



# Voices 4 Wellbeing

Rochdale Borough Local Involvement Network

## Have Your Say on Dementia!



### Event Report

March 2011

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In Partnership with



Heywood, Middleton and Rochdale

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## Introduction

Voices 4 Wellbeing is Rochdale Borough's Local Involvement Network (LINK). Established 1<sup>st</sup> April 2008 by the Department of Health, LINKs were set up to enable organisations, community groups and individuals (anyone with an interest in improving health and social care services), to have a say about how health and social care services could or should be improved at local level.

Further information can be found at [www.voices4wellbeing.co.uk](http://www.voices4wellbeing.co.uk)

In 2010 Voices 4 Wellbeing carried out engagement work within the Rochdale Borough. The Dementia Strategy and issues around Dementia were highlighted as a major concern. As a result it was agreed to put Dementia on Voices 4 Wellbeing's Workplan. Working in partnership with a number of other organisations an interactive event was planned to examine the issues further. This report evidences the findings.

Voices 4 Wellbeing would like to acknowledge and thank Rochdale and District Disability Action Group (RADDAG), Rochdale Boroughwide User Forum, Mind, Advocacy in Mind, Partnership for Older People's Project (POPPs), Alzheimer's Society, Rochdale Carer's Association, NHS Heywood, Middleton & Rochdale Primary Care Trust and Rochdale Metropolitan Borough Council.

*Many thanks for all of your support*

*Julie Harris*

*Development Officer*

*&*

*The Voices 4 Wellbeing Team*

## Executive Summary

Having worked in partnership with Rochdale and District Disability Action Group (RADDAG), Rochdale Boroughwide User Forum, Mind, Advocacy in Mind, Partnership for Older People's Project (POPPs), Alzheimer's Society, Rochdale Carer's Association, NHS Heywood, Middleton & Rochdale Primary Care Trust and Rochdale Metropolitan Borough Council, Voices 4 Wellbeing planned an event to engage with the public on issues in relation to Dementia. The event *Have Your Say on Dementia* took place on the 11<sup>th</sup> March 2011. This report details the findings.

The key findings can be found on pages 6-9 of this report and the recommendations made can be found on page 12. In the main those engaged with at the event felt that:

- Much more information is needed around Dementia
- GP's and other frontline health and social care professional need more training around the causes, treatments and effects Dementia can have on people living with Dementia and their carer's.
- More service provision is needed for people living with Dementia and their carer's
- Continuation of the development of the Memory Wellbeing Cafes is needed

A copy of this report will be sent to relevant health and social care commissioners with a cover letter requesting a response to the recommendations made in this report. Voices 4 Wellbeing will continue to help support organisations and individuals in highlighting issues and concerns about Dementia and will also continue to work with the Alzheimer's Society and Primary Care Trust commissioners.

## The Event: Have Your Say on Dementia

Voices 4 Wellbeing's *Have Your Say on Dementia* event took place on the 11<sup>th</sup> March 2011 at the Castlemere Community Centre. Approximately 54 people were in attendance. Following a registration and refreshment period, the event was opened by Voices 4 Wellbeing Manager Saeed Anward. Saeed introduced Sue Clarke: Locality Manager for Greater Manchester Central and West – Alzheimer's Society who was to chair the event.

Sue Clarke and her colleague first gave an overview of the new Memory Wellbeing Dementia Cafes at various venues across the Rochdale Borough. A stall had been set up to provide further information during the event. Sister Candy James from the Watergrove Memory Clinic was then invited to speak.

Candy gave an overview of the different types of dementia's, the symptoms and the causes. Additionally Candy provided some statistical information about Dementia:

- There are 750,000 people known to have dementia in the UK
- 16,000 of these are below 65, and 11,500 are from the BME community
- 2 thirds of people with dementia are women
- The chance of developing dementia doubles with every 5 years of life
- 60,000 deaths per year are directly attributable to dementia. Reducing the onset of dementia by 5 years could prevent half of these
- Family and friends being carers saves the UK over £6 million per year
- 2 thirds of people with dementia live in the community, with 1 third in care homes
- Only 40% of people with dementia receive a diagnosis

Candy also talked about the ways of treating dementia, such as the use of drugs, support and care. She then read excerpts from Christine Brighton's experiences of dementia, and discussed her own experiences of her mother having dementia.

A question and answer session then followed and can be found on page 10 of this report.

Sue Clarke then introduced the next speaker, Fozia Waseem: Commissioning Manager for Heywood, Middleton and Rochdale Primary Care Trust, also the local lead on the Dementia Strategy.

Fozia gave an overview of the Dementia Strategy and suggested that a good report to read would be the 'Dementia UK' report. Fozia then provided some statistical information:

- By 2025 there will be over 1 million people living with dementia in the UK
- There are just approximately 1500 people in Rochdale Borough with dementia. This is an estimate, and there is likely to be more. 1500 is 1.5% of the total population.
- There is a significant number of people within the borough with early onset dementia

## The Event: Have Your Say on Dementia

Fozia explained that the National Dementia Strategy has around 18 objectives, and 14 of those are local. It has been difficult to meet these in Rochdale due to a lack of staff. The PCT have been carrying out a work to raise awareness, and have managed to secure funding to support an intermediate care team.

The PCT have also been looking at links with the *Memory Wellbeing Clinic*. The waiting time has been reduced from 7 months to around 3 months. There is a lot of work going on with regards to getting GP's to support people and having the prescribing service in the surgery. This work is in a pilot stage at a surgery in Milnrow and if this is successful it will be rolled out across the borough. The PCT are working with the Alzheimer's Society towards having six *Memory Wellbeing Cafes* in Rochdale, and there is a need to increase the profile of these.

Fozia explained that there is a lot of pressure with the budget, and the PCT have to provide services on a shoestring. They are working with local organisations to discuss ways of these organisations helping with this. The PCT is also looking at improved quality of care in hospitals, and training for nurses to improve skills and knowledge not just in hospitals, but care home staff as well. They are also trying to reduce the use of anti-psychotic medicines.

Fozia ended her talk by saying that the PCT would like people and organisations to support them. There is a lot of good work going on the borough that the PCT are not always aware of, and it is important to work together.

A question and answer session then followed and can be found on page 11 of this report.

Next to speak was Margaret Connolly a carer who was invited to the event to speak about her experience of caring for her husband who had been suffering with Dementia. Recently bereaved, Margaret gave a very moving account of the effect Dementia had on both her and her husband. Margaret spoke of the man her husband was before the disease and how she watched his mental and physical health deteriorate and the difficulties of caring for her husband. Margaret felt that health and social care professionals need to listen to carers more and provide more information and support.

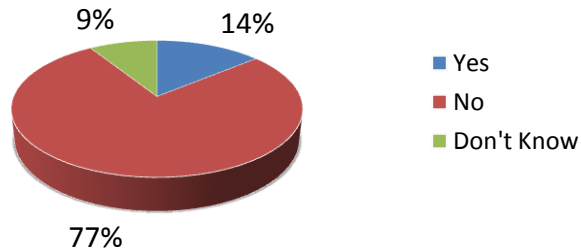
**I would like to acknowledge and thank Margaret Connolly for her very worthwhile contribution to the event at such a difficult time in her grief; a very brave lady.**

Following the speakers, was a chance for the attendees to have their say on Dementia using the interactive *Ask the Audience* equipment, kindly loaned by Heywood, Middleton & Rochdale Primary Care Trust. The survey questions and results can be seen on pages 6-9 of this report.

To close the event a poem by Christine Pinder (Pinder 2007) was read by Robin Parker

## Interactive Survey Results

### 1) Do you feel that there is enough information available to the public about Dementia?



### 2) What information sources with regards to Dementia are you aware of?

- Television
- Internet
- Carers Resource
- Memory Wellbeing Clinics
- Libraries

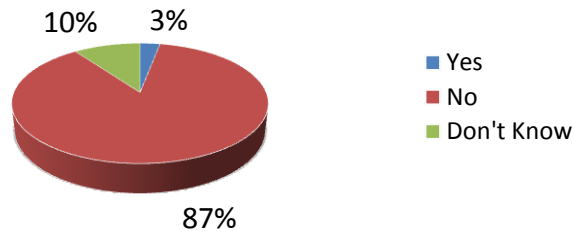
### 3) How would you like to receive information?

- One-to-one sessions
- Audio/video
- Pass information on through family and friends
- Online information for carers\*
- Radio (including stations in languages other than English)
- GP's having the correct information to make referrals

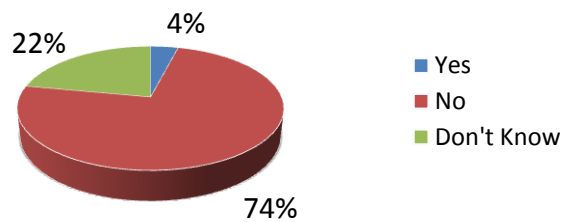
\*Sue Clarke from the Alzheimer's Society informed the audience of a Website called *Talking Point*. This is a Website which provides information about Dementia for carer

## Interactive Survey Results

### 4) Do you feel that there is enough service provision for people living with Dementia in Rochdale?



### 5) Are there enough services for carers of people living with Dementia in Rochdale?



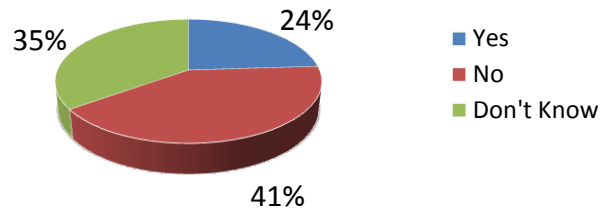
### 6) What services do you feel should be available to people living with Dementia and their carers?

- More in house services/one-to-one
- More training for GP's to help with diagnosis
- Night-time services
- Nurse training – especially when there is a crossover between mental health and physical health problems – staff seem to specialise in one or the other\*
- More awareness and training for carers

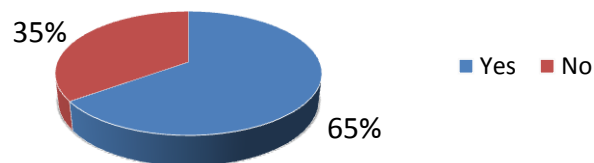
\*Fozia Waseem a commissioner from Heywood, Middleton & Rochdale Primary Care Trust informed the audience that Dementia training is now being included in nurse training.

## Interactive Survey Results

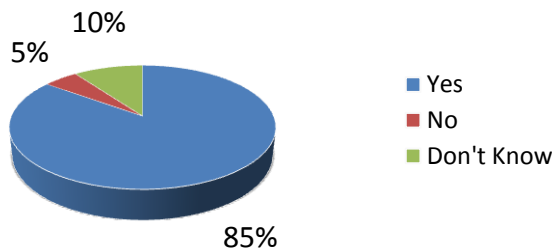
7) If you have experience of Dementia, do you feel that the diagnosis was made soon enough?



8) Have you heard of the new *Memory Wellbeing Cafes* for people living with Dementia, their carer's, family and friends?



9) Are you interested in visiting the *Memory Wellbeing Cafes*?

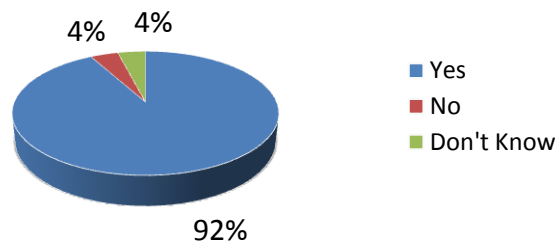


## Interactive Survey Results

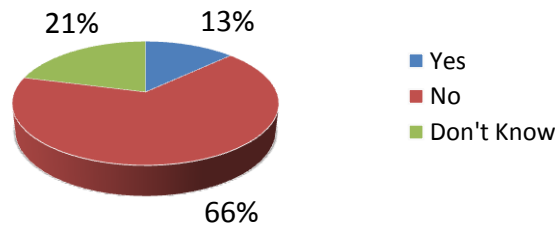
### 10) What would you expect from the *Memory Wellbeing Cafes*?

- Information
- Support
- Sign-posting to services
- Sharing tips and knowledge
- Channelling of people's views and experiences
- Basic information on what to do when caring for someone living with Dementia

### 11) Would you visit your GP to get a diagnosis of Dementia?



### 12) Do you believe that your GP has enough skills and knowledge in relation to Dementia?



## Speaker Question & Answer Sessions

### Sister Candy James Questions & Answers

**Q1. What advice would you give to someone who has an 86 year old family member with memory problems? How do you get them into the memory clinic?**

Answer. You need to act now, and get their GP to refer them to the memory clinic.

**Q2. What types of medication are used? Are they produced by the big drug companies or is there a holistic approach?**

Answer. The drugs available at the moment are from the drug companies. These are not a cure, but can slow down the development of dementia. They do not work with everyone, and there seems to be a rough split of 1 third of people they help a lot, 1 third they help a little and 1 third they do not help at all.

With regards to other medications, you should always discuss these with your GP before taking.

**Q3. What is the waiting time at the memory clinic? What is being done to improve this?**

Answer. The waiting time is currently around 3 months. The memory clinic is a non-commissioned service, so being commissioned would help with reducing this wait.

**Q4. 10 years ago, there were problems around people living on their own who are developing dementia and are vulnerable, but nothing could be done. Is that still the case?**

Answer. They are doing much better now. The situation was very different 10 years ago and there was less specific diagnosis around dementia, but it is now honed in on finding out which type of dementia a person has. With regards to people living alone, the staff can go and talk to those people and try to persuade them to come in, but they cannot force them.

**Q5. Is there such a thing as an 'at-risk' age group?**

Answer. Not specifically. As you get older, the chance increases. It is worth remembering that there are significantly more people without dementia than with dementia.

**Q6. With regards to Lewy Body dementia, is that common in people with parkinson's disease?**

Answer. There is some crossover.

**Q7. People with Parkinson's need to be informed that this could develop. It is important to give more information.**

Answer. That's a good point. It might be a good idea for the Alzheimer's Society to contact the Parkinson's nurses to discuss ways of doing this.

**Q8. What help is there for people who speak other languages?**

Answer. We are able to book interpreters in advance, as this requirement is usually noted on the referral form. Two of the consultants also speak other languages.

## Speaker Question & Answer Sessions

### Fozia Waseem Questions & Answers

**Q1. There is a big problem in the borough with literacy. Are there plans for doing short courses for carers to get skills to deal with this?**

Answer. The current work is just the tip of the iceberg, so feedback like this is helpful to assist in planning for the future.

**Q2. How did the stakeholders meeting go?**

Answer. A lot of people who should have gone were not invited, so there is going to be a follow up event to ensure these people have an opportunity to attend.

**Q3. As a carer giving support 24/7, it can be difficult to attend the café's because they are only on a set day for 2 hours per month in each area. There is a need for a 'hub' for immediate and accessible information and support. The information from the café's (such as experiences and stories, help and tips) should also be available online for people who cannot access the café's.**

Answer. The feedback is appreciated and this will be taken back to Tania\*. There have been early discussions about having a hub for information, but funding is an issue.

**Q4. In terms of education and support for carers, the funding goes mainly to educating carers of people with a functioning mental health problem. There is a need for specialised training.**

Answer. Good point. The PCT are working with the council and are trying to make sure that dementia training is included in the education package.

**Q5. There is a lack of knowledge and experience in staff working in care homes.**

Answer. We need to feed this back to the commissioners to highlight these issues.

**Q6. Is there a care home in Rochdale that is just for people living with dementia?**

Answer. There are care homes that specialise in dementia, but it is a Department of Health priority to increase awareness of these issues.

\*Tania Taylor Development Officer for the Alzheimer's Society and leading on the Development of the cafes has since added:

*'People are welcome to get in touch with me on 01706 926 666 for information, support and advice over the phone if they are unable to attend the cafes'*

## Recommendations

### **1. Provision of more information about Dementia:**

- Via GP's and other health care professionals
- One-to-one sessions with a Dementia Adviser upon diagnosis
- Through radio and in a variety of languages
- Audio and video
- Promotion of where to access information

### **2. More service provision for people living with Dementia and their carers:**

- In-house services
- More support from GP's
- Night-time services
- Awareness training for carers

### **3. Continuation and further development of the *Memory Wellbeing Cafes* with the provision of:**

- Support
- Information
- Sign-posting to other services
- Basic information on what to do when caring for someone living with Dementia

**4. It is strongly recommended that more training be made available/mandatory for GP's, Nurses and other frontline health and social care professionals on the symptoms of Dementia and the needs of patients living with Dementia. Health and social care professionals should also be made more aware of the role and support needs of carers**

**5. Recommended that commissioners meet with Voices 4 Wellbeing to discuss the recommendations made in this report**

\*Voices 4 Wellbeing would like to acknowledge that some of these recommendations may already have been recognised as a need and work to make improvements may already be underway

## Evaluation of the Event

### 1. What was your main reason/s for attending the event?

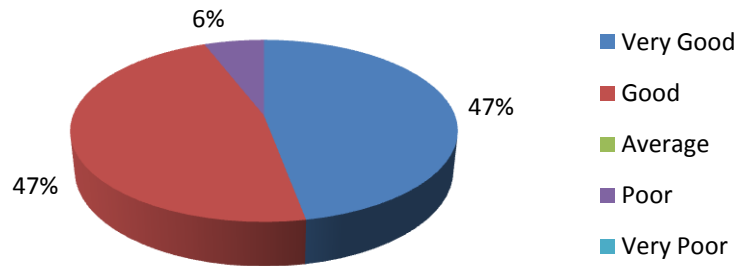
- Representing Pennine Care as a Governor for Rochdale people so I can take back concerns from the public and to report to the relevant persons
- More info
- Mother had some problems after strokes
- To gain a better understanding of the subject
- Feed in views/concerns
- Was asked to speak. Was also very interested
- Participate
- To get information RE: Dementia
- Knowledge
- I want to know about dementia
- Previous involvement with people with dementia and their primary carers on holidays (respite)
- As a carer
- To learn about dementia
- To learn about dementia
- To have more knowledge about dementia

### 2. Was there anything else you would have liked to have been included?

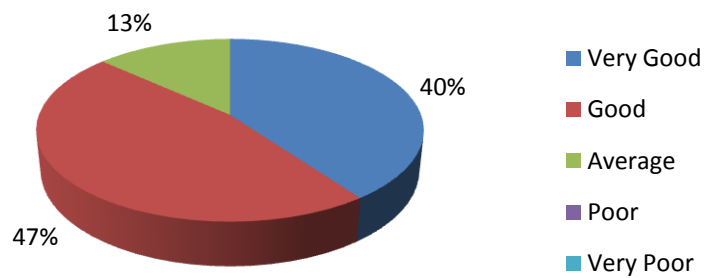
- More info on warning signs (early) and how to help sufferers to understand their problems
- More time for speakers
- More time for audience contribution
- It would not have been possible in the time, but clearly there was a desire of people to share experiences which could be a future workshop
- An interpreter next time
- No
- Just more time
- More information
- More information
- It was sufficient

## Evaluation of the Event

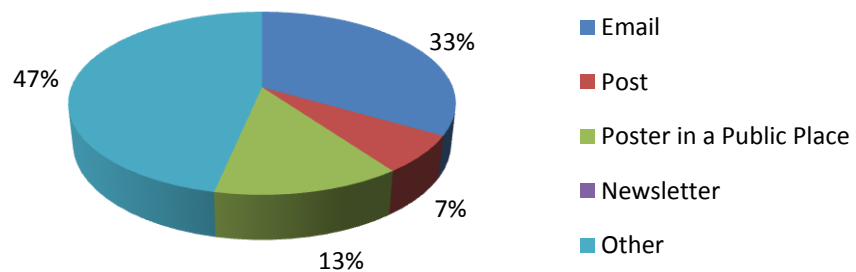
### 3) How would you rate the venue?



### 4) How would you rate the refreshments?



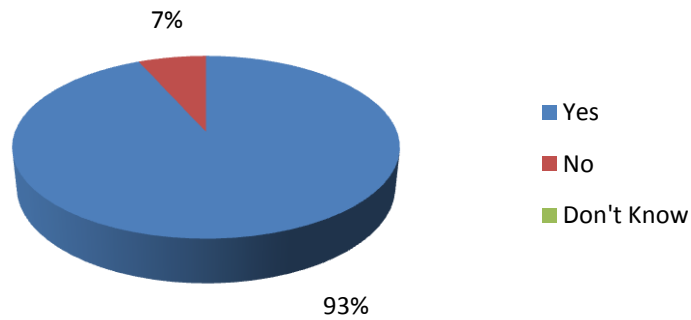
### 5) How did you find out about the event?



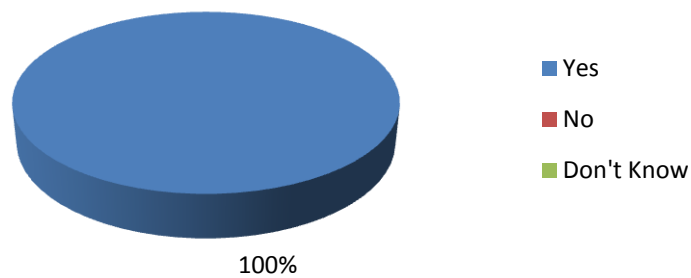
Other: Memory Wellbeing Clinic, RUBF, Online, invited to participate, V4W planning meeting, Tania Taylor at a carers meeting, from a friend

## Evaluation of the Event

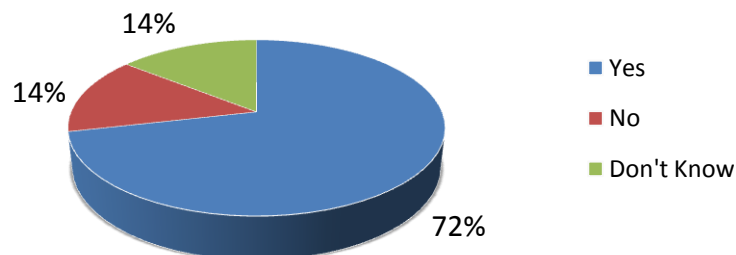
6) Programme for the day: Was it clear, did you feel you knew what was going to happen?



7) Did you feel that the right professionals attended?



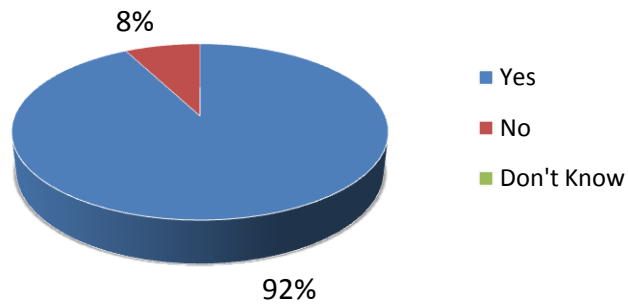
8) Did you feel your questions were answered?



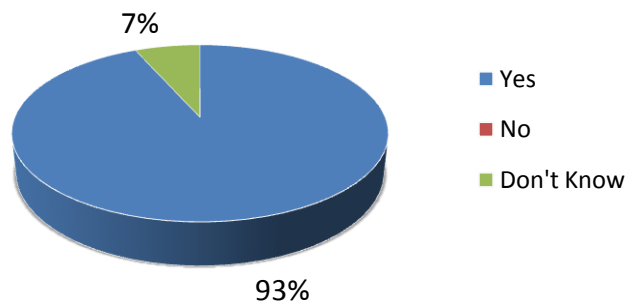
\*Comment to question 8: *Not enough time*

## Evaluation of the Event

9) Did you feel as though you were listened to?



10) Would you attend another of V4W's events?



## Conclusion & Next Steps

This report has identified some of the concerns residents of the Rochdale Borough have with regards to Dementia. The *Have Your Say* on Dementia event enabled promotion of the relatively new Dementia Memory Wellbeing Cafes, speakers to share knowledge about the types of Dementia, the symptoms and causes of Dementia and provide an overview of the Dementia Strategy. Additionally the general public were engaged with throughout.

It is clear from the work carried out that the residents of the Rochdale Borough feel more training is needed for medical professionals so that the correct information about Dementia can be shared at initial access to services. Also clear is the need for the continuation and development of the *Dementia Memory Wellbeing Cafes*.

Voices 4 Wellbeing will endeavour to hold some follow up work later in 2011 and will continue to work closely with other organisations, service commissioners and the general public to develop and improve service provision for those living with Dementia and their carer's.

In the meantime a copy this report will be sent to relevant health and social care commissioners with a cover letter requesting a response to the recommendations made in the report.

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