

# LIV Well when Life Is Limited: Technology to Support Independence at Home

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**Abstract.** There has been significant growth in technologies and services creating ‘care at home’ ecosystems for people with life-limiting conditions such as dementia. Dementia is one of the leading causes of disability and loss of independence that causes a heavy burden for families and caregivers. There is a clear need to support independent living of people living with dementia and their caregivers. Health technologies can help to foster supported living and social connection. The LIV app, developed by Miroma Project Factory and piloted in collaboration with CSIRO, was designed to achieve these aims. Here we describe the development and functionality of the app and present the preliminary findings from the pilot trial.

**Keywords.** Dementia, caregiver, mobile health technology, independent living

## 1. Introduction

When facing temporary issues such as recovering from an injury or an operation; chronic conditions which we need to manage over time; or complex conditions requiring an array of interventions - most of us would choose to do this in the comfort of our own home, rather than external, often institutionalised, care. Hence, there has been significant growth in technologies and services creating ‘care at home’ ecosystems. These reduce the burden on public health by empowering individuals to manage their health and independence more proactively, with the aim of keeping them living healthily at home longer. They help users better understand their own health and abilities, and take individual actions and interventions to retain both their control and their independence.

These technologies are particularly relevant for people living with dementia and their carers. Dementia is a progressive disease characterized by gradual impairment of brain function and is associated with difficulty with independently carrying out activities of everyday living [1-3]. It is associated with a high prevalence of depression (~25%) and anxiety (~75%), exacerbating impairment in everyday functioning [4-6] and significantly affects quality of life (QoL) of patients and their families. Currently around half a million Australians live with dementia, 70% of whom live in the community with almost 1.6 million people involved in their care [7]. The number of people living with dementia is expected to rise worldwide from 55 million to 78 million in 2030. This will affect the efficiency of the healthcare system and the delivery of health services. To

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mitigate this impact, there is an emphasis on fostering autonomy and self-management. Research shows that while caregivers incur a significant burden and have substantial need for services, they are not using them, mainly due to lack of awareness [8]. While support services can improve the QoL of caregivers [9], there are a large number of unmet needs in dementia due to lack of knowledge about existing services, a threshold to using services and insufficient service offers [10]. Other barriers include the lack of public promotion of services, stigma around dementia, and personal disinclination to ask for support from others. Technology-based solutions have the potential to help circumvent these barriers [11,12], and evidence of the uptake of health-related apps by people living with dementia suggest an improvement in activities of daily living [13].

A novel digital tool, the LIV app, funded by the Australian Department of Health, was designed and developed by Miroma Project Factory (MPF). The main aims are (1) improving the lives of people living with life-limiting conditions and their caregivers, and (2) facilitating independent living in their own homes for longer through easy access to supportive communities, information, and services.

MPF has received a prestigious Australian Good Design Award Winner Accolade in the Digital Design category in recognition for outstanding design and innovation in developing the LIV app. CSIRO has collaborated with MPF to conduct a pilot trial to evaluate LIV for usability, accessibility, impact on ability to live independently and knowledge of local services. In this paper, we describe the development and functionality of the app together with preliminary outcomes from the ongoing pilot trial.

## 2. Methods

### 2.1. Development of the LIV app

LIV is a digital tool that forms a key part of the care at home ecosystem by making life easier for carers of people with chronic conditions, and for the impacted individuals themselves. The first iteration of the LIV app has been designed as an online directory for people living with dementia or carers to check in, seek and receive support from people in similar positions; seek assistance from their local community and access resources about dementia and information about local services. It is available for both Android and iPhones, both handset and tablet, and accessible via its website ([www.livtheapp.com](http://www.livtheapp.com)). LIV has four main features:

- Local services: relevant and useful community, health and commercial services.
- Forums: peer-based groups for support, advice or just validation of experience.
- Resources: information relevant to living with and caring for dementia.
- Community of care: the ability to invite friends, family, and local community to a private social network to ask for, or offer, assistance or share updates. Participation is limited to responding to tasks; with some forum participation and no ability to invite others to join or add to the community of care circle.

### 2.2. Pilot study to assess usability of the LIV app

Following privacy assessment, ethics approval was granted from CSIRO Human Research Ethics Committee (CHMHREC 2021\_044\_HREC) for a 3-month pilot trial to explore how people might use the app. Recruitment was facilitated by StepUp for

Dementia Research, Dementia Australia, and the Australia Dementia Network. Participants included people living with dementia who had the cognitive capacity to provide informed consent (n=12); caregivers, where the care provision is past or present (n=12); and community members invited by either of the former participant groups (n=10). All participants needed to have access to an appropriate device or computer to access the app and the ability to comprehend sessions and materials in English. Participation was not recommended for people with significant hearing or vision impairment that would make engagement with the project difficult. Data was collected via log data usage and three electronic surveys (baseline, midpoint, and end of trial).

### 3. Results

#### 3.1. Co-design sessions reveal an interest in accessing services and forums

MPF undertook co-design sessions with people with early onset dementia, those with more advanced dementia, those in between, and with carers across these disparate age groups. It was clear that regardless of whether the person had mild or severe dementia, if they retained their comfort and familiarity with technology (web or app) they were likely to find LIV useful. Additionally, as the tool is as focussed on carers as it is on people living with dementia, their technical capabilities are as relevant.

The hypothesis underpinning development was that the function of greatest interest would be tasks, where people can ask for or offer support with small tasks around the home, such as watering plants, minding someone while the carer was absent or collecting small shopping items such as milk. Surprisingly, those either with mild dementia symptoms, early in their dementia diagnosis or with younger onset dementia felt that the forum, local services, and messaging components of the app would be most useful, but recognised that the care circle and tasks would be more relevant over time. Older people, predominantly carers, felt that the carers forum, services, and journal area were more useful, and that they would need to get over their socially ingrained need to be independent before they would ask for help, even in the form of everyday tasks. This suggests the app has varying levels of usefulness at different stages in the condition.

#### 3.2. Log data supports the popularity of social connection

Log data analysis of events (defined as any interaction with the app) showed that people living with dementia and carers had a similar number of interactions over the course of the trial (1109 and 1103, respectively) and that, as expected, their usage far exceeded that of community members (192 events), for whom participation is restricted.

Our preliminary analysis assessed interaction with nine app components. These are referred to as 'activities' and included care circle, dashboard, forum, journal, messages, resources, services, settings, and tasks. Carers used these components the most (513 activities), followed by people living with dementia (343 activities) and community members (79 activities) (Figure 1). Focus group findings were both supported and not supported – Carers used the forums activity more often than the task activity (131 activities compared to 32) supporting this finding; however, the use of the task and service activities were similar (32 and 31 activities respectively).

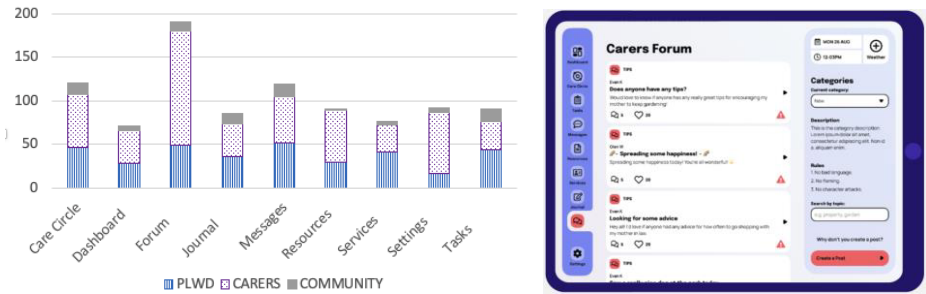


Figure 1: Relative number of activities undertaken in the app by people living with dementia (blue stripes); caregivers (purple dots) and community members (grey boxes), with preference for the carer's forum (right).

People living with dementia used messages and forums more than any other function. In fact, for all participants, social function activities (care circle, forum, messages, tasks) were used more often than individual activities (journal, resources, services).

While participants used the app frequently in the first month (between 1 and 12 app activities per day), app usage did diminish over the 3-month period. This was partly to do with the busy lifestyle led by carers, and the amount of support they were able to access, independent of the app.

*“Living with a person with Alzheimer’s can be busy but also is rewarding. I am fortunate to have lovely carers, family and friends who all support us.” C1131*

#### 4. Discussion

The LIV app connects people living with dementia to their community and empowers them to choose how they are supported in living independently for longer. The app links friends, family and local community in one central place - a community of care. Through this ‘care circle’, people can offer, ask for and receive the support they need. The app provides information on local services, based on postcode or (with permission) GPS location (mobile only) data; and aims to reduce stigma associated with dementia for community members through providing reputable resources.

While a variety of mHealth applications exist to support people living with dementia and caregivers, there are critical gaps to be filled. The functionalities currently provided can be categorised into six themes [14], tracking (of patients), task management (medication), monitoring (patient activity and health), caregiver mental support [15], resources for patients and caregivers [15-17], and caregiver communication platforms [15,17]. Current inadequacies of apps available for caregivers include lack of comprehensive support, the absence of functionalities for early dementia diagnosis and the integration of caregivers in the patient’s care management [14]. The LIV app addresses these inadequacies in part by linking carers and patients with resources, services, and community support to meet social, intellectual, behavioural and health needs. This in turn reduces the burden on the public health system, and provides avenues for discourse in designing community care environments connected by health technologies. Health adjusted life expectancy (HALE), which takes into account time spent living with a life limiting condition, can be up to 10 years below total life expectancy [18]. This indicates that some portion of all our lives will be compromised and hence health technology enabling independence is relevant for the entire population.

## 5. Conclusion

Supporting people with life-limiting conditions to live at home independently for longer will require a suite of ‘care at home’ technologies. These technologies enable people living with conditions like dementia, and their carers, to interact with their communities and broader society to access resources, services and support for everyday activities. LIV forms part of this care at home ecosystem, providing access to the elements underpinning healthy independence and the agency to LIV well when life is limited.

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## References

- [1] Dementia in Australia 2021: Summary report, Australian Institute of Health and Welfare, Canberra, 2021.
- [2] Prince M, Dementia and risk reduction. in, World Alzheimer report 2014, 2014.
- [3] Robinson L, Tang E, Taylor JP, Dementia: Timely diagnosis and early intervention, *BMJ* 350 2015, h3029. doi: 10.1136/bmj.h3029
- [4] Goodarzi Z, Mele B, Guo S, Hanson H, Jette N, Patten S, Pringsheim T, Holroyd-Leduc J., Guidelines for dementia or Parkinson’s disease with depression or anxiety: A systematic review, *BMC Neurology* 16 2016, 244. doi: 10.1186/s12883-016-0754-5
- [5] Riley RJ, Burgener S, Buckwalter KC, Anxiety and stigma in dementia *Nursing Clinics* 49 2014, 213-231. doi: 10.1016/j.cnur.2014.02.008
- [6] Van der Mussele S, Bekelaar K, Le Bastard N, Vermeiren Y, Saerens J, Somers N, Mariën P, Goeman J, De Deyn PP, Engelborghs S., Prevalence and associated behavioral symptoms of depression in MCI and dementia, *Int. J Geriatric Psych* 28 2013, 947-958. doi: 10.1002/gps.3909
- [7] Dementia statistics, in, *Dementia Australia*, 2020.
- [8] Brodaty H, Thomson C, Thompson C, Fine M, Why caregivers of people with dementia and memory loss don’t use services, *Int J Geriatric Psychiatry* 20 2005, 537-546. doi.org/10.1002/gps.1322
- [9] Farina N, Page TE, Daley S, Brown A, Bowling A, Basset T, Livingston G, Knapp M, Murray J, Banerjee S, Factors associated with the quality of life of family carers of people with dementia: A systematic review, *Alzheimer’s & Dementia* 13 2017, 572-581. doi: 10.1016/j.jalz.2016.12.010
- [10] van der Roest HG, Meiland FJ, Comijs HC, Derksen E, Jansen AP, van Hout HP, Jonker C, Dröes RM., What do community-dwelling people with dementia need?, *International Psychogeriatrics* 21 2009, 949-965. doi: 10.1017/S1041610209990147
- [11] Span M, Hettinga M, Vernooij-Dassen M, Eefsting J, Smits C, Involving people with dementia in the development of IT applications, *Ageing Res Rev* 12 2013, 535-551. doi: 10.1016/j.arr.2013.01.002
- [12] Brown EL, Ruggiano N, Li J, Clarke PJ, Kay ES, Hristidis V, Smartphone-based health technologies for dementia care, *J Applied Gerontology* 38 2019, 73-91. doi: 10.1177/0733464817723088
- [13] Yousaf K, Mehmood Z, Awan IA, Saba T, Alharbey R, Qadah T, Alrige MA, A comprehensive study of mobile-health based assistive technology for the healthcare of dementia and AD, *Health Care Mgt Sci* 23 2020, 287-309. doi: 10.1007/s10729-019-09486-0
- [14] Kim E, Baskys A, Law AV, Roosan MR, Li Y, Roosan D, The empowerment of Alzheimer’s disease caregivers with mhealth applications, *NPJ Dig Med* 4 2021 131. doi.org/10.1038/s41746-021-00506-4
- [15] Ruggiano N, Brown EL, Shaw S, Geldmacher D, Clarke P, Hristidis V, Bertram J, The potential of information technology to navigate caregiving systems, *J Ger Soc Work* 62 2019, 432-450. doi.org/10.1080/01634372.2018.1546786
- [16] Gupta G, Gupta A, Barura P, Jaiswal V, Mobile health applications and android toolkit for Alzheimer patients, caregivers and doctors, *Biological Forum—An Int J*, 2019, 199-205.
- [17] Núñez-Naveira L, Alonso-Búa B, de Labra C, Gregersen R, Maibom K, Mojs E, Krawczyk-Wasielewska A, Millán-Calenti JC. Understaid, an ICT platform to help informal caregivers of people with dementia, *BioMed Res Int* 2016 2016, 5726465. doi: 10.1155/2016/5726465
- [18] Australian Burden of Disease Study: Methods and supplementary material 2018. AIHW, Canberra 2021.