



Enfield Joint Dementia Strategy 2011-2016:

**A Summary of Submissions Received in Response to
the Consultation**

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INTRODUCTION

This document provides a summary of submissions received in response to public consultation on the draft dementia strategy. It also sets out the Council and NHS Enfield response to the comments and suggestions that were received.

In addition to the public consultation on the strategy, stakeholder input was sought during the development of the draft strategy. Two stakeholder workshops were held to develop the strategic objectives and commissioning intentions and these were well attended by service user representatives, carers, voluntary and community sector providers, primary care, Mental Health Trust, Health, Social Care and Housing.

CONSULTATION PROCESS

Formal public consultation on the draft dementia strategy was undertaken over a 3 month period from 1 November 2010 to 28 January 2011.

Stakeholder and public views on the strategy were sought through the following means:

- A e-questionnaire on the Enfield Council website
- Live consultation events with:
 - Carers (2 events involving over 40 carers)
 - Over 50's Forum
- Health and Social Care Partnership Boards
- Health and Social Care Scrutiny Panels

The consultation was publicised through the following means:

- 192 posters distributed to GP surgeries, libraries, health and social care providers and voluntary sector services.
- An advertisement in the Enfield Independent.
- Letter to all carers on the carers register and all carers of people who use the Age Concern Parker Centre services.
- A notice in EVAeNews (the electronic newsletter of the Enfield Voluntary Association).
- An email to staff in NHS Enfield, Health and Adult Social Care staff, acute trusts, voluntary and community sector providers, and independent and private providers.
- A notice in Enfield Staff Matters.

RESPONSES

A total of 37 questionnaires were completed either online or in writing. A further 11 written responses were received; most representing the views of organisations or networks of organisations, including submissions from:

- Barnet, Enfield and Haringey Mental Health Trust
- Barnet and Chase Farm Hospital Trust
- LINKS
- Enfield Disability Action
- Enfield Asian Welfare Association
- The Alzheimers Society

In addition verbal feedback was received at consultation meetings, including:

- Two events for carers
- Over 50's forum
- Health and Social Care Partnership Board meetings
- Health and Social Care Scrutiny Panel meetings

The majority of respondents who completed the questionnaire agreed with the proposed direction that is set out in the strategy.

Strategic Objectives

- 81% of respondents either agreed or strongly agreed with the strategic objectives
- 6.3% of respondents neither agreed or disagreed with the strategic objectives
- 12.5 % disagreed with the strategic objectives

Commissioning Intentions

- 79% of respondents either agreed or strongly agreed with the commissioning intentions
- 9.1% of respondents neither agreed or disagreed with the commissioning intentions
- 9.1 % disagreed with the commissioning intentions

SUMMARY

The collation process involved reading each of the narrative responses that were received. On reading the responses, a number of key themes emerged and comments were allocated to one or more theme headings. A lengthy and wide ranging response will have been allocated to a number of theme headings while shorter responses and comments have been allocated to just one or two theme headings. The groupings are useful indicators of where there is common ground with the following themes being most prominent in the responses received:

- Awareness and Prevention
- Day Opportunities
- Workforce
- Support for Carers
- Continuing Care
- Early Diagnosis
- General Hospital Quality
- Access to information, advice and guidance
- Home Care
- End of Life Care and advance planning
- Services for younger people
- Diversity
- Funding and Implementation

A number of comments did not easily fit under any of these themes and are summarised under 'additional comments'.

What follows is a summary of responses collated under each theme heading, followed by a response from the Council and NHS ENFIELD.

1. Awareness and Prevention

A number of respondents commented on the importance of raising awareness amongst both health and social care professionals and the general public. Along side this, it was felt that there are good resources available, for example, from the Alzheimer's Society, but that these could be made better use of. Increasing awareness amongst GPs was seen as particularly important and it was suggested that GPs need a clear pathway to provide information on when, where, and to which services they should refer.

Awareness raising for the general public should include awareness of the needs of people with dementia and also of the services that are available.

Several respondents stated that there should be more emphasis in the strategy about prevention and the link between healthy lifestyles and a reduced risk of vascular dementia. It was suggested that leisure services and

the voluntary sector should be supported in offering opportunities for people to stay fit and healthy, and that awareness of current opportunities, for example, walking groups, should be increased.

Response:

The strategy makes a commitment to increasing both awareness of dementia and availability of local services. It also commits to increasing people's knowledge of how to reduce their risk of developing vascular dementia through making healthy lifestyle choices, including linking with existing health promotion activities and awareness campaigns. Further detail will be developed during the implementation of the strategy and comments received during the consultation will inform this work.

The following additional commissioning intention has been added to the strategy as a result feedback received:

'Develop and implement a local dementia care pathway, spanning early diagnosis to the end of life, and ensure that people with dementia, carers and health and social care professionals are aware of this pathway.'

2. Day Opportunities and Respite Care

There were many responses about the need to increase the provision of good quality day opportunities and respite care. As well as increased provision, a number of respondents commented on the need for services to be more flexible and responsive to individual needs, choices and preferences. Specific gaps that were highlighted include night sitters, increased opening hours to support working carers, transportation problems, and greater geographical spread of services across the borough.

Respondents were very clear about the value of good quality day care and respite in both supporting carers and providing a better quality of life for people with dementia. Respondents also highlighted the importance of these services in keeping people out of residential/nursing care for longer and in reducing the number of avoidable hospital admissions.

Day opportunities should include structured activities, cognitive stimulation, behavioural therapy, multi-sensory stimulation and exercise therapy.

Response:

The need for more flexible day opportunities and respite services that are responsive to individual needs is recognised as a key priority within the strategy. These services not only enhance people's quality of life and reduce

pressures on family carers, they also play an important role in reducing admissions to residential care and hospital care.

Enfield is committed to the development of more and better services that support people to remain in the community for as long as possible. As a result of the research and consultation undertaken in the development of this strategy, the following additional commissioning intention has been added to the strategy:

‘Allocate additional funding for the development of increased flexible day opportunities and respite care that is responsive to individual needs including the needs of carers.’

“Through review, promote local initiatives to make more effective use of existing resources currently invested in day opportunities to provide increasingly flexible responses to peoples expressed needs.”

3. Workforce

It is apparent from the number of comments regarding the workforce that this is a key concern for a number of respondents. Several respondents expressed concerns regarding the skills and competencies of home care staff, and one respondent suggested that a specialist dementia care agency should be commissioned. It was recognised that low pay and status of home care workers, as well as high turn over, make improving skills difficult. However it was also stated that training for home care workers is vital if inappropriate hospital admissions are to be reduced. It was also suggested that there needs to be a greater awareness of the Mental Capacity Act and that all staff should understand how to undertake capacity assessments.

It was evident that respondents thought that a greater emphasis should be put on workforce development and training for all health and social care staff, including GPs, A&E staff, general hospital staff, ambulance staff, care homes staff, home care staff, and related agencies, for example, police, and it was suggested that a comprehensive local workforce commissioning plan be developed.

Response:

The strategy gives priority to improving the skills and competencies of the workforce and sets out a number of associated commissioning intentions, including the development of a local dementia workforce plan and ensuring that commissioned providers of services deliver appropriate dementia training to their staff.

Due to the large number of responses that reinforced the importance of improving the skills and competencies of the workforce, development of the workforce will be a key priority for implementation in year one of the strategy.

4. Support for Carers

Two consultation events were held for carers and were attended by over 40 people who provided feedback both verbally and in writing. Carers were enthusiastic about the direction set out in the strategy but also expressed a general feeling of frustration, distress and anxiety regarding the lack of support to them in their caring role.

Key issues that carers articulated included:

- More support is required to enable people to stay in their own homes however there are no additional proposals in the strategy.
- Carers are often very old themselves and get very little respite from their 24 hr caring role.
- Carers need training at the time of diagnosis.
- Support should also be available for carers of people living in care homes.
- The needs of disabled carers should be recognised.
- How will younger carers be supported?
- Need to include training for carers in dysphasia and risks of aspiration
- There is a lack of appreciation of the role of carers and of the high proportion of cost that is borne by carers.
- Carers need support to look after their own health.
- Carers need to be informed of their rights.
- Support groups and mentoring would be beneficial
- A closer focus on the experience of people with dementia and their carers, recognising their diversity and the contribution they make to their own wellbeing and that of the community, would strengthen the strategy

Another key issue that carers raised concerned the planned closure of the Continuing Care In-Patient Wards at Chase Farm Hospital (The Oaks and Silver Birches) and this summarised separately below under 'Continuing Care'

Response:

The need for further development of flexible respite and day opportunities to enable carers to better support their loved ones at home is addressed in point 2. above where a commitment to additional funding has been made. In addition, the following commissioning intention has been added to the strategy as a direct result of feedback from carers:

'We will provide funding to support the development of a peer support group for carers of people with dementia that will enable carers to support each other, share information and advice, give carers a stronger voice and provide a forum for training.'

5. Continuing Care

A number of carers expressed concern at the potential reprovision of the Continuing Care In-Patient Wards at Chase Farm Hospital. Specifically, carers spoke of the high level of stress and anxiety that they were experiencing due to the lack of communication regarding the closure, the timeframes for closure, and the lack of information on proposed alternative service provision.

Carers expressed concern that the potential reprovision of these services was not referenced in the strategy and that there were no plans outlined for the development of services to meet the needs of the growing number of people with dementia who have significant psychological and behavioural symptoms of dementia.

Reassurance was sought regarding the financial impact of transferring patients to the community where there would be a financial assessment of service user contributions to the cost of their care and where continuing care is fully funded by the NHS.

Response:

Continuing joint work with Enfield NHS will seek to ensure that there is open and urgent communication with those people who live in Continuing Care In - Patient Wards, and with their families and carers, to clarify the future intentions about these three sites and the services provided.

6. Early Diagnosis

There was general support for making diagnosis easier and earlier and comments on the long waiting list for diagnosis from the Memory Clinic. There was also comment that earlier diagnosis would increase the need for support services and that this needed to be accounted for in the strategy.

It was suggested that as home care staff come into contact with many people who have some level of dementia that is not formally diagnosed, they could be provided with training to recognise the signs and refer people for treatment.

Response:

The benefits of early diagnosis are clear and the strategy identifies earlier diagnosis as a key priority. The strategy makes a commitment to developing the Memory Treatment Clinic model in line with NICE guidance to enable it to have a greater role in diagnosis and to better manage existing and future demand. It also recognises the impact that an increase in the number of people who are diagnosed at an earlier stage in their illness will have on the

demand for treatment and support services and the need to account for this in our planning.

With regard to training for home care staff, this will be included in the development of our plan to improve the skills and competencies of the workforce.

7. General Hospital Quality

An issue that featured in a number of responses concerned the poor quality of services for people with dementia in general hospital settings.

Respondents identified a lack of awareness, understanding and empathy around dementia and gave examples of the difficulties that have arisen because of this. Specific suggestions about how to address this issue included:

- More dementia specialists in general hospitals
- Speech and Language Therapy input
- Dementia training for general hospital staff, including appropriate use of medication

This theme should be read in conjunction with the comments included under the Workforce theme as training was suggested by many respondents as a key mechanism for improving quality.

Response:

We are committed to improving the quality of care provided to people with dementia in general hospital settings and will work with our local hospitals to do this. A key focus will be on working with hospitals to improve quality through training and specialist support for staff and we will ensure that general hospital staff are included in our local workforce development planning.

8. Access to Information, Advice and Guidance

One issue that came up frequently was the need to improve access to information, advice and guidance. There was comment regarding the lack of information, particularly when someone is first diagnosed, and that carers have to research this for themselves. Other issues included difficulty contacting services and the lack of advice and information for self funders.

There were a number of suggestions to how the provision of information could be improved, including:

- Running regular surgeries
- Ensuring that staff who come in to contact with people with dementia have access to information
- Give people a named contact person/support worker
- Advice on how to choose respite and residential care
- A clear Dementia Care Pathway should be made available
- More funding to voluntary organisations, for example the Alzheimer's Society and Age Concern
- Provide hard copies of information
- Care Homes to advertise which ones are suitable for people with dementia

Several respondents commented on the pilot dementia adviser services, suggesting that a face-to-face service is preferred. It was also suggested that the dementia advisor service should be linked in with other information and advice agencies to ensure choice and multiple access points. One respondent wanted to know what alternative provision would be put in place if it was decided, as a result of evaluation, not to continue commissioning this service. Other respondents commented on the need for counselling and advocacy services.

Response:

We are committed to improving access to the provision of information, advice and guidance, through both this strategy and through a wider programme of work within the Council that is transforming the way that services are provided.

A new information and advice module has been developed for the Enfield website. It is simple to use and covers all aspects of adult social care. In addition, a new Health and Adult Social Care Access Team is being established. This will provide a single point of access for people who want to speak to someone to get information, advice and guidance.

Further to this, the Council is also reviewing the role of the voluntary and community sector and plans to develop a greater role for the sector in terms of information, advice and guidance.

Finally, we will continue to develop the dementia adviser service to ensure that it can meet the need for information and guidance of people who have recently been diagnosed and their carers. This will include exploring the potential for the service to provide face to face support.

GPs also have a key role in the provision of advice and guidance and we will work to improve this through the implementation of an agreed dementia pathway.

The planned development of carer support groups will also play a key role in improving access to information, advice and guidance.

9. End of Life Care and Advance Planning

There were a number of responses that highlighted the need for support to enable people to plan their care in advance, with one respondent suggesting that advance care planning should be part of the pathway of early diagnosis and support. It was suggested that carers need to be given advice on how to obtain Power of Attorney and that the cost of applying for Power of Attorney can be prohibitive.

It was suggested that all care providers should be required to have End of Life policies and that providers who implement the Gold Standard Framework should be offered higher rates.

Response:

Based on the feedback that we received regarding end of life care, we have strengthened the commissioning intentions regarding the dementia pathway and advance planning. They now include a commitment to:

Ensuring that end of life care is included in the local pathway for dementia.

Ensuring that people are given information on advance planning, at an early stage.

Ensuring that care home staff are trained and supported so that they feel more confident in adhering to advance care plans.

These developments will be implemented through the continued roll-out of the Gold Standard Framework for end of life care. We will commission a facilitator to support care home and primary care providers to implement the framework, and care homes will continue to receive quality payments for achieving the Gold standard.

Sharing of information and support for carers will also be enhanced through the planned development of peer support groups.

10. Diversity

The overall theme with regard to diversity was that everyone has unique, individual needs and that services need to be able to meet these needs.

It was suggested that meeting the needs of BME Groups should be incorporated throughout the strategy rather than a separate objective. Comment was made that there are a wide variety of ethnic groups in Enfield who are culturally, socially and economically diverse and that the strategy should include breakdowns of Greek and Turkish speakers as language is important in dementia. For example, the standard memory test is designed for people with English as a first language. Many people revert to their first language when they have dementia.

A number of respondents emphasised the importance of services that are tailored to people's specific, individual needs, particularly those who have other disabilities such as sensory impairment, mental health needs or learning difficulties.

Response:

Our aim is to commission services that are able to respond to people's individual needs, including their cultural needs.

It was not the intention of the strategy to limit our approach to BME groups to just one strategic objective however due to the predicted increase of dementia in BME groups over the next 10 years we do think that a separate objective is needed. We agree that we need to be more explicit about the needs of BME groups being taken into account in implementation of all the objectives and have revised the strategy accordingly.

The needs assessment has been revised to include more a more detailed breakdown of BME groups.

There is a national drive towards enabling patient choice and developing services that are responsive to individual needs (or 'personalised'). This strategy has been developed as part of a wider local work programme to develop personalised services and take forward the recommendations outlined in *Putting People First* which includes a commitment to Person centred planning and self directed support.

11. Funding and Implementation

Many respondents expressed concern about the ability to implement the strategy in the current economic environment and with the lack of ring fencing for dementia funding. There was also concern about the commitment to

implementation with the move to a single management structure across the 5 North London PCTs and the planned devolvement of health commissioning to GP consortia. Respondents stressed the importance of ensuring that implementation of the strategy links in with other local developments such as the Barnet, Enfield and Haringey Mental Health NHS Trust's consultation on 'Improving services for people with Dementia and Cognitive Impairment'.

Questions were asked regarding when the strategy would be implemented and how progress will be monitored and it was suggested that there should be carer involvement in monitoring and feedback.

Response:

We recognise the concerns that people will have regarding the challenges that we face in implementing this strategy in a time of unprecedented change to the NHS and in the context of an extremely challenging financial environment.

Health and social care commissioners are committed to the implementation of the strategy and to working in partnership to achieve this. Discussion and engagement with the emerging Enfield GP consortia has already begun and the Council and its Health partners governance arrangements will continue to provide leadership in implementing the strategy.

In response to the feedback we have received, we have now made a commitment to explore options for making the most effective use of resources to support the development of carer support and increased flexible day opportunities and respite care.

The strategy will be implemented over a 5 year period from 2011-2016 and feedback from the consultation will assist us in developing priority actions for the first year of implementation. As set out in the strategy, implementation will be overseen and monitored by the Older Peoples Mental Health Group which includes carer representation and stakeholders will be involved in implementation planning. The Older Peoples Mental Health Group will also be responsible for developing a communication and engagement plan that will set out how stakeholders will be informed and engaged throughout the implementation.

12. Additional Comments

- There are few/no services for younger people with dementia and a pathway is needed. Are there any plans to provide day care for younger people?

Response:

We recognise that there are gaps in the provision of services for people with dementia and also gaps in our knowledge of what is needed now and in the

future. As there are only very small numbers of younger people with dementia in Enfield, we plan to explore the potential of jointly commissioning services for younger people with dementia with our neighbouring boroughs of Barnet and Haringey. The first step in the commissioning process will be to undertake a joint assessment of the needs of younger people with dementia in order to plan appropriate services to meet those needs.

- Improve Intermediate Care Provision for people with dementia

Response:

Updated DH guidance for Intermediate Care recommends that Intermediate care should be able to meet the needs of people with dementia or mental health needs.

The strategy makes a commitment to ensuring that people with dementia are able to access Intermediate Care services by providing all Intermediate Care staff with core training in dementia and access to advice and support from specialist mental health staff.