Happy hearts: a caregiver's guide to assisting patients with heart failure

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HAPPY HEARTS: A CAREGIVER’S GUIDE TO ASSISTING PATIENTS WITH HEART FAILURE

by

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Masters of Occupational Therapy, University of North Dakota, 2016

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This Scholarly Project paper, submitted by Stephanie Carlson and Ashley Waller in partial fulfillment of the requirement of Master of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Signature of Faculty Advisor
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ABSTRACT

The purpose of this scholarly project was to develop a holistic guide that could be provided by occupational therapists (OTs) to caregivers of individuals with heart failure (HF). A thorough literature review was completed on the impact that caregiving for individuals with HF has on mental, physical and environmental aspects of the caregiver and their role as a caregiver. The literature revealed that there is a significant number of individuals with HF and the role of caregiving is on the rise. As the need for caregivers’ increases, the demands associated with caregiving responsibilities increases accordingly. Activities that caregivers assist HF patients with are: bathing, dressing, toileting, feeding, medical health, home care, financial assistance, and medication assistance. The current literature lacks information pertaining ways caregivers received and utilized resources to improve quality of life while caring for an individual with HF. Based on the unmet needs of caregivers of individuals with HF, Happy Hearts: A Caregiver Guide to Assisting Patients with Heart Failure was created.

Guided by the Person-Environment-Occupation Model, this guide addresses the transactive interaction between the person, environment and occupation and strives to achieve the best fit between those components. The Adult Learning Theory was also considered in the creation of this guide as it presents concepts that assist with the most effective methods of learning for adults. By using this model, it provided a way for the information to be followed and easily understood by caregivers of various educational levels.
Within this caregiver guide, the following areas are addressed: the definition and stages of HF, the role of the caregiver, the role of healthcare professionals, the physical and mental factors that influence caregiving, optimizing the caregiver’s environment, and maximizing efficiency in the caregiver role. A supplemental guide was created to demonstrate how OTs can educate and assist caregivers of HF in their everyday lives. Overall, this guide was created to find the best fit between the caregiver’s health and caring for the individual with HF.
CHAPTER I
INTRODUCTION

Heart Failure (HF) is a chronic and progressive condition that affects all individuals with a majority consisting of those within the elderly population (Barkman & Pooler, 2009; Center for Disease Control and Prevention, 2015). Heart failure is the inability of the heart to pump effectively which leads to an inefficient amount of blood pumped out of the heart to meet metabolic and circulatory demands of the body (Barkman & Pooler, 2009; Houston, Kalathiya, Kim, & Zakaria, 2015).

There are four stages of HF that affect an individual’s functional ability to participate in daily tasks (Hunt & Chair, 2001). The first stage of HF consists of an individual having conditions that are associated with HF, but not showing the signs or symptoms of HF (Hunt & Chair, 2001). The conditions that are associated with the first stage include systemic hypertension, coronary heart disease, diabetes mellitus, and a history of alcohol abuse. The second stage consists of the presence of structural heart disease associated with HF but still an absence of signs or symptoms (Hunt & Chair, 2001). Examples of evidence associated with heart disease include previous heart attack, left ventricular hypertrophy, left ventricular dilation, and asymptomatic valvular heart disease. The third stage is the presentation of symptoms of HF with underlying structural heart disease (Hunt & Chair, 2001). This can be seen in patients who may be receiving care for a prior symptom of HF, are not asymptomatic, and/or who show signs of dyspnea or fatigue due to insufficient cardiac output. The fourth stage of HF is identified as an
individual showing signs of advanced structural heart disease with marked symptoms of HF at rest despite maximal medical therapy and involves specialized interventions (Hunt & Chair, 2001). Patients within this stage of HF usually have frequent hospitalizations, are awaiting heart transplant in the hospital, have in home care with continuous mechanical support, and/or are within the hospice setting. Constant monitoring and assistance it needed at many of the HF stages and can lead to the patient requiring additional care.

Although the HF patient can continue to be independent during the initial stages of HF, functional limitations do eventually appear with the progression of the condition. These can present as decreased ability of the HF patient to independently complete dressing, feeding, bathing, toileting, medical health, financial assistance, home care, and medication compliance which is why many of the individuals with HF require the assistance of a caregiver (Moghimi, 2007; Vellone et al., 2015). Due to caregivers providing extensive care to individuals experiencing HF, they may experience caregiver burden which can lead to decreased mental health, physical strain, stress, anxiety, depression, and reduced participation in leisure activities (NAC, 2015). This can lead to reduced quality of life for both the caregiver and HF patient.

The aging population is growing as a majority of the baby boomers are reaching retirement age. Due to sedentary lifestyles and unhealthy behaviors, the prevalence of HF is increasing. Because more individuals are being diagnosed with HF which leads to functional limitations, the need for caregivers is increasing. According to The National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) (2015), approximately 43.5 million individuals are providing unpaid caregiving
services to a relative with a disability or illness. On average, caregivers spend about 24 hours a week providing care to a loved one, with some caregivers providing more than 41 hours (NAC & AARP, 2015).

By completing a thorough literature review, the authors found that the role of caregiving consists of an individual providing needed care (assistance with medical care, activities of daily living, or financial obligations) to another individual who has a disability or illness which has lead to a decrease in the person’s ability to care for themselves (NAC & AARP, 2015). Because a lot of time is required to care for an individual with HF, many caregivers experience a reduced quality of life caused by declines in mental and physical health (NAC and AARP, 2015). In addition, many caregivers experience difficulties communicating with healthcare professionals about the HF patient’s needs, locating support and resources focused on respite services, obtaining transportation and receiving education about equipment, medical services, and resources that may assist with caregiving for an individual with HF (Doherty, Fitzsimons, & McIlfatrick, 2015; Ornstein, Smith, & Boal, 2009). Because education, services and support are important for caregivers to effectively care for the patient with HF, these needs should be addressed in order to decrease caregiver burden and increase quality of life for both the caregiver and individual with HF.

Occupational therapists (OTs) are crucial in providing education and resources for helping individuals and their caregivers with increasing participation in everyday occupations. With the provision of the caregiver guide, Happy Hearts: A Caregiver’s Guide to Assisting Patients with Heart Failure while using the OT supplemental guide, OTs are able to provide assistance to not only the caregiver but also the patient with HF.
This guide was developed with the intention of providing the caregiver with a definition of what HF is, what they can do for the individual with HF at each stage, what their role is, what the health professionals’ roles are, how to maintain physical and mental health, what environmental modifications are available, and what respite is and how to access respite services in order to decrease caregiver burden while maintaining health and wellness.

This caregiver guide was developed following the Person-Environment-Occupation (PEO) Model and the Adult Learning Theory in order to provide educational information understandable to the caregiver and helping the caregiver find the right fit between the person, environment, and occupation aspect within their lives. The PEO Model was an adequate model to use as it demonstrated the transactive approach of the personal aspects, the occupation of caregiving for an individual with HF, and how the environment influenced daily interactions associated with caring for an individual with HF. The person aspect is a unique entity that carries out a variety of roles which can change across the lifespan, the occupation aspect is a compilation of activities and tasks that are meaningful to the person or population, and the environmental aspect places importance on the cultural, socio-economic, institutional, physical, and social aspects from the perspective of the person, household, neighborhood, or community (Law et al., 1996). Occupations in the environments listed would determine the roles, activities or behaviors that a person demonstrates as a transactive interaction (Law et al., 1996). The Adult Learning Theory is centered on the learning preferences of adults, and since a majority of caregivers of individuals with HF are adults, this theory was appropriate to use for this caregiver guide as it placed emphasis on the fact that adults are self-directed.
learners, they have a variety of previous knowledge that contributes to the experience of learning, and it is critical that an adult be ready to learn both physically and emotionally (Knowles et al., 1998).

With the use of the caregiver guide, Happy Hearts: A Caregiver’s Guide to Assisting Patients with Heart Failure, it is the hope of the authors that caregivers will be able to take care of the individual with HF while experiencing a satisfactory quality of life and decreasing caregiver burden. By decreasing caregiver burden such as decreased physical and mental health, the caregiver is able to provide quality care to the individual with HF, maintain health and wellness, and be able to provide caregiving services to the individual with HF for a longer period of time within the home environment.
CHAPTER II
LITERATURE REVIEW

The authors completed a thorough literature review in order to develop a caregiver guide for patients with HF. The purpose of the review was to gain a better understanding of the role of caregiving, common characteristics of caregivers, caregiving responsibilities, psychosocial and physical aspects of caregiving, the interaction between the caregiver and patients experiencing HF, caregiver level of burden, what caregiver needs are when providing care, and environmental factors that have an effect on the provision of caregiving services. In order to locate literature to develop this guide, the authors searched common databases (PubMed, CINAHL, Google Scholar, Academic Search Premier, OT Search, American Journal of Occupational Therapy, Canadian Journal of Occupational Therapy, Sociological Abstracts and PsychInfo) using key terms such as: congestive heart failure, heart failure, cardiovascular conditions, caregivers of individuals with HF, caregiver burden, caregiver needs, programs for caregivers, caregiver respite, quality of life, informal caregivers, caregiver roles, causes of injuries, caregiving, transportation accessibility, chronic diseases, depression, telehealth, technology, physical injuries, physical strain, musculoskeletal injuries, occupational therapy, and occupational therapy interventions. From the authors’ search, a variety of literature articles were located that focused on the experiences of caregivers and individuals who had been diagnosed with HF.
Defining Heart Failure

Heart Failure is a progressive, chronic condition which affects over 5.1 million Americans annually (Center for Disease Control and Prevention, 2015). Heart failure can affect individuals in any age group, but is most prevalent in the elderly population (Barkman & Pooler, 2009). According to the CDC (2015), Americans spend approximately $32 billion dollars on health care services due to HF with a majority of costs associated with utilization of hospital services, medications, and missed work. Heart failure is produced by factors that reduce the pumping ability of the heart (Barkman & Pooler, 2009). Ultimately, when cardiac output, or the amount of blood pumped out of the heart, is insufficient to provide adequate blood flow to meet metabolic and circulatory demands, HF occurs (Houston, Kalathiya, Kim, & Zakaria, 2015).

The Stages of Heart Failure

The American College of Cardiology and the American Heart Association have developed guidelines in order to classify HF into four stages (Hunt & Chair, 2001). The initial stage is characterized by an increased risk of developing HF due to conditions that are strongly associated with it, however the individuals in this category are not yet showing signs or symptoms of HF. Examples of diagnosis in the initial phase include systemic hypertension, coronary heart disease, diabetes mellitus, or history of alcohol abuse, cardiotoxic drug therapy, or family members with chronic disease of the heart muscle.

The second stage of HF is described by the presence of structural heart disease that is associated with HF in the absence of signs or symptoms of HF (Hunt & Chair, 2001). Example of diagnoses falling into the second stage include previous heart attack,
left ventricular hypertrophy, or the thickening of heart wall, left ventricular dilation, and asymptomatic valvular heart disease.

The third stage of HF Hunt & Chair (2001) identified is characterized by current or prior symptoms of HF with underlying structural heart disease such as patients receiving care for a prior symptom of HF who are not asymptomatic, or show dyspnea or fatigue due to insufficient cardiac output. The fourth and final stage of HF Hunt & Chair (2001) is identified as advanced structural heart disease, marked symptoms of HF at rest despite maximal medical therapy and involves specialized interventions. Examples of diagnoses in this area include frequent HF hospitalizations resulting in an inability to be discharged, currently awaiting heart transplant in the hospital, in home care with continuous mechanical support, and the hospice setting. Due to the high instance of hospitalizations and decreased ability to care for themselves, many individuals experiencing HF need the assistance of a caregiver to aid with completion of daily tasks and obtain needed health services.

Occupation of Caregiving for Patients with Heart Failure

The Role of Caregiving for Patients with Heart Failure

The National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) (2015) reported that approximately 43.5 million individuals, within the past year, have provided unpaid caregiving services to a relative with a disability or illness. Caregiving entails providing needed care (assistance with medical care, activities of daily living, or financial obligations) to an individual who has a disability or illness that has decreased the individual’s ability to care for themselves (NAC & AARP, 2015). Caregivers spend on average about 24 hours a week providing
care to a loved one, with some caregivers providing more than 41 hours (NAC & AARP, 2015). This shows that caregivers devote a majority of their time throughout the week to caring for the individual with a disability or illness, which does not leave significant time for other important or meaningful tasks for the caregiver. Caregivers provide for their patients by assisting with activities such as: dressing, feeding, bathing, toileting, medical health, financial assistance, home care, and medication assistance (Moghimi, 2007; Vellone et al., 2015). With the decrease in time available to the caregiver to take care of personal obligations such as self care tasks or leisure participation, caregivers can start to experience a decrease in physical and mental health known as caregiver burden.

The length of time caregiving can also affect relationships amongst caregiver and their patient. Rothing et al. (2014), describe that as the role of caregiver progresses across time, the other familial roles a caregiver holds become overshadowed. This conflict of roles between caregiver and patient can often strain the relationship over time (Rothing et al., 2014). This ultimately strains the entire family and can result in isolation of family members (Rothing et al., 2014).

**Personal Aspects of Caregiving for Patients with Heart Failure**

**Caregiver Characteristics of Patients with Heart Failure**

According to Lum et al., (2014) 95 percent of caregivers for patients with HF are female, and 68 percent also work full or part time. Pressler et al. (2009) reported that approximately 43 percent of caregivers of patients with HF were spouses, 13 percent were adult children, and 7 percent were a relative, friend or other known individual. This indicates that a majority of caregivers of patients with HF are individuals that have a close and personal relationship with the patient. Buck et al. (2013) showed that a majority
of caregivers contribute support to patients with HF with self care activities such as: medication management, monitoring blood pressure, dietary needs, obtaining resources, scheduling medical appointments, contacting health care professionals, organizing information, exercises, weight monitoring, monitoring edema, fatigue management, and motivation for care activities. Due to caregivers providing a considerable amount of assistance and care to patients with HF, many caregivers need increased resources and support in order to decrease caregiver burden and increase the HF patient’s health and participation in self care activities (Buck et al., 2013).

**Experiencing Caregiver Burden While Caring for a Patient with Heart Failure**

Caregiver burden can be experienced by caregivers due to the high need for their services when caring for an individual with HF. Caregiver burden includes: decreased mental health, physical strain, stress, anxiety, depression, and reduced participation in leisure activities (NAC, 2015). According to NAC and AARP (2015), approximately 40 percent of caregivers experience a high level of burden due to their caregiving role. Ornstein, Smith, and Boal (2009) found that the unmet needs of caregivers have a large influence on caregiver burden. When needs of the caregivers are unmet, caregivers have higher instances of caregiver burden, but when those needs can be met through multidisciplinary care, caregivers and HF patients experience an increase in overall health and well being (Doherty et al., 2015; Ornstein et al., 2009).

Agren, Evangelista, and Stromberg (2010) found that caregiving responsibilities for individuals with HF have increased due to reduced hospital stays. Because patients are now transitioning home faster, the decrease in time at the hospital and the increase in responsibilities have lead to an increase in caregiver burden (Agren, Evangelista, et al.,
Contributors that have been identified with the increase in burden include strain, personal disappointment, environment, isolation, and emotional experiences, with strain being the highest contributor (Agren, Evangelista, et al., 2010). According to Agren, Evangelista et al. (2010), caregivers who had poorer mental health, decreased perceived control, and reduced physical health had a higher chance of experiencing burden. Additionally, Agren, Evangelista, et al. (2010) found that when the HF patients had co-morbidities, lower personal control of the disease, and decreased mental performance, caregivers experienced increased burden.

In assessing the health related quality of life of caregivers caring for patients with HF, Saunders (2009) also found that finances played a significant role. Although the specifics of the cost of informal caregiving are largely unknown, it was identified as a specific domain of burden in caregiving (Saunders, 2009). When assessing burden across a length of time, Sautter et al. (2014) found that the caregiver experience was relatively stable throughout one year. Additionally, prevalence of perceived burden of care remains similar in the first year of caregiving as well as the last year of life. This indicated to healthcare workers that an early intervention for caregivers is effective as burden of care is often perceived to be similar regardless of the stage of the disease (Sautter et al., 2014).

**Heart Failure Patient and Caregiver Relationships**

The relationships between patients and caregivers are influenced by a variety of different variables. Lum et al. (2014) found that the higher quality of relationship the caregiver saw with the patient, the less the caregiver perceived burden in tasks of caregiving. Relatedly, the lower quality the relationship between caregiver and patient, the higher caregiver burden was perceived. Often the caregivers are from the home
environment of the patients and are spouses, children, parents, siblings, or other extended family members (Graspa et al., 2014). Graspa et al. (2014) also describes the family as the foundation of the environmental support system for caregivers. Although 73 percent of caregivers knew of psychological support systems in the hospitals, only a minor portion utilized them and a majority relied on family members for support. Andreu et al. (2015) described that caregivers in this population had an increased rate of both hospitalizations and depression when caring for patients with a lack of familial support and an increased duration of care.

Luttik et al. (2009), focused on the experiences of female versus male caregiver partners and the extent of caregiver involvement with patients diagnosed with Congestive Heart Failure (CHF). Luttik et al. (2009) completed their study using an experimental group (individuals with CHF patient partner) and a control group consisting of the general public (individuals with a healthy partner). They found that female caregivers in the experimental group had decreased well being and perceived health compared to male caregivers in the experimental group one year post hospital admission (Luttik et al., 2009). In addition, female partners experienced worse psychosocial health, energy, and pain than males in both the experimental and control group (Luttik et al, 2009). Luttik et al. (2009) reported that this could be due to how each genders view their roles and whether females experience higher stress due to family and social obligations whereas males experience stress concerning work and financial obligations. Although no significant findings surfaced concerning quality of life between partners of individuals with CHF and those in the general population, interventions should be considered,
especially with female partners, in order to improve caregiver and patient health (Luttik et al., 2009).

Caregivers not only have to account for the physical well being of their patients, but their cognitive and psychosocial aspects as well. Foster et al. (2011) illustrated how cognitive impairments, depression, and executive functioning overall have a negative impact on patients with HF as the condition progresses. This decline in cognition could in turn have a negative impact on a patient’s engagement in meaningful tasks. Over time, participation in instrumental activities of daily living, leisure occupations, and social occupations was significantly restricted in patients with progressing HF (Foster et al., 2015). This information suggests that as HF progresses in a patient, caregivers will be required to care for not only basic self care tasks, but other encompassing areas of occupation as well.

**Psychosocial Aspects of Caregiving for Patients with Heart Failure**

Psychosocial health is important for caregivers as it determines the care they provide to the patient diagnosed with HF. According to Agren, Stromberg, Jaarsma, and Luttik (2015), in their study involving caregiver and HF patient partner dyads, both the caregiver and patient had a slight increase in perceived health following a three psycho-educational session administered by a multidisciplinary team. Even though there were slight increases in perceived health following the psycho-educational interventions, no significant decreases in caregiver burden were evident. Agren, Stromberg et al. (2015) thought that this lack of decreased caregiver burden in caregivers at baseline was due to subjects reporting a modest amount of burden in their experiences. Although there was a
slight increase in perceived health, the use of a psychoeducational intervention may be beneficial to caregivers and patients with HF (Agren, Stromberg et al., 2015).

Depression in caregivers of individuals with HF is a topic of discussion in the literature. Andreu et al. (2015) described a positive correlation between depression in caregivers, hospital readmissions, and an increased duration of care. Caregivers who initially have at risk or beginnings of deterioration of mental health status were found to present with increased depressive symptoms as the health of the patient they cared for declined and the caregivers were forced to make more decisions regarding their patient’s health; these aforementioned depressive symptoms can negatively influence a caregiver’s ability to provide effective care to their patient (Andreu et al., 2015). In addition, Pressler et al. (2009) found that caregivers who had increased depressive symptoms versus those that did not were more likely to experience negative life changes over time and experience decreased emotional health. Aspects that may lead to increased depression in caregivers are whether the caregiver believes they are able to take on the tasks of caregiving and if they have confidence with identifying the needs of the patient (Marcuccilli et al., 2014).

Moriarty et al. (2015) found that age can play a significant role in mental health for informal caregivers. Caregivers of an older age demonstrated more resilience in regards to the stress that corresponds with the occupation of informal caregiving when compared with caregivers of a younger age (Moriarty et al., 2015). Moriarty et al. (2015) noted that issues in mental health for informal caregivers of a younger age were significantly more prevalent than when compared to caregivers of an older age or caregivers of the same age who had recently been bereaved. Furthermore, caregivers
noted that persistent worry and stress were also a part of everyday life when caring for a loved one with HF (Marcuccilli et al., 2014). This stress did not significantly reduce throughout the duration of the study, suggesting that caregivers without resources for dealing with significant stress will not necessarily be able to experience reduced stress without intervention.

Amount of sleep can affect a caregiver’s mental health as well as these other factors. Pawl et al. (2013) noted that caregivers who experienced poor sleep habits were more likely to experience anxiety and a greater frequency of maladaptive coping methods, such as smoking, when compared with non-caregivers’ mental health and coping habits. Sleep loss can also influence the stress a caregiver experiences relating to their roles, and can put them and a greater likelihood of chronic disease themselves (Song, 2015).

The caregiver’s confidence plays an important role in whether the caregiver believes that they are able to contribute to self care activities and increase quality of life for the patient with HF (Vellone et al., 2014). According to Vellone et al. (2014), 80 percent of caregivers felt confident with being able to follow treatment advice, 61.4 percent about identifying HF symptoms, and 50.9 percent concerning if the treatment provided was able to alleviate HF symptoms. Caregivers were less confident with preventing symptoms and being able to decrease symptoms when they were occurring (Vellone et al., 2014). Vellone et al. (2014) found that higher caregiver confidence led to improved caregiver contribution to self care maintenance, leading to better patient outcomes. With caregivers beliefs that they are able to take care of the needs of the HF
patient, caregivers are able to provide better care to the patient and increase patient compliance with self care activities.

Length of time engaging in informal caregiving can affect mental health aspects as well. Moriarty et al. (2015) noted that a prolonged risk in declining mental health status exists with people of working age. This risk is influenced by disruptions to normal working life, employability, and attendant social support networks; all of these factors can contribute to longer-term mental health problems in young informal caregivers (Moriarty et al., 2015).

**Physical Aspects of Caregiving for Patients with Heart Failure**

Caregivers assist HF patients with completing multiple tasks throughout the day. Caregivers provide patients who are experiencing physical limitations with toileting, bathing, dressing, mobility, transfers and other associated physical tasks that can possibly lead to caregiver injury or discomfort (Darragh et al, 2013). According to the Canadian Association of Occupational Therapists (2010), older caregivers are at higher risk compared to younger caregivers with experiencing physical injuries due to pre-existing health issues, taking on unsafe health behaviors, having increased health restrictions and being subjected to increased physiological stress from caregiving activities. Physical characteristics that caregivers may experience include musculoskeletal injuries, sleep disorders, lack of energy, aggravation of current health conditions, and increased illnesses which can lead to decreased physical health (CAOT, 2010; Darragh et al., 2013; Gibson et al., 2015; Pawl et al., 2013).
Caregivers may experience musculoskeletal injuries from the physical stresses associated with lifting and repositioning a patient for completion of daily tasks. Darragh et al. (2013) reported that 38 percent of caregivers experienced high to extremely high amounts of physical stress from caregiving activities. In conjunction with the physical stress experienced, 75 percent of the caregivers reported experiencing lower back pain which led to a decrease in work, caregiving tasks and other important activities (Darragh et al., 2013). According to Darragh et al. (2013), pain ratings ranged between a three in the upper extremity to five in the back and knees, with seven being the highest during increased activity in the lower back, ankles, and upper extremities. Characteristics of the patient that can contribute to physical injury consist of the patient's ability to assist the caregiver, the physical characteristics of the patient, the physical requirements of the task, and the environment (Darragh et al., 2013). Due to limitations caused by physical injuries, caregivers can experience difficulties with caring for the patient with HF and decreased quality of life.

Caregivers may experience decreased physical health from the strain associated with caregiving activities. Pressler et al. (2013), found that physical health-related quality of life in caregivers remained poor and did not change across an eight month timeframe. This could possibly lead to a further decrease in caregiver physical wellbeing and quality of life if no changes were made to improve health (Pressler et al., 2013). Similarly, Fredman, Doros, Cauley, Hillier, and Hochberg (2010) found that, with instances of chronic stress, caregivers had a higher chance of experiencing metabolic syndrome which is associated with serious health problems such as heart disease. The authors found that indicators of metabolic syndrome can lead to mobility limitations and decreased walking
speed, which is also associated with decreased health and increased mortality (Fredman et al., 2010). Fredman et al. (2010) found that female caregivers who experienced stress and had indicators for metabolic syndrome had increased chances of experiencing decreased mobility and physical health. Due to having indicators of metabolic syndrome and increased stress, caregivers who have mobility limitations and health problems can experienced decreased quality of life and not be able to provide effective care for the patient (Fredman et al., 2010). In addition to experiencing decreased health, caregivers may also lack sufficient sleep to cope with stressful caregiving situations and allow their body time to regenerate.

Sleep is often an area that can be overlooked by healthcare professionals assisting caregivers in overall physical health. Caregivers in the home were found to be tired most of or all of the time at a significantly higher rate than those who were not caregivers Gibson et al. (2015). Furthermore, lack of sleep has been associated with greater fatigue and poorer health in caregivers (Pawl et al., 2013). Lack of sleep and the subsequent fatigue decreased family caregivers’ quality of life and can lead to implications in health and wellness overall (Pawl et al., 2013). Because sleep is essential for having the energy throughout the day for caregiving tasks, caregivers who lack sleep may experience decreases in health which can negatively impact the patient with HF.

**Caregiver Needs When Caring for Patients with Heart Failure**

A focus on the caregivers’ needs is essential for increasing quality of life for both the caregiver and the individual with HF. According to Ornstein et al. (2009), a majority of caregivers within urban populations’ required increased support concerning financial obligations, affordable housing, home based care, household tasks, medical information,
transportation and emotional support. Doherty, Fitzsimons, and McIlfatrick (2015) found common themes within their systematic narrative review centered on caregiver needs associated with psychosocial supports, daily living (leisure and personal healthcare needs), and health care system navigation. The studies completed by Ornstein et al. (2009) and Doherty et al. (2015) were found to have common similarities in the caregivers’ needs associated with assistance with information concerning the medical system and obtaining psychosocial/emotional support.

Caregivers’ health needs are also an integral factor to consider when assessing occupational performance in caregiving. Bradley (2003) suggests that there has been a lack of attention in regard to the health of caregivers of those with chronic diseases. Caregivers’ health may be overlooked to the point that the caregiver may experience more unmet needs than the patient (Bradley, 2003). Saunders (2009) suggested a need for healthcare professionals to create self report and physiological wellness screenings for caregivers of patients with HF in order to decrease further potential physical or mental decline and alleviate additional burden on the healthcare system.

Caregivers also experience significant emotional changes when initially beginning to care for an individual with HF. Caregivers who began to care for an individual with HF after a significant surgical event such as the implantation of a left ventricular assist device reported feeling self doubt in their caregiving abilities, although increased time was reported to alleviate some of these feelings (Marcuccilli et al., 2014). This indicates many caregivers would benefit emotionally and have increased confidence with caregiving tasks if more efficient methods of education and respite time were available to them in the community.
Respite Time for Caregivers of Patients with Heart Failure

Respite is essential for caregivers in order for them to take time away from caregiving responsibilities and decrease caregiver burden. Respite is associated with activities that provide a caregiver with time away from caregiving duties (Utz, Lund, Caserta, & Write, 2012). Respite can be provided informally or formally by friends, family members, co-workers, or other relatives (Utz et al., 2012). It may also entail fulfilling other obligations or rest breaks (Utz et al., 2012). In some instances, respite services may be provided by healthcare agencies or adult care services (Utz et al., 2012). According to the findings found in the study completed by Utz et al. (2012), the study participants had utilized respite adult care services, on average, for 33 hours per week for approximately 1.8 years. Over half of the caregiver participants in the study conducted by Utz et al. (2012) were paid employees and worked approximately 32 hours per week.

For some caregivers, work was a valuable respite activity providing social interactions and time away from caregiving responsibilities with lunch breaks providing time away to take care of other needed obligations (Utz et al., 2012). Other respite activities included: periodic naps or relaxation time, time with family and friends, exercise, helping others, travelling, hobbies and leisure, religious activities, personal health and wellness, watching television, preparing meals, and housework (Utz et al., 2012). While respite opportunities may be available, many caregivers, whether additionally employed or not, are not able to find enough time throughout the day for themselves (Utz et al., 2012). With increased resources on respite services and education on time management skills, caregivers would have more opportunities to complete
important and meaningful tasks. In addition to respite services, caregivers would also benefit from increased accommodations and support within the caregiving environment.

**Environmental Aspects of Caregiving for Patients with Heart Failure**

**Influences of Environment on Caregivers of Patients with Heart Failure**

Often the caregivers are from the home environment of the patients and are spouses, children, parents, siblings, or other extended family members (Graspa et al., 2014). Graspa et al. (2014) described the family as the foundation of the environmental support system for caregivers, and although 73 percent of caregivers knew of psychological support systems in the hospitals, only a minor portion utilized them and a majority relied on family members for support.

Home modifications are a factor that affects not only the patients, but their caregivers’ environment as well. Aplin & Gustafsson (2015) described that while home modifications were viewed as positive if done properly, some families experienced difficulties and additional stresses with the installation process; subsequently, this lead the families to have a negative experience with the home environment modification process. Additionally, some families viewed the change in their environment to be negative from a societal standpoint, describing large exterior modifications as reflective of disability or sickness (Aplin & Gustafsson, 2015).

**Transportation Accessibility for Caregivers of Patients with Heart Failure**

Access to transportation is an issue in healthcare that has been increasing in the past few years. Barriers to accessing affordable transportation can lead to negative effects on patients’ health including: rescheduled or missed appointments, delayed care, and missed or delayed medication use (Syed et al., 2013). The result of the negative effects of
inaccessible transportation can lead to even worse outcomes for patients, particularly in the realm of chronic diseases (Syed et al., 2013). The populations that are most often affected by a lack of availability in transportation are dominated primarily by those who earn lower incomes or are underinsured or uninsured (Syed et al., 2013). Ornstein et al. (2009) in their study concerning the unmet needs of caregivers of homebound patients, found that out of 56 participants, 26.8 percent stated that transportation services were difficult to obtain. Since transportation services are an important aspect of obtaining medical care for the patient, having no availability for transportation services can be detrimental to the patient's health. According to Ornstein et al. (2009), following an intervention focused on a home-based primary care (multidisciplinary) program consisting of physicians, nurses, social workers, patients, caregivers, friends and family, there was a significant decrease in the inability of caregivers to obtain transportation by almost 20 percent. This indicates that an at-home care team focused on education and provision of services can assist caregivers and patients with decreased stress of trying to locate needed services. However, these services can be costly, and other methods of delivering these services into caregivers’ natural environment can be considered.

**Telehealth Services & Technology for Caregivers of Patients with Heart Failure**

Telehealth services are an emerging area in healthcare. Telehealth is “the remote service delivery of health care services using information and communication technologies in which the provider and service recipient are in different physical locations” (Carson, 2015). Telehealth, also known as telemedicine, is accepted as an emerging model of service delivery within occupational therapy’s scope of practice, and involves health care services, health information, and health education (Carson, 2015;
telehealth is a method of delivering services that has the opportunity to increase overall
population health while containing costs in the process.

Telehealth can be used by healthcare professionals to assist clients in the
development of skills, education on assistive technology and adaptive techniques
modification of environments, and creation of habits and routines that promote overall
health (American Occupational Therapy Association, 2013). This concept of service
delivery is in alignment with the profession of occupational therapy in that it allows
healthcare providers the opportunity to access rural populations, decrease overall costs on
the health system, and increase population health (Carson, 2015).

When transitioning from the hospital to home, Chiang et al. (2012) evaluated
family caregiver burden, stress mastery and family function in family caregivers who
utilized telehealth interventions and traditional interventions with discharge planning
with HF patients. At one month follow-up, both the traditional intervention group and the
telehealth intervention group reported significantly better family function, higher stress
mastery, and less caregiver burden, as well as feeling more secure in monitoring the
condition of the HF patient they were caring for (Chiang et al., 2012). Telehealth
interventions have also been shown to be effective with rural caregivers who face higher
levels of stress and overburden related to their caregiving role (Dollinger et al., 2007).
Using telehealth in rural areas gives healthcare providers the opportunity to assist
informal caregivers with a variety of cultural backgrounds (Dollinger et al., 2007). These
findings indicate the value and effectiveness of telehealth in successfully managing
health in caregivers of those chronically ill as well as caregivers in rural areas. (Chiang
et al., 2012; Dollinger et al., 2007). Griffiths et al. (2010) also found that the use of the telehealth home messaging units with caregivers of veterans was beneficial to caregivers but showed no significant changes in self-rated depression, burden and caregiving self-efficacy following three months. This means that the telehealth messaging units did provide valuable assistance to caregivers, but did not provide enough assistance to decrease the negative effects associated with caregiving.

In addition to telehealth services, many caregivers are now able to utilize technology for services that can assist with caregiving responsibilities. Andruszkiewicz and Fike (2015) found that more caregivers are using technology for obtaining services. Such services include transportation assistance, ways to help maintain the home, devices for monitoring the patient, technology to assist with staying connected in the community, medication reminders, online support tools, assists with grocery shopping, and apps for additional caregiving services (Andruszkiewicz & Fike, 2015). Technology that Andruszkiewicz and Fike (2015) found that can assist caregivers with daily activities include apps and online resources for obtaining services such as Uber for transportation, Handy for home cleaning and maintenance, home delivery options with grocery shopping, Reminder Rosie for medication reminders, Lively for monitoring daily activities, and CareLinx for hiring, paying, and managing professional caregiver services. According to Andruszkiewicz and Fike (2015) many of the technologies available are still unknown by caregivers, which emphasizes the importance of providing the information and educating the patient and caregiver about the services available. By providing caregivers with information about emerging technologies, they can experience reduced burden with caregiving obligations (Andruszkiewicz & Fike, 2015).
Theoretical Framework

With the copious amount of information provided previously, an occupational therapy framework is required to organize and conceptualize it to ensure ease of access for both caregivers and OTs. The Person-Environment-Occupation (PEO) model was the primary theory used to help guide the literature review and subsequent product of this scholarly project. The PEO model is focused on finding the best fit between the client, their desired occupation, and the environment in which they participate (Law, 1996). This model is client-centered in that it focuses on the individual or population’s specific needs in the dynamic and transactive relationship between the person, environment and occupation (Law, 1996). Below is an overview of the three main concepts of the model.

- **Person**: a unique entity who simultaneously carries out a variety of roles. These roles change across the lifespan and are dynamic (Law, 1996). The person is a compound of mind, body, and spiritual qualities, and calls upon abilities or skills of the person such as motor performance, sensory capabilities, cognitive aptitude and general health to accomplish successful occupational performance (Law, 1996).

- **Occupation**: compilation of activities and tasks that are meaningful to the person or population and closely correlated (Law, 1996). Activity is the basic unit of a task in which a person engages in within their occupational experience. It is a singular pursuit which can be compounded to create a task (Law, 1996) such as typing on a computer. A task is therefore a set of purposeful activities that are engaged in to accomplish occupational performance (Law, 1996) such as creating a report or assignment on a computer. Occupation is then further defined as
multiple tasks that are functional, self-directed, and dynamic across the lifespan (Law, 1996) such as the occupation of a student. These activities and tasks fulfill engagement in occupation by meeting the individual or population’s needs of self-maintenance, expression, and fulfillment in a variety of environments and contexts (Law, 1996). Law (1996) further explained that occupations are influenced by time patterns that create occupational routines of the individual over the lifespan.

- Environment: places importance on the cultural, socio-economic, institutional, physical, and social aspects from the perspective of the person, household, neighborhood, or community (Law, 1996). Law (1996) incorporates the environment as a broad concept that outlines how persons interact in a variety of settings. Occupations in the environments listed would determine the roles, activities or behaviors that a person demonstrates (Law, 1996).

The interactions between these concepts are analyzed to maximize occupational performance in the client by looking at the goodness of fit between person and environment, occupation and environment, and person and occupation to locate discrepancies (Law, 1996). This model is used to facilitate occupational therapy practice by allowing therapists to obtain a clear-cut, comprehensive understanding of complicated occupational situations (Strong et al., 1999).

The Adult Learning Theory was an additional theory used to assist development of this project (Knowles, Holton, & Swanson, 1998). The Adult Learning Theory is known for its focus on the learning preferences of adults, and since a majority of caregivers of individuals with HF are adults, this theory was appropriate to use for this
project guide (Knowles et al., 1998). The Adult Learning Theory takes into consideration that adults are self-directed learners, they have a variety of previous knowledge that contributes to the experience of learning, and it is critical that an adult be ready to learn both physically and emotionally (Knowles et al., 1998). The most important concept of the Adult Learning Theory, when considering this resource guide, is that adults are problem-based learners rather than subject-based learners (Knowles et al., 1998). This concept directly applies to this resource guide in that it is education for the caregiver that is based on the assumption that there is a discrepancy or problem in the caregiver’s overall health and wellness.

Summary

HF is a progressive disease in which the heart is unable to effectively pump blood throughout the body to satisfy its needs for oxygen and other nutrients (Houston et. al., 2015). HF affects over 5.1 million Americans each year with about $32 billion dollars spent on health care associated with HF such as hospital services, medications, and missed work (CDC, 2015). The American College of Cardiology and the American Heart Association have developed guidelines in order to classify HF into four stages with the first stage focused on the risks associated with heart disease, the second on the presence of heart disease, the third stage on the presence of structural heart disease with previous or current HF symptoms, and the fourth stage characterized by advanced structural heart disease and the presence of symptoms in the patient at rest. Because HF leads to increased hospitalizations and decreased energy for participation in self care activities, caregivers are needed in order to assist the HF patient with completion and management of daily tasks.
Caregivers are an important aspect of a HF patient’s life and assist the patient with tasks that can be difficult such as self care maintenance, medication management, and attending medical appointments. Common general characteristics of caregivers include individuals who are female and are spouses, close family, or friends of the patient with HF (Lum et al., 2014; Pressler et al. 2009). A few areas that caregivers assist with include: activities of daily living, instrumental activities of daily living, leisure participation, advocating for patients, and symptom management (Buck et al., 2013). Due to caregivers providing a considerable amount of assistance to individuals with HF, many caregivers experience burden of care. Approximately 40 percent of caregivers experience a high level of caregiver burden. This burden can manifest in various ways, including decreased mental health, physical strain, stress, anxiety, depression, reduced participation in leisure activities, trouble navigating the medical system, and financial stress (Doherty et al., 2015; NAC, 2015; Saunders, 2009). Relationship quality between caregivers and their patients was described as having an indirect relationship with caregiver burden (Lum et al., 2014). Similarly, caregivers often utilize other family members as sources of support before utilizing hospital or community resources (Andreu et al., 2015; Graspa et al., 2014). The lack of this support was associated with increased hospitalizations and psychosocial decline in patients with HF (Andreu et al., 2015).

Caregivers may have difficulty obtaining needed services and resources due to a lack of knowledge related to the healthcare system, not knowing what resources are available and having no information about what services they can access in their community. Common areas that caregivers may need support with include financial obligations, affordable housing, home based care, physical assistance, caregiver health,
household tasks, navigating the healthcare system, transportation and psychosocial support (Doherty et al., 2015; Ornstein et al., 2009). Some needs may include environmental changes which can be often overlooked. This aspect of the environment such as home modifications, can affect caregivers in positive or negative ways depending on the caregiver’s viewpoints and social standards (Aplin & Gustafsson, 2015).

Utilization of resources such as telehealth and technology has been found to assist caregivers with locating and assisting with daily caregiving needs (Andruszkiewicz & Fike, 2015; Chiang et al., 2012; Dollinger et al., 2007; Griffiths et al., 2010). With these resources, caregivers are able to decrease instances of burden and stress and improve the quality of life for both the patient and themselves (Andruszkiewicz & Fike, 2015; Chiang et al., 2012; Dollinger et al., 2007; Griffiths et al., 2010).

The PEO model was used as the primary guide for the authors in producing this resource for assisting caregivers with caring for an individual with HF. The PEO model is focused on finding the best fit between the client, their desired occupation, and the environment in which they participate (Law, 1996). This model is client-centered and involves a transactive relationship between the person, environment and occupation (Law, 1996). The person aspect is the unique entity that simultaneous carries out a variety of roles within an environment (Law, 1996). The occupation aspect is multiple tasks and activities that are completed to meet the fundamental needs of a client’s meaningful roles. Examples of this include self-maintenance, expression, and accomplishments within specific contexts and environments across the lifespan (Law et al., 1996). The environmental aspects to consider within occupations and roles include cultural, socio-economic, institutional, physical, and social aspects that form the perspective of the
person, household, neighborhood, or community (Law, 1996). This model can be used by OTs in a variety of settings to inform practice (Strong et al., 1999). This transactive process has been found to guide the process of occupational therapy in difficult, multifaceted, and involved client scenarios (Strong et al., 1999).

In addition, the Adult Learning Theory was incorporated to assist the development of this project as it focuses on the learning preferences of adults (Knowles, Holton, & Swanson, 1998). Since many caregivers of individuals with HF are adults, this theory was appropriate to use for this project guide (Knowles et al., 1998). The Adult Learning Theory takes into consideration that adults are self-directed learners, they have a variety of previous knowledge that contributes to the experience of learning, and it is critical that an adult be ready to learn both physically and emotionally with the most important concept being that adults are problem-based learners rather than subject-based learners (Knowles et al., 1998). This concept directly applies to this resource guide in that it is education for the caregiver.

Occupational therapy is an appropriate discipline to assist in the creation and implementation of a resource guide. Occupational therapy analyzes the individual’s participation in all meaningful areas of life and uses a variety of methods to promote wellness in a particular individual, group, or population. Due to the extensive background OTs have in evaluating and addressing the health of caregivers, this discipline is appropriate to create and implement this resource guide with caregivers.

In conclusion, the authors created this product to address the various aspects of being a caregiver for an individual with HF. A product such as this has not yet been created for individuals who are caring for patients with HF, and the lack of continuity of
care for this population calls for the creation and implementation of a product such as this by qualified healthcare professionals. This product will provide caregivers with methods to increase their own health and wellness while providing quality care to the patient. Many caregivers describe aspects of burden related to the role of caregiving which can lead to unhealthy habits, psychosocial distress, and overall decrease in quality of life. This product, Happy Hearts: A Caregiver Guide to Assisting Patients with Heart Failure, is to be a resource guide used by caregivers of individuals with HF in order to assist them in taking care of their own health and wellness.

Being a caregiver requires extensive amounts of time and dedication for patients with HF. Having decreased health and the inability to obtain support can hinder the caregiver’s ability to utilize effective coping skills and maintain healthy routines which can increase hospital admissions and affect the quality of life for the patient. The caregiver’s role will change with the progression of the disease; this can lead to an increase in time, physical strain, and mental and emotional burnout.

The utilization of this resource guide will benefit caregivers’ overall health and wellness including physical, psychosocial, emotional, and environmental aspects related to the occupation of caregiving. In addressing these aspects of health, it is the authors’ hope that caregivers will achieve a balance in the transaction between themselves, their occupation of caregiving and their environment in order to effectively care for individuals with HF.
CHAPTER III

METHODOLOGY

The authors developed this guide, Happy Hearts: A Caregiver Guide to Assisting Patients with Heart Failure, in order to provide caregivers of patients with HF a way to manage their lives with information organized and easily accessible in one location. The information within the guide includes ways that the caregiver can manage contacts and questions for health professionals, education and information about the diagnosis of HF, information that assists with caregiver physical and mental health, environmental information and resources to assist with environmental factors that can contribute to mental and physical health, and ways to located respite services.

The Person-Environment-Occupation (PEO) Model was used to develop and establish this guideline for the scholarly project. The PEO Model was utilized due to its ability to demonstrate the transactive approach of the personal aspects, the occupation of caregiving for an individual with HF, and how the environment influenced daily interactions associated with caring for an individual with HF. The person aspect is a unique entity that simultaneous carries out a variety of roles. These roles can change across the lifespan and are dynamic (Law et al., 1996). The person is a compound of mind, body, and spiritual qualities, and calls upon abilities or skills of the person such as motor performance, sensory capabilities, cognitive aptitude and general health to accomplish successful occupational performance (Law et al., 1996). The occupation aspect is a compilation of activities and tasks that are meaningful to the person or
population and closely correlated (Law et al., 1996). Activity is the basic unit of a task in which a person engages in within their occupational experience. A task is therefore a set of purposeful activities that are engaged in to accomplish occupational performance (Law et al., 1996). Law et al., (1996) further explained that occupations are influenced by time patterns that create occupational routines of the individual over the lifespan. The environmental aspect places importance on the cultural, socio-economic, institutional, physical, and social aspects from the perspective of the person, household, neighborhood, or community (Law, 1996). Law (1996) incorporates the environment as a broad concept that outlines how persons interact in a variety of settings. Occupations in the environments listed would determine the roles, activities or behaviors that a person demonstrates (Law, 1996).

The Adult Learning Theory was also used to assist development of this project (Knowles, Holton, & Swanson, 1998). The Adult Learning Theory focuses on the learning preferences of adults, and since a majority of caregivers of individuals with HF are adults, this theory was appropriate to use for this project guide (Knowles et al., 1998). The Adult Learning Theory places emphasis on the fact that adults are self-directed learners, they have a variety of previous knowledge that contributes to the experience of learning, and it is critical that an adult be ready to learn both physically and emotionally (Knowles et al., 1998). This concept directly applies to this resource guide in that it is education for the caregiver in order to be knowledgeable about healthy behaviors when caring for themselves and the patient with HF.
In order to establish this guide to assist caregivers, a thorough literature review was completed from December 2015 to February 2016. Literature was located that focused on information associated with caring for patients with HF. Multiple articles were identified utilizing well known databases such as PubMed, CINAHL, Google Scholar, Academic Search Premier, OT Search, American Journal of Occupational Therapy, Canadian Journal of Occupational Therapy, Sociological Abstracts and PsychInfo. In order to locate pertinent articles to support the creation of this guide, the authors searched assorted combinations of the following terms: congestive heart failure, heart failure, cardiovascular conditions, caregivers of individuals with heart failure, caregiver burden, caregiver needs, programs for caregivers, caregiver respite, quality of life, informal caregivers, caregiver roles, causes of injuries, caregiving, transportation accessibility, chronic diseases, depression, telehealth, technology, physical injuries, physical strain, musculoskeletal injuries, occupational therapy, and occupational therapy interventions.

Following our literature review, caregiver unmet needs were identified such as difficulties communicating with healthcare professionals about the HF patient’s needs, locating support and resources focused on respite services, obtaining transportation and receiving education about equipment, medical services, and resources that may assist with caregiving for an individual with HF (Doherty, Fitzsimons, & McIlfatrick, 2015; Ornstein, Smith, & Boal, 2009). In addition, having resources that focus on helping the caregiver with staying healthy both mentally and physically were identified as high importance. Identification of these needs is what led to the creation of this guide, Happy Hearts: A Caregiver Guide to Assisting Patients with Heart Failure.
Happy Hearts

A Caregiver’s Guide to Assisting Patients with Heart Failure

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Mandy Meyer, Ph.D.
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Introduction
As an individual who is caring for someone with heart failure, there may be various aspects of your life that become overwhelming and challenging such as taking care of your health, talking to healthcare professionals, taking time to yourself, and located needed items to assist with caregiving activities in the home. This manual was made to help you find the right fit between you as a person, the job of caregiving, and your home and/or social environment.

**What to Expect from this guide**

This guide defines and organizes the characteristics of heart failure, your physical health and mental health, your home environment, and the role you fill as a caregiver in depth. The hope is for you to live a healthy and happy life while fulfilling your role as a caregiver.

There are also questions to consider throughout the guide that you can apply directly to your life. Additionally you will find ideas to help you with ways to maintain your health while organizing areas of your life.
Defining Heart Failure & Heart Failure Stages
Heart Failure

This condition occurs when the heart is no longer able to move oxygen through the blood in a way that adequately reaches all parts of the body. The heart muscle is no longer able to sufficiently contract, or squeeze, the blood through its chambers. Heart failure can be a result of any cardiac condition that decreases the pumping ability of the heart. There are four different stages that individuals progress through with heart failure that will be outlined in this manual.

Who does heart failure affect?

- Heart failure can occur in anyone, but it primarily affects the older population
- According to the American Heart Association, heart failure affects over 5 million individuals in the United States

How fast is the onset?

- The onset of heart failure is usually a slow, progressive build-up of factors that affect the heart
- Although the duration of progression is generally slow between the stages of heart failure, that time can vary depending on the individual and their specific condition(s)

The stages of heart failure are outlined on the following pages.

Center for Disease Control and Prevention, 2015; Barkman & Pooler, 2009
Symptoms of Heart Failure

There are many different symptoms that can be present in heart failure. Symptoms can vary depending on the person and the stage of the condition. The following list includes common symptoms of heart failure, but is not a comprehensive list of the symptoms that can occur.

Common Symptomatology of Heart Failure:

- Shortness of breath
- Chronic, dry, unproductive cough
- Respirations that gradually increase in depth, also known as Cheyne-Stokes respirations
- Pulmonary edema
- Fatigue that increases as the day progresses
- Weakness
- Confusion or impairments in memory
- Anxiety or restlessness
- Insomnia
- Significant changes in urinary output
- Malnutrition
- Cyanosis, also known as a bluish discoloration of the skin due to lack of oxygen
- Arrhythmias, also known as irregular or abnormal heart rate

This list is not comprehensive, but may include some symptoms your loved one experiences. It is important to have access to medical attention should symptoms progress or worsen in your loved one.

Hunt & Chair, 2001
Stage 1

In the first stage of heart failure is being at risk of developing heart failure. Although there are not any structural or functional problems in this stage, the risk comes from having conditions that are associated strongly with heart failure.

Examples of conditions that occur in Stage 1:

- Systemic hypertension (high blood pressure)
- Diabetes mellitus
- Coronary heart disease
- History of cardiotoxic drug therapy
- History of alcohol abuse
- Family history of cardiomyopathy

The function of the individual is not impaired in Stage 1, but prevention is a key aspect to consider in this stage of heart failure.

Hunt & Chair, 2001
What to Expect at Stage 1

During the first stage, your loved one will demonstrate the signs and symptoms of heart failure through conditions such as hypertension, diabetes and heart disease. It is important for you, as a caregiver, to assist with reducing habits that can lead to heart failure. Things you can do to slow down the process and reduce the chances of your loved one from experiencing heart failure include:

- Plan out reduced fat, healthy meals to make
- Work on an exercise routine with your loved one such as walking around the block or taking an exercise class
- Encourage your loved one to quit smoking
- Encourage reduced alcohol intake
- Make meals low in sodium
- Monitor existing conditions (diabetes, high blood pressure, etc.)
Stage 2

In the second stage of heart failure there is a presence of heart disease in the structure of the heart. No signs or symptoms of heart failure are yet present.

Examples of conditions that occur in Stage 2:
- Previous heart attack
- Valvular heart disease without symptoms
- Enlargement of the left chamber of the heart
- Dilation or dysfunction in the left chamber of the heart

The function of the individual may be impaired in Stage 2, and it is important to have contact with your primary care provider in this stage.
What to Expect at Stage 2

During the second stage, your loved one may demonstrate a decrease in function associated with damage to the heart. Damage may be due to the conditions such as a heart attack, enlargement of the left chamber of the heart, and valvular heart disease. Things you can do to assist your loved one with maintaining function include:

- Continue with reduced-fat, healthy meals
- Work on an exercise routine with your loved one and their physician to maintain health and wellbeing
- Encourage your loved one to quit smoking
- Encourage reduced alcohol intake
- Continue with low sodium meals
- Monitor existing conditions (diabetes, high blood pressure, etc.)
- Monitor for fatigue, decrease in self care, and loss of energy
- Assist your loved one with medication reminders if prescribed by their physician
Stage 3

In the third stage of heart failure, your loved one experiences current symptoms of heart failure or has experienced symptoms prior. Additionally, in this stage the heart has underlying structural heart disease.

Examples of conditions that occur in Stage 3:

- Difficult or labored breathing due to decreased pumping ability in the left chamber of the heart
- Fatigue due to decreased pumping ability in the left chamber of the heart
- Receiving treatment for prior symptoms of heart failure without current symptoms

The individual may be experiencing impairments in some areas of life and require assistance. Level of assistance required is variable and changes depending on the person.

Hunt & Chair, 2001; Microsoft Office, 2007
What to Expect at Stage 3

During the third stage, your loved one will demonstrate a decrease in function associated with damage to the heart. Damage to the heart may cause difficulty breathing, fatigue, muscle loss, swelling in the lungs, abnormal heart rhythm, fluid retention, sleep difficulties, and stomach problems. Things you can do to assist your loved one with maintaining function include:

- Continue with reduced-fat, healthy meals
- Talk to your loved one’s physician about continuing exercise
- Encourage your loved one to quit smoking
- Encourage reduced alcohol intake
- Continue with low sodium meals
- Monitor symptoms of heart failure (swelling, difficulty breathing, clammy/blue tinted skin)
- Contact physician if symptoms are causing your loved one difficulties
- Assist your loved one with medication reminders if prescribed by their physician
Stage 4

In the fourth stage of heart failure the structure of the heart is in advanced heart failure. There are marked symptoms of heart failure apparent at rest regardless of medical treatments. There is a need for specialized interventions from medical professionals.

Examples of conditions that occur in Stage 4:

- Frequent hospitalizations for treatment of heart failure or cannot be discharged due to severity of disease
- Awaiting a heart transplant in the hospital
- At home with continuous support
- In a hospice setting for management of heart failure

In this stage your loved one requires much assistance with caring for themselves. Medical professionals from many different backgrounds are intervening with your loved one to assist with optimizing quality of life.

Hunt & Chair, 2001; Microsoft Office, 2007
What to Expect at Stage 4

During the fourth stage, your loved one will need significant help with everyday tasks. During the advanced stage of heart failure, it is important to ask health care professionals about the needs of your loved one as well as information about what you can do to help your loved one at this stage. Things you can do to assist your loved one with maintaining function include:

- Continue with low sodium healthy meals
- Continue to monitor symptoms of heart failure (swelling, difficulty breathing, clammy/blue tinted skin)
- Communicate with healthcare providers on symptom management, medications, and your loved one’s needs
- Assist your loved one with reminders and taking medications
- Monitor device care (pacemaker or left ventricle assist devices (LVADs))
- Monitor fluid retention
- Help your loved one feel comfortable
Your Role as the Caregiver
**Being a Caregiver**

Being a caregiver is a difficult job. It requires a lot of time and dedication to your loved one. It can be hard on you physically and mentally while not allowing much time for other personal tasks. As a caregiver, you are responsible not only for yourself, but also for your loved one with heart failure. Being a caregiver, you face many challenges in finding the best match between you as a person, the job of caring for your loved one, and the environment you are in.

Your health is important. You are the primary care provider for your loved one and being healthy is vital in order to continue caring for your loved one.

Provided on the following pages are ways to make your job of caregiving a little easier by listing what ways to organize your role as a caregiver, what is needed during each stage of heart failure and how to encourage your loved one to assist with self care tasks.
Providing Help at Each Stage of Heart Failure

Stage 1

During the first stage, your loved one will demonstrate the signs and symptoms of heart failure through conditions such as hypertension, diabetes and heart disease. Your loved one is still independent at this stage with self care activities, but may need assistance with:

- Managing medications
- Healthy meal planning
- Management of existing conditions (monitoring symptoms, controlling blood pressure, and controlling diabetes)
- Speaking to healthcare providers about management of existing conditions
- Planning exercise routines and healthy behaviors

Hunt & Chair, 2001
Stage 2

During the second stage, your loved one may demonstrate a decrease in function associated with damage to the heart. Your loved one remains independent with self care activities, but may need assistance with:

- Continued healthy meal planning
- Managing medications
- Management of existing conditions (monitoring symptoms, controlling blood pressure, and controlling diabetes)
- Speaking to healthcare providers about management of existing conditions
- Planning exercise routines and healthy behaviors
- Assistance with monitoring fatigue, decreased participation with self care, and energy loss

Hunt & Chair, 2001
Stage 3

During the third stage, your loved one will demonstrate a decrease in function associated with damage to the heart. Damage to the heart may cause difficulty breathing, fatigue, muscle loss, swelling in the lungs, abnormal heart rhythm, fluid retention, sleep difficulties, and stomach problems. During this stage your loved one will need more assistance with activities such as:

- Dressing with assistive equipment
- Grooming tasks with assistive equipment
- Bathing/Showering with bench or shower chair
- Getting in and out of bed
- Getting in and out of chairs
- Preparing light meals with frequent rest breaks
- Getting around the community with walker or wheelchair
- Getting around the home with walker or wheelchair
- Assistance with monitoring fatigue, decreased participation with self care, and energy loss
- Management of existing conditions (monitoring symptoms, controlling blood pressure, and controlling diabetes)
- Planning exercise routines and healthy behaviors
- Contacting healthcare providers concerning symptoms of heart failure
- Managing medications

Hunt & Chair, 2001
Stage 4

During the fourth stage, your loved one will continue to show signs of heart failure and will need significant help with everyday tasks. During the advanced stage of heart failure, it is important to ask health care professionals about the needs of your loved one as well as information about steps to take. During this stage your loved one needs significant assistance with activities such as:

- All dressing, bathing/showering, and grooming tasks
- Meal preparation
- Managing medications
- Assistance with monitoring fatigue, decreased participation with self care, and energy loss
- Communicating with healthcare providers about symptoms of heart failure and keeping loved one comfortable
- Getting around the home and community in a wheelchair
- Managing and monitoring electronic transplant, pacemaker or assistive devices for the heart
- Lifting and moving to and from bed, toilet, chairs, shower/bath, vehicle and wheelchair

Hunt & Chair, 2001
Answer the questions below in order to determine what areas of caregiving are hard on you emotionally and physically and how ready you are to make changes in your life in order to increase your health and wellbeing.

What aspects of your life make it difficult to fulfill the role of caregiver?
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________

How ready do you feel to make positive changes in your life to maximize your health and wellbeing?
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
_________________________________________________________________________
Encouraging Your Loved One

During the first three stages of heart failure, it is important to allow your loved one to help with completion of self care activities as much as possible. This can decrease the strain on you while giving your loved one a sense of control over their life. During the fourth stage, it is important to allow your loved one to help with what they can while also providing comfort. By letting your loved one participate as much as possible, they can feel a sense of independence while you can decrease your chances of feeling overwhelmed and fatigued. Ways to motivate your loved one with participating in activities include:

- Provide positive feedback with successful task completion
- Assist only when needed
- Talk to your loved one about tasks they want to complete
- Give your loved one plenty of time to complete tasks

You are an important part of your loved one’s life and it is important that planning and completion of self care tasks is a collaborative team effort between you and your loved one. By having this collaborative relationship you and your loved one can experience better health and quality of life.
The Role of Healthcare Professionals In the Healthcare System
Healthcare Professionals

As a caregiver, you may encounter a large variety of healthcare professionals who are assisting your loved one. It can be difficult to remember the roles that each member of the team takes, and what treatments they may be doing to maximize your loved one’s health. This section gives you a reference to the general roles each member of the healthcare team fulfills.

As a caregiver, you will meet many healthcare professionals and be given a large amount of information. Along with providing definitions, the following pages help you with ways to store contact information for your loved one’s healthcare team to ensure you can contact them with any questions you may have regarding your loved one’s care.
**Primary Care Physician:** Responsible for the first contact of care for a health concern. Diagnoses, evaluates, and provides general treatment options; is able to prescribe medications. The primary care physician continues to provide care for an individual across the lifespan.

Name: ________________________________

Position: ________________________________

Phone: ________________________________

**Cardiologist:** A specialized doctor who focuses on caring for the heart. The Cardiologist provides specific diagnoses, evaluation, and treatment for cardiac care.

Name: ________________________________

Position: ________________________________

Phone: ________________________________
**Pharmacist:** Responsible for preparing, dispensing, and regulating medicinal drugs. Provides education regarding side effects of medications and how to properly take medications.

Name: ________________________________________________

Position: ______________________________________________

Phone: ________________________________________________

**Nurse:** Responsible for providing everyday care, helping manage interventions, administering medications, and providing general health education.

Name: ________________________________________________

Position: ______________________________________________

Phone: ________________________________________________
**Occupational Therapist:** Responsible for evaluation and interventions to assist individuals to gain independence in all aspects of life. Assists with self-care, mental function, mood, and modifications to the environment, especially in the home.

Name: ____________________________________________

Position: __________________________________________

Phone: ____________________________________________

**Physical Therapist:** Responsible for evaluations and interventions to improve the physical stamina and function in individuals. Assist with home evaluations.

Name: ____________________________________________

Position: __________________________________________

Phone: ____________________________________________
Respiratory Therapist: Responsible for evaluation and interventions to improve an individual’s ability to breathe adequately and independently. Monitors changes in breathing and lung capacity.

Name: ________________________________________________________________

Position: ______________________________________________________________

Phone: ______________________________________________________________

Dietician: Responsible for planning meals for patients to maximize nutrition. Tracks what the individual eats and drinks and provides education on a heart healthy diet.

Name: ________________________________________________________________

Position: ______________________________________________________________

Phone: ______________________________________________________________
**Social Worker:** Responsible for helping the individual with heart failure and their family find resources such as medical equipment, and information regarding finances and insurance.

Name: ___________________________________________________________

Position: __________________________________________________________

Phone: ___________________________________________________________

**Certified Nursing Assistant (CNA):** Responsible for assisting with general self-care tasks. Is directed and supervised by other healthcare professionals such as nurses.

Name: ___________________________________________________________

Position: __________________________________________________________

Phone: ___________________________________________________________
Factors that Effect Caregiver Physical Health
Injuries

Caregiving can be hard on your body. When helping the person you are caring for with everyday activities it is important to be careful to not injure yourself. Common signs of bodily injury include:

- Muscle tension
- Aching joints
- Fractures
- Difficulty moving
- Back pain

Other signs that may appear if you are over working your body include:

- Increased tiredness or lack of energy
- Headaches
- Sleep difficulties
- Frequent illness

On the following pages are ways you can reduce bodily injury in order to stay healthy.

Invision Sally Jobe, 2016
General Safe Lifting & Moving Guidelines

It is important to follow safe ways of lifting and moving. Provided are safe lifting and moving tips to assist you when moving or lifting your loved one in the home in order to prevent injuries to your body.

- Be aware of the person you are lifting and their abilities so that you can anticipate possible difficulties when moving
- Keep your stomach muscles tight, back straight, and use your leg muscles to lift
- Keep head and neck aligned with back
- Do not twist or rotate your body
- Move your whole body in the direction of where you are moving your loved one
- Position yourself close to your loved one and make sure your footing is stable
- Be sure to communicate what you are doing when moving or positioning your loved one
- Do not attempt to move someone who is too heavy; get someone to help

CCOHS, 2016; Orthoinfo, 2016
• Make sure that your loved one does not grasp you around the neck as this could result in injury to you
• Have your loved one put their hands on your shoulder to prevent injury to you
• Make sure that the area where you are doing the lifting or moving is clear of clutter and furniture

* Do not grab your loved one under his or her armpits as this could injure the person you are moving
* Maintain the natural curve to your back while lifting
* Do not bend at the waist
* Use leg muscles to complete the lift or move

By following these recommendations, you can reduce injury to both you and your loved one while maintaining safety and wellbeing.

CCOHS, 2016; Orthoinfo, 2016
Safety in the Home

As a caregiver, it is important to check the area around you and prepare before starting to move or lift your loved one to increase safety in the home. Provided is an area checklist to aid in checking your surroundings before completing a move or lift during caregiving activities in order to reduce injuries to you and your loved one.

**Area Checklist for**

- All area rugs are secure or moved to prevent tripping
- All furniture is clear of area or removed to allow room for lift or move
- Area of move is stationary and secure
- All pets are removed from the area or secured to prevent tripping
- Cords are secure and not in path of move in order to reduce tripping
- Lighting is adequate to complete the move or lift
- Area is free of noise or distraction to increase focus on the move or lift
- Location of move is close by to decrease injury
- Person caring for is able to be moved
- Person caring for is aware of the move or lift
- Someone is available to help with a heavy lift
- Wheelchair is locked to prevent injury
Contact Information to Help with Lifting

When caregiving, it is important to have contact information close by in order to get assistance with moves and lifts that are too heavy or difficult. Provided is an area you can keep information of individuals who are able to come and assist you if needed.

Name: _________________________________________
Phone: ____________________
Times Available to Help: __________________________

Name: _________________________________________
Phone: ____________________
Times Available to Help: __________________________

Name: _______________________
Phone: ____________________
Times Available to Help: __________________________

Name: _______________________
Phone: ____________________
Times Available to Help: __________________________
Specific Ways of Moving and Lifting

The following information can assist you with moving your loved one to another location. Provided are specific ways to move during different tasks.

Moving Loved One to Edge of Bed

- Raise height of bed to comfortable working height (if adjustable)
- Move loved one a single body section at a time (feet first, than mid-section, than head and neck)
- Roll, lift, or pull loved one in direction of sit (never push as this can cause injury)

Moving Up in Bed

- Raise height of bed to comfortable working height (if adjustable)
- Lower head of bed so loved one is laying flat
- Lower or remove bed rails if present
- Place one arm beneath and the other at your loved ones shoulder area to guide
- Get as close to loved one as you can
- Bend knees, spread feet apart to stabilize, and back straight
- Communicate and use verbal cues such as “now” when ready
- Have loved one help to adjust and move up in bed

CaregivingHelp, 2014
Moving from Bed to Wheelchair

- Make sure wheelchair brakes are locked
- Have wheelchair close for move
- Have loved one hold onto farthest armrest on wheelchair
- Wrap your arms around person’s waist and clasp hands
- Bend your knees, keep feet far apart and stable, and have back straight
- Provide verbal cue to initiate move such as “now”
- Lift and shift footing a quarter of a turn to wheelchair
- Adjust armrests and footrests so person you are caring for is comfortable
- You can also use this technique when moving from a chair to a wheelchair

Moving from Wheelchair to Bed

- Make sure wheelchair brakes are locked
- Bring wheelchair as close as possible to bed or move surface
- Ask person to place hand on bed rail or on your shoulders
- Wrap your arms around person’s waist and clasp hands
- Bend your knees, keep feet far apart and stable, and have back straight
- Provide verbal cue to initiate move such as “now”
- Lift and shift footing a quarter of a turn to wheelchair
- Keep close to person and stabilize footing
- If possible unlock breaks and move wheelchair
- Ask person caring for to place hands on bed to sit
- You can also use this technique when moving from a wheelchair to a chair
Types of Lifts for Moving and Lifting

If you are unable to move or lift your loved one, there are other options available that can assist you and prevent injury. Provided below are two options that can help you with moving or lifting your loved one from one location to another within the home.

1. Sling Lift: A sling lift (powered Hoyer lift) is an alternate way to help you to lift and move your loved one from one location to another. The sling lift involves placing a sling under your loved one’s body which gets hooked to a cradle so that it supports your loved one’s weight. The cradle can be raised, lowered, and moved from one location to another.

   - Benefits of the Sling Lift include:
     - Helps with safely moving heavier persons
     - Assists with moving persons not able to stand independently

   - Disadvantages include:
     - Requires a large space to maneuver
     - Difficult to move on carpet
     - High cost

_Picture 1. Sling Lift. 2016._
Photograph. Yorhom Medical Essentials.
2. **Sit-to-Stand Lift**: A Sit-to-Stand lift is another alternate way to help you to lift and move your loved one from one location to another. The Sit-to-Stand lift assists by placing a sling under your loved one’s arms (while sitting) which is attached to two connected lift arms. The arms are connected to a base that is able to be moved. Your loved one grabs the handles on the lift and puts their feet on the foot rest while knees and shins are pressed against support pads. Your loved one is then raised to standing position and moved toward the designated location.

- **Benefits of the Sit-to-Stand Lift include:**
  - Helps with safely moving heavier persons
  - Provides opportunity for your loved one to assist with move
- **Disadvantages include:**
  - Requires a large space to maneuver
  - Difficult to move on carpet
  - High cost

*Be sure to talk to your loved one’s doctor or an occupational therapist for other equipment options to help you with moving or lifting your loved one in the home.*

Advanced Healthcare Network, 2016; Yorhom Medical Essentials, 2016
Stretching

Stretching is a good way to relax muscles and increase flexibility to prevent muscle strain and injuries. As a caregiver, you will be able to complete these stretches in your home environment to increase your strength for caregiving tasks. Stretches can be completed during anytime of the day, but are especially important before moving or lifting your loved one. The following are some stretches to assist you with preparing your body for moving or lifting tasks and decreasing injury.

Things to Remember when Stretching:

- Always warm up before a stretch to get muscles ready
- Breath normally while stretching, never hold your breath
- Go slowly into each stretch so as not to cause injury
- If you feel a shooting or stabbing pain, stop stretching

*Always talk to your doctor before starting a stretching routine to make sure you are healthy enough for stretches
Neck Stretch

- This stretch can be done while standing or sitting
- Keep feet flat on floor shoulder width apart
- Slowly turn head to the right making sure not to tilt or tip head forward or backward.
- Turn till feel a slight stretch without pain
- Hold 10 to 30 seconds
- Now turn head to the left and do the same as the right
- Hold 10 to 30 seconds
- Repeat 3 to 5 times

Shoulder Stretch

- Stand with back against the wall
- Feet flat on floor and shoulder width apart
- Put arms straight out to the side against the wall
- Bend elbows up so hands are now facing the ceiling and the back of your hands touch the wall behind you
- Hold for 10 to 30 seconds
- Bring arms forward while still bent so that they are facing towards the floor with palms against the wall behind you
- Hold for 10 to 30 seconds
- Repeat 3 to 5 times alternating between pointing hands at ceiling and pointing hands at floor
Upper Body Stretch
- Stand towards the wall slightly farther than arms length away with feet shoulder width apart
- Be sure not to stand too far back or this could result in injury
- Lean body forward so hands are against the wall at shoulder height and shoulder width apart
- Keep back straight slowly walking hands up the wall till you feel a slight stretch
- Hold 10 to 30 seconds
- Slowly walk hands back down to shoulder height
- Repeat 3 to 5 times

Chest Stretch
- This stretch can be done while standing or sitting
- Make sure feet are flat on the floor, shoulder width apart
- Hold arms at your side with elbows straight and palms facing forward
- Slowly move arms back while squeezing your shoulder blade until you feel a slight stretch
- Hold for 10 to 30 seconds
- Repeat 3 to 5 times

NIH, 2016
**Back Stretch**

- Sit on front portion of a chair with arm rests
- Have feet flat on the floor, shoulder width apart
- Slowly turn your waist towards the left while keeping your hips straight
- Turn your head to the left
- Put left hand on armrest of chair and right hand on outer left thigh till you feel slight stretch in back
- Hold for 10 to 30 seconds
- Repeat on right side
- Repeat, alternating sides, 3 to 5 more times

NIH, 2016
Exercise

Exercising helps your muscles to stay strong and protected while moving or lifting your loved one. It can also assist with reducing stress that can arise from completing caregiving tasks. Exercises can be completed in your home and assist you with maintaining strength for caregiving tasks.

*Be sure that before starting an exercise routine you talk to your physician to determine if you are healthy enough for exercises.

Also, be sure that before completing any exercise routine that you complete a warm up and a cool down after to decrease muscle injury. Warm ups are at the beginning of completing an exercise routine and consist of either stretching your muscles or walking at a light pace for approximately one minute. Following your exercise, complete a cool down, such as walking at a normal pace, in order to reduce injury to your muscles.

Provided are some exercises you can do in a short amount of time to increase your strength and reduce your chances of experiencing injuries.
Push Ups Against the Wall

- Stand on the balls of your feet at arms length from the wall
- Place your palms on the wall making sure they are in line with your shoulders
- Keep your back and legs straight
- Lean your body toward the wall
- Slowly push away with arms which will put you back at your starting position
- Repeat

Side Crunch

- Stand up straight
- Raise your left arm above your head
- Rotate your left leg at the hip while turning your toes out
- Crunch your left elbow and left knee together like you’re pinching your waist
- Return to regular standing position
- Repeat previous steps, but this time on right side
- Continue while alternating sides
**Side Step Squat**

- Stand with feet together
- Step your left foot out to your left bending knees and hips slightly while keeping back straight
- Bring the right foot to meet the left so that you are standing with feet together again
- Repeat previous steps but to your right side
- Continue while alternating sides

Bowman, 2014; ElderGym, 2016; Microsoft Office, 2007
Cat and Camel Exercise

- Start by getting on your hands and knees either on your bed or the floor making sure you can safely get back up
- Keep your back in a neutral position
- Round your back up and bring your head down to make like a cat arching its back
- Then reverse by allowing your back to relax forming the valley between the camel’s two humps.
- Return to starting position
- Repeat 10 times

*Keep these tips in mind during Cat and Camel exercises:

- Remember to keep breathing in through your nose and out through your mouth
- Keep your stomach muscles tight and maintain pelvis in a natural position to start
- If feeling pain in your wrists, lower yourself onto your elbows
- Use gardening pads to protect knees if kneeling on the floor

Bowman, 2014; ElderGym, 2016
Sit Backs

- Slowly sit back as far as you can while staying comfortable
- If needed, have a chair or sturdy surface behind you so you do not fall back too far
- Return to the start position
- Repeat 10 times

*Keep these tips in mind during Sit Back exercise:

- Tighten your stomach muscles
- Stop if feet start to come off the floor
- Keep your back straight as you sit back

Bowman, 2014; ElderGym, 2016
Protecting Your Joints

Protecting your joints is essential when caregiving for your loved one. Not protecting your joints can lead to weakness, pain and possible injuries. The following information provides you with ways to protect your joints so you will be able to continue to help your loved one with everyday activities within the home environment.

Try to:

- Be aware of the position of your body
- Keep body in its natural position as much as possible for tasks
- Be aware of pain lasting over two hours following completion of a task
- Take breaks in between activities
- Use utensils or tools with large grip handles
- When opening jars use palm of hand and shoulder to twist or use jar grips which are tools available at retail stores to assist with gripping onto and opening a jar
- Have tasks at a good height to prevent bending at waist or twisting the body
- Stay healthy and active to prevent weakened joints
- Use large muscle groups for tasks
- Use a commercial reacher, a tool that you can purchase to assist with picking items from floor
- Plan the next day’s activities to determine what they involve and how you are going to accomplish the tasks
• Alternate between tasks and rest breaks
• Stabilize body and spread weight of task between multiple joints
• Have a chair near in order to sit down and rest during tasks
• Keep frequently used items in easy reach to prevent awkward body positions or bending
• Have someone help with tasks

Avoid:
• Putting your body in uncomfortable and awkward positions
• Overusing your joints which can lead to injury and pain
• Completing activities that puts strain on joints
• Completing activities requiring tight grip
• Doing activities requiring tight pinch, grip, or twisting motions
• Bending to pick up items off the floor
• Trying to get everything done at one time
• Trying to do everything yourself

For additional information on ways to protect your joints please talk to your doctor or an occupational therapist for assistive equipment and alternate ways of completing tasks.
Maintaining Energy

Some tasks you do while caregiving can be tiring and seem to take all of your energy. It is important to be aware of fatigue experienced throughout the day as being too tired can cause injury to you and your loved one. Provided below are ways that you can conserve energy throughout the day in order to be able to accomplish all caregiving tasks within the home environment.

- Get a good night’s sleep in order to have energy for the day
- Plan the next day’s activities to determine what they involve and how you are going to accomplish the tasks
- Save less important tasks for a later time
- Prioritize tasks throughout the day
- Alternate between tasks and rest breaks
- Take frequent breaks in between activities
- Have a chair near in order to sit down and rest during tasks
- Keep frequently used items accessible
- Have frequently used items in one location
- Adjust areas of your home so that items are easy to reach
- Have someone help with tasks
- Get a cart to transport items around the home
- Use assistive equipment such as a reacher, jar grip, shower bench for bathing, or hands free headset for talking on the phone
- Gather all items needed before starting a task

University of Washington Medicine, 2015
• Keep a journal of tasks that cause more fatigue during the day
• Make large meals in advance and store for later dates
• See if your grocery store delivers groceries to your home
• Have lists of items you need from the store written out
• Have all tasks on one floor such as laundry, kitchen, bedroom and bathroom to decrease walking distance or climbing stairs

Provided on the following pages are a task journal, grocery list section, and a way to assemble items for a task in order for you to manage your energy while organizing your life.

Advance Healthcare Network, 2016; Microsoft Office, 2007
Daily Task Journal

This is a task journal to assist you with determining what tasks have an effect on your energy. It can help you assess whether a task increases your energy, decreases your energy, or has no effect on your energy. List the task, the importance level, and place a check in the box associated with how the task affects your energy.

<table>
<thead>
<tr>
<th>Task</th>
<th>Importance (High or Low)</th>
<th>Increases Energy</th>
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Grocery List

Use this grocery list to plan and organize items you need at the store so that you can retrieve items quickly while saving time for other tasks.

Item ______________________________________
Location in store ______________________________
Price ______________________________________

Item ______________________________________
Location in store ______________________________
Price ______________________________________

Item ______________________________________
Location in store ______________________________
Price ______________________________________

Item ______________________________________
Location in store ______________________________
Price ______________________________________

Item ______________________________________
Location in store ______________________________
Price ______________________________________
Organizing Your Tasks

Use this section to organize items needed for each task so that the items are available and easily accessible.

Task ____________________________________

Items needed________________________________________

____________________________________________________

Are items within reach: Yes ☑  No ☐

Task ____________________________________

Items needed________________________________________

____________________________________________________

Are items within reach: Yes ☑  No ☐

Task ____________________________________

Items needed________________________________________

____________________________________________________

Are items within reach: Yes ☑  No ☐
Task ____________________________________

Items needed______________________________________________________________

Are items within reach: Yes ☐ No ☐

Task ____________________________________

Items needed______________________________________________________________

Are items within reach: Yes ☐ No ☐

Task ____________________________________

Items needed______________________________________________________________

Are items within reach: Yes ☐ No ☐

Task ____________________________________

Items needed______________________________________________________________

Are items within reach: Yes ☐ No ☐
Getting Enough Sleep

Sleep is important in order to have the energy needed for caregiving activities. Without sleep, an individual can have decreased concentration, increased fatigue and reduced immune system functioning. This can lead to injury, sickness and accidents. It is important for you as a caregiver to get a good night’s sleep to have the energy during the day to complete tasks and take care of your loved one within the home environment. The following information can assist you with getting a good night’s sleep and increasing your energy throughout the day.

- Try to get about 8 hours of sleep each night
- Create a sleep schedule
- Avoid caffeine before bedtime
- Create a bedtime routine (ex: every night go to bed at the same time)
- Avoid exercising before bedtime
- Try not to consume alcohol before bedtime
- Avoid large meals as this can possibly cause indigestion
- Avoid medication that delay or make getting to sleep difficult
- Try not to take a nap after 3 pm

National Caregiving Alliance, 2016; NIH, 2011
• Take a warm bath before going to bed
• Take a moment to relax before getting ready for bed
• Remove environmental distractions such as bright lights, sounds and overly warm temperatures
• Do a short relaxing activity if you are finding it hard to fall asleep
• Avoid using electronic devices (iPad, smart phone or tablet) before bed
• Contact your doctor if you feel that sleep disturbances are possibly from sleep apnea, restless sleep, anxiety or bodily pain

Provided on the following pages are ways to keep a sleep schedule and plan relaxing activities before bed.
Sleep Schedule

Sleep is an important part of everyday life. In order to get a good night’s sleep, you may need to organize your bedtime routine and establish the time for each task leading up to getting into bed. Provided is a way for you to create a schedule of what you may do in order to get ready for bed.

What activities do I have planned for the next day: ____________
________________________________________________________________
________________________________________________________________
________________________________________________________________

What do I need to do to get ready for the next day: ____________
________________________________________________________________
________________________________________________________________
________________________________________________________________

What do I need to do to my sleep environment to reduce distractions: __________________________________________________________________
________________________________________________________________
________________________________________________________________

What things make it difficult for me to get to sleep: ____________
________________________________________________________________
________________________________________________________________
Time I am going to do my relaxing activity: _______________

Time I am getting my night clothes on: _______________

Time I am going to do other tasks to get ready for bed:
- Task _______________________  Time________________
- Task _______________________  Time________________
- Task _______________________  Time________________
- Task _______________________  Time________________
- Task _______________________  Time________________
- Task _______________________  Time________________

What activity am I going to complete to relax me before getting ready for bed __________________________________________

Do I need to set an alarm: ☐ Yes ☐ No  What time: ______

Time I am going to get into bed: _______________________

Microsoft Office, 2007
Planning Relaxing Activities

Think about relaxing activities that you like to do that can calm you and help you to get a better sleep. Relaxing activities can be knitting or reading a good book. List these activities in the following spaces so that you can view and retrieve the items when needed.

A List of My Favorite Relaxing Activities

Activity _______________________________________________________
Location of item_________________________________________________
How it relaxes me _________________________________________________

Activity _______________________________________________________
Location of item_________________________________________________
How it relaxes me _________________________________________________

Activity _______________________________________________________
Location of item_________________________________________________
How it relaxes me _________________________________________________
Activity ________________________________________________
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Location of item________________________________________
How it relaxes me ______________________________________

Activity ________________________________________________
Location of item________________________________________
How it relaxes me ______________________________________
Factors that Effect Caregiver Mental Health
The tasks you have to complete as a caregiver in addition to your other routines can be difficult and create imbalances in your life. Caregiving tasks can impact your mental health and make it difficult to live your life to its fullest. There are many diverse psychological factors that can affect the way you fulfill your role of caregiving.

Psychological factors that impact a caregiver’s mental health can include burn out, stress, social supports, leisure activities, and coping skills. By addressing these factors directly, caregivers are more able to find the best fit for them in how to maintain optimal mental health and complete their role as a caregiver.

Some of the indicators of impaired mental health include:

- Not being able to focus on tasks
- Changes in activities you enjoy
- Changes in relationships with others

These indicators of changes in mental health are common among caregivers who have just begun taking on this role or have been in the role of caregiver for an increased amount of time.
Burn Out

Caregiver burn out occurs when a caregiver is in a state of physical, emotional, and mental exhaustion. Changes in attitude and ability to provide care are common.

Who does burn out affect?
- Burn out affects all caregivers who care for someone with a chronic illness. It is a result of not accessing the help you may need as a caregiver

What puts you at risk?
- You are put at a greater risk if you do not make time to care for yourself on a daily basis
- Fewer familial or social supports increase the risk of caregiver burnout
- Increased time being a caregiver for a loved one puts you at a greater risk of caregiver burnout

How do you avoid burn out?
- Caregiver burn out is most easily avoided if you as a caregiver take time to attend to your needs as well as those of your loved one
- Caregiver burn out is decreased by building a firm foundational social support system
- Caregiver burn out is decreased by using appropriate coping skills in your everyday routine

Doherty et al., 2015; Ornstein et al., 2009
If you have experienced burn out before, what did it feel like?

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What did you do before to help decrease your burn out?

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Stress

Stress is a result of the actions your body makes following a stimulus. Stress can be healthy or unhealthy for you, and is ultimately dependent on the amount you undergo and deal with it.

What effects does it have on you?

- Stress can have many different effects on you, and can vary from person to person.
- Although stress looks different in everyone, some common symptoms include increased blood pressure, headaches, insomnia, and changes in mood.

Which areas of your life are causing you stress?

- The areas of life that cause the most stress in caregivers can vary depending on the person, but commonly include caregiving tasks, social or home environments, and work tasks.

How do you lessen the stress that you have?

- One of the most effective ways to lessen stress is to identify what triggers it in you and then use a coping skill that is effective for you in that situation.

Moriarty et al., 2015; Marcuccilli et al., 2014
What are some of your common triggers to stress?

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___________________________________________

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What does stress feel like to you? How would you like to change that?

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Coping Skills

Coping skills are actions a person takes to decrease stress. These skills take time and practice to be effective, but you can use them on a daily basis to help manage your stress.

Why should you use them?

- Coping skills can be used almost anytime, anywhere! You do not have to worry about side effects from coping skills such as those possibly caused by prescribed medications.

When can I use them?

- Some coping skills can be used at any time and in any place. Other coping skills are more specific and can only be used at certain times in certain places.

Marcuccilli et al., 2014
What are some examples of coping skills you use currently in your life?

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___________________________________________
___________________________________________
___________________________________________

Are they appropriate for your needs in your daily life?

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___________________________________________
___________________________________________
Coping Strategies

As a caregiver, it is important to find ways to reduce stress in order to stay healthy. Using coping strategies can assist with reducing stress or anxiety you may experience during caregiving tasks. Some strategies that you may want to try for coping with stress include:

- **Relaxation Strategies**
  - Breathing Techniques
  - Guided Imagery
  - Progressive Muscle Relaxation

- **Journaling**

- **Exercise**

- **Volunteering at a local community organization**

- **Creative Crafts/Arts**

- **Talking to a friend or family member**

- **Taking time for yourself**

- **Respite Care**
Deep Breathing

Often when stress is experienced, your breathing will increase and cause your body to increase tension. Deep breathing exercises are meant to help relax and calm your body. As a caregiver you can utilize these exercises within a variety of environments without having to purchase costly equipment.

Steps to Deep Breathing Exercises

- Take a deep breath in through your nose until your lungs feel full
- Slowly exhale through your mouth while thinking of a calming word such as “peace,” “relax,” or “calm”
- Repeat this sequence 10-15 times
- If possible, it may be helpful to close your eyes during these exercises to assist in calming your mind

What are some places or situations this exercise would be helpful in?

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Guided Imagery

This coping strategy involves removing yourself from a situation by picturing a peaceful scene in your imagination. This strategy is meant to help you achieve a state of relaxation and calmness. You can use this strategy anywhere you have a few minutes and a quiet space, such as your home, to assist you with reducing stress experienced by caregiving tasks.

Steps to Complete Guided Imagery:

- Pick a scene that you personally find relaxing.
  - Scenes could include:
    - A tropical beach
    - A beautiful snowfall
    - An autumn afternoon
    - Sunrise on a farmstead
    - Summertime in a wild flower meadow
    - A crackling fire in winter
- Close your eyes and imagine yourself in this place with no interruptions
- Relax your muscles and slow your breathing.
- Low, relaxing music playing in the background may assist in gaining full relaxation
What are some places or situations this exercise would be helpful in?

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Progressive Muscle Relaxation

One of the results of stress can be tension in your muscles that can lead to stiffness and pain. This muscle stiffness can occur anywhere in the body, but during caregiving tasks can be most prevalent in the neck, shoulders, and back. This strategy requires 5 to 10 minutes to complete, and is most effective when lying in bed or sitting in a chair while in a quiet environment.

Steps to Complete Muscle Relaxation

- Select one portion of muscles (Example: shoulders, arms, your stomach, etc.)
- Contract or squeeze the selected muscles for 10 seconds.
- Slowly relax them over the course of 5 seconds while exhaling.
- Select the next group of muscles and repeat the steps.
- Continue until all tense muscles have been addressed and your body feels calm.

What are some places or situations this strategy would be helpful in?

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Social Supports

Social support is when you are cared for and have assistance from other people in the community. Social supports help you become a part of a larger social network.

Who are social supports?

- Social supports can be anyone you have a positive social relationship with, whether it be with your family members, friends, co-workers, or other individuals in the community

Why are they important?

- Social supports are important as they can help decrease stress and burden in your life
- These support systems provide you with people you can talk to when stress and burn out are high and they can help to increase your involvement in the community and with meaningful activities
- Social supports are especially important for caregivers to develop as the amount of stress related to caregiving can be difficult to cope with alone

Graspa et al., 2014; Andreu et al., 2015
How do you build new supports?

- Building a social network can be challenging to do along with your caregiving tasks, but it is important to do to reduce isolation, depression, anxiety, or other impairments to mental health.

Who are your social supports?

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________________________________________________________________________________________

How well are you able to maintain these relationships with friends or family?

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What challenges do you face with maintaining relationships with others?
Leisure

Leisure is defined as the use of free time for enjoyment. As a caregiver, finding free time to do the things you enjoy can be challenging, but is very important for maintaining balance in your life and maintaining your own personal identity.

What are your potential barriers to engaging in leisure activities?

- There are many potential barriers to engaging in leisure activities you enjoy. Some of these could include lack of time, low energy, or lack of resources

What do you need/want to spend more time doing?

___________________________________________

___________________________________________

___________________________________________

What barriers stop you from engaging in these activities?

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___________________________________________

___________________________________________

Moriarty et al., 2015
Provided is a checklist for you to identify leisure activities that you enjoy, would like to try, or what barriers prevent you from participating in leisure activities. In the boxes provided, place a check in the box associated with leisure activities you have previously done or would like to do more. Also, in the last box, list what barriers keep you from participating in each leisure activity.

**Leisure Activity Checklist**

<table>
<thead>
<tr>
<th>Activities</th>
<th>I’ve done this in the past month</th>
<th>I would like to do this more</th>
<th>Barriers to Engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go out to eat with friends</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arts and Crafts</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Go to a movie or play</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteer locally</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gardening</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baking and Cooking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fishing and Hunting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hiking and Walking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Music</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Computer or Board Games</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Home Environmental Modifications
As a caregiver, you may spend large amounts of time in your home environment caring for your loved one. The environment you live and work in is important to consider when thinking about your health as a whole. The purpose of this section of the manual is to provide you with resources you can use to adapt your environment to maximize its function.

Within this section, you will find information on

- Ergonomics in the home
- Options for adaptive equipment
- Technology and Telehealth resources

After you review this section, take time to contact your Occupational or Physical Therapists. These healthcare providers have the knowledge to assist you in fitting the following information into your specific home.
Ergonomics

Ergonomics is how people move and work in their environment. The focus of ergonomics here is to find the best fit between you, the demands of caregiving, and your home.

Why is this important?
- It is important to consider ergonomics in your home to provide you with a safer environment for both you and your loved one
- By using ergonomics in your home, you can prevent injuries and optimize your efficiency with caregiving tasks
- Home evaluations are completed by an occupational therapists and are one way of looking into your environment and identifying changes that can be made in order to make caregiving tasks safer for you and your loved one

Who can you contact?
- To learn more about ergonomics and home evaluations, contact an occupational or physical therapist on your loved one’s team

Aplin & Gustafsson, 2015
What can you do to incorporate ergonomics into your home?

- There are some simple solutions that you may be able to incorporate into your home that will increase its safety and function.

Some examples of easy ergonomic fixes include:

- Remove throw rugs to reduce tripping hazards
- Arrange materials needed for caregiving tasks in one location to prevent additional searching for materials
- Place schedule of medications or other necessary caregiving tasks in viewable place for easy reference
- Rearrange furniture to ensure a clear walking path exists
- Adjust the height of chairs, beds, or dressers for ease of mobility
- Reposition items your loved one uses often to reachable locations
- Reduce clutter and organize items by category
- Remove dangerous objects from the home such as frayed electrical cords
• Add railings or ramps to allow access into and within the home
• Consider adaptive equipment, devices that can assist with completing activities, and other technologies

The following pages define and list several types of adaptive equipment that may assist you with caregiving tasks.

* For more specific environmental modifications in your own home, a home evaluation may be appropriate. Please contact your loved one’s physician or an occupational therapist for any questions you may have on types of home modifications.
Adaptive Equipment

Adaptive equipment consists of different devices that people can use to help them complete everyday tasks. These devices can help with things such as bathing, dressing, toileting, grooming, feeding, and mobility.

Why is this important?

- Adaptive equipment is important to consider because with training, it can increase the independence of an individual who has heart failure, and it decreases the amount of help they will need from a caregiver.

Who recommends adaptive equipment?

- Depending on the equipment, usually an Occupational or Physical Therapist will recommend adaptive equipment.
- Occupational and Physical Therapists are qualified to look for areas of self-care that individuals need help in, and determine if certain equipment will help them complete tasks on their own.
Where can you get it?

- Adaptive equipment is available through your healthcare providers, such as an occupational therapist, who will recommend certain equipment for your loved one to increase their independence and decrease your caregiver burden.
- Usually individuals get equipment from a provider through the hospital they are receiving treatment at; however, some third party resources are available as well. Ask your provider for options in your area.

How much does it cost?

- The cost of adaptive equipment depends on the device you order. Devices that use higher levels of technology are usually more expensive than those that are of lower technology.
- To learn more about what your insurance will cover regarding adaptive equipment, contact your Social Worker or the healthcare provider who recommended the piece of equipment.
How about other options for adaptive equipment funding?

- Locate local funding within your community by talking to your loved one’s physician or an occupational therapist

- Contact organizations such as:
  - Assistive Technology Industry Association at [www.atia.org](http://www.atia.org)
Types of Adaptive Equipment for Self-Care

- **Reacher**: This is a long-handled tool that helps a person grab objects that are too far for them to reach for or in hard to reach places. Requires grasp and coordination to use.


- **Dressing Stick**: This is a long handled tool that helps a person who has difficulty dressing or undressing the lower portion of the body. It requires grasp and coordination to use.

• **Sock Aid**: This is a tool that helps a person put their socks on. It requires coordination and arm strength.

![Sock Aid](Picture 5. Sock Aid. 2016. Photograph. Yorhom Medical Essentials.)

• **Grab Bar**: This is a tool that is mounted on a wall. It provides a person with a handle to use as leverage to pull themselves up to a desired position such as from a bed or chair.

![Grab Bar](Picture 6. Sock Aid. 2016. Photograph. Yorhom Medical Essentials.)

• **Bedrails**: These tools are placed on the side of the bed. They function similarly to grab bars and help a person get in to and out of bed safely.

![Bedrail](Picture 7. Bedrail. 2016. Photograph. Yorhom Medical Essentials.)

Yorhom Medical Essentials, 2016
• **Tub Bench/Shower Chair**: This is a tool that helps a person enter and exit a tub/shower safely. It is a sturdy bench or chair that either extends out of the tub or sits in the tub/shower and gives a person a stable place to sit while they are bathing.


• **Raised Toilet Seat**: This is a tool that mounts directly onto a standard toilet to raise the height and make it easier to get on and off of the toilet. May come with arms on either side to increase stability.


• **Walker**: This is a tool that is used to increase stability when walking. It can come with brakes or other attachable storage compartments.

• **Wheelchair**: This is a tool that is used to increase functional mobility. It is for a person who cannot walk long distances or stand for long periods of time and tires easily.


**And many more!** Talk to your doctor or an occupational therapist for additional options.
Telehealth and Technology

Finding transportation to and from medical appointments and other services can be challenging for a caregiver. Telehealth and other technologies are emerging to help with this problem, especially in rural communities.

- Telehealth is a service delivery method of healthcare services using information through technology to provide healthcare services. The provider and the recipient are in different locations and communication occurs primarily through the computer via video calls, chats, or emails.

Is this an option for you?

- Telehealth is an emerging area of healthcare, and may be available to you in your area. For more information regarding telehealth services, ask your primary care physician for more information.

AOTA, 2013; Carson, 2015; Chiang et al., 2012; Dollinger et al, 2007
How else can technology help you in your everyday life?

- Many apps are available to assist you with balancing all of the responsibilities you have in your everyday life. Apps are programs that can be downloaded onto your smartphone or other wireless device to assist you in areas you may be struggling with.
- The following page provides ideas for different apps you can utilize to ease stress and create a better fit for you between you, your caregiving tasks, and your environment.

Andruszkiewicz and Fike, 2015; Carson, 2015; Chiang et al., 2012; Microsoft Office 2007
Apps to Consider:

- Uber
  - For transportation services
- Handy
  - For assistance in home cleaning/general maintenance and options for home grocery shopping
- Reminder Rosie
  - For reminders related to medication management
- Lively
  - For monitoring daily activities and tasks
- CareLinx
  - For hiring, paying, and managing professional caregiving services for respite care

What areas of your life would be more easily managed with technology?

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Andruszkiewicz and Fike, 2015
Respite Opportunities
As a caregiver, you may be wondering what opportunities are available to help you take time away from caregiving responsibilities. It is important for you to talk to your doctor or an occupational therapist to determine what kinds of respite services are available in your area. The following pages describe what respite is, what it can do for you, how to plan for respite services, and how to get in touch with individuals who can help you access respite services.

Remember that there are services available in the community to assist you with taking time for yourself in order to help ease the burden of caring for your loved one.

**What is Respite?**

Respite is a way for you to take time away from caregiving responsibilities. It can be participating in leisure opportunities within the community, completing hobbies or other tasks that you find meaningful.
What Can Respite Do for You?

Respite time is a way for you to decrease burnout, stress, and being overwhelmed by your caregiving responsibilities. It can provide you with a sense of control over your life. Some ways that you can spend your respite time include:

- Taking a vacation
- Doing hobbies or crafts that you enjoy
- Taking time to visit with friends and family
- Going to lunch with a friend
- Taking a relaxing bath
- Taking time to read a good book
- Going shopping
- Taking advantage of respite services in your community
- Taking a nap
- Volunteering in the community

ARCH National Respite Network, 2015; Utz, et al., 2012
What Respite Opportunities are Available?

Many respite opportunities are available in your community to assist you with taking time away from caregiving. Ask your doctor or an occupational therapist about resources and options that can provide you with respite opportunities.

Other organizations that can assist you with finding respite service include:

- Your State Respite Coalition
- Your State Lifespan Respite Program
- Your State Respite Registry

In addition to the above, other options include:

- Hiring informal or formal care services
- Contacting Easter Seals for respite services
- Contacting Adult Day Care Centers

The provided planning section is for you to organize your respite time in order to decrease feeling overwhelmed while having time to yourself.

ARCH National Respite Network, 2015; Utz, et al., 2012
Planning Respite Activities

What are some activities that you like to do? _________________
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________________________________________________________________
________________________________________________________________

How can you organize your time to include one to two of these activities per week? _________________
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________________________________________________________________
________________________________________________________________

What days of the week are you available to take time to participate in respite activities? _________________
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________________________________________________________________
________________________________________________________________
Who could help you with taking care of your loved one in order to participate in respite activities? ____________________________

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What services are in your community to assist you with taking care of your loved one for respite activities? ____________________________

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What funds do you have available to participate in respite activities? ____________________________

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______________________________________________________
Who will be with you while you enjoy your respite activities? ____
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What are some other activities you would like to do but have not had time? _____________________________________________
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How can you plan to include these activities in the future? ______
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__________________________________________________________________
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__________________________________________________________________
Wrap up

As a caregiver, your job is rewarding but can become overwhelming. You are your loved one’s best resource for services and assistance, and it is important that you are healthy in order to complete caregiving tasks. It is the authors’ hope that this guide can assist you with ways to decrease injuries and burdens, and be able to locate services and resources within your home and community environment. This guide has been created for you to increase your health and wellbeing while maintaining the role of caregiver.

You are encouraged to utilize this guide as you see fit within you and your loved one’s home environment. Questions are provided as a way for you to consider aspects of your life that may be limiting your role as caregiver such as decreased physical and mental health, barriers to your environment and lack of respite opportunities. In addition, lists and worksheets are provided to assist with decreasing limitations while increasing your health and wellbeing. This will help you participate in your role as caregiver.

This guide was created by occupational therapists to assist you with finding the best way to maximize your role as caregiver while maintaining health in order to complete caregiving tasks within your home environment. The authors’ thank you for what you do as a caregiver in order to increase your loved one’s quality of life.
References


Occupational Therapist’s Supplemental Guide

“Happy Hearts: A Caregiver’s Guide to Assisting Patients with Heart Failure”
Nature of the Challenges Caregiver Face

The needs of a caregiver who is responsible for an individual with HF are complex. In the United States, over five million individuals have HF and require varying degrees of assistance from others (Center for Disease Control and Prevention, 2015). With the increasing rate of HF, more caregivers are expected to assist these individuals with activities and tasks in their everyday lives. When addressing the health of the individual with HF, the health of their caregiver may be missed by healthcare professionals.

By completing a thorough literature review, the authors have identified several pertinent areas of interest for OTs to address with caregivers. These areas were identified as most challenging for caregivers in order to maintain quality of life and complete their caregiving role. These areas include the following: physical health, mental health, environmental factors, the role of the caregiver, and overall resource education. If left unaddressed by the healthcare community, the unmet needs of caregivers have a large influence on caregiver burden (Ornstein, Smith, and Boal, 2009). However, if the needs of caregivers of individuals with HF are met, both the caregivers and the patients have a greater opportunity for increased health and wellness (Doherty, Fitzsimons, & McIlfatrick, 2015). It is the authors’ hope that this guide becomes an opportunity for OTs to address the health of the caregiver in addition to the patient, and to fill the gap that exists in continuity of care for caregivers of patients with HF.
Purpose of the Guide

The purpose of this guide is to assist caregivers of patients with HF in learning realistic strategies to improve their health and quality of life. Caregivers experience many challenges as they complete their caregiving tasks, and this guide is meant to be a resource that can assist in decreasing some of the burden experienced. The caregiver’s guide is divided into sections and addresses the following:

- **Heart Failure:** Caregivers are educated on the definition and stages of HF as it progresses, and what to expect in each stage. Common symptomology of HF is also described.

- **The Role of the Caregiver:** The role of a caregiver is defined, and reflective questions are provided to encourage thoughtful reflection on what areas may need to be addressed in the caregiver’s life to maximize their quality of life with caregiving tasks.

- **The Role of Healthcare Professionals:** This section educates caregivers on the different roles each healthcare professional on the team takes, and provides spaces to collect contact information should they have to contact them.

- **Factors Affecting Physical Health:** Strategies for safe lifting and moving, stretching, exercise, joint protection, energy conservation, and healthy sleep habits are provided in this section to facilitate healthy habits within the role of caregiving.
• **Factors Affecting Mental Health:** Information regarding burn out, coping skills/strategies, stress, social supports, and leisure are provided in this section. Specific coping strategies are outlined with instructions for caregivers to utilize throughout their day in various environments.

• **Environmental Modifications:** This section gives information on home evaluations, ergonomics within the home, use of common adaptive equipment, and technology or opportunities to use telehealth. Caregivers may have specific questions regarding where to get adaptive equipment or access home evaluations/telehealth opportunities in your area.

• **Being a Caregiver:** The occupations a patient engages in may change as their health declines. This section outlines how various occupations and engagement in activities may look throughout the stages of HF.

• **Respite Opportunities:** This section provides the caregiver with options for accessing respite through formal agencies and in everyday life.

Throughout the guide, reflective questions are provided to facilitate application to each caregiver’s specific circumstances. Schedules are provided to allow for specific application of material to the caregiver’s day to day tasks, and checklists are provided to assist in critical thinking of material and application to life. However, as an OT, additional resources can be provided to ensure all pertinent programs within the facility or community are utilized.
PEO Model Foundations

The Person-Environment-Occupation (PEO) model was the primary theory used to help create *Happy Hearts: A Caregiver’s Guide to Assisting Patients with HF*. The PEO model is focused on finding the best fit between the client, their desired occupation, and the environment in which they participate (Law, 1996). This model is client-centered in that it focuses on individuals’ specific needs in the dynamic and transactive relationship between the person, environment and occupation (Law, 1996). Below is an overview of the three main concepts of the model.

- **Person**: a unique entity who simultaneous carries out a variety of roles. These roles change across the lifespan and are dynamic (Law et al., 1996). The person is a compound of mind, body, and spiritual qualities, and calls upon abilities or skills of the person such as motor performance, sensory capabilities, cognitive aptitude and general health to accomplish occupational performance (Law et al., 1996).

- **Occupation**: compilation of activities and tasks which are meaningful to the person or population and closely correlated (Law et al., 1996). Activity is the basic unit of a task in which a person engages in within their occupational experience. It is a singular pursuit which can be compounded to create a task (Law et al., 1996). A task is therefore a set of purposeful activities that are engaged in to accomplish occupational performance (Law et al., 1996). Occupation is then further defined as multiple tasks that are functional, self-directed, and dynamic across the lifespan (Law et al., 1996).
Environment: places importance on the cultural, socio-economic, institutional, physical, and social aspects from the perspective of the person, household, neighborhood, or community (Law et al., 1996). Law et al. (1996) incorporates the environment as a broad concept that outlines how persons interact in a variety of settings. Occupations in the environments listed would determine the roles, activities or behaviors that a person demonstrates (Law et al., 1996).

The PEO model analyzes the interactions between the concepts in order to maximize occupational performance. This is achieved by finding the best fit between the person, occupation, and the environment. As an OT, additional evaluation of the specific interactions (person-environment, person-occupation, occupation-environment) can be completed. This action can guide practice with caregivers in order to provide the best insight into areas of need within occupational performance.
When to Give the Guide to a Caregiver

The OT should give Happy Hearts: A Caregiver’s Guide to Assisting Patients with Heart Failure to caregivers when their loved one is advancing to Stages 3-4 of HF, or when their loved one is initially evaluated for OT services. When the OT gives the guide to the caregiver, it is essential that the OT describe the purpose, and provide contact information should the caregiver have any questions regarding the guide. The OT should describe their role in treating caregivers and how they can assist with the areas addressed in the guide.
OT Follow Up Evaluation

The OT should follow-up with the caregiver briefly at each OT session or once per month. The OT should verbally interview and evaluate the caregiver’s progress throughout the manual and provide clarification of concepts as needed. The OT should be prepared to address significant discrepancies in the caregiver’s occupational performance in individualized occupational therapy sessions as the need presents itself. Collaboration between the OT, caregiver, and patient with HF on a regular basis is required to address concerns and ensure that the best fit between the person, occupation, and environment is achieved.
References


CHAPTER V

SUMMARY

This purpose of this scholarly project was to develop a guide for caregivers of individuals with HF to be used in combination with OT to increase quality of life for both caregivers and the individual with HF. The inspiration for this guide was the identification of unmet needs of caregivers that can contribute to experiences of caregiver burden which can lead to decreases in mental and physical health (Doherty, Fitzsimons, & McIlfatrick, 2015; Ornstein, Smith, & Boal, 2009). It was found that there are limited guides available that address the caregiver’s needs or provide resources on improving caregiver health. This, along with a lack of literature that addresses ways to meet the needs of caregivers, is what led to the development of this guide. This guide provides caregivers with a way to care for the individual with HF while also addressing unmet needs by supplying information concerning supports available, how to increase health and wellness, and how to obtain needed equipment in order to care for someone with HF within the home environment.

Overall, this guide was meant to be used by caregivers as a thorough and efficient way to increase health and wellness while providing care to the individual with HF by way of an OT. Although this guide provides a considerable amount of information to be used by caregivers, there are some limitations that exist. One limitation of this guide is that it only provides information to caregivers of individuals with HF and does not address other caregivers such as those who care for individuals with other diagnoses or
formal caregivers. Care should be taken to address needs of all caregivers no matter who they are caring for by the OT using effective clinical reasoning skills.

Another limitation is that this guide has not been implemented into practice, so effectiveness has not yet been determined. Research should be done to assess whether this guide is beneficial for caregivers of individuals of HF in order to determine whether the information should be utilized during treatment. By implementing this guide into practice, practitioners would be able to determine its effectiveness and whether it is an advantage to incorporating into practice when working with caregivers of individuals with HF.

Lastly, this manual was developed with a home setting in mind and does not support generalizability to other settings. By using this guide, OTs should be careful to adapt the guide as needed in order to meet the needs of the caregiver safely within other environments. In addition, OTs should take into consideration the size, barriers, and available areas within the home before providing the guide as some of the recommendations for exercises, modifications, or activities may not be adequate in certain home environments.

One recommendation would be to first trial this guide in practice to determine effectiveness. In addition, contacting associations such as the National Caregiver Alliance, National Alliance for Caregiving, or the Caregiver Action Network to promote this guide would be beneficial and provide another way to obtain feedback from caregivers about the guide’s resourcefulness. Also, networking with other professionals who have experience with caregivers of individuals with HF can provide additional information from the health professional point of view to further assist with answering
common questions that caregivers may have on services, supports, and resources for future development of this guide.

Barriers to implementing this guide into practice can be due to not having the ability to educate and inform OTs of its existence. This can be reduced by contacting and promoting the guide on the American Occupational Therapy Association website with information that focuses on OTs and caregiving or contacting local OT associations to promote the guide and how it can benefit caregivers of individuals with HF. Another potential barrier may be educating caregivers who are not receiving OT services. This can be reduced by contacting associations, such as the National Caregiver Alliance, National Alliance for Caregiving or the Caregiver Action Network to educate and promote the use of the guide for increasing caregiver health and wellness.

To search out feedback and experiences with the guide, the authors could request information from associations concerning the guide’s effectiveness and impact on caregiver health and wellbeing. The authors could also send out surveys or short questionnaires on the guide’s effectiveness, caregiver feedback, caregiver outcomes and whether it influenced the care provided to individuals with HF. In addition, the authors could contact OT associations or the American Occupational Therapy Association about possible feedback related to the use of the caregiver guide in order to determine if it needs modifications or additional information concerning the OTs using the guide, caregiver and patient health, the caregivers’ feedback on content and helpfulness, and treatment outcomes.
This guide will provide the caregiver of an individual with HF a way to reduce caregiver burden while maintaining positive physical and mental health. Through OTs providing this guide, caregivers will have a better health outcome while providing quality care to the individual with HF. Caregivers will be able to utilize this guide however they see fit to increase their health and wellbeing while maintaining their role as caregiver within a home environment. It is the authors’ hope that the use of this guide will provide a means for the caregiver to maintain health, be provided with resources, and have essential needs met in order to increase the quality of life for both the caregiver and the individual with HF.
REFERENCES


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