

# INFORMATION SHEET

## Mental health problems in people with learning disabilities



In the general population it has been estimated that there are more people in hospital for mental health problems than for all other diseases combined. Mental health problems place enormous burdens on carers, social and medical services. They reduce the person's quality of life and their ability to cope.

People with learning disabilities are just as likely to have mental health problems as the rest of society, with a lot of research suggesting that they are in fact more likely to suffer from a mental health condition. Yet their problems usually go unnoticed because the symptoms can be lost amongst other behaviours which they may display. It is essential to be aware of potential mental health problems, and to get them assessed and treated without delay.

***All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.***

***Please see the end of this information sheet for details of how to support us.***

***We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [www.surveymonkey.co.uk/r/cbfresources](http://www.surveymonkey.co.uk/r/cbfresources).***

### **What is a mental illness?**

The NHS defines mental illness as a condition that significantly interferes with an individual's cognitive, emotional or social abilities e.g. depression, anxiety, schizophrenia.

The symptoms of mental illnesses usually follow a specific pattern but this can be difficult to spot if you're not sure what to look for. Being clear on what the symptoms are and noticing these patterns in behaviour can help doctors make a diagnosis.

### **Is there a link between mental health problems and challenging behaviour?**

Mental illness can lead to changes in a person's behaviour or possibly cause an increase in challenging behaviour. Research has found that when challenging behaviour becomes more severe it can be connected to an increase in the symptoms of a mental health problem. It has even been suggested that challenging behaviour can sometimes be another symptom of depression. Although, it's important to remember that other factors can cause challenging behaviour and for more information please see our information sheet: 'Understanding Challenging Behaviour'.

There are three main ideas around the link between challenging behaviour and mental illness:

- Primary: where the behaviour is a direct result of the mental illness, e.g. Jon uses aggression in response to hearing voices

- Secondary: where a behavioural response to a symptom of the illness creates challenging behaviour, e.g. Greg screams in response to a flashback, Tony, his carer, responds negatively and Greg then uses aggression against Tony
- Consequential: where the behaviour begins as in primary but is reinforced by others and becomes learned behaviour, e.g. Shaun had become aggressive as part of his mental illness, and noticed that he got a lot more attention when he did so. Despite the medication helping his mental illness, he continued to use aggression as a way of attracting the attention he needed from others.

### **Is challenging behaviour itself a mental health problem?**

Behaviours are described as “challenging” mainly because they break social rules, i.e. that it is wrong to hurt others, hurt one’s self, destroy property or otherwise disrupt other people’s lives. There are many reasons why someone might display these kinds of behaviours. The fact that a person shows challenging behaviour does not mean that they have a mental health problem. This is probably true for most individuals with a learning disability. However, some people *do* have both types of problem.

*When a person has mental health problems and displays challenging behaviour, the picture becomes very complicated. It is often difficult to know whether the challenging behaviour is happening partly because of the mental health problem, or whether the challenging behaviour has completely different causes, maybe relating to problems in the person’s home or school for example.*

### **Can having a learning disability affect the development of a mental health problem?**

A wide range of factors influence a person’s mental health. Mental health is closely related to the quality of a person’s physical and social environment. Having good social supports, respect within society and an interesting and stimulating environment are all factors which can help protect our mental health. If we do not have these strong supports we are more vulnerable to mental health problems.

In addition, the *level* of learning disability can be an important factor when assessing the individual’s mental health needs. In people with severe or profound learning disabilities, mental health problems are likely to relate to complex brain, nervous system, genetic and other biological abnormalities.

People with mild or moderate learning disabilities are more likely to be affected by social risk factors like parental rejection, long-term institutionalisation, poor social networks, lack of self-esteem etc. It is also important to remember that many people with learning disabilities, even if they have a good quality of life now, may continue to suffer from the effects of their past life. Long periods in an institution and/or early parental rejection may affect the rest of the person’s life.

## **What are some examples of common mental health problems?**

*NB. Giving medication to people with severe learning disabilities should only be done under the supervision of an experienced professional. See the CBF's information sheet on 'Use of Medication' for further information & advice.*

	<b>What is it?</b>	<b>Why?</b>	<b>Treatment</b>	<b>Further Info*</b>
<b>Depression</b>	<p>In the general population, depression is the most common mental health problem in adults, occurring in about 13% of all people at some time in their lives.</p> <p>The main symptoms of depression are:</p> <ul style="list-style-type: none"> <li>• low mood</li> <li>• loss of interest or pleasure in almost all activities</li> <li>• loss of energy</li> </ul> <p>Other symptoms can include:</p> <ul style="list-style-type: none"> <li>• weight loss or gain</li> <li>• changes in sleep pattern</li> <li>• agitation</li> <li>• loss of ability to concentrate</li> <li>• suicidal thoughts</li> </ul>	<p>There is no single cause of depression. It can be a combination of many different factors including:</p> <ul style="list-style-type: none"> <li>• an imbalance in brain chemistry</li> <li>• illness</li> <li>• social influences</li> <li>• genetics</li> </ul> <p>It occurs most often in people who have no close relationships. People with learning disabilities who live alone are therefore at high risk.</p>	<ul style="list-style-type: none"> <li>• antidepressants</li> <li>• therapies such as cognitive behavioural therapy (which can be adapted for people with learning disabilities)</li> </ul>	<p><a href="http://www.aboutlearningdisabilities.co.uk/depression-learning-disabilities.html">www.aboutlearningdisabilities.co.uk/depression-learning-disabilities.html</a></p> <p>Easy read: <a href="http://www.rcpsych.ac.uk/pdf/Depression%20ld%20final.pdf">www.rcpsych.ac.uk/pdf/Depression%20ld%20final.pdf</a></p> <p>Books Beyond Words: 'Ron's feeling blue' &amp; 'Fiona's feeling sad' <a href="http://www.booksbeyondwords.co.uk">www.booksbeyondwords.co.uk</a></p>
<b>Bipolar Disorder</b>	<p>Symptoms of bipolar disorder include:</p> <ul style="list-style-type: none"> <li>• periods of depression, followed by a highly elated mood</li> <li>• extreme mood swings along with changes in thinking and behaviour</li> <li>• symptoms of 'elated' periods include excessive 'high' or euphoric feelings, and decreased need for sleep</li> </ul>	<p>The exact cause is unknown but factors include:</p> <ul style="list-style-type: none"> <li>• a chemical imbalance in the brain</li> <li>• genetics</li> <li>• social influences</li> </ul>	<ul style="list-style-type: none"> <li>• medication including mood stabilisers and antidepressants</li> <li>• psychological treatments (therapy)</li> <li>• lifestyle changes (exercise, diet changes and sleep)</li> </ul>	<p><a href="http://www.nhs.uk/Conditions/Bipolar-disorder/Pages/Treatment.aspx">www.nhs.uk/Conditions/Bipolar-disorder/Pages/Treatment.aspx</a></p> <p>Easy Read: <a href="http://www.rcpsych.ac.uk/pdf/Bipolar%20ld%20final.pdf">www.rcpsych.ac.uk/pdf/Bipolar%20ld%20final.pdf</a></p>

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<b>Anxiety Disorders</b>	<p>Anxiety can be seen as a mental health problem when the feelings of anxiety or dread are so out of proportion to what is happening that normal daily routines are disrupted.</p> <p>Types of anxiety disorder include:</p> <ul style="list-style-type: none"> <li>• panic disorder</li> <li>• phobias</li> <li>• obsessive-compulsive disorder</li> </ul> <p>All anxiety disorders are usually associated with physical symptoms such as increased heart rate, shortness of breath, sweating, trembling, shaking, chest pain, discomfort and nausea.</p>	<p>The exact cause of anxiety disorders is not understood although factors include:</p> <ul style="list-style-type: none"> <li>• brain over activity</li> <li>• chemical imbalances in the brain</li> <li>• genetics</li> <li>• history of stressful and traumatic experiences</li> <li>• long term health conditions</li> </ul>	<ul style="list-style-type: none"> <li>• psychological treatments such as cognitive behavioural therapy</li> <li>• applied relaxation</li> <li>• medication</li> </ul>	<p>Easy Read:  <a href="http://www.rcpsych.ac.uk/pdf/Anxiety%20Id%20final.pdf">www.rcpsych.ac.uk/pdf/Anxiety%20Id%20final.pdf</a></p>
<b>Post-Traumatic Stress Disorder</b>	<p>Post-traumatic stress disorder is an anxiety disorder caused by very stressful, frightening or traumatic events.</p> <p>PTSD can develop immediately after someone experiences a disturbing event or it can occur weeks, months or even years later.</p> <p>Someone with PTSD will often relive the traumatic event through nightmares and flashbacks.</p> <p>They may also have problems sleeping.</p>	<p>A number of possible reasons have been suggested:</p> <ul style="list-style-type: none"> <li>• due to abnormal level of the stress hormone</li> <li>• changes in the brain and emotional processing</li> <li>• as a survival mechanism (so you're more prepared if it happens again)</li> </ul>	<ul style="list-style-type: none"> <li>• psychotherapy such as cognitive behavioural therapy or 'eye movement desensitisation and processing'</li> <li>• antidepressants are sometimes used if psychotherapy has been unsuccessful</li> </ul>	<p><a href="http://www.disabled-world.com/disability/types/psychological/ptsd-learning.php">www.disabled-world.com/disability/types/psychological/ptsd-learning.php</a></p> <p>Easy Read:  <a href="http://www.easyhealth.org.uk/sites/default/files/post%20traumatic%20stress%20disorder%20%28PTSD%29%20.pdf">www.easyhealth.org.uk/sites/default/files/post%20traumatic%20stress%20disorder%20%28PTSD%29%20.pdf</a></p>
<b>Psychoses</b>	<p>Psychoses are serious mental health problems in which the person partly or totally loses contact with reality. The symptoms are typically bizarre, with core symptoms being:</p> <ul style="list-style-type: none"> <li>• Delusions (a belief in something which is untrue)</li> <li>• Hallucinations (false perceptions e.g. the person seeing, hearing, feeling, smelling or tasting something that is not actually there)</li> </ul>	<p>Psychotic conditions can occur for a variety of reasons:</p> <ul style="list-style-type: none"> <li>• use of or withdrawal from alcohol and drugs</li> <li>• as part of a head injury or a physical illness that disrupts brain functioning</li> <li>• from a major stress in a person's life (e.g. death or change of living circumstance)</li> </ul>	<ul style="list-style-type: none"> <li>• antipsychotics</li> <li>• psychological treatments such as cognitive behavioural therapy</li> </ul>	<p><a href="http://www.intellectualdisability.info/diagnosis/recognizing-psychosis-in-nonverbal-patients-with-developmental-disabilities">www.intellectualdisability.info/diagnosis/recognizing-psychosis-in-nonverbal-patients-with-developmental-disabilities</a></p> <p>Easy Read:  <a href="http://www.rcpsych.ac.uk/pdf/psychosis%20Id%20final.pdf">www.rcpsych.ac.uk/pdf/psychosis%20Id%20final.pdf</a></p>

	<b>What is it?</b>	<b>Why?</b>	<b>Treatment</b>	<b>Further Info*</b>
<b>Schizophrenia</b>	Schizophrenia is a long term psychotic condition. Usually starting in early adulthood, with episodes occurring throughout life. A prevalence of around 3% is the accepted statistic in those with learning disabilities (though many think this is an underestimate). This is 3 times higher than the prevalence in the general population.	It is unclear what the cause is, possible causes are: <ul style="list-style-type: none"> <li>• a link to brain dysfunction</li> <li>• family history (genetic predisposition)</li> </ul>	A combination of: <ul style="list-style-type: none"> <li>• medication</li> <li>• therapy</li> </ul>	<a href="http://www.mind.org.uk/information-support/types-of-mental-health-problems/schizophrenia/#.WDR3i31Pjis">www.mind.org.uk/information-support/types-of-mental-health-problems/schizophrenia/#.WDR3i31Pjis</a>
<b>Dementia &amp; Alzheimer's Disease</b>	There are a number of different types of dementia including Alzheimer's disease (the most frequent) and multi-infarct dementia (the brain is damaged by burst blood vessels - infarcts).  Dementia involves worsening in many aspects of mental functioning including: <ul style="list-style-type: none"> <li>• memory</li> <li>• cognition</li> <li>• emotional state</li> </ul>	<ul style="list-style-type: none"> <li>• linked to a number of changes happening throughout the brain</li> <li>• genetics (people with Down syndrome are particularly prone to Alzheimer's disease)</li> </ul>	There is currently no cure for dementia or Alzheimer's, though medication is available for Alzheimer's that can temporarily reduce some symptoms or slow down the progression of the condition in some people.	<a href="http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103">www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103</a>  <a href="https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/d/dementia">https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/d/dementia</a>  Easy read: <a href="http://www.rcpsych.ac.uk/pdf/Dementia%20ld%20final.pdf">www.rcpsych.ac.uk/pdf/Dementia%20ld%20final.pdf</a> Books beyond words 'Ann has dementia' <a href="http://www.booksbeyondwords.co.uk">www.booksbeyondwords.co.uk</a>
<b>Problems arising from brain injury</b>	Problems from brain injury vary depending on the nature of the injury or damage. A wide variety of different symptoms can occur including disturbances of consciousness, attention and perception.	Physical damage to various areas of the brain.	Treatment options vary depending on the severity of injury and the area of the brain damaged. Treatments include: <ul style="list-style-type: none"> <li>• surgery</li> <li>• rehabilitation</li> <li>• therapy</li> </ul>	<a href="http://www.nhs.uk/conditions/Head-injury-severe/Pages/Introduction.aspx">www.nhs.uk/conditions/Head-injury-severe/Pages/Introduction.aspx</a>

*\*The CBF cannot guarantee accuracy of external websites; links are provided for further reading and medical advice should be sought about mental health of individuals.*

## **What can be done to improve mental health?**

### **1. Recognise the problem**

The first step to mental health care is for the problem to be *recognised*. This can be difficult in people with learning disabilities as many are unable either to know that a problem exists, or to find treatment on their own. *This means that someone else has to recognise that the person is showing signs of mental health problems.*

If the symptoms are very severe, the mental health problem is more likely to be identified. In many cases however, the signs may be so mixed up with other behaviours related to the person's learning disabilities or challenging behaviour that the mental health problem remains unrecognised. Studies have confirmed that this is the case, as many people with depression and anxiety are not diagnosed or treated for their condition.

*Families, support workers and direct care staff working with people with learning disabilities have a crucial role in recognising potential symptoms.* They are in the best position to identify significant behaviour change and to make appropriate referrals if needed.

There are some special assessment tools to help people recognise mental health problems as early as possible. A widely used tool is the *PAS-ADD Checklist (Revised): a mental health questionnaire*, written in everyday language, designed for use specifically by care staff of people with learning disabilities. It helps record a range of problems which may be part of a mental health illness.

## **2. Get the best possible assessment**

For people with a mental health problem who do not have a learning disability, the first assessment is usually a clinical interview with a mental health professional. Lack of, or limited verbal communication makes it hard for people with learning disabilities to do this so reports from other people such as family members and care staff are very important in the process of diagnosis.

The clinical picture can be very complicated, especially when there is a mental health problem and challenging behaviour. Many assessments may be needed over time, including direct observations and evaluation of biological, psychological, social, family and environmental factors.

To get a mental health assessment there are different processes across the country. This is because there will be different services available in each area. To start the process a carer should firstly contact the person's key worker or GP, and ask how to get an initial assessment of potential mental health problems within the local Health Service. Some areas of the UK offer Instant Access to Psychological Therapies (IAPT) and work has been done to make these services more suitable for people with learning disabilities.

## **3. Treatment**

It is often not known the exact reason why a person develops a mental health problem, and it is also not possible to know how they might respond to any particular treatment. This can make treatment complicated and several treatment options may be recommended. As the person's progress is monitored, the treatment plan may be changed in the light of the new evidence. For people with learning disabilities treatments should be watched closely and adapted to suit their needs.

*Examples of treatments:*

- *Medication:* There are a number of published standards for the use of medications in the psychiatry of individuals with learning disabilities. Recommendations include: multi-

disciplinary assessment of need for medications, use of minimal effective dose, regular attempts to reduce dosage, monitoring of side effects and integration with other treatments. Please see the CBF's information sheet 'Use of Medication' for more information.

Although medications can be highly effective, it is important to remember that most mental health problems probably have multiple causes. Medication cannot change the environment, or cure problems arising from early life trauma. In most cases additional forms of intervention are necessary as well.

- *Cognitive Therapy*: Using cognitive therapy with people who have a learning disabilities is relatively new, but there are some promising results. Anger management has been found to work well with individuals with mild to moderate learning disabilities. Using relaxation training to treat anxiety disorders has also had good results, including in people who have severe learning disabilities.
- *Psychotherapy*: The term psychotherapy can mean a variety of therapies including psychodynamic psychotherapy and counselling. People with a learning disability are highly likely to have experienced early-life emotional trauma, and doctors have recognised that some of the more able individuals with learning disabilities can benefit from psychodynamic psychotherapy, as long as the language and content is changed to suit their needs. However these treatments often need relatively well-developed verbal communication skills and an increased level of understanding.
- *Educational Interventions*: Providing information and education about mental health problems is important, both for the individual and for his/her support network.

#### **Further information:**

- The Royal College of Psychiatrists' Faculty of the Psychiatry of Learning Disability and the Leicestershire Partnership NHS Trust have produced a series of very accessible information for people with mental health problems and learning disabilities <http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/learningdisabilities.aspx>
- 'Supporting Complex Needs: A practical guide for support staff working with people with a learning disability who have mental health problems' produced by Turning Point and the Estia Centre.
- 'Books Beyond Words' have a number of books about specific mental health conditions available at a cost, but it is possible to request them from your library.

#### **Reference:**

Moss, S.C (2002) *The PAS-ADD Checklist (Revised)*. Brighton: Pavilion Press

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### **The Challenging Behaviour Foundation**

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email [info@thecbf.org.uk](mailto:info@thecbf.org.uk), or visit our website: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

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