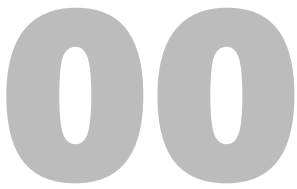

Occupational Therapy Co-Designing a New Pathway of Diagnostic Support for People Living with Dementia

Journeying through Dementia 2020-2023



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0.1 Foreword by the Scottish Dementia Working Group

The Scottish Dementia Working Group (SDWG) is a national, member led campaigning and awareness raising group, for people living with a diagnosis of dementia in Scotland. The SDWG was set up in 2001 and has gone from strength to strength since it was established and you can find out more about our work [here](#). We are absolutely delighted to have been invited to write a Foreword for this national improvement project.

We began working with the occupational therapists on this national project in 2011, at a national self-management workshop and were a speaker at the launch of this project in 2020 sharing what occupations are important to us to live well with dementia. We also had the opportunity to offer ideas on the Journeying through Dementia postal packs, which we have to say we loved opening our resources when they arrived in the post.

Access to good quality, timely post diagnostic support remains a priority for our group and we can see how Journeying through Dementia, delivered by occupational therapists can support us, and the importance of peer support in the community.

We are delighted that occupational therapists have reached out to people living with dementia and co-designed peer group self-management intervention with the ultimate aim to support us to continue to stay connected to our local communities and the people that are important to us.

This report highlights the importance of collaborative team work. This work, led by occupational therapists, can also compliment the work of post diagnostic support offered to people living with dementia by a named link worker and clearly demonstrates the importance of partnership and collaborative working at an important time for a person and their family when diagnosed.

We now look forward to seeing the next steps of this work, as outlined on page 28 and seeing how the three actions noted as the outcome from this improvement project become a reality to ensure people living with dementia have access to occupational therapy.



run by people with dementia

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0.2 Acknowledgments

Thanks to The Alliance Self-Management Fund which provided funding, for this second test of change (Phase II) to transform access to occupational therapy rehabilitation as a post diagnostic intervention.

A huge thank you to the occupational therapy facilitators and leaders who supported this work during a pandemic and the ongoing recovery including

Alison McKean, Christine Bark, Claire Martin, Dawn Sherriff, Fiona O'Donnell, Fiona Maclean, Gill Gowran, Jacqui Chung, Jacqui Pike, Kate Lawson, Lynsey Dow, Michelle Dunn, Michelle Weems, Michelle Murray, Paula Graham, Sharon Logan and Wendy Chambers.

Thank you to the staff at both the Alzheimer Scotland Dementia Resource Centre, Fife and Broomhill Gardens and Community Hub, Inverclyde for supporting us to deliver this work in a community setting.

And finally and most importantly to all the people living with dementia and their families who agreed to join in this new and innovative occupational therapy intervention, sharing their stories and experiences to ensure we can support the ambition of people having enhanced access to occupational therapy at an early point in their diagnostic journey.

If you have any questions on this report, please email us at AHPDementia@alzscot.org and follow us on twitter at [@ScotJtDementia](https://twitter.com/ScotJtDementia) and [@AHPDementia](https://twitter.com/AHPDementia).



Introduction and context

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1.1 Introduction

Dementia remains a priority for Scottish Government (2023) with a local delivery plan standard that everyone newly diagnosed with dementia will be offered a minimum of one year's post-diagnostic support. This should be co-ordinated by an appropriately trained link worker and result in a person-centred support plan (Public Health Scotland 2023). Allied Health Professionals (AHPs) are supporting the delivery of Scottish Governments Local Delivery Plan Standard and this improvement project demonstrates one method to support this national standard.

Connecting People Connecting Support (Alzheimer Scotland 2017, 2020) is the national framework for transforming the contribution of AHPs to the lives of 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) drive the transformation of AHP services in providing accessible and condition specific signposting to help, advice and rehabilitation for the person with dementia and their supporters. The aim is to ensure that each person receives the right AHP support, at the right time, and in the right setting.

The developing evidence on the benefits of AHP early interventions, the value of supported self-management and rehabilitation in enabling 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. This evidence increasingly emphasises greater use of self-management approaches, highlights the contribution of technology and recognizes the strength of interventions that have been co-created and in partnership with individuals living with the condition. In addition to this, there are obvious benefits to obtaining a dementia diagnosis, and it remains our ambition that more people get timely access to good quality post-diagnostic support delivered by AHPs utilizing their specialist rehabilitation skills.

This report shares the development of an occupational therapist specialist intervention engaging with NHS boards to implement and integrate post-diagnostic occupational therapy Journeying through Dementia (Mountain and Craig 2012, Craig et al 2023). 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 they wanted to have the opportunity to access groups that did not just talk about the diagnosis but offered practical advice and support of how to continue to live well with dementia.

The first test of change in 2019 involved two demonstrator sites ([see report here](#)) and the occupational therapists insights were documented in a recent book chapter (Craig et al 2023). This current improvement project aimed to retest in a number of demonstrator sites to support scale and spread of the occupational therapy post diagnostic intervention.

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1.2 Self-Management, Rehabilitation and Dementia

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 (Weeks et al 2012). 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 biopsychosocial 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.

Dementia policy in the UK has focused on the importance of delivering a timely diagnosis. 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 and rehabilitation.

The World Health Organization, define rehabilitation as “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments” (World Health Organisation, 2011). The World Health Organization (WHO) recognizes dementia as a public health priority and recommends the delivery of rehabilitation for people with dementia in providing person centered care that optimizes independence (World Health Organisation, 2017). In the WHO recent publication, ‘The package of interventions for rehabilitation’, further supports the role of rehabilitation in dementia care delivered by occupational therapy (World Health Organisation, 2023).

However, research concluded multidisciplinary rehabilitation as relevant to dementia care, requires a reframing of practice that both educates emerging health professionals regarding the outcomes that may be achievable for people with dementia (Cations, et al., 2020).

As a group of occupational therapists leading this work, we believed that people living with dementia have a right to access rehabilitation and occupational therapists are ideally placed to contribute to this, using evidence based interventions such as Journeying through Dementia, to support people to continue to live as independently as possible with dementia, therefore reducing the demand on health and social care services and increasing the person quality of life.

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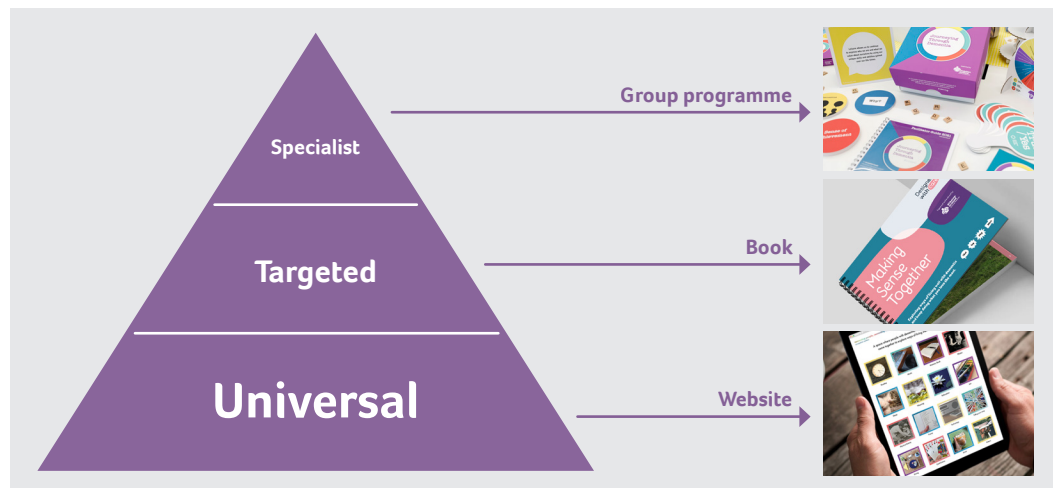
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1.3 The AHP approach in dementia

The evidence-based AHP approach in dementia that is described in Connecting People, Connecting Support (Alzheimer Scotland 2017, 2020) was based on over two years of extensive consultation and information-gathering. The policy aims to maximise the AHP contribution to high-quality, cost-effective dementia services that are tailored to the needs of individuals, reflect the best available evidence and are delivered by a skilled AHP workforce. The fundamental understanding driving the approach is that people living with dementia can benefit from AHP-led interventions. Early intervention and support to maintain independence are critical: they can help minimise the impact of the symptoms of dementia and improve quality of life. The AHP approach was integrated into this improvement project, providing a foundational underpinning from which all occupational therapists were able to use their skills, experience and understanding of the person. We know people with dementia and those who support them benefit greatly from a biopsychosocial approach to care that acknowledges the interactions of the neurological, psychological, physical, environmental, social and emotional elements, so the AHP approach delivers the biopsychosocial approach and further supports the principles of this improvement project.

1.4 Tiered Approach to Access Occupational Therapy



At a time of wide transformational change in health and social care in Scotland, the AHPs in Scotland have adapted the Pyramid of Support (Scottish Government 2019) and co-designed a tiered approach to provide access to AHPs. This is outlined in CPCS (Alzheimer Scotland 2020) and inclusive of **universal** with access to a range of evidence based self-management resources, **targeted** where AHPs work collaboratively tailoring advice or education and **specialist** with direct access to AHP-led rehabilitation interventions. It is important to be clear about what was meant by 'enhanced access' to occupational therapy with the ultimate goal of ensuring AHP expertise and knowledge is available every day and when people with dementia and those who support them need it. This was central in our approach to this national improvement project.

An Occupation Focus to Rehabilitation

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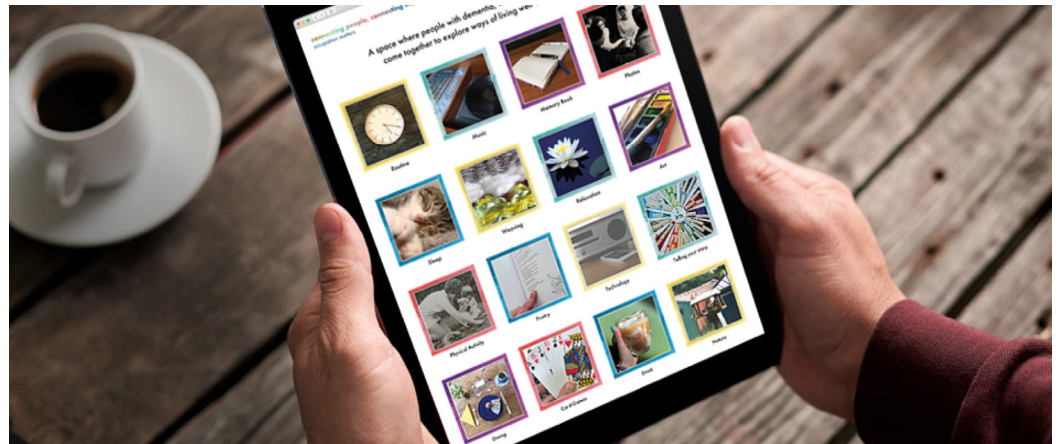
2.1 An Occupation Focus

Tom Kitwood (Kitwood, 1997), 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.

2.2 A Tiered Approach to Journeying Through Dementia

During this test of change, we took the opportunity to design and apply a tiered approach to enable people with dementia and their families to access occupational therapy skills and resources at an early point in their dementia journey. The provision of an occupation-based pathway of support at **Universal, Targeted and Specialist** rehabilitation levels is outlined below.

Universal - an interactive website (www.connectingpeopleconnectingsupport.online)



Early intervention through collaboration at universal is key and an online resource was designed and launched in March 2020 to provide information, activities, and support to those who needed it in their own home, entitled Connecting People, Connecting Support: Occupation Matters. The online resource offers 32 topics full of information and resources, to explore ways to live well with dementia. Each topic includes stimuli for conversation (**chat**), activities to try (**try**), an interactive puzzle (**play**) and signposts to further resources (**more**). The materials have been tried, tested, and recommended by people living with dementia and those who support them. Using film, illustration and photography, the website is simple to navigate and information is easy to digest.

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Targeted - Making Sense Together



Feedback from people with dementia and occupational therapy facilitators in phase one of the improvement project, highlighted a lack of resources aimed at families, friends and carers. Supporters fully recognized the value of aiming the group specifically for people with dementia but felt that they could play a more active role if they were also equipped with understanding and skills. This could also potentially reduce their anxiety. Claire Craig and Helen Fisher worked with people living with dementia, facilitators of the programme and the wider team to create a resource named 'Making Sense Together'. This provided a booklet version of the Connecting People Connecting Support online resource that could be completed at home with friends and family.

Specialist - Journeying through Dementia



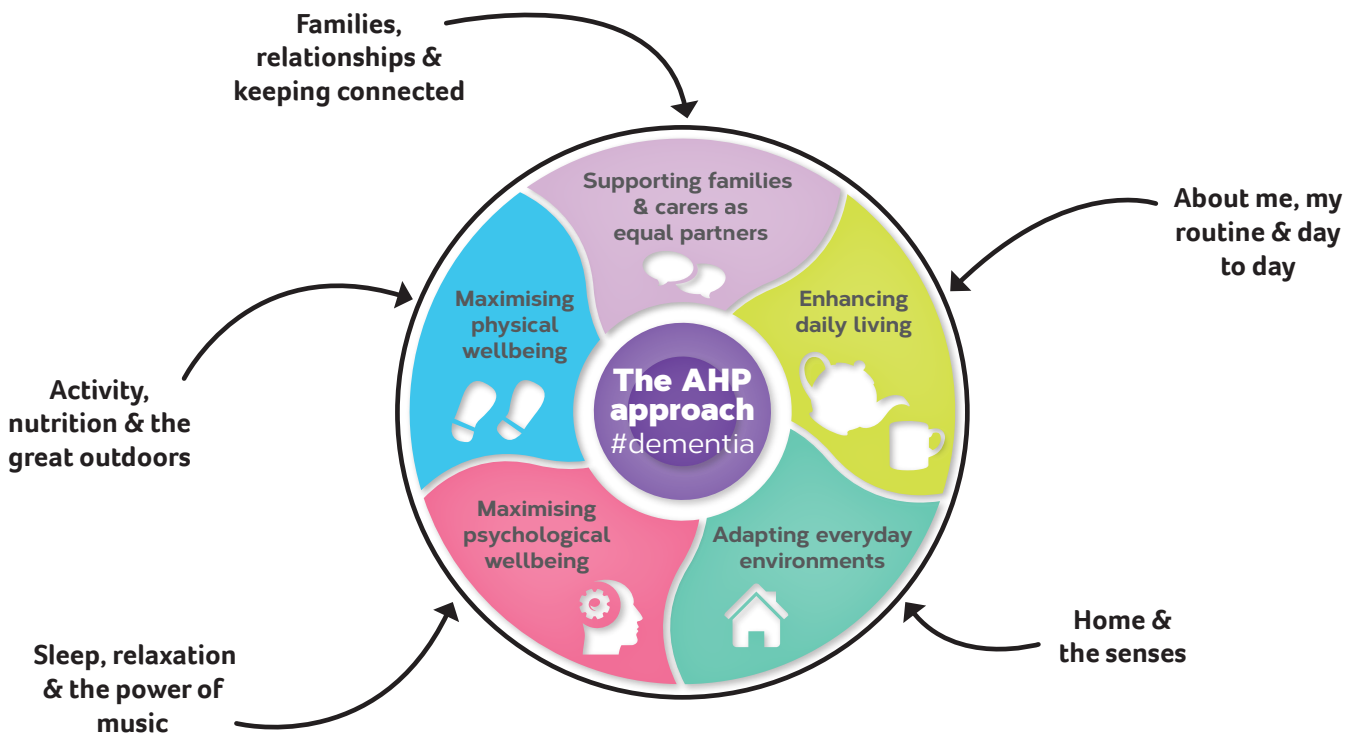
Journeying through Dementia is underpinned by the premise that there is a relationship between the activities we participate in and health and wellbeing. The aim of the programme is to promote continued engagement in meaningful activity through equipping individuals with the knowledge, skills and understanding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

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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, et al., (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 generalize learning outside of the group is supported well by Graaf’s research on home based occupational therapy for people with dementia dating back to 2006 (Graaf, et al., 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. They were linked into the original intervention and also mapped to the AHP approach (Alzheimer Scotland 2017, 2020) and outlined below.



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2.3 Journeying through Dementia – *Delivered*

When integrating Journeying through Dementia in practice in this second test of change, there was a need to reconsider how to deliver Journeying through Dementia during a pandemic. This included modifying the resource whilst retaining the core principles of the evidence based intervention. With this in mind, Claire Craig and design researcher Helen Fisher, worked to create a resource pack that could be delivered to participants home which would then support engagement in an online group and support 1:1 sessions. Much thought and consideration were given to the design and the topics in the original work remained but divided into 5 postal packs. These materials reflected well the core principles of the Journeying through Dementia Programme, positioning the person living with dementia as the expert, a continued focus on the peer-to-peer support group, and inclusion of a menu-led approach.

The postal packs afforded greater consideration to the role of the persons family and friends, providing an opportunity for discussion around the topics, and the opportunity to work together to complete activities. The online resource of Connecting People, Connecting Support online, is also referenced within the booklets and supporters can access the resources and activities at a time to suit them.

Prior to the use of the postal packs, the content was evaluated by the Scottish Dementia Working Group and the feedback from this group gave us the confidence to change the delivery methods at pace. As a result this opened up options for delivery to include a blended or socially distanced approach if the group was held face to face. This agility meant that it was possible to respond to the rapidly changing context that occurred as a consequence of the COVID-19 pandemic.

Scottish Dementia Working Group Feedback

"It was a privilege to receive this through the post"

"It's almost like a meditation you're going through while you're looking at all these bit's – you're noticing. And I think that's actually quite good!" ... "You're getting the whole range of senses being prodded"

"The 'what was important to me' section was very thought provoking' and I thought that would be excellent as a discussion tool – sitting down with someone"

"There was a lovely welcome card but unfortunately because it's in hand writing, I can't read it!"

"I look forward to meetings online because they do give me a routine and a sense of purpose."

"It was useful as a sort of therapy, because it did convince me that I am still active, I haven't lost much of my life"

"The section in the book about reading, I found quite distressing because I can't, I've lost that ability now"

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Each postal pack that was created maintained design features around whether it was aimed at use for face-to-face delivery or for those undertaking a blended approach with the latter entitled 'Journeying through Dementia – Delivered'. The detail of this work can be seen in Appendix 1. A website was created www.jtd.org.uk to help the occupational therapy group facilitators in preparing and delivering this updated version of Journeying through Dementia and included information regarding the resources available, videos from previous work, highlighting the impact of the intervention, and video guides for packing the postal resources.



A Post Diagnostic Improvement Project

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3.1 A National Occupational Therapy Improvement Project

Implementation and integration of the evidence based Journeying through Dementia programme within the demonstrator sites in Scotland was underpinned by an improvement approach (Langley 2009) using a variety of improvement tools summarized below.

1. **Community of practice** was established with all the demonstrator sites, supported by national leadership and design support. Communication with all relevant parties was key throughout the development stage to ensure collaborative working and to identify a collective and shared workplan. This included the creation of a twitter account, @ScotJtDementia which aimed to share information and relevant updates about the project and the establishment of a Microsoft Team channel for the demonstrator sites. A vision of change was created with the occupational therapists involved with an emphasis on the need to increase early access to occupational therapy for people living with dementia and their families.
2. **Forcefield analysis** was used to consider and identify the forces for and against the change. The group worked collaboratively to prioritize these issues and strategies were then identified to reduce the impact of the opposing factors and strengthen the supporting factors. The strategies identified included the need to consider referral pathways to the groups, developing national and local action points. From the work communication materials were designed to enhance stakeholder engagement with local Post Diagnostic Support leads in local Health and care partnerships.
3. **National project charter** was created, including a national driver diagram, and each of the test sites were encouraged to replicate this within their localities.
4. **Family of measures** were identified collaboratively to include both qualitative and quantitative measures. It remained important to gather information relating to the experience of people living with dementia, their supporters and the occupational therapists acting as facilitators. It was also critical the measures were applicable to the test sites locally, reflected national measurement and only necessary data was collated. Sites were encouraged to share their involvement in the work with local Quality Improvement departments in order to ensure adherence to local information governance policy. The detail of the measures can be seen in Appendix II.
5. **Framework for planned improvement** was used throughout the project, underpinned by a 'rapid cycle change' (Plan, Do, Study, Act) approach, focused 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?

My vision for Journeying through Dementia is...

"to reach people in a way that is meaningful and relevant to them"

"to improve the choice of specialist occupational therapy treatment available"

"to be embedded in our service with positive reviews, seen positively by referrers and provided as a treatment across our locality"



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The occupational therapy national improvement project was officially launched on the 1st October 2020 during self-management week and aimed to provide an opportunity for the occupational therapists in the demonstrator sites to discuss the intervention and begin to consider how they would integrate this into local service delivery. The event included a welcome and introductions from Henry Simmons, Chief Executive, Alzheimer Scotland and Alison Keir, Professional Practice Lead, Scotland, Royal College of Occupational Therapy, and also feedback from representatives of the Scottish Dementia Working Group who spoke openly about what occupations were important to them.

“12 months from now I would like to be telling people that this is something they can ask to be referred to and have folk that have done it to share their experiences, and to have data that demonstrates improvement.”

“12 months from now I hope to offer a group with a new approach that is professionally presented. Having the materials adds value and will hopefully ensure the group participants feel valued. Share the positive results with multi-disciplinary colleagues.”

3.2 Integrating Technology

In recognition that delivering the intervention digitally proposed a change in the way of working for both occupational therapy facilitators and potential participants, guidance documents were created taking on board advice and suggestions that had been shared nationally through publications, resources, and webinars.

The original occupational therapy facilitator guide was updated, and additional documents were created to support online groups, one for participants and one for occupational therapy facilitators. These documents included information and suggestions relating to the structure of the sessions as well as handy tips to consider before, during and after the online sessions.

The project team were also mindful that access to technology and inexperience with technology could potentially be a barrier to participation in an online based group. Support was explored and further information shared with the sites that may have assisted with this. This included information relating to Connecting Scotland – a Scottish Government initiative that aimed to support digitally excluded households get online. Further information was provided relating to organizations such as Ability Net that could offer IT support.

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The national improvement project, while launched in October 2020, the first cohort of groups began in June 2021 due to the ongoing impact of the pandemic. Each of the test sites were supported as they worked to balance local challenges and pressures with the result that the intervention was delivered at different times and using a mixture of virtual and face to face delivery.

The outcomes shared in this section of the report will focus on general impacts in three health and social care partnerships, with 35 participants and 5 occupational therapy group facilitators from June 2021 until March 2023. All detailed data was stored locally to support evaluation in each of the health and social care partnerships. This section of the report offers a general overview of impact and maintain groups participants confidentiality.

4.1 Local delivery and leadership

During the implementation of this project, two delivery methods were tested.

1. **Online and community.** In one HSCP, participants were offered the opportunity to attend a one hour digital group, as evidence suggested that this was an effective length of time to facilitate online engagement. Participants were also offered a follow up 1:1 contact for which all participants chose a telephone call rather than a virtual session using Near Me. This 1:1 contact provided participants the opportunity to further explore themes covered in the session, discussion and support around personal issues raised, and also allowed for reinforcement of the plan for the next group session with a reminder given regarding any tools required. The groups had two facilitators and 3 participants. This did pose initial challenges to sourcing referrals for the group. The second group, in this same HSCP was face to face in a local Alzheimer Scotland resource centre with two facilitators and 4 participants. The group facilitators outlined the different impact of their delivery methods outlined below.

Face to face delivery



- *Introduced from the outset to the Alzheimer Scotland DRC, with a focus from the beginning on community connections.*
- *Participant's indicated this to be the preferred model of delivery.*
- *Real time interaction and responses more in the moment than online.*
- *Travel time for some; 1 participant arrived 30-40 mins early for the group due to her daughter's work commitments.*
- *The timing of the group was restricted by availability of the DRC – did not work well for therapists.*
- *Morning group did also not work well for person with depression.*

Digital delivery



- *Afforded the opportunity to open the group up to people living across Fife.*
- *Allowed for sharing of experiences and knowledge despite covid restrictions.*
- *Cut out travel time.*
- *Quick efficient access to online materials that could then be screen shared.*
- *Difficulties experienced with technology on occasion, especially initially.*
- *2 participants were reliant on spouse to connect them.*
- *Took staff and patients time over the initial sessions to become accustomed to the technology.*

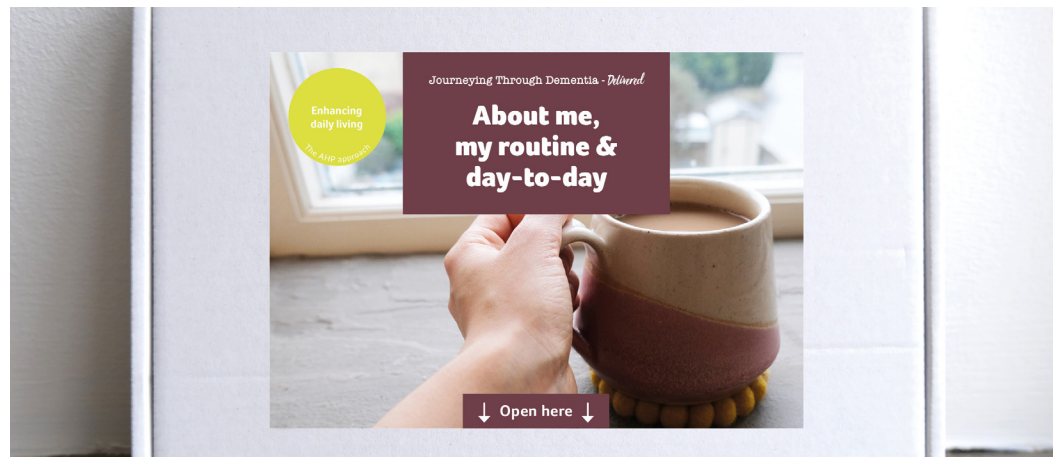
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2. Community. In a further two HSCP, the team offered an 8-12 week face to face group intervention for one hour in a local community hub, chosen specifically for its design and welcoming atmosphere. The venue offered the opportunity for participants and their supporters to use the café both pre and post group and they also hosted a number of community groups already within the space which supported community connection. They chose to use the Journeying through dementia delivered postal packs, as whilst initially designed with a virtual delivery in mind, they were beneficial in supporting face to face delivery whilst maintaining at that time, COVID safe practices. Due to the ongoing restrictions of the pandemic cohort numbers initially were small, a maximum of 3 participants, this has now increased to 5. To date (September 2023) 9 cohorts have been completed with recorded outcome measures of 28 participants and a 10th group is planned.

In all the groups, there was a very high attendance record. Facilitators were encouraged to record and review any reasons for non-attendance to allow for any barriers to attendance to be addressed as early as possible. Only 1 participant withdrew due to ill health and this person was invited to attend a second cohort held later in the year.

All groups chose to use the postal packs to facilitate the sessions as they were beneficial in supporting face to face or on line delivery whilst maintaining COVID safe practices.

“The Alzheimer Scotland Dementia Resource Centre was a fantastic venue for the group; the space was open, bright and spacious and we had everything we needed included a safe space to leave materials if required. All the staff in the centre were very approachable as noted by both the facilitators and the participants, and were welcoming and helpful. They...joined in our final week (and) ... spoke about the resources that were available locally to the individuals which she had specifically tailored. Holding the group in a community venue supported the aim of the group from the outset, sparking an interest in what else the resource centre had to offer.”



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In the three HSCP, referrals to the groups were mainly from local team members. Information was shared with all relevant stakeholders including teams involved in the delivery of post diagnostic support with samples of the resource shared for potential referrers to understand the potential of this new intervention.

“I have referred a number of people I support into the Journeying Through Dementia group I personally have seen the difference the group has made to many of them. From when I first refer them, where they are nervous shy and apprehensive to when they finish the group where they have a new lease of life and seem so much more positive.”
(Post diagnostic link worker feedback)

In one HSCP, contribution of occupational therapy has been integrated into their dementia care co-ordination programme including Connecting People, Connecting support online integral to a local dementia app, and Journey through Dementia positively integrated into the local post diagnostic pathway, acknowledging the group enabled people to access peer support, engage in meaningful activities and remain connected to their community (RSM 2022).

“The topics explored at the group were tailored to the individuals to maximise positive outcomes for the people living with dementia involved; ‘the group themselves decide which topics they want to focus on. It is part of a post diagnostic approach, and it is about homing in the skills that people have, and how they can retain those skills, but it also looks at some of the emotional well-being as well’ (thematic interview).”
(RSM 2022:40)

In another HSCP, the existing post diagnostic pathway has been enhanced by offering a further treatment intervention for individuals to help them in their dementia journey. The process to implementing Journey through Dementia into local occupational therapy process can be seen on the next page.



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The occupational therapists in this HSCP were recognised as category winner for the Innovation of The Year both within their local services and within their Health Board;

“To recognise any individual, team or department responsible for developing and implementing an innovative service, method, technology, or process that has made a significant difference to quality of care, wider population health or care, service delivery or the wellbeing of our own staff or to efficient use of resources.”

4.2 Impact for people living with dementia

Building understanding of the impact of the work and the experiences of people with dementia is central to this project. A number of data collection tools were therefore integrated into this intervention.

The Quality of Life – Alzheimer’s Disease (QOL-AD) (Logsdon et al 1999) was conducted with participants at the outset and repeated at the end of the intervention in order to offer a comparison of scorings. Emotional indicators and functional measures demonstrated increased knowledge in the condition and development of coping mechanisms. The majority of participants measured an improvement in quality of life, for one participant the quality of life was maintained and for three there was decline. The decline in quality of life was followed up and was attributed to the group participants have a number of other co-morbidities which affected and impacted on quality of life on a daily basis.

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Participants were invited to create their own goal which was reviewed at the mid-point and again at the end of the intervention. All participants reported they had achieved these either in part or fully. A selection of personal goals included:

- To continue with my garden*
- Meet new people and chat*
- Attend other groups with people like me and feel wanted and relaxed*
- Share memories and talk in a group*
- Get out of the house and go to more activities*

Weekly group experience was captured at the end of each group session, when participants were invited to offer feedback regarding their experience of the group. A summary of the feedback is shared below.

Something I've enjoyed...

- *Its having the company, it lifts you*
- *Been fun doing it, which makes you do it again*
- *Everybody seems to be relaxed and talking about things*
- *Having a routine*
- *I've loved every minute of it. You've brought me from the pits today right up*
- *Being out with people.*
- *Speaking about technology and communicating more*

Something I've found useful...

- *Just you being there is great for me, knowing that you care*
- *Sitting with people that understand how you're feeling. I can just be myself*
- *Everything is useful when you are speaking to other people*
- *It's got my mind moving a bit more*
- *I feel more relaxed and can speak to people; able to say what you want to say*
- *Ideas for using my mobile phone, tips to help my memory*

One thing I would change...

- *No, I'm here for anything that will help me to keep going*
- *No it's lovely I like seeing you all it's the highlight of my day or my week. I don't feel like I'm stuck here on my own. Maybe somebody does care about us*

One thing I will remember...

- *Tell my girls it was lovely to have met you and you will be here each week*
- *I'll tell them about the photos and about how we spoke about their wedding dresses*
- *That I had a laugh*
- *Feel free, can talk, get it off your mind and then you feel better*
- *I loved every minute of the group, attending each week made me happy and content knowing I had support*

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Within Scotland work has been undertaken at a national level to provide information about how helpful post diagnostic support has been for people living with dementia and their carers, this is called the post diagnostic single quality question (Focus on Dementia , 2021). The test project asked the question upon completion of the group intervention with an option to add any comments to support the answer.

Post diagnostic support single quality question



A final data tool to capture the experience of group participants at the end of the group sessions was to ask, “Overall, how helpful has Journeying through Dementia been to you? with three options (helpful, neither helpful nor unhelpful, unhelpful) and space for further comments. A summary of the comments are highlighted below:

”

“It was a blessing when I got to attend the group, I felt relaxed and able to speak about things close to me”

“It’s good to be with people to talk and for support”

“Excellent information... know where to go for more help”

“I feel I have learned things I didn’t think of before to help my memory”

“I have learned more about dementia and feel I have had time to digest my diagnosis”

“I have met others and feel I am not alone”

The overall aim of Journeying through Dementia is community connectiveness. Following a 10 week group in one of the test sites, course participants voiced an interest in staying connected and a new community group was developed. In one of the other groups, participants from the community group, 2 of the 4 participants continued attending the Alzheimer Scotland dementia resource centre where the group took place.

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4.3 Impact for family carers

The demonstrator sites in this test of change began to consider the impact for families of the participants and while this was not collected as routine practice, positive feedback was received by the occupational therapy facilitators.

“My husband is brighter after the group, he looks forward to going each week. It gives me a rest and time to talk to my family, enjoy coffee knowing my husband is safe and well”



“This is a really nice place to visit, my mum is enjoying the group. It’s good to spend time with my mum in the café, we reserve our table every week.”

“I think they [postal packs] were one of the plus points. Some of the questions you wouldn’t have thought of but they were relevant. We filled out parts in the Friends booklet together and she remembered our first holiday.”

“Going through [the postal pack] and talking about it when it came through, we wouldn’t have done that [had those conversations] without the book”

4.4 Impact for the occupational therapy group facilitators

To review the impact for the occupational therapy group facilitators, weekly reflections were integral to the group process with each facilitator being encouraged to complete this at the end of every group. This served to support the group facilitator role, was beneficial to the development of the work and was personal to each occupational therapist. Facilitators were also offered the opportunity to attend weekly support sessions with the project lead with the purpose to support one another, offer an open space to share reflections and feedback. Following completed delivery of the group intervention, facilitators completed a case study and extracts are included below. This enabled facilitators to reflect on their role of delivering Journeying through Dementia.

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Extract from the occupational therapy case study: Test site 1

What were reasons for you wishing to be part of the Journeying Through Dementia demonstrator sites?

To be part of an occupational based intervention to support people experiencing dementia. To offer a safe space to people who are experiencing anxiety, isolation during covid and to learn coping strategies to maintain their quality of life.

What did you hope Journeying through Dementia was going to achieve?

For the participants to engage with the journey through dementia group topics to improve their knowledge of their conditions and ways in which they can live happy and healthily. To offer and support each person to meet others that are experiencing the same things. Provide education about dementia to highlight and increase knowledge of diagnosis and prognosis of same. To encourage the participation of interventions that may help with cognition. To develop a positive attitude and demonstrate the benefit of peer support in a group like Journeying through Dementia. To maintain a good quality of live through discussion, problems solving and most importantly grade and adapt the sessions to suit the needs of the individual participants.

What do you think was the impact to your practice?

I was more confident in facilitating an occupational therapy group given the restricted over the past 18 Months. I am aware of the significant changes in people experiencing dementia and their carers during covid restricts. It has helped me reflect, grade and adapt my approach

What do you think the benefit has been to your organisation?

It has highlighted the need for occupational therapy to be part of a person's journey through dementia and mental health conditions. It has reinforced the need for more intervention to be facilitated by occupational therapists.

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Extract from the occupational therapy case study: Test site 2

What was learnt and how could this learning be used in the future?

The timing of the group needs to be carefully considered; we held the face to face group on a Tuesday am largely due to availability of the space. This was difficult for the facilitators who didn't work a Monday. Existing commitments in the afternoon meant we often had to rush off immediately after the group and time to write notes, reflect, plan and prepare for the next session was more challenging.

What were the key elements for success through being involved in Journeying Through Dementia?

- The resources – having something so professionally presented was so important and frequently commented upon.
- The venue – we couldn't ask for better
- The postal packs were imperative to being able to deliver this successfully online and also served well as a helpful resource that could be shared within face to face groups. Again they were very professionally presented and showed investment in the participants with something they could reflect on throughout their journey, and share with supporters.
- Facilitation – rooted in occupation this needs to be delivered by occupational therapy staff. Given our experience it is recommended these clinicians should be experienced and knowledgeable in facilitating groups and also in working with people with dementia to adapt and grade activity. It is recognized that in the existing occupational therapy service there are a number of Band 3 clinical support workers that could work alongside an experienced occupational therapist to deliver the group with the right support and supervision, however this would ideally be at a Band 4, Assistant Practitioner level.

What do you think was achieved for the family/caregiver being involved in Journeying through Dementia (if applicable)?

- Support from services – knowing that they were not alone.
- Knowledge to help support their spouse/family member through the journey.
- Different ideas to support engagement with family.
- An activity that they could work on together.

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4.5 The impact for design research

A unique element of this work was the involvement of design researchers (Lab4Living). The quality of the materials and messages communicated in relation to how individuals were valued was integral to the project and were identified as being a critical success factor by facilitators of the programme. As noted previously, the intervention was reviewed and developed based on the feedback and learning from phase I but also in response to the changing delivery of the intervention because of the covid-19 pandemic. It was important that participants had a mode for feeding back their thoughts for which a postcard was created that could be returned to the designer upon completion.

The resources were developed through an iterative process, shaped by the experiences of people living with dementia. Initial feedback was provided by the Scottish Dementia Working Group. As the programme progressed participants and facilitators were encouraged to identify potential strengths and limitations. The feedback mechanisms employed meant that comments could be responded to immediately and ensured changes were made in a timely fashion. In this way people living with dementia were recognized as experts in relation to the design of the materials and played a central role in their evolution throughout the project. Comments such as the following are representative of the overall feedback that was given:

“It’s like a meditation you’re going through while looking at all these bits – you’re noticing. And I think it’s actually quite good! You’re getting the whole range of senses being prodded”
(person with dementia, Scottish Dementia Working Group)

“It was useful as a sort of therapy, because it did convince me that I am still active, I haven’t lost much of my life” ***(person with dementia)***

“The illustrations and design are first class. They’re nice and bright. They’re well done and good quality” ***(person with dementia)***

Family members and facilitators commented on the value of the physical materials to prompt and scaffold conversation and to spark deeper conversation.



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4.6 The impact of national leadership

A dedicated one day a week AHP Project Lead role based in Alzheimer Scotland was a critical success factor for the national occupational therapy improvement project. The role was for 18 months and led the adoption of the project during a pandemic. The impact of the role is highlighted in the infographic outlined below.



Website statistics from June 2023



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Journeying through Dementia is an occupation-based intervention that enables people at an earlier point in their dementia journey to engage in meaningful activities, maintain community connectedness and supports independence and wellbeing following a diagnosis. It combines self-management and group based peer support to improve quality of life. The intervention is a high quality, evidence based intervention that provides rehabilitation and self management strategies for people living with dementia, supporting them to live as independently as possible, reducing the demand on health and social care services. To be most beneficial people living with dementia should have access to this intervention early in their journey, and therefore ongoing communication and multi-disciplinary working with all key stakeholders is imperative.

This report has provided a summary of phase two of a national occupational therapy improvement project to design occupational therapy post-diagnostic support for people living with dementia in three HSCP in Scotland, involving 35 people with lived experience and 5 occupational therapy group facilitators.

This work has demonstrated that it has been possible to integrate Journeying through Dementia into a local post diagnostic pathway with positive impact for people living with dementia and their families. This group based programme facilitated by occupational therapists, enabled people to access peer support, engage in meaningful activities and remain connected to their local community. It demonstrates the unique contribution of occupational therapy in post diagnostic support to enable people with dementia to achieve outcomes important to them.

In spite of the challenges posed by the devastating impact of the pandemic on access to services available to people with dementia, the occupational therapy team were able to adapt and implement the evidence-based intervention, creating a blended model of delivery which could be delivered remotely, face to face or a combination of both. To support the implementation, innovations were developed in partnership with people living with dementia, service leads and occupational therapists and included:

- **An interactive website www.connectingpeopleconnectingsupport.online with 32 practical resources to support the content of Journeying through Dementia**
- **A web-platform www.jtd.org.uk and group facilitators handbook developed to help you as facilitators in preparing and delivering Journeying Through Dementia.**
- **A series of five postal packs to aid in the scaffolding of conversation during online and community occupational therapy facilitated group sessions created for people with dementia and their supporters (appendix 1)**

This extended service model was found to provide people living with dementia with the support they required leading to improvements in quality of life and enabling participants to achieve their individual goals. Occupational therapists have the specialist knowledge and skills to understand the crucial relationship that happens between the individual, their environment and their chosen occupations which has ensured the success of this national improvement project.

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Keys to the success of this intervention are outlined below:

Person living with dementia

- Personalised and individualised approach by developing menu led topics for conversation
- Groups for peer support to learn and practice new strategies with follow up 1:1 follow up sessions
- Importance of the environment the group takes place, in an accessible community and local venues

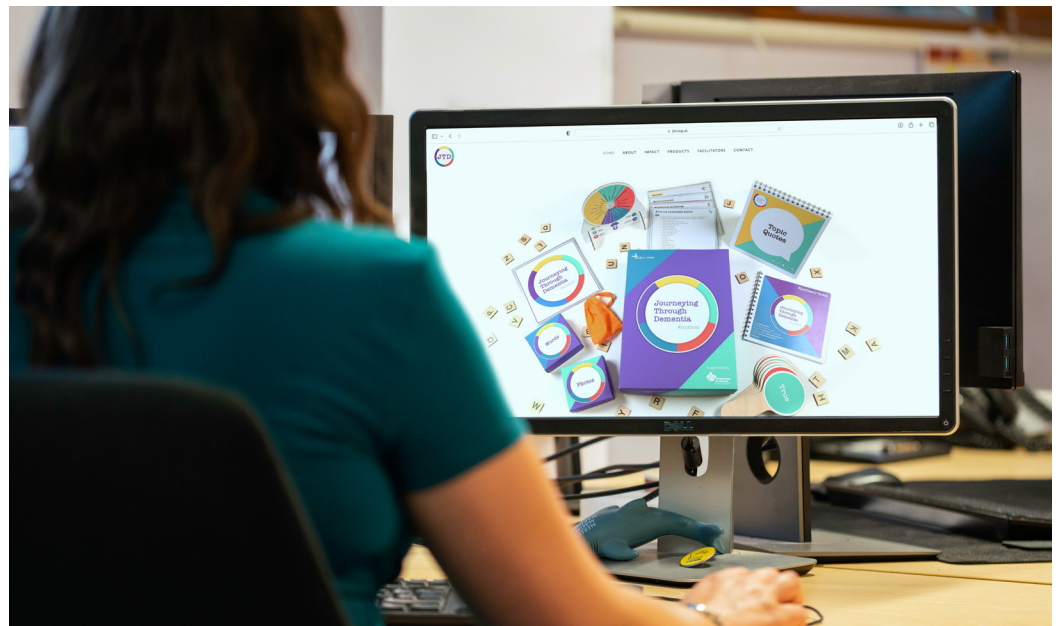
Occupational Therapy Facilitators

- Built in time for reflection and peer support in their role as group facilitators
- Connect with the persons supporters, as appropriate and at the request of person with dementia
- Developed positive therapeutic relationships in the groups and full use of their therapist skills.

Occupational Therapy contribution to post-diagnostic support

- Build measurement tools into the group process that measure personal outcomes, occupation outcomes and quality of life and share the impact locally and nationally.
- Integrate the tiered approach to occupational therapy access in the three levels
- National and local leadership to implement the change in service provision, aligning to the post diagnostic pathway, communicating with all key stakeholders

www.jtd.org.uk



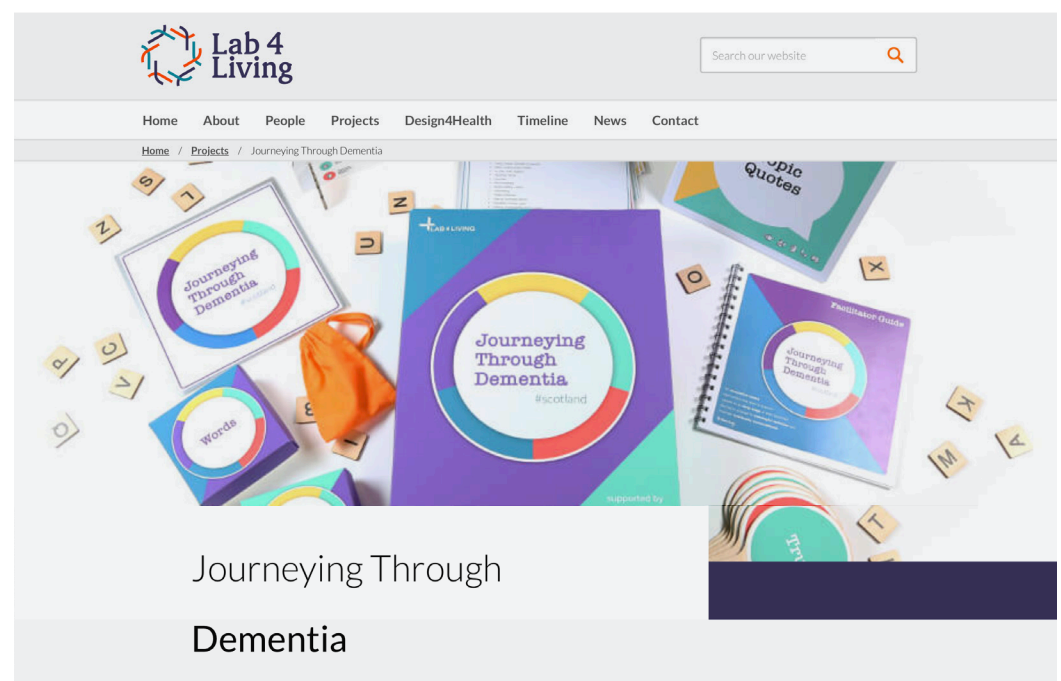
It is recommended the delivery of Journeying through Dementia remains a core role for Occupational Therapy in Scotland to support the delivery of Scotland's Dementia Strategy (2023) Connecting People, Connecting Support (Alzheimer Scotland 2020) and the vision that rehabilitation empowers people to manage their health conditions (WHO 2023).

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We know since writing this report, Journeying through Dementia has already been further implemented in three more HSCPs and Inverclyde occupational therapist have started to plan cohort 10. Moving forward, we will scale and spread this work, learning from this test of change and extending this programme of activity with additional demonstrator sites across Scotland. The next steps are summarised below:

1. **Celebrate** the success of the work, launching this report, with the film, in Inverclyde HSCP November 2023. The film can be viewed at <https://lab4living.org.uk/projects/journeying-through-dementia/>
2. **Scale and spread** this occupational therapy post diagnostic intervention, reviewing and refining the measurement framework based on all the feedback from key stakeholders and will include data requirements developed from practice.
3. **Support sustainability** of the programme by the occupational therapist in Inverclyde HSCP who were integral to this phase of the improvement programme.
4. **Connecting People Connecting Support online** will be updated with a continued emphasis of lifestyle matters and the health benefits of occupation to support brain health.
5. **Design and develop a whole system** occupational therapy Post Diagnostic Support pathway to be researched incorporating a tiered rehabilitation pathway incorporating brain health (Fullerton et al 2023) occupational therapy home based memory rehabilitation (McKean et al 2023) and Journeying through Dementia (Craig et al 2023).
6. **Share the work nationally and internationally**, including with local higher education institutions who educate our occupational therapy students.



<https://lab4living.org.uk/projects/journeying-through-dementia/>

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The following shows the materials provided to facilitators throughout the trials. These materials were co-developed and various iterations made between 2020-2023.

Grab and go fold out information:

Journeying through Dementia - Delivered - Introduction

Journeying through Dementia - *Delivered* is an occupation based online group intervention facilitated by Occupational Therapists. It aims to provide individuals living with dementia with the skills, knowledge and techniques to promote continued engagement in meaningful activity as the condition progresses.

The programme is underpinned by a series of key principles:

- A focus on promoting occupational engagement in the home.
- Recognition of the power of the group and peer sharing.
- Positioning the individual as an expert of their condition and how it impacts on their life.
- Customisation of the programme through enabling individuals to choose topics that are relevant to their needs.
- Focus on rehearsing of skills in the home and community.



Content of the programme

- The programme is focused around a series of online peer to peer group sessions.
- The topics from these sessions were identified by people living with dementia as being important.
- These topics link to the policy document Connecting People, Connecting Support which was also informed by what people told us was important to them.
- There is also a face-to-face group programme called Journeying through Dementia on which this online intervention is based.
- The online version was developed in recognition that COVID-19 has led to a change in how services are delivered and the *Delivered* materials are a response to these changing circumstances.



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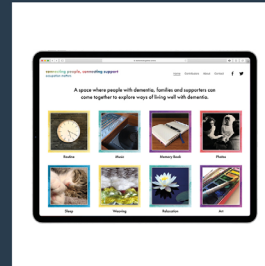
Resources

Our research showed that combining resources that are sent to the homes of group participants with online sessions can help promote engagement. We have therefore developed a range of physical and on-line resources to support group facilitation.

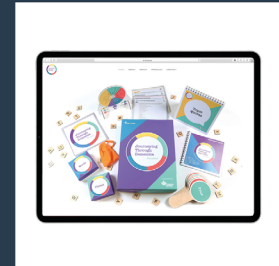
Resources include:



5 different postal packs full of activities and resources around a theme that can be posted to participants homes.



www.connectingpeopleconnectingsupport.online
Web platform of information and activities for people with dementia and their supporters.



www.jtd.org.uk
Website housing the evidence and impact of Journeying through Dementia for Occupational Therapists and staff.

How it works

- This 8-12 week programme comprises of weekly online group sessions, each of 50 minutes - 1 hour duration which are supplemented by online 1:1 meetings.
- Participants will receive a pack by post which relates to a series of topics based around a theme.
- Individuals have the opportunity to think about and complete activities ahead of the group and the group then becomes a focus for deeper exploration and sharing.
- The hope is that between sessions that individuals will have the opportunity to rehearse activities so they can feed back to the group their experiences and problem solve together any challenges they faced.
- Each pack comprises of a booklet which acts as a journal that individuals can complete and materials to complement these. Each booklet contains 2-3 themes and ideas for 2 creative or leisure activities.

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Each group session comprises of 4 elements:

- **Information** sharing (why the topic is important)
- **Chat/discussion** (based on the chat section of the booklet exploring opportunities and challenges in relation to the topic)
- **Sharing** of top tips or a quiz to capture group ideas and understanding
- **Planning** of something the group can try during the following week and thinking of the next session's focus



The structure of a typical group session could look something like this:

- Welcome
- Ice breaker: Tea bag taste test! (Each pack contains a different tea bag - what did they think to this weeks tea bag?)
- Checking in and feeding back: how did individuals got on during the previous week?
- Introduction to the theme of the session
- Discussion/chat questions
- Sharing of top tips/quiz
- Planning an activity for everyone to try and thinking of next week's session

There will be weeks when the group want to feed back on their experiences of trying something new. Offering space for this to happen is important and at no point should you feel that you have to explore a different topic each week. Far better for the group to evolve naturally with a balance of sharing and learning new things.

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Resources

A key principle of the overall approach is to allow individuals the opportunity for choice and decision making. In an online scenario this could be more tricky.

Our suggestion is that all groups begin with the booklet **'About me, my routines and day-to-day'**.

The first group session should be **'about me'**.

At the end of the group invite participants to decide whether they will focus on **routine, memory or checklists**. Through offering simple choices group members are then able to select an activity they will find helpful and at the same time not feel overwhelmed by choice.

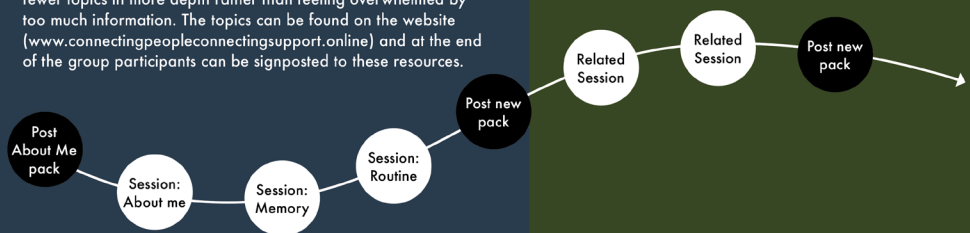
As you begin to gain a sense of group members and their individual goals you will start to identify further topics that they may find interesting/useful.

When the group feels ready to move beyond the theme they have been exploring you will post the next pack out.

We would not anticipate that the group would work through all five packs. The number of packs seeks to reflect the breadth of interests of potential participants.

It is more important that the group feels confident in exploring fewer topics in more depth rather than feeling overwhelmed by too much information. The topics can be found on the website (www.connectingpeopleconnectingsupport.online) and at the end of the group participants can be signposted to these resources.

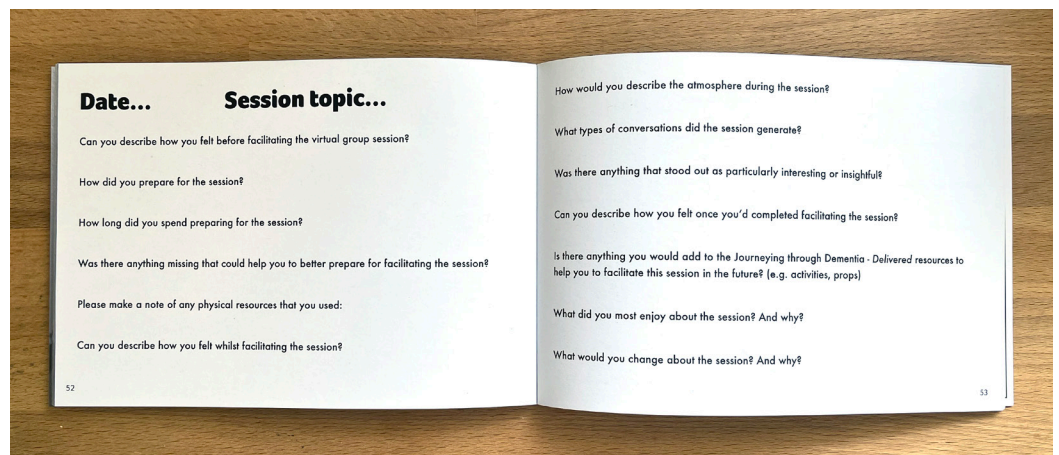
Example journey:



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Facilitator guide including the context, aims, approach, how to facilitate sessions, how to gather feedback and reflections and the under pinning evidence and philosophy:



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Blogs

Click on the images to read more:


12 OCT 2021 **#AHPsDayScot 2021 #Appreciate**
by talkingdementia



Allied Health Professions Day 2021
Celebrate Appreciate
Inspire Connect
#AHPsDayScot #AHPsDay

I am delighted to be writing this blog today, the second of five from @AHPDementia, as we celebrate #AHPsDayScot & #AHPsDay on 14 October 2021. One of the four themes for this day is #Appreciate, with that in mind I would like to take the time to share a little of the work that has been happening to deliver *Journeying through Dementia* within Scotland and #Appreciate the hard work and efforts of all those involved in bringing this intervention to Scotland. The past 18 months have been incredibly challenging however throughout this time I have had the privilege of working with a fantastic group of people, from our colleagues at *Sheffield Hallam*, to a group of Occupational Therapists across Scotland, who are enthusiastic and keen to make a real difference to the lives of people living with dementia.

15 JUL 2021 **Journeying through Dementia: An Update**
by talkingdementia



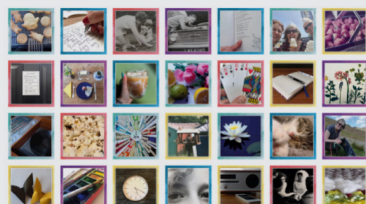
Hi, my name is Ashleigh Gray and I am AHP Project Lead at Alzheimer Scotland for 'Journeying through Dementia'. I was asked to put together a blog to provide an update on the work we have been doing and I decided to do this by putting together a poem. Please take a minute to listen to my vlog and let us know what you think, you can listen by clicking on *my poem*

Families, relationships & keeping connected

2 JUN 2021 **Connecting People, Connecting Support on-line**
by talkingdementia

occupation matters #dementiaawareness

connecting people, connecting support
occupation matters




14 OCT 2020 **#Connect on #AHPsDayScot**
by talkingdementia



Allied Health Professions Day 2020
Celebrate Appreciate
Inspire Connect
#AHPsDayScot #AHPsDay

I am delighted to be writing this blog today on #AHPsDayScot to celebrate and talk about some of the work we are doing in Scotland to deliver a peer to peer occupation based intervention called Journeying

10 OCT 2019 **Journeying through Dementia in Aberdeenshire #SelfManagement**
by talkingdementia



Journeying Through Dementia
#scotland

Self-Management Week is 7th -11th October and takes place every year to raise awareness and showcase the huge benefits self-management can bring to people's lives. Enjoy reading about our AHP approach to self-management when working with people living with #dementia.

We are delighted to share with you our experience of delivering Journey through Dementia in

27 JUN 2019 **Journeying through the Fellowship**
by talkingdementia

Beginning a Clinical Fellow

"How was your training?" I was asked by a colleague, having returned to the department following two days attending the NES AHP Careers Fellowship workshops; "It was really good" was my response but in hindsight this doesn't seem to quite cover everything I had gained. How did I communicate how incredibly supportive and encouraging it was being and learning with people who, like me, were there because of their drive to improve services and learn from that experience. How did I put into words how thought provoking and motivating it was to hear speakers, clearly so knowledgeable and passionate within their own areas of expertise. Also, and importantly, how did I bring this learning back and use this to guide and support me in my project, but also to support me and my team in my day to day clinical work?

I have a few ideas but in the meantime applications have opened for the next cohort of the fellowship. I have taken this opportunity to share more information with my team regarding the fellowship, including how supportive it has been learning with different people, from different professions and working in different clinical areas. I have encouraged all the staff in my department, including the support workers, to consider applying as the fellowship is a great opportunity. Click on the link below for further information:

14 MAR 2019 **Journeying through Dementia Designing Post Diagnostic Support with People with Dementia**
by talkingdementia



Journeying Through Dementia
#scotland

Appendix II

01 Introduction and Context

02 An Occupation Focus to Rehabilitation

03 A Post Diagnostic Improvement Project

04 Measuring Impact and Outcomes

05 Summary

05 Summary

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Measure for success: measurement & data capture points

What	Measure	Base-line	Wk1	Wk2	Wk3	Wk4	Wk5	Wk6	Wk7	Wk8	Wk9	Wk10	Wk11	Wk12	F/U
Demographic	Attended/DNA/CNA	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Personal experience	Occupation goal orientated question	X						X							X
Quality of life	QOL-AD completed by participant	X													X
Single quality question	3 question likert scale														X
Group experience	Group reflection integral to the group process		X	X	X	X	X	X	X	X	X	X	X	X	
Therapist experience	Weekly reflections, integral to the group process		X	X	X	X	X	X	X	X	X	X	X	X	
Design of the resources	Postcards returned directly to Helen (Designer)					X				X					
Personal experience Impact of Journeying through Dementia	Film the experience of the people in the group – face to face														X
Therapist experience	Record the experience of the occupational therapists in focus groups (Zoom)														X



Alzheimer Scotland is Scotland's national dementia charity. Our aim is to make sure nobody faces dementia alone. We provide support and information to people with dementia, their carers and families, we campaign for the rights of people with dementia and fund vital dementia research.

@AHPdementia
www.alzscot.org

This work is underpinned by research developed by Lab4Living at Sheffield Hallam University during 2020-2021. Lab4Living is an interdisciplinary research group based on a collaborative community of researchers in design, healthcare and creative practice.

@Lab4Living
www.lab4living.org.uk

Designed with Care specialise in developing products for those experiencing dementia, older generations and their families. Each product is backed by research and has been developed with people affected by dementia to make sure that they are designed with meaning, purpose and care.

www.designedwithcare.co.uk