

Challenges facing primary carers of people with dementia:

Opportunities for research

**Findings from a two-stage prioritization exercise with
members of the Alzheimer's Society Research
Volunteer Network**

Summary

Alzheimer's Society is a major funder of all types of dementia research. Over the last 10 years we have developed an innovative programme of public and patient involvement that integrates the eventual users of research in the selection, design, delivery and dissemination of research. We pro-actively involve carers and people with dementia in identifying and generating research questions, and developing areas of research.

In this report we present challenges and difficult situations faced by carers of people with dementia. The findings are based on a two-stage survey carried out with almost 100 carers and former carers who are members of Alzheimer's Society Research Volunteer Network. The aim of this report is to highlight issues that are relevant and important to carers, with the hope it will stimulate and galvanise research in these areas. We challenge the scientific community to look at the challenges identified in this report, and build on them through high quality research proposals for funding by Alzheimer's Society or other funding bodies.

We recognise that the information presented here represents the challenges faced by a single stakeholder – that of carers – and that the views of people with dementia are not presented. As such this document should not be interpreted as a strategy for Alzheimer's Society social care research. We also welcome researchers to challenge our classification and interpretation of the responses to identify alternative themes for research.

Alzheimer's Society and the Research Network volunteers welcome approaches from researchers who would be interested in exploring the topics identified by in this report further, with the ambition to develop (and get funded) research proposals which address these topics. This may be in the format of focus groups, surveys, in partnership applying for funding or other novel ways to involve patients and public in all stages of research.

Alzheimer's Society has an active priority setting partnership with the James Lind Alliance to prioritise unanswered questions about the prevention, diagnosis, treatment and care of dementia from a multi-stakeholder perspective. To see how this is progressing please visit: www.alzheimers.org.uk/dementiapsp

Method

The challenges were identified using a two-stage priority setting process, whereby participants were first asked to submit responses to an open-ended question, and then rank commonly occurring responses in order of their priorities.

In the first stage, Alzheimer's Society Research Volunteer Network were posted a paper based survey that asked them to identify up to three challenges or situations that have arisen during their personal experiences of dementia, which might benefit from research. They were asked to include anything that felt important to them even if they were not sure it was a researchable topic.

Sixty-one research network volunteers responded to the survey, submitted 166 different situations. These were grouped together in to common themes by Alzheimer's Society Research staff, working with a small steering group of two clinicians and three lay members. The grouping and title of each theme was refined in consultation with the steering group and during two focus groups with Research Network members. In total 26 common themes were identified – each had been mentioned by at least three carers responding to the survey.

In the second stage of the survey, Research Network volunteers were asked to identify ten themes from the complete list of 25 that they considered to be most relevant and of highest priority to them. These are presented in a prioritised list in this report.

About the participants in this survey

Alzheimer's Society has a large public and patient involvement network which contains 225 members who are all a primary current or former carer or a person with dementia. The majority of members are carers or former carers. All members of the network were invited to take part in this research exercise.

The first and second stages of the survey were completed by 61 and 96 people respectively. In the first stage 13 carers and 46 former carers completed the exercise (two anon). In the second stage 19 carers, 70 former carers and 1 people with dementia responded (six anon). At the second stage, respondents were asked at what age was the person when diagnosed with dementia (or estimated if not formally recognised). The average age was 70 years (range 48 – 89 years). Nineteen respondents cared for someone who had an early-onset dementia (<65 years).

The number of people with dementia that completed either stage of the exercise was very low, and therefore the focus of this report is on the challenges identified by carers. The number of people who cared for someone with an early-onset dementia is also over represented compared to the general population.

Results

The findings are presented as a summary list, followed by the individual responses submitted in the first stage of the survey.

Challenges identified by carers of people with dementia

1. Receiving good, person centred care whilst in residential care homes (65%)
2. Receiving good, person centred care whilst in hospital (63%)
3. Getting access to appropriate help and support to keep caring at home (60%)
4. Obtaining a diagnosis (55%)
5. Dignified end-of-life care (51%)
6. Obtaining information and support for the carer around the time of diagnosis (49%)
7. Providing appropriate and stimulating recreational activities for people with dementia (46%)
8. Supporting people with dementia who do not have informal carers or close family (46%)
9. Recognition and management of pain (44%)
10. Obtaining appropriate respite care (43%)
11. Managing sleep, changes in sleep patterns and wakefulness of a person with dementia (42%)
12. Communication problems between professional staff members providing care for people with dementia and between professional and informal carers (40%)
13. Avoiding prescription of anti-psychotic medications to control challenging behaviour (39%)

14. Incontinence (39%)
15. Ensuring the health and wellbeing of family (particularly elderly) carers (38%)
16. Technologies that assist a person with dementia to live independently (32%)
17. Getting access to appropriate services for younger people with dementia (32%)
18. Medication management and ensuring person with dementia takes prescribed medications (30%)
19. Coping with secrecy, dishonesty and repetitive behaviours (26%)
20. Difficulties with dentistry, audiology, and optometry examinations during dementia (23%)
21. Avoiding anxiety for the person with dementia (22%)
22. Understanding causes and communicating about risk of dementia (20%)
23. Understanding nutritional requirements and providing appropriate nutrition and vitamin supplementation to people with dementia (19%)
24. Choosing a care home (18%)
25. The role of maintaining personal beliefs and faith during dementia (7%)

The percentage following each statement shows the number of carers that indicated the issues was one of their ten highest priorities during the second stage of the survey. Participants were asked to identify ten themes from 25 (40%).

A further issue regarding the training of professional caring staff was identified during stage one, but not included during stage two because it was not regarded to a challenge faced by carers.

1. Receiving good, person centred care whilst in residential care homes

Resident distressed and saying will call police- but in no way aggressive. Put on medication and sleeping most of day for 3 months until family able to question medication. After hip breakage, resident classed as incontinent when could have been toileted. Mother crying when wetting herself.

Residents subjected to unsuitable and confusing television watching! Family visiting daily took resident to quieter area with only quieter and slower programmes with non upsetting scenes. Talking about what is on as one would do with young children- resident becomes happier and enjoyment gained.

Identify clear and simple guidelines/principles of good dementia care, ie "A charter of quality care".

I think everyone would agree that improvement in care in nursing homes is essential but how do you ensure this is carried out? All research shows improvement at the time of study but this is not carried through in the majority of cases in the long term.

To research and promote good standards in care homes. I feel it is necessary to work with national organisations e.g. government, HHS/SS large providers to ensure good dissemination and implementation.

In my experience much pain/discomfort and compromised quality of life caused by the lack of care given to the senses of the person suffering from dementia.

Given the widely varying standards of care currently available in care homes, we need to move towards establishing a national standard and programme of effective dementia care and support training for all care home staff which would be a legal requirement monitored by an effective standards body with relative powers to act and take remedial action accordingly.

Care plans for new residents. Are these prepared for the convenience of service staff or for the resident (his/her relations) and junior staff?

I would like to see more staff in nursing homes for those with dementia and home carers with better English so they can talk and be understood by residents. Elderly confused people often with some degree of deafness can live an existence which could be compared to solitary confinement- in a nursing home staffed by foreign staff with poor English and who are often very busy as the minimum nurses required by law are employed.

My Mum was diagnosed with pernicious anaemia at the same time she was diagnosed with Alzheimer's Disease. Caring for her at home, she received an injection for PA every 12 weeks. Result, more energy, lucidity and awareness. BUT by the end of week 9 she declined suddenly, unable to function. I pointed this out to the GP and asked if she could have the jab week 10. reaction: Totally inappropriate. Upon entering a care home the pattern continued. I approached the new GP about week 10, receiving the same reaction. After nearly a year, the GP, after yet another collapse, suddenly said to me 'OK, you win. She can have it week 10'. This made a huge difference to her general wellbeing and although the AD progressed I feel sure its progress was retarded.

Interaction within nursing homes between residents with or without dementia. I often saw my mother become very agitated when another resident came close, sometimes trying to touch her. She was immobile and unable to move away from the unwelcome contact. At one stage she fell and was pulled up (or so she said!) By another resident who actually dislocated her shoulder. The hospital doctor was very dismissive of her account due to her own dementia.

2. Receiving good, person centred care whilst in hospital

Ignorance, lack of knowledge, avoidance etc in hospitals. Much talk is made of the lack of care to people with dementia in hospital for medical reasons but nothing is done. It happened with my wife 20 years ago- it is still happening today.

Evidence of hospital management of patients with dementia when they are admitted to a general hospital. I have found the hospital's management of the dementia aspect woefully inadequate. They seem unable to deal with the fact a person cannot speak or indicate any response to questioning/requests, or deal proactively with incontinence for instance. Irritation with the patient can ensue.

My wife slipped off the bed and cracked a bone in her leg and was taken into hospital. I think normally such a break would have meant a short stay in hospital of a few days. For reasons I fail to understand she was kept in hospital for 5 months. When she eventually came home she had lost the limited amount of mobility she had gone in with. Her discharge from hospital was made difficult by social worker demands. The type of caring I had to get used to had changed completely.

Mum was admitted into hospital five times suffering from malnutrition and always dehydration. The nursing staff simply didn't have enough time to deal with all the patients' needs. It doesn't take a degree-trained nurse to feed an AD patient or give them a drink etc. Do any hospitals employ staff who deal just with these 'general' tasks, having been trained to work with AD patients who find themselves in unfamiliar surroundings?

Problem which we read about many times is hospital care/treatment of dementia patients.

Failure of the health service in hospital care for dementia patients. Inadequate aftercare following hospitalisation.

When my mother was hospitalised (on several occasions) the admitting doctors would insist on asking her medical questions despite my advising them she had Alzheimer's and her responses could not be relied upon. Is it possible to prepare information for admitting doctors who frequently seem unfamiliar with the disease and its effects on the patients?

A lot of research is being done to improve care for people with dementia in hospital. Similar work needs to be done for outpatient appointments (x-rays, scans etc). Emergency care in A&E and doctors' surgeries. Most carers have their own horror stories of hospital and surgery appointments. A lot more understanding is needed within the NHS in general.

When my mother fell and broke her wrist she was admitted to an orthopaedic ward. The staff had no understanding whatsoever of how to look after a patient suffering from dementia. She was continent when she went in and incontinent when she was discharged. Her broken bone had healed but her condition in every other way had deteriorated and she had lost a considerable amount of weight.

The problems encountered by sufferers when hospitalised.

The quality of nursing staff looking after dementia patients.

How patients with AD are managed/treated in hospital. Mum was treated I feel inappropriately during a 2 week hospital stay – because the staff didn't know how to approach and manage her – didn't make sure she drank, didn't help her to the loo (so she got UTI) etc. How can this be avoided – as the upset accelerates the dementia process.

Obedying a consultant's order not to stay with my husband when he had a gastroscopy. The result was disastrous and a bad memory that stayed with him even though he had severe memory problems at that time.

Mum was mobile and continent until spending 3 weeks in hospital. They kept her in bed with pads on during that time despite her shouting to get up and go to the toilet. When she moved into a nursing home they did the same, listening to the hospital staff rather than my mum or me. This caused her enormous distress- she had advanced dementia but still had sufficient awareness to feel trapped and humiliated. The day before she died she told me "I can't live like this"

Holistic whole life consideration by every specialist rather than own specialism only- physical and mental needs.

Ability to make next hospital appointment before leaving the hospital.

3. Getting access to appropriate help and support to keep caring at home

When trying to get attendance allowance for my mother she told lies about how independent she was and that she didn't need any help. This was very frustrating for her carers who needed the support of others. Should benefits/social care be more aware that carers' views need to be taken into account?

Looking after my father (who had terminal cancer) and my step-mother with vascular dementia, in our home was very challenging. We had numerous assessments by various health care professionals but absolutely no practical help; this was over a 3 year period. There is no practical help for families to take on the responsibility of care for relatives.

My step-mother died at home with us. She was bed bound for 5 days. We paid private carers to come in 3 times a day but had no help from district nurses. I asked for visits and no one came. I telephoned and left messages for mouth sponges- they did not come. We were completely unsupported, not knowing when or how she would die.

Barbara had numerous urine infections when living with us and I always had to take her to the GP/practice nurse to get her checked and have antibiotics prescribed. She was always distressed at these visits — why couldn't district nurses come to the home and do the diagnosis?

No Admiral Nurses in our area so families are not supported. Desperately need to evaluate this service and roll it out nationwide.

We need to evaluate the cost effectiveness of Admiral Nurses and other similar schemes.

We could tell from the medication log kept in Mum's kitchen before she was admitted to a care home, that it was usually a different person who'd come, morning and evening, to administer her meds. There was no continuity, no opportunity for any relationship to develop, for the carers to get to know Mum, the best way to approach her, her likes and dislikes, things that would 'set her off'. How important is continuity in care, prior to admission?

Care at home for my mother was poor – carers were task-orientated, had little understanding of dementia and took advantage of her vulnerability (e.g. would not turn up or not give her the allotted time).

4. Getting a diagnosis

A huge problem for us was my mother's implacable refusal to acknowledge that there was a problem, and to allow any examination or investigation by any health professional. Without diagnosis we could get no help or support, but without her cooperation we could not get a diagnosis.

Early diagnosis because of some GPs not accepting what a carer reports- therefore diagnosis is delayed.

Need to look at depression and dementia to give clearer diagnoses of each one.

I was shocked when I realised my mother could not understand the rules of 'sudoku' as she was a very good crossword solver. Could I have done something at this point to alert the doctor? (I had no idea she was developing Alzheimer's disease and dementia)

Obtaining a diagnosis of Alzheimer's for my mother took several years. I would constantly ask for her to be tested as I had witnessed the deterioration. However, the tests would invariably be undertaken on one of her 'good days' so she would not score high enough. This led to a tardy diagnosis and reduced her quality of life quickly and drastically. Can we find a more reliable method of identifying the disease?

The first challenge I encountered whilst caring for my mother was actually getting a diagnosis. I saw a decline in my mother's mental health and her ability to cope with normal daily life but when I spoke to her GP he refused to discuss the matter or to advise me. He said my mother must be the one who consulted him and she denied there was any problem, as this was 'impossible'.

Early and positive diagnosis of AD is obviously desirable to enable early treatment, but it appears that many GPs are slow (reluctant?) to recognise symptoms and refer patients. Research is needed to monitor GPs' awareness/inhibitions in this regard and possibly offer training.

The early diagnosis of the disease.

My sister's condition clearly worsened but her mental test score hardly lowered. Therefore this test is insufficient.

5. Dignified end-of-life care

I would like to see a Hospice type movement for Alzheimer's and other dementias but I don't know how a research project could be applied to this topic.

My cousin dying in a hospice showed me what can be achieved by way of person centred care- in contrast to the distinguished teaching hospital where he was diagnosed.

Hospitals/nursing homes need clear policy, decision making process about when and if to feed people in final stages with AD by tube down the throat, whether to hydrate by drip, and when and if to use a PEG instead. Further complicated because nursing homes can not use drips/feed by tube. Sometimes in order to return from hospital to nursing home need a PEG. Very upsetting and often painful for person with dementia who cannot understand why. Think in hospitals, tubes used because easier for staff rather than time spent feeding by hand. Several problems of insufficient staff time to feed patients by hand in both hospitals and nursing homes

End of life care for the person with dementia: the practical and ethical issues faced by carers and the medical profession. (Ideally to result in some guidelines)

What can we do as carers to ensure Quality of Life to the end?

Next of kin: confused legal position likely to cause many family disputes when interpreted incorrectly by medical professionals.

6. Obtaining information and support for the carer around the time of diagnosis

I feel it would be really beneficial if research could be centred on designing a standard procedure for easing beginner carers into their new role and disseminating it amongst healthcare professionals. I recall that when I became a carer (many years ago) I asked whether there was any sort of guidance available which would help me to do the job well. I was met by stares of blank incredulity and my question was ignored.

After initial diagnosis it is rarely possible for carers to have “one to one” meetings with the consultant to discuss matters freely. Many carers have told me they could have coped much better if this opportunity had been available.

How/what to say to friends/neighbours/relatives about dementia to give best support to person with dementia and carer.

Is there a place/need for training carers? I am ‘feeling’ my way as Mum’s dementia develops and use local Alzheimer Society resources when I need to e.g. I have learnt how to ‘converse’ - i.e. don’t contradict, tell white lies if it means Mum doesn’t get upset etc. I suppose these could be called ‘learning how to live with and AD sufferer’.

Looking at specialist assistance for helping carers, such as technology or other aids and perhaps basic training for carers, it was so difficult for our family to suddenly have to care for my father, who was always independent and we were not trained carers. You obviously learn as you go along and all the family gave support and care, but this is not always the case and it is this that wears people down.

Stigma, even today there exists a stigma relating to dementia with many people. So called friends fade away even from the family of the person with dementia.

Information to educate carers is required on how dementia sufferers’ tastes change e.g. food, clothes, interest, rather than reading at random in a letter here or a newsletter article there.

Training for carers – respite care. Also some doctors appear as puzzled with the situation as the carers. Maybe a checklist which might help some people who are not very good at joining social groups.

The relationship between Alzheimer’s sufferers and their family carers.

7. Providing appropriate and stimulating recreational activities for people with dementia

One day is much the same as everyday- perhaps more recreation, music events, activity events- painting, music, singing groups not just in homes; for people with dementia cared for at home.

Quality of life in nursing homes. No mental stimulus, no sense of being a part of a family. Encouragement to participate in daily living to a much greater degree.

When my mother was in the late stages of Alzheimer's she was admitted to a care home. We selected a home where the owner and staff were caring but even there little was done to simulate or occupy the residents. They spent most of the day just sitting in upright chairs in a large room staring into space.

In the care home Mum became is dated: she hated being sat "in that box" (the lounge) "with old men and women all round the walls staring": once a week bingo, once a month an entertainer, Thursday mornings art work. So I volunteered to lead a weekly war-time music hall session- they'd all join in, singing or lah-lahing, some tapping toes in time with the music. They'd smile. We'd play grandma's shopping bag and other old gamers. But when Mum died the owners didn't want me to continue. How do other 'care' homes help residents to be involved and spend their time?

8. Supporting people with dementia who do not have informal carers or close family

This theme was not identified in the original written responses during stage 1. However, it emerged as a strong theme during two focus groups that were held to reflect on the first-stage responses.

As someone who has no spouse or close family, I wonder what would happen to me if I was diagnosed with dementia in the future.

9. Recognition and management of pain

Headache in vascular dementia – any way to ameliorate – co-codamol, paracetamol, and ibuprofen presented but very patchy response.

Pain relief – more is now known it could be the cause of aggressive or irrational behaviour. Is there any other way to recognise it?

In late stage dementia, my mother couldn't register or communicate any pain. Was it part of her brain that had deteriorated or died? The same was evident with another woman with dementia in the same residential care home. It is good for the PWD in many respects but could endanger safety and that of others.

10. Obtaining appropriate respite care

Evidence needed to back up calls for increased provision of quality respite care.

Carers logically are concerned about the reduction of respite beds.

Research into the part played by respite care in enabling carers to continue to look after loved ones at home might be of value.

Respite care availability is important for carers and patients but my experience has been that care homes generally provide very uncongenial resources and respite patients are deposited amongst residents, who are mostly sleeping or staring into space and very little attempt is made to provide activities or other stimulation. My wife tried three care homes for day respite, but the experience was much the same in all, so that after a few weeks we had to give up since she was dreading the day. Better person-centred care generally in care homes is obviously required, but research may be needed into respite aspects.

From my own experience of caring I believe that if there had been a more effective system of respite care available, we would have been able to maintain the care role for much longer than we were able to. There is a pressing need to study the social and cost benefits of establishing a formal policy and program of respite care for carers.

My husband and I have cared for a parent and now an aunt. We have met some good professionals but often frustrated by the following areas of care: 1. difficulty in convincing staff that the answers from parent/aunt are not accurate!; 2. identifying 'successful' providers of respite care, how this is achieved etc, so that carers feel confident to use them.

Although there is some provision for day or respite care for people with dementia, it would be so much more effective if patients with all kinds of problems could attend the centres together as this would reflect life as it is and provide for more stimulus for all.

11. Managing sleep, changes in sleep patterns and wakefulness of a person with dementia

The hardest manifestation for my husband is tiredness- sleeping 10-12 hours per night and 1-2 in the afternoon. Therefore we're unable to go out for day or concerts or matinees. Any suggestions to help with sleeping requirement (without sleep he is unable to function)

Whilst caring for my mum, I identified patterns of behaviour which was in effect a 4-day cycle, in which I would regularly predict what sort of day she would have including predicting which night in 4 she would not sleep. Once I identified this pattern of behaviour it made it easier to care for my mum. I wonder whether this is something more common amongst dementia sufferers.

Can a 90 year old with vascular dementia sleep too long for her own good? How far should we attempt to regulate sleep patterns?

The impact of broken sleep cycles has enormous burden on wellbeing, particularly for the carer.

12. Communication problems between professional staff members providing care for people with dementia and between professional and informal carers

Lack of communication between community psychiatric nurse and social worker.

Care home staff asking permission from patient/resident to put sides of bed up- confused resident saying no- Resident then falls out of bed and breaks hip. Family had said yes when patient is asleep.

In nursing care- GP rarely visited father- just relied on verbal report from nurse. However, as English was a second language for nurse, communication with father became problematic.

Communication between doctors and carers/family. In my case this was almost non-existent. It was only when my mother was 'asked to leave' a nursing home that the word dementia was used, although looking back I can now see she must have been suffering for a long time. With more information I could have made a better choice of home where she could have received more appropriate care with less upheaval and I would have known what to expect.

Continual changes in social workers every time mum went into hospital ie one before, one during and one afterwards. I lost count of how many dealt with her during the last 2 years. This made continuity difficult & she was unable to form any kind of relationship with them. They often had limited knowledge of how to deal with the aggressive side of her dementia.

I would like to see more staff in nursing homes for those with dementia and home carers with better English so they can talk and be understood by residents. Elderly confused people often with some degree of deafness can live an existence which could be compared to solitary confinement- in a nursing home staffed by foreign staff with poor English and who are often very busy as the minimum nurses required by law are employed.

13. Avoiding prescription of anti-psychotic medications to control challenging behaviour

Anti-schizophrenic medication was prescribed over long period of time with questionable benefits

Being eventually unable to avoid anti-psychotic medication for my husband. How much did this contribute to his rapid decline at that point?

I believe we should continue pressure to eliminate the over-extended use of antipsychotic drugs, especially in smaller care homes with less well-qualified staff who are inclined to add them to a patient's regular medication schedule when they have been once prescribed. In this connection GPs should be made to recognise and act on the need for a review after the first six weeks.

Continue to fund alternatives to inappropriate use of drugs to 'control' patients' behaviour.

Any aggressive behaviour is always triggered by something serious! All carers need to look for and identify those triggers. With that knowledge, difficulties can probably defused and calmed. People with dementia lose the ability to express themselves and any frustration so it is up to the people in a caring role to learn about their personal history and the 'whole' person! And not prescribe or use anti-psychotics.

14. Incontinence

I believe there is a need to provide more and better help and support for carers at home when a dementia patient becomes incontinent, as well as supporting the carer in establishment of appropriate new routines and obtaining supplies of pads and other aids.

Matters relating to bladder and bowel control/lack of/non-functioning etc. Life of secret, quiet desperation because of bladder and bowel problems of PWD. Carers need help.

Managing AD sufferers who have bowel problems – constipated or diarrhoea. I have a dreadful time when these have happened as Mum loses all toiletry capabilities and doesn't recognise what a toilet is for. Why does this happen? How can we help? We get very little help from nurse, carers in this situation.

15. Ensuring the health and wellbeing of family (particularly elderly) carers

The extent to which GPs/specialists monitor the health of both patients and carers.

Research into GP surgeries, e.g. can carers access times to speak about their health issues and 'cared for' with flexible appointment times? Is there good information available? Is there an understanding of the complex issues of patient confidentiality?

To try and provide better support for elderly carers, who are often people with little understanding of medical or basic psychological matters compared with people under say 75 years of age. Their situation needs monitoring as much as the situation of the dementia patient. My father cared for my late mother to the point where I believe it damaged his own health, but he would not give up his role until he collapsed and was admitted to hospital.

16. Technologies that assist a person with dementia to live independently

I had a problem with my wife when she went 'walk about'. I had a set routine where I contacted the police if she failed to appear before it got dark. At times she was in real danger. We need a well designed electronic tagging system for corners to trace AD patients. There are some folk who object to tagging for ethical reasons, but they fail to appreciate that an AD patient's freedom depends on their carer being able to cope with difficult situations. I believe that 'life line' have various gadgets which could be of use for carers when AD patients wander.

In the early stages, there are many issues around employment for people with dementia. There are too many inappropriate health & safety concerns, which force people to leave their jobs.

Developing personalised aids memoire/prompts for PWD. Potential for programmable audio. video devices to remind 'what to do next'/'what happens next'.

Assistive technologies which help families monitor loved ones from outside their homes. With technology rapidly expanding, especially in the use of smart phones and associated apps, many of the currently short range (in home only) devices could surely now be able to interface with mobile phones to alert carers further afield. I live 5 minutes drive away but can find nothing to work more than about 300m

Benefits of labelling, colour coding and signposting places & items in the home environment to promote a level of continuing independence.

Assistive Technology – to what extent can the speed and scope of technological developments be utilised in allowing dementia sufferers to retain their independence and remain in their own homes for a much longer period of time.

For many carers, keeping their cared for in their own homes, remaining within family and close to friends and families for as long as possible is a priority. Help in achieving this via assistive technology, improved support services and better guidance would be invaluable.

Maintaining independence of a person with dementia is important so that carers and close family can also maintain their hobbies and enjoy quality of life. It is assumed that a carer wants to stay at home.

17. Getting access to appropriate services for younger people with dementia

For early onset dementia in younger adults, what type of therapy I support is most beneficial? E.g. group versus one to one and is insight preserved for longer in this age group? I'm thinking under 50 or thereabouts

Evaluation of day care for younger people with dementia. There seem to be closing their specialist younger people with dementia centres and putting all ages together. But they are so inappropriate. Surely specialist centres are 'better' for this group.

Evaluation of the costs/benefits of cognitive behaviour therapy/training for people with early onset dementia.

18. Medication management and ensuring that a person with dementia takes prescribed medications

Problems with many drugs that people with dementia are given cause problems.

The extent to which GPs/specialists keep patients and carers properly informed about changes of medication and their possible after-effects.

Those prescribing medication do not take enough care or consider where drugs clash with Aricept or other Alzheimer's drugs. My mother was on Aricept and this started a heart problem. The heart specialist prescribed a heart drug. Mum became unwell. I complained at the next visit to the memory clinic. Research showed the two drugs clashed. Lack of care with control of medication. Mum had some drugs stopped and different ones started. Failure in GP control of repeat prescription process resulted in Mum being given both sets of drugs. Nearly died.

We often found it hard to get Dad to swallow his medicines, even when he had a bite to eat with it. He'd take a drink, but the pill would stay in his mouth.

Hospitals will not provide dementia medication to in-patients (unless they are military). The care home would invariably fail to send my mother's medication with her when she was hospitalised, resulting in an absence of medication for a time period. She would then regress and this loss of cognitive awareness could not be made up when medication was re-started. Can this loss be measured and used to initiate a change of policy?

When I first started taking responsibility for aspects of Mum's life, my biggest shock was to find three months worth of repeat prescriptions sitting on a shelf in our local pharmacy. The tablets in her flat were mostly past 'use by' date. The pharmacist had called Mum several times to (unsuccessfully) remind her to collect. He'd also called her surgery several times. I know of at least 2 other incidents like this! How many drugs are wasted in this way? How much harm is being done because many people aren't taking correct drugs? At the very least some feedback from pharmacies to doctor' needs to be put in place- test results could be seriously skewed if doctors believe patients are taking drugs when they are not.

19. Coping with secrecy, dishonesty and repetitive behaviours

The need for coping strategies for carers when dealing with the effects of dementia- especially repetitiveness, secretiveness, and many other behavioural divergences from “normal” behaviour. This relates to general awareness raising about the impact of dementia.

Whilst talking to both my parents during their journey of dementia- I found that they both had a tendency to return to “favourite” topics and that friends coped with this repetition better than I did- by not appearing to notice. Is this general?

A typical and major symptom of young onset dementia or Pick’s Disease is collecting or ‘saving’ any items. This can be serious and seen as ‘shoplifting’ although it is blatantly obvious it isn’t because the stealing is done very obviously, never discreetly. No swag-bag used! The police, supermarket staff, petrol stations, shops could benefit from information and awareness of this devastating effect of the dementia.

20. Difficulties with dentistry, audiology, and optometry examinations during dementia

Mouth and dental hygiene in hospitals and nursing homes seems virtually non-existent. I see no evidence of routine brushing of teeth and dental decay is rampant where a resident is unfortunate enough not to have dentures but their own teeth. Widespread use of sweetened drinks instead of plain water compounds the problem. They should be banned unless resident refuses water and dental hygiene should have the prominence of skin care, as a routine.

Hearing aids and techniques for prescription for people who cannot understand the testing procedure.

AD patients often cannot take the standard tests given by dentists, opticians and audiologists. For example, before developing AD my wife was regularly given a test by her optician to detect glaucoma in her eyes. When she developed AD the optician was no longer able to administer this test, meaning there was the chance she could go blind. There are services and methods of getting around these difficulties which should be made plain to carers.

We had problems getting correct eye tests and dental treatment.

When living at home, we had problems getting accurate sight tests to improve glasses and problems with teeth (wouldn't open mouth for dentist).

Why are dentists, opticians and hearing-aid specialists so hard to find to visit residents with dementia in care homes?

My Mum had several eye tests in my presence. My general impression each time was that she did not understand the instructions (the optician did not agree with me). The last test she had (after which she was registered blind) she only managed to read one ginormous letter 'N' appearing on its own. The optician gave her a long time to look at this letter and eventually she said 'N'. The other letters presented to her had been in groups. I think she could see them but could not remember what they were called. After this test and being registered blind she could, for instance, tell me how many fingers I was holding up. Before she finally was unable to talk, she would say things like "she lives in there" pointing to the bedroom door through which the carer would enter to attend to her. So she must have been able to see the door. Many other examples I could give.

Hearing loss and dementia- akin to eye testing, devising means to test and then counteract the effects of hearing loss (and associated impaired communication) in those with dementia.

21. Avoiding anxiety for the person with dementia

Improving care of people with dementia when they have to be in a general medical ward for a non-dementia related condition – many procedures i.e. taking blood, can be very frightening and the person will resist and not understand why it is necessary.

Research into how to reduce agitation, fear and anger in people with dementia. E.g. is it reduced by trying to rationalise by carers or by some other means?

Whilst my husband had only physical disabilities we were able to discuss and implement management of each problem as it arose. Now dementia has come along this is no longer possible as my husband cannot grasp the concepts I try to explain. This bewilderment quietly changed to anxiety and then fear which I see in his eyes all the time despite my constant reassurance. Although I have researched this endlessly there seems to be no effective help for this problem.

From my experience of caring, I believe that a person's past life/personality and coping mechanisms are crucial to how they respond to the changes which occur when dementia symptoms begin to affect their daily life. When short term memory was failing her, my mother's long term memories, some of which were traumatic, became more present to her, especially as she lived alone. This caused much angst for her and anxiety for us as a family. How to deal with such issues? Often other pressing health problems can be more readily treated. Further, in care homes, staffing ratios do not allow for time spent with those obviously wishing to have a conversation about their fears and those displaying aggressive tendencies are sedated and/or moved to EMI units.

Stimulation, e.g. music/ridiculous antics of carer seem to induce recognition and relaxation.

22. Understanding causes and communicating about risk of dementia

The patient in earlier years expressed consumption of water from lead piping and food cooked in aluminium saucepans.

The risks of general anaesthesia triggering dementia or speeding its development, and what might be done to reduce this. With major surgery for eg cancer, there is likely to be no choice, but if the risk is known and recognised maybe some precautions can be taken. In my own case, my wife, who was already being treated for depression, was diagnosed with acute rectal cancer, aged 75, and underwent major surgery. The operation was successful and the cancer did not return, but the symptoms of dementia (already evident to me, but not diagnosed) increased following the operation. The one benefit that was that it finally led to the diagnosis of AD within six months.

In our case my wife suffers from Rheumatoid arthritis which was diagnosed in 2002. AD was first seen in 2007. Is there an interplay between these 2 conditions where treatment of the first causes the 2nd?

The thought for many years that there could be a link between 'alcohol induced amnesia' and eventual development of Alzheimer's Disease

23. Understanding nutritional requirements and providing appropriate nutrition and vitamin supplementation to people with dementia

There is contradicting evidence for vitamin requirements. Could the Society produce a leaflet on what already might be best practice for supplements?

Alzheimer's patients seem to require higher sugar foods. Any advice?

Problem with ensuring patients get correct nutrition or added vitamins. Could this be done as part of regular checks- are these done?

People with dementia don't eat as much and loss weight; this causes anxiety for the carer.

My mother forgot how to eat and drink, which necessitated a move to a home.

24. Choosing a care home

How can we detect and support carers in their experience of guilt if a person can no longer be at home. Preparation, justification, emotional support etc.

Could care homes be graded like hotels? ie 'star' status system. Maybe this could be an incentive for owners and help families trying to do their best for loved ones. The inspectorate may have ideas.

My mum was cared for in a home run by nuns in which she benefited greatly from the general atmosphere of (Christian) love- as in fact so did I. Are there any measurable standards that carers can look for and which might help when they are making that difficult choice?

Research into the effectiveness of information given to patients/carers about entitlements to funding for long term care and the assessment process and appeal process when patients transfer from hospital to residential or nursing home care – self-funders are rarely given this information which is complex.

Is it time to consider the way which care homes are categorised? In my experience, dementia becomes a problem for paid care staff when there are behavioural issues such as wandering or outbursts of aggression. Passive behaviour which does not present an unmanageable burden is tolerated, but this does not mean that increased needs are being met. In residential care, dementia symptoms which are passive in nature are, at best, met with patronised caring and, at worst, ignored. In nursing homes, or EMI care, dementia symptoms which are expressed aggressively are at best dealt with using more appropriate sedatives and, at worst, treated using anti-psychotic medication.

My experience with my mother showed that it is difficult to get residential care homes to accept people who are already diagnosed with AD. My mother was diagnosed with AD in August 2005. She needed to move to a care home near me (she lives 25 miles away) in December 2005. She had mild AD at that stage and was not nearly bad enough for a nursing home. A care home manager advised me it was usually better to get people into a care home before they had been diagnosed with AD. Eventually a home accepted her after the memory clinic psychiatrist wrote her a 'reference'. If it had not been for this, and for the fact she was self funding it would have been very hard to get a residential care home to accept her.

Provision of residential care. Both in the public and private sectors fewer and fewer homes are being provided.

25. The role of maintaining ones belief's and faith during dementia

The importance which care homes attach to providing for the spiritual needs of dementia patients.

Practising one's faith while living with dementia: how faith communities can embrace the person with dementia and the carer

How to improve training of some medical, hospital, care home or domiciliary staff who care for people with dementia

This theme was not scored during the second stage of scoring, since it was not considered a challenge facing carers. The number of responses grouped under this theme suggests that carers see the training of medical, hospital, care home or domiciliary staff as an area that needs to be given high priority.

A topic which I know comes up regularly already is the quality of care/treatment of dementia patients in hospital. I had the opportunity over the course of the final months of my mother's life to observe very diverse standards of care, particularly in the attitudes of staff- luckily for us, the good exceeded the poor but it made those with poor attitudes more conspicuous. I wonder how much training is given to nursing and auxiliary staff about different needs of dementia sufferers.

Need to work with care staff to improve the understanding of dementia in all its forms (training)

The need for dementia awareness to become a core element in nurse training and to be mandatory annual update for all staff on general, surgical and especially orthopaedic wards. (Role play scenarios would be good)

Could psychologists/anyone produce a questionnaire which would help in the selection of individuals to work as carers? I believe if individual does not care then training protects employer rather than those being looked after.

The need for home/social care staff to have better training in dementia awareness. All too often my late mother's carers took at face value her assurances that she had eaten, bathed, taken her medication for example, when that was not the case.

I think attention should be given to designing, and getting universally adopted, a standard course, or even a manual, for healthcare professionals, especially in hospitals, to educate them in the importance and implementation of person-centred care of patients with dementia. I have had occasion time after time to observe in acute hospitals that ward staff, while generally good, seemed to be lacking in understanding of the special needs of patients with dementia.

As an old 1050s State Registered Nurse, I coped with the nursing care of my husband from diagnosis to death at home apart from 2 periods -10 days in hospital respite care and a 2 day stay in an acute hospital ward for a chest infection (that was not treated). Both these situations made his condition much worse. GP, hospital staff, both doctors, nurses and carers, should have much better training so that they understand the complexities of dementia.

I have no personal experience of residential care homes although I have visited one or two, so I would say that staff in these homes also need a much higher standard of training. I would like to see stricter guidelines for the standard set for recruitment. Care of patients with dementia should be seen as a specialist area, much the same as intensive care, theatre or paediatrics are, and not somewhere for just about anyone to work – and when communication between care and patient can be difficult, cultural and language differences should be acknowledged.

When my father became extremely unwell whilst still at home, we had few viable options provided to us by our GP. He suggested occupational therapy and physio when my dad was clearly very confused, unwell and agitated. My question is what do GPs know about dementia and can we look to improve their response if needed?

Care workers and nurses – some staff arrived with one hours video training. More acknowledgement for the work they do might be recognised in some way, giving it some status in society as a whole.

When my mother had to be taken to hospital, paramedics and A&E staff had little understanding of dementia.

The training of carers who look after dementia patients/sufferers.

Acute wards for the elderly – how qualified are the staff in dementia? Training is necessary. My experience was dire, no knowledge of dementia

Would like to know that all those from every discipline who deal with PWD have training. It should be mandatory. – could the AS ensure this? E.g. via training programmes.

Orphan responses/ unclassified

The responses in this category could not be grouped with any other answers and therefore were not included in the second stage of the survey.

Do brain scans help to identify which senses will be affected? For example why some sufferers lose their power of speech. My husband retained clear speech till the day he died even though his thought processes were greatly affected.

Physical exercise

Sexual activity is never discussed- is there a link?

In my sister's later stages we couldn't understand a word she said to us but when she talked to her own image in a mirror – she thought it was our mother – we could understand clearly every word. In the care home she talked to another lady who spoke in a similar manner and they both seemed to understand each other.

Dad was always a keen musician and singer. Something happened with his dementia – at the start having music on would settle him, but then suddenly we found it made him angry, particularly violins! This was long after he understood what he could no longer do. It wasn't frustration at no longer being able to make music, rather it was a radical change in the way his brain interpreted what he was hearing.

When caring for my Mum at home in addition to AD & PA (incontinence etc) she was registered blind; she needed me to take her arm and guide her everywhere. We lived in a former bungalow, both with bedrooms on ground floor. One morning I awoke at 6am to hear crashing and banging from Mum's room. I found her standing by the bed packing a case, which she had fetched from upstairs! (Normally she could not remember my father, who had died 3 years previously). She told me that Dad had been and was coming to fetch her. Normally she spoke very little, but she chatted all day as if no AD. She remembered family, asked after them etc. after tests the GP confirmed a 'water infection'. Once treated, she reverted back to AD state. When moved to a care home I was informed one day by a surprised nurse that Mum was very lucid. I said it would be 'water infection' and was told 'Nonsense'. Later I received an apology. It was!

The patient experiences sensitivity to minor pain (taking exercise; sharp tasting food) but takes pleasure from sweet tastes.

The physical/mental abuse of vulnerable dementia patients – especially those without living relatives.