

## Issue 6: *Online support and informal caregivers*

Welcome to *Evidence at a Glance No. 6*.

This issue of *Evidence at a Glance* focuses on the role of online support in reducing social isolation and addressing the social needs of informal care partners.

There has been a growing amount of literature on the role of the internet in increasing access to information and support for people with dementia and their care givers in the last few years. The [article](#) discussed in this issue - *The role of internet-based digital tools in reducing social isolation and addressing support needs among informal caregivers: a scoping review*<sup>1</sup> - is a review of the research findings from 23 studies involving caregivers for people with many health issues including dementia.

Social isolation in the article is defined as “a state in which an individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts”.<sup>1</sup> Social inclusion is defined as social integration, support and access to resources. The review found that these social inclusion elements could be addressed by internet-based [digital tools](#)<sup>2</sup>.

<sup>1</sup>Newman, K., Wang, A.H., Wang, A.Z.Y. , Hana, D. (2019). The role of internet-based digital tools in reducing social isolation and addressing support needs among informal caregivers: a scoping review. *BMC Public Health* 19, 1495. doi.org/10.1186/s12889-019-7837-3. Retrieved from <https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-7837-3>

<sup>2</sup> Internet -based digital tools are defined as “programs, websites or online resources that can make tasks easier to complete. A lot of these can be accessed in web browsers without needing to be downloaded, and you can access them both at home and in work.” Reference <https://engage.dhsc.gov.uk/digitalpassport/tools/>

### Methods

The study was a systematic review of 23 research studies identified in the published literature and grey literature. Most of the studies used qualitative or mixed methods methodologies. The aims of the study were to identify:

- The digital tools informal caregivers used for social support;
- How digital tools reduced social isolation and address the support needs of informal caregivers,
- Whether informal caregivers have unmet needs that could be met by internet-based digital tools.

### Key Findings

The internet resources used in the studies by caregivers included discussion groups and blogs, peer-to-peer or facilitated support groups, Facebook groups and social media, along with internet information and communication.

The authors identified three major themes in the papers.

### ***Searching for and receiving support.***

- Caregivers searched for other people's health stories online that were similar to their stories.
- Informational and emotional support were frequently sought as well as offered by caregivers.
- Online groups were a forum for sharing experiences and expressing emotion.

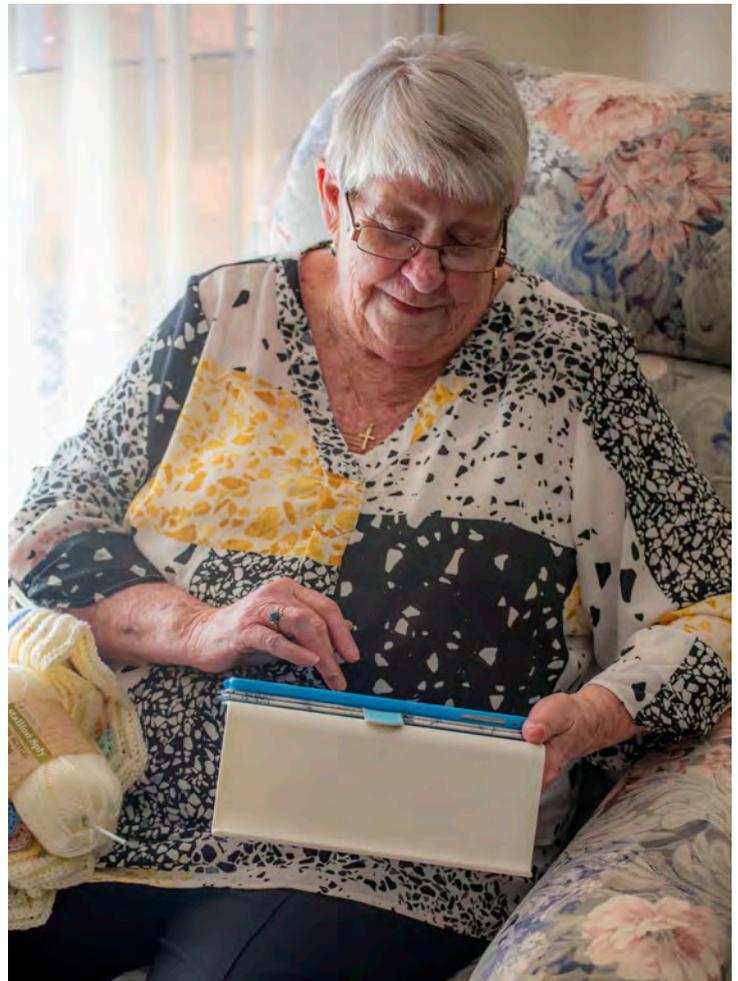
### ***Getting a sense of social inclusion and belonging.***

- Studies found that caregivers using internet-based platforms accessed resources, got social support and felt included in a meaningful social network.
- A study of dementia caregivers found that learning about others experiences and responses also reduced their sense of loneliness and isolation.

### ***Benefits and challenges of internet-based support.***

- Highlighted advantages included anonymity (which allowed greater honesty for some), instant access to support, and that sharing experiences can provide hope for others. It could also overcome limitations of geography, particularly for those in rural areas. Other advantages included receiving support at home and being able to craft messages before sending them.
- A range of technical issues were a problem for some, technical support from health professionals was necessary to resolve the issues in some cases.

The authors found that care partners often did not have personal contacts with people with experience with providing support for their loved ones and often desired to contact people who did. They concluded that internet-based digital tools could be a cost effective and convenient way to develop programmes to support caregivers. These programmes can help caregivers develop communities, gain support and access resources.



### Questions for discussion

1. Do you provide any online support for your members living with dementia?
  - a. Has this only begun since Covid-19 or did you do this before?
  - b. Do you think it would be useful to continue this form of support when physical distancing is no longer necessary?
2. Have you thought of providing caregivers and people living with dementia with help to access online support?
  - a. If yes in what ways (now or the future)?
3. Do you work with other organisations that use internet-based support systems?
  - a. Are there ways that you could link in with these platforms?
4. Do you provide information for your families on other assistive technology such as location devices, memory assistance devices, sensor mats.

### Technology and dementia resources

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