Bristol Dementia strategy
Living well with dementia

Feeding back from the consultation
December 2011

Thank you for your comments on the 'Living well with dementia' draft Joint Dementia Strategy. The comments that we received were very helpful and demonstrated to us the high level of interest in the issue of dementia care in Bristol. As we cannot respond to every comment individually, this document attempts to draw out the main themes and to explain to you our response to them.

Please note that the strategy sets out the themes and overall direction of travel in relation to dementia services and is not intended to focus on the detail. However, the detailed comments that we received are most useful and we will ensure that we take account of them in the implementation.

Issue	Comments	Response
1. Focus of the strategy to include carers	That the strategy should overtly focus on both people with dementia and their carers in recognition of the vital role that carers play in the care and support of people with dementia	We have consequently made changes throughout the document to reflect this (e.g. in the executive summary etc.) The needs of carers are fully addressed within our Joint Carers Strategy which will work in parallel with

		the Dementia Strategy. Additionally, there are new dementia services that are particularly aimed at supporting carers
2. Distribution of funding throughout the care pathway	The opinion was expressed that the strategy should not represent a shift in funding from 'secondary' care to earlier intervention. Rather, that it should instead represent an overall increase in funding at all stages of the 'dementia care pathway'	• Our current pattern of funding represents a historic weighting towards the more intensive end of service provision, and an associated lack of investment in early intervention and primary care level services. We recognise that people with dementia should have their particular needs met by any services (including 'mainstream' community and neighbourhood facilities). However, some services may need support to provide the most appropriate help to them and their families, particularly at the early stages • We maintain the need to redistribute funding and services to ensure they are appropriately distributed along the entire 'care pathway', with increased emphasis on prevention and early intervention. We also need to change the way services are provided if they are to be affordable, with more emphasis on lower level, preventative services, which may require some shift of resources away from the current focus on specialist services for people

		with higher levels of need. It would be expected that, with such interventions, as well as use of wider community resources, there will be a reduced need for the current levels of services at the secondary level • From our recent consultation, it is clear that some people are concerned that the Dementia Strategy is aimed at reducing the provision of specialist services in order to invest in more prevention and early intervention. Whilst this is true, it is important to emphasise that the overall aim of the Strategy is to ensure that a broader range of support is available across the whole spectrum of need. It also aims to reduce the need to be seen in specialist services by improving the quality of the support provided by mainstream services • In the medium to long term we hope this will result in less demand on specialist services because more people will have their needs met in 'mainstream' services. For example, diagnosis is often carried out by the Memory Service currently but in future GPs will more commonly diagnose and only refer people with more complex needs for

		specialist help. Similarly many people may be admitted to specialist care homes who could spend a longer period at home with the help of Assistive Technology, improved reablement services and better trained home care staff or in a non-specialist care home setting. One of the main areas for development to deliver this is training of the workforce, across all sectors and disciplines and this will be a key strand of the workplan over the coming months
3. Primary Care support	• To enable GPs to prescribe dementia medication • To have social care and health focussed services at a primary care level in order to better support people in Primary Care and to avoid them advancing into secondary services	These are important points which we have strengthened in the strategy
4. The importance of monitoring, evaluation and review	• The need to ensure the appropriate measurement of the short and medium term objectives and actions before being able to move onto the longer term ones • The importance of ongoing evaluation and it feeding into future strategic and service development	We have reinforced these points in the strategy to show that the development of longer term measures is dependent upon the fulfilment of the short and medium term ones.
5. Measurement of effectiveness	There needs to be ways of measuring both the effectiveness of services and their value for money. The Strategy mentions value for money with no explanation of what it means and how it can be measured	These are helpful comments and we have integrated them into the strategy. All services need to be able to show their effectiveness, that they are achieving outcomes - making a tangible difference in people's lives. We also

		need to be able to show that they are good value for money and have means of measuring this. The Bristol City Council Enabling Commissioning Framework is designed to improve consistency around commissioning including being more robust about how we evaluate service impact
6. Safeguarding issues within independent sector non-regulated provision	Concerns were raised about a potential lack of safeguarding of vulnerable adults in some unregulated independent sector provision, for example services that might be bought with a direct payment/individual budget	These are of course very important issues, but they are not purely 'dementia' specific. We will ensure that the particular issues of vulnerability that might be faced by people with dementia are incorporated in all Safeguarding policy and practice and that quality monitoring arrangements are put in place for new types of provision that is not subject to the current means of accreditation and monitoring e.g. services bought through Self Directed Support (individual budgets)
7. Continuity of contact with services	The desire was expressed for a single worker to work with a family throughout their time needing services. This was partly to avoid multiple workers working with, for example, the person with dementia and their carer, and partly to mitigate the experience of high turnover of staff	We recognise the disruption and confusion that can go with rapidly changing and multiple staff from different services. We are exploring the provision of a robust system for supporting a family (and the various professionals that might be involved with them) through the dementia care pathway. Staff turnover is not easy to control, but the need for continuity of staffing and contact with a family is recognised. We also recognise the importance of sharing information and assessments

		across services and we will include this in the work
8. Accuracy of the data	It was pointed out that in places, the data that is provided is old, incomplete or inaccurate	We have reviewed the data and ensured that accurate and most up to date data is included in the final strategy. We also recognise the need to update the data regularly
9. Correction to 'Extra Care Housing'	The references to 'Very Sheltered Housing' should be corrected to 'Extra Care Housing'	This has been done throughout the document
10. Equalities	• That equalities issues need to be better integrated throughout the document • The level of data particularly about dementia amongst BME communities is incomplete • There does need to be more about cultural awareness in relation to communities needing to understand about dementia, what it is, how it affects people and gaining cultural acceptance of it. More education and community outreach. • Needs far more about workers of all types gaining greater cultural competency in relation to understanding some of the cultural barriers/issues around acknowledgement/acceptance of dementia	• We agree and have ensured that these issues are integrated throughout the document and implementation plans • We agree that we need more accurate data collection. We will do more work to understand the need and then renew this information • We particularly acknowledge the need to undertake more consultation and engagement with different BME groups and to connect with communities and community leaders. We also need to ensure that awareness raising about dementia takes place throughout Bristol's communities • We will undertake to ensure that equalities issues in relation to dementia, particularly the specific race equality and cultural issues are built into all staff training and appraisal programmes. Providers already have clear

		expectations in relation to work on equalities issues and we will ensure that this is covered specifically in relation to dementia
11. Understanding future demand for services	It is unclear how, given the incomplete nature of some of the data, we will know what services to plan and put in place for the future	We must be able to predict the future demand for services. As this work moves forward we will gain greater evidence of such demand and develop a better understanding of different levels of potential need at different stages in the dementia care pathway so that we can put in place appropriate services
12. The location of dementia care in the NHS	That dementia services should be understood as a 'long term condition' rather than its current definition as a 'mental health' issue	It is recognised that dementia has been viewed as a mental health issue in the past. We also recognise the potential for stigma that can be associated with mental health services which may lead to some people with dementia and their carers being reluctant to access appropriate services. However, as the experience of the condition becomes more common we are committed to developing services to support people to manage the condition at home with the support of non-specialist services where possible and appropriate, with more specialist services reserved for the most complex issues. We would also anticipate that by embedding dementia more in long term conditions-management the issue of stigma will also be reduced

13. Community Nurse for Older People role	• That Community Nurses for Older People have an important role in delivering primary care level services to people with dementia • The CNOP role is not listed in the appendix • The Bristol Dementia Local Action Plan highlights the role whilst this draft strategy does not	The CNOP role has now been incorporated into the list of services in Appendix 1
14. Need for ongoing support	There is a desire for ongoing support for people who may not require medication or further services, but who might nonetheless find some kind of contact with services useful in order to afford them a straightforward way in if/when necessary	• The work on the development of the dementia care pathway should address this issue • The work towards the establishment of a dementia 'key worker'/'advisor' function as part of the care pathway recognises this need • The Memory Cafes now provide an ongoing and light touch way for people to stay in contact with services and engage with them as and when they may need them

7th December 2011