

Dementia in the Family

The impact on carers



**Alzheimer's
Research
UK**

The Power to Defeat Dementia

Contents

- 1 | Introduction 3

- 2 | Executive summary 4

- 3 | About the research 5

- 4 | The stories of families living with dementia 6

- 5 | Awareness of dementia 16

- 6 | The impact of dementia 19
 - Changing relationships 20
 - Social isolation 24
 - Psychological and physical health 27
 - The financial cost 31

- 7 | Conclusions 34

- 8 | Resources 36

Introduction

At Alzheimer's Research UK we have a vision of a world where people are free from the fear, harm and heartbreak of dementia.

THERE ARE CURRENTLY 850,000 PEOPLE IN THE UK LIVING WITH DEMENTIA

and 700,000 friends and family
caring for a person with the
condition.



Dementia is a word used to describe a group of symptoms that occur when brain cells stop working properly. This happens inside specific areas of the brain, which can affect how you think, remember and communicate.

The condition has a huge impact on people's lives and is now the biggest killer of women and third biggest killer of men in the UK.

But dementia is caused by diseases that can be cured.

In order to highlight the impact of dementia and the importance of investing in research to defeat the condition, we commissioned Opinion Leader to spend time with family carers to understand how caring for a loved one affects them.

We want to understand the experiences of people caring full-time for someone with dementia and examine the relationship between a person with dementia and their carer.

This report highlights the challenges and the hardships, but also the rewards and the touching moments. The research shines a light on the reality of living with

dementia, both for the person with the condition and those who often sacrifice personal well-being to ensure their loved one gets the best care they can provide.

It is clear that we urgently need a breakthrough.

Research into the prevention, treatment and cure is the only way we will defeat dementia.

At Alzheimer's Research UK we are committed to funding the highest quality research to improve the lives of people with dementia and those who care for them, and ultimately to defeat the condition.

Dr Matt Norton, Head of Policy and Public Affairs
Alzheimer's Research UK

Executive summary

Dementia

- **Is an umbrella term:** it is actually caused by many different diseases and in some cases a combination of more than one. 'Dementia' describes a group of symptoms caused by these diseases such as memory loss, confusion and personality change. Alzheimer's disease is the most common cause of dementia.
- **Touches the lives of millions of people:** there are currently 850,000 people in the UK living with dementia and 700,000 friends and family members caring for a person with the condition. Over 24 million people know a family member or friend with dementia.

Caring for a family member with dementia

- **Is challenging:** carers manage difficult changes in their loved ones' behaviour and personality, including aggression in some cases. Caring full-time can leave family members feeling socially isolated and having to meet hidden costs.
- **Is rewarding:** caring is often a very rewarding experience that can strengthen family bonds through the close and intimate relationship shared.
- **Can change family relationships:** changes in behaviour and personality can cause family carers to treat their loved one in a different, more childlike way. Carers' relationships with siblings can also become strained as the amount of care increases.
- **Impacts psychological and physical health:** the negative health consequences of looking after a family member with dementia are well documented.

We want to see

- **A breakthrough in research:** research into prevention, treatments and cure is the only way that we will ultimately defeat dementia. Alzheimer's Research UK is committed to funding the highest quality research to improve the lives of people with dementia and those who care for them.

About the research

WE WANTED TO UNDERSTAND WHAT IT IS LIKE TO PROVIDE FULL-TIME CARE

for a loved one with dementia and how it impacts on daily life.

To do this Opinion Leader worked with families to produce a rich description of individual experiences, by conducting a series of four ethnographic studies of family carers for people with dementia. In addition to spending a day with each family observing them as they cared for their loved one, the carers were asked to complete a diary in which they recorded their experiences of providing care over the course of a week.

Their experiences are presented in this report and in a series of short films. These films are designed to be viewed in tandem with this report and can be viewed here: <http://www.alzheimersresearchuk.org/carers-stories>

The case studies were purposely chosen to include different types of relationships between the person with dementia and their carer. They were also chosen to include people at different stages of the condition. This allowed us to understand the impact of the condition from a range of perspectives and experiences.



Pedro (43) looks after his mum **Mary** (75) who has advanced Alzheimer's disease.



Linda (46) looks after her dad **Bill** (82) who is in the early stages of dementia and has Cerebrovascular disease.



Donald (86) looks after his wife **Lillian** (88) who has mild symptoms of Alzheimer's disease.



Mary (62) looks after her brother **Donald** (82) who has Alzheimer's disease and learning difficulties.

Full details of the circumstances of those involved in the research are included in each case study.

We would like to thank all of the families who gave their time to take part in this research.



The stories of families living with dementia



Case Study 1

Pedro and Mary's story

Pedro is 44 and cares for his mum Mary who is 75. Mary was diagnosed with Alzheimer's disease by her GP when she was 66. This diagnosis came as a huge shock to the family. Pedro works as a supermarket delivery driver. When he is working a professional carer visits twice a day. Mary also goes to a day centre once a week.

Mary's physical and mental health has become considerably worse since her diagnosis. At the beginning her short-term memory deteriorated and she started to become confused in previously normal situations. This progressed to getting lost in once familiar surroundings. In one incident a member of the public found Mary lost and confused in a shopping area and called Pedro at work, who then took a break from work to pick her up.

Case Study 1

Pedro and Mary's story

Over time Mary has become increasingly violent, especially when Pedro provides intimate personal care. Mary was also temporarily banned from the day centre she attends as a result of her violent behaviour. Pedro thinks that a lack of stimulation during this time resulted in an accelerated decline in her condition. A once fit and strong lady, Mary now needs assistance to walk, drink, eat and use the toilet.

Pedro sees it as his duty to care for his mum and will resist her going into a care home at all costs. He finds the psychological impact of caring for his mum very difficult. He gets upset when she is aggressive towards him physically and verbally; providing personal care is particularly traumatic as she becomes distressed and sometimes strikes out at him.

Pedro doesn't want to lose the emotional connection with his mum and holds on to glimpses of her personality as it was before her dementia - an occasional smile, a laugh and a few words.

Pedro is currently a delivery driver but has been offered a promotion to become a senior manager. He feels unable to take this job because he needs the flexibility, which he has as a delivery driver, to pop in and check everything is okay during the day, or to drop everything if Mary has a crisis.

Pedro has dramatically reduced the time he spends on his hobbies of cycling or playing pool, as he does not want to leave his mum for long periods of time.

What most upsets Pedro is the feeling of gradually losing his mum and not knowing how much she is aware of her situation.

Providing care for his mum has had positive and negative impacts on their relationship. In some ways it has brought them closer together. Pedro said that his mum never used to cuddle him, but that she frequently does now. There have also been wonderful moments for him, where she has shown that she needs him and appreciates him, once saying after a 'good' day, "look after me".

There are strains too, which result in him feeling low and exhausted, and when she has 'bad' days the psychological and physical impact on him is significant.



Case Study 2

Mary and Donald's story

Mary is 62, she is the second youngest of 15 siblings and cares for her eldest brother, Donald, who is 82. They live together in her house, sharing a bedroom because Donald needs constant supervision. She is a strong woman and this comes from her close-knit but very large family. Mary worked as a carer for many years but had to give this up because of complications with her health, which meant she could no longer juggle caring for her brother and a professional role.

Donald was diagnosed with Alzheimer's disease in 2013 by their GP. He has a learning difficulty and a heart condition, and is registered disabled. In the past ten years, he has suffered a stroke, had a heart bypass, and very recently a heart attack. Donald takes medication for his heart condition, but not for his dementia. He eats sporadically, gorging sometimes and at other times eating very little. He doesn't sleep well and some nights not at all. Donald is fully dependent on Mary's care.

Case Study 2

Mary and Donald's story

Donald's mental health is deteriorating and his behaviour is changing as a result. Apart from short-term memory loss, Donald is becoming more stubborn and jealous of others. Mary's caring background means she has had a lot of experience of dementia and when she found Donald rummaging through bins, requiring certain items to be arranged in a specific way or going for walks with an unknown destination, she recognised the onset of the condition.

Mary's own health is poor. She has Chronic Obstructive Pulmonary Disease (COPD) and a bag inside her stomach from an earlier health incident which left her in a coma; as a result of this she is registered disabled. She believes it is her responsibility to be Donald's primary carer; however she knows that she will not be able to cope alone when the disease progresses to the later stages and as her own health deteriorates. Mary shares a bedroom with Donald and therefore regularly has sleepless nights. She admits that she does not eat well.

Mary receives some support from her wider family, but she does not think they understand the emotional and physical impact of full-time care on her life.

Mary's social life is limited, she no longer plays bingo and only speaks to her friends on the phone.

Her daughter and her siblings live nearby and regularly pop in to check up on them or deliver the daily papers for Donald. Mary feels lucky to have such support and knows her family are there to help her when needed (to allow her to go on shopping trips or out for occasional meals), and share the responsibility of future decisions about Donald's life.

Mary's deep understanding of how Alzheimer's disease affects behaviour, together with her experience of being a professional carer, has given her a deep-rooted dislike for care homes. She regards them to be "waiting rooms for the undertaker". This impacts the care she provides and her views on the future of Donald's life. Mary is fiercely against medication for Donald's Alzheimer's and refuses to turn anything into a routine, as she sees this combination as a downward spiral.

**Like many carers,
Mary prioritises Donald's
health and needs over
her own.**

When Donald's condition becomes more severe, Mary is aware that her own health will place limitations on the care she can provide. She wants Donald to remain as independent as possible, so that "the good days remain good", and hopes her family will provide the necessary support when one-to-one care is no longer possible. She has seen many families feud when this happens and hopes hers can pull through.



Case Study 3

Linda and Bill's story

Bill, 82, moved into his daughter Linda's home three years ago when he was diagnosed with Alzheimer's disease. Linda has a husband, three children and a dog. She had to use her savings to build an extension to the family home so that Bill can have his own private area of the house. Bill is full of fun and energy. He used to be an engineer and ran his own company building parts for nuclear submarines.

Bill has a very poor short-term memory; he often makes himself a coffee and then forgets he has just made it. He'll occasionally go out to get a paper, forgetting that he has already been to get one earlier that morning. When he returns and realises he gets upset and frustrated with himself.

Case Study 3

Linda and Bill's story

Linda said that the run-up to Christmas was particularly difficult. Bill bought Christmas cards almost every day and wrote them out to people, forgetting that he had previously done this. He was also recently targeted by scammers when he was out shopping and they stole £500 from him. He felt ashamed that this had happened and did not want to admit it to Linda. Bill has few physical symptoms of the disease but there have been a few occasions when he has struggled with continence when out and about.

Linda is up before 7am to send business emails; she then takes the children to school and looks after dad and the rest of the family for the rest of the day. At 11pm she finally has 'me time' which she uses to run her business,

before going to bed between 1am and 2am. She is in poor physical health and has a blood condition which means she has low energy levels despite being on the go for 19 hours a day.

Recently Linda was so exhausted that she stayed in bed until midday, which is unheard of for her. Her husband does flexible hours and works from home providing occasional respite. She used to exercise a lot but has not been able to do much since she started to care for her dad and has put on five stone. She has joined a gym but rarely has time to go. She would like to get a full-time job at Glasgow Airport where she previously worked but her caring responsibilities make this impossible.

Caring has changed the dynamic of the relationship. Linda now has to act in a very maternal way towards her dad.

Linda feels like she is climbing a mountain every day. She juggles running a business with looking after both her young family and her dad.

Their situation has also brought them closer together because of the amount of time they spend together. They share many special moments, like walks along the river and trips to the shops.



Case Study 4

Donald and Lillian's story

Donald cares for Lillian, 88, his wife of 62 years. Both are quick humoured and Donald has a warm and resilient outlook on life. He was a lithographic artist but was made redundant when computer technology advanced. Donald and Lillian are very much in love and as life partners they try to do everything together. He is her sole carer. Lillian was diagnosed with Alzheimer's disease by her GP two years ago when she was 86 years old.

Lillian's health is deteriorating, both mentally and physically. A decline in her short-term memory was the first thing Donald noticed, but since then he has also seen changes in her personality.

Case Study 4

Donald and Lillian's story

Lillian is reliant on medication for various health conditions and has recently started taking medication for her Alzheimer's. Donald believes this is successfully calming her. Physically, Lillian is losing her ability to hear and she has lost her balance to the extent that she is only able to walk with crutches. She would love to be able to go out on trips but neither of them are physically well enough.

Donald regards Lillian and her health as his responsibility; her happiness and needs are his first priority. Although his health is stable, Donald also relies on a variety of medication that he takes each morning.

Donald helps Lillian with all activities of daily living, washing and dressing her everyday, preparing food and medication for her and "keeping his temper" in response

to Lillian's changing personality. Donald does not receive much outside help, and wants to provide as much care for Lillian as he can to make sure they remain as independent as possible.

A number of Donald's friends have passed away with dementia and he regards this to be a great injustice.

Donald is thankful for the medication Lillian is now taking for her Alzheimer's, and regards medication positively. Donald believes it to be "just slowing the progression down"*², but it has made life calmer again. Donald recalls instances prior to starting medication when Lillian was stubborn and they argued a lot. This caused him considerable distress, but Lillian cannot remember. Donald has gout and simply takes a pill to keep it under control. He compares the scientific advances for gout, which can now be controlled rather than typically fatal, with the current situation for Alzheimer's, and hopes there will be similar advances in treatments for the disease.

Donald has little concern for his own health, he just feels lucky to be sharing his old age with his loved one.

Donald's understanding of dementia is limited to a belief that it is a mental health condition and his main sources of information about Alzheimer's disease are the television and newspapers.

Donald cherishes his and Lillian's life together. Donald is religious and believes they will be "looked after".

Donald's understanding and acceptance of life is inspiring.

* Despite Donald's perception, medications that are currently available only have a modest affect on reducing the symptoms of the disease, they do not slow down progression.



Findings

Awareness of dementia



As with previous qualitative research, the carers in our case studies demonstrated a limited understanding of dementia and the diseases that cause it, their knowledge was predominantly based on their personal experience (1). There was a limited understanding of the pathological deterioration that takes place and very little understanding of the mechanisms by which this occurs. Their awareness that dementia is

caused by one or more diseases was also limited, instinctively it was thought to be a mental health issue. They were much more aware of the effects on behaviour, although there was little desire to understand how the disease would affect their loved one in the future, with the prospect of learning more about the condition linked to an unhappy vision for the future.

“ACCORDING TO WHAT I READ AND SEE, IT HAPPENS TO SO MANY PEOPLE, IT’S NORMAL. IT’S A NORMAL HAPPENING... I DON’T LIKE TO THINK ABOUT IT, TO BE QUITE HONEST. I JUST HOPE THERE WILL BE SOMEBODY THERE TO LOOK AFTER US WHEN IT HAPPENS PROPERLY.”

Donald

Awareness of dementia

“WELL IT’S TOO COMPLICATED FOR ME. THE ONLY THING I KNOW, AS FAR AS LILLIAN IS CONCERNED, IS HER MEMORY.”

Donald

Brain deterioration

There was a limited awareness of the pathological deterioration involved in dementia, which was closely linked to understanding of the biological processes behind the diseases that cause it. Some carers regarded dementia as simply a decline in memory whereas others believed all aspects of cognitive functioning were affected. Their understanding of this aspect of the condition was directly related to the symptoms they had seen their loved one exhibit. Recent research supports this finding and suggests that many carers do not attribute some symptoms to the condition because of a lack of understanding (2).

Only Pedro and Mary understood that brain deterioration can also affect physical motor skills.

All of the participants were aware that there is currently no cure, but medication can be used to ease symptoms for a short space of time. The lack of understanding of treatments was particularly evidenced by the perception that the current medicines used to treat Alzheimer’s slowed progression of the disease. In fact these only have a limited affect on symptoms.

“I JUST KNOW THAT ALZHEIMER’S IS DEGENERATIVE AND I BELIEVE YOUR BRAIN CELLS ARE PRETTY MUCH DYING. PART OF YOUR BRAIN IS LITERALLY JUST DYING AND KIND OF WASTING AWAY”

Pedro

Changes in behaviour

All of the carers we spoke to understood that dementia changes behaviour and personality. This understanding typically came from the carer’s personal experience and not from a general knowledge of the condition. The behavioural aspects that were associated with the disease were: repetitive speech and behaviours, wandering, lack of appetite and sleep disturbance. From a personality perspective, carers recognised that dementia can result in the person becoming agitated, stubborn and in some cases aggressive.

Awareness of dementia

“I THINK IT’S A CHANGE IN THE INDIVIDUAL PERSON THEMSELVES, DOING THINGS THEY WOULDN’T NORMALLY DO, SPEAKING IN A WAY THEY DON’T NORMALLY SPEAK, PUTTING THINGS AWAY AND THAT THEIR ATTITUDE CHANGES.”

Mary

Deepening their knowledge

Existing evidence suggests that by increasing their knowledge of the condition, both from a biological and caring perspective, carers can improve the quality of care they provide and increase their own ability to manage the situation (3). However, there was little appetite amongst family carers to deepen their knowledge of the disease. News articles were the most accessible source of information but most had little time, energy or appetite to absorb new information, and some appeared not to want to find out more. The prospect of learning more about the condition was linked to an unhappy vision for the future that would only exacerbate worry and unhappiness.

The carers were aware that health deteriorates as the disease progresses, but there was some reluctance to know the details. For example, they did not know how quickly deterioration can happen or how it would manifest itself. They preferred to deal with the condition day by day.

The impact of dementia

WHAT CARERS TOLD US



It changes
relationships



Carers
often
become
socially isolated

It negatively
impacts both



psychological
and **physical health**



There is an
increased
**financial
cost**

Changing relationships



All of the carers felt that dementia had changed their relationship with their loved one. However, Donald, who was caring for his wife, believed that the impact was quite small.



Caring for their loved one also affected the carers' relationships with other family members because of the resentment and guilt caused by one family member taking on the vast majority of the caring responsibility.

Existing research shows that family carers often treat their loved one in a different, more infantile way because

of the impact of the condition on their behaviour and personality (4). The carers we spoke to all demonstrated this to an extent and they particularly struggled to cope with behaviours such as anger and frustration, which sometimes in turn led to physical violence by the person with dementia. The emotional impact of all these factors led carers to become frustrated and depressed (5).

Impact of changing behaviour

Pedro and Linda felt that their relationship with their respective parents had changed from an adult relationship to a parent-child relationship. Pedro described this as being the reverse of him being a child and his mum being the parent. He felt that his mum was undergoing a process of 'unlearning'.

Changing relationships

Some carers felt that they had to treat the person they were caring for like they would a child, for example by providing reassurance about situations and hiding things that might harm them. Mary felt her relationship with her brother Donald was changing as his behaviour became more unpredictable. As a result of his learning disabilities Donald has always been reliant on his family and had an adult-child relationship with Mary, however as Mary has become more involved in his care, her actions have become more maternalistic and therefore their relationship has becoming increasingly parent-child like.

“I DEFINITELY HAVE BECOME THE PARENT, AND EVEN WHEN HIS JACKET’S NOT SITTING RIGHT, I’LL FIX HIS JACKET FOR HIM, JUST MAKE SURE THAT’S HE’S WARM ENOUGH, THAT HE’S GOT HIS HAT ON, THINGS LIKE THAT.”

Linda

In contrast to this, Donald did not seem to believe that his wife Lillian’s behaviour had altered their relationship significantly. They spend their time at home as they always have, and Lillian’s condition has not appeared to drastically change Donald’s role in her life. It appears that because Donald and Lillian have grown old together, Donald views dementia as part of their evolving relationship and therefore places less emphasis on the impact of the disease.

“SHE’LL FIGHT ME, YOU CAN SEE THE LITTLE MARKS THERE WHERE SHE’S TRYING TO PINCH ME ALL THE TIME, AND SHE’LL TRY AND BITE YOU, AND SLAP YOU AND ALL KIND OF STUFF.”

Pedro

Impact on family relationships

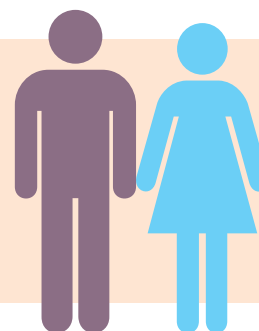
Carers explained to us that as dementia progressed, they noticed increasingly aggressive behaviour that they sometimes found difficult to deal with. As other studies have suggested, coping with aggressive and violent behaviour was frequently difficult, both physically and psychologically, and often leads to stress for carers (6). Pedro had bruises and marks where he had been hit by his mother and the other carers described examples

of aggressive behaviour, particularly during help with physical tasks, such as dressing.

Repetitive behaviour frequently resulted in frustration for carers because they had to repeat themselves or explain things many times. Erratic eating and drinking was difficult to deal with as it required careful monitoring by the carer and occasionally resulted in conflict when the person with dementia refused to eat or drink.

Changing relationships

...coping with aggressive and violent behaviour was frequently difficult...



Carers talked about their family member becoming stubborn and sulking if they did not get their way. Some felt that this was akin to childlike behaviour. For example, Bill often still thought he was allowed to drive, forgetting that he had been told by his GP that he was no longer allowed to. **When he was prevented from driving, and could not remember, or understand why, he became frustrated and fed up. This in turn caused stress for Linda, as she had to calm Donald and cope with his repetitive behaviour.**

“I DO HAVE BROTHERS WHO DON’T SEE MY DAD; THEY DIDN’T WANT TO KNOW ABOUT MY DAD’S ILLNESS, SO THEY JUST WALKED AWAY. I DON’T SPEAK TO THEM NOW, NOT AT ALL.”

Linda

Impact on relationships with the wider family

Carers’ relationships with siblings typically became strained as the amount of care required increased. This led to some siblings falling out with each other and to feelings of resentment. Carers UK suggest that 57% of carers lose touch with family or friends as a result of their

caring responsibilities, leading to increased isolation and emotional distress (7). Carers also felt that other family members did not understand the physical and emotional strain that caring places on them, which led to further resentment.

Changing relationships

There were a number of reasons for family detachment. Worryingly, given the stigma that we know still surrounds dementia, **some family members did not want to keep in contact with their relative when they found out they had dementia.** Others refused to believe that the condition was as far progressed as it was.

Research by the International Longevity Centre shows there is still a perception that dementia is 'just part of getting old', rather than a disease (8), and the perception appears to be used to justify family disengagement.

“IT GIVES DAD AND I THE CHANCE TO BE TOGETHER, BEFORE, WHEN HE LIVED IN HIS OWN HOUSE WITH MY MUM, WE HAD A GOOD BOND BUT IT’S NOT THE BOND THAT WE HAVE NOW SO I CAN’T SAY ITS ALL BAD.”

Linda

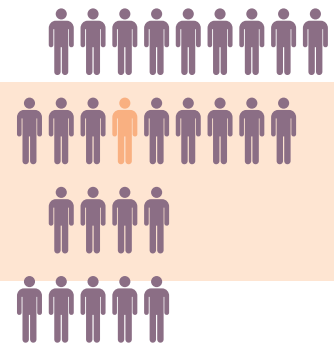
Unexpected positives

Despite the challenges and frequent negative impact, caring is often a very rewarding experience that can strengthen the bonds in a relationship (9). There were elements of caring that the carers we spoke to viewed in a far more positive light. This included seeing behaviours which reminded them of the family member before the onset of the condition, and the bond created through the close and intimate relationship they now shared.

Social isolation



Family carers have little ability to socialise and any 'me' time is lost, as caring duties and the needs of the family member are prioritised.



This is not unusual; according to Carers UK, eight in 10 (83%) carers have felt lonely or socially isolated as a result of their caring responsibilities (10). Despite this isolation, the carers strongly emphasised the positive

aspects of being able to provide support at such a crucial time in their loved one's life.

Shouldering the responsibility

Mary thought that her shouldering the responsibility of caring for her brother was convenient for the rest of family. Although they visited and provided intermittent help, they did not shoulder the responsibility, nor experience the isolation that she feels because she is unable to leave him for any period of time. Mary is not alone; according to a national survey of carers, 75% feel that people don't understand the impact of caring on their personal and social wellbeing (11). Despite this isolation, Mary feels lucky to have family who can help occasionally, and this stops her from feeling constantly lonely.

Social isolation

“I’M NOT SAYING ANYTHING AGAINST THEM, I DON’T MEAN BADNESS TOWARDS THEM, BUT I’M HERE 24/7. THEY CAN COME FOR TWO HOURS AND THEY CAN GO AND HAVE MEALS WITH THEIR FAMILY. IF I’M GOING OUT FOR A MEAL WITH MY DAUGHTER, DONALD’S GOT TO COME AS WELL.”

Linda

Donald, who cares for his wife Lillian, is isolated from friends and family. They very rarely go out and he discourages family from visiting. Nor does he update them on Lillian’s condition because he does not want them to get upset, as he does not regard her health to be their responsibility. Donald’s case is not unusual; male carers face particular challenges, often as a result of a lack of self-identification as carers, or willingness to seek support.

Research suggests that many male carers are reluctant to describe themselves as carers or seek support with their caring role (12).

“THEY’RE WORKING ALL THE TIME AS WELL, THEY’VE GOT THEIR OWN PROBLEMS. THEY’RE SO BUSY WITH THEIR WORKING LIVES. I DON’T THINK THEY’VE GOT SPACE FOR IT, I DON’T WANT TO BURDEN THEM WITH IT.”

Donald

Impact on personal goals

Caring for a family member with dementia can be a 24 hour, seven days a week responsibility. It is both emotionally and physically exhausting and can leave some carers with little energy or enthusiasm for anything else. Pedro and Linda wanted to pursue activities such as exercise, going out with friends and spending more time alone with their partners, but feelings of worry and guilt about leaving their loved one alone override pursuing these passions and personal goals.

The absence of a social life was a sacrifice recognised by carers, but they considered it their duty and

responsibility to look after their loved one. Care for their family member was prioritised over their own wellbeing, and this finding corresponds to the findings from other studies (5) . It was clear that all the carers we spoke to sacrificed their social lives to provide round the clock care for their loved one, but this was justified through a strong sense of duty and responsibility. They prioritised their caring responsibilities over personal time, holidays and romantic relationships.

Social isolation

“IT WOULD BE A NICE IDEA TO GO AND RIDE MY BIKES MORE, IT’S LIKE A SENSE OF FREEDOM, WHEN YOU’RE ON YOUR BIKE IT JUST FEELS SO FREE, YOU’RE IN YOUR OWN LITTLE WORLD.”

Pedro

This attitude leads to a resilience, which in turn can create a positive emotional response and help carers maintain their wellbeing despite tiring and stressful circumstances (9).

All of the carers were aware that respite care was potentially available and could be used to provide a much needed break. However a sense of duty and responsibility meant that none of the carers sought or received this type of support. The carers did not think that it would be appropriate or practical to leave their loved one with a friend or full-time carer.

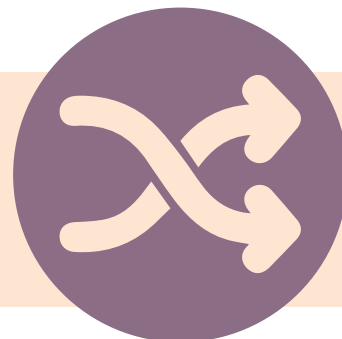
“I’VE GOT TO WATCH OTHER PEOPLE WITH HIM AND IF THEY CAN’T DO IT, THEY CAN’T DO IT. I CAN’T MAKE SOMEBODY DO SOMETHING. THEIR WORK’S IMPORTANT, THEIR KIDS ARE IMPORTANT, THEIR FAMILY’S IMPORTANT.”

Mary

Psychological and physical health



The negative health consequences of looking after a family member with dementia, particularly the effects on mental and physical health, are well documented (10).



The mental and physical health of family carers taking part in this study was poor and appears to be related to the progression of the condition. All of the carers experienced high levels of stress and depression and

these symptoms were further exacerbated by social isolation. It is clear that these factors contribute to the ill-health and exhaustion observed in the carers (11).

Psychological health

Existing research suggests that stress is a common health problem for carers of people with dementia (12). The carers we spoke to all appeared stressed and saddened by their duty as a carer. The responsibility of providing around the clock care had a negative impact on their psychological wellbeing, and this was exacerbated by the sadness of feeling that they are gradually losing their loved one.

Psychological and physical health

Changes in the behaviour and personality of the person with dementia also caused stress and frustration. Carers have to constantly adapt their emotional and physical relationship to the needs of the person with dementia.

Feeling isolated can have a significant detrimental impact on health. A lack of social connections is as damaging to our health as smoking 15 cigarettes a day and has a bigger impact than well-known risk factors such as obesity (13).

“THERE’S A LOT OF MENTAL STRESS THERE BECAUSE YOU’RE THINKING, FRIGHTENED TO SLEEP, WHAT IF HE GETS UP AND WANDERS OUT OF THE DOOR DURING THE NIGHT? I’M WORN DOWN... I LIE AT NIGHT AND I GO, ‘WELL HAVE I DONE THIS? HAVE I DONE THAT?’ THEN I’M STARTING TO QUESTION MYSELF.”

Mary

Physical health

The physical health of the carers was poor. They were exhausted as a result of sleep deprivation, carrying out all of the household chores, extra cleaning and laundry as well as moving or lifting their loved one. The carers who were in the poorest health (Mary and Donald) found moving and lifting their loved one a huge strain.

“I PUT DONALD’S HEALTH BEFORE MY OWN BECAUSE I KNOW HOW FAR I CAN GO AND WHEN I NEED HELP, HE DOESN’T KNOW. SO I’VE GOT TO PUT HIM FIRST.”

Mary

Psychological and physical health

“YOU GET DOWN WITH IT BUT I DON’T GET DOWN AN AWFUL LOT BECAUSE IF I SANK DOWN THERE THEN I WOULDN’T GET BACK UP AGAIN SO THERE’S NOT REALLY ANY POINT BECAUSE YOU’VE GOT TO GET UP THE NEXT DAY AND DO IT ALL OVER AGAIN SO WHY BOTHER ABOUT IT.”

Linda

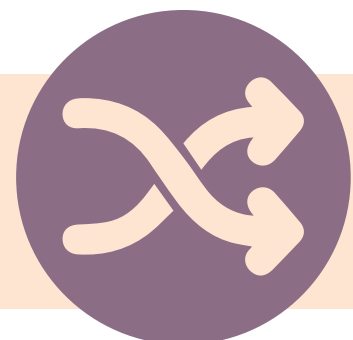
The high level of responsibility carers felt towards their caring duties, in combination with selflessness, left some carers feeling ambivalent towards the maintenance of their own health. This lack of self-care when experiencing poor health is alarming, as evidence shows that a carer’s ability to provide a high level of

care decreases in line with their own health (16). Despite carers feeling as though they are prioritising the health of their loved one, if their own health deteriorates this will ultimately have a detrimental impact on their ability to care for them.

Coping strategies

Carers find different ways of coping, such as social support, spirituality, knowledge and positive outlook (14). Linda had a self-confessed ‘cup half full’ approach to life and focused on the positive aspects of providing care, which helped her get through the day. Mary’s experience of being a professional carer made her feel competent, and she looked at the situation realistically. Her skills and knowledge clearly helped her to manage and cope (15).

Donald only acknowledged certain symptoms of Lillian’s disease, such as short-term memory loss and slight personality changes.



Psychological and physical health

Donald regarded Lillian's other symptoms (e.g. loss of balance, hearing difficulties, body coordination and tiredness) to be the result of old age. He had a positive outlook on life and felt lucky to still be sharing it with his companion.

At times Pedro became depressed with the situation, especially when looking after his mum became particularly hard. He, like Donald, placed huge emphasis on the good memories to help him through.

“I NEED TO FACE REALITY. I NEED TO FACE THE FACT THAT ONE DAY I’M GOING TO HAVE TO LET GO, AND I DON’T KNOW HOW I’M GOING TO FEEL. NO MATTER HOW THE REST OF THE FAMILY FEELS. WILL I FEEL GUILTY? I DON’T KNOW THE ANSWER, IT’S A HORRIBLE HORRIBLE ILLNESS.”

Mary

Future concerns

All expressed concern and anxiety about the future because of the unpredictable nature of disease progression. Consequently, they tried to engage in positive thinking by only looking at the short term and by remembering the past.

The financial cost



There are a number of different ways in which a carer's financial situation can be affected. The State of Caring 2014 survey found that 54% of carers struggled to pay household bills and 35% cut back on essentials like food and heating to make ends meet (17).



Reduced work opportunities

Providing care for a parent reduced the job opportunities available to Linda and Pedro. Pedro was offered a management position but had to turn it down because of the lack of flexibility, which he needs to be able to look

after his mum. Linda has had to reduce the scope of her jewellery cabinet business because she is unable to leave her dad at home by himself for extended periods of time.

The financial cost

“THEY ASKED ME TO BE A TEAM LEADER AT WORK. AS SOON AS THEY ASKED ME I WAS LIKE, ‘WELL, MY MUM.’ I COULD HAVE GONE FOR IT, BUT BECAUSE OF MUM, PRETTY MUCH DIDN’T”

Pedro

Impact of hidden costs

In addition to reduced work opportunities and income, there are direct financial costs to providing care. These include:

- higher energy bills
- specialist food
- higher phone bills
- higher transport costs
- care products
- equipment and adaptations (18).

The carers in our study said the biggest cost came from increased use of utilities because the family were at home most of the day, as well as increased levels of washing due to incontinence. In Linda’s case she built an extension to her house for her dad, which used up all of her savings.

Carers can also experience an impact on their benefits.

In addition to carer benefits, Mary receives disability benefits. She recognises that if another family member lived in the house to help her care for Donald she would receive less money to pay for his needs. Consequently,

she does not want help as her income would decrease and the prospect of this is motivating her to remain as independent as possible.



The financial cost

“IT’S MORE EXPENSE HAVING MY DAD HERE, BECAUSE OBVIOUSLY WE’RE HAVING TO PAY FOR MORE HEATING, MORE LIGHT, ELECTRICITY, FOOD AND WHEN WE HAVE GONE ANYWHERE, THERE’S ALWAYS THAT EXTRA PERSON TO PAY FOR.”

Linda

Long term uncertainty

The two older carers (Donald and Mary) were aware of, and concerned about, significant care costs in the future as the condition progresses. They were saving their money in case of this eventuality and consequently reduced their current standard of living because of an uncertain future.

“I GET A DISABLED PENSION AND I’VE GOT THE MOBILITY CAR THAT MY DAUGHTER DRIVES. DONALD ALSO GETS A DISABLED PENSION. SO ONE OF MY SISTERS WILL PUT SOME OF DONALD’S MONEY AWAY. THAT GOES AWAY EVERY FOUR WEEKS, BECAUSE WE DON’T KNOW WHAT THE FUTURE’S GOING TO BRING. THERE WOULD NEED TO BE SOMETHING THERE WHEN HE NEEDS IT”

Mary



Conclusions

Conclusions

Caring for someone with dementia puts a huge strain on the carer's physical and mental health as well as straining, at times to breaking point, the relationships with other family members.

SPENDING A WHOLE DAY WITH CARERS AND THEIR FAMILY MEMBER WITH DEMENTIA

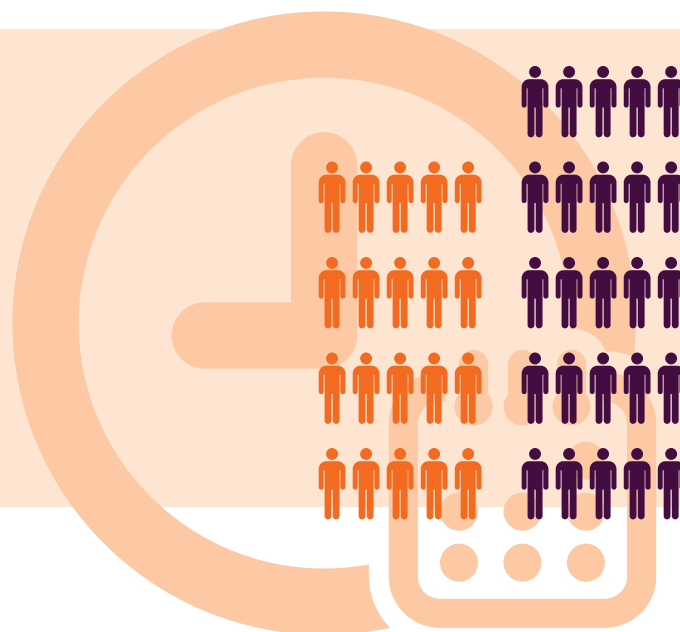
made a strong impression on the researchers.

The selflessness shown by the carers we spoke to is impossible to put into words and we are so grateful for the opportunity to tell their stories.

Understanding of dementia is limited and there is little desire to improve this as the carers we spoke to are worried about how they will cope when things deteriorate. They would prefer not to fully understand the prospects for the future and live in the now.

Caring for someone inevitably changes the dynamic of a relationship. For people caring for someone with dementia there is an additional sense of loss of the person they once knew. When this is coupled with challenging behaviour and the emotional and physical stress, this can make the act of caring for someone with dementia a significantly emotional experience.

Like many other carers, carers of people with dementia feel socially isolated. Some carers actively isolate themselves from their family because they want to protect them from knowing a family member has dementia, or quite how severe the condition has become. The sense of 'losing their loved one' also resulted in some wider family members emotionally isolating themselves from the person with dementia.



The physical and mental health of carers deteriorates as a result of the stresses and strains of providing care, as with other carers.

The combination of the physical and psychological impact of caring for someone with dementia make this a particularly exhausting and challenging role.

All of the carers we spoke to needed to be able to drop everything to look after their loved one. This need for flexibility limits the types of jobs that carers can do and can limit their income.

However, despite all the difficulties in providing care, fundamentally the carers were positive about their responsibilities. Some felt lucky to be able to spend so much time with their loved one, and some felt comforted by knowing that they were providing the best possible care for their loved one.

Resources and further information

1. Boots LM et al (2015) Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *Int Psychogeriatric*. Jan 8:1-10
2. Stokes L et al (2014) The dementia diagnosis: a literature review of information, understanding, and attributions. *Psychogeriatrics*. doi: 10.1111/psyg.12095
3. Taylor DH, et al (2008). Trajectories of caregiving time provided by wives to their husbands with dementia. *Alzheimer Disease and Associated Disorders*. 22(2):131–136
4. Ho SC, et al. (2009). Impact of caregiving on health and quality of life: a comparative population-based study of caregivers for elderly persons and noncaregivers. *Journal of Gerontology, Series A: Biological Science and Medical Science*. 64(8):873–879
5. Boots LM et al (2015) Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *Int Psychogeriatric*. Jan 8:1-10
6. Wilks SE, Little KG, Gough HR, Spurlock WJ (2011). Alzheimer's aggression: influences on caregiver coping and resilience. *J Gerontol Soc Work*. 54:260-75
7. Carers UK (2014) State of Caring Survey 2014. Carers UK
8. Bamford, S et al. (eds) (2014) New perspectives and approaches to understanding dementia and stigma. International Longevity Centre
9. Carbonneau H, et al (2010) Development of a conceptual framework of positive aspects of caregiving in dementia. *Dementia*. 9 (3):327–353
10. Carers UK (2014) State of Caring Survey 2014. Carers UK
11. Carers UK (2014) State of Caring Survey 2014. Carers UK
12. Carers Trust and Men's Health Forum (2014) Husband, Partner, Dad, Son, Carer? Carers Trust
13. Haley, W. (1997) The family care givers' role in Alzheimer's disease. *Neurology*, 48 (suppl. 6), S25 -S29
14. Lavretsky H, et al (2010). Improving depression and enhancing resilience in family dementia caregivers: a pilot randomized placebo-controlled trial of escitalopram. *American Journal of Geriatric Psychiatry*. 18:154-62
15. O'Rourke N, Kupferschmidt AL, Claxton A, Smith JZ, Chappell N, Beattie BL (2010). Psychological resilience predicts depressive symptoms among spouses of persons with Alzheimer disease over time. *Aging Ment Health*. 14:984-93
16. Contador I, Fernández-Calvo B, Palenzuela DL, Miguéis S, Ramos F (2012). Prediction of burden in family caregivers of patients with dementia: a perspective of optimism based on generalized expectancies of control. *Aging Ment Health*. 16:675-82
17. Holt-Lunstad (2010) Social Relationships and Mortality Risk: A Meta-analytic Review. *PLoS Med* 7(7): e1000316. doi:10.1371/journal.pmed.1000316

Resources and further information

18. Murphy A. (2014) The effect of dementia on patients, informal carers and nurse. *Nursing Older People*. 26, 5, 27-31
19. Parker, D et al (2008) Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Journal of Evidence Based Healthcare*. Jun;6(2):137-72
20. Carers UK. (2014) State of Caring Survey 2014. *The State of Caring 2014*
21. Wilks SE, Croom B (2008). Perceived stress and resilience in Alzheimer's disease caregivers: testing moderation and mediation models of social support. *Aging Ment Health*. 12:357-65
22. Carers UK (2014) *Caring & Family Finances Inquiry: UK Report*

If you are interested in discussing **Dementia in the Family** in more detail, please contact **Dr Matt Norton**, Head of Policy and Public Affairs on **01223 824575**.

Alzheimer's Research UK
3 Riverside, Granta Park
Cambridge, CB21 6AD
www.alzheimersresearchuk.org

Registered charity no. 1077089 and SC042474