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# Life Care Plans : a Resource for Caregivers

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Philadelphia College of Osteopathic Medicine

Department of Psychology

Life Care Plans: A Resource for Caregivers

By Carolyn E. Rutherford

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Psychology

August 2004

## Dissertation Approval

This is to certify that the thesis presented to us by Carolyn E. Rutherford on the (15) day of (March), 2004, in partial fulfillment of the requirements for the degree of Doctor of Psychology, has been examined and is acceptable in both scholarship and literary quality.

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Dedicated to the loving memory of my mother

Caroline Darrah Rutherford

## Acknowledgments

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## Abstract

Life Care Plans have been used since the early 70s, primarily to assist in litigation involving catastrophic illness or injury. In the last decade Life Care Plans have become an important component in the field of litigation and rehabilitation. However, to date no studies have explored the impact having a Life Care Plan may have for the family Caregiver.

Literature supports the need Caregivers have for detailed and concise information about their loved one's condition, plan of care and future needs. This study investigated the perceived helpfulness of the Life Care Plan to Caregivers.

Using a 5-point Likert Scale, Caregivers were asked to rate how helpful 37 different areas contained in a Life Care Plan were to them. The second purpose of the study was to explore coping styles caregivers use in a stressful situation. Relationships between Caregivers and their coping styles were also explored.

Seventy Four Caregivers responded to the survey. Caregivers rated all 37 areas at least "fairly helpful" to them. Most helpful to the Caregiver was information regarding the future costs. More than 90 percent of Caregivers responding indicated that they found the Life Care Plan as "very helpful" or "extremely helpful" in understanding the future costs involved.

Using the Ways of Coping Questionnaire, several coping styles of Caregivers were explored. It was hypothesized that there would be a positive correlation between the Helpfulness scale and the Seeking Social Support Scale, measured by the Ways of Coping Questionnaire. This reached statistical significance at the .001 level. No other hypothesis reached statistical significance.

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## Chapter 1

### Introduction

The care and management of patients with catastrophic illness or injury comprises the single largest cost to the health care system in the United States (National Center for Health Statistics, 1992). The last several decades have shown advances in the fields of technology and medicine that have increased the survival rate (Go, DeVivo, & Richards, 1995). Surviving life-threatening illness has often been accompanied by the need for lifelong care. The changing healthcare system has forced Caregivers to take an active role (Elliott & Shewchuk 2000). This care is often provided by or directed by a parent, spouse, or other relative.

Disabilities, and how they affect the patient, vary greatly; however they all result in the need for specialized and ongoing care and treatment. The illnesses or injuries may have affected many areas of a patient's life, including cognitive limitations or changes, and physical or behavior. There may be ongoing needs for medical care, treatments, medications and therapies. This may be as difficult, or more difficult, for the Caregivers than the patients themselves (Livingston, 1987; Koskinin, 1998).

Interest in the effects of disabling illness on Caregivers is not new to the psychological literature. Research on caregiving has been well documented, especially in the field of gerontology (Clipp & George, 1993; Deimling & Bass, 1986; Zarit, 1989; Deimling, Smerglia & Schaefer, 2001; Morris, Morris & Britton, 1989). Professionals working in the field of aging since at least the 1960s have addressed this issue, with frequency.

There is wide agreement that families typically perform a number of functions for their members, including socialization, emotional support, economic subsistence, personal care, recreation, and identification (Turnbull, Barber, Behr & Kerns, 1988). Many families continue

all of these functions while enduring the stress of having a member with a catastrophic illness or injury not associated with the aging process.

The term “catastrophic illness” includes disabling conditions, such as diabetes, multiple sclerosis, cardiac disorders, or severe pulmonary disease, to name a few, and is reflective of conditions that are either insidious or abrupt in their onset (Weed, 1995). This may include severe traumatic brain injury, spinal cord injury, amputations, severe burns, organ transplants and debilitating diseases, such as cancer and AIDS. Family members of individuals with catastrophic illness or injury are often ill prepared for the care that is required, partially because the patient’s needs were not well anticipated (Lipman,1999).

Factors such as the physical and/or cognitive impairment of the patient can be direct sources of stress to family members. Additionally, parents may be faced with the added stress of experiencing daily declines in the health of their child. Additional stresses can include the lack of information concerning the illness or injury. The fear of the unknown and future may add to this stress, and can result in a great deal of psychological distress including anxiety, depression and crushing guilt (Lipman,1999).

### *History of Stress, Caregivers and Catastrophic Injury*

Literature in the field has universally identified the perceived stress, both physical and emotional that may be placed on the Caregivers (Alfano, Neilson, & Fink, 1994; Chwalisz, 1992; Brooks, Campsie, Symington, Beattie & McKinlay, 1986; Elliott & Shewchuk, 2000). Perceived stress is defined as the perception that the situation exceeds one’s available coping resources (Lazarus & Folkman, 1984).

As family members assume more responsibility helping patients adhere to prescribed self-care and medical regimen, the increased responsibility may lead to high levels of distress, or what is referred to as “Caregivers burden” (Zarit, 1989). Caregivers burden relates to the physical, psychological or emotional, social and financial problems that can be experienced by Caregivers of ill individuals (George & Gwyther, 1986). Almost 75 percent of Caregivers of individuals with catastrophic illness or injury have reported elevated levels of stress (Deimling, et al., 2001).

Traumatic Brain Injury (TBI) is an example of a common catastrophic injury that frequently creates havoc on the lives of Caregivers (Gervasio & Kruezer, 1997). Throughout North American brain injuries are a leading cause of childhood disability (Haley, Cioffi, Lewin & Baryza, 1990; Johnson & Gerring, 1992). The impact of TBI on the survivor’s family is well documented. Studies have examined TBI-related stresses that have an adverse impact on the Caregivers. Depression was found to be the greatest within the first month after the injury, compared to 6 and 12 months later. Depression was not found to be related to the severity of the injury or to the parent versus spouse relationship to the patient. Studies by Oddy, Humphrey and Uttley (1978) and Livingston (1987) also found no difference between the mother Caregivers or wife Caregivers relationship within severely injured survivors. Guerriere and McKeever (1997) interviewed mothers with children who sustained a brain injury. These mothers reported that their lives had been radically altered because of their children’s injuries. Their view of life had been dramatically changed. Many of them stated that they now view life as precarious, unpredictable and dominated by fate. They also reported a sense of generalized anxiety and worry about what was going to “happen next.”

A person with a Traumatic Brain Injury could experience a wide variety of symptoms. Common symptoms may include compromised cognitive abilities, resulting in the need for assistance with activities of daily living, behavioral problems, psychological problems, and physical complications resulting from the brain injury. This places additional developmental needs for the brain-injured patient that the individual without a brain injury will not require.

Initial care will often require extensive medical evaluations. Evaluations may include CAT scans, MRI studies, neurological testing, neuropsychological testing, physical and occupational evaluations, audiology screening and speech, language, and swallow studies are common. The extent of the injury and the results of the medical evaluations often result in a need for rehabilitation initially, as well as throughout the child's development and often throughout his or her life. Occupational, physical, speech and language, and psychological evaluations as well as therapy, are therapeutic modalities commonly needed periodically throughout a lifespan.

In addition to medical testing non-medical assessments may be warranted. These may include architectural evaluations for the patient's environment, aids for independent living, driving evaluations and vocational testing, if appropriate. A patient with TBI will often require diagnostic and educational testing more extensive than the non-injured individual. In some cases with school-age children who suffer traumatic brain injury, there may be a need for home schooling for a period of time or possibly for the child's entire educational period. In the most severe and complicated cases a need for home care and respite care, to relieve the parents from the daily care burden may be required. A child that is not able to be managed at home may require full or part time care in a residential facility.

Routine medical care that will be required throughout life will be much more extensive than for the child who did not experience a TBI. The Caregivers is also faced with the reality of not only the injury, but also unforeseen complications. Frequent complications may include depression, behavioral problems, seizures, increased risk of falls and future TBI. In later years, early onset of dementia may occur. Increased care or supportive living situations are likely to occur at an earlier age. This can be overwhelming for Caregivers.

Mothers of children with disabilities were found to have low self-esteem and decreased feelings of maternal competence and have reported feeling anxious, sad and burdened (Leonard, Brust, & Nelson, 1993; Ray & Ritchie, 1993; Simon and Smith, 1992). High levels of family burden and parental distress from severe traumatic brain injury suggests that families may benefit from anticipatory guidance. Several studies have compared spouses and parents in their experience of burden. Although the experiences do not differ greatly, Allen, Linn, Gutierrez and Willer (1994) found parents appeared more burdened by concerns about their head-injured child's life-long needs.

Family Caregivers often report a lack of confidence in managing home care problems. Solving problems is a major concern of Caregivers of persons with brain injuries. Therefore, Caregivers' abilities in solving both routine and unanticipated problems may be critical in explaining their adjustment (Grant, 1999).

Another example of a catastrophic injury is spinal cord injury occurring predominately among young adults. Improvement in emergency care and surgical interventions have increased life expectancy following spinal cord injuries, so that in some cases the life expectancy approaches that of the general population (Go et al., 1995). The extent of recovery from a spinal cord injury depends on the amount of damage and location to the spinal cord. Similar to

traumatic brain injury, a spinal cord injury occurs without warning. Motor vehicle accidents account for almost 50 percent of spinal cord injuries. Falls, gunshot wounds and sports injuries are responsible for the majority of the remaining spinal cord injuries. Traumatic brain injury and spinal cord injury populations are both at-risk populations, who have undergone potentially life-threatening physical trauma and have prolonged hospital stays with significant disabilities (Koskinin, 1998).

Among the many disabilities that may be incurred by children, spinal cord injury represents not only a devastating injury to children, but one that is replete with secondary complications. No other childhood disability, congenital or acquired, results in such abrupt motor paralysis, sensory loss, bowel, bladder and sexual dysfunction, temporary cessation of developmental milestones, alteration in poor growth in the paralyzed extremities, contractures and severe spasticity (Vogel & DeVivo, 1996). Spinal cord injury in childhood can result in underachievement in areas of social, educational and emotional functioning. This drastically alters leisure activities in families and often forces lifestyle changes for the child, his or her family and Caregivers' (Brooks, Campsie, Symington, Beattie, & McKinlay, 1987; Elliott, Godshall, Herrick, Witty & Spruell, 1991). As with families who have a member that experience a traumatic brain injury, management of a family member with spinal cord injury is an ongoing process of rehabilitation and habilitation efforts. These needs will continue to change throughout the patient's lifetime.

Traumatic spinal cord injury is an insult to the spinal cord that can result in alterations of normal motor, sensory, and autonomic functions (Staas, Christopher, Formal & Gershkof, 1993). Traumatic spinal cord injury is considered to be a permanent condition, with very few people experiencing significant long-term recovery. Individuals who have had no improvement within



the first six months to one year are considered to have permanent injury with no likelihood for significant functional improvement. Numerous physiological changes occur in almost every system of the body as a result of spinal cord injury.

Normal physiological control of the cardiovascular system are lost in spinal cord injury from the injured vertebral level down. Loss of blood pressure is a common problem. Deep vein thrombosis has been recognized as a significant cause of morbidity and mortality in spinal cord injured patients. The incidents of deep vein thrombosis occurs in more than 80 percent of spinal cord injury cases (Waring & Karunas, 1991).

Patients with spinal cord injury experience a number of physiological changes in the gastrointestinal tracts. Gastrointestinal bleeding is often an early complication of spinal cord injury. Bowel incontinence poses serious social, recreational and vocational limitations for the patient. Patients with a high-level spinal cord injury are totally dependent on others for the assistance and management of their bowel incontinence. Individuals with a low spinal cord injury may require assistance with a bowel program and may experience gastrointestinal upset or diarrhea frequently (Cardenas, 1992). Urinary incontinence results in low spinal cord injury patients. The patient is likely to require a catheter. An increase of urinary tract infections, as well as skin breakdown, are common occurrences (Cardenas, 1992).

In the case of spinal cord injury, Family Caregivers may become the primary sources of assistance for activities including toileting. Toileting a child during the “tender years” is an expected role of every parent. However, continuing this role through adolescence and adulthood is not only unexpected, but often met with feelings of emotional discomfort due to the loss of control of such basic bodily functions and the highly personal natures of these needs.

Anemia is prevalent in the spinal cord injured population (Hirsh, Menard & Anton, 1990). Even with all risk factors controlled for, patients with a spinal cord injury are two times as likely to develop coronary artery disease (Bauman, Razam, Spunger, & Machac, 1994). Due to the decreased physical activity level and tendency to gain weight, adult onset diabetes mellitus often occurs in a patient with spinal cord injury. Several studies have established a glucose intolerance of individuals with spinal cord injury (Duckworth, 1989). Due to the gastrointestinal problems experienced by patients with spinal cord injury, there is an increased risk and rate of development for peptic ulcer disease and gastritis (Epstein, 1981). Other medical complications significantly affect this population. Pre-existing conditions generally become worse when combined with a spinal cord injury. Some conditions, although not directly related to the traumatic spinal cord, are complicated by the injury.

In addition to the medical complications of this injury, social, emotional and vocational issues are greatly affected. Psychological adjustments to the sudden onset of a severe disability will require a great deal of understanding from the Caregivers' so the patient can resume a functional role at home and in the community. Social and recreational activities that the patient previously was involved in are likely to be drastically affected. This can also have a similar significant impact on the Caregivers (Shewchuk, Richards, & Elliott, 1998). A Caregivers may not know what alternative activities may be possible.

Patients with spinal cord injuries can often have their lives enhanced with the use of various types of durable medical equipment. Wheelchairs, either manual, electric or both, along with home modifications may greatly enhance the patient's level of functioning. Transportation becomes a major issue with spinal cord injured patients. Although with appropriate equipment, many patients are able to drive independently, Caregivers may not only be responsible for

transporting their loved ones to all appointments, but ensuring that they have a vehicle that is able to adequately carry the patient, as well as room for a wheelchair. Tetraplegics may not be able to manage in the family automobile, but may require an accessible van with a wheelchair lift. The simple act of how to transport a loved one can become a confusing maze of choices, which needs to be made by the Caregivers, usually not knowledgeable in this area.

Giving consideration to the level of injury, patient's educational level and past work history, re-entering the workforce needs to be assessed. Often patients and Caregivers are not aware of the vocational options available to the spinal cord injury patient.

As with other catastrophic injuries and illnesses, aging, combined with a spinal cord injury often leads to increased pain and decreased functional status. Pain has been reported to occur in more than 90 percent of individuals with a spinal cord injury (Melzack, 1973). A functional decline generally occurs 15 to 20 years post injury for the average patient (Menter, 1995). Spasticity can become difficult to control. As the person ages medications may no longer be effective and a need for alternative treatments may be required. Fatigue with a decline in strength and increase in weakness is reported as one of the most common problems affecting the quality of life (Menter, 1995). The patient and Caregivers are faced with a multitude of changes.

Because of the complicated physical, medical and psychological issues encountered by a patient with a spinal cord injury, the needs are constantly changing replacing additional demands on Caregivers (Weitzenkamp, Gerhart, Charlifue, Whiteneck, & Savic, 1997). Spinal cord injury results in numerous medical challenges throughout the life of the patient. Needs regarding medical care, products, supplies, and equipment can be overwhelming for the Caregivers. Like all illnesses and injuries, these patients have a unique set of needs that must be reviewed and addressed on an ongoing basis. Interventions and assistance need to be provided for the

Caregivers to help in coping with the changing demands of providing care to their loved one (Elliott & Shewchuk, 2000).

### *Caregivers of Catastrophically Ill and Injured*

As the literature has shown, a child or adult with a crisis or a critical illness can be overwhelming and stressful for parents and Caregivers. Once the initial injury or medically critical period is stabilized by the medical community, attention may be directed toward the Caregivers, yet specific needs may remain unidentified. When perceived needs are not accurately identified or addressed, the combination of incongruencies and the significant stress of having a critically ill relative can result in anxieties escalating to a crisis event. Attention has focused on the stressors experienced by family members of critically ill relatives. Empirical research has identified sources of stress-related factors to psychosocial factors and the physical environment (Carter, Miles, Bufort & Hassanein, 1985; Miles, Carter, Spicher, & Hassanein, 1984), changes in parental role (Jay & Youngblut, 1991) and parental uncertainty (LaMontagne, Johnson & Hepworth, 1995; Mishel, 1983; Tomlinson, Kirschbaum, Harbaugh, & Anderson, 1996). Several research studies have been conducted to ascertain the perceived needs of family members of critically ill adults (Docker et al., 1988; Freichels, 1991; Mathis, 1984; Molter, 1979; Rodgers, 1983); however, exploration of parental needs in the critical care pediatric population is limited (Fisher, 1994; Kasper & Nyamathi, 1988; Kirschbaum, 1990). Molter (1979) conducted an exploratory, descriptive research study to identify the needs of relatives of critically ill patients. The findings of the study indicated the priority needs identified included honest, accurate information from caring personnel.

Caregivers to survivors of traumatic brain injury found that although they had been given information at the time of the injury, they could not remember it. The lack of knowledge was a source of fear and frustration for the Caregivers (Chwalisz, 1992). Caregivers reported wanting ones information about their family member's condition, plan of care and prognosis, throughout each phase of care or recovery. When Caregivers are feeling overwhelmed by lack of information or knowledge about the course of illness or injury, they may be more likely to view their situation as hopeless and underestimate their existing resources. Research on lessening Caregivers burden suggests that an obvious practice recommendation would be to develop interventions that would enhance Caregivers' perceptions of their available resources and decrease catastrophic appraisals (Chwalisz, 1996).

A Life Care Plan, a comprehensive document, provides a concise plan for current and future needs of an individual with a catastrophic illness or injury. It provides information on a standard of care for the individual that is both needs and outcomes driven (Weed & Berens, 2000). Offering a consistent, concise and time efficient method that provides a framework of needs and services, the Life Care Plan is considered a valuable comprehensive tool (Weed, 1995). Much attention has been paid to value of the Life Care Plan to the catastrophically ill or injured patient and their medical treatment team.

Life Care Plans have become an important component in the rehabilitation field. The Life Care Plan can be used as a tool to communicate needs and serve as a guide to identify anticipated care and services for catastrophically ill or injured patients throughout their lives (Caragonne & Sofka 2001; Reid, Deutsch, Kitchen, Aznavoorian, 1999; Shepherd & Pittman, 1996, Weed, 1998).

As healthcare providers, we need to give more attention to what information we are providing our patients and their families. Illnesses and injury vary considerably in their natural history, treatment and prognosis. Information that is specific to the individual case can provide the guide for Caregivers to navigate their individual situations.

A Caregiver's perception of how much control the patient has over his or her condition and ability to perform activities of daily living may also influence Caregivers stress and ability to cope. (Karp & Tanarugachock, 2000). Following diagnosis, Caregivers may make a considerate effort to empathize with their ill or disabled spouse, child, parent or sibling, often believing that the combination of medical care and their own loving care will solve the problem. It is believed by many in the field that if Caregivers were clearly informed about what to expect regarding their loved ones' course of illness or injury and amount of control the patient does or does not have, the Caregivers may feel less angry and better equipped to manage Caregivers responsibilities. (Karp & Tanarugachock, 2000)

The Life Care Plan may provide Caregivers the expert information to make decisions and solve problems that they will likely encounter with the continuing and complex needs of their loved one. However, to date, no research has explored the efficacy of the Life Care Plan to the family or the non-professional Caregivers of a catastrophically ill or injured person.

### *Family Caregivers*

As family members assume more responsibility helping patients adhere to prescribed self-care and medical regimens, they may experience high levels of distress, or what is referred to as "Caregivers burden" (Zarit, 1989). Caregivers burden relates to the physical, psychological

or emotional, social and financial problems that can be experienced by primary Caregivers of ill individuals (George & Gwyther, 1986). In fact, almost 75 percent of Caregivers of individuals with catastrophic illness have reported elevated levels of stress (Deimling et al., 2001). While the concept of Caregivers burden has been studied extensively with the elderly population, less attention has been paid to Caregivers of individuals who may experience catastrophic illness or injury during childhood or as a young adult.

### *The Impact of Caregivers burden*

There is no single explanation in the literature for the etiology of Caregivers burden. Research has included a great deal of variability regarding how the term has been conceptualized and measured. In a review of studies regarding the conceptualization of Caregivers burden, it was concluded that the term was best defined as the “negative, subjective experience of the Caregivers” (Chwalisz, 1992, p.190).

An important component in this definition is perceived stress, which is defined as the perception that the situation exceeds a person’s available coping resources (Lazarus & Folkman, 1984). Perceived stress has been found to consistently predict negative outcomes among Caregivers of individuals with a variety of illnesses and injuries.

Caregivers of brain-injured patients have reported symptoms of depression, disorientation, forgetfulness, and pragmatic deficits during social interactions and logical reasoning difficulties. Gervasio and Kreutzer (1997) found that more than 40 percent of Caregivers of TBI patients had clinically elevated scores on the Brief Symptom Inventory (BSI), indicating severe psychological distress. Caregivers of TBI patients have also reported

decreased levels of perceived social support and elevated levels of perceived stress in relation to various daily difficulties (Pelletier, Alfano, & Fink, 1994).

Several studies have examined stress levels of Caregivers of individuals with spinal cord injury (SCI), and have found that spouses, parents, or other relatives who were the primary Caregivers often experienced a great deal of physical and emotional distress (Alfano, et al., 1994; Koskinin, 1998; Pelletier et al., 1994; Peters et al., 1992; Weitzenkamp et al., 1997). Weitzenkamp et al. (1997) found that on average, SCI Caregivers had more symptoms of depressive affect (feeling “blue,” excessive crying) and somatic depression (sleeplessness, loss of appetite) than non-Caregivers. Primary Caregivers of SCI patients also reported high levels of fatigue, anger, resentment, and overall mental weariness.

The stress of caregiving may not only have a negative impact on the Caregivers, but in turn, may affect the patient. Caregiver’s anxiety and depression were found to be significantly correlated with emotional and behavioral functioning of the patient. The concordance of distress level between patients and Caregivers was high, ranging from .55 to .72 on measures of progressive severity, anxiety, and quality of life. This reflects findings reported in studies of couples coping with a chronic disease (Stommel, Given, & Given, 1990) and suggests that addressing mental health needs of Caregivers may not only relieve their own depression but may alleviate the patient’s distress as well. Perhaps observing the Caregiver’s distress adds to the perception of being a burden on the part of the patient and thus exacerbates his or her own distress.



### *Factors That Contribute to Caregivers Burden*

The predominant model of the caregiving process, proposed by Pearlin, Mullan, Semple and Skaff, (1990), is that Caregivers adjustment is a function of a variety of interactions between environmental and individual factors. An understanding of these factors is critical, in order to develop necessary preventive and remedial strategies to help alleviate the stress that Caregivers experience.

### *Insufficient Resources*

One reason for the burden experienced by Caregivers of catastrophically ill patients is that while the patient may have a network of individuals who provide some degree of care, primary care is usually given by just one individual, who may seriously lack the resources to provide such care (Deimling et al., 2001) The primary Caregiver is usually the family member who satisfies the greatest number of the following five criteria: a) he or she is a spouse, parent, or spouse-equivalent; b) has the most frequent contact with the patient; c) helps to support the patient financially; d) has most frequently been a collateral in the patient's treatment; and e) is the one contacted by treatment staff in case of an emergency. The burden of the primary Caregivers may not only include providing actual care, but making life-altering decisions, coordinating necessary resources, and exploring treatment in areas in which the Caregivers may not be familiar. The constant burden on the primary Caregiver can result in a great deal of psychological distress, including anxiety, depression and crushing guilt (Chwalisz, 1996).

### *Styles and Traits of Caregivers*

Certain personality dispositions of Caregivers may contribute to Caregivers burden, as caregiving may be particularly difficult for individuals who possess traits that render them vulnerable. For example, individuals who score higher in neuroticism (Hooker, Monahan, Shifren, & Hutchinsen, 1992) and those who view the caregiving role as distressing (Chwalisz, 1996) report more distress and burden than other Caregivers. Additionally, when Caregivers have tendencies to problem-solve in an impulsive and careless manner, such tendencies have been found to be significantly associated with poor psychological adjustment, both at the time of the patient's initial diagnosis and one year later (Chwalisz, 1996).

A Caregiver's perception of how much control the patient has over his or her illness and ability to perform activities of daily living may also influence Caregivers burden (Karp & Tanarugachock, 2000). Following diagnosis, Caregivers may make a considerable effort to empathize with their ill spouse, child, parent, or sibling, often believing that a combination of medical treatment and their own loving care will solve the problem. Negative emotions are likely to arise if a Caregivers starts to believe, possibly erroneously, that the ill individual is not assuming appropriate responsibility for getting well. If Caregivers were better informed about what to expect regarding the patient's course of illness and amount of control the patient truly has, the Caregiver may feel less angry and better prepared to handle the caregiving responsibilities.

### *Solutions for Caregivers*

Social supports also serve to buffer the effects of caregiving stress. Research on social support has consistently demonstrated that absence of a close and/or confiding relationship is associated with increased risk for relapse or nonremission in depression (Cronkite, Moos, Twohey, Cohen & Swindle, 1998; Dean, Kolody & Wood, 1990; George, Blazer, Hughes, & Fowler, 1989; Sherbourne, Hayes, & Wells, 1995; Swindle, Cronkite, Moos, 1998). Actively seeking and obtaining social support may result in Caregivers feeling less emotionally vulnerable.

Research has shown that when Caregivers reorganize family tasks and activities so that treatment of the patient's illness becomes part of their family life, greater adjustment to the caregiving responsibilities took place (Jerrett, 1994; Gallo & Knafl, 1998). Parents' psychological distress in 57 families in which there was a child with a chronic illness were examined. Most parents (59 percent of mothers and 67 percent of fathers) reported significant levels of distress linked to the number of illness-related parental responsibilities. These findings suggest that care activities can be a major stressor for Caregivers and that interventions directed to streamlining caregiving responsibilities, or adjusting them and incorporating them into family activities, have the potential for lessening overall distress.

The community is another source of Caregivers support, but many individuals are not familiar with how to go about accessing resources. Gill and Khurana's (2000) study focused on the impact of caregiving on family members of individuals with Shy-Drager Syndrome. The authors drew the conclusion that in order to prevent further burden or stress, a referral to a multidisciplinary health service needed to occur. They suggested that a case management team

of nursing, social work, and physical therapy could work with the Caregivers and identify issues and available resources. They predicted that such determination of the patient's needs may allow Caregivers to cope with a patient's demands and may improve the quality of life of both the patient and the Caregivers.

Research on lessening Caregivers burden suggests that an obvious practice recommendation would be to develop interventions that would enhance Caregivers' perceptions of their available resources and decrease catastrophic appraisals (Chwalisz, 1996). When Caregivers are feeling overwhelmed, they may be more likely to view their situation as hopeless, and underestimate their existing resources. Training in social problem-solving may assist the Caregivers to more realistically perceive existing resources (D'Zurilla & Nezu, 1999). For example, when an individual is confronted with a difficult problem or set of problems, but has poor problem-solving ability, the person's sense of predictability, mastery, and control is likely to be reduced. As a result, negative stress effects may occur, such as depression, anxiety, or maladaptive behavior (D'Zurilla & Nezu, 1999). If Caregivers are provided with some type of intervention that incorporates social problem-solving training, this intervention is likely to enhance predictability, mastery, and control, which may result in an amelioration of the negative stress effects.

### *Social Problem Solving*

The term "problem-solving" may be defined as the "self-directed cognitive-behavioral process by which a person attempts to identify or discover effective or adaptive solutions for specific problems encountered in everyday living" (D'Zurilla & Nezu, 1999, p. 10). As per this

definition, problem solving can be described as a conscious, logical, and purposeful activity. “Social problem-solving” is the term that has been popularized in the fields of clinical, counseling, and health psychology for this phenomenon (D’Zurilla & Nezu, 1982). The adjective “social” in this term is used to highlight the notion that the focus of study is on problem solving that occurs within the natural social environment. As a result, theory and research on social problem solving has included a variety of problems in living, such as impersonal (e.g. money management), personal and interpersonal (e.g. emotional difficulties), interpersonal (e.g. familial conflicts) and societal (e.g. disease management).

Social problem solving has been described as a “learning process, a general coping strategy, and a self-management method” (D’Zurilla & Nezu, 1999, p.11). A prescriptive model of social problem solving was originated by D’Zurilla and Goldfried (1971), and expanded and refined by D’Zurilla and Nezu (1982, 1990). In this model, effective problem solving methods are described, which increase the probability of adaptive coping outcomes. Social problem solving involves three variables in order to effect adaptive coping outcomes: 1) orienting responses, which are at the metacognitive level, and serve a motivational function; 2) problem-solving skills, which are critical for effective problem-solving performance; and 3) basic cognitive skills, which underlie the performance level and affect one’s ability to learn and implement necessary problem-solving skills.

In D’Zurilla and Nezu’s model (1982, 1990), it is assumed that problem-solving outcomes are basically determined by two major, partially independent processes: 1) problem orientation and 2) problem-solving proper. Problem orientation is the motivational aspect of the problem-solving equation, whereas problem-solving proper is the process by which one attempts

to construct an effective solution to a particular problem through the application of rational problem-solving techniques and strategies.

Problem orientation is comprised of “an intentional set to recognize problems when they occur during the course of everyday living and a set of relatively stable cognitive-emotional schemas that describe how a person typically thinks and feels about problems in living and his or her own problem-solving ability” (D’Zurilla & Nezu, 1999). A positive problem orientation will result in positive emotions and approach tendencies, and will set the occasion for problem-solving activities by maximizing effort, persistence, and tolerance for uncertainty and frustration. A negative problem orientation, however, produces negative emotions and avoidance tendencies, increases destructive worrying, and reduces one’s ability to tolerate frustration and uncertainty.

In the model described above, problem-solving proper involves the application of four major problem-solving skills that are designed to enhance the probability of finding the most effective solution: 1) problem definition and formulation; 2) generation of alternative solutions; 3) decision making; and 4) solution implementation and verification. Each of these skills is a set of specific goal-directed tasks that enable an individual to solve a particular problem successfully.

The purpose of the initial task of the problem-solving process is to gather as much information about the problem as possible, clarify the exact nature of the problem, set goals that are attainable and realistic, and reappraise the significance of the problem in order to achieve personal and social well-being (D’Zurilla & Nezu, 1999). Solutions are then generated, with as many alternatives as possible, in order to maximize the likelihood that the “best” will be found.

The individual then needs to evaluate the available solutions and select the most appropriate one for implementation

According to the theory of problem-solving therapy, social problem solving is an essential process of coping that enhances adaptive situational coping and behavioral competence, which then buffers the negative effects of stress on one's psychological and physical well-being (D'Zurilla & Nezu, 1999). Social problem-solving ability should then be related to a wide range of both adaptive and maladaptive responses, such as how Caregivers react to the stress of having to care for individuals with catastrophic illness.

### *Social Problem Solving with Caregivers*

There is some evidence suggesting that social problem-solving ability, including one's problem orientation, might be related to caregiving effectiveness. In a recent study focusing on family Caregivers of persons with recent-onset physical disability, Elliott and Schewchuk (2000) reported that when Caregivers had an impulsive/careless problem-solving style, there was acceptance of disability at discharge from a rehabilitation program. Moreover, in a study focusing on Caregivers of individuals with Alzheimer's Disease, Rothenberg, Nezu, & Nezu (1995) reported that all three dysfunctional problem-solving dimensions (negative problem orientation, impulsivity/carelessness style, and avoidance style) were positively related to symptom severity, whereas the two constructive dimensions (positive problem orientation, and rational problem solving) were negatively related to this criterion measure.

Negative problem orientation was also found to be related to depression and anxiety in Caregivers of patients with spinal cord injuries (Elliott, Shewchuk, Richards, Palmatier and

Margolis, 1997). Because family members who are responsible for the day-to-day care of chronically ill patients experience high levels of distress and frequent problems, training in problem-solving skills may be a particularly useful approach in helping family Caregivers in general cope more effectively in this role (Nezu, Nezu, & Houts, 1993).

A problem-solving based program was designed to enhance the caregiving skills of family Caregivers of cancer patients. The “Prepared Family Caregivers Course” utilized the D’Zurilla and Nezu (1982) Problem-solving Therapy model as a means of providing the following types of information to family Caregivers of cancer patients: a) understanding the problem; b) when to get professional help; c) what can be done to deal with, as well as prevent, a problem; d) identifying obstacles when they arise and planning to overcome them; and e) carrying out and adjusting the plan. Manuals have been developed (Houts et al., 1997) that contain guided problem-solving plans across a variety of physical (e.g. fatigue, hair loss, appetite difficulties) and psychosocial (e.g. depression, anxiety) problems that cancer patients commonly experience. The manual uses the acronym COPE to illustrate various problem-solving operations, where C = creativity, O = optimism, P = planning, and E = expert information. Although no controlled studies have yet been conducted with this protocol, Bucher, Houts, Nezu, and Nezu (1999) have reported that this program has been positively evaluated regarding participant satisfaction and acceptability of the treatment approach.

Studies have indicated a positive association between adequate problem-solving abilities in Caregivers and patient adjustment to disability (Noojin & Wallender, 1997). Social problem-solving abilities have been found to be associated with Caregivers adjustment.



### *Life Care Plans*

A Life Care Plan (LCP) is a “dynamic document based upon published standards of practice, comprehensive effectants, data analysis and research, which provides an organized concise plan for current and future needs with associated costs, for individuals who have experienced catastrophic injuries or have chronic health care needs” (Weed & Berens, 2000, p.1). Essentially, the LCP provides a “road map” for case managers to follow, providing services to meet the needs identified in a comprehensive yet cost-effective manner.

An LCP outlines both the short and long term needs of an individual with catastrophic illness, and provides a standard of care for that individual that is both needs driven and outcome oriented (Weed & Berens, 2000). In terms of the overall expected outcome, the LCP should a) maximize independence, b) enable the patient to live or function in the least restrictive environment, c) minimize medical complications, and d) plan for productive work activity. In order to produce a successful LCP, extensive planning, prevention, and problem solving need to take place (Reid et al. 1999).

### *History and Development of Life Care Planning*

Life care planning is an outgrowth of research that began in the late 1970s and was first extensively used in the publication *Damages in Tort Action* (Deutsch & Raffa, 1981). Litigators discovered that it was critical to have a means for communication among all parties involved in an injury case, to determine the precise needs of individuals who acquired disabilities. The LCP

became a means of communication for this type of information, and was considered to be a clear, concise, and precise tool.

In its beginning stages, the foremost application of life care planning was through the consultation process. Consultation, primarily with insurance carriers and attorneys involved in injury litigation, developed into an important area of practice for rehabilitation professionals. The demand generated by participants in the litigation process significantly influenced life care planning and enhanced its credibility and acceptance, both within and outside the courtroom.

Those involved in litigated injury and illness cases began to recognize that individuals with disabilities and their families need a concise summary of a plan that could be taken away from an evaluation and used as a guideline for further reference. Catastrophic case management signaled the drastic need for proactive planning, rather than simply reacting to circumstances that dictate immediate needs. The LCP was designed to break the effects of disability into the most basic components and assess each concern in detail. The new approach was geared toward prevention of problems, rather than “management by chaos.” The LCP takes into consideration the injury or disability, the needs, goals, interests and preference of the individual, the needs of the family, and advantages and disadvantages of the geographical region in which the individual and family resided (Reid et al., 1999).

The concept of life care planning, as a specific approach to catastrophic case management, was developed by Paul Deutsch and Frederick Raffa (1981) when they published the original format in the legal literature. Offering a consistent, concise, and time efficient method for providing a framework of services, the LCP was considered to be a valuable, comprehensive tool (Weed, 1995).

The LCP has become a common element in tort litigation involving severe to catastrophic injury and disability. When the LCP is required in legal cases, it is usually the result of someone having suffered a severe, catastrophic disability as a result of the alleged harmful act of another.

It is in this legal context that the LCP is described as the overall service and care plan designed to sufficiently provide the services and commodities necessary to achieve optimal outcomes as related to severe or catastrophic disability resulting from an injurious event (Caragonne & Sofka, 2001).

As litigation expenses have dramatically risen with the increasing complexity of trials in catastrophic injury cases, mediation has steadily replaced trials as the mechanism for dispute resolution. Long before mediation commences, the life care planner will have provided a comprehensive report about the injured party's medical and quality of life needs to the lawyer who has hired the planner. In mediation, the life care planner's role is not to be involved in the actual negotiations, but to provide the necessary information leading to full implementation of the LCP when the plan can be fully funded. At the very least, the planner can suggest settlement money toward anticipated expenses in cases where obtaining full funding seems to be legally impossible (Shepherd & Pittman, 1996).

The application of LCPs has expanded outside of litigation. For example, Worker's Compensation cases are also using LCPs (Weed, 1998). It is estimated that more than 10,000 catastrophic work injuries occur annually. An LCP is designed to provide comprehensive guides to workers' compensation payers.

The use of life care planning has also been related to the use of a managed care approach when dealing with complex medical cases. As managed care has been a strong factor in health care decisions, the LCP has had several applications for private insurance management of health

care services. It also has strong applications for insurance companies, managed care organizations, workers' compensation, personal injury, facility discharge planning and government funded vaccine injuries. HMOs have used this procedure to assist the projection of costs that a catastrophically impaired patient would have. The LCP is a strategy that managed care organizations, as well as the gatekeepers of managed care programs, have incorporated into their recommendations for the planning of medical care, in order to avoid errors and omissions (Weed, 1998).

### *Components of Life Care Planning*

The LCP is a comprehensive and lengthy plan that includes numerous areas. The plan should be logical, clear, and able to be reproduced by another person. Accordingly, the process is standardized in order to maintain consistency in each aspect of the development of the plan (Caragonne & Sofka, 2001).

### *Background Information of the Patient*

The initial report of an LCP includes basic, identifying information about the patient, including the date of injury or illness, a description of the injury or illness, social information, and hobbies and leisure activities. The patient's educational history is also included in detail. Testing information from an educational institution, if available, is also included. Employment history and interests, if relevant, in addition to the patient's skills and strengths, are also assessed and included.

A major portion of the report will contain a review of the medical history, including 'pertinent medical information, a medical records summary, and all medical contacts, such as general family practitioners, surgeons, radiology reports, emergency room reports, physiatrists, psychologists and neurologists. Reports by these professionals are also included in this section. Medications, including doses and frequencies, as well as the physician who prescribed them, and the purpose of the prescription is addressed.

More specific information about the patient and his or her illness is delineated in the LCP. For example, the patient's activities are addressed, including his or her ability to walk, stand, sit, climb, balance, stoop, kneel, crouch, crawl, reach, handle, finger, feel, talk, hear, smell and lift. A "typical day in the life of the patient" may be provided. This is done in a narrative form but could also be documented by a brief videotape explaining the typical activities of daily assistances needed to perform them. The LCP also includes an area for the patient's subjective complaints. It is in this section that the patient and/or Caregivers, could address what they feel is the largest obstacle pertaining to the patient's condition at this time. Psychological information is also included in this section. At the conclusion of the narrative report, the life care planner's impressions regarding the patient and the interview are noted.

### *Projection of Future Treatment*

The production of an accurate life care plan requires that the life care planner possess the ability to demonstrate a vast amount of knowledge for a wide range of disciplines and subject areas. Such areas include, but are not limited to: architecture of homes and buildings related to accessibility, complications and outcomes associated with different disabilities, disability rights,

economics, law, medicine, social work, psychological impact, specialized therapies, and technology. Psychological interventions should take into consideration the current demonstrative needs of the individual and his or her family, as well as future adjustments anticipated.

The life care planner may recommend any or all of the following: physical therapy, occupational therapy, speech evaluation, dietary consult, psychological evaluation, recreational therapy, physiatrist, neurosurgeon, gastroenterologist, and orthopedic surgeon. Along with potential assessments and consultations, projected therapeutic modalities are addressed, which are dependent upon the result of the medical evaluations. Such modalities may include individual and family psychotherapy, physical therapy, occupational therapy, behavior modification programs, case management, and speech therapy.

In a separate section of the LCP, all supplies that are related to the illness or injury are addressed. Supplies may include feeding tubes, syringes, and disposable items, such as incontinence briefs and surgical wraps. Bowel/bladder program supplies, suction machines, and nebulizer machines may also be included. In the case of an orthopedic injury, there may be a separate section in the life care plan that addresses the wheelchair needs, including type, maintenance and replacement. Dependant upon the injury, orthotics and prosthetics may be addressed.

The Life Care Planner also notes any home furnishings and accessories that are necessary for adequate management of the illness. Examples of home furnishings or accessories could include a power hospital bed, an air loss mattress, hand held shower, hooyer lifts, portable ramps, adaptive clothing, and environmental control units. In order to maximize the patient's independence, the Life Care Planner assesses the feasibility of certain aides for independent

living, and delineates them. Additionally, health and maintenance items are addressed, which may include exercise mats, stationary bicycle or a treadmill. A membership at a local YMCA to facilitate exercise or an aquatics program may be recommended.

Diagnostic studies, which may be recommended from the evaluations, can include CAT scans, x-rays, EEGs, blood work, or urinalysis. Medications that may be recommended for future use, but are not currently utilized, will be included, indicating the anticipated age of the patient when using the medication, the anticipated age of suspending the medication, and a frequency or replacement schedule, as well as the cost.

The question of who will actually provide the caregiving, and the costs associated with the caregiving, is addressed in this section. As caregiving needs may change throughout the course of the patient's illness, the life care planner needs to determine who is going to provide the primary care, as well as secondary care, through each stage of illness or injury. The life care planner may give more than one option to the Caregivers. One option may include an unpaid Caregivers, such as a parent, who provides almost 24-hour care, and is not utilizing any outside resources.

Although the Caregivers may work with another family member or individual to complete 24-hour-a-day care, the Life Care Planner needs to address the actual needs of the patient so that projected costs could be included in the event that the present Caregivers may not be able to continue that role. In this section, the appropriate needs of the individual and the qualifications of the person to provide care would be determined, including whether an attendant for custodial care would be sufficient. Or the patient may need skilled care, could be provided by a home health aid, a certified nurse's assistant, a licensed practical nurse, or a registered nurse, depending on the state law. All of these needs are indicated on the LCP. Included is the

year the need began, the frequency, the purpose and the cost. These needs are dictated by medical professionals, who would be either the patient's treatment team or consultative sources.

For a needs assessment of the patient to be a continuous process, some type of case management should occur. Even the most comprehensive life care plan may become quickly outdated because of the changing medical, emotional, psychological or social needs of the patient. If a case manager is built into the plan, he or she can not only provide routine supervision of the case and services, but also make necessary revisions to the plan. The inclusion of a case manager allows the LCP to become a revisable and workable document, which continues to meet the needs of patients and their families.

Potential complications, which are often unpredictable, are also addressed, so that every individual who utilizes the LCP will be aware and as prepared as possible for these complications. This area is not only important from a financial perspective, but also from an emotional and psychological standpoint. It is in this section that the varying course of the patient's illness is described. This provides Caregivers with a clear understanding of the possible outcomes for their loved one. Although the most desirable outcome would be that the physician who is coordinating all aspects of the patient's care would communicate such potential complications to the Caregivers, this does not always occur. The LCP may be the only source that a Caregivers will have to identify these issues. Education of potential complications may serve to decrease anxiety about the patient's illness by empowering the family with the knowledge and confidence to manage the patient.

After development of the life care plan, the rehabilitation professional's first and foremost role is as a teacher who must be prepared to educate all parties concerned so that effective and well informed decisions can be made regarding how to meet future needs. The life



care plan should serve as an educational tool to communicate conflicts and issues in an understandable manner.

### *Life Care Planning and Social Problem Solving*

When Caregivers are involved in the formulation of an LCP, the process contains many of the elements that are included in social problem-solving. Social problem-solving includes gathering relevant information about the problem, attempting to further one's knowledge about the problem to increase understanding, and setting realistic goals. When dealing with complex issues, the problem solver begins with a broad problem and tries to break it down into specific subcomponents, in order to understand and deal with it more effectively (Parnes , Noller, & Biondi, 1977). The LCP mirrors this process by utilizing a variety of experts from different disciplines to identify problem areas for the patient.

Life care planning may also enhance a Caregiver's sense of predictability, mastery and control, by providing the Caregivers with a tool to anticipate the patient's needs, the course of the illness, and potential complications.

Although life care planning has been an important component of rehabilitation psychology, there have been no studies that examine the impact that an LCP could have on the coping styles used by Caregivers.

### *Statement of Purpose*

Although Life Care Plans have become an important component in the field of rehabilitation, to date no studies have examined the impact a Life Care Plan may have for the family or non-professional Caregivers.

Literature supports the need Caregivers have for detailed information on their loved ones' condition, plan of care and prognosis. This study investigated the perceived usefulness of a Life Care Plan to Caregivers. The study asked Caregivers how useful, if at all, they found the Life Care Plan in the numerous areas it addressed. The Caregivers had an opportunity to rate each area as it relates to the present time, as well as how useful they perceived it may be for future needs.

Background information was obtained regarding the patient and the identified nonprofessional Caregivers. The diagnosis of the patient was requested to examine if one catastrophic illness or injury is more likely than others to have a Life Care Plan prepared than other illnesses or injuries. Results identified Caregivers, and their genders. Differences in the age of Caregivers, geographic location, relationship to patient and diagnosis of the patient were obtained.

The Caregiver's use of coping styles, when in a specific stressful situation, was explored through the self-administered Ways of Coping Questionnaire. The current study explored the coping styles of Caregivers who had access to the Life Care Plan that was prepared. The study sought to determine if having access to this information may be related to the Caregiver's use of more positive coping styles. A comparison of Caregivers who were not familiar with the Life Care Plan was made. Coping styles were noted. The Caregivers were given the opportunity to

provide any additional information regarding their experiences, which will add to research on Caregivers of catastrophically ill or injured populations.

This study sought to determine if Caregivers identify the Life Care Plan as a tool that may be useful to understand present and future specific needs of their loved one in the numerous areas of their life that may be affected. The possible differences in coping skills among Caregivers was examined to determine if there may be a pattern of more positive or healthier coping skills used by Caregivers who have individualized specific and concrete information and a plan developed for their loved one.

### *Hypotheses*

- 1) Caregivers, who have access to the LCP prepared for their loved ones, would rate the areas on the Rutherford Life Care Plan Helpfulness Scale (RLCPHS), as at least “fairly helpful” (an average of “3” or higher).  
Caregivers, who have access to the prepared LCP, would report that having information about their loved ones’ injury or illness can help them understand their loved ones’ current needs, functional levels, and future requirements. It would also help them understand information they need for making decisions that may profoundly affect their own roles and goals as well as their loved ones.
- 2) There would be a negative correlation between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Distancing Scale on the Ways of Coping Questionnaire. The LCP carefully lays out the objective reality of the situation and the steps that may be

- required to resolve, or at least manage, the situation. The presence of the LCP makes it more difficult to detach or minimize the situation.
- 3) There would be a positive correlation between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Seeking Social Support Scale, as measured by the Ways of Coping Questionnaire. Caregivers with a LCP will know what resources may be helpful in different areas. This knowledge will be able to direct them to people and agencies they can utilize as resources if they feel a need.
  - 4) There would be a positive correlation between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Accepting Responsibility Scale, as measured by the Ways of Coping Questionnaire. A LCP will provide the Caregivers with needed knowledge to take responsibility.
  - 5) There would be a negative correlation between the Rutherford Life Care Helpfulness Scale (RLCPHS) and the Escape Avoidance Scale, as measured by the Ways of Coping Questionnaire. Caregivers who find the LCP helpful will have healthier coping skills and not fall back on unrealistic or self-defeating styles.
  - i) There would be a positive correlation between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Planful Problem-Solving Scale as measured by the Ways of Coping Questionnaire. With the knowledge of options available or unavailable the Caregivers will be able to take an effective action to change a situation.

## Chapter 2

### Method

#### *Subject Recruitment*

Patients who suffer a catastrophic illness or injury are likely to receive assistance for care from both professional Caregivers as well as one or more nonprofessional/family Caregivers. Nonprofessional/family Caregivers for this study were recruited from certified Life Care Planners who prepared a Life Care Plan report for their loved one. Life Care Planners holding a national certification were contacted for assistance in forwarding the surveys to Caregivers. The Life Care Plans are almost exclusively prepared for a patient who has experienced a catastrophic illness or injury. Patients who suffer a catastrophic illness or injury are likely to receive assistance in their care from both professional Caregivers, as well as one or more nonprofessional Caregivers.

#### *Inclusion and Exclusion Criteria*

Inclusion Criteria – Conservative criteria Inclusion for participation in this survey were utilized. Life Care Plans are used frequently by attorneys and insurance companies for litigious reasons. These Life Care Plans may be completed by individuals with or without a medical background or training, varying degrees of education and experience, and a range from very limited to extensive training in methods of preparing LCPs. The Caregivers of identified patients who consented to return the survey were obtained only from Life Care Planners who have

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completed an educational and training program, and have obtained National Certification in Life Care Planning.

Caregivers were required to be 18 years of age or older, and must have performed one or more functions listed as criteria for Caregivers. Caregiving functions included money management, medical decisions, emotional support, personal care, making decisions for the patient, and providing transportation.

Exclusion Criteria – Caregivers providing assistance to loved ones who are six months or less postinjury or illness were excluded.

### *Design*

In this study a nonexperimental survey research design was used. The survey, which was sent by mail, was anonymous. It consisted of three sections. Part I included demographic and background information related to the medical diagnosis of the patient, gender and age of patient, onset or diagnosis date, patient's living arrangement and state of patient's residence. Caregivers were asked information, including the length of time the Caregiver has been involved in active care, relationship of the Caregivers to the patient, Caregiver's gender and age, and state of residency. In reference to the Life Care Plan, Caregivers were asked if they were aware that a Life Care Plan was prepared for their loved one. They were also asked who initiated the Life Care Plan, how the information was acquired, if they had a copy of the Life Care Plan and finally if they had knowledge of any planned updates for the document.

The next section of the survey asked the Caregivers to rate helpfulness in the different areas of care that the Life Care Plan addresses. This section solicited the Caregivers' opinions

regarding their perceived helpfulness of the Life Care Plan to them. Initially the Caregivers were asked three questions regarding the overall helpfulness of the Life Care Plan. The remaining 34 questions were broken down into specific areas addressed in Life Care Plans. The Caregivers were asked to rate each area as they felt it was or was not of help to them for present needs and as they perceive it was or was not be of help to them in understanding their loved ones' current and future needs. Caregivers rated each question on a 5-point Likert Scale in each area of the Life Care Plan. For areas of care that did not apply to their loved one (i.e., aids for ambulation in a fully ambulatory patient) Caregivers were asked to indicate that it was not applicable.

Caregivers rated their perception of helpfulness in understanding these areas as (1) no help to them at all, (2) a little helpful, (3) fairly helpful, (4) very helpful or (5) extremely helpful.

The final part of the survey included The Ways of Coping Questionnaire by Folkman and Lazarus (1988). This questionnaire was designed to identify the thoughts and actions that an individual has used to cope with a specific stressful encounter. The format used was a 4-point Likert Scale to indicate the frequency with which they use each strategy. The Ways of Coping Questionnaire identifies eight coping strategies, which are identified as subsets within the questionnaire. Caregivers were also provided with two open-ended questions asking them to share any additional information they chose. Completion of the survey averaged 30-40 minutes.

### *Measures*

The Rutherford Life Care Plan Helpfulness Scale (RLCPHS) with 37 questions is a 5-point Likert Scale used to identify the degree of helpfulness in understanding a specific area of care or needs addressed in a Life Care Plan. This is a newly developed scale. The scale was



initially reviewed by several Life Care Planners and clinicians in the field of Care Management and Rehabilitation. Feedback was requested to review the survey and indicate if there were any questions on the survey they did not feel directly related to information on the Life Care Plan. They were also requested to provide feedback on any areas that they felt needed to be included in the survey. After reviews and revisions the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) was finalized.

The second measure used the Ways of Coping Questionnaire by Folkman and Lazarus (1988). This was designed to identify the thoughts and actions that an individual has used to cope with a specific stressful encounter. The questionnaire was designed to be answered in relation to a specific encounter. Specific directions to Caregivers requested that they “take a few minutes and think about the MOST stressful situation that you have experienced in the past MONTH. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that involved your loved one.”

Internal consistency estimates of coping measures and scales generally fall at the low end of the traditionally acceptable range. The alpha coefficients for the eight scales on the Ways of Coping Questionnaire are higher than the alphas reported for most other coping processes. Five of the subscales were used for this survey. The Subscales used were Distancing, Seeking Social Support, Accepting Responsibility, Escape-Avoidance and Planful Problem Solving. The items on the Ways of Coping Questionnaire possess face validity. The strategies that are described in the coping questionnaire are those strategies that individuals report using to cope with various stressful encounters. The Ways of Coping Questionnaire has been used in numerous studies.

Procedures used with this questionnaire are not standardized, but rather vary slightly depending upon the individual researcher's needs. The directions for use of the Ways of Coping indicated that this is to measure a specific stressful encounter, rather than one's general style of coping with stress.

### *Procedures*

Certified Life Care Planners were contacted by mail requesting their assistance for this study. They were requested to forward the survey package to "Caregivers" of patients for whom they completed a Life Care Plan (LCP) within the last five years. Life Care Planners who are currently providing case management services to the patient or family were asked to be excluded from the study. The identified Caregivers of the patients were asked to complete the three-part survey.

The anonymous surveys to be completed by Caregivers were sent by mail. Caregivers received a cover letter explaining the purpose of the study and asked to complete the questionnaire. The cover letter sent to the Caregivers accompanying the survey informed them that their participation is voluntary and all information would be forwarded anonymously. Caregivers were asked to return the completed survey in a self-addressed stamped envelope that was forwarded to them in the survey package.

## Chapter 3

### Results

#### *Description of Participants*

Seventy Four Caregivers responded to the survey. All indicated that they were aware of having a LCP prepared for their loved one. Of these Caregivers 92 percent indicated that they were in possession of the LCP.

The age ranges of the patients were from 4 to 62 years. Seventy-two percent of the patients were male and 20 percent were female. The majority of patients had the accident/diagnosis within the last 3 years (74.6 percent). Of the patients, 85.3 percent live with the Caregivers, 10.6 percent received a diagnosis more than 10 years ago; these were pervasive developmental disorders occurring at birth or shortly after.

All Caregivers responding indicated that they provided assistance in multiple areas of care. The Caregivers represented 18 states. They ranged in age from 25 to 74 years, with 64 percent of those responding indicating they were 45 to 54 years old. Eighty-four percent of the Caregivers were female. There was almost equal representation between mothers and wives. Fathers represented 5.3 percent and husbands 9.3 percent. Additional data is summarized in Table 1.

The Rutherford Life Care Plan Scale (RLCPS) asked the Caregivers to rate how helpful they found the LCP. In rating the helpfulness of the LCP in understanding the medical condition of their loved one, 84 percent rated it as “very helpful” or “extremely helpful.” For 94.5 percent of the Caregivers the LCP was rated as “very helpful” or “extremely helpful” in understanding

the future needs of their loved one. More than 90 percent of those responding indicated that the LCP was “very helpful” or “extremely helpful in understanding the future costs involved.

Results of each question on the RLCPS is summarized in Table 2.

### *Analysis*

Hypothesis 1: As hypothesized, Caregivers who had access to the Life Care Plan prepared for their loved one, rated it as at least “fairly helpful,” an average score of “3” or higher on the Rutherford Life Care Plan Helpfulness Scale (RLCPHS). All Caregivers responding indicated that they were aware that they had a Life Care Plan prepared for their loved one. All but five Caregivers indicated they had a copy of the Plan. Due to the small number of Caregivers who were aware of the Plan, but were not in possession of it, this group of Caregivers were included with those who were in possession the Life Care Plan. The mean score on all questions addressing the helpfulness of the Life Care Plan was 3.36 or above.

### *Correlation Analysis*

Hypothesis 2: It was hypothesized that there would be a negative correlation between perceived helpfulness as assessed on the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Distancing Scale, a subscale of Ways of Coping Questionnaire. Contrary to the stated hypothesis, there was a small negative, nonsignificant relationship between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the subscale of Distancing ( $r = -.009$ ,  $p = .468$ ).

Hypothesis 3: As hypothesized, there was a significant correlation between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Seeking Social Support Scale ( $r = .420$ ,  $p = .000$ ). This finding suggests that Caregivers who were aware of what resources may be required were also likely to use support as measured by the Ways of Coping Questionnaire. The higher the score on the Rutherford Life Care Plan Helpfulness Scale (RLCPHS), the higher the score on the Seeking Social Support scale on the Ways of Coping Questionnaire.

Hypothesis 4: There would be a positive correlation between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Accepting Responsibility Scale, a subscale of the Ways of Coping Questionnaire. Contrary to the stated hypothesis, there was a small negative nonsignificant relationship between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Accepting Responsibility subscale, ( $r = -.095$ ,  $p = .210$ ).

Hypothesis 5: It was hypothesized that there would be a negative correlation between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Escape Avoidance Scale, as measured by the Ways of Coping Questionnaire. Contrary to the stated hypothesis, there was no

statistically significant relationship between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Escape Avoidance Scale, ( $r = .013$ ,  $p = .456$ ).

Hypothesis 6: It was hypothesized that there would be a positive correlation between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and the Planful Problem-Solving Scale, as measured by the Ways of Coping Questionnaire. Contrary to the stated hypothesis, there was no statistically significant relationship between the Rutherford Life Care Plan Helpfulness Scale (RLCPHS) and Planful Problem Solving, ( $r = -.064$ ,  $p = .293$ ).

The above correlations are summarized in Table 3.

## Chapter 4

### Discussion

This study had two purposes. First, it was to investigate the perceived helpfulness of a Life Care Plan to the nonprofessional Caregivers, for a person with a catastrophic illness or injury. The second purpose was to explore the Caregiver's use of coping styles, as measured by the Ways of Coping Questionnaire.

As predicted, overall Caregivers found the Life Care Plan "very helpful." The lowest mean score for any of the questions relating to an area of the Life Care Plan was 3.36. The small group of Caregivers comprised entirely of mothers who had children diagnosed with pervasive developmental disorders generally rated the LCP less helpful compared to the other Caregivers responding. This is not surprising as they were an average of 10 years postdiagnosis. This group of Caregivers had been dealing with the situation for a significant length of time and were more likely educated and adjusted to the scope of their situation.

The Rutherford Life Care Plan Helpfulness Scale (RLCPHS) first asked the Caregivers a general question. They were asked how helpful they found the LCP in understanding the

medical condition of their loved one. Eighty-Four percent of all Caregivers rated the Life Care Plan as “very helpful” or “extremely helpful” in understanding the medical condition of their loved one. In 94 percent of the responses, Caregivers rated the Life Care Plan as “very helpful” or “extremely helpful” in understanding the FUTURE needs of their loved one. In understanding CURRENT needs of their loved one, 86 percent of the Caregivers rated it as “very helpful” or “extremely helpful.”

The honest, accurate information of the patient’s current and future needs is critical for family members. This is addressed in a descriptive study by Molter as far back as 1979. Although many Caregivers realized they had been given medical information at the time of the injury, they could not remember it. Caregivers also report wanting information about the patient’s condition and prognosis throughout each phase of care. The Life Care Plan provides the Caregivers with a comprehensive and detailed summary of the information the Caregivers was probably given in bits and pieces by the medical community.

However, because of the amount of information provided, usually at a time when the Caregiver is emotionally overwhelmed, it is often forgotten or not fully understood. As a written document, the information can be reviewed and referred to at a pace the Caregivers is more likely to understand and retain. This is of critical importance to both the patient and Caregivers. “Caregiver burden” (Zarit, 1989) can be experienced by individuals when they assume responsibility helping patients. Additional distress can occur because of the lack of information. Because almost 75 percent of Caregivers for patients with a catastrophic illness or injury reported elevated levels of stress (Deimling et al, 2001) it is not only the identified patient that is often in need of medical or psychological care. A Caregiver plays a critical role in the care for the patient in addition to the professional care the patient receives. With our changing healthcare

system, the Caregivers is commonly placed in a situation where he or she is responsible for an active role in the care of the patient (Elliot & Schewchuk, 2000).

In this survey all of the 74 Caregivers responding, indicated that they performed assistance to the patient in multiple areas of care. Areas of assistance included money management, personal care (i.e., bathing, dressing, and hair care), transportation, emotional support and making medical decisions for the patient. With the need for Caregivers to play such vital and active roles it is important that they are able to maintain their physical and emotional health. Any resource that could prove to be helpful to the Caregivers should be explored and considered for use in helping the Caregivers obtain and maintain an optimal level of health.

Another area of the LCP endorsed as “very helpful” or “extremely helpful” by more than 75 percent of Caregivers, included understanding what the most critical medical issue may be in the future and understanding what medical complications could occur currently and in the future. As previously discussed, a Caregiver is likely to be faced with coping not only with the extensive care that may be required throughout the lifespan, but also unexpected complications occurring as a result of the illness or injury. Complications can include not only medical issues but emotional and behavioral problems that can be unexpected and very difficult for the Caregivers to cope or understand. This may be as difficult, or more difficult, for the Caregivers as compared to the patient (Livingston, 1987; Koskinin, 1998). The Caregivers must be educated in the unique needs his or her loved one may experience, as catastrophic illnesses and injuries can be expected to result in changing medical needs and complications, placing new and additional demands on the Caregivers. The ability for a Caregiver to have the understanding of what may occur in the future may greatly assist in preparing and coping with the changing needs of his or her loved one. This understanding may also help the Caregivers identify the resources, both



physical and emotional, that they may need to assist them with the demands of providing care to their loved ones.

Interesting to note, the area with the lowest scores, endorsed by less than 52 percent of Caregivers as being “very helpful” or “extremely helpful,” was understanding the suggestions for counseling currently or in the future. It is possible that although Caregivers endorsed understanding the need for counseling now and in the future as “somewhat helpful,” they may not view counseling as vitally important as other areas. The overwhelming physical needs of the patient, such as medical care and testing, and therapies and financial burdens, may be the more primary focus of the Caregivers’ attention.

The lower scores in this area may have another explanation. Possibly when they initially received the Life Care Plan, the Caregivers had an increased understanding of their situation and became involved in a support system. This theory seems to be supported by the correlation that Caregivers who rated the LCP as helpful in understanding the patients’ needs also rated “Using Social Support,” as measured by the Ways of Coping Questionnaire, as a coping skill they use in dealing with a stressful event. Endorsing “Using Social Support” as a coping skill indicates that they endorsed using resources that included talking to someone about their feelings, talking to someone who could do something about the problem, and getting professional help. Because these Caregivers are already involved in using social supports, they have already acknowledged the need and understanding for counseling. They may not view the information included in the Life Care Plan in the area of “understanding the need for counseling currently and in the future” as helpful because the survey indicates they may already be implementing counseling in their life. It is possible that these Caregivers used informed social supports, such as friends, relatives or clergy. These Caregivers may not feel the need to use formed counseling resources.

The questions regarding the helpfulness in understanding the financial costs involved currently and in the future, received the highest scores. More than 73 percent of Caregivers indicated they found the LCP “extremely helpful” in understanding current financial costs. The highest mean score on any question was 4.68, with more than 80 percent of Caregivers rating LCP “extremely helpful” in understanding the future financial costs. The area of the costs involved in catastrophic illness and injury is of critical importance, as it is the financial costs of the catastrophic illness or injury that initiates the preparation of the majority of Life Care Plans.

The financial impact of the illness or injury needs to be addressed by the patient or Caregivers if the patient is unable. The Life Care Plan does not address the financial resources that may be used or may be available. However, it is critical the family have an in depth understanding of the extent of costs involved for ongoing care. This will assist them in making decisions concerning the care needed and making the choices that are best based on a clear understanding of the needs and financial costs. This information may also assist the family in exploring the financial resources that they may be able to pursue. The financial costs involved are of critical importance in managing the care of the patient. This information will be used by most members of the health care team involved with the patient’s care. In a case where litigation is involved, understanding the financial impact of the case may be the basis for the amount of money awarded or allocated. When everyone involved clearly understands what the needs are that drive the costs, the case will be much more manageable. The results of the RLCPS are included in Table 3.

The second purpose of this study was to explore the coping styles one uses in a specific stressful situation. Only one of the hypotheses reached statistical significance. The scale “Seeking Social Support” was significant at the .001 level. Caregivers who endorsed the Life

Care Plan as being at least “somewhat helpful” to them also endorsed the coping style that uses tangible, emotional and informational support. It was expected that Caregivers with the advantage of having received information contained in the Life Care Plan would use a coping style that utilized these resources to get through a stressful situation. This included items such as talking to someone about their feelings, and accepting sympathy and understanding from someone. This coping style also uses professionals as a resource for help. It was felt the LCP provided the Caregivers with specific information that may encourage them to reach out to others for support and concrete assistance when they experience a difficult situation. The fact that this was statistically significant is important for Caregivers, as this coping style is viewed as a positive and healthy option. Caregivers will most likely encounter ongoing stressful situations throughout the life of their ill or injured loved one. The use of positive coping skills is critical to the emotional well being of the Caregivers.

Other coping styles identified on the Ways of Coping Questionnaire that are associated with healthier styles of coping were not endorsed by Caregivers. This may mean that having detailed information does not lead to choosing healthy coping styles. However, it is likely Caregivers who have detailed information about their situation were able to cope with their situation effectively by using a support system as their major resource. If this is the case, then they may not endorse other coping styles, even other healthy styles, because “using social support” may be their exclusive coping style.

In addition to the structured questions asked of Caregivers, there were areas which allowed Caregivers to add any comments they chose. Some of the Caregivers explained in more detail how they found the LCP especially helpful. A common theme was that the LCP “helped us realize the realities of the future.” Many elaborated in this area that detailed the stressful

situation expressing their feelings of fears and frustrations in coping. One Caregiver spouse stated that “anything very stressful to my husband means it is very stressful to me.” Caregivers also added comments indicating they were grateful that someone was interested in their opinions and feelings as the focus is usually on the patient and not on the Caregiver.

### Limitations

Results of this study are limited. Only Caregivers who were aware a Life Care Plan was prepared for them responded to the survey. There are several reasons this may be. Some Life Care Planners contacted the investigator indicating they would not participate in the study. Reasons given included they were not active in preparing Life Care Plans, limited time or energy needed to assist with the mailing, and fear of confidentiality issues. Another reason for not assisting with mailing the surveys to Caregivers were the lack of any contact with the family or knowledge of the Caregivers. Some Life Care Planners indicated that the Plan was prepared at the request of a third party (usually an insurance company or attorney) without the knowledge of the patient or family. This may explain why no survey was returned from a Caregiver who was not aware of the Life Care Plan. This group of Caregivers seems to have been selected out in the mailing process. The small number of Caregivers returning surveys obviously limits the information that can be gained.

### *Future Directions*

If the results of this preliminary study are indicative of most family Caregivers, it would appear that the Life Care Plan may be a very-underutilized resource for Caregivers. When a

family experiences a catastrophic illness or injury of a loved one it can be overwhelming.

Families receive information and suggestions from many sources. The amount and nature of the information can be voluminous and confusing. Because so many issues are involved with the management of a catastrophic illness or injury, it is difficult for a family to absorb and process all of the information. The Life Care Plan, which presents specific organized information addressing each area of functioning, could greatly assist Caregivers, especially in the early years of understanding and managing their situation.

Since standardizing the Life Care Plan, use has increased significantly. The use of the Life Care Plan in pursuing litigation is well established. However, using the Plan to assist Caregivers in the understanding of their loved one's needs should be further explored.

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*Table 1**Demographic Summary**Age of Patient*

	N	Percent
<21 years	12	16.3
21- 28 yrs.	23	31.3
33-50 yrs.	24	32.7
> 50 yrs.	15	20.7

*Gender of Patients*

	N	Percent
Male	54	72
Female	15	20

\* 5 did not indicate gender of patient

*Medical Diagnosis of the Patients as told to Caregivers by Medical Professionals*

	N	Percent
Traumatic Brain Injury	41	56
Spinal Cord Injury	23	30.7
Developmental Disorder	8	10.7
Other	2	2.6



## Age of Caregivers

	N	Percent
25-34 years	3	4.0
35-44 years	12	16.2
45-54 years	48	64.9
55-64 years	10	13.5
65-74 years	1	1.4

## Amount of Time as Caregivers

	N	Percent
< 1 year	0	0
1-5 years	61	82.4
5-10 years	5	6.8
> 10 years	8	10.8

Table 2

*Summary of Individual Questions on the Rutherford Life Care Plan Scale*


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To what extent has the LIFE CARE PLAN been of help to you:

Question	MEAN	S.D.
1. Understand what the medical condition is of your loved one	4.20	1.06
2. Understand the current medical needs of my loved one	4.30	.84
3. Understand the future needs of my loved one	4.57	.64
4. Understand what type of medical evaluations may be needed (i.e. doctor, special list, therapist) CURRENTLY	3.75	1.07
5. Understand what type of medical evaluations may be needed (i.e. doctor, special list, therapist) IN THE FUTURE	4.26	.78
6. Understand what medications patient may be needed CURRENTLY	3.79	1.04
7. Understand what medications patient may be needed IN THE FUTURE	4.13	.89
8. Understand what the most critical medical issue is CURRENTLY	3.86	1.05
9. Understand what the most critical medical issue may be IN THE FUTURE	4.23	.87
10. Understand the tests that may be needed (i.e. e-rays, blood tests, MRI, psychological) CURRENTLY	3.67	1.09
11. Understand the tests that may be needed (i.e. x-rays, blood tests, MRI, psychological) IN THE FUTURE	3.98	.97
12. Understand what surgical procedures may be needed (i.e. plastic surgery, shunt revisions, operations) CURRENTLY	3.85	1.02
13. Understand what surgical procedures may be needed (i.e. plastic surgery,		

shunt revisions, operations) IN THE FUTURE	4.09	.86
14. Understand what routine care may be needed CURRENTLY	3.82	1.12
15. Understand what routine care may be needed IN THE FUTURE	3.88	.88
16. Understand the suggestions for counseling CURRENTLY	3.36	1.32
17. Understand the suggestions for counseling IN THE FUTURE	3.41	1.35
18. Understand what medical complications could occur (i.e. infections, fractures, trauma) CURRENTLY	3.97	1.02
19. Understand what medical complications could occur (i.e. infections, fractures, trauma) IN THE FUTURE	4.12	1.02
20. Understand if a wheelchair or other piece of equipment is needed for mobility CURRENTLY	4.45	.70
21. Understand if a wheelchair or other piece of equipment is needed for mobility IN THE FUTURE	4.55	.66
22. Understand what orthotics or prosthetics may be needed (i.e. artificial limbs, braces) CURRENTLY	4.44	.70
23. Understand what orthotics or prosthetics may be needed (i.e. artificial limbs, braces) CURRENTLY	4.44	.70
24. Understand what type of equipment may help to increase independent functioning (i.e. customized vehicle, ramps, home modifications) CURRENTLY	4.63	.62
25. Understand what type of equipment may help to increase independent functioning (i.e. customized vehicle, ramps, home modifications) IN THE FUTURE	4.48	.82

26. Understand the amount of skilled nursing care that may be needed CURRENTLY	3.75	.96
27. Understand the amount of skilled nursing care that may be needed IN THE FUTURE	4.38	.78
28. Understand the amount of attendant that may be needed (non-medical care) CURRENTLY	3.98	1.08
29. Understand the amount of attendant that may be needed (non-medical care) IN THE FUTURE	4.25	.88
30. Understand if care in a residential/long term care facility may be needed CURRENTLY	3.61	1.09
31. Understand if care in a residential/long term care facility may be needed IN THE FUTURE	4.22	.98
32. Understand the suggestions for school or other educational training CURRENTLY	3.92	1.53
33. Understand the suggestions for school or other educational training IN THE FUTURE	4.10	1.25
34. Understand the suggestion for vocational plans or work plans CURRENTLY	4.42	.87
35. Understand the suggestion for vocational plans or work plans IN THE FUTURE	4.35	.87
36. Understand the financial costs involved CURRENTLY	4.47	1.05
37. Understand the financial costs involved IN THE FUTURE	4.68	.80

Table 3

*Summary of Correlations (N= 74)*

RLCPS	
Subscales of Ways of Coping Questionnaire	
Distancing	
Pearson Correlation	-.009
Sig. (1-tailed)	.468
Seeking Social Support	
Pearson Correlation	.420 **
Sig. (1- tailed)	.000
Accepting Responsibility	
Pearson Correlation	-.095
Sig. (1- tailed)	.210
Escape-Avoidance	
Pearson Correlation	.013
Sig. (1- tailed)	.456
Planful Problem Solving	
Pearson Correlation	-.064
Sig. (1- tailed)	.293

\*\* Significant at .001 level

## Appendix A

Dear Caregiver,

I am interested in learning more about how individuals who provide one or more areas of care to a loved one cope with their situation. You received this questionnaire because at some time in the last five years a report called a Life Care Plan was completed for your loved one. The Life Care Plan is the report that identified the current and anticipated needs, both medical and non medical, of your loved one. It was prepared to address these issues at the time it was prepared as well as addressing these anticipated needs for the future.

This survey is being forwarded to you anonymously. I have asked Certified Life Care Planners to forward this survey to caregivers of patients who had a completed Life Care Plan. You may not have been the one that requested the plan to be prepared. It may have been completed at the request of a Case Manager, a medical professional, an insurance company or an attorney.

I am especially interested in family members who have used the Life Care Plan to assist them with planning the care of their loved one. However, EVEN IF YOU ARE NOT, familiar with the Life Care Plan, I am interested in how you cope with stressful situations related to the care and decision of your loved one.

Please complete as much as you can. I would also appreciate any comments you would like to add. THIS IS ANONYMOUS. There will not be any way to trace your identity with your responses. I would greatly appreciate if you would answer all the questions as honestly as you can.

THANK YOU VERY MUCH FOR YOUR TIME

Sincerely,

Carolyn E. Rutherford M.Ed., M.S., NCC, CCM, NCGC, ABDA, LPC

## Appendix B

Dear Life Care Planner,

I would like to contribute to the field of Life Care Planning and caregivers. I need your assistance. As part of my Doctoral Dissertation I am forwarding an anonymous survey to caregivers of patients who have had Life Care Plans prepared.

Most of the research to date on caregivers has focused on the stress and burdens associated with care giving for an elderly spouse or parent, especially one with a dementia. A caregiver to a patient with a chronic or catastrophic illness or injury not associated with aging or dementia has similar stress. However, it may also be accompanied by a lack of understanding about the medical, psychosocial, and rehabilitation issues associated the patient's condition, at the present as well as how the condition will impact the patient's needs in the future.

I am interested in determining if a Life Care Plan may be viewed as a useful tool to caregivers. I would like to know if a Life Care Plan is perceived by caregivers as providing them with knowledge about their loved one's condition as it relates to specific areas that are standard areas of a Life Care Plan.

The survey will be addressed to "Caregiver" at the address of the patient or their guardian. All envelopes contain the survey with a self addressed stamped envelope, which the caregiver will be asked to return. This information will be anonymous. Only basic demographic information related to the patient is requested.

I am requesting your assistance in directly forwarding the survey to the clients, which you have, completed full life care plans, in the last THREE years. Please do NOT forward the survey to any patient that is CURRENTLY receiving active case management from the Life Care Planner who completed the LCP.

I greatly appreciate your help in furthering the research in the area of Life Care Planning and the completion of my dissertation.

Sincerely,

Carolyn E. Rutherford, M.Ed., M.A., M.S., NCC, CCM, NCGC, ABDA

## SURVEY

**Information about the patient**

1. Medical Diagnosis of the patient as told to you by medical professionals:
  - a) Traumatic Brain Injury
  - b) Cerebral Palsy
  - c) Spinal Cord Injury Location of Injury \_\_\_\_\_
  - d) Severe
  - e) Mental Retardation
  - f) Burns: Please Describe: \_\_\_\_\_
  - g) Spinal Bifida
  - h) AIDS
  - i) OTHER: \_\_\_\_\_
2. Patient's Date of Birth: Month \_\_\_\_\_ Year \_\_\_\_\_
3. Gender of the Patient: MALE or FEMALE
4. Year of accident, illness, or injury: \_\_\_\_\_  
Year of diagnosis (If different) \_\_\_\_\_
5. Does the patient live:
  - a) With you
  - b) With other family or friend
  - c) In a residential facility for the short term
  - d) In a residential facility for the long term
  - e) Other: \_\_\_\_\_
6. State the patient lives in: \_\_\_\_\_
7. Does the patient live in a
  - a) Large city
  - b) Small city
  - c) Large town
  - d) Small town
  - e) Very rural area
  - f) OTHER: \_\_\_\_\_



**Information about you (the caregiver):**

8. What are the tasks or responsibilities you help your loved one with:
- a) Money management
  - b) Medical decisions
  - c) Emotional support
  - d) Personal care (bathing, dressing, hair care, shaving, etc)
  - e) Making personal decisions for the patient (not money or medical)
  - f) Transportation for errands, shopping or to medical appointments
  - g) OTHER: \_\_\_\_\_  
\_\_\_\_\_
9. How many years have you been involved in some type of care giving for the patient?
- a) Less than one year
  - b) One up to five years
  - c) Five up to ten years
  - d) Over ten years
10. Your relationship to the patient:
- a) Mother
  - b) Father
  - c) Wife
  - d) Husband
  - e) Significant other
  - f) Sister
  - g) Brother
  - h) OTHER: \_\_\_\_\_
11. Your Gender: MALE or FEMALE
12. Your age:
- a) Under 25 years
  - b) 25-34 years
  - c) 35-44 years
  - d) 45-54 years
  - e) 55-64 years
  - f) 65-74 years
  - g) 75-84 years
  - h) 85 years or older
13. State that you live in: \_\_\_\_\_

## Please answer these questions about the Life Care Plan Report:

14. Do you know that a LIFE CARE PLAN was prepared and written for your loved one?

- a) Yes
- b) No

15. When information was provided to the LIFE CARE PLANNER did you meet with him/her?

- a) In person
- b) By telephone
- c) Other \_\_\_\_\_
- d) Do not remember

16. When was the LIFE CARE PLAN completed? Approximate year: \_\_\_\_\_

17. Who asked to have the LIFE CARE PLAN completed?

- a) Family
- b) Insurance Company
- c) Attorney
- d) Case Manager
- e) OTHER: \_\_\_\_\_

18. Do you have a copy of the LIFE CARE PLAN?

- a) Yes
- b) No

19. Does the LIFE CARE PLAN get updated?

- a) Yes      Approximately how often? \_\_\_\_\_
- b) No
- c) I do not know

20. How has the LIFE CARE PLAN helped YOU the most?

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Please circle the number to the response that best describes the extent the LIFE CARE PLAN has helped you.

1 Not helpful at all	2 A little helpful	3 Somewhat helpful	4 Very helpful	5 Extremely helpful	N/A Does not apply
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To what extent has the LIFE CARE PLAN been of help to you:

- |   |   |   |   |   |   |     |
|---|---|---|---|---|---|-----|
| 1. Understand what the medical condition is of my loved one   | 1 | 2 | 3 | 4 | 5 | N/A |
| 2. Understand the <i>current</i> needs of my loved one  | 1 | 2 | 3 | 4 | 5 | N/A |
| 3. Understand the <i>future</i> needs of my loved one   | 1 | 2 | 3 | 4 | 5 | N/A |
| 4. Understand what type of medical evaluations may be needed (i.e. doctor, special list, therapist) CURRENTLY           | 1 | 2 | 3 | 4 | 5 | N/A |
| 5. Understand what type of medical evaluations may be needed (i.e. doctor, special list, therapist) IN THE FUTURE       | 1 | 2 | 3 | 4 | 5 | N/A |
| 6. Understand what medications patient may be needed CURRENTLY  | 1 | 2 | 3 | 4 | 5 | N/A |
| 7. Understand what medications patient may be needed IN THE FUTURE  | 1 | 2 | 3 | 4 | 5 | N/A |
| 8. Understand what the <i>most critical medical</i> issue is CURRENTLY  | 1 | 2 | 3 | 4 | 5 | N/A |
| 9. Understand what the <i>most critical medical</i> issue may be IN THE FUTURE  | 1 | 2 | 3 | 4 | 5 | N/A |
| 10. Understand the tests that may be needed (i.e. x-rays, blood tests, MRI, psychological) CURRENTLY                    | 1 | 2 | 3 | 4 | 5 | N/A |
| 11. Understand the tests that may be needed (i.e. x-rays, blood tests, MRI, psychological) IN THE FUTURE                | 1 | 2 | 3 | 4 | 5 | N/A |
| 12. Understand what surgical procedures may be needed (i.e. plastic surgery, shunt revisions, operations) CURRENTLY     | 1 | 2 | 3 | 4 | 5 | N/A |
| 13. Understand what surgical procedures may be needed (i.e. plastic surgery, shunt revisions, operations) IN THE FUTURE | 1 | 2 | 3 | 4 | 5 | N/A |
| 14. Understand what <i>routine</i> care may be needed CURRENTLY   | 1 | 2 | 3 | 4 | 5 | N/A |

15. Understand what *routine* care may be needed IN THE FUTURE 1 2 3 4 5 N/A  
 Please circle the number to the response that best describes the extent the LIFE CARE PLAN has helped you.

1	2	3	4	5	N/A
Not helpful at all	A little helpful	Somewhat helpful	Very helpful	Extremely helpful	Does not apply

To what extent has the LIFE CARE PLAN been of help to you:

**Psychosocial**

16. Understand the suggestions for counseling CURRENTLY 1 2 3 4 5 N/A

17. Understand the suggestions for counseling IN THE FUTURE 1 2 3 4 5 N/A

**Possible Complications**

18. Understand what medical complications could occur (i.e. infections, fractures, trauma) CURRENTLY 1 2 3 4 5 N/A

19. Understand what medical complications could occur (i.e. infections, fractures, trauma) IN THE FUTURE 1 2 3 4 5 N/A

**Equipment Needs**

20. Understand if a wheelchair or other piece of equipment is needed for mobility CURRENTLY 1 2 3 4 5 N/A

21. Understand if a wheelchair or other piece of equipment is needed for mobility IN THE FUTURE 1 2 3 4 5 N/A

22. Understand what orthotics or prosthetics may be needed (i.e. artificial limbs, braces) CURRENTLY 1 2 3 4 5 N/A

23. Understand what orthotics or prosthetics may be needed (i.e. artificial limbs, braces) IN THE FUTURE 1 2 3 4 5 N/A

24. Understand what type of equipment may help to increase independent functioning (i.e. customized vehicle, ramps, home modifications) CURRENTLY 1 2 3 4 5 N/A

25. Understand what type of equipment may help to increase independent functioning (i.e. customized vehicle, ramps, home modifications) IN THE FUTURE 1 2 3 4 5 N/A

**Personal Assistance**

- 26. Understand the amount of skilled nursing care that may be needed CURRENTLY 1 2 3 4 5 N/A
- 27. Understand the amount of skilled nursing care that may be needed IN THE FUTURE 1 2 3 4 5 N/A
- 28. Understand the amount of attendant that may be needed (non-medical care) CURRENTLY 1 2 3 4 5 N/A
- 29. Understand the amount of attendant that may be needed (non-medical care) IN THE FUTURE 1 2 3 4 5 N/A

**Facility Care**

- 30. Understand if care in a residential/long term care facility may be needed CURRENTLY 1 2 3 4 5 N/A
- 31. Understand if care in a residential/long term care facility may be needed IN THE FUTURE 1 2 3 4 5 N/A

**School/Educational/Vocational**

- 32. Understand the suggestions for school or other educational training CURRENTLY 1 2 3 4 5 N/A
- 33. Understand the suggestions for school or other educational training IN THE FUTURE 1 2 3 4 5 N/A
- 34. Understand the suggestion for vocational plans or work plans CURRENTLY 1 2 3 4 5 N/A
- 35. Understand the suggestion for vocational plans or work plans IN THE FUTURE 1 2 3 4 5 N/A

**Costs**

- 36. Understand the financial costs involved CURRENTLY 1 2 3 4 5 N/A
- 37. Understand the financial costs involved IN THE FUTURE 1 2 3 4 5 N/A

**Comments:**

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## Appendix D

### INSTRUCTIONS

To respond to the statements in this questionnaire, you must have a specific stressful situation in mind. By “stressful” we mean a situation that was difficult or troubling for you, either because you felt distressed about what happened, or because you had to use considerable effort to deal with the situation.

We are interested in a situation that involved **your loved one that has been identified as having a catastrophic illness or injury**. Take a few minutes and think about the MOST stressful situation that you have experienced in the past MONTH. Before responding to the statements, think about the details of this stressful situation, such as where it happened, who was involved, how you acted, and why it was important to you. While you may still be involved in the situation, or it could have already happened, it should be the most stressful situation that involved your loved one that has been identified as having a catastrophic illness or injury that you experienced in the last month.

As you think about the situation make notes about the situation so you can refer to them as you answer the questions.

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As you respond to each of the statements, please keep this stressful situation in mind. **READ EACH STATEMENT CAREFULLY AND INDICATE BY CIRCLING 0, 1, 2, OR 3 TO WHAT EXTENT YOU USED IT IN THE SITUATION.**

- Key:
- 0 = Does not apply or not used
  - 1 = Used somewhat
  - 2 = Used quite a bit
  - 3 = Used a great deal

**PLEASE TRY TO RESPOND TO EVERY QUESTION**

0 = Does not apply or not used    1 = Used somewhat    2 = Used quite a bit    3 = Used a great deal

- |  |   |   |   |   |
|--|---|---|---|---|
| 1. I just concentrated on what I had to do next – the next step. ....                                  | 0 | 1 | 2 | 3 |
| 2. I tried to analyze the problem in order to understand it better. ....                               | 0 | 1 | 2 | 3 |
| 3. I turned to work or another activity to take my mind off things. ....                               | 0 | 1 | 2 | 3 |
| 4. I felt that time would have made a difference –<br>the only thing was to wait. ....                 | 0 | 1 | 2 | 3 |
| 5. I bargained or compromised to get something positive<br>from the situation. ....                    | 0 | 1 | 2 | 3 |
| 6. I did something that I didn't think would work,<br>but at least I was doing something. ....         | 0 | 1 | 2 | 3 |
| 7. I tried to get the person responsible to change his or her mind. ....                               | 0 | 1 | 2 | 3 |
| 8. I talked to someone to find out more about the situation. ....                                      | 0 | 1 | 2 | 3 |
| 9. I criticized or lectured myself. ....   | 0 | 1 | 2 | 3 |
| 10. I tried not to burn my bridges, but leave things open somewhat. ....                               | 0 | 1 | 2 | 3 |
| 11. I hoped for a miracle. ....  | 0 | 1 | 2 | 3 |
| 12. I went along with fate; sometimes I just have bad luck. ....                                       | 0 | 1 | 2 | 3 |
| 13. I went on as if nothing had happened. ....   | 0 | 1 | 2 | 3 |
| 14. I tried to keep my feelings to myself. ....  | 0 | 1 | 2 | 3 |
| 15. I looked for the silver lining, so to speak;<br>I tried to look on the bright side of things. .... | 0 | 1 | 2 | 3 |
| 16. I slept more than usual. ....  | 0 | 1 | 2 | 3 |
| 17. I expressed anger to the person(s) who caused the problem. ....                                    | 0 | 1 | 2 | 3 |
| 18. I accepted sympathy and understanding from someone. ....   | 0 | 1 | 2 | 3 |
| 19. I told myself things that helped me feel better. ....  | 0 | 1 | 2 | 3 |
| 20. I was inspired to do something creative about the problem. ....                                    | 0 | 1 | 2 | 3 |
| 21. I tried to forget the whole thing. ....  | 0 | 1 | 2 | 3 |
| 22. I got professional help. ....  | 0 | 1 | 2 | 3 |

Go on to next page

0 = Does not apply or not used    1 = Used somewhat    2 = Used quite a bit    3 = Used a great deal

- |  |   |   |   |   |
|--|---|---|---|---|
| 23. I changed or grew as a person. ....  | 0 | 1 | 2 | 3 |
| 24. I waited to see what would happen before doing anything. ....  | 0 | 1 | 2 | 3 |
| 25. I apologized or did something to make up. ....   | 0 | 1 | 2 | 3 |
| 26. I made a plan of action and followed it. ....  | 0 | 1 | 2 | 3 |
| 27. I accepted the next best thing to what I wanted. ....  | 0 | 1 | 2 | 3 |
| 28. I let my feelings out somehow. ....  | 0 | 1 | 2 | 3 |
| 29. I realized that I had brought the problem on myself. ....  | 0 | 1 | 2 | 3 |
| 30. I came out of the experience better than when I went in. ....  | 0 | 1 | 2 | 3 |
| 31. I talked to someone who could do something concrete<br>about the problem. ....                             | 0 | 1 | 2 | 3 |
| 32. I tried to get away from it for a while by resting or taking a vacation. ....                              | 0 | 1 | 2 | 3 |
| 33. I tried to make myself feel better by eating, drinking,<br>smoking, using drugs, or medications, etc. .... | 0 | 1 | 2 | 3 |
| 34. I took a big chance or did something very risky<br>to solve the problem. ....                              | 0 | 1 | 2 | 3 |
| 35. I tried not to act too hastily or follow my first hunch. ....  | 0 | 1 | 2 | 3 |
| 36. I found new faith. ....  | 0 | 1 | 2 | 3 |
| 37. I maintained my pride and kept a stiff upper lip. ....   | 0 | 1 | 2 | 3 |
| 38. I rediscovered what is important in life. ....   | 0 | 1 | 2 | 3 |
| 39. I changed something so things would turn out all right. ....   | 0 | 1 | 2 | 3 |
| 40. I generally avoided being with people. ....  | 0 | 1 | 2 | 3 |
| 41. I didn't let it get to me; I refused to think too much about it. ....                                      | 0 | 1 | 2 | 3 |
| 42. I asked advice from a relative or friend I respected. ....   | 0 | 1 | 2 | 3 |
| 43. I kept others from knowing how bad things were. ....   | 0 | 1 | 2 | 3 |
| 44. I made light of the situation; I refused to get too serious about it. ....                                 | 0 | 1 | 2 | 3 |

Go on to next page



0 = Does not apply or not used    1 = Used somewhat    2 = Used quite a bit    3 = Used a great deal

45. I talked to someone about how I was feeling..... 0 1 2 3
46. I stood my ground and fought for what I wanted..... 0 1 2 3
47. I took it out on other people. .... 0 1 2 3
48. I drew on my past experiences; I was in a similar situation before. .. 0 1 2 3
49. I knew what had to be done, so I doubled my efforts  
to make things work..... 0 1 2 3
50. I refused to believe that it had happened..... 0 1 2 3
51. I promised myself that things would be different next time. .... 0 1 2 3
52. I came up with a couple of different solutions to the problem. .... 0  
3
54. I tried to keep my feeling about the problem from interfering  
with other things..... 0 1 2 3
55. I wished that I could change what had happened or how I felt. .... 0 1 2 3
56. I changed something about myself. .... 0 1 2 3
57. I daydreamed or imagined a better time or place  
than the one I was in..... 0 1 2 3
58. I wished that the situation would go away or somehow  
be over with. .... 0 1 2 3
59. I had fantasies or wishes about how things might turn out. .... 0 1 2 3
60. I prayed..... 0 1 2 3
61. I prepared myself for the worst. .... 0 1 2 3
62. I went over in my mind what I would say or do. .... 0 1 2 3
63. I thought about how a person I admire would handle  
this situation and used that as a model. .... 0 1 2 3
64. I tried to see things from the other person's point of view..... 0 1 2 3
65. I reminded myself how much worse things could be. .... 0 1 2 3
66. I jogged or exercised. .... 0 1 2 3

**Stop Here.**