Norfolk Older People’s Strategic Partnership Board

Minutes of the meeting at Breckland District Council Offices, Dereham Wednesday 6th November 2013

Present:	
Joyce Hopwood	Norwich Older People’s Forum
Ann Baker	South Norfolk Older People’s Forum
Lesley Bonshor	Carer’s Council for Norfolk
Emma Boore	Borough Council of King’s Lynn and West Norfolk
David Button	Norfolk Council on Ageing
Denise Denis	Norfolk Independent Care
Hazel Fredericks	West Norfolk Older People’s Forum
Jan Holden	Norfolk County Council Community Services
Charles Ison	Broadland Older People’s Partnership
Paul Jackson	Norfolk County Council
Hilary MacDonald	Age UK Norfolk
Ellis Layward	North Norfolk Clinical Commissioning Group
Shirley Matthews	Breckland Older People’s Forum
Emma McKay	Acute Trusts
Emily Millington-Smith	Norfolk Older People’s Forum
Kate Money	Norwich Older People’s Forum
Anna Morgan	Norfolk Community Health and Care NHS Trust
Mick Sanders	Norfolk County Council and Norwich CCG
Carole Williams	Norfolk Council on Ageing
Pat Wilson	Co-Opted Member
Speakers:	
Zena Aldridge	Age UK Norfolk
Neil Ashford	Norfolk and Suffolk NHS Foundation Trust
Chris Carter	Home Instead Senior Care
Diane Collins	Age UK Norfolk
Joanna Crown	Carer
Willie Cruickshank	Norfolk & Suffolk Dementia Alliance
Pauline Davies	Norfolk & Suffolk Foundation Trust (Mental Health)
Heather Edwards	Come Singing Dementia Choirs
Lynden Jackson	The Debenham Project
Karina Kennell	Norfolk Alzheimer’s Society
Jan Holden	Norfolk County Council Community Services
Martyn Patel	Norfolk & Norwich University Hospital
In Support:	
Annie Moseley	Age UK Norfolk
Catherine Wilkinson	Norfolk County Council
Apologies: Harold Bodmer, Sue Whitaker, Niki Park, Catherine Underwood, Phil Yull, Linda Rogers, Jane Warnes, Chris Mowle, David Russell, Peter McGuinness, Graeme Duncan, Jo Ardrey	

1.	**Welcome by the Chair** Joyce welcomed everyone to the meeting.

2.	**Minutes** The minutes of the meeting held on 11th September 2013 were agreed. Mick Sanders said that where Handyperson Services had been in place, these had been were provided by district councils through their Home Improvement Agencies (HIAs). Supported Housing funding was being reviewed as part of Norfolk County Council's budget consultation and this will include consideration of the NCC's contribution to Home Improvement Agency funding.
3.	**Election of Chairman** One nomination for the position of Chairman had been received, for Joyce Hopwood. There being no further nominations, Joyce Hopwood was duly elected as Chairman.
4.	**Election of Vice Chairman** One nomination for the position of Vice Chairman had been received, for Kate Money. There being no further nominations, Kate Money was duly elected as Vice Chairman. The Chairman noted that Ann Baker had chosen to stand down from the Vice Chairman's position, and thanked her for her hard work in progressing the work of the Partnership.
5.	**Terms of Reference** It was agreed to adopt the updated Terms of Reference which reflected the developed membership and views of the Board.
6.	**Co-options** It was noted that John Perry-Warnes was standing down from the Board due to health issues, and that Graeme Duncan had also chosen to stand down. Both were thanked for their input to the Partnership Board during their terms of office. It was agreed to co-opt Pat Wilson to the Board.

Dementia: Changing the Culture

7.	**Giving people with dementia a voice** - Karina Kennell, Advocacy Manager, Norfolk Alzheimer's Society Karina introduced the work of this new service for Norfolk, which was funded by Norfolk County Council. The service gave a voice to people who found it very difficult to do so ('instructed advocacy'), and also offered representations under best interest 'non-instructed advocacy' when a person didn't have the mental capacity to speak up for themselves. A new Bill was being presented in the House of Lords requiring advocacy services to be made available. Referrals could be received from any source, including service users, carers, social services and hospitals. All users of the service would receive help with their issue via an action plan until a satisfactory solution was reached. Information to assist with independent decision making was also offered.

	Examples of advocacy services could include reviewing a care package where a carer feared repercussions if they complained, or assistance with transition from a hospital ward to a care home when no family or friends were available. The service was working well with partner organisations such as the Admiral Nurses, and lessons were identified from each case to inform better ways of working. Karina will signpost people for legal advice e.g. on Lasting Power of Attorney and the Mental Capacity Act.
8.	**Dementia friendly towns and villages** - Lynden Jackson, Chair of the Trustees, The Debenham Project, Suffolk Lynden introduced the work undertaken to make Debenham the first Dementia Friendly community in the country. This had been prompted by the national Dementia Strategy (2009) - an initial meeting within the community had highlighted dementia as a cause for concern in Debenham. It was acknowledged that awareness raising activities would be useful, highlighting the impact of dementia on individuals and carers. A public meeting was set up, which was attended by a GP, a retired neurologist, a mental health social worker, and Lynden. The key outcomes of this meeting were goodwill, a desire to do something, and a wish to move forward without waiting for strategies to be issued. 25 volunteers attended the first meeting, and initial work focussed on the community (local motivation), support to family carers who take the brunt of the illness, and on people with dementia themselves. There was a great deal of support from statutory agencies, and the scheme was launched with 170 people, and rudimentary services including a website, a confidential helpline and a lunch club. The scheme had grown in size and scope, but did not replace professional services. It now offered an advice service, social activities, emergency respite care with fully trained carers, and support during diagnosis. Debenham and the surrounding area had a population of 6,500 (with a further 2,000 in the GP catchment area) and it was estimated that 70-100 families were supporting someone with dementia. The Debenham Project had supported around 60% of these cases since October 2012, where previously the diagnosis rate had been around 35%. Around 175-200 person sessions were delivered each month, and there were 107 volunteers within the project. Around 60 of these were active, and their activity rate was kept low e.g. an afternoon a fortnight, as ‘they had lives to live’. The project had been designed and evolved on goodwill, and owned and developed by the community – it evolved from the bottom up. Any dementia friendly project needed to be proactive, with encouragement and leadership of volunteers. The service was free at the point of delivery. The three keys points were: • Make it simple – do one thing at a time; • Make it local – helping friends; • Make it work – it will if your heart is in it. Lynden was asked how had the challenges of data protection been

	addressed. He said that this had been overcome by doing only what was reasonable or necessary. The Project was exempt from data protection but did have policies which encompassed those principles. Police checks were undertaken where necessary, but most work was undertaken with families and not vulnerable people. Where work was undertaken with a vulnerable person, all legal requirements were met. However most people were known to each other within the community (self-checking). Tasks were broken down with one person heading up responsibility of a small group, and a small group had an overview role. Core funding was an issue, as volunteers could not be expected to meet their own expenses. Lynden wanted local authorities and health to recognize that dementia communities needed encouragement with some core funding over several years as the initiative needed to be sustained.
9.	**Pabulum cafes and life story books** - Joanna Crown, Carer; and Diane Collins, Pabulum Co-Ordinator, Age UK Norfolk Joanna spoke to the group about her experiences of caring for her mother who suffered with severe arthritis, and who then developed dementia. She saw the gradual decline and found it difficult to understand how an individual could remember the past so vividly, but forget the present – it was confusing and frustrating. Joanna was invited by Diane Collins, Pabulum Coordinator for Age UK Norfolk to attend a Pabulum café with her mother, and found it a warm and welcoming experience. A reminiscence table was themed as a talking point, and the group engaged in activities such as singing, talks, exercise, quizzes and lunches. Diane suggested that Joanna's mother was supported to make a book of photos and reminiscences about her life, and a volunteer came to work with her mother while another talked to Joanna – both found this a heartening experience. Joanna and her mother were proud of their book, and it had provided Joanna with a lovely reminder of her mother. Ex-carers were always welcome back as part of the Pabulum café family as the loss of someone for whom they have been a long-time carer could be particularly hard.
10.	**Therapeutic singing groups for people living with dementia** - Heather Edwards, Chair of 'Come Singing' choirs for people with dementia and their carers Heather briefed the group on the 'Come Singing' initiative which facilitated around 20 sessions each month mostly in and around Norwich for people with dementia and their carers. They were provided in a wide range of care settings including hospitals, nursing and residential care homes, day centres and housing with care. Each session was led by a music leader with understanding of dementia and was carefully planned with music and neuro-rehab exercises, then a sequence of songs. Games and activities such as hand bell ringing were encouraged - the key theme was to have fun. Trained and supported volunteers had a crucial role in supporting the singers and their carers and making sure everything ran smoothly. The initiative brought trust and well-

	being, and provided a supportive setting. The Come Singing organisations had been on the radio, and had set up a flashmob singing event in John Lewis in Norwich. All sessions were free of charge and the service was highly valued. The aim was to expand this across the county - music leaders were welcomed to join the scheme, and would be given training to set up their own groups.
11.	**Dementia Friendly Libraries** - Jan Holden, Assistant Head of the Library Service, Norfolk County Council Jan said that research had shown that libraries were not dementia friendly places, and that staff awareness of dementia had been raised by initiatives such as joining the Alzheimer's Society Dementia Friends scheme. Libraries in Wymondham, Swaffham and Wells were now dementia friendly. Activities had been planned for Dementia Awareness Week, and book stock including practical help for carers of people with dementia and books for children to help understand the condition had been added to the collection. Reminiscence kits were available for loan to individuals or groups. They had worked with Cognitive Stimulation Therapists (CST) from the Norfolk Dementia Care Academy on a 14 week evidence-based course for people with mild to moderate dementia, which had now been used with men on a life sentence in Norwich prison. Bibliotherapy, involving shared reading, was another way of working with people with dementia and had been used in Wells, Swaffham and Wymondham. The 'Surf's Up' scheme, supported by the Big Lottery, trained older people to use the internet, with many older people being carers for people with dementia. This included help with day to day tasks such as online shopping. People with dementia and their carers who went to the Swaffham Community Cafe supported by Age UK Norfolk could come to libraries for the course and then to use the internet. Library layouts in many of the 47 libraries had been improved to make them more dementia friendly.
12.	**Home care, family and community** - Chris Carter, Owner and Managing Director, Home Instead Senior Care Chris said that the traditional system of family and community care needed support. 13% of over 60's needed some form of care, with this figure set to double. People with dementia needed more personal care, more hours of care and greater supervision, and their care needed to be regularly monitored and readjusted. There was a need to value both family care givers and paid carers better, and for specialised knowledge, skills and understanding, including techniques to manage behaviour, and help for unpaid carers to better look after their own health. Continuity of care was really important so the paid carer understood the person's needs. More people with dementia were able to live within the community, but the community did not get training to cope with this. Home Instead Senior Care found that 50% of people using their service had dementia, and they provide City and Guilds accredited training for both their paid staff and for the unpaid family carers. So far, 50 unpaid carers had undertaken their half day workshops which were also open to non Home

	Instead family carers, and they have had very positive feedback. The key to success was communication, training and working together.
13.	**Admiral Nurses – their role and development** - Pauline Davies, Manager for the Dementia and Complexity in Later Life Pathway, West and Central, Norfolk and Suffolk Foundation Trust (Mental Health); and Zena Aldridge, Admiral Nurse Lead, Age UK Norfolk Pauline said that a dementia was really a diagnosis of a terminal condition - the prognosis would depend on the patient's age and condition, and could be between five and ten years. Admiral Nurses provided a focus on the clinical picture which would include many cognitive, emotional and behavioural changes which would have a wide impact on everyday life. The aim was to ensure that the person could live normally within the community for as long as possible. Unpaid carers could help the person with dementia have as normal, meaningful and joyful life as possible and understand their choices. But many carers for people with dementia had problems themselves with their physical and mental health, and often put off getting the health care they needed. Carers were achieving a considerable financial saving to the health system and maintaining their own health and wellbeing was crucial. The Norfolk and Suffolk Foundation Trust had a service for people with complexity in later life, and wanted to offer early diagnosis and treatment, involving the patient even when the condition was complex or acute. They wanted to keep people out of acute hospitals wherever possible. Zena said that Admiral Nurses primarily supported unpaid carers of people with dementia. She was a band 7 nurse employed by Age UK Norfolk for two years with funding primarily from the People's Health Trust. They were piloting a service with 7 GP practices in mid-Norfolk to clarify the dementia pathway, alongside 2 band 6 Admiral Nurses employed by the Norfolk and Suffolk Foundation Trust (1.65 full-time equivalent) who were caseworkers. 104 referrals had been received since May 2013, and around 86 people were currently receiving support from Admiral Nurses. Carers who did not need their service were referred on to other support. Referrals could come from GPs or from carers themselves – those from outside the pilot area were referred on, and they worked closely with partner agencies to signpost people on to the right support. Recent examples of case work included a carer who had looked after her husband for 10 years during which time his health had significantly deteriorated. The carer had her own health issues but had been putting off the surgery she needed, and had become suicidal. She felt that her role was a part of being a wife and didn't see herself as a carer. Admiral Nurses had given her an opportunity to discuss her situation and provide emotional and psychological support especially during the transition of diagnosis. Early support could prevent crisis situations. The service was being evaluated and would identify how the Admiral Nurse model might fit within a range of post diagnostic support.
14.	**Changing the culture in acute hospitals** - Dr. Martyn Patel, Consultant in Older People's Medicine, Norfolk and Norwich University Hospital (NNUH)

	Martyn was the lead dementia consultant at NNUH. He said dementia was one of the hospital's top priorities as around one third of their 900 beds were occupied by patients with cognitive impairment but most of whom were being treated under different specialisms, and also because the numbers of people with dementia would continue to increase. Timely diagnosis was crucial – for the last twelve months, all people aged 75+ admitted to the hospital for a non-elective reason had been asked memory assessment questions, and their carers were also asked for their views. Those scoring less than 8 on a ten point memory score were referred to the Norfolk and Suffolk Foundation Trust's Memory Assessors for a dementia assessment. Of the 600 - 800 people aged 75+ admitted each month to NNUH, around 50-60 were screened as having potential problems. It was very important to raise awareness with consultants in all specialisms of the importance of timely diagnosis, as they encounter patients who were in hospital because of a physical illness but who had cognitive impairment - some consultants needed to be convinced of the value of timely diagnosis. Training staff in dementia awareness was also crucial – they had a dementia coaching programme provided by the Norfolk Dementia Academy to train ten members of staff as Dementia Coaches, and all new staff received basic dementia awareness training which was appropriate to their role. They had also received government funding for 4 Dementia Support Workers in a non-clinical role, led by a registered nurse to enhance the hospital experience of people with dementia and their carers, starting with in-patient areas, and also to support patients who had had a diagnosis of dementia and their carers. They had time to talk to patients and carers, and also provided information and signposting, and helped patients and their carers fill in 'This is me' booklets so staff understood more about them. The library would shortly have reminiscence boxes to loan to wards, and the Dementia Support Workers had been supplied with new name badges with the first name in large, friendly letters. Research projects, clinical trials and other initiatives were also being undertaken in preparation of increasing numbers of people with dementia.
15.	**Dementia Care Coaches for the workforce – paid and volunteers** Willie Cruickshank, Director, Norfolk and Suffolk Dementia Alliance Willie outlined the six principles of care, compassion, competence, communication, courage and commitment. Dementia training wsa now mandatory at the Norfolk and Norwich University Hospital. The dementia competence framework went from 'unconsciously incompetent' to' consciously competent', with greater training needs the further away the person was from clinical knowledge. The University of East Anglia (UEA) had undertaken a study into training needs in acute hospital trusts in Norfolk and Suffolk, and found that 92% of staff reported insufficient training in relation to caring for people with dementia. For example, paramedics received no dementia training. This was now being offered in nursing schools and on paramedic training. Only around 40% of learning was transferred into practice, because of

	factors to do with the learner, with the training intervention and with the work environment. The learner needed to see the value in the training, the training design and delivery needed to be appropriate to the learner, and In the work environment coaching (one-to-one learning), mentoring (informal support), and role modelling (example of good care) were all important. The ideal was that everyone would be trained in basic dementia awareness, working up the scale. Three hundred and seventy Dementia Care Coaches had been trained so far, with a coordinator based in Norfolk, but most were used in residential care and home care while the primary care sector was less keen to engage. Further training places had been offered to the acute sector, and ambulance trusts - 280 learners were currently going through the course.
16.	**Questions and comments** Some people and their carers were fearful of dementia and having a diagnosis**.** Willie Cruickshank said that this, and the fact that GPs were concerned post-diagnosis support wasn't available, were two of the reasons behind the low diagnosis rate. Robust post-diagnosis support was needed for patients, and 50% reported no support available after diagnosis. Dr Neil Ashford said that the 30% diagnosis of dementia by GPs Waveney in 2001 had risen to 70% when he left – increasing numbers helped raise awareness of the value of timely diagnosis. The challenge was in convincing GPs, and many meetings had taken place since the national dementia strategy had been introduced in 2009. Bringing together the Clinical Commissioning Groups (CCGs) to highlight the services available could help. A focus on giving patients and carers access to support and advice was needed - if they didn't know what was available, how could they find out and how could it be made more accessible? There was a need to recognise that the vast majority of over 75s were not computer literate and needed accessible information on paper, and information and advice provided face to face. Joyce Hopwood said that people in a crisis in hospital weren't always able to absorb information, and talks were underway with Norfolk County Council to produce an older people's handbook similar to the carer's handbook. This would bring all the information into one place so that there was a clear idea of the routes that could be followed. This would give the reader time to refer back and digest the information. It was suggested that electronic copies of relevant leaflets and booklets could be given to Annie Moseley (anniemoseley@talktalk.net) for forwarding to Dr. Neil Ashford. Many rural communities relied on mobile and home visit library services – they were local and had a big role in providing information. Jan Holden confirmed that funding for travel expenses was available for those attending libraries' Surf's Up and their reading events. Libraries were community hubs and, working with partners, could provide information for people with dementia and their carers. Identifying people as carers and supporting them was crucial.

	If someone has dementia but doesn't want to get a diagnosis, one way forward might be to talk to their GP as GPs are the key route to diagnosis; otherwise, they could be referred through adult safeguarding procedures if there is risk.
17.	**Any Other Business** A free performance of a play was being put on at the City College on 23rd November, focussing on dementia. Members of the group were asked to complete the yellow forms highlighting their priorities in readiness for the Away Day on 4th December 2013, which would be hosted at Breckland Council. The next meeting of the Norfolk Older People's Strategic Partnership is on **Wednesday 5th March 10.0am – 1.0pm at County Hall Cranworth Room** **followed by an informal discussion over a sandwich lunch with the speakers until 2.0pm.** Members of the public are very welcome to attend.