



## John's Campaign: for the right to stay with people with dementia in hospital

**Implementing John's Campaign:** We believe that each hospital or trust should implement John's Campaign according to its particular circumstances. These are our guiding principles.

- **Carers should have access to the patient whenever they are needed.** This may be during the day or the night. (By "carers" we mean whoever primarily supports the person with dementia when they are not in hospital.)
- **The patient's needs are at the centre of this access principle.** Whatever supports their personal well-being is likely to make their medical treatment more effective and will promote their secure discharge.
- **Carers should be welcomed.** They are an essential part of the patient's team.
- **Carers have a right – but not a duty – to be with the person they care for.** John's Campaign focusses on the unpaid "family" carer. However, if a person with dementia is primarily supported by someone who is paid (eg a trusted home help or companion) that person will be equally welcome.
- **Carers are there to nurture, not to nurse.**

Here are some Frequently Asked Questions in case they help you in your own hospital. Please do ask any others that occur to you. Someone will have the answers if we don't. (julia-jones@talk21.com)

### **Who are the key people who will help me put these principles into practice in my hospital?**

**The true answer is everyone.** A hospital's welcoming attitude to its patients with dementia and their carers is evidenced as much by the ancillary staff as by the chief nurse or senior consultant. That's why a network of dementia friends and champions throughout the hospital is such a bonus. If you have such a network, do keep them fully informed.

**The most obvious people to take an overall lead are the dementia specialist nurses with the support of senior managers** (such as their directors of nursing). However there have also been hospitals where the patient experience managers, safeguarding specialists or geriatricians have been the primary motivators.

**The support of ward managers is vital.** There are several hospitals where individual ward managers have implemented John's Campaign on their own wards knowing they are doing the right thing for their patients and have then spread their good practice to other colleagues. It is ward managers who will put a welcome poster on their door, a smile on their face and who will do their best to organise the sometimes tricky accommodation adjustments to enable a carer to stay if this is what the patient needs

**Look at the roles in your own hospital.** Some hospitals have discharge managers who begin their work as soon as the patient is admitted. They will work closely and constructively with carers. Learning disability teams may already have useful experience to share. Perhaps you already have carer support or family liaison workers? *And, when in doubt, ask paediatrics how they manage.*

### Which are the key locations for implementation?

**A number of hospitals have begun by implementing Johns Campaign on their elderly care or dementia wards.** We welcome implementation on individual wards when this springs from individual commitment but we also believe it's important to work towards a **whole hospital approach**. People with dementia will be admitted for the full range of medical and surgical conditions and they'll need the support of their carers wherever they are. Moves within the hospital should be kept to a minimum as disorientation is a major problem. Issuing a carer's passport / carer's sticker / family card will enable the patient's most essential supporter to navigate the system with them.

**Trust-wide is even better than hospital-wide implementation.** It makes no sense to have welcoming policies in the acute hospital but not in the rehabilitation or community facilities. The principles of Johns Campaign are already being accepted by mental health units but we'd like to spread the message to agencies such as the ambulance service. Think of your patient's journey from the moment they have to leave their own surroundings. Do all you can to make it easier for them to continue to be supported by the people they already know and trust.

Once you've decided on your system, your PALS department / communications team / website manager are vital partners, sharing the message on both internal and external networks.

### How do we identify carers?

**In a perfect world this would already have been done** and the information available in the patient's file. In that same perfect world the carer and patient would already have worked together to have personalised details about the patient ready in a "This is Me" (Alzheimer's Society) document or similar.

**In this world you may need to prompt the people** who identify themselves as sons, daughters, spouses, next-door neighbours, significant others, best friends (etc) to recognise that they are also carers. You may decide to have a definition – or a carers' charter – on your website. You may include the question "Are you a carer?" on a poster. If the patient depends on someone in the outside world, you hope they'll have that support in hospital as well. Though, if the carer makes the decision to have a break, you have to respect that.

### Are carers' passports essential?

**Some hospitals like to have some form of identification for carers** that differentiates them from other visitors. This can serve to allay ward staff fears that they will be "swamped" with people. It can also serve as a form of empowerment for carers who may feel nervous about accessing a ward outside visiting hours. Carers' passports can be linked with reduced car-parking costs and/or meals at staff rates. They can also be linked to carers' information packs (see below). However it's important to realise that some carers can find being given too much paperwork can be a little alarming. Some hospitals have chosen a simple sticky badge or a "family card". Others offer lanyards. The key issues are identification and empowerment.

### Why offer carers' information packs?

**This is your chance to introduce carers to the ways of your hospital or ward.** Spell out the hygiene requirements, explain the ward timetable, educate them in the roles and responsibilities of the doctors and nurses and the needs of the other patients on the ward. Indicate some of the areas where they might like to help – but remember all the time that they are not your unpaid nursing staff. An elderly husband who offers to comb his wife's hair "the way she likes it" is just as valuable to her well-being as the energetic daughter who whisks around with sheets and pureed meals.

**You can do more.** If you are in partnership with community organisations, social care or primary care, you can also use the information pack to include items that help to support the carer themselves. While the carer is in your hospital it could be an ideal moment to find out what further information or training they need to help them cope at home. Are they managing okay with lifting, for instance? Dementia is a progressive disease, can a specialist nurse help them understand and manage the possible next stages? Dementia is also a terminal disease. Is this the moment to initiate a sensitive discussion about end-of-life wishes if this has not already been done?

### What are the likely problems?

- Doctors may find it difficult to complete their rounds as quickly as before if they are giving information to carers as they go. Improved communication is one of the most obvious benefits of having carers present when professionals (not only doctors) are assessing their loved ones. It only becomes a problem if families are over anxious and interrupt another patient's consultation or want to have the information repeated to many separate members. You may need to manage expectations.
- Nurses may feel self-conscious about being observed in their work. You may need to build their confidence and encourage their communication skills. Again the benefits are obvious – just think of the way that children's nurses work and how reassuring this is to their patients. The presence of a trusted carer will help in so many small ways – such as convincing the patient that it is safe to accept the medicine that a nurse is offering.
- Overnight stays can present a problem when the carer is not the same gender as the other patients in the bay. A ward manager is responsible for the privacy and dignity of all their patients and sometimes this will need to be explained. However "where there's a will there's a way" and ward managers will already know very well that a distressed, uncomforted patient has the potential to disturb everyone else in their area. Every effort must be made to enable the carer to stay if they believe their relative needs them.
- In the past restricting visitor access has been seen as a part of infection control. Once the importance of carers as part of that patient's support team has been accepted then they are no longer visitors and should be subject to the same routines as staff. Some hospitals have re-written their anti-infection protocols to recognise this. Education is the key.
- Confidentiality. There is the confidentiality of other patients – which has only to be explained and respected – and the confidentiality between the health professional and the patient. Patients with dementia are already likely to have given permission for information – sharing and many carers will also have powers of attorney. The other side of confidentiality is effective communication and it is clearly nonsense to exclude the carer from

conversations where they will already have knowledge of prior- and simultaneously-existing conditions and also from treatment plans which they are going to be crucial in implanting.

- Ward overcrowding is unlikely to happen. Sadly not every patient has relatives able and willing to support them and if you are worried about cramped conditions you can decide to issue one carer passport per patient and leave the family to pass it amongst themselves if there are enough of them to run a support rota.
- Carer exhaustion is a real problem. You can be helpful about this but not paternalistic. No carer is going to want to sit up at night unless they are convinced it's necessary so you have to support their decisions. A patient with dementia who declines catastrophically in hospital will be far greater anxiety to their carers when they leave. That's why this campaign began.

### **What about the people who have no one?**

In wards where carers are welcome it has been noticed that the other patients benefit from the improved social atmosphere that welcomed-carers bring with them. Many hospitals also use volunteers, dementia support workers, members of their chaplaincy team to offer companionship to those without family care.

### **Remind me, why are we doing all this?**

You are implementing Johns Campaign for reasons of common humanity and compassion. People with dementia do not have the cognitive capacity to cope with a hospital stay on their own. Always remember the parallel situation of parents supporting their children through this frightening and sometimes pain-filled experience. Also many of your colleagues will have been touched by dementia in their families. They will have personal understanding to share.

### **There are also many quantifiable benefits:**

- Reduction in the incidence of delirium
- Reduction in falls
- Improvement in hydration and nutrition
- Better communication
- Willingness to accept treatment
- Improvement in management of continence
- Improved recognition of pain
- Maintenance of movement and general functioning
- Reduction in complaints
- Better discharge

Many of these benefits will also be supported by the other actions towards making hospitals dementia-friendly – like improved signage, adoption of the Butterfly Scheme etc. You can think of John's Campaign as one of many possible strategies to make your hospital a better place for people with dementia and their families. **But if you do only one thing, do this.**

**Please tell us when you are adopting the campaign** so we can add you to our list and map. Tell your community partners, such as carers' organisations, local Alzheimer's organisation. Put up posters and banners, tell your local press **and make sure it's clearly on your website.**