

Improving outcomes for people with dementia during a hospital stay

Background

People living with dementia experience vastly worse outcomes than those without a cognitive impairment when admitted to hospital. They are more likely to suffer falls, become dehydrated, malnourished and experience greater anxiety and confusion. They therefore tend to stay in hospital up to four times longer than average, and the majority are unable to return to their own homes when discharged. The most vulnerable have just 3% chance of having their needs met.

When healthcare professionals are aware of a person's needs and preferences, of the things that matter to them, not only can they avoid traumatic mistakes but they can also build a relationship with that person. Where a relationship exists empathy can develop which leads to an improvement in the standard of care. Better care can lead to an improvement in outcomes such as an increase in the number of people able to return to their own home, which reduces the amount and therefore cost of support required, as well as enhancing the person's quality of life.

Mycarematters is being developed to provide a way of making available a person's needs and preferences to hospital staff in a simple and timely manner. It is an online platform where a person or their carer can upload the information they want healthcare professionals to know about them as a person. They are guided through about 20 questions, providing information about their dietary preferences, their mobility needs, level of assistance required for personal care etc. and have the opportunity to upload photos and details of two emergency contacts. On submission of this information they are provided with a Mycarematters code.

Hospital staff can use the code, together with a person's name and date of birth, to view and print out a person's Mycarematters record.

Aims

To establish whether the provision of a person's needs and preferences via an online / printed out set of information can make a difference to the outcomes they experience during a hospital stay.

Methods

The trial is being run in the rehabilitation wards of two community hospitals in Sussex where it is estimated 50% of patients usually have some form of cognitive impairment. We are inviting patients, or carers on their behalf, to store their needs and preferences on an online platform called Mycarematters, working with them at the bedside to complete this. This involves setting up an online account and going through a list of questions, loosely

following the set of information recorded on the paper-based Remember-I'm-Me Care Charts that have been developed and refined during the past 5 years. This information is then being accessed by the hospital staff, printed out and filed in the patients' folder that is stored at the end of their bed. The information is visible to all hospital staff, and the file has to be looked at at least once every two hours when staff do a comfort round.

Results

The trial is ongoing and in addition to collecting qualitative evidence relating to any change in the wellbeing of patients, their families and the staff, the following outcomes are being measured:

- Reduced length of stay
- A reduction in complaints
- Higher uptake of the recording of personalised information using this system in place of the current paper versions.
- Increased uptake of the use of personalised information to inform care among staff in the pilot services.

Conclusions

From anecdotal evidence collected to date, we are confident that an improvement in the provision and quality of information about what matters to a person, and where staff act on that information, will result in improved outcomes for people with dementia undergoing a stay in hospital.

Limitations

A facility like Mycarematters will only work if a) hospital staff are aware of its existence and b) that hospital staff understand the importance of knowing about the whole person and the impact it can have on the quality of care they can provide.

Reg's Story

Reg is 94 and lives with his wife Betty, who is 92. They have been married since 1944, when Reg was given two days' leave from the Royal Marines to marry his sweetheart. Betty explained that Reg is regularly admitted to hospital with kidney infections because he doesn't drink enough, and that makes him unsteady on his feet and he becomes very confused and even delirious.

In providing the information to complete a Mycarematters record for Reg, Betty explained he'd already fallen out of bed twice whilst in hospital. At home he always has his walker parked by his bed so he can get to the bathroom without help. That's not been happening in hospital so we asked Betty if she'd said anything about his walker to the hospital staff. She hadn't and it was clear that she didn't want to interfere, it was not her place to do so. But she was quite happy for it to go on Reg's Mycarematters record.

This was not the only time people demonstrated an expectation that hospital staff know best, that they didn't want to waste their time with seemingly innocuous information. By generating a Mycarematters record in advance, whether anticipating a hospital stay or not, those issues are sidestepped altogether.



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