NHS
London
Clinical Networks

Nutrition and Carer involvement for people with dementia in hospital;

Learning from the London Dementia Clinical Network

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Background

Poor care in hospital can have devastating, life changing consequences for someone with dementia. At least 25% of hospital beds are occupied by people with dementia and on average people with dementia stay more than twice as long in hospital then other patients over 65 years old (Alzheimer's Society 2016).

In September 2016 the Directors of Nursing were invited to join a working group to set up a process to support the improvement of the quality of care in hospital for people with dementia across London. The working group represented acute, community and tertiary care from across London. It was agreed that a peer review process, where nursing leaders review care in other hospitals and offer direct constructive peer feedback would be used. Visits were followed up with a brief report for the Trust.

After two pilot reviews, the group decided to focus on nutrition and carer involvement in the first 48 hours of hospital admission. No clear best practice guidance was found on these specific areas; therefore the working group developed their own guidance and peer review tool. Information to inform the content of this tool was gained from policies, guidance documents, evidence and expert opinion. Information was sought from a variety of professionals including directors and assistant directors of nursing, occupational therapy, speech and language therapy, dietetics, consultant liaison psychiatry and professional bodies. You can find a copy of the guidance document here.

Peer Reviews

Peer reviewers typically spent a minimum of two hours observing care and compiled a one page report. In some cases the reviewer was able to visit Trust's areas of excellence and meet a broader range of clinical leads including the medical director and dementia lead as well as undertake the audit. Feedback was given directly to

the director of nursing or nominated clinical lead. Six peer reviews were completed across London (including pilots).

Learning from the peer reviews was jointly analysed. The key themes that emerged were staffing, dementia awareness, leadership, carer presence, 24 hour nutrition and personalised care.

Staffing

During peer review visits there was full staffing on wards and staff appeared enthusiastic. However whilst meeting safe staffing levels some ward staff expressed frustration in not being able to do as much as they would like, due to dependency needs of patients and current skill mix. In one hospital the Trust had invested in an enhanced care programme where a team of health care assistants work specifically with patients with cognitive impairment (in addition to safe staffing levels). This Hospital had also utilised a fund to invest in technology aids to support patients including access to memory programmes and music therapy- other patients and visitors on the ward expressed positive views on the impact these roles had had not only for the receiving patients but also other patients.

In one hospital trained nurses were only seen with patients during drug rounds (at the time of observation). Bay nursing was encouraged with allocated health care assistants to bays. Difficulties were noted caring for people with dementia in side rooms.

Other staff were highlighted to play an important role including, pharmacists, hostess, medical team, porters and therapists.

On specialist wards and those caring for the elderly there was excellent examples of kindness, compassion and understanding but this was more difficult to identify within emergency department environments and general medical wards. In these areas staff expressed that it was more challenging to maintain the safety of patients who were aggressive or wandered. In emergency department staff were aware of the

restrictions in supporting frail patients due to the nature of the workload and environment, with some examples of concerted efforts to try and improve the patient experience including investment in volunteers and enhanced healthcare assistants.

Dementia awareness

In one ward staff were not aware that two of their patients had dementia, despite it being on the hand over form. One ward used forget-me-not symbols on the white board to indicate who had dementia or delirium. The majority of wards were using relevant documentation such as “All about me” but the extent to which these had been completed, developed in co-production with patients and carers was less clear.

All Trusts visited had invested and embraced dementia awareness training but the numbers and priority appeared to vary between directorates. Those staff who had attended relevant courses gave positive feedback. The use of dementia champion type roles was also welcomed.

Leadership

Excellent examples of leadership were noted across visited hospitals including clinical experts. Commitment and passion was noted in senior management. There was awareness in one hospital of the change in culture was required to improve care and strong visible leadership was in place. The majority of Trusts had a clear strategy in place. Patient and user engagement in the development and implementation of strategies was less clear.

Carer presence

The majority of Hospitals had embraced John’s campaign or a localised similar approach with senior nurses advocating this. Carers were encouraged to help their loved ones eat and drink on the ward. There was however some wards that had not participated or chosen not to participate in the campaign.

It was often noticed that patients were unaccompanied with no relatives in emergency departments. One hospital had a volunteer in the emergency department; part of their role was to provide food and drink. We found that volunteers were generally in elderly care departments and not in emergency departments.

24 hour nutrition

Protected meal times were in place. During lunch time on wards patients were well supervised (if needed) and red trays were used. Outside of meal times a lack of encouragement / assistance for people to have a drink was noted, this was also highlighted in the emergency department

Patients were seen without any water cups and water cups out of reach; these patients were not able to for a drink or ask for help and were therefore extremely vulnerable. Leftover food and cold cups of tea were noted to be a particular issue in the emergency department, but not solely. On some occasions it was noted that some patients with dementia had no water jugs at all which had not been noticed or addressed. In some emergency departments food and drink were available but not routinely offered- dependent on staffing and how busy the unit was.

Personalised care

In the majority of hospitals patients were not dressed, were in bed and had bed rails up. All appeared to have bed rails in place. However, in one hospital staff were seen to be offering patients a choice of their clothes for the day and actively encouraging patients to get dressed. One ward had a sensory room which was underutilised. On one ward the hostess knew all the patients, greeted them and knew how they all liked their drinks, Some wards used beakers with lids for drinks as a matter of course. There appeared to be little or no choice offered to patients about what

drinking vessel they would prefer– no patients appeared to have been asked if would prefer a a “normal” cup, a beaker or a beaker with a lid.

Areas for further reflection/consideration

Standards of care vary across hospitals and wards within the same hospital at times.

Key themes identified:

- Lack of access to fluids
  - It was not uncommon to see patients without fresh water or cups in reach
  - Few patients were being supported to drink outside of meal times
  - There was a lack of personalised care in relation to nutrition, with patients’ individual preferences sometimes not being sought.

- Staffing issues
  - There was sometimes not enough staff on duty to adequately meet patients’ hydration and nutritional needs. Unless there are volunteers available it appears that the ability of staff to address the nutritional needs of patients in the emergency department is impaired.

  - The majority of patients in the emergency department with cognitive impairment were unaccompanied and as such without the support required to ensure needs were met

- Involvement of carers
  - On units where relatives were requested not to attend wards at meal times some relatives expressed concern that their loved ones nutritional needs might not be being met

Notable Practice

- Staff working with older people and people with cognitive impairment were passionate and committed
- Excellent examples of clinical leadership were seen- in one case a clinical lead had become a champion for open visiting and involvement of patients in all aspects of care having previously been reluctant
- Where Trusts had invested in additional support roles- staff on the wards felt less pressured, patients appeared less anxious and relatives expressed positive feedback
- All Trusts had strong Executive commitment and leadership which transcended down to middle management and senior clinical staff

Summary

It is imperative that people with dementia in hospital receive adequate nutrition and hydration. This needs to be considered 24 hours per day and throughout the hospital, including the emergency department and be personalised. Carers can play a key role to support this, but many people will not have a carer with them, therefore other forms of support need to be in place.

The challenge in supporting people in emergency departments is evident and the network appreciates how busy hospitals are and how challenging it can be to consider the holistic care of all patients at all times. The review was undertaken with the patient as central with the aim of providing Trusts with reflection and ideas on how small changes could make a difference to the experience of patients and carers. If the experience of users is good, the working environment and outcomes are more positive. The network wants to acknowledge the excellent care witnessed and the degree of commitment and enthusiasm displayed by staff- in particular nursing staff. The following two key reflective points are offered as a way in which Directors of

Nursing can consider what small steps could be taken to further improve the patient experience within their own Trusts.

Two take home messages:

It appeared that the majority of older patients in emergency department were unaccompanied

During mealtimes on wards good practice was witnessed – this was not the case outside of meal times

Next steps

The London Directors of Nursing are asked to consider the benefits of this work and where a focus could prove helpful going forwards. Possible outcomes from this work and ways to share learning could include the following

- Clinical lead asked to share her experience and impact of carer engagement open visiting/carer involvement.
- Trusts with initiatives around volunteers can share their experiences
- Those with enhanced carers can share the progress, planning and implementation of the same.

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