

Richmond Dementia Report

Emerging learning and recommendations in the context of COVID-19
across the local dementia prevention and care pathway



Public Health



Abstract

This is a report of a virtual mini-workshop on dementia carried out in Richmond during the COVID-19 pandemic. It sets out emerging local learning and makes recommendations about improvements to meet the changing landscape across prevention, diagnosis, and care of dementia in the context of COVID-19.

Acknowledgements

The report author extends thanks to Dr Nike Arowobusoye for providing invaluable expertise and assistance throughout all aspects of this workshop report. Thanks also to Shannon Katiyo, DPH, and the Adult Social Care SMT for their support and contributions. Most importantly, thanks are extended to all attendees of the workshop who took the time to work collaboratively, taking a whole system approach to this work.

Foreword

I welcome this report, which covers much of the work undertaken in recent months to revise and refresh the Council's Joint Dementia Strategy and captures key priorities for action, not least, better support for carers. I commend the recommendations and actions and thank all those who participated on behalf of the many residents who will benefit from the next steps in the journey towards our next Joint Dementia Strategy.



A handwritten signature in black ink that reads "Piers Allen".

Councillor Piers Allen

Chair of the Adult Social Services, Health and Housing Services Committee and Chair of the Health and Wellbeing Board

COVID-19 has highlighted many of the challenges people with dementia, their families, carers, and others working in dementia care face each day. This report and workshop build on the Council's Joint Dementia Strategy. I look forward to the recommendations and actions being implemented. I thank all those who have developed these recommendations and will be helping to implement them.



A handwritten signature in black ink that reads "Roger Crouch".

Councillor Roger Crouch

Dementia Champion

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1 Introduction

This is a report of the virtual mini-workshop on dementia carried out in Richmond during the COVID-19 pandemic.

It sets out emerging local learning and makes recommendations about improvements to meet the changing landscape across prevention, diagnosis, and care of dementia in the context of COVID-19. It is intended for use by the partners across the dementia system such as carers support, day care centres, dementia commissioners, people working with older people and their carers. Specifically, it will also add to the body of evidence for the work taking place in Richmond as part of the dementia strategy refresh.

2 Background

COVID-19 is present and affecting all aspects of health and wellbeing across the dementia pathway. It was identified that people living with dementia, both diagnosed and undiagnosed, in care homes or at home, are vulnerable and at high risk of poorer outcomes from COVID-19.

Ensuring an equitable and sustained response to dementia is a key priority in Richmond. In 2019, Richmond Council undertook work to review and refresh its dementia strategy. This work was led by the Adult Social Care and Public Health Directorate and is overseen by the Richmond Dementia Prevention and Care Leadership Group (DPLG). The findings highlighted the growing need for a clear, consistent and co-ordinated offer of advice, support and targeted intervention from all agencies, working together for people with dementia (and those that care for them), that improves dementia awareness, access to equitably distributed dementia related services, and quality of local dementia-related service (Appendix 1).

The findings highlighted the growing need for a clear, consistent and co-ordinated offer of advice, support and targeted intervention from all agencies.

During the COVID-19 pandemic, DPLG members identified and discussed the emerging impact of COVID-19 for people with dementia and their carers and families. At the same time, the potential for COVID-19 to make daily life particularly challenging was highlighted; locally by the ASC & PH Carers lead and the community dementia nurses, in published emerging guidance from British Geriatrics Society which has informed NHS guidance, and subsequent PHE guidance.

Thus, the Richmond DPLG decided to hold a mini-workshop to bring local agencies together to better understand how they can work during the COVID-19 pandemic and mitigate the impact on people affected by dementia and their carers and families. As the pandemic initially unfolded, day centres and respite care reduced due to 'lockdown', and the dementia community nurses and dementia clinical leads expressed their need to do some work on establishing better links and understanding of what is available to meet the social needs of their less complex patients, once all medical needs have been addressed. Since the workshop, there has been a recent Alzheimer's UK report which brings together further evidence from a wide range of sources to shine a light on the impact of COVID-19 on people who have dementia and those who care for them

3 The workshop

The virtual mini-workshop was planned to supplement work taking place with dementia system leaders and their stakeholders from across Richmond Council, Adult Social Care, Public Health, CCG, voluntary sector, and national charitable bodies (Appendix 1).

The workshop aimed to provide an opportunity to gain insight from service providers, health and care professionals on the issues that people with dementia and their carers face, and to come together to outline ongoing plans for a dementia offer within the context of COVID-19 and beyond. The objectives were to improve support for people with dementia and their carers in the community to prevent crisis and hospital admission.

The discussions looked at the current awareness of how each organisation has responded to COVID-19.

4 Dementia in the COVID-19 pandemic

Initial reports from the dementia community nurses stated the closure of day services and social support groups remained a challenge, and that additional support was required for the family pre and post diagnosis.

The workshop brought to life the many challenges presented by the COVID-19 pandemic. This included:



Recognising the contribution of unpaid carers to responding to the need that dementia conditions have deteriorated.



Carers neglecting their own health and wellbeing needs.



GPs reporting increased disruptions in people's routines due to COVID-19, leading to a deterioration in functions both physical and mental decline.



People with dementia became unpredictable with changes in routines / increased wandering.



Self-isolation disproportionately affecting elderly individuals, whose only social contact is often outside the home.



Recognising the absence of day care services (at the time of writing this report).



Recognising the increased need for more outreach service and support to minimise the risks of cognitive decline.

5 Key emerging themes

The following themes were identified within the discussions of the workshop:



Positive working

There is a great deal of positive working together already in place to reduce risk within the community, however it was identified that there is still additional work to be done to improve upon this.



The need for improved NHS and Adult Social Care partnership working

A key theme to emerge is the need for better partnership working between health and social care in managing dementia. Participants acknowledged the need for a seamless support structure so that a strong solid structure is in place to ensure after discharge care or pre-crisis interventions. The voluntary sector commented that even without COVID-19, there was general acknowledgment that there is a lack of standardised access to post-diagnostic services outside of the memory assessment services following diagnosis. It was noted that referral rates into community support needed to be improved, and one way to address this is to actively promote these support services to local GPs to increase referral rates.



The importance of a pre-crisis approach and being 'winter ready'

The workshop participants raised the importance of early identification of people living with dementia who are likely to be affected by a second wave of COVID-19, either because they are isolated, or because of reduced local authority care packages. The group felt that social services sitting in the Community Mental Health Trust MDT meetings would help them work together to be aware of the patients who might need more support in crisis or on post discharge.

The discussion further suggested that low-level interventions such as psychosocial interventions are best delivered at pre-crisis stage and the group felt that that others could provide low-level support once the clinical needs had been met. This support does not need to be community nurse led. To further support crisis aversion and improve the community support offer, it was acknowledged that the Alzheimer's Society and other similar voluntary organisations could deliver low-level psychosocial support.

The discussions also focused on how else people with dementia and their carers can be supported:



Improved support for carers

Unpaid carers report that they are struggling and finding it difficult to maintain both their own health and the health and wellbeing of the people that they care for with dementia. The potential of using social prescribing for low-level support, and to deliver dementia awareness training to social prescribing colleagues was raised. The care navigators and social prescribing link workers were seen as a living 'directory of services' and expanding the training offer to include them will enhance their provision. The workshop also acknowledged that there needs to be increased dementia training provision for home carers.

It was acknowledged that good level of contact and support must be available to unpaid carers; provision of online meeting platforms such as Zoom, have enabled a significant level of contact and support to unpaid carers, which has been vital, and while it does not substitute face to face contact it needs to be maintained. Enabling unpaid carers to get online is however only part of the solution.

The disparity in receiving support to unpaid carers (between self-funders and those who are not self-funding) was raised as a concern. It was acknowledged that although everyone is entitled to a carers assessment, the value of receiving this is not often understood.



Re-working the day care provision

Day centres were highlighted as a main source of respite care and the impact of the closure of day centres on unpaid carers was a key focus of the session which garnered a lot of discussion. The discussion focused on the need for a revision of the day care provision, in the current climate. Suggestions included a hybrid offer combined with more outreach support. Day centres also requested support and guidance to provide clarity of what can and cannot be done when remobilizing the service throughout COVID-19 times. It was suggested by the group that there was a need to review COVID-19 testing in day centres. In addition to this, it was also reported that there has been a reluctance of patients and unpaid carers to contact their GP for medical concerns in fear that this would add an extra strain on them.



Improved support to care homes

The discussion mainly centred around identifying who works with the care homes, whether this be LBRuT Quality Assurance Team or the SWL CCG or a combination of both. Both council-owned care homes and non-funded care homes reported the need for continued support and guidance. The workshop raised possible solutions for better connections across the health and social care landscape. LBRuT and SWL CCG could consider, in collaboration, the potential to establish a named and accountable care coordinator, such as that described in a recent NICE report. LBRuT and SWL CCG could collaboratively work to ensure recognition of dementia in local care homes is optimised and recorded effectively when recognised, and LBRuT and Richmond CCG could consider reviewing the need to standardise access to screening services, where appropriate, within local day centres and care homes when it is safe to do so.



Digital solutions

The workshop participants acknowledged that support workers should be enabled /trained to use digital solutions, using what is already there (such as iPads etc for connecting with families and carers) but at the same time ensuring there is a balance between digital and traditional communication/service delivery methods. It was the consensus within the discussions that a digital support offer is not the solution for everything/everyone.

Further discussion considered digital solutions for the recently produced Dementia Directory of Services and whether this could be transferred to an app-based platform.

6 Discussion and conclusion

Although the local implementation of the Dementia Prevention and Care Pathway and action plan across LBRuT is underway, the workshop highlighted areas where more work is needed and where senior council wide and member level support would add benefit. There is a pressing need to understand the implications on prevention, care, and support and to understand any enhanced local action and response.

The initial loss of the day care centre provisions across the borough due to COVID-19 restrictions, emphasised the need for more outreach support, support for unpaid carers and training of support workers in dementia, especially in this current climate.

Health and social care professionals are seeing more challenges for unpaid carers due to the lack of respite care and a reduction in care packages. This reduction has created added stress on unpaid carers who may be struggling themselves, especially with how to deal with new behaviours they are seeing, such as when their loved one goes 'wandering' in social distancing times. There is thus a need for a 'tips and tricks' style support.

In addition to physical protection from the virus infection, the psychological needs for client and unpaid carers have increased during the COVID-19 pandemic. Mental health and psychosocial support should be delivered to unpaid carers who exhibit signs of exhaustion and burnout because of the COVID-19 lockdown and local restrictions in place.

Health and social care professionals are seeing more challenges for unpaid carers due to the lack of respite care and a reduction in care packages.

Many patients and carers are not confident to access IT related support or have technicians in their home to set up equipment due to fear of contracting COVID-19, and nursing homes need to encourage more interactions with families, such as introducing IT support in lieu of family visits.

This deterioration in functions both physical and mental seen in clients living alone with a package of care in place but who are no longer receiving regular visits from family, have resulted in increased care home placements to ensure care needs are met. We know from previous research that Richmond has a lower proportion of care home beds per 100,000 people aged ≥ 65 yrs in South West London (2,800 per 100,000). This is shown in Appendix 2. This will need to be re-examined as part of any work being done to improve the dementia offer.

Furthermore, there is a potential issue of disparity of support to carers (those that care for people with dementia who are self-funded and those people with dementia who receive funded support) even though the implication of the crisis remains the same. The issue in Richmond is that people may not see the value of the carers' assessment, especially if they have not engaged with social services before, leading to possible delays in getting support.

7 Recommendations

The workshop concluded that the following recommendations be taken forward:



SWL CCG, South West London and St George's Mental Health Trust and SWL ICS could consider reviewing current referral pathways both within and post COVID-19 times. The importance of facilitating Social Services attendance at MDT meetings will support this.



Work is needed to encourage care homes to think differently about the potential to increase family interactions.



Adult Social Care Lead to ensure all social work teams are fully aware of the range of services offered such as carers assessment as well as regular reassessment of care for patients within their home setting.



There is a need for dementia champions across the Adult Social Care Directorate.



LBRuT, SWL CCG and South West London and St George's Mental Health Trust should audit the proportion of frontline care professionals who have completed NICE recognized dementia awareness training.



To add low-level psychosocial support to unpaid carers to the current dementia pathway.



To consider increasing availability and flexibility of respite care, including day care centres, and home care to facilitate unpaid carer wellbeing and reduce isolation.



To review Alzheimer's Society training for unpaid carers offer as part of the carers hub contract.



There is a need for support to navigate the support system for all unpaid carers, regardless of funding status.



To better understand the current digital offer and what digital solutions could be implemented to improve this offer.

8 Actions and next steps

The workshop proposed the following actions and next steps:

- i. The report will be distributed to all agencies working with dementia, and the findings shared with the carers centre.
- ii. The recommendations will be taken to the DPLG for discussion by the delivery subgroups. Individual actions were disseminated to members of the workshop and can be followed by the DPLG. By utilising the expertise within the DPLG and utilising the timely opportunity to influence the dementia refresh, it is recommended that the DPLG act as a steer for any plans that are to be developed.
- iii. The recommendations have been shared with the Executive Director and Assistant Director of Adult Social Care to discuss as part of the transformation programme.



Appendices

Appendix 1. List of Attendees

Organisation

Adult Social Care and Public Health,
London Borough of Richmond upon Thames

Attendees

Sydney Hill, Head of Health and Care Strategy
Jane Miller, Day Centre and Transport Assistant
Manager (Woodville)
Rosemary Lambe, Service Manager

Nadine Hassler, Care Act Programme Coordinator
Harmeet Bhundia, information Officer

Gill Ford, Head of Strategic Performance
Di Manning, Head of Commissioning Adult Social
Care and Provider Management

Dr Nike Arowobusoye, Consultant in Public Health
Tamatha Macey, Senior Public Health Lead

Steve Shaffelburg, Commissioning Manager
Paul Banks, Commissioning Officer

South West London and St George's
Mental Health Trust

Dr. Lola Velazquez Guerra, Consultant Psychiatrist

South West London CCG

Dr Stavroula Lees, Clinical Lead
for Mental Health at SWL CCG
Arlene Thomas-Dickson,
Senior Transformation Manager Mental Health
& Personalisation (Richmond)

Hounslow and Richmond Community
Healthcare NHS Trust

Nina Jalota, Community Dementia Practitioner
Teresa Keegal, Community Dementia Practitioner

Local day care provision

Jacqui Parris, Chief Executive Officer,
Homelink Day Respite Centre
Julie Dacosta, Crossroads Care

Voluntary sector organisations working
with people with dementia and their carers

Tanya Williams, Alzheimer's Society

Appendix 2. Dementia care home and day care support in Richmond

We know from previous research that Richmond has a lower proportion of care home beds per 100,000 people aged ≥ 65 yrs in South West London (2,800 per 100,000). There are 46 care homes in Richmond, 29 cater for those aged ≥ 65 yrs, totalling 845 care home beds for those aged ≥ 65 yrs. PHE calculate that, for every 100 people with a registered diagnosis of dementia in Richmond, there are 41.5 care beds. This is less than the average ratio of beds available in London (51.3 per 100) and England (69.2 per 100).

Although few, what is reassuring is the quality of care beds in Richmond is significantly higher (100% “good or outstanding”) than average in London (51.3%) and England (69.2%). We also hear from local carers for people with dementia, who voice a need for more day centre capacity in the borough.

We know that most people affected by dementia live in private accommodation. Many of those with mild dementia will live independently in this context. However, for people living in private accommodation who are not independent, their care will come from informal sources, formal ‘home care’ provision and day-centre services. In Richmond receiving formal ‘home care’ is less ‘home care’ provision than is provided on average regionally and nationally, proportional to population size.

At present, there are 4 centres which provide day care in the borough. However, the data also describes a deficit in the capacity of these services. In 2013/14, 48.1 per 100,000 ($n=220$ adults received day care services in Richmond, significantly fewer than average in London and England (268.3 and 301.1 per 100,000 adults respectively).



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For more information or questions please contact Tamatha on tamatha.macey@richmondandwandsworth.gov.uk December 2020

Abbreviations

ASC & PH Adult Social Care & Public Health
CCG Clinical Commissioning Group
DPH Director of Public Health
DPLG Dementia Prevention and Care Leadership Group
GP General Practitioner
LBRuT London Borough Richmond upon Thames
MDT Multi Disciplinary Meeting

NICE National Institute for Health and Care Excellence
PHE Public Health England
SMT Senior Management Team
SWL CCG South West London Clinical Commissioning Group
SWL ICS South West London Integrated Care System

Public Health

