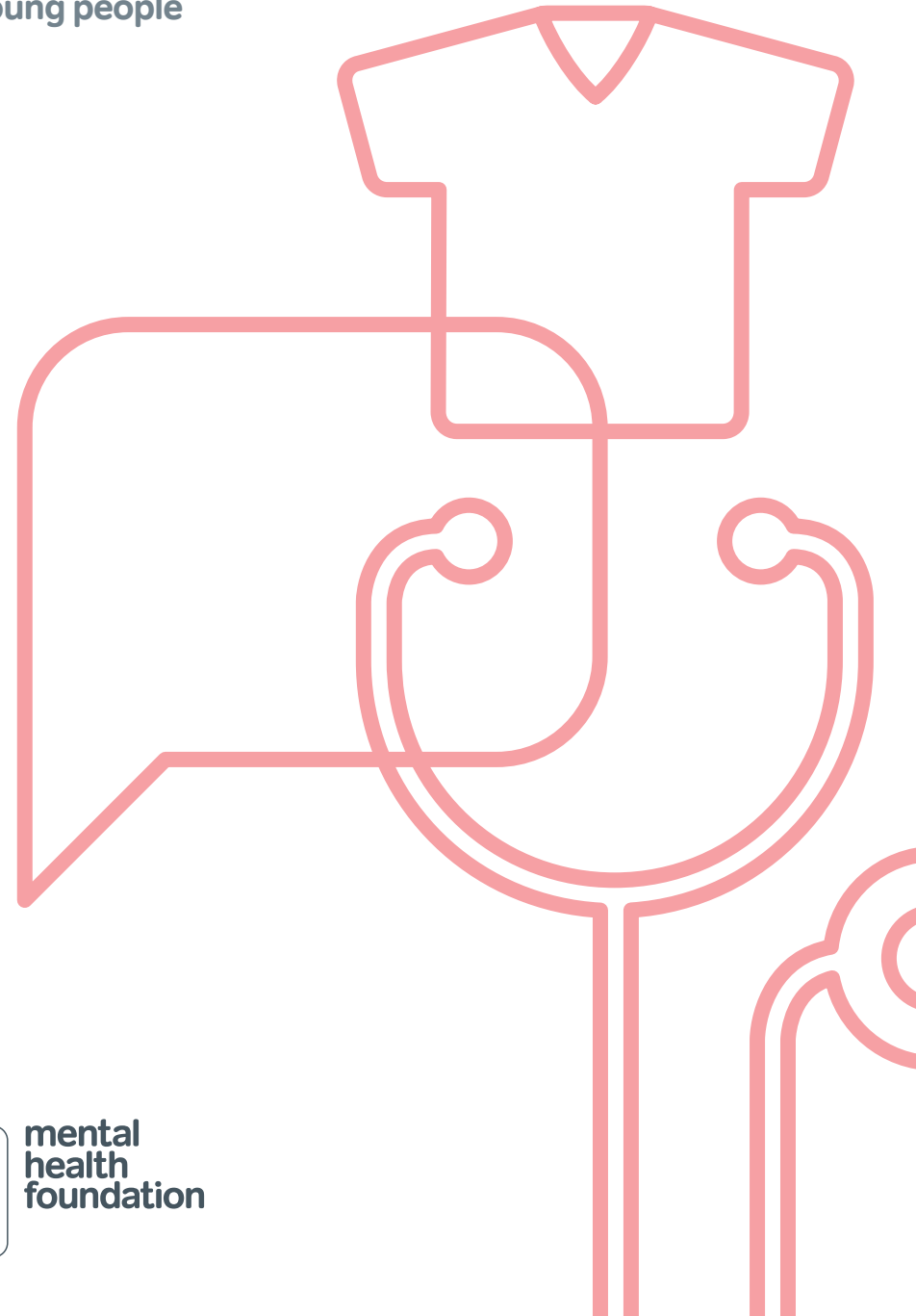




The milk's in the oven

A booklet about
dementia for children
and young people



Mental Health Foundation

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Website
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2350846

changing
minds



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.

Dr Andrew McCulloch
Chief Executive
Mental Health Foundation

Welcome to The Milk's In The Oven

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 a memory is?

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

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



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.

01 Moving

- Walking
- Catching a ball
- Running

02 Understanding

- Being able to speak, finding the right words
- Understanding what is going on around us
- Finding your way somewhere

03 Thinking

- Concentration
- Making Plans
- Solving Problems
- Thinking before we speak and act

04 Recent Memory

- 5 minutes
- Last week
- Last school holidays

05 Sight

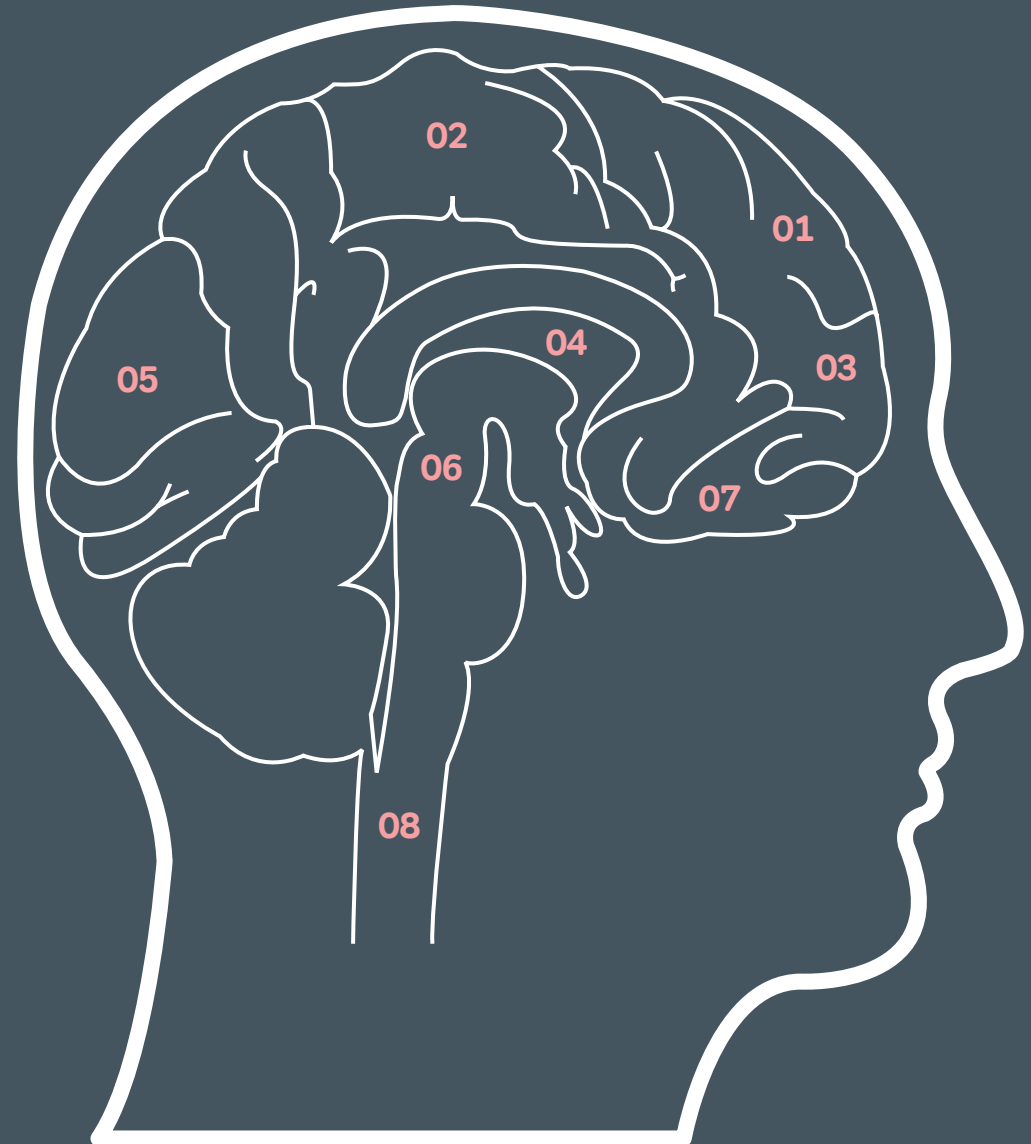
06 Co-Ordination

- Balance
- Understanding what we see, hear, touch, smell

07 Memory

- Being able to remember what we have seen, heard touched, smelt and being able to find our memories

08 Brain Stem



Our brain 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.

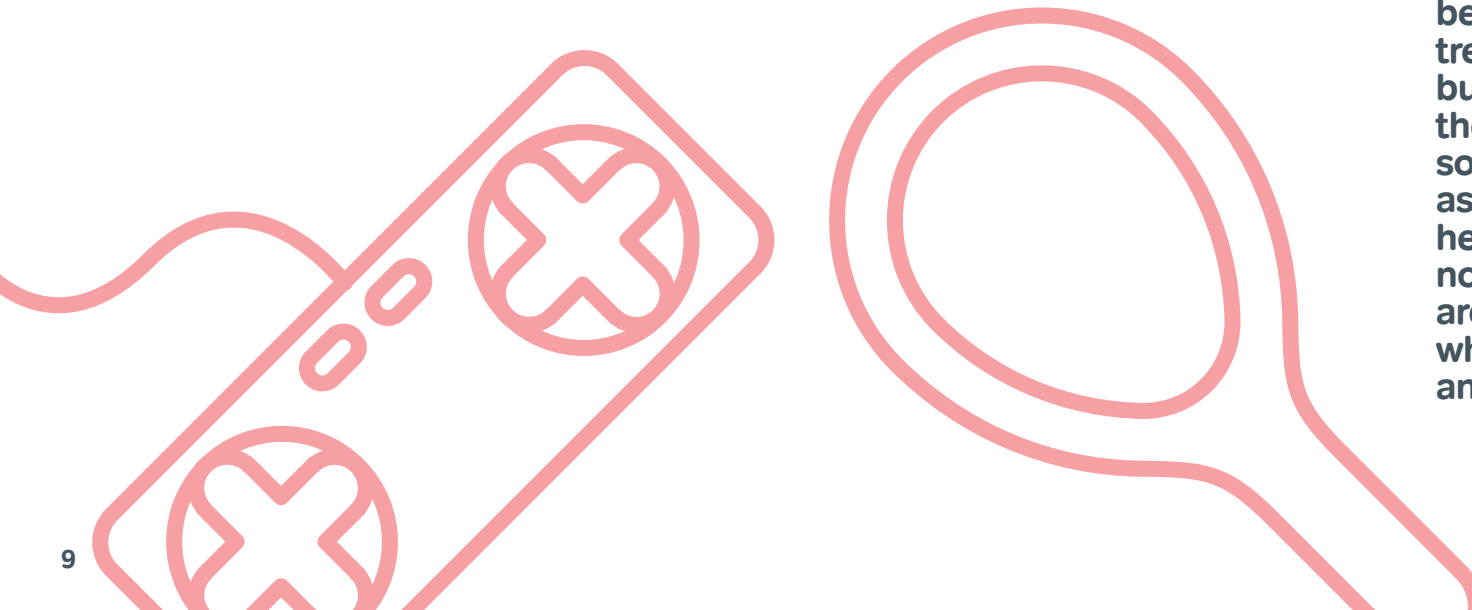
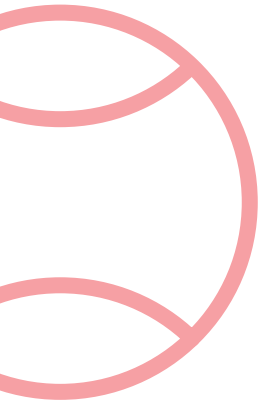
Once these brain cells are dead, they cannot grow again, so this affects what the person with dementia is able to remember, think and do. This is why they find it harder to do all the different things that they used to do every day.

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 damaged).

Most people with dementia have either one of these two kinds, but there are other kinds too. 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 could 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.



‘Nothing
really makes
sense to
me now.’

Rachel – 79 years old – has dementia.
This quote shows the confusion that Rachel feels.

How Does Someone With Dementia Feel?

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 1

Sit or lie down. Close your eyes 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.

Exercise 2

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.

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

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.

‘Confused’ ‘Lonely’
‘Useless’ **‘Depressed’**
‘Worthless’ ‘Irritable’
‘Angry’ **‘Embarrassed’**
‘Helpless’ ‘Frightened’

We asked some children
'What do you think it would be like to lose
your memory?' This is what they said:

'dark' 'blank head'
'crazy' 'weird' 'annoying'
'terrible' 'sad' 'you won't
remember anything
and you'll be lost' '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.'

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?

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.

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 and 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

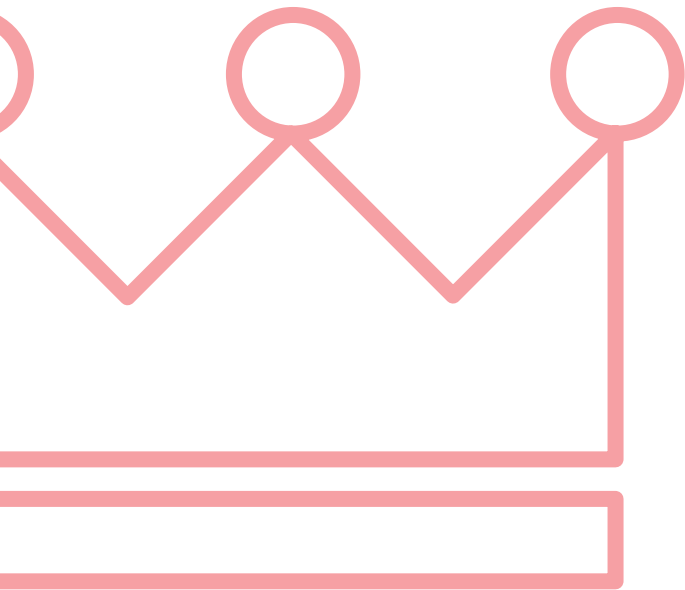
But if they don't remember who I am what's the point? Some days will be harder than others. It depends how long the person has had dementia. As the dementia gets worse they will find it more and more difficult to remember names and faces, even of their family and friends. This can be very upsetting and 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.

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.



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'

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 from 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 3

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 UK

Age UK aims to improve later life for everyone through providing information and advice, campaigns, products, training and research.
www.ageuk.org.uk

Age UK England

York House
207-221 Pentonville Road
London N1 9UZ
Helpline: 0800 169 6565
Contact@ageuk.org.uk

Age Scotland

Causewayside House
160 Causewayside
Edinburgh EH9 1PR
0845 125 9732
enquiries@ageconcernandhelptheagedscotland.org.uk

Age Cymru

Tŷ John Pathy
13/14 Neptune Court,
Vanguard Way
Cardiff CF24 5PJ
029 2043 1555
enquiries@agecymru.org.uk

Age Northern Ireland

3 Lower Crescent
Belfast BT7 1NR
028 9024 5729
info@ageni.org

Alzheimer Scotland – Action On Dementia

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

22 Drumsheugh Gardens
Edinburgh EH3 7RN
www.alzscot.org
Alzheimer@alzscot.org
Helpline: 0808 808 3000

Alzheimer's Society

Leading UK care and research charity for people with dementia and their carers. Publishes a range of factsheets on all aspects of dementia, including information for carers, and runs a national network of support groups and other services for carers through its local branches.

Devon House
58 St Katharine's Way
London E1W 1LB
020 7423 3500
enquiries@alzheimers.org.uk
National Dementia Helpline
0845 300 0336
Mon–Fri 8.30am–6.30pm

British Red Cross

44 Moorfields
London EC2Y 9AL
0844 871 1111
information@redcross.org.uk
www.redcross.org.uk

Crossroads Care

10 Regent Place
Rugby CV21 2PN
0845 450 0350
www.crossroads.org.uk

Offers free home care by trained workers to give carers a break.

Crossroads Caring Scotland

24 George Square
Glasgow G2 1EG
0141 226 3793
www.crossroads-scotland.co.uk

Counsel And Care

Provides advice and information service for older people, their carers, relatives and professionals working with them.

Twyman House
16 Bonny Street
London NW1 9PG
020 7241 8555

Advice line 0845 300 7585
advice@counselandcare.org.uk
www.counselandcare.org.uk

Crossroads Caring For Carers (NI)

7 Regent Street
Newtownards
Co Down
BT23 4AB
028 9181 4455
mail@crossroadscare.co.uk
www.crossroadscare.co.uk

Mental Health Foundation

Sea Containers House
20 Upper Ground
London SE1 9QB
020 7803 1100
www.mentalhealth.org.uk
info@mentalhealth.org.uk

NHS Direct

Helpline: 0845 46 47
Health information and advice service. Open 24 hours a day.

National Council For Palliative Care

The Fitzpatrick Building
188-194 York Way
London N7 9AS
020 7697 1520
020 7697 1530
enquiries@ncpc.org.uk

Dementia UK

6 Camden High Street
London NW1 0SH
020 7824 7200
info@dementiauk.org
www.dementiauk.org.uk

Samaritans

Confidential helpline offering emotional support for people who are experiencing feelings of distress or despair, including those that could lead to suicide.

Helpline 08457 90 90 90
(24 hours)
www.samaritans.org
jo@samaritans.org

Further Reading

Dear Grandma
Alzheimer Society of Ireland,
1999.

This is a story book for children aged eight years and over to help to explain dementia and Alzheimer's disease. The book focuses on two children and their experience with their grandma and the changes that her condition brings.

For copies call
00353 1800 341 341
email
info@alzheimer.ie

www.alzheimer.ie

What's Happening to Grandpa?
Maria Shriver

Kate is becoming increasingly concerned when her beloved grandfather tells her the same stories again and again and then forgets her name. So she creates a photo album of their favourite shared memories to help them both cope with his progressing Alzheimer's disease.

Little Brown & Co, 2004.
ISBN 978 0 31600 101 4

The Granny Project
Anne Fine

Ivan, Sophie, Tanya and Nicholas can't believe it. Their parents are planning to put their grandmother into a home. She's a bit dotty – sometimes demanding, often annoying but she's as much a part of their lives as their shambolic house or the whirring of the washing machine. So they decide to take action and The Granny Project is launched, with spectacular results...

Corgi Children's Books,
2006 (new edition)
ISBN 978 0 55255 438 1

Long and Winding Road: Young Person's Guide to Dementia
Jane M Gilliard,
Tony Robinson

This book was written to explain to children the different forms of dementia and what happens to people with dementia and their families.

It describes how young people may be affected and how they may feel, and offers practical suggestions to help overcome some of the difficulties. Above all, this book aims to dispel the fear and loneliness that may affect young people when someone they love gets dementia.

Wrightson Biomedical
Publishing Ltd, 1995
ISBN 978 1 87181 631 0

**About My Grandfather...
About My Grandmother...**

A video produced by the Alzheimer's Society in which children talk about their experiences of living with their grandparent who has dementia.

Available to watch/download from:
http://alzheimers.org.uk/site/scripts/news_article.php?newsID=95

Talking to Children about Your Illness

Free leaflet from the Alzheimer's Society suggesting how to tell children if you or another person in their family has dementia. 'The key is to be honest, and to allow children to feel their emotions.'

www.alzheimers.org.uk/site/scripts/download.php?fileID=734

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