LIVING WELL WITH DEMENTIA





A REPORT OF THE ADULTS AND HOUSING SCRUTINY COMMITTEE

PREFACE

DEMENTIA TASK AND FINISH REVIEW GROUP

In Darlington, there are approximately 1453 people living with dementia, a figure which is set to rise to 2269 by 2030.

Dementia affects one person in 20 aged over 65 years and one in five aged over 80 years, whilst fewer than half ever receive a diagnosis.

With these facts in mind and acknowledging this condition will inevitably touch most of our lives at some time, in November 2015, the Adult and Housing Scrutiny Committee agreed to undertake a review of Dementia care available within the Borough of Darlington.

We adopted a population-wide approach based on Public Health England's first dementia profiling tool to consider all aspects affecting Dementia care from prevention to end of life care and everything in between.

The aim of the review was to find out what work was being carried out within Darlington by all organisations involved in Dementia care, ensuring that the person living with dementia and their carer was always at the heart of our work to better understand the devastating impact this can have on people's lives.

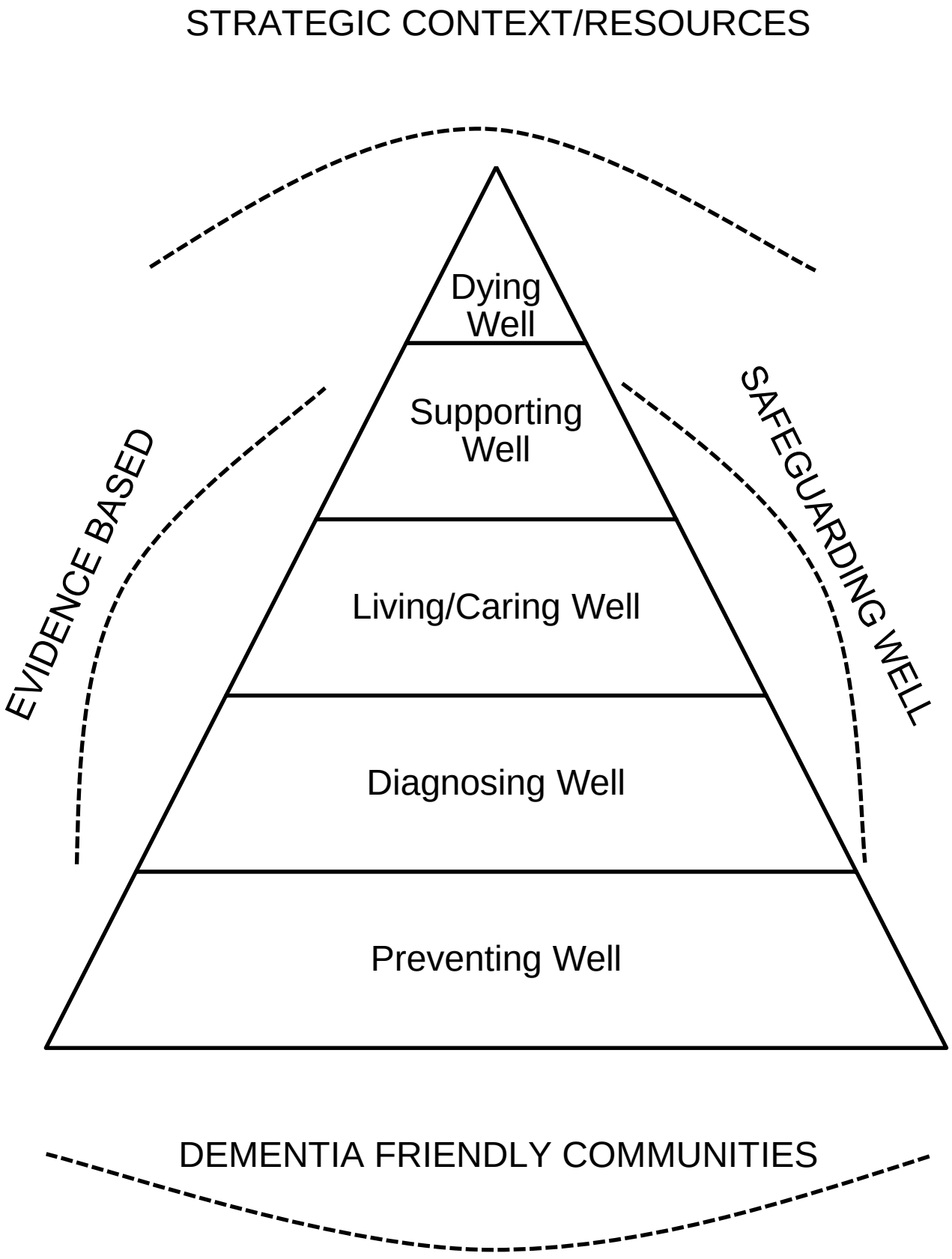
We wanted to gain an understanding of both current services and future plans. The Scrutiny Committee have learned so much about the on-going work around Dementia care, including the many activities and support delivered by the third sector, and welcomed all suggestions for improvement.

The Scrutiny Committee hopes the recommendations contained within this report can ensure we can go forward as a community which is able to understand the needs required to be a Dementia Friendly Town, whether that is through individual actions, support in the community or the provision of services and development of facilities, all of which are essential for people living with dementia and their carers.

Our thanks and appreciation go to everyone involved in this journey and it rests with us all to continue to work together to ensure living and caring for people living with Dementia in Darlington can mean living a full and rewarding life.

Councillor Sue Richmond
Chair of Adults and Housing Scrutiny Committee

Dementia Review Model



SUMMARY OF RECOMMENDATIONS

Ref	Recommendation	Responsibility	Progress/Completion Date
	STRATEGIC CONTEXT/RESOURCES		
R1.	That the Cabinet Member for Adult Social Care and Housing be appointed as the Council's Dementia Champion.	Councillor Veronica Copeland, Cabinet Member for Adult Social Care and Housing	January 2017
R2.	That the Governance arrangements around the County Durham and Darlington Dementia Strategy be reviewed and strengthened as part of its refresh to ensure its accountability.	Suzanne Joyner, Director of Children and Adult Services, Darlington Borough Council	March 2017
R3.	That the refreshed Strategy be forwarded to the Health and Well Being Board for approval and to the Adults and Housing and the Health and Partnerships Scrutiny Committees.	Suzanne Joyner, Director of Children and Adult Services, Darlington Borough Council	April 2017
R4.	That, through the Strategy Implementation Group, all partner organisations work together to build on current practice and appoint a named practitioner to lead and co-ordinate treatment and support for people living with dementia and their carers across health and social care	Suzanne Joyner, Director of Children and Adult Services, Darlington Borough Council	September 2017
	PREVENTING WELL		
R5.	That, Public Health, Darlington Borough Council, continue to organise more local campaigns/publicity to raise public and professional awareness about life-style changes, such as stopping smoking, eating healthily, drinking alcohol sensibly, exercising more and having regular health checks which may help prevent certain forms of	Miriam Davidson, Director of Public Health, Darlington Borough Council	September 2017

	dementia.		
R6.	That this Review Group supports the call by the Alzheimer's Society for an increased awareness and a better focus on preventative services for people from BAME and LGBT communities and that it undertakes a publicity campaign to appoint more champions from across these communities.	Alzheimer's Society	July 2017
R7.	That the Cabinet Member for Children and Young People ensure that all opportunities to raise awareness of dementia to young people, including prevention are taken, and seek reassurance that any training or campaigns that are being delivered are tailored to their needs.	Councillor Cyndi Hughes, Cabinet Member for Children and Young People	January 2017
R8.	That attendance at a Dementia Friends information session be mandatory for all Members of Darlington Borough Council.	Councillor Veronica Copeland, Cabinet Member for Adults and Housing	March 2017
R9.	That, arising from the Dementia Friends information sessions, each Member identify one action arising from the session which they will take forward.	Councillor Veronica Copeland, Cabinet Member for Adult Social Care and Housing	September 2017 and March 2018
R10.	That awareness raising about dementia be included as part of the Council's Induction Programme and that the Dementia Friends Information sessions be publicised to all Council employees, with all Managers identifying key staff who would benefit from attending these sessions to assist in their roles.	Elizabeth Davison, Head of Finance and Human Resources, Darlington Borough Council	March 2017
	DIAGNOSING WELL		
R11.	That re-assurance be sought from the Darlington Clinical Commissioning Group that early diagnosis of dementia is a priority for it and that all GP practices are aware of the need to follow the referral pathway.	Lisa Tempest, Director of Performance, Planning and Assurance, Darlington Clinical Commissioning Group	January 2017

R12.	That to ensure that a consistent quality of information is provided as part of the referral pathway, the Darlington Clinical Commissioning Group monitor the use of the template by all GP's within Darlington when undertaking referrals.	Lisa Tempest, Director of Performance, Planning and Assurance, Darlington Clinical Commissioning Group	July 2017
R13.	That the Darlington Clinical Commissioning Group encourage all GP's and practice staff to undertake dementia awareness training.	Lisa Tempest, Director of Performance, Planning and Assurance, Darlington Clinical Commissioning Group	February 2017
R14.	That the Darlington Clinical Commissioning Group ensures that every person living with dementia receives their annual check-up to review and assess their care needs and that it continues to monitor and record this.	Lisa Tempest, Director of Performance, Planning and Assurance, Darlington Clinical Commissioning Group	July 2017
	LIVING/CARING WELL		
R15.	That the Adults and Housing Scrutiny Committee look at the Carers Strategy and ensure that structures and services are in place to support carers in their role and to allow them to live a life of their own alongside their caring role.	Adults and Housing Scrutiny Committee	February 2017
R16.	That the success of the Darlington Dementia Action Alliance in making Darlington a Dementia Friendly Town be noted and that the Darlington Partnership, through its work, raise the profile and work of the Alliance to all sectors.	Seth Pearson, Chief Executive Officer, Darlington Partnership	February 2017
R17.	That this Group recognises the excellent work being undertaken to deliver services by the third sector and improved commissioning within that Sector be undertaken to ensure value for money.	Christine Shields, Assistant Director, Commissioning, Performance and Transformation	March 2017

R18.	That the Tees, Esk and Wear Valley NHS Foundation Trust review its processes to ensure that a high proportion of people diagnosed with dementia are offered the opportunity to be referred to appropriate third sector support services.	Carl Bashford, Head of Service, Tees, Esk and Wear Valley NHS Foundation Trust	November 2017
R19.	That the Darlington Dementia Action Alliance be requested to develop a standard 'starter pack', (in consultation with carers) which would include 'this is me, which can be used across all services for people diagnosed with dementia as an introductory guide to sources of assessment, advice and support for people living with dementia and their carers.	Lisa Holdsworth, Service Development Officer, Darlington Borough Council	March 2017
R20.	That Darlington Borough Council's Place Scrutiny Committee consider, through the Local Plan process, the scope to support people living with dementia when designing future builds.	Ian Williams, Director of Economic Growth, Darlington Borough Council	February 2016
R21.	That Darlington Borough Council look at how it can support people living with dementia in all of its public buildings, particularly when undertaking re-design work taking into account current research and recommendations	Guy Metcalfe, Head of Property and Asset Management, Darlington Borough Council	March 2017
R22.	That this Group supports the work of the Dementia Hub and would like to see its further development and re-location to the Dolphin Centre to enable a wider cross-section of the community to benefit from the services and support provided whilst accessing a range of other public activities.	Dementia Action Alliance and Mike Crawshaw, Head of Leisure and Culture, Darlington Borough Council	March 2017

	SUPPORTING WELL		
R23.	That the progress being made by the County Durham and Darlington NHS Foundation Trust be noted and that the outcome of the National Dementia Audit and the action plan be forwarded to the Adults and Housing Scrutiny Committee when appropriate.	Janet Mortimer, Dementia Specialist Nurse, County Durham and Darlington NHS Trust	April 2017
R24.	That the Good Friends scheme be extended to include dementia trained and approved therapeutic volunteers to support patients living with dementia in hospital and community settings, with hobbies and personal interests.	Gillian Peel, Age UK, Darlington	March 2017
R25.	That the County Durham and Darlington NHS Foundation Trust and Darlington Borough Council look, through the Better Care Fund Discharge to Assess project, at how the needs of people living with dementia and their carers are fully considered prior to discharge.	James Stroyan, Assistant Director, Adult Social Care, Darlington Borough Council/Christine Shields, Assistant Director Commissioning, Performance and Transformation	March 2017
R26.	That this Group supports and acknowledges the excellent work being undertaken by some Care Homes within the Borough and, through the Care Home Forum, expects to see good practice being shared and developed across those homes and all staff/carers attend a Dementia Friends Information Session and all care homes encouraged to join the Darlington Dementia Action Alliance.	Jeanette Crompton, Development and Commissioning Manager, Darlington Borough Council	March 2017
R27.	That the Adult and Housing Scrutiny Committee undertake a piece of work to look at domiciliary care.	Jeanette Crompton, Development and Commissioning Manager, Darlington Borough Council	April 2017
R28.	That Adult Social Care achieve a significant increase in the use of assistive technology to enable people living with dementia to remain independently in the community for	James Stroyan, Assistant Director Adult Social Care and Pauline Mitchell, Assistant Director, Housing and	March 2017

	as long as possible.	Building Services.	
	DYING WELL		
R29.	That the dementia pathway should recognise the effect a diagnosis can have on lives and make appropriate links with the end of life pathway.	Carl Bashford, Head of Service, Tees, Esk and Wear Valley NHS Foundation Trust	March 2017
R30.	That a joint piece of work be undertaken with the Adults and Housing and the Health and Partnerships Scrutiny Committees in relation to the end of life pathway.	Adults and Housing Scrutiny Committee and the Health and Partnerships Scrutiny Committee	June 2017
	SAFEGUARDING WELL-BEING		
R31.	That the Adults Safeguarding Board satisfy itself that all organisations should are aware of the key principles of Making Safeguarding Personal and that those principles are championed through the Adults Safeguarding Board, where key partners are represented.	Pixley Clark, Head of Review and Development (Children and Adult's Safeguarding)	March 2017
R32.	That the specific needs of people living with dementia should be defined and encouraged through the Adults Safeguarding Board.	Pixley Clark, Head of Review and Development (Children and Adult's Safeguarding)	March 2017

Introduction

1. This is the final report of the Dementia Review Group, established by the Adults and Housing Scrutiny Committee to look at the dementia pathway and support and advice services in Darlington.

Background Information

2. At a meeting of the Adults and Housing Scrutiny Committee held in November 2015, it was agreed to establish a Review Group to look at the dementia pathway and support and advice services in Darlington.

3. A wide number of issues have been considered and discussed at the meetings and these are referred to in the notes attached **(Appendix 1)**.

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

   Councillor Culley
   Councillor Kane
   Councillor Knowles
   Councillor Lister
   Councillor Mills
   Councillor M Nicholson
   Councillor EA Richmond
   Councillor S Richmond
   Councillor Storr
   Councillor Tostevin

5. The Group was led by Councillor S. Richmond.

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) Miriam Davidson, Director of Public Health, Darlington Borough Council;
   (b) Judith Stonebridge, Public Health Speciality Registrar, Darlington Borough Council;
   (c) Rachel Osbaldeston, Public Health Portfolio Lead, Darlington Borough Darlington;
   (d) Jeanette Crompton, Development and Commissioning Manger; Darlington Borough Council;
   (e) Lisa Holdsworth, Service Development Officer, Darlington Borough Council;
   (f) Hazel Neasham, Head of Housing, Darlington Borough Council;
   (g) Nigel Nicholson, NHS North of England Commissioning Support Unit;
   (h) Janet Mortimer, Dementia Specialist Nurse, County Durham and Darlington NHS Trust;
   (i) Kate Marshall, Discharge Co-ordinator, Ward 52, County Durham and Darlington NHS Trust;

(j) Carl Bashford, Head of Service, Tees, Esk and Wear Valley NHS Foundation Trust;
(k) Sarah McGeorge, Clinical Director, Tees, Esk and Wear Valley NHS Foundation Trust
(l) GP representatives, Darlington Clinical Commissioning Group;
(m) Jenny Leeming, Dementia Support Worker, Alzheimer's Society;
(n) Julia Laverick, Service Manager, Alzheimer's Society;
(o) Jane Welsh, Stakeholder Relations Officer, North East Alzheimer's Society;
(p) Mike Vening, Independent Chair of the Darlington Adults Safeguarding Partnership;
(q) Emma Chawner, Safeguarding Board Business Manager;
(r) Julie Wheatley, Team Manager for Adult and Older Persons Mental Health Services – Darlington Borough Council;
(s) Margaret Young, Interim Operations Manager, Darlington Borough Council;
(t) Keilly Storr, Social Worker, Darlington Borough Council;
(u) Janette Hewison, Team Manager for Older Persons Mental Health Services (Health);
(v) Andrea Goldie, Healthwatch Darlington;
(w) Inspector Gray, Durham Constabulary;
(x) Managers of a number of care homes within Darlington;
(y) Gary Emmerson, Darlington Clinical Commissioning Group/MIND;
(z) Gillian Peel, Age UK;
(aa) a number of Carers; and
(bb) Shirley Burton, Democratic Manager, Darlington Borough Council.

Structure of Report

7. This report is a brief summary of the evidence considered by the Review Group with the main recommendations arising.

8. The report covers :-

(a) Terms of Reference
(b) Methods of Investigation
(c) What is Dementia
(d) Prevalence
(e) Strategic Context/Resources
(f) Preventing Well
(g) Diagnosing Well
(h) Living/Caring Well (at home, in care homes/ residential care/extra care settings and in hospital)
(i) Supporting Well
(j) Dying Well
(k) Safeguarding Well-Being
(l) Monitoring and Review of Recommendations

9. In covering the above, the Review Group adopted a triangular approach to its work to ensure that the outcomes focused on the strategic context, the development of dementia friendly communities and safeguarding.

Terms of Reference

10. The Terms of Reference were agreed at the first meeting of the Review Group held on 19 November, 2015. These were :-

    (a) to establish current national policies relating to dementia and how these relate to local strategies and partnerships including prevalence/types of dementia/associated and future costs;

    (b) to review local care and services for people with dementia in terms of :-

        (i) early identification and diagnosis;
        (ii) support to live at home;
        (iii) hospital care;
        (iv) care home settings; and
        (v) end of life care

    (c) to establish levels of local awareness of Dementia, how people with dementia are involved in the community and the vision for a Dementia Friendly Community;

    (d) to review support to carers and families;

    (e) to review information and advice available; and

    (f) to establish how local health and social care economy will develop dementia services within the next 3 to 5 years.

Methods of Investigation

11. The Review Group met on a number of occasions between November and June 2016 and the notes containing the discussions held at those meetings are attached **(Appendix 1).** Members were also invited to participate in a Dementia Friends Information Session and the following Members took part :-

    (a) Councillor Kane
    (b) Councillor Knowles
    (c) Councillor M Nicholson
    (d) Councillor Mills
    (e) Councillor S Richmond
    (f) Councillor T Richmond
    (g) Councillor Storr
    (h) Councillor Tostevin

12. Some Members have also gone on to undertake Dementia Friends Champion training. A Dementia Friends Champion is a volunteer who encourages others to make a positive difference to people living with dementia in their community. They are also able to run Dementia Friends information sessions to inspire other people to become Dementia Friends and help to create dementia friendly communities and

support the Darlington Dementia Action Alliance (formed in March 2016).

13. The methods of scrutiny and types of evidence considered by the Group comprised :-

    (a) presentations by Council Officers and external partners;
    (b) site visits to meet users of dementia services and see the places where people living with Dementia were treated and/or cared for in the Borough;
    (c) visits to locations providing advice services;
    (d) mystery shopping; and
    (e) research of a wide range of documents and background material, including information included on the Council's website http://www.darlington.gov.uk/health-and-social-care/adult-social-care/keeping-healthy-and-well/dementia/
    (f) Department of Health Dementia Atlas https://shapeatlas.net/dementia/#6/52.945/-2.147/l-p65/b-11A

14. The Chair of the Group (Councillor S Richmond) also met a number of carers who had family members living with dementia to hear about their personal experiences and journey and Members of the Group also visited a number of Care Homes which contracted with the Council and the results of those findings are summarised at **Appendix 3**.

15. A list of background papers used for consideration is set out in **Appendix 2**.

What is Dementia?

16. There are approximately 100 types of dementia, the most common types of which are :-

    (a) Alzheimer's disease;
    (b) Vascular dementia;
    (c) Mixed dementia;
    (d) Dementia with lewy bodies; and
    (e) Frontemporal dementia

17. Dementia is a clinical syndrome characterised by a widespread loss of mental function, including memory loss, language impairment, disorientation, changes in personality, self-neglect and behaviour which are out of character (Department of Health 2001). One of the main causes of disability in later life, it has a huge impact on capacity for independent living.

18. Dementia can affect people of any age, but it is most common in older people. An increase in the percentage of older people is predicted, accompanied by a 61 per cent increase in people with dementia by 2026. The effect of an ageing population will impact on the numbers of people living with dementia, the health and social care needs of people with dementia and the needs of their carers.

19. ‘Everybody’s business’ (Department of Health 2005) suggested that more than 20 per cent of the over 80 population nationally, live with dementia.

20. People with dementia will often have problems with some of the following :-

    (a) thinking clearly;
    (b) remembering things;
    (c) communicating;
    (d) doing day-to-day things like cooking or getting dressed;
    (e) rationale thinking; and
    (f) empathy to those around them.

21. People with dementia can be :-

    (a) depressed (this is not necessarily a symptom of dementia and for many individuals depression can be a secondary condition that should be treated as such rather than within dementia care);
    (b) subject to mood swings and aggression; and
    (c) prone to wandering or getting lost

22. More details about the types of dementia can be found using the following link www.alzheimers.org.uk

Prevalence (taken from Joint Strategic Needs Assessment)

23. Nationally, dementia is the main cause of mental health admissions among older people, accounting for 41 per cent of all mental health admissions (21 per cent unspecified dementia, 14 per cent vascular dementia and five per cent Alzheimer’s disease) (APHO 2008).

24. The national hospital admissions rate for dementia amongst 75-79 year olds is approximately 200 per 100,000 rising to around 600 per 100,000 at 85 and over. It is estimated that after the age of 60 the prevalence of dementia doubles every five years so that about 22 per cent at 85 and 30 per cent of those aged 95 are affected.

25. Dementia affects one person in 20 aged over 65 years and one in five over 80 (Hoffman et al., 1991). Fewer than half of older people with dementia ever receive a diagnosis.

26. Dementia prevalence in Darlington is predicted to increase between 2014 and 2030. The proportion of people aged 65 and over with dementia in Darlington is predicted to increase from 1,408 in 2014 to 2,269 by 2030, a rise of nearly 900 cases. 1,452 people aged 18 and over in the Darlington Borough Council area have dementia.

27. In January 2016, Public Health England published the first dementia profiling tool on the Fingertips website http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/0/gid/1938132894/pat/6/par/E12000001/ati/102/are/E06000005. The profile, which is publically available, presents data following

the dementia pathway of care including indicators for prevalence, preventing well, diagnosing well, living well, supporting well and dying well. It allows benchmarking against other areas and is to be updated at regular intervals as new data becomes available.

28. People with Downs syndrome have an increased risk of developing Alzheimer's disease. Three per cent of people with Downs syndrome in their 30s have dementia, rising to 40 per cent in their 50's. By the age of 60, people with downs syndrome have a 55 per cent chance of developing dementia compared to a five per cent chance within the general population. The actual numbers are small but with more people with Downs syndrome now reaching older age there will be increasing numbers of people with Downs syndrome and dementia, who will require specialist assessment and support.

29. The prevalence rates of individuals with learning disabilities in the adult population in England is estimated by the Department of Health to be between 1.9 per cent and 2.7 per cent, whilst for the under 65 age group the prevalence of Downs syndrome is 6.25 per 10,000 of the general population and is 0.36 per 10,000 for people aged 65 and over. Further, the prevalence of dementia in people with Downs syndrome in England is estimated to be 8.9 per cent in people aged 45-49, 17.7 per cent in people aged 50-54, 32.1 per cent in people aged 55-59 and 25.6 per cent in people aged 60 and over. (*Dementia North East England – A demographic and service profile)*

Strategic Context/Resources

30. According to research, the cost of dementia in the UK to the NHS, local authorities and families is approximately £23 billion a year and is set to rise to £27 billion by 2018.

31. The cost of dementia could be significantly reduced if more preventative work was undertaken and there was an improvement in diagnosis, treatment and support and care to prevent hospital admissions. The cost and the challenges faced by partner organisations as a result of the limited resources available was raised on a number of occasions and although we acknowledged that organisations were working within financial constraints we felt that they could work better together to maximise the use of the resources available.

32. A County Durham and Darlington Dementia Strategy 2014-17, has been developed to identify actions to improve outcomes for people with dementia and their carers in County Durham and Darlington. The strategy brings together key stakeholders across the area from both health and social care to set out a range of priority areas across the whole spectrum of dementia from diagnosis, through to care and support, to end of life care.

33. The Chair of the Strategy Implementation Group attended a meeting to discuss the progress against the Strategy and progress is being made to deliver the actions contained therein and we were re-assured that it would deliver its objectives. We did, however, feel that more public awareness of these objectives would be beneficial and that the governance arrangements around the delivery of the

Strategy should be reinforced to ensure on-going accountability for the delivery of the outcomes.

34. We also noted that the Strategy was being refreshed.

35. We did feel that Darlington Borough Council should appoint a Dementia Champion.

RECOMMENDATIONS R1 – R4

(a) That the Cabinet Member for Adult Social Care and Housing be appointed as the Council's Dementia Champion.

(b) That the Governance arrangements around the County Durham and Darlington Dementia Strategy be reviewed and strengthened as part of its refresh to ensure its accountability.

(c) That the refreshed Strategy be forwarded to the Health and Well Being Board for approval and to the Adults and Housing and the Health and Partnerships Scrutiny Committees.

(d) That, through the Strategy Implementation Group, all partner organisations work together to build on current practice and appoint a named practitioner to lead and co-ordinate treatment and support for people living with dementia and their carers across health and social care.

Preventing Well

36. Dementia is not very well understood and people often don't ask for help because there is still a stigma attached or they think, wrongly, that the symptoms are a normal part of ageing and that nothing can be done. Even when a diagnosis has been made, people living with dementia and their carers often don't ask for help. There needs to be a fundamental change in how health professionals manage people living with dementia and a review of the key part they play in signposting to appropriate support. The creation of Dementia-Friendly Communities may help with this.

37. Dementia is very common and can affect anyone whatever their gender, ethnic group or age and people with learning disabilities are particularly at risk. Although at present the medical research has not established how it can be completely prevented, preventative measures may reduce the risk of dementia, by adopting healthy lifestyle choices, especially in mid-life. Regular physical exercise, maintaining a healthy weight, not smoking and drinking only in moderation are all linked to a reduced risk of dementia.

38. We were aware of the National Institute for Health and Care Excellence (NICE) Guidance NG16, which sets out the need for both national organisations and local government departments which influence public health to develop and support population-led initiatives to reduce the risk of dementia by making it easier for people to stop smoking, be more physically active, reduce their alcohol consumption; adopt a healthy diet and achieve or maintain a healthy weight. All of

these initiatives mirror the healthy lifestyle initiatives already in place within Healthy Darlington, and although there is no way that dementia can be completely prevented, the adoption of a healthy lifestyle approach, may lower the risk of some forms of dementia.

39. Preventative work is essential to reduce the costs associated with dementia care and awareness raising about the signs of dementia is key to ensuring early diagnosis to ensure that patients get the appropriate treatment to enable them to have the best quality of life for as long as possible. We particularly looked at the impact of dementia on black Asian and minority ethnic (BAME) communities and on those in the lesbian, gay, bisexual and transgender (LGBT) communities and felt that guidance relating to these communities needed to be strengthened and targeted and that training and awareness raising around the specific cultural needs of these groups should also be improved. The Alzheimers Society recognises that people from BAME communities face significant barriers when accessing support and the lack of cultural sensitive dementia services. Families can be reluctant to use services that do not meet cultural or religious needs.

40. We also felt that although there was a lot of information available about spotting the signs of dementia and how to reduce its risk, there was little evidence of local health campaigns promoting healthy life-styles linked to helping prevent the risk of dementia, particularly early onset dementia amongst younger people. It was noted that Tees, Esk and Wear Valley NHS Foundation Trust were working with younger people and that workshops were being undertaken.

RECOMMENDATIONS R5 to R10

(a) That, Public Health, Darlington Borough Council, continue to organise more local campaigns/publicity to raise public and professional awareness about life-style changes, such as stopping smoking, eating healthily, drinking alcohol sensibly, exercising more and having regular health checks which may help prevent certain forms of dementia.

(b) That this Review Group supports the call by the Alzheimer's Society for an increased awareness and a better focus on preventative services for people from BAME and LGBT communities and that it undertakes a publicity campaign to appoint more dementia champions from across these communities.

(c) That the Cabinet Member for Children and Young People ensure that all opportunities to raise awareness of dementia to young people, including prevention, and seek reassurance that any training or campaigns that are being delivered are tailored to their needs.

(d) That attendance at a Dementia Friends information session be mandatory for all Members of Darlington Borough Council.

(e) That, arising from the Dementia Friends Information session, each Member identify one action arising from the session which they will take forward.

(f) That awareness raising about dementia be included as part of the Council's

Induction Programme and that the Dementia Friends Information sessions be publicised to all Council employees, with all Managers being requested to identify key staff who they feel would benefit from attending these sessions to assist in their roles.

Diagnosing Well

41. Being diagnosed with dementia at an early stage is important. It helps people to plan ahead while they are still able to make important decisions on their care and support needs and on financial and legal matters. It also enables them and their families to receive practical information, advice and guidance on the challenges they face and may delay or prevent unnecessary admissions into hospital or care homes.

42. The Darlington Clinical Commissioning Group advised us that diagnosis rates were improving in Darlington, with the latest figure being 76.3 per cent (compared to the national diagnosis rate of 67 per cent), and that these figures were now being reviewed and monitored on a monthly basis.

43. It was also, as part of its Clear and Credible Plan 2013/13-206/17, planning to improve the care for people with dementia as one of its key aims in addressing the needs of the changing age profile of the population of Darlington.

44. As part of the discussions we had with various people throughout this process, we heard about the importance of 'Person Centred Care' and a number of aids to stimulate memories and share experiences with others such as memory boxes and life story boxes and we felt that it was important to commence a Life Story Book from diagnosis. Life Story Books work as an intervention for people with dementia and their families, in terms of promoting individual care, improving assessment, building relationships between care staff and families as well as improving communication. The Book is a collaborative process with family members and friends and the emphasis is placed on using images and photographs to bring the story book 'to life'.

45. Following a meeting with two GP's representing both urban and rural practices in Darlington, we were re-assured with the information we received, however, further re-assurance was sought that all practices within Darlington were adopting the same approach for diagnosis and referral. There was some evidence that the quality of information contained in GP referrals was variable and this could affect the commencement of the appropriate clinical pathway.

46. We were also re-assured by the work being undertaken by the Tees, Esk and Wear Valley NHS Foundation Trust (TEWV) and were of the opinion that the pathway for referral and diagnosis was being implemented by that Trust. The target assessment of four weeks following referral was generally being met and assessments were undertaken sooner if the GP's felt it was urgent.

RECOMMENDATIONS R11 to R14

(a) That re-assurance be sought from the Darlington Clinical Commissioning Group

that early diagnosis of dementia is a priority for it and that all GP practices are aware of that and the need to follow the referral pathway.

(b) That to ensure that a consistent quality of information is provided as part of the referral pathway, the Darlington Clinical Commissioning Group monitor the use of the template by all GP's within Darlington when undertaking referrals.

(c) That the Darlington Clinical Commissioning Group encourage all GP's and practice staff to undertake dementia awareness training.

(d) That the Darlington Clinical Commissioning Group ensures that every person living with dementia receives their annual check-up to review and assess their care needs and that it continues to monitor and record this.

Living/Caring Well

47. Dementia can affect all aspects of a person's life as well as their families, however people living with dementia can live well and independently for quite some time after the condition's onset with the right care and support. Once diagnosed it is important that people keep themselves as healthy and independent as possible, for as long as possible.

48. Keeping an active social life is key to helping someone living with dementia feel happy and motivated and there are a range of activities taking place within the voluntary sector in Darlington designed to help people in the same situation such as dementia cafes, singing for the brain, St Hilda's Day Centre and a Carers Club. The Darlington Clinical Commissioning Group Carers Fund and Darlington Borough Council provide significant investment in these services delivered by the voluntary sector agencies, however, it was highlighted that more could be done to relieve pressures by improved commissioning with the voluntary sector.

49. Providing support to carers plays a crucial role in enabling both the carer and the person with dementia to live well for as long as possible and for appropriate end of life support to be provided for the person with dementia and their carer and we were overwhelmed by the role of carers. We did feel that more support should be available to carers to enable them to continue to undertake their role without adverse impact on their own health and well-being.

50. We noted the current support available to carers through existing service providers, including the Alzheimer's Society, and the views of carers expressed in the meeting with Councillor Sue Richmond around the information and advice that they need to support them in their caring role. It was stated that this should be provided in a timely manner by a trained specialist worker (Dementia Advisor/Support Worker) who is able to judge the right time to provide the information referred to in points (a) to (g) below :-

    (a) financial and legal information, including Lasting Power of Attorney(s), wills and benefits advice;

(b) training and education for carers (delivered by way of a carers training course), due to funding this is ad-hoc and not delivered regularly, including information about dementia and how it can affect someone and how to manage the different types of symptoms and behaviours that dementia can lead to;

(c) respite, domestic and other help available within the home;

(d) emotional support/counselling;

(e) explanation and information on the diagnosis and what that means for the individual;

(f) practical tool kit for dealing with everyday life and developing strategies to enable someone to stay independent at home; and

(g) signpost and refer directly to other support when appropriate (e.g. social services, lifeline, Darlington Association on Disability)

51. The worker should also be able to support the carer to navigate the health and social care systems and to access appropriate community resources for both them and the person they care for.

52. The Darlington Dementia Hub, an initiative of the Darlington Dementia Action Alliance, which aims to provide a one-stop shop for information, advice and referrals, to help those living with dementia to get the support they need has recently been established and is held at Crown Street Library every second Tuesday of the month. Grant funding to resource the Hub is not available at the present time.

53. We heard about the work of the Alzheimer's Society to provide support to help people living with dementia to make choices, live independently at home for as long as possible, to improve their quality of life and to improve their sense of well-being and we were concerned about its views in relation to the lack of a support pathway in Darlington. There was evidence to suggest that there was some resistance, for a number of reasons, to signpost those diagnosed with dementia and their carers to the support available through the Society. We also felt that, although there was a wealth of information to provide help, support and guidance to the community from various sources, there was no standardised approach to the collation of that information and its verification to ensure that the correct referral pathway was followed.

54. We were delighted with the success of the Darlington Dementia Action Alliance which brings together organisations from public, private and charity sectors, not just from health and social care, but from sectors such as the emergency services, retailers and transport operators and community facilities, with the aim of encouraging local communities to become dementia friendly by increasing awareness of the condition and how the community can work together to reduce stigma.

55. We heard lots of examples of how services, businesses and communities were working to support people living with dementia in the community and some examples of this were :-

(a) Durham Constabulary – the launch of the Herbert Protocol, which was a simple risk reduction tool to help the police in their search for people with dementia who go missing. It is hoped that the scheme will assist in finding missing people more quickly and effectively by collecting vital personal information and a photograph which can then be circulated quickly to all partners;

(b) County Durham and Darlington Fire and Rescue Authority – the provision of advice, as part of their safe and wellbeing visits, to people living at home with dementia on how to stay safe in their own homes by identifying potential hazards that might pose a risk to someone living with dementia. Staff have also received dementia training to enable them to spot the signs and make referrals when appropriate;

(c) Arriva Bus Services – the introduction of the Coin Recognition Chart on its buses to assist customers who may struggle to understand their coinage;

(d) Darlington Train Station – its success in becoming the third station in the Country to be awarded 'Dementia Friendly Status; and

(e) Sainsbury's Darlington – work to ensure that retail services can be more dementia friendly and testing out new ways to deliver better outcomes for customers living with dementia.

RECOMMENDATIONS R15 to R22

(a) That the Adults and Housing Scrutiny Committee look at the Carers Strategy and ensure that structures and services are in place to support carers in their role and to allow them to live a life of their own alongside their caring role.

(b) That the success of the Darlington Dementia Action Alliance in making Darlington a Dementia Friendly Town be noted and that the Darlington Partnership be requested, through its work, to raise the profile and work of the Alliance to all sectors.

(c) That this Group recognises the excellent work being undertaken to deliver services by the third sector and improved commissioning within that sector be undertaken to ensure value for money.

(e) That the Tees, Esk and Wear Valley NHS Foundation Trust review its processes to ensure that a high proportion of people diagnosed with dementia are offered the opportunity to be referred to appropriate third sector support services.

(f) That the Darlington Dementia Action Alliance be requested to develop a standard 'starter pack' (in consultation with carers), which would include 'this is me', which can be used across all services for people diagnosed with dementia as an

introductory guide to sources of assessment, advice and support for people living with dementia and their carers.

(g) That Darlington Borough Council's Place Scrutiny Committee consider, through the Local Plan process, the scope to support people living with dementia when designing future builds.

(h) That Darlington Borough Council look at how it can support people living with dementia in all of its public buildings, particularly when undertaking re-design work taking into account current research and recommendations.

(i) That this Group supports the work of the Dementia Hub and would like to see its further development and re-location to the Dolphin Centre to enable a wider cross-section of the community to benefit from the services and support provided whilst accessing a range of other public activities.

Supporting Well

56. People living with dementia should be supported to live independently in their own homes for as long as possible and we heard from representatives from Adult Social Care and Tees, Esk and Wear Valley Foundation Trust about the services provided by social workers and community nurses to enable this. A couple of case studies were discussed which demonstrated some of the types of cases which the services were involved with, together with the support packages and assistive technology available to enable them to be independent and to live at home for as long as possible, based on a risk approach.

57. Many people with dementia may eventually need support in a care home which could be a residential care home or a nursing home, depending on their needs.

58. Following a number of visits to care homes who were currently contracting with the Council, we were re-assured with our findings, an analysis of which can be found at **Appendix 4.** We saw some examples of good practice within the care homes we visited and there was consistent and high quality care across those homes. The work of the Care Homes through the Residential Care Home Forum is contributing towards this high quality of care.

59. We also visited Rosemary Court, an Extra Housing Scheme, as an example of a housing provision which had been designed, furnished and decorated to ensure that people with dementia and a wide range of other health needs and disabilities can live independently with the appropriate care and support. Within the Scheme, there is a room that has been replicated as a flat and this has many of the devices which are available within the telecare offer to promote health, wellbeing and independence for the person and the carer. There are three other extra care housing schemes in Darlington.

60. Someone living with dementia may need to go into hospital for either, a planned, or emergency, procedure and this can be disorientating and frightening and might make them more confused than usual. We were re-assured by the work being undertaken by the County Durham and Darlington NHS Foundation Trust (CDDFT)

for both in-patients and emergency admissions to A and E and were of the opinion that good progress in relation to supporting and developing services for patients living with dementia was being made however, we felt there was still a long way to go for it to become a dementia friendly hospital, but accepted that this was due to available funding and resources. We were particularly impressed with the approach of the Dementia Specialist Nurse in driving forward the improvements within the Trust and in developing services.

61. We were concerned about information we were given in relation to the challenges on occasions of getting care packages in place following discharge, particularly in relation to domiciliary care.

62. The Trust were working towards to actions contained within the Dementia Strategy for County Durham and Darlington and had also developed its own County Durham and Darlington Foundation Trust Dementia Plan 2015-17 which addressed the key recommendations within the Fix Dementia Care: Hospitals and the good progress made in caring for in-patients, their carers and families.

RECOMMENDATIONS R23 to R28

(a) That the progress being made by the County Durham and Darlington NHS Foundation Trust be noted and that the outcome of the National Dementia Audit and the action plan be forwarded to the Adults and Housing Scrutiny Committee when appropriate.

(b) That the Good Friends scheme be extended to include dementia trained and approved therapeutic volunteers to support patients living with dementia in hospital and community settings, with hobbies and personal interests.

(c) That the County Durham and Darlington NHS Foundation Trust and Darlington Borough Council look, through the Better Health Programme's Discharge to Assess project, at how the needs of people living with dementia are fully considered prior to discharge.

(d) That this Group supports and acknowledges the excellent work being undertaken by some Care Homes within the Borough and, through the Care Home Forum, expects to see good practice being shared and developed across those homes and all staff/carers attend a Dementia Friends Information session and that all care homes be encouraged to join the Darlington Dementia Action Alliance.

(e) That the Adult and Housing Scrutiny Committee undertake a joint piece of work to look at domiciliary care

(f) That Adult Social Care achieve a significant increase in the use of assistive technology to enable people living with dementia to remain independently in the community for as long as possible.

Dying Well

63. Dementia is a terminal condition and people living with dementia should be able to end their lives with dignity and free from pain. Dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life to enable people to die with dignity and respect and in the place of their choosing, whilst also supporting carers during their bereavement.

64. The National Institute for Health and Care Excellence (NICE) have developed quality standards which define clinical best practice in this area and we challenged representatives from TEWV about the services it provided in relation to End of Life Care for those living with dementia. We were of the opinion that End of Life care was being delivered in accordance with those quality standards and there was evidence to suggest that end of life care was discussed with patients, their families or carers at the start of the process and was reviewed throughout. End of life care also includes support for family members.

65. We also heard about the care given to patients living with dementia at St Teresa's Hospice and the changes, adaptations and staff training it had undertaken to ensure they were supported to live and die well.

RECOMMENDATIONS R29 to R30

(a) That the dementia pathway should recognise the effect a diagnosis can have on lives and make appropriate links with the end of life pathway.

(b) That a joint piece of work be undertaken with the Adults and Housing and the Health and Partnerships Scrutiny Committees in relation to the end of life pathway.

Safeguarding Well-Being

66. People with dementia may be subject to mistreatment and abuse in the community, or in care homes and hospitals because they are more vulnerable. Early symptoms can affect communication and reasoning skills and consequently they may not be able to understand or explain to others what is happening to them. Everyone has the right to be treated with dignity and make their own choices in life and it is important that a person living with dementia is treated with dignity and respect at all times and that appropriate safeguards are put in place to protect them. Under the Mental Capacity Act 2007, a person is presumed to be able to make their own decisions unless all practical steps to help them to make a decision have been taken without success.

67. We were re-assured by the role and work of the Darlington Adults Safeguarding Partnership Board in ensuring the safeguarding of vulnerable adults. The Board have undertaken a making safeguarding personal multi-agency thematic audit which looked, in detail, at four individual cases, two of which involved individuals who had received a diagnosis of dementia. The learning from the audit was that where the adult at risk does not have capacity to make safeguarding decisions, agencies throughout the safeguarding process must recheck and review with the adult their views and outcomes. The evidence from the audits suggests that this was variable at the time but it was recognised that practice was constantly

improving and that there had been real improvements over the last twelve months.

68. All decision-making should be undertaken within the Mental Capacity Act 2007 guidance which clearly states views and wishes should be considered when making a best interest decision where an individual lacks capacity. It is vital that they are supported and represented during this process and, where possible, individuals are supported to build their capacity in relation to that.

69. Positively, all agencies (Durham Constabulary, Tees Esk and Wear Valley NHS Foundation Trust, County Durham and Darlington NHS Foundation Trust and Darlington Borough Council) to a degree, practiced the making safeguarding personal principles but recognised it was variable and that multi-agency training on making safeguarding personal needs to be promoted with a particular focus on adults at risk without capacity that fluctuates. We did feel that there should be more awareness raising in relation to the existence of the Board.

70. We were also confident that the principles of Making Safeguarding Personal were being adopted throughout the pathway to enable patients to feel in control and to support them in making difficult decisions.

RECOMMENDATIONS R31 to R32

(a) That the Adults Safeguarding Board satisfy itself that all organisations are aware of the key principles of Making Safeguarding Personal and that those principles are championed through that Board, where key partners are represented.

(b) That the specific needs of people living with dementia should be defined and encouraged through the Adults Safeguarding Board.

Monitoring and Review of Recommendations

71. As a result of this Scrutiny Review, we have identified a number of recommendations. These recommendations range from easy and quick fixes to changes that need to occur over the longer-term and require senior management commitment and drive.

72. The Adults and Housing Scrutiny Committee will seek an update on the progress of these recommendations in six months' time to review the extent to which any changes have happened as a result of this review and to actively encourage all partners to implement as many of the outstanding recommendations as possible.

APPENDIX 1

DEMENTIA REVIEW GROUP

19th November 2015

PRESENT – Councillor S Richmond (in the Chair); Councillors Culley, Kane, Knowles, M Nicholson; T Richmond and Storr.

D1. DEMENTIA – Following the decision by the Adults and Housing Scrutiny Committee to establish a Review Group to look at Dementia services, the Group met to receive an overview of the work being undertaken in Darlington; how it could add value to that work; and to consider how it wished to undertake its review.

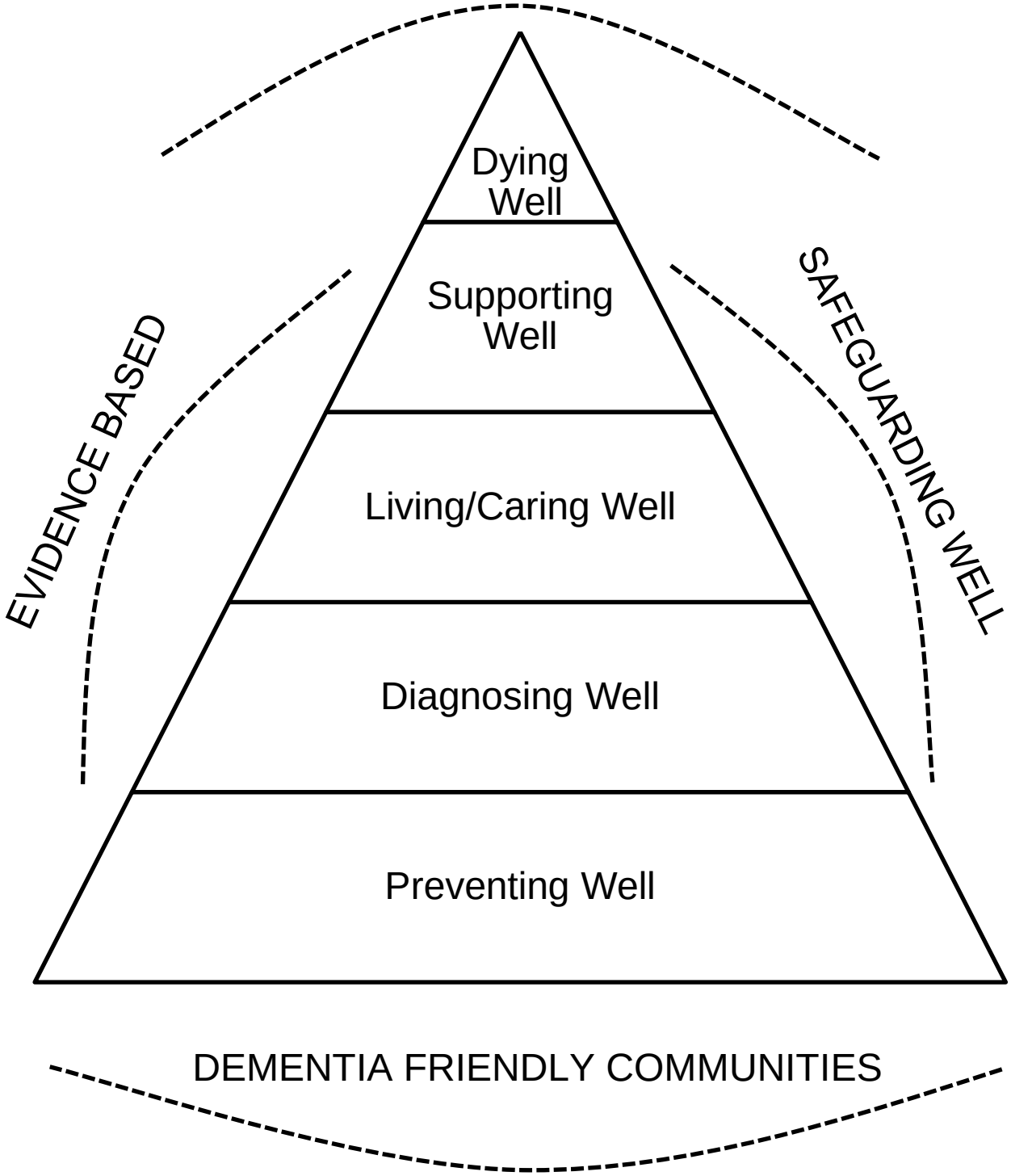
Lisa Holdsworth gave Members an overview of some of the work being undertaken and the key statistics in relation to dementia and made reference to a number of documents which could be circulated to Members for information. The documents would give Members a greater understanding about the condition, the national context, including statistical information and research; and would help to inform Members generally about the condition and its effects.

Reference was made to the work being undertaken by the Darlington Dementia Action Alliance to make Darlington a dementia friendly community and to ensure understanding about the condition from society as a whole; to the role of Dementia Friends and Champions and how to raise awareness about those roles and how to become a Dementia Friend or Champion.

Members discussed how they could support dementia friendly communities by raising awareness within the communities they represented and by signposting to other agencies and support services available and it was suggested that information sessions to become a Dementia Friend could be offered to all Members.

Discussion ensued on the need for the groups work to be focussed around safeguarding adults whether they are living with Dementia or as carers and the need to also ensure the welfare of young persons who may also be carers for relatives with dementia; and to environmental changes which could be made which would contribute towards Darlington becoming a dementia friendly Town.

The Chair gave an overview on areas which the Group could focus its work and the triangle below demonstrates the thoughts of how the review group could structure its work within the six headings :-



IT WAS AGREED – (a) That the terms of reference for the Group be approved.

(b) That the Director of Public Health be invited to attend the next meeting of this Review Group to discuss preventative measures as the first stages of this Review.

DEMENTIA REVIEW GROUP

14th December 2015

PRESENT – Councillor S Richmond (in the Chair); Councillors Culley, Kane, Knowles, Mills, M Nicholson; T Richmond and Storr.

D2. DEMENTIA – PREVENTION – The Group met to discuss with the Director of Public Health the preventative measures which could be taken by individuals to reduce the risk of dementia and the role of Councillors, as community leaders, in promoting and raising awareness of those measures to residents and their local communities.

Reference was made to the National Institute for Health and Care Excellence (NICE) Guidance NG16, which set out the need for both national organisations and local government departments which influenced public health to develop and support population-led initiatives to reduce the risk of dementia by making it easier for people to stop smoking, be more physically active, reduce their alcohol consumption; adopt a healthy diet and achieve or maintain a healthy weight. All of the initiatives mirrored the healthy lifestyle initiatives already in place within Healthy Darlington, and it was highlighted that, although there was no way that dementia could be completely prevented, the adoption of a healthy lifestyle approach, may lower the risk and that this positive message needed to be conveyed to residents of Darlington.

Discussion ensued on the role of local Councillors in promoting the services available within their Wards, identifying what could help communities to become more healthy; supporting and promoting the healthy lifestyle initiatives already in place; and by signposting to the various services available.

Members were advised of the creation of the Darlington Dementia Hub, a new one-stop shop for information, advice and referrals to help people living with Dementia to get the support needed, which was held at Crown Street Library every second Tuesday of the month. The Hub was an initiative of the Dementia Action Alliance and was supported by a number of organisations which were part of that Alliance. Grant funding to resource the hub was not available at the present time. Reference was also made to the role of the Dementia Adviser from the Alzheimers Society in assisting people with dementia and their carers to identify their needs, in providing individuals with support and helping them maintain their independence, improving their sense of well-being and by putting them more in control of their lives.

Members questioned whether all the services within the hub were joined up and it was suggested that a ‘secret shopping’ exercise would be useful to give Members the re-assurance that they were and that all of the organisations were providing the correct advice and support.

Discussion ensued on the need to ensure that messages did not stigmatise people by suggesting that people who developed dementia were at fault and the need to ensure

that any stigma was identified and tackled; the need to ensure that information and services were available to all cultural backgrounds; the need to look at services for people who developed early on-set dementia to ensure that enough support was provided to those people; the different forms of dementia; the formation of the Dementia Action Alliance and its work in making Darlington a Dementia Friendly Town; estimated numbers of people with dementia which was referenced in the Joint Strategic Needs Assessment and which was predicted to rise as the population aged; the evidence which suggested that people with learning difficulties because of increased longevity would develop dementia; the need to ensure that young people were educated and made aware of dementia and the key messages about prevention and to the work of the Scout Organisation through the Million Hands project to raise awareness through that Organisation.

Members concluded that there was a wealth of information available to the community to provide help, support and guidance and that that information should verified to ensure that the correct referral pathway is followed.

IT WAS AGREED – (a) That, as in interim measure, the poster promoting the Darlington Dementia Hub be circulated to all Members and that they be requested to request owners of appropriate public buildings within their wards to display it to raise awareness of the Hub and the partner agencies involved.

(b) That the NICE Guidance NG 16 in relation to approaches to delay or prevent the onset of dementia be circulated to all Members of the Review Group for information.

(c) That the following key preventative measures to prevent the onset of dementia be noted :-

- sustained ill health in old age is not inevitable. The risk of developing dementia, disability and frailty may be reduced and, for some, onset can be delayed and the severity of the conditions reduced;
- smoking, lack of physical activity, alcohol consumption, poor diet, being overweight or obese and loneliness are all avoidable risk factors for dementia, disability and frailty;
- the earlier in life that healthy changes are made, the greater the likelihood of reducing the risk of dementia, disability and frailty;
- there are health gains that can be made by changing behaviours even in mid-life; and
- health behaviours are more likely to be maintained if they are built into everyday life.

(d) That a mystery shopping exercise of the Darlington Dementia Hub be undertaken to ensure that all the services involved are joined up and the correct advice and support pathway was being followed.

DEMENTIA REVIEW GROUP

13th January, 2016

PRESENT – Councillor S Richmond (in the Chair); Councillors Culley, Kane, Knowles, Mills, T Richmond, Storr and Tostevin.

D3. DEMENTIA – STRATEGIC CONTEXT – The Group met Nigel Nicholson from the NHS North of England Commissioning Support Unit and Chair of the Implementation Group for the County Durham and Darlington Dementia Strategy and Jeanette Crompton, Development and Commissioning Manager to receive an overview of the contents of the Dementia Strategy for County Durham and Darlington 2014-17 and the role of the Implementation Group which had been established.

It was reported that the Implementation Group was made up of a number of organisations, including Darlington Borough Council, such as Tees, Esk and Wear Valley NHS Foundation Trust (TEWV); County Durham and Darlington NHS Foundation Trust (CDFFT); Durham County Council; Healthwatch Darlington and Healthwatch County Durham, third sector organisations, carers and the three local clinical commissioning groups and its role was to adopt and take forward all actions as set out in the strategy.

Particular reference was made to the action which required the national diagnosis target of 67 per cent to be exceeded and it was reported that Darlington was currently above that national average with a diagnosis rate of 76 per cent and that this could be evidenced by the registers which each GP practice was required to hold. It was reported that the information held varied from practice to practice depending on the demographics of the area it served, however, on the whole the information should be fairly consistent.

Members were advised of the work being undertaken through the community initiatives through training programmes, dementia friends and the establishment of the Darlington Dementia Hub at Crown Street Library; the work being undertaken by TEWV in relation to end of life care for people with dementia, offender health, those with learning difficulties and ensuring good access to diagnostic scans; the Health Needs Assessment work stream, research and the establishment of a web-based information system, Dementia Connect, which it was hoped would be up and running in the next few weeks.

Discussion ensued on the work of the Darlington Dementia Action Alliance in making Darlington a Dementia Friendly Town and encouraging and assisting developers to think, as part of the design process, of making buildings dementia friendly and in encouraging more individuals and service providers to become dementia friends and part of the Alliance, and taxi drivers were highlighted as an important group; and to training which was undertaken with professional staff within organisations to raise awareness of dementia and how to support people with dementia. Members questioned how the

training was undertaken and delivered and it was reported that this was done on an individual basis by each organisation.

Reference was made to a new Dementia profile which had been launched by Public Health England on the 12th January, 2016, which would enable local authorities and CCG's to access comparative information. The profile shared key information, such as how many people had dementia broken down by area and age; the number of people who had received an NHS health check; the number of people who had depression, emergency hospital admission numbers' and where people with dementia die. It was intended that the launch of the profile would help commissioners fulfil objectives and improve outcomes for people with dementia and their carers.

At the last meeting of the Review Group, members discussed the support available to young people who had early onset dementia or who were carers for someone with dementia and it was reported that the numbers were low, however, TEWV were working with this particular group and that workshops were being undertaken between now and May 2016.

Discussion ensued on the governance arrangements for the implementation of the Strategy; the commissioning arrangements for services; any gaps within the strategy and the challenges ahead.

In terms of the Strategy, Members were advised that the next steps were to refresh it to ensure that the actions were still appropriate and would ensure the delivery of an integrated pathway from diagnosis to end of life.

IT WAS AGREED – (a) That the thanks of this Group be extended to Jeanette and Nigel for the information provided at this meeting which has been extremely useful in assisting the Group with its work.

(b) In relation to the Strategy :-

(i) this Group is satisfied with the progress made in delivering the actions contained therein and is re-assured that it will deliver its objectives;

(ii) looks forward to receiving the refreshed Strategy document in due course; and

(iii) requests that the Governance arrangements around the delivery of the Strategy be re-enforced.

DEMENTIA REVIEW GROUP

2 February 2016

PRESENT – Councillor S Richmond (in the Chair); Councillors Kane, Knowles, M. Nicholson, T Richmond and Storr.

D4. DEMENTIA – DARLINGTON SAFEGUARDING ADULTS PARTNERSHIP BOARD – The Group met Mike Vening, Chair of the Darlington Safeguarding Adults Board and Emma Chawner, Safeguarding Board Business Manager to receive an overview of work and role of the Safeguarding Adults Partnership Board.

It was reported that the Board, which was chaired by Mike, as an Independent member, was a statutory body which met bi-monthly and worked on six key principles of safeguarding practice, which were re-inforced by the Care Act 2014. The six principles were :-

- empowerment;
- prevention;
- proportionality:
- protection;
- partnership; and
- accountability

The Board was made up of a number of key organisations, who were involved in reducing the risk of abuse and neglect and protecting adults at risk of harm and exploitation. Its role was to listen to and understand the feelings and opinions of service users and then focus its work around any areas of required improvement and hold other agencies to account. There was at this stage, no forum for its accountability, however, it was envisaged that this would change in the near future.

It was reported that partners on the Board, held a strategic role within their own organisations and should be able to speak for that organisation with authority, commit their organisation on policy and practice matters and hold their organisations to account They were also expected to represent the Board at other partnerships and forums they attended, highlighting the work that the Board undertook and sharing actions to ensure that all partnerships were complimenting each other in their objectives.

In addition, the Board had also created four sub-groups, Policy and Implementation, Quality and Performance, training and communications and a Learning and Improvement Group which met regularly and reported back into the Board on their workings. Particular reference was made to the role of the Quality and Performance Sub-Group in scrutinising the attendance of members at the Board and the sub-Groups as well as their contribution to the partnership and this was important to ensure the effective operation of the Board.

Discussion ensued on the need to communicate to the public the work and role of the Board to ensure its success and reference was made to the development of an independent micro-site which was being established which would stand alone from the current Darlington Borough Council site. It was suggested that it would be useful if a section on both the Darlington Adults Safeguarding Board and the Darlington Children's Safeguarding Board be included in a future edition of the One Darlington magazine.

Particular reference was made to the principal of Making Safeguarding Personal and the need to ensure that there was an emphasis on what would improve the individual's quality of life and well as their overall safety. Making Safeguarding Personal aimed to ensure that individuals were supported and encouraged to make their own decisions and to give informed consent and this was a priority of the Board. Emma reported that a review of a number of cases was to be undertaken to test whether the key principles of making safeguarding personal had been applied in those cases and it was suggested that, if possible, a case review of an individual with dementia be reviewed and that the outcome of that review be reported back to a future meeting of this Group.

The Chair reported that, as part of the work of the Dementia Review Group, Members would be visiting both Darlington Memorial Hospital and West Park Hospital and it was suggested that making safeguarding personal be a key part of the questioning at that visit to ensure that other partners were aware and following the key principles.

Reference was made to a piece of work which was being undertaken by one Police Authority in the Country to collect personal information about individuals suffering with dementia and who were at risk of becoming a missing person, to enable them to have a starting point about their whereabouts. This information was to be given only with consent. It was suggested that the Fire Authority might also have a role to play in this project when they were visiting homes as part of their safety and well-being checks for vulnerable adults.

Mike reported that the Adults Board was working closely with the Children's Board and, although they worked to different legislation, they worked together on areas of common interest and best practice and lessons learnt were shared. To demonstrate effectiveness of the Board it was essential that members challenged effectively and sought evidence to seek reassurance that vulnerable adults were protected using case studies and quantitative data and this was open to scrutiny.

Discussion ensued on how the Board and the Adults and Housing Scrutiny Committee could work together in the future and compliment the work of each other.

IT WAS AGREED – (a) That the thanks of this Group be conveyed to Mike and Emma for attending this meeting and for the valuable input and oversight.

(b) That the Darlington Safeguarding Adults Partnership Board's Annual report and Strategic Plan be submitted to a future meeting of the Adults and Housing Scrutiny Committee and that both bodies work together in the future to meet joint objectives.

(c) That, if a case review of a person with dementia is undertaken as part of the case reviews, the outcome of that review be submitted to a future meeting of this Group to enable Members to form a view on whether the principles of making safeguarding personal were adopted.

DEMENTIA REVIEW GROUP

9 February 2016

PRESENT – Councillor S Richmond (in the Chair); Councillors Knowles, M. Nicholson, T Richmond and Storr.

D5. DEMENTIA – COUNTY DURHAM AND DARLINGTON NHS FOUNDATION TRUST (CDDFT) – DARLINGTON MEMORIAL HOSPITAL - The Group met Janet Mortimer, the Dementia Specialist Nurse from the County Durham and Darlington NHS Foundation Trust to discuss her role and the work the Trust was doing to improve and develop its services to those experiencing living with dementia and their carers.

Janet explained that she had previously worked on ward 52 which was predominantly occupied by patients with dementia or parkinsons disease and she explained the roles and responsibilities of the staff on that ward.

The Dementia Specialist Nurse reported that she had been in post since February 2015 and had been able to develop her role since that date. Her first task was to determine where the trust was and where it needed to be in driving forward improvements within the Trust for living with dementia and their carers and it was clear that Janet was passionate about her role in driving forward these improvements and in developing services.

The Group made reference to the Alzheimers Society's recent publication 'Fix Dementia Care: Hospitals', which marked the start of a new campaign to look at the experiences of people affected by dementia in a range of health and care settings. The Group challenged some of the key recommendations contained within that document such as :-

- *fast-tracking admission*

  It was reported that it was important that admission pathways were re-designed so people with dementia didn't have to wait for long periods of time in a traumatising A and E environment and Members were advised of the work being undertaken in A and E to improve that environment to make it more dementia friendly. Members also had the opportunity to visit Ward 52 and the outpatients area to look at the work undertaken to make both of those areas more dementia friendly in accordance with the dementia friendly principles, with improved signage, music, bold painting on doors and frames. By making changes to the physical environment, it was proven that falls and aggressive behaviour can be reduced. It was planned that all areas within the hospital would adopt the same principles and uniform approach as and when funding allowed. It was reported that patients with dementia tended to stay in hospital twice as long as other

people over the age of 65.

- *Dementia Support Workers and A Dementia Friendly Workforce*

  Members were made aware of the training package in place within the Trust to ensure that hospital staff at all levels, had a general knowledge and awareness of dementia. They were advised of the Health Education England's (HEE's) Dementia Awareness Training Programme which had been adopted, which defined three tiers of competency training. Janet reported that she provided staff training and approximately 4000 staff right across the organisation had now received this. Although dedicating time to training did prove challenging for ward staff on occasions because of the ward pressures they faced.

  Discussion took place on the role of the Alzheimer's Society Support Worker in providing advice and support to patients and their carers and it was reported that discussions were taking place on whether a room could be made available within the hospital for that Adviser to use on a regular basis to offer advice and support for patients and carers. Posters were also being devised which signposted staff and relatives to the services available.

- *Personalising Care*

  The Group discussed the This is Me and the Forget-me-not schemes which were used across care settings for people with dementia to provide background information on their needs, preferences, likes, dislikes and interest to allow clinical staff to see the person as an individual and deliver the appropriate care and they were advised of the shoe box initiative within the Trust to encourage patients and their carers to fill the shoe box with personal possessions to stimulate their memory and encourage communication about their past. Janet also advised that, if requested, there was facility for carers to stay with patients with dementia throughout their time in hospital and that visiting hours were relaxed. It was reported that the Forget-me-not scheme was being looked at for future implementation but, had not, as yet been implemented.

  Discussion took place on the work which was being done by James Cook hospital in Middlesbrough in relation to dementia, particularly around the This is Me and Forget-me-not schemes and the recruitment of volunteers to undertake shared activities with dementia patients during their stay in hospital and how this could perhaps be facilitated with the CDDFT in conjunction with the voluntary sector.

- *Preventing Falls*

  It was reported that the hospital environment could be confusing and

disorientating for people with dementia and the Group had already heard about the work to make wards more dementia friendly which helped to reduce this, however, on occasions falls did occur and the Group were advised of the falls bundle which was in place in these events.

- *Discharge Co-ordination*

  The Group had the opportunity to speak to the Discharge Co-ordinator who outlined the work she did to ensure that patients had a health and social care assessment and that an appropriate support package was in place prior to their discharge. She confirmed that from initial admission, the future care needs of patients were discussed and considered with family members, involving wherever possible, the patients themselves in accordance with the making care personal principles, however, there were challenges on occasions in getting care packages in place, particularly in relation to domiciliary care.

- *A Dementia Strategy*

  It was reported that the Trust was working towards the actions contained within the Dementia Strategy for County Durham and Darlington and had also developed its own County Durham and Darlington Foundation Trust Dementia Plan 2015-17. The Plan addressed the key recommendations within the Fix Dementia Care: Hospitals and set out the good progress made in caring for in-patients, their families and carers. However, it was accepted that the Trust did have a long way to go to becoming a dementia friendly hospital but that the foundations were there to be built upon.

In addition to challenging the key recommendations, Members also discussed the diagnostic route for anyone with concerns about a friend or relative with memory loss, which would be to the local GP for assessment in the first instance and for onward referral to the memory clinic if necessary and were advised that there was currently no direct diagnostic for people living with Dementia from the Trust to the Tees, Esk and Wear Valley Foundation Trust.

Reference was made to the patient led assessments of the care environment (PLACE) which had taken place within the Trust in 2015 and Janet reported that dementia had been one of the sections within that assessment for the first time last year and, although, the Trust had not done particularly well in that area, it had given her some leverage to raise her work as a priority within the trust as a result of that assessment. The National Dementia Audit, which examined the care provided to people with dementia in acute hospital settings, was also due to be undertaken this year and it was envisaged that the outcome of that would be available in November 2016 and that an action plan arising from that Audit would be developed.

Reference was also made to the involvement of the Mental Health Liaison Team for adults and older people which was based in the Mulberry Centre; to the role of the dementia Clinical Lead within the Trust , how any complaints were dealt with, the development of a sensory garden in the hospital grounds; re-admission rates for those with dementia; the principles around making safeguarding personal and the internal safeguarding processes in place together with the links with Adults Social services; and the challenges ahead.

IT WAS AGREED – That the thanks of this Group be extended to Janet Mortimer for her time and invaluable input.

DEMENTIA REVIEW GROUP

17 February 2016

PRESENT – Councillor S Richmond (in the Chair); Councillors Knowles, M. Nicholson, T Richmond, Storr and Tostevin.

D6. DEMENTIA – TEES, ESK AND WEAR VALLEY NHS FOUNDATION TRUST (TEWV) - The Group met Carl Bashford, Head of Service and Sarah McGeorge, Clinical Director, Tees, Esk and Wear Valley NHS Foundation Trust (TEWV) to discuss the services provided by TEWV to support people to live well with dementia from early symptoms to end of life, particularly in relation to the provision of mental health dementia care services. Currently, dementia accounts for approximately 70-80 per cent of the activity within the mental health services for older people. The aim of the Trust was, in partnership, to enable people to live at home for as long as is possible, based on a risk approach.

The Darlington Community mental health service offers assessment, diagnosis and treatment for older people who live in a community setting who have mental health problems, including dementia, and to those who live in a 24 hour residential and nursing setting. There is also a Liaison Team who work in all of the CDDFT acute and community hospitals. The Team is made up of Community Psychiatric Nurses, Doctors, Support Workers, Occupational Therapists, Physiotherapists, Psychology and social services staff and provide a range of services, including memory services, diagnosis of dementia and monitoring of medication. Patients can self-refer to the service, however referral is usually via a GP.

Members questioned whether there had been an increase in the number of referrals during the period that the financial incentive to GPs to diagnose a patient with dementia was in operation.

The aim of the dementia care service, along with other services involved, was to enable people living with dementia to continue to live at home, independently for as long as possible, and we were advised of some of the devices and assistive technology which were available to support independent living. We had previously looked at some of these devices on our visit to Rosemary Court and had a live demonstration.

Sarah outlined the clinical pathway followed once a referral was made to the service and it was reported that the target response time for an assessment following referral was four weeks, and this was generally met, however, assessments were undertaken sooner, if the GP making the referral felt it was urgent. It was reported that the quality of information contained in GP referrals was variable and that this could affect commencement of the appropriate clinical pathway. Some GP's did explain the process from the outset to patients, however, some patients weren't aware of the reasons for referral, the assessment and diagnosis process. TEWV confirmed that, as part of the face to face appointment, the assessment and diagnostic process were discussed with patients and their carers if consent was given and advice and support offered where appropriate.

Following referral, patients were usually assessed by a relevant professional generally either by a doctor or a nurse in the presence of a carer if possible, and information obtained from that assessment was shared with the Team within the Unit. Once investigation results were available, the diagnosis is discussed with the patient and the carer by a psychiatrist or an advanced nurse practitioner and a programme of care agreed. The diagnosis was a clinical one based on lots of information/testing/experience. Not all referrals were diagnosed as dementia there were other reasons for presenting symptoms such as delirium/temporary confusion (or depression) and there was also an agreed clinical pathway when this was the case. There were a lot of people with these temporary conditions in acute hospitals.

The TEWV dementia care pathway, which had been developed enables it to deliver person-centred services based on the most up to date evidence, development of memory services and follow the Trust's strategic goals and mission statements towards delivering high standard of care.
Discussion ensued on the provision of memory clinics within GP practices, which there was evidence to suggest worked well in other areas, and the benefits to those with dementia of holding those clinics in familiar surroundings and to the work currently being undertaken. It was confirmed that this was not something which was being taken forward within primary care in Darlington at the current time.

Reference was made to the funding for the service and the need to make year on year savings which was becoming difficult; the need for better working between the Mental Health Teams and GP's to make better use of resources and deliver excellent services; staffing levels within the mental health teams and the filling of vacant posts. Particular reference was also made to caseloads and to the role of the clinicians who supported patients in those less complex cases and, in more complex cases, to the role of Care Coordinators; the use and different types of memory drugs which could temporarily alleviate symptoms or slow down the progression of dementia in some cases, but not all, and the overall care of those living with dementia in terms of non-drug related treatments such as therapeutic activities and support. Young onset dementia was more difficult to diagnose and presented additional difficulties with more clinical time needed for that particular group and it was reported that a young onset dementia service consisting of minimum psychiatric time, a community psychiatric nurse and an occupational therapist was offered.

Discussion ensued on the work being undertaken to raise awareness of the need for early diagnosis to ensure patients get the appropriate treatment to enable them to have the best quality of life for as long as possible; the importance of preventative work to reduce to the costs associated with dementia care and to the need to change the perception that memory loss was part of the normal ageing process.

Members challenged the approach of the Trust to Making Safeguarding Personal and the Trust referred to the training given to staff to ensure the principles of this were adopted throughout the pathway to enable patients to feel in control and to support them in making difficult decisions. The principles also enable practitioners to focus on a person-centred approach which was not process driven and enabled them to use their skills, knowledge and professional judgement in relation to safeguarding. It was reported that end of life care was discussed with patients, their families or carers at the

start of the process and was reviewed throughout.

Discussion ensued on the challenging behaviours which were sometimes associated with patients who have dementia and it was reported that it was important for practitioners to understand the cause of this behaviour in the first instance to help them to determine how to respond to these challenges and how to respond to try to prevent it. Sometimes it was necessary to prescribe medication to help with these behavioural symptoms at a last resort, but the first stage was to use non-drug approaches. The monitoring of anti-psychotic drugs was monitored by the Clinical Commissioning Group.

Reference was made to the current public consultation in relation to improving mental health services for people with dementia in County Durham and Darlington which was due to end at the end of March 2016 and the options available within that consultation were outlined to Members. In summary, the consultation sought to seek the views of local people on the future location of assessment and treatment beds for older people living with dementia in County Durham and Darlington. As fewer people with dementia needed to spend time in hospital, inpatient care was now the exception rather than the norm and occupancy levels and the number of admissions had reduced over the last two years which meant it was necessary to review the current location and configuration of assessment and treatment beds. There were currently three 10-bed wards in County Durham and Darlington one ward at the Bowes Lyon Unit, Lanchester Road Hospital in Durham and two wards at Auckland Park Hospital in Bishop Auckland.

When asked about the challenges which the Trust faced, the issues referred to were the year-on-year reduction in finances, the ageing workforce within the trust and the loss of experience when staff retired and staff recruitment. Reference was also made to the County Durham and Darlington Dementia Strategy which was due to be refreshed and the need for the governance around that Strategy to be improved to demonstrate accountability.

In relation to the benefits, the cultural change to meet individual needs and personalising care, together with the implementation of the pathway, the ability to treat people living with dementia as individuals and not in a prescribed way and the reduction in the use of antipsychotic drugs were referred to. It was reported that the use of assistive technology would enable people to live longer in the community without the need for full residential care and reference was made to the need for consideration to be given to building bungalows when developments were being considered.

RESOLVED – That the thanks of this Group be extended to Carl and Sarah for their time and invaluable input.

DEMENTIA REVIEW GROUP

8 March 2016

PRESENT – Councillor S Richmond (in the Chair); Councillors Knowles, Mills, T Richmond, Storr and Tostevin.

D7. DEMENTIA – ALZHEIMERS SOCIETY - The Group met Jane Welch and Julia Laverick from the Alzheimer's Society to discuss the support services provided by the Alzheimer's Society to people living with dementia and their carers in Darlington.

They outlined the Dementia Adviser service which provided support to help people living with dementia to make choices, live independently at home for as long as possible, to improve their quality of life and to improve their sense of well-being. Examples of support which were provided such as advocacy, assistance with power of attorneys, signposting to local groups and support, support for carers and housing advice, were given. They also provided support for families and carers to identify the care and support needed and how to access services. More complex cases were allocated a Dementia Support Worker.

Reference was made to the partnership working with other organisations and particular reference was made to some of the difficulties experienced in working with GP's and Adult Social Care in Darlington and the limited number of referrals made to the Society from those professions. The representatives felt as though there was some resistance from GP's and, understandably, once a diagnosis was received, there was sometimes some reluctance from patients to accept this and ask for support, however, it was emphasised that the role of the Alzheimer's Society was not to information overload but to ensure people were aware that there was support available when needed. It was reported that the services provided by the Alzheimer's Society within Darlington were under-utilised and strong relationships with other professionals needed to be developed and a support referral pathway to established. Staff spent a large amount of time promoting the services with limited resources which could be better utilised elsewhere, which, in turn could relieve pressures on limited GP and Council resources.

The representatives made reference to the Carer Information and Support Programme (CrISP) which offered information sessions in a group environment where carers could share experiences and identify local services and to the positive feedback received following those sessions and to the Right to Know campaign which aimed to ensure that more people living with dementia received a formal diagnosis and that everyone diagnosed was fully supported afterwards. It was reported that evidence showed that Darlington had good diagnosis rates but that the gap between those rates and the numbers reached to offer support demonstrated the lack of referrals to the service.

Reference was made to the Darlington Dementia Hub which was based at the Crown Street library which it was felt could be improved but was the best of what could be

achieved at the present time with the resources available and to the success of the Darlington Dementia Action Alliance.

Discussion also ensued on the work of Age UK and the Darlington Association on Disability (DAD) and Members questioned whether all the organisations worked together and what approaches had been made to develop links to enable joined-up working which it was felt was not currently cohesive and the role and influence the Darlington Dementia Action Alliance might have in taking this forward.

Reference was also made to the North East and Tees Valley Combined Authority's which were being launched and to the devolution deal between the local Council's within those areas and whether dementia could be included in any future devolution deals between those Authorities to enable meaningful integration of budgets to be implemented locally to improve the quality of care for people with dementia in the north east. Members highlighted the difficulties with this in view of the cross boundary working with Darlington and County Durham and the Tees Valley.

Despite some frustrations with the support pathway, the representatives concluded that there were a lot of success stories and case studies of people living well with Dementia in Darlington.

IT WAS AGREED – That the thanks of this Group be extended to Jane and Julie for their input to the work of this Group

DEMENTIA REVIEW GROUP

29 March 2016

PRESENT – Councillor S Richmond (in the Chair); Councillors Culley, Kane, T Richmond and Storr

D8. DEMENTIA – ALZHEIMERS SOCIETY - The Group met Jenny Leeming from the Alzheimer's Society to further discuss the support services provided by the Alzheimer's Society to people living with dementia and their carers in Darlington and the role of the Darlington Local Dementia Action Alliance (LDAA).

The services offered by the Alzheimers Society were outlined and Jenny explained that her main role was to improve the offer of support in Darlington and to provide 1:1 support to people living with dementia and their carers.

She gave a presentation on the work of the Darlington Local Dementia Action (LDAA) which was made up of a group of local organisations and businesses committed to transforming the lives of people with dementia and their carers and to the role and success of the that Alliance in making Darlington a dementia-friendly community. Particular reference was made to the successful work undertaken to train and raise awareness of dementia with staff at the railway station and to the recent initiative of the Fire and Ambulance services to gather health and well-being information, with the person's consent, as part of their community safety work. Examples of cases where staff within services who had received dementia awareness training had helped people who were living with dementia in the community were provided.

Reference was also made to a document produced by Public Health England entitled Health Matters: Midlife approaches to reduce dementia risk which outlined the scale of the challenge, the risk factors for dementia, who was most at risk, the call for a national focus on prevention and lifestyle changes to reduce the risk. Particular reference was made to the statistics in relation to those living with dementia across age groups, but particularly amongst black and south Asian ethnic groups and it was reported that the Alzheimers Society were developing links to engage more with these communities.

It was reported that the main challenge for the Society was the difficulties experienced in working with GP's in Darlington and the Community Mental Health Team at West Park and the limited number of patient referrals from them. The initial referral was an important part of the pathway as it enabled those diagnosed and their carers to receive early advice and support from the society if they so wished, and it was reported that work would continue to try to develop links to integrate dementia services across primary care and wider health and social care services. It was accepted that an increase in referrals would impact on the work of the support workers. Continuity of support offered to people with dementia and their carers was also stated as a challenge. Working with schools to raise awareness with young people was also a priority going forward.

In addition to the support provided to those living with dementia and their carers, the Alzheimers Society also provided support as part of end of life care and one important element of that support was to help and discuss with individuals and their families, the

options available to them and ensure that the end of life care was personal and reflected their wishes. Support for carers through a transition period following death was also provided.

The Group expressed an interest in speaking to some carers either on an individual or group basis and Jenny offered to contact some carers to see if they would be willing to participate in the work of the Group.

IT WAS AGREED – That the thanks of this Group be extended to Jenny for her input to the work of this Group

DEMENTIA REVIEW GROUP

13 April 2016

PRESENT – Councillor S Richmond (in the Chair); Councillors Culley, Kane, T Richmond and Storr

D9. DEMENTIA – ALZHEIMERS SOCIETY - The Group met some operational staff from Adult Social Care and Tees, Esk and Wear Valley NHS Foundation Trust (TEWV) to discuss the support services provided by social workers and community nurses to support people to live well in the community with dementia.

Reference was made to the dementia pathway which started with an initial assessment by services at TEWV, usually following a referral from a GP and the process which then followed once the diagnostic results were received and the on-going support available to both those living with dementia and their carers. In relation to early on-et dementia (under the age of 65), it was reported that it was important to ensure that any diagnosis was definitive as it had a more significant social impact on their lives and that there were specialist staff at TEWV to support these families. There was also an Occupational Assessment worker who could work with individual employees and their employers to assist them with appropriate measures which could be put in place if requested.

A couple of case studies were discussed which demonstrated some of the types of cases which the services were involved with, the support packages and assistive technology available which could be put in place to help people living with dementia and their carers, to be independent and to live at home for as long as possible, based on a risk approach and how joint working across partners was beneficial and effective to this approach. A cultural change by the community to understand how to support those who lived with dementia in the community was needed and the role of Dementia Friends and the work of the Darlington Dementia Action Alliance was important to facilitate this. Reference was made to the work of voluntary organisations in providing support and advice, particularly Age UK which provided a lot of practical support.

It was reported that initial assessments could be undertaken away from West Park Hospital and within community settings if requested so people didn't have to wait in what could be a traumatising environment and that approaches had been made to GP practices to use surgeries.

Discussion ensued on the co-location of workers, the limited resources available and the need for services to work together in the most cost-effective way and challenge more effective ways of working; the advantages of the Multi-Disciplinary Teams in being able to develop relationships and gather intelligence from each other; the number of referrals in relation to ethnic minorities and the travelling communities and the recognition of those differing needs.

In relation to the care and support received within care homes, it was reported that TEWV had 3 full time community psychiatric nurses working within care homes to review and maintain those with dementia in those homes for as long as possible, which often involved dealing with challenging behaviour.

Reference was made to the formal training staff were required to undertake as part of their professional development and the valuable knowledge and skills they gained through practical experience.

In relation to challenges, the lack of recognition about the illness being terminal and parity about the effect a diagnosis could have on lives was highlighted together with the need to tackle the stigma associated with dementia and for more understanding from the community about those living with dementia in their own communities.

IT WAS AGREED – That the thanks of this Group be extended to the Officers for their input into the work of this Group.

MEETING WITH COUNCILLOR SUE RICHMOND AND A NUMBER OF CARERS

Key points raised and discussed included :-

Carer Information

A Dementia Advisor/Support Worker should be trained and able to assist or be able to judge when to signpost in each of the areas detailed below. The support of a carer and the introduction of the information detailed here is clearly a long term project over several years. Some actions are needed early in the support process. Most of the information, training and support can only be introduced slowly over the years as the disease develops. Burdening a carer with a mass of information too early is a mistake to be avoided.

Since the Dementia Support Worker cannot be expected to be the same person over a long period, the use and development of a comprehensive, well-designed Carer Support Plan is essential.

Financial and Legal arrangements

A general financial review is required very early in the process, to make the carer aware of what lies ahead and the range of legal and financial arrangements which need to be put in place, depending on their circumstances and those of the cared for.

Lasting Power of Attorney (Financial) is essential as soon as possible. The process of obtaining and completing the forms needs to be explained in detail.

Changes to Wills may be needed to deal with future management of assets, joint accounts etc.

Changes to house ownership arrangements may be required - tenants in common/joint tenants

Making Directives for Health Care, Lasting Power of Attorney (Health) which are needed in End of Life, or serious illness, situations. A Red DNR Form may need to be discussed and arranged.

If brain or other organ donation is a request of the carer or the cared for, this needs to be arranged.

Writing down a life story or recording an NHS "This is Me" document to go with the person with dementia may be an option. This is useful if the cared for goes into a new environment which may be unsettling or distressing.

Allowances and Financial Assistance

Carers Allowance needs to be applied for in some financial circumstances and may need expert help.

An Attendance Allowance needs to be applied for. The forms are difficult and the assistance of an expert Advisor/Support Worker is needed. This is paid to the person with Dementia but will be administered by the carer in most cases.

The Disabled Blue Parking Badge can be applied for with expert help and can be a very useful aid to Carers.

Where the personal savings of the cared for exceed £23,250, a detailed explanation of the rules is required, for the case where paying for care homes becomes necessary. These rules may be different in different Borough Council areas.

A general review of benefits and allowances is required; this is a difficult and very complex area needing detailed training.

Training and Education

A training course for Carers is essential. This should cover :-

Dementia – there are various causes of dementia, how the brain is damaged, and how this affects memory and behavior.

Medication management, including ordering, how to give it to the cared for, what medications are used, what their effects are, when to ask for liquid forms, likely side effects, when to ask for “evening wandering” medication.

Medical and clinical advice on the importance of hydration, regular toileting, avoiding urinary infections, recognisng that urinary infections can cause confusion and unsettling behaviour.

Strategies for avoiding falls, recognising when people with dementia feel unstable, designing rooms to avoid tripping and falling hazards.

Remembering that dementia causes problems with spatial orientation and space perception.

Recognising that repetitive behaviour may be a signal for discomfort, thirst or other needs which people with dementia have severe problems with expressing themselves.

Why eccentric, challenging or violent behaviour arises and techniques for dealing with it.

Progressive management as the condition progressively and inevitably worsens, including the likely time scales e.g management of continence.

Guidance on useful web sites, booklets, books and other useful sources of information

[The Alzheimers Society CrISP courses are excellent. If a Carer then has questions and wants more information, this can and should be made available.]

Respite, Domestic and Other Home Help

Day Care is a boon to Carers and (in Darlington) is offered by AgeUK and at least one Care Home. This can start at one day a week for familiarisation and trial, increasing as required by the carer.

As the disease progresses, help with bathing, and a range of other domestic tasks becomes a necessity. The costs are a necessary part of managing the disease and saving the NHS money. Any visiting domestic help must be consistent and given a minimum of an hour for each visit (to avoid the well-known “15-minute-visit, anyone-will-do” disasters).

Contacts and Occupational Therapy services for the supply of Home Equipment are needed as time passes - commodes, shower chairs, bath seats, walking aids, seat raisers, wheel chairs, etc.

Sources of electronic security, surveillance, safety alarms, locks, taps being opened and left open, domestic appliances being switched on and left on, are needed. Advice in the use of this equipment is needed.

General Counselling

Carers need a personal, known, trusted, emergency contact for when things go wrong or become too difficult to handle or they have just "had enough". The Dementia Advisor/Support Worker of this proposal is ideal.

Counselling is required to emphasise the necessity for clear breaks for the carer, to avoid two people being hospitalised and under medical care and supervision.

Advice is needed on Care Homes in the area and which are Borough Council Approved.

General advice is needed on progressive management as the condition worsens. This will need detailed discussion to allow for personal variations, preferences and abilities.

Advice is needed on the special problems of those who look after parents, siblings, friends, neighbours or others, and are trying to do a full-time job as well. This needs to be included in the Personal Carers Support Plan (Appendix 3).

The Carer's Advisor/Support Worker will be instrumental in combatting the still prevalent reaction of repulsion from and non-acceptance of dementia. This must still be common amongst carers and family, who need help to overcome it.

Counselling will be needed on the need not to leave things too late before full time care is arranged and a difficult situation becomes a serious crisis.

Reading lists should be recommended, including books by authors writing of their experiences in dementia caring.

MEETING WITH COUNCILLOR S RICHMOND AND KNOWLES WITH GP'S (PRIMARY CARE)

Met with two GP's representing both urban and rural practices in Darlington

Journey from presenting at GP practice is to undertake 6 x CIT questionnaire and blood tests to rule out physical illness

Patients would then be referred to West Park memory clinic for a scan and more in-depth memory tests

Dependant on diagnosis (3-6 weeks), care managed through TEWV services in partnership with GP – shared care approach

Quality Outcome Framework requires annual review by GP for people with Dementia

Vascular Dementia care more difficult insofar as no drug treatment and no discernible on-going care

End of Life Care advanced pathway implemented and MDT meetings improving integrated approach to care

Training available to staff but individual approach to this adopted by each practice

Little evidence of systematic referral to voluntary support.

APPENDIX 2

Background Papers

Dementia Strategy for County Durham and Darlington 2014/17
Living well with dementia: A National Dementia Strategy
Prime Minister's Challenge of Dementia - Delivering major improvements in dementia care and research by 2015
Alzheimer's Society factsheets www.alzheimers.org.uk
Stirling University
Joint Strategic Needs Assessment (JSNA)
Dementia Action Alliance
Dementia Journey Mapping
Fix Dementia Care Hospitals, Alzheimer's Society
Assistive Technology Customer Journeys – Case Studies
Lifeline Services Telecare Referrers information and manual
County Durham and Darlington Foundation Trust Dementia Plan 2015/17 and various internal documents and manuals
Person Centred Pathway of Care for Dementia – Tees, Esk and Wear Valley NHS Trust
Public Health England entitled Health Matters: Midlife approaches to reduce dementia risk

Visits

Age UK, Darlington
Darlington Mind
Lifeline Services
Darlington Memorial Hospital
West Park Hospital
Care Homes