together in dementia everyday

Making Shared Care a Reality

The experiences of family carers when the person they have looked after goes into a care home

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Contents

01

Background

This project arose following discussions amongst tide's carers in its fortnightly on-line coffee morning and the Tide Advisory Group (TAG). It was clear that people's experiences of shared care when the person they support goes into a care home vary considerably – from excellent to poor. The discussions coincided with an invitation in January 2025, to join the Public Engagement Network, part of Choice Support, that is funded by the Care Quality Commission (CQC) to encourage and facilitate feedback in relation to regulated services, especially from marginalized and under-represented groups. Tide saw this as an opportunity to gather views from the wider tide membership as a vehicle for feeding back to CQC and to inform future developments within the charity.

02

Executive Summary

A questionnaire was circulated from January 9th to February 10th, 2025, amongst tide's networks across the UK, exploring the issues around making shared care a reality for carers of people with dementia, once the person they cared for had moved into a care home. It was clear from the responses that there are some care homes that are getting it right. They are proactive in engaging with carers and support them in feeling part of the team. Carers are actively involved and have no fear of speaking out if the need arises:

> "The care home and all its staff have been brilliant. I feel part of them, and they have always been grateful for my help, and I have been appreciative of all their nursing, care and kindness. The manageress and staff have always been approachable and friendly and helpful."

02. Executive Summary

However, it is clear from the responses that there is a lack of consistency across care homes. tide wishes to raise awareness of this disparity and make recommendations for future action. The following represents the list of tide recommendations to support the development of shared care within the care home environment.

- **Acknowledge Carer Experiences** – Recognise the emotional and physical toll of caring for someone with dementia, including stress, exhaustion, and feelings of guilt or loss. These feelings may still be present after the person with dementia has gone into care. Indeed, they may be experienced more powerfully after the person with dementia has moved to a care home.

- **Increase Focus on Shared Care as Part of Statutory Inspection Regimes** – whilst some reference is made to inclusive approaches to care in inspection regulations, there is space to develop specific requirements in relation to carers receiving support to maintain active involvement in providing Shared Care.

- **Actively Champion the Existence of a Shared Care Philosophy Across all Relevant Care Home Literature** – By positively and proactively sharing information about carers' active and ongoing involvement, a huge amount of anxiety and fear can be allayed before the move into care takes place.

- **Actively Support Staff in Shared Care Skills Development** – Ranging from the development of policies and protocols within the home to training opportunities with external providers including tools like Life Story Work. Shared Care will only become a consistent practice in those homes that actively champion its development through trained, skilled and aware staff members.

- **Value and Actively Seek Carer Knowledge** – Carers hold deep insights into the person's history, preferences, and needs. Involve them as key partners in care planning and daily routines wherever possible. Carers' knowledge is an important resource with unique insights into enhancing the care of the person with dementia.

- **Provide Compassionate Communication** – Approach carers with empathy, patience, and understanding, ensuring they feel heard and valued.

02. Executive Summary

- **Provide Clear and Consistent Communication** – The provision of single points of contact with a responsibility to relay communication in a clear and timely manner holds the potential to resolve many issues before they arise.

- **Signpost to Advocacy Services** – It can be forgotten that carers need advocacy too. Make use of any local advocacy services and make sure information about these services is freely available.

- **Offer Flexible Involvement** – Recognise that carers may have varying capacities for involvement based on their health and well-being, personal commitments and emotional readiness.

- **Create a Welcoming Environment for Carers** – Foster a culture where carers feel comfortable visiting and participating without feeling like outsiders. Do not make the carer responsible for staying involved. Extend invitations towards them, no matter how small and seemingly insignificant the interaction.

- **Be Transparent and Inclusive** – Keep carers informed about changes in their loved one's health and well-being, encouraging open dialogue and shared decision-making.

- **Provide Emotional Support** – Offer signposting to carer support groups, counselling or respite opportunities to help them cope with stress and transition.

- **Recognise Carer Grief and Loss** – Understand that carers may experience living grief and a sense of loss even while their loved one is still alive. Sensitivity to this can improve engagement.

- **Encourage Carer Peer Support** – Facilitate opportunities for carers to connect with others going through similar experiences, such as carer support meetings or informal gatherings like coffee mornings.

03

Introduction

> "After years of being the sole carer for my mum, I went overnight from a carer to a visitor. It was a change I did not want and was not ready for."

When a person with dementia moves into a care home, their unpaid carers — usually family members or close friends — face a profound shift in their role. While the daily hands-on care may change, their emotional connection and deep understanding of the person remain invaluable. At tide, we believe that carers must continue to be recognised as essential partners in care, ensuring that the person with dementia receives support that is truly person-centered. However, carers often feel excluded from decision-making and uncertain about their ongoing role once formal care begins.

Through our research and engagement with carers, tide has highlighted the importance of listening to and involving carers in shaping dementia care policies and practices. Our Moving Forward (1) resource captures these experiences, with carers sharing the emotional impact of transition and the need for ongoing involvement. As one carer reflects, "I felt like I had lost my purpose overnight, but I still knew my husband better than anyone else." Another carer emphasises the importance of communication with care home staff, stating, "Being involved in decisions, even in small ways, makes such a difference. I still feel like I'm part of his life."

This report explores the need to support carers to remain engaged in their loved one's life after they enter a care home. It examines the barriers to involvement, the benefits of partnership between carers and care providers and makes some initial practical recommendations for ensuring that carers continue to play a meaningful role.

By valuing carers' insights and experiences, we can create a more compassionate and effective dementia care system that truly puts people and relationships at its heart.

04

Methodology

In **Making Shared Care a Reality**, tide has taken a carer-led approach to exploring an often under-researched and misunderstood aspect of dementia care: how to ensure that carers remain involved in the lives of those they support after they move into a care home. To shape this work, in January 2025 tide convened a dedicated working group of carers who brought their lived experience to the forefront by designing a questionnaire to gather insights on this critical issue. The questionnaire was circulated via Survey Monkey for a four-week period across tide's network, reaching carers from all four nations of the UK. A total of 63 responded, shedding light on the barriers and opportunities for creating a more inclusive approach to shared care. The free text responses were grouped into themes with the aim of highlighting the most prevalent issues.

The findings from this research will directly inform the development of best practice guidelines for care home providers, ensuring that carer involvement is embedded into dementia care. The importance of this work has already been recognised, with interest expressed by the CQC in England. Discussions are already in motion with the Care Inspectorates in Wales, along with plans to initiate contact with the Care Inspectorate Scotland and the Regulation and Quality Improvement Authority in Northern Ireland.

A copy of the survey is available here:
https://www.surveymonkey.com/stories/SM-4pEmhdbsrAmbdVivklOLww_3D_3D/

05

Terminology

> ‘Shared care refers to the active involvement of carers in ongoing personal care routines, social activities and formal care planning within the home, to the level and extent agreed with the carer.’

Shared Care – It is understood that not all carers will want to provide active support when the person they care for moves into a care home. For those that do want to continue, shared care refers to the active involvement of carers in ongoing personal care routines, social activities and formal care planning within the home, to the level and extent agreed with the carer. The carer is viewed by care home staff as an essential part of the care team engaged in supporting the person with dementia.

Person-Centred Care – Instead of offering a concise but inevitably limited definition, the Health Foundation (2) has identified a framework that comprises four principles of person-centered care:

1. Affording people dignity, compassion and respect.
2. Offering coordinated care, support or treatment.
3. Offering personalised care, support or treatment.
4. Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life.

The active involvement of carers in providing care and support after the move to a care home has clear and compelling relevance for all four principles of person-centred care.

Life Story Work – tide defines LSW as ‘understanding what life that person has had, what their life is now and their wishes for the future. It’s an activity in which the person with dementia is supported by family members or others to gather and review their past life events and build a personal biography. It is used to help the person understand their past experiences and how they have coped with events in their life.’

06

Questionnaire Responses

Question 1

Please give us a brief outline of the circumstances that gave rise to the person you care for going into a care home.

The first question sought to place responses against the reality of caring for someone with dementia. As a charity, tide seeks to constantly raise awareness of the challenges many carers face on a daily basis. Carers tell us that it is the unique intensity of caring for someone with dementia that creates a wish to stay involved as an active care partner. Nuanced communication, often forged over a lengthy period of cognitive decline, runs the risk of being lost without the active engagement of carers.

Sixty-three carers responded to this question.

Safety

Thirty-two respondents expressed specific fears about safety.

Carers of people with dementia face unique and complex challenges in ensuring their safety, as the condition affects memory, judgment, mobility, and awareness of danger. Unlike some other disabilities, dementia can lead to unpredictable behaviors such as confusion about familiar environments and difficulties recognizing risks. Carers must constantly monitor and anticipate potential hazards, from preventing falls and accidents to ensuring the person does not leave home unsupervised or consume unsafe substances. Additionally, changes in perception and cognition can make it difficult for individuals with dementia to follow safety instructions or understand why certain precautions are necessary, leading to frustration and resistance. Night-time agitation, increased vulnerability to scams or exploitation and the need for constant supervision add further to the emotional and physical toll on carers. Balancing independence with safety while respecting the person’s dignity requires patience, creativity, and ongoing adaptation, often without sufficient external support or respite.

Unable to meet the care needs of person with dementia

Thirty respondents said that their ability to provide a level of personal care and support had fallen below an acceptable level. This included challenges with incontinence, nutrition, mobility, dressing, sleep and medication that prompted the move to a care home. This also included situations where paid carers were in attendance as well as carers who were caring in isolation.

Carer Burnout

Five respondents talked specifically about their own burn out and inability to carry the weight of caring. Despite this number being relatively low, there is no doubt that carer exhaustion was a factor in the decision to seek residential care for a far larger number of respondents.

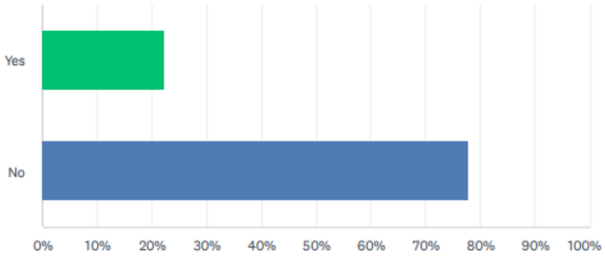
Carer burnout is a high risk for those supporting a person with dementia, as the nature of the condition presents unique and complex challenges. Unlike many other disabilities, dementia is progressive and affects not only physical abilities but also cognition, communication and personality, requiring carers to constantly adapt to changing needs. The emotional toll of witnessing ongoing decline, coupled with the unpredictability of symptoms such as memory, agitation or confusion, can lead to chronic stress and exhaustion. Unlike carers for those with stable conditions, dementia carers often experience a prolonged period of living grief, mourning the gradual loss of the person they once knew while still providing care. Additionally, the invisible nature of dementia can lead to a lack of understanding from others, leaving carers feeling isolated and unsupported. The 24/7 nature of dementia care, including disrupted sleep due to night-time agitation or confusion, further exacerbates burnout. Without adequate respite, emotional support and recognition of their role, dementia carers are at high risk of physical and mental health issues, making it crucial to provide them with sustained assistance and meaningful involvement, even after the person they care for moves into a care home.

> “My husband has Lewy Body dementia. I kept him at home as long as I was able to, but I could no longer leave him alone. I was getting no sleep, and he was becoming more uncooperative. I simply woke up one morning – exhausted, hopeless and aching in every arthritic limb – and realised I just couldn’t do it anymore. He had also started to escape, and I realised even when I was in the house, I could no longer keep him safe or myself sane.”

Question 2

Were you aware of the principle of shared care when the person you care for went into care?

Answered: 63 Skipped: 0



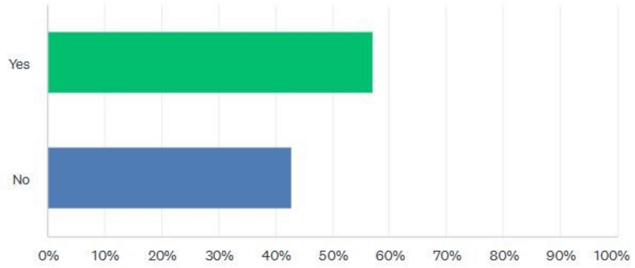
ANSWER CHOICES	RESPONSES	
Yes	22.22%	14
No	77.78%	49
Total Respondents: 63		

Whilst it is heartening that fourteen people entered the process of moving the person they cared for into care armed with knowledge around shared care, the overwhelming majority did not. When carers are unaware of the principle of shared care, the transition can feel abrupt and disempowering. Many carers assume that once formal care begins, their role significantly diminishes or ends altogether, leading to feelings of loss, guilt, and exclusion. Without an understanding of shared care, they may struggle to advocate for their ongoing involvement, leaving them disconnected from the person they care for and uncertain about how to contribute to their well-being; carers in these circumstances may question their identity and often ask us “am I still a carer now?” This lack of awareness can also impact the person with dementia, who may experience increased distress and confusion if familiar routines, preferences and relationships are not maintained. Furthermore, care home staff may not actively engage carers in decision-making, missing valuable insights that could improve the quality of care. Ultimately, failing to introduce carers to the concept of shared care early on risks isolating both carers and those living with dementia, reducing opportunities for a truly person-centered approach.

Question 3

Was the principle of shared care actively offered by the care home? For example, were you actively encouraged to share your experience and knowledge of the person you care for to improve their experience of the care home?

Answered: 63 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	57.14%	36
No	42.86%	27
TOTAL		63

Carers appreciate it when care homes actively offer shared care, rather than expecting them to find their own way to stay involved. For those carers who had experienced a proactive approach, their comments reflected their appreciation:

> “The staff make me very welcome and very often ask if I would like to eat with him. I am glad to help in his care and I believe the staff appreciate my willingness to help, not least on those days when my husband shows very challenging behaviour. If he is not in the mood for a visit, I make a point of chatting to the more able old ladies who appreciate a friendly face. I think this too is appreciated. Certainly, the staff are very kind to both of us but there is little more I could do with my husband practically as he has become very aggressive on occasions. There is no bar to taking him out – were I able to cope with him on my own – and I have never felt excluded. His care is always discussed with me, and I would be happy to raise any concerns I had with the staff should it become necessary.”

Many carers, after years of providing intensive support, feel a sudden loss of purpose and connection when their loved one moves into care. Without proactive engagement from staff, they may assume their role has ended or feel hesitant to step forward. Care homes that take the initiative by inviting carers to participate in care planning, encouraging regular visits and facilitating meaningful involvement in daily activities were hugely appreciated by carer respondents. Proactively fostering shared care helps maintain continuity, reduces distress for both the carer and the person with dementia and strengthens trust between families and care providers. A structured approach — such as designated liaison staff, scheduled check-ins, and clear communication channels —ensures that carers feel valued and supported rather than sidelined. By embedding shared care into practice from the outset, care homes can create a truly person-centered environment where the carer’s expertise and emotional bond remain an integral part of dementia care.

Question 4

If 'No', could you please give some examples of how you were excluded from providing shared care?

Twenty-seven respondents offered examples of how they had been excluded from actively providing shared care.

Imposition of a 'Settling in' Period

Two respondents talked about being asked not to visit so that the person they cared for could 'settle in'.

Research indicates that family involvement from the outset is associated with positive outcomes for residents with dementia, including improved quality of life and reduced behavioral and psychological symptoms (3). Therefore, excluding carers during this critical transition period deprives both the individual and the care home staff of essential support and knowledge, potentially hindering the person's adjustment and well-being.

Superficial and Unclear Process with Lack of Information Sharing to Care Staff

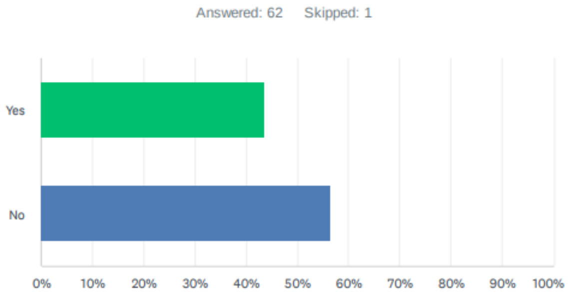
Fourteen respondents talked about a certain vagueness in terms of their active involvement in shared care within the home.

Numerous examples were given around filling in a questionnaire about the person they cared for, yet that vital information didn't seem to trickle down to those who were responsible for providing direct care. This sense of disconnect was a source of frustration for carers. Several respondents also said that they felt like they were in something of a 'no man's land', where they said they had not been actively excluded, but neither had they been actively included. Several carers described feelings of having to be overly friendly to appear non-threatening to care staff. There was a fear of being viewed as 'troublesome'.

> “As a family member it’s overwhelming and you’re often in a vulnerable position and don’t know what the so-called rules are. I would say it’s down to the home manager to lead by example and maybe use this language of shared care.”
>
> “I was encouraged by the care home to give dad a “settling in” period and that visits may initially cause more upset to him until he accepted, he was not coming home.”
>
> “Inconsistency of staff (no real ‘key worker’, changing ‘teams’, high number of different staff involved in care). Poor communication (difficulty reaching staff by phone, no easy access to accurate records of care, care staff/management tensions with relatives caught in the middle). Staff disinterest in the ‘little’, more intangible, things that mean so much to the resident and the family.”

Question 5

Were you able to negotiate with the care home’s manager and staff, how much you would stay involved in your relative or friends care?



ANSWER CHOICES	RESPONSES	
Yes	43.55%	27
No	56.45%	35
TOTAL		62

It is essential that carers can negotiate flexible involvement in the care of the person with dementia, ensuring their continued connection and contribution while respecting their own well-being. All carers' circumstances are different — some may wish to be actively involved in daily routines, while others may prefer a supportive but less hands-on role. Flexibility allows carers to engage in a way that suits their emotional readiness, practical commitments and the evolving needs of their loved one. Rigid or one-size-fits-all policies can alienate carers, making them feel either overwhelmed by expectations or excluded from meaningful participation. By working collaboratively with carers, care home staff can create tailored approaches that recognise the carer's invaluable knowledge and provide opportunities for involvement that enhance the well-being of both the person with dementia and the carer themselves. It would appear from the carer responses to this question, that there is room to improve opportunities for flexible involvement for carers.

Question 6

Please feel free to give us more information about your experiences of shared care. For example, if the home uses Life Story Work and how you were involved in this, or if your involvement leads to the adopting/adapting of language that reassures, comforts and builds confidence of the person you care for.

Value of Life Story Work

Eighteen respondents talked about their positive experiences in the care homes that used Life Story Work. Carers described the difference that it made to improvements in care and relationships. Perhaps the most uplifting responses described what happened when carers were proactive and produced their own Life Story Book for their parents:

> “Prior to moving into the care, we had visited with Dad and had given the home manager a summary of his comprehensive life story. On arrival the manager engaged straight away with Dad making a connection that proved she had read his story. She was not familiar with Life Story Work but immediately found it helpful. When Dad moved into the home he had his Life Story Book with him, (not in the office), and was very proud of it, showing it to other residents. Every member of staff sat with him to read his book, and his care plan was built on that. Staff agreed that it helped them to get to know my dad better and respect the life he had led. They went on to implement Life Story Work with other residents and their families with my guidance. From the day of dad’s arrival in the home he was treated with respect, and I was an equal partner in his care. Whilst the staff cared for all his needs, I was able to spend quality time with him as a daughter. Towards the end of dad’s life, we were able to put in place his wishes to stay there and not be transferred to hospital. The care staff treated Dad, and me, with the utmost respect and dignity when he died.”

> “I provided a life history of the person to give the care home some background into her life and previous experiences. I am encouraged to visit the home at any time, and to raise any concerns or issues direct with staff and the home manager in person or via email. The home arranges monthly family meetings with the manager when any issues can be raised and discussed. The home encourages me to bring in personal items for the person to make her feel at home. When the person was admitted, I had a two-hour meeting with the home manager who went through all the issues and questions I had, using a checklist from the Alzheimer’s Society web site.”

The presence of Life Story Work within homes seemed to create all kinds of relationship bridges between carers and staff. It has huge potential for creating trust and rapport. If carers feel that care staff are interested in knowing the person they care for in a deeper sense, the doorway to honest and compassionate communication opens on both sides. It lays an important foundation stone in making shared care a reality.

Six respondents talked about their experiences where Life Story Work was used in the home with negative outcomes. All the complaints related to not putting the information into practical action and a lack of understanding about its significance. It underscores the importance of ensuring that the Life Story Work process is embedded fully within all care planning and practices to be fully effective. Gathering the information and then not using it was a source of dissatisfaction for carers.

> “They said all the right things, had lovely forms to complete and welcomed input but pretty much ignored my knowledge or advice, ignored all previous accepted routines, completely stripped my husband of everything that made him, him.”
>
> “At the first care home, despite the fact I had supplied his life story book on entering the home it was never used. They never told him before they changed him. As far as they were concerned, I was there each day, so I should look after him! I fed him, but they said he was uncooperative when they tried to and put him on a diet of soft food. If I wasn’t there, he was expected to sit in a chair in front of tv all day.”

Eight respondents said that even without Life Story Work in place, they felt that the care home was including them as an equal partner:

> “I cannot praise mum’s care home enough. They involve us in everything from mum’s medical care through to what she likes, eats etc. They have family meetings every quarter to involve residents and families to discuss various aspects of the care they provide. This includes the menus, activities, cleanliness of the home, laundry etc.”

Twelve respondents felt very pessimistic about the running of the care home, and they described situations where they felt utterly excluded:

> “Home couldn’t care less. Unprofessional. Staff may have basic dementia training but no awareness. Lack of activities. A prison.”
>
> “There is no shared care, we ask and get told what the care is.”
>
> “Care home staff aren’t interested in any of this.”

One respondent went into greater detail about the logistical constraints that hindered the creation of shared care within the home:

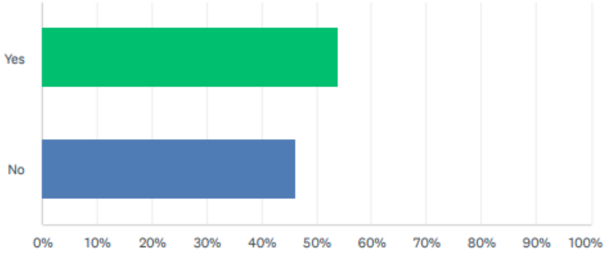
> “I think this concept is little more than a pipe dream in reality! Care home staff turnover is often very high and agency staff usage is high. This militates against staff investing much time in getting to know residents. I’ve lost count of the number of so-called key workers X is supposed to have assigned to her to understand her life and care needs. Many, but not all staff, take on a task orientated and functional approach to providing care and take little interest in X’s previous life and what she might want and need. Relevant life information was given to the Home and is in her care plan file, but staff never seem to read it. Her PA does her best when she is there to keep reminding staff of X’s previous life but tends to focus on the basics of ensuring staff provide personal care properly. There are some staff who take a genuine interest in X and adopt suitable approaches to caring for her but there is a lack of consistency in this approach across all staff.”

06. Questionnaire Responses

The UK's health and social care system has been severely strained after years of austerity and the lasting impact of the COVID-19 pandemic. A decade of underfunding and budget cuts has left services struggling with staff shortages, increased demand, and deteriorating infrastructure. The pandemic further exposed these vulnerabilities, overwhelming hospitals, care homes, and community services while placing immense pressure on healthcare workers. Social care, already underfunded, faced some of the worst consequences, with care homes experiencing devastating losses and a mass exodus of staff due to burnout and low pay. Despite government pledges for reform, many care providers and charities warn that without urgent investment, the system will continue to fail those who rely on it most, particularly older people and those with long-term conditions such as dementia. The recent increase in National Insurance contributions for employers is having a big impact and causing immense stress for residents and family carers because of huge increases in fees. Enlisting the support of carers currently has possibly never been so important. Given the context of underfunding and crisis, the care, knowledge and energy that many carers bring to care homes are valuable resources.

Question 7

Have you had concerns about any aspect of care in the care home?



ANSWER CHOICES	RESPONSES	
Yes	53.97%	34
No	46.03%	29
TOTAL		63

06. Questionnaire Responses

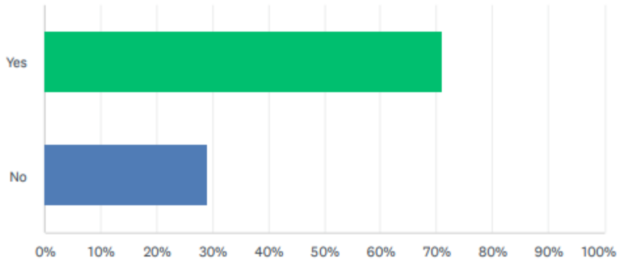
In England, the quality of dementia care in care homes exhibits significant variability, leading to concerns about carer satisfaction. A major review by the CQC (4) highlighted that in approximately 29% of care homes, assessments failed to comprehensively identify all a person's care needs, and in about 34% of care homes, the care provided did not adequately address residents' mental health, emotional, and social requirements. This inconsistency in care quality has resulted in less than four in ten carers expressing satisfaction with the support available for people living with dementia. The Alzheimer's Society emphasizes the urgent need for improvements, stating, "The inconsistency of care found here means many people are rightly worried about being admitted to hospital or having to move into care" (5).

The findings of this study fall broadly in line with levels of dissatisfaction cited in the CQC review.

Question 8

If yes, were you able to raise your concerns with the care home or with the Care Quality Commission?

Answered: 38 Skipped: 25



ANSWER CHOICES	RESPONSES	
Yes	71.05%	27
No	28.95%	11
TOTAL		38

Once more, it is heartening that most carers appeared to be confident in addressing any concerns. There were, however, eleven respondents who did not feel confident in raising their concerns. This audience has valuable insights to ensure that everyone feels able to express concerns without fear or anxiety and in full confidence that their concerns are taken seriously.

Question 9

If you were able to raise your concerns, could you outline what action was taken, if any?

Of the forty respondents to this question, eight carers responded with either N/A or that they had no concerns with the home.

Fear of Repercussions Including Eviction

Four carers talked about being fearful of the repercussions of complaining. The main fear being the resulting expulsion of the person they care for out of the care home.

> "They asked us to find another care home."
>
> "I raised concerns with the care home in a gentle way, as other families who raised concerns more stridently found their relative evicted. Nothing ever changes."
>
> "I knew that I could go to CQC but didn't do so. Not for the first time I was acutely aware that the very people I would be complaining about were the ones who held my father's life in their hands."
>
> "It's tricky, because I've witnessed people raising concerns being advised that they might like to start looking for another care home! Because I was a nationally known dementia care activist, they knew that I was on the side of best care and because I offered education uncritically, they welcomed it."

Care home staff must be aware of the inherent power differential when engaging with carers of people with dementia. When a loved one moves into care, many carers feel a profound loss of control, shifting from being a primary decision-maker to relying on professionals for their relative's well-being. This imbalance can leave carers feeling vulnerable, uncertain, or even fearful of challenging decisions made by staff. Care home professionals, as the gatekeepers of information and care, must approach interactions with sensitivity, ensuring that carers feel respected and included rather than sidelined. Proactively fostering open, collaborative relationships—where carers' insights are valued, and their concerns are taken seriously—helps to reduce this power imbalance.

Twenty-three carers gave examples of positive changes that had been made but the vast majority of these were qualified in some way. Issues may have been partially addressed, or addressed fully and then slid back to previous unsatisfactory practices over a period of time:

> "Concerned that staff were sometimes forgetting to add thickener to drinks. Raised concerns twice and action was taken to update lists and procedures in kitchen. Concerned about lack of interaction/stimulation for mum apart from tv. I brought some jigsaws in for mum and now staff regularly get these out for mum to do. Also raised concerns about mum being anxious at night as not able to get up to use the loo but couldn't alert staff. Not resolved this one yet."
>
> "My mum was given the wrong medication resulting in her being admitted to hospital. I raised my concerns about the home and the council's safeguarding department. A review was held but all that I was told by email was one member of staff would have additional training. I was told I wasn't allowed the minutes to the meeting."
>
> "The Manager or Deputy Manager responded to my concerns. This is over the three plus years my Mum has lived there. However, they haven't always been actioned, or they have been addressed on one occasion but then the same issue has arisen again."

> “Concerns are raised individually with management or collectively through relatives’ meetings. They are always listened to and noted but not always followed up.”

There were four examples of positive changes with no qualifications. For example:

> “An extra support care staff was brought in to help support my loved one on a one-to-one basis.”

Six carers described situations where they were either too exhausted to act at the time, or had complained and there was an unsatisfactory outcome:

> “General concern for my mother’s welfare was the reason an advocate called for a meeting with staff members and why I wanted to get her home. The meeting was not good, and I came away very upset feeling totally excluded and that what I thought and knew about my mother didn’t count for anything.”
>
> “The concerns are around stimulation as my relative spends all day in her room and gets bored and lonely. Raised and they have admitted they can’t meet her needs, so we are changing home.”
>
> “I was told my standards were too high. In nine months, he had lost 5 stone in weight! Eventually we hit a crisis, and he was admitted to hospital. That was the first time I’d seen good care. I refused to allow him to go back to that home, and eventually he was moved to a wonderful new home, where he gained weight, was engaged with and thrived for a further three years.”

Question 10

If you were not able to raise your concerns, what were the main obstacles to speaking out?

Of the twenty-eight carers who responded, ten of the responses were N/A or that concerns had been listened to.

The remaining carers talked about a mixture of obstacles including:

- Staff being too busy
- A lack of a local alternative care home
- Carer burn out in speaking up
- Not knowing who to talk to
- Not wanting to rock the boat and cause unwanted repercussions
- Not wanting to upset care home staff
- Cultural differences when care home staff are not British though this was not expanded on in terms of specific issues.

> "There were times when I did not speak out as I felt that I should 'pick my battles', as it were, although it did not usually feel like a 'battle' as such but either I didn't want to 'rock the boat' or I didn't feel that I had the strength to raise that particular issue again. Barriers to communication included shift patterns, annual leave and changes in staffing i.e. the head of care was given extra leadership responsibilities (covering for maternity leave) reducing the time available for her to conduct care reviews etc. but that change was not made clear to us and emails were not always answered promptly."

Question 11

What would have helped you to feel more able to speak out?

Of the thirty-nine carers who answered this question, sixteen said either N/A or that they had no issues with the home.

The twenty-three remaining responses fell under the following categories:

Communication Issues

Most responses included an element of challenging communication dynamics. Suggestions for improvements included:

- Not always having to ask for information
- To have a single point of contact who has responsibility for ensuring the flow of information
- To make speaking out feel safe through the development of an inclusive culture in the home. To know that feedback will be welcomed by all staff
- To be actively reassured by staff to encourage open communication
- To have no fear of repercussions if a carer does speak out.

Education and advocacy

Three carers responded that they had gained much benefit from both formal carer education programmes, and from counselling and advocacy services.

‘There’s nothing to be done’

Several respondents felt that there was nothing that could be done, claiming that high levels of staff turnover or lack of interest were too much of a barrier to the existence of true shared care.

07

Recommendations

It is clear from the comments that many homes are getting it right and this is greatly valued by carers. However, it is also clear from the responses that there is a lack of consistency across care homes. tide wishes to raise awareness of this disparity and make recommendations for future action. The following represents the list of tide recommendations to support the development of shared care within the care home environment.

Key Points for Care Home Staff to Consider When Engaging with Carers of People with Dementia

- **Acknowledge Carer Experiences** – Recognize the emotional and physical toll of caring for someone with dementia, including stress, exhaustion, and feelings of guilt or loss. These feelings may still be present after the person with dementia has gone into care.

- **Increase Focus on Shared Care as Part of Statutory Inspection Regimes** – whilst some reference is made to inclusive approaches to care in inspection regulations, there is space to develop specific requirements in relation to carers receiving support to maintain active involvement in providing Shared Care.

- **Actively Champion the Existence of a Shared Care Philosophy Across all Relevant Care Home Literature** – By talking positively and proactively about carers' active and ongoing involvement, a huge amount of anxiety and fear can be allayed before the move into care takes place.

07. Recommendations

- **Actively Support Staff in Shared Care Skills Development** – Ranging from the development of policies and protocols within the home to training opportunities with external providers including tools like Life Story Work. Shared Care will only become a consistent practice in those homes that actively champion its development through trained, skilled and aware staff members.

- **Value and Actively Seek Carer Knowledge** – Carers hold deep insights into the person's history, preferences, and needs. Involve them as key partners in care planning and daily routines wherever possible. Carers' knowledge is an important resource with unique insights into enhancing the care of the person with dementia.

- **Provide Compassionate Communication** – Approach carers with empathy, patience, and understanding, ensuring they feel heard and valued.

- **Provide Clear and Consistent Communication** – The provision of single points of contact with a responsibility to relay communication in a clear and timely manner holds the potential to resolve many issues before they arise.

- **Signpost to Advocacy Services** – It can be forgotten that carers need advocacy too. Make use of any local advocacy services and make sure information about these services is freely available.

- **Offer Flexible Involvement** – Recognise that carers may have varying capacities for involvement based on their health and well-being, personal commitments, and emotional readiness.

- **Create a Welcoming Environment for Carers** – Foster a culture where carers feel comfortable visiting and participating without feeling like outsiders. Do not make the carer responsible for staying involved. Extend invitations towards them, no matter how small and seemingly insignificant the interaction.

- **Be Transparent and Inclusive** – Keep carers informed about changes in their loved one's health and well-being, encouraging open dialogue and shared decision-making.

07. Recommendations

- **Provide Emotional Support** – Offer signposting to carer support groups, counselling, or respite opportunities to help them cope with stress and transition.

- **Recognise Carer Grief and Loss** – Understand that carers may experience anticipatory grief and a sense of loss even while their loved one is still alive. Sensitivity to this can improve engagement.

- **Encourage Carer Peer Support** – Facilitate opportunities for carers to connect with others going through similar experiences, such as carer support meetings or informal gatherings.

08

Next Steps

Tide is committed to doing all it can to campaign for change in line with the published recommendations. The report will be circulated widely and the information gathered from carers will go on to develop a Best Practice guidance document aimed at supporting care home staff in making Shared Care a reality. In the mid-term, tide will also be seeking funding to develop a training support session for care home staff which will be offered as part of tide's Carer Development Programme.

For anyone interested in finding out more about the proposed resources, please contact: **carers@tidecarers.org.uk**

09

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10

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