

Open Report on behalf of Glen Garrod, Executive Director of Adult Care and Community Wellbeing

Report to:	Councillor Mrs P A Bradwell OBE, Executive Councillor for Adult Care, Health and Children's Services
Date:	15 - 26 April 2019
Subject:	Community Based Support Service for People with Dementia and their Families
Decision Reference:	I017038
Key decision?	Yes

Summary:

The Council currently commissions a Dementia Family Support Service, which is provided by the Alzheimer's Society. The current contract is due to end on 30 September 2019.

The aim of the service is to offer support and guidance for people with dementia to live at home independently for longer and to ensure that people are better enabled to live well with dementia through provision of meaningful support and services, in turn preventing crises, unscheduled hospital admissions and premature transition into long term residential care. The current service provides support to only those people who have a diagnosis of dementia. The service also provides support and guidance to family and carers of people with dementia so that they can support the person with dementia to continue in their caring role and maintain their own health and wellbeing.

Since the current contract started in October 2015, Lincolnshire County Council has made a commitment to continue to commission a Dementia Support Service in the Joint Dementia Strategy 2018.

This report seeks to present the case for re-commissioning the Dementia Support Service on the basis of the work undertaken and seeks approval:-

1. To agree to re-commission a community based service supporting people with dementia, their families and carers.
2. To agree proposed changes to the scope and specification of the service to include:-
 - Rename the service as the "Dementia Community Support Service"
 - To include provision of support for people that have not yet received a diagnosis of dementia; essentially those with mild cognitive impairment.

Recommendation(s):

That the Executive Councillor:

1. Agrees to re-commission a community based service supporting people with dementia, their families and carers.
2. Agrees proposed changes to the scope and specification of the service to include:-
 - Rename the service to "Dementia Community Support Service"
 - To include provision of support for people that have not yet received a diagnosis of dementia; essentially those with mild cognitive impairment.

Alternatives Considered:

1. Negotiate a revised contract with the current provider

The Council has an existing contract for a Dementia Family Support Service; the contract does not have provision for any further extension.

2. To do nothing

The Council have made a commitment within the Lincolnshire Joint Strategy for Dementia 2018-2021 to commission a post-diagnosis family support service to succeed the current Dementia Family Support Service agreement, which will help promote resilience, healthy lifestyles, and physical and mental wellbeing. In that context a failure to provide that support may trigger a legal obligation to consult and/or engage with affected people.

Reasons for Recommendation:

1. The Dementia Community Support Service will be the only service provided by the Council for dementia sufferers and their families and carers. The extensive engagement carried out has demonstrated the need for and appreciation of ongoing support. The Council through the Lincolnshire Joint Strategy for Dementia 2018-2021 has committed to the provision of a dementia support to ensure that people with dementia and their family carers are supported to live well no matter what stage of their illness. In that context a failure to provide that support may trigger a legal obligation to consult and/or engage with affected people.
2. The alternatives considered have been deemed unsuitable in delivering the required outcomes of the service.

1. Background

1.1 Strategic and Policy Drivers

- 1.1.1 The re-commissioning of the service will support both local and national policy objectives:-
- 2.1.2 Dementia is one of the most significant health and social care priorities of current times with diagnosis rates increasing in the aging population. Dementia will have profound impact on the person with dementia's life, but it also has a major effect on the person's family and friends (*Source: Joint Strategic Needs Assessment*).
- 1.1.3 The Prime Minister's Challenge on Dementia 2020 (Department of Health, February 2015) discusses the need for support to be provided to people with dementia.
- 1.1.4 The Care Act 2014 requires local authorities to assess carers' needs for support. The Act introduced a legal right for carers to access support services and this must be tailored to address the specific needs of carers for people with dementia with the aim of improving independence and wellbeing, and helping to prevent or delay the need for on-going care and support.
- 1.1.5 The Lincolnshire Joint Strategy for Dementia 2018-2021 sets out Lincolnshire County Council's commitment to commission a dementia support service that promotes resilience, healthy lifestyles, and physical and mental wellbeing.
- 1.1.6 The Joint Health and Wellbeing Strategy for Lincolnshire (2018) includes dementia as one of the key priority areas. Highlighting the need for comprehensive and integrated pathways throughout the dementia journey, support for people with dementia, prevention programmes for vascular dementia, greater integration and awareness within neighbourhood teams, wider professionals and the public.
- 1.1.7 As suggested above, national and local policy highlight the need for a service to be provided to support people with dementia, their family and carers.

1.2 Level of Need

- 1.2.1 It is estimated that there are over 11,000 people aged 65+ and around 200 people under 64 years old living with dementia in Lincolnshire. Diagnoses rates differ across the different CCGs in Lincolnshire, on average 65% have received a diagnosis however diagnosis rates are as low as 59% in South West Lincolnshire. Work is ongoing to increase the diagnosis rates to be in line with the benchmark of 67% set out in the NHS Mandate 2017 - 2018.

1.2.2 The service also supports family members and carers of people with dementia. The Council commissioned the Lincolnshire Carers Support Service which is delivered by Carers FIRST and between the period of 1 February 2018 and 1 February 2019 they supported 897 carers that cared for a person who had a diagnosis of dementia.

1.2.3 Figures show that between 5% and 20% of people aged over 65 are affected by Mild Cognitive Impairment (MCI) (Source: Lincolnshire Joint Dementia Strategy 2018). 282 people were diagnosed with MCI in the past twelve months (Source: Lincolnshire Partnership NHS Foundation Trust).

1.3 Current Service Issues and Performance

1.3.1 The current service has been running since 1 October 2015 and is being provided by the Alzheimer's Society. The scope of the service is set out in paragraphs 1.3.5 to 1.3.8 below. The contract was extended by a further year taking the end date to 30 September 2019. The agreed budget for the service is for £300,000 per annum and the Alzheimer's Society have been providing this contract for £279,000 per annum. The current service provides support only after individuals have received a diagnosis of dementia.

1.3.2 The contract has been monitored through the contract management process and the provider has to submit quarterly performance information.

1.3.3 To provide some context to the number of people being supported by the service, below are the figures for the last three years of the contract:-

	Number of Referrals	Number. of CrISP* Programmes Delivered
Year 1	1351	9
Year 2	1304	14
Year 3	1546	18

*CrISP – Carers Information and Support Programme: Training provided to carers of people with dementia on the condition, different symptoms and behaviours, how to care for someone with dementia, how to respond to different behaviours and coping mechanisms they can use.

1.3.4 A number of issues with the current contract have been identified, these are detailed below:-

1.3.5 The original contract was modelled on the service supporting around 2,400 people per annum. From the figures detailed above, in year 3 the service had capacity to provide support to a further 854 people. This could indicate the service is underutilised and that further work is required on service promotion and awareness raising. As part of the engagement work carried

out and explained in section 4 below, comparisons have been made with other local authorities which confirm that we should be able to support more people than we are for the budget we have, a comparison that was made in relation to this statement was with East Sussex who have a budget of £400,000 to support 4,600 people in 2018/20 (previously supporting 3,600 people with a budget of £356,000 in 2018/19). The individual cost per person for East Sussex is £87. In comparison, the Lincolnshire County Council service (using year 3's figures) is £194 per person.

- 1.3.6 The current specification splits the service into two types of support: Information and Advice (I&A), and Care Navigation. At the start of the contract this resulted in a high level of I&A being provided through the service with the majority of support being over the phone and via leaflets being left or sent in the post. Through contract management, this approach to the service has been developed over the duration of the contract and the change to the majority of cases being delivered through care navigation can be evidenced in the graph shown in Appendix 1A. This highlights that the majority of referrals now received are for support through care navigation.
- 1.3.7 The provider experienced barriers in working in partnership with other health and social care organisations and the third sector. With involvement from the contract manager barriers with the third sector were improved, however partnership working with social care remained poor. This was due to perceived barriers with social care being unable to refer to the service through Mosaic, however a paper referral was available and through engagement it was found that this was not being used due to social care teams being unaware of the service.
- 1.3.8 It was a requirement of the current specification for the provider to establish a working group which would bring together relevant stakeholders and partners. This has not been achieved due to governance arrangements not being put in place. This issue has been reviewed through contract management arrangements a number of times but not been resolved to date. This issue has adversely impacted on a number of things including clear pathways into the service, wider knowledge of the service and what it can offer.
- 1.3.9 The service promotion undertaken by the current provider has not generated the expected referral levels. It was cited by them that further work was required on promotion of the service. Within the current contract there were no specific resources for promotion of the service, instead support workers spent a limited amount of their time on this. This can be evidenced by considering the data collected by the provider which shows the sources of the referral into the service with the most common being self/family referral therefore suggesting that all necessary pathways from other organisations have not been fully established.

1.3.10 The incumbent provider has highlighted many incidences where the current title of the service "Dementia Family Support Service" has caused confusion with people that use services the assumption that this service is only for the family of the person with dementia. This is evidenced by the fact that the majority of referrals into the service have been by the carer of the person with dementia, this was recorded as 80% of all referrals in year 3 of the contract being for the family/carer.

1.3.11 When the contract was established, a number of Key Performance Indicators (KPIs) were set with the intention of gathering information about the services key metrics. As this was a relatively low value new service with no performance baseline to measure against the intention was to better understand what the service could do before targets were set. A dashboard has been developed for the last two years of the contract which provides an overview of the KPI data. This can be found in Appendix 1B. The KPIs focus on areas including, source and number of referrals into the service, the outcomes of the referral for example whether the referral resulted in support and if they were supported by the service, which type of support they received, i.e. care navigation, information and advice.

1.3.12 Highlights that can be drawn from the KPIs from the most recent reporting period are as follows:-

- In relation to the Care Navigation element of the service, 95% of people that use services who responded to feedback questionnaires stated that they have been provided with useful information.
- 65% of people that use services who responded to feedback questionnaires stated that they have been provided with coping strategies to help them or the person they cared for feel more able to continue with practical tasks.
- 92% of people that use services who responded to feedback questionnaires stated they felt they could contact the worker for support

These highlights build a picture of the positive impact the service has been having on people that use services.

1.3.13 All of the above identified issues with the current service have been thoroughly considered when re-designing the revised service specification to ensure similar issues do not arise again. The issues raised can be found in section 7 below.

1.4 Engagement

1.4.1 A number of types of engagement have been undertaken to understand the impact that the current service has had on stakeholders and people that use services. The findings from the engagement have helped to shape the planning and design of the new revised specification. An overview of the types of engagement undertaken can be found below:-

- 1.4.2 A snap survey was conducted at the end of 2018 to gain a good understanding of how the service could be provided in a way that best supports people with dementia, their family and their carers'. This was sent to people with dementia and their carers'. 106 people responded to a snap survey, 97% of these were carers or family members of someone with dementia or MCI.
- 1.4.3 The commissioning team have attended a number of support groups which people with dementia and their carers attend run by Sleaford Dementia Support, South Lincolnshire Dementia Support Service and Tonic Health. Feedback received suggested that few affected people were aware of the service provided by the Alzheimer's Society which was disappointing. In addition, a Lincolnshire Partnership NHS Foundation Trust engagement event held for carers was attended to understand the carer's journey when the person with dementia is receiving support from the NHS.
- 1.4.4 An internal survey was sent to practitioners to ask about their experience of the service, what had gone well and what could be improved in the future. In addition, commissioners attended social work team meetings to discuss the current service to understand their views from an operational perspective.
- 1.4.5 Some benchmarking activity also took place with 8 local authorities to understand the services they were commissioning including, scope of services, contract value, payment mechanisms, partnership working with existing Admiral Nurse services and service capacity and demand.
- 1.4.6 Findings were also taken from the annual carer's survey to help understand the carers experience of accessing services that support people with dementia.
- 1.4.7 Health colleagues, Lincolnshire County Council practitioners and Carers FIRST were sent questionnaires' regarding the service and face to face engagement has been conducted with Lincolnshire Partnership NHS Foundation Trust, South West Lincolnshire Clinical Commissioning Group, Healthwatch Lincolnshire, Dementia UK and The Alzheimer's Society.
- 1.4.8 Wider market engagement was conducted to try and understand the market's position in relation to delivery of services of this nature. This involved a market engagement questionnaire for interested parties to complete and return.

1.5 Engagement Findings

A summary of the findings following all elements of engagement described above are as follows:-

- 1.5.1 Snap survey analysis highlighted that only 7% of respondees had recognised that they had accessed the Dementia Family Support Service however, 43% had accessed services provided by the Dementia Family Support Service (Alzheimer's Society, CrISP sessions). This data supports the concerns around promotion and awareness of the service. The survey also confirmed that for carers and the person with dementia, the most important type of support they could receive was having someone available to talk to throughout the dementia journey (in the survey, this equated to 67% of the people with dementia, 78% of the family/carer respondees)
- 1.5.2 Too much emphasis is put on the I&A element of the current service with too much support being over the phone and via leaflets being left or sent in the post. This feedback was received via the support groups attended and through contract management..
- 1.5.3 People that accessed the service reported being very appreciative that the service gave them a named person they could contact if anything changed, or something happened and they needed further support. This was valuable to them as no other service was able to offer this and some people (particularly those with vascular dementia) felt they had been set adrift after the diagnosis.
- 1.5.4 People require support throughout the dementia journey; support at an earlier stage would be beneficial to discuss potential diagnosis and what this might mean for individuals. This was confirmed through the snap survey results.
- 1.5.5 The current approach to promotion of the service undertaken by the Alzheimer's Society has not been successful at increasing referrals with many of the public and most adult care practitioners still being unaware of the service and what it can offer.
- 1.5.6 The majority of the local authorities that were approached who provided a dementia support service also provided support to people pre-diagnosis as well as post-diagnosis of dementia. Most of the services were also jointly commissioned with clinical commissioning groups. The comparisons made in relation to numbers of people that use services supported for the available budget confirmed that our budget should be able to support more people.
- 1.5.7 Further work is required in relation to establishing partnership working practices with health, social care and the third sector to further develop the dementia pathways. This work is essential to the success of the service and therefore should be a key requirement within the specification. Documents collating all of engagement data can be found at Appendices 2A and 2B.

1.6 Continuation of Service

- 1.6.1 Dementia is one of the most significant health and social care priorities of the current time and with no cure foreseen in the near future there is a very clear drive from health and social care on the need for raising awareness of how healthy lifestyles can reduce the risk of developing dementia.
- 1.6.2 For individuals that receive a diagnosis of dementia the impact on their lives is profound, this also has a major impact on their family and informal carers who can find themselves in a world of health and social care terminology, processes, treatments etc. that is completely new to them.
- 1.6.3 The Dementia Community Support Service can provide support for people with dementia, their family and carers throughout the whole journey of dementia through to end of life and bereavement. This support will delay the need for more intensive health and social care services as well as preventing carer breakdown.
- 1.6.4 It is the only service provided by the Council for dementia sufferers and their families and carers. The extensive engagement has demonstrated the need for and appreciation of ongoing support. The Council through the Lincolnshire Joint Strategy for Dementia 2018-2021 has committed to the commission a post-diagnosis family support service to succeed the current DFSS agreement which will help promote resilience, healthy lifestyles, and physical and mental wellbeing. In that context a failure to provide that support may trigger a legal obligation to consult and/or engage with affected people.
- 1.6.5 The cost of the service per user is £194, this is based on current referral levels, which of course we would be expecting to increase.
- 1.6.6 If the Council is able to continue with a dementia service then the engagement carried out demonstrates that outcomes would be improved by making changes.

1.7 Proposed Changes to the Service

- 1.7.1 Based on the evidence gathered and detailed within this report, the proposed changes to the scope of the service are explained below:-
 - 1.7.1 The service will be renamed to Dementia Community Support Service.
 - 1.7.2 It is proposed that the County's offer of support for people with dementia and their family and carers will be delivered through a tiered level of support. This can be seen in a diagram in Appendix 3. The Dementia Community Support Service will deliver tier 2 support that is bespoke to individual needs, supporting people to live well within their local communities. The support includes some advice and signposting but is mainly practical support, care navigation and activities that promote wellbeing and social

inclusion. Tier 1 is advice which is available through various different information and advice services already provided by the council (i.e. the Customer Service Centre, the Lincolnshire Cares Support Service, the Wellbeing Service and Connect to Support Lincolnshire) and tier 3 is support for people with multiple and complex needs, provided through health and social care, as well as the admiral nurse pilot scheme, due to commence in June 2019.

- 1.7.3 The specification will clearly set out what support the council would require which will be flexible support based on individual's needs and the outcomes to be achieved as well as developing individuals' and communities resilience. The support will include some information, advice and signposting but will mainly focus on the provision of practical support to navigate the health and social care systems, support to prolong living independently, access activities that promote wellbeing and social inclusion, learning about the condition and different coping strategies, advice throughout the dementia journey, what they may need to expect and support in planning for the future.
- 1.7.4 The service will continue to be the first point of contact for people with dementia and their family and carers, providing them with a named person they can contact throughout the dementia journey.
- 1.7.5 There will be more emphasis on the provider to develop and maintain good partnership working practices with health, social care and the third sector to further develop the dementia pathways as well as developing a clear and widely recognised referral pathway into the service. This will further increase awareness of the service within different organisations and in turn increase referral rates. This activity will be included within the performance management of the contract allowing the Council to hold the provider to account if this requirement is not being delivered.
- 1.7.6 The partnership working and pathway development will be supported by relevant Lincolnshire County Council staff to ensure that there is a good understanding of the referral pathways into the service for operational Council staff that would be using it.
- 1.7.7 The specification will be clear on what promotion and engagement the service will need to carry out, for example; clear branding of the service (Dementia Community Support Service), clinics based at GP's, memory clinics, attending practitioner team meetings etc.
- 1.7.8 Widen the scope of the service to provide support to people with MCI, to support prevention of dementia, and to help more people understand the condition, understand the diagnosis process and what a diagnosis could mean for them and giving them time to be able to plan for the future, supporting them to remain as independent for as long as possible, delaying the need for health and adult care intervention.

1.7.9 KPI's will be developed to place a focus on the information that is gathered from the provider that will need to demonstrate their performance against the outcome of the specification. Mechanisms will be built into the contract to ensure that the provider can be held to account if performance levels are not being met.

1.7.10 In relation to the existing Carers FIRST service referred to in paragraph 1.2.2, there is an acceptance that there will be elements of duplication between the Dementia Community Support Service and this service. It will be a requirement of the provider to ensure that referrals are made between services when applicable. In addition, the contract will be managed to ensure that the providers will work together to ensure pathways are effective to ensure minimal duplication where possible.

1.8 Procurement Approach

1.8.1 The intention to re-commission the Dementia Community Support Service for a further 3 years, with the option to extend for a further 2 years would be delivered by the way of a competitive tender process in accordance with regulations 74 to 76 of the Public Contract Regulations 2015 (Annex A) under "Light Touch Regime" utilising an Open Procedure method. This approach is being proposed due to the limited number of potential providers within the market. The decision as to which provider is awarded the single provider status will be based on their evaluation performance.

1.8.2 The Invitation to Tender (ITT) evaluation will focus on service quality and the capability of the provider to deliver the required work and quality outcomes as outlined in the specification.

1.9 Market Engagement Questionnaire

1.9.1 A Prior Information Notice was issued October 2018 which included a market engagement questionnaire for interested providers to complete and return. The questionnaire covered contract duration, contract attractiveness, performance management and contract payment.

1.9.2 Five questionnaires were returned, the responses have helped to inform the procurement strategy and specification development. The responses indicated that providers would be keen to have a minimum three year contract both from a practical and financial perspective with a block contract payment as the most appealing for this type of service. The questionnaire helped to confirm that there is interest from the market for this type of contract other than just the incumbent provider and the responses suggested some level of performance related payment would be acceptable to the market.

1.10 Contract Duration

1.10.1 The Commercial Team propose a contract duration of three years. This contract term was confirmed through the market engagement phase as the minimum contract length providers would consider as financially viable. In addition to the three year contract term, the ability to extend the contract for a further two years (one + one) should be included to provide the Council with options at the end of the initial contract period.

1.11 Pricing Structure

1.11.1 The annual budget for the Dementia Community Support Contract is currently £300,000, it is proposed and has been confirmed by finance that the budget will remain the same; therefore the potential total contract value for the five years will be £1,500,000.

1.11.2 The pricing model is still being developed. One option being considered is to set a baseline which is in line with the current number of people being supported within the current contract and includes a percentage increase year on year to be met by the provider; this element of the service would be delivered through a block payment arrangement. Referrals into the service over and above this baseline figure would be through payment via a unit cost. Both elements would not be able to exceed the £300,000 annual budget allowance.

1.11.3 This approach would help to encourage the provider to work on increasing referrals to generate further payment and ultimately supporting a greater percentage of the cohort of people.

1.11.4 In addition to this, inclusion of a payment mechanism linked to performance is being considered so as to ensure that if service delivery falls below expected performance levels that remedial action can be linked to payment. This approach has been confirmed through the market engagement and liaison with local authorities who are using a similar approach.

1.12 Procurement and decision making timeline

Adults and Community Wellbeing Scrutiny Committee	10 April 2019
Issue Invitation to Tender	30 April 2019
Evaluation Period	3 – 14 June 2019
Standstill Period	1 – 10 July 2019
Contract Award	11 July 2019
Mobilisation Period (2.5 months)	15 July – 30 September
Go Live	1 October 2019

2. Legal Issues:

Equality Act 2010

Under section 149 of the Equality Act 2010, the Council must, in the exercise of its functions, have due regard to the need to:

- * Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the Act
- * Advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it
- * Foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

The relevant protected characteristics are age; disability; gender reassignment; pregnancy and maternity; race; religion or belief; sex; and sexual orientation

Having due regard to the need to advance equality of opportunity involves having due regard, in particular, to the need to:

- * Remove or minimise disadvantages suffered by persons who share a relevant protected characteristic that are connected to that characteristic.
- * Take steps to meet the needs of persons who share a relevant protected characteristic that are different from the needs of persons who do not share it.
- * Encourage persons who share a relevant protected characteristic to participate in public life or in any other activity in which participation by such persons is disproportionately low.

The steps involved in meeting the needs of disabled persons that are different from the needs of persons who are not disabled include, in particular, steps to take account of disabled persons' disabilities.

Having due regard to the need to foster good relations between persons who share a relevant protected characteristic and persons who do not share it involves having due regard, in particular, to the need to tackle prejudice, and promote understanding.

Compliance with the duties in section 149 may involve treating some persons more favourably than others.

The duty cannot be delegated and must be discharged by the decision-maker. To discharge the statutory duty the decision-maker must analyse all the relevant material with the specific statutory obligations in mind. If a risk of adverse impact is identified consideration must be given to measures to avoid that impact as part of the decision making process.

- 2.1 The key purpose of the service is to support people with dementia, together with their families and carers.
- 2.2 An Impact Assessment has been completed and a copy of it is appended to this report (Appendix 4). It is clear within the proposal for this service that the service will remain open to all groups regardless of protected characteristic if recommissioned.

- 2.3 The Impact Assessment considers both the positive impacts of continuing the service and the adverse impacts of not continuing the service. Adverse impacts are identified on older people, people with a disability and women as a result of the service not being re-commissioned. Mitigation exists for these impacts on the availability of support through the health service and specifically GPs. The effect of this however would be to draw individuals into the health service rather than give them and their carers support to improve their lives and live independently for longer.
- 2.4 There is also a risk that a change of provider will impact on persons with a protected characteristic arising out of the employment impact on staff. The staff employed by the current provider will be affected by the end of the current contract. Mitigating factors will relate to the legal protections that will be in place through TUPE, if it applies, and general employment laws. The contract that will be entered into will also contain clauses requiring the contractor to comply with the Equality Act.
- 2.5 Given these mitigations and having regard to the adverse impacts it is open to the Executive Councilor to conclude that having considered the duty she considers that any potential there is for differential impact or adverse impact can be mitigated.

3. Joint Strategic Needs Analysis (JSNA and the Joint Health and Wellbeing Strategy (JHWS)

The Council must have regard to the Joint Strategic Needs Assessment (JSNA) and the Joint Health & Well Being Strategy (JHWS) in coming to a decision.

- 3.1 The Lincolnshire Joint Strategic Needs Assessment (JSNA) recognises that dementia is one of the most pressing challenges for health and social care with an estimated 850,000 people in the UK living with dementia.
- 3.2 It is estimated that in 2017 there were 11,752 people aged 65 and over living with dementia in Lincolnshire which is predicted to increase by 74% to 20,427 by 2035, this increase is higher than the predicted increase nationally of 70%.
- 3.3 The Joint Health and Wellbeing Strategy for Lincolnshire (2018) includes dementia as one of the key priority areas and states that we will commission a post-diagnosis family support service to succeed the current Dementia Family Support Service agreement which will help promote resilience, healthy lifestyles, and physical and mental wellbeing.
- 3.4 Highlighting the need for comprehensive and integrated pathways throughout the dementia journey, support for people with dementia, prevention programmes for vascular dementia, greater integration and awareness within neighbourhood teams, wider professionals and the public.

3.5 The Dementia Community Support Service will support a number of these themes around Dementia:

- Offering a community based support service for people with dementia and their families and carers throughout the different stages of the dementia journey.
- Improve and enable integrated working between different health and social care services, neighbourhood teams, community services etc.
- Raise awareness of dementia and what can be done to reduce the risk of developing dementia.

4. Crime and Disorder

Under section 17 of the Crime and Disorder Act 1998, the Council must exercise its various functions with due regard to the likely effect of the exercise of those functions on, and the need to do all that it reasonably can to prevent crime and disorder in its area (including anti-social and other behaviour adversely affecting the local environment), the misuse of drugs, alcohol and other substances in its area and re-offending in its area

4.1 This service is unlikely to contribute to the furtherance of the section 17 matters.

5. Conclusion

5.1 Dementia is one of the most significant health and social care priorities of the current time and with no cure foreseen in the near future there is a very clear drive from health and social care on the need for raising awareness of how healthy lifestyles can reduce the risk of developing dementia.

5.2 For individuals that receive a diagnosis of dementia the impact on their lives is profound, this also has a major impact on their family and informal carers who can find themselves in a world of health and social care terminology, processes, treatments etc. that is completely new to them.

5.3 The Dementia Community Support Service can provide support for people with dementia, their family and carers throughout the whole journey of dementia through to end of life and bereavement. This support will prolong the need for more intensive health and social care services as well as preventing carer breakdown.

6. Legal Comments:

The Council has the power to enter into the contract proposed. The legal considerations to be taken into account in reaching a decision are dealt with in the Report.

The decision is consistent with the Policy Framework and within the remit of the Executive Councillor.

7. Resource Comments:

The Dementia Family Support Service, currently provided by the Alzheimer's Society, is due to end on the 30 September 2019. The budget for the existing service is £0.300m with annual service costs totalling £0.297m. This report seeks to present the case for the continued provision of this service via a procurement process for the same budgetary value as the existing contract. I can confirm that the Council has sufficient budget to fund the service. I can also confirm that current commissioning intentions and delegated approvals recommended within this report meet the criteria set out in the Council's published financial procedures.

8. Consultation

a) **Has Local Member Been Consulted?** – Not applicable

b) **Has Executive Councillor Been Consulted?** - Yes

c) Scrutiny Comments

This decision will be considered by the Adults and Community Wellbeing Scrutiny Committee on 10 April 2019 and the comments of the Committee will be reported to the Executive Councillor prior to her making her decision.

d) **Have Risks and Impact Analysis been carried out?** - Yes

e) **Risks and Impact Analysis** - Attached at Appendix 4

9. **Appendices** - These are listed below and attached to the report.

Appendix 1A	Type of Support Provided - The Alzheimer's Society
Appendix 1B	Key Performance Indicator Dashboard - Performance of the Current Service
Appendix 2A	Engagement Summary
Appendix 2B	Engagement Report on Dementia Community Support Service - Snap Survey Results
Appendix 3	Delivery Model Diagram
Appendix 4	Equality Impact Assessment

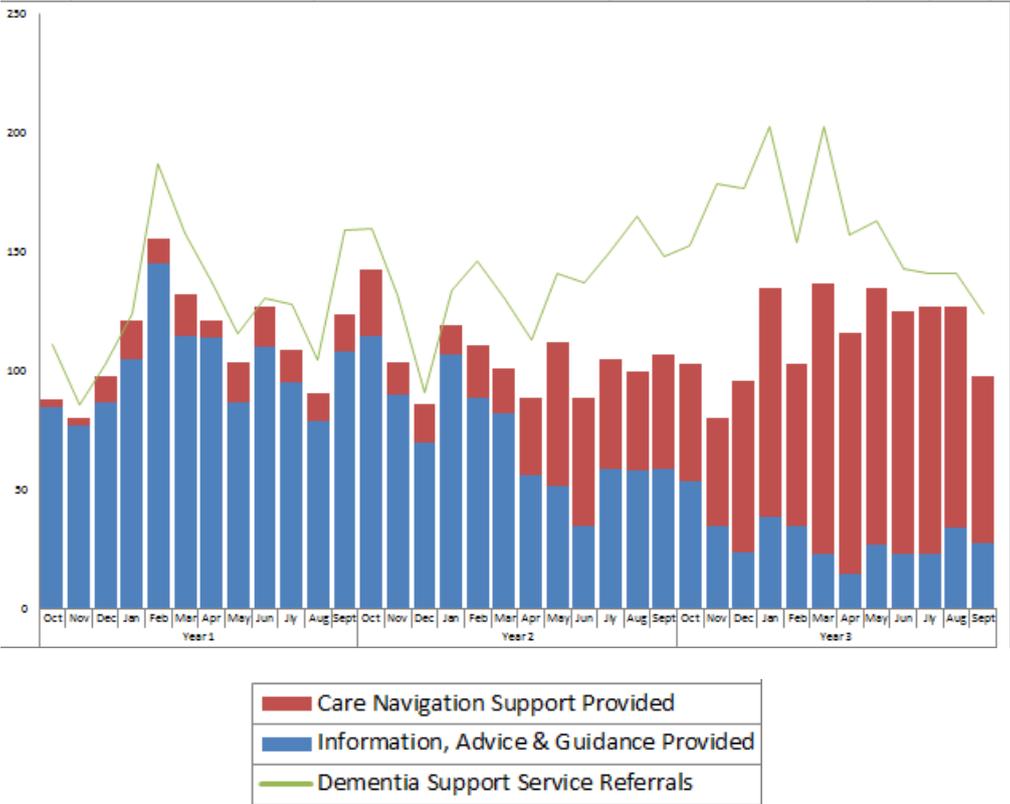
10. Background Papers

No Background Papers within the meaning of section 100D of the Local Government Act 1972 were used in the preparation of this Report

This report was written by Karley Beck, who can be contacted on 01522 553695 or at karley.beck@lincolnshire.gov.uk

Type of Support Provided - The Alzheimer's Society

Graph to show the move from service focus on information and advice to care navigation



DEMENTIA FAMILY SUPPORT SERVICE
PERFORMANCE INFORMATION

YEAR 3 2017-18

DFSS KPI 01	Referrals into the Service	Measures	Contract Year	Quarter 1				Quarter 2				Quarter 3				Quarter 4			
		Time Period	2017/18	Oct-17	Nov-17	Dec-17	Q1 Total	Jan-18	Feb-18	Mar-18	Q2 Total	Apr-18	May-18	Jun-18	Q3 Total	Jul-18	Aug-18	Sep-18	Q4 Total
		Hospital Referrals	319	31	43	38	112	63	23	28	114	33	17	18	68	10	13	2	25
Community Referrals	1619	122	136	139	397	140	131	175	446	124	146	125	395	131	128	122	381		
Total Referrals	1938	153	179	177	509	203	154	203	560	157	163	143	463	141	141	124	406		
New Contact	1087	N/A	N/A	N/A	N/A	157	113	160	430	123	158	98	379	92	107	79	278		
Returning Contact	327	N/A	N/A	N/A	N/A	46	41	43	130	34	5	45	84	49	21	43	113		
% New Contacts	76%	-	-	-	-	77%	73%	79%	77%	78%	97%	69%	82%	65%	76%	64%	68%		

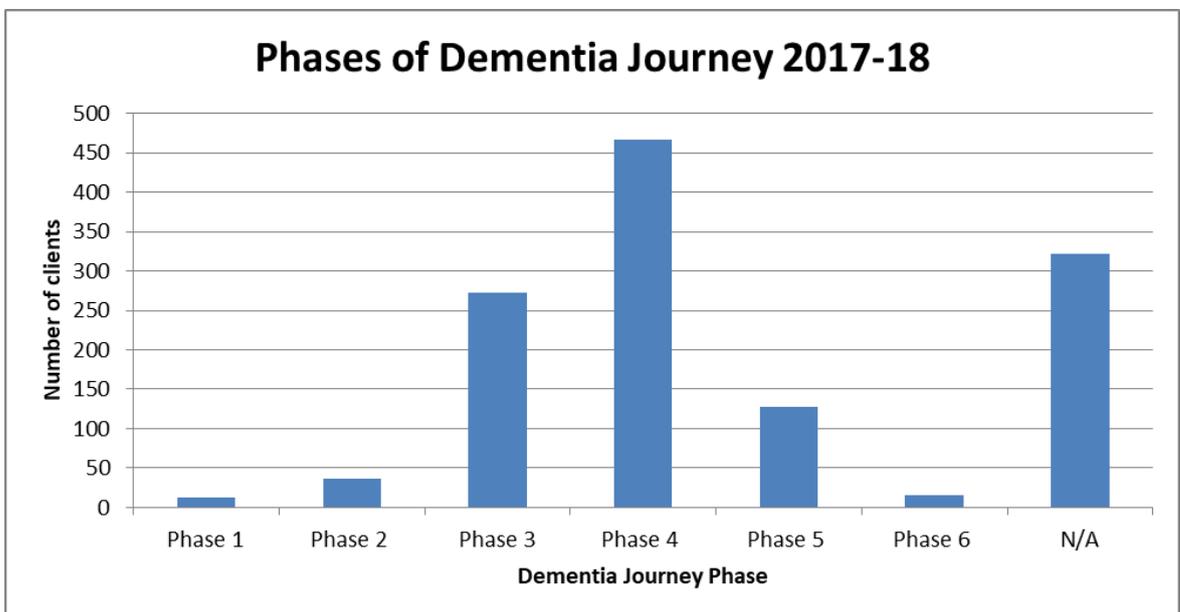
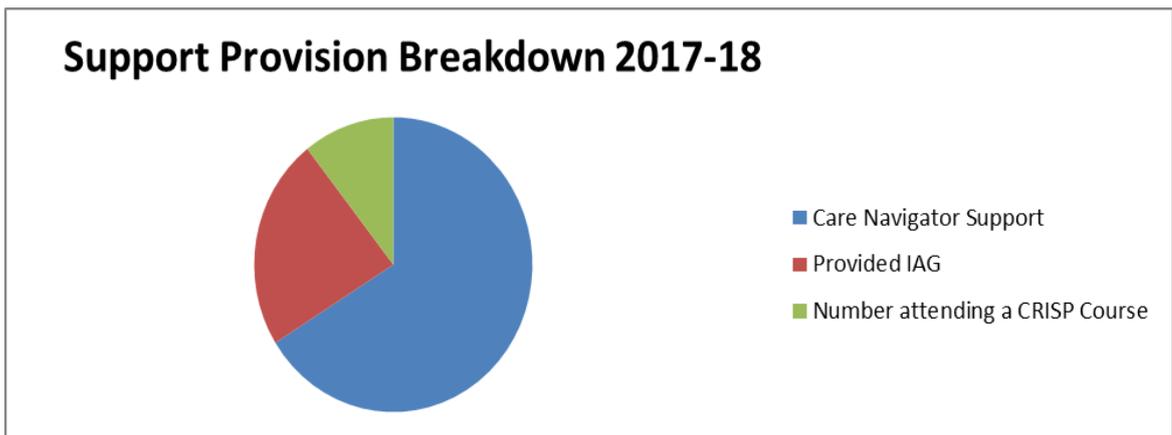
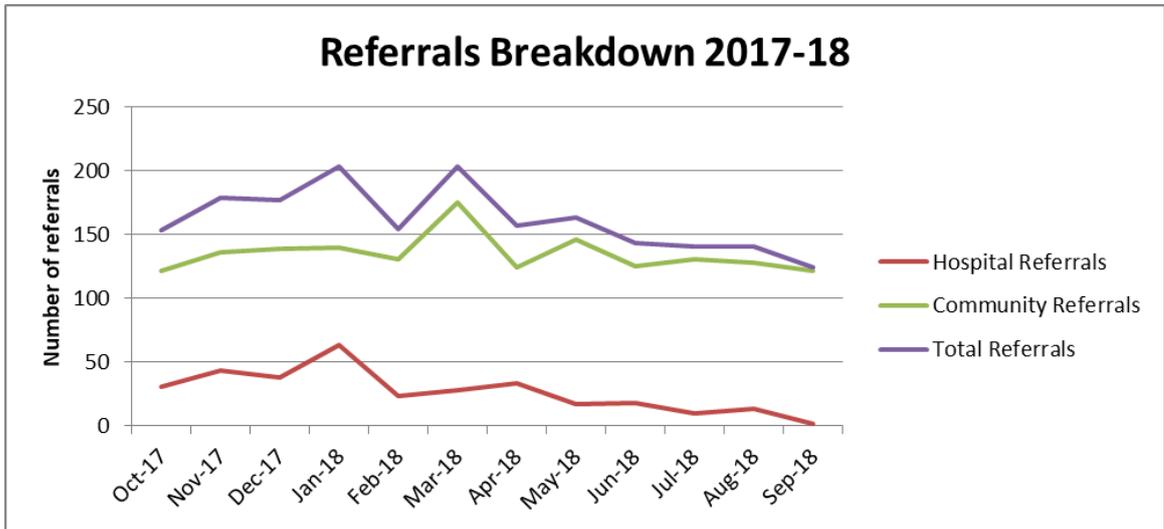
DFSS KPI 02	Referral Outcome	Measures	Contract Year	Quarter 1				Quarter 2				Quarter 3				Quarter 4			
		Time Period	2017/18	Oct-17	Nov-17	Dec-17	Q1 Total	Jan-18	Feb-18	Mar-18	Q2 Total	Apr-18	May-18	Jun-18	Q3 Total	Jul-18	Aug-18	Sep-18	Q4 Total
		Total Number Supported	1544	113	129	146	388	143	114	158	415	116	137	125	378	127	127	109	363
Total Cases Terminated	384	40	50	25	115	56	40	45	141	41	26	18	85	14	14	15	43		
Total Number still in Triage process	10	0	0	6	6	4	0	0	4	0	0	0	0	0	0	0	0		
% Referrals converted into Support	80%	74%	72%	82%	76%	70%	74%	78%	74%	74%	84%	87%	82%	90%	90%	88%	89%		

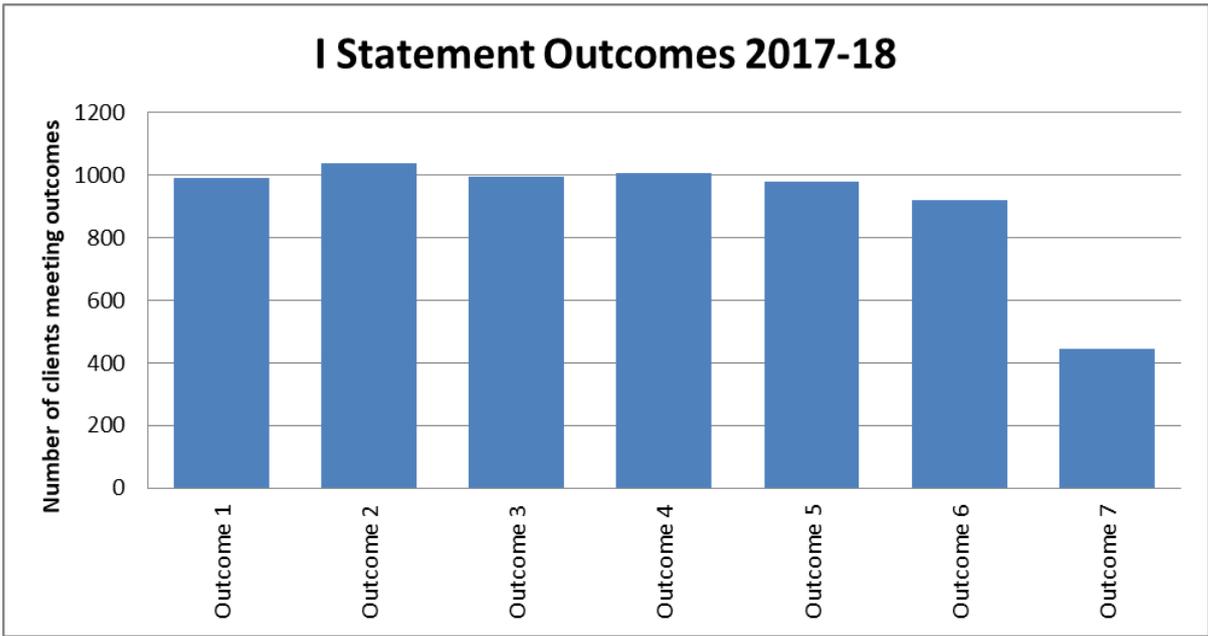
DFSS KPI 02a	Supported by the Service	Measures	Contract Year	Quarter 1				Quarter 2				Quarter 3				Quarter 4			
		Time Period	2017/18	Oct-17	Nov-17	Dec-17	Q1 Total	Jan-18	Feb-18	Mar-18	Q2 Total	Apr-18	May-18	Jun-18	Q3 Total	Jul-18	Aug-18	Sep-18	Q4 Total
		Total Number Supported	1544	113	129	146	388	143	114	158	415	116	137	125	378	127	127	109	363
Care Navigator Support	1022	49	45	72	166	96	68	114	278	101	108	102	311	104	93	70	267		
Provided IAG	360	54	35	24	113	39	35	23	97	15	27	23	65	23	34	28	85		
Number attending a CRISP Course	164	10	49	50	109	8	11	21	40	0	2	2	4	0	0	11	11		

DFSS KPI 02b	Reasons for Case Terminated	Measures	Contract Year	Quarter 1				Quarter 2				Quarter 3				Quarter 4			
		Time Period	2017/18	Oct-17	Nov-17	Dec-17	Q1 Total	Jan-18	Feb-18	Mar-18	Q2 Total	Apr-18	May-18	Jun-18	Q3 Total	Jul-18	Aug-18	Sep-18	Q4 Total
		Total Number Declining the Service	199	13	25	17	55	31	22	26	79	25	14	7	46	7	6	6	19
Total Number of Inappropriate Referrals / No Dementia Diagnosis	67	4	13	2	19	8	7	9	24	4	8	4	16	1	4	3	8		
Total Number Unable to Contact	118	23	12	6	41	17	11	10	38	12	4	7	23	6	4	6	16		

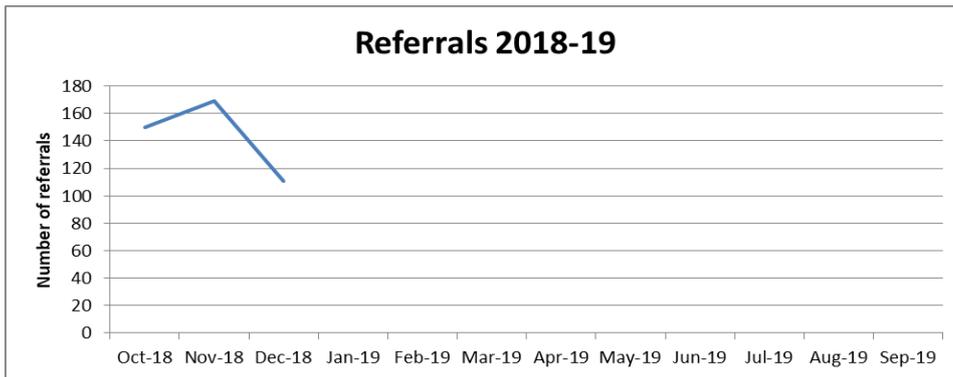
DFSS KPI 03	Phases of the Dementia Journey	Measures	Contract Year	Quarter 1				Quarter 2				Quarter 3				Quarter 4			
		Time Period	2017/18	Oct-17	Nov-17	Dec-17	Q1 Total	Jan-18	Feb-18	Mar-18	Q2 Total	Apr-18	May-18	Jun-18	Q3 Total	Jul-18	Aug-18	Sep-18	Q4 Total
		Phase 1	13	2	5	4	11	N/A	N/A	N/A	N/A	1	0	0	1	0	0	1	1
Phase 2	36	6	2	9	17	N/A	N/A	N/A	N/A	1	5	7	13	1	4	1	6		
Phase 3	272	40	19	23	82	N/A	N/A	N/A	N/A	38	33	36	107	32	31	20	83		
Phase 4	467	37	41	40	118	N/A	N/A	N/A	N/A	50	49	65	164	67	59	59	185		
Phase 5	127	16	12	23	51	N/A	N/A	N/A	N/A	11	16	7	34	16	9	17	42		
Phase 6	15	4	4	2	10	N/A	N/A	N/A	N/A	0	0	1	1	2	1	1	4		
N/A	321	38	47	26	111	N/A	N/A	N/A	N/A	56	55	25	136	23	37	14	74		

DFSS KPI 04	Statement Outcomes; clients identified as meeting outcomes	Measures	Contract Year	Quarter 1				Quarter 2				Quarter 3				Quarter 4			
		Time Period	2017/18	Oct-17	Nov-17	Dec-17	Q1 Total	Jan-18	Feb-18	Mar-18	Q2 Total	Apr-18	May-18	Jun-18	Q3 Total	Jul-18	Aug-18	Sep-18	Q4 Total
		Outcome 1	990	71	59	73	203	112	93	117	322	60	83	100	243	96	64	62	222
Outcome 2	1036	86	72	82	240	126	95	119	340	60	80	102	242	92	67	55	214		
Outcome 3	994	75	70	76	221	121	92	113	326	53	79	100	232	95	61	59	215		
Outcome 4	1005	89	73	84	246	126	91	111	328	53	80	97	230	89	61	51	201		
Outcome 5	978	71	67	78	216	110	90	109	309	57	83	99	239	94	65	55	214		
Outcome 6	919	57	56	62	175	107	91	104	302	54	76	96	226	92	66	58	216		
Outcome 7	445	29	30	21	80	32	31	63	126	21	29	59	109	45	53	32	130		

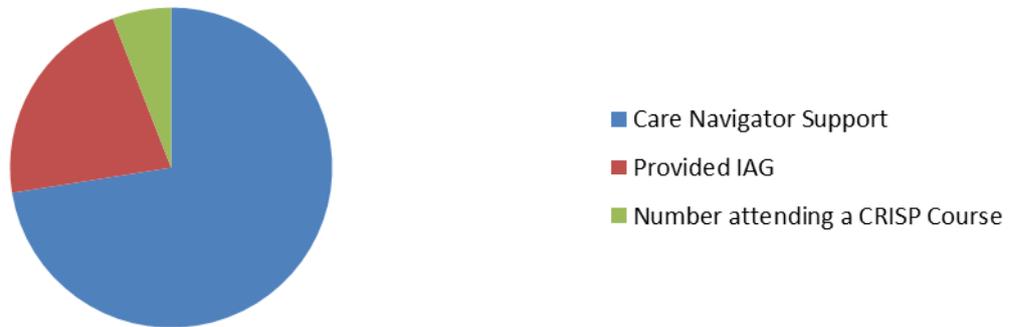




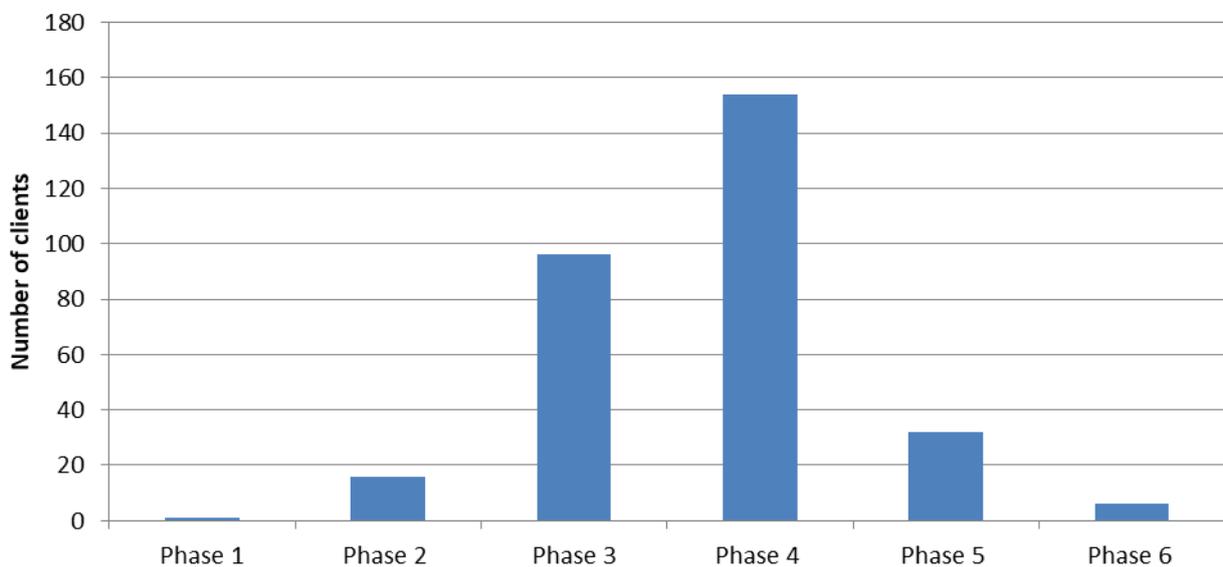
Year 4 - 2018-19

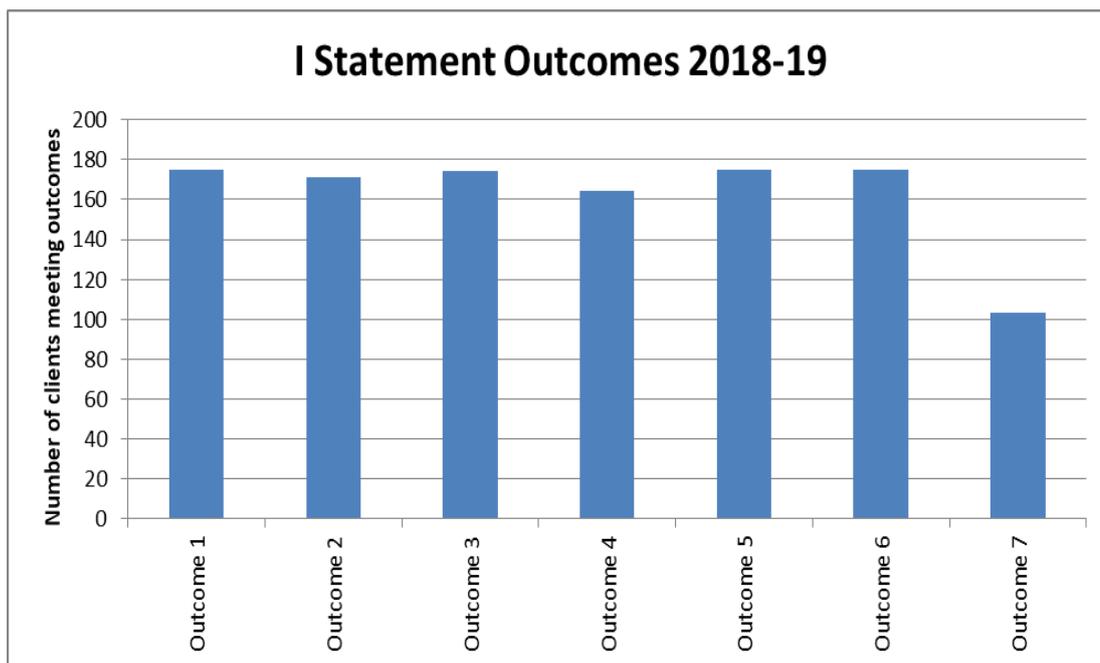


Support Provision Breakdown 2018-19



Phases of Dementia Journey 2018-19





Notes

Phases of the Dementia Journey

Phase 1 - Memory or changing behaviour problems have prompted me to seek help

Phase 2 - Learning that the condition is Dementia

Phase 3 - Learning more about the disease, how to manage, options for care and support

Phase 4 - Getting the right help at the right time to live with Demetia, prevent crisis and manage together

Phase 5 - Managing at more difficult times, including if possible to live at home

Phase 6 - Receiving care, compassion & support at the end of life

I Statements

Outcome 1	I have personal choice and control or influence over decisions about me
Outcome 2	I know that services are designed around me and my needs I have support that helps me live my
Outcome 3	life
Outcome 4	I have the knowledge and know-how to get what I need.
Outcome 5	I live in an enabling and supportive environment where I feel valued and understood
Outcome 6	I have a sense of belonging and of being a valued part of family, community and civic life
Outcome 7	I know there is research going on which delivers a better life for me now and hope for the future

Engagement Summary

Type of Engagement Conducted	Findings
<p>Summary of engagement completed for strategy (4 support groups attended where people with dementia and their carers attended)</p>	<p>Summary of comments collected:</p> <ul style="list-style-type: none"> - Wellbeing is important. - Living healthy, exercising has helped some. - Difference in level of support in different areas. - I get information from the Parkinson's Society. I didn't know we could get help from the Alzheimer's Society. - Feelings of isolation, public interaction can be difficult but it is important. - People have experienced difficulties in getting a diagnosis – few have positive experience (again area differences). - Felt required a family member/carer to be able to 'shake things up' for diagnosis to happen – concern over people who do not have anyone. - Long time to get diagnosis. 2-3 years. - Other health conditions receive attention from health/GP's – dementia takes a back seat or treat dementia as inevitable symptom of old age. - Lives dramatically change, for PWD and for carers and family members. - Issues around emergency support at crisis. Don't know where to go. - Mention carers first, and good that they had access to persons record (mosaic) not a lot of people even mentioned the DFSS. - A lot of different assessments for different services. - Feel nothing is joined up everything is working separately. No link between memory clinic, GP and people living with dementia. - End of life care good, but felt not a lot/good support before this. - Activities and groups are good. But sometimes its not what need, or too many, or not enough or not local. - Continuing healthcare – unable to access as dementia is seen as social care need when actually it is a health need. - No night care provision, little respite provision that can access. - Information pack would be useful – Received information a little bit at time. - Services are only as good as Lincolnshire County Council contract allows them to be.

Type of Engagement Conducted	Findings
<p>Carers Survey 17/18 (copy in folder 'reports' filtered to show feedback from cares of people with dementia Q:\Commissioning Team\AFLTC Commissioning Team\1.TEAM FOLDER\DFSS Contract\Procurement 2019\Reports\Copy of Lincolnshire 17-18 Carers Survey - Dashboard - v0.3.5 (2).xlsm</p>	<p>92/324 carers that filled out the survey, care for someone with dementia. Satisfaction with support or services receive:</p> <ul style="list-style-type: none"> - 29% extremely dissatisfied. - 18% quite satisfied - 19% very satisfied - 15% extremely satisfied. <p>Carers use of support or services in past 12 months:</p> <ul style="list-style-type: none"> - 57% received I&A - 38% support from group of someone to talk in confidence with - 8% training for carers - 2% support to remain in employment. <p>68% do some of the things they enjoy, but not enough. 64% feel they have some control over their daily lives but not enough. 25% feel they have no control over their daily lives. 57% feel they have some social contact with people but not enough. 19% feel isolated.</p> <p>Finding information:</p> <ul style="list-style-type: none"> - 36% fairly easy to find. - 14% fairly difficult to find - 5% very difficult to find. <p>Additional comments informative. Discuss Carers first, dementia UK a lot but not a lot of mention of DFSS or Alzheimer's society. A lot of mention about too many leaflets to wade through, struggling to understand information given etc.</p>
<p>Carers FIRST feedback – Malcolm Ryan (September 2018)</p>	<ul style="list-style-type: none"> - More communication now between CF and DFSS, regular meetings. - Frontline staff maintains regular contacts to keep each other updated. - Support each other at community events. - Prompt after receiving referral. - Regularly refer into CF. - Joint visits been useful. - Introduced a dementia CSAC to regularly contact DFSS and discuss barriers and improvements in each areas. - Received feedback from people sometimes all they receive is large amount of leaflets. - Waiting list for side-by-side. - Sometimes logistics of joint visits is too difficult or too daunting for carer. - Only short term support. (feedback from carers) - No professionals at support groups to advise – ran by volunteers. <p>Suggestions for future:</p> <ul style="list-style-type: none"> - More face-to-face and practical support. - Sitting service for those living with dementia – benefit carer.

Type of Engagement Conducted	Findings
<p>South West Lincolnshire Clinical Commissioning Group Feedback – Rachel Redgrave (September 2018)</p>	<ul style="list-style-type: none"> - Responsive and flexible, keen to try new ideas. - Engage at strategic level. - Engaged well with integrated neighbourhood teams. - Easy electronic referral route established. - Issues again it has been too much over the phone and too much leaflet handing out. <p>Suggestions:</p> <ul style="list-style-type: none"> - Encourage more face to face at home or in GP practices. - More integration with Lincolnshire Partnership NHS Foundation Trust Memory assessment services. - Improve support to care homes. - Ensure people that phone national helpline are asked if they would like a follow up with the local DFSS. -
<p>Meeting with Kate Marshall – Dementia Support South Lincs</p>	<ul style="list-style-type: none"> - Struggle for funding. - Have had grant from managed care network (this is one off and need to have plans in place to be sustainable) - Not a lot for young onset dementia – square hole club. - Not a lot of support for males. - Peterborough – dementia resource centre – advised to look into this. - Other contacts: - Bex Nesso - Sleaford support - Michael Morris – Tonic health, Spalding
<p>Lincolnshire Partnership NHS Foundation Trust Engagement event on Carers Pathway</p>	<ul style="list-style-type: none"> - Johns campaign - to promote carers having the ability to stay with person care for in the hospital if they have dementia to prevent deterioration. - DAA – 'We statements' - What carers want: <ul style="list-style-type: none"> o Knowing who to go to – who to contact o Telephone numbers given can be useless o More face-to-face communication o Someone to follow up on visits/calls to ensure people are doing ok.
<p>Meeting: Admiral Nurse consultant Dementia UK</p>	<p>Discussion:</p> <ul style="list-style-type: none"> - Tier 1& tier 2 overlap – should be provided at memory service and preferably with pre-diagnosis support. (support pre diagnosis – get support in place, information available then not has critical intervention needed straight after diagnosis.) - Post diagnosis is critical point for support. - Could take long time to get diagnosed, then after diagnosis memory clinic (Lincolnshire Partnership NHS Foundation Trust) would do follow up 6-8 months after – unless no medication provided then they do NO follow up. - Need to ensure easy process for referring up to admiral nurses and back down to support service. - Neighbourhood teams would be biggest referrer into Admiral nurse service, but needs to be pathway for dementia support

Type of Engagement Conducted	Findings
	<p>service and carers service.</p> <ul style="list-style-type: none"> - With no admiral nurses in post now – where to DFSS refer up to?? Neighbourhood teams?? Back to Lincolnshire Partnership NHS Foundation Trust ? - DFSS suggested designated engagement/awareness officer – can understand why. - Social isolation is big issues and adds to complexity. - Awareness of different cultural issues there might be. - Consider transition points throughout journey and what support available - at each – crisis points – most people will need support at each transition point. - Support worker needs to be suitably trained – know health and care systems and how they work. - Wakefield – have groups where carers and PWD use different rooms – CH will find out more. - Check with Lincolnshire Partnership NHS Foundation Trust what CST offer is. <p>Suggestions made:</p> <ul style="list-style-type: none"> - Side by side support for PWD to allow carers to attend groups. - Enable carers to have discussion outside of home (carers service complete carers surgery's) - When group support provided difficult when mix of people at different stages of journey. - Admiral nurse could support CrISP 2 (higher level). - Volunteering/befriending is important - Need more awareness in GP practices – anyway can join up work with them? Refer at annual review/flu jab/health check etc. - Check carers service for awareness raising - Everyone clear on pathways – everyone must know where can refer to. Joined up working needs to be clear. - Do DFSS report on type of dementia? - Need provider to report on what support has been provided at what stage. - PREVENTION: delay and reduce need for care and support.
South Lincs Dementia Support Group	<ul style="list-style-type: none"> - Stopped receiving support when person cared for went into care home. - Time with people who are experiencing same is vital. Aware of what experiencing, what to expect in future. - Stopped support when person they cared for passed away. 'People got lost when a partner dies' - Forgotten by Alzheimer's society. - Set up own support groups after Alzheimer's society stopped providing support in south of county. - Needs a 'personal touch' 1-1 contact. - Don't send information out in post. - 'Sitting services' are valuable, provided in area by volunteers.

Type of Engagement Conducted	Findings
	<ul style="list-style-type: none"> - See GP as main source of information. - Need main point of contact. - Home visits as well as group support. - Always reactive – told by DFSS to call if need anything – people won't call as struggle on – need the service to 'check in' with people. - Experienced support workers is crucial. - Ex-DFSS employer – 'need more effective way of measuring effectiveness of service as service is tick box exercise.' - Undue focus on providing information - Need to raise awareness of condition to wider communities. - Successful facebook group
Tonic Health Spalding	<ul style="list-style-type: none"> - Engagement with carers. - Not heard of the DFSS. - If require support/assistance go to staff at Tonic health dementia support group. - Felt along after diagnosis. - Everyone cared for someone with different behaviours and different level of insight into condition. - Looked forward to the day at Tonic health, person with dementia enjoyed day and allowed carers to get things done they needed to do. - Don't know where to go for support other than tonic health.
Sleaford Dementia Support Group	<ul style="list-style-type: none"> - People had heard of Alzheimer's society, not heard of DFSS. - A lot felt that they had no support other than support group. - Support group was first point of contact if needed any help or had questions needed answering. - Successful facebook group
Social Worker Team Meetings: Lincoln Gainsborough	<ul style="list-style-type: none"> - Need information at GP's, representative at GP's or pop up clinics - Pop up clinics in outlying villages/coffee mornings - No one in Lincoln team had heard about DFSS. - Some in Gainsborough team had heard about the service. Others didn't understand why service required as SW provide signposting and care navigation. Advised service would be available to people that were not involved with AC yet. - Suggested facebook presence, more advertising, different ways - Service provides training/awareness for practitioners. - Needs to be provided for people before diagnosis. - DFSS attend Gainsborough neighbourhood team so staff know about the service from those meetings. - People require actual practical support – support with transport, sitting service, support to attend activities etc. - Service needs to work well with carers service - Will they work with children? Children may be living in a home with grandparents with dementia.

Snap Survey Results

Engagement Report on Dementia Community Support Service

Snap Survey

- 106 people responded to the snap survey.

Family member or friend of someone diagnosed with dementia	55
Carer of someone diagnosed with dementia	31
Family member or friend of someone with memory difficulties	10
Person with memory difficulties	3
Carer of someone with memory difficulties	1
Person diagnosed with dementia	0

Q2. Have you been in touch with any organisations or services for people with Dementia or with memory difficulties, their families or carers.

- 68% reported they had been in touch with an organisation or service for people with dementia.

Q3. What type of support services have you accessed.

A variety of different services were listed in the free text.

32% had been in touch with the Alzheimer's society, only 7% reported they had been in contact with the DFSS.

If you add everyone who mentioned the Alzheimer's society, the DFSS and CrISP sessions the total was 43%.

20% reported they had been in contact with the Lincolnshire Carers Service (most referred to carers first)

Other types of services were:

- Respite/short break
- Charity & voluntary organisations
- CMHT
- Online information
- Memory services
- GP
- Support Groups/cafes/coffee mornings
- Activities Eg. Golf, singing.

Q4. At what point do you think it is most useful for people with dementia, their family and carers to START to access a dementia support service.

When receiving a diagnosis of dementia	73
When needing to consider different care options	64
To live well after receiving a diagnosis of dementia	61
When first start to experience memory difficulties	42
When attending memory assessment/test	34

Answers given under 'Other' were:

- On-going support,
- Support at any time during the journey
- As and when required.

Q5. How important do you think the following types of support are for the PERSON WITH DEMENTIA

Top Answers were:

- Someone available to talk to throughout the dementia journey (67%)
- Advice on available services and groups (56%)
- Time spent socialising (with family/friends etc.) (55%)
- Support groups (49%)

Q6. In what other ways do you think a PERSON WITH DEMENTIA could be supported

A lot of people mentioned something other than groups due to the person becoming immobile or lacking communication and/or confidence to take part/attend.

Other ways to support PWD were:

- Specialist advice and information
- Training sessions
- Variety of types of support
- Support to attend activities/groups
- Forward planning/knowing what might come next
- More regular support eg. Weekly, someone can contact when needed.
- Practical support Eg. Form filling, personal care, housework, transport
- More awareness of condition, trained/knowledgeable staff

Q7. How important do you think the following types of support are for FAMILY & CARERS of someone with Dementia.

Top answers were:

- Someone available to talk to throughout the dementia journey (78%)
- Advice on available services and groups (69%)
- Information (verbal, leaflets, online) (65%)
- Time spent socialising (with family/friends etc.) (61%)

Q8. What other ways do you think the FAMILY & CARERS of someone with Dementia could be supported.

Answers:

- Respite/short break from caring/sitting service
- Training & information sessions
- Emotional support
- On-going/regular support
- Someone to talk to
- Link with others experiencing same
- Access to MH urgently/when needed/for carer

Response demographics

Age 64 and under	65
Age 65 and over	31
Prefer not to say	4

Female	78
Male	20
Prefer not to say	2

Boston	9
East Lindsey	9
Lincoln	5
North Kesteven	29
South Holland	12
South Kesteven	14
West Lindsey	15
Out of county	2

Delivery Model Diagram



Aldridge, Z and Burns, A. – ABC Tiered model of Post Diagnostic Support (2016).

Tier 1 is advice which is available through different information and advice services provided by the council (ie. the Customer Service Centre, the Carers Service, Wellbeing Service and Connect to Support Lincolnshire).

Tier 2 support will be the Dementia Community Support Service, it is a bespoke service and will provide support for individuals with mild cognitive impairment or a diagnosis of dementia, their family and carers. This support will be community based and will

support people to live well within their local communities. The support includes some advice and signposting but is mainly practical support, care navigation and activities that promote wellbeing and social inclusion.

Tier 3 support is for people with multiple and complex needs. This will be delivered through the Admiral Nurses. The Admiral Nurse service has been let with an initial 2 year pilot delivered in partnership with St Barnabas and NHS Colleagues and is due to start May 2019.
