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An Interactive Manual for Informal Caregivers of Cerebral Vascular Accident (CVA) Survivors

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AN INTERACTIVE MANUAL FOR INFORMAL CAREGIVERS OF CEREBRAL VASCULAR ACCIDENT (CVA) SURVIVORS

By

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Advisor: Deb Hanson, Ph.D, OTR/L

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of the

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Master’s of Occupational Therapy

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APPROVAL PAGE

This scholarly project paper, submitted by Lindsay Draayer, MOTS and Kaila Gunderson, MOTS in partial fulfillment of the requirement for the Degree of Master’s 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.

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Title An Interactive Manual for Informal Caregivers for CVA Survivors

Department Occupational Therapy

Degree Master’s of Occupational Therapy

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ABSTRACT

Based on data from the literature review and clinical experience, an interactive manual was developed for occupational therapists to utilize when working with caregivers of cerebral vascular accident (CVA) survivors. CVA survivors display difficulty in basic personal cares such as eating, dressing, and general mobility within, but not limited to, the first year following the onset of the CVA. An interactive caregiving manual was created that addresses the needs of a caregiver of a CVA survivor during their transition from hospital to home. This focused education program enhances communication between the family caregiver of the CVA survivor and the occupational therapist. The manual will enable the caregiver to develop the skills and techniques involved in assisting their family member, will provide education necessary for the caregiver to decrease levels of burnout and stress over time, and will result in increased quality of care in the home setting.
CHAPTER I

INTRODUCTION

In today’s fast paced healthcare system many clients and families are hurried out the door with packets and brochures on their diagnosis and expected to return home with little to no help. Upon returning home clients and family members may be left questioning “what is the next step?” Cerebral Vascular Accident (CVA) affects nearly 700,000 people each year with approximately two-thirds surviving leading to many families lives being affect (Radomski & Trombly, 2008). Eighty percent of CVA survivors who are discharged return home to the support of their family (Adams, 2003). In many cases family members become informal caregivers for their loved ones with little to no prior knowledge or education regarding their new role. The unpredictable nature of a CVA creates a unique and ever changing experience for the caregivers of these individuals, creating an even more difficult role if education is not provided (Silva-Smith, 2007). The burnout rate for informal caregivers is high, and can result in physical decline, emotional decline leading to a decreased level of care for their loved one (Smith, Lawrence, Kerr, Langhorne & Lees, 2003).

Due to the lack of information and education provided to caregivers of CVA survivors we have developed a caregiving manual to meet the needs of informal caregivers and their loved ones. The occupational therapist will be involved in the
rehabilitation period to work with the caregiver and CVA survivor while utilizing the caregiving manual.

The focus of this scholarly project is to develop an interactive manual that supports the needs of the caregiver and the CVA survivor with the assistance of the occupational therapist during the transition period from hospital to home. The Occupational Adaptation Model (OA) is utilized to support the therapy process. This concept of “self mastery” is emphasized in this model, which allows an individual to function independently within their chosen role or activity. According to Lotus Shyu, Chen, Chen, Wang, & Shao (2008) medical assistance and support does not typically follow throughout the recovery phases. By providing the tools and skills necessary for the caregiver to guide their future, independent adaptation and self efficacy is achieved.

It is recommended that the manual is used upon discharge from the in-patient hospital. The occupational therapist will provide the manual to the caregiver and their loved one that will assist them throughout the course of outpatient therapy. The manual will provide a guide for interaction between the caregiver and the occupational therapist. It is not intended to be used as a ‘stand alone’ product; instead it is to be used in sections that can fit into the roles and routines of an informal caregiver.

The following chapters describe the process of developing an interactive caregiving manual for informal caregivers of CVA survivors. Chapter II provides a review of literature that assists in the identification of caregiver’s needs and necessary education for assisting a caregiver in their new role. Chapter III provides a description of the methodology in designing the interactive caregiving manual. Chapter IV provides introduction to the product and its implications for use. Chapter V summarizes the
proposed use of the product, the products strengths and weaknesses, implementation and recommendations for future use.
CHAPTER II
LITERATURE REVIEW

Cerebral Vascular Accident (CVA) affects nearly 700,000 people each year with approximately two-thirds surviving. Many families are therefore affected (Radomski & Trombly, 2008). In many cases family members become informal caregivers for their loved ones with little, to no prior knowledge or education regarding their new role. The unpredictable nature of a CVA creates a unique and ever changing experience for the carers of these individuals creating an even more difficult role if education is not provided (Silva-Smith, 2007).

When a CVA occurs disorders of the brains vessels lead to decreased blood flow, decrease oxygen in the cells, and ultimately tissue death or infraction. Two different types of CVA’s can occur. An ischemic CVA is when a blockage occurs in the vessels of the brain which causes blood flow to stop. A hemorrhagic CVA occurs when one of the blood vessels in the brain breaks causing the blood flow to escape into the brain (Radomski & Trombly, 2008). Depending on the part of the brain in which the CVA occurs, different deficits can develop in a persons function. These deficits can range from, paralysis of the limbs, spatial and perceptual deficits, impulsivity and judgment problems, visual deficits, and short term memory problems. A CVA can cause a wide range of physical and psychological changes leading to a more complex role for the family caregiver. These physical and psychosocial changes that occur with the onset of
CVA lead to an impairment of functioning in daily activities. Routine tasks that were once simple may become labored and time consuming leading to increased dependence on the caregiver. Certain skills are vital for caregivers to provide the level of care necessary to sufficiently assist the CVA survivor to complete daily tasks. A caregiver’s role may include assistance with mobility, self cares, meal preparation and home management, psychosocial support, community reintegration, communication, leisure exploration, social supports, and a variety of other daily activities. The role of an informal caregiver may appear simplistic, however, is complex and requires lifestyle changes. These complex skills require education by health care providers prior to discharge period.

CVA Survivor and Caregiver Needs

Both the CVA survivor and the family caregiver possess different needs for the recovery of a CVA. In both cases basic understanding of what a CVA entails is important to create a foundation for further information. An understanding of the medical background, resulting symptoms and the impact on the caregiver is important.

Caregivers experience the same educational need for basic CVA information as the loved one they care for. This information is typically not provided due to time constraints with inpatient stay. Caregivers are forced to seek out their own information in regard to providing care and support to their loved one. Silva-Smith (2007), identified caregivers as “seeking” by asking questions, observing, listening to interactions among staff and the patient, and reaching out to other families for support. The search for a better understanding does not stop at the beginning stages, but carries on through the
duration of recovery. CVA recovery is a long term process and depending on severity many effects of a CVA may be dealt with for a long period of time.

The role of the caregiver is a multifaceted one. The assistance the caregiver provides is not only physical, but emotional for their loved one while trying to maintain their normal roles and routines. Silva-Smith (2007) conducted interviews 4 weeks prior to discharge and 4 weeks post discharge with caregivers to gain a better understanding of the adaptation to the new caregiving role. Data suggested that 5 dimensions of “resurrecting life” occur during role adaptation. Areas that are affected by the new caregiving role are in daily life, management of multiple roles, personal relationship with the CVA survivor, personal future plans, as well as the time caregivers have for themselves. The increased stress and burden on the caregiver is no surprise but can be eased with education and outside support.

The physical demands associated with being a primary caregiver are numerous. The CVA survivor will likely have deficits resulting from the CVA that will decrease their independence in daily tasks. Mobility, dressing, hygiene, and other more complex tasks like cooking a meal will all require assistance from the caregiver. These previously simple talks will now become a part of the caregiver’s new role. This new role requires education on how to properly complete these tasks safely for both the caregiver and the CVA survivor. Research suggests that commonly reported needs for information are patient handling and falls management (Murray, Young, Forster, Herbert, & Ashworth, 2006). If these areas are not covered during inpatient hospitalization the caregiver may transition to the sole caregiver with little to no knowledge or skills related to their physical role. In addition to physical care of their loved one, the caregiver’s physical,
emotional, and psychological needs should be examined. Hoffmann and McKennas (2006), survey study revealed that average age of a caregiver was 61.3 years old. Age can be a factor in level and quality of care provided to the CVA survivor. Frequent lifting and bending are required to assist their loved one with mobility and daily tasks in their home and in the community. These high levels of care can lead to caregiver strain and decreased physical abilities without proper education (Steiner, Pierce, Drahuschak, Nofziger, Buchman & Szirony, 2008).

Environmental adaptations may need to be made for safety issues in the home. Recommendations for home modifications can be made by an occupational therapist during a home evaluation. However, not all families will receive this assistance adding more responsibility to the caregiver. Typical education occurs only during inpatient stay and little support is provided following discharge (Lotus Shyu, Chen, Chen, Wang, & Shao, 2008). Various home adaptations can be made to increase safety and ease of mobility for the patient when they return home. These adaptations can decrease the strain and possible burnout felt by the caregiver. In addition to these changes being beneficial to the physical demands of caregiving, they also provide a sense of calm knowing that their home is a safe environment for the CVA survivor.

Caregivers need to adapt to the role of physical supporter but also need to meet the needs of supporting their loved one psychologically. Although a stroke survivor presents with physical deficits, much of the recovery process can be directly related to the stroke survivor’s mental health. Some people may suffer from depression, or anxiety that may affect their ability to fulfill their recovery goals (Recovery after Stroke). CVA survivors may lose their daily roles, routines, and community and social experiences
following their CVA. This loss of self can occur for the caregiver as well with their increased commitment to their new role. Both the caregiver and CVA survivor can work together to use coping skills as a way to combat negative thoughts and emotions during the recovery phase. O’Connell and Baker (2004), identified helpful coping skills such as humor, family and friend supports, taking a break, remaining positive and adapting to change. The burnout rate for informal caregivers is high, and can result in physical decline and emotional decline leading to a decreased level of care for their loved one. Smith, Lawrence, Kerr, Langhorne & Lees (2003), interviewed informal family caregivers following discharge. Interviews revealed that caregivers felt “abandoned” and their time was spread thin as they found themselves attending several appointments, organizing transportation, and aiding in mobility for their loved one. Home health services were also explored for informal caregivers; however, this service did not always fit with their personal needs due to restricted range of tasks, limited time available, or the high expense of services. Becoming educated on resources, techniques and other strategies to deal with a changing role are vital to the well being of an informal caregiver. Barriers for education can and do occur at all phases of recovery. This may lead to a misinformed, uneducated, and overwhelmed caregiver.

**Phases of Recovery**

A variety of frameworks for phases of recovery have been explored in research and illustrate the feelings, emotions, and physical changes that occur throughout the process of rehabilitation for a CVA survivor and their family caregiver. Silva-Smith (2007) suggests that the process of “restructuring life” occurs in three phases starting prior to discharge and following after discharge has occurred. These phases are the
waiting phase where the caregiver is anticipating and hoping for the identification of needs their family member possesses, education on their new role, and finding out what happens next. During the second phase of “restructuring” that occurs during the transition from hospital to home caregivers are trying to set a daily routine and work schedule, complete household tasks like cooking and cleaning, maintain social relationships and find time for themselves. The final phase is referred to as the “stabilizing phase” in which caregivers have established routines, their sleep is improving, they are reintegrating into the community, planning trips, and are experiencing fewer safety issues.

Cameron and Giganac (2007) created a framework for addressing support needs of family caregivers of CVA survivors during their transition from hospital to home, also separating the rehabilitation phase into sections. The five sections categorized include event/diagnosis, stabilization, preparation, implementation and adaptation. Event/diagnosis and stabilization occur during the acute care portion of the CVA survivor’s medical care. The preparation phase occurs during inpatient rehabilitation and the final two phases, implementation and adaptation, make up the community portion of the model (Cameron and Giganac 2007). For each recovery phase, caregiver support needs and caregiver outcomes are outlined. During the event/diagnosis period caregivers and CVA survivors benefit from education on the basic diagnosis, prognosis, and current treatment. Training is not necessary at this time however emotionally the caregiver may need someone to talk to for support. Information on current care needs occurs during the second phase and continues through the remaining phases. Education and skills training are needed during the third or preparation phase. The emotional supports for the caregiver
are still an important part of information and care for the caregiver. Feedback to the caregiver is an important part of the educational experience during the preparation, implementation and adaptation phases. The CVA survivor will obtain different outcomes depending on the varying levels of care and education provided by the caregiver. The ultimate goal at the end of the fifth phase is for the patient to be educated, have improved self efficacy, psychological well being, social supports, and community reintegration (Cameron and Giganac 2007). Use of several phases separates the stages of recovery and each phase has a unique set of needs for the client and the caregiver. Delivery of the education to a caregiver needs to be timely but also delivered by a skilled professional who can provide the best instruction for their needs.

Garrett and Cowdell (2005) studied the needs of caregivers from day to day in the hospital setting. They found at the day two phase patients and caregivers seek to understand the diagnosis and provisions of the results of the stroke. During this phase patients and caregivers are most comfortable receiving this information from a medical professional. They report that at day 20 patient and caregivers seek to understand managing symptoms and medications. In this phase of recovery both caregivers and patients find it helpful for professionals to use drawings, pictures and scans to provide a visual explanation of what has happened. At day 90, they found that caregivers and patients question why this happened and expressed concerns about the time frame of recovery. Throughout each phase both caregiver and patients sought out visual educational material to have a clear understanding of the transitions of recovery.

Home health care is an alternative form of education that can be provided long term or as adjunct to discharge. Home going safety evaluations can be used to make the
transition to home safer and less stressful for the caregiver. Occupation based practice and family centered care can be accomplished by taking social systems of the family into consideration as well as looking at the family as a “unit of intervention”, and focusing on the family’s identified needs (DeGrace, 2003). Home visits can be used to communicate with the family members and ultimately create a safe environment that is more individually fit for the client and families needs. When an occupational therapist goes into the home of a CVA survivor, it is essential to include the needs of the client, the caregiver and other family members that may be involved with care for the individual. The home environment can be an ideal location to educate on more focused areas of care such as bathing, mobility, and other self cares.

Many professionals are qualified to educate patients and families; however lack of communication among professionals may lead to replication of information or lack of information delivery. Patients often prefer the physician to educate during the early phases of medical care as the information at this time is focused toward the diagnosis, prognosis and more medical based issues. Kaufmann, Schuling, The, Meyboon-De Jong (2004) report that when patients receive most of their information from speech therapists, physiotherapists, and neurologists, caregivers are receiving most of their information by rehabilitations specialists, speech therapist, and the physiotherapists. Even though information is being provided by many professions verbally during the hospital stay, education can be duplicated leading to patients and families being overwhelmed. Over half of caregivers and patients were given information once or twice, more than a third of patients were given information 3-6 times, and fifteen percent were given information more often than 6 times. Large amounts of information from different professionals at the
same time is overpowering and intimidating to families and patients during recovery. Collaboration among professionals in regard to patient and family education is essential to the rehabilitation program to provide the best care possible.

**Barriers**

When clients and caregivers are sent home they may be left questioning what is the next step. Eighty percent of stroke survivors who become discharge return home to support of their family (Adams, 2003). In today’s fast paced healthcare system many clients are hurried out the door with packets and brochures on common questions they may have upon returning to the community. Ostwald, Swank & Khan (2008), reported CVA patients spend an average of 45.4 days in inpatient rehabilitation and can be discharged even sooner if medical staff are informed that a family member will be providing care at home. It was reported by CVA survivors that they had only reached 50% of their recovery function at the point of discharge from inpatient care. This extends a heavy and medically focused role on to the caregiver with little to no education provide in most cases (Ostwald, Swank & Khan, 2008). Materials that are provided for educational purposes often do not meet the needs of client’s and their caregivers to be successful in the community and in their homes. Caregivers are overwhelmed by the lack of quality educational materials provided and the readability of written information.

Currently educational tools that are provided to families and clients in a hospital setting are written at a reading level that surpasses that of the caregivers. Karten (2007) revealed that caregivers and clients have a limited health literacy that leads to decreased medical compliance, and increased hospitalization rates that ultimately lead to a decline
in health. Caregivers and family members are often left to make significant medical decisions for their loved one after receiving limited and misunderstood information.

The reading level of the materials provided to families continues to be an area of concern for patient education. Hoffman & McKenna (2005) found that the average reading level of caregivers and clients ranged from a 7th grade to 9th grade reading level, and the educational materials were written at an 11th grade reading level. The materials that provided visuals for better understand only met educational adequacy 44.4 percent of the time. And 33.3 percent of the materials did not include captions to explain what the graphics were and how they were important to the patients care. The time frame that information is provided to families can be a significant factor in the comprehension and understanding of the educational materials. Feelings of stress, lack of control, confusion, helplessness and fatigue may impact the client and caregivers ability to retain and understand information. Because of the many phases of recovery it is vital that information and educational materials are presented at appropriate times.

*Information Delivery.* Educational materials might be provided through verbal instruction, practical examples, visual demonstrations, hands on practice, internet and community based resources, and written information. All of these forms of educational material can be effective on their own; however, combining several strategies to create a more comprehensive learning experience is ideal. Providing different learning modalities will help to keep patient education client centered and individualized.

Karten (2007) explores the writing used in educational materials and suggests that focusing on one specific idea and organizing this information like a conversation helps to keep the readers attention. When choosing words for educational products, he or she
suggests avoiding words or phrases with multiple meanings that may confuse the reader. Medical educational materials are described as having a different “culture” to someone who is not in the medical field. Keeping educational information at a level that can be understood by any person who may not be a part of the “medical culture” is attributed to successful information exchange (Karten, 2007).

Garrett, & Cowdell (2005) indicate that patients and caregivers express a need for educational materials to be presented verbally and in written form for optimal educational value. Patients and family caregivers also indicate the use of visual information through drawings, pictures, tables and graphs to promote a comprehensive portrayal of CVA recovery.

Steiner, et al. (2008) examined the use of web based educational tools for CVA survivors and caregivers. An estimated 117 million American adults are thought to use internet based education materials to better understand their illness and roles in recovery. Internet based sources are gaining credibility and are becoming more positive ways for people to gain medical information. Caregiver information for the family members of CVA survivors is one area that lacks research and resources to aid in the caregiving role. Due to this lack of research Pierce, Steiner, and Govoni (2002) completed a feasibility study for caregivers of CVA survivors which was internet based. Participants were supplied with “caring-web” equipment for internet based television for educational needs. Problems that occur with these types of technology are speed of access, ability to access, availability of timely response to questions, cost of equipment.

Educational and informational tools do currently exist for CVA survivors and their family caregivers; however, they only partially meet the needs of the patients. In
most educational materials there is not an emphasis put on client centered care. Each situation is different for each family and those needs must be addressed.

As mentioned previously web based, written, verbal explanation, and physical practice, can all be helpful for educational purposes. With the combination of ideal delivery time, formatting of educational materials, collaboration among health care professionals, and client centered care can create a more seamless transition from hospital to home can be created

Product. Information gathered in the literature review revealed there is a need for a client and caregiver focused educational tool. In the early phases of recovery patients and families are surrounded by physicians, or general practitioners and information delivery is medically focused. This information related to diagnosis, prognosis, and other possible medical complications is the central focus of need for patients and their families.

The Occupational Adaptation Model (OA) guided the development of the caregiving manual. The manual utilizes the 3 significant components of OA as a framework for manual organization. These components include person readiness, occupations and the environment.
CHAPTER III

METHODOLOGY

Information was gathered for a literature review utilizing Harley French Library databases, text books, and internet resources. The Pub Med database in the Harley French Library was used to research information regarding caregiver needs, readability of educational materials for patients and caregivers, and reviews of existing educational materials and caregiving manuals. Text books were utilized for information regarding Cerebral Vascular Accident (CVA) and for understanding the occupational therapy and caregiving relationship.

The literature review revealed that caregivers of CVA survivors felt “abandoned” and their time was spread thin as they found themselves attending several appointments, organizing transportation, and aiding in mobility for their loved one (Smith, Lawrence, Kerr, Langhorne & Lees 2003). Support and education were identified as essential in providing caregivers with a foundational knowledge of CVA, guidance through transition from hospital to home, and the tools necessary to plan for their future role as caregiver.

A caregiving manual was designed to fit the personal needs of the caregiver and their loved one. Existing caregiving manuals address basic information for caregivers but lack efficiency and timeliness through the phases of recovery and caregiving. According to Kaufmann, Schuling, The, Meyboon-De Jong (2004) over half of caregivers and patients were given information once or twice, more than a third of patients were given
information 3-6 times, and fifteen percent were given information more often than 6 times. Large amounts of information from different professionals at the same time is overpowering and intimidating to families and patients during recovery. By providing information throughout the continuum of care, the initial, transition, and ongoing recovery phases can be addressed at the correct time to meet caregiver needs.

Literature suggests that caregivers need information and education based on physical needs, emotional needs and environmental changes. The areas that are affected by the new caregiving role are their activities of daily living, management of multiple roles, their personal relationship with the stroke survivor, their personal future plans, as well as the time they have for themselves (Silva-Smith, 2007). The increased stress and burden on the caregiver is no surprise but can be eased with education and outside support. The manual developed therefore addresses the above areas.

In the early stages of CVA recovery family members of caregivers need background information to provide a foundation for their future as a caregiver. During the event/diagnosis period caregivers and CVA survivors benefit from education on the basic diagnosis, prognosis, and current treatment (Cameron and Giganac, 2007). Training is not necessary at this phase of recovery and may be more appropriate during the transition to their home environment. Because this basic information provides the foundation for subsequent materials, the caregiver manual begins with a review of diagnoses, prognosis, and the role of each health care provider in CVA recovery.

Following the transition to home, social supports can provide physical and emotional assistance to a caregiver in their times of need. During the second phase of “restructuring” that occurs during the transition from hospital to home, caregivers are
trying to set a daily routine and work schedule, completing household tasks like cooking and cleaning, maintaining social relationships, and finding time for themselves. This can be an overwhelming experience for caregivers and social supports can be used as a healthy coping strategy. The manual therefore provides education and resources during the transition from hospital to home. The manual is broken down into sections so not to be overwhelming and to provide support where it is needed.

Once the CVA survivor is discharged from the hospital, family support from medical staff is rare and at times can be nonexistent. An occupational therapist can assist in providing education and skills necessary to the caregiver for independent function within the community. According to Cameron and Giganac, (2007) the ultimate goal at the end of the fifth phase is for the patient to be educated, have improved self efficacy, psychological well being, social supports, and community reintegration. The caregiving manual is formatted to facilitate development of an independent and confident caregiver that can function successfully after cessation of professional guidance.

The Occupational Adaptation (OA) theory supports the information found in the literature review. Self mastery is a focus within the OA model that encourages an individual to function independently within their chosen role or activity. As research has suggested, medical assistance and support does not typically follow throughout the recovery phases. By providing the tools and skills necessary for the caregiver to guide their future, independent adaptation and self efficacy is achieved.

The information gathered in the literature review suggested common deficiencies in existing caregiving educational tools. By understanding the needs associated with informal caregivers and CVA survivors, an interactive caregiving manual was developed
for caregiver, occupational therapist, and CVA survivor during the transition from hospital to home.
CHAPTER IV
PRODUCT

The focus of this scholarly project is to develop an interactive manual that supports the needs of the caregiver and the CVA survivor with the assistance of the occupational therapist during the transition period from hospital to home. Due to the lack of information and education provided to caregivers of CVA survivors a caregiving manual has been developed to meet the needs of informal caregivers and their loved ones. The occupational therapist will be involved in the rehabilitation period to work with the caregiver and CVA survivor while utilizing the caregiving manual.

The caregiving manual was developed using the Occupational Adaptation (OA) Model as a framework for the design. The Occupational Adaptation Model (OA) supports the information found in the literature review. Self mastery is a focus within the OA model that encourages an individual to function independently within their chosen role or activity. Areas of person readiness, occupations, and environments were used as a guide to develop sections in the manual.

Two manuals were created to support the caregiver in the transition period to their home environment. One manual is directed for therapist use that includes descriptions of how the manual will be used to benefit the caregiver and their loved one. The therapist manual also includes additional evaluations as well as resources to provide as needed with the use of the caregiving manual. See Appendix A. The caregiving
manual is intended to provide background information regarding CVA and its symptomology, and to provide resources for addressing emotional and physical needs of the caregiver. Once readiness skills are addressed, the caregiver is encouraged to identify valued occupations in the caregiver role and environmental features of identified occupations. See Appendix B.

Once the occupational therapist reviews the information provided by the caregiver, collaboration occurs to create a future caregiver plan. The occupational therapist has the freedom to provide additional resources to the caregiver regarding areas of need. At this point caregivers can add additional resources to the manual to keep all educational material in one place for future references.

This interactive caregiving manual was developed for caregiver, occupational therapist and CVA survivor to assist in the transition from hospital to home as placed in the following pages. Through use of this manual, cooperation and collaboration between the therapist, caregiver, and CVA survivor is enhanced. The therapist is able to provide client centered and holistic care for both the CVA survivor and the caregiver. The caregiver is also directed to reflect on the caregiving experience and initiate positive experiences to support life transition and a sense of control throughout the recovery process.
CHAPTER V
SUMMARY

The purpose of this scholarly project was to assist caregivers of CVA survivors in adapting and progressing in their caregiving role. This was achieved with the use of the interactive caregiving manual that was created for informal caregivers of CVA survivors. The manual developed be used as a way to encourage collaboration between caregiver and occupational therapist and to provide information and skills that the caregiver can use to guide them to independence in the caregiving role.

A caregiving manual was developed to assist in the transition from hospital to home for caregivers of CVA survivors. Two manuals were created to use with caregiver and occupational therapist to create and interactive and collaborative approach to caregiving. The caregiving manual includes background information regarding CVA, emotional and physical strategies for caregiving, and self assessments to assist in planning for the future. The therapist manual mimics the caregiving manual, and in addition provides further therapist resources for individualized care. This format will create a client centered and holistic experience for the caregiver and their loved one.

The collaborative format is a strength of the product and allows for caregiver empowerment with therapist support. The interactive approach ensures the therapists understanding of the CVA survivor and the caregiver’s level of care in the home and creates an open communication line between caregiver, CVA survivor, and their
occupational therapist. Two manuals were created to address the caregiver perspective and the therapist perspective. Each manual is designed with consideration of the reader. The caregiving manual has large print to increase ease of readability. The therapist manual focuses of instruction and application of the information provided to guide therapy. The manual follows the occupational adaptation (OA) model which allows for self mastery. This will encourage the caregiver to take charge of their current and future roles as a caregiver.

This manual focuses on the transition period from hospital to home leaving out the initial stages of inpatient recovery. This manual is limited for use in outpatient or rehabilitation type settings, and is not applicable in the initial rehabilitation phase.

It is recommended that the manual is used upon discharge from the in patient hospital. The manual will be provided by the occupational therapist and is meant to follow the caregiver and their loved one through the course of outpatient therapy. The manual will provide a guide for interaction between the caregiver and the occupational therapist. The caregiving manual is broken down into sections. These sections were created to follow the natural progression of recovery and transition that caregivers and CVA survivor experience. Each section can be used on its own until the caregiver is ready for the next phase.

The caregiver manual might be altered and applied to a variety of populations and caregiver experiences. For example, people with spinal cord injuries and their caregivers as well as people with multiple sclerosis and their caregivers could benefit from a focused and individualized caregiver plan. Further development could include a pilot study in an outpatient facility as well as adapting the manual to be used with different
populations. An additional manual following the same format could be completed for use in the inpatient stay of the CVA survivor and their informal caregiver.

With over 700,000 people each year being affected by CVA many family members are becoming informal caregivers with little to no education or training. This manual provides the tools necessary to transition a family member to the caregiving role.
REFERENCES


http://www.stroke.org/site/PageServer?pagename=SYMP


Appendix A
Dear Occupational Therapist:

The following is a caregiving manual for CVA survivors and their informal caregivers. The manual is used to create an interactive aspect to education during the transition from hospital to home. The caregiver will receive a caregiving manual that includes sections as follows:

I. Background Information
   CVA Information
   ACT F.A.S.T.
   Role of Healthcare professionals
   Role of Occupational Therapist

II. Valued Activities
   Occupations
   Interest Survey
   Environmental Concerns

III. Self-Assessments
   Dealing with change
   Caregiving assessment
   Self Inventory of Physical Abilities
   Cognitive Well Being

IV. Caregiver Self Plan
   Emotional Care
   Physical Care

V. Therapy Plan/Therapy Resources

These sections include educational information, self inventories, self reflection and space for therapist recommendations and resources. The manual has been developed based on the Occupational Adaptation (OA) model. Upon completion of the manual, the caregiver will have the tools necessary to plan and implement occupations essential to their continued role as a caregiver.

Additional evaluation tools will be included in the occupational therapist's manual and will not be included in the caregivers manual. These evaluation tools will be noted in your manual, so necessary communication of these sections can be initiated by the occupational therapist.
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Section I: Background Information
This background information is provided to the caregiver to help them to understand implications of CVA. In this section information is provided to assist the caregiver with general understanding of what a CVA is, ways of future detection, and the roles of the professionals that may be involved your loved ones care. Additional information and resources can be given to the caregiver to assist with individualized needs.

**What does “CVA” mean?**
- A CVA occurs when blood flow stops or ruptures inside a vessel of the brain. When blood can not move in the vessels the brain loses oxygen and shuts down.

**What will happen after the CVA?**
- CVA can cause:
  - One sided weakness or paralysis
  - Loss of sensation
  - Speech problems
  - Vision
  - Memory

*The severity of CVA is different from person to person. Some people experience minimal symptoms while others can lose significant function.

**How long until my loved one is well again?**
- CVA recovery varies from person to person; however, most gains are made within the first year following the CVA.
- Recovery can continue to occur for several years following a CVA with proper treatment.
Why does CVA occur?

CVA is more likely to re-occur for those who have already experienced a CVA. CVA’s can be prevented, and the focus for prevention is critical. Here are some risk factors for CVA, as well as ways to detect a CVA in its early stages.

Risk Factors

- High Blood Pressure
- High Cholesterol
- Diabetes
- Smoking
- Poor Diet
- Lack of Exercise
- Family history of CVA
- Previous CVA

Ways to Prevent

- Low salt diet
- Regular exercise
- Do not smoke
- Moderate alcohol consumption
- Weight control
- Diet and nutrition

Ways to detect a CVA

These five major signs of CVA are identified by the National Institute of Neurological Disorders and Stroke

- Sudden numbness or weakness of the face, arm, or leg (especially on one side of the body)
- Sudden confusion, trouble speaking or understanding speech
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden severe headache with no known cause

*The following page can be removed and placed anywhere within the home that is easily visible to all family members.*
ACT
F.A.S.T

Face
• Ask the person to smile.
• Does one side of the face droop?

Arms
• Ask the person to raise both arms.
• Does one arm drift downward?

Speech
• Ask the person to repeat a simple sentence. Is it correct?
• Are the words slurred?

Time
• If the person shows any of these symptoms, this is important.
• Call 911 or get to the hospital fast.

This is a simple test to use to detect if someone may be experiencing a CVA. (National Stroke Association)
These areas of occupation are defined in the caregiving manual to assist with education of the occupational therapy “language”. This may also be a helpful resource for you as the therapist when discussing these areas with your client.

Nursing

Nurses educate CVA survivors about routine health care, such as how to follow a medication schedule, and how to care for the skin. Nurses also work with survivors to reduce risk factors that may lead to a second CVA, and provide training for caregivers.

Physician

A physician’s primary responsibility is for managing and coordinating the long-term care of CVA survivors, including recommending which rehabilitation programs will best address individual needs. Physicians are also responsible for caring for the CVA survivor's general health and providing guidance aimed at preventing a second CVA.

Physical Therapist

A physical therapist helps to bring back physical function for movement and balance following a CVA.

Speech Therapist

A speech therapist helps survivors to re-learn language skills for communication and thinking.
Occupational Therapist

Occupational therapists use activities or occupations to assist their clients to reach an independent lifestyle that best suits their personal habits, roles and routines.

As occupational therapists, we are working to understand your valued roles so we can best help you to participate as a caregiver. As a new caregiver, you have been placed into a new role that creates many new responsibilities and demands. We recognize these new parts of your life and have created a manual with the purpose to provide resources and encourage your participation in activities that are associated with your new role.

We realize this new role will be demanding, so we have provided information related to physical and emotional aspects of caregiving. You will see that your routines at home have changed. We will help you to explore activities in detail, including the physical, social, and cognitive demands of the activities and the environments in which they occur. As a result realistic adaptations and modification can be made that are a fit for you.

*Definitions adapted from, The National institute of Neurological Disorders and Stroke*
Section II:
Valued Activities
This section is used to assist the caregiver and their loved one with identification of valued occupations and which environments they occur in. This section will provide you, their therapist, with areas of occupational need and environmental needs of your clients. An evaluation template is included in the environment section of the manual. This can be used as a home evaluation tool for assessing environmental needs in the home.

The following areas will be targeted:
- Social participation
- Activities of Daily Living
- Instrumental Activities of Daily Living
- Rest and Sleep
- Education
- Work
- Leisure
What are Areas of Occupation?

These areas of occupation are defined in the caregiving manual to assist with education of the occupational therapy “language”. This may also be a helpful resource for you as the therapist when discussing these areas with your client.

**Social Participation**: Engagement in activities within the community or with your family or friends. Example: Going to have coffee with a friend.

**Activities of Daily Living (ADL’s)**: Activities that are focused toward taking care of yourself. Example: Brushing your teeth.

**Instrumental Activities of Daily Living (IADL’s)**: Activities that assist with daily life in your home or community. These are more complex than ADL’s. Example: Cooking a meal.

**Rest and Sleep**: Restorative rest and sleep that helps you participate in other activities healthfully. Example: getting a full 8 hours of sleep at night.

**Education**: Activities needed for learning and participating in your environment. Example: Taking a class in photography.

**Work**: Engagement in work or volunteer activities. Example: Working part time at a grocery store.

**Leisure**: An activity that is voluntary and personally motivating to you. Example: Going fishing.
This survey will be completed by the caregiver. The caregiver is instructed to share the results of the survey and follow-up questions with their therapist upon completion. The survey and questions are designed to provide information necessary for a treatment plan and continued support of the caregiver and their loved one. It is important to collaborate with the caregiver to guide the development of a future plan for success as a caregiver.

### Interest Survey

**Indicate the areas of occupations that are important to you and your loved one by making an X. For these areas of importance, rate their difficulty from 1-3 using the scale below.**

**Levels of Difficulty:**
1. Going Well
2. Needs Work
3. Very Difficult

<table>
<thead>
<tr>
<th>Items of Importance</th>
<th>Level of Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activities of Daily Living</strong></td>
<td></td>
</tr>
<tr>
<td>Bowel and Bladder Management</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Dressing</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Eating</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Feeding</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Functional Mobility</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Personal Device Care (walker, wheelchair)</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Personal Hygiene and Grooming</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Sexual Activity</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Instrumental Activities of Daily Living</td>
<td>1 2 3</td>
</tr>
<tr>
<td>------------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Care of others (Including caregivers)</td>
<td></td>
</tr>
<tr>
<td>Child rearing</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Communication management</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Community mobility</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Financial management</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Health management maintenance</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Home establishment and management</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Meal preparation and cleanup</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Religious observance</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Safety and emergency maintenance</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Shopping</td>
<td>1 2 3</td>
</tr>
<tr>
<td><strong>Rest and Sleep</strong></td>
<td></td>
</tr>
<tr>
<td>Rest</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Sleep</td>
<td>1 2 3</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Formal educational participation</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Informal personal educational interest exploration (beyond formal education)</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Informal personal education participation</td>
<td>1 2 3</td>
</tr>
<tr>
<td><strong>Work</strong></td>
<td></td>
</tr>
<tr>
<td>Employment interests and pursuits</td>
<td>1 2 3</td>
</tr>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>Employment seeking and acquisition</td>
<td></td>
</tr>
<tr>
<td>Job performance</td>
<td></td>
</tr>
<tr>
<td>Retirement preparation and adjustment</td>
<td></td>
</tr>
<tr>
<td>Volunteer exploration</td>
<td></td>
</tr>
<tr>
<td>Volunteer participation</td>
<td></td>
</tr>
<tr>
<td>Leisure participation</td>
<td></td>
</tr>
<tr>
<td>Social Participation</td>
<td></td>
</tr>
</tbody>
</table>

**For the Caregiver:**

What areas of occupation (activities) are working well?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

In which areas of occupation might you struggle?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Prioritize: Which activities would you like to address first? Please rank in order.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Environmental Concerns

This section addresses the importance of environment to the engagement in occupational activities. The caregiver will complete the following table and questions while reflecting on the results of the interest survey. The caregiver will indicate the most important occupations to them and their loved one as well and the level of difficulty experienced while engaging in these occupations.

*At this time it may be appropriate to complete an occupation focused environmental assessment. This assessment may help to determine any adaptations necessary so engagement in occupations is more accessible. The Occupational Therapy Home Evaluation is in Appendix A.
Reflect back on the areas of occupation that are most important to you. Of these occupations indicate the 5 most important to you in the space provided below under “area of occupation”. List the activity and the location in which the activity is experienced. See example below.

<table>
<thead>
<tr>
<th>Area of Occupation</th>
<th>Activity</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example: Leisure</td>
<td>Gardening</td>
<td>Outside in my backyard</td>
</tr>
<tr>
<td>1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Of the occupations that you currently participate in, which are the most difficult for you and your loved one at this time?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Do the environments in which you participate in make the activity more difficult? If yes, explain.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

List ways below that you could adapt or change these environments to make the activities easier for you and your loved one.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Section III:
Caregiver Self Assessments
This section will provide assessments for the caregiver and their loved one that assess the following areas:

- Dealing with change
- Caregiving self questionnaire
- Physical abilities
- Cognitive abilities

The caregiver will be instructed in their manual to share the assessment results with the occupational therapist to assist with client centered care and an individualized treatment plan. As the therapist, you can provide more information to meet the needs of the caregiver and their loved one if necessary.
Transition is the process of dealing with change. When taking on the new role as caregiver many changes occur from the time of injury to reintegration into the community. Three stages of transition include:

1. **Endings**
   - Leaving something known
   - Plunging into the unknown
   - A period of grieving for the “good ol’ days”

2. **Neutral Zone**
   - Suspended
   - Disconnected from the old way, but clear about the new way
   - Uncertainty and discomfort

3. **New Beginnings**
   - The new way is clear
   - Transition from the unknown to the known
   - Encouragement and excitement about the future

**For the Caregiver:**

1. List changes good and bad that you have faced with your new caregiving role.
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

2. What stage from the previous table are you in when dealing with change?
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

3. Which of these changes is the most difficult? What contributes to the difficulty?
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

**For Your Loved One:**

1. List changes good and bad that you have faced thus far in your transition.
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

2. Which of these changes is the most difficult? What contributes to the difficulty?
   __________________________________________________________
   __________________________________________________________
Caregivers are often so concerned with caring for their loved ones needs that they lose sight of their own wellbeing. Please take a few minutes to answer the following questions.

**Caregiver Self Assessment Questionnaire**

**During the past week or so, I have...**

1. Had trouble keeping my mind on what I have been doing
   - Yes
   - No

2. Felt that I couldn’t leave my loved one alone.
   - Yes
   - No

3. Had difficulty making decisions.
   - Yes
   - No

4. Felt completely overwhelmed
   - Yes
   - No

5. Felt useful and needed
   - Yes
   - No

6. Felt lonely
   - Yes
   - No

7. Been upset that my relative has changed so much from his/her former self
   - Yes
   - No

8. Felt lose of privacy or private time
   - Yes
   - No

9. Been edgy or irritable.
   - Yes
   - No

10. Had sleep disturbance due to caring for loved one
    - Yes
    - No

11. Had a crying spell
    - Yes
    - No

12. Felt strain between work and family responsibilities
    - Yes
    - No

13. Had back pain
    - Yes
    - No

14. Felt ill
    - Yes
    - No

15. Been satisfied with the support my family has given me
    - Yes
    - No

16. I have found my loved one’s living situation to be inconvenient or a barrier of care
17. On a scale of 1 to 10 with 1 being “not stressful” and 10 “very stressful”, please rate your current stress level _____

18. On a scale of 1 to 10, with 1 being “very healthy” to 10 being “very ill”, please rate your current health compared to what it was this time last year. ______

*Adapted from American Medical Association (Caregiver Self-Assessment Questionnaire*
Listed below are several situations you may find yourself in as caregiver. Indicate your comfort level with the following situations by marking a number from the table below.

<table>
<thead>
<tr>
<th>Circle the number that corresponds with your comfort level</th>
<th>Least Comfortable</th>
<th>Somewhat Comfortable</th>
<th>Comfortable</th>
<th>Very Comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transferring my loved one to use the bathroom</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Being at home alone with my loved one with no extra help</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Assisting in showering/bathing of my loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Assisting with dressing upper body of my loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Assisting with dressing lower body of my loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Using my own strength to help my loved one move and transfer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Making modifications to the home to make a safe and easy environment to live in</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Using proper techniques to decrease injury to myself and my loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Putting on and taking of splints correctly (If applicable)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Assisting with medication management for my loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Encouraging my loved one to be as independent as possible</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>----------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Leaving the home and entering the community with my loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Leaving my family member home alone</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
You are beginning many new things in your caregiver role. What information are you feeling comfortable with and where do you want more information?

I feel comfortable with my knowledge of

- [ ] CVA background information
- [ ] Coping strategies
- [ ] Social supports
- [ ] Living a healthy lifestyle
- [ ] Medical professionals role in providing care
- [ ] Types of deficits related to CVA
- [ ] Safety information

I would like more information on

- [ ] CVA background information
- [ ] Coping strategies
- [ ] Social supports
- [ ] Living a healthy lifestyle
- [ ] Medical professionals role in providing care
- [ ] Types of deficits related to CVA
- [ ] Safety information
Section III: Caregiver Self Care Plan
This section allows the caregiver to evaluate possible items to include in their personal therapy plan. At this point the caregiver begins to utilize the skills and information obtained in previous sections. As the therapist, encourage the caregiver to take the lead in their future as a caregiver. At this point in the manual you can provide caregivers with resources for more information on strategies for emotional care and physical care.

**Emotional Care**

*What are coping skills?*

Coping skills are strategies that are used to offset stressors, anxieties and challenging experiences in a healthy way.

* Here are some examples of coping strategies you can use:

- Breathing techniques
- Visualization
- Progressive muscle relaxation
- Simple stretches
- Take a 5 minute time out
- Journaling
- Scrapbooking
- Cooking/baking
- Talking to family/friends
- Reading a book
- Humor
- Exercise

Indicate 3 ways you can cope with daily stressors from the list above.

1. ______________________________________
2. ______________________________________
3. ______________________________________
Other? ____________________________________

When can these coping skills be used?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
What environments help you relax?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Who are your social supports?
  1. _______________________________________
  2. _______________________________________
  3. _______________________________________

In what situations will you utilize these supports?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Physical Care

Refer back to your inventory of physical demands. Indicate physical risk areas that you may be at risk for as a caregiver.

☐ Back injury
☐ Physical exhaustion
☐ Environmental safety concerns
☐ Inability to take breaks
☐ Lack of supports
☐ Other____________________________________________

Check the appropriate boxes in the following chart.

<table>
<thead>
<tr>
<th>Skills I use now…</th>
<th>Skills I would like to try…</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Eat a well balanced diet</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Exercise</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Get adequate sleep</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Use healthy coping strategies</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Engage in healthy relationships with family and friends</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Practice proper lifting techniques</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Communicate what you need</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Express yourself creatively</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>Take frequent breaks during work tasks</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Use back protection strategies</td>
</tr>
<tr>
<td></td>
<td>Incorporate social interactions into your daily routine</td>
</tr>
<tr>
<td></td>
<td>Encourage Independence for loved one</td>
</tr>
</tbody>
</table>

How can you use the skills in the previous chart to reduce your risk for injury?
________________________________________________________________________
________________________________________________________________________

How will you incorporate the skills you would like to try into your daily routine?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

What other information do you wish to receive from your occupational therapist?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Section IV: Therapy Plan
In this section a therapy plan will be developed by the caregiver to assist in creating an individualized treatment plan for their continuing role as a caregiver.

The following section is an opportunity for the caregiver to develop a plan to optimize independence for their loved one. This plan can also help the caregiver adapt to their new caregiving role by establishing a routine and defining each other’s roles. The first part of this section describes the therapy plan and is followed by a section that allows the therapist to provide resources to support the therapy plan. For example, if the caregiver is having difficulty adapting to their new role emotionally, the therapist may provide a resource related to coping skills. Additional resources are available in Appendix B. The therapist resources can be added by the therapist in addition to already developed information.

Example:

Activity/occupations: *Washing dishes*

What will the caregiver do?

*Rinses dishes*

What will the CVA survivor do?

*Places dishes in dishwasher*

What will the therapist do?

*Teaching different adaptations to the environment, such as adding a chair next to the dishwasher*
Therapy Plan

Date:_________________________________________________

Activity/occupations:__________________________
What will the caregiver do?
____________________________________________
What will the CVA survivor do?
____________________________________________
What will the therapist do?
____________________________________________
____________________________________________

Revision Date:________________________________________

Successes:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Challenges:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Revisions:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Therapist Resources
Therapy plan

Date:_________________________________________________

Activity/occupations:____________________

What will the caregiver do?
________________________________________

What will the CVA survivor do?
________________________________________

What will the therapist do?
________________________________________
________________________________________

Revision Date:________________________________________

Successes:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Challenges:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Revisions:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Therapist Resources
Therapy Plan

Date:_________________________________________________

Activity/occupations:________________________

What will the caregiver do?
________________________________________

What will the CVA survivor do?
________________________________________

What will the therapist do?
________________________________________

________________________________________

Revision Date:________________________________________

Successes:
________________________________________________________________________
________________________________________________________________________
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Challenges:
________________________________________________________________________
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Revisions:
________________________________________________________________________
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________________________________________________________________________
Therapist Resources
Therapy Plan

Date:_________________________________________________

Activity/occupations:______________________________
   What will the caregiver do?
       ________________________________
   What will the CVA survivor do?
       ________________________________
   What will the therapist do?
       ________________________________
       ________________________________

Revision Date:________________________________________

Successes:________________________________________________________________________
________________________________________________________________________
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Challenges:_______________________________________________________________________
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Revisions:_______________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Therapy Plan

Date:_________________________________________________

Activity/occupations:____________________

What will the caregiver do?
________________________________________

What will the CVA survivor do?
________________________________________

What will the therapist do?
________________________________________

________________________________________

Revision Date:________________________________________

Successes:
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Challenges:
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Revisions:
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Therapist Resources
Therapy Resources
This section is not in the caregiving manual. This form can be used as a template for the home evaluation. If a home evaluation is completed, this information as well as the adaptive devices form should be shared with the caregiver and their loved one.

If a home evaluation is not completed by the occupational therapist a caregiver self assessment of home safety is provided in Appendix B.

**Client Status**

________________________________________________________________________
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**Entrances:**
Front door
Width
________________________________________________________________________
________________________________________________________________________
________________________
Approach
________________________________________________________________________
________________________________________________________________________
________________________
Floor Surface
________________________________________________________________________
________________________________________________________________________
________________________
Back door
Width
________________________________________________________________________
________________________________________________________________________
________________________
Bedroom:

Entrance


Mobility Space


Function of Closet and Drawers


Use of furniture and bed


Use of lights


Other


Bathroom:

Entrance


Mobility Space


Use of lights
Sink

Shower/Tub

Toilet

Other

Living Room/Dining Room:

Entrance

Mobility Space

Use of lights

Furniture
Other

Kitchen:

Entrance

Mobility Space

Use of lights

Table and Chairs

Counters

Appliances

Cupboards
Laundry:

Entrance

Mobility Space

Use of lights

Washer

Dryer

Counter

Other
Emergency and safety aspects:

Cell Phone Use

Emergency Contacts

Emergency Call Buttons

Other

Therapist Recommendations
Adaptive Equipment

☐ Check the boxes of devices that maybe helpful to the caregiver and their loved one.

Kitchen
☐ Rocker knife
☐ Adapted plate
☐ Swivel spoon
☐ Other___________________

Bathroom
☐ Raised toilet seat
☐ Commode
☐ Long handled scrub brush
☐ Adapted tooth brush
☐ Adapted toothpaste holder
☐ Other___________________

Dressing
☐ Long handled shoe horn
☐ Reacher
☐ Button hook
☐ Leg lifter
☐ Sock aid
☐ Elastic shoe laces
☐ Other___________________

Mobility
☐ Four wheeled walker
☐ Cane
☐ Wheelchair
☐ Walker bag
☐ Walker tray
☐ Other___________________
The community environment is an important part of mobility for you and your loved one to practice and re-integrate into your lifestyles. There may be many questions that arise when leaving your home for the first time. Questions like, “Will the wheelchair fit in the restaurant?” or “What will people think when they see us now?” can be scary. Being prepared will help ease the anxieties that are associated with community mobility. Here are some things to keep in mind while you prepare for re-entering the community.

**How will we get there?**
- Bus
- Car
- Walk
- Ride from a friend
- Subway
- Other

**Keep in mind!!!**
- Your loved one should not be driving unless he or she has been cleared by your doctor. Occupational therapists can do driving evaluations to see if your loved one is safe to drive. Contact your therapist with more questions about driving evaluations.
- If your loved one cannot drive there are other ways for them to get from place to place independently, such as a city bus or taxi service.

**Where are we going?**
Once you plan where you will be going, keep these tips in mind. This list can be used as a mental checklist before you go somewhere new.

- Does your loved one have an effective way to communicate in this setting?
- Will your loved one be able to move in and out of the building? (Door width, ramps, etc.)
- Once inside the building is there a large enough space to move about safely?
- Is the weather suitable and safe for mobility at this time?
- Does this location have areas we can sit and rest if needed?
- Is the area well lit?
- Is there an accessible bathroom?

*Ask your therapist for local resources that may help you adapt to your environment, or adapt to your current community environment.*
When a person suffers from a CVA many areas of their life are affected. One of the most significant changes that will occur is in a person’s physical environment such as their home. Certain areas of your home may more difficult than others for your loved one to move about in. Use this assessment below to identify areas in your home where you may need more assistance.

*Share this checklist with your occupational therapist upon completion. This will assist your therapist develop a complete evaluation of your home.

<table>
<thead>
<tr>
<th>Environment</th>
<th>Indicate if the environment works well, needs work, or is not available at all for your loved one.</th>
<th>Yes, and works well</th>
<th>Yes, but needs work</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Driveway/Parking</td>
<td>Is the parking space close enough to the door?</td>
<td></td>
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<tr>
<td></td>
<td>Is there adequate space to get into and out of the car?</td>
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<tr>
<td>Pathway/Curb</td>
<td>Is there a pathway from the driveway to the house?</td>
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<td></td>
<td>Are pathways smooth and safe to walk on?</td>
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<tr>
<td></td>
<td>Are the curbs manageable?</td>
<td></td>
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<tr>
<td>Entrance</td>
<td>Are there steps? If so are they in good condition?</td>
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<td></td>
<td>Are the railings in good repair on both sides?</td>
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<td></td>
<td>Is there a ramp?</td>
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<td></td>
<td>Does the ramp have handrails on both sides?</td>
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<tr>
<td>Door</td>
<td>Is the door wide enough to move through?</td>
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<td></td>
<td>Is there enough room to maneuver while opening the door and moving into the house?</td>
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<tr>
<td>Category</td>
<td>Question</td>
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<td>--------------------------------------------------------------------------</td>
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<tr>
<td>Safety Features</td>
<td>Is the door area well lit inside and out?</td>
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<td></td>
<td>Are the door locks easy to operate?</td>
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<tr>
<td>Doors and Hallways</td>
<td>Are the doorways and hallways wide enough to move inside the home?</td>
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<td></td>
<td>Are the thresholds between rooms easy to move through without tripping or losing balance?</td>
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<td></td>
<td>Are the hallways free from obstructions?</td>
<td></td>
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<tr>
<td>Stairs</td>
<td>Are the stairs in your home easy to climb and descend?</td>
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<td></td>
<td>Are there handrails running along both sides of the stairs?</td>
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<td></td>
<td>Are the handrails secured?</td>
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<td></td>
<td>Is the space in the stairwell adequate for moving up and down?</td>
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<td></td>
<td>Are the stairwells well lit?</td>
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<tr>
<td>Kitchen Appliances</td>
<td>Can the oven be opened safely and easily?</td>
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<tr>
<td></td>
<td>Are the stove/oven controls easy and safe to reach?</td>
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<tr>
<td></td>
<td>Are the electrical outlets within reach?</td>
<td></td>
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<tr>
<td>Kitchen Counters</td>
<td>Are the counters at a good working height for you and your loved one?</td>
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<tr>
<td></td>
<td>Is there a need for open space below the counters so you can sit while working?</td>
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<tr>
<td>Kitchen Table</td>
<td>Is the table at a good height?</td>
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<td></td>
<td>Is there room to move safely around the table?</td>
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<tr>
<td>Kitchen Lighting</td>
<td>Is there enough lighting to work in areas for cooking, cleaning and food preparation?</td>
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<tr>
<td>Bathroom</td>
<td>Is the sink at a good height?</td>
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<td></td>
<td>Are the faucet controls easy to use?</td>
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<td>Is the mirror at a good height for you?</td>
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<td></td>
<td>Is the tub or shower easy to get into and use?</td>
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<td></td>
<td>Is there a tub or shower seat?</td>
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<td>Does the shower head have a hand held unit?</td>
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<td></td>
<td>Is the shower or tub covered with a non-slip surface?</td>
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<td>Do you need grab bars by the toilet?</td>
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<td></td>
<td>Do you need grab bars in the tub or shower?</td>
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<tr>
<td>Room</td>
<td>Question</td>
<td>Answer</td>
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<tr>
<td>Bathroom</td>
<td>Is the toilet paper within reach?</td>
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<td></td>
<td>Are the light switches easy to turn on and off?</td>
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<td></td>
<td>Are the electrical outlets within reach?</td>
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<td></td>
<td>Is storage within reach?</td>
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<td></td>
<td>Is there space to maneuver in the bathroom?</td>
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<td></td>
<td>Is the bathroom well lit?</td>
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<td>Bedroom</td>
<td>Is the bed easy to get in and out of?</td>
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<td></td>
<td>Is there space for dressing and undressing?</td>
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<td></td>
<td>Is storage accessible?</td>
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<td>Are closet rods and shelves within your reach?</td>
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<td></td>
<td>Are drawers easy to open and close?</td>
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<td></td>
<td>Is there space to move around in the bedroom?</td>
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<td></td>
<td>Is there a chair for dressing and undressing?</td>
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<td></td>
<td>Is the bedroom well lit?</td>
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<td></td>
<td>Are electrical outlets within reach?</td>
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<tr>
<td>Living Room</td>
<td>Are appliances (TV, stereo, etc.) within easy reach?</td>
<td></td>
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<td></td>
<td>Are controls and appliances easy to use?</td>
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<td></td>
<td>Is the floor surface free of scatter rugs or any other tripping hazards?</td>
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<td></td>
<td>Are electrical outlets within reach?</td>
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<td></td>
<td>Are lights switches easy to reach and turn on and off?</td>
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<td></td>
<td>Does the furniture arrangement allow you adequate room to move around?</td>
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<td></td>
<td>Is the room well lit?</td>
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<td></td>
<td>Are switches easy to reach?</td>
<td></td>
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<tr>
<td>Dining Room</td>
<td>Is the floor surface free of scatter rugs and anything else you could trip on?</td>
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<td></td>
<td>Is the dining room easily accessible from the kitchen?</td>
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<tr>
<td></td>
<td>Is there space to move around in the living room?</td>
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<tr>
<td>Laundry Room</td>
<td>Are the appliances easy to reach and use safely?</td>
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<td></td>
<td>Are the dials easy to read on the appliances?</td>
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<tr>
<td>Question</td>
<td>Answer</td>
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<td>------------------------------------------------------------------------</td>
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<tr>
<td>Is there a table to set items?</td>
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<tr>
<td>Is the laundry room on another level from the living areas?</td>
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<tr>
<td>Is there space to move around in the laundry room?</td>
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<tr>
<td>Is the laundry room well lit?</td>
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</tbody>
</table>

Adapted from the “Consumer’s Guide to Home Adaptation
Energy Conservation

Breaking up physically active periods with rest periods, resulting in increased amount of physical activity (Radomski & Trombly Latham, 2008)

Tips for Energy Conservation

Organize Your Tasks
- Get the things you need before you start your task
- Store items together, that you use together, and place them in easy reach

Delegate Work to Others
- Think about the tasks that are difficult for you mentally or physical and ask someone for help

Schedule Your Time
- Make a daily schedule
- Break strenuous or difficult jobs into smaller segments i.e. do one load of laundry each day of the week instead of five in one day
- Set realistic priorities
- Balance difficult tasks with less difficult ones

Balance Rest and Work
- Take 5 minute breaks for each hour of continuous work
- Plan 20-30 minute rest periods throughout the day

Environmental Changes
- Keep work surfaces like chairs and tables at the correct height to eliminate strain on your body
- Use adaptive equipment to help make your job easier as a caregiver

Body Mechanics
- When standing to work...
  - Use balanced posture
  - Shift weight to change positions to distribute weight and force
  - Take breaks every 30-60 minutes
- When handling objects
  - Bend at your hips and knees when lifting
  - Lift using your legs
  - Maintain back natural curves

Adapted from Energy-Saving Techniques work sheet
Back strain and sprain are common concerns for caregivers of people with physical disabilities. Frequent lifting and bending to assist with daily tasks can lead to back pain for a caregiver. Common factors that contribute to back pain are weak abdominal muscles, lack of adaptive equipment, repetitive motion and poor body mechanics. Simple adaptations can be made to perform necessary movements the best way possible to prevent back injury (Corcoran, 2003)

- Avoid twisting
- Be close to the object or person you are moving
- Lift with your legs, not your back
- DO NOT lift someone or something alone if you are not confident you cant do so
- Avoid jerking movements, move smoothly
- Keep feet apart to keep a wide base of support

* Additional resources with pictures of proper techniques for lifting may be helpful.
REFERENCES


Appendix B
An Interactive Manual for Informal Caregivers of CVA Survivors

Caregiver Manual

Lindsay Draayer, MOTS
Kaila Gunderson, MOTS
Deb Hanson, OTR/L
University of North Dakota
2009
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Section I:
Background Information
Since your loved one has experienced a CVA you have probably been bombarded with new terms and information. In this section information is provided to assist you with general understanding of what a CVA is, ways of future detection, and the roles of the professionals that may be involved in your loved one’s care.

**What to Know about a Cerebral Vascular Accident (CVA)?**

**What does “CVA” mean?**
- A CVA occurs when blood flow stops or ruptures inside a vessel of the brain. When blood can not move in the vessels the brain loses oxygen and shuts down.

**What will happen after the CVA?**
- One sided weakness or paralysis
- Loss of sensation
- Speech problems
- Vision
- Memory

*The severity of CVA is different from person to person. Some people experience minimal symptoms while others can lose significant function.*
How long until my loved one is well again?

- CVA recovery varies from person to person; however, most gains are made within the first year.
- With proper treatment, recovery can continue to occur for several years following a CVA.

How to prevent a CVA?

CVA is more likely to re-occur for those who have already experienced a CVA. CVA’s can be prevented and the focus for prevention is critical. Here are some risk factors for CVA, as well as ways to detect a CVA in its early stages.

Risk Factors

- High Blood Pressure
- High Cholesterol
- Diabetes
- Smoking
- Poor Diet
- Lack of Exercise
- Family history of CVA
- Previous CVA

Ways to Prevent

- Low salt diet
- Regular exercise
- Do not smoke
- Moderate alcohol consumption
- Weight control
- Diet and nutrition
Ways to detect a CVA

These five major signs of CVA are identified by the National Institute of Neurological Disorders and Stroke

• Sudden numbness or weakness of the face, arm, or leg (especially on one side of the body)
• Sudden confusion, trouble speaking or understanding speech
• Sudden trouble seeing in one or both eyes
• Sudden trouble walking, dizziness, loss of balance or coordination
• Sudden severe headache with no known cause

*The following page can be removed and placed anywhere within the home that is easily visible to all family members.
ACT F.A.S.T

Face
- Ask the person to smile.
- Does one side of the face droop?

Arms
- Ask the person to raise both arms.
- Does one arm drift downward?

Speech
- Ask the person to repeat a simple sentence. Is it correct?
- Are the words slurred?

Time
- If the person shows any of these symptoms, this is important.
- Call 911 or get to the hospital fast.

This is a simple test to use to detect if someone may be experiencing a CVA. (National Stroke Association)
Role of Health Care Professionals

Nursing

Nurses educate CVA survivors about routine health care, such as how to follow a medication schedule, and how to care for the skin. Nurses also work with survivors to reduce risk factors that may lead to a second CVA and provide training for caregivers.

Physician

A physician’s primary responsibility is to manage and coordinate the long-term care of CVA survivors, including recommending rehabilitation programs that will best address individual needs. Physicians are also responsible for caring for the CVA survivor's general health and providing guidance aimed toward preventing a second CVA.

Physical Therapist

A physical therapist helps to bring back physical function for movement and balance following a CVA.

Speech Therapist

A speech therapist helps survivors to re-learn language skills for communication and thinking.
Occupational Therapist

Occupational therapists use activities or occupations to assist their clients to reach an independent lifestyle that best suits their personal habits, roles and routines.

As occupational therapists, we are working to understand your valued roles so we can best help you to participate as a caregiver. As a new caregiver, you have been placed into a new role that creates many new responsibilities and demands. We recognize these new parts of your life and have created a manual with the purpose to provide resources and encourage your participation in activities that are associated with your new role.

We realize this new role will be demanding, so we have provided information related to physical and emotional aspects of caregiving. You will see that your routines at home have changed. We will help you to explore activities in detail, including the physical, social, and cognitive demands of the activities and the environments in which they occur. As a result realistic adaptations and modification can be made that are a fit for you.

Definitions adapted from, The National institute of Neurological Disorders and Stroke
Section II: Valued Activities
Exploration of different types of activities and various occupations can result in positive experiences and increased quality of life. In the following section, ideas and resources are included for occupational activities that may be used by you and your loved one.

**Areas of Occupation**

- Social participation
- Activities of Daily Living
- Instrumental Activities of Daily Living
- Rest and Sleep
- Education
- Work
- Leisure

*The following areas will be targeted:*
What are Areas of Occupation?

**Social Participation:** Engagement in activities within the community or with your family or friends. Example: Going to have coffee with a friend.

**Activities of Daily Living (ADL’s):** Activities that are focused toward taking care of yourself. Example: Brushing your teeth.

**Instrumental Activities of Daily Living (IADL’s):** Activities that assist with daily life in your home or community. These are more complex than ADL’s. Example: Cooking a meal.

**Rest and Sleep:** Restorative rest and sleep that helps you participate in other activities healthfully. Example: getting a full 8 hours of sleep at night.

**Education:** Activities needed for learning and participating in your environment. Example: Taking a class in photography.

**Work:** Engagement in work or volunteer activities. Example: Working part time at a grocery store.

**Leisure:** An activity that is voluntary and personally motivating to you. Example: Going fishing.
When a person suffers from a CVA, many areas of their life are affected. Certain areas of occupation may be more difficult than others for you and your loved one. Use this assessment below to identify areas of occupations where you may need more assistance.

Upon the completion of this survey, your therapist will use the results to create an individualized treatment plan for you and your loved one. This will help your therapist to understand what is important to you, so these areas of occupations will be addressed.
Indicate the areas of occupation that are important to you and your loved one by making an X. For these areas of importance, rate their difficulty from 1-3 using the scale below.

**Levels of Difficulty:**
1-Going Well
2-Needs Work
3-Very Difficult

<table>
<thead>
<tr>
<th>Items of Importance</th>
<th>Level of Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activities of Daily Living</strong></td>
<td></td>
</tr>
<tr>
<td>Bowel and Bladder Management</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Dressing</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Eating</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Feeding</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Functional Mobility</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Personal Device Care</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Personal Hygiene and Grooming</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Sexual Activity</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Toilet Hygiene</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Instrumental Activities of Daily Living</td>
<td>1 2 3</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Care of others (Including caregivers)</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Child rearing</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Communication management</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Community mobility</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Financial management</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Health management maintenance</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Home establishment and management</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Meal preparation and cleanup</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Religious observance</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Safety and emergency maintenance</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Shopping</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

**Rest and Sleep**

<table>
<thead>
<tr>
<th>Rest</th>
<th>1 2 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

**Education**
<table>
<thead>
<tr>
<th>Formal educational participation</th>
<th>1 2 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal personal educational interests exploration (beyond formal education)</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Informal personal education participation</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

**Work**

<table>
<thead>
<tr>
<th>Employment interests and pursuits</th>
<th>1 2 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment seeking and acquisition</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Job performance</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Retirement preparation and adjustment</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Volunteer exploration</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Volunteer participation</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Leisure participation</td>
<td>1 2 3</td>
</tr>
<tr>
<td>Social Participation</td>
<td>1 2 3</td>
</tr>
</tbody>
</table>

Adapted from the Occupational Therapy Framework (2008)
For the Caregiver:
What areas of occupation (activities) are working well?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
In which areas of occupation might you struggle?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Prioritize: Which activities would you like to address first? Please rank in order.
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

*This information will be helpful for your occupational therapist to see. He or she can get a better idea of areas you would like some more help with, and which areas are important to you. Share this with your therapist at your next meeting.
Engagement in occupations can change dramatically when experienced in different environments. Some environments may create an easier or more pleasant experience, while others may make an activity more difficult. Environmental considerations are important when engaging in activities. The following section will assist with identifications of occupations and the environments they are experienced in.

*If difficulties are occurring with the occupations you participate in due to environmental concerns, your occupational therapist may complete an assessment of your environment to make changes. These changes can lead to increased participation in these occupations and environments.
Reflect back on the areas of occupation that are most important to you. Of these occupations indicate the 5 most important to you in the space provided below under “area of occupation”. List the activity and the location in which the activity is experienced. See example below.

<table>
<thead>
<tr>
<th>Area of Occupation</th>
<th>Activity</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example: Leisure</td>
<td>Gardening</td>
<td>Outside in my backyard</td>
</tr>
<tr>
<td>1.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Of the occupations that you currently participate in, which are the most difficult for you and your loved one at this time?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Do the environments in which you participate in make the activity more difficult? If yes explain now.

______________________________________________________
______________________________________________________
______________________________________________________
______________________________________________________

List ways below that you could adapt or change these environments to make the activities easier for you and your loved one.

______________________________________________________
______________________________________________________
______________________________________________________
______________________________________________________

*Ask your therapist for resources regarding community mobility for you and your loved one.
Section III:
Caregiver Self Assessment
This section of the caregiving manual focuses on you and your adjustment to the caregiver role. You may be experiencing emotional and physical changes that are distressing. You may find the following self assessments helpful to you and your loved one for identify areas of change/need.

**Dealing with change**

Transition is the process of dealing with change. When taking on the new role as caregiver many changes occur from the time of injury to reintegration into the community. Three stages of transition include:

1. **Endings**
   - Leaving something known
   - Plunging into the unknown
   - A period of grieving for the “good ol’ days”

2. **Neutral Zone**
   - Suspended
   -Disconnected from the old way, but clear about the new way
   - Uncertainty and discomfort

3. **New Beginnings**
   - The new way is clear
   - Transition from the unknown to the known
   - Encouragement and excitement about the future
For the Caregiver:

1. List changes good and bad that you have faced with your new caregiving role.

______________________________________________________
______________________________________________________
______________________________________________________

2. What stage from the previous table are you in when dealing with change?

______________________________________________________
______________________________________________________
______________________________________________________

3. Which of these changes is the most difficult? What contributes to the difficulty?

______________________________________________________
______________________________________________________
______________________________________________________

For Your Loved One

1. List changes good and bad that you have faced thus far in your transition.

______________________________________________________
______________________________________________________
______________________________________________________

2. Which of these changes is the most difficult? What contributes to the difficulty?

______________________________________________________
______________________________________________________
Caregivers are often so concerned with caring for their loved ones needs that they lose sight of their own wellbeing. Please take a few minutes to answer the following questions.

**During the past week or so, I have...**

1. Had trouble keeping my mind on what I have been doing  
   □ Yes  
   □ No

2. Felt that I couldn’t leave my loved one alone.  
   □ Yes  
   □ No

3. Had difficulty making decisions.  
   □ Yes  
   □ No

4. Felt completely overwhelmed  
   □ Yes  
   □ No

5. Felt useful and needed  
   □ Yes  
   □ No

6. Felt lonely  
   □ Yes  
   □ No

7. Been upset that my relative has changed so much from his/her former self  
   □ Yes  
   □ No

8. Felt lose of privacy or private time  
   □ Yes  
   □ No

9. Been edgy or irritable.  
   □ Yes  
   □ No

10. Had sleep disturbance due to caring for loved one  
    □ Yes  
    □ No
11. Had a crying spell
   □ Yes
   □ No

12. Felt strain between work and family responsibilities
   □ Yes
   □ No

13. Had back pain
   □ Yes
   □ No

14. Felt ill
   □ Yes
   □ No

15. Been satisfied with the support my family has given me
   □ Yes
   □ No

16. I have found my loved one’s living situation to be inconvenient or a barrier of care
   □ Yes
   □ No

17. On a scale of 1 to 10 with 1 being “not stressful” and 10 “very stressful”, please rate your current stress level ____

18. On a scale of 1 to 10, with 1 being “very healthy” to 10 being “very ill”, please rate your current health compared to what it was this time last year. ____

*Adapted from American Medical Association (Caregiver Self-Assessment Questionnaire)
Listed below are several situations you may find yourself in as caregiver. Indicate your comfort level with the following situations by marking a number from the table below.

<table>
<thead>
<tr>
<th>Circled the number that corresponds with your comfort level</th>
<th>Least Comfortable</th>
<th>Somewhat Comfortable</th>
<th>Comfortable</th>
<th>Very Comfortable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transferring my loved one to use the bathroom</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Being at home alone with my loved one with no extra help</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Assisting in showering/bathing of my loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Assisting with dressing upper body of my loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Assisting with dressing lower body of my loved one</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Using my own strength to help my loved one move and transfer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Making modifications to the home to make a safe and easy environment to live in</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Using proper techniques to decrease injury to myself and my loved one | 1 | 2 | 3 | 4
---|---|---|---|---
Putting on and taking of splints correctly (If applicable) | 1 | 2 | 3 | 4
---|---|---|---|---
Assisting with medication management for my loved one | 1 | 2 | 3 | 4
---|---|---|---|---
Encouraging my loved one to be as independent as possible | 1 | 2 | 3 | 4
---|---|---|---|---
Leaving the home and entering the community with my loved one | 1 | 2 | 3 | 4
---|---|---|---|---
Leaving my family member home alone without me being there | 1 | 2 | 3 | 4
---|---|---|---|---
Assisting therapists with continued safe use of adaptive equipment in the home i.e. walker or cane use | 1 | 2 | 3 | 4
---|---|---|---|---

*Share this with your occupational therapist as it will help him or her in creating an individualized treatment plan for you and your loved one.
You are beginning many new things in your caregiver role. What information are you feeling comfortable with and where do you want more information?

I feel comfortable with my knowledge of

☐ CVA background information
☐ Coping strategies
☐ Social supports
☐ Living a healthy lifestyle
☐ Medical professionals role in providing care
☐ Types of deficits related to CVA
☐ Safety information

I would like more information on

☐ CVA background information
☐ Coping strategies
☐ Social supports
☐ Living a healthy lifestyle
☐ Medical professionals role in providing care
☐ Types of deficits related to CVA
☐ Safety information
Section IV:
Caregiver Self Plan
This section is a chance for you to develop your own caregiving plan based on collaboration with your therapist as well as the information and education you have received previously in the manual.

**Emotional Care**

*What are coping skills?*

Coping skills are strategies that are used to offset stressors, anxieties, and challenging experiences in a healthy way.

* Here are some examples of coping strategies you can use:

- Breathing techniques
- Visualization
- Progressive muscle relaxation
- Simple stretches
- Take a 5 minute time out
- Journaling
- Scrapbooking
- Cooking/baking
- Talking to family/friends
- Reading a book
- Humor
- Exercise
Indicate 3 ways you can cope with daily stressors from the list above.

1. _______________________________________
2. _______________________________________
3. _______________________________________
Other? ___________________________________

When can these coping skills be used?

______________________________________________________
______________________________________________________
______________________________________________________

What environments help you relax?

______________________________________________________
______________________________________________________
______________________________________________________

Who are your social supports?

1. _______________________________________
2. _______________________________________
3. _______________________________________

In what situations will you utilize these supports?

______________________________________________________
______________________________________________________
______________________________________________________
Physical Care

Refer back to your self inventory of physical demands. Indicate physical risk areas that you may be at risk for as a caregiver.

- Back injury
- Physical exhaustion
- Environmental safety concerns
- Inability to take breaks
- Lack of supports
- Other___________________________________________

Check the appropriate boxes in the following chart.

<table>
<thead>
<tr>
<th>Skills I use now...</th>
<th>Skills I would like to try...</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>☐ Eat a well balanced diet</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>☐ Exercise</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>☐ Get adequate sleep</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>☐ Use healthy coping strategies</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>☐ Engage in healthy relationships with family and friends</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>☐ Practice proper lifting techniques</td>
<td>☐</td>
</tr>
<tr>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>☐ Communicate what you need</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>Express yourself creatively</td>
</tr>
<tr>
<td></td>
<td>Take frequent breaks during work tasks</td>
</tr>
<tr>
<td></td>
<td>Use back protection strategies</td>
</tr>
<tr>
<td></td>
<td>Incorporate social interactions into your daily routine</td>
</tr>
<tr>
<td></td>
<td>Encourage independence for loved one</td>
</tr>
</tbody>
</table>

How can you use the skills in the previous chart to reduce your risk for injury?
______________________________________________________
______________________________________________________
______________________________________________________

How will you incorporate the skills you would like to try into your daily routine?
______________________________________________________
______________________________________________________
______________________________________________________

What other information do you wish to receive from your occupational therapist?
______________________________________________________
______________________________________________________
______________________________________________________
Section V: Therapy Plan
In this section a therapy plan will be developed by you, the caregiver, to assist in creating an individualized treatment plan. The skills and information you have developed and learned in this manual provide you with the tools necessary to plan for your future as a caregiver.

The following section is an opportunity for you to develop a plan to optimize independence for your loved one in meaningful tasks. This plan can help you adapt to your new caregiving role by establishing a routine and defining each others roles.

Example:
Activity/occupations: Washing dishes
   What will the caregiver do?
      Rinses dishes
   What will the CVA survivor do?
      Places dishes in dishwasher
   What will the therapist do?
      Teaching different adaptations to the environment such as adding a chair next to the dishwasher
Therapy Plan

Date: ___________________________________________________________

Activity/occupations: ________________________________
  What will the caregiver do?
  ___________________________________________________________
  What will the CVA survivor do?
  ___________________________________________________________
  What will the therapist do?
  ___________________________________________________________
  ___________________________________________________________

Revision Date: __________________________________________________

Successes:
  ___________________________________________________________
  ___________________________________________________________
  ___________________________________________________________

Challenges:
  ___________________________________________________________
  ___________________________________________________________
  ___________________________________________________________

Revisions:
  ___________________________________________________________
  ___________________________________________________________
  ___________________________________________________________
Therapist Resources
Therapy Plan

Date: ______________________________________________________________

Activity/occupations: ______________________
  What will the caregiver do?
  ________________________________________________
  What will the CVA survivor do?
  ________________________________________________
  What will the therapist do?
  ________________________________________________
  ________________________________________________

Revision Date: ________________________________________________________

Successes:
  ______________________________________________________________
  ______________________________________________________________
  ______________________________________________________________

Challenges:
  ______________________________________________________________
  ______________________________________________________________
  ______________________________________________________________

Revisions:
  ______________________________________________________________
  ______________________________________________________________
  ______________________________________________________________
Therapist Resources
Therapy Plan

Date: _________________________________________________

Activity/occupations: ___________________________
  What will the caregiver do?
  ____________________________________________

  What will the CVA survivor do?
  ____________________________________________

  What will the therapist do?
  ____________________________________________
  ____________________________________________

Revision Date: __________________________________________

Successes:
  ____________________________________________
  ____________________________________________
  ____________________________________________

Challenges:
  ____________________________________________
  ____________________________________________
  ____________________________________________

Revisions:
  ____________________________________________
  ____________________________________________
  ____________________________________________
Therapist Resources
Therapy Plan

Date: _________________________________________________

Activity/occupations: _________________________________
  What will the caregiver do?
  _________________________________________________
  What will the CVA survivor do?
  _________________________________________________
  What will the therapist do?
  _________________________________________________
  _________________________________________________

Revision Date: __________________________________________

Successes:
  ____________________________________________________
  ____________________________________________________
  ____________________________________________________

Challenges:
  ____________________________________________________
  ____________________________________________________
  ____________________________________________________

Revisions:
  ____________________________________________________
  ____________________________________________________
  ____________________________________________________
Therapist Resources
Therapy Plan

Date: ______________________________________________________

Activity/occupations: __________________________
  What will the caregiver do?
  ________________________________________________
  What will the CVA survivor do?
  ________________________________________________
  What will the therapist do?
  ________________________________________________
  ________________________________________________

Revision Date: ______________________________________________

Successes:
  ________________________________________________________
  ________________________________________________________
  ________________________________________________________

Challenges:
  ________________________________________________________
  ________________________________________________________
  ________________________________________________________

Revisions:
  ________________________________________________________
  ________________________________________________________
  ________________________________________________________
Therapist Resources
REFERENCES


