

# Young Onset Dementia Carers' Forum

17<sup>th</sup> October 2018 – Birchwood Leisure Centre, Hatfield



1	<b>Present</b>
	<p><b>Carers</b> 9</p> <p><b>Speakers</b> Gemma Hawkesbury – Admiral Nurse Sam Balding – Young Onset Dementia Worker, Age UK</p> <p><b>Carers in Herts</b> Sally Stratford (<b>SS</b>) – Forum leader Paula Campbell – CinH Carer Support Advisor Toby Purnell – CinH volunteer</p>
2	<b>Welcome</b>
	<p>All carers and speakers were welcomed to the forum. The content of the meeting was explained, along with the facilities of the building. Personal introductions were made by all those present.</p>
3	<b>Gemma Hawkesbury – Role of Admiral Nurses</b>
	<p>Gemma introduced herself and explained that she covers North and Central Hertfordshire. She then explained the role of an Admiral Nurse:</p> <p>An Admiral Nurse provides the specialist dementia support that families need when things get challenging or difficult. The nurses work alongside people with dementia, and their families by giving them one-to-one support, expert guidance and practical solutions. The nurses are there for the carers to help them to look after their own health and well-being whilst caring for someone with Dementia. They can offer practical advice and support as well as refer them to other services; the most important part is being there to listen to the carers.</p> <p>There are currently 4 Community Admiral Nurses and 1 based in Lister Hospital. It is hoped that 2 nurses will be placed within hospices in the near future. All Nurses provide help during usual office hours on weekdays only.</p> <p>Referrals can be made via HertsHelp. Admittedly there have been a few hiccups with this process, but it is thought that this now works better.</p> <p>If a carer encounters any problems with referrals, they should contact Carers in Herts for assistance.</p> <p>Admiral Nurses liaise with the Memory clinic, Adult Care Services, and Community Mental Health teams.</p> <p>They also provide educational support, as a way of sharing information.</p> <p>Currently, there are no waiting lists for help within North and East Hertfordshire. Some of the carers present were already accessing Admiral Nurses but the majority had not heard of this service.</p>

<b>5</b>	<p><b>HertsWise – Young Onset Dementia Support</b></p> <p>Sam Balding from HertsWise attended the meeting to let carers know about the support that she can offer people with Young Onset Dementia and their carers. She offers groups, activity groups and one to one support as well as working age benefit advice. Sam then discussed some of the benefits available to carers and the cared-for, and also Lasting Powers of Attorney.</p> <p><b>Attendance Allowance:</b></p> <ul style="list-style-type: none"> <li>• A 30-page form is needs to be filled in</li> <li>• It is accessed by the carer or the cared-for</li> <li>• Two levels: Day <u>or</u> Night Need (a lower amount); or Day <u>and</u> Night Need (a higher amount)</li> <li>• In order to receive this payment, the carer or cared-for must match at least half of the criteria</li> <li>• It is only paid to those over 65 years of age</li> <li>• This benefit does not have a Mobility component like Personal Independence Payment</li> <li>• Applying for/receiving this benefit allows access to Carers Allowance and other benefits</li> <li>• Applying for/receiving this benefit triggers a reduction in Council Tax and an application for Housing Benefit</li> </ul> <p><b>Carers Allowance:</b></p> <ul style="list-style-type: none"> <li>• Paid to those under 65 years of age</li> <li>• Those over 65 years of age are eligible to apply, with any State Pension paid possibly topped-up by Pension Credit</li> <li>• If a carer over the age of 65 is ineligible for the Carers Allowance, the carers State Pension may be adjusted with a Carer Premium</li> </ul> <p><b>Council Tax Reduction:</b></p> <ul style="list-style-type: none"> <li>• Triggered by Attendance Allowance; Personal Independence Payment; or if the homeowner has a severe mental impairment</li> <li>• The reduction is 25%</li> <li>• Contact Age UK for the form to apply for this</li> <li>• Other reductions can be triggered             <ul style="list-style-type: none"> <li>○ If the homeowner live alone. The reduction is 25%</li> <li>○ If the carer leaves their home empty in order to live with their cared-for. The reduction is 100%</li> <li>○ If the homeowner has a disability. The reduction can be 50% or 100%</li> </ul> </li> <li>• Checks can be made by the council to ensure eligibility is still valid</li> </ul> <p><b>Lasting Power of Attorney (LPA):</b></p> <ul style="list-style-type: none"> <li>• Age UK can help prepare the LPA paperwork</li> <li>• There are two separate LPA – Health and Welfare; and Property and Financial Affairs</li> <li>• Age UK does <b>not</b> charge to do this, but welcome a donation</li> <li>• The only mandatory cost is the registration fee – currently £84 for each LPA. The LPA is registered with the Office of the Public Guardian. Once registered the Property and Financial Affairs LPA is active immediately; the Health and Welfare is not. However, in reality, whilst the cared-for has</li> </ul>
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	<p>mental capacity, either LPAs do not have to be enforced/used</p> <ul style="list-style-type: none"><li>• When you wish to use either LPA, one should notify the organisation or person you are dealing with</li><li>• Each LPA can have Primary and Replacement Attorneys (in order retain the eligibility of the LPA in all circumstances), who can act either Jointly (i.e. together) or Severally (i.e. independently)</li><li>• If a LPA becomes invalid, it is possible to apply to the Court of Protection to become a Deputy. However:<ul style="list-style-type: none"><li>○ It costs a minimum of £400 to arrange this</li><li>○ It can take a significant period of time (a real-life example was given in which a Deputyship had taken 10 months to arrange)</li></ul></li></ul> <p>Once authorised, the Deputy has to make a yearly return explaining how the money of the cared-for has been used, and explaining all decisions taken relating to their care and wellbeing.</p> <p>To access Sam's Young Onset Dementia support please see the link below: <a href="https://www.ageuk.org.uk/hertfordshire/our-services/dementia-support/young-onset-dementia-support/">https://www.ageuk.org.uk/hertfordshire/our-services/dementia-support/young-onset-dementia-support/</a></p> <p>Or call Herts Help:</p> <p><b>Monday - Friday, 8am - 6pm</b></p> <p><b>0300 123 4044</b></p>
<b>6</b>	<b>Clarification/Questions/Comments on the HertsWise Presentation</b>

	<p>Other useful information:</p> <ul style="list-style-type: none"> <li>• <a href="#"><u>Turning Point - Herfordshire Carers Support Service</u></a>                      Watford, Three Rivers &amp; Hertsmere. Tel 01438 724995                      Service provides short periods of respite to carers of people with young onset dementia.</li> <li>• <b>Young onset dementia support group</b>                      West Herfordshire. Tel 01923 894222                      Tuesday-Friday, 9am-5pm, an opportunity for carers to meet others and share their experiences and support each other in an informal environment.</li> </ul> <p><a href="https://www.youngdementiauk.org/south-east"><u>https://www.youngdementiauk.org/south-east</u></a></p> <ul style="list-style-type: none"> <li>• Sunnyside Rural Trust offer activities during the day for people with Young Onset Dementia, including things like gardening.</li> </ul> <p><a href="http://www.sunnysideruraltrust.org.uk/"><u>http://www.sunnysideruraltrust.org.uk/</u></a></p>
<b>7</b>	<b>Closing Information</b>
	<p>Carers and 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"><u>sally.stratford@carersinherts.org.uk</u></a></p> <p><b>Next forum</b></p> <p>Next years forums have yet to be planned, carers will be informed of these by email or post in the new year.</p>