

# Young Onset Dementia Carers Forum

27<sup>th</sup> February 2020

Birchwood Leisure Centre, Hatfield



<b>1</b>	<b>Present</b>
	<p><b>Carers</b> 4</p> <p><b>Speakers</b> <b>James Salmon</b> - Senior Commissioning Manager Integrated Health and Care Commissioning Team (Working on behalf of Hertfordshire County Council, East and North Hertfordshire CCG, Herts Valleys CCG) <b>Tara Patterson</b> – Young Onset Worker Hertswise</p> <p><b>Carers in Herts</b> <b>Sally Stratford</b> – Involvement and Development Worker Dementia <b>Rosemary Willis</b> – Carer Support Advisor</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.</p>
<b>3</b>	<b>Dementia Strategy Discussion</b>
	<p>James introduced himself and explained his role: he is a commissioner for services who is employed by both Hertfordshire County Council and the NHS, the Clinical Commissioning Groups (CCG) on both sides of the county. One of his current responsibilities is coordinating the next Dementia Strategy for Hertfordshire. James explained that he is very keen for this to be written with involvement of the public, carers and service users so he is happy to attend meetings like this and other events to engage with people. There will be some public consultations in the spring, one each side of the county.</p> <p>We then looked at the different priorities of the Dementia Strategy and discussed what is important to carers of someone with young onset Dementia.</p> <p><b>1. Promoting health and wellbeing:</b> We need to help people to keep healthier in later life to reduce the risk of dementia developing. We also need to help people with dementia maintain their independence and physical and emotional mental health.</p> <p>It was felt that this section needed to be worded very carefully as we are not aware what causes dementia and you can lead a very healthy lifestyle but still get dementia. It needs to be clear that this is not a normal process of ageing.</p> <p><b>2. Enabling equal and timely access to diagnosis:</b> People with concerns about their memory should have timely access to diagnosis and treatment regardless of ethnicity, race or disability. Information should be in a format that is accessible to people who do not speak or read English and it should be culturally appropriate and age appropriate.</p> <p>For people with YOD there needs to be good links with specialist hospitals to ensure that these people are linked back into the post diagnostic support that is</p>

available locally. Specialist diagnosis is important - if we are aware of the type of dementia then we can plan better for the future and know what to expect from that type of dementia. This helps the carer, in their preparation and how to care.

### **3. People with dementia have access to appropriate care and support services:**

People with dementia will have access to a range of services to support them in aspects of their physical, emotional and mental health, and managing their affairs, from diagnosis through to end of life. Services will be designed around the patient and carers needs recognising that dementia affects people in many different ways. People with learning disabilities and dementia, and people with young onset dementia will receive support that is appropriate to their specific needs.

Carers said that services seem to withdraw after diagnosis, that they are left in the dark not knowing where or how to access support. They feel that there are currently no services for further down the journey when the person has more advanced dementia and behaviours. There are no day centres specifically for people with YOD or many other services for this group.

Information is not clear and there are so many different organisations offering so many different services – no one point of contact. 3 carers in the room needed support but were unclear where to go or how to access it. One carer had contacted health services for support, was referred to social services who have now referred him back to health and the wait time for support is 3 months.

### **4. Supporting Carers of people with dementia:**

We will ensure that training and support is available for carers of people with dementia. This should be designed around the carer's needs and preferences. We will ensure that support is provided so that carers can attend training, or take a break, knowing that the person they care for will be safe and well looked after. We will also support the delivery of Hertfordshire's carer's strategy, including supporting carers to continue working and to access health and support services to maintain their own physical, emotional and mental health wellbeing.

Carers have to retire early to care, even if this is not what they planned or is financially the best decision. A care co-ordinator would help carers to access all the support that they needed, as and when it was appropriate to them. Currently, carers don't understand services, who delivers what and can help them with what.

### **5. Preventing and responding to crisis:**

People will be supported to make plans for the future in advance. There will be accessible and flexible alternatives to hospital admission wherever possible, and people and their carers will have good information about the options available to them when their condition worsens.

Carers at the session did not know how to access crisis support. They felt that yearly reviews with a psychiatrist may help to prevent crises as they could pick up issues and other health problems earlier and put relevant support services in place.

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	<p><b>6. Developing dementia friendly communities</b></p> <p>We will build on the work that is already underway to develop dementia friendly communities by actively encouraging and supporting all partners and communities to commit to becoming dementia friendly. We are evaluating possible approaches, including a model based on the commissioning of a Dementia Friendly Community Co-ordination resource.</p> <p>Carers felt that communities should just be friendly not dementia friendly. It should be looked at what impact the adjustment would have on everyone, not just people with dementia.</p>
4.	<b>Hertswise YOD services</b>
	<p>Tara Patterson introduced herself and explained that she is a YOD worker as part of Hertswise. They offer support for those under 65 who are living with dementia, including those who have a learning difficulty in addition to their diagnosis. Their Young Onset Dementia Support Workers can help with:</p> <p><b>Group Activities</b></p> <ul style="list-style-type: none"><li>• Each hub is different, providing a range of fun and exciting activities each week e.g. tie-dying bag making, musical memoirs, fudge making and games day! To find your nearest Hertswise group activity hub <a href="#">click here</a></li></ul> <p><b>One to One Activities</b></p> <ul style="list-style-type: none"><li>• If you don't feel confident in joining a group but would still like support to access activities and pursue benefits, then coming along to our One to One Activities sessions is a great first step.</li></ul> <p><b>Information and advice</b></p> <ul style="list-style-type: none"><li>• A service to help you explore your rights, entitlements, and access to other benefits</li></ul>
6	<b>Closing comments and information</b>
	<p>Carers and the speakers were thanked for attending and invited to stay for lunch where they could talk to the Tara Patterson or Rosemary Willis, Carer Support Adviser for more support and advice.</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 58 69 69 or <a href="mailto:sally.stratford@carersinherts.org.uk">sally.stratford@carersinherts.org.uk</a></p> <p><b>Next forums</b></p> <p>Tuesday 16<sup>th</sup> June 1.30pm-3.30pm at Birchwood Leisure Centre, Hatfield. The topic for this forum will be respite care. A light lunch is provided before the Forum. Please call <b>01992 58 69 69</b> to book a place.</p>

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