

# Depression in People with Learning Disability

## Introduction

Some people have special difficulty in learning to talk, look after themselves and in coping with schooling and preparation for adult life. This disability, once called mental handicap or retardation, is now known as learning difficulty or disability. The disability can be quite mild or so severe that independent life is impossible.

Many people will get depressed at some time in their lives, including people with learning disability. Bereavement, disappointment, stress, or illness are some possible causes, but depression may also occur for no apparent reason. Generally periods of depression are short but sometimes they last much longer, when special help is needed.



Because depression is so common, it is usually easy to spot. As well as obvious feelings of sadness or misery, symptoms may include a loss of interest in previously enjoyed activities, agitation and restlessness, disturbances of eating and sleeping, lack of motivation and a loss of self confidence and self esteem. People who are depressed may be able to talk

about their feelings to their family, friends or workmates, and to their GP. Talking is an important part of getting better.

The problem for many people with learning disabilities is that they are not able to express their feelings easily in words. So their actions may have to speak for them. Sudden changes in behaviour or mood, or not being able to do things they could previously do may all be important signs of depression. These changes in behaviour are often mistakenly viewed as just a phase, and so the right help may not be given. Unfortunately, it can be all too easy to forget that people with learning disabilities have feelings, too.

In this leaflet we suggest ways in which depression in people with learning disability can be better recognised, and how they can be helped.

## How do you recognise depression?

Feeling low or sad is not the only sign of depressive illness. Other common symptoms include:

- less interest in activities which are usually enjoyed.
- feeling tired all the time.
- no get up and go.
- eating too little or too much.
- losing weight.
- inability to sleep or waking up too early.
- sleeping all the time.
- avoiding other people.
- inability to relax or restlessness.
- being snappy and irritable.
- feeling bad or guilty, or worthless.
- loss of confidence.
- thinking life isn't worth living.

People with learning disabilities are just as likely to get depressed as other people. But the way they show it can sometimes be different from the picture painted above, especially when there are communication problems. Other signs to look out for are:

- sudden or gradual changes in usual behaviour.
- seeking reassurance.
- loss of skills.
- loss of bowel or bladder control.
- loss of ability to communicate.
- outbursts of anger, destructiveness or self harm.
- physical illness.
- complaining about aches and pains.
- wandering or searching.

### Some people's stories

**Derek** was a 33 year old man with autism. He was doing well at his local Social Education Centre but then, over a few weeks, one of the other students died suddenly of a heart attack, new students arrived and his favourite tutor left. Derek never mentioned these events but he gradually became more and more withdrawn. He didn't want to be touched and became very upset if anyone came near him. His activities at the Centre were disrupted and he could no longer travel there on the bus. Derek also stopped taking part in his local church activities which he had done for years. He lost weight, became anxious and afraid, would not speak and took hours to finish even simple tasks.



**Sandra** had severe learning and communication difficulties. She lived alone with her mother until she was 45, when her mother had a stroke and could no longer care for her. As Sandra had always been a quiet, placid person, she was moved to a small group home run by Social Services. At first she showed no signs of being upset, although she would sometimes pull her own hair. This problem gradually got much worse until she had almost no hair left. Sandra then started to pick at spots and scratches on her skin until they became badly infected. When very upset she would scream and bang her head, and it was almost impossible to comfort her.

Staff in the home just thought this was attention seeking behaviour and that the best thing to do was to ignore it. This had no effect and the problems grew worse.

**Jane** left home to go to College when she was 19. She had Down's syndrome and had done very well at her school for children with severe learning disability. Within 4 months she had stopped speaking, become very withdrawn and obviously unhappy. Her parents took her away assuming that something bad must have happened at College. Instead of cheering up Jane became quite aggressive. After breaking several cupboards in her bedroom one day, she was admitted to hospital. It took the psychiatrist some time to get to the bottom of Jane's depression. It turned out that her mother's sister Sarah had died 2 days before Jane's first weekend home from College. Her aunt had been like a grandmother to Jane and had even looked after her as a baby because of her mother's postnatal depression. Jane went back to College at the end of the weekend with the barest mention that Sarah had gone to heaven. She was not involved in the funeral, and no-one mentioned Sarah's name again in Jane's presence.

**Paul** was 22 when his younger brother, Mark, left home to go to university. Later the same year his older sister got married and moved away from the neighbourhood. Life at home was very different for Paul and his parents. He missed the companionship of his brother and the regular visits of his friends. His brother always stood up for Paul, and Paul's own social activities had relied considerably on Mark's support. Paul began to wet the bed regularly, and one day he smeared faeces on the bathroom wall. One day he got lost on the way home from his part-time job. His mother was so worried about him that she went to talk to Paul's GP about him and he referred him to the Specialist Community Learning Disability Service.

## **Causes**

People looking after someone with learning disability who is depressed usually want to know why. The reasons differ from one person to the next, and often there is more than one cause.

### **Loss**

Although depression sometimes strikes out of the blue, it is often triggered by some unhappy event such as a bereavement, or a favourite carer leaving. These events affect most people with learning disability at some time, although not everyone gets depressed. Sometimes one loss can then lead on to other major changes. For example, after parents have died, people with learning disability are often moved to emergency residential care. This means they lose their home, their familiar possessions and routines, as well as their parent and carer.

Many people with learning disability find change difficult to cope with. Routine can be important but often other people make decisions which affect their lives without any warning or any personal choice or control.

Usually people can work through their feelings about an unhappy event and come to terms with it. People with learning disability will probably need help to do this. Sometimes a more serious and persistent depression develops. This is a particular risk for people with learning disability because carers often miss the early signs of depression.

### **Health Problems**

Physical illness or simply the presence of a long term disability may trigger depression. Often it is a combination of illnesses which take their toll over a number of years. Although this may make the depression more understandable, it doesn't mean that treating any associated depression is a waste of time!

Sometimes depression may be provoked by the body's chemistry being affected by a physical illness such as an underactive thyroid gland. Sometimes drugs prescribed to treat another condition can make a person depressed. The GP is well placed to check these things out.

### **Abuse**

People with learning disability are at risk of being neglected and physically or sexually abused, because they cannot easily protect themselves, or may not be able to tell other people what has happened. Abuse may lead to depression.

## **Other factors related to depression**

Personality may play a part in depression with some people seeming to be more vulnerable than others, perhaps because of the way they were raised or because they were born with a depressive tendency. Generally speaking, women get depressed more often than men. Hormones probably play a part, as with monthly mood changes before each period. Some people who get depressed will also have times when they are elated and overactive. This form of depression, known as manic depression, tends to run in families.

## Getting help

First you have to be aware that your friend or relative may be depressed. The time to get help is when any changes in behaviour, withdrawal or gloom have gone on for some weeks. Then you should seek professional help. Most family doctors are quite used to dealing with emotional problems. But very few family doctors will have had training in how to recognise depression in people with learning disabilities. So don't forget that you are the expert when it comes to telling the doctor about the changes you have noticed in the person you are worried about. You may have to explain that the depression is not part of the condition which caused the learning disability, but is something new and different.

The doctor will probably appreciate your being present to help explain what has been happening. It may be necessary for a psychiatrist who has special training in working with people with learning disability to be consulted.

In severe depression, most people feel that life is not worth living. Thoughts or actions suggesting that people may want to harm or even kill themselves should always be taken seriously - they mean help is definitely needed. However, changes in mood or behaviour may be caused by problems other than depression, so it is wise to have a careful health check by the GP, before deciding that any changes are due to depression. Physical illness and chronic pain are themselves causes of depression in some people with learning disabilities, and both physical as well as emotional illness will need attention.

## Prevention

Bereavement or other major changes in life are probably the most common causes of depression. Although it is not possible to protect people with learning disability from events of this kind, proper preparation and explanation can help to prevent them becoming too distressed. Moving from home to live in the community, separation from families, siblings leaving home, the loss of a favourite care worker, the need to adapt to frequent staff changes or the moves of other residents, are familiar experiences for people with learning disability. Often, greater stability could be achieved through better planning or organisation of resources, to make as few changes as possible. If this is not possible, more attention to explaining (in whatever way is most

suitable) why, what, when, or where changes will take place, and who they will involve, can greatly reduce stress and anxiety. Helping people to express their worries and feelings, at the level that suits them best, can also help to reduce, or even avoid many problems.



## Treatment

### Psychological Approaches

Psychological approaches play an important role in the treatment of anyone who is depressed. The opportunity to talk about problems, and finding practical ways of dealing with them, are essential parts of treatment. Counselling and psychotherapy can be very successful with people with learning disability too, as long as they are adapted to their levels of communication and understanding.

Books, photographs, pictures or drawings, for example, may help them to understand or explain their feelings better than words alone can do. Sometimes, people with severe learning and communication disability cannot be helped in this way. Instead treatment may need to concentrate on changing the people or the surroundings where they are living. For example, Jane got much better after a family meeting in which her aunt's death was discussed and to which her parents brought some photographs of Sarah (Jane's aunt). She



needed some bereavement counselling but gradually began to enjoy a more ordinary life. Paul slowly improved after it emerged that he had got lost looking for his sister's new house. With the support and understanding of his family, he was helped to develop a new circle of friends who enjoyed similar leisure activities to himself. With the help of local learning disability services, he and his family began to explore how he could leave home too, and the support he would need. Psychological approaches need not rule out other

methods, such as medical treatment. There is no point in trying to do without drugs if they are needed.

### Drug Treatment

When depression is severe, for example when there is loss of weight and poor sleep, an anti-depressant drug will be needed. The doctor who prescribes the anti-depressant drug will warn the person with learning disability or carer about common side effects such as a dry mouth or feeling a bit drowsy or dizzy. The doctor will also want to know about any other medications, including any from the chemist, that are already being taken. Anti-depressants can take up to 4 weeks to have their full effect. They should be taken for at least 4 to 6 months after the depression has lifted, for it may reappear if the tablets are stopped too soon. The prescribing doctor, usually the GP, will see how the treatment is going with regular appointments and will advise on when to stop the tablets. Please see our leaflet on [antidepressants](#) for more information.

### Social Support

Loneliness or lack of anything interesting to do during the day may be a cause of depression, or can make depression worse. Help from Social Services, voluntary organisations, parent groups and other support groups will be needed to deal with such problems.



Derek became much less distressed and anxious after being given anti-depressant medication, but he still remained very resistant to being approached by anyone. A special programme was developed to help him gradually tolerate the presence of other people. For Sandra, after anti-depressant medication had successfully reduced her general distress, a more stimulating daily

programme in her residential home, reduced the amount of hair pulling and picking. Opportunities for greater contact with her mother were also supported.

## Getting better and staying well

The cases of Derek, Sandra, Paul and Jane show how as well as medical help, attention to other aspects of daily life are needed if progress is to continue. The quality of life for many people with learning disability is often limited and unstimulating. They may only receive the attention they need when their behaviour gives rise for concern. If their emotional and practical needs are not then met, such problems are likely to re-emerge. So any treatment must also focus on ways of improving the general quality of their lives.

## Problems

Although depression in people with learning disability can usually be treated successfully, it is not always possible to get back all the skills that have been lost, especially if the illness has lasted a long time. Some people may get into a pattern of doing less, or of avoiding certain activities. Too much pressure to return to how things used to be will not help them. Derek, for example, had been severely depressed for almost 2 years before he received the right sort of treatment, and during this time, he had almost completely stopped talking. Although he then made good progress, he has never gone back to talking in the way he used to. Attempts to make him talk just made him very anxious again but he now communicates willingly in writing instead. For Paul, life could never be the same without his brother and sister at home. His supporters needed to help him make the transition from adolescence to adulthood.

## What can you do to help depressed people?



**DO** ask for help. It's not normal for someone to feel depressed just because they have a disability.

**DO** be patient and remember that depression is an illness, and that most people get better.

**DO** make sure they keep taking any tablets they are on, but watch out for any side effects and report these to the doctor or nurse immediately.

**DO** listen to how they feel, and if they are having counselling, help them to keep their appointment.

**DO** encourage eating and drinking properly - the right nourishment and enough of it. People with depression often lose weight.

**DO** encourage going out and joining in activities they have previously enjoyed, but don't bully them into doing things.

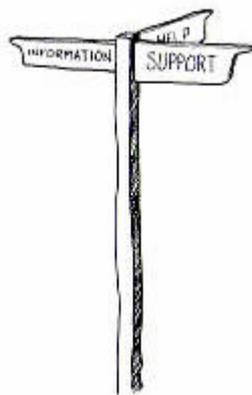
**DON'T** forget your own needs - it can be very wearing living with a depressed person. Talking to other carers can be helpful, as can having regular breaks.

**DON'T** think depression is a slur on the family or on your care. Be clear that it is not a form of madness.

**DON'T** make decisions about a change of home when someone is depressed. It's much harder to cope with a move at such a time.

If your doctor suggests ways in which you might help to deal with some of the problems, do try to carry these out.

## Organisations that can help



**AFASIC - Association for speech impaired children:** 347 Central Markets, London EC1A 9NH.

**Carers National Association:** Ruth Pitter House, 20-25 Glasshouse Yard, London, EC1A 4JT. Tel: 020 7490 8818 Helpline: 0345 573 369 (Monday to Friday 10am-12 noon & 2pm-4pm)

Fax: 020 7490 8824 Email: [internet@ukcarers.org](mailto:internet@ukcarers.org)

To help anyone who is caring for a sick, disabled or elderly frail friend or relative at home.

**Change:** Unity Business Centre, Units 19 & 20, 26 Roundhay Road, Leeds, LS7 1AB. Tel +44 (0)113 243 0202. Fax: +44 (0)113 243 0220. Email: [changepeople@btconnect.com](mailto:changepeople@btconnect.com).

CHANGE fights for the rights of learning disabled people especially people with learning disabilities who are deaf or blind.

**CRUSE - Bereavement Care:** 126 Sheen Road, Richmond, Surrey TW9 1UR. Tel: 0870 167 1677 (national phone number)

**Down's Syndrome Association:** Langdon Down Centre, 2a Langdon Park Teddington, TW11 9PS Tel: 0845 230 0372

The Down's Syndrome Association is a membership led and driven organisation, open to anyone who wishes to join. Full membership which confers voting rights, is open to parents, adults with Down's syndrome and their carers.

**Mencap:** 123 Golden Lane, London EC1Y 0RT. Tel: 020 754 0454 Fax: 020 7696 5540

**Mind:** Granta House, 15-19 Broadway, London E15 4BQ

Tel: 020 8519 2122 Fax: 020 8522 1725 Email: [contact@mind.org.uk](mailto:contact@mind.org.uk)

Mindinfoline: 8522 1728 (London) 08457 660163 (outside London area codes)

**National Autistic Society:** 393 City Road, London EC1V 1NG. Tel: 0845 070 4004 Fax: 020 7833 9666 Email: [nas@nas.org.uk](mailto:nas@nas.org.uk)

Exists for the provision of support for children with autism and their carers. Aim is to encourage a better understanding of autism and to pioneer specialist services for people with autism and those who care for them.

**Mind Cymru:** 3rd Floor, Quebec House, Castlebridge, Cowbridge Road East, Cardiff CF11 9AB Tel: 02920 395123.

**Rural Minds:** c/o South Staffs CVS, 1 Stafford Street, Brewood Staffs ST19 9DX

Tel: 02476 414366 Fax: 02476 414369 Email: [ruralminds@ruralnet.org.uk](mailto:ruralminds@ruralnet.org.uk)

Publishes a wide range of literature on all aspects of mental health.

**Samaritans** P.O. Box 90 90, Stirling, FK8 2SA Tel: 08457 909090 in the UK or 1850 609090 in Eire (the number of your local branch can be found in the telephone directory)

Samaritans is a registered charity based in the UK and Republic of Ireland that provides confidential emotional support to any person who is suicidal or despairing; and that increases public awareness of issues around suicide and depression.

## Suggested reading

### **WHEN MUM DIED or WHEN DAD DIED**

by S. Hollins & L. Sireling (1994) 2nd Edition. Books Beyond Words, The Royal College of Psychiatrists.

### **SKALLAGRIGG**

by W. Horwood (1988) Penguin.

### **AM I ALLOWED TO CRY? - Study of Bereavement amongst People who have Learning Difficulties**

by M. Oswin (1991) Souvenir Press.

---

Original leaflet produced with the help of an educational grant from The Down's Syndrome Association

---

Copyright: © Royal College of Psychiatrists, 1998

Illustrations by Martin Davies Leaflet last revised: 1996  
Online edition updated with minor amendments July 2001