End of Year Report
2014-15

Admiral Nursing Service
London Borough of Sutton

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Dementia affects the whole family so we support the whole family
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Introduction and Background

There are an estimated 850,000 people in the UK living with a diagnosis of dementia and 670,000 people acting as a primary carer for a loved one with dementia, although in actuality the latter figure is likely to be much higher as whole families share the care of a loved one, each acting as a carer and potentially needing support in their own right. To put this into a local context, the Dementia UK report (2007) estimated the prevalence of dementia in Sutton at 1.1% of the population, or an estimate of 2,102 people (based on the data of the 2011 census) although with rising rates of incidence of dementia this figure is likely to be higher.

The Admiral Nursing (AN) Service for the London Borough of Sutton (LBS) and Sutton Clinical Commissioning Group (CCG) was initially commissioned as part of the Sutton CCG transfer of re-ablement funds to LBS. These funds form part of the Better Care Fund (BCF) pooled budget arrangements with Sutton CCG. One band 7 Admiral Nurse was formally established as a permanent post within London Borough of Sutton Adults and Safeguarding Service in 2013 and was recruited to in January 2014.

A key goal of the Admiral Nursing Service was to enhance and complement existing services whilst avoiding duplication. With this in mind, commissioners engaged local stakeholders in service planning and development; agreeing where the Admiral Nurse would be best placed within the dementia pathway, establishing clear lines of communication, and fostering transparency and sharing of best practice. It has been important that the service has been able to be flexible and reactive, adapting as it developed to ensure it provided support to the right individuals and that it collaborated with existing services.

In January of 2014 a scoping exercise was undertaken by the Admiral Nurse (AN). This involved discussions with all stakeholders including families living with dementia. As a result of this exercise, and with the support of the Steering Group, an Operational Policy was developed and agreed by all partners and the service was opened to referrals in March 2014.

The existing evidence base for Admiral Nursing

Admiral Nursing has a strong evidence base for its efficacy in a range of different settings. An analysis of the caseload over one month (November 2013) in NHS Telford and Wrekin showed cost savings of over £17,000 in terms of savings on GP contacts and respite provision (Lee, T, et al, 2014). This evidence has been built upon by the most recent cost benefit analysis of the Norfolk Admiral Nursing Service which showed savings of over £440,000 over a 10 month period with a team of 3 Admiral Nurses (Aldridge and Findlay, 2014). These savings included delayed admissions to care homes, a reduction in hospital admissions (both acute and mental health), and a reduction in the referrals to psychological therapies. Additionally, surveys carried out as part of this evaluation showed 60% of GPs reporting a reduction in contact time as a result of the Admiral Nursing Service.
The current referral pathway and model of care

Admiral Nurses are qualified nurses with significant clinical experience of specialising in dementia care. Traditionally they have been qualified mental health nurses but more recently the role has been opened up to all qualified nurses if they have the required clinical skills and experience. They provide support to families affected by dementia by using a relationship centred model to provide care management, psychological interventions and educative approaches to help family carers and people with dementia to live well with the condition. Admiral Nurses work holistically with families, addressing the needs of the family carer as well as those of the person with dementia. Their aim is to empower family carers and encourage problem-solving approaches as well as providing psychological support to avoid crisis and breakdown.

Through their supportive, mentoring, education and advisory role, Admiral Nurses also raise awareness and increase understanding of dementia with professional colleagues. They offer supportive education to GPs, district nurses, health visitors, mental health teams, memory services, and staff in day care, domiciliary care, residential care and nursing homes. This allows the reach of the Admiral Nurses and their expertise to extend well beyond the families on their direct caseload.

The service in Sutton currently operates with the following referral criteria:

» Referrals are accepted from any professional within health, social services or the voluntary sector who is working with the family living with dementia. To make a referral to the Admiral Nursing Service the following criteria must be met:

• The person being cared for has a diagnosis (or likely diagnosis) of dementia

• The person with dementia is registered with a GP within Sutton CCG

• The carer is providing a significant level of care

• The carer agrees to their referral to the Admiral Nurse

» Additionally referrals must identify a need that impacts on the persons caring role or is a consequence of their caring role including at least one of the below:

• The presence of significant risk factors and complex needs, which affect the carer’s ability to look after the person with dementia and maintain a safe environment.

• Where the carer feels unable to cope or needs help in making choices or decisions about care and requires support either to continue caring or to come to terms in relinquishing their caring role.

• Where there is conflict between the carer and the person with dementia or conflict exists within the family, which affects the carer’s ability to care for the person with dementia.
Finally, the carer’s identified needs cannot be met by other local services. This is important, as a key component of the Admiral Nursing Service is complementing existing services within the dementia pathway, working alongside them and picking up cases when needs become more complex. Whenever possible, Admiral Nurses work collaboratively with other services, to ensure there is seamless care for families along the entire dementia journey.

A triage system is currently in place which ensures that only appropriate cases are accepted on to the Admiral Nurse caseload and that other support services are appropriately utilised. An illustration of the Admiral Nursing Casework model can be seen in Appendix 1.

**Demographic reporting and discussion**

![Referrals by month](image)

The above graph illustrates the volume of referrals by month for the first year. There were a relatively large number in March 14 which was the date that the service officially went ‘live’. This was mainly due to a high number of cases being ‘held’ by other services in anticipation of the Admiral Nursing Service becoming available. This demonstrates the need felt by other professionals for a service such as this. The dip in May-June 14 can be explained by the Admiral Nurse being on extended period of leave during those two months. During the last part of the year we can see a general upward trend in the volume of referrals as the service becomes more widely known. There is another sharp drop in March 14 which was when a waiting list had to be put into operation due to the high volume of referrals. A communication was sent to all potential referrers to advise of this which will have impacted on the numbers of referrals received.
Unsurprisingly the highest volume of referrals were from within social services which is where the AN service is also based. The working relationship with the Carers Centre is also highlighted in the above chart and the volume of referrals from them also includes carers and families who attended the clinic sessions that have been held there. The Older Peoples Community Mental Health Team (CMHT) also feature in the top three referrers. It is interesting to note that there were only 6 referrals during the first year from the Alzheimer’s Society. This indicates that they are successfully supporting the families at the ‘low symptom’ stage of their dementia journey but there may be potential for working together to identify when families may be starting to need that more intensive support and potentially reducing the number of referrals coming through at crisis point. This would be worth considering in the future development of the service.

There are notably few referrals from primary care and from Sutton and Merton Community Services (SMCS) who provide the intermediate care services locally. Hospital inpatient services have also referred less than expected. It is recognised that the service has not been able to promote itself fully across Sutton due to limited staffing resource and this is an area that will be improved upon in the next stage of the service. Some other notable exclusions from the above table include sheltered housing schemes, care homes and day centres who may all be aware of families who would benefit from the service but who may not be aware of how to access it.

Table 2 - Referrals sources

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The results are as would be expected for a service working with families living with dementia, with a higher proportion of people over the age of 55. There may be some scope for targeting younger carers locally who are currently under represented in the numbers and this will need to be considered in the future service plan.

The data on gender of referrals is also in line with national data which indicates that the majority of carers of people with dementia are female (Alzheimer’s Research Trust, 2015; Princess Royal Trust for Carers, 2011). However it may be helpful for the future development of the service to look at how well male carers are being supported compared to their female counterparts and if there are ways we can increase the uptake of the service by men.
The data from the number of referrals shows that 14.64% of carers referred to the Service were from BAME background. This is likely to be an underestimate as, because of the way ethnicity data was collected, the “White or White British” category also includes information from people who would have described themselves as White Other (White Europeans etc.). According to the 2011 Census, 27% of the entire adult population of Sutton is from an ethnic minority group; however if we consider the population of interest for the caseload (aged 45 +), the percentage from a BAME group lowers to 20% and if we further narrow it to those over the age of 65 the percentage drops to 16%, indicating a relatively young BAME community in the area. The Service has therefore quite likely reached the majority of the families from an ethnic minority background in need, however more work can be done to facilitate access to the service to the remainder of the population and plan for a likely increase in the uptake as the BAME population grows older.
These results are in line with the trend noticed earlier with regards to the gender distribution, as well as mirroring what we know internationally about carers being most often wives and daughters (Erol, R. et al, 2015). This is also reflected in the recent analysis of the callers to the Admiral Nursing DIRECT Helpline (Dementia UK, April 2015), as well as in larger studies (Newbronner, L. et al, 2013).

**Key Performance Indicators for the Service**

The original Service Specification for the LBS AN Service identified the following Key Performance Indicators (KPIs) with regards to the clinical work of the service.

### Patient and Carer outcomes

<table>
<thead>
<tr>
<th>KPI</th>
<th>%</th>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carers self report increased support in their caring role</td>
<td>100%</td>
<td>AC-QOL - administered at outset and at 3 monthly intervals.</td>
</tr>
<tr>
<td>Carers self report reduced levels of stress due to their caring role</td>
<td>75%</td>
<td>AC-QOL - administered at outset and at 3 monthly intervals.</td>
</tr>
<tr>
<td>Carers self report improved quality of life</td>
<td>75%</td>
<td>AC-QOL - administered at outset and at 3 monthly intervals.</td>
</tr>
</tbody>
</table>

### Economic outcomes

<table>
<thead>
<tr>
<th>KPI</th>
<th>%</th>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduction in non-elective admissions for families on Admiral Nurse caseload</td>
<td>15%</td>
<td>RUD; Retrospective risk analysis of caseload – quantification of delayed or avoided inappropriate admission to care or acute</td>
</tr>
</tbody>
</table>

### Innovation culture outcomes

<table>
<thead>
<tr>
<th>KPI</th>
<th>#</th>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>To hold a minimum of 4 workshops per annum, per locality for community staff</td>
<td>4</td>
<td>No. of workshops held during the year</td>
</tr>
</tbody>
</table>

Table 7 – KPI and Indicators

### Chosen tools and indicators

The **Adult Cares Quality of Life Scale (AC-QoL)** is a validated tool that was developed by the Princess Royal Trust for Carers, measuring quality of life across eight domains:

- Support for caring
- Caring Choice
- Caring Stress
- Money Matters
- Personal Growth
- Sense of Value
- Ability to Care
- Carer Satisfaction
The scale measures the Overall quality of life (QoL) of Adult Carers as Low, Mid and High, as well as giving the same indication for each subscale, allowing analysis of the different aspects that contribute to the overall experience of caring.

<table>
<thead>
<tr>
<th></th>
<th>Low</th>
<th>Mid</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall QoL Score</strong></td>
<td>0-40</td>
<td>41-80</td>
<td>81+</td>
</tr>
<tr>
<td><strong>Individual Sub-Scales score</strong></td>
<td>0-5</td>
<td>6-10</td>
<td>11+</td>
</tr>
</tbody>
</table>

Table 8 – AC-QoL Scores and Ratings

Throughout the evaluation period it has been administered to all carers who received casework intervention, and repeated on review or discharge to measure the effectiveness of the AN intervention. Three scores directly relate to the KPIs: Support for Caring (KPI 1); Caring Stress (KPI 2); and Overall Quality of Life (KPI 3).

In the results section we’ll first present this data; the additional information provided by the subscales will be presented in a subsequent section as although not directly related to the KPIs it provides a fuller picture of the caseload, as well as valuable information for future service development.

The **Resource Utilisation in Dementia (RUD)** scale was included in the evaluation plan. It is a validated tool often used in dementia research to measure to impact of an intervention on healthcare resource use. Data was collected using an adapted form of this tool for the first 6 months. At the 6 monthly reporting stage some difficulties were noted with this scale. Firstly it was sometimes difficult for carers to remember how often they had used certain services over the previous three months which called into question the accuracy of the data collected in some cases. The scale also produces a very bulky data set and with no extra resource for data analysis it was outside of the scope of the Admiral Nurse to properly analyse this. Additionally, while the scale was very good at highlighting those cases where a family were already high users of health care service and showing a subsequent reduction in use, it did not adequately capture those cases where a risk of healthcare resource use was identified but was avoided altogether. In light of the above difficulties an alternative evaluation method was sought.

The **Retrospective risk analysis of the caseload** was chosen in line with the Norfolk Evaluation model (Aldridge and Findlay, 2014), and involved carrying out a retrospective analysis of all the cases who had received the Admiral Nursing intervention during the first year. Referral forms and case notes were examined and it was recorded where there was an identified risk of admission to hospital, use of A&E or admission to care or nursing home at the point of referral. The cases were then tracked to see if this risk was avoided or delayed and for how long. Other outcomes were also recorded such as whether there was support to seek a diagnosis as a result of intervention and if a referral to IAPT was avoided. This methodology was chosen as it helped bringing to light not only reductions in uptake of other services, but also inappropriate admissions that had been altogether avoided for families that were not already service users. It was felt that this method was the best way of giving an estimate of the costs savings to the health and social care systems as a result of the Admiral Nursing Service.
Results

Patient and Carer Outcomes

The graphs below present the average scores at Assessment and Review for the Overall Quality of Life of carers, Support for Caring – Quality of Life and Caring Stress – Quality of Life.

The average Assessment score for the Overall QoL and Support for Caring – QoL sit within the ‘low’ range, with the Caring Stress - QoL just passing the ‘mid’ range mark. These low scores indicate that there are problems or difficulties.

The average Review scores are well within the ‘mid’ range for the Overall QoL and Caring Stress - QoL, and in the high range for Support for Caring - QoL, showing significant increases across the three fields (see table 10 below).

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Average value at assessment</th>
<th>Average value at end of Year 1</th>
<th>Change (in %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall QoL Score</td>
<td>38.2</td>
<td>56.4</td>
<td>+47.6%</td>
</tr>
<tr>
<td>Support for Caring</td>
<td>4.3</td>
<td>11.0</td>
<td>+155.2%</td>
</tr>
<tr>
<td>Caring Stress</td>
<td>5.7</td>
<td>9.4</td>
<td>+64%</td>
</tr>
</tbody>
</table>

Table 9 – AC-QoL scores at Assessment and Review (Overall QoL, Support for Caring and Caring Stress)

This indicates that the referral criteria have been successful and that those on the caseload are families with more complex needs.

This is further illustrated by the positive shifts that have occurred between Assessment time and Review time in the given ranges: whilst at Assessment stage most of the caseload’s scores fell in the ‘low’ and ‘mid’ range, the vast majority of the scores at Review stage sat within the ‘mid’ and ‘high’ range (see Table 11).
Table 11 – Shifts in percent of caseload in AC-QoL ratings between Assessment and Review

<table>
<thead>
<tr>
<th></th>
<th>Support for caring QoL rating</th>
<th>Caring stress QoL rating</th>
<th>Overall QoL rating</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>Mid</td>
<td>High</td>
</tr>
<tr>
<td>Assessment</td>
<td>69%</td>
<td>31%</td>
<td>0%</td>
</tr>
<tr>
<td>Review</td>
<td>3%</td>
<td>38%</td>
<td>59%</td>
</tr>
</tbody>
</table>

Table 12 shows the changes in percentage of the caseload between Assessment and Review in the three areas of the AC-QoL in exam.

<table>
<thead>
<tr>
<th>AC-QoL scores</th>
<th>Changes for the caseload between Assessment and Review</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Support for Caring Score</td>
</tr>
<tr>
<td>Increased QoL</td>
<td>Review score HIGHER than Assessment score</td>
</tr>
<tr>
<td>No change in QoL</td>
<td>Review score SAME AS Assessment score</td>
</tr>
<tr>
<td>Decreased QoL</td>
<td>Review score LOWER than Assessment score</td>
</tr>
</tbody>
</table>

The overwhelming majority reported increased support in their caring role (100%), reduced stress due to caring role (88%) and improved quality of life (100%).

This indicates that targets have been far exceeded and that carers reported a positive impact of the Admiral Nursing Service.

The biggest increase has been seen in the ‘Support for Caring’ subscale, with the average score on assessment indicating a low quality of life in this area, and the review/discharge score sitting just within the ‘high’ rating. This subscale looks at how supported the carer feels by professionals, how well their needs are taken into account and how much they feel they can get all the information and practical support they need. An increase in this subscale fits with the role of the AN and is a good indication that the service is fulfilling its aims.

The ‘Caring Stress’ subscale showed a more modest improvement in the average score, with a 64% increase. This indicates a positive improvement in areas such as feeling depressed, stressed and mentally/physically exhausted. It would be beneficial to have some qualitative data around carers’ experiences of this in order to explore and enhance our understanding of the interventions offered by the AN. It would also be interesting to look at the scores for each question in this subscale as it seems likely that the AN intervention would have made a bigger difference to the question around depression than perhaps the one around physical exhaustion and this will form a recommendation for further evaluation.
Economic Outcomes

The following table gives the estimated cost saving to Health and Social Care as a result of the Admiral Nursing Service.

<table>
<thead>
<tr>
<th>No. of families</th>
<th>Avoidances</th>
<th>Unit cost</th>
<th>Total saved (£)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care home admissions delayed/avoided (in weeks)</td>
<td>13</td>
<td>370</td>
<td>£455</td>
</tr>
<tr>
<td>Nursing home admissions delayed/avoided (in weeks)</td>
<td>8</td>
<td>181</td>
<td>£499</td>
</tr>
<tr>
<td><strong>Total (Social Care)</strong></td>
<td></td>
<td></td>
<td><strong>£258,669</strong></td>
</tr>
<tr>
<td>Acute general admission avoided</td>
<td>14</td>
<td>14</td>
<td>£2,658</td>
</tr>
<tr>
<td>A&amp;E attendances avoided</td>
<td>5</td>
<td>5</td>
<td>£117</td>
</tr>
<tr>
<td><strong>Total (Health Care)</strong></td>
<td></td>
<td></td>
<td><strong>£37,797</strong></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td><strong>£296,466</strong></td>
</tr>
</tbody>
</table>

Table 13 – Estimated cost savings

The estimates for social care are based on figures obtained from London Borough of Sutton for Elderly Mentally Infirm (EMI) residential placements (£455 pw) and for EMI Nursing Placements (£499 pw). These figures are a snapshot of the first 12 months of the service being operational and in cases where ongoing support from the Admiral Nurse continues to negate the need for a placement some of these costs savings will continue to rise.

The estimates for health care are based on figures obtained from Sutton Clinical Commissioning Group (CCG) for A&E attendances (£117 per attendance) and emergency hospital admissions (£2658 per admission).

This shows a significant cost saving to both the health and social care systems in Sutton as a result of the service.

<table>
<thead>
<tr>
<th>Additional information from Retrospective Risk Analysis</th>
<th>No. of carers or pwd</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support to seek diagnosis</td>
<td>6</td>
</tr>
<tr>
<td>Negated referral to IAPT</td>
<td>13</td>
</tr>
</tbody>
</table>

Table 14 - Additional information from Retrospective Risk Analysis of Caseload

The Retrospective Risk Analysis of the caseload also highlighted 6 cases in which the Service had supported the diagnosis process and 13 instances where a referral to IAPT for carers was avoided by supporting and improving their emotional and psychological wellbeing.
The reduction in the uptake of emergency services correlates with the results of the AC-QoL that show an increase in the overall QoL of the family carers on caseload, in particular in the areas of Support in Caring, Caring Stress and Ability to Care where the larger positive shifts were registered. This would suggest a lower need of unplanned and inappropriate placements or hospital admissions due to better support to families and better abilities to care for their loved ones, rather than a denial of access to services. Ongoing evaluation of the expanded service should look at including an external analysis of the cost savings of the service. There will also be potential for further increasing the savings to the health care system by working much more closely with primary care to identify cases where there is a high risk of inappropriate use of unplanned care and targeting these families for support.

**Innovation culture outcomes**

The service also has the remit of providing consultancy and training to other professionals across Sutton.

Due to the small resource of the team in the first year the KPI of providing 4 workshops within the year was reviewed so that a focus on clinical work and evaluation could be maintained, shifting to an informal approach. There is some evidence from case studies which indicates this has been successful, most notably in influencing the safeguarding process.

Now that funding has been secured for three more Band 6 Admiral Nurses we will be able to take this work forward, working more closely with primary care and providing formal training for other professionals. There has also been some work started around supporting the practice of colleagues within our sheltered housing schemes locally.

It will be important that this work is robustly evaluated to ascertain its effectiveness and plans for this evaluation are being made by the Steering Group in anticipation of the expanded service.
Additional information

Results of the additional sub-scales of the AC-QoL

Although not directly correlated to the Service’s KPIs, the remaining six sub-scales of the AC-QoL provide valuable information on the wellbeing of the carers that can help informing the future development of the Service.

In this section we present these results, alongside considerations for the refinement and improvement of the Service.

The table below shows the change, in percentage, across the additional subscales of the AC-QoL:

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Average score at Assessment</th>
<th>Average score at Review</th>
<th>Change (in %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability to Care</td>
<td>5.6</td>
<td>9.8</td>
<td>+74.3%</td>
</tr>
<tr>
<td>Caring Choice</td>
<td>6.4</td>
<td>9.9</td>
<td>+55.1%</td>
</tr>
<tr>
<td>Money Matters</td>
<td>7.4</td>
<td>8.1</td>
<td>+8.6%</td>
</tr>
<tr>
<td>Personal Growth</td>
<td>7.0</td>
<td>9.9</td>
<td>+41%</td>
</tr>
<tr>
<td>Sense of Value</td>
<td>7.9</td>
<td>9.9</td>
<td>+24.2%</td>
</tr>
<tr>
<td>Carer Satisfaction</td>
<td>7.6</td>
<td>9.69</td>
<td>+27%</td>
</tr>
</tbody>
</table>

Table 15 – Additional Sub-scales - Average scores at Assessment and Review, and changes in percentage

Changes in all AC-QoL Subscales (in %)

Table 16 – AC-QoL Subscales, changes in percentage
Positive change can be observed across the board, but in particular in two of the areas focus of the KPI section above (Support for caring and Caring Stress), as well as in the Ability to Care, indicating that the AN intervention has been effective in enhancing carers’ sense of competence.

The ‘Ability to Care’ subscale looks at the how well the carer feels able to look after the needs of the person they care for, how well they feel they can manage difficult situations and how competent they feel they are at caring.

This is one of the scales that it was hoped the AN would be able to make a positive difference in and this is reflected in the marked 74.3% increase in the average score. The Assessment and Review averages both sit within the ‘mid’ range, but moving from the very bottom of the range up to the top end at Review. It should be noted than any increase in this subscale, and in particular the questions around ability to manage difficult situations, is likely to have a positive impact on that families need to use unplanned and urgent care resources.

The ‘Caring Choice’ subscale showed a 55.1% average improvement – this scale looks at how much the person feels they have control over their own life and if they are able to choose ventures outside of caring.

The average Assessment score is in the ‘mid’ range but the average Review score, although reaching again the top end of the range, does not get above the ‘mid’ range scale. This would benefit from further evaluation and perhaps some qualitative data to explore people’s experiences of how their choices are limited by caring and how they can best be supported in this area.

The ‘Money Matters’ subscale showed the smallest increase, increasing by only 8.6%. The average score at both Assessment and Review here were in the ‘mid’ range. 69% of the people were in the ‘Mid’ and ‘High’ range at Assessment and mostly stayed there on Review.
It is not a great surprise that the AN intervention is not able to make a great deal of difference to how a family feels about their financial situation. We know that carers often face financial hardships as a direct result of their caring role and while support to apply for benefits may make a small difference it is always going to be difficult to make a big difference to a carer’s quality of life in this area.

The ‘Personal Growth’ subscale looks at how much the carer feels they have grown and developed and the positive experiences of their caring role. The average score on Assessment was already in the ‘mid’ range and after intervention there was an average 41% increase. Although a positive increase was seen in this subscale it was not as high as some of the other sub scales and this would merit further investigation in the form of qualitative data on experiences relating to this sub scale.

The ‘Sense of Value’ sub scale measures the extent to which the carer feels valued by the person they are caring for and how positive their relationship is. This scale showed an average 24.2% increase which confirms the role of the AN in supporting relationships within families. Average on Assessment is in the ‘mid’ range and stays in this range at Review. The average scores show a modest increase, however individual scores show at times a very marked improvement in the relationship between the carer and person with dementia (between 4 and 7 points increase). Whilst at Assessment 28% of the group had a ‘low’ score, only 16% did so at Review. At the same time, the percentage of the caseload that had a score in the ‘high’ range increased from 28% at Assessment to 41% at Review. A substantial part of the caseload (44%) did not show any change during the intervention time but they were consistently either in the ‘high’ range or mostly at the top end of the ‘mid’ range (10 points, with only 3 carers recording a score of 8 or below), showing that a good level of wellbeing was maintained. It is important to remember that every family living with dementia is facing a very unique set of circumstances and that improvements in some sub-scales will sometimes be harder to achieve than others.

The final subscale of ‘Carer Satisfaction’ looks how satisfied the person is with their life as a carer and their feelings about being a carer. This sub scale showed a 27% average increase as a result of AN intervention.
Both Assessment and Review averages were within the ‘mid’ range. This is another scale that would merit qualitative analysis into the future.

It is worth noting that while there has been an increase across all subscales none of the average scores, apart from ‘Support for Caring’, reach the level of ‘high’ range of quality of life. The dementia journey of family carers is influenced by the ever evolving nature of the condition, and we cannot possibly expect a continuous linear improvement. Dr Penny Hibberd, for example, describes the journey as a fluid 4-phase cycle (Figure 1). Family carers experience ‘Recognising’, ‘Transforming’, ‘Stabilising’ and ‘Moving On’ phases, in conjunction with the arising of transition points in the journey of the person they care for. New needs can bring otherwise stable families back to a ‘Recognising’ phase where more help is needed and Quality of Life might very likely drop. Providing the right level of support can help building resilience in family carers and helping them to transition back to a ‘Stabilising’ phase. It would be of interest to track this over a longer period of time to see if higher levels of quality of life could be achieved over a longer time frame.
Conclusions and recommendations for further evaluation

The results of the first year evaluation have been extremely positive and indicate that the service is bringing positive outcomes for the families it aims to support as well as saving the health and social care economy in Sutton money by avoiding inappropriate admissions to hospital and care/nursing homes.

The evaluation has highlighted some areas that would merit more in-depth investigation. In terms of the demographics we need to look at the experience of male cares and families from BAME backgrounds using the service and what the barriers to them accessing it might be and how we can overcome this. It would also be beneficial to examine the data to ascertain if the outcomes are any less favourable for different demographic groups.

While the AC-QoL scale has provided invaluable data in terms of how the service is improving quality of life for carers, it would add richness to this data if we also had some qualitative measures that could explore the experiences of carers and families of using the service. This would help us to understand why we are seeing the outcomes we are and if there are any areas where the experience could be improved.

The cost analysis gives a very favourable picture of the Admiral Nursing service in terms of money saved to the health and social care economy. This would benefit from ongoing evaluation as the service expands and from an independent evaluation in order to verify the findings from the first year. More qualitative measures would also help us ensure that the reasons for the costs savings are not due to families being denied access to services.

As the service expands the consultancy and training role of the Admiral Nurse will be fully realised and this element of the role will also need robust evaluation; this will need to be considered by the Steering Group in the ongoing service development plans. It will be important to obtain the views of professionals who work alongside the service to evaluate the difference it has made in their practice areas.

A notable gap in the evaluation is around the clinic sessions carried out in partnership with the Carers Centre. It will be important to know whether this service is providing favourable outcomes, particularly as we look to increasing the number of these sessions and offering them within primary care settings.

While no formal qualitative data has been collected from carers or professionals, the service has received feedback from both which has been overwhelmingly positive. The results of this evaluation are backed up by other evaluations of Admiral Nursing nationally and make a valuable contribution to the overall evidence base. Sutton is now in an excellent position to continue to build on the success of the first year of the service with the establishment of three more posts. It is hoped that with the recommendations from this report we can further build on the evidence base and that this can be used to inform service delivery locally but also influence commissioning decisions nationally. Dementia will continue to present a huge challenge to health and social care services and Admiral Nursing offers a positive solution for both families living with dementia and commissioners.
Case Studies

Adele and John* – a brief educational intervention

Adele was referred to the Admiral Nursing Service by social services following concerns about aggression from her husband, John, and him walking and becoming lost which she was struggling to manage.

John was under the care of the OPCMHT who were monitoring the dementia and medications but his unwillingness to engage made it difficult for them to offer any additional support. The need to help Adele understand and develop practical skills for managing risky behaviours would have been outside the scope of other local services, therefore the referral was accepted for Admiral Nurse support.

I was not able to meet with John due to his reluctance to accept his diagnosis or engage with professionals therefore meetings were arranged away from the home. Assessment identified that Adele was struggling to find information on the rarer type of dementia that John had been diagnosed with. Adele was an intelligent and logical lady and wanted a greater understanding of the disease and its effects, she told me she felt other professionals had shied away from telling her what the future might hold. Therefore an educational intervention using apps on the iPad to explain the structure of the brain and the effect the disease was having was utilised. This helped Adele to understand why her husband behaved in certain ways which made it easier for her to support him.

Again, this needed to be backed up with robust emotional support; hearing about what might happen in the future is frightening and upsetting although it was important for Adele to have this information. Practical skills building in managing difficult behaviours was used as well as information on assistive technology that might be of help. Links were also made with support groups specific to John’s type of dementia. Although quite early on in the dementia journey and not currently requiring any formal care support, discussions were had about when this might be needed and how Adele would access this in the future. Although John was not willing to engage in learning about his dementia and accepting it, Adele felt better armed to encourage conversations with him and help him to plan for the future.

This intervention was carried out over just 3 sessions spread across three months and resulted in an increase in carer quality of life. Resource utilisation was not effected as neither John or Adele had accessed primary care services prior to or during the intervention period however the work in building skills and networks for Adele is likely to decrease resource utilisation in the future.

*All names in the case studies have been changed to protect the privacy of individuals.
Mark and Claire* – Supporting relationships

Mark was caring for his daughter Claire who had a diagnosis of Down’s Syndrome and dementia. A referral was made by the Clinical Learning Disability Team as he was struggling to manage his caring role as the dementia was starting to progress.

A comprehensive assessment identified that Mark was struggling to cope with the advancing dementia, both emotionally and in terms of adapting his communication and ways of responding. Claire was still accessing support services specific to her Down’s Syndrome and this coupled with Mark’s unwillingness to accept the dementia has meant he had not engaged with support from the Alzheimer’s Society. He also worried that he would have not be able to relate to others there being a father caring for his daughter.

Intervention centred around helping Mark to learn new communication styles and ways of interacting that do not focus on ‘achieving’ something as a result. This was particularly hard for Mark as he had spent so many years trying to increase Claire’s skills and independence. This work involved sessions with Mark alone but also with him and Claire together. This practical support and advice had to be backed up by robust emotional support in order for it to be effective, helping Mark to explore and manage his own feelings around the diagnosis. Support was also given in managing low mood and anxiety.

Additionally this case involved providing advice on continence issues, linking in with district nurses and OT, support around mental capacity and best interest regarding a potential hip operation for Claire, and helping Mark support and share his new skills with his wife who did not want to engage with the Admiral Nurse directly.

After a few months of intensive intervention (fortnightly visits) Mark is now being seen 3 monthly with a view to reducing this further if things continue to go well. Mark’s self reported quality of life has increased dramatically and his relationship with Claire has improved. Mark is confident in knowing where he can go for support if things change and that he can link back in with the Admiral Nursing Service if and when he needs in the future.
A referral was received from the Alzheimer’s Society for Kelly who was supporting her father who has a diagnosis of vascular dementia.

Kelly had left her own family home to live with her father and care for him full time. She was struggling to manage her father’s agitation and was reported to be at high risk of carer breakdown. Other local services didn’t have the resources to provide practical and emotional support tailored to the level of complexity and so Kelly was referred to the Admiral Nursing Service.

On the first contact, Kelly was experiencing high levels of distress associated with her father’s agitation and her perceived inability to manage this positively. She expressed feeling unable to continue with things as they were. Initial assessment involved exploring with Kelly the possible reasons for the increased agitation and arranging for a GP review to rule out infection, as well as looking at pain management. Once this was excluded, sessions were undertaken to help Kelly explore what was happening for both her and her father during these periods of agitation, identifying triggering factors and helping her develop strategies for avoiding and managing these triggers. Additional needs around OT assessment, advice on benefits and finances and review of current care package were identified and onward referrals were made as needed. Support was given in helping Kelly explore with her wider family opportunities for her to take a break from her caring role and advice was given on managing stress and anxiety. Information was also given on support groups for Kelly, to give her an outlet for managing the stress associated with caring.

This was another relatively short term intervention which resulted in increased self reported quality of life for Kelly, allowed her to continue in her caring role and to feel more positive about it and her relationship with her father. The Admiral Nurse is no longer making regular visits but Kelly can connect back in with the service as and when things change and further support might be needed.
Michael and Larry* – Support with Safeguarding

Michael had a diagnosis of vascular dementia. He was living at home with his son Larry who was his main carer. Father and son have lived together for a number of years, preceding the diagnosis of dementia and had a close, but at times fiery relationship.

Following the diagnosis there had been little in the way of follow up and monitoring and it was some years later that the family drew the attention of services, when Michael was admitted to hospital with a fracture and bruising. The nurses of the ward suspected abuse by his son Larry and instigated the safeguarding process. A decision was made for Michael to move from the hospital to a respite placement while the investigation was ongoing. All professionals involved felt that long term placement would be the outcome of this. Larry was distressed by the allegations and at being separated from his father and so a referral was made to the AN service.

It became apparent quite quickly that neither father nor son wanted to be living apart from one another. Michael, whilst having difficulties with mobility, was still a very strong man. He was also very strong willed despite his cognitive impairment. Michael told us that he and Larry argued, this was how their relationship had always been, but Michael did not feel there had been any physical abuse and he was keen to get back home.

During the AN assessment with Larry it became clear that the injuries Michael had suffered were a direct result of improper manual handling practice. None of this was done with any malice, Larry had simply never had any training or support in how to support his dad properly as his mobility declined.

As a result of the AN assessment, support from an Occupational Therapist was sought to put in the right equipment and give sessions to Larry on proper manual handling so that he felt confident in supporting his dad without causing him harm. The assessment also identified needs around understanding dementia and education was provided, as well as support in developing communication skills and dealing with some of the symptoms and behaviours Michael was experiencing as a result of the dementia. There was also a need for some ongoing support around Larry’s own mental health and wellbeing, helping him come to terms with the dementia and start to think about the future. The AN was also able to help him to gain some trust in the professionals who he felt had ‘accused’ him of ‘abuse’.

Backed up by the robust AN assessment, the AN was also able to have conversations with social work colleagues to help shape the safeguarding process into something that was more about supporting the family rather than a punitive process. The intervention was able to successfully avoid an inappropriate nursing home admission and mitigate the risk of further acute hospital admissions.
Appendix

Admiral Nurse Casework Model

- Triage Zone
  - Triage Assessment
  - Discharge

- Casework Zone
  - Holding
  - Intensive Intervention
  - Maintaining
  - Review
    - Maximum 3 months after Triage Assessment and 6 months after last review
    - Discharge

- Discharge Zone
  - Discharge

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