Journeying through Dementia: Designing Self-Management Support with People with Dementia

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Acknowledgments

We would like to dedicate this report to Bridgetta Menton, a dedicated, inspiring and motivated occupational therapist who was an integral part of the start of this project in Scotland.

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Introduction

Dementia remains a priority for Scottish Government with a commitment that all people newly diagnosed with dementia will receive appropriate support following diagnosis, with that support being either the current model of post-diagnostic support, or care coordination, based on the 8 Pillars Model of Integrated Community Support.

AHPs are supporting Scottish Governments dementia strategy commitment of offering everyone newly diagnosed the guaranteed minimum of one year of appropriate post-diagnostic support, contributing to the revised national post-diagnostic dementia service offer to enhance its focus on personalisation and personal outcomes in the delivery of post-diagnostic services.

Connecting People Connecting Support (Alzheimer Scotland 2017, 2020) is the national framework for transforming the contribution of AHPs to supporting people living with dementia and those who support them. Its aspiration is that people have better access to AHPs regardless of age or place of residence, from pre-diagnosis to diagnosis and throughout their illness. The four principles and ambitions for change in Connecting People Connecting Support (CPCS) support and drive the transformation of AHP services to meet the needs of people living with dementia and those who support them to provide accessible and condition specific signposting to help, advice and rehabilitation ensuring people get the right AHP support, at the right time, and in the right setting.

The developing evidence on the benefits of AHP early interventions, supported self-management and rehabilitation on helping people to live well with dementia is overwhelming. It is therefore imperative that AHPs develop and/or adopt models of practice based on the evidence and which reflect greater use of self-management, technology-based, co-created and partnership approaches. In addition to this, there are obvious benefits to obtaining a dementia diagnosis earlier rather than later, and it remains our ambition that more people are diagnosed earlier and get timely access to good quality post-diagnostic support delivered by AHPs

Background

Dementia is a long term neurological condition impacting on the lives of over 850,000 people who have been diagnosed with the condition in the United Kingdom. The condition is progressive and at present there is no cure. However, there are a growing number of accounts by people describing how it is possible to live well in the midst of dementia (Weaks, Wilkinson, Houston, McKillop, Bryden, Scottish Dementia Working Group). Many of these focus on the importance of developing strategies to enable continued engagement in meaningful activities and life roles. These qualitative accounts, the on-going focus on early diagnosis and the recognition of the value of psychosocial interventions have led to a realization that people with early stage dementia can be enabled to draw on their retained skills and develop

strategies to cope with their symptoms so that independence can be retained for as long as possible.

Journeying through Dementia is an occupation-based intervention that aims to support people at an early stage of their dementia journey to engage in meaningful activities and maintain community connectedness.

The programme was developed in partnership with people with dementia who spoke of the value they attached to continued participation in everyday occupations and in new learning. Throughout all the co-creation activities, people with dementia were clear that wanted to have the opportunity to access groups that did not just talk about the diagnosis but that offered practical advice and support of how to continue to live well with the condition

An occupational focus

Kitwood, saw engagement in occupation as central to being connected and engaged in life and a core facet of personhood. This very much reflects the central premise of occupational therapy that: people are active beings with abilities and the need to participate in activities to express themselves through the things they do and that these human activities either sustain or undermine health and wellbeing. The role of occupational therapy is to recognize where health conditions prevent participation in valued activities and to work with the individual to overcome these challenges either through modification in relation to how the activity is performed or through the development of compensatory skills and abilities.

Journeying through Dementia is underpinned by the premise that there is a relationship between the activities we participate in and health and wellbeing. The aim of the program is to promote continued engagement in meaningful activity through equipping individuals with the knowledge, skills and understanding of ways to continue to do the things they enjoy for as long as possible. The importance of this cannot be underestimated.

The broader evidence base

Dementia policy has focused on the importance of delivering a timely diagnosis. Indeed, as early as 2013, the G8 Summit on Dementia prioritized early intervention and care in the community and people's own homes. As a consequence, increasing emphasis has been placed on interventions that support individuals immediately following diagnosis. This has coincided with a societal movement to promote living well with dementia which recognizes that people with early stage dementia can be enabled to self- manage, challenging long-standing perceptions.

Journeying through Dementia sits within this broader context and is completely congruent with a growing body of evidence in relation to self-management. The intervention embodies best practice in relation to the wider evidence base. For instance, the **menu-led approach** which enables the intervention to be customized to the needs of the group reflects well the mixed methods study undertaken by Boots, de Vugt, Kempen and Verhey (2016) of the value attached by people with dementia and their families to flexible choice and the importance of personal contact.

The inclusion of **individual sessions** and emphasis on **out of venue activities** to enable individuals to enact and generalise learning outside of the group is supported well by Maud Graaf's research on home based occupational therapy for people with dementia dating back to 2006 (Graaf 2006). Subsequent studies applying Graaf's work to a UK population identified the value that people with dementia place on the opportunity to participate in existing hobbies as well as develop new interests.

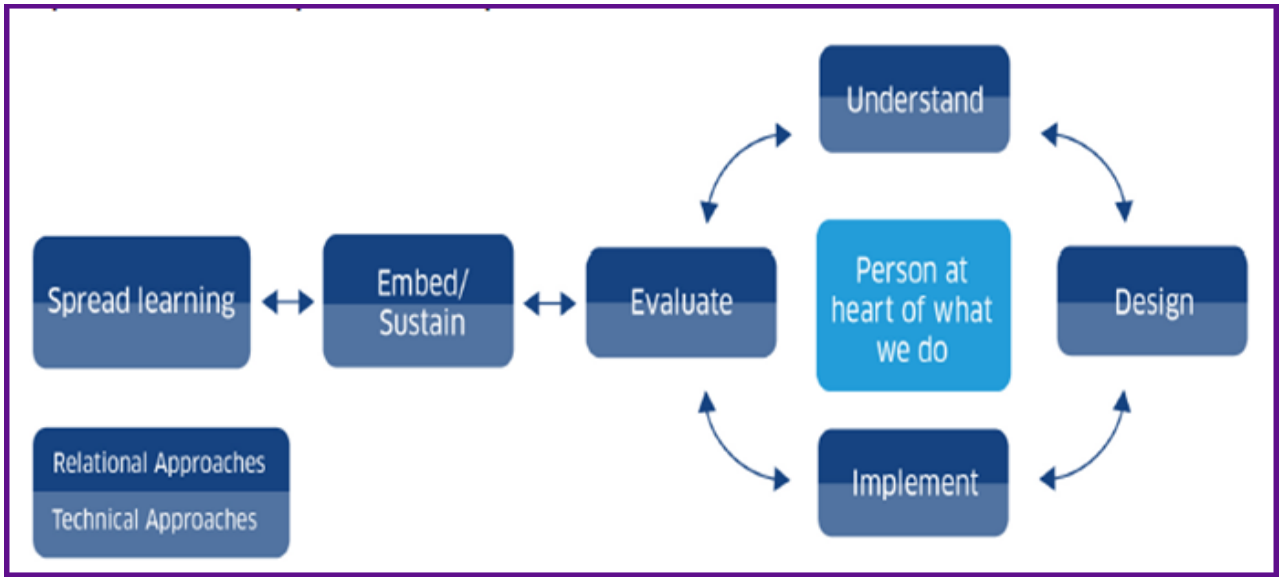
The **topics** explored within Journeying through Dementia reflect well the findings of a systematic review of self-management interventions for people with dementia and mild cognitive impairment (Quinn et al 2015) and concurrent self-management studies suggest that the topics people living with dementia particularly value are: engagement with favourite activities, maintaining relationships, planning for the future and local resources. The study highlighted the importance of interventions that foster independence and reciprocity, promote social support and improve self-efficacy and recognized that supported self-management interventions can bring additional benefits including creating social support networks and facilitating the development of friendships.

An Improvement Project

Implementation and integration of Journeying through Dementia within the two demonstrator sites in Scotland has been underpinned by an improvement approach that aims to fully realise the impact of the ambitions across health, social care and partner organisations. A core component of the improvement project was the use of a *Framework for Planned Improvement* underpinned by a 'rapid cycle change' (Plan, Do, Study, Act) approach, the model focuses on three key questions:

- What are we trying to accomplish?
- How will we know that a change is an improvement?
- What changes can we make that will result in an improvement?

This enables us to review the work on an ongoing basis and respond to local services, local population and local occupational therapists, whilst also delivering an evidence based post diagnostic intervention.



Source: Adapted from work originally developed by Healthcare Improvement Scotland.

The groups – practical work

Journeying through Dementia recognises 3 key ingredients to the intervention; a weekly two-hour group session, out of venue sessions and individual sessions. The intervention is primarily based around the group work which can be conducted over 8 – 12 sessions. The sessions take a menu led approach with 22 sessions available based around five themes reflecting the AHP approach (Alzheimer Scotland 2017, p.20). This offers participants the

opportunity to select the session's most pertinent to their need, therefore the group is customised and tailored to meet the needs of the participants. Each group was facilitated by two Occupational Therapists and held in community venues which were accessible with one having been awarded Dementia Friendly status.

One site chose to use a room within the local library, with the other selecting a community centre which incurred a fee of £10.50 per hour. In selecting these venues consideration was given to the geographical context of the area covered by the Occupational Therapy service in order to best meet the transport needs of the potential participants, including availability of parking and public transport links. Additional considerations included accessibility of toilets, tea/coffee facilities and the suitability of the space available in terms of light, size and comfort.

Signage was available within the intervention packs and used to guide participants, and staff within both venues were welcoming and supportive. The group facilitators took time to greet and welcome the participants each week to support a comfortable and relaxed environment and ensured participants were safe and supported, if required, when leaving.

Within the groups a number of options were used to support the participants in selecting preferred sessions; participants used the coffee break blethers, included within the pack, to review a summary of each session and consider the relevance and interest individually, and the content of the discussion and conversations helped to guide in identifying future session themes and topics. Group facilitators utilised the structure within the facilitators guide to plan the session but the flexibility within allowed for sessions and activities to be tailored to the needs and preferences of the participants. The groups were as practical as possible, reflecting the research that indicates people with dementia want a group that is not just talk but action, with several different activities suggested within each topic. Participants were supported and encouraged to engage as much as they felt able and comfortable to within each session, with the facilitators striving to create an environment that was a safe space for people to openly share their thoughts, feelings and experiences of living with dementia and the impact that this was having on their ability to engage in valued occupations.

Additional materials were used throughout all sessions including a flip chart to document and highlight pertinent information with written information provided as appropriate. Group facilitators supplemented the sessions with further information, for example, signposting to local services and community groups, checklists and tip sheets relating to session content. All participants were provided with the coffee table blether booklet and encouraged to record thoughts and ideas from each session.

The concept of peer support was vital to the group and was repeatedly commented upon through feedback at the end of each session. Participants were encouraged to discuss and share skills, and strategies identified to support ongoing participation in activity and engagement in their communities. Subsequently, ensuring there was a balance between guiding the discussion, imparting information while making efforts to maintain a safe space

where everyone's voice was heard and people felt safe to share their feelings, was a key area of focus for the Occupational Therapists in facilitating each session.

The intervention also recognises the key role offered by supporters; family and friends who support the person with dementia in their journey. Inviting supporters to the groups was not viable for one group but for the other they were invited to the first, mid and final group session.

In addition to the group session, out of venue sessions were offered to provide practical support, the opportunity to try out skills and strategies, to build confidence and reinforce relationships with the community. During the two groups these included visiting a local shop of interest, visiting a harbour, and a walk along a local beach. Additional opportunities were available for 1:1 session's out with the group to further explore issues highlighted and reinforce information from the group to help the person to facilitate change.

Results

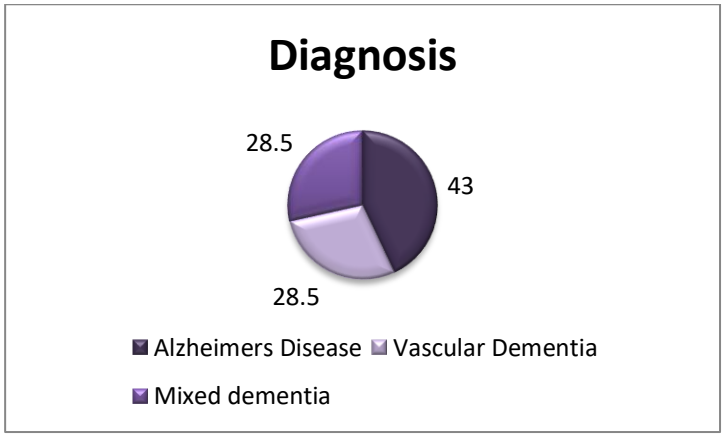
Demographic Data

Demographic information was collated onto a Microsoft Excel workbook, updated by the author, based on previous work by Dr Duncan Pentland at Queen Margaret University and Alison McKean, Alzheimer Scotland.

The information was collated by group facilitators through initial interview with the patient and review of supporting documentation e.g. written referral, to allow and support identification of potential commonalities within the participant group. Data was entered by group facilitators at the beginning of the intervention with updates added at indicated data collection points. Each participant was allocated a numerical digital non identifiable number to use and Occupational Therapists recorded information as per the post diagnostic support (pds) minimum dataset which included health board, Integrated Joint Board (IJB), gender, living status, accommodation type, subtype of dementia, carer input, age and a note of relevant co morbidities (recorded as per the International Consortium for Health Outcomes Measurement (ICHOM) Dementia data set). A further four sheets were included to record the scores from identified outcome measures with a final sheet providing guidance around data entry options. Please refer to Appendix 1 for full demographic details.

Following screening seven participants were invited to attend the groups. All seven had a diagnosed Dementia (Table 1), with an age range of 56-85 and two were female and five male which is significant given that a higher percentage of people living with dementia are women. All the participants had at least one co-morbidity with a maximum of two reported for each participant; lung disease was reported on three occasions; heart disease was reported on three occasions; diabetes twice; kidney disease twice and depression before dementia was reported once, highlighting that the people that engaged in this intervention were living with other conditions as well as Dementia.

Table 1: Diagnosis



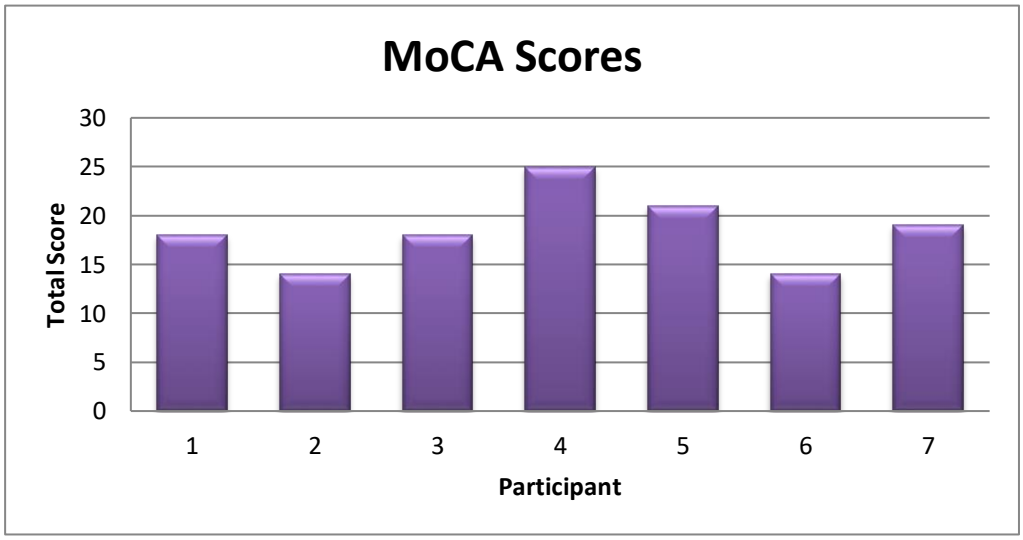
Montreal Cognitive Assessment

The Montreal Cognitive Assessment (MoCA) was designed in 1996 Dr Ziad Nasreddine as a rapid screening instrument for mild cognitive dysfunction (Nasreddine et al 2005). The MoCA is designed to be administered in approximately 10 minutes and assesses a number of cognitive domains; attention and concentration, executive function, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation (Appendix 2). Scores range between 0 and 30; a score of 26 or over is considered to be normal. The following ranges may be used to grade severity: 18-25 = mild cognitive impairment, 10-17= moderate cognitive impairment and less than 10= severe cognitive impairment. However, research for these severity ranges has not yet been established (https://www.mocatest.org/faq/).

The MoCA was conducted with all participants prior to commencing the group, during screening sessions within the patient's own home.

Scores ranged from 14-25 for the seven participants engaging in the intervention (Table 2).

Table 2: MoCA



The target demographic for a post diagnostic support group is people living with mild to moderate dementia therefore this range of scorings was anticipated. Following delivery of the intervention it was agreed not to conduct MoCA at the six and twelve month follow up points, due to changes in licensing of the tool.

Quality of Life in Alzheimer's Disease (QoL-AD)

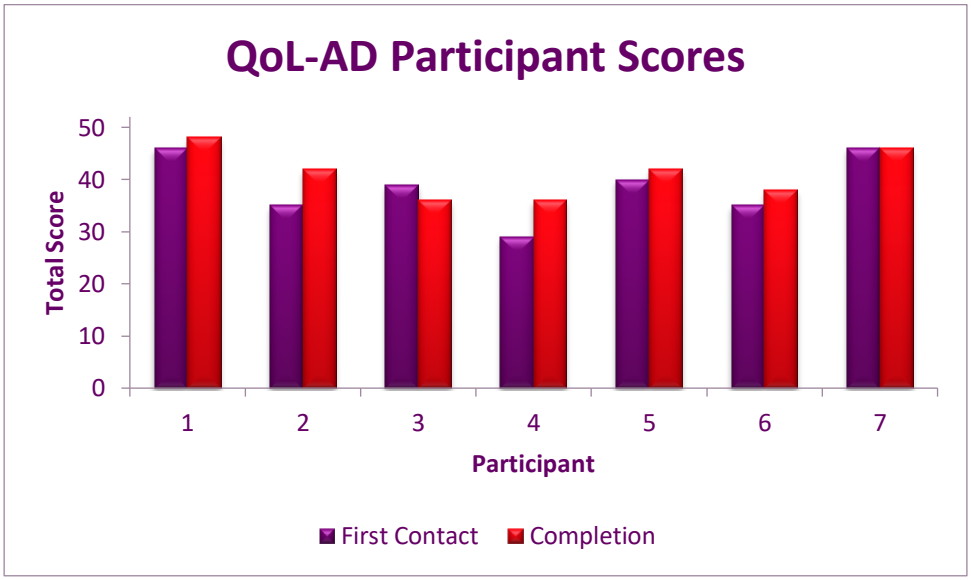
The QoL-AD was developed by Logsdon et al (1996) to provide both a patient and caregiver report of the patient's quality of life. To facilitate its use with cognitively impaired individuals, the QOL-AD uses simple and straightforward language with a multiple-choice format consistent across all questions and the opportunity to add in any comments. Specific items were selected based on a review of the literature, with the questionnaire comprising of 13 items in total which include the opportunity to give an opinion of the patients' physical health and wellbeing, mental health, routines and living situation, and relationships (Appendix 3). Items are rated on a 4-point scale with 1 being poor and 4 being excellent, allowing total scores to range from 13 – 52, therefore the higher overall score, the better perceived quality of life.

The QoL-AD was conducted with participants along with the MoCA during initial screening appointments within the person's own home, the caregiver element of the tool was completed in a number of ways dependent on the individual's circumstances e.g. one carer completed with group facilitator over the phone, another received it in the post, completed and returned.

Findings are as follows;

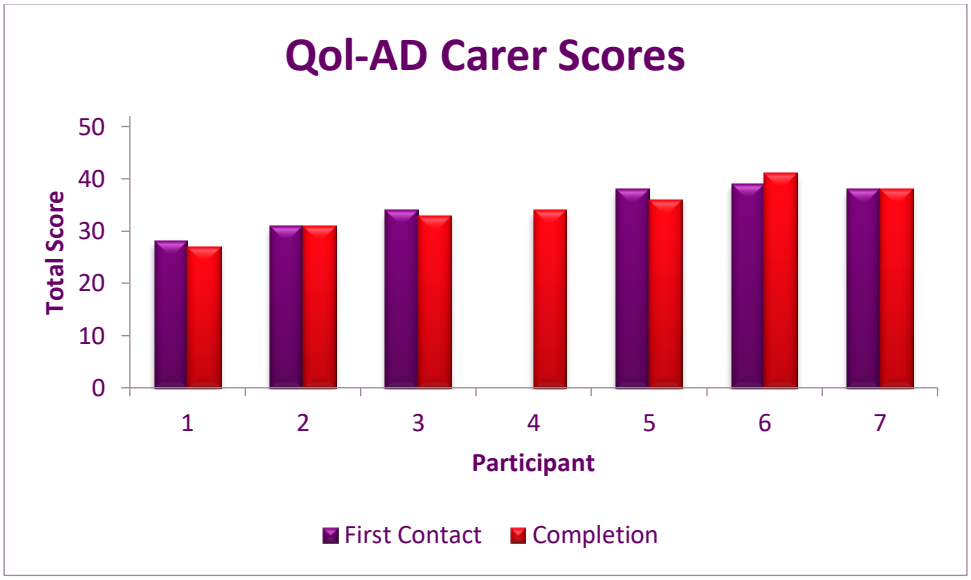
Participant scores ranged from 29 – 46 at outset and 36 – 48 at reassessment (Table 3). Five participants reported improvement in quality of life when they repeated the measure following completion of the group, for one person their scoring was unchanged, and one person reported deterioration in perceived quality of life.

Table 3: QoL-AD Participant Scores



Carers were offered the opportunity to complete the QoL-AD based on their perception of the patient's quality of life; responding to the same list of items and using the same scale as the patient. Scores ranged from 28 – 39 at outset; 27 – 41 at end (Table 4). One carer reported an improvement in perceived quality of life, two carer's scorings were unchanged, and three carers reported deterioration in perceived quality of life when the measure was completed upon completion of the intervention. No comparison was available for participant 4 as no QoL-AD score was gathered at the beginning.

Table 4: QoL-AD Carer Scores



Of note within our findings caregivers consistently rated quality of life lower than the participant; this is reflective of research which suggests a number of biases may attribute to this including the persons own beliefs or values, the relationship with the person and any depression or caregiver burden.

Participant Experience

In order to record the experience of the people in the group, the Occupational Therapist facilitators posed four questions at the end of each group session and recorded and collated the responses (Appendix 4). These questions were designed in order to illicit information relating to the participants experience of the session including what they found to be of benefit and of use, and anything they may have changed.

Thematic analysis was used to examine the information gathered and three themes were identified which reflected the experience of the participants within the group. This was then mapped back to occupation and the Person – Environment – Occupation Model of Occupational Performance (Law et al 1996) used to highlight the findings.

Person

Within the model the person is presented as "a dynamic, motivated and ever-developing being, constantly interacting with the environment" (Law et al., 1996, p.17). The model views the person holistically, recognising that each person "brings a set of attributes (performance components) and life experiences to bear on the transaction described as occupational performance, including self-concept, personality style, cultural background and personal competencies." (Law et al., 1996, p.16). Journeying through Dementia takes a strengths based approach where participants abilities are seen as key resources positioning the individuals very much as the experts at managing their condition. Facilitators aimed to guide the discussion, ensuring everyone's voice was heard whilst also encouraging participants to use their own resourcefulness and appreciate the resources of others within the group. People taking part in the programme spoke openly of their experience within the group, sharing their thoughts and experiences and the impact the programme was having on their engagement in meaningful activities:

"It takes me beyond bumbling through."
"The more you do the more you can do."
"I feel more confident."
"I have new friends I don't think I will ever forget."
"When I go home from here I feel better."
"I really enjoy myself."
"I love coming along and getting to know others."
"It's been a really super day."

Environment

Law et al (1996) offer a broad definition of the environment which "gives equal importance to the cultural, socio-economic, institutional, physical and social considerations of the environment." (p.16), recognising that all these aspects shape and are shaped by the person.

The facilitators strived to create an environment which was a safe space for people to openly share their thoughts, feelings and experiences of living with dementia and the challenges faced when engaging in valued occupations. Participants appeared to value the opportunity for open communication and frequently commented on this element of the group within the feedback:

"Comfortable sharing what we do."

"No judgement."

"Being around people that understand what I am going through."

"Saying what you like, and don't have to worry about what you say."

This was supported by the physical and social environments which were carefully selected and shaped by the group facilitators where possible, and any feedback relating to suggestions for improvement e.g. "more pens for next week" were taken on board.

"Relaxed atmosphere."

"I feel we're helping one another being on the same wavelength."

"I feel very comfortable and feel I can speak openly."

Occupation

This aspect of the model considers what people do within their environments and proposes three elements – activity, task and occupation - which are "defined discreetly but presented together to emphasise the close relationship" (Law et al., 1996, p.16) Law et al. further defined occupations as "those clusters of activities and tasks in which the person engages in order to meet his/her intrinsic needs for self-maintenance, expression and fulfilment. These are carried out within the context of individual roles and multiple environments." (p.16).

The group participants repeatedly commented on the value of the conversations and sharing of knowledge and experience throughout the course of the group interventions. Feedback suggests they found sharing and talking with others enjoyable but also reported it was useful:

"Everyone sharing their stories."

"Memory strategies discussed."

"Content discussed provided clarity and cleared things in my head."

Journeying through Dementia is underpinned by the premise that there is a relationship between the activities we participate in and health and wellbeing, as such emphasis is further placed on 'doing' and the participants' feedback frequently made reference to the activity undertaken within the group session. Participants often commented that the information and knowledge gained through the activity was the one thing they would take away from the

session and commented positively on specific content of the sessions including the importance of routine and the introduction to the memory maintenance list, as well as fire safety and environmental information.

“Highlighted things I probably knew already but didn’t realise. Just by seeing it there in this context.”

“Taking a step back, think, re-evaluate can I change the way I do things.”

“Understanding Dementia more.”

“When I go home from here I do more.”

Carer Feedback

Carers/Supporters offered feedback informally and formally via a number of methods; therapists on one site generated a feedback form to gather information (Appendix 5) for which one was completed:

Table 5: Carer Feedback

Since attending the group, I have noticed that my relative is...	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
1. More confident about their future	☐	☒	☐	☐	☐
2. Generally happier	☐	☒	☐	☐	☐
3. Communicating more	☐	☒	☐	☐	☐
4. More active	☐	☐	☐	☐	☐
5. Using new ways to cope with their memory problems	☐	☐	☒	☐	☐

Further comments relating to feedback in Table 5 included:

"More willing to converse with people."

"[He] can't be more active due to severe heart failure."

"[He] really enjoyed the Journeying through Dementia group, always came home happier and lighter."

Carers also provided feedback during informal contact with group facilitators and at review points;

"My dad is really enjoying the group on Thursday morning. Telling me everyone gets on well and has fun. But teaching him how to deal with dementia, he was tidying up as that's what you had been speaking about one week. Thank you so much for your support and kindness".

"He is brighter and more motivated to do things around the home."

“His mood has improved.”

“When he returned home from the group, he was happy and very pleased with himself.”

“We could have done with this support [Occupational Therapy and specifically Journeying through Dementia] when he was first diagnosed. At that point we were just left in shock and didn't know what to do.”

Occupational Therapist Experience

Creating an open environment where individuals felt comfortable and safe to share their knowledge and experience was fundamental to ensuring a positive experience for all involved. The Occupational Therapists facilitating the groups had a great deal of knowledge, skills and experience in working within older adults' mental health and specifically with people living with dementia which enabled and supported them to create an open environment and encourage connections in building group rapport (Please see Appendix 6 for Therapist biography) . These skills also enabled the facilitators to share information and knowledge with the participants in relation to the context of the discussion and the local community. The skill of an Occupational Therapist in the ability to adapt the way an activity is performed, making adjustments to the environment, using compensatory techniques, recognizing and drawing on existing skills or developing new ones, are essential in order to deliver the intervention effectively and support the best possible outcomes for the participants.

Several methods were used to gather information relating to the experience of the Occupational Therapists who acted as group facilitators for Journeying through Dementia.

Templates were used on a weekly basis to support facilitators in recording their thoughts and feelings before, during and after the group (Appendix 7). These also provided an opportunity to consider what resources had been used and what additional information was provided by the facilitators. Taking the time and space to complete these following the group was a beneficial opportunity in allowing space to reflect on what had went well and what could have gone better, with facilitators then able to incorporate any suggestions into planning and preparation for the next session.

At the end of the group intervention, facilitators each selected one patient and completed a case study (Appendix 8) in order to provide background information relating to the patient's journey into Occupational Therapy and Journeying through Dementia, and also to highlight the impact of having participated in the intervention. This also allowed an opportunity for the Facilitators to reflect on their experiences of delivering Journeying through Dementia, which was later filmed (https://www.youtube.com/watch?v=tYImfidI4_w&feature=emb_logo). A spotlight report was used to collect background information and the local context.

From the information gathered a total of eight themes emerged; a funnelling approach was taken in order to primarily explore three main themes within this report. The additional information gathered will be used in a variety of ways to inform future work of the project.

1. **Facilitation**

   Each of the Occupational Therapists involved in delivering the intervention commented on the importance of having good facilitation skills in order to deliver the group as effectively and efficiently as possible. The facilitators aimed to provide a group environment that was relaxed and fun, but also used gentle reinforcement and

collaboration to ensure inclusion for all present and progression through the materials.

The materials and resources available within the toolkit offered support in delivering the intervention however it is felt vital that the group is facilitated by Occupational Therapists as their experience and knowledge in activity analysis and the ability to adapt and grade activity is fundamental to supporting the participants to continue to engage in the activities that are important to them. The facilitators had a great deal of knowledge, skill and experience of working within Older Adult Mental Health services and specifically working with people with dementia, which supported them in supplementing sessions with additional information. This also enabled them to advise and guide the participants as appropriate whilst also encouraging participants to use their own resourcefulness and appreciate the resources of others within the group.

2. Group Membership & Referrals

Journeying through Dementia aims to support people in the early stage of their dementia journey to continue to engage in meaningful activities; in order to facilitate the intervention and target this support in the most effective way possible facilitators agreed pre-screening was a vital aspect of identifying those for whom the intervention may be most suitable. Ensuring potential referrers understood the purpose and aims of the group was important and whilst no formal inclusion or exclusion criteria were used, the MoCA was used as a screening tool to provide information relating to cognition and facilitators supplemented this with information gathered from a number of sources in order to identify people that may benefit from the intervention. Five of the participants that engaged in the intervention were existing patients within the Occupational Therapy Service and had participated in additional functional assessments which also proved beneficial in supporting group formation.

Both groups were smaller in relation to number of participants than originally anticipated, however feedback from participants highlighted the small group size enhanced their experience. During the screening process it was felt important that participants were at a similar stage of their dementia journey to have a positive impact on dynamics and experience however it was challenging identifying people in the early stages of their dementia journey. Following screening there were a number of referrals for whom the intervention was felt unsuitable; often these people had been recently diagnosed however they were not at an early part of their dementia journey. This further highlights the importance of ensuring clear information is provided to referrers.

3. Flexibility of the Programme

Facilitators agreed Journeying through Dementia is a high quality resource which provided a structure to each session but also offered flexibility in being able to adapt to the needs of the participants and incorporate 1:1 and out of venue sessions to support programme delivery. The topic wheel and booklets proved beneficial to support initial discussions around selecting appropriate sessions, as relationships were established this process became easier as the participants identified topics they wanted to look at in more detail. Having a menu of themes available was incredibly valuable in supporting a person centred approach, the dynamics of the intervention in which the participants were very much supported and encouraged to exercise choice and be active participants in the sessions further empowered people to take ownership of the group as the weeks progressed. The power of being able to share and talk openly in a safe space about what a diagnosis of dementia meant to the them individually proved invaluable and was commented on frequently by the participants in their feedback.

Conclusion

This initial phase of work has successfully demonstrated that Occupational Therapy can help to improve quality of life for people living with dementia, utilising Journeying through Dementia as an evidence-based intervention, to support people to manage their own health and wellbeing.

The findings gathered over the course of the 8-week intervention highlight that people living with dementia, and the therapists delivering the intervention, found it to be beneficial and of value in supporting people to live well and manage their own health and wellbeing. The data collected from carers/supporters further encourages these findings however further consideration to their role is recommended within future delivery of the intervention. Findings from the full evaluation of this work and lessons learnt will inform the future of this project with specific consideration given to gathering of data, capturing the experiences of the individuals involved and ensuring that carers feel included in the programme.

Initial plans had been to share the learning from this project through the use of presentations, posters and films. Further demonstrator sites were identified, and Phase II of the project was planned for Spring 2020, with the support of funds from The Alliance, which included a project lead role one day per week for 12 months. These were unfortunately postponed as the country went into lockdown due to COVID-19. The restrictions imposed had a significant impact on all those involved in the project with project leads and therapists unable to join the project due to being deployed to other areas to support the AHP COVID-19 response nationally and locally. People with dementia were not able to access NHS services timely for a diagnosis of dementia nor access the post diagnostic pathways and interventions that would typically have been offered to support them and their carers.

The project did however continue, in a modified way, in partnership with Alzheimer Scotland and colleagues in Sheffield Hallam University. An online resource was designed to provide information, activities and support to those that needed it in their own home (www.connectingpeopleconnectingsupport.online) and this will be integrated into the project going forward. Plans for 6 month and 1 year follow up sessions to complete the full evaluation were also not possible due to COVID-19 and the personal circumstances of the staff facilitating the groups.

Launch of the next phase for this project has now been rescheduled for 1st October 2020 and seven demonstrator sites are motivated to re-engage, with the potential for one more. The project lead is developing the improvement methods and measurement plan, with ongoing close collaboration with colleagues in Sheffield Hallam University and Queen Margaret University. Due to the continued restrictions of COVID-19 and local lockdowns, delivery of the peer to peer self-management group will be reviewed and plans for future delivery will continue to consider the aim of supporting the rights-based values of the work and intervention components. A blended method of delivery is anticipated that includes digital platforms and greater use of printed resources that can be sent to people's homes to ensure

there is no exclusion from the programme due to access to technology. Near Me will be used for any 1:1 interventions and Microsoft Teams for the delivery of the group-based intervention as these digital platforms are already available to the NHS and supported by the Scottish Government digital strategy. There will be further work with local digital leads to ensure the occupational therapists facilitating the intervention have access to these resources, and this will be considered in the referral pathway for individuals. Microsoft Teams will also be used to connect with the occupational therapists to support them in their practice.

The work of the project will continue to be communicated via social media to share findings and updates, and connect with people living with dementia, families and supporters. Several Blogs are available via the blog site "Let's Talk about Dementia" and a dedicated Twitter account has been created @ScotJtDementia.

The need for a post diagnostic specialist intervention by occupational therapy is now needed more than ever because of the impact of COVID-19 and the lock down restrictions. The programme will continue to take an improvement approach, work in collaboration, and ultimately contribute to the delivery of Scotland's post diagnostic standard by integration joint boards.

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Appendices

Appendix 1 – Demographic Data

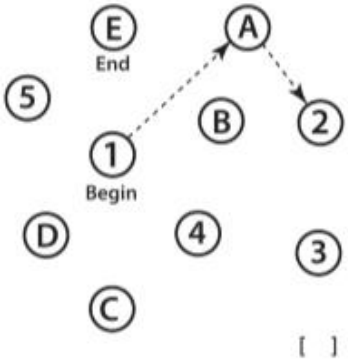
Journeying through Dementia Client information (2 sites)									
Anon Identifier	Health Board	IJB	Gender	Living alone	Accommodation type	Subtype of dementia	Carer Input	Age	Comorbidities
001	F (Fife)	S37000032 (Fife)	02 (Female)	01 (Yes)	01 (Mainstream owne	03 (Mixed type Deme	01 (Yes)	76	03
002	F (Fife)	S37000032 (Fife)	01 (Male)	02 (No)	01 (Mainstream owne	03 (Mixed type Deme	01 (Yes)	78	03
003	F (Fife)	S37000032 (Fife)	02 (Female)	01 (Yes)	01 (Mainstream owne	01 (Dementia in Alzhe	01 (Yes)	85	01
004	F (Fife)	S37000032 (Fife)	01 (Male)	02 (No)	01 (Mainstream owne	01 (Dementia in Alzhe	01 (Yes)	56	03, 10
005	N (Grampian)	S37000002 (Aber	01 (Male)	02 (No)	01 (Mainstream owne	02 (Vascular Dementi	02 (No)	85	01, 06
006	N (Grampian)	S37000002 (Aber	01 (Male)	01 (Yes)	01 (Mainstream owne	02 (Vascular Dementi	02 (No)	80	05, 06
007	N (Grampian)	S37000002 (Aber	01 (Male)	02 (No)	01 (Mainstream owne	01 (Dementia in Alzhe	01 (Yes)	71	01, 05

Appendix 2 – Montreal Cognitive Assessment (MoCA)

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME :
Education : Date of birth :
Sex : DATE :

VISUOSPATIAL / EXECUTIVE — POINTS



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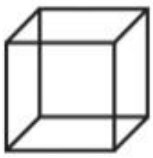


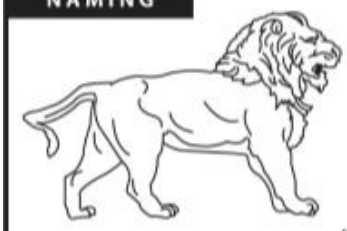
[ ] [ ]

Draw CLOCK (Ten past eleven) (3 points)

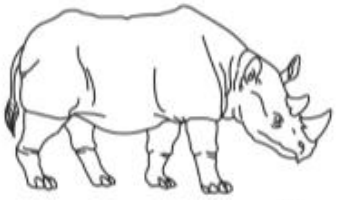
[ ] Contour [ ] Numbers [ ] Hands

__/5

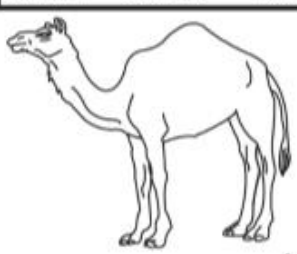
NAMING



[ ]



[ ]



[ ]

__/3

MEMORY Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

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
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B

__/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 UNCUED recall only
Optional	Category cue						
	Multiple choice cue						

__/5

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City

__/6

© Z.Nasreddine MD **www.mocatest.org** Normal ≥ 26 / 30

TOTAL __/30

Add 1 point if ≤ 12 yr edu

Administered by: _____

Appendix 3 – Quality of Life in Alzheimer's Disease (QoL-AD)

Quality of Life in Alzheimer's Disease cont'd **QOL-AD**

UWMC/ADPR/QOL
Aging and Dementia: Quality of Life in AD
Quality of Life: AD
(Participant Version)

ID Number	Assessment Number	Interview Date	Score (for clinician's use only)
☐☐☐☐☐☐	☐☐	☐☐ ☐☐ ☐☐ Month Day Year	

Instructions: Interviewer administer according to standard instructions. Circle your responses.

1. Physical health	Poor	Fair	Good	Excellent	
2 Energy	Poor	Fair	Good	Excellent	
3. Mood	Poor	Fair	Good	Excellent	
4. Living situation	Poor	Fair	Good	Excellent	
5. Memory	Poor	Fair	Good	Excellent	
6. Family	Poor	Fair	Good	Excellent	
7. Marriage	Poor	Fair	Good	Excellent	
8. Friends	Poor	Fair	Good	Excellent	
9. Self as a whole	Poor	Fair	Good	Excellent	
10. Ability to do chores around the house	Poor	Fair	Good	Excellent	
11. Ability to do things for fun	Poor	Fair	Good	Excellent	
12. Money	Poor	Fair	Good	Excellent	
13. Life as a whole	Poor	Fair	Good	Excellent	

Comments:
_____
_____

Total

Appendix 4 – Participant Feedback

Appendix 5 – Carer Feedback Document

Carer Feedback Form

Your relative has been attending the Journeying through Dementia Group facilitated by the Occupational Therapy Service, for the past 8 weeks. We would be grateful if you could take a few minutes to provide some feedback.

Since attending the group I have noticed that my relative is...	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
1. More confident about their future	☐	☐	☐	☐	☐
2. Generally happier	☐	☐	☐	☐	☐
3. Communicating more	☐	☐	☐	☐	☐
4. More active	☐	☐	☐	☐	☐
5. Using new ways to cope with their memory problems	☐	☐	☐	☐	☐

6. Since attending the Journeying through Dementia group, have you noticed any significant changes in your relative's behaviour?

7. Any other comments?

Appendix 6 – Therapist Biography

Therapists 1 & 2

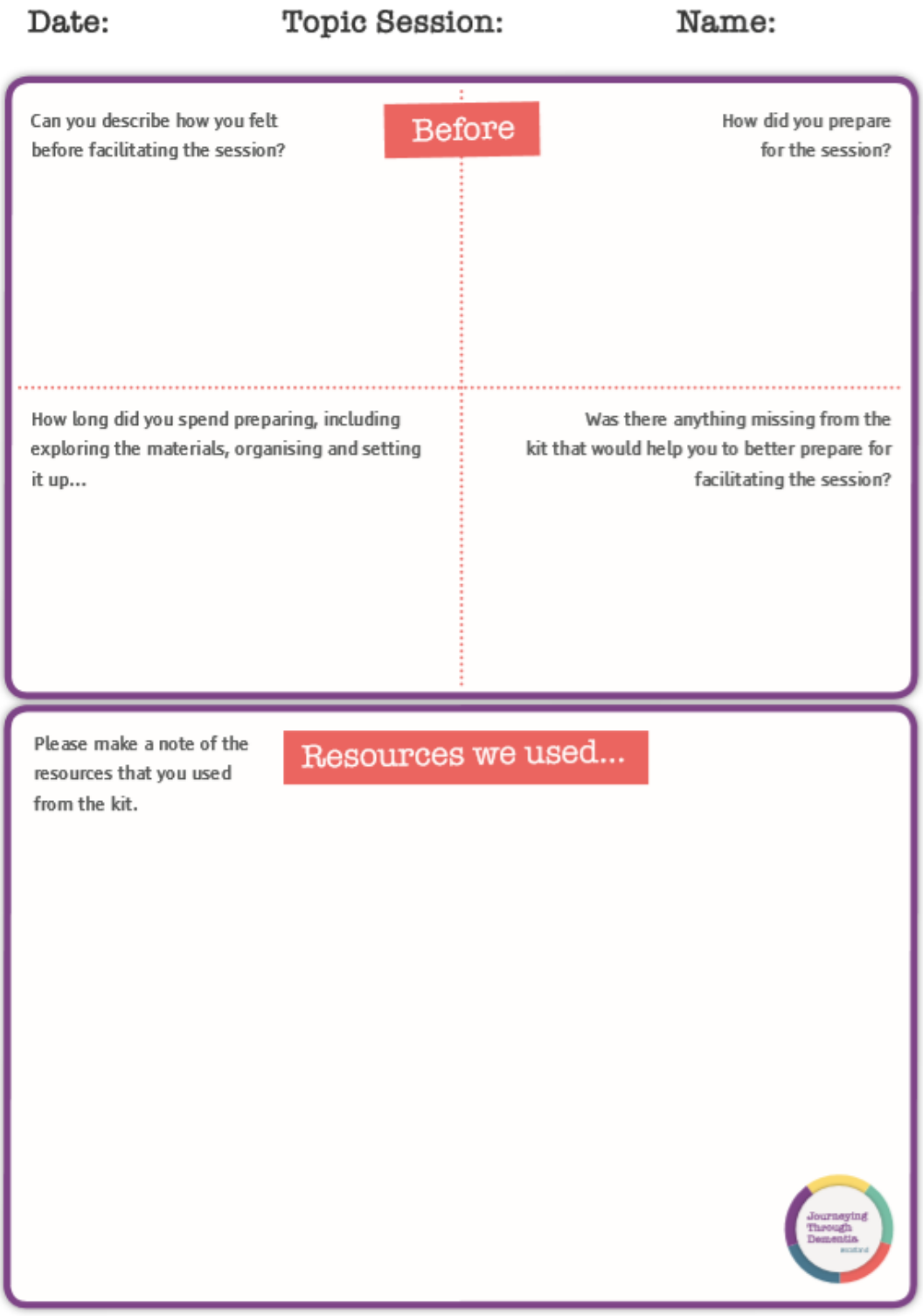
Based in Fife, Therapists 1 and 2 have a wealth of skills, knowledge and experience within Mental Health Services and working specifically with people living with dementia, within a variety of settings. Both therapists are passionate about offering support to people throughout their dementia journey and have been supported within their service to be involved in both the Occupational Therapy Home Based Memory Rehabilitation work, as well as the Tailored Activity Programme.

Therapist 1 was further supported within the Journeying through Dementia project by the NHS Education for Scotland, Allied Health Professions Careers Fellowship, which offered funding to participate in a workshop based learning programme whilst supporting an additional role in the project in collating the data and sharing the learning.

Therapists 2 & 3

Therapists 2 and 3 worked together to deliver the intervention to rural Aberdeenshire. Both therapists worked within Older Adult Mental Health Services to provide assessment and therapeutic intervention to adults aged over 65 with functional and organic illness, and bring an abundance of knowledge, skills and experience to the programme. This includes involvement in the national pilot of Occupational Therapy Home Based Memory Rehabilitation and specific interests such as the NMAHP Digital Health and Care Leadership Programme, which Therapist 3 is undertaking to support the development of the 'Enhancing Lives through Technology Project' in NHS Grampian. This knowledge and expertise will offer further insights into the future use of digital technology within Journeying through Dementia.

Appendix 7 – Facilitator Feedback



Date: **Topic Session:** **Name:**

During

Can you describe how you felt whilst facilitating the session?

How would you describe the atmosphere during the session?

What types of conversations did the session generate?

Was there anything that stood out as particularly interesting or insightful?

After

Can you describe how you felt once you'd completed facilitating the session?

Is there anything you would add to the kit to help you to facilitate this session in the future? (resources, activities, props)

Which activities did you most enjoy? And why?

Which activities would you loose/change? And why?

Appendix 8 – Case Study Document

Occupational Therapist's reflective case study
Journeying through Dementia

Purpose

The Occupational Therapist's reflective case study shares the learning from the initial demonstrator sites for *Journeying through Dementia* to reflect and share learning.

Occupational Therapist: Date Completed:

Situation

Which board area/partnership did Journeying through Dementia *take place?*
How was the person referred to you?
What was the reason for the referral?

Objective

What were reasons for you wishing to be part of the Journeying through Dementia *demonstrator sites?*
What did you hope Journeying through Dementia *was going to achieve?*

Action

How many times did you work with the person?
Did you also work with family carers?

Results from Journeying through Dementia

What do you think was achieved for the person living with dementia?
What do you think was the impact to your practice?
What do you think the benefit has been to your organisation?

Conclusion

What was learnt and how could this learning be used in the future?
What were the key elements for success through being involved in Journeying through Dementia*?*
What do you think was achieved for the family/caregiver being involved in Journeying through Dementia *(if applicable)?*

Please include any feedback you received or stories you were told.

Appendix 9 – Poster

Appendix 10 – Poster 2

Journeying through Dementia: Designing Self Management Support with People with Dementia

Ashleigh Gray, Elaine Hunter, Dr Claire Craig, Helen Fisher,
Susan Haynes, Emma Ingram & Bridgetta Menton

Project Description

Journeying though dementia is an evidence-based programme that has been created by occupational therapists and people with dementia. It aims to promote continued engagement in meaningful activity through equipping individuals at an early point of their dementia journey with the knowledge, skills and understanding of ways to continue to do the things they enjoy for as long as possible.

The intervention was introduced to Scotland and implemented in two demonstrator sites. Utilising an improvement methodology data was gathered to capture the impact of the self-management intervention for people living with dementia and Occupational Therapists facilitating the groups, with a view to sharing the learning and scaling the project wider within Scotland.

Background/rationale

Journeying through Dementia is underpinned by the premise that there is a relationship between the activities we participate in and health and wellbeing. Finding ways to continue to engage in and participate in these activities is important for everyone and more so for individuals living with long-term conditions such as dementia. The importance of this cannot be underestimated and is currently the focus of dementia policy and also of a growing societal movement to promote living well with dementia (see 2013 G8 Summit).

This movement recognizes that people at an early stage of their dementia journey can be enabled to self-manage their condition and to experience a good quality of life through keeping connected to and drawing on resources in the wider community. The intervention directly supports delivery of ambition one of Connecting People, Connecting Support (Alzheimer Scotland, 2017) of enhanced access to enable people to be supported to look after their own health and wellbeing.

Conclusion and what next

Occupational Therapy can help to improve quality of life for people living with dementia, utilising Journeying through Dementia as an evidence based intervention, to support people to manage their own health and wellbeing.

Additional funding has been secured through The Alliance to progress this work to additional sites in Scotland, supporting people living with dementia to shape the way they are supported and information they receive to suit their needs, enabling them to continue to live well and remain connected to their community.

Results/outcomes

71%

71% of participants who engaged in the programme reported improved quality of life as measured using QoL-AD

Key success factors (Therapist feedback)

- Facilitation
- Group membership
- Flexibility of the resource

Positive feedback from participants and carers in relation to personal experience, the impact of the environment and the occupations that they were engaging in

Participants
- *"I feel more confident"*
- *"I feel we're helping one another being on the same wavelength".*
- *"When I go home from here I feel better and do more."*

Carers
- *"He is brighter and more motivated to do things around the home"*
- *"He really enjoyed the Journeying through Dementia group, always came home happier and lighter."*

Therapist
- *"This is the first time I've been involved in a group where people with dementia were given the opportunity to share their experiences and that was really valuable for people."*

For more information contact :
Ashleigh Gray: ashleigh.gray1@nhs.net @ashleigh_gray1
@lab4living @AHPDementia #withOTuCAN

NES AHP Careers Fellowship Scheme
#AHPCF2019

Reference: Alzheimer Scotland 2017. Connecting people, connecting support. Transforming the contribution of allied health professionals in dementia in Scotland 2017 – 2020 www.alzscot.org/ahp

Blogs

Journeying through Dementia Designing Post Diagnostic Support with People with Dementia, Dr Claire Craig, 14 March 2019

https://letstalkaboutdementia.wordpress.com/2019/03/14/journeying-through-dementia-designing-post-diagnostic-support-with-people-with-dementia/

Journeying through the Fellowship, Ashleigh Gray, 27 June 2019

https://letstalkaboutdementia.wordpress.com/2019/06/27/journeying-through-the-fellowship/

Journeying through Dementia in Aberdeenshire, Emma Ingram and Bridgetta Menton, 10 October 2019

https://letstalkaboutdementia.wordpress.com/2019/10/10/journeying-through-dementia-in-aberdeenshire-selfmanagement/

#Connect on #AHPsDayScot, Ashleigh Gray, 14 October 2020

https://letstalkaboutdementia.wordpress.com/2020/10/14/connect-on-ahpsdayscot/