

Sue Ryder

Dementia Together Service

Updated: A mid-term evaluation of the Dementia Together Service by Sue Ryder, Ipswich, Suffolk.

Christopher Hayre

Katie Tyrrell

Ruth Strudwick

July 2018

CONTENTS

| | |
|--|----|
| Executive Summary | 3 |
| Acknowledgements | 3 |
| 1.0. Introduction | 4 |
| 1.1. <i>Why the service was developed</i> | 4 |
| 1.2. <i>Dementia Together</i> | 5 |
| 1.3. <i>Triage Levels</i> | 6 |
| 1.3.1. Level 1 – Curious | 6 |
| 1.3.2. Level 2 – Concerned | 6 |
| 1.3.3. Level 3 – Crises | 6 |
| 1.4. <i>Service Delivery</i> | 7 |
| 1.4.1. Information | 7 |
| 1.4.2. Navigation | 7 |
| 1.4.3. Peer Support | 8 |
| 2.0. Methodology | 9 |
| 2.1. <i>Ethics</i> | 9 |
| 2.2. <i>Methods</i> | 9 |
| 2.3. <i>Data Analysis</i> | 10 |
| 3.0. Findings & Discussion | 11 |
| 3.1. <i>Questionnaires</i> | 11 |
| 3.1.1. Persons with Dementia (PwD) | 11 |
| 3.1.2. Carers of PwD | 13 |
| 3.1.3. PwD and Carer Comments | 15 |
| 3.1.4. Volunteers | 17 |
| 3.1.5. Stakeholders | 17 |
| 3.1.6. Dementia Together Staff | 19 |
| 3.2. <i>Focus Groups</i> | 19 |
| 3.2.1. Denial and acceptance: The value of the Dementia Together Service | 20 |
| 3.2.2. Family centred-care: Building confidence amongst PwD and carers | 22 |
| 3.2.3. Avoiding crisis point | 24 |
| Conclusions | 26 |
| Recommendations | 27 |

Executive Summary

This report summarises data collected as part of the initial evaluation of the Dementia Together Service by Sue Ryder. Initial findings highlight pertinent experiences of those currently utilising the Dementia Together Service. Persons with dementia (PwD), carers, volunteers, staff and stakeholders were asked about their experiences. Initial questionnaire findings suggest that the majority of PwD and carers were either satisfied or very satisfied with the service offered by Sue Ryder. These responses are supported with qualitative findings that Dementia Together helped PwD overcome denial, provide a family-centred approach and, importantly avoid crisis point. Respondents felt that the service provided appropriate sign posting, enabled individuals to better manage their condition, avoid crisis, and enhance both physical and mental wellbeing. Further, carers have found it particularly useful in being able to manage and care for PwD, with all but one carer agreeing or strongly agreeing that the service has enhanced their day-to-day practices. Whilst some stakeholders felt that the service did not support their roles, it is important to acknowledge that many stakeholders were not yet clear how their roles could be supported by the Dementia Together Service. Further, a majority of the stakeholders felt that the Dementia Together Service offered a 'one-stop-shop' that provides a PwD and their families the necessary information needed in order to best manage their condition. The initial findings presented in this report highlight some positive aspects of the Dementia Together Service. In addition to the initial focus group analysis, follow-up questionnaires and in-depth analysis of focus groups will help provide greater depth of experiences of key stakeholders.

Acknowledgements

The University of Suffolk would like to thank the collaborative efforts made by Jo Marshall, Tracey Shields, Alana Page, Sharon Barber and the Dementia Together Team. We would also like to thank all participants that have taken part in the study to date. Their valued input has enabled a critical approach when evaluating the service.

It is also important to note the support from Katie Tyrell at the University of Suffolk. Thank you all.

1.0. Introduction

Dementia Together was jointly commissioned by Ipswich and East Suffolk, West Suffolk Clinical Commissioning Groups (CCGs) and Suffolk County Council in April 2017. The service is led by Sue Ryder who work in partnership with a number of local organisations to deliver the service.

1.1. Why the service was developed

In building a specification for a new peri-diagnostic dementia service for East and West Suffolk, co-production with service users, carers and providers had delivered consistent feedback. Although there was a comprehensive range of services and organisations serving the needs of Suffolk people affected by dementia, people were overwhelmed by the myriad of differing offers, the different organisations, how they can be accessed, and which are most appropriate to their needs. This was leading to poorer outcomes, accelerated crises and dependency. Commissioners' views on the previous dementia pathway were that it was too complex, passive, impersonal, deficit-focused and overly concentrated on expensive acute interventions. It did little to maintain independence and build resilience.

Commissioners wished to move towards a service model that complements the Integrated Health and Social Care principles of delivering secondary and tertiary prevention. A model which is locally focused, delays or mitigates crisis, empowers service users, improves and simplifies access to advice and information and encourages independent, community-based 'living well'. Improving outcomes and enabling people with Dementia and their carers to move through the system as required

In March 2016, The Suffolk Joint Strategic Needs Analysis was updated and found there are an estimated 12,800 people with dementia living in Suffolk which is

expected to rise by approximately 40% to 17,700 by 2025, and by over 90% to 24,400 by 2035. Despite recent rapid rises in local dementia diagnosis rates, it is estimated that 40-45% (5,000) of people with dementia in Suffolk have still not received a formal diagnosis, and therefore do not have access to therapeutic interventions and support. There is a three and a half-fold variation in the rates of dementia diagnosis between GP practices in Suffolk; this level of variation is unlikely to be explained by clinical variation alone, and may be contributing to health inequalities. Applying national estimates of incidence to the local population, there would be an expected 500 new cases of dementia approximately per year in those aged over 65 years.

1.2. Dementia Together

The scope of the new model was large and ambitious. Dementia Together, led by Sue Ryder takes a community asset-based approach working in partnership with a number of organisations. These include statutory services such as The Norfolk and Suffolk Mental Health Trust, Suffolk Community Services and Suffolk County Council but also local Dementia Action Alliances and community groups, with a view to simplifying the pathway for people needing support, making the most of and building on support available and encouraging growth in local support and information available.

The service works with a wide and varying scope of service user needs. Service users are people affected by dementia, including family carers. This includes people concerned about dementia, pre-diagnosis, during and after diagnosis and through every stage of the condition. Dementia Together triages people referred to the service to ensure people concerned about dementia, people with dementia and their carers, receive the right response at the right time and in the right place. The helpline is also a point of reference and advice for health and social care professionals and voluntary sector organisations.

People can access the service via various routes or self-refer. Triage will determine the level of support they receive. People can be supported by a Dementia Navigator or via the helpline.

1.3. Triage Levels

1.3.1. Level 1 – Curious

Anyone who may simply have a question or is seeking information about dementia. They may or may not have a diagnosis but at the present time the condition is not causing them great concern or impacting greatly on their daily lives.

1.3.2. Level 2 – Concerned

Dementia is clearly having a detrimental impact on quality of life for the person and or main carer. This may be due to deteriorating cognitive function or other health concerns. Circumstances changing such as bereavement, living alone, becoming housebound or unable to access transport causing social isolation. Support networks may have been withdrawn e.g. due to employment problems, transport and financial issues. There is risk of carer break down or crises developing.

1.3.3. Level 3 – Crises

Physical or mental health deterioration requiring urgent specialist health professional intervention. Sudden main carer breakdown where patient is reliant on this, requiring urgent review of care and support involvement of Suffolk Social Care evident. Clear safeguarding issue raising serious urgent concern regarding welfare of the patient. Dementia Together provides interventions at level 1 and level 2 and will refer onwards to the appropriate organisation for level 3 interventions.

1.4. Service Delivery

The service delivers in three key areas;

- Provision of high quality information
- Navigation
- Support

1.4.1. Information

A single (free phone) Telephone Contact Number hosted by Sue Ryder's hub responding to referrals, people already registered with the service and anyone including health and social care professionals who wish to seek advice and information. Telephone information, advice and support available 7 days per week. Monday to Friday 9am to 6pm and weekends 10am to 4pm. A level 2 navigator always available to ensure high quality consistent advice and information.

The web based information system is managed by Sue Ryder. Following consent, all referrals are registered on to the information system which contains all relevant information in order to support on-going effective navigation and support so the person does not have to continually retell their story. The system registers all contacts and data necessary for the effective quality monitoring and evaluation of the service.

Website - A standalone dedicated website containing trusted information and advice regarding prevention and living well with dementia. It contains a directory of local support services and dementia friendly universal services and events which is updated by individual providers and monitored by Sue Ryder.

1.4.2. Navigation

Sue Ryder employs a small team of skilled Dementia Navigators (level 2) who each cover a geographical area of the county. These navigators become involved when the needs of the service user are clearly more complex, a full holistic assessment is indicated or a home visit is needed. These staff are all trained dementia care coaches, skilled and able to give high quality information, advice and

education, assessment, making referrals or signposting and assistance with accessing local sources of support. The navigators work closely with Dementia Action Alliance (DAA) and local support groups in their area and aim to make links with all GP practices. Local Dementia Navigators (level 1) are a personalised local contact for people who are affected by dementia to provide trusted basic information, signposting and befriending to enable people to cope and live well in their local communities. These are volunteer roles and have a clear link to the level 2 navigator working in their geographical area re training and supervision and the hub regarding referrals, updating of information system and triage to level 2.

1.4.3. Peer Support

Prior to Dementia Together, Sue Ryder ran a number of dementia (Synergy) cafes across the county. These groups are now run by local community organisations but continue to be supported by Sue Ryder Dementia Navigators. The aim in year 1 was to grow more peer support through DAA and local community groups. This has proved to be a challenge; although funding for DAA was available, uptake was low. There has however been a small increase in the overall number of groups which all have a link to a Sue Ryder navigator. There are still gaps and a need for more local peer support both groups and 1:1 befriending, but capacity of navigators is limited to establish these and this is also true of most DAA who are volunteers and whose primary focus is raising awareness of the condition rather than setting up/operating support groups. Sue Ryder plans to work with Suffolk MIND in year 2 to form a newly diagnosed, younger persons group Sue Ryder will also continue to work with Suffolk Community Foundation who administer local trust funding for dementia projects to ensure projects are funded which meet the needs and gaps identified. Since April 2017 the service has registered over 1100 people and made over 2100 face to face contacts. In November 2017 it was recognised with a Health Service Journal award winning the category for integrated commissioning for carers.

2.0. Methodology

The methodology will now be outlined. It is important to recognise that this updated interim report provides results of paper and online questionnaires, coincided with an initial analysis of three focus groups involving PwD, carers and navigators. A full analysis of the focus groups, supported with follow-up questionnaire data will be present in the final report, due in March 2019.

2.1. Ethics

It was important to ensure that the methodology and methods intended for evaluating the Dementia Together Service remained fit for purpose and were ethically sound. An agreed protocol by all stakeholders offered a methodology that would collect pertinent data relevant to those utilising the service. Upon ethical approval by the University of Suffolk, the proposal underwent governance checks internally within Sue Ryder. Following agreement, the study began. It was important that all participants were recruited in an ethical manner. Three members of Sue Ryder staff recruited and consented individuals into the study. The participant information sheet (PIS) enabled participants to read and acknowledge their part within the evaluation, whilst being able to ask questions and/or queries prior to being recruited into the study. Upon the participant being fully aware of his/her participation within the study participants were then consented into the evaluation, which then enabled data collection to commence.

2.2. Methods

Paper-based questionnaires were utilised for PwD, carers and volunteers in order to evaluate the Dementia Together Service. Each questionnaire enabled the collection of quantitative data, in the form of a Likert scale to enable a rated response. This was supported with the collection of qualitative data by using open ended questioning. This enabled respondents to openly express their experiences

for questions that could not be numerically attributed. Additional comments to provide context to questionnaire responses were added by the interviewer.

In support of this initial quantitative approach, focus groups were utilised with participants central to the Sue Ryder project. PwD, carers and navigators were purposively selected in order to ensure data collection remained appropriate and, importantly answer the outcomes of the Dementia Together Service. The first author remained the key facilitator during all three focus groups, with support from a member of the Dementia Together team. The focus groups schedules were delivered using open-ended questioning, supported with proffered prompts. Each focus group lasted between 45 minutes to 1 hour with data recorded using a digital recording device and then transcribed verbatim.

2.3. Data Analysis

Questionnaires were coded and analysed using SPSS, focusing particularly on descriptive statistics. Qualitative responses to open-ended questions were analysed using thematic analysis to identify key themes. These preliminary findings are outlined and discussed in the following section. Further discussion surrounding the analysis of focus groups and follow-up questionnaires will be explored upon data collection. Focus groups will be analysed using thematic analysis and follow-up questionnaires utilising descriptive statistics.

Upon transcription of the audio files the first and second author analysed the transcripts utilising a thematic analytical approach. Each researcher remained blinded to the other researcher in order to enhance rigour of the evaluation. Comparisons were discussed, with some important 'initial themes' recognised (see section 3.2.)

3.0. Findings & Discussion

3.1. Questionnaires

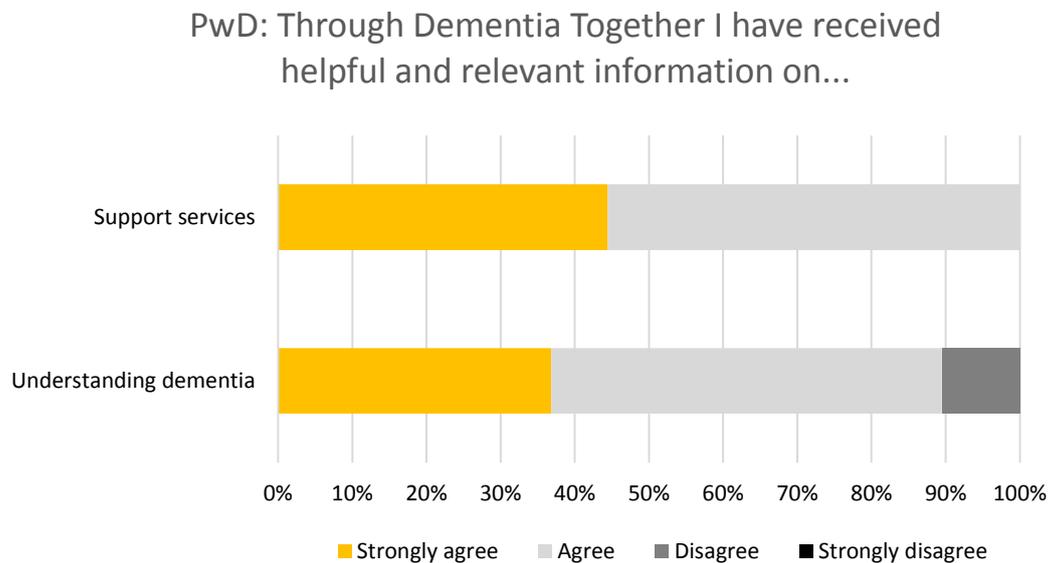
This section will offer a preliminary analysis of questionnaire data gathered to date as part of the Dementia Together Service evaluation. Questionnaire responses were gathered from persons with dementia (PwD) ($n = 26$), their carers ($n = 31$) and volunteers ($n = 1$). Further questionnaire responses were also collected from Dementia Together staff members ($n = 5$) and external stakeholders ($n = 71$).

3.1.1. Persons with Dementia (PwD)

A total of 26 PwD responded to the paper questionnaire. PwD were initially asked to describe their involvement with Dementia Together and what services they had experienced. The majority of individuals had been visited by a Navigator ($n = 25$). Individuals also suggested they had attended a dementia café ($n = 4$), contacted the helpline ($n = 3$) or attended a support group ($n = 3$). No PwD suggested a Dementia Together volunteer had visited them. The majority of PwD had contact with the Dementia Together Service within the past month of responding to the questionnaire (42.3%) or the past 3 months (38.5%). Fewer PwD suggested they last had contact with the Dementia Together Service 6 months ago (19.2%).

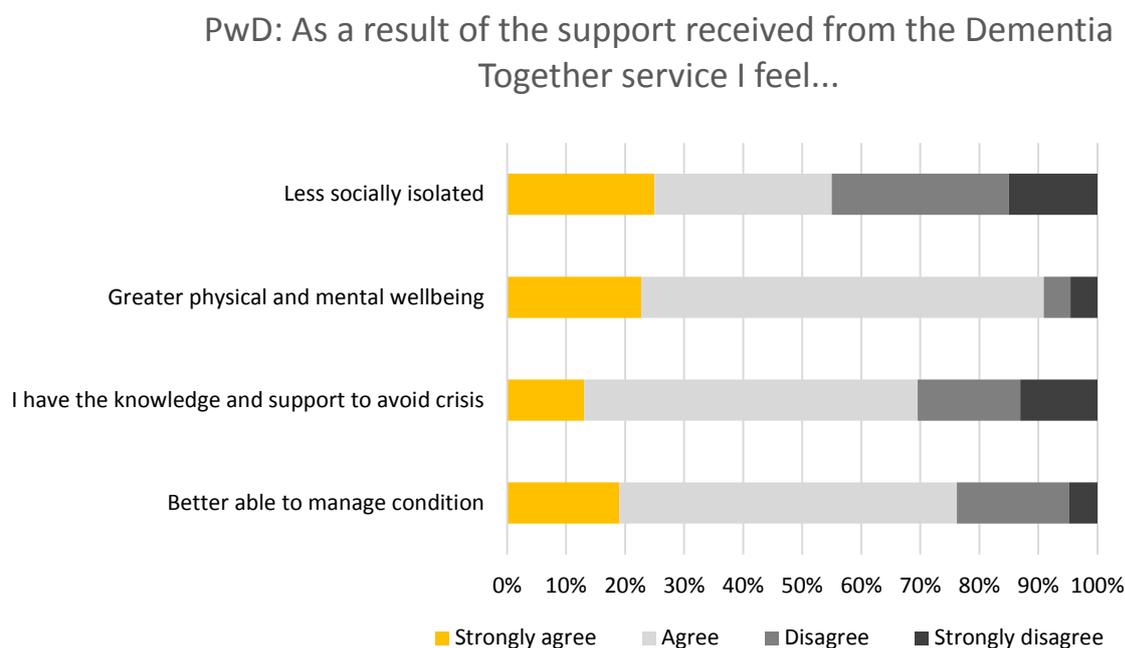
PwD were then asked a series of questions regarding their experience and impact of the service upon their knowledge, wellbeing and the support received. The majority of PwD strongly agreed or agreed that after contact with the Dementia Together Service they felt they had a better understanding of dementia and the services available to them (*Figure 1*). It should however be noted that some PwD felt as if they were unable to answer or felt as if the question regarding understanding of dementia ($n = 4$) or available support services ($n = 5$) was not applicable at the time of the questionnaire or were unable to recall receiving the information. This was reflected in some of the survey comments, for example some of the PwD were described as being 'unable to recall' or 'unable to remember receiving leaflets'.

Figure 1: The levels of agreement across PwD with statements regarding the usefulness and relevance of information received from the Dementia Together service.



The PwD were then asked how much they agree with various statements regarding how they felt after receiving support from the Dementia Together Service. The majority of PwD who answered the questionnaire agreed that the Dementia Together Service had enabled them to better manage their condition. They had the knowledge to avoid crisis and felt as if they had greater physical and mental wellbeing (*Figure 2*). PwD were likely to feel less socially isolated after receiving support from the Dementia Together Service, however a total of 9 individuals disagreed or strongly disagreed with this statement.

Figure 2: The levels of agreement across PwD with statements regarding the support received from the Dementia Together Service.



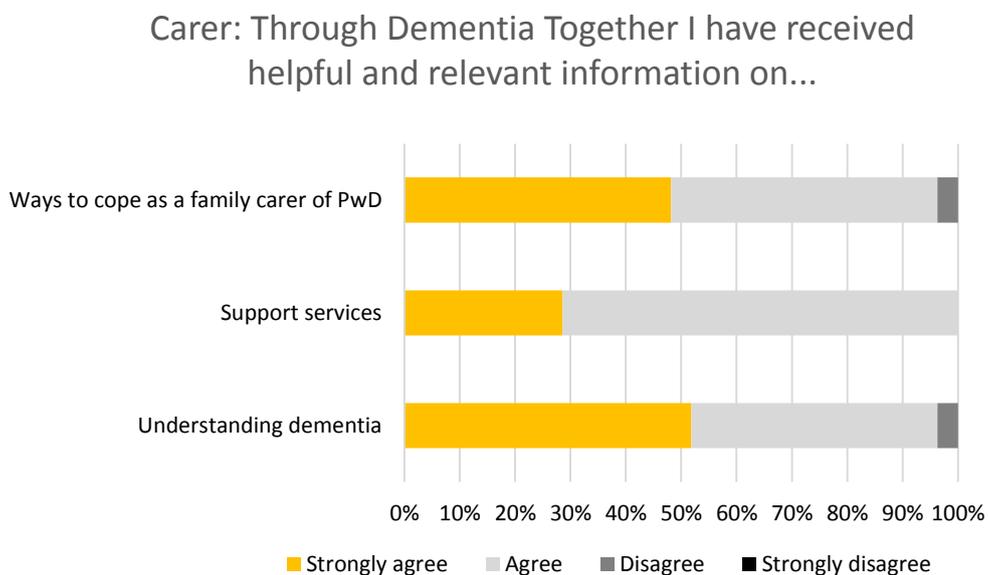
Finally, PwD were then asked how satisfied they were with the service provided by Dementia Together. Of the 23 individuals who answered this question, the majority were very satisfied ($n = 11$) or satisfied ($n = 11$) with the service provided. Only one PwD suggested they were unsatisfied with the service provided.

3.1.2. Carers of PwD

A total of 31 carers responded to the paper questionnaire. Similarly, to PwD carers were initially asked to describe their involvement with Dementia Together and what services they had experienced. Most individuals had been visited by a Navigator ($n = 29$). Individuals also suggested they had contacted the helpline ($n = 13$), attended a dementia café ($n = 8$), attended a support group ($n = 6$) or had been visited by a volunteer ($n = 1$). Most carers suggested they had contact with the Dementia Together Service within the last 3 months of responding to the questionnaire (58.1%) or the past 1 month (29.0%). Fewer carers suggested they last had contact with the Dementia Together Service 6 months ago (19.2%). Carers were also asked a series of questions regarding their experience and impact of the

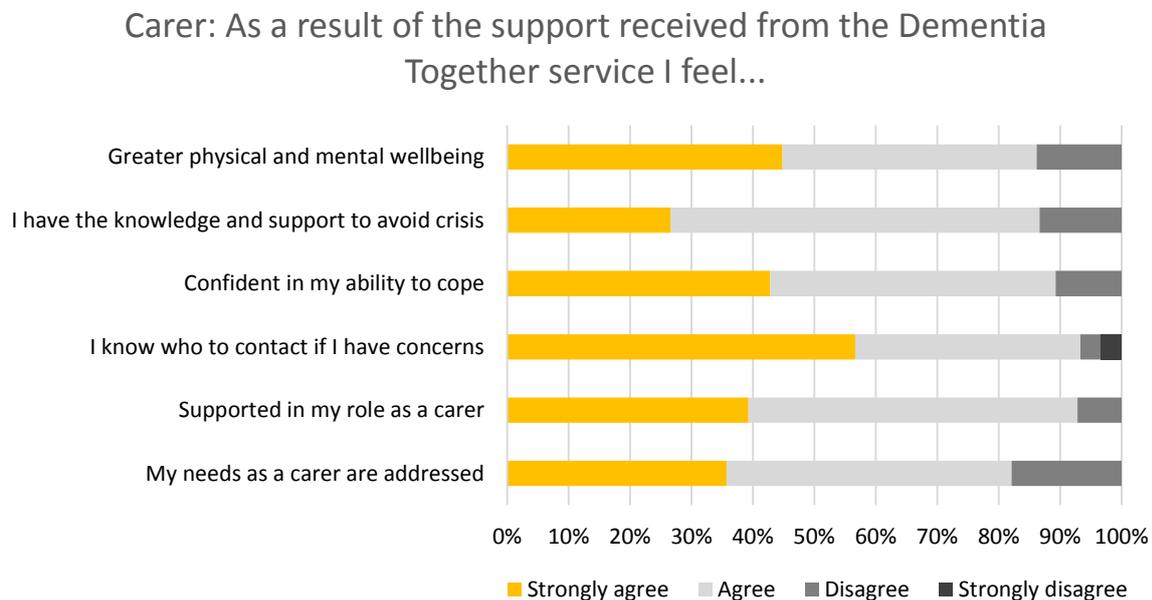
service upon their knowledge and wellbeing and the support received. All carers either strongly agreed or agreed that they received helpful information about services available (*Figure 3*). All but one carer suggested that they strongly agreed or agreed that they received useful information about dementia and ways to cope as a carer. In some cases, carers felt they were unable to respond to the statements regarding understanding of dementia ($n = 3$) and ways to cope ($n = 3$) as they ‘have not had a chance to read the information provided yet’ or have ‘not been able to follow through any recommendations’ or felt as if they were already able to cope.

Figure 3: The levels of agreement across carers with statements regarding the usefulness and relevance of information received from the Dementia Together Service.



Carers were then asked how much they agree with various statements regarding how they felt after receiving support from the Dementia Together Service. The majority of carers who responded to these statements strongly agreed or agreed that the Dementia Together Service had enabled them to feel an increased sense of wellbeing, develop knowledge and confidence, feel supported and have their needs addressed (*Figure 4*).

Figure 4: The levels of agreement across carers with statements regarding the support received from the Dementia Together Service.



Finally, Carers were asked how satisfied they were with the service provided by Dementia Together. Of the 29 individuals who answered this question, all were either very satisfied ($n = 17$) or satisfied ($n = 12$) with the service provided.

3.1.3. PwD and Carer Comments

Comments derived from the survey were analysed to identify key themes across both PwD ($n = 23$) and carers ($n = 18$). The comments provided reveal that individuals have used the Dementia Together Service across all stages of dementia, from pre-diagnosis through to individuals in the later stages of the dementia journey, thus reflecting an inclusive service. A few PwD commented upon the help which they received from the service, including the assistance from navigators in completing activities relevant to themselves specifically, for example completing care plans and attending appointments. In addition, one particular comment suggests that a navigator provided advice to the carer so that the PwD could start cooking again, an activity which he had always enjoyed. This individualised and person-centred support was valued by both PwD and carers.

'Prior to meeting the navigator (PwD) felt as if in the wilderness, but now that someone cares.' – PwD

The importance of support was evident in comments provided by PwD and carers. Comments provided by PwD suggest that social support, whether a direct influence of the service provision or as a result of the networks surrounding the individual prior to contact with the Dementia Together Service, are important to wellbeing. For example, one PwD suggested that if he did not attend the Memory Lane Cafe he would feel isolated, whilst another PwD suggested they are able to relax amongst their peer group at the dementia café. On the other hand, some PwD did not recognise a reduction in social isolation (*Figure 2*) due to pre-formed social networks with neighbours, friends, activity groups and support groups. Nonetheless, feeling connected to others was reflected as important across comments, with some PwD suggesting that they are 'keen to meet other people of a similar age and at a similar stage of their dementia journey'. However, it should be noted that attending support groups was not considered as necessary for all PwD and is dependent upon the context in which the individual is situated.

In addition to social support, both PwD and carers describe gratitude toward the service for providing practical support. For example, one PwD suggested the listening skills of the navigator had benefitted them. From the perspective of carers, having a service which was readily available and enables them to 'feel there is someone to turn to at the end of a phone line when support is needed' is crucial:

'I feel confident that I would be supported with compassion and lack of judgement, which is very important.' – Carer of PwD

Caring for PwD is complex, and this was reflected in comments from carers. Some carers were unable to comment completely upon some of the questions as a

result of not having time to read materials or follow through on any of the advice received from the navigator. The stage of dementia is also important to consider, as mentioned in the first theme, some carers felt they could not comment much upon the benefits of the assistance they had received due to finding their own ways of coping with caring responsibilities, presumably as a result of being a long-term carer. It may be interesting to consider at which point carers typically access the service longitudinally as the evaluation continues.

3.1.4. Volunteers

Data from only one volunteer were collected; additional responses will be sought as the evaluation continues.

3.1.5. Stakeholders

A total of 71 responses to an online survey for external stakeholders were collected as part of the preliminary interim analysis. Individuals who responded to the survey were from various different organisations, including the local council, NHS services and third sector charitable organisations. The majority of stakeholders had given information out on the services provided by Dementia Together ($n = 37$). Stakeholders also signposted their clients to Dementia Together ($n = 30$), referred a client directly to Dementia Together ($n = 15$) or had a client referred to their organisation directly via the Dementia Together Service ($n = 17$). 12 stakeholders suggested they had other forms of contact with the service, including operational, management and partnership meetings. A total of 21 respondents had not yet had contact with the Dementia Together Service, of these the majority of stakeholders were unaware of the service or are not working directly with PwD and thus it hasn't been necessary to make a referral. A couple of stakeholders suggested they had not yet made a referral as the Dementia Together service is not available in Waveney.

Stakeholders were then asked about what the benefits of Dementia Together are for PwD and their carers. The majority of respondents commented upon the benefits of having a central service, a 'one-stop-shop' that provides all the

information needed by a PwD and family carers. Also, having a single point of access in which information about a PwD and their situation was gathered centrally meant this was not then repeated after subsequent contact with the service. In addition to this, the importance of having the ability to provide face-to-face contact within the community was considered to be of vital importance. Support from individuals who were specialists within the field of Dementia was also considered highly appropriate and necessary to a service of this nature.

Stakeholders were also asked whether they feel that Dementia Together has helped support them in their role. Similarly to the previous question, stakeholders describe the service as being useful as a way of signposting individuals to a single source and providing advice and information.

'It is good to be able to signpost and refer to a local service dedicated to supporting people with dementia.' - Stakeholder

A few stakeholders did not feel as if the service necessarily supported them in their role, but suggested it is nonetheless a valuable service for carers. It is therefore important to open further communication in order to understand where some stakeholders are positioned within the service. Some stakeholders who work with PwD and their carers suggested that the service enables them to signpost and provides useful information, which is applicable to them in their everyday role. Finally, stakeholders were asked whether they had any suggestions on how the service may be developed. Whilst many stakeholders did not answer this final question ($n = 31$), some suggested employing additional staff, ensuring information is up to date, ensuring easy access to the website and ensuring a quick referral to external organisations after initial contact as service improvements. Several comments made referred to the need for more external advertisement to 'raise the profile' and ensure the service is more visible. In addition, stakeholders also suggested that further dissemination of information across a variety of organisations (e.g. GP surgeries, family carer services and social care) would be beneficial. A few

stakeholders suggested that extending the service to include the district of Waveney in Suffolk would also be of use.

3.1.6. Dementia Together Staff

Five Dementia Together staff responded to the online survey, which consisted of three open-ended questions. Similarly to stakeholders, Dementia Together staff were asked about what they perceive the benefits of the Dementia Together Service to be for PwD and their carers. All staff suggested that the benefit of the Dementia Together Service was the accessibility as well as having someone to talk to, provide reassurance and practical support. The immediacy and ease of having a hotline for carers and PwD to contact was also considered highly beneficial.

Staff were then asked about their experience of working in Dementia Together as a multi-agency service. All staff reported the importance of working collaboratively with individuals across other professions, as it allowed them to be an advocate for service users as well as draw upon existing support networks and resources from external organisations.

Finally, staff were asked to comment upon how the service may be developed in future. The consensus amongst the five respondents was the importance of recruiting more navigators, volunteers and befrienders to improve service provision and ensure sustainability.

3.2. Focus Groups

Focus groups remained a central part of evaluating the Dementia Together Service because it enabled an exploration of thoughts and feelings associated with key stakeholders, PwD, carers and navigators. The findings presented below are part of a preliminary initial thematic analysis, which was undertaken by two researchers at the University of Suffolk. It is anticipated that this report will provide

great insight of data collection to date, yet in the final report this analysis will be combined with data yet to be collected, the follow-up questionnaires.

3.2.1. Denial and acceptance: The value of the Dementia Together Service

A theme identified within the evaluation was the complexity surrounding 'denial' and 'acceptance' of receiving a diagnosis of dementia. Participants [PwD] retrospectively reflected back on their initial diagnosis of dementia, commenting on some initial thought processes of being diagnosed with the condition:

'...I knew I was getting worse and I knew...the real difficulty is acceptance...'

PwD

'I was in denial...I was a very independent person...and so to kind of...let somebody into my life...and try to sort out the chaos...um...in my mind and what is going on...I am fighting against it...you know but...it is...what Sue Ryder has helped me deal with is...um face up to it...'

PwD

This data reflects how a PwD may struggle to accept their diagnosis during the early stages of diagnosis, but as recognised by one participant, he identified the importance and impact of the Dementia Together Service on his life and how it supported him to 'face up' to his diagnosis. Similar narratives were portrayed by those caring for PwD. For example, after a PwD had taken part in the focus group, he later reflected back on the focus group experience with his wife. Interestingly, the presence of other individuals [PwD] around him enabled him to critically reflect on his own positionality. This was later reflected with his wife:

'...but being here today he said ooh, I think I have learned a lot...and he is much happier...he is sitting in there talking...sitting there talking to [name], and it has been really good...so um...and he says I think I am going to be able to accept it now, whereas before, he was in denial. I said oh you are actually prepared to use the dementia word, before I had to say the d word, I could not mention dementia or memory problems.'

Carer

These insights not only reveal the benefits to PwD from providing support within the community, but interestingly, PwD undergoing the focus groups themselves felt that it enabled them to talk about their condition with peers. This sense of peer-support amongst PwD within the focus group is important to comment upon as it can be viewed as advantageous within this methodological approach aimed at evaluating the Dementia Together Service. This finding also interconnects with comments made by a navigator(s) during their focus group. For example, one navigator commented upon the challenges introducing PwD into groups:

'Um what we do as well is we introduce people to groups, because you will find people will be reluctant to take that first step...and actually go to a group, but there have been, there are occasions when all of us, have taken people along, and that is just introducing them, opening that door and that whole new support, open up a whole new world for them'.

Navigator

'I get a lot of help...but um the...one we go to...on a Friday...is a really...like Heaven'.

PwD

Thus whilst navigators remain central in providing support and introducing PwD into groups (as recognised by the narrative above), the methodological process in this evaluation, in addition, supports the conjecture that focus groups in the evaluation have also benefited PwD socially, enabling them to critically reflect on the condition. In short, this may be an important consideration for prospective researchers wishing to undertake exploratory research concerning dementia and, more importantly, those diagnosed with dementia.

3.2.2. Family centred-care: Building confidence amongst PwD and carers

It remained apparent from the focus groups that dementia was impacting the lives of those individuals diagnosed with dementia, but also those who were caring for the PwD. There remained a general consensus that carers felt that the Dementia Together Service enabled them to seek help and support. This is captured by one participant below:

'I feel confident in phoning and asking for help'

Carer

On the other hand, another participant detailed her difficulties accepting help, affirming that she felt it was her 'duty' and would be 'letting him down' should she not take full responsibility:

'We were brought up you carry on regardless, what comes to you and you accept it...it is something I cannot rid of one way or the other, I do not want to let him down by not doing my duty, 60 something years of marriage, and you have got to be doing this...I am told I am silly but your brain is telling you it is not, you have got to do what you do, for worse or better.'

The narrative above identifies an important empirical finding. Whilst on the whole participants were wholly grateful of the Dementia Together Service, some carers may not initially seek out help in order to maintain a sense of 'pride'. This is important to reflect upon in this evaluation because it reaffirms that some carers may not seek assistance voluntarily and thus may require additional support initiatives in order to 'make that first step'. In short, the onus on a carer to 'make contact' may potentially hinder both PwD and carer.

An additional theme that supports the family-centred approach offered by the Dementia Together Service is evident in maintaining the everyday norms of a person living with dementia. For example, prior to being diagnosed with dementia one gentleman enjoyed cooking with his wife in the home, yet after living with dementia, he felt that he was unable to perform such activities. The carer explained how important this activity was for him and how the navigators had helped facilitate this activity, enabling the PwD to fulfil his passion for cooking:

'Named person' [PwD] was very negative at one point and I phoned and they [Sue Ryder] helped navigate me to 'named navigator'. 'Named navigator' came round and was chatting, and asked him [PwD] what his hobbies were, he used to love to cook and then he would not cook anymore, because he had left the cooker on a couple of times... if I supervised, well not supervised, double checked that he had left nothing on, and if we did things more together, and that worked for some time...'

Carer

This approach adopted by the navigator highlights the impact of offering this holistic support. First, it encouraged a PwD to engage with an activity he/she had previously enjoyed. Second, it is evident that the navigator helped both the PwD and carer to work together in order to reach an enjoyable outcome (for both). This approach offers a holistic perspective of engaging both PwD and carer in the family

centred way. This is further supported by a navigator within the focus group, suggesting that whilst their approach remains short-term, it is family centred which supports the PwD and carers journey:

'We can take people to peer support, and do that and we always knew that the difficulty would be not holding onto people for too long, from day one, but I think that is what makes our service so good is that people are not passed...from us to a different service, you know, the whole Dementia Together is about the journey...yeah is that we have got to do the journey with them'.

Navigator

The initial insights above highlight the value of the Dementia Together Service. Not only does the service enable carers to seek out help and advice, but it enables a sense of self-confidence. It is important to recognise this holistic model adopted by Sue Ryder, which remained evident in the example of re-establishing a cooking regime with a PwD and his wife [carer]. This not only offered fulfilment with the PwD, but also with the carer in being able to enjoy activities together, as a family.

3.2.3. Avoiding crisis point

As identified in section 1.3.3 there remained an increased emphasis on limiting crisis amongst carers supporting PwD within the Dementia Together Service. Upon analysis of the focus group data, participants recognised how 'crisis' had been avoided. Two examples stand out. First, one carer reflected back on her experiences caring for her mother. She recollected her feelings of despair and being in 'quite a bad place' prior to engaging with the Dementia Together Service, who made her feel like she was being listened to:

'The only other thing I would say is that she made me feel like um, it was ok to ask for help, um, it is not always, it is not always the um...the answer you get from the social services, and another time...I was in quite a bad place and I needed some help, and as I said she made me feel like I was, it was quite alright.'

Carer

The narrative above identifies the value of having a level 1 and level 2 support system in place. The participant felt that she had received limited support by other agencies, yet when introduced to the Dementia Together Service, she had now felt that she was getting the help she and her mother needed. The suggestion of a 'bad place' reflects the possibility of this carer progressing into crisis, which appears to have been prevented due to level 1 and level 2 interventions offered by the Dementia Together Service.

Second, an additional avoidance of crisis was also recognised by a PwD. When asked how the Dementia Together Service had facilitated their day-to-day life, living with dementia, there was praise for the service, due to the limited attention prior:

'It was not clearly explained to me...what...it is...the effects of it...I had to wait a whole year, or go through...a lot of issues...before...I went back to complain to my doctor...that they just sent me over to Sue Ryder...so I was going to Sue Ryder, and they are brilliant, because they helped me kind of, educate myself, and you know...supported me....'

PwD

The participant then moved onto explain how he felt humiliated within this own community, with derogatory comments made:

'In the black community, they mock you, they humiliate you, they degrade you, they are not very nice...they do not...they look at the person and say they are stupid...I have had nasty comments made to me you know... because they do not want to engage and learn.'

PwD

It was evident within the focus group that this gentleman had undergone experiences that may have escalated to a crisis point. The feeling of the condition not being explained correctly, supported with personal, socio-cultural and environmental issues, it remains apparent that the support offered by the Dementia Together Service enabled him to manage and regain confidence in 'self' and get the support and education required.

Conclusions

The conclusions offered provide some insight into the data collected to date. At present, the evaluation has explored the views and attitudes of PwD, their carers, volunteers, stakeholders and staff. Further, an initial analysis of focus group data has been undertaken. An in-depth analysis, supported with follow-up questionnaire data will be available in the final report.

For PwD it was apparent that the majority either strongly agreed or agreed that after contact with the Dementia Together Service they felt they had a better understanding of dementia and available support services. Further, it is encouraging that the majority of PwD felt that the Dementia Together Service had enabled them to better manage their condition, avoiding crisis, and enhance both physical and mental health. This is also reflected in the focus groups with the majority of PwD either satisfied or very satisfied of the service offered by Sue Ryder.

All but one carer suggested that they strongly agreed or agreed that they received useful information about dementia and ways to cope as a carer. It is important to recognise that some carers were unable to respond to statements regarding 'understanding of dementia' and 'ways to cope' as they 'had not had a

chance to read information provided' or have 'not been able to follow through any recommendations. Carers on the whole, however, felt that the Dementia Together service provided a sense of wellbeing, developed knowledge and confidence and enabled them to feel supported, whilst having their needs addressed. The avoidance of crisis was again recognised within the focus groups, which Sue Ryder have facilitated.

For those stakeholders who undertook the online survey a majority of these had been given appropriate information about the services provided by Dementia Together, effective signposting and referrals into the service. The majority of the stakeholders felt that it was a central service, a 'one-stop-shop' that provides all the information needed by a PwD and their family members. Whilst a small number of stakeholders felt that it did not support them in their role, they did however acknowledge the value for carers.

For staff, whilst only 5 people were recruited into the study there are some themes worthy of note. Staff reported the importance of working collaboratively with individuals across other professions, enabling them to be an advocate for service users as well as draw upon existing support networks and resources from external organisations. Further, a consensus amongst the five respondents was the importance of recruiting more navigators, volunteers and befrienders in order to improve service provision and ensure a sustainable service.

Data from one volunteer were collected. It would be unwise to make a rational conclusion based on this sample. As the evaluation progresses, additional findings will help uncover the views and attitudes of volunteers and other stakeholders who utilise the service.

Recommendations

Recommendations will be made following analysis of the full evaluation and data set of Dementia Together Service offered by Sue Ryder, including an in-depth analysis of qualitative focus group interviews. Interim recommendations are:

- Increasing stakeholder engagement: Sue Ryder may benefit from additional marketing around the Dementia Together Service, aimed particularly at key stakeholders and how the service can influence their everyday working role.
- Some carers may not reach out to services that may help them due to a sense of pride. It is important, therefore, to reflect on how best to reach out to these individuals who may not seek initial support.
- Some carers for PwD reported being unable to follow-up on any of the information provided by the Dementia Together Service. During the second phase of the evaluation it may be useful to follow up with these individuals to generate more insight into the potential impact of the service, as well as to identify any reasons for lack of engagement with the advice given.