



# **DEMENTIA CARE IN HOSPITALS: FROM THE PERSPECTIVE OF CARERS**

2018



# About the NFWI

The National Federation of Women's Institutes (NFWI) is an educational, social, non-party political and non-sectarian organisation. It was established to ensure that women are able to take an effective part in their community, learn together, widen their horizons, improve and develop the quality of their lives, and together influence local, national, and international affairs on issues that matter to them and their fellow members.

Founded in 1915, the NFWI is the largest voluntary women's membership organisation in the UK with some 220,000 members in over 6,300 Institutes across England, Wales, and the Islands. The NFWI has a long history of undertaking educational work and campaigning on a diverse range of issues. The first NFWI mandate was passed in 1918 and since then the organisation has accumulated a wide-ranging portfolio of policy concerns on a local, national, and international level. The NFWI resolution process means that members play a central role in defining policy and bringing issues onto the organisation's national agenda.

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## **Acknowledgements**

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# Foreword



In June 2016, WI members voted to pass a resolution calling upon government and the NHS to improve dementia care in hospitals and allow families greater access to wards.

Our Carers Welcome campaign is simply about ensuring that carers of people living with dementia have the opportunity to be with their loved one and support them in the way they wish to and are entitled to. The benefits are undeniable and many hospitals have already implemented changes in their policy and practice, motivated by the stories of people such as Dr John Gerrard (John's Campaign).

However, as our research, and that of others, shows there is still much more to be done. Too many carers told us that their loved one's wellbeing suffered unnecessarily as a result of poor dementia care and a lack of willingness on the part of hospital staff to engage with them. Our findings also reveal that despite significant progress in some hospitals, others are reluctant to allow carers on the ward outside of normal visiting hours in spite of the potential benefits for patients, their carers and hospital staff.

Without question, people living with dementia and their carers should have full confidence in the quality of dementia care in hospitals and know that their rights will be upheld. I hope the recommendations set out in this report and the powerful first-hand experiences of more than 200 carers will inspire tangible change and prevent others from going through the same ordeal.

A handwritten signature in black ink that reads "Lynne Stubbings". The signature is written in a cursive style.

**Lynne Stubbings, NFWI Chair**

# Executive summary

This report presents the findings of the NFWI's research into dementia care and support for carers in hospital, based on 221 personal experiences obtained through an online survey and 18 telephone interviews. In order to provide a benchmark against which the results could be measured, it draws together best practice guidelines from England and Wales and information contained within the NHS Constitution and Health and Care Standards.

It is important to note that pockets of good practice were identified. It is clear that over the last five years, a number of hospitals have extended their visiting hours and introduced measures to improve their offer of support to carers. This is encouraging and we hope that by highlighting such examples and building the evidence base for their wider adoption, an increasing number of people living with dementia and their carers will receive the care and support they need and deserve.

Sadly, at this moment in time, dementia care is far from good enough in many cases, with hospitals failing to treat patients with dignity and respect and provide an adequate level of care. 66% of carers who took part in our survey could recall a time when the nursing or health care needs of their loved one were not met. 41% of carers said that 'all or most of the time' hospital staff did not meet their loved one's care needs in relation to their dementia. These findings are deeply concerning and necessitate an urgent need for further action. It is also worrying that few carers feel supported, with only 3% offered a 'carer's passport' and 2% shown around the ward.

In instances where carers receive little or no support, it is evident that drastic action is not always needed. We heard from many respondents how the smallest of gestures from hospital staff, such as a smile, a chair or a cup of tea could have made a significant difference to their experience while their loved one was in hospital.

This report calls on acute hospital providers in England and Local Health Boards in Wales to allow and make it easier for carers to stay with their loved one outside of visiting hours. To help address inadequacies in dementia care and in how some hospital staff engage with carers and patients, it calls for further action to: raise awareness of the NHS Constitution; ensure that staff who are working with people with dementia are fully equipped with the necessary knowledge and skills; encourage the presence and involvement of carers; and make certain that patients and carers are not left alone in a ward and unable to raise their concerns with a member of the nursing staff.

Finally, it calls on the relevant inspectorates in England and Wales to conduct thematic reviews of dementia care in acute hospitals to promote good practice and ensure that issues in relation to the quality of care are acted upon.

# Key findings and recommendations

## 1. Carer access to the hospital ward

### Findings

- 38% of carers were able to visit their loved one outside of visiting hours
- 26% of carers had unrestricted visiting hours
- 20% of carers who were not allowed on the ward outside of normal visiting hours were told by hospital staff that it would have been disruptive to ward routines. 17% were told it was because of a lack of space or the ward not being designed for it
- 37%\* of carers said that being allowed on the ward and involved in the delivery of care as much as they wanted to be had a positive impact on their loved one
- 26%\* of carers said their loved one was adversely impacted because they were not allowed on the ward and involved in their care as much as they wanted to be

*\* Note: these percentages are based on 177 respondents*

## RECOMMENDATIONS

1. We call on acute hospital providers in England to introduce a carer passport scheme across every hospital as we believe this would be beneficial to family carers and people living with dementia. This should set out the support carers should expect and we recommend that it includes the offer of flexible or open visiting hours, enables carers to assist at mealtimes and reflects the principles and values of the NHS Constitution.
2. We endorse the National Audit of Dementia's recommendation that the presence and involvement of key carers should be promoted by nursing and medical directors. We agree that this should be complementary to, and not in replacement of, care provided by staff.
3. We urge ward managers to ensure that carers are made aware of flexible or unrestricted visiting hours and associated schemes. This information should be available in a range of formats.
4. We endorse the National Audit of Dementia's recommendation that carers should be encouraged by ward managers and multidisciplinary teams to attend during mealtimes whenever they want.
5. We urge health boards in Wales to provide facilities that are responsive to the needs of dementia patients and would make it easier or more feasible for family carers of those with dementia to stay with their loved ones in hospital. Cwm Taf University Health Board, for example, has introduced a number of changes to improve ward-based dementia care, including extended visiting hours for carers in every community hospital ward. These changes have had a positive impact, with more patients being discharged home and lower staff sickness rates. We would like to see all health boards in Wales introduce measures such as these across hospitals.

## 2. Involvement of carers in health and care planning

### Findings

- Only 30% of carers said that hospital staff recognised and valued their role as a carer ‘all or most of the time’
- 37% of carers believed that staff did not listen to and, where appropriate, act on the information they provided about their loved one
- Upon admission, 50% of carers were included in discussions about their loved one’s care and treatment
- 68%\* of carers said they were involved in their loved one’s discharge plan

*\* Note: this percentage is based on 191 respondents*

### RECOMMENDATIONS

1. We urge all acute hospital providers in England to implement Principle 4 of the NHS Constitution which states that “Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment”.
2. We endorse the National Audit of Dementia’s recommendation that a heading prompting discussions with carers should be included in patients’ case notes. The 2017 National Audit of Dementia found that this is not standard practice across hospitals, with only 57% of case notes audited containing a section dedicated to this. This should be implemented across all hospitals and we urge ward managers to ensure that staff complete this where appropriate.
3. We urge hospital boards, hospital managers and ward managers to ensure that there is a member of the ward nursing staff present on the ward at all times.

### 3. Quality of hospital care and involvement of carers

#### Findings

- 41% of carers said that 'all or most of the time' hospital staff did not meet their loved one's care needs in relation to their dementia. A further 36% said they were met only some of the time
- 66% of carers could recall a time when the nursing or health care needs of their loved one were not met, 23% of whom said this happened more than 5 times
- 42% of carers said their loved one was not treated with dignity and respect while in hospital
- 67% of carers said their loved one's Alzheimer's disease or dementia became worse as a result of their stay in hospital

#### RECOMMENDATIONS

1. We urge acute hospital providers in England and health boards in Wales to ensure that all staff who provide care to people with dementia receive ongoing training in the appropriate level of dementia care. It is important that this training equips staff with a good understanding of how people with dementia can be affected by hospital environments and emphasises the value of taking more time to support them.
2. We endorse the National Audit of Dementia's recommendation that hospital Chief Executive Officers should ensure that a dementia champion is on hand to assist staff 24 hours a day, 7 days per week. To help improve dementia care, we agree with the findings of a 2017 review by the University of Hertfordshire that clinical experts such as these could support staff to develop their skills and promote the hospital's agreed standards of dementia care.<sup>1</sup>
3. We call on the Care Quality Commission in England and Health Inspectorate Wales to conduct thematic reviews of dementia care in acute hospitals.
4. We urge NHS England to further raise awareness of the NHS Constitution among patients, NHS staff and members of the public and to publish its plans on how this will be achieved.
5. We urge NHS Wales and health boards to raise further awareness of 'Putting Things Right' among patients and carers so that they are aware of the procedure for raising any concerns about care received.

<sup>1</sup> Handley, M., Bunn, F., Goodman, C. 2017. 'Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realistic review'. *BMJ Open*. 7(7), p.e015257. <http://bmjopen.bmj.com/content/bmjopen/7/7/e015257.full.pdf>

## 4. Meeting carers' needs

### Findings

- 42% of carers said that hospital staff did not support them as a carer
- Only 3% of carers said they were offered a 'carer's passport'
- 3% of carers said they were provided with rooms and facilities to stay overnight or for long stretches of time
- 2% of carers said they were shown around the ward and given an explanation of the hospital routine by staff

### RECOMMENDATIONS

1. We urge the National Institute for Health and Care Excellence to reflect the views and experiences of carers of people with dementia in its guideline on the provision of support to adult carers, due to be published in July 2019. It is important that this guidance recognises the significant value of flexible and open ward visiting times and other practical measures designed to support carers during hospital admission. These include the opportunity to complete a carer's survey, book appointments with nursing staff and the provision of facilities to enable carers to stay overnight where possible.
2. We call on acute hospital providers in England to introduce a carer passport scheme across every hospital as we believe this would be beneficial to family carers and people living with dementia. This should set out the support carers should expect and we recommend that it includes the offer of flexible or open visiting hours, enables carers to assist at mealtimes and reflects the principles and values of the NHS Constitution.
3. We urge Health Inspectorate Wales to follow in the steps of the Care Quality Commission and produce an information leaflet for family members who care for someone in hospital. This should set out their rights and the support they should expect to receive during the duration of their loved one's stay in hospital.
4. We encourage the Care Quality Commission to include a prompt in their inspection framework for acute hospitals focussed on the rights of carers in a hospital setting. This should ask whether staff understand the rights of carers, how they communicate these rights and make sure they are upheld.

## Methodology

This report is based on data obtained through qualitative and quantitative methods. Between February and June 2017, WI members and non-members with experience of caring for someone with dementia who has spent time in hospital as an inpatient were invited to take part in an online survey.<sup>2</sup> In total, 304 responses were received of which 250 were complete. To explore the link between carer access to the ward and patient experience, 18 semi-structured interviews were carried out with survey respondents. 9 interviews were held with individuals who indicated that they were not allowed on the ward and involved in the care of their loved one as much as they wanted to be and it had an adverse impact on them. An equal number of interviews were held with individuals who reported the opposite. The quotes used throughout this report are taken from the open-ended questions of the online survey and the telephone interviews which were audio recorded and transcribed with the consent of participants.

## Sample

To be eligible to take part, the help and support provided by the respondent must not have been part of paid employment. Of the 250 participants who completed the survey, 88% (221) indicated that the person they have experience caring for was admitted to hospital at some point over the last 5 years. The findings presented in this report are based on this cohort. Unless otherwise stated, figures quoted from the online survey are a percentage of 221.<sup>3</sup> Information that was provided in relation to a hospital admission that took place more than five years ago (12%) has not been included as it is beyond the remit of this study.

98% of respondents were carers for a family member, indicating that the majority of unpaid carers for people with dementia are relatives. Only 2% were a carer for a friend and less than 1% for someone else.

<sup>2</sup> Paper copies were also provided on request

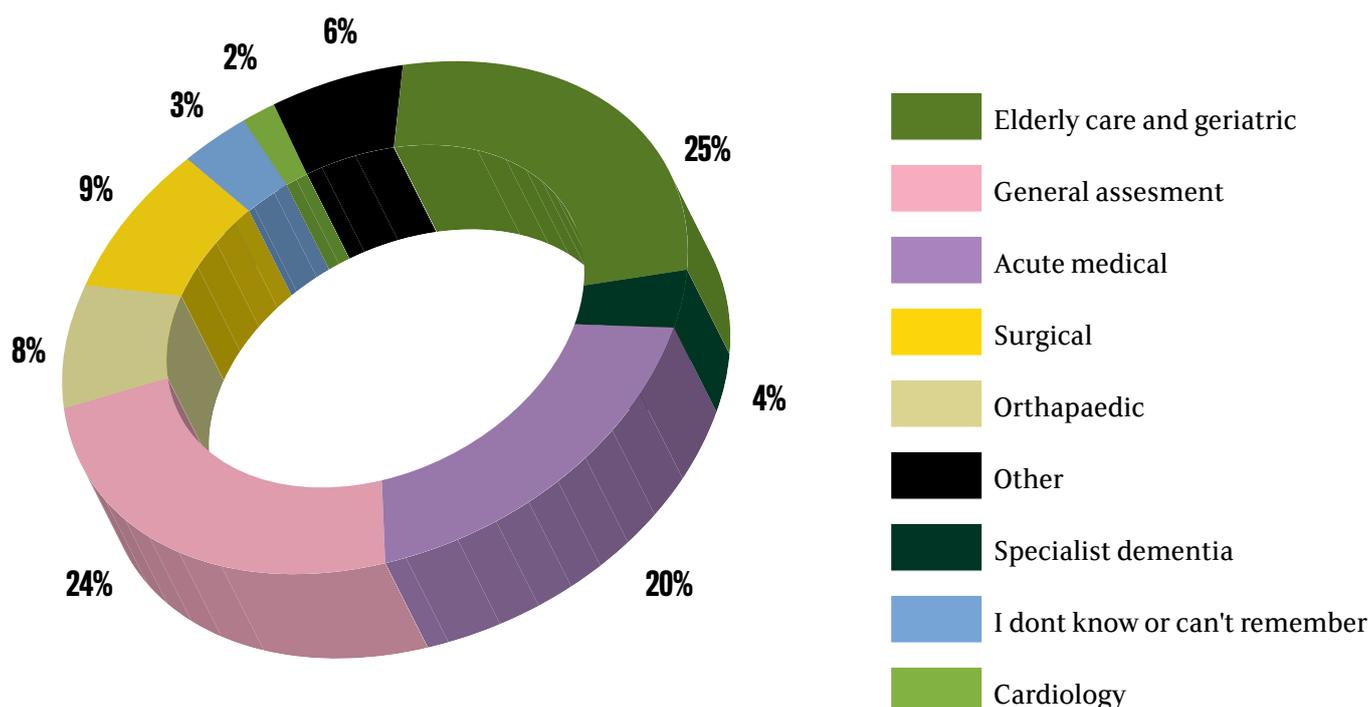
<sup>3</sup> The survey design meant that certain questions would be skipped depending on how the respondent answered. Invalid responses were also removed.

# Context - Reasons for hospital admission in patients with dementia

## Our findings

Our findings show that in only 9% of cases, the decision to admit a person with dementia to hospital is planned. In the vast majority of cases (90%) it is because of an emergency.<sup>4</sup> More often than not, dementia is not the primary reason why people with the condition are admitted. For the loved ones of our respondents, the most common reasons included issues related to a fall (17%), an infection such as a urinary tract infection (16%), a broken bone or fracture (11%) and pneumonia (10%).<sup>5</sup> Consequently they are admitted to a variety of different wards that are not necessarily equipped to support someone with dementia.

## Q What type of ward were they admitted to?<sup>6</sup>



Most reported that in the last five years, their loved one had been admitted to hospital more than once (72%). 10% of respondents reported that their loved one had been admitted between five and ten times.

<sup>4</sup> 1% of respondents did not know or could not remember.

<sup>5</sup> The question 'what was the main reason why they were admitted to hospital for treatment?' was answered by 198 respondents. The percentages are of 198.

<sup>6</sup> The question 'what type of ward were they admitted to' was answered by 221 respondents, 218 of the responses were valid. The percentages are of 218.

# 1. Carer access to the hospital ward

According to the audit standards that were measured as part of the 2017 National Audit of Dementia, carers should expect to have unrestricted hospital visiting hours. This standard is classified as 'type 1'. Failure to meet a type 1 standard is considered to "result in a significant threat to patient safety, rights or dignity and/or would breach the law".<sup>7</sup> The value of flexible visiting hours is also recognised by the dementia assessment and improvement framework produced by NHS Improvement. To achieve 'outstanding' hospital care for people with dementia, it recommends that "the principles of John's campaign are supported" and "facilities are available for families/carers to stay overnight".<sup>8</sup>

## Our findings

Our findings suggest that between hospitals there is a considerable degree of variation in the approach taken towards carer access. Less than half of the carers we surveyed said they were able to visit their loved one outside of normal visiting hours (38%) and even fewer said they were given unrestricted access (26%).

Respondents were given numerous and varied reasons as to why they were not allowed to stay in the ward outside of normal visiting hours. The most common was that it would have been disruptive to ward routines (20%), followed by a lack of space or the ward not being designed for it (17%) and that it was not fair to other patients and their carers (7%). Confidentiality issues were referenced by 2% and health and safety issues by 5%.

Some carers reported feeling helpless and believed that staff were exerting their authority with little or no consideration for the implications for them or the patient. Some explained that they were left in a very difficult position of not knowing whether or not to press staff and risk causing annoyance (and so they believed risk the quality of care provided to their loved one) or take a step back.

**"You feel powerless. The other complication is that you've got somebody ill in the ward who you want them to look after and not to take out their agro that they have with you on the patient. And it's it always a very fine line about what you do...because you want to protect the person who's there"**

## Q If you were not allowed to stay on the ward outside of normal visiting hours, what reasons did staff give you?

20%	It would have been disruptive to ward routines
17%	Ward not designed for it or a lack of space
7%	Not fair to other patients and their carers
5%	Against normal procedure
5%	Not enough staff capacity
5%	Health and safety issues, such as infection control
2%	Confidentiality issues

*"They virtually chucked us out of the ward. And I knew what I was entitled to if you like but it didn't make any difference because the power isn't with the carer. The power is with the hospital staff"*

*"They wouldn't give me any reasons, they just said it wasn't allowed and that was all there was about it"*

*"I was unfortunately forced to stick to visiting hours. They were absolutely adamant about it. They had the doors locked. No you can't come in until you know the buzzer goes. Then you come in and we give you a three minute warning and then you leave"*

<sup>7</sup> Royal College of Psychiatrists. 2017. National Audit of Dementia Round 3 (NAD 3) – Audit standards. <http://www.rcpsych.ac.uk/pdf/NAD%20R3%20Standards%202017.pdf>

<sup>8</sup> NHS Improvement. 2017. Dementia assessment and improvement framework. [https://improvement.nhs.uk/uploads/documents/Improving\\_dementia\\_care\\_FINAL\\_v5\\_111017.pdf](https://improvement.nhs.uk/uploads/documents/Improving_dementia_care_FINAL_v5_111017.pdf)

*when the second bell goes and we shut the door behind you. There were no deviations. Absolutely no give way”*

One of the most common times of the day that carers would like to have been given access to the ward was during meal times. This is when they felt their loved one needed additional support to ensure that they ate and to observe how, or whether, staff were assisting them on a daily basis.

*“I particularly wanted to be there at meal times to see if anyone actually gave her any food because sometimes people put a plate of food on a trolley at the end of the bed and say there’s your lunch and they don’t check that they can reach it or are even aware that it’s there”*

*“When they say relatives are not to be there - in normal cases this is food times. And food time is the time when you need to be there especially with people with Alzheimer’s or dementia. They don’t work out that they need to feed themselves. They say they’ve eaten and they haven’t eaten. They say they’ve drunk and they haven’t drunk. My mum was petrified and I swore that I would never leave her in a hospital again without sleeping on the floor”*

*“She’d also been trying to feed herself. She’d had her lunch but it was all over the bed and there was much more on the bed than ever went down her I imagine...If I’d been able to go in and feed her it would have been a help”*

*“They bring a menu round for meals and dad couldn’t understand that at all”*

Where carers were allowed to stay beyond visiting times, many believed this had a positive impact on their loved one (37%).<sup>9</sup> A further 26% felt that their loved one was adversely affected by the fact that they were not allowed on the ward and involved in their care as much as they wanted to be.<sup>10</sup> Having flexible access to the ward meant that carers had the ability to visit their loved one as and when they were able to, fitting it in around other commitments such as work and family. Carers also spoke about how simply being with their loved one provided them with invaluable comfort and reassurance that only they could provide.

*“Because I was there my mum was fantastically calm”*

*“We could talk with her and just keep her calm. She was frightened I think”*

*“He was perfectly capable of feeding himself, he was perfectly capable of choosing what he wanted meal wise. You know, we were just there and kept him company”*

*“He got to the stage where he couldn’t read for himself. He used to find it quite comforting that I was reading to him”*

*“She was in there for five weeks which is a long time. Although she didn’t know what day of the week it was. So every day would be, you know, ‘am I going home today am I going home today?’ I think I was able to alleviate a lot of the anxiety around the length of time that she was there. She knew that I was going to be coming every day, more than once a day”*



**“He sort of responded and squeezed my hand and smiled when I was around”**

<sup>9</sup>This question was answered by 221 respondents. 177 of these responses were valid. The percentages are of 177.

<sup>10</sup>This question was answered by 221 respondents. 177 of these responses were valid. The percentages are of 177.

*“He also, you see, didn’t always understand it was a hospital so sometimes he thought we’d put him in a home... just being there all of the time giving that reassurance I think helps. Otherwise people get a bit stuck in a loop of worrying”*

*“My mum was very distressed, we didn’t know at the time but she did have delirium. She was very anxious and shouting and, you know, just generally at high level of anxiety... I think just having somebody in there helped because we could sort of keep an eye on her”*

*“Every time I went he made the effort to try and smile - I felt that he knew I was there”*

Respondents believed that their presence on the ward was vital as, following admission, their loved one’s often became disorientated, confused and, in some cases, reluctant to engage with staff. This was in part due to the loss of familiar routines.

*“He was in a six bed ward; he didn’t understand why there were other people there. But he also, for example, couldn’t remember where the bathroom was because the bathroom obviously in the ward is in a completely different orientation to his bedroom bathroom at home”*

*“What I saw really was the disorientation so almost back to before he’d begun to cope with really basic things you know. His washbag was put in a little locker beside the bed which for us wouldn’t be a problem – he couldn’t find it. He didn’t know whether he’d brought any clothes with him so he spent the whole day in pyjamas... And of course he did have clothes but they weren’t in the place that he would find clothes at home”*

*“The first morning I got there he’d spent all night, literally all night, trying to get out of the ward. They had to lock the ward. And he just walked up and down and disturbed the other residents and kept packing his bags. I mean, he was completely and utterly exhausted when I came in... and that carried on obviously the whole time that we weren’t allowed to be there because he didn’t know that we were going to come back. He thought he’d been abandoned every time we left”*

**“One of the things that the coordinator said to me is often we find that people are coping very very well in their own environment. People don’t recognise they’ve got Alzheimer’s or dementia. Because the whole of the world around them is worked so they can live with it. Put them in a strange situation in hospital and you take away absolutely everything”**

*“I think she knew she was in hospital but she didn’t really know what was going on at all - she was just sitting there waiting for something to happen I think. I mean all she was really interested in at that stage was just where her next meal was coming from and who was looking after her I think”*

*“People with Alzheimer’s if they’re in a ward with other people get very agitated and very worried. I’ve had experience of that on a couple of other occasions when she was in hospital”*

While many respondents felt that they and their loved one benefited from, or would have benefited from, extended visiting hours, several believed that even if it had been an option they would not have necessarily taken up the offer as they needed respite in between visits. This highlights the importance of staff being aware of, and sensitive to, the preferences and circumstances of each individual carer.

*“It’s very tiring, you know, it’s quite hard work and I don’t think it’s easy for anybody to stay the whole time... My sister and I sort of took it in turns, you know, we did a few hours each. We managed but anyone on their own would have found that extremely difficult”*

*“I think some carers are actually glad to have a bit of respite in a way when the people are being cared for in hospital. But I know also a lot of carers want to be there all the time – it depends really on the situation I think”*

## **RECOMMENDATIONS**

1. We call on acute hospital providers in England to introduce a carer passport scheme across every hospital as we believe this would be beneficial to family carers and people living with dementia. This should set out the support carers should expect and we recommend that it includes the offer of flexible or open visiting hours, enables carers to assist at mealtimes and reflects the principles and values of the NHS Constitution.
2. We endorse the National Audit of Dementia’s recommendation that the presence and involvement of key carers should be promoted by nursing and medical directors. We agree that this should be complementary to, and not in replacement of, care provided by staff.
3. We urge ward managers to ensure that carers are made aware of flexible or unrestricted visiting hours and associated schemes. This information should be available in a range of formats.
4. We endorse the National Audit of Dementia’s recommendation that carers should be encouraged by ward managers and multidisciplinary teams to attend during mealtimes whenever they want.
5. We urge health boards in Wales to provide facilities that are responsive to the needs of dementia patients and would make it easier or more feasible for family carers of those with dementia to stay with their loved ones in hospital. Cwm Taf University Health Board, for example, has introduced a number of changes to improve ward-based dementia care, including extended visiting hours for carers in every community hospital ward. These changes have had a positive impact, with more patients being discharged home and lower staff sickness rates. We would like to see all health boards in Wales introduce measures such as these across hospitals.

## 2. Involvement of carers in health and care planning

The benefits of communicating with carers to the delivery of person-centred care are recognised by the NHS Constitution, the National Institute for Health and Care Excellence (NICE) and other best practice guidelines such as The Triangle of Care. There is general agreement that carers possess information about their loved one's history, needs and well-being which is vital to ensuring that people with dementia receive the right care. In 2010, following research conducted by the Department of Health into the views of 4,000 carers, the Government concluded that “involving carers in planning and designing hospital discharge arrangements and individual care packages is common sense”.<sup>11</sup>

### **NHS CONSTITUTION**

The NHS is guided by 7 key principles which set out what families and their carers should expect from services across the healthcare system.

**Principle 4** provides that: “Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment”

### **NICE CLINICAL GUIDANCE. DEMENTIA: SUPPORTING PEOPLE WITH DEMENTIA AND THEIR CARERS IN HEALTH AND SOCIAL CARE**

“Good communication between care providers and people with dementia and their families and carers is essential, so that people with dementia receive the information and support they require”

### **TRIANGLE OF CARE GUIDE, DEVELOPED BY THE CARERS TRUST AND THE ROYAL COLLEGE OF NURSING**

The Triangle of Care “describes a therapeutic relationship between the person with dementia (patient), staff member and carer that promotes safety, supports communication and sustains wellbeing”

The guide notes that involving carers will:

- “Offer better outcomes for the person with dementia”
- “Enable staff and services to ensure they have a fuller picture of the person's needs and how their dementia affects their behaviour and general wellbeing”
- “Provide peace of mind for carers that the person they care for is receiving the best and appropriate treatment possible”

<sup>11</sup> HM Government. 2010. Recognised, valued and support: Next steps for the Carers Strategy. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213804/dh\\_122393.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf)

## Our findings

As part of the telephone interviews we asked carers to describe how they were involved in the care of their loved one. A number of carers explained that their loved one relied heavily on them to speak on their behalf and relay important information about their medical history and health and care needs to hospital staff. Several carers indicated that without this information, there was a risk that staff would be, and in some cases they believe were, treating their loved one on the basis of inaccurate or incomplete information.

*“When it comes to dealing with people with Alzheimer’s they can understand what’s going on but they can’t verbalise. So I used to explain everything to my mum and then say is that what you want and she’d either nod or shake and then we’d talk to the doctor. The doctor would talk to her and he would look at me while he was talking and he knew that I wouldn’t be speaking for her”*

*“I don’t think that in many cases he actually told them the extent of his symptoms or, you know, how he was feeling with the medication he was being given or you know and he certainly didn’t understand what was happening to him. On one occasion he was very frightened”*

Close involvement in their loved one’s care and treatment plan was made easier when carers were given more flexible access to the ward.

*“I slept on the bed and I could hear my mum – if she had a worry I could just get up... At 7 o’clock in the morning I had to be up and ready because surgeons come round slap bang early in the morning. Now if nobody is there when doctors do their rounds with the patient, the patient can tell them anything and you need to be aware of what is going on”*

While the NHS Constitution and best practice guidelines clearly recognise the importance of involving families and carers in decisions regarding their loved one’s care, the findings of our research suggest this is not always the reality. Only 30% of respondents said that hospital staff recognised and valued their role as a carer, while the same percentage reported that all or most of the time they did not. A further 38% indicated that they were valued only some of the time.

**“You have to understand that that person is going to say yes I’m well. They’re not going to say what’s been happening because they can’t remember it. You know, they’re not going to tell the doctor they haven’t been eating for the last three days”**



**30%**

said that hospital staff  
**RECOGNISED  
AND VALUED**  
their role as  
a carer



**38%**

said that  
they were  
**VALUED ONLY  
SOME OF THE  
TIME**

This is reflected by the high number of respondents who reported a lack of involvement in discussions about their loved one's care and treatment. Upon admission, only 50% were included in such discussions. 37% also felt that staff did not listen to and, where appropriate, act on the information they provided about their loved one. This not only puts at risk the ability of hospital staff to provide the right care but can cause significant concern for carers. It is likely that this is at least partially responsible for an increase in the level of stress that was reported by 80% of carers during their loved one's hospital stay.



“People just kind of get rule bound you know and you weren't allowed and that was it. You couldn't argue. We're not visitors, we were carers”

Many respondents explained that despite their deep understanding of how their loved one had been affected by dementia and their specific care needs, they felt intentionally kept out of discussions. Only 24% of carers were able to provide feedback to staff. Some described scenarios where they were ignored and had to push for the voice of their loved one to be heard.

*“We could see that he was getting worse, because we knew what was normal for him, you know. Somebody gets admitted and they're ill but the hospital staff have never seen that person well before they went there so they have nothing to compare it with. They just think oh its dementia, you know. Everything is put down to the dementia. And of course it wasn't. He was physically ill”*

*“I spoke to the occupational health therapist on the phone and I said can I be there when you assess her and she said no. It's about your mums rights. But mum didn't even know what day of the week it was”*

*“I think the other thing was to stand her corner with the doctors when she was particularly ill. And say this isn't just a confused demented old lady. This lady is actually ill. She isn't just being awkward. This isn't what she's normally like. She is ill”*

Many reported difficulties obtaining basic and vital information about the condition of their loved one and the treatment they were receiving. One of the challenges identified was the shortage of nursing staff on the ward to approach and the availability of doctors.

*“It was very difficult to find anybody to speak to actually that would speak to you. Just knowing how she was and everything was ok. It probably didn't make a lot of difference actually to her it was more for our peace of mind I suppose”*

*“It was so hard to actually find somebody to talk to. There were times on the ward where there was no staff at all. There was one Sunday afternoon when the only person I could find was a cleaner”*

*“My husband was in hospital for 7 weeks. I rarely knew what they were doing as they were always 'too busy'”*

*“Nobody was ever available. Nobody seemed to know what was going on”*

*“They were very busy but if I had been able to speak to someone at each visit just to ask about progress without feeling guilty that would have been better”*

*“There were very rarely any staff around to speak to and when I did find someone they always seemed too busy to speak”*

*“I wanted to know what the doctors were undertaking with my husband. All too busy and their pagers or mobile phones were going off constantly so no time for my questions”*

*“The ward was understaffed and the nurses too busy”*

*“The ward was so busy - we didn't have an awful lot of conversation with the nursing staff”*

Others felt that staff were simply reluctant to engage with them, sometimes without reason. Some described how they felt staff had little or no interest in speaking to them and saw responding to any questions as an unnecessary burden on their time.

*“They looked upon me as a nuisance because I kept asking questions; I kept trying to get something going. And I was in the way, I was told I was in the way and you know we haven't got time we're busy people all this sort of stuff. And they basically kept fobbing me off and pushing me out”*

*“When he's been an inpatient I've felt totally you know sort of like a spare part really. Because he gets very frightened, he looks to me for reassurance you know. You can't get him to understand why he has a cannula in his arm or something like that and I sit and I try and explain it. But really I'm thinking well I don't know actually what's going through it – whether its painkillers, just fluid or what. Because they just don't say. They sort of blind you with science. You know, just won't explain it”*

*“A lot of the time there were a lot of staff around the nurses station and I felt as though I was interrupting them. They were unfriendly as though there was a barrier”*

*“I think what I found most distressing was the lack of communication because every day I would say ‘so how's mum been today anything changed.’ Well you know we can't talk to you about that - we haven't seen the doctor yet”*

*“I don't want to do the nurses job for them, that's not really my thing, but I think communication about what was happening and progress because I didn't really understand the significance of this salt level change. So if somebody could have taken the time to explain to me what was going on, what the impact was, how it was being sorted and whether there was any improvement. But there was nothing really. Nobody expressed or showed me any concern like your mum hasn't eaten today or she has a little bit more to drink. There was nothing like that”*

However, our survey also revealed a number of very positive examples of staff involving and encouraging carer participation in health and care planning. 68% of respondents to our survey, for example, reported that they were consulted in their loved one's discharge plan.<sup>12</sup> Several carers also commented on their personal experiences.

*“I really think that they do listen to you”*

**“We did what we could but I mean the staff didn't really want to engage with us. I think they just saw us as a nuisance...I don't know what they thought – we were trouble makers of some sort”**

<sup>12</sup> The question 'were you involved and consulted in your loved one's discharge plan' was answered by 191 respondents. The percentage is of 191.

*“When he went into hospital I was at the end of the phone or I was there so I was 100% included in everything”*

It was recognised by a small number of interview participants that their own career as a nurse was at least in part responsible for a more positive relationship with staff and a better hospital experience for their loved one. For those carers unfamiliar with the hospital environment this is a key cause for concern.

*“Because I’m a retired nurse and she was in hospital when I actually worked there I think it was a lot easier for me. So I knew, you know, I knew the questions to ask. I knew what my rights were. And so I did not have a problem but I can imagine that it would be somewhat different for others”*

## **RECOMMENDATIONS**

1. We urge all acute hospital providers in England to implement Principle 4 of the NHS Constitution which states that “Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment”.
2. We endorse the National Audit of Dementia’s recommendation that a heading prompting discussions with carers should be included in patients’ case notes. The 2017 National Audit of Dementia found that this is not standard practice across hospitals, with only 57% of case notes audited containing a section dedicated to this. This should be implemented across all hospitals and we urge ward managers to ensure that staff complete this where appropriate.
3. We urge hospital boards, hospital managers and ward managers to ensure that there is a member of the ward nursing staff present on the ward at all times.

## 3. Quality of hospital care and involvement of carers

Best practice guidelines produced by the Department of Health and separately by the National Audit of Dementia recognise the valuable role that carers can play in helping to ensure that their loved one receives the personalised care and support they need whilst in hospital. Guidance produced by Alzheimer's UK sets out many and often small ways that carers can assist hospital staff in the care of their loved one. These range from practical help, such as helping the person to the toilet and assisting them to eat and drink, to emotional support and reassurance.<sup>13</sup> For people with dementia, NICE notes that relationships and interaction can help to improve overall well-being demonstrating the wider importance of carer involvement such as this.<sup>14</sup>

### DEPARTMENT OF HEALTH GUIDANCE . DEMENTIA-FRIENDLY HEALTH AND SOCIAL CARE ENVIRONMENTS

**Principle 8:** Promote engagement with friends, relatives and staff

“As dementia progresses, more one-to-one support may be needed and the involvement of relatives can help to ensure this is provided at an appropriate level”

### NATIONAL AUDIT OF DEMENTIA 2017

**Audit standard 9.11:** “Carers are asked about the extent to which they prefer to be involved in the care of the person with dementia while on the ward, e.g. help with personal care or at mealtimes, looking after clothing, spectacles or hearing aids, enjoyable pastimes”

This standard is classified as something that “a ward would be expected to meet in normal practice”.

Carers should not, however, need to step in order to fill a gap in care that should be provided by hospital staff. The NHS Constitution is clear in setting out the legal rights of patients with regards to the quality of care they are entitled to. These include the rights set out below.

### NHS CONSTITUTION

Patients have the right to:

- “Receive care and treatment that is appropriate to you, meets your needs and reflects your preferences”
- “Be treated with a professional standard of care, by appropriately qualified and experienced staff”
- “Be protected from abuse and neglect, and care and treatment that is degrading”
- “Be treated with dignity and respect, in accordance with your human rights”
- The NHS Constitution also expects staff to “maintain the highest standards of care and service, treating every individual with compassion, dignity and respect”.

<sup>13</sup> Alzheimer's Society. 2015. Hospital Care. [https://www.alzheimers.org.uk/download/downloads/id/1819/factsheet\\_hospital\\_care.pdf](https://www.alzheimers.org.uk/download/downloads/id/1819/factsheet_hospital_care.pdf)

<sup>14</sup> NICE. 2006. Dementia: supporting people with dementia and their carers in health and social care. <https://www.nice.org.uk/guidance/cg42/resources/dementia-supporting-people-with-dementia-and-their-carers-in-health-and-social-care-pdf-975443665093>

## Our findings

Across the online survey and telephone interviews, carers spoke about the importance of their role in providing practical assistance to their loved one, such as helping them to eat and drink and assisting with personal hygiene. Without their help, several carers felt that their loved one would not have received the necessary care and risked prolonging their stay in hospital. In a small number of cases, carers felt they needed to step in and provide a basic level of care to their loved one because staff did not have the time that was required to spend with each patient - something which was recognised and appreciated by respondents.

*“It would have been difficult for the staff to make sure that she was drinking because she would take ages to drink and to eat. You know, I wouldn't expect the staff to have time for that”*

*“I think us being there just made the difference because obviously when you're there you're focussing on your one person, they're very stretched, they're focussing on, I don't know, 20 people aren't they”*

*“If they [the nurses] needed help, then I would offer to help. I was in the room all the time”*

Other respondents, however, explained how staff appeared ill-prepared to support someone with dementia. This is especially concerning given that 62% indicated that prior to being admitted to hospital, their loved one required someone to look after them full-time. A further 28% said part-time care and support was required. Given the gap between the level of care that was needed and that which was provided, it is therefore unsurprising and very worrying that 41% of respondents reported that 'all or most of the time' they felt hospital staff did not meet their loved one's care needs in relation to their dementia. A further 36% said their needs were met only some of the time.

When asked to reflect on their loved one's condition whilst in hospital, we heard how 37% of the loved ones of our respondents lost weight, 27% became de-hydrated and 15% became malnourished.<sup>15</sup> While we recognise that people in later stages of dementia can experience loss of appetite and have difficulties swallowing, we are concerned that this could indicate that many are not receiving very basic levels of care.

*“Her care would not have been possible because the amount of time that I actually spent not just sitting with my mum but it was actually, you know, caring for my mother. I would wash my mum, I would make sure her teeth were clean, I helped her with her food, with her fluids, with her personal hygiene. All of those things. So my mum had a good experience”*



**41%**

felt hospital staff  
**DID NOT MEET  
THEIR LOVED  
ONE'S NEEDS**  
in relation to  
their  
**DEMENTIA**

<sup>15</sup> Respondents could select as many options that applied.



Our findings suggest similar shortfalls in the general care and treatment of patients with dementia, with 66% of respondents able to recall a time when the nursing or health care needs of their loved one were not met. 23% of whom said this happened more than 5 times. One respondent told us:

*“mum wasn't able to feed herself and ...they ended up putting a feeding tube in because they couldn't be bothered to feed her”*

Another explained:

*“I was actually sitting there one day when one of the care assistants came, took the chart of the end of the bed and just ticked all the boxes, you know, is the patient in pain whatever ... put it back and walked away. She never even glanced at the bed”*

When we isolate the responses of carers based on where their loved one was admitted, it is clear that being on a geriatric or elderly care ward does not necessarily mean access to better dementia care. Our findings suggest the opposite. 15% of carers whose loved one was admitted to a

geriatric or elderly care ward reported that their care needs were met all or most of the time, while when we combine the results of all other wards this figure increases to 23%.

Carers who took part in the telephone interviews explained why they felt there was this shortfall in care. Many reported that staff did not appear interested in trying to accommodate the needs of a patient with dementia and lacked training in dementia care. They explained how some staff were only interested in the primary reason why they had been admitted to hospital, which was dementia in less than 10% of cases.<sup>16</sup> It is clear that this has significant consequences. 42% of respondents to our online survey felt that their loved one was not treated with dignity and respect while in hospital.

*“Nobody gave her anything unless I was there and I did”*

*“Mums dementia meant that she couldn't always take things in the first time. So she needed time and patience and repeat. I could be generous and say they didn't have the time. Personally I think they didn't care”*

*“I went in one time and there was a doctor trying to take blood and she'd turned her arm mostly into a pin cushion because mum didn't understand what was happening and there*

<sup>16</sup> The question 'what was the main reason why they were admitted to hospital for treatment?' was answered by 198 respondents. The percentage is of 198.



**42%** felt that their loved one was **NOT TREATED WITH DIGNITY AND RESPECT** while in hospital

*was no attempt to try and sort of calm her down, explain it, hold her hand or anything. She was just stabbing her with needles”*

*“I always used to go to his GP appointments with him. And the GP would say what’s this that and the other and he would look to me to answer... So for me, he wasn’t getting the full benefit out of being in hospital because they couldn’t have got the answers out of him that they wanted. They must have been guessing half the time what was wrong with him. They had no time at all, you know, for him”*

*“I tried desperately to get hold of the physios and one day I was successful and got hold of a young girl who said ‘well she won’t cooperate so we can’t do anything’. And I said you do know she has dementia so she won’t cooperate if she doesn’t know who you are or what’s going on. And it was like I’d switched on a light bulb or something”*

*“Now they did put the little flower above bed to say she had dementia but they really weren’t bothered because I said well she has got dementia so you need to talk to her. ‘Yea but we’re not interested in that’. This was the senior nurse on duty. ‘We’re only interested in getting her health sorted out. We can’t fix the dementia so we’re not even going to be bothered’. And I was like I’m not asking you to fix the dementia, I’m just asking you to take it into consideration. They really weren’t bothered about anybody. Mum wasn’t the only one; I witnessed things on other patients as well”*

*“I think they weren’t nasty, they were sympathetic, but they would say things like well you know we are a diabetes ward and we’re not really set up for that kind of stuff. Because we don’t know him, we don’t know what he needs. And I was saying well no exactly and that’s exactly why I’m saying I need to be with him or his carer needs to be here”*

*“She was put in a general assessment ward which I can only describe as a cattle market. She was put next to a walkway with constant comings and goings. This aggravated her dementia”*

*“My difficulty was some of the staff knew about dementia and the other staff had not been on the training. The staff who knew about it, who’d been on the training would sit there with you and try and unpick what was happening. Some of the other staff could be quite difficult”*

*“They could see that mum was very confused and they couldn’t cope with her. She was trying to get out of bed. She wasn’t supposed to be. She was just being very difficult and she was better with us”*

*“I actually complained to the hospital about the attention and treatment that dad was getting because I didn’t think they were recognising his mental health issues at all”*

*“When he left the hospital as much had been done medically as there could have been but not anything for the dementia”*

*“She’d become obsessed by something and sometimes you could do something that would break it and sometimes you couldn’t... Some of the staff could but not many of them. I think it was about personalising care”*



**“They showed a disappointing lack of awareness I guess for a hospital really. A lack of awareness of what a dementia patient might need and what the impact might be of being in hospital”**

*“I don't think they took the right care of him, someone with dementia who just needs, you know, speaking to and approaching correctly”*

*“I let them know mum wasn't normally like this but I think they were sort of more focussed on the reason she was in there which was she'd broken her leg”*

*“There was no interaction or anything there for him as someone with dementia. I think they need to get their acts together there are so many people with dementia now”*

In some instances the offer of support to hospital staff was welcomed and encouraged because it was recognised that the patients carer could assist them and help to ease their loved one's distress.

*“I think it must have been the second morning I got in there and somebody who had been on duty at night was actually pleased to see me because they'd obviously had to cope with him all night wondering about”*

*“They did actually ask us to stop with my mother because she was very agitated and confused and she didn't want to be in a hospital. She was quite distressed... They weren't really used to dementia patients or didn't seem to be”*

Others, however, reported a markedly different experience and felt they were not encouraged to assist staff and support their loved one.

**“I was an asset,  
I felt, to the staff. And I  
think I was seen as that”**

**“The staff didn't involve us. We involved ourselves. You know, we took him to the toilet, made sure he was safe... He stopped eating. But we tried to help with eating and drinking, just generally keeping him, you know, feeling that we were there for him”**

*“I wish now that I'd had a bit of encouragement to help with things like, you know, feeding and stuff like that”*

*“We could have been really helpful. They just didn't want it... I think we sort of gave up because things were just so difficult”*

One carer who participated in a telephone interview offered an explanation for this. She believed that it was down to how the staff perceived her – as a visitor, not a carer.

As a consequence, although this should not be necessary, participants commented on the importance of demonstrating their value to hospital staff if their loved one was to receive the level of dementia care and support they needed.

*“I think you need to be assertive and I think you need to be able to demonstrate, you know, how you are in effect helping them to look after your mum or dad. And I think if you can put it in a positive sense and to say look I understand, you know, there are other patients in the ward”*



**67%** reported that their loved one's  
**ALZHEIMER'S DISEASE OR DEMENTIA BECAME WORSE**  
as a result of their stay in hospital

Often in addition to the practical help they were able to offer, several carers who participated in the telephone interviews described the small changes they were able to make to their loved one's immediate surroundings in hospital to help them feel more relaxed. This also served to assist staff in their care of the patient. However, the findings of our survey suggest that carers are rarely (in less than 3% of cases) offered this opportunity to personalise and adjust their loved one's surroundings.

*“I photocopied and laminated some of her familiar photographs with explanations of who they were so that staff could sort of relate to that with her and knew a bit of her history. She was a very experienced nurse”*

*“I took a radio into the ward and I had it on all the time. Classic FM – it may sound barmy but it is really calming and as soon as the music is on you will find that people with Alzheimer's will calm down. If we were in a group ward then we wouldn't have been able to have the radio on. I know you can have earphones but people with Alzheimer's won't allow that, they don't want that sort of thing to happen”*

*“We found Smooth radio and we were able to sing with dad and things like that”*

*“One of the things that happens if you're in hospital with dementia is that you get disconnected from your life, you know, because you can't hold those memories. We took him paper and photographs and stuff like that which the staff obviously couldn't do”*

*“If you spent time with her you could recognise she wasn't processing, she wasn't retaining. People who are with them all the time recognise that and know the coping strategies. And put them in place subconsciously”*

*“She couldn't remember what was happening. I wrote her a letter and I faxed it through to the ward. I said just put that in front of her. She was clinging on to this paper because she then knew what was happening”*

As a progressive disease, it is difficult to speculate the extent to which deterioration can be attributed to the quality of dementia care in hospitals. However, the findings of our survey suggest that carers believe it is at least a significant contributing factor. 67% reported that their loved one's Alzheimer's disease or dementia became worse as a result of their stay in hospital.

## RECOMMENDATIONS

1. We urge acute hospital providers in England and health boards in Wales to ensure that all staff who provide care to people with dementia receive ongoing training in the appropriate level of dementia care. It is important that this training equips staff with a good understanding of how people with dementia can be affected by hospital environments and emphasises the value of taking more time to support them.
2. We endorse the National Audit of Dementia's recommendation that hospital Chief Executive Officers should ensure that a dementia champion is on hand to assist staff 24 hours a day, 7 days per week. To help improve dementia care, we agree with the findings of a 2017 review by the University of Hertfordshire that clinical experts such as these could support staff to develop their skills and promote the hospital's agreed standards of dementia care.<sup>17</sup>
3. We call on the Care Quality Commission in England and Health Inspectorate Wales to conduct thematic reviews of dementia care in acute hospitals.
4. We urge NHS England to further raise awareness of the NHS Constitution among patients, NHS staff and members of the public and to publish its plans on how this will be achieved.
5. We urge NHS Wales and health boards to raise further awareness of 'Putting Things Right' among patients and carers so that they are aware of the procedure for raising any concerns about care received.

<sup>17</sup> Handley, M., Bunn, F., Goodman, C. 2017. 'Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realistic review'. *BMJ Open*. 7(7), p.e015257. <http://bmjopen.bmj.com/content/bmjopen/7/7/e015257.full.pdf>

## 4. Meeting carers' needs

Considering the needs of carers when a person with dementia is admitted to hospital and delivering support that takes account of their role as partners in care are recognised by the NHS Constitution, CQC and the Health and Care Standards as good practice.

### HEALTH AND CARE STANDARDS - WALES

**Standard 4.1 Dignified Care:** “People’s experience of health care is one where everyone is treated with dignity, respect, compassion and kindness and which recognises and addresses individual physical, psychological, social, cultural, language and spiritual needs” [‘People’ includes carers].

### WHEN AWARDING A HOSPITAL WITH A GOOD OR OUTSTANDING RATING, THE CQC LOOKS FOR THE FOLLOWING PRACTICE:

- Carers are given the opportunity to complete a carers survey
- Carers are showed around the ward and explained the hospital routine
- Carers are able to book appointments to meet with the nursing or medical staff caring for their loved one
- Carers are offered extending visiting times

### NICE CLINICAL GUIDANCE DEMENTIA: SUPPORTING PEOPLE WITH DEMENTIA AND THEIR CARERS IN HEALTH AND SOCIAL CARE

“Health and social care managers should ensure that the rights of carers to receive an assessment of needs, as set out in the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004, are upheld”

This responsibility has been further clarified in the updated draft guidance (Dementia: assessment, management and support for people living with dementia and their carers) which states:

Practitioners should “advise carers about their right to the following and how to get them:

- a formal assessment of their own needs (known as a ‘Carer’s Assessment’), including their physical and mental health
- an assessment of their need for short breaks and other respite care”

There are also a number of other ways that hospital staff can assist carers, such as the offer of a carer information pack, an induction to the ward and a dedicated carer support service. Examples such as this are identified by the National Audit of Dementia and the Triangle of Care as best practice which wards should aim to meet.

### Our findings

As part of the telephone interviews, we asked carers to describe the support that was offered to them during their loved one’s stay in hospital. Our findings reveal a small number of examples of hospital staff making the time to understand and

meet their needs. We heard how some carers were offered the opportunity, or allowed on request, to stay overnight with their loved one and about the difference this made.

*“They put us up in this very small room but they provided pillows and cushions and you know blankets for us so that we could stay there with our dad so were with him the whole time”*

*“They said I could stay overnight, you know, if I really wanted it they could get a camp bed for me. They did look after me”*

We also heard of examples where carers were not required to pay for parking during their loved one's stay or were simply offered cups of coffee.

*“My brother sister and I, we had coffees all through the night and they didn't make us pay for it and they put it on china cups”*

*“They were just so supportive of me....Sometimes the news wasn't good and they were just so empathetic. They would come and give me a hug, they would sit down and give you a cup of tea. Although they're busy they just seemed to find time out of nowhere just to sort of be with you and be there for you”*

However, our findings suggest that this type of support is experienced by the minority of carers. Only 10% of respondents to our online survey felt that their own needs as a carer were recognised and met to the best of the hospital's ability, while 42% said that staff did not support them as a carer.

Notably, only 5 respondents (less than 3%) reported that staff showed them around the ward and explained the hospital routine, 7 were offered a carer's passport and 6 were provided with rooms and facilities to stay overnight or for long stretches of time. This could explain, at least in part, why only half of the respondents felt welcome on the ward 'all or most of the time'. When asked what they would have needed to feel more comfortable, many carers mentioned very small gestures such as the offer of a drink, a chair and a friendly welcome.

*“The offer of a cup of tea would have been good and maybe being allowed to bring in a snack to the ward”*

*“A chair to sit on - frequently none available!”*

**“The hand of friendship  
would have made the world  
of difference!”**



**42%** said that staff  
**DID NOT SUPPORT THEM AS A CARER**



**“They basically kept fobbing me of and pushing me out. I didn’t even know that there were any carer’s rights”**

*“Staff actually knowing who you were”*

*“To recognise who I was and who I was visiting”*

*“The staff just to say hello and goodbye”*

*“Acknowledgement of my role, the offer of beverages, somewhere comfortable to sit & not squashed”*

*“A cup of tea and given a chance to go to the toilet without having to ask”*

*“A comfortable chair. Somewhere to make a drink/snack when restaurant closed. Relatives’ room to stay overnight if required. Acknowledgement - sometimes I felt invisible or like unpaid help on the ward”*

*“A pass card for the ward would have meant we could have left the ward to go to the loo”*

*“To be welcomed with a smile from the more senior medical staff”*

In addition to information about their loved one, carers also require and value information about their own rights and responsibilities. However, our findings show that hospital staff rarely raise this subject with carers with just 10% of respondents to our online survey reporting that they were helped to understand their entitlements. Consequently, we heard how many were left unaware that they had any rights at all.

*“I don’t think my carers rights as such ever came into question actually. I didn’t know anything else really I suppose”*

*“There wasn’t a carer’s policy in place when I was working. I didn’t have a booklet to say look your mum has been diagnosed with Alzheimer’s. This is what is available to you, no”*

*“I don’t think it occurred to me to ask for anything as a carer”*

## RECOMMENDATIONS

1. We urge the National Institute for Health and Care Excellence to reflect the views and experiences of carers of people with dementia in its guideline on the provision of support to adult carers, due to be published in July 2019. It is important that this guidance recognises the significant value of flexible and open ward visiting times and other practical measures designed to support carers during hospital admission. These include the opportunity to complete a carer's survey, book appointments with nursing staff and the provision of facilities to enable carers to stay overnight where possible.
2. We call on acute hospital providers in England to introduce a carer passport scheme across every hospital as we believe this would be beneficial to family carers and people living with dementia. This should set out the support carers should expect and we recommend that it includes the offer of flexible or open visiting hours, enables carers to assist at mealtimes and reflects the principles and values of the NHS Constitution.
3. We urge Health Inspectorate Wales to follow in the steps of the Care Quality Commission and produce an information leaflet for family members who care for someone in hospital. This should set out their rights and the support they should expect to receive during the duration of their loved one's stay in hospital.
4. We encourage the Care Quality Commission to include a prompt in their inspection framework for hospitals focussed on the rights of carers in a hospital setting. This should ask whether staff understand the rights of carers, how they communicate these rights and make sure they are upheld.

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