

QUALITY OF LIFE TO THE END OF LIFE

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State Bar of Texas
42ND ANNUAL
ADVANCED ESTATE PLANNING & PROBATE
June 13-15, 2018
Dallas

CHAPTER 24

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Marjorie specializes in estate planning. Since 1977, she has been working with individuals and families in structuring plans which provide a unique approach to tax and family planning. She now represents several generations within a family as the family members work to pass on their legacies through the generations. Marjorie's areas of practice include: Estate Planning, related Business Planning, Taxation, Trusts, Wills, Probate and Estate Administration.

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Marjorie is a frequent speaker before professional and lay groups on estate planning topics from the most basic to sophisticated planning topics and from creative ways to address unique family situations to cutting edge tax topics including presentations on: Wealth Transfer Principles; GRATS and Sales to Intentionally Defective Grantor Trusts: Why, When and How – Maximizing Benefits and Minimizing Risks; Estate Planning for the Dysfunctional Family; The Prince and the Pauper: A Look at Trust Distribution Standards; Preserving the Grantor's Intent Under Changing Circumstances and Litigious Beneficiaries: A Planner and Litigator's Perspective; Building Blocks of Wills; Creative Use of Trusts; Incentive Trusts: Considerations, Uses and Alternatives; On Loving and Leaving a Legacy - an Alternative to the Incentive Trust; Estate Planning: Retooling our Techniques under Current Law Using Estate Planning Techniques to Accomplish our Clients' Objectives; Estate Planning with Divorce in Mind; Planning to Defect: Multiple Uses of Intentional Grantor Trusts; Toolbox of Sophisticated Estate Planning Techniques; Planning with Split Interests - QPRTS; GRATS, Joint Contribution Annuity Trusts, Split Purchase Annuity Trusts, Sales to Defective Grantor Trusts and Intentionally Defective Grantor Trusts; Often Overlooked Estate Planning Techniques; Estate Planning for Non-Traditional Families and Estate Planning-The Process; Advanced Transfer Techniques; Electronic and Paperless Practice: How Technology Changes the Way We Think; Handling Future Shock: Impersonal Technology and Decreased Tax Concerns Collide - Keeping and Serving the Clients in a Changing World; The Malleable Trust: Carrying out the Grantor's Intent as Individuals, Families and Societies Change and Evolve; Distribution Clauses: Carrying out the Grantor's Intent to Protect, Motivate, Empower and Train (co-authored with Lee S. Meyercord); Second Generation Estate Planning: The Human Side; The New World of Estate Planning Post 2012; and Legacy Planning: Guidance from Research in Human Development, Motivation and Family Systems.

Marjorie was one of the original co-authors of the 4 volumes of the Texas Practice Guide on Wills, Trusts and Estate Planning (2000-2004). Marjorie is the author of an estate planning guide for lay individuals entitled "Estate Planning: The Process" which can be downloaded from the website www.stephensguthrie.com.

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QUALITY OF LIFE TO THE END OF LIFE

I. INTRODUCTION.

Like many of us, I have had a number of personal experiences with the aging process and with end of life situations. I have dealt with an aging parent. I have two siblings who died both with an end of life issue. One was “revived” after his heart stopped only for us to later realize that his revival was only to subsistence, to “live” in a persistent vegetative state. One of my sisters became unable to swallow, losing over 100 pounds in a year. She rejected the mush they wanted to feed her in a nursing home and rejected a PEG tube to feed her. Her boyfriend agreed and took her home with him and she lived with him for her last months eating “regular” food, enjoying popcorn and Reese’s peanut butter cups even though they were neither safe nor healthy. She enjoyed those last months rather than enduring life in a nursing home. Another brother has been diagnosed with ALS. He continues to function at the highest possible level, seeking such assistance and support as is necessary for him to continue to practice law, be social and enjoy life.

And I see myself and my friends age. My sister-in-law is a nurse and is passionate about maintaining quality of life. She has seen those who have and she has seen those who have not. She supports the cottage community concept. My “swim group friends” have coffee after our swims and discuss how we need to have a “Last Resort” rather than a nursing home. However, we don’t conceptualize what this may really mean. We may discuss a situation from our family and share our feelings, but we rarely consider what quality of life means for us. In the midst of my family experiences with quality of life and the end of life, I read Atul Gawande’s book, *Being Mortal*. I owned it for a year before I read it. I wanted to have read it but I didn’t really look forward to reading it. I thought it would be depressing. I thought it was only about the last few weeks. Finally I got the audio book and listened to it on a road trip. My sister-in-law shared part of the listening on the trip. I realized that the book was really about quality of life to the end of life. I felt that we all could benefit from reading it and that we should all consider the quality of our life in all of our decisions throughout our lives. In a sense this outline, this presentation, is an application of Gawande’s book to the practice of estate planning.

The changes we go through in the first 20 years of life receive much attention. We focus on our children and seek to challenge and motivate them. We decline as we age. The decline is inevitable. But we continue to want to be the master of our lives. We want to do all we

can do just as a child growing up wants to do all that she can do. We assume that our children will be motivated, that they will want to be the master of their lives and we seek to do what we can to facilitate that. But with our parents or other elderly individuals we seek to keep them safe, not independent. We don’t even realize how much having control over certain aspects of their life means to the individual. That having control may be the difference between thriving and decline.

Atul Gawande in his book, *Being Mortal*, begins with a discussion of the inevitable breakdown of our bodies. “By age 85, working memory and judgment are sufficiently impaired that 40% of us have textbook dementia.”¹ This breakdown is not a linear process and occurs at different times and rates for different people. The aging process has little to do with our genes. It has more to do with wear and tear. Gawande cites Leonid Gavrilov, a researcher, as arguing “that human beings fail the way all complex systems fail: randomly and gradually.”² As the defects increase, “the time comes when just one more defect is enough to impair the whole, resulting in the condition known as frailty.”³

In addressing the problems encountered with age, we have checklists to determine whether an individual can be independent. The individual may then go from being almost totally independent, lose some of his abilities and then he is considered to be unable to be independent. The change is dramatic to the living conditions of the individual even though the point at which that occurs may not be dramatic. One day they are the master of their lives and the next, every part of their day is determined for them. We fail to recognize or appreciate or value the importance of maintaining as much control over life as possible.

Aging and experiencing the breakdown of our bodies and minds randomly and gradually is a new phenomenon. In the past individuals rarely lived into old age. Their deaths were from disease or accidents and they were sudden. With the increasing period of decline, it is important to maintain autonomy and our sense of purpose on whatever level we are able for as long as we are able. Considering this in advance of, or early in the decline (evidently we peak at about 40 and it’s downhill from there), is very important to our quality of life.

II. WHY ATTORNEYS?

We are the ones that see the client in a non-medical setting and can provide the documents and structures to support their decisions. Over the years I have changed the way I structure plans and what I discuss with clients. As our documents are automated and the tax laws require less tax planning, our roles are returning to that

¹Gawande, Atul. *Being Mortal*. New York: Picador, 2014, 31.

²*Ibid.*, 33.

³*Ibid.*, 34.

of counselor. We also provide the legal documents for disability, as well as testamentary, as an essential part of an estate plan. In representing a client in their testamentary plan we focus on how to carry out Grantor intent. In carrying out Grantor intent, it is not just so that the persons or charities who receive the Grantor's property are the ones that they would like, but also so that the property has the desired effect on or use by the beneficiary that the Grantor intended.

We prepare disability documents so that our clients select the individuals they want to handle their affairs and make the decisions for them in the event of disability. However, little thought is given to guidance to ensure that their disability is handled as they would like. Little thought is given to ensuring that decisions will be made as they would want. In taking the action for that to occur we must know, or rather their agent must know, what they want. In representing a client in the distribution of their property to their children, I ask them what they hope for and what they fear. Their responses to these questions guide me in structuring their plan.

I now realize these same questions are relevant in structuring their disability documents. What do they hope for and what do they fear in the event of a disability or in their later years? The answer to this question is more challenging than the question of what they hope for and what they fear for their children. Thinking about, worrying about, hoping for our children has been on our minds for years. The thought of our disability, our aging process is one that we avoid thinking about. We may assume that others will take care of it whether it is a spouse or a child. But most likely we deny that it will happen to us. We will be independent and then we will die. Those who have thought about it are generally those that have experienced the decline, disability and increasing incompetence of a parent or close family member. As estate planners we can serve our clients by providing them with information and a way to think about this time in their lives when they are able to do so with perspective and clarity.

III. WHAT IS THE QUALITY OF LIFE?

A. Overview.

Gawande quoted Juergen Bludau, a geriatrician in his book, *Being Mortal*, that "The job of any doctor is to support quality of life, by which he meant two things: as much freedom from the ravages of disease as possible and the retention of enough function for active engagement in the world."⁴ Most doctors see the first as a medical problem but not the second. For the individual, the second is very important and often ignored. And for a geriatrician, the second is a medical problem.

Although there is a shift of priorities as we age, what brings us joy throughout life is what brings us joy as we age. We want to be independent. We want to have a purpose in our life. We want to be engaged in our surroundings. We want to contribute. We want to connect with those we love.

Over time there will be less ability to be physically active and we will lose part of our mental function so what it is to be actively engaged at 40 will be different than what it is to be actively engaged at 80. We are all individuals and have our own life course. Active engagement for an unimpaired person is different than for a person who has some impairment. Active mental engagement for a genius is different than active mental engagement for a person of normal intelligence. It cannot be standardized so that all people who reach a certain age will have a designated physical activity level and designated mental activities. Each individual is different. Each individual must be addressed as an individual. Each individual can provide us with guidance on what this means for him or her.

B. Active Engagement in the World.

Active engagement in our world is a core aspect of our quality of life. Active engagement will vary with the individual but there are some common characteristics.

1. Flow.

Flow is a concept developed by Mihayli Csikszentmihalyi to describe what he found in his research on the psychology of an enjoyable life. The assumption was that things or people could make us happy but what Csikszentmihalyi found was that happiness came from an individual's engagement in the world.

In his research, Csikszentmihalyi had people carry a beeper that rang at random intervals. When the beeper went off the individual recorded what he was doing and described his emotional state. Through his research Csikszentmihalyi determined the elements that comprise the optimal experiences and joy in our lives. He reported and discussed his findings in *Flow, the Psychology of Optimal Experience*. The experience of happiness is one that each individual creates for himself. It is not something that someone else provides for you. The individual must have the control in his life to engage. Providing the environment for engaging is a challenge at the beginning of life and at the end of life. However, for efficiency and safety, the living situations that are structured for an aging person are ones that control their activities and schedule.

Csikszentmihalyi found that individuals were most happy, most satisfied with their lives when they were

⁴*Ibid.*, 41.

totally engrossed in an activity and stated that these experiences had eight components:

“First, the experience usually occurs when we confront tasks we have a chance of completing. Second, we must be able to concentrate on what we are doing. Third and fourth, the concentration is usually possible because the task undertaken has clear goals and provides immediate feedback. Fifth, one acts with a deep but effortless involvement that removes from awareness the worries and frustrations of everyday life. Sixth, enjoyable experiences allow people to exercise a sense of control over their actions. Seventh, concern for the self disappears, yet paradoxically the sense of self emerges stronger after the flow experience is over. Finally, the sense of the duration of time is altered; hours pass by in minutes, and minutes can stretch out to seem like hours.”⁵

These activities are autotellic, referring “to a self-contained activity, one that is done not with the expectation of some future benefit, but simply because the doing itself is the reward.”⁶ The effect of these experiences is to lift “the course of life to a different level. Alienation gives way to involvement, enjoyment replaces boredom, helplessness turns into a feeling of control, and psychic energy works to reinforce the sense of self, instead of being lost in the service of external goals. When experience is intrinsically rewarding life is justified in the present, instead of being held hostage to a hypothetical future gain.”⁷

Cziksztentmihalyi labeled these autotellic experiences as “flow.”

As important as the activities, it is informative to consider the alternative. Cziksztentmihalyi did research to find out how eliminating flow experiences from their lives affected people. He stopped the experiment after two days stating “... the general deterioration in mood was so advanced that prolonging the experiment would have been unadvisable.” The effect was similar to the six symptoms of “generalized anxiety disorder” in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV):

- Restlessness or feeling keyed up or on edge
- Being easily fatigued
- Difficulty concentrating or mind going blank
- Irritability
- Muscle tension
- Sleep disturbance⁸

Consider how these symptoms would be interpreted in an older person. Perhaps they need to be sedated. Perhaps they need to sleep more. Perhaps they are having memory problems. All of these symptoms in an older person would be interpreted as the need for less engagement, more structure, more medications. Yet we thrive on flow. We thrive on focus. We thrive on effort. It is important to our sense of self. It improves our sense of self efficacy. It provides much of the enjoyment in life. We seek it out. It is natural to us. Without it we can seem a little crazy. And if we are older we can seem a little demented.

2. Being Present.

The very young and older individuals live in the present more than any other group. This living in the present, not thinking about life, is what Eckhart Tolle found was what provided quality of life: “‘Your purpose – the fullness of life – is just to be here now,’ he says. ‘To be the space for whatever happens. Try to do that often throughout the day. The length of time doesn’t matter. Always choose now.’”⁹

3. The Focus of Our Attention.

As we age we cannot restore our physical body to its youthful state, but as long as we have our mind or even a part of it we can control what we focus on. Winnifred Gallagher, author of *RAPT*, was diagnosed with an advanced stage of cancer. She committed not to let the cancer control her life. As she put it:

“Through many months of chemo, surgery, more chemo, and daily radiation, I mostly stayed focused on taking care of business in the present – suddenly all I could count on – and on things that matter most and make me feel best: big ones like my family and friends, spiritual life, and work, and smaller ones like movies, walks, and a 6:30 p.m. martini.”¹⁰

In her book, *RAPT*, Gallagher discusses and chronicles the many benefits of paying attention to our feelings, our circumstances, our work, our ability to make decisions,

⁵Csiksztentmihalyi, Mihaly. *Flow: The Psychology of Optimal Experience*. New York: Harper Collins, 1990, 49.

⁶*Ibid.* 67.

⁷*Ibid.* 69.

⁸*Ibid.*

⁹Gallagher, Winnifred. *Rapt: Attention and the Focused Life*. New York: Penguin Books, 2009, 210.

¹⁰*Ibid.*, 3.

our creativity, our motivation, our health, and the meaning we derive from life. As she put it “Paying rapt attention, whether to a trout stream or a novel, a do-it-yourself project or a prayer, increases your capacity for concentration, expands your inner boundaries, and lifts your spirits, but more important, it simply make you feel that life is worth living.”¹¹ “... the difference between ‘passing the time’ and ‘time well spent’ depends on making smart decisions about what to attend to in matters large and small, then doing so as if your life depended on it. As far as its quality is concerned, it does.”¹²

a. *Wired to be negative.*

We are more motivated by fear of loss than by gain. In aging this propensity results in focusing on what we have lost or are afraid of losing rather than on what we have, the good things in our life. This focus can have a self-fulfilling prophecy effect. If we focus on the negative, on losses we cannot regain, at least not to our previous level, then we are likely to become depressed. We will withdraw, aggravating the problem. The withdrawal and depression itself will have an impact on our functioning:

“Paying attention is an individual effort, but it’s also a kind of social cement that holds groups together and helps them feel part of something greater than themselves. When they’re focused on either a social activity or a task, the moods of even fragile or stressed people, including breast cancer patients, bulimics, and chronic depressives, are no different from those of average subject in control groups but drop precipitously when they’re alone or have nothing to attend to.”¹³

Consider the impact of “efficient” nursing home. They are “taken care of.” They do not have tasks and they have been taken away from the social group they had in their pre nursing home life.

b. *Work and Play.*

Gallagher quotes Mihalyi Csikszentmihalyi and his research on flow to illustrate the importance of focus on our sense of well-being. Work grounds our life. Gives us satisfaction. Provides a sense of well-being. Work may cease to provide that level of satisfaction through mastery (it no longer challenges us), a shift in priorities (it no longer is the focus of our attention) or a decline in our capabilities (so that we can no longer perform at the

same level). At that time, the answer is not to just sit back on the couch and “enjoy life.”

“Based on [Csikszentmihalyi’s] studies of daily experience conducted over long periods with thousands of subjects, he says, a benign, pleasant state ‘doesn’t seem natural to most people and has to be worked on and developed. Those who learn to control their inner experience will be able to determine the quality of their lives, which is as close as any of us come to being happy.’”¹⁴

For the individual whose work no longer challenges them, they can add a new vocation or avocation to their business. Gallagher uses “the highly cerebral” Thomas Jefferson as an example who enjoyed “making and designing simple, useful things, such as keys and a plow.”¹⁵ A pianist slowed the tempo of his pieces slightly so that he could continue to perform the masterpieces.

The importance of flow on the quality of our lives, requires time and planning. During our work life, life is structured to provide us with certain times we focus. Our weekends however require us to plan for the activities that will stimulate and engage us.

“The antidote to leisure-time ennui is to pay as much attention to scheduling a productive evening or weekend as you do to your workday. This can seem counterintuitive, says Csikszentmihalyi, ‘because you assume that it will be pleasant to decide spontaneously what to do. But that’s much more complicated than you think.’ Saturday may be okay, because you’ll do some chores and errands, then go out or see friends at night. However, by Sunday noon – not coincidentally, the unhappiest hour in America – you may have run through your options and wind up slumped on a couch, suffering from the Sabbath existential crises. It’s at just such unfocused, unproductive times, says Csikszentmihalyi, that ‘people start ruminating and feeling that their lives are wasted and so forth.’”¹⁶

The Sunday blues is the retirement or aging challenge. Activities and new pursuits must be planned and learned to engage us as we age, our capabilities change and our priorities shift.

¹¹*Ibid.*, 10.

¹²*Ibid.*, 12.

¹³*Ibid.*, 85.

¹⁴*Ibid.*, 106.

¹⁵*Ibid.*, 107.

¹⁶*Ibid.*, 109.

c. *Cultivate the experiencing self & the benefit and risk of adaptation.*

We are adaptable and can adjust to changing circumstances. We may have a new challenge and we adapt to it so that our energy and focus is no longer on that area. Gallagher cites the fact that lottery winners do not retain the glow of winning the lottery and paraplegics are frequently quite happy. They focus on the joys in life that they do have. Adaptation can help us to address the declining abilities we have with aging but can also prevent us from seeing the joys of everyday life.

It is important to keep the pleasures of everyday life in our awareness. We may decide to move ourselves or our parent to a retirement facility or assisted living so that we/they have the additional assistance in their life. However, before that move, the pleasures of daily life should be considered, the ones we are no longer attending to. When they are no longer available, we, or our parents, may mourn their loss. Keeping a daily journal of the pleasures in each day, noting at night what we are grateful for in our daily lives, can provide an awareness that will enrich our lives and an appreciation of the parts of life that we want to maintain.

d. *Avoiding Learned Helplessness.*

One of the major issues that the aging face is the decline in their capability coupled with an abdication of their control over their lives. This combination sends them into a downward spiral. They become depressed, hopeless, affecting their mental and physical health. The reaction to this level depression and sense of hopelessness is very different for the young adult and the aging individual. The young adult receives psychotherapy, cognitive therapy, medication, with a focus on hope and what their lives have to offer. For the older individual, it is frequently seen as evidence of cognitive decline, thereby creating a self-fulfilling prophecy. In discussing the cost of depression on the economy Gallagher states:

“Depression costs the American economy about \$44 billion a year in lost productivity due to affected employees’ reduced ability to concentrate, remember, and make decisions.”¹⁷

Controlling your attention can change your physical and mental health. Jon Kabat-Zinn has worked with the chronically ill and those with chronic pain on improving the quality of their lives. His primary tool is mindfulness.

“After spending three decades teaching sick people how to use attention to ‘fall awake’ and improve their health, Kabat-Zinn concludes that ‘the knowledge that you’re only here for a very short time, plus tender-hearted mindfulness, lets you live inside your experience with freedom and possibility. For many people, much of life is a kind of nightmare. The only way out is waking up – attending to reality.’”¹⁸

Ellen Langer conducted a now famous study with aging individuals. She took elderly individuals, infirm, many using walkers, with various cognitive problems and took them for a week long retreat where they were told they would not receive any assistance with their luggage, that they were not allowed to use their walkers. The retreat was a time-travel to 1959, the years when this group was twenty years younger. All music, all TV programs, all magazines, newspapers, everything around them was the year 1959. The group was transformed mentally and physically. They responded more, engaged more, were independent and their physical being was improved.¹⁹

C. Purpose.

As Gawande noted, shifting the focus to relationships and to the here and now does not equate to a shift to safety and security. The shift is to those relationships closest to us but we continue to focus outside ourselves, to seek to reach beyond ourselves. We continue to find meaning beyond ourselves. There is more than this shift of perspective - it is how we are in the world. If the individual is in a nursing home or other situation in which she is unable to focus and engage in the world outside of herself then regular visits from family are insufficient to provide meaning. When that same individual lived at home she had personal projects, gave to others and could initiate contact with family and friends. The sense of purpose for the individual and her sense of autonomy are important components. The individual must have autonomy and purpose in their relationships with family and friends in order to provide meaning. Autonomy and purpose were also two of the three areas Daniel Pink highlighted in *Drive*, his book about motivation. We are motivated by autonomy and purpose throughout our lives and autonomy and purpose sustain the quality of life in our last phase of life.

Many individuals have difficulty as they age and are unable to assist others as they have in the past. The individual who has a sense of purpose from being of service to others or caring for others will modify the way in which they serve or care for others. When Bill

¹⁷*Ibid.*, 192.

¹⁸*Ibid.*, 198.

¹⁹ *Ibid.*, 136-137.

Thomas, a physician, became the director of a nursing home in upstate New York he re-envisioned and re-created the nursing home to provide the individuals with a life and he did this by surrounding them with living things and giving them a purpose in their care.

1. Service to Others.

Gawande discusses the shift in one's purpose with Felix Silverstone, a doctor whose wife had medical problems and had moved into a retirement home in his early 80s. He had a number of medical problems but had been able to continue to work until that time. He felt that the move would kill him. His life felt like it had no purpose. However, he was focused on service and was proactive. One primary focus was the care of his wife, but he also set up a committee to improve health care service, set up a journal reading for retired physicians and guided a resident through an independent research study.²⁰

2. Caring ... for Anything.

Silverstone was functioning at a higher level and may be indicative of the actions of someone living in a retirement home. Individuals living in nursing homes may not be able to be as engaged as Silverstone. But it does not take that level of engagement to be engaged with all its additional benefits.

“In a study in the 1970s Ellen Langer and her colleague Judith Rodin conducted a study in a nursing home. One group was encouraged to make more decisions for themselves, such as when to receive visitors and whether and when to watch a movie and were also given a houseplant to care for. A second group was given a houseplant but were told that it was the nurse's obligation to take care of the plant. After a year and a half, the first group not only was more engaged and cheerful but also had half the number of deaths as the second group.”²¹

D. **Autonomy.**

Individuals want to be independent. A primary focus of Keren Brown Wilson's work to develop an alternative to a nursing home (discussed below) was to find how to make life worth living for the elderly. Wilson gave them autonomy. They want to be the master of their own lives. One of the problems with care for the elderly is that control is taken away from them and not having control can lead to a type of learned helplessness. The individual will give up and no longer take the initiative. Learned helplessness is an issue in many other situations including abusive relationships,

but our focus here is with the impact when “care” is “taking control” of another individual's life.

1. Individual - Autonomy Begins With the Individual.

The individual must be given the opportunity to be autonomous as we saw in the Langer and Rodin study. But several other factors are important.

a. *Acceptance.*

The individual must accept their decline and limitations so that he/she can take the steps to maintain the quality of life. Silverstone recognized that there were tasks that he did automatically at one time in his life but that he could no longer rely on that. When he got dressed each morning he focused on each step that he was taking to ensure that he continued the process to completion.

b. *Positive Attitude.*

In order to extend oneself and take the initiative to remain in control, the individual must believe that taking the initiative will make a difference. Life must be seen as one with continuing possibilities.

c. *Willingness to Try New Things.*

Along with the positive attitude is the willingness to try new things. A friend of mine works at an assisted living facility. The facility realized that the residents needed more activity but many were quite frail. They proposed a Tai Chi class but most of the residents did not want to do Tai Chi since it was un-American.

2. Home.

Continued independence is also possible while staying at home if the individual will make the changes necessary in his/her home and will seek the assistance to handle the things that he/she cannot.

3. Institutional.

I had a preconceived notion of nursing home care and assisted living. Nursing home was to provide for persons who were mentally or physically unable to care for themselves. Assisted living was a way station to more intensive care. But Gawande discusses the origins of each kind of care and it is clear that there are other options to the traditional nursing home. Institutions operate to be profitable, efficient and to minimize risk. They are not designed to provide quality of life. Looking at the history and a few groups that don't fit the norm provide a view of the possibilities.

²⁰Gawande, 49-50.

²¹*Ibid.*, 124.

a. *Origin of Nursing Homes.*

Gawande provides a helpful history of the origin of nursing homes.²² In the 1930s the elderly were increasingly living in poor houses. They had exhausted their savings and had no way to support themselves. In the mid 1930s the Social Security Act was passed to provide elderly individuals with some means of support. But the elderly continued to populate poor houses. The reason was that they were too infirm to live on their own. In the 1940s the Hill-Burton Act was passed to provide everyone with a hospital reasonably close to where they lived. One outcome was that the elderly who lived in poor houses were perceived to have a medical problem and sent to a hospital. Hospitals were overwhelmed with the chronically infirm. They sought help from the federal government and funding was provided for housing for an extended period of “recovery.” As Gawande noted, nursing homes were not intended to be residential facilities, they were intended to clear out hospital beds. When Medicare was passed in 1965, Medicare would only pay for the services of a facility that met basic health and safety standards. When a number of the nursing homes could not meet those standards and the elderly would have no place to go that would accept Medicare, the government started a policy of “substantial compliance.” As Gawande points out, this concept was a total fabrication. But the homes did fill a need and over time improved in quality but, as Gawande notes “... the core problem persists. This place where half of us will typically spend a year or more of our lives was never truly made for us.”²³

Nursing homes were designed to provide institutional care. The individual has no control, no autonomy, no say in his/her day. None of the elements of quality of life are present in nursing homes. Gawande cited Erving Goffman’s book, *Asylum*, in his comparison of nursing homes to prisons. In our lives we live, work, play and sleep in different places with different people. In institutions we do not. Gawande quoted Goffman:

“First, all aspects of life are conducted in the same place and under the same central authority. Second, each phase of the member’s daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day’s activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials.

Finally, the various enforced activities are brought together in a single plan purportedly designed to fulfill the official aims of the institution.”²⁴

The nursing home was focused on efficiency and safety, not on living. A nursing home provides its residents with a “life” that none of the owners would want to live. One would think that someone would create an alternative to this way of living. Surprisingly the “assisted living” concept was created as a form of nursing home, not as an interim care facility.

b. *Origin of Assisted Living.*

There have been efforts to either develop an alternative to the nursing home or to change the conditions in a nursing home.

Keren Brown Wilson developed an alternative to the nursing home. She called it “Assisted Living.” Her mother was disabled and wanted to have a place that was more like a home, not an institution. The key to the different concept was to provide the same level of care but to allow the individual to have control over his/her daily living. Gawande described the autonomy of the residents:

“The residents had control over the schedule, the ground rules, the risks they did and didn’t want to take. If they wanted to stay up all night and sleep all day, if they wanted to have a gentleman or lady friend stay over, if they wanted not to take certain medications that made them feel groggy; if they wanted to eat pizza and M&M’s despite swallowing problems and no teeth and a doctor who’d said they should eat only pureed glop – well, they could. And if their mind had faded to the point that they could no longer make rational decisions, then their family – or whomever they’d designated – could help negotiate the terms of the risks and choices that were acceptable. With “assisted living” as Wilson’s concept become known, the goal was that no one ever had to feel institutionalized.”²⁵

Wilson sought to provide an environment that maintained the quality of life even when the individual could not handle some or many of his/her daily activities. The key was control. She created an environment in which the residents had autonomy. They did not have the institutional environment described above by Goffman.

²²*Ibid.*, 68-72.

²³*Ibid.*, 72.

²⁴*Ibid.*, 74.

²⁵*Ibid.*, 91

The concept was popular. There was a demand. Wilson built more of her facilities. She took the concept public and had a private offering on Wall Street. Others saw how popular the concept was and began building facilities that they called “assisted living” but were not using Wilson’s model. Providing the residents with the level of autonomy that Wilson had was not as efficient. Assisted living then became a way station between independence and a nursing home. Once again the residents were treated like children or prisoners and the facilities were operated more efficiently.

4. Other Efforts to Alter the Environment of a Nursing Home.

Bill Thomas, a physician, became the director of a Nursing Home in upstate New York. His background was as an emergency room physician. In working with the nursing home, he wanted to address the three plagues of living in a nursing home: boredom, loneliness, and helplessness. He converted the lawn to a vegetable and flower garden. He brought plants into every room and brought in cats, dogs, parakeets, rabbits and chickens. He brought in children with an on-site child care for the staff and an after school program.

The use of drugs fell in half and deaths fell 15%. But as Gawande put it:

“The most important finding was that it is possible to provide them with reasons to live, period. Even residents with dementia so severe that they had lost the ability to grasp much of what was going on could experience a life with greater meaning and pleasure and satisfaction. It is much harder to measure how much more worth people find in being alive than how many fewer drugs they depend on or how much longer they can live. But could anything matter more?”²⁶

There are a few nursing homes other than Wilson’s concept and Thomas’ expansion that provide a place where the residents can live and not just exist. The elements that are important are autonomy and purpose. The residents have their own room. They can make decisions about their lives. They need care but they still want to be the master of their lives.

E. Meaning.

1. Large or Small.

Gawande cited Josiah Royce’s 1908 book, *The Philosophy of Loyalty*, in which he sought to determine why existing, having ones daily needs met was empty and meaningless. Gawande describes Royce’s thinking

“The answer, he believed, is that we all seek a cause beyond ourselves. This was, to him, an intrinsic human need. The cause could be large (family, country, principle) or small (a building project, the care of a pet). The important thing was that, in ascribing value to the cause and seeing it as worth making sacrifices for, we give our lives meaning.”²⁷

2. Meaning is Important Throughout Life.

Gawande pointed out, based on the psychological research of Abraham Maslow, the drive for growth is a higher order of need. First we have a need for safety and security, then for relatedness and belonging, then for personal growth and then for self actualization. We do not climb back down this ladder and stop seeking growth and then withdraw from belonging until we feel safe and secure. As Gawande points out:

“Reality is more complex, though. People readily demonstrate a willingness to sacrifice their safety and survival for the sake of something beyond themselves, such as family, country, or justice. And this is regardless of age.”²⁸

Those who are older report more life satisfaction than those who are younger. Our need for autonomy and purpose is with us throughout our life.

3. Virtue as the Gyroscope of Life.

Reflecting on one’s values, on the “virtues” of wisdom, courage, temperance, justice, humanity (love) and transcendence provides a framework for considering the last quarter of life. Attending to our days, our actions, our thoughts and our relationships that reflect these virtues can focus our attention on the areas that enrich our lives and our experiences.

F. Variance by Individuals.

Each individual is unique. Each individual will find different aspects of life that give it meaning and richness. These things include those things that we focus on to the point of being engrossed in, to a state of flow. We learn new things or learn things that can provide the engagement and challenge as our abilities decline. In addition, living in the present and enjoying those things of the moment, whether they are a walk outside, movies and a 6:30 martini or eating chocolate ice cream provide quality for our lives. Being aware of these things and savoring them, can make the difference between existence and quality of life and will inform the decisions we make if aging requires additional care or restricts our horizons.

²⁶ *Ibid.*, 125.

²⁷ *Ibid.*, 126.

²⁸ *Ibid.*, 93.

G. Effect of Time.

We have all heard the saying that no one on their death bed wishes they spent more time at the office. Meaning remains important but there is a shift of priorities. Gawande cites the research of Laura Carstensen, a Stanford psychologist. Carstensen had a near fatal accident at age 21 and as she lay in the hospital recovering she shared the area with several elderly women with broken bones. She observed how they were treated compared to her. Their lives were considered over and hers was seen as one with possibility. She received therapy, attention and care. The elderly women received a passing wave. Her priorities shifted from the future to the here and now. That started an interest in aging that she took into her studies and ultimately into her research. Years later she formulated a hypothesis that the shift in how we seek to spend our time is based on how much time we have. When you perceive yourself to have decades, you focus on growth, achievement, “self-actualization.” When you perceive your time to be short, you shift your focus to those close to you, to the here and now. She found that individuals with terminal illnesses, after 9/11, during the SARS epidemic, or in uncertain political situations all shifted their focus to those close to them and to the here and now. When the crisis was over they shifted back to focus on achievement and creativity.²⁹

IV. CHALLENGES

There are challenges in addressing the quality of life to the end of life. I resisted even reading Gawande’s book for a year. It seemed so depressing but in reading it, in reflecting on the rest of my life I realize that considering the quality of my life now, before I need any assistance in my care, is essential to maintaining the quality of my life to the end of my life.

A. Decline is Gradual.

We begin the decline after age 40 but most of the first losses are insignificant to our daily life. We cannot run as fast. We cannot read without glasses. We may need hearing aids. At some point though the losses will create a situation in which we need assistance and how we think about and how we address that need, is an important part of maintaining the quality of our life.

B. We Are Adaptable.

In *The Happiness Hypothesis*, Jonathan Haidt discusses the “adaptation principle.” We are adaptable. We adapt to changes in our lives, our circumstances and our health. He uses the example of the lottery winner and a person who has a spinal cord injury and becomes a paraplegic. Clearly immediately following these two situations, these two individuals would report very

different happiness levels, but in a year, they each return to the level of happiness before the event. We suffer a medical issue, we address it. We adapt. The challenge to this adaptability is that in some senses we do not know what we will want in a given situation. We do not know what will be an issue.

C. We Hope ... or Deny.

Our medical system has been focused on a “cure” and thus we consider the end result of a visit to a doctor is that we will be cured. We likely don’t ask the doctor what our life would be like with or without a given procedure. We hear the risks and side effects of a treatment but we don’t hear that the best result is an impaired life or an extra two months of life. And those two months are ones lived with the side effects of the treatment.

D. Our Attitudes Change.

A change in our attitude goes hand in hand with being adaptable. We may consider a situation one that we would not want but then when we are in that situation, we may find that we feel differently. Or we may not admit that we are in the situation that we wanted to avoid. In *Being Mortal* one of the individuals that Gawande worked with elected to have surgery that had a significant risk of shortening his life and making it much worse. The surprising aspect of this situation is that he had gone through this with his wife and told his son not to let him ever be like that but, that is exactly what occurred. The hope that the surgery will give him back his life. The surgery and the complications left him significantly worse, repeating what occurred for his wife that he vowed to avoid.

E. Conflict Between the Elder Person’s Desires and the Children’s Desires.

The older person wants to continue to be the master of his life. He wants independence and control. His children want him to be safe.

1. What the Children Want.

The individual’s children are looking for someplace close within driving distance, looks pleasant, within budget, where their parent will be cared for, will be safe and will be able to handle future declines in functioning.

2. What the Individual Wants.

The individual wants independence and control. Gawande’s mother-in-law said what she missed most were her friendships, privacy and a purpose to her days.³⁰

²⁹ *Ibid.*, 97-99.

³⁰ *Ibid.*, 75.

3. Reality of the Options.

Most nursing homes or other residential facilities are unlikely to provide these two critical components regardless of the services offered. In order for the facilities to make a profit, provide a safe environment and meet the individual's basic needs; more structure and supervision is required. Everyone is on the same schedule, eats the same foods. The nurses are monitoring the individual's health and, to ensure safety, will require that they use a walker if they are unsteady. If they don't take their required medications, then nurses will require that the individual come to the nurses' station to take their medication. Any defiance results in more control. The result is a form of learned helplessness. The worst nursing homes confine the individuals, may strap them down, subdue them with psychotropic medications and take whatever action is most efficient, regardless of how dehumanizing. The good ones may tease the resident as they take away the brownie or other prohibited food. "In almost none does anyone sit down with you and try to figure out what living a life really means to you under the circumstances, let alone help you make a home where that life becomes possible."³¹

Just as parents were reluctant to let go of control of children because they think they can guide them into a productive life; in old age the individual is controlled more and more for "their own benefit."

4. The Conflict.

Quoting from Gawande on his discussion with Keren Brown Wilson:

"A colleague once told her, Wilson said, "We want autonomy for ourselves and safety for those we love." That remains the main problem and paradox for the frail. "Many of the things that we want for those we care about are things that we would adamantly oppose for ourselves because they would infringe upon our sense of self."

She puts some of the blame on the elderly. "Older people are in part responsible for this because they disperse the decision making to their children. Part of it is an assumption about age and frailty, and it's also a bonding thing that goes on from older people to children. It's sort of like, 'Well, you're in charge now.'"

But, she said, "it's the rare child who is able to think, 'Is this place what Mom would want

or like or need?' It's more like they're seeing it through their own lens." The child asks, "is this a place I would be comfortable leaving Mom?"³²

V. QUALITY OF LIFE - CONSIDERATIONS FOR THE LAST QUARTER OF LIFE

A. Quality of Life - Normal Aging

1. Decline is Normal - Acceptance Provides Freedom.

In order to plan for quality of life to the end of life, we must accept that there will be decline. We cannot run a 5K at age 70 in the same time that we could at age 40. Decline is inevitable. Accepting that decline will occur gives us the opportunity to maintain quality of life during that time. We want to be the master of our lives to the end of life. We want autonomy and purpose. We struggle with maintaining these since it is evident that autonomy at 90 is not what it was at 40. If there is decline then that does not mean that we concede defeat and move to an institutional life. We compensate for the ways that we have declined. Just as we would buy a pair of glasses or purchase hearing aids, we also seek to bridge the gap in other ways on what we can do and what we can no longer do. A key component is to accept what we can and cannot do. One impediment to acceptance is the fear that admitting a decline will mean moving someone out of their home to a nursing home. To avoid this reaction by family members or others, discussions with those individuals well in advance of these times is important.

2. Independent Living.

A tool used to assess a person's ability to live independently is the list of Activities for Daily Living and list of Independent Activities for Daily Living.

a. *Activities for Daily Living.*

In living alone, the individual will need to be able to handle the following daily aspects of living.

- Handle their bathroom needs
- Feed themselves
- Dress themselves
- Bathe themselves
- Groom themselves
- Get out of bed
- Get out of a chair
- Walk

These basic activities are ones that will be needed each day.

³¹ *Ibid.*, 76.

³² *Ibid.*, 106.

b. *Independent Activities of Daily Living.*

If you lack the following then you are considered to lack the capacity to live safely on your own

- Shop for yourself
- Prepare your own food
- Maintain your housekeeping
- Do your laundry
- Manage your medications
- Make phone calls
- Travel on your own
- Handle your finances

Most people lacking one or more of these tasks are still capable of being independent if they receive some assistance. They want to bridge the gap rather than have all of these tasks performed for them.

3. Bridging the Gap.

a. *Historical Perspective.*

In the past the family lived as a unit. In the US one change was for the children not to be dependent on their parents. Parents sold their homes and “retirement living” became a goal of the “golden years;” playing golf in sunny Arizona in a retirement community. Parents did not live close to their children and children planned their lives as their own family unit, not as an extended family unit.

Gawande compares this situation to his father who lived in India. He rode a horse to check on his fields until past 100. He would never have been allowed to do that in the US. US won’t allow people to take risks. His riding the horse would not be considered safe. If he did that and broke a hip, they would not allow him to return home. “They’d insist that he go to a nursing home. But in my grandfather’s premodern world, how he wanted to live was his choice, and the family’s role was to make it possible.”³³

b. *Daily Living.*

If the individual cannot do one or more of these activities, he will need assistance. That assistance can be provided in his home or he can move to a living arrangement either with family or in a residential facility that will provide assistance in the areas needed. These activities seem like obvious ones but consider them. If the individual has difficulty with some of these tasks but sometimes with mishaps, such as a fall, the family may consider assisted living but that change will significantly impact the individual’s life. As there are more of the items that a person lacks in the first category, then they will either need extensive home care or will need to live in a more structured setting. However, for quality of life, the more that the individual

can handle these items with assistance, the higher the quality of life. For example, consider dressing. If they can do part of it then having someone assist can allow them to continue to handle this area. It may be considered inefficient since a nurse can dress the individual in a shorter period of time than the individual can dress herself. As noted earlier, Silverstone, one of the individuals interviewed by Gawande, said that he realized he needed to focus on tasks that were automatic. One example he gave was dressing. Focusing on dressing and having the assistance to do so has a much different outcome than dressing someone. Not only are they in control of an aspect of their life but they also are maintaining some of the skills needed to be independent.

c. *Independent Activities of Daily Living.*

From a review of these items, the items in the independent activities can be provided by a family member or caregiver. If the individual can handle the items in the first category, the ones in this category are more easily provided by a family member, assistant or household help. The assistance of a caregiver is not actually needed. If the individual can have someone else provide these activities or assistance in these activities, the individual can likely maintain a higher quality of life at home than in a residential facility. With Uber and Lyft an individual can continue social activities even if he cannot drive

4. Seeking Medical Advice - From Whom Can Make the Difference.

One of the issues that must be addressed in aging is that it is not a medical problem. There will be medical problems but aging itself is not a medical problem. If the medical advice we seek interprets everything as a medical problem then we are likely to receive advice that provides medical treatment but without regard to quality of life. As Gawande expressed it:

“We want doctors who will fix things. We want to view medicine as a way to give us a fountain of youth. Geriatrics begins with acceptance that we age. Acceptance of decline. It gives us resilience to handle the decline. It requires attention to the body and its alterations. It requires vigilance over nutrition, medications, and living situations. And it requires each of us to contemplate the unfixables in our life, the decline we will unavoidable face, in order to make the small changes necessary to reshape it.”³⁴

³³ *Ibid.*, 16.

³⁴ *Ibid.*, 46.

a. *Geriatrician v Internist.*

Gawande cited a study that reflects the potential difference in care between a geriatrician and an internist as follows:

“Several years ago, researchers at the University of Minnesota identified 568 men and women over the age of seventy who were living independently but were at high risk of becoming disabled because of chronic health problems, recent illness, or cognitive changes. With their permission, the researchers randomly assigned half of them to see a team of geriatric nurses and doctors – a team dedicated to the art and science of managing old age. The others were asked to see their usual physician, who was notified of their high-risk status. Within eighteen months 10 percent of the patients in both groups had died. But the patients who had seen a geriatrics team were a quarter less likely to become disabled and half as likely to develop depression. They were 40 percent less likely to require home health services.”³⁵

b. *Difference in Approach.*

If the patient has a medical issue that will not shorten or impair his enjoyment of life, then that medical condition will likely not be treated. A slow growing tumor for a 90 year old is an example of that condition. Again Gawande looked at what they did do stating:

“What they did was to simplify medications. They saw that arthritis was controlled. They made sure toenails were trimmed and meals were square. They looked for worrisome signs of isolation and had a social worker check that the patient’s home was safe.”³⁶

B. Quality of Life - Terminal Conditions.

There is a different set of considerations when there is a disease, a near fatal event, a terminal condition. The decision then is not primarily having the assistance to maintain one’s activity level or arranging for care that provides for autonomy and purpose. The decision at that time is the impact of the disease or condition on your quality of life and the impact of the treatment on your quality of life.

1. Medical Advice, Communication, Getting the Whole Picture.

In these conditions the individual and his family are likely to turn to the doctor for advice. The doctor will provide advice on treatment, not on life. The consideration and thus the discussion on the life we want to live does not occur. As Gawande expressed the situation:

“Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers.”³⁷

A few of the problems that we encounter at this time are:

a. *Being told honestly what the situation is.*

The focus is on the treatment and the side effects but not what the living conditions and expected survival time are without treatment and the living conditions and expected survival time are with treatment

- (1) Gawande cited Tolstoy’s *The Death of Ivan Ilyich* as an example of the impact of avoiding the truth about a medical condition. What bothered Ivan Ilyich the most was the deception.
- (2) Understanding the choice being made. For example, let’s assume that the choice is whether or not to have surgery (or it could be chemo or radiation treatment). Consider the difference in these two situations:

If you have no surgery, you will continue to live but there will be no improvement from your current situation. If you have surgery, there is the possibility of the restoration of most of your function but there is the possibility of death in surgery.

If you have no surgery you will live another year. You will not have any change in your condition but the symptoms of the disease are slight. With the surgery you will have the risk of a number of complications and the benefit is that your life would be extended by two months.

These are very different situations but they may be presented to the patient as if they were the same. The “treatment” for this condition is surgery. The question that needs to be asked but frequently is not, is what is

³⁵*Ibid.*, 44.

³⁶*Ibid.*, 45.

³⁷*Ibid.*, 9.

life like if I do have surgery and what is life like if I do not have surgery.

b. *And If the Patient Was Told, Did He Hear What He Was Told?*

Everyone wants hope. They hear what they want to hear. They hear the possibilities, not the likely scenario. The doctor will explain the treatment options, but they focus on what the treatment is without considering and discussing what those treatments really give you. The cancer doctor in *Being Mortal* said when he meets with a new patient, he considers giving the individual one to two years of life while the patient and the family are thinking ten to fifteen years, even though no time period has been mentioned. The treatment is also considered without regard to the side effects of the treatment. Perhaps the treatment gives a couple more months but the side effects make all the remaining months miserable.

2. Knowing What Makes Life Meaningful for the Individual.

This is the area that requires a discussion. One of the situations discussed by Gawande was that of a psychology professor at Berkley, who was retired with a mass growing in his spinal cord. He was 74. If he had the surgery to remove the mass, there was a 10% chance of leaving him quadriplegic and death was a possibility. But without the surgery there was a 100% chance. His daughter had his medical power of attorney and asked him “what level of being alive is tolerable to you”. He said, “well, if I’m able to eat chocolate ice cream and watch football on TV, then I’m willing to stay alive. I’m willing to go through a lot of pain if I have a shot at that.”³⁸

His daughter would never have guessed since she didn’t ever remember him watching a football game. As it turned out he developed bleeding during the surgery and likely would be a quadriplegic. The doctors asked if they wanted them to go back to save his life. She asked if he could eat chocolate ice cream and watch football on TV. He would, so they proceeded with the surgery. Without this conversation she would have either let him go, or if she agreed to go forward with the surgery would have felt terrible about the difficult rehabilitation he had.

3. Misconceptions of Palliative Care.

An individual does not want to hear that the doctor recommends hospice. That sounds like a death sentence, as if the doctor and everyone is giving up on you. Whereas the use of hospice is not foregoing treatment, it is not a “death with dignity” decision, it is a matter of priorities. First, quality of life, second treatment.

4. The Questions to Ask.

Susan Block, a palliative care specialist at Gawande’s hospital, has the following list of questions that she covers before decisions must be made:

What do they understand their prognosis to be?
 What are their concerns about what lies ahead?
 What kinds of trade-offs are they willing to make?
 How do they want to spend their time if their health worsens?
 Who do they want to make decisions is they cannot?³⁹

C. **Quality of Life - Near the End.**

Having the discussions about the quality of life and the life worth living in the prior section are essential in navigating the end of life. An essential component is the discussion prior to the end of life and recognizing that the difference in palliative care is not that treatment is suspended but that the quality of life becomes as important as the treatment is.

VI. ASSISTING THE CLIENT IN FOCUSING ON QUALITY OF LIFE

Over the course of my years in practice, the focus on decisions regarding disability have shifted. Over time, not only have powers of attorney become a routine part of the basic estate planning documents but so have medical powers of attorney and Directives regarding end of life. As medicine has become more adept at keeping us alive, we as individuals seek to extend our lives. The focus is on extending life but it is extending the period with the quality of life that we are seeking. The distinction between extending life and extending the period with the quality of life is difficult to address at the end of life or when the situation presents itself to us. We hear about a treatment and think years while the doctors might be thinking months. We think about being returned to a full active life and mental state; whereas the doctor may be thinking of a much more limited existence. We generally see clients at a time when there is no medical issue. That time is a time to consider, to reflect on the quality of life to the end of life. As we consider the appointment of agents on property and medical powers of attorney, we can also open consideration of the quality of life and not just the extension of life. We are in a unique position. How can we do that?

As Csikszentmihalyi (*Flow*) and Newport (*Deep Work*) both found, a key component to an individual’s happiness is focusing on an activity to the point of absorption. This activity can be an intellectual pursuit or it can be engaging in a physical activity or hobby. Continuing activities in which the individual can focus

³⁸ *Ibid.*, 183.

³⁹ *Ibid.*, 182-183.

is a key part of that individual's engagement in life. Newport found that, in our distracted world, managing attention, our focus and reflecting on our values provided the process to recognize the things that give life richness, meaning. In *Rapt*, Gallagher found that the quality of her life depended on what she paid attention to.

There are two aspects to addressing the quality of life to the end of life. The first aspect is for the client to consider what life quality is to him/her and the second is to communicate that to his/her family. As attorneys we support and facilitate these two aspects and provide the documentation to authorize the implementation of a client's life quality plan. We have considered the quality of life at two different times. The quality of life as a client's ability to handle all matters for himself declines. The second is the quality of life during an acute illness or end of life time.

A. Quality of Life as Capacity Declines.

1. Threshold Question.

What are the most important qualities of the client's life or what is it that is essential to the quality of his life?

The individual should always consider and request that his family ask, consider and use as a guide in his care, what it is that makes life meaningful to that individual. This question keeps the family focused on the individual's well-being and not just the individual's care. The individual may want to take risks such as being more physically active that the family would not agree to unless they realized the importance of those activities. In addition, what makes an individual's life meaningful may change over time.

2. Control.

What we have seen is that the key to maintaining quality of life is to retain as much control as the individual is capable of exercising. This care includes:

Providing assistance to handle all of those life tasks that the individual is unable to handle for himself. The family may provide the assistance. The assistance can be provided by an aid, assistant or caregiver.

Having control over one's daily schedule including as much control as possible over sleep, wake, activity and eating schedules.

Selecting one's own activities, television shows or movies.

Choosing one's food and diet as much as possible including the timing of meals and the decision to eat foods that may not be ideal food for that person's health.

3. Purpose.

Each individual needs a purpose to their lives. The individual's level of functioning will determine the effort to engage in purpose. Purpose is something beyond themselves and could include:

When the individual is functioning at a high level intellectually, this purpose may be an extension of some area in which he/she was involved professionally. It could also be providing care or involvement with grandchildren or other children such as in a reading program.

Having a group that the individual participates in and is an integral part of whether it is a book club or card games.

Caring for a garden or a plant.

Caring for a pet. The individual can have full responsibility for the pet or can provide part of the care. The pet can be a dog, a cat, a parakeet.

4. Relationships.

Frequently the relationships are with family members but may also include friends and other acquaintances. The network of relationships one has while living at home may need to be facilitated if the individual is unable to drive. With Uber and Lyft, we can continue to be engaged even if we are no longer able to or feel comfortable with driving.

B. Quality of Life: End of Life.

Planning for quality of life at the end of life is more complex partly because it is unclear when we are at "the end of life." There may be an incident such as a heart attack, cancer or a disease the course of which is uncertain. And it is the uncertainty that makes consideration of the action well in advance of the occurrence of such situation so important.

1. Focus on Communication and Potential Miscommunication.

a. *Asking for clarification of the prognosis with and without the treatment not just of the disease but of the quality of life and understanding the potential side effects of treatment on the quality of life.*

Consider Gawande's conversation with the cancer doctor who said that when a new patient comes into his office, he usually is thinking "how can I give them a good one or two years." The patient is thinking that the outcome of treatment is another 10 to 15 years. Neither time period is specifically discussed, the doctor, the patient and the family are all coming from a different place in terms of prior knowledge, experience, hope and denial.

Words that may accurately reflect the situation can feel cold and abrupt. Hope is part of the fuel for coping. However, understanding the situation is essential in making decisions.

Gawande met with a patient and was aware that the disease could not be “cured” and he used the phrase “prolong your life.” In discussing this first discussion with the family at a later time they commented on that phrase and the cold stark picture that it projected.

My brother who was diagnosed with ALS repeatedly heard the phrase “manage your decline.” Hope was not offered, even though there continues to be research in this area and the course of ALS varies dramatically from person to person.

A palliative care nurse told Gawande that words matter. If asking about an end of life situation, instead of saying “if you are close to death” ask them what they want “if time is short.”

But avoiding the discussion can be equally disturbing.

In Tolstoy’s *The Death of Ivan Illyich*, Illyich knew he was dying but no one acknowledged it.

As Gawande noted when a person has a terminal condition, the focus is on the treatment to be taken and its side effects. But one of, if not the most important part of this discussion is what that treatment provides if it is successful. The treatment may only provide a couple of months of life while diminishing the quality of life dramatically.

2. Questions to Consider.

Kathryn Mannix is a palliative care doctor. In her book, *With the End in Mind*, Mannix provides a number of stories of individuals using palliative care dispelling many of the horrors of dying as well as illustrating and reflecting on the positive period this time can be for the family at the end of a loved one’s life. At various points in her book she provides a “Pause for Thought” after providing several stories. These “pauses” provide guidance for anyone who is considering discussing their desires with their family regarding quality of life to the end of life. In “Pause for Thought: Naming Death,” some of the questions for an individual’s reflection include:

“If you were approaching your own death, who would be the important people to tell? Who do you hope would tell you if they knew that their death was approaching?

....

How do you and the people you are closest to make their views known? Do you all like to tell people clearly, or do some of you prefer to drop hints? How good are the rest of you at picking up each other’s cues?

Do you know what kind of care your loved ones would like as their life’s end approaches? Or have you assumed that what you would like is also what they would like, or that you will be able to guess if you need to?

If you were close to dying, would you prioritise being as awake and alert as your condition would allow, or would you prefer to be sleepier and less aware of the situation and the people around you?

What balance do you see between the length of time you live, and the quality of life you are living? Do you think that, if you had a choice, you would choose to accept or to forgo treatments that extend your life if they do not restore quality? Would you prefer to live for as long as possible, even if it means being supported by machines in an intensive care unit, or to make plans that declare at what level escalation of treatments should stop, to focus on comfort instead of prolonging life? Do you feel confident that, if you suddenly became life-threateningly ill, your closest family and friends would know your wishes and preferences about your care?”⁴⁰ (emphasis added)

The italicized portion of the quote focuses directly on the quality of life contrasted with the length of life.

I am not alone in thinking that hospice was the action when you had given up or everyone around you had given up on restored health. Hospice meant facilitating death. But as I have read Gawande’s book and the other books cited in the bibliography I realized that hospice is the reversal of priorities from treatment at all costs to quality of life first and treatment second.

VII. THE ROLE OF DISABILITY DOCUMENTS IN QUALITY OF LIFE

The following is a brief non-comprehensive discussion of disability documents. I refer you to an outline by Melissa Willms, *End of Life Issues*, presented in 2014 at the Advanced Elder Law Course for a discussion of each of the disability documents and to the

⁴⁰ Kathryn Mannix. *With the End in Mind*. New York: Hachette Book Group Inc., 2016, 165-166.

outline by Donald Totusek and Lora Davis included with the materials for this conference discussing the 2017 legislative changes to the Texas Durable Power of Attorney statute.

In this outline I will provide a brief description of the various documents that are used emphasizing the areas that are important to consider in focusing on the quality of life to the end of life. Of primary importance is the cooperation and interaction of the individuals who are in charge of property matters have with the individuals who are making medical decisions. These decisions are inextricably interwoven and are, or should be, implemented by agents who are informed of the individual's intent and are working together to carry out that intent. In particular the decisions made as an individual's condition declines involve decisions that require varying amounts of money and time and sometimes substantial amounts of both time and money. For anyone who has gone through this process with a relative, they are aware that the time in determining what type of care is best and where that care is available can be confusing as well as time consuming.

Everyone needs a team. The only time I have seen the quality of life kept at the forefront of decisions when one individual is making all the decisions, is when that individual is the spouse of the individual who is suffering declines with age. I believe we have all met with couples who both appear to be functioning quite well, only to have one spouse die and the surviving spouse's deficiencies become evident as well as being exacerbated by the spouse's death. Sometimes one spouse is covering the other spouse's deficiencies and sometimes they are each covering some of the deficiencies of the other.

A. Durable Power of Attorney.

The power given to an agent under a power of attorney is very broad. As noted above, it is rare that all power can be given to one person and have the quality of life of the individual receive the attention that it should. The failure to provide the attention is frequently not due to a lack of caring by the agent. It is partly due to the overwhelming responsibility and extraordinary amount of time it takes to manage these decisions for another. In addition, as noted above the agent, particularly a child, will focus on their parent's (friend's) safety, not the quality of their life. If a child is named as the first and sole agent on a power of attorney and on the medical power of attorney that child is likely to feel that they must handle everything on their own. The parent/client needs to refocus these responsibilities so that they are handled by a team and that the individual has communicated with the team preferably directly, but alternatively through a letter of instructions.

B. Medical Power of Attorney.

The Medical Power of Attorney is important not only because it designates the person the client wants to make medical decisions but also because as a part of that process, the client considers who would make the type of decisions that he/she would in deciding on what medical treatment. Generally this person shares some of the client's thoughts and values on life as well. Selecting the medical power agent is the first step in considering the quality of life team.

C. Revocable Living Trusts.

The revocable living trust is the primary and best vehicle to use in creating a team and a process to ensure that the quality of the client's life will be considered as a part of the aging and disease process. The Trustee can be a member of the family or can be a corporate trustee. The primary function of the Trustee will be to maintain good records and handle the investments. The Trustee may also have distribution powers but the distributions are to be the decision or upon consultation with a team. The team consists of the agents that the client named on his/her powers of attorney, and other individuals that the client is confident understand the client, what he/she values and what components are important to the individual's quality of life. These individuals are ones that the individual is confident would make decisions that consider his/her desires and values and consider quality of life as a priority.

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