



Kent and Medway
Clinical Commissioning Group

Improving care for people living with dementia and complex health needs, across Kent and Medway

NHS Kent and Medway CCG Engagement Team

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1 Introduction

NHS Kent and Medway Clinical Commissioning Group (KMCCG) is working with its partners to improve dementia care. There is an increased need for dementia care within the population, and with KMCCG being a recently formed organisation, potentially an inconsistency as to the services available and gaps in certain services. The partnership is led by a clinical 'service improvement group' and has commissioned data gathering to understand current use of services and the impact of population increases and recent service changes as well as considering national best practice.

This report gathers the views of people living with dementia, their families and carers, support organisations and health and care staff from a range of different settings, as well as from the wider public. The research was carried out to inform proposals to improve dementia care for people living with dementia and complex health needs across Kent and Medway at an early stage.

This research was carried out between mid-October 2020 and mid-January 2021 during the coronavirus pandemic when everyone was coping with an unprecedented situation that affected services and people's ability to take part in research as they would in normal circumstances.

We would like to thank everyone who took the time to contribute particularly those who shared their personal stories of living with dementia in their families and the impact felt by themselves and their loved ones.

This research was preceded by three other pieces of research which will also help us to plan effectively:

1. Between mid-May and early August 2019, engagement staff designed, planned and carried out community engagement with people living with dementia, their families and carers and voluntary sector volunteers and staff. This engagement collected views on existing support services and any additional needs or perceived 'gaps' in community based services and activities. Over 11 weeks, 266 people participated, 117 across east Kent and 149 across west Kent. Views shared were very consistent across the areas. Below is a word cloud illustrating the main discussion themes.



2. There was also engagement over the same period with 11 families whose loved ones with dementia and complex care needs were receiving specialist residential care at the Frank Lloyd unit run by Kent and Medway Partnership Trust, funded through Continuing Healthcare. The discussions covered both the broader proposed changes for people living with dementia and complex care needs, but focused mainly on the implications for the patients and their families of relocation to alternative residential care. Feedback covered the following areas:
 - making sure that existing patients and their families were supported through the transition process
 - understanding and responding to the needs of each individual patient
 - involving families and carers in the decision-making processes.
3. During 2020 there was research funded by the [NIHR Applied Research Collaboration Kent, Surrey and Sussex \(ARCK KSS\)](#) and carried out by the Time for Dementia Research team at Brighton and Sussex Medical School looking at how Covid-19 lockdown has affected dementia patients and their carers in Kent, Surrey and Sussex. The interim findings were shared to help inform services as they respond to ongoing pandemic. Please see page 18 for more information.

1.1 Population

Kent and Medway has a diverse population, with pockets of deprivation dotted across the county, with affluent areas across west Kent, densely populated coastal towns with high levels of deprivation and an aging population. The largest number of people from Black Asian and minority ethnic (BAME) populations live in Medway, Dartford, Gravesham and Swanley.

Across Kent and Medway, there is currently an estimated 27,000 people living with dementia. Of these, approximately 15,000 people have mild dementia, 8,750 have moderate dementia and 3,500 have severe dementia. At the moment, two thirds of people with dementia live in their own homes and one third live in care homes. The number of people living with dementia in Kent and Medway is expected to rise to over 38,000 by 2030.

2 Research methodology and response rate

Due to the restrictions that the pandemic brought particularly during lockdown, people are being advised to remain home and maintain social distancing, so engagement with people has had to be carried out in a Covid-safe way.

It was obviously more difficult than usual to reach people, and the response rate to engagement activities is lower than might have been expected pre-Covid. The demands of the pandemic on health and care services meant staff were extremely hard pressed and had less time to respond.

To mitigate the impact on response rates we worked with our colleagues across the NHS to share details of how to be involved through their various staff channels (bulletins, online portals, message groups and staff meetings), with their patient and carer groups, and

foundation trust memberships; and through our partners in local authorities with their staff and residents. As well as publicising the opportunity through our community bulletin which goes to 10,000 individuals and voluntary and community organisations. We also used our social media channels to promote the opportunity to take part and shared details with the media. We also used online surveys and telephone or video calls e.g. Microsoft Teams, Zoom etc.

And by working in partnership with the KMCCG local area patient groups and our community researchers and voluntary and community sector partners with their patient forums, we were able to reach out to people with lived experience as well as to gather the views of the wider community. KMCCG Engagement team developed several ways to engage different groups of people. They were:

- **Patient and carers journals or personal stories** were given to us by eight people with lived experience of dementia, another 12 people sent in personal stories or were interviewed to share their experiences.
- **Eight focus groups** were held with existing voluntary or community support groups. 102 people took part, most of whom had lived experience of supporting someone with dementia either in their family or through their organisation. They took part in video discussions on services and gave views about how to improve care.
- **Online staff survey** was distributed to NHS staff, Care Homes, Domiciliary Care and voluntary and community organisations. There were 70 responses from across all health and care services.
- **Online public survey** had 190 responses from across Kent and Medway including people who may not have direct experience of dementia services
- **11 existing local area patient groups and forums** in which 121 people took part in video discussions and then cascaded the information to their individual networks or groups. Eight were supported by KMCCG with members from PPGs and voluntary and community organisation representatives. Three forums were supported by Engage Kent: older people's forums, disability forum and Mental Health Action Groups.

3 Findings from the Patient and Carer Journal or personal stories

To further understand families and their loved ones experience of living with dementia, a journal was created (Appendix C). The purpose of this journal was for the families to share their thoughts, feelings and emotions of their everyday lives and for us as readers, to appreciate and recognise what their daily life is like. It was also used to record where support had been given or was lacking and any improvements hoped for. Alternatively some people submitted their thoughts by letter or email and others were interviewed.

There were eight journals completed, all by carers, caring for loved ones at home and 12 messages were received from people with their family story, or information on services, or with offers to share their experiences. The journals were completed by carers living across Kent. The age of the carers ranged between 55 and 74 and their loved one tended to be

their mum, dad or husband in some instances it was both parents who were living with dementia.

They shared a little about their loved ones with dementia, who have had interesting and varying lives, from being a retired GP to working in retail or as a labourer, to being a housewife. And their interests range from music and dance, to playing sport, reading and helping others and volunteering.

There were four main themes which were articulated strongly throughout the journals. These strongly suggest there is a need for support for those living with dementia and their families in the community so they can remain safe and well at home; and how health and care services could be improved:

- respite care
- consistency in services
- access to services
- support for carers

3.1 Respite care

This was a strong theme throughout the journals, particularly as the carers were living with their loved ones and with them 24 hours a day, seven days a week.

“To be able to book a range of weekend breaks and/or one or two one week breaks during a year; this will keep me going and I’ll know I’ve got a break coming”

There was concern about what to do if both parents were living with dementia and taking one for an appointment and needing care for the other for a short time in the day.

“I really could do with having someone to sit with either of my parents while I take the other to the doctors or to hospital as that is very difficult. But in these Covid times that is really not possible. I took my Dad for his Covid swab test at the Will Adams Centre today and had to take my mum with me, I still do not know what I am going to do on Monday afternoon with my mum when my Dad has his procedure???”

There were concerns about the stress and strain dementia can put on families, where respite care may be able to resolve some of this.

“In the last 2 years I have found it almost impossible to go away for a night or a weekend. This has created real friction with our daughter, who is worried about me, and angry with her father for basically taking me over as she and I used to go away together regularly – we both miss this.”

And it was noted the importance of the loved one with dementia having a little independence and being given the opportunity to take part in activities without their husband, wife or family.

“I would like there to be more things locally for my husband to do without me so that we both get a break from each other.”

3.2 Consistency of services

There were concerns raised about the how fragmented services supporting people with dementia are and the challenges families face in bringing those together so their loved one is treated holistically.

“The main problem is that services/teams are really fragmented and it is really difficult to find out who is responsible for dealing with what.”

3.3 Access to services

Many people shared experience of the services they used. Many had had strong support from various different service providers: pharmacists, GPs, occupational therapists, social care, carers, specialist diagnostic services, admiral nurses, specialist mental health services, cleaning companies, and a variety of community based support services through voluntary agencies and adult education.

“Carer’s support was brilliant. The most reassuring thing was having a card that said I was a carer and that if I was in an accident that someone would be in trouble! I wasn’t able to make use of many of their services as I could not get away for long enough or I was trying to earn money, but I could take Jeff to one support group which was helpful. They might have been able to help with settling in when we moved but I didn’t know about them in time.

The Parkinsons nurse was a life-saver as so few people seem to understand Parkinsons.

Social services were really helpful when I called up in floods of tears and said I couldn’t cope any longer!”

They also spoke of their difficulties in accessing services: one family spoke of the difficulty of finding services that have a full understanding for the different types of dementia. Others spoke of the difficulties they encountered when the person with dementia was able to mask their need or ‘seem much better than they really were during assessment’, or if they were capable of refusing the services offered and not letting domiciliary carers in to help. Others recorded feeling that access to help was prohibited because they were self-funding so were left to find services themselves.

“Financial assessment done over the phone and they were told they had £500 per month to buy their own care. Outgoings did not consider gardening costs, household repairs, mums hair (one thing she did for herself).

The Care Navigators came to their home – left loads of leaflets and numbers – no follow up.

They left mum to ring everyone, explain the story over and over and get rejected.”

3.4 Support for Carers

When reading the journals, you could feel the stress the family were feeling when caring for their loved one living with dementia and immense strain they are under on a daily basis. One area mentioned was mental wellbeing.

“I do sometimes find it a mental strain rather than a physical one, as I have had to learn a whole new set of life skills, as my husband used to do a lot around the house and a lot of other things which I have to do now.”

“Having both parents suffering from dementia simultaneously has been a nightmare.”

“I’m only 62 now, and I want to live!”

Financial stress and worry was highlighted, particularly in the longer term when full time care is needed.

“my Mum and Dad are not allowed to pay me for doing this as if we are financially assessed it will look like we are trying to take money from the tax man or from a care home should they need to go into one”

“I haven’t mentioned my fears about our finances and having to pay for care in the longer-term.”

4, Focus groups

Due to the pandemic, it was a real challenge to engage with dementia support groups, as many were not meeting physically. Some were meeting virtually, by using Zoom, and some more general support groups agreed to discuss improving dementia care and encourage those with relevant experience to attend. These discussions reflect the experiences of the families who shared their personal stories in their journals and some of the themes are similar.

Table one shows the groups visited and the number of carers and loved ones who attended.

Table 1

Support Group	Number of People spoken to
Carers First	12
Dartford and Swanley Dementia Support Group	20
Forget Me Knots Support Group	18
Gravesend/Safe harbour Dementia Support Group	14
Medway Neurological Network	9
SUNshiners Support Group	6
wHoo Cares Support	5
Swale Community Empowerment Network	18

Community Health Researchers	33
MTW carers focus group	3

The discussions with and the views of people at the support groups, were very similar to those mentioned by the patient/carers and raised in the other groups.

The top four themes were:

- respite care
- health and wellbeing of carers and families
- support services for carers
- care plans

4.1 Respite care

The groups suggested respite care was imperative for carers and families especially the importance of having day care as well as short week/weekend breaks.

“regular respite to ‘recharge the batteries’ would help significantly.”

“There is no support”

“Need time just to go and have a cup of coffee with friends”

“Carers would like a holiday away from caring role”

However, one group discussed whether respite care is unaffordable for some, and the person living with dementia may not want to attend.

The group as a whole agreed that it was not always affordable and in general the cared for did not want to attend anyway.

And the suggestion was to provide an affordable service, which caters for all.

“having affordable day care services with more of a holistic approach to the cared for. Services should not be means tested and should be available to all.”

One person mentioned how important respite care is in a crisis, although it is not readily available when needed.

“Respite services are extremely valuable in times of crisis, especially for carers. These services were said to be difficult to find.”

A concern that was raised was the availability of respite care at short notice, particularly if a carer was taken ill.

“What is available if the main carer became ill and couldn’t provide care anymore?”

During the pandemic fewer services are running either online group calls, or by sending activity packs or making phone calls to check on families.

“My husband has definitely missed his Alzheimer’s groups. I wonder if that is why he’s so unmotivated now”

3 days a week, he would have gone to a group and had lunch there. None of them are operating now.

4.2 Health and wellbeing of carers and families

There were concerns raised about the carers’ and the wider families’ health and wellbeing and the effects of looking after their loved one with dementia.

“Caring for them affects me and my family very much. It is a draining job which is like babysitting two toddlers. Their moods can keep changing and I have to adapt to it each and every time.”

“Some days I don’t get time to keep aside for my family. I get so tired that I would just hit the bed and wake the next day. The list is endless and each day we have a different situation at home.”

4.3 Support services for carers

There were mixed feelings about support for carers and it looked like this depended on where in Kent and Medway people live and the service they were seeking support from.

A positive comment was:

“The MCH ‘Dementia Crisis Support Team’ was praised, especially the Admiral Nurses. they were very good, very helpful for us……. We were lucky to get an excellent Admiral Nurse – every family should be allocated an Admiral Nurse.”

Facilitators from the focus groups captured feedback which was not so positive:

“The overall feel from the group was that they did not feel well supported in their carer role.”

“A lot of carers mentioned they had to fight for what they needed, most seem to just accept they have to fight.”

And one of the participants said:

“You have to be bloody minded and fight hard to get the support you need”

People felt there is a need for a single point of access, where people can go for all your information, rather than having to find things out piecemeal.

“There needs to be something similar to a single point of access (a bit like the crisis service). Someone needs to know about the different types of dementia to make sure people are signposted to the right service.”

And the need for a support service to “check in” with families regularly.

“Patients need regular contact i.e. a weekly phone call, rather than waiting for a crisis to happen.”

A suggestion from many of the discussions was to have a list of organisations which offer support and when they available and their contact details. It was highlighted that a directory of service like this would be really helpful; however it would be challenging to keep updated. A route map of what to expect was also suggested as the wealth of written information was too much to understand given at diagnosis.

4.4 Care plans

Discussions about care plans were less positive as there were feelings that not all services were using the plans.

“care plans, devised by multi-disciplinary teams, were only really being provided as part of Secondary Care (dementia care was mainly being provided by GPs)”

And some care plans weren't working due to them not being assigned a care coordinator.

“We do have a care plan and it says that we have a Care Coordinator, but we haven't got one.”

One facilitator shared that the group felt:

“Those that DID have a care plan said that it was not working well because they had NOT been given a care coordinator”

The groups agreed the statement below, is how a care plan should work:

“People diagnosed with dementia (particularly those with moderate or severe dementia) should be given a Care Plan and assigned a 'Care Manager' (not just those receiving Secondary Care). The provider/point of contact of this care plan service should be clearly identified, e.g.GP or MCH or KMPT. Role of Care Pathway Manager/ Care Navigators at Primary Care Network level heading a multi-disciplinary team should be clarified.”

5 Findings from the staff survey

In this survey, the questions were focused on several areas including: personalised care, change in level of needs and staff training and specialist support. We had 70 members of staff respond from across care homes, domiciliary care, hospital trusts, community trusts and voluntary and community organisations. All of the services and organisations we shared the survey with, were affected by the pandemic, which will have affected the response rate.

It should be noted that some questions have been skipped by some people, which means there will not be a 100 per cent response to all questions.

The highest staff response rates are from staff working across east Kent; however we had a good response from all localities, as diagram one shows.

Diagram 1

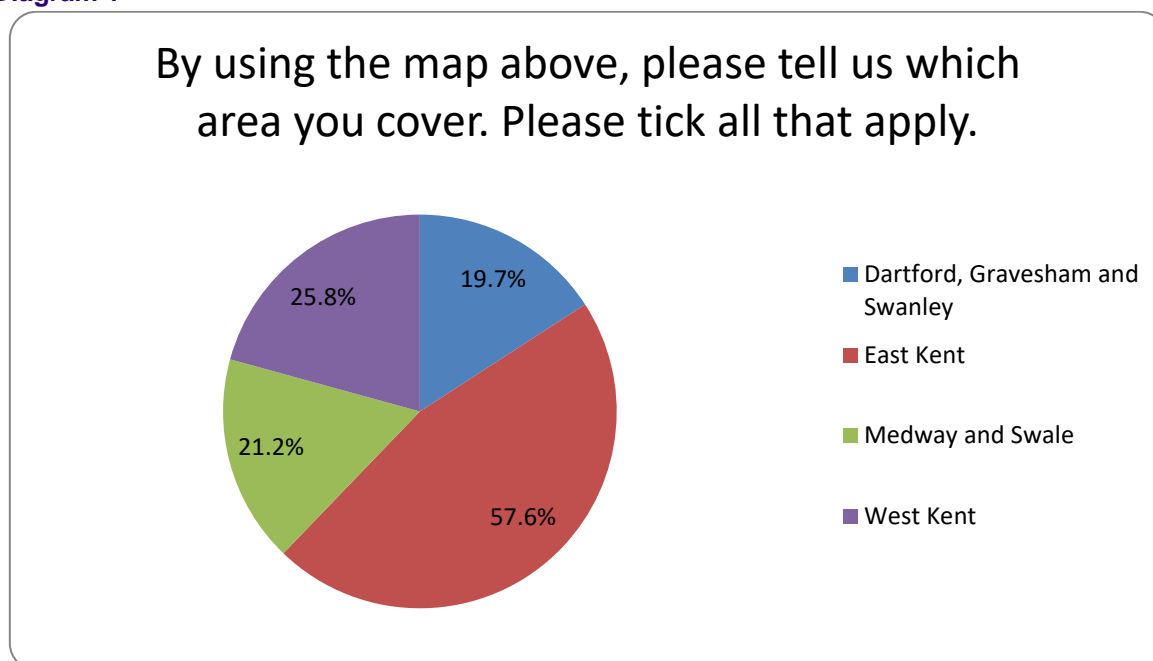


Table two below shows the different organisations the staff are employed by. The 16 responses categorised as “other” included community care, primary care and community organisations.

Table 2

Answer Choice	Response Per Cent	Response Total
1 Acute Trust	9.0	6
2 Community Trust/Community Service	20.9	14
3 Domiciliary Care Services	4.5	3
4 Nursing Home	3.0	2
5 Residential Care Home	6.0	4
6 Secondary Mental Health Services	9.0	6
7 Social Care Service	7.5	5
8 Voluntary and Community Organisation	23.9	16
9 Other (please specify):	23.9	16
answered		67

The survey was carried out in five sections:

- personalised care and the importance of care plans
- changing levels of need

- how to support people in a crisis
- staff training and specialist support
- improving healthcare for people with dementia

5.1 Personalised care and the importance of care plans

The first section asked staff about how a care plan assisted them to care for the person living with dementia.

- 81 per cent of responses from staff felt the care plan helped them to manage any changes in the person's health.
- 25 per cent stated there is a lot of information in the care plans to manage a person's behaviours,
- However 47 per cent say there is information, but only some which is not detailed enough to help them to manage a person's health.

Table three below shows how the staff ranked in order of importance statements suggesting the benefits of a care plan

Table 3

	Answer Choice	Total Score	Overall Rank
1	Patient/resident's dignity is respected	251	1
2	Everyone involved in their care has the same information	197	2
3	We know what the patient responds best to and any triggers which confuse or anger them.	195	3
4	We know of any choices or directions about healthcare given by the patient, their carer or family	164	4
5	We know which medications are being used and current symptoms	108	5

It can be seen that staff feel the main benefit of a care plan is the dignity of the person living with dementia is respected and everyone involved in their care has the same information, and the staff know what the patient responds to best and any triggers which confuse or anger them.

A care plan called '[This is Me](#)' was referred to frequently by carers. It contains details of the person living with dementia and guides and advices services that support them, to take a person centred approach to their care. Please note this frequently came up as a useful tool when talking to carers, or patient groups but some individuals were concerned that it wasn't used sufficiently by staff in residential care.

On the survey, staff were also asked about the support the families receive: 70 per cent of responses felt that families do not receive the help they need to look after themselves, including their own physical and mental health and wellbeing. However, 84 per cent of

respondents felt confident they could signpost families to appropriate services if they needed to.

5.2 Changing levels of need

This section of the survey focussed on services staff uses when a person starts to show signs of being unwell or display challenging behaviours during working hours. When this happens, responses indicated that staff's first point of contact is the local GP (64 per cent), followed by the specialist mental health team (49 per cent) or those they would seek advice and guidance from their line manager, care manager or from a local dementia organisation (33 per cent).

Table four below lists the services staff would go to during working hours:

Table 4

Answer Choice		Response Per Cent	Response Total
1	GP Practice	64.6	42
2	Urgent Treatment Centre	4.6	3
3	Hospital Emergency Department	7.7	5
4	NHS 111	23.1	15
5	Specialist Mental Health Service Team	49.2	32
6	Community Geriatrician/Nursing Service	13.8	9
7	Ambulance Service	16.9	11
8	Other (please specify):	33.8	22

And table five shows the service staff would go to outside of working hours, specifically evenings and weekends.

Table 5

Answer Choice		Response Per Cent	Response Total
1	GP Practice	4.7	3
2	Urgent Treatment Centre	6.3	4
3	Hospital Emergency Department	10.9	7
4	NHS 111	60.9	39
5	Specialist Mental Health Service Team	25.0	16
6	Community Geriatrician/Nursing Service	3.1	2
7	Ambulance Service	25.0	16
8	Other (please specify):	31.3	20

It can be seen that the top four services staff would use outside of working hours are:

- NHS 111 – 61 per cent
- Other – 31 per cent which includes crisis team, rapid response team or Crossroads
- Specialist mental health team – 25 per cent
- Ambulance Service – 25 per cent

5.3 How to support people in a crisis

Question 10 on the survey asked: if there have been occasions where you have been unable to access crisis/urgent support, what has usually happened?

When a member of staff is unable to access crisis support, 67per cent of respondents would send the person to hospital, 22 percent would support them by offering one to one support in the place where they live, or refer them to the rapid response team.

One respondent commented:

“It is very rare to get one to one at home day or night. Night-sits can delay a person going into hospital or a care home. Sometimes its the carer who needs a break as they have had no sleep. The person with dementia has a urine infection, delirium and requires supervision until anti-biotics work. The NHS should block purchase care home beds so that they can be used when the need arises instead of sending people to A/E dept and then assessment can be completed there.”

98 per cent of respondents agree that there is a need for a crisis/urgent care service as you can see from diagram two.

Diagram 2

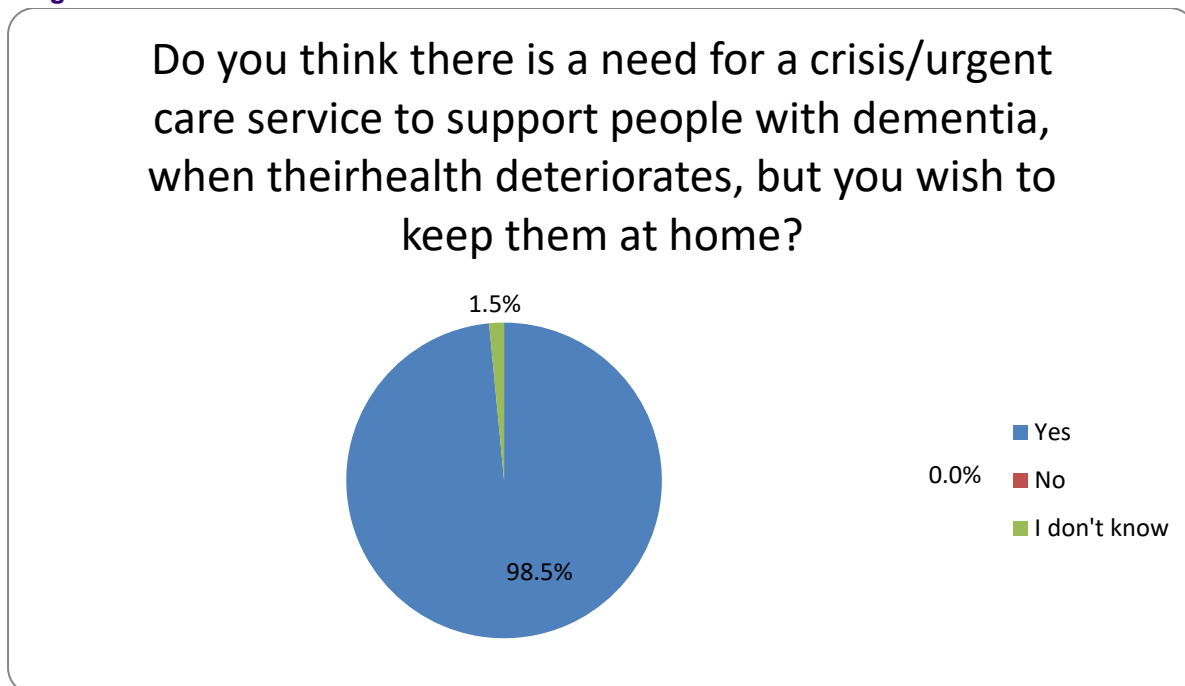


Table six below outlines the hours the respondents feel the service should be available.

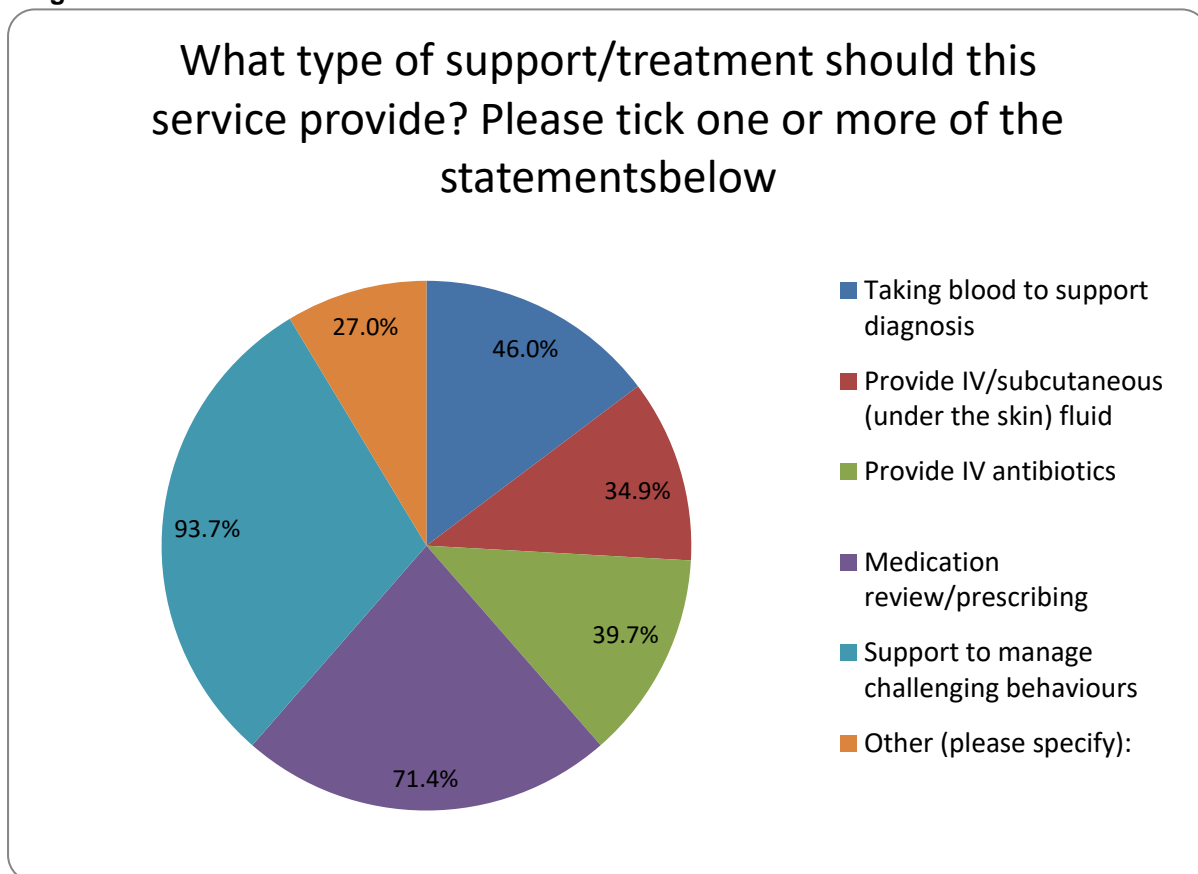
Table 6

Answer Choice		Total Score	Overall Rank
1	Monday to Sunday 24/7	293	1
2	Monday to Sunday 9am-8pm	230	2
3	Monday to Friday 8am-8pm and Saturday and Sunday 9am-5pm	223	3
4	Monday to Sunday 9am-5pm	164	4
5	Monday to Friday 9am-5pm	95	5

Table six shows that respondents feel the service should be available Monday to Sunday 24 hours a day, seven days a week.

The answers to the question ‘what type of support/treatment should this crisis service provide?’ are set out below in diagram three

Diagram 3



Please note respondents could choose more than one aspect so the percentages reflect that.

5.4 Staff training and specialist support

Table 7

Answer Choice		Response Per Cent	Response Total
1	Yes, we are specially trained in dementia care for our patients	54.5	36
2	Yes, we receive training annually	27.3	18
3	Yes, occasionally	19.7	13
4	No, I was trained before I arrived	3.0	2
5	No, there is no time for extra training	3.0	2
6	No, there are not enough staff to release people for training	6.1	4
7	No, we are monitored and supported whilst providing care.	3.0	2
8	Other (please specify):	24.2	16

Table 7 above shows that 54 per cent of respondents are specially trained in dementia care, whilst 27 per cent receive dementia training annually and 24 per cent (other) receive one off training e.g. e-learning, or dementia friends training.

60 per cent of respondents explained they receive training and support on how to manage challenging behaviours and 36 per cent said they don't receive training like this.

For question 16, respondents were asked to tick any services they use to support people living with dementia to stay active and well, the responses are set out in Table 7 below.

Table 8

Answer Choice		Response Per Cent	Response Total
1	GPs	50.0	28
2	Geriatricians	33.9	19
3	Specialist Mental Health Nurses	48.2	27
4	Admiral Nurses	37.5	21
5	Occupational Therapy	46.4	26
6	District Nurses	50.0	28
7	Physiotherapy	44.6	25
8	Voluntary organisations offering patients advocacy or support activities such as Dementia UK, Alheimers Society, Age UK	62.5	35
9	Social Care - advice on support, benefits	48.2	27
10	Other (please specify):	23.2	13

**Please note the overall total is above 70 as people were able to choose more than one service.*

It can be seen 62 per cent of respondents seek support from voluntary and community organisations, 50 per cent speak to the GPs and district nurses, and 48 per cent contact social services and the specialist mental health team.

5.5 Improving healthcare for people with dementia

The final section of the survey asked respondents what they felt would improve health and care for people with dementia, and checked on the difference the pandemic had made.

The top three improvements that were suggested by the respondents are:

- more support, education and help for carers and families (41 per cent)
- respite care (15 per cent)
- more specialist dementia training and education for staff (12 per cent)

The top three greatest challenges identified by respondents prior to the pandemic were:

- carer and family access to support (43 per cent)
- carer breakdown and stress (16 per cent)
- communication and information sharing (8 per cent)

And the top three challenges identified by respondents during the pandemic are:

- access to services (56 per cent)
- social isolation (34 per cent)
- person living with dementia understanding the purpose of personal protective equipment (PPE), hand washing and social distancing (25 per cent)

6 Research on the impact of the pandemic

A recent piece of research by funded by the NIHR Applied Research Collaboration Kent, Surrey and Sussex (ARCK KSS) and carried out by the Time for Dementia Research team at Brighton and Sussex Medical School was shared with us as were the results of a focus group conducted by Maidstone, Tunbridge Wells NHS hospitals (MTW).

In June and July 2020, during the first national lockdown, 248 family carers from across Kent, Surrey and Sussex (already recruited to the Time for Dementia programme) answered questionnaires which aimed to discover:

- the quality of life of people caring for someone with dementia
- the quality of life of people with dementia
- levels of social functioning of people with dementia, and
- the cognitive, functional ability of people with dementia.

The researchers also interviewed 12 carers to find out about their experience of day-to-day life during the pandemic.

This exercise has been repeated again, with 200 carers responding to the second questionnaire and a further 10 carers interviewed. The second round of data is currently being analysed and will be reported in the next few weeks.

The interim findings show that the impact of Covid-19 has been particularly impactful on carers living with someone with dementia.

Preliminary analysis of the questionnaire data showed:

- living with the person with dementia had a negative association with carer quality of life
- female carers reported lower quality of life of the person with dementia during lockdown compared to male carers
- female carers reported reduced social functioning in the person with dementia, compared to male carers

During the first round of Covid-19 restrictions, carers reported having a lack of freedom and a loss of control. Carers also stated that they were not able to have a break, and were unable to meet their own needs, as well as the needs of the person with dementia. Changes in emotional wellbeing, such as anger, sadness and exhaustion were also discussed.

Carers reported Covid-19 having an impact on the person with dementia, mainly a lack of understanding of the current pandemic or need for restrictions and a lack of stimulation. A reduction in dementia support services and a noticeable acceleration in cognitive decline of the person with dementia were noted by some. As reported earlier in the focus groups and when people shared individual stories.

“I’ve lost him during lockdown. We sit in the front room and although we are together, I am on my own. He doesn’t initiate any conversation.”

Carers also reported the difficulty of interacting with services if they aren’t fully involved in the care being provided.

“Better support from the hospital would have been important. Mum needed to be there to hear what the Doctor said on his rounds as Dad didn’t remember”

“I HATE phone consultations. My husband can’t do them and he just passes the phone back. The Haematology consultant and the GP both try to talk to him on the phone and every time we go through the same rigmarole of trying to explain that they need to talk to me instead as his carer”

7 Findings from public survey

The online public survey and the discussions with existing patient groups and forums focused on three broad questions:

1. What types of support do you think people with dementia and complex care needs and their families and carers would need, to help them live independently at home for as long as possible and avoid crises and unplanned stays in hospital?
2. What should good quality of care look like for people with dementia and complex needs, and their family and carers?
3. We have had suggested a number of guiding principles for improving services for people with dementia and complex care needs.

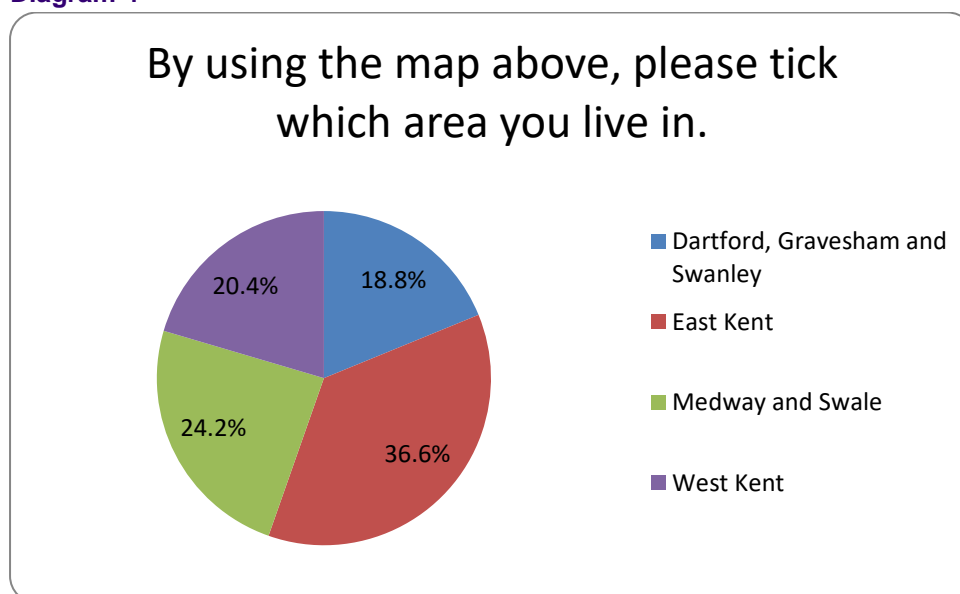
People were asked to place the principles listed below in order of importance.

- Treating the person with dignity and respect.
- Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests.
- Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them.
- Make the best use of the existing resources and expertise.
- Learn from best practice examples elsewhere.

We also asked: “What other guiding principles could we include to improve care for people with dementia and complex care needs?”

Diagram four below shows there was a good spread of responses from across Kent and Medway. In total, there were 190 responses.

Diagram 4



143 (75 per cent) of the respondents were female and table nine shows the age range of respondents.

Table 9

Answer Choice		Response Total
1	Under 18	0
2	18-24	2
3	25-34	5
4	35-44	18
5	45-54	22
6	55-64	45
7	65-74	68
8	75-84	18
9	85+	1

Table ten shows the ethnicity of the respondents who completed the monitoring question

Table 10

Answer Choice		Response Per Cent	Response Total
1	White British	93.7	164
2	White Irish	0.6	1
3	White Eastern European	1.1	2
5	Black African	1.7	3
7	Black British	0.6	1
9	British Asian	1.7	3
12	Mixed Race	0.6	1

The top three types of support people felt families and their loved ones need were:

- personal care in the home
- regular contact with a care navigator/support worker/case worker, and
- quality of care.

7.1. Personal care in the home

The importance of care being provided in the home was a prominent feature. The respondents highlighted day-to-day care being important, help with getting up and dressed and preparing of breakfast, lunch and dinner. Also people highlighted the benefits of socially interacting with the person living with dementia and encouraging them to take part in stimulating and physical activities.

7.2. Regular contact with a care navigator/support worker/case worker

Regular scheduled visits agreed with the person with dementia and their family where possible. In order to build a relationship and recognise the person’s individual needs it is preferable to assign the same carer.

7.3 Quality of care

The most mentioned factors when recommending good quality care were:

- a consistent service – same environment, same support worker etc.
- good communication and information
- integrated and seamless service

7.4 The principles guiding this work

The respondents were asked to rank in order of importance some guiding principles, which are shown in Table 11 below.

What should be the guiding principles for this work to improve dementia care for those with complex care needs

Table 11

Answer Choice		Overall Rank
1	Treating the person with dignity and respect	1
2	Make the best use of the existing resources and expertise	2
3	Learn from best practice examples elsewhere	3
4	Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests.	4
5	Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them.	5

It can be seen from the table that treating the person with dignity and respect is most important, followed by making the best use of existing resources and knowledge and learning from best practice elsewhere.

There were other suggestions of guiding principles to be included: consistent service and care, that services are integrated and seamless, and good communication and information.

8 Feedback from existing local area patient groups and forums

There are eight local area groups across Kent and Medway facilitated by the KMCCG; and we also spoke to three county wide forums supported by Engage Kent. These are made up largely from patient participation group (PPG) members, Healthwatch volunteers, residents associations and local voluntary and community organisations.

Table 12 below shows the number of people who attended the meetings:

Table 12

Local Area Group	Number of Attendees
Ashford	9
Canterbury and Coastal	11
Dartford, Gravesham and Swanley	6
Medway	11
South Kent Coast	23
Swale	5
Thanet	10
West Kent	24
County Mental Health Action Group (MHAG)	8
Disability Forum	9
Older People's Forums, including over 50s forums	5

The groups were asked the same questions as the public survey (Appendix E) which focused on: what type of support people living with dementia and complex care needs want, what good quality care looks and feels like and commenting on and contributing to the guiding principles for this work to improve dementia care.

Across all the groups there were five themes that were discussed the most, which were:

- support for carers
- integration of services
- importance of care plans
- respite care
- importance and need for staff training

8.1 Support for carers

The dominating theme across all groups was the importance of support for carers, who were caring for their loved ones at home.

People highlighted that the amount of information given to families at the point of diagnosis, varies by locality. Some families are given too much written information to take away at diagnosis and were unable to take it all in, whereas others find

'they aren't given enough help with what happens after diagnosis and where they can go for support.'

It was suggested that it would be helpful to have a care navigator, or a support /link worker to provide families with ongoing support with:

- identifying local community support groups
- helping them to understand the diagnosis and what it means
- supporting them to claim for financial help and their entitlements, and

- how to seek other interventions as the disease progresses and circumstances change.

Many people suggested more awareness raising of dementia, the early signs and symptoms and the services to visit, in order to start the process of diagnosis early.

8.2 Integration of services

All groups discussed services which currently support people living with dementia. It was made clear that these services do not always work together and families have to tell their story more than once. It should be noted, dementia services are not the only service this affects but it may cause particular difficulties for people living with dementia. What sometimes happens is families are missed and “slip through the net” or families end up having to chase services for various reasons.

“I can spend a whole day just chasing services about my mums care”

Many felt services, particularly health and social care, need to work better together, they should take a ‘person centred approach’ and be consistent.

8.3 Care plans

There was mixed views about care plans, although one group agreed the importance of a care plan; they were clear it would only work if the person living with dementia, their family and the services involved, all had sight of the care plan and owned it.

“The family and the carers should be in the Care Plan and involved from the onset”

8.4 Respite care

All groups raised the issue of respite care and the importance of carers having a break which will benefit them mentally and physically.

“Respite needs to be factored into the community care so that carers do not end up burnt out and the family can continue fully supported.”

“Carers need respite, a decent amount of respite and please do not forget young carers. There’s a time when the person with dementia needs to go to a residential setting to give the carer 24/48hrs break, and also times that someone comes into their own home so the carer can go for a walk knowing their loved ones are being taken care of.”

The importance of overnight respite, whether provided in a residential/care home or in the person’s own home.

“Night cover is needed. Whatever care goes on during the day, people at night can become frightened. The night time is a strong issue which can result in people having to go into a residential/care home setting.”

“Night cover/night support to help the person even if they are living with the family, so the carers can get a rest.”

8.5 Staff training

There were discussions about staff training and there was a feeling this needs to be more frequent, not just for care homes but also for hospital staff and private care companies.

“Training isn’t mentioned and staff in care homes need extra training and to increase their understanding. This would need to be for both formal and informal carers.”

“It is essential that community carers or domiciliary care services have mandatory training on dementia.”

9 Other learning points for the future

There are several specific suggestions within the feedback from the focus groups, which commissioners should take into account and consider as suggestions for improving dementia care. They build on the feedback and themes within the report.

Also, there are a couple of points which were mentioned which we believe should be considered by commissioners and their partner organisations when developing proposals for improving services/care.

1. There was a strong suggestion of services needing to be more integrated and working together better. This was in particular reference to the NHS and social care working together and the individual’s care plans being person-centred and available to all services.
2. There were comments made about the behaviour of a loved one living with dementia as they are very good at showing others that everything is fine and they are managing or coping. A particular reference was made to social services when they visited and carried out an assessment.

“My father in law managed to deceive Social Services by coming across as being well and his dementia wasn’t as progressed as it was. He was in denial of the diagnosis.”

3. People reiterated that services need to take into account the carer and or families experience as well as the person living with dementia. In Canada there is a culture of families and carers being considered care partners.

“Principle 3 is very important – take into consideration the individual’s needs, but stay connected to family and carers.”

4. The importance of housing associations was raised. Many people living with dementia live in sheltered housing and the housing organisations can play a vital role looking out for their tenants.

“Make sure to include housing – social housing and the support it offers is an important part of the picture which is too often over looked. Sheltered housing could be a key partner.”

5. Families of loved ones living with dementia shared their fears over finances and how they will be able to live once their loved one goes into a care home; or if they need to give up work/retire permanently. It was highlighted that there is a need for funding streams for families’ needs to be coordinated and readily available.

“Continuing Healthcare, personal budgets and direct payments need to run smoothly to give families control and support in their own homes.”

6. The importance of care homes and both the continuing health care (CHC) assessment process and the process by which families find a suitable care home was raised. It needs to be easier to find homes which can happily care for and manage people with dementia and complex care needs which may include challenging behaviour. This was specifically raised by the families who had used the Frank Lloyd Unit. Sometimes it took several changes to locate the right place and people were extremely pleased when they found somewhere which worked well for their loved one. It was felt that more support could be given to assist in the challenge.

Jeff had Alzheimers, Dilys had Parkinsons and later dementia: this is an extract from their story:

“they moved into sheltered accommodation near one of my brothers where house prices were lower, and I would also relocate to the area so there was a good support network. My mother was concerned about leaving all the support services she had in place – and she was right – there seemed little joined up thinking and we felt we were starting again with everything.

My parents paid for carers to visit 4 times a day and I went round at least once a day. My brother and his wife also supported weekly. Other family visited when they were able. Her GP suggested that the stress on her was making her condition worse and that we should try a fortnight’s holiday for Jeff, in a care home. He settled in really well, but Dilys found she couldn’t cope without him. I found the level of care too great and so she went into a home for respite. However, the home could not manage and she ended up in hospital. She was released to an assessment placement but ended back up in hospital. Her assessment showed that she needed nursing care rather than a care home, and once we found a suitable home, she lived there happily for the last 6 years of her life.”

10 Conclusion

This research has clearly shown that there is a need for more support for families and carers who are supporting a loved one who has dementia and potentially complex needs. The need for this has been made all the more poignant by the pandemic and the pressure of being locked down with many support and public services having to work remotely.

Early and universal assistance to people so they can find suitable help and support would be welcomed - single points of access, care coordinators, directories of services and route maps of what to expect – with a human guide, were all suggested.

Services are well used and many were praised, but in terms of improvement people felt there should be more effort to make them accessible, consistent, integrated, person centred and always there when both the person living with dementia and/or their carer needs them.

Staff supporting people living with dementia and their families do use care plans, and receive training – but others felt it wasn't necessarily consistent enough or evident in how people worked.

Staff feel they know where to signpost people to for support and know which services to call upon when a person shows challenging behaviours, yet they also recognised that carers and families felt unsupported and the majority 98 per cent of our respondents agreed a crisis service was needed not just in working hours but 24 hours, seven days a week.

And that, most of all, no-one should feel they are on their own or unsupported.

“It feels like us against the world at times.”

Appendix A

Improving care for people living with dementia and complex care needs - Staff Survey

1. Introduction

NHS organisations across Kent and Medway are thinking about how to improve care for people with severe dementia and complex care needs. In 2020, there are estimated to be 27,000 people living with dementia in Kent and Medway. This number is expected to rise to 38,000 over the next 10 years. Roughly two thirds of people who have dementia live in their own homes and one third live in care homes. Dementia can be mild, moderate, or severe.

- 15,000 or 55.4 per cent of people will have mild dementia
- 8,750 or 32.1 per cent of people will have moderate dementia
- 3,500 or 12.5 per cent of people will have severe dementia.

Research shows that it is better for people who have dementia and complex care needs to continue to live in their own homes, for as long as possible: meaning that we need services to continue to support them and their families and carers where they usually live. When people with dementia cannot stay in their own home they usually move to a care home to receive the care they need.

Sometimes people with dementia can exhibit behaviours which can challenge both their families, and care staff. Over time they may experience difficulties with mobility or deterioration in their health which means they are better looked after somewhere else for a short period. Perhaps they need a medication review, or specialist care, particularly if they are exhibiting difficult or challenging behaviours; they may even be admitted temporarily to a hospital inpatient bed, or a specialist care facility.

We need to make sure that there is the right level support in all parts of the health and care system, to respond to changes in people's health particularly when the symptoms are severe, and prevent, or manage, any crises.

We also need to recognise and support families and carers and understand that their physical and mental health can be affected, especially when the person whom they care for has complex needs.

We need to hear from care home staff, domiciliary carers, NHS and social care staff and those voluntary organisations who support people living with dementia and their families to cope with changes in their health. We want to understand how well our care system is working, whether there are any gaps, such as out of hours or crisis care, and if there are any innovations and assistance you would want to improve the running of your service and its resilience. We are particularly keen to hear from you at this difficult time, when Covid-19 is challenging many aspects of our health and care system and revealing increased strains on those coping with a debilitating condition like dementia.

Please take 15 minutes to complete this short survey by Friday 15 January 2021.

Kent and Medway



1. By using the map above, please tell us which area you cover. Please tick all that apply.

Dartford, Gravesham and Swanley

East Kent

Medway and Swale

West Kent

2. Please tick the organisation you work for:

Acute Trust

Community Trust/Community Service

Domiciliary Care Services

Nursing Home

Residential Care Home

Secondary Mental Health Services

Social Care Service

Voluntary and Community Organisation

Other (please specify):

Personalised Care

3. If you have an integrated care plan for each of your patients/ residents, does this help you to identify and manage changes in people's health?

Yes

No

I don't know

4. Does this plan contain information about the person which helps to identify triggers for behaviours that can challenge services and how to manage it?

Yes, a lot of detailed information

Yes, some information

No

I don't know

5. From the list of potential benefits associated from personalised care plans below, please put them in order of importance, where 1 is the most important to 5 being the least important.

- Patient/resident's dignity is respected
- Everyone involved in their care has the same information
- We know what the patient responds best to and any triggers which confuse or anger them.
- We know which medications are being used and current symptoms
- We know of any choices or directions about healthcare given by the patient, their carer or family

6. Do you think the family/carers of the people you look after, receive the help they need to look after themselves, and their own physical and mental health?

Yes

No

I don't know

7. Are you aware of local organisations which offer families help and advice who you can refer them to?

Yes

No

I don't know

Comments:

Changing levels of need

8. If a patient/resident's health gets worse, or their behaviours become more challenging where do you go for support during usual working hours?

GP Practice

Urgent Treatment Centre

Hospital Emergency Department

NHS 111

Specialist Mental Health Service Team

Community Geriatrician/Nursing Service

Ambulance Service

Other (please specify):

9. Which service do you go to for support outside of working hours, in the evenings, and at weekends?

GP Practice

Urgent Treatment Centre

Hospital Emergency Department

NHS 111

Specialist Mental Health Service Team

Community Geriatrician/Nursing Service

Ambulance Service

Other (please specify):

10. If there have been occasions where you have been unable to access crisis/urgent support, what has usually happened?

The patient/resident has been admitted to hospital

The patient/resident has been admitted to a mental health hospital

The patient/resident has been admitted to a Care Home

The resident has been given one to one support in the place where they usually live

Other (please specify):

11. Do you think there is a need for a crisis/urgent care service to support people with dementia, when their health deteriorates, but you wish to keep them at home?

Yes

No

I don't know

12. Please indicate below the working hours that you think would be most appropriate for a community-based crisis service. Please rank in the order you would prefer.

Monday to Friday 9am-5pm

Monday to Sunday 9am-5pm

Monday to Friday 8am-8pm and Saturday and Sunday 9am-5pm

Monday to Sunday 9am-8pm

Monday to Sunday 24/7

13. What type of support/treatment should this service provide? Please tick one or more of the statements below

Taking blood to support diagnosis

Provide IV/subcutaneous (under the skin) fluid

Provide IV antibiotics

Medication review/prescribing

Support to manage challenging behaviours

Other (please specify):

Staff training and specialist support

14. Have you received specific and regular training on delivering care for people with dementia?

Yes, we are specially trained in dementia care for our patients

Yes, we receive training annually

Yes, occasionally

No, I was trained before I arrived

No, there is no time for extra training

No, there are not enough staff to release people for training

No, we are monitored and supported whilst providing care.

Other (please specify):

15. Do you receive regular training and support on how to manage behaviours that can challenge services?

Yes

No

I don't know

16. Do you receive any external support to help keep your patients well and active? Please tick any professionals or groups that support you.

GPs

Geriatricians

Specialist Mental Health Nurses

Admiral Nurses

Occupational Therapy

District Nurses

Physiotherapy

Voluntary organisations offering patients advocacy or support activities such as Dementia UK, Alzheimers Society, Age UK

Social Care - advice on support, benefits

Other (please specify):

Improving health and care for people with dementia

Improving health and care for people with severe dementia and complex care needs is very challenging, never more so than now.

17. From your perspective, what improvements could be made for caring and supporting someone living with dementia?

18. From your perspective what is the greatest challenge about caring and supporting someone living with dementia usually, when there is not a pandemic?

19. From your perspective what is the greatest challenge about caring and supporting someone during a pandemic and Covid-19 measures and protocols are in place?

20. Are there any further comments you would like to make?

About You

Please tell us a little about yourself. All information we receive will be anonymised and it will help us to monitor who has responded.

21. Please tell us your gender

Male

Female

Prefer not to say

22. Please tick your age group

Under 18, 18-24 25-34 35-44 45-54 55-64 65-74 75-84 85+

23. Please tick your ethnicity or ethnic group

White British White Irish White Eastern European

Gypsy or Traveller

Black African Black Caribbean Black British

Asian British Asian Nepalese Bangladeshi

Mixed Race

Arab

Somali

Chinese

Appendix B

Improving care for people living with dementia and complex care needs - Public Survey

Introduction

NHS organisations across Kent and Medway are thinking about how to improve care for people with dementia and complex care needs. In 2020, there are estimated to be 27,000 people living with dementia in Kent and Medway. This number is expected to rise to 38,000 over the next 10 years. Two thirds of people who have dementia live in their own homes and one third live in care homes. Dementia can be mild, moderate, or severe. Approximately:

- 15,000 or 55.4 per cent of these people have mild dementia.
- 8,750 or 32.1 per cent of these people have moderate dementia.
- 3,500 or 12.5 per cent of these people have severe dementia.

Evidence shows it is better for people with dementia to continue to live in their own homes for as long as possible. Services are needed which support them where they live, so any changes or fluctuations in their health can be managed and any crisis prevented or dealt with appropriately. We recognise the impact on families and carers and want to make sure the care and support we provide for people living with dementia takes account of their needs too.

Kent and Medway Clinical Commissioning Group is working with its partners, and people living with dementia and their carers to improve dementia care. We are at an early stage of developing proposals for an intensive community service for people with dementia which will support people in the own homes and care homes (both residential and nursing) at times of crisis and urgent need, with the aim of avoiding hospital admission where possible. There will also be a need for specialist support for people with dementia and beds for those with the most challenging behaviour and complex needs until their health improves.

We are gathering the experience and views of people living with dementia and their carers, and of staff from health and social care to feed into this process at an early stage.

We would also like to hear your views, as a member of the public.

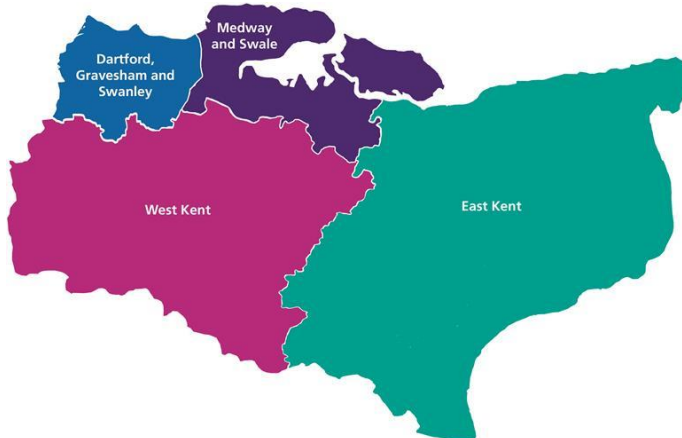
We are interested in your views about the principles which should improve the quality of care provided for people living with dementia. What you would expect and want for yourself or your loved ones if you were to develop dementia?

If you want to respond as an interested member of the public, please complete our survey by Friday 15 January 2021.

We also want to hear from people with lived experience of dementia care and their families/carers. If you know someone who might have a story to share, please ask them to contact us at kmccg.engage@nhs.net or call Katie Blissett on 07545934705. We're happy to let them choose how best we capture their personal story.

Kent and Medway

1. By using the map above, please tick which area you live in.



Dartford, Gravesham and Swanley

East Kent

Medway and Swale

West Kent

2. What types of support do you think people with dementia and complex care needs and their families and carers would need, to help them live independently at home for as long as possible and avoid crises and unplanned stays in hospital?

3. What should good quality of care look like for people with dementia and complex needs, and their family and carers?

4. We have had suggested a number of guiding principles for improving services for people with dementia and complex care needs. Please place the sentences below in order of importance to you.

- Treating the person with dignity and respect
- Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests.
- Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them.
- Make the best use of the existing resources and expertise
- Learn from best practice examples elsewhere

5. What other guiding principles could we include to improve care for people with dementia and complex care needs? Please list any suggestions below

About You

Please tell us a little about yourself. All results will be anonymised; this information will help us to monitor who has responded.

6. Please tell us your gender

Male Female Prefer not to say

7. Please tick your age group

Under 18 18-24 25-34 35-44 45-54 55-64 65-74 75-84 85+

8. Are you

Heterosexual (Straight) Gay or Lesbian Bisexual Prefer not to say

Other (please specify):

9. Do you have a disability?

Yes

No

Prefer not to say

10. Do you care for someone else?

Yes, child/children

Yes, an adult/s

No, I don't care for someone else

11. Please tick your ethnicity or ethnic group.

White British White Irish White Eastern European

Gypsy or Traveller

Black African Black Caribbean Black British

Asian British Asian Nepalese Bangladeshi

Mixed Race

Arab

Somali

Chinese

Appendix C

Improving care for people living with dementia and complex care needs

The NHS in Kent and Medway want to design a service which supports people living with dementia to stay where they live, so any changes or fluctuations in their health can be managed and any crisis prevented or dealt with appropriately. We also need to make sure we provide care and support to meet the physical and mental health needs of families and carers.

NHS Kent and Medway Clinical Commissioning Group (CCG) is working with partners including Kent and Medway NHS and Social Care Partnership Trust, local hospitals, local authorities, care homes, voluntary and community sector and others to develop this new model of care. There is a clinical reference group leading the work and exploring best practice models, and gathering evidence on current services, and people's needs.

This autumn and winter we are seeking views from as many people as possible to help us design a new service, which will provide support to people with dementia and their carers, at times of crisis and avoid a hospital admission where possible.

We are proposing a dementia support service to supplement the community services already provided in Kent and Medway which will provide a crisis response, to people living in their own homes and in care homes. The aim will be to prevent admission to hospital when possible, as this can produce poor outcomes for people with dementia.

We need your help this autumn, as we want to hear from people with lived experience of dementia and complex care needs.

Stories told by individuals from their perspective, can provide us with an opportunity to understand your experience of the care you or your loved one have received; helping us to learn from the good, and the bad and look at what can be done to improve people's experience in the future.

For this journal, we would like to hear about how you cope in a crisis, the types of service you rely on, and any gaps you see in care and support services and any improvements you would want?

About You

Please tick which area of Kent you live: East Kent Dartford, Gravesham and Swanley Medway and Swale West Kent

Please tell us your gender: Male Female Prefer not to say

Please tick your age group: Under 18 18-24 25-34 35-44 45-54 55-64 65-74 75-84
85+

Please tell us your ethnicity or ethnic group:

Are you: caring for a loved one with dementia living with dementia

How long the person has been living with dementia/caring? Years Months

Please tell us in the box below, a little bit about the person who has dementia

Their name, age and a little bit about them: where do you live, what did they do, what do they enjoy doing, have they any interests or achievements they are proud of?

Please tell us about what it's like for you day-to-day living with dementia or caring for someone with dementia

- Living every day and how you cope
- the support services you use
- any gaps or support you need which aren't there?
- Is there any one/organisation who has been particularly helpful and ideas for how things could be improved?

Thank you for taking the time to share your story with us. We hope that by learning from your experiences we can help to improve the services on offer to support people living with dementia, and help their families too. If you would like to record your story on film, or share more details, please leave your name and contact details:

Name:

Contact details (Phone/Email):

Appendix D

Improving care for people living with dementia and complex care needs - Public Survey

Community Focus Group Briefing, Questions and Answer Template, November 2020

What are we trying to do

NHS organisations across Kent and Medway are thinking about how to improve care for people with dementia and complex care needs. In 2020, there are estimated to be 27,000 people living with dementia in Kent and Medway. This number is expected to rise to 38,000 by 2030. Of these approximately 15,000 people have mild dementia, 8,750 have moderate dementia and 3,500 have severe dementia. Roughly two thirds of people with dementia live in their own homes and one third live in care homes.

Evidence shows it is better for people with dementia to continue to live in their own homes for as long as possible. Services are needed which support them where they live, so any changes or fluctuations in their health can be managed and any crisis prevented or dealt with appropriately. We recognise the impact on families and carers and want to make sure the care and support we provide for people living with dementia takes account of their needs too.

Kent and Medway Clinical Commissioning Group is working with its partners, and people living with dementia and their carers to improve dementia care. We are at an early stage of developing proposals for an intensive community service for people with dementia which will support people in the own homes and care homes (both residential and nursing) at times of crisis and urgent need, with the aim of avoiding hospital admission where possible. There will also be a need for specialist support for people with dementia and beds for those with the most challenging behaviour and complex needs until their health improves.

We are gathering the experience and views of people living with dementia and their carers, and of staff from health and social care to feed into this process at an early stage. We also want to hear from people who may not have direct experience but who can tell us about what they would expect.

What we want to find out

The CCG and its partners in the NHS want to know about people's current experiences of dementia care. We also want to find out about what needs to be improved and also what you think about what matters most – the principles for improvement. What you would expect and want for yourself or your loved ones if you were to develop dementia.

Who we want to hear from

We are interested in hearing from anyone with an experience of dementia support or of caring with someone with dementia. We are interested in hearing from families about what they would expect and want – even if their loved ones do not have complex needs. We know community groups in Medway and Swale are particularly good at reaching families who would not normally speak to the NHS or to public services – people who may be living in difficult circumstances or who have other barriers to speaking out.

The CCG is also speaking to care home staff and to those who work in frontline services.

What we will do with results

The facilitators will create a record of each discussion using a discussion pro-forma. All information will be anonymous –no names will be supplied. This will be collated by MVA and passed to NHS Kent and Medway Clinical Commissioning Group.

FOCUS GROUP DISCUSSION GUIDE

Welcome and thank you for volunteering to take part in this focus group. You have been asked to participate as your point of view is important. I realise you are busy and I appreciate your time.

1.	Introduction: Introduce self and any co-facilitators – including from the CCG/MVA. Tell the group what your role is and the roles of the other facilitator. NHS organisations across Kent and Medway are thinking about how to improve care for people with dementia and complex care needs. Evidence shows it is better for people with dementia to continue to live in their own homes for as long as possible. Services are needed which support them where they live. Kent and Medway Clinical Commissioning Group is working with its partners, and people living with dementia and their carers. We want to build an intensive community service to support people in the own homes and in care homes (both residential and nursing) at times of crisis and urgent need. The aim is to avoid hospital admission where possible. The project is at an early stage – there are no right or wrong answers – we want to know what matters to families, to carers and to professionals in the community.
1.1.	Consent:

	<ul style="list-style-type: none"> - To facilitate our recollection of this session I/we take notes during the session on what is being said – is that okay with everyone? Also [If recording the session] may I record the discussion? (if yes, switch on the recorder) - Everyone should now have seen a copy of the Participant Information and Consent Sheet? (Has everyone read and understood the information given in this document (check that everyone has and respond to any questions)? By remaining and participating in this session, I am now assuming that you are given consent to take part in this research project.
1.2.	<p>Anonymity:</p> <ul style="list-style-type: none"> - Despite notes being taken, I would like to assure you that the discussion will be anonymous. You should try to answer and comment as accurately and truthfully as possible. - I and the other focus group participants would appreciate it if you would refrain from discussing the comments of other group members outside the focus group.
1.3.	<p>Ground rules:</p> <p>Ask the participants to agree ground rules for the session – suggested rules might include:</p> <ul style="list-style-type: none"> - Only one person speaks at a time. There may be a temptation to jump in when someone is talking but please wait until they have finished. - There are no right or wrong answers - You do not have to speak in any particular order - When you do have something to say, please do so. There are many of you in the group and it is important that I obtain the views of each of you - You do not have to agree with the views of other people in the group <p>Does anyone have any questions? (answers). OK, let's begin</p>
1.4.	<p>Warm up:</p> <p>First, I'd like everyone to introduce themselves. Can you tell us your name? (if appropriate your role/ what you do)</p>
2.	<p>The services used by you/ your families/ your clients</p> <p>Find out how many people in the group are family carers or have direct experiences of dementia – in what way Can you tell us a bit about which services you use to support care for people with dementia, or how you get help or support? (if from community organisations – which services in the community do you offer? Tell us a bit about what you do to support people? How do the families you work with get help and support for dementia care?)</p>
2.1	<p>What works and does not work currently for families and carers?</p> <p>Please tell me what is good about the services which currently exist to help people? What do families use which work?</p> <p>What works less well? Where are the gaps?</p>
3.	<p>What support do families need to live independently and avoid crises</p> <p>When there is a crisis or your family or the families you work with have a change in circumstances, what happens and what support is there?</p> <p>What types of support do you think people with dementia and complex care needs and their families and carers need to help them live independently at home for as long as possible and avoid crises and unplanned stays in hospital?</p>
4.	<p>The principles for improved services.</p> <p>Families and paid and unpaid carers have told the CCG about what matters to them. We have used these discussions to develop some principles for care for people with dementia and complex care going forward and we want to know what you think about these principles.</p> <p>Do you think any or all of these are all important, or are some more important than others? Are there any principles which should be added?</p> <p>Read out or show the principles on a slide to the group – ask them to add to these if they feel anything is missing, whether any are more important than others and why.</p> <p><i>“There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.”</i></p> <ul style="list-style-type: none"> • Treating the person with dignity and respect. • Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests. • Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person-centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them. • Make the best use of existing resources and expertise. • Learn from best practice examples elsewhere

5	Anything else? Is there anything else you wish to tell us about what might help people with dementia stay in their home?
6.	<p>Close the focus group session</p> <ul style="list-style-type: none"> - Thank you for participating. This has been a very successful discussion and your opinions are valuable to NHS Kent and Medway Clinical Commissioning Group - I will send a report summarising today's discussions to Medway Voluntary Action. They will collate the information in this report with other focus group reports from Medway – and all of this data will be passed to the CCG - The CCG and its partners will use the information to plan improvements to community based services. - I would like to remind you that any comments featuring in this report will be anonymous. - Thank you once again for your time and this focus group session is now closed.

FOCUS GROUP REPORT TEMPLATE

Please ensure this form is completed and returned to MVA's Involving Medway programme team no later than Friday 18th December.

On completion of the group, the outcomes need to be reported and submitted for consideration in the formal consultation. Remember, the simple sense tests for your reported outcomes are:

- Could you give this to the average person to read?
- Would they understand it?

Introduction	
1. Record of group	
Facilitator Details	
Note Taker Details	
Date group session held	
How the event was held – zoom?	
Number of participants	
Anonymised Demographics (e.g. 4 male, 4 female, aged xx to zz, all of whom were service users)	
General Questions Summary. Please ensure you include:	
<ul style="list-style-type: none"> • participant quotations • details derived from probing questions • general visual and audio observations (e.g. body language, strong consensus, questions receiving strong responses, raised voice)) 	
2. Services used/ offered	
List the situation of the participants and which services are used by families locally	
3. Living independently, avoiding crises	
List support needed by local families to live as long as possible at home	
4. Principles	
Which are the most important principles? Anything else to add to them	
5. Anything else	
What else matters to people with dementia and their carers?	
Further comments/ views	
Report Completed by	
Date completed	

Once completed, please return this form to MVA's Involving Medway programme team by 18th December:

involvingmedway@mva.org.uk

Appendix E

Questions



1. What types of support do you think people with dementia and complex care needs and their families and carers would need to help them live independently at home for as long as possible and avoid crises and unplanned stays in hospital?

2. What should good quality of care look like for people with dementia and complex needs, and their family and carers?

Questions



3. We have listed a number of guiding principles for our work suggested by patients and the public. Do you think any or all of these are all important or are some more important than others? Are there any principles which should be added?

"There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible."

- Treating the person with dignity and respect.
- Place the person at the centre of their care: understanding their history, lifestyle, culture and preferences, including their likes, dislikes, hobbies and interests.
- Family, carers and the person with dementia (where possible) should always be involved in developing a care plan based on person-centred care. Their knowledge and understanding of the person is extremely valuable to make sure the care plan is right for them.
- Make the best use of existing resources and expertise.
- Learn from best practice examples elsewhere