

Surviving dementia as a carer

Anne Haughie



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Abstract

This article highlights the issues and problems that carers must face when looking after someone with a dementia related illness. Many carers become seriously depressed, isolated or even marginalised and the demands of the caring role can cause many physical, mental and emotional health problems that if not addressed can lead to complete mental breakdown and ultimately 'burnout'. The key to surviving as a carer is in developing an understanding of the nature of dementia, together with a realistic attitude to the never ending workload and then to adopt effective coping strategies. This involves accessing and accepting help from many sources; these include cognitive behaviour therapy, complementary practitioners, joining a support group, maximising income and developing a healthy lifestyle. A number of practical suggestions are made that will help a carer maintain physical and mental well-being; some simple tried and tested pleasurable activities are also recommended. The ultimate key to survival is maintaining a sense of humour. Although written primarily for carers, this article will also be of interest to health-care professionals involved in dementia care. A comprehensive list of relevant addresses and telephone numbers is included.

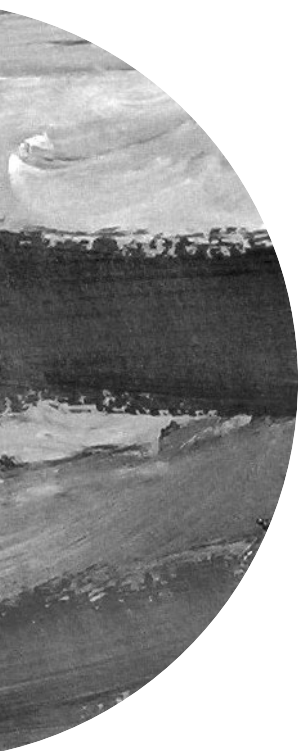
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Dementia affects people from all walks of life. Carers, usually partners or close family members, have diverse backgrounds with varied life experiences. Mostly, we are thrust into the role without any prior qualifications, training or preparation for dealing with what lies ahead.

Such is the nature of dementia that often, in its early stages, nobody but the carer knows there is a problem. A forgotten word, a half-finished sentence, a faraway look, or a flash of fear in frightened eyes. Now you see it, now you don't. Initially, the shift in personality is almost imperceptible. Himself or herself, only more so. Odd behaviour rationalised: A, B, C, or D — Accuse! Bluster! Confabulate! Deny! As the condition progresses, you are faced with situations that would tax the Wisdom of Solomon and are challenged by behaviour that would try the patience of even the most saintly of Saints. There are episodes of forgetfulness or confusion when things are lost or hidden. Keys, watches and wallets are favourites, although knickers and underpants also turn up in the most unlikely of places. Ice cream is stored in the microwave and cornflakes in the freezer. Items disappear into a shopping bag without being paid for. Scissors, socks and even shovels are purchased every shopping trip to then sit forgotten at the back of the broom cupboard or garden shed. Finances are muddled. Bills unpaid or paid twice over. Clothing is worn inside out, back to front, six at a time and, sometimes, not at all. Personal hygiene is neglected. Who needs a bath or shower if you had one four weeks ago? Unsavoury, unappetising and unspeakable habits develop. Why use the loo if you can pee in a cup? Rituals and obsessive or compulsive behaviour dictate that peas must be eaten standing up but definitely not before you've knocked three times on the ceiling!

Intransigence, temper tantrums, aggressive or violent behaviour alternate with panic attacks, acute anxiety and childlike dependency. Can't cook! Won't cook! Shan't! So there! Leave me alone! Don't you dare leave me! Please don't leave me! The same interminable questions are asked again and again. Where did I lose my marbles? Who is the Prime Minister anyway? Does anybody care! Fact and fantasy become interwoven. Insight flies out the window. Lucidity is interspersed with episodes of paranoia. The postman and the window cleaner are plotting to run off with Grandma's silver candlesticks. There may even be delusional thoughts when you are accused of all manner of indiscretions. Oh would that you had the energy or the time but you are expected to be there when you are needed and, what is more to the point, even when you are not!

As the demands placed on you become more and more unreasonable, you discover that being the carer of someone with a dementia is rather like competing in the 'high jump' — sooner or later, no matter how good you are or how hard you try, you just cannot jump any higher. Unlike the athlete, carers do not land elated to a round of applause; we land depressed, defeated and demoralised.



When we are in a caring role, it is essential to remember that there is a limit to our energy, good nature, patience and tolerance. Otherwise we will end up feeling like Ixion, the figure in Greek mythology who was bound to a wheel that revolved endlessly round the heavens. We will certainly be unable to fulfil our role effectively if we become chronically over tired or ill through stress. If we fail to heed the warning signs that we are becoming overstressed, we begin to dread each day and our role as a carer eventually becomes an impossible burden. We therefore need to learn how to manage our reactions to stress in order to help us go on caring.

Stress is a normal part of life. It is the way we react to changes and different situations. Like changes, stress can be positive or negative. Positive stress helps us channel our energies to perform well. Without positive stress we would never achieve anything worthwhile. But even positive stress needs to be balanced with time off for relaxation in order to build up reserves of physical and emotional energy. If stress is constant, we experience negative stress and we become increasingly distressed. Negative stress can cause many ailments, ranging from tension headaches or high blood pressure to complete mental breakdown.

'Burnout' is a state of physical, emotional and mental exhaustion caused by long term involvement in situations that are emotionally demanding. It is a very real potential health problem facing a carer who lives permanently in an emotionally charged environment and who feels under constant pressure to be unselfish and understanding. Whilst it is quite normal to feel tired and bad-tempered at times or to experience bouts of weepiness or edginess when the going gets rough, 'burnout' is when we feel so chronically ground down that we feel we can no longer cope. 'Burnout' is often accompanied by a growing feeling of isolation or lack of control. We may experience feelings of utter hopelessness, hostility to the person we are caring for, resentment of other family members or friends and complete disillusionment with the doctors and health-care professionals with whom we come into contact. We fall into a miasmatic pit from which we can find no escape. It is often impossible to recover our original motivation once we have reached this stage.

The first strategy for preventing 'burnout' is to be aware of it as a potential problem. If we understand that we are at risk and can learn to recognise the early warning signs of stress, we can take action to protect ourselves before we start to burn out. As a carer, we spend much of our life attending to the needs of someone who is dependent on us for their every need. But what about our own needs? Paying attention to our own needs isn't selfish and doesn't mean that we don't care. Instead, this will provide our mind and body with the essential maintenance and nourishment that will allow us to go on caring. Like a privet hedge that needs to be cut back regularly if it is not to get out of hand, a carer's commitments to the demands placed on him or her need regular pruning in order to prevent overload. The key is knowing where the critical point is and stepping back before we step beyond it.

Every day we will encounter things that drain us with little opportunity to be nourished. If we are more drained than nourished, it is inevitable that our inner reserves will eventually run dry. If we are constantly giving out, we also need to have as much coming back in. When managing our personal finances, we all know that income must match or, even better, exceed expenditure but we rarely think to apply this strategy to managing our emotional energy. We need to examine the various aspects of our life that drain us and then weigh these up against those aspects that give us what we need in order to thrive. How does the balance look? A bit grim?

Sometimes it is the expectations we have of ourselves that can put us under most pressure creating intense psychological strain. Can we really expect ourselves to be Superman or Superwoman all the time? It is natural to aspire to high standards and ideals but it is extremely wearing when we cannot achieve them all. How many of those 'must do's' and 'should do's' are realistically achievable by one person with limited energy stocks? When it becomes impossible to juggle all the demands something has to go. This may involve accepting that we can often achieve more by doing less. It is essential to prioritise and to ask ourselves what would be the consequences if we don't achieve everything we expect of ourselves. Will the person we are caring for really come to any harm if we say 'No!' or 'I need a break!' once in a while? Even dementia sufferers cannot have their own way all of the time. Will it really be such a catastrophe if we leave the dusting for another day or don't iron the sheets until tomorrow or even don't iron them at all? Remember — spiders need homes and laundry baskets are not meant to be empty — they are designed to have laundry in them!

Many carers become seriously depressed and feel isolated or even marginalised when they are alone day after day with the person they are caring for. Letting off steam to a sympathetic ear from time to time can help enormously. Talk to your Community Psychiatric Nurse or Social Worker about how you feel. Part of his or her role is to provide carers with emotional support. Find out if there is an Admiral Nurse in your area; these nurses specialise in dementia care and understand the problems facing carers. The Alzheimer's Society has a national helpline staffed during office hours by people who are experienced in all aspects of dementia and who can also put you in touch with support groups and other organisations that you may find helpful. Of course, as we all know, crises (unlike health-care professionals) don't keep office hours or take holidays! If you feel alone or desperate, need to hear a friendly voice or you just want to cry in the middle of the night, the Samaritans are always there, whatever the hour, whatever the reason. Talking to other carers and hearing about their experiences can be very therapeutic — there are telephone networks as well as support groups. While nobody can ever walk a mile in your shoes, we've all trudged up a few steep hills and through some pretty inhospitable terrain.

No-one can be in complete control of all of life's stresses all of the time but we can learn how to manage these more effectively. If we recognise the situations that cause us to feel stressed and we are aware of our reactions to these, we can begin to develop ways to deal with the problems. We may need help to do this and accepting this can be very painful. While most of us don't feel embarrassed about asking for help or technical support when our car won't start or our computer programme crashes or the washing machine goes berserk and floods the kitchen, we all find it harder to ask for help when we think we may risk exposing an area of our own weakness or vulnerability. We often perceive our difficulties in coping as a carer as personal failure or lack of personal qualities rather than as in the nature of the impossibility of dementia.

Developing a positive attitude to the problems we experience as a carer is an important skill in managing stress. Cognitive behaviour therapy (CBT) can help us to understand the role that our mind plays in how we feel and how we respond to what is happening to us and the person we are caring for. Sometimes we are too close to the problems and become overwhelmed by their enormity or we get bogged down by going over the same ground again and again. It is easy to become involved in infuriating and emotionally draining circular arguments with the person we are caring for. A cognitive behaviour therapist can help us to look at things from a different perspective and to think more flexibly. It may not be possible to change our overall situation but we can be helped to handle that situation and the way we react to it more positively. For example, we can learn how to respond to challenging behaviour. If we think about the behaviour patterns that most wind us up or grind us down, we can decide whether realistically we can change them. Often we can't. We all accept that we cannot change the weather. We may grumble about it but we know there is nothing we can do other than adapt to its vagaries or leave the country. Dealing with dementia is really no different. Once we understand this, we can start to learn new coping strategies. With help we can also come to terms with our anger and frustration and overcome depression, low self-esteem and negative thoughts. Feeling good about ourselves and being confident helps us to develop assertiveness and negotiation skills and a 'won't be made to feel guilty', 'won't be bullied', 'won't be ground down' approach to the challenges of being a carer.

Financial worries add greatly to stress and there are several benefits and allowances to which carers are entitled that will help improve your financial situation. Tackling the complicated forms and paperwork can be very daunting but if you contact the Benefits Agency (Social Security) arrangements can be made for an adviser to visit you at home and help you fill in the forms or talk you through them over the phone. If you or the person you are caring for has become muddled or behind with tax affairs, it is tempting to ignore the tax demands and bury your head in the sand, which just makes everything more scary and difficult to face. In these circumstances, the Inland Revenue will give you a sympathetic hearing (trust me!) together with practical advice. Arrangements can usually be made for penalties to be deferred or even waived and for you to be given extra time or help to complete the tax return. You may also find it reassuring to discuss your financial affairs with an Independent Financial Adviser (IFA) who can assist with budget planning and help you to maximise your income and any savings or investments you have. A solicitor will advise on legal matters such as setting up an Enduring Power of Attorney so that you can sign

documents and take important decisions with regard to property and financial affairs on behalf of the person you are caring for. Your local Citizens Advice Bureau can advise on finding an IFA and a suitably experienced solicitor.

For many carers becoming 'home manager' is often a completely new role that dumps previously unfamiliar challenges on us. After years of being able to rely on someone else to deal with those niggling little jobs such as putting up shelves and curtain rails, replace leaking tap washers, move heavy furniture around the home, climb up stepladders to change light bulbs or go rummaging around in the loft for the Christmas tree, or assemble flat-packed furniture with a screw driver that has a mind of its own (Omgod!) suddenly we have to cope alone. It is often these trivial but essential tasks that become the last straw to break the camel's back at a time when we have so many additional stresses to cope with. A telephone call to your local office of Age Concern will put you in touch with their 'Handy Person Service'. There is no charge for their help; you just pay for the cost of any materials required.

Physically fit and healthy people are better able to handle stress than those who are not. A healthy lifestyle includes following a balanced diet with limited intake of caffeine, salt and fatty foods, cutting back on the cigarettes and down on the alcohol (oh dear!) watching our weight and introducing some moderate daily exercise such as a brisk walk or a swim. Establishing a regular sleep pattern is also very important. There are many relaxation techniques that can help; these include breathing exercises, muscular relaxation, visualisation, meditation or quiet contemplation.

A referral by your GP to a homeopathic practitioner, aromatherapist or other complementary practitioner may also be helpful; these professionals have excellent listening skills and can advise on the many natural remedies that can help with stress related problems. Some of these treatments are available free to carers through the NHS. Your doctor or practice nurse will know what is available. Many local authorities run low cost, physical activity and leisure schemes (PALS) at local sports and recreation centres that introduce people to a wide range of carefully graded exercise and activities that aid physical and mental well-being. Again speak to your doctor or practice nurse or contact your local Leisure and Recreation Services via your Town Hall for further information.

The Carers Gateway (Kirklees) is an organisation that is funded by Social Services and the local authority and runs an extensive programme of activities and training for carers in Kirklees, together with social and respite breaks in an informal setting. Transport and care cover are available. Many branches of the Alzheimer's Society also provide training for carers. The Dementia Relief Trust (the organisation that trains Admiral Nurses) and the National Association for Providers of Activities for Older People (NAPA) both hold workshops and training events which informal carers as well as professionals are welcome to attend. Carers UK and The Princess Royal Trust for Carers are two more useful organisations to contact.

Don't forget about your spiritual needs; these can be met in a variety of ways, not necessarily religious; a vase of beautiful flowers, a work of art or classical music can all work wonders for your spiritual well-being — try listening to Ludovico Einaudi's piano music on his album 'I Giorni'. Even if you are unable or do not wish to attend a place of worship or feel you cannot pray or do not believe in the power of prayer yourself, you may appreciate a pastoral visit or find the knowledge that others are thinking about you and praying for you to be of great comfort.

One very important matter you may have felt too embarrassed to bring up with anyone — and doctors often hesitate to probe — is your sexual needs. If you have previously enjoyed an active and fulfilling sex life with a spouse or partner and are deprived of this as his or her dementia progresses, this can have a devastating effect on your emotional wellbeing. Or if you have had sexual or relationship problems for a long time but you previously had an interesting job or social life that compensated for this, you may experience feelings of resentment, frustration, loneliness or great unhappiness as these outlets are denied you in the need to be a full-time carer. If you simply try to ignore your sexual needs or attempt to repress them, your inner turmoil will inevitably come back to haunt you in your dreams; this can cause sleep disturbances, physical symptoms or even severe depression. Talking your feelings through with your doctor, priest, therapist, counsellor or trusted friend can help you come to terms with the problems and explore ways to meet your needs. You may wish to contact Relate; its counsellors are experienced in supporting people through all

kinds of emotional conflicts; they are entirely non-judgemental and anything you discuss with them is completely confidential and will never be disclosed to anyone.

Physical and emotional well being will improve if you learn to enjoy what little free time you have and stop feeling obliged to cram every minute of your day with work and chores. A pleasurable activity can help you to relax and unwind and to be effective, this does not even need to take you away from home or the person you are caring for. Put on headphones, turn on some relaxing music and drift off into a world of sun, sand, sea and sangria. Make a reminiscence or memory box by collecting together favourite photographs and objects that bring back memories of happy events in your life.

A pet can be a wonderful companion but, if pet ownership is not practical or possible for your circumstances, a national charity called Pets as Therapy (PAT) has local volunteers who will visit individuals or groups regularly with a dog, cat or even a rabbit specially chosen for its friendly nature and 'cuddle-ability'. Many people derive a great deal of pleasure from attracting wild birds into their garden. The acrobatic antics of a couple of blue tits hanging upside down from a peanut feeder are delightful to watch. A group of starlings or sparrows squabbling over some food scraps or elbowing each other out the way so they can take a bath in a shallow bowl are hilarious. A robin or a blackbird will soon have you trained to appear at the same time every day with some grated cheese or a few raisins or sultanas. If you dig up a couple of juicy worms, the robin may even become bold enough to take them from your hand. Lack of a garden isn't a problem; there is a vast range of feeders that can be attached to a window or window ledge. You can even buy worms in tubs! Magazines, catalogues and feeding guides that are available free of charge from the Royal Society for the Protection of Birds (RSPB) and many seed companies can open up a whole new world of never ending entertainment through your letter box and living room window. Get out to the local park and feed the ducks — they will never fail to cheer you up as they dip and dive 'up tails all' or come waddling to greet you, especially when they have their ducklings in tow. And of course, you will also meet people of all ages who will enjoy a chat.

At the end of the day, a critical factor in hanging on to your stress levels depends on hanging on to your sense of humour. Laughter remains the best medicine of all and is the cure for many ills. After all, it is quite normal and perfectly reasonable to feel like murdering someone who is difficult and demanding — it only becomes unreasonable if you actually go ahead and do it!

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Useful addresses and telephone numbers

Carer support, information and training

Alzheimer's Society

Gordon House
10, Greencoat Place
London
SW1P 1PH
National helpline: 0845 300 0336
Website: www.alzheimers.org.uk

North Kirklees Alzheimer's Branch Office: 01924 444074
North Kirklees Support Groups: Roy Isherwood,
01274 870154

Carer's Gateway (Kirklees)

6/8 St Peter's Street
Huddersfield
HD1 1DH
Tel: 01484 226050
email: carers.gateway@kirkleesmc.gov.uk

The Dementia Relief Trust

6 Camden High Street
London
NW1 OJH
Tel: 020 7874 7210
Website: www.fordementia.org.uk

Carers UK

20-25 Glasshouse Yard
London
EC1A 4JT
Information line: 0808 808 7777
Website: www.carersonline.org.uk

Princess Royal Trust for Carers

142 Minorities
London
EC3N 1LB
Tel: 020 7480 7788
Website: www.carers.org

National Association for Providers of Activities for Older People (NAPA)

Contact: Tessa Perrin
12 Walter Way
Silver End
Withan
Essex
CM8 3RJ
Tel: 01376 585225

Age Concern

Astral House
1268 London Road
London, SW16 4ER
National Information Line: 0800 00 9966
North Kirklees Office: 01274 871328
Website: www.ace.org.uk

Emotional support

Samaritans

The Upper Mill
Kingston Road
Ewell
Surrey, KT17 2AF
National helpline: 08457 90 90 90
Website: www.samaritans.org

Relationship problems

Relate

Herbert Gray College
Little Church Street
Rugby
CV21 3AP
National helpline: 08451 304 010
Website: www.relate.org.uk

Coping strategies

British Association for Behavioural and Cognitive Psychotherapies:
Globe Centre
PO Box 9
Accrington
BB5 2GD
Tel: 01254 875 277
Website: www.babcp.org.uk

Spiritual support

Faith in Elderly People (Leeds): 01943 879320
Huddersfield Deanery Project for Older People:
01484 300094

Financial advice

Benefits Enquiry Line: 0800 882 2200
Inland Revenue: 0845 915 5996
Citizens Advice Bureau: 020 7833 2181

Physical activities and exercise

Kirklees Active Leisure: 01484 234097

Companion animals and birds

Pets As Therapy (PAT)

17 Ambrook Road
Reading
RG2 8SL
Tel: 08702 401 239
Website: www.petsastherapy.com

Royal Society for the Protection of Birds (RSPB)

The Lodge
Sandy
Bedfordshire
SG19 2DL
Tel: 01767 680551
Website: www.rspb.org.uk