

This booklet was created by Dr Angela Livingstone, consultant psychiatrist with VDDS, with input from the clinical team and incorporating feedback from both carers and peer support workers.

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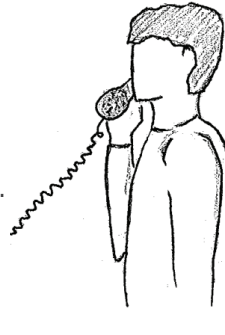
COMPLAINTS

When we have finished we will ask how we did. A complaint is when you tell someone if you are not happy with us.

It is OK to complain.

If you are not happy you can tell us why and we will try to help.

Your family or carers can also complain.



HOW DO YOU COMPLAIN?

You can call our manager. The telephone number is **(03) 9231 1988**.

OTHER WAYS TO COMPLAIN

Disability Services Commissioner **1800 677 342** (free call)
1300 726 563 (TTY)

Health Services Commissioner **1800 136 066**

Community visitors **1300 309 337**

MORE INFORMATION

You can ask us for more information. Our phone number is **(03) 9231 1988**

You can visit our website **www.vdds.org.au**

You or your family or carer will also get a *Victoria's Charter of Human Rights and Responsibilities* brochure, and a copy of this brochure.



**ST VINCENT'S
HOSPITAL**
MELBOURNE
A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

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**ST VINCENT'S
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*Inspired
by
You*

Dual Disability

Carers' Resource for Dual Disability



INTRODUCTION

If you are a carer who is supporting anyone living with a dual disability, we want this booklet to help you. We want to let you know about dual disability, and about the Victorian Dual Disability Service. We also want to share information about how disability and mental health affect each other, and to offer advice about some common experiences.

When caring for someone with a dual disability it can be hard to remember your own needs. You may feel stressed or overwhelmed, and this can affect your relationships with others. We want to share some ways to notice and manage times that you are feeling stressed, so that you can look after your own health as well as that of the person you care for.

WHAT IS DUAL DISABILITY?

If a person living with an intellectual disability or autism spectrum disorder also develops a mental illness, this is called a dual disability. Intellectual disability and autism spectrum disorder may make it hard for the person to understand and manage their mental illness. It can be difficult both for the person and their carers.

People with an intellectual disability or autism spectrum disorder are just as likely to develop a mental illness as anyone else. When the person finds it hard to communicate or people do not know them well, a mental illness may be harder to recognise. In some people with an intellectual disability or autism spectrum disorder the symptoms of mental illness can also look different.

For people with an intellectual disability or autism spectrum disorder the main way that a mental illness becomes visible can be a change in their behaviour. Some behaviours that could be seen include withdrawal and sadness or fear. Others can include screaming, breaking things, aggression, risk-taking or self-injury. New behaviour problems can emerge with the onset of a mental illness and longstanding problem behaviours may increase in severity or frequency.

If the person with a dual disability finds it difficult to understand complex ideas or feelings, or has trouble telling others what is wrong, these behaviours may be the only sign of mental illness. This can lead to the person being seen as 'bad' instead of having their mental illness recognised and treated.

WHAT SERVICES ARE AVAILABLE?

Public mental health services in Victoria are good at recognising and treating mental illness for most people, but when they are seeing people with a dual disability the clinicians may need some help. The Victorian Dual Disability Service can help public mental health clinicians with advice, training and formal second opinions.

There is also a network of mental health community support services (MHCSS) which help support people with a mental illness in practical ways. People with a dual disability can get support through these agencies as well as through disability support providers.

The family doctor or general practitioner for a person with a dual disability can also ask for help from the Centre for Developmental Disability Health Victoria (CDDHV), or the person may be able to see a private psychiatrist or psychologist.

HOW CAN I HELP THE PERSON?

There are many ways in which you can help the person you care for. If you know the person well you may be able to ask for help for them. You may be able to tell mental health workers important information to help with diagnosis and management.

You may be able to help the person with a dual disability to let others know what they are thinking and feeling. You may be able to help them to understand what might be happening to them. You can also help support the person through what can be a frightening and emotional time.

WHAT TREATMENTS CAN HELP IN DUAL DISABILITY?

Although most treatments for mental illness for people with a dual disability are similar to those for anyone else, people with a disability may be more at risk for side effects of medication. They may also have difficulties in letting people know about side effects, and may require modification of other treatments (such as psychological therapy). It is important to ask about side effects and risks when your doctor or clinician is considering any new or additional treatment, and to ask if ongoing treatments are still appropriate.

COMMON MENTAL ILLNESSES - DEPRESSION

Someone with depression may have:

- A low mood (feel sad),
- Unhappy thoughts
- Physical problems like tiredness or pain, or trouble sleeping
- Sometimes people lose their appetite, and sometimes they eat more to feel better.
- People can also feel irritable or aggressive.
- They may not want to do their favourite activities or lose interest in social events.
- They may talk or communicate less, and not be able to do things they used to do.
- Some people may hurt themselves or do risky things. Thoughts of suicide or death are common and asking about them does not make them worse.
- Usually these changes will have been present for at least a few weeks.

For people with a dual disability, depressed mood may not be obvious and irritability may be more likely. They may argue more or be easily frustrated about things that would not normally bother them. Eating and appetite changes may not be as noticeable, particularly if the person does not do their own cooking or needs help with eating.

In severe (psychotic) depression the person may believe that they are bad or worthless. They may think that they have done something wrong or should be punished. They may hear horrible voices calling them names or telling them bad things will happen to them. The person may believe that they are dying or even that they are already dead. When depression is severe the person's thoughts may become very slow and they may speak very slowly or softly. Their mind might feel empty. Guilt and hopelessness need to be taken very seriously because the person may try to hurt or kill their self.

COMMON MENTAL ILLNESSES - MANIA

Mania can be thought of as the opposite to depression. The person's mood is usually high rather than low. Hypomania is the less severe form and if there are psychotic symptoms or the person is very badly affected the episode is called a manic episode. People who have episodes of hypomania and mania can also get depression and for this reason the illness is called bipolar affective disorder.

Someone with mania may have:

- An elevated or irritable mood
- More energy or activity than usual
- Less need for sleep
- More speech or faster speech, or for some people more sign language
- Laughing at inappropriate times or laughing uncontrollably
- Thoughts that jump from subject to subject
- Risky or impulsive behaviour

Sometimes the mania can cause psychotic symptoms, where the person loses touch with reality. They may believe that they have a high-level job, a famous partner or have been chosen by God. They may believe they are extremely clever or talented, or wealthy. The person may hear voices talking to them which tell them they are good, clever or special. A person with mania may be vulnerable if they try to form sexual relationships, gamble or spend too much money. There is also a medical risk because of reduced sleep, overactivity, reduced oral intake and they often believe they don't need medication for physical problems.

COMMON MENTAL ILLNESSES - ANXIETY

Anxiety is an emotional state that everyone will experience at some time, and in some situations it can be normal and even helpful. It becomes a problem when it occurs for no apparent reason, when it is excessive, when it interferes with a person's normal activities or when it causes distress.

Although people with a dual disability may have the same anxiety symptoms as anyone else, they may also present with different symptoms. They may feel irritable, restless or angry. They may have difficulty recognising that they are anxious if they have lived with their fears and worries for many years and they may find it difficult to describe what they are feeling and thinking.

Because many physical and mental illnesses can present with anxiety symptoms, where a person presents with an anxiety disorder (especially if this is new) a specialist assessment is required.

OTHER MENTAL ILLNESSES - PSYCHOSIS

Psychotic disorders are illnesses in which people lose touch with reality, and people with a disability may be more likely to develop a psychotic illness than other people. When someone is psychotic they may believe things that are not true (delusions) hear or see things that are not there (hallucinations) and have disorganised thoughts, speech and behaviour. The person often has difficulty understanding what is real and what is not. This can cause distress and risk for that person and others.

Common psychotic disorders include schizophrenia, schizoaffective disorder and substance-induced psychosis, but psychotic symptoms can also occur in other conditions such as depression or mania.

It may be difficult to identify psychotic symptoms in people with a dual disability, especially where there is a severe disability where understanding and communication are affected. For some people assessment may depend on observations of behaviour.

Some behaviours which might suggest psychotic illness in someone with intellectual disability or autism spectrum disorder include:

- Appearing distracted or preoccupied
- Staring off to the side during conversation
- Nodding and gesturing as though listening to a conversation when alone
- Pointing or reaching out when there is nothing there
- Sudden unexplained outbursts
- Appearing worried, scared and watchful
- Unable to attend to normal self-care (eating, dressing, toileting)
- Not following their usual routine or participating in activities
- Disorganised behaviour
- Breaking things

Behaviours that put the person or others at risk can also occur or be exacerbated as a result of psychotic illnesses and these may be the only observable signs.

OTHER MENTAL PROBLEMS – DRUG AND ALCOHOL PROBLEMS

For most people with a disability, as for most other people, some use of alcohol or other substances may not result in any problems with their health or behaviour. Unfortunately, many people in the general community have a problem with using alcohol or other drugs (legal or illegal), and people with disabilities are no exception.

Having a disability may also increase the risks for those who drink or use substances more heavily, and this may cause problems for their physical and mental health, as well as social and behaviour problems.

People with low self-esteem, poor social skills or a mental illness are more likely to use drugs or alcohol in harmful ways. The risk is also higher for people under stress or people who live where drugs or alcohol are available and where other people use them commonly. People are less likely to use drugs or alcohol in harmful ways if they have involved and caring people supporting them and are encouraged to make healthy choices.

Treatment of drug and alcohol problems may include brief intervention, counselling, specific psychological therapies and group therapy, which can all be modified for a person with a disability.

Specialist help is recommended, and the involvement of a carer is likely to lead to better engagement and better outcomes.

A useful resource for family members and carers is Counselling Online, and details can be found at www.counsellingonline.com.au Other resources include the Alcohol and Drug Information Service (ADIS) and the details for this in Victoria are (03) 9416 1818 and freecall 1800 888 236.

OTHER MENTAL PROBLEMS - DEMENTIA

People with intellectual disability are at a higher risk of dementia. Dementia is a brain disease where people gradually lose their memory and can have changes in their ability to think and control their mood, and in their personality.

Often the first sign of dementia that is noticed by others is forgetfulness, where the person may forget what they have just eaten or the conversation that they have just had. They may find it difficult to remember the names of new people or to name everyday things such as a pen or a spoon. Other signs may be getting lost in familiar places, not recognising people they previously knew, not being sure how to complete a familiar task such as laying the table or getting dressed.

There is usually a gradual decline in abilities and often the development of behavioural and psychiatric problems such as aggression, irritability, anxiety, paranoia and hallucinations.

In people with a disability it may be difficult to decide if cognitive difficulties are due to the disability or the onset of dementia. In addition, a decline in function may not be as obvious if the person has always needed a lot of supports. The carer's role is especially important when considering a diagnosis of dementia as it is important to know what the person is normally capable of and if there has been any change.

People with Down Syndrome are at a high risk of dementia. It tends to occur at a much younger age: thirty or forty years before the general population, and they may lose their abilities faster than people in the general population.

When dementia is suspected a specialist referral should be made early on, as the person should have early access to diagnosis and treatment of their illness. In Victoria, specialist assessment can be done by Cognitive Dementia and Memory Service (CDAMS) clinics. The state-wide contact number for these clinics is 1300 135 09.

WHAT CAN I DO IN A CRISIS?

In a crisis, if you are concerned about the health or safety of a person you care for, or the safety of others, it is very important to consider whether the person needs the assistance of police or an ambulance. Consider if there is any way you can make the situation less agitating for the person, and if there is anything you can say or do that might help them to calm down.

It may be appropriate to call your Area Mental Health Service. There are acute mental health services available in a crisis situation and these services can be accessed by going to the following website and calling the psychiatric triage service for your area: <http://www.health.vic.gov.au/mentalhealthservices/adult/>

WHAT SUPPORTS CAN HELP ME?

Carers Australia (and Carers Victoria) supports the 2.7 million unpaid carers across the country, whose work is estimated to be worth \$60.3 billion a year. They advocate for carers in policy and research, provide information, advice, education and training to carers, and can organise practical respite and support for carers including counselling. Details of Carers Victoria can be found at <http://www.carersvictoria.org.au>

If the person you care for is engaged with the local Area Mental Health Service you may be able to receive support from a Carer Consultant or a Carer Peer Support worker. You may also be eligible for funding through the Carer Support Fund – this is a Government fund established to assist family members or friends with the costs of caring for a person with a mental illness. Tandem (www.tandemcarers.org.au) is the carer organisation in Victoria which focuses on those who care for people with a mental health problem, and they provide a range of carer supports.

Commonwealth Respite and Care centres provide support, respite and information to carers across Australia, and their details can be found at <http://www.australia.gov.au/information-and-services/benefits-and-payments/carers>

In addition to seeking further support, it might be useful to keep some practical strategies in mind:

- **Learn about mental health.** This will help you understand and help others understand what it is, and why someone with mental health problems might react in a certain way.
- **Make your own health a priority.** Eat well, exercise regularly and try to sleep well. Develop routines that support you in maintaining a healthy lifestyle.
- **Have your own GP.** It is common to be so focused on looking after the person you support that you forget about the importance of addressing your own health. This might mean routine check-ups or seeing your doctor when you are beginning to feel stressed.
- **Learn to accept support from others.** Be open to their efforts to help you.
- **Maintain hope.** It's important that you maintain optimism and hope, and that you continue to see the person, not the illness or the behaviour.

– Keep healthy boundaries.

This can help ease the tensions in your relationship with the person you are caring for, and prevent cycles of anger, frustration or resentment from repeating.

WHERE CAN I GET MORE INFORMATION?

If you want more information from VDDS you can call us on (03) 9231 1988 or visit our website at www.vdds.org.au

If you have a problem or a complaint you can also call:

Disability Services Commissioner

1800 677 342 (free call)
1300 726 563 (TTY)

Health Services Commissioner

1800 136 066

Community visitors

1300 309 337

If you would like to provide feedback on this resource please email the VDDS at vdds@svha.org.au. Please provide your contact details so we can get back to you.

ABOUT THE VICTORIAN DUAL DISABILITY SERVICE

The Victorian Dual Disability Service is a joint mental health initiative between St. Vincent's Health (Melbourne) and Melbourne Health. The service is multi-disciplinary and operates within the mental health policy framework in Victoria. At a state wide level the VDDS is responsible for:

- Developing a model of best practice
- Providing assessment and consultation services to staff within the Victorian Area Mental Health Services
- Promoting access to Victorian Area Mental Health Services for consumers with a dual disability
- Facilitating partnerships and collaborative treatment planning through consultation and liaison

TARGET POPULATION

Victorian residents aged 16 years and over who are current consumers of Mental Health Services and have a known or suspected intellectual disability.

REFERRAL PROCESS

Contact is welcomed from any source, however referrals for assessment are limited to patients who are either registered or are likely to be registered with the Victorian Area Mental Health Service, or people over 15 with a disability living within the Northern and metropolitan Western Division of the Department of Human Services, receiving a funded service from Disability Services. Phone advice is available for people who do not meet these criteria. For more information please visit our website www.vdds.org.au

REFERRALS & ENQUIRIES

Please contact the VDDS Duty worker on (03) 9231 1988.

TRAINING / EDUCATION

The VDDS also provides education and training to staff employed in Mental Health Support Services across the state. To request training on dual disability or for further information please phone (03) 9231 1988.

The VDDS provides a brochure to clients when they are seen to inform them of the VDDS process and of their rights and responsibilities. This is reproduced below:

(Version January 2016)

The Victorian Dual Disability Service (VDDS) Consumer Information Brochure

This brochure provides information relating to:

- The VDDS
- The assessment process
- Your rights and responsibilities
- Seeking your consent

The Victorian Dual Disability Service (VDDS) is a mental health service for people with learning problems. This brochure tells you why we are seeing you, about your rights and responsibilities, and asks if you agree to be assessed.

WHEN DO WE SEE YOU?

- We see you when you think something is wrong with your mental health
- OR
- when someone else is worried about your mental health.



WHY DO WE SEE YOU?

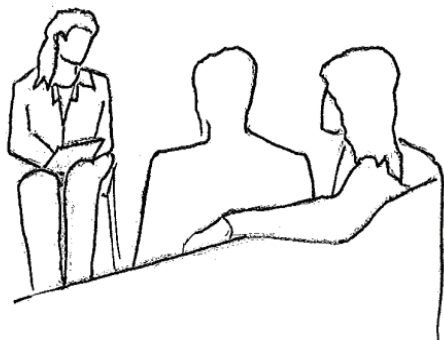
- To work out if you have mental health problems.

Mental health problems can change how you feel, think or behave



WHAT WILL HAPPEN?

- We come to meet you and talk to you.
- We may talk to your family or carers, and we may talk to other people who know you.
- We may look at your medical records.
- When we have finished we will tell you what we think.



- We will come back another day and talk to you about what the letter says.
- We will talk to the people looking after you about what the letter says
- You can ask to see and read the letter

There is no cost.



We will ask you:

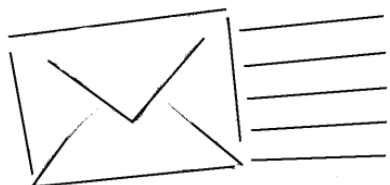
- Where you want to see us.
- If you would like anyone else to be there.
- If you would like an interpreter.
- Who we can talk to about you.
- Who we can write to about you.

WHAT ARE YOUR RIGHTS?

When you meet us we will:

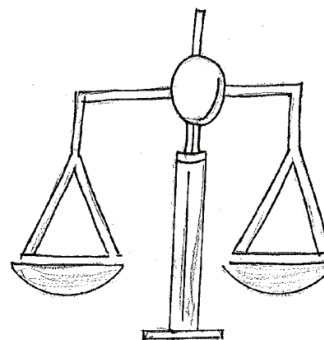
- See you somewhere safe.
- Treat you fairly.
- Allow you to say and think what you want.
- Help you to say what you want.

Then we write a letter.



- The letter says what we think will help you feel better.
- The letter says how people can help you.

- Explain things to you so that you understand.
- Help you make decisions about your life.
- Ask other people to help you with hard decisions.
- Keep your information private.
- You can ask us for access to your health records.



If you don't want to see us:

You can say no.

It's OK to say no.

Sometimes we will talk to other people who are allowed to make decisions for you.



YOUR RESPONSIBILITIES

Personal information

- You tell us what is wrong.
- You tell us how you are feeling.
- You tell us what makes you feel better or worse.
- You tell us who is helping you.
- You let us talk to other people who know about your problems.



Behaviour

- You are respectful to staff.
- You do not break things.
- You do not shout.
- You do not hit people.

