

DEMENTIA

CHOOSE THE BEST CARE

Preparing for the future:
From organising your finances
to searching for the right care
home for you or your loved one



Know the signs
This week
is Dementia
Awareness Week™



ALZHEIMER'S SOCIETY

How I manage
Jane Ward talks
about life as a
full-time carer



PRIVATE

PHOTO: ROBERT KNESCHKE / SHUTTERSTOCK.COM



All we have is now - learning to live in the moment

Feelings become heightened when experiencing a dementia
Experiencing dementia reveals what matters most in life
Exploring the meaning behind peoples words and behaviours is the key
Learning that BEING in life matters more than 'doing' is a way to live well with dementia



Dr David Sheard
Chief Executive / Founder

CHALLENGES

A diagnosis of dementia can come as a shock. Even when anticipated, it brings many challenges for both the person themselves, and for their friends and family. But there are many sources and strategies available to help make life easier

Looking to the future

Jane Ward was travelling the world until her mother Ella developed vascular dementia several years ago. Now, instead of camping in the Himalayas, Jane camps in her mother's living room, making sure she has everything she needs, 24 hours a day. There are thousands of people like Jane around the country, who give up so much to make sure their loved one is safe, happy and cared for. At Alzheimer's Society, we are proud to give Jane support, fight to improve her mother's rights and fund research that could help find a cure for the condition which has changed both of their lives so dramatically.

This Dementia Awareness Week™ we are pleased that public awareness and understanding of dementia is growing, with big names such as Terry Pratchett and Glenn Campbell telling the world they have the condition. But much more needs to be done. One in three people over

65 will die with dementia, yet investment into dementia research is eight times less than that spent on cancer.

For the unsung heroes caring for people with dementia day in and day out, it can be hard to know where to turn for help. In addition to worries about their loved-ones' health, carers have to make difficult decisions about their welfare, financial affairs and other legal matters. The emotional, physical and financial burden on carers can be immense. They save the NHS an estimated £6bn per year, yet many struggle to make ends meet.

But help is out there. The Alzheimer's Society offers advice, information and support for carers on every aspect of dementia - from finances to diet to legal questions. Our National Dementia Helpline offers advice, and directs callers to the best services and support in their area. Our support workers help negotiate the intimidating and confusing process of applying for financial support. Our campaigners fight tirelessly to influ-



Jeremy Hughes
Chief Executive, Alzheimer's Society

TOP TIPS

Dementia Awareness Week™

- 1 Treat the person with respect and dignity
- 2 Be a good listener and communicator and stay in touch
- 3 Offer practical help - shopping or mowing the lawn can make a big difference
- 4 Find out more about dementia and seek out support groups and help in your area
- 5 Call Alzheimer's Society for more help and support on 0845 300 0336 or visit alzheimers.org.uk

ence decision makers and frontline workers, to help improve the treatment and support people with dementia receive.

This Dementia Awareness Week™ we are asking people to remember people living with dementia. The theme aims to take the fear out of dementia. People must realise that individuals living with dementia are the same people they were before developing the condition. But as well as reducing fear and stigma, remembering the person can be incredibly beneficial in helping to connect with a person living with dementia. Using songs, images or stories from earlier in their life can be extremely helpful - that's why interactive Alzheimer's Society projects like Singing for the Brain are so popular.

If you need more information, visit alzheimers.org.uk/remembertheperson to find out about Dementia Awareness Week™ events in your area. Together, we can raise awareness, provide support, campaign, and ultimately, find a cure for this devastating condition.



WE RECOMMEND



Helena Herklots,
Services Director,
Age UK

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'Firstly, an obvious but critical point; make sure that all important papers are in order and that family members know where to find them'

MEDIA
PLANET

We make our readers succeed!

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Dedicated dementia care for the people you love the most

We all want the best for the people we love, but there may come a time, particularly if you’re responsible for caring for someone with dementia, when you feel you are no longer able to cope or to offer the very best quality of care at home.

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For further information about Care UK’s dementia services or to find out where your nearest Care UK home is please call us on 0800 011 4217 or visit www.careuk.com/dementia

Residential Care Provider of the Year 2011 – HealthInvestor Awards

INSPIRATION

Question: What are the issues to confront when considering a care home for someone with dementia?

Answer: The decision to place a loved one in a care home is never reached easily. But the right one can make all the difference to their emotional and physical health - and to your peace of mind

Find the key to happiness

CHANGE

It's vital to find the right care for everyone. For some people, it is more appropriate to find support so they can stay in their own home - but if residential care is the right choice, the right home can make a huge difference, says Louise Lakey, policy manager at the Alzheimer's Society.

"People need to be able to live their life happily and well," says Louise. "This means identifying an environment that gives them choice, control and helps them feel valued."

It is vital to ensure the home has staff qualified and trained in dementia care, as well as medical training for any other needs the person might have. Some homes are registered to provide nursing care, for example, which means they have a qualified nurse on duty 24 hours a day.

But dementia care is also about helping the person feel loved and respected. A good home can mean a good quality of life: this means



CHOOSING THE RIGHT HOME. It is important to visit care homes at different times of the day to help in the decision making process

PHOTO: LISA F. YOUNG/SHUTTERSTOCK.COM

treating people with dignity, respect and warmth, providing opportunities for social interaction and the chance to do things they enjoy, as well as being able to make decisions on their own, says Louise. "We've heard from many people who have talked about their loved one becoming happier and calmer, just by moving to a home where the staff really understand their needs."

For friends and family, moving a relative into a home can be unsettling for everyone involved, points out Louise. But sometimes a care home can be the right decision - for the person with dementia or for the carer. The act of caring can be physically demanding and if the carer's health is suffering, moving the person with dementia into the right home can be a relief physically and emotionally. Just as

the right care can enhance a person's quality of life, the wrong care can damage it.

"If a person's needs are not met in terms of diet, activities, religious or cultural needs, it can have a negative impact on health and wellbeing. If staff don't know how to deliver good care for someone with dementia there is a danger the person could be left on their own, which could lead to them becoming frightened, distressed, or withdrawn."

The Alzheimer's Society has produced their top tips on choosing a care home which you can access at alzheimers.org.uk/carehomes. After reading these, it's a good idea to look at the information available on the Care Quality Commission's website. This lists homes in your area and states if a home meets essential standards of safety and quality.

The next step is to contact the home and ask about the level of care, fees and the waiting list. You could also ask your local

Alzheimer's Society office if they could recommend any homes in your area.

Visit a number of homes, and return to the same home several times, at different times of day. See how it feels, how staff interact with residents, and if they relate to people on an individual basis. Ask if staff have had any dementia training. You could also investigate arranging a trial stay for your loved one. Find out if the home offers specialist care that would meet their needs, and ask about dietary options, entertainment and trips out. Don't forget to ask your loved one how they feel - and which home they prefer.

To help people make the right decision, the Alzheimer's Society has designed a free guide on choosing a care home, which is available to download free at alzheimers.org.uk in the 'About dementia' section.

EMILY DAVIES

info.uk@mediaplanet.com



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NEWS

The secrets of my strength

Question: Jane Ward provides continuous care for her mother, who has dementia. How does she cope?

Answer: From writing down her feelings to pursuing her own interests and talking to others in similar circumstances – the situation requires several different strategies

Jane Ward's mother, Ella Fuller, 82, has vascular dementia. After Ella's diagnosis three years ago, Jane changed jobs so she could be around more to help. She soon became a full-time carer, visiting daily. Then last winter when it snowed, it wasn't worth the risk of going home so I stayed behind, and have been camping out in her lounge ever since," she says.

"I do just about everything," Jane explains. "I make sure she dresses appropriately for the weather, and through the day I keep her entertained, make her meals and ensure she takes her medication. I also take her out to places to eat that are appropriate."

Every Monday Jane, who has worked as an engineer and then as an English language teacher across the world, has five hours of respite care. "This gives me time for myself because other times, even when she's asleep, I am still always alert listening for her." How does Jane manage? "If I have had a bad night I



LEARNING FROM EXPERIENCE. Jane Ward, whose mother has vascular dementia, finds that understanding the reasons behind the illness helps her to cope

PHOTO: PRIVATE

write it down: you expend it by getting it down on paper. Also, the engineer in me wants to know what is going on so I have been doing a lot of

reading, too. Part of me is my mother's daughter who just wants to care for her, but another part of me is analysing why she's doing things and

FACTS

■ **Dementia is** a term used to describe various different brain disorders that have in common a loss of brain function that is usually progressive and eventually severe. There are many types: most common are Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

■ **750,000 people** in the UK have dementia; the number being diagnosed is steadily increasing

■ **60,000 deaths** a year are directly attributable to dementia.

■ **Diagnosis is** often difficult, particularly in the early stages. The GP is the first person to consult, who may then refer to a specialist consultant. It can include conversations with the person and their relatives, a physical examination, memory tests and/or brain scans.

SOURCE: ALZHEIMER'S SOCIETY

behaving that way. When you realise what's behind the behaviour it helps an awful lot in not taking it personally.

"I have also found ways to have interests that fit in with caring: I've started taking pictures of the birds in the garden." Jane sees a counsellor every six weeks. "For a long time I have travelled to a lot of new places and fitted in with different cultures: I'm treating this as another adventure, almost. I'm at home with someone I know well, but she's not the same.

"Sometimes Mum really upsets me: I never used to cry in front of her, but now I allow myself to cry if I need to. One thing my mum can still do is just be my mum - if she sees I'm upset she can still give me a cuddle and reassure me. For me, that really helps. They are still the person they always were."

Jane suggests seeking out specialised information and support groups: "I'm a member of a carer support group and of Alzheimer's Society. It's amazing to know someone else is going through the same thing as you.

"It is also important to learn to forgive yourself. You can beat yourself up about things you could have done better, but it's vital to accept you are only human."

EMILY DAVIES

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Caring for the carer

Being a carer can be very difficult – but there are ways to relieve the burden

When you're caring for someone with dementia, it can be easy to ignore your own needs. It's much easier to cope if you look after your own wellbeing, and there is lots of support available to you.

Be prepared for the fact that you will need support at some point. You will probably need different types of help, ranging from practical care to give you time off from caring to having someone to talk to about your concerns.

Think about what help you might need, and where you can get it, before you actually need it. That way, when the time comes, you'll know where to turn.

Be explicit about what support you need, especially when you are seeking support in the form of services, and be assertive and persistent.

Make it clear that you cannot continue with your caring role unless you receive the support that you need for yourself.

Consider a support group or an online discussion forum such as Alzheimer's Society's Talking Point - forum.alzheimers.org.uk/forum

LOST

MEMORIES, INDEPENDENCE, IDENTITY, MIND

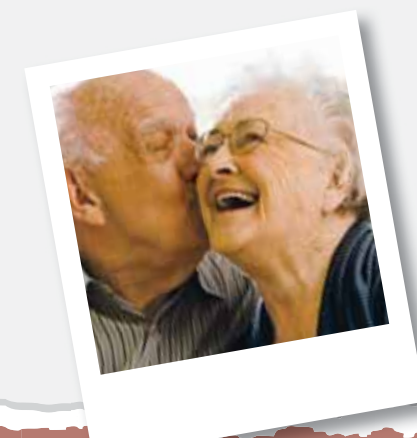
Often people living with dementia and their families feel **lost...**



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NEWS



PLAN AHEAD
It is important to
organise your finances
while you still have the
capacity to do so
PHOTO: EDBOCKSTOCK/
SHUTTERSTOCK.COM

The importance of control

Question: Why is it so vital for a person with a dementia diagnosis to have the financial and other aspects of their life in order?

Answer: To ensure that in the future their affairs will be set up in a way that they have chosen; and that decisions they are no longer able to make are made in their best interests and reflect their views and wishes as closely as possible

If someone has been diagnosed with dementia, it is important that they organise their financial, legal and personal affairs while they still have the mental capacity to do so, says Helena Herklots, services director at Age UK.

“Firstly, an obvious but critical point; make sure that all important papers are in order and that family members know where to find them,” Herklots points out.

The Mental Capacity Act 2005 (2005 Act) has been in full force since October 2007. It aims to protect people who may not be able to make certain decisions for themselves and to empower them to



‘It’s vital to know what assistance may be available to help you meet the costs of care’

Helena Herklots
Services Director, Age UK

make their own decisions when possible. It makes provision for people, while they have the mental capacity to do so, to choose someone (the attorney) to manage important decisions on their behalf. They will be able to do this through a lasting power of attorney. There are two types:

■ a property and affairs pow-

er that gives the attorney authority to make decisions about financial affairs

■ a personal welfare power that gives the attorney authority to make decisions about healthcare and personal welfare.

Paying for care needs, such as support at home or in a care home, can be a complicated topic.

FACTS

■ **Make sure** that all important papers are in order: these might include bank and building society statements, records of mortgage or rent, insurance policies, a will, tax and pension details and bills or guarantees.

■ **It is important** to make sure that

the person with dementia and their carer are receiving all the benefits to which they are entitled. For full details contact the head office of the Department for Work and Pensions (DWP, previously the Benefits Agency).

SOURCE: ALZHEIMER'S SOCIETY

Herklots advises. “It’s vital to know what assistance may be available to help you meet the costs of care.”

The first step towards getting help from social services is to ask the local authority to carry out a care (or needs) assessment. The local authority must carry out an assessment of your needs if you appear to be someone who might need the type of assistance it can provide. They have to consider eligibility for services and assess individual needs without regard to financial circumstances: they have a legal duty to meet eligible needs.

Once these needs have been identified, a means test will be carried out. The means tests are based on Government guidance. A person’s carer also has a right to an assessment of their needs and support services, such as respite care.

Age UK is the lead funder of The Disconnected Mind project, a unique study that will unlock the solutions to healthy mental ageing. For more information, visit www.ageuk.org.uk

EMILY DAVIES

info.uk@mediaplanet.com

The future’s bright

Advancement in technological research and development now bring new hope to those with dementia – and to their families, increasing safety and easing anxiety

There are many types of technology available to aid people with dementia and their carers. My Beacon is the name of a family of devices, developed by NHS Innovations South East and Follow Us, which aim to track a person who suffers from short-term memory loss if they wander, become lost and cannot find their way home. It combines GPS and GSM technologies, housed in a digital watch that allows a carer to determine the individual’s location, direct to their mobile phone.

This technology allows a person suffering with short-term memory loss to be given more freedom to live their daily life, and reduces the anxiety and worry for carers. In certain instances a person’s condition means they are forced to leave the family home for a residential care facility: in this case, assistive technology can allow the person to remain in their home and with their family for much longer. Research suggests that should a patient become lost, the likelihood that they will be institutionalised increases greatly.

“It was so wonderful not having to worry,” says one carer, who looks after her husband who has dementia. “My husband has had to go into a care home now, but we are so grateful for the extra time that being able to locate him gave us together.”

Wandering can happen at any time, without an assistive device the person may only be found after many hours, for example by a police helicopter, and may need hospitalisation, which further adds to the trauma.

The use of a fully operational GPS and GSM-based system can ensure that should someone wander and become lost, they can be located quickly at any time of day or night, anywhere in the world.

The relevant ethical considerations are discussed in detail at www.wanderingindementia.co.uk

Dr Tahsin Choudhury is innovation manager at NHS Innovations South East

Do you have what it takes to be a Dignity Champion?

Dignity in the care of the elderly is a sensitive topic these days especially when the prevention of abuse of the elderly in care is high on the agenda of local authorities and the Care Quality Commission which regulates the care industry.

Regal Care Homes, which operates homes throughout England, has been a major proponent of dignity in the care of the elderly. Dignity is particularly of importance when it comes to care of residents with dementia. A member of staff at Loose Court, one of Regal's homes in Kent, had this to say 'Being a champion for dignity is something that I believe passionately in as we all receive care or know someone important to us who is receiving care. It doesn't take much, indeed it is the little things that count most and being a champion is about just having the mindset of asking how can I make this better, then acting on it.' The Dignity in Care Campaign was launched by the Government to stimulate a national debate around the need for people receiving care services to be treated with dignity. The aim is to create a care system where there is a zero-tolerance approach to the abuse of, and disrespect towards, older people. The campaign is about winning hearts and minds, changing the culture of care services and placing a greater emphasis on the quality of care services in, for example, hospitals, care homes and home help services.

What is a Dignity Champion?

Dignity Champions are people who believe that ensuring dignity and respect for people using care services is a cause worth pursuing. To Dignity Champions, being treated with dignity isn't an optional extra, it's a basic human right. They believe it is not enough that care services are efficient. They must be compassionate too. Champions aim to work in partnership with care providers to improve the quality of services. Dignity Champions are people who, in their own way, are committed to taking some action, however small, in order to create a care system that has compassion and respect for those using its services. Don't be put off by the term 'Champion'. The role is not intended to require lots of time, energy and experience. For example, even commending staff on a personal level for



Hawthorn Lodge in Nottingham: another dignity proponent at Regal

respecting dignity helps this campaign. Dignity Champions include health and social care managers and frontline staff. They also include MPs, councillors, non-executive directors, members of local action groups and Local Involvement Networks, and people from voluntary and advocacy organisations. People who use care services, their relatives and carers, as well as members of the public, are also becoming Dignity Champions.

Should I be a Dignity Champion?

The first question to ask yourself is: do I care about making services better for people, treating people as individuals, ensuring that they feel respected and getting the basics of care right? If so, you qualify. Each Dignity Champion's role varies depending on their knowledge and influence and the type of work they are involved in. The role should not be onerous, there are many small things that you can do that can have a big impact on people's lives. Champions choose how active they want to be – there are no requirements to be met.

If you are interested in knowing more about Dignity in Care or Dementia Care for your loved one please contact drop in at any one of our care homes around England. Details of the homes can be found at regalcarehomes.com. Alternatively write to the Programme Manager (Dignity Champions) at info@regalcarehomes.com



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'The service provided by Guideposts Trust is excellent and sets an example that others in the care industry should follow'
(Carer, Warwickshire)

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Guideposts Trust – leading the way in dementia care and support

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