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NHS and Social Care Partnership Trust

We are a
group
in the **deep** Network



Dementia
Friendly
Kent

Alzheimer's
Society
Leading the
fight against
dementia



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Kent DEEP Meet-Up Report April 11th, 2018 hosted by MemoryBilia

60 people from Kent-based DEEP groups came together this month for their first county-wide Meet-Up.

The Meet-Up was designed and facilitated by MemoryBilia - from planning the agenda, to finding and checking the venue and chairing the event and workshops. Wayne, who chaired the event, so powerfully said he felt thrilled to be at such an event where 50% of the people in the room (himself included) lived with a diagnosis of dementia.

The comments from the tags which adorned the 'feedback tree' speak volumes (see photo at end of report) but included: 'Inspirational and part of a new family', 'People with dementia supporting each other- empowering and inspiring EVERYONE', 'A brilliant time that MUST be repeated often. Thanks'

Getting together and meeting up with people from across the county we considered how the network can connect and work together in the future. Six themed table workshops also collected valuable insight from a mixture of people living with dementia, professionals, students, and family members.



Special thanks to Bethan Iley for taking away reams of flip chart paper to write up the notes from the workshops!

Massive thanks to MemoryBilia and the 'Dream Team' steering group for making it such a great day.

Round-Table discussions produced a wealth of fantastic ideas about Post diagnostic groups designed and facilitated by people living with dementia

Facilitators

- **Partnership in facilitation.** Professionals and people living with dementia should co-facilitate post-diagnostic groups.
The same people should be present at all sessions to provide consistency.
- **Including a facilitator living with dementia is important.** They can help with communication between the professionals and group members. They can also act as a guide or role model and can provide reassurance.
- **Facilitators need specific skills.** Interpersonal skills, understanding of dementia, patience, and a calm demeanour are all important. The facilitators should undergo training on how to simplify information without being patronising.
- **Facilitators should be aware of group members' language preferences.** They should avoid terms which members identify as negative. For example, some people with dementia dislike the term “service users” because they see it as dehumanising or taking the focus away from the person. Facilitators would benefit from becoming familiar with relevant DEEP guidelines, including those regarding language about dementia.

Running the group

- **Ensure person-centred care.** Any professionals who co-facilitate must have the group members' needs central to the group.

- **Groups can be boring.** This is especially true for those in the earlier stages of dementia. Facilitators should ensure they are engaging and there is a challenging element to the group. This could include activities or promoting lively discussions.



- **Involve social workers.** It was suggested that social workers could be invited to a session in order to promote understanding and access to social services.

- **Include peer support.** Allow group members to discuss their shared experiences and relate to each other's' experiences.

- **Practicalities are important.** The right number of sessions needs to be

identified – too many is stressful, too few will leave you with a feeling of incompleteness. The location needs to be central and dementia-friendly.

Developing the agenda

- **Designed for people with dementia, by people with dementia.** What professionals want to include and what people with dementia hope to learn about can be very different. The agenda should be designed collaboratively by people with dementia, their carers, and professionals.

- **Groups should also address the needs of carers.** Carers could be included in the group, or invited to a parallel group.
- **Groups should be directed by the members.** The group should cover topics which the members hope to learn about in a non-judgemental way. The group should be a self-governing safe space. Facilitators should encourage members to find their own ways. For example, there could be one set introductory session which the group can build off.
- **The key message should be that “you are not alone”.** This could be achieved through sharing ideas, telling personal stories, and sharing coping strategies.
- **Include practical topics as well as emotions.** The agenda should include important information such as benefits, blue badges, travelling, and where to access support.

Consistency

- **Groups need to be consistent across the sessions.** This helps people with dementia by reducing anxiety and promoting understanding of the group. The same facilitators should attend every session.
- **Create a national agenda.** This would ensure that everyone receives the same group regardless of their location, and would stop the “postcode lottery” of services. Each session should have a set theme, but the sessions themselves should be directed by the members.

- **Create a national network of facilitators with dementia.** They could periodically hold a conference and discuss what is going well and what needs improving. This would allow consistency across the country.
- **Use a “buddy” system.** This would ensure that the person with dementia knows who to contact if they have questions or worries.

Too much information

- **People living with dementia receive too much information.** Post-diagnostic groups provide too much written and verbal information in one go, which is difficult to take in.
- **Provide a “pocketbook” of local services.** There are lots of organisations for similar services so a brief summary would be easier to understand. Tailor this for both the person and their supporters.
- **Create a website with all the information in one place.** This would make it easier to review the information after the group, and for carers to access it. Technological support should be provided for people who are less confident with using the internet.
- **Present information using a diverse range of media.** Including video clips of people living with dementia which are relevant to the theme of the session would help.

Adapting for individual needs

- **“One size fits all” does not work for people with dementia.** Easily delivered groups are good for facilitators, but not best for the members.
- **Ensure good communication.** Consider the individuals’ preferences of writing, emails or phone calls. Do not assume every person has a supporter to help them. Find a way to include those without supporters.
- **More consideration of disabilities is needed.** There should be alternatives if locations or activities are unsuitable.
- **Groups should be age-appropriate.** All groups should be altered for younger people. Younger people want different information and have different practical needs. Recruit from a wide area to avoid a longer wait.
- **Include carers if the person living with dementia would like them there.** Alternatively a parallel group for carers could be offered.
- **Group members should be similar.** Meeting people with later-stage dementia can be frightening early on. It can be hard to relate to others’ stories if they are very different from you. Groups could be matched by abilities and age.
- **Tailor content for the audience.** Include relatable stories from people with similar life circumstances.

- **Some people need individual sessions.** Individual sessions should be offered when needed to avoid excluding people.

Addressing emotions

- **Provide emotional support before the group.** Having the chance to talk to someone about your feelings about the diagnosis would help with accepting it before the group starts.
- **Acknowledge and normalise conflicting emotions.** It is okay to feel both relieved and upset. Validate all emotional responses to the diagnosis.
- **Discuss that the diagnosis can be frightening.** This helps the group to remain honest and open, while also providing an interesting discussion.
- **Promote acceptance.** Using the word “dementia” addresses stigma so can be very powerful. However, some people find the word frightening. The use of the word “dementia” should be tailored to the group.
- **Provide reassurance to the person with dementia and their support network.** Family and friends who understand can help someone to process their emotions.

Continuing support after groups

- **It is unclear who should support people with dementia after their groups finish.** Services should work together to promote joined-up care centred on love, care and compassion.
- **Provide networking opportunities.** Local opportunities should be promoted to encourage contact with others after groups end, including free activities such as volunteering or activism. A newsletter could help people living with dementia to stay in contact. Facilitators should be aware that not everyone can afford paid groups such as COGS Club.
- **Signposting.** Group members should be clearly told where to access help after the group finishes. This should include access to social services, local peer support groups and local charities.
- **Follow up after the group ends.** Attendees reported that they would like to have had a follow-up group a year after their diagnosis.

Topics:

- **What is dementia?** Many people fear the unknown. Letters, stories and poems could be used to promote understanding.
- **Things you can do after your diagnosis.** This could include information about local services and DEEP groups.

- **Navigating healthcare.** Many people would like advice about how to access their GP and other services when they are not dementia-friendly.
- **Healthy living.** Some people would like to know what they could do to slow the progression of their dementia. Providing evidence-based information about medication and keeping healthy lifestyle could help.
- **Tiredness.** Provide information about the mental fatigue dementia brings, and advice on how to cope with this.
- **Coping strategies for emotions and practical problems.** For example, teaching practical skills such as how to manage cooking.
- **Talking about your diagnosis.** Advice for discussing dementia with family members and friends who do not have dementia.
- **Planning for the future.** Including information about benefits and legal processes such as Power of Attorney
- **Maintaining relationships.** Provide advice to both the people living with dementia, and their supporters.



'By myself I am a twig, but together we make a strong branch' – Andrew
Who and what are you?



How can DEEP groups continue to work together in Kent? (Facilitated by Tom)

These DEEP groups are in Kent:

- SUNshiners – Dover
- Forget-Me-Nots – Canterbury
- Memorybilia – Maidstone/Medway
- Phoenix – Ashford
- Pathfinders – Swale

This session was aiming to find ways that groups can work together in the future. The following ideas were discussed:

- **Annual Kent DEEP conference.** This could be co-ordinated by Clare Streeter who is the KMPT Dementia Volunteer Co-ordinator.
- **Create a shared website.** This could be used for uploading minutes or topics for discussion. The website could be hosted through the DEEP website. “Sparkling Moments” updates could be posted on this website.
- **Have a dedicated communications team.** They could run a newsletter and plan more networking events. Events could be about specific topics such as PIP benefits.

- **Create working groups for Kent-wide projects.** For example, a working group could create a guide for younger-onset dementia for Kent GPs. These groups could host training days and talk to commissioners, as face-to-face communication is more powerful.
- **Find ways to include people who do not attend DEEP groups.** Local forums such as Hythe Active Dementia Groups could be included. KMPT Dementia Envoys could be used for this.
- **Find resources to utilised.** The Working Together grant managed by Hospital Trusts could be considered. Transport, locations and funding are needed.
- **Share tips and ideas.** For example, how to manage emotions while attending DEEP groups or events.



Living with dementia and using technology (facilitated by Wayne)

- **Technology can be used to help sensory problems.** Hearing aids help with hearing loss. Photosensitive glasses help with adjusting to changing light conditions.
- **Calendar apps.** Calendar apps can synchronise between devices so you can find important dates wherever you are.
- **Transport apps.** Travel apps can help you with driving, walking or public transport. Most are free to use, e.g. National Rail app for trains; Stagecoach or Arriva apps for buses; Google Maps app for driving and walking directions.
- **Some DEEP group members get asked to help with app development.** One attendee is helping with the app “Zipabout” which helps people living with dementia use public transport. It is important to clarify if app developers want feedback or an endorsement.
- **Some apps use location tracking or in-app purchases.** Please be aware of this for safety reasons.
- **Power packs and portable chargers.** Portable chargers are very helpful if you are out for a long time because they stop your battery from running out.
- **Smart speakers such as Google Home or Alexa.** Smart speakers can be used to remind you of events, or tell you the time if you wake up at night. Google Home has artificial intelligence which learns the way that you speak so it feels natural to use. Smart speakers can be overwhelming if you don’t understand them or forget how to use them.

- **Voice recognition and activation.** Voice-enabled devices are more user friendly as you do not need to remember passwords.
- **Self-driving cars.** Self-driving cars might require a driving license, but their usefulness would depend on the person's confidence.
- **Tools for cooking.** Dementia-friendly appliances include slow cookers, combination oven-microwaves, and "smart" appliances.
- **Utilise videos and interactive guides.** For example, step-by-step video guides could help people with preparing and cooking food.
- **Self-service checkouts.** Self-service checkouts are stressful because they do not make allowances like a human cashier can.
- **Location tracking.** Friends and family members could be given access to location tracking services in case you get lost.
- **Salespeople and IT support must be trained about dementia.** People who sell or set up technology must understand what it is like to live with dementia. Instructions should be slow and clear. IT support should account for communication preferences and could give reminders.

- **Better advertising.** Technology for people with dementia needs to be advertised better as many people are not aware of what is available.
- **Technology workshops for people with dementia.** These could teach people living with dementia how to use their devices.
- **Technology is expensive.** Social services could subsidise smart technology for people with dementia.
- **Remember that technology is a tool.** The person is more important than the technology.
- **Dementia Research Institute investments.** £20 million is being invested in research into “care and technology” development for people with dementia.
- **Alzheimer’s Society online shop.** Their shop has simple technology for the less “tech-savvy” such as easy-to-use smart calendars.



Living with dementia and staying healthy (facilitated by Ruth)

- **Keep yourself busy.** Staying mentally active is very important so keep up with your hobbies. You could play music, do crafts or see friends.
- **Walk regularly.** It is important to get fresh air and exercise. You can walk more by walking instead of driving or joining a walking group.
- **Take part in physical exercise.** You could do lower intensity exercise such as yoga, Pilates, gardening or tai chi. You could take up a sport, go swimming, start dance classes or go to the gym.
- **Get a pet.** Pets promote wellbeing through companionship.
- **Eat healthily.** Include plenty of whole grains, legumes, fruit and vegetables in your diet. Try to avoid sugary and salty snacks.
- **Maintain a healthy weight.** A healthy body promotes a healthy mind.
- **Stay hydrated.** Drink mostly water.
- **Avoid isolating yourself.** Meet up with friends and family regularly. If you do not have friends or family, join a regular group or club.
- **Get enough sleep.** This will help to avoid mental tiredness.

- **Do new things.** Go on holidays to new places or try new activities.
- **Have a good routine.** Having a routine helps to prevent confusion. Try to include health habits such as walking into your routine.
- **Talk openly about your feelings.** Talk to family and friends about how your dementia is affecting you.
- **Carry a crisis card or medical alert tag.** This will ensure people know how to help you if something happens.
- **Get regular health check-ups.** See your GP, dentist and optician as often as you need to.
- **Make the most of available support.** Don't feel guilty about accessing services if you need to.
- **Take time to relax.** Meditation and mindfulness techniques can help to reduce stress.



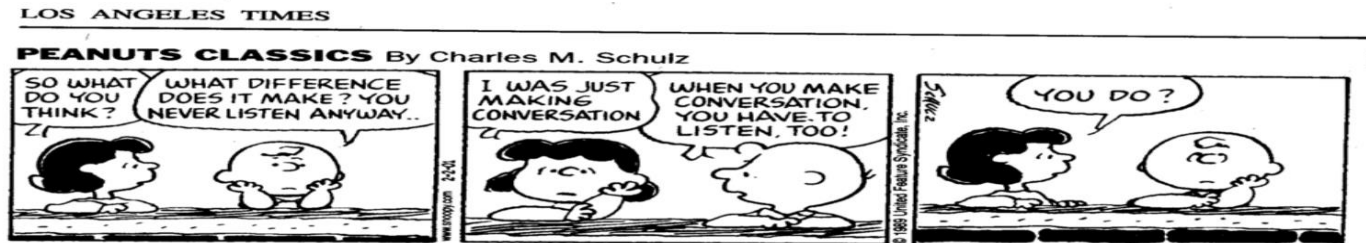
What you wish you'd known when first diagnosed with dementia (facilitated by Dudley)

- **I wish I'd known about the stigma attached to dementia.** Some people have a negative attitude towards people with dementia. I wish I'd known that some family and friends might stop contact.
- **I wish that I'd known about services for people with dementia.** More signposting would have been helpful. Peer support groups and the DEEP network are particularly good. A six-monthly newsletter could provide updates on local services.
- **I wish I'd known that I was not alone.** There are peer support groups which help in reducing fear and isolation.
- **I wish I'd known how my dementia might affect me and others around me.** Information needs to be tailored to the person's circumstances.
- **I wish I'd known how to access health and social care.** Sometimes services are not dementia-friendly.
- **I wish I'd known that dementia does not mean life is ending.** There are inspiring and encouraging people in the DEEP network.
- **I wish I'd known how to talk to others about dementia.** It can be difficult to explain dementia and to ask for help.
- **I wish I'd known that I needed to plan for the future.** It is important to talk to family and friends about future plans such as power of attorney.

What does “dementia-friendly” really mean?

- **Dementia-friendly means awareness, acceptance and understanding.** It means working together with the core value of respect.
- **Dementia-friendly means education.** It means providing training on dementia and ensuring that all employees understand it. It means working with younger generations to improve their understanding.
- **Dementia-friendly means knowing boundaries.** Touch and childish language can be patronising for people with dementia.
- **Dementia-friendly means involvement.** Organisations should consult people with dementia before making changes to signage or services. Dementia-friendly communities should work collaboratively with people living with dementia to understand the difficulties they experience.
- **Dementia-friendly means a person-centred approach.** Services should be tailored to meet individual needs. Services should ask the person questions about what they’re struggling with, and offer them choices.
- **Dementia-friendly means having dementia allies.** The Dementia Friends initiative was good for raising awareness but now people living with dementia need allies. Communities should enable people with dementia to live the best, most independent life they can.

- **Dementia-friendly means making social change.** It means shaping communities through empowerment and enablement. It means campaigning for people's rights, because what is good for people with dementia is good for everyone. Joint decision-making between services and people living with dementia should be promoted.
- **Dementia-friendly means a non-discriminatory and non-judgemental approach.** It means including people with respect and recognition.
- **Dementia-friendly means improving access.** It means reforming the environment to make it less confusing. It means promoting access to information and providing assistance. It means collaborating to remove barriers.

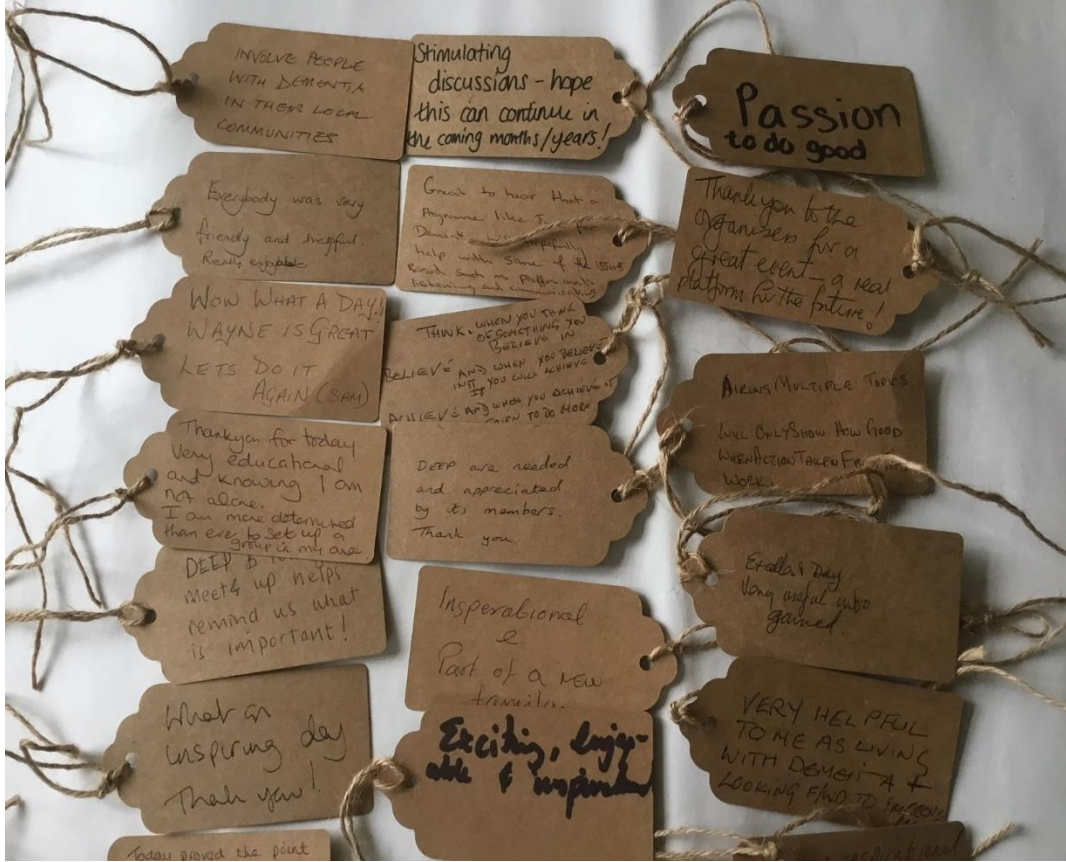


Discussion Feedback

Keeping safe in the home (facilitated by Lorraine)

- **Find solutions to problems and challenges.** Use the “three S’s”: Simplifying, scheduling, and breaking down the sequences of actions of events.
- **Stay organised.** Keep your possessions in consistent places so they do not get lost. White boards can help with remembering dates and keeping letters visible.
- **Use safety and security systems.** Let people you trust know alarm codes in case something happens.
- **Develop good routines and habits.** This will help you to feel in control.
- **Keep information about your medication.** You may need it in the future.





THANK-YOU!

Thank you
by its members
and appreciated
and all needed

What an
inspiring day
Thank you!