Dementia Strategy Stakeholder Event Report

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INTRODUCTION

Kingston Dementia Strategy Stakeholder Event was held on 11th June 2015 at the Quaker Centre in Kingston.

The purpose of the event was for a wide range of people to have the opportunity to make comment on the draft dementia strategy, and to discuss actions and priorities.

It was attended by approximately 50 individuals from a variety of organisations including:

- Patients and their family and carers, including some who responded to the consultation by Age UK in Summer 2014
- Your Healthcare (community health services)
- Adult Social Care, Kingston Council
- GPs
- Older People’s Community Mental Health Team, Southwest London & St George’s Mental Health Trust
- The Alzheimer’s Society
- Staywell Kingston
- Kingston CCG (NHS commissioning organisation)
- Kingston Voluntary Action
- Public Health, Kingston Council
- Housing, Kingston Council
- Councillors, Kingston Council
- Home Instead (personal home care provider)
- Kingston Hospital
- Kingston Citizens Advice Bureau
- Healthwatch Kingston

Everyone was welcomed to the event by Councillor Julie Pickering, the lead member for Health and Social Care, who set out what we were trying to achieve for people in Kingston. This was followed by a presentation about local need from Sue Redmond, Director of Health and Adult Social Care, Kingston Council.
Richard Williams, a family member of someone with early onset dementia, gave a presentation about their experience of living with dementia. Some of the key points from his talk were the importance of:

- Local services working together to provide a comprehensive package of care, and to understand what each other does
- Supporting individuals to live as meaningful a life as possible based on their needs and interests - one size does not fit all
- Putting individuals in touch with others in similar circumstances
- Researching better the numbers and needs of people in Kingston with early onset dementia

This was followed by an overview of the draft strategy from Dr Phil Moore, Kingston Clinical Commissioning Group's clinical lead for mental health, and a local GP.

The rest of the event involved participants working in groups to review the strategy, identify gaps, suggest actions and agree priorities.

**GROUP WORK - FEEDBACK**

1. **Reviewing the draft strategy and identifying any gaps**

The draft strategy has four parts to it. Each of these were reviewed and key feedback from discussions at this event are set out below.

1.1 **Improving wellbeing and raising awareness, reducing risk**

The proposed objectives for discussion were:

| 1. Improve awareness and understanding of dementia by public and professionals, to reduce stigma and to improve recognition of dementia and the ways to seek help. |
| 2. Reduce risk of developing dementia (particularly vascular dementia) and other mental health problems |
| 3. Enable people to be as resilient as possible by promoting good physical and mental health and wellbeing |
| 4. Empower people with dementia and their carers to have a voice and a role in developing support and services that enable them to ‘live well’, for example through groups. |
| 5. Achieve a dementia-friendly Kingston through working with others |

Participants feedback:

- Awareness-raising in schools e.g. Alzheimer’s Society 'Dementia for schools programme' and Intergenerational groups. Awareness-raising seems to be targeted generally at older groups, so needs to also cover younger people and those living
alone. Being pro-active about raising awareness – e.g. High street presence, road shows. Community talks – awareness about services

- Dementias not Dementia – important especially for improving awareness and being aware of the different needs.
- Use Radio Jackie.
- Develop Community Networks
- Research – lifestyle, knowledge, being informed gives you control.
- Early input – education on reducing risk.
- “Labelling” in records etc so people can see if someone is identified as vulnerable (although not all people will want this)
- Strategy is too generic so far, need to clearly consider age, gender and ethnicity for people with dementia and for carers. Marginal communities – not know what excluded. Support in community for people of other ethnicities
- Young onset should be included
- Bring in all relevant agencies – transport etc. Target groups for education, police transport
- Safe places in community where you can go e.g.
  - Similar to Neighbourhood Watch
  - Police
- Dementia champions
- Healthy work place initiatives

1.2 Timely diagnosis, assessment and intervention

The proposed objectives for discussion were:

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<tr>
<td>1.</td>
<td>Improve identification and timely diagnosis of dementia, using a good quality memory service.</td>
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<td>2.</td>
<td>Ensure people with dementia and their carers are able to navigate and understand the range of support available, by providing easily accessible, good quality, timely information about the illness, as well as the services available at diagnosis and throughout the course of their care</td>
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<td>3.</td>
<td>Improve skills and knowledge of health and social care staff, voluntary sector, home care agencies, care homes and carers about the diagnosis, treatment, care, and interaction with, people who have dementia</td>
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<td>4.</td>
<td>Improve the co-ordination of care for people with dementia, particularly the links between dementia care and mental health and physical health care</td>
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Participants feedback:

• Don’t ignore those who don’t want a diagnosis.
• Listen to family, they know best.
• Stigma still with professionals reluctant to make diagnosis.
• It’s a really hard process – a long time, the journey should be faster
• Ensure support after the diagnosis has been given
• The effects of a diagnosis – look at what is helpful / consistency of information / implications.
• Diagnosis delivered at home? If appropriate
• Need to include dual diagnosis and interaction with other conditions, e.g. stroke, depression and diabetes.
• Need to know where to go when you have questions
• How to respond to people with dementia - skills of dealing
• Too easy to give a leaflet, not enough interaction with a person about what the conditions means to them. Hands on support.
• FACS (Fair access to care services) banding means some people who do not meet criteria get very little.
• Needs a better link between the Care Act and this strategy regarding a focus on prevention.

1.3 Living well - Increasing support in the community living with dementia
The proposed objectives for discussion were:

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<td>1.</td>
<td>Ensure equitable access for people with dementia to the full range of universal support services, such as handy person services, transport, housing, falls services, re-ablement and advocacy support.</td>
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<td>2.</td>
<td>Ensure sustainable local peer support and learning networks for the exchange of practical advice and emotional support for people with dementia and their carers</td>
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<td>3.</td>
<td>Listen to carers of people with dementia, and understand their needs, and provide the information, advice, training and support that they identify they need at all stages of dementia</td>
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<td>4.</td>
<td>Decrease social isolation and loneliness of people with dementia and their carers.</td>
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<td>5.</td>
<td>Enable people to live at home for as long as they choose</td>
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<td>6.</td>
<td>Ensure there is a choice of good quality community personal support services for people living at home and their carers, including personal home care and day care.</td>
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<td>7.</td>
<td>Improve the quality of care in general hospitals for patients who have dementia</td>
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8. Ensure co-ordinated timely discharge from hospital, reducing hospital length of stay for patients with dementia and increasing the proportion of people able to return to their usual place of residence following hospital treatment.

Participants feedback:

- Person with dementia needs to remain central. Support should be individualised and person-centered. Talk to patients to see what people wants or liked to do and see how they can access this. Diverse range of support is needed, use Personal budget. NB Personal budgets are not well understood. People don’t understand what support they need. More advice and listening needed. People with dementia and carers/family should be visible, not just accepted/included.


- Transport is a gap – people need to be able to get to groups – being ready when transport comes can be difficult. Allowing time.

- Commissioning needs to be more outcome-led.

- Practical help – support in home
  - Help to get out of home
  - - Right support for you to help increase resilience
  - A named carer

- Peer support groups – establishing networks/ Forums for different types
  - Older People with dementia
  - Older Carers
  - Younger people
  - Younger carers

- It can be very difficult to get involved in life, community. The experience of some people with dementia and their carers were variously described as protected, introverted, insular, and isolated – some people may need help to live, with support for activities of daily living, but others also need help to accept help.

- How are going to keep listening to people with dementia and carers?

- Not everyone wants to be called “carer”.

- Carers’ needs e.g. health needs, advice, someone to talk to; knowing where to go. Not just for carer – accepted out in community i.e. dementia friendly community to support people to live fulfilled lives. Social acceptance. Things to do as a couple. Effect on wider family networks
• Those living alone need to be considered as having special circumstances. Social isolation is a big problem – support for nursing groups to help them?
• The living well section includes tales of hospital care, but not primary care and practical applications

1.4 High quality acute care – crisis care, care home care and end of life care

The proposed objectives for discussion were:

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<td>1.</td>
<td>Improve services and the system response for individuals and their carers experiencing or at risk of a crisis, meeting their needs and keeping them connected to their local community.</td>
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<td>2.</td>
<td>Improve the quality of long term care (care homes) for people with dementia and mental health issues, including reducing avoidable admissions to hospital.</td>
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<td>3.</td>
<td>Ensure appropriate care of people with challenging behaviour.</td>
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<td>4.</td>
<td>Raise the standards of care for people with dementia reaching the end of life.</td>
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<td>5.</td>
<td>Improve the availability of and access to create alternative accommodation to prevent early entry into residents/nursing care.</td>
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Participant feedback:

• Appears to be too much focus on crisis in this section on crisis – but should be focus on continuity. Focus more on keeping life as normal as possible (and retaining Identity)

• Practical support, when things go wrong in the house.

2. Suggesting actions

A summary of actions that were suggested during group discussions at this event are shown below. Participants were asked to propose actions that would contribute to meeting the objectives of the dementia strategy. After gathering key actions from the groups, each action was voted on, and those in bold were the most popular actions.

2.1 Improving wellbeing and raising awareness, reducing risk

Suggested actions:

- **Develop a dementia-friendly community** - increase number of community places that are dementia friendly – menu of activities for people (10)
- Support businesses etc to share good practice about how to be dementia friendly. Also support patient and carers to inform businesses etc on their experiences (4)
- Empowering individuals to improve their wellbeing. Physical and mental including hobbies.
- Public awareness and Education campaign, including for those living with dementia. Awareness about how dementia affects people differently (10) Good bits and bad bits.
- Challenge stereotypes – see the person, not the illness
- Dementia friendly training for children. Schools awareness programme.
- What is a dementia-friend? What is dementia-friendly? Share good practice.
- Life-long prevention programme include diet and exercise. Start young.

2.2 Timely diagnosis, assessment and intervention
Suggested actions:
- Single framework that everyone uses and a single place for accessing all services (20+). Possibly a local dementia hub, with website for those that will use it - a One Stop-Shop (health, financial, social care, legal housing, etc)
- Pre-diagnosis support (signposting/navigating) e.g. easy access to diagnostic service, pre-diagnosis counseling, as well as post diagnostic support
- Joint training programme for staff (5) – put together directory of training, and put on good quality, consistent training. Training across different professions. Who do we prioritise? High priorities are Care homes, hospital, home care, and housing. Lower priority are retail, transport, banks, police, theatre, post office.
- Avoid stigma where people present for diagnosis
- Health, social care, housing, transport, retail, police
- Co-designing diagnosis, assessment and treatment services – focus on FUNCTION, don’t be confined by form
- Early surveillance for people living alone, people new to country etc by agencies who have contact with them at home (should they refer to GP or Dementia Advisor?)
- Consider developing a single pathway – single integrated service (note patients come into pathway at different points)

2.3 Living well - Increasing support in the community living with dementia
Suggested actions:
- Create different forums to feed in ideas about what people want and where and help them to be involved in service design. Groups working together to map out services and identify gaps
- Consistent commissioning over a long period rather than short term projects (20+ votes)
- Dementia friendly activities in the day; more variety taking into account that not everyone wants the standard offer. Cater for people in different stages of dementia.
Relaxed performances at the theatre. Companions to go to London for younger age groups. Have centre of excellence as local as possible.

- **Transport (10)** transport provision to get to activities. Driver can be part of support network.
- **One identified person to support you through the journey (20+)**
- **Respite - research different ways to provide respite for carers to have a break. Be creative. Develop menu of options (15+)**

- Peer support learning networks – ensure ongoing funding
- Carer support. Provide practical help. More carers training e.g. CRISP. Also look at alignment with staff training – can some be combined?
- Adapted houses for supported living. Research dementia villages. Support/help in peoples own homes.
- Support people living alone and those from BME groups.
- Create mobile local hubs build on existing resources; pub, church hall, library each day services > people. (7)Accessible across the borough – north and south. Amy Woodgate. Cinnamon project.
- Work with businesses to become dementia friendly. Staff training – help people with booking in theatre for example. (7). Also seek sponsorship from businesses and involve art, college, theatre, use Dementia Alliance
- Medical alert system
- Assistive technologies
- Advocacy support
- Personal budgets. Use to design your own support network.
- Bridge between hospital care and out of hospital support.
- Develop support for men – Men in Sheds

2. **4 High quality acute care – crisis care, care home care and end of life care**

Suggested actions:

- Carers’ card – make it easier to get – send in post (10). ‘Message in a bottle’. Wider consistency of delivery
- Contact details for how and who to contact out of hours (to avoid A&E etc)
- **Contingency plan, early discussion for end of life care (20+).** Anticipate crisis. Care homes should be included in this.
- Upskill friends to be dementia-friendly, so they can support their friends with dementia to continue to socialize and keep up their hobbies. Especially important for men (15)
- **Build on integrated model of care especially with mental health services and also a broader range of services, e.g., housing, police. (25+).** How do we join care up?
- Extend the use of specialist teams across care homes - IMPACT team, Rapid Response Team.
- Reablement for all
- Timely funding for placements (continuing care and end of life care)
- Challenging behavior support – share expertise, knowledge, education. Up skill domiciliary care staff of agencies in basic skills for working with people with dementia
- Build on the consistency of Co-ordinate my Care so plans are communicated across systems and people’s choice can be retained
- Care Home staff to be trained to Level 2 in dementia
- Flexibility in care plans. Ensure they are outcome focOused (not task oriented) especially for domiciliary care.
- Care plans (adult social care and primary care) must focus on people social and emotional needs
- Increase access to services by people in residential services – put more reablement in the care home sector (4)
- The Herbert Protocol\(^1\), being used in Worcester Park -use more (5).
- Share expertise and grow learning.
- People (not machine) available out of hours for people in crisis.
- Help friends of those with dementia to know how they can support/be educated, especially as they are important in reducing social isolation of the person with dementia.

**NEXT STEPS**
The draft strategy will be revised to take account of a range of feedback received during June 2015, including the views gathered at this stakeholder event, and the consensus view from three committees and boards, including the Kingston Health and Wellbeing Board.

An action plan will be developed. Some of the feedback from this stakeholder event will be incorporated into the action plan, rather than the strategy.

**THANK YOU**
The organisers of the stakeholder day wish to thank all the participants for their full, frank and constructive involvement in this event.

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\(^1\) An assessment tool for police to support people with dementia in crisis.