Examination of the effectiveness of web-based interventions that have been developed for informal caregivers of people with dementia: an umbrella review

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Examination of the effectiveness of web-based interventions that have been developed for informal caregivers of people with dementia: an umbrella review

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University of Pittsburgh, 2021

Abstract

The numbers of caregivers for people with dementia (PWD) is at catastrophic levels in the United States. Approximately one in ten families are compelled to be caregivers at any given time due to illness or injury. The majority of PWD are living at home and consequently this forces family members and friends into caregiver positions. Dementia does not strike the population equally. Those at higher risk for dementia are racial or ethnic minorities, those who are poverty-stricken and have lower education levels. America's population of those over the age of 65 will grow exponentially in the coming decades. This will have significantly more impact on the US socially and economically as our population continues to age. The economic value that caregivers provide to PWD in the billions of dollars. Our current formal healthcare system, such as long-term service placements cannot support the placement of this sum of PWD. Most families prefer to keep their loved ones at home as long as possible. Caregivers are crucial to our healthcare system continuing to function financially and logistically. This umbrella review seeks to investigate the results of systematic reviews for web- and internet-based interventions with or without therapeutic intervention to decrease caregiver depression, anxiety, and isolation, and to increase competence and self-efficacy. After following PRISMA criteria of evaluation, results suggest that electronic interventions decrease mental health conditions, while increasing motivation and self-efficacy. Methods include an exhaustive search of Medline (OVID) for systemic reviews, only to find that

previous systemic reviews on this subject matter are limited. Five systematic reviews meet the established *a priori* inclusion criteria. This exemplifies the limited attention to technological interventions in our healthcare system. The public health significance for this topic is that web- and internet-based interventions will serve to reduce the cataclysm of caregivers of PWD that are expected to infiltrate long-term care facilities, thus aiding the social and economic outcomes for the United States healthcare system.

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Preface

I would like to thank my advisor, Dr. Elizabeth Felter, for her help and support. Without her genuine caring and encouragement this process would have been nearly impossible. I would like to thank Dr. Julie Donahue for her excitement about my interest in caregiving policy issues. She helped to keep me get engaged and excited at a time when I had doubts about what I had chosen to do. I would like to thank Dr. Steven Albert whose amazing networking helped me to find a wonderful practicum experience that drove this essay. I would also like to thank Helena Von Ville, from library systems, who worked tirelessly to help me with the search strategy even when I felt we were speaking two different languages! Her patience and empathy will not be forgotten. I would like to acknowledge all the professors, in BCHS and other departments at the Graduate School of Public Health, who assisted me when I was determined to stick with the topic of caregivers even when it might not have fit the exact template for each class. Two of the most amazing TA's I have ever come across – Greg Procario and Jessica Cheng – thank you so much for your dedication and help that went above and beyond the call of duty! This day would not be possible without either of you!

Lastly, I would like to thank my family. My children continually expressed their pride with the decision I made to return to school and take on a new challenge at this stage of my life which touched me deeply. My husband's love and support helped to keep me motivated and on track even at the most difficult times over the past two years. Thank you to all of you, I love you deeply.

1.0 Introduction

An informal caregiver (heretofore referred to as caregiver) is considered an unpaid individual (spouse, partner, family member, friend, or neighbor) who participates in the facilitation of daily living activities or medical tasks. Caregivers experience more depression, anxiety, and health issues than the general population. Most caregivers (80%) are caring for people with dementia (PWD) in their homes.[1] Every year, there are more than 16 million people in the United States that provide over 17 billion hours of unpaid care for family members and friends with dementia.[1] Most caregivers (66%) are women, and 25% of caregivers are "sandwich generation" caregivers which means that not only do they care for an aging parent, but also for children under the age of 18.[2]

The rates of dementia that are being cared for do not strike equally across our population.[3] Populations at greater risk include women, minorities, and older Americans classed as those over the age of 65. [3] For example, a woman's lifetime risk for developing Alzheimer's disease once she reaches the age of 45 is 1 in 5. [4] Women are at higher risk than men for Alzheimer's and symptoms of dementia for several reasons. [4] Women face more challenges than men in their lifetime such as having lower educational levels, fewer economic resources, higher levels of stress, and typically providing more care for their families. [4] Genetics factor into dementia as well. Women who carry a gene called APOE4, which carries fat into the bloodstream, have a greater risk for developing dementia than men with the same gene do. Depression and anxiety are risk factors for the development of dementia, and these mental health conditions are more common for women. [9] Women may be able to mask the early onset stages of dementia due to having better verbal memory at earlier stages then men, thus resulting in later diagnoses for women. [4]

Of importance is the fact that racial and ethnic disparities, particularly older African Americans are twice as likely to have Alzheimer's disease as whites. [4] Hispanics are 1.5 times as likely as non-Hispanics to develop symptoms of dementia. [4] Access to regular health care may be a precipitating factor in this discrepancy that leads to a later diagnosis [4]

As many as one in ten older Americans suffer from dementia, or Alzheimer's disease. [3] Dementia is one of the country's most common health conditions for people over the age of 65. [3] The number of Americans living with Dementia could more than double by 2050. [3] With the bulk of the population aging, our formal geriatric healthcare system will become overwhelmed without the dedication of caregivers. [2] Alzheimer's is the most common cause of PWD. [5] The most common symptoms of dementia include memory loss, difficulty concentrating, difficulty with problem-solving and difficulty with language. [2] Dementia is one of the most common health conditions for family caregivers, those that are often charged with caring for PWD. [3] According to the Center to Advance Palliative Care, dementia is listed as one of the top eight reasons for caregiving. [5] Caregivers spend an average of 24 hours a week providing care and support for their charge, but that number is an underestimate due to self -report and the duties that are not often considered. [3]

AARP and the National Alliance for Caregiving did a special survey report in 2020, to document the mental and physical effects of caregiving for someone with dementia. They found that 36% of family caregivers described their circumstances as "highly stressful".[6] Since the study began in 2015, the proportion of caregivers that described their health as excellent or particularly good has fallen from 48% from 41%. [6] Caregivers describe depression, mood swings and resentment as a result of their caregiving duties. [6] Finally, the American Psychological Association, found that for those aged 55 to 75, those who are caregivers are 23% more likely to

have a high level of stress hormones leading to high blood pressure, as well as a 15% lower immune response making them more vulnerable to infectious disease. [6]

1.1 Historic interventions for caregivers of dementia

Caregivers of PWD need assistance with education of the symptoms and progression of dementia as well as the basics of caretaking duties that will be undertaken while caring for someone with dementia at home to avoid caregiver burnout. [6] Caregivers need social, or peer supports to rely on so that they can share what they are experiencing with another person. [3] Caregivers of PWD need to be aware that increased depression, anxiety, and decreased self-efficacy are normal life stressors. [5] Caregivers may need to seek outside help for their own self-care. [5]

Historically, the approach to caregivers of PWD was psychosocial. An intervention would work to improve ways that an individual interacts with their environment by exploring underlying feelings and motivations that may be aiding or blocking certain behaviors. In order to do this type of intervention there is a painstaking process of face-to-face evaluations and assessments of the identified person seeking treatment (the caregiver) and how they function within their social structures. One of the main goals would be to achieve the best adaptation of the person in their environment.

For caregivers of PWD, this would likely involve individual, family and group therapy. Group sessions would often be educationally based, regarding dementia, family relationships, and communication methods. Caregivers are overwhelmed by the multitude of tasks they have and the shortage of time, making this a difficult and overwhelming approach. While these skills are

valuable, to an already overwhelmed caregiver the time commitment may add to attrition in therapy.

The circumstances of COVID-19 have brought to light a revolution of technological mainstreaming for therapeutic interventions. Caregivers often have difficulty leaving care recipients (PWD) home alone without being tended to. Technological interventions have offered caregivers the opportunity to be assisted with managing behaviors of PWD, education of dementia and peer support while they remain at home. According to Mather and Scommegma, researching ways to make the lives of caregivers easier is a "duty of our public health system".[2] Studies investigating interventions with caregivers and the use of technological interventions are growing in our country. The aim of this study is to determine whether a web- or internet-based intervention that includes instruments of education, peer support, and resources will positively influence outcomes for caregivers of PWD including decreased depression and anxiety, and increased self-efficacy of the caregivers being studied.

2.0 Literature Base

2.1 Definition of Dementia

The National Institute of Health and the Alzheimer's Association divide stages of dementia into three categories of Alzheimer's.

- Preclinical: Some brain changes may be in progress, but indicative clinical symptoms are not yet distinct [8]

- Mild cognitive impairment (MCI): Memory loss or other cognitive issues are greater than normal for the patient's age and education however they do not inconvenience their level of independence. [8]

- Alzheimer's dementia: The final stage of dementia including significant memory loss, difficulty with word recall, visual or spatial difficulties which are notable enough to impair a person's ability to be independent. [8]

Dementia is a generic designation of symptoms. [3] The symptoms that dementia describes are those that are caused when otherwise healthy brain cells are damaged and lose communication capabilities with each other. [3] These changes will likely cause deterioration over time, thus leading to difficulties with memory loss, thinking disruption, and behavior changes. [3] These subtle changes can also cause hallucinations and delusions. [3] Roughly 33% of those with dementia will experience hallucinations and delusions once dementia has progressed. [3]

2.2 Different types of dementia

There are other types of dementia that cause people to experience symptoms. [8] Vascular dementia is a type of dementia describing difficulties with reasoning, planning, judgment, memory, and general thought processes caused by damage to the brain from reduced blood flow.[8] The most common cause of artery blockage to the brain is a stroke, and the severity and location of the stroke may determine a person's ability to think and reason. [8] A characteristic that is unique to vascular dementia is that unlike Alzheimer's related dementia thought processes decline in noticeable steps, while with Alzheimer's related dementia there is a steady decline that is noticeable. [8]

There is a type of dementia called dementia with Lewy bodies Disease. [8] Lewy bodies dementia is considered the second most common type of progressive dementia after Alzheimer's related dementia. [8] Lewy Bodies are small proteins that develop in the brain, and can account for modification to brain cells leading to problems with memory, thinking, sleep and movement. [8] Parkinson's disease can be another cause of Lewy Bodies dementia. [8] People with Lewy bodies disease experience problems that affect movement, memory, thinking, changes in alertness and attention, rigid muscles, slow movement, tremors, and hallucinations. [8] Lewy bodies dementia is progressive and can cause severe dementia, aggressive behavior, depression, increased risk of falls, and typically causes death approximately eight years after the onset of symptoms. [8]

There is a cause of dementia called frontotemporal dementia. [8] This type of dementia leads to changes in the front and sides of the brain that affect behavior, personality, and language difficulties. [8] Frontotemporal dementia is a result of portion of the frontal and temporal lobes of the brain shrinking. People with this affliction may have drastic changes in their personalities and become socially inappropriate, impulsive, or emotionally indifferent, or lose the ability to use

language properly. [8] A risk of this type of dementia is that patients may be misdiagnosed as psychiatric patients, or as having Alzheimer's disease. However, Frontotemporal dementia occurs at younger ages than Alzheimer's related dementia, usually between the ages of 45-65. [8]

2.3 Demographics of Caregivers

In 2019, as baby boomers (those now aged between 55 and 73) age they bring new challenges to the country's aging population. [3] In 2014, 40% of people aged 55 and older were still working or actively looking for work. [3] This number is referred to as the labor force participation rate and is expected to be one of the fastest growing segments of the working population through 2024. [3] By 2026, there is a projection of workers aged 65 to 74, and 75 and continuing to rise to explosive proportions. [3] Many workers will be employed past the time that they are eligible for social security benefits. [3] Caregivers will need to deal with employment issues more than ever before while also caring for their loved ones. [3] There is an implication that individuals in the workforce could be experiencing the beginning stages of dementia themselves which clearly could be problematic. [3]

In 2015, there were 15.7 million Americans caring for a recipient over the age of 50 that had dementia. [2] According to the Center to Advance Palliative Care, dementia is listed as one of the top eight reasons for caregiving. [10] Caregivers spend an average of 24 hours a week providing care and support for their charge, but that number is an underestimate due to self -report and the duties that are not often considered. [10] A recent survey of caregivers conducted by the National Alliance for Caregiving and AARP Public Policy Institute indicated that roughly 50% of informal caregivers provided care for less than 12 months, while 25% provided care for at least five years.[10]

The economic value of care provided to recipients of dementia was $217.7 billion in 2014. [1] With the population aging at such an accelerated rate, it is not known how much this amount might multiply. [2]

2.4 Women as Caregivers

Women who are caregivers have unique situations. Some studies demonstrate that 53-68% of caregivers are female caregivers and that they take responsibility for more physical caregiving duties such as bathing, toileting, and dressing. [11] When women take on the role of caregiver, they are 2.5 times more likely to live in poverty compared to women who are non-caregivers. [11] The monetary cost to women caregivers alone based on lost wages and Social Security benefits is $324,044 for the lifespan of caregiving, averaging at about $11,000 per year. [11] Research indicates that 54% of female caregivers have one or more chronic health conditions themselves, compared to 41% of non-caregiving women. [11]

More than 96% of all caregivers provide help with activities of daily living (ADLs) such as personal hygiene, dressing and undressing, getting in and out of bed, medication management, grocery shopping, transportation, or using technology. [2] Nearly 2/3 of female caregivers are employed, yet they come from disproportionately lower income households. [9] They live at under twice the federal income poverty level. [11] The monetary cost to women due to lost wages and Social Security benefits over a lifetime is $324,044. [11]

Female caregivers have physical and mental health issues that surface due to the added stress of caring for a chronically ill family member. [11] They are shown to have increased alcohol and substance use. [11] Along with recipients they report chronic conditions such as heart attack/heart

disease, cancer, diabetes, and arthritis, at nearly twice the rate of female non-caregivers (45% vs 24%).[11] Caregivers report increased rates of physical ailments such as acid reflux, headaches, and general pain or achiness.[2] They have an increased tendency to develop serious illness and have high levels of obesity and body pain.[2] Research indicates that female caregivers have lower immune responses which puts them at risk for frequent infection, slower wound healing, and higher risk for cancers.[2] Women who are caring for a spouse for more than nine hours a week double their risk of having a heart attack or diabetes.[2]

Race is a factor of the dispersion of caregivers in the United States. In America, 62% of adult female caregivers identify as White, 13% identify as African American, 17% identify as Hispanic and 6% identify as Asian-American.[2] As the population ages, it will become more racially diverse, with projections that those that are non-Hispanic whites will drop from 77% to 55%.[9] More than half of caregivers that are African American care for an older adult and a child under the age of 18 at the same time. This is referred to as "sandwich caregiving"[2] More than 11 million women in America, 25% of all caregivers, are caring for an adult family member while simultaneously caring for children at home.[2] Historically in the U.S. minorities have difficulties accessing health care due to mistrust of the healthcare system.[2] The level of mistrust factors into the sandwich caregiving generation.[2]

2.5 Theoretical Model

The theoretical model approach to technological advances for adult caregivers is an important factor. It is necessary to provide caregivers with education of dementia and peer support, and to simultaneously decrease their depression and anxiety, and increase their self-efficacy.[12]

One theoretical model that serves this purpose sufficiently is the andragogical theory of learning.[12] Between 1980 and 1984, Malcolm Knowles created five assumptions of adult learners. The five assumptions of adult learners are that they (1) have an independent self-concept and can direct their own learning, (2) have accumulated a reservoir of life experiences that are rich resources for learning, (3) have readiness to learn due to tasks related to their changing social roles, (4) are problem-centered and interested in immediate application of knowledge, and (5) are motivated to learn by internal rather than external factors [12] As part of this model, adults feel "accepted, respected and supported.," and since adults are responsible for managing many areas of life, they are also capable of conducting and planning their own learning. [12]

There are four principles of andragogy that are also applied to adult learning that encourage electronic interventions for caregivers of PWD. First, adults are involved in the planning of their education and interactions so that topics are salient to them. [12] In other words, they only seek out subject matter that they find useful. Second, the experience of the education and interactions, including any past mistakes made are part of the basis for learning activities and self-acceptance.[12] Third, adult learners are engaged in subjects that are immediately relevant and impactful in their lives. [12] Finally, adult learning is problem-centered as opposed to content oriented. [12]

An example illustrating the use of andragogy in healthcare would be use of digital interventions by aging populations. [12] Technological interventions are a likely advantageous and attractive method of promoting self-care and self-management using electronic methods such as the internet, mobile phone utilization, and text messages. [12] Electronic interventions offer the availability of clinicians to check in on the progress of patients. [12] Internet-based interventions have the advantage of offering self-care information, education, behavioral support, and peer support to patients that are ready to engage. [12]

Electronic interventions are incredibly cost-effective when compared to face-to-face visits since once the platform is created, patients can access them an infinite number of times without the worry of staffing, room requirements and copays. [12] Technological interventions can work as an accompaniment to clinician-delivered interventions, by delivering routine aspects of education and intervention, changing health behaviors, and allowing clinicians to focus on potential complex tasks like care recipient progress and the functioning of the family unit. [12] Another cost reductive factor is the reduction of the need for paper-based information being printed out for each patient.[12] There is no longer a need for production, printing, and distribution of large amounts of costly hard copy materials after face-to-fact visits because patients can access web-based interventions 24-hours a day when they might normally find it difficult to find time to schedule in-person visits. [12]

Electronic interventions have the advantage of reaching numbers of people that current medical and mental health clinicians could not possibly reach. [12] Bradbury suggests that "most households in the Western World have access to the internet; over 71% of households have accessed the internet in the United States, adding that over 90% of the population currently have access to and use mobile phones." [12] Parts of electronic interventions can include text, pictures, interactive videos, sessions, or goals. For example, a user might take in a session on healthy eating.[12] This might include several pages of educational information about food groups and then a guide to setting goals. [12] Questionaries could be included about current behavior, tracking food choices, and an active plan to change habits. [12] This information can be shared with a clinician for feedback of personalized emails or text messages to offer support or suggestions. [12]

Data can be collected quantitatively and qualitatively. As Bradbury describes there are deductive and inductive techniques to gathering data that will result in quantitative and qualitative results accordingly for interventional research purposes. [12] These findings would need to be

gathered to create the best plan of intervention to serve the maximal effectiveness, acceptability, and feasibility of the intervention for the patient population. [12]

3.0 Methods

This study used an umbrella review, (a systematic review of reviews) to investigate the effect of technological interventions with caregivers of PWD published between 2005-2020 (see Table 2). Umbrella reviews offer a way to review data regarding electronic interventions for caregivers comparing existing published results. [13] Umbrella reviews give a researcher the chance to review what systematic reviews have shown in the past. [13] Doing an umbrella review with reproducible methods by determining eligibility criteria *a priori* of a search allows the researcher to gauge the risk of bias. [13] An umbrella review, allows the intention to collect, analyze and present descriptive characteristics of the systematic reviews and important clinical outcomes. [13] Findings will be discussed as they relate to the purpose, objective, and research question regarding the effectiveness of technological interventions for caregivers of PWD scaling the caregiver's levels of depression, anxiety, and self-efficacy. [11]

The search strategy included key-terms and database specific terminology**.** A literature review was conducted using Medline OVID and NCBI. The following table (Table 1) displays the terms that were used in the OVID search. The NCBI search used the keywords *caregiver, dementia, web-based, internet, systematic, and meta-analysis.* Any additional articles were extracted using the reference lists at the end of key articles. Articles were limited to those published in English from 2005 to 2020. The search terminology for the OVID search engine included:

Table 1 Medline (OVID) Search Strategy

1	Caregivers/
2	(caregiver* or caregiving or care partner* or (care adj1 giver*)) ti, ab, kf
3	1 or 2
4	(family or father* or grandmother* or grandfather* or husband or informal or mother* or spouse or unpaid or wife). ti, ab, kf
5	3 and 4
6	internet/ or internet access/ or internet-based intervention/ or social media/ or computers/ or microcomputers/ or computers, handheld/ or smartphone/
7	(internet or online or web). ti, ab, kf
8	6 or 7
9	5 and 8
10	limit 9 to English
11	limit 10 to yro-"2005-2020"
12	"systematic review". Pt. or "Systematic Reviews as Topic"/ or (data adj2 (extract or extracting or extractings or extraction or extraction)). ti, ab, kf. or ((cochrane adj2 database adj2 systematic adj2 reviews) or (evidence adj2 technology adj2 assessment)).jn. or (((comprehensive* or integrative or mapping or rapid or scoping or systematic or systematical or systematically or systematicaly or systematicly or umbrella) adj3 (bibliographical or bibliographically or bibliographics or literature or review or reviews)) or (state adj3 art adj1 review) or (research adj2 synthesis) or ((data or information) adj3 synthesis)). ti, ab, kf. or ((review adj3 (rationale or evidence)).ti,ab. and "review".pt.) or (cinahl or (cochrane adj3 (trial or trials)) or embase or medline or psyclit or (psycinfo not (psycinfo adj1 database)) or pubmed or scopus or (sociological adj1 abstracts) or (web adj2 science)).ab. or "MetaAnalysis".pt. or "meta-analysis as topic"/ or "network meta-analysis"/ or ((meta adj2 (analyse or analyser or analyses or analysis or analytic or analytical or analytics or analyze or analyzed or analyzes)) or metaanalyse or Metaanalysen or metaanalyser or metaanalyses or metaanalysis* or metaanalytic or metaanalytical or metaanalytics or metaanalyze or metaanalyzed or metaanalyzes).ti,ab,kf

13	11 and 12
14	(dementia or Alzheimer*).ti.ab.kf.

When undertaking evidence-based research, it is important to address a clinical question that is relevant to a specific patient or problem in the population that is being studied. The pneumonic tool "PICO" assists the researcher with this process, by identifying the key impressions that answers that clinical question. [14] "Building good clinical questions usually involves three out of the four elements of PICO. [12]

PICO rules were here as follows. The studies were limited to English to be considered for this umbrella review. Outcomes (O) will ideally decrease depression, anxiety, and isolation for caregivers (P) of PWD and increase self-efficacy in the same caregivers leading to an increased quality of life via a (I) technological intervention that is web-based or via the internet aimed at caregivers.

3.1 Search Strategy

We have examined previous systematic studies that have done internet/web-based intervention with caregivers of PWD to determine if they assist in education, peer-support, and resource assistance. Our goal was to ascertain what, if any gaps existed in ongoing research using the PRISMA protocol. The PRISMA protocol is the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Protocols. [13] This was used *a priori* to determining eligibility criteria. (Moher, D et al, 2015) The protocol helps to reduce any capricious decisions that might be made during data extractions. [13] Duplication of materials provided the benefit of reducing the

dilemma of bias related to data selection during the research process. [13] It was imperative that the systematic review protocols occur prior to the definition of eligibility criteria, in consonance with meticulous approaches as delineated by associated protocols. [13] The groundwork of a protocol was a fundamental ingredient of the systematic review process. [13] It established that a systematic review was deliberately prepared and that what was prepared was documented a priori to the review, upholding fidelity, accountability, research, integrity, and transparency. [13]

3.2 Eligibility Criteria

The first criteria on the PRISMA checklist were that of Identification. [13] We had already identified this report as a systemic, or umbrella, review. The next criteria that we used was PRISMA rationale to describe the rationale for the review in the context of what was already known. We collected systematic reviews that already existed on web-based/internet interventions for caregivers of PWD to collect the studies that already exist and the gaps there may be in existing research. We also provided an explicit statement of the question the review will address with reference to PICO elements. (P-Participants, I-Interventions to be used, and O-Outcomes expected for this example) we will specify the study characteristics (such as PICO, study design, setting, and time frame) to be used as criteria for eligibility for the review.

The eligibility criteria were:

Included

- All reviews considered were systematic or scoping reviews.
- Presentation assessing the effectiveness of an intervention that includes Population, Intervention, Comparator, and Outcome (PICO) elements

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- Systematic reviews that addressed a question that would include qualitative PICO elements.
- Systematic reviews with qualifying criteria such as age (over 18)
- Systematic reviews with interventions that were electronic – either web-based or over the internet
- Systematic reviews that were limited to English
- Systematic reviews that had taken place within a community setting such as the caregiver's or care recipient's home
- Systematic reviews that reported an outcome from the technological intervention
- Systematic reviews that included participants that are informal caregivers (non-paid)
- Systematic reviews that included care recipients who are experiencing dementia,
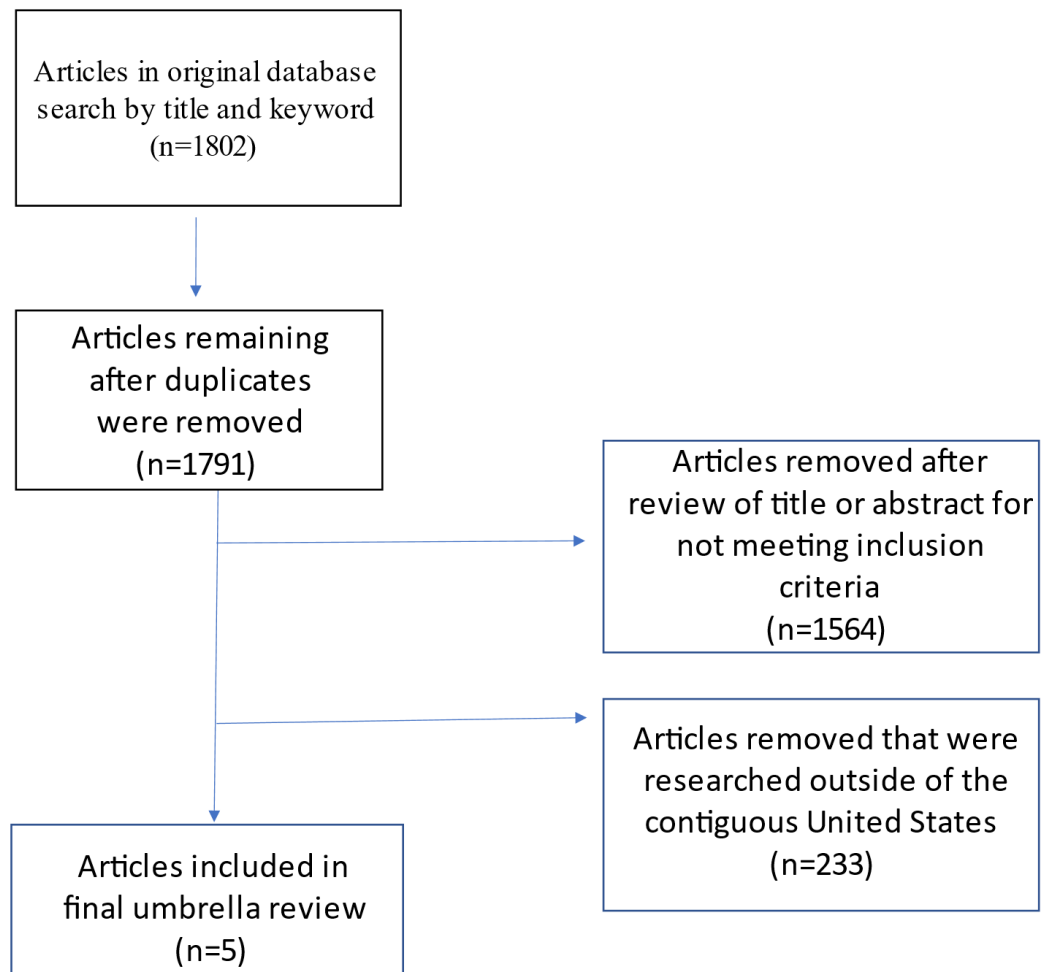.

Excluded

- Systematic reviews that incorporated theoretical studies or published opinion as their primary source of evidence
- Reviews that were not systematic reviews
- Systematic reviews that were prior to the year 2005
- Systematic reviews that were not in English
- Systematic reviews that were outside of America
- Systematic reviews that included paid caregivers
- Systematic reviews that included care recipients that do not exhibit dementia
- Systematic reviews where care recipients were in daycare or acute care.
- Systematic reviews that had primary interventions such as face-to-face or group contact that was not initiated by electronic means.

The resources were used by describing the databases with the dates of coverage. This included a present draft of search strategy to be used from the OVID (Medline) search engine so that it may be repeated. Lists and definitions of all outcomes for which data was sought, including prioritization or main and additional outcomes with rationale showing both benefits and harms of interventions was investigated. The risk of bias, describing anticipated methods for assessing risk of bias of individual studies was also investigated.

3.3 Data Management

Data was gathered and managed manually, resulting in a synthesized PRISMA flow chart. (See Figure 1) We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Protocols 2015 (PRISMA-P 2015) *a priori* to determining eligibility criteria. [15] One elemental piece of PRISMA-P is the PRISMA checklist. [15] The checklist consists of 17 items that may or may not be used by authors who intend to further the establishment of concentrated reporting and protocols for a systemic review. [15] Listed, are the items on the PRISMA checklist that have been designated for this paper: 1a) Identification: this review will be an umbrella review of systematic reviews based on electronic interventions (web- or internet-based) for caregivers of PWD; 6) Rationale: this umbrella review will investigate prior research of electronic interventions for positive and negative outcomes to see if there are any gaps in outcomes; 7) Explicit statement of the question including Participants, Intervention, Comparators (if relevant), and Outcome (PICO): does an electronic intervention (I) that offers education, peer support, and resources decrease levels of depression and anxiety and increase self-efficacy (O) in caregivers of PWD (P)?; 8) Specify study characteristics: the study characteristics include the use of PICO that are significant in the course of an umbrella review of caregivers of PWD between the years of 2005-2020?; 9) Information Sources: Medline/OVID will be searched between the years of 2005-2020; 10) Search Strategy: the search will include concepts such as MeSH, caregivers, internet, English, 2005-2020, systematic reviews and the draft search can be seen on Table 1; 11a) Data Management: the mechanism that will be used for data management will be an Excel Worksheet and a PRISMA flow chart; (See Figure 1) 11b) Selection Process: studies will be selected based on title and context screening if they meet inclusion eligibility; 11c) Data collection process: planned method of extracting data from reports will be manual; 13) Outcomes: data will be sought for any outcomes

that include results from interventions that were web- or internet-based. This will be true regardless

of whether outcomes are beneficial or harmful; and 14) Risk of bias: risk of bias will be assessed

by comparing studies in a critical manner both at the outcome and study level. [15]

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Figure 1 PRISMA Flow Chart

4.0 Results

There were five articles reviewed for this essay. See [Table 2](#) Literature Synthesis for an illustration of the synthesis of the articles that were used for the review of this paper. All but one study used a Random Controlled Trial to determine if a web- or internet-based intervention would best serve the caregiver of PWD population. The fifth study attempted to evaluate a systemic review of literature on eHealth interventions, to identify determinants of successful implementation using the Consolidated Framework of Implementation Research Theory (CFIR). Christie et al. determined that little attention had been paid to implementation theory overall. The authors noted that electronic interventions are a positive format for caregivers of PWD but stressed that the need for implementation strategies cannot be ignored in the process of evaluating electronic interventions for caregivers. [14] The four remaining articles were systematic reviews of RCTs. The aims of the interventions that remained varied slightly, but generally focused on the well-being of the caregiver. These included the assessment of efficacy of internet-based interventions in ameliorating health outcomes, [15] evaluating effects of internet-based supportive internet access, [15] describing the literature of online learning, [15] identifying gaps in literature, [15] present recommendations for caregivers of PWD, [16] improving client engagement and accessibility, [17] lowering delivery costs,[18] improving contact with health providers, [17] improving peer interactions, [17] increasing level of information/education, [17] increasing level of perceived decision support, [17] and increasing psychological support. [17] Two of the four reviews, Leng and Pleasant, included measures to determine effects of the intervention on the care recipient as well.[16-17]

The outcome measures for each of the four remaining reviews were similar. Outcome measures included determinations for levels of depression, anxiety, stress, self-efficacy, burden, and quality of life. [15-18] Four reviews indicated reduced levels of caregiver anxiety because of the electronic interventions. [15-18] Three of the four reviews showed decreased levels of caregiver depression. [15-16,18] Two of the four showed reduction in overall caregiver stress and burden, with increased self-efficacy. [15,17] Only one review showed and overall increase in the general quality of life. [17] The two reviews that took care recipients into consideration determined that electronic interventions with caregivers had potential benefits to decreasing neurobehavioral psychiatric symptoms and general stress in the recipients of care. [15,17]

More specifically, Leng et al discuss Internet-Based Supportive Interventions for Family Caregiver of People with Dementia: Systematic Review and Meta-Analysis. Leng began with a count of 9110 studies upon the initial database search, with an additional 7 identified through other sources. [21] For duplication purposes, 3412 studies were removed. [21] Records were then reviewed by title and abstract and 5516 were excluded. [21] There was a full text review of the remaining 182 records. During the full text review, 165 records were excluded because participants were family caregivers of people with other chronic diseases (n=36), participants were professional dementia caregivers (n=9), the interventions was not delivered via the internet (n=26), outcomes were only related to suer feasibility or friendliness (n=14), the study design was not an RCT (n=57), the study protocols were not acceptable (n=16), and review of the articles (n=7). [21] The number of articles left for Leng to review was 14.

This review explored not only the effects of personalized and generalized formats of internet-based supportive interventions significantly reduced such symptoms as depression and perceived stress. [21] Leng also stated however, that evidence failed to support the efficacy of

internet-based supportive interventions on caregiver burden, coping competence, caregiver

reactions to care recipient behavioral symptoms, or their quality of life. [21] Subgroup analysis also

shows that both personalized and non-personalized formats of interventions had significant

beneficial effects on depression and perceived stress. [21] The effect size of the non-personalized

format compared with the combined effect size of the personalized format was larger, meaning

that personalized format intervention was more beneficial for dementia caregivers. [21]

Christie et al authored A systematic review on the implementation of eHealth interventions

for informal caregivers of people with dementia. The focus was on trying to identify determinants

of successful outcomes for caregivers of PWD. They found 46 articles with 204 statement on

implementation to include in their systematic review on implementation theory relating to eHealth

of caregivers for PWD, and grouped them into four categories: 1) Determinants of successful

outcomes associated with eHealth applications; 2) informal caregivers; 3) organizations that use

implementation theory during their interventions; and 4) interventions that do not fit into the

previous three categories and must be investigated based on determinants of a wider context.[22]

These authors included studies in their systematic review that were after 2007. [22] Christie et al

picked this date as they felt that any studies from more than ten years prior to publishing their

study would be outdated. [22]

Christie's analysis was mapped onto the Consolidated Framework for Implementation

Research (CFIR). Mapping the four specified determinants revealed that most focus was the

characteristics of the intervention and the caregiver while limited attention was paid to the

organizational and wider context determinants. [22] Given that the dementia population is expected

to grow threefold by 2050, Christie et al felt the need for increasing innovation in the field of

eHealth research. They define 'eHealth' as "the use of information and communication

technologies for health" which originally came from WHO in 2018, being described as behaviorally based and transforming delivery to the internet. [22] Transforming interventions to the internet greatly increases accessibility to underprivileged communities, rural communities, and those who would have difficulty seeking successful face-to-face interventions. [22] Interventions can be in many forms such as online courses for tablets or smartphones. Increasing the modes of contact helps to increase accessibility for both peer and psychological support because the interventions have a lower threshold for access of participation and the ability to reach more isolated populations that might normally struggle to access traditional services. [22]

Their analysis was mapped onto the Consolidated Framework for Implementation Research (CFIR). Mapping the four specified determinants revealed that the most focus was on the characteristics of the intervention and the caregiver while limited attention was paid to the organizational and wider context determinants. [22] Christie et al found that the largest thematic category for the determinants was 'Characteristics of the eHealth application', as 116 of the 204 determinants fell into this category. [22] In terms of the development process of the interventions, the importance of user-involvement throughout the process, and allowing for enough time to improve the website were recurring and identified as important factors. [22]

Two of the original 46 references were implementation studies. best applied to this population group. [22] Interestingly, only one study of the 46 references had the word 'implementation' in its title. That fact suggests that implementation research with eHealth interventions for caregivers of PWD is still in its infancy as stated by the authors. [22] While they determined that this study did not show results that they had expected, they did stress that future research should stress a focus on implementation theory relating to caregivers of PWD. [22] Christie et al concluded that eHealth interventions are encouraging for improving the lives of caregivers

and reducing strain on health care services by enabling caregivers to keep their loved ones at home longer. [22] They emphasize, however, that it is imperative that future research prioritizes implementation research and evaluates barriers and facilitators to long-term use in the community.[22] Finally, they believe that without implementation and evidence-based strategies, researchers that are developing eHealth interventions for caregivers of PWD will find it hard to engage the necessary stakeholders of the necessity of their use, thus allowing innovative interventions to make a difference in the lives of the caregivers who would benefit from them. [22]

Hopwood et al initially identified 2325 studies for their systematic review, Internet-Based Interventions Aimed at Supporting Family Caregivers of People with Dementia: Systematic Review. [23] They included 40 articles for their final review.[23] The interventions that they studied varied in the types and number of components, duration and dose, and outcome used to measure effectiveness.[23] The different interventions focused on contact with health or social care providers, peer interaction, provision of information, decision support and psychological support. [23] Hopwood determined that the overall quality of the studies was low. [23] This made interpretation and the ability to generalize the results of the findings difficult. [23] However, most of the studies suggested that the interventions might be beneficial to the caregivers' well-being for such things as positively impacting depressive symptoms, anxiety, and burden. [23] Several small RCTs suggested that the support that was provided online was of particular benefit. Online information was seen as most beneficial when it was personalized specifically for each individual and used as a portion of a multicomponent intervention. [23] Support groups that were provided online were appreciated by most participants and showed positive effects on stress.[23] Online guidance by a professional was valued by caregivers viewed it as additional personalization and emotional support, leading to a reduction in overall caregiver burden. [23]

Hopwood and colleagues intended to identify the key components of existing internet-based interventions to support caregivers of PWD, develop an understanding of which components are most valued by caregivers, and consider the evidence of effectiveness of internet-based interventions that are designed to support caregivers of PWD. [23] Previous research had focused on the effectiveness of interventions; however, these had neglected to perform thorough descriptions of the content of the interventions and their acceptability by caregivers. [23] Most of the interventions were designed to be personalized. Whether it was to address the needs of the caregivers who were providing care to people with different stages of dementia, offering bilingual websites, addressing the needs of caregivers from minority ethnic groups, restricting the intervention to caregivers experiencing stress, burden, depression, or anxiety.

Outcome measures showed a large variation, such as data on the benefit of the interventions, the impact on well-being, quality of life, burden, competence, and physical and mental health. Rating scales were used to gauge the impact of the interventions based on thematic appraisals in five categories: 1) peer support, 2) contact with a health or social provider, 3) provision of information, 4) decision support, and 5) psychological support. Some themes were in a public or private forum accordingly where the caregiver could choose the platform, such as peer support. Others, such as provision of information, served more practical purposes. For some caregivers, this may be the only reason for the intervention, and part of the explanation for rates of attrition in an intervention. For other caregivers, these RCTs are multicomponent interventions that included the provision of information and established positive impacts on depression, anxiety, and stress. [23] Caregivers did express frustration when they were required to review information that did not meet their specific needs. [23] When the information was more individualized, caregivers

considered it more useful, which proposes that information is an important part of interventions, but that personalization should also be a focus of the intervention. [23.]

In Effectiveness of online dementia caregivers training programs: A systematic review, Pleasant et al stated that it was widely theorized that psycho-educational educational training programs improved dementia care, and that a developing method to disperse educational content to caregivers was via the internet. [24] As Christie declared, Pleasant and colleagues stated that online training allows for education to extend to rural and underpopulated areas where, for instance, geriatric specialists are not likely to be available, and in geographic areas where interdisciplinary perspectives and resources might not be available. [24] Again, this speaks to the accessibility and personalization that web-based interventions offer to interventions that might not otherwise be available.

Pleasant examined studies from the years 2000-2016, with the feeling that prior to the year 2000 remote interventions were delivered primarily through CD-ROMs. [24] The initial sample size for this systematic review was 368. Due to duplication, 118 studies were removed. [24] After an abstract review, 198 studies were removed for not meeting eligibility requirements, leaving 52 articles. [24] The remaining articles underwent a full-text review for eligibility at which point an additional 34 articles were disqualified for reasons of eligibility leaving a final count of 18 articles for this systematic review.

There were many interactive platforms with video and audio lessons that were found during this review. Interactive exercise included quizzes, activities, exercises, online forums, and homework. [24] Three of the studies included a live facilitator who was able to provide feedback on interactive activities and was available for consultations and questions. [24] Feedback highlighted the importance of the interactive and personalized component among the studies. [24] Repeatedly,

this stresses the usefulness of individualizing caregiver interventions to affect outcome measures. Guided learning was used more frequently by more experienced caregivers, suggesting that newer caregivers were interested in all the facets of the training while more experienced caregivers were more interested in customized the training based on their own specific needs. [24]

All the studies in the Pleasant review described the intervention and the control groups. Half of the sample demonstrated that the control and intervention groups were similar at baseline or were at least able to describe how differences were controlled for in the analysis. [24] The entire sample was available to perform short-term follow up surveys, and one study was able to perform a long-term follow-up.

There were nine outcomes of interest for Pleasant's review. They included knowledge, competency, self-efficacy, caregiver burden, caregiver stress, depression, anxiety, care recipient status, and satisfaction. [24] Results included that four of the studies had a mix of significant and non-significant findings. [24] Two of the studies did not have significant main outcomes. [24] The most widely used outcome was knowledge which was evaluated in 63% of the trainings and improved in 75% of studies post-training. [24] Self-efficacy was evaluated in 37% of the studies with positive gains reported in 86% of caregivers post training. [24] Caregiver stress and burden were included as outcomes in 26% and 16% respectively. [24] Two studies decreased caregiver stress and two had mixed results. [24] Caregiver burden was relieved in two out of three studies, and caregiver competency was appraised in three studies, with improvement shown in one study. [24] Care recipient status was a result that was shown in four studies as the frequency of behavioral and memory problems that are often associated with dementia. [24] In addition, two studies showed improvement in behavioral and psychological symptoms of dementia as rated by the caregiver. [24]

In sum, Pleasant et al describes the internet-based interventions as a "strength, with its ability to reach caregivers across the globe and to disseminate high-quality content to caregivers."

Scott et al authored caring for the carer: a systematic review of pure technology-based cognitive behavioral therapy (TB-CBT) interventions for dementia carers. In "Caring for the Carer" Scott et al determined that face-to-face delivery of cognitive behavioral therapy is not necessarily optimal for caregivers. They believe that technology-based formats of CBT have been developed with the idea that client engagement can be improved and made more accessible, with lower delivery costs, and probable benefits for caregivers. [25] Scott and colleagues performed a systematic review of trials of TB-CBT interventions for caregivers of PWD from 1995. They initially found 442 articles. [25] Once acceptance criteria were enforced, they secured studies if quantitative data was accessible, and if there was no active therapist. [25] Four articles were used for this systematic review. Two of the trials were randomized and two of the trials were waitlist control trials. [25]

Scott's groups began by explaining that a tailored CBT intervention was more effective than a traditional CBT intervention. [25] The explanation of traditional CBT included a background of 50 RCTs focused on improving adjustment for caregivers. [25] These interventions are typically given in a group format, across several weekly sessions, focused on improving psychoeducational discussions about dementia, proficiency instruction, relaxation, and conflict resolution, all to enhance caregiver coping. [25] Meta-analytic data promote that CBT-based intervention are successful in generating short-term benefits for caregivers that are significant. [25] Some of these benefits would include reduced burden, depressions, and anxiety, and increased well-being. [25] More significant outcomes have been found in CBT interventions that have been tailed to meet personal needs and conditions for each caregiver and care recipient. [25] Personalized CBT

interventions have been shown to also reduce depression, improve mood and self-efficacy, and decrease behavioral and psychological symptoms in the care recipient. [25] In addition, these affects have lasted longer, being sustained at three and four-year follow-ups. [25]

The high costs of face-to-face CBT delivery is prohibitive. [25] High costs are not just monetary but include the fact that face-to-face delivery is not always ideal as there are many things to consider. [25] One thing to consider is the high cost of delivering the intervention such as overhead, but there is also the high refusal rate to group-based CBT, particularly for the male population. [25] One must also consider the difficulties that people outside of metropolitan areas may have attending face-to-face interventions. [25] Lastly, the restrictions of being a caregiver make it difficult to attend face-to-face interventions. [25]

Alternative approaches that can be used to improve caregiver engagement are desirable. Technology-based CBT is one of those alternative approaches. [25] TB-CBT involve similar content as face-to-face CBT programming, and they have the potential to reach larger numbers of caregivers. [25] Technologically based interventions have been shown to be effective to decrease depression. [25] It provides easy access to evidence-based CBT intervention for a large population at a greatly reduced cost. [25] The ability to provide cost-effective interventions is vital if the needs of caregivers rise as they are expected to do. [25] Scott et al surmise that TB-CBT , might serve as a first level of intervention in a universal intervention system for caregivers of PWD. [25]

Scott and his group were tentative giving positive outcome measures. The TB-CBT interventions may exhibit a possible impact in lowering caregiver depression. [25] However, with such a small sample size and such a small number of participants, they hesitate to make conclusions about the efficacy of the TB-CBT interventions beyond that of tentative. [25] Even within their small sample size they found issues with blinding, randomization, attrition, and established study

protocols. [25] They did state that they still believe that pure TB-CBT offer benefits over traditional face-to-face CBT, particularly for caregivers who have unique situations when it comes to accessing services. [25] This is an important finding, given that caregiver depression can be a significant factor when it comes to early institutionalization of a care recipient. [25]

Table 2 Literature Synthesis

Authors	Objective	Number of Studies in Systematic Review	Dates of Systematic Review	Outcomes and Measurement	Risk of Bias
Christie, H., Bartels, S., Boots, L., Tange, H., Verhey,F., and deVuot, M	To perform a systemic review of literature to study the implementation of eHealth interventions of informal caregivers of people with dementia and identify determinants of successful outcomes.	46 articles on implementation were included, grouped into four categories: 1) Determinants associated with eHealth application, 2) informal caregivers, 3) implementing organization, and 4) general wider context.	Articles published before 2007 were excluded from this review. 2007 was chosen as the cut-off year because the authors believed that studies from over 10 years ago would be outdated.	Researchers determined there was a mismatch between researching eHealth interventions for caregivers of PWD and CFIR to assess the implementation. There was a notable lack of research using CFIR matching information that had accumulated from eHealth studies.	Due to the fact that there was a lack of information from which to draw conclusions that were available using CFIR implementation the authors did not determine a risk of bias.

Hopwood J., Walker, N., McDonough, L., Rait, G., Waleters, K., Illiffe, S., Ross, J., and Davies, N.	To identify the key components of existing internet-based interventions that exist to support family caregivers of PWD, develop an understanding of which components are most valued by caregivers and consider the evidence of effectiveness of internet-based interventions that exist and are designed to support family caregivers of PWD.	A total of 2325 was identified of which 40 were included.	Articles for this systemic review were dated as recently as January 2020, however, the authors did not state a beginning date for their systemic review.	Outcomes included data on the practicality of interventions, as well as the impacts on well-being, QOL, burden, competence, physical and mental health	There was a risk of selection bias due to the fact that the pool of interventions was drawn only from peer-reviewed studies.
Leng, M., Zhao, Y., Li, C., and Wang, Z.	To assess the efficacy of internet-based interventions that support mitigating negative health outcomes for	Initially 9110 studies were identified from electronic databases. After removing duplicates and 165		Outcome measures showed that caregivers from the internet-based intervention group	Most of the studies included randomization but some did not have allocation

	family caregivers of PWD	studies that did not meet eligibility requirements the authors retrieved 182 full-text articles for evaluation. A total of 17 studies involving 2202 caregivers of PWD were included in the systematic review.		exhibited mitigation of depressive symptoms and stress/ distress compared to control group. Caregiver burden, satisfaction and coping competence showed significant improvement after intervention.	concealments which led to selection bias. Performance bias was present due to the fac that it was difficult to blind the participants. Detection bias was categorized as low. Attrition bias was unclear, no evident of selective reporting bias.
Pleasant, M., Molinari, V., Dobbs, D., Meng, H., and Hyer, K.	Systematic review of online training programs to analyze the evidence for online programs to disseminate future interventions, identify gaps, and present recommendations to	The initial identification of articles included 368 in the database. Duplication removal reduced the number to 118 for this systematic review. Eligibility criteria by	The authors examined evidence from online dementia-based caregiver training programs between 2000	Measurement of outcomes was for knowledge, competency, self-efficacy, caregiver burden, stress, depression and anxiety. Growth or improvement was	

	create useful training programs in the future.	abstract review reduced remaining records to 52. Full text review for eligibility reduced articles to 18. (peer reviewed)	and 2016. They believed that prior to 2000, most remote interventions were delivered through teleconferencing and CD-ROM.	supported in knowledge, self-efficacy, anxiety, depression, caregiver burden and satisfaction.	
Scott, J., Dawkins, S., Quinn, M., Sanderson, K., Elliott, K., Stirling, C., Schic, B., and Robinson, A.	Systematically review the quality and effectiveness of technology-based CBT, and evaluate the level of functioning of the caregivers as time passes.	A total of 442 titles/abstracts were pulled following the initial search. Most of the articles were removed because they were 1) not RCT with quantitative results, 2) did not report carer psychosocial outcomes, 3) interventions was	These authors performed a systemic review from 1995 onward.	Technology-based CBT interventions may show an impact in reducing caregiver depression. Due to the small number of trials (4) conclusions must remain tentative.	There was a risk of the bias not being randomized due to the rate of attrition and small sample size

		technology-based, and 4) the intervention was not PURELY technology based. The final number of articles reviewed was four.			

5.0 Discussion

Currently we are experiencing a world amidst a pandemic. The pandemic has led the US to see how adaptable technology is for therapeutic interventions. This is the time for alternative approaches to traditional therapy to take root. Internet-based interventions can have the same content as face-to-face interventions, with the potential to reach huge masses of people that are in desperate need.

Electronic interventions are a valuable deliverable. All the authors in this umbrella review supported the idea that electronic interventions were desirable for the caregiver population. Scott et al went as far to say that "these types of interventions have been shown to be effective in reducing psychosocial distress and health-related risk factors across a range of health conditions including diabetes, asthma, arthritis, cancer, epilepsy, and depression," and that "alternative approaches to improve client engagement with interventions via technology-based formats have been developed to reach those most in need." [25] There is an overarching conclusion that technological-based interventions can serve caregivers of dementia, or any other chronic or acute illness. (See Appendix A *Example of a basic web- or electronic-based Intervention*for sample of personalized electronic intervention for caregiver of a PWD)

As discussed in the reviewed articles, electronic interventions address a myriad of issues that caregivers encounter on a regular basis. First, they are uniquely suited to improve accessibility to a range of supports. The nature of electronic interventions mean that they can be accessed via the internet either on computers or on mobile devices, at home or in other locations where the internet can be accessed. Given the digital divide this has meaningfulness for caregivers in lower-income and rural communities, where access to both in-person supports and reliable internet can

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be a challenge. [23] Additionally, caregivers who have disabilities may be able to access supports via technology such as using read-aloud or subtitle/closed-caption functions or access materials in translation that they might not otherwise have access to.

As discussed previously, personalization or individualization is an especially important factor when developing an electronic intervention. When targeting an electronic intervention towards caregivers of PWD, or any other health concerns, it is vital to individualize programming just as an intervention would be individualized with face-to-face contact. Much like a treatment plan, individualization of an electronic intervention would include a salient psychoeducational component, along with therapeutic exercises to match each caregiver's issues. It would also be possible to have an on-call staff available for crisis situations so that caregivers know that there is still staff available when they are needed. With high rates of attrition due to high levels of depression, anxiety, and isolation in this population, it is vital to get these points correct.

Affordability is another asset of electronic interventions. Compared to the cost of a full staff, office overhead, travel of caregivers and/or staff, materials needed for traditional education, resources and support models, electronic interventions are a low-cost option. This also helps with accessibility for underprivileged communities since the intervention is not at an exorbitant cost.

Although none of the articles in this author's review touched on it, there is an issue with caregiver burnout. The higher the level of burnout felt by the caregiver, the poorer the level of care given to the recipient. [6] Logic leads to the conclusion that a recipient cared for under the conditions of caregiver burnout might end up in a long-term care facility sooner rather than later. One potential consequence of increased caregiver burnout if the approach of interventions for caregivers is not changed to honor personalization and accessibility across determinants, not only

for caregivers of PWD but for caregivers in general, is that our healthcare systems will not be able to handle the numbers of people that flood long-term care facilities.

The theoretical model of andragogical learning supports the acceleration of technological interventions with caregivers. There are older adult learners who 1) are able to direct their own learning with guidance, 2) have developed life experience by dealing with a loved one who has dementia that is a rich motivation for learning, 3) has learning needs that are related to changing social roles as they take on the role of caregiver, 4) are problem-centered to help with the needs of taking on the role of caregiver to immediately make positive changes in a difficult situation, and 5) are motivated to learn by pressing internal factors to improve their living situation. [12]

Leng et al supported this in their study when they personalized their experimental pool by adding a therapeutic element to the technological piece of the intervention. [23] Their outcome results reinforced this by the number of positive traits that were changed in caregivers: they described mitigation of caregiver depression, stress, and distress, and significant improvement with caregiver burden, satisfaction, and coping competence. [22]

Like Leng, Hopwood et al wanted to identify key components that were already available and established, to maintain support to caregivers of PWD. [23] They determined that the most effective intervention in their search came from psychological support used in conjunction with online information when specifically tailored to the individual caregiver. [23] Online peer support groups showed appreciation by most participants and a positive effect on stress. [23] The online contact with a professional exhibited that a participant respected easy access to the incorporated pragmatic consultations and poignant consultations leading to a decrease in burden and strain. [23]

Pleasant et al aimed to describe literature that applied to online learning. This was particularly salient to the andragogical theory. Their goal was to identify gaps in current research

and to present recommendations for future interventions. [24] They found that what was most effective was to personalize interventions with a combination of technology and live interactions, and to concentrate not only on the caregiver experience, but the experience of the care recipient.[24] The recommendation they have for future research was to continue mentorship beyond the educational piece for caregivers. [24]

Much like Pleasant, Scott et al examined technology-based CBT for caregivers of PWD, noting a concern for the care recipients as well as the caregivers. Their concern was that depression in caregivers might lead to behavioral and mental health problems in care recipients.[25] They were interested to see if technologically based interventions had any effect on delaying institutionalization of PWD. [25] This was another group that had the belief that interventions should be designed to meet specific original needs of each participant. [25] They were able to show (through follow-up surveys) over a three- to four-year period, that the individualized tailored interventions were able to help caregivers maintain levels of decreased depression, increased mood, coping, and self-efficacy. [25] In addition, care recipients' responses during this time-period showed decreased behavioral and psychological symptoms related to dementia. [25]

All five reviews found positive implications for technology-based interventions, four of which noted decreases in aspects of caregivers' negative mental health functioning and increases in caregivers' confidence. Results showed that when questioned about cultural experience, beliefs, needs, values, likes and dislikes, and religious preferences caregivers felt profound benefits regarding depressive symptoms and perceived stress. [23] This was achieved via questionnaires or psychological coaches that touched base with caregivers periodically, thus resulting in tailored interventions. [24] The personalization of web- or internet-based interventions is a key factor based on consumer feedback and research results.

There are a number of areas where researchers should address future studies to better understand how to best develop electronic interventions. Of the reviewed studies, only two of the four agreed that personalized formatting was viewed as an important positive aspect of interventions to elevate caregiver experience and decrease attrition rates. [23,24.] More work needs to be done to understand how best to design materials to be attractive and useable to caregivers, particularly in light of differing access to the internet across the country.

The research on the usage of electronic interventions for caregivers is in its infancy, but early indications are that they can support caregivers in meaningful ways. Andragogical learning theory supports that electronic delivery of interventions is a suitable learning style for adults, tailored specifically to the adult brain, and based on caregiver demographics, an ideal style of learning and intervention.

5.1 Limitations

There is one significant limitation of this umbrella review. The number of systematic studies found regarding web- or internet-based interventions for caregivers of PWD was scarce. The search was reduced to five studies resulting in a randomization bias. However, even the minimal research that exists for a search of systematic studies on web- and internet-based technology for caregivers of PWD indicates that technological intervention could be beneficial in several ways to the caregiver population.

## 5.2 Future implications of electronic interventions

It is worth reiterating Mather and Scommegma's statement that "researching ways to make the lives of caregivers easier is a duty of our public health system." [2] Studies investigating interventions with caregivers and the use of technological interventions have positive implications for the future of caregiver interventions. The research base of technological interventions is not standardized which is an important factor for using it with large numbers of people. Standardization of the intervention would prove to equalize treatment interventions when we refer to accessibility, language and cultural differences, and a base with which to personalize and standardize interventions in the future. Currently there is a lack of evidence-based self-help programs. [23] There is a growing need for cost-effective, readily available resources. [23,24] Stakeholders in global proportions need to address the influx of growing dementia patients, and therefore caregivers, over the next 30 years. [23]

Electronic interventions offer a convenient, economical method for delivering psychological interventions to caregivers. However, future research needs to investigate their long-term efficacy and consider potential moderating and mediating factors and the mechanisms that effect these programs. These actions will help to provide more targeted interventions to this population. [25] Leng et al agrees that internet-based interventions should be tailored in the future according to the wants and needs, personal situations and dementia severity of the care recipients.[23] Leng also believes that it is important to focus not only on the caregivers, but on the care recipients progress, since the goal is the well-being of both parties. [23] Leng also points out that issues of security and privacy need to be addressed. [23] The details that are being discussed by users are personal and private, and users need to be assured that the tools they are using are secure. [23] Leng

also supports a mixed-methods concentration for future research, stating that a qualitative content offers deeper insight into a caregiver's experiences and adds to pure quantitative data. [23]

Interventions need to be personalized to continue mentorship beyond education and to avoid attrition rates, [23] to improve the well-being of both parties involved. [24] In the near future, research needs to continue to look into mixed methods approaches that share both qualitative and quantitative components and outcome measures, [22] along with a broader evaluative effectiveness of internet-based interventions. [25] Interventions will prove effective not only for caregivers of PWD but for caregivers of many chronic conditions such as cancer, diabetes, arthritis, asthma, epilepsy, depression, and phobias, as point out by Scott and colleagues. [25] The pandemic of 2020 might be the perfect opportunity for the mental health and medical communities to realize how valuable web- and internet-based interventions are.

Appendix A Example of a basic web- or electronic-based Intervention*

CAREGIVER HANDBOOK

The Complete Guide to Help You Through Your Caregiving Experience
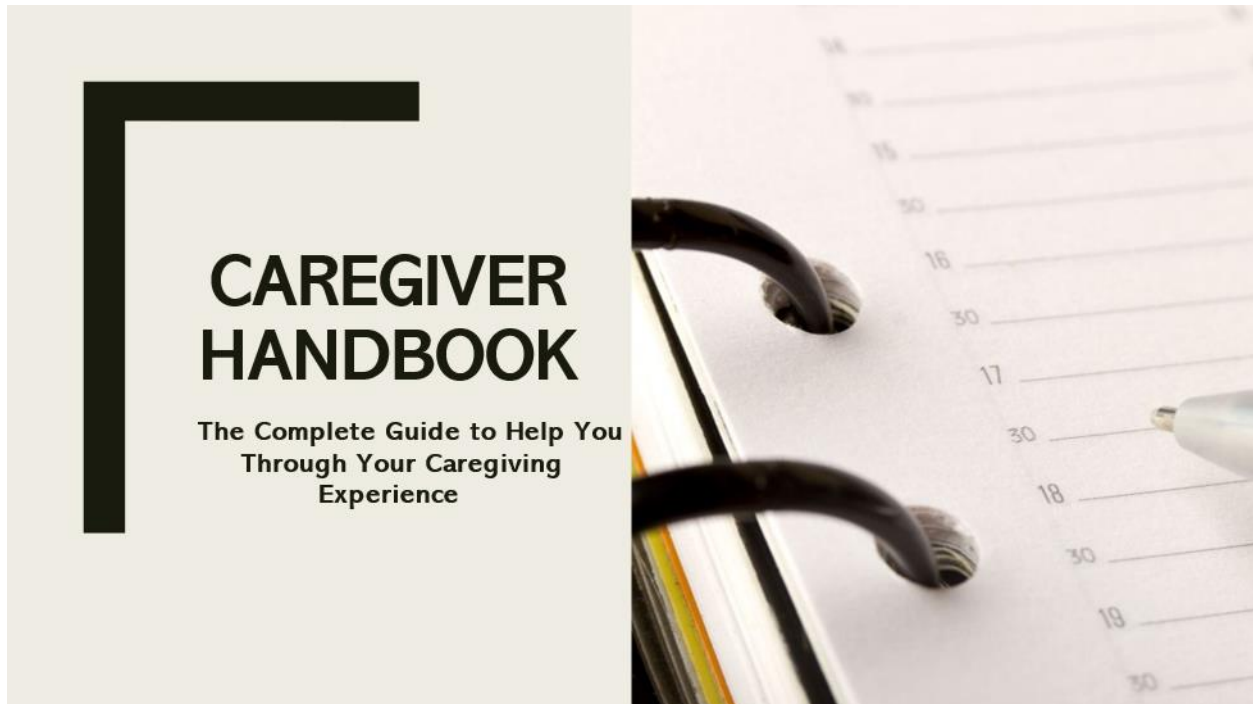
This handbook......

Inside this handbook you will find four separate guides that you can look at whenever you need to. You will always have this information at your fingertips whenever you need it. Some pages will contain links and descriptions to each of the four guides.

Do not use this handbook to replace the advice of a medical professional. This is a guide to help you become the best caregiver possible.**If you think you have a medical emergency, please… call 9-1-1**

Inside this Handbook

- [Emergency Grab and Go Forms](#)
- [Caring for Someone With Dementia](#)
- [Being a Caregiver](#)
- [Caregiver Wellness](#)
- [Caregiver Journal](#)

Emergency Grab and Go

The Emergency Grab-and-Go guide is where you can keep all important medical information for the person you take care of.

- Insurance information
- Doctor's name, address and phone number
- Pharmacy address and phone number
- Medication names and dosages
- Allergies
- Medical conditions
- Legal information
- Transportation information
- Emergency contacts
- You can access this information on your phone in an emergency, or you can print it out so that you have it available on paper if necessary.
- Either way, all the information you would need in an emergency is in one place. This way you would not have to answer a lot of questions in the emergency room – you can hand over the electronic file.

Emergency Grab and GO
Everything you need in one place in an emergency

*To get through this guide simply scroll down.

45

Health Insurance Information

My loved one's information

Name_____

SSN _____-_____-_____

Street Address:_____

City/State/ZIP:_____

Phone: _____

Email Address: _____

Date of Birth: _____/_____/_____

Employer:_____

Employer Phone:_____

Primary Health Insurance Provider

Private_____   Medicare_____   Medicaid_____   Other_____

Company (if private):_____

Member Number:_____

Group Plan Number: _____

Member Services Phone Number: _____

Care Manager/Service Coordinator Name:_____

Secondary Health Insurance (if any)

Private_____   Medicare_____   Medicaid_____   Other_____

Company (if private):_____

Member Number:_____

Group Plan Number: _____

Member Services Phone Number: _____

Care Manager/Service Coordinator Name:_____

Care Manager/Service Coordinator Phone Number:_____

Doctor's Information

Primary Care Doctor:_____

Primary Care Doctor's Phone:_____

Specialist Doctor:_____

Specialist's Phone:_____

Specialist Doctor:_____

Specialist's Phone:_____

Attendant Care Provider:_____

Attendant Care Provider Phone:_____

Respite Care Provider:_____

Respite Care Provider Phone:_____

Medication Information

Pharmacy, Medications, Doses, Over the Counter Medications, Herbal Supplements and Allergies

Pharmacy/Medication Information

Pharmacy Name:_____

Pharmacy Phone Number:_____

Patient's Date of Birth:____/____/_____

Pharmacy Address:_____

Mail Order Pharmacy:_____

Mail Order Pharmacy Phone Number/Website:_____

Prescription Medications

Prescription Medications	Medication 1	Medication 2
Dosage	_____	_____
Time Taken	_____	_____
Reason for Taking	_____	_____
Start Date	_____	_____
End Date (if applicable)	_____	_____
Prescribed by	_____	_____
Side Effects to Watch For	_____	_____

Prescription Medications

Prescription Medications	Medication 3	Medication 4
Dosage	_____	_____
Time Taken	_____	_____
Reason for Taking	_____	_____
Start Date	_____	_____
End Date (if applicable)	_____	_____
Prescribed by	_____	_____
Side Effects to Watch For	_____	_____

If your Appendix requires further subsections, use the App Subsection Style to continue adding content.

Prescription Medications

Prescription Medication	Medication 5	Medication 6
Dosage	_____	_____
Time Taken	_____	_____
Reason for Taking	_____	_____
Start Date	_____	_____
End Date (if applicable)	_____	_____
Prescribed by	_____	_____
Side Effects to Watch For	_____	_____

Allergies

	Allergen	Reaction	Treatment	Last Occurrence
1.	_____	_____	_____	_____
2.	_____	_____	_____	_____
3.	_____	_____	_____	_____
4.	_____	_____	_____	_____
5.	_____	_____	_____	_____
6.	_____	_____	_____	_____
7.	_____	_____	_____	_____
8.				

Over-the-Counter Medications

Allergy Relief_____
Antacids_____

Aspirin/Other Pain Relief or Fever Reduction_____
Cold/Cough Relief_____

Diet Pills/Drinks or
Shakes_____

Herbal
Supplements_____

Laxatives_____

Sleeping Pills_____

Vitamins/Minerals_____
_____

Other

Health History

Health History and Lifestyle Choices

Health History
Which of these conditions apply to your care recipient presently or in the past?

		Any Other Conditions:
Alcoholism _____	Arthritis _____	
Asthma _____	Cancer _____	_____
Diabetes Type I _____	Diabetes Type II _____
Emphysema_____	Glaucoma _____	_____
Heart Condition _____	Hemodialysis _____	_____
Hepatitis A_____	Hepatitis B _____	_____
High Blood Pressure _____	High Cholesterol _____
Intellectually Disabled _____	Kidney Disease _____ _____
Rheumatic Fever _____	Seizures _____	_____
Stomach Problems _____	Stroke _____	_____
Tuberculosis_____	Tumor _____	_____

Lifestyle of Care Recipient:

Smoking Yes_____ No_____

If Yes, packs per day_____

Number of years_____

Alcohol Use
Yes _____ No_____
Drinks per week_____
Number of years_____

Transportation service

Non emergent transportation service that is used

Non-emergent Medication Transportation Company/Name:

_____

Non-emergent Medical Transportation Company/Name Phone:

_____

Transportation

Legal Concerns

- Advance Directives
- Healthcare Proxy
- Living Will
- Power of Attorney
- DNR

Advance Directives

- Advance directives are legal documents that a person writes to tell the healthcare team what medical care and treatment he or she wants or doesn't want.

- When a person can't speak for him or herself or is too sick or unable to make decisions, these documents make wishes known.

- Having advance directives in place for your loved one will make sure he or she gets the care desired, or forgoes the treatment not wanted.

- Advance directives cover two types of info:

- » The kinds of treatment wanted or not wanted by the family member

- » The person put in charge of making healthcare decisions if the family member isn't able to

Choose your medical decision maker

Who to choose as your decision maker
- Someone who is over the age of 18
- Someone who knows your well
- Someone who will be there when you need them
- Someone who you can trust to make decisions about what is best
- Your decision maker cannot be your doctor or a medical professional unless they are a family member
- In the state of Pennsylvania, if you do not choose a person to make your decisions, someone will be chosen for you, but they may not be aware of your wishes

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What can my decision maker do?

- A decision maker can no to, change, stop or choose:
  - Doctors, nurses, social workers
  - Hospitals, clinics, or where you live
  - Medications, tests, or treatments
  - What happens to your organs and body after you die

The decisions you make

Your decision maker needs to know your wishes about:
- Life support treatment such as CPR, electrical shock treatments to start your heart
- Ventilators
- Dialysis
- Feeding tubes
- Transfusions
- Surgery
- Medicines
- Spiritual wishes
- Where you wish to die (hospital or at home)
- What your burial wishes might be

Who is your decision maker?

I want my decision maker to be:

_____

Phone number: _____

Address: _____

Relationship: _____

If the first person cannot be available or chooses not to, then I want:

_____

Phone number:_____

Address:_____

Relationship_____

When my medical decision maker is active

Place an x next to the sentence you agree with

○ My medical decision maker may make decisions for me right after I sign this form

○ My medical decision maker my only make decisions for me after I cannot make decisions for myself.

Flexibility of your decision maker

○ My decision maker may change any medical decision if my doctors think it is best for me

○ My decision maker my not change any of my decisions. I want my wishes followed exactly as I have laid them out, even if my doctors recommend something different

○ My decision maker may change some of my decisions if the doctors think it is the best things for me, however these are the decisions I NEVER want to be changed:

_____
_____

Making your own health care choices

My life is only worth living if:

__ I can talk with family or friends

__ I can wake up from a coma

__ I can feed, bathe, or take care of myself

__ I can be free of pain

__I can live without being hooked up to machines

__My life is always worth living no matter how sick I am

__ I am not sure

If I am dying

It is important that:

__ I am at home

__ I am in the hospital

__ I am in a hospice

__ I am not sure

Religion

Is religion or spirituality important to you?

__ Yes

__ No

If yes, what is your religion? _____

What do you want your doctors to know about your religious or spiritual beliefs?

_____

_____

_____

Life Support

__ Try all life support treatments that might help. I want to stay on life support even if I am suffering

__ Try all life support but if they do not work and there is no hope of my getting better, I do NOT want to stay on life support. Please stop.

__ I do not want life support treatments. Just keep me comfortable.

__ I want my medical decision make to decide for me

__ I am not sure

Organ Donation

__ I want to donate my organs

    __Any organ

    __ Only specific organs: _____

__ I do NOT want to donate organs

__I want my decision maker to decide

__ I am not sure

Autopsy

__ I want an autopsy

__ I do not want an autopsy

__ I only want an autopsy if there are questions about my death

__ I want my decision maker to decide

__ I am not sure

What do you want your doctors to know about funeral or burial wishes

_____

_____

Signatures

Your Signature _____

Date _____

Witnesses

Witnesses much be

- Over the age of 18

- Know you

- See when you sign this form

- Cannot be your medical decision maker, health care provider, work for your health care provider, or work at the place that you live, they also cannot be related to you, or benefit financially from you if you would die.

Witness signatures

- I hereby swear that _____ signed this form while I watched and that they were thinking clearly and were not force to sign in any way.

Witness #1

Signature: _____ Date: _____

Print your name: _____

Address: _____

Witness #2

Signature: _____Date: _____

Print your name: _____

Address: _____

Healthcare Proxy

- This form of advance directive allows someone to name a healthcare substitute.

- This substitute will make legal healthcare decisions for the person.

- Healthcare Proxy Form: A form filled out that gives another person the right to act on healthcare matters for another person.

- Each state has its own laws and rules about this decision-making process.

- Contact your state's Department of Health to learn the laws and obtain the form that applies for your state.

Living Will

- This is a written account of what healthcare treatment a person wants or doesn't want in the future.
- This document makes sure a person's wishes and decisions are followed, if he or she is not able to make them.
- Healthcare teams and family members must abide by these legally-binding wishes.

DO NOT RESUSCITATE (DNR) ORDER

This document makes sure the wishes of a person who doesn't want CPR or other life-sustaining methods used if his or her heart or breathing stops are met. Here are some things to keep in mind:

» The DNR order must be signed by a doctor

» If you are a family member caregiver, you may also need to sign the order

» The DNR order will still be in effect, even if no healthcare proxy has been chosen

» There is also an Out-of-Hospital DNR Order that tells emergency staff not to perform CPR if your family member's heart fails while at home. This order must also be signed by a doctor.

Many states have POLST (Physician Orders for Life-Sustaining Treatment) forms that allow for DNR orders to be followed when patients are taken from one healthcare setting to another. See POLST.org for more information and to learn about the laws in your state.

Power of Attorney

Name:_____

Phone:_____ Cell:_____ Work:_____

Agent Address:_____

Agent Work Address:_____

Document Location:_____

Document Contact Name:_____

Legal Help

- It's wise to speak to a lawyer about these documents and certain financial concerns.

- A lawyer can help you set up a will or estate plan, as well as give advice on key matters in the life of your care recipient.

- Legal assistance may be available in your community.

- Care Managers/ Service Coordinators may be able to connect you to a resource.

Caring for someone with Dementia

- It can be very distressing to learn how to interact with a loved one whose decline ends up in irregular behavior and personality changes.

- Continue to learn about the stages of the disease……

Mild Cognitive Impairment

- Some people may be told they have mild cognitive impairment (MCI) at first.
- This is a condition that can cause noticeable but small changes with the way a person thinks, their judgement, their memory and their ability to speak.
- People with MCI may develop dementia over time.

The most common types of dementia

- Alzheimer's disease
  - Alzheimer's disease is the most common form of dementia. It causes changes in brain cells that effect the way the cells communicate with each other and can lead to memory loss.
  - People may find it hard to remember recent conversations, names, and events.
  - When Alzheimer's progresses, people may become disoriented and they may have a harder time speaking.
  - It is not uncommon for people with Alzheimer's disease to experience hallucinations and delusions.

What are dementia-related hallucinations like?

- Hallucinations are related to your senses.
- Hallucinations can happen when someone sees, hears, tastes, feels, or smells things that are not actually present.
- It is easy for hallucinations to cause disruptions in daily life.
- Look for these signs:
  - *A person sees or hears people or animals that you know are not there.*
  - *A person sees relatives who do not live there or have passed away.*

What is the difference between hallucinations and delusions?

- Delusions are different than hallucinations.
- Delusions occur when people believe things that are not true:
    - *People might believe that certain comments are specifically directed at them*
    - *People might believe that there are strangers in the house*
    - *People might believe that someone is hiding or stealing from them*
    - *People might believe that someone is trying to harm or poison them*
    - *People might believe that they have been abandoned*

Tips for caregivers

- Decide if any action is needed
    - *Is the hallucination/delusion upsetting your loved one?*
    - *Is your loved one frightened?*
    - *Is the hallucination/delusion encouraging your loved one to do anything dangerous?*
    - *If the hallucination/delusion is not causing any harm, it may be best to react to it calmly and monitor it over time.*

Try not to get into arguments

- When someone has been diagnosed with dementia, it is common that they might say hurtful things.
    - *Try to realize this is their brain cells malfunctioning, and not the person you know and love talking from their heart*
    - *Try to not take what your loved says personally*
    - *Try to think about what might be behind what they are saying.*
        - Are they scared? Cold? Angry? Lonely?
        - Then reflect on that feeling: "I see you are _____"
        - Try to reassure them as best you can that they are safe and you will protect them

BEING A CAREGIVER

Tips, Building Blocks and helpful information to best serve your caregiver recipient

When in doubt….

DISCLAIMER: This book provides general information about caregiving and related issues. The information does not constitute medical advice and is not intended to be used for the diagnosis or treatment of a health problem or as a substitute for consulting with a licensed health professional. Consult with a qualified physician or healthcare practitioner to discuss specific individual issues or health needs and to professionally address personal medical concerns.

When in doubt, always contact your health professional

Caregivers

Caregivers are broadly defined as family members, friends or neighbors who provide assistance to a person with a chronic illness or disabling condition.

Maybe you have been trained to be a caregiver, completed coursework or have professional certification. You may have a healthcare background and may have made it your working life to tend to the needs of others.

Maybe you are new to the role of caring for a family member or friend who can no longer care for him or herself, and do not know where to begin.

This handbook will be helpful regardless of your situation.

Who can be a caregiver?

Providing care for a person is rarely easy. The time spent caring for someone who cannot care for him or herself can drain you physically and emotionally.

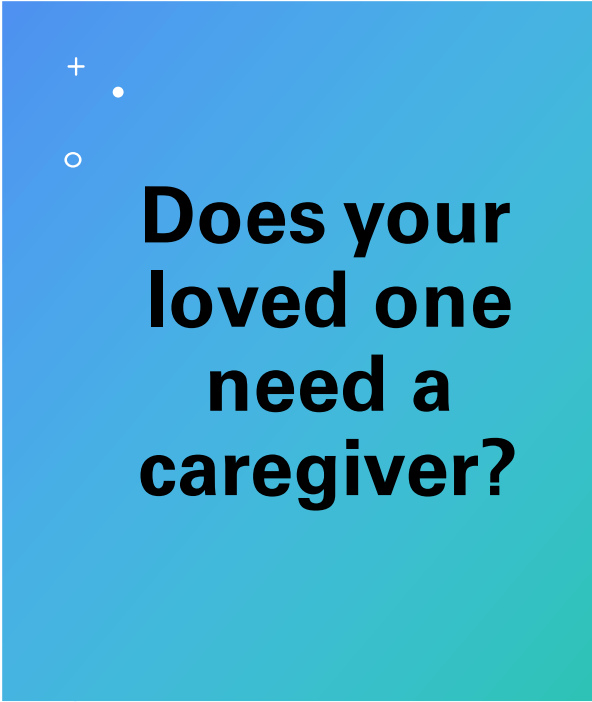**Who can be a caregiver?**

- **A parent for a child**
- **A child for an older disabled parent**
- **A spouse**
- **A niece, nephew or grandchild**
- **A neighbor**
- **A hired professional**
- **You**

Caregiver Basics:
As a caregiver, you may share in the responsibility of someone's well -being. A caregiver will often provide for many basic functions for a person in need, such as:
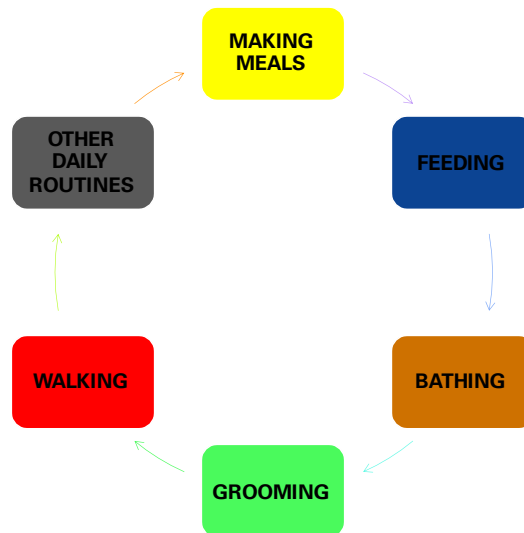
Does your loved one need a caregiver?

Keep an eye out for these possible signs that your loved one might need extra care and attention:

- **The house is messy and in disorder**
- **Bills are unpaid and mail is piled up**
- **Dirty dishes are piling up in the sink**
- **Food is spoiling or has gone bad in the refrigerator**
- **Trash is piling up**
- **Plumbing issues are causing odors**

Roles of a Caregiver

As a caregiver, you wear many hats: doctor, nurse, lawyer, secretary, accountant, chauffeur, cook, housekeeper and social worker. Your duties may include:

- Keeping track of information on your loved one's condition, treatment and care
- Monitoring your loved one's health
- Helping your loved one make choices about his or her health
- Handling your loved one's daily and emotional needs
- Keeping track of financial dealings on behalf of your loved one
- Planning for your loved one's future care and treatment

Relationship Issues

Getting to know your care recipient is important in providing the kind of care he or she needs.**Your relationship may intensify during this time, in good and bad ways**

The secret to success is that it is really about the two people taking care of each other during a difficult time. It's all about give and take. Realizing this will lead to a relationship that thrives.**Be gentle, be caring and be understanding**.

Why be a caregiver?

Caregiving provides many positive experiences for the caregiver.

- **You feel good about yourself when you are useful, especially by helping others who cannot care for themselves.**

- **You may see this care as a way of paying back your parents for taking care of you when you were growing up.**

- **You are motivated by the belief that you are doing the right thing. And often you are.**

Challenges of Caregiving
Caregiving is not without challenges. It's not uncommon to experience:

Loss of privacy	Limits on free time or a social life and other family members	Giving up vacations, hobbies or favorite activities
Physical and mental exhaustion	Frustration with not making progress with care recipient	Financial strain

Communication is Key

Your care recipient may worry about being a burden, taking up your time and asking too much of you. Think about these tips:

Show respect

Watch what you say – try not to use phrases like "You never…" or "You always…"

Allow him or her to show independence – your loved one has a right to his or her dignity, so allow him/her to do things in his/her own way

Be reassuring when talking to your care recipient. Remember they have not gone through this before, and they are challenged as well.

Communication Tips for both of you

Remember	Remember this is a hard situation for both of you.
Compassion	Be compassionate to your care recipient and yourself. Listen to their feelings and try to be in touch with your own
Fears	Notice fears and react in a positive manner
Disagreements	Work through disagreements to reach a solution, even if you need to step away for a few minutes to cool off
Time	Set aside time each day when your care recipient knows you have the time and energy to listen. You are both going through a lot, and deserve time for each other

Bathing with Respect

Imagine having to bathe and dress the person who bathed and dressed you when you were young. This role reversal can be hard when you are caring for your parent. Here are a few tips:

- An elderly person may withdraw or become angry over the situation.
- You both may be embarrassed.
- Have a professional attitude when touching your elderly person's body.
- Slow down and describe what you are doing as you go. Taking a more relaxed approach will feel less like you are invading their personal space.

10 Tips to make things easier for one of the toughest jobs you will ever do

PREPARE. Figure out your schedule and how much time you can devote to taking care of another person.	**ORGANIZE.** Organize medical and legal info to keep it up-to-date, in order, and easy to find.	**GET SUPPORT.** Seek information and advice from other caregivers and support groups.	**COMMUNICATE.** Learn the best ways to communicate with the doctors, healthcare team, and your care recipient	**GET HELP.** Don't be afraid to take help when other people offer it!
STAY HEALTHY. Take care of your own health so you are strong and well enough to care for another person.	**GET REST**. A good night's sleep every night and regular breaks during the day will help you concentrate and have the energy to provide care for others.	**BE AWARE OF YOUR FEELINGS.** Depression can be an issue when caring for another person. If you start to notice that you feel overwhelmed, talk to your doctor or another professional.	**GET TECHNOLOGY.** Personal computers, tablets and smartphones can keep you connected to healthcare and pharmacies.	**GET TO KNOW YOURSELF.** Figure out what makes you tick and how understanding yourself can make you a great caregiver

Safety in the home

Safety for you and your care recipient Is a priority!!

- **Check that you and your care recipient are both wearing appropriate shoes with non-slip soles.**
- **Ask the doctor or pharmacist to check for medications that may cause side effects, such as dizziness or drowsiness.**
- **See an eye doctor at least once a year and update eyeglass prescriptions.**
- **Remove all tripping hazards.**
- **Improve lighting and add grab bars and rails where needed.**
- **Get calcium and vitamin D from food or supplements**
- **Get screened for osteoporosis to lower risk of hip fractures**
- **Install motion detectors and night lights in halls and bathrooms**
        (continued~~~~~~~~~~~~~~~~>)

Safety Checklist

ALL ROOMS AND HALLWAYS:

- Get electrical cords out of the way and secured to walls
- Free walkways of furniture and clutter
- Make sure carpeting and rugs are secured with non -slip backing
- Assure that all light bulbs and switches are working

BATHROOMS:

- Install grab bars in showers and near toilets if needed
- Install non-slip bathmats secured with suction
- Install nightlights
- Install bathroom rugs or mats with non -slip backing
- Make sure the bathrooms are free of clutter with room to more around
- Have a shower or bench chair available

Safety Checklist

BEDROOMS:

- Bedside table with a secured lamp
- Clear walkway from bed to bathroom
- Sturdy chair to sit in while dressing

KITCHEN:

- Assure that all items are reachable without a stool
- Sturdy chair to sit while making food
- No cracks or edges on kitchen floor
- Keep electrical cords away from water sources

Safety Checklist

STAIRS:

- **Free of clutter**
- **Room to move at the top of the stairs**
- **Secure handrails that are at the appropriate height**
- **Have well-lit stairways with working switches at the top and bottom**
- **Secure carpeting on the steps**

Other Safety Tips

- **When not in use, store clothing, bedding and other items where they can be reached with ease**
- **Place brightly colored tape on the edge of each step. This will signal you're at the drop-off point.**
- **Make sure all floorboards are even.**
- **Put a liquid soap dispenser in the shower. Slips and falls can happen when trying to pick up a dropped bar of soap.**
- **Make sure the water is set at a safe temperature (120 °F or lower).**
- **Make sure items used often are placed within easy reach.**
- **Lock up cleaning supplies or flammable liquids.**

Be the Best Caregiver You Can Be
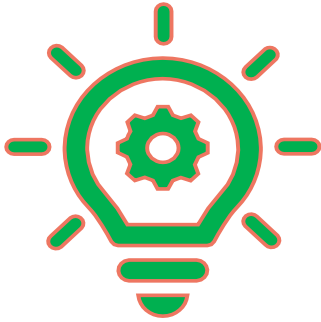
Remember these are tips to help you be the best caregiver you can be. Only you know what will make your specific situation the healthiest and safest situation the best one for you and your care recipient.

Caregiver wellness (<~~link)

Caregiver wellness focuses on helping you to take care of yourself so that you can be the best and healthiest caregiver available:

- Stay healthy eat well, sleep well, relax, exercise
- Recognizing stress to avoid caregiver burnout
- How to delegate tasks
- How to juggle a work schedule
- Knowing your rights
- Support groups

Caregiver Wellness

How to take care of yourself while taking care of someone important to you

Understanding your role

One of the keys as a Caregiver, is to know that YOUR well-being is IMPORTANT. With your health, safety and emotions in check, you will be better prepared to care for your loved one. So, do not expect perfection as a Caregiver, take care of yourself, give of yourself and define yourself with the power to care.

Take care of yourself

As a caregiver, there are a lot of demands on you physically, mentally and emotionally. You may feel the pressure and stress of your situation, and think you are in over your head with little or no control.

There are things that you can do to make it easier. Take care of yourself as best as you are able. Try not to see this as yet another responsibility, but the best way to care for those who need it~

See Your Own Doctor if you Need to

Make it a point to keep all your doctor appointments.

Follow his or her instructions and take your prescribed medicine and vitamins.

Know your boundaries and don't try to do too much.

Get your own health in order so you can care for a loved one.

Let's see if you are experiencing any of these common signs of stress since becoming a caregiver:

- **Anxiety**
- **Depression**
- **Irritability**
- **Tiredness/run down feeling**
- **Sleep problems**
- **Short Temper**
- **Problems focusing**
- **Smoking or drinking more**
- **Eating more or less than usual**
- **Neglecting duties**
- **Giving up activities that you enjoy**
- **Health problems**

Take time to Relax

Set aside just a few minutes in the middle of your day to get stress levels under control. Practice a routine of deep breathing, clearing your mind and focusing on positive thoughts.

Positive thoughts

Repeating phrases or mantras may help you reduce stress and bring yourself back to calm. Here are some examples to get you started:

- Peace is a choice
- Everything will be ok
- I don't have to be perfect
- Stay calm and carry on
- Surrender what is out of my control

Rest, Relax, Recharge

*If at any time you feel you are too overwhelmed to function please contact your doctor or a

If you can, it's essential to switch off your caregiver mode and relax. Stress and burnout are real risks.

Here are some suggestions that are affordable ways to reduce stress:

- Take a long bath
- Take a walk
- Cook something you love
- Read a book or magazine
- Go to a movie or watch an old favorite on TV
- Do some planting or gardening
- Practice yoga
- Call a friend
- Listen to your favorite music

Healthy Foods

Although it may seem difficult, try to fuel your body with the best things available to give you lasting energy:

- **Fresh fruits**
- **Vegetables**
- **Whole grains, like brown rice or oatmeal**
- **Lean proteins, like fish, chicken, eggs or beans**
- **Healthy fats like nuts and olive oil**

Surprisingly, sugar and caffeine may seem like they provide energy, but that energy does not last. The energy rush crashes quickly, leaving you more tired.

Fitness for You

• Caring for someone else can be time consuming and exhausting. Spending your free time exercising might seem like the last thing on your list

Exercise can:

- Keep you from getting sick
- Help you sleep better
- Give you more energy
- Lower stress
- Make you a better caregiver

If exercising feels more like a chore, you're much less likely to do it. The good news is exercise can be easy and fun. It doesn't have to be a full gym workout five times a week.

TURN CHORES INTO FITNESS Gardening, raking leaves, mowing the grass, shoveling snow, grocery shopping and washing the car burn calories and keep you active and moving. You can even turn on your favorite music and dance while you do household chores!

GET ACTIVE WITH THE KIDS Grab your kids and go for a hike, play basketball, get to the park and be active. They need exercise as much as you do. Hold friendly competitions each week and get everyone involved

The idea is to get 30-40 min of moderate exercise three or more times a week, and don't forget to check with your doctor before starting any exercise program!

Ask for Help!!!!

You can't do this alone. And you shouldn't have to. Trying to tackle all the duties and burdens of caring for a loved one on your own won't work.

If you can, **delegate duties** to family members
- **Someone to shop**
- **Someone to cook**
- **Someone to do laundry**

Say YES if a friend asks if they can help you out!!
Many people want to help, and you will welcome the relief

The reality of life is that you may have to juggle working along with your caregiving challenges. Remember:

- Trying to find a balance can lead to emotional fatigue, physical exhaustion and overall distraction both at work and at home
- Talk to your employer. Many employers are more generous and accommodating with your time if you talk to them so that they know the pressure you are under and the details of what is going on. Some companies will also assist in finding community resources, counseling, legal and financial aid and support groups for caregivers.
- Speak to someone from your HR department or read your employee handbook to find out what your employer's policies may be.
- Ask about the possibility of changing work hours to better suit caregiving demands

Managing Caregiving & Work

You are not alone!

KNOW YOUR RIGHTS

The federal **Family and Medical Leave Act (FMLA)** provides eligible workers with 12 weeks per year of unpaid leave for family caregiving. **You can't lose your job security or health benefits during these times** . Ask your HR department for more info.

DID YOU KNOW?

You may be eligible for tax benefits as the caregiving relative to an older adult in the form of tax breaks or financial help. Check out irs.gov or call 1-800-829-1040 to learn more

Support Groups

Sometimes finding friends, allies and emotional outlets nearby can be a challenge. That's where support groups come in. **They're great resources to lean on** when you're:

- **First becoming a caregiver**
- **Learning about caregiving**
- **Dealing with the stress of caregiving**
- **Sharing stories and concerns with others who have similar experiences**

Support Groups

Listen to you

Listen to your concerns and problems

Answers

Give expert answers to your questions and offer advice.

Listen to others

Give you the chance to listen to others who have issues and need advice. In time, you'll be able to offer advice to others in need.

Learn

Allow you to learn quickly that you aren't alone in this. Others are in the same situation, with similar problems and challenges.

- Some of these groups may be found locally. Others you'll be able to reach online.

HOW SUPPORT GROUPS WORK

- **Group members live nearby and meet often**
- **You make new friends and speak about your concerns**
- **The meetings offer a social outlet, so you do not feel all alone**
- **Meetings will be held at a set place and time**
- **Support groups help you learn about local resources from other group members. (these may include doctors, specialists, health and financial programs, etc)**

ONLINE SUPPORT GROUPS

- **Members from all over the world talk about their concerns**
- **Groups are found online through websites, message boards, social media (like Facebook) or by word of mouth by other caregivers or healthcare providers**
- **These are ideal if you have difficulty leaving the house**
- **They are easy to reach at any time**
- **Finding answers to the most unusual questions is likely as someone has probably experienced what you are now**

You can find a community support group by checking the local phone book, by dialing the United Way at 2 -1-1, by asking your doctor or hospital or by calling your Care Manager/Service Coordinator

Resource Information

- **The following slides have contact information for numerous types of resources. Remember – you are not alone. Resources are always available. It can be difficult to reach out for help when you feel burdened by everything that is going on in your life right now. Try not to let that burden turn into isolation Isolation can lead to caregiver burnout, and caregiver burnout will not help you or the person you are caring for.**

Resources for Caregivers

AARP
aarp.org

Eldercare Locator
1.800.677.1116
Eldercare.gov

CAN (Caregiver Action Network)
Caregiveraction.org

POLST (Physician Orders For Life-Sustaining Treatment)
POLST.org

Stroke
1-800-STROKES (787-6537)
Stroke.org

Brain Injury Association of America
www.BIAUSA.org

Serious Mental Illness
1-800-950-NAMI (6264)
NAMI.org

Medicare
Medicare.gov

Medicaid
Medicaid.gov

Disability
Disability.gov

U.S. Living Will Registry
 uslivingwillregistry.com

[CaregiverJournal](#) (<~~link)

The Caregiver Journal is a place that reviews some important information about self care, and it also gives you the opportunity to personally reflect on how you are experience caregiving. This isn't an assignment or something anyone will ever ask to see. You may find that it helps you define some goals with your care manager or service coordinator later in treatment, but it is for your eyes only..

A Place for your thoughts

CAREGIVER JOURNAL

* To get through this guide simply scroll down.

CAREGIVER JOURNAL

This Journal will give you a place to record experiences and to write down your feelings and concerns. It may also help you understand some of the things you are going through that you can discuss with your therapist or counselor.

DAILY LIFE

Describe how your loved one's dementia has an impact on your daily life? Are there any other conditions that your loved one has that you are dealing with along with dementia?

_____
_____
_____
_____
_____
_____
_____
_____

TOP CONCERNS

What are the top three difficulties or concerns you have as a caregiver?

1. _____
   _____
   _____

2. _____
   _____
   _____

3. _____
   _____
   _____

Have you needed any supportive services or accommodations? Do you feel you have had any trouble getting them?

_____
_____
_____
_____
_____

SERVICES AND ACCOMODAT

CHALLENGES

What challenges have you encountered as a caregiver?_____
_____

What challenges are you worried about encountering the future?
_____
_____
_____
_____
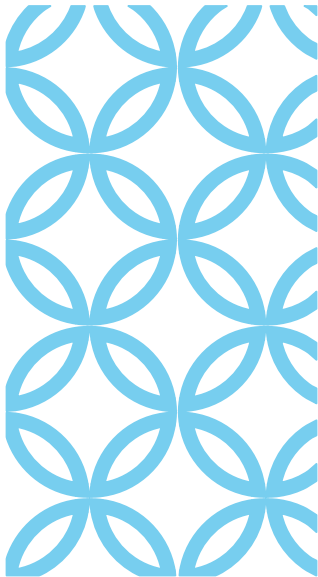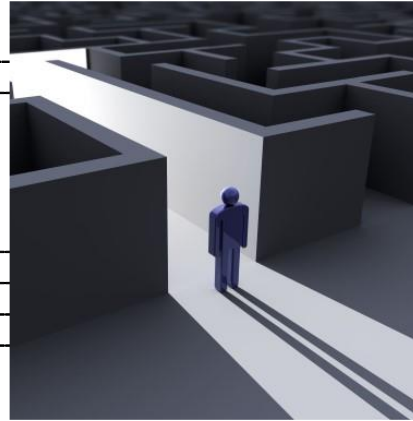
Without guilt, you must take care of yourself. If you are notwell-rested and healthy, you cannot tend to the healthcare needs of others. The people who count on you want you to be fit and well. Do you feel you are taking care of yourself or neglecting yourself? Describe how.

_____
_____
_____
_____
_____
_____

TAKE CARE OF YOURSELF!

SLEEP WELL

Don't cut back on your sleep schedule. Trying to get more done by sleeping less rarely works You need more sleep than you think you do. Eight hours a night is normal. Cheating yourself of this precious downtime means

» You could become moody

» You could feel like you have low energy

» You may not be very productive or patient

» You may be more prone to stress

SLEEP

GET SLEEP

Try charting your sleep on the next page. Notice if it has any impact on your mood or productivity over the next week.

SLEEP CHART

DAY	HOURS OF SLEEP	MOOD ENERGY(NEXT DAY)
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		
13.		
14.		

EAT WELL

While it is difficult, eating the best foods will give you the most energy:

» Fresh fruits

» Vegetables

» Whole grains, like brown rice or oatmeal

» Lean proteins, like fish, chicken, eggs or beans

» Healthy fats like nuts and olive oil

Surprisingly, sugar and caffeine may seem like they provide energy, but they don't last. The energy rush crashes quickly, leaving you more tired.

EATING HEALTHY FOODS

This is hard to do when your time and energy is focused on caring for someone else. Give yourself credit for eating healthy foods and keep a log of when you do so! Try it on the next page...
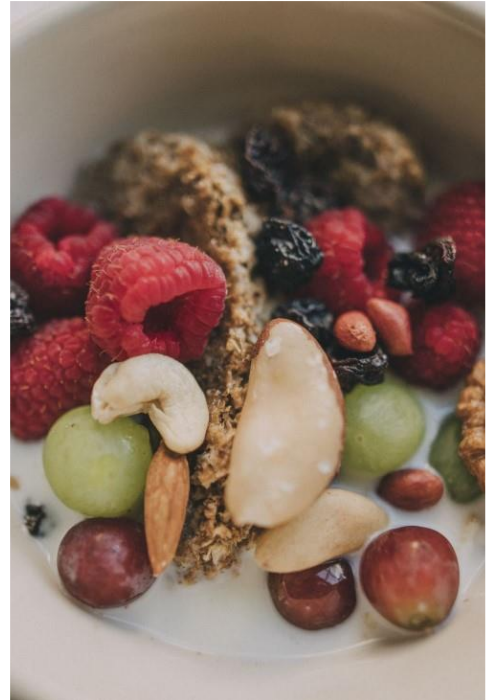
I ATE HEALTHY FOOD!!

DAY	MEAL OR SNACK	FOOD
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		
13.		
14.		

FIND TIME TO RELAX

Setting aside time to unwind and meditate can be a great stress reliever. If you don't have a block of time, even just a few minutes in the middle of your day can get stress levels under control. Practice a routine of deep breathing, clearing your mind and focusing on positive thoughts. Consider adding yoga or stretching to relax even more.

WHAT ARE THE BEST TIMI

**What are the best times during my day that I can find to relax even if it's only for a few minutes??**

_____
_____
_____

Caring for someone else can be time-consuming and exhausting. Spending your free time exercising might seem like the last thing on your list. But it just might be the best thing for your body. Exercise can:

' Keep you from getting sick

' Help you sleep better

' Give you energy to last through the day

' Lower blood pressure and cholesterol

' Lower stress

' Make you a better caregiver
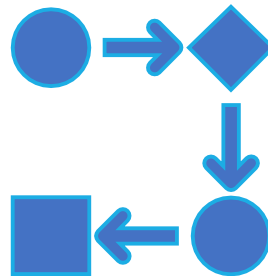
EXERCISE

THINK ABOUT WAYS TO EXERCISE

Think about ways you can get exercise into your schedule:

Take your care recipient for a walk! You will both enjoy the change of scenery!

Find a fitness buddy! Motivate each other to develop a fitness routine and enjoy the company.

Try a fitness class! If you can get out, you will meet new people, learn new things and improve your wellness all at the same time.

Dance! You can do this alone or even with your care recipient if they are mobile. This helps your balance and its fun!

MORE WAYS TO EXERCIS

Try team sports that you maybe didn't think of before: bowling, volleyball, tennis. These can all keep you active and help you meet new people

Believe it or not, chores keep you active as well! Gardening, raking leaves, mowing the grass, shoveling snow, grocery shopping, and washing the car are all ways to help you burn calories and stay fit!

EXERCISE

If you can, try to do 30-40 minutes of moderate exercise three or more time a week. This will assure you are getting vital self care help you be the best caregiver you can be!

**Before you start any new exercise program, always check with your doctor or healthcare provider.

THIS CHART MIGHT HELP YOU DISCOVER EXERCISE TRENDS THAT YOU HAVE

DAY	TIME	EXERCISE	LENGTH OF TIME
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
11.			
12.			
13.			
14.			

STRESS

As a caregiver, there are a lot of demands on you physically, mentally and emotionally. You may feel the pressure and stress of your situation, and think you are in over your head with little or no control. Watching for the signs of stress can help you better handle it. The next page lists some common signs of stress. As you run down the list, check the signs of stress that you feel might be weighing you down or problematic for you. If these are causing you to worry, mention it to your doctor or other healthcare professional.

_____Anxiety

_____Irritability

_____Sleep Problems

_____Feelings of Resentment

_____Sleep Problems

_____Health Problems

_____Feelings of resentment

_____Depression

_____Feeling Run Down

_____Short Temper

_____Neglecting Duties

_____Cutting back on free time activities

None of these signs should be taken lightly. Being Overstressed can turn into caregiver burnout. That's why it's important to talk to a healthcare provider early if you notice that you are experiencing multiple signs of stress at once.

SIGNS OF STRESS

RELAXING ACTIVITIES

IT'S ESSENTIAL TO SWITCH OFF YOUR CAREGIVER MODE AND RELAX. STRESS AND BURNOUT ARE REAL RISKS. HERE ARE SOME EASY WAYS TO RELAX THAT CAN REDUCE CAREGIVER STRESS

Watch a movie

Take a hot bath

Take a walk or garden

Bake your favorite dish or dessert

Go to the library and listen to music

HOW DO YOU LIKE TO RELAX?

What are your favorite ways to relax?

_____
_____
_____

Don't forget about these when you notice that you are feeling stressed!

DON'T GO IT ALONE!

You can't go it alone. But sometimes finding friends, allies and emotional outlets nearby can be a challenge. That's where support groups come in. They're great resources to lean on when you're:

» First becoming a caregiver.

» Learning about caregiving.

» Dealing with the stress of caregiving.

» Sharing your stories and concerns with others who have similar experiences.

SUPPORT GROUPS

Support groups listen to your concerns and problems, giving expert answers to your questions and offering advice. You also listen to others who have issues and need advice. In time, you will be able to offer advice to others in need. The first thing you will quickly learn is that you are not alone in you experience Others are in the same situation, with similar problems and challenges.

Some of these groups may be found locally. Others you'll be able to reach online.

HOW SUPPORT GROUPS WORK

Local in-person groups:

» Group members live nearby and meet regularly or online

» At each session, you make new friends and speak about your concerns while listening to others.

» The meetings offer a social outlet and a chance to get out of the house, so you don't feel all alone.

» In most cases, the meetings will be held at a set time and place. Attending regularly will help you get the most out of these support group sessions.

» Learn about local resources from the other local group members. These may include doctors and specialists, health and financial programs or other outlets that could be of help to you

Have you ever been to support Groups? What was your experience there?_____
_____
_____
_____
_____
_____
_____

HAVE YOU BEEN TO SUPPORT GROUPS?

ONLINE SUPPORT GROUPS

» Group members are from all over the world, meeting online to talk about their concerns.

» You can find these groups online through email, websites, message boards, social media or through recommendations from healthcare providers.

» If you're short on time or can't leave the house, these online support groups may be ideal.

» These groups are most likely easy to reach at any time, offering help when you need it.

» Help will come from a variety of online participants, so finding answers to even your most unique questions and concerns is likely.

You can find a community support group by checking the local phone book by dialing the United Way at 2-1-1

ONLINE SUPPORT GROUPS

HAVE YOU SEARCHED ANY SOCIAL MEDIA FOR ONLINE SUPPORT GROUPS? DID YOU FIND ANY, AND IF SO, WHAT WAS YOUR EXPERIENCE WITH THEM?
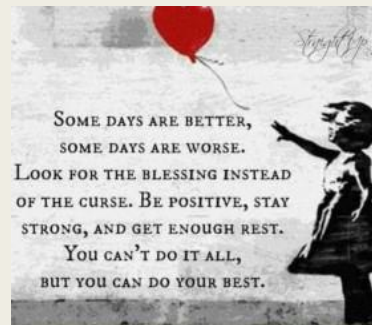
_____

_____

_____

_____

REMEMBER.......

Caring for someone is rarely easy. The balance between taking care of a loved one's health, safety and emotions can be overwhelming. This workbook is here to give you some tools and resources to help you care for a family member, a friend, or a relative

The key is that when providing care, YOUR well being should be at the top of your priority list. With your health, safety and emotions in check, you will be better prepared to care for someone else. So, take care of yourself, give of yourself and define yourself with the power to care.

SOME DAYS ARE BETTER, SOME DAYS ARE WORSE. LOOK FOR THE BLESSING INSTEAD OF THE CURSE. BE POSITIVE, STAY STRONG, AND GET ENOUGH REST. YOU CAN'T DO IT ALL, BUT YOU CAN DO YOUR BEST.

A POEM FOR CAREGIVERS
~DOLLIE DOGWOOD

*This is an electronic modification that was done from a leaflet called "My Caregiver Journal" during my practicum at Centene Corporation/PA Health and Wellness. The original can be found at https://www.pahealthwellness.com/content/dam/centene/Centene%20Corporate/web-files/My-Caregiver-Journal.pdf

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