



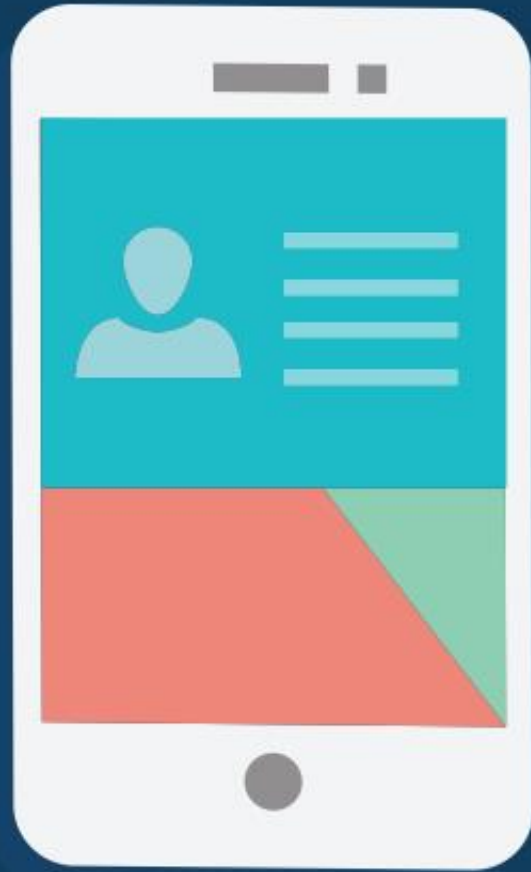
Social Media and Smart Health Technology for Caregivers of People with Dementia

*Joel G. Anderson, PhD, CHTP, FGSA
Associate Professor, College of Nursing*



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Changing demographics

An increasing number of these caregivers are using the internet to gather information and younger caregivers are most interested in receiving support via social media including blogs.



Adult Internet users who have sought support and health information on the Internet



Internet users using social media

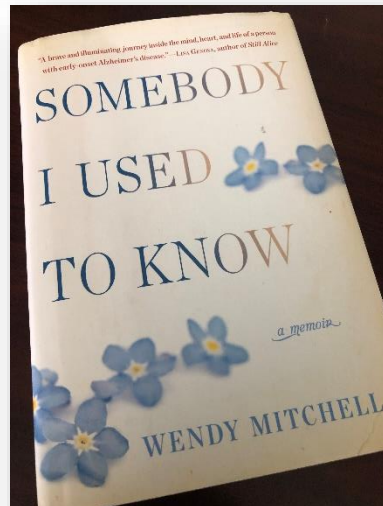


Use the Internet for health information or to read about someone else's experience



Search online for individuals with similar health experiences


Wendy P. Mitchell



Wendy Mitchell
@WendyPMitchell

Sharing my journey, if anyone chooses to read it, of living as well as I can with dementia near Beverley. Follow my blog - whichmeamitoday.wordpress.com

Joined March 2015




Which me am I today?

One person's experience of living with dementia

Blog Gallery Home

Home

Hello and welcome to my blog. On the 31st July 2014 I was diagnosed with Young onset dementia. I may not have much of a short-term memory anymore but that date is one I'll never forget.



Me - 59 years young with my wonderful daughters.)

I'm 62 years young, live happily alone in Yorkshire, have 2 daughters and I continued to work full time in the NHS until the end of March 2015, when I chose to take early retirement to enable me to enjoy being me while I'm able. I have never 'tweeted', 'blogged' or 'face-booked' in my life but since I was diagnosed, everything else in my life has changed, so why not this. I hope you find my ramblings of interest.

I started this blog to allow me, in the first instance, to write all my thoughts before they're lost. Luckily the part of my brain that allows me to type hasn't broken yet and I find that easier than talking. I have calendars that take care of the future but this blog serves as a reminder of what I've done and said in the past - it now serves as my memory. If anyone chooses to follow my ramblings it will serve as a way of raising awareness.

Recent Posts

- A not so secret love affair..... April 5, 2019
- Another punishing but wonderful day in London.... April 4, 2019
- My daughter telling her side of our story....plus... April 3, 2019

YoungDementiaUK
Informing. Influencing. Inspiring.

Alzheimer's Research UK
Defeating Dementia

Join dementia research

People with Dementia and Twitter

The screenshot shows a journal article page with a purple header. The journal title 'Dementia' is centered in the header, and the 5-Year Impact Factor '1.671' is in the top right corner. Below the header is a navigation bar with links for 'Journal Home', 'Browse Journal', 'Submit Paper', 'About', and 'Subscribe'. On the left is an 'Article Menu' sidebar with options: 'Download PDF', 'Full Article', 'Content List' (with sub-items: Introduction, Method, Results, Discussion), 'Figures & Tables', 'Article Metrics', 'Cite', 'Share', 'Request Permissions', and 'Related Articles'. The main content area features the article title 'Identifying people with dementia on Twitter' by Catherine Talbot, Slobhan O'Dwyer, and Linda Clare. It includes the publication date (August 6, 2018), a DOI link, and an Altmetric score of 110. The 'Abstract' section begins with the text: 'There is a growing body of research on the use of Twitter by people with health conditions, but it does not include people with dementia. In this brief report, we aim to: (1) determine whether people with dementia are using Twitter; (2) provide an estimate of the number of Twitter account holders who identify as having a diagnosis of dementia; and (3) examine the demographic characteristics of these account holders. Tweetcatcher was used to identify tweets containing the search terms 'dementia' or 'Alzheimer'. These data were systematically searched to locate account holders who identified themselves as having a diagnosis of dementia, and a content analysis was conducted of these account holders' profiles. Thirty account holders self-identified as having a diagnosis of dementia. The average age of account holders was 59 years and the majority were located in North America or the UK. Although the majority of account holders reported having Alzheimer's disease or did not specify a type of dementia, some rare forms of dementia were also evident. The sample consisted of relatively young account holders and contained more men, which might suggest that other groups are under-represented on Twitter. The majority of account holders considered themselves a dementia activist or were affiliated with a dementia organisation. The findings suggest that people with dementia, with varying demographic characteristics and a range of diagnoses, are active on Twitter. These account holders are more frequently male, relatively young, and dementia activists.'

People with Dementia and Twitter

Themes:

- Nothing about us without us
- Collective action
- Experts by experience
- Living with dementia not suffering from it
- Community
- Stories of dementia

Caregivers and Twitter

symplur

TECHNOLOGY ▾ RESEARCH PRICING HEALTHCARE HASHTAGS ▾ COMPANY ▾ LOG IN 🔍

Home / Healthcare Hashtags / #AlzChat / Transcript

#AlzChat Transcript

Healthcare social media transcript of the #AlzChat hashtag.
Mon, March 25th 2019, 4:00PM – Mon, March 25th 2019, 6:00PM (America/New_York).
See #AlzChat Influencers/Analytics.

[Tweet](#)

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- Access to over 100,000 #AlzChat tweets
- Filter tweets by Healthcare Stakeholders
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Hilgos Foundation @IRememberBetter a month ago
It's time for #AlzChat Topic today: Dementia care Springtime activity ideas @creativitycare @TommyTommytee18 @nursesKidONE @AlzJoyThruTears @SrCareComer

Erin Partridge @2littlewings a month ago
Making connections between what we're doing together in any given moment & the seasons is a good idea as long as the primary goal isn't reality-orientation, quizzing, or trivia. 1/2 #AlzChat

nursesKidONE @nursesKidONE a month ago
RT @IRememberBetter: It's time for #AlzChat Topic today: Dementia care Springtime activity ideas @creativitycare @TommyTommytee18 @nursesKi...

creativityincare CIC @creativitycare a month ago
Hi and welcome all to #AlzChat Todays Topic: dementia care Springtime activity ideas with hosts @IRememberBetter @creativitycare Hoping Spring has arrived for you all in the West :)

Erin Partridge @2littlewings a month ago
We also need to watch out for infantilizing through the materials we provide for seasonally-themed groups....so much of what is out there on the market is meant for kids. Good rule of thumb: Joyful? Yes. Bright? Yes. Child-like? NO. 2/2 #AlzChat

Caregivers and Blogs

“The Church of Online Support”: Examining the Use of Blogs Among Family Caregivers of Persons With Dementia

Joel G. Anderson, PhD, CHTP, Elizabeth Hundt, RN, NP-C, ACNS-BC, Morgan Dean, RN, [Show all authors](#) ▾

First Published December 4, 2016 | Research Article | [Check for updates](#)

<https://doi.org/10.1177/1074840716681289>

[Article information](#) ▾



Abstract

Many individuals, including dementia caregivers, use blogs to share their experiences. These blogs contain rich narratives representing an untapped resource for understanding the psychosocial impact of caring for a person with dementia at the family level. The present study used blogs written by caregivers of persons with dementia to explore how these individuals leveraged this medium as part of the caregiving experience. Blogs written by self-identified informal caregivers of persons with dementia were identified using a systematic search method, and data were analyzed using a qualitative thematic analysis. Four themes emerged from the narratives: social support through communication and engagement, information gathering and seeking, reminiscing and legacy building, and altruism. By understanding the ways in which individuals providing care for persons with dementia use social media as part of the caregiving experience, family nurses can develop interventions and services aimed at improving caregiver burden and quality of life.




Themes

- Social support through communication and engagement
- Information gathering and seeking
- Reminiscing and legacy building
- Altruism

Caregivers and Blogs

Original Articles

“A Fine Line That We Walk Every Day”: Self-Care Approaches Used by Family Caregivers of Persons with Dementia

Joel G. Anderson , PhD, CHTP, FGSA , Elizabeth Hundt, PhD, RN, NP-C, ACNS-BC, CCRN-CSC, Morgan Dean, BSN, RN & Karen M. Rose, PhD, RN, FGSA, FAAN 

Pages 252-259 | Received 31 May 2018, Accepted 07 Jul 2018, Published online: 13 Nov 2018

 Download citation  <https://doi.org/10.1080/01612840.2018.1499156>

 Check for updates

 Full Article  Figures & data  References  Citations  Metrics  Reprints & Permissions  Get access

Themes

- Health and wellness
- Altruism and activism
- Reminiscing and legacy building
- Social support
- Information exchange
- Organization and planning
- Spirituality

Caregivers and Blogs

Behav. Sci. 2019, 9(3), 22; <https://doi.org/10.3390/bs9030022>

Open Access Article

“Like Death is Near”: Expressions of Suicidal and Homicidal Ideation in the Blog Posts of Family Caregivers of People with Dementia

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(This article belongs to the Special Issue [Suicide, Homicide, and Self-Harm in Family Carers](#))

 Full-Text |  PDF [264 KB, uploaded 4 March 2019] |  Review Reports

Abstract

Background: The challenges of providing care for someone with Alzheimer's disease and related dementias (ARD) have been associated with increased stress, poor mental and physical health, social isolation, and financial distress. More recently, caregiving has been associated with high rates of suicidal and homicidal ideation, but the research on these phenomena is limited. The present study analyzed a sample of blogs written by family caregivers of people with ARD to explore thoughts of suicide and homicide expressed by these caregivers. **Methods:** Blogs written by self-identified informal caregivers of people with ARD were identified using a systematic search method and data were analyzed using a qualitative thematic analysis.

Themes

- End-of-life care
- Thoughts of death and euthanasia by the person with ARD
- Surrogate decision making
- Thoughts of suicide by the caregiver
- Thoughts of homicide and euthanasia by the caregiver

Caregivers and Blogs

Themes regarding strategies to support caregiving

- Modifying the physical and personal environment
- Engaging the person with ADRD
- Seeking outside assistance
- Using complementary therapies
- Planning and organization
- Reminiscing and traditions

FamTechCare



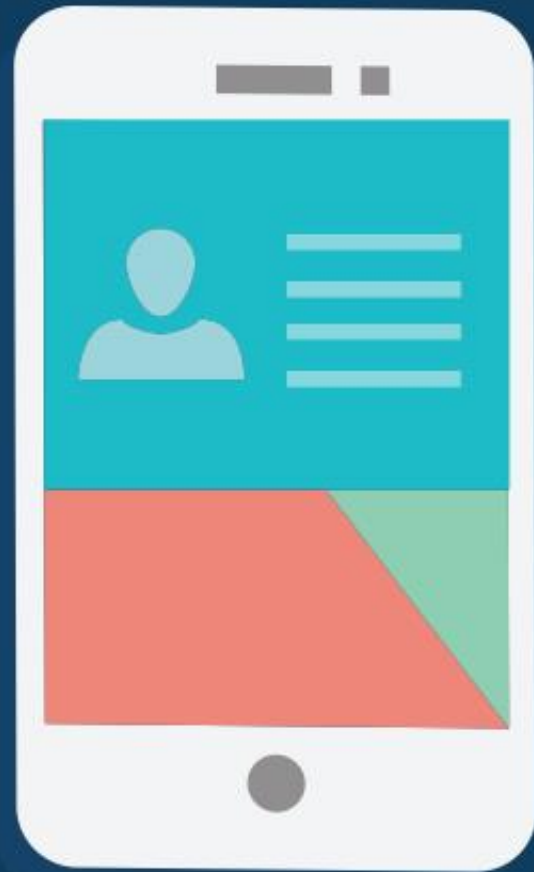
FamTechCare uses new technology to link family caregivers to experts for guidance in managing disruptive behaviors, supporting continued care at home while reducing the negative effects of caregiving.



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Next Steps





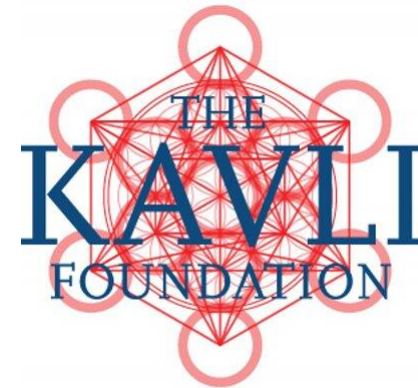
Web- and mobile-based applications

- Can reach a broad audience in a short period of time
- Are easy and affordable to access and use
- Cater to a large variety of audiences

SHAPE of CARE



Funded by the Kavli Foundation, the aim of this project is to develop a mobile app to be used by persons with dementia and their family caregivers to provide support to improve quality of life for patients and their families.



Family Quality of Life for LGBTQ+ Caregivers of People with Dementia



Project Partners



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Photo by Joel Anderson

Tusen
takk!

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