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Carers' perspectives on hospital dementia care

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Medical Crises in Older People: a NIHR research programme 2008-2013
And
Better Mental Health: a SDO research study 2008-2011

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Workstream 1: towards improving the care of people with mental health problems in general hospitals. Development and evaluation of a medical and mental health unit.

Workstream 2: Development and evaluation of interface geriatrics for older people attending an AMU

Workstream 3: Development and evaluation of improvements to health care in care homes

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Summary

The authors describe their experiences as carers of parents with dementia, including hospital care and the Medical and Mental Health Unit evaluated in the MCOP research programme. They provide reflections on their experiences and what they have found out since. The purposes of this paper is to provide a personal story that helps illuminate the research and outputs of the MCOP programme, to support education, and to challenge policy-makers, commissioners, clinicians and researchers. The paper is based on a talk given by the authors to an open conference in Nottingham on 26th April 2013, at which findings from the MCOP Medical and Mental Health workstream were presented.

Our story and our parents' stories

We are two of three children whose parents were affected by dementia. Our brother does not live locally and is in full time employment. We have been involved in the care of our parents at varying levels of intensity for 15 years. Mother, aged 89 died May 2011 and Father aged 92, in August 2012.

Mum

Mum's behaviour began to change in her 70s. She gradually became disengaged from what had been her interests. She gave up knitting and sewing, and she became more and more belligerent and erratic. It occurred slowly at first but gradually the pace of deterioration increased and we began to realise help was needed. Our maternal grandmother had dementia too. Father's reaction was often anger and it was all very difficult. By 2005 we decided to ask the GP to visit and his initial reaction was that Social Services might help. My sister suggested that maybe what was required was a diagnosis. The GP acted swiftly and a psychiatrist visited their home within weeks gave a diagnosis of dementia and set in train assessment at a day centre and in turn introduced the wonderful Jack Dawe ladies. Jack Dawe is a specialist dementia home care service in Nottingham. The flexibility of help the scheme provided was one of its biggest assets. During this time we, as carers, were kept afloat by Jack Dawe. It had a multidisciplinary team that supported and were accessible to the frontline care staff.

During the time Mum was supported by the Jack Dawe ladies, she had cause to be hospitalised. We both felt somewhat frustrated at the number of times an explanation of mum's dementia had to be given to hospital staff and mostly we felt we were never really listened to. As a result we never felt that Mum was assessed as a whole person. Later, Father was persuaded that the time had come for further help and Mum was accepted by a local care home in July 2010, just under a year before she died.

One of us was a Community Pharmacist, and the other had a degree in Food Science, which included some physiology, so we understood the basic language and were reasonably confident to ask and discuss. Throughout our experience we have often commented to each other "how do other people cope without these skills?"

Father

Shortly after Mum had died, in September 2011, Father rapidly declined. We detected the change, and an appointment at the GPs was made. We had to push hard for Father to be referred to the psychiatrist to be assessed as we were very aware that it can take months to get an appointment. We both found the reluctance difficult, as we understood that early diagnosis is recommended. He was seen in January 2012. In the interim, Father's behaviour deteriorated quite severely but without a diagnosis the correct help could not be accessed and we were not able to register him on the waiting list of care homes specialising in dementia care. Father was becoming totally irrational and unsafe. In fact, just before Christmas 2011 we had to seek advice from the local psychiatry service on a Friday evening which resulted in the administration of some emergency medication which calmed Father and restored the situation to a manageable level and we got through until the holidays were over without having to resort to calling the emergency services. We think this was only possible because of our assertiveness and prior pharmacological knowledge.

The consultation crept nearer but a fall at home led to a call to the emergency services. Hospitalization was the only option. The ambulance men listened and reassured and in the emergency department we felt Father was in good hands. They listened and gave assurance and confidence that he would be treated respectfully and appropriately. However, we worried that once in the hospital things might not go so smoothly. Father, like so many elderly people had a list of malfunctioning parts. Also we knew that his mental health had deteriorated. He was sent to the admissions ward and then on to the Medical and Mental Health Unit. We work as a team so Margaret was the first to visit. She rang in amazement – "Kate this is good, do you know? I was approached by the ward sister she gently asked who I was and then she said I need to tell you that your Father has dementia and did I understand what that meant. She was lovely, Kate, I was able to tell her our situation and experience." When Kate first visited dad on ward B47 she was greeted by sister sitting by Father's bed. 'How are you?' she said. Kate also thought "This person understands dementia".

Having experienced dementia through Mum's long illness we knew Father's diagnosis was only a matter of time. The ward sister sat me down and explained that Father had been diagnosed with dementia. She asked what we knew about the illness. We told her quite a lot because Mum had had the same condition over 10-12 years until she had died the previous May. The ward sister encouraged us to talk, listened to our experience with Mum, how Father had coped magnificently, even learning to make bread and cakes to keep up the standards they were used to. It seemed very cruel that, four months after her death, he started to show symptoms of dementia. It was particularly hard that he himself recognised the symptoms.

The ward sister continued to listen to how we had coped thus far with support from our extremely understanding husbands and children. This illness affects not only the patient but their extended family, both physically and emotionally. Whenever we left home for more than a short while we made sure the other one was available to answer the phone. Margaret told the ward sister how just before Christmas she'd gone shopping but arrived home ten minutes later than planned which meant that her sister hadn't gone to the carol concert she was wanting to attend. Margaret spoke of how she'd gone to the local shops for about an hour one morning and came home to discover fourteen messages on the answer phone from Father all wondering where she was and why she wasn't answering. When she phoned he wasn't aware of the messages he'd left.

It was this last incident that made us realise we couldn't continue like this and although we had managed to find some paid help going into Father three times a day, it was not ideal and it wasn't solving the problem. The lack of diagnosis prevented the access to the real help we needed.

The ward sister said you can't carry on like this. It was something we both knew but for a professional to say it somehow made the decision to find a care home for Father easier. We visited the ward regularly. Ward staff were always calmly walking round checking if patients or carers needed help or advice. On one occasion, the ward sister walked up to me holding a patient's hand. She introduced me and explained that the lady was concerned her visitors hadn't arrived yet, all the time reassuring the lady they would be here soon but also making me aware that if I needed to talk about anything she was about.

The ward was calm and organised, where you felt both patients and carers were being cocooned with kindness and treated with total dignity and respect. The ward staff were obviously a well organised team and included the extended family in that team to ensure the best outcome for both the patients and their families and themselves. It became apparent that the staff knew and understood that most carers on that ward were exhausted and knew that a dementia diagnosis was only going to increase their stress levels but managed somehow to find the time and energy to care for us all in an individual way. We were comfortable and able to relax a little knowing that the staff not only understood the needs of the patient but that the carers needed the space and time to move on to the next stage of the journey.

Discharge began to be a real possibility and it was agreed that Father could not safely go back home but we were not rushed into finding a home for him. We again realised that the staff on this ward worked as a team, each professional an integral and respected part of the whole package. We found a home and, following the manager of the care home's assessment, all was set for discharge. We asked if it would be possible to avoid the discharge lounge (an area of the hospital where patients being discharged wait to be transported home so as to free up a medical bed a few hours sooner) and we were told that they discharge directly from the ward, which was another huge relief. They also accompanied him to the care home and this, we found hugely helpful. Our parents were married for 69 years and had lived in the same house all that time. We were confident that this change was best left to the professionals: both for Father, and for us.

Father left the Medical and Mental Health Unit restored, fit enough to continue being taken for a walk in the nearby park. His physical body was back in balance and his mental state was manageable in a home where 24 hour care was supplied. The support systems were all once more engaged, the outreach renal nurses and the physiotherapy all kicked in and we felt a huge sense of relief.

We began to relax a little and allowed ourselves time to reflect and felt that really in the scheme of things and amid the stories you hear we truly felt that we had been guided and supported and that Father and ourselves could not have asked for more. We knew that Father would never "get better" but it was as good as it could be.

Father was admitted twice more to the hospital both times following falls. Both times the care and assessment in A&E was thorough and appropriate but the following spell on the wards was a different story. It was so different that we were pushed into writing to the hospital to ask why in the same hospital could there be such different care. Not all wards used a multidisciplinary team approach which included us and Father as part of the team. Not all wards had a team where mutual respect was obvious, generating a working environment of relative calm in what is a highly charged environment. Not in all wards was there always someone to talk to and where the staff smiled at each other and always had time for their difficult and demanding patients. The reply to our initial letter explained that Ward B47 was a pilot research project with extra funding. Staffing levels were higher than on other wards and the research was taking place both to assess how to improve the care and to see if this would lead to a reduction in the length of stay and re-admittance to the hospital of patients with physical illnesses and dementia.

Our reflections

Dealing with people with dementia does not only require compassion, it also requires trained staff and enough of them to manage those extraordinarily difficult moments of irrational behaviour from stubbornness, forgetfulness and belligerence through to very disruptive and aggressive moments. We are concerned that to deliver patience and compassion for 12-13 hour shifts for 3 successive days is asking a great deal - we have seen care workers in tears in care homes in the community. We have to accept that good quality trained care is essential to cope with different problems arising on wards dealing with elderly people with multiple problems, combined with a dementia diagnosis. We all know that staff cost money, but this fact has to be faced.

In an ideal world we would clone the team on the Medical and Mental Health Unit and spread them liberally throughout the hospital but, failing and in addition to that, we would like to suggest the following, some of which might be considered to be a challenge:

- It is important to have a good and experienced ward sister, someone who can lead, motivate and show junior staff how it should be done.
- We also valued the approach of the doctors who were not remote and readily engaged with us and other carers.
- It would be helpful if social services on wards could have access to current information regarding vacancies in care homes, not to recommend, but to, at least, remove the need for time consuming and unnecessary phone calls. Carers of dementia patients are often themselves elderly. All are exhausted and in need of care themselves.
- We were lucky in that there were two of us, not exactly young and not always fit ourselves, but when it came to finding a care home we could both drive and having experienced Mum's care, we thought we knew what we were looking for. We also wondered what you would do if you were an elderly spouse having been told that 24 hour care is essential for your husband or wife. Where do you start? A list of bus routes could be available, so that people could work out if the location was easily accessible.
- It is an awful decision to make - deciding to put a loved one in care - without any guidance at all on what and where is out there. Speaking to carers on other wards, some had no idea how these facilities are financed and were very anxious to know how to access this sort of information. Health care professionals must remember that the carer is coping with information about the acute physical illness as well as having to deal with an emotional upheaval. A person to explain and talk through the options and access to a website where bed availability in care homes is logged would be hugely helpful. If this is reinforced with written information so much the better. It would speed up the discharge process.
- Having joined a PPI group and listened to other carers, we suggest the introduction of a 'passport scheme' to make life easier both in and out of

hospital. One lady said her husband liked a daily bath and that the change in his behaviour was remarkable when she managed to facilitate this. Another spoke of how her husband liked to stand up to eat. Having this type of information easily available alongside the usual medication list could make life better for the patient and easier for those caring for them in and out of hospital.

- Food can also be an issue. Arguments can arise when patients deny all knowledge of ordering the food they are presented with. Could a trolley service be introduced where patients are offered a choice and it is delivered there and then? We have seen this operating in the maternity unit and it seems to work OK there. Carers could also be involved here perhaps selecting food on behalf of the patient.
- Joined up thinking between in and out patient care is vital. Good communication between GPs, social care and hospital wards will lead to better care for the patient but also fewer hospital admissions and shorter stays. A hospital appointed community link professional within the hospital who can provide advice over the telephone would help. We found that the senior Jack Dawe ladies filled this gap within the community and we strongly feel that you cannot divorce the care in the community from that in the hospital.
- There have been many occasions when we were called to resolve a behavioural situation with one or other of our parents even within a care home environment. We lived relatively locally to our parents, there were two of us to share the burden, and we had husbands who have never said "Oh no, not again!" But imagine being aged 80, unable to drive, and with no family support. We have heard many say that "once the dementia takes hold, the family disappear, unable to cope." What will happen to those who do not have such able families?
- Care homes also need to be kept up to date with current research and provide accurate assessments of their capabilities. We were shocked and very surprised to be told by Father's initial care home that after his third hospital admission his risk of falling and other needs had become too great for them to cope with resulting in him having to stay in a hospital bed longer than necessary while we found yet another home.

- We found the specialist dementia home care service, Jack Dawe, to be invaluable and were dismayed when we understood that the senior level ladies were disbanded. The care offered was reduced. Funding was said to be the issue. We have now experienced excellence on a ward and we do not wish this to go the same way. The future is specialist dementia care in the community integrated with specialist dementia care in hospital. We all have to accept that it is trained professionals caring for people within the community and the hospital working together as a large team that will improve the care and deliver it with dignity and hopefully reduce the need for frequent hospital admissions.

Conclusion

We would like to thank the Medical and Mental Health Unit for the way they cared for Father and us and hope that the outcomes of the research learnt from this ward will be transferred quickly to other wards, care homes and the community.