



John's Campaign: for the right of people with dementia in hospital to have their carers with them at any time

John's Campaign has the potential to change attitudes and effect widespread improvement in the quality of care for people with dementia in hospital. We believe it should be a standard across the UK and that institutions should be judged according to their success in implementing its principles.

The problem: As a group, people with dementia fail to thrive in hospital. A recent report by the Alzheimer's Society confirms they stay longer, are less safe and experience worse outcomes than their peers without this disability.ⁱ Their levels of functioning decline, they are less likely to return to their own homes and more likely to be readmitted within 30 days. Issues of consent and capacity, dignity and equality are all problematic. Satisfaction levels are low and complaints from families high. Above all, people with dementia need person-centred care and extra attention paid to their physical and psychological well-being yet because of their cognitive and communication difficulties, this may be almost impossible for hospital staff to provide.

Towards a solution: People who are living with dementia in the community are enabled and supported by their carers, the experts-by-experience. Carers are "the dementia patient's voice and memory"ⁱⁱ and if a carer is willing to continue their support through a hospital admission, it makes no sense to put barriers in their way. They should be welcomed as crucial members of the multi-disciplinary care team. **There is [clear evidence](#) that involving carers increases patient safety, improves outcomes and contributes massively to patient and family satisfaction.**ⁱⁱⁱ Ward sisters who already welcome carers say: "we couldn't manage without them."^{iv}

John's Campaign core proposals:

- 1) Carers of people with dementia should have unrestricted access if the person for whom they care is admitted to hospital. This must include staying overnight if necessary.**
- 2) Carers should not just be allowed but should be welcomed. They should be included throughout the patient's treatment if they are willing and the patient is in agreement or appears comfortable with this.**

These proposals are simple, compassionate and beneficial to the individual, the hospital and the wider community. They are in line with the revised NHS Constitution (Oct 2015) and they address the needs of a specific disadvantaged group. They are cost-neutral.

Issues to be addressed & the measurement of success:

- 1) Identifying carers:** whilst the support that a carer can provide to a patient with dementia is analogous to that provided by parents when children are admitted to hospital, the identification of carers may be less clear cut. Many people with dementia will be living with a partner, spouse or children; others will have given power of attorney. As progress continues in implementing the Care Act 2014 more carers will be identified on records kept at GPs surgeries, on "This is Me" documents, even within NHS codes. Many hospitals work with their local carer organisations to encourage [self-identification](#).^v

Quality Measure: Patients' records should contain the name and contact details of a person identified as a primary carer.

- 2) Differentiating carers from visitors:** Many hospitals choose to differentiate between carers and visitors by using a carer's passport or badge. Sometimes these are linked to benefits such as reduced parking or meals at staff prices. All we stipulate is that **the welcome for carers should be overt**, eg posters on ward doors, banners at the hospital entrance and a clear statement on the website cf. [Bristol Carers Charter](#).^{vi} Hospitals who sign up to our campaign currently do so by making a public commitment on the website hosted by the *Observer*. **We would like to see this information shared on NHS Choices.**

Quality Measure: The welcome to carers should be immediately obvious and whatever schemes are in place should be consistently and openly applied.

- 3) Confidentiality of patient information:** If sharing medical information with a carer during treatment is felt to be an issue, the patient should be asked to give consent at admission. Previous consent for information-sharing will almost certainly be stored at the GP surgery or care home. As "the dementia patient's voice and memory" the carer will know about pre-existing conditions and medication. Carers provide continuity in a fragmented system and are most likely to ensure that the hospital treatment continues to be effective after discharge. Health professionals should welcome their contribution to discussion.

Quality Measure: This consent should be visible in the patient's records. Records will show that the carer's input has been sought for, listened to and valued from the moment the patient was admitted – as in this [good practice example](#).^{vii}

- 4) Impact on staff time:** This is an immediate fear for both doctors and nurses. Although carer-input saves nurses' time, keeps patients safer and improves effective communication with clinicians, this is a potential problem that must be acknowledged and managed – eg by explaining ward round times and procedures to carers as in this [good practice example](#).^{viii} Professor David Oliver, president of the British Geriatric Society and a practising geriatrician, is acutely aware of this issue. Despite this, he is a committed supporter of open visiting "We've done this on my home ward and I wouldn't turn the clock back"^{ix}

Quality Measure: Welcome information provided for carers includes clear explanation of ward procedures and manages expectations in a constructive and courteous manner.

- 5) Staff Confidence:** Unlike paediatric nurses, staff in adult wards are not used to being watched while they work and may initially feel a lack of confidence when attending to a patient with a carer present. Communication skills may be an issue. Staff must be allowed to voice these worries and given support through clinical supervision and training to help manage them with confidence. Partnerships with carer organisations will help build understanding and mutual trust. It may help staff to know that all evaluations of open visiting received so far highlight a significant reduction in complaints. 77% of staff [surveyed at Imperial Healthcare NHS Trust](#) stated that open visiting improved communication.^x

Quality Measure: Staff training includes information on working with carers and opportunities to improve communication skills. Clinical supervision is in place. Senior staff are supportive. Carer liaison is strong.

6) Privacy and dignity of other patients: The Carers Welcome information will need to make clear that there may be times they are asked to leave a bay when discussions or procedures involve another patient.^{xi} Careful attention will need to be paid to overnight arrangements. However, as carers will only wish to stay at night if they believe that their loved one will be distressed or at risk, their input must be valued. It will repay hospital budgets to facilitate their staying and it will also, potentially, make night time more restful for all. Such arrangements sit easily with improved end-of-life care, as in this [good practice example](#).^{xii}

Quality measure: clear explanations and appropriate arrangements in place to safeguard privacy and dignity of all patients.

7) Infection control: Hospital infection control policies that routinely exclude visitors (eg in a noro-virus outbreak) will need to be reviewed, as exclusion can have an extremely harmful effect on this group of patients who depend upon the presence of their carers. As above, carers should be considered as an essential part of the team and educated to have the same level of hygiene awareness as clinical staff. The NHS could provide central guidance.

Quality measure: clear, updated policies. Hygiene training and infection control an essential part of carers welcome.

8) “Protected mealtimes”: We hope that there are no longer any hospitals who exclude carers at meal times. Suitable nutrition & hydration is an NHS Fundamental Standard and the involvement of family members at mealtimes is specifically mentioned.

Quality measure: welcome to carers and volunteers to assist at mealtime should be made clear. Guidance/induction re hospital procedures should be offered via the Carers Welcome pack.

9) Caring for Carers: Carer exhaustion is a real hazard but hospital admission is not a substitute for respite. A paternalist decision to exclude carers “for their own good” is fundamentally misguided. Involuntary separation is painful and, if the patient declines because of unsupported hospital stay, the long-term impact on the carer will be worse. Hospitals who welcome carers as valued members of the patient’s team should take the same care of them as they would other members of the team. Carers should also be made aware of any health and safety issues appropriate to their stay. The best hospitals will take this opportunity to offer carers personal support – [as in this good practice example](#) ^{xiii} Nevertheless, hospitals must remember there is no **duty** on family carers to be involved. If a carer continues to care while their dependent is in hospital they should not suffer financially for this – eg costs of parking should be considered. It is also wrong that they should lose carers’ benefits if they are continuing to care. However, if a carer chooses not to be involved in care during a hospital admission, the hospital must respect this, cf [Yeovil Carers Charter](#) ^{xiv}

Quality Measure: Personal support for carers is readily available within the hospital and opportunities are taken for signposting to services in the community. There may be partnership with local carer organisations and opportunities for peer support.

10) People with dementia who do not have carers: The sad fact that some people may be coping with dementia unsupported by family carers is no reason for hospitals to restrict access by the carers of others. Welcoming carers onto wards changes the atmosphere for

everyone. Once the importance of nurturing patient wellbeing has been established, we hope hospitals will feel additionally motivated to involve volunteers, chaplains or dining companions in assuaging the loneliness and enhancing the care of those who do not have regular carers: “making the difference between good and excellent”^{xv}

Quality measure: ward records will demonstrate a variety of initiatives and regular, committed visitors to humanise care and promote well-being for all dementia patients

There is already a range of indicators which may be used to measure the value of welcoming carers of people with dementia into hospitals: reduction in incidence of delirium, reduction in falls, better discharges, improved outcomes (facilitated by improved communication), fewer complaints, greatly increased levels of patient and family satisfaction.^{xvi} This is never more important than at times when the end-of-life may be near. Adoption of the simple principles of John’s Campaign throughout all care settings will go far to reducing the current unacceptable variation in end-of life care as well as the “Russian Roulette” of widely fluctuating standards as identified by the Alzheimer’s Society. Perhaps it is a counsel of expediency but it is also intrinsically right and in full accordance with the NHS Constitution which has recently been revised to include families and carers explicitly.

Call to Action: John’s Campaign was founded 30.11.2014 and is UK wide. Currently 230 hospitals and hospital wards have made a public pledge of their welcome to carers and there will be many more. The Scottish Government is using John’s Campaign as part of a suite of measures to promote person-centred care in all their hospitals and, within HSCNI, the Dementia Together Initiative has contacted all their 400 care homes as well as hospitals encouraging them to join. In England and Wales a strong steer must come from the top to ensure that this quality improvement is implemented countrywide.

John’s Campaign has the support of Age UK, the Alzheimer’s Society, British Geriatric Society, Prof Alastair Burns (National Clinical Director for Dementia), The Butterfly Scheme, Carers Trust, Carers UK, Dementia UK, Dementia Together NI, Faculty of Psychology for Older People, Gold Standards Framework, National Audit of Dementia, Parkinson’s UK, Patient Opinion, Point of Care Foundation, Royal College of Nursing.

ⁱ Alzheimer’s Society *Fix Dementia Care: Hospitals* (Jan 2016)

ⁱⁱ Susanne Hasselmann: past carer of dementia patient in hospital, Lay Member at South Eastern Hampshire CCG, NHSCC board member (comments in a personal capacity)

ⁱⁱⁱ <http://johnscampaign.org.uk/docs/external/open-visiting-briefing-paper-trafford-hospital.pdf>

^{iv} Source: Interview with Carole Tookey, Head of Nursing University Hospitals Bristol NHS FT (Jan 2015)

^v <http://www.ipswichhospital.nhs.uk/forpatientsandvisitors/are-you-a-family-carer.htm>

^{vi} http://www.uhbristol.nhs.uk/media/2507394/carers_boards_poster_july_2015_final.pdf

^{vii} <http://www.theguardian.com/society/2016/jan/09/johns-campaign-emergency-admissions>

^{viii} <http://johnscampaign.org.uk/docs/external/musgrove-park-hospital-open-visiting-guidance.pdf>

^{ix} *British Medical Journal* <http://www.bmj.com/content/351/bmj.h4959> (Sept 2015)

^x <http://www.johnscampaign.org.uk/imperial-college-healthcare-johns-campaign-staff-survey.pdf>

^{xi} <http://www.musgroveparkhospital.nhs.uk/media/405976/Open-visiting-guidance-Final.pdf> (op cit)

^{xii} <http://www.theguardian.com/society/2015/oct/16/johns-campaign-family-rooms-mid-yorkshire-trust>

^{xiii} <http://www.theguardian.com/society/2015/oct/23/johns-campaign-support-the-carers>

^{xiv} <http://www.yeovilhospital.co.uk/wp-content/uploads/2015/08/Carers-Charter-final.pdf>

^{xv} Liz Charalambous: <https://idea.nottingham.ac.uk/blogs/posts/volunteers-dementia-and-acute-hospitals>

^{xvi} Evidence available or forthcoming from Nottingham delirium reduction project, Heart of England open visiting evaluation, New Haven and Athelon wards carer support evaluations (HACW)