

Dementia Carers Zoom Forum

18th August 2020



1	Present
	<p>Carers 6</p> <p>Carers in Herts Sally Stratford – Involvement and Development Worker Dementia</p> <p>Speakers James Salmon - Senior Commissioning Manager Robert Coupland – Commissioning Officer Integrated Health and Care Commissioning Team, Working on behalf of Hertfordshire County Council, East and North Hertfordshire CCG, Herts Valleys CCG</p>
2	Welcome
	All carers were welcomed, introductions were completed and carers were informed that there would be notes sent out from the meeting.
3	Dementia Strategy
	<p>James Salmon, senior commissioning manger, explained that the dementia strategy for Hertfordshire had ended in 2019 and that work had begun to write the next 5-year plan when we were hit by COVID-19. Public consultations were due to take place just as we went into lockdown. After discussions with Hertfordshire County Council, Health and the voluntary sector it was decided not to carry on with the public consultation and to wait to write the 5 year strategy, but to create a one year plan to help people with dementia and their carers recover from COVID-19. The one-year plan will be based on the same areas as the strategy but will look at what is needed imminently.</p> <p>James then shared the plan which is included at the end of the notes.</p>
4	Questions and comments
	<ul style="list-style-type: none"> • Respite, day centres and visits to carer homes are a priority to carers. Carers are struggling with not being able to visit the person they care for who is in a care home. Garden visits have begun but these do not help or work for people with dementia as the visitor must wear a mask and must stay 2 metres apart. James informed carers that the guidance for care homes is a broad list of things and each home is to make up its on decision based on many different factors including people in the home, the building etc. This is not helping carers as care homes are not listening to individual cases and carers have not seen the person, they care for, for over 5 months now and there does not seem to be an end to this. <p>It was suggested that risk assessments for care homes need to be looked at – are these personalised enough? What is the quarantine process? How can people visit safely? James and Robert are to look into this and see what they can do to help the situation for carers.</p> <p>The Alzheimer’s Society are doing a campaign to try and get one family member per resident in a care home keyworker status to enable carers to visit and help with care needs as they used to. This is on going and has not been achieved yet – for more information see the link: https://www.alzheimers.org.uk/news/2020-07-09/open-letter-secretary-state</p>

Dementia Carers Zoom Forum

18th August 2020



- Care homes are important alongside carers at home – are Hertfordshire County Council looking at means and ways to support people to be able to be cared for at home? This is not only a short-term need but long term too – more work needs to go into this, allowing more people to choose to stay at home rather than going into a care home. James/Robert to take this forward.
- Zoom support is not helpful for people with dementia – it can cause hallucinations so may not be an effective way of delivering services such as the diagnostic service – James explained that this would not suit all but could be one of the ways of carrying on diagnosing people if we were to have another lockdown.
- Looking at enabling GPs to diagnose people with the support from specialist nurses would not work for everyone – James explained that the more complex cases would still attend the Early Memory Diagnosis and Support Service (EMDASS). People still need to be able to access the post diagnosis support and further professional support if needed throughout the dementia journey.
- More support for carers and those people being cared for at home – carers are not contacted or checked in on at all, we would like a call to see how we are and how everything is going. This would help us not feel so isolated. We only seem to get help when we are in a crisis. James explained that they are going to introduce yearly health checks for people with dementia and this should include their carers. This would mean that people are contacted once a year at least. We discussed carers assessments – the carers present do not receive yearly carers assessments. This does not seem to happen on a regular basis to carers who are not in receipt of any services. James to feed this back.
- Services for Young Onset Dementia – there is a lack of services for people with young onset dementia, their needs are quite different and need to be considered. James/Robert to ensure this is included in the plan.

7 Closing comments and information

Carers were thanked for attending.

The next session will be on **Thursday 17th September 2pm - 3.30pm** with the Alzheimer's Society who will discuss the support they can offer you and give support and advice, as well as answer any questions you might have. Please call the office and book a place if you would like to attend on 01992 58 69 69.

Sally Stratford

sally.stratford@carersinherts.org.uk

Dementia Carers Zoom Forum

18th August 2020



1. Executive Summary

In February 2020, Herts Valleys CCG approved a programme of public consultation to inform the Hertfordshire Dementia Strategy 2020-2025. As a result of the Covid-19 pandemic, the consultation was postponed.

On July 16th, 2020 the Hertfordshire Coproduction Board convened a workshop with representation from across the health, care and voluntary sector, with carer presence, to discuss the immediate priorities for dementia support in Hertfordshire, in the light of concern about the significant impact of the Covid-19 pandemic on this cohort.

This action plan sets out these priorities, and proposed streams of work to improve health and wellbeing for people with dementia and their carers.

The proposal now is to postpone the full public consultation exercise for one further year, and instead develop a 1-year action plan to address the urgent problems facing people with dementia and their carers. The public consultation will then be carried out in full, to shape the longer-term strategy from 2021, with full engagement from patients and carers, voluntary sector partners, and statutory health and care organisations.

A number of further steps need to be completed in order to firm up timescales, deliverables, and organisational input in a number of areas of the draft 2020-21 action plan appended to this document, but at this stage the Commissioning Executive are asked to:

- Approve the postponement of the full public consultation for one further year
- Endorse the action plan (appended below) and next steps, and provide any further steer

2. Impact of Covid-19 on persons living with dementia and their carers in Hertfordshire

2.1. Dementia has been identified as closely associated with deaths from Covid-19, both directly, and indirectly:

- The most common main pre-existing condition for people dying of Covid-19 in England and Wales was dementia and Alzheimer's disease, with 6,887 deaths (20.4% of total).
- Even apart from Covid-19, in April deaths from dementia in England were 80% higher than usual and 50% higher in Wales.

(Alzheimer's Society, at end of May 2020)

Dementia Carers Zoom Forum

18th August 2020



2.2. This has been reflected in the decline in number of patients on GP registers with a recorded diagnosis of dementia:

- Herts Valleys practices reported a drop of around 400 patients (5%) diagnosed as having dementia, between January and June, beyond seasonal variation.

2.3. Anecdotally, carers, voluntary sector partners, and social care teams have reported increasing risks of physical and cognitive decline, and carer stress and breakdown because of services and social contact being cut during lockdown.

3. Strategic Priorities

The Dementia Coproduction Board agreed that the seven proposed overall objectives of the strategy (as previously agreed with Commissioning Executive) remain valid at this time, but that particular areas of work should be prioritised, in line with the impact of Covid-19 and lockdown on people with dementia and their carers. The seven proposed overall objectives are:

1. **Promoting Health and Wellbeing**
2. **Enabling equal and timely access to diagnosis**
3. **People with Dementia have Access to Appropriate Care and Support Services**
4. **Supporting Carers of People with Dementia**
5. **Preventing and Responding to Crisis**
6. **Developing Dementia Friendly Communities**
7. **Ensuring Equal Access to Health and Care Services for People with Dementia**

4. Immediate Priorities for 2020-21

4.1. The coproduction board agreed that within these overall objectives, there are several priority actions to deliver this year which would enable a holistic response to the acute challenges being faced by people with dementia currently. The over-riding priority was to provide enhanced support to carers, to reduce carer breakdown, crisis presentations, and to improve quality of life.

Dementia Carers Zoom Forum

18th August 2020



- 4.2. Work is underway to reopen day opportunities as a key source of carer respite, but these are likely to be at greatly reduced capacity. Support groups such as Hertswise have shifted online in many cases, and this needs to be encouraged further with enhanced access to technology and support. Respite care in care homes faces challenges around quarantining and public perceptions around risk. We need to look creatively at new opportunities to relieve the pressure on carers, potentially through e.g. using home care services differently.
- 4.3. Carers also need additional training and support around lockdown related issues including staying safe and managing providers in the case of direct payments. They need consolidated and up to date information about services and support available to them. Admiral nurses are increasingly busy responding to carers and families struggling in the face of a reduction of services, and we need to look at expanding or further supporting these and other crisis prevention services.
- 4.4. There are developing local and STP pathways that we need to ensure continue to work for people with dementia, including frailty pathways, social prescribing, primary care service development, MDT clinic models, prevention of admission pathways, and hospital discharge protocols and accommodation. It is important to use any opportunity now to prepare for subsequent localised disruptions to services.
- 4.5. Care homes and providers have received support from the wider system, and there are ongoing programmes of training being delivered by HCPA and others. There is likely to be further need for guidance and support to providers around managing social distancing, reducing isolation and loneliness, maintaining social functioning and cognitive skills, swabbing and the use of mental capacity act/ MHA, digital communication, and sensory impairments for service users with dementia.
- 4.6. For the general population, we need appropriately timed messaging about the importance of seeking support when concerned about memory problems, and a range of acceptable options open to people about how and where they may receive a diagnostic service, including in primary care settings. We need to promote the take up of technology and challenge assumptions about people with dementia not being able to use technology. It will be increasingly important to promote the physical and mental health of people – through e.g. exercise and cognitive stimulation – to prevent or lessen the impact of dementia in the absence of normal social contact. We need to develop meaningful engagement with BAME communities and work to reduce health inequalities.

Dementia Carers Zoom Forum

18th August 2020



5. Next steps

- 5.1. The Herts Valleys CCG Dementia Task and Finish Group will be stood up as a sub-group to the Frailty Steering Group, and will oversee delivery of the strategy in west Herts.
- 5.2. The Hertfordshire Dementia Coproduction Board will continue to meet to oversee delivery across County. This paper will be presented to HCC Adult Care Management Board, and East and North Herts Joint Commissioning Programme and Partnership Committee in the coming weeks.
- 5.3. Conversations are underway with HV CCG patient engagement team about consulting with the patient networks about the strategy and promoting it at other upcoming events.
- 5.4. There is a need for this programme of work to align closely going forward with the cell structure in HV CCG, as well as the organisational units mentioned in 4.4. above.
- 5.5. Further work to refine the workplan deliverables and timeframes will be undertaken in the coming weeks, with regular progress reporting back to the Frailty Steering Group via the dementia Task and Finish Group.

6. Recommendations

The Commissioning Executive are asked to:

- Approve the postponement of the full public consultation for one further year
- Endorse the action plan (appended below) and next steps, and provide any further steer

Dementia Carers Zoom Forum

18th August 2020



Appendix - 2020-2021 Dementia Action Plan

<u>Action</u>	<u>Timescale</u>	<u>Target</u>
1. Promoting health and wellbeing		
1.1. Facilitate visiting in care homes in care homes as quickly as is safe to do so	<i>Ongoing – new guidance from August 1st</i>	All homes have clear plans for enabling social contact
1.2. Increase social connectedness by enabling access to technology – increase number of people in care homes/ own homes with access to social contact through tech	<i>Dec 2020</i>	X new service users supported to access digital
1.3. Expansion of cognitive stimulation therapy and associated tools, apps, train the trainer schemes - develop business case	<i>Sept 2020</i>	Business case agreed
1.4. Increase opportunities for physical activity for people with dementia	Opportunities to be scoped by Sept 2020	
1.5. Raise awareness of the risk of scams facing vulnerable people during the pandemic	Opportunities to be scoped by Sept 2020	
2. Enabling equal and timely access to diagnosis		
2.1. Clear patient backlog for EMDASS	<i>Oct 2020</i>	Restore average waits for diagnosis to <12 weeks
2.1.1. Reopen clinics to maximum safe capacity – review capacity/resourcing here also	<i>Aug 2020</i>	
2.1.2. Deploy home and virtual assessments where appropriate	<i>Aug 2020</i>	
2.1.3. Clarify roles around work-up/diagnostics in primary/secondary care	<i>Aug 2020</i>	
2.1.4. Provide pre-diagnosis support to support people to engage with the process better and maintain their condition while waiting for their assessment	<i>July 2020 – in place</i>	
2.2. Establish robust diagnosis in primary care pathways		Non-complex cases diagnosed closer to home in more familiar setting Business case and investment approved Dementia diagnoses made as result
2.2.1. Look at quick wins – GPs can already diagnose in primary care – recirculate the guidance	August 2020	
<ul style="list-style-type: none"> • Action coding clean up guide across primary care • Diagnosis in primary care (pragmatic resource for GPs, 25 common questions, DIADEM tool) 	September 2020	
2.2.2. Nurse specialist roles piloted/rolled out to support GPs – linked into MDTs and frailty clinics	From October 2020	
2.2.3. Link to care home DES to increase referrals and diagnosis in care homes	September 2020	

Dementia Carers Zoom Forum

18th August 2020



<p>2.3. Awareness campaign in communities and primary care – “Dementia hasn’t been locked down – if you are worried, you can seek help from your GP and it is safe to do so” to encourage the public to come forward and seek a diagnosis</p> <ul style="list-style-type: none"> Information published on available services and how to access them, from diagnosis through to end of life Tailored delivery of messages to BAME communities where necessary 	<p>Comms plan agreed August 2020</p>	<p>Increase in referrals to EMDASS (or other diagnosis services)</p>
<p>3. People with Dementia have Access to Appropriate Care and Support Services</p>		
<p>3.1. Facilitate reopening of day services and groups</p>	<p>Ongoing – reviewing plans with providers Aug 2020</p>	<p>Number of places available</p>
<p>3.2. Establish rare / YOD / later stages day opportunities, including opportunities relevant to BAME communities</p>	<p>Feb 2021</p>	<p>Number of places available</p>
<p>3.3. Review/ expand HPFT care home support team</p>	<p>Business case if applicable by November 2020 (links to diagnosis nurse specialist project)</p>	
<p>3.4. Promote guidance and support for carers and service users using direct payments to successfully purchase their support</p>	<p>August 2020</p>	
<p>4. Supporting Carers of People with Dementia</p>		
<p>4.1. Facilitate the restart of respite services, and scope opportunities for refocusing resources to sitting/extended home care where care home respite places not utilised</p>	<p>Ongoing for restart; September 2020 for business case for refocusing to homecare</p>	
<p>4.2. Proactively offer a carer’s assessment and contingency plan to every carer of someone with dementia to identify and provide for their support needs</p>	<p>Ongoing – ACS currently calling ‘red’ rag rated service users</p>	<p>Number of ACS KIT calls and carers’ assmts/ contingency plans taken up</p>
<p>4.3. Expand the counselling offer for carers, incorporating issues such as guilt and isolation</p>	<p>Scoped by December 2020</p>	
<p>4.4. Expand the offer of training to carers to support them to manage while services are reduced/alterd</p>	<p>November 2020 – already agreed</p>	
<p>5. Preventing and Responding to Crisis</p>		
<p>5.1. Develop business case for expansion of admiral nursing service</p>	<p>Sep 2020</p>	<p>Business case brought forward</p>
<p>5.2. Consolidate the developments of prevention of admission, and hospital discharge pathways, made during pandemic response to ensure people with dementia are supported away from hospital wherever possible in case of future outbreaks</p>	<p>Sept 2020</p>	

Dementia Carers Zoom Forum

18th August 2020



5.3. Raise the profile of safeguarding, including issues of carer safety, to restore incident reporting to normal levels	Ongoing	Promotion across health and care services, and police
5.4. Restore thresholds for community crisis services to normal levels	TBC	
6. <u>Developing Dementia Friendly Communities</u>		
6.1. Build on the wave of volunteers who have joined health and care services, and increase the number supporting people with dementia	Ongoing	Number of volunteers
7. <u>Ensuring Equal Access to Health and Care Services for People with Dementia</u>		
7.1. Develop further guidance and support for social care providers around swabbing – consent, mental capacity, facilitating social distancing in communal living settings for people with dementia etc., including for people with dementia and sensory impairments	<i>September 2020</i>	
7.2. Ensure DNAs to any service are actively followed up, recognizing people may be reluctant to access	<i>Ongoing communication of best practice to health and care services</i>	
7.3. Assess and develop current levels of access care homes have to OTs, CPNs and other allied health professionals to for dementia support – through development of new community MDT structures	<i>Nov 2020</i>	
7.4. Implement annual reviews for people with dementia, as detailed in STP dementia pathway	<i>Nov 2020</i>	
7.5. Investigate deployment of dementia friendly PPE e.g. window masks	<i>Nov 2020</i>	