

Health & Wellbeing / People's Scrutiny

# Dementia Spotlight Review

20 March 2017

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# Preface

The impact dementia has on the lives of those who are living with the condition and their family is massive yet can be little understood outside the family. This light touch report is part of ongoing work to encourage more people to be aware of dementia and how it can change lives so radically.

There is some excellent work being carried out in Devon to provide support and spread awareness in the community. The County Council is well placed through its networks to help facilitate reaching all parts of Devon. As we all know one body cannot do this work alone but by drawing as many partners together such as memory cafes, dementia alliances and district authorities as examples of how support can be provided.

A key point we learnt from the evidence heard from our witnesses during this review was the importance health and wellbeing brings to our lives. If we want to improve the life expectancy for ourselves and our families, being [physically active](#) and taking part in social interaction can play a vital role.



**Councillor  
Sara Randall Johnson**

Sara Randall Johnson  
Chair

# Introduction

The following members — Councillors Sara Randall Johnson (Chair), Channon, Clarence, Squires, Wragg and Wright— would like to place on record its gratitude to the witnesses who contributed to the spotlight review. In submitting its recommendations, the Group has sought to ensure that its findings are supported with evidence and information to substantiate its proposals.

At the People's Scrutiny Adults' Standing Overview Group meeting on 28 September 2016 it was determined to undertake a detailed piece of work on dementia care jointly with Health & Wellbeing Scrutiny. The following terms of reference were agreed:

1. To review the progress on developing a Devon strategy for dementia – the dementia 10 point plan
2. To examine why Devon has more people in residential care with dementia than its statistical neighbour comparator group the County Council benchmarks against.
3. To identify the variety of initiatives being driven across the County to make cities, villages, towns and parishes more inclusive for people living with dementia and their carers.
4. To review the County Council's role encouraging partnership working between groups and organisations to build on existing support and reduce duplication.
5. To report back to the People's Scrutiny Committee on the findings of the review.

On 16 January 2017 the spotlight review on dementia was undertaken. Time and resources necessitate that this report provides a snapshot approach to further highlight issues relating to dementia in Devon. This brief report does not in any way pretend to be an exhaustive exploration of these issues.

# Recommendations

## Recommendation 1

That the County Council continues to roll out a programme of dementia awareness training, encouraging all members and staff to become [Dementia Friends](#). To ensure that front line staff, in particular, engage more sympathetically and with an increased level of understanding with those people with dementia.

## Recommendation 2

That a refresh of the mapping on the [Dementia Roadmap for Devon](#) website is undertaken to evaluate the level of community support for dementia across Devon and the work undertaken in the localities to ensure there is a consistency of provision across the County.

## Recommendation 3

That as a landlord, Devon Farm Estates Committee considers the finding of Plymouth University's recent research into the impact of dementia on the farming community and how it might affect the County Council's tenants.

## Recommendation 4

That learning from the memory cafes, [Dementia Friendly Communities](#) and Dementia Friends approach is extended to Learning Disability services.

# Summary

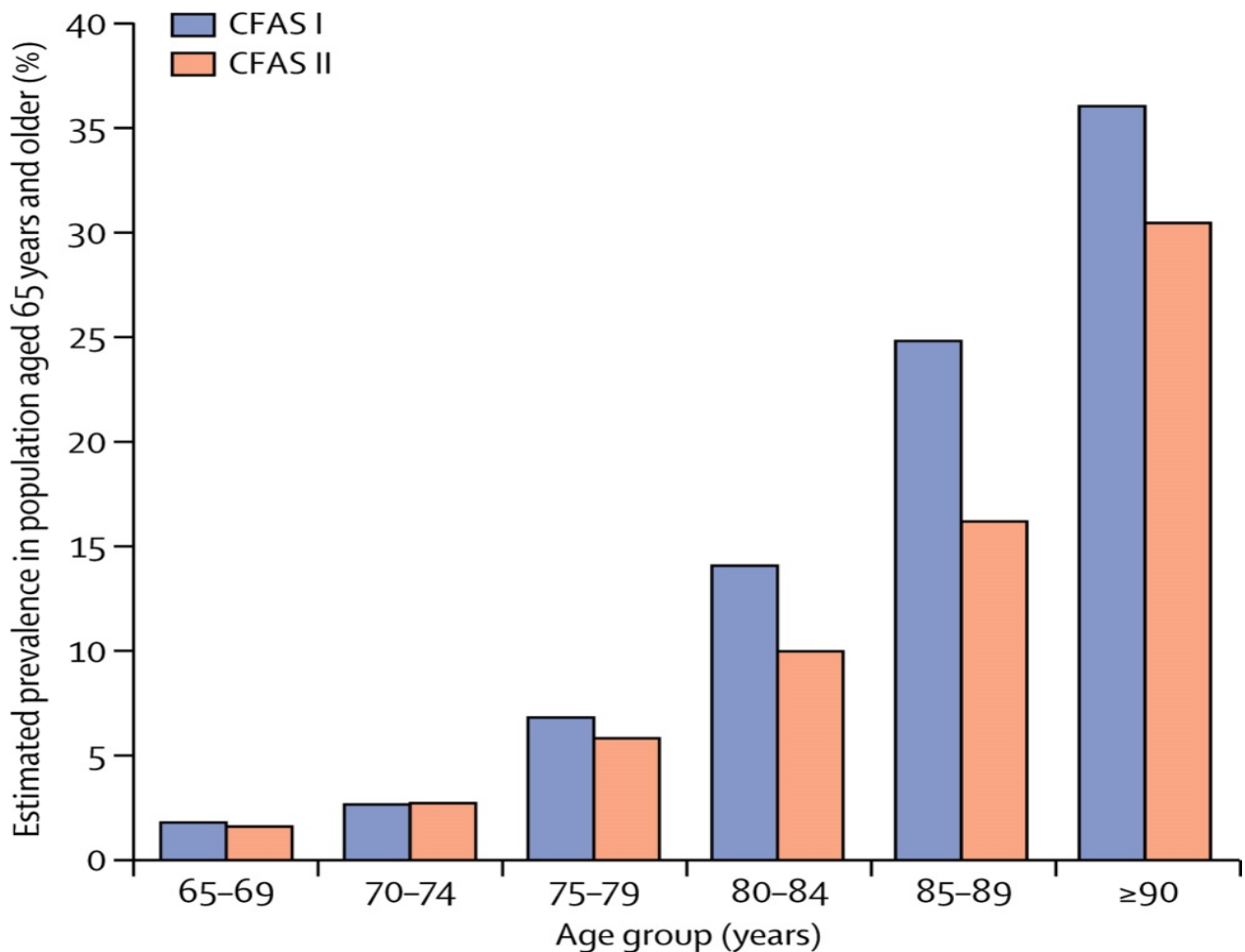
It is clear that there have been fantastic developments over the last decade in dementia awareness, diagnosis, care and carers support. Medical professionals have a much greater understanding and awareness of dementia when it presents and are better able to offer advice and signposting at an earlier stage. Community support in many areas of Devon is excellent. Memory cafes have been a huge success, being relatively cheap to set up and maintain, as long as there is a reliable source of volunteers – they provide good value.

However the County Council still needs to further work to support communities and external organisations promoting dementia friendly activities, recognising the many benefits and positive impact that various activities can have for people with dementia. One of the biggest challenges is ensuring that there is a consistency of provision across the County. The success of the work happening in towns such as Honiton is clear, but other communities need to be galvanised to do the same. Particularly given the impact of inward migration of older people and retirees to Devon and that this is not recognised fully in the County Council's funding arrangements.

Prevention through education is key to reducing demand for services in future. Greater dementia awareness and education is still needed amongst the general public, but also for County Council staff and members, particularly around the different types of dementia, and the possible contributory factors. The County Council needs to do more to demonstrate that Devon is dementia friendly, working in partnership with the district councils and the NHS.

# Overview

## UK Dementia Incidence Rate



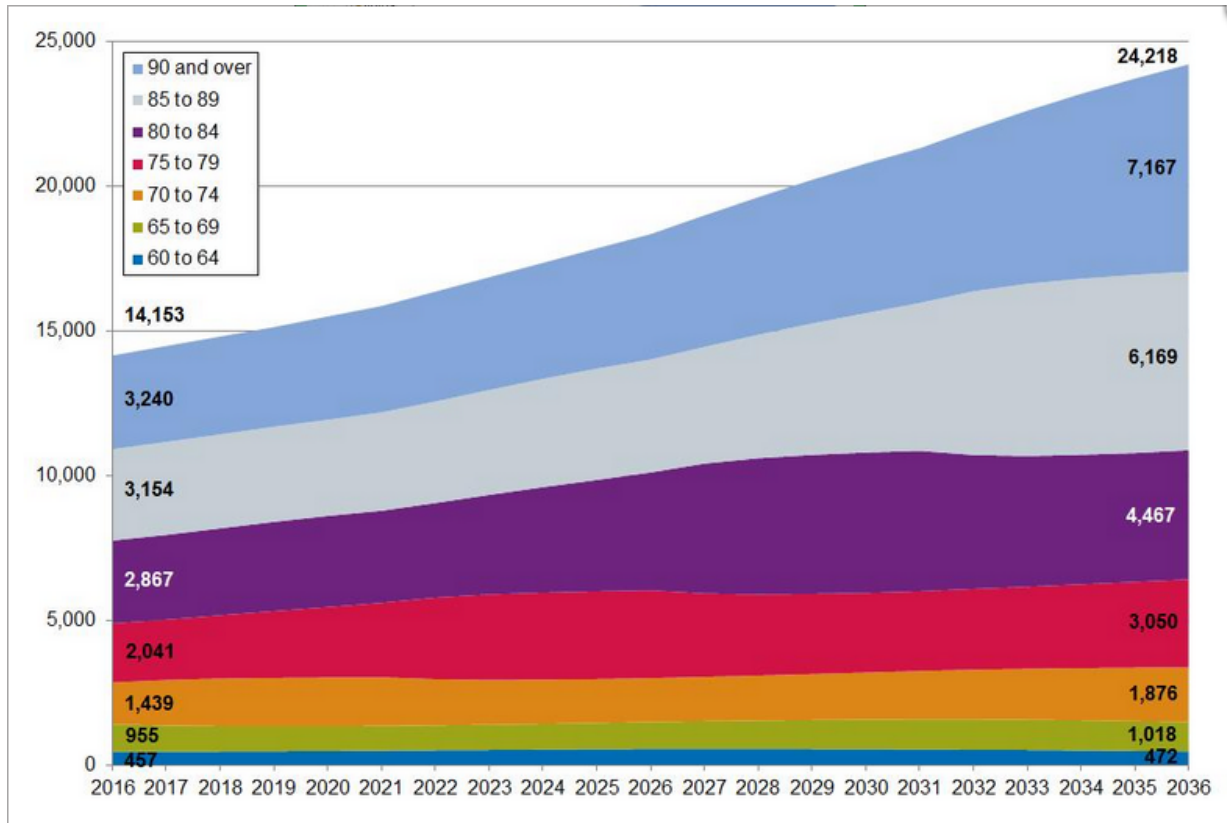
N.B. [The Cognitive Function and Ageing Studies \(CFAS\)](#) were population based studies investigating dementia and cognitive decline of individuals aged 65 years and over.

Alzheimer's Society figures indicate that there are currently more than [850,000](#) people living with dementia in the UK. This figure is predicted to rise to over 1,100,000 by 2025 and 2,000,000 by 2050.

In 2016, around 14,200 people living in Devon (1.83% of the population) were estimated to have dementia; this is set to increase to 24,200 (2.79%) by 2036. Unsurprisingly, parts of Devon with older populations have a higher prevalence of dementia. Data indicates that the incidence rate of dementia has decreased over time i.e. your individual chance of developing dementia is less today than in the past, however, as people live longer, the prevalence of dementia among the general population has and will continue to increase. Devon is below the national average but typical of its comparator group in terms of dementia prevalence; diagnosis rates have almost doubled in the last 10 years.

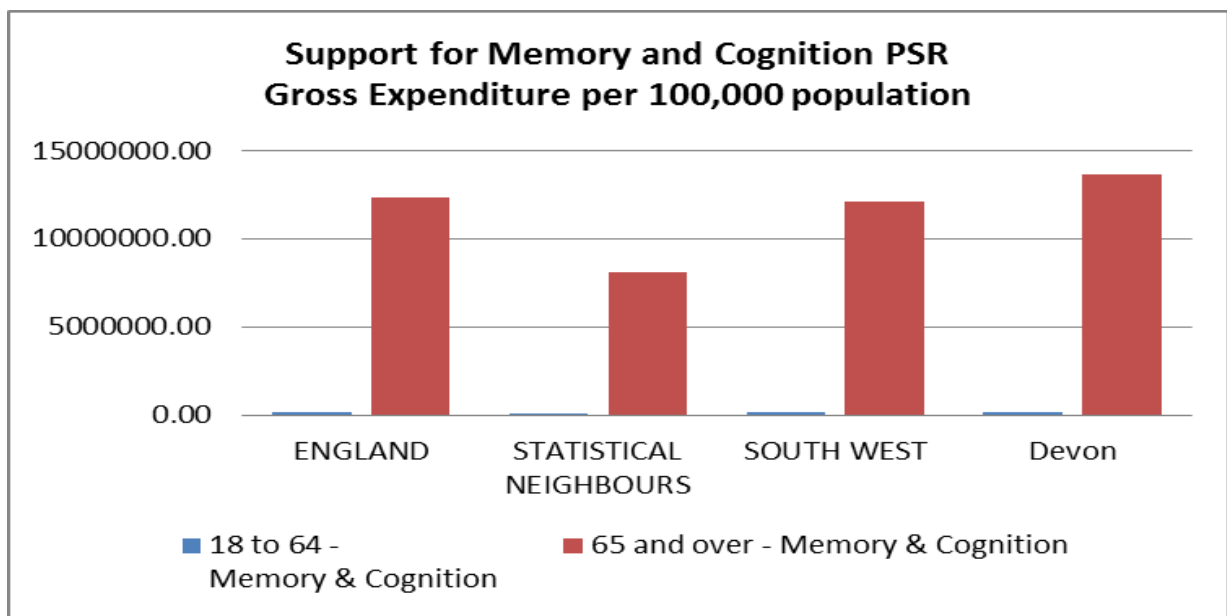
Dementia has different causes; Alzheimer's disease is the most common cause at 63%, vascular dementia at 17%, with other causes being much rarer; almost 50% of people with dementia in Devon have mixed dementia (both Alzheimer's disease and vascular dementia). It is estimated that based on the usual progression of the illness the current prevalence figures in Devon indicates approximately 55% of people with dementia to be at the mild stage, 32% moderate, 13% severe reflecting the gradual progression of the disease.

## Devon Dementia Prevalence Forecast



Devon spends more on dementia services and support than the England and South West average, and more than its statistical neighbour average; evidence shows that people in Devon go into residential care sooner than in other areas, so their stay tends to be longer. People with dementia are more likely to suffer from other health conditions; some such as urinary tract infections are avoidable, and when present can be an indicator of poor care.

## Comparative Spend On Dementia





# Key Issues

## Risk Factors

There are clear links between vascular dementia and lifestyle factors, but there is also evidence linking lifestyle to Alzheimer's. Many of the same behaviours which impact on physical health, such as smoking, alcohol consumption, physical activity and diet can affect an individual's chances of developing dementia. In Devon:

- Smoking rates are relatively low;
- Alcohol consumption is relatively high;
- People are on average quite active, but there is a significant group of people who are doing less than 30 minutes of activity a week;
- People are eating more healthily than in other parts of the country;
- The biggest risk factor by far is age; people are living longer and are physically healthy for longer, meaning dementia is more prevalent.

'Mid-life' is a key time in addressing lifestyle factors that can increase an individual's chance of developing dementia. The [NHS Healthcheck](#) programme provides information on dementia to those over 65, but lifestyle changes need to happen before this time. Keeping socially active and maintaining good mental health are key preventative factors. People do not always associate lifestyle factors such as physical activity and alcohol consumption with conditions like dementia – education around this is important ([Devon's One Small Step](#) healthy lifestyle service focuses on this). The NHS [One You](#) campaign targets people at 'mid-life', providing advice on how to make healthier lifestyle choices.

Plymouth University has recently carried out a yearlong research into the experience of dementia in agricultural communities, the impact on farmers, their families, the business and home lives. The study [Rural dementia – we need to talk](#) identifies four areas of concern; the farm environment; a reluctance to ask for help; support services and changing rural communities.

## Diagnosis

Nationally, the NHS is aiming to increase formal dementia diagnosis; early diagnosis can prevent crises and treatments can slow progression. GPs are today better trained to recognise the signs and offer support for those presenting with dementia, however some people will still not be able to acknowledge their disease or take up support/treatment. Diagnostic tests include ruling out other illnesses such as depression, thyroid function etc, family history is considered and MRI scans undertaken. Over the next 5 years the NHS ambition is to offer a consistent standard of care for patients newly diagnosed, supported by named clinicians or advisors, proper care plans developed in partnership with patients and families and options of personal budgets. In addition, the dementia challenge calls for a broader coalition between statutory services, communities and businesses.

## Communities

There is an increasing amount of community support available for those with dementia and their carers such as memory cafes and the Dementia Support Service. Patient post diagnosis experience is better than in the past. Provision however is inconsistent and capacity still needs to be built within communities, supported and enabled by the Council.

The Council has a key role in supporting communities to be safe, healthy and prosperous by delivering, commissioning and enabling a wide range of services including dementia support, as well as areas such as domestic abuse, hate crime and community cohesion. The challenge for the Council is how it supports communities in all these areas at a time when funding is reducing and demand often increasing. Rurality and isolation adds additional complexities. The Council is now taking on a greater enabling role, working with community groups to deliver these services and has seen some great success across the County.

Honiton Dementia Action Alliance brings together groups and organisations across the community committed to transforming the lives of people with dementia and their carers. Honiton Dementia Action Alliance was named by the Alzheimer's Society as the Dementia Friendly Rural Community of the year 2016.

## Memory Cafes

In 2016 the [Devon Memory Café Consortium \(DMCC\)](#) was formed, gaining charitable status (making it eligible for funding applications), to give oversight to all cafes; today there are 50 cafes across Devon, all run by volunteers and around half have so far joined the consortium. The DMCC works closely with the County Council and Devon Partnership NHS Trust to run dementia awareness courses and share information/data across the various cafes.

Honiton Memory Café formed in 2011, is run by volunteers, many of whom are those who have cared for people with dementia. Honiton Dementia Alliance is also looking at providing other services/activities to reach those with dementia who do not attend the memory café, but who may need help with activities such as shopping or visiting the hairdresser. A recent survey indicated that the three most popular activities were walking for leisure, eating out and visiting the cinema/theatre. In direct response to this survey a walking group has been established led by trained volunteers, and Devon Wildlife Trust are currently looking to contribute; a pub lunch group has also been set up and is attended regularly by around 30 people; work has been undertaken with Sidmouth Theatre, with regular visits arranged where specific seats are made available; and once a month a nostalgic cinema event is held, where films chosen by audience are shown in the Beehive Community Centre.

Free dementia awareness sessions have been delivered at the library, where members of the public have proven to be keen to learn. Sessions have also been delivered to local firms of solicitors, supermarkets, banks, chemists and a the local bowls club; those who sign up to the Honiton Dementia Alliance receive a sticker to display in their window, showing that they are dementia trained. The memory café works closely with the youth groups including the scouts and girl guides; sixth formers from the local college volunteer at the café. County councillor locality budget funding has been used to produce various literature, including an awareness leaflet included with the local paper, and a guidance booklet for customer facing workers, as well as using social media. Memory cafes and other dementia support groups such as singing groups, also benefit hugely from small scale fund raising and donations, which can make a big difference to the lives of those who use these groups.

## Dementia 10 Point Plan

The County Council and NEW Devon CCG's joint Dementia 10 Point Plan has been developed to provide assurance and to evidence the impact and improvements in the experience of people with dementia and their carers in Devon; it centres around:

- Reducing Risk – lifestyle changes, keeping healthy, particularly help to combat vascular dementia.
- Diagnosing well - diagnosis rate in Devon today is around 60%, in contrast with 40% in 2011.
- Informing, supporting and navigating – Alzheimer's Society currently provide post diagnosis support for the County Council and a contract for a new service will commence July 2017.
- Meaningful activity – inclusion and enablement.
- Person centred care – living well at home.
- Carers – support/respite.
- Hospital & care homes – dementia friendly.
- Housing and telecare – specially designed or adapted.
- Workforce – informed and trained.
- End of life care – support to plan for this time.

## The Carer's Journey

A carer shared his experience of being a carer for someone with dementia, and the changes in service provision and attitudes towards the condition he has seen since his wife first began to display symptoms in 2004:

- Despite seeking expert medical attention in 2004 the carer and his wife first noticed a change in her behaviour, they did not receive a diagnosis for two and half years; at this time diagnosis involved monitoring changes over six month periods, as well as MRI scans and ultrasounds.
- The diagnosis was delivered by six medical professionals, across a table, and the advice offered was to 'ask the mental health nurse for some tips on your way out'; the experience was bewildering for both of them, and they left feeling on their own.
- The carer was pleased to report that experiences of diagnosis are very different today, that GPs and other professionals are much better informed, more empathetic, able to provide reminiscence reading material and signposting to dementia specialist or friendly day care and home care services, as well as support for carers; post diagnosis follow up care is much improved.
- In the past hospitals have struggled to deal with patients with dementia due to lack of training and understanding; they had a poor experience back in 2008, but had recently visited the RD&E in Exeter and had a much more positive experience, where staff were better informed.

The carer identified some areas which he feels could be improved further including:

- Specific support for carers, which recognise that this need changes over time in line with the development of the cared for person's condition; key point - 'a carer is not a volunteer'.
- Recognising the range of support that a carer may need, including practical help in the home to undertake new roles, the provision of safety information, being able to maintain social contact, keeping themselves healthy and well and knowing when to ask for help; carers also need support when the person they are caring for goes into full time care, this can be a difficult time when they can feel a range of emotions including relief, guilt, loneliness.
- Support for those with dementia to stay within their own community, which can be a particular issue for rural families who can particularly feel isolated from services and social contact.
- Greater research is needed; link between different forms of dementia and lifestyle factors needs to be understood; the carer and his wife have taken part in a number of research programmes and encourage others with dementia and their carers to do the same.
- Day and respite care is still lacking in many areas, and transport to services is also wanting.
- Private dementia care is very expensive, particularly when this is needed on a long term basis.

## Exeter City Council

Exeter City Council (ECC) published on its [2 March 2017](#) People Scrutiny Committee agenda a Dementia Friendly Council review. The final report of the task & finish group includes 15 recommendations aimed at highlighting ECC's role as a member of the Exeter Dementia Action Alliance and the steps it is taking towards becoming a dementia friendly organisation, ensuring that the services offered strive to reflect the needs of individuals.

The recommendations to ECC's Executive include:

- a) Encourage organisations such as the Alzheimer's Society, memory cafés and Age Concern to apply for allotments for use by those with dementia.
- b) Outlines the work of this Task and Finish Group, in a press and social media release, highlighting that the Council can offer appointments later in the day, upon request.
- c) Establishes what information sharing there is already between Council departments in respect of vulnerable individuals, such as those with dementia and investigate the process for recording and sharing new information.
- d) Continues to support dementia friendly staff training across the Council, encouraging staff to become Dementia Champions.
- e) Looks into providing different modules of more in depth training for officers who work directly with members of the public.
- f) Explores dementia training as a compulsory requirement before a Hackney carriage/Private Hire driver's licence is granted.
- g) Ensures that dementia friendly engagement is reflected and considered in the social inclusivity dimension of evaluating procurements.
- h) Requires trained front line staff in particular to wear dementia friendly badges and a forget-me-not sign to be placed in a prominent place in the Customer Service Centre.
- i) Investigate the viability of providing a second toilet and/or carry out improvements to the existing toilet (including access) in the Customer Service Centre subject to costings and available resources.
- j) Provides clearer signposting for the toilet in the Customer Service Centre subject to costings and available resources.
- k) Provides a higher level of dementia awareness training for security staff.
- l) Investigates the potential for dementia friendly red coat tours.
- m) Ensures that information concerning dementia friendly activities is available at the tourist information centre.
- n) Encourages such organisations as the Devon Wildlife Trust and Active Exeter to adopt a dementia friendly approach in the provision of activities.
- o) Consider whether a similar review of other front line services within the Council should be undertaken at this stage and if so, to prioritise the order for review.

## Site Visits

Councillors Sara Randall Johnson (Chair) and Rob Hannaford (Vice-Chair) of the People's Scrutiny Committee accompanied by Richard White, Social Care Commissioning - Sector Lead, undertook site visits to 3 care homes on 29 November 2016. The following issues were raised by the care home managers / noted by members:

### Mapleton Community Care Home, Ashburton Road, Newton Abbot

- The County Council worked with Stirling University to create the Devon Centres for Dementia concept and to develop refurbishment projects at Mapleton and Woodland Vale in Torrington. In addition to excellence in ergonomic design many innovative technologies have been employed in the design of these homes to try to give the best outcomes to the people who live there, promoting their continued wellbeing.
- This design principal has also maintained a practical approach in providing an environment that is safe and efficient to work within. Best practice in the use of colour, light and space has been integral to the design. The Stirling concept advocates sub dividing accommodation into smaller suites each with its own front door and communal facilities serving a number of bedrooms. This model of care of living in small units/suites is designed to be less institutional and much more akin to a domestic setting with people doing the washing-up, baking, laundry as they might in their own homes.
- Predominantly the care home has people under a duty of County Council care aged between late 60s- 90s. The average length of stay at Mapleton is just under 2 years.
- Almost all of the residents receive regular visitors. It would however be hugely beneficial to have enduring volunteer arrangements.
- Mapleton does not have any contact with dementia groups in the area, despite Newton Abbot being a dementia friendly town.
- A lot depends on how isolated a person becomes within a community as to the level of crisis they are in and the need for them to enter a care home

### Private Care Home 1

- Most of the older people in the home have dementia. Only 2/3 of the residents have some level of capacity. The frailty of the adults in the home has significantly increased in the last 3 years. Care homes are now similar to what used to be thought of as a nursing home with the average stay being less than 2 years. Those older people entering the home now are that much more vulnerable, often at a point of crisis and as a result are a challenging group. There is a need to look much earlier at individual's pathways.
- Market sufficiency and keeping care to budget are difficult to manage.
- It is not possible to do a full activities programme at the moment given the lack of clients.
- There are issues with the waiting time on client reassessments.
- Commissioners are also looking to put together a trusted provider model for assessments. The priority always has to be that people are getting the best possible care outcomes.
- The need to take a longer term view on extra care housing.

## **Private Care Home 2**

- One of the struggles is 24/7 care too late, where people are at home with an inadequate care package until they reach crisis point with a fall for instance and then are moved into care. The elderly care system relies on equally elderly carers looking after husbands/wives. There is something of a disconnect between, expectations, scrutiny and inspection.
- The key factors are quality and price. There is a pressure with the minimum wage.
- The most vulnerable group are the over 80s. It is a challenge moving forward to deal with the increasing number of frail older people. Devon has an aging population, with people living longer with complex needs – that is the key issue. People will not be coming into care homes for longer periods now - that time has gone. Instead there is a heavy reliance on families.
- The development / planning of new towns needs to take into account care for the elderly.

## Contributors

The spotlight review received evidence on **16 January 2017** from the following:

Witness	Position	Organisation
Damian Furniss	Senior Manager - Performance, Policy and Involvement	Devon County Council
Tina Henry	Health Improvement & Policy Lead	Devon County Council
Simon Kitchen	Head of Communities	Devon County Council
Jenny Richards	Joint Commissioning Manager for Older people's mental health and dementia	Devon County Council / NEW Devon CCG
A	Carer	
David Light	Trustee	Devon Memory Café Consortium
Heather Penwarden	Chairman	Honiton Dementia Action Alliance Steering Group
Melinda Pogue-Jackson	Policy Officer	Exeter City Council
Anne-Marie Hawley	Scrutiny Programme Office	Exeter City Council
Solveig Sansom	Senior Manager – Strategic Commissioning Older People	Devon County Council

## Bibliography

- [Dementia Carers Pathways](#)
- [Dementia Friendly Communities](#)
- [Dementia Friendly Council Task and Finish Group Report, People Scrutiny Committee, Exeter City Council \(2017\)](#)
- [Dementia Task Group Report, Health & Wellbeing Scrutiny \(2012\)](#)
- [Guide for Councillors: Transforming the quality of life for people with dementia in the community](#)
- [Our Dementia, Our Rights](#)
- [Reducing your risk of dementia](#)
- [Rural dementia – we need to talk](#)

Copies of this report may be obtained from the Democratic Services & Scrutiny Secretariat at County Hall, Topsham Road, Exeter, Devon, EX2 4QD or by ringing 01392 382232. It will be available also on the County Council's website at:

[http://www.devon.gov.uk/index/councildemocracy/decision\\_making/scrutiny/taskgroups.htm](http://www.devon.gov.uk/index/councildemocracy/decision_making/scrutiny/taskgroups.htm)

If you have any questions or wish to talk to anyone about this report then please contact:

Dan Looker

01392 382232/ [dan.looker@devon.gov.uk](mailto:dan.looker@devon.gov.uk)