

# “Recall”

## The newsletter for Dementia Carers

Issue 8

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For more information about anything in this newsletter or to find out more about our support for carers of people living with Dementia, contact:

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*Making carers count*

## Welcome

As a new year fast approaches we are busy planning for 2018. Next year we will be holding Dementia Carers' Forums, Young Onset Dementia Carers' Forums, Dementia Representatives Group and training sessions. We will also be developing some support for the carers of people with learning disabilities who have Dementia.

Before we move into 2018 though, we wanted to reflect on what we have achieved this year. In the following pages you will be able to read about what we have done to support you with issues around Dementia services and the gaps in services. We hope you have seen some changes!

If there are any issues you would like us to raise or topics you would like us to cover at the Forums then please let me, Sally Stratford, Involvement Worker for Dementia and Older People, know. You can call me on 01992 58 69 69 or email me at [sally.stratford@carersinherts.org.uk](mailto:sally.stratford@carersinherts.org.uk)

Sending you Season's Greetings.



## Introducing our Admiral Nurse team

Our team of four Admiral Nurses is complete. We are working with Dementia UK to host the nurses as part of the county's improved Dementia Service.

The team consists of Admiral Nurses Hayley Cooper, Gemma Swainsbury and Julie Lloyd



with Lesley Potter as the Lead Admiral Nurse.

Our Admiral Nurses work alongside people with Dementia and their families giving them one-to-one support, expert guidance and practical solutions.

If you need support from the county's Dementia Service, including the Admiral Nurses, please call HertsHelp on 0300 123 4044.

*Pictured (far left group; l-r Hayley, Lesley and Gemma) Then newest recruit Julie.*

## You said... so the following happened...

We value what you tell us about your experiences caring for someone with Dementia or using health and social care services.

We take your feedback to those planning or providing services, such as the Dementia Strategy group that consists of organisations including Hertfordshire County Council, Herts Care Provider Association, various NHS organisations including Herts Valleys Clinical Commissioning Group (CCG) and East and North Herts CCG and Hertfordshire Local Pharmaceutical Committee.

Here we take a look at some of the issues you have raised and what has been done to address them:

You said ...	Action taken ...
<p><b>Young Onset Dementia Support:</b> You felt there are very few services or little support available for people with Young Onset Dementia and their carers.</p>	<p>We set up a Young Onset Dementia Carers' Forum so this group of carers can have a voice in shaping services for them and the person they care for.</p> <p>The Dementia Strategy group also told us that people diagnosed in specialist hospitals with Young Onset Dementia can be referred by their GP to EMDASS (the Early Memory Diagnosis and Support Service) where they will receive support and advice. On discharge from EMDASS they would be referred to community services and have information about where to go for activities, advice and help.</p>
<p>About <b>Care Workers</b> you said that:</p> <ul style="list-style-type: none"> <li>• It was difficult to find paid Care Workers;</li> <li>• Paid Care Workers were unreliable; and</li> <li>• Communication with the Care Agency was hard or poor.</li> </ul> 	<p>Paid Care Worker Providers attended our Dementia Forum in Hemel Hempstead to discuss provision. Hertfordshire County Council staff including Frances Heathcote, Assistant Director of Health and Community Commissioning, attended our Forums in Watford &amp; Letchworth. They spoke about how services were commissioned and monitored. We also surveyed Dementia carers known to us to get their views about finding paid Care Workers. The results were shared at a Dementia Strategy group meeting. The issue will be revisited in the next year.</p>
<p><b>Better training offer:</b> You want better access to training to help you in your caring role.</p>	<p>We supported Dr Arun Jha, a Consultant Psychiatrist &amp; Medical Lead at Hertfordshire Partnership University NHS Foundation Trust (HPFT), to deliver some training sessions (March 2017). Dr Jha is trying to secure funding to provide more regular training.</p>
<p><b>Respite Care:</b> You told us you want to be able to access regular respite care that you can book in advance.</p>	<p>Hertfordshire County Council has continued to provide beds following a pilot scheme at Woodland View, Stevenage; Premier Court, Bishop's Stortford and Lancaster Court, Watford. Call 0300 123 4040 to book or learn more.</p>

You said ...	Action taken ...
<p><b>Service provision changes:</b> You expressed concern about Hertfordshire County Council's plans to increase charges for certain community based adult social care support such as transport to day services.</p>	<p>We organised an event on Carers Rights Day (Nov 24<sup>th</sup> 2017) to give carers the opportunity to learn more about the plans from Iain MacBeath, Hertfordshire County Council's Director of Adult Care Services. Carers there helped shape a consultation response, raising key concerns.</p>
<p><b>Dedicated conference:</b> You requested a Hertfordshire Dementia Conference for carers.</p>	<p>This has been agreed by the Dementia Strategy group and is in the planning for 2018.</p>
<p><b>Bladder and Bowel Care Service:</b> You told us about problems you were having with the service, for example getting suitable continence products or concerns over the limited number of products supplied (too few).</p>	<p>In October 2017 we held a workshop for carers to discuss the issues with Hertfordshire Community NHS Trust, which delivers the service.</p>
<p><b>Better support:</b> Some of you felt there was little or no support during the later stages of caring for someone with Dementia.</p>	<p>We found out that Cruse offer free support during the later stages of Dementia (<a href="http://www.cruse.org.uk">www.cruse.org.uk</a>) Macmillan are also introducing some support for Dementia carers in 2018. We have four Admiral Nurses in post to provide advice and support.</p>
<p><b>Continuing Healthcare:</b> You expressed concern about the length of time it was taking for Continuing Healthcare decisions to be made by the NHS Clinical Commissioning Group (CCG).</p>	<p>We raised this issue at the Dementia Strategy group meeting and Ed Knowles, Assistant Director for Health Integration at Hertfordshire County Council, is to work with the CCGs to improve this process.</p>
<p><b>Changes to Community Dementia Services in Hertfordshire:</b> You were upset that the Alzheimer's Society wasn't going to be running community services and that you didn't know what was happening.</p> 	<p>We held a Dementia Carers' Forum with Hertfordshire County Council (the commissioners) and all the providers of the county's new Dementia Service so that you, the carers, could ask questions and express your concerns.</p> <p>We included information about the change on our website and in our newsletters and magazine Carewaves. Service providers have also provided updates at Forums.</p>

## Device to prevent nuisance calls now available for people with Dementia

Vulnerable people, including those with Dementia, who are receiving nuisance calls can now apply for a FREE call blocking device.

The National Trading Standards Scams Team has Government funding to provide trueCall devices, which check incoming calls. You can learn more at

[www.truecall.co.uk/product-p/tcs.htm](http://www.truecall.co.uk/product-p/tcs.htm) or apply for one at

[www.friendsagainstscams.org.uk/callblocker](http://www.friendsagainstscams.org.uk/callblocker) There is no phone number, but anyone can apply on behalf of a vulnerable person.

## Diary Dates

All carers are welcome to our Dementia Carers' Forums. They provide an opportunity to meet others, get information and have your say about caring issues. Your views will be taken forward to those planning or providing health and care services.

### Dementia Carers' Forum meetings:

**Monday 15<sup>th</sup> January 2018**

**Monday 14<sup>th</sup> May 2018 (1pm - 3pm)**

**Monday 17<sup>th</sup> September 2018**

At Hertford Theatre (River Room),  
The Wash, Hertford, SG14 1PS.

**Monday 12<sup>th</sup> March**

**Tuesday 10<sup>th</sup> July (1pm - 3pm)**

**Tuesday 20<sup>th</sup> November**

At Stanborough Centre (Armstrong Room), 609 St Albans Road  
**Watford**, WD25 9JL.

**Young Onset Dementia Carers' Forums** - For carers of someone diagnosed with Young Onset/Early Onset Dementia.

**Wednesday 25<sup>th</sup> April 2018**

**Wednesday 17<sup>th</sup> October 2018**

At Birchwood Leisure Centre (Sportsman Room), Longmead,  
**Hatfield**, AL10 0AN.

**Sessions are from 10am - 12.15pm unless otherwise stated.**

**A sandwich lunch is available after the 10am Forums and from 12.30pm for the 1pm meetings.**

### To book your place:

☎ **01992 58 69 69**

@ **[contact@carersinherts.org.uk](mailto:contact@carersinherts.org.uk)**

🌐 **[www.carersinherts.org.uk](http://www.carersinherts.org.uk)**

Please contact us if you don't have your own transport and want to discuss travel plans or if you require help with the costs of alternative care.

## Places available at music therapy groups

People with Dementia and their carers can benefit from some music groups in Hertfordshire as music has been found to stimulate parts of the brain and enhance memory.

The **Musical Herts project**, run by Music24, has groups that meet in three Hertfordshire venues: Mayhem Theatre, Hoddesdon, Hampson Park Community Centre, Stevenage and Pump House Theatre & Arts Centre, Watford.

Each group meets twice a month and participants enjoy singing, improvisation with a range of instruments, dancing and refreshment.



If you wish to join a session or learn more please call Teela Hughes on 07521 248091 or email [info@music24.org.uk](mailto:info@music24.org.uk) or visit [www.music24.org.uk/musicalherts](http://www.music24.org.uk/musicalherts)

Alternatively, you could try **Herts Musical Memories**, created in response to the closure of the Alzheimer's Society's Singing for the Brain groups. There are 12 groups across Hertfordshire and to find out if there is a service near you please contact Kerry Brabant on 020 8950 5757 or email [admin@hertsmusicalmemories.org.uk](mailto:admin@hertsmusicalmemories.org.uk)

## Get more involved as a Carer Representative

The Dementia Representative Group consists of Carer Representatives, who are registered with Carers in Hertfordshire and want to be involved in speaking up on behalf of Dementia carers.

If you wish to join the Group we would love to hear from you. We offer training and support and you can work remotely if you have difficulty in getting out.

For more information or to express an interest please call 01992 58 69 69 or email [sally.stratford@carersinherts.org.uk](mailto:sally.stratford@carersinherts.org.uk)

The Group's 2018 meetings are on: **Tuesday 9th January, Monday 26th March, Tuesday 26th June, Wednesday 26th September** at **Birchwood Leisure Centre, Longmead, Hatfield, AL10 0AN.**

Meetings held from **10.30am - 12.30pm**. Please contact us to book a place.