

End of life care for people with dementia

October 2009

Foreword by the Chief Executive of Marie Curie Cancer Care

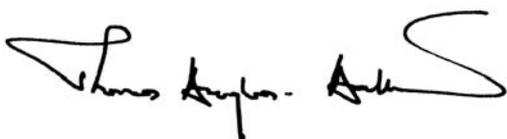
Marie Curie Cancer Care is delighted to have led this assessment of end of life care for people with dementia in the London Borough of Haringey. To do this work we have relied on a strong partnership with the local NHS Trust and Mental Health Trust, the local authority and the charities of the National Council for Palliative Care and For Dementia.

Dementia is a chronic progressive neurodegenerative illness which has a terminal outcome over an average range of 3 to 8 years (Xie *et al* 2008). Nationally, end of life care for patients with advanced dementia has been poorly researched, and service provision in the UK is generally poor.

This report is based upon: discussions at meetings with health service professionals who have cared for a wide range of people with dementia; conversations with carers of people with dementia; and an analysis of the histories of care received by a small sample of people with dementia who died in Haringey between May 2008 and March 2009. The findings enrich our collective understanding of the experience of care for a vulnerable and growing number of people as well as those who care for them and should help to inform future planning of joint service delivery.

It is striking that caring for people with advanced dementia is often punctuated by significant crises. During these times of crisis there is an urgent need for support and carers frequently turn to emergency and acute hospital services for help. This help often triggers an emergency admission that can lead to expensive and inappropriate interventions that take the individual away from their familiar surroundings and those who usually care for them. To improve care at the end of life, we must learn how to ensure care needs are anticipated before a crisis occurs and services are coordinated so that they respond appropriately.

The scale and complexity of caring for people with advanced dementia is of concern to us all and will require innovative and compassionate solutions, based on a robust understanding of need. We will use these examples to inform our ongoing research and development work and identify those changes that might have the most potential for improving care.



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Project team

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Acknowledgements

We would like to thank the health and social care staff, working throughout the London Borough of Haringey, who gave us their time to be interviewed or participate in our focus group meetings. Our local health and social care commissioners have been very supportive of this project and we also thank the steering group for their input. Most importantly, we thank the carers who had been recently bereaved and who generously shared their experiences of caring for a person with dementia and provided us with their personal and enlightening insights.

About the Marie Curie Palliative Care Research Unit, University College London (MCPCRU)

The MCPCRU is based in the Department of Mental Health Sciences at University College London (the Royal Free Campus). The unit is expanding rapidly, reflecting the commitment of Marie Curie Cancer Care to supporting high quality research in end of life care which will lead to improvements in care for those affected by advanced progressive life threatening illnesses including cancer through the implementation of evidence based practice. Staffed by a strong expert team of palliative care research specialists including health psychologists, research nurses, statisticians, a health economist and systematic reviewer, the unit provides leadership to create and foster an active research culture throughout Marie Curie Cancer Care, and ensure that there is effective dissemination and utilisation of new knowledge both within the charity and beyond. The unit has established effective collaborations locally, nationally and internationally. Its main research themes include:

- Evaluation of interventions
- Clinical and cost effectiveness of innovative practice
- End of life care planning
- Continuity of care
- Spirituality
- Assessment of psychological need
- Rehabilitation in advanced diseases
- Patient and carer palliative assessments in advanced dementia
- End stage renal disease, in particular maximum conservative management
- Palliative care in other advanced non-cancer conditions
- Cochrane systematic reviews

Executive summary

As our population ages, the number of people dying who have dementia will increase rapidly. Nationally and internationally it is acknowledged that care for this client group is poor. Overall the quality of end of life care available to these patients requires improved co-ordination both nationally and, as indicated through this project, locally in Haringey across health and social care agencies.

For this project in Haringey our methodology included an audit of a small sample of nine case notes, interviews with a small cohort of seven carers of people with dementia who had recently died and a series of focus group meetings and interviews with professionals to enable a detailed pathway analysis for this patient group. It is important to note that the statutory partners (NHS Haringey, Barnet Enfield and Haringey Mental Health Trust and Haringey Council) work with several thousand service users / patients, including those that have been diagnosed with dementia, at any given time, and that there are approximately 16,000 informal carers in Haringey.

The objectives of this project were to:

- Identify key issues of importance and concern to patients, carers and services
- Identify any barriers for dementia patients and their carers in accessing good quality end of life care
- Scope existing services in Haringey for this patient group
- Suggest cost effective recommendations to enable improved care pathways and outcomes for people with dementia at the end of life

We identified key themes and recommendations that fell under the following categories:

Pathway of care: There is a need for a holistic dementia care pathway in the borough, to support staff in giving appropriate interventions at times of crisis, increase preventative services, and reduce inappropriate admissions to an acute hospital. Care for people with dementia requires greater co-ordination, and raised awareness and understanding among professionals of the range of services available. Some people with dementia appeared less likely to receive good palliative care and their carers received limited support.

→ **Enable the identification and implementation of a local dementia care pathway, spanning early diagnosis to the end of life**

Impact of hospitalisation: Admission to the acute hospital (where up to 50% of patients on geriatric wards will have dementia) was detrimental to patients with advanced dementia and stressful for their carers. Hospitalisation was seen as being the only option in times of medical and social crisis. Acute hospital staff appeared not to have sufficient training and skills to provide good end of life care to people with dementia, with carers often having to provide basic nursing care. Economic analysis suggests these admissions are not cost effective and in many cases unsuitable.

→ **Enable adequate co-ordinated pro-active community care to avoid inappropriate acute admission and deaths in hospital so that a person with dementia can be cared for at the end of their life in a familiar place of care**

→ **Ensure that acute hospital staff receive continuing training and support in caring for people with dementia**

Financial implications: Costs from a commissioning perspective were an average of £25,000 for each person with dementia in the last six months of their life of which 18% of these costs were due to acute hospital care based on a review of nine cases.

Advance care planning: (*definition: a process of discussion between an individual and their care providers; it enables a person to make clear their wishes for future care*) Advance care planning in the borough would appear to be rare, but it is important to note that this is not dissimilar to the national picture. Many staff were concerned about medico-legal action if they *did not* send someone to hospital or attempt resuscitation. Advance care planning should be carried out earlier in the disease course and this is another reason for the implementation of a dementia care pathway.

→ **Enable people with dementia and their carers the opportunity and support to discuss and document advance care plans**

→ **Ensure that care home staff are trained and supported so that they feel more confident in adhering to advance care plans**

Impact on carers: The seven carers interviewed indicated they were often in poor physical health themselves and stressed and burdened by their role and this is in line with national and international findings. They found the array of services available was not straight forward to access at the times they needed them, reporting that it felt at times 'confusing' to know who to contact. This was magnified at the end of life where health and social care needs increase rapidly.

→ **Enable patients and carers to benefit from a single assessment process**

→ **Improve the visibility amongst professionals and carers of the services available to people with dementia and their carers**

Skills and training: A wide range of health and social staff came into contact with patients with dementia and many staff groups reporting they needed additional knowledge and skills to provide better support for this patient group.

→ **Ensure that staff in health and social settings who care for people with dementia have appropriate training and support**

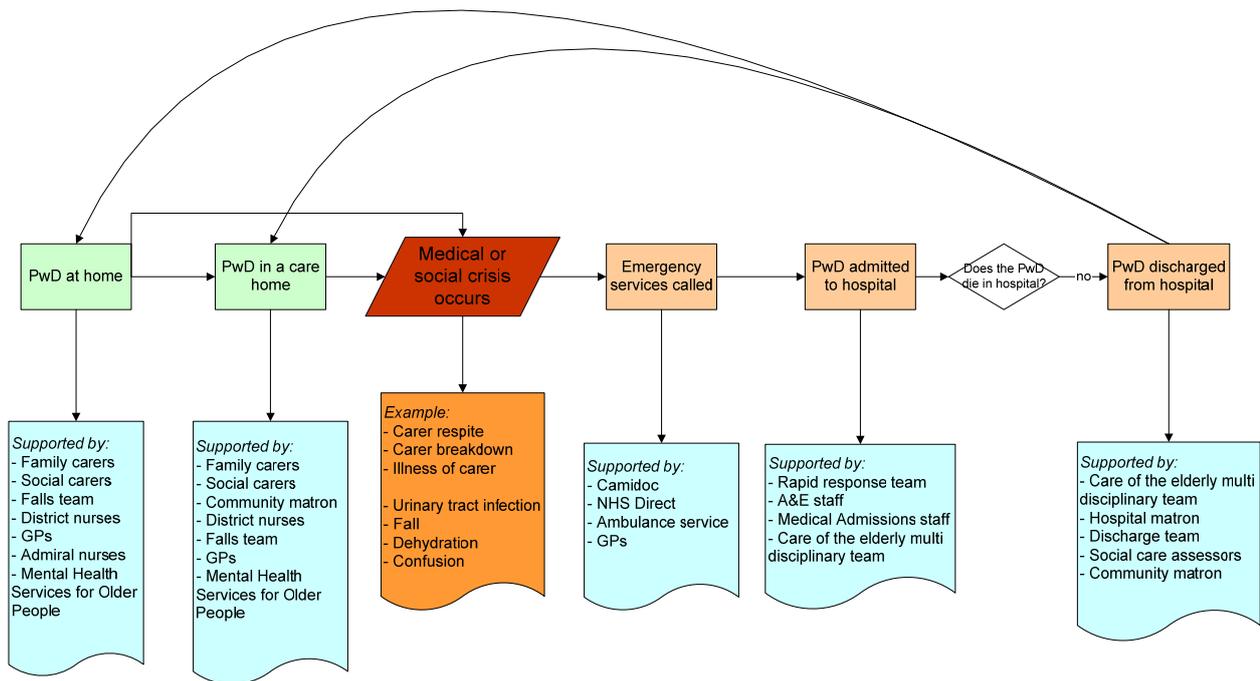


Figure 1: Typical example of the end of life journey for a person with dementia

This figure summarises many of our key findings. It shows the many different health and social care professionals who may come into contact with a person with dementia (PwD). Whilst some families were involved with several services and agencies, there appeared to be a clear need to improve connectivity and coordination between them.

Examples of good practice found during the course of the project include:

- The Community Matron employed by NHS Haringey to support residents in residential and nursing homes had improved the links between health and care home staff, resulting in better communication, easier access to medical advice and in many instances reducing the need for hospital admission
- Carers spoke highly of services such as the Memory Clinic, Admiral Nursing and the Community Palliative Care Team
- The Gold Standards Framework was being piloted in four care homes in the borough
- Haringey Adult Services Day Opportunities Centres for people with dementia were highly thought of, and their programme included carer meetings that were available to their carers after the death of a person with dementia

Conclusion

The time at which a medical or social crisis occurs for a person with advanced dementia and/or their carer(s) is a pivotal point when, if appropriate services were available, the person with dementia could remain in their familiar place of care until the time of their death.

With timely support in the community, it would be possible to prevent some crises occurring, or in the event of the crisis happening, provide an intervention that would reduce the need for a hospital admission. Our findings indicate that episodes of hospital care negatively affect the health and the quality of life for people with dementia, and that frequently the reason for admission could have been appropriately treated in the community. Evidence is emerging from other cities that where rapid response community teams have been introduced it has led to a substantial reduction in end of life hospital admissions – as these services offer a co-ordinated and proactive, rather than reactive, service model.

Whilst many of our findings reinforce those of the recent National Dementia Strategy and End of Life Care strategy, we also suggest that small changes to local health and social care services could significantly improve end of life care for people with advanced dementia who live in Haringey, as well as provide potential cost efficiencies, and greater value for money. This is particularly important in the context of public sector spending assumptions in the short to medium term.

Introduction

Over the last 10 years there have been great improvements in the quality of end of life care available for people with cancer. Marie Curie Cancer Care has investigated the needs and constraints for accessing end of life care for a number of patient groups, for example, those with cancer or end stage cardiac failure. Along with a number of partners it was felt to be timely to undertake a review of end of life care for people with dementia. Currently, 700,000 people in the United Kingdom have dementia and our ageing population means that one in three of us will die whilst suffering from dementia. The recent national End of Life Care and Dementia strategies (Department of Health) have highlighted how people with dementia often have poor access to good quality end of life care. It is estimated that in the London Borough of Haringey 1,579 people have dementia. Haringey is economically and socially polarised, with higher levels of social deprivation in the east of the borough. Haringey is also one of the most ethnically and culturally diverse boroughs in the country, with over half its population originating from a black or minority ethnic background. The borough is served by a number of acute hospital trusts, a mental health trust and numerous residential and nursing homes; community services are provided by the London Borough of Haringey Council.

Aims of the project

This project aimed to identify the major barriers for people with dementia and their carers in accessing good quality end of life care and suggest cost effective ways of enabling improvements based on review findings.

Methods

To undertake the scoping and data retrieval, the project team used a method adapted from the Marie Curie Cancer Care Delivering Choice Programme (<http://deliveringchoice.mariecurie.org.uk>). Through in-depth interviews with carers and service providers, a detailed case note audit and pathway analysis we have identified key issues of importance and concern to people with dementia, their carers and staff in Haringey.

Carer interviews: Seven carers who had recently been bereaved were interviewed to discuss their experiences of supporting a person with dementia in the last six months of their lives. Interviews lasted approximately one hour and usually took place in their home. Two wives, three daughters, one son and one key worker in a care home agreed to be interviewed. Twelve people were approached.

Focus groups: Focus group meetings were held with the palliative care team, District Nurses, care home managers, hospice staff, Adult Services care managers and Admiral Nurses. One to one meetings were held with local GPs, staff from North Middlesex Hospital, London Ambulance, CAMIDOC (the out of hours service for the NHS in Haringey), Barnet, Enfield & Haringey Mental Health Trust, a care agency, Asian Carers and a Community Matron. The purpose of the meetings was to identify their involvement in caring for people with dementia and to discover areas both of good practice and for improvement.

Case note audit and health economic analysis: The medical records of nine people with dementia who had died in the preceding nine months were reviewed. These were purposively sampled by gender and ethnic backgrounds. The information was retrieved from a variety of sources including hospital and social care records. Information regarding their health and social care received in the last six months of life was collected and collated. Despite receiving the necessary permissions we were not granted access to individual general practice patient records and thus we assume that some important data may be missing. Costs of purchasing care for these people were estimated over the last six months of life, including costs related to accommodation, provision of formal care, hospital admissions, contacts made with community health service providers, equipment and medications prescribed. Costs were estimated from the perspective of the UK Department of Health and Local Authority Adult Services Departments.

Data analysis and synthesis: Material from the detailed interviews and focus groups was transcribed and coded thematically by two members of the project team. The project team then identified the five key themes. We provide evidence for where services are working well, and where improvements are required. The steering group generated many of the recommendations for improving care.

Project management and oversight: The project steering group met four times during the study and helped to develop the protocol and support the methodology in providing suggestions for people to participate in the study. The group included a wide range of local professionals and key stakeholders - including a Palliative Care Consultant, a District Nurse, a GP, Adult Services and Primary Care commissioners, a representative from Alzheimer's Society, an expert by experience, a Community Matron and a Consultant from Mental Health Services for Older People. Before commencing the work, we obtained the necessary local audit/ ethics committee permissions to carry out the study.

A detailed methodology and audit resource pack will be made available on line via the Marie Curie Cancer Care website <http://www.mariecurie.org.uk/dementiaproject2009> so that this data collection and analysis approach can be replicated in other locations, if desired.

Pathway of care

Key messages

- The need to increase knowledge and awareness amongst professionals of the services available to people with dementia and the referral criteria and pathways
- The need to improve channels of communication between care services and agencies
- Services tended to be reactive, with evidence of crisis management in the delivery of care
- The need to improve co-ordination and continuity of care – to support carers in accessing services and routine follow up care
- A difficulty with predicting the disease trajectory and time of death

Supporting evidence

In the terminal stages, people with dementia often have complex medical and social needs that should receive co-ordinated input from a number of agencies. In Haringey, co-ordination of care often was not strong, having particular implications during out of hours (i.e. overnight and at weekends) where care was being provided by professionals who might not be aware of the dementia diagnosis. Many agencies within the borough were providing end of life care to people with dementia – without necessarily being aware they were doing so. Agencies having frequent contact with this group included:

District Nurses: By the time referrals for people with dementia were made to District Nursing teams they would have multiple problems. Physical health problems were the key criteria for District Nurse involvement. District Nursing teams used the Functional Assessment of the Care Environment for Older People (FACE) tool and incontinence pathways with no separate tools specific to dementia assessment or routine recording.

Routine GP services: Frequently, even in people with advanced dementia, no formal diagnosis would have been made. District Nurses would recognise the symptoms and flag their assessment to GPs but this appeared often not to be followed up further. Registers for the Quality Outcomes Framework (QOF) for dementia and the Gold Standards Framework (GSF) appeared not to be cross-referenced and did not record the severity of the dementia. Local GPs would value having a national coding system within READ to record the severity of dementia.

The 999 ambulance service: Ambulance services were frequently called to see people with dementia, often responding to a 999 call at night. The person with dementia did not necessarily require an admission to hospital but the care was breaking down. There were three frequent scenarios:

1. The person with dementia had a care package but it was not fully meeting their specific needs
2. There was an adequate package of care but the carer could no longer cope
3. No package of care – the carer was managing alone

Scenario 3 was the most difficult to deal with. The crew would probably admit the person with dementia to hospital (easy option) as, out of hours, the alternatives were very limited.

Out of hours GP service (CAMIDOC): CAMIDOC was contracted to supply out of hours services for Haringey residents between 6.30 pm and 8.30 am every night and all weekend. They employed approximately 350 doctors on a sessional basis throughout a number of London boroughs. They did not have access to GP computer systems or the District Nurse database in Haringey and relied on information from the carer and any previous out of hours contact recorded within on their own systems. A report was provided to the patient's GP the following day. They did not have strong links with community teams.

Care agencies: Social care was provided by both private agencies and Adult Services within the borough, through home visiting and day care services.

Comments

"We probably do not know enough about where or who to refer to." *District Nurse*

"Lots of resources, it is just knowing where they are – no direct paths to the right place." *Care agency*

"Just as you get used to a service in Haringey, it is gone again." *GP*

"There are not enough community matrons." *Acute staff*

"We are frequently required to attend the home of patients in the evening when things go wrong." *District Nurse*

"NHS Direct has a low threshold when they refer persons to another health provider, this can play a part in patients being admitted to hospital unnecessarily." *GP*

"Need to change approach. Since inception of the Care Quality Commission, death is seen as a failure. At the end somebody panics and the patient is sent to hospital" *GP*

"It is not easy to get a patient with dementia through the Continuing Care panel – it is difficult to know when they are at the end of life and it frequently comes as a shock when they die" *District Nurse*

The following cycle was typically described by a local GP and by care home managers:

The person with dementia starts refusing food and drink, becomes dehydrated and develops a chest infection. Care home staff become anxious and feel obliged to send the resident to hospital as there is concern that the GP and/or care staff will be held liable if they do not do so. The hospital staff initiate intravenous fluids and explain to the family that the cause of the problem is dehydration. The family have a sense of guilt about placing their relative in a care home and question whether the care staff are able to provide the appropriate support. Hospital staff do not have the time for 1 – 1 patient care. The patients with dementia are being handled in an environment and by staff who are unfamiliar to them. The hospital staff are anxious to discharge the patient as soon as possible. The person with dementia returns to the care home or an alternative care setting. Care home staff spend a lot of time to try and get the resident to drink and they pick up a little but staff cannot give this level of attention continuously and therefore the person with dementia becomes dehydrated and prone to further infection and the cycle begins again until the patient dies - usually in hospital.

The coroner and police at the time of death: Death often occurred out of hours and this was particularly distressing for carers. There were times when insufficient information to enable the GP called to the scene to say that the death was expected meant they had to call the police to investigate the death.

Case study: "The Saturday my father (aged 96 years) died, only one of the carers turned up, so I helped to wash and dress him. When we were done at 10am, he stopped breathing. The carer said she had to call an ambulance – it was the procedure. What do you do when someone dies? The ambulance came and called CAMIDOC and said it was not an expected death – they did not 'do' unexpected deaths, so the police were called. The police doctor was not available until 7pm that night so the two police men sat outside our house in the police car for a couple of hours. CAMIDOC had last seen father on the Tuesday and eventually 'found their records' and agreed to come and confirm the death; the police then went away." - *Carer at home*

Dementia is not a recognised primary cause of death. It was rarely mentioned on death certificates and is only admissible as a secondary cause of death.

Case study: "The GP wrote the death certificate with Alzheimer's disease as the cause of death. The registrar said he would not accept this – Alzheimer's could not be the cause of death, so we had to get the GP to rewrite the certificate." – *Carer*

The trajectory of decline in people with advanced dementia: Many professionals remarked on how difficult it was to know when the person with advanced dementia is entering the dying phase.

Examples of good practice

- The Community Matron had good links with Adult Services care managers: the role had made a huge difference to staff and residents in care homes "it is the greatest improvement in residential care in the last few years." - *Adult Services Manager*
- "Admiral Nurses (*specialists nurses trained to support carers and people with dementia*) are fantastic - if you are in their system." - *GP*
- "The memory clinic gave the diagnosis...and leaflets about dementia and what the likely future held for disease progression" - *Carer*

Recommendations

The implementation of a holistic and multi-agency dementia care pathway so that people with dementia can receive an early diagnosis, support and information about what to expect; where professionals are clear about which agencies should be referred to at which time. This will improve the quality of end of life care for people with dementia.

"The loss of the Health Advisors for the Elderly has had a detrimental impact for people with dementia"

Palliative care team

"Did not realise that Macmillan nurses could visit non cancer patients." *Residential care manager*

"It is difficult to predict when a resident is going to die - those who you expect will return following an admission, do not and those that you think you will not see again, come back." *Care home staff*

"Difficulty in enabling staff, carers and GP to acknowledge that the person with dementia is in the terminal phase and when it's not clear, there is a tension about what to do or not to do in the event of a sudden change in the patient's condition." *Community professional*

"A Palliative care crisis intervention team is needed in London to prevent unnecessary end of life admissions." *Ambulance manager*

"Death had been expected for many years but not more so that week than any other. I had a prayer in my bag every time I was away - just in case - the possibility was with you all the time." *Carer*

"There is a gap in services available because of no rapid response team to support residents/staff when crisis occurs." *Community professional*

Impact of hospitalisation

Key messages

- Admission to hospital can appear to carers and emergency response teams to be the only option when a crisis occurs
- In acute hospitals at any one time, approximately 50% of patients over the age of 75 years having unplanned medical admissions will have dementia with 25% being in the advanced stages – this was confirmed by a recent audit carried out in a local hospital ward
- People with dementia can deteriorate markedly during a hospital admission
- Hospital staff find it difficult to cope and respond to the needs of people with dementia, causing a reliance on family carers for basic nursing care e.g. feeding and management of agitation
- The environment is not therapeutically conducive to people with dementia, particularly those who are dying: acute wards are busy and noisy
- The processes and pathways of care in an acute hospital provide little continuity of care
- A cycle of repeated admissions commonly occurs in the months leading up to death

Supporting evidence

Repeated and possibly inappropriate admissions at the end of life: Admission was normally the result of a crisis and a 999 call. People with dementia would enter the system via an initial assessment in A&E, and then be placed in the admissions ward, with transfer to a medical ward in the acute hospital if no elderly care beds were available, followed by a subsequent transfer to an elderly care ward if/when a bed became vacant. The reasons for admission were frequently urinary tract infections, falls, confusion, dehydration, frailty and dementia, carer respite and where a care package had broken down. Care in a hospital setting was governed by process and could seem inflexible in its response to the needs of people with dementia.

Case study: "He fell at the care home and broke his hip. He was admitted to hospital but they did not know how to cope with him at all. I was told that he would be up and walking within one day, but seven days later he was still just lying in his bed. I was the one to encourage him to walk. I fought for him to be discharged as the hospital was not a good environment for him. By this time no one else was able to feed him. He was readmitted to the care home and I told the staff that I did not want him to be readmitted to hospital; I was visiting every day and he died shortly afterwards at the care home." - *Carer*

Difficulties in providing good quality end of life care on acute medical wards:

Acute hospital staff wanted to provide good quality care but were concerned they did not have the necessary skills and resources to manage people with advanced dementia:

- It is difficult for ward staff to support patients with dementia "who have no capacity to get themselves better." – *Acute ward staff*
- "It is not always possible to provide the 1 - to -1 nursing when it is needed. When 1 - to - 1 nursing is available it can depend on the skills of the nurse undertaking the task." – *Acute staff*
- "Care in hospitals for patients with dementia needs reviewing as staff are floundering. Hospitals are task orientated and resource limited." - *Admiral Nurse*

Poor outcomes for people with advanced dementia: A recurring theme that emerged from interviews with staff and carers was the detrimental impact that periods in hospital had on people with advanced dementia.

Comments

"Every time he went into hospital he deteriorated."

Carer

"Hospitals today are very different from even five years ago; the emphasis is on rapid treatment and discharge – with lots of people looking after each patient, preventing continuity of care."

Acute staff

"Usually return from hospital in a worse state – mentally disrupted and with sores."

District Nurse

"The hospital layout does not lend itself to wandering or agitated patients – wandering patients get a very 'raw deal'."

Acute staff

"Need a specialist in the hospital who can coordinate care for dementia patients."

Admiral Nurse

"Send an elderly patient with dementia to hospital and they will probably die.' A&E is not the place for palliative dying patients."

GP

"He had no dignity – one day I came and found him with no clothes on his bottom half, no slippers and stood in a pool of water – he was trying to pour himself some water from a jug with a lid on into a polystyrene cup and couldn't get it right. No one helped him to eat or drink."

Carer

The medical cause of a hospital admission could be resolved in a relatively short period, but sometimes if a comprehensive or new health and/or social care package was needed to be put into place then it could take longer to be put in place prior to the patient's discharge. This could involve the hospital and community matrons, social worker, district nurse and the community psychiatric nurse. In that time it was possible for other issues to arise, associated with the dementia (e.g. inability to self care, feed and drink, mobility problems) and patients would be prone to catching further infections.

"People with dementia are admitted to hospital because there is no where else for them to go... hospital is not a good place for them as they are not in familiar surroundings and risk hospital acquired infections." - *Acute hospital geriatrician*

An additional burden on family care givers: Ward staff relied on carers to provide insight of the behaviours and needs of the person with dementia during assessments and to provide basic care such as feeding and drinking. They also relied on information from the community matrons and for details of medications from the patient's GP and this was not always easy to access.

Case study: In all the many admissions her husband made to hospital, she only met one member of staff who showed any compassion – a young new nurse. "There was an absolute absence of compassion." She would find tablets left in a pot by his bedside which he obviously was unable to take for himself. Hospital staff looked to her to care for him while he was in hospital. - *Carer*

Examples of good practice

- "When a patient dies 'it is an honour' to be present - we will call the family and make the patient comfortable. We put them in a separate room if possible."- *Acute ward staff*
- A bereavement booklet was provided to the relatives and close carers of patients who die in hospital.
- Plans were underway to enable an alarm system to be triggered if a wandering patient attempts to leave the ward. Previously they relied on staff vigilance.
- A diabetic patient with dementia was admitted from a care home following a collapse because of low blood glucose. The rapid response co-ordinator visited the home to find out about her meal patterns and explain to care staff steps to take to prevent a further collapse and readmission.

Recommendations

- The provision of high quality and joined up support to family carers and care staff in the community to prevent hospital admissions
- Personal and pro-active case management for people with dementia who are no longer self caring and becoming increasingly frail
- The provision to carers of a suitable plan for their support

" The critical thing is back up from medical services when you need it" – *Adult Services manager*

"Patients with dementia have such high intensive needs."

Acute nursing staff

"The impact of cancer treatments seems to cause a rapid deterioration in any dementia symptoms experienced by the patient"

Palliative care team

"One thing in hospital that seems to work well is the palliative care team."

Admiral Nurse

"He had wandered from his ward -when the doctor tried to get him back he hit out. They got security in, sedated him and he slept for 24 hours with no food or drink - that was in the last three months of his life."

Carer

"The hospital could not deal with her as she was too noisy."

Carer

"They have no message to their brain of hunger."

Ward staff

"Such a great help if carers are willing to help with feeding."

Ward staff

"Hospital staff tried to cope with him, but they did not have the resources. He was asleep for most of the time, but when awake he was wandering."

Carer

"Hospitals are not familiar with dementia."

Carer

"It is very difficult to watch a patient deteriorate and there is not much that you can do."

Ward staff

Resource use and financial impact

Key messages

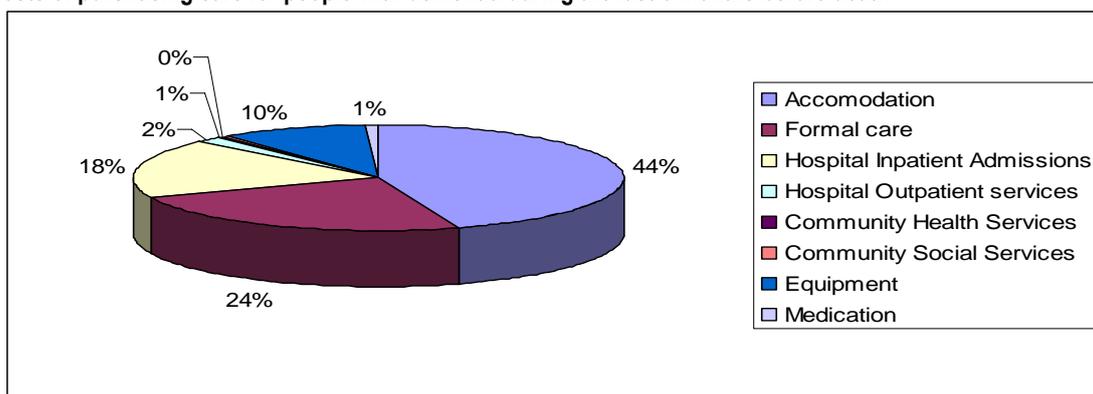
- The average cost of purchasing care over the last six months of life for the nine cases reviewed is estimated at nearly £25,000 per person with dementia
- Costs are higher for people with dementia in care homes and hospitals, than for those living at home
- Accommodation comprises the bulk of costs for people with dementia in care homes or hospitals, whereas formal paid care, hospitalisations and housing modifications make up the majority of costs for people with dementia living at home
- Hospitalisation represents almost 20% of the total average costs of care, and occurs more frequently among people with dementia cared for at home
- In the majority of cases reviewed, the people with dementia were admitted to hospital for ambulatory conditions that could have been treated within the community

Supporting evidence

Total costs of purchasing care

- The average total cost of purchasing care per person with dementia was £24,278 during the last six months of life (range £8,141 - £38,271).
- £5,105 (21%) of these costs were commissioned by the Department of Health including hospital inpatient admissions, hospital outpatient services, medication and community health services.
- £19,172 (79%) of these costs were commissioned by the council's Adult Services including accommodation, formal care, equipment, and community services.
- The average cost of purchasing care for people with dementia living at home was £19,854 per person over the last six months of life, whereas the average cost of purchasing care per person living in a residential/nursing care home or hospital was £37,029.
- By recognising the costs per person associated with informal care provided to people living at home, total costs of care were estimated to increase to £36,844 over the last six months of life (£38,704 for people living at home, and £37,029 for people in supported care).
- These results are comparable with recent research reporting the total annual cost per person with severe dementia to be £37,473 for people in the community, and £31,296 for people in care homes (2005/2006 values, Knapp et al., 2007). As the bulk of costs are likely to be incurred in the last six months of life, our estimates in 2009 values, based on small numbers are comparable.
- Figure 2 illustrates a detailed breakdown of total costs, and shows the majority of costs were associated with accommodation provided in a residential home or hospital (44%), or formal care provided at home (24%).

Figure 2: Costs of purchasing care for people with dementia during the last 6 months before death



Accommodation: Three of the people with dementia lived in supported accommodation, one in a residential home, and two on a NHS continuing care hospital ward. These accommodations were estimated to cost between £24,000 - £36,000 over six months per person.

Formal care: Formal care costs ranged between £1,433 and £16,811 depending on the number of carers and frequency of visits. For the three people with dementia with regular daily home carers, the cost of their formal care per person was approximately £15,000 over the last six months of life.

Hospital in-patient admissions: Inpatient admissions represented 18% of the average cost of care over the last six months of life. Five people with dementia were admitted to hospital at least once during the last six months prior to their death, three of whom died in hospital. Most people had two admissions, while one recorded three admissions. Length of stay ranged from two to 40 days, with an average of 12 days. All admissions were unplanned, requiring ambulance transport. The average cost of admissions over the last six months of life ranged from £5,651 to £9,956. The weighted average was £4,356 allowing for people without any admissions.

Reasons for admission: Reasons for admission were varied and are listed below, with the corresponding treatment received in hospital. In the majority of cases the people with dementia were admitted for conditions that could have been treated within the community.

Table 1: Reasons for admission to the acute hospital

Reason for admission	Treatment received
Not eating or drinking	IV fluids; abdominal ultrasound; catheterised
Constipation, lower abdominal pain, no mobility	IV fluids
Shortness of breath, cough, drowsiness - pneumonia	IV antibiotics and fluids
Acute on chronic confusion	Antibiotics
Poor oral intake, chesty, shaky	SALT assessment, IV antibiotics.
Pale, unresponsive, chesty cough, found unconscious	Nebuliser, IV fluids
Shortness of breath, confusion, pneumonia	IV antibiotics, nebuliser, CT head and neck
Shortness of breath, chest infection	IV antibiotics
Fall/head injury	CT head; IV fluids
Right leg swollen	Ultrasound and CT abdomen; Warfarin
Vaginal bleeding and reduced appetite	IV fluids; renal ultrasound

Equipment: A variety of equipment was used to assist with caring for people with dementia at home, including hoists, sliding sheets, transfer boards, a wheelchair, a stair lift, hospital beds, over-bed tables and pressure relieving mattresses; some families installed ground floor showers or stair lifts. Costs ranged between £148 and £13,000 (median £253; weighted mean £2,400, 10% of total costs).

Medications: Prescribed medications numbered up to 21 in the last six months before death, and cost an average of £189 per person with dementia (range £34 - £551, 1% of total costs). Antidepressants, protein pump inhibitors (PPIs), analgesics, hypnotics, anti-hypertensives, beta-blockers, statins and laxatives were the most commonly prescribed medications. The majority of medications were ongoing.

Community health services: Community health services cost an average of £159 per person. The main community health services accessed by people were District Nurses (2 patients), community mental health nurses (1 person) and Admiral Nurses (2 people).

Community care services (council): Home assessments were conducted by an occupational therapist for four people, and care packages and arrangements were reviewed by social workers for three people. As these services were not accessed frequently, or by all people, it is not possible to give an accurate estimate of average weighted cost in the context of the limitations below.

Limitations

- Findings should be interpreted with caution as they are based on a very small sample of patients
- We were unable to estimate what proportion of accommodation and formal care was self funded by families or the person with dementia and what proportion was funded by the Adult Services
- Permission to access GP notes was not obtained in the majority of cases. Accordingly we cannot be confident that all the services accessed by patients have been captured. Counts of community health and social services, and hospital admissions may be underestimated

Recommendation

- The generation of strategies which aim to promote the cost effective treatment of conditions in the community rather than in hospital. This would help reduce the overall costs of care as well as help maximise patient and carer health, wellbeing and quality of life

Advance care planning

Key messages

- Evidence that health and social care agencies need to increase the level of information and support provided to patients and carers; to understand and use advance care planning for people with dementia when they are considering end of life issues
- Staff do not always have the confidence to adhere to advance directives or resuscitation orders
- Care Quality Commission (CQC) regulations could create pressure to avoid deaths in residential care
- No universally recognised system for the transfer of information regarding advance care planning, advance directives or resuscitation orders

Supporting evidence

Advance care planning (ACP) for people with dementia (including for example 'do not resuscitate decisions') was rare in the nine case files reviewed, a finding reinforced by focus group discussions.

"It is the absolute bread and butter of our role to talk to the family about the patient's prognosis - we do not find that the family have previously had conversations with professionals in the community." - *Acute hospital geriatrician*.

It appeared that a Do Not Resuscitate status (DNR) agreed in hospital was not specifically transferred to community agencies other than mentioned within the GP discharge letter from the hospital. If ambulance services were called, they would attempt resuscitation in the absence of an advanced directive.

Advance care planning helps prevent inappropriate and distressing attempts at resuscitation of people with advanced dementia occurring:

Case study: In the last six months of life, her mother (aged 89 years) had breast cancer as well as advanced dementia – it was agreed with medical staff that her mother would not receive treatment for her cancer. One morning her mother suffered a heart attack at home. She was sitting on the edge of the bed and then rolled her eyes and fell backwards. The ambulance was called to the scene and ambulance staff tried to resuscitate her mother ("my mother would not have wanted it"). They worked on her for 20 minutes before stopping the resuscitation attempt. - *Carer*

Where an advance care plan was in place, it may not be acted upon

The reasons for this are complex. In an emergency situation, professionals and carers do not always have the confidence to adhere to advance care plans; many were concerned about potential litigation or charges of negligence. Thus the 'default' position was to attempt to resuscitate.

"Where there is a properly constituted Advance Directive then it would be honoured by ambulance staff. However people still called the ambulance. Relatives and staff became overwhelmed in a crisis." - *Ambulance manager*

Example: A wife panicked when her terminally ill husband collapsed and called 999 – based on the information she gave, she was advised to carry out CPR (Cardio-pulmonary resuscitation) while the crew travelled to her. However when it was realised that an Advance Directive was in place, the ambulance crew stopped CPR. - *Ambulance manager*

Even when advance care plans are in place in nursing homes, through the Gold Standards Framework, patients are still often transferred to hospital.

Comments

"What do you do when someone dies?" *Carer*

"People are loath to have the conversation about what to do when your loved one dies – do not call the ambulance service." *Ambulance manager*

"Advanced decisions – not round here." *GP*

"Important to get GPs to embrace the GSF and LCP – if patients are reviewed in a structured way other benefits will follow." *Ambulance manager*

"Have only known one statement of wishes." *Palliative care team*

"We were never asked what his wishes might have been. We had to make the decisions; he was not able to decide by then." *Carer*

"No one ever asked about resuscitation or not." *Carer*

"He had no will and did not have an advance decision or living will – nothing like that." *Care home key worker*

"My mother did not have spiritual needs in the last six months. My mother had nothing." *Carer*

"Ideally there would be a multi-disciplinary meeting between the GP and other professional carers with the family present to consider the person's future but there is insufficient time for the GP to do this for every care home resident." – *Community professional*

When advance care plans are in place they can be very useful

Case study: Prior to admission for an operation, her mother signed a DNR document. She had had frequent conversations with her daughter over many years that she would not want to live in a vegetative state. However she did not have a living will. For a number of years she was bed bound with advanced dementia and medical complications. At medical review meetings, the daughter suggested that her mother should be taken off those drugs that were prolonging her mother's life. Agreement was reached that her mother should be taken off drugs that were life extending but given drugs for pain. It was also agreed that her mother would not be given antibiotics if she caught an infection. It had been agreed that there would be no PEG feeding. The daughter had not discussed syringe driver feeding with the medical team and feared this would be the next step. However her mother died before this dilemma materialised. As a result of witnessing her mother's experience, the daughter has a living will in triplicate, discussed with her sons and held by her GP. - *Carer*

They can be used to open up family discussions and avoid conflict:

Example: A son started CPR on his terminally ill father and called the ambulance (while his mother/the wife was away from the home). When the ambulance crew arrived they found the son and mother/wife arguing over whether to proceed with CPR. - *Ambulance manager*

Example: "Carers face a constant dilemma. A man had dementia and heart problems. He was admitted to hospital often for his heart condition. His wife overheard staff say that they were not going to treat him as he had dementia but no-one was communicating directly with her." Her Admiral Nurse is uncertain whether she should be preparing the wife for planning ahead - for comfort care - or both? It is often not clear. – *Admiral Nurse*

Examples of good practice

- Consultants on the Care of the Elderly wards at the acute hospital were proactive in holding discussions with relatives of patients with advanced dementia when it is appropriate to institute a Do Not Attempt Resuscitation (DNR) status
- Training in the Gold Standards Framework for end of life care was being piloted within four care homes in the borough
- Without exception, staff who were interviewed all praised the support provided to patients by the community palliative care team
- Admiral Nursing teams do get involved in helping develop advance care plans – "we do, but perhaps not as much as we should."

Recommendations

- Staff caring for people with advanced dementia in local residential and nursing homes need additional training and support in the use of advance care plans (ACPs)
 - ACPs need to be discussed and considered early in the disease trajectory
 - Learning from Gold Standard Framework pilots needs to be implemented and supported throughout the borough
 - A model similar to the Palliative Care (PC) register should be considered:
 - The patient's GP practice notifies CAMIDOC that the patient is to be included on their PC register - this is immediately added to the CAMIDOC database
 - Status is updated regularly - a monthly email is sent by CAMIDOC to the GP confirming that the patient is remaining on the PC register
 - The patient remains on the PC register until they die or CAMIDOC are informed differently
- Such a register should link to the ambulance services

"Families do have to take some responsibility for initiating conversations with medical staff about the future progression of the patient's illness. However relatives have a hard time coming to terms with the idea that someone is approaching death."

Community professional

"If we had had prior knowledge of the patient, her condition and information stating the terminal stages of her illness, or a contact number we could have rung 24/7, then the resuscitation attempt would have been stopped very early on."

Ambulance manager

"GP is the trigger for enabling a resident to be included within the PC register. GPs are only inclined to think of this if the resident is suffering from cancer. Where a resident is in pain they will link to the PC team."

Community professional

"Relatively low input into terminal care package - our role is either to signpost or give a drug."

GP

"GPs are not really interested as dementia is not a disease they can 'fix'."

Care agency

"If the death goes well it is a privilege to be involved."

Care home manager

The impact on carers

Key messages

- Carers interviewed say they were frequently being asked to supply similar information to support staff and agencies
- Carers identified they had limited awareness of the services to which they are entitled
- Carer crisis may be caused by a breakdown in the care package
- Carers might be asked to make end of life care decisions on behalf of their relative with limited knowledge, understanding and support
- There is limited bereavement support for carers – both for relatives and care staff

Supporting evidence

Amongst the seven carers interviewed and in the focus group discussions, there were reported difficulties and confusion in accessing services: Carers reported they had to be proactive in accessing support – with limited evidence seen of routine follow up that might prevent a crisis. The system appeared to work reactively in many cases.

Case study: A carer described how 'nothing happened routinely' – she always had to initiate contact with services e.g. a District Nurse was scheduled to come and change her mother's catheter at regular intervals but they would not turn up as expected, so she would have to make contact about when they were coming with the knock on consequence that on the day of a catheter change, when care staff would delay getting her mother dressed until after the procedure had been undertaken, they were always uncertain how to manage the routine of the day. - Carer

Care packages did not always meet the needs of the person with advanced dementia or their carer: Many carers described the difficulties in dealing with the person's incontinence and failure to use the toilet properly, causing a lack of rest and sleep for the carer due, for example, to changing bed sheets in the night etc. Mobility problems, lack of insight or denial about conditions, reduced ability to communicate and relate to their family carers own needs, were issues which frequently impacted on the relatives'/carers' own health and well-being.

Case study: A daughter continued caring for her father with dementia at home, plus coping with her own illness and treatment for breast cancer. She found it very difficult that her father did not/could not acknowledge her own illness. No support was offered to her as the carer – "self help was the answer, there was no-one to turn to." - Carer

Adult Services were able to provide homecare support. However there was evidence that the time allocated for visits was sometimes not enough to undertake all tasks, such as getting the person washed and dressed. Home care agencies were not always able to provide continuity in care staff, hampering relationship building with the person with dementia, and meaning the family carer would be asked numerous times about their needs and wishes.

Day care support is also available within the borough, and is available seven days per week, with people more usually being offered three days per week.

Example: "Respite care is not easily accessible – there should be more choices available for carers and people with dementia. Marie Curie is only available in the last days/weeks of life. It would help people stay at home for longer if more respite was available and reduce the risk of emergency admissions. The system is too rigid, cumbersome and slow –we had a carer/person with dementia who applied before Christmas and they were told that it would not be possible until April 2009 (the new financial year) – and is still waiting!" – Admiral Nurse in May 2009

Carers of people with advanced dementia at times have significant needs of their own: Dementia is a chronic progressive disease placing huge and long standing demands and strain on close carers.

End of life care for people with dementia

Comments

"The stoicism of patients and carers is remarkable – I am always shocked at how far it has got before they seek help. The older generation are not the 'worried well'."

GP

"The impact on carers' lives is devastating." Admiral nurse

"Not a glamorous disease – become a social pariah."

GP

"Carers are more at their 'wits end'." Palliative care team

"Why has the dementia test not changed? – fine for those with IQ of 100, but takes no account of those with a high IQ. The diagnosis of dementia came so late." Carer

"It is a major issue for carers to support people with dementia at home in the palliative care stage." Adult Services manager

"My mother died five years ago – it is very hard not to be able to say goodbye. It creeps up on you, but five years ago I realised that my mother could not look after herself and her husband was covering for her."

Carer

Frequently the family carer is either of a similar age as the person with dementia and could also be suffering from health problems of their own or is an adult child who is in employment or with other family commitments.

Example: A man in his 70's with an 11 year history of dementia has been constantly looked after by his wife - "he is like a child, never out of her sight. Her own health is now deteriorating and yet she will not have treatment as she is unwilling to leave her husband to the care of others." - GP

"It can be difficult if the husband and wife are not with the same practice – it is not always easy to link up with other GPs to provide the support or care needed for both parties." – GP

Carers described significant difficulties in maintaining a job at the same time as caring for a person with dementia.

"Five years ago at the age of 55 years I gave up work to care for my father - it is very difficult to pick up your life again afterwards. I have not worked since." - Male carer

Carers have to make important decisions with limited knowledge or support

There were professional groups interviewed who had not heard of Admiral Nursing and were unaware of the team's existence in Haringey or their knowledge was limited, and therefore the service was not being suggested to carers who might benefit from Admiral Nursing support.

"A residential home is normally the last resort for people; families are influenced a lot by their history, life experiences and cultural norms in reaching a decision to admit a family member into a care home although quite a lot of residents in a care home have few or no family carers or visitors." - Adult Services manager

Support for carers and staff after bereavement

As a local GP described: "There is not enough support for carers in bereavement. They have had to support a person with dementia who has a socially embarrassing disease for a long time; they are frequently riddled with guilt that they have not been able to cope with caring for the person at home. They do not access services early enough and then there is a crisis. If support can be made available early enough it is much better."

Staff in residential and nursing homes often experienced grief when a resident dies, but this was not always acknowledged.

Examples of good practice

- Those carers who had received support from an Admiral Nurse spoke highly of the service
- A dementia café had recently been introduced
- Day care centres supported carers by offering carer meetings which continued to be available to carers after the death of the person with dementia

Recommendations

- Patients and carers would benefit from a single assessment process; this is likely to produce cost savings as it will reduce duplication
- The Admiral Nursing service needs to be marketed more widely
- Additional support is needed for relatives and care home staff after a person with dementia dies
- The development of a dementia care pathway would enable a single point of access, a more coordinated approach to quality care and additional signposting and support for carers

"We had to make important decisions about his treatment; we found this hard and needed advice and support."

Carer

"I miss him - every day I think of him, he was a great character."

Care home key worker

"We are not good at looking after our own staff and do not allow for the death of a resident sufficiently and the impact it can have on carers who may have developed a strong relationship with a resident - this particularly applies to day staff."

Adult Services manager

"It is OK to go home when kids are sick, but not when parents are. This can be a huge issue for men."

Carer

"For families it is slow motion bereavement."

Adult Services manager

"The Admiral Nurse was very supportive - I do not know what I would have done without her"

Carer

"It was about being my mother's advocate."

Carer

Skills and training

Key messages

- A wide range of health and social care staff come into contact with people with advanced dementia; there is a clear need to increase their knowledge and awareness of the likely disease progression
- Care staff in residential homes are not required to be trained nurses and therefore need to rely on medical services when faced with a resident with medical problems
- Nursing staff in the acute setting are trained to deal with medical problems but have limited knowledge or resources to cope effectively with all the behaviours associated with dementia
- Many staff groups reported that they did not feel that they have all the necessary knowledge and skills to increase the quality of support for people with dementia

Supporting evidence

The ambulance service: "Dealing with patients with dementia is not part of the crews' training package – it is touched on but is not sufficient. The organisation is looking at an end of life electronic training package." – *Ambulance manager*

In the acute hospital: Some staff had limited understanding of all the care needs a person with dementia required. For example, carers cited examples of nursing staff leaving food and drink by the patient's bedside when the person with dementia was incapable of understanding what to do with it and was therefore unable to feed themselves.

Case study: Staff on the ward had limited skills or awareness of dementia and called the wife day and night when they had problems. She was called at 2am on one occasion and found three nurses trying to contain her husband in a corridor; one staff member was hit by him. "It was not his fault; he couldn't understand why they were doing these things to him." When she cared for him they said "oh, he is like a baby with you." His wife had to visit every day for long periods to ensure her husband's well-being and to provide much of his care as the staff did not have the knowledge of how to handle him. - *Carer*

Adult Services and care homes: Staff turnover within care homes could be high; therefore investment in training needed to be ongoing.

Staffing levels are usually minimal in dementia units; this is not adequate as there is frequently a requirement for two carers to be attending to one resident." – *Community nursing staff*

Hospice: Staff rarely had contact with people with dementia and showed concern about their limited ability to manage the behavioural and psychiatric symptoms.

Examples of good practice

- The role of Community Matron had become an integral part of the support network for care home staff to learn about caring for their residents and having the confidence to care for them appropriately
- Admiral Nurses were providing education and training for carers

Recommendations

- Commissioners need to ensure access to appropriate training is available to staff (particularly those in an acute hospital) who care for people with dementia
- The Haringey Gold Standards Framework programme needs to include a dementia training component

Comments

"There is always room for more training – links with the community play a big part in this"
Adult Services manager

"The role of community matron has made a huge difference to the staff and residents in care homes – it is the greatest improvement in residential care in the last few years."
Adult Services manager

"Staff at the hospital need to have more knowledge and skills to care for people with dementia."
Carer

"He was very distressed in hospital and kept pulling out his tubes – he didn't understand what was happening to him and they didn't know how to help him. One time he pulled his drip out, we asked for it to be put back and they said a specialist team had to do this. He went the whole day without anything to drink. This made him become more agitated"
Carer

"Always room for better practice"
Acute staff

"A stronger therapy presence in care homes would be good. 'No rehab potential' is frequently given as justification for not providing therapy and sometimes this is a 'cop out'. Therapy staff have little understanding of the issues for people with dementia."
Community professional

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Last accessed 02/09/2009

Partnership organisations for this project:

Marie Curie
Cancer Care

www.mariecurie.org.uk

NHS Haringey

www.haringey.nhs.uk

Barnet, Enfield and
Haringey Mental
Health NHS Trust

www.beh-mht.nhs.uk

Haringey Council

www.haringey.gov.uk

For Dementia

www.fordementia.org.uk

National Council
for Palliative Care

www.ncpc.org.uk