



The
milk's
in the
oven

Semi-Skimmed Milk
Pasteurised • Homogenised
LESS THAN 2% FAT

A booklet about dementia for children and young people

Mental Health Foundation



Welcome to The Milk's in the Oven

Lots of people helped with the researching and writing of this booklet. Young people said what they thought about dementia and growing older (there are comments from them throughout the booklet). Some of the families, friends and carers of people with dementia said what it was like for them knowing someone with dementia. People with dementia also contributed remarkable and moving insights to their thoughts and feelings.

This booklet was originally written by Lizi Hann and published by the Mental Health Foundation in 1998. We have updated the original version and are grateful to Alzheimer Scotland for their support in making this possible.

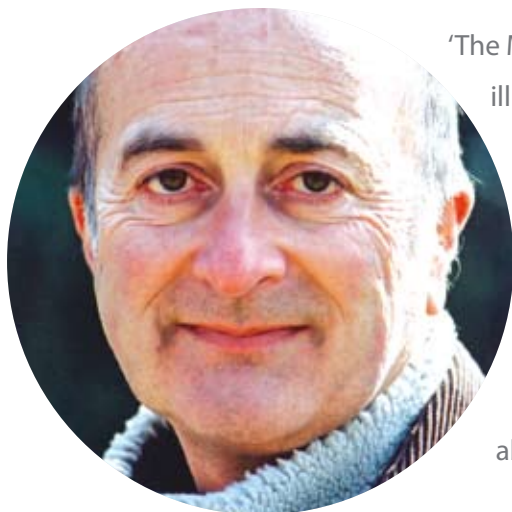


Alzheimer Scotland
Action on Dementia

Andrew McCulloch

Dr Andrew McCulloch
Chief Executive, Mental Health Foundation

Introduction by Tony Robinson



'The Milk's in the Oven' is about an illness called dementia. Although it almost always happens to older people, it's important that we all know about it. We should all try to learn what happens to people who develop dementia and think about how we can help them.

Some of you may know somebody who has dementia. Maybe they live with you and you help to take care of them. If so, you won't need me or anyone else to tell you how difficult and upsetting it can be. You want to look after people you love, but it's not easy to know what to do for the best when someone has dementia. Often people with dementia forget how to do things, so they might put the milk away in the oven, instead of the fridge. Sometimes you feel really angry because nothing you do seems to make any difference. The booklet tells you about how people with dementia behave and feel, and gives you a few ideas to try and help you understand more.





If you don't know anyone who has dementia, read this booklet anyway. Your mum or dad or a teacher might want to read it as well and talk about it with you. You might find out that one of your friends has a granny or grandad with dementia - I'm sure it would really help them to be able to talk to you about it.

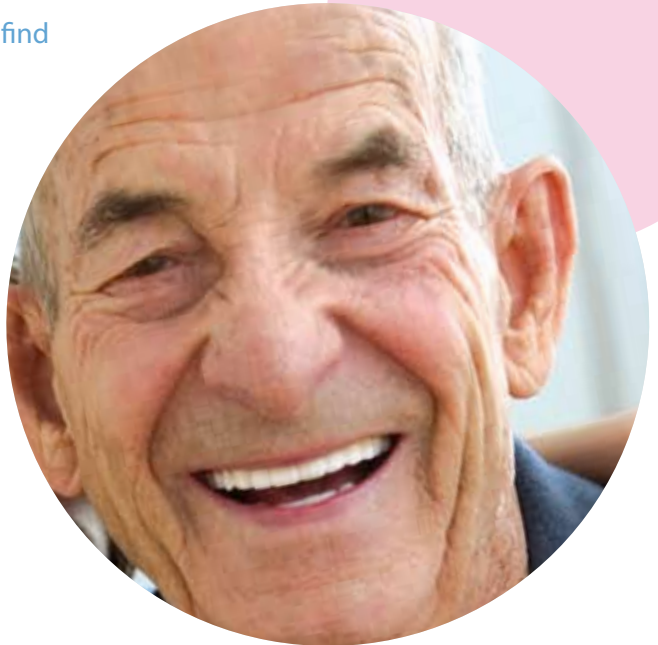
I know what it is like to live with someone who has dementia and how important it is for other people to understand. Both my mum and dad had dementia and I found the whole thing really difficult to cope with. People with dementia can act strangely. Sometimes this is quite funny, but sometimes it's frightening or embarrassing. However they behave, it's much easier to deal with if you understand why. I hope you will spend a little while reading this booklet - it'll really make a difference if you do.

Tony Robinson

What is dementia?

Dementia is caused by different illnesses which affect certain parts of the brain. When someone has dementia, they may find that:

- their memory gets worse and worse
- they become muddled and confused
- after a time, they may find it difficult to do things they used to do, like getting dressed, or making a meal.





How would you describe what memory is?

We asked some 9 and 10 year old children how they would describe memory. Here is what some of them said:

- a part of your brain that stores important things
- something that helps you remember stuff
- a store cupboard that can lose things
- a dark place with lots of things
- pictures left in my head
- a thought of the past
- fix it in my mind
- remembering

What do you mean by memory?

Memory is a very important part of all of us. It helps us to make sense of the world around us.

Our memory helps us to know who we are, where we are and what we are doing.

Our memory helps us remember things like:

- how to dress ourselves in the morning
- the names of our friends and families
- the letters in the alphabet
- where we live
- what the date is

In fact, it helps us store everything we need to know to live our lives. So, if someone has dementia they become more and more muddled and confused.





So how might someone behave if they are muddled and confused?

Often people with dementia forget how to do things - for example, they might put the milk away in the oven, instead of the fridge, or mistake the fridge for the washing machine.

They may lose their way in places they know, get dressed in the middle of the night or set off to find a place or people that they remember from the past. For example, they may think they are going off to school, as they used to do many years ago.

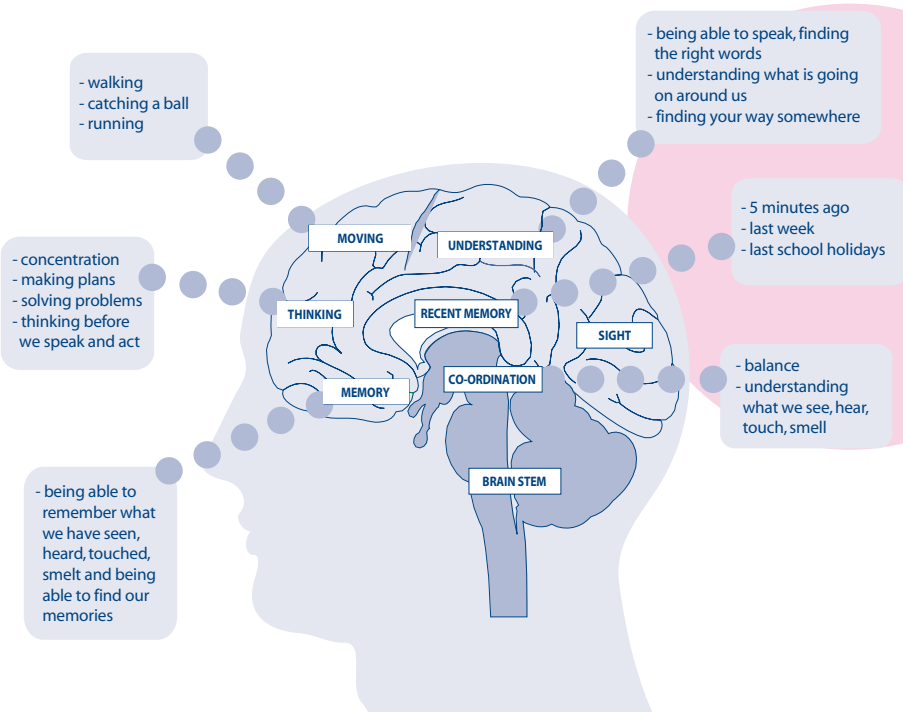


They may become confused when using things like the telephone and forget which day of the week it is.

When someone has dementia, they will find it gets harder to make sense of the world around them.

Why do people get dementia?

As you probably know, our brain is a very complicated organ. It has many different parts which help us to do many different things.



It helps us to do things like:

think, move, speak, write, play sport, play computer games

In fact, it controls everything that we do every moment of the day. So if something goes wrong with part of our brain, then we are going to find it very hard to do certain things.





Inside our brain are millions of brain cells (called neurons). When someone has dementia it is because some of these brain cells have become damaged and started to die.

Once these brain cells are dead, they cannot grow again, so this affects what the person with dementia is able to remember, think and do. This is why they find it harder to do all the different things that they used to do every day.

There are many different kinds of dementia and many different reasons why people get the disease. The different kinds of dementia have different names. If you know someone with dementia, you might hear names of different kinds of dementia and wonder what these are. It could be Alzheimer's disease (named after the doctor who first identified it), or it could be vascular dementia (named after the blood vessels in the brain which get changed).

Most people with dementia have either one of these two kinds, but there are other kinds. Mostly, the ways dementia changes people's lives are similar.

It is important to remember that people cannot catch dementia, like they can chicken pox or flu. Also, if a member of your family has dementia, it doesn't mean you are more likely to get it. Most cases of dementia do not run in the family.

Sometimes we might know what might be causing dementia, so we can try to treat the person with medicine or pills, but at other times we just don't know why the brain cells become damaged and die so that, bit by bit, the brain stops working as well as it used to. Medicine or pills may help some people for a while but they do not cure people. Scientists and researchers are doing a lot of work to try and find out why dementia happens to some people and not others.





How does someone with dementia feel?

"Nothing really makes sense to me now."

(Rachel – 79 years old – has dementia.)

This quote shows the confusion that Rachel feels.



Exercises – What does having dementia feel like?

Here are two exercises that people who are learning how to care for people with dementia sometimes do. It helps them to imagine what dementia feels like. Try it for yourself.

Exercise One:

Sit or lie down. Close your eyes. Imagine you are in the middle of a thick, thick fog. Sit still and quiet and listen to all the sounds around you. What can you hear? Maybe cars, people's voices or the television? Listen for a couple of minutes, soaking up all the sounds.

Now keeping your eyes closed, imagine that you no longer recognise the sounds, they are all coming at you in a jumble. Imagine that the volume has been turned up, that someone is spinning you round and round, and you feel frightened and confused. You don't know where you are, who anybody is and what all the sounds mean.

This is what someone with dementia can feel like.





Exercise Two:

Close your eyes again and imagine what it would be like getting ready for school when you can't remember where you put your shoes, don't know the way to school or what you are supposed to do when you get there.

Now and again it will feel as if the fog lifts and people with dementia can suddenly make sense of everything for a moment. But then the fog comes down and they feel lost again.



Here are some of the words used by people who have dementia to describe how they feel:

angry
lonely
irritable
depressed
worthless
helpless
confused
frightened
useless
embarrassed

Many people with dementia know that something is wrong, especially during the early stages. They are losing a lifetime of stored memories, and there is nothing they can do about it. So it is understandable that they feel some of these emotions.





So what might it feel like to lose your memory?



“My memory, it slims away.”

We talked about memory at the beginning of the booklet. We know that it is very important to us. So what do you think it would be like if you found your memory fading away?

We asked some children “What do you think it would be like to lose your memory?”

This is what they said:

- dark, blank head
- you won't remember anything and you'll be lost
- crazy, weird

- annoying
- terrible
- sad
- good because you forget your bad memories and bad because you forget all your family
- not funny - you would miss the ones who you loved for a long, long time.



Someone with dementia might agree with some or all of the above statements. Sometimes it may well feel like they have a 'dark, blank head', and sometimes they will struggle to remember the names and faces of their family.

It is very important to remember that the person with dementia still has thoughts, feelings and emotions. But these thoughts, feelings and emotions are all jumbled up.

Sometimes they will be able to remember something that happened many years ago, as if it was yesterday, and at other times they will feel as if they are surrounded by the thick fog that we talked about at the beginning of the chapter.





Everyone who has dementia is different

“These people have lived for a long time, they have been babies, children and adults. Many have been through a world war. In their time they have seen man go to the moon, aeroplanes built, cars become part of everyday life, televisions, DVDs, mobile phones and the internet all appear.”

Psychiatric nurse

It is easy to forget that the person with dementia is still an individual. They have their own thoughts and feelings and their own ways of coping with their illness.

Let's think about you for a moment. Sit and think about these questions:

What is your favourite food?

Who is your favourite band/singer?

Which football team do you support?

What makes you happy?

What makes you angry?

What is your best subject at school?

No two people will have the same answers to all of these questions.

As you grow older, all the experiences that you have throughout your life - starting from the moment you are born - become part of your life.

These experiences help to shape your character and personality and this is what makes each of us different and special in our own way.

Everyone with dementia has their own character and personality, even if it seems hidden and changed because of the dementia. Sometimes it will seem as if they are a completely different person from who they were before, but they are not blank people with blank minds.





It's easy to forget that people with dementia have a past.

Talking to someone with dementia about their past - even for a few minutes - can give them a lot of pleasure and helps us to remember they have led a full and active life. It also helps to make their present worthwhile.

How do the people around them feel?

On the opposite page is a list of words. People who know someone with dementia have used these words to describe the way they feel.

Those of you who know someone with dementia - especially if it is someone you know very well, like your grandparent, or another member of your family - may well have felt some of these feelings yourself.

When something is different, when something happens to someone that we don't understand, we all feel confused and frightened.

When it is someone that we love, we want to help and might start to feel useless and frustrated if we can't. When the person with dementia behaves in a way that we don't expect, we can feel embarrassed, frightened or angry - and then we feel guilty for feeling all of these things!

It can be very difficult time for everyone.

Here are some of the words used to describe how people who know someone with dementia have felt:

guilty **frustrated**
helpless **embarrassed**
confused **angry**
frightened **lonely**
useless **sad**





Did you notice how similar these words are to the ones used on page 14 which describe how people with dementia say they feel?

Sometimes the person with dementia will make you feel frightened, embarrassed or angry - try to remember that they will probably be feeling the same way as you, even if they do not say so.

What can I do about these feelings?

All these feelings that we have talked about are perfectly natural. It is part of life, and part of coping with things that go wrong to feel sad, frustrated and angry.

But there are some feelings that we have talked about that we can do something about:

Feeling confused: once you have learnt something about what the person with dementia is going through, it will help you to feel less confused about why they behave the way they do.

Feeling angry and frustrated: maybe your mum and dad are spending a lot of time with your grandparent (or whoever it is who has dementia) and they don't seem to have much time for you. Remember that the situation is difficult for everyone. Your mum and dad are going to want to do everything they can for the person with dementia. Try telling them how you feel - they may have been too busy to notice and will be pleased you have told them - they have probably been worrying about you too!

Feeling embarrassed: a lot of people don't understand what dementia is, and they won't understand what you are going through. You might feel ashamed of your grandparent and not want other people to see them behaving so strangely. But remember, the person can't help having dementia, any more than if they had caught chicken pox or the flu. Maybe you could explain to your friends what your grandparent is going through and help them understand about dementia.

Feeling guilty: there are times when you might feel guilty. This might be because:

- you feel you aren't doing enough to help
- you feel like you don't love your grandparent (or the person with dementia) any more, they just irritate or embarrass you
- you just don't want to spend any time with them because it's too difficult





You can be sure that your mum and dad (or whoever is looking after the person with dementia) also feel the same way sometimes. It is difficult to like or love someone when they have changed so much, especially if they don't seem to know who you are anymore. Remember that you can only do as much as you feel able to. Talk about it - you are not alone!



Feeling useless: there is never any need to feel useless. There are things you can do to help the person with dementia - it will not cure their dementia, but it will certainly help them to feel loved and wanted.

What can we do to help?

The most important thing you can do for the person with dementia is to make a little bit of time for them.

Whether they are living in their own home, in a care home, in hospital or with you and your family, time is the most important thing that you can give to the person with dementia. And it doesn't have to be much - five minutes of sitting and chatting, or showing them a picture you have drawn, or a photo that they may recognise could make a world of difference. Here are some other ideas:

- go for a short walk together
- make a scrap book for them of past and recent events
- play music together - maybe you play an instrument, or they have a favourite record/CD that you could play
- write a simple diary together to help them remember what's happening now, something you have done together
- just sit and hold their hand for a few minutes - it can feel very comforting and reassuring to have your hand held





Of course, all these things may not be possible all of the time, and there may be days when you just don't feel like spending any time with them. That's fine too - you can only do as much as you feel like doing.

Here are some ideas that children came up with:

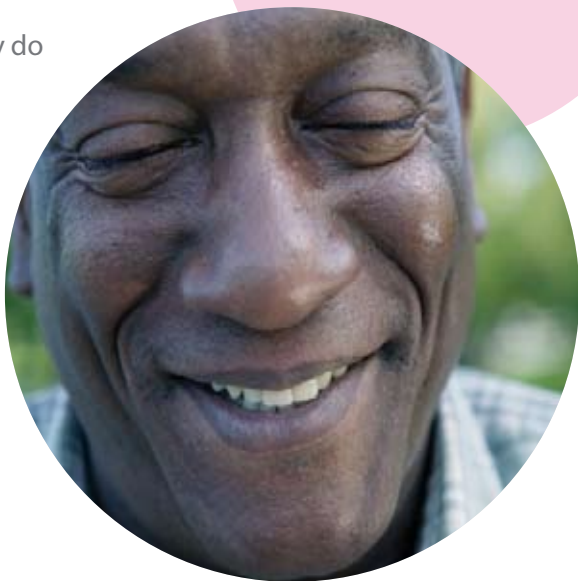
- **visit them, help with shopping - anything**
- **support them**
- **listen to them**
- **make them happy**
- **be good to them**
- **help them out - be kind to them**

But if they don't remember who I am what's the point?

Some days will be harder than others. It depends how long the person has had dementia. As the dementia gets worse they will find it more and more difficult to remember names and faces, even of their family and friends.

This can be very upsetting and you might wonder *"what's the point in spending time with them?"*

But there will be times when they do know what's going on. This could be in the middle of the night, or when they have a moment alone, or when you are with them. It will give them a great deal of happiness to know that you care about them.





For a person with dementia to know that they are loved, respected and cared for by their family is probably the most important thing in their life.



How would you like to be treated when you are older and less able to look after yourself?

No matter how old someone is or how ill, they are still a person. And even though they may not always show it, they are people with feelings - just like you and me.

We should always treat a person with dementia just as we would like to be treated when we are older.

We asked some children how they would like to be treated when they are older. This is what they said:

- looked after
- like a King
- very nicely, because I'll be fragile
- nicely, kindly
- with respect and kindness
- like a young man
- normally
- to be respected
- I would like to be treated decently
- I would like to be treated with love





Sometimes it is difficult to treat someone with respect and kindness when they have dementia. They might be rude to you, shout at you or simply not recognise you. Always remember that it is their dementia making them behave that way and that it's not your fault, and it's not their fault. All you can do is your best.



Dementia and the future

Lots is being done in the scientific and medical world to try and understand dementia and to find more ways to help people and to find a cure. Until there is a cure and a way to prevent people ever getting dementia, lots more needs to be done to help everyone understand dementia and to make sure the best kinds of help are available from family members, friends, doctors, nurses, care staff and others.

We can all try to help people who have dementia by being as understanding as we can, helping them whenever possible and telling other people what we have learnt about dementia.

Most of all though, it's important to remember that, even though a person who has dementia might act in a way that is upsetting or confusing sometimes, they are still the same person that they always were.

Exercise Three:

Who do you think needs to know about dementia?

Think of every kind of person you can.

What do you think they need to know? Try and think of everything that would help different kinds of people.





Useful contacts

AGE CONCERN ENGLAND

Astral House
1268 London Rd
London SW16 4ER
020 8765 7200

www.ageconcern.org.uk

Helpline: 0800 00 99 66

Provides advice on a variety of older people's issues, such as benefit entitlements and legal concerns. Can also help you find local support groups. Helpline open 7am-7pm every day.

AGE CONCERN CYMRU

Ty John Pathy
13/14 Neptune Court
Vanguard Way
Cardiff CF24 5PJ

029 2037 1566

www.accymru.org.uk

AGE CONCERN NORTHERN IRELAND

3 Lower Crescent
Belfast BT7 1NR
028 9024 5729

AGE CONCERN SCOTLAND

Causewayside House
160 Causewayside
Edinburgh EH9 1PR
0845 833 0200

www.ageconcernscotland.org.uk/

Helpline: 084 5125 9732

ALZHEIMER SCOTLAND

22 Drumsheugh Gardens
Edinburgh EH3 7RN
0131 243 1453

www.alzscot.org

Alzheimer@alzscot.org

Helpline:

0808 808 3000

Scotland's leading charity for people with all forms of dementia and their carers. Helpline open 24 hours.

THE ALZHEIMER'S SOCIETY

Gordon House
10 Greencoat Place
London SW1P 1PH
020 7306 0606

www.alzheimers.org.uk

enquiries@
alzheimers.org.uk

Helpline:

0845 300 0336

The leading UK care and research charity for people with dementia and their carers. Produces an extensive range of fact sheets on all aspects of dementia, and runs a national network of support groups and other services through its local branches. Its helpline is open 8.30am-6.30pm Monday to Friday, offering advice, information and support for everyone affected by dementia. Its website features a chatroom for people to exchange thoughts and feelings.

BRITISH RED CROSS

44 Moorfields
London EC2Y 9AL
0870 170 7000

www.redcross.org.uk

Offers crisis respite sitting services, to enable people who care for someone with dementia to take a break.

CHILDLINE

24 hour helpline

0800 1111

A free helpline for children and young people in the UK

www.childline.org.uk

CROSSROADS CARE SCHEMES

10 Regent Place
Rugby
Warwickshire CV21 2PN
www.crossroads.org.uk
01788 573653

Offers support for people with dementia in the home. Trained workers provide free home care.

FOR DEMENTIA

6 Camden High Street
London NW1 0SH
020 7241 8555

Tel: **020 7874 7210**

www.fordementia.org.uk

Promotes nursing care for people with dementia.





**MENTAL HEALTH
FOUNDATION**

Sea Containers House
20 Upper Ground
London SE1 9QB
020 7803 1100

www.mentalhealth.org.uk
mhf@mhf.org.uk

The leading UK charity working in mental health and learning disabilities. Undertakes research, develops services, designs training, influences policy and raises public awareness about all aspects of mental health and learning disabilities, including dementia.

NHS DIRECT

Helpline: 0845 46 47
www.nhsdirect.nhs.uk

Health information and advice service.
Open 24 hours a day.

SAMARITANS

Helpline:
8457 90 90 90
www.samaritans.org

Confidential emotional support for people who are experiencing feelings of distress or despair, including those which may lead to suicide. Helpline open 24 hours a day.

Further Reading

Dear Grandma

1999 published by the Alzheimer Society of Ireland. Available by mail order from:
Alzheimer House
43 Northumberland Ave,
Dun Laoghaire,
Co Dublin, Eire
tel: 00353 1284 6616
email: info@alzheimier.ie
web: www.alzheimer.ie
(Contains a primary school lesson plan)

What's happening to Grandpa?

Maria Shriver,
Little Brown & Co &
Warner Books, 2004
ISBN: 0-3160-0101-5

You are Words

Dementia Poems. Edited and introduced by John Killick. Published by the Journal of Dementia Care, Hawker Publications
tel: 020 77202108
email: remi@hawkerpublications.com

The Granny Project

Anne Fine,
Egmont Books Ltd, 2002
ISBN: 0-7497-4832-X

Granny's little carers

Christine Harwood,
Can be downloaded from the Alzheimer's Society website.
www.alzheimers.org.uk/news_and_campaigns/alzheimers_awareness_week/grannycarers

The long and Winding Road: a young person's guide to dementia

Jane Gilliard,
Wrightson Biomedical Publishing Ltd, 1995
ISBN: 1-8718-1631-9

About my grandfather, about my grandmother

This video shows children talking about their experiences of living and loving their grandparents who have developed a form of dementia. To arrange a viewing, please contact your local branch of the Alzheimer's Society. The video is also available to view at www.alzheimers.org.uk/news_and_campaigns/alzheimers_awareness_week/video.htm

Explaining to children

Alzheimer's Society leaflet can be downloaded at www.alzheimers.org.uk





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Mental Health Foundation

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For more information about dementia, please visit www.mentalhealth.org.uk

To order additional copies of this booklet, please email mhf@mhf.org.uk or call us on 020 78031100

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Sea Containers House, 20 Upper Ground, London SE1 9QB

Tel: 020 7803 1100 Fax: 020 7803 1101

www.mentalhealth.org.uk

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