

# Adults Scrutiny Committee Agenda



10.00 am Tuesday, 11 February 2020  
Committee Room No. 2, Town Hall,  
Darlington DL1 5QT

**Members of the Public are welcome to attend this Meeting.**

1. Introductions/Attendance at Meeting
2. Declarations of Interest
3. To Approve the Minutes of the Meetings of this Scrutiny Committee held on 17 December 2019 and 14 January 2020 (Pages 1 - 4)
4. Living Well with Dementia - Dementia Task and Finish Review Group - Update – Report of Director of Children and Adult Services (Pages 5 - 140)
5. Support to Carers – Report of Director of Children and Adult Services (Pages 141 - 158)
6. Work Programme – Report of Managing Director (Pages 159 - 176)
7. SUPPLEMENTARY ITEM(S) (if any) which in the opinion of the Chair of this Committee are of an urgent nature and can be discussed at this meeting
8. Questions

A handwritten signature in black ink, appearing to read "Luke Swinhoe".

**Luke Swinhoe**  
Assistant Director Law and Governance

**Monday, 3<sup>rd</sup> February 2020**

**Town Hall  
Darlington.**

**Membership**

Councillors Bell, Clarke, Crumbie, Mrs Culley, Curry, Holroyd, Layton, M Nicholson, Preston, Renton and A J Scott

If you need this information in a different language or format or you have any other queries on this agenda please contact Paul Dalton ([paul.dalton@darlington.gov.uk](mailto:paul.dalton@darlington.gov.uk)), during normal office hours 8.30 a.m. to 4.45 p.m. Mondays to Thursdays and 8.30 a.m. to 4.15 p.m. Fridays

## **ADULTS SCRUTINY COMMITTEE**

Tuesday, 17 December 2019

**PRESENT** – Councillor Curry (in the chair); Councillors Bell, Clarke, Crumbie, Mrs Culley, Holroyd, Renton and A J Scott.

**APOLOGIES** – Councillors Layton, M Nicholson and Preston.

**ALSO IN ATTENDANCE** – Councillor Mills.

**OFFICERS IN ATTENDANCE** – James Stroyan (Assistant Director, Adult Services), Christine Shields (Assistant Director, Commissioning, Performance and Transformation), Paul Neil (Programme Manager) and Paul Dalton (Elections Officer).

### **AD23 DECLARATIONS OF INTEREST**

There were no declarations of interest reported at the meeting.

### **AD24 TO APPROVE THE MINUTES OF THIS SCRUTINY COMMITTEE HELD ON 22 OCTOBER 2019**

Submitted – The Minutes (previously circulated) of this Scrutiny Committee held on 22 October 2019.

**RESOLVED** - That the Minutes of the meeting of this Scrutiny Committee held on 22 October 2019 be approved as a correct record.

### **AD25 BETTER CARE FUND 2019/20: FOR INFORMATION**

The Director of Children and Adults Services submitted a report (previously circulated) to update Members on the 2019/20 Darlington Better Care Fund Plan submission, and of Better Care Fund plans beyond the current period.

The submitted report stated that the Better Care Fund (BCF) was a programme spanning both the NHS and Local Government, which sought to join up health and care services so that people can manage their own health and well-being and live independently within their communities for as long as possible. Members were informed that the Fund brings together ring-fenced budgets from Clinical Commissioning Group (CCG) allocations, and funding paid directly to Local Government, and that the 2019/20 plan was based on seven broad workstreams to support the delivery of the BCF priorities.

The submitted report advised that the planning guidance for the 2019/20 submission was published on 18 July 2019, with a final submission date of 27 September 2019, following approval by local Health and Well-Being Boards, and that approval letters would be issued during December 2019, following regional scrutiny of all BCF plans.

Members entered into discussion on the strong performance in terms of delayed transfers of care, and the potential effect of winter pressures on discharge arrangements.

**RESOLVED** – (a) That the submission of the 2019/20 plan and the expected timescales for approval, be noted.

(b) That the current position in respect of the BCF for 2020/21, be noted.

## **AD26 PERFORMANCE INDICATORS QTR 2 2019/20**

The Assistant Director (Adult Services) submitted a report (previously circulated) which provided Members with performance information against key performance indicators for 2019/20 at Quarter 2.

The submitted report outlined the twelve indicators monitored by the Adults Scrutiny Committee, ten on a six-monthly basis, and two annually. The submitted report stated that, of the ten indicators reported on a six-monthly basis, four indicators demonstrated an improved performance compared to the same point last year; three indicators showed a performance not as good as that recorded at the same time last year, however are still on track to achieve service targets set; and that three indicators were not comparable, and were reviewed at a point in time.

Members highlighted and challenged several variables within the performance data and heard that some of these variables were due to seasonal pressures or counting issues, however Members were reassured that it was normal to see some fluctuations as a result of individual choices, or as a result of the comparatively small size of a specific data set.

Members were satisfied that on the whole performance remained strong across the key performance indicators, and that the local authority compared favourably both regionally and nationally, though recognised that the focus should be on maintaining the current level of performance, and that any further improvements were likely to be marginal.

**RESOLVED** – That the performance information provided within the submitted report be noted.

## **AD27 WORK PROGRAMME**

The Managing Director submitted a report requesting that Members gave consideration to the Work Programme items scheduled to be considered by this Scrutiny Committee during 2019/20, and to any additional areas that Members would like to be included.

Members noted a number of updates to the Work Programme and entered into discussion on the progress of the Support for Autism cross-party working group.

**RESOLVED** – (a) That the report be received.

(b) That Councillors Curry and A. J. Scott be nominated to represent this Committee on the Support for Autism cross-party working group.

## **ADULTS SCRUTINY COMMITTEE**

Tuesday, 14 January 2020

**PRESENT** – Councillor Curry (in the chair); Councillors Mrs Culley, Curry, Holroyd, Layton and M Nicholson.

**APOLOGIES** – Councillors Bell, Clarke, Crumbie, Preston, Renton and A J Scott.

**ALSO IN ATTENDANCE** – Councillor Mills.

**OFFICERS IN ATTENDANCE** – Paul Wildsmith (Managing Director), Elizabeth Davison (Assistant Director – Resources), James Stroyan (Assistant Director - Adult Social Care) and Paul Dalton (Elections Officer).

### **AD28 DECLARATIONS OF INTEREST**

There were no declarations of interest reported at the meeting.

### **AD29 MEDIUM TERM FINANCIAL PLAN**

The Chief Officers Executive submitted a report (previously circulated) which proposed a Medium Term Financial Plan (MTFP) for 2020/21 to 2023/24, and which also included setting a budget and council tax increase for 2020/21, for consultation. It was reported that the submitted report had previously been considered by Cabinet at its meeting held on 7 January 2020.

The submitted report stated that the Council had faced significant challenges over the last decade following the economic downturn and reduction in public sector spending and noted that the Council had been successful in responding to these challenges to date, though cautioned that there were still financial pressures to be faced.

The submitted report referenced the Core Offer Budget, which had been agreed following an in-depth and detailed review of all services and a significant consultation exercise in 2016, and which had allowed for the creation of a small Futures Fund, allocated to discretionary services. It was also noted that in subsequent MTFPs, Members had agreed to use unallocated balances of £4.7m to invest in five areas identified as having great value to the community, and that the above considerations provided the basis for the proposed MTFP.

In introducing the submitted report, the Assistant Director - Resources highlighted a number of pressures (summarised at Paragraph 15, and within Appendix 2, of the submitted report), and noted a projected expenditure for 2020/21 of £89.609m.

The Assistant Director – Resources subsequently outlined projected income and savings, which included income from the Revenue Support Grant, the New Homes Bonus, additional Social Care funding, Council Tax income, and National Non-Domestic Rates (NNDR), and cited savings made as part of the Adults Services Transformation Programme and a reduction in pension scheme contributions, which in itself yielded a return circa £7m. It was stated that the projected income for 2020/21 was £90.116m, and therefore balanced for the next year, however it was noted that in Year 4 there would be a reliance on £6m of reserves.

Reference was made to the Futures Fund, with £2.081m of the original £4.7m allocation committed to Futures Fund themes to date, with a balance of £1.019m remaining, and Members were advised that Cabinet had agreed to bolster the Futures Fund by a further £1.8m from unallocated balances to replenish priority funding and support the Council's ongoing priorities for a further two years to 2023/24.

It was noted that particular pressures in the Adults remit were in terms of the costs of domiciliary packages, and the increase in the living wage, though it was stated that savings made would offset these costs, and that much work had already been undertaken.

Members entered into discussion on invest to save schemes, and the costs associated with extra homes.

**RESOLVED** - That this Scrutiny Committee has no comment to make on the proposed schedule of fees and charges for those services within its remit, supports the Council Tax increase of two per cent and the two per cent Adult Social Care precept for the next financial year, and endorses the Futures Fund investment of £1.8m.

### **AD30 THE COUNCIL PLAN 2020-2023**

The Chief Officers Executive submitted a report (previously circulated) which outlined a proposed Council Plan, which in turn set out a vision for the Council and the key actions the Council would take to achieve that vision. It was reported that the submitted report had previously been considered by Cabinet, at its meeting held on 7 January 2020, and it had been agreed that the proposed Council Plan 2020-2023 be circulated for consultation.

In introducing the submitted report, the Managing Director stated that the Plan which set out the vision and priorities of the Council had been reviewed to reflect the vision and priorities of the new Council administration, however it continued to support the key aims of the Community Strategy – 'One Darlington: Perfectly Placed' - and continued to build on the work undertaken in previous years.

**RESOLVED** - That Cabinet be advised that this Scrutiny Committee has no comments on the draft Council Plan 2020-23.

## ADULTS SCRUTINY COMMITTEE 11 FEBRUARY 2020

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### 'LIVING WELL WITH DEMENTIA' DEMENTIA TASK AND FINISH REVIEW GROUP - UPDATE

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#### SUMMARY REPORT

#### Purpose of the Report

1. To enable Members to give consideration to the work of the Dementia Task and Finish Review Group, receive an update on the progress made in terms of the recommendations, and determine whether the recommendations remain relevant and viable.

#### Summary

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. The Review Group met on a number of occasions between November 2015 and June 2016 and a number of recommendations in terms of the headings Strategic Context and Resources, Preventing Well, Diagnosing Well, Living/Caring Well, Supporting Well, Dying Well, and Safeguarding Well-Being were approved by the Adults and Housing Scrutiny Committee.
4. These recommendations were subsequently approved by Cabinet at its meeting held on 17 January 2017 and by Council at its meeting held on 26 January 2017.
5. A copy of the final report of the Dementia Task and Finish Review Group for Members' information is attached to this report at **Appendix 1**, with a matrix of the recommendations and a list of the actions undertaken to date at **Appendix 2**.
6. A copy of the Dementia Strategy for County Durham and Darlington 2014-2017 is attached at **Appendix 3**, together with an outline of the Dementia Governance Structure at **Appendix 4**.

#### Recommendations

7. Members are requested to consider the progress made in terms of the recommendations and determine whether the recommendations remain relevant and viable.

**Suzanne Joyner**  
**Director of Children and Adult Services**

**Background Papers**

No background papers were used in the preparation of this report.

Author: Paul Dalton



S17 Crime and Disorder	This report has no implications for Crime and Disorder
Health and Well Being	Increased awareness of issues surrounding dementia could have a positive impact on people's health and well-being
Carbon Impact	There are no issues which this report needs to address.
Diversity	There are no issues relating to diversity which this report needs to address
Wards Affected	The impact of the report on any individual Ward is considered to be minimal.
Groups Affected	The impact of the report on any individual Group is considered to be minimal.
Budget and Policy Framework	This report does not represent a change to the budget and policy framework.
Key Decision	This is not a key decision.
Urgent Decision	This is not an urgent decision
One Darlington: Perfectly Placed	To enable people to be more healthy and independent and to provide a safe and caring community.
Efficiency	The outcome of this report does not impact on the Council efficiency agenda.
Impact on Looked After Children and Care Leavers	This report has no impact on Looked After Children or Care Leavers

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# 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.

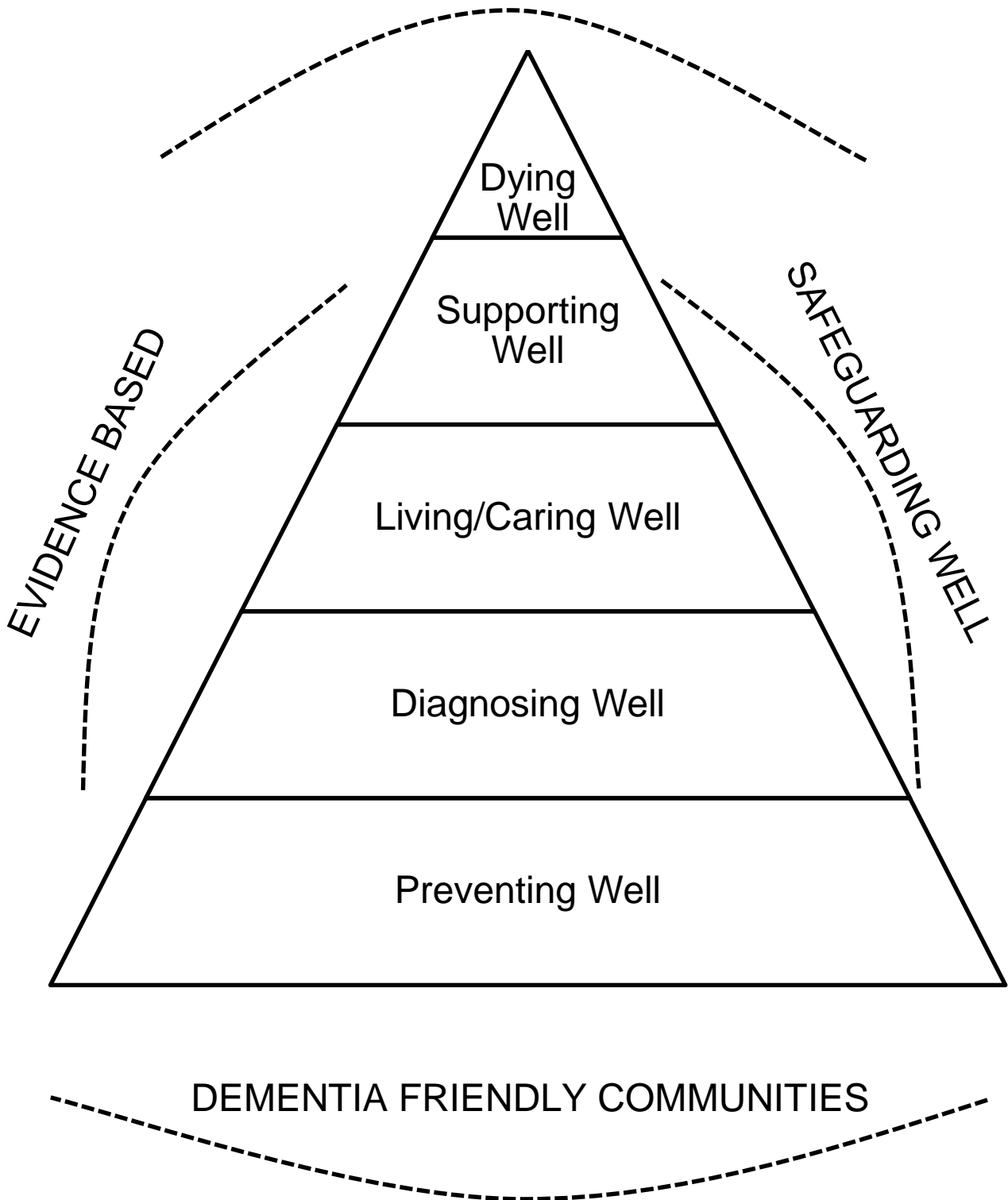
The Scrutiny Committee hopes the recommendations contained within this report can ensure we can go forward as a community which is able to understand the needs required to be a Dementia Friendly Town, whether that is through individual actions, support in the community or the provision of services and 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

STRATEGIC CONTEXT/RESOURCES



# SUMMARY OF RECOMMENDATIONS

Ref	Recommendation	Responsibility	Progress/Completion Date
<b>STRATEGIC CONTEXT/RESOURCES</b>			
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 coordinate 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
<b>PREVENTING WELL</b>			
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
<b>DIAGNOSING WELL</b>			
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
<b>LIVING/CARING WELL</b>			
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.	
<b>DYING WELL</b>			
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
<b>SAFEGUARDING WELL-BEING</b>			
R31.	That the Adults Safeguarding Board satisfy itself that all organisations should be 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) Frontotemporal 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](http://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.

**DEMENTIA REVIEW GROUP**

19<sup>th</sup> 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.

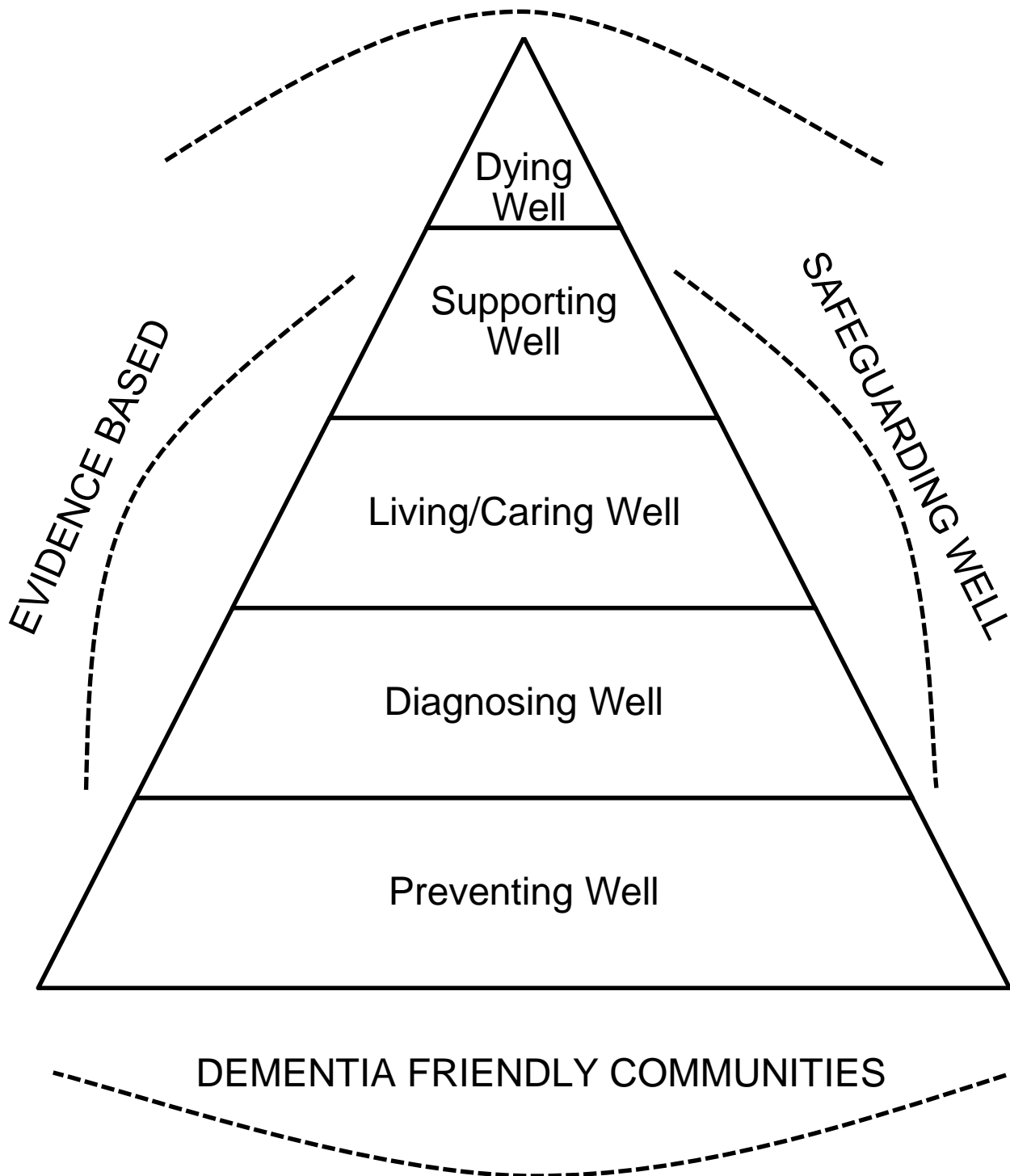
Reference was made to the work being undertaken by the Darlington Dementia Action Alliance to make Darlington a dementia friendly community and to ensure understanding about the condition from society as a whole; to the role of Dementia Friends and Champions and how to raise awareness about those roles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

## STRATEGIC CONTEXT/RESOURCES



**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

14<sup>th</sup> 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 reassurance 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 be 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

13<sup>th</sup> 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 12<sup>th</sup> 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-set 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, recognising 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.

## 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](http://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

Ref	Recommendation	Responsibility	Progress
<b>STRATEGIC CONTEXT/RESOURCES</b>			
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	The Council's Dementia Champion is appointed by designation, with Councillor Rachel Mills, the Cabinet Member for Adult Services, the current Champion.
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	The Dementia Strategy for County Durham and Darlington 2014-2017, and the governance arrangements, are attached at <b>Appendix 3 and 4.</b>
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	The Dementia Strategy for County Durham and Darlington 2014-2017 was last submitted to the Health and Well-Being Board on 27 <sup>th</sup> January 2015 and has not been refreshed since this date.

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	Dementia now sits within the Frailty Pathway. The appointment of a Lead Practitioner is the responsibility of Health to nominate a person to this role, and therefore further agreement / discussion is required.
<b>PREVENTING WELL</b>			
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 dementia.	Miriam Davidson, Director of Public Health, Darlington Borough Council	Public Health have undertaken a number of key awareness raising campaigns which support people with dementia.
R6.	That this Review Group supports the call by the	Alzheimer's Society	Specific work has been undertaken to raise awareness of dementia for people from BAME and LGBT communities. This has been undertaken



	<p>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.</p>		<p>by the commissioned Dementia Adviser Service provided by the Alzheimer’s Society, with some work also undertaken by Aapna Services.</p> <p>Work already undertaken includes the delivery of a number of Dementia Friends information sessions to people from the Sikh, Bangladeshi and West Indian communities, plus some specific work with ARQ in relation to the LGBT community.</p> <p>Work to raise awareness of dementia for people from BAME and LGBT communities will continue in 2020-21.</p>
R7.	<p>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.</p>	<p>Councillor Cyndi Hughes, Cabinet Member for Children and Young People</p>	<p>Responsibility now sits with Councillor Paul Crudass, the Cabinet Member for Children and Young People.</p>
R8.	<p>That attendance at a Dementia Friends information session be mandatory for all Members of Darlington Borough Council.</p>	<p>Councillor Veronica Copeland, Cabinet Member for Adults and Housing</p>	<p>Responsibility now sits with Councillor Rachel Mills, Cabinet Member for Adults Services. A number of Dementia Friends Sessions have been arranged for Members accordingly.</p>

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	Responsibility now sits with Councillor Rachel Mills, Cabinet Member for Adults Services. Individual actions are the responsibility of Members accordingly.
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	<p>The Council is now registered as a Dementia Friendly organisation. The intranet contains a webpage with information and videos.</p> <p>Council Employees have also received information via 'The Briefing', including advising employees of available training.</p> <p>HR have conducted work with Managers to identify staff who will benefit from training within their roles.</p> <p>Information regarding Dementia Friend Organisation, including video and how to become a Dementia Friend included within induction.</p> <p>Awareness raising also undertaken through the PDR process.</p>
<b>DIAGNOSING WELL</b>			
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	Lisa Tempest, Director of Performance, Planning and Assurance,	Darlington CCG received a copy of the final report from Health and Partnerships Scrutiny Committee Meeting in December. We have agreed that the report and recommendations will be considered at a CCG Executive Management Team meeting in February / March. We will be able to feedback further after the Executive Management Team.

	practices are aware of the need to follow the referral pathway.	Darlington Clinical Commissioning Group	
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	Darlington CCG received a copy of the final report from Health and Partnerships Scrutiny Committee Meeting in December. We have agreed that the report and recommendations will be considered at a CCG Executive Management Team meeting in February / March. We will be able to feedback further after the Executive Management Team.
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	Darlington CCG received a copy of the final report from Health and Partnerships Scrutiny Committee Meeting in December. We have agreed that the report and recommendations will be considered at a CCG Executive Management Team meeting in February / March. We will be able to feedback further after the Executive Management Team.
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	Lisa Tempest, Director of Performance, Planning and Assurance, Darlington Clinical	Darlington CCG received a copy of the final report from Health and Partnerships Scrutiny Committee Meeting in December. We have agreed that the report and recommendations will be considered at a CCG Executive Management Team meeting in February / March. We will be able to feedback further after the Executive Management Team.

	continues to monitor and record this.	Commissioning Group	
<b>LIVING/CARING WELL</b>			
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	An item – ‘Support for Carers’ appears elsewhere on this Agenda.
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	<p>The Dementia Action Alliance has reformed as the Dementia Friendly Darlington Steering Group. A consultation event took place in March 2019, following which a report was written and circulated widely.</p> <p>This report identified a number of areas for action and the benefit that a Dementia Friendly Community Coordinator could bring to the development of a more dementia friendly Darlington. Approval has been given for this service to be commissioned from April 2020. Prior to the new service being commenced, work is already being undertaken to develop a Dementia Friendly Haughton / Springfield / Whinfield area of Darlington.</p>

			The initial focus of this work will be the delivery of Dementia Friends information sessions and attendance at the Haughton Residents Association meeting. Development will then be organic depending on community interest and need. Once the Dementia Friendly Community Coordinator is in post, work will also be able to commence in other areas of Darlington. Circulation of the report also identified a number of new members of the Dementia Friendly Darlington Steering Group, all of whom are able to support the development of a more dementia friendly Darlington.
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	Darlington Borough Council continue to commission services which support people with dementia and their carers and have recently initiated pilot projects across the Borough, some of which directly support people with dementia.
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	Responsibility of Tees, Esk and Wear Valley Trust – Mental Health Trust.
R19	That the Darlington Dementia	Lisa Holdsworth,	An information pack has been developed and is distributed via West

.	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.	Service Development Officer, Darlington Borough Council	Park Hospital. It is also available for distribution by other organisations as required.
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	This covered in Policy DC3 (Point d (i)) – Health and Wellbeing of the draft Local Plan. These changes will be agreed by Cabinet, and subsequently Council, on 20th February 2020.
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	The works undertaken in relation to the Civic Reception area within the Town Hall had full regard to current research and recommendations. The responsibility for this function subsequently no longer sits within the nominated Officer's remit and now sits with Corporate Landlord.

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	Discussions took place regarding the relocation of the Dementia Hub to the Dolphin Centre but this did not take place due to the change in arrangements for the proposed library relocation. The delivery of the Dementia Hub at Crown Street Library was not effective, so has been discontinued.
<b>SUPPORTING WELL</b>			
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	Responsibility of the County Durham and Darlington NHS Foundation Trust.
R24	That the Good Friends scheme be extended to include dementia trained and approved therapeutic volunteers to	Gillian Peel, Age UK, Darlington	The Good Friends Scheme is currently being reviewed.

	support patients living with dementia in hospital and community settings, with hobbies and personal interests.		
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	Arrangements are in place as part of the assessment process which ensure the needs of people with dementia and their families/carers are considered and personalised support put in place prior to discharge.
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	Dementia awareness raising sessions and information sharing is undertaken as part of the provider forum meetings held with local care homes. Managers from several local care homes have joined the Dementia Action Alliance.



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	A new contract for Domiciliary care was put in place in October 2016 which successfully supports people with dementia.
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 as long as possible.	James Stroyan, Assistant Director Adult Social Care and Pauline Mitchell, Assistant Director, Housing and Building Services.	Uptake of Assistive Technology has increased over the last 2 years and a pilot project is currently underway to further increase the support offered by new technology.
<b>DYING WELL</b>			
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	Responsibility of Tees, Esk and Wear Valley Trust – Mental Health Trust.

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	<p>Members of the Adults and Housing Scrutiny Committee and the Health and Partnerships Scrutiny Committee commenced a joint review to look at the end of life pathway for those people with dementia, and a scoping meeting was held on 25 April 2017.</p> <p>The final report was presented to the Health and Partnerships Scrutiny Committee on 5 December 2019.</p>
<b>SAFEGUARDING WELL-BEING</b>			
R31	That the Adults Safeguarding Board satisfy itself that all organisations should be 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)	Safeguarding arrangements have changed therefore discussion and agreement is needed. In summary – principles of Making Safeguarding Personal have all been met and needs of people with dementia have been championed.
R32	That the specific needs of people living with dementia	Pixley Clark, Head of Review and	Safeguarding arrangements have changed therefore discussion and agreement is needed. In summary – principles of Making Safeguarding

	should be defined and encouraged through the Adults Safeguarding Board.	Development (Children and Adult's Safeguarding)	Personal have all been met and needs of people with dementia have been championed.
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2014-2017

# Dementia Strategy

for County Durham  
and Darlington



Final Draft



Prepared by the Dementia Strategy Task Group for County Durham and Darlington:



North Durham Clinical Commissioning Group  
Durham Dales, Easington and Sedgefield Clinical Commissioning Group  
Darlington Clinical Commissioning Group  
County Durham and Darlington NHS Foundation Trust  
Tees, Esk and Wear Valleys NHS Foundation Trust  
City Hospitals Sunderland NHS Foundation Trust  
North Tees and Hartlepool NHS Foundation Trust

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## Contents Page

Executive Summary .....	5
1. Introduction .....	8
A new drive to improve dementia care and support .....	8
What we have done to develop the new strategy .....	9
Next steps .....	10
2. Our Challenge in County Durham and Darlington .....	11
The number of people with dementia in County Durham and Darlington .....	11
Prevention .....	12
Challenges in the Community – waiting time and antipsychotics .....	13
Challenges at Hospital .....	14
Admissions by people with dementia .....	15
Readmissions by people with dementia to non-mental health providers .....	16
Readmission avoidance services and associated conditions.....	17
Future of care .....	19
Reinforcing the needs for action .....	20
3. Ambition Map for Dementia Diagnosis Rates and Dementia Direct Enhanced Service .....	21
Improving rates of diagnosis.....	21
Better coding .....	22
4. Black Asian and Minority Ethnic (BAME) Groups .....	23
5. Learning Disabilities .....	24
6. Young Onset Dementia .....	25
Prevalence .....	25
Demand for young onset dementia .....	25
Young onset dementia services.....	26
7. Prisoners and Dementia .....	27
8. Living with Dementia .....	29
Reinforcing the need for action.....	30
9. Carers .....	31
10. Supporting dementia carers and professionals to allow people with dementia to live well in last years of life .....	32
11. People with Dementia and Police Services .....	34
12. Research and Innovation .....	35
DeNDRoN led research .....	35
Promoting dementia research in primary care .....	36



Early diagnosis .....	36
Record sharing .....	37
Challenging behaviour .....	37
13. Healthwatch County Durham and Healthwatch Darlington Consultation on Dementia .....	38
What are we doing well? .....	38
Areas for improvement .....	38
What is working well? .....	39
14. Dementia Costs .....	40
Current costs .....	40
Impact of admissions by people with dementia .....	40
Better care fund. ....	41
15. Our Current Services and Training Programmes .....	43
16. Framework of Priorities – what we will aim to do .....	45
Prevention .....	45
Diagnosis and support after diagnosis .....	46
High quality compassionate support .....	47
Greater personal control .....	48
Reducing inappropriate medicine.....	49
End of life .....	50
Dementia education and training .....	50
Dementia friendly communities .....	51
Research .....	52
Better data and evidence .....	53
Comments from Healthwatch County Durham and Healthwatch Darlington .....	53
17. How will we work to implement the strategy?.....	54
Implementation and governance .....	54
What steps will we take to implement the strategy?.....	54
How will we know if we are achieving the aims of the strategy?.....	54
18. Summary Action plan for the next 12 months .....	55
References .....	56
Glossary .....	58
Appendix 1 – National Dementia Strategy.....	60
Appendix 2 – Support in Developing the Dementia Strategy.....	63





## Executive Summary

### Introduction

In County Durham and Darlington, the Clinical Commissioning Groups (covering Durham Dales, Easington and Sedgfield; North Durham and Darlington) have teamed up with Durham County Council and Darlington Borough Council, as well as the providers of dementia services, Healthwatch County Durham and Healthwatch Darlington to develop a new strategy for dementia.

The future needs of people with dementia and their carers need to be planned. A dementia strategy task group was set up to plan the future needs. The group took a stocktake of services, talked to people with dementia and their carers as well as people looking after them, identified the gaps and priorities along with what new things we need to do differently. Our aim is to ensure that the population in County Durham and Darlington have the best possible services in place for those who have dementia, their carers and families, as well as those who have not yet been diagnosed with dementia along with a focus on prevention.

As part of developing this strategy, Healthwatch County Durham and Healthwatch Darlington have already spoken to nearly hundred and thirty people to ask them about their experiences in accessing dementia services. The lessons have helped focus the strategy, which will be updated annually.

### What are the problem areas?

People are living longer and more people are expected to have dementia. But there are several challenges we need to focus upon :

- to screen all those who may have dementia or are at risk of developing it
- to support people who have dementia to reduce risk of hospital admission, timely discharge and not return to hospital unnecessarily because of a lack of support in the community
- to reduce the number of people with dementia who spend last days of their life in hospital rather than at home or at their preferred place of care
- to ensure that people with dementia and their carers get the best possible support at all points of their journey
- to give the most appropriate and clear information to people with dementia so they can be signposted to access as much support as possible
- to improve how we can reach out to and support more young people at risk of developing dementia early
- to ensure services work together and talk to each other so they are better joined up and can support different groups of people such as:
  - those who may develop dementia because of alcohol or substance misuse
  - those with learning disabilities who may have a higher risk of developing dementia early



- Black Asian and Minority Ethnic Groups who may not have the same access to dementia services
- prisoners who may develop young onset dementia or when they are older, and to ensure they get the same support as other people with dementia, especially when they leave prison

### **What are we planning to do to address these problems?**

We have identified many actions that the implementation group will focus on over the next three years. We have developed a framework of priorities of what we will aim to do. We will:

- look at ways to make more people aware of what they can do to prevent dementia
- deliver improved dementia training more widely to all key staff including GPs and frontline staff
- look at developing new ways to avoid getting people with dementia admitted or readmitted to hospital,
- auditing the use of antipsychotics
- improve support to people with dementia who have challenging behaviour, and also the possibility of using dementia support workers in hospital
- look at all the pathways and make sure they are interlinked so that the highest quality compassionate care is provided, and where there are service gaps, aim to fill them
- develop a single point of knowledge/ information, such as a directory, that holds up to date information on all services, so people with dementia, their carers can have better control over their care and throughout all stages of their dementia. This information will be used by clinicians and commissioners too to help signpost people with dementia to a wide range of services
- implement plans for dementia support to be a part of end of life pathways and planning ahead by the person with dementia, so every person is treated with dignity and respect
- pilot projects to enable Dementia Friendly Communities to be rolled out over the next three years
- develop greater awareness of the research we do on dementia, and promote more opportunities for people with dementia to join the register as patients willing to take part in research
- carry out a Dementia Health Needs Assessment so that we have a better understanding of the needs of people with dementia in the region, and engage with various groups to obtain their views.

A six-week consultation consisting of public meetings and drop in sessions took place in advance of this strategy being approved by the Clinical Commissioning Groups in County Durham and Darlington, and Durham County Council and Darlington Borough Council.

Please note that the data gathered to produce reports generated by the map of dementia, is not complete, and is in some parts historical, so does not necessarily apply to actual performance by the providers at the time the data was accessed via the interactive map of



dementia. It is however the best available data that has been used to make deductions, rather than conclusions. As more data will be added to the map of dementia the reports will be revised accordingly.

An Implementation Group consisting of the group that drafted the strategy along with others and user representatives, will be established immediately, to drive this strategy forward. We will review the strategy annually and report out to the public on what improvements we make.



## 1. Introduction

### **A new drive to improve dementia care and support**

The first strategy was a Joint Commissioning Strategy for Older People and Mental Health in 2009. That joint strategy incorporated objectives from the National Dementia Strategy for England which the Department of Health announced in 2009. It was not a blueprint for local services, but rather guidelines for local service providers to enable them to set priorities according to local needs. The joint strategy was reviewed when the Prime Minister's Challenge on Dementia came out in 2012, to become the second strategy with an implementation plan for 2012-2014. That Second strategy has been used during the last two years by commissioners and providers in County Durham and Darlington who as a dedicated working group made good progress in implementing the plan for the region.

This new document sets out the third strategy County Durham and Darlington for 2014-2017. It incorporates new information that has been announced during 2013 and 2014, as well as the new organisational arrangements we are now operating in.

There is an aspiration for the future that people with dementia must get the best support possible in the community so that unnecessary admissions to acute services can be avoided, and that those who are discharged from acute services are well supported in their communities closer to home.

In April 2013, NHS England set out a new mandate (see reference 1) with the Clinical Commissioning Groups which makes them legally responsible for ensuring that they commission healthcare services that are fit for the population. In the mandate, there are five priority areas and one of them focuses on making diagnosis, treatment and care for people with dementia, including support for carers, among the best in Europe by 2015. The mandate is being refreshed and a new addition will set a further ambition agreed by NHS England that by 2015 two thirds of the estimated number of people with dementia in England should have a diagnosis, with appropriate post diagnosis support.

NHS England has arrangements to establish a Strategic Clinical Network for Dementia covering the North East. This network looks for innovative ideas from clinicians to take steps to ensure that future services for dementia have improved outcomes for people with dementia which will be even better. So over time, the strategy will be influenced by the views of that network.

In December 2013 the Department of Health published a report, 'Dementia – a state of the nation report on dementia care and support in England'; (see reference 2). This report expands on the National Dementia Strategy that was published in 2012. The report has ten key priority aims for the future, some which are new. It says that society as a whole also has a role to play. It says that we now need the communities to be more aware of dementia and those who care for people with dementia are encouraged to seek help and support. In the



communities people must feel able to go about their daily lives safely and free of stigma. Our strategy will address this through a range of community based public health initiatives. Another priority aim is the need for more joined up research, which we have also addressed in the strategy. The need for more research in the future will grow. In December 2013, a G8 summit held in London focussed on dementia as well as the need for more research. All these countries agreed on a commitment to build an international effort to approach the problem of dementia together.

In February 2014 an announcement was made to support the ambition set out as part of the Prime Minister's Challenge on Dementia, NHS England will invest £90 million in diagnosing two thirds of people with dementia by March 2015 (see reference 3). It will focus on areas where the time taken to carry out diagnostic assessments is more than the average of six weeks.

This new strategy also gives attention to five new areas not previously addressed in the last strategy: prisoners with dementia; people with learning disabilities and those with young onset dementia; people with dementia belonging to Black, Asian and Minority Ethnic (BAME) groups, and people with dementia who frequently contact the police.

### **What have we done to develop the new strategy?**

The strategy task group looked at the first strategy (for 2012-14) and did a stock take on its dementia projects to confirm what it has achieved and what we still needed to do. The group asked Healthwatch County Durham to work with Healthwatch Darlington, on a patient journey consultation with people with dementia and their family/carers. The results of this consultation have informed us where services and patient experiences can be further improved.

We also engaged directly with clinicians to ask them for their views on what should be a priority in our strategy.

The task group recognises that overview and scrutiny plays a key role in developing social care and health strategies and driving service improvement. In Durham, the Adults, Wellbeing & Health Overview and Scrutiny Committee has received a presentation on services in the County, development of the strategy and future plans. Further meetings are planned with the Overview and Scrutiny chair.

We are committed to maintaining an open and positive relationship with Overview and Scrutiny within both Durham and Darlington and welcome any future requests for further engagement.



## **Next steps**

In this strategy, we have identified actions that set the direction of travel for an implementation group to implement, and report out to stakeholders on their progress.

We have agreed to initiate a Health Needs Assessment on Dementia for County Durham and Darlington. This has not happened ever before and the results will help us focus on areas that need improvement in the future. The results from this Health Needs Assessment will be available during 2014-2015. We will need to engage with some stakeholders when carrying out that assessment.

Every year we will refresh the strategy and make it clear what we did achieve and did not achieve. So, there will be the opportunity to incorporate the lessons learnt from the health needs assessment in the following year.

## 2. Our challenge in County Durham and Darlington

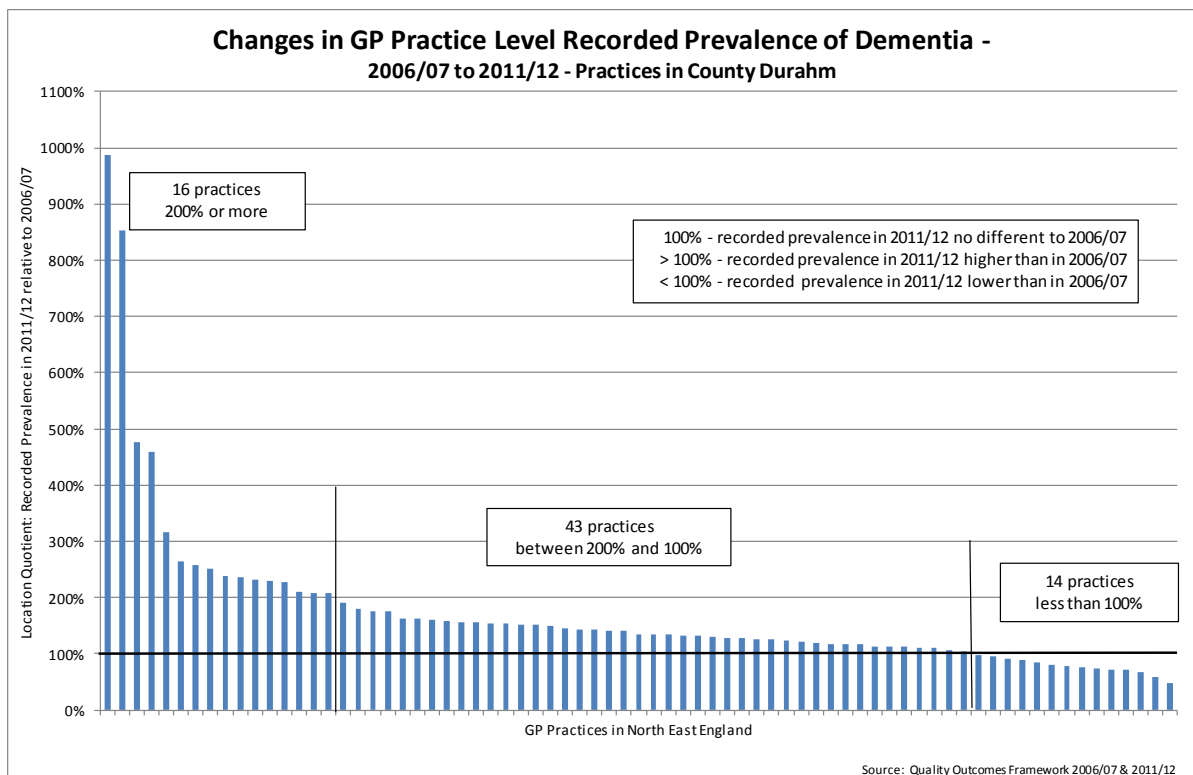
This section focuses on what we believe are the challenges we must address in our strategy:

- The increasing numbers of people with dementia in our area
- The need for more healthy living schemes to be promoted
- Challenges in the community from the State of the Nation Report
- Challenges at hospital from the State of the Nation Report
- Challenges on the future of care from the State of the Nation Report

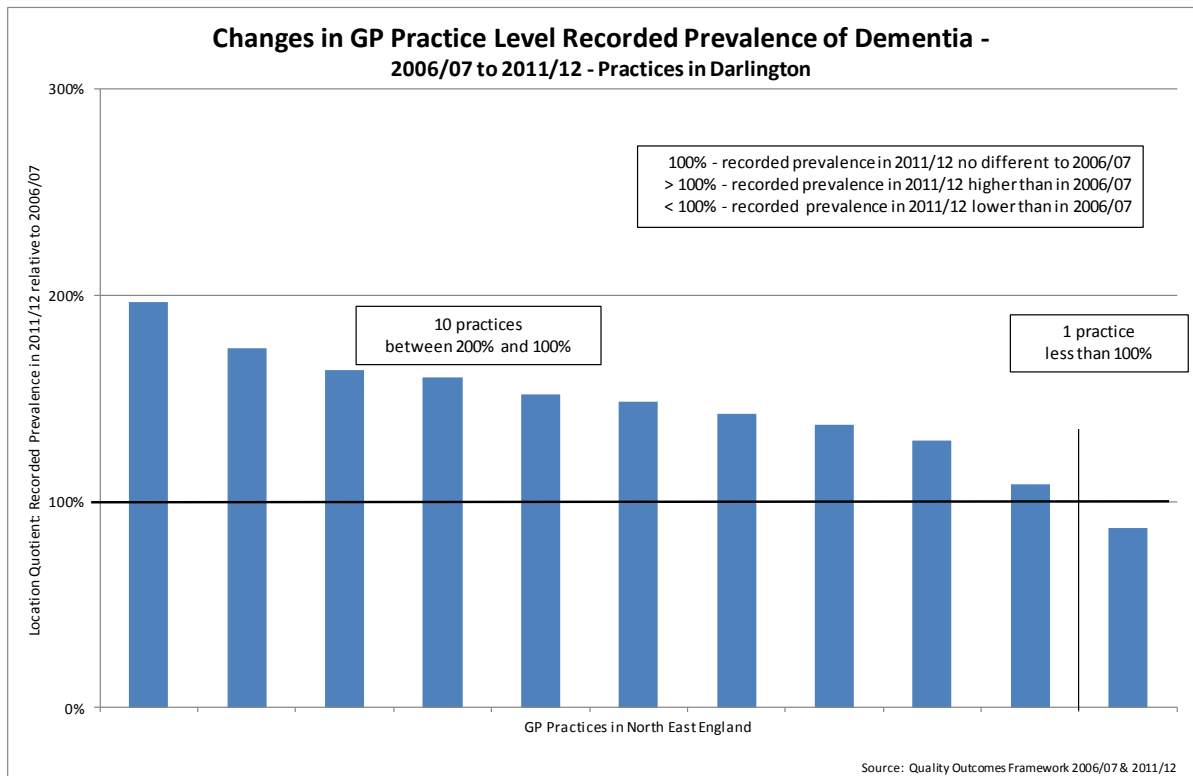
### The number of people with dementia in County Durham and Darlington

Our population is living longer and the proportion of older people with dementia will increase. We know from information gathered by the North East Public Health Observatory, that most of the GP practices in County Durham have seen an increase in the proportion of their patients who have dementia over the past five years. Of all 73 practices, 59 of them have recorded at least two-fold (100%) increase in proportion of the population who have dementia during the past five years.

This increase supports the estimated prediction that the numbers of people with dementia in England is set to double in the next 30 years (Prime Minister’s Challenge on Dementia).



The situation is similar in Darlington. Information from North East Public Health Observatory also shows the prevalence of people with dementia has increased over the past five years. The table below shows that all but one of the GP practices has experienced at least a two-fold (100%) increase in the proportion of people with dementia.



**Action: Capacity to meet diagnosis needs**

We will strategically plan and communicate as to how we will meet the increasing demand in number of people with dementia who need screening and access to diagnostic services.

**Prevention**

The State of the Nation Report on dementia care and support in England reminds us that dementia can in some cases be delayed or prevented. Around 60 percent of people with dementia have Alzheimer’s disease. Approximately 20 percent have vascular disease and many people have a mixture of the two. Vascular dementia results from problems with the blood supply to the brain – without enough blood, brain cells can die. The effects of vascular dementia can be minimized or prevented altogether through a healthy lifestyle. Smoking and obesity, for example, affect many types of dementia, in particular vascular dementia.





Helping people to understand the impact of their lifestyle could help them to make better, more informed choices and reduce their risk of developing vascular dementia.

So far, the national focus has been around improving diagnosis of dementia. In our strategy we will take this further and focus on opportunities to prevent dementia through healthy lifestyle programmes. The implementation group will establish joint working relationships with public health and promote preventative projects through all primary and secondary care services (GP practices, alcohol services etc.)

### Action: Prevention

We will take action to promote the benefits of healthy life style programmes to the public, making it clearer that the risks of developing vascular dementia (as well as other life threatening conditions like cancer, heart disease and stroke) can be reduced.

We will review opportunities for promoting dementia awareness through all possible contacts, such as substance misuse and alcohol teams as well as primary care.

### Challenges in the community – waiting time and antipsychotics

The State of the Nation Report measures four areas in the table below and suggests where improvements need to be made by the Durham Dales, Easington and Sedgefield Clinical Commissioning Group (DDES CCG) and Darlington Clinical Commissioning Group (D CCG), and the main provider, Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV).

Type	Measure	Comments
Checking for dementia (the percentage of people diagnosed)	DDES CCG 65.3%	Average for England
	D CCG 61.4%	Average for England
	North Durham 56.7%	Average for England
Waiting to be tested by TEWV	Durham Dales/Sedgefield area 1 week	Good
	Easington area 3 weeks	Should move to 1 week
	Darlington 1 week	Good
	North Durham 3 weeks	Should move to 1 week
Waiting for results from TEWV	Durham Dales/Sedgefield area 6 week	Above average
	Easington area 9 weeks	Should move to 6 weeks
	Darlington 7 week	Should move to 6 weeks
	North Durham 9 weeks	Should move to 6 weeks
Prescribing antipsychotics in dementia	No data available	Need to take steps to obtain and centralise the data and compare to baselines

Measures from interactive map of dementia, 08/04/2014, <http://dementiachallenge.dh.gov.uk/map/>



There are some 'Gold Standard' models where CT scanning for diagnosis takes place on the same day, such as at James Cook Hospital that significantly reduces the time taken to complete a diagnosis.

During 2012-2013 an audit looking at the use of antipsychotic drugs for patients was undertaken across County Durham and Darlington. The audit focused on data from 2011. The audit aimed to ascertain whether patients with a diagnosis of dementia who were prescribed antipsychotic medication were prescribed in line with recommended guidance e.g. they are prescribed an atypical antipsychotic, namely Risperidone, and for a period of less than 12 weeks. However, we acknowledge that some antipsychotic medication is prescribed appropriately.

The audit shows that the percentage of those patients who have been prescribed the medication for longer than the recommended 12 weeks had increased slightly for some localities covered by the Clinical Commissioning Groups in County Durham and Darlington. Recommendations were made in the report, and a further audit is recommended to find out what improvements have been made using 2012 and 2013 data.

#### Action: Waiting time and antipsychotics auditing

We will work with providers to monitor and review waiting times for tests and results, and agree on improving targets and bringing uniformity in waiting times across the areas covered.

We will explore how we can audit the prescribing of antipsychotics with appropriate resources.

#### Challenges at hospital

The State of the Nation Report measures four areas in the table below and suggests where improvements need to be made at hospitals by three main providers – North Tees and Hartlepool NHS Foundation Trust (NTH); City Hospital Sunderland NHS Foundation Trust (CHS) and County Durham and Darlington NHS Foundation Trust (CDDFT) for the population in Durham Dales, Easington and Sedgefield Clinical Commissioning Group (DDES CCG), Darlington Clinical Commissioning Group (D CCG) and North Durham Clinical Commissioning Group (ND CCG).

Area	Locality	Provider/measure	Comments
Looking for dementia in Hospital	DDES CCG	NTH 100%	Good
		CHS 96.73%	Average
		CDDFT 89.56%	Mixed results, needs improving
	D CCG	CDDFT 89.56%	Mixed results, needs



			improving
	ND CCG	CDDFT 89.56%	Mixed results, needs improving
Assessing dementia in hospital	DDES CCG	NHT 99.73%	Above average
		CHS 100%	Good
		CDDFT 96.15%	Above average
	D CCG	CDDFT 96.15%	Above average
	ND CCG	CDDFT 96.15%	Above average
Referring patient for further tests	DDES CCG	NHT 100%	Good
		CHS 100%	Good
		CDDFT 97.67%	Above average
	D CCG	CDDFT 100%	Good
	ND CCG	CDDFT 100%	Good
Length of stay in hospital	DDES CCG	NHT longer	Needs improving
		CHS longer	Needs improving
		CDDFT longer	Needs improving
	D CCG	CDDFT longer	Needs improving
	ND CCG	CDDFT longer	Needs improving
Going back to hospital	DDES CCG	NHT same	Average
		CHS more likely	Needs improving
		CDDFT more likely	Needs improving
	D CCG	CDDFT more likely	Needs improving
	ND CCG	CDDFT more likely	Needs improving
Dying in hospital	DDES CCG	NHT more likely	Needs improving
		CHS more likely	Needs improving
		CDDFT more likely	Needs improving
	D CCG	CDDFT more likely	Needs improving
	ND CCG	CDDFT more likely	Needs improving

Measures from interactive map of dementia, 08/04/2014, <http://dementiachallenge.dh.gov.uk/map/>

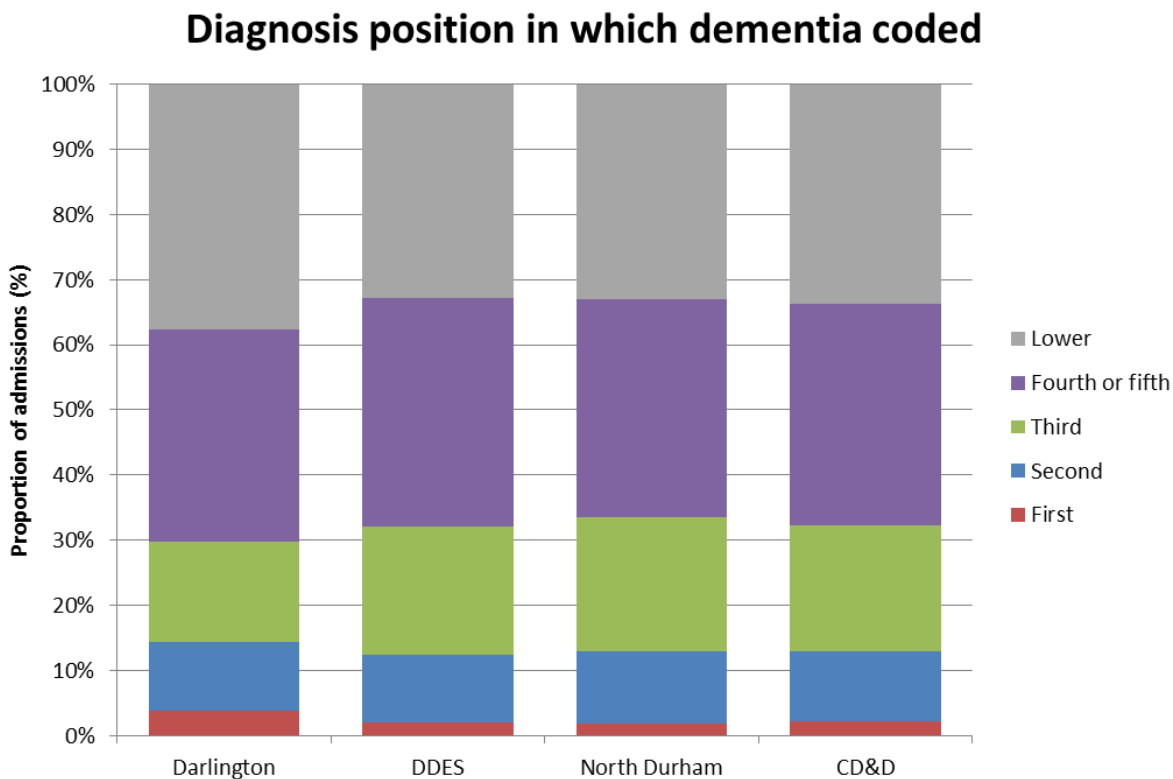
**Action: Review dementia in hospitals and understand what can be done to keep dementia patients out of hospital**

We will work together to review literature and examples of good practice, to identify suitable initiatives for development which we will jointly invest in, with the aim of reducing the need for people with dementia to stay in hospitals for longer than necessary and to reduce the likelihood of them dying in hospital.

**Admissions of people with dementia**

Admissions of people with dementia very often come with other conditions that require treatment, or are a factor which may influence the person with dementia’s care or recovery. An analysis of data from April 2013-February 2014 showed very few patients are admitted to acute hospitals with a primary diagnosis of dementia (2.2%), however 32% of admissions was deemed of sufficient importance to causation / care that dementia is one of the first three

recorded diagnosis. 66% of admissions had dementia coded as one of the five most relevant diagnosis recorded. This is shown in the bar charts below:



This means, two thirds of all people admitted to acute hospitals who have dementia, will usually have the dementia recorded as a secondary condition. Where dementia is given as one of the first few recorded diagnosis, this should represent dementia being a significant contributor to causing admission or having a significant impact on the patient’s care.

We note that successful projects such as an acute liaison and care home liaison service has been working specifically for the past two years to improve the experience of people in hospitals or care homes who have dementia.

**Readmission of people with dementia to non-mental health providers**

A key focus for the strategy task group is around taking necessary steps to reduce the readmission of patients with dementia. As shown above, many admissions to non-mental health providers concern a co-morbidity of dementia with other conditions requiring treatment or where dementia is a factor which may influence the patient’s care or recovery. This presents a challenge for not only the community and acute providers, but for local services in taking steps to avoid unnecessary readmission to hospitals within 30 days and 90 days.

An analysis of data covering patients registered with a member practice of Durham Dales, Easington and Sedgefield Clinical Commissioning Group, North Durham Clinical Commissioning Group and Darlington Clinical Commissioning Group and unregistered



patients within their boundaries shows an average 12% patients with dementia are readmitted to non-mental health providers within 30 days of discharge from a prior admission, and 20% within 90 days of discharge from a prior admission.

#### Admissions within 30 days of discharge from a prior admission - May 2013 to Feb 2014

CCG / Point of Delivery	Admission within 30 days of discharge from prior admission	Admission NOT within 30 days of discharge from prior admission	Admission with readmissions status not known	Total	% of dementia related admissions in month that are 30 day readmissions
<b>Darlington</b>	<b>43</b>	<b>364</b>	<b>2</b>	<b>409</b>	<b>10.5%</b>
Acute	43	343	2	388	11.1%
Community Hospital		21		21	0.0%
<b>DDES</b>	<b>147</b>	<b>1123</b>	<b>7</b>	<b>1277</b>	<b>11.5%</b>
Acute	142	1061	6	1209	11.7%
Community Hospital	5	62	1	68	7.4%
<b>North Durham</b>	<b>135</b>	<b>872</b>	<b>4</b>	<b>1011</b>	<b>13.4%</b>
Acute	122	778	4	904	13.5%
Community Hospital	13	94		107	12.1%
<b>CD&amp;D</b>	<b>325</b>	<b>2359</b>	<b>13</b>	<b>2697</b>	<b>12.1%</b>

#### Admissions within 90 days of discharge from a prior admission - May 2013 to Feb 2014

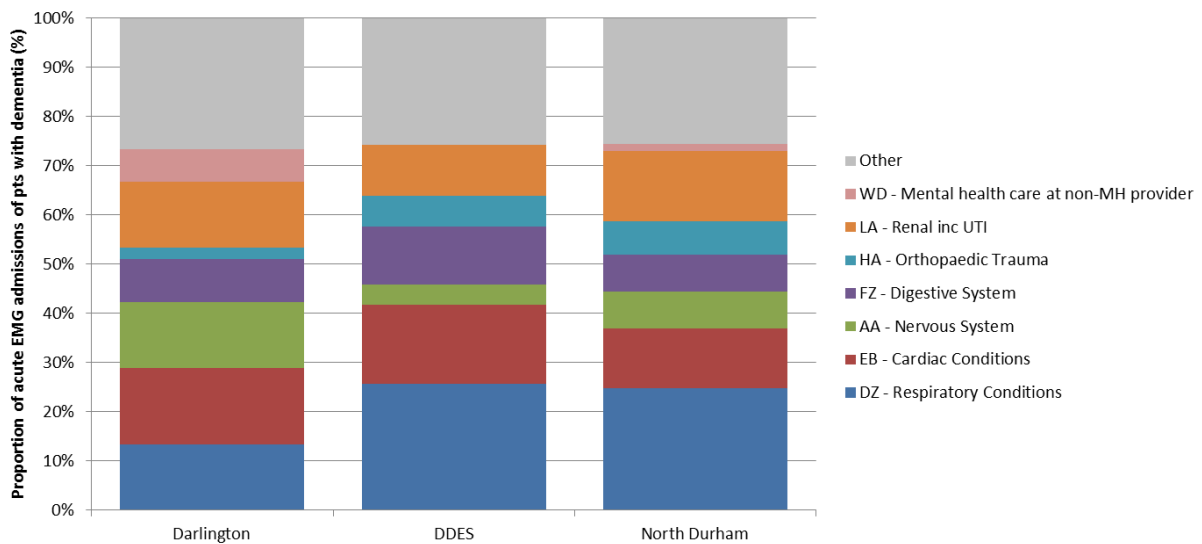
CCG / Point of Delivery	Admission within 90 days of discharge from prior admission	Admission NOT within 90 days of discharge from prior admission	Admission with readmissions status not known	Total	% of dementia related admissions in month that are 90 day readmissions
<b>Darlington</b>	<b>72</b>	<b>335</b>	<b>2</b>	<b>409</b>	<b>17.6%</b>
Acute	72	314	2	388	18.6%
Community Hospital		21		21	0.0%
<b>DDES</b>	<b>248</b>	<b>1022</b>	<b>7</b>	<b>1277</b>	<b>19.4%</b>
Acute	239	964	6	1209	19.8%
Community Hospital	9	58	1	68	13.2%
<b>North Durham</b>	<b>229</b>	<b>778</b>	<b>4</b>	<b>1011</b>	<b>22.7%</b>
Acute	205	695	4	904	22.7%
Community Hospital	24	83		107	22.4%
<b>CD&amp;D</b>	<b>549</b>	<b>2135</b>	<b>7</b>	<b>2697</b>	<b>20.4%</b>

### **Readmission avoidance services and associated conditions**

There are some generic admission and readmission avoidance services and pilot projects taking place at both primary care level and at care homes around County Durham and Darlington. In the Easington locality of Durham Dales, Easington and Sedgfield Clinical Commissioning Group a dementia dedicated admission / readmission avoidance pilot project has been taking place and will continue to do so during 2014-2015. It aims to see how the use of dedicated care coordinators giving reablement support people with dementia would reduce their risk of admission or readmission. To date, the pilot, although being short in duration and covering a limited geographical area, has demonstrated that people with dementia value highly the support of dedicated care coordinators around the time when they were discharged from hospital. Although not yet conclusive, this pilot scheme has to date brought the rate of readmission down from what is usually 12% within 30 days of a person being discharged from hospital, to 6%.

In trying to understand the reasons behind readmissions, a breakdown of data from May 2013-February 2014 covering County Durham and Darlington examined the grouping of conditions and procedures within the NHS payment system. This provides a useful summary of the main reason for a readmission and shows very few patients are readmitted with dementia being the primary diagnosis.

**Comparison of 30 day readmission by HRG sub-chapter (2013/14 YTD)**



This above chart is not population weighted across Durham Dales, Easington and Sedgefield Clinical Commissioning Group, North Durham Clinical Commissioning Group and Darlington Clinical Commissioning Group. It however indicates there is very little difference between Durham Dales, Easington and Sedgefield and North Durham Clinical Commissioning Groups as to the condition that require readmission for a patient with dementia. Darlington Clinical Commissioning Group however has a lower proportion of readmissions made up of respiratory conditions and a higher proportion of readmissions that the other clinical commissioning groups made up of nervous system conditions.

In conjunction with dementia friendly communities, people with dementia and their carers make it clear that they would prefer to remain living at home for as long as possible. This approach will delay or avoid the need for residential or nursing care. Alongside making the general community dementia friendly; suitable domiciliary care, day services and telecare initiatives will assist with this approach, as well as a more specialist forms of housing, such as extra care and dementia specific housing schemes.

**Action – Develop dementia admission and readmission avoidance services**

The implementation group for the strategy will:

- Share examples of good practice across the county where people with dementia are being discharged from hospital faster, and learn from those case studies.
- ‘Deep dive’ into readmission data to obtain a wider understanding of possible reasons



differences in conditions that require readmission for a patient with dementia, between the Clinical Commissioning Group areas, and take any necessary action to address those differences.

- Review the range of admission and readmission avoidance projects and services to ensure that they continue to reduce the likelihood of a patient with dementia being admitted to hospital following discharge from a prior admission, and take steps to strengthen the benefits of the services so they are more consistent across the region. Alongside this work, we will explore options for strengthening support for people at home, including housing options.

## Future of Care

The table below shows the percentage of people expected to be living with dementia in the areas from what is known about the local population. It also shows those who have not signed up to 'Dementia Friendly Communities' initiatives, and the number of research projects taking place with memory clinics.

Type	Measure	Comments
<i>People expected to be living in the community with dementia</i>	DDES CCG 1.24%	Average for England
	D CCG 1.37%	More than average for England
	ND CCG 1.18%	Average for England
<i>Dementia Friendly Communities sign up</i>	Durham Dales/Sedgefield – nil	Need to sign up
	Easington - nil	Need to sign up
	D CCG -nil	Need to sign up
	ND CCG	Need to sign up
<i>Research studies into dementia treatment and care being run by memory clinics</i>	Durham Dales/Sedgefield –nil	Need to increase to five (average)
	Easington area – 1 study by TEWV	Need to increase to the average of five
	D CCG – 2 studies by TEWV	Need to increase to the average of five
	ND CCG – 2 studies by TEWV	Need to increase to the average of five

Measures from interactive map of dementia, 08/04/2014, <http://dementiachallenge.dh.gov.uk/map/>

The Prime Ministers Challenge on Dementia (launched March 2012, see reference 4) identified a series of commitments to action. Creating dementia friendly communities is one of the commitments in the challenge. The dementia friendly communities' programme focuses on improving the inclusion and quality of life of people with dementia. It is envisaged



that a dementia friendly community (which can be a village, town, city, borough or even an organisation) is one that shows a high level of public awareness and understanding so that people with dementia and their carers are encouraged to seek help and are supported in their community. Such communities are more inclusive of people with dementia, and improve their ability to remain independent and have choice and control over their lives.

All communities wishing to become accredited as dementia friendly must meet a set of foundation criteria specified by the Alzheimer's Society, who are responsible for the administration of the national programme. In Durham, plans are being developed to establish at least two town 'pilot sites' to follow the recognition process, within Barnard Castle in the South and Chester-le-Street in the north of the County identified at this stage.

In Darlington, similar plans are being developed in partnership with a care provider with experience in this area to establish dementia friendly communities within the extra care housing schemes across the borough.

**Action: Roll out Dementia Friendly Communities programme and review arrangements for research studies at memory clinics**

Durham and Darlington will complete pilot projects for the Department of Health Dementia Friendly Communities programme in 2014/15. We will use the lessons learnt from these projects to support further communities in Durham and Darlington to enter the accreditation process and become, and remain, recognised as dementia friendly, with the aim of rolling out accreditation across Durham and Darlington.

We will review access to services, including the making of reasonable adjustments (such as transport) to ensure people with dementia can benefit from a range of services.

The above actions set out in section 2 will be taken forward by a new implementation group for this strategy. There are additional actions in a Framework for Priorities set out in section 16, which will also be implemented.

### **Reinforcing the need for actions**

Healthwatch County Durham and Healthwatch Darlington undertook a consultation in January to March 2014 (see Section 13). Members of the public identified all the above challenges in this section, and support the need for action to improve the experience from diagnosis to end of life care for carers, family members and patients with a diagnosis of dementia.





### 3. Ambition Map for Dementia Diagnosis Rates and Dementia Direct Enhanced Service

#### Improving rates of diagnosis

The diagnosis rate is planned nationally and there is a need to improve it. Diagnosis rates on average in England are just 48 per cent, which despite being a two per cent increase from 2012, means there are still around 416,000 people in England who are living with dementia but who are not diagnosed.

NHS England expects that by 2015 (in the refreshed mandate to CCGs) two thirds of the estimated number of people with dementia in England should have a diagnosis, with appropriate post diagnosis support.

Based on the Ambition Map for Diagnosis Rates (see reference 5) the following diagnosis rates are estimated using data from the year 2011/12 covering the localities of the new CCGs in the region. In the last two columns are the diagnosis rate ambitions for the next two years. The challenge for the CCGs is to ensure that appropriate steps are taken to meet those targets.

Clinical Commissioning Group	Diagnosis Rate (adjusted) 2011/2012	CCG Diagnosis Rate 2013/14 (as at Nov 2013)	CCG Diagnosis Rate Ambition 2014/15*	CCG Diagnosis Rate Ambition 2015/16*
Durham Dales, Easington and Sedgefield	56.99%	66.20%	66.53%	67.00%
Darlington	51.06%	62.20%	64.03%	67.06%
North Durham	52.05%	56.70%	62.03%	67.01%

*\*At the time of writing this strategy, those diagnosis rate ambitions were proposals to the Area Team (for Durham, Darlington and Tees area) and were awaiting approval.*

This target is dependent on the length of the pathway beginning with an assessment at GP practice level, leading to a full assessment by memory clinics including scans.

During 2013-2014 a new Dementia Direct Enhanced Service programme was released by NHS England (see reference 6). In County Durham and Darlington, 95% of all GP practices signed up to this programme. In signing up to the programme the GP practices agree to make an opportunistic offer of assessment for dementia to 'at-risk' patients and, where agreed with the patient, to provide that assessment. The GP practices will report on the numbers of at risk patients who are offered and receive an assessment, and who agree to be referred for an



assessment. As gateway keepers, the GP practices are expected to see an increase in patients being diagnosed for dementia. The data on the progress made is not presently available, however NHS England have agreed to extend the Dementia Direct Enhanced Service programme for 2014-2015. There will be a need to review the data and agree on any actions that can be taken to enhance the diagnosis rates so that the target of two thirds of the estimated number of people with dementia in County Durham and Darlington can be met by 2015.

### **Better coding**

During 2013-2014 an exercise was taken to cross reference the dementia codes on the GP practices system against the codes on the acute system within the Mental Health Older People's Service at Tees, Esk and Wear Valley's NHS Foundation Trust (TEWV). This was done because there was evidence that some people with dementia registered (with the right codes) with the GP practice were not registered within the acute services, and vice versa. A significant number of 'mismatches' were identified and the coding was improved. This worthwhile exercise needs to be encouraged.

#### **Action: Monitor and improve dementia diagnosis rate**

The implementation group for the strategy will:

- Review activity data connected to the Dementia Direct Enhanced Service.
- Support practices that have not yet signed up to the Dementia Enhanced service or have a low uptake and share the best practice.
- Look for wider actions around engaging with other teams such as substance misuse/alcohol team.
- Be mindful about the future of Direct Enhanced Services for dementia and explore where local actions can be taken to increase the dementia diagnosis rate.
- Encourage and support improved coding and coding matching exercises on people with dementia between GP practices and secondary care dementia services.
- Consider piloting new screening tools that may be more effective and efficient.



## 4. Black, Asian and Minority Ethnic (BAME) Groups

In July 2013 the All-Party Parliamentary Group on Dementia found that many people from BAME communities did not receive a diagnosis of dementia, preventing them from having access to support and treatments that could help them live well with the condition (State of the Nation, page 8). Amongst those who did seek help, there was generally felt to be a lack of culturally sensitive dementia services.

In the North East, the BAME population is low in comparison to the rest of England. Nevertheless there will be BAME communities that will be at a disadvantage and be experiencing an inequality of outcomes when accessing dementia diagnosis and post diagnosis care. There is a need to understand what initiatives are currently in place to support BAME communities in County Durham and Darlington, and to compare case studies with good practices.

### **Action: Black, Asian and Minority Ethnic Groups**

We will explore options for establishing a user led group or consultancy that will engage directly with the range of BAME groups to scope their needs, gaps and priorities for improving support for people with dementia, which the strategy group will consider implementing.



## 5. Learning Disabilities

The State of the Nation Report has highlighted that people with learning disabilities have an increased risk of developing dementia and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s (see reference 7).

In County Durham and Darlington progress needs to be improved on the following areas:

- There needs to be a data exercise to establish the numbers of people with learning disabilities including those from GP practices that have not signed up to the Direct Enhanced Services for people with learning disabilities
- There are no defined pathways between GP practices and learning disabilities teams who can carry out specialised assessments on people with learning disabilities.
- There is a lack of knowledge/awareness among many carers about dementia in people with a learning disability. The symptoms are often unrecognised and therefore not brought to the attention of GPs in the first place.

### **Action: Learning disabilities and dementia**

We will plan together how we will:

- Promote greater awareness to primary care services, of issues around the diagnosis of dementia of people with learning disabilities.
- Explore appropriateness of existing pathways to memory clinics and strengthen the interface between primary and secondary care services for people with learning disabilities.
- Focus on interacting with the learning disabilities teams who will undertake specialised assessments for dementia with people with learning disabilities.
- Establish the best pathways that will enable a clear interaction between primary care and the specialised learning disabilities teams.



## 6. Young Onset Dementia

### Prevalence

The Alzheimer's Society (2002, see reference 7), estimates that there are about 18,500 younger people with dementia in the UK, suggesting that young onset dementia may occur in 1 in 1400 people between the ages of 40 and 65. However the Society states this is likely to be an underestimate and the true figure could be up to three times higher.

Figures below are based on LA mid-2006 estimates, using age range 40-64 to estimate prevalence rates against Alzheimer's Society suggested prevalence rates for this age range.

*For County Durham and Darlington (mid 2006 Local Authority population estimates), this would equate to approximately 147 individuals, as follows:*

Area	Population aged 40-64 years	Prevalence based on 1:1400
County Durham	171,500	123
Darlington	33,600	24
<b>Total</b>	<b>205,100</b>	<b>147</b>

There are currently 203 patients younger than 65 who are open to services within County Durham and Darlington Mental Health Service for Older People.

### Young onset dementia services in County Durham and Darlington

Young people can develop dementia and this particular group require support from dedicated consultant sessions, dedicated and specialised psychological services, nursing and IT staff with skills in assessment and the management of Young Onset Dementia.

Tees Esk and Wear Valleys NHS Foundation Trust (TEWV) provide aspects of this service in County Durham and Darlington.

In South Durham and Darlington whilst dedicated resources are in place, there remains a gap in provision for neuropsychology. Whilst patients receive a range of required interventions, the full complement of recommended interventions needs to be expanded.

In North Durham, there is currently no dedicated resource and limited specialist interventions, and patients with suspected young onset dementia are seen within community teams by generic staff. Activity information shows considerably lower numbers than in South Durham



and Darlington where there is a dedicated resource. The current number of patients seen by the teams is also significantly lower than prevalence figures would suggest. It is recognised that the support offered to people with Young Onset Dementia could benefit from being connected to other services for rare conditions, such as Huntington's disease which has some symptoms of dementia. It is also recognised that staff providing Young Onset Dementia services would benefit from having access to a single point of information to enable them to support the person with dementia and their carers at the earliest opportunity.

Plans are in place to expand the range of support. It is understood from past experience that when a dedicated resource has been put into place, an increase in referral rates from GPs follows, as has been the case in South Durham and Darlington. This is largely owed to the fact that Young Onset Dementia is recognised as a gap by GPs and other service providers.

#### **Action – Young Onset Dementia**

The implementation group will review the services for Young Onset Dementia and consider actions to address gaps in provision and resources.



## 7. Prisoners with Dementia

Older prisoners are the fastest-growing section of the prison population. Care UK (working with TEWV as their sub-contractor for mental health services) is the current provider of prison healthcare services and is responsible for ensuring the provision of high quality mental health services to all prisoners in accordance with NICE Quality Standards and best practice. This include interventions for supporting self-help, provision of counselling services, nurse led services, general psychiatry and for those presenting with more complex mental health care needs access to Older Person, Psychiatry, Forensic Learning and Disability, Forensic Psychiatry and Clinical Psychology Services.

All those with a serious mental illness and/or a suicide risk will be identified at the initial reception screening led by a qualified nurse. Prisoners identified as having mental health and/or substance misuse problems, will be referred to the mental health team and will be seen within 5 days for a secondary screen where a more in-depth assessment will be undertaken to further understand mental health and substance misuse problems. The prisoner would then be assessed according to their level of need and sign posted appropriately. Care UK is responsible for the implementation and maintenance of robust pathways for older patients which comply with the Department of Health document “A pathway to care for Older Offenders (DH, 2007a). Care UK also regularly report achievement against a prison specific quality and outcomes framework which contains a specific clinical indicator in relation to Dementia. This requires Care UK to maintain and report monthly on a register of patients diagnosed with dementia, the percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months and the percentage of patients with a new diagnosis of dementia, with a record of FBC, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12 and folate levels recorded within the last 6 months.

Below are figures confirming two identified cases for Durham for the year 2013-2014 to date.

Measure / location	HMP Frankland (High Security prison)	HMP-YOI Low Newton (Women’s prison)	HMP Durham (local prison)	HMP Holme House (local prison Stockton-on- Tees)
DEM001 – Register	1	0	1	1
DEM002 – Reviewed in previous 12 months	67.5%	70%	52.5%	100%
DEM003 – Tested within 6 months of new diagnosis	80%	80%	80%	-



**Action: Prisoners with dementia**

There is a pressing need to consider how to manage the health/social care interface and meet the needs of prisoners and others with social care needs. This is likely to require discussions with colleagues from Adult Social Care to negotiate and agree solutions, as this issue is likely to become more prominent as the prison population continues to age.





## 8. Living with dementia

In North of England, we have had the lowest percentage of patients with dementia (from GP Patient Survey data – a postal survey in 2012 and 2013) compared to the rest of England, who felt they did not have sufficient support from local services/organisations (State of the Nation Report, page 23). This is currently at just under 10% of those surveyed. Whilst this compares favourably with other regions in England, this percentage has risen between 2012 and 2013. Our challenge is to find out why this has been increasing, and what more we can do to stop it increasing, and to bring it down in the future.

We feel there is a growing need to support carers more widely, and for greater working in partnership. The critical time seems to be when someone is first diagnosed with dementia. The impact is profound, on the person as well as their family and others in their life. The State of the Nation Report cites two key reasons for this: it can be too late to get power of attorney when the diagnosis is given, causing problems and financial hardship for families; and secondly, earlier prior knowledge of a diagnosis could help families explore support networks and take advantage of them earlier.

We must ensure that carers do not have difficulties in obtaining a diagnosis for the person they care for. We presently do not know the extent of this possible problem for carers in County Durham and Darlington.

We must ensure carers are given information on legal issues and managing money. The Carers Trust (2013, see reference 8) found that many carers had learned about Lasting Power of Attorney too late. There is also a need to consider what should be done in situations when a person with dementia has the capacity to make decisions with healthcare staff and may wish to maintain a level of confidentiality from their own carers. In these situations, the carers will require support. Likewise, support for carers, who may hold Powers of Attorney, but feel their rights are not being heard or respected; needs to be considered.

There is currently no national measure of the provision of post diagnosis support. However work is underway by NHS England to develop an indicator for this which will be part of the NHS Outcomes Framework in the future.

Results from the consultation led by Healthwatch County Durham and Healthwatch Darlington identified the following needs:

- Carers would benefit from more support and intense support/counselling to be offered at the earliest point of diagnosis. This should extend to the families of patients as well as their primary carers. There is a need to ask, 'How will the diagnosis affect your family members?'
- Some carers have struggled to get an early diagnosis and have had to fight and push for further tests and investigation from the outset. Results have shown that an early



diagnosis and early treatment is vital in delaying the effects of dementia. The diagnosis of dementia can overlap with tests for other conditions such as depression and anxiety and this can make a clear diagnosis initially difficult to establish.

- Many carers have described not being informed of the help required to assist them manage their lives post diagnosis including any financial help, and legal issues they may need to address. Many have been unaware of any entitlements to benefits, or allowances and as such have been unable to get the help or support they require at the detriment of the independence and wellbeing of the dementia patient.

#### **Action: Carer and Post diagnosis support**

The implementation group for the strategy will appoint a carer representative on to the group. The group will identify what improvements to supporting people with dementia and carers can be made. The implementation group will consider improvements to the wider sharing of appropriate information, with a view to using tools such as patient passports to enable improvements to the implementation of care packages and referrals.

Develop a single knowledge base to access all types of information that people with dementia and their carers would benefit from, to cover all stages of dementia pathways.

#### **Reinforcing the need for action**

The actions set out in this section strongly correlate to the findings of Healthwatch County Durham and Healthwatch Darlington consultation during their interviews with dementia patients, family, carers and staff. It is absolutely imperative that carers are given more support and that intense support/counselling is offered at the earliest point of diagnosis and this support should extend to the families of patients as well as their primary carers.

There is a key concern around the quality of signposting of people with dementia and their carers to other support services. Many carers described not being informed of the help required to assist them manage their lives post diagnosis including any financial help, and legal issues they may need to address. Many have been unaware of any entitlements to benefits, or allowances and as such have been unable to get the help or support they require at the detriment of the independence and wellbeing of the dementia patient. This reinforces the need for a single point of access of information to assist with the signposting of people with dementia and their carers.

A central point of information will also help primary and secondary care staff consider pathway options that exist in the community, that people with dementia who are under their care, and their carers, may benefit from.



## 9. Carers

Carers play a critical role in supporting people with disabilities. Carers also have their health and wellbeing needs, which need to be supported. The current Direct Enhanced Service for dementia 2013-2015 focuses on people with dementia, it also places an expectation that health checks on carers are carried out. There will be opportunities to look closer at how widely the Direct Enhanced Service for dementia is being taken up by GP practices in respect to supporting carers and how this can be supported further,

Objective 7 of the National Dementia Strategy (2009) requires the implementation of a carer's strategy. It is recommended that unpaid carers need to be given access to a wide range of support to help them in caring for people with dementia. In particular, the carer's strategy should focus on people with dementia and ensure that effective assessment, support and short breaks (respite) packages are available.

Durham County Council and Darlington Borough Council, both offer a range of support to carers. It is critical that the carers are fully aware of all the services that are on offer, and providers are able to have up to date information to assist with signposting carers to the range of services on offer. A Joint Commissioning Strategy for Carers was prepared by Durham County Council and Darlington Borough Council for 2009-2013.

The consultation led by Healthwatch County Durham and Healthwatch Darlington confirms that there is scope for improvement for awareness and signposting for available services for their optimum utilisation. There is a signposting and information role for Healthwatch in this area that needs to be developed.

### **Action: Supporting Carers**

A new generic Joint Carers Commissioning Group will deliver the actions of the Joint Health and Wellbeing Strategies for County Durham and Darlington.

We will monitor the Direct Enhanced Service for dementia to check the uptake of health checks for carers, and we will increase the awareness of this service to other groups who are also supporting the carers. We will explore ways to support services especially primary care for health checks for carers.



## 10. Supporting dementia carers and professionals to allow people with dementia to live well in last years of life

A growing number of the population are living longer with more co-morbidities, including dementia. Sadly, people with dementia do not fare well in hospital as the unfamiliar surroundings exacerbate their condition. Often, families/children live some distance from elderly parents and are unable to care for them as they would wish, which often results in care home admissions. This leads to feelings of guilt for family members/carers as well as distress to the person with dementia.

There is scope to improve communication between families and the people responsible for their care including their doctors. There is also significant scope to improve advanced care planning as currently, lack of plans is one of the major factors that may lead to hospital admissions some of which are avoidable.

NICE Dementia Guidance (see reference 9) recommends that 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 of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death.

In addition, there needs to be set an expectation that at the point of diagnosis, memory clinics initiate the use of 'This is Me' and encourage people with dementia and their carers to take it with them whenever they access health and social care services and ensure staff in those care settings ask to see it.

Not all of our workforce are skilled in looking after people with dementia and the end of life – neither are the end of life care processes, and documentation, reflective of accommodating end of life discussions in the last years of life for people with dementia.

To enhance the skills of mainstream services, and to bring focused and expert support for dementia carers in line with the national dementia strategy the Clinical Commissioning Groups in County Durham and Darlington have commissioned additional dementia practitioner expertise. Practitioners will support professionals, people with dementia in all patient settings, across the health and social care systems, regardless of the care or home setting.

Many Trusts across the North East including CDDFT have signed up to the 'Deciding Right' document (see reference 10) and as such this will hopefully improve the pathway and steps for patients at the end of life.

A new unplanned admissions Direct Enhanced Service scheme is available for 2014-2015. It has been introduced as part of a move to reduce unnecessary emergency admissions to



secondary care. With this scheme there would be scope to provide multidisciplinary support for patients with dementia who are at risk of admission.

**Action: End of life/palliative care for people with dementia**

We will take steps to promote awareness through education and pathway development/liaison with end of life groups, not only within primary and secondary care settings but develop enhanced awareness for people with dementia and their carers so that people with dementia will have the opportunity to be supported to plan ahead the last years of their life.

We will plan to have additional resources to enable practitioners specialising in end of life/palliative care to interact with and offer support into all parts of the health and social care systems.

We will also explore ways to encourage reviews of the emergency admissions data for people with dementia from all the CCGs involved.

We will consider how the new unplanned admissions Direct Enhanced Service can be used to provide greater multidisciplinary support for people with dementia who are at risk of admission.



## 11. People with Dementia and Police Services

It has been formally raised by Durham Constabulary that some people with dementia will make emergency calls to the police to report suspicious activity and concerns, such as a burglary or theft which have subsequently been classed as non-crime due to the complainant having dementia.

A search of the log for January to March 2014 showed 147 callers where 'dementia' was noted in the record covering both County Durham and Darlington. There is currently no accurate way of identifying all dementia related callers, and there is a need to compose a list of all incidents and create a map of the locations of where the calls came from.

Some people with dementia may live alone for the main part of the day and can make high numbers of repeated calls to the police, which cause a drain on resources. There has been a case where an average 6 calls per week have been made by one person over a period of several months concerning a single recurring matter. A significant concern is also that a person with dementia, who has a record of making regular calls, could be at risk should a real incident occur within their household.

### **Action: Review what can be done to handle callers who have dementia**

The implementation group will engage with the appropriate steering group that will review what can be done to hold better data on people with dementia who make regular calls to the police, and to consider how they can be handled without putting the person with dementia at risk

## 12. Research and Innovation

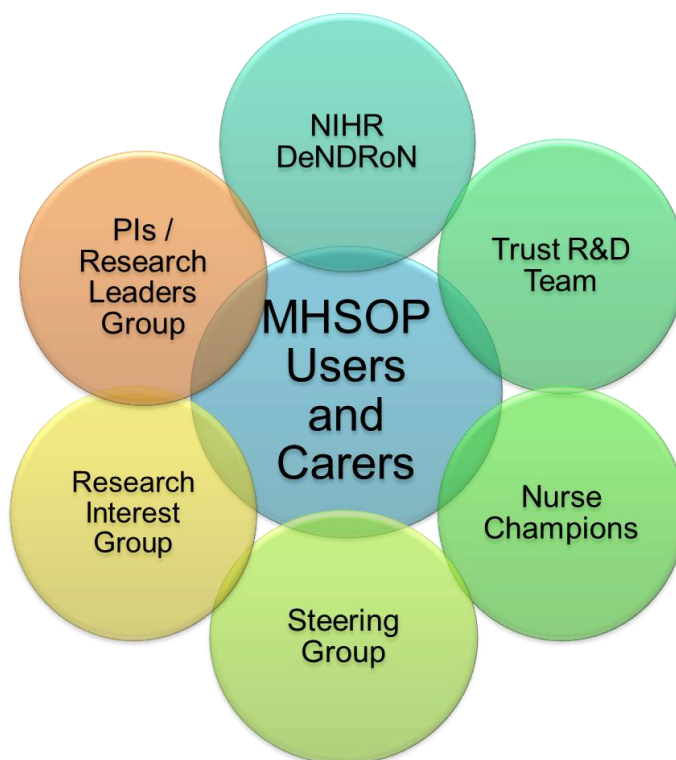
Research is vital to improve care in dementia and to improve mental health and wellbeing throughout the disease process.

The Call for Action (NHS England, July 2013, reference 11) highlights the need to support research amongst people with dementia. The State of the Nation report advocates that research has the potential to make a real difference to those with dementia and their families. It identifies the need for further research: towards faster diagnosis; towards new types of treatments; towards a cure; into how people with dementia can live well with the condition, around their decision-making ability and the reduced use of anti-psychotics in vascular dementia; understanding the disease and genetic factors; ways to tackle preventable dementia related disabilities.

### DeNDRoN led research

Tees Esk and Wear Valleys NHS Foundation Trust (TEWV) is the main provider of dementia services in the Durham and Darlington. The majority of TEWV's research is undertaken within the older people's mental health services team and those people with dementia on the research register. The research projects are supported by DeNDRoN (Degenerative and Neurological Disease Research Network, reference 12) which is the main network which is part of the National Institute for Health Research (NIHR) Clinical Research Network (see reference 13).

The research arrangements at TEWV are outlined in the diagram below:





Within the above arrangement, the progress on research during the last year is such that:

- An MHSOP research interest group was set up and activity to date collated
- Collaborative relationships were established with Trust R&D team & DeNDRoN
- Governance structures were built and embedded to support rapid collective decision making
- A steering group recognised within Trust governing structures, was developed with new Terms of Reference.

There are currently 1078 research recruits associated to dementia research at TEWV, and this figure has increased year on year since 2009. NIHR has a wide portfolio of research at TEWV and the largest in terms for recruits, accounts for dementia research at 23%, a figure that has more than doubled in a year.

Of all research at TEWV, looking at the uptake in different service areas, the largest area is in dementia which has doubled in its volume of research projects during the last year.

As assessment of gaps and opportunities to strengthen research into dementia identified the following actions:

- Patients are given information about research opportunities
- There is an increase in the uptake of the DeNDRoN Dementia Research Register
- There is an increase in the number of patients with dementia that we refer to studies
- Increase the capacity of research skills by increasing the number of Principal Investigators for DeNDRoN studies; increasing research skills; undertaking more peer-reviewed research articles and hosting a research conference
- Consider how research studies can be devised within TEWV in parallel with DeNDRoN led studies.

### **Promoting dementia research in Primary Care**

Whilst much dementia research takes place within the Mental Health Older People's Service, there should be opportunities for people with dementia to take part in diagnosis studies from the outset, such as in primary care settings. The promotion of the research register at primary care level should be encouraged. There should also be scope to include patients with other conditions in dementia research even when they may not yet be diagnosed with dementia, so that knowledge of preventative measures that can be taken in the future can be tested.

### **Early diagnosis**

Early diagnosis is the first positive step in this process enabling decisions to be made and plans to be implemented whilst a good cognition is still evident and capacity is retained.





Current pathways of care show gaps in the evidence of robust pathways to provide support whilst minimising stigma during this post diagnostic period.

Innovation is required to ensure that patient empowerment at this early stage of the disease is retained appropriately through to end of life.

This process would encompass shared decision making to develop individualised care pathways and include medication management, planning for home care, financial physical and emotional carer support, advanced decision making records and end of life care.

### **Record sharing**

Organisational innovation is necessary to improve timely cross care communication; of high priority is improvement in record sharing to enable swift, appropriate review and care with insight into co- morbidities and patient choice, this should include building a better understanding of each care provider's role for patient's, carers and other service providers.

### **Challenging behaviour**

One of the most demanding areas of dementia care is the presentation of behaviour that challenges; some evidence shows that this can be a direct result of unmet needs. Development of joint psychosocial-medical understanding and communication is a priority to minimise the impact of BPSD (behavioural and psychological symptoms of dementia) and is a focus area for underpinning care of these patients.

#### **Action: Research**

We will scope all research studies and pilots and their timelines so that we can promote awareness of this work at both primary and secondary care levels, so the profile of research is raised more widely.



### 13. Healthwatch County Durham and Healthwatch Darlington Consultation on Dementia

The Dementia Strategy Task Group wanted to ensure that the strategy would be developed with local and up to date input from people with dementia and their carers from the outset.

Healthwatch County Durham and Healthwatch Darlington were commissioned to carry out a consultation with people with dementia and their carers, in a range of settings. The aim was to capture their experiences of having gone through a journey, from pre-diagnosis to diagnosis and leading to post diagnosis support.

Over 130 people were met at 18 meetings and 115 survey questionnaires were completed.

The consultation aimed to establish examples of good and poor practice. Examples of good practice would translate into outcomes that people with dementia and their carers should expect to experience when receiving health and care services at primary care, community and acute settings.

The consultation found that on the whole there seems to be room for improvement in the dementia pathway although there were some very good comments about dementia services which could possibly be rolled out throughout County Durham and Darlington.

Findings from the consultation are summarised below:

#### **‘What are we doing well?’**

- The time scale for diagnosis once the memory test is offered
- People who are offered access to groups and dementia cafes and use them value the support from these services and use them well
- Some Carers were offered a lecture and education on Dementia and this was found to be extremely helpful.

#### **‘Areas for Improvement’**

##### Signposting and information

- More educational information is needed to be provided at diagnosis
- More information to be available to carers regarding respite care
- Access to benefit advice and information on what financial help is available, prescriptions, other health needs
- Increased awareness regarding how dementia patients can make small lifestyle changes that can reduce risks of vascular dementia

##### Personalisation

- More choice in what services are available and how to access them.



- Services should be 'personalised' at the present time they are not individual enough for people at different stages of dementia. For example, a person with early stage dementia might benefit from a slightly different package of activities and integration compared with others.

### Support

- The lack of free care available to patients and families – the care many people access has to be paid for
- The lack of support groups in some areas of the catchment area – most of the groups people attend are run by voluntary organisations and rely on family members to take the person with dementia to and from the groups
- More practical support for people to fill in forms
- More peer support
- More support for families - who asks the families as well as the primary carer as to how it is affecting them
- Respite care for carers.

### Joined up service delivery

- The lack of knowledge surrounding dementia – comments regarding medical staff treating physical symptoms but not treating mental health symptoms
- Lack of home visits for patients who are housebound from GP, the need for regular contact from GPs and mental health services. Once a diagnosis is made the dementia patient and the carer/family member feel that they are 'left to cope'
- Health vs. social care argument – Patients need cognitive, stimulative and motivational activities/therapies to keep them from deteriorating, this is classed as a social care need and therefore not provided by health. Social care services appear not equipped or funded to take on this service.

### **“What is working well?”**

- Support groups/memory cafes and singing for the brain, for those who can attend, are welcomed and talked about positively
- A few people we spoke to have been offered educational 'lectures' on dementia once a diagnosis has been made, this has helped them to understand dementia more. Very positive feedback on this was received
- Services are very good for certain people once access to them is obtained.

A report is being compiled at present to expand on the above points.

### **Action: Actions in response to findings**

The implementation group will receive the report on the consultation and discuss the recommendations to determine what actions should be prioritised for 2014-2015 and 2015-2016.



## 14. Dementia Costs

As the population grows and ages there will be more people with dementia to care for, the cost of this care is expected to rise significantly. It is expected to cost more than the costs for cancer, heart disease and stroke services in the future. This section outlines the costs of dementia services that has been spend during 2013-2014, including the impact of admissions by people with dementia. It also outlines forthcoming steps that will take place to bring more acute services into the community, closer to home.

### Current spend on acute and community based dementia services for County Durham and Darlington

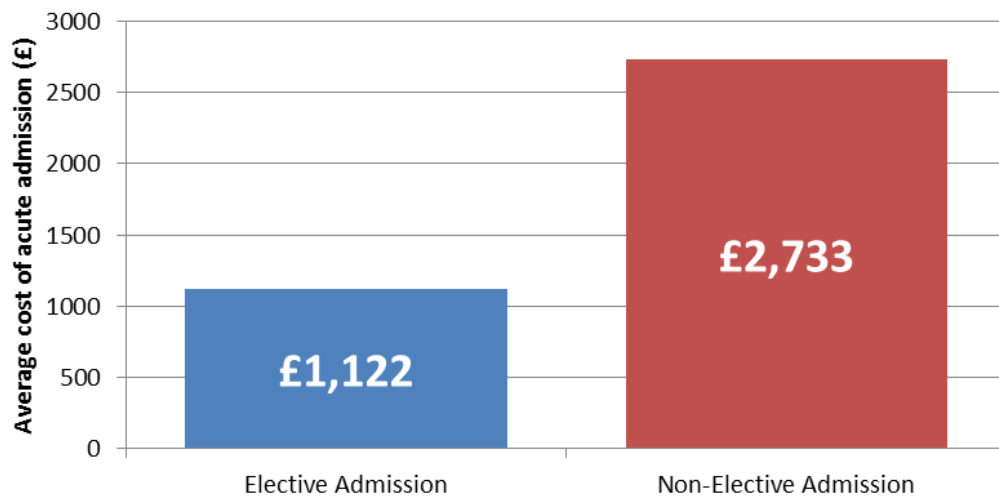
Location	Service	Spend in 2013/2014
Durham	Dementia Cafes	£10k
	Dementia Care Adviser Service	£240k
	Dementia Reablement Care Coordinators	£46k (part year)
	National Dementia Friendly Environment Pilot Programme – to be used across 8 separate pilot schemes	£1,024k (from Department of Health)
Durham and Darlington	Joint Carers Emergency Support Service (generic)	£10k for Durham £2k for Darlington £5k for Darlington CCG £31k for DDES and North Durham CCGs
Darlington	Dementia Adviser- includes the Dementia Cafes- funded by DBC Dementia Support Worker- funded by Alzheimer's Society	£64k
Durham and Darlington	Acute	Not currently available
	Memory Clinics	Not currently available
	Young Onset Dementia	Not currently available

**Impact on Admissions by people with Dementia**

One of the financial ‘burdens’ of dementia is that it increases the costs of an admission. This is the case when the dementia is not necessarily the first recorded diagnosis, but is a recorded diagnosis contributing to causing a patient’s admission or having a significant impact on their care.

The average cost of a non-reflective admission for a patient (any age) with dementia is significantly higher than the average cost for non-elective admissions of all patients aged 75 years and over (£2,310, 18% higher). Elective admissions of dementia patients are significantly more costly than the average for all elective admissions of patients aged 75 years and over (£934, 20.1% higher). Higher costs for acute admissions for dementia patients would be expected as for many admissions; the presence of dementia will trigger a higher tariff payment as a complicating co-morbidity, and are potentially more likely to attract excess bed day charges for very long admissions. This is demonstrated in the table below:

**Average cost of acute admissions of a patient with dementia (2013/14)**



**Better Care Fund**

From April 2015, through funding reallocations, councils and the NHS will pool £3.8 billion in the Better Care Fund (see reference 14), to work with each other and the voluntary sector and it is expected that local areas will use some of this to improve care for people with dementia, such as providing access to dementia advisers, reminiscence services and counselling. The best areas already do this and the Health Secretary is asking Health and Wellbeing Boards to make this a reality across the country.



**Action: Securing future funds for dementia services**

We will as a group consider carefully what priorities need to be commissioned in the future, and ensure that there are no duplications in projects and that all funding will be used as effectively as possible to bring more services closer to home.



## 15. Our current services and training programmes

Across County Durham and Darlington a range of dementia services are commissioned to support people with dementia and carers, as well as to train up the service staff providing the services. The services can be categorised into a number of types of services, and some of the services are being piloted at present for possible expansion in the future. Below are services currently being commissioned for 2014-2015. The services and projects have been aligned to the National Dementia Strategy (Appendix 1, and see reference 14).

Type of Service	Service name	Alignment to National Dementia Strategy Objectives	Locality		
			Durham Dales, Easington and Sedgefield	North Durham	Darlington
Primary care	GP screening with Direct Enhanced Service	2, 3	Yes	Yes	Yes
	Memory Clinics	2, 3,	Yes	Yes	Yes
Community	Therapeutic activities – Singing for the Brain	5, 6	Yes	Yes	Yes
	Dementia Advisers	4, 5, 6	Yes	Yes	Yes
	Dementia Cafes	5, 6	Yes	Yes	Yes
	CMHT	11	Yes	Yes	Yes
	Reablement Coordinators	9, 11	Part, pilot	No	No
	Just Checking Teleservice	10	Yes	Yes	Yes
	Walking Safe Telecare	10	Yes	Yes	No
	Floating Support Services for Users	6	Yes	Yes	No
	Community Intermediate Care Beds (generic)	9	Yes	Yes	Yes
	Carers	7	Yes	Yes	Yes



	Emergency Support				
	Carers Support Service	7	Yes	Yes	Yes
	Joint Carers Breaks	7	Yes	Yes	Yes
	Care First to Carers – Carers assessments	7	Review	Review	Yes
Residential	Dementia Awareness Care Home	11	Yes	Yes	Information not currently available
	Training to Nursing Home Staff	13	Yes	Yes	Yes
	Care Home Liaison within MHSOP Teams	11	Yes	Yes	Yes
	Care Homes Pilot for GP access to patients	9, 11	n/a	n/a	Subject to evaluation by CCG
	Dedicated Extra Care Scheme	11	Yes	No	Yes
Acute	Acute Hospital Liaison	8	Yes	Yes	Yes
	Training to staff	13	Information not currently available		
	Dementia environmental audit training	13	Information not currently available		

*Note that in that the above list is not exhaustive and there are other services that are at present subject to funding.*

#### **Action: Current services**

We will explore the need to develop a central model of care across County Durham and Darlington with which all pathways will align starting with the existing pathways we have for people with dementia, so that the efficiency and appropriateness of timely referrals will enable diagnosis and post diagnosis support to be provided at the earliest opportunity, reducing costs in the longer term. The implementation group will address existing gaps within the care pathways.





## 16. Framework of priorities - What we will aim to do

This framework sets out the actions the strategy implementation group will aim to implement in order to achieve the priorities set out in the 'State of the Nation' Report. The actions against each priority action have been informed through extensive engagement amongst the strategy task group for County Durham and Darlington. In November 2013 an event took place between the Clinical Commissioning Groups in Durham and Darlington; the providers and the councils, to agree on the steps we need to take to form the new strategy. The strategy group then carried out a stocktake to establish where we were with the previous strategy, and agree on the gaps. The strategy group then carried out an exercise to prioritise actions for the short term; long term and for continuation. Proposed actions were then shared with clinicians who may not have been part of the strategy task group. The clinicians added their views on projects and services that require improving to help prioritise which actions should be taken forward in the short term (2014-2015) and the long term (2014-2015) and also what is presently happening but needs to be continued. As a result we have ensured that our framework of priorities has been developed with the input of clinicians.

It should be noted that the priorities in this section may overlap with each other, and some of the short term actions are ones that should be initiated soon, but may take time (more than a year) to be fully implemented.

### Prevention

*Because the choices we make affect our risk of developing vascular dementia, we need to support people to make healthy choices to help them avoid getting the condition.*  
*State of the Nation Report, 2013*

#### Short term actions

- Identify three planned health and wellbeing projects and interact dementia awareness into them
- Plan to build dementia screening into the Health MOTs model
- Plan for training to raise dementia awareness in the substance misuse/ alcohol abuse teams.

#### Long term actions

- Making dementia part of other wellbeing programmes which will be reviewed over time

Alignments with the National Dementia Strategy Objectives: Objective 1



## Diagnosis and support after diagnosis

*Local NHS Clinical Commissioning Groups and local councils need to work together to ensure that, by 2015, two thirds of people with dementia have a proper diagnosis and get appropriate treatment.*

*State of the Nation Report, 2013*

Dementia diagnosis will continue as Direct Enhanced Services during 2014-2015 and will enable more targeted screening across all GP practices and to review the list of those with suspected dementia or mild cognitive impairment regularly.

We should consider the high index of suspicion of dementia in people with falls, carer strain, with people not attending appointments and review those cases.

The standardising of codes and cross referencing between the GP practices and the providers has been to identify more people with dementia who may not have been registered with this condition. However, there is a need to consider the needs of the carers too.

There are concerns around patients who do not want to be referred to secondary care for assessment and reluctance from some professionals to refer patients to specialised service as there is controversy around potential benefits of diagnosis as debated in the national and medical media. There is an opportunity to discuss this matter with experts in primary and secondary care to decide what more can be done around education to debate this. Though it may be appropriate that some people do not need referral but many other factors including carer support as well as advanced care planning is still as important.

### Short term actions

- Plan to standardise care home dementia awareness training
- Plan a strategic approach for rolling out dementia cafes
- Extend dementia reablement admission avoidance services and potential to pilot multi-disciplinary working as per the existing evidence base.
- Reflect on existing dementia services and supporting those with learning disabilities
- Reflect on offender health and what the prevalence of prisoners with dementia is, and what levels of support they receive
- Consider the need for dementia awareness to be part of other pathways such as stroke and diabetes
- Review gaps in services for people with Young Onset Dementia and what support should be put into place such as befriending schemes.

### Long term actions

- Set a minimum level of understanding for frontline staff e.g. mandatory training and learning course
- Involve the foundation trusts educational point of view into educational training
- Plan on setting an improved target for diagnosis.
- Develop central service directory – easily accessible family/carers/ staff



- Standardise service across areas; make sure all involved link in with best practice/ pathways. Liaise with on the Northern Dementia Clinical Network to inform models of good practice and care
- More extensive roll out of “This is me” amongst wider teams
- Possible establishment of memory clinics run by memory nurses in primary care initially to review established cases as a step forward, progressing in time to reviewing new patients. Easington area is planning trials for this in local practices.

#### Action that need to be continued

- Continue and develop care home liaison service based on evaluations.
- Debate on the best way for clinicians and GPs to proactively lead screening and diagnosis of dementia
- Take steps to continue the emphasis on screening for dementia by GP
- Continued training for health care staff
- Roll out learning from Department of Health / Department for Education programme on dementia training – post April.

#### Alignments with the National Dementia Strategy Objectives: Objective 2, 3, 4

#### **High quality, compassionate care everywhere**

*We need to give people with dementia and their carers care and support that is flexible, appropriate, timely and provided by skilled staff whether at home, in hospital or in a care home.*

*State of the Nation Report, 2013*

The concerns identified are around lack of integrated information systems between acute and mental health services where the patient has to wait for results. There are also some issues around licences to access results remotely. There is a need to look closer into improving this because a large number of dementia patients end up in hospital and often for a long period.

At present, there are no penalties for discharge being delayed due to social reasons for mental health providers as opposed to patients admitted with acute medical problems. As a result some dementia patients have their discharge delayed unnecessarily due to a lack of funding arrangements being agreed. There is a need to consider the potential for a time bound target becoming a target for the provider.

In the new over-75 named GP enhanced service rolled out from 2014; the communication between GP's, AEs, paramedic staff as well as the 111 service should improve and hopefully, reduce some unnecessary admissions.



County Durham and Darlington NHS Foundation Trust have a Teesside based project with Newcastle College around specialist end of life training to reduce A&E and admissions. This project has the potential to be rolled out more widely.

### Short term actions

- Agree on steps to develop clear path ways that all will sign up to and play a part
- Better links between the End of Life and Dementia strategies
- Consider role of a 'crisis team' for patients who are in residential care and may have challenging behaviour etc. could be used – with some flexibility for the team to deal with patients, who may need to be assessed for dementia at primary care level
- Plan to standardise care home dementia awareness training.

### Long term actions

- Recruit and evaluate effectiveness of the workforce of the ISIS (Integrated Short Term Intervention Service In County Durham) and RIACT (Responsive Integrated Assessment Care Team in Darlington) teams to focus on supporting people with dementia
- To review the criteria for acceptance of referral amongst community matrons who presently do not accept patients with mental health needs.
- Housing for people with dementia to avert crisis care home admission
- Dementia workers in the hospital.

### Actions that need to be continued

- Increase confidence of care homes to deal with people at End of Life – training, support and liaison
- Summary care records – sharing of patient records between primary and secondary care needs to be improved with information technology improving the interface
- Young Onset Dementia dedicated assessment and specialist support services based around memory clinics.

Alignments with the National Dementia Strategy Objectives: Objective 2, 3, 4, 5, 6, 7, 8, 9, 10, 11

### **Greater personal control**

*We need to enable people with dementia and their carers to exert control over their care and over their lives throughout all stages of their dementia.*

*State of the Nation Report, 2013*

Healthwatch County Durham and Healthwatch Darlington carried out an engagement consultation and their high level findings are set out in section 13.



It has been identified that there is no single up to date centralised source of information on what services that support people with dementia in the region. Some information is available within generic directories. There is a widespread need for up to date centralised information to be made available to all stakeholders to enable signposting to be improved. Providers and commissioners need to work together to establish that a new directory of dementia services will be kept up to date, and made accessible to all.

#### Short term actions

- Guidance on identifying care & care registration
- Staff within Foundation Trusts' need to be more aware of carer services & how to refer to these
- Develop appropriate responses to managing delirium to maintain person at home
- Focus on fall prevention/physical health for individual – training, awareness, link with carers
- Review the availability and effectiveness of community related carer and befriending services and how well health and social care services are joined up when proactively offering information to people with dementia and carers i.e. direct payment.

#### Long term actions

- Develop comprehensive issues carers register
- Expand the reablement agenda with increased personal support and cover for people with dementia
- Carers to be able to access support in an emergency
- Describe and implement Care Act (2014) requirements for training on dementia
- Develop and deliver dementia housing scheme (Durham County Council) and associated services input
- More extreme care services housing scheme
- Nominate a Dementia Clinical Lead in each GP practice.

#### Actions that need to be continued

- 'Walking safe' scheme
- Joint Carers emergency support
- Dedicated Mental Health support for carers
- Dementia adviser service/ dementia café's providing important support to carers – need to embed these and have a consistent approach across area
- Consider specialist breaks/ holidays for individuals with carers. Build on the promised carer service to maintain leadership
- Increase awareness of telecare options/ services – invest in some.

Alignments with the National Dementia Strategy Objectives: Objective 3, 4, 5, 6, 7, 10



## Reducing inappropriate medication

*NHS and social care organisations must continue to reduce the inappropriate prescribing of antipsychotic medication for people with dementia.*

*State of the Nation Report, 2013*

Managing antipsychotic medication is covered in section 2.

### Short term

- Re-audit the information on the prescribing of Risperidone by GP practices across County Durham and Darlington against the NICE Guidance, compare against past audits and report out findings with actions.

Alignments with the National Dementia Strategy Objectives: Objective 11, 18

## End of life care

*Health and care professionals must be made aware of the alternatives to dying in hospital. Everyone with dementia and their families should have 'planning ahead' conversations with their doctor. End of life care should be excellent with every person treated with dignity and respect.*

*State of the Nation Report, 2013*

Section 10 covers the need for end of life/palliative care services to be supported with resources and the need for the team to be supported by

### Short term

- Implementation of plans for dementia to be included in end of life path way
- Standardised pathway for decisions on End of Life, within all teams
- Care home training should be a rewarded focus – Consider widening the approach.

### Long term

- Commission additional dementia specialised staff to support end of life/palliative care pathways and interact this across all parts of the health and social care systems
- Focused training for care staff EOL and pathway
- Maintaining experience – Admiral Nurses – we need to know what they are.

### Actions that need to be continued

- Training around advanced decisions



- Better planning around preferred place and death while individual has capacity.

#### Alignments with the National Dementia Strategy Objectives: Objective 12

### **Dementia education and training**

*All NHS and social care staff should be aware of the signs of dementia and how best to support people with the condition, their families and carers.*

*State of the Nation Report, 2013*

So far 60,000 people have signed up to the Alzheimer's Society Dementia Friends programme. In February 2014 the Department of Health confirmed that leading British businesses have signed up to the cause which will see a further 190,000 people becoming Dementia Friends.

#### Short term

- Scope the range of training for dementia to assess where there are gaps and where efficiencies of provision of training can be made
- Organisations to proactively participate in dignity action days
- Seek to use the six C's approach (Care, Compassion, Competence, Communication, Courage, Commitment) in dementia services.

#### Long term

- All health and social care services have had training in recognising and dealing with dementia.
- Extension of The Gold Standards Framework (GSF) dementia programme -The GSF End of Life Care for People with Dementia Distance Learning Programme was introduced as a pilot programme to identify the level of need for bespoke dementia care for people nearing the end of their lives. The success of the programme is currently being evaluated with a view to further rollout – consideration should be made of extending this across the county.

#### To be continued

- Dementia modules/ training for staff
- Increase of dementia friends/ dementia champions across services and commissioners and public.



## Alignments with the National Dementia Strategy Objectives: Objective 13

### **Dementia Friendly Communities**

*We need to create a dementia friendly society. We urge national businesses to become dementia friendly and to encourage their local branches to take this forward in their communities. We ask everyone to become a Dementia Friend so that more people know how they can help support people with dementia and their families.*

*State of the Nation Report, 2013*

Section 2 -Our challenges, Future of Care, refers to the need for dementia friendly communities to be expanded. In County Durham and Darlington no Dementia Friendly Communities have yet been rolled out, however a pilot will commence in two locations and plans will be put into place for a regional roll-out of the programme.

#### Short term

- Chester-le-Street and Barnard Castle identified as Dementia Friendly Communities. Initial pilots will be implemented.

#### Long term

- To roll our dementia friendly communities initiatives over next three years with the Alzheimer's Society.

## Alignments with the National Dementia Strategy Objectives: Objective 2, 3, 4, 5

### **Research**

*We need more dementia research and more people taking part in clinical trials. We ask those who fund research to strive ever harder to get the most from the excellent ideas, people and resources this country has to offer.*

*State of the Nation Report, 2013*

#### Short term

- Tees Esk and Wear Valleys NHS Foundation Trust to review how awareness of research in dementia has increased amongst its staff and how they link in to this.
- Review the update of studies attached to memory clinics, to plan for more studies to be spread more consistently across the region
- To explore federating practices around research in mental health and dementia.

#### Long term

- Consider the need for highest level commitment from mental health trust as well as at the CCG level promoting the need for more research.





## Alignments with the National Dementia Strategy Objectives: Objective 16

### **Better data and evidence**

*We call on national health and care organisations – such as NHS England, Public Health England, Health Education England, the Care and Quality Commission and the Health and Social Care Information centre – to work with the academic and research communities, the voluntary sector, industry and central government to improve the availability and quality of data on dementia*

*State of the Nation Report, 2013*

There will be five actions for primary care which are around estimating the true prevalence and other actions.

A Health Needs Assessment on dementia will be initiated and the findings will enable the strategy to be refreshed in 2015. The improved data and information will inform the development of new actions.

## Alignments with the National Dementia Strategy Objectives: Objective 17

### **Comments for Healthwatch County Durham and Healthwatch Darlington on Consultation**

The over-arching theme coming from the consultation feedback (see Section 13) is the need to improve access and the availability of information. Giving dementia patients and their families this information at the point of diagnosis will help and equip them with the knowledge they need to manage the condition. This needs to be the main priority and the first step to supporting people to maintain their independence and to make informed choices.

There is an urgent need for a 'living' directory of up to date information on all services covering the whole care pathway for people with dementia and their carers to be implemented to enable effective signposting to support services.

The dementia strategy group appreciate Healthwatch County Durham and Healthwatch Darlington's involvement in the development of this strategy.

#### **Action: Implementing the actions**

We will review all the actions we have identified and realistically prioritise them for implementation. Some actions will happen in 2014-2015 and others will start in 2015-2016 and beyond. We will review all actions each year as we refresh our strategy.



## 17. How will we work to implement the strategy?

### Implementation and Governance

The strategy task group will become the implementation group for this strategy. It will report to the Care Closer to Home Group of the Clinical Programme Board which is represented by the Clinical Commissioning Groups in County Durham and Darlington. The implementation group will escalate any issues to the Care Closer to Home Group. It will also report its progress to the Mental Health Implementation Group for County Durham, and the Mental Health Strategy Group at Darlington Borough Council.

### What steps will we take to implement the strategy?

The implementation group will adopt all actions set out in this strategy. It will meet every month during the first 12 months of this new strategy. It will closely monitor its developments and plan collaboratively to prioritise all areas of work as well as identify new projects that need to be considered to improve the outcome of people with dementia and carers.

### How will we know if we are achieving the aims of the strategy?

We will obtain data on the diagnosis rates, waiting times and antipsychotic medication, and other things such as research studies and compare them against past data to see where improvements are being made.

We will obtain user representatives to join the implementation group and ensure that they play a key role in informing the context and development of new priorities.

As a group we will take definitive steps to obtain the views of people with dementia and carers, as well as service providers, to do a reality check that their outcomes are being achieved.

We will publish our progress each year as we refresh the strategy and actions.



## 18. Summary Action plan for the next 12 months

This strategy captures a range of actions which the implementation group will focus on. The implementation group will meet monthly to plan in greater details how it will achieve the project outcomes.

The critical milestones for the next 12 months are:

- Establish communications task group to engage with stakeholders – April to September 2014
- Begin Health Needs Assessment on Dementia – April to October 2014
- Implementation Group is formed June 2014
- Appoint user representatives onto the implementation Group June 2014
- Refresh the strategy with new actions February 2015 to March 2015
- Communicate out the progress and refreshed actions April 2015 to June 2015



## References

- 1 NHS Mandate, <https://www.gov.uk/government/publications/nhs-mandate-2014-to-2015> (November 2013, accessed 08/04/2014)
- 2 Dementia – A State of the Nation Report on Dementia Care and Support in England, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/262139/Dementia.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf) (December 2013, accessed 08/04/2014)
- 3 NHS to Tackle Long Waits for Dementia, <https://www.gov.uk/government/news/nhs-to-tackle-long-waits-for-dementia-assessments> (February 2014, accessed 08/04/2014)
- 4 Prime Ministers Challenge on Dementia – Delivering Major Improvements in Dementia care and Research by 2015, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215101/dh\\_133176.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf) (march 2012, accessed 08/04/2014)
- 5 Putting Dementia on the Map, <http://dementiachallenge.dh.gov.uk/map/> (November 2013, accessed 11/03/2014)
- 6 Dementia Direct Enhanced Service Specification, <http://www.england.nhs.uk/wp-content/uploads/2013/03/ess-dementia.pdf> (accessed 11/03/2014)
- 7 The Rising Costs of dementia in the UK, Alzheimer’s Society, 2007 [http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=342](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=342) (accessed 08/04/2014)
- 8 A Road less Rocky – Supporting People with Dementia, [http://www.carers.org/sites/default/files/dementia\\_executive\\_summary\\_english\\_only\\_final\\_use\\_this\\_one.pdf](http://www.carers.org/sites/default/files/dementia_executive_summary_english_only_final_use_this_one.pdf) (2013, accessed 08/04/2014)
- 9 Dementia NICE Guidance CG42, <http://guidance.nice.org.uk/CG42/NICEGuidance/pdf/English> (2006, updated March 2013, accessed 08/04/2014)
- 10 ‘Deciding Right, Northern Clinical Networks and Senate, [http://www.cne.org.uk/securefiles/140408\\_1545/Deciding%20right%20leaflet%201Feb14.pdf](http://www.cne.org.uk/securefiles/140408_1545/Deciding%20right%20leaflet%201Feb14.pdf) (February 2014, accessed 08/04/2014)
- 11 The NHS Belongs to the People – a Call to Action, <http://www.england.nhs.uk/2013/07/11/call-to-action/> (July 2014, accessed 08/04/2014)
- 12 DeNDRoN, Dementias and Neurodegenerative Disease Research Network, <http://www.northeastdendron.org.uk/dementia-studies> (accessed 08/04/2014)
- 13 National Institute for Health Research, <http://www.nihr.ac.uk/Pages/default.aspx> (accessed 08/04/2014)



- 14 Integrated Care – Better Care Fund, [http://www.local.gov.uk/health-wellbeing-and-adult-social-care/-/journal\\_content/56/10180/4096799/ARTICLE](http://www.local.gov.uk/health-wellbeing-and-adult-social-care/-/journal_content/56/10180/4096799/ARTICLE) (accessed 08/04/2014)
- 15 Living Well with Dementia – a National Dementia Strategy, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/168220/dh\\_094051.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf) (2009, accessed 08/04/2014)



## Glossary

<b>Organisational Abbreviations</b>	
<b>Abbreviation</b>	<b>Description</b>
AEs or A&E	Accident and Emergency Departments
CDDFT	County Durham and Darlington NHS Foundation Trust
CHS	City Hospital Sunderland NHS Foundation Trust
DBC	Darlington Borough Council
DCC	Durham County Council
DCCG	Darlington Clinical Commissioning Group
DDES	Durham Dales, Easington and Sedgefield Clinical Commissioning Group
ISIS	Integrated Short Term Intervention Service In County Durham
LA	Local Authority
NDCCG	North Durham Clinical Commissioning Group
NICE	The National Institute for Health and Care Excellence (NICE) is a non-departmental public body of the Department of Health in the United Kingdom, serving both the English NHS and the Welsh NHS.
NIHR	National Institute for Health Research (NIHR)
NTH	North Tees and Hartlepool NHS Foundation Trust
RIACT	Responsive Integrated Assessment Care Team
TEWV	Tees, Esk and Wear Valleys NHS Foundation Trust
DeNDRoN	Degenerative and Neurological Disease Research Network

<b>Terms:</b>	
<b>Abbreviation</b>	<b>Description</b>
Alzheimer's Disease	Alzheimer's disease is the most common form of dementia. It was first described by German psychiatrist and neuropathologist Alois Alzheimer in 1906 and was named after him. Most often, Alzheimer's disease is diagnosed in people over 65 years of age, although the less-prevalent early-onset Alzheimer's disease can occur much earlier.
Antipsychotics	Are medicines designed to reduce the mental symptoms of people with a psychosis type of mental health problem. Symptoms, include delusions, hallucinations, or disordered thought. This group of medicines have a sedative property and are sometimes used to treat people with a dementia illness, to reduce the agitation, distress and trauma that the individual may be experiencing. They are carefully monitored to avoid over-sedation.
B12	Vitamin B12, a water-soluble vitamin with a key role in the normal functioning of the brain and nervous system, and for the formation of blood.
BAME	Black, Asian and Minority Ethnic (BAME) groups
BPSD	Behavioural and psychological symptoms of dementia
CT Scan	Computed Tomography (CT) is a technology that uses computer-processed x-rays to produce tomographic images (virtual 'slices') of specific areas of the scanned object, allowing the user to see what is inside it without cutting it open. This is a common head scan used to help the clinician form a diagnosis.
Dementia	A term used to describe a gradual deterioration in the brain caused by destruction of brain cells by disease factors. There are several described types of dementia and Alzheimer's Disease is the most commonly known form.
Dementia Register	A General Practice Register created within each General Practice to list patients with a diagnosis of a Dementia condition, regardless of the type. This list is used to help monitor and review patients with a Dementia at practice level.



<b>Terms:</b>	
<b>Abbreviation</b>	<b>Description</b>
Down's syndrome	Down syndrome (DS) or Down's syndrome, also known as trisomy 21, is a genetic disorder caused by the presence of all or part of a third copy of chromosome 21. It is typically associated with physical growth delays, characteristic facial features and mild to moderate intellectual disability.
EOL	End of Life
FBC	Full Blood Count – is a test panel requested by a doctor or other medical professional that gives information about the cells in a patient's blood. A scientist or lab technician performs the requested testing and provides the requesting medical professional with the results
GP or GPs	A General Practitioner (GP) is a medical practitioner who treats acute and chronic illnesses and provides preventive care and health education to patients in the community where they live.
Hospital	In the dementia strategy document, the references to a hospital admission or stay is usually referring to a General Hospital or Community Hospital and not a specialist Mental Health hospital designed to assess and treat people specifically with Dementia problems.
Huntington's disease	Huntington's disease (HD) is a neurodegenerative genetic disorder that affects muscle coordination and leads to cognitive decline and psychiatric problems. It typically becomes noticeable in mid-adult life. HD is the most common genetic cause of abnormal involuntary writhing movements called chorea, which is why the disease used to be called <i>Huntington's chorea</i> .
Neuropsychology	Neuropsychology studies the structure and function of the brain as they relate to specific psychological processes and behaviours.
Prevalence	Prevalence, in epidemiology (the study of disease), is the proportion of a population found to have a condition (typically a disease or a risk factor such as smoking or seat-belt use). It is arrived at by comparing the number of people found to have the condition with the total number of people studied, and is usually expressed as a fraction, as a percentage or as the number of cases per 10,000 or 100,000 people.
R&D	Research and Development
Vascular Dementia	Vascular dementia is the second most common form of dementia after Alzheimer's disease. It is caused by reduced blood flow to the brain because there is a problem with the blood vessels that supply it. Parts of the brain become damaged and eventually die from a lack of oxygen and nutrients. Unlike other forms of dementia, many cases of vascular dementia can be prevented. Vascular Dementia is sometimes described as "multi-infarct dementia", due to the fact that multiple blockages in blood vessels in the brain, cause infarcts (death to the brain tissue/cells).



## Appendix 1 – National Dementia Strategy

### The themes and objectives of the strategy

There are 17 objectives, which focus on four key areas for improving the quality of life for people with dementia and carers raising awareness and understanding, early diagnosis and support, living well with dementia and making the change (implementing the Strategy).

#### **Objective 1: Public information campaign**

A significant national awareness campaign is proposed that focuses on explaining what dementia is, the importance of diagnosis, help that is available, reducing stigma and promoting prevention. It suggests that local complementary campaigns should also be run.

#### **Objective 2: Good quality early diagnosis and intervention**

The Strategy proposes local commissioning of a good quality memory service which can provide early specialist diagnosis as well as appropriate intervention and support. [Memory services](#) might most appropriately be based in a community setting.

#### **Objective 3: Good quality information**

Good quality [information](#) should be available for people with dementia and their carers. A one year review of existing information is proposed, followed by the development and distribution of a set of good quality information on dementia and services. Information on [local service provision](#) should be tailored to that area.

#### **Objective 4: A dementia adviser**

Following diagnosis, all people with dementia should have access to a dementia adviser who can act as a point of contact for information and signposting to other services. The focus of work would be to help people with dementia to navigate the health and social care system. The DH proposes a series of demonstrator sites to examine which dementia adviser model works best and to evaluate impact on quality of life.

#### **Objective 5: Peer support and learning networks**

The Strategy proposes the development of peer support networks such as [support groups and dementia cafes](#) for people with dementia and their carers. The intention is to provide practical and emotional support, reduce social isolation and promote self-help. The Strategy proposes a demonstration and evaluation programme to evaluate peer support activity.

#### **Objective 6: Improved community personal support services**

It is recommended that an appropriate range of services needs to be put in place to support people with dementia and their carers in their own homes, with a range of options available from early intervention to specialist services. A dedicated programme will establish an evidence base on which specialist services are effective.

#### **Objective 7: Implementing the Carers' Strategy**

It is recommended that unpaid carers need to be given access to a wide range of [support](#) to





help them in caring for people with dementia. In particular work on the Carers' Strategy should focus on people with dementia and ensure that effective assessment, support and short breaks (respite) packages are available.

### **Objective 8: Improving care in hospitals**

The Strategy proposes three key changes to dementia care practice in acute hospitals.

- Identifying a senior clinician who will be responsible for quality improvement in dementia
- Developing an explicit agreed care pathway for people with dementia in hospitals, explaining how people with dementia will be cared for, by whom and in what way
- The development of specialist older people's mental health liaison teams that can support staff throughout hospitals to care for people with dementia.

### **Objective 9: Improving intermediate care**

Intermediate care services support people who have had a serious health incident. They allow these people to remain in their own homes without requiring hospital care, or to recover from a stay in hospital. Many intermediate care services currently wrongly exclude people with dementia. The DH issued new guidance on intermediate care in 2009, with explicit reference to people with dementia.

### **Objective 10: Housing and telecare**

People with dementia should be included in locally developed housing options and should be able to take advantage of [assistive technology](#) and telecare.

### **Objective 11: Improving care in care homes**

The Strategy recommends a number of steps be taken to improve quality of care in care homes:

- A named senior member of staff should take the lead for improving quality of dementia care in every home.
- This senior staff member should develop a local strategy for management and care of people with dementia.
- [Anti-psychotic medication](#) should only be used when appropriate.
- Specialist in-reach services should be commissioned to provide specialist advice and guidance on improving care.
- Other in-reach services such as primary care, pharmacy, dentistry should be available.
- Specialist guidance for care staff on best practice in dementia care should be provided.

### **Objective 12: Improving end of life care**

Palliative care at the [end of life](#) needs to be improved. This objective suggests the involvement of people with dementia in planning end of life care in keeping with the principles of the [Mental Capacity Act](#). Local work on the [End of Life Care Strategy](#) needs to consider dementia. The Strategy proposes a programme of demonstration, piloting and evaluation projects to assist development of end of life care in dementia.

**Objective 13: Workforce competencies, development and training**

All health and social care staff involved in the care of people with dementia should have the skills to provide the best quality care to people with dementia and their families. The DH will work with representatives of all bodies involved in professional, vocational and continuing professional development to agree the core competencies required in dementia care. Those bodies will then consider how to adapt their curricula. Commissioners of services should specify dementia training as a requirement for service providers.

**Objective 14: Joint local commissioning and World Class Commissioning**

The Strategy recommends that local commissioning and planning mechanisms need to be established to determine how best to meet the needs of people with dementia and their carers. These should be informed by the Dementia World Class Commissioning guidance developed to support the Dementia Strategy.

**Objective 15: Improved registration and inspection of care homes**

Registration and inspection regimes should reflect the need for good quality dementia care. The Strategy includes a statement agreed with the [Care Quality Commission](#) setting out how they expect to regulate and inspect care homes.

**Objective 16: Dementia research**

The DH will work with the Medical Research Council to convene a summit of research funders and scientists interested in dementia research. This will be used to generate a plan for the development of dementia [research](#) in the UK.

**Objective 17: National and local support for implementation**

The DH will provide regional support to commissioners and providers implementing the Strategy to ensure progress.

**Objective 18: Antipsychotic medication**

There should be reductions in the prescribing of antipsychotic medication for people living with dementia.



## Appendix 2 – Support in Developing the Dementia Strategy

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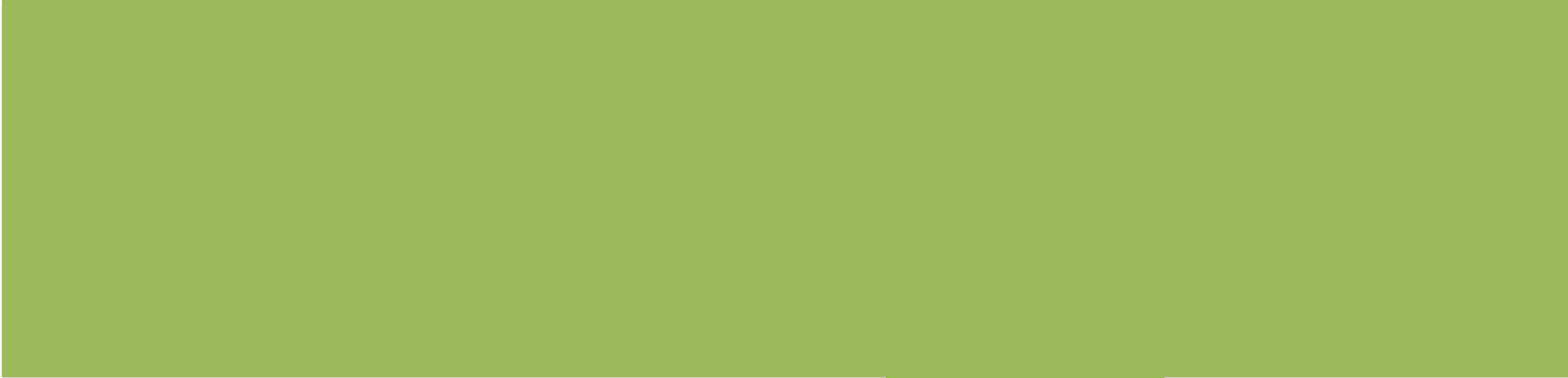
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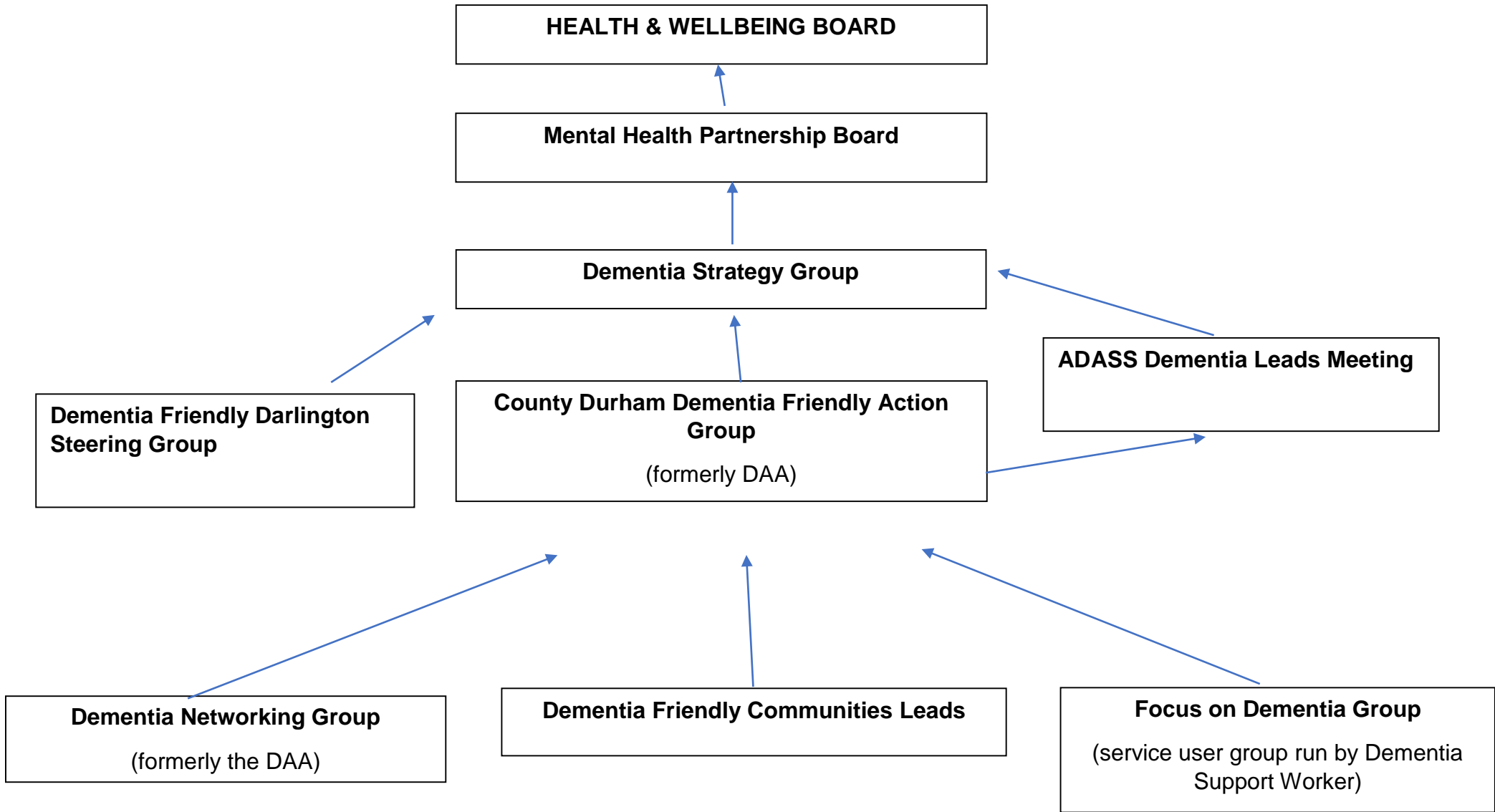
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**Dementia – Governance Structure**



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**ADULTS SCRUTINY COMMITTEE**  
**11<sup>th</sup> February 2020**

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**SUPPORT TO CARERS**

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**SUMMARY REPORT**

**Purpose of the Report**

1. To provide information about support to carers in Darlington and an update on Darlington's Carers' Action Plan 2018-20.

**Summary**

2. The 2011 census identifies 11,048 carers in Darlington, 2758 (25%) of whom are providing care for 50 or more hours per week. 197 of these were aged 0-15 and the largest group of carers (37%) is those aged 50-64.
3. Darlington Carers' Strategy Steering Group (CSSG) has developed a Darlington Carers' Action Plan in response to the national Carers Action Plan which was published in June 2018. Darlington Carers' Action Plan is attached as Appendix 1.

**Recommendation**

4. It is recommended that :-
  - (a) Members note the content of this report
  - (b) Members act as champions for carers in Darlington and consider how to support progress of the carers' agenda in Darlington

**Suzanne Joyner**  
**Director of Children and Adults Services**

## Background Papers

National Carers Action Plan 2018-20  
 Darlington Carers' Action Plan 2018-20

Lisa Holdsworth : Extension Ext 5861

S17 Crime and Disorder	There are no implications arising from this report.
Health and Well Being	Carers can experience poor health as a result of their caring responsibilities. Identifying and supporting carers contributes to supporting their health and wellbeing and the health and wellbeing of the people for whom they care.
Carbon Impact and Climate Change	There are no implications arising from this report.
Diversity	Caring affects all groups of people in Darlington.
Wards Affected	All
Groups Affected	Carers are the group primarily affected.
Budget and Policy Framework	N/A
Key Decision	N/A
Urgent Decision	N/A
One Darlington: Perfectly Placed	Supporting carers contributes to supporting the 'One Darlington' Healthy Darlington theme.
Efficiency	Research published by Carers UK in 2015 indicates that unpaid carers in Darlington provide support to the value of £224 million.
Impact on Looked After Children and Care Leavers	This report has no impact on Looked After Children or Care Leavers



## MAIN REPORT

### Information and Analysis

5. The 2001 census identified 10,064 carers in Darlington, 2330 (23%) of whom were providing care for 50 or more hours per week.
6. By 2011, this number had increased to 11,048 of whom 2,758 (25%) were providing care for 50 or more hours per week. The largest group of carers (37%) are those aged 50-64.

<b>Age</b>	<b>Number</b>
0-15	197
16-24	543
25-34	915
35 -49	2807
50-64	4124
65+	2462

7. Darlington's Carers' Strategy Steering Group (CSSG) meets bi-monthly and its remit is to:
  - (a) lead on the development of Darlington's Carers' Strategy and Action Plan, taking into account national legislation and policy guidance and the views of local carers, and to monitor progress on implementing it
  - (b) share good practice in relation to all carers, including parent carers and young carers
  - (c) ensure that the carer voice is heard and informs the development and delivery of support and services for carers in Darlington
8. The Group is co-chaired by Darlington Carers Support and Humankind Young Carers Service, which are commissioned jointly by the Council and Darlington CCG to provide:
  - (a) information, advice and guidance
  - (b) 1:1 support tailored to individuals' needs
  - (c) group activities to enable carers to meet others in similar situations and to take time out from their caring roles
  - (d) individual carer breaks
  - (e) awareness raising with health, social care and education professionals to raise the profile of all groups of carers and ways of meeting their needs
9. The national Carers Action Plan 2018-20 sets out the cross-government programme of work to support carers until 2020. It is structured around 5 themes, each of which includes a number of subheadings:
  - (a) Services and systems that work for carers: raising awareness of and promoting best practice amongst health professionals; raising awareness amongst social workers; supporting requirements of the 2014 Care Act and the 2014 Children

and Families Act; personalisation; Mental Health Act 1983 and supporting carers.

- (b) Employment and financial wellbeing: improve working practices; flexible working; returning to work; financial support.
  - (c) Supporting young carers: identification of young carers; improving educational opportunities and outcomes; improving access to support services; transition for young adult carers.
  - (d) Recognising and supporting carers in the wider community and society: technology and innovation; recognition of carers; community engagement; loneliness.
  - (e) Building research and evidence to improve outcomes for carers: research to improve the evidence base.
10. It should be noted that a number of these areas focus on the need to identify carers in health and community settings and in their education and workplaces, in order to be able to ensure that they are able to access the support and advice they need in a timely manner to enable them maintain their wellbeing and to manage their caring role as effectively as possible.
11. Darlington Carers' Action Plan sets out the Darlington response to the national Carers Action Plan and identifies a number of key areas to progress:
- (a) Services and systems that work for carers including: continuation and development of work in GP surgeries to make them more carer friendly; link to the work already being undertaken by Dementia Friendly Darlington; providing access to training and development opportunities for carers; improving social work staff's awareness of carers' needs and the support available to them; continuing to enable carers to access carers breaks.
  - (b) Employment and financial wellbeing including: review of access to Employers for Carers (EfC) membership for DBC employees and employees of Small and Medium Enterprises (SMEs) in Darlington; increased awareness of carers' rights and needs for employers in Darlington and individual working carers.
  - (c) Supporting young carers including: continued awareness raising in schools and colleges and with health and social care professionals; review of DBC Young Carers Assessment and Young Carers Transition Assessment processes.
  - (d) Recognising and supporting carers in the wider community and society including: development of carer friendly communities; widening access to the Carers Card; considering how to respond to the loneliness agenda in relation to carers; recognising and supporting hard to reach carers in Darlington.
  - (e) Building research and evidence to improve outcomes for carers: considering survey outcomes and how to respond to them to improve support for carers in Darlington.
12. Members of the CSSG are currently working to deliver the actions identified. The focus of this work also reflects the need to identify carers in health and community

settings and in their education and workplaces. Outcomes of this work include:

- (a) Continued awareness raising by Darlington Carers Support - a total of 457 new carers were registered from April 2018 – March 2019, 100 more than the same period the previous year.
  - (b) An increase in referrals from GP surgeries to Darlington Carers Support (a total of 135 from April 2018 – March 2019).
  - (c) A total 1349 carers were registered with Darlington Carers Support as at 11<sup>th</sup> November 2019.
  - (d) Continued provision of a range of breaks tailored to individual need, both to people with eligible social care needs and through third sector providers with continued Better Care Fund (BCF) carer breaks funding. Commissioned Carers Support providers also offer flexible breaks to both individuals and groups.
  - (e) Award of BCF carer breaks funding to widen access to the Carers Card in Darlington.
  - (f) Continuation of EfC membership jointly with Durham County Council. This has enabled the provision of a training session for DBC managers regarding the needs of working carers and how best to support them. Plans are also being made for the delivery of a joint session for SMEs and Health partners across County Durham and Darlington which will take place on 6<sup>th</sup> February 2020.
  - (g) A total of 142 young carers were supported by Humankind from 1<sup>st</sup> April 2018 – 31<sup>st</sup> March 2019. (138 of these were under 18 and 4 were aged 18-25).
  - (h) A total of 137 young carers were supported by Humankind from 1<sup>st</sup> April – 11<sup>th</sup> November 2019. (132 of these were under 18 and 5 were aged 18-25).
  - (i) As at 11<sup>th</sup> November 2019, 31 schools had achieved Young Carers Charter status. 4 more are on Amber and 5 are on Red. Work is ongoing by Humankind to encourage the remaining schools to achieve Charter status. In addition, Darlington College has also achieved Charter Status
  - (j) Work is ongoing to make changes to the Young Carers Assessment process with the intention that Young Carers Assessments will to be undertaken by Humankind. Discussions regarding how to implement this are in progress.
  - (k) Work is ongoing to develop a Young Carers Transition Assessment process.
13. It is anticipated that support to carers will be included in the Government's plans for Adult Social Care. In the interim, in the absence of any specific requirements, the CSSG will be reviewing progress against the actions identified in the Darlington Carers' Action Plan 2018-20 and identifying further actions going forwards to progress the carers' agenda in Darlington.

### **Outcome of Consultation**

14. Darlington's Carers' Strategy and Action Plan is developed and monitored by the CSSG taking into account the views of carer members of the group and the wider views of carers as relayed by the Carers Support providers.

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## Darlington Carers Strategy Group Carers Action Plan 2018 - 2020

Primary Theme	National Strategy Actions	Progress so far in Darlington	Action Points- to be explored and tasked to members of the group	By whom	Relevant Dates
1. Services and systems that work for carers	1.1 Carer Friendly GP Surgeries	1.1 Darlington Carer Support (DCS) and Young Carers (DYC) have identified link workers in all GP Surgeries, deliver regular presentations and build on the GP Carers Registers that are held by all surgeries. There are also notice boards/a carers corner in all surgeries.	1.1a. Attend 6 weekly West End Locality Partnership (WELP) Practice Manager meetings.	DCS and DYC	6 weekly
			1.1b. Attend the Annual Time Out session and include the Employers for Carers (EFC) information.	DCS,DYC	Annually
			1.1c. DAD, DYC, DCS to keep noticeboards up to date in surgeries.	DAD, DYC,DCS	Quarterly
			1.1d. All services to update Living Well Directory at least annually	All Strategy Group Members	Annually
	1.2 End of life care and bereavement support	1.2a. St Teresa's Hospice offers support to family/carers of anyone with a life limiting illness, through end of life care and following bereavement. This includes the provision of 1:1 support, support groups, complementary therapies and specialist support for children and young people.	1.2a St Teresa's Hospice to: <ul style="list-style-type: none"> <li>• seek funding for a social work and a social work assistant post.</li> <li>• pilot a "Time Out" workshop for carers, exploring such topics as self-care, communication styles &amp; relaxation techniques</li> <li>• offer a social event for carers at Christmas.</li> </ul>		

		<p>1.2b. Alzheimer's Society staff accessed qualification in end of life.</p> <p>1.2c. DYC offer targeted support and referrals to counselling services.</p> <p>1.2d. DCS offer 6 months support and counselling services</p> <p>1.2e DAD delivering end of life care training to direct payment employees and personal assistants</p> <p>1.2f Healthwatch report on bereavement and gaps left since end of course to be circulated</p>	<p>1.2b To identify other organisations' plans going forward.</p> <p>1.2c. Highlight gap in bereavement services and counselling across our networks.</p>	<p>ALL</p> <p>All Strategy Group Members</p> <p>Healthwatch</p>	<p>March 2019</p> <p>December 2018 and ongoing</p> <p>31.08.19</p>
	1.3 Armed Forces specialist support	1.3a. Veterans Society and Age UK North Yorkshire and Darlington (Age UK NYD) provide a Veterans Support Service for all veterans born before 1950. Also Help for Heroes.	<p>1.3a. Ongoing support and signposting for veterans through Age UK veterans project and Café.</p> <p>1.3b. DCS link with Triangle of Care and specialist provision at West Park.</p> <p>1.3c. Complete a scoping exercise of wider local and national agencies to access improved support.</p>	<p>Age UK Veterans Project</p> <p>DCS</p> <p>Strategy Group to agree way forward</p>	<p>Ongoing</p> <p>Ongoing</p> <p>June 2019</p>

	1.4. 2020 Dementia Challenge	1.4a. Dementia Friendly Darlington is working to ensure that Darlington is becoming increasingly dementia friendly. Some work has already taken place in the town centre and in Cockerton.	1.4a. Additional focused work in the town centre has been identified. This will include the delivery of Dementia Friends information sessions to businesses.	Members of Dementia Friendly Darlington	Ongoing
		1.4b. County Durham and Darlington NHS Foundation Trust (CDDFT) are working towards improving the environment for people with dementia and carers, staff training, audit and research to improve services.	1.4b. CDDFT part of Dementia Friendly Darlington with ongoing initiatives.	CDDFT to update	Ongoing
		1.4c Alzheimers Society has completed a consultation and identified gaps	1.4c Report to be circulated and next steps	Alzheimers Society	30.09.2019
	1.5. Carers training and learning opportunities	1.5a. A range of training and learning opportunities is already in place, including training provided by DAD; DCS training i.e. first aid, dementia, "Stress less and relax"; DYC healthy eating training; Darlington ARQ; Alzheimer's' CRISP training; Mind self- help course	1.5a. Review current training offer to assess if there is overlap. Focus on core facilitation where possible.	Strategy Group	Quarterly
			DAD latest newsletter on training to be circulated from Independent living hub  Link into Living Well Directory. Map out all training and look at joint sessions and bids	DAD	Done

			<p>1.5b. DAD to continue to circulate info on Skills 4 Care funding and Community Foundation funded courses to Carers.</p> <p>1.5c. Invite Martin Webster to a future meeting to link in and update on Local Offer.</p>	<p>DAD</p> <p>Lisa Holdsworth</p>	<p>Quarterly</p> <p>MW invited but did not respond</p>
	1.6. Improve Social Work practice	<p>1.6a. Sarah Gibbon from DBC operational staff attended an ADASS Regional Carers Network carers assessment workshop in August 2018 to explore good practice.</p> <p>1.6b. DBC carers assessment practice guidance has been drafted and issue is anticipated in January 2019.</p> <p>1.6c. DYC and DCS deliver regular Carer Awareness sessions to DBC staff. DCS agreed with Paige Thomason (Principal Social Worker) to be part of student social worker induction programme, to include work shadowing. Also feeding into Social Care team meetings.</p>	<p>1.6a. A document was produced following this meeting which will be taken to the ADASS Branch meeting for sign off.</p> <p>1.6b. Issue is now likely to be in February 2019</p> <p>1.6c. Continue to deliver joint training/ awareness raising to Social Care and other relevant teams</p>	<p>DBC</p> <p>DBC</p> <p>DCS</p>	<p>Ongoing</p> <p>Following review to update this As and when required</p>



	1.7.Continue to enable carers to access Carer Breaks	<p>1.7a. Carers are able to access carer breaks via a number of routes, including:</p> <ul style="list-style-type: none"> <li>• BCF carer breaks funding (via DAD, Darlington Mind, Age UK North Yorkshire and Darlington &amp; St Teresa's Hospice);</li> <li>• Personalised breaks via DCS, DYC as part of their carer support contracts</li> <li>• Carer breaks via DBC Adult Social Care if eligible needs are identified following a care and support needs assessment of the person who needs care and support and a carer's assessment of their carer.</li> </ul> <p>1.7b. DCS access funding for breaks from grant making bodies i.e. Carers Trust, Community Foundation etc.</p>	<p>1.7a. BCF carer breaks funding has been allocated annually. However, the BCF is currently under review. If the BCF continues to be available, the intention would be to maximise the availability of this or successor funding to support the provision of carer breaks.</p> <p>1.7b. DCS will continue to access funding from wider grant making bodies i.e. Carers Trust</p>	<p>DBC</p> <p>DCS</p>	<p>Following review to update this</p> <p>Sep-19</p>
	1.8 Mental Health Act 1983- Improve dignity and respect	<p>1.8a. Darlington Mind works closely with carers, service users and key agencies to promote dignity and respect within all of its service provision. We work with a range of stakeholders to ensure those who are subject to the provision of the Mental Health Act are provided with a range of support systems, advocates, support workers and services which meet their particular needs.</p>	<p>1.8a. Ongoing</p>	<p>Mind</p>	<p>Ongoing</p>

		1.8b. DCS attend Triangle of care meetings with TEWV to influence and develop Carer recognition with this	1.8b. DCS will continue to engage with the Triangle of Care agenda and liaise with TEWV to ensure a stronger pathway to access support.	DCS	Ongoing
	1.9. Consultations with Carers to find out if the services and systems work for them	1.9a. Healthwatch's role is to gather information to influence decision making eg Care Home research.  1.9b. Mind consult with Carers accessing their dementia service. 1.9c. DCS use feedback and consult to find solutions to problems with services. 1.9d. DYC consult on service provision twice a year.	1.9. Healthwatch review and report on CAMHs will be complete by Oct 19	Healthwatch Survey	Oct-19
2. Employment and financial wellbeing	2.1a. Employers for Carers (EfC) membership	2.1a.- EfC umbrella membership is available to DBC and Durham County Council staff, health organisations and SME employers across County Durham and Darlington  2.1b. DCS and DYC utilise the EfC resources as part of their current contract  2.1c. A carers page is available on the DBC intranet	2.1a. DBC to review EfC membership and scope out possibility of further funding. Lisa Holdsworth to access the statistics of usage to aid this.  2.1b. DCS and DYC continue the promotion of the EfC resources until March 2020.  2.1c To be reviewed and updated annually	Renewed Membership until March 2020  DCS & DYC  Lisa Holdsworth	Mar-20  Ongoing March 2020  Ongoing

		2.1d. DCS has access to regional employer support information.	2.1d. DCS to access the Gateshead Carers resources to support employers and employees across Darlington, also link to Carers Trust pilot in north east	DCS	Mar-19
		2.1e. DYC and DCS to explore funding to develop work with employers across DBC area	2.1e. DYC and DCS action.	DYC and DCS	Ongoing
	2.2 Job Centre partnership work	2.2a DCS, DYC, DAD all work with the local Job Centres including attending local events for Carers and delivering ongoing training and advice to Job Centre Staff.	2.2a. Work closely with CAB, Job centre plus and other relevant agencies to sign post carers and provide up to date information and benefit checks.	DYC, DCS, DAD	Sep-19
	2.3 Carer Passport, policies and best practice	2.3a. DfE locally pioneered an in-house Carer Support Network which is now national and seen as best practice. The Network had 102 members as at 20.11.18 and is also open to DBC staff.  DfE also have Civil Service Carer Passport and Carer Charter which is available to all staff. The wider Civil Service now adopted these.	2.3a. Use the DfE best practice resources to support Strategy Group Members to consider adopting Carer Passports in house and look at policies.	2.3a. All members of Strategy Group to consider this	Jun-19

		2.3b. DCS now has in house Carer Passport for all staff. Other members of the Strategy Group have flexible work practices. DCS also working on Carer Passport for businesses and link with discount card.	2.3b DCS developing discount card and carer passport for businesses locally	DCS	Ongoing
	2.4 Carers Rights Day and Carers Week.	2.4a.DCS coordinated Carers Week event 2018, all members of group held own events or worked in partnership in 2018. DCS held open office event for Carers Rights Day in partnership with NECA and CAB.	2.4a Strategy Group to work together on joint activities for both using a community access approach linking with employers, community groups and local events for 2019.	Strategy Group members	June and November 2019 and 2020
	2.5 Benefit and grant support	2.5a. DCS and DYC working with Job Centre to support those Carers claiming Carer benefits. Attending Carer events to promote the services and register new Carers. Delivering training to Job Centre staff regularly and attending monthly drop in with work coaches. DAD support Job Centre with Access to Work issues.  2.5b. CAB working with DCS on "Darlo Millions" project  2.5c. Age UK offer benefit support and advice.  2.5d DYC/Humankind - Basics Workstream, Maximising income and overcoming food poverty - Emma?	2.5a. Continue this work.  2.5b. Strategy group members to signpost to CAB  2.5c. Age UK project  2.5d Humankind?	DCS and DYC  Strategy Group members Age UK	ongoing  Ongoing  Sep-19

	2.6 Raising awareness with local employers	2.6a- Annual Carers Rights Day activities to highlight working Carers rights in press, newsletters and local events, see 2.4 above for actions  2.6b. Previous engagement with EE by DBC and DFE.	2.6a To consider a partnership approach to employers when delivering Dementia Friends training, to include carer awareness. DCS to include EfC toolkit when delivering training to GP surgeries.  2.6b. Scope out future engagement with local employers	Strategy Group to plan future employer engagement activities  Strategy Group	Sep-19  Jun-19
3. Supporting young carers	3.1 Schools work-identification	3.1. Deliver training through School Charter to schools to help with early identification of young carers. 21 Amber, 7 red - March 2019	DYC to continue to deliver training and promote the School Charter. 4 additional schools to achieve School Charter status	DYC	Ongoing December 2019
	3.2 Awareness raising	3.2a. Deliver training to other relevant agencies to help identify young carers and young adult carers.	3.2a Deliver 8 training sessions annually plus general awareness raising within other presentations. Provide update training as required	DYC	Ongoing
	3.3 Local authority-Education department	3.3. Ask Local authority education department what they are doing to achieve this goal	Contact Eleanor Marshall re Schools Link pilot.	DYC	Apr-19
	3.4 Target seldom heard and isolated young carers	3.4a. New young adult carers leaflet and awareness raising campaign to take place to raise referral rates into the service. 3.4b. Darlington ARQ working to identify and support LGBT Young Carers.	3.4a.Engage the Mental Health Leads Network  3.4bDeliver training to Darlington ARQ	DYC  DYC	Dec-18  Nov-18

05/11/2019

	3.5 NHS Young Carer Health Champion Programme	3.5. DYC exploring this but has no resources to do this so would need funding	Engage any of the free NHS Health Champion Events, plus look at a bid for funding a worker to target these areas.	DYC	Ongoing
	3.6 CAMHs referral pathway	3.6a. Darlington Mind receives referrals from a range of services, including from CAMHs but are not directly part of the CAMHs referral pathway. Weekend DCAFE – Self harm/young people with self-esteem issues Saturday/Sunday 11-2pm	3.6a. Engage with CAMHs Triangle of Care as this develops. Link with Victoria Wright	Darlington Mind	Ongoing
	3.7 Transitions from Young to Young Adult to Adult Carer	3.7a. Links with local colleges in place but need more resources to improve. Work ongoing between DYC, DCS and Horizons Young Adult Carers Service to support transitions. What are other agencies including local authority and NHS doing?	3.7a. Disseminate reviewed DYC marketing and deliver a regular drop in at Darlington College and one off events in other providers as necessary. Also continue with internal referral pathways.  3.7b. Review of DBC Young Carers Assessment and Young Carers Transition Assessment processes	DYC  DBC	Jan-19  Jul-19
4 Recognising and supporting carers in the wider community and society	4.1 Carer friendly communities	4.1a. Discount card in place which is well placed to build into a local Carer Community Passport, but more resources will be needed to develop this. However, carers are still not always recognised or referred for support	4.1a. As part of the discount card review we can consider re launching the card and building on it as a community passport. Possible link with economic regeneration and Town Centre Manager Marion Ogle to take this forward	Strategy Group to discuss and plan way forward	Sep-19

		4.1b However, carers are still not always recognised or referred for support.	4.1b All agencies to work in partnership to promote recognition and referrals	ALL	Ongoing
	4.2 Healthy Ageing led by Age UK	4.2a. Partners including AUKNYD are delivering services in line with core aims of the Healthy Ageing & Caring initiatives, including local access to support groups, respite opportunities including exercise and healthy eating, advocacy and information & advice which all contribute towards maintaining positive mental and physical wellbeing as we age.	4.2a. All agencies to work in partnership to strengthen referral and signposting links to facilitate awareness of services which support the Healthy Ageing Campaign, particularly around services beneficial to Carers.	JW to invite new worker to next meeting to contribute and update	30.08.2019
	4.3 Changing Places Toilets initiative	4.3. There are Changing Places toilets in the ground floor lobby at the Dolphin Centre and the Out Patients Department at Darlington Memorial Hospital.	Ensure that carers are aware of these.	Strategy Group members	Feb-19
	4.4 Loneliness Agenda	4.4a. All members of Strategy Group run projects, training, support groups and other events that work to prevent loneliness at present and intend to continue this work.	4.4a. Consider how to respond to the cross-government loneliness strategy which was published in October 2018	Strategy Group members	Mar-19
		4.4b. DBC Living Well Directory aims to bring all the information together locally on what is available.	4.4b. All groups to encourage use of the Living Well Directory to promote the Local Offer and utilise all available groups and resources to the maximum effect.	Strategy Group members	Ongoing
		4.4c. Healthwatch working on loneliness agenda - research via social media	4.4c Feedback from Healthwatch		

	4.5. Recognising and supporting hard to reach carers	4.5a. Work is ongoing to raise awareness of the needs of carers of people with dementia in the BAME and LGBT communities. This will also assist with raising the profile of all groups of carers in these communities.	4.5a. Contracts in place until 22.4.19; + 1 extension clauses available until 22.4.20	Alzheimer's Society and Aapna Services	Ongoing
		4.5b. DCS working with GP Practices to launch a support group for Bangladeshi community	4.5b. 1 <sup>st</sup> meeting has been arranged	DCS	Ongoing
		4.5c. AAPNA and Alzheimers Society work - need update.			
5. Building research and evidence to improve outcomes for carers	5.1a Find out what local research has been gathered i.e. DOH, Local Authority, DWP, Universities, Regional research	5.1a. Need to gather examples of local, regional and national research and evidence any recent research by local voluntary sector organisations i.e. Healthwatch, CAB ARQ have students working with them who would be keen to take on some research.	5.1a. Strategy Group to work together to discuss this and plan a way forward. Local research? Is there a local student that would like to do this as their dissertation?	Strategy Group	Jun-19
	5.1b. National Carers Survey	5.1b. Data available on National Carers Survey which compares results regionally	5.1b. Group to look at this and decide if any action is needed	Strategy Group	Oct-19
	5.1c. DCS Carers Survey	5.1c- Information on outcomes for Carers accessing DCS service could be used to inform strategy group plans	5.1c DCS Survey due in March2019. Results to be shared with group	DCS	Jun-19



## **ADULTS SCRUTINY COMMITTEE 11 FEBRUARY 2020**

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### **WORK PROGRAMME**

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#### **SUMMARY REPORT**

##### **Purpose of the Report**

1. To consider the work programme items scheduled to be considered by this Scrutiny Committee and to consider any additional areas which Members would like to suggest should be added to the previously approved work programme.

##### **Summary**

2. Members are requested to consider the attached draft work programme (**Appendix 1**) for the remainder of the Municipal Year, which has been prepared based on Officers recommendations and recommendations previously agreed by this Scrutiny Committee in the last Municipal Year.
3. Any additional areas of work which Members wish to add to the agreed work programme will require the completion of a Quad of Aims, in accordance with the previously approved procedure (**Appendix 2**).

##### **Recommendations**

4. It is recommended that Members note the current status of the Work Programme and consider any additional areas of work they would like to include.
5. Members' views are requested.

**Paul Wildsmith  
Managing Director**

##### **Background Papers**

No background papers were used in the preparation of this report.

Author: Paul Dalton

S17 Crime and Disorder	This report has no implications for Crime and Disorder
Health and Well Being	This report has no direct implications to the Health and Well Being of residents of Darlington.
Carbon Impact	There are no issues which this report needs to address.
Diversity	There are no issues relating to diversity which this report needs to address
Wards Affected	The impact of the report on any individual Ward is considered to be minimal.
Groups Affected	The impact of the report on any individual Group is considered to be minimal.
Budget and Policy Framework	This report does not represent a change to the budget and policy framework.
Key Decision	This is not a key decision.
Urgent Decision	This is not an urgent decision
One Darlington: Perfectly Placed	The report contributes to the Sustainable Community Strategy in a number of ways through the involvement of Members in contributing to the delivery of the eight outcomes.
Efficiency	The Work Programmes are integral to scrutinising and monitoring services efficiently (and effectively), however this report does not identify specific efficiency savings.
Impact on Looked After Children and Care Leavers	This report has no impact on Looked After Children or Care Leavers

## MAIN REPORT

### Information and Analysis

6. The format of the proposed work programme has been reviewed to enable Members of this Scrutiny Committee to provide a rigorous and informed challenge to the areas for discussion.
7. Each topic links to the outcomes and the conditions in the Sustainable Community Strategy – One Darlington: Perfectly Placed:-

#### **SCS Outcomes:**

- a) Children with the best start in life
- b) More businesses more jobs
- c) A safe and caring community
- d) More people caring for our environment
- e) More people active and involved
- f) Enough support for people when needed
- g) More people healthy and independent
- h) A place designed to thrive

#### **Three Conditions:**

- a) Build strong communities
- b) Grow the economy
- c) Spend every pound wisely

8. In addition, each topic links to performance indicators from the Performance Management Framework (PMF) to provide robust and accurate data for Members to use when considering topics and the work they wish to undertake. There are some topics where appropriate PMF indicators have not yet been identified however; these can be added as the work programme for each topic is developed.

### Forward Plan and Additional Items

9. Once the Work Programme has been agreed by this Scrutiny Committee, any Member seeking to add a new item to the work programme will need to complete a Quad of Aims.
10. A copy of the Forward Plan has been attached at **Appendix 3** for information.

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**ADULTS SCRUTINY COMMITTEE WORK PROGRAMME****2019/20**

<b>Topic</b>	<b>Timescale</b>	<b>Lead Officer</b>	<b>SCS Outcome</b>	<b>Darlington Conditions</b>	<b>Link to PMF (metrics)</b>	<b>Scrutiny's Role</b>
Dementia Task and Finish Review Group - Update	11 <sup>th</sup> February 2020	Christine Shields	More people healthy and independent  A safe and caring community  More people active and involved	Build strong communities		To receive an update on the previously agreed recommendations of the Dementia Task and Finish Review Group.
Support to Carers	11 <sup>th</sup> February 2020	Christine Shields	More people healthy and independent  Enough support for people when needed	Building strong communities		To look at the Carers Strategy and Implementation Plan 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.

<p>Community Equipment Service</p>	<p>11<sup>th</sup> February 2020</p> <p><b>Report deferred pending completion of service review.</b></p>	<p>Christine Shields</p>	<p>More people healthy and independent.</p> <p>More people active and involved</p>	<p>Spend every pound wisely</p>	<p>ASC 005 ASC 015</p>	<p>To monitor spend and review the operation of the contract following its award in 2015.</p> <p>Case studies</p>
<p>Adult Social Care Transformation Programme</p>	<p>31 March 2020</p>	<p>Christine Shields/ James Stroyan</p>	<p>A safe and caring community</p> <p>Enough support for people when needed</p>	<p>Building strong communities</p>		<p>Update on progress of all work streams</p>
<p>Performance Management and Regulation</p> <p>Regular performance reports to be programmed</p> <p>End of Year Performance (including Compliments, Comments and Complaints)</p>	<p>To be programmed.</p>	<p>James Stroyan/ Christine Shields</p>	<p>More people healthy and independent</p> <p>A safe and caring community</p> <p>Enough support for people when needed</p>	<p>Build strong communities</p> <p>Spend every pound wisely</p>	<p>Full PMF suite of indicators</p>	<p>To receive quarterly monitoring reports and undertake any further detailed work into particular outcomes if necessary.</p>

Deprivation of Liberty Safeguards (DoLS)/Mental Capacity Act	To be programmed.	James Stroyan	A safe and caring community  Enough support for people when needed	Build strong communities	ASC 063 ASC 064	To look at the outcomes and experiences of those who lack capacity and are subject to a DoLS and to look at how partners work together to ensure high quality services and outcomes.  Update on impact following new legislation
Quality Assessment – Annual Monitoring of local care homes for older people	September 2020	Christine Shields	Enough support for people when needed	Spend every pound wisely		To look at the outcome of the assessment and undertake any further work if necessary.

**Task and Finish Review Group(s)**

**‘Loneliness and Connected Communities’ Task and Finish Review Group** – commenced Tuesday, 28<sup>th</sup> January 2020;  
**‘CQC Ratings in the Borough of Darlington’ Task and Finish Review Group** (Health and Housing Scrutiny Committee lead with invitation to Chair and Vice Chair of Adults Scrutiny Committee to attend/participate) – commenced Monday, 18<sup>th</sup> November 2019.

**Additional Work:**

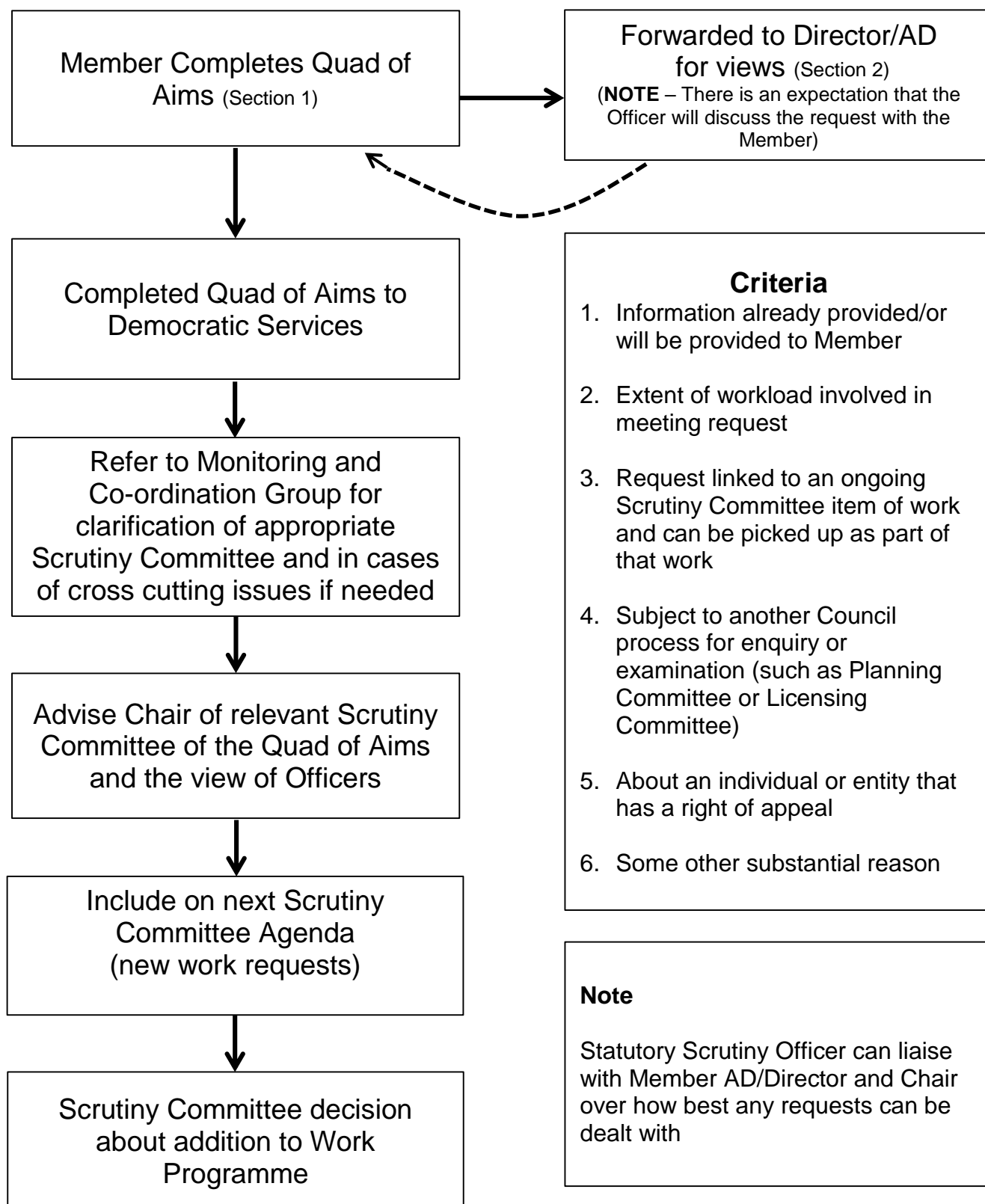
**Visits to Extra Care, Care and Nursing Homes** (Quality Assessment – Annual Monitoring of Local Care Homes for Older People):

- Ventress Hall Care Home, 22-28 Trinity Road, Darlington – 2pm, Wednesday, 15<sup>th</sup> January 2020;
- Rosemary Court, Blackton Grove, Darlington, DL1 4UB – 2pm, Wednesday, 29<sup>th</sup> January 2020;

- North Park Care Home, l'anson Street, Darlington, DL3 0SW – TBC
- Oak Lodge, Stockton Road, Haughton-le-Skerne, Darlington, DL1 2RY - TBC



## PROCESS FOR ADDING AN ITEM TO SCRUTINY COMMITTEE'S PREVIOUSLY APPROVED WORK PROGRAMME



# QUAD OF AIMS (MEMBERS' REQUEST FOR ITEM TO BE CONSIDERED BY SCRUTINY)

## SECTION 1 TO BE COMPLETED BY MEMBERS

**NOTE** – This document should only be completed if there is a clearly defined and significant outcome from any potential further work. This document should **not** be completed as a request for or understanding of information.

REASON FOR REQUEST?	RESOURCE (WHAT OFFICER SUPPORT WOULD YOU REQUIRE?)
PROCESS (HOW CAN SCRUTINY ACHIEVE THE ANTICIPATED OUTCOME?)	HOW WILL THE OUTCOME MAKE A DIFFERENCE?

Page 168

Signed Councillor .....

Date .....

**SECTION 2 TO BE COMPLETED BY DIRECTORS/ASSISTANT DIRECTORS**  
**(NOTE – There is an expectation that Officers will discuss the request with the Member)**

	Criteria
1. (a) Is the information available elsewhere? Yes ..... No ..... If yes, please indicate where the information can be found (attach if possible and return with this document to Democratic Services) .....	1. Information already provided/or will be provided to Member
(b) Have you already provided the information to the Member or will you shortly be doing so? .....	2. Extent of workload involved in meeting request
2. If the request is included in the Scrutiny Committee work programme what are the likely workload implications for you/your staff? .....	3. Request linked to an ongoing Scrutiny Committee item of work and can be picked up as part of that work
3. Can the request be included in an ongoing Scrutiny Committee item of work and picked up as part of that? .....	4. Subject to another Council process for enquiry or examination (such as Planning Committee or Licensing Committee)
4. Is there another Council process for enquiry or examination about the matter currently underway? .....	5. About an individual or entity that has a right of appeal
5. Has the individual or entity some other right of appeal? .....	6. Some other substantial reason
6. Is there any substantial reason (other than the above) why you feel it should not be included on the work programme? .....	

Page 169

**Signed** ..... **Position** ..... **Date** .....

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## DARLINGTON BOROUGH COUNCIL FORWARD PLAN

### APPENDIX 3

#### FORWARD PLAN FOR THE PERIOD: 1 JANUARY 2020 - 31 MAY 2020



#### **What is a Forward Plan?**

The Forward Plan is a list of all of the decisions, which are due to be taken by Cabinet. The Plan also includes all Key Decisions to be taken by Cabinet, a Member of the Cabinet or a designated Officer in accordance with the Local Authorities (Executive Arrangements) (Access to Information) (England) Regulation 2012. It also gives notice of the decisions that are likely to be taken in private. These decisions need to be published on the Forward Plan at least 28 clear days before the decision is to be taken. The Plan is updated on an ad hoc basis, but at least once a month. It can be accessed on the Council website [www.darlington.gov.uk](http://www.darlington.gov.uk).

#### **What is a Key Decision?**

A key decision in the Council's constitution is defined as to:

1. result in the Borough Council incurring expenditure which is, or the making of savings which are, significant having regard to the budget for the service or function to which the decision relates; or
2. be significant in terms of its effects on communities living or working in an area comprising one or more wards in the Borough.

#### **What are the reasons that a report can be held in private?**

Whilst the majority of the Executive decisions listed in this Forward Plan will be open to the public and media organisations to attend, there will inevitably be some decisions to be considered that contains, for example, confidential, commercially or personal information.

The Forward Plan is a formal notice under the Local Authorities (Executive Arrangements) (Meetings and Access to Information) (England) Regulations 2012 that some of the decisions listed in this Forward Plan will be held in private because the report will contain exempt information under Schedule 12A of the Local Government Act 1972 (set out below) and that the public interest in withholding the information outweighs the public interest in disclosing it.

1. Information relating to any individual
2. Information which is likely to reveal the identity of an individual
3. Information relating to the financial or business affairs of any particular person (including the authority holding that information)
4. Information relating to any consultations or negotiations, or contemplated consultations or negotiations, in connection with any labour relations matter arising between the authority or a Minister of the Crown and employees of, or office holders under the authority

## **DARLINGTON BOROUGH COUNCIL FORWARD PLAN**

5. Information in respect of which a claim to legal professional privilege could be maintained in legal proceedings
6. Information which reveals that the authority proposes:–
  - (a) to give under any enactment a notice under or by virtue of which requirements are imposed on a person; or
  - (b) to make an order or direction under any enactment
7. Information relating to any action taken or to be taken in connection with the prevention, investigation or prosecution of crime.

### **Who takes Key Decisions?**

Under the Council's constitution, key decisions are taken by Cabinet.

### **Are only Key Decisions listed in the Forward Plan?**

The Council only has a statutory obligation to publish key decisions and decisions that are to be heard at a private meeting, however, all decisions to be taken by Cabinet are included on the plan to give Scrutiny Committees and the public an early indication of decisions to be made.

### **What does the Forward Plan tell me?**

The Plan gives information about:

- What decisions are coming up
- What key decisions are coming up
- When those decisions are likely to be made
- Which decisions will be held in private
- Who will make those decisions
- The relevant Scrutiny Committee that the decision relates to
- What consultation will be undertaken
- Whether the decision will be an open or closed report (and the reason why) (public and press are not allowed to access closed reports and will not be able to stay in the Cabinet meeting when a closed report is being considered)
- Who you can contact for further information

### **How to make representations**

Members of the public have a right to make representations to the Council, including whether they think that any items we are proposing to consider in private should be dealt with in public. The Council will consider any representations before a decision is taken.

Anyone who wishes to make representations to the decision maker about a particular matter should do so in writing, at least a week before it is due to be considered, either by letter or email to Lynne Wood using the contact details set out below.

### **How and who do I contact?**

## DARLINGTON BOROUGH COUNCIL FORWARD PLAN

Each entry in the Plan indicates the names of all the relevant people to contact about that particular item.

For general information about the decision-making process and for copies of any documents outlined in the Forward Plan please contact Lynne Wood, Elections Manager, Democratic Services, Resources Group, Town Hall, Feethams, Darlington, DL1 5QT. Tel: 01325 405803. Email: [lynne.wood@darlington.gov.uk](mailto:lynne.wood@darlington.gov.uk).

<b>Title</b>	<b>Decision Maker and Date</b>	<b>Page</b>
Rail Heritage Quarter	Cabinet 7 Jan 2020	<b>Error! Bookmark not defined.</b>
Capital Works required at Crown Street Library	Cabinet 7 Jan 2020	<b>Error! Bookmark not defined.</b>
Capital Strategy and Capital Programme	Council 20 Feb 2020 Cabinet 7 Jan 2020	<b>Error! Bookmark not defined.</b>
Medium Term Financial Plan	Council 20 Feb 2020 Cabinet 7 Jan 2020	<b>Error! Bookmark not defined.</b>
Housing Revenue Account	Cabinet 7 Jan 2020	<b>Error! Bookmark not defined.</b>
Council Plan 2020/23	Council 20 Feb 2020 Cabinet 7 Jan 2020	<b>Error! Bookmark not defined.</b>
Permit System to Manage and Co-ordinate Roadworks	Cabinet 7 Jan 2020	<b>Error! Bookmark not defined.</b>
Schedule of Transactions	Cabinet 7 Jan 2020	<b>Error! Bookmark not defined.</b>
Darlington Crematorium Refurbishment - Update	Cabinet 7 Jan 2020	<b>Error! Bookmark not defined.</b>
Objection to Waiting Restrictions in Banks Road	Cabinet 3 Mar 2020	<b>Error! Bookmark not</b>

**DARLINGTON BOROUGH COUNCIL  
FORWARD PLAN**

		<b>defined.</b>
Calendar of Council and Committee Meetings 2020/21	Cabinet 4 Feb 2020	<b>Error! Bookmark not defined.</b>
Project Position Statement and Capital Programme Monitoring - Quarter 3	Cabinet 4 Feb 2020	<b>Error! Bookmark not defined.</b>
Revenue Budget Monitoring - Quarter 3	Cabinet 4 Feb 2020	<b>Error! Bookmark not defined.</b>
Schools Admissions 2021/22	Cabinet 4 Feb 2020	<b>Error! Bookmark not defined.</b>
Climate Change Cross Party Working Group	Cabinet 3 Mar 2020	<b>Error! Bookmark not defined.</b>
Darlington Station Improvements and Growth Zone	Cabinet 4 Feb 2020	<b>Error! Bookmark not defined.</b>
Darlington Borough Local Plan 2016/36 - Publication Draft	Council 20 Feb 2020 Cabinet 11 Feb 2020	<b>Error! Bookmark not defined.</b>
Medium Term Financial Plan	Council 20 Feb 2020 Cabinet 11 Feb 2020	<b>Error! Bookmark not defined.</b>
Housing Revenue Account	Council 20 Feb 2020 Cabinet 11 Feb 2020	<b>Error! Bookmark not defined.</b>
Capital Strategy and Capital Programme	Council 20 Feb 2020 Cabinet 11 Feb 2020	<b>Error! Bookmark not defined.</b>
Treasury Management Strategy and Prudential Indicators	Council 20 Feb 2020 Cabinet 11 Feb 2020	<b>Error! Bookmark not defined.</b>
Council Plan 2020/23	Council 26 Mar 2020 Cabinet 3 Mar 2020	<b>Error! Bookmark not defined.</b>
Local Transport Plan	Cabinet 3 Mar 2020	<b>Error!</b>



**DARLINGTON BOROUGH COUNCIL  
FORWARD PLAN**

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Education Services Capital Programme	Cabinet 3 Mar 2020	<b>Error! Bookmark not defined.</b>
Regulation of Investigatory Powers Act (RIPA) 2000	Cabinet 3 Mar 2020	<b>Error! Bookmark not defined.</b>
Agreed Syllabus for Religious Education	Cabinet 28 Apr 2020	<b>Error! Bookmark not defined.</b>

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