

The Milk's in the Oven

A booklet explaining
dementia to children





By **Lizi Hann**



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Welcome to **The Milk's in the Oven.**

I have had lots of help from lots of people whilst researching and writing this book. I spent time talking to young people who told me what they thought about dementia and growing old (there are comments from them throughout the book). I spoke to some of the families, Friends and carers of people with dementia who told me what it was like for them knowing someone with dementia. I also spent a lot of time with people who are suffering from dementia. They spoke to me and gave me a remarkable and moving insight to their thoughts and feelings. Writing this book has been a hugely rewarding voyage of discovery for me and I hope you learn as much reading it as I did writing it.

Lizi Hann



This booklet 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 this illness 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 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. Sometimes you feel really angry because nothing you do seems to make any difference. This booklet tells you more about how people with dementia behave and feel, and gives you a few ideas to try and help you understand.

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 this illness - 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. My 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.

A handwritten signature in blue ink, appearing to read 'Tony Robinson'.

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

What do you mean by 'memory'?

I asked some year 5 children how they would describe **memory**. Here is what some of them said:

A part of your brain that stores important things. (Rachelle)

Like a store cupboard that can lose things. (Stacey)

A dark place with lots of things. (Tobias)

Pictures left in my head. (Andre)

Something that helps you remember stuff.

(Bianca)

Fix it in my mind. (Oliver)

A thought of past. (Theo)

Remembering. (Lee)

How would you describe what memory is?

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 it is**

In fact, it helps us remember *everything* that 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 wander off.

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.

(See *How does someone with dementia feel?*)

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**) who's job is to send messages around the brain. When someone has dementia it is because some of these **brain cells** have become 'sick' and started to die.

Once these brain cells are dead, they cannot grow again or send messages to each other, so the person with dementia becomes more and more ill. 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 suffer from it.

It 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 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 'sick' and die. Scientists and researchers are doing a lot of work to try and find out why this happens.

How does
someone with
dementia feel?

Nothing really makes sense to me now.

(Rachel, 99 years old. Rachel suffers from dementia.)

This quote shows the confusion that Rachel feels.

An Exercise

Below is an exercise that people who are learning how to care for people with dementia sometimes do. It helps to them imagine what dementia feels like. Try it for yourself:

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 of the sounds around you. What can you hear? Maybe cars, people's voices, a bang, laughter, the television? Listen for a couple of minutes, soaking up all of 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.

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

Here are some of the words used
by people who have dementia

frustrated



frightened

worthless

embarrassed



confused

angry



lonely



useless



depressed

irritable

helpless



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

So what might
it feel like
to lose your
memory?

My memory it slims away.

(Someone with dementia)

We talked about memory at the beginning of this book. 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?

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

This is what they said:

Dark, blank head. (Daley)

*You won't remember anything and
you'll be lost. (Marie)*

Crazy, weird. (Francis)

Annoying. (Alex O)

Terrible. (Michael and Paul)

Sad. (Craig)

*Good because you forget your bad memories
and bad because you forget all your family.*

(Andre)

*Not funny. And you would miss the ones who
loved you for a long, long time. (Oliver)*

Someone suffering from dementia may well agree with all these 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 must feel confusing and frightening.

It is very important to remember that the person with dementia still has thoughts and feelings. But these thoughts and feelings are all jumbled up - just as we talked about in *Why do people get dementia?*



Sometimes they will be able to remember something that happened many years ago, as if it was yesterday and a sound can trigger a long lost memory. 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 suffers from dementia is different

'These people have lived for a long time, they have been babies, children and adults. Many have been through one world war, and some two. In their time they have seen man go to the moon, aeroplanes built, cars become a part of everyday life, televisions, videos, electric trains, computers, segas and calculators all appear.'

(Becky Turner, 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.

Lets 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 old, 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 their illness. Sometimes it will seem as if they are a completely different person from who they were before they became ill - but they are not blank people with blank minds.

Look at the words on page 10, and the quote on page 12. If these people were all the same and had blank minds, they would not have been able to think of these things.

Photos of some people suffering from dementia

Have a look at each face. Then have a look at the list of jobs opposite. See if you can guess which job each person used to do.



Rachel



Harry



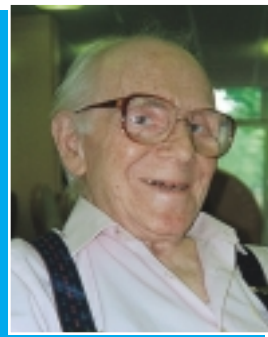
Rose



Yetta



Peter



David



Marie

Jobs

Head of sewing
at Selfridges Department Store

Market stall holder

Secretary

Furniture maker

A tailor

who sometimes made clothes for the Royal Family
(and who travelled the world!)

Social worker


Seamstress

What sort of life would you have if you were a tailor for royalty, a market stall holder or a social worker?

It's easy to forget that these people 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.

Answers: Yetta - Head of sewing at Selfridges Department Store; Peter - Market stall holder; Marie - Secretary; David - Furniture maker; Rose - Seamstress; Harry - Tailor; Rachel - Social worker



How do the people around them feel?

On the next 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 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 is a very difficult time for everyone.

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

frustrated



frightened

guilty

embarrassed



confused

angry



lonely



useless



sad

helpless



Did you notice how similar these words are to the ones on page 10 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 as you.

What can I do about these feelings?

All the feelings that we have looked at 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 looked at that we can do something about:



Feeling confused: once you have learnt something about what it is 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 your grandparent.

Try telling them how you feel - they may have been too busy to notice and will be pleased that 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 being ill, 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 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 at home, in a special nursing home, in hospital or with you and your family in your home, time is the most important thing that you can give to the person suffering from dementia. And it doesn't have to be much - five minutes of sitting and chatting, or showing them a picture you've drawn, or a photo that they may recognise will make a world of difference. Here are some other ideas:



- **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,**

- go for a short walk together,
- write a simple diary together to help them remember what's happening now
- just sit and hold their hand for a few minutes if this is all they can do.

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 the children came up with:

Support them. (Charlie)

Visit them, help with shopping - anything.

(Rachelle)

Listen to them. (Jess)

Make them happy. (Mitchell)

Be good to them. (Dareen)

Help them out. Be kind to them. (Mark)



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 disease 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 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 and 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 very important.

How would you like to be treated when you are old and frail?

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 the person with dementia just as we would like to be treated when we are old and frail.

I asked some children how they would like to be treated when they are old and frail. This is what they said:

Very nicely, because I'll be fragile. (Stacy)

Nicely, kindly (Craig and Charlene)

With respect and kindness. (Dareen and Rachelle)

Like a young man. (Mitchell)

Normally. (Alex M)

To be respected. (Mark and David)

I would like to be treated decently. (Andre)

I would like to be treated with love. (Damien)

Looked after. (Leanne)



Like a king. (Theo)

Sometimes it is difficult to treat someone with respect and kindness when they are ill. They might be rude to you, shout at you or simply not recognise you. Always remember that it is their illness making them behave the way they do. 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 a cure. So, hopefully, one day no-one will suffer because either they or somebody that they are close to has dementia.

Until that happens, we can all try to help those people who are suffering 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.



Further Reading

'You are Words', Dementia Poems. Edited and introduced by John Killick.
Published by the Journal of Dementia Care

Where to get further help and advice

Age Concern England

Astral House
1268 London Road
London SW16 4ER
Tel: 020 8765 7200

Age Concern Northern Ireland

3 Lower Crescent
Belfast BT7 1NR
Tel: 028 9024 5729

Age Concern Scotland

113 Rose Street
Edinburgh
EH2 3DT
Tel: 0131 220 3345

Age Concern provides lots of information and advice about older people.

Alzheimer's Society & CJD Support Network

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

Alzheimer's Society

(Northern Ireland)
403 Lisburn Road
Belfast BT9 7EW
Tel: 028 9066 4100

Alzheimer's Society

(Welsh Development Office)
Tonna Hospital
Neath
West Glamorgan SA11 3LX
Tel: 01639 641938

The Alzheimer's Society is the leading care and research charity for those with dementia.

Alzheimer Scotland - Action on Dementia

8 Hill Street
Edinburgh EH2 3JZ
Tel: 0131 243 1452
24 hour Freefone helpline
0808 808 300

Help for people with dementia, their carers and families.

MIND (National Association of Mental Health)

Granta House
15-19 Broadway
Stratford

London E15 4BQ
Tel: 020 8519 2122

Info line:

020 8522 1728/ 08457 660 163
9.15am - 4.45pm

Mon, Weds, Thurs, Fri
2.00pm - 4.45pm Tues

*Works for all those who need help
and advice on mental health
matters.*

The Mental Health Foundation

83 Victoria Street
London SW1H 0HW
Tel: 020 7802 0300

The Samaritans

UK-wide helpline 08457 90 90 90

*24 hour helpline offering support
to those in crisis or need.*

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As the UK's leading charity concerned with both mental health and learning disabilities, the Mental Health Foundation plays a vital role in pioneering new approaches to prevention, treatment and care. The Foundation's work includes: allocating grants for research and community projects, contributing to public debate, educating and influencing policy makers and health care professionals.