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Managing care challenges related to lack of awareness in the person with dementia: Report of a stakeholder consultation

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Table of Contents

Supplementary information available online at **https://bit.ly/Awareness_Consultation**

1. Responses to structured questions
2. Text matrices for free text responses
3. Additional survey responses reported separately

Summary

Dementia care should be centred on the person with dementia, taking into account the person's needs and preferences. This can be difficult if the person with dementia lacks awareness of changes related to dementia. They may appear reluctant to discuss changes or unable to recognise any needs.
Awareness tends to decline as dementia progresses. However, individuals vary, with some people showing more awareness as they adjust to the diagnosis. For others, lack of awareness is a persisting condition which holds challenges for care provision. It can lead to worse outcomes for people with dementia. We don't know the best ways to handle these difficult situations in dementia care. There is little published evidence about managing lack of awareness. I therefore carried out a stakeholder consultation to gather views, report experiences, and help find areas where further work is needed.
I asked those involved in dementia care about their experiences around lack of awareness. I wanted to find out the extent of problems arising from lack of awareness, the type of problems encountered, and how these are managed. The project focused on care for people with dementia who live at home. I consulted with informal carers, clinicians, and professionals working in homecare or social care. We had discussions in small groups and shared an anonymous online survey. I also used information from previous interviews with people with dementia to show their views and share some background to this work.
The online survey was completed by 24 informal carers, 19 clinicians and 11 homecare/social care professionals across nine UK regions. Nearly all the people responding had encountered lack of awareness; 75% reported encountering it often or extremely often. Lack of awareness affected the care pathway with delays reported in referrals, diagnosis and starting care packages. Disagreements were commonly experienced due to lack of awareness, both at home and in clinical settings. There were concerns about safety and safeguarding. In some cases there was complete breakdown of care at home. These situations were managed with a flexible and patient approach and avoiding confrontation where possible. The report found a number of areas where care could be improved:

1. Information. More information is needed for people with undiagnosed dementia and their family members around the time of emerging symptoms and signs of dementia. Information for the general public should explain the variation in personal awareness of dementia symptoms and the value of early referral.

2. Resources for education and training. More educational resources are needed for informal carers. Specific training about awareness for clinicians and homecare professionals is needed. These resources would improve understanding of awareness issues and enable sharing of effective strategies.

3. Technology. Access to technological solutions such as CCTV and video doorbells could improve home safety for people who lack awareness and live alone.

4. Proactive approach. A proactive approach by primary care clinicians could help earlier identification of dementia and recognition of awareness difficulties in individuals. Documenting awareness status in primary and secondary care records could help guide tailored care plans.

Background and objectives

A diagnosis of dementia implies a decline in everyday functioning,[1] with impaired abilities caused by dementia-related pathology in the brain. Some people with dementia show little awareness of changes or difficulties related to dementia and/or avoid acknowledgement of the diagnosis.[2] Lack of awareness, also known as anosognosia, can result directly from disease in brain areas that are essential to the processes of forming awareness,[3] which is more prevalent in severe dementia. However, apparent lack of awareness can also arise from psychological reactions to changes, reflecting an avoidant coping style, or unconscious denial.[4, 5] These reactions may be encountered particularly in people with early dementia or around the time of diagnosis. Additionally, the onset of dementia can be insidious, meaning that in early dementia the person might simply not notice gradual changes in abilities until a critical situation arises.

During the dementia illness trajectory, an individual might be aware of some aspects of altered functioning for example declining memory, but unaware of changes in other areas such as social functioning.[6] They may be aware of the diagnosis, but not of the implications of that diagnosis for themselves or for others.[2] Awareness and the expression of awareness vary between individuals at any stage of dementia[7] and can change over time. Awareness may decline in a non-linear way[8] or steadily deteriorate in association with amyloid accumulation in Alzheimer's disease.[9] Conversely, some studies have demonstrated improvements in awareness over time for some individuals, which might reflect adjustment to diagnosis in early dementia.[10, 11] With this degree of variability, awareness is not considered to be an all-or-none phenomenon but clinically, there are some people with dementia for whom lack of awareness is more pervasive and problematic.

Awareness assessment is complicated and without a gold standard measure[12] and is not yet established in dementia clinical care.[13] Even so, studies have estimated the prevalence of awareness problems with results ranging widely from 21% to 81% in early-stage dementia.[7] A study using multidimensional methods of assessing awareness in people with mild-to-moderate dementia found low awareness in approximately 33% of the participants.[14] Research studies using a range of assessment methods indicate that lack of awareness can be associated with worse outcomes for the person with dementia regarding rates of institutionalisation,[15] and higher carer stress, burden and care costs.[16, 17]

Best practice in dementia care involves a person-centred approach, considering the individual's needs and preferences.[13] These can be difficult to determine if the person with dementia denies any problems and seems unaware of any decline in abilities. This can make it difficult to openly talk about their needs and the kind of help that might be useful. However, little is known about how to manage situations related to low awareness. A recent study highlighted the need for training for healthcare staff to recognise and manage reduced awareness in people with dementia.[18] Although better awareness can enable individuals to make use of cognitive rehabilitation programs,[19, 20] there is no indication that forced acknowledgement of dementia symptoms or diagnosis would be helpful for an individual. Studies have shown that quality of life, wellbeing and mood may be worse for people with better awareness of their difficulties.[21, 22] A recent literature review found a small number of intervention studies that explored enhancement of awareness, with limited efficacy or suitability for use in everyday

care.[23] None of the interventions were directed at assisting informal carers or clinicians in managing awareness challenges.

In this project, I have consulted with interested parties involved in the care of people with dementia who live at home. Through small group discussions and an online survey, I have asked informal carers, clinicians, and homecare/social care professionals about their experiences of encountering lack of awareness, the type of problems encountered and how they are handled, and what would help towards better management. The aim was to find out

- the extent of the problem
- the nature of the problems encountered
- best ways for managing situations arising from lack of awareness.

This would help to identify areas requiring further research, and where more supportive interventions are needed. Finding solutions to support people with dementia to continue living safely in their own homes would align with current government policy in England.[24]
The consultation has been supplemented by information from previous interviews with people with mild-to-moderate dementia conducted in an earlier study,[14] to provide further context and, where available, illustrate their views about awareness of dementia. A patient and public involvement and engagement group provided insights on the topic area and reviewed the proposed survey questions.

Methodology

Small group consultations

Separate small group meetings were held with representatives providing unpaid care at home (informal carers, also referred to as 'carers' in this report), clinical care (clinicians), and organisations providing paid care (homecare/social care professionals). The meeting with informal carers was held in person and comprised five people with current or past experience as a carer. The clinicians' meeting involved a consultant geriatrician and three people from a nursing background who work in senior positions within dementia post-diagnostic support services and was held online. For homecare/social care professionals, online meetings were held with two senior members of staff from homecare organisations and a social care researcher with extensive experience in care provision.
In these meetings, awareness challenges in the context of dementia care were discussed, confirming the importance and range of the topic, with a discussion around draft questions for the survey.

Online survey

The anonymous survey was distributed digitally through known contacts in clinical research networks, homecare research networks, and carer support networks. The survey was live for eight weeks from June 23rd to August 18th, 2025, using the Qualtrics platform. Questions were tailored to either informal carers, clinicians, or homecare/social care professionals. Initial questions about demographic details were followed by seven Likert-type questions for each group and three free text questions about awareness. The survey questions and response options are shown in Appendix A. For the informal carers, additional demographic questions were included about the cared for person.
The demographic information was used to describe the survey respondents. Bar charts for each group were used to show responses to the Likert-type questions about awareness. Where questions were comparable, responses for the groups were shown in combined charts. Free text responses were examined separately for each group of respondents. Areas of concern were categorised and described for each question, and individual responses were tabulated in text matrices. Individual quotes from the free text responses have been used in the report to illustrate the findings.
Informed consent was detailed at the start of the survey, and survey responses were only collected if the consent statements were checked and the final responses were submitted online. Ethics approval was provided by the University of Exeter Medical School Research Ethics Committee, reference number 8487474.

Previous interviews with people with dementia

It would be difficult and was considered inappropriate to gain views about awareness from people with dementia through an anonymous online survey, with no prior knowledge of their perception of their condition. Instead, a secondary dataset was used. This helps to make best use of data that people have contributed to in the past. The available dataset was extensive and suitable for purpose, and although collected in 2008, it continues to be relevant for the phenomenon under discussion. Interviews with people with mild-to-moderate dementia were

conducted as part of the Memory Impairment and Dementia Awareness Study (MIDAS).[14] MIDAS received ethical approval from Wales Research Ethics Committee 5 (reference 05/WNo01/45). Approval for unrestricted secondary use of the anonymised data by researchers new to the research team was confirmed by Wales Research Ethics Committee 5 in 2016.

In that study, as well as using other quantitative awareness measures, awareness was categorised with a global awareness rating based on qualitative analysis of interviews with the person with dementia and a carer. Here, I have studied interview transcripts for the four people judged as showing no evidence of awareness, in comparison with four cases matched by age and gender, who were judged to show extensive awareness. Transcripts for a further ten people with extensive awareness were examined for any reflections about awareness. The case-matched groups of people with either little or extensive awareness comprised three females and one male in each group, with ages ranging from 78 to 90. The remaining group of ten people who demonstrated better awareness were three females and seven males, with an age range of 51 to 81.

Consultation findings

Who completed the survey?

The online survey was completed by 54 respondents, i.e. 24 informal carers, 19 clinicians and 11 homecare/social care professionals, with a range of roles in care provision. See Figure 1.

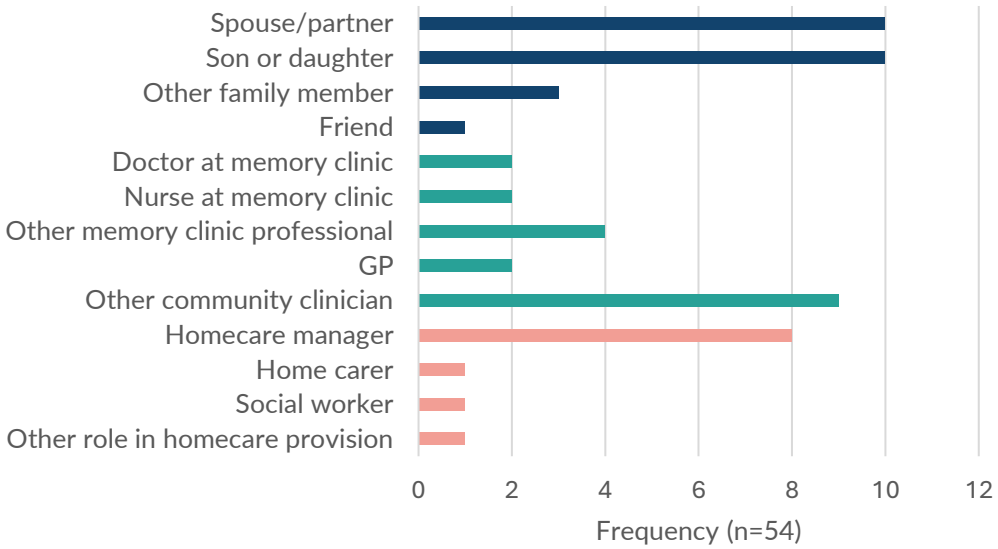

Figure 1. Role of survey respondents

Other roles: Other memory clinic professionals were clinical psychologists (n=3) and a dementia specialist. Other community clinicians were clinical psychologists (n=2), community nurses working in dementia care or mental health (n=5), a social prescriber (n=1) and an occupational therapist. Homecare professionals included one dementia support worker.

Two informal carers reported that the problem with lack of awareness related to the primary carer, not the person with dementia. Accordingly, regarding issues arising from lack of awareness their responses are reported separately in the supplementary information. Two clinicians indicated they worked only in care homes. Their responses have been reported separately in the supplementary information as this consultation focuses on people with dementia who live at home. The homecare/social care respondents included just one social worker, and the group is referred to as 'homecare' in this report.

Table 1. Gender and ethnicity of survey respondents

		Carers	Clinicians	Homecare
Gender	Female	20	16	10
	Male	4	3	1
Ethnic group	White	23	16	11
	Asian		2	
	Prefer not to say	1	1	

Nearly half of the informal carer respondents were spouses of the person cared for and were generally older than the clinicians or homecare professionals; see Figure 2. The majority of respondents in all groups were female, from white ethnic groups (see Table 1), representing a range of regional locations, with nearly half from the south west of England; see Figure 3.

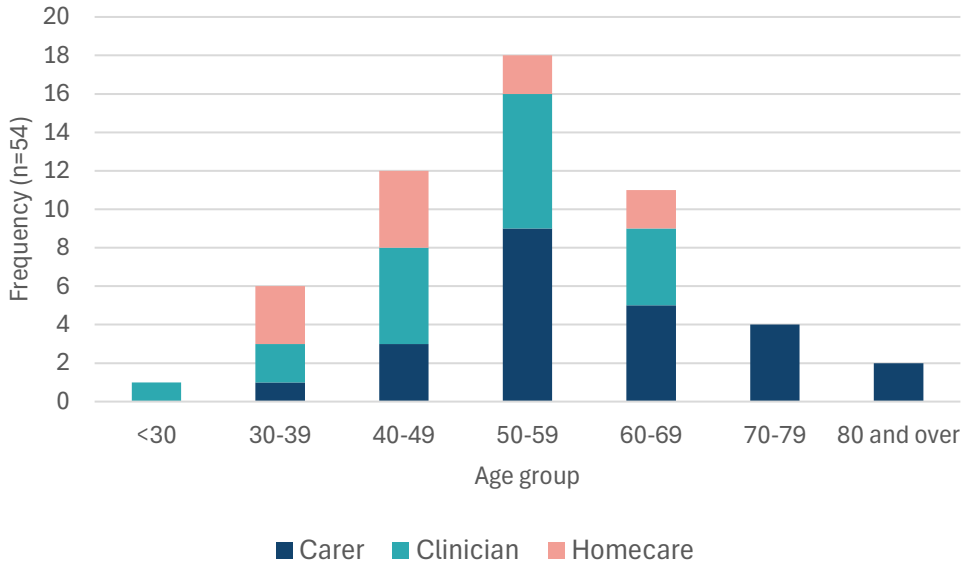

Figure 2. Age group of respondents

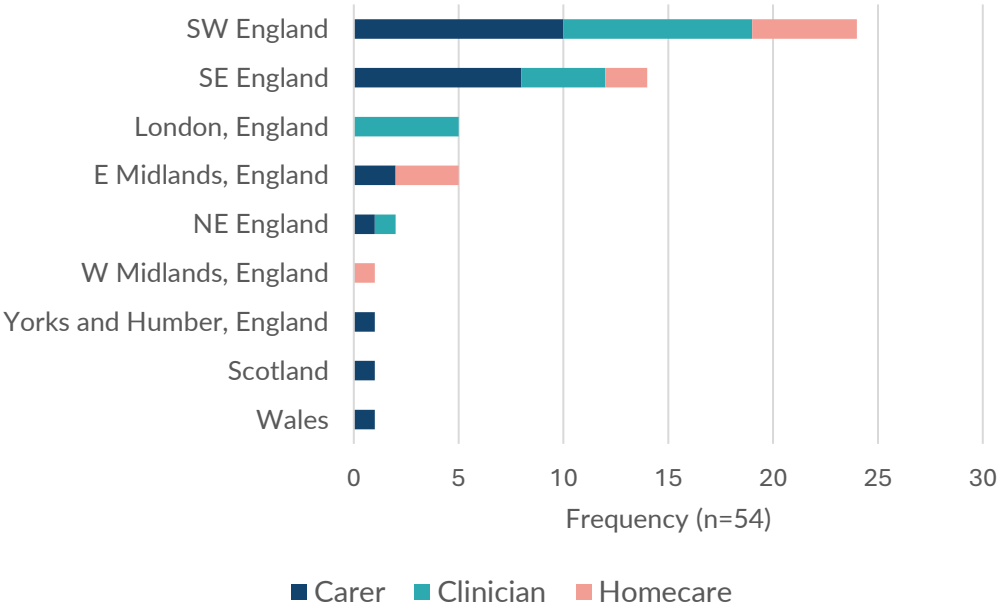

Figure 3. Regional location of respondents

For the informal carers, 11 people were living with the person they cared for; 13 were not living with the person cared for. Amongst the persons with dementia cared for by these informal carers there were 13 males, 11 females, all in ethnic group white, with one person aged 50-59, 10 aged 70-79, 13 aged 80 and above.

How often is a lack of awareness encountered in dementia care?

The initial group meetings indicated the extent of the problem, being frequently encountered and often problematic, and this was confirmed in the survey responses. See Figure 4. Nearly all the people responding had encountered lack of awareness; 75% reported encountering it often or extremely often.

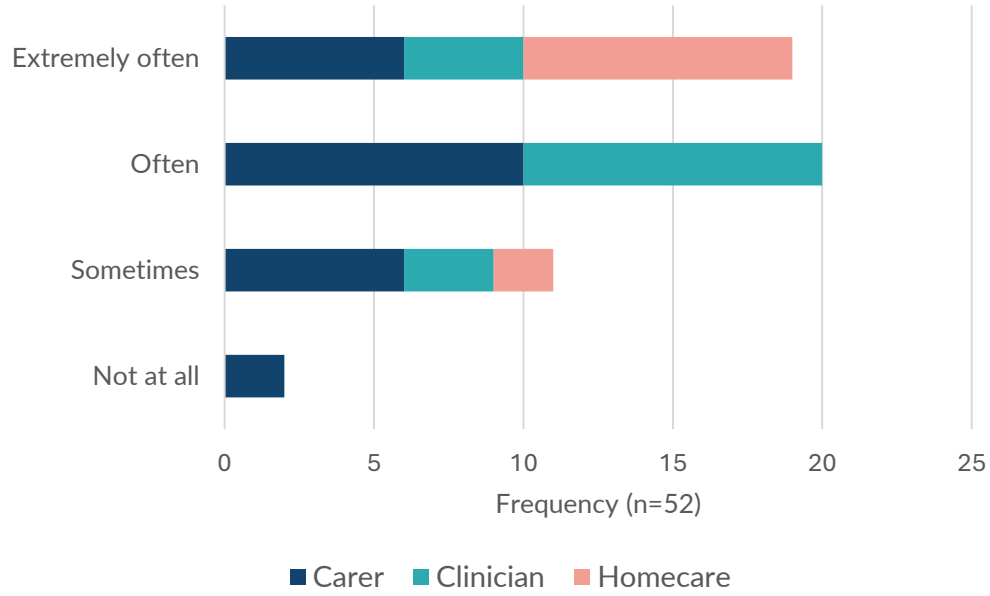

Figure 4. Encountering lack of awareness

Informal carers were asked whether they thought the person they cared for was currently aware of the diagnosis, with approximately equal numbers reported as being aware (11/24) and not aware (10/24) and three carers being unsure.

Clinicians agreed that lack of awareness was a common and significant problem encountered in dementia care.

"Anosognosia is a common feature in dementia and often affects multiple elements of the person's diagnosis, treatment, care and overall well-being."

"Significant effect on accessing appropriate help and support for the person and carers."

Informal carers describe how individuals have denied the condition or refused to accept any mention of 'dementia'. A lack of understanding of the condition and prognosis led to individuals not understanding why they could not act independently in all activities. Being unable to anticipate future problems, individuals were reluctant to accept early help, for example, being resistant to setting up a Lasting Power of Attorney for finances due to not recognising the future need. Even if the diagnosis was acknowledged, there was sometimes lack of awareness of changes in abilities due to dementia.

"Is aware she has dementia but thinks she is invincible".

Homecare professionals commented on denial as being frequently encountered. However, they observed that sometimes an individual makes use of early coping strategies such as calendars and memory aids, which might indicate an underlying recognition of dementia-related changes, even if this is not overtly acknowledged.

Main problems and consequences

Delays in the care pathway

The majority of respondents reported some delay in the care pathway related to lack of awareness. Five of the informal carers reported a delay in referral of more than a year. See Figure 5.

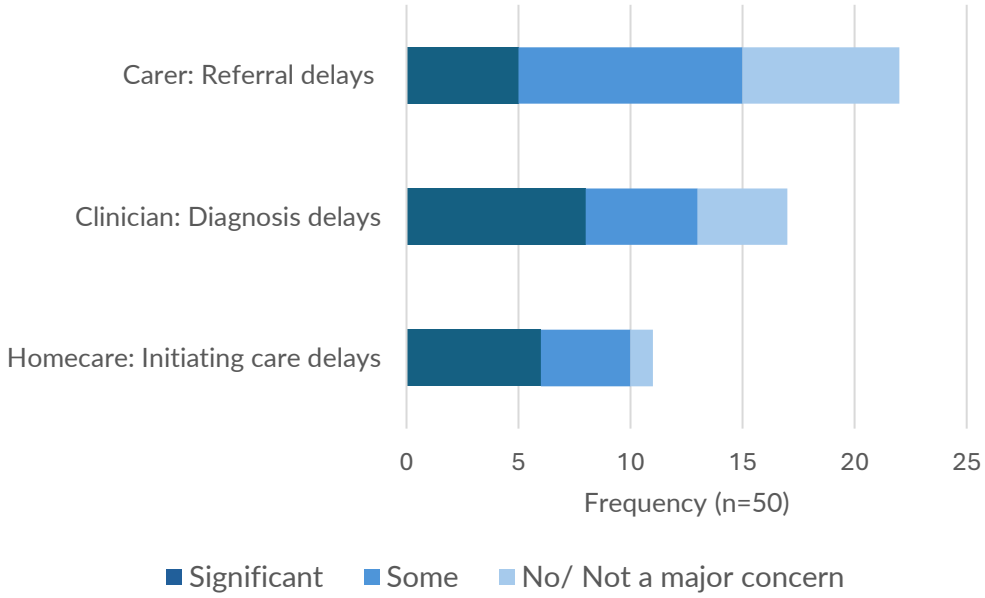

Figure 5. Delays in the care pathway

Carers reported delays due to individuals' refusal to attend the GP for an initial assessment or not attending follow-up. One carer described an interval of six years between the first GP appointment to discuss concerns and the next appointment that resulted in referral for diagnosis. This long delay in making the diagnosis may have contributed to the shock experienced by the individual when the diagnosis was eventually confirmed. Another carer felt that the lack of acceptance of the condition may have made the situation more "*...terrifying and isolating*" for that person, whose health suffered due to not seeking support earlier. Clinicians confirm that reluctance to accept referral for assessment and late presentation to memory clinic are common; a delay of 6-8 months on average between initial referral and the repeat referral was estimated by one clinician.

"Family want them to go (for assessment), and they think nothing is wrong".

Clinicians felt that the delays related to lack of awareness increase risks to the person with dementia and can result in mismanagement of other physical health conditions and safeguarding concerns. The absence of safety nets afforded by diagnostic recognition of dementia has resulted in persons going missing. There can be a detrimental effect on unpaid family carers, increasing isolation and delaying access to carer support, with mental health breakdown in some cases. Low level neglect such as poor hygiene, dehydration and mild

malnutrition can lead to significant risks, particularly in a person who lives alone and rejects early help.

When care is offered, rejection of the care package is common if the person does not recognise or accept their difficulties, and/or believes they are managing adequately without support.

"For example, patients believing that they go out and do all their own shopping when they have not left the home."

Therapeutic strategies such as cognitive rehabilitation approaches are not possible if the individual refuses to discuss or is unable to recognise that these are needed.

In some cases, an individual can manage physical self-care tasks but only if prompted. The need for prompting is often overlooked in care provision whether self-funded or publicly funded. Homecare professionals describe how care is commonly initiated late, often in response to a crisis, and the window for facilitating more independent living is missed. This can result in the family trying to manage complex needs with inadequate support, leading to failure to cope by the person with dementia and the family carers. Individuals may completely refuse the service offered or refuse to pay. They might resist help and not let the care worker into their home. This can reflect an underlying belief that they are successfully managing their own care, for example personal care or preparing meals, even though there is apparent self-neglect.

Disagreements

Nearly all the respondents reported an area of disagreement related to lack of awareness (45/50), in particular around the type of homecare needed, or affecting acceptance of the diagnosis. See Figure 6.

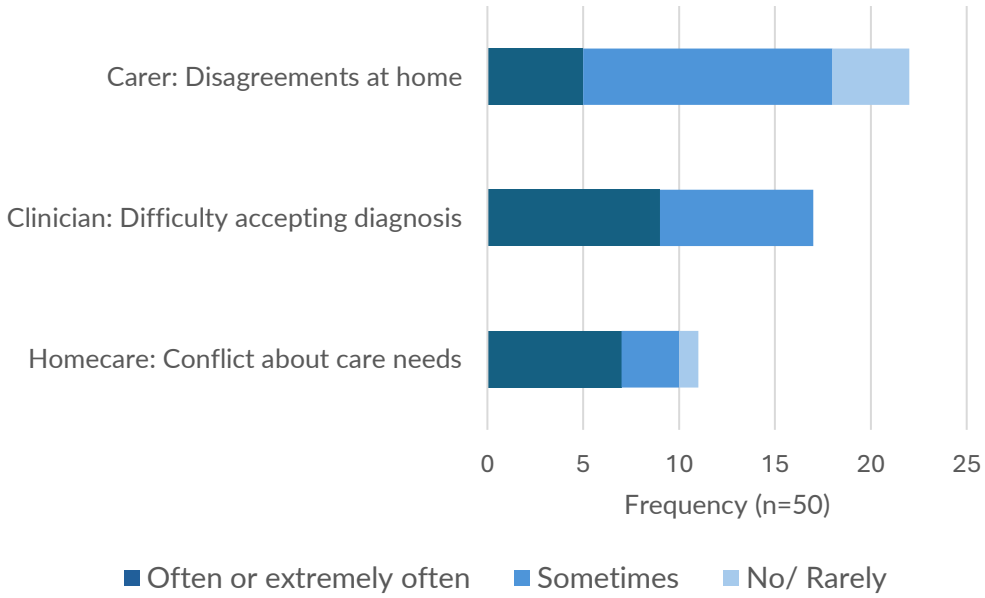

Figure 6. Disagreements related to lack of awareness

Carers shared how lack of awareness can result in the individual with dementia getting angry, not understanding the need for things to be done differently. Clinicians have observed

significant challenges and friction for family members who are trying to offer help or address safety concerns. Clinicians witness arguments about whether or not the carer had told the

individual something, or when objects are misplaced and believed to be 'hidden' or 'stolen' by the carer. At times, family members resort to accessing services behind someone's back, risking an angry reaction from that individual. Irritability and verbal or physical aggression can arise due to perceived over-involvement and control over daily activities by a family member, for example when changing systems for payments and establishing a key safe for carers' use.

Similarly, homecare professionals have experienced the person becoming annoyed with the care-worker or defensive about their needs, leading to conflict. This could restrict the type of care provided, reported as happening often or extremely often by the majority of the homecare respondents, and affecting widespread areas of care. See Figure 7. Showering can be a difficult area of care for homecare professionals to complete. Often the individual is already up and dressed in yesterday's soiled clothing and reluctant to undress and start again when the homecare worker arrives.

For clinicians, discussing the diagnosis and the implications are difficult when the person lacks awareness. Difficulties with discussions about the diagnosis and medication were acknowledged by 17 clinicians, with seven reporting this happens often or very often. Sometimes, the diagnosis is met with disbelief and questioning of the doctor's judgement, or outrage is directed towards the doctor. Post-diagnostic support and medication are rejected as believed to be unnecessary. Other areas of health management could also commonly be affected, for example, with poor self-management of diabetes, resulting in hospital admissions. Denial of mobility problems can lead to a refusal to use aids, and increased risk of falls. Planning for the future and discussing end of life care is resisted. Family preferences regarding diagnosis disclosure can sometimes add to this problem.

"In early diagnosis, people often feel 'normal', making it difficult to support them to apply processes now which will help them in the future."

"Sometimes I am told by the family not to use the word 'dementia' and use 'memory problems', but this becomes difficult to get the support they need by not addressing dementia."

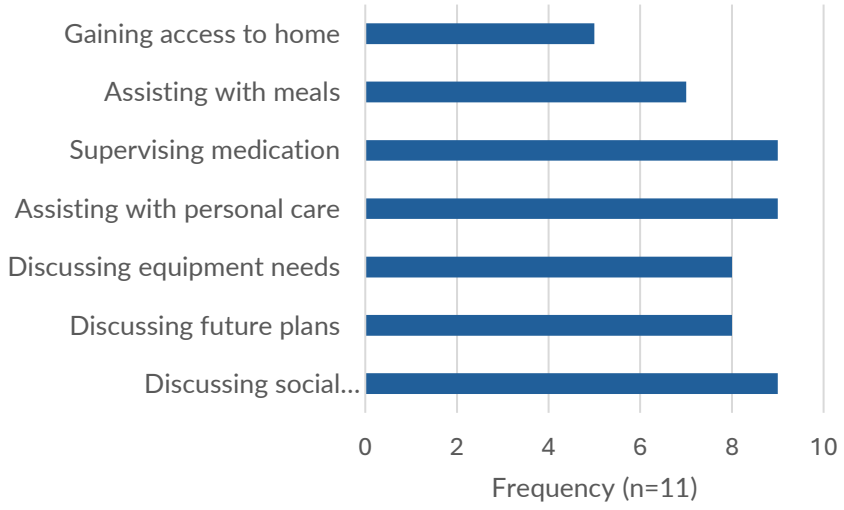

Figure 7. Homecare professionals report areas of conflict

Problematic areas of care

Carers sometimes experience problems in the wider community due to the person with dementia handling social situations differently or resisting available community support; see Figure 8. Social behaviour can be affected by lack of awareness, and the area most frequently endorsed by carers was concern over the person's emotional response to others, for example, making disinhibited comments in public and not being aware that this has caused offence. One carer described the individual's lack of understanding of the carer's own health condition and needs. Lapses in personal care with implications for comfortable social interaction included forgetting and not noticing details in dressing, such as managing shoe laces and trouser zips or choosing inappropriate clothing to wear and not brushing hair and teeth.

However, sometimes the problem arose from another person's reaction to dementia. One carer described an upsetting incident when a taxi driver became unpleasant and withdrew the regular service for the person with dementia as he "*…wasn't her carer.*" At times, interactions with healthcare staff were unsatisfactory, with unrealistic expectations around communication when seeing the person with dementia alone and not considering the appointed attorney when appropriate.

Sometimes, family members lack an understanding of what care professionals can achieve or '*make*' their relative do. Homecare professionals recognise the essential involvement of family members but acknowledge this can sometimes lead to conflicting views in decision making. Different views expressed by family members sometimes upset the mood of the relative and "*…this can be very difficult to manage in a domiciliary care environment*."

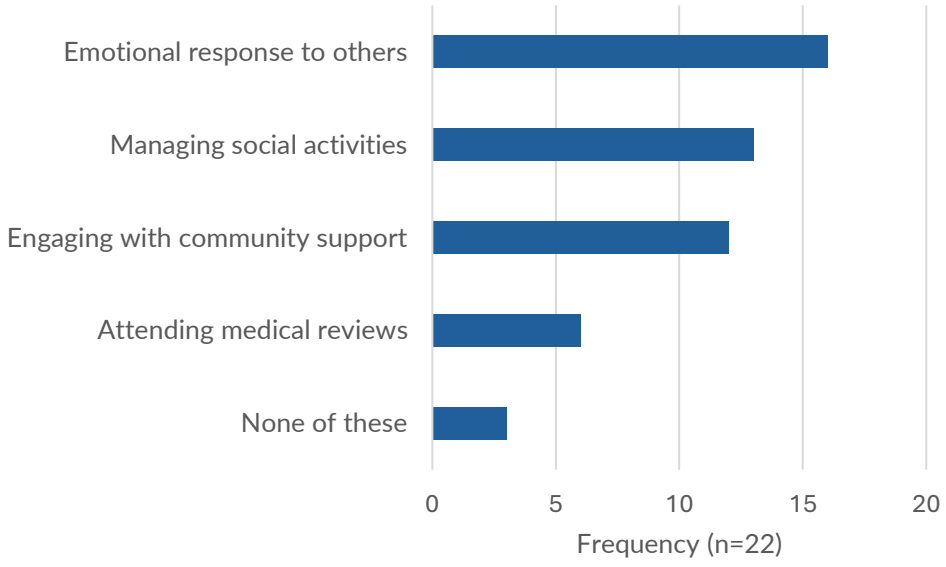

Figure 8. Carers report social activities affected by lack of awareness

Safety or safeguarding concerns

Concerns about safety or safeguarding resulting from lack of awareness were endorsed by the majority of respondents. Six carers and seven clinicians reported this happens often or extremely often; see Figure 9.

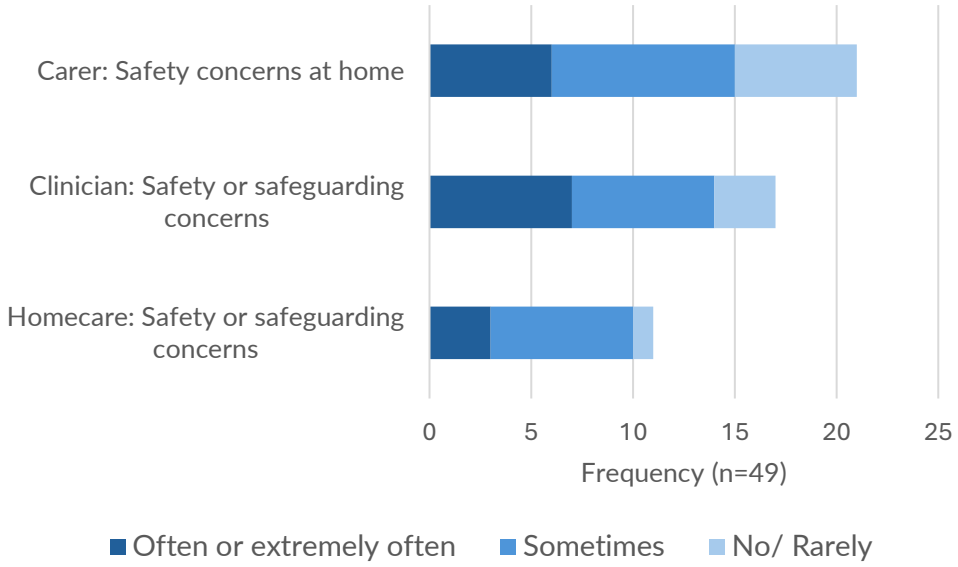

Figure 9. Safety or safeguarding concerns

Carers expressed many concerns about keeping the person safe in the context of low awareness.

> *"Thinks they are still able to do everything they used to, but I can see they aren't always safe doing so."*

Concerns about activities were reported by 22 informal carers, most commonly concerned about safety of going out alone. See Figure 10.

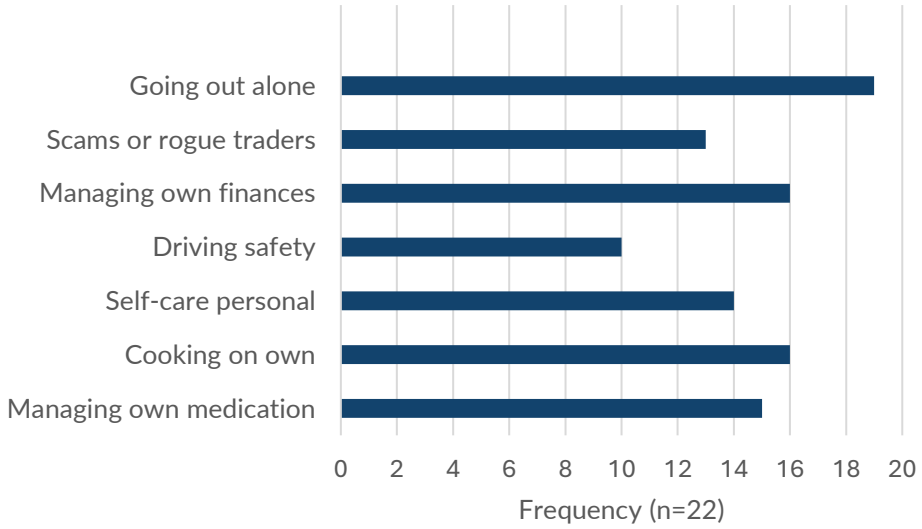

Figure 10. Carers report safety risks and activities of concern

Common concerns were around travelling alone on public transport and getting lost or, as a pedestrian, crossing the road or negotiating traffic but making misjudgements about the place or timing of the crossing. Some carers held concerns about driving. Awareness difficulties encountered around driving were not just about safe handling of the vehicle but included awareness for navigation and making appropriate decisions before embarking on a journey. In the home, safety issues were around cooking, using sharp objects or power tools for gardening or DIY, or concerns about being taken advantage of, particularly if online. In some instances, individuals had walked in front of buses, stepped out onto a dual carriageway when the pedestrian light was red, accidentally set fire to clothing while cooking, failed to renew insurance when due, accepted scams or were subject to a distraction robbery.

Clinicians also reported the dangers of online financial scams or fake relationships, for which intervention is difficult, particularly if the person with dementia has capacity and the right to refuse help or to make unwise decisions. At times, there can be very serious risks of financial, physical or sexual abuse.

Clinicians also held concerns about people who continued to drive despite having difficulties, and who were less likely to stop driving voluntarily. Particular challenges can arise when supporting younger people with dementia, for whom it may be unsafe to continue working. Identifying safety concerns inside and outside the home and helping an individual understand why they need more support can be difficult, with high stakes.

"Risks can be very high e.g. people getting lost for days, physical health deteriorating significantly, family and carer break down".

Homecare professionals frequently encounter areas of risk, but communication can be difficult when the individual client lacks understanding or does not acknowledge the areas of concern. Even when the client is deemed to have capacity to make decisions, they may lack understanding of the full potential implications. Adverse outcomes can result, for example, medication errors due to inaccurate self-administration leading to a hospital admission, neglect

of care needs regarding continence and neglect of skin care leading to skin breakdown. Consequences can be particularly dangerous for people with dementia who live on their own. Homecare professionals can be obstructed in their efforts to implement measures to mitigate risk. It can be very upsetting for the professional to know that the individual is at high risk and not coping but still refusing any help. A complete refusal and cancellation of care, putting the vulnerable person at greater risk, can necessitate a safeguarding referral regarding neglect. Among the worst scenarios, there had been a deterioration in an individual's physical health due to malnutrition, dehydration and infection, requiring hospital admission and ultimately, early demise.

Breakdown of homecare

In some cases, lack of awareness was thought to have contributed to the breakdown of homecare, reported by the majority (21/27) of clinicians and homecare professionals, and considered a significant factor by eight of these respondents.
Carers acknowledge the strain that results from their role. The carer's role of continual prompting and checking can be a source of frequent stress and concern and becomes exhausting. In one case, a move to residential care resulted perhaps sooner than would have been needed if help had been accepted earlier by the person with dementia.

Clinicians describe situations of care refusal until a crisis point is reached, by which time there are limited opportunities for support. This might lead to a hospital admission, otherwise avoidable, or the use of statutory services, sometimes inappropriately.
Conflict in accepting support can result in family breakdown and loss of relationships for the person with dementia, or abandonment by the family through frustration. Worst scenarios include a much more rapid loss of independence than needed, with an admission to hospital or care home, or even death due to self-neglect and lack of intervention.

"At the extreme stage, there can be a high degree of agitation around personal care."

"Lack of insight always ends in social crisis and carer burn out quicker."

Sometimes the systems are slow to respond, as described by a homecare professional:

"It took several months of reporting concerns and various serious incidents for the client…eventually housing and the local authority acted to find the client a safe setting to live in."

Strategies and suggestions

Around lack of awareness in general

The common theme from all respondent groups revolved around using a person-centred approach carried out with kindness and understanding, acknowledging the individual's identity as a person, not just as a person with dementia, and protecting their self-esteem.
Carers have found it helpful to use prompts and provide clear instructions, without removing the opportunity for the person to attempt activities.

"Enabling is everything: do it with them not for them."

Constant watchfulness was needed for undertaking small tasks. Even so, it is difficult, and "*…time away*" may be required.

For clinicians, it is important to help the individual recognise their ongoing value and their role, even if this is not the same as before diagnosis. From the first GP contact onwards, it helps to reiterate the message that "*…a person may not themselves be aware of their difficulties but others around them will be*." For example, it can be useful at an early stage to introduce the possibility of not being able to drive in the future, even if still competent to drive at the time of diagnosis.
For some people with dementia, psychological therapy can help with denial by "*…dispelling fears and overcoming avoidance of the subject or of feared words*."
Team working is essential. Social care agencies or befriending services can be helpful. Good communication across social and health care is desirable but not always achieved.
Homecare professionals draw on general techniques around personalised care using communication methods appropriate for interacting with people with dementia, remembering that "*…each person is different*." Continuity of care is helpful where possible.

"Regular carers (care professionals) to build the relationship and consistent approach, scripted responses and no arguing or negative responses."

"Talking to the client calmly, with relaxed body language."

Clinicians reported that capacity assessments are used to guide best interest decisions, and sometimes not intervening may be the best action at that time. This is echoed in comments from homecare professionals that the Mental Capacity Act is sometimes required but acting directly against a client's wishes can escalate a situation and is "*...rarely safe or appropriate*" because of the risk of frustrating the client further. Risks of physical aggression directed at the care professional and working in a hostile environment are to be avoided for all concerned.

"We need to avoid putting staff into situations that leave them questioning their job role and deciding that a retail or hospitality role would be far easier."

Managing delays in the care pathway

These situations were handled by carers with a combination of gentleness, patience and perseverance. Carers describe continual prompting (for example to attend a doctor's appointment), and gentle conversations to remind and persuade the person to accept support. Strategies include providing support "*...with love*", "*...ease and forward thinking*", "*...keeping things light*" and "*...avoiding confrontation*". Other suggestions are to act on concerns as early as possible, get information, be dementia aware, speak to other carers.

"We suggested she had a well person check with the GP. I spoke to the GP prior to the appointment to share my concerns."

Some carers shared how difficult it can be to know the best way to proceed. On their role in persuading a relative to accept care, a carer reflected:

"Perhaps we were more protective due to past experiences."

Another carer appreciated that the diagnosis may have meant more to them than to the person with dementia.

"Although she agreed to the assessment, she asked not to be given the result, she didn't want to know but understood that I needed to know."

With clinicians, strategies again are around being patient, gently encouraging the person to engage with assessment, giving the person time to come round to the idea that they need help. Careful communication means finding a way of wording that is acceptable to that person, without being too confrontational. Offering a joint assessment at a home visit with a known and trusted professional (e.g. the GP) can be successful.

When an individual insists that there are no problems contrary to family concerns, the clinician sometimes suggests following the process of diagnosis anyway "*...to prove the others wrong*". It can be helpful to suggest potential benefits of confirming a diagnosis, such as possible medical treatments or subsequent financial support. In some cases, the clinician had to watch and wait as the person had capacity to make their own decisions, only intervening if safeguarding concerns were apparent.

When care is refused, it can be helpful to have wider discussions about dementia and the importance of maintaining the current quality of life even with dementia. Starting with a low level of support is less threatening than going straight to a full package of care. Having a multi-disciplinary team (MDT) approach is important, maintaining good communication with social care providers. Sometimes, safeguarding referrals are indicated.

Homecare professionals describe a range of ways in which care can be introduced gently and gradually, through small steps, which can be increased over time. Staff can be introduced in ways that feel more comfortable for the client such as "*...family friends, nurses, gardeners, or cleaners*". There can be benefits to not wearing a staff uniform, to enable a different approach to care entry.

"Beginning with just one visit per week to build trust and familiarity."

"Offering a low level of service i.e. bit of shopping, bit of cleaning, bit of general help to start off with to develop a trusting relationship over time."

"Early engagement allows individuals to gradually become comfortable with having people in their homes, which can significantly increase their willingness to accept care in the future."

Managing disagreements

Carers describe some strategies, and some things to avoid doing.

"Refer to 'old age' and offer to help 'as I am younger'."

"No point in saying 'you have dementia'."

"Never argue, it's pointless."

"Never ever say 'you can't do that'. Let them try with close supervision."

One carer shared their learning curve about avoiding arguments.

"Whereas I used to want to be right, I now only want to be happy. I accept responsibility."

For clinicians, working with the individual to build up trust is key, with a "*quiet and calm persistence*", engaging in open and honest dialogue without causing alarm. This can be approached from different angles.

"I think they know they have dementia but as I am not saying it, they are accepting and trusting that I am trying to get them help."

"Frank and honest discussions with the person lacking insight can be surprisingly helpful but this takes experience to know when, how and who with. This can also easily antagonise."

Communication needs to be sensitive and deliberate. It helps to keep sentences short, allowing enough time for a response and engaging directly with the individual, not just their carer/family member.

"Being kind, compassionate, smiling, sets the right tone for a difficult topic and usually means it does not become a difficult conversation."

A particular person (e.g. a doctor, nurse, GP, or a friend) may be successful in discussing concerns where others have met a defensive response. Pre-diagnostic counselling can be helpful in some cases. Using direct guidance rather than offering a choice about treatment

preferences can sometimes help reduce their anxiety around decision making. Peer support can be valuable.

"Meeting other people with dementia who speak openly about their struggles and ways to address difficulties can help."

Homecare professionals try different approaches to offering support, working alongside the person without taking away their independence where possible. For personal care issues, it is helpful if the carer is familiar and trusted by the person, so time spent in building up a relationship is valuable. Distraction techniques are sometimes useful. If mealtime assistance was refused, sometimes meals were prepared anyway, even though the client said they did not want it, so they had access to it. "*Sometimes the visual cue and smell of food can trigger the appetite*."

Through these stages, it is important to "*...validate feelings*" and act with patience, with a "*...calm, consistent, and understanding approach*." Concerns are discussed with the client, and with family members or the appointed attorney when appropriate. Frustration from family members or even care professionals can lead to setbacks in the person accepting support. The involvement of other professionals, including a social worker, is important; sometimes raising a safeguarding referral is required.

Managing problem areas

Carers can find it difficult to resolve issues concerning interactions with other people. Few strategies were described. Personal care lapses can be addressed with "*...gentle prompting and humour*". One carer described occasional arguments when the person cared for showed a lack

of understanding for the carer's own health needs. One family found the diagnostic pathway was slow and unhelpful with unexpected obstacles and had to report poor quality of care several times.

Clinicians working with the family or informal carers offer support, advice and practical techniques, whilst also acknowledging the reality of how challenging this can be. Clear communication is essential, and professionals can help take some of the burden from the family around decisions, for example about stopping driving. Communication with the carer by text or email outside of visits can be useful to avoid inflaming a situation for the person with dementia when meeting all together. Family members may need guidance about not placing their standards on the relative when compromise might be more successful e.g. "*If that was me* (a carer), *I would want a wash every day*". Education for the family might include how the brain works, how to communicate with someone with memory problems, and about lack of insight. Advice to "*...roll with the resistance rather than confronting*" can be helpful.

Similarly, homecare professionals aim to work closely with the family, with open discussions and an explanation of limitations when care refusal occurs regularly, inviting family input. Access to safe spaces in the community, for example a memory café, library, or friendship group, is recognised as important for the person and carer to visit and socialise.

"We will also seek advice from family as to any techniques they may have found that may result in the desired outcome."

However, gaining family consensus "*…is important, but not always possible*". MDT meetings can be helpful to plan a way forward.

Managing safety or safeguarding concerns

Carers describe the difficult process of slowly introducing changes to ensure safety, but "…this is not always successful", or "…unfortunately, normally have an argument".

Strategies for managing trips out include not going out alone, holding hands when crossing roads, and the carer providing a running narrative describing or pointing out hazards in the surroundings. For public transport, scheduling simple (train) journeys with someone to help at both ends was helpful. Concerns around driving can be avoided by removing the car (for example, saying it's at the garage), or informing the DVLA of the diagnosis but not assisting in the paperwork for reapplication. For one person who enjoyed car journeys, the carer arranged to take him out daily for a drive and scheduled a longer time in transit when taken to day care.

At home, doing things differently or doing things together are common solutions, with an emphasis on the benefits of doing differently, such as not having to drive. Carers describe cooking together or supervising the cooking. Distraction can be useful to move away from a potentially dangerous situation. It can be helpful to turn the situation round; … can *you* help *me* with this…, and finding another reason for doing things differently, not always because of 'dementia'.

"Whilst I still want him to retain skills and be as independent as possible, I now have to be more involved."

Changes in the home can include technology to improve safety, with the use of a video doorbell linked to the carer's phone, or CCTV or sensor systems around the house.

"Try to allow some independence but make the environment safe."

Clinicians make use of protocols and surveillance to address safety risks. These include MDT working with risk assessments and planning for contingencies "*…to support the family and ensure this support doesn't break down*". Referrals to outside agencies such as occupational therapy and the fire brigade for home assessments can help identify and reduce risks at home. Carer education and support is vital. Safeguarding alerts and referrals are used to mitigate risks. In some cases, more secure care environments are needed. Likewise, areas of self-neglect are encountered by homecare professionals, and can necessitate a safeguarding referral to avoid more adverse outcomes.

A summary of strategies is shown in Appendix B.

What would help?

Earlier diagnosis and earlier support

Although not universally expressed, some carers consider early diagnosis to be important for the family and the person with dementia.

"The diagnosis has helped me to get more help and support, also to understand why she does what she does."

"Sometimes showed more awareness and would have benefitted from more support at these times."

Carers would like more help around earlier detection of symptoms and prompting to enable earlier diagnosis, allowing access to appropriate support for the person with dementia and the carer.

"More support from clinicians to help suggest to the patient regarding dementia symptoms and issues arising in them."

"Offer more proactive diagnosis and support even if the patient themselves hasn't booked the appointment for that purpose."

Clinicians suggest wider public information campaigns which might highlight and help address the delays in accessing support. One homecare organisation described already working with local communities to emphasise the importance of introducing some form of support early for people with dementia.

More support

Carers needed more support than was available in adjusting to the diagnosis.

"Needed more support to help us to cope with our past experiences and accept this diagnosis and find ways to adapt life to cope with the progression of dementia together."

Clinicians agreed that counselling for people with dementia and families could match that offered, for example, to cancer patients. Homecare professionals suggest the need for training for families, "*to gain greater understanding of what is happening to their loved one*."

Better funding

More practical assistance was indicated by carers, with financial implications.

"Fitting CCTV has allowed me to leave her for small amounts of time but is very expensive!"

"Some help with cleaning."

A clinician suggested that better financial renumeration should be offered to support informal carers, as a more realistic financial incentive to take on this role.

Homecare providers have highlighted the overall problems around inadequate funding for social care, where initiation of care is delayed until a crisis occurs. Within established care packages there are funding barriers to providing best practice, for example when assisting in mealtimes, being able to offer the type of food for which an individual has actually expressed preference and then having time to eat together.

Working together

Carers felt that care could be improved by better communication and working as a team, with professionals "*…working with the families and carers that are supporting the person*". There is scope for closer working with the family.

> *"Would have liked to feel part of a team supporting my relative so that we could do our best to help them live as well as possible."*

> *"Talk to the carers about how best to communicate and work with the individual."*

Carers would like professionals to be aware of the lasting power of attorney for health, if this has been set up, to ensure that the appropriate person is involved in care discussions. Clinicians such as GPs would like more time and to be able to provide better continuity of care.

Education and training

Clinicians recognised that training for primary care staff could help identification of people with undiagnosed dementia enabling more proactive care, particularly for housebound patients. Homecare professionals expressed a need for more education in general around awareness issues. This should include training on "*…dealing with insight or denial so they can approach a person in a calmer way, building a rapport quicker*", as well as education for family, friends and healthcare professionals "*…on how best to approach these conversations and introductions*".

Adapted dementia services

Clinicians suggest that clinical care provision would benefit from a more holistic approach from a specialist dementia team across community, hospital and social care services. "*This should cover people without diagnosis also*." Carers pick up on this, asking for the use of "*…dementia-friendly communication even if a diagnosis is not yet in place*". Clinicians suggest that GPs should

be encouraged to consider awareness issues/anosognosia as part of the referral information. In some areas, "*Referrals without formal informed consent are routinely rejected*", leading to delays in diagnosis, treatment, support and future planning. There needs to be "*Responsive dementia wellbeing services that can be involved with people with undiagnosed dementia*".

Homecare professionals suggest that individuals with dementia and their families need better access to specialist services, with more focused joint support for people with dementia who live alone. This could target smoother and faster implementation of strategies in crisis situations.

The full responses to the structured survey questions and text matrices for the free text responses are available in Supplementary information online at **https://bit.ly/Awareness_Consultation**

Views from people with dementia

From the MIDAS interview transcripts, the people with extensive awareness noticeably had a good understanding of their diagnosis and were able to describe strategies that they used to manage everyday tasks such as writing notes, making lists, keeping a daily routine, rituals for remembering medication, using microwave meals instead of cooking, or stopping driving.

"I said, "I've decided I'm going to stop driving. I think I'm going to be a danger on the road."

Very few strategies were described by the people with no evidence of awareness.

"I sit quiet and ... tell myself, 'Now there's something I've got to do about …."

This group also showed less concern about the future, and no particular worries were described.

"Any worries? No, I don't think so, no. I can't think of anything."

"I don't think much about the future to be truthful."

In contrast, the more aware people discussed the future and the likelihood of needing residential care at some stage, with associated worries and sadness for some.

"I don't mind if it stays where I can control it as I can now. What worries me is where I can't control it."

If she dies first then I've got things that I have to do and with a deteriorating…..mental capacity that's rather frightening."

"I see the future as being pretty hopeless really."

In the wider group with better awareness, some people reflected on being aware of changes and reactions to being diagnosed with dementia.

"I knew I had it. I was just glad it was confirmed and something would get – I felt as though something would get done about it now, before it had got too bad".

"It's hard to sort of explain because it's part of you wants to know and the other part doesn't. Then you're frightened of it...that erm you don't know what erm cos I've never really known anybody with it."

"I'm aware of a very slow, steady er deterioration."

Reactions from other people were noticed and commented on by this group.

"I think all of our many friends are aware of – of my problem um….but I – everyone's kindly, nobody's condescending."

"People don't realise that it's actually Alzheimer's they just think it's old age and I can get away with that. I know it's more than that."

"To be honest I was devastated when I actually got the news. But I was also relieved. Because at first, I felt I wasn't believed."

One individual with dementia gave this advice for other people who realise their memory is changing: "*…you should straight away go and see about it.*"

Conclusions

There is a recognisable subgroup of people with dementia who lack awareness of dementia-related changes or who may deny any problems.

Whilst people who have good awareness are able to reflect on their condition, make plans and adopt strategies to manage ongoing activities, it is difficult to approach these issues with people who seem unaware of changes or deny that any help is needed.

Lack of awareness in people with dementia is recognised as a specific and significant problem by informal carers, clinicians and homecare professionals. It can have serious consequences for people with dementia and their family members, as well as having an impact on professional workers.

Whilst there are known stresses inherent in dementia caregiving, there are additional challenges when caring for someone who lacks awareness of dementia-related changes and the consequent care needs. For informal carers, the lack of a shared understanding of situations can disrupt relationships and interfere with everyday decision making, leading to increased stress. For health and homecare professionals, best practice of person-centred care becomes difficult to achieve. The existing care pathways do not adequately recognise the problems, and there can be obstacles to accessing appropriate care and support for this group of people with dementia.
Some of the daily problems encountered can be experienced in other situations of dementia care, and some of the strategies used come from general best practice with principles of person-centred or tailored care. Other problems are specific to lack of awareness, and require specific strategies for management, before crises develop.

Common strategies are based on a flexible and patient approach, allowing the person to build up trust with the care provider, and considering different ways of managing familiar activities. A team approach is needed, as exemplified by the 'triangle of care', with the family supported by and working with the clinical and social care teams, and with access to community resources. Safeguarding considerations are frequently required.

More bespoke strategies are developed by informal carers who need to 'think outside the box' at times to maintain participation and enjoyment for people with dementia in activities whilst staying safe. Home care organisations are innovative in finding adapted approaches for care entry and promoting public awareness of the importance of starting support early. Clinicians, reliant on good communication within the care network of families and homecare providers, often have central roles and responsibilities in making decisions at key points or crises.

This can be very challenging. Carers describe the stress, leading to exhaustion and the need for some time away. Clinicians report being blamed for difficult conversations and having their professional judgement questioned. Homecare professionals describe experiencing hostile environments when providing care, which can have implications for workforce sustainability. For people with dementia, awareness of the implications of a dementia diagnosis can bring

sadness, but lack of awareness can increase confusion and isolation, as well as numerous safety risks.

Unclear best practice. Optimal management remains unclear and various strategies may need to be trialled before finding the best approach for a specific person and circumstance. An individual has the right to refuse a medical referral and reject care provision and currently there is no straightforward solution for enabling people to get the right sort of support without a clinical assessment and diagnosis. Clinicians value listening to the patient to deliver person-centred care but meet an ethical dilemma when care needs and patient preferences clearly conflict.

What is truth? In clinical care, it can be difficult to establish accuracy of accounts. Confabulation by a person with dementia may be encountered, and families may need education about this. A further complication can arise if the informal carer has their own health problems, which might include cognitive impairment, or otherwise lacks capability for being a carer. The carer themself may show little awareness of dementia or the need to adjust and provide more support. This is an area that could be further investigated outside of this report. In contrasting circumstances, sometimes matters are dealt with by 'therapeutic lies', a tactic which may be more commonly used in residential settings caring for people with more severe dementia, and could be examined in more detail.

Other areas for research. This consultation exercise focused on people with dementia who live in their own homes, but difficult situations related to awareness also occur in care homes. In a population of people with more severe dementia and more impaired communication, changes in sensory awareness can become increasingly apparent. This can affect personal care needs such as continence management, requiring sensitive care to maintain the individual's personal dignity and well-being, and is an area of care that could be explained further in staff training programs. It can be difficult to distinguish whether apparent lack of awareness has a neurological or psychological basis, for which differing care strategies or interventions may be indicated. This is an area of dementia care which requires further exploration.

Limitations of this consultation

The consultation involved a small sample of people from known networks, who may have been motivated to respond if they had experienced significant issues around lack of awareness. Responses represent subjective experiences, and it is not possible to clarify accounts for example, regarding the frequency of safeguarding events related to lack of awareness, and there was little representation from social services. However, the draft report has been shared with representatives from the consultation groups, to check the validity of the conclusions. Although survey respondents came from a wide regional area, ethnic diversity within the sample was limited, with respondents mainly from white ethnic groups.

Key messages

Lack of awareness is commonly encountered in dementia care and can have serious consequences for the person with dementia and significant implications for effective care provision. Building on these consultation findings, there are a number of areas that could be addressed to improve care:

1. Information. More information is needed for people with undiagnosed dementia and their family members around the time of emerging symptoms and signs of dementia.
This would be helped by providing more information for the general public:

- about dementia and how personal awareness of dementia symptoms can vary
- advice on who to ask and what to do when a family member shows little awareness of apparent changes
- a shared appreciation of the value of early referral even in cases of lack of awareness of difficulties, to access appropriate support before crises develop.

2. Resources for education and training. More educational resources for informal carers and specific training for clinicians and homecare professionals would improve understanding of awareness issues and highlight best practice.

- Carer resources and professional training could promote the sharing of strategies that are already used effectively to manage difficult situations.
- A forum for sharing concerns would also help to identify specific carer support needs.
- Conversations with professionals about dementia and awareness should identify and address organisational obstacles to diagnosis and support. An important emphasis would be on using different approaches to communication when discussing diagnosis and offering care.

3. Technology. Access to technological solutions could improve home safety for people who lack awareness and live alone.

- Personal budgets for dementia care could be used to fund equipment such as CCTV and video doorbells to help informal carers monitor safety in the home whilst respecting the privacy and autonomy of the person with dementia.

4. Proactive approach. A proactive approach by primary care clinicians could facilitate earlier identification of dementia and recognition of awareness difficulties in individuals. Documenting awareness status in primary and secondary care records could help guide tailored care plans.

- A proactive approach could address better continuity of care in primary care and closer monitoring of vulnerable individuals, with closer working with family members. This could lead to earlier identification of dementia symptoms, even when these are not acknowledged by the individual.
- Referrals to secondary care should routinely include information about the degree of awareness shown by the person being referred.
- Routine collection and recording of awareness data by secondary care clinicians could help to tailor clinical care as well as benefit research. Towards this aim, suitable clinical tools for awareness assessment should be made available.

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Appendix

Appendix A. Survey questions
Appendix B. Summary of strategies used

Appendix A. Survey questions

Informal carers
Sometimes people with dementia can seem unaware of changes due to dementia. This can be due to the disease, or as part of coping or denial about the condition. It might mean that they don't recognise memory problems, or over-estimate their ability to carry out everyday tasks.

1. Have you come across this in situations with any person with dementia you have cared for?

Not at all

Rarely

Sometimes

Often

Extremely often

2. Has lack of awareness in an individual with dementia led to any delays in initiating home care?

Not at all

Rarely

Sometimes

Often

Extremely often

3. Has lack of awareness in an individual with dementia restricted the type of care you can provide?

Not at all

Rarely

Sometimes

Often

Extremely often

4. Has lack of awareness in an individual with dementia resulted in disagreements or conflict about the help needed during home care?

Not at all

Rarely

Sometimes

Often

Extremely often

5. If you have noticed a lack of awareness, which areas of care provision have been problematic? (Please tick as many as applicable)

Gaining access to home

Assisting with personal care

Supervising medication

Assisting with meals

Discussing equipment needs

Discussing future plans e.g. Lasting Power of Attorney, living situation

Discussing social activities and community support

None of these

6. Has a lack of awareness in an individual with dementia resulted in any significant safety or safeguarding issues?

Not at all

Rarely

Sometimes

Often

Extremely often

7. Do you think that lack of awareness has contributed to breakdown of home care for any of your clients?

No, definitely not

No, was not the main reason

Not sure

Yes, was a factor in care breakdown

Yes, definitely

8. In your own words, what are the main problems you have encountered, if any, due to low awareness in a client with dementia?

9. How have you handled these situations? What has been the worst consequence?

10. What strategies have you found helpful? Do you have any other ideas or suggestions about the best way to manage these situations? What else would you need to help you manage better?

Clinicians

Sometimes people with dementia can seem unaware or lack insight about changes due to dementia. This can be due to the disease, or as part of coping or denial about the condition. It might mean that they don't recognise the diagnosis or memory problems, or they over-estimate their ability to carry out everyday tasks and decline appropriate support.

1. Have you come across this in situations with any person with dementia you have cared for?

Not at all

Rarely

Sometimes

Often

Extremely often

2. Has lack of awareness in an individual led to any delays in diagnosing dementia?

No, not to my knowledge

Yes, but rarely

Yes, in some cases

Yes, this often happens

Yes, this is extremely common

3. Has lack of awareness led to an individual having difficulties in accepting the diagnosis of dementia?

Not at all

Rarely

Sometimes

Often

Extremely often

4. Has lack of awareness in an individual led to difficulties in discussing dementia care and/or prescribing appropriate medication?

Not at all

Rarely

Sometimes

Often

Extremely often

5. Has a lack of awareness in an individual with dementia led to any difficulties in other areas of health management such as managing continence, nutrition, treating long term conditions such as diabetes, or recognising non-dementia symptoms?

No, not to my knowledge

Yes, but rarely

Yes, in some cases

Yes, this often happens

Yes, this is extremely common

6. Has a lack of awareness in an individual with dementia resulted in any significant safety or safeguarding issues?

No, not to my knowledge

Yes, but rarely

Yes, in some cases

Yes, this often happens

Yes, this is extremely common

7. Do you think that lack of awareness has contributed to breakdown of home care (paid or unpaid) for any of the people you care for?

No, not to my knowledge

Yes, but rarely

Yes, in some cases

Yes, this often happens

Yes, this is extremely common

8. In your own words, what are the main problems you have encountered, if any, due to low awareness in a person with dementia you have cared for?

9. How have you handled these situations? What has been the worst consequence?

10. What strategies have you found helpful? Do you have any other ideas or suggestions about the best way to manage these situations? What else would you need to help you manage better?

Homecare and social care professionals

Sometimes people with dementia can seem unaware of changes due to dementia. This can be due to the disease, or as part of coping or denial about the condition. It might mean that they don't recognise the diagnosis or memory problems, or they over-estimate their ability to carry out everyday tasks and decline appropriate support.

1. Have you come across this in situations with any person with dementia you have cared for?

Not at all

Rarely

Sometimes

Often

Extremely often

2. Has lack of awareness in an individual with dementia led to any delays in initiating home care?

Not at all

Rarely

Sometimes

Often

Extremely often

3. Has lack of awareness in an individual with dementia restricted the type of care you can provide?

Not at all

Rarely

Sometimes

Often

Extremely often

4. Has lack of awareness in an individual with dementia resulted in disagreements or conflict about the help needed during home care?

Not at all

Rarely

Sometimes

Often

Extremely often

5. If you have noticed a lack of awareness, which areas of care provision have been problematic? (Please tick as many as applicable)

Gaining access to home

Assisting with personal care

Supervising medication

Assisting with meals

Discussing equipment needs

Discussing future plans e.g. Lasting Power of Attorney, living situation

Discussing social activities and community support

None of these

6. Has a lack of awareness in an individual with dementia resulted in any significant safety or safeguarding issues?

Not at all

Rarely

Sometimes

Often

Extremely often

7. Do you think that lack of awareness has contributed to breakdown of home care for any of your clients?

No, definitely not

No, was not the main reason

Not sure

Yes, was a factor in care breakdown

Yes, definitely

8. In your own words, what are the main problems you have encountered, if any, due to low awareness in a client with dementia?

9. How have you handled these situations? What has been the worst consequence?

10. What strategies have you found helpful? Do you have any other ideas or suggestions about the best way to manage these situations? What else would you need to help you manage better?

Appendix B. Summary of strategies used

Area of concern	Psychosocial approaches	Practical strategies	Professional processes	Team working
Lack of awareness in general	Person-centred Kindness Patience Perseverance Enabling Avoid confrontation	Prompts Clear instructions Watchfulness Time out	Continuity of care Flagging future issues Psychotherapy around denial Acknowledging the difficulties/care challenges Capacity assessments	Multidisciplinary team: healthcare, social care and family Community resources Safe spaces
Delays and disagreements	Reframe the problem: Offer to help 'as I am younger'. Doing things differently, for another reason. Validate feelings Humour Use acceptable wording Emphasise potential benefits of confirming diagnosis Discussion about maintaining current quality of life	Act on concerns early Be informed Prompting Arrange 'well person' check Offer low level support initially Introduce care staff in different roles (sometimes without uniform)	Joint assessment with trusted professional Encourage diagnostic process anyway Pre-diagnostic counselling Allow time to build up trust Find the best person for difficult discussions Safeguarding referrals if indicated Provide support for family when difficult decisions faced Remote communication with family if needed	Peer support: engaging with other people with diagnosis Report poor care Education for family members Training for professionals
Safety	Turn the problem round: can you help me with this Distraction	Not going out alone Holding hands crossing road and giving narrative Careful planning train journeys Remove access to vehicle Arrange car journeys for enjoyment Cook together Technology in the home	Risk assessment Contingency planning Safeguarding alerts	Outside agencies for home safety assessments

Thank you for reading the report. Our contact details can be found below.

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