



## Admiral Nursing in Lincolnshire

June 2019 saw the introduction of specialist Admiral Nurses in Lincolnshire to support families living with dementia. Admiral Nurses are specialists who provide tier 3 support to those with the most complex and difficult situations. They work alongside families and other professionals when things become increasingly challenging. Working on a 1:1 basis, Admiral Nurses provide expertise and knowledge to support carers facing the challenges of the present and future.

Lincolnshire has a number of unique challenges. Although one of the largest counties, its population is very dispersed, and on average slightly older. It also has a variety of affluence, deprivation, and health outcomes including a higher incidence of dementia risk factors such as high blood pressure, diabetes and obesity. Historically, diagnosis rates have also varied, although efforts are in place to address this issue.

St Barnabas Hospice and Lincolnshire County Council both recognised the need to increase support for carers and people living with dementia in Lincolnshire. What resulted was a unique hybrid of hospice and community-based Admiral Nurses with the aim of not only improving the quality of life and resilience of carers, but also to improve access to appropriate palliative care services for people with dementia.

### Referrals

The two main criteria for referral to the service are that the person with dementia is registered with a Lincolnshire GP and has a confirmed or highly suspected diagnosis of dementia, with the referrer asked to identify the main needs and background information.

In the first year of clinical activity (August 2019 – July 2020), the service received 634 referrals resulting in a total of 557 people receiving support from the Admiral Nurse Service. The discrepancy in these two numbers is accounted for by re-referrals, and inappropriate or declined referrals.

The majority of referrals came from Primary Care and the Neighbourhood areas (43%), followed by Mental Health Services (18%), then Social Services (12%). Referrals from hospice and palliative care teams accounted for 9% of referrals.

The largest share of the referrals by area came from East Lindsey, Spalding, and Boston which between them accounted for 44%.

The referral rate increased steadily over the first half of the initial year of service, as would be expected with a new service becoming more embedded and established and the general public becoming more aware of our presence. The average number of referrals per month for the whole period is 53. However, since the arrival of the COVID-19 pandemic, the number of referrals decreased for several months, but began to increase again in July. Since the end of January, the recommended team caseload size has been exceeded.

The primary reasons for referral to the service were due to a change in the presentation of the person with dementia, a request for an assessment by an Admiral Nurse, information support, and skills acquisitions for the carer. When considering these reasons against the main needs

found at assessment (health and wellbeing of the carer, skills in coping with changing behaviours and symptoms, looking to the future and time for self), it highlights the impact that symptoms of dementia have not only on the person with dementia but on their support networks and loved ones.

Demographic information collected during interaction with the service was also reviewed to add insight into the experience of being a carer in Lincolnshire. For example, nationally between 60-70% of carers are female, and supporting people with dementia over the age of 75, both of which are broadly in line with our referrals. However, we do appear to have a higher percentage of carers referred to the service who are retired.

Of those referred to the service, a higher proportion than nationally averages would suggest were diagnosis with vascular dementia. Similarly, we supported more males living with dementia than female. Again, national figures suggest that females are more likely to develop dementia, but of an Alzheimer's type. This may contribute to the referrals we are seeing but is also likely to be due to other factors such as williness and ability to access support, health issues and coping mechanisms.

Whilst dementia primarily effects older people, it is not a disease of old age. The Lincolnshire Admiral Nurse service has supported 15 people diagnosed under the age of 65 in its first year. Carers referred to us have, on average, been in a caring role for 4.5 years within a range of 1-15 years.

Carers referred to us were overwhelmingly of white British backgrounds (97% people with dementia, 99% family carers).

Referrals received by the service have reflected a diversity of need in Lincolnshire. There are challenges in ensuring that people are referred to the appropriate service for their needs, but work continues on ensuring a smooth transition between services. As the service caseload has expanded, work has continued in developing a robust triage and caseload management process as well as discharge planning to ensure effective and timely support from the Admiral Nurse Service.

### Activity

As the referral activity and case load sizes have increased, so too has the amount of clinical, liaison and administrative activity. When comparing the first and second half of the year, there was an 84% increase in clinical activity. However, since March, this has primarily been via phone.

The Lincolnshire Admiral Nurse Service is primarily intended as home-based service. However, the impact of COVID meant that the service was remodelled to a preferentially phone-based service to reduce risks for carers and staff. Home visits did continue where there was evidence of increased risks of carer breakdown, safeguarding or communication issues. This meant that the Admiral Nurses have continued to be available to provide support for families in Lincolnshire through this challenging time.

The impact of COVID in the second half of the service's first year has seen an increasing need for emotional and psychological support for carers and people with dementia. Those effected by dementia have been amongst the most disadvantaged by the restrictions enacted to reduce the spread of COVID. The Admiral Nurse Service has continued to provide the vital support to ensure that carers are supported.

In their clinical roles, Admiral Nurses provide targeted therapeutic interventions to meet the needs of carers. These interventions can be varied and range from providing psychosocial support, supporting the management of co-morbidities and frailty, education for carers, and identifying complex end of life care needs. Specialist skills and knowledge used in these interventions can also vary and include case management, advocacy, advance care planning, CBT techniques, and prescriber level medication support.

The number of interventions has generally increased month by month over this year, with a total of 4,438 recorded interventions. The most common interventions are themed around providing emotional and psychological support, assessment (both initial and ongoing), provision of specialist knowledge and developing coping strategies.

Although the monthly referral rate decreased following the introduction of COVID restrictions, the clinical input from the Admiral Nurses increased. This was a reflection of the additional support provided by the Admiral Nurses to ensure that existing carers were supported, and safety maintained, but also reflects the increasing complexity of cases that have been referred and the increasing emotional and psychological support needed to support carers and people with dementia during this time.

When taken as an overall average of the year, the length of time a carer may have received input from an Admiral Nurse ranges from 66 to 101 days. There is no set timeframe on how long an Admiral Nurse may be supporting an individual carer and their family. During the assessment phase of their involvement, needs and goals are mutually identified and discussed with the nurse, who will remain involved until these goals are met or further needs are identified. When a carer is discharged, they have the ability to self-refer back to the service should needs change once more.

Admiral Nurses not only support families living with dementia, utilising their specialist skills and knowledge, they are also well placed to support education, strategic planning and provide specialist knowledge and expertise to the wider multi-disciplinary team. Individual nurses have supported best interest meetings, multi-agency planning and have been invited to sit on Dementia Expert Reference Group for Lincolnshire.

The service has supported several education sessions which have been less frequent since the COVID pandemic. They continue to support other professionals informally during MDT meetings and during reviews of specific cases.

## Outcomes

The service has two main performance indicators. KPI 1 was set out in the service specification and the KPI 2 introduced as benchmarking. For KPI 1, the service aims to provide initial contact with carers within 5 working days from the receipt of the referral in 80% of cases. This was achieved in 75% of cases, with the average monthly times ranging between 3.3-9.0 days, with 24% being contacted on the same day. At the end of June, the triaging process was altered to reduce this average time further and provide a more robust clinical process.

For KPI 2 (assessment commenced within 28 calendar days in 80% of cases), the average time to commencing an assessment process was 24 days (Ave range 9.6-50.0 days) with 35% of assessments started with 7 calendar days.

One issue that we are not able to reflect in these figures at this time is where contact has been attempted but been unsuccessful resulting in a delay in commencing input from the nurses.

The service has several key quality outcomes;

- Self-reported improvement in carer quality of life
- Improved ability to cope in caring role
- Impact on likely admissions or transfer of care
- Evidence of positive experience of care
- Impact on other professionals' caseloads and ability to support those with dementia.

Two surveys were sent out towards the end of the first year of service. A carers survey was sent out to carers who had been discharged from the service and given consent to be contacted again and another to senior professionals in the wider health, social and voluntary sector.

### Carers feedback

Of the respondents to the carer survey the majority stated that they would be likely or extremely likely to recommend the service.

Carers also stated that the nurses had listened to their concerns, showed compassion and respect, explained information in a comprehensible way, and built good relationships with them. They also felt that the nurses had been helpful in sharing information and exploring the impact of dementia and provided much needed emotional support. Carers also reported that the Admiral Nurses had offered a more personal approach than they had previously received, and that the nurse displayed specialist knowledge in their interventions.

When asked if Admiral Nurses had made a difference, the majority reported that the Admiral Nurse had improved their ability to care for the person with dementia, had increased the ability of the carer to influence and make important decisions, and supported the carer in adjusting to their role and maintaining their relationship with the person with dementia.

The majority of respondents also felt that they would have struggled to continue in their caring role without input from an Admiral Nurse resulting in more time spent with their GP or visits to A&E.

### Quality of life

During the initial assessment, Admiral Nurses complete a quality of life survey with carers which is then repeated at a later stage. Overall, there was an improvement in scores from an average of 47/100 to 66/100. The largest improvement in subscales was observed in support for caring, caring choice, and ability to care. There was also evidence of a reduction in the amount of carer stress.

### Professional stakeholders

Professional stakeholders felt that the Admiral Nurse Service provided a good response to referrals and queries and that it had supported them in gaining a better awareness of how to support those living with dementia and increase their own professional understanding of dementia.

Comments from the survey also indicated that the presence of the Admiral Nurses facilitated MDT discussions and care planning, added expertise to support and inform decision making, reduced the potential for crisis, improved person-centred care, and impacted on unplanned hospital admissions.

### Impact of the service

When asked what the impact would be if there was no Admiral Nurse Service, professionals stated that there would be a reduction in essential support for those with dementia, additional pressures to partner services, and increased carer breakdown.

## Conclusions

During its first year of service the Admiral Nurse Service has become embedded in the local area and demonstrated a positive impact on the lives of people living with dementia in Lincolnshire. This evaluation report has shown that the Admiral Nurses are beginning to impact the lives of carers. The variety of needs within Lincolnshire is perhaps reflected in the differing rates. However, work continues to better understand these needs and how this informs future development of the service.

A challenge for the service remains quantitative measurements of system wide changes. Whilst the service cannot claim to attribute any system impact to itself, evidence is increasing of a contribution to an improvement in the lives of those living with dementia in Lincolnshire.

The arrival of COVID has had a profound impact on the whole health, social and voluntary sector. It has been a factor in this landscape for a significant portion of the length the service has so far been operating and its lasting impact is yet to be seen. What has been apparent is that many families living with dementia have been increasingly affected by lack of access to other means of support, isolation and challenges in continuity of care for those with dementia.

The Admiral Nurses have continued to operate in this time, increasing the amount of practical, psychosocial, and specialist support both to carers and professional colleagues. We have shown that those primary needs picked up during assessment - health and wellbeing of the carer, skills in coping with changing behaviours and symptoms, looking to the future and time for self - can be positively impacted by Admiral Nurses and measured using review processes and quality of life surveys.

The carers survey was able to demonstrate improvement in quality of life for carers, enabled carers to be more involved in decision making, supported independence for person with dementia, and enabled carers to better care for the person with dementia - all key outcomes for the service. This first year of service, has enabled individual nurses to develop into their role, gain an understanding of the area they cover and begin to influence at a local and personal level the lives of families living with dementia.

This report has provided some initial evaluation of carer's experience to better understand how the service can improve this. Therefore, this report has evidenced that carers following Admiral Nurse interventions are reporting greater abilities to cope, reducing time taken up with other services, and take better care of themselves will lead to system wide effects.

The addition of positive outcomes through working with other services also shows evidence of this by increasing confidence of staff to support those living with dementia, reducing crisis interventions, and increasing accessibility to specialist collaborative care.

The provision of formal education to increase knowledge, as well as showcase specialist skills to upskill colleagues across the health and social community is a key element of the role of the Admiral Nurse. By tailoring formal and informal training around the needs of different services, Admiral Nurses are able to demonstrate improved care. The Admiral Service will continue to seek innovative means of collaborative work, facilitating education and learning within Lincolnshire.

Dementia is a palliative diagnosis and the hosting of the service with St Barnabas helps to highlight and frame the response to dementia in the context of supporting people with a life limiting condition. By providing an innovative service and establishing a course of knowledge and expertise

within the county, the Lincolnshire Admiral Nurse Service is therefore ideally placed to continue this process of joining up services and provide a holistic family centred approach to care.

### Main achievements

The Lincolnshire Admiral Nurse Service has achieved much in its first year, below are a few main achievements:

- Establishment of Admiral Nurse Service in Lincolnshire
- Recruiting and retaining specialist nursing posts in Lincolnshire
- Recognition of added value of Admiral Nurses at strategic level
- Continued support and positive impact for carers during COVID pandemic
- Positive regard generated with other professionals and services
- Intelligence gathering on profile of impact on dementia in Lincolnshire
- Improvement in the experience of dementia in Lincolnshire
- Enabled carers to be more involved in decision making, increase self-care, coordinate care and continue to support the person with dementia

### Priorities going forward

In its first year the Admiral Nurse Service has achieved much but through service development and this evaluation process, several themes have emerged to focus on in the next year and beyond.

- Use data generated by the service to better understand the needs profile of carers in Lincolnshire.
- Utilise data gathered over the two-year project to articulate future workforce needs.
- Continue to refine the process of case load management to ensure timely referral response and assessment.
- Further develop multi-disciplinary working with hospice teams and neighbourhood areas.
- Ensure accurate recording of supporting evidence such as supporting best practice.
- Review education needs of dementia care in Lincolnshire and ascertain where the Admiral Nurse Service can have most impact.
- Continue with virtual consultation project.
- Continue to review activity data to support understand the impact of the service.