensitive emotional nature
- ✦ people who have had a difficult childhood (for example physical abuse, sexual abuse, neglect, over-strictness)
- ✦ women
- ✦ people with an intellectual disability.

Although there are many factors that can lead to depression, all of these may lead to changes in the brain.

The symptoms of depression are thought to be due to changes in natural brain chemicals called neurotransmitters. These chemicals send messages from one nerve cell to another in the brain. When a person becomes depressed, the brain can have less of certain of these chemical messengers. One of these is serotonin, a mood regulating brain chemical.

As mentioned in Chapter 3 in addition to receiving first aid the person with an intellectual disability should also have a comprehensive management plan developed to address their mental health problem.

## First Aid for depression in people with an intellectual disability

1. Assess risk of suicide or harm
2. Listen non-judgementally
3. Give reassurance and information
4. Encourage and support the person to get appropriate professional help. *The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered.*
5. Encourage the person to use any self-help strategies they may have. *The person with an intellectual disability may need support to do this.*



*When administering Mental Health First Aid to people with an ID keep the following suggestions in mind.*

- ❖ *Speak in a calm quiet voice*
- ❖ *Focus on one topic at a time. Because the person may be confused, keep your conversation simple.*
- ❖ *Be patient and wait for responses.*
- ❖ *Keep an upbeat attitude and let the person know that you are available and supportive.*

### Action 1: Assess the risk of suicide or harm

More than 2,500 Australians of all ages and from all walks of life die by suicide each year, leaving behind, friends, families and whole communities who are scarred by the loss of their loved ones. A person may feel so overwhelmed and helpless about life events, that the future appears hopeless. They may think suicide is the only way out. Depression is a major risk factor for suicide, there are others listed in the box below.

#### The SAD PERSONS suicide risk assessment tool<sup>25</sup>

**S**ex: males kill themselves for times more often than females

**A**ge: certain ages groups are more at risk

**D**epression: depressed persons are significantly more at risk

**P**revious attempt: more likely to attempt in future.

**E**thanol: alcohol abuse very often implicated in suicide

**R**ational thought: more prone to suicide if psychotic (out of touch with reality)

**S**ocial network: the less social support, the greater the risk

**O**rganised plan: greater risk if suicide plans are organised

**N**o spouse: greater risk of suicide if there is no partner

**S**ickness: a chronic physical sickness makes suicide more likely

Suicidal thinking and high risk taking behaviour in those with an intellectual disability should always be investigated. The method chosen by a person with an intellectual disability may not have any lethal potential but may have been chosen because the person believed it would be fatal, so the intent is still there.<sup>10</sup>

People with an intellectual disability, especially those with more significant levels, often engage in self injurious behaviour (SIB). Very commonly, SIB is a result of the person's inability to communicate their boredom, loneliness, anger, or physical pain to others.

### The two most important risk factors to look for are:

#### 1. Current plan

Does the person have a plan about how they will kill themselves? Have they got the means to do it? People with an intellectual disability may not be able to answer your questions. You may need to ask a support person who is with them and survey their environment for evidence. Evidence may include a collection of weapons or rope. Use concrete language and avoid abstract concepts.

#### 2. Previous Attempt

Has the person attempted to kill themselves in the past? Another factor that may increase the risk that someone will choose suicide as a way to end their suffering is if a significant person in their life has chosen suicide.

#### Warning signs of suicide

- expressions of wanting to die, not wanting to go on living, to put an end to their relentless suffering.
- organising their affairs
- giving away possessions
- sudden change (better or worse) of appearance or behaviour
- no longer including themselves in plans for the future
- withdrawing into themselves.

If you think someone may be at risk, ask the following question directly: **“Are you thinking of killing yourself?”** or **“Are you planning suicide?”**

The person with an intellectual disability may not understand the term ‘suicide’. You may need to use the words “kill or hurt yourself” instead.

People with an intellectual disability may often want to give you what they think is the “right” answer. Therefore they may say “yes” when in fact the answer is “no” or vice versa. It is important to tell them that you want to hear how they are really feeling and that you are not there to judge them. You're there to help them either way.

**Take seriously any communication of distress. If you believe the person is at risk of harming themselves, seek professional help immediately.**

### How to help a suicidal person

1. Do not get involved physically if person is distressed and threatening.
2. Ensure the person is not left alone – stay with the person if you consider the risk of suicide is high or try to arrange that someone be with them while they get through the immediate crisis.
3. Seek immediate help:
  - ❖ phone the mental health crisis number
  - ❖ phone Emergency 000 or
  - ❖ take the person to a hospital emergency department or
  - ❖ take the person to a GP
4. If the person is consuming alcohol or drugs, try to stop them from consuming any more.
5. Try to ensure the person does not have ready access to some means to take their life.
6. Encourage the person to talk. Listen without judgement. Be polite and respectful. Don't deny the person's feelings. Don't try to give advice.
7. Give reassurance about a favourable outcome for the person.

## Action 2: Listen non-judgementally

- ◆ Engage the person in discussing how they are feeling. People with an ID often have trouble recognising their emotions and expressing them verbally. You may need to give them additional time to think and respond, as well as offer alternative means for them to tell you how or what they are feeling (eg, pictorially, role play)

Listen to the person without judging them as weak. These problems are not due to weakness or laziness – the person is trying to cope. Be empathetic to their concerns and provide comfort where possible.

- ◆ Don't be critical of them. Don't express your frustration at the person for having such symptoms. Privately acknowledge your anger or frustration and deal with it.
- ◆ Don't give glib advice such as 'pull yourself together' or 'cheer up'. The person doesn't have control over their behaviour or mood at this time. You are there to support not to judge or punish.

Observation of body language is important, especially so if the person has communication difficulties. When listening to a person with an intellectual disability you may need to use more checking questions and paraphrasing to ensure that you have understood correctly. It is far better to ask the person to repeat what they said, or say it in a different way, than to pretend that you have understood them or to assume that you have understood.

## Action 3: Give reassurance and information

Help the person to feel hope and optimism and to realise that:

- ◆ depression is common and those attending to them know what to do
- ◆ depression is not a weakness or character defect
- ◆ effective treatments are available for depression
- ◆ appropriate and effective help is available from a GP and/or counsellor
- ◆ depression is not laziness – depression makes people 'motivationally challenged'

- ◆ depression takes a while to develop and sometimes takes a while to resolve, but will get better faster with the right help.

For people with an intellectual disability information and reassurance needs to be given in a way that will promote understanding, e.g. Keep sentences short and simple and don't use jargon; write or draw ideas on paper for them. Check their understanding by asking them to tell you in your own words or way what you have just told them.

Information and education on depression should be made available to staff and carers in order for them to provide appropriate and ongoing support.

## Action 4: Encourage and support the person to get appropriate professional help

There are several types of health professionals who can provide help for depression.

The person with an intellectual disability may need additional support to link them with appropriate professional help. These professionals will require good information about the person with an intellectual disability, so it is important a support person knows the client well.

You may need to stay with them longer or, if possible, arrange for yourself or someone else (perhaps a family member or existing support worker) to assist them to access this professional. Pictures, drawings and diaries may be useful tools to help the person describe the feelings and worries they are experiencing, particularly in counselling.<sup>16</sup>

It is important to take with you to any professional's appointment any information that has been collected regarding the person's behaviour or moods that you think may be relevant, along with details on any current medications they are taking. It is also important that the accompanying support person finds out what happened in a session or appointment so that this can be followed up or reinforced outside the clinical setting.

### GPs

For many people who are depressed, their GP will be the professional they first turn to for help. A GP can provide the following types of help:

- ◆ looking for a possible physical cause of the depression (for example medication side-effect)
- ◆ explaining depression and how the person can best be helped
- ◆ prescribing antidepressant medication if needed

- ◆ referring the person to a counsellor or clinical psychologist who can help them learn ways of overcoming depression
- ◆ referring the person to a psychiatrist particularly if the depression is severe or long-lasting.

People can help a GP make a quicker diagnosis by telling the doctor directly that they think they are suffering from depression. Some GPs are more comfortable dealing with depression than others. A GP should be willing to take the time to listen to the person, should be warm and sympathetic, and should take account of the person's treatment preferences. If a person is not happy with their GP, they should not hesitate to get help from another one. The beyondblue website has a list of GPs with a particular interest in depression

### Counsellors and clinical psychologists

Counsellors and clinical psychologists specialise in the psychological treatment of mental health problems. They are not medically qualified, so they cannot prescribe antidepressants or other drugs. Counsellors and psychologists vary a lot in their training and in their experience of helping people with depression.

A counsellor or clinical psychologist can provide a person with the following types of help:

- ◆ an opportunity to talk about problems and to be listened to in an emotionally supportive and non-judgemental way
- ◆ specific methods for overcoming depression and preventing its recurrence.

A good counsellor or clinical psychologist will use methods to promote coping, such as cognitive behaviour therapy (CBT) or interpersonal psychotherapy.<sup>24</sup> *Cognitive behaviour therapy* is based on the idea that how we think affects the way we feel. When people get depressed they think negatively about most things. There may be thoughts of how hopeless the person's situation is and how helpless they feel, with a negative view of themselves, the world and the future. Cognitive behaviour therapy helps the person recognise such unhelpful thoughts and change them to more realistic ones. Cognitive behaviour therapy may only be applicable for those with mild or upper/moderate levels of intellectual disability.

*Interpersonal psychotherapy* helps people to resolve conflict with other people, deal with grief or changes in their relationships, and develop better relationships.

Ideally the counsellor or psychologist would have an understanding of or experience in intellectual disability. This would help them to recognise the need to adapt their approach for the person perhaps incorporating the use of charts, pictures, photos, drawing, diaries and other concrete visual means.

If a person wants help from a counsellor or clinical psychologist they can contact one themselves (counsellors and clinical psychologists are listed in the Yellow Pages) or get a recommendation from their GP or ring the Australian Psychological Society referral service (Toll free 1800 333 497) or [www.psychology.org.au](http://www.psychology.org.au). Medicare does not cover all private counsellors and clinical psychologists, so they can be very expensive. However Medicare (with a GP's referral) does now provide differing levels of rebate for psychologists, clinical psychologist, and social workers registered with them depending on their level of qualifications. Some private health funds will cover psychologists. Free counselling is available through telephone counselling services such as Lifeline, although this will only offer a supportive relationship rather than specific help to overcome depression.

### Psychiatrists

Psychiatrists are medical specialists who treat mental health problems. Psychiatrists generally only treat people who have severe or long-lasting problems. They are experts on medication and can help people who are having side-effects from their medication or interactions with their other medications.

Psychiatrists can also be helpful to people who have depression combined with other medical problems. It is possible to see a psychiatrist only by getting a referral from a GP. A GP might refer a patient to a psychiatrist if they are very ill or are not getting better quickly. Most psychiatrists work in private practice, but some are attached to hospitals. Only in the most severe cases of depression, or where there is a danger a person might harm themselves, is a depressed person admitted to hospital. Most people with depression are treated successfully in the community.

### Disability Services

Thought should be given to whether it is best for the person with an intellectual disability to see a professional who has experience working with people who have intellectual disability. Psychologists with this kind of experience usually work in specialist services for people with a disability. These can be located by contacting the government agency in your state that has responsibility for people with disability. (See helpful resources Chapter 3 for website details).

If the person is not already linked in with a disability service, a referral should be considered, taking note of the decision-making capacity and wishes of the person with an intellectual disability. If the person is being supported by a disability service, they may already have a GP, psychologist, counsellor or psychiatrist that they regularly see. If so, you may need to provide them with support to access this person.

Your state government disability service may be able to help locate a psychiatrist with experience treating people with intellectual disability.

It may also be useful to talk with the intake officer at the agency about their providing case management for the person you are concerned about, if this is needed. You should seek consent for this from the person if they can give it, or from their legal guardian.

### Family and friends

Family and friends are a very important source of support for a person who is depressed. Recovery is quicker for people who feel supported by those around them. Family and friends can help by:

- ◆ listening to the person with depression without judging them as weak or being critical of them
- ◆ encouraging the person to get appropriate professional help

- ◆ checking if the person is feeling suicidal and taking immediate action if they are the person, and helping out if they cannot manage
- ◆ providing the same support as they would for a physically ill person. These include sending get-well cards, flowers, phoning or visiting.

In looking to family and friends for support, it is important to keep in mind that they may be under stress or 'burnt out' due to their burden of care.

### Action 5: Encourage and support the person to use any self-help strategies they may have

There has not been much research on the effectiveness of the many self-help strategies that people use to relieve depression. The ones below have some support from the literature:<sup>24</sup> A GP should be consulted before taking any new medication or supplements.

- ◆ St John's Wort (this should not be taken together with antidepressants or other prescribed medication) Because people with an intellectual disability may already be on medication, and the potential for contraindications St John's Wort should not be taken unless suggested by GP or Psychiatrist.
- ◆ exercise as part of everyday life, even incidental exercise is valuable. It doesn't necessarily require a special program.
- ◆ exposure to sunlight early in the morning
- ◆ acupuncture
- ◆ alcohol avoidance for people with drinking problems.

- ◆ massage therapy
- ◆ relaxation therapy
- ◆ folic acid and vitamin B12
- ◆ yogic breathing
- ◆ SAME (available from health food shops).

Depression support groups may be a useful source of mutual support and information. These are available in many areas.

The person with an intellectual disability may not have any self-help strategies due to their reduced cognitive abilities, lack of experience & education. Disability specific services may offer specialised education programs to assist people to learn self-help strategies and generalise them into their every day life. It is useful to contact the state government disability service in your locality for information about what is available.

If the person with an intellectual disability does have some strategies, they may need a reminder as to what they are, and then additional support to put these into practice.

### Treatments that work for depression

A team of Australian mental health researchers has reviewed the scientific evidence for the effectiveness of a wide range of treatments for depression.<sup>10</sup> The following rating system was developed to show the treatments whose effectiveness was best supported by the evidence:

😊😊😊 These treatments are very useful. They are strongly supported as effective by scientific evidence.

😊😊 These treatments are useful and are supported by scientific evidence as effective, but the evidence is not strong.

😊 These treatments may be useful and have some evidence to support them. More evidence is needed that they work.

Listed below are medical, psychological, life-style and alternative treatment that work. Those that have more faces have more evidence to support them. Any of these treatments may be useful for a person with mild to moderate depression. However, a person who is severely depressed will need to include medical treatment.

Medical treatments	Rating
Antidepressants	Adults ☺☺☺ Adolescents ☺
Electroconvulsive therapy (ECT)	Very severe depression only ☺☺☺
Transcranial magnetic stimulation	☺
Psychological treatments	
Cognitive behaviour therapy (CBT)	☺☺☺
Interpersonal psychotherapy	☺☺
Reading depression self-help books based on CBT	☺☺
Psychodynamic psychotherapy	☺☺
Lifestyle and alternative treatments	
Exercise	☺☺
Light therapy	Seasonal winter depression ☺☺ Non-seasonal depression ☺
St John's wort*	☺
Acupuncture	☺
Alcohol avoidance (for people with drinking problems)	☺
Massage therapy	☺
Relaxation therapy	☺
SAMe+ (S-adenosylmethionine)	☺
Folate	☺
Yoga breathing exercises	☺
<p>* St John's wort should not be taken together with antidepressants. This herb has interactions with a number of prescribed medications. + SAMe can lead to mania in people who suffer from bipolar disorder.</p>	

### Treatments for Depression in People with an intellectual disability

Most of the common or major treatments listed in the table above have been used in some form with people with intellectual disability and depression. Cognitive behaviour therapy (CBT) has been adapted for use with people with mild intellectual disability and depression. However research support for their efficacy is sadly lacking compared to the non-intellectually disabled population. The following are possible treatments and/or support strategies.<sup>10</sup>

- ◆ Encourage the person to plan pleasant activities in advance. This will give them, something to look forward to, a sense of structure and of control.
- ◆ Try to maintain normal routine. Consistency will give the person a sense of normalcy, safety and of being supported. You need to be careful not to push or force the person into complying. This could result in the person becoming increasingly irritable. Over time this may lead to anger and challenging behaviour.

- ◆ Try to reduce irritations and demands on the person when loss of motivation is present.
- ◆ Antidepressant medication.
- ◆ Psychotherapy (e.g. cognitive therapy).
- ◆ Social skills training in order to help them develop opportunities and expand their social networks.
- ◆ Exercise.
- ◆ ECT (electroconvulsive therapy) in the case of very severe depression. There are strict regulations guiding it's use. For example in NSW if the person is unable to provide consent the matter must be referred to the Mental Health Review Tribunal.
- ◆ Education of individual and support staff about depression.

## Helpful resources for depression

### Websites

A review of Australian websites for depression<sup>26</sup> found the following to be the best.

#### BluePages

<http://blupages.anu.edu.au/>

This website was developed by the Centre for Mental Health Research at The Australian National University. It provides questionnaires to allow self-assessment of anxiety and depression as well as information on medical, psychological and alternative treatments, a link to a site that teaches how to apply cognitive behaviour therapy skills in daily life, a downloadable relaxation tape, a list of resources for depression nationally and in various states, and a search engine covering other depression websites.

#### 'beyondblue': the national depression initiative

<http://www.beyondblue.org.au/>

This is the site of a national initiative to increase community awareness about depression. The site gives questionnaires to assess depression as well as information on the causes of depression, long-term outcomes, and medical and psychological treatments. It also give psychological self-help methods (activity planning, stress reduction, managing sleep, being assertive), a bulleting board and resources such as a downloadable video, patient education leaflets, links, bulletins and research reports. This site includes a chat room.

#### Black Dog Institute

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

The Black Dog Institute is an organisation based in Sydney which provides clinical services, education and research on bipolar disorder. The website gives information about the disorder, including a self-assessment test, and downloadable fact sheets and a spoken education program.

#### Clinical Research Unit for Anxiety and Depression (CRUFAD)

<http://www.crufad.unsw.edu.au>

This site comes from the University of New South Wales and St Vincent's Hospital in Sydney. It is divided in to three sections: self-help clinic, support for professionals, and research. The site includes a depression quiz, information about effective treatments, suggestions for planning activities and problem solving, a list of pleasant activities, and cognitive behaviour therapy materials and links. The downloadable fact sheets are particularly useful.

#### InfraPsych

<http://www.infrapsych.com>

This site is owned by a company established by an Australian psychiatrist. It gives information in a question and answer format covering symptoms, causes, frequency of depression, depression management, sources of help and medical and psychological treatments. There is also a questionnaire for self-assessment of depression. This site has information on medication side effects.

#### MoodGYM

<http://moodgym.anu.edu.au>

This site teaches people to use ways of thinking which help prevent depression. It is based on cognitive behaviour therapy.

#### DepressioNet

<http://depressioNet.com.au>

This is a site developed by people who have experienced depression. As well as giving a range of information about depression, it includes a chat room, stories from contributors, poems, and quotes, news items from the press, information about books, websites, conferences and other events, and summaries of research studies.

#### SANE Australia

<http://www.sane.org/>

SANE Australia is a national charity to help people with mental illness. Its website has some very good downloadable information sheets on depression. It also has a telephone helpline providing information 180018 SANE (7263)

#### Suicide Prevention Australia

<http://www.suicidepreventionaust.org/Home.aspx>

Suicide Prevention Australia is a non-profit, non-government organisation working as a public health advocate in suicide prevention.

#### Centre for Developmental Disability Health Victoria

<http://www.cddh.monash.org/index.html>

Has a link to a depression checklist for intellectual disability that carers can complete and take to a GP appointment.

#### National Institute of Mental Health (US government)

<http://www.nimh.nih.gov/healthinformation/depressionmenu.cfm>

This site gives a wealth of excellent, up-to-date information on depression and suicide in the form of downloadable booklets and fact sheets.

**See Chapter 3 for additional disability and mental health websites**

## Self-help books

David D. Burns (1980). *Feeling good: The new mood therapy*. Information Australia Group. Melbourne. ISBN 0 949338 59 1.

This self-help book is based on cognitive behaviour therapy.

Anthony Jorm, Helen Christensen, Kathy Griffiths, Ailsa Korten and Bryan Rodgers (2001). *Help for depression: What works (and what doesn't)*. Centre for Mental health research, Canberra. ISBN 0 7315 4890 6.

A wide range of treatments for depression are described in the book.

Susan Tanner and Jillian Ball (2001). *Beating the blues-a self-help approach to overcoming depression*. Susan tanner and Jillian ball, Sydney. ISBN 0646 3622 X.

This self-help book teaches skills based on cognitive behaviour therapy.

## National telephone support

Lifeline counselling

Phone 13 11 14 (cost of a local call, 24 hours)

<http://www.lifeline.org.au>

Kids Help Line

Phone 1800 55 1800 (freecall, 24 hours)

<http://www.kidshelp.com.au>

Mensline Australia 1300 78 99 78

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

Lifeline's Just Ask (mental Health Information and Referral Service)

Phone 1300 13 11 14 (cost of a local call, Mon-Fri 9am-5pm)

<http://www.justask.org.au>

## Mental Health Crisis Numbers

**ACT** Mental Health Triage Service, 24hrs, 7 days  
**1800 629 354** or **02 6205 1065**

**NSW** Ring nearest hospital

**NT** Darwin Top End Mental Health Services  
**08 8999 4988**

**QLD** Call Emergency Services **000** or  
Lifeline **13 11 14**

**SA** Crisis Team **13 14 65**

**TAS** **03 6233 2388** or **1800 332 388**  
(9am – 11pm) or nearest hospital

**VIC** Suicide Helpline Victoria **1300 651 251**  
Ring nearest hospital which will contact  
nearest Crisis Team

**WA** Crisis team **1800 676 822**

## Support groups

Find out more about support groups throughout Australia from the Bluepages website  
[http://bluepages.anu.edu.au/help\\_and\\_resources/state\\_by\\_state/](http://bluepages.anu.edu.au/help_and_resources/state_by_state/)

CHAPTER 5  
ANXIETY DISORDERS



## 5 Anxiety disorders

### What is an anxiety disorder?

Everybody experiences anxiety at some time- anxiety can be quite useful in helping a person to avoid dangerous situations and motivate them to solve everyday problems. Anxiety can vary in severity from mild uneasiness through to a terrifying panic attack. Anxiety can also vary in how long it lasts, from a few moments to many years.

An anxiety disorder differs from normal anxiety in the following ways.

- ◆ it is more severe
- ◆ it is long lasting
- ◆ it interferes with the person's work or relationships.

Many people with an anxiety disorder do not realise that there are treatments which can help them have a better life. Although up to 1 in 10 (10%) Australian adults suffer from an anxiety disorder, less than half seek professional help for it<sup>1</sup>

For people with an intellectual disability, this incidence has been reported to be as high as 27%.<sup>19</sup>

Anxiety and stress disorders are often overlooked in people with an intellectual disability, mainly due to communication difficulties. In those with more severe or profound intellectual disability characteristics of these disorders are often misdiagnosed as challenging behaviour.<sup>21</sup>

There are several conditions associated with intellectual disability in which individuals may display some symptoms of anxiety. eg. Autism Spectrum Disorder, Epilepsy, Williams Syndrome. Anxiety here is usually directly related to the condition and not a separate anxiety disorder, even so people with these conditions may still develop anxiety disorders. The first aid strategies and treatments mentioned here are appropriate regardless of the origins of the anxiety.<sup>11,12,19</sup>

### General Symptoms of Anxiety<sup>27</sup>

Anxiety can show in a variety of ways: physical, psychological and behavioural.

#### Physical

Cardiovascular: palpitations, chest pain, rapid heartbeat, flushing.

Respiratory: hyperventilation, shortness of breath

Neurological: dizziness, headache, sweating, tingling and numbness

Gastrointestinal: choking, dry mouth (increased drinking), nausea, vomiting, diarrhoea

Musculoskeletal: muscle aches and pains (especially neck, shoulder and lower back), restlessness, tremor and shaking.

Unfounded physical health concerns.

When reporting physical symptoms likely to be indicative of anxiety, people with an intellectual disability may not use medical terms and may be less specific about the location of their symptoms.

#### Psychological

Unrealistic and/or excessive fear and worry (about past or future events), mind racing or going blank, decreased concentration and memory, indecisiveness, irritability, impatience, anger, confusion, restlessness or feeling 'on edge' or nervousness, tiredness, sleep disturbances, vivid dreams, depressed mood. Due to their difficulty with describing their emotional states, a person with an intellectual disability may be more likely to report their inner experience by talking about physical sensations.

#### Behavioural

Avoidance of situations, obsessive or compulsive behaviour, distress in social situations, phobic behaviour. In people with an intellectual disability behavioural symptoms may present as self injurious behaviour, aggressive behaviour, disruptive or defiant behaviour, self soothing behaviours (e.g. rocking, eating, or bathing) 'clingy' or over-demanding behaviour, withdrawal, seeming to 'freeze', overactivity and sexual dysfunction<sup>12,14,17,68</sup>

## A test for anxiety: the Goldberg Anxiety Scale<sup>28</sup>

In the past month for most of the time:

1 Have you felt keyed up or on edge?

2 Have you been worrying a lot?

3 Have you been irritable?

4 Have you had any difficulty relaxing?

5 Have you been sleeping poorly?

6 Have you had headaches or neck aches?

7 Have you had any of the following: trembling, tingling, dizzy spells, sweating, urinary frequency, diarrhoea?

8 Have you been worried about your health?

9 Have you had difficulty falling asleep?

### Interpretation

Score one point for each 'Yes'. Most people have some of these symptoms. The average number of symptoms experienced by Australian adults is 4. The higher the score, the more likely a person will experience disruption in their daily life. About 12% of adults get a score of 8 or more on this scale. A person with a high score may have an anxiety disorder.

For those adults with a mild intellectual disability the above questions may be used with only minor adaptation to wording. However for those with more significant intellectual disability, observation of behaviour in relation to the theme in each question may be a more effective means.<sup>23</sup>

Physical illness and the effects of medication may be an underlying cause of an anxiety disorder and should be ruled out first if possible.<sup>12</sup>

It is important when considering the symptoms of various anxiety disorders to do so in the context of the developmental level of the person with an intellectual disability, particularly their cognitive and emotional capacity.<sup>29</sup> People with an intellectual disability often have reduced insight into their emotions and feelings as well as a reduced ability to verbally communicate these clearly. It therefore may be more useful to rely more on observable behaviours rather than self-reports.<sup>11</sup> Behavioural signs of anxiety disorder are often mis-diagnosed as due to one of the more readily recognised disorders. eg schizophrenia.

The greater the level of intellectual disability, the more likely it is that anxiety will be demonstrated through the person's behaviour. However not all challenging behaviour is due to anxiety disorder. There may be other environmental factors (e.g. disliking another person in the environment, or not wanting to carry out a particular task) that are the reason for challenging behaviour.<sup>12</sup>

There are many different types of anxiety disorders. The main ones are generalised anxiety disorder, panic disorder, phobic disorder, post-traumatic stress disorder and obsessive-compulsive disorder. The following table below shows how common each of these are.

## Percentage of Australian adults who suffer from an anxiety disorder in any year<sup>1</sup>

Type of anxiety disorder	Men	Women	Adults
Post-traumatic stress disorder	2.3%	4.2%	3.3%
Generalised anxiety disorder	2.4%	3.7%	3.1%
Social phobia	2.4%	3.0%	2.7%
Panic disorder	0.6%	2.0%	1.3%
Agoraphobia	0.7%	1.5%	1.1%
Obsessive-compulsive disorder	0.3%	0.4%	0.4%
<b>Any anxiety disorder</b>	<b>7.1%</b>	<b>12.1%</b>	<b>9.7%</b>

The study of these disorders in the intellectually disabled population suggests that:

- ✦ The rate for *Generalised Anxiety Disorder* (GAD) is similar if not higher than in the general population.<sup>11,12</sup>
- ✦ There seems to be uncertainty about the true extent of *phobias* in people with intellectual disability. This may in part be due to the difficulty of diagnosing this condition in this population. Adults with an intellectual disability appear to have similar rates of phobias as those of children without an intellectual disability. This is possibly due to the fact that they share some common lifestyle characteristics such as
  - lack of control over their life,
  - a feeling of powerlessness,
  - not having the means to avoid the source of their phobia,
  - being more likely to experience failure due to lack of knowledge or skills,
  - lack of insight, and underdeveloped problem solving skills.<sup>19</sup>
- ✦ It has been reported that adults with an ID have a higher rate of specific phobias (eg. spiders, heights, specific situations) than the general population.<sup>12</sup>
- ✦ There is little information about prevalence of *Post Traumatic Stress Disorder* (PTSD) for people with an intellectual disability. However, the literature suggests that when they are exposed to trauma, PTSD develops at a rate comparable to the general population.<sup>29</sup> Limited recognition of PTSD in people with intellectual disability may mean that its symptoms are attributed to other psychiatric diagnosis (e.g. schizophrenia). Diagnosis of PTSD in those who have limited ability to describe their thoughts, feelings and mood is difficult.<sup>29</sup>

It is thought that people with an intellectual disability, due to increased vulnerability (associated with greater dependence, living in unsuitable and sometimes stressful environments), are at a greater risk for experiencing repeated traumatisation and hence PTSD.<sup>23</sup>

- ✦ Rates of *obsessive compulsive disorder* range from 1%-3.5% in the intellectually disabled population<sup>12</sup> as compared with 1-2% for the non intellectually disabled population<sup>19</sup>. Ritualistic/compulsive behaviours themselves are common in adults with intellectual disability; however their cause is not always apparent. As well as occurring in people with an intellectual disability who have psychiatric disorders, such as schizophrenias and affective disorders, ritualistic/compulsive behaviours also occur for people with, autism spectrum disorder,<sup>30</sup> Cornelia de Lange, Rubinstein-Taybi and Prader-Willi syndromes.<sup>11</sup>

### Generalised anxiety disorder (GAD)

- ✦ The main symptom of generalised anxiety disorder is overwhelming, unfounded anxiety and worry (about things that may go wrong or one's inability to cope) accompanied by multiple physical and psychological symptoms of anxiety or tension occurring more days than not, for at least six months. People with generalised anxiety disorder worry excessively about money, health, family and work/day options, even when there are no signs of trouble. For people with an intellectual disability this may also include friendships, relationships with staff and carers. This anxiety appears difficult to control.
- ✦ Physical symptoms include fast or pounding heart, headaches, stomach pains, tremors, muscle tension, inability to relax, dizziness, sweating and dry mouth.
- ✦ Psychological symptoms include excessive worry, irritability, restlessness, feeling on edge, difficulty concentrating, mind going blank and sleep disturbances.
- ✦ Generalised anxiety disorder can make it difficult for people to concentrate at work, function at home and generally get on with their lives.
- ✦ PKU (Phenylketonuria) and William's syndrome have been associated with GAD in the intellectually disabled population.

## Panic disorder

- ◆ A person with a panic disorder suffers from panic attacks (see box) and is afraid that a panic attack might occur.
- ◆ A panic attack is a sudden onset of intense apprehension, fear or terror. These attacks can begin suddenly and develop rapidly. This intense fear is inappropriate for the circumstances in which it is occurring.
- ◆ The person experiencing a panic attack often feels there is impending doom or death. Many of the symptoms are physical ones such as dizziness, shaking, feeling sweaty, nausea, hyperventilating and rapid heartbeat. Many of the physical symptoms can appear similar to those of a heart attack.
- ◆ Once a person has one of these attacks, they often fear another attack and may avoid places where attacks have occurred.
- ◆ Also, people may avoid exercise or other activities that may produce physical sensations similar to those of a panic attack.
- ◆ Note that there are some medical conditions that have symptoms similar to panic attacks (for example arrhythmias of the heart).

### Symptoms of a panic attack

A person having a panic attack will have several of the following:

- ◆ increased awareness of heart beat
- ◆ sweating
- ◆ trembling or shaking
- ◆ feeling of choking, shortness of breath or smothering
- ◆ chest pain or discomfort
- ◆ nausea or abdominal distress
- ◆ feeling of unreality or feeling detached from oneself or from the surroundings
- ◆ feeling dizzy, unsteady, light-headed or faint
- ◆ fear of losing control or going crazy
- ◆ fear of dying
- ◆ numbness, tingling or pins and needles
- ◆ chills or hot flushes.

## Phobic disorders (specific phobias, agoraphobia and social phobia)

- ◆ A person with a phobia avoids or restricts activities because of fear. This fear appears persistent, excessive and unreasonable.
- ◆ They may have an unreasonably strong fear of specific places or events and often avoid these situations completely. Commonly feared situations include leaving home; crowds or public places; open spaces; speaking in public; travelling in buses, trains or planes; and social events.

- ◆ **Agoraphobia** involves avoidance of situations because of the fear of a panic attack occurring. Some people avoid leaving their home for fear of a panic attack occurring. Other people avoid certain situations (for examples shops, driving in a car) where a panic attack has occurred.
- ◆ **Social phobia** is the fear of any situation where public scrutiny may be possible, usually with the fear of behaving in a way that is embarrassing or humiliating. Their key fear is that others will think badly of the person. Social phobia often develops in shy children as they move into adolescence. People with ASD (Autism Spectrum Disorder) often display symptoms of social phobia as part of their disorder. Fragile X syndrome is also often associated with social anxiety.
- ◆ People may have **specific phobias**, for example fear of spiders or fear of heights. Because they only involve specific situations, these phobias are less disabling than agoraphobia and social phobia.

## Acute stress disorder and post-traumatic stress disorder (PTSD)

- ◆ Acute stress disorder and post-traumatic stress disorder occur after a distressing or catastrophic event. This event may involve actual or threatened death, or serious injury. Alternatively it may involve witnessing such an event or learning about such an experience of a family member or close friend.
- ◆ In acute stress disorder the person gets over the events within a month, whereas in post-traumatic stress disorder the distress lasts longer.
- ◆ Only some people experiencing acute stress disorder will go on to develop PTSD. A person is more likely to develop post-traumatic stress disorder if their response to the traumatic event involves intense fear, helplessness or horror. A study of Vietnam War veterans exposed to the traumatic events of war found that 205 of them developed post-traumatic stress disorder.<sup>31</sup>
- ◆ A major symptom is re-experiencing the trauma. This may be in the form of recurrent dreams of the event, flashbacks, intrusive memories or unrest in situations that bring back memories of the original trauma. In people with an intellectual disability, flashbacks and memories may be more vague or distorted or may be re-experienced and reported as a 'recent event'.<sup>26</sup> Because of a reduced ability to communicate about their symptoms, it may appear that the person with an intellectual disability who is experiencing a stress reaction is having hallucinations.
- ◆ There is avoidance behaviour, such as persistent avoidance of stimuli associated with the event, emotional numbing, which may continue for months or years, or reduced interest in others and the outside world. In an attempt to avoid certain situations or stimuli the person with an intellectual disability may display aggressive, escape or non-compliant behaviours.<sup>25</sup>

- ◆ People with an intellectual disability may express their fear by screaming, crying, nightmares, cringing when approached by people, hiding, and wearing several layers of clothing while sleeping. They may also show persistent signs of increased arousal (hyper vigilance, irritability, exaggerated startle response, outbursts of rage, insomnia, enuresis, encopresis).

## Obsessive-compulsive disorder (OCD)

- ◆ This form of anxiety disorder is the least common but is a very disabling condition.
- ◆ Obsessional thoughts and compulsive behaviours accompany the feelings of anxiety. Obsessional thoughts are recurrent thoughts, impulses or images that are experienced as intrusive, unwanted and inappropriate and that cause marked anxiety. Most obsessive thoughts are about fear of contamination or harm. In the person with an intellectual disability these are less prominent and compulsions alone may be the predominant symptom.<sup>7</sup>
- ◆ Compulsive behaviours are repetitive behaviours or mental acts that the person feels driven to perform in response to an obsession in order to reduce anxiety. Common compulsions include the need to wash, check and count.
- ◆ Obsessive-compulsive disorder begins in adolescence and is often a lifelong illness with a waxing and waning course.
- ◆ Compulsions and stereotypic behaviour can be difficult to distinguish between in the person with an intellectual disability. Typically individuals engaged in stereotypic behaviour do not seem to want to stop the behaviour or be distressed by it. In contrast, people with compulsive behaviours may try to resist performing the behaviours, which cause distress.<sup>10</sup>
- ◆ Repetitive thoughts and ritualistic behaviours associated with OCD have sometimes been misdiagnosed as indicating autism.<sup>18</sup>
- ◆ Five types of compulsion have been identified as common in people with intellectual disability:<sup>10</sup>
  - *Ordering* compulsions (e.g. arranging objects/people into certain spots).
  - *Completeness/incompleteness* compulsions (e.g. closing doors, dressing and undressing).
  - *Cleaning/tidiness* compulsions (e.g. repeatedly cleaning one body part, must take out the garbage when full).
  - *Checking/touching* compulsions (e.g. touches items repeatedly)
  - *Grooming* compulsions (e.g. checks self in mirror excessively).
- ◆ Due to the inability of many people with an intellectual disability to identify the thoughts and feelings associated with their need to perform behaviours, it becomes important to observe for behavioural indicators of OCD such as, aggression when rituals are interrupted, tense facial expression, clingy behaviour, agitated outbursts, behaviour that resembles hyperactivity.<sup>19</sup> The ability to identify rituals and thoughts as irrational and dysfunctional may be lacking for those with an intellectual disability. This however should not rule out OCD as an explanation for the person with intellectual disability's symptoms.<sup>10</sup>

## Mixed anxiety and depression

- ◆ Many people with anxiety problems do not fit neatly into a particular type of anxiety disorder. It is common for people to have some features of several anxiety disorders.
- ◆ A high level of anxiety over a long period will often lead to depression, so that many people have a mixture of anxiety and depression. It has been estimated that 66% of people with an intellectual disability and OCD will also experience major depression at some point in their lives.<sup>19</sup>
- ◆ The literature reports that the rate of anxiety and depression for people with intellectual disability is about the same as for the general population.<sup>12</sup>
- ◆ Substance misuse frequently occurs with anxiety disorders, perhaps as a means of self medication to help relax. However, ongoing alcohol and other drug misuse can lead to increased anxiety.

## What causes anxiety disorders?

Anxiety is mostly caused by perceived threats in the environment, but some people are more likely than others to react with anxiety when they are threatened. These are:

- ◆ People who had a very anxious parent.
- ◆ People with a more sensitive emotional nature who tend to see the world as threatening.
- ◆ People who have had a difficult childhood (for example physical abuse, sexual abuse, neglect, over-strictness).
- ◆ Women.
- ◆ People with an intellectual disability. They often have difficulty with change and new situations and have at times a heightened sensitivity to factors in the environment that others may not detect. They also tend to have few or ineffective coping strategies and reduced problem solving abilities.

Anxiety symptoms can also result from:

- ◆ Some medical conditions; hyperthyroidism, vitamin B12 deficiency, seizures and cardiac conditions such as arrhythmias.
- ◆ Side effects of certain prescription drugs
- ◆ Certain non-prescription drugs: caffeine, cocaine, LSD, ecstasy and speed.

Some people develop ways of reducing their anxiety that cause further problems. For example, people with phobias avoid anxiety-provoking situations. This avoidance reduces their anxiety in the short term but can limit their lives in important ways. Similarly, people with compulsions reduce their anxiety by repetitive acts such as checking or washing hands. The compulsions then become problems in themselves.

People with an intellectual disability may develop aggressive or self harm behaviours in order to try and cope with or to communicate their anxiety.

As mentioned in Chapter 3 in addition to receiving first aid the person with an intellectual disability should also have a comprehensive management plan developed to address their mental health problem.

## First Aid for anxiety disorders in people with an intellectual disability

1. **Assess risk of suicide or harm**
2. **Listen non-judgementally**
3. **Give reassurance and information**
4. **Encourage and support the person to get appropriate professional help. *The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered***
5. **Encourage the person to use any self-help strategies they may have. *The person with an intellectual disability may need support to do this***



***When administering Mental Health First Aid to people with an ID keep the following suggestions in mind.***

- ❖ ***Speak in a calm quiet voice.***
- ❖ ***Focus on one topic at a time. Because the person may be confused, keep your conversation simple.***
- ❖ ***Be patient and wait for responses.***
- ❖ ***Keep an upbeat attitude and let the person know that you are available and supportive.***

### Action 1: Assess the risk of suicide or harm

People with anxiety disorders have a higher risk of suicide, particularly if depression is present. See 'How to help a suicidal person' in Chapter 4. With anxiety disorders there is also the possibility that a person may have an exaggerated belief that they are at risk of harm. For example a person may have a strong but unrealistic fear that they will come to great harm, such as have a heart attack. This fear can spiral up into a panic attack.

People with an intellectual disability can be very suggestible so it is important not to put words into their mouth when you are trying to assess the risk of suicide or harm.

## How to help a person having a panic attack

1. If you are unsure whether the person is having a panic attack, a heart attack or an asthma attack, and/or the person is in distress, call an ambulance.
2. If you know the person is having a panic attack and not a heart or asthma attack, move the person to a quiet safe place.
3. Focus their attention and thinking on something visible like clothes or jewellery they are wearing.<sup>19</sup>
4. Help to calm the person by encouraging slow, relaxed breathing in unison with your own. Encourage the person to breathe in for 3 seconds, hold for 3 seconds and then breathe out for 3 seconds (you can get them to use the second hand on a watch).
5. Be a good listener, without judging.
6. Explain to the person that they are experiencing a panic attack and not something life-threatening such as a heart attack.
7. Explain that the attack will soon stop and they will recover fully.
8. Assure the person that someone will stay with them and keep them safe until the attack stops.

## How to help a person who has experienced a traumatic event

**The most important thing is to give information about the situation and to offer practical help for the necessities of life such as food, accommodation and contact with family.**

1. **Let the person tell their story if they wish, but do not push them to do so if they don't want to.** People who experience a traumatic event have their own pace for dealing with the trauma. In trying to help such a person it is important to let them set the pace and not force the issue. Urging someone into a discussion of a traumatic event may actually re-traumatise a victim. (Research has shown that a routine session of critical incidence debriefing, also called psychological debriefing, does not reduce the risk of post-traumatic stress disorder developing after a traumatic event.)<sup>32</sup>
2. **Be a patient and sympathetic listener, before giving any advice.** Make personal contact and listen non-judgmentally before making any recommendations for help.
3. **Validate the person's stress reactions as being normal responses to abnormal events.** Explain that stress reactions are normal for days or even weeks after a trauma and that people usually have a normal recovery of their emotions. These stress reactions include shock, fear, grief, emotional numbing, indecisiveness, worry, unwanted memories, fatigue, difficulty sleeping, being easily startled, distrust and irritability.
4. **Encourage and support the person to reach out to other people who can provide support and share feelings about what is happening.** Encourage traumatised people to talk with family, friends, support workers and work colleagues, following their own instincts on how much they say and with whom they talk. Don't tell the person to stop reliving and simply forget the trauma, and to get on with life. People with an intellectual disability may need additional support to engage others. They may have problems initiating this contact. Are there people around who the person feels they can talk to and are familiar with the person's method of communication? Visual methods such as drawings, pictures etc may be required to assist the person to communicate how they are feeling.
5. **Advise the person not to alcohol or drugs to cope.** Instead advise them to use simple relaxation methods. People with an intellectual disability may require support to use even simple relaxation techniques.
6. **If the stress reaction persists for more than a month, encourage and support the person to seek professional help.** If the person continues to experience stress reactions or severe distress that interferes with normal functioning after a month following the trauma, encourage and support the person to seek professional help, if not yet sought.
7. **If you work for an organisation that has policies relating to the reporting of serious incidents for clients, follow these.**

## Action 2: Listen non-judgementally

- ◆ Listen to the person without judging them as weak. These problems are not due to weakness or laziness – the person is trying to cope. Be empathetic to their concerns and provide comfort where possible.
- ◆ Don't be critical of them. Don't express your frustration at the person for having such symptoms. Privately acknowledge your anger or frustration and deal with it.
- ◆ Don't punish their behaviour.
- ◆ Don't give glib advice such as 'pull yourself together'. The person doesn't have control over their behaviour or mood at this time, you are there to support not to judge

- ◆ Avoid confrontation unless necessary to prevent harmful acts.

With any statement you make as you listen to a person with an intellectual disability, remember to focus on one topic at a time and be patient in expecting responses. You may need to use more checking questions and paraphrasing to ensure that you have understood correctly. It is far better to ask the person to repeat what they said, or say it in a different way, than to pretend that you have understood them.

## Action 3: Give reassurance and information

Help the person to feel hope and optimism and to realise that:

- ◆ an anxiety disorder is a common and those attending to them know what to do.
- ◆ an anxiety disorder is not a weakness or character defect
- ◆ effective help is available for overwhelming anxieties
- ◆ skills can be learned to reduce the effects of stress and anxiety
- ◆ anxiety can be unpleasant but is rarely harmful.

### In addition to providing reassurance and information, other First Aid strategies to use before professional assistance becomes available include:

- ◆ reduce some of the environmental factors that may be contributing to the persons anxiety levels such as the amount of noise or number of people.<sup>16,19</sup>

#### For PTSD:

- ◆ help the person feel safe. Assure them that they are in a safe place and there is no one there who is going to hurt them.
- ◆ don't force the person to confront the fear immediately
- ◆ wherever possible remove triggers from the environment
- ◆ if you think the person is experiencing a flashback, try and anchor them in the 'here and now' by quietly reminding them where they are and what the current circumstances are.

- ◆ do not assume that touches or hugs will be reassuring for the person with an intellectual disability who is experiencing PTSD. The initial trauma may have involved physical contact, so ask if it is all right to comfort in this way.

#### For OCD<sup>19</sup>:

- ◆ don't reinforce the person by becoming involved in their rituals
- ◆ provide reassurance that the feared event is unlikely

Information and education on anxiety disorders should be made available to staff and carers so they can provide appropriate and ongoing support.

For people with an intellectual disability information and reassurance needs to be given in a way that will promote understanding. eg. Keep sentences short and simple and don't use jargon; write or draw ideas on paper for them. Check their understanding by asking them to tell you in your own words or way what you have just told them.

Anxiety often produces frightening physical sensations, frightening thoughts and/or mental effects such as poor concentration and memory. Concentrating on physical symptoms will only increase the fear and anxiety. The person needs to concentrate on controlling anxiety, not the physical symptoms. These physical symptoms will pass when anxiety is controlled.

## Action 4: Encourage and support the person to get appropriate professional help

The person with an intellectual disability may need additional support to link them with appropriate professional help. These professionals will require good information about the person with an intellectual disability, so it is important a support person knows the client well.

You may need to stay with them longer or, if possible, arrange for yourself or someone else (perhaps a family member or existing support worker) to assist them to access this professional. Pictures, drawings and diaries may be useful tools to help the person describe the feelings and worries they are experiencing, particularly in counselling.<sup>16</sup> It is important to take with you to any professional's appointment any information that has been collected regarding the person's behaviour or moods that you think may be relevant, along with details on any current medications they are taking. It is also important that the accompanying support person finds out what happened in a session or appointment so that this can be followed up or reinforced outside the clinical setting.

See a GP first, a good GP should provide:

- ✦ a full physical check to ensure there is no physical condition causing the symptoms
- ✦ education about the nature of the anxiety disorder
- ✦ ongoing appointments for counselling and support
- ✦ referral to a clinical psychologist or mental health worker who can provide cognitive behaviour therapy.

Anxiety disorders are better treated with counselling or psychological techniques than with medication, both for effectiveness in the short term and in the long term, after treatment has concluded.<sup>33</sup> Medication may be appropriate in certain circumstances:

- ✦ For short term control of anxiety. However regular use of these may lead to dependence and is likely to result in the return of fear or panic symptoms when discontinued.
- ✦ A prescription for antidepressants if panic attacks are frequent and severe, if obsessive-compulsive disorder is disabling or if the person is significantly depressed.

### Disability Services

Thought should be given to whether it is best for the person with an intellectual disability to see a professional who has experience working with people who have an intellectual disability. Psychologists with this kind of experience usually work in specialist services for people with disability. These can be located by contacting the government agency in your state that has responsibility for people with disability. (See helpful resources Chapter 3 for website details).

If the person is not already linked in with a disability service, a referral should be considered, taking note of the decision-making capacity and wishes of the person with ID. If the person is being supported by a disability service, they may already have a GP, psychologist, counsellor or psychiatrist that they regularly see. If so, you may need to provide them with support to access this person.

Your state government disability service may be able to help locate a psychiatrist with experience treating people with intellectual disability. It may also be useful to talk with the intake officer at the agency about their providing case management for the person you are concerned about, if this is needed. You should seek consent for this from the person if they can give it, or from their legal guardian.

The literature suggests that the following 'best counselling approaches' are appropriate for use with the intellectually disabled population. Obviously the more significant the intellectual disability the more adaptations (i.e. use of visual and additional communication aids) will need to be made by the counsellor or those supporting the client.

### The best counselling approaches for post-traumatic stress disorder<sup>33</sup> are those that encourage or assist the person to:

- ✦ explore details and emotions surrounding the original experiences and to the cues in the current environment that evoke the traumatic memories, until they lose their power to disturb. If given early after a trauma, prolonged exposure to disturbing memories can even prevent post-traumatic stress disorder from developing.<sup>34</sup> This type of therapy should only be carried out by experienced specialist therapists
- ✦ control hyperventilation with slow, controlled breathing
- ✦ control bodily feelings of anxiety with progressive muscle relaxation.

### The best counselling approaches for generalised anxiety disorder<sup>33</sup> are those that encourage the person to:

- ✦ practice daily relaxation methods (for example progressive muscle relaxation, breathing exercises) to reduce physical symptoms of tension
- ✦ identify and challenge exaggerated worries to reduce anxiety symptoms
- ✦ use structured problem-solving to deal with problem situations and worries
- ✦ use graded exposure to difficult situations.

**The best counselling approaches for phobic disorders<sup>33</sup>** are those that help to plan a series of steps to enable the person to confront and get used to feared situations (that is, graded exposure to feared situations). The basic elements of graded exposure are as follows:

- ◆ Identify a small first step towards the feared situation (for example, take a short walk away from the home with a family member).
- ◆ This step should be practised for one hour a day until it is no longer frightening.
- ◆ If the feared situation still causes anxiety, the person should practice slow and relaxed breathing, telling themselves that the panic will pass within 30 minutes. It is best if the person does not leave the feared situation until the fear subsides.
- ◆ Move onto a slightly more difficult step and repeat the procedure (for example spends a longer time away from home).
- ◆ Take no alcohol or anti-anxiety medication for at least four hours before practising these steps.
- ◆ A friend or family member should be identified who will help in overcoming the fear.

**The best counselling approaches for panic disorder<sup>33</sup>** are those that encourage or assist the person to:

- ◆ stay where they are until the attack passes
- ◆ concentrate on controlling anxiety by slow, relaxed breathing
- ◆ realise panic attacks seem long but in reality generally only last a few minutes
- ◆ identify exaggerated fears which occur during panic (for example fear of having a heart attack, fear of not being able to escape)
- ◆ discuss ways to challenge these fears (for example, the person reminds themselves, 'I am not having a heart attack. This is a panic attack and it will pass in a few minutes').

**The best counselling approaches to obsessive-compulsive disorder<sup>33</sup>** are those that encourage or assist the person to:

- ◆ Resist carrying out compulsions. This is facilitated by treatment with cognitive behaviour therapy, which involves entering situations that evoke the obsessive thoughts but not carrying out the compulsive behaviours.

### **Action 5: Encourage and support the person to use any self-help strategies they may have.**

Remind the person of the following:

- ◆ Anxiety is best overcome by confronting fears rather than avoiding them.
- ◆ The longer and the quicker fears are confronted, the sooner they will get better.
- ◆ Practise daily relaxation methods to reduce physical symptoms of tension.
- ◆ Reduce caffeine intake to 300mg or less per day (see following table).
- ◆ It is also a good idea to reduce any other stimulants such as noise, removing themselves from a 'busy' environment.
- ◆ Partake of leisure time and pleasurable activities.
- ◆ Get adequate sleep.
- ◆ Practise controlled breathing methods (slow, relaxed breathing) to reduce physical symptoms of anxiety, fear and panic. Avoid breathing too deeply or rapidly (hyperventilation) as this can cause physical symptoms of panic.

- ◆ Identify and challenge exaggerated worries and pessimistic thoughts.
- ◆ Accept that avoiding feared situations allows the anxiety or fear to grow even stronger.
- ◆ Follow a set of specific steps to help overcome fear or phobia.
- ◆ Talk about your anxiety problems with other people at self-help groups.

The person with an intellectual disability may not have any self-help strategies due to their reduced cognitive abilities. Disability specific services may offer specialised education programs to assist people to learn self-help strategies and generalise them into their every day life. It is useful to contact the state government disability service in your locality for information about what is available. These services may be open to suggestion if they do not currently have programs that might be helpful, so it is worth asking if they can set something specific up for the person you are concerned about. If the person with an intellectual disability does have some strategies, they may need a reminder as to what they are, and then additional support to put these into practice.

<b>Caffeine content of food and drinks</b>	
<b>Product</b>	<b>Caffeine (mg)</b>
<b>COFFEE</b>	
Instant, weak, 1 level teaspoon	45
Instant, strong, 1 heaped teaspoon	90
Brewed, percolated, 200ml	100
Drip method, 200ml	140
Espresso (short black)	80
Cappuccino	80
<b>TEA</b>	
Bag or brewed, weak, 200ml	20
Bag or brewed, strong 200ml	70
<b>SOFT DRINKS</b>	
Coke, 375ml	50
Pepsi, 375ml	38
Red Bull Energy Drink	80
Red Eye Platinum	65
<b>CHOCOLATE</b>	
Dark, 50g	33
Milk, 50g	12
Table modified from The CHOICE Health Reader Jan/Feb 2001	

## Helpful resources for Anxiety Disorders

### Websites

#### **National Institute of Mental Health (US government)**

National Institute of Mental Health (US government)

<http://www.nimh.nih.gov/healthinformation/anxietymenu.cfm>

This website has a wealth of good information on anxiety.

#### **Clinical Research Unit for Anxiety and Depression (CRUfAD)**

<http://www.crufad.com>

This site was developed by the University of New South Wales and St Vincent's Hospital, Sydney, phone (02) 9332 1188. See the site's 'self-help' section for downloadable evidencebased fact sheets.

#### **Macquarie Psychology Clinic**

<http://www.psy.mq.edu.au/MUARU>

This is the site of the Psychology Clinic of Macquarie University, Sydney, phone (02) 9850 8000; This site gives information on anxiety disorders in young people and also social phobia in adults.

#### **Panic Online**

<http://www.med.monash.edu.au/mentalhealth/paniconline>

Panic Online is an online resource and treatment program for people with panic disorder. It is based at Monash University, Melbourne. It has to be used in collaboration with a person's treating doctor.

#### **Mental Health Information Centre**

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

"Providing information, education and support to consumers, carers, health practitioners and the wider community on all aspects of Anxiety"

**See Chapter 3 for additional disability and mental health websites**

## Self-help books

Edmund Bourne (2005). *The anxiety and phobia workbook*. 4th Ed New Harbinger Publications, Oakland CA. ISBN 1-57224-413-5.

This is an excellent self-help book based on cognitive behaviour therapy.

Isaac Marks (2001). *Living with fear*. McGraw- Hill Education, Berkshire England. ISBN 0077097580.

This book is also based on cognitive behaviour therapy. It includes a very useful chapter on self-help for fears and anxiety. Research has shown that people with phobias who follow the instructions in this chapter improve as much as people treated by a professional.

Ronald M. Rapee (1998). *Overcoming shyness and social phobia*. Lifestyle Press, Killara NSW. ISBN 0 9585453 08.

This book teaches how to overcome social phobia using cognitive behaviour therapy.

Bev Aisbett (1999)

*Living With It – a survivors guide to panic attacks*.

Harper Collins Australia.

ISBN: 978-0207180408.

An easy to read book with cartoons to cover the topics of changing negative thoughts, seeking professional help and learning skills of recovery.

CHAPTER 6  
PSYCHOSIS



## 6 Psychosis

### What is psychosis?

Psychosis is a general term to describe a mental health problem in which a person has lost some contact with reality. There are severe disturbances in thinking, emotion and behaviour. Psychosis severely disrupts a person's life. Relationships, work and self-care are difficult to initiate and/or maintain.

The main psychotic illnesses are schizophrenia, bipolar disorder (manic depressive disorder), psychotic depression, schizoaffective disorder and drug induced-psychosis.

Psychotic illness are not among the most common mental health problems. Psychosis affects less than 1% of Australian adults in any year.<sup>4</sup> However, over a lifetime the risk of developing schizophrenia is 1%<sup>36</sup> and bipolar disorder 2%<sup>37</sup>

People in the early stages of suffering from psychosis often go undiagnosed for a year or more before receiving treatment. A major reason for this is that psychosis often begins in late adolescence or early adulthood and the early symptoms involve behaviours and emotions which are common in this age group. Many young people have some of these symptoms without developing psychosis.

### Common symptoms when a psychotic disorder is developing. <sup>38</sup>

#### Changes in Emotion and motivation:

- ◆ depression
- ◆ anxiety
- ◆ irritability
- ◆ suspiciousness
- ◆ blunted, flat or inappropriate emotion
- ◆ change in appetite
- ◆ reduced energy and motivation

#### Changes in thinking and perception

- ◆ difficulties with concentration or attention
- ◆ sense of alteration of self, others or the outside world (for example feeling that self or others have changed or are acting differently in some way)
- ◆ odd ideas
- ◆ unusual perceptual experiences (for example a reduction or greater intensity of smell, sound or colour)

#### Changes in Behaviour

- ◆ sleep disturbance
- ◆ social isolation
- ◆ reduced ability to carry out work and social roles.

It is unfortunate that psychosis often takes so long to be treated. The consequences of delayed treatment include:<sup>38</sup>

- ✦ slower and less complete recovery
- ✦ poorer long-term functioning
- ✦ increased risk of depression and suicide
- ✦ slower maturing psychologically and slower uptake of adult responsibilities
- ✦ strain on relationships with friends and family and subsequent loss of social supports
- ✦ disruption of study and employment
- ✦ increased use of alcohol and drugs
- ✦ loss of self-esteem and confidence
- ✦ greater chance of problems with the law.

A person showing symptoms of early psychosis may eventually be diagnosed as having one of the following psychotic disorders.

## Schizophrenia

Schizophrenia is nothing to do with 'split personality'. The term schizophrenia means 'fractured mind' and refers to changes in mental function where thoughts and perceptions become disordered.

About 1% of people develop schizophrenia at some stage in their lives.<sup>36</sup> Nearly three-quarters of sufferers are young people between the ages of 16 and 25 when first affected. Schizophrenia is a bit more common in males than and males tend to develop it earlier than females. The onset of the illness may be rapid, with symptoms developing over several weeks, or it may be slow and develop over months or years. About a third of people who develop schizophrenia have only one episode and fully recover, another third have multiple episodes but are well in between, and a third have a life-long illness.

The prevalence of schizophrenia in intellectual disability is reported to be around 3%, which is about three times higher than in the general population. The reason for this is not clear, however a partial explanation for this may be due to genetic risk factors and increased rates of obstetric complications.<sup>12</sup>

A diagnosis of a psychotic disorder in those with a severe ID or severe communication difficulties is difficult and rarely made, as diagnosis relies largely on the person being able to explain their internal experiences<sup>17</sup>.

The major symptoms of schizophrenia include:

### Delusions

These are false beliefs of persecution, guilt, special mission or exalted birth, or being under outside control.

The nature of delusions and the way they are expressed by a person with an intellectual disability are similar to that in the general population, however the content of the delusions tends to be less bizarre. The person with an intellectual disability is more likely to express delusions through their behaviour. Delusions may present in a person with intellectual disability as:

- ✦ new avoidance or 'fears'
- ✦ irrational beliefs not expressed before
- ✦ bizarre accusations of others
- ✦ glaring with intense anger at strangers or previously liked others
- ✦ sudden medication refusal<sup>39</sup>

Control by external forces is a common delusion. Caution is needed when these statements are encountered in the person with an intellectual disability, because they generally have less control over their everyday lives than most and it may be a reality that others are controlling them.<sup>12</sup>

### Hallucinations

These are false perceptions. Hallucinations most commonly involve hearing voices, but can also involve seeing, feeling, tasting or smelling things. These are perceived as very real by the schizophrenic person, but are not actually there. The hallucinations can be very frightening, especially voices saying negative comments about the person. Because their delusions and hallucinations are so real to them, it is common for people with schizophrenia to be unaware they are ill.

People with intellectual disability are likely to experience and express hallucinations in ways that are consistent with their communication and developmental ability. The kind of hallucinations they experience may also be a function of their limited life experiences and interests, so they may be expressed in broader or more simplistic terms.<sup>17</sup> When asking a person with an intellectual disability about their auditory hallucinations it may be wise to do so on a number of occasions to check for consistency in their presentation.<sup>12</sup>

As with delusions, the person with an intellectual disability is more likely to demonstrate an hallucination through behaviour. Some of the common behaviours suggesting an hallucination include:

- ◆ talking to non-existent people
- ◆ turning their head or nodding as if listening to someone no one else hears
- ◆ reporting conversations not heard by others
- ◆ sniffing the air, as if smelling something not smelt by others
- ◆ pushing or brushing unseen objects off their body
- ◆ scratching
- ◆ covering their eyes or ears as if to block out hallucinations
- ◆ 'shadow boxing'

It is important in relation to both delusions and hallucinations to remember that the presentation of these may actually represent some other condition or actual reality for the person with an intellectual disability rather than a symptom of psychosis. For example:

- ◆ because of their limited cognitive ability and social understanding, they may believe that a carer is trying to hurt them if they don't get on with that staff member or another staff member decreases their level of support to the person.
- ◆ a person may also report that others are staring at them, which they may well be due to their 'different' appearance.
- ◆ 'fantasy thinking' may be due to other conditions such as autism and not a psychotic symptom.
- ◆ it is not uncommon to see a person with an intellectual disability talking to themselves or carrying on a conversation with an imaginary person or an inanimate object. Self talk may be the person's way of coping with stress or of processing information. They may have 'imaginary friends' with whom they talk when lonely or bored or frightened.
- ◆ a person with an intellectual disability may have trouble recognising their own thoughts and may attribute them to others.<sup>12</sup>
- ◆ hallucinations can occur in some medical conditions, for instance when a person has a high fever.

### **Thinking difficulties**

There may be difficulties in concentration, memory and ability to plan. These make it more difficult for the person to reason, communicate and complete daily tasks.

### **Loss of drive**

The person lacks motivation even for self-care. It is not laziness.

### **Blunted emotions**

The person has a lack of or inappropriate emotions.

### **Social withdrawal**

This may be due to loss of social skills or fear of interacting with others.

Additional symptoms in a person with intellectual disability might include;

- ◆ deterioration of language skills or decrease in the use of language
- ◆ speech no longer present or making sense.
- ◆ sudden appearance of new unusual mannerisms.
- ◆ not moving from one position for a long period of time.
- ◆ general skill deterioration.
- ◆ lack of expression or emotions.
- ◆ previous reinforcers become no longer effective.
- ◆ aggressive behaviour. It has been reported that most individuals with intellectual disability and schizophrenia will present with some aggressive behaviour. This may be in direct response to distressing thoughts and feelings.<sup>19</sup>

The important thing to look for in people with an intellectual disability is a change in the person's behaviour or level of functioning. Symptoms that are due to the person's intellectual disability will tend to be constant and long standing.<sup>12</sup>

### **Bipolar Disorder**

People suffering from bipolar disorder (manic depressive illness) have extreme mood swings, fluctuating between periods of depression, mania and normal mood. It can take a long time for bipolar disorder to be diagnosed correctly because the person needs to have had episodes of both depression and mania. During episodes of **depression** the person has some or all of the symptoms listed in Chapter 4 Depression.

The difference between mania and depression for people with an intellectual disability is not as distinct as they are for the general population. It is reported that the rates for people with an intellectual disability who experience more than four episodes of either mania or depression in a year (rapid cycling) is greater than for the general population.<sup>68</sup> The interpersonal problems experienced as part of bipolar disorder are less pronounced in the intellectually disabled population than in the general population<sup>19</sup>.

Bipolar disorder affects 2% of people, with males and females being equally affected. It is commonly first diagnosed when people are in their 20s.<sup>37</sup> Several studies have reported higher rates of bipolar disorder among people with intellectual disability than in the general population. Prevalence rates range from 0.9%-4.8% compared to 2% for the general population.<sup>19</sup>

### **Mania**

The following are the common symptoms of mania and how they may present in a person with intellectual disability.

#### **Increased energy and overactivity**

- ◆ pacing, rarely sitting
- ◆ fidgeting
- ◆ working on many activities at once
- ◆ increase in rituals or compulsions
- ◆ skipping from activity to activity, leaving tasks uncompleted
- ◆ inability to sit through previously pleasurable activities

#### **Elated mood**

The person will feel high, happy, full of energy, on top of the world, invincible.

- ◆ smiling, hugging or being affectionate with people who previously weren't favoured, enthusiastic greeting of everyone
- ◆ getting into other people's space
- ◆ hitting out at a previously favoured person
- ◆ boisterous, playfulness and constant excitement, extreme excitement
- ◆ over-reactivity to small incidents, e.g. excessive laughing and giggling
- ◆ self injurious behaviour (SIB) associated with irritability
- ◆ nasty teasing
- ◆ difficult to redirect<sup>10,19</sup>

### **Need less sleep than usual**

The person can go for days with very little sleep.

- ◆ behavioural challenges when prompted to go to bed
- ◆ constantly getting up at night
- ◆ seeming rested after not sleeping
- ◆ working on activities in their room during the night
- ◆ ready for work extremely early

### **Irritability**

This may occur if others disagree with a manic person's unrealistic plans or ideas.

Some of the literature suggests that in the intellectually disabled population irritability is more predominant than elation or elevated mood. This is likely to lead to higher levels of aggression being associated with Bipolar Disorder in this group.

In a person with an intellectual disability presentation may include:

- ◆ aggressive behaviours (both physical and verbal) particularly in response to minor things that he or she wouldn't normally react to.
- ◆ self-injurious behaviour (SIB)
- ◆ pacing
- ◆ refusals to co-operate
- ◆ destructive behaviour

### **Rapid thinking and speech**

The person may talk too much, too fast and keep changing topics.

- ◆ increase in singing, swearing, vocalisations
- ◆ continually repetitive or disorganised speech
- ◆ screaming
- ◆ constant interrupting
- ◆ increase in non-verbal communication
- ◆ decrease in ability to listen
- ◆ disconnected thoughts
- ◆ quickly changing subjects
- ◆ reporting that ideas are moving too fast

### **Lack of inhibitions**

The person may disregard risks, spend money extravagantly or be very sexually active.

- ✦ increased masturbation
- ✦ sexualising previously platonic relationships
- ✦ teasing others
- ✦ fondling others
- ✦ increase in intrusive behaviours like touching, hugging, clinging
- ✦ stripping
- ✦ giving away/spending money

### **Grandiose delusions**

These involve very inflated self-esteem such as a belief that the person is superhuman, especially talented or an important religious figure. In a person with an intellectual disability these delusions are usually simpler.

- ✦ making improbable claims. Care is needed to make a distinction between “wishful thinking” and grandiose ideas. People with intellectual disability sometimes maintain that they are a staff member or possess skills they do not have. It is likely that such thinking may be grandiose if the person becomes highly distressed when their claims are challenged
- ✦ wearing excessive make-up
- ✦ dressing provocatively
- ✦ demanding rewards
- ✦ inappropriate remarks.

### **Lack of insight**

The person is so convinced that their manic delusions are real that they do not realise they are ill.

### **Other signs**

Additional signs that may present in a person with intellectual disability and Bipolar Disorder include:

- ✦ sudden or gradual changes in usual behaviour
- ✦ seeking reassurance
- ✦ loss of skills
- ✦ loss of bowel or bladder control
- ✦ loss of ability to communicate
- ✦ physical illness<sup>67</sup>

It is important to remember that many of the symptoms associated with a manic episode are often typical features of intellectual disability, e.g. poor judgement, distractibility, excessive activity, aggression, etc. The key to determining whether a person is having a manic episode is to compare their current functioning with previous functioning. Before assuming that the person with an intellectual disability is experiencing mental health problems, look for other factors which may account for the presence of some of the signs or symptoms, eg. hormonal changes in women, medical conditions such as epilepsy, hypoglycaemia, hyperthyroidism, substances such as caffeine, medication side effects and various environmental and seasonal factors.<sup>10,12</sup>

### **Psychotic depression**

Sometimes depression can be so intense it causes psychotic symptoms. For example, the person may have delusions involving guilt, severe physical illness or hopelessness.

### **Schizoaffective disorder**

Sometimes it is difficult to tell the difference between schizophrenia and bipolar disorder as the person has symptoms of both illnesses.

### **Drug induced psychosis**

This is a psychosis brought on by the use of drugs. The symptoms usually appear quickly and last a short time (from a few hours to days) until the effects of the drug wears off. The most common symptoms are visual hallucinations, disorientation and memory problems. Drugs that can cause psychosis are marijuana, cocaine, ecstasy, amphetamines (speed) and magic mushrooms.

Although drugs can sometimes be the sole cause of psychosis, in other cases they can trigger another psychotic illness such as schizophrenia in someone who is vulnerable to it. People sometimes take drugs as a way of coping with a developing psychotic illness, but these drugs can make the symptoms worse and the disorder difficult to diagnose<sup>40</sup> Refer to the next chapter for more information about cannabis and schizophrenia.

### **What causes psychosis?**

It is believed that psychosis is caused by a combination of factors including genetics, biochemistry, stress and other factors

### **Schizophrenia**

The following factors are involved in the development of schizophrenia:<sup>36</sup>

### **Genetic factors**

Although schizophrenia is not directly inherited, people who have a parent who is affected are more likely to develop schizophrenia. Schizophrenia affects only 1% of the general population compared to 10% of people who have an affected parent. Note that most people (90%) who have an affected parent do not develop schizophrenia.

### **Biochemical factors**

The changes in the brain caused by schizophrenia are not fully understood. However, a chemical messenger called dopamine seems to be involved.

### **Stress**

The onset of schizophrenia often follows stressful events in a person's life. However, stress is not in itself the cause of schizophrenia. Rather it acts as a trigger for an episode for people who are vulnerable to the disorder. It was once believed that poor family relationships, especially with the mother, were the cause of schizophrenia. This is now known to be wrong. However, family tension may contribute to a relapse in the person with schizophrenia.

There are great differences amongst us all in how well we cope with life events. People with intellectual disability have reduced coping skills and therefore are likely to have difficulty managing events that would not trouble others. For a person with an intellectual disability, increased stress could be due to a favourite carer leaving or new carer starting, changes or loss of day placement, work or accommodation, or a new house mate or a house mate with challenging behaviour.

### **Other factors**

There are a range of other factors which make small contributions in some cases. These include head injury, complications around birth or being born in winter.

## **Bipolar disorder**

The causes of this disorder are not fully understood. However, the following factors are known to be involved.<sup>37</sup>

### **Genetic factors**

Although bipolar disorder is not directly inherited, people who have a parent affected are more likely to develop the disorder.

### **Biochemical factors**

Mania, like depression, is believed to be associated with a chemical imbalance in the brain.

### **Stress**

Stress may play a part in triggering symptoms in vulnerable people.

For a person with intellectual disability increased stress could be due to a favourite carer leaving, changes or loss of day placement, work or accommodation, a new house mate or a house mate with challenging behaviour.

### **Other factors**

There is some evidence that mania is more common in spring and depression in winter. The reason for this is not clear.

As mentioned in Chapter 3 in addition to receiving first aid the person with intellectual disability should also have a comprehensive management plan developed to address their mental health problem.

## First Aid for psychosis in people with an intellectual disability



1. Assess risk of suicide or harm
2. Listen non-judgementally
3. Give reassurance and information
4. Encourage and support the person to get appropriate professional help. *The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered*
5. Encourage the person to use any self-help strategies they may have. *The person with an intellectual disability may need support to do this*

**When administering Mental Health First Aid to people with an ID keep the following suggestions in mind.**

- ❖ *Speak in a calm quiet voice*
- ❖ *Focus on one topic at a time. Because the person may be confused, keep your conversation simple.*
- ❖ *Be patient and wait for responses.*
- ❖ *Keep an upbeat attitude and let the person know that you are available and supportive.*

### Action 1: Assess the risk of suicide or harm

People who are psychotic may be at risk of self-harm or, occasionally, of harming others. Both these risks need to be considered.

#### (a) When a person is at risk of self-harm

Psychotic disorders involve a high risk of suicide. About one in ten people suffering from schizophrenia completes suicide.<sup>42</sup>

If you think the person is at risk of hurting themselves, check this out by some direct questioning. Ask such questions as:

- ◆ Recently have you been thinking a lot about death or dying?
- ◆ Are you thinking of killing yourself?
- ◆ Have you thought about how you would do it?
- ◆ Can I be assured you will not act on suicidal ideas? Have you thought about the effect your death will have upon your family or friends?
- ◆ What help could make it easier for you to cope with your problems at the moment?

Contrary to common belief, this type of questioning does not encourage a person to pursue suicidal behaviour.

When asking questions of a person with an intellectual disability it is important to:

- ◆ communicate in a way that will assist them to understand eg. by using visual aids,
- ◆ check they have understood what you are asking by getting them to tell you in their own words, pictures, signs what they think you are asking them.
- ◆ avoid asking leading questions.
- ◆ be aware that people with an intellectual disability will often answer in the affirmative in order to please or appear capable so check that what they say is what they really mean.

See the box in Chapter 4 on 'How to help a suicidal person' for specific information on how to provide help.

Auditory hallucinations may include hearing "command voices" telling the person to hurt themselves or others.

#### (b) When the person is at risk of harming others

A very small percentage of people with psychotic disorders may threaten violence. Unfortunately the media tends to publicise the few people with mental illness who become violent. In fact, violence accompanying a mental illness is not common.<sup>25</sup> Violence is more common if alcohol or other drugs are involved.

## **Interacting with a person with an intellectual disability who is threatening, angry or violent**

At times a person with intellectual disability may physically or verbally threatening, express anger and behave violently as part of a mental health crisis. If the person does become threatening, angry or violent there are steps that can be taken in a number of areas.<sup>29</sup> Some of these are:

### **Personal Safety**

As with medical First Aid, the first consideration is your own safety. Do not get involved physically to stop the violence (for example a fight) or to restrain the violent person, unless in self-defence.

### **Safety of others**

You may also need to think about the safety of others in a situation where the person is volatile.

- ◆ make sure others are aware of the situation
- ◆ keep the area clear of other clients and distractions while you help the person. Ask other staff members to support other people present
- ◆ check if there is a crisis plan for dealing with emergencies and, if not one should be developed as soon as possible
- ◆ you could contact the on-call manager, if this is part of the protocol, before calling the police.
- ◆ when you call the police tell them that the person has a mental illness and an intellectual disability and may require medical help. Ask if possible that they send a plain-clothes police officer so the person will feel less threatened.

### **Speaking and listening**

The things you say and how you say them can play an important part in defusing a situation that is volatile.

- ◆ talk clearly and slowly
- ◆ keep your voice at a normal tone, be firm but do not shout or raise your voice
- ◆ listen carefully to what the person says
- ◆ give the person time
- ◆ ask them to explain what has upset them
- ◆ acknowledge what the person says, but try not to agree or disagree with them
- ◆ reassure them if they are worried
- ◆ do not make promises that cannot be kept
- ◆ comply with reasonable requests. This will provide the person with a feeling that they are somewhat 'in control'
- ◆ be non-judgemental, non-critical and avoid using threatening language
- ◆ do not try to reason with the person about their delusions and hallucinations
- ◆ do not pretend that you can see or hear the hallucinations or delusions.

### **Body language**

The way you communicate nonverbally can also have a significant calming effect on an angry person.

- ◆ act in a calm manner, even though you may not feel calm
- ◆ adopt a neutral stance
- ◆ keep your hands at your side and avoid folding your arms or pointing
- ◆ stay at the same level as the person – if they are sitting, you should sit, if they are standing, you should stand
- ◆ do not stand directly in front of the person
- ◆ make eye contact (but remember some people, such as those with autism, do not like this)
- ◆ keep eye contact natural, glance away occasionally to avoid staring.

### **Use the physical environment for protection and calming.**

- ◆ try to create a calm, no-threatening atmosphere
- ◆ keep a comfortable and safe distance between yourself and the person
- ◆ always know where your nearest exit is and keep yourself between the person and the exit
- ◆ consider whether the environment can be changed to prevent the situation getting worse
- ◆ ensure the privacy, respect and dignity of the person
- ◆ be aware of the potential hazards, in case the situation escalates.

## Responding to a person with intellectual disability who is showing signs of mania

- ♦ reduce stimulation eg. radios, TV's
- ♦ reduce consumption of stimulants (tea, coffee, chocolate)
- ♦ don't get caught up in the person's euphoria or unrealistic expectations
- ♦ don't try to argue or convince the person that his/her plans are unrealistic
- ♦ keep conversations brief and to the point since a person with mania has a very short attention span.
- ♦ try not to be authoritative. But be firm, practical and realistic. Don't try to force the person to do something as this will likely result in aggression or SIB.
- ♦ limit their ability to spend money
- ♦ encourage sleeping via a soothing environment (eg soft music, low lighting, and minimal stimulation) and other techniques which may cue sleep such as reading stories, a glass of milk, engaging in a bedtime routine.<sup>19</sup>

**In addition to the first aid strategies above the following are longer term treatment options.<sup>10</sup>**

- ♦ mood stabilizing medication
- ♦ psychotherapy (usually with an educational focus on understanding and managing Bipolar Disorder)
- ♦ environmental/social modifications (eg. increased supervision to ensure safety)
- ♦ education of the individual and support staff /carers regarding Bipolar Disorder.

### Action 2: Listen non-judgementally

- ♦ Listen to the person without judging them as weak. These problems are not due to weakness or laziness. Be empathetic to their concerns and provide comfort where possible.
- ♦ Speak calmly, clearly and in short sentences.
- ♦ Do not be critical of them. Don't express your frustration at the person for having such symptoms. Privately acknowledge your anger or frustration and deal with it.
- ♦ Don't give glib advice such as 'pull yourself together'. The person doesn't have control over their behaviour or mood at this time, you are there to support not to judge or punish.

- ♦ Avoid confrontation unless necessary to prevent harmful or dangerous acts.
- ♦ Do not argue with a person about their delusions and hallucinations. Accept that these irrational perceptions are real for them. However, do not pretend these hallucinations or delusions are real to you.
- ♦ Do not try to humour them or agree with them.

When listening to a person with an intellectual disability you may need to use more checking questions and paraphrasing to ensure that they have said what they really mean and that you have understood correctly.

### Action 3: Give reassurance and information

When the person is in a psychotic state, it is usually difficult and inappropriate to try to give them information about psychosis. When the person is more lucid and in touch with reality, try to help the person to realise that:

- ♦ you want to help them and those attending to them know what to do
- ♦ psychosis (schizophrenia or bipolar disorder) is not a common illness but it is very well known and researched
- ♦ psychosis is not a weakness or character defect
- ♦ effective medications are available to relieve their confusion and distress

Do not make promises you cannot keep and do not lie. This can create an atmosphere of mistrust and add to the person's distress.

For people with an intellectual disability, information needs to be given in a way that will promote understanding for the person:

- ♦ keep sentences short and simple
- ♦ don't use jargon  
write or draw ideas on paper for them
- ♦ check their understanding by asking them to tell you in their own words or way what you have just told them
- ♦ acknowledge their emotions
- ♦ reduce any unnecessary stresses
- ♦ ground the person in reality. Discuss what they are doing, ate at lunch, the weather and anything else which refers the person back to reality
- ♦ maintain normal routines
- ♦ help the person to stay away from unhelpful substances such as alcohol, caffeine and other unprescribed drugs.

## Action 4: Encourage and support the person to get appropriate professional help

It is important to get the person to medical help as early in the illness as possible. A person with a psychotic illness needs to see a doctor and be placed on appropriate medication. There are several types of health professional who can provide help for psychosis: The person with an intellectual disability may need additional support to link them with appropriate professional help. These professionals will require good information about the person with an intellectual disability so it is important a support person knows the client well.

You may need to stay with them longer, or if possible, arrange for yourself or someone else (perhaps a family member or existing support worker) to assist them to access this professional. Pictures, drawings and diaries may be useful tools to help the person describe the feelings and worries they are experiencing, particularly in counselling.<sup>16</sup> It is important to take with you to any professional's appointment any information that has been collected regarding the person's behaviour or moods that you think may be relevant, along with details on any current medications they are taking. It is also important that the accompanying support person finds out what happened in a session or appointment so that this can be followed up or reinforced outside the clinical setting.

### GPs

A GP is the first professional to turn to. A GP can provide the following types of help:

- ◆ make an initial diagnosis
- ◆ prescribe medication
- ◆ refer the person to a psychiatrist for specialist assessment and advice on medication.

### Psychiatrists

Psychiatrists are medical specialists who treat mental health problems. A GP should refer a person with a suspected psychotic illness to a psychiatrist for diagnosis and expert advice on medication. Most psychiatrists work in private practice but some are attached to hospitals or community mental health centres. A person who is severely psychotic may need to have a short stay in hospital to stabilise them.

### Mental Health Teams

Most regions in Australia have a mental health crisis team. The mental health crisis team will provide appropriate help, including attendance in the community to assess a person with a mental health crisis, direction to appropriate help and telephone support and information.

Many community health centres have a mental health team which will provide ongoing help to a person with psychosis to manage medications, self-care, housing and finances, and will give general support and counselling.

The mental health team may require input and support from those caring for or supporting the person with an intellectual disability. They will not necessarily have an understanding of intellectual disability and the implications for the person's communication and ability to process information.

### Disability Services

Thought should be given to whether it is best for the person with intellectual disability to see a professional who has experience working with people who have an intellectual disability. Psychologists with this kind of experience usually work in specialist services for people with disability. These can be located by contacting the government agency in your state that has responsibility for people with disability. (See helpful resources Chapter 3 for website details). If the person is not already linked in with a disability service, a referral should be considered, taking note of the decision making capacity and wishes of the person with an intellectual disability. If the person is being supported by a disability service, they may already have a GP, psychologist, counsellor or psychiatrist who they regularly see. If so, you may need to provide them with support to access this person.

Your state government disability service may be able to help locate a psychiatrist with experience treating people with intellectual disability. It may also be useful to talk with the intake officer at the agency about their providing case management for the person you are concerned about, if this is needed. You should seek consent for this from the person if they can give it, or from their legal guardian.

### Family, direct support workers and Friends

Family, friends and direct support workers are a very important source of support for a person with a psychotic illness. A person is less likely to relapse if they have a good relationship with their family.<sup>43</sup> Family and friends can help by:

- ◆ listening to the person without judging them or being critical of them
- ◆ keeping their life as stress-free as possible to reduce the chance of a relapse
- ◆ encouraging the person to get appropriate professional help
- ◆ checking if the person is feeling suicidal and taking immediate action if they are

- ◆ providing the same support as they would for a physically ill person. These include sending get-well cards, flowers, phoning or visiting the person, and helping out if they cannot manage
- ◆ look for support from a support group.

In looking to family and friends for support, it is important to keep in mind that they may be under stress or 'burnt out' due to their burden of care.

### What to do if the person does not want help

When a person is very psychotic, they may lack insight into their illness and see no need to seek help. There is no easy solution if a psychotic person is unwilling to seek professional help. However, the following may be helpful:

- ◆ call the local mental health crisis team and discuss the situation with them

- ◆ talk to other people who have been in a similar situation, for example at a mental health carers' support group
- ◆ make an appointment for yourself with a GP or a mental health professional to talk about the problem
- ◆ contact your local mental health service to be informed about the legal provisions for involuntary admission to hospital. Each state and territory has provision for mentally ill people to be admitted to hospital without their consent
- ◆ help develop an advance directive (also known as a wellness plan, relapse prevention plan or a personal directive).

### Action 5: Encourage and support the person to use self-help strategies they may have

Many people with a psychotic illness also have depression and/or an anxiety disorder. The self-help strategies recommended for depression and anxiety are also appropriate for people with schizophrenia or bipolar disorder. However, they are not to be used as the main source of treatment. Mental health professionals must be consulted.

The person with an intellectual disability may not have any self-help strategies due to their reduced cognitive abilities. There are disability specific services that offer specialised education programs to assist people to learn self-help strategies and generalise them into their every day life.

It is useful to contact the state government disability service in your locality for information about what is available. These services may be open to suggestion if they do not currently have programs that might be helpful so it is worth asking if they can set something specific up for the person you are concerned about.

If the person with an intellectual disability does have some strategies, they may need a reminder as to what they are, and then additional support to put these into practice.

Support groups for sufferers and their families may be very helpful (see the following resources).

## Helpful resources for psychotic disorders

### Websites

#### Black Dog Institute

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

The Black Dog Institute is an organisation based in Sydney which provides clinical services, education and research on bipolar disorder. The website gives information about the disorder, including a self-assessment test, and downloadable fact sheets and a spoken education program.

#### Australian Bipolar Website

<http://members.iinet.net.au/~fractal1/fhello.htm>

The Australian Bipolar Website was set up by a private individual with bipolar disorder. It is a comprehensive site for sufferers and friends and family. A web support group is available online.

#### Early Psychosis Prevention and Intervention Centre

<http://www.eppic.org.au>

The Early Psychosis Prevention and Intervention Centre (EPPIC) is a program in the western metropolitan region of Melbourne. It is a psychiatric service aimed at meeting the needs of older adolescents and young adults with emerging psychotic disorder. This website has a good resource page with excellent downloadable information sheets on psychosis.

#### SANE Australia

<http://www.sane.org/>

SANE Australia is a national charity to help people with mental illness. Its website has some very good downloadable information sheets on psychotic disorders. It also has a telephone helpline providing information 180018 SANE (7263)

#### National Institute of Mental Health (US government)

<http://www.nimh.nih.gov/>

This website gives a wealth of good information on schizophrenia, bipolar disorder and other mental illnesses.

## Support Groups

The **Schizophrenia\Mental Illness Fellowship** provides support for people with schizophrenia and their families in all states and territories. For contact details in your area, see the White Pages.

There are also groups supporting people with bipolar disorder in many regions. These go under various names. They can be contacted through local mental health services.

Support for family members is available from the **Association of Relatives and Friends of the Mentally Ill (ARAFMI)**. For contact details in your area, see the White Pages.

Carers Australia can provide support for the family. <http://www.carersaustralia.com.au>

## Books

Anne Deveson (1998). *Tell me I'm here*. Penguin, Ringwood Vic. ISBN 0 14 027 257 7.

This book tells of an Australian family's experience of a son with schizophrenia.

Madeleine Kelly (2000). *Life on a roller-coaster: Living with depression and manic depression*. Simon and Schuster, Sydney. ISBN 0 7318 0948 3

This Australian guide to living with bipolar disorder was written by a person who has suffered from it.

Brian Johnston (1998). *Enhancing recovery from psychosis: a practical guide*. Department of Human Services, South Australia. ISBN 0 7308 5679 8.

This is a workbook developed from a cognitive behaviour therapy program for psychosis. It gives a step-by-step recovery program to assist a person with psychosis to work with a health worker.

**CHAPTER 7**  
**SUBSTANCE USE DISORDERS**



## 7 Substance use disorders

### What is a substance use disorder?

Using alcohol or drugs does not in itself mean that a person has a substance use disorder (SUD). Substance use disorders include any of the following:

- ✦ **dependence** on alcohol or a drug
- ✦ use of alcohol or a drug which **leads to problems at work school or home, or to legal problems**
- ✦ use of alcohol or a drug at a level which is **causing damage to health**. The damage may be physical (such as hepatitis from self-administration of injected drugs) or mental (such as depression secondary to heavy consumption of alcohol)

### The symptoms of substance dependence are:

- ✦ tolerance for the substance (person needs increased amounts over time or gets less effect with repeated use)

- ✦ problems in withdrawal (person experiences withdrawal symptoms or uses the substance to relieve withdrawal symptoms)
- ✦ use of larger amounts or over longer periods than intended
- ✦ problems in cutting down or controlling use a lot of time is spent getting the substance, using it, or recovering from its effects
- ✦ the person gives up or reduces important social, occupational or recreational activities because of substance use
- ✦ the person continues using the substance despite suffering from its effects

Approximately 8% of Australian adults have a substance use in any year, with men more than twice as likely to be affected as women.

Alcohol use disorders are about three times as common as drug use disorders (see table below). Cannabis accounts for more drug use disorders than any other illicit drug. These figures do not include tobacco-smoking, which affects around a fifth of Australian adults.

### Percentage of Australian adults who suffer from a substance use disorder in any year<sup>1</sup>

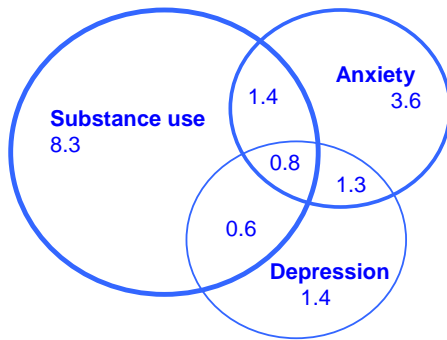
Type of disorder	Males	Females	Persons
Alcohol	9.4%	3.7%	6.5%
Cannabis	2.7%	0.8%	1.7%
Stimulants	0.3%	0.1%	0.3%
Sedatives	0.4%	0.4%	0.4%
Opioids	0.2%	0.2%	0.2%
<b>Any substance use disorder</b>	<b>11.1%</b>	<b>4.5%</b>	<b>7.7%</b>

People with Substance Use Disorders (SUDs) also tend to have other mental health problems. The diagrams below show the overlap between substance use and anxiety and depressive disorders for men and women.

People with psychotic disorders also have a high rate of SUDs<sup>4</sup>. This is often called 'dual diagnosis'. (In the disability sector this term is used to describe people with an intellectual disability who have mental health problems). One reason for this association is that many people use alcohol and drugs as a type of self-medication for anxiety, depression or psychosis.<sup>40</sup> Users of alcohol and other drugs report that these substances can have a calming effect.

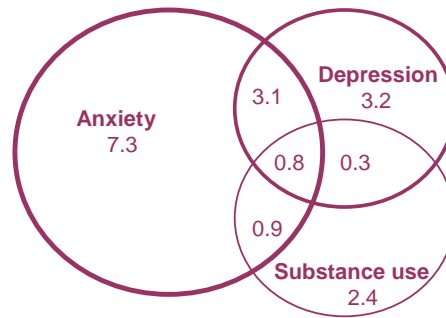
However, alcohol and drug use can also cause other problems in a person's life and heavy use may contribute to or exacerbate a mental health problem.

### Overlap of Depressive, Anxiety & Substance use Disorders



**The overlap (%) of depressive, anxiety and substance abuse disorders in Australian men<sup>1</sup>**

One in four men (25%) with a substance use disorder has an underlying depressive or anxiety disorder.



**The overlap (%) of depressive, anxiety and substance abuse disorders in Australian women**

One in two women (50%) with a substance use disorder has an underlying depressive or anxiety disorder.

Unfortunately, often the underlying disorders are not recognised. To get the best outcome, both the substance use disorder and the depressive or anxiety disorder need to be treated at the same time.

There is relatively little information about Substance Use Disorder in those with an intellectual disability, however it appears that between 1 and 6% of people with intellectual disability have a problem with the use of alcohol or other drugs<sup>44,45,46,47</sup> This is lower than the general population. Predictably, use of these substances is generally restricted to those with lesser degrees of disability.<sup>48</sup>

Drug and alcohol abuse are less likely in supported environments where staff are involved in the person's social life, where there is some kind of tenancy agreement involving conduct or where money is under the supervision of staff.<sup>9</sup> Limited income and a lack of knowledge about how to purchase drugs in particular may limit a person with intellectual disability's access to substances.

However, there are now a greater number of adolescents and adults with an intellectual disability living in the community. This provides opportunities for greater freedom from restriction, autonomy, income and access to the community, as well as respect for individual choices. These conditions have provided greater opportunity for substance use and misuse.<sup>23</sup> However, once they have started, it appears that people with intellectual disability are less likely to give up use than their non-disabled peers.<sup>49</sup>

Given the problems with low self esteem that are common to people with an intellectual disability, they appear to be particularly prone to reliance on alcohol and other drugs for a sense of being an equal and belonging that these offer and for the way they can compensate for poor social skills. People with an intellectual disability are also more vulnerable to stress and have reduced self regulation and coping skills. They may therefore be more likely to resort to alcohol and cigarettes as a way of coping with their mental health symptoms.

A number of associated medical and psychological difficulties common to those with a SUD are likely to be magnified in people with an intellectual disability who suffer from a SUD.

## Alcohol

Alcohol makes people less alert and impairs concentration and coordination. In small quantities, alcohol causes people to relax and lower their inhibitions. They can feel more confident and often act more extroverted. However, alcohol can also make people more prone to aggression and antisocial behaviour. If a person is feeling suicidal, they are more likely to attempt suicide if they are under the influence of alcohol.

### Measuring drinks

A standard drink contains about 10 grams of alcohol. The table below shows different alcoholic drinks that are equal to one standard drink.

Low alcohol beer	Regular beer	Table wine	Port or sherry	Spirits or liqueurs
2 x 285 ml (middies/pots)	2 x 285ml (middy) or ¾ can/stubby	100ml	60ml	30ml (nip)

**Example: two double scotches plus a middy of ordinary beer are equivalent to 5 standard drinks**

### National medical health and Research Council 2001 guidelines for low-risk drinking <sup>50</sup>

LEVEL OF HEALTH RISK	MEN	WOMEN
<b>For risk of harm in the long term:</b>		
Low Risk	Up to 4 standard drinks per day, no more than 28 per week	Up to 2 standard drinks per day, no more than 14 per week
Risky	5 to 6 standard drinks per day, no more than 29 to 42 per week	3 to 4 standard drinks per day, no more than 15 to 28 per week
High Risk	7 or more standard drinks per day, 43 or more per week	5 or more standard drinks per day, 29 or more per week
<b>For risk of harm in the short term:</b>		
Low Risk	Up to 6 standard drinks per day, no more than 3 days per week	Up to 4 standard drinks per day, no more than 3 days per week
Risky	7 to 10 standard drinks per day	5 to 6 standard drinks per day
High Risk	11 or more standard drinks per day	7 or more standard drinks per day

**Alcohol-free days** are recommended because research shows that a person has to use alcohol regularly to become dependent on it. Even people who drink at low levels over time will acquire some tolerance to alcohol. People who only drink intermittently are less likely to develop a tolerance to alcohol and withdrawal symptoms. Many Australians have a mild degree of alcohol dependence. An early sign of dependence is finding it hard to stop drinking after two or three drinks. People who drink at high levels over a long period may develop physical or psychological problems. The AUDIT Questionnaire on the next page was developed by the World Health Organisation to assess alcohol problems.

### How much is too much?

The effects of alcohol vary from person to person (health, age, diet, other drug). Women are advised to drink less than men because their bodies tend to break down alcohol more slowly. The National Health and Medical Research Council recommends at least two alcohol-free days per week.<sup>50</sup> For men, it is recommended that no more than four standard drinks are consumed per day. For women, it is recommended that no more than two standard drinks are consumed per day. The second table below shows that above those levels, there are health risks.

## AUDIT (Alcohol Usage) Questionnaire <sup>51</sup>

1) How often do you have a drink containing alcohol?

0 Never    1 Monthly    2 2-4 times a month    3 2-3 times a month    4 4 or more times a week

2) How many units of alcohol do you drink on a typical day when you are drinking?

0 1 or 2    1 3 or 4    2 5 or 6    3 7, 8 or 9    4 4 or more

3) How often do you have six or more units of alcohol on one occasion?

0 Never    1 less than monthly    2 monthly    3 weekly    4 Daily or almost daily

4) How often during the last year have you found that you were not able to stop drinking once you had started?

0 Never    1 less than monthly    2 2monthly    3 weekly    4 Daily or almost daily

5) How often during the last year have you failed to do what was normally expected of you because of drinking?

0 Never    1 less than monthly    2 monthly    3 weekly    4 Daily or almost daily

6) How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?

0 Never    1 less than monthly    2 monthly    3 weekly    4 Daily or almost daily

7) How often during the last year have you had a feeling or guilt or remorse after drinking?

0 Never    1 less than monthly    2 monthly    3 weekly    4 Daily or almost daily

8) How often during the last year have you been unable to remember what happened the night before because you had been drinking?

0 Never    1 less than monthly    2 monthly    3 weekly    4 Daily or almost daily

9) have you or someone else been injured as a result of your drinking?

0 Never    2 Yes but not in the last year    4 Yes, during the last year

10) has a relative or friend or doctor or another health worker been concerned about our drinking or suggested you cut down?

0 Never    2 Yes but not in the last year    4 Yes, during the last year

**How to score: The grey area contains the score for the response to its right.**

**Maximum Score = 40**

**A score of 8 or greater indicates a drinking problem which requires further attention**

### Long term effects of alcohol on the body<sup>52</sup>

**Heart:** high blood pressure, irregular pulse, enlarged heart, damaged heart muscle, heart failure.

**Brain:** memory loss, confusion, poor planning and organisation, hallucinations, fits, impaired ability to learn new things, loss of balance.

Alcohol is associated with increase in epilepsy and has an adverse interaction with anti-epileptic medication. This may increase the likelihood of seizures and can lead to further brain damage. Given that epilepsy is more common among people with intellectual disability, they are at a greater risk of their epilepsy being worsened by alcohol misuse.<sup>48</sup>

**Liver:** impaired liver functioning, severe swelling and pain, inflamed liver (hepatitis), cirrhosis (scarring), liver cancer.

**Muscles:** weakness, loss of muscle tissue.

**Pancreas:** painful inflammation, bleeding.

**Lungs:** infection.

**Stomach and intestines:** inflamed lining, bleeding, ulcers.

**Genitals and reproductive system:** impotence, shrinking of testicles, damage to unborn child.

**Skin:** flushing, sweating, bruising.

**Nervous system:** tingling and loss of sensation in hands and feet caused by nerve damage.

**Motor skills:** poor coordination results in accidents, especially when operating machinery or driving vehicles.

**Personality:** alcohol is a depressant, not a stimulant as many people think. It appears to intensify your present mood. If you are happy, you relax, feel more self-confident and outgoing. If you are depressed, you can feel more despondent.

**Appearance:** alcohol contains a lot of kilojoules and can put on weight.

**Money:** regular use of alcohol can be expensive.

**Work:** intoxication or being hung-over makes work difficult and less efficient.

**Law:** the use of alcohol can be associated with many legal problems. Alcohol is present in around half the homicides in Australia, and also associated with many suicides, assaults (including rape) and thefts.

### Alcohol use disorder and other mental health problems

There is a high rate of other mental health problems in people who have an alcohol use disorder. For example, people with alcohol dependence are over four times more likely to suffer from an anxiety disorder or depression and are six times more likely to have symptoms of psychosis.<sup>53</sup>

The National Health and Medical Research Council has recommended that people with mental health problems take particular care with their drinking.<sup>50</sup> They may need to consider not drinking at all if they cannot keep within the recommended drinking levels or if their symptoms persist. People who are depressed and sometimes drink excessively have a much greater risk of self-harm and suicide. Heavy drinking can also make the symptoms of anxiety and depression worse. While drinking alcohol can bring some relief from anxiety in the short term, it can lead to worse symptoms of anxiety or depression in the long term, particularly with high levels of consumption. Alcohol use is also associated with poorer outcomes for people who suffer from schizophrenia.

As well as high rates of mental health problems in heavy drinkers, there is also a higher rate at the other end of the spectrum, in non-drinkers. Non-drinkers have higher rates of anxiety disorders and depression than moderate drinkers, who tend to have the best mental health.<sup>53</sup> The reasons for the association are not fully understood.

## Tobacco

Tobacco is so widely used that we do not usually think of it as a mental health issue. However, there is a high rate of mental health problems in people who smoke tobacco. Smokers are more than twice as likely to suffer from an anxiety disorder or depression, and are more than four times more likely to have symptoms of psychosis.<sup>15</sup> Tobacco users are also more likely to have a substance use disorder involving alcohol or other drugs. Which comes first is not always clear.

## Cannabis (Marijuana)

Cannabis is the most widely used illicit drug in Australia, with 39% of people aged 14 or over having used it at some time in their lives. For most people, use is only occasional. Only around 2% of the population have a problem with cannabis abuse or dependence.<sup>1</sup>

There is still not a clear picture of the prevalence of smoking among people with an intellectual disability and estimates vary from 1% to 36% of the population.<sup>54,55</sup> Anecdotal evidence suggests that older people with disability are more likely to smoke than those who are younger.

There is an association between cannabis use and schizophrenia. The more frequent the use of cannabis, the greater the risk of a diagnosis of schizophrenia over the next 15 years. It is believed that chronic use of cannabis may precipitate schizophrenia, but only in vulnerable people. For further details, see the following [cannabis and psychosis fact sheet](#).

Cannabis use is associated with other mental health problems. Adults who use cannabis are more than twice as likely to suffer from an anxiety disorder or depression and have more than three times the risk of suffering from psychotic symptoms.<sup>53</sup> Adolescents who use cannabis are more likely to suffer from depression, to have conduct problems, to drink excessively and to use other drugs.<sup>56</sup> Again, which came first is not always clear.

Given the reduced coping skills of people with intellectual disability, it is possible that they may be more prone to the triggering of psychosis that cannabis can produce.

Research suggests the majority of cannabis users significantly reduce consumption during their 20s when responsibilities increase and life stability occurs. However, for people with an intellectual disability, this change may not occur to the same degree. This is due to ongoing needs for support, social difficulties and limited work opportunities. As such, it is possible that cannabis smokers with an intellectual disability may have less motivation to stop using cannabis when they reach adulthood.<sup>49</sup>

## Amphetamines

Amphetamines belong to a category of stimulant drugs and have the temporary effect of increasing energy and apparent mental alertness.

Amphetamines come in many shapes and forms and are taken in different ways. They can be in the form of a powder, tablets, capsules, crystals or liquid. Amphetamines are known on the street by such terms as 'crystal', 'base', 'ice', and 'shabu'.

People use amphetamines for different reasons. Some use these drugs to get 'high' and dance all night. Others use them to stay awake for long periods of time. Amphetamines can reduce tiredness and increase endurance. However, as the effect wears off, a person may experience a range of effects including depression, irritability, agitation, craving, increased appetite and sleepiness.

A particular mental health risk is amphetamine psychosis or 'speed psychosis' which involves symptoms similar to schizophrenia. The person may experience hallucinations, delusions and uncontrolled violent behaviour. The person will recover as the drug wears off, but is vulnerable to further episodes of psychosis if the drug is used again.<sup>57</sup>

Amphetamines are frequently prescribed for people with an intellectual disability. They have been found to be effective in managing disorders such as ADHD.<sup>59</sup> When prescribed and administered properly, amphetamines are a valuable treatment. The dosage prescribed is much lower than is typical for recreational use and unlikely to be addictive. However those supporting people with an intellectual disability should ensure that medication is reviewed regularly and their use monitored for the possibility of inadvertent addiction.

**What is cannabis?**

Cannabis is the general name for marijuana, 'grass', 'pot', 'weed' and 'hashish'. Cannabis comes from a plant and is smoked or eaten. It is a 'depressant' drug (that is, one that slows down thinking and the nervous system) and can also cause mild hallucinogenic effects.

**How many people use cannabis?**

Cannabis is the most widely used illicit drug. Recent studies indicate that about 30% of the population have tried cannabis at some time, particularly those under the age of 35.

**Why do people use cannabis?**

Some people use cannabis, like alcohol, to help them to relax. Some use cannabis because they feel it helps them with conversation and in social situations, while others use cannabis in an attempt to cope with life's problems.

**Are there any dangers in using cannabis?**

Most people who use cannabis don't experience any obvious harmful effects, but regular use may produce a number of short term effects including paranoia, confusion, increased anxiety, and even hallucinations, which can last up to several hours. Longer term risks may include asthma and bronchitis, cancers of the mouth, throat and lungs, poor concentration and memory, learning difficulties and occasionally psychosis.

**What is psychosis?**

A psychosis is a condition where a person experiences some loss of control with reality. A person with psychosis can experience any one or more of the following symptoms: auditory hallucinations (hearing voices that aren't there), visual hallucinations (seeing things which aren't there), delusions (believing things that aren't true), jumbled thoughts and strange behaviour.

**Does cannabis cause psychosis?**

It is believed that cannabis use may cause a condition known as drug-induced psychosis which can last for up to a few days and is often characterised by hallucinations, delusions, memory loss and confusion. However, in some cases, cannabis may contribute to the development of a serious mental illness, such as schizophrenia.

**How does cannabis affect someone who is already experiencing psychosis?**

Cannabis use can prolong the duration of symptoms of mental illness and can lower a person's chances of recovering from a psychotic episode.

**Who is most at risk from cannabis use?**

People most at risk are those with a family history of psychotic illness or those who have already experienced a psychotic episode. People with a family or a personal history of psychotic illness should avoid drugs like cannabis completely and try other, healthier ways of relaxing.

**What about other drugs?**

Although this fact sheet focuses on cannabis, other legal and illicit drugs should not be ignored. For example, some evidence suggests that substances such as alcohol and amphetamines have a greater effect than cannabis in the development of psychosis.

**Where can I turn to for help?**

In Victoria only, patients, support staff, friends and family can ring 13 15 70, 24 hours a day, for the cost of a local call, for confidential information and counselling.

There is a booklet called *Getting out of it: How to cut down or quit cannabis* which can help people who want to stop using cannabis. To obtain a copy, ring the Australian Drug Foundation on (03) 9278 8100 or download it from this website <http://www.adf.org.au/cannabis/>.

## Ecstasy

Ecstasy or MDMA is a stimulant drug which also has hallucinogenic properties. It is used as a 'party drug' by some young people. In the hot and crowded conditions of dances, users can develop an adverse reaction which in extreme cases can result in death. To reduce this risk at dances, users need to maintain a steady fluid intake, and rest and cool down.

When coming off ecstasy, users often experience depressed mood. The long-term effects of using ecstasy are of particular concern. There is considerable evidence from experiments on animals that ecstasy damages nerve cells in the brain that use a chemical messenger called serotonin. Research on people who have regularly used ecstasy shows that they have altered levels of serotonin, memory problems, changed appetite, loss of sexual interest and a range of mental health problems.<sup>60</sup>

## Heroin

Heroin is a type of opioid. Opioid drugs also include morphine, opium, and codeine, all of which derive from the opium poppy. Heroin produces a short term feeling of euphoria and wellbeing and relieves pain. However, the drug has a high risk of creating dependence.

Although it receives a lot of publicity, heroin is not a widely used drug in Australia. Less than 2% of the Australian population reports having used heroin at some time, and less than 1% report using it in the past year.<sup>61</sup>

However, heroin overdose is a major cause of death for young adults in Australia. Non-fatal overdoses are also common in users.

Most people who are dependent on heroin have associated problems such as depression, alcohol dependence and criminal behaviour. Heroin users are also at high risk for suicide.

There is very little research on the use or effects of cocaine, heroin, ecstasy or amphetamines on those with an intellectual disability. As previously mentioned, use is likely to be lower compared to those without an intellectual disability due to the level of independence that is required to obtain them. However when used side effects may be more severe due to the interaction with pre-existing medical or psychological disorders.

## What causes substance use disorders?

Different substances affect the brain in different ways. People use substances because of these effects, which include increasing feelings of pleasure or decreasing feelings of distress. Exploring the use of drugs among people with intellectual disability is a new field, however it seems that they use them for the same reasons as members of the general population.<sup>62</sup> Some substances cause dependence, in which case the user may eventually take the substance mainly to reduce their withdrawal symptoms. The table below shows the risk of dependence from various substances.<sup>63</sup>

Substance	Pleasure giving	Physical withdrawal problems	Psychological withdrawal problems
Alcohol	Moderate	Strong	Moderate
Tobacco	Strong	Slight	Strong
Cannabis	Slight	Slight	Slight
Amphetamine	Moderate	Slight	Moderate
Ecstasy	Moderate	Slight	None
Heroin	Strong	Strong	Strong

Substance use typically starts in adolescence or young adulthood and some proportion of these users will develop a substance use disorder depending on the properties of the drug. If a person has not started using a substance by age 30, then it is unlikely they will ever develop a problem with that substance.

Most of our knowledge about the causes of substance use disorder relates to alcohol but the causes of other drug disorders are likely to be similar.

### Causes of alcohol use disorders

There is no single cause of alcohol use disorders. Rather, there are many factors which increase a person's chances of developing such a disorder.<sup>64</sup> These include:

#### Availability and tolerance of alcohol in society

Where alcohol is readily available and socially acceptable, alcohol disorders are more likely to develop. This applies not only to society as a whole, but to particular social groups within a society.

#### Social factors

Certain groups are more prone to alcohol disorders, including males, people with low education and income, people who have had broken marriages, and certain occupations with a drinking culture (men working as building tradesmen, waiters and bar staff, construction and mining labourers or food tradesmen; women working as specialist managers or sales representatives).

As previously mentioned, for those with an intellectual disability, alcohol use can be a way of attempting to "fit in" and "feel normal" and secure acceptance by nondisabled fellow drinkers. The positive feeling associated with this can result in the person with an intellectual disability relying on and overusing alcohol.

#### Genetic predisposition

People who have a biological parent with an alcohol use disorder are more likely to develop one themselves, even if they are adopted into a family with no alcohol use disorder.

#### Alcohol sensitivity

Some people are physiologically less sensitive to the effects of alcohol than others and these people are more likely to drink heavily and develop an alcohol use disorder.

There is some suggestion that those with an intellectual disability have lower tolerance to alcohol over time and that smaller amounts are needed to feel intoxicated. At the same time it seems to take less alcohol to produce social difficulties and health complaints.<sup>65</sup> This may be because an intellectual disability and associated difficulties magnify the effects of alcohol.

#### Learning

People can learn a habit of heavy drinking. This habit is maintained because alcohol has been associated with pleasant effects or a reduction of stress.

#### Other mental health problems

People who suffer from depression, an anxiety disorder or psychosis may use alcohol as a type of self-medication.

As mentioned in Chapter 3 in addition to receiving first aid the person with intellectual disability should also have a comprehensive management plan developed to address their mental health problem.

## First Aid for substance use disorders in people with an intellectual disability

1. **Assess risk of suicide or harm**
2. **Listen non-judgementally**
3. **Give reassurance and information**
4. **Encourage and support the person to get appropriate professional help. *The person with an intellectual disability may need support to find this kind of help and to take advantage of what is offered***
5. **Encourage the person to use any self-help strategies they may have. *The person with an intellectual disability may need support to do this***



***When administering Mental Health First Aid to people with an ID keep the following suggestions in mind.***

- ❖ ***Speak in a calm quiet voice***
- ❖ ***Focus on one topic at a time. Because the person may be confused, keep your conversation simple.***
- ❖ ***Be patient and wait for responses.***
- ❖ ***Keep an upbeat attitude and let the person know that you are available and supportive.***

### **Action 1: Assess the risk of suicide or harm**

**If a person is thinking of suicide**, alcohol will increase the chances they will harm themselves or complete suicide. To help a person who is suicidal, follow the steps listed in Chapter 4 Depression. If a suicidal person is drinking alcohol, urge them to stop drinking any more.

**If the person is injecting drugs**, it is important that they use in a way that it does not result in other harm to themselves, such as infectious diseases or overdose. This approach is called 'harm minimisation'. Drug injectors need to use new needles and not to inject alone, as accidental overdose is always a possibility.

### **If there is an intentional or unintentional overdose**

, the person may become unconscious. Any unconscious person needs immediate medical attention and their airway kept open by rolling them onto their side, clearing their mouth and tilting their head back gently and facing down slightly, so that any vomit can drain out. A conscious person needs monitoring as they may deteriorate into unconsciousness.

## How to help if a person has overdosed

### If a person is unconscious:

1. Keep person's airway clear. Roll person onto side into recovery position as shown above. Clear any vomit from mouth with two fingers. Tilt person's head back gently and slightly down.
2. Phone 000 for an ambulance. State the person is unconscious from a drug overdose.
3. Try to find out what substances have been used. This could be the person's prescribed medication, so ask if they have taken more than they should. If unknown, save some vomit if available. This information will assist the ambulance officers to give the most appropriate help.
4. Keep the person warm, especially if alcohol is involved.

### If the person is conscious:

1. Phone the Poison information Centre on 13 11 26 or Emergency 000 and follow their directions.
2. Do not give the person and food or fluids unless told to by a health professional. Explain to the person that it will be safer to eat or drink after a professional has examined them.
3. Reassure them that help has been sought and you will stay with them until it arrives.
4. Try to find out what substances have been used. This could be the person's prescribed medication, so ask if they have taken more than they should. If unknown, save some vomit if available. Where possible provide the details of the client's medication to the medical staff. This information will assist the medical staff to give the most appropriate help.
5. Keep the person warm, especially if alcohol is involved.

### Action 2: Listen non-judgementally

- ✦ Listen to the person without judging them as bad or immoral. Be empathetic to their concerns and provide comfort where possible.
- ✦ Do not be critical of them. You are more likely to be able to help them in the long term if you maintain a non-critical approach. Try not to express your frustration at the person for having substance use problems. People with an intellectual disability are frequently told what to do and substance use may be a way of obtaining some autonomy or escaping. Criticism may merely reinforce some of the issues that may have led towards the substance abuse.
- ✦ Don't give glib advice such as 'show some will power'. This sort of advice conveys criticism. It is too abstract and might not be understood well by a person with an intellectual disability.
- ✦ Avoid confrontation with the person unless necessary to prevent harmful or dangerous acts.

## Interacting with a person with an intellectual disability who is threatening, angry or violent

At times a person with intellectual disability may physically or verbally threaten, express anger and behave violently as part of a mental health crisis. If the person does become threatening, angry or violent there are steps that can be taken in a number of areas.<sup>29</sup> Some of these are:

### Personal Safety

As with medical First Aid, the first consideration is your own safety. Do not get involved physically to stop the violence (for example a fight) or to restrain the violent person, unless in self-defence.

### Safety of others

You may also need to think about the safety of others in a situation where the person is volatile.

- ◆ make sure others are aware of the situation
- ◆ keep the area clear of other clients and distractions while you help the person. Ask other staff members to support other people present
- ◆ check if there is a crisis plan for dealing with emergencies and, if not one should be developed as soon as possible
- ◆ you could contact the on-call manager, if this is part of the protocol, before calling the police.
- ◆ when you call the police tell them that the person has a mental illness and an intellectual disability and may require medical help. Ask if possible that they send a plain-clothes police officer so the person will feel less threatened.

### Speaking and listening

The things you say and how you say them can play an important part in defusing a situation that is volatile.

- ◆ talk clearly and slowly
- ◆ keep your voice at a normal tone, be firm but do not shout or raise your voice
- ◆ listen carefully to what the person says
- ◆ give the person time
- ◆ ask them to explain what has upset them
- ◆ acknowledge what the person says, but try not to agree or disagree with them
- ◆ reassure them if they are worried
- ◆ do not make promises that cannot be kept
- ◆ comply with reasonable requests. This will provide the person with a feeling that they are somewhat 'in control'
- ◆ be non-judgemental, non-critical and avoid using threatening language
- ◆ do not try to reason with the person about their delusions and hallucinations
- ◆ do not pretend that you can see or hear the hallucinations or delusions .

### Body language

The way you communicate nonverbally can also have a significant calming effect on an angry person.

- ◆ act in a calm manner, even though you may not feel calm
- ◆ adopt a neutral stance
- ◆ keep your hands at your side and avoid folding your arms or pointing
- ◆ stay at the same level as the person – if they are sitting, you should sit, if they are standing, you should stand
- ◆ do not stand directly in front of the person
- ◆ make eye contact (but remember some people, such as those with autism, do not like this)
- ◆ keep eye contact natural, glance away occasionally to avoid staring.

### Use the physical environment for protection and calming.

- ◆ try to create a calm, no-threatening atmosphere
- ◆ keep a comfortable and safe distance between yourself and the person
- ◆ always know where your nearest exit is and keep yourself between the person and the exit
- ◆ consider whether the environment can be changed to prevent the situation getting worse
- ◆ ensure the privacy, respect and dignity of the person
- ◆ be aware of the potential hazards, in case the situation escalates.

### Action 3: Give reassurance and information

Help the person to realise that:

- ✦ SUDs are a common and those attending to them know what to do.
- ✦ some people are more prone to these disorders than others. .
- ✦ people care and want to assist them deal with the alcohol or drug problem.
- ✦ many people have been able to stop using drugs and alcohol. Using celebrities who have been in the media as examples may help the person with a disability to feel a sense of hope.
- ✦ check their understanding by asking them to tell you in their own words or way what you have just told them.
- ✦ often depressive and/or anxiety disorders may underlie a substance use problem and there are effective treatments for anxiety and depression (see Chapter 4 and 5).

### Action 4: Support and encourage the person to get appropriate professional help

People who have a substance use disorder often do not want to change. The person could be in any of the following stages.<sup>66</sup>

1. **Precontemplation.** The person sees no need to change.
2. **Contemplation.** The person has thought of the pros and cons of their substance use but is not sure about changing.
3. **Preparation.** The person is ready to take action to change.
4. **Action.** The person is attempting to change and avoiding situations which might trigger their substance use.
5. **Maintenance.** The person has changed and is working to prevent themselves from relapsing back to substance misuse.
6. **Relapse.** In any permanent changes, relapses can happen at first

Unless the person is at the stage where they are prepared to change, it is unlikely that any treatment will succeed. People who are ready to change are those who see the disadvantages of their substance use as outweighing the advantages. Poorer problem solving abilities of people with an intellectual disability make it likely that they will need significant support to see that the disadvantages of their substance use may outweigh the advantages.

The best way to help people who are not ready to change is to try to discuss, without moralising, the disadvantages of their substance use. Given the benefits that substance use may provide for a person with an intellectual disability (e.g. escape, self-medication, socialisation, a sense of feeling normal) suggestion of change can be met with great resistance.

Therefore if a person is not ready to change, the focus of efforts should be on developing a relationship which allows discussion about the disadvantages of alcohol or drug use.

There are several types of health professional who can provide help for substance use problems: The person with an intellectual disability may need additional support to link them with appropriate professional help. These professionals will require good information about the person with an intellectual disability so it is important that a support person knows the client well.

You may need to stay with them longer or if possible, arrange for yourself or someone else (perhaps a family member or existing support worker) to assist them to access this professional. The use of pictures, drawings and diaries may be useful tools to help the person describe the feelings and worries they are experiencing, particularly in counselling.<sup>16</sup> It is important to take with you to any professional's appointment any information that has been collected regarding the person's behaviour or moods that you think may be relevant, along with details on any current medications they are taking. It is also important that the accompanying support person finds out what happened in a session or appointment so that this can be followed up or reinforced outside the clinical setting.

#### GPs

For people who are ready to change the best help is to see a GP about the problem. It is known that people are more likely to reduce their substance abuse if the GP gives information on the harms involved and gives clear advice to cut down or to stop substance use.

#### Drug and alcohol specialists

For people who have more serious drug or alcohol problems, a GP may refer them to a doctor who specialises in the field. A person can also be referred to a drug and alcohol counsellor for ongoing support.

There are very few drug and alcohol specialists who also have experience in working with those with an intellectual disability. Therefore it is advisable that a carer or support person work closely with the drug and alcohol counsellor so treatments can be best adapted to the skills and capacity of the client.

### **Disability Services**

Thought should be given to whether it is best for the person with an intellectual disability to see a professional who has experience working with people who have an intellectual disability. Psychologists with this kind of experience usually work in specialist services for people with disability. These can be located by contacting the government agency in your state that has responsibility for people with disability. (See helpful resources Chapter 3 for website details). If the person is not already linked in with a disability service, a referral should be considered, taking note of the decision making capacity and wishes of the person with an intellectual disability. If the person is being supported by a disability service, they may already have a GP, psychologist, counsellor or psychiatrist that they regularly see. If so you may need to provide them with support to access this person.

Your state government disability service may be able to help locate a psychiatrist with experience treating people with intellectual disability. It may also be useful to talk with the intake officer at the agency about their providing case management for the person you are concerned about, if this is needed. You should seek consent for this from the person if they can give it, or from their legal guardian.

### **Family and friends**

Family and friends are very important source of support for a person with a substance use problem. Family and friends can help the person to seek professional help. Also they can help reduce the chances of relapse after a person has quit. People are more likely to start using again if there is an emotional upset in their life and the family can try to reduce this possibility. In looking to family and friends for support it is important to keep in mind that they may be under stress or 'burnt out' due to their burden of care.

### **Action 5: Support and encourage the person to use any self-help strategies they may have.**

There are a number of booklets available to assist quitting alcohol or drugs. These are available from the Australian Drug Foundation, the National Drug and Alcohol Research Centre and SANE Australia (see the following resources). A national telephone QUITLINE 13 18 48 exists for tobacco use. The person with an intellectual disability may need help with reading and understanding the content of these brochures. This assistance should be provided in a non-judgemental and motivational way to help the person want to quit.

Support groups may be a useful source of mutual support and information. There are support groups for both substance users (Alcoholics Anonymous) and for their families (AL-ANON, Drugs in Family).

While groups for substance users might not be suitable for the majority of people with an intellectual disability, they should not be ruled out as a source of help. It is worth contacting the organiser of such a group to explore the possibilities for the person with an intellectual disability whom you are concerned about.

The person with an intellectual disability may not have any self-help strategies due to their reduced cognitive abilities. There are disability specific services that offer specialised education programs to assist people to learn self-help strategies and generalise them into their every day life. It is useful to contact the state government disability service in your locality for information about what is available. These services may be open to suggestion if they do not currently have programs that might be helpful so it is worth asking if they can set something specific up for the person you are concerned about.

If the person with an intellectual disability does have some strategies, they may need a reminder as to what they are, and then additional support to put these into practice.

Other strategies or suggestions for people with an intellectual disability and SUDs are:

- ✦ Encourage the person to get involved in activities that are inconsistent with using drugs or alcohol. Possible suggestions include going to venues where alcohol or drugs are not available or playing sport where the adverse effects of alcohol or drugs on performance may be highlighted.

- ✦ Encourage the person to engage in activities at times that would make substance use difficult. (e.g. planning events that the person enjoys at times just before they would likely go out to look for substances or use them)
- ✦ Support the person in engaging with peers who do not use substances. This can be helpful because often people use substances as a way of socialising.
- ✦ Explore the possibility that the misuse may be due to an underlying mental disorder and then support the person in receiving treatment for this.
- ✦ Support the person in developing skills that may reduce substance use or relapse. This might include social skills training or assertiveness training to resist offers by others to start up again.



## Helpful resources for substance use disorders

### Websites

#### Australian Drug Foundation

<http://www.adf.org.au>

The Australian Drug Foundation (ADF) is an independent, non-profit organisation working to prevent and reduce alcohol and drug problems in the Australian community. Its website is a good source of factual information and most types of drugs used illegally.

#### Australian Drug Information Network (ADIN)

<http://www.adin.com.au>

This site is funded by the Australian Department of Health and Aging to provide a central point of access to Australian drug and alcohol information.

#### National Drug and Alcohol Research Centre

<http://www.med.unsw.edu.au/ndarc>

This centre (NDARC) is based at the University of New South Wales and is funded by the Commonwealth Government. Its aim is to increase the effectiveness of treatment for drug and alcohol problems in Australia. Its website has information and online ordering for some excellent cheap booklets on different drug problems.

#### Drug Information Website

<http://www.drugsinfo.nsw.gov.au>

This website tells what the NSW Government is doing about drugs. It also gives fact sheets on illicit drugs, legal information, online publications and links to international drug websites.

#### SANE Australia

<http://www.sane.org>

SANE Australia has for sale two quit-smoking guides, one for consumers and one for supporters.

#### Australian National Tobacco Campaign

<http://www.quitnow.info.au>

This website gives online information and advice on quitting smoking.

#### Australian Govt Alcohol Information

<http://www.alcohol.gov.au>

This website gives information on alcohol-related health, science, news and government policy.

#### Alcoholics Anonymous

<http://www.alcoholicsanonymous.org.au>

#### Narcotics Anonymous

<http://www.naoz.org.au>

See Chapter 3 for additional disability and mental health websites

### Telephone Services

#### Quitline

National smoking quitline, 24 hours a day phone 131 848

<http://www.quit.org.au>

#### Alcohol and Drug Information Services (ADIS)

These services are available across Australia, 24 hours a day and will try to answer any questions about alcohol, tobacco or other drugs.

#### Queensland

Phone (07) 3236 2414, freecall 1800 177 833

#### New South Wales

Phone (02) 9361 8000, freecall 1800 422 599

#### Victoria

Phone (03) 9416 1818, freecall 1800 136 385

#### Western Australia

Phone (08) 9442 5000, freecall 1800 198 024

#### ACT

Phone (02) 6205 4545

#### Northern Territory

Phone (08) 8922 8399, freecall 1800 131 350

#### South Australia

Freecall 1300 131 340

#### Tasmania

Phone (03) 6222 7511, freecall 1800 811 994

#### National

Phone 1300 368 186 (Family Drug Support)

<http://www.fds.org.au>

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