

# Dementia Carers Forum

6<sup>th</sup> March 2019

South Hill Centre, Hemel



<b>1</b>	<b>Present</b>
	<p><b>Carers</b> 26</p> <p><b>Speakers</b> Keith Mupita - Service Line Lead (East &amp; North) Hertfordshire Partnership NHS Foundation Trust Caroline Finch – Interim Transformation Lead Hertfordshire Partnership NHS Foundation Trust</p> <p><b>Carers in Herts</b> Sally Stratford – Involvement and Development Worker Dementia Paula Campbell – CinH Carer Support Advisor Karen Denny – Project Officer CinH</p>
<b>2</b>	<b>Welcome</b>
	<p>All carers and speakers were welcomed to the forum, and informed that it was a very relaxed and informal session so that the carers could participate in the discussion. Karen Denny spoke briefly about the Carers in Hertfordshire's Passport, which is a discount card for carers. It offers a variety of discounts across the county as well as helping to identify you as an unpaid carer. Karen explained that she was available throughout the morning and at lunch to help with new applications and renewals.</p>
<b>3</b>	<b>Presentation</b>
	<p>Keith and Caroline introduced themselves and thanked us for the opportunity to come and speak to carers about the services provided by Hertfordshire Partnership NHS Foundation Trust (HPFT).</p> <p>HPFT provide a variety of services including the diagnosis service EMDASS (Early Memory Diagnosis and Support Service), community older people services and recovery therapy services.</p> <p>Who has had experience of EMDASS?</p> <p><math>\frac{3}{4}</math> of the carers had experience of EMDASS and had the following comments:</p> <ul style="list-style-type: none"> <li>• EMDASS service was good but on discharge I was left with nothing. The GP who is supposed to support me and be my contact person did not want to get involve</li> <li>• There is not enough responsibility taken by the GP regarding the care of someone with Dementia once you are discharged to their care</li> <li>• EMDASS was not a good experience for someone with mixed conditions (Parkinson's and Dementia) medication was not considered</li> <li>• On the whole EMDASS was good but there was too long wait between seeing the consultant and the Alzheimer's support worker. We had to wait three and a half months, we needed this support and information earlier to help us understand and come to terms with the diagnosis</li> <li>• EMDASS pathway is not clear – there is a leaflet being designed, agreed to send this out to carers for consultation before going to print.</li> <li>• Memory clinics are no longer available. These were very helpful especially regarding medication, hallucinations and other behaviours relating to the dementia. When these clinics were closed I felt isolated, and left to deal with things alone, unsupported</li> <li>• GP's are general probationers, they are not the right people to look after</li> </ul>

# Dementia Carers Forum

6<sup>th</sup> March 2019

South Hill Centre, Hemel



someone with dementia

- Once I am discharged from EMDASS do I see consultant again? Yes the GP can refer you to the community team if support is needed.
- The 38 week pathway is not 38 weeks; I did not receive services for this length of time. I only received 3 calls during the 38 weeks and did not release that it was a pathway. There was no clear information about the pathway and what I would receive.
- Once the person is diagnosed the carer goes through the first grieving process, there seems no support for this. Carers need specialist counselling
- As part of EMDASS I was offered a 6 week course but this never happened
- It is difficult to understand the pathway, see where we are on it and who is responsible for providing which bit of support/services. Perhaps there could be a profile of the person with dementia which shows where you are and what support you are receiving and will receive next?
- It took 5 years for me to get a diagnosis for my mother – GP's did not listen to us and would not refer us for a diagnosis. We saw 5 different GP's and in the end we got some help, this needs to be better.
- On discharge from EMDASS my wife (the person with dementia) received a confidential letter from HPFT which was a survey about their services that she had relieved. This was highly inappropriate and should not be sent to people with dementia. It is also not a good use of resources.
- HPFT wrote to my wife regarding her continuing health care, this was also inappropriate. My wife is in the later stages of dementia and would not be able to understand this. I have lasting power of attorney, they should have written to me. The funding was withdrawn which has been very stressful especially as her condition has deteriorated.

HPFT are looking at re-investing some money into community services from the closure of one of our treatment and assessment units – prospect house. We are going to fund two more Admiral Nurses to work alongside the other 4 community Admiral Nurses that are hosted by Carers in Hertfordshire. We are also looking at supporting care homes, to help them to manage peoples challenging behaviour to prevent hospital admissions, improve the process of applying for continuing health care by employing a specialist team to carry out the assessments, look at using assistive technology better and improving crisis support in the community. What would help you to carry on caring in the community?

- Why are you supporting care home to deliver what they are already funded to deliver? This support needs to be in the community to help carers to care on caring for longer and prevent/deal people having to use care homes.
- The CCG's are under pressure to reduce continuing health carer funding, my wife has lost hers even though her condition is deteriorating
- We had a continuing health care assessment and got told that we would never get awarded it as it was their decision whatever the carers said – always make a complaint if you are not happy with the service that you receive from HPFT. We are very willing to discuss things with you and improve services.
- The process of continuing health care is not clear – a booklet is being

# Dementia Carers Forum

6<sup>th</sup> March 2019

South Hill Centre, Hemel



	<p>produced. It will be shared with carers for consultation before printing.</p> <ul style="list-style-type: none"> <li>• Day to day help with everyday issues is needed – a support line</li> <li>• Specialist Dementia Nurses to help with medication - we do have prescribing nurses but they work in our services perhaps we could open these up to the community? This will be feedback to HPFT.</li> <li>• More crisis support – where do we get this help? HPFT have a crisis support team which is open 7am-9pm. Outside of this you can access the Crisis assessment team CAT which is 24 hours. You can access both through the single point of access (SPA) Tel: 0300 777 0707 Email: <a href="mailto:hpft.spa@nhs.net">hpft.spa@nhs.net</a></li> </ul>		
4	<p><b>Clarification/Questions/Comments on the Presentation</b></p>		
	<table border="1"> <tr> <td data-bbox="223 728 416 2065">Comments</td> <td data-bbox="416 728 1422 2065"> <ul style="list-style-type: none"> <li>• My mother is currently in Victoria Court, after being moved there from Elizabeth Court. She is unable to live anywhere else due to her dementia. There will be more people with dementia in the future, yet you are closing beds. I am very concerned about this and where all of these people will live.</li> <li>• Alzheimer’s society has a community team who offer 1:1 support to the person with dementia and their carers. You can self-refer to this service through Hertshelp on 0300 123 4044 Carers said that the support from Alzheimer’s society was brilliant, the feedback on the Hertswise(Age UK and partners) was not so positive with carers feeling that they were not experienced enough in dementia.</li> <li>• More practical support around caring for someone with dementia is needed. Café’s/support groups/coffee mornings/hubs are all very well but skills taught around the practical aspects of caring would be far more beneficial and carers to carry on caring for longer. Some of the skills needed to be taught are how to shower someone, how to get in and out of the house, how and where to go on holiday, how and what to feed someone, how to increase their fluid intake, how to identify a urinary infection.</li> <li>• Training for carers must include the physical aspects of caring as well as the emotional, including where to get support when you need it.</li> <li>• Crisis support - What do I do in a crisis? Where do I get support? You can access support from:</li> <li>•</li> </ul> <p><b>Alzheimer’s society</b> – 1:1 support, information and guidance for people with dementia, their carers and families. Contact Hertshelp <b>0300 123 4044</b> or email <a href="mailto:info@hertshelp.net">info@hertshelp.net</a></p> <p><b>Admiral Nurses</b> – The nurses will provide intensive support to carers of someone with dementia, who are in or at risk of crisis. Support could include tailored training, relationship management and liaison with other health and social care professionals. Contact Hertshelp <b>0300 123 4044</b> or email <a href="mailto:info@hertshelp.net">info@hertshelp.net</a></p> </td> </tr> </table>	Comments	<ul style="list-style-type: none"> <li>• My mother is currently in Victoria Court, after being moved there from Elizabeth Court. She is unable to live anywhere else due to her dementia. There will be more people with dementia in the future, yet you are closing beds. I am very concerned about this and where all of these people will live.</li> <li>• Alzheimer’s society has a community team who offer 1:1 support to the person with dementia and their carers. You can self-refer to this service through Hertshelp on 0300 123 4044 Carers said that the support from Alzheimer’s society was brilliant, the feedback on the Hertswise(Age UK and partners) was not so positive with carers feeling that they were not experienced enough in dementia.</li> <li>• More practical support around caring for someone with dementia is needed. Café’s/support groups/coffee mornings/hubs are all very well but skills taught around the practical aspects of caring would be far more beneficial and carers to carry on caring for longer. Some of the skills needed to be taught are how to shower someone, how to get in and out of the house, how and where to go on holiday, how and what to feed someone, how to increase their fluid intake, how to identify a urinary infection.</li> <li>• Training for carers must include the physical aspects of caring as well as the emotional, including where to get support when you need it.</li> <li>• Crisis support - What do I do in a crisis? Where do I get support? You can access support from:</li> <li>•</li> </ul> <p><b>Alzheimer’s society</b> – 1:1 support, information and guidance for people with dementia, their carers and families. Contact Hertshelp <b>0300 123 4044</b> or email <a href="mailto:info@hertshelp.net">info@hertshelp.net</a></p> <p><b>Admiral Nurses</b> – The nurses will provide intensive support to carers of someone with dementia, who are in or at risk of crisis. Support could include tailored training, relationship management and liaison with other health and social care professionals. Contact Hertshelp <b>0300 123 4044</b> or email <a href="mailto:info@hertshelp.net">info@hertshelp.net</a></p>
Comments	<ul style="list-style-type: none"> <li>• My mother is currently in Victoria Court, after being moved there from Elizabeth Court. She is unable to live anywhere else due to her dementia. There will be more people with dementia in the future, yet you are closing beds. I am very concerned about this and where all of these people will live.</li> <li>• Alzheimer’s society has a community team who offer 1:1 support to the person with dementia and their carers. You can self-refer to this service through Hertshelp on 0300 123 4044 Carers said that the support from Alzheimer’s society was brilliant, the feedback on the Hertswise(Age UK and partners) was not so positive with carers feeling that they were not experienced enough in dementia.</li> <li>• More practical support around caring for someone with dementia is needed. Café’s/support groups/coffee mornings/hubs are all very well but skills taught around the practical aspects of caring would be far more beneficial and carers to carry on caring for longer. Some of the skills needed to be taught are how to shower someone, how to get in and out of the house, how and where to go on holiday, how and what to feed someone, how to increase their fluid intake, how to identify a urinary infection.</li> <li>• Training for carers must include the physical aspects of caring as well as the emotional, including where to get support when you need it.</li> <li>• Crisis support - What do I do in a crisis? Where do I get support? You can access support from:</li> <li>•</li> </ul> <p><b>Alzheimer’s society</b> – 1:1 support, information and guidance for people with dementia, their carers and families. Contact Hertshelp <b>0300 123 4044</b> or email <a href="mailto:info@hertshelp.net">info@hertshelp.net</a></p> <p><b>Admiral Nurses</b> – The nurses will provide intensive support to carers of someone with dementia, who are in or at risk of crisis. Support could include tailored training, relationship management and liaison with other health and social care professionals. Contact Hertshelp <b>0300 123 4044</b> or email <a href="mailto:info@hertshelp.net">info@hertshelp.net</a></p>		

# Dementia Carers Forum

6<sup>th</sup> March 2019

South Hill Centre, Hemel



	<p><b>Dementia UK's helpline</b> –<a href="tel:08008886678">0800 888 6678</a> <a href="https://www.dementiauk.org/">https://www.dementiauk.org/</a></p> <p><b>Crisis support service</b> - Access through the single point of access SPA Tel: 0300 777 0707 Email: <a href="mailto:hpft.spa@nhs.net">hpft.spa@nhs.net</a></p>
--	---

<b>5</b>	<p><b>Closing comments and information</b></p> <p>Carers and the speakers were thanked for attending and invited to stay for lunch.</p> <p>If there are any issues that carers would like to look at in future forums then please let Sally Stratford know on 01992 586969 or <a href="mailto:sally.stratford@carersinherts.org.uk">sally.stratford@carersinherts.org.uk</a></p> <p><b>Next forums</b> Wednesday 15<sup>th</sup> May at Hoddesdon Baptist Church, a light lunch is provided following the Forum. Please call <b>01992 586969</b> to book a place.</p>
----------	---



# Dementia Carers Forum

6<sup>th</sup> March 2019

South Hill Centre, Hemel

