Admiral Nurses – providing the specialist dementia support families need on the Isle of Wight

Isle of Wight Admiral Nurse service
Annual evaluation report 2016-17
Message from the Isle of Wight Admiral Nurse team

We are pleased to share our evaluation report for 2016-17 which we have written with support from Anne-Marie Love and the Service Evaluation team at Dementia UK. This was the first year of our Admiral Nurse service on the Isle of Wight.

During the year we have worked to provide the specialist dementia support that families need – through psychological support, expert advice and information to help families understand and cope with their thoughts, feelings and behaviour and to adapt to the changing situation of living with dementia. We have used a range of interventions to help people live positively, develop skills to improve communication and maintain family relationships. We have also been working with others in the health and social care system so that the needs of families are addressed in a coordinated way.

In our first year...

- We supported 290 carers and 281 people with dementia
- 89% of carers said they would recommend our service
- 96% of carers told us that our service helped provide them with ways of responding to and coping with changes in the behaviour of the person with dementia
- 92% of those living with dementia had one or more co-morbidity
- In 28% of cases we are working with multiple family members
- Stakeholders we spoke to told us that our service is having an impact on delaying and reducing the need for care and support from other services

In this report we celebrate the highlights of this year working to improve the lives of families affected by dementia and we look forward to using the evidence we have collected to develop our service in the coming year. Thanks to everyone who has worked with us to make our achievements, in this first year, possible.

Carol, Jasmine, Lindsay, Hannah & Pauline (Admiral Nurse Team)
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Introduction
Helping families face dementia

Admiral Nurses provide the specialist dementia support that families need.

When things get challenging or difficult, Admiral Nurses work alongside people with dementia, their families and carers: giving the one-to-one support, expert guidance and practical solutions people need, and that can be hard to find elsewhere.

Admiral Nurses are continually trained, developed and supported by Dementia UK. Families that have their support have someone truly expert and caring by their side - helping them to live more positively with dementia in the present, and to face the challenges of tomorrow with more confidence and less fear.

Admiral Nurses intervene quickly– averting avoidable and costly crises, and ultimately reducing hospital admissions and early residential care.
Dementia in the UK

850,000 people living with dementia in the UK
Source: DoH, 2017

62% of people with dementia are women and 38% are men
Source: DoH, 2016

670,000 carers of people with dementia in the UK
Source: Alzheimer’s Society, 2013

Dementia is estimated to cost £26.3 billion per year
Source: Alzheimer’s Society, 2014

Set to rise to 1 million people by 2025
Source: DoH, 2017

40,000 are under 65
Source: DoH, 2017

Dementia on the Isle of Wight

• The proportion of all island residents diagnosed with dementia (1.4%) is the highest in England, and double the England average (JSNA Dementia, March 2016).

• There are an estimated 2,494 people aged 65+ living with dementia on the island, of which 1,804 have a diagnosis of dementia (Quality Outcomes Framework Recorded Dementia Diagnoses, June 2017).

• 139,395 people live on the Isle of Wight and over one in four (26.6%) of the population is over 65. Over the next 10 years, the number of 65-79 year olds will increase by nearly 17%, while the over-85s will increase by 40% (JSNA Demographics and Population, June 2017).

• 92% of people living with dementia on the island have one or more chronic long-term condition and 46% have 10 or more chronic long-term conditions, highlighting the complexity of caring for people with dementia and the need to consider their full range of physical and mental health needs (Adjusted Clinical Group Tool, 2016).

• 40,000 are under 65
Source: DoH, 2017

Carers

• There’s a growing number of family carers – it’s estimated that one in three people will care for someone with dementia in their lifetime. Around 540,000 people care for someone with dementia in England. Half of them are employed, 66,000 have cut their hours to care for a family member and 50,000 have left work altogether (NHS England, 2017).

• Caring for someone with dementia can have many impacts on family life, including:
  – changes to relationships
  – poorer physical and mental health
  – social isolation for carers
  – financial burden

(Alzheimer’s Research, 2015).

• The Alzheimer’s Society estimates that the contribution of unpaid carers of people with dementia in the UK totals £11.6 billion per annum (Alzheimer’s Society, 2014).
What is Admiral Nursing?

Admiral Nurses are registered nurses who have specialist knowledge of dementia care

They provide support to families living with dementia

They provide education, leadership, development and support to other colleagues and service providers

We asked our Admiral Nurses to map how they work across the NHS Well Pathway for Dementia to provide expert clinical, practical and emotional support for families. This is what they told us:

Preventing Well
- Raising awareness
- Reducing stigma
- Health promotion
- Health checks
- Disseminating information
- Care education
- Community engagement
- Preventative management of risks to health, e.g. falls, delirium, poor nutrition, reduced mobility, incontinence, polypharmacy and depression

Diagnosing Well
- Peri-Diagnosis support
- Education others about varying an atypical symptoms of dementia to improve early identification
- Specialist navigation of services
- Encouraging timely assessment
- Identifying barriers to seeking diagnosis

Supporting Well
- Specialist holistic bio-psycho-social assessment
- Psycho-social interventions
- Family focussed interventions
- Managing and identifying co-morbidities and complex needs
- Person-centered care planning
- Developing coping strategies
- Non-pharmacological management of behavioural and psychological symptoms of dementia

Living Well
- Positive risk taking
- Managing transition
- Advanced care planning
- Building resilience in families
- Symptom management
- Crisis prevention
- Relationship support
- Promoting independence
- Managing grief, loss and bereavement
- Enabling access to life outside caring
- Promoting/enabling inclusion and participation

Dying Well
- Difficult conversations
- Identifying end of life and access to preferred place of care
- Recognition of dying phase
- Emotional support and pre and post bereavement counselling for families
- Guidance on use of prognostic indicators
- Symptom identification e.g. pain

Admiral Nurse activities supporting people with dementia and their families throughout the pathway

Case management and care co-ordination, advanced care planning, integration and partnership working, specialist support and advice for professionals, education and training, influencing policy and strategy continuity and communication, research and evaluation, promoting best practice, navigation of health and social care system, advocacy, counselling, reducing stigma.

The Admiral Nurse service on the Isle of Wight

Our team of Admiral Nurses covers the whole of the island and assists, supports and empowers people living with dementia and their carers with complex care needs, enhancing their skills, capabilities, emotional resilience and ability to cope. We work with the whole family – involving professional carers (where appropriate) – in order to deliver holistic, person-centred care, from post-diagnosis to bereavement.

Our care and support is available to people with dementia who:

- are cared for by family members within the family home,
- live alone,
- live in a care home setting.

Our team consists of four band 6 Admiral Nurses (3.4 whole time equivalents (WTE)) and a part time administrator. During 2016-17 there have been three WTE Admiral Nurses in post for the majority of time due to staff illness. We work within the island’s Integrated Locality Services, managed by the Memory Service, Isle of Wight NHS Trust. Our team sits within the Memory Service multidisciplinary team (MDT) where we work alongside community psychiatric nurses, occupational therapists, social workers and consultants. We also work with a small number of paid carers, residential care home staff and the Admiral Nurse within the Earl Mountbatten Hospice.

We work in partnership with the Admiral Nurse at Earl Mountbatten Hospice on the island to:

- run a support group for people with dementia and their carers, offering them the chance to engage in meaningful activity and harness the benefits of reminiscence therapy, cognitive stimulation therapy and life story work.
- run a support group for carers so carers can access peer support.*

*NICE guidelines recommend that carers have access to peer support opportunities.
Our referral pathway

We accept referrals from GPs, Memory Service colleagues, social services, third sector organisations and other health and social care professionals. Families discharged from our service can self-refer back into the service if their needs change. (Figure 1)

The person with dementia must have a formal diagnosis, be an island resident and be registered with a GP on the Isle of Wight, while their carer must be struggling to cope with the complex, challenging needs and/or behaviours of the person they care for.

Referrals come through to the Memory Service to our Admiral Nurse administrator, who allocates the referral to one of the four Admiral Nurses on a locality basis. Referrals are then triaged by the Admiral Nurse in order to identify families with complex levels of need who will be added to their caseload.

Families whose needs may be better met by other services are helped to access the most appropriate support as part of the triage process. This includes referring on to the Admiral Nurse based within Earl Mountbatten Hospice, who specialises in end of life care for a person with dementia and their family.

Fig.1 - Referral sources
Our service is an integral part of the local dementia pathway on the Isle of Wight and we provide specialist clinical, practical and emotional support for families across the domains of the national Well Pathway for Dementia:

**Preventing well**
We offer support and education to family carers on preventative management of risks to health.

**Diagnosing well**
We educate others about varying and atypical symptoms of dementia to improve early identification and enhance carer understanding of diagnosis, symptoms, behaviours, treatments and approaches to care.

**Supporting well**
We conduct specialist, holistic bio-psychosocial assessments with the person with dementia and the carer, as a foundation for delivering person-centred interventions.

**Living well**
We support with transitions and adjustment to changes in the caring relationship, building resilience in families.

**Dying well**
We address difficult conversations around advance care planning, and work with the hospice-based Admiral Nurse to offer support at end of life.

Our service aims to support families in dealing with the complexities of caring for someone with dementia, reducing the risk of crises and enabling the person with dementia to be cared for in their own home for as long as possible, where this is the preferred place of care.
A day in the life of an Admiral Nurse on the Isle of Wight

8am-9.30am – Admin, email and telephone (referrals, queries, requests)

My day typically starts with checking new referrals, responding to emails, updating my online diary and reading up on any out of hours correspondence. I will also catch up on any note writing from the day before and send emails or make phone calls resulting from visits I had yesterday. Today that includes making a referral to social services and updating an occupational therapy colleague from the Memory Service on a referral I am completing to their service.

Finally, I prepare myself for the day ahead by reading over my notes about the families I am seeing today and gathering the relevant information to take on my visits. By 9.30am I am usually on route to my first visit. Travel time can range from 15 to 40 minutes across my locality.

10am-12.30pm – Home visits: (our team usually allocates about an hour for follow up visits and two hours for a new assessment)

10am-11am

10am is my first visit of the day. I am visiting Mrs B who cares for her mother who has advanced Alzheimer’s disease. Mrs B has been receiving Admiral Nurse support for the past 18 months; she has found the journey of dementia with her mother to be very stressful, particularly around issues of poor dietary intake (leading to nutritional deficiencies and increased risk of falls), resistance to care and verbal hostility. Mrs B has, as a result, been experiencing feelings of low mood, anxiety, frustration, isolation and despair.

I spend an hour with Mrs B listening to the events of the past week in her caring role and providing emotional support and advice where required. This support includes validating her feelings and emotions around the changing presentation of her mother and supporting her with the change in relationship and roles they are both adjusting to. I suggest that she may benefit from meeting others who are caring for someone with dementia and provide Mrs B with the details of the Admiral Nurse carers group, which focuses on peer support and is facilitated jointly by the Admirals Nurse team and a voluntary sector carers organisation.

11am-11.20am

I am on route to my next appointment. Travel takes about 20 minutes.
11.20am-12.20pm
I spend another hour at this visit with a gentleman, Mr D, who has been receiving Admiral Nurse support for a year. He cares for his wife who has young onset Alzheimer’s with symptoms of psychosis. His wife’s Alzheimer’s has deteriorated very quickly and she now requires round the clock supervision and care. Mr D has found the progression of the illness to be hugely emotional and has suffered feelings of profound grief and loss over their marriage but is passionate about keeping his wife at home for as long as possible.

I spend the hour discussing emotional coping skills for him to utilise and behaviour management strategies for when his wife becomes confused, agitated and frightened, which can be frequently. We also discuss the possibility of accessing the bereavement support service provided by the psychologist at the local hospice for the ongoing grief he is experiencing. He agrees to consider this and we agree to review this at our next planned visit.

12.20pm-1pm
I find somewhere to stop for a quick lunch before heading back to the office.

1pm-2.30pm – Admin, emails and telephone
After lunch I return to the office and check my emails again, write up notes from the morning visits and make some follow-up phone calls. There are two referrals waiting for me, one of which is urgent. After triage, I respond to the urgent referral by contacting the carer by telephone and following discussion arrange an appointment to visit them. I also email our administrator to send an appointment letter to the family in respect of the other referral.

While I am at my desk the occupational therapist I made a referral to this morning comes over to ask about the family the referral relates to “I thought I’d catch you while you were here rather than send an email.” We spend 10 minutes discussing the case before I have to leave for my next appointment.
2.30pm-4pm – Home visits

2.30pm
I am back on the road to my final appointment of the day. It takes approximately 15 minutes to drive from the office to the appointment location.

2.45pm
The lady I am seeing this afternoon, Mrs G, supports her 50-year-old brother, Mr C, who lives in residential care; he has moderate Alzheimer’s and a moderate learning disability. He has not settled well into residential care and the home has been struggling to manage his frequent displays of physical hostility, high anxiety and risk of absconding. Mrs G really wants her brother to remain in the residential home because they have got to know him, he is familiar with the local area and it is very nearby to where she lives so she can see him regularly.

Mrs G and I meet at the residential home and initially spend 20 minutes talking with her brother about how he is feeling and assessing his overall well-being. We then spend approximately 30 minutes talking with senior care staff about Mr C’s behaviours, his medication regime and activity/occupational therapy timetable. We all agree that increased structure to the day and purposeful activity via one-to-one support from a local Specialist Learning Disability Outreach Service may help to alleviate some of Mr C’s stress, anxiety and low mood during this transition stage into residential care and on an ongoing basis; this will be organised via the local authority.

4pm-4.30pm
After leaving the residential home I make some notes to enable me to record my visit the following day. I phone the office to say I have finished for the day and make my way home.
Developing our evaluation skills and capacity
Getting Evidence into Admiral Nursing Services

Our Admiral Nurse team on the Isle of Wight is one of seven Admiral Nurse teams taking part in Dementia UK’s Getting Evidence into Admiral Nursing Services (GEANS) programme. GEANS aims were to build our skills and capacity to evaluate our service, and integrate data collection and service improvement into our daily work.

A co-produced evaluation framework was developed to identify the activities of Admiral Nurses and define outcomes for our work with families and supporting best practice for other professionals.

These outcomes reflect the domains of the NHS Outcomes Framework (NHSOF) for England and the Adult Social Care Outcomes Framework (ASCOF) to match key commissioning priorities for Clinical Commissioning Groups (CCGs) and local authorities. Therefore, we concentrated our data collection efforts to produce evidence on three key themes:

- improved quality of life for carers and people with dementia.
- positive experience of Admiral Nursing.
- delaying and reducing the need for care and support.

This report presents an overall picture of our service activity to date, its emerging impact and recommendations for developing the service.

GEANS Evaluation Framework

**Inputs**
- Cost of commissioning or delivering the service, e.g.
  - Nurse salary and on costs
  - Travel /mileage
  - Admin support
  - Facilities and equipment
- Patient and carer input
  - Travel costs
  - Time spent receiving care
  - Time invested in patient involvement activities
- Nurse skills
  - Qualifications
  - Competencies and experience
- Nurse network
  - Access to wider multi disciplinary team
  - Relationships with local voluntary sector

**Activities**
- What nurses do
  - Support best practice
  - Work with families
- How they do it
  - Practices
  - Behaviours
  - Processes
- Who they do it to
  - Caseload
  - Casemix

**Outputs**
- Countable episodes of supporting best practice
- Countable episodes of work with families

**Outcomes**
- Improved quality of life for carers and people with dementia
- Positive experience of Admiral Nursing
- Delaying and reducing the need for care and support
Evaluation objectives of Admiral Nurse service

The main objectives of the evaluation were to:

- describe the Admiral Nurse service on the Isle of Wight
- use the agreed evaluation framework to identify our activities and define outputs and outcomes
- report performance against key outputs and outcomes for our service
- develop our capacity and skills to undertake service evaluation and improvement activities.

Methodology

A mixed-method evaluation design (collecting quantitative and qualitative data) comprising the following key data collection methods was used:

- **Recording information on our caseload and activity in a comprehensive database**
  - We recorded our caseload and activity data on WANDA (database).
  - We monitored our performance each month against KPIs.

- **Case studies**
  - We wrote three case studies.

- **Postal/online carer survey**
  - 75 of our carers completed our carer survey.

- **Stakeholder feedback**
  - Four professional stakeholders and one member of our steering group took part in a telephone interview.

The methodology ensured that all Admiral Nurses in our team were actively involved in the evaluation process.

GEANS objectives 2016/17

1. To evaluate seven newly established Admiral Nurse services over one year (May 2016 – May 2017) in terms of the activities they undertake, the caseload they serve, indicators of process quality, carer experience, professional experience and outcomes for people with dementia and their carers.

2. To build into the teams the evaluation skills and mindset needed for service judgement and improvement and to identify the organisational skills and resources required to undertake service evaluation.

3. To support each team in creating individual evaluation reports on service performance and recommendations for improvement.

4. To aggregate the results from all the teams into an overall report on the value of Admiral Nursing to be published by Dementia UK in Autumn 2017.

5. To develop and pilot tools for data collection (such as carer survey, quality of life indicator, activity dashboard) that can:
   - Be made available to the wider Admiral Nursing community.
   - Generate robust outcomes data on quality of life and evidence of Admiral Nursing’s impact on the health economy.

6. Provide evidence of useful measures that could be integrated into the DementiaUK database, Compass.

7. To inform and describe the Admiral Nursing service model.

8. Develop the support mechanisms needed for teams to continue to evaluate and improve their services beyond GEANS.

These objectives were developed in collaboration with senior Admiral Nurses, senior staff from Dementia UK, experienced evaluation consultants, Dementia UK’s Expert Reference Group on research and evaluation and the GEANS advisory group. The nurses had access to the Service Evaluation team at Dementia UK throughout the year through training, site visits, workshop sessions and had support from the team with data collection, analysis and report writing.

Further information on the methodology and the GEANS project is available on request from: evaluation@dementiauk.org.
Describing our activity in 2016-17

In this section we describe:
• the number of families on our caseload
• the families we work with
• referrals to our service
• our work with families and other professionals
• supporting best practice
The number of families on our caseload

During 2016-17 we worked with 290 carers and 281 people with dementia – in approximately 28% of cases we have been working with multiple family members in addition to the main carer.

Our active caseload in June 2017 consisted of 119 families (figure 2).

Fig. 2 – Families worked with by Month

Between April 2016 and June 2017 there were 242 discharges: 184 where our work with the family was complete; nine were inappropriate referrals, and 49 were because the family declined the referral to our service.

Fig. 3 – Discharges by month

Managing our caseload

Our service utilises the Admiral Nurse casework management model – which has three casework zones: holding, maintaining and intensive.

After referral, initial triage is used to identify families with high or complex needs who require intensive support. We prioritise these referrals over those with lower levels of need, who are placed within a maintaining or holding caseload. As part of this model, Admiral Nurses use expert clinical judgement to determine when a family is discharged from the service.

Our average caseload per WTE Admiral Nurse grew from nine in April 2016 to 40 in June 2017. However, between January and April 2017 our average caseload per month was in excess of 60 cases – peaking at 67 in February.

We therefore decided to undertake a review of the families in the ‘holding’ part of our caseload in May 2017. As a team we used our clinical judgement to determine whether some families could be discharged from the service (with an understanding that they would be able to self-refer back if their needs became more complex).

As a result of this exercise, our average caseload for each Admiral Nurse reduced to 40 families in June 2017, with a total of ten families in a ‘holding’ caseload (compared to 56 in April 2016).

Description of discharges

Inappropriate – Referrals sometimes come through where following initial contact with the carer it emerges that they require referral to another service.

Completed – Our work with the family has been completed and they no longer require the support of the Admiral Nurse (they can self-refer back in the future, should the need arise).

Declined – Sometimes a referral comes through and when contact is made with the carer their situation has changed and they feel they no longer require the support of the Admiral Nurses. Examples of this can be when their loved one has been admitted to a residential home, or their care support has increased thus reducing their level of stress.
The families we work with

Most of the carers we have been working with are:
• female (76%)
• aged 55-84 years old (74%)
• the wife, husband or partner of the person with dementia (60%).

The person they are caring for are:
• slightly more likely to be male (53%)
• most likely to be aged 75 and over (81%)

Fourteen of those being cared for have early onset dementia (aged under 65 at time of diagnosis).

Fig. 4 - Gender and age of carer and person with dementia (numbers)

Fig. 5 - Relationship to person with dementia
Ethnicity was recorded for 97% of carers and 98% of those with dementia. All but one carer and one person with dementia identified themselves as White (545 as White-British, four as White-European, three as White-Irish and two as White-other).

Nearly all of those with dementia have one or more co-morbidity recorded (92%). This information is not recorded for our carers but we did ask carers taking part in our carer survey whether they had any of the health conditions in figure 6 – 29% of carers responding to our survey said they had a long-standing illness and/or sight or hearing loss.

**Fig. 6 - Carers health conditions (numbers)**

- A mental health problem or illness: 6
- Other: 10
- A recently diagnosed illness: 10
- None of the above: 13
- A physical impairment or disability: 14
- A long-standing illness: 19
- Sight or hearing loss: 19
Referrals to our service

Since April 2016 there have been 353 referrals to our service (328 were new referrals and 25 were re-referrals).

The average number of referrals per month was 24.

Referrals came from a range of sources (see figure 7) – most came from the Memory Service (146) and GP practices (109).

**The most common primary reasons for referral to our service were:**
- presence of carer stress/anxiety and/or depression.
- carer and/or person with dementia having difficulty adjusting to diagnosis of dementia.
- need for support with developing skills to care for person with dementia.

**The most common secondary reasons for referral were:**
- need for support with developing skills to care for person with dementia (n=147).
- need for information (about dementia/services/benefits etc) (n=119).
- presence of carer stress/anxiety and/or depression (n=77).
- carer/family need support with managing risk (n=58).

<table>
<thead>
<tr>
<th>Primary reason for referral</th>
<th>No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presence of carer stress/anxiety and/or depression</td>
<td>69</td>
</tr>
<tr>
<td>Carer and/or person with dementia having difficulty in adjusting to diagnosis of dementia</td>
<td>68</td>
</tr>
<tr>
<td>Need for support with developing skills to care for person with dementia</td>
<td>67</td>
</tr>
<tr>
<td>High levels of distress/change in presentation of the person with dementia</td>
<td>57</td>
</tr>
<tr>
<td>Carer neglecting or unable to address their own needs</td>
<td>19</td>
</tr>
<tr>
<td>Need for information (about dementia/services/benefits etc)</td>
<td>6</td>
</tr>
<tr>
<td>Carer neglecting or unable to address person with dementia's needs</td>
<td>1</td>
</tr>
<tr>
<td>Difficulty in adjusting to transitions between care environments</td>
<td>1</td>
</tr>
<tr>
<td>Carer/family need support with managing risk</td>
<td>1</td>
</tr>
<tr>
<td>Family carer needing support around end of life issues</td>
<td>1</td>
</tr>
</tbody>
</table>

**Fig. 7 – Referrals by Source 2016-17**
Our work with families & other professionals

How we work
Our service works with families and other professionals in a number of ways (see figure 8). During 2016-17 our work comprised of a large number of phone calls (1,176), face to face visits (721) and letter/report writing (673).

Where we work (face to face)
Most of our work takes place in families’ homes (see figure 9) and this fits in with the Admiral Nurse model that aims to empower families to stay together, in their own homes for as long as possible and preventing crisis, unscheduled hospital admissions and premature transitions into residential care.

It is important that we work within the family home because this enhances relationship building (puts people at ease) and strengthens assessment.

By working within the home we gain a good understanding of what’s important to the family and can observe any environmental factors that may signal a need for intervention/referral on to other services (e.g. occupational therapy) that can help the person with dementia remain at home. However, our support does also extend to residential/nursing homes and community care agencies if needs arise.

Fig. 8 – Activity data (Apr 16 – June 17)

Fig. 9 – Face-to-face activity location (numbers)
Assessments and interventions

During the first two months of our service most of our activities consisted of initial assessments with families and as the service developed our activities were mainly interventions (see figure 10).

Our types of intervention depend on individual need and circumstances. The vast majority of interventions centre on providing emotional support to carers, and advice around behaviour/symptom management as the dementia progresses. Our team also provides care coordination for the family as needed. Care coordination typically involves liaising with GPs, consultant psychiatrists, social workers, occupational therapists and community nurses to address the needs of the family as a whole.

![Fig. 10 - Assessments and interventions (total numbers)](image-url)
Group work
Our role is flexible in terms of offering facilitation of groups that provide families with opportunities for social networking and peer support. During 2016-17 we have worked with Earl Mountbatten Hospice and Carers Isle of Wight (a local voluntary organisation) to deliver groups to meet the needs of our families living with dementia.

Example 1 – Since November 2016, we have been running a regular carers social group in partnership with the Admiral Nurse at Earl Mountbatten Hospice, which is held at the hospice in Newport. Approximately 18 people attend this group on a regular basis and a recent evaluation showed that 100% of those attending have found the sessions beneficial and would recommend the group to friends and family if they needed similar support.

Example 2 – We have recently set up a peer support group, which is also held at Earl Mountbatten Hospice. Our team met with the manager and a support worker from Carers Isle of Wight to explore whether a carers group to provide peer support would be beneficial to the families on the Isle of Wight experiencing complex emotional difficulties. We agreed that Admiral Nurses and Carers Isle of Wight would facilitate the group, and that it should also include support for the person with dementia. A second meeting was held to finalise arrangements and agree responsibilities. This meeting also included the Admiral Nurse from Earl Mountbatten Hospice and representatives from the Parkinson’s Society, to ensure that we were engaging with other organisations on the island who could support this initiative. We agreed that two Admiral Nurses would facilitate the group (one from our team and one from the local hospice) and two members of Carers Isle of Wight. To date we have held two of these groups, supporting 11 carers, while volunteers cared for the people with dementia in another room.

Some feedback from evaluation of our social group for carers
“It’s good to relax and talk to people with similar experiences. Nice to unwind. Also to ask advice if needed.”

“My mum likes it very much. The group gets better every time. Such a happy afternoon. Loved Nigel playing the piano! Thank you all. We enjoy the memory items from the museum too. Tricky sometimes being during lunchtime, often haven’t had time to eat. Maybe we could bring a picnic!”

“My wife and I both find great benefit in the support that we are receiving. More sessions would be fantastic. We feel less isolated.”
Supporting best practice

Example 1 – Working with GP practices
Our team delivered a presentation to a group of approximately 60 Isle of Wight GPs and 20 practice nurses/care navigators to provide an overview of our service and education around the Admiral Nurse role. Three Admiral Nurses delivered the presentation as part of a pre-arranged practice staff education day.

There was discussion around the Admiral Nurse service, the interventions we can provide and the criteria for referral. Time was allowed for questions and answers at the end.

Example 2 – Working with residential homes
The manager of a care home contacted our team for advice and guidance to ensure that what she and her team were doing for a resident with dementia – who was becoming increasingly physically and verbally aggressive – was correct, up to date and appropriate.

We initially discussed what the home currently does on a regular basis to meet the needs of the person with dementia and checked what care plans were in place for this resident. From this, it was clear the home and the other care workers were working appropriately to meet the needs of the person with dementia. It was also clear the manager ensures the best care approach is in place to meet each individual resident’s needs at all times and ensures safe practice is maintained.

Our team advised that it would be beneficial for the staff within the home to have tier 1 and tier 2 training to help maintain best practice and the best care for people with dementia. Our team liaised with the Admiral Nurse based at the local hospice, who provides tier 1 and 2 training to residential and nursing homes, to set this up. We advised the manager to contact our team at any point in the future for further advice and guidance.
Evaluating our activity in 2016-17

In this section, we present evidence on our performance in relation to our service KPIs and our achievements against the outcomes defined in our evaluation framework.

Service Key Performance Indicators (KPIs)

KPI 1 – 90% of clients referred to the service are contacted by letter or phone by an Admiral Nurse within 10 days after receipt of referral

KPI 2 – 90% of clients have an initial assessment within six weeks of referral to the service

Outcomes

Positive experience of Admiral Nurse service

Improved quality of life for families affected by dementia

Delaying and reducing the need for care and support
Admiral Nurse service KPIs

We monitored the following KPIs during 2016/17 to assess the responsiveness of our service:

- KPI 1 - 90% of clients will be contacted by letter or phone by an Admiral Nurse within 10 days after receipt of referral
- KPI 2 - 90% of clients will have completed an initial assessment within six weeks of referral

Performance against these are shown below (figs 11 & 12)

**Fig. 11 – Clients contacted within 10 days of referral**

All four of the referrers we spoke to said that the Admiral Nurse service responds to requests in a timely manner, with two adding ‘absolutely’.

The main factor impacting our performance against these KPIs during 2016-17 was our team working at less than full capacity for the majority of the time due to staff illness. As our team returned to full capacity performance against our KPIs has improved.
Admiral Nurse service Outcomes

Evidence for our outcomes was gathered from our carer survey, telephone interviews with a sample of stakeholders and case studies

Carer survey

75 carers took part in our survey (37% response rate)

Most were the wife, husband, partner of the person with dementia

**Fig. 13**

<table>
<thead>
<tr>
<th>Wife/Husband/Partner</th>
<th>Daughter/Son</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>52</td>
<td>12</td>
<td>5</td>
</tr>
</tbody>
</table>

Most were female

**Fig. 14**

<table>
<thead>
<tr>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>14</td>
<td>56</td>
</tr>
</tbody>
</table>

66% look after the person with dementia 24 hours per day

**Fig. 15**

<table>
<thead>
<tr>
<th>24 hours a day</th>
<th>1 to 3 hours a day</th>
<th>7 to 12 hours a day</th>
<th>4 to 7 hours a day</th>
<th>Occasionally</th>
</tr>
</thead>
<tbody>
<tr>
<td>47</td>
<td>4</td>
<td>8</td>
<td>8</td>
<td>4</td>
</tr>
</tbody>
</table>

The average age of carers was 71 years (ages ranging from 41 - 95).
The average number of years they had been looking after the person with dementia was 4 years (responses ranged from 1 year – 13.5 years).

Stakeholder interviews

Five stakeholders (from memory service and local voluntary organisations) took part in telephone interviews carried out by the service evaluation team at Dementia UK.

Case studies

We wrote three case studies - one is included in this report.
Outcome 1: Positive experience of Admiral Nurse service

“[The Admiral Nurse] has been excellent. Could not have been more pleasant and understanding. Incredible.”
- Carer

“It is a wonderful service and I hope it will remain.”
- Stakeholder
Carers’ experience of Admiral Nurse service

Carers responding to our survey generally reported having a positive experience of the Admiral Nurse service in relation to the amount of contact, ease of contact, how good the Admiral Nurse had been and the ‘friends and family test’ question on whether they would recommend the service (widely used in the NHS). Most carers had:

- first used the Admiral Nurse service within the past year (88%).
- been in contact with the service during the last three months (70%).
- had 1-4 contacts with the service (73%).

Amount of contact

Most carers (70%) felt that the amount of contact was ‘about right’, with 22 people saying that ‘it wasn’t enough’ and they would have liked more.

Ease of contact

80% of carers said it was ‘very easy’ or ‘fairly easy’ to make contact with the service.
How good the Admiral Nurse was in key areas

We asked carers how good the Admiral Nurses had been in a number of areas. Most carers found the Admiral Nurses either ‘very good’ or ‘good’ in all areas (figure 18), particularly:

- Listening to carers.
- Showing compassion, respect and understanding to carers.
- Explaining things to carers in ways they can easily understand.
- Building trust and rapport with carers.
- Giving carers enough time and ensuring that they didn’t feel rushed.

![Fig. 18 - How good the Admiral Nurse has been at ...](image)

![Fig. 19 - How likely are you to recommend the Admiral Nurse service? (N=83)](image)

On the ‘friends and family test’, widely used in England, 89% of our carers answering this question said that they would be either ‘extremely likely’ or ‘likely’ (see figure 19) to recommend the Admiral Nurse service to someone they know who needed similar care and support.
Stakeholders’ experience of Admiral Nurse service

Stakeholders reported having a positive experience in relation to contact with and responsiveness of the service.

Contact with the service
Stakeholders taking part in the telephone interviews were asked about what types of contact they had with the Admiral Nurse service and whether the type of contact and frequency of contact were appropriate for their needs. All said that they had face to face, email and joint working contact.

All of the stakeholders (n=4) felt that the type and frequency of contact they had with the service were appropriate for their needs.

<table>
<thead>
<tr>
<th>Type of Contact</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face to face</td>
<td>4</td>
</tr>
<tr>
<td>Email/letter</td>
<td>4</td>
</tr>
<tr>
<td>Joint working</td>
<td>4</td>
</tr>
<tr>
<td>Telephone</td>
<td>2</td>
</tr>
<tr>
<td>Attended training session delivered by Admiral Nurse</td>
<td>2</td>
</tr>
</tbody>
</table>

Responsiveness of Admiral Nurse service
Stakeholders were asked whether the Admiral Nurse service responds to requests in a timely manner.
All (n=4) said that the service did this, with two adding ‘absolutely’.

“It helps a great deal that we are in the same office – means we can discuss the more complex cases and share information… Three of the Admiral Nurses were in yesterday and I am currently working with two of them, we were able to discuss the cases we are working jointly on.”

“We no longer have to wait for this service. We have a huge older persons’ population and also high diagnosis of dementia on the island. Carers deserve this service, in their own home. Having access to all the knowledge and skills allows them to work with someone to enable them to support right through to end of life. Having someone there saying ‘we know it is difficult, you are doing a good job’. It is an incredibly valuable service’” - Stakeholder

“It has had nothing but a positive effect on the island.” - Stakeholder
How stakeholders described what our service does

To help us understand how our service is viewed by our stakeholders we asked them to describe what our service does:

“They support carers who are caring for someone with dementia type illness. They also engage with care agencies – so for example, when sometimes the care agencies threaten to pull out because of the ‘behaviour’ of the person with dementia, the Admiral Nurses will speak to them and tell them about strategies they can use, so can then stop the agencies pulling out. They will also speak with consultants at the hospital – we had a case, a person with dementia, he was told by the consultant that actually he doesn’t have any pain and basically to go away. The nurses intervened to talk to the consultant and staff [to say] that person with dementia does have pain. They will also tell them about people with dementia who are not aware they have pain, but that they do have pain.”

“Provide what I class as a counselling service for carers and provide advice for the person being cared for and the carers. They are like a lifeline for those people. They are also helpful for me – as I don’t get all the phone calls anymore from families. Not every family with dementia needs social services but for the ones that do, the Admiral service has alleviated my role. We work closely together and do joint visits. They are help for me – the carers feel secure and confident with them, so this has added confidence to my role as well as people knowing that we know what we are talking about (because we are doing the visits together). It makes the carers feel more secure – people feel less lonely and less ‘I can’t cope with this problem’, so it has added a lot for people with dementia and their carers.”

“When I tell patients about the Admiral Nurse service I say it is primarily there to support carers of someone with dementia – they won’t ignore the person with dementia but the primary role is to support the carers. They will support the carers with managing, dealing with and coping with the changes their family member is going through. Talk about how it will change behaviour and support them so that they can manage it as best they can. They also have groups for the carer and the patients at the Earl of Mountbatten Hospice. Sometimes we will do joint work with complex cases where we will work as a team where we will support people with Parkinson’s and the Admiral Nurses will support the carer.” When asked what complex was: “an example: we have one family where the husband (who has dementia) has been quite a dominant and controlling husband, which the wife said she accepted as she had married him, but as the dementia has progressed this has become quite physical, following her around. The wife is not a good coper and does not manage stress well. So we visited the family together, I kept the person with dementia occupied so that the Admiral Nurse was able to talk to the wife alone and support her (the person with dementia is quite suspicious of his wife and won’t let her out of sight, so we had to work together so that we met the needs of both the person with dementia and wife).”

“They are there supporting carers to meet the needs of their loved one with dementia. They provide practical support, guidance, education and training. They are also involved in preventative work with families – supporting people with dementia and carers within the home situation, looking at end of life and planning for the future.”

“Admiral Nurses support carers and identify carers of a person with dementia. They provide both emotional and practical support. They also act as a conduit to other services. In terms of KPIs there are several indicators, one is a reduction in unplanned admissions to the hospital site. Which has been successfully achieved. They also work closely with other services linked to memory and dementia – statutory and voluntary services.”
Reflections on our service by stakeholders and carers

**Stakeholders**

**Referral criteria** – all of the stakeholders we spoke to knew that there was a form for making referrals, however none were completely sure of what our referral criteria was. One stakeholder felt that the referral criteria for the service should be clearer as this was perhaps resulting in some inappropriate referrals to the service. “There is a form. I think that the criteria when starting out a new service like this, perhaps should have been better, so people are clearer about what they do. GPs refer every new case where someone is diagnosed with dementia as soon as they can, which is not really helpful. The nurses then get tied up in all the referrals and have a waiting list.”

*In the coming year we will ensure that criteria for making referrals is clear to our stakeholders.*

**Working with the voluntary sector** – one of our stakeholders from the voluntary sector spoke about opportunities for more joint working with the service and some of the barriers to this, including difficulties for a service sitting within the NHS sharing information with voluntary sector organisations and feeling that the referral criteria was not clear, resulting in the Admiral Nursing service receiving referrals for all new diagnoses. This stakeholder could see real value in the Admiral Nursing service being able to work more closely with the voluntary sector to enable people on the island to have the best support and felt there was “scope for more of the step up step down approach”, highlighting an understanding that the Admiral Nurse service works with families at a different level to other organisations.

*Working more with other voluntary sector agencies on the island is something that our team has started to develop e.g. through jointly delivering groups and will be something we continue to develop in the coming year.*

**Carers**

**Carers’ suggestions on how the service could be improved** – we asked carers if they had any suggestions on how our service could be improved. Twenty-eight carers added some comments, most were on the following three areas:

**No improvements as happy with the service**

“None at all, brilliant in every way, kind, caring, and I couldn’t have managed without the help of x.”

“Stay as you are.” “Just continue the excellent work.”

**More Admiral Nurses to meet demand on the island**

“I’m sure they have a very important heavy workload so in an ideal world more Admiral Nurses would be the answer.”

“It is a great service but there are not enough nurses to care with demand on the Isle of Wight which has a large aged population.”

“There needs to be more on the island. The population is mainly elderly and 141,000 people live there. I believe there are only 4/5 nurses on the island. It’s not enough to help the amount of people suffering with the effects of this disease.”

**More time spent face to face with their Admiral Nurse**

“More time spent face to face.” “To have more time for face to face visits.”

**One carer spoke about needing the service earlier**

“I should have had support from an Admiral Nurse two years ago. When I did have contact with an Admiral Nurse it was at crisis point. I was unaware of Admiral Nurses, my GP put them in touch, maybe this should have been earlier.”
Outcome 2: Improved quality of life for families affected by dementia
**Carer quality of life**

Feeling supported, having confidence in your abilities to cope, care and influence are important when it comes to quality of life for family carers. We therefore asked carers about how helpful the support our service offers was, and whether our service was making a difference in key areas of their lives.

Support – nearly all who were offered and said they needed the following areas of support from the Admiral Nurse found this helpful:
- sharing information/explaining the impact of dementia (59 out of 60).
- assessing needs of carer and person with dementia (58 out of 60).
- help finding and accessing local services offering support (51 out of 53).
- providing carer with ways of responding to and coping with changes in behaviour of the person with dementia (45 out of 47).
- providing carer with emotional support (45 out of 48).

**Making a difference (see figure 20)** – in nearly all areas asked about, more carers felt that the service was making a difference than not. (N.B. response rate to each area varied depending on whether carers felt it was applicable to them). 67% felt the service had made a difference in their ability to take better care of the person with dementia and 65% felt the service had made a difference to their confidence in their ability to cope.

**Fig. 20 – Difference the Admiral Nurse has made**

<table>
<thead>
<tr>
<th>Area</th>
<th>Difference</th>
<th>No difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>The confidence I have in my ability to cope</td>
<td>21</td>
<td>39</td>
</tr>
<tr>
<td>My ability to take better care of the person with dementia</td>
<td>18</td>
<td>37</td>
</tr>
<tr>
<td>My ability to make adjustments to and maintain my relationship with the person with dementia</td>
<td>25</td>
<td>36</td>
</tr>
<tr>
<td>My ability to make adjustments to and maintain my relationship with the person with dementia</td>
<td>22</td>
<td>33</td>
</tr>
<tr>
<td>My ability to influence or make important decisions about the care of the person with dementia that I look after</td>
<td>20</td>
<td>33</td>
</tr>
<tr>
<td>Coordination of support from other health &amp; social care professions involved in the care of the person with dementia</td>
<td>21</td>
<td>31</td>
</tr>
<tr>
<td>Enabling the person with dementia to be as independent as possible</td>
<td>30</td>
<td>21</td>
</tr>
<tr>
<td>The opportunities I have for time off from caring</td>
<td>28</td>
<td>19</td>
</tr>
</tbody>
</table>

**What some of our carers said:**

“**I found having the support and the Admiral Nurse was very beneficial during a traumatic time.**”

“**[The Admiral Nurse] always offered reassurance that I could contact her...I felt supported knowing I could ask and receive help at any point.**”

“**The support given by the Admiral Nurse is very different [to that of other professionals] because it helped me have an insight into the needs of my husband.**”
Stakeholder interviews

Our stakeholders were asked whether they felt the service had made a difference to the quality of life for families and improved care for families.

Quality of life

All of the stakeholders felt that the Admiral Nurse service had improved the quality of life for families

• “It is through the support they provide and knowing that they are there to support, knowing they can do things if required.”

• “It does, especially one nurse I work with who has really good rapport with the families we work with together. This rapport makes the families feel safe and they know they can rely on this person. Even if the Admiral Nurse is just there – we had a person with dementia who had to go into hospital and the Admiral Nurse was there with his wife, so she knew someone was there for her/for them.”

• “Again, I think that this happens through a joint effort of Admiral Nurses and the Memory Service. We all work together well.”

• “The island has been left behind in relation to carer support. There are lots of reasons including transport issues so a lot of the carers groups don’t reflect the need. Because the Admiral Nurses support in the community, in people’s homes, this is a need that is long, long overdue. The Admiral Nurses provide dedicated support and families know that someone is on your side. Their experience, skills, knowledge, coming from your perspective, enabling you to positively connect and engage with your loved one.”

Improved care

All of the stakeholders thought that the service had improved care for families

• “It gives them more security, someone is there for them. Even if someone is just there to talk to them at the end of the phone, it makes a difference. Makes people know they have someone who will respond to them if they have a bit of a low time.”

• “Generally it is quite well known that if we don’t support carers then they are not going to be able to support patients. Carers provide an excellent unpaid service taking pressure off hospital and care home beds. Carers also allow the person to stay at home as long as possible. The Admiral Nurse service helps carers be able to do this (be carers).”

• “The service is involved long-term with families. Locally they are involved in carer and people with dementia groups. Carers then become involved in understanding and taking part in helping people to progress with their life. The Admiral Nurses help to engage the carer and people with dementia again and maintain that relationship as long as possible.”
Outcome 3: Delaying & reducing the need for care and support
Carers

Carers were asked whether not having access to an Admiral Nurse over the past 12 months would have made a difference in seven areas of their life, only 9 said that it would have made no difference:

- 43 said they would have struggled more on their own.
- 20 would have seen their GP more for themselves.
- 13 would have seen their GP more for the person with dementia.
- 11 would have been unable to continue as a carer.
- Nine said the person with dementia would have needed to move to a care home.
- Four said the person with dementia would have gone to A&E more often.

4 carers added the following about the difference having access to the Admiral Nurse had made:

“I would have felt more isolated.”

“My GP only offered SSRIs and I think I would have become more stressed and depressed had I not had an Admiral Nurse.”

“I would have been much more stressed and needy in terms of whom to talk to.”

“I would have been unaware that there is support for carers who care for those with dementia, it is an isolating state.”

Fig. 21 - Carer impact of not having access to an Admiral Nurse (n=64)

The person with dementia would have had to go to Accident and Emergency more often
The person with dementia would have needed to move into a care home or nursing home
It would have made no difference
I would have been unable to continue as a carer
I would have seen my GP more for the needs of the person with dementia
I would have seen my GP more for my own needs
I would have struggled on my own

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<tbody>
<tr>
<td>The person with dementia would have</td>
<td>4</td>
</tr>
<tr>
<td>have had to go to Accident and</td>
<td></td>
</tr>
<tr>
<td>Emergency more often</td>
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<tr>
<td>The person with dementia would have</td>
<td>9</td>
</tr>
<tr>
<td>have needed to move into a care home</td>
<td></td>
</tr>
<tr>
<td>or nursing home</td>
<td></td>
</tr>
<tr>
<td>It would have made no difference</td>
<td>9</td>
</tr>
<tr>
<td>I would have been unable to</td>
<td>11</td>
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<tr>
<td>continue as a carer</td>
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<tr>
<td>I would have seen my GP more for</td>
<td>13</td>
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<tr>
<td>the needs of the person with</td>
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<tr>
<td>dementia</td>
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<tr>
<td>I would have seen my GP more for my</td>
<td>20</td>
</tr>
<tr>
<td>own needs</td>
<td></td>
</tr>
<tr>
<td>I would have struggled on my own</td>
<td>43</td>
</tr>
</tbody>
</table>
**Stakeholders – difference the Admiral Nurse service has made**

We asked our stakeholders whether they thought our service had made a difference in avoiding crisis points for families and whether our service had the potential to delay long-term care home placement and reduce unplanned hospital admissions.

**All felt the service had helped avoid crisis points for families.**

> “Admiral Nurses provide the family with the confidence that allows families to highlight issues and they then offer support and address problems before it become a crisis.”

> “There is one example where the Admiral Nurse has a good relationship and rapport with a ‘difficult’ person who is a carer – who has lots of bereavement issues and some lifestyle issues and the Admiral Nurse is fantastic with this carer and helped avoid crisis points.”

> “Think it is a lot about avoiding crisis – if it wasn’t for the Admiral Nurse service there would be more crises.”

> “I sit beside them and they are always on phone calls. Just a telephone call can solve a problem almost at crisis level and stop this becoming a crisis, because you know you have someone at the end of the phone and if it’s more serious you can get a home visit.”

All said that the service had the potential to delay long-term care home placement. Stakeholders spoke about the support provided to carers by the Admiral Nurse service as being important in this.

> “They can reduce carer stress and support the carer in their caring.”

> “…they can enable people to return home from hospital and stay at home longer through the support provided to carers.”

Four stakeholders felt that the Admiral Nurse service had the potential to reduce unplanned hospital admission – two added that they felt they had already seen reductions in the numbers of people with dementia having unplanned admissions.

> “There used to be a lot of people with dementia admitted through the ED/assessment wards. I think the number of patients has dropped since the Admiral Nurse service... My understanding and feeling in the last few months of my role was that ED admissions were less.”

> “Yes, there has been a definite reduction in unplanned admissions to the general hospital.”

Yes, because they can give advice, because they are nurses they can stop a crisis happening.”
Impact if Admiral Nurse service no longer existed

Our stakeholders were asked what the impact would be on their service and families affected by dementia if the Admiral Nurse service no longer existed. Responses included increases in contacts from families, loss of support for families, more crisis situations and more admissions to acute care.

Impact if Admiral Nurse service no longer existed?

“IT would be a little like opening up a black hole, I wouldn’t like to think about it. There would be an impact on hospital admissions, increase in number of people with dementia admitted to ED. There would be an impact on discharges to the home environment as support from carers would not be there to do this. Carers would feel abandoned, bereft. The provision of confidence, skills, knowledge would be removed and that would be devastating…This would have an impact on our acute economy – through increases in admissions and delays in discharge home. It would be huge.”

“Families wouldn’t get the support – there would be more crisis situations, more admissions to hospital and more resident care home placements.”

“I would get lots more phone calls, I wouldn’t have the peer support at visits.”

“The impact on me and Memory Service staff is that our role would have to expand.”

“The Memory Service would have more crisis contacts. The families would feel that a massive support network had been removed.”

Through their responses to the questions about impacts and the difference the Admiral Nurse service makes, stakeholders have clearly expressed that they felt that our service is having an impact on delaying and reducing the need for care and support from other services.
Case study – Molly and David

Avoiding carer breakdown - improving health and wellbeing - reducing risk of avoidable hospital admission

Background
Our service received a referral from a GP for a carer with high levels of stress. Molly is the main carer for her husband David, who has a diagnosis of Parkinson’s disease and Lewy body dementia. At the time of the referral David had been admitted to hospital with haematuria and Molly had been staying on the ward for several hours during the day and at times during the night to support him. In addition to this the couple’s daughter, who is recovering from chemotherapy, was also living with them. All of this was having an impact on Molly’s health, stress levels and her ability to cope with her caring role.

Needs identified
I completed an assessment with Molly, using the Admiral Nurse 18 point assessment framework which includes assessing needs of the person with dementia and the carer and identifying possible risks. I identified a number of needs for Molly and David:

• Molly was neglecting her own medical needs and was not accessing the reviews she required for her asthma.
• She admitted to feeling depressed and was struggling with her caring role, highlighting a need for respite.
• She was lacking the motivation and did not feel confident to contact social services to request a review and was also lacking any social contact outside of the family and the paid carers.
• Molly expressed her fears about future care needs and ensuring that hers and David’s wishes are followed.
• David experiences moderate cognitive impairment and vivid hallucinations disturbing his and Molly’s sleep.
• David required a review for diabetes via his GP surgery, however Molly was unable to transport him to the surgery due to his mobility problems.
Interventions and results

Following this assessment, I put a number of interventions in place to address the above needs. These were based around the person-centred needs of both Molly and David. Due to the significant stress being experienced by Molly, communication skills and the building of a therapeutic relationship was paramount in achieving a positive outcome for them both. I provided Molly with the opportunity to express her feelings and explore the support she required. I then provided Molly with emotional support around the losses and adjustments in her life and around planning for the future. She discussed her concerns about effectively communicating with professionals while dealing with the heightened emotions within her home.

- I provided education regarding management of the visual hallucinations i.e. not correcting David but providing reassurance and demonstrating an understanding of David’s associated fear – although the hallucinations are still present, these are now more manageable.
- With Molly’s consent to share information with relevant professionals, I contacted their GP to request a home visit to review David’s physical health including his diabetes and informed the GP of my concerns regarding Molly’s mood and her asthma review the physical health reviews for both Molly and David have taken place. Molly was prescribed a trial of anti-depressants which the GP will review. There have been no further hospital admissions for David at the time of writing.
- I made a referral to social services to request a review of the care package with a view to introducing respite – the first period of respite has taken place.
- I discussed completion of an advance care plan to address Molly’s need to plan for the future – to be completed at next visit.
- I supported Molly to liaise with social services about her concerns regarding the care agency currently providing support as she was worried that if she made a complaint the care package would be withdrawn – a new care agency is being sourced.

Outcomes

This case highlights a number of areas where input from our service was successful in achieving positive outcomes and improving the carer’s and person with dementia’s health and wellbeing:

- Avoiding carer breakdown – Molly has reported that her stress has significantly reduced as a result of our support.
- Reducing risk of distress to the person with dementia and carer when managing hallucinations – due to increased skills and confidence in Molly.
- Reducing risk of hospital admission for both carer and person with dementia – due to their physical health needs being met.
- Reducing risk of early transfer to 24-hour care environment for the person with dementia – by reducing the high levels of carer stress and putting in place planned respite care, increasing ability to carry on caring.
- Completion of advance care plan as this will reassure Molly that their future needs are met.
**Recommendations**

**Developing our evaluation skills and capacity**

As part of evaluating our service we reviewed the data we had about our caseload, which enabled us to reflect on the casework model we were using and change our practice. We will continue to review our evaluation data to inform our service delivery and management of risk.

**Our KPIs**

We would like to develop our KPIs next year to more fully capture the work we are doing, in addition to responsiveness of our service. Areas to consider are:

- delivery of group work
- supporting best practice
- offering families the opportunity to discuss advanced care planning.

**Our service’s activity and development**

We will continue to develop our relationships with statutory and voluntary organisations on the island and look for further opportunities for joint working.

We will continue to ensure that our service is responsive to the needs of families living with dementia and to the organisations we work with.

We will work to refine and promote our referral criteria to those we work with in the coming year.

We will work closely with other organisations to address gaps in the dementia pathway identified in our evaluation – e.g. post-diagnostic support and need for ‘lower level’ support from other organisations.

**Our outcome measures**

We would like to look at new ways of capturing carers’ quality of life and a measure of stage of illness – so that we can ensure the interventions and support offered are appropriate and effective.

We would like to be able to show whether our service is having an impact on the local health economy.
References


7. Isle of Wight JSNA Dementia, March 2016. Available at: https://www.iwight.com/azservices/documents/2552-Dementia-2016-FT-RB-v0.4-v1.pdf Last access:01.09.2017


10. 2011 Census. Available at: https://www.ons.gov.uk/census/2011census
Appendices

Appendix 1 - Outcome framework domains

**Quality of Life of carers and people with dementia – enhanced quality of life for people with care and support needs (ASCOF domain 1, NHSOF domain 2)**

- Carers can balance their caring roles and maintain their desired quality of life (ASCOF 1D – carer reported quality of life, NHSOF 2.4)
- Enhancing quality of life for people with dementia (NHSOF 2.6 Estimated diagnosis rate for people with dementia. Dementia & a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life)

**Ensure that people have a positive experience of care and support (ASCOF domain 3, NHSOF domain 4)**

- Carers are respected as equal partners (ASCOF 3C carers who report that they have been included or consulted in discussions about the person they care for)
- People know what choices are available to them locally, what they are entitled to, and who to contact when they need help (ASCOF 3D ease with which people find information about support)
- Improving people’s experience of integrated care (NHSOF 4.9 / ASCOF 3E)

**Delaying and reducing the need for care and support (ASCOF domain 2)**

- Earlier diagnosis, intervention and reablement means that people and their carers are less dependent on intensive services (ASCOF 2B / NHSOF 3.6 at home 91 days after discharge)
- When people develop care needs, support received is in the most appropriate setting and enables them to regain their independence (ASCOF 2F: Dementia – a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life)
- Reducing time spend in hospital by people with long-term conditions (NHSOF 2.3 Unplanned hospitalisation for chronic ambulatory care sensitive conditions)
If you’re caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call 0800 888 6678 or email helpline@dementiauk.org
Open Monday – Friday, 9am – 9pm
Saturday and Sunday, 9am – 5pm

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