Dementia: "I'M STILL ME"
How can we create a more positive future?

Report

from the Open Space Event
held on 27 September 2018
at Princes Park, Dartford, Kent

Hosted by

Alzheimer's & Dementia
SUPPORT SERVICES

Contents

Over view of this Open Space event

What was the event about?

The compelling Question for the meeting was Dementia: ‘I am still me’ Together, how do we create a more positive future?

What is an Open Space?

‘Open Space runs on two fundamentals: passion a responsibility. Passion engages the people in the room. Responsibility ensures things get done. A focusing theme or question provides the framework for the event. The art of the question lies in saying just enough to evoke attention, while leaving sufficient open space for the imagination to run wild.’

Harrison Owen, Developer of Open Space

While Open Space is known for its apparent lack of structure and welcoming surprises, it turns out that the Open Space meeting or organisation is very structured – but the structure is so perfectly fit to the people and the work at hand that it goes unnoticed in its proper role of supporting (not blocking) best work.

www.openspaceworld.org

Open Space is a method for holding meetings that means **people self-organise.** There are no speakers, no set agenda and timings are loose. The people who come create the event on the day. They suggest the **agenda** and they organise their own **discussion groups**. They then set their priorities for continuing action at the end using **‘dot democracy’** via coloured stickers. Often a follow-up group is formed.

Open Space works best when: ‘a **major** issue must be resolved, characterised by significant **complexity** and **diversity**, the pressure of potential or actual **conflict** and a decision time of **yesterday’**

Harrison Owen, Developer of Open Space

An Open Space event focuses on a key question that matters for the groups or communities involved. The people who come suggest topics for discussion around this question that matter to them – their **passions** – and they take **responsibility** for the discussions and for the resulting action. They do not create a ‘wish-list’ for other people to do.

Both passion and responsibility are key to the success of open space. This means that each participant needs to make sure they are always contributing and/or learning – if not the **‘law of two feet’, or law of mobility**, means you move on to another discussion which you can contribute to or learn from. Being self-organised means, **you** organise your own time so that you get the most out of the event.

Harrison Owen developed and popularised Open Space from 1985. He felt the best bits of conferences or meetings were always the breaks and aimed to create those kinds of conversations all the time. He drew on ways of holding meetings he saw in West Africa and in other traditional communities. Aspects of open space may feel familiar to you. To find out more visit: openspaceworld.org . For training to use Open Space click here

Who was there?

Seventy people took part. The majority were from all parts of Kent. At least 23% of the participants were 'Experts by Experience – people living with dementia or close family members supporting someone with dementia. For the list of participants, see page 35.

The Welcome

Liz Jewell, Chief Executive of Alzheimer's & Dementia Support Services, the host organisation, welcomed participants. Liz encouraged everyone to use the opportunity to make a contribution and experience participating with the system as an equal, to tackle together the issues important to people affected by dementia.

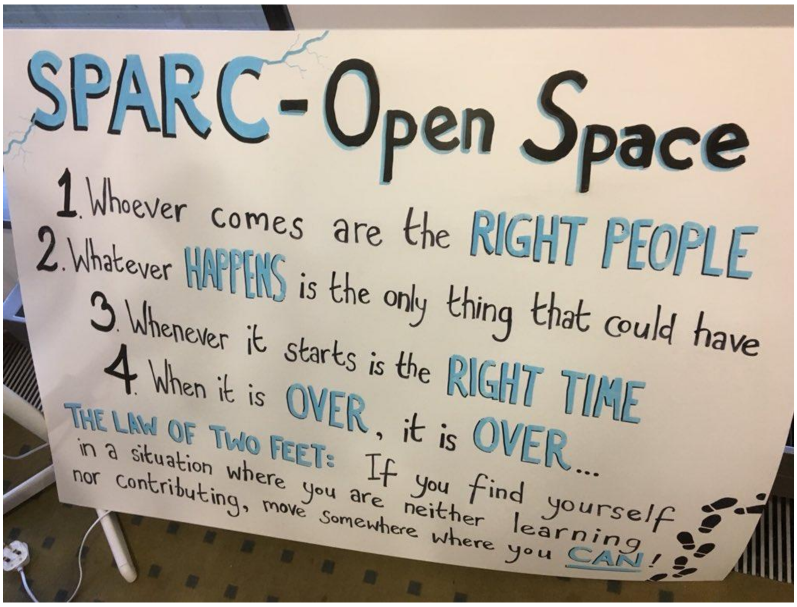
'***This is a brilliant opportunity to talk to people from across the system and really hear what the issues and opportunities are on the front line. I challenge anyone to leave here today with out gaining something valuable – that's what is amazing about Open Space.'***

Opening the circle

The facilitator Sheila Marsh explained the guiding principles of Open Space meetings:

1. Who ever comes is the right people
2. When ever it starts is the right time
3. What ever happens is the only thing that could have
4. When its over it is over
5. The law of 'two feet' or 'two wheels':

   If you're not learning or contributing in a discussion, move on to another.



SPARC - Open Space

1. Whoever comes are the RIGHT PEOPLE
2. Whatever HAPPENS is the only thing that could have
3. Whenever it starts is the RIGHT TIME
4. When it is OVER, it is OVER...

THE LAW OF TWO FEET: If you find yourself in a situation where you are neither learning nor contributing, move somewhere where you CAN!

Setting the Agenda

Sheila invited people in the room to identify any issue or opportunity related to the theme that they would be willing to convene a discussion about. Each person wrote their topic on a large posy-it note, read it out to the circle and posted it on the wall. When there were no more suggestions for new topics, the convenors reviewed all the issues raised. There were timeslots for up to 21 discussions, and the agenda was set by those in the room around what was important to them.

Discussion and live reporting

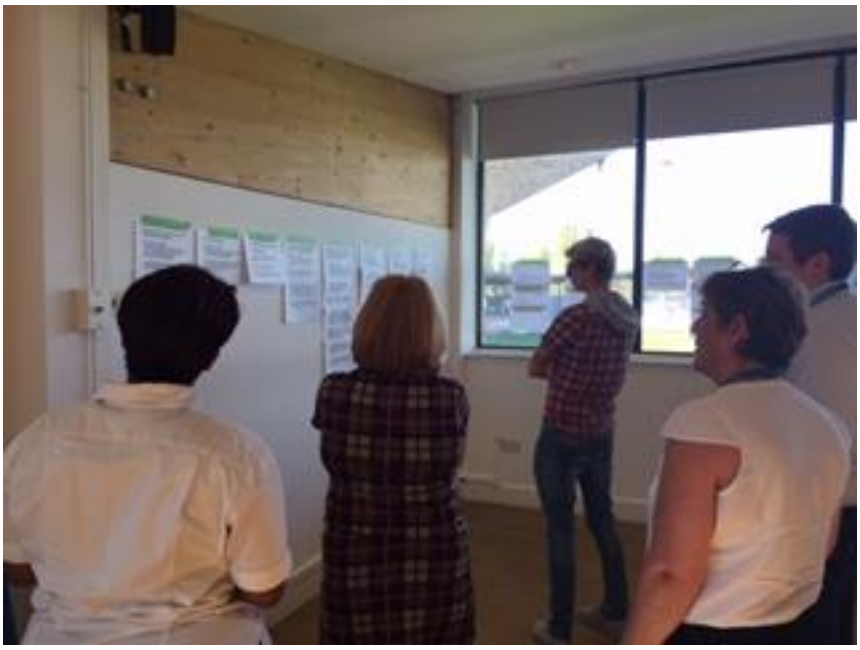
Participants came and reviewed the agenda to choose which discussions to start off at. Groups quickly formed at the meeting points around the room which had bridge theme

The first round of discussions started at 11:00am, the second at 12:00, and the third at 1:15.

Groups recorded their main discussion points and recommendations for action on reports sheet and brought them to a ‘Ne

Identifying Priorities

After rounds of discussion, participants used ‘Dot Democracy’ to identify their priorities to take forward. Each participant had seven sticky dots that they could use in any combination to vote on the recommendations from each group.



Closing Circle

After the 'Dot democracy' phase, everyone cam together to 'close the circle'. Sheila gave immediate feedback on what issue had gained most votes. Each person had an opportunity to give a brief reflection on the day and then Liz Jewell closed the event by thanking everyone for taking part, clarifying the next steps and wishing people a safe journey home.

Next Step

1. Report to be circulated
2. Action planning meeting on Wednesday 10th October at Ebbsfleet Football stadium, 10:00am – 12:30pm.

Top priorities from ideas for action following ‘dot democracy’

Participants voted on the collected ‘top ideas for action’ from all the 21 discussion groups using red dots. The top voted ideas and the top ten discussion topics are show below: these will be the key focus of the follow-up meeting on 10 October.

Top ranked action ideas

Rank	Action idea	Number of votes
1	Information after diagnosis should be accessible (like a bounty pack in maternity services) [*this idea came up several times*]	21
2	Massive drive to educate society: - o Dementia friends o School education programmes	17
3	Dementia as mandatory training. Like with moving and handling etc.	12
4	‘This is me’ forms in hospital and GP waiting rooms, or before admittance. Complimentary to medical records.	11
5	Provide a one to one session with carers and family members to allow time for personal questions around what to expect as the disease progress, to learn more about how to deal with challenging behaviours and more about the services Alzheimer’s & Dementia Support Services and others can offer	10
5	Allowing the people living with dementia to live independently for as long as possible	10
7	Caring for the carer	7

Top ten topics

Rank	Discussion topic	Total number of votes
1	Training for healthcare professionals	31
2	How can post diagnosis service be improved	21
3	Why and how do you keep proving you have dementia	20
4	Dementia comes in a 'can' (CAN DO!)	19
5	What do you want to see on TV and films about dementia?	17
6	What do I do WHEN?	16
7	What experiences do you want others to see through your eyes?	15
7	Encouraging activity groups for health and increasing more normalised rather than specialised participating groups in local communities	15
9	Creativity & Reading and community resources	13
10	Socially active	10

Discussion Group reports

Topic: Assessments - what should be focused on?

Convener Lisa and Holly

Who was there? Lisa, Holly, Liz, Jayne, Stephen, Lyn, Jo, Penni, Clare

Key discussion points

- Assessment process for those with dementia
- Being more dynamic around assessments, time and day
- What is the purpose of the assessment? What next?
- How do we become more collaborative? Leave assessment with the patient

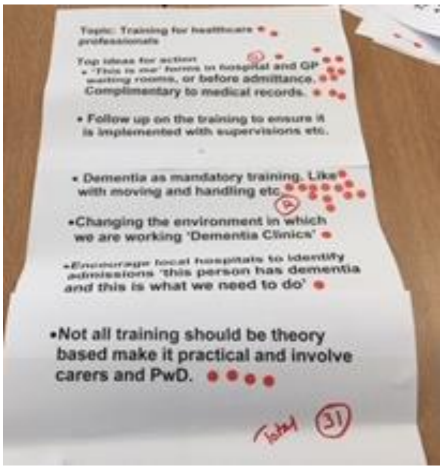
Top ideas for action:

- Collaborative picture
- Make the patient in charge/'own their assessment/building blocks'
- Review of how services are commissioned – are we all on the same page?

Topic: Training for healthcare professionals.

Convenor: Joseph O'Toole

Who was there? Mel, Clive, Arlene, Dee, Ravi.



Topic: Training for healthcare professionals

Top ideas for action
- 'This is me' forms in hospital and GP waiting rooms, or before admittance. Complimentary to medical records.
- Follow up on the training to ensure it is implemented with supervisions etc.
- Dementia as mandatory training. Like with moving and handling etc.
- Changing the environment in which we are working 'Dementia Clinics'
- Encourage local hospitals to identify admissions 'this person has dementia and this is what we need to do'
- Not all training should be theory based make it practical and involve carers and PwD.

Total 31

Main points of discussion:

- Putting yourself in the other persons shoes is great for training and giving you perspective.
- Inductions at hospitals and GP surgeries that are specific to that workplace. Supervisions and having the right people to make sure things are being done the way they should be/ have been trained to be done.
- Involve carers and family of Person with dementia win training get a different sometimes more accurate picture.
- Follow up on training and if the training is translating into practice.
- GP surgeries need some continuity, Dementia Lead Dr's for example.

Top ideas for action:

- 'This is me' forms in hospital and GP waiting rooms, or before admittance. Complimentary to medical records.
- Follow up on the training to ensure it is implemented with supervisions etc.
- Dementia as mandatory training. Like with moving and handling etc.
- Changing the environment in which we are working 'Dementia Clinics'
- Encourage local hospitals to identify admissions 'this person has dementia, and this is what we need to do'
- Not all training should be theory based make it practical and involve carers and Person with Dementia.

Topic: Change Language: Separate the person from the disease

Convenor: Angie

Who was there? Lindsay; Lisa; Holly; Lynne; Another

Main points of discussion:

- Labeling the individual- perpetuates the sigma
- Human nature to categorize
- Uncertainty of progress of the disease
- No map of effects of the different types of dementia

Top ideas for action

- Bespoke services – accessible to all with support for individual needs
- To broadcast in a positive way – what individuals can do even though they have dementia. Having a positive slogan/strapline, for example the current cancer one,

  “A life with cancer is still a life”
- Care journey in place to inform individuals with dementia and their supporters of possible interventions after diagnosis.

Topic: Connection of Organisations (Singing from the same song sheet)

Convenor: Thomas Beaumont

Who was there? Thomas Beaumont (Medway CCG), Dudley and Teresa Pearce (Living with Dementia), Wendy Lakin (DGS CCG)

Key discussion points:

- Services fully aware of each other's services. E.g., GP, Memory Assessment, Social Care, Crisis, etc.
- NHS and Local Authority Disconnect.
- Improved contact between services
- People need support to be able to continue what they were doing before diagnosis. Not just dementia cafes. E.g., dancing, swimming, etc. Enable people to continue with their lifestyle.

Top ideas for action:

- Greater use of MDT's (Professional Group Meetings). Provide a joint message.
- Consistent message of support/advice across services/community.
- Greater information sharing with external services so that appropriate and consistent messages are shared. "Make every contact count and consistent".

"I'm still me! The only thing that should change is the amount of support I need to continue being me!"

Topic: Creativity & Reading and community resources

Convenor: Katie & Lyndsey

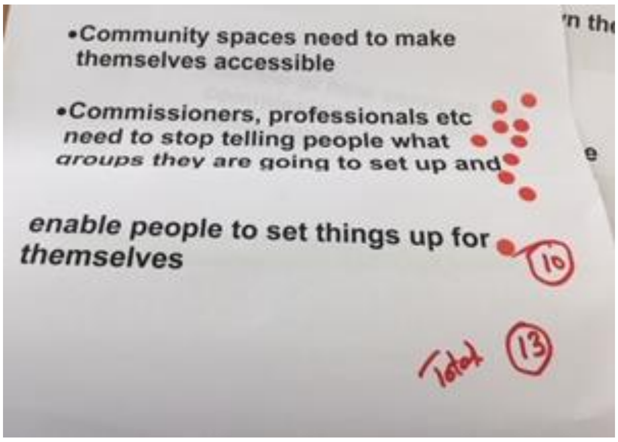
Who was there? Russ, Pat, Alan, Katie, Lyndsey

Key discussion points:

- The importance of creativity and arts for people with dementia
- The use of libraries and reading for people with dementia
- How people find out about the groups and resources that are available to them
- Health and safety can be used as a reason not to activities

Top ideas for action:

- Working together for cross fertilization of ideas
- You have to get to know your people
- New ideas need to be generated – something as simple as cooking or repairing a hoover can be good
- Community spaces need to make themselves accessible
- Commissioners, professionals etc need to stop telling people what groups they are going to set up and enable people to set things up for themselves



•Community spaces need to make themselves accessible

•Commissioners, professionals etc need to stop telling people what groups they are going to set up and

enable people to set things up for themselves

10

Total 13

Topic: Dementia comes in a 'can' (CAN DO!)

Convener: Thomas Beaumont

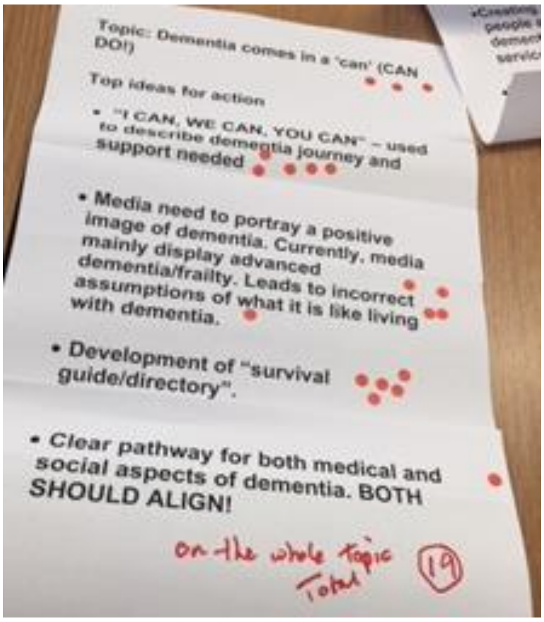
Who was there? Thomas, Wayne, Sandie, Angie

Key discussion points

- Discovered good coping strategies through dementia journey.
- Must not lose belief that you can live well with dementia. CAN DO ATTITUDE
- Medical and social decisions made based on future rather than present. Leads to assumptions.
- Use of wording can change perception of condition and what is possible.

Top ideas for action:

- "I CAN, WE CAN, YOU CAN" – used to describe dementia journey and support needed.
- Media need to portray a positive image of dementia. Currently, media mainly display advanced dementia/frailty. Leads to incorrect assumptions of what it is like living with dementia.
- Development of "survival guide/directory".
- Clear pathway for both medical and social aspects of dementia. BOTH SHOULD ALIGN!


Topic: Dementia comes in a 'can' (CAN DO!)

Top ideas for action

- "I CAN, WE CAN, YOU CAN" – used to describe dementia journey and support needed
- Media need to portray a positive image of dementia. Currently, media mainly display advanced dementia/frailty. Leads to incorrect assumptions of what it is like living with dementia.
- Development of "survival guide/directory".
- Clear pathway for both medical and social aspects of dementia. BOTH SHOULD ALIGN!

on the whole topic
Total ⑲

Topic: Do you stay with fantasy or bring the person back to reality?

Convener Denise

Who was there? Sharon, Ann Cavell, Shelly, Wendy Lakin, Clare Pye, Iain, Denise Witon, Grahame Hardey

Key discussion points

- What effect does the fantasy have on them?
- Why remind someone of painful events for them to forget tomorrow
- Are anti-psychotic drugs really the answer?
- People with dementia in care often feel imprisoned

Top ideas for action:

- Some can undergo rehabilitation to address trauma that's reoccurring but questionable
- Knowing the person and their short-term memory will be a way to decide how to approach, deciding to engage in fantasy
- Validate their feelings
- Understanding their past may explain their present
- Safeguarding staff but also educating and training them in techniques to deal with people living with dementia (i.e. distraction, engage in their reality, learn enough about them to engage in other conversations.
- Tips and techniques for how to distract or defer people with dementia and fantasies

Topic: Driving assessment the same for all to keep independence

Convener: Dudley

Who was there? Dudley, Rachel, Teresa, Andrea, Nicola

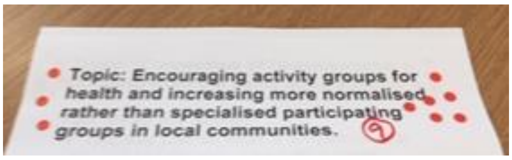
Key discussion points

- Procedure for driving assessments, is there a procedure?
- More communication between the DVLA and GP? +person living with dementia

Top ideas for action:

- Across the board system for quantifying person’s ability and mental capacity to drive
- Dementia reviews by dementia professions to assess mental capacity

Topic: Encouraging activity groups for health and increasing more normalised rather than specialised participating groups in local communities



Topic: Encouraging activity groups for health and increasing more normalised rather than specialised participating groups in local communities. ⑨

Convener: Louise and Kay

Who was there? Karen, Lindsay, Sandie, Sue, Arlene, Stephen, Russ, Denise, Aga, David

Key discussion points

- Persons affected by dementia also can have other health issues.
- Activities to access - one to one and group-going to the pub, playing sports, table tennis, golf, the gym, swimming, cinema, walking. Maybe using a buddy system.
- More available and accessible linked information about what is on offer.
- How do we link knowledge of awareness and advertising on what's on offer?
- Information given by professionals especially on training for doctors, nurses and other health care professionals.

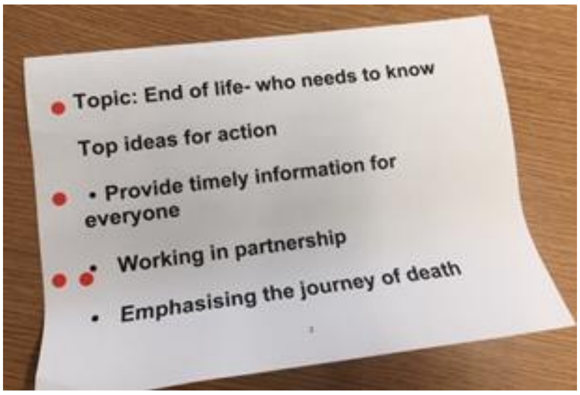
Top ideas for action:

- Accessing information, awareness, advertising, and services and groups sharing together. Directory of services for every area like "Right Move" as everyone knows that. Information from community magazines, GP's, Library's, Chemists and Gyms as people often visit these.
- More dementia friendly communities and care navigators and information hubs.
- Having more choice about what happens at the day centre, offering flexibility and wanted activities and taking people out. Challenging staying in one room for a whole day.
- Tools kits for normalised groups in society to help them open their doors for all including persons affected by dementia. Groups may fear responsibility, but the person affected by dementia wants to hold on to their own responsibility but may need just a little help.
- Expecting the community services to be all inclusive rather than we having to fight for access.

Topic: End of life - who needs to know

Convenor: Ross Mullis

Who was there? Ross, Russ, Holly, Lisa, Aga, Nicola



Topic: End of life- who needs to know

Top ideas for action

- Provide timely information for everyone
- Working in partnership
- Emphasising the journey of death

Main points of discussion:

- Advanced care planning is important
- We can’t skirt around the fact that end of life will happen
- Family carers are grateful for as much knowledge as they can get
- There is no difference between death and a diagnosis of dementia and death without a diagnosis
- It’s everybody’s business

Top ideas for action

- Provide timely information for everyone
- Working in partnership
- Emphasising the journey of death

Topic: Find out what an individual person with dementia's likes, interests and needs are!

Convenor: Lorraine Brown

Who was there? Bob & Maria Malkin, Agniesta Dahldorf, Julia Burton-Jones, Lorraine Brown

Main points of discussion:

- Our past lives, work and travels
- No bus to get to church (no Sunday buses)
- Musial tastes known means we can offer fun activities – singing sparks memories
- Have a laugh and joke with other men
- Transport – one bus an hour makes independence harder, especially if late or cancelled

Top ideas for action:

- Knowing people's names is important and how people want to be addressed
- Opportunities to 'talk about the old times' preserves identity
- Watching old TV shows together reminds us of our earlier days
- Understanding cultural identity and history perhaps of racism
- Understanding beliefs and attitudes we grew up with
- Building relationships of trust helps in offering sensitive support

Topic: How can post diagnosis service be improved

Convener: Beverley Newman

Who was there? Sheila. Nicola. Lynne. Ross. Denise. Eve. Madelene. Debbie

Key discussion points:

- Why have DVH stopped referring people to Alzheimer's & Dementia Support Services?
- How can people feel best supported post diagnosis and ongoing?
- How can to Alzheimer's & Dementia Support Services monetize their activities e.g. finding care home service

Top ideas for action:

- Give people to Alzheimer's & Dementia Support Services contact details and bullet points on services offered and key points of information.
- Provide a key contact to keep in touch overtime.
- Give people time to access services but help with more immediate practical steps such as Council Tax reduction.
- Create a clear pathway to follow, so to Alzheimer's & Dementia Support Services becomes the constant, allowing people to bounce in and out of their services.
- Create support and information for people who have their case closed by Social Services due to being self-funding.
- Provide a one to one session with carers and family members to allow time for personal questions around what to expect as the disease progress, to learn more about how to deal with challenging behaviours and more about the services to Alzheimer's & Dementia Support Services and others can offer

Topic: How do we engage with communities from diverse communities

Convenor: Dee and Ravi

Who was there? Ravi, Dee, Shelly, Jo, Liz, Clive, Claire, Carla, Hardeep, Bal, Nicola, Eve, Joseph, Rachael

Key discussion points:

- Guidance and support required,
- Continuity of person centered care
- Disjointed services - need cohesion of all services and transparency
- Awareness and information of services available
- Menu of information /Better communication
- Passport – This is you
- Media Involvement
- Receiving information at the correct time
- Communities will only engage at crisis point
- 24 Hour Helpline

Top ideas for action:

- Raise awareness through easy language, religious places/ community events/GP surgeries/Shopping centres
- CD / Audio information in different languages/ Bounty pack for Dementia
- Surveys at GP practices

Topic: Peer Groups/Dementia cafe

Convenor:

Who was there?

Main points of discussion:

- Helpfulness of peer support groups to discuss all situations that affect those living with Dementia (confidential)
- Not enough peer support groups, people on waiting list in Medway
- Train Facilitators to have more groups
- Peer groups are for all who accepted their diagnosis
- Listening to others with Dementia

Top ideas for action:

- Talk to Alzheimers society about new peer groups in Medway, explore possibility of setting up a new group in Medway as there is currently a waiting list
- After diagnosis get directed to right place –info pack on services available and include tips and up to date information (bounty pack)
- Peer support group may not need professional facilitators all of the time

Topic Person centred groups

Convener Jayne East

Who was there? Kay Evans, David Evans, Jo

Main discussion points

- Specific groups for a person's interest
- More society friendly
- Mixing groups

Top ideas for action

- Training and raising awareness of dementia
- Encouraging groups to set up their own agenda
- Making groups open – not dementia specific (dementia friendly)

Topic: Socially Active

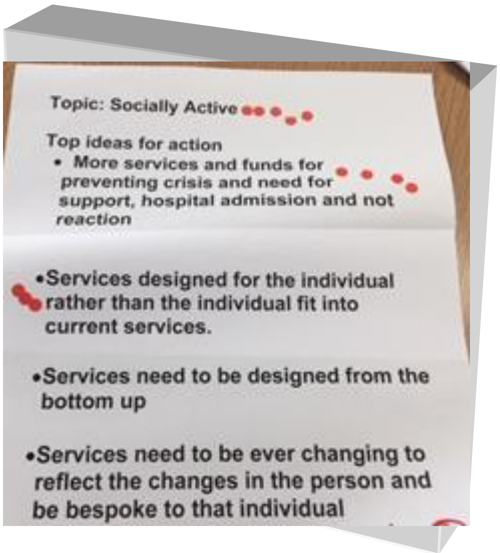
Convenor: Nic and Penni

Key discussion points:

- Peer Support
- Move away from Term “day care”
- Carers valuing their contribution
- Promote sense of self value and purpose
- Activities bespoke to individual
- Prevention not reaction

Top ideas for action:

- More services and funds for preventing crisis and need for support, hospital admission and not reaction
- Services designed for the individual rather than the individual fit into current services.
- Services need to be designed from the bottom up
- Services need to be ever changing to reflect the changes in the person and be bespoke to that individual
- Social prescribing, individual can shop for services – market place



Topic: Socially Active

Top ideas for action

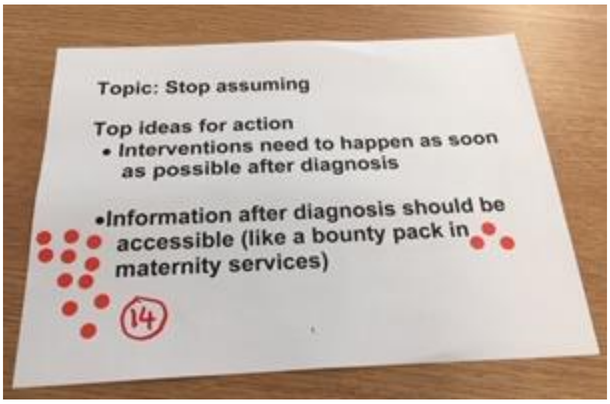
- More services and funds for preventing crisis and need for support, hospital admission and not reaction

- Services designed for the individual rather than the individual fit into current services.

- Services need to be designed from the bottom up

- Services need to be ever changing to reflect the changes in the person and be bespoke to that individual

Topic: Stop assuming



Topic: Stop assuming

Top ideas for action

- Interventions need to happen as soon as possible after diagnosis
- Information after diagnosis should be accessible (like a bounty pack in maternity services)

⑭

Convenor: Wayne

Who was there? Wayne, Rachel, Katie, Alan

Main points of discussion:

- Assumptions work both ways, Professionals make assumptions about people living with dementia (PLWD) but also PLWD make assumptions about services and professionals.
- People must get the support they need at the right time and not just 6 weeks after diagnosis
- Assumptions that person living with dementia can’t do rather than can do!
- As soon as people ‘do for’ a person living with dementia they stop being able to do for themselves and that costs the country £££s.

Top ideas for action:

- Interventions need to happen as soon as possible after diagnosis
- Information after diagnosis should be accessible (like a bounty pack in maternity services)

Topic: This is me - Where are they?

Convenor: Iain Tredway

Who was there? Clare, Julia, Iain, Louise, Shelley, Joe.

Main points of discussion:

- Biggest concern is the lack of amount of ‘This is me’ packs.
- How can we access these resources? Why aren’t they being completed?
- There needs to be more awareness and advertising of ‘this is me’ packs.
- Timing of handing these out is VERY important.
- ‘My faith matters’ are just as important as ‘this is me’. We need to understand people’s needs.

Top ideas for action:

- Visit care homes/people and talk about these packs or even supply them.
- We need to know where we can access these resources, such as red bad packs.
- Have these forms in places such as Doctors surgeries for people to fill in whilst they are waiting.
- For Alzheimer’s society and dementia support workers to give out and encourage use of ‘this is me’ packs and link in with hospitals.

Topic: Treat every person as a unique individual with dementia

Convenor: Lorraine Brown

Who was there? Clare Wilton, Denise, Ian, Julia, Graham Hardy, Jayne East, Clare Pye, Julia Burton-Jones, Ian Tredway

Main points of discussion:

- See the person not the dementia
- How media presents the uniqueness
- Focus on strengths and what they can do
- find out my history, "what makes me tick" my experience
- judgments made-need to "change the ace of dementia" young onset/labels used to restrict

Top ideas for action:

- Support tailored to the personality and support to allow the uniqueness to be expressed increasingly over time.
- Educating society e.g. through dementia friends (Inc. schools)
- Positive role models/stories/adventures
- Positive messages at diagnosis from medical profession-give hope/use respectful language
- Creating new social networks for people affected while also creating a dementia friendly society e.g. taxi service, swimming pools.
- Time for support workers to make deep connections

Topic: What do you want to see on TV and films about dementia?

Convenor: Andreea Helen David

Who was there? Amanda, Wendy, Jayne

Main points of discussion:

- What services are available
- Why the negative connotation
- What does having dementia really mean
- Dementia is not a mental health issue

Top ideas for action:

- Have subjects into documentaries and TV Series like including the services into community
- Understanding the importance of an early diagnosis
- Educating society
- Stop the use of the word dementia or demented in a derogatory way
- The need to join up all of the positive actions taking place from organizations and groups of volunteers and carers.
- Underline the need on offering the right training to care home staff.
- Break down myths like the driver's license etc.
- Equip the community to provide the support the family and friends need
- Informing family and friends about what dementia is even when the person living with dementia refuses to admit it.
- Understand the patients and their past.
- The benefits of music and arts on everyone not only the ones living with dementia.
- Allowing the people living with dementia to live independently for as long as possible.

Topic: What experiences do you want others to see through your eyes.

Convenor: Denise

Who was there? Lorraine, Arlene, Jo, Eve, Aga, Maria, Robert, Ravi, Andreea, Clare, Louise, Jan

Key discussion points:

- Reaching a younger audience
- Needs to be seen every day
- Visual impairment,
- Mixing smells
- Understanding - what is dementia

Top ideas for action:

- Perception- visually showing what people experience i.e. Stairs looking like a ramp, escalators being disorientating, paper money to coins because the latter lose their markings.
- Showing how the general public react to someone living with dementia
- Protective about advertising I have Alzheimers (not wanting to be viewed as vulnerable)
- Speech – talk slowly, coherent, keeping eye contact
- Care for carers- how are they coping (getting the blame and other tricky situations)
- Positive role models
- Diversity (culture, beliefs)
- Try and see the invisible illness

Topic: WHAT DO I DO WHEN?

Who was there? Katherine, Sharon, Mel, Clive, Steve, Katie

Key discussion points

- Carer Stress/breakdown
- Diagnoses needed?
- Trusting professional opinions
- Advanced Care Planning
- Navigating Systems for appropriate support

Top ideas for action:

- Carer training – i.e. Memory clinic is 6-week intense course? Too much – need for follow up or Idea of Dementia 'bounty' pack
- Early Intervention
- Utilising appropriate services
- Standardisation of services
- Problem solving – signposting pathways, resources
- Caring for the carer

Topic: Why and how do you keep proving you have dementia.

Convenor: Wayne

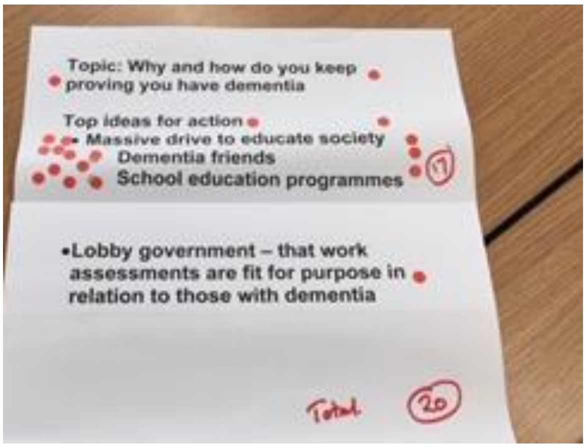
Who was there? Liz, Wayne, Iain

Key discussion points:

- Dementia is still ‘poor relation’ and often has to be proven again and again – especially if young onset.
- Have to prove your diagnosis every 4 months – fit for work – if under 65 years
- Have to pay for driving assessments every 6 months
- ‘Picked on’ by the state / Society. Driven by ‘fear’ promoted by the media. The fact Dementia is now recognized as the No1 killer just fuels it
- The assessment is geared towards known and physical disabilities – they don’t recognize a diagnosis of dementia (despite the fact there is no hope of getting better) and the assessment doesn’t capture the limitations of having dementia and its impact upon being able to work
- Cancer is recognized as a terminal illness (but can recover) dementia is not (can’t recover)
- Individuals are forced to go through the trauma of proving they have a condition – they sorely wish they didn’t have – every 4 months.
- To live well – you need a steady foundation this work assessment for under 65’s undermines that.

Top ideas for action:

- Massive drive to educate society
    - Dementia friends
    - School education programmes
- Lobby government – that work assessments are fit for purpose in relation to those with dementia



Topic: Why and how do you keep proving you have dementia

Top ideas for action
- Massive drive to educate society
    - Dementia friends
    - School education programmes ⑰
- Lobby government – that work assessments are fit for purpose in relation to those with dementia

Total ⑳

Closing comments of participants

- It’s really good to hear different opinions, professionals and people with dementia giving us a direction.
- We all want the same thing, just pulling it all together.
- The conversations were so energizing, and I didn’t want to leave. I’ve come away with lots of ideas and things to do.
- Thank you for sharing your experiences – I have learnt such a lot.
- I have discovered so many services today- how do we get people to know about them and access them? I will think about this myself and for all of us.
- Massive thank you to all of you people who have come. I didn’t know so many services existed. Doing this event age 21, I have learnt so much.
- It’s been a really useful meeting lots of people, lots that will be helpful and lots I didn’t know about.
- Good to get ideas and opinion from lots of organizations and how to improve things.
- Really encouraging group, inspiring, we talked about being our own problem solvers. It’s been very good to get the networking.
- I found the Open Space fascinating, the range of voices. The need to join up what we have already is very clear.
- I am from education services and there is lots of disjointedness Which we need to bring together. It’s been interesting
- I love Open Space and the freedom to move, But the conversations were so good that I didn’t move at all! I would love to see a set pathway with timings.
- It’s been a privilege to be here in the room with likeminded people, lots of common strands came out throughout the day. With common thoughts we can bring things together.
- The need to tackle some of the negative attitudes about dementia came up a lot today.
- I really learnt from people with dementia who are here today thank you.
- Very interesting day lots to think about.
- Thank you for sharing your experiences and knowledge.
- I have been blown away by peoples compassion to people with dementia.

- It’s been lovely being here. I’ve learnt a lot - we need to take what we have learnt back to our own places of work and build on this.
- I really enjoyed the Open Space and the fact we came up with what to talk about on our own . People discussed, what’s important to them.
- I’m a glass half full person, there is lots that isn’t right but there is lots on offer, but it’s just needs joining up, there is lots that is right.
- I would advise us all to be positive, to get on top of it and stay up.
- People being able to access advice and support at an early stage, advice and support that is individual to them is very clear. Thank you
- Interesting meeting people and hearing interesting things.
- I am surprised how many of us here have this horrible illness. I have thoroughly enjoyed today
- Thank you very much to the organizers.
- There have been common themes across the groups. Thank you for today
- It’s been a very special day and I feel quite emotional. It’s been a privilege to be here. Many frustrations but today has been very positive and gives hope.
- This proves you can use services and give people what they want, not what other people assume they want.
- I have learnt so much, sometimes you have to be open-minded. I will press on.
- Thank you to the organizers it’s been a very positive day. Information is power
- Brilliant day thank you for inviting me. So lovely to meet people, professionals and people with dementia. I’ve got a great deal from today.
- I want to say two things 1) just how encouraging it is that everyone wants the same things. 2) I have learnt lots about how many myths are still out there.
- I cross pollinated! The solution to different things is very similar, work better together … information for a positive future
- I have really enjoyed all the discussions. To listen, to come and give, people with dementia and professionals it’s been amazing.
- Wonderful to feel listened to and heard and people want to do something about it together.
- Privileged to be here and allowing me to put my case and professionals who will follow our ideas.

Participant list and contacts

Name		Organisation / Role
Katie	Antill	Alzheimer’s and Dementia Support Services
Ravi	Atwal	KCC
Thomas	Beaumont	NHS Medway Clinical Commissioning Group
Amanda	Bedzrah	NHS West Kent CCG
Nicola	Begley	Carers First
Deborah	Bloomfield	Alzheimer's & Dementia Support Services
Lisa	Bonifacio	Hilton Nursing Partners
Lisa	Bonifacio	Hilton Nursing Partners
Jo	Bradley	Ellenor
Eileen	Branton	Expert by Experience
Martin	Branton	Expert by Experience
Lorraine	Brown	Expert by Experience
Julia	Burton-Jones	Diocese of Rochester
Susan	Butcher	Alzheimer’s Society Kent and Medway
Sharon Ann	Cavell	Hergest & Cavell Funeral Directors
Claire	Coney	Solicitor Hatten Wyatt
Agnieszka	Daldorph	Age Exchange
Holly	Dalton	Hilton Nursing Partners
Holly	Dalton	Hilton Nursing Partners
Andrea Helen	David	
Dee	Dhadwal	DGS Supporting Independence Team
Clive	Dyche	
Jayne	East	Dementia Support
Wayne	Eaton	Expert by Experience
Kay	Evans	Expert by Experience

David	Evans	Expert by Experience
Alan	Foreman	Seven Oaks Counselling
Sheila	Francis	Expert by Experience
Katherine	George	Dartford and Gravesham NHS Trust
Karen	Gibbs	West Kent Housing Association
Hardeep	Gill	Solicitor Hatten Wyatt
Grahame	Hardy	NHS Dementia Specialist Nurse
Russ	Hargreaves	Ellenor
Madelene	Harrett	Alzheimer's & Dementia Support Services
Stephen	Harvey	Albert Hunt Trust
Karen	Heath	Kasbah
Liz	Jewell	Alzheimer’s and Dementia Support Services
Melanie	Jones	Ellenor Nurse
Denise	Kilshaw	Alzheimer’s and Dementia Support Services
Pat	Knight	Seven Oaks Counselling
Wendy	Lakin	Dartford Gravesham and Swanley & Swale CCGs
Nicola	Lambert	Alzheimer’s and Dementia Support Services
Lynne	Lidstone	Alzheimer’s and Dementia Support Services
Clare	Lux	Kent and Medway Partnership Trust
Gordan	Maynard	Expert by Experience
Maria	Melkin	Expert by Experience
Robert (Bob)	Melkin	Expert by Experience
Ross	Mullins	Alzheimer’s and Dementia Support Services
Beverley	Newman	Expert by Experience
Penni	Norris	Carers First
Joseph	O’Toole	Alzheimer’s Society
Teresa	Pearce	Expert by Experience

Dudley	Pearce	Expert by Experience
Lindsay	Prestage	Kent County Council
Lynfa	Price	Board of Trustees Alzheimer’s and Dementia Support Services
Clare	Pye	Board of Trustees Alzheimer’s and Dementia Support Services
Arlene	Rabrukwa	Student (Canterbury)
Bal	Rathore	Alzheimer’s and Dementia Support Services
Angie	Robinson	Hilton Nursing Partners
Rachel	Spencer	Kent Fire and Rescue
Sarah	Symes	Expert by Experience
John	Symes	Expert by Experience
Ian	Tredway	Medway NHS Foundation Trust
Sandie	Wade	Alzheimer’s and Dementia Support Services
Eve	Wilkinson	Alzheimer’s and Dementia Support Services
Denise	Wilton	Expert by Experience
Louise	Winetroube	Alzheimer's Society
Shelley	Young	Kent Police North Kent CSO
Jan		

Facilitator: Sheila Marsh
Open Space support: Roma Iskander

PublicServiceWorks Partnership
www.publicserviceworks.com

New ways of thinking doing in difficult times

www.publicserviceworks.com

Contact sheila@publicserviceworks.com or roma@publicserviceworks.com