Occupational Therapy Co-Designing Post-Diagnostic Support for People Living with Dementia

Journeying through Dementia 2020-2023

Ashleigh Gray, Elaine Hunter, Claire Craig, Helen Fisher | November 2023

Alzheimer Scotland
Action on Dementia
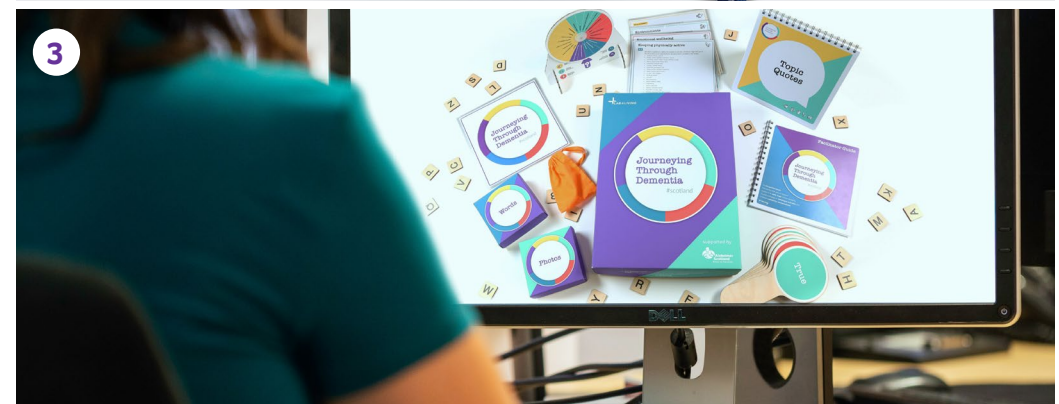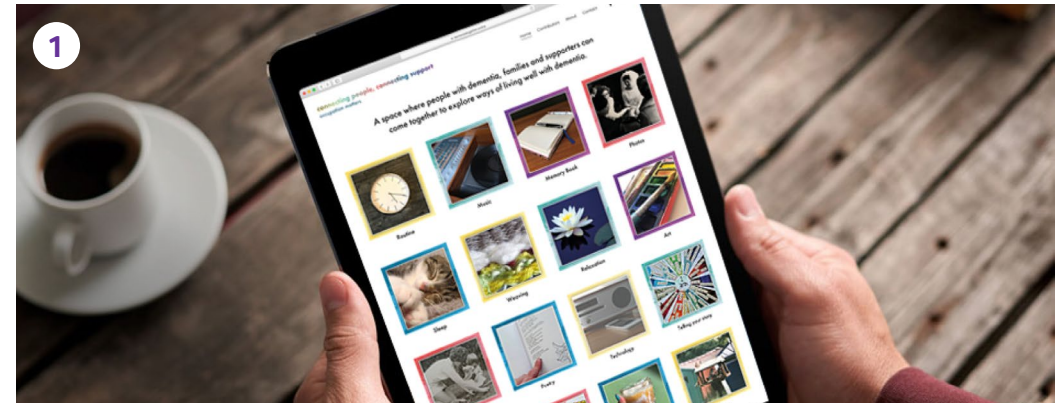
NHS SCOTLAND

Lab 4 Living

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 is 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.

To support the implementation, innovations were developed in partnership with people living with dementia, service leads and occupational therapists and included:

1. **An interactive website www.connectingpeopleconnectingsupport.online with 32 practical resources to support the content of Journeying through Dementia**

2. **A series of five postal packs to aid conversation during occupational therapy facilitated group sessions created for people with dementia and their supporters**

3. **A web-platform www.jtd.org.uk and group facilitators handbook developed to help you as facilitators in preparing and delivering Journeying Through Dementia**

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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.

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

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).

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 Inverlcyde 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.