

Appropriate care in hospitals for people with dementia

2016 Annual Meeting Resolution

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Appropriate care in hospitals for people with dementia

'We call upon HM Government and the NHS to provide facilities to enable carers to stay with people with Alzheimer's disease and dementia that have been admitted into hospital.'

Proposer's Position

The proposer's intention is to improve the hospital care of those with dementia (but who may have been admitted to hospital for an unrelated condition) by calling for hospitals to provide facilities to enable their carer to stay with them at any time during their hospital stay.

Providing 'facilities' could mean a hospital welcoming carers outside normal visiting hours, providing places such as family rooms to enable carers to stay, or any other provision that would practically allow carers to spend time in hospital wards.

Every hospital ward is different, which means that the facilities they will be able to provide will be different. The point is that wards would be adapting their practices to better accommodate the needs of their patients that have dementia.

The proposer argues that providing carers with greater access to their loved one with dementia will improve the health and wellbeing of the patient, reduce long-term financial burdens on the NHS, and ensure that dementia care is person-centred.

What is dementia?

Dementia is an 'umbrella' term to describe the symptoms of more than 100 conditions that can impair cognitive processes, such as memory, mood, thought, and behaviour. Alzheimer's disease is the most common cause of dementia, but is by no means the only one and its symptoms are varied, complex, and sometimes difficult to diagnose. One of its overarching consequences is that the person afflicted is often less able to care for him or herself as time goes on. Currently, there is no cure.

Dementia is a global health crisis, impacting more people than cancer, heart disease, or stroke. In the UK alone there are 850,000 people living with dementia and that number is expected to rise to over one million in just five years.

Dementia is the leading cause of death for British women and according to the Department of Health over 20 million people in the UK have a close friend or relative with the condition.

Carer's passports similar to the below are currently being used by Imperial College Healthcare Trust. This is an example of one type of 'facility.' The passport allows the carer to visit outside of normal visiting hours. Passports like these can be also be used to help the carer access reduced car-parking charges or pay staff rates for meals. All of these provisions will make it easier for the carer to stay with their loved one.

NHS Trust

I am a carer

I am the main carer for this patient
and this card allows me to visit them
outside of visiting hours.



Credit: Elisa Cunningham
elisacunningham.com

Why are people with dementia admitted to hospital?

Some wards in some hospitals are designed for the care and treatment of people with dementia. These types of wards may be referred to as 'specialist dementia wards' and they typically admit patients with severe dementia related healthcare needs or those at the end of their life.

However, most people with mild to moderate dementia receive care for their dementia from a wide variety of providers in the community, not hospital, setting. In fact, it is very rare for a patient with mild to moderate dementia to be admitted to hospital directly because of their dementia.

Yet, we know that 25% of all hospital beds are filled by someone with dementia. So, what is going on? Why are these patients admitted in such high numbers if not for their dementia?

The reality is that patients with dementia are usually admitted to general hospitals because of a healthcare need that may stem from their underlying dementia, but is technically a discrete health issue, such as a chest infection or fractured bone. These patients enter hospital so that nurses and doctors can treat their infection or mend their bone or wound.

'Poor care in hospital can have devastating, life-changing consequences for someone with dementia.'

Jeremy Hughes, Chief Executive Alzheimer's Society

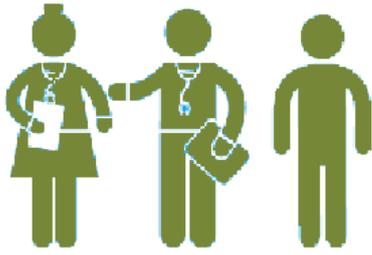
What is hospital care like for someone with dementia?

Patients with dementia are found in almost every ward in every kind of hospital that caters to adults. This means that sometimes they are being treated in wards which may not be suitable for someone with their condition who finds new, noisy, or busy environments frightening.

To compound this, many doctors and nurses may be unaware that the patient they are treating for an infection or hip fracture even has dementia. This means that while the patient may be receiving first-class medical treatment for their acute illness, their additional mental health related needs can be neglected.

This has led to the following stark findings as reported by the Alzheimer's Society:

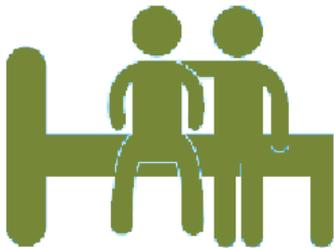
- ◆ 33% of people with dementia who are in hospital for an unrelated condition **never** return to their own homes
- ◆ According to their carer, 47% of people that go in to hospital are physically less well when they leave and 54% are less well mentally
- ◆ On average people with dementia stay in hospital **twice** as long as other patients
- ◆ Almost 60% of carers report that their loved one with dementia was not treated with dignity and understanding in hospital
- ◆ 92% of carers report that their loved one found the hospital environment frightening



Almost 60% of people felt that the person with dementia they know **wasn't treated with dignity or understanding** while in hospital



92% of people say hospital environments are **frightening** for the person with dementia they know



90% of people say the person with dementia they know became **more confused** while in hospital

Alzheimer's Society (*Fix Dementia Care, 2016*)

What is being done to fix these failings in dementia care?

'Our vision is to create a society by 2020 where every person with dementia, and their carers and families, from all backgrounds, walks of life and in all parts of the country...receive high quality, compassionate care from diagnosis through to end of life care.' - David Cameron, Prime Minister's Challenge on Dementia 2020

The pervasive and widespread reach of dementia means that dementia care will invariably be impacted by the wider health policy landscape and vice versa. Due to the **National Dementia Strategy** (2009), the **National Dementia Vision for Wales** (2011), the **Prime Minister's Dementia Challenge** (2012), and the **Prime Minister's Challenge on Dementia 2020** (2015), there is more awareness amongst health professionals than ever before about the needs of people with dementia and an explicit recognition that dementia care must be a health and social care priority.

Significant progress has been made over the past 5 years: 59% of people with dementia now receive a diagnosis and appropriate post-diagnosis support, over 600,000 care and hospital workers have received Tier 1 Dementia Training, £50 million has been invested in dementia friendly environments in hospitals and care homes, and over £60 million is now spent annually on dementia research.

Dementia Friends & Champions

Additionally, charities have led the way in transforming what we know about dementia and how we treat people with it in our homes, surrounding community, and workplaces.

In 2013, the Alzheimer's Society in conjunction with Public Health England launched *Dementia Friends*, a strategic initiative to change people's perceptions of dementia. The *Dementia Friends* programme has signed up over 1 million people, who pledge to do things large and small to help people living with dementia. The *Dementia Friends* initiative in Wales was launched in February 2014 and has signed up nearly 8,000 friends.

People can also sign up to be a *Dementia Friends Champion*, a volunteer who runs Dementia Friends Information Sessions every month and serves as a vital point of contact for other dementia friends and those in need of information about dementia.

As part of the Prime Minister's Dementia Challenge (2012) the NFWI joined the **Dementia Friendly Communities Champion** group, a group of business and community leaders who meet regularly to work to ensure different sectors, spaces, and communities can become more dementia friendly.

Dementia Friendly Hospitals

In October 2012, the **Dementia Action Alliance**, in partnership with the NHS Institute for Innovation and Improvement, launched a **Call to Action** for the improvement of care for people with dementia in acute hospitals. All acute hospital trusts in England were asked to publicly commit to adapting their practices to be dementia friendly. 164 acute hospital trusts signed on to what is now called the *Dementia Friendly Hospital Charter*, which outlines how they will make their wards dementia friendly.

Additionally, in March of 2016 the Government announced new plans for the Care Quality Commission to include standards of dementia care in their inspections of hospitals. The Welsh Government has also made dementia friendly hospital care a priority with the 2015 commitment by the Minister for Health and Social Services to improve the care of patients with dementia in general hospitals.

However, despite this suite of guidance and public commitment, studies have shown (such as the National Audit of Dementia) that these quality standards for dementia care in general hospitals are not being enforced or adequately monitored.

The Role of Carers

Over half a million people in the UK act as a primary unpaid carer for someone, usually a family member, who has dementia; the majority of these carers are women. These unpaid carers save the NHS an estimated £11 billion annually. They are the expert sources of knowledge about their loved one who has dementia.

What rights do carers have in hospitals?

Carers have certain rights as set out in the **NHS Constitution**. Carers are supposed to be consulted in all decisions regarding the care of their loved one and they are also, where appropriate, to be involved in their loved one's care plan. Services should also be tailored to fit around not only the patient's needs, but their carers' as well. However, many carers and medical staff are unaware of these rights.

The impact of carers for patients with dementia

Ensuring better access for carers and consulting them in the treatment of their loved one— from admission until discharge— has been proven to ensure a better quality of care for patients with dementia and leads to improved outcomes.



However, many hospitals treat carers like normal visitors, **restricting them to normal visiting hours only**. There is currently no obligation for hospitals to ensure that their patients with dementia have access to their carers whenever they most need them, such as during meal-times.

John's Campaign

The campaigning group *John's Campaign* was launched in 2014 by Nicci Gerrard and Julia Jones after Nicci's father's hospital experience completely accelerated his dementia. In Nicci's words:

'My father was a doctor and then a businessman. He was very clever and also enormously competent; he could make things, fix things, solve problems...About 10 years ago he was diagnosed with dementia. It was a slow but steady decline, with accelerations when was ill or upset...But he remained largely cheerful...

Then in February [2014] he went into hospital with leg ulcers that weren't responding to antibiotics. He was there for five whole weeks, and for as long as I live I will regret that we didn't understand sooner what this prolonged stay would mean....**He went in strong, mobile, healthy, continent, reasonably articulate, cheerful and able to lead a fulfilled daily life with my mother. He came out skeletal, incontinent, immobile, incoherent, bewildered, quite lost....**I am certain that if he had not laid in hospital for five weeks, with no one who loved him to take care of him, he would not have descended into such a state of incapacity.' (*The Guardian*, 29 November 2014)

John's Campaign is calling for families and carers of people with dementia to have the same rights as parents of sick children, and be allowed to remain with their loved one in hospital for as long as they deem necessary. Since the launch of the campaign, the Care and Support Minister wrote to the Chief Executives of all trusts asking them to allow carers to stay on the ward like parents and over 200 hospitals have publicly committed to making changes in order to allow carers to stay. However, it still remains up to each individual ward to determine its own policy. Some wards are innovating and figuring out how to have carers on the ward; others have yet to make substantive changes.

Arguments for the resolution

1. It is clear from the evidence that not all hospitals have taken steps to be dementia friendly and vulnerable patients are suffering as a consequence. Now may be the time for the WI to urge more action to enforce the quality standards that are already in place.
2. As this campaign does not call for a statutory right or duty, but rather for hospitals to voluntarily reform, there is potential for individual WIs to be agents of change and work with their local wards across the country to achieve its aims.
3. While this resolution focuses on hospitals, WI members are also able to draw on the NFWI's existing work on the Prime Minister's Dementia Challenge in order to take broader action to ensure their communities are dementia friendly.

Arguments against the resolution

1. *John's Campaign* is already the established voice on this issue and it has had tremendous success. With over 200 hospitals committed to making changes to allow carers on their wards is there really more for the WI to add?
2. Hospitals face a very challenging care climate at the moment, with the financial environment forcing hospitals to make difficult efficiencies. This resolution may be an unfeasible 'ask' at this time.
3. An unintended consequence of this resolution is that hospitals displace the burden of adequately caring for their patients with dementia on to family members and carers. Not everyone has a carer, but every patient with dementia deserves to be treated in a dementia friendly environment. Might this resolution lead to further inequities down the line and put more burden on already overworked carers?

Groups to contact for further information

The Alzheimer's Society

Devon House, 58 St Katharine's Way, London, E1W 1LB
Tel: 020 7423 3500 Email: enquiries@alzheimers.org.uk
Website: www.alzheimers.org.uk/

John's Campaign

Website <http://johnscampaign.org.uk>
Email: julia-jones@talk21.com

Please note that John's Campaign is run entirely by volunteers Nicci and Julia so they may not have the capacity to respond to all queries.

NFWI Public Affairs Digest

Keep up to date with the resolutions process and with NFWI campaigns by signing up to the Public Affairs Digest. Sign up by emailing pa@nfw.org.uk and stating your name, WI and email address. The digest will be delivered to your email inbox once a month and bring up to date information on all aspects of NFWI public affairs work.