

Implementing John's Campaign

Introduction

Nursing people who have a diagnosis of dementia can be challenging but fulfilling. As the UK has an ageing population there will be increasing numbers of people in hospital who have a dementia; it is clear that dementia care skills must become core skills.

Sensitivity, compassion and empathy are core qualities, as are listening and communicating. These qualities should be valued as professional strengths that will provide effective care to meet the patient's needs, whilst paying attention to their individuality and offering support, compassion and respect to family carers. They are the key to the wellbeing of people with a dementia.

John's Campaign is a movement to help NHS staff recognise the importance of working with family carers as equal partners in the care and support of people with a dementia who are in hospital. This booklet gives you some simple and practical solutions to implement changes in visiting hours for patients who have dementia.

Introducing John's Campaign into your hospital, wards and departments is the right thing to do. It will ensure the best possible patient experience for the person with a dementia, their carer, and the staff and demonstrate that your hospital wants to provide the best experience for them.

What is John's Campaign?

The campaign calls for a policy welcoming family carers onto the wards outside of the normal visiting times, according to the needs of the person with a dementia and not restricted by stated visiting hours.

Hospital stays are generally detrimental to people with a dementia; they often experience longer stays and poorer outcomes than the general population. All too often, when the acute episode of care has ended the person with a dementia has lost their prior level of functioning and is unable to return home; devastating for the person with a dementia and the family, with significant cost consequences for on-going care.¹

Involving the family carer from admission to discharge has been proven to help ensure a better quality of care, an improved patient experience and improved outcomes (patient experience data provides an important evidence base on standards of care).

The key focus behind John's Campaign is an open visiting culture; supporting carer access to the hospital outside of normal visiting hours, to enable them to be with the person with a dementia when they may be stressed, anxious, upset or lonely.

A hospital admission may also be the first time a carer has been recognised or recognises themselves as such. Hospitals are well placed to identify family carers and offer support and advice that will help the carer retain their own wellbeing.

Why support John's Campaign?

John's Campaign brings benefits to both patients and staff. It can help patients feel calmer and less disorientated to have their carer or family member close by. This can help with communication and the medical treatment they are in hospital to receive. Staff could find that this helps them deliver treatment efficiently and effectively at the same time as supporting the individual wellbeing of the patient.

There is strong national support for John's Campaign.

In March 2015, Norman Lamb (then Minister of State with responsibility for care services) and Alistair Burns (National Clinical Director for Dementia, NHS England), wrote to NHS Trusts to ask them to consider supporting John's Campaign:

'The request is for the carers of people with dementia who are in hospital, to be allowed the option to stay with that person outside of normal visiting hours or even overnight. We are cognisant that this is a practice which hospitals have adopted widely since the early 1990s for the parents of children staying in hospital.

We are also conscious that many general hospitals offer accommodation for parents to stay overnight.'

Hospital wards and departments are very busy places, with many people – technicians, allied health professionals, medical and nursing staff – all working together to deliver the best care that they can to patients. Unfortunately for a number of reasons this often excludes carers.

People who have a dementia or cognitive impairment can find hospitals a hostile and difficult environment; with strange smells, noises, lights, routines, equipment and people. It can be scary, disruptive and disorientating for them.



‘Support of a carer can be **invaluable** for a person with a dementia.’

Those who function at an adequate level in their own environment may upon admission to hospital and finding themselves alone be propelled into a state of anxiety and confusion. This makes it difficult for the person to understand their surroundings, follow simple instructions and give personal information or reflect their feelings. Communication can become very fraught and difficult on all sides.

The outcome of this situation is that patients may appear to be uncooperative and awkward; not being able to understand what is being asked of them and finding following simple directions impossible. It can make treatments and interventions more difficult to administer and more painful to receive. This is where the presence and support of a carer can be invaluable for a person with a dementia.

Why is John's Campaign important for hospitals, wards and departments?

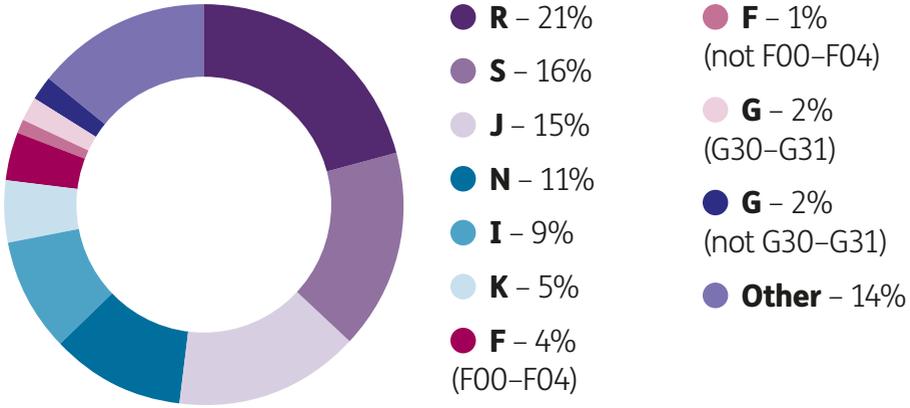
Planned and unplanned admissions to hospitals for people with dementia are a serious issue which have a negative impact on maintaining levels of functioning and independence. People with a dementia generally experience longer hospital stays and have a higher staff dependency, as additional staff may be required to carry out simple procedures, treatments and interventions. They may also be required to deal with issues around nutrition and hydration and monitoring patient safety.² All will have an increased financial cost.

- The average stay of a person with a dementia is two weeks; this is significantly longer than for the general population and can be much longer if rehabilitation is needed.³
- Delayed transfers of care can become a problem if the person with a dementia is unable to return home and a community placement is required.⁴
- One third of people with a dementia who go into hospital for a non-dementia related physical condition never return to their own homes.⁵
- Forty-seven per cent of people with a dementia who go into hospital are physically less well and able when they leave.⁶
- Fifty-four per cent of people with a dementia who go into hospital are mentally less well when they leave than when they went in.⁷



People with a dementia currently occupy 25% of hospital beds in the UK.⁸

Reasons why people with a dementia are admitted to a general hospital:⁹



ICD10 (2015) Classifications	
● Chapter R	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified.
● Chapter S	Injury, poisoning and certain other consequences of external causes.
● Chapter J	Diseases of the respiratory system.
● Chapter N	Diseases of the genitourinary system.
● Chapter I	Diseases of the circulatory system.
● Chapter K	Diseases of the digestive system.
● Chapter F (not F00-F04)	Mental and behavioural disorders – dementia related.
● Chapter F (not F00-F04)	Mental and behavioural disorders other than dementia.
● Chapter G (G30-G31)	Alzheimer disease and other degenerative diseases of the nervous system.
● Chapter G (not G30-G31)	Diseases of the nervous system.

Why does it help to have carers around outside normal visiting hours?

Emergency and planned admissions to hospital are difficult experiences for any individual, but can be particularly traumatic for people with a dementia, often resulting in significant distress and deterioration of their condition.

While short stays in hospital may be clinically beneficial, consideration must be given to the impact on the individual with a dementia, in particular the change in routine and the disorientating effect of changes to the living environment.

When a person with a dementia is admitted to hospital a familiar face can help them feel safe and experience less anxiety.

John's Campaign may challenge the culture of a hospital. But we know treating people with dignity is a key measure of a person-centred organisational culture. When undignified care is allowed to become the norm and there is no overarching organisational focus on dignity, poor practice and poor patient experience is the result.

Working as equal care partners with family carers will ensure the best outcome for people with a dementia.

The task of delivering high quality, dignified care becomes more achievable using a person-centred approach.¹⁰ Research shows that better patient outcomes are achieved when staff see the person behind the illness, know the individual's life story¹¹ and understand what's important to them.



'Better patient outcomes are achieved when staff see **the patient behind the illness.'**

Unfortunately sometimes organisations and hospital staff do not recognise a family carer as the expert advocate for the person with a dementia. A carer is able to communicate, reassure, and explain. They can undertake a nurturing rather than nursing role and work in partnership with the hospital professionals, helping to ensure that person-centred care can be delivered and an early discharge is facilitated.

This role can vary; it may be explaining what treatment or intervention is going to happen, or explaining to the person with a dementia what they will be expected to do. For example, getting a cannula in and keeping it in, understanding a catheter and not trying to pull it out, giving reassurance to relax when being examined, letting ward staff know what behaviour to look out for if the person needs the bathroom, and helping with washing, dressing or eating. It may be reading with them or holding their hand whilst they settle for the night or even staying the night.



‘A carer is able to **communicate, reassure, and explain.**’

These are the simple, positive things that will improve care, the patient experience and discharge outcomes and most importantly help the person with a dementia to retain their level of functioning and independence when they return home.

Implementing John's Campaign

Implementing John's Campaign does not have to be difficult; small changes can make big differences to the patient experience and staff satisfaction and improve patient outcomes.

Ideally improvements should be hospital-wide but sometimes small pilots in wards and departments will help to test the change, give rapid feedback and demonstrate improvements, which can be audited, tweaked and rolled out to a wider audience.

Get a group of interested people together; it always helps if there is a core group who can support each other if the going gets tough.

One



Share your vision

- Start to mention this to the people you work with, in the context of improving the patient experience, nursing care, discharge times and patient engagement.
 - Think about what would be the positive and negative aspects of implementing John's Campaign in your organisation.
 - Consider local policies around safeguarding, infection control, privacy and dignity for all wards, as well as the confidentiality of other patients and the hospital's current visiting policy.
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Two



Find the evidence to support your ideas, making sure it fits with latest objectives of your trust

- Find evidence to show why implementation of John's Campaign would be a good thing, for example, inpatient surveys, carer's surveys or feedback from staff about caring for patients with dementia.
- Identify all the challenges that you feel you may come across and think about the solutions – so you are prepared.
- Design a high level project plan – this can be used as a discussion document.
- Present your idea, get people at all levels on board.

Three



Getting going: map out what currently happens on your ward (baseline audit)

- Do people with a dementia have the best patient experience possible?
 - Are carers encouraged to work with the team as equal partners?
 - When are carers allowed on the ward?
 - How are informal carers treated, are they made to feel welcome?
 - Do you help carers recognise their caring role?
 - Does the ward team make best use of the information and support that carers can give?
 - Are carers actively enabled by staff to support the person with a dementia during interventions and treatments?
 - How does the staff team feel about working in partnership with carers – will they embrace it?
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Four



What would need to change to implement John's Campaign and improve the delivery of patient centred care

- What would relatives need to make them feel more comfortable on the ward?
 - What would the ward need to do be able to accommodate carers?
 - Practical considerations such as extra chairs and curtains?
 - How could extra capacity be ensured in the wards or bays?
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Five



Develop a policy statement and promote the campaign to staff

- Check the existing visitors or carers policy to which you may be able to add.
- Develop a policy statement which clearly outlines the organisation's commitment and how it will work in practice.
- The policy statement should be supported by the CEO, Medical Director, Director of Nursing or Chief Operating Officer.
- Look into whether you can include a section on your approach to the campaign and the role of carers in dementia training and hospital inductions.

Six



Communicating the campaign to carers

- Carers and relatives should be introduced to the nurse in charge on their first visit – see ‘Meeting the Carer’, p15.
 - Add details of the campaign to your existing information for carers, such as website pages and leaflets.
 - Use posters on ward doors and other entrance displays to indicate wards which are participating in the campaign.
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Seven



Think about how to audit the initiative

- You will probably want to compare the baseline audit data with recorded change data at six weeks, three months and six months.
 - Use the data to inform other data collection, i.e. family and friends test, slips, trips and falls or complaints.
 - You may want to survey carers of people with a dementia to assess the impact on carer satisfaction and awareness levels.
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See ‘Links and resources’ on p21 for more ideas to help you promote and implement the campaign in your organisation.

Meeting the carer

Identification of carers

A carer is someone who cares for a friend or family member so that they can continue normal daily functions. People who are very ill or frail can be very dependent on their carer.

Hospitals provide an important setting to identify carers; often husbands, wives and significant others do not identify themselves as carers and don't really feel that this is what they are doing.

They also may not acknowledge the strain their caring role can place on their own wellbeing. The NHS has a responsibility to identify carers and promote their health and wellbeing.

On admission – either at A&E for unplanned admissions, or wards and departments for planned and elective admissions – there needs to be an opportunity to clearly identify and record that there is a carer involved who needs to be a partner in the care of the patient.

It may be helpful to meet with the children's department managers and ward staff to get an idea of how involving parents as equal partners in the care of their child works; children's wards have been doing this successfully for years.

The initial meeting

Carers who have been a part of John's Campaign tell us that the opportunity to have an open discussion is helpful in building trusting relationships.

When a person with a dementia is admitted to hospital, the first meeting that the hospital staff have with carers and relatives is key. This gives the named or allocated nurse in charge the opportunity to discuss in detail what John's Campaign means to your ward or department.

It's best at this time to explain clearly how John's Campaign will work. This allows carers to ask questions and means that from the outset staff and carers are working together in partnership to provide the best care and support for the person with a dementia.

This is also the opportunity to discuss issues such as infection control, matters of privacy and dignity, confidentiality and practical considerations such as bathroom facilities and meal arrangements. It may be necessary to outline the limitations of what can be offered in each ward.



‘Discuss in detail what John's Campaign means to your ward or department.’

Implementation FAQs

How can staff ensure confidentiality is maintained?

Everyone must be mindful of confidentiality, capacity and consent issues. The confidentiality of other patients may mean that family carers will be asked to leave the ward or bay for short periods while handover or treatments are being carried out. The nurse in charge should discuss and explain this in the initial meeting so that carers will be aware of what to expect.

What about privacy and dignity?

There may be issues with privacy and dignity in wards and bays – particularly in single sex areas. Carers can be asked to have the curtains around the bed closed at certain times and be encouraged to sit in communal areas of the ward or leave the area when ward rounds or other confidential or private matters are being attended to.

Could wards become overcrowded?

Carers need to understand that they must be responsible for not overloading the bed area and ensuring that relatives do not upset the balance of the bay or ward.

How do we help prevent the spread of infection?

Staff should demonstrate and help the carer to be aware of infection control guidelines and practicalities. Wards must insist on high level of hand hygiene. Take advice from microbiologists on any unusual cases.

How do I ensure there are adequate safeguards for my patients?

Adhere to the hospital safeguarding policy and follow local arrangements. You should contact the safeguarding lead about any concerns.

What about hospital parking and other facilities for carers?

Different organisations have different offers available for carers with regard to parking and other facilities. Find out what your local arrangements are and inform carers of the options available.

How can the initiative be financed?

The cost to integrate carers into a partnership of care in monetary terms is very low but the value for the person with a dementia and the organisation is high.

Wards often set up an Endowment Fund or seek help from hospital friends to buy recliner chairs and other equipment.

Will carers have to stay the night – and what about their wellbeing?

John's Campaign advocates for carers to stay overnight should they wish as there may be times when it is crucial for the wellbeing of a person with a dementia.

There may be times when supporting a carer to stay overnight seems not to be possible. This could be due to a ward activity or lack of capacity to accommodate people other than patients on the ward. However it is important that organisations make this work and carers are facilitated to stay overnight if they wish, as night times in strange and noisy places are frightening and difficult for people with a dementia.

If there is a need for the family carer to stay throughout the night every effort must be made to accommodate this, using side rooms, sitting rooms or other spaces.

If it's not possible, the carer should be supported to stay until the person is relaxed and calm. Family carers and staff need to build a rapport to enable the carer to feel comfortable leaving their loved one in the care of the staff when they are asleep or resting.

Family carers should also be encouraged to think about their own health and to make sure that they are getting enough sleep and exercise to refresh them to support their loved one for another day.

Is there a CQUIN relating to the campaign?

John's Campaign has been included as one of the 29 indicators for the NHS commissioning for quality and innovation policy framework in 2016/17 for acute hospitals and mental health providers in England.¹²

The requirements of the CQUIN include:

- Policy statement – this should clearly set out the provider's commitment to John's Campaign, including where and how the campaign will be adopted. It is important to involve local groups of patients and carers to ensure that the policy has relevance for the people most directly affected by its recommendations.
- Implementation plan – this guide should provide a useful starting point for developing an implementation plan to support the policy.
- Training programme – as part of the Standard Contract 2016/17, providers will be required to ensure that appropriate dementia and delirium training is available to staff through a locally determined training programme (this formed part of the National Dementia and Delirium CQUIN 2015/16). Providers are asked to include in this training programme their approach to John's Campaign and the role of carers, and to report on this addition to their commissioner.

- Carers Survey – the 2015/16 Dementia CQUIN requires provider to undertake a survey of carers for people with dementia, to ensure that they feel adequately supported. From 2016/17 this will be included in the Standard Contract. Providers will be required to ascertain the impact that their adoption of John’s Campaign has had on carer satisfaction. The details will be agreed with the commissioner.
- Promotional materials – there is no specific requirement for how the information should be made available to carers. Different approaches have been used by the Trusts and Hospitals that have adopted John’s Campaign.

Some examples include:

- Posters on ward doors
- Permanent display of information at hospital entrances
- Information pack
- Carer’s Passport – to distinguish the carer from other visitors

See ‘Links and resources’ on p21 for more ideas to help you promote and implement the campaign in your organisation.

Links and resources

Positive practice examples

Please see the following resources which have more details about how John's Campaign has been introduced in hospitals. They will give you some ideas about how you could introduce it in your care setting.

Identifying carers (Ipswich)

www.johnscampaign.org.uk/docs/external/ipswich-caring-for-carers.pdf

A carers' charter (Yeovil)

www.johnscampaign.org.uk/docs/external/yeovil-carers-charter.pdf

Visiting information for carers (Bristol)

www.johnscampaign.org.uk/docs/external/bristol-info-for-carers.pdf

Open visiting guidance (Musgrove Park)

www.johnscampaign.org.uk/docs/external/musgrove-park-hospital-open-visiting-guidance.pdf

Welcome poster for carers (Imperial)

www.johnscampaign.org.uk/images/ward-poster.jpg

A welcome banner (Hampshire)

www.johnscampaign.org.uk/images/hampshire-hospitals-johns-campaign-support.jpg

Information for carers about John's Campaign (East Lancs)

www.johnscampaign.org.uk/docs/external/east-lancashire-partnership-in-care.pdf

Carer's pass (Mid Essex)

www.johnscampaign.org.uk/docs/external/meht-carers-pass.pdf

Carer's pass (Imperial)

www.johnscampaign.org.uk/images/carers-passport-1.JPG

www.johnscampaign.org.uk/images/carers-passport-2.JPG

Leaflet for carers (Bradford)

www.johnscampaign.org.uk/docs/external/bradford-district-care-support-for-carers.pdf

People with dementia facing an operation (Kingston)

www.johnscampaign.org.uk/docs/external/kingston-hospital-theatres-dementia-leaflet.pdf

Welcoming carers to emergency admissions (Wishaw)

www.theguardian.com/society/2016/jan/09/johns-campaign-emergency-admissions

Welcoming carers to mental health ward (Worcestershire)

www.theguardian.com/society/2015/oct/23/johns-campaign-support-the-carers

Welcoming carers to critical care (Manchester)

www.theguardian.com/society/commentisfree/2016/aug/26/johns-campaign-welcoming-carers-at-hospital

Training staff in carer awareness (Newcastle)

www.johnscampaign.org.uk/docs/external/newcastle-upon-tyne-carer-awareness.pdf

Conversation prompts for nurses (East Lancs)

www.johnscampaign.org.uk/docs/external/east-lancashire-a-communication-aid-to-assist-nurses.pdf

Evaluating the project (Trafford)

www.johnscampaign.org.uk/docs/external/open-visiting-briefing-paper-trafford-hospital.pdf

Evaluating the project (Imperial)

www.johnscampaign.org.uk/docs/external/imperial-college-healthcare-johns-campaign-staff-survey.pdf

You can find out more on the NHS England website:

www.england.nhs.uk/nhs-standard-contract/cquin/

Carers Passports

Some organisations have successfully implemented a carer passport or badge as a means of identification for carers. Carers UK has published a report examining how a Carer's Passport can help improve the level of support given to carers, with examples of different initiatives.

The report is available on the Carers UK website:

www.carersuk.org/for-professionals/policy/policy-library/carer-passport-identifying-carers-and-improving-support

The Triangle of Care for Dementia

This guide and self-assessment tool adapts the Triangle of Care to ensure carers of people with a dementia are identified and supported, with examples of best practice. It was developed in partnership by the RCN and the Carers Trust and is aimed at acute hospitals.

The Triangle of Care for Dementia can be found online on the Carers Trust website:

www.professionals.carers.org/triangle-care-dementiaa

Useful organisations

John's Campaign

More information and resources can be found on the John's Campaign website: www.johnscampaign.org.uk

Age UK

We provide advice and information for people in later life through our Age UK Advice line, publications and online. Visit: www.ageuk.org.uk

Age UK Advice: 0800 169 65 65

Lines are open seven days a week from 8am to 7pm.

In Wales, contact Age Cymru: 0800 022 3444.

www.agecymru.org.uk

In Northern Ireland, contact Age NI: 0808 808 7575.

www.ageni.org

In Scotland, contact Age Scotland by calling Silver Line Scotland: 0800 470 8090 (This is a partnership between The Silver Line and Age Scotland) www.agescotland.org.uk

Alzheimer's Society

Offers advice, information and support to people with a dementia, their families and carers.

Tel: 0300 222 1122

Email: enquiries@alzheimers.org.uk

www.alzheimers.org.uk

In Scotland, contact Alzheimer Scotland

Tel: 0808 80 808 3000

Email: helpline@alzscot.org

www.alzscot.org

Carers Trust

Offers practical help and assistance to carers. You can search on their website for local carers services in your area. Tel: 0844 800 4361.

In Scotland, contact: 0300 123 2008

In Wales, contact: 029 2009 0087

www.carers.org

Carers UK

Provides information and support for carers, including information about benefits. Tel: 0808 808 7777 (in Northern Ireland, call 028 9043 9843).

www.carersuk.org

Parkinson's UK

Provides information and support to people with Parkinson's disease and their families. Tel: 0808 800 0303.

www.parkinsons.org.uk

Nicci Gerrard and Julia Jones founded John's Campaign in 2014

Nicci's father John was living well with a dementia at home, independent and mobile, until a routine admission to treat leg ulcers turned into a five week stay in which he rapidly deteriorated.

When Nicci shared her father's story in *The Observer*¹³ many other carers and relatives got in touch to say they too often felt excluded from the care of their loved one when they were admitted to hospital, inspiring the founding of the campaign.

In the last two years the campaign has inspired 400 hospitals to sign up.

References

- 1 Counting the Cost, Alzheimer's Society, 2009.
- 2 Older people's experiences of dignity and nutrition during hospital stays: secondary data analysis using the Adult Inpatient Survey, London School of Economics, 2015.
- 3 *Ibid.*
- 4 Fix Dementia Care Hospitals, Alzheimer's Society, 2016.
- 5 www.england.nhs.uk/statistics/statistical-work-areas/delayed-transfers-of-care/2016-17-data/
- 6 Counting the Cost, Alzheimer's Society, 2009.
- 7 *Ibid.*
- 8 Counting the Cost, Alzheimer's Society, 2009.
- 9 'Reasons why people with dementia are admitted to a general hospital in an emergency', Public Health England, 2013.
- 10 Kitwood (1997), Brooker and Latham (2016).
- 11 Lifestory network www.lifestorynetwork.org.uk/
- 12 CQUIN guidance, www.england.nhs.uk/nhs-standard-contract/cquin/cquin-16-17/
- 13 www.theguardian.com/society/2014/nov/29/nicci-gerrard-father-dementia-hospital-care-elderly

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