WM directors of adass adult social services
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NHS England
West Midlands Strategic
Clinical Network

WEST MIDLANDS DEMENTIA POST DIAGNOSIS SUPPORT SERVICES

EVENT REPORT

> “Books on prescription dementia collection available from the local library. Especially Pictures to Share books are helping my mother in law to relax and remember and they are a great resource to use when we’re not sure what to talk about.”

> “Not knowing much about Alzheimer’s and its progression I find it difficult to know if we are at the correct stage to ask for help.”

> “Day care for my husband suffering from double incontinence. Just one day a month would help
> No one will give personal care.
> I am completely cut off from society.”

CONTENTS

FOREWORD

- By 2015 there will be 850,000 people with dementia in the UK(1).
- There are 40,000 younger people with dementia in the UK.
- There are 25,000 people with dementia from black and minority ethnic groups in the UK.
- There will be 1 million people with dementia in the UK by 2025.
- Two thirds of people with dementia are women.
- The proportion of people with dementia doubles for every five-year age group.
- One in six people aged 80 and over have dementia.
- 60,000 deaths a year are directly attributable to dementia.
- Delaying the onset of dementia by five years would reduce deaths directly attributable to dementia by 30,000 a year.
- The financial cost of dementia to the UK is £26 billion per annum.
- There are 670,000 carers of people with dementia in the UK.
- Family carers of people with dementia save the UK £11 billion a year.
- 80 per cent of people living in care homes have a form of dementia or severe memory problems.

Statistics such as this show the urgency and need for improvements in both timely diagnosis and post diagnostic support services for people diagnosed with dementia in England.

They underpinned the recent project run jointly by the West Midlands Strategic Clinical Network (WMSCN), ADASS (Association of Adult Directors of Social Services) and IEWM (Improvement and Efficiency West Midlands) to scope post diagnostic dementia services across the West Midlands region, to find out what is working and where, to try to understand the experiences of the people using those services and to share innovative models of care that make a difference to the lives of people diagnosed with dementia, their carers and their families.

This report highlights the key findings from our survey results, the outcomes from the regional Post Diagnostic Support Event held in October 2015, and provides information on a number of innovative models used by commissioners and providers in the West Midlands for those diagnosed with dementia.

THE NATIONAL PICTURE

One in three people over the age of 65 will develop dementia. There are 835,000 people in the UK diagnosed with dementia, with over 700,000 of this number in England*(2) Dementia is a progressive condition but people can live with it for 7-12 years after diagnosis if it is diagnosed early enough.

The Prime Minister's Challenge on Dementia of 2012 set out an ambition that by March 2015 two thirds of people estimated with dementia in England should have a diagnosis of dementia and access to appropriate post diagnostic support and care.(3) Recent initiatives have seen the diagnosis rate in England rise from 46% in 2012 to the latest figure of 67.2% in January 2016.

The prevalence of dementia is expected to double in the next 30 years, but dementia doesn't just impact on the person who has it, it also impacts on their partners, carers and families, and sometimes employers, so it is vital that effective, high quality services are also available to cope with this increasing need following diagnosis.

WHAT IS POST DIAGNOSTIC SUPPORT?

Post diagnostic support (PDS) covers a range of services and information available to help those diagnosed with dementia and their carers, both immediately after diagnosis and onwards. It must be on-going and flexible to adapt to the changing needs of the person, carer and family as the disease progresses. For many carers, and for those with Young Onset Dementia, this can also include employer awareness and support.

PDS includes many different options in many different settings – in primary care, in memory assessment services, in the community and is provided by many different agencies within the NHS, Local Authorities, charities and voluntary agencies. It includes things such as signposting to up to date and locally available services, medication and medication reviews, carer support, cognitive stimulation therapy, dementia friendly communities and so on – whatever helps those diagnosed with dementia and their carers to live as well as possible for as long as possible with their condition.

However experiences show that there is wide variation across the West Midlands in the type and availability of post diagnostic support available to those needing it, and many have difficulty both finding and accessing support.

> “The GP advised us to put her in a care home as she was old.”

> “[on diagnosis] they basically said ‘go home and get on with it’. There was no support whatsoever nor from the GP. It was very distressing for my Father who was the main carer and had no understanding of the problems or what might have been available in the way of support.”

WHY IS PDS IMPORTANT?

Good quality, accessible and effective PDS is key to enabling those living with dementia and their carers to live well with the condition for as long as possible.

The NHS Citizen Assembly took place on 25th November with ‘Support for people with dementia post diagnosis’ being selected by citizens as 1 of 5 NHS England top priorities for discussion with citizens raising the following priorities; timely diagnosis, personalised care plans, access to support services for those with dementia and their carers and a need for greater awareness and understanding to help people understand and recognise the symptoms of dementia and to get rid of the stigma around dementia.

However there is also a growing evidence base for the clinical and cost effectiveness of this support which includes interventions such as cognitive stimulation therapy, carer support interventions, peer support and START programme of psychological support for carers of people with dementia (STrAtegies for RelaTives START) for example.

THE LOCAL PICTURE

The dementia diagnosis rates across the West Midlands also continue to rise, with an average of 65.9% in January 2016. However there remains considerable variation in diagnosis rates across the region and considerable variation in appropriate, available and accessible PDS services.

There are a number of reasons for variation, including poor understanding by clinicians of current services, where they are and how to access them, lack of commissioned services and the gap between health provided services and social care, and third sector services. There are many examples of excellent work regionally but this often happens in isolation and is not shared across disciplines, agencies or regions leading to a 'post code lottery' for those diagnosed with dementia and their carers.

The West Midlands Strategic Clinical Network (WMSCN), Association of Directors of Adult Social Services (ADASS) and the Improvement and Efficiency West Midlands (IEWM) ran a series of surveys during April to June 2015 for commissioners of services, providers of services and the users of those services, and their carers, to try and understand what PDS services currently exist in the region and where improvements might be made (Additional surveys for those with dementia and their carers were collected in August to September 2015). The results of those surveys formed the basis of acknowledge and information sharing event held on 14th October 2015 to highlight areas of innovation, both regionally and nationally around PDS, that are being provided.

WEST MIDLANDS REGION

COVERED BY WM SCN AND ADASS

DEMENTIA POST DIAGNOSTIC SUPPORT SURVEYS

The project scope looked at PDS from point of diagnosis and the support currently available to people diagnosed with dementia and their carers wherever they were in the West Midlands. We wanted to try and identify what was working well, where there were gaps in services, how people found out about available services – where they were, what they were, how to access them, what their experiences were of using them, and so on.

Initial information gathering was done by an on-line survey (Survey Monkey) for each Clinical Commissioning Group and for each Local Authority across the West Midlands, with three different surveys from three different perspectives:

- Commissioners of health and social care, and wider wellbeing services that impact dementia.
- Groups of people with dementia and their carers, including representative groups e.g. local Alzheimer's Societies. The survey questions were compiled with the input of patient representatives.
- Providers who routinely signpost people with dementia and their carers to services e.g. Memory Assessment Clinics, Advice and Support services.

Further information on the survey questions can be found at http://www.wmscnsenate.nhs.uk/strategic-clinical-networks/our-network/mental-health-dementia-and-neurological-conditions/current-projects/dementia1/

SURVEY RESULTS

NUMBER OF RESPONSES

Commissioners Survey	Providers Survey	Public Survey
• 29 responses (6 incomplete) • All 14 LA areas covered • 15 out of 18 CCG areas covered	• 136 responses (93 incomplete) • All 14 LA areas covered though 1 only has incomplete survey • Type of organisation: 36% NHS, 8% LA, 31% third sector, 13% independent sector, 11% don't know	• 143 responses (62 incomplete) • 13 out of 14 LA areas covered • 11.1% were people with dementia, 88.9% carers of people with dementia • Timespan since diagnosis: • < 1 year: 15% • 1-3 years: 36% • 3-10 years: 45% • > 10 years: 4%

GOOD NEWS STORIES

- 79% of respondents to the public survey (those with dementia and carers of people with dementia) said the diagnosis of dementia was communicated sensitively.
- 92% of people with dementia feel safe and supported to live in their own home.

> **"Vascular dementia…Consultant handled very well, fully informed assistance."**

- Commissioners reported that all (LA) areas have a support pathway for people with dementia and their carers.
- Commissioners reported that in all but 4 out of the 14 (LA) areas routinely given a named dementia advisor/navigator with this being in the process of being implemented by nearly all of the others.

> **"People tell us they have really benefited from having the links to a dementia advisor, someone they can go back to again and again for advice and support."**

- 85% of providers who responded to the survey believe the Care Act safeguarding requirements are understood and implemented.
- Respondents to the public survey valued the impact of services, including the value of dementia advisors:

> “Books on Prescription Dementia collection available from the local library. Especially Pictures to Share books are helping my mother in law to relax and remember and they are a great resource to use when we’re not sure what to talk about.”

> “My wife has Alzheimer’s and vascular dementia, our GP has been very good with both myself and my wife and we are very pleased with the outreach nurse assistance.”

> “We have received excellent help from the Alzheimers Society and Age UK. The Dementia Cafes are also extremely helpful.”

KEY MESSAGES FROM THE SURVEYS

GENERAL

- **Lack of awareness around what is commissioned and provided** – all commissioners have a support pathway for people with dementia, but only 55% of providers said they had and 28% didn’t know. The link between services making referrals and signposting was recognised as being particularly crucial in these pathways

> “We often come across people that have never heard of us, when everyone is supposed to be told at time of diagnosis, so either it is not happening or they are forgetting.”

> “Strong links between the memory clinics, consultant and assessing clinicians has produced a good pathway.”

- **Impact of co-morbidities on people diagnosed with dementia and also their carers** – 91% of those diagnosed with dementia had at least one additional long term health problem and 33% of carers did (mobility and breathing problems the most common). However only about a third of these respondents felt that services were designed around them and their needs – the impact of this will be accentuated if a person has co-morbidities.

- **Issues around early diagnosis** – the majority of respondents felt that their diagnosis of dementia had been made early but at the same time many had battled for years to have a diagnosis made.

> **“My GP twice advised against referral to the memory service because he said there was no cure and no point in knowing. The third year I asked he acceded.”**

- **Transport is a significant barrier to accessing services**. Commissioners identified transport as a barrier, and providers in 4 out of 10 (LA) areas identified transport as a gap in service provision.

> **“Transport is always an issue for people accessing our services.”**

INFORMATION AND SIGNPOSTING

- **Signposting and information provision is the biggest barrier to people accessing services** - For commissioners and providers the biggest barriers to people accessing services are that people with dementia and their carers struggle to find out about services and that referral opportunities are missed due to lack of awareness amongst professionals. ‘The right services don’t exist’ (Cognitive Stimulation Therapy services particularly) and ‘the right services exist but lack capacity’ were also very important.
- **Issues around the timing of information provision and signposting** in that commissioners of services generally believe that services are available any time post diagnosis, but provider and public experience is that information provision was concentrated around the time of diagnosis.

> **“I was provided with a pile of documents and booklets after diagnosis. I did not read them, alas they were just too much at one time and too early. I have had nothing since.”**

> **“Sometimes they have the information they need at the time but then don’t come back for support until they are really desperate, as often people don’t like to be thought of as not being able to manage.”**

- **GPs and memory services not signposting as effectively as envisaged**. Commissioners felt that GPs and memory services were the most important signposters to services. However although providers and the public agreed these were important, they felt that the third sector and the Council were the most important, and commented on lack of information and signposting to services.

> “It is hard to find key people… who are willing to learn about new services…GPs do not return calls. Memory clinics are too busy to learn about new services”

- **Dementia advisors** – access is more restricted than envisaged. In 10 LA areas commissioners said that patients diagnosed with dementia were routinely given a dementia advisor, but only 36% of provider responders stated that was the case despite the value that is clearly ascribed to dementia advisors. Only 20% of respondents with dementia had been supported by a dementia advisor and 38% of carers.

> “People tell us they have really benefitted from having the links to a Dementia advisor, someone they can go back to again and again for advice and support.”

> “Dementia advisors are provided but have limited capacity.”

UPTAKE OF SERVICES FOR THOSE DIAGNOSED WITH DEMENTIA

- **Services underutilised**. Low uptake in medication support (0%), self care (10%), counselling (10%), opportunity to get involved in research (10%) and independent advocacy (10%) - yet most of these services are commissioned in all or nearly all (LA) areas commissioning them.
- **Most accessed services**. Memory support services (60%), respite/ replacement care services (40%), and peer support/ dementia cafés (40%).
- **Untapped potential to be involved in dementia research**. Although 43% of responders felt they could contribute to dementia research, only 12% had.

UPTAKE OF SERVICES FOR CARERS OF THOSE DIAGNOSED WITH DEMENTIA

- **Services commissioned and under/ not utilised**. Low level uptake of respite/ replacement care services (12%), Independent advocacy (13%), opportunity to get involved in dementia research (13%), support from a dementia telephone line (17%) and Counselling (21%). Yet all but one commission respite/ replacement care services and advocacy services.
- **Most accessed services for those caring for people with dementia** were information and guidance on dementia (73%), local information pack or information prescription (52%).

CARE ACT AND BETTER CARE FUND AWARENESS

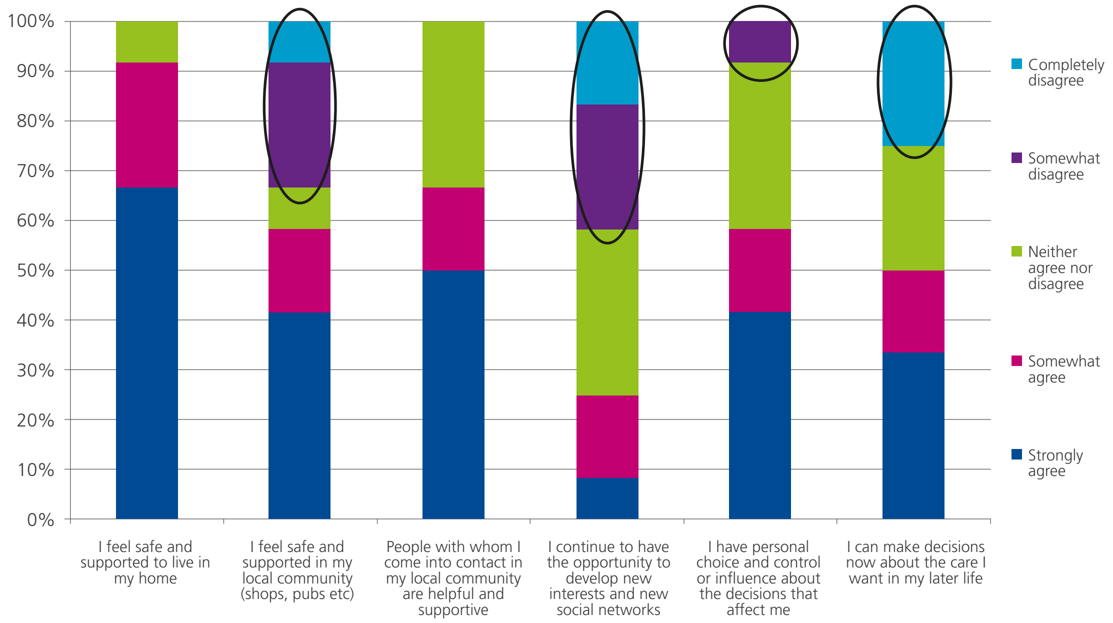
- The majority of areas understand and have implemented requirements from the Care Act around safeguarding and advocacy, but only a minority in relation to the wellbeing principle, preventative services and the duty to integrate health and social care services.
- Just over 50% of areas have Better Care Fund metrics that relate to dementia. There are a range of metrics – number of referrals to memory service, diagnosis rates, memory assessment clinic waiting times, acute admissions relating to dementia, admissions to long-term care, prescribing of anti-psychotic medication, carers signposted to educational resources, number of people attending dementia training, delayed transfers of care, reablement improvement.

Further information on survey results can be found on the West Midlands Strategic Clinical Network website – http://www.wmscnsenate.nhs.uk/strategic-clinical-networks/our-network/mental-health-dementia-and-neurological-conditions/current-projects/dementia1/

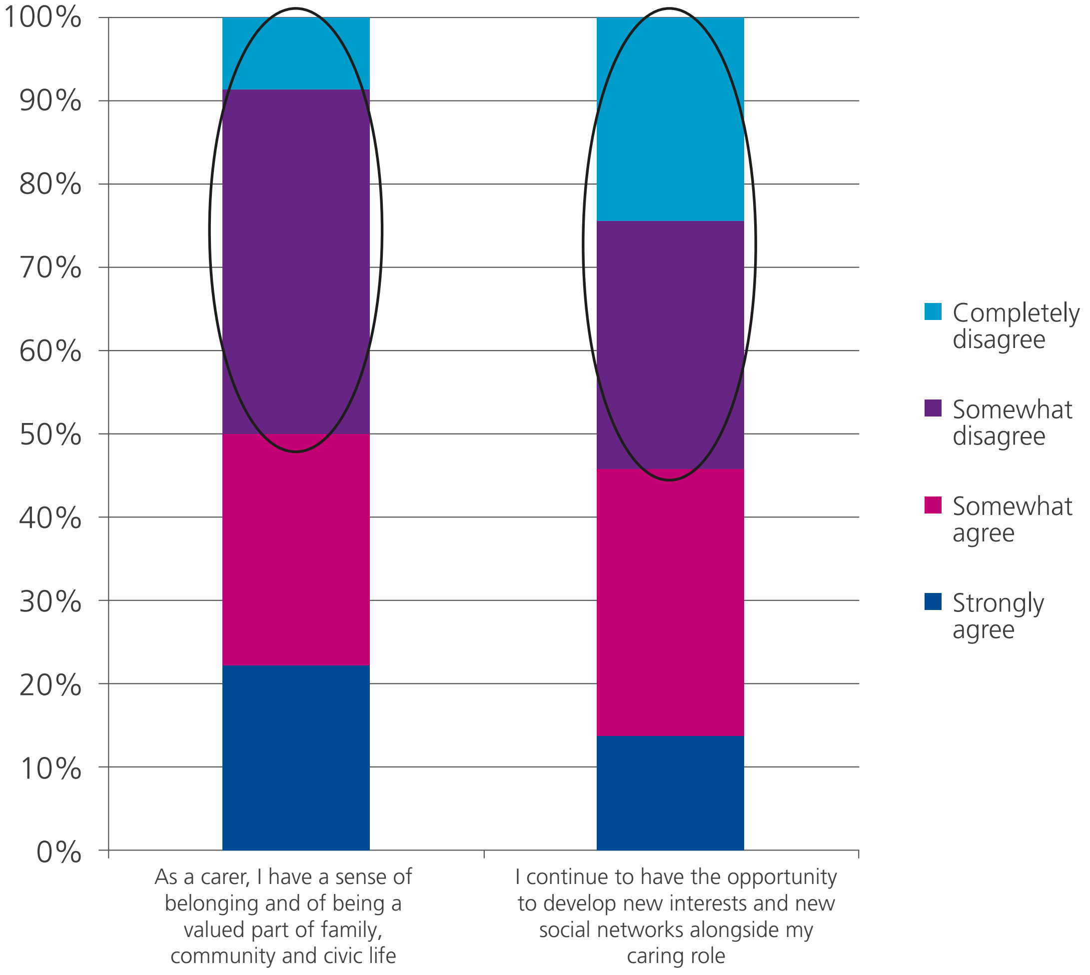
The high level mapping of dementia PDS services overview can be found in Appendix 1.

* Survey results are statistically invalid due to low number of responses however still represent the experiences of the individuals concerned.

OUTCOMES FOR PEOPLE WITH DEMENTIA – AREAS FOR CONCERN



OUTCOMES FOR CARERS OF PEOPLE WITH DEMENTIA – AREAS FOR CONCERN



> “Day care for my husband suffering with double incontinence just one day a month would help. No one will give personal care. I am completely cut off from society.”

> “My Father would have benefitted from a specialist male dementia support person such as an Admiral nurse…He found it difficult to talk to anyone except me about the problems he was having because of the dementia affecting my mother.”

CELEBRATING AND LEARNING EVENT 14TH OCTOBER 2015

Over 100 commissioners, providers and people with dementia and their carers attended the full day event. The purpose of the day was to share learning in dementia PDS across health and social care to:

- Understand the experiences of those diagnosed with dementia and their carers around PDS services;
- Identify common themes and practical solutions;
- Learn about new service models from across the region;
- Share best practice;
- Opportunity for discussion, question & answer sessions and networking;
- Listen to national experts, including Professor Alistair Burns, National Clinical Lead for Dementia, and Ewan King, Social Care institute for Excellence.

PANEL DISCUSSIONS

In the afternoon there were panel discussions around key issues identified from the survey. The panels consisted of around 5 people from the West Midlands or beyond, commissioners, providers and those with dementia and carers, who from their experience were able to provide interesting experience on the issue in question. Following an initial introduction by each of the panel members on the issue in question, free format questions were invited from the floor.

PANEL 1 – CREATING A RETURN ON INVESTMENT FOR DEMENTIA SERVICES

The 2015 West Midlands dementia post diagnostic support survey identified that the biggest barriers to people accessing services are perceived by commissioners and providers to be around the quality of information provision and signposting to appropriate services and support. In addition lack of capacity across all services is impacting on the availability of support that is able to be provided, allowing people’s situation a free rein to deteriorate to crisis point where intervention becomes much more costly.

As commissioners how can we argue the case for more investment in pre-crisis dementia support, and in particular in improved information and signposting? How do we prioritise investment across dementia post diagnostic support services, and where can we better make use of existing community capacity to complement this investment?

Key points from Panel 1 discussion

- ‘Necessity is the mother of invention’ – starting up community groups where there are gaps in services. Loneliness and isolation are a big issue.
- Personal Assistants Model - 12 week support to achieve ‘good journey in dementia’ for those newly diagnosed.
- Dementia Centres of Excellence: Eden model of care to improve quality of life – through creating flexible, creative model will keep people in homes for longer and is a real community asset.
- Lighthouse – learn about dementia early on, and open up hospital to community so they learn how to make people’s homes easier to live in when they have dementia.
- Dementia Gateway – Used dementia advisors to upskill others. Mapped what is available in wider community. Telecare to prevent admissions and achieve timely discharge. Getting better at asking only once.
- Social return on investment (ROI). Recent research showing big social ROI. How do you persuade different parts of health economy to invest? Agewell done ROI for Falls Prevention – not that complicated, though acknowledged falls is easier than dementia.
- We still have block contracts for same services – we are still ignoring personalisation. Need West Midlands movement for personalisation, particularly in dementia services.
- Better Care Fund to address pre-crisis for dementia. Using integrated carers support service, identify carers at risk, and put in support packages – some evidence of impact. But difficult with families under stress about proving they would otherwise have ended up in hospital, easier about staying at home.
- Can we learn from other successful pathways e.g. diabetes, learning disabilities, and need to make mainstream.
- Potentially use key milestones, like in LD, to identify short term outcomes and identify solutions around milestones.
- Need to make sure focus on quality, integration and personalisation of services, not just cost, otherwise it won’t work.
- How do you fund lead in time for new services – need funding, local funding very helpful, where not part of national organisations. Micro-providers need also to be able to take risks, and need to create West Midlands insurance policy for micro-providers.

Panel 1 – Resources

Walsall – Personal Assistance Model

Dudley Dementia Gateway

Sandwell – Lighthouse community resource

Worcestershire – Admiral Nurses

PANEL 2 – LINKS IN TO PRIMARY CARE FOR DEMENTIA SERVICES

The 2015 West Midlands dementia post diagnostic support survey identified that whilst GPs were a very important signposter to advice and support, at diagnosis and soon after diagnosis and on follow up appointments, often this did not happen.

How can we make sure that everyone diagnosed with dementia accesses appropriate advice and support through their interactions with their GPs, throughout the progression of their dementia. Can Advanced Care Planning and regular health and medication reviews help achieve this? How can we make the link through from primary care into good advice and support more seamless care?

Key points from Panel 2 discussion

- Lots of good practice around Primary care diagnosis, not a clear pathway for all patients. Pathways shouldn't depend on post code, could it be clearer? Why reinvent the wheel?
- GP or community diagnosis (Coventry and Shropshire examples) has reduced waiting times for patients and carers.
- More education for GPs
- Pooled budgets and joint commissioning for Social Care and Health Care to avoid patients going down one path or the other. Stoke on Trent have a multi-disciplinary model that is jointly commissioned.
- Could the region adopt the iSpace project and develop dementia friendly GP practices?
- GPs and Community Care to manage long term conditions as well as dementia to avoid multiple appointments

> **My wife was diagnosed with Alzheimers. The lack of self esteem and confidence felt by my wife difficult to cope with. However on good days her lovely sense of humour shines through."**

> **"Alzheimer's local group a great support and help - friendship speakers confidentiality laughter tears all compassionate and the ability to share ones confusion and unhappiness that has changed and frightened a married unison."**

Panel 2 Resources

Walsall – Integrated mental health teams

Shropshire – Integrated residential and domiciliary provision

Stoke on Trent – Dementia Primary Care Liaison Service

Telford and Wrekin – Use of Admiral Nursing in a primary care perspective

Wessex Academic Health Science Network – iSPACE Dementia Friendly Practices

Herefordshire – Primary care facing specialist dementia nurse model

PANEL 3 – INTEGRATING DEMENTIA PATHWAYS WITH OTHER HEALTH CONDITIONS

91% of people with dementia who responded to the 2015 West Midlands dementia post diagnostic support survey, had at least one additional long term health problem. A significant minority, 33% of carers, also had at least one long term health problem. Mobility and stamina and breathing difficulties were the biggest impacts for both people with dementia and their carers.

How can our dementia pathways better recognise that people with dementia are almost certain to have other long term health problems? How can we integrate care and support for dementia better with care for other long term health problems? How can our support for carers better recognise that they may well have long term health problems as well?

Key points from Panel 3 discussions

- Shropshire - Doing local dementia roadmap, not national. Over 20 in the country. Dementia leadership training in Shropshire Partners in Care (SPIC) to create passion around dementia.
- Coventry Discharge 2 Assess – combined care in home with OT and support from family and carers. Includes dementia locksmith – trained dementia worker to unlock person with dementia and what makes them tick. Been going 9 months. Very cost effective - costs half of a residential placement. 68% stay at home.
- Solihull – Working with particularly care homes with high hospital admissions, Integrated community teams, invested in team to work across system included enhanced assessment team. Everything being done is about looking at how to make person-centred. Much more to do.
- Worcestershire – Early Intervention Dementia Service (EIDS). Help people to live as well as possible, taking people through assessment and diagnosis which treat as life-changing news rather than medical stage.

Panel 3 Resources

Worcestershire – Early Intervention Dementia Service can be found at the West Midlands Strategic Clinical Network website at http://www.wmscnsenate.nhs.uk/home/

Or at http://www.worcester.ac.uk/documents/Evaluation_Report_EIDS_Executive_Summary.pdf

Social Care Institute of Excellence (SCIE) also has examples of innovative models which can be found at http://www.scie.org.uk/

PANEL 4 – CREATING A SUSTAINABLE DEMENTIA ADVISOR SERVICE AND CARER SUPPORT

The 2015 West Midlands dementia post diagnostic support survey identified dementia advisors/ navigators as being a very valued service. People value having someone they can go back to again and again for advice and support. However with funding constraints, our survey indicated that only a minority have accessed a dementia advisor, and there were comments around their increasing caseloads and limited capacity. The survey also identified that three quarters of carers have accessed information and guidance but very few have used a dementia advisor, and the take-up of services to support the carer is very low.

What is an appropriately sized dementia advisor service? How can we make best use of the voluntary sector, community resources and other dementia support services such as Admiral Nurses to extend the reach of dementia advisors? Since our survey indicated that carers were much bigger consumers of information and guidance, should dementia advisor models have a greater focus on carers? Can dementia advisors help carers access services, and improve their outcomes, and provide better opportunities for them to develop interests and social networks?

Key points from Panel 4 discussion

- SCIE. Run Dementia Gateway focused on carers, paid mostly but also family. All resources co-produced. Integration for dementia is implicit.
- Agewell, Sandwell. Dementia should be seen as a long term condition. Partner with Better Understanding of Dementia in Sandwell (BUDS) to ask for help where need specialist dementia expertise. Looking to develop young onset dementia and early diagnosis, driven by those with dementia.
- Dementia is not part of basic nurse training currently! Needs to be addressed urgently. University of Worcester providing dementia input into nursing conference today, which is starting to address this. HEE about to publish framework setting out what people at different levels should know about dementia, which is also a start. Coventry funding Admiral Nurse from next year who will help to educate student nurses.

- Dementia wards in Sandwell – Partner with Better Understanding of Dementia in Sandwell (BUDS) supporting these. In Solihull moved away from having separate wards.

Panel 4 Resources

Shropshire – Community groups, and service user perspective/ Care and Share

Sandwell – Better Understanding of Dementia in Sandwell (BUDS)

Wolverhampton – Dementia Action Alliance

Information and documents about PDS services and models are continually added to the WM SCN website –

http://www.wmscnsenate.nhs.uk/strategic-clinical-networks/our-network/mental-health-dementia-and-neurological-conditions/current-projects/dementia1/

APPENDIX 1

HIGH LEVEL MAPPING OF DEMENTIA SERVICES ACROSS THE WEST MIDLANDS – OVERVIEW

This information is taken from the results of the commissioner survey run in June 2015 and may not be representative of the views or experiences of people diagnosed with dementia and their carers who may have used them.

- All Clinical Commissioning Groups (CCG) / Local Authority (LA) areas have a support pathway for people diagnosed with dementia and their carers, although not all areas could say that these were available for the public to view.
- Local dementia services are mostly identified to people with a diagnosis of dementia and their carers through discussions with their GP, discussions with the Memory Assessment Service, the voluntary sector or by council/ LA. Half of the geographical area covered used locally tailored information packs or information prescriptions.
- All areas commissioned or provided the following services that could be accessed by people with a diagnosis of dementia, either at diagnosis or at any time following diagnosis:
  - Specialist dementia advisor – non clinical
  - Memory support services
  - Dementia cafés/ peer support
  - Assistive technology
  - Medication support
  - Training in managing dementia (self care)
  - Fall prevention services
  - Independent advocacy
  - Respite/ replacement care services

  Some, though not all, commissioned specialist dementia nurses, signing for the brain, counselling and provided information on how to get involved in dementia research.

  The same services were also available for those caring for people diagnosed with dementia for most of the CCG/ LA areas in the West Midlands.
- Services not currently commissioned/ provided that CCGs/ LAs feel could improve outcomes for people diagnosed with dementia include:
  - Post diagnostic counselling
  - Early onset dementia

  - Continence services for people diagnosed with dementia
  - Cognitive stimulation therapy (CST)
  - Cognitive behavioural therapy (CBT)
  - Mobile night care

  Services not currently commissioned/ provided that CCGs/ LAs feel could improve the outcomes for carers of people diagnosed with dementia include:

  - Pre and post diagnostic counselling
  - Availability of bedded respite that can be accessed at short notice
  - Peer support phone service

- The majority of CCGs/ LAs routinely give people diagnosed with dementia a named dementia advisor, the majority of these were classed as 'special dementia advisor – non clinical'. Three areas did not provide dementia advisors or nurses.
- The majority of CCGs/ LAs commissioned or provided services supporting those with Young Onset Dementia, young carers, people living in residential or care homes, people with learning disabilities (LD) and those from black and ethnic minorities populations (BME).

  Services not currently commissioned that CCGs/ LAs feel may help to improve outcomes for people diagnosed with dementia and their carers who may have special needs are:

  - Specific support for those caring for those with LD and dementia
  - Increased young onset dementia services
  - Support for those with rarer dementias
  - Nurse led service to go in to care homes to diagnose people with dementia

- CCG/ LA commissioners and providers felt that the two biggest barriers to people diagnosed with dementia accessing services available to them were:

  1. lack of awareness by dementia sufferers, their families and carers of available services
  2. lack of awareness by health professionals of services, leading to missed referral opportunities

  Other issues included that health and social care staff struggled to find out about services, lack of services and/ or lack of capacity in services were also factors that created barriers.

- All LAs understand the implications of the Care Act and the majority have implemented the requirements. A minority understand the implications but, at the time of the survey, had not yet implemented the recommendations.

  - Wellbeing principle
  - Preventative services so that people retain/ regain skills and confidence and deterioration is delayed

  - Safeguarding
  - Advocacy
  - Duty to integrate health and social care services
- Half of LAs have metrics around dementia as part of the Better Care Fund, with others planning to include some in the future
- All areas engaged with the Alzheimer's Society to engage with the public around dementia, those diagnosed with dementia and their carers. Age UK and Dementia Action Alliance were also involved in all but one geographical area. Other organisations involved were Healthwatch, CCG patient groups or representatives, GP practice patient participation groups and Dementia UK.

Further information on the surveys and survey results can be found on the WM SCN website.

ORGANISATION WEBSITES

ADASS (Association of Adult Social Services)

http://www.adass.org.uk/home/

IEWM (Improvement & Efficiency West Midlands)

http://www.westmidlandsiep.gov.uk/

SCIE (Social Care Institute for Excellence)

http://www.scie.org.uk/

WMSCN (West Midlands Strategic Clinical Network)

http://www.wmscnsenate.nhs.uk/home/

WMSCN Dementia Resources

http://www.wmscnsenate.nhs.uk/strategic-clinical-networks/our-network/mental-health-dementia-and-neurological-conditions/current-projects/dementia1/

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