

## Warwickshire Shadow Health & Wellbeing Board

24 January 2013

### Dementia in Warwickshire – The Warwickshire Dementia Strategy, National Dementia Declaration, Dementia Care and Support Compact

#### Recommendations

That the Warwickshire Shadow Health and Wellbeing Board:

1. Sign up to the National Dementia Declaration and action plan (attached as Appendix 2).
2. Lead the implementation of the actions associated with the Prime Minister's 'Challenge on Dementia' as defined within the letter to the chair from the Care and Support national sub group (attached as Appendix 1)
3. Make Dementia a priority.
4. Support the organisation of a conference on Dementia scheduled for the Summer of 2013.

#### 1.0 Key Issues

- 1.1 The National Dementia Strategy sub group has written to all chairs of Health & Wellbeing Boards and asked them to, as part of the Prime Ministers 'Challenge on Dementia', to consider:
- Reviewing your local Dementia Strategy with particular emphasis on enablement and intermediate care access for people with dementia, accommodation solutions, end of life support and health and social care workforce development
  - Ensuring the needs of people with dementia and their carers are part of the Joint Strategic Needs Assessment process
  - Whether you need to make dementia a priority in your Joint Health and Wellbeing Strategies.
  - Signing up to the National Dementia Declaration and joining your Local Dementia Action Alliance to work with local partners to drive forward improvements for people with dementia in your area (link below).  
(copy of letter attached as appendix 1)

## **2.0 Context**

- 2.1 “Dementia results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills, and those skills needed to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care.” (National Dementia Strategy 2010).
- 2.2 Warwickshire’s Dementia Strategy was approved by Cabinet in February 2011. Significant progress has been made to establish the profile of the work of the Dementia Strategy Board including its extension to a sub-regional board with Coventry.

### **2.3 What are the big issues?**

- The projected increase in the number of people with dementia in Warwickshire is currently estimated to rise by 39% between 2011 – 2021 (pop: 7166 – 9940).
- The prevalence of dementia increases with age, at present, 1 in 14 people aged over 65, and 1 in 6 people aged over 85 have some form of dementia.
- Combined with the projected increase in older people in Warwickshire, as a result of people living longer, there is likely to be an increase in demand for services to support people with dementia as well as their carers and families.
- Between 2010 and 2030, it is estimated that the number of older people with dementia in Warwickshire will double, to more than 13,000. The majority of these will be aged 75 and over.
- Dementia diagnosis is low; according to the Alzheimer’s Society only 38% of dementia cases in the West Midlands are diagnosed. In 2008 less than 50% of the predicted number of people with dementia were recorded by their GP as having dementia.
- Currently, in the UK, around two thirds of people with dementia live in private households.
- It is not currently known how many people with dementia are funding their own care both in residential care and in their own home.

### **2.4 What do we need to do?**

- 2.5 Warwickshire Partners already have a substantial programme of work underway, overseen by our local Dementia Board. This inter-agency group enjoys customer and carer representation and is overseeing the implementation of “Living Well with Dementia”, our dementia strategy for

Warwickshire (attached as Appendix 2). Its primary focus aligns to the four priorities defined by the national strategy and are:

- 2.6 Awareness and Understanding:** A lack of understanding of dementia can lead to a number of problems including symptoms not being recognised early enough leading to poor access to services and poor outcomes.
- 2.7 Early Diagnosis and Support:** Early diagnosis is key to providing the right support to both service users and carers in a timely manner.
- 2.8 Living Well with Dementia:** Users and carers highlight that once diagnosed with dementia they require a range of services that fully meet changing needs. Whilst there are already a number of services in Warwickshire that offer both support and services to people living with dementia, it is recognised that there is more to be done to make sure the highest quality support and services are available to people with dementia and their carers.
- 2.9 Making the Change:** Service users and carers in Warwickshire have told us that the National Dementia Strategy recommendations for an informed and effective workforce are key to improving services.

### **3.0 Response and Proposals for Future Action**

- 3.1 The following outlines the progress made against the four priorities contained in the Care and Support sub group letter and proposals for future action:
- 3.2 Reviewing your local Dementia Strategy with particular emphasis on enablement and intermediate care access for people with dementia, accommodation solutions, end of life support and health and social care workforce development**
- 3.3 Enablement** – information, advice and signposting has been cited by people with dementia and carers as the primary enabler. With this as the primary focus and led by the Director of Public Health, the workstream for Awareness and Understanding have developed the Dementia Portal. Cited, by the Prime Minister in December<sup>1</sup>, as a model of good practice the portal aims to be a clear and simple place for good information for all stakeholders, including GPs, health and social care staff as well as people with dementia and carers <http://www.warwickshire.gov.uk/livingwellwithdementia>
- 3.4 The Books on Prescriptions, launched in September 2012, is also yielding positive results with over 200 books loaned in the first three months of adding dementia related titles to this initiative.
- 3.5 During 2012 the reablement service extended their services to include people with dementia as a new cohort and staff have been training specifically to support those with a wide range of needs who are assessed as having potential to still benefit from a reablement service.

- 3.6 Additionally there is a growing evidence base for the use of Assistive Technology. Warwickshire is building on the research to date on the use of iPads and working in partnership with Coventry University to evaluate the extent to which such technology supports the management of challenging behaviour. Family carers are benefiting from a system known as 'Just Checking' which allays fears and concerns about the safety of someone who may live alone and has dementia. There is also a growing evidence base for the cost benefits to using technology and with this in mind a conference is being arranged for the Spring/Summer across the Partnership.
- 3.7 **Intermediate Care** - Warwickshire Adult Social Care fund a series of 'Moving On Beds' across the county to support appropriate discharge from hospital. As an example, during March – July 2012, 60 people were discharged from hospital into the moving on beds. In addition and through an alliance and partnership between WCC, SWFT and SWCCG the Discharge to Assess (D2A) Project, which aims to improve discharge processes for patients including those with dementia to appropriate destinations, has been established. The D2A model is based on three pathway destinations. Pathway 2 'discharge to assess' where home is not an option at the point of transfer but permanent residential care is not inevitable will include transfer to homes that include therapeutic and reablement over a 6 week period to enable residents to go home with little or no ongoing support required. The aim of this Intermediate Care model is to maximise peoples' capacity for independent living, increase the number of people able to remain living at home and reduce the number of people permanently admitted to long term care. The project has been confirmed as Countywide and the governance will now include representation from NWCCG and C&RCCG together with the relevant Trusts.
- 3.8 **Accommodation Solutions** – There are 160 homes of which 95 are for older people - the latter will all have some involvement with dementia even if they don't 'specialise'. 48 of the older people homes 'specialise' in dealing with dementia but this is increasing all the time as the demand for pure residential continues to fall and the rate of diagnosis increases. In line with national guidance, there is an expectation that up to 25% of people living within an Extra Care Housing setting will have some level of dementia. There is a requirement therefore for providers to ensure that they have the staff in place to manage this level of need. WCC is on course to deliver 500 'affordable' ECH units by 2014/15, which suggests well over 100 people who are suffering with dementia will be living within an ECH setting. WCC is also looking to provide more specialised housing with care models to meet the needs of those with say Autism and Dementia. With this in mind, an Outline Business Case is currently being drafted in preparation for a forthcoming tender for up to 5 smaller WCC-owned sites, which would be better suited to bespoke and specialised services. These sites and some larger schemes being developed by the independent sector, e.g. 178-unit scheme being developed by Orbit at Leamington Queensway, would see the introduction of the 'Locksmith' model to Warwickshire, which has been progressed elsewhere by Prof Dawn Brooker and the Extra Care Charitable Trust.

<http://www.extracare.org.uk/extracare-communities/care-and-well-being/dementia-care.aspx>

**3.9 End of Life Support** – People with dementia who are dying should have the same access to EOLC services as those without dementia. However, treatment decisions differ for people with dementia from other people approaching end of life in two ways. First, the decline in health is less predictable and more variable, making prognosis difficult. Second, the deterioration in communication skills prevents people with dementia from expressing their views and wishes later in the disease pathway. Most people with dementia die in residential care or in hospital. For Warwickshire currently over 55% of people die in hospital despite 80% stating that they want to die in their own home<sup>ii</sup>. For some, the pattern of their last year or months of life can be one of both comfort and dignity. But others experience mental and physical pain alongside physical deterioration and malnutrition; frequent, unhelpful and costly admissions to hospital; and a reduction in quality care and dignity. An improvement in access to high-quality care for all people with dementia approaching the end of life is needed. This is being progressed with care homes through initiatives such as the Care for VIPS and also a training for staff within care homes around End of Life Care given the high number of people admitted from residential care in to an acute setting who die within 24/48 hours after admission. Further work and investment is required to support families so that more people with dementia are supported and able to die at home. We will work to ensure that end of life plans are considered at an early stage of an individual's journey with dementia by promoting this via our information portal and paying particular attention to raising the awareness of advance care directives and future plans when we re-design our community support services. Often these conversations are happening too late resulting in the person with dementia not being able to make their EOLC wishes and preferences known.

**3.10 Health & Social Care Workforce Development** – Work has commenced with providers of residential and nursing care through a quality premium payment incentive scheme and with a dementia training programme that supports the provider workforce to raise standards and improve quality of care. We have already delivered the care fit for VIPS (valuing, Individualised, perspective, social) <http://www.carefitforvips.co.uk> to over 90 care home managers in 2012 that provides training in person centred care which promotes valuing people, providing Individualised care, looking at services from the perspective of the person living with dementia and promotes the social-psychological support needed to compensate for the disability of cognitive loss. We plan to build on this in 2013 with the introduction of a leadership training course for care home managers, developed by Professor Dawn Brooker at the University of Worcestershire and to expand this further through the Dementia Declaration to the health and social care workforce.

- **Ensuring the needs of people with dementia and their carers are part of the Joint Strategic Needs Assessment process**

The needs of people with dementia and their carers are a key part of Warwickshire's Joint Strategic Needs Assessment. Dementia is also a key theme of the JSNA and is currently being reviewed and updated.

<http://jsna.warwickshire.gov.uk/2012/01/31/dementia/>

- **Whether you need to make dementia a priority in your Joint Health and Wellbeing Strategies.**

Dementia fits well with the three priorities contained in the Health & Wellbeing Strategy and should therefore be considered as a high priority for all agencies. The Health & Wellbeing Board are in a good position to give Dementia the profile that it requires to drive innovation and service solutions so that people with dementia live well and their carers and families are able to support them for as long as possible.

- **Signing up to the National Dementia Declaration and joining your Local Dementia Action Alliance to work with local partners to drive forward improvements for people with dementia in your area.**

The Dementia Action Alliance is made up of over 100 organisations committed to transforming the quality of life of people living with dementia in the UK and the millions of people who care for them. Members of Dementia Action Alliance have signed up to a National Dementia Declaration.

The National Dementia Declaration was created in partnership with people with dementia and their carers, the Declaration explains the huge challenges presented to our society by dementia and some of the outcomes the dementia action alliance are seeking to achieve for people with dementia and their carers. Outcomes range from ensuring people with dementia have choice and control over decisions about their lives, to feeling a valued part of family, community and civic life. Each signatory to the Declaration publish their own Action Plans setting out what they each will do to secure these outcomes and improve the quality of life of people with dementia by 2014.

- 3.11 The National Dementia Declaration has 7 key outcomes and can be found at [http://www.dementiaaction.org.uk/info/3/national\\_dementia\\_declaration](http://www.dementiaaction.org.uk/info/3/national_dementia_declaration)
- 3.12 An action plan for Warwickshire linked to the National Dementia Declaration is attached as Appendix 2

## Background papers

1. <http://www.warwickshire.gov.uk/livingwellwithdementia>
2. [http://www.dementiaaction.org.uk/info/3/national\\_dementia\\_declaration](http://www.dementiaaction.org.uk/info/3/national_dementia_declaration)

3. <http://jsna.warwickshire.gov.uk/2012/01/31/dementia/>
4. <http://www.carefitforvips.co.uk/>
5. <http://www.extracare.org.uk/extracare-communities/care-and-well-being/dementia-care.aspx>

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<sup>i</sup> [http://www.guardian.co.uk/social-care-network/2013/jan/03/warwickshire-dementia-portal-brings-information?CMP=tw\\_t\\_gu](http://www.guardian.co.uk/social-care-network/2013/jan/03/warwickshire-dementia-portal-brings-information?CMP=tw_t_gu)

<sup>ii</sup> Joint Strategic Needs Assessment for Warwickshire – Dementia 2012.