END OF LIFE CARE FOR PEOPLE WITH DEMENTIA

A JOINT REPORT OF THE HEALTH AND PARTNERSHIPS AND ADULTS AND HOUSING SCRUTINY COMMITTEES

September 2019

PREFACE

Members will be aware that a review ‘’Living well with dementia’’ was undertaken and finalised in 2016 by the Adults and Housing Scrutiny, and that this identified a recommendation for a joint piece of work to be undertaken by Adults and Housing and the Health and Partnerships Scrutiny Committees to look at the end of life pathway for those living with dementia.

Dementia refers to a range of conditions that affect the brain resulting in progressive and sometimes severe cognitive decline that may manifest as memory loss, confusion, disorientation or personality change. Dementia can affect people of any age, but it is more common among people over the age of 65 years.

Dementia is a terminal condition and people living with dementia should be able to end their lives with dignity and free from pain.

The aim of the review was to identify the services available in Darlington to ensure dementia sufferers were receiving adequate care and support at the end of their lives, including support available to carers during their bereavement.

The Scrutiny Committee hopes the recommendations contained within this report can ensure that the quality of life for those people living with Dementia in Darlington is supported to allow a death with dignity and respect.

Our thanks and appreciation go to everyone involved in this review.

Councillor Wendy Newall, Chair of the Health and Partnerships Scrutiny Committee (to 6 May 2019)

Councillor M Knowles, Chair of Adults and Housing Scrutiny Committee (to 6 May 2019)

Introduction

1. This is the final report of the Joint Review of End of Life (**EOL**) Care for People with Dementia established by the Health and Partnerships Scrutiny Committee and the Adults and Housing Scrutiny Committee.

Background Information

2. Following a recommendation in the final report of the Adults and Housing Scrutiny Committee Review 'Living Well with Dementia' in December 2016 a Joint piece of work was undertaken to look at the EOL pathway for those with dementia.

3. A scoping meeting was held on 25 April 2017 and further meetings held on 10 December 2018 and 20 February 2019.

4. All Members of the Health and Partnerships and Adults and Housing Scrutiny Committees were invited to participate in the Review and the following Members attended meetings:

   Councillor Heslop
   Councillor Kane
   Councillor Knowles
   Councillor Newall
   Councillor Nutt
   Councillor EA Richmond
   Councillor S Richmond
   Councillor H Scott

5. The Group was led by Councillor Wendy Newall, Chair of the Health and Partnerships Scrutiny Committee during the course of the Review.

6. The Review Group acknowledges the support and assistance provided in the course of their investigations and would like to place on record its thanks to the following:

   (a) Dr Malcolm Moffatt, Speciality Registrar in Public Health
   (b) Miriam Davidson, Director of Public Health
   (c) Ken Ross, Public Health Principal
   (d) Dr Nicholson, Consultant and Janet Mortimer, Specialist Nurse – County Durham and Darlington Foundation Trust (CDDFT).
   (e) Alison Marshall, Nurse Consultant and Diane Farrell – St Teresa's Hospice

Methods of Investigation

7. The Review Group met on three occasions between April 2017 and February 2019 and the notes containing the discussions held at those meetings are attached **(Appendix 1).**

8. Members have independently visited various organisations to ask a set of questions provided by the Centre for Public Scrutiny on scrutinising services for people with dementia and to assure us that peoples with dementia were receiving the best care at the EOL care.

9. The organisations or services which Members visited/contacted included St Teresa's Hospice, Darlington Memorial Hospital, Rosemary Court Care Home, Darlington Manor Care Home, Springfield Care Home, Tees, Esk and Wear Valley NHS Foundation Trust Mental Health Services for Older People and Healthwatch Darlington.

10. Dr Moffat has been assisting the Review Group and he has met separately with Dr Nicholson, Consultant on EOL Care at the Darlington Memorial Hospital and Alison Marshall, Nurse Consultant and Senior Care Staff at St. Teresa's Hospice.

11. Dr Moffat also gave Members a presentation on existing evidence on EOL Care for people with dementia.

12. An ambition to improve the treatment that people with dementia receive at the end of life was highlighted in the National Dementia Strategy (2011). It advocated for better End of Life care across care settings that made full use of the planning tools in the Mental Capacity Act, developing End of Life care pathways for dementia and promoted better pain relief and nursing support for people with dementia at the end of their life.

13. Members of the Review Group have also considered the NICE Guidance on *'Dementia: assessment, management and support for people living with dementia and their carers'* (published 20 June 2018). Professionals and practitioners are expected to take this guidance fully into account, alongside the individual needs, preferences and values of their patients or the people using their service.

14. We have also considered a White Paper defining optimal palliative care in older people with dementia and recommendations from the European Association for Palliative Care.

Findings

15. Dementia is a life-limiting disease without curative treatments. Patients and families need palliative care specific to dementia.

16. For a given disorder, people with dementia are 4-6 times more likely to die than people who are cognitively intact.

17. There is evidence to support the view that people with dementia receive poorer EOL Care in terms of access to palliative care.

18. People with dementia may receive less analgesia than other people as they are less likely to be able to express their feelings of pain.

19. People with dementia are less likely to die in their own home.

20. Discussions with care providers in Darlington have indicated a mixed picture of the current offer to people with dementia who require EOL care.
    St Teresa's Hospice offers a variety of services however they felt that support from the hospice was often not requested for patients with dementia despite there being suitable services available.
    They have undertaken dementia-friendly training for all public-facing staff and a dementia-friendly building audit.

21. DMH / CDDFT Consultant in Palliative Care Medicine and Specialist Nurse stated that although CDDFT does not have a specific pathway for EOL care for people with dementia it is included in their overall EOL care strategy and that there were a number of projects across the trust supporting this group of patients.

22. They noted that within the trust not every ward had a 'dementia champion' however all staff receive dementia awareness training and EOL training is mandatory for clinical staff.

23. It was perceived that carers were often unprepared for EOL discussions and that there was poor or limited awareness in some cases among carers about the clinical progression of advanced dementia.

Conclusion

24. There are many positive things happening in relation to End of Life care for those suffering from dementia and there are examples of good practice, however it appears that services could be better connected.

25. Dementia is, and should be acknowledged to be, a terminal illness. As such, advance care planning is essential in ensuring that people with dementia have the best chance of a good death and that their preferences around death and dying are recorded and respected. Working with GPs and other providers (including the memory clinic at DMH and old age psychiatry services at West Park Hospital) to build advance care planning into the initial discussions that follow diagnosis and ensuring that families and carers are involved in these discussions and are prepared for the realities of advanced dementia, would likely result in less distress and uncertainty at the EOL.

26. Research shows that families and carers are less likely to advocate for medical intervention at the EOL when they have a clearer understanding of the clinical course of advanced dementia – as such, finding opportunities to have these sometimes-difficult discussions about EOL care early in the dementia journey will benefit patients and their loved ones during the later stages of the disease. Producing written guidance to this effect is important, but equally important is

making sure that clinicians and carers feel supported and equipped to have these conversations.

27. People with advanced dementia would benefit from having a central coordinator, who would be explicitly identified within their care team who is able to advise when medical interventions may not be in the patient's best interests and who has a subtler understanding of how the patient expresses pain and distress. This might be a GP, a carer or a family member. Identifying this individual early in the disease process, making sure that they are aware of the individual's wishes and preferences, and providing them with a clear understanding of the natural progression of advanced dementia and what to expect at the EOL, will improve the EOL experience for this population if they are actively involved in decisions about the patient's care. This individual should be explicitly identified as part of the advance care planning process.

28. At present, there is not a bespoke pathway in place for EOL care for people with dementia in Darlington. Developing such a pathway, in conjunction with CDDFT, TEWV, GPs, St Teresa's hospice and care/nursing homes, may improve recognition of terminal decline in patients with dementia, avoid unnecessary medical intervention, and result in more joined-up care delivered between different providers. The hospice has good links with most relevant providers in Darlington – St Teresa's, working with the support of the dementia alliance and Dementia UK, may be well placed to lead on the development and roll-out of a bespoke pathway. This process should also involve the many independent sector/charity organisations that support the care of people with dementia. Care providers should also be encouraged and supported to consider measures that would enhance the EOL care experience for people with dementia in their own settings. For example, in CDDFT, allocating dementia champions to all DMH wards, familiar with the EOL care requirements of people with dementia, and expanding current initiatives at UHND into DMH would begin to improve the local offer to this currently underserved patient group. However, it is important to emphasise that improving EOL care for people with dementia is best achieved by avoiding unnecessary hospital admissions, and that measures that improve communication between partners and awareness of the particular needs of dementia are likely to reap the most significant benefits.

Recommendations

29. The Health and Partnerships Scrutiny Committee together with the Adults and Housing Committee make the following recommendations, they are informed by expert opinion as described in the literature and by discussion with local providers.

a) That advanced care planning be built into initial discussions that follow diagnosis, ensuring that families and carers are involved.

b) That an individual contact within the care team be explicitly identified as part of the advance care planning process.

c) That a Bespoke pathway be developed in conjunction with NHS Providers, St Teresa's Hospice and care/nursing homes.

d) That unnecessary hospital admissions be avoided for people with dementia.

30. Members of the Health and Partnership Scrutiny Committee and Adults and Housing Committee request that the NHS Clinical Commissioning Group consider the recommendations a) to d).

Monitoring and Review of Recommendations

31. The Health and Partnerships Scrutiny Committee will seek an update on the progress of the recommendations in six months' time to review the extent to which any changes have happened as a result of this review.

Appendix 1

End of Life (EOL) Scoping Meeting – 25 April, 2017

Present:- Councillors Newall, EA Richmond, S Richmond and H. Scott.

Karen Graves, Democratic Officer.

Apologies – Councillors J Taylor and Tostevin.

Members met to 'brainstorm' issues which require further information/clarification on EOL Care prior to a meeting with relevant health organisations to discuss those issues.

To assist the discussion Members gave consideration to the Centre for Public Scrutiny's publication '10 questions to ask if you are scrutinising end of life care for adults'.

NOTE – Within each Question were several supplementary questions detailed in the publication.

Cllr S Richmond referred to the 'Tips for Scrutinising end of life care' with the CfPS publication and in particular the fact that end of life care was a vast and cross cutting area, affecting virtually all conditions and places of care. In view of this Cttee's may wish to focus on one aspect at a time, such as support for carers at the end of life, or end of life care for people with dementia.

Members were unanimous that their investigations should include carers, with particular emphasis on stress and the impact on their mental health.

Members gave consideration to the 10 Questions to Ask as follows :-

Q1 - What is the need in your area?

It was agreed that this information should be available from Darlington CCG, however it was noted that the National Council for Palliative Care (NCPC) had published guides available at www.ncpc.org.uk/publications which were available free of charge.

Q2 – Is there a clear strategy, supported by dedicated resources, for meeting end of life care needs in your locality, covering different settings and sectors of care?:

It was agreed that The Trusts and Darlington CCG be invited to a future meeting to discuss their Strategies.

Q3 – Is there a clear structure for workforce development and training across settings and sectors of care?

Cllr S Richmond suggested that Jeanette Crompton, Development and Commissioning Manager, may be able to assist with training needs in Care Homes and Domiciliary Care.

It was agreed that Karen Graves approach Jeanette Crompton with a view to determining training needs.

Q4 – Is there a clear structure for monitoring end of life care?

Cllr Newall suggested that Jane Bradshaw of St Teresa's Hospice be approached to provide examples of good practice from the hospice staff and individual carers as it was felt that case studies would be too intrusive. Cllr Scott stated that the Hospice was a good place to gain this information as it was commissioned to provide the service.

It was agreed that Jane Bradshaw be invited to a future meeting to provide examples of good practice.

Q5 – Practical Support for Patients, Families and Carers – How are these needs met when a patient is nearing end of life?

Health and Social Care teams work together to meet these needs and it was suggested that Jenny Leeman of the Alzheimer's Society be invited to a future meeting to discuss.

It was agreed that Karen seek contact details for Jenny with a view to attending a future meeting.

Q6 – Place of Care and
Q7 – Is there a Clear Process in your locality for Assessment of needs, Care Planning and Advance Care Planning for End of Life Care?

Members agreed that Q6 and Q7 should be combined and discussed the need to ensure that care settings had particular places for dementia suffers reaching EOL; Power of Attorney and Benefits were fully explained and available to carers/family members; and the best practice of Middleton Hall Retirement Village. It was suggested that Jeremy Walford, Managing Director was very hospitable and would welcome Members to the Village.

Members also raised concerned that dementia sufferers were being placed unnecessarily in care homes where stimulation was not always met.

It was agreed that Members endeavour to undertake a visit to Middleton Hall Retirement Village to perceive and observe best practice.

NOTE – KG has looked on the Middleton Hall website and found a link to 'arrange a visit' which can be completed. The Hall then contact direct to organise.

Q8 – Co-ordination of Care due to the Variety of Professionals Involved in EOL Care

Q9 – Do you know what local patients and carers want from Services?

It was stated that patients were happy if people were kind to them and that, due to the nature of the illness, it often depended upon the patient on the day as to their wants and needs. Staff, patients and carers needed to be involved in developing and evaluating EOL care services. It was also suggested that Age UK are contracted out to go to people's homes and offer help and support.

It was agreed – Not sure anything was actually agreed on Q9

Q10 – Raising Public Awareness

Not discussed but accept that DBC has a vigorous awareness Campaign for Dementia patients.

Notes on meeting with Dr Malcolm Moffat 5/11/18

Malcolm provided a paper from Centre for Public Scrutiny and a suggested set of questions regarding " how good is care for people with dementia at the end of life '' :

Questions

Is there a joint plan for improving the quality EOL care for people with dementia?

- Is this joined up with the area's wider EOL Strategy?
- What progress is being made?

Is there an integrated approach to commissioning personalised services across health, care and the independent sectors which can provide the opportunity for people with dementia to die well at home?

Are relevant workers, e.g. social workers, proactive in suggesting that people with dementia and carers could consider EOL preferences while they still have capacity to do so?

Is full use being made of Mental Capacity Act planning tools to maximise people's control e.g. advance care planning, lasting power of attorney?

What measures are in place to ensure that staff in hospitals, hospices and care homes understand the care needs of people with dementia who are dying, particularly pain relief and nutrition?

- Is this monitored?

What support is provided to carers, if required, through death and bereavement?

Are there a range of services across all settings geared-up to providing appropriate support?

- Is this included in service specifications?

Are there clear referral pathways promoting ease of access to people with dementia?

He will forward the most recent NICE Guidance

He is meeting with Dr Nicholson, consultant on EOL at DMH

He is also hoping to meet with a newly appointed clinician at DMH who will work in the community

He had also met with Alison Marshall at St Teresa's who is keen to be involved as is the nurse consultant there

Malcolm will also chase up the CCG's lead GO on EOL /dementia and relevant clinician at West Park

Voluntary Sector

AgeUK

Alzheimer's Society

Who is best contact for DBC

Initial Meeting

H&P / A& H members

To agree way forward

To apportion tasks

Eg Visit Nursing Homes

Extra care facilities (Rosemary Court)

Alzheimer's Society

Age Uk

Carers

Malcolm will update on his meeting with consultants at DMH and other outstanding issues

Suggested that as Malcolm tied up with exams for next two months m

Members pursue enquires and we arrange a further meeting in the new year to report back and invite relevant speakers

End of Life for Care for People with Dementia Review Group

10 December 2018

Present– Councillors Heslop, Kane, Knowles, Newall, Nutt and H. Scott.

Apologies – Councillor J Taylor.

Officers – Dr Malcolm Moffat, Speciality Registrar in Public Health

Purpose of Meeting – To discuss care for people with dementia at the end of life.

- Dr Moffat circulated 3 documents to Members – a list of suggested questions from the Centre for Public Scrutiny on scrutiny of end of life care for dementia patients; NICE Guidance 2018 on assessment, management and support for people living with dementia and their carers; and Public Health England data for dementia in Darlington.

- Dr Moffat advised Members on the work that he was undertaking and he was speaking with various stakeholders in CCDFT about the launch of a patient passport which would contain important information about diagnosis and End of Life preferences.

- Members discussed the various places that Members can visit and ask the suggested questions (above) to assure Members that patients with dementia are receiving the best care at the end of life.

  IT WAS AGREED – (a) That,

  Councillor Newall visit Rosemary Court Care Home and Darlington Manor Care Home;
  Councillors Knowles and Kane visit Springfield Care Home and Darlington Memorial Hospital;
  Councillors Heslop and Nutt to visit Tees, Esk, Wear Valley NHS Trust; and
  Councillor H Scott to visit St. Teresa's hospice.

  (b) That all Health and Partnerships Scrutiny and Adults and Housing Scrutiny Members be contacted to see if they would be willing to visit other organisations ie. Age Uk, Alzheimers Society, Healthwatch and carers.

  (c) That Members conclude their visits by the end of January when the Group will meet again to collate their findings.

End of Life for Care for People with Dementia Review Group

20 February 2019

Present– Councillors Heslop, Kane, Knowles, Newall, and H. Scott.

Officers – Dr Malcolm Moffat, Speciality Registrar in Public Health

Presentation – Dr Moffat gave members an overview of National Strategies and published literature regarding End of Care for People with Dementia. The Presentation outlined the case for change; Objective 12 of the National Dementia Strategy (2011) in relation to improved end of life care for people with dementia; NICE guideline (2018) for Dementia: assessment, management and support for people living with dementia and their carers; a qualitative study (Lee et al, 2015) giving expert views on the factors enabling good end of life care for people with dementia; the 11 domains (57 recommendations) contained in the White Paper defining optimal palliative care in older people with dementia; and the Sampson report published in 2010 on Palliative Care for People with Dementia.

Visits/Contact with Organisations – Members of the Group have been making contacting and/or visiting the organisations listed below and shared their feedback on the questions put to the organisations (questions from the Centre for Public Scrutiny):

Councillor H Scott – St Teresa's Hospice

Councillors Kane and Knowles – Darlington Memorial Hospital, Manor Care Home and Springfield Care Home.

Councillor Heslop – Tees, Esk and Wear Valley foundation Trust Mental Health Services for Older People

Councillor Newall – Rosemary Court Care Home

Email response from Healthwatch.

Action – Members agreed that they intended to continue to make contact with the Alzheimers Society and other Independent Care Homes; and invite Dr. Nicholson, consultant on End of Life Care at the Darlington Memorial Hospital and Alison Marshall, Nurse Consultant and Senior Care Staff at St. Teresas Hospice to attend a future meeting of the Group.