

# Gloucestershire National Dementia Strategy Local Action Plan Summary

**Living well with dementia - a National Dementia Strategy** was published by the Department of Health in February 2009. It set out a vision for transforming dementia services with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting.

NHS Gloucestershire, along with its partners in health, social care and the voluntary sector, has produced a Local Action Plan, to ensure the county meets the vision set out in the National Dementia Strategy.

Below is a progress report to show some of the ways in which services and support for people living with dementia are being improved in the county.

## Effective Management Systems

A key part of the Local Action Plan is joint working. NHS Gloucestershire works closely with Gloucestershire County Council, Gloucestershire Hospitals NHS Foundation Trust, 2gether NHS Foundation Trust and the voluntary sector. Engaging with community groups, LINk and local politicians has played an important role in communicating key messages.

The Dementia Project Management Board meets on a regular basis and is made up of representatives from across the health community, social care and the voluntary sector.

The countywide dementia project group has worked closely with a number of people living with dementia in Gloucestershire whose invaluable contribution has provided a unique opportunity to place the person with dementia at the centre of the project.

## Objective 1: Improving public and professional awareness and understanding of dementia

This was a key objective, identified 18 months ago as a national priority. Since then much work has been done to develop relationships with local media to promote positive messages about dementia and enhanced the skills of the project team in taking opportunities to raise public and professional awareness. The appointment of an Older People's Communication Manager on a fixed term contract helped with the success of this objective.

As part of the work to improve professional awareness, in November NHS Gloucestershire held its third Gloucestershire Primary Care Dementia Summit at Cheltenham Racecourse. The event was attended by GPs, nurses, social care staff and other community partners.

The summit launched the revised Primary Care Dementia Pathway, with the theme focussing on appropriate prescribing and alternatives to prescribing antipsychotic drugs, with workshops looking at a range of key issues such as end of life care, giving diagnosis, art, care homes. Stands at the venue provided delegates with an opportunity to gain more information about services provided in the county. The event brought together GPs and primary care teams from across the county to listen to international, national and local speakers, including people living with dementia.

In addition members of the Dementia Project Management Board have been actively engaging in a wide range of meetings, discussion groups, local events and training to carers, community groups, health and social care professionals. Including:

- Locality GP commissioning groups
- South West Dementia Partnership Conference
- Regional Commissioning Network
- Gloucestershire Primary Care Dementia Summit
- Community Nurse workshops
- GP Protected Learning Time events
- Carers Forum
- Gloucestershire BME Community Event
- Local councillors

## **Objective 2: Good-quality early diagnosis and intervention for all**

Working closely with clinicians in Gloucestershire has been a key part of the Local Action Plan. To support this the Dementia Project Management Board has benefited from the input and advice of Dr Martin Freeman, the county's GP Clinical Lead for Dementia, Dr Ian Donald, General and Old Age Medicine Consultant, Gloucestershire Hospitals NHSFT and Dr Martin Ansell, Consultant Psychiatrist at 2gether NHS Foundation Trust, who also is Chair of the South West Memory Assessment Service Expert Reference Group.

As part of the objective to improve early diagnosis, 2gether NHS Foundation Trust launched a reshaped county-wide Memory Assessment Service (MAS) in November 2010. The MAS is based on a "hub and spoke model", with open access to single point of referral. The hub triages referrals and allocates patients to locality teams for assessment. The MAS is supported by Managing Memory 2gether Carers' Education Programme which includes sessions for the person with dementia and an introduction to the Living Well Handbook.

The Project Management Board has met with Learning Disabilities commissioners and providers to understand the relationship between the Primary Care Dementia Pathway and the Learning Disabilities Memory Assessment to address any issues for people with learning disabilities who may develop dementia.

The Equality Impact Assessment of the Gloucestershire National Dementia Strategy Local Action Plan has been instrumental in identifying other areas where access to services needs to be improved.

### **Younger onset dementia**

Feedback from younger people living with dementia in Gloucestershire has identified a lack of support and services which reflect the needs of younger people with dementia. To address this resources have been allocated to the Alzheimer's Society to develop their existing Pub Club, which has been rebranded as Good2Go and works in partnership with people living with dementia.

Funding has also been allocated for a year-long project with the Cobalt Unit in Cheltenham which allows the MAS clinicians to access enhanced diagnostic tools for the more complex types of dementia found in younger people. Making an accurate diagnosis as early as possible helps ensure people get the right treatment for their condition as soon as they need it.

### **Black and minority ethnic groups**

Two workshops with multicultural representation have been held to explore what support and information would be appropriate to different community groups. The message shared was that dementia affects people in the same way whatever their background, but many cultures do not necessarily recognise dementia as an illness.

The workshops have produced seven key actions which will be included in the updated Local Action Plan:

1. Training on cultural awareness for health and social care staff, particularly GPs
2. Flexible translation services
3. Training on dementia for community groups
4. Better use of media to raise awareness of services and support
5. Better understanding of community networks
6. Flexible, culturally sensitive outreach and respite services
7. Monitoring of services.

In light of the workshop the Dementia Project Management Group's community champions have volunteered to develop plans to set up a multicultural memory club in partnership with third sector groups and district councils in Gloucestershire.

### **Objective 3: Good-quality information for those with diagnosed dementia and their carers**

After consultation with people living with dementia and their carers, the need for a flexible information resource was identified as a priority.

This idea was developed to produce a handbook, owned by the person with dementia, that provides information after diagnosis and includes information for health and social care staff about the individual's needs. It includes the Alzheimer's Society's This is Me, DisDAT distress tool and the Gloucestershire Advanced Care Plan.

As a result the Living Well Handbook was launched in September 2010.

More than 900 copies of the handbook are now in circulation in Gloucestershire, beginning to appear in GP surgeries and hospital wards. Funding from the South West Strategic Health Authority has enabled translation of the handbook into Chinese, Polish, Czech, Urdu, Gujarati and Bengali. Winning the Success in Partnership Working category of the South West Health and Social Care Awards on October 2010 was extremely important in generating interest and demand for the handbook.

Review of the impact of the handbook will be through case studies, but some initial feedback has been received from people with dementia:

*“Liked the information and chance to index personal requirements”*

*“Very comprehensive. Pitched about right. Hard to suggest improvements”*

*“I no longer feel alone”*

Access to the Living Well Handbook is still developing, and is available free from:

- Managing Memory 2gether
- Memory Assessment nurses
- Alzheimer’s Society and Dementia Advisors
- Carers Gloucestershire
- Caring with Confidence
- Community Hospitals
- NHS Gloucestershire offices

#### **Objective 4: Enabling easy access to care, support and advice following diagnosis**

The Alzheimer’s Society was commissioned to provide three full-time Dementia Advisors (DA) for one year from August 2010, with the intention of widening access in the three designated areas after the first year. The role is an integral part of the Primary Care Dementia Pathway and the DAs work closely with the Managing Memory 2gether service.

The service has grown quickly in the two rural areas (Berkeley and the North Cotswolds) but at a slower rate in the urban base (Gloucester City), however this is now improving. There is also case study evidence to show that the DA service has been effective in preventing admission for one individual and facilitating discharge for another.

#### **Objective 5: Development of peer support and structured learning networks**

Collaboration with the Alzheimer’s Society and resources allocated to the six district councils to develop a network of peer support groups is beginning to show results by the number of new groups opening. Two groups have opened and plans for a further nine are at different planning stages. The planned groups include a multicultural group and one for younger people with dementia

The aspiration was to have at least 12 new groups across the county by March 2011, with inspiration drawn from the successful Devon Memory Café network. In reality, it has taken time to develop the volunteer support and ensure sustainability.

The three DAs have established good working relationships with local support groups and the Managing Memory 2gether service. The DAs incorporate their information pack into the Living Well Handbook where issued.

Exploratory talks have been initiated with Fair Shares to look at whether Time Banks meet the needs of people with dementia. Initial discussions suggest that the existing scheme is suitable for those with dementia and their carers.

### **Objective 6: improved community support services**

An information portal has been developed using Your Circle branding to set it apart from the Gloucestershire County Council internet site ([www.yourcircle.org.uk](http://www.yourcircle.org.uk)). This is to increase accessibility for those who people might not see themselves as needing help from social services. The Living Well Handbook will be placed on Your Circle.

Training has been given to the voluntary care sector and other organisations to enable them to provide their own information on the portal. Training is currently in progress for library staff, Village Agents and other community groups so they can help others to access information via the portal.

Personal budgets are currently being offered to all older clients. This enables more flexibility in how people organise the support they need. Person-centred support plans are in place, with all social care staff trained to enable them to guide and facilitate people to develop their own support plans with their carers. Person-centred support plans are also reflected in design of the Living Well Handbook.

### **Objective 7: Implementing the carers strategy**

Carers' involvement has been crucial in understanding and shaping the direction of travel for Gloucestershire dementia services. Carers have contributed to the development of the Living Well Handbook and Primary Care Dementia Summit workshops, and act as vocal and articulate champions.

The successful bid for Department of Health South West funds for improving carers support will be used to design a learning package to supports health and social care professionals' understanding of the needs of those caring for people living with dementia.

### **Objective 8: Improved quality of care for people with dementia in general hospitals**

Clinical leads are identified for all three health trusts (NHS Gloucestershire, Gloucestershire Hospitals NHS Foundation Trust and 2gether NHS Foundation Trust) with strategy and improvement plans in place. Care Quality Indicators have been influential in raising the profile and needs for people with dementia and their carers. Initiatives have included care plans for people with known dementia and one for suspected or mild cognitive impairment; these are supported by reasonable adjustments guidelines.

The health trusts have committed to the regional Hospital Standards for Dementia framework. Training of Dementia Care Mappers has taken place, with at least one mapper in each organisation. The next step is to plan mapping activities and to assess if any improvements are needed to improve services for patients with dementia.

The Mental Health Liaison service has been restructured and re-commissioned to provide an age inclusive service which includes dementia.

Secondary care Old Age Psychiatrists and Old Age Medicine consultants have been working collaboratively to support primary care in actions identified following the anti-psychotic prescribing audit.

### **Objective 9: Improved intermediate care for people with dementia**

Training for community teams has continued with 30 Domiciliary Care staff starting the second cohort of Dementia Link Worker training. A total of 125 Community Steps staff are also following the pathway.

The Reablement Project is in place to deliver an equitable countywide reablement pathway which will incorporate intermediate care and enablement. A number of workstreams, including workforce development and training and finance and capacity modelling, are in place to support this.

### **Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers**

Dementia training for scheme managers remains a priority with the Dementia Training and Education Strategy. Telecare has been explored for sheltered housing, but there are concerns about cost and compatibility of existing technology and scheme managers themselves felt that training was more helpful and effective at this time.

### **Objective 11: Living well in care homes**

A bid for Department of Health South West funds for testing a Dementia Quality Mark in care homes was successful, and multi agency work is beginning to plan the implementation of this accreditation scheme.

A team of care home managers is currently receiving dementia leadership training to support the Dementia Link Worker programme, and is ideally placed to support new ideas and challenges.

### **Objective 12: Improving end of life care for people with dementia**

Close collaborative work continues between National Dementia Strategy and End of Life Care Strategy and the localised versions of each, with information and updates included in the respective newsletters.

The joint working group has produced a summary document on pain assessment for those with impaired communication or cognition, which recommends:



- The British Pain Society and British Geriatric Society (2007) algorithm for assessing pain in the older person
- The Gloucestershire NHS Foundation Trust Pain Score Tool on admission for all patients
- The Abbey Tool for assessment in acute care settings where the person is not known, or carers are not available and the person can not communicate pain
- The DisDAT Tool for assessment in partnership with the person and carer, and as a more comprehensive review to follow up any Abbey Tool assessment.

Feedback from the group has been incorporated into the Dementia Link Worker training. The group has developed an action card and supporting flyer to support recognition and treatment of pain in people with dementia. Pain assessment tools and information can be found on [www.gloucestershire.gov.uk/dementiatraining](http://www.gloucestershire.gov.uk/dementiatraining)

The Gloucestershire National Dementia Strategy Local Action Plan has been cross referenced with the Gloucestershire Suicide Prevention Strategy; this action plan does not have specific actions to prevent suicide, but identifies depression as a possible diagnosis in the Primary Care Dementia Pathway, and recognises the need to support carers with education and needs assessments.

### **Objective 13: An informed and effective workforce for people with dementia**

The Joint Gloucestershire Dementia Training and Education Strategy continues to support workforce development, with keen regional interest in adopting the Gloucestershire model across the South West. The priorities for year three of the Action Plan include Scheme Managers, Primary Care Teams and community groups.

### **Objective 14: A joint commissioning strategy for dementia**

The Public Health Dementia Review has been completed and will be reviewed in Autumn 2011/12. Joint work with colleagues from Swindon has begun to explore how outcomes for the person with dementia can be used as a measure rather than traditional process targets.

### **Chapter 16: Prescribing anti-psychotic medication**

A multi agency, multi professional audit of primary care was completed in 2010 with the interim project report submitted for the Strategic Health Authority Anti-Psychotic Prescribing Audit January 2011. The report identifies the issues that the audit raised, and contains a number of actions to address the issues. Gloucestershire is well placed to respond to the Dementia Action Alliance's campaign - The Right Prescription: a call to action on the use of anti psychotic drugs for people with dementia (June 2011)

### **Summary**

Joint working between Gloucestershire's three NHS trusts, Gloucestershire County Council and third party and voluntary groups has been a key part of the success of the last 18 months. The partnership working has helped identify gaps in service provision and to ensure services are more joined up.

Progress has been made to ensure the right information is available for the right people, whether they are healthcare professionals, carers or people with dementia, at the right time.

Work to help people improve their skills and provide appropriate care for people living with dementia will continue, alongside the development of specific tools such as the Living Well Handbook and the pain assessment tool.

We have started to reach out to the different and diverse communities within Gloucestershire to ensure we can support people with dementia, whatever their background and make sure we provide the information and tools which are appropriate for them.

## The next steps

Whilst great progress has been made in the last 18 months there is still work to do to improve the quality of care for people in Gloucestershire living with dementia and the support available for those who care for them.

Priorities over the coming months will include working closely with GPs and primary care teams to improve training and education around dementia. Money from the Department of Health South West funds has already been allocated for a project to engage with GPs, this will be lead by Dr Martin Freeman, NHS Gloucestershire's Clinical Lead for Dementia.

Another key area will be looking at how we care for people with dementia in a hospital setting, whether it is one of the main general hospitals in Gloucester or Cheltenham or one of the smaller community hospitals. This will include work to make sure staff have the appropriate training to identify the needs of patients with dementia, ensuring our hospitals provide the right environment for those with dementia and that the regional hospital dementia standards are met and maintained.

We know a diagnosis of dementia can be frightening and daunting, both for the person with the condition and their family or friends. In Gloucestershire we are working hard to educate and support the people who care for someone with dementia. Our Dementia Training Programme is available on the [www.gloucestershire.gov.uk/dementiatraining](http://www.gloucestershire.gov.uk/dementiatraining) can be accessed by anyone.

More than three quarters of the county's care homes now have a Dementia Link Worker – a member of staff who receives intensive training from Dementia Education Nurses and then shares their skills and knowledge with other staff in the home. We know that this is improving the quality of dementia care within homes. Our training is now expanding to cover community care services, the private sector and voluntary organisations.

We want to make sure anyone who cares for someone with dementia has the information and training they need.

We need to continue to make dementia a talking point and to challenge the assumptions that many people make about those living with the condition.

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