

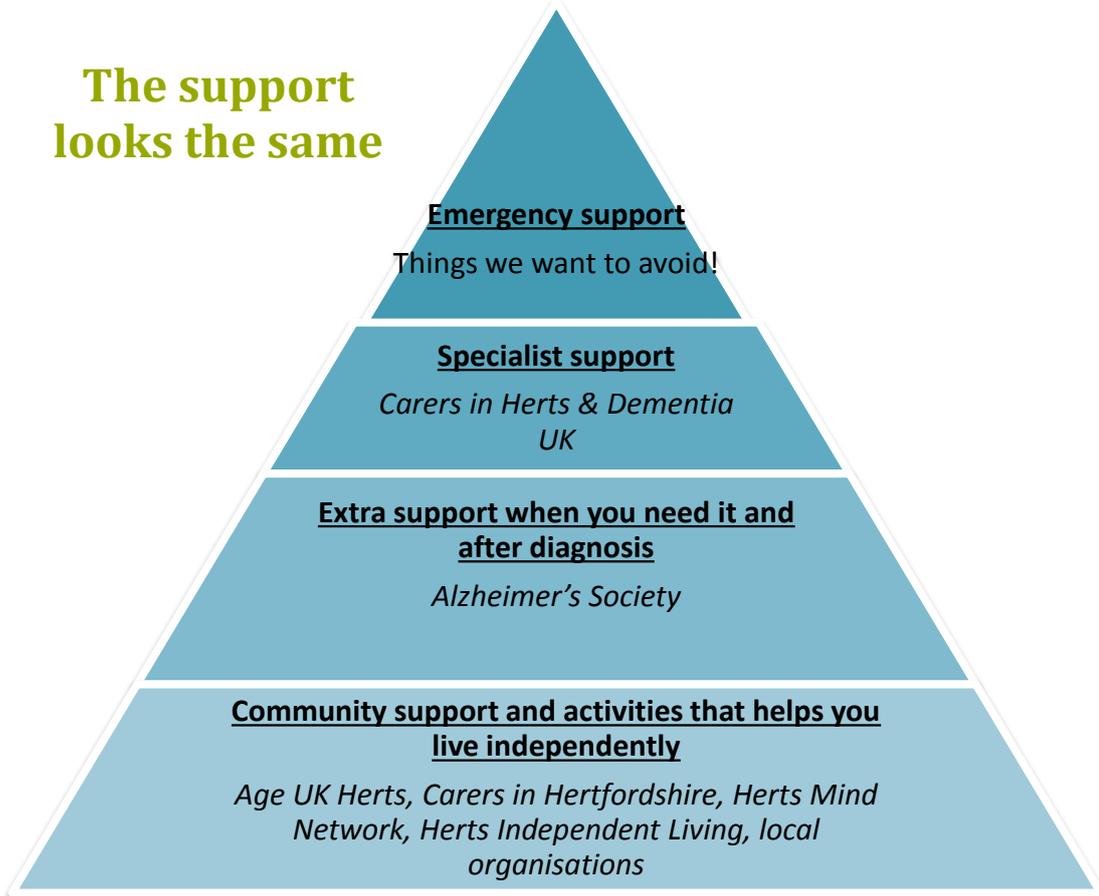
# Dementia Carers Forum

## Notes of a meeting held on 19<sup>th</sup> January 2017

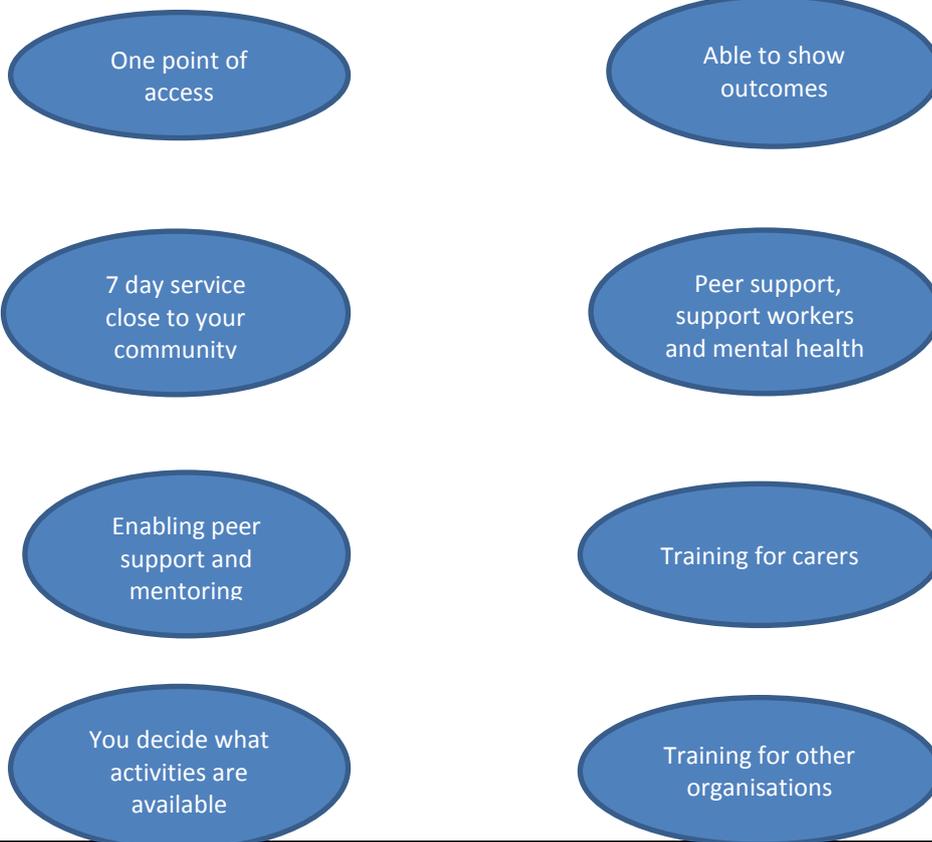
Bishops Stortford Baptist Church,  
Twyford Road Bishops Stortford CM23 3LJ

1	<b>Present</b>	
	Carers present 15 Professionals present 12 Speakers 5	
	Sally Stratford Mike Ormerod	Carers in Hertfordshire
2	<b>Welcome</b>	
	Mike welcomed everyone to the forum.	
3	<p><b>Tender outcomes for the Dementia community Services in Hertfordshire-</b> Tom Johnson- Commissioning and Monitoring Manager, Hertfordshire County Council Ruth Harrington - Head of Community Wellbeing Services, Hertfordshire County Council Victoria Lyons – Dementia UK Jan Gough – Age UK Scott Eastwood – Alzhiemers Society</p> <p>Tom Johnson opened the presentation, outlining the changes in dementia services.</p> <p style="text-align: center;"><b>Community Dementia services in Hertfordshire</b></p>	

## The support looks the same



## What did you tell us you needed?



## What now?

1. A gradual change to dementia services
2. More opportunities to meet other carers and attend groups, not less.
3. All existing groups and attendees of groups consulted about what services are available going forward.
4. Existing staff have the opportunity to apply for roles that are advertised
5. Alzheimer's Society continues to be important partners and are recognised as experts
6. Age UK Hertfordshire and their partners bring a range of expertise both in running activity services and in supporting people with dementia, their carers and families.

**Every person who has support now will continue to be supported**

## Detail on - Activities

- Countywide (10 **districts**), person-centred, holistic, accessible and flexible services (7/7)
- **Herts Help** Single Point of Access (SPA), triage, tell story once (partnership CMS)
- Lead partner: Governance, Project Manager, **Community Information Network Advisers** (LPA, Digital, Signposting, Home visits, Navigation across Lots and supporting people with changing needs) (EMDASS), **Grant Fund, Steering Group and Partnership Board**
- Partners: **Locality Workers** (one per district) and a **Specialist Carer Support Worker**. Locality Worker (supported by volunteers): **121, groups** (10 week cycle), groups+ (district base) and **training** (evaluation plan) for organisations. Group activities to include singing with new activities co-produced

## Detail - Accessibility

- Herts Help **SPA** – Single Number
- **Seamless** referral process
- Partnership ‘One’ **CMS**
- **Steering group**
- Community Information Network Adviser (**CIN**) – navigation across lots
- Groups (contribution based/ **no one refused** basis)
- Times **7/7** with flexibility and evening sessions
- **Supported** to access transport
- Co-produced / **Equality Impact Assessed** activities
- Accessible venues in all **10 districts**
- Range of **promotional materials** with publications inc **Dementia Roadmap**
- Promotion of services to **Health** (GP, Pharmacies etc), **Social Care, Voluntary Sector** and **Private Sector**
- **Community** Network Organisations communication **links**
- Service **launch** (each district)
- Enhanced access to organisations (**training**)

*Jan Gough – CEO Age UK Herts*

## Detail - Specialist Dementia Support

- Alzheimer’s Society will provide individualised 1:1 support to people newly diagnosed with dementia, their carers and families as part of the post diagnostic support within EMDASS
- Community 1:1 support will also be provided to those people who have been transferred from EMDASS, referrals from Lot 1 & Lot 3, as well as those people contacting Alzheimer’s Society directly
- Information and signposting will be provided by Dementia Advisers, supported by volunteers. More complex cases will be referred on to the Dementia Support Workers
- If there is an identified need referrals will be made into Lot 1 and/or Lot 3
- Monthly well-being telephone checks will be made to all non-active cases.

*Scott Eastwood – Stakeholder Relations,  
Alzheimer’s Society*

## Detail - Admiral nurses

- What can an admiral nurse do?
- How will this help me?

Victoria Lyons – Dementia UK

## Any other questions

### **For questions on the new service:**

Call Herts Help: 0300 123 4044

*Carers in Herts will attend your existing carers group in February and March*

### **For complaints or concerns:**

Email: [cwb.support@hertfordshire.gov.uk](mailto:cwb.support@hertfordshire.gov.uk)

Write:

Dementia | Community Wellbeing Team | Farnham House | Six Hills Way, Stevenage | SG1 2FQ

4	<b>Clarification/Questions/Comments on the presentation</b>	
	Question	<b>Was there any dialogue/communications with doctors about these new services and subsequently, an input from them?</b>
	Answer	(HCC Commissioner) Yes, definitely. The money for this tender is from health as well as the County Council. Health has invested in this model as they can see the benefits to their services as well as to the community. GPs sit at CCG meetings and this is where the link is made between them and EMDASS. <i>One carer stated that her GP in Watton-at-Stone were completely unaware of dementia services. Ruth Harrington stated that Herts Help would be more than happy to approach them.</i>
	Question	<b>It took three years for EMDASS to diagnose my wife with dementia and there was no mention of early onset (also called Young Onset Dementia). There appears to be no support for them. What assurances are there for the provision of support for those younger people being diagnosed?</b>
	Answer	(Dementia UK) This is very common as it is hard and complex to diagnose. Admiral nurses do a lot of work with those with early onset dementia. It is assured that admiral nurses work with and support all types of dementia.
	Question	<b>I am worried about losing my current support and feel the whole situation has been handled very badly. I was told that all carers had been consulted to these changes but this has not been the case.</b>
	Answer	(HCC Commissioner) Alzheimer's Society will continue as they are. There are no cuts in the dementia contract. Community dementia support has increased by £250,000 per annum. If carers are supported, then they are able to continue caring and support the wider health and social care system. Age UK have more resources to reach out to a bigger number of people. There were nine different consultation events held across ten districts. <i>(Three members of the forum from Broxbourne, Ware and Hertford stated they were unaware of any events. At this point, one member asked the room how many people had been consulted about the changes and 3 out of approximately 30 said they had).</i>
	Question	<b>Early onset is completely different and I feel there's no real support for this. All groups seem to be focussed on older people.</b>
	Answer	(Age UK) Age UK will tailor support according to the need. The new community model has been designed to be flexible and accommodate everyone. CinH is also doing great work within the community. Age UK will be supporting the 13,000 people not currently supported. We are not moving into a new model without listening to the carers and HCC are investing more towards support
	Question	<b>Where are you getting your information from? Very old</b>

		<b>people in isolated areas have no information about services. We happened to find out about Singing for the Brain, but unless we were registered with someone like CinH, how would we know?</b>
Answer		(Age UK and HCC Commissioner) The new community model is looking to improve communications and the communications plan. All Herts Help partners are looking to promote HH by sending out the details via email, parish newsletters, magazines, primary care. <i>At this point the carer pointed out that in her particular case, none of these would be helpful to this person as they would not use any of this media. She suggested that an official letter be sent outlining the types of services that are available. HCC stated they are working hard to look for people in these situations. They are campaigning to promote HH wider into the community. It became apparent that the person with care needs in this particular case was living in Flexicare accommodation. HCC work with Flexicare providers and the key worker at the Flexicare scheme should be able to refer them to the right support.</i>
Question		<b>What numbers of 1-1 support workers are being reduced?</b>
Answer		(Alzheimers Society) Staff are currently going through consultations, but this cannot be discussed at present due to confidentiality and HR restrictions. However, everyone who is receiving support now, will continue to do so. Any referrals via EMDASS, CinH, Age UK, Dementia UK etc. will be dealt with in the same way. Through the new model, Dementia Support Advisers can offer advice via telephone, or in more complex cases, face to face support. (HCC Commissioners) There is a change in the process as of March. The investment in 1-1 has been kept the same, but the model will be changing slightly. By the end of February/beginning of March, changes will be more apparent.
Question		<b>There were many questions asked about Singing for the Brain and concerns about the groups being stopped and different facilitators being brought in.</b>
Answer		(Age UK) Singing for the Brain would continue as normal until March. As of then, and in keeping in line with the new model, singing groups can continue if that is what people want, but under a different name as the current one is copyright and can no longer be used. The dates that were previously booked for these sessions will continue and venues are actively being sought for March-May. The new groups will be in local venues to enable communities easier access. The current facilitators cannot be guaranteed but they are in the process of being briefed regarding the new changes. Age UK will work with the Alzheimer's Society to seek training on how to facilitate future groups. Age UK will meet with facilitators to discuss the new roles and keep in line with TUPE and employment legislation. It is stressed that the current facilitators need to be spoken to first. The original

		plan was to go out and meet people face-to-face, such as today, to explain the transition happening after March and not for them to have received a letter at Christmas time. Age UK are going to speak to all groups to explain that there are no immediate changes, but transitional and as seamless as possible
	Question	<b>I am a carers champion in a GP surgery and maintain regular contact with carers. It was our Patient Group that fed back to us about the changes. It would have been useful for us to have known about these changes, in order that we could have been referring correctly.</b>
	Answer	CinH) We will be sending out a letter tomorrow to explain all of the changes to all of our registered dementia carers. CinH are going to inform the fourteen carer groups currently running in the next month.
	Question	<b>You mentioned in your presentation about groups that meet being in a ten week cycle. Does this mean you can only attend for ten weeks?</b>
	Answer	Age UK) The groups will be in the ten districts on a ten week cycle. We will facilitate the low support groups to start with for ten weeks. After the cycle has ended, we will continue to give support to the group to help it to run independently. This model is happening now, locality groups have set up making it easier for local residents as they use community halls, church halls etc. This is at little or no cost, enabling other groups to continue, and for there to be more groups locally for people to attend.
	Question	<b>In these coming months, we need to be listened to. Do you have definitive answers?</b>
	Answer	(Age UK) The model is designed to be responsive, not prescriptive. It is difficult to say 'this is the plan' as this is not how the model works. We will have ten full time locality workers and a specialist carers support worker in order to build as much flexibility as possible
	Question	<b>My mother has dementia and also has breast cancer. When dealing with Addenbrooke's Hospital, they do not recognise her dementia when contacting her. She will received automated telephone calls, which she is unable to deal with.</b>
	Answer	(Alzheimer's Society) Alzheimer's Society is currently talking with hospitals to change practices where possible and by working with NHS England. (Dementia UK) An Admiral Nurse is being posted in Addenbrookes as well as several other hospitals, to deal with situations such as this.
	Question	<b>Back in 2007 when my husband was diagnosed we I had no support and he was just referred to a community psychiatrist. I then found 'Turning Point' who proved to extremely helpful and provide a good service for people with early onset dementia and their carers. Other than that, I would have to ring 999 on occasion.</b>
	Answer	(HCC Commissioners) Our contract still continues with Turning Point and has been extended

	Question	<b>Young people with learning disabilities – how does this new model support them?</b>
	Answer	(Age UK) The Lot 1 service supports learning disabilities. We are working closely with a Team Manager from the Community Learning Disability Service who is willing to sit on a steering group and get things moving forward ASAP. HCC are looking a pathway of support between learning disability and early onset. Admiral nurses will work across all areas.
<b>6</b>	<b>Mike closed the meeting and invited everyone to stay for lunch.</b>	