



DEMENTIA MAINTENANCE COGNITIVE
STIMULATION THERAPY PROGRAMME

FINAL EVALUATION REPORT
FOR



May 2018

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1 INTRODUCTION

1.1 Aims of the programme

The Dementia Maintenance Cognitive Stimulation Therapy¹ (MCST) / Reminder Finder (RF) Programme was developed by Age UK² to help them understand the relative benefits and acceptability of different approaches to delivering MCST based support. The pilot programme also explored the potential benefits to carers of the different approaches, as well as the practical feasibility of delivering different MCST-based models. Whilst MCST and RF sessions follow the same format, the main difference is that RF sessions are longer in duration (MCST is delivered over one to two hours, whereas RF sessions are delivered over 4 hours).

Since Age UK started its MCST programme in early 2017, six Local Age UK pilot sites have completed MCST and/or RF sessions:

- ★ Age UK Nottingham and Nottinghamshire – MCST
- ★ Age UK Walsall – MCST
- ★ Age UK Teesside – MCST
- ★ Age UK Mid Devon – RF
- ★ Age UK Wirral – MCST and RF
- ★ Age UK North Tyneside – MCST and RF

Appendix 1 provides further detail about each of the pilot's structures and delivery formats, whilst Appendix 2 provides an outline process map which details the main components of the set up and delivery process.

This report provides detailed findings relating to the experience of, and learning from, delivery of MCST/RF, as well as exploring sustainability and scalability of the model. It also provides an assessment of the impact of the intervention on participants and carers. Learning from the evaluation has contributed to the production of the Age UK Dementia CST toolkit (Toolkit) for other local Age UK's seeking to establish MCST based interventions in their areas.

1.2 Purpose of the evaluation

The overall purpose of the evaluation was to:

- ★ evidence the effects of the approaches to MCST-based support adopted
 - for programme participants
 - for carers
- ★ understand the acceptability and practical feasibility of providing effective support for people with mild to moderate dementia, and their carers
- ★ gather learning and good practice that will inform future service development
- ★ provide feedback to enable Age UK to contribute to a stronger evidence base for sustainable delivery of MCST support

¹ CST, or 'Cognitive Stimulation Therapy', is a brief intervention, developed by researchers at University College London (UCL), for people with mild to moderate dementia. CST is an evidence-based treatment, developed following extensive evaluation of research evidence. UK Government NICE guidance on the management of dementia, recommend the use of group Cognitive Stimulation for people with mild to moderate dementia, irrespective of drug treatments received. Longer-term, or 'maintenance CST', is based on CST structures and aims to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group. The effects of CST appear to be comparable to those reported with the currently available anti-dementia drugs.

² Refers to Age UK national

The core questions that the evaluation sought to answer were:

- ★ how effective are the models adopted in delivering support to carers and people with mild to moderate dementia?
 - what works?
 - what could work better and what difference would that make?
- ★ what are the differences in benefits for participants and for carers?
- ★ what are the elements that are key to delivering effective and acceptable support?

1.3 Methodology

The methodology used for the evaluation included the collection and analysis of both quantitative and qualitative data. The clinical efficacy of MCST is already proven³, therefore the evaluation methodology focussed on gaining evidence and learning about application of MCST-based approaches across the pilot projects.

1.3.1 Quantitative data

Staff in the projects facilitated the collection of participant and carer data at the beginning of their projects to establish a baseline, with follow-up surveys after 12 and 24 weeks of support. Participant feedback was gathered using the DEM-QOL validated assessment tool which is designed to measure health related quality of life for people with dementia. DEM-QOL explores participant feelings (including cheerfulness, anxiety, frustration, confidence and energy levels), memory (including people, events and decision making) and everyday life (including relationships, health and support), as well as an overall assessment of quality of life. See Appendix 5 for full questionnaire.

Carer feedback was gathered using a self-completion survey, distributed at similar intervals, which explored carer support, relationships, time for themselves and other aspects of wellbeing and self-care (see Appendix 4).

Figure 1 – Total numbers of surveys

| Surveys | No. received – DEM-QOL | No. received – Carers Radar |
|------------------|------------------------|-----------------------------|
| Baseline Survey | 52 | 30 |
| Mid-point Survey | 28* | 23 |
| Final Survey | 43 | 25 |

*one project captured baseline and final survey data only

1.3.2 Qualitative data

The evaluation team carried out semi-structured telephone interviews with each of the projects teams to explore experience and learning from the development and start-up phase of project delivery. The qualitative data from these interviews was analysed using manual codification and thematic analysis to synthesise data and draw out findings for an interim report and to inform development of the Toolkit.

In addition, site visits were carried out with all projects. These included:

- ★ interviews with project leads, session facilitators and volunteers
- ★ observation of session delivery
- ★ focus groups with participants

³ Spector et al (2003) Efficacy of an evidence based cognitive stimulation therapy programme for people with dementia: randomised controlled trial. *British Journal of Psychiatry*, 183 248-254

Separate semi-structured interviews (17 in total) were carried out with carers to gain a more detailed understanding of the impacts the service may have had on their wellbeing, and to get their perspective on any changes in the person they care for.

To capture learning from project leads about their progress towards sustainability, additional semi-structured interviews were also carried out at the end of their pilot projects.

Informal learning from programme advisory group meetings and learning sessions with MCST developers at UCL was also captured, and relevant learning included in the analysis for this report.

1.3.3 Using a collaborative approach

To help Age UK to focus the programme and evaluation most effectively, the evaluators worked closely with the programme team and with project leads from local Age UKs to refine the programme theory of change, which is included at Appendix 3. Delivery partners were also closely involved in selecting evaluation tools for participants and agreeing the focus for survey questions for carers.

1.3.4 Data limitations

As a pilot programme for a service designed to support people in small groups, it was always anticipated that numbers of survey responses from participants and carers would be small. Drop-out of participants from some of the projects, along with challenges for delivery staff in recruiting carers to complete surveys resulted in a total of 36 matched baseline and final participant surveys and 25 matched carer surveys being used in the evaluation.

However, given that the efficacy of an MCST-based approach had already been proven, the main function of the quantitative data was to help identify aspects of the programme that worked more or less effectively, and to aid comparison between the approaches adopted. Therefore, the relatively small sample size still provides useful data.

In addition, as is common in pilot programmes, some sites experienced challenges in starting up and maintaining their projects. Although this had an impact on the data it was possible to collect, both qualitative and quantitative data was obtained from all the projects involved.

2 INTERIM PHASE LEARNING

An interim report, produced in November 2017, drew together key learning from the setting up and early delivery of locally responsive MCST-based support at the six different sites, and was used to inform the production of the Toolkit. The Toolkit will provide a framework for local Age UKs and other delivery organisations thinking about setting up similar services in their areas.

This section provides a brief summary of the key learning included in the interim report and used to inform the development of the Toolkit.

2.1 Identifying and training staff

Most projects have used existing staff, extending current hours or switching projects, to deliver MCST/RF. This has provided an opportunity for professional development which most staff have embraced. Attitude and approach has been as important as experience in selecting staff. Although experience of working with people with dementia is important, facilitation skills in a group setting, and an ability to help participants relax, enjoy themselves and feel at ease is also key. As one staff member put it:

“Facilitators need to be good observers. They need passion and energy and to care and engage with (participants) as individuals”

Being experienced at supporting carers is also important. Carers need to be confident leaving the person they care for with someone else. In addition, staff need to be able to develop relationships with carers as well as participants, to be able to signpost them to other help and support when needed.

The programme provided training for staff from each project. Feedback from staff was mainly positive, although it is clear from feedback that it is difficult to pitch this at a level that is appropriate for everyone. In addition, project leads suggested that if future projects needed to pay for training and resources, this could be a potential barrier. The MCST user manuals⁴ provided were universally welcomed and seen as an excellent resource, not only for the projects themselves but potentially for wider use across local day care services. Delivery staff used the manuals flexibly, suggesting that if a group was not responding to a particular activity it could be adapted to better suit their needs. Having a core structure was widely seen as a strength of the approach with the ability to adapt activities to suit the group and best utilise the skills of the facilitators. Some preferred a more creative approach to activities with others incorporated more physical activity, e.g. chair-based exercise, into the sessions.

2.2 Practicalities

Being local to the target client group was seen by most projects as important in making the service as accessible as possible. All the pilot projects used their own venues, although one local Age UK has since moved the service into community venues. The importance of a pleasant welcoming space was seen to be key, with facilities to provide hot drinks and lunch. One project successfully incorporated participant's involvement in making their own lunch as an additional activity in their sessions. Familiarity with the venue was also seen to be helpful, enabling participants to settle into the group more quickly and taking away the stress and anxiety of somewhere new.

⁴ Published by The Journal of Dementia Care and available at <https://www.journalofdementiacare.co.uk/store.htm>

While some projects provided transport to their venues, for others transport was sometimes a challenge, particularly where participants needed to use public transport. Many participants were driven to sessions by carers, with several others taking taxis. Challenges of travelling in darkness in winter led to one project to restructure, cancelling an early evening session.

2.3 Pathways / Participant recruitment and retention

Recruitment of participants proved to be a major challenge for most projects, which was at odds with the limited service provision for people with dementia reported in all project areas. Links with memory clinics were seen as an important factor in addressing this challenge long term, particularly if a pipeline can be established from existing CST support into MCST/RF services. Local relationships are a key enabler and also a potential challenge, with projects experiencing varied responses from memory clinics, primary care teams, social workers and other local service providers. Positive feedback from participants and professionals has been an important enabler in encouraging referrals, although primary care staff in some areas are still reluctant to refer to a provision that has a charge attached.

Participant numbers are deliberately low for MCST-based interventions (guidance recommends groups of five or six) but remained relatively stable over the course of the programme. In areas with few services to refer participants on to after completion of their initial MCST/RF sessions, projects have increased participant numbers for new rounds to enable them to retain some existing members whilst providing places for new participants. Attendance at some projects has fluctuated, mainly due to other health issues experienced by participants. For a few participants, increases in the severity of their dementia has led to difficulties in sustaining participation in the group. However, this is not an unexpected outcome as the groups are specifically focussed on those with mild to moderate dementia, so as a person's condition progresses they would no longer be suitable for this type of intervention.

2.4 Delivering the service

As with any group, members take time to settle in and become comfortable with other group members. For people with dementia, it is particularly important for staff to be supportive and sensitive to the needs of individual group members and tailor delivery accordingly. This posed some challenges in the early stages for staff new to the format and learning as they went along. Group dynamics can also be a challenge, with staff aware of the importance of making sure participants felt comfortable with their surroundings and others in the group. Creating the right gender balance was sometimes difficult. At one project, a female participant stopped attending an otherwise all male group early in the project.

The small group sizes were seen by staff, participants and carers to be a major strength of the programme, with staff able to give more personal attention to individuals and to facilitate quality interaction across the group. However, the high staff-to-participant ratio, and associated costs, pose some challenges for long term sustainability. Additionally, the intensive nature of the support is demanding on staff and concerns were raised about how sustainable the intervention is without a wider team of trained facilitators to draw on.

The structure of MCST and the manuals created a solid basis for staff delivering MCST-based support. Although the training provided recommended that MCST be delivered for 24 weeks, the programme allowed for local variation in timescale, with some projects extending support to 40 weeks and beyond and others delivering support in blocks of 12 weeks. However, resources provided do not address how to support participants to transition out of the service, whether because the course has ended, or a participant's condition has deteriorated. Uncertainty has caused anxiety for some participants and carers, and transition planning is something that may need to be incorporated into future thinking about MCST-based support.

3 WHAT DIFFERENCE DOES MCST/RF MAKE FOR PEOPLE WITH DEMENTIA?

The following sections provide details of findings from evaluation of the whole programme, incorporating feedback from participants, carers, delivery staff, project leads and local Age UK decision makers. It includes quotes and descriptive examples to illustrate key findings.

In addition to the DEM-QOL survey described above, the evaluation gathered qualitative feedback from participants using interviews and focus groups to understand the difference MCST/RF makes for people with dementia.

3.1 Experience of participation

In interviews and focus groups, participant feedback about the service was overwhelmingly positive. Some participants found it more difficult to articulate the difference the sessions made to them than others, but everyone said they enjoyed participating. We discuss the commonly reported themes in the following sections.

“We all enjoy ourselves, I like singing the song and speaking with the rest of the group”

3.1.1 Social support

Feedback from participants highlighted the importance of the social aspects of the sessions, especially the opportunity to make friends and spend time in 'good company' with people they felt comfortable with. Several participants talked about how friendly the sessions were and how everyone gets along.

“I feel as if I can relax with people”

Several participants said that having fun is important to them and how much they enjoy the laughter in their sessions. This was apparent at all the sessions evaluators observed.

“They're a good group ... sometimes take the mickey but we always have a good laugh”

For many, the opportunity to have good conversation in surroundings where they could just be themselves and not feel under any pressure was seen to be a real benefit. Whilst many had been apprehensive about joining the group, they also reported having made new friends and valued a safe space to be themselves.

“You know you'll always like it when you get there”

3.1.2 Ownership and belonging

The sense of belonging was valued by many participants, who had felt more isolated since their diagnosis. The groups give a sense of being part of something and provide the space to try to do things for themselves, alongside others who are in a similar situation.

“It feels special to be part of the group”

Participants enjoyed being involved in decision-making and the challenge of some of the activities. They also valued the freedom to not participate if they felt they didn't want to or were unable to.

“No-one takes over, no one bosses you around”

3.1.3 Participating in different activities

Participants enjoyed doing a range of activities and, whilst all preferred some more than others, many suggested that doing activities together as a group made them feel more confident.

“Some things, like crosswords, can be difficult to tackle on your own but together you feel you can do it”

The variety of activities kept participants engaged. Many participants reported feeling more confident with some activities than others. A few said that they struggled to express themselves and reported finding some of the word games most challenging but, in most cases, participants felt able to engage where and how they felt able.

“I like all activities... there's something different every week”

Many participants appreciated that activities stretched them a little, with feedback suggesting that they found they exercised their minds and it made them think more about new and different things.

“It keeps the cogs in our brains going”

“ (Some activities) take you back to the old days – stuff I haven't talked about for ages”

One site supported participants to make their own lunch. While several suggested this was something that they don't normally do, a few did report that they had started getting more involved preparing food at home since making lunch at the sessions.

3.1.4 Health benefits / increased physical activity

Although attitudes to physical activities were mixed, the sessions provided an opportunity to help participants move a bit more. Most sessions involved some level of physical activity and have helped participants to do a bit more than they otherwise would have. This, for a small number of participants, has acted as a catalyst to do more outside of the sessions as well.

“We (husband and wife) go out more... out walking – I was beginning to get stiff but not so much now”

3.1.5 Other benefits of participation

Participation in activities, a sense of achievement and a supportive environment were all perceived to help participants' confidence. Several suggested that they were apprehensive when they first attended and that their confidence had been knocked by their diagnosis.

“...was nervous when I first came – told I was too quiet, so I'm not anymore”

As well as increasing their own confidence, some participants suggested that attending the sessions, and the changes that had resulted, increased the confidence of the people around them in terms of the person's level of ability.

Jack⁵ was diagnosed with dementia last year. When he decided to attend the sessions at the Age UK centre in town, his wife was 'horrified' that he had to get there on his own and insisted he take a taxi. Jack took a while to settle into the group as he is still 'getting used to it' (his diagnosis) but now he really enjoys the group and says he knows it is making a difference. Now he gets the bus to the group and does shopping on the way back. Both Jack and his wife are more confident about what Jack can do, and he is delighted to have got some of his independence back, and feels he has regained trust in what he can do for himself.

Participants valued the things that helped them feel 'more normal' and gave them more of a life outside their day to day routine. Participants also valued the time it gave to allow their carer to do something for themselves.

“ (It) gets me out of my husband's way – gives him a break”

Arthur was very withdrawn when he first started to attend the group and said very little when his wife dropped him off. He has now settled into the group well and has slowly grown in confidence and really come out of his shell. He enjoys contributing during group activities and particularly enjoys word challenges. Arthur feels the sessions are making a big difference to him, helping to bring back memories which gives him and his wife other things to talk about.

When asked about the difference attending had made, some participants were clear about the effects on them and on their physical and mental health. A number of participants also reported that they socialised more, had joined other activities and/or went out more on their own than had been the case before attending the sessions.

“I was a shy person when I started coming but now... not so shy”

“ (It) makes you start to think again and look at yourself different... from the outside”

⁵All names in these examples have been changed

“I just wanted to do something about it (dementia)...not going to let this beat me”

“Would recommend it to anyone with a diagnosis”

3.2 Maintaining quality of life for people with mild to moderate dementia – DEM-QOL survey findings

As outlined in section 1.3.1, the evaluation used a validated research tool (DEM-QOL) to assess any changes in participant quality of life. Respondents rate 28 different aspects relating to quality of life under the following categories:

- ★ feelings
- ★ memory
- ★ everyday life⁶

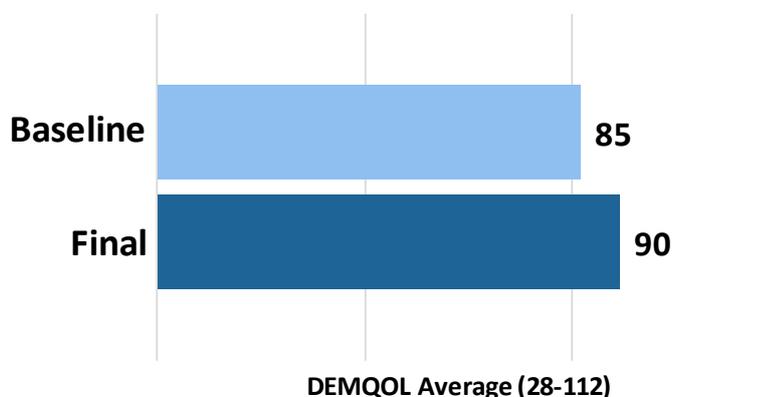
DEM-QOL also includes a final question which asks respondents to rate their overall quality of life, on scale ranging from poor to very good (scored as 1-4).

An overall score based on participant responses is generated. An increase in score reflects a positive change.

3.3 Overall DEM-QOL scores

The figure below sets out the average total DEM-QOL score across all respondents fully completing a DEM-QOL survey at the baseline and final stages:

Figure 2 – The average total DEM-QOL score has increased slightly



N=30

⁶ Comparisons in this report are from baseline surveys, carried out at the start of each project, to 'final' surveys, most of which were carried out towards the end of the initial 24 week programme.

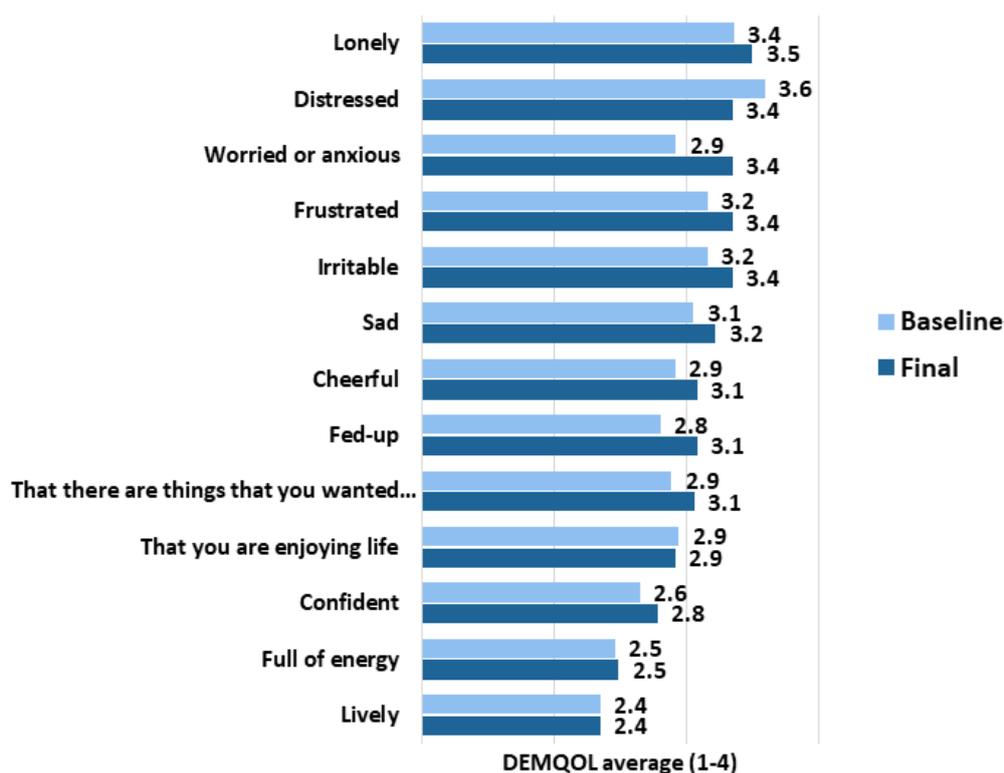
It would be reasonable to anticipate that scores would slightly decrease for people with dementia receiving no intervention over a six month period. As demonstrated in the chart above, there has been a slight increase in the average total score which therefore suggests an improvement in quality of life.

We have also analysed each individual category/domain to assess whether there were any particular themes or trends. Findings are discussed in the following sections. The graphs show comparisons between participant responses at the start of their MCST/RF and their responses at the end across a range of wellbeing parameters. For details of specific questions, see the DEM-QOL tool in Appendix 4.

3.3.1 Feelings

The data suggests that there has been maintenance or slight improvement across all but one of the measures in 'feelings' category. Feeling worried or anxious shows the greatest improvement.

Figure 3 – Most measures in relation to respondents' feelings increased slightly or were maintained

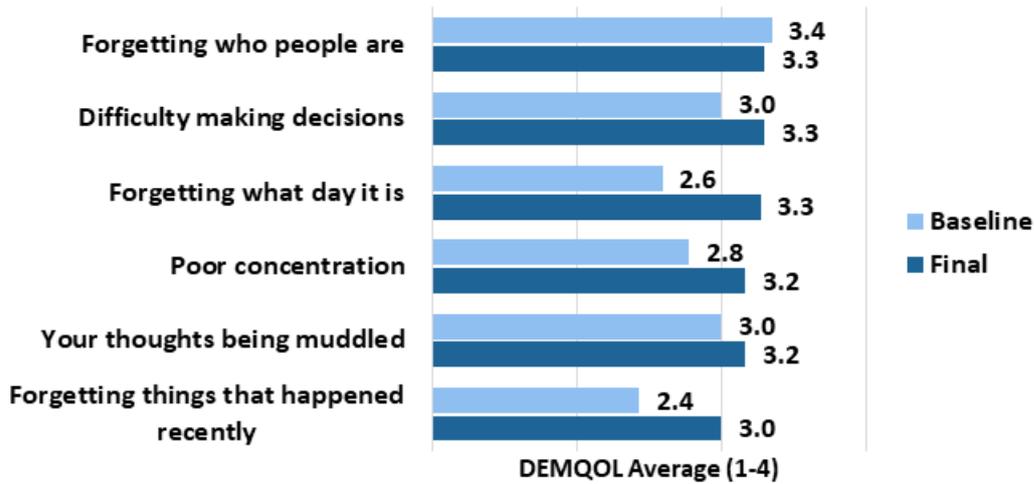


N=35-36

3.3.2 Memory

The data suggests all measures for 'memory' are showing either a slight or moderate improvement, with the exception of "Forgetting who people are", which shows a very slight decrease. Participants report greatest improvement in "Forgetting what day it is", and "Forgetting things that happened recently".

Figure 4 – Most measures relating to respondent’s memory have seen very slight increases

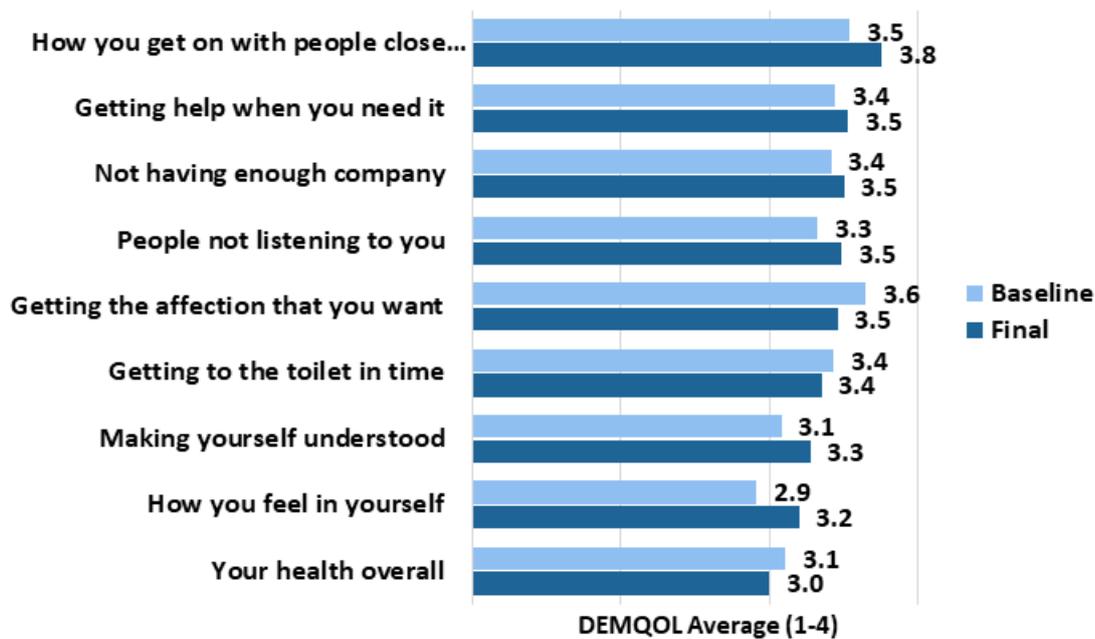


N=35-36

3.3.3 Everyday life

In line with the ‘feelings’ and ‘memory’ categories, all but one of the measures for ‘everyday life’ show a slight improvement or maintenance. The only measure showing a slight decrease is “Getting the affection that you want”⁷.

Figure 5 – Most measures relating to everyday life have improved slightly



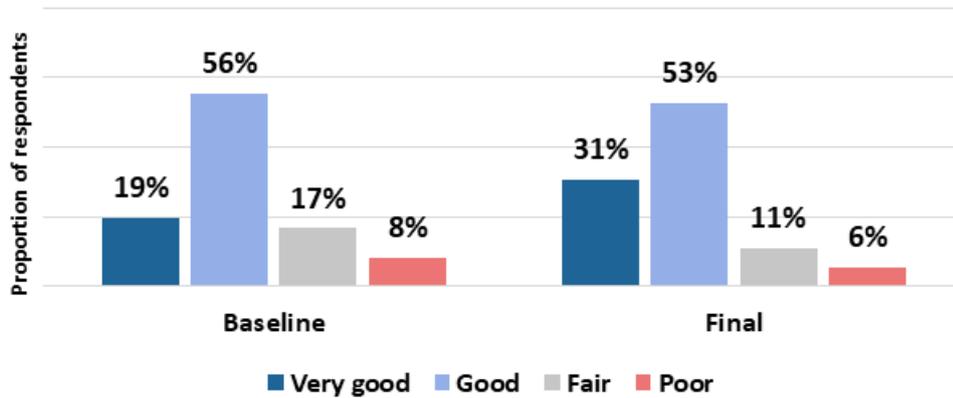
N=35-36

⁷ Note that values are rounded up to one decimal place. If two decimals were considered, then “Your overall health” would also show a small decrease.

3.3.4 Quality of life

Responses from matched participant surveys showed a substantial increase (19% to 31%) in those rating their overall quality of life to be "very good" in the final survey. Overall respondents' ratings of their quality of life as 'Good' or 'Very Good' rose from 75% to 84%.

Figure 6 – Respondents’ perceptions of overall quality of life had increased by the end of the programme



N=36

3.4 Comparing MCST and RF participant experience and outcomes

Changes between the baseline and final DEM-QOL surveys, in terms of total DEM-QOL score and analysis of individual domains, shows very similar shifts across MCST and RF participants. Likewise, qualitative feedback from participants, carers and delivery staff relating to the experience and benefit for participants was consistent across both models.

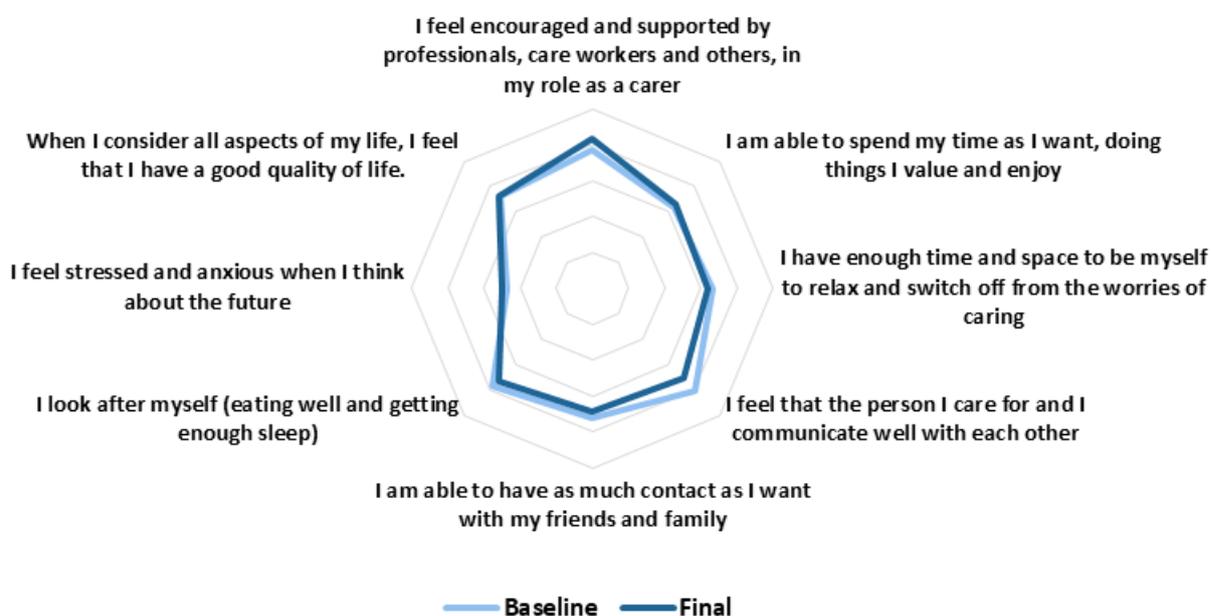
4 RESPITE AND SUPPORT FOR CARERS

The evaluation surveyed carers using a 'radar' of ten measures relating to support, wellbeing and self-care, as well as gathering qualitative feedback through semi-structured telephone interviews. The findings from these approaches are discussed in the following sections.

4.1 Carer surveys

The carer survey asked respondents to score how they felt against a range of statements relating to aspects of wellbeing and quality of life. Figure 7 presents the findings from analysis of respondents that had completed both the baseline and final survey, showing ratings at the start of the programme (light blue) and ratings at the end (dark blue).

Figure 7 – Most measures showed little change⁸



N=25

Findings indicate that from the beginning of the programme, carers have felt encouraged and supported by staff but continue to feel anxious about the future.

Survey findings also indicate that carers do not feel as if they have more time for themselves, to do the things they enjoy, although some qualitative feedback gathered through the carer interviews is in contrast to that. Likewise, the survey results suggest that there has been a slight decrease in the extent to which carers feel they communicate well with the person the care for, whilst qualitative feedback would generally suggest otherwise.

Interestingly, when comparing responses from carers of participants in MCST and carers of participants in RF, MCST carers reported a slight decrease against most measures whereas RF carers reported a slight increase. This suggests that carers of people participating in RF are reporting benefit for themselves from the intervention.

⁸ The further from the centre of the radar, the more positive the score.

4.2 Feedback from carer interviews

4.2.1 Support needs

Many carers shared their frustration at the lack of support for people with dementia. They reported that this lack of support, and societal attitudes to people with dementia, impacted on their lives and that it was difficult to know where to look for support and advice.

“It’s hard to know where to look to find out what’s available for people”

Some carers also expressed concerns that health professionals were focused on the condition and not on the person. A few suggested that GPs and primary care staff were reluctant to refer people with dementia to any support other than medical treatment, and that the gaps in services left few options open to people with dementia and their carers.

“there is next to nothing out there for people that are newly diagnosed, it’s all for people much further down the line”

“too focused on a medical model – lots of talk about drugs and inhibitors”

4.2.2 Value of respite

The programme was designed to provide some level of 'respite' for carers. In interviews with carers it was clear that this aspect of the support provided more benefit for some carers than others. In some cases, carers waited in, or close to the venue for the duration of the sessions, while others spent time with friends, did shopping and errands or spent time with other family members.

“I really just kill time because I don’t drive”

“I do like having the grandchildren to myself for a while ...they tend to wind him up so it’s a lot calmer”

There does seem to be some difference between carers of participants at MCST sessions and those at RF. The shorter session time for MCST can limit what carers are able to do, whereas the longer RF sessions provide more opportunity for carers to take some 'real time out'. However, even those that had a shorter period of respite still valued the break that it gave them. Another influencing factor was the extent of caring responsibility, with those that were not full-time carers feeling less need for respite, and being more focussed on the benefits for the person they care for.

“I think it’s more beneficial to (husband) than to me. A longer session might give me more time”

“It gives me an hour or 2 to myself – I can shut off for a bit. It’s a bit demanding. Sometimes I go for a walk with the granddaughter. My friends are good – sometimes I get time with them and some girl talk”

Jenny has always been involved in her local community and, although she is happy to care for her husband and spend time with him, she felt as if she was missing out a bit recently. She says the Reminder Finder session her husband attends allows her to have some time to herself. It lets Jenny help out with a toddler group in the morning then get a couple for hours in the afternoon to do things on her own. Jenny and her husband travel together to the toddler group and he walks from there to the Age UK centre. Jenny picks him up in the town after the sessions. She says she enjoys the freedom it gives her.

4.2.3 Effects on the carer themselves

Carers tended to focus their feedback more on the difference the support made to the people they care for, rather than on the difference to themselves. However, the majority spoke about the value and benefit of having a happier and livelier person coming home after the session, and the reassurance of someone else that they can trust taking responsibility for a few hours.

“It’s nice to know he’s being looked after”

“a weight off my mind”

Most carers though were able to express the difference the respite made to them and the value they placed on being able to do some things for themselves

“I haven’t had a holiday for five years so it’s really important to get a little break. The best therapy is meeting with friends and having a laugh. I’m trying to have a social life so I don’t crack up”

Having a break was seen by many carers as being important in helping them continue to care. It gave them an opportunity for some self-care and time for them to focus on something other than the person they care for and their dementia.

“I have space. I feel as if I can concentrate more on other things otherwise everything is focused on (husband) – shaving, dressing, getting his breakfast, getting him a cuppa ...everything”

Brenda spends four to five hours a day caring for her mother. Now that her mum attends Reminder Finders it has given her that time back, for that day, to do other things. This has enabled her to spend more time with her husband and even get away overnight to see her son. She also has time to spend with her grandchildren on her own. Brenda feels that Reminder Finders has helped to reduce her stress levels and improve her overall quality of life.

For some carers, the sessions have also helped change their attitude to the capabilities of the person they care for and for some has changed what they do together. Knowing the types of activities they are doing during the sessions has helped carers to see that there is more that the person they care for can do, and the things they can still be enjoying together.

“It gives me confidence in what he can do – how he can get there on the bus. That takes a lot of pressure off me”

“He does a lot at home now – puts the washing away. He copes pretty well - takes the washing out and pegs it up with different coloured pegs”

4.2.4 Differences in the person they care for

Most carers see a positive change in the person they care for – commenting on the improvement in their mood and anxiety levels, with some carers reporting that it was sustained in the days following the session. Several carers talked about scheduling family events to coincide with this positive mood, with some carers reporting that the person they care for is now calmer and happier in social situations.

“I can see the difference in him from when I drop him to when I pick him up again – he’s so much happier and chatty.”

“It’s the happiest day of the week for her – she comes back smiling from ear to ear.”

Most carers reported an improved perception of the capability of the person they care for and, just as importantly, carers spoke about the person they care for being more confident in their own abilities. Some carers also spoke about how the increased confidence in the person they cared for had also led to them taking part in new social groups and activities.

“It’s helped me to see what she is still able to do for herself – you get to a place where you are trying to do everything without realising there is still a lot they can do, and want to do, for themselves.”

“..real, tangible benefits - (participant) had lost her independence but more confident now. The stimulation makes her more alert, more aware, more functioning”

“He would never have gone to something like that (social group) before he had done this”

When asked about whether communications and relationships had improved with the person they cared for, several reported that they would always discuss the session and that this gave them new things to talk about. In some instances, carers also felt that there had been an improvement in their loved one's overall communication, as well reporting that reading and writing skills had improved.

“It's given us different things to talk about – there are different things we talk about before the sessions start”

Through the respite that the sessions provide, and the benefits and changes they had seen in the person the care for, several carers spoke about being more upbeat and positive when thinking about the future – not just for themselves but also for the person they care for.

“(It) gives him purpose – a reason to get up”

“he's started to write again”

4.2.5 Value for money

All the carers interviewed felt the financial cost was manageable for them and that it represented good value for money. One carer reported that the change they had seen in the person they care for was priceless, whilst another commented that it was a small price to pay for the benefit it provided. A few expressed concerns about whether everyone would be able to afford to pay, and many felt that the service should be universally available.

“Think it is good value for money – it's nothing really in this day and age – I don't know what we would do without it.”

Some carers commented that it cost less than they would have to pay to get carer support in the home, but was a much better option, due to the stimulation and social connection that MCST/RF sessions provide. These were two important aspects that carers felt would be lacking if they opted for home-based support.

“You would have to pay more per hour to get someone to come into your home but don't get same level of stimulation”

4.2.6 Quality of care

The majority of carers also gave unprompted feedback on the quality of the care and support they, and the person they cared for had received through the service. They reported confidence in staff to look past the condition and see the person, and that the person they care for was in good hands whilst at the sessions. All the carers we spoke with valued the service for themselves and for the person they cared for and reported that they would have no hesitation in recommending it to others.

5 LEARNING FROM PROJECT STAFF

The principal focus of the pilot programme has been to understand the practical issues around delivering MCST-based support. As part of capturing learning from the pilot projects, evaluators visited each of the pilot sites and interviewed project leads, delivery staff and volunteers about their experiences and observations.

Much of this learning has informed the development of the Toolkit that Age UK has produced for potential future projects. This section provides a brief summary of key findings from the visits, and from additional telephone interviews with project leads and delivery staff towards the end of the pilot.

5.1 Learning from project start up and delivery

Project leads had shared much of their early learning as the programme has progressed – helping to inform development of the Toolkit. In follow-up interviews at the end of their initial projects they were asked again about key learning.

5.1.1 Setting up an MCST/RF group

Project staff talked about the importance of establishing good relationships with potential referral partners and promoting the service effectively. Some talked about needing a longer lead time than anticipated to develop referral routes and recruit participants. A couple suggested that, in an ideal world, a longer pilot and evaluation reports being produced before the end of the pilot would enable projects to use the evidence gathered for business cases and funding bids to help with sustainability and continuity of service.

Several stressed again the importance of selecting staff carefully talking about the importance of them having good group skills as well as experience in dealing with people with dementia. One also expressed the importance of staff knowing and understanding what they are 'signing up to' and the time and energy that needs to go into planning and delivery. Developing rapport and trust with carers to be able to ease their anxiety and reassure them was also highlighted.

Staff suggested that getting the right group dynamics was key to being able to deliver effective support to all group members. Effective assessment of people's level of ability was seen as very important, to ensure there wasn't too wide a variation in the group make up. Some suggested it was good to visit people in their own home to get to meet them before they attended the sessions while others felt that, to get a proper understanding of how people would cope with the group and the environment, assessments should be done in the centre. They also thought this helped the carer know where they were going, gave them an opportunity to see the venue and talk to staff, thereby helping to reduce their anxiety. Different assessment tools, including Montreal Cognitive Assessment (MOCA) and Addenbrooke's Cognitive Examination (ACE-III), were tried by some projects with varying success, and another ran trial sessions for potential participants. This was less of an issue for projects that drew participants from existing services, as they already had a good understanding of the individuals, and carers were already familiar with the premises and the staff.

In administering the group, staff at one local Age UK suggested that it was easier to take payment for all sessions at the beginning of the course so that this didn't take up staff and carer time each week. They also felt it encouraged regular attendance. Other local Age UKs had also offered a pre-payment discount.

5.1.2 Sustaining effective delivery

Some local Age UKs have been looking at the possibility of training for additional staff to allow for staff leave and turnover. Four have already trained 4 staff each to allow them to rotate for a second round, because of the

intensity of the programme. Some also reinforced the importance of good preparation for the sessions and the need to ensure that sufficient time was given to allow for this. Furthermore, some staff also spoke about the importance of allowing, and taking, time to reflect on the session to inform future planning.

All delivery staff involved in the evaluation reported that they liked the structure, enjoyed the approach and saw benefits for the people they worked with. Although the sessions were intense, staff themselves also got a lot of satisfaction from them. All found the manual and resources useful but, some suggested they might need more ideas to maintain a longer programme. Several also mentioned the need for more training and better links with other projects to help increase their understanding and give them new ideas for sessions, especially for staff less experienced in working directly with people with dementia. Some also felt that peer support would be valuable, especially for new staff. A support session for delivery staff, facilitated by Dr Aimee Spector from UCL, was well received and provided an opportunity for staff to raise questions and share ideas.

5.2 Difference MCST approach has made to staff

All projects spoke about the value of MCST/RF in giving staff a new opportunity for development, giving them new, transferable skills and a chance to use their existing skills and experience in a new and productive way. Several spoke about increases in the confidence of staff members who had not previously delivered support in this way. It also resulted in several staff members taking on increased responsibility and some helping develop the project and design new sessions. The new opportunities and obvious difference MCST made for participants were highlighted as contributing to increased staff morale in some projects. Working in pairs to deliver the service had also created new and productive working relationships in some projects.

All the staff we spoke to had been happy to take up the opportunity to deliver MCST. Several said they had enjoyed the challenge and valued the chance to do something new and different for clients. Some also reported that it had given them useful new insight into their work more widely, and a greater understanding of their clients. Several reported using their new skills and knowledge in other parts of their work and incorporating MCST activities into other groups they supported. Those staff who had taken part in the training and/or had been to national meetings had enjoyed learning from, and sharing experiences with, staff from other projects.

5.3 Perceived difference MCST has made for participants and carers

All the delivery staff reported that they had observed a positive difference in those participating in the sessions. Staff spoke about participants blossoming, with the initial apprehension of attending the group giving way to feeling comfortable with people in a similar situation and developing friendships. Staff also reported increased confidence and improved communication skills with people who had been reluctant to engage at the start of the project, happily talking about a range of subjects as the sessions progressed. This extended further with examples of participants talking more comfortably about their condition due to everyone being in a similar situation.

“Seeing clients regain their confidence; wanting to go out and wanting to achieve again”

The structure of the sessions made it easier to observe improvements in memory function from week to week, with many participants more able to remember the date and share what they had done during the week. Staff also reported increased engagement in discussions of current affairs, as participants increased confidence meant they felt better able to speak in the group and express their ideas. One local Age UK administered the cognitive function assessment tool they had used (Montreal Cognitive Assessment) again at the end of the project and reported improved or stable scores for all their participants.

Many of the staff talked about the value of small group numbers in enabling them to tailor the sessions to suit individual member abilities and preferences, particularly as they became more experienced with the structure and tools. These staff members felt that this increased the difference the sessions made to participants.

Staff talked about a range of observable improvements in participants as the sessions progressed, including:

- ★ energy levels
- ★ mobility
- ★ communication skills
- ★ interaction with the activities and with other group members
- ★ confidence and memory function

Staff also talked about the laughter and joking that increased as group members became more comfortable with staff and other group members, and reported how rewarding this was for them.

“(It’s) worth everything you put into it – with perseverance the outcomes are superb”

“Watching them work together as a team – producing something they were proud of”

Several staff reported that they had received informal feedback from carers about improvements in participants' moods, experienced for days after the session. Hearing this feedback from carers was reported to be very rewarding for staff and furthered their belief that it was a worthwhile thing to be doing.

Staff also perceive the sessions provide a valuable break for carers themselves, something that they don't necessarily get from other provision. Although not all projects had strong links with carers, staff from several projects highlighted the importance of relationships with carers where possible. Although one service suggested that carers were less interactive in MCST than RF, with less of a relationship with staff, two of the projects delivering MCST talked about their ability to speak with carers and signpost them to support where needed.

5.4 Key successes

MCST based interventions are seen by staff to deliver benefits for the organisation, the staff involved and of course participants and their carers. When asked about what they perceived to be the key successes the following were consistently cited:

- ★ **Empowering participants** – helping participants to become less dependent on carers and showing carers, and themselves, what they are capable of
- ★ **Positive outlook** – helping to give people a more positive outlook about the future, and the confidence to do new things
- ★ **Benefit for carers** – the support and respite that projects have been able to provide to carers
- ★ **New provision** – not just as a new service approach that the local Age UKs have been able to offer their client group, but also in the fact that it provides an option for people with dementia when there are so few other services locally
- ★ **Staff development** – giving staff new skills, new opportunities and seeing confidence grow

- ★ **Increased staff morale** – staff that have had an opportunity to do something new, and see the benefits it has for those participating
- ★ **Sustainability** – for those continuing to offer the service, its continuation is seen as a key success of the pilot
- ★ **Transferring the skills and learning** – MCST approaches/activities now being used more widely, particularly for those offering other day care services.
- ★ **Learning more about the participants** – for those that have recruited participants from existing clients, they have learned more about those clients and as a result can better tailor other support and provision to meet their needs
- ★ **Seeing the changes in participants** – watching participants grow and develop over time has been hugely rewarding for those involved in delivery of the sessions

5.5 Changes in relationships with other organisations

In addition to highlighting the importance of good relationships with referral partners, some project leads talked about the need to be proactive in developing partnerships and networks, particularly with health and social care staff, but also with other voluntary sector organisations and deliverers of services for older people and people with dementia. Understanding the ecosystem in the local area was seen to be key to developing a strong service offer to 'complement not compete'. It is also an important aspect of being able to signpost and identify opportunities for people following their participation.

There were significant differences in service structure and provision in the different project areas that acted as enablers and barriers. One local Age UK suggested that the absence of an Alzheimer's Society branch in their area had provided them with an opportunity to pilot and now roll out MCST support for people with dementia more easily than it might have otherwise been. This was reinforced by another local Age UK who felt that clinical staff saw the Alzheimer's Society as the primary referral route for all people with dementia, which had been a barrier to referrals to the local Age UK MCST project.

5.6 Relationships with funders and commissioners

All the local Age UKs had worked hard to develop good relationships with funders and commissioners, doing presentations and talks and sharing messages about the value and efficacy of MCST. One reported there had been a lot of interest in the suggestion that MCST can keep people independent longer and they were hoping to use the evaluation findings to bolster their case. A few local Age UKs suggested that getting key decision-makers on board could be helped if they were able to encourage them to come and see it in action. One is planning an 'open day' for social services staff to build their confidence in making referrals, and has already included MCST in a successful tender. However, others also highlighted that there was limited opportunity for MCST to become a commissioned service, particularly with the current strain on funding for existing statutory services.

There was some suggestion that Age UK could provide evidence and advocacy for MCST at a national level to improve awareness and buy-in at a strategic level and generally help raise the profile of MCST-based support. It was still felt, however, that the projects were struggling with wider cultural perceptions of the value of the voluntary sector and the services it can provide. One local Age UK had deliberately branded its care arm as a social enterprise to address perceptions that voluntary sector services are 'cheap and second rate'. All the local Age UKs believe they are well run and well placed to deliver dementia support, but some feel the current economic climate and attitudes to the sector have been significant barriers in building and expanding their dementia support and MCST services.

“We know what we're doing and we can save money”

5.7 Learning for sustainability

Whilst all the project leads reported that they wanted to continue to provide MCST / RF support, some said that the challenges highlighted above had the potential to impact on the longer-term sustainability of their projects.

Whilst at least one local Age UK expressed concerns about charging for the service and used Age UK funding to provide support free of charge, all felt that it was important to find ways to fund MCST/RF sustainably. All the pilot projects have looked at detail costings and identified appropriate charges for their second round of delivery. Several have submitted proposals and business cases to CCGs and other funders with varying levels of success. One local Age UK has had CCG funding for a day service including an MCST component, while another is hoping for support from the CCG, through their local mental health commissioner.

One local Age UK is in the final stages of being commissioned by a local sports club that are interested in supporting people in the local community with dementia. Furthermore, this local Age UK also aspires to deliver MCST in other community venues as a charged-for service but is currently exploring feasible pricing structures that ensure it is financially viable whilst not being a barrier to participation.

Some local Age UKs have used the learning from their pilot project to revise their delivery plans for a second round. One has moved from delivering MCST to RF, feeling that the MCST sessions were too short, too rushed, and had variable attendance because people stayed away rather than turn up late. Another has moved from RF to MCST because they felt that the longer sessions were too intense for staff and tiring for participants.

One local Age UK is interested in the development of carer-led Individual Cognitive Stimulation Therapy (iCST) resources, currently being developed by UCL to give carers tools to support the person they care for. Another has adopted the idea of 'homework' – carers discussing and using the activities from the sessions – that was developed in another pilot. Both local Age UKs felt that this helps improve communications between participants and carers.

One local Age UK has moved its MCST sessions into other community settings after delivering the pilot in their community centre. Another is providing taster sessions in other part of their area to explore how to deliver services nearer to participants in an area where they see travel as a significant barrier to attendance.

In addition to a national role in championing MCST-based support for people with dementia, local Age UKs suggested several other ways they felt Age UK could provide longer term support. These included:

- ★ support for marketing MCST at a national level and producing marketing resources that could be adopted locally
- ★ clear messages on Age UK's role in supporting people with dementia
- ★ continuing to provide MCST training and resources
- ★ producing or disseminating up to date research and evidence on CST / MCST
- ★ talking with commissioners

5.7.1 Where projects are now

As is often the case in pilot programmes, the six local Age UKs took varying amounts of time to establish, and therefore are currently at different stages of delivery. Most have delivered the recommended 24 weeks of MCST/RF support and are now either continuing to deliver the service with their existing cohort or have started a second round with some new participants.

All the local Age UKs have learned from their experience of delivering MCST-based support and are modifying their structures and formats. Figure 8 shows some of the key changes.

Figure 8 – Changes in delivery

| Local Age UK | Initial structure | Current delivery |
|------------------------------|--|---|
| Nottingham & Nottinghamshire | MCST (6 members) | Currently running a new group in their day service after the initial group finished. Also exploring delivery in other community venues. |
| Walsall* | MCST (6 members) | Currently recruiting new members for a second round of MCST following completion of 24 weeks with pilot group. |
| Teesside | MCST (6 members) | Continuing to deliver MCST. Moved to community venue – recruiting new members for 2 nd round starting July 2018. Will be paid service but seeking funding for further development and roll-out. |
| Mid Devon | RF (6 members) | RF group continuing after 24 weeks with new members – currently 9 members (2W 7M) average attendance 6-8. |
| Wirral | Both MCST (5 members) and RF (6 members. 24 week course) | RF groups continuing – now with 12 members (6 from previous RF, 3 from MCST group & 3 new). 7 on waiting list Structured more like a club with new members joining and no proposed end date (although funding currently available only until July 2018) No longer delivering MCST Funding/commissioning required for long term sustainability (business case submitted to CCG) |
| North Tyneside | MCST (7 members) and RF (6 members) | Continuing to deliver MCST and RF to 24 weeks. Planning new MCST (2 hour) groups at 3 centres delivering different 12 week programmes in each centre, each quarter and rotating. |

*On 31 March 2018, Age UK Walsall became a subsidiary of Accord Housing, known as Accord Care and Support – Age Matters. The organisation will continue to deliver vital local services to older people, including MCST.

6 CONCLUSIONS AND CONSIDERATIONS FOR THE FUTURE

6.1 Benefits of an MCST-based approach

The findings demonstrate that MCST-based approaches can deliver benefits for participants, their carers and the organisations delivering them. We summarise these benefits in the following sections.

6.1.1 For people with dementia

At the most basic level, the MCST offering adds to the very limited options that are available to people with dementia and their carers.

The findings suggest that MCST/RF contributes to the maintenance to the different components of wellbeing measured in DEM-QOL relating to feelings, memory and everyday life. Furthermore, the findings demonstrate that there is a positive shift in relation to participants' perceptions of their overall quality of life.

Qualitative evidence from participants, and that received from carers and staff through their own observations, reinforced that the following benefits were also commonly realised:

- ★ enjoyment, having fun and increasing levels of happiness
- ★ a sense of belonging, being part of something and making new friendships/social connections
- ★ increased confidence in participants own ability and to try other new things
- ★ improvements in communication, including reading and writing
- ★ improvements in memory and mental ability
- ★ having more energy and the providing the opportunity to be more active

6.1.2 For carers

Whilst quantitative data suggests that carer outcomes have been limited, with very little change across the components of wellbeing, support and self-care being measured, the qualitative evidence paints a different picture.

Feedback from carers suggests that the benefits are more pronounced than the survey results would suggest. They value the time that it provides for them to do things for themselves – whether it's volunteering, running errands or spending more time with friends and family – it reduces the pressure and stresses that they experience. It provides a welcome break from feeling that you have sole responsibility for someone.

Another benefit for carers, which cannot be undervalued, is the improvements that they see in the person they care for. This, in some instances, has translated into an improved home life, and confidence in what the person they care for is able to do.

6.1.3 For the local Age UK

Local Age UKs have also experienced a range of benefits through their participation in the programme. At an organisational level feedback suggests it has had a positive impact reputationally, with credibility amongst partner and funders being enhanced. It has also provided the organisation with new skills, experience and learning that can be transferred to, and be of benefit, in other services they provide.

For the staff involved in delivery it has given them a new and rewarding opportunity to work with clients, whilst developing new skills and taking on new responsibilities. Being able to directly see the benefits of their work on people affected by dementia and their carers is motivating and had a positive impact on morale.

6.2 Comparisons between MCST and Reminder Finders

A core requirement of this evaluation was to understand the differences in effectiveness, acceptability and appropriateness between MCST and Reminder Finder formats. This is discussed in the following sections.

6.2.1 How effective are the models in delivering support for people with dementia?

The main difference between MCST and RF is the duration of the sessions, with RF being longer. However, feedback from participants was largely consistent across both models in terms of their experience of participation and what they get from it. Likewise, observations from delivery staff and carers relating to experience and benefits for participants suggest that there is little difference.

Similarly, changes between the baseline and final DEM-QOL surveys, where the majority of measures showed a slight increase or a maintained level, shows very similar shifts across MCST and RF participants.

Based on our findings, we conclude that both models provide effective support for people with dementia with no apparent differences between them in terms of experience and outcome.

6.2.2 How effective are the models in delivering benefits for carers?

When analysing the carer survey responses collectively there is very little change across the aspects of wellbeing, support and self-care being measured. However, when looking at the responses from carers of MCST and RF participants separately the findings suggest that there is a slight decrease from baseline to final survey across the majority of measures for MCST participant carers and an improvement for RF participant carers.

Qualitative evidence from carers suggests that the **type** of benefits experienced are similar regardless of the delivery format. However, what does seem to be different is the **extent** of the benefit, with carers of RF participants reporting a more pronounced level of benefit for themselves.

Another influencing factor in the type and extent of benefit realised for the carer was related to the intensity of their caring responsibilities. This ranged from those that were full-time carers, to those that visited their loved one a couple of times a week. For those that did not have full time caring responsibilities the pressures and stresses were not as pronounced and the need for respite less. The most important thing for them was that their loved one was having a positive experience and were benefitting from the sessions.

The findings enable us to conclude that carers of those that participated in RF sessions, and those that had full time caring responsibilities, experienced a more profound benefit due to the additional respite time provided.

6.2.3 How acceptable and appropriate are the models for participants – what works? What could be improved?

Feedback from participants, carers and project staff has been overwhelmingly positive about the structure and format of both MCST and RF sessions. Initial assessment and selection of participants plays a crucial role in ensuring appropriateness and acceptability. There has been good retention of participants across MCST and RF provision which would also suggest that participants enjoy it and find it worthwhile.

RF participants appeared to have a higher starting point in terms of baseline DEM-QOL measures, which may suggest a more moderate level of dementia and therefore longer sessions being more appropriate and acceptable.

Whilst some carers did report that the person they cared for seemed tired after the longer RF sessions this does not appear to have had a negative influence or affected acceptability.

Going forward there are examples of projects that have opted to change from MCST to RF or vice versa based on their experience, with one project feeling that the length of MCST sessions made things feel rushed, whilst another felt that the longer sessions of RF was too intense for staff delivering.

The findings do not suggest any differences in acceptability or appropriateness between MCST and RF, however at a local level one model may be preferred over the other by the delivery organisation.

6.3 Critical success factors and enablers

A number of critical success factors and enablers have emerged through the learning and experience of the pilot projects:

- ★ **Opportunities in local area** – there needs to be sufficient gaps in local provision that can be addressed through MCST/RF provision and/or can complement what already exists. Furthermore, ensuring accessibility for the local population and tackling any anticipated barriers (e.g. transport) is important.
- ★ **Relationships** – developing and/or strengthening relationships with other local organisations and promotion of MCST/RF provision to ensure referral streams and pathways can be forged. This is both in terms of people entering the service but also for when groups come to an end. Good relationships with memory clinics were highlighted as important in several projects.
- ★ **Referral pathways** – linked to the above, the time required to develop referral pathways should not be underestimated and sufficient lead in time should be considered. Relationships with local memory clinics have been a challenge in some areas and might be something that could be supported through AUK influencing at a national level. However, these are issues that are likely to vary depending on local context
- ★ **Staff** – ensuring delivery staff are equipped with the necessary skills, experience and resources to conduct group facilitation with this client group is essential. Furthermore, confidence and willingness to embrace a new opportunity is also important.
- ★ **Balancing continuity with resilience** – Continuity of delivery staff is an important aspect of developing the environment, trust and familiarity/understanding of the participants. It also contributes to the ongoing development of staff through experience. However, resilience of the service can depend on having other staff that can support the sessions in the absence of staff that usually deliver.
- ★ **Participant selection** – effective assessment of participants plays a vital role in ensuring the acceptability and appropriateness of MCST/RF. Furthermore, understanding the preferences of individuals can help to inform the balance of the group (e.g. in terms of gender split) and also selection/tailoring activities to meet the needs/ability of group members.
- ★ **Adherence to format** – the evidence base developed in regard to the benefits on cognitive function are based on the delivery format set out in the training and user manuals. The structure and format have also been received positively by delivery staff, participants and carers. Adherence to the defined format is therefore essential.
- ★ **Post participation** – As touched on already, having referral routes/signposting options for participants and carers when the sessions come to an end (or when a participant's condition deteriorates, and they can no longer participate) needs to be considered and planned from the outset.

6.4 Future considerations

Overall, the findings from this evaluation suggest that MCST-based approaches can be delivered effectively by local Age UKs in a way that is acceptable, appropriate and generates benefits for all involved. The following are areas to consider as Age UK moves forward.

6.4.1 Role of Age UK (national) going forward

The majority of local Age UKs involved in the pilot are committed to sustaining and in some instances, expanding the MCST/RF offering. Furthermore, the intention is that other local Age UKs will develop a MCST/RF offering. Therefore, Age UK continues to have a vital role in supporting the sustainability and expansion of MCST/RF over and above the toolkit that is being produced. We would suggest that consideration is given to the following:

Promotional materials

Developing a suite of materials that are tailored to a range of different audiences (e.g. clinicians, commissioners, carers), and that draw on the existing evidence base could greatly assist local Age UK's in their awareness raising/promotional activities. It could also support the development of bids to potential funders. Having them available electronically for local Age UKs to download and print would minimise any cost implications for Age UK.

Championing MCST at a national level

Being a champion for MCST based approaches at a national and strategic level should be a continuing role for Age UK. Identifying and creating opportunities to further promote the value of the service, both in terms of filling a gap in available provision, but also the potential benefits for people with dementia and their carers can enhance and complement work done at a local level by local Age UKs.

Training and resources

The cost of training and resources to support set up and delivery of MCST/RF has the potential to act as a barrier to new local Age UKs coming on board. It could also prevent the expansion of the offer for those already delivering and/or the resilience of existing services. Therefore, we would encourage Age UK to consider ring fencing an allocation of funding that can be used to support training of new staff and purchase of the user manuals. Another option would be to explore the feasibility of a train the trainer model. Some local Age UKs expressed an interest in new developments, including iCST⁹. Training to support staff to in turn support carers in this may also be valuable.

Making links

Whilst the Toolkit will undoubtedly provide a host of useful advice and guidance for other local Age UKs interested in establishing MCST/RF provision, there is likely further benefit from speaking directly to those that have direct experience of set up and delivery. Age UK have an opportunity to facilitate those links and enable the conversations to take place.

6.4.2 Dual focus

Whilst the primary beneficiary of MCST/RF is people with dementia, this pilot, and evaluation, has also helped to demonstrate the benefits it can have for carers. This presents something for consideration for every local Age UK that delivers MCST/RF – do they approach it with a dual focus and seek to maximise the benefits for both participants and carers or a single focus aimed at people living with dementia.

6.4.3 Starting with sustainability in mind

Understandably, as the purpose of the pilot was testing feasibility and effectiveness of delivery of MCST/RF, by the mid-point several local Age UK's were still unclear or uncertain about whether the service would be sustained or how it would be. Now that the pilot has demonstrated it can be delivered effectively it is important that a plan for longer term sustainability is in place from the outset. There is simply too much of an investment required in the preparation and set up for it to be a short term offer.

⁹ One-to-one support for people with dementia based on the MCST model and designed to be used by carers



APPENDICES

APPENDIX 1 – PROJECT STRUCTURES AND FORMATS

The original approach was designed around 45 minute sessions. Pilot projects were funded for 2 hour (MCST), or 4 hour (RF) sessions, so staff adapted the structures accordingly, delivering 2 or more 'main' activities from the MCST manual per session. Example structures – observed during visits by evaluation partners – are set out in the table below.

Project structures and formats

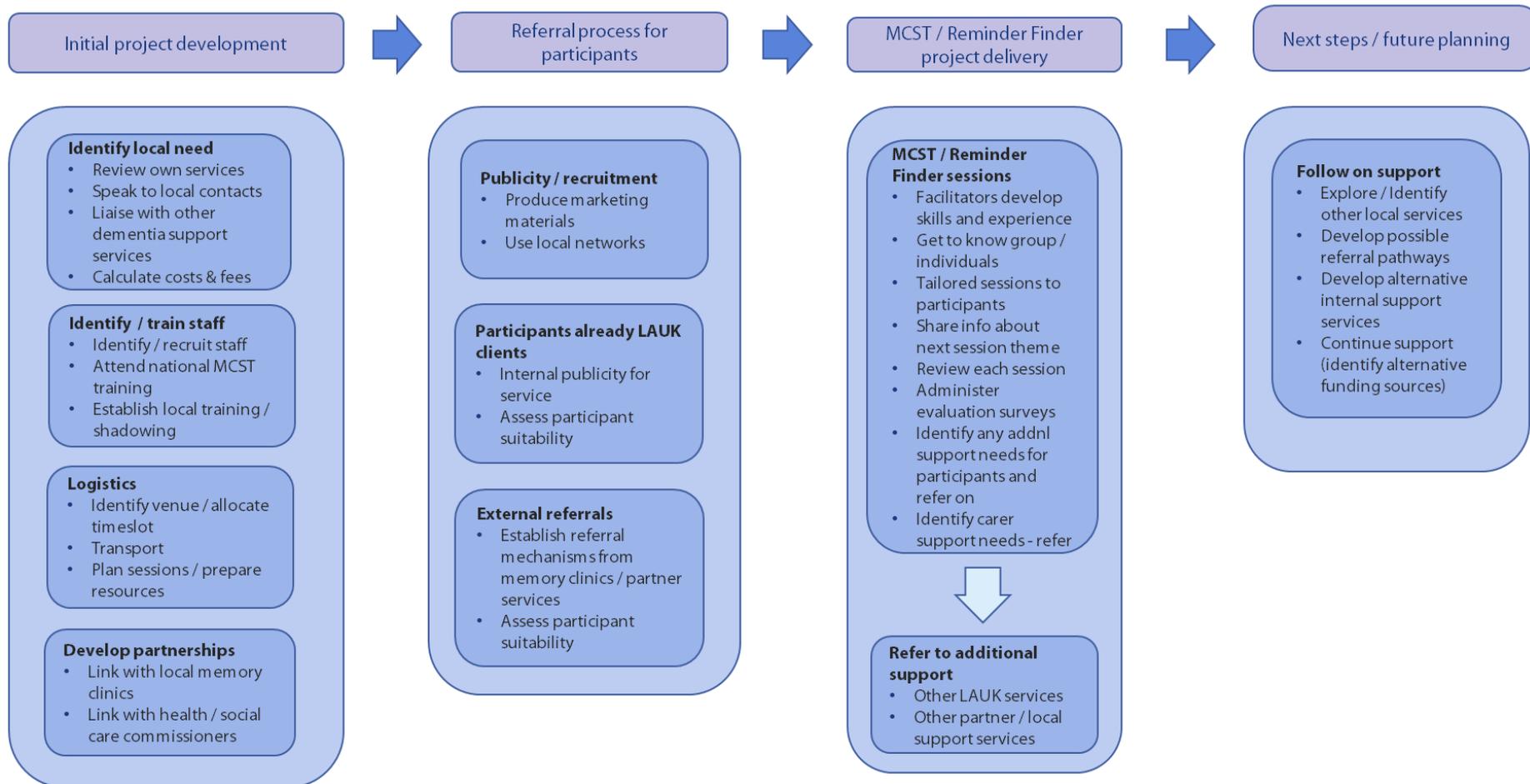
| Project | Group | Day / time / length | New / existing clients | Venue / travel | Format (at site visit) | Staffing |
|-------------|--|---------------------|--|---|---|--|
| MCST | | | | | | |
| Nottingham | "Super six" 6 members (all women) | Friday pm 1 hour | Existing clients (from day care services) | Own venue where they deliver day services Participants are existing users of day services - move to separate room to run MCST sessions | Tea and welcome / intro (song / weather / newspaper story) Physical activity (ball throw - names and favourite colours) Main activity (arts and craft) Song at end of session | 2 facilitators Table seating |
| Walsall | "Charlies Angels" 6 Members (2W / 4M) | Tuesday am 2 hours | Mix of existing clients / memory clinic self-referrals | Own venue (day centre) Participants travel by taxi / bus or brought by carer / family member | Tea and welcome / intro (weather / newspapers / song) Physical activity (ball throw / names) Activity 1 (Theme: Travel) Song Activity 2 (Theme: Faces - old pics of group members) Closing (summary / reminders) | 2 facilitators Table seating |
| Teesside | "The Forget-Me-Nots" 6 Members (4W / 2M) | Thursday pm 2 hours | Mix of existing clients (3) and Sanctuary / memory clinic self-referrals | Own venue (day centre) Participants travel by taxi / bus or brought by carer / family member | Tea and welcome / intro (weather / song / newspapers) Physical activity (ball) Main activity (Theme: film stars and their sons / daughters) Word game (hangman) Closing (summary / song / reminders) | 2 facilitators plus ex-carer volunteer as addnl support Table seating |

| Project | Group | Day / time / length | New / existing clients | Venue / travel | Format (at site visit) | Staffing |
|-----------------|---------------------------------------|--|---|--|--|--|
| Wirral | 5 Members (3M / 2W) | Monday 4 til 6pm 2 hours | New no previous CRT | Own venue Participants travel by taxi / bus or brought by carer / family member | Tea on arrival (some involved) / intro / what they had been doing this week Main activity - discussion about childhood (toys brought along by facilitator as prompts) Physical activity (bowls) | 2 facilitators, seated in a circle with lounge area with open plan kitchen |
| N Tyneside | 7 Members (6W / 1M) (6 at site visit) | Monday am 2 hours | Existing wellness centre clients (attend regular sessions on other days). | Own venue (wellbeing centre attached to residential care) Participants - LOCAL AGE UK transport provided. | Tea and toast / choose lunch (group song as background) Welcome / intro Physical activity (carpet bowls) Tea break Word activity (hangman) | 2 facilitators Seating around the room |
| Reminder Finder | | | | | | |
| Mid Devon | At time of visit 5 members (all M) | Monday 9.30 to 2.30 5 hours - break for lunch | Recruited from other groups. Recent new members from a CST group that closed. | Own venue Participants travel by taxi / bus or brought by carer / family member | Welcome - discussion about current affairs / weather / what have they been doing this week Seated exercise Activity - identifying food concealed in bags by feel Hot lunch (provided) Activity food - blind tasting | 2 facilitators - at least 1 group member beyond moderate |
| Wirral | 6 at time of visit | Friday 10-2.30 pm 4.5 hours inc lunch | New (self-referred) and existing clients No previous CRT | Own venue Participants travel by taxi / bus or brought by carer / family member | Tea and welcome / discussion about their week / crosswords completed with facilitator. Activity 1 - Thinking cards prepare their own sandwich lunch sit at table and chat whilst eating lunch Activity 2 scrabble (no scoring) games to finish | 2 facilitators. Room with open plan kitchen participants can access. Newspaper present but not used. |

| Project | Group | Day / time / length | New / existing clients | Venue / travel | Format (at site visit) | Staffing |
|------------|--|---|--------------------------------------|---|--|--|
| N Tyneside | "Friends" 6 Members (2W/ M) 5 at site visit | Tuesday 11 to 3 4 hours (including lunch) | Existing day centre clients | Own venue (wellbeing centre attached to residential care) Participants already at day care session - move to separate room | Tea and welcome / intro (weather / song) Main activity - session 1 (Theme: local history - landmarks near members' homes) Lunch Main activity - session 2 continuing am theme (visit from local history expert) Physical activity Closing (summary / reminders) | 1 main facilitator 2nd available as needed Table seating Extends 45 min sessions to 1 hour |

APPENDIX 2 – PROCESS MAP

MCST / Reminder Finder start up / delivery process



APPENDIX 3 – THEORY OF CHANGE

Theory of change: By understanding the practical issues around different approaches to delivery of MCST, AUK will be able to make best use of their capacity to provide effective support for people with mild to moderate dementia and their carers.

By supporting skills development, and capture and sharing of the learning from the programme AUK will be able to continue to improve the effectiveness and acceptability of MCST based approaches and contribute to a stronger evidence base for sustainable delivery of MCST support.

By developing, delivering and extending provision of effective, acceptable and well recognised approaches to supporting people with mild to moderate dementia, AUK can contribute to a better understanding of how people can live well with dementia

INPUTS

AUK funding and support (staff time)
LAUK staff time and resources (application / development and delivery)
Development of support mechanisms for learning and sharing (advisory group meetings / project portal etc.)
MCST training and manual
External evaluation / evaluation support

ACTIVITIES

Application / project selection
Staff / volunteer recruitment / training
Setting up of learning and sharing mechanisms (advisory group / project portal / commissioning evaluation)
MCST / Reminder Finder sessions developed
Participant assessment / recruitment
DEM-QOL / carers outcomes assessments
Analysis of evidence / reporting of outcomes
Learning and sharing
Links established with other services

OUTPUTS

Numbers sessions delivered (physical activity content)
Numbers participants / carers supported (continued participation)
Patient / carer outcomes assessments completed

Staff / volunteers trained
Information sharing sessions

Awareness raising / learning dissemination sessions / events

External networks established

OUTCOMES

Participants:

Increased social networks / access to support
Quality of life maintained / improved
Sense of wellbeing maintained / improved
Communication skills maintained / improved
Relationship with carer maintained / improved
(Physical activity levels increased)

Carers

More time for themselves
Increased access to support / information
Improved relationship with person they care for
Improved quality of life / wellbeing / confidence

AUK / LAUKs

Toolkit produced from learning
Staff / volunteers skills and confidence increased
Evidence for effectiveness of support available to AUK / LAUKs involved
Better links with relevant VCS organisations / commissioners

IMPACTS

Awareness of programme / MCST approaches increased
MCST acceptability increased
Learning made available to establish more MCST based services
More funding into approach
New projects established
MCST based support more widely available for people with dementia and carers
People with dementia and carers better informed / better supported / better able to cope / plan next steps
Pathways through care for people with dementia / carers more clearly understood
Carers better understanding of routes into other support (own and person with dementia)
Improved perception / understanding of support available for people with dementia
Reduced pressure on other dementia services (health and social care)
Evidence for effectiveness of approaches used more widely available
Learning contributes to better understanding of how people can live well with dementia



APPENDIX 4 – CARERS SURVEY

EVALUATION OF MAINTENANCE COGNITIVE STIMULATION THERAPY PROGRAMME INFORMATION FOR CARERS

The programme the person you care for is attending is being evaluated by Brightpurpose, an independent research organisation, to help Age UK understand what difference the programme makes to people with dementia and their carers.

Age UK are doing this because they want to be able to inform future decision making about provision of services for people with dementia so that at a national scale these valuable services can be provided efficiently and effectively. They want to be able to change things so that services like these can as good as it can be; and that no matter where they are in the country families living with dementia will have access to this kind of service.

We will be asking the person you care for to take part in some interviews over the course of the programme to see how things are changing for them. These will take place outside of the sessions time so that they do not interfere with their activities. The staff can talk to you more about what’s involved with that process if you have any questions.

We would also like to get some feedback from you, to understand what difference having this service available makes to your life. We have a short self-completion survey which we would like you to complete at the beginning, midpoint and end of the programme. Staff will facilitate this and collect in your completed surveys.

The information you provide is confidential and we will anonymise your answers before we pass them to the research organisation. Your personal details will be held securely and not passed on to any third party.

We know time is precious but this is a really important piece of work so we hope you can spare a few minutes to complete the survey. Please sign below if you consent to taking part and complete the survey attached.

Name: Carer No: (to be completed by staff)

I understand what I am being asked to do and I consent to participating in the evaluation as described to me.

Signed:

Date

Project Code -

Carer No.

Thank you for taking the time to complete this short questionnaire. Please read the following statements carefully and indicate your response to each statement by putting a cross through the number which reflects how you feel.

I feel encouraged and supported by professionals, care workers and others, in my role as a carer

Strongly disagree

1 2 3 4 5 6 7 8 9 10

Strongly agree

I am able to spend my time as I want, doing things I value or enjoy

Strongly disagree

1 2 3 4 5 6 7 8 9 10

Strongly agree

I have enough time and space to be myself to relax and 'switch off' from the worries of caring

Strongly disagree

1 2 3 4 5 6 7 8 9 10

Strongly agree

I feel that the person I care for and I communicate well with each other

Strongly disagree

1 2 3 4 5 6 7 8 9 10

Strongly agree

I am able to have as much contact as I want with my friends and family

Strongly disagree

1 2 3 4 5 6 7 8 9 10

Strongly agree

I look after myself (eating well and getting enough sleep)

Strongly disagree

1 2 3 4 5 6 7 8 9 10

Strongly agree

I feel stressed and anxious when I think about the future

Strongly disagree

1 2 3 4 5 6 7 8 9 10

Strongly agree

When I consider all aspects of my life (eg relationships, feelings, health, social life), I feel that I have a good quality of life

Strongly disagree

1 2 3 4 5 6 7 8 9 10

Strongly agree

APPENDIX 5 – DEM-QOL



EVALUATION OF MAINTENANCE COGNITIVE STIMULATION THERAPY PROGRAMME

PARTICIPANT CONSENT FORM

The programme you are attending is being evaluated by Brightpurpose, an independent research organisation, to help Age UK understand what difference this programme makes to people with dementia.

We would like you to help us with the evaluation by taking part in a short (20-30minute) interview before we start the programme. We will then interview you part way through the programme and again at the end so we can see what has changed for you since attending the programme has made to you. The information you provide is confidential and we will anonymise your answers before we pass them to the research organisation.

Your personal details will be held securely and not passed on to any third party.

Your participation in the evaluation is entirely voluntary and you can stop at any time if you do not wish to continue.

You will be asked to give your consent each time you are interviewed.

Name:..... Participant number:.....

I understand what I am being asked to do and I consent to participating in the evaluation as described to me.

Signed:.....

Date

Project
Code -

Participant No.

DEMQOL (version 4)

Instructions: Read each of the following questions (in bold) verbatim and show the respondent the response card.

I would like to ask you about your life. There are no right or wrong answers. Just **give the answer that best describes how you have felt in the last week. Don't worry** if some questions appear not to apply to you. We have to ask the same questions of everybody.

Before we start **we'll do a practice question; that's one that doesn't count.** (Show the response card and ask respondent to say or point to the answer) In the last week, how much have you enjoyed watching television?

a lot quite a bit a little not at all

Follow up with a prompt question: Why is that? or Tell me a bit more about that.

For all of the questions I'm going to ask you, I want you to think about the last week.

First I'm going to ask about your feelings. In the last week, have you felt.....

- | | | | | | | | | |
|--|--------------------------|-------|--------------------------|-------------|--------------------------|----------|--------------------------|------------|
| 1. cheerful? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 2. worried or anxious? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 3. that you are enjoying life? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 4. frustrated? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 5. confident? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 6. full of energy? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 7. sad? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 8. lonely? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 9. distressed? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 10. lively? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 11. irritable? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 12. fed-up? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 13. that there are things that you wanted to do but couldn't? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |

Next, I'm going to ask you about your memory. In the last week, how worried have you been about.....

- | | | | | | | | | |
|--|--------------------------|-------|--------------------------|-------------|--------------------------|----------|--------------------------|------------|
| 14. forgetting things that happened recently? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 15. forgetting who people are? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |
| 16. forgetting what day it is? | <input type="checkbox"/> | a lot | <input type="checkbox"/> | quite a bit | <input type="checkbox"/> | a little | <input type="checkbox"/> | not at all |

17. your thoughts being muddled? a lot quite a bit a little not at all
18. difficulty making decisions? a lot quite a bit a little not at all
19. poor concentration? a lot quite a bit a little not at all

Now, I'm going to ask you about your everyday life. In the last week, how worried have you been about.....

20. not having enough company? a lot quite a bit a little not at all
21. how you get on with people
close to you? a lot quite a bit a little not at all
22. getting the affection that
you want? a lot quite a bit a little not at all
23. people not listening to you? a lot quite a bit a little not at all
24. making yourself understood? a lot quite a bit a little not at all
25. getting help when you need it? a lot quite a bit a little not at all
26. getting to the toilet in time? a lot quite a bit a little not at all
27. how you feel in yourself? a lot quite a bit a little not at all
28. your health overall? a lot quite a bit a little not at all

We've already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate.....

29. your quality of life overall? very good good fair poor

30. Any other issues raised
