Norfolk Older People's Strategic Partnership Board

Minutes of the meeting at County Hall, Norwich
Wednesday 11th September 2013

Present:	
Joyce Hopwood	Chair of Norfolk Older People's Strategic Partnership, and Chair of Norwich Older People's Forum
Sue Whitaker	Cabinet Member for Adult Social Services Norfolk County Council (present for part of the meeting)
Niki Park	Environment, Transport & Development, Norfolk County Council
Paul Jackson	Communications, Norfolk County Council
Laura McCartney-Gray	Engagement, Norwich Clinical Commissioning Group (CCG)
Oliver Cruickshank	Engagement & Communications, South Norfolk CCG
John Everson	Health and Social Care Integrated Commissioning Team
Marcia Perry	Nursing Quality & Operations, Norfolk Community Health & Care NHS Trust
Phil Yull	Partnership Development, Department for Work and Pensions (DWP)
Phil Wells	Chief Executive, Age UK Norwich
Jane Warnes	Chair, Norfolk Housing Alliance
Jo Ardrey	Westminster Home Care and Norfolk Independent Care
Lesley Bonshor	Carers' Council
David Button	Norfolk Council on Ageing
Carole Williams	Norfolk Council on Ageing
David Russell	North Norfolk Older People's Forum
Pat Wilson	Broadland Older People's Partnership
Kate Money	Norwich Older People's Forum
Ann Baker	South Norfolk Older People's Forum
Hazel Fredericks	West Norfolk Older Person's Forum
Peter McGuinness	Great Yarmouth Older People's Network
Emily Millington-Smith	Norfolk Older People's Forum
Graeme Duncan	Co-opted Member
Speakers:	
Willie Cruickshank	Director, Norfolk and Suffolk Dementia Alliance
Neil Ashford	Consultant Psychiatrist, Norfolk and Suffolk Foundation Trust
Moira Goodey	Carer
Jo Ardrey	Branch Manager, Westminster Home Care Norwich
Dr Helen May	Consultant in Older People's Medicine, Norfolk & Norwich University Hospital
Nikki Shaw	Manager, Shipdham Manor and Member of Norfolk Independent Care
In Support:	
Paul Anthony	Corporate Support Manager, Norfolk County Council
Annie Moseley	Supporting the Norfolk Older People's Strategic Partnership, Age UK Norfolk
Hayley Yallop	Administrative Support, Democratic Services, Norfolk County Council

Apologies for absence were received from: Harold Bodmer, Catherine Underwood, Emma McKay, Anna Morgan, Carol Congreave, Hilary MacDonald, John Clemo, Linda Rogers, Chris Mowle, Shirley Matthews and Charles Ison.

1	**Welcome by the Chair** Joyce welcomed everyone to the meeting. Joyce introduced Sue Whitaker, the Cabinet Member for Adult Social Services. She also welcomed Paul Jackson, Laura McCartney-Gray and Oliver Cruickshank as new Board members. Joyce noted that Mary Granville-White was taking leave of absence, and David Russell was acting as Chair of North Norfolk Older People's Forum until March 2014 On behalf of the Board Joyce recorded her thanks to James Bullion, who had taken up a new post in Essex, for all the support he had given the Partnership during his time in Norfolk. Joyce reminded everyone that October 1st was international Older People's day, and many events had been organised across the county to celebrate the lives and contribution of older people.
2	**Minutes** The minutes of the meeting held on 12 June 2013 were agreed.
3	**Matters Arising** 3.1 Handy Person's Scheme - It was noted that the services delivered by the home improvement service were being reviewed by a lead Commissioner and the future options would be reported to the Supporting People Commissioning Board. 3.2 A Carers' Experience - The last bullet point under Item 7 was amended to read " A befriending service offered support including out of office hours in the late stages of her husbands illness and continued into bereavement" 3.3 Health and Wellbeing Board - Joyce reported that the Health and Wellbeing Board two overarching priorities were reducing inequality as a way of improving health, and increasing integration, and that they would be focusing on the needs of children aged 0 – 5s, on reducing obesity and on dementia..
	Dementia – The Effects of Failure to Diagnose in a Timely Way
4	**The Norfolk Picture** Willie Cruickshank, Director of the Norfolk and Suffolk Dementia Alliance, and Neil Ashford, Consultant Psychiatrist at the Norfolk and Suffolk Foundation Trust, outlined the picture in Norfolk. Willie highlighted: • That dementia costs the UK 2 times as much as cancer, 3 times as much as heart disease and 4 times as much as stroke, but only £0.38p was spent on research for every £1.0 on cancer research • It was the medical condition that older people worried about most

- That dementia was a clinical syndrome – a group of symptoms - not a normal part of aging, and is caused by disease such as Alzheimers disease, vascular dementia, and Lewy Body dementia.
- It leads to organ failure – the brain failing, just as other organs such as kidneys fail. This is different from the normal cognitive decline of older people; the difference between normal decline and dementia could be difficult to diagnose.
- Whilst the condition was more common in older people, younger people could suffer from early onset dementia.
- That 1 in 3 in the population will develop dementia after the age of 65.
- That North Norfolk had one of the highest proportions of older people in the country.
- That dementia was projected to increase in Norfolk by 62% by 2025.
- That 80% of residential care beds were occupied by people with dementia.
- That two thirds of people with dementia were living at home.

Neil said that:

- That there was a low diagnosis rate in West Norfolk (only 32% of those expected to have dementia had been diagnosed), and a higher chance of them ending up in residential care (The two were not unrelated).
- If they weren't diagnosed, they weren't able to access services to help them live well with dementia in their own homes, and were likely to end up in a crisis situation - possibly in hospital - which in turn could lead to a loss of self-care skills and confidence, and put the individual on a course to residential care.
- That the estimated cost of people living with dementia living in the community was £24,128, and for residential care was £35,424.
- That £373 million in total was spent on people with dementia in Norfolk each year, but that less reliance on residential care would lower the cost - we need to take more steps to transfer the cost of care from the highest cost acute hospital care where most of this money is now being spent to residential or home care.
- The Prime Minister launched the dementia challenge in 2012 to raise awareness and build on progress made through the national Dementia Strategy.
- That most of the wards at the Norfolk and Norwich University hospital have a patient/s with dementia, so all staff needed to be aware of how to care for the needs of someone with dementia.
- That the government has set a target of 66% of people with dementia being diagnosed in a timely way by 2015..
- If people with dementia were diagnosed early, and were able to make an advance care plan and put in place a Lasting Power of Attorney, they could be confident that their wishes for the end of their life would be respected.
- The importance of the role of Dementia Specialist Advisers: there were five in Norfolk, but funding for these posts was precarious and only guaranteed until March 2014. Dementia Advisers were one of the most important elements of the dementia pathway, particularly in anticipating a crisis and calling in additional support in a timely way.

5 **Reasons Why Older People aren't being Diagnosed in a Timely Way**

Neil Ashford, the Consultant Psychiatrist at the Norfolk and Suffolk Foundation Trust, explained why older people do not receive an early diagnosis:

- Diagnosis rates can vary greatly between GP practices, but rates in Norfolk were:
  - West Norfolk CCG – 33%
  - North Norfolk CCG – 40%
  - South Norfolk CCG – 41%
  - Norwich CCG – 42%
  - Great Yarmouth and Waveney CCG – 51%
- The national Dementia Czar said that it was important to screen people properly on admission to hospital; improving services for people with dementia ('Finding, Assessing and Supporting and Referring') is one of the four national 'Commissioning for Quality and Innovation' (CQUIN) goals for 2013
- Hospital patients who were diagnosed by a specialist in the acute hospital used to be referred back to their GP for further support which led to delays, but this has now changed and they are referred direct to the memory clinic.
- Reasons why people were not being diagnosed:
  - Person not wanting a diagnosis therefore need to raise awareness /educate the general population.
  - The GP feels that the condition is not curable so what is the point.
  - The GP feels that diagnosis will swamp service need.
  - GPs may not feel confident that they can diagnose.

6 **Effects of Failure to Diagnose in a Timely Way on Older People and their Families**

Moira Goodey (Carer) spoke on the affects of failure to diagnose early.

- Moira said that the person she cared for was not diagnosed until a late stage when admitted to hospital.
- Because of the late diagnosis, services were not put in place and it was then too late for her to make decisions for herself.
- When the person first became unwell she hadn't wanted to recognise her symptoms or see herself as vulnerable, and she as carer had respected this, but early diagnosis was essential. Without this they had lived from crisis to crisis which could have been prevented.
- Moira believed the GP felt that a diagnosis would have been detrimental to the patient, but this took away the opportunity for the person she cared for to make her own decisions. It was not just a matter of finance, but because the GP felt he was being "kind".
- Various treatments were available, but whenever the person she cared for entered hospital, she returned with her condition deteriorated which would not have been the case had she remained at home. She was given a book to read in the hospital but staff didn't know she couldn't read it.
- If a carer has talked to the person when they are in the early stages of dementia and finds out what is important to them, they can convey

what their wishes are for their care, finances and the end of their life.

- Moira felt the GP patronised her and didn't appreciate the stress she was under as the carer - it was so frustrating and hard when things were very difficult, not to have someone to talk to who knew about dementia and the services available. She was told not to rock the boat, and wasn't listened to.
- Early stage intervention and support can slow down the onset of dementia, and would have meant less cost to the system. It would have helped her immensely as a carer.

7 Effects of Failure to Diagnose in a Timely Way on Home Care Services

Jo Ardrey, Branch Manager, Westminster Home Care, Norwich outlined the effect on home care services:

- When you first visit, you can see that things are not right, and can ask the family about the life history of the person, and when things began to change.
- Prescriptive care for a person with dementia does not work and does not benefit the individual. Short visits do not provide sufficient time for carers to engage with the person.
- Families of people with dementia who provide 24/7 care are often reluctant or too frightened to seek advice, and might take their frustration and stress out on the person they are caring for as they don't understand what is wrong. They don't know about all the help that is available such as assistive technology.
- Her company encourages family members to take part in the training of their paid care workers, so that families can learn helpful ways forward, such as not to challenge the person they care for if they say something that isn't right.
- It was important to make sure that home care for people with dementia was sufficiently funded so that they had their particular needs met, and could live longer in their own homes with continuity of care.

8 Effects of Failure to Diagnose in a Timely Way on Hospitals

Dr Helen May, Consultant in Older Peoples Medicine, Norfolk and Norwich University Hospital (NNUH) outlined the effects on hospitals:

- NNUH had the largest older people's medicine (OPM) site in the country. There were 8,500 discharges per year, and 300 to 400 patients at any one time. They had six base wards including for stroke, orthogeriatric medicine (fragility fractures) and a dementia speciality ward.
- The average length of stay (LOS) in NNUH was 4.4 days, but for OPM generally it was 12.2 days, and for older people with dementia it was 21 days.
- 1 in 3 patients in the NNUH have some cognitive impairment - around 200 in-patients across all wards in the hospital.
- Helen outlined the Quality and Innovation (CQUIN) FAIR process used to assess for dementia every patient over 75 who was admitted so that people could be referred on to appropriate support, but acute hospitals are not necessarily the right place to assess people for dementia.

Helen described three case histories of older people admitted to NNUH, and the effects of failure to diagnose dementia in a timely way on hospitals, families and carers and on patients:

- Effects on hospitals
  - Prolonged length of stay
  - Complaints
  - Staff uncertainty
  - Is this delirium? Is there underlining dementia?
  - Wrong diagnosis attached

- Effects on families and carers
  - Crisis management
  - Uncertainty
  - Hospital complications
  - Complex discharge planning
  - End of life issues

- Effects on the patient
  - De-conditioning whilst in hospital (reduced muscle strength through inactivity)
  - Increased confusion
  - Unfamiliar environment
  - Risk of fall and injury e.g. on hard hospital floors
  - Risk of infection
  - Risk of not returning home

9 **Effects of Failure to Diagnose in a Timely Way on Care Homes**

Nikki Shaw, Manager Shipdham Manor, and Member of Norfolk Independent Care. Nikki explained:

- That Shipdham Manor was a 42 bed residential home specialising in dementia care, and she had been Manager for seven years, and before that a Ward Sister.
- Five years ago none of the residents had received a formal diagnosis of dementia, but 60% had signs of the condition, so she got professional support.
- She undertakes pre-admission visits to assess the needs of potential residents, but dementia can be difficult to diagnose and sometimes families are reluctant to say that the person has dementia in case they wouldn't be accepted as a resident or because they don't understand the impact of dementia on the person they care for and the support they need. Families often attribute memory loss to other reasons, while issues at home can be hidden from relatives/carers because the person concerned has a specific routine.
- All new admissions cause some disruption to the home as it is the existing residents' home, but the admission of someone with undiagnosed dementia is particularly difficult as the staff are not able to prepare properly – e.g. thinking what lounge might be best for them and the other residents, and where would be best for them to sit in the dining room.
- Sometimes an undiagnosed person may need to be moved on to a home which can meet their particular needs, and a second move is

likely to have major impact on them.

- Residents who have not had a diagnosis do not understand what is happening to them.
- Failure to diagnose has an impact on the individual's treatment plan and the support they receive – they may miss out on the medication and other support they need.
- Failure to diagnose has an impact on staff and the way they do their job – if the home doesn't specialise in supporting people with dementia, some staff may feel incompetent and perhaps give up their job.
- Failure to diagnose impacts on the ability of the home to judge an individual's capacity to make decisions.
- Failure to diagnose can mean that appropriate financial support isn't available

10 Effects of Failure to Diagnose in a timely Way on Psychiatric Services

Neil Ashford, Consultant Psychiatrist, Norfolk and Suffolk Foundation Trust, outlined the current redesign of services because of pressures on budgets:

- There needs to be specialist diagnosis – is it dementia, and if so, what type, so that treatment and support can be provided, and specialist intervention at different stages such as in a crisis when the condition is complex, and at the end of life.
- All the above were delivered with limited resources and staff, as the NHS was required to make 20% savings which, for the Trust, amounted to £2 million over a four year period. Services were therefore being redesigned to focus on timely diagnosis, and intensive support for people in crisis or approaching crisis and at risk of admission.
- Around 3% of the Trust's patients were in beds costing 50% of the Trust's income, so the prime target for savings was preventing admissions
- One way they could do this was by setting up dementia support teams for people with dementia living in the community - an intensive support team for people with dementia had been piloted in central Norfolk and would be rolled out to the east and west of the county.

Late presentation to their services often meant:

- A person was already in crisis, there was no care plan in place, the carer was no longer able to cope and the person required extensive support/institutional care options..
- Resources had to be focused on crisis intervention so that there were less available for less intensive services, resulting in longer waits for a diagnosis and an increased risk of crisis admission.
- No-one knew of the person's wishes for their care and for the end of their life which could have been used to guide decision-making

Neil said that his ambitions for the service within their limited resources were:

- To meet demand for timely diagnosis
- To establish an integrated care pathway where someone who had several medical conditions and also needed social care and emotional support was linked with a care manager/case manager, based usually

in primary care, who would coordinate the different parts of the system and bring in specialist support/advice as required.

11 Questions and Discussion

During the ensuing discussion the following points were raised:

- So far as saving money through early diagnosis was concerned, it was noted that it cost around £1,000 per month to employ a part-time Dementia Adviser who could significantly reduce the number of hospital admissions. The CCGs had agreed to continue to fund the existing Advisers until the end of the year by transferring resources from another area. Also, work would be carried out over the coming six months to do a full assessment of the benefits of the investment as part of integrated support for dementia sufferers.
- That there was a financial advantage to early diagnosis in that it could enable the person with dementia to qualify for non-means tested Attendance Allowance at the earliest possible stage of the condition. This was part of person's journey through the illness.
  Action: Phil Yull undertook to speak to the Norfolk County Council Welfare Rights Officers.
- Need to take some major strategic decisions about how money is invested. Also what is the role of general practioners/primary care in early stage support? Neil pointed out that having a Case Manager to link with all the different services care could help with GP's workloads.
- Need to recognise that GPs are required to have a wide general knowledge of health matters but not necessarily a lot of knowledge on specific issues like mental health and dementia. Work was being undertaken in two CCG's (West Norfolk and North Norfolk) to identify GPs' understanding of dementia diagnosis and the information they needed. When completed this should help focus resources.
- Dr. Augustine Pereira was now leading for Norfolk Public Health on dementia. He felt that even though more is spent on dementia in Norfolk than many other areas, the Health and Wellbeing Board needs to look at the whole health spend and ensure sufficient resources are spent on mental health, and at innovative ways of using those resources to support people with dementia.
- Helen May agreed that the unnecessary admission of patients with dementia had a unsustainable impact on bed availability. NNUH needed at least another 53 beds to cope with this, but the situation could be resolved if the flow through the hospital could be improved. They also need to work with the ambulance service to prevent unnecessary admissions.
- Neil Ashford reported on a pilot to create a database of all people diagnosed with dementia to inform hospitals/social services/ambulance service/voluntary sector.
- Steve McCormack, Mental Health Commissioning Manager for the CCGs and Social Care, said that in West Norfolk a Joint Assessment Team (mental health/Norfolk Community Health and Care/social services staff) was being piloted to help ambulance crews assess situations involving a dementia patient and provide fast support so that paramedics could safely return the patient home.

- Need to ensure that all organisations are aware of the needs of carers in terms of dementia awareness.

12 Any Other Business

12.1 Norfolk Bus Forum

Carole Willams reported that she was now a Member of the Norwich Bus Forum and that a public meeting with bus providers and County Council representatives was taking place on 16th November at County Hall (10.30 to 12.30) with representatives from the County Council and the bus operators.

Carole also reported that Connect and Anglia buses (but not First bus) had produced a single timetable for the Greater Norwich area with a map.

12.2 Norfolk County Council 2014 - 2017 Budget Consultation

Paul Jackson reported that Norfolk County Council was about to launch a 12 week consultation on their budget with effect from 19th September and running to 12th December. This would include publishing information on the internet, while those with no computer access could request paper copies.

A special edition of "Your Norfolk" would be devoted almost entirely to the budget consultation; and a series of meetings were being arranged with stakeholders, including all the Older People's Forums.

Paul said that if there were any questions he could be contacted on paul.jackson@norfolk.gov.uk.

12.3 Care UK

Phil Wells noted that in some reports Age UK was being confused with Care UK which, given the current bad publicity over their new contract, was causing Age UK some reputational damage.

13 Informal Discussion

During the informal discussion over lunch, the following key points were raised:

- That limited (15 minute) slots for home care did not give paid carers sufficient time to recognise problems and whether someone needs to access the dementia services.
- That over the next 5 to 10 years resources must be used to the best effect to provide integrated services around the needs of individuals. Also, we need to create dementia friendly communities.
- How do we recognise individuals "below the radar", particularly those who do not visit their GPs regularly?
- People don't know where to go for information
- After diagnosis it would help to have a key worker who would coordinate all the services
- Problems for people in West Norfolk who have to travel to the Julian Hospital in Norwich for specialist inpatient services and care.
- The specialist diagnosis of dementia is based on the person's story – how they have changed over time; relatives can be very helpful here.

and will focus on **‘Dementia – changing the Culture.’** Meetings are open to the public.