

Maintenance Cognitive Stimulation Therapy (MCST)

Pilot Programme Evaluation Report

September 2019 to March 2020

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Introduction

Cognitive Stimulation Therapy (CST) is an evidence-based¹ group treatment for people with mild to moderate dementia and is the only non-pharmacological therapy specifically recommended to improve cognition, independence and wellbeing by the National Institute for Health and Care Excellence (NICE)².

Longer-term or **Maintenance Cognitive Stimulation Therapy (MCST)** is based on CST structures and aims to actively stimulate and engage people living with mild to moderate dementia, whilst providing an optimal learning environment and the social benefits of a group setting.

MCST participants take part in meaningful and stimulating activities proven to help maintain memory and mental functioning. The groups provide a fun, supportive environment where people can build new friendships and share experiences. Each session covers a different theme with a range of activities including:

- discussions on various topics
- number/word games
- team games and quizzes
- physical activities
- creative and musical activities

A pilot coordinated by Age UK in 2017/18³ found that MCST sessions contributed to the maintenance of group participants' wellbeing relating to their feelings, memory and everyday life. These measures would usually be expected to decrease over time for people with dementia who do not attend sessions.

Following a successful application for funding from Age UK's Grant Programme: MCST within Joining Forces, **Age UK Lancashire** were able to develop a pilot model in order to enhance our existing offer to veterans and to address a clearly identified local need for dementia support within our area of benefit. We developed and delivered the MCST pilot programme between September 2019 and March 2020.

¹ 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

² Dementia: assessment, management and support for people living with dementia and their carers
NICE guideline [NG97] Published date: 20 June 2018

³ <https://www.ageuk.org.uk/our-impact/programmes/maintenance-cognitive-stimulation-therapy-mcst/>

We expected the pilot programme to complement our work with local older people living with dementia, currently offered through our Day Time Support, Dementia Community Links, Dementia Hub and Joining Forces services.

Identification of need was based on:

1. Health priorities within the Healthier Lancashire and South Cumbria STP
2. The rising incidence of dementia within our area of benefit. 2016/17 Quality & Outcomes framework figures indicated 15,649 known cases of dementia across the STP (0.9% of the whole STP population). West Lancs CCG recorded a prevalence significantly higher than the England average (0.76%) at 0.95% and this is expected to increase by 31% in West Lancs by 2026.
3. The increasing demand for our existing dementia support services.

Consultation with older people and their carers through our recently formed Dementia Hub.

The MCST pilot programme fitted clearly into Age UK Lancashire's strategic priorities for 2019-22 to:

1. Meet the needs of the local Lancashire population by providing high quality services that are responsive to the needs of local older people and our commissioners.
2. Work collaboratively, ensuring the best outcomes for customers.
3. Ensure our workforce is multi-skilled and that we are sharing our knowledge.
4. Increase the diversity of referrals and customers that we engage with.
5. Work closely with our commissioners to bring gaps in delivery to their attention.
6. Identify new products, customers, and areas for our services.

The MCST pilot programme also supported us to deliver against commitments set out within **Age UK Lancashire's** Dementia Action Alliance Plan:

https://www.dementiaaction.org.uk/members_and_action_plans/1610-age_uk_lancashire

We seek to encourage opportunities for local people to feel more confident, supported, enabled, valued, independent and healthy as individuals and within the wider community. Delivering this programme helped us to achieve our purpose for Lancashire veterans living with dementia.

2. Aims

Through the pilot programme, we aimed to achieve the following outcomes:

1. Deliver an MCST course to 4-8 older veterans living with mild to moderate dementia in West Lancashire.
2. Continually engage at least 4 veterans throughout the duration of the pilot.
3. Establish interest and demonstrate demand for future MCST projects.
4. Assess and monitor participants' (and their carers) cognitive ability and/or quality of life throughout duration of course.
5. Develop a sustainable delivery model.
6. Deliver at least 12 sessions, with around 6 older people continually engaged or committed to engage for up to 24 weeks (or more) and all monthly project reports and updates submitted within scheduled parameters.
7. Evaluate effectiveness of delivery model in terms of:
 - impact on participants' cognitive functioning and quality of life
 - impact on unpaid carers' wellbeing
 - sustainability

3. Course overview and picture gallery

Programme Structure and Format

Group Details	<ul style="list-style-type: none"> • 6 participants (all male veterans) • Group name “Betterans” chosen by one participant and agreed by all
Day/Length	<ul style="list-style-type: none"> • Mondays 12.30 – 3pm
New/existing clients	<ul style="list-style-type: none"> • Mix of new and existing Day Time Support and Dementia Community Links clients
Duration of programme	<ul style="list-style-type: none"> • 12 weekly sessions with a break for Christmas • Welcome meeting for participants and their carers a week before start date • Evaluation session 4 weeks after course end
Venue/Travel	<ul style="list-style-type: none"> • Own venue (Wellbeing Centre) • Participants brought by carer or taxi
Cost	<ul style="list-style-type: none"> • £180 payable in advance
Format	<ul style="list-style-type: none"> • Lunch provided upon arrival • Welcome and theme song • Reality orientation using whiteboard (date, time etc.) • Main activity e.g. categorising objects, team quiz • Tea break • Closing with summary, singsong and issuing of take home task/reminder sheet
Staffing	<ul style="list-style-type: none"> • 2 trained facilitators plus a volunteer where possible for additional support

Core session themes

- **Independent lunch prep** – participants were encouraged to prepare their own lunch using foods provided such as bread/rolls, sandwich fillings, salad and crisps. This encouraged independence, choice and cooperation whilst

staff encouraged regular feedback and welcomed new suggestions for lunch ideas.



- **Name badge** – worn every week by staff and participants to act as a reminder, build rapport and reduce anxiety around forgetting names.
- **Whiteboard** – used at the beginning of each session, this helped with orientation of time, date, place and topic and generated discussion on the weather, seasons and current affairs.
- **Singing** – a ‘signature’ song was agreed by the group in Week 1 and was sung at each session. The chosen song was “Bless ‘Em All”.
- **Take home task** – a one page visual aid to take home, detailing the date and theme of the next session and encouraging the bringing in of any relevant materials. This helped to thread sessions together, prompt action and keep participants and their carers informed of what to expect next.

Session topics*

Session 1 – My Life

Session 2 – Current affairs

Session 3 – Food

Session 4 – Being creative

Session 5 – Number games

Session 6 – Team games/quiz

Session 7 – Sound

Session 8 – Physical games

Session 9 – Categorising objects

Session 10 – Household treasures

Session 11 – Useful household tips

Session 12 – Thinking cards

* The MCST manual provides a detailed guide for up to 24 weekly themed sessions, some of which repeat on set weeks e.g. Household treasures on sessions 10 & 22. During our 12 week pilot, we adhered to the format laid out in the manual and found at Week 12 Thinking Cards was a good topic to end on, enabling participants to reflect on their thoughts about the course and what they had enjoyed the most.

The 12 MCST sessions delivered put the key principles of Cognitive Stimulation Therapy into practise which include mental stimulation, multi-sensory triggers, encouraging new ideas and opinions, involvement and inclusion, choice and respect, continuity and consistency and reminiscence and fun.

Picture gallery



Throwing a ball whilst saying a response to a particular topic proved a fun and stimulating activity during many sessions e.g. naming animals beginning with the letter A, B, C and so on.



Current affairs week – discussion around the news and media outlets, how these have changed over time and what our preferences are. Also sharing interesting stories from copies of 1950's newspapers to generate further discussion and opinions.



Food Week – working in teams to match the food dishes to their country of origin e.g. paella with Spain. Visual images of foods and national flags aid with recall.





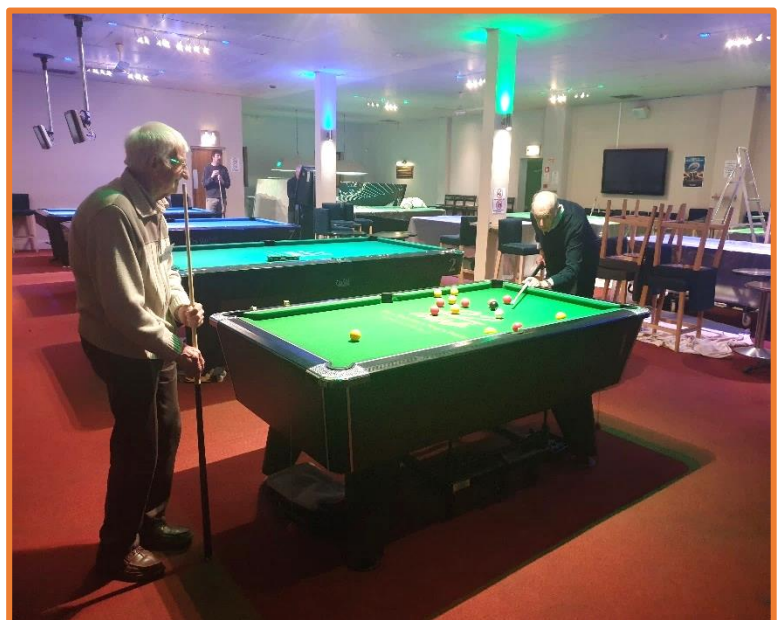
Being creative week – sharing examples of past hobbies such as artwork before choosing from a variety of garden bird feeders and wooden Christmas decorations to make.



Team games/quiz week – a festive themed session before a midway break for Christmas and New Year. Turkey sandwiches, Christmas crackers and novelty hats add extra fun and enjoyment to the team games and competitions!



Sound week – 1950's musical bingo followed by the opportunity to play a variety of instruments including guitar, bongos and a rainstick! The group also chose to sing The Leaving of Liverpool.



Physical games week – a fun and energetic warm up game with the parachute before a trip to the nearby snooker hall for some friendly competition and the opportunity to buy refreshments!



Categorising objects week – looking for similarities and differences between a range of items found around the home including tools, kitchen utensils and items of clothing.



Household treasures week – an opportunity for participants to bring in items from home such as old kettles and irons, compare old with new and discuss personal preferences.

4. Results: MCST evidence base - what difference does it make?

We measured both **quality of life** and **cognitive functioning** of course participants at the beginning and end of the course. We also asked participants to share what they had enjoyed about the course in a few words. The following results highlight the impact and effectiveness of MCST on group participants.

Quality of Life Assessment

Using DEMQOL, a patient reported outcome measure designed to enable the assessment of health-related quality of life of people with dementia, group participants rated 28 different aspects relating to quality of life in the following categories: **feelings**, **memory** and **everyday life**. See Appendix 1 DEMQOL.

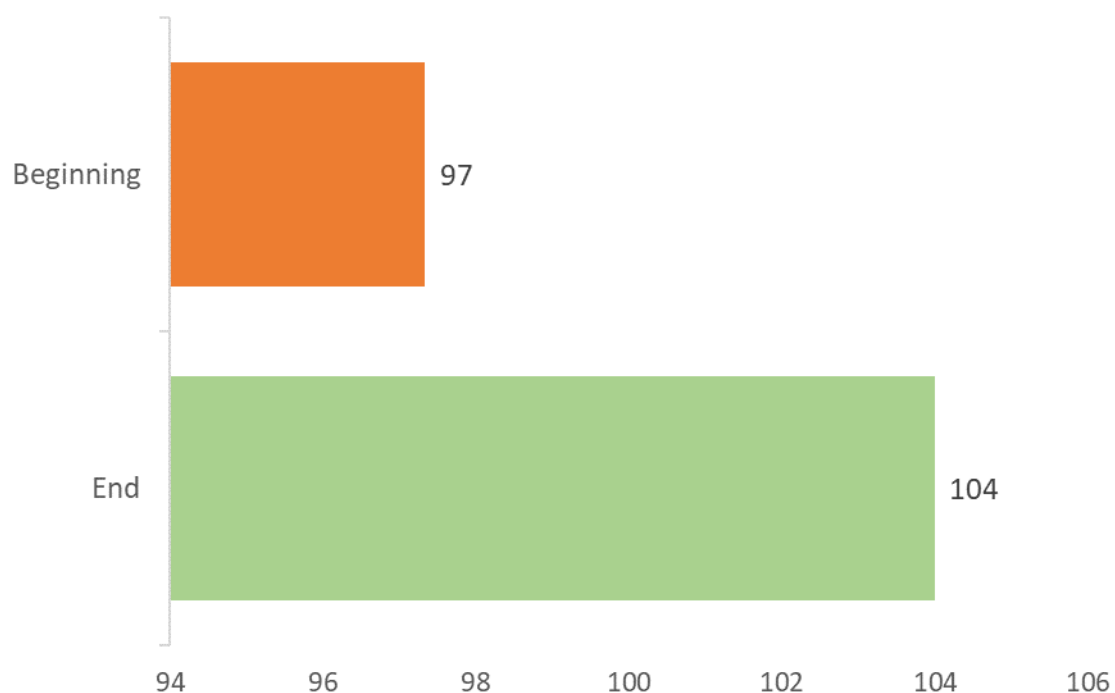
DEMQOL responses range from feeling '*a lot*' to '*not at all*' with a respective score of 1-4, some specific elements of scoring within the category being reversed. *See Appendix 1.

DEMQOL also includes a final question rating overall quality of life from '*poor*' to '*very good*', also scored as 1-4.

Figure 1 overleaf shows the average total DEMQOL score across all participants fully completing a DEMQOL survey at the beginning and end stage of the course:

Quality of Life

Fig 1 – The average DEMQOL score across the group **increased** by 7.2% from beginning to end.



It would be reasonable to anticipate that scores would slightly decrease for people living with dementia receiving no intervention over a 3 month period. As demonstrated in figure 1, there has been an increase in the average total score from Week 1 to Week 12, suggesting an **improvement in quality of life**.

Feelings

Fig 2 – Most measures relating to feelings **improved or were maintained**.

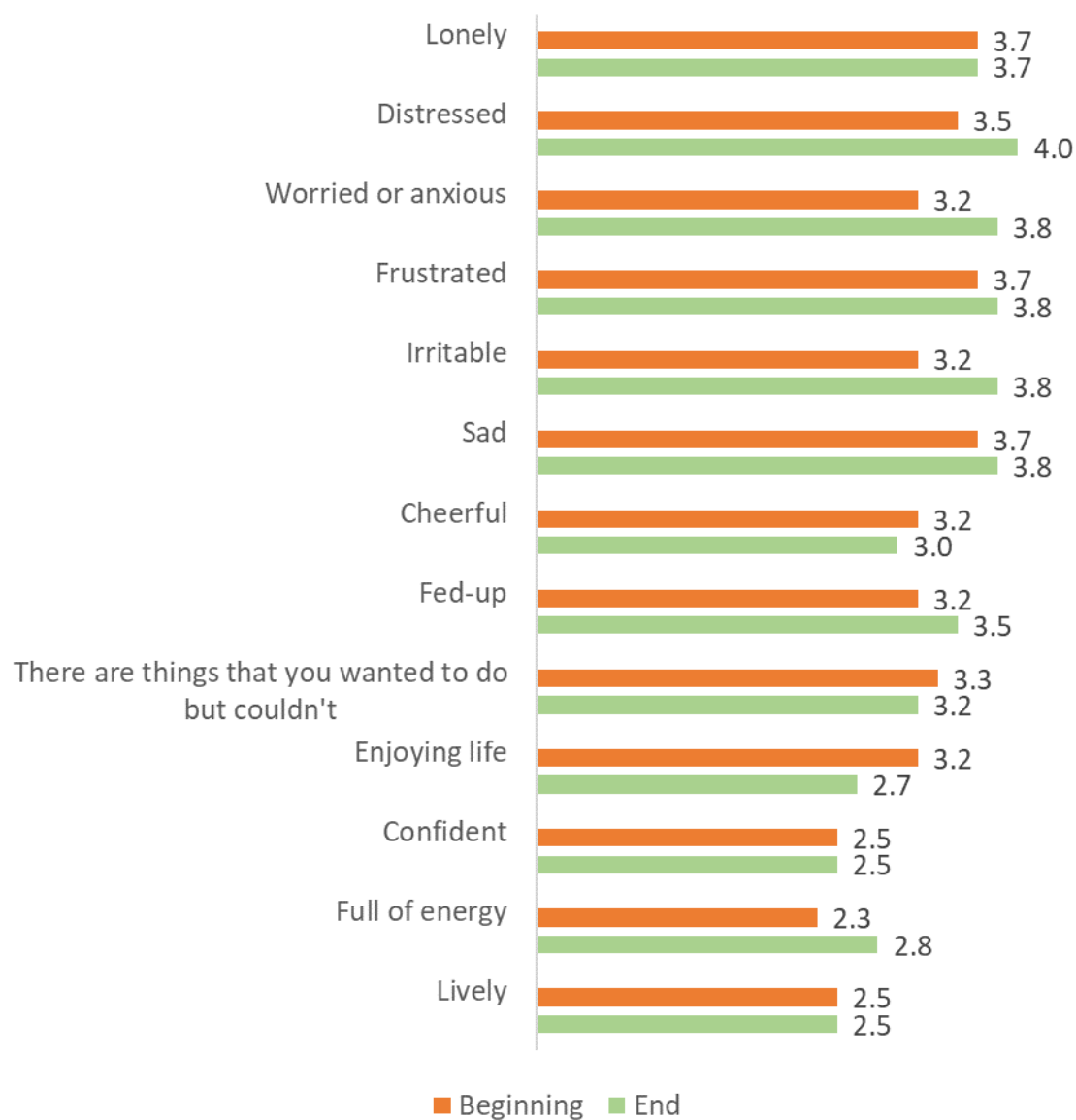


Fig 2 data suggests that 10 out of 13 measures relating to participants' feelings improved or maintained. Most notable improvements were in *feeling worried or anxious*, *feeling distressed*, *feeling irritable* and *feeling full of energy*. Scores which were lower at the end point related to *feeling cheerful*, *things that they wanted to do but couldn't* and *enjoying life*.

Memory

Fig 3 – Most measures relating to memory **improved**.

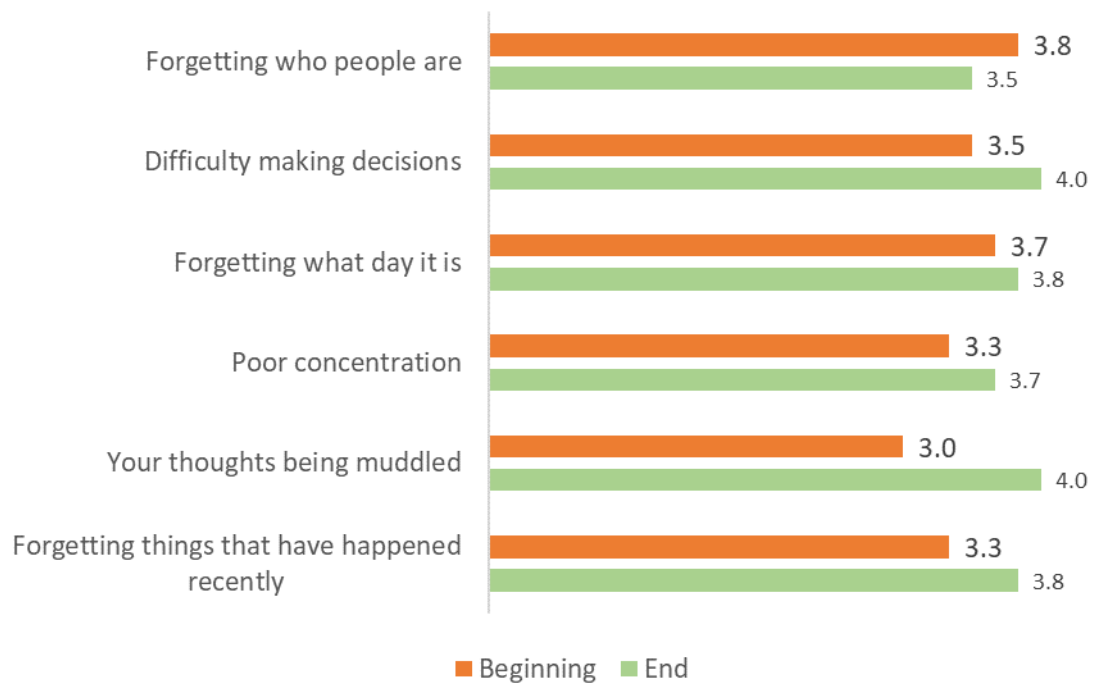
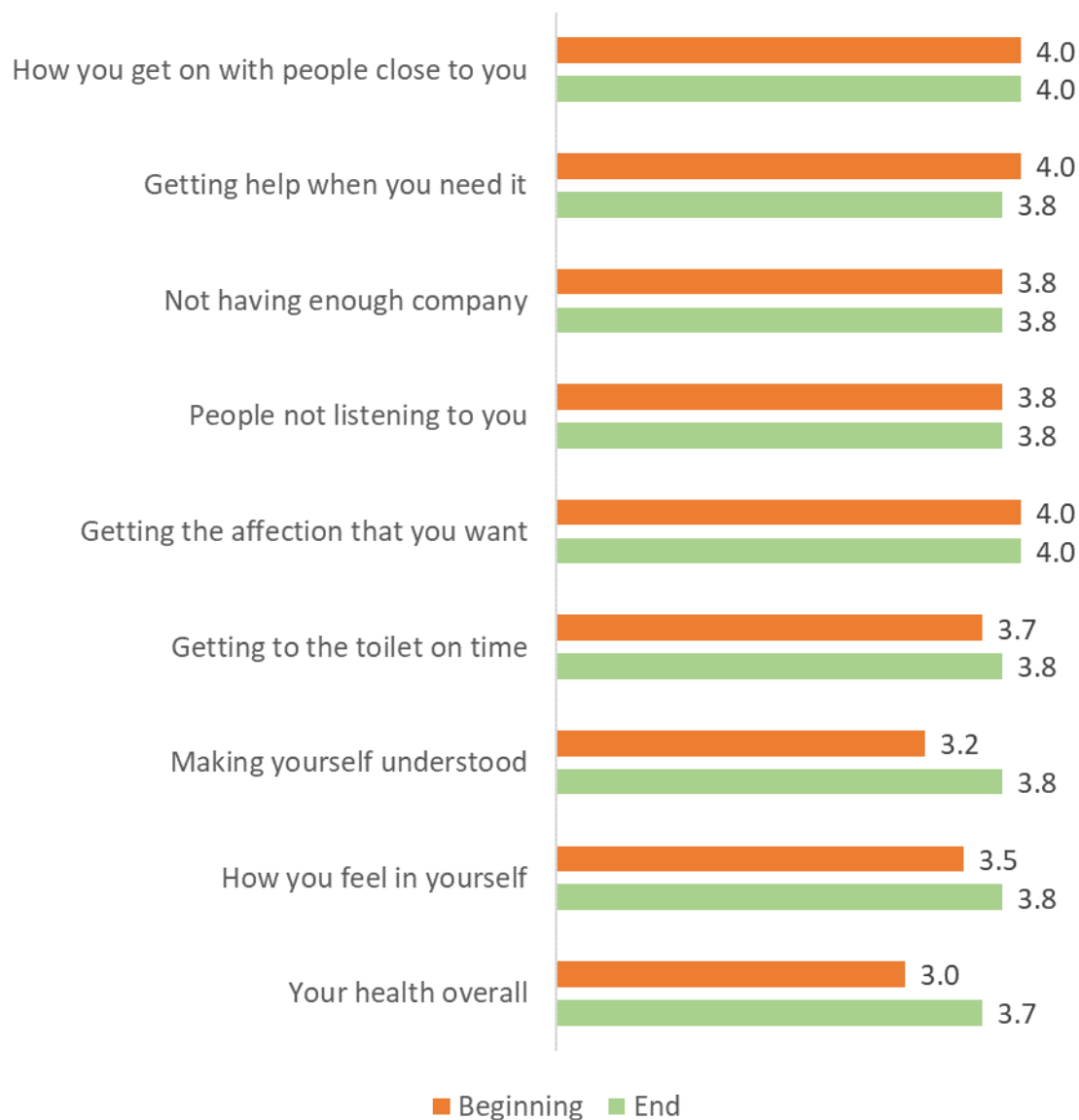


Fig 3 data suggests that 5 out of 6 measures relating to participants' memory improved, most notably in relation to *Your thoughts being muddled*.

Everyday Life

Fig 4 – Most measures relating to everyday life **improved or were maintained**.



Data in Fig 4 suggests 4 out of 9 measures relating to participants' everyday life improved - most notable in *Making yourself understood* and *Overall health*, 4 maintained and 1 decreased in *Getting help when you need it*.

Overall Quality of Life

Fig 5 – Overall quality of life **improved significantly** from beginning to end.

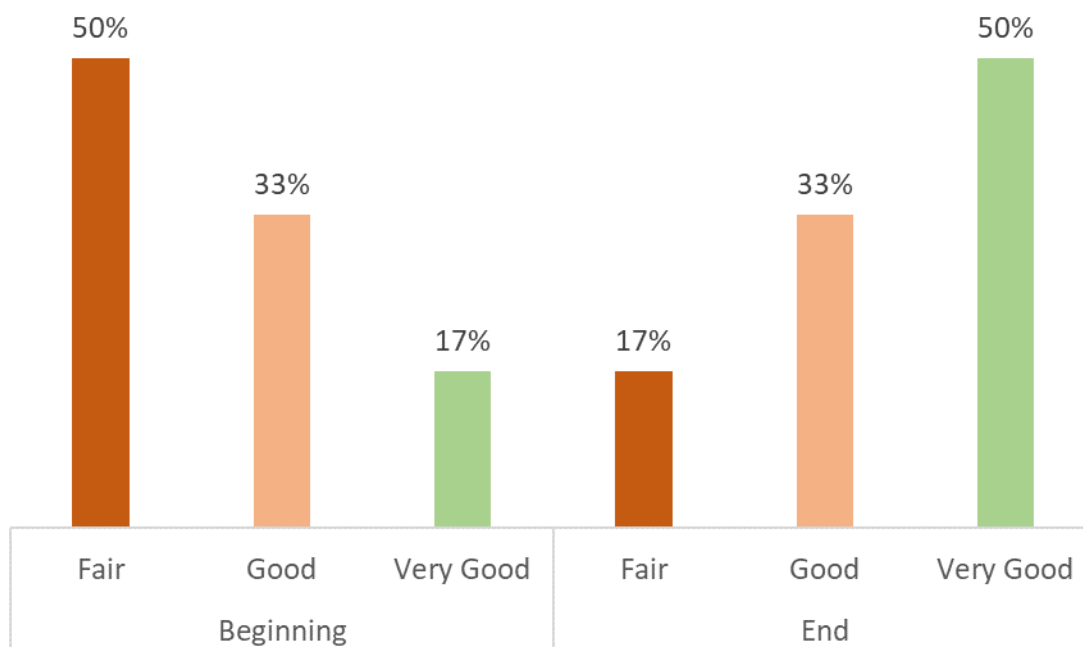


Fig 5 data demonstrates a substantial increase (17%-50%) in those participants rating their overall quality of life as *very good* in the final survey.

Cognitive Functioning

We conducted the Montreal Cognitive Assessment (MoCA) assessment to measure cognitive functioning of participants at the beginning and end of the course. See Appendix 2 MoCA.

MoCA assesses different cognitive domains including attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations and orientation.

Fig 6 – MoCA **scores increased** across the group from beginning to end.

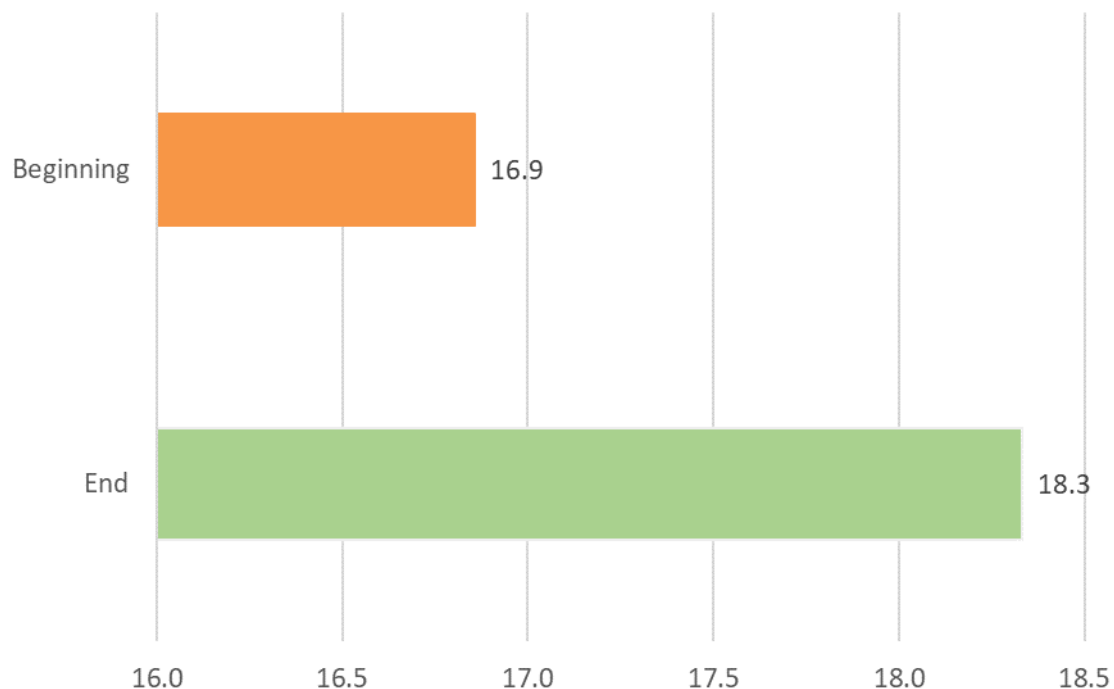


Fig 6 data demonstrates that average **cognitive functioning of participants improved** by 8.2% from beginning of the course to end.

Feedback from Participants

When asked what they had enjoyed about the MCST programme, participants rated the company and engaging activities highly:

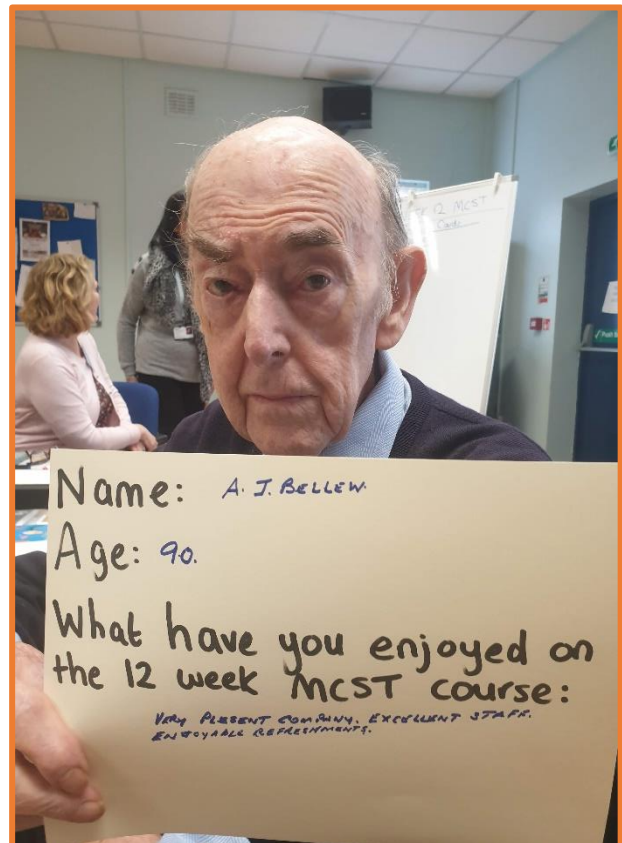
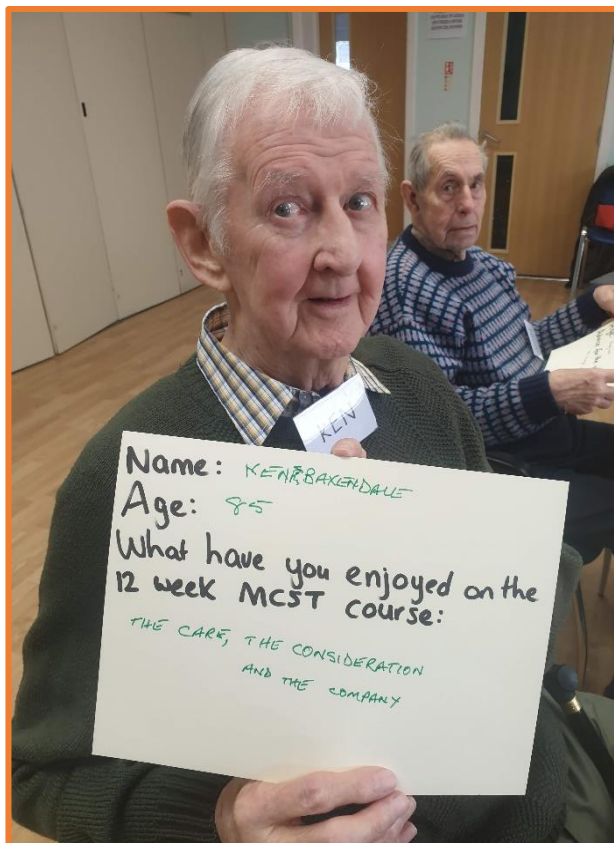
“Stimulating friends and leaders.”

“The care, the consideration and the company.”

“Meeting other people and the things we did and talking amongst us all.”

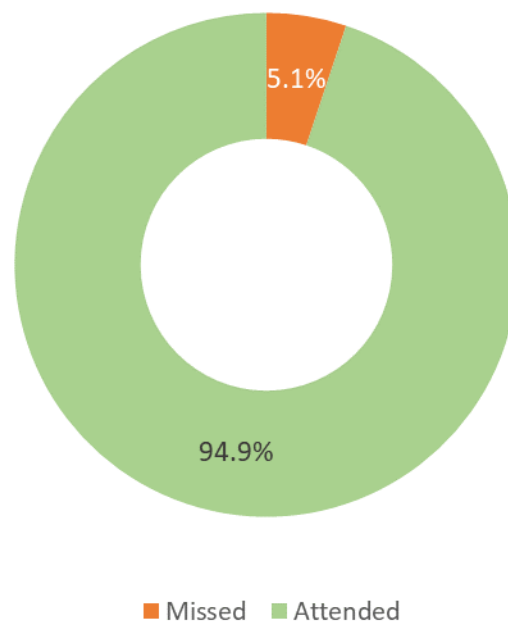
“Very pleasant company and excellent staff. Enjoyable refreshments.”

“This was an excellent course with an excellent group of people – both those who ran the course and colleagues that attended.”



Attendance

Fig 7 – attendance levels remained high throughout the 12-week course with absences caused solely by holiday or temporary ill health.



Feedback from both participants and carers supports these findings:

“I was a bit hesitant about joining but later didn’t want to go home.”

“Not coming on a Monday will be a great miss. Would like the opportunity to repeat.”

“He seems to look forward to going to the MCST sessions when I tell him he is going.”

“He gets up and ready quicker.”

5. Respite and support for carers

We asked carers to complete a wellbeing survey with additional comments sheet at the beginning and end of the programme. Using a 'radar' of 10 measures, the survey asked carers to score how they felt against a range of statements relating to aspects of wellbeing and quality of life including support, self-care and relationships. See Appendix 3 Carers Survey.

The radar chart in Figure 8 presents findings from initial (orange) and final (green) survey. The further from the centre (strongly disagree), the more positive the score (strongly agree) except for *feeling stressed and anxious* in which case the score is reversed.

The most significant improvements were *I am able to have as much contact as I want with friends and family* and *I feel that the person I care for and I communicate well with each other*, suggesting MCST has a positive impact on communication in a range of social scenarios benefitting both carer and participant:

“Maybe for an hour after the session we can have a conversation or I will say something and he will pick up on it. He is interested in what's on the radio for maybe an hour too.”

“More communicative. Is affectionate – had become distant.”

We also asked carers to tell us about how their loved one was coping on a day to day basis in their own words. One carer told us:

“Memory is slightly better e.g. he uses his diary without prompting. It's almost like having the man I married back again”.

Carers felt less stressed and anxious at the end point and were looking after themselves better:

“I wasn't going to bring him every week but found myself in a routine which I enjoyed.”

Carers expressed a desire to continue with MCST and were worried about the lack of meaningful opportunities available after the course end:

“It would be beneficial if something similar could be organised on a weekly basis permanently. The greatest problem these days is that he has no motivation to do anything. Left to his own devices he just sits and then after a while, falls asleep.”

“I would highly recommend the group and it would be great if Age UK were able to offer some follow up/continuation of the group.”

Encouraging participant's motivation and sense of purpose were a common theme emerging from the carers' feedback:

“The course has offered him structure which is lacking in his life and enabled him to spend time with others as he is quite isolated. Although he found motivation to do the homework difficult at times, he always came back very positive and invigorated.”

“[Name] was fairly chatty on the way home from the sessions and seemed more ‘alive’ as it were. He has started singing around the home again which he used to do.”

“[Name] was always keen to go to the sessions. Your work to improve his and other lives is very valuable.”

Although the feeling supported by professionals, care workers and others as a carer measure slightly reduced, qualitative feedback from carers indicates that this is in reference to aspects of the caring role taking place in the home environment:

“The responses given are not a reflection on the support from staff at Age UK who have been excellent in their communication and support for my Dad.”

Feedback suggests that increases in confidence for participants led to changes at home with carers struggling to balance the practicalities of this:

“He is sure everything is back to 'normal'. He is much improved i.e. volunteers to wash dishes and do ironing etc. but he does it very poorly as he wants to do it independently and not with me. He is very confident and memory much improved but his ability to perform tasks is worse if anything (not caused by the course, just time).”

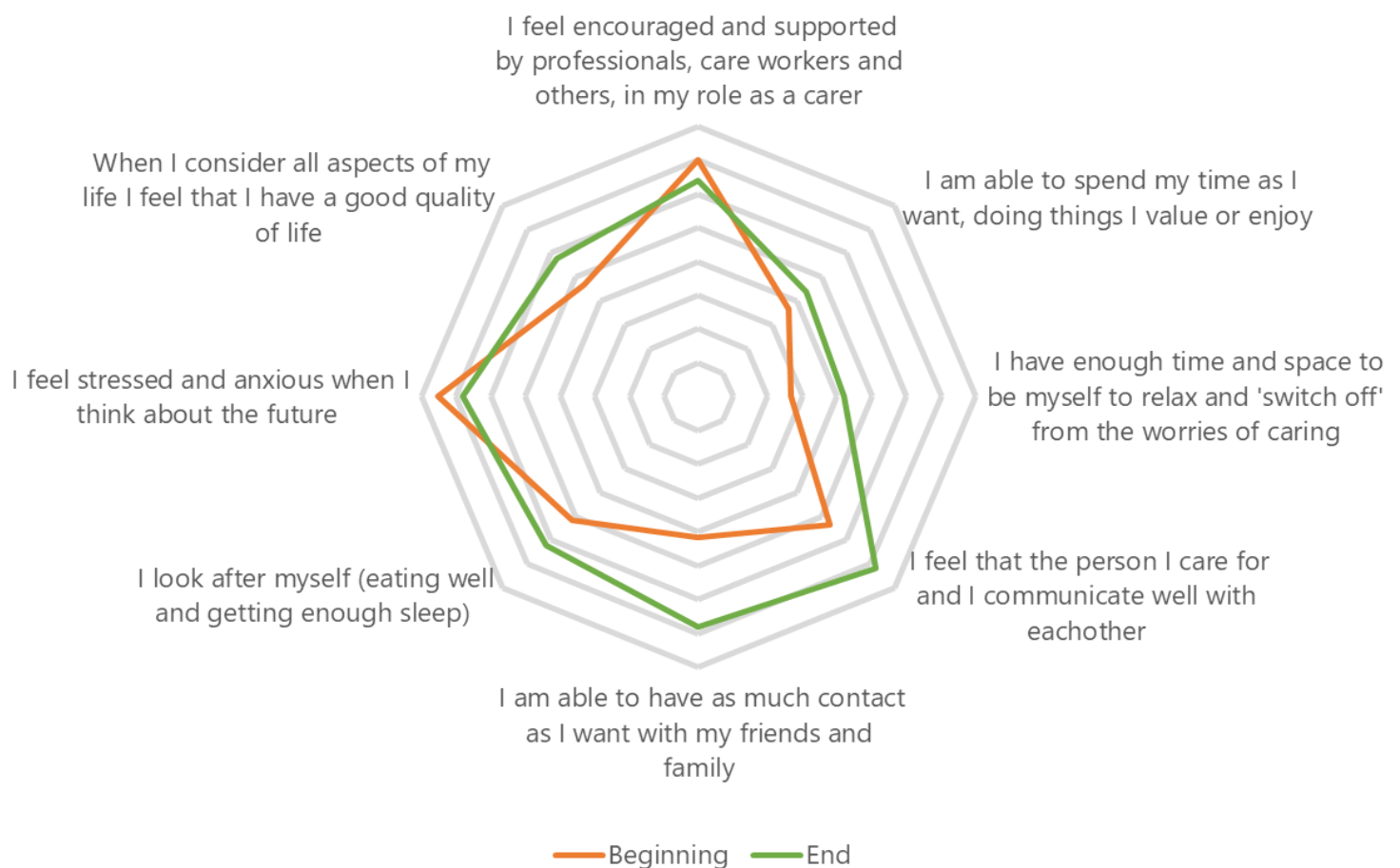
“I really respect and understand the ethos of services not to encourage dependency and to enable people to be as self-supporting as possible. However, I think this puts a lot of additional stress on to carers and assumes individuals have support outside services which is not always the case.”

It became apparent during the course that participants were feeling more confident and motivated to attempt tasks independently at home. We were acutely aware of the lack of options in the local area to support continuation of a structured programme of activities in the home environment.

As a result, we have sought additional funding to enable the training of staff in facilitating Individual Cognitive Stimulation Therapy (iCST). We plan to offer iCST awareness sessions to carers and family members of those living with dementia in the future, to support the ongoing maintenance of cognitive stimulation at home.

Carers Survey

Fig 8 - **seven of eight measures relating to carers wellbeing improved** from beginning of the course to end.



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

6. Learning from project staff

As part of the Joining Forces within MCST grant programme, Age UK Lancashire were able to fund two existing employees from the Dementia Community Links team to be trained in the principles and delivery of Cognitive Stimulation Therapy and to facilitate a 12 week MCST pilot programme for Lancashire veterans living with dementia.

The MCST pilot project staff had existing experience of working with people with dementia and their carers and were attracted by the opportunity to be involved in a non-pharmacological NICE recommended treatment and learn new and rewarding transferable skills.

Planning

With supervisory support, a project plan was drafted which detailed the actions to be taken from the pre-planning phase through to post-course reporting. Following a visit to Age UK Wirral to observe MCST provision and learn from the experiences of the staff there, the project plan was amended to reflect the following changes:

- **Transport** – this no longer formed part of the core offer as it was felt that those who attended would need a viable and sustainable independent means of transport. This decision was influenced by the experience of local transport issues and limited affordable provision.
- **Food/refreshments** – lunch was now included as part of the core offer as it was felt that this promoted independence and provided a social platform at the beginning of each session. Participants would be encouraged to prepare their own lunch and sustain practical skills for longer.
- **Extended session time** – the original session time of 2 hours was extended by 30 minutes to incorporate lunch and allow enough time to work through the core activities without feeling rushed.
- **Budget** – in order to accommodate the extended session time, the cost of additional hours for food preparation and admin before and after each session was offset by the original budget allocated towards transport costs.
- **MoCA assessment tool** – additional training was undertaken to support the use of the MoCA rapid screening tool in the assessment of mild cognitive dysfunction. This tool aided participant selection and supported in the measuring of cognitive baseline and follow up scores.

Referrals and Participant Selection

Project staff were directly involved in the promotion, referral and assessment pathway and successfully attracted interest in the pilot from a variety of sources. Referrals came from existing Age UK Lancashire services, family and friends, the Dementia Hub and partner agencies including Alzheimer's Society, Dementia Nurses, Carers Support services and Dementia Friendly Communities.

Although the pilot programme required participants to be veterans, there was a high level of interest from a wider group of individuals living with dementia, proving demand for MCST in the area and resulting in the creation of a waiting list for those seeking future consideration.

Project staff were aware that group composition was an important factor in determining the effectiveness of groups and this led to a thorough assessment process based not only on cognitive ability but factors such as willingness to engage, levels of agitation and severe physical health concerns.

Potential participants were assessed in the home environment before being invited to a Welcome Meeting with their carers where they completed an initial DEMQOL questionnaire and Carers Survey. It was at this point that one potential participant did not wish to engage any further with the programme and was signposted to alternative provision.

Programme Delivery

The small group size of six participants was seen by project staff to be a major strength of the programme, allowing for more personal attention to individuals and quality interaction across the group. Staff did find the intensive nature of the support and the time needed to plan, deliver and report on sessions quite demanding and felt that sustainability of the programme would be improved with a wider team of trained staff to draw on. Although the sessions were intense, staff got a lot of satisfaction from them and enjoyed the structure, content and approach.

Project staff used the Making a Difference 2 manual to help plan sessions, keeping to the principles of CST whilst maintaining a pragmatic approach to the needs of the group and allowing for choice. Having already worked within dementia support services, staff were acutely aware that people with dementia can experience very different symptoms from one day to the next. As such, being able to modify sessions to meet the needs of the group participants was seen as an important feature for effective implementation.

Participant engagement

Monitoring Progress forms helped record levels of attendance, mood, engagement, communication and interest of each participant, enabling staff to adapt and plan the programme for future sessions. See Appendix 4. A Take Home Task sheet was also created by project staff as a way of motivating participants to remain engaged in the programme, involving carers at home and providing a simple reminder of the next session. This proved popular, with several participants creating their own 'homework folder' to bring along with them to each session.

Creating a friendly and welcoming environment was considered essential by project staff, who were responsive to the needs of participants and their carers and keen to build rapport and trust. Participants were warmly welcomed in each week and given a name badge to wear before being invited to prepare themselves lunch and chat. Understandably, there were occasions when participants arrived late and so having lunch before the main activity ensured that they didn't miss out on course content.

Transport challenges

Although most participants were brought along by carers, transport did prove to be a challenge for some participants due to lack of available volunteer community car drivers. Staff explored the possibility of taxi sharing but as participants were widespread across the geographical area, they each had to pay for a return fare which for some, meant overall transport costs exceeded that of the course itself. Furthermore, those who did use taxi companies often found the experience stressful and confusing, especially where delays and payments were involved. On balance, it was felt that future MCST programmes would benefit from a viable volunteer driver scheme within the project and a new volunteer role has since been created to support up to three individuals with transport to and from sessions.

Perceived Impact on Participants and Carers

Project staff built up a rapport with the participants over the course of the pilot programme and became trusted and familiar group facilitators, maintaining close contact with carers as well. There were occasions when carers needed signposting for extra support, reassurance as to how they were managing their loved one at home or just a non-judgemental listening ear. It was felt that maintaining close contact with carers helped them to better support their loved one at home.

One carer lived abroad but was keen to be kept updated on her father's progress by email, so staff shared photographs of him engaging with the sessions and provided her with regular feedback. On one rare occasion when she was visiting home, staff agreed to her joining the group towards the end of a session to observe for herself how much her father was benefitting from the programme.

Over the course of the 12 weeks, staff observed positive changes in the participants which were often noted by carers at home too. All of the participants became more confident in making themselves lunch, engaging in new activities and communicating with both project staff and each other as the weeks went by. Less questions were asked about when the session would end or how they would get home as they settled into a structured routine and began to relax and enjoy themselves.

One participant who was very quiet during the initial half of the course due to a slight speech delay became much more confident in joining in conversations as the programme progressed. Another participant was able to stay awake and engaged for the entire session by the end of the programme as staff worked with carers to encourage him to wear his hearing aids each week.

Unfortunately, one participant suffered a leg injury part way through the course and was unable to attend three consecutive sessions. Staff and family became concerned that he was losing confidence in re-joining the group and so a phone call was made to encourage him to return which proved successful. Staff sent out a copy of the latest Take Home Task sheet so that he could plan his return and he happily engaged with the last three weeks of the programme.

Post-Participation

Project staff invited all participants and their carers for a follow up meeting four weeks after course end to report their findings from the MoCA, DEMQOL and Carers Survey assessments, advise on next steps for course participants and to present each one with a personalised photograph album of their time on the course. The photograph album served as a fond reminder of the fun and enjoyment they had experienced both individually and as a group and was gratefully received by all.

Carers were asked a series of questions around how their loved one had been managing since the course ended, whether they felt the course has been value for money and if they would recommend the course to others. All said they would recommend the course and agreed it was value for money. They couldn't think of anything they would like to change about the course other than for it to run for longer.

Interest in future CST provision was high as some carers had noted a deterioration in their loved one since the course had ended. One of the participants himself spoke of missing the company of the others. A few carers swapped contact details with the intention of meeting up in the future whilst others showed an interest in coming along to the monthly Dementia Hub.

Many participants were already engaged with Day Time Support, Dementia Cafes and Singing for the Brain sessions but it was still felt that MCST offered them something extra in terms of the small group sizes and stimulating activities on offer.

Project staff agreed to keep all participants and their carers updated on future opportunities for CST programmes and felt motivated to develop further provision across Age UK Lancashire having themselves witnessed the impact of the therapy on those they had supported.

Project staff continue to share their experience and passion for MCST within their teams and wider networks and look forward to developing their own skills and training through the iCST programme.

7. Conclusions and considerations for the future

Benefits of an MCST based approach

For people with dementia

The findings of the 12-week pilot programme suggest that MCST contributes to the maintenance of the components of wellbeing as measured by DEMQOL relating to feelings, memory and everyday life. Findings also demonstrate a positive shift in relation to participants' perceptions of their overall quality of life.

Observation and evidence from participants, carers and project staff reinforces that the following benefits for people with dementia were also commonly realised as a result of the pilot programme:

- a sense of belonging and making new friendships
- opportunity to voice opinions and share experiences
- fun and enjoyment
- increased confidence in own ability to try new things
- improvements in communication both within the group setting and at home
- improvements in memory and mental ability
- an increased sense of independence
- enhanced levels of motivation, energy and purpose

For carers

Quantitative and qualitative data gathered via the Carers Survey and additional comments sheet at the beginning and end of the course suggests that MCST contributes to the following carer outcomes:

- witnessing improvements in the person they care for
- better communication with their loved one
- increased levels of self-care
- more time to themselves
- more time to see friends and family
- feeling less anxious about the future
- keen to be considered for future MCST carers awareness sessions

For Age UK Lancashire

The benefits of the MCST programme for the organisation include:

- new skills, experience and learning that can transfer across services
- positive impact on morale and motivation for staff involved in delivery
- new and rewarding opportunities to work with people affected by dementia and their carers
- enhanced credibility amongst partners and funders
- increased referrals into existing services

Referrals and wider impact

Referrals into our Dementia Community Links service increased during the MCST launch period and coupled with the continued success of the Dementia Hub which successfully migrated online during Covid-19, we are able to reach a new audience providing us with more opportunities to support those living with dementia and to have wider impact across Lancashire.

Future considerations

A number of critical success factors have emerged through the learning and experience of the MCST pilot project which bear influence on the sustainability of future provision:

- **Staff** – delivery staff need to be equipped with the necessary skills, experience, passion and resources to facilitate group sessions. Continuity of staff is an important aspect of developing trust and familiarity amongst participants, however having other trained staff to draw on during periods of absence and to ease the intensive nature of the support can help to sustain the service.
- **Time** – sufficient time is needed for the comprehensive planning and preparation of sessions and resources, therefore allocation of staff hours in advance of each session should be allowed.
- **Resources** – MCST requires a range of resources for each session such as the Making a Difference 2 manual, whiteboard, music player and soft ball as well as ongoing provision of materials relevant to the given topic e.g. instruments in Sound Week. Costs need to be considered from the outset although some items can be hired, brought in from home or borrowed from other services. Access to a printer/copier is essential.
- **Participant selection** – effective assessment of participants plays a vital role in ensuring the appropriateness and acceptability of MCST. Furthermore, understanding the preferences of individuals can help to inform the balance of the group and tailor activities to meet the needs and abilities of all participants.

- **Barriers** – anticipated barriers to attending the sessions such as transport need to be tackled to ensure accessibility for suitable participants. Creation of a volunteer driver role should be considered as an essential part of future course delivery. Virtual delivery of programmes online can help to tackle Covid-19 social distancing restrictions and the provision of resources such as tablets and internet access need to be explored further.
- **Post participation** – having referral and signposting routes for participants and carers once the programme comes to an end needs to be considered and planned from the outset to avoid gaps in service.

Opportunities

Age UK Lancashire are pleased to report that we have been successful in securing additional funding from external sources to deliver additional MCST courses to West Lancashire residents living with mild to moderate dementia. We believe that we are the only provider delivering MCST therapy in this area and possibly in Lancashire.

More recently, we have also secured funding from the national Age UK's Covid-19 Emergency Appeal to train more staff in the delivery of MCST sessions as well in the facilitating of iCST awareness sessions to carers of those living with dementia across Lancashire. Interest in both delivery models continues to grow via our existing Age UK Lancashire services including Dementia Community Links and the Zoom Dementia Hub and waiting lists for future provision have now been created in Central, North and East Lancashire.

For further information about Age UK Lancashire's Cognitive Stimulation Therapy or Dementia Support Services please call 0300 303 1234

or visit: <https://www.ageuk.org.uk/lancashire/our-services/>

Appendices

Appendix 1 DEMQOL

Appendix 2 MoCA

Appendix 3 Carers Survey

Appendix 4 Monitoring Progress Form

Appendix One - DEMQOL

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 practise 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"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 2. worried or anxious? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 3. that you are enjoying life? ** | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 4. frustrated? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 5. confident? ** | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 6. full of energy? ** | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 7. sad? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 8. lonely? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 9. distressed? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 10. lively? ** | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 11. irritable? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 12. fed-up? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 13. that there are things that you
wanted to do but couldn't? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <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"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 15. forgetting who people are? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 16. forgetting what day it is? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |

- | | | | | |
|---|---|---|--|--|
| 17. your thoughts being muddled? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 18. difficulty making decisions? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 19. poor concentration? | <input type="checkbox"/> <input type="checkbox"/> a lot | <input type="checkbox"/> <input type="checkbox"/> quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> 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? | <input type="checkbox"/> <input type="checkbox"/> a lot | c quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 21. how you get on with people | | c quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| close to you? | <input type="checkbox"/> <input type="checkbox"/> a lot | c quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 22. getting the affection that | | c quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| you want? | <input type="checkbox"/> <input type="checkbox"/> a lot | c quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 23. people not listening to you? | <input type="checkbox"/> <input type="checkbox"/> a lot | | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 24. making yourself understood? | <input type="checkbox"/> <input type="checkbox"/> a lot | c quite a bit | | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 25. getting help when you need it? | <input type="checkbox"/> <input type="checkbox"/> a lot | c quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 26. getting to the toilet in time? | <input type="checkbox"/> <input type="checkbox"/> a lot | | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 27. how you feel in yourself? | <input type="checkbox"/> <input type="checkbox"/> a lot | c quite a bit | | <input type="checkbox"/> <input type="checkbox"/> not at all |
| 28. your health overall? | <input type="checkbox"/> <input type="checkbox"/> a lot | c quite a bit | <input type="checkbox"/> <input type="checkbox"/> a little | <input type="checkbox"/> <input type="checkbox"/> 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

** items that need to be reversed before scoring

Appendix Two - MoCA

MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME :

Education :

Date of birth :

Sex :

DATE :

VISUOSPATIAL / EXECUTIVE		Copy cube		Draw CLOCK (Ten past eleven) (3 points)		POINTS				
				<div style="display: flex; justify-content: space-around;"> <div>[] Contour</div> <div>[] Numbers</div> <div>[] Hands</div> </div>		___/5				
NAMING										
						___/3				
MEMORY		Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.					No points			
		1st trial	FACE	VELVET	CHURCH	DAISY		RED		
		2nd trial								
ATTENTION		Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [] 2 1 8 5 4 Subject has to repeat them in the backward order [] 7 4 2					___/2			
		Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [] FBACMNAAJKLBAFAKDEAAAJAMOF AAB					___/1			
		Serial 7 subtraction starting at 100 [] 93 [] 86 [] 79 [] 72 [] 65 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt					___/3			
LANGUAGE		Repeat : I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. []					___/2			
		Fluency / Name maximum number of words in one minute that begin with the letter F [] _____ (N ≥ 11 words)					___/1			
ABSTRACTION		Similarity between e.g. banana - orange = fruit [] train - bicycle [] watch - ruler					___/2			
DELAYED RECALL		Has to recall words WITH NO CUE		FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUE recall only	___/5
				[]	[]	[]	[]	[]		
Optional		Category cue								
		Multiple choice cue								
ORIENTATION		[] Date	[] Month	[] Year	[] Day	[] Place	[] City	___/6		
© Z.Nasreddine MD Version November 7, 2004		Normal ≥ 26 / 30		TOTAL		___/30				
www.mocatest.org						Add 1 point if ≤ 12 yr edu				

Appendix Three – Carers Survey

Evaluation of MCST Programme for Carers

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	Strongly agree	10
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	Strongly agree	10
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	Strongly agree	10
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	Strongly agree	10
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	Strongly agree	10
I look after myself (eating well and getting enough sleep)	Strongly disagree	1	2	3	4	5	6	7	8	9	Strongly agree	10
I feel stressed and anxious when I think about the future	Strongly disagree	1	2	3	4	5	6	7	8	9	Strongly agree	10
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	Strongly agree	10

Appendix Four – Monitoring Progress Form

Date:

Maintenance CST Programme

Monitoring Progress Form

Names of Members	Attended? Yes/No	Interest	Communication	Enjoyment	Mood
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					

Rate **each area** in relation to today's session with a number from 1 to 5 as follows:

Interest: 1 = No interest 2 = Little interest shown 3 = Some interest shown

4 = Interest shown 5 = Great interest shown

Communication: 1 = No communication 2 = Little communication 3 = Some response

4 = Communicates well 5 = Communicates very well

Enjoyment: 1 = Does not show enjoyment of the session today

2 = Very little enjoyment today 3 = Some enjoyment shown

4 = Enjoys the session 5 = Enjoys the session greatly

Mood: 1 = In very low mood today; appears depressed or anxious

2 = Low mood today 3 = Some signs of good mood

4 = General good mood today

5 = Very good mood; appears happy and relaxed today

Session theme:

Activities used today:

Comments: