

Why Dementia: 2015 and Beyond Conference Report

4th February 2015

The Cambridge Belfry Hotel, Cambourne

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Chair of Mid Essex CCG**

and

**Dr Sunil Gupta, Dementia Ambassador for Midlands and East Region
and Member of the Governing Body of Castle Point and Rochford CCG.**

**Hosted by the East of England Strategic Clinical Network for Mental Health,
Dementia, Neurology, Learning Disability and Autism**

Contents

Introduction	page 3
Speakers	page 4
Key Themes and Discussion	page 7
Next Steps	page 7
Appendix A: Delegates	page 8
Appendix B: Delegate Responses	page 8
Appendix C: Summary of the Evaluation Forms	page 11
Reference List	page 16

Introduction

The East of England Strategic Clinical Network (SCN) for Mental Health, Dementia and Neurological Conditions works to enable and facilitate whole system improvements and patient outcomes, supporting, influencing and working alongside commissioners and other stakeholders.

Strategic work is required to understand the current rates of diagnosis and consider the reasons behind variation and different levels of diagnosis. This will also provide the opportunity to consider the benefits and lessons from increased awareness and increased numbers of people becoming known to services, inform planning processes, supportive actions and tools, and enable service and quality improvements.

Service users and representative groups consistently confirm that post diagnostic support remains the biggest gap in service provision, and therefore the biggest opportunity for improvement and the SCN is actively engaged with all stakeholders to support and enable improvement for people with dementia in the East of England.

Improving dementia services is a positive commissioning story, but further work is required on the tools, approaches, and support that are necessary to fulfil the potential within dementia commissioning, and provide service users with the confidence that they will be able to live well with dementia.

The main body supported by the SCN in dementia is the Strategic Dementia Advisory Group for the East of England (SDAG). This provides a fully integrated and expert body for advice, transformation and dialogue between partners in dementia care across the region.

Our priorities for 2014-2016 are dementia diagnosis rates and post-diagnostic support.

We are committed to proactive and effective co-production of our work, in collaboration with service users, carers and their representatives.

The SCN hosted this conference “Why dementia:2015 and beyond” to continue to support the system across the East of England to achieve the dementia diagnosis ambition and to encourage the delegates to look beyond the diagnosis rate to look at new and innovative models in memory assessment and post diagnostic support.

Speakers

Professor Alistair Burns – National Clinical Director for Dementia

Why diagnose dementia in primary care?

Professor Burns gave a very interactive and inspirational presentation on the national dementia work. The three key parts to the Prime Ministers Challenge on Dementiaⁱ were improvements in health and care, Raising awareness and better research. Dementia research funding has increased by 50% since 2010/11 and now 4.5% of people with dementia are involved in research, up from 1% although more work still needs to be doneⁱⁱ. Delegates were encouraged to become dementia friendsⁱⁱⁱ and to continue to use the national focus on dementia to raise awareness locally.

Professor Burns was keen for the audience to understand that although there is significant focus on achieving the national 67% dementia diagnosis rate we must not forget about the provision of good post-diagnostic support. Delegates were sign posted to key documents from the Alzheimer's Society^{iv and v} and Royal College of General Practitioners Road Map^{vi} for further information.

Delegates were encouraged to ask questions through the presentation. Questions raised included; Are GPs able to make the diagnosis of dementia? The answer was a clear yes, for certain patients and only if the GP felt comfortable in making the diagnosis. Delegates were sign posted to the Dementia Primer^{vii} and Pragmatic Resource for GPs.^{viii} In order to facilitate timely diagnosis and support for people within care homes the delegates were sign posted to Diagnosing dementia in care homes – why, and how to, do it^{ix}.

A series of “I” statements have been developed by people with dementia which the delegates were interested in;

- **I was diagnosed in a timely way**
- **I know what I can do to help myself and who else can help me**
- **Those around me are well supported and are in good health**
- **I get the treatment and support, which are best for my dementia, and my life**
- **I feel included as part of society**
- **I understand so I make good decisions and provide for future decision making**
- **I am treated with dignity and respect**
- **I am confident my end of life wishes will be respected. I can expect a good death.**
- **I know how to participate in research**

Susie Peachey – NHS IQ

Dementia assessment and diagnosis – the options

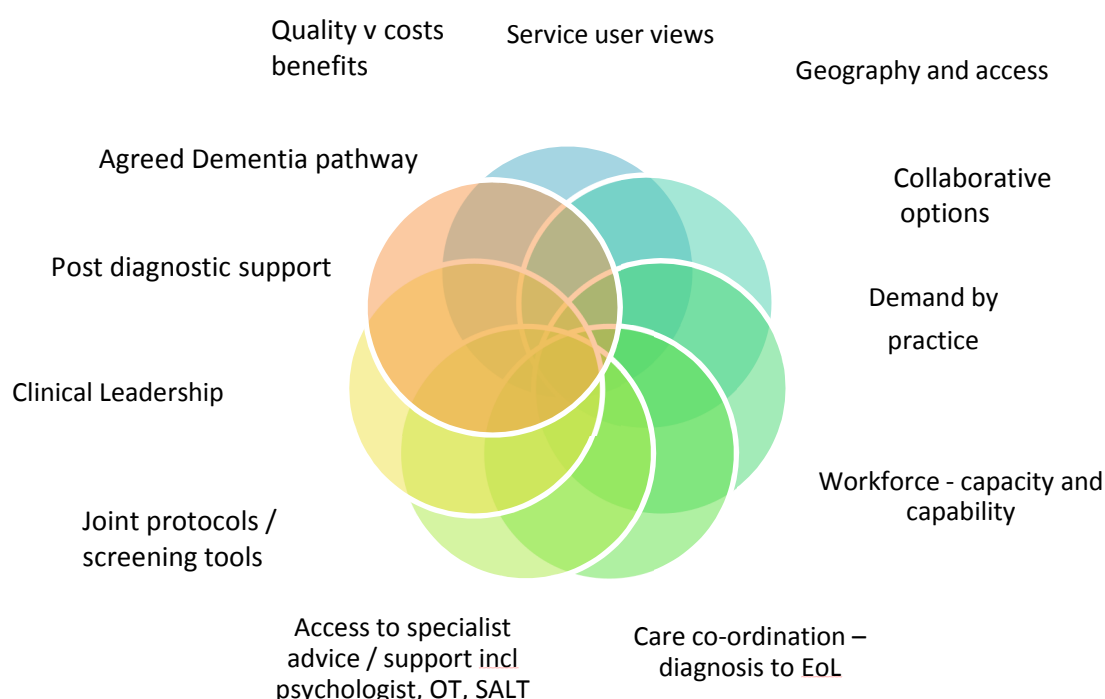
A series of visits to CCGs and memory services were made by Professor Alistair Burns with support from NHS IQ. The findings from the visits have been summarised in two Dementia Diagnosis and Care in England - Learning from Clinical Commissioning Groups^x and Best practice in Memory Services: Learning from across England^{xi}.

The typical dementia pathway from a professionals perspective is usually linear however, patients and their families rarely experience a linear progression. They have different needs at different times and changing circumstances. Susie discussed the three main models of memory assessment;

- Specialist led (examples included Salford and Isle of Wight)
- GP based with specialist outreach (e.g. Gnosall and South Manchester)
- Primary Care led (e.g. Dudley, Wiltshire and Bexhill on Sea)

Susie was keen to stress that no one model is better than the other; they all have their own pros and cons. The things to consider are shown in Figure 2.

Figure 2: Things to consider for a memory service



Some essential requirements from a memory service are;

- *Excellent clinical relationships between local commissioners and providers*
- *Joint clinical development of pathways of care for primary care , intermediate care hospitals & the acute trust*
- *Pathways that cross organisations (mental health, community and acute sectors) & reduce the ‘noise in the system’*

Caroline Ignatius – Carer

Patient Story

Caroline gave a very moving account of caring for her mother with dementia. One of the key things that would have made the families lives easier after their mother was diagnosed was access to dementia friends training iii. This was a surprise to many of the delegates as it’s often considered as an awareness raising tool rather than as a tool to support carers. The delegates were really inspired to change the way they thought about this.

Irene Lewsey - Senior Mental Health Commissioner, Basildon and Brentwood CCG, Derek Rowell - Basildon Borough Council and Jackie Smith - Dementia Nurse Specialist, SEPT Basildon and Brentwood CCG go to the Dementia Village

A group from Essex including members of the council, the CCG and specialist nurses visited the dementia village in Holland in December 2014, with a view to building one in Essex within the next five years. The delegates were amazed to hear about how different care for people with dementia can be. There was excellent integration of the village with the local community and the village attracted approximately 150 volunteers from the community. The community was encouraged to make use of the villages’ facilities including a restaurant, pub and shop. There were fewer falls and no concerns over challenging behaviour within the dementia village. The delegates were really inspired to bring this vision to the United Kingdom and signed up to lend their support in writing business cases to encourage this to happen. The talk finished with an excellent quote which is worth remembering.

“For elderly people with dementia, the world is small. Great deeds no longer count. It’s the simple things that make life worth living: your own home, a safe place, and if possible - doing what you feel like”

Key Themes and Discussion

During the presentations and questions from the delegates a number of key themes emerged. The delegates were asked to consider these during the afternoon discussion session.

1. Training
 - Workforce
 - Prescribing
 - Nurses
 - Doctors
2. What does good post diagnostic support look like?
3. How do we integrate services?
 - From a commissioning perspective?
 - From a provision perspective?
4. How do we learn and share about good practice?
5. Care homes
 - Awareness
 - Advanced life planning
 - Prescribing
 - Behaviour
6. What makes a dementia friendly town/city?
7. New models of working

The delegates were also asked to consider;

- a) What works well currently?
- b) What needs to change to support patients through the dementia pathway?
- c) What three things do I wish I had known 12 months ago?

On the 21st February the next phase of the Prime Minister's Challenge was launched, Prime Minister's Challenge on Dementia 2020^{xii}. Some of the key aspirations listed within the document correlate with the key themes from the conference including education, awareness raising and meaningful post diagnostic support.

Next steps from delegates on the day

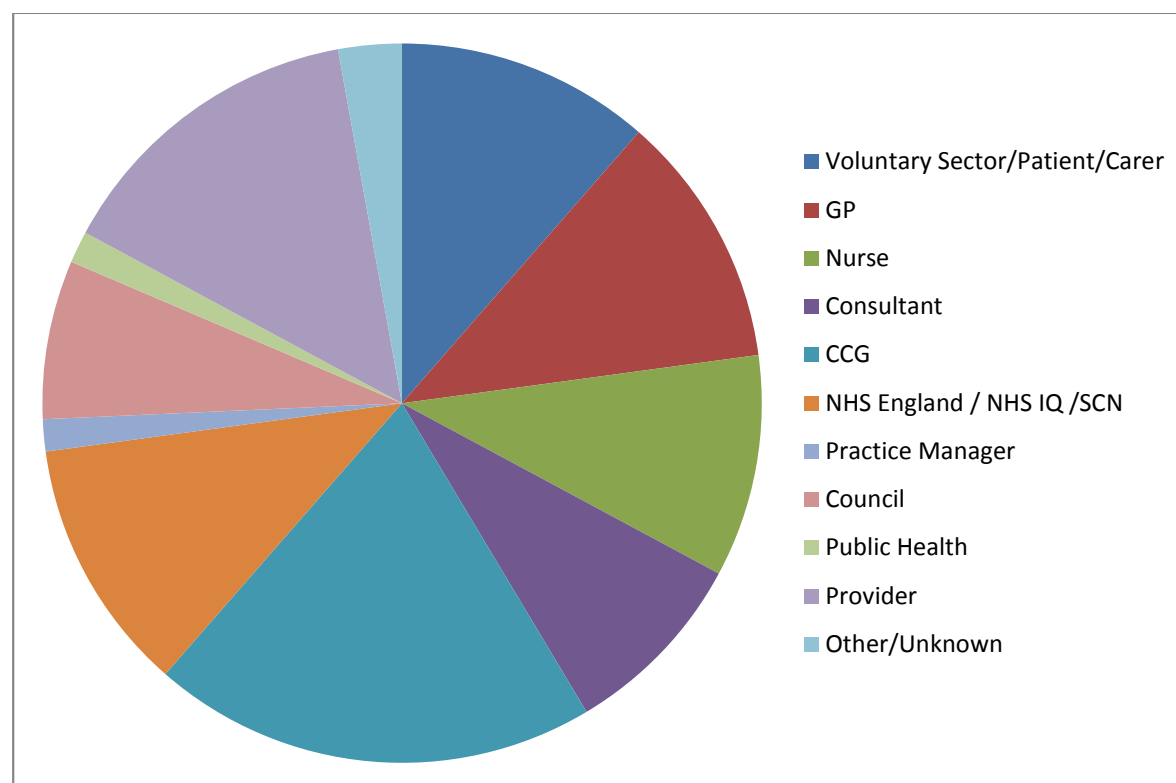
- Follow up event with Alistair Burns in 3-4 months time
- Outcomes based event on dementia
 - What is our aspiration for the region?
- Capture models and ways of working across the region – pull into one place and send out
- Follow up event with real examples of where work has been done i.e. Gnosall model
- Look into GP training

Appendix A

Delegates

Seventy delegates attended the conference (see fig 1 for breakdown)

Figure1: Delegate Summary



Appendix B: Delegate responses

1. Training
 - GP training so that they can train the carers
 - To include medications, diagnosis, managing challenging behaviour and managing confusion.
 - Brief compulsory GP training - part of the re-accreditation?
2. Post diagnostic Support (PDS)
 - Need for carer and patient education
 - Advanced plans
 - Resources for living well
 - A recovery orientated care plan – What keeps me well? Early warning signs? Crisis response.
 - Minimum standards for post diagnosis support are required
 - Don't operationalise too much to allow for innovation
 - Very reliant on patient, carers and families, the GPs feel naïve on post diagnosis support
 - There is literature to say that some things work so they should be in there

- Formal PDS pathway may not work for all as some people might not be ready to receive support at certain points
- 3. Integration
 - We need a one stop shop which involved the third sector, social services and mental health
- 4. Sharing good practice
- 5. Care homes
 - How can we incentivise the private sector to make things better?
 - Regulation or financial incentives are tools.
- 6. What makes a dementia friendly town/city?
- 7. New models of working

a) What works well currently?

- Diagnosis service is good
- Communication is good
- System is more interested in new ideas/collaborative working/doors are opening
- Dementia intensive support team
- Liaison psychiatry
- Some patches of high diagnosis rates
- Co-location of memory clinic and voluntary and community sector (VCS)
- Keeping things simple
- VCS working together cohesively
- Conversations around joint commissioning building
- Specialist dementia team which is flexible and can move staff around to where they are needed (but more staff still required)
- Anti-psychotic drug reviews for GPs through community dementia services
- Reviews in GPs surgeries after the patient is stabilised on their medication
- GP fast track access back in to services if the person deteriorates
- Dementia support workers in Memory Assessment Services (MAS) at the time of disclosure for support and beyond
- Nurses doing diagnosis (and medication) with good relationships with GPs
- Dementia advisors in MAS but are people being diagnosed elsewhere having access to them?

b) What needs to change to support patients through the dementia pathway?

- Follow up after initial diagnosis
- Who will keep the list of resources?
- How can we add value to the dementia review for GPs?
- Health, social care and third sector integration
- Education
 - i. Challenging behaviour
 - ii. Prescribing
 - iii. Legalities
- Joint commissioning

- Move away from short term grant funded services
- Less emphasis on crisis intervention / more intervention on early support
- Pragmatic approach to diagnosis
- Make sure that staff within the acute general hospital are trained in looking after people with dementia
- Memory cafes
- More singing for the brain services
- Community dementia nurses
- Single point of access for people in crisis that the GP and carer can access
- Nurses able to diagnose and prescribe
- Palliative care model to have social care too
- Outcomes- what are we expecting? Professional work force development and people going through the patient journey
- Information- person may not be ready for all the information and might not be in the right format- lots of leaflets
- Get better at involving more people to support them
- Be flexible on how we commission
- How we respond to gender issues in the care home population – need to configure services differently
- Pre-emptive prescription for delirium (people with infections). Give patients a box of urine dipstix so they can dip their own urine
- Put number of social care and Alzheimer’s Society on GP template for yearly dementia reviews and link to up to date leaflet.
- In crisis have psychiatry, social services, Alzheimer’s Society – give number for patients to contact in future if problems e.g. challenging behaviour

c) *What three things do I wish I had known 12 months ago?*

- The “I Statements” for dementia
- The dementia village exists and might come here
- We as a service need to provide clearer information to GPs of what we did, what should follow on and how to get back

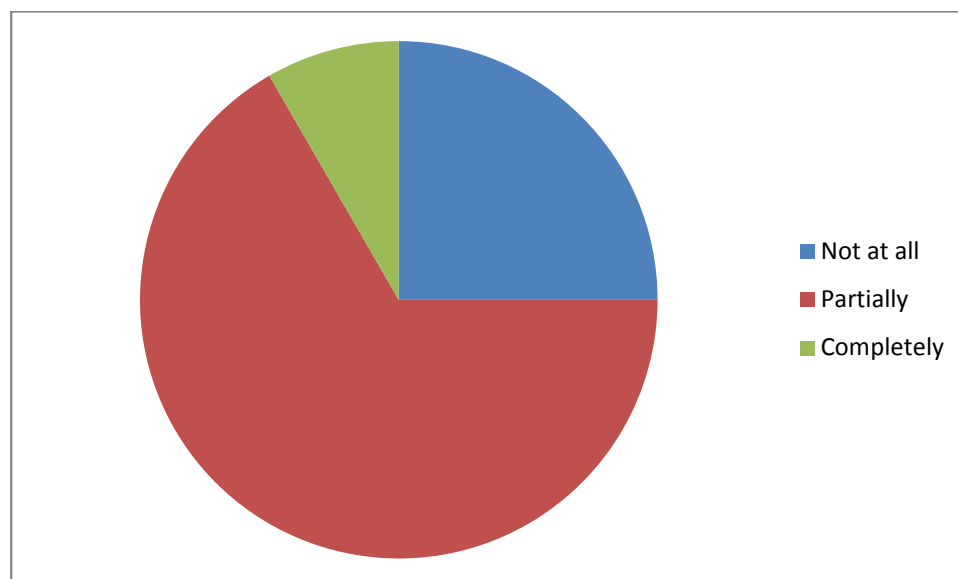
Appendix C: Summary of the Feedback Forms

Twenty four delegates completed an online feedback questionnaire.

Why diagnose dementia in primary care?

By Professor Alistair Burns, National Clinical Director for Dementia

Has the presentation changed your views on diagnosing dementia in primary care?



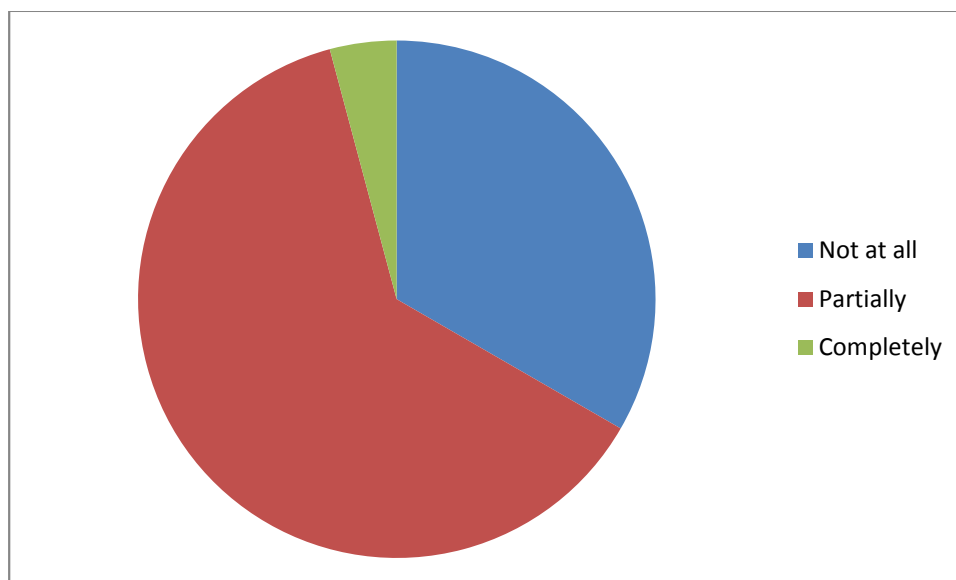
Key Comments

- Support still needed for Primary Care re diagnosis
- Be prepared to diagnose earlier and with more confidence
- That scanning is not and has never been necessary to make a diagnosis
- Many models of diagnosis- need to make relevant to area
- I still believe that a specialist led service is best but I am happy to look at better integration with primary care and co-location.
- Very thought provoking
- It was helpful to clarify the debate and the thinking.
 - However, I came away very clear that we should not diagnose dementia in primary care until and unless:
 - A clear package of INTEGRATED community-based services is in place (including social support, dementia nurses, support on power of attorney/DNAR) is in place.
 - The package of community-based services can be simply, reliably and readily accessed.
 - The local CCG has designed and funded clear primary care pathways for diagnosis, with appropriate specialist supervision, nursing support and GP training.
- Good to hear such a positive speaker and seemed very approachable also
- Very inspiring talk

Dementia Assessment and Diagnosis – The Options

By Susie Peachey, NHS IQ

Has the presentation changed your views on dementia assessment and diagnosis?



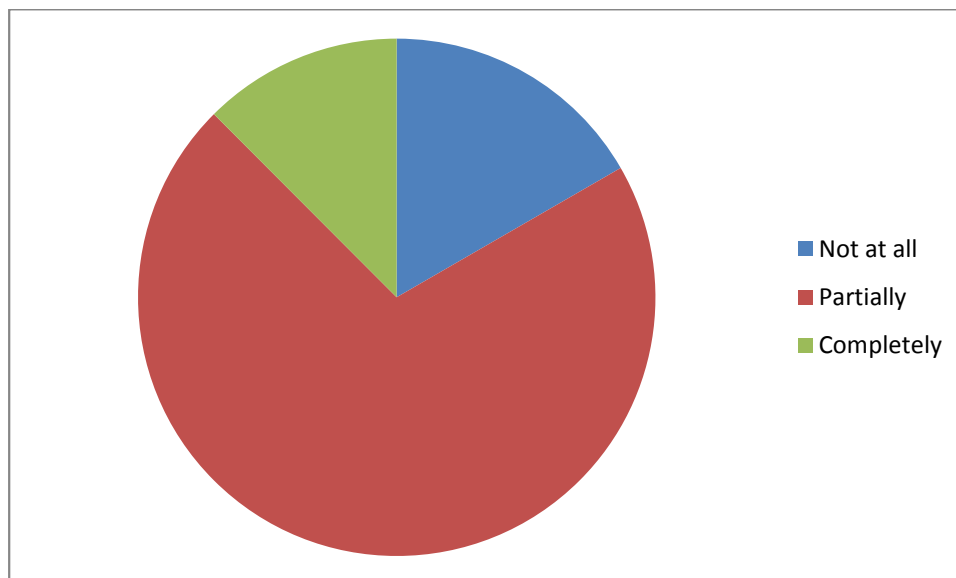
Key Comments

- Really useful to hear about the different models being used
- Although case examples were mentioned it may have been helpful to look at what worked well and learn from some issues areas had faced. As mentioned each area is different and so should be approached as such.
- Very timely as in our service we are thinking about other models
- More information needed about the different models to see whether any of these would work locally

Patient Story

Told by Caroline Ignatius

Has the presentation changed your views on dementia diagnosis, living with dementia and post diagnostic support?



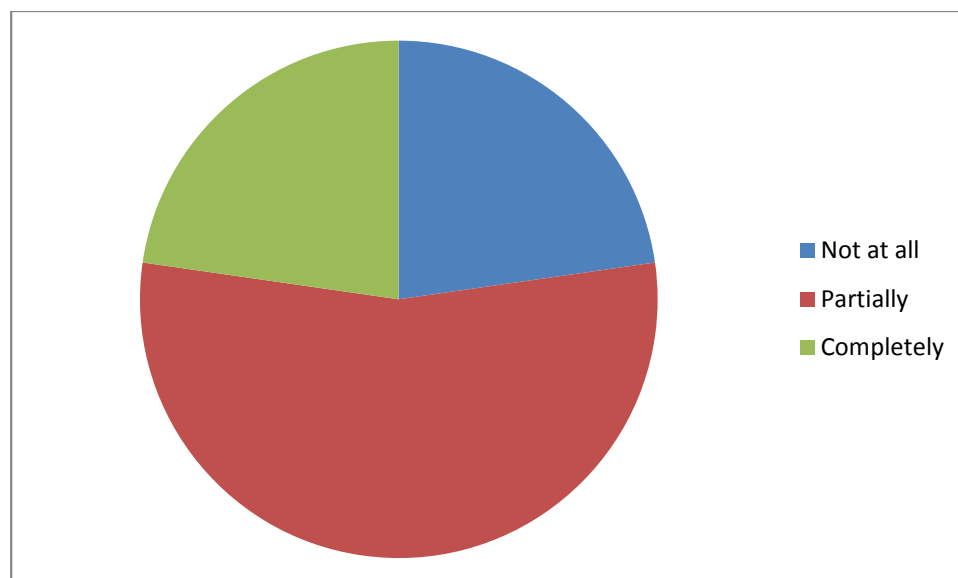
Key Comments

- Look to have dementia friends training within hospital for families whose relative is diagnosed as an inpatient, within 4 weeks of diagnosis.
- Need to become a dementia friend
- Helped to get the patients' needs across
- Look at support whilst awaiting assessment
- It is always poignant to hear the voice of someone who is LIVING the situation and to be mindful of the aspects of care that matter most in order to shape our services to better serve the patient and their carer
- Altered my perception of the reality of living with dementia
- Very interesting to hear carer perspective and the dementia friends campaign
- It highlighted from a carer point of view how delays in follow up have a negative impact and simple support has a very good positive impact.
- Made me think about telling people at diagnosis about friends sessions
- Fantastically brave and honest talk from an amazing daughter of a lady living with a dementia. The best presentation of the day!

Basildon and Brentwood CCG go to the Dementia Village

By Irene Lewsey, Derek Rowell and Jackie Smith

Has the presentation changed your views on the caring for people with dementia?



Key Comments

- We need to think outside the box re care homes
- Inspired a paradigm shift.
- I want to live there!
- I was already aware of person centred care but this radical risk taking approach was challenging and refreshing.
- I really hope that with the support of local gov they get this off the ground!
- I am not involved in commissioning, but it was useful to hear how the dementia village functions and how we can hope to achieve these ideals here in UK.
- Really interesting overview of this cutting edge style of supporting people through their dementia experience and really focusing on a person and relationship approach to dementia care and support. Interesting ideas around freedom and liberty and "challenging behaviour"
- "Don't change the patient; change the context in which they live".

What works well currently and what needs to change to support patients through the dementia pathway? Facilitated group work session

What actions are you taking away to work on?

- Starting a dementia friends session at the hospital for relatives of those who we diagnose
- Continue to encourage GP practices to improve diagnosis rates, and work with Social Services colleagues to better design post-diagnosis services.
- Keeping Dementia/carers on the Patient Experience agenda in the sub-regional team
- To continue working on standards for diagnostic and post-diagnostic support pathways within the County
- will look at dementia pts on anticholinergics and review my MCI patients
- I am working on the dementia village project.
- Look at support of carers between identification of concern and assessment.
- We have identified there is a need for our patients and their carers to have access to a 'one stop' support/contact point especially in a crisis, this could avert unnecessary hospital admission and direct people to the correct services.

What future events would you look to the SCN to host?

- Post diagnostic support pathway event
- Similar information sharing events and opportunities to develop ideas on best practice and innovation.
- A more experimental conference with real 'in practice' issues being addressed.
- Similar events, pre and post diagnostic pathways, integrated dementia solutions , best practice models in dementia service and/or care
- Similar information sharing events and opportunities to develop ideas on best practice and innovation.
- Care pathways for people with Personality Disorders

Reference List

- ⁱ **Prime Minister's challenge on dementia** - Delivering major improvements in dementia care and research by 2015
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- ⁱⁱ **Join Dementia Research**
www.JoinDementiaResearch.nihr.ac.uk
- ⁱⁱⁱ **Dementia Friends – Alzheimer's Society**
<https://www.dementiafriends.org.uk/>
- ^{iv} **The Dementia Guide – Living Well With Dementia**
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- ^v **Remembering Together: Making a life history book**
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