



**Report on
respite provision: community, day,
residential and nursing for older people
with a mental health diagnosis**

I. Summary

This report was undertaken to address the key objectives of National Mental Health Strategy 'No health without mental health' (2011), the National Dementia Strategy (2009) and the national and local shift in mental health services for older people away from inpatient provision to care within the community.

This report provides an overview of the:

- National Strategies.
- Demography of older people with a mental health diagnosis and predicted growth in this population.
- Current respite provision in the London Borough of Richmond
- The key findings of the responses from the Carers respite survey undertaken in March 2012
- Key recommendations

Please note that throughout the report the term mental health diagnosis includes functional mental health (e.g. depression and psychotic disorders) and organic mental health e.g. all types of dementia.

A draft version of this report was circulated for comment to the Older Peoples Mental Health Strategy Group.

II. Background

A. The national mental health strategy '*No health without mental health*'¹ published in 2011 has at its heart that mental health is everyone's business; the strategy has 6 key objectives:

1. More people will have good mental health
2. More people with mental health problems will recover
3. More people with mental health problems will have good physical health
4. More people will have a positive experience of care and support
5. Fewer people will suffer avoidable harm
6. Fewer people will experience stigma and discrimination

Respite provision can sit within all 6 objectives but the 4th objective clearly identifies the need for a positive experience of care and support. The strategy states that people 'should be given the greatest choice and control over their own lives, in the least restrictive environment.'

The DOH living well with dementia; a national dementia strategy (2009) states the following in relation to respite care (pg 48)

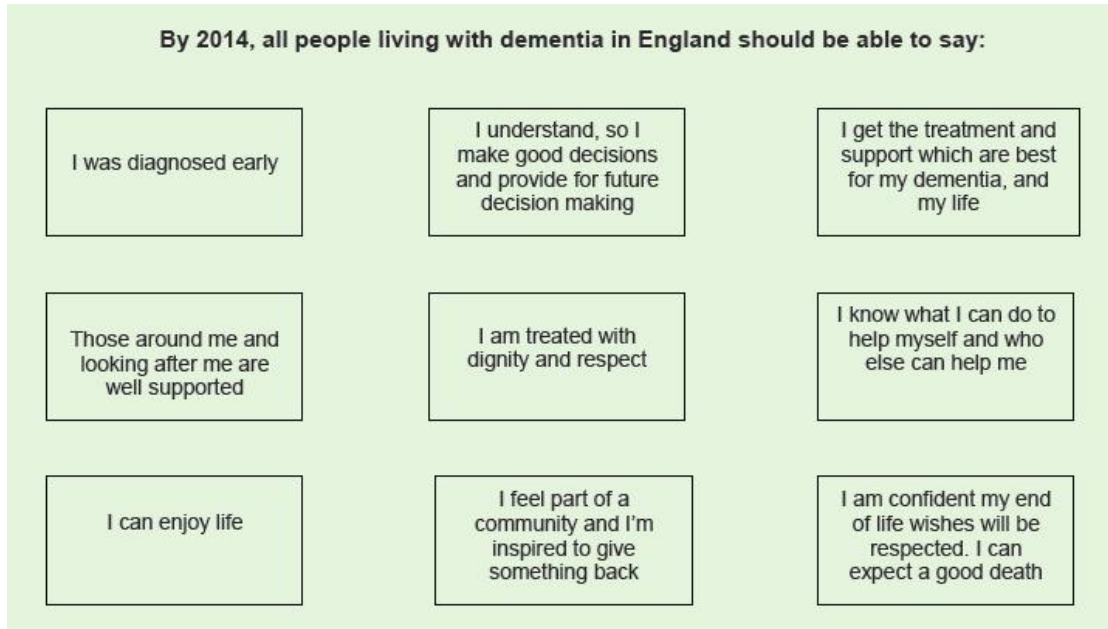
'Outcomes include reduced stress and risk of crises for carers, and extended capacity for independent living for people with dementia

- respite care/breaks that provide valued and enjoyable experiences for people with dementia as well as their family carers;

¹ DH – no health without mental health

- flexible and responsive respite care/breaks that can be provided in a variety of settings including the home of the person with dementia; ‘

B: Department of Health. ‘Quality outcomes for people with dementia – building on the work of the National Dementia Strategy’ DH 2010; are illustrated below



C: NICE Dementia Guidance² provides guidance on the identification, diagnosis and treatment of those with dementia. Some of the key points relevant to this work include:

- Memory assessment services should be the single point of referral for all those with a possible diagnosis of dementia
- As far as possible dementia care services should be community based

Health and social care managers should ensure that carers of people with dementia have access to a comprehensive range of respite/short-break services.

D: The Kings Fund published ‘*Mental health and the productivity challenge*’ in 2010³; its recommendations were:

- A high priority for commissioners should be reducing unnecessary bed use in acute and secure psychiatric wards. This can be achieved by strengthening crisis resolution teams, developing alternatives to admission, improving services for those with complex needs and improving step down options.

They cite a number of papers which suggest that crisis and home treatment teams (CRHT) can be highly effective in reducing unplanned admissions to hospital. They also cite evidence that various forms of peer support can reduce the likelihood of psychiatric hospitalisation and demand for other services. CRHT teams were introduced in adult services initially and their introduction in older people’s services is a more recent development.

² NICE (2011 update). *Dementia supporting people with dementia and their carers in health and social care*. NCG42. NICE, originally published 2006, updated in 2011.

³ Naylor, C and Bell, A (2010). *Mental health and the productivity challenge. Improving value for money*. The King’s Fund, 2010.

In relation to older people specifically they state that the provision of older people’s crisis and home treatment teams can reduce hospital admission rates by up to 31% as well as reducing length of stay and re-admission rates.

There has been a shift in the use of inpatient beds within the South West London cluster, which has been driven by the closure of wards run by South West London and St George’s Mental Health NHS Trust and by the introduction of specialist Intensive Home Treatment teams. It is noted that these ward closures were initiated by the provider SWLSTGT and a temporary inpatient arrangement is in place whilst ongoing discussions are taking place regarding the future of inpatient care.

III. Demography

Overall, the population in Richmond is projected to increase by 15% by 2025; with a slight increase in the proportion of the general population that is aged 65+ and 75+ (increase from 11.5% to 12.4% - 65+ years and from 5.81% to 6.43% - 75+ years). The 65+ population is projected to increase by 18% by 2020; with the 75+ population projected to increase by 16% by 2020.

Table 1: Population projections to 2020 for those aged 65+ and 75+

| | 2012 | 2013 | 2014 | 2015 | 2020 | % increase 2012-2020 |
|-----|--------|--------|--------|--------|--------|-------------------------|
| 65+ | 25,200 | 26,000 | 26,800 | 27,100 | 29,700 | 17.9% |
| 75+ | 11,800 | 11,800 | 12,100 | 12,100 | 13,700 | 16.1% |

Source: ONS 2008 based Subnational Population Projections

Given the likely increases in the older population; it is important to consider the degree to which services will be required to meet increased demand over the coming years.

Carers:

There is currently no reliable data for the number of carers caring for an older person with a mental health diagnosis. However it is well documented that the impact on carers of caring for people with mental health needs is immense and can lead to carers themselves suffering from depression and other mental health disorders as a result of the difficulties they face.

Mental Health and people aged 65+

At least 1 in 4 people will experience a mental health problem at some point in their lifetime and 1 in 6 adults have a mental health problem at any one time. The 2007

Adult Psychiatric Morbidity Survey among Adults in Great Britain⁴ found that 23% of those responding in England reported at least one psychiatric disorder and 7% reported two or more disorders at any one time.

The key mental health disorders affecting older people include:

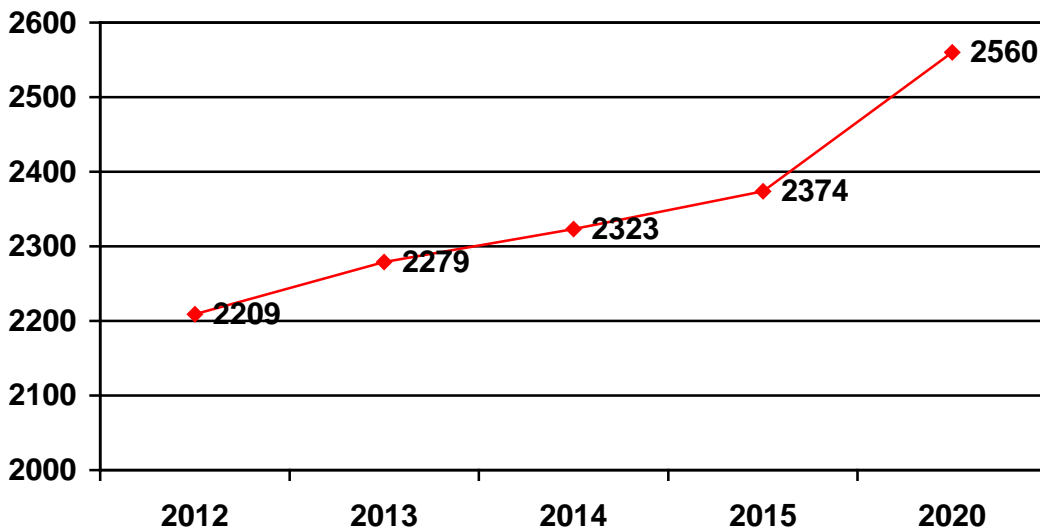
- Depression and anxiety
- Dementia
- Psychotic disorders

⁴ 2007 Adult Psyc survey www.ic.nhs.uk/pubs/psychiatricmorbidity07

The data available on the Projecting Older People Population Information (POPPI) website highlights the change in estimated numbers of older people with specific conditions over a number of years. The following graphs outline the trend in the projected numbers of people aged 65+ with depression (figure 1), severe depression (figure 2) and dementia (figure 3) in Richmond.

The number of older people diagnosed with depression is predicted to increase by 165 people by 2015 (7% increase), and 351 people by 2020 (16%).

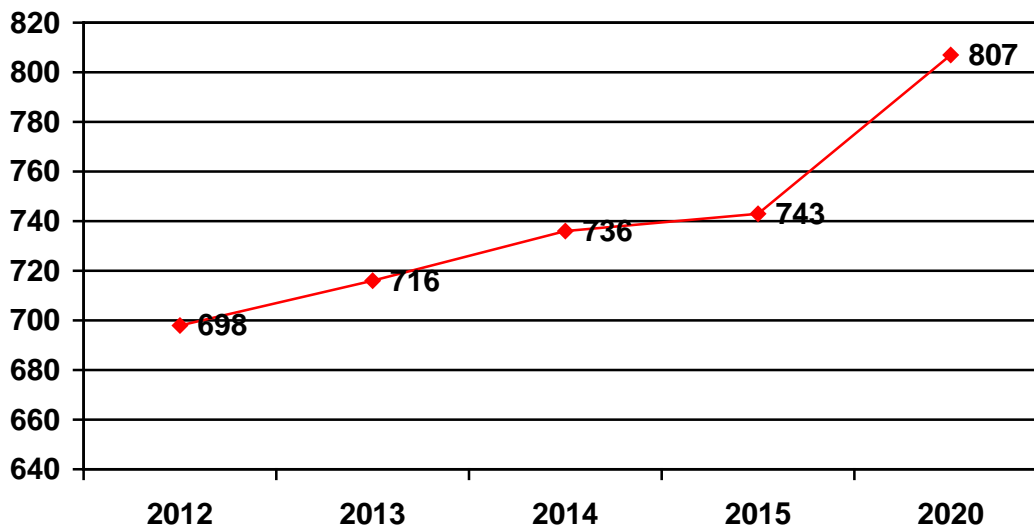
Figure 1: People aged 65 and over predicted to have depression Richmond, 2012- 2020



Source: Projecting Older People Population Information System (POPPI), May 2012

A similar picture emerges with severe depression (figure 2), with a predicted increase of 45 older people diagnosed with severe depression by 2015 (6% increase) and 109 people by 2020 (16% increase).

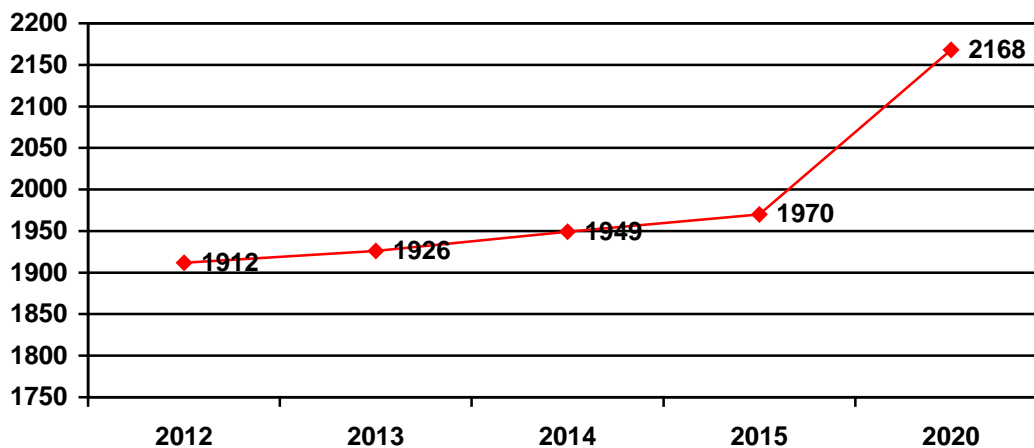
Figure 2: People aged 65 and over predicted to have severe depression, Richmond 2012-2020



Source: *Projecting Older People Population Information System (POPPI), May 2012*

Increases in the number of people with dementia are predicted to take place, with approximately 158 more people with dementia in 2015 (3% increase) and a 13% increase by 2020 (256 additional older people with dementia).

Figure 3: People aged 65 and over predicted to have dementia, Richmond, 2012-2020



Source: *Projecting Older People Population Information System (POPPI), May 2012*

Whilst there will be an increase in the number of older people with mental health conditions it is worth noting that the proportion of older people with depression, severe depression and dementia will remain constant, this means that the predicted increase is most likely due to an aging population (more people aged 65 and over) rather than a higher prevalence of mental health conditions.

Table 2: Projections in older people with mental health problems; 2012-2020

| | 2012 | | 2020 | | Change | |
|-------------------|------|----------|------|----------|--------|-------|
| | n | % of pop | n | % of pop | N | % |
| Depression | 2209 | 8.8% | 2560 | 8.6% | 351 | 15.9% |
| Severe depression | 698 | 2.8% | 807 | 2.7% | 109 | 15.6% |
| Dementia | 1912 | 7.6% | 2168 | 7.3% | 256 | 13.4% |

Source: Projecting Older People Population Information System (POPPI), May 2012

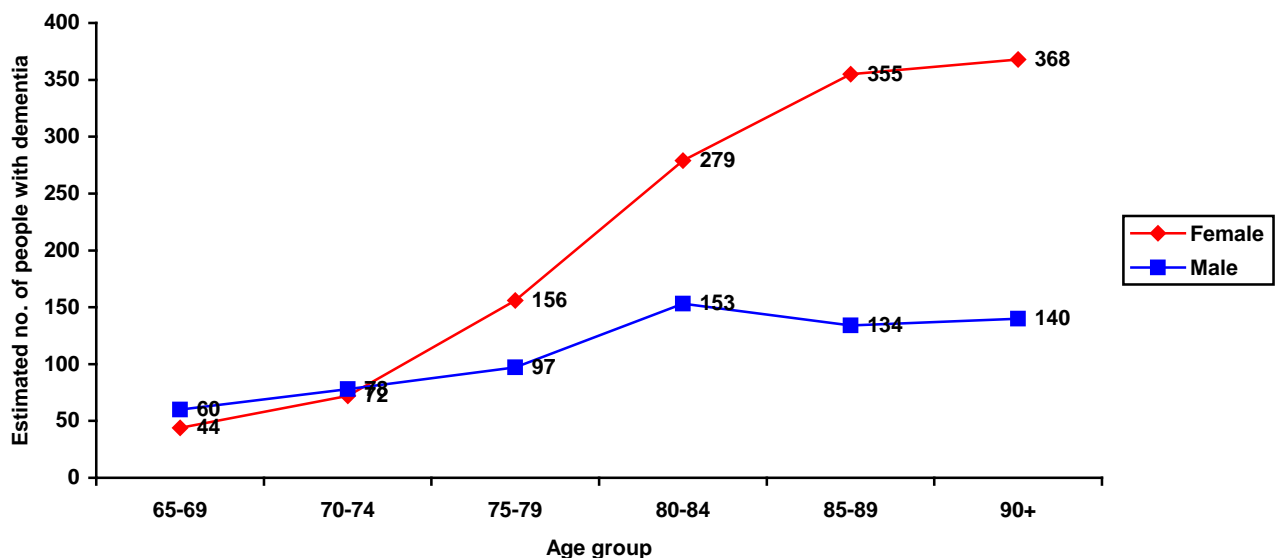
Psychosis and Older People

Prevalence of probable psychosis by age = 0.1% taken from Adult Psychiatric Morbidity Assessment 2007 for those aged 65-74.

(Projections based on ONS 2008 based Sub national Population Projections)

The table below illustrates the prevalence of dementia by gender.

Figure 4: Dementia prevalence by gender and age band – 2012



Source: POPPI 2012

Black and ethnic minority groups and older people

According to Census 2001 data, approximately 5% of the borough population aged 65+ are from BME communities, although ONS data released in 2007 showed 6% aged 65+ are from BME backgrounds.

Most people aged 65+ from a BME group are age 65-74 (718 people – 7%), only 64 (2%) of those aged 85 and over are from BME backgrounds.

There is likely to be an increase in older people from BME background due to the higher proportion of people age 55 – 64 from BME groups. Services aimed at older people will need to meet more diverse cultural needs in the future.

Table 3: OP age groups and BME population - 2007

| | 65-74 | 75-84 | 85+ |
|-------|--------------|--------------|------------|
| % BME | 7% | 4% | 2% |

Office of National Statistics, Projecting Older People Population Information System, 2009 (Please note the most recent census information has not yet been published by the Government)

IV. Current Respite Provision

For the purpose of this report respite provision is defined as a service or person that enables the carer to have a break from their caring role.

Current respite options include

- Personal budgets
- Home Care
- Day Care
- Residential and nursing home placements

i. Funding

The Council currently spends £794,000 on EMI respite services. This includes Woodville Day Centre, EMI residential respite and EMI nursing respite. The Council recognises that Woodville Day Centre provides a service for both service users and carers (and that some service users will not have a carer) .

Additionally, in 2011/12 the Council spent £111,000 on respite services which include NHS Carers Breaks and Carers direct payments. Please note that all the above expenditure is in relation to services for Older People.

The Council has recently commissioned a Carers Hub. The provision of respite for carers of people with dementia will form part of this service.

The total value of this contract is £1,161,988 over the next 3 years, 2012-15.

These costs do not include home care which may also provide a respite opportunity for carers.

ii. Accessing Respite Services

All carers can either contact their existing Social Worker or the London Borough of Richmond (LBRuT) Access team. People who are able to Self fund their care will be signposted to organisations that provide respite; if a person they care for meets the

Fair Access to Care (FACS) (**appendix A**) criteria of substantial or critical needs they may be eligible for some financial assistance. Self funders who require assistance with this process (through their own needs) will be supported by the Council.

The link below provides information and advice on social care charges

http://www.richmond.gov.uk/home/health_and_social_care/adult_social_care/i_need_help_with/information_legal_and_financial_issues/social_care_charges.htm

The process

A Self Directed Support Assessment is completed and a support plan is put in place for each Service User. Respite may be included in this support plan and included in the budget allocation at this stage.

The service user can opt to manage their own personal budget (direct payment or ask the Council to manage their budget for them)

iii. Respite Care within the Service Users own home

This can be provided by

- Home Support Agencies
- Through personal budgets which allows service users to purchase their own personal assistant.
- Richmond Crossroads.

iv. Short notice respite

Crossroads are grant funded by LBRuT to provide the Emergency Respite service for the borough and have two staff members available to respond to these requests.

v. Day Care

The London Borough of Richmond has one dedicated day centre for older people with dementia who meet the FACS eligibility criteria of substantial or critical ; The Woodville Centre at Ham. It is open 7 days a week and is also available to self funders.

Woodville has

- 30 places available Monday – Friday
- 15 places Saturdays and Sundays.

Monday - Friday attendance (April 2012)

Attendance rate was 81% (93% of places were booked)

Saturday and Sunday attendance (April 2012)

Attendance rate 69% (76% of places were booked)

There are currently 60 people on the Woodville Register attending between 1 and 7 days per week. There is currently no waiting list.

The referral and attendance rate trend is increasing each month for both weekday and weekends.

vi. Voluntary sector provision

Homelink Day Respite Centre runs a day centre in Whitton.

Homelink Day Respite Centre is open 5 days a week; out of the 135 clients attending each week 70 have either an organic or functional mental health condition.

Homelink are able to provide a service for people with mild to moderate dementia. The service will take self referrals (via the carer) and is open to self funders.

Monday is the Mental Health specialist day with 25 clients attending.

At present there are 11 people who have a mental health diagnosis on the waiting list (NB this is a snapshot figure and is subject to change).

Taking into account the 141 people each week with a dementia diagnosis that attend either Woodville or Homelink Day Respite Centre or who are on a waiting list, this makes up 7.4% of the predicted number of older people with a dementia diagnosis in 2012. Taking into account the projected increase in older people with dementia in the borough, this indicates that by 2015 there will be approximately 146 people with dementia attending a day centre (five additional people), and 160 older people by 2020 (19 additional people).

vii. Residential and Nursing Care respite.

The Council has a block contract with one provider in the borough; Care UK. Within this contract there is provision for 1 Elderly Mentally ill (EMI) nursing respite bed. This respite bed can be accessed by anyone with eligible needs who comes through the Council, but it cannot be accessed directly through Care UK.

Data collected for the last 4 years 2008 -2012 shows that the average occupancy rate for this bed was:

- 67% for 2008/9
- 59% for 2009/10
- 62% for 2010/11
- 29% for 2011/12

The Council (through the brokerage team) spot purchases all other residential respite beds and nursing respite requests for people with a functional or organic mental health diagnosis. The brokerage team spot purchase from 53 different providers; 13 of these are from within the borough of Richmond. Out of these 13, 3 are registered to provide EMI nursing care. The bed vacancy list is updated on a weekly basis and requests for respite can be made to each individual provider up to 2 weeks before the respite is required.

NB All providers will prioritise a permanent placement over a respite placement.

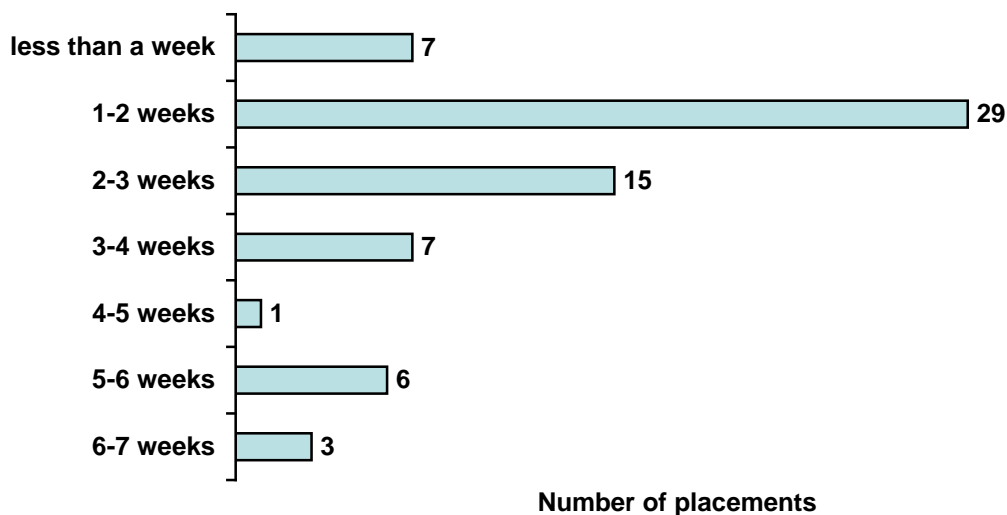
The Council's brokerage team are responsible for finding all respite beds. This involves ringing around providers that have vacancies, which usually results in the family being offered a choice of up to 3 residential homes. In the last financial year each respite placement request has been met.

Most (72%) requests throughout the year were for residential EMI respite.

Table 4: EMI respite placements through The Council’s brokerage April 2011 – March 2012

| Month | Residential | Nursing | Total |
|--------------|-------------|-----------|-----------|
| April | 7 | 2 | 9 |
| May | 1 | 1 | 2 |
| June | 8 | 1 | 9 |
| July | 4 | 1 | 5 |
| August | 6 | 4 | 10 |
| September | 4 | 2 | 6 |
| October | 0 | 1 | 1 |
| November | 3 | 3 | 6 |
| December | 2 | 0 | 2 |
| January | 1 | 1 | 2 |
| February | 4 | 2 | 6 |
| March | 11 | 2 | 13 |
| Total | 51 | 20 | 71 |

Figure 5: Number of weeks each placement lasted



NB The 68 respite placements related to 38 people

Currently all requests for EMI respite through the Council are met, with half of placements (51%) made throughout 2011-12 being placed in the borough.

Table 5: Number of EMI respite placements placed in vs. out of borough

| Month of placement | In borough | Out of borough | % in borough |
|---------------------------|-------------------|-----------------------|---------------------|
| Apr 2011 | 4 | 3 | 57% |
| May 2011 | 3 | 1 | 75% |
| Jun 2011 | 2 | 3 | 40% |
| Jul 2011 | 6 | 4 | 60% |
| Aug 2011 | 4 | 3 | 57% |
| Sep 2011 | 4 | 7 | 36% |
| Oct 2011 | 2 | 2 | 50% |
| Nov 2011 | 2 | 1 | 67% |
| Dec 2011 | 1 | 2 | 33% |
| Jan 2012 | 0 | 3 | 0% |
| Feb 2012 | 2 | 1 | 67% |
| Mar 2012 | 4 | 3 | 57% |
| Total | 34 | 33 | 51% |

V. Future Respite provision

i. The carers view

In March 2012 carers of older people with a mental health diagnosis were asked by the London Borough of Richmond to complete a short questionnaire to gain their views of how they would like to receive/purchase respite services in the future. A number of options were presented to these carers and they were asked to give their opinion on each.

Over 1000 paper questionnaires were distributed via a number of key providers of services to carers and the cared for (listed in the acknowledgements section of the report). The providers were asked to circulate the questionnaire to relevant carers. The carers returned the questionnaire to the Council in a pre-paid envelope.

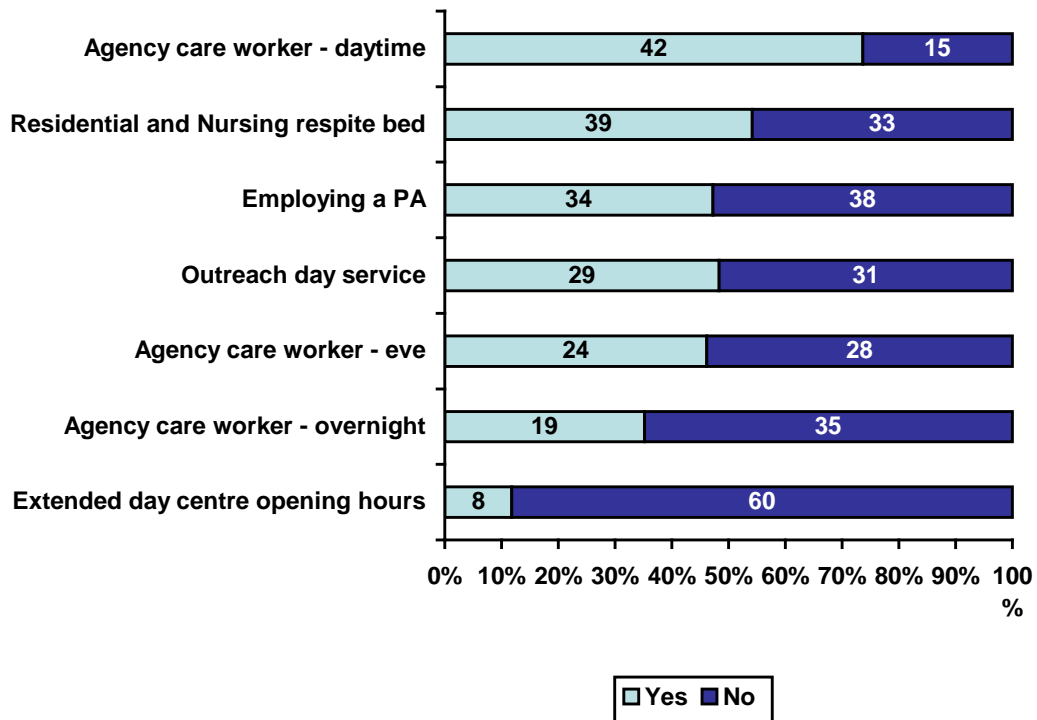
79 carers completed the survey.

Please see **appendix B** for a copy of the questionnaire and **appendix C** for a report of the findings. The service user i.e. the person with a mental health diagnosis was not surveyed for their view on respite and there are recommendations at the end of the report to address this gap for the future.

VI. Summary of the key findings from the respite report and their impact on future plans

All carers were aware that all options would need to be purchased. Figure 6 below compares demand for different types of respite provision.

Figure 6: Proportion and number of carers that would use each type of respite options



Respite Options

1. Employing a personal assistant

34 of the carers expressed interest in employing a personal assistant (47%)

How we are going to use this information to Plan for the Future

This figure informs us that this is a viable option that needs to be continued to be promoted to carers. (Carers were given information on how to find out more about employing a personal assistant on the survey)

Cost

The current cost of employing a personal assistant is no more than £13.00 an hour.

2. Home support workers provided through an agency in the service users home

74% wanted home support workers to provide a service during the day, 46% wanted the option for home support after 6pm and 35% wanted the option for overnight care.

How we are going to use this information to plan for the future

The Home Support contract is currently out to tender, it specifically addresses the requirements of the homecare provider to demonstrate it can meet the needs of people with dementia and the needs of all carers.

The Home Support services will be available seven days per week, 52 weeks per year. Standard Home Support Services will be delivered between 07:00 and 23:00.

The provision of Home Support services also covers live in care, where it is expected that services will be provided 24 hours per day. The provider may also be required to provide services throughout the night through a waking or sleep in night's service. The hours and timing of the service is to be agreed between the provider and the Service User.

The providers that will be accepted on the Home Support Framework are not guaranteed any volume of business and they are required to meet the trends in the future demand for the Home Support services.

3. Outreach Day service option

This option enables people with a MH diagnosis to continue with their preferred activities (e.g. walking, socialising, and hobbies pastimes) by having assistance to do these things.

29 carers responded that they were interested in this option (31 were not).

How we are going to use this information to plan for the future

The opportunity to employ a personal assistant will enable carers to develop this option.

Additionally the Home Support contract clearly specifies that activities may take place within or outside the home (outreach) – see below.

Activities to support the achievement of individual outcomes will typically, but not exclusively, include the following:

Meeting basic physical needs, including:

- Getting up, going to bed, bed making
- Dressing and undressing
- Washing, bathing and general grooming (personal hygiene)
- Preparing meals and light snacks, eating and drinking
- Using the toilet, maintaining continence, managing incontinence
- Moving about, handling and transferring (mobility)
- Supervising, encouraging, helping with medication
- Shopping for everyday requirements, collection of pensions and other state benefits

Living in a clean and tidy environment, including:

- General housework including vacuuming, cleaning, washing up, tidying up and disposal of refuse and other waste materials
- Laundry and ironing

Keeping active and engaged in community life, including:

- Activities that sustain ability, identity and independence. Losing a sense of purpose can be damaging to general mental health and remaining active helps to sustain social interaction.

- Enabling opportunities to pursue individual hobbies and interests as directed by Service Users, undertake tasks related to the running of the home, excursions and outings which promote user independence and engagement. Opportunities to go out and activities that result in a sense of achievement are also important for all, irrespective of their individual needs
- Encourage Service Users to maintain their relationships with their friends and families and participate in community groups and associations, religious and non religious activities.

Access to social contact and company; including

- Social support - conversation, reading, letter writing, phone calls
- Encouragement, confidence building, listening
- Ensuring personal safety and security meaning that the Care Worker will facilitate that the Service User will feel safe and secure inside or outside their home
- Having control over everyday life, including
- Exercising choice and control over daily living activities

The support from the Provider's staff must be delivered in a way that is:

- Culturally sensitive; respectful; courteous; dignified and humane.

All activities agreed as part of a Support Plan will support Service User empowerment and will be underwritten with the understanding that Service User choice, control and independence is paramount.

Please note the service provider will also be required to seek the Carers feedback.

Cost

The cost of a home support worker through an agency is currently no more than £15.34 an hour.

4. Day Centre provision

60 (88%) of the respondents were happy with the current day centre hours (9-5)

Only 4 carers wanted day centre to open at 8am and only 5 carers wanted the day centre to open between 5 and 10pm

Woodville Day Centre

The trend for referrals and occupancy rates is increasing on a monthly basis.

The centre is increasingly being used to host dementia related information and support groups.

Cost

£62.60 per day (includes transport and lunch)

Homelink Day Respite Centre

Homelink are currently considering developing a caring café on alternative Saturdays They also have plans to build a new Homelink Centre within the same site which will give them the capacity to take an extra 15 clients a day.

Cost

£21.50 for one day; additional days cost £33 a day.

Private developments

Hampton Care opened a Day Care Centre for people with dementia in February 2012.
Monday – Friday 9.30 - 4.30pm.

Cost

£80 a day

How we are going to use this information to plan for the future

The demographic information and the carers respite survey findings would imply there is currently no need to increase day care provision.

The demographic trends for early onset dementia are not yet available this may influence carers views on extended opening hours in the future. Anecdotally we know that extended hours may allow a carer to continue in full time work.

5. Residential and nursing respite provision

39 (54%) of carers who responded to this question said they would want the option of purchasing a residential or nursing home bed. 33 of the carers stated they would not consider this option.

Of the 39 carers who wanted this option 38% wanted to be able to access this option twice a year.

How we are going to use this information to plan for the future

The demographic information informs us that there will be an increase in older people with a mental health diagnosis in line with the predicted increase in the ageing population.

The Council is currently able to source and place requests for residential and nursing respite but also recognises that the carer is unable to book respite more than 2 weeks in advance of when the respite is required. The Council recognises the additional stress that this may incur for the carer and service user.

Market forces do not allow residential and nursing respite to be pre booked prior to 2 weeks before the date of respite. The provider cannot afford to keep a bed reserved and empty; the Council or a self funder cannot afford to bridge this gap.

The only pre bookable EMI bed in advance in LBRuT is a Nursing bed which is currently underused.

Contract re-negotiations with Care UK and the Council are to take place and the consideration of the under use of the respite nursing EMI bed and the availability to self funders will be included in these discussions.

The Council will explore the viability of developing a Shared Lives respite scheme for older people with dementia or a functional mental health diagnosis. Shared lives is a model of care that enables people with dementia to benefit from spending short breaks in carers' homes, living as part of their family.

Cost

The cost of a residential or nursing bed is subject to market forces and it is strongly recommended for self funders that 3 quotes are sought when looking for respite provision.

The viability of developing a shared lives respite scheme will include the full costs of the potential service.

Additional information for carers

Carers Assessment

If a person is caring for an adult, the Council can undertake a carer's assessment at the same time as doing an assessment of the needs of the person being cared for to assist the understanding of what help might be needed to support the carer in their caring role. The Council can also undertake carers assessments separately regardless of whether the cared for person is assessed.

The carer's assessment will involve a social care practitioner asking what kind of support the person being cared for needs, whether the carer is able to provide it and what help might improve the carer's situation. The carer can talk to the social care practitioner about financial worries, their health, and any concerns about future needs. The social care practitioner will discuss some of the different support options available to help carers and enable the carers to access them so that they carry on caring with adequate support.

The Council may be able to help carers with:

- Advice and information
- Emergency planning
- Financial support and advice
- Introduction to support groups
- Advice about respite care for time off
- Signposting to voluntary and health services

NHS Carers Breaks

This is a scheme which is administered by the Council and funded by the NHS (South West London Richmond Borough Team) to support carers who are either resident or look after someone who is a resident in the London Borough of Richmond upon Thames whose health and/or wellbeing is being affected by their caring situation (e.g. back injury, stress-related illness, psychological ill-health). Carers can apply for a one-off grant of £250 April 2012 to March 2013 to pay for an activity, short break, regular therapy or holiday, or towards a training course). The application form needs to be endorsed by a health or social care professional or a support worker from a carer support organisation.

The Memory Service

This is a new service for Richmond residents .The objectives of the new memory service include:

- to promote and facilitate early identification, treatment and referral and encourage eligible patients to attend assessment
- to provide a high-quality accurate diagnosis of dementia that is communicated in a person-centred way to both the person with dementia and their carers and which meets the individual needs of the person with dementia and their carers
- inclusive of a carers' needs assessment to ensure that the service is delivered in a considered, timely and co-ordinated manner
- pre and post diagnosis counselling support

Formal and informal counselling for carers

The newly commissioned primary mental health service (Richmond Wellbeing Service) will be available to carers with a mental health condition initially via a referral from a GP.

Informal counselling and support is available through Carers organisations including but not limited to Richmond Carers Centre, RB Mind and The Alzheimer's Society.

VII. Summary and Recommendations

The NICE dementia guidance states that; As far as possible dementia care services should be community based. Health and social care managers should ensure that carers of people with dementia have access to a comprehensive range of respite/short-break services.

The information in this report provides us with evidence of how this is currently being achieved, and how this may be achieved in the future.

The relatively small response (79 carers) to the Carers respite survey gives some insight into the services that are perceived as currently important to develop for these carers.

The report does not consider the views of the person with an organic or functional mental health diagnosis.

The process of collating information for this report has also highlighted the gap in service provision for carers of older people with a functional mental health diagnosis. (There was no one organisation that represented these carers) this is now being addressed through the recommendations.

Recommendations

- All service users (and their carers) who meet the substantial and critical FACS criteria and are eligible for Council funding will continue to be given advice on receiving a direct payment to enable them to employ a personal assistant.
- The Home support contract to be robustly monitored to ensure that the performance targets are met, particularly regarding the level of knowledge skills and understanding of dementia of the home support worker.
- The carer's and service user's views on the Home Support worker will be essential to inform performance monitoring. This requirement is in the service specification.
- To request that the contract negotiations with Care UK include the use of the respite EMI nursing bed to be reconfigured to an EMI residential bed and the possible access to this bed by self funders who meet the substantial or critical FACS criteria.
- The Council to continue to monitor the FACS eligible requests for residential and nursing respite and the ability to meet all these requests.
- The Council to explore the development of a shared lives respite scheme for older people with dementia.
- The Council to continue to assist self funders who are unable to manage their own respite.
- To work with our partner agencies to monitor the impact of early onset dementia and respite service provision.
- The memory service to develop advanced directives / anticipatory care plans with the person with dementia so their views on respite can be taken into consideration in the future
- The CMHT to ensure people with a functional MH diagnosis have completed an advanced directive which has considered respite preferences.
- RB Mind to expand their valued work with mental health carers to include carers of older people with a functional mental health diagnosis. From July 2012.
- To actively promote carers assessments
- To respond to Department of Health forthcoming guidance forthcoming/legislation in relation to carers

- To ensure the LBRuT Carers website is kept up to date
- To present this report and its findings to the older people's mental health strategy group for further discussion.
- To send the Respite Survey report of findings to all the distributing organisations to enable the carers to be able to view the contents.

Acknowledgements

Thank you to everyone who has contributed to this report. Particular thanks to the Carers who completed the Carers Respite Questionnaire ; Friends of Barnes Hospital Cathy Sheldon and Mary McNulty for contributing to the design of the Carers Respite questionnaire ; The SWLSTGT community mental health teams, The Alzheimer's society , Richmond Crossroads , Age UK , Richmond Carers Centre , Homelink , Elleray hall , Barnes Green Centre. RUILS. LBRuT Quality Assurance; Finance and Bed Brokers the Integrated Health and Social Care teams, Woodville and Sheen Day Centres, NHS Richmond; The Older Peoples Mental Health Strategy Group.

References and useful web links

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http://www.kingsfund.org.uk/publications/mental_health_and.html

Projecting Older People Population Information System (POPPI), May 2012

http://www.richmond.gov.uk/home/health_and_social_care/adult_social_care/i_need_help_with.htm

<http://www.carers.org/local-service/richmond>

Fair Access to Care Eligibility Criteria

The council **provides** services to people that meet **Critical** and **Substantial** eligibility criteria

Critical – when:

- Life is, or will be, threatened; and/or
- Significant health problems have developed or will develop; and/or
- There is, or will be, little or no choice and control over vital aspects of the immediate environment; and/or
- Serious abuse or neglect has occurred or will occur; and/or
- There is, or will be, an inability to carry out vital personal care or domestic routines; and/or
- Vital involvement in work, education or learning cannot or will not be sustained; and/or
- Vital social support systems and relationships cannot or will not be sustained; and/or
- Vital family and other social roles and responsibilities cannot or will not be undertaken

Substantial – when:

- There is, or will be, only partial choice and control over the immediate environment; and/or
- Abuse or neglect has occurred or will occur; and/or
- There is, or will be, an inability to carry out the majority of personal care or domestic routines; and/or
- Involvement in many aspects of work, education or learning cannot or will not be sustained; and/or
- The majority of social support systems and relationships cannot or will not be sustained; and/or
- The majority of family and other social roles and responsibilities cannot or will not be undertaken.

The council **does not** provide services to people that only meet **Moderate** or **Low** criteria

Moderate – when:

- There is, or will be, an inability to carry out several personal care or domestic routines; and/or
- Involvement in several aspects of work, education or learning cannot or will not be sustained; and/or
- Several social support systems and relationships cannot or will not be sustained; and/or
- Several family and other social roles and responsibilities cannot or will not be undertaken.

Low – when:

- There is, or will be, an inability to carry out one or two personal care or domestic routines; and/or
- Involvement in one or two aspects of work, education or learning cannot or will not be sustained; and/or
- One or two social support systems and relationships cannot or will not be sustained; and/or
- One or two family and other social roles and responsibilities cannot/will not be undertaken.



Respite Survey

**for carers of people with dementia
or**

an older person (65 years +)

with a mental health diagnosis

February 2012

Information for carers

Who is a carer?

You are a carer, whatever your age, if you provide unpaid help to a partner, child, relative, friend or neighbour, who couldn't manage without you. This could be due to age, physical or mental illness, addiction or disability.

What is respite?

When someone else takes over your caring routine so that you can have a break or holiday, it is called respite care.

As a carer how do I get support and advice?

Please look at the London Borough of Richmond upon Thames website for helpful information.
http://www.richmond.gov.uk/being_a_carer

You can contact the London Borough of Richmond's Access Team either for a [carer's assessment](#) . (A financial assessment is not required as part of a Carers assessment)

Or

For an [assessment](#) for the person you care for. This will enable you to look at suitable support for yourself. The person you care for will be required to complete a financial assessment and we may then ask for a contribution towards the costs.

To find out what help is available to you even if the person you care for doesn't receive or want support you may want to ask for a Carers assessment.

Even if you are not eligible for help from us, there are voluntary organisations in Richmond who will be able to offer you advice and support. You can find out more about these organisations from the London Borough of Richmond upon Thames website: or by contacting the following:

London Borough of Richmond's Access team:

Phone: 020 8891 7971 (prefix 18001 for Text phone Users)

SMS Text: 07507 512 733

Fax: 0800 014 8359

Email: adultsocialservices@richmond.gov.uk

Richmond Carers Centre:

Website: <http://www.carers.org/>

Carers Support Line: 020 8867 2380

Address: 5 Briar Road, Twickenham, TW2 6RB

Respite Survey

By answering the following questions you will provide information to help us develop future respite provision in Richmond.

Please note for the purpose of this survey the word 'dementia' is used generically and includes Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and any other dementia related disease.

**Only complete this survey if the person you care for lives in the
London Borough of Richmond upon Thames
Please return the survey before 14th March 2012**

Section 1: About your caring role

1. Do you care for a person with dementia?

- Yes
 No

2. Do you care for a person over 65 with a diagnosed mental health condition?

- Yes
 No

Section 2: Respite care *within* the home of the person with dementia/mental health condition: Personal Assistant option

Carers can purchase care for the person they look after through a Personal Assistant 'Finding Service' e.g. Richmond Users Independent Living Service (RUILS) or by recruiting their own paid carer worker through a Care Agency or personal advertisement. This is a very flexible way for you to arrange the time and frequency of respite and enables carers to choose the person that will provide the respite and how the time is used e.g. within or outside the home.

3. Would you like to know more about employing a personal assistant?

- Yes
 No

*To find out more about employing a personal assistant contact the Access Team on
020 8891 7971*

Section 3: Respite care *within* the home. Care workers provided through an agency option (The agency carer stays with the person with dementia/mental health condition)

If you were able to purchase a respite *agency* service **within** the home (this could be regularly or on an occasional basis)

4. I would like to be able to purchase respite during the day for....
Please tick [✓] all that apply

- 2 hours
- 4 hours
- 6 hours
- 8 hours
- Would not want respite during the day

5. I would like to be able to purchase respite after 6pm for....
Please tick [✓] all that apply

- 2 hours
- 4 hours
- 6 hours
- Would not want respite after 6pm

6. I would like to be able to purchase occasional respite overnight for.... (e.g. 7pm to 7am)
Please tick [✓] all that apply

- 1 night
- 2 nights
- 3-5 nights
- 6-7 nights
- Would not want respite overnight

7. Do you think you would use respite during the day /night?
Please tick [✓] all that apply

- Weekly
- Monthly
- Occasionally

Section 4: Respite care *within* the home of the person with dementia/mental health condition: Outreach Day Service option

This could be a **new** option to purchase. An outreach worker would come to the house of the person with dementia and assist them to continue their preferred activities both outside and inside the home. (Please note if you employ a Personal Assistant you will have this choice).

Each activity would need to meet a specific outcome. Examples are given below:

| Activity | Outcome |
|---|---------------------------|
| To go for a walk with | To stay fit and healthy |
| To accompany the person to go to the shops. | To have choice & control |
| To assist with maintaining friendships | To remain socially active |

8. Would you be interested in an outreach day service?

- Yes
- No

9. If yes how many hours would you like to be able to purchase a day?
Please tick [✓] tick all that apply

- 2 hours
- 4 hours
- 6 hours

10. Do you think you would use an outreach service
Please tick [✓] all that apply

- Weekly
- Monthly
- Occasionally

Section 5: Respite care away from the person with dementia's /mental health condition's home: Day Centre provision option

11. Most local day centres are open between 9am - 5pm; are you happy with these hours?

- Yes
- No

If you have answered yes go to question 16

12. Would you like to purchase day centre care at an earlier time ...

- 7am
- 8am
- Would not like the day service to open earlier

13. Would you like the option to purchase evening care?

Please tick [✓] all that apply

- Up to 6pm
- Up to 7pm
- Up to 8pm
- Up to 10pm
- Up to midnight
- Would not like evening care

14. If the day centre was able to stay open between 5pm - 10pm; which evenings would you be most likely to use and purchase care for?

Please note the hourly rate to pay would need to be higher than the day time rate

Please tick [✓] all that apply

- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday

15. Do you think you would use evening care...?

Please tick [✓] all that apply

- Weekly
- Monthly
- Occasionally

Section 6: Respite care away from the person with dementia's home: Residential and Nursing Respite option

16. Would you consider purchasing a residential or nursing home respite bed?

- Yes
- No

17. If yes how long would you want each period of respite to last?

Please tick [✓] all that apply

- 3 or less days
- 4 to 5 days
- 6 to 9 days
- 10 to 13 days
- 14 to 20 days
- 21 days or more

18. How many times in a YEAR would you envisage wanting to use this service?

- Once
- Twice
- 3 or 4 times

Thank you for taking the time to complete this
Respite Survey

Please return the survey to the centre that you received it from (e.g. Homelink, The Caring Cafe, Woodville Day Centre, or use the prepaid envelope enclosed)
Please return the survey before March 14th 2012



Respite Survey

Collation of answers

Carers of people with dementia
or an older person (65 years +)
with a mental health diagnosis

Date: April 2012

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Methodology

In March 2012 the views of carers of older people with dementia or another mental health diagnosis were asked to complete a short questionnaire to gain their views of how they would like to receive respite services in the future. A number of options were presented to these carers and they were asked to give their opinion on each.

Paper questionnaires were distributed to a number of key providers of services to carers and the cared for including the caring café, Homelink and Woodville day centre, and these providers were asked to circulate the questionnaire to relevant carers to complete via a self-completion method and send their views back to the council in a pre-paid envelope.

Questionnaires did not ask for any personal information about the person completing the questionnaire and were therefore completely anonymous. It is possible that the same carer would have received the questionnaire via more than one provider, as it was not possible to control for this, although it is unlikely that carers would take the time to fill the same questions in twice.

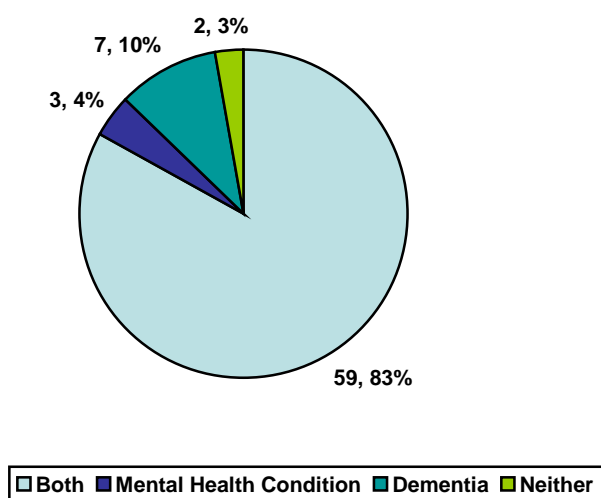
Due to the way the questionnaires were administered it was not possible to track questionnaires and report on response, therefore the findings represented in this report are not a true reflection of the views of all carers of those with dementia or a mental health diagnosis, but are reflective of a subset of views. A total of 79 carers completed and returned a questionnaire. The remaining report is based on the views of these 79 carers.

1 About the carer completing the survey

All carers were asked to state both whether they care for someone with dementia and whether they care for a person aged over 65 with a diagnosed mental health condition.

Of the carers that filled in and returned a survey, the majority (83%) said that they cared for someone with both dementia and a mental health condition. It is likely that as dementia is a type of mental health condition that people saw this as being the same thing and it is unlikely that all these service users had dementia as well as a co-existing mental health condition. The full break down of how people responded at these questions is illustrated in figure 1.1 below:

Figure 1.1: Whether respondent cares for person with dementia or mental health condition



Base: All respondents (77)

2 Respite options

There are a number of different ways that carers get respite from their caring role. A total of 5 options for respite were presented to carers throughout the survey and questions were asked about each option to gain the carers views on each one. This section reports on the views for all 5 respite options, section 3 then summarises what the most popular options for respite were amongst these carers.

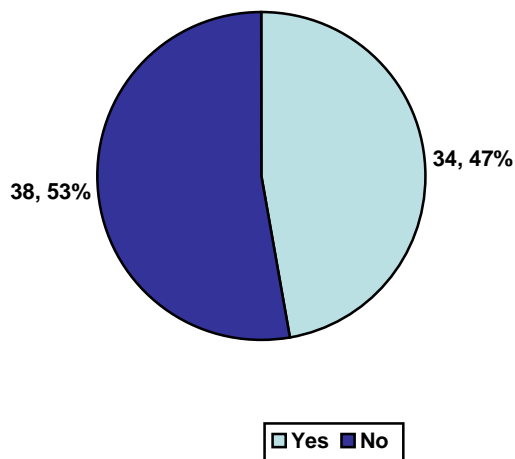
2.1 Personal Assistant Option

Carers were presented with the option to receive care for the person they care for in the home, via a personal assistant. This option is set out below:

Carers can purchase care for the person they look after through a Personal Assistant 'Finding Service' e.g. Richmond Users Independent Living Service (RUILS) or by recruiting their own paid carer worker through a Care Agency or personal advertisement. This is a very flexible way for you to arrange the time and frequency of respite and enables carers to choose the person that will provide the respite and how the time is used e.g. within or outside the home.

All carers were asked if they would like to know more about employing a personal assistant. Responses were quite split, with 47% of carers saying they would like to know more about this option, whilst 53% did not.

Figure 2.1: Whether want to know more about employing a Personal Assistant



Base: All respondents (72)

2.2 Care workers provided through an agency option

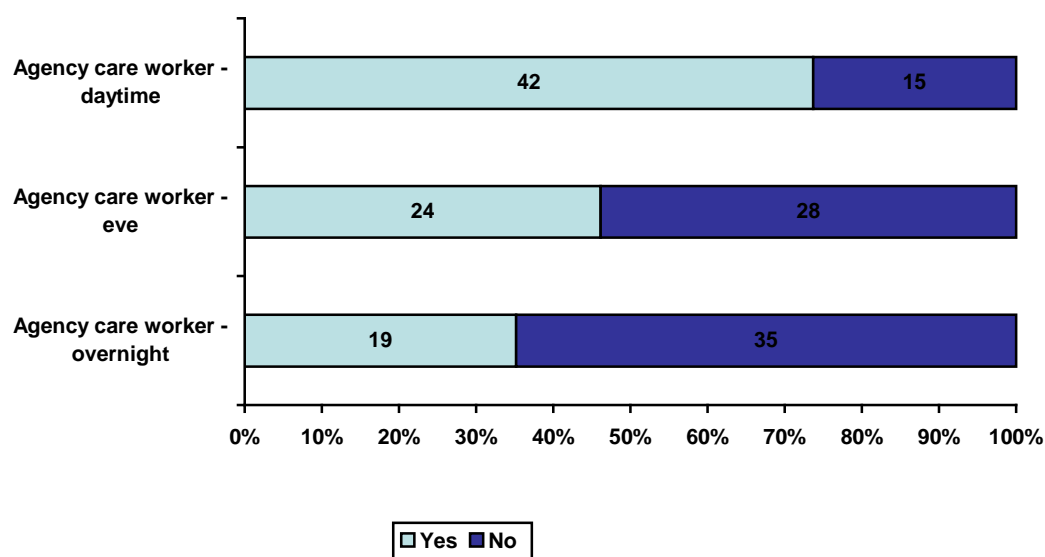
This option means getting a care worker who works for a home care agency to come to the cared for persons home and provide care, either regularly or on an occasional basis.

Carers were asked whether they would like to purchase the agency respite service during the day, with 74% saying they would like to and 26% that would not want respite via an agency during the day.

When asked whether they would like this option after 6pm in the evening, the majority (54%) said they would not like to purchase evening respite agency care, with 46% of carers saying that they would like this respite option.

Carers were also asked whether they would like to purchase occasional overnight respite, with 35% wanting this option, whilst 65% would not want an overnight respite service.

Figure 2.2: Whether the carer would purchase respite through an agency care worker and the times of day they would use this service



Base: All respondents (52, 54, 57)

2.3 Outreach Day Service option

A third option of an outreach day service in the cared for person's home was presented as follows:

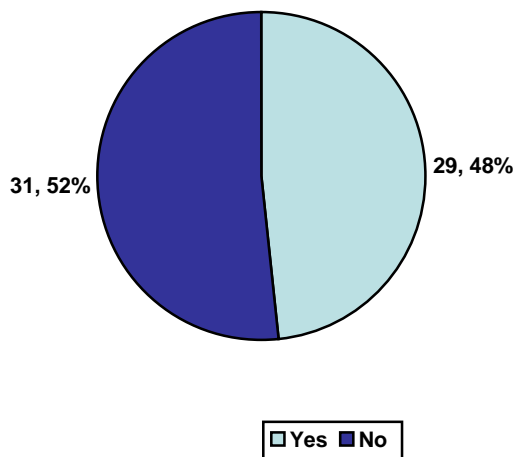
*This could be a **new** option to purchase. An outreach worker would come to the house of the person with dementia and assist them to continue their preferred activities both outside and inside the home. (Please note if you employ a Personal Assistant you will have this choice).*

Each activity would need to meet a specific outcome. Examples are given below:

| Activity | Outcome |
|--|-------------------------------------|
| <i>To go for a walk with</i> | <i>To stay fit and healthy</i> |
| <i>To accompany the person to go to the shops.</i> | <i>To have choice & control</i> |
| <i>To assist with maintaining friendships</i> | <i>To remain socially active</i> |

When asked whether they would be interested in an outreach day service, 48% of carers said that they would be, with 52% that were not interested in this option.

Figure 2.3: Whether interested in an outreach day service

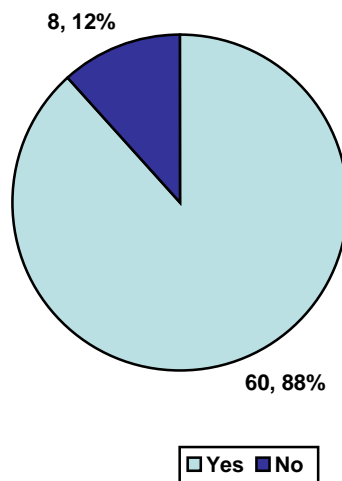


Base: All respondents (60)

2.4 Day Centre Provision option

There are already day centres set up within the borough for people with dementia and mental health problems. Most local day centres are open between 9am and 5pm. Carers were therefore asked whether they were happy with these opening hours, with 88% being happy with the current opening hours and 12% (or 8 carers) not being happy with these opening hours.

Figure 2.4: Whether happy with day centre opening hours



Base: All respondents (68)

Those that were not happy with the opening hours were asked some further questions about when they would like local day centres to open. Please bear in mind

that bases are particularly small when looking at these questions as the majority of carers were happy with current opening times, therefore it would be difficult to generalise these results to the views of other carers.

Carers were asked whether they would like local day centres to be open at an earlier time, with four carers saying they would like day centres to open at 8am and two carers said they would not like their day centres to open earlier. No carers wanted their day centre open at 7am.

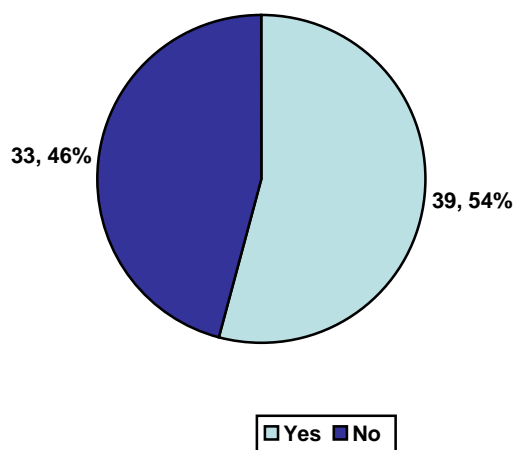
Of the eight carers that said they would like extended opening times for local day centres, all wanted day centres that were open later.

Of the eight carers wanting extended opening hours that meant day centres being open later, only 5 carers stated what evenings they would want day centres to be open between 5pm and 10pm. All five carers wanted evening opening on a Thursday, with only two carers wanting evening opening on a Saturday.

2.5 Residential and nursing respite option

All carers were asked if they would consider purchasing a residential or nursing home respite bed, with just over half (54%) saying that they would, whilst 46% would not consider this respite option.

Figure 2.5: Whether would consider purchasing a residential or nursing home respite bed



Base: All respondents (72)

When asked how many times per year carers envisaged using this service, responses differed, with 25% of carers saying they would envisage using overnight

respite once a year, 38% twice a year and 38% who would use it three or four times a year.

3 Respite preferences

Figure 3.1 below combines a number of questions asked throughout the questionnaire in order to look at which respite options were the most popular amongst carers.

The most popular option was to purchase care workers through an agency in the daytime, with 42 carers (74%) saying that they would use this service. The residential and nursing home respite bed option was also popular, with 39 carers (54%) that would consider this respite option.

On the whole carers seemed to think that the current opening hours of local day centres met their needs, with only 8 carers (12%) wanting extended opening hours. There was also less demand for having an agency care worker in overnight, with 19 carers (35%) wanting to use occasional overnight respite service.

Figure 3.1: Comparing demand for different respite service options

