

Dementia Review – Interim Progress

Background

1. In coming to a decision to review this topic, the Health Scrutiny Committee recognised certain key objectives and the following remit was agreed:

Aim

2. To look at the experience of older people with mental health problems (and their families/carers) who access general health services for secondary care in order to identify where improvements may be required.

Key Objectives

- i. Where patients with mental health conditions access general, secondary health services, investigate whether their mental health problems are recognised and whether the connection is made between them and the required treatment.
- ii. To identify ways in which healthcare professionals may assist patients with mental health conditions to overcome the barriers they face when accessing secondary care.
- iii. To investigate ways of improving the safety of patients with mental health conditions and the secondary healthcare providers who have contact with them.
- iv. To develop initiatives for improving the experiences of mental health patients using general, secondary health care and their families/carers.

Consultation

3. An informal evidence gathering session was held on 1st September 2008. Members received evidence from carers of relatives with dementia and from representatives of the following organisations:
 - York Older People's Assembly
 - Age Concern, York
 - Alzheimer's Society
 - York Carer's Forum
 - York Carer's Centre
 - Epilepsy Action

- York & District MIND
- York LINK (Local Involvement Network)
- City of York Council Social Services Department
- North Yorkshire and York Primary Care Trust (NYYPCT)
- York Hospital
- York Foundation Trust

4. The evidence received at this event is detailed in the paragraphs below.

Information Gathered

Evidence received from carers

5. Information was received from several relatives and carers and their experiences are detailed below:

Experience 1

- A carer who had looked after a relative with dementia for 12 years had had both good and bad experiences when her relative had accessed secondary care services. When her relative had been diagnosed with cancer the consultant had been excellent and had made sure that the patient understood what was being said. The carer was involved throughout the consultation and in instances where the patient became confused or answered incorrectly the carer interceded on the patient's behalf. She said that people suffering with dementia often understood what was being said but found it difficult to remember details.
- The carer had kept a diary during the last days of her relative's life and this recorded some of her experiences. When her relative was diagnosed with terminal cancer she was admitted to the Elderly Medical Unit at York Hospital. The senior doctor arrived and refused to let the carer be present during his examination of the patient and drew the curtain in front of her. He did not take the fact that the patient was also suffering from dementia into consideration.
- The patient was told that she needed surgery but the carer was unclear as to how this information had been communicated to the patient or whether the patient had understood and remembered what she had been told.
- The patient was subsequently transferred to a ward where there was no senior sister on duty. The carer explained to a member of staff on the ward that another relative was travelling long distance to see the patient and asked if it was okay for the patient to be briefly visited outside of the usual visiting hours. The carer was spoken to very rudely and comments were made about 'all patients having dementia and if she allowed this visit then they would all want it'. The carer felt that these comments were inappropriate.
- The carer had also requested that staff use E45 cream on the patient's sores but this request was ignored and consequently the patient became uncomfortable but was unable to express this to staff.

- ❑ The patient was sat in a chair for 4 hours, which considering her bedsores and other ailments was an inappropriate position and would have been very painful.
- ❑ Due to the dementia the patient had difficulty swallowing and during the course of the patient's stay in the hospital she was put on an inappropriate diet. Staff were informed that the patient had difficulty swallowing and needed a different diet and liquid pain relief. The carer was told that they could not provide this unless they had evidence that the patient could not swallow from the speech therapist. The speech therapist was not available as it was the weekend and it was 72 hours after admittance before a visit was organised.
- ❑ The carer requested that her relative be admitted to a Hospice. The Doctor that she spoke to was new and did not know the name of the Hospice and had to ask the carer.
- ❑ The patient was finally referred to the palliative care nurse who did not come until late in the day. The ward they were in was noisy and had very little privacy and was unsuitable for meetings of this nature. The palliative nurse agreed that a Hospice bed was appropriate. A bed was available but there was no ambulance available to transport the patient and the carer was told that the transfer would take place the next day but only if the ambulance wasn't needed for an emergency.
- ❑ The patient was unconscious when transferred to the Hospice and passed away early the next morning. The carer likened the patient's experiences to that of a third world death.
- ❑ The carer felt that the staff at the hospital had not been sufficiently trained to deal with patients who had dementia and any training that had been given to staff had not implemented.

Experience 2

- ❑ An e-mail was received from a carer who raised concerns that dementia patients attending York Hospital for unrelated conditions may not be recognised as suffering from dementia and it may not be taken into account when communicating with them. They may be asked to carry out certain procedures, or take a new medication, but have forgotten what is asked of them before they leave the hospital. Her relative, who had recently been diagnosed with Alzheimer's disease, had to attend the pacemaker clinic as an outpatient. The carer had offered to accompany her relative, but the relative had refused this request, as she did not recognise that she had memory problems. The carer contacted PALS (Patient Advice and Liaison Services) at the hospital and requested to be told of any instructions that had been given to her relative; the request was refused and the carer still has no idea of what her relative was told at that visit.
- ❑ The above carer feels that dementia patients often present extremely well to strangers. Busy clinic staff may not have access to a patient's full records, or may not look at anything other than the condition they are

dealing with. It would then be very likely that advice given would not be remembered or carried out. If somebody was admitted to hospital then it would become obvious to ward staff if their patient had memory problems; but with fast appointments in clinics it would be very difficult to recognise that her relative had dementia unless you were talking to her for at least a quarter of an hour, which is most unlikely with the lack of time available to individual appointments.

6. A representative of the Alzheimer's Society circulated a handout that detailed experiences of some of the members of the York and Selby branch of the organisation; these are detailed below:

Experience 3

- ❑ A person with dementia may have no understanding of what is wrong with them. Staff on the ward were not proactive in stopping a patient walking on a broken leg and risking further injury.
- ❑ The patient did not understand that she was having a bath and became very alarmed. The patient's hair was washed but not dried.
- ❑ The carer was always happy to help feed the patient and saw this type of relative support as essential in ensuring patients with dementia got properly fed during their hospital stay. She felt that staff sometime objected to her helping with these basic tasks and is opposed to any restriction on visiting hours that excludes visitors during mealtimes.
- ❑ Both of the patient's hearing aids (clearly labelled with the patient's name) went missing during the stay. This made communication impossible. Before they went missing the carer checked the batteries, as staff did not see this as part of their role.

Experience 4

- ❑ A person with dementia was admitted to York Hospital from a local care home where the care provided was excellent. Her carer and relative felt that the ward staff were only concerned with the physical damage (broken leg) and 'hadn't got a clue' about the patient's dementia. The ward sister was sympathetic but admitted that staff did not have the relevant expertise and they relied on relatives/carers to look after patients with dementia.
- ❑ When the patient's blood pressure was taken she was frightened and staff did not understand that simple procedures like this can be terrifying for people with dementia.
- ❑ The doctor had prescribed morphine but the nursing staff seemed very reluctant to administer this. The carer/relative had found a glass of water spilt on the floor after the patient had refused to take paracetamol.
- ❑ The carer/relative was able to feed the patient at meal times but sometimes arrived when food had already been left out. The patient had

no understanding that the food that had been left out was for her. The carer/relative has since raised concerns that visiting is no longer allowed during mealtimes, which could result in patients with dementia not eating.

Experience 5

- A patient with Alzheimer's and severe sight impairment was admitted to hospital at the request of her GP. Both the Alzheimer's and the sight impairment were pointed out to staff but despite this there was no supervision or help with meals or medication.
- During visiting hours medication was often found spilt all over the bed table and the floor and was left for relatives/carers to clear up. The patient's relative felt that she went without food and medication and staff seemed unconcerned. The relatives were very concerned especially as another confused patient was witnessed picking up the discarded medication.
- Relatives asked permission to visit the patient at mealtimes; the ward sister agreed to this. On arrival a staff nurse pointed to a notice on the wall and said, 'can you not read that visitors are not allowed at meal times.' On being informed that the ward sister had given permission for the lady to be fed, she turned her back and walked off.
- Whenever there was a change of staff the family felt that they had to start all over again as there had been no real communication between staff. When first admitted to York Hospital the patient could walk.
- The only time the patient got out of her chair by the bed was when relatives walked her up and down the ward as the staff said it took 3 or more people to get her to stand up. By the time she was discharged she was completely dependent and unable to walk.
- After 4 months the patient was sent to a special ward for older people with mental health difficulties at Selby Hospital because it was felt that being on a general ward with sick patients was not good for her. Although the patient was meant to be based on this ward the actual practice was to move her to the ward during the day and return her to the general ward at night, which was a confusing and disorientating experience for someone suffering from dementia.
- After 5 months the relatives received a telephone call to say that the patient would be discharged the following day. No arrangements had been made for care or appropriate equipment to be provided to the relatives/carers. On being taken home a care package was arranged to help the family care for their relative at home but after only one day the care staff refused to return because the family had not been provided with a hoist to move the patient with. This left the relatives, who both had back problems, to cope with all the lifting.

Evidence received from voluntary services

7. Several Voluntary Organisations gave evidence at the session and this is set out below:

Age Concern

8. A representative of Age Concern read out an e-mail a colleague had sent her. This highlighted the issue of people with dementia who live alone and their relationship with their GPs. This detailed the case of a dementia sufferer who lives alone in one of the suburbs of York. This person sometimes makes appointments to see their GP and then forgets to tell the Age Concern representative. They would then struggle with things such as booking taxis and collecting prescriptions. In one recent incident the person had been given a letter by her GP to go for an X-ray. It was only after persuading the receptionist at the surgery to look up this information that Age Concern were aware and were able to assist the patient to the appointment. The Age Concern representative has since spoken to the GP and they now work closely to support the needs of the person with dementia.
9. The Age Concern representative mentioned another incident of a lady having been given a hospital appointment. The lady had forgotten what the appointment was for and when Age Concern tried to assist her they were denied any information, as they were not next of kin.
10. On a visit to one of the elderly persons' wards at York Hospital the Community Services Manager at York Age Concern witnessed elderly patients crying out for different reasons; all of whom were being ignored. She felt that because the patients were elderly then nobody was talking to them. She felt that it was much easier to support patients and their families/carers once a diagnosis of dementia had been.

Older People's Assembly

11. A representative of the Older People's Assembly thought the evidence that had been received so far was frightening, especially for single older people. Dementia was a disease that slid slowly into people's lives and did not happen overnight. When all the things that had so far been discussed were combined with a non-family orientated GP service that only offered people 10 minutes slots and seldom came out to visit them in their own homes then this could be said to accentuate the problem of loneliness. He also felt that care workers were poorly paid and staff needed to look holistically at a patient's circumstances.

Alzheimer's Society

12. The Alzheimer's Society offers a befriending service for carers and has had recently had some lottery funding. They are shortly hoping to offer a befriending service to people with dementia.
13. The Alzheimer's Society had put together a leaflet entitled 'This is me'. The leaflet would include information on an individual patient i.e.: photo, date of

birth, primary carer, medication, diet, and assistance required. Patients/carers could hand this leaflet to a member of staff in the hospital to inform them of details that they would need to know. At the moment the Society were trying to introduce the idea of the leaflet into hospitals. Some nursing homes had already agreed to their use and had found them very useful.

MIND

14. The Director of the York & District branch of MIND reiterated that they too offered a befriending service. He raised the concern of dementia sufferers becoming dehydrated, as they couldn't always take liquids without assistance. He also said that if a patient was happy with their care they were more likely to accept that they needed it and more successful relationships tended to be built. He also raised concerns regarding the access and support the traveller community had in relation to dementia care as they were a hard to reach group that were often overlooked. They were likely to either get lost in the system or forgotten and early intervention and pro-active responses, along with intensive support could be beneficial and make a huge difference. Discussions drew out the need for sensitivity in relation to diverse cultural needs.

General discussion

15. Both MIND and Age Concern also offered befriending services. The Alzheimer's Society also offered a 'care and coping' course which ran continuously.
16. The Media and Campaign Officer for the Alzheimer's Society said that there was still a huge stigma surrounding dementia and it was important to stress that people could still live productive and useful lives after diagnosis.
17. The Age Concern representative said that some Ward Committees had provided monies for community support workers. Even if they only visited people once or twice a year they could assist with the identification of those with the early stages of dementia. The support workers also took elderly persons to social events to help avoid loneliness and depression. Members of the Committee asked if statistical information on the number of care workers funded by Ward Committees could be provided and Age Concern agreed to look into this.

Evidence received from service providers

18. Several Service Providers attended the session and provided the following information:

York Hospital & North Yorkshire and York Primary Care Trust (PCT)

19. The Directorate Manager for Elderly Services at York Hospital stressed that they were now dealing with an aging population, which put strains on the available resources. There had been recent investment in terms of staffing but some of the stories that had been heard today had highlighted problems that caused by a lack of staff. There were some wider training issues around

dealing with patients with dementia when they were admitted to hospital for secondary care and these needed to be explored. It was known that 50% of people that were admitted to hospital had mental health problems. There was also an increase in the numbers of people being diagnosed with dementia. The length of stay in hospital for a patient with a mental health problem tended to be longer than those without and there were rarely enough activities to keep them occupied.

20. The Hospital, along with their colleagues in the PCT, had been investigating the possibilities of a 'psychiatric liaison service'. Discussions indicated that this was a multi-agency scheme, which unfortunately had been stalled due to a lack of funding. There was a need to push this further forward to provide the link between the community and the hospital. A lot could be gained if there could be a liaison between interested groups. At the present time the 'psychiatric liaison service' does not exist although a pilot had been undertaken some time ago. The pilot scheme had produced some clear anecdotal evidence on the benefits of the service.
21. There were proposals for a new scheme that would allow care workers to go into people's homes immediately after discharge from hospital. These workers would be specifically trained to deal with the needs of the people they were assisting. It would be rapid response care but for short periods of time.
22. She also acknowledged that there was a need to improve staff attitudes and support for staff whilst at the same time looking at involving carers more.
23. Representatives of York Hospital confirmed that they had recently set up a new protected mealtimes initiative. Those patients who needed assistance at mealtimes were served their meals on a red tray so that staff could easily identify them. Training had been provided to all staff and nutrition audits were undertaken.
24. One of the problems with mealtimes had been that things carried on as normal throughout them. Under the new initiative visitors are not allowed during mealtimes, doctors do not visit (except in emergencies) and staff do not undertake duties other than helping the patients with their meals. The new initiative would be monitored.

Specialist Nurse for Mental Health (York Hospital)

25. The Specialist Nurse for Mental Health (York Hospital), who worked mainly in the elderly units, said that her role was mainly reactive rather than proactive. When a patient on a ward was causing a problem then she would assess the situation and offer advice on possible solutions. She felt that she offered a good service but was a one-member team. She would only offer advice on a patient in the early stages of dementia if she were called in because the patient was causing a problem. She felt that there was a need for training in mental health issues and that attitudes towards mental health problems needed to be changed. Discussions were had around how much training medical staff in other directorates had on mental health issues and it was generally agreed that there was a lot of room for improvement.

City of York Council

26. The Service Manager for the Social Work Department at City of York Council (CYC) pointed out that there should be a named nurse for each patient on a hospital ward. Further discussion identified that carers and relatives were not always familiar with hospital systems and may not know how to access this information.
27. She raised the fact that consultants and doctors that worked on the elderly wards had different attitudes towards the care of those with dementia than those working in other areas of the hospital. She said that it was very easy for people with dementia to come into hospital and be discharged without their mental health needs being noticed. If a patient did not 'cause problems' or a problem is not highlighted by staff then their mental health could easily go unnoticed.

Issues Arising

28. Members felt that the evidence gathered to date had raised the following concerns and issues that needed to be addressed.

Accessing & Sharing Information

- In the age of computerised record keeping is there no way that patients who have a diagnosis of dementia, live alone and need more support could be flagged up in some way
- Different service providers had different computer systems and these were not always compatible with each other
- It would be very easy to flag up on GP notes if a patient had dementia & no relatives. The Voluntary Organisations such as Age Concern and Alzheimer's Society would then be able to assist
- There was difficulty sharing confidential information across agencies.
- Is there a way that certain information could be shared with voluntary organisations to enable them to assist their clients

Involvement of Carers/Relatives

- Older people and their families often did not know how to deal with the early stages of dementia (pre-diagnosis) and were often not given enough support. Once a patient was 'in the system' they (and their families/carers) were more likely to get the support they needed
- The importance of keeping carers/relatives involved during a patient's stay in hospital
- Poor pay for care workers
- There was a fine balance between knowing when to ask the patient questions and when to ask the carer/relative. It was noted that people with dementia could be convincing.
- There was a need to improve carer experiences.

Attitudes towards dementia

- There is a lot of ignorance surrounding dementia and many people do not know how to deal with parents who are incapacitated by it. Better publicity may help
- Attitudes towards mental health needed to be changed

Dementia patients and the hospital environment

- The importance of keeping carers/relatives involved during a patient's stay in hospital
- Hospital visiting times and supervision at meal times
- Practical considerations are very important when a patient is in hospital (i.e. working hearing aids, whether a patient can eat and drink unaided)
- Clinicians in 'short appointment clinics', such as the outpatients' clinics may not always have full medical history on hand and may not recognise that a patient has memory problems/dementia
- Hospital staff do not always talk to relatives/carers but amongst themselves
- It is sometimes difficult to get hospital staff to take on board the concerns that carers have or to listen to the information that they can provide about the needs of the patient
- Carers/relatives are not necessarily familiar with hospital systems. Is there anything that can be done to change this?
- How should the needs of elderly people, especially those with dementia, be met when attending hospital appointments and during hospital stays?
- There was a lack of private space for meetings and assessments to take place in the hospital environment

Psychiatric Liaison Service

- The fact that a 'psychiatric liaison service' did not exist at the present time.
- Information regarding what a liaison service would provide is attached at Annex A to this report

Voluntary Organisations

- Not everyone is aware of voluntary organisations and what they can do to assist. The general public are not always given a good picture of what is out there in terms of moral support

General

- Family GPs no longer exist and often are not aware of a person's history
- We are an aging population and thus there will be more people with dementia
- People's choices must be respected
- Many people are reluctant to accept that they have dementia
- There was a fine balance between knowing when to ask the patient questions and when to ask the carer/relative. It was noted that people with dementia could be convincing.

- The need to maintain the health and safety of the patient at all times and for positive relationships to be built.

Options

29. Members will need to consider whether they have enough information to produce a draft final report and identify some appropriate recommendations.
30. If Members feel that they need further evidence they will need to indicate whom this information should be gathered from and when they would like to receive it.

Recommendation

31. It is recommended that Members consider and agree:
- Whether it is necessary to gather further information and if so from whom and when
 - If the above is not considered necessary then to make appropriate recommendations to be included in the draft final report.

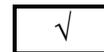
Reason: To progress this review

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**Interim Report
Approved**



Date 11.09.2008

Wards Affected:

All

For further information please contact the author of the report

Background Papers:

None

Annexes

Annex A – What a liaison service would provide.