# **Preparing for the End-of-Life in Diaspora**

Presented by Professor Joseph A. Balogun\* at the Third Annual Physical Therapy Alumni Convention of the Obafemi Awolowo University (OAU), USA Chapter, held at the Cameo Ballroom, Tuft Valley Resort Center, Ellicott City, MD

Mr. Chairman

**Guest Speakers** 

Ladies and Gentlemen

All Protocols Observed.

### **Preamble**

It gives me great pleasure to be here today to address this gathering marking the third Annual Physical Therapy Alumni Convention of the Obafemi Awolowo University (OAU), USA Chapter. The topic of my presentation, "Preparing for End of Life in Diaspora" is not the most enchanting discussion to have, but it is one that dare not be avoided. I, therefore, understand why I was scheduled to give my presentation at end on the program. End-of-life (EOL) discussion is a morbid topic; yet a very critical phenomenon because death is an experience that is universal. I hope at the end of this presentation you will have something beneficial to take home.

This presentation, which is a continuation of the "life-skills" speech that I gave at this convention last year, was inspired by my recent experiences in making EOL decisions while participating in the planning of burial of friends and colleagues. I came away from each experience with the conviction of the need to bring EOL issues out of the closet in my community.

The topic of my presentation is far removed from the "meat and potatoes" of physical therapy; a discipline that I have devoted my academic life contributing to its knowledge base. I brought this topic to this convention because, I believe I have some influence amongst this audience and I would like to use that "social capital" effectively and responsibly.

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## **Scope of the Presentation**

I would like to set the scope of my presentation and provide operational definitions for two key words ("End-of-life" and "Diaspora") that are central to this discussion. End-of-life is a generic term commonly used to describe a retail product, indicating that the product is at the end of its lifetime; about to expire, and a vendor will no longer be selling it. In this presentation, EOL refers to death or to a person with a terminal disease. Decisions relating to EOL may include the use of modern technology to prolong life even in vegetative state, or the use of drugs intentionally to end-life.

The other primary term in this presentation-"Diaspora"- was defined by the *WorldNet Dictionary* as the dispersion of the Jewish people from Palestine after the Babylonian exile in 358 BC. In this presentation, "Diaspora" refers to the immigration of Africans from their homeland. Specifically, I will focus on EOL issues within the Nigerian community in the USA; a community to which I belong.

Nigerians in Diaspora, hold allegiance to two homelands; a place of ancestral birth and an adopted or naturalized country. As first generation immigrant in the USA, we maintain close relationship with our parents and next-of-kin in Nigeria. We operate and live in two "worlds" (Nigeria and USA) with obligations to both "worlds."

### **EOL Defined**

The death of a relation or friend brings about a catastrophic change in the lives of individuals left behind. Death is about the only predictable occurrence in life and a price we all have to pay. Shakespeare said that "death is a necessary end that will come when it will come." Death has been feared for ages as attested to by Julius Caesar who said "Cowards die many times before their death, the valiant never tastes of death but once."

To the believers in the audience, there are many references in the Holy Scriptures pertaining to death. The first mention of death in the Bible was in the Garden of Eden. Adam was alone; Eve had not yet been created. God told Adam that he could eat of every tree in the garden except for "the tree of the knowledge of good and evil". If he ate from that tree, "you shall surely die". (Gen. 2:17). So, mankind was not created as mortal beings and death is a punishment. God's words to Adam as he sent him out of the garden were, "For dust you are, and to dust you shall return". Adam and Eve got a look at the consequences and severity of the first ever death when Cain killed Abel. The Bible has different ways of expressing death. "And Enoch walked with God; and he was not, for God took him." (Genesis 5:24). Later in Genesis, "So the Lord said, I will destroy man whom I have created from the face of the earth; both man, and beast, and the creeping thing, and birds of the air; for I am sorry that I have made them." (Genesis 6:7). Isaac "gave up the ghost" (Gen. 35:39) and so did his son, Jacob.

In the Quran, life and death was also referenced in Surah 39, Ayah 42: "It is Allah that takes the soul (of men) at death; And those that die not (He takes) during their sleep: those on whom He has passed the decree of death, He keeps back (from returning to life), but the rest He sends (to their bodies) for a term appointed. Verily in this are signs for those who reflect."

Most affected by death are the survivors, especially when the deceased is young and at his/her prime. In different cultures, the cause of death is often attributed to many factors. For example, among the Yoruba's, in Nigeria, it is often believed that through the use of mystic powers, spouses are responsible for the death of their husbands. In such circumstances, the spouse and her offspring(s) are often denied the right to the husband's assets and custodian of the children. Several anecdotal reports and empirical data have emerged on death and grief since the '60's with the classic works of Kubler-Ross (1969) and Kavanaugh (1974). There are a few research work done in Nigeria on attitudes towards death and grief (Asonibare 1984; Uba 1985; Jimoh 1985; Balogun 1990).

Attitude towards death in Europe and America has changed considerably, but we Nigerians still have a vague and hazy knowledge and attitude about death and dying. Consequently, we do not like to discuss it. The problem is also compounded because many Nigerians do not believe people die naturally (except due to old age) but as a result of some supernatural forces unknown to man.

Despite the inevitability of death, one is never really prepared for its occurrence. We react to death and grief differently. Understanding of death and grief were pioneered by Kubler-Ross (1969), and her research has broadened our knowledge and attitudes towards death.

# Stage VII Worry Stage VI Guilt Stage II Anger Stage III Bargaining

**Kubler-Ross' Grief Paradigm** 

### **Case Studies**

At this juncture, I would like to share three case studies on EOL decisions that I have closely observed and participated in the last three years.

**Vignette #1:** I met Mr. B in Denton, Texas in 1992 through an uncle of mine. We both found out, to our disbelief and amazement, that our village in Nigeria is only 8 miles apart. Mr. B was a gregarious Yagba man who is very proud and always excited to speak the dialect. We both maintained close relationship through the telephone, but we never saw face-to-face since we first met in 1992. His telephone call at Christmas and Thanksgiving is a regular. Often, we share our family experiences and discussed Nigerian politics.

I received a telephone call one day, in March 2009, informing me of Mr. B's sudden death. I later found out that he died of a massive myocardial infarction. He was survived by his spouse and four daughters. My wife and I travelled to Denton, TX to attend his memorial service, which was a very traumatic event for both of us. We learnt during the visit of the disagreement within the family here and in Nigeria on where he will be buried. The daughters preferred that their father be buried in the USA. The family members back home, to whom the wife is closely connected, demanded that his corpse be brought back to Nigeria.

Unfortunately, his spouse was not financially capable of coming up with the financial resources needed to transport his corpse home. Mr. B was self employed and does not have a life insurance policy or any meaningful retirement portfolio. A relative back in Nigeria came to the family's rescue and paid for the transportation of his corpse and the funeral arrangement in Nigeria. Another major hurdle that had to be crossed in transporting his corpse to Nigeria was obtaining the necessary paperwork from the Embassy in Washington. His Nigerian passport had expired and none of the children had a valid Nigerian passport. At the end, only the wife was able to travel to Nigeria for the burial. Funeral arrangement is stressful enough under "normal" situation, but the challenges that this family faced under this unusual condition is mindboggling and pathetic.

Vignette # 2: Dr. A was a friend and a fellow Yagba man. He was on the faculty at OAU and we returned to the USA about the same time in 1990. Until his passing, we maintained close relationship and a telephone call from him during the weekend is a delight and something that I always look forward to. We often spent the time talking about our experience at OAU and Nigerian politics. Dr. A enjoyed life and his laughter is characteristically unique and infectious. He often travelled to Nigeria at least once every year to visit his aging mother and brother. He was a Nigerian patriot extraordinaire with a big heart. He battled prostate cancer for 5 years and we believed it was in remission until pancreatic cancer came calling. He gallantly fought this unwelcomed enemy until he succumbed to the disease after 9 months. My wife and I were able to visit him in Savannah, Georgia where we met him in frail health. He died two days after we returned home from the visit.

Dr. A left behind a wife, two daughters, two sons and a granddaughter. On his passing, there was a stalemate within the family in deciding his final resting place. The family in Nigeria demanded that his corpse be brought back home. Obtaining the travel paperwork from Nigerian Consulate in Atlanta was a challenge because their Nigerian passport had expired. His wife and one of his daughters were able to travel to Nigeria for his burial.

**Vignette #3:** A Nigerian colleague of mine at work lost his wife after a protracted battle with breast cancer. Following radiation therapy and surgery to repair a collapsed lung, she was admitted in the hospital and kept on life-support in the intensive care unit (ICU) for over three months. In the USA, it costs between \$10,000 -\$15,000, per day for ICU treatment. Over a three-month period, the cost of her treatment is estimated at over a \$1 million. Without a health insurance policy, the family would have been saddled with huge medical bills.

Aside from cost, keeping a loved one on life-support in the ICU is a traumatic experience that is fraught with physical exertion and emotional stressors. The spouse is, a loving and caring gentleman who stood by his wife till the end. He was at her bedside day and night for the duration of his wife's hospitalization. He only comes home for a quick shower and occasional meal. My wife and I happened to be in the hospital the day she passed and we will never forget the fierce debate we had in a small hospital room, regarding the burial arrangement, particularly her final resting place. The family decided in favor of USA.

### **Case Studies' Commonalities**

There are salient threads to the three case studies that I have presented. The commonalities are:

- 1. The death of the individuals cited in the case studies was unexpected. They are relatively young (age range from 45 to 62 years).
- 2. Each left behind a spouse and children.
- 3. Each had strong family ties in the USA and Nigeria.
- 4. Unfortunately, none of the three had a *Will* that specified their EOL wishes and desires. Therefore, the decisions were left to those left behind to make.
- 5. Finance was a major factor in many of the decisions that were made by the family. There was no credible estate planning in place.
- 6. There were no specific written instructions on their burial location preference; either Nigeria or USA.

# **Planning for EOL and Associated Challenges**

<u>Selecting the Final Resting Place:</u> Selection of one's final resting place is a decision that must be openly discussed in each family. The decision is usually influenced by financial, cultural, and emotional factors. There is no right, wrong, or easy answers, just your desire. The loved ones must be fully apprised of the location of the final resting place.

A discussion about the issue is warranted; if possible it should be included in your *Will*. Individuals with strong family ties in Nigeria must have this unsettling conversation with spouse, children, family back home, and next-of-kin. At a recent vacation in Pittsburgh, over dinner, our 17 years old daughter suddenly asked where we would both like to be buried. We have on previous occasions had this important "talk" but apparently she brought it up as a gut check on her part. My wife and I both reaffirmed our wishes and desires on our final resting place.

<u>Burial or Cremation?</u> In the USA, statistics reveal a trend that a large percentage of the population is selecting cremation over burial. On the other hand, cremation is unknown, albeit a taboo, in many cultures such as Nigeria. However, there are advantages and disadvantages to both choices. A burial place or grave comes as a cultural or religious tradition with a place to return to and give comfort to the survivors. A grave is a place where a permanent memorial can

be erected; therefore, it is more expensive than cremation due to required land fees. Cremation offers more flexibility for service options as burial can take place at a later date; it saves land and the remains can be kept or scattered as desired.

<u>Funeral Costs:</u> No matter what final arrangements are chosen, there are costs involved. Specifically, the cost of the coffin/casket; in cases of burial overseas, the cost associated with land and or air transportation; and the cost associated with the services offered by the funeral home. There are several logistical hurdles, such as obtaining required travel documents and permits, to contend with if the body will be flown to Nigeria. The cost of the container or casket used for the body is determined by its type/make as well as the deceased wishes.

In the USA, the cost of caskets can range in price from \$200–\$65,000. While the cost of cremation urns can range in price from \$50-\$3,650. The cost of vaults for burial range in price from \$700–\$9,890. The funeral homes usually provide basic funeral services with varying costs. Basic funeral services range in price from \$1,000–\$1,775. Immediate burial prices usually range from \$725–\$2,635. Direct cremation prices can range from \$1,000–\$2,255. Embalming ranges in price from \$400–\$525. "Outer" burial containers include both vaults and liners. Vaults surround the casket entirely and usually range in price from \$750–\$1,100. Liners often do not surround the casket entirely and can range in price from \$285–\$525.

# **Estate Planning to the Rescue**

In general, people in the Western world engage in a lot of planning. They have plan for their schedules, careers, work projects, weddings, vacations, retirements, and disposition of estates after death. On the other hand, we Africans do less planning and often "go with the flow." Case in point, we have perfected the "African time" concept of lateness to formal ceremonies/events. It is not unusual for a Nigerian to show up 5 hours late for an event. A request for an "RSVP" to an event is often ignored. It is therefore, particularly not surprising that we put off planning for our end-of-life. Unfortunately, by not planning or sharing our ideas with those we love, others make decisions for us at the very time when we are unable to make them.

A pertinent question to ask is: who will take responsibility for my desires and wishes when I'm ill, incapacitated or when I have passed on? Is it my spouse, daughter, son or a relative? Have you ever given this question any thought? If you have not, I strongly recommend estate planning for you. Estate planning is the process of anticipating and arranging for the disposal of your assets when one dies. Estate planning typically attempts to eliminate uncertainties over the administration of your asset by maximizing its value through reduction of taxes and other expenses.

Estate planning is usually the last thing on our minds. However, we need to do it as soon as possible when we are intellectually capable. Death is unpredictable and if failing to have one's affairs in order, adds trauma on top of the tragedy and agony for the people left behind. Failure to have a plan will make managing your estate complex and emotional for those left behind.

A comprehensive estate plan will include the following:

1. A Will which is a legally binding document (See Appendix) that clearly states the distribution of your estate (properties/asset). If you have children less than 18 years, you

should specify in your *Will* who should be their guardian if you die or become incapable of making life decisions. You must name beneficiaries for your retirement plans and life insurance policies. It is essential to carefully select the beneficiaries of these assets and review them periodically to ensure they will be distributed in accordance with your wishes.

- 2. A Durable Power of Attorney for Medical Care which is the best protection against ending up spending weeks, months, or years in a vegetative state marginally being kept alive by the use of artificial life-sustaining technology. A Do Not Resuscitate (DNR) order, which instructs medical personnel, including emergency medical personnel, not to use resuscitative measures is also included. You must also appoint a designee who will make decisions about your medical care if you are unable to communicate. You can name a health care professional if you prefer a non-relative to make such decisions for you. If you fail to name a non-relative, the hospital and the courts will name a relative if there's one available. Note that the Durable Power of Attorney for Medical Care does not authorize anyone to make legal or financial decisions for you. That is done through the Durable Financial Power of Attorney.
- 3. A Durable Financial Power of Attorney is a legally binding document that you sign. It designates a trusted person to act for you if you become incapacitated. A lawyer should help you complete these documents. A Durable Financial Power of Attorney Affairs clearly identifies assets and finances of the owner. You must appoint a designee to handle your estate if you became incapacitated or die. Make sure you have a valid, up-to-date Will, or Trust documents.
- 4. Living Will, also called "Instructions," "Directive to Physicians," or "Declaration," specifies whether you want heroic measures be used to sustain your life if you become incapacitated and are in chronically degenerative medical state. These instructions generally apply to specific circumstances that may arise near the end of your life, such as prolonged unconsciousness.

These estate plan documents are affordable and will not "break the bank." The cost of a standard *Will*, put together by a lawyer, is less than \$300. Sample of a Durable Power of Attorney for Medical Care, a Durable Financial Power of Attorney and a *Living Will* can be obtained on line at: http://www.rocketlawyer.com/docLanding? docCategoryId.

## **Take Home Points**

Since we do not know when the Almighty will call any of us, you need to address the following critical EOL issues:

- 1. Your child is the most treasured commodity you have, even after you pass away. Consequently, you need to build up a credible and stable financial portfolio to support the education of your child in case you pass away unexpectedly. In addition to your employer's benefit package which traditionally includes a medical/dental insurance, retirement plan, you need to invest in a 401k supplemental retirement plan. For those in the audience who are self employed, I strongly recommend you consult a financial planner to design a financial portfolio that will meet your need.
- 2. You need to obtain a life insurance policy that includes funeral cost. This will make your burial less painful for your family.

- 3. You need to obtain a home mortgage insurance that covers your death and or that that of a spouse. Paying the monthly mortgage is a struggle for most two income families. The absence of a spouse creates an additional financial burden that can be a challenge. Inability to pay a mortgage within two months of one's passing, will lead to foreclosure of one's most precious asset. Foreclosure on your home could send your loved ones into the street or into homeless shelters.
- 4. Since the Nigerian constitution allows for "dual citizenship" you have much to gain by having a current Nigerian passport for yourself and your entire family. It is not a "status symbol" to only have an American passport. If you die and your wish is that your body be transported back home, an expired Nigeria passport will make honoring your wish a challenge.
- 5. Take video recordings and pictures of yourself and your family at special events to document your life. This will make planning your burial memorable and less painful.
- 6. Keep all your insurance information, medical, long-term care, life and special needs policies in an easily accessible place. Inform your designee where these documents are located or provide a copy to him/her.
- 7. You should write out specific instructions for your funeral preferences (burial or cremation), location of your final resting place, and how your funeral will be paid for.

### **Conclusion**

My best friend and ardent critic, my wife, has always told me to make my speech short. I have learnt over the years to listen to her wise counsel because it has served me well. I would like to end my presentation on this note with the belief that you all find something useful to take home. Before closing, I would like for each of you to take the following pledge. Audience, please stand with your right hand raised.

I, the spouse of ----- (mention the name of your spouse) do hereby solemnly pledge that I'll have the "talk" about EOL with my family and promise that I'll take the necessary steps to have in place appropriate plans that will make my "life-after" memorable for my family. So help me God.

Have a great time at the conference, find time to share your experiences at OAU and live a full and productive life!