



Who Cares?

**An Information Booklet written
by Carers for Carers.**





© Peter Jones, 2018

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means electronic, mechanical, photocopying, recording or otherwise, without prior permission in writing of the author.

A publication of Growing Compassionate Communities
Reg Charity No 1176047



Table of Contents

Foreword. Debbie Hyde, Carers Commissioning Manager	Page 4
Introduction. Peter Jones Chair, Growing Compassionate Communities.	Page 5
Amanda's Story.	Page 6
Wendy's Story.	Page 9
Anne's Story.	Page 11
Jean's Story.	Page 13
Legal Information. Anthony Webber, Coles Miller Solicitors.	Page 16



Foreword.

Debbie Hyde, Carers Commissioning Manager

The number of people caring for someone is huge, one in ten, and rising. Many people do not recognise themselves as carers, they are just helping a family member or friend. They care because they love them, and they would not manage without the help. Many carers are 'hidden' for this reason.

These stories give good information that may help others in a similar position. It is hard to understand what is happening when someone you have known for a long time develops dementia. Hearing about it is one thing, living with it quite another. Meeting other carers can also be of great help, as you can swap tips and stories.

I would recommend trying to put into place the Powers of Attorney if possible. I had this when I was a carer, and it made both of our lives much easier, so don't leave it too late.

Supporting carers is my job, but reading this booklet brought back many memories.



Introduction. Peter Jones.

Chair, Growing Compassionate Communities.

Carers are often the forgotten people in the life of the cared for. They don't seem to figure in the thinking or cultural context of caring for somebody. Often they are missed out in strategic planning for care services. In my experience, their voice does not seem to be heard among the clamor of professional voices.

It is the purpose of this booklet and the general vision of Growing Compassionate Communities to provide inclusive communities where voices like those of carers can be heard, listened to and understood. We can then include these people too.

This booklet offers a vehicle where carers can reflect and share their stories with the wider community, perhaps offering important insights from their journey to other carers who don't yet have a voice.

If you would like to contribute to this booklet in future publications, please contact me. We would love to have more voices heard.

07856 579 750

peterjonescipn@outlook.com



Amanda's Story

Hugh Marriotts book "The Selfish Pig's Guide to Caring" was given to me when I started caring for my dad who was diagnosed with Alzheimer's. It was written for Carers who are anything but selfish but prone to feelings of guilt often brought on by fatigue and isolation. I found it invaluable and it helped me develop my own humorous angle on dealing with dementia.

It cannot be stressed enough that the Carer needs to look after herself/himself. She must strive against isolation. It's all too easy to hide away from the world, turning down invitations and keeping your problems to yourself. Eventually people do give up on you.

Dementia is the new cancer: the "C" word is now the "D" word and as part of our mental health, needs to be spoken about openly. Once we learn to share our worries and anxieties, the load of caring will lighten.

Socialising with or without your cared for one is vitally important. Tips and experiences shared and that feeling of "you are not alone", strengthens your mental health and joining a local Carers group means you can meet other Carers on a regular basis which provides valuable friendship and support.

Exercise, be it a walk in the fresh air, or at your local fitness



centre, increases endorphins, crucial to assist in your caring role. This is leading from the front : your cared for one may be reluctant but will usually join in and reap the benefits too.

This will also promote better sleep.

Taking time to relax, having a hobby and seeking help from your GP when you need it, all assist in your caring role.

Nutrition is extremely important and a good time to sit down and share a meal which you both enjoy. Drinking plenty is essential too as dementia sufferers can be prone to urinary tract infections.

Clothing can be a minefield. Often inappropriate clothing is worn and they can easily become too hot or too cold and have to be reminded to remove a heavy woollen sweater on a hot day.

A day in the life of my Dad with dementia

I would lay out his clothes ready for morning, in reverse order, i.e. his pile of clothes with underwear placed on top. He would need plenty of time to shave, shower and dress, before coming downstairs for breakfast. This he would prepare himself. Coffee, sugar, bread, kettle and toaster all in close proximity to assist his memory.

After breakfast he would read his daily paper and attempt the quick crossword before going out for his morning walk "around the block". In his coat pocket was a card supplied by the Alzheimer's society with his name and address, just in case.



At midday he would have his lunch: bread cheese and fruit, after which he would go upstairs for a nap. This would be followed by another walk and dinner would always be around 6.30. Routine is everything!

A wipe clean board for messages, post it notes and a notebook and diary were all part of the kit to aid his memory. I made a set of cards for each day of the week which stated simply the day, the time for a particular activity and the name of any person involved e.g. " Wednesday, at 10.30, Jeffrey will collect you in his minibus and take you to day centre. " There was also a card with the telephone numbers of myself, my husband, my daughters and my brother.

I developed coping strategies using humour and distraction and soon learned not to argue with him e.g. If he said he was reading a particular novel for the first time, I didn't correct him and say "actually Dad you only read that one last week" but went along with his version of events. Patience is indeed a virtue!

The Alzheimer's Solution by Drs. Dean and Ayesha Sherzai, is a good read, providing insight into the impact on the brain, of nutrition, exercise, sleep and interaction with others.

Early diagnosis was key to assisting my father in his experience with Alzheimer's disease. It meant that he took Aricept (Donepezil) right from the start and regular mini mental tests proved that the drug was shoring up his memory.

Also reducing his alcohol intake was helpful. In fact with healthy eating he was able to stop taking tablets for his high blood Pressure!



Wendy's Story.

My Dad with Lewy bodies dementia.

My dad was diagnosed finally with Lewy bodies dementia after several very upsetting incidences over a period of time. His unsteadiness on his feet at times led the doctor to think he might have Parkinsons, this apparently is quite common with the Lewey bodies form of dementia. Dad came to stay with us initially, when things started to make his life fall apart. There is nothing more upsetting than to see that strong person, your dad, who has always been there for you turn into someone so different. He became the child and the roles were reversed.

I never forget on one particular day, I came home from work and he started to point to some rooftops of the houses behind us. He said, those men have been working on those roofs all day and they don't appear to have done anything at all. At first I said, what men? I then realised he could really see men there!! I went along with it in the end, as he got quite angry when I first said "I can't see any men dad". On another occasion he needed to use the bathroom, he got quite upset and desperate. My husband said what's the matter dad? He said those people are in the bathroom and I badly need to go, my husband did no more than went into the bathroom and say quite sternly. "Please get out, dad needs the toilet and you have no right in here" when he came out he said "it's ok dad they have gone" thanks Ralph says dad and quietly went in. He would at times wake us up in the middle of the night banging on our door saying, there are loads of people down stairs and I can't get rid of them, he was really upset, every light was on in the house, he was quite terrified.



Over time he was seeing things more and more, thank goodness nothing too awful, sometimes cats and various animals. He eventually went into a wonderful caring dementia unit in a local home. One incident that you can almost see the funny side of. We visited one day and noticed the television in the main resident's lounge was missing. When we queried this, you could see they did not want to say. I said, come on what's happened? Well the carer said, Dennis was watching a football match and he got quite excited, so much so he decided to join in the match! He ran at the television to kick the ball!! of course he smashed the television. They did not want him to get into trouble, they knew he could not help it, needless to say, we went out and bought and paid for a big screen to be installed up on the wall in dad's name. Hopefully the residents are still enjoying watching it still today. He got worse over the years and was not really understandable, the one thing I valued though was that he thought I was my mum, this meant an awful lot to me.

Sadly after four quite happy years in the home being very well looked after, he tried to walk out of the main lounge and had a bad fall from his full six foot height he fell flat. The home insisted on caring for the man they had come to love and respect until he passed away.

My biggest joy when I see any of the helpers today is that they always say, whatever he did, he was always a gentleman, that was my dad.



Ann's Story.

Looking After Someone with Dementia

My Mother was diagnosed with Vascular Dementia about 4 years ago. Thankfully it has been a very slow progression since then although at the time I expected her to deteriorate much more rapidly. Medication was prescribed to slow the progression but unfortunately by the time this was done my Mother was at a stage where she refused to take it. When this happens there is little you can do. Luckily the progression of this illness appears to continue to be very slow. In fact my Mother continues to live alone with just some additional support a situation I did not anticipate but am very pleased she is still able to.

What I have learnt is that there are various types of dementia and that it affects each person differently. We have some days where Mum is quite on the ball and others where she will appear to be vague and very repetitive. She will forget to have a meal or even a drink, she will sometimes forget the word for something but talk about the past and we can have a pleasant conversation.

The best explanation I heard was that the brain is like a set of Christmas tree lights. Each time you get the box out you are never quite sure which lights will work and each time you put them away you are not sure if the same ones will work next time. I have found that new places and situations are the most difficult keeping to a pattern is the easiest. People with dementia can almost have a panic attack if they are in a new place and find



themselves alone for a few minutes. That does not mean that you do not try something different you just need to remember things like stay outside the cubicle if they go to the toilet in a new place give them a little bit more reassurance if you are going somewhere new. Do not expect them to settle the first time but don't give up try again.

The more stimulation they have the better things are. We still go shopping but I go to the smaller supermarkets and I check the fridge and cupboards before we go even though we have a list so I can help Mum. You need a lot of patience not to get cross or frustrated when hearing the same tale or concern. What is important is to remain calm the more information I have the better I feel about dealing with the issues that do arise. I take Mum to dementia friendly afternoons and also to dementia friendly carpet bowls. We have made a number of new friends both with and without dementia but we talk and support each other and Mum gets the stimulation of meeting new people. I also registered as Mums carer at the Doctors, you do not have to live with the person to do this and it means that when I ring for an appointment they do everything they can to fit it in around my lifestyle as I still work this is most welcome.

Dementia does not come with a label it is not a visible disability, luckily where we live we have only ever been met with consideration and the more people learn and become aware of dementia life becomes easier for those with it and those who care for them



Jean's Story.

My Journey as a Carer

My husband's symptoms of dementia developed slowly over the past 6 years and first you put it down to old age. I noticed that he was getting very forgetful; he was not able to process or work out what he had to do. Any family gatherings, he would just sit and smile, but not take any active part in conversations. And if there became an opportunity he would escape to another room or go to sleep. He found it difficult to find the right words and make decisions.

His diagnosis was confirmed as **Vascular Dementia** 6 years ago, and he now has both long term and short term memory loss.

From here he became progressively worse and the doctor finally told him that he could not drive any longer.

As time went by I involved Social Services and he agreed to go to the local day centre, twice a week. This he really loved and at first, he was able to partake in some of the activities that they offered. He always came home happy, not able to tell me what he had been doing, but obviously he had enjoyed the days out.

Over the past year his dementia rapidly took a downward tumble and he became very dependent on me, from doing his personal care i.e. showering, shaving, dressing, etc. His food had to be pureed and he had to be fed like a baby. At



the day centre he would not eat and this was becoming a problem to them.

His body clock completely changed, and he was up at night, he would get up six or seven times and just wander around. Then during the day, he would want to sleep.

He used to go into Respite Care a few times a year, and this seemed to work well, he was confused where he was, but he did not cause any fuss. He just went along with the flow, and this gave me a few days to have time to myself.

He finally got to the stage that he did not know who I was or any of his family and still today he has no recognition of us.

After coping with this situation for over a year I finally made the decision with the support of my family and Social Services to place him into permanent residential care.

He has been in residential care for four months and for the first three, my daughter and myself have had to go in every day to feed him as he would not feed for them, and they are not allowed to force feed. After introducing him to a completely sweet diet he eventually started eating again. And now in the past 3 weeks he has started feeding himself and cannot eat enough, at last he has turned the corner and seems very settled and happy, and just loves the care staff that look after him.

He is very settled in his new home and he is not at all stressed when the family leave, and that makes us all feel slightly better, know that he is happy.

Dementia is a very cruel and heart-breaking disease and unless



dementia has touched your life you have no idea what it is like. You cannot argue or reason with that person, you must go along with what they are saying and agree. This can at times be very hurtful.

I found dementia stressful to deal with but joining the local carers group helped me to discuss my feeling and talk to other people who are experiencing similar difficulties. With this support it made my journey slightly easier.

I feel that I cared for my husband as long as I could and he enjoyed his quality of life for as long as possible.

My life after 56 years of being together will not be the same, but I now have to try and move on and do thing with my family and friends and keep busy.

More importantly to talk to other people who understand the situation, and to remember all of the happy times.



Powers of Attorney and General Suggestions for carers .

Anthony Weber. Solicitor. Coles Miller.

At the point where it becomes clear that either you or your partner are starting to struggle to look after your own personal finances, it is critical that legal advice is sought from an appropriate specialist solicitor on an urgent basis

Wills

Firstly it is important that you review whether your will is up to date. For instance if you, your partner or another close family member has been diagnosed with a progressive condition it is immediately urgent that you check what this means for any will and consider revising it. It might be appropriate to leave the share of your estate that you would have left to the vulnerable person to a group of Trustees for them to look after instead of giving the assets to the person concerned. Obviously this type of will trust involves a large degree of trust in the people you might choose to manage your assets after your death and there may be potential issues regarding Inheritance Tax, Income Tax and Capital Gains Tax that require some thought.

It is relatively simple and low cost to instruct a solicitor to review and or update your wills- always use a solicitor who is insured, and regulated by the Law Society and the Solicitors Regulation Authority.



Powers of Attorney or Court of Protection

It is always worth remembering that a Will only carries any legal weight after you have actually died. If before your passing there is a period of months or even years in which you or a loved one lose the ability to manage your own financial affairs, the existence of a will appointing potential executors is of no help. Your family are likely to find that your savings accounts are locked and unavailable and that other arrangements need to be made to pay for any care required. Any property that is owned with the person's name on the title deeds (solely or jointly) will also become unsaleable if the owner loses the ability to understand the documents and process involved in its sale if no one has the legal power to step in.

When someone loses mental capacity to deal with their own affairs, unless they have signed a valid power of attorney, their loved one(s) will need to make an application to the Court of Protection to see whether the Court is prepared to appoint him, her or them to look after the finances of the person concerned. The Court could choose to appoint someone that they would not have chosen, possibly an estranged family member or possibly a Social Worker. In addition the delays costs and ongoing court involvement can make a difficult situation even more stressful and it can take many months for even a straight forward unopposed application to be dealt with.

Lasting Powers of Attorney for both financial decisions and for health and welfare matters are available and need to be signed whilst the person granting the potential power to make these



kind of decisions can still understand the implications and frankly the risks involved. Some conditions can be included as additional safeguards if appropriate and the original documents can be deposited with your solicitor with written instructions as to the circumstances when you are happy for usable copies to be released to your attorneys.

Although the costs of making Lasting Powers of Attorney are more substantial than the costs of making wills these documents can help ensure the people you trust are put in the driving seat if things go wrong and again seeking specialist advice from a solicitor is likely to give you all of the pros and cons to enable you to make a fully informed decision. The likely costs of ongoing involvement with the Court of Protection are likely to dwarf any legal and court fees involved in setting up Powers of Attorney.

If you think you may need help but will struggle to make it into any of our offices we are happy to come to you. My firm has offices in Bournemouth, Poole, Broadstone, Wimborne and Christchurch and act for clients who need our help all over Dorset. Most of us have special accreditation as specialists such as membership of Solicitors for the Elderly and or of the Society for Trust and Estate Practitioners. We try to ensure all of our staff are warm, friendly and helpful and can help with any legal issues arising from these types of situations.




Caregiver

I am the caregiver, the watcher, the guide
I walk down the hall with you by my side
a smile, a laugh, a hug or embrace
I watch the worry fall away from your face
I am the caregiver, the watcher, the guide
I walk down the hall with you by my side
I am your compass, your shining north star
I try to remind you of just who you are
I am the caregiver, the watcher, the guide
I walk down the hall with you by my side
Pictures and letters, music of old
keep your mind warm and away from the cold
I am the caregiver, the watcher, the guide
I walk down the hall with you by my side
the routine of night shows no wear and tear
the light of the morning so soon will be here.

- Lee McCurley





When you are a
caregiver, you know that
everyday you will touch a
life or a life will touch
yours.

Anonymous

For more information, please contact:

Peter Jones,

Chair Growing compassionate communities

07856 579 750

peterjonescipn@outlook.com

ISBN 978-1-899499-83-0