

PATIENTS' FORUM

FOR THE LONDON AMBULANCE SERVICE

DEVELOPING PRE-HOSPITAL CARE FOR PEOPLE WITH DEMENTIA

OUR DEMENTIA CHALLENGE TO THE
LONDON AMBULANCE SERVICE
AND THE LAS COMMISSIONERS

PATIENT CENTRED CARE

2014-5

Patients' Forum Ambulance Services (London) Ltd.

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- COMMUNITY RESPONDERS – SISTER JOSEPHINE UDIE
- EQUALITY AND INCLUSION – KATHY WEST
- INFECTION PREVENTION AND CONTROL – MALCOLM ALEXANDER
- LEARNING BY EXPERIENCE – MALCOLM ALEXANDER
- MENTAL HEALTH COMMITTEE – MALCOLM ALEXANDER
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- SAFEGUARDING – LYNN STROTHER

Prime Minister's Dementia Challenge

Imagine feeling confused and afraid because close friends and relatives seem like strangers; being unable to leave the house alone because you might not be able to find your way back; or seeing the fear in your loved one's face, as they struggle to make sense of familiar surroundings.

For many people in this country, this is the reality of everyday life. 670,000 people in England are living with dementia. An estimated twenty one million people in our country know a close friend or family member with dementia – that's 42% of the population. One in three people aged over 65 will have dementia by the time they die. And as life expectancy increases, more and more people will be affected.

Dementia is one of the biggest challenges we face today – and it is one that we as a society simply cannot afford to ignore any longer. We have made some good progress over the last few years, but there's still a long way to go.

Our research knowledge on dementia lags behind other major diseases such as cancer or heart disease. People with dementia and their carers still face a lack of understanding from public services, businesses and society as a whole. And as many as half of all dementia sufferers in this country are unaware that they have the condition, meaning that they cannot get the help that they and their families need.

So I am determined that we will go further and faster on dementia – making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition. Of course the Government doesn't have all the answers, and we can't fix everything overnight. But with a sustained and concerted effort from all parts of society, I believe we can make a real difference – and we are determined to do so.

A handwritten signature in black ink, reading "David Cameron". The signature is written in a cursive, flowing style with a long horizontal stroke at the end.

Dementia Care

COMMISSIONING THE LAS IN 2014-5

STATEMENT FROM COMMISSIONING INTENTIONS – MARK DOCHERTY

“The number of people with dementia is increasing; ambulance crews are often the first point of contact for with people with dementia, who may come to the attention of the service as a result of primary incidents such as falls. We need LAS staff to have increased knowledge and awareness of dementia to assist in the identification of patients who require dementia-appropriate community services, and initiation of appropriate liaison / links with these services. There should then be fewer unnecessary admissions for patients with dementia to hospitals as a result of collaborative work between the ambulance service and health and social care organizations.”

OUR DEMENTIA CHALLENGE TO THE LAS AND THE CLINICAL COMMISSIONING GROUP COMMISSIONERS

People with dementia are more likely to be admitted to hospital and once admitted their length of stay is longer and their experience of care is often disturbing, resulting in worse outcomes, e.g. poorer cognitive status and higher mortality. Some of these hospital admissions are for chronic conditions, which can lead to preventable acute episodes, e.g. congestive heart failure, diabetes, asthma, angina, epilepsy and hypertension. Appropriate interventions and active care and treatment in the community can reduce the need for hospital admission. However, the indications are that the admission rate for people with these conditions who have dementia is higher than for people who do not have dementia ('Counting the Cost', Alzheimer's Report, 2009).

Dementia is not usually the main reason for a call to the LAS; the 999 call is usually for falls, acute infections (e.g. urinary tract infections), stroke, 'transient ischaemic attack' and difficulty in breathing. There are numerous forms of dementia, including Alzheimer's Disease, vascular dementia, Pick's Disease (frontal temporal dementia), dementia with Lewy bodies, Korsakoff's syndrome, and Creutzfeldt-Jakob disease (CJD). There are other rarer causes of dementia, e.g. multiple sclerosis, motor neurone disease, Parkinson's disease, Huntington's disease and Binswanger's disease. The wide range of dementia types and causes needs to be understood by those who treat patients requiring urgent or emergency care, and during hospital admission. Sometimes, the LAS may be dealing with people with dementia who are not yet diagnosed, but who present with cognitive impairment due to dementia.

People with dementia are core users of acute health care. At any one time, one quarter of hospital beds are occupied by people with dementia aged over 65. Evidence suggests there are ongoing problems with the quality of care for people with dementia in hospital, and that there are many avoidable admissions. Counting the Cost (Alzheimer's Society, 2009) found unacceptable variation in quality of care for people with dementia on general hospital wards. The report's research found over half (54%) of carer respondents felt the person's dementia symptoms worsened as a result of their time in hospital. Nearly half (46%) reported that the person's general health deteriorated. Individuals were staying in hospital longer than other people who were admitted for the same reason but did not also have dementia. Around one in three people with dementia who went into hospital from their own home were discharged into a care home. In short, many hospitals are struggling to ensure that people with dementia are discharged appropriately.

Overall the evidence suggests that many hospitals are struggling to provide care for people with dementia. However, there is growing recognition of the need to improve care. In England, the 2012/13 Operating framework identifies care of people with dementia in hospital as a priority. The framework also set out a Commissioning for Quality and Innovation (CQUIN) target on improving diagnosis of dementia in hospitals (Department of Health, 2011).

As a result of the £50 million Department of Health funding made available following the Prime Minister's Dementia Challenge, for 'dementia friendly environments', some London Hospitals are among the 116 successful projects to have received DH funding. Some, e.g. Guy's and St Thomas' Hospitals, have set up ground-breaking approaches to providing care for patients with dementia. It appears that most of the projects concentrate on complex care once a patient has been taken to hospital or social care. There does not appear to be a London-based project that deals specifically with pre-hospital urgent and emergency care.

A dementia referral pathway ought to address this and ensure the right kind of care in the right kind of setting, where clinical staff have experience of dealing with patients who have dementia. This approach could reduce length of stay in hospital and the sometimes harmful effects of hospital admission (e.g. infection and depression) and reduce overall NHS costs. The East of England referral pathway, for example, has a proven record of leading to a reduced length of stay and reduced costs and because of its success, the pathway is being evaluated for use in Basildon, Southend and Ipswich NHS Trusts.

PATIENTS WHO FALL AND NEED ASSESSMENT FROM THE LAS

The Forum has raised the issue of effective clinical assessment and pathways for people who have falls. The key issues raised by the Forum are:

- The primary assessment of patients by front line clinical staff
- Delayed responses because of low capacity to respond to Cat C calls
- Absence of specialist ‘falls teams’ for LAS staff to refer to in the community

The proposal for paramedics to transfer some patients who have had falls to local ‘falls teams’ instead of taking them to A&E has been abandoned, because GPs on local Clinical Commissioning Group (CCGs) would not support this improved approach to patient care. The intention was to secure immediate, expert advice, support and rehabilitation for patients who have had falls, but instead paramedics will either take patients who need additional care to A&E or refer them to their GP. Referral to GPs for patients requiring urgent follow up care does not appear to be in the best interests of patients.

OUR VISION FOR THE LAS – PRE HOSPITAL DEMENTIA CARE

Given the Prime Minister’s Dementia Challenge, the Patients’ Forum is committed to campaigning for the development of dementia care pre-hospital pathways for patients in London.

Although the Commissioners for the LAS previously expressed a great deal of interest in improving care for people with dementia, their priorities have changed due to the serious challenges faced by the LAS to meet both category A and C targets.

The Patients’ Forum for the LAS recommends that the LAS Commissioner adopt the following measures to improve the care of people with dementia.

- 1) LAS should be specifically commissioned to provide services that focus on the needs of increasing numbers of people who suffer from cognitive impairment.**
- 2) Develop clear effective dementia pathways between the LAS and the LAS commissioners (CCGs), together with acute hospitals and where possible community care professionals to ensure ‘right care first time’.**
- 3) Unnecessary hospital admissions should be avoided.**

- 4) **Ensure the LAS Clinical Support Desk has the expertise to advise clinical staff on meeting the needs of people with dementia, especially with regard to assessing cognitive impairment and pain.**
- 5) **Require dissemination of 'clinical advice' for clinicians, that provides clinical and social information about the needs of people with dementia including information on communication and an awareness of the medication that a patient with dementia might have been prescribed.**
- 6) **Require Effective Dementia Training for LAS Frontline Staff:**
 - **Create better information sources for clinical staff to enable them to gain access to more information about pre-hospital dementia care including the website of the Alzheimer's Society.**
 - **More effective training and resources for LAS clinicians to enable them to carry out more comprehensive assessment at home and gain direct access to alternative care pathways leading to treatment at home, respite and where necessary admission to units that are 'dementia aware'.**
 - **Development of communication tools in conjunction with other agencies, for front-line staff, that can be used in the person's home to include a variety of information sources such as the patient's likes and dislikes, previous occupation and other useful information which will assist in gaining the patient's trust and minimising anxiety.**
- 7) **Commissioners review the need for paramedics to have direct access to local Falls Teams, in order to prevent inappropriate transfers to A&E and to ensure expert clinical care for patients who have fallen.**
- 8) **Clinical audit should be carried out to analyse the consequences and benefits of referring patients who have cognitive impairment and have a fall, to GPs, A&E and other specialised care options.**
- 9) **Paramedic training and practice should include the comprehensive NICE assessment, including a comprehensive cognitive assessment that enables paramedics to identify patients who may have dementia.**

- **Prime Minister's challenge on dementia - Delivering major improvements in dementia care and research by 2015**
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf
- **Alzheimer's Society Dementia 2012 Report**
<http://www.alzheimers.org.uk/dementia2012>
- **Improving services and support for people with dementia, NAO**
http://www.nao.org.uk/publications/0607/support_for_people_with_dement.aspx
- **Living well with dementia: A National Dementia Strategy Good Practice Compendium – an assets approach.** Section 26 (pg 91) Improving the clinical care provided by ambulance clinicians. Great Western Ambulance Service (GWAS)