

A group for people with young onset dementia, facilitated by the Kensington & Chelsea and Westminster Memory Service and Age UK Kensington & Chelsea with a Dementia Peer Support Worker

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# Young Onset Dementia

- A person aged under 65 with a diagnosis of dementia
- Projected figures 16,400 – 41,000 in UK (Alzheimers Research UK) which is 2-5% of those with a dementia diagnosis
- Typically a lack of age appropriate support and tend to fall into older adult services

# Peer Support

- In February 2011, the Department of Health commissioned the Centre for Mental Health and the NHS Confederation's Mental Health Network to pilot the national 'Supporting Recovery' programme that became known as ImROC.
- The ImRoc Programme has recommended the use of Peer Support Workers to drive recovery focused organisational change. ImROC recognises the value of a range of different roles for Peers in all types of mental health service.' Repper (ImROC Briefing, June 2013)

# Dementia Peer Support Workers

- The KCW Memory Service has employed 5 Dementia Peer Support Workers to date during the project – people living with dementia and working as part of the team
- Dianne, Dementia Peer Support Project Worker was employed by the KCW Memory Service in January 2013
- Roles for the Dementia Peer Support Worker's have included co-facilitating groups, consultation, representation and much, much more.....!
- Dementia Peer Support Workers are currently unique to CNWL

# Cross voluntary and statutory sector working

- Services often commissioned in a joint or complimentary way – in this example, the Age UK K&C Dementia Advisor is commissioned as part of the Kensington, Chelsea & Westminster Memory Service (NHS)
- Can help facilitate continuity of care
- Both services are committed to user led services and with different tasks are able to complement each other's roles . For example, statutory support ensures attention to issues of risk and need in the work and the voluntary sector has greater flexibility in budgetary matters and can reach those people who may be situated outside statutory provision.
- Sharing knowledge and skills
- Ensuring we're not doubling up

# Cross voluntary and statutory sector working

Studies of previous examples of cross sector working have resulted in a variety of outcomes:

- 'Multidisciplinary and multisector teams were associated with improved access to services, better care provision and quality, improved health status and high satisfaction among older people and their carers' (Kodner, 2006)
- 'Facilitating teamwork across organisational boundaries was challenging. The quality of the relationships between professionals was a key success factor' (Harris et al, 2010)
- 'Partnership with the voluntary sector worked well to reduce stigma' (Gupta & Kapwepwe, 2007)

# Format of the Group

- Set up by Age UK K&C Dementia Advisor due to lack of resource within borough. Extended out to Westminster and funding raised independently.
- A monthly social group, facilitated by Dementia Advisor, Young Onset Dementia Specialist Social Worker, Young Onset Dementia Specialist Nurse and Dementia Peer Support Worker
- The focus is on a stimulating activity. Group attendees let us know where they would like to go and what they would like to do (e.g. tours of Kensington Palace and Temple church, picnics in Hyde Park, Boat trips to Greenwich, Wildlife Photographer of the Year exhibition, etc)

# Outcomes

- 16 younger pwd regularly invited, in addition to family carers
- Arts venues within the borough have received dementia training and become 'dementia aware'
- Attendees have accessed activities they'd never engaged in before



# Advantages

- Increased stimulation, social interaction and support from attendees – including carers
- A wider catchment of service users including those currently under the care of statutory services and those who have been discharged or seen privately/historically
- Ability to tailor the group in meaningful ways
- Younger people with a dementia get to meet others undergoing a similar (never the same!) experience
- Opportunity for Peer Support, to share strategies, etc

# Advantages cont'

- Inclusion of a Dementia Peer Support Workers creates combination of expert by experience and expert by knowledge – gives greater sense of authenticity coming from someone who has that shared experience
- Staff are able to pick up any issues arising amongst attendees
- Group referrals usually come via memory service and then are able to be 'captured and held' by voluntary sector due to cross sector facilitation within the group
- Activities are more relevant to age and physical health

# Advantages cont'

- A vehicle for the implementation of the recovery model and personalised services within the two boroughs
- Fostering close working relationships between voluntary and statutory services within the two boroughs
- Provision of the sole specialist service and psychosocial intervention for people with young onset dementia in the two boroughs
- Facilitating a group within the community helps to educate others about dementia and reduce the stigma which can be attached to a diagnosis, which sits well with the idea of a 'dementia friendly community'



# Some Challenges

- **Working with limited budget and resources – have had to become very creative with access to venues! Difficulty attracting further funding – it's a small, niche group of people**
- **No transport currently. Attendees need to be independent travellers or employ support via direct payments /personal budgets to access the activities**
- **Growing number of attendees and therefore staff resources will need to increase correspondingly**

# The Team!



# Questions



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