



Independent evaluation of the Dementia Carers Advice and Support Service For Signpost Stockport for Carers



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Background to the evaluation

Signpost Stockport for Carers was awarded a 3-year Big Lottery grant which allowed them to establish a new Dementia Carer Advice and Support Service, or DCASS, from June 2015. The bid was co-developed and supported by colleagues and practitioners working in local dementia care, from social care and older adults' mental health care services, as it was recognised that there was a local gap in support for people diagnosed with dementia and their family carers, particularly post-diagnosis and following discharge from clinical services.

A condition of the Big Lottery funding was that an independent evaluation was completed at the end of the funding period. This report is intended to fulfil that requirement, but Signpost also wish to use the evaluation as a learning and development tool for the service and the organisation more widely, and to understand more clearly the role that DCASS plays in dementia care and support in Stockport.

This insight-led evaluation was commissioned in February 2018 and was conducted during March – May 2018. Four methods have been used to gather the data and insight that is reported:

- Semi-structured, facilitated group discussion with existing carers who have first-hand experience of caring for someone with dementia and using the DCASS service, and Signpost services more generally in many cases. 32 individual carers participated in the discussions, across 3 separate sessions. They represented a varied cross-section of family carers supporting people with different dementias. Some participants had become a carer following a relatively recent diagnosis, whilst others had been caring for someone for many years in their home, including the transition into a care home, and for some their loved ones had passed away. They were a mixture of adult children caring for parents and people caring for their partners/spouse. Carers reported experiences of dementia covering early-onset, vascular, Alzheimer's, Lewy-bodies associated with Parkinson's and frontotemporal (FTD) dementias.
- A carers' survey was distributed via a mailing list and it was also made available online. The aim of the survey was to quantify how carers found out about the service, the way they used DCASS and how they believe that they have benefitted, or not, from the support available. 21 responses to the questionnaire were received and as such the survey results are not robust, but they provide an insight into carers needs and views.
- A semi-structured method of gathering the views of dementia professionals and practitioners from other organisations and services operating in Stockport, which included social care, the older people's community mental health team / The Memory Assessment Service or MAS, the Alzheimer's Society, the hospital-based 'RAID' psychiatric liaison team, and clinical staff with older age psychiatry specialisms. This information was collated from the completion of 3 response forms, 2 face-to-face interviews and one telephone conversation.

- Analysis of a range of aggregated management information routinely collected by Signpost to understand and monitor the service and a meeting with the DCASS team. These were used to sense-check and develop an accurate picture about service usage, volumes, type of contact, advice and information offered, onward referrals and access to other support, and the range of financial benefit / increase in household income as a direct result of the DCASS service.



Signpost Stockport for Carers

Carers are people who support a family member or friend, who could not manage without this help due to illness, disability, alcohol or drug addiction, a mental health disorder or a long-term condition.

Established over 30 years ago, Signpost is a specialist carers support organisation operating in Stockport. It is a user-led organisation but amongst its Board members and employees there are also current and former carers. Signpost is an independent charity supporting unpaid carers from the age of six upwards, with a mission to advocate for and support carers, helping them to manage their caring role, sustain their own health and wellbeing, and balance their role with a life of their own.

Signpost provides a range of practical, financial, psychological and emotional wellbeing services in the community to both adult and young carers. These include a counselling service, Wellbeing and Engagement workers who help link carers to community and social activities, the new Changing Times project that supports carers through some of the major transitions in the caring journey, including end of life care and the end of their caring role, and the Carers Connect project which utilises a wide range of methods to bring carers together for peer support. Signpost also runs informal education and self-care courses including 'Managing Your Money' and 'Life after Loss' workshops. In the 12 months from March 2017 – February 2018:

- 6,331 carers registered with Signpost received the quarterly newsletter which gives details of opportunities and resources for carers in Stockport
- 891 carers directly accessed Signpost's services
- 651 (73%) were new referrals.
- 722 carers (81%) accessed services or support to manage finances and claim entitlements

The Dementia Carers Advice and Support Service or DCASS

The DCASS service was originally conceived with partners from Pennine Care NHS Foundation Trust and Adult Social Care to address a gap in the support that was available for individuals and families affected by dementia. At the time of making the BIG Lottery bid in 2014/15, rates of dementia diagnosis in Stockport had increased fourfold, driven by an increase in prevalence as the population ages, a greater general awareness of dementia, and investment by Pennine Care NHS Foundation Trust in the diagnostic Memory Assessment Service. Alongside these changes, there was a shared recognition amongst dementia practitioners that current provision could not meet the ongoing information, advice and support needs that follow a diagnosis of dementia, which many family carers reported experiencing.

The DCASS service was developed in response to these needs, which are typically information, financial, social, psychological, planning and practical needs related to caring for someone with dementia. It is designed to provide holistic support, personalised to an individual carers circumstances, whilst recognising changing clinical or safeguarding issues and referring to professional practitioners in these instances. As with many physical and psychological health conditions timely, relevant and tailored help and advice following a diagnosis can facilitate the process of acceptance and adaptation for families, and so the initial referral to DCASS is made by the Memory Assessment team at the first visit.

The discussion groups and survey strongly corroborated this practice, as many carers reported being referred to DCASS via this route and the survey responses showed that the vast majority of carers had first contacted DCASS during or within 6 months of diagnosis. Positively, some carers also reported being referred to DCASS by their GP, Signpost workers or their social worker, but this was the exception rather than the norm.

Following referral, a DCASS worker then arranges to visit the carer / family, either at a home visit, or a place of the carers choosing. At the first visit, a range of advice and information is offered based on a conversation which helps to highlight the carers immediate needs. This typically includes a discussion about the form of dementia diagnosed and the effects of this, including the impact on the relationship with their loved one. Financial and wider rights, entitlements and support are also discussed and the DCASS worker will complete the Attendance Allowance claim form with the carer, where this is relevant. This initial support is followed up around 8-10 weeks later with a call to check progress with any financial entitlements and how the carer and the person living with dementia is coping.

For some carers, the relationship with the service is an ongoing one, coming back to DCASS as circumstances change and as the nature and extent of their caring role evolves to meet the inevitable progression of dementia. For other carers, this may be their main contact until a crisis or if their loved one passes away, and they may come back to Signpost for bereavement support or to come to

terms retrospectively with their experience as a carer. The carers who responded to the survey had mainly used DCASS on an ongoing basis, some over 5 times, but most commonly on 1-3 occasions.

As well as supporting families around the time of the initial diagnosis of dementia, DCASS also works closely with Pennine Care’s hospital mental health liaison team, known as RAID. The RAID team provide psychiatric liaison and assessment within Stepping Hill hospital, for adults suffering from acute mental health problems, making appropriate plans for discharge. DCASS support the RAID team where people with dementia attend or are admitted to hospital, conducting joint visits to support a smooth and timely discharge back to the community. These are often people with advanced dementias and DCASS works relatively intensively for short periods with these families and carers to help to alleviate and manage the changing circumstances and support the carer to cope.

The profile of carers receiving support through DCASS is balanced across age groups, based on 2017/18 management information, and includes people aged from 30 to 85+, but carers most likely to use DCASS are typically aged between 45-84. This suggests a combination of spouse/partner carers and adult children/family carers. Using data from the same year, 39% are full-time carers, 35% are retired, 17% are in either full or part-time employment and 5% are economically inactive, with the status of the remaining 4% unknown. In terms of gender, around two thirds are female carers and a third are male.

Of the 298 carers who accessed DCASS in the year to the end of April 2018, 75% were caring for upwards of 30 hours per week and of those, 31% were providing care for more than 50 hours a week. The table below also shows how long carers using DCASS in 2017-18 had been caring for.

Years in a caring role	% of service users
0 – 1	7.7%
1 – 2	49.6%
2 – 3	11.4%
3 – 4	8.7%
4 – 5	6.7%
5 – 10	7.3%
More than 10	8.3%

*Based on 298 carers accessing DCASS in 2017-18

Nearly 50% of all carers using DCASS in this year had been caring for between 1-2 years, which is likely to reflect the referral relationship with the Memory Assessment Service and suggests that DCASS is supporting many new carers who are in the earlier stages of caring for someone with dementia, which is one of the objectives of the service.



Understanding dementia and the experience of dementia care through this evaluation

Dementia was described by one carer in the focus group as an 'enigma'. The idea that dementia is difficult to identify, understand and characterise came up regularly throughout the evaluation. DCASS staff, practitioners and carers described dementia in terms of its 'symptoms' and presentation, which in the initial stages can be subtle and intermittent. These are compiled here to give an overview of the complexity of dementias and the range of challenges faced by carers in supporting and caring for someone with dementia:

- Lack of confidence
- Disliking being left alone
- Inability to complete self-care activities such as having a wash or making a cup of tea
- Excessive interest in objects in the home environment
- Incontinence
- Loss of interest in hobbies / watching the television
- Apathy and excessive sleepiness
- Not being able to read
- Difficulty in choosing or making decisions
- Agitation, aggression and quickness to anger
- Unsociable or uninhibited behaviour
- Loss of interest/avoidance of necessary life activities e.g. banking, cooking
- Wandering
- Getting lost
- Night-time waking
- Falling

Many people with dementia and their families do not have ongoing need for clinical support, but it is the wider financial, social, behavioural, psychological and practical help that enables carers and the people they are caring for to cope with their dementia.

Carers who participated in the focus groups reflected on their experiences of caring describing it as a slow slide into caring as their loved one gradually lost their independence, alongside a huge learning curve and challenge to adapt to the changing physical, behavioral and psychological symptoms of dementia as it progresses, and their role as a care-giver. Some carers reported a keen sense of 'being on their own' with dementia, which for some also led to being and feeling overloaded with responsibility. One carer supporting her mother with advanced dementia said: *"You're always on a knife-edge."* Another who had cared for her mother for 7 years, reported that she had realised that the longer she had been caring, the more she needed to be in touch with people with the same experience.

Carers also discussed how they had seen changes in themselves, including behaving in ways which they know are untypical for them due to the practical and emotional pressures they are under, to feelings of guilt at not being able to cope and in making tough decisions about long-term care.

Professionals and practitioners referred to the complex nature of dementia care and the challenges for carers:

"This population are incredibly vulnerable as they are supporting their loved ones who have a life-limiting condition without training, or knowledge about negotiating health and social care systems, whilst on pensions and, more often than not, managing their own health needs. Having DCASS has meant that there is someone dedicated to work with them to not only address all of these issues but also to support their emotional wellbeing."

Contributors to the evaluation also believe that support for people with dementia and their families is inadequate, nationally and locally. Some long-term carers reflected on the fact that there had been more support available from voluntary sector organisations in the past, but many of these services or activities were no longer available. One carer described this as 'false economy' because if voluntary sector services are withdrawn it will have a 'knock-on' effect on the NHS, mental health services and social care, as well as carers.

Summary of main insights from the evaluation

- i. The DCASS service effectively meets a local need in dementia care that was expressed consistently by carers and practitioners, which is **holistic, timely, ongoing information, psychological, financial, social and practical advice and support for individual and families throughout their dementia journey.**
- ii. Carers and practitioners recognised the **significant strengths of the DCASS team, which include personalised, dedicated, compassionate and flexible support and advice to carers, through workers who have very good knowledge and expertise regarding dementia.** This has enabled them to add value to the service that they provide, becoming strong and effective advocates for dementia and dementia care in Stockport, appropriately influencing non-dementia services, and being able to make effective judgements about risks which are associated with caring for people with dementia.
- iii. Of the 4 outcomes assessed within this evaluation, **advice and support which met emerging needs relating to finances and benefits, information and practical advice about dementia and dementia care, and a timely emotional or psychological sounding board were highly relevant to and valued by carers.** These needs were addressed to a high standard by the DCASS team based on the carer and practitioner feedback.
- iv. Maintaining physical wellbeing in particular, and remaining socially connected, did not appear to have the same immediate relevance and importance for carers, compared to the 3 outcomes above. This is potentially a new insight arising from this evaluation. In the future, **more specific and pertinent outcomes could be developed to reflect more closely what carers want or need to enable them to remain physically healthy and socially connected.**
- v. **The DCASS service enhances dementia provision in the statutory sector,** responding to the wider needs of people with dementia and their families, which statutory services cannot meet on an ongoing basis due to the demand on services and the high needs of this group of service users/patients. There is scope to develop collaborative practices further and systematically extend the reach of the DCASS service.
- vi. There is real-world insight based on carers and practitioners' experiences to also suggest that **DCASS reduces demand on statutory services** by:
 - Reducing the support needed by carers from their GP to cope with the circumstances and pressures associated with dementia care, and therefore reduce visits to the GP
 - Delaying or avoiding early re-referrals from the GP to the Memory Assessment Service e.g. typically a re-referral less than 2-3 years after diagnosis and discharge from the MAS
 - Supporting earlier discharge from hospital for people with advanced dementia, as the carer is well supported as an integral part of the care plan

Detailed analysis

Evaluating the service against the 4 outcomes for carers:

1. Financial & benefits advice and support

The DCASS service has recorded the financial gain that users of the service have accrued collectively. This is summarised by year in the table below, along with average gain per carer and the cumulative total to the end of April 2018. The service expects the final total to be well in excess of £2M as over 50 carers were still to be contacted to record their financial gain through the DCASS service (at the point of collating this information and reporting it for the purposes of this evaluation).

Year	Collective financial gain for carers	Number of carers using DCASS	Average financial benefit per carer
June 2015 – 2016	£591,499	332	£1,781
2016 - 2017	£558,167	256	£2,180
2017 – April 2018	£807,425	298	£2,709
Cumulative June 2015 – April 2018:	£1,957,091	886	£2,208

For many carers in the discussion groups, there was an immediate association between what the DCASS service provides and support to claim eligible benefits, in particular, attendance allowance. Although the response to the survey was small, when asked what types of help they had received from DCASS, 19% of carers identified ‘benefit and entitlement support’ which was the most frequent response alongside ‘information and a better understanding about dementia and its symptoms’.

When carers were asked in the survey how the additional financial support benefitted them, the most commonly identified responses (each at 27.5% of the total responses) were ‘to pay for practical assistance for the person I care for’ and ‘to pay for things that make it easier to continue doing things together’. However, some of the responses also indicated that the additional resources helped to pay for essentials and supported general money management. 30% of the total responses indicated that the additional resources helped to pay for fuel bills, helped to avoid debt and eased carers general money worries.

In the discussion groups, several carers recounted examples of applying for benefits independently and being unsuccessful, or they said that claiming entitlements felt daunting and exhausting to tackle as a carer and it was therefore not always a priority. One discussion group believed that the reason why unsupported benefit claims are often unsuccessful is because carers don’t recognise and therefore underestimate how much care they are providing. This is consistent with the idea that

caring for someone with dementia creeps up slowly, becoming a force of habit, which is sometimes outside of the carers immediate awareness.

One carer who had been caring for 18 months said that it had not occurred to him that they would need financial assistance because of a dementia diagnosis, but in fact financial support quickly became very important as their ability to work became more difficult. Another carer of her mother who had been diagnosed with vascular dementia 18 months prior, had given up her job. Describing this decision, she said: *'I couldn't give up my Mum, so I had to give up my job'*. These examples highlight the importance of financial advice and assistance for carers of people with dementia throughout their caring journey.



2. Informed and supported

Throughout the evaluation, and expressed particularly strongly in carers feedback and views, the role of DCASS appears to be instrumental in enabling carers to get easy and timely access to a wide range of information and advice about dementia. The survey suggests that carers can have mixed and conflicting feelings when they first contact the DCASS service, including shock and uncertainty, but also being reasonably confident whilst knowing that they need help with some specific issues.

All of the discussion groups clearly and assertively identified that a dementia diagnosis prompts lots of questions, for which advice and support is needed to help make sense of it. One carer commented that a diagnosis of dementia is like entering *'unknown territory'* and similar reflections were repeated by carers, directly and indirectly, across the discussion groups. Another carer observed that *'Signpost can open doors you didn't know were there.'* Carers also described the importance of 'in the moment' support and information, which can help carers to grasp the complexities of dementia and its symptoms as they change and emerge.

The survey also asked carers to describe their thoughts and feelings *after* receiving help from DCASS and the most frequent responses indicate a consistency with carers' wider comments. Beginning with the most frequently reported, after receiving support from DCASS, carers said:

- I understood more about what help is available
- I felt more in control of our situation
- I understood more about dementia
- I knew where I was going to get help from and how

In discussion, carers pointed out that a strength of DCASS was its capacity to put a dementia diagnosis in context or perspective and help families to see the bigger picture, when they were often unable to. Many carers also specifically praised and appreciated the way the DCASS service is delivered. This ranged from the face-to-face and telephone support that is the default offer from the service, to the expert knowledge and experience on the topic of dementia and dementia care, and the honesty, reassurance, positivity and compassion shown towards them by the DCASS workers.

'Information' and 'being informed' took on several meanings for carers, including:

- ❖ Information for family members who suspect their loved one may be developing a dementia
- ❖ Information to support a better understanding about dementia and its symptoms
- ❖ Knowing about the financial rights and benefits available to carers
- ❖ Understanding what practical help is available for people with dementia and their carers
- ❖ Information which supports adaptation to a new situation or circumstances
- ❖ Being better informed about how services and support for dementia in Stockport fit together

A distinct type of information and support which was mentioned by some participants in all three discussion groups was assistance to understand what lay ahead post-diagnosis and how to plan for this. It was noticeably mentioned as a priority by several adult carers of parents and by the partners of people with earlier onset dementia. One carer referred to this as '*future proofing*', another said that a list of broad headings would have been helpful, that could be used as a prompt for family carers to think about what they may need to consider or plan towards. Several carers indicated that they had received support from DCASS to help them with forward planning and decision-making. For some, planning for the future also included the frightening contemplation of what would happen if they also developed dementia.



3. Psychological and physical wellbeing

If a dementia diagnosis is likened to a step into the unknown, it is not surprising that carers also reported that it requires psychological adjustment. For some carers this is coming to terms with their family member's diagnosis, for others it was the recognition that they had become a permanent carer for their partner or parent, whilst some carers became more aware of the responsibility they now carried, alone in some cases, and a growing need to be connected with people who can understand the experience of dementia care.

Many carers in the discussion groups referred to receiving assistance from DCASS which took the form of help and advice to develop alternative ways of coping emotionally and practically. Carers gave examples of the changed behaviour of their family member and the significant personal, social, emotional and physical challenges this could present. One carer commented that DCASS provided a backstop, offering informal emotional support and reassurance when it was most needed, which several carers stated unequivocally had enabled them to carry on with their caring role. This included experiencing feelings of guilt at not being able to cope. Examples were also given of advice that the DCASS team had given, which carers felt that professional staff would not have been able to offer as frankly e.g. to avoid disagreeing with their loved one as a way of managing daily interactions and frustrations.

What is striking about the survey responses, is that very few carers identified that DCASS had supported them to look after their own physical or emotional health, and nor had it increased (or decreased) their self-motivation to do so in the majority of cases, yet in the discussion groups the emotional and coping support provided by the DCASS team was widely referred to and valued. However, carers did not spontaneously mention their physical health.

There are a number of interpretations for this difference. The first is that the support that the DCASS service provides does not directly support carers to manage their own physical wellbeing in a practical sense, but in discussion, several carers indicated that their contact with DCASS had given them increased 'permission' to consider their own needs. The reality of caring may simply make it too difficult to take many practical steps towards carers improving eating habits, keeping physically active, getting out and about and attending their own health appointments.

The discussion groups may have been a better vehicle for carers to discuss and air their experiences and thoughts about the emotional support they have received from DCASS, which many carers indicated had benefitted their psychological wellbeing and ability to cope and care.

Should DCASS continue as a long-term service, consideration could be given to the appropriateness of improvements in physical wellbeing as an achievable or desirable outcome for carers of people with dementia. Seeking to improve the physical wellbeing of carers undertaking an intensive and difficult caring role is undoubtedly relevant in theory, but it may not be the most immediate or pertinent outcome to focus on in practice.



4. Socially connected and confident

The importance of remaining socially connected to others and retaining social confidence, with and without their loved one, as a way of mitigating the social and emotional isolation that can accompany an intensive caring role was not articulated as an explicit need or priority for carers in either the

survey or the discussion groups. Interestingly, no-one participating in the survey indicated that they had used the DCASS service, or Signpost services more generally, with a view to taking a break from caring or had used financial entitlements to pay for care while they take a break. However, some carers indicated in the survey that support from Signpost had enabled them to meet other people or make new friends - it is assumed by accessing the social and peer support opportunities provided or facilitated by Signpost.

The importance of having somewhere to go outside of the home environment, and sometimes apart from the person they were caring for, was mentioned by several carers in the discussion groups. There appeared to be various motives for this, which were often complex and layered:

- ❖ To have a break from caring and 'time away'
- ❖ As an outlet, especially meeting and talking to people who have gone through similar experiences
- ❖ As a way of managing the general lack of recognition and acceptance of dementia in wider society
- ❖ Having a specific physical location to visit to meet other carers and receive information or support
- ❖ As a relief from the sense of loneliness and physical, social and emotional isolation some carers experience
- ❖ To help manage feelings about being a carer of someone with dementia
- ❖ To manage well-meant attempts by friends or family to help, which were based on misinterpretations of what is actually needed, or alternatively, to be surrounded by supportive friends and family

A number of carers in the discussion groups identified that Signpost and the Heatons Centre was somewhere they associated with having somewhere to go to attend groups or activities, receive advice and support, and meet other carers in similar situations. One carer specifically said that he would have liked a mentor or 'buddy' to talk to, who *'had been through it themselves'*. This appeared to be linked to a keen sense of uncertainty and not knowing what would happen in the future.

Based on this evaluation, although it is clear that carers recognise the value of having social and family connections, this is not necessarily linked to the avoidance of social isolation. Remaining connected to people who are understanding and supportive or simply being able to spend time away from their caring role on their own or with likeminded people, appears to fulfill a range of needs experienced by carers.

The group of carers who are likely to be most at risk of isolation and loneliness are potentially those living with and caring for a spouse, partner or parent as the main carer, providing many weekly hours of care, for someone whose needs require intensive attention. However, carers in this position are also the least likely to be able to leave the house, to take a break, or go out with their loved one.

For carers in this position, the alternative that the DCASS service provides is informal emotional support 'at the end of the phone' and holistic, responsive and practical support to help to manage the

circumstances, which was described by many carers in the discussion groups and by professional staff.



Practitioner and professional perspectives

The 6 dementia practitioners and professionals who responded to the evaluation had a good overview and understanding of the DCASS service, although in the case of 1 practitioner this was generalised to what Signpost offers for carers. This respondent said that in his practice Signpost is the natural referral for any carers issues and he was able to give examples of Signpost workers progressing issues for carers which complemented and supported his role as a social worker.

Of the 5 other practitioners, 4 considered themselves to have an active, working relationship with the DCASS team ranging from 1-3 years long and 1 colleague had a working knowledge of the DCASS service.

Practitioners were asked for their perspectives on the advantages or strengths of the service and any disadvantages or opportunities for change or improvement. As with carers, practitioners were also asked to identify any alternatives to the DCASS service and they were additionally encouraged to give their views on the implications for dementia care in Stockport if the DCASS service is unable to continue. This was with a view to understanding the contribution and impact of the DCASS service and how it fits into the local dementia care 'pathway'.

Perceived strengths:

- From its early development DCASS has responded to the need, and gap in local provision, that it was designed to deliver in the original BIG Lottery bid

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- It provides in one package of support and advice, the route to free local services for carers of people who are living with dementia, including assistance to successfully claim the financial entitlements they are eligible for
 - It enhances dementia provision in the statutory sector, responding to the wider social, financial and emotional needs of people with dementia and their families, which statutory services cannot meet on an ongoing basis due to the demand on services and the high needs of this group of service users/patients
 - It has developed close and effective collaborative practice with professional teams, who have confidence in the support that DCASS will offer carers
 - The DCASS service offers personalised, dedicated, compassionate and flexible support and advice to carers, through workers who have very good knowledge and expertise about dementia
 - This expertise has translated into the DCASS workers being able to make effective judgements about risk and manage risk associated with people with dementia and their families
 - This experience and depth of knowledge around dementia has also enabled the team to become strong advocates for carers when circumstances have required it
 - DCASS excels in its support for vulnerable carers who find themselves in challenging caring situations, who are the only carer, or who may need additional help for other reasons e.g. couples where both partners have dementia

Opportunities for further development:

No practitioners pointed to any specific disadvantages of DCASS, but several suggestions were made to enhance the provision. Two practitioners indicated high satisfaction with their relationship with DCASS and could not identify any improvements.

- There was a recognition that the DCASS information, advice and support offer underpins local dementia provision, reinforcing and strengthening it. Considering this, and subject to service capacity, it would be beneficial for the service to try to systematically and strategically extend its joint working and cross-referring to other agencies
- This would also help to reach more carers e.g. by attending more groups and meetings where carers of people living with dementia already regularly meet
- Because dementia care is a complex and evolving field, staff training needs to keep pace with new insights and understanding, including new clinical developments but also some of the more difficult social aspects of dementia caring e.g. domestic abuse, substance-misuse and alcohol-related dementia

- Older male carers are often perceived by professional partners to be especially vulnerable and more focus could potentially be given to supporting and following-up these carers
- Although finding so-called 'hidden' carers is always challenging, the service could consider how it raises awareness of and reaches people who may be caring for someone with dementia, without spotting the presence of a dementia or recognising the extent of the care they are providing



The role of DCASS in dementia care in Stockport

DCASS has been operating in Stockport for 3 years and one aim of the evaluation was to understand how it has contributed to local dementia care provision, who are its main beneficiaries, what alternative care and support options there are in Stockport and what the impact would be if the service was withdrawn.

Alternatives to DCASS

Although carers and practitioners knew of other services locally that could support some aspects of the information, social and emotional needs of carers of people living with dementia, no-one was able to identify a specialist dementia support service which offered a holistic package.

Some carers recalled services which they had found helpful but were no longer operating in Stockport, and some referred to nationally recognised dementia charities where they knew they could get information online, but carers felt that the value of DCASS is that it is a local service, meaning that the information is more pertinent, and the provision is interactive and interpersonal. Practitioners pointed towards more general provision alongside dementia information, advice and signposting, but these services were not considered to have the dual benefits of a dementia-specific

offer that provides tailored and continuing support for carers, which is how both carers and practitioners characterised the DCASS service throughout the evaluation.

Carers and people living with dementia as beneficiaries

Practitioners said that the most immediate benefit of DCASS is for carers themselves, providing an ongoing source of support throughout an individual's and family's dementia experience and journey. Several practitioners reflected that lack of ongoing support for carers of people with dementia, especially as the condition progresses and carers have been providing support for an extended time, which reduces the ability of carers to cope. Poorly supported carers can experience a deterioration in their own physical and mental health and this can ultimately lead to the person they are caring for entering long-term care earlier, such as residential or nursing home care.

The view was that DCASS is currently providing access to ongoing support for carers especially for those people who have been discharged from the Memory Assessment Service (following diagnosis and treatment planning) back to Primary Care / the care of their GP. The implication was that the availability of a service like DCASS can help to delay or avoid a break-down in care, which in turn can delay the need for long-term care for the person living with dementia.

Although the experience of dementia care is highly personal and dependent on individual, family, social and financial circumstances, carers who participated in the evaluation appeared to want to continue caring for their loved one at home, despite often difficult circumstances. There was a palpable sense that long-term care was a last resort.

Statutory services as beneficiaries

The 4 practitioners with an active working relationship with DCASS all recognised that formal NHS and social care services directly benefitted from DCASS. There were two dimensions to this. The first is that the social, emotional and financial support that DCASS offers to carers enhances the quality, consistency and effectiveness of the clinical care that statutory services provide. This leads to a balanced and holistic local offer for carers and people living with dementia.

The second dimension is that DCASS is acknowledged as enabling clinical services to deploy their capacity and resources towards new referrals and to deliver the specialist clinical work they are designed for. Both the Memory Assessment Service (MAS) and the hospital-based RAID team acknowledged this and recognised that due to the demands on their service and the high-intensity and complex needs of people living with dementia, they are not always able to adequately address the needs of the carer, and certainly not in the medium to long-term.

By supporting people living with dementia and their carers, the DCASS service is considered likely to:

- Reduce the support needed by carers from their GP to cope with the circumstances and pressures associated with dementia care, and therefore reduce visits to the GP
- Delay or avoid early re-referrals from the GP to the Memory Assessment Service e.g. typically a re-referral less than 2-3 years after diagnosis and discharge from the MAS
- Support earlier discharge from hospital for people with advanced dementia, as the carer is well supported as an integral part of the care plan