

About my friend

This booklet is for you if your friend has dementia.

Dementia is when parts of the brain stop working as well as they did.

It can be upsetting if one of your friends is not the same as they used to be.

This booklet will explain the changes you are seeing in your friend. It will tell you about people who can help.

Other booklets in this series

The journey of life: how people change from babies to older people

About dementia: for people with learning disabilities

About my friend

For friends of people with Down's syndrome and dementia



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About my friend: for friends of people with Down's syndrome and dementia ISBN 978 1 904082 92 7

Down's syndrome and dementia resource pack: for carers and support staff ISBN 1 904082 37 8

About the British Institute of Learning Disabilities

The British Institute of Learning Disabilities is committed to improving the quality of life for people with a learning disability by involving them and their families in all aspects of our work, working with government and public bodies to achieve full citizenship, undertaking beneficial research and development projects and helping service providers to develop and share good practice.

How to use this booklet

This booklet has been designed to help people with learning disabilities understand the needs of their friends or other people they know who have Down's syndrome and dementia.

Ideally, it is helpful to ensure that people with learning disabilities understand ageing and the lifecycle before using this booklet. We would recommend using *The journey of life* booklet first.

This booklet describes the dementia process and how the person may change over time. It starts with the early problems of memory and confusion. It then goes through the additional difficulties that are present at the later stages including the eventual death of the person with dementia. It highlights the need for support at this difficult time.

The booklet can be used with individuals or in small groups. The booklet is written for staff and carers to use with people with learning disabilities. We recommend that you take the individual through the booklet quite carefully before giving the booklet to them. Talking about these sensitive issues, particularly the

deterioration of a friend and their friend's eventual death, can be very emotional for people. Understanding that their friend is changing and is unable to do the things that they have always done is very upsetting, and the person will need a lot of support over a long period. Reading the booklet and discussing its content with carers can help the friend come to terms with the changes. It may also allow them to find ways to help their friend as the dementia progresses.

This booklet has large print text and corresponding pictures of a man with Down's syndrome as he develops dementia. This is to enable people with learning disabilities to see how the same person changes over time. The same person is depicted in *The journey of life* booklet making the two resources compatible. Depending on the ability of the people you are caring for, the words can either be read with them or used as an aid to help you talk about the pictures. Another booklet *About dementia* is written for more able people who have further questions about dementia.



What is dementia?

This booklet may help you to understand about people with Down's syndrome who get dementia.

Dementia is when parts of the brain stop working as well as they did. Dementia is one of the special problems that can happen as people get older.

It can be upsetting if one of your friends is not the same as they used to be.

This booklet will explain the changes you are seeing in your friend. It will tell you about people who can help.



Your friend will start to change

With the start of dementia your friend may not be able to do all the things that they could do.

Your friend may forget things. They may get muddled up.

Your friend may do things that seem odd, like putting things in the wrong place.

You should tell someone about this. Their family or staff can ask for help. Their doctor, nurse or social worker can find the right people to come and talk to them and find out what is wrong.



Your friend will need more help

Later on you may see more changes in your friend.

Your friend may do things more slowly. They may need more help with stairs. They may need more help getting on to buses or down kerbs.

Your friend may need more help to do lots of things they could do, like dressing, washing and doing things they enjoy.

They may need changes in their home, like rails in the bathroom and toilet.

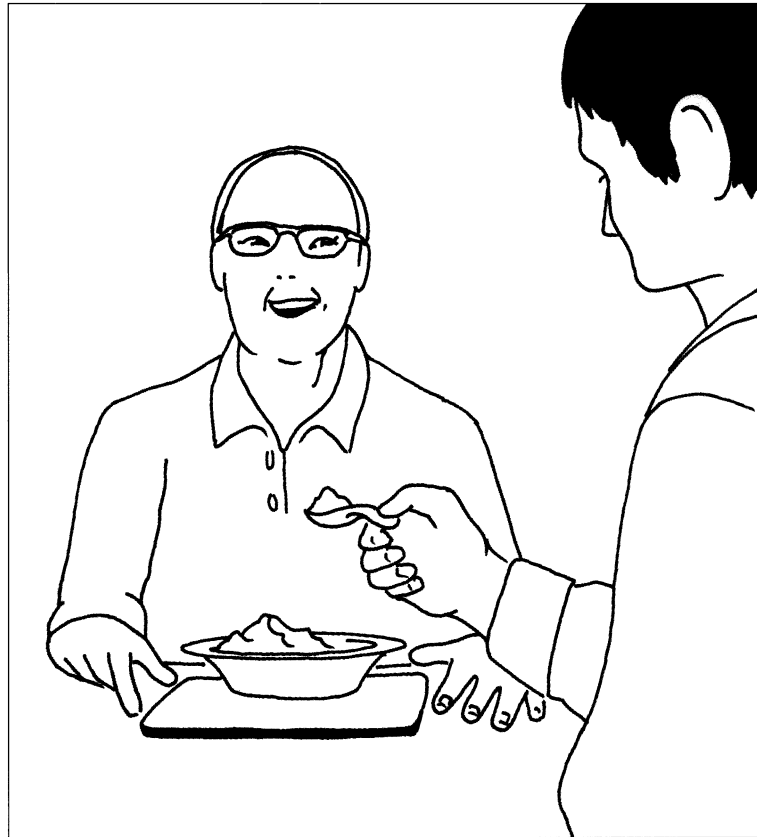


You may be upset or worried

They may need more help with eating and drinking. Sometimes it may be harder to understand what they are saying.

You may get upset and so may your friend. Family and staff might use pictures to help.

Sometimes your friend may not be as friendly. They may say or do strange things. They may shout or hit people. They may cry a lot. This may worry you. Family and staff will help to sort things out.

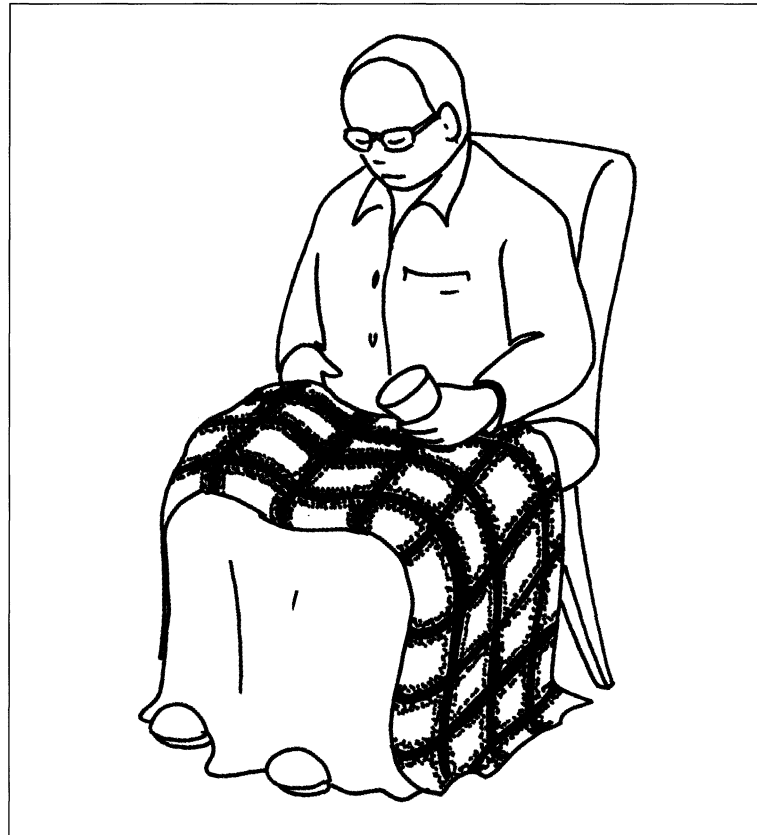


Your friend will change a lot

As time goes on, your friend will change a lot. They may look different. They may need lots of help to do simple things. More people may help with caring for your friend.

Your friend may not remember who you are. They may not know who their family or staff are. This may upset you.

Sometimes they may not be able to stay in their own home. They will need a new home where people can give them more care. If this happens you can go and visit them.

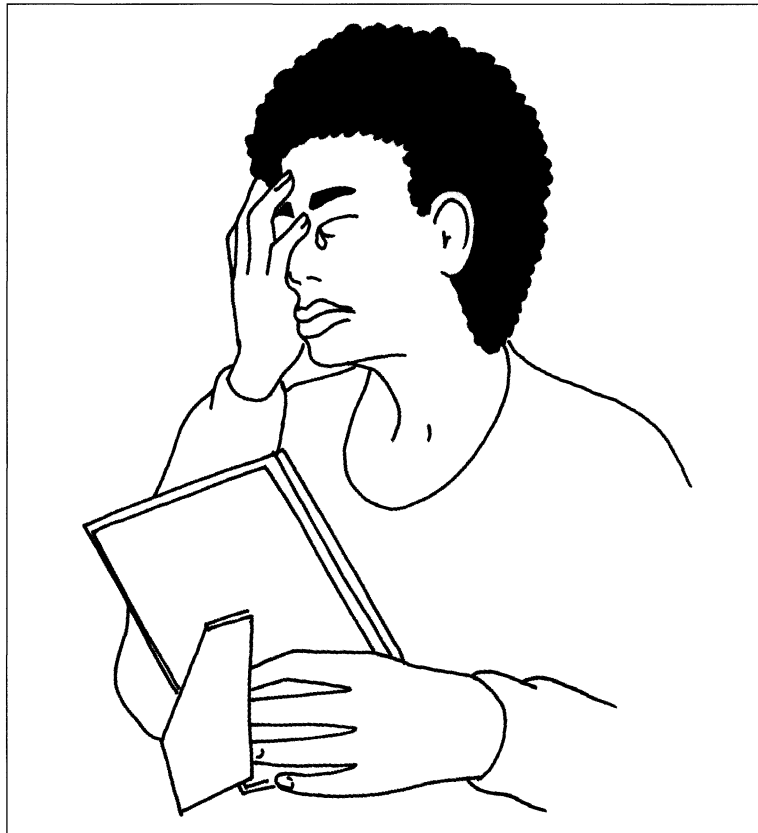
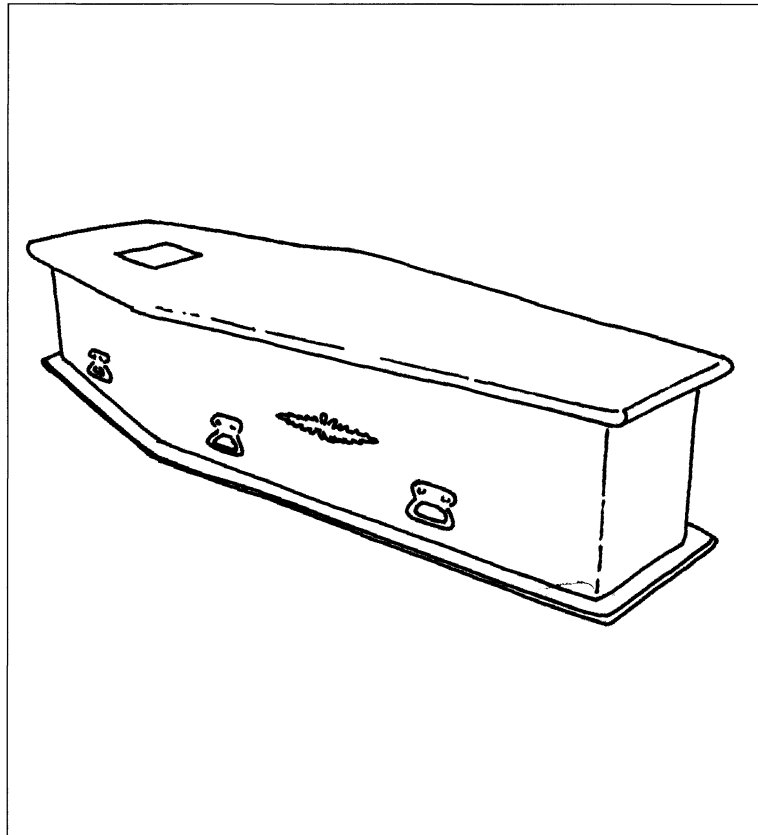


Your friend may sleep a lot

By this time your friend will need someone to wash and dress them and take them to the toilet. They may need to be fed. They may not be able to walk. They may spend more time in bed and sleep a lot.

People may be worried that your friend will die. You may be able to visit your friend and say goodbye.

It is OK to be sad and upset. It may remind you of other people who have died.



When your friend dies

When your friend dies, you can go to the funeral. This is a special service to say goodbye to your friend.

Every funeral is different. You can talk to your family or staff about it and what will happen.

Most people feel sad for a long time. It is OK to cry.

It may help to look at photos. You can think about the good times you had together.

It is important to talk about your friend.

