

DEMENTIA: *"I'm still me..."*

Together, how can we create a more positive future?



Report of the Meeting of 10th October at Ebbsfleet Football Club, Northfleet, Kent, held to follow up the proposals from the Open Space Event, 27 September 2018



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Alzheimer's & Dementia
S U P P O R T S E R V I C E S

Report of the Follow up Meeting to the Open Space Event

10th October 2018

Overview

The aim of this meeting was to produce firm action plans to make sure things would change following the positive and fresh ideas raised at the Open Space Event on 27 September.

18 people met to work on planning, amounting to a just over a quarter of the people who came to the Open Space event, which was a great level of commitment.

This report sums up the [discussions](#) and [plans](#) made and will be sent to everyone who was involved in planning and coming to the Open Space event and to the follow up meeting. This means everyone can contact the people coordinating the resulting action to offer their involvement and help. And everyone who couldn't get to the follow up meeting now has a chance to take action themselves, including issues that were not worked on in the follow up meeting, but which they think are important.

The follow up meeting started from the report of the Open Space event, especially the [top proposals for action](#) that participants had voted on.

Sheila Marsh, who facilitated the Open Space event led the follow up meeting.

Discussion 1: common themes and key overall issues

Sheila invited everyone to 'walk and talk' with a partner looking at the posters from 27th September in order to think about what had struck them as a common or especially important theme from the whole event.



The following themes were raised. It was agreed these are **core principles that should underlie all work with people living with dementia and their carers:**

Everyone living with dementia should be treated as a unique individual and have support built around them and who they are, so empowering them.

Information is vital to everything right from the start and till the end, including how it is communicated.

Providers of support and other services must join up and communicate with each other constantly.

The diagnosis process must be smooth and include a focus on the benefits of diagnosis.

Education for professionals, carers and the public is a basic building block to achieve all the above.

Discussion 2: Which of the top priority actions and topics should we take forward now?

Sheila invited everyone to work in 3 groups to look at the lists of top priorities voted for at the Open Space event. Groups were asked to propose up to 3 areas of action. To identify the most positive areas to work on Sheila suggested groups think about whether any of the proposals were:

ALREADY HAPPENING
QUICK AND EASY TO MAKE HAPPEN – ‘QUICK WINS’
REQUIRING SERIOUS NEW JOINT EFFORT
SOMETHING ONE ORGANISATION COULD TAKE ON

Groups reported back their suggestions for immediate action planning from the listed priorities, which were grouped together into 5 areas for action:

- **Personalisation of services and of the experience of living with dementia.** Along with this goes 1 to 1 sessions for the person with dementia and for carers, humanising information through having a person giving information and having a single point of contact or hub for all questions – no questions are stupid questions!
- **An information pack that is fit for purpose and standardised county wide**
- **Education for younger people** – seen as a key group to influence for a more positive future
- ***This is Me* forms:** make them visible and used.
- **Mandatory training on dementia and cognitive impairment:** for all professionals and voluntary sector workers.



Discussion 3: planning for action

Four of these proposals were worked on by groups. People chose which area of work they were most interested in and went to that group. Some people chose to work on two or more groups if that was their interest.

Each group produced a clear action plan and identified who would do what. The following pages contain these plans.

Everyone who came to the Open Space event is invited to think which of these they can take part in, and/or if they wish to take up action on other priorities that came out of the day.

Action Plan 1

Topic/Practical idea for action	<p style="text-align: center;">Personalisation of Services</p> <p>1:2:1 sessions / Humanise information / Single point of contact</p>
Co-ordinator(s)	<p>Liz Jewell Liz.jewell@alz-dem.org Wayne Eaton wayne@chewtor.co.uk Denise Kilshaw Denise.Kilshaw@alz-dem.org Iain Tredway iain.tredway@nhs.net Sam Sheppard Samantha.sheppard@kent.gov.uk</p>
What we want to achieve	<ol style="list-style-type: none"> 1. Identify: - <ol style="list-style-type: none"> a. Need (Everyone needs) b. Might need (flexibility in order) c. Might want 2. One point of contact <ol style="list-style-type: none"> a. Information b. Partnership working c. Regular meetings 3. Change the thinking = 'How to facilitate the continuation of living / doing as I have always lived/ done' <ol style="list-style-type: none"> a. Organisations b. Families & Community
Scope of the topic/idea	<ul style="list-style-type: none"> • Huge = Cultural transformation • Regular meetings in public places • Ongoing • Need to embed in other activities – need to build on existing activities
Who's Interested?	<p>Contact details (phone, email) Everyone in the room! joseph.otoole@alzheimers.org.uk Dudley Pearce dwpearcel@yahoo.com Lorraine Brown irainbow777@yahoo.co.uk thomas.beaumont@nhs.net Katie.antill@alz-dem.org Johnportman@talktalk.net Rachael.spencer@kent.fire-uk.org Dee.dhadwal@kent.gov.uk Lisa Sakutombo – 07985462581 Amanda Bedzran a.bedzran@nhs.net Dudley Pearce dwpearcel@yahoo.com Samantha.sheppard@kent.gov.uk Sarah.taylor@alz-dem.org Sandie.wade@alz-dem.org Wayne Eaton wayne@chewtor.co.uk Iain Tredway iain.tredway@nhs.net Denise Kilshaw Denise.Kilshaw@alz-dem.org Katie.antill@alz-dem.org Katherine George – Katherine.george@nhs.net</p>

<p>Who else might want to be involved?</p>	<p>Everyone – keep the invitation open</p> <p>Diagnostic centres GP's [Aim to achieve a Kent wide approach] CCG's KMPT Fire and Rescue Active people with dementia DAA – utilise this body to take action</p>
<p>Next meeting</p>	<p>November / early December</p> <p><i>*Review of Open Space Event & Progress in 6 months</i></p>
<p>Who will commit to contacting others who might want to be involved?</p>	<p>Liz = Write up a mini strategic plan Feedback respective organisations with a clear brief</p> <ol style="list-style-type: none"> a) Outcomes b) Actions c) What the respective organisations need to do <p>Wayne / Denise / Iain = Take the material from the Open Space event to other groups to test the findings (<i>Keep record of which group & numbers</i>)</p>



Action Plan 2

Topic/Practical idea for action	<p style="text-align: center;">'Information Pack – fit for purpose</p> <ul style="list-style-type: none"> - Standardised county wide - Could be leaflet format
Co-ordinator(s)	<p>Thomas Beaumont</p> <ul style="list-style-type: none"> • thomas.beaumont@nhs.net <p>Katie Antill</p> <ul style="list-style-type: none"> • Katie.antill@alz-dem.org
What we want to achieve	<ol style="list-style-type: none"> 1. The pack is fit for purpose 2. Standardised across the county <ul style="list-style-type: none"> ○ With small local variations
Scope of the topic/idea	<ul style="list-style-type: none"> • Building on existing work (Faversham DAA, KMPT) • Fairly small project <ul style="list-style-type: none"> ○ Review ○ Design (Physical & electronic) ○ Distribute & communicate • Series of meetings to; review, design & distribute
Who's Interested?	<p>Contact details (phone, email)</p> <p>thomas.beaumont@nhs.net</p> <p>Katie.antill@alz-dem.org</p> <p>Lorraine Brown jrainbow777@yahoo.co.uk</p> <p>Johnportman@talktalk.net</p> <p>Rachael.spencer@kent.fire-uk.org</p> <p>Dee.dhadwal@kent.gov.uk</p> <p>Lisa Sakutombo – 07985462581</p> <p>Amanda Bedzran a.bedzran@nhs.net</p> <p>Dudley Pearce dwpearcel@yahoo.com</p> <p>Samantha.sheppard@kent.gov.uk</p> <p>Sarah.taylor@alz-dem.org</p>
Who else might want to be involved?	<p>KMPT/CCG'S/ Local Authorities (Social Care) / Voluntary Sector/ Kent Fire & Rescue/ Community Wardens/ KCC Dementia Friendly Team/ People living with Dementia</p>
Next meeting	<p>Mid November / early December</p> <p>Alzheimer's & Dementia Support Services – offering up a room.</p>
Who will commit to contacting others who might want to be involved?	<p>Rachel = Dementia friendly team KCC Wardens</p> <p>Tom = KMPT CCG's Medway Council Voluntary Sector Lorraine</p> <p>Katie = KCC Social Care</p>

Action Plan 3

Topic/Practical idea for action	'This is me' Form
Co-ordinator(s)	Sandie Wade <ul style="list-style-type: none"> • Sandie.wade@alz-dem.org
What we want to achieve	<ol style="list-style-type: none"> 1. Person centred form giving social information that can enable personalised care planning and easier interaction 2. A form that is used across Health & Social Care 3. A form that is completed whilst patients have as much cognitive ability as possible 4. Could be attached to the 'Bounty Pack' and be promoted at Dementia Café's
Scope of the topic/idea	<ul style="list-style-type: none"> • Large – across all services • It requires more than one meeting • It is an ongoing project • Needs to build on the existing framework
Who's Interested?	Contact details (phone, email) <ul style="list-style-type: none"> • Sandie.wade@alz-dem.org • A.bedzrah@nhs.net • Iain.tredway@nhs.net • Jo.dron@nhs.net
Who else might want to be involved?	Families / Patients / Carers/ Doctors/ Key workers/ Professionals/ All Contact Wardens (Sheltered housing)
Next meeting	
Who will contact others who might want to be involved?	



Action Plan 4

Topic/Practical idea for action	Education of Younger People
Co-ordinator(s)	<p>Sarah Taylor</p> <ul style="list-style-type: none"> • Sarah.taylor@alz-dem.org <p>Joseph O'Toole</p> <ul style="list-style-type: none"> • joseph.otoole@alzheimers.org.uk
What we want to achieve	All young people to be Dementia Friends (<i>Person with Dementia to be included in the Dementia Friends Session</i>)
Scope of the topic/idea	<ul style="list-style-type: none"> • National • Infinite • Building on existing work
Who's Interested?	<p>Contact details (phone, email)</p> <p>Sarah.taylor@alz-dem.org</p> <p>joseph.otoole@alzheimers.org.uk</p> <p>Dudley Pearce dwpearcel@yahoo.com</p> <p>Lorraine Brown irainbow777@yahoo.co.uk</p>
Who else might want to be involved?	<p>Kay and David Evans - kaydave64@sky.com</p> <p>Memorabilia</p> <p>Oasis Academy</p> <p>DAA – to get schools to join</p> <p>Health Education England</p> <p>Minster of Education</p> <p>Project Salus – peter.heckel@projectsalus.co.uk</p>
Next meeting	
Who will commit to contacting others who might want to be involved?	<p>Sarah = DAA</p> <p>Dudley = Local MP Gillingham & Rochester</p> <p>Lorraine = DAA</p> <p>Joe = Alzheimer's Society Dementia Friends & Education</p>

Follow-up meeting participants

name	organisation	contact
Liz Jewell	Alzheimer's & Dementia Support Services	Liz.jewell@alz-dem.org
Dudley Pearce	Memorybillia	dwpearce@yahoo.com
John Portman	Alzheimer's Society volunteer	johnportma@talktalk.net
Sandie Wade	Alzheimer's & Dementia Support Services	Sandie.wade@alz-dem.org
Thomas Beaumont	Medway CCG	Thomas.beaumont@nhs.net
Rachael Spencer	KRFS	Rachael.spencer@kent.fire-uk.org
Amanda Bedzrah	WKCCG	a.bedzrah@nhs.net
Lorraine Bow	Experts by experience	Lrainbow777@yahoo.com
Wayne Eaton	Experts by experience	wayne@chewtor.co.uk
Iain Treadway	Medway NHS Foundation Trust	Iain.treadway@nhs.net
Denise Kilshaw	Alzheimer's & Dementia Support Services	Denise.kilshaw@alz-dem.org
Katie Antill	Alzheimer's & Dementia Support Services	Katie.antill@alz-dem.org
Samantha Sheppard	KCC	Samantha.sheppard@kent.gov.uk
Sarah Tayler	Alzheimer's & Dementia Support Services	Sarah.tayler@alz-dem.org
Joseph O'Toole	Alzheimer's Society	Joseph.otoole@alzheimers.org.uk
Liza Sakutombo	Experts by experience	07985462581
Dee Dhadwal	KCC Adult Social Care	Dee.dhadwal@kent.gov.uk
Katherine George	DVH	Katherine.george4@nhs.net