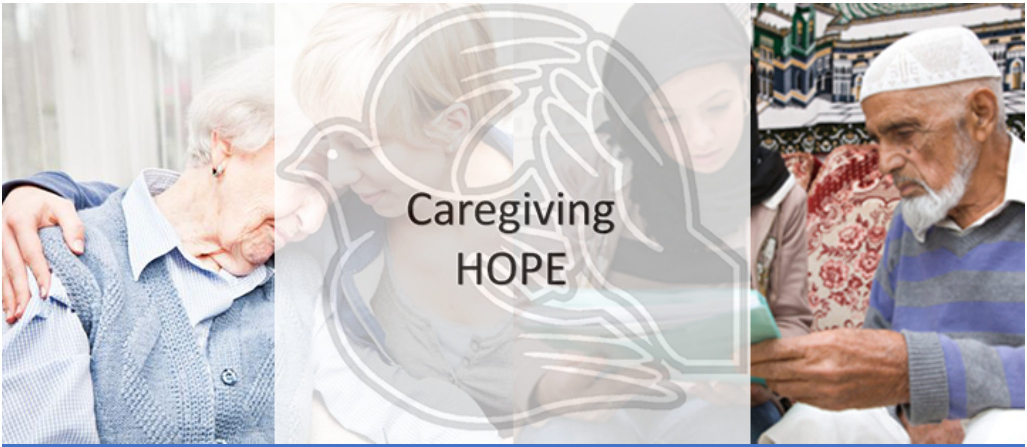

Living with Dementia: The Carer's Experience

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The Caregiving HOPE Team

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This book is dedicatedt book to all the carers who gave their time to support the Caregiving HOPE study.

Foreword

Dear Reader,

I have worked with carers (family members who provide support to a relative living with dementia) for over ten years. What has struck me is how often it is assumed by health care professionals that carers are obligated, willing and prepared to provide care for relatives.

This provided the inspiration for my research- The Caregiving HOPE study. I was very grateful to the Alzheimer's Society for funding this work and University of Bradford for 'hosting' the project. The study explored how obligated, willing and prepared carers felt and whether this influenced their psychological health. We included over 700 carers in this study and followed their experiences over the course of one year to explore changes over time. I got to know 20 carers in particular who agreed to be interviewed and provided me with photographs from their lives. This book contains extracts from these interviews and their photos. The stories presented are direct quotes from carers with minor modifications made to improve readability. The carers wanted to share their stories with you in the hope that their experience helps others. I certainly learned a lot from these inspirational individuals; from Bradley I learned about relationships and commitment, from Jamila I learned about hope and from Fred how to cope with guilt and grief.

The book has been split into six main chapters but does not need to be read in any particular order. The names of all the individuals involved with this project have been changed to protect their identity. The carers who participated in this project are from diverse cultural backgrounds, wives, husbands, adult children, daughter in laws and even grand children. The oldest carer was aged 73 years young and the youngest, aged 18 years. This project has taken three years to complete and has been a team effort. The Caregiving HOPE team consists of academics, carers, people living with dementia, carer support workers, members of the public and volunteers from the Alzheimer's Society. I am very grateful to the team for their support and help with this project. I will be forever grateful to all the carers who gave me their time for this project. I have learned so much from them and thank you for taking the time to read their stories.

Sahdia Parveen

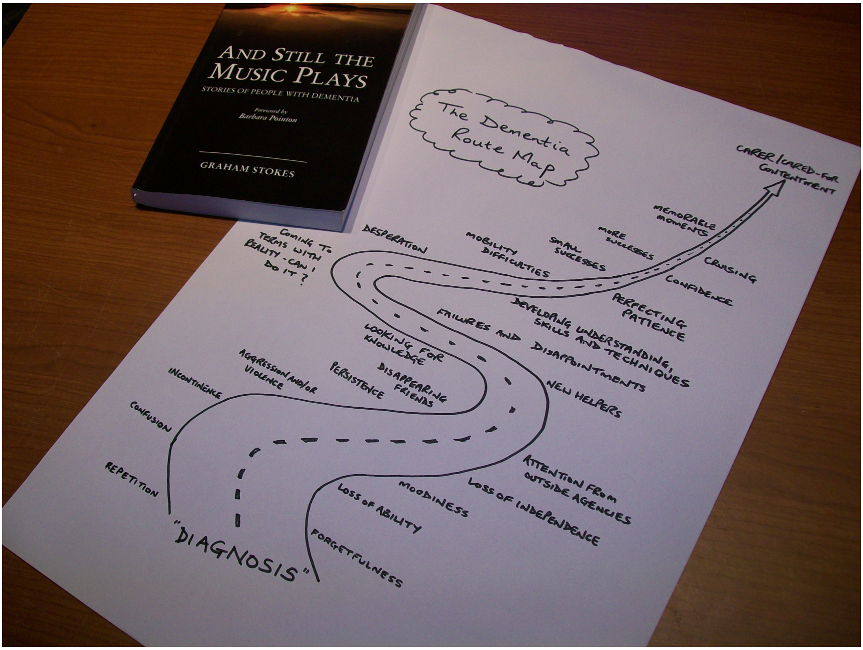
Contents Page

What is Dementia?

- Dementia is a term for a group of conditions whose symptoms may include memory loss, problems with organising and planning, language, problem solving and changes in mood and behaviour.
- Changes may be small at first but may become severe enough to affect the person’s daily life.
- It is important to remember that dementia is not a normal part of aging.
- Dementia is caused by diseases of the brain.
- There are several different types of dementia and the most common is Alzheimer’s Disease.
- Each person is unique and will experience dementia differently.
- Although there is no cure for dementia, there are treatments and support available to help people manage their symptoms and lead active and meaningful lives.

Diagnosis

The diagnosis of dementia involves several steps and can be a stressful and emotional experience for people. It involves the person or family member recognising something is wrong and visiting their GP, who will usually refer the person to a specialist. The specialist will conduct an assessment which includes: taking a history, a physical examination, tests of mental ability (memory) and brain scans. In this chapter family members discuss their experiences of receiving a diagnosis.



The Dementia Roadmap by Eric

Diagnosis

The one thing I probably would have changed is having that difficult conversation with a parent much earlier. I knew what was happening, I knew that he was developing dementia, and we'd had the signs for quite some time, but it's so difficult for a daughter to say to a father 'Your memory's not so good, dad, let's do something about it'. Finding the right time to say that is difficult. I don't think I consciously postponed it because we were coping, but I also knew that it was important to get a diagnosis. It was actually finding the right time to do it because he was fiercely independent.

Jessica

Diagnosis

I wanted a name for the condition! I was sick of being told, oh, it was mental health. Before mum got the diagnosis, because she had a history of mental health issues, that's the route they went down. She was in various psychiatric wards. They even tried ECT on her, nothing worked. So, finally getting a name for this condition means then you can start treating it. Well we know there's no cure for it, they can start dealing with it, I can say my mum's got vascular dementia. So you're in this limbo situation until you get that diagnosis. From my own sense I knew it wasn't Alzheimer's because mum wasn't saying things and forgetting. *Kasim*

Diagnosis

When I first went to the GP with my mum, when she kept identifying that she thought she had dementia, it must have been so frustrating for her not to remember things, and it was getting more regular, the GP just went through basic things like what's your name, where do you live, what's the day of the week, and who's the Prime Minister? And at that stage obviously my mum could answer those questions, but even the GPs then didn't know much about dementia, otherwise why wasn't my mum referred at least two years ago to a dementia specialist or a psychiatrist, when I repeatedly took her to a GP?

Rachel

He'll do something and two minutes later he'd forgotten all about it, which wasn't like him at all. So then, eventually I went to my own doctor, it would have been 2012, and I said I think Pete's got dementia. In fact, the GP only said the other week
'You recognised it yourself, I didn't have to do it, did I?' And I said, 'No, I'd experienced it with my mum".

Sarah

Diagnosis

Once she received her diagnosis, Anne was determined that she was going to continue her activities and go independently, and just deal with it, and she did that for a long time. We used to practice it, we used to say ’Ok so I’ve met you for the first time, what are you going to say to me?' and she would say ’My name is Anne and I’ve got Alzheimer's disease, but that doesn't get in the way of me doing things that I normally do, so I’m not going to remember any of your names but just show me how to do things and I’ll learn as much as I can, and just get on with it'. It sounds silly that we practised it, but we did, we sat down and said 'What are you going to do when somebody says 'Are you ok?' or 'You just asked me that question', what are you going to say to that?' I think that helped her. That basically was our beginning, the beginning of our journey.

Bradley

Living with Dementia

This chapter focuses on carers' experiences of living with a relative with dementia and how they managed various situations.

Living with Dementia

I was beginning to get concerned that what she needed was more consistency, as far as seeing me is concerned, and so I decided that I would come up in a morning and spend the whole morning with her, and then the afternoons I'd fit in all my other commitments into an afternoon. That was very releasing in a sense, freeing, because I was no longer trying to juggle everything, and so the stress was taken away. It's required me to change my lifestyle completely because in order to get up here for 6:30am I have to get up at five o'clock in the morning, and I walk up here so it's good exercise for me because it's two miles. I live two miles away, so I now have to go to bed about nine o'clock in order to get my right amount of sleep.

Bradley

Living with Dementia

I didn't realise what a strain that would be either, you know, having to manage their money, and manage their household as well, that was very stressful. We did power of attorney when dad was still compos-mentis relatively, because we did it as soon as the psychiatrist diagnosed him and we saw the psychiatrist, he told us this is the best time to do this even though you don't necessarily need it now, you know, which was good advice, I think.

Rebecca

One of the obvious things was how to talk to somebody with advanced dementia, and not to criticise but to go with them, you know, and I distinctly remember having arguments with my dad, and that's very, very common, I know, and then you think 'I shouldn't have done that.'

Jessica

I suppose to some extent, it's also how you're behaving with them, like with bad behaviour, your instinct is to be angry with their bad behaviour as you would be if it was a child, and you've really got to subdue that kind of irritation, that sort of anger because that then translates into your response which might be sharper, it might be sharp, it might be justified, but that just makes them respond back again because they haven't got the know how to temper it down. *Eric*

Living with Dementia

That’s a whiteboard with pen and eraser. I’ve got this relationship with my mum-in-law where I know her and I love her. However, the professional carer hasn’t got that bond, so I don’t want the carer to be with my mum-in-law all day, it’d be too much. They need breaks, so I’d have different people in the morning and different people in the afternoon, and the whiteboard I put down all the information like contact numbers of people who they can rely on. If there is any emergencies, doctors, all of those numbers are on the whiteboard, taxi numbers, when she goes out, what she needs, making a list, you know, walking stick, don’t forget, her glasses. I’d make a list, and when the carer in the morning would finish and the carer in the afternoon started, we’d have one section on the white board, if there’s any messages that they must remember, to let the other person know, just to make a quick note on the board, that kind of thing.

Living with Dementia

So it was all about ideas about how to keep her occupied, and we went through the jigsaw routine, knitting and all that stuff, but we were just couldn't think of enough ideas. You get something going and then her illness changes, it’s so that actually it doesn't work for very long. I think the thing that we kept going the most time, which stemmed from the knitting, was getting the ball of wool and winding it into a ball, she would be content to sit, I’d given her a ball of wool, I’d put it over there, I’d give her the end, and she’d sit there winding it up, so that end disappeared, and then I’d give her another one and off she’d go again, she’d spend all day doing that, and she was content with that, because if she didn’t have something to do, then she would be very unsettled.

Eric

Rajan and his mum organising coins to keep her brain stimulated.

And that's the other thing I've realised, through probably my own errors, is that you're best to ask a closed question rather than open ended, because if you're giving them a choice, it's then hard for them to make that decision. For example, I'll say to my mum, "What did you do yesterday? Did you go to park?" So that she can try and process it.

Rachel

I did end up, I sort of had to, I used to put all his clothes out on the, where he slept with twin beds in the back bedroom. I used to put them on the spare bed and I used to lay them out, you know, trousers, shirt or jumper, underpants, socks, vest, all in a line, and then on a morning after he'd been washed or bathed, he'd come back into the bedroom and I'd sort of sit on the bed and I'd say, "Come on now, get dressed." Quite often he'd put the underpants over the top of the pyjama bottoms you know, so we'd to start again, as long as I could, I let him do it himself because all the clothes are there, laid out in order and I used to say, "Come on then, what's next?" I suppose I forced him into doing a lot of things, or encouraged, we won't say forced, encouraged. Used to say, "Come on, what goes on next now?" and then he'd look at himself and say, "Oh, my pants," and then pick them up. But I think yeah, you grow with the illness.

Rebecca

Living with Dementia

He was living in the past basically, so I got photographs and I asked the whole of the family for old photos, and I did this album of, of my mum and dad's, it started out just being about my dad's life, because it was just for him, then it got changed to my mum and dad's relationship, marriage, and all the rest of it. We used to all of us, sit and look through it all the time, and my dad could remember himself as a child. He never recognised himself in the pictures where he was older, he'd say, "Who's that?" I'd say, "It's my dad." I found it really useful for me as well, you know, in sort of looking back and remembering the good times and all. It sounds really corny doesn't it? But it was really nice to do that, pictures of my brother and I when we were kids on holiday with mum and dad and things like that. I thought was very helpful in remembering what a nice life we'd all had together. *Rebecca*

Living with Dementia

It's really hard to know what a journey it's going to be. It's a good job that you don't know. It is a good job because you don't know how much you're going to get angry. I suppose anger, anger and guilt are the two things that I was least prepared for, and yet I knew, I knew in the abstract anger and guilt are around hugely but to actually experience the anger and guilt. Sometimes the anger towards the person with dementia after repeat question after repeat question and I would say, "Oh shut up, you know I've told you 100 times," and she doesn't understand, she can't help what she's saying. But I would say, "Oh shut up," you know, and that takes you by surprise. I still feel guilty about so many things. I could have done things so differently, I could have managed things so differently. I could have coped for longer with her aggression than I was doing. If I'd known what was coming, I would never had had her admitted to hospital. I would never have agreed. I could have protected her in so many ways. There's so many shoulds around. I should have done something, and yet here in the end, you are only human. *Bradley*

I mean one of the things that I sort of learnt fairly early on as I say, there's no point in trying to reason. They were living in a different world from what you are. And you either have to get in that world with them or it drives you bonkers, you know. So that's what I did. *Rebecca*

Living with Dementia

I'd learned long ago that, some of the more effective methods of managing behaviour has been to change the subject, and to see whether that would, would get rid of the preoccupation that she'd got on certain things. Change the subject, do something else, and see whether that got rid of what was happening, not to challenge it straight on, not to deal with something as if it were a reality, a fact, but to switch thinking, and that often worked. So I've never disagreed with Anne, I'd never go head to head with her on anything, that just made things worse, that lesson you learn quite quickly. I used to use non-verbal communication quite a lot, even before she stopped being able to speak, so, we've always been a very tactile couple, so non-verbal hugs and this sort of thing.

Bradley

He used to take the milk from the fridge and put it behind the sofa. I used to look for the milk and yoghurt and then the fridge would be empty and all the things hidden all over the corners of the house. It was so difficult. I am unable to take off my shoes because they will disappear. It was so difficult for me, very difficult. I put a lock on the outside and inside of the kitchen, so when I'm cooking he doesn't come in. You can't stop him either. Like there's so many sweets there, he'll put them all into his mouth and then he'd get a bad stomach and diarrhoea. Then to look after that, it's so difficult. I feel so much at ease now since I've put the locks on both inside and outside kitchen door.

Aisha

Living well with Dementia

I used to worry a lot about what people thought. Every time somebody had a conversation with my mum I would jump in and quickly complete her sentences, complete things that she was doing. It was more of a way of protecting her. Now if someone is having a conversation with her, I don't finish her sentences off. Why should I? It is what it is, it's also more accepted, the condition. As time has gone, my brothers and sisters said, "Right, we need to let everybody know that this is what she's got so everyone understands why she's doing whatever." I went into the protective mode, whereas my brothers and sisters were like, "No, no, we need to let people know." As time has gone one I'm becoming more and more open, so when people have come around and said to me, "So you took her to the doctors what have the doctors said then, there must be something going on," and I'll say, "Well, she's been diagnosed with Alzheimer's." You do find that Indians, anything mental illness related, they just write you off.

Jamila

I found it really difficult to pre-plan what we were going do at weekends, making sure [the family] were available as well. I've got another sister-in-law and, she's very business orientated, so again, you know, to get them to, get a fixed weekend or anything like that was really difficult and so we made a decision: "Oh, right, okay, let's just do the last weekend of the month, can we agree on one of the sister-in-laws being here?" kind of thing. That kind of worked but not very well. But, you know, it's stuff like that that people should really think about, especially if they've got other family members who can help. As a family we need to make sure that everyone, not just my dad is being looked after, we all look after each other and we all respect that and give time.

Samara

This responsibility is almost thrust on you, that you have to kind of get on with it. You have to become a nurse, my wife was a legend. She was changing my mum's pads; she was double incontinent and it was really difficult. Just got on with it. I became so familiar with medication as you do, I knew what doses worked and what didn't, and what she was on and what she wasn't.

Kasim

I just wanted to keep her legs going, because I heard that people can't climb stairs, they forget to walk and that kind of stuff. So, basically, it's just to keep her going as well, because, you know, obviously exercise is very important.

Rajan

Living with dementia

With somebody with Alzheimer’s, you have to prepare for everything. She’s now beginning to wee herself and things like that so we've ordered her some, just as a trial, ladies pull ups and things like that. Just to trial it really because my guess is she’s not going to like them. She’s very proud and she's not going to like them but we have to try them. We’ve ordered her bed covers, plastic bed covers to go under her sheets and things like that. She's only just starting, I think she’s had one episode of weeing herself at night. So just have to keep preparing for things. We are learning as we go along as well, what we need and what we don't need. There’s certain things you know beforehand that you need. *Jamila*

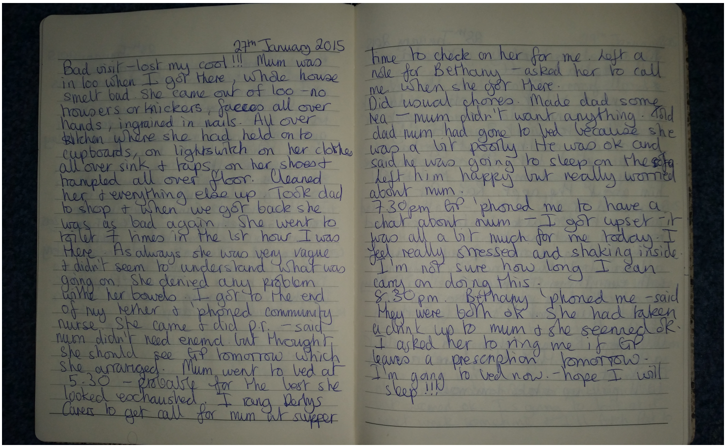
Coping with Caregiving

Sometimes providing care and support for someone living with dementia can become stressful. In this chapter family members discuss how they cope and manage with difficult situations and how they feel. It is important to remember providing care and support is not always stressful but can be a positive and rewarding experience.

Coping with Caregiving

One of the most useful things I found, and I guess this is why I started writing in the care magazine, was other people's experiences. Nobody knows it better than those that have been through it themselves, you know. Even though every patient is different or every person is different. *Rebecca*

I keep my day-to-day diary, that's a good idea because when you're under immense stress you can't always remember everything, and I think also being a nurse I'm always acutely aware of producing evidence … And plus when, when at the end of the day, you want to maybe look back over things you don't always see what was happening clearly. *Rachel*



27th January 2015

Bad visit – lost my cool!!! Mum was in loo when I got there, whole house smelt bad. She came out of loo – no trousers or knickers, faeces all over hands, ingrained in nails. All over kitchen where she had held on to cupboards, on lightswitch on her clothes all over sink + taps, on her shoes + trampled all over floor. Cleaned her + everything else up. Took dad to shop + when we got back she was as bad again. She went to toilet 7 times in the 1st hour I was there. As always she was very vague + didn't seem to understand what was going on. She denied any problem withe her bowels. I got to the end of my tether + 'phoned community nurse. She came + did p.r. – said mum didn't need enema but thought she should see GP tomorrow which she arranged. Mum went to bed at 5.30 – probably for the best she looked exhausted. I rang Derbys Carers to get call for mum at supper time to check on her for me. Left a note for Bethany – asked her to call me when she got there.

Did usual chores. Made dad some tea – mum didn't want anything. Told dad mum had gone to bed because she was a bit poorly. He was ok and said he was going to sleep on the sofa. Left him happy but really worried about mum.

7.30pm GP 'phoned me to have a chat about mum – I got upset – it was all a bit much for me today. I feel really stressed and shaking inside. I'm not sure how long I can carry on doing this.

8.30pm. Bethany 'phoned me – said they were both ok. She had taken a drink up to mum + she seemed ok. I asked her to ring me if GP leaves a prescription tomorrow. I'm going to bed now. – hope I will sleep!!!

Coping with Caregiving

You have to seek support and advice from other people. Now, you know, you can obviously get support, advice, information from leaflets and the internet and all that kind of thing but I'm keen on engaging with other people and one of the reasons is, people can describe things in a different way that you've not thought of. I've often found it is very revealing because they're processing it very quickly. They don't have time really to think about it. And so they're coming to you with a gut reaction. Straight away. And part of the time you think, 'Well alright, if they give it more thought they might come up with something different', you know, but some of the time it is… 'Gosh that's a different way of looking at it. I'd not thought of that before' I'll take it away and think about that.

Bradley

Coping with Caregiving

I've learnt now to cope with it, you see, and then I leave things alone for a few minutes, I might go out of the room if I'm getting a bit frustrated with myself, and come back, and things are back to normal, whatever normal is, you know, he's forgotten what he's said, but it's hurtful at times.

Sarah

I try to be cheerful about it as well. Am I going to do anyone any favours in going around with a mournful face about it? No, it's only going to upset people, there's enough upset in the world without me adding to it. I'm bringing some fun to the people she's sat next to as well, they smile at me, and grin or something, or you know, join in, and it's, I'm trying to just make her life as good as it can be, while there is the opportunity.

Matthew

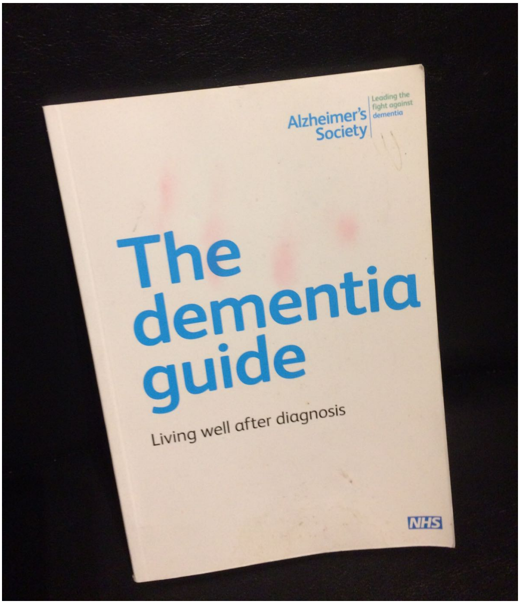
That was the other thing that sustained me, I've got some good friends and they stuck with me through, through the most difficult bit, especially the, what I call work colleagues, because I was working with them very closely … And they stuck with me through it, that was important.

Bradley

Coping with Caregiving

Every person, everybody with Alzheimer's, everyone that's been diagnosed, Alzheimer's affects them differently. So there's not a textbook anywhere which can teach me how to deal with her condition. So it's just, it is just, you know, it's about recognising her changes, recognising her needs, and then just, and then just you know, knowing how, and only you can know that, because you're in that situation.

Jamila



Coping with Caregiving

That's the eating, that's the eating healthily. Now, let's see, since I started running I've been concerned about eating. And that's pretty much my diet [laughs]. I'm not vegetarian, but I'm verging on being vegetarian because I don't eat very much meat apart from chicken occasionally and fish, I do eat fish and chicken but nothing much else. That helped me to feel that I'm retaining my own fitness, it's a little bit like the running. I'm retaining my own fitness. Uh, my biggest fear is that I'll predecease Anne.

Bradley

Coping with Caregiving

I think also being able to talk to more people, share experiences, but everyone I met at that stage was sort of, you know, wonderfully good at it, just able to keep their loved one at home forever and ever, and this sense of I haven't succeeded here. I subsequently found that one of the 'wonderfully good at it' ones, he got through his caring with the aid of a couple of bottles of whisky a week and 20 cigarettes a day. Suddenly I realised, yes, perhaps I was doing reasonably well under the circumstances.

Matthew

People need to be prepared, they need to have an inner reserve of patience, and somehow recharge the batteries. I know it's difficult when you don't want to let go of somebody for a long period, but you need to. I used to have the couple of hours when one of her friends would come and take Heidi out, and maybe I didn't recharge me battery in the right way at those times, maybe I rushed around and got some jobs done that it would've taken me days to do with Heidi as they say 'in tow'.

Fred

Coping with Caregiving

I keep a diary, which is one of the things that's sustained me throughout, because I could go away, no matter how traumatic the day had been, and actually writing it down and logging it and thinking about it, made it more manageable and more, I was more able to think clearly.

Bradley

The most important thing I think about is not having any sort of plans, like, you plan a holiday or things like that, you're not sort of, doing that, so you're just trying not to get into that position where you're just thinking nothing's gonna happen, you know, just gonna be stuck here all the time, you know you got to get out of thinking like that really.

Alan

You don't cope do you? You're just biding your time, any peace you would get would be a relief. Ok mums quiet for about 10 minutes, make the most of it kind of thing, and then it would start again. Hours turned into days, and days turned into weeks, that's how we coped. It was tough.

Kasim

Nothing I can do in my power to stop those changes. Faith is an important part of my life, faith and hope. I have a strong belief in God, and I believe this is what he's planned and this is just what we have to deal with. Faith and hope keeps me going, keeps me going through the changes, the challenges.

Jamila

Coping with Caregiving

When I have a tough day, all I've got to see is him (dog) and it puts a smile on my face, and it's only a dog. Sometimes at work I'm having a really difficult day. I'll go to the toilet, and I'll cry and cry and cry, compose myself and come back out, and I just think God, how am I gonna cope with it. And I've noticed so many times, there's a dog walking by, because I work for, you know, for the Eye Department, so we get a lot of people in with their dogs, so there's always a dog there. So for me, forget even our dog, it's just dogs in general. They're calming, they're soothing, they have a positive effect, and they tell you in some weird way, 'don't worry about it'.

Jamila

Coping with Caregiving

I go mosque and I go one day for exercise, 1 hour and one day I go swimming. So, it's making me release stress. I get to appreciate myself to take this time out, because if I leave it to my mother-in-law and husband they say ‘Oh leave it don't go’ but still I want to go. I want to learn something as well. Fresh air for myself as well.

Ambreen

I go along to the church to meet people, and have lunch with them, but more so for the company. What I’ve found during this caring process is, it’s very isolating and I know now that I spend far too much time on my own and sometimes you think ‘How do I get myself back’. *Rachel*

Coping with Caregiving

Now, I especially like this photo because not only does it represent us doing activities and taking her out for walks, we try and take her out a lot. This week we've taken her out to Costa so many times, she loves going out for a tea and cake and stuff like that. Not only does it represent going out for walks and keeping her brain stimulated, but the rainbows represent hope, it represents miracle, it represents positive things. For me, rainbows have always been a positive thing in my life.

Jamila

Coping with Caregiving

I was very much conscious about giving myself a break and my husband a break on a regular basis. So one day, I would stay with my mum-in-law, and he'd go to the gym or something like that. The next day it'd be my turn to go out and he would stay home, and even though I hadn't joined a gym or anything like that, there's a community group that I joined, they encourage people to exercise and stuff like that. So I joined them, I learned how to ride a bike.

Samara

I will be honest with you, sometimes I lose my temper and then I cry, thinking, 'Oh, I shouldn't have said that, I shouldn't have,' you know, and then you see him crying, that upsets me even more that I upset him.

Jyoti

Coping with Caregiving

I love my garden. Again, it's just a place to get away from it all. To be on your own if you want to be on your own, and think things through, and take out your frustrations. A bit of digging is a good thing to do when you're feeling a bit frustrated, or chopping down a few bushes or something like that. So, yeah, it was a stress relieving mechanism, I would say.

Rebecca

Coping with Caregiving

So for work, you know, we need to strike a balance with that. And my managers understand but at the same time, I just feel a bit uneasy about telling my managers that, “Look, I’ve gotta get away for this appointment.” I can’t do anything about it, it falls bang in the middle of the day. We try to get appointments first thing in the morning or towards the end of the evening, but not everyone works like that.

Samara

Always try and keep yourself a bit happy and merry otherwise you’ll just, you know, get yourself down. It’s pointless. Watch plenty of comedy shows, we do.

Rajan

We coped, we managed, we got through it. And I think that’s the message to other carers as well. It’s really important for people to have faith, you might go through some instability, some insecurities whatever, at the time, but things do work out.

Kasim

Using Services

In this chapter, carers describe their experience of using dementia and carer services.

Using Services

I got pleasure from taking her to wellbeing cafes. There was music, there was a turn on as they say, and she would sit there, clapping her hands, she would get up and dance, or shuffle around. We would dance together and we had our last dance together, at one of those wellbeing cafes. I broke down half way through it, and wept and wept and wept and people, including the psychiatric social worker who was there just ran in and grabbed Heidi, because I couldn't hold her up. I'd gone. And I, and perhaps in a way I knew that was the end. I don't know why. So she enjoyed dancing with me, we weren't dancers, but we shuffled!

Fred

Using Services

We're just going to trial the day centre, just see how she goes, you know, there's always the element of in new surroundings, new people and it might not sit well with her. We're thinking about just giving it a go maybe one day a week or within the next month just have one session and see how she goes. I do think, you know, you shouldn't be embarrassed to ask for outside help, you should try and get whatever help is out there and you should absolutely explore all your options and utilise whatever is out there to help you.

Jamila

I contacted the Alzheimer's Society and they're very, very good, and they have coffee afternoons. We've joined a memory club up at the church, which is run partly by, it's not run by the Alzheimer's Society, but in association with them. And we go to another one, second Monday in the month, and that's a good one, because that's where the people with dementia sit on their own and they have reminiscence times, and the carers go upstairs, and believe me us women we chew things over, but it's amazing what you can learn from each other.

Sarah

Using Services

She didn’t initially want to go to a day centre, when we arranged that. But she said she would go because that gave me a break and that was her reason. She was doing something she didn’t really fancy doing, but she knew I needed some break from caring. To be able to stand back as much as that, it’s a really huge thing to do.

Bradley

Through just word-of-mouth and friends and stuff like that, we found a carer who was a care manager, not in work at the moment, who wanted to go part-time and just do a couple of hours, you know, she wasn’t quite retired, but she was more lady of leisure and she just wanted to do couple of hours a week here and there kind of thing. So we paid her to come, and she was absolutely brilliant. Absolutely brilliant. She knew how to handle my mum-in-law, in terms of if she gets angry, annoyed, or anything like that, how to calm her down. That was a really good find but, you know, it was like needle in a haystack. Who do we get? How do we get? Are they trustworthy? We had to rely a lot on the judgements of our friends.

Samara

Residential Care

In this chapter carers discuss their experiences of moving their relative into a care home and how they chose the care home.

Residential Care

I recognised that he was becoming socially isolated at home, because I couldn’t be with him all the time and living alone obviously. The manager of the care home made a direct connection with him immediately, the staff were very, very good, fantastic home, he made friends straight away, because people were interested in him as a person, and then all the connections with him, and there was an older lady of a hundred who made a beeline for him, and he just made friends. I mean, he had things going on, he was active, so, he settled very quickly. Every time we went we’d take him out for a walk, just round the local streets, because he liked to do that. It was about keeping him physically active and doing what he liked to do. So we did that and, within a very short period of time, well, within the first week, I knew that I could trust the staff. And it was about trust.

Jessica

Residential Care

I think my parents would worry a lot about what other people would think if my grandmother went to live in a nursing home. The community would judge us for not being able to care properly. I'm not really bothered by what other people think, at the end of the day my grandmother deserves the best care and if that's in a nursing home, then I'll take her.

Nasreen

Obligation and duty as a Muslim and as a son, to look after the parents no matter what. The community judges individuals on that, rightly or wrongly, they do. So putting my mum in a care home, so again I needed permission from the Imam, can I seek help? Help for respite as a Muslim? He said they could hear mum, because they're next door neighbours, she needs 24/7 care so yes you are permitted to do that. So the fact that he's given the blessings to do it, I'm still conscious of what the community will think.

Kasim

Residential Care

I visited so many that gradually, it dawned on me exactly what I wanted to find out. I wanted to find out how stable they were and how adaptable they were, and so I used to turn up at the most inconvenient time without any knowledge that they got that I was coming. I would turn up on the door step and I'd say, "All right, it's lunchtime, but I still want to talk about an admission, and I want to be shown around please." So they would have to somehow juggle their staff in order to take me around whilst they still trying to feed and you know all of that. I would also talk to the residents, the ones who were able to talk, find out what they thought about people, and also look at how long people, how long the staff had been here. What their turnover was. That was a critical thing for me, particularly looking at their middle management.

Bradley

In the care homes, I wanted to see some interaction between staff and residents, and that there was care that was being shown, and that there wasn't a smell as soon as you walked through the door, that is not acceptable in terms of incontinence. I'm not the sort of person who wants to look for a sort of five star hotel place, it's about care, relationships that matter first, rather than the quality of the upholstery. *Jessica*

Residential Care

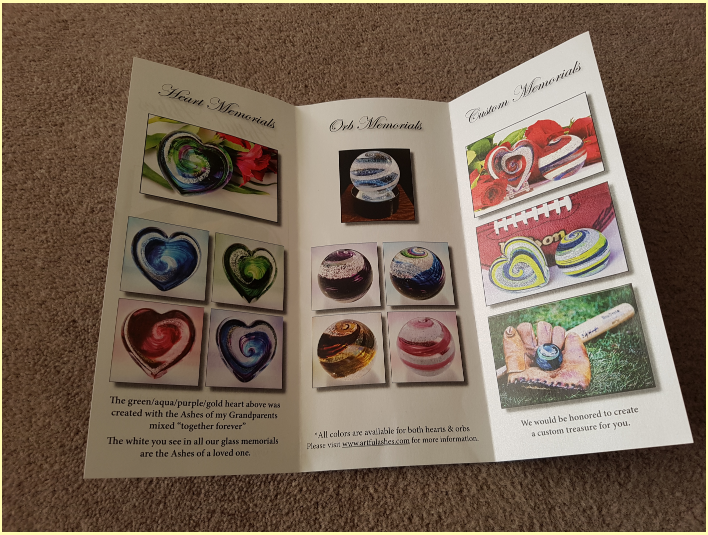
Well, I think if you're going to look, as soon as you get there and walk through the door, really I think you've an idea of if it's good or bad. The way it looks and things I think has a lot to do with it, but I think it's when you go, you've just got to ask questions and if they don't really know the answers or anything, it doesn't seem as if they really know what's happening or what they're doing. Just look at the settings and what they provide, things like that, you know, you've really got to ask questions to be honest, you know, don't be frightened of asking for something that you want to know. I suppose the more you look at them the more you know. And then there's also the CQC reports online. That's what we did and there were quite a few that we didn't know about. Sometimes, most of the time you go, and they're really disappointing, even though people say, "Oh, it's nice, I knew somebody that went there," or, that's not always the case when you go.

Alan

I suppose I've got used to the fact that he's not coming home, I think you just get on with things don't you.

Sarah

End of Life Care



Heart Memorials

Orb Memorials

Custom Memorials

The green/aqua/purple/gold heart above was
created with the Ashes of my Grandparents
mixed “together forever”

The white you see in all our glass memorials
are the Ashes of a loved one.

*All colors are available for both hearts & orbs
Please visit www.artfulashes.com for more information.

We would be honored to create
a custom treasure for you.

This chapter includes carers describing the emotions they experienced once the person with dementia passed away. Guilt was a major theme for carers with many struggling to cope with guilt as they reflected on their caregiving experience. During the project, Fred became ill and his wife Heidi (who had vascular dementia and cancer) had to move into a care home where she passed away. This chapter mainly focuses on Fred’s story and his photographs that he wished to share with you.

End of Life Care

I felt quite emotional really, because it was only two months, since mum passed away, and I got a little bit choked up, and that's the first time that it kind of hit me. After mum passed away, you kind of go through, as Muslims, you're almost there for the community, people come, see you, three days of official mourning kind of thing. But you don't get a chance to grieve yourself, and then it hits you afterwards, that flippin' heck, you know, you've lost your mum. So I literally immersed myself into work, because I, you know, admittedly went through a period of depression after that. So many emotions, you know, the fact that mum was ill, she had so many complications, and she passed away. I didn't feel I could talk to anyone apart from my immediate family. I'm the youngest of my family, and I felt as though I was doing, well, I did more in terms of mum's care and, no one reached out to me, this is all kind of very personal stuff I'm sharing.

Kasim

End of Life Care

I had to calm myself down, and that didn't just happen once, it happened a good couple of times, like two or three times and that's the guilt that was playing on my mind after she had died, I was like talking, having talks to myself: "Samara, could you just not cope, could you not just understand that she's ill and, you know, why did you have to say those kind of things to her? Why did you have to shout at her? It's not her fault," that kind of thing.

Samara

The will is ready, it has been for many years. When he was able to understand, he only had dementia a little bit then, we made his will then. Even now, I'm okay, but I have made my will. It is very important to do so, because the children may fight afterwards and that's not right.

Aisha

Fred's Story

When I go out to places of pleasure that she liked, I always take a little plastic bookmark that I had made, laminated, by the undertaker, with a little prayer on the back and, Heidi's photo and an inscription on the front. I always take that in my diary with me, when I go to places that she enjoyed, so she comes with me to those places, well, it's just my way of coping with her still coming with me. How long I will need to do that I don't know, but I need to do it now.

The keyring Fred had made using Heidi's ashes

Fred's Story

I can't tell you what I'll do next, I've no idea. I know that I need to decorate the staircase and I can't bring myself to do it. I think that I'm trying to occupy myself and not park my backside in this chair too much, although I'm trying to just have a bit of time, me time, sat in the chair. It's different now from when I was a carer, so I'm trying to give myself a bit of that time but I don't like not being active and I realise I need to be doing exercise so I'll go out to do that exercise or I'll clean the house from top to bottom like Heidi used to. But doing decorations and things like that, I'm finding it very difficult, I'm finding it difficult to concentrate on the gardening which I loved.

Things remind you, don't they, from time to time about these things, little things come up and remind you and hit, kick you in the teeth, in a bereavement situation. Various things I can think of. I had to go through Heidi's sympathy cards to me after Heidi's death yesterday, just to remember whether we'd got one from somebody, and it came to me, and I read one of them from one of her friends, that made me cry, the wording on it made me cry yesterday.

We were sat in the church talking, the other day and I noticed the lady had the shoes on that Heidi had a pair of. It had good and bad memories. I had to say to the lady, “I’m sorry, I’m looking at your feet but your shoes remind me of my wife, they’re Rieker shoes.” It reminded me of the good times of Heidi getting those and giving comfort to her and it reminded me of the bad times when I had to get on my hands and knees each time to put Heidi’s shoes on and when I shouted at her, “Lift your foot up, not that one, the other one,” when I was out of patience, so it reminded me of the good times and the bad times again.

Can’t get rid of the guilt, in a fortnight it’ll be the first anniversary of Heidi’s death but the guilt is still there that I didn’t appreciate. Towards the end when I was poorly and I hadn’t realised it, before I went into hospital, every day I was shouting and swearing at things, throwing things around and shouting at her, shouting at myself, just shouting. But I know there were good times and people are still saying to me, “Do you remember you did this and you did that and you used to walk and you always held hands.” Yeah, yeah I do remember that, but I remember more the guilt, the bad times when I didn’t have the patience with her, and she was such a patient person. I think of role reversal, she once said something about that to me, and that cut me, because she had so much patience and she wouldn’t have been like that with me, I’m sure.

Many carers spoke about guilt and the difficulties of managing negative emotions. This photo was taken by Jamila and it reminds her that there is hope in every situation.

I pray, and I ask for her forgiveness. Doesn't absolve me in any way. People say the passage of time will help you and you will not feel the same about it, a lady said it yesterday, her husband had died of dementia, and she said. "It's gets easier, doesn't it?" I didn't want to discourage her and I didn't want to say anything, but no it doesn't, not much, it may well, I don't know and I haven't found any ways of actually coping with it. If there is a guilt there, it has to come out.

Heidi's slippers

Final words

“Someone who has memory problems, Alzheimer's, you should keep them happy, keep them engaged, empower them, and I think you can lead a normal life. Empowerment is a huge element.”

Jamila

I try not to be too hard on myself, because as a carer you just take it all on. You take it on. And you’re a human being at the end of the day.

Samara

Available support

We would like to thank all the carers who shared their stories and photos for this book. They hoped their story would be useful and provide comfort to others.
If you need support please contact the following organisations.

Alzheimer's Society

This charity is designed to support people with dementia and those who care for them. Despite its name, the charity does not exclusively help people with Alzheimer's disease, as there are many types of dementia. Its website is a comprehensive source of information and includes information on symptoms of dementia, caring for someone with dementia, news and activities (on both a national and a local level), training and other resources. There is also an online forum on which people with dementia and their carers can discuss their experiences together.

Website: http://www.alzheimers.org.uk/

Helpline telephone number: 0300 222 11 22

Email: enquiries@alzheimers.org.uk

Dementia Action Alliance

This movement aims to bring about a society-wide response to dementia by encouraging and supporting communities and organisations to take practical actions to enable people to live well with dementia. Its website provides information (including contact details) about a large number of dementia-focused initiatives right across England, most of which offer support and advice to carers of people with dementia.

Website: http://www.dementiaaction.org.uk/

Telephone number: 0207 423 5186

Email: dementiaactionalliance@alzheimers.org.uk

Dementia UK

This service is run by admiral nurses- nurses who specialise in supporting people with dementia and their family members. They can give you more information about dementia and also tell you about support available locally to you.

Website: http://www.dementiauk.org
Telephone number: 0207 697 4160
Email: info@dementiauk.org

Carers UK

This is the UK's largest charity supporting and campaigning on behalf of carers. Its website provides advice and resources relating to a wide range of carer issues, including financial and practical support, health and wellbeing, work and careers, relationships, equipment and technology. There is also an online forum on which people with dementia and their carers can discuss their experiences together.

Website: http://www.carersuk.org/
Advice line telephone number: **0808 808 7777**
Email: advice@carersuk.org

Carers Trust

The UK's largest provider of comprehensive carer support services, this organisation coordinates a network of over 140 Carers' Centres (independent charities which provide carer support and advice in local communities) located in most major towns and cities. Its website provides comprehensive information on (among others) social care support services, carer wellbeing, dealing with healthcare problems, and how to cope with caring responsibilities. There is also an online forum on which people with dementia and their carers can discuss their experiences together.

Website: http://www.carers.org/
Helpline telephone number: 0844 800 4361
Email: info@carers.org

Carers Direct

Carers Direct provides a national helpline service for carers, offering confidential information and advice. This service is part of the NHS and a webchat is also available between 9am to 6pm Monday to Friday on the website.

Website: http://www.nhs.uk/conditions/social-care-and-support-guide/Pages/what-is-social-care.aspx
Telephone number: 0300 123 1053

“Life is a preparation for the future; and the best preparation for the future is to live as if there were none.” Albert Einstein

The Caregiving HOPE study explored how obligation, willingness and preparedness influences the wellbeing of family members providing care to a relative living with dementia. This book is a collection of quotes and photos describing the experience of carers.