



#### Notice of meeting of

#### **Scrutiny Management Committee**

**To:** Councillors Galvin (Chair), Aspden, Pierce (Vice-Chair),

Scott, Simpson-Laing, Taylor, R Watson and I Waudby

**Date:** Wednesday, 17 December 2008

**Time:** 5.00 pm

**Venue:** The Guildhall

# **AGENDA**

#### 1. Declarations of Interest

At this point in the meeting, Members will be invited to declare any personal or prejudicial interests they may have in the business on the agenda.

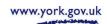
# **2. Minutes** (Pages 3 - 6)

To approve and sign the Minutes of the meeting held on 17 November 2008.

# 3. Public Participation

At this point in the meeting members of the public who have registered their wish to speak regarding an item on the agenda or an issue within the Committee's remit can do so. Anyone who wishes to register or requires further information is requested to contact the Democracy Officer on the contact details listed at the foot of this agenda. The deadline for registering is Tuesday 16 December 2008 at 5 pm.





# 4. Final Report of the Health Scrutiny Committee – Dementia Review (Pages 7 - 70)

This report presents the final report from the Health Scrutiny Committee regarding their Dementia Review.

# **5. Scrutiny Review Support Budget** (Pages 71 - 74)

This report summarises the position to date on expenditure against the budget available specifically for supporting scrutiny reviews in 2008/9 and seeks Members views on the available budget for 2009/10, with a view to making a recommendation to the Council as part of the budget setting process.

# 6. Any other business which the Chair decides is urgent under the Local Government Act 1972

# **Democracy Officer:**

Name: Simon Copley

Contact details:

- Telephone (01904) 551078
- E-mail simon.copley@york.gov.uk

For more information about any of the following please contact the Democracy Officer responsible for servicing this meeting:

- Registering to speak
- Business of the meeting
- Any special arrangements
- · Copies of reports

Contact details are set out above.

# **About City of York Council Meetings**

#### Would you like to speak at this meeting?

If you would, you will need to:

- register by contacting the Democracy Officer (whose name and contact details can be found on the agenda for the meeting) no later than 5.00 pm on the last working day before the meeting;
- ensure that what you want to say speak relates to an item of business on the agenda or an issue which the committee has power to consider (speak to the Democracy Officer for advice on this);
- find out about the rules for public speaking from the Democracy Officer.

A leaflet on public participation is available on the Council's website or from Democratic Services by telephoning York (01904) 551088

#### Further information about what's being discussed at this meeting

All the reports which Members will be considering are available for viewing online on the Council's website. Alternatively, copies of individual reports or the full agenda are available from Democratic Services. Contact the Democracy Officer whose name and contact details are given on the agenda for the meeting. Please note a small charge may be made for full copies of the agenda requested to cover administration costs.

#### **Access Arrangements**

We will make every effort to make the meeting accessible to you. The meeting will usually be held in a wheelchair accessible venue with an induction hearing loop. We can provide the agenda or reports in large print, electronically (computer disk or by email), in Braille or on audio tape. Some formats will take longer than others so please give as much notice as possible (at least 48 hours for Braille or audio tape).

If you have any further access requirements such as parking close-by or a sign language interpreter then please let us know. Contact the Democracy Officer whose name and contact details are given on the order of business for the meeting.

Every effort will also be made to make information available in another language, either by providing translated information or an interpreter providing sufficient advance notice is given. Telephone York (01904) 551550 for this service.

যদি যথেষ্ট আগে থেকে জানানো হয় তাহলে অন্য কোন ভাষাতে তথ্য জানানোর জন্য সব ধরণের চেষ্টা করা হবে, এর জন্য দরকার হলে তথ্য অনুবাদ করে দেয়া হবে অথবা একজন দোভাষী সরবরাহ করা হবে। টেলিফোন নম্বর (01904) 551 550।

Yeteri kadar önceden haber verilmesi koşuluyla, bilgilerin terümesini hazırlatmak ya da bir tercüman bulmak için mümkün olan herşey yapılacaktır. Tel: (01904) 551 550

我們竭力使提供的資訊備有不同語言版本,在有充足時間提前通知的情况下會安排筆譯或口譯服務。電話 (01904) 551 550。

Informacja może być dostępna w tłumaczeniu, jeśli dostaniemy zapotrzebowanie z wystarczającym wyprzedzeniem. Tel: (01904) 551 550

#### **Holding the Executive to Account**

The majority of councillors are not appointed to the Executive (38 out of 47). Any 3 non-Executive councillors can 'call-in' an item of business from a published Executive (or Executive Member Advisory Panel (EMAP)) agenda. The Executive will still discuss the 'called in' business on the published date and will set out its views for consideration by a specially convened Scrutiny Management Committee (SMC). That SMC meeting will then make its recommendations to the next scheduled Executive meeting in the following week, where a final decision on the 'called-in' business will be made.

#### **Scrutiny Committees**

The purpose of all scrutiny and ad-hoc scrutiny committees appointed by the Council is to:

- Monitor the performance and effectiveness of services;
- Review existing policies and assist in the development of new ones, as necessary; and
- Monitor best value continuous service improvement plans

#### Who Gets Agenda and Reports for our Meetings?

- Councillors get copies of all agenda and reports for the committees to which they are appointed by the Council;
- Relevant Council Officers get copies of relevant agenda and reports for the committees which they report to;
- Public libraries get copies of **all** public agenda/reports.

City of York Council	Committee Minutes
MEETING	SCRUTINY MANAGEMENT COMMITTEE
DATE	17 NOVEMBER 2008
PRESENT	COUNCILLORS GALVIN (CHAIR), ASPDEN, FRASER (AS SUBSTITUTE FOR BLANCHARD), SCOTT (FROM 5.20PM, FOR PART OF ITEM 4 AND ITEMS 5-6), SIMPSON-LAING, TAYLOR, R WATSON (FROM 5.15PM, FOR PART OF ITEM 4 AND ITEMS 5-6) AND WAUDBY
APOLOGIES	COUNCILLOR BLANCHARD

#### PART A - MATTERS DEALT WITH UNDER DELEGATED POWERS

#### 20. DECLARATIONS OF INTEREST

Members were invited to declare at this point in the meeting any personal or prejudicial interests they might have in the business on the agenda.

Councillor Fraser declared a personal non-prejudicial interest in agenda item 4 (Update on the Work of the Health Scrutiny Committee) as he was one of the Council's representatives on the Hospital Foundation Trust and a member of the retired sections of Unison and Unite.

Councillor Waudby declared a personal non-prejudicial interest in agenda item 4 (Update on the Work of the Health Scrutiny Committee) as her daughter was employed by York Local Involvement Network (LINk).

#### 21. MINUTES

In relation to minute 15 (Final Report of the Barbican Ad-Hoc Scrutiny Committee – Sale of the Barbican) of the meeting of the Scrutiny Management Committee held on 15 September 2008, Members asked officers to check that the Committee's comments were being reported to the Executive for consideration with this item.

RESOLVED: That the minutes of the meeting of the Scrutiny

Management Committee held on 15 September 2008 and the minutes of the Barbican Ad Hoc Scrutiny Committee held on 16 July 2008 be signed as a

correct record.

#### 22. PUBLIC PARTICIPATION

It was reported that there had been no registrations to speak at the meeting under the Council's Public Participation Scheme.

#### 23. UPDATE ON THE WORK OF THE HEALTH SCRUTINY COMMITTEE

Members received a report which presented a summary of the work undertaken by the Health Scrutiny Committee since April 2008.

The topics that the Committee had looked at included Local Involvement Networks (LINks), dental provision and the 'Dementia Review'.

The Chair of the Committee requested that political groups considered the benefits of continuity of membership for the Health Scrutiny Committee when putting forward nominations for places in the future, in order to allow Members to build on their training to date and develop a good knowledge of the complex structures and processes in the health service.

In relation to the three year government funding for the Council to commission a host organisation to enable, support and facilitate the LINk, Members queried whether the funding would continue in the longer term.

Members thanked the Chair of the Health Scrutiny Committee for the report.

RESOLVED: That the report be noted.

REASON: To inform Scrutiny Management Committee of the

work and progress of the Health Scrutiny Committee.

#### 24. PROTOCOL ON JOINT SCRUTINY REVIEWS

Members received a report which asked them to consider adopting a protocol to enable joint scrutiny reviews to be undertaken in York should the need arise.

A draft protocol was attached as Annex A of the report.

RESOLVED: That the protocol to allow joint scrutiny work to be

carried out be adopted, subject to minor alterations being brought back to a subsequent meeting in

relation to the following:1

a) How proportionality would be achieved for the City

of York Council membership;

b) How the arrangements would apply if more than

two authorities were involved.

REASON: To ensure Members can fully take part in scrutiny work

that may impact on more than one geographical area.

**Action Required** 

1 - To bring back minor alterations.

#### PART B - MATTERS REFERRED TO COUNCIL

#### 25. REVIEW OF THE COUNCIL'S OVERVIEW AND SCRUTINY FUNCTION

Members received a report which set out the findings to date of a project, undertaken by officers within the Democratic Services Team, to review the existing arrangements at City of York Council for fulfilling the legislative requirements for facilitating Overview and Scrutiny within the council. It considered the existing arrangements at York in the light of recent research and experience from other authorities, sought to highlight some key areas of variation and went on to present potential alternatives to the current scrutiny structure within the council. It asked Scrutiny Management Committee to consider a revised structure, in order to simplify the existing arrangements by bringing them more in to line with other authorities and to make more effective use of the limited resources available.

The report presented the following options for consideration:

- Option A To remove the existing Scrutiny Committees from the structure and give authority to each of the Executive Member Advisory Panels (EMAPs) to carry out all of the scrutiny function in relation to the services under their individual portfolio areas;
- Option B To replace the existing Scrutiny Committees with an increased number of alternative Scrutiny Committees, and remove EMAPs from the decision making structure;
- Option C To replace the existing Scrutiny Committees with an increased number of alternative Scrutiny Committees, and retain EMAPs, for the recording of Executive Member decisions, but clearly define their role to ensure they do not undermine the scrutiny function;
- Option D To make no change to the Scrutiny Committees and decision making structure, but clearly define the role of EMAPs to ensure they do not undermine the scrutiny function and allow for policy development work (currently considered by EMAPs in part) to be considered by Scrutiny Management Committee instead, in line with Section 21 of the Local Government Act 2000, with Executive Member decisions continuing to be recorded at EMAPs.

Options A-C would also involve the removal of the Strategic Policy Panel from the structure. If none of the options were adopted, some changes would still be needed to the current structure to meet the requirements of existing or forthcoming legislation.

Some Members supported Option B and expressed the view that it provided clarity in the roles of the different bodies and individuals in the decision making structure, and a properly resourced scrutiny function to hold the Executive to account. Other Members supported a version of Option C, modified to strengthen the status and increase the resourcing of scrutiny, on the grounds that EMAPs had an important discursive role and provided an opportunity for backbench and minority group members to be informed of and comment on items for decision.

# Page 6

RECOMMENDED: That Option B be adopted and a Committee of Council

be formed to consider the detailed implementation of this model and the constitutional changes required.<sup>1</sup>

REASON: To improve the Council's Overview and Scrutiny

function.

[Note: Councillors Aspden, R Watson and Waudby requested that their votes against the recommendation to Council above be recorded.]

**Action Required** 

1 - To refer to Council.

GR

Councillor J Galvin, Chair [The meeting started at 5.00 pm and finished at 6.25 pm].



# **Scrutiny Management Committee**

17<sup>th</sup> December 2008

Report of the Head of Civic, Legal & Democratic Services

# Final Report of the Health Scrutiny Committee – Dementia Review Summary

1. This report presents the final report from the Health Scrutiny Committee regarding their Dementia Review.

# **Background**

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

#### Aim

3. 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

- 4. As part of the review the following organisations and individuals were consulted:
  - York Older People's Assembly
  - Age Concern, York
  - Alzheimer's Society
  - York Carer's Forum
  - York Carer's Centre
  - Epilepsy Action
  - York & District Branch of Mind
  - York LINk (Local Involvement Network)
  - Individual Carers
  - City of York Council Social Services Department
  - North Yorkshire & York Primary Care Trust (NYYPCT)
  - York Hospital Foundation Trust
  - Yorkshire Ambulance Service (YAS)
  - Local GPs
  - Local Medical Committee

#### **Options**

5. Having considered the findings contained within the final report and its annexes attached, Members may choose to support all, some or none of the recommendations shown in paragraph 7 of this report, and provide their comments prior to the report being considered by the Executive.

# **Analysis**

6. In regard to the aims and objectives of this, the final report attached analyses all of the information gathered.

# **Summary of Recommendations Arising from the Review**

- 7. The recommendations arising from the Dementia Review are:
  - i. That the York Hospital Trust, in liaison with other appropriate service providers\* be urged to develop and implement the Psychiatric Liaison Service (Annex A). The development of this programme to be a benchmark for training and support for staff working with dementia patients who access secondary care.

\*The Yorkshire Ambulance Service is to be included amongst the service providers, whilst acknowledging the unique nature of their role.

REASON: To enable the development of the Psychiatric Liaison Service to progress.

- ii. That all service providers be urged to review their arrangements for staff training in relation to recognising and working with those with an underlying condition of dementia. Any such review should include:
  - Promoting the use of Link nurses and investigating the possibility of nominating Link clinicians within defined staffing groups.
  - Investigation of the large gaps in training.
  - The utilisation of the variety of sources for training provision including the Alzheimer's Society and other voluntary sector organisations.
  - o Investigation into the pooling of resources between service providers.

REASON: To ensure that all staff are adequately trained to care for the needs of dementia patients accessing secondary care.

- iii. That secondary care provider clinicians be urged to acknowledge the positive contributions that can be made by a patient's carer to that patient's ongoing programme of treatment (whilst recognising the issues surrounding patient confidentiality). Clinicians are also urged to take the following into consideration:
  - Where it is recognised that there may be an underlying mental health condition to provide written details of any medication and/or treatment plans to the patient.
  - The issue of carers' information being logged on a patient's notes to be urged as good practice and an ongoing dialogue between medical practices and the York Carer's Forum to be maintained to allow for effective databases to be kept.

REASON: To ensure that carers are involved as much as possible whilst still recognising the need for patient confidentiality.

iv.

- a. That all service providers be urged to work with the relevant voluntary organisations (Alzheimer's Society, York & District branch of Mind, Age Concern, Older People's Assembly etc) to develop new initiatives and to promote the awareness of dementia (including the provision of an information leaflet for carers).
- b. That commissioner and service providers discuss the 'This is Me' initiative further with the Alzheimer's Society with a view to adopting it within their individual organisations. The Committee wished it to be known that they were very impressed with this particular initiative.

REASON: To promote and increase dementia awareness and to encourage positive initiatives to be widely and effectively used.

v. That York Hospitals Trust, where possible, be urged to adopt a flexible approach during a dementia patient's stay in hospital, for example flexibility in hospital visiting hours and flexibility at mealtimes to allow carers to assist patients with eating.

REASON: To involve carers during a patient's stay in hospital to assist them in settling into an unfamiliar environment.

That all relevant parties be urged to resolve the ongoing issues surrounding the implementation of a universal 'Shared Care Record System' (Annex C refers).

REASON: To resolve ongoing issues

vi. That all service providers (CYC, NYYPCT, YAS and York Hospital Trust) report back to the Committee in 6 months time to inform them of the progress that has been made.

REASON: To ensure that the recommendations are being addressed.

# **Corporate Priorities**

8. The review relates to the following corporate priority:

'Improve the health and lifestyles of the people who live in York, in particular among groups whose levels of health are the poorest.'

# **Implications**

- 9. **Financial** There are no known direct financial implications for the Local Authority associated with the recommendations arising from this review. The Committee were mindful that there may be some financial implications for other health service providers in terms of providing funding to develop the Psychiatric Liaison Service and training of staff.
- 10. **Legal** Section 3(3) of the 'The Local Authority (Overview and Scrutiny Committees' Health Scrutiny Functions) Regulations 2002' states that 'Where an overview and scrutiny committee requests a response from a local NHS body to whom it has made a report or recommendation, that body shall respond in writing to the Committee within 28 days of the request.'
- 11. There are no know Human Resources (HR), Equalities or other implications associated with the recommendations arising from this review or from this report.

# **Risk Management**

12. There are no known risks associated with the recommendation within this cover report or with the recommendations stemming from the review.

#### Recommendations

13. Members are asked to note the contents of the attached final report and its annexes and provide comments on the findings and recommendations as shown in paragraph 7 of this report.

Reason: To inform the Executive's consideration of the final report.

#### **Contact Details**

Author: Chief Officer Responsible for the report:

Tracy Wallis Quentin Baker

Scrutiny Officer Head of Civic, Legal & Democratic Services

Scrutiny Services 01904 551004

Tel: 01904 551714

Report Approved ✓

Date 05.12.2008

#### **Specialist Implications Officer**

#### Legal

Quentin Baker Head of Civic, Democratic & Legal Services 01904 551004

Wards Affected: List wards or tick box to indicate all

All 🗸

For further information please contact the author of the report

#### **Background Papers:**

None

#### **Annexes**

Annex 1 Annex A	Final Report – Dementia Review Psychiatric Liaison Service
Annex B	Comments from front line staff at York Hospital
Annex C	Response from the Local Medical Committee
Annex D	National Dementia Strategy
Annex E	Care on a Hospital Ward – Information provided by the Alzheimer's
	Society
Annex F	E-mail from Dr David Geddes
Annex G	'This is Me' Leaflet produced by the Alzheimer's Society
Annex H	Extract from 'Essence of Care - Patient focused Benchmarks for
	Clinical Governance'

This page is intentionally left blank



# **Health Scrutiny Committee**

3<sup>rd</sup> November 2008

### **Dementia Review**– Final Report

#### **Background**

- 1. This review topic developed from ongoing discussions relating to the Health Scrutiny work plan. Whilst no formal feasibility report was prepared for this topic there had been extensive discussions over a period of time in relation to various mental health issues.
- 2. At a meeting of the Health Scrutiny Committee held on 31<sup>st</sup> March 2008 it was reported that North Yorkshire and York Primary Care Trust (NYYPCT) were undertaking a lot of work around mental health issues and they suggested that a complementary piece of work that the Health Scrutiny Committee could undertake was around people with dementia accessing secondary care and how their needs were being met. Members of the Committee, therefore, agreed to undertake a review on this subject.

#### Remit

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

#### **Aim**

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

- 4. As part of the review the following organisations and individuals were consulted:
  - York Older People's Assembly
  - Age Concern, York
  - Alzheimer's Society
  - York Carer's Forum
  - York Carer's Centre
  - Epilepsy Action
  - York & District Branch of Mind
  - York LINk (Local Involvement Network)
  - Individual Carers
  - City of York Council Social Services Department
  - North Yorkshire & York Primary Care Trust (NYYPCT)
  - York Hospital Foundation Trust
  - Yorkshire Ambulance Service (YAS)
  - Local GPs
  - Local Medical Committee

#### **Information Gathered**

5. During the course of this review, at informal sessions and formal meetings Members gathered the following evidence. Many representatives of the organisations listed above attended one of the informal sessions.

#### **Evidence received from carers**

6. Information was received from several relatives and carers and their experiences are detailed below<sup>1</sup>:

#### **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

<sup>&</sup>lt;sup>1</sup> Members of the Committee wished it to be known that positive experiences were expressed during the course of the review but inevitably this report concentrates on the problems that are faced.

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 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.
- 7. A representative of the Alzheimer's Society outlined some of the experiences they had been informed of. 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**

8. Several voluntary organisations gave evidence at the session and this is set out below:

#### **Age Concern**

- 9. 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.
- 10. 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.
- 11. 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**

12. A representative of the Older People's Assembly thought that the evidence received during the course of the evidence gathering session 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**

- 13. 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.
- 14. The Alzheimer's Society had put together a leaflet entitled 'This is me' (Annex G). 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.

#### **York & District Mind**

15. 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.

#### Other

- 16. Both the York & District branch of Mind and Age Concern also offered befriending services. The Alzheimer's Society also offered a 'care and coping' course which ran continuously.
- 17. 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.

18. The Age Concern representative said that some Ward Committees had provided monies for community support workers. Even if they only visited people once of 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**

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

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

- 20. 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 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.
- 21. 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. Earlier work had shown that reductions could be made in a patient's length of stay with the use of a liaison service. There was clear anecdotal evidence that there was a need for the service to be used before and after hospital admissions.
- 22. 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.
- 23. 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.

- 24. 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.
- 25.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.
- 26. Staff were wary of over diagnosing or making too early a diagnosis of dementia in patients.
- 27. Members of the Committee and representatives of the NYYPCT discussed the possibility of pooling training resources with Bootham Park Hospital. NYYPCT confirmed that there were no problems with staff accessing training at other venues the only issues related to the suitability of different courses for staff at different levels.

#### **Specialist Nurse for Mental Health (York Hospital)**

28. 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**

- 29. 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.
- 30. 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.

#### **Evidence from front line staff at York Hospital**

31. Members visited front line staff at York Hospital on 6<sup>th</sup> October 2008. Notes of the comments made in relation to their experiences of caring for patients suffering from dementia who accessed secondary care are attached at Annex B to this report. During the course of these discussions a document entitled 'Essence of Care – Patient focused Benchmarks for Clinical Governance' was mentioned. The relevant extract from this document is attached at Annex H to this report. The entire document is available on the Department of Health Website at www.dh.gov.uk.

#### **Evidence from Yorkshire Ambulance Service (YAS)**

- 32. At a formal meeting on 6<sup>th</sup> October the Committee received evidence from the Locality Manager at YAS. He made the following points:
  - Ambulance personnel were usually the patient's first line of contact after a GP and they received very little guidance in relation to patients that were affected by dementia.
  - When responding to 999 calls ambulance personnel were often unaware of what type of call they were attending as only basic information had been obtained.
  - Ambulance crews analysed each case and situation on arrival but they
    were trained to obtain as much information from those at the scene as
    possible, this included information given by relatives and carers.
  - o Ambulance personnel did not receive specific training on dementia.
  - Staff were trained on the requirements of the new Mental Capacity act 2005 and a Safeguarding Adults policy would shortly be ratified by the Trust.
  - Crews were instructed to contact Social Services if they felt that an elderly patient was at risk.
  - Every 999/emergency situation was different and crews learned by experience over a period of time.
  - Crews were only with patients for a short period of time compared with other health professionals.
  - Any training was good but ambulance personnel already had to learn a great deal of information in a short period of time.
  - They received very few complaints in relation to the way they catered for those with dementia.
  - Although staff were experienced they could miss signs if patients had trauma or were dehydrated.
  - Relatives/carers were always encouraged to travel with patients in the ambulance and this included staff from residential homes accompanying residents to hospital.

#### **Evidence received from other sources**

#### **Response from the Local Medical Committee**

33. Details of the response received from the Local Medical Committee is attached at Annex C to this report.

#### Other documents received in Evidence

- 34. The following additional documents had been circulated to Members during the course of the review and had been received in evidence:
  - National Dementia Strategy for England update September 2008 (Annex D)
  - Care on a Hospital Ward a leaflet produced by the Alzheimer's Society (Annex E)
  - An e-mail from Dr David Geddes regarding carers' names being logged on patients' notes (Annex F)

# **Issues Arising**

35. The following issues arose out of the evidence gathered during the course of the review:

#### **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
- Members expressed concern that the Strategic Health Authority (SHA) should be attempting to change the excellent EMISWEB intranet system used by GPs and pointed out that a compatible IT system should be used across all agencies.

#### **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
- o 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

#### **Training**

- Those who worked on elderly wards did not receive additional training in caring for patients with dementia.
- It was unfortunate that a forum arranged on mental health issues at York Hospital had been cancelled at short notice due to staff unavailability.
- Members referred to the fact that people were living longer and the elderly population was increasing; due to this there would be an increased incidence of dementia and there was possibly a need for more formal training for ambulance personnel.

#### **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

#### Other

- 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
- o 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.
- Of the twelve benchmarks of 'essence of care' significant developments had been made in all areas apart from mental health.

# **Analysis**

- 36. Members analysed the evidence and issues arising set out above at an informal meeting held on 21<sup>st</sup> October 2008. Their considerations led to the draft recommendations below.
- 37. Representatives of service providers and commissioners will have an opportunity to comment on the draft recommendations at the formal meeting on 3<sup>rd</sup> November 2008.

# **Corporate Priorities**

38. The review relates to the following corporate priority:

'Improve the health and lifestyles of the people who live in York, in particular among groups whose levels of health are the poorest.'

# **Options**

39. Having considered the information contained within this report and associated annexes, Members may decide to amend and/or agree the recommendations within the report.

# **Implications**

- 40. **Financial** There are no known direct financial implications for the Local Authority associated with the recommendations in this report. The Committee are mindful that there may be some financial implications for other health service providers in terms of providing funding to develop the Psychiatric Liaison Service and training of staff.
- 41. **Legal** Section 3(3) of the 'The Local Authority (Overview and Scrutiny Committees' Health Scrutiny Functions) Regulations 2002' states that 'Where an overview and scrutiny committee requests a response from a

local NHS body to whom it has made a report or recommendation, that body shall respond in writing to the Committee within 28 days of the request.'

42. There are no know Human Resources (HR), Equalities or other implications associated with the recommendations in this report.

# Risk Management

43. There are no known risks associated with this report.

#### Recommendations

- 44. In light of the above report Members are asked to agree the following recommendations:
  - 1. That the York Hospital Trust, in liaison with other appropriate service providers\* be urged to develop and implement the Psychiatric Liaison Service (Annex A). The development of this programme to be a benchmark for training and support for staff working with dementia patients who access secondary care.

\*The Yorkshire Ambulance Service is to be included amongst the service providers, whilst acknowledging the unique nature of their role.

REASON: To enable the development of the Psychiatric Liaison Service to progress.

- 2. That all service providers be urged to review their arrangements for staff training in relation to recognising and working with those with an underlying condition of dementia. Any such review should include:
  - Promoting the use of Link nurses and investigating the possibility of nominating Link clinicians within defined staffing groups.
  - Investigation of the large gaps in training.
  - The utilisation of the variety of sources for training provision including the Alzheimer's Society and other voluntary sector organisations.
  - Investigation into the pooling of resources between service providers.

REASON: To ensure that all staff are adequately trained to care for the needs of dementia patients accessing secondary care.

3. That secondary care provider clinicians be urged to acknowledge the positive contributions that can be made by a patient's carer to that patient's ongoing programme of treatment (whilst recognising the issues surrounding patient confidentiality). Clinicians are also urged to take the following into consideration:

- Where it is recognised that there may be an underlying mental health condition to provide written details of any medication and/or treatment plans to the patient.
- The issue of carers' information being logged on a patient's notes to be urged as good practice and an ongoing dialogue between medical practices and the York Carer's Forum to be maintained to allow for effective databases to be kept.

REASON: To ensure that carers are involved as much as possible whilst still recognising the need for patient confidentiality.

4.

- a. That all service providers be urged to work with the relevant voluntary organisations (Alzheimer's Society, York & District branch of Mind, Age Concern, Older People's Assembly etc) to develop new initiatives and to promote the awareness of dementia (including the provision of an information leaflet for carers).
- b. That commissioner and service providers discuss the 'This is Me' initiative further with the Alzheimer's Society with a view to adopting it within their individual organisations. The Committee wished it to be known that they were very impressed with this particular initiative.

REASON: To promote and increase dementia awareness and to encourage positive initiatives to be widely and effectively used.

5. That York Hospitals Trust, where possible, be urged to adopt a flexible approach during a dementia patient's stay in hospital, for example flexibility in hospital visiting hours and flexibility at mealtimes to allow carers to assist patients with eating.

REASON: To involve carers during a patient's stay in hospital to assist them in settling into an unfamiliar environment.

6. That all relevant parties be urged to resolve the ongoing issues surrounding the implementation of a universal 'Shared Care Record System' (Annex C refers).

REASON: To resolve ongoing issues

7. That all service providers (CYC, NYYPCT, YAS and York Hospital Trust) report back to the Committee in 6 months time to inform them of the progress that has been made.

REASON: To ensure that the recommendations are being addressed.

_				
Cor	ntact	t De	เรลเ	ıs

Annex F Annex G

Annex H

	_				
Author: Tracy Wallis Scrutiny Offic Scrutiny Serv 01904 55171 Specialist In	vices .	Chief Officer Resp Quentin Baker Head of Civic, Dem 01904 551004 Final Report Approved		-	
Legal					
Quentin Bake Head of Civic 01904 55100	c, Democratic & Le	egal Services			
Wards Affect For further in		e contact the autho	or of the rep	ort	All 🗸
Background	Papers:				
None					
Annexes					
Annex A Annex B Annex C Annex D Annex E	Response from the National Demention	ront line staff at York ie Local Medical Cor	mmittee	d by the	Alzheimer's

'This is Me' Leaflet produced by the Alzheimer's Society

Extract from 'Essence of Care - Patient focused Benchmarks for

E-mail from Dr David Geddes

Clinical Governance'



# CYC – Health Scrutiny – Dementia review 1<sup>st</sup> September 2008 Additional Information from York Hospital

#### WHAT A LIAISON SERVICE WOULD PROVIDE.

- Improved access to an initial mental health assessment and treatment for all patients.
- Early screening on admission with regard to mental health needs
- In depth assessment of mental health need for patient's in order to ensure the appropriate care, treatment and management of these needs at the same time as their physical health needs are being met.
- Ensure suitable risk assessments are undertaken regarding mental health need in order to reduce length of stay and prevent further loss of independence.
- Optimise and expedite discharge for patients with mental health needs.
   E.g. discharge home with care package instead of nursing/ residential home placement.
- Appropriate assessment for transfer to transitional and intermediate care for those with mental health needs.
- Reduce readmission rates for this patient group by ensuring comprehensive mental health assessment and referral onto specialist services.
- Training and awareness sessions for general hospital staff and ongoing modelling of patient centred care.
- Provide a source of information, advice and support to hospital staff regarding crisis management for patients in acute distress.

# Page 30

- To offer advice and support in developing ongoing plans of care to enable staff to deal with challenging behaviours, both during current and subsequent admissions.
- Improve joint working across all agencies particularly when assessing ongoing after care needs. Provide a link between Mental Health services (NYYPCT), Social Services (CYC) and general hospital services.

### Staffing required

Team Leader – specialist nurse in post Additional nursing Occupational Therapist 2 Sessions of psychiatrist Social worker Support Staff

Sue Beckett Heather Sweetman Dr. Kesavan

September 2008

#### Comments from front line staff at York Hospital

Members of the Committee visited front line staff at the hospital on 06.10.2008. They spoke to 3 Members of staff from the Trauma and Orthopaedic Unit (a Health Care Assistant, a Staff Nurse and a Deputy Sister) and also a Matron. They made the following comments in relation to their experiences of caring for patients suffering from dementia who accessed secondary care:

#### **Training**

- There were large gaps in training provision and Members of staff on non-elderly wards did not have sufficient training in caring for patients with dementia.
- A forum had been set up for staff in relation to mental health issues but most of these had been cancelled at short notice, as staff were unavailable to attend. The Matron thought that these could possibly be revamped and was willing to explore the possibility of this.
- As part of their general nurse training qualified staff receive a 7 or 8 week placement that covers caring for people with mental health conditions. Much of the time staff were expected to learn about care for dementia sufferers 'as they went along'. The Health Care Assistant (HCA) had received no formal training in this respect other than "on the job" training/experience.
- □ There were link nurses for things such as manual handling and infection control. It was suggested that there could also be a link nurse for mental health.
- Staff felt that formal training in dementia care would be helpful. Discussions were had surrounding using a link nurse to do this. The link nurse would then cascade information learned down to other members of staff on the ward.
- □ There were twelve benchmarks of 'essence of care' and significant developments had been made in all areas apart from mental health.

#### **Communication & Provision of Information**

- □ Communication between the patient and members of staff could be difficult especially when a carer wasn't present.
- □ The information that staff had was often from a printed sheet which frequently did not indicate the social needs of a patient.
- If a patient has no carers/family then communication can be very difficult as there is very little information regarding the social

background of the patient (i.e. what they like to eat, what their usual routines are).

- □ If the patient is admitted from a care home the care assistant may not know them very well (especially if there has been a recent shift change). A written handover sheet is given to staff at the hospital when the patient is admitted from a care home but if there is not enough information on this then staff will ring the care home and ask for more information about the patient. This sheet would usually indicate whether the patient was suffering from dementia.
- □ The possibility of a checklist of standard information that staff could mark off once received was discussed.
- It was the 'little things' that could make a patient feel comfortable such as knowing what they liked to be called, what they liked to eat etc. In the case of patients with dementia there was a higher need for social care even if they were on hospital for a physical problem.
- If a patient had been referred to hospital by a GP then he/she will have some knowledge of the patient's history and this would be passed on to staff.
- Discussions were had regarding continuity and staff handovers.
   Communication between staff was good whilst working and when the shifts changed.
- Information was also passed on to the multi-disciplinary areas such as physiotherapists and occupational therapists.
- Staff should let the bed manager or the Matron know that they need extra staff to assist with vulnerable adults and if they want a visit from the Specialist Health Nurse.
- A safety briefing was carried out at all shift handovers. Discussion were had as to whether this could be elaborated.
- Discussions were had in relation to the 'This is me' document that the Alzheimer's Society were developing. Hospital staff thought this was a very good idea and would be a useful tool for them.

#### **Hospital Environment & Patient Experience & Safety**

- □ The hospital environment is often alien and therefore frightening for patients suffering from dementia. It is common for dementia sufferers to feel uncomfortable outside of familiar surroundings.
- □ A patient will have suffered a traumatic experience (i.e. a fall) that has required admission to hospital. When a patient also suffers from dementia this can heighten the trauma.

- Patients with dementia can often be unsettled when they are unfamiliar with their surroundings and the people near them.
- If a patient presents with confusion (but has not been diagnosed with dementia) then the staff would initially look at ruling out infection as a cause. Once this had been done and if the patient was still confused then they would look at exploring whether there was an underlying mental health issue causing the problem. They were supported by the elderly medicine physicians who would come and visit the patient and advise the staff. There was also a Nurse Specialist in Mental Health.
- □ If a patient does not feel safe and calm then this will have a negative impact on the rest of the ward.
- To assist with patient safety patients with similar needs were often kept together in one part of the ward to allow staff to keep a closer eye on them.
- Patients with dementia often feel more at ease with some personal belongings near them. In the surgical wards this is not always possible due to the risk of infection. Infection control limited the hospital as to what personal belongings a patient could bring with them.

#### **Staff Time Constraints**

- □ Staff on a busy ward (such as trauma and orthopaedics) can sometimes struggle to spend time with patients to reassure them that everything is okay.
- If a ward is short staffed then it was a struggle at mealtimes. It was also more difficult to watch high dependency patients and to prevent patients from falling and wandering.
- Some patients on the surgical ward require one to one care for 24 hours a day and staffing levels had been increased to cope with this and ensure patient safety. Staff would still be under pressure at busy periods of the day though.
- □ The Matron liaised regularly with the teams regarding staffing issues. If there were issues then, where possible, other staff were sent to assist on a ward.
- Mealtimes, drug distribution and answering patient bells often clashed. There were some very busy times of the day, especially teatime when all of the above happened and patients were still coming back to the ward post operation.
- Staff had concerns regarding patient's dignity when they were disorientated. Certain events could be upsetting for staff, patients and

visitors and needed to be avoided. It was important to make the patient feel at ease but time did not always allow for this to be as effective as it could be.

□ There was only one Specialist Mental Health Nurse and if this area could be expanded it would be beneficial to all.

#### **Involvement of Carers**

- □ Staff do, where possible, encourage carers to provide information about the patient in order to care for them in the most appropriate way.
- Carers are also encouraged to help the patient at meal times and normal routines and where possible are incorporated outside of the normal visiting times. [Not sure whether this happens on all wards due to the protected meal times scheme].
- Staff try and get patients with dementia to follow a routine that they like and this can be achieved with the support of carers and family.
- Staff felt that communication could be improved with more carer involvement.

#### General

- People were living longer and therefore there were more instances of dementia in patients.
- Sometimes, in the early stages of dementia, the family would cover up for any problems there were.
- □ The introduction of a Psychiatric Liaison Service would be beneficial

#### Response from the Director of YOR Local Medical Council Limited

Having read through your paper, I can see where your concern lies, though I think almost every GP in York would take offence at the suggestion that family doctors no longer exist - most GPs of my age (40's) went into primary care as a positive choice to be family Doctors, and care deeply about the relationship between their Practices and the local communities.

The system we have is essentially a "shared care record system" between primary care and secondary care, it involves software called EMISWEB, building a local intranet between GP surgery systems and the Hospital - York and Selby are unique in having this system and ideally it should be a national example of excellence, but sadly it uses systems that are unpopular with the Strategic Health Authority (SHA), and hence gets little publicity from the Primary Care Trust (PCT).

Technically, GPs already have access to the hospital IT notes - and now consultants have access to summary pages of the GP records, although this does require patient/carer consent, so communication at ward level is still key. What it means is a Consultant any time of night or day can access the current drugs and recent entries for GP records and get a better picture of what has gone on, and also access demographic data including contact details.

This system mirrors the intended aims of the National NHS IT system but is about 2-3 yrs ahead of national developments, it is at threat as the SHA wants all practices to drop the EMIS system and change to an alternative software supplier - Systemone, which does not have this functionality. GPs at present are resisting this despite intense pressure from both the SHA and PCT as we feel for York it would be a backward step.

Every GP has a database of patients with a diagnosis of dementia and every GP should be carrying out an annual review of carer contact details - it is part of the quality and outcomes framework introduced with the GP contract in 2003-4, and one of the 157 new targets introduced for GPs at that time. The template for that is clearly defined and we are audited on achievement - a small payment (£125 annually per average practice of 5800 patients) is made to maintain this database. I have attached 2 "screenshots" of our template as used locally, which as you can see records whether or not there is a carer (not always the case) and contact details - also recording the relationship of the carer as well.

This page is intentionally left blank

## National Dementia Strategy for England update September 2008

This update is to inform Alzheimer's Society staff in England about work in progress on the Dementia Strategy. An Arena page on the NDSE is in development where this update and further information on the Strategy will be posted.

#### 1. Publication date change

The publication date for the NDSE has been changed from October to mid-November. At this stage there is no specific publication date.

#### 2. OMT sub group

A cross-directorate Operational Management Team (OMT) group has been set up to plan the Society's response to the NDSE on an ongoing basis. This group has met twice and will be meeting monthly for the foreseeable future. The purpose of the group is to ensure the Society is prepared to respond to the Strategy across the organisation.

Members of the group are Mary Garvey (Services), Linda Seaward (Marketing and Publishing), Louise Lakey (Policy), Phil Shoesmith (Business Planning), Alison Watt (Fundraising), and Andrew Chidgey (Policy and Campaigns and chair of the group). Please contact any of them with questions you may have.

#### 3. A reminder on what the draft Strategy proposes

The draft National Dementia Strategy for England describes a 5-year transformation plan for dementia in England. It has 15 recommendations.

- 1. Increased public and professional awareness of dementia through public awareness campaigns.
- 2. An informed and effective workforce through improved training.
- 3. Good quality early diagnosis through the development of more memory services which can diagnose and treat people with dementia.
- 4. Better access to information for people with dementia and their carers
- 5. Access to advice through a care adviser.
- 6. Better care in hospitals through older people's mental health liaison teams, clinical leads and developed care pathways.
- 7. Home care to be provided by a specialist dementia care service.
- 8. Improved access to short breaks/respite services.
- 9. NHS and local authorities to create joint dementia plans.
- 10. Improved access to intermediate care services where people are supported at home to keep them out of hospital, prepare them for hospital or to help them to recover from a hospital stay.
- 11. Better care in care homes through appointing dementia care leaders, specialist healthcare support and getting councils to ask for better standards in their contracts.
- 12. Change the system of registration for care homes so that all homes should be able to take people with dementia.

- 13.13. Make sure there is good information on the delivery of the Strategy in the future.
- 14. Create a research strategy on research that looks at how different research funders can collaborate to improve research efforts.
- 15. Support for implementation of the Strategy at a local and national level.

To see the full Strategy please go to www.dh.org.uk/dementia

#### 4. Society consultation response

The Society has made a formal consultation response to the Department of Health on the draft Dementia Strategy consultation, drawing on the views of 300 carers, 50 people with dementia, and a variety of other staff and volunteers. In addition the Society continues to have discussions with the Care Services Minister and the civil servants working on the Strategy.

The main points of the submission were as follows:

- This Strategy if implemented effectively within 5 years will make a significant difference to quality of life for people with dementia.
- The Strategy needs new money: The Society estimates that the cost of implementing the Strategy will be £600 million per year. This would require initial funding of £160 million in year 1 and £260 million in year 2 in order to begin changing practice. Over time service redesign will deliver efficiencies, but in the short term new money will be required.
- The vision of the Strategy: Although there must be an emphasis on transforming care and support, it must not be forgotten that this Strategy is about transforming the experience and lives of people with dementia.
- **Awareness:** Before a large-scale public awareness campaign, there is a need for robust research at the outset to establish baseline measures of the current levels of awareness, knowledge and stigma and the exact form that this stigma takes.
- Workforce development: The Society believes that the Strategy must incorporate a much stronger workforce development plan, following the precedent set in the End of Life Care Strategy. Although the Department does not have the power to make training mandatory, it can ensure workforce development through providing strong leadership to drive the agenda forward, working with key organisations and through the regulation system.
- **Diagnosis:** The care and support needs of individuals who do not have a clear diagnosis and their potential carers must be outlined.
- **Early intervention:** Barriers to low-level interventions, such as the Fair Access to Care Services criteria, must be addressed. It is unacceptable to have a system that works against providing any help to people with lower level and moderate needs.
- Access to dementia drug treatments: The Strategy is undermined by the current NICE guidance, which restricts access to drugs for people in the early stages of the disease. The role of dementia drugs in supporting people with dementia to live independently for longer must be specified.
- End of life care: The recently published End of Life Care Strategy did not adequately address the specific needs of people with dementia. End of life

- care for people with dementia has now fallen between the two strategies and must be urgently addressed.
- **Transport:** Consideration must be given to transport, which is a vital aspect of the infrastructure needed to support the care of people with dementia and carers.
- The needs of individuals: The Society welcomes the fact that the Strategy is an inclusive document, however, the importance of considering the unique needs of individuals must be highlighted where appropriate, for example younger people with dementia, people from black and minority ethnic groups and people with learning disabilities.

#### Key areas where extra detail is needed include:

- The dementia adviser role: To ensure that the role is provided consistently across England, it is vital that there is a clear job specification and an understanding of how it fits in with other roles such as outreach workers. The Society estimates with dementia care advisers acting to sign post people to services and a case load of 200 people, this would require between 650 and 950 dementia care advisers.
- Home care support: The Strategy should further emphasise some of the benefits of the different types of support discussed and encourage commissioners to support their development.
- Regulation in care homes: To ensure that care homes can deliver their primary role of providing care to people with dementia, it is vital that the new CQC registration requirements EXPLICITLY stipulate that all care homes can take people with dementia.
- Care home capacity: The absolute number of places needed will continue to rise and the Strategy must advise commissioners to acknowledge and address this issue.
- Antipsychotic drugs: The DH review must ensure that nonpharmacological alternatives to drugs are available and implemented.
- **Peer support networks:** The Strategy makes some reference to peer support networks where people with dementia and carers can support each other and learn how to live with dementia. These need increased emphasis in the Strategy.
- Abuse: The Strategy must put in place measures to prevent abuse, including adequate training, ongoing support and supervision, and legal protection.
- **Personalisation:** It is essential that personalisation is a strong thread throughout the Strategy, underpinning all the recommendations.
- Ensuring implementation: Delivering the Strategy will require cross-governmental working and the Strategy must give consideration to how this will be achieved. It is vital that progress is monitored on an annual basis, as has been committed to in the Stroke Strategy, with a benchmarking activity to lay out the current situation. Leadership at a national and regional level is vital for the Strategy's success.
- Research: Alzheimer's Society believes there should be prioritisation of funding for dementia research, for example by the Medical Research Council.

The full submission is on the Society website under consultation responses. <a href="http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200168">http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200168</a>

Please contact Louise Lakey <u>louise.lakey@alzheimers.org.uk</u>, 0207 423 3581 or Alice Jarratt <u>alice.jarratt@alzheimers.org.uk</u>, 0207 423 3580 for more information.

#### 5. Political influencing update

Thank you to all branches who have been in contact with their MPs to ask them to press the Government for financial commitment to the Strategy. Some branches have been able to meet their MP, while others have written. If you have not done so, please write to your MPs asking them to press Ivan Lewis, Care Services Minister for funding.

Central office is building on this work by lobbying target MPs and Peers and at the party political conferences. All MPs in England have been contacted.

This week the Society is releasing opinion poll evidence which shows that amongst the over 55 year olds (the age group most likely to vote), dementia is feared more than cancer, heart disease or stroke. In addition three quarters of people cannot explain which political party has the best policies for older people. For further details please see the website.

In the October edition of Living with Dementia magazine members of the Society in England will be asked to send their MP a 'Fund the Dementia Strategy' postcard. Branches will be sent a further batch of postcards to distribute.

Please contact Sarah Thomas <u>sarah.thomas@alzheimers.org.uk</u>, 0204 423 3585 or Vicki Combe <u>vicki.combe@alzheimers.org.uk</u>, 0207 423 3584 for more details.

#### 6. Regional seminars

The next round of area forums (October/November) will be provided with updates for discussion and possible action.

A series of regional seminars is being arranged for the end of October/early November to ensure that staff and volunteers who are in contact with local NHS and social care commissioners are in a position to put the case both for the Dementia Strategy and for the role of the Society in responding to it. Area managers are nominating staff and volunteers to attend these initial events which will also put attendees in a position to be able to advise others.

### 7. Commissioning tool kit

A tool kit folder for staff and volunteers in contact with health and social care commissioners is being created. This will have a booklet setting out the case for dementia which will arm our staff with information so they are better placed to persuade commissioners about the case for Dementia Strategy implementation and will also act as information to leave with commissioners. In addition there will be information leaflets about the different aspects of the

service offer that the Society can provide (e.g. Dementia care adviser, training...). This information will be available in digital form on Arena by the end of October followed as quickly as possible by printed materials.

Please contact Andrew Chidgey for more information achidgey@alzheimers.org.uk, 0207 423 3583.

#### 8. Service offer update

Many staff have asked for advice on what they should be saying to commissioners in their discussions about new services. Because we do not yet have a National Dementia Strategy, and cannot be sure exactly what will be in it, it is hard to be exact about our contribution to its implementation. In this interim period we need to continue to promote our organisation and its services, being positive about our intention to contribute fully to the implementation of the new strategy.

- The Society strongly welcomes the focus in the draft Strategy on the need for better information services, proposals for dementia adviser role and the need for an informed and effective workforce.
- There now needs to be much greater clarity in the final Strategy document about the role of dementia adviser and how it is envisaged it will fit with other existing services.
- The Society believes that the third sector is well placed to provide the new dementia adviser service. We want to be involved, and have begun work on developing the dementia adviser service, drawing on our vast experience of delivering information and support services to people with dementia and their carers.
- We are developing our information services so that they better meet individual needs. We will develop tools to enable better access to information about <u>local</u> services for people with dementia.
- We will establish demonstration sites around England for the new services, where rigorous evaluation will provide evidence of the impact of the service on the quality of life of people with dementia.
- We already have a track record in the delivery of training, and we intend to build on this.
- We are unlikely to publish externally the details of our proposed new dementia adviser role and other services until after the launch of the National Dementia Strategy in November.

#### **Further information**

An information challenge project group has been established, chaired by Mary Garvey. This group will

- Develop our information tools and technologies.
- Develop the role of dementia adviser.
- Develop demonstration sites that will be fully funded and fully evaluated.
- Communicate about this work.

Work has begun on all the above. A group of staff from across services will work on the development of the dementia adviser role. At the time of the

launch of the National Dementia Strategy, we will be ready to share publicly the details of our new dementia adviser service.

New services will have some features in common with our existing services. There is no intention that they replace these services. We want more services for people with dementia. In time, particularly when the learning from the evaluation becomes available, some of our existing services may adopt some of the methodologies and tools of dementia advisers. Any changes resulting from the launch of new services will happen in a planned way.

Please contact Mary Garvey <u>mgarvey@alzheimers.org.uk</u>, 0207 423 3531 for more details.

#### 9. PCT letter

Given that the Dementia Strategy publication date has moved to November this will be well after the planning round for the financial year 2009/10 has started. The Society will be writing to all PCT Chief Executives in England explaining the priorities identified in the Strategy in the next week. If there are any Chief Executives who branches or area teams would not like us to write to because there is already close contact on this please contact Alice Jarratt by emailing <a href="mailto:already.given:

#### 10. External messages

The communications plan for the National Dementia Strategy for England is being reviewed in light of the close of the consultation. An update will be posted on Arena including our revised key messages. Meanwhile if you are asked for an media interview on the strategy please contact your Regional Campaigns and Media Officer or Gayle Wing, head of media relations on 0207 423 3595 <a href="mailto:gwing@alzheimers.org.uk">gwing@alzheimers.org.uk</a> for a briefing.



## Care on a hospital ward

Someone with dementia may be admitted to a general or specialist hospital ward either as part of a planned procedure, such as a cataract operation, or following an accident, such as a fall. Hospital environments can be disorientating for a person with dementia, and may make them appear more confused than usual. However, there is much that can be done to help them adapt to the new environment. They will need reassurance, along with timely and sensitive support. This factsheet is designed for friends, family or caring professionals. It covers some of the issues that should be considered and explains the standards of care that people with dementia and carers should expect.

## Help from hospital staff

Ward staff will not necessarily know that an individual has dementia, or may lack experience in working with people with dementia, so it is helpful if relatives and friends can give them information on how dementia is affecting the individual and suggest ways of assisting and communicating with the person. This will make it easier for ward staff to ensure that the person with dementia is comfortable.

Staff should be happy to answer any questions and discuss any issues you may have. If they seem too busy to talk, ask to make an appointment - ideally with the named nurse. The named nurse (who is always a trained nurse) will be responsible for co-ordinating the person's care. This meeting will be an opportunity to discuss any concerns, and should provide a good basis for future communication. If any problems arise later, they can then usually be sorted out through the named nurse. If you want to discuss the person's condition or treatment in more depth, ask to make an appointment to see the doctor or the consultant.

Some hospital trusts provide a mental health service. Assessment and advice from a member of this team can help nursing and medical staff manage any difficulties the person may be experiencing as a consequence of their dementia. If you are concerned that the person's dementia is deteriorating, you may want to make an appointment with the mental health team.

You may also want to make an appointment to see the hospital social worker. The social worker can advise on a range of matters, such as:

- problems getting to and from the hospital to visit
- benefits
- residential and nursing care
- · help at home
- difficulties for carers or friends or family, such as illness, disability, stress or other commitments that may affect their ability to visit or to continue to care for the person. These should also be discussed with the named nurse.



## Information about the person with dementia

It is important that all staff are aware of the person's dementia. The named nurse should explain to other members of staff how dementia can affect the person's behaviour and communication. They should also tell staff how the person prefers to be addressed - for example, informally, such as 'Charlie', or formally, such as 'Mr Cohen'.

As information can become lost or forgotten, it can help if a friend, carer or family member writes down some important information about the person with dementia. This written information can be given to the named nurse at the first meeting, and should be held in the person's notes. One side of A4 paper is quite enough. The information should include:

- the name by which the person wishes to be known
- brief details of their normal routines, including whether they need reminders or support with washing, dressing, going to the toilet, eating and drinking or taking medication
- information about foods they particularly like or dislike, or any difficulties they have eating
- illness or pain that may bother them
- any cultural or religious needs
- information about sleeping patterns
- whether the person likes to be active or inactive for example, if they walk about - and what can calm them when they are agitated.

It may be helpful to include some tips for staff. For example:

- 'Mr Cohen finds it helpful if people talk slowly and give one piece of information at a time.'
- 'Saul is more likely to understand if people maintain eye contact while they are talking to him.'
- 'Miss Sellers can feed herself with a spoon if someone cuts her food up.'
- 'Ravi often rocks and holds his tummy if he is in discomfort or pain.'

It may also help staff to communicate and gain more insight into the person with dementia if they have details of the person's:

- close family members or friends
- pets



- living situation for example, whether they live with others or alone
- past occupation
- particular interests.

If the person with dementia frequently walks around the ward, this may make staff anxious. If this is likely, explain that the person finds it comforting to walk around and that staff will need to accommodate this. You may need to describe what degree of supervision is required. You could also emphasise the benefit of involving the person in suitable activities on the ward.

## Tips: how you can help

#### Practical assistance

If you choose, you may be able to help with the person's personal care (for example, taking them to the toilet or supporting them at mealtimes). If you would like to do this, discuss it with the named nurse. Other ways in which you can help might include:

- cleaning spectacles and checking on hearing aids
- making sure clothes are discreetly labelled in case they are mislaid
- thinking of enjoyable pastimes or items to occupy the person's time.

## **Providing reassurance**

- Familiar objects, such as photographs on the bedside table of family members or a much-loved pet, can be very reassuring for a person with dementia on an unfamiliar hospital ward. They can also provide staff with a good talking point. If the person still reads, you could provide a notebook, so staff and visitors can write messages, reminders and details of when they are next visiting.
- Noise and bustle on the ward can add to the person's confusion and heighten their levels of anxiety or agitation - particularly at busy times, such as ward rounds or visiting hours. You could ask if there is a quiet room or day room that the person can visit to get away from the bustle and relax in peace.

## **Eating and drinking**

- Mealtimes in a busy hospital environment can be difficult and stressful for a
  person with dementia. Make staff aware of any difficulties that the person
  has at mealtimes, and how they can help. Make sure the person is given the
  option of eating in the dining room, if there is one, or at their bedside if they
  prefer.
- Make sure staff help the person with dementia to eat and choose food if necessary, and don't assume that the person isn't hungry or doesn't want their food if they don't seem keen to eat it. Some people with dementia cannot eat their food without reminders and prompts at mealtimes. Staff are often extra busy at mealtimes, and may be grateful for any help you can offer in helping the person to eat. You may like to discuss this with the named nurse.
- If the person has difficulty swallowing, ask if they can be assessed by a speech and language therapist, or if food can be provided in a soft or pureed texture. If the person is not eating well, or is losing weight, the named nurse should contact the hospital dietitian. The dietitian will co-ordinate a nutritional care plan with nursing and catering staff, which may involve prescribing high-energy drinks or specific foods.
- If the person with dementia is very unwell, they may not want to eat or drink. 'Tube feeding' may be suggested as a means to help a person receive food and fluids. The terms 'nasogastric' or 'gastrostomy' (PEG) tubes are often used. The decision to tube feed should only be made respecting the wishes of the patient and in full discussion with carers or relatives.

### Medication

- Doctors should discuss the person's medication, and any changes, with the person with dementia and their carer or relatives.
- If the person is prescribed sedative medication, this may make them more confused. It may be possible to reduce the dose or stop the medication altogether. If you have any concerns, discuss these with the doctor. (For more information about avoiding drugs unless they are really necessary, see

Factsheet 408: Dementia: Drugs used to reduce behavioural symptoms.)

## Complaints

If you have any problems with the person's treatment or care, discuss these first with the named nurse. He or she should explain why things went wrong and how they will be put right. Use the following tips to complain effectively:

• Try to start on a positive note by mentioning something you have appreciated about the person's care.



- Try to make the complaint specific for example, on three occasions you came in and saw that the drugs on the table had not been taken. It may help you to have the details written down.
- Try to stay calm.

If it is not possible to sort the problem out on the spot, keep brief notes, as it is easy to forget details. The notes should include:

- · what occurred and when
- who you contacted or discussed this with, and what their response was.

If the problem still cannot be resolved, ask to see the ward manager or make an appointment with the consultant. Alternatively, you may prefer to contact the patient advice and liaison service (PALS). PALS acts on behalf of patients and families, and liaises with hospital staff to help resolve problems and concerns quickly.

## **Discharge**

Discharges should be planned, and carers or family should receive advance notice. However, decisions can often be made quickly, so you should begin preparations as soon as the person goes into hospital. The social worker can advise on the suitability of residential or nursing care, or on ways of helping when the person returns home. An occupational therapist can assess the home environment to advise on any aids to help support the person living at home. (See Factsheet 453, Hospital discharge.)

If the person has received specific advice and input from a specialist (for example, a dietitian) while on the ward, make sure follow-up care is arranged. Ask for contact numbers for further review once the person is back in the community.

#### At the end of life

- If the person is in the last stages of life, those who are close to them may want to stay with them outside visiting hours. Discuss possible arrangements with staff.
- Depending on the nature of the person's illness for example, if the doctor feels the person is likely to have a heart attack - you may need to consider your views on resuscitation. The medical team and consultant should always discuss such issues and decisions with the main carer or family members. It may help to talk it through with family or friends. If anything is unclear, ask them to explain any terminology they use.



 The person may have set out their own wishes regarding resuscitation in an advance decision, in which case you need to simply follow their wishes (see Factsheet 463, Advance decision).

Your local Alzheimer's Society branch will always be willing to talk to you and offer advice and information to support your needs.

For more information, Dementia Catalogue, our specialist dementia information resource, is available on the website at alzheimers.org.uk/dementiacatalogue

#### Factsheet 477

Last updated: July 2008 Last reviewed: July 2008

Reviewed by: Polly Hauxwell, Head of Service Development, Alzheimer's

Society

#### E-mail from Dr David Geddes

The issue of carers being logged on patients notes has been for a long time pushed as good practice - supported by the sterling work of the Carers group in York. Each practice has a lead for carers issues and tries to maintain a database of carers for their patients. - Difficulties always arise because of course quite often a carer will not be registered at the same practice as the patient - and the database is notoriously difficult to keep up to date.

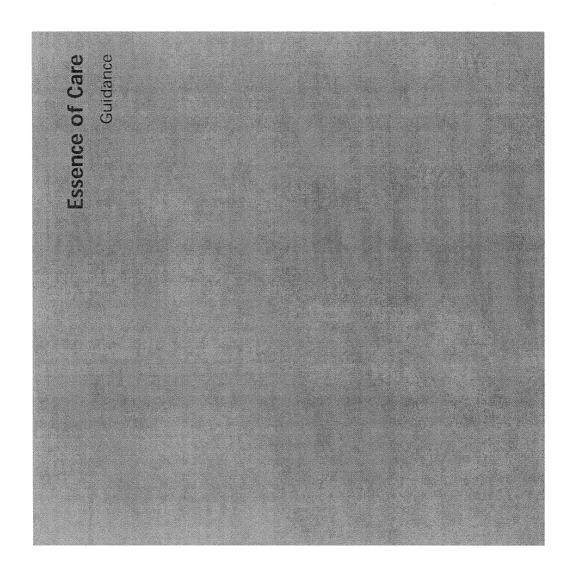
I spoke with the carers group recently to see how we can support this as an ongoing piece of work, - the carers group have also updated their information guide to practices. This page is intentionally left blank



## **Essence of Care**

Patient-focused benchmarks for clinical governance

## NHS Modernisation Agency



#### INTRODUCTION

This document contains the toolkit for benchmarking the fundamentals of care. This includes the background to *Essence of Care* (page 1), a description of the benchmarking tool (page 3), how to use the benchmarks (page 4) and record forms for developing action and business plans (appendices one to seven). Nine sets of benchmarks are also included. It is intended that health and social care personnel<sup>1</sup> use this document to address issues of concern within their areas of work and or to improve services already provided.

#### **BACKGROUND**

The NHS Plan (2000) reinforced the importance of 'getting the basics right' and of improving the patient experience. The Essence of Care, launched in February 2001, provides a tool to help practitioners<sup>2</sup> take a patient-focused<sup>3</sup> and structured approach to sharing and comparing practice. It has enabled health care personnel<sup>4</sup> to work with patients to identify best practice and to develop action plans to improve care.

Patients, carers and professionals worked together to agree and describe good quality care and best practice. This resulted in benchmarks covering eight areas of care:

- Continence and bladder and bowel care
- Personal and oral hygiene
- Food and nutrition
- Pressure ulcers
- Privacy and dignity
- Record keeping
- Safety of clients with mental health needs in acute mental health and general hospital settings
- Principles of self-care

It should be recognised that all sets of benchmarks are interrelated. For example, there are elements of *privacy and dignity* that link with *continence and bladder and bowel care*.

¹It is recognised that people are cared for in a variety of settings. For brevity the term 'health' will be used to include 'social' personnel, care or organisations.

<sup>2</sup>In the *Essence of Care* the term 'professional' refers to any registered health care practitioner regulated by a professional statutory body. The term 'practitioner' refers to any health care employee delivering direct patient care. Unless otherwise stated, the term 'carer' refers to both formal and informal carers, including families, relatives and significant others.

In July 2002 work began to develop further benchmarks focusing on communication between patients and or carers and health care personnel. These were written in response to requests from those taking part in the initial compilation of the *Essence of Care*, as well as many patients, carers and practitioners who have since used the *Essence of Care* toolkit. The new set of benchmarks complement the existing eight sets and relate closely to, for example, the *record keeping* and *privacy and dignity* benchmarks.<sup>5</sup>

The benchmarks have been presented in a revised format that takes account of the experience and comments of those who have been using the *Essence of Care*. Although the format of the original benchmarks has been simplified the *benchmarks of best practice* and *poor practice* remain the same. In addition, the intervening steps to best practice have been removed since these may vary according to local circumstances.

The benchmarks are relevant to all health and social care settings. Therefore, the *Essence of Care* is presented in a generic format in order that it can be used in, for example, primary, secondary and tertiary settings and with all patient and or carer groups, such as in paediatric care, mental health, cancer care, surgery and medicine. It is important that those benchmarking (including patients and carers) agree the indicators that demonstrate best practice within their area of care.

<sup>&</sup>lt;sup>3</sup>Please note that the term 'patient' also includes 'service-user', 'consumer', 'client', etc. For brevity the term 'patient' will be used to cover all of these unless otherwise stated.

<sup>&</sup>lt;sup>4</sup>The term personnel refers to any person employed by the care provider who communicates with the patient. <sup>5</sup>Initially there were two sets of communication benchmarks, one for communication with patients and health care personnel and one for communication with carers and health care personnel. However, at the final review stage it was noted that each set of benchmarks incorporated values that were very important to both patients and carers. In view of this the two sets of benchmarks were merged to provide one stronger set of benchmarks for reviewing wider practice in relation to issues that are pertinent to both patients and carers.

#### CONTENT OF BENCHMARKING TOOL

The Essence of Care benchmarking toolkit comprises of:

- an **overall patient-focused** outcome that expresses what patients and or carers want from care in a particular area of practice
- a number of **factors** that need to be considered in order to achieve the overall patient-focused outcome

Each factor consists of:

- **a** patient-focused **benchmark of best practice** which is placed at the extreme right of the continuum
- **a continuum** between poor and best practice. The benchmark for each factor guides users towards best practice
- **indicators** for best practice identified by patients, carers and professionals that support the attainment of best practice
- information on how to use the benchmarks
- accompanying forms to facilitate documentation

#### **USING CLINICAL BENCHMARKS**

Essence of Care benchmarking is a process of comparing, sharing and developing practice in order to achieve and sustain best practice. Changes and improvements focus on the *indicators*, since these are the items that patients, carers and professionals believed were important in achieving the benchmarks of best practice. The stages involved in benchmarking are highlighted below broadly they are:

Stage One - Agree best practice

Stage Two - Assess clinical area against best practice

Stage Three - Produce and implement action plan aimed at achieving

best practice

Stage Four - Review achievement towards best practice

Stage Five - Disseminate improvements and or review action plan

Stage Six/One - Agree best practice

To assist you the relevant documentation is included in the appendices.

The process can be accomplished using the PDSA cycle (Plan, Do, Study, Act) (see Langley et. al., 1996 cited in Modernisation Agency, 2002) that has been designed to test a 'change idea'. For more information about the model for improvement refer to the *Improvement Leaders Guides on Measurement for Improvement* available at:

www.modern.nhs.uk/improvementquides/measurement

#### BENCHMARKING PROCESS

#### STAGE ACTIVITY

ONE Agree best practice

- ◆ Consider the patients' or carers' experiences and outcomes, and how current care is delivered. The clinical governance questions and general indicators<sup>6</sup> (see appendix one and two) may provide useful quidance at this step
- ◆ Agree clinical benchmarks to be considered (appendix three)
- ◆ Establish a comparison group<sup>7</sup> (appendix four)
- ◆ Consider the overall outcome and the benchmarks of best practice
- ◆ Using the general indicators (appendix two) and specific indicators agree the evidence that the comparison group consider necessary to be provided in order to achieve the benchmarks of best practice

TWO Assess clinical area against best practice

- ◆ Obtain baseline information by observing practice, using audit and involving patients in the clinical area
- ◆ Consider the indicators and provide evidence that represents current achievement towards best practice (appendix three)
- ◆ Consider barriers which prevent achievement of best practice (appendix three)
- ◆ Compare and share best practice so that good practice is not wasted. Some comparison groups find considering their positions on an E (poor practice) to A (best practice) continuum useful to stimulate discussion

<sup>6</sup>General indicators are common to all sets of benchmarks. Specific indicators are particularly relevant to the factor with which they are identified.

#### **BENCHMARKING PROCESS**

#### **STAGE ACTIVITY**

#### THREE Produce and implement ◆ Produce an action plan detailing: action plan aimed at

achieving best practice

- - the changes that need to be made to improve practice
  - who is responsible for leading the changes
  - the time scale in which these should occur
- ◆ Actions should be realistic, achievable and measurable (appendix five)
- ◆ Carry out the action plan

#### FOUR Review achievement towards best practice

- ◆ Document activities, any improvement, problems and or unexpected observations (appendix six)
- ◆ Analyse data and evaluate actions did the patients' or carers' experiences or outcomes improve? Did service delivery benefit from changes made? (appendices three and six)
- ◆ If there is no improvement review activities in action plan
- ◆ Share with comparison group

#### FIVE Disseminate improvements and or review action plan

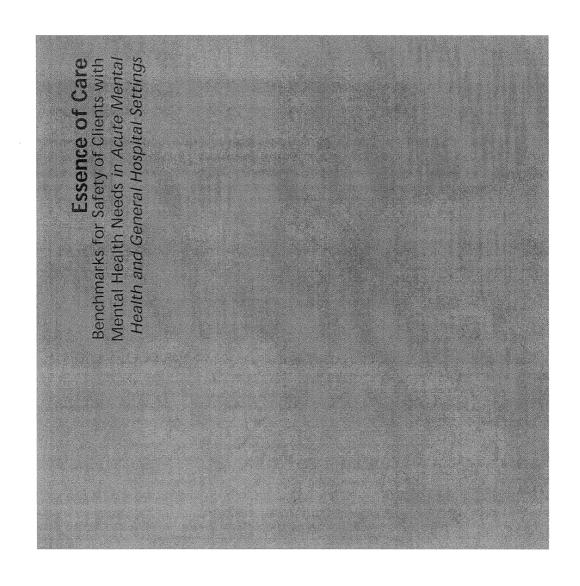
- ◆ If improvements are identified, disseminate good practice and implement change as widely as appropriate through comparison group and other organisational systems
- ◆ Include in organisation's business planning cycle, clinical governance plan and quality report via relevant managers, and clinical governance and quality leads (appendices one and seven)

#### SIX Agree best practice

◆ As stage one

<sup>7</sup>The aim of the comparison group is to compare and share practice likely to contribute to attaining the benchmarks. This is in order that members can support each other in progressing towards best practice. A comparison group may consist of individual health care personnel, members representing a team, members representing an organisation and so on. The group should include individuals who have an interest in achieving best practice as well as individuals who can represent patient and or carer involvement in the process.

## NHS Modernisation Agency



For the purpose of these benchmarks:

Safe = freedom from physical, mental, verbal abuse and or injury to self and others.

Secure = emotional safety

Relational security = clients needs are met through the development of trusting and genuinely therapeutic relationships with the client by members of the care team within safe and fully explained boundaries

Engagement = clients have staff who connect with them continuously, in an atmosphere of genuine regard, instilling feelings of well being, safety, security and sanctuary

Harm = to injure, hurt or abuse

NB: This benchmark was completed specifically for use in Acute NHS general settings but may be applied to any care setting

## Benchmarks for Safety of Clients with Mental Health Needs in Acute Mental Health and General Hospital Settings

## Agreed client-focused outcome

## Everyone feels safe, secure and supported with experiences that promote clear pathways to well being

	Factor	Benchmark of best practice			
1	Orientation to the health environment	All clients are fully orientated to the health environment, in order to help them feel safe			
2	Assessment of risk of clients with mental health needs harming self	Clients have a comprehensive, ongoing assessment of risk to self with full involvement of client to reduce potential for harm			
3	Assessment of risk of clients with mental health needs harming others	Clients have a comprehensive, ongoing assessment of risk to others with full involvement of client to reduce potential for harming others			
4	Balancing observation and privacy in a safe environment	Clients are cared for in an environment that balances safe observation and privacy			
5	Meeting clients safety needs	Clients are regularly and actively involved in identifying care that meets their safety needs			
6	A positive culture to learn from complaints and adverse incidents related to harm and abuse	There is a no blame culture which allows a vigorous investigation of complaints and adverse incidents and near misses and ensures that lessons are learnt and acted upon			

#### Factor 1 - Orientation to the health environment

Clients are not orientated to their care setting.
Therefore they do not feel safe

#### Benchmark of best practice

All clients are fully orientated to the environment, in order to help them feel safe

F

A

Full orientation: - made familiar with and understand the philosophy, people, services, environment, policies/processes/ procedures and physical layout, know how to access key worker and relevant information

## Indicators of best practice for factor 1

- clients are orientated and how orientation is focused around the client groups' cognitive skills
- somebody is responsible for orientating the client to the ward which can include staff and other clients
- specific action is taken to make women and other vulnerable service users feel safe and secure
- resource materials such as booklets and videos are used to promote orientation
- appropriate topics are covered in the orientation
- a person is identified who talks through what will happen to them and who will be initially looking after them
- key workers are identified and whether consideration is given to individual needs

## Factor 2 - Assessment of risk of clients with mental health needs harming self

Clients do not have an assessment made of their risk of harm

#### Benchmark of best practice

Clients have a comprehensive, ongoing assessment of risk to self with full involvement of client to reduce potential for harm

#### Indicators of best practice for factor 2

- the key indicators of risk are included in the risk assessment tool questions
- assessment is undertaken by inpatient and community teams prior to discharge and whether this includes assessment of risk and joint case review which includes discharge planning
- users are involved in the training of staff, to ensure that assessment and management is appropriate and sensitive to specific needs, for instance, religion and culture, age related needs, human rights, child protection, previous, history of life events: and to specific treatments such as medication and ECT
- knowledge of a clients' history, social context and significant events since admission are ascertained, recorded and shared
- staffs attitudes to self harm are ascertained, measured and supported
- any outside user agencies are used to act as support or information for clients who self harm such as the national self harm network, SHOUT, black and minority ethnic voluntary organisations
- procedures are in place to ascertain presence of and to identify misuse of alcohol and drugs

## Factor 3 - Assessment of risk of clients with mental health needs harming others

Clients do not have an assessment made of their risk of harming others

#### Benchmark of best practice

Clients have a comprehensive, ongoing assessment of risk to others with full involvement of client to reduce potential for harming others

## Indicators of best practice for factor 3

- the risk assessment questions asked and tool used include the key indicators of risk
- assessment is undertaken by inpatient and community teams prior to discharge and whether this includes assessment of risk and joint case review
- knowledge of a client's history, social context and significant events since admission are ascertained, recorded and shared (including sharing and liaison between general and mental health areas)
- health care personnel attitudes to harm are ascertained, measured and supported and how this is done
- outside user agencies are used to act as a support or information mechanism
- procedures are in place to ascertain presence of and to identify misuse of alcohol and drugs
- further support is available for example, Rape Crisis, Incest Survives and The Samaritans

## Factor 4 - Balancing observation and privacy in a safe environment

Clients are not accorded privacy nor cared for in an environment that allows safe observation

#### Benchmark of best practice

Clients are cared for in an environment that balances safe observation and privacy

F

Α

#### Indicators of best practice for factor 4

- there is an up to date observation policy, who is involved, for instance, the multi disciplinary team and whether this is audited. This should include who observes the client and the qualifications, for example, qualified or unqualified, the status awarded the task and how it is ensured that observations are supportive and therapeutic
- resources allow the increased observation of clients in the evening and at night and prior to discharge
- the skill mix, roles and attention to gender of practitioners have been adapted to release them to carry out clinical observations, for example, administrative support
- opportunities are taken for maintaining privacy and dignity during observations
- you inform or educate the client regarding the observational processes and how their satisfaction with these processes are ascertained
- carers' satisfaction with observation and privacy is ascertained
- the privacy of women and other vulnerable groups are secured
- environmental safety checks are made regarding removal of any obstructions to observation and preventing access to means of suicide and, for example, window opening, safety glass, structures that could be used in suicide by hanging, safe storage of drugs and other harmful products and the effective administration of drugs to prevent stockpiling

### Factor 5 - Meeting clients safety needs

Clients ongoing safety needs are not considered

#### Benchmark of best practice

Clients are regularly and actively involved in identifying care that meets their safety needs

F

- A

Review: - Care plan review intervals should be agreed individually and reviewed/evaluated as stated in the care plan NB: Negotiated evidence based care plans and personal crisis plans are an integral part of the Care Programme Approach (1999)

#### Indicators of best practice for factor 5

- safety needs are addressed in the care plan and regularly considered in care reviews and how this is acheived
- clients are encouraged to express any safety and security concerns
- the quality of care plan documentation is assessed and audited and how this is done
- clients are involved in negotiating choice of primary nurse for example, gender
- the client has a copy of the care plan in a format that they understand, and how clients can demonstrate that they understand, input into and are in agreement with it (gain ownership). If not why?
- communication barriers are overcome and how this is achieved
- known clients are enabled to detail personal crisis plans and preferences when well, where these are recorded and kept and how these are taken into account and used during an acute crisis
- further support is sought from agencies such as Rape Crisis, Incest Survives and the Samaritans

# Factor 6 - A positive culture to learn from complaints and adverse incidents related to harm and abuse

Clients do not feel able to report adverse incidents and complaints

#### Benchmark of best practice

There is a no blame culture which allows a vigorous investigation of complaints and adverse incidents and near misses and ensures that lessons are learnt and acted upon

Ε

Δ

Adverse Incidents/Experiences – may involve actual or implied harm and includes physical, sexual, psychological, verbal and emotional abuse.

#### Indicators of best practice for factor 6

- the complaint procedure is made user friendly, accessible, and useable, particularly for vulnerable groups and how barriers to communication are overcome
- systems are in place for staff, practitioners or carers to report practitioners who are abusive or harmful
- critical incidents such as acts of violence, aggression, seclusion and procedures and policies are audited, including ensuring that action is taken if required
- risk related information is collected and used in determining resources and monitoring performance and to inform training
- outside agencies or advocates or user groups are involved in audit of complaints and critical incidents and evaluation of services
- when critical incident reviews occur, there are client and staffing debriefing arrangements in place and how these influence practice

This page is intentionally left blank

This is about me in my home, an environment I am familiar with, and with people I know and who know me well. I will need time, support and reassurance in an environment I don't know.

My Name

I like to be known as

Where I currently live

\* I agree that the information in this leaflet may be shared with health and care workers.

Carer/the person who knows me best

I would like you to know

## **About me**

My home & Family things that are important to me	
My early years	

My hobbies and interests

Things which may worry or upset me

What helps me to relax

Date completed: By whom:

Relationship to patient:





## **Scrutiny Management Committee**

**17 December 2008** 

Report of the Head of Civic, Democratic & Legal Services

#### **SCRUTINY REVIEW SUPPORT BUDGET**

## Summary

1. This report summarises the position to date on expenditure against the budget available specifically for supporting scrutiny reviews in 2008/9. It also seeks Members views on the available budget for 2009/10, with a view to making a recommendation to the Council as part of the budget setting process.

## **Background**

- 2. This Committee has the constitutional right to consider and recommend to Council a suitable scrutiny budget, to be used for the effective support of any agreed reviews during a year.
- 3. For the 2008/9 financial year, scrutiny was allocated a basic budget of £6,000 to support its reviews. However, an additional sum of £14,000 was also set aside by Council from the Contingency Fund to undertake further research/consultancy work requested by the ongoing Traffic Congestion Ad-Hoc Scrutiny Sub-Committee. As a result, it is understood that year on year a research/consultancy support budget of £20,000 is now available, subject to any savings cuts which the Council may, of course, decide to make against this budget at its Budget Meeting in February 2009.

#### **Budget Monitoring**

- 4. As at December 2008, expenditure against this budget is £570. So, far the full resident survey planned by the Traffic Congestion Ad Hoc Scrutiny Sub-Committee has not yet been effected and was originally estimated to cost around £17k. It is still possible that that survey could be commissioned, undertaken and charged for within the current financial year. However, that would become more unlikely as time progresses.
- 5. In September 2006, a sum of £250 of expenditure was allocated per Scrutiny Committee or Ad-Hoc Sub-Committee to support administrative and consultative processes associated with their reviews from this budge. This was agreed on the basis that requests for more funds could be made to Scrutiny Management Committee (SMC).

**6.** Only one request for additional funds has been made to SMC this year so far – this being from Education Scrutiny Committee in respect of its school governors review, when they requested a further £650 to undertake a full survey.

#### Consultation

7. The Head of Financial Services has been consulted on the preparation of the report to ensure it complies with the constitutional and statutory requirements for feeding into the budget process for 2008/9.

## **Options**

- 8. The information on budget expenditure in 2008/9 to date is merely for noting. However, Members have the constitutional right to consider what recommendation they wish to make to Council in relation to the allocation of budget for supporting scrutiny reviews in 2008/9. Council will receive that recommendation at its budget meeting on 21 February 2008, consider it and set an appropriate figure for this budget accordingly.
- 9. Members also have the option to review the sum allocated for spend on each agreed review. As referred to in paragraph 5 above, that amount is currently £250 but is relatively low. Given the on year increase in this support budget, Members may wish to consider revising the sum initially awarded for reviews, by increasing it to £500.

## **Analysis**

- 10. Members should consider what scrutiny support budget they wish to recommend to the Executive, taking into account the following issues:
  - a. Current level of expenditure;
  - b. What the budget is used for now and what it could be used for in 2009/10:
  - c. The current budget climate in general;

#### What is or Could the Budget be Used for?

- 11. Currently, and over the past 2 financial years, this budget has been used to cover expenditure on the following range of consultative events and information gathering exercises:
  - a. Community meetings
  - b. Drop in centre events
  - c. Site visits to other local authorities or places of interest related to the scrutiny taking place
  - d. Publicity associated with any of the above
  - e. Conferences and training events in relation to any Member training on scrutiny or an ongoing review.

- f. Surveys/questionnaires
- g. Consultant fees (where appropriate). In the last 2 years, technical experts (eg. In relation to Traffic Congestion Review) have been co-opted onto the Scrutiny Committees and given their time, freely.
- 12. In the next financial year, it is anticipated that the budget will be largely used in much the same way. However, it is envisaged that the decision taken by Council to adopt an alternative scrutiny structure will have an effect upon this budget. As from the Annual Meeting in 2009, there are likely to be more standing scrutiny committees with wider remits and in turn, it is possible that they will undertake a greater number of reviews and commission more of the above information gathering exercises.

In view of the decision by Council, Members may take the view indeed that they should make no comment on this budget to the Executive at this time, until further progress has been with the structural arrangements arising from Council's decision.

## **Corporate Direction & Priorities**

13. This report in terms of budget monitoring and making recommendations on a suitable level of budget for supporting scrutiny reviews, helps contribute to an effective and successful scrutiny process. This in turn supports the Council in moving forward in line with the direction statements set out in the recently refreshed Corporate Strategy.

## **Implications**

- 15. **Financial** Constitutionally, SMC is delegated to recommend to Council an appropriate support budget for scrutiny reviews.
- 16. There are no Human Resources, Equalities, Legal, ITT, Crime & Disorder or other implications associated with this report

## Risk Management

17. There are no known risks associated with this report other than a possibility that scrutiny might be allocated a budget by the Council it feels is wholly inadequate for supporting its reviews, if SMC fails to make a recommendation. This may be considered to be particularly relevant at a time when the Council is changing its existing scrutiny structure.

#### **Recommendations**

- 17. Members are asked to
  - (i) note the report, the current budget position and to recommend a budget to the Council for supporting scrutiny reviews;
  - (ii) consider whether they wish to increase the amount initially allocated for research supporting agreed reviews to £500 per review.

Reason: To enable a robust scrutiny review support budget to be set for

the 2009/10 financial year.

#### **Contact Details**

Author: Dawn Steel Democratic Services Manager Tel No. 01904 551030	Chief Officer Responsible for the report: Quentin Baker Head of Civic Democratic & Legal Services								
161140. 01304 331000	Report Date Approved		ate	12 December 2008					
Specialist Implications Officer Patrick Looker Principal Accountant Tel: 01904 551633	r(s)								
Wards Affected:				All	$\checkmark$				
For further information please contact the author of the report									
Background Papers:									
None.									
Annexes									
None.									