



Innovation,
Applicability and
Transferability

Australian iSupport for Dementia Research Update

Background

iSupport is an evidence-based online dementia education and skills training program for family carers. Originally developed by the World Health Organisation (WHO), it was adapted and tested for the Australian market.

'iSupport aims to prevent and/or decrease mental and physical health problems associated with caregiving and to improve the quality of life of those caring for people with dementia.' - WHO

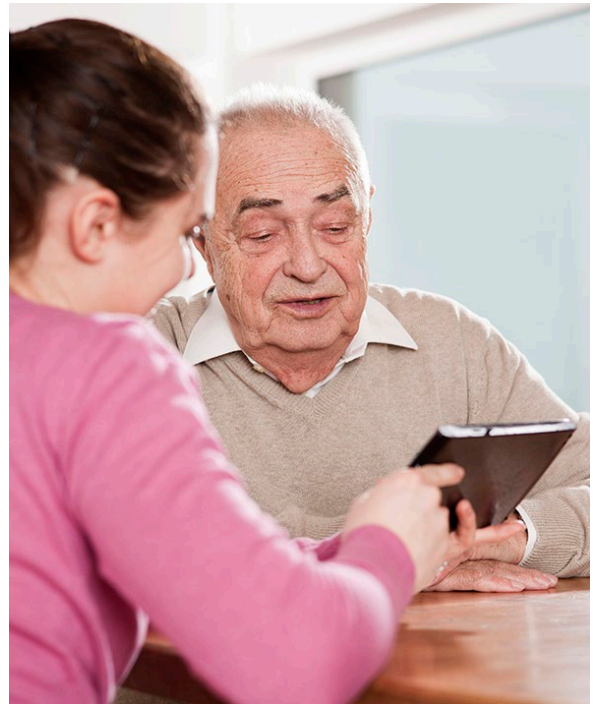
Resthaven was a project partner in the three-phase project, working with carers of people living with dementia to test the effectiveness of the program in Australia.

Following the initial pilot project in 2019, the project was funded by a Medical Research Future Fund 2020 Dementia Ageing and Aged Care Mission grant and a 2020 Dementia Centre for Research Collaboration (DCRC) World Class Research Projects grant.

iSupport for Dementia

The iSupport for Dementia research project was designed in three phases with an aim to adapt the program for the Australian environment.

The education and support program is offered across five online modules that support, educate and assist carers to develop skills that will enhance their caring role.



The modules cover a range of information and skills development within the following topics:

1. introduction to dementia
2. being a caregiver
3. caring for me
4. providing everyday care; and
5. dealing with behaviour changes.

The modules are available online and via a hard copy to optimise the reach and utilisation within a self-directed learning approach. The approach provides opportunity for adaptation for individuals, groups and cultural groups. The resources are available in multiple languages.

All modules consist of brief readings, descriptive examples and several exercises. Carers receive feedback as they work through each exercise.

Phase one of the research project focused on co-design activities and was delivered in 2022 by iSupport Program facilitators. During this phase, Resthaven worked with family carers and tested a set of online education modules. The modules focused on what is dementia and its impacts, and how carers can better support themselves and the person living with dementia.

Phase two involved offering the online modules and was directed from the learnings during the initial phase.

Phase 2 results indicated a significant improvement in how participants managed changed behaviours, and registered an improvement in overall Quality of Life.

Carers reported that most value was derived from the support and learnings they received from each other's real-life experiences, during the facilitated online support meetings.

To add to this, they also identified that online only communication limits development of rapport between carers in the Resthaven participant demographic. Most indicated that they would like a face to face activity at the commencement of the support group. This would make them feel more comfortable in participating in online meetings more quickly, encouraging them to open up in online conversations.

Phase Three

The third and final phase of the project commenced in the second half of 2024.

Carers of existing Resthaven clients living with dementia were given the opportunity to participate by attending virtual support meetings.

Meetings commenced in September 2024 and continued for six months.



At Resthaven, the third phase of the project introduced an online support approach, where the iSupport project lead supported participating carers via monthly online meetings. Small carer groups met online to discuss the iSupport modules, share lived experiences, learnings and provided valuable peer support. The groups were restricted in size to optimise engagement.

During phase 3, a total of 35 carers attended online sessions across four groups. The forum gave carers an opportunity to share their experiences and learnings and their caring journey.

Participants were encouraged to build relationships with peers outside of the group.

Findings

Where there was a sense of trust or a current relationship with the carer and the staff and/or organisation, there was greater participation, highlighting the importance and value of trusted relationships.

For a carer, endurance in their journey is enhanced with an ability to share their experience and learn from others who are also having a similar experience. Even with a strong family network, carers need an opportunity to



be able to speak freely and share their emotions without fear of judgement. Carer support programs, including iSupport, enable this.

The iSupport program is an online offering. A broader carer support program with a blend of face to face as well as online connections, would potentially result in increased engagement, rather than a stand-alone virtual model.

Recommendations

The following recommendations are provided from the feedback of carers and staff who participated in the Partnership in iSupport program.

1. The optimal timing for introduction to the Partnership in iSupport program is early in the carer journey, close to the time of diagnosis.
2. Partnering in iSupport should be offered within a suite of support options for carers supporting someone with a diagnosis of dementia.
3. Funding for carer support programs should be provided specifically for the carer role.
4. An exit plan post completion of the program could be developed and offered to carers with organisational support. The self-directed carer group was not embraced by the participants.
5. Carer support programs offered across different organisations should be collated and promoted within a central portal
6. The hard copy resource would benefit from review and update to a more user-friendly version.

These findings will be considered by the Flinders University iSupport research team.