

# Journal of Life Care Planning



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## Editor's Message

Since the last issue of the *Journal of Life Care Planning* was printed in March, there has been lots of activity underway in the life care planning community. In May, the 2017 Life Care Planning Summit was held with over 100 attendees from various disciplines and representing multiple professional organizations. This well-attended event provided a necessary and lively discussion about costing procedures in life care planning, a critical component to our practices. Jamie Gamez, one of the hard-working organizers of the event, has provided a brief synopsis of the events that occurred in Denver in May. A detailed accounting of results of these proceedings will be provided to the membership in the next issue of the *Journal of Life Care Planning*. The importance of these proceedings cannot be overstated and as you read the enclosed articles, note how many times references are made to past Summit proceedings.

Also in May, the results of the 2017 IARP elections were announced. The IALCP section board members are a combination dedicated professionals from disciplines including nursing, rehabilitation counseling, economics and occupational therapy, reflecting the richness of experience and diversity of professionalism that has made IARP a leader in rehabilitation for over 30 years. It is this diversity that provides our professional organization a brilliance that is borne, not out of a singular vision or discipline, but from a multi-disciplinary collectiveness that will continue to produce the research, textbooks, articles and conferences that propel the field of life care planning forward. It goes without saying that anyone who dedicates themselves to serving in our professional community deserves commendation, but, in my opinion, this becomes even more meaningful when coupled with the notion that most of these individuals are self-employed, meaning that their volunteer activities likely result in some degree of financial loss to them. To familiarize our readership with the newly elected board members, a brief introduction provided by each new board member is contained in this issue.

By the time our next issue is ready for press, we will be preparing for the annual IARP/ISLCP annual conference. Again, this underscores the multiple opportunities that IARP provides to both educate those interested in life care planning and for us to learn from each other about emerging practices and research. At this conference, we welcome feedback about the *Journal of Life Care Planning* and encourage you, as the reader, to thoughtfully consider how you can contribute. We will have opportunities to participate in data collection activities on-site and if independently publishing manuscript is not something of interest to you, participation in these ongoing research activities may be your best way to contribute.

In this issue, we have contributions from authors who are first-time contributors to our journal, including Dr. Stephanie Lusk, a rehabilitation professor whose research interests include substance use. She has contributed to our understanding of this issue by writing about the pharmacological effects of marijuana as well as an examination of the legalities of the substance. This article could not have been completed without the cooperation of a group of life care planners who shared their experiences of inclusion of medicinal marijuana in life care plans. While they anonymously contributed to this endeavor, they know who they are and I want each of them to know that through their collective wisdom, our readership will learn and grow professionally.

In this issue, we also have contributors including Dr. Mary Barros-Bailey, Dr. Irmo Marini and Dr. Michael Shahnasarian, who undoubtedly are recognized as experts in the field of rehabilitation. Through their decades of research and publications, they have enriched our knowledge base through their tireless efforts. A noble endeavor indeed it is to continue to contribute to our body of research with the prolific careers that each of these individuals has.

I want to take a minute to thank two individuals, without whom these last two issues would not have happened. First, Nancy Mitchell has continued to provide our readers with interesting ethical dilemmas to be pondered as well as guidance offered to us by our ethical codes. These provide not only the opportunity for us to earn necessary CEUs, but more importantly they provide us guidance of how to proceed if, in our practices, we are faced with these difficult situations. In this issue, she has again contributed the *Ethics Interface* column with opportunities for both CEUs and professional development. The second individual whom I want to thank is Dr. Melissa Wilkins. Dr. Wilkins has helped to facilitate the publications of the last two issues by engaging in both her individual research interests, as well as by endlessly helping to generate new and interesting topics for articles and finding authors who can contribute new ideas to our journal. Thank you, Melissa, for spending hours talking through various concepts and research designs with me and for your painstaking APA manual research, a task that no one, trust me no one, can claim to enjoy. We hope, through the collective efforts of all of the individuals who contributed to this issue, you both enjoy the enclosed articles and find something in the issue that benefits your life care planning practice.

- **Tanya Rutherford Owen**, Ph.D., CRC, CLCP, CDMS, LPC

In the last issue of the *Journal of Life Care Planning*, vol 15(1), in the article entitled Complexity of Surgery Pricing and Implications for Life Care Planners, the authors included the following sentence, “The American Association of Nurse Life Care Planners Nurse Life Care Planning Scope and Standards of Practice (2014) indicates that nurse life care planners ‘obtain costs for items and services in a life care plan using provider/ vendor contacts . . . and obtain costs for items and services in a life care plan using internet sources’ (p.21).” The third method, as implied by the ellipses, is “Other considerations used in determining Life Care Plan cost: Geographic location.”

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## 2017 Life Care Planning Summit Proceedings at a Glance

*Jamie N. Gamez, MA, CRC, CCM, CDMS*

On May 19th and 20th the 2017 Life Care Planning Summit was held in Denver, Colorado and was attended by 102 Life Care Planners from around the country. The Summit was sponsored by the International Association of Rehabilitation Professionals (IARP) and the Life Care Planning Section/International Academy of Life Care Planners (IALCP) and was chaired by Cloie B. Johnson, MEd and Susan Grisham, RN. The planning committee included Tracy Albee, Debra Berens, Jamie Gamez, Sherry Latham, Karen Preston, Patricia Rapson and Denise Wren. There were also numerous volunteers who contributed to the success of the Summit. Many thanks to all who made this event possible.

The first day of Summit proceedings consisted of targeted presentations and panels related to the goal of further defining "associated costs" with education and discussion of how costs are derived and appropriate ways to determine and utilize collateral sources. During the general session on May 19th, the focus was on providing a foundation of knowledge for the nominal group process which would unfold during the second day of Summit proceedings.

Presentations and panels covered the following topics:

Foundation, Venues for a Life Care Plan, Collateral Sources and Costs. Participation and discussion among Summit attendees was encouraged throughout the day. Organizational updates were also provided by the ICHCC, IARP, IALCP, FLCPR and AANLCP. Additionally, the results of the Life Care Planning Collateral Source Survey were disseminated. These detailed results will be shared in the full write-up of the 2017 Life Care Planning Summit.

The second day consisted of rotating focus groups relying on the modified nominal group technique with the goal of reaching consensus on the themes of the Summit. The threshold for acceptance of consensus statements is as follows: 1. Unanimous consensus statements are those that were agreed upon by 100% of participants. 2. Majority view statements are those that were agreed upon by 75% - 99% of participants.

The 2017 Life Care Planning Summit concluded with animated group discussion on the outcome of the nominal group process. An in-depth review of Summit proceedings and outcomes is currently in development and will be published in the next issue of the *Journal of Life Care Planning*.



## 2017 IALCP Election Results

On June 6, 2017, IARP announced the results of the 2017 IARP leadership election results. Elected to the IARP Life Care Planning (IALCP) Section Board were:

Jody Masterson, Chair Elect  
Nancy Mitchell, Board Member at Large  
Ron Smolarski, Board Member at Large  
Debbe Marcinko, Representative to the IARP Board of Directors

These members have agreed to serve our membership for a two-year term. By way of introduction or re-introduction, the elected members have shared with JLCP readers a little information about themselves.

### **Jody M. Masterson, RN, MSN, CRRN, FIALCP- Chair Elect**

Jody currently serves the IARP membership as a member of the Ethics committee. Jody graduated from Villanova University with a Bachelor's Degree in Nursing in 1977 and a Master's Degree in Nursing in 1983, and continues to work as an adjunct clinical professor of nursing at Villanova University. After a career as a staff nurse, Jody began life care planning in 1998 which she continues today. In 1999 Jody received her Certification in Rehabilitation Nursing (CRRN) and in March 2004 was awarded the Fellow Status in the International Academy of Life Care Planners (FIALCP). Jody is a member of the following professional organizations: Sigma Theta Tau International Honor Society of Nursing Alpha Nu Chapter, American Association of Rehabilitation Nurses (ARN), International Association of Rehabilitation Professionals, American Nurses Association and American Association of Nurse Life Care Planners.

### **Nancy Mitchell MA, OTR/L, CLCP, FIALCP, Board Member at Large**

Nancy is an occupational therapist with 40+ years of experience in various rehabilitation settings. Nancy holds a master's degree in gerontology with an emphasis on aging with a disability. She became a certified life care planner in 1998 and was named a Fellow International Academy of Life Care Planners in 2005. Nancy has published articles in the *Journal of Life Care Planning* and *Journal of Legal Nurse Consultants* as well as a chapter for the *Life Care Planning and Case Management Handbook*. Nancy writes the quarterly Ethics Interface article for the *Journal of Life Care Planning* and chairs the ethics committee for the column.

### **Ron Smolarski, MA, IPEC, CLCP, CEA, CRC, LPC, CCM, CVE, CRV, CDEII -Board Member at Large**

Ron earned a MA in rehabilitation counseling from Michigan State University and a BBA in Business/ Economics from Western Michigan University. Ron is a member of numerous associations, including: the International Academy of

Life Care Planners, National Association of Forensic Economists, the National Association of Disability Evaluating Professionals and the American Rehabilitation Economics Association. He is a diplomate of the American Board of Vocational Experts. He is also a diplomate of the American Board of Medical Psychotherapists, and the International Association of Rehabilitation Professionals. Ron's work is grounded in both the rehabilitation and economic concerns of people with disabilities, with over forty years of experience in the field of Rehabilitation and Economics. His articles on Life Care Planning have appeared in national journals, legal publications and the *Care Giver Educational Guide for Children with Developmental Disabilities*.

### **Debbe Marcinko, MS, CRRN, CCM, CRC, CLCP, LPC, MSCC, CNLCP**

Debbe will be continuing in her role as liaison to the IARP board. Debbe has extensive leadership experience in our community, having previously served our membership through the International Academy of Life Care Planners as an Education Committee Member (2013-2015), as the IALCP section Director at Large in 2013, Chair elect in 2014 and 2015, Chair in 2015-16 and as a member of the IARP Board of Directors in 2016. She has served as a Conference Committee Member (2011-2015) and as the conference co-chair in 2016. Debbe earned a B.S. in Nursing and a M.A. in Rehabilitation counseling from Edinboro University of Pennsylvania. Please find below a message from Debbe:

*I am honored to be elected as the IALCP Section Representative to the IARP Board. As representative to the board it is my responsibility to participate in IARP Board meetings and activities to communicate our section's goals and activities, assuring the needs of the section are heard. I have been privileged to serve on IALCP / IARP educational and conference committees, as IALCP Section Director at Large and Section Chair, and most recently Representative to the Board. These positions have increased my understanding of the needs of our section as how we fit into the global organization. I will continue to work to voice the needs and concerns of our section members and promote the professional growth and advancement of Life Care Planning. Moving forward, I would like to see an increased awareness and strengthening of the practice of Life Care Planning through ongoing research, cooperative relationships with academic institutions, educational programs and other organizations. I welcome input and discussion from our section members, and potential members, and look forward to serving as your representative.*

These members will join with, or continue to serve with the IALCP current section leadership. These individuals dedicate endless hours to serve our membership. Please be sure when you see them at conferences to say a quick thank you, for all that they do. I will use this forum to say a collective "thank you" on behalf of the entire membership.





# Cultural Experiences and International Practices of Life Care Planners: Results of an Exploratory Research Study

Mary Barros-Bailey

## Abstract

An exploratory study of the multicultural and cross-cultural experiences of life care planners identifies common themes in the areas of communication, access/use of medical or other health systems, and the role of the family. Themes specific to other areas of multicultural or international practice were also identified. Implications for practice, professional development, and future research are discussed.

**Keywords:** Culture, Multicultural, International, Diversity, Life Care Planning

## National and International Issues in Life Care Planning

For this research, culture was defined as “any unit of people in any society or region that share beliefs, lifestyles, ethnicity, or customs in common” (Barros-Bailey, 2017). Culture could be contained within national borders or extend internationally. This research sought to explore the issues of culture and international practice as well as themes for life care planners nationally and internationally.

Virtually nothing is known about how culture impacts life care planning practice, regardless of whether the plan was developed within or across national borders. In 2008, the Life Care Planning Summit considered a consensus item that stated, “... life care planners may utilize literature to become familiar with and update current knowledge on the evaluatee’s diagnosis, population, and cultural background” (Preston, Pomeranz, & Walker, 2008, p.56), but it does not appear to have been adopted (C. Johnson, personal communication, November 16, 2016). The updated *Standards of Practice for Life Care Planners* states, “The life care planner considers cultural and linguistic factors that may influence the assessment, development, and implementation of the plan” (IALCP, 2015, p.34). More recently, religious traditions and beliefs as cultural considerations for life care planners were addressed in the literature (Cosby, 2016). These general references to culture reflect the full extent of what was found (Barros-Bailey, 2017).

Life care planning practice internationally garners about the same lack of attention in the literature. Between the 2001 and 2009 *Life Care Planning Survey: Process, Methods, and Protocols* (Neulicht, et al., 2002; Neulicht, Riddick-Grisham, & Goodrich, 2010), a very subtle, but important, additional question was added to the questionnaire. In 2001, the researchers asked if the life care planner provide services at a local, regional, or national basis. By 2009, the questionnaire expanded the response options to include international services and found that over 11% of

respondents developed life care plans internationally over the preceding five years (Neulicht et al., 2010). A cursory review of case law over the last two decades also found instances of life care plans developed for international locations, such as Mexico (*Banuelos v. Secretary of the Department of Health and Human Services, 1990*; *Martinez v. P.J.’s Lumber, Inc., 2009*), Nicaragua (*Royal Caribbean Cruises, Ltd. v. Cox, 2011*), and the Philippines (*Aggarao v. Mol Ship Management Company, LTD, 2012*) to name a few.

Diversity of religion and ethnicity are but two examples of groups within the national or world population that are often considered when the topic of culture arises. With religious affiliation, the most recent data collected by the United States [U.S.] Census was in 2008. That year, the U.S. population was just over 304 million (U.S. Census, 2017c). That same year, the agency’s *American Religious Identification Survey* estimated that of the 228 million adults in the country, 76% identified themselves as Christian belonging to more than 30 denominations; 4% identified themselves as Jewish, Muslim, Buddhist, Unitarian/Universalist, Hindu, Native American, Sikh, Wiccan, Pagan, Spiritualist, or other religions; about 15% identified as having no religion; while 5% refused to answer. Even accounting for those who did not report having a religion or who refused to answer, well over 60% of the entire U.S. population are thought to ascribe to a religious belief system; and this identity plays a part in the development of a life care plan. Understanding if or what impact someone’s religious beliefs may have from the start of the evaluation to the final recommendations may impact the validity of the plan itself. Cosby (2016) cited some practical points to keep in mind when developing life care plans for individuals from various religious cultures.

Ethnicity is often the topic many people first affiliate with culture. Whether domestically or foreign born, the U.S. continues to grow ethnically more diverse with the Hispanic and Asian populations experiencing the fastest growth (U.S. Census, 2011). Between the decennial census in 2010 and to the writing of this article in the spring 2017, the population of the U.S. grew by nearly 16 million inhabitants, with a birth every 8 seconds, a death every 12 seconds, and an international migrant every 33 seconds (U. S. Census, 2017a).

Some of these migrants come to visit (called non-immigrants), and some come to stay (called immigrants). In either state of migration, diversity continues to describe the U.S. In 2016, the U. S. Department of State issued nearly

10.4 million non-immigrant visas, almost double the 5.8 million visas issued in 2009 (U. S. Department of State, 2017c). By continent and starting with the three highest country rates, the most non-immigrant visas were issued by the U.S. Department of State (2017c) to:

- Africa: South Africa, Nigeria, and Egypt
- Asia: India, China (mainland and Taiwan), and South Korea
- Europe: Russia, Poland, and Great Britain/Northern Ireland
- North America: Mexico, Jamaica, and Dominican Republic
- Oceania: Australia, New Zealand, and Tonga
- South America: Brazil, Colombia, and Argentina

On the other hand, immigrant visas to the U.S. in 2016 totaled nearly 618,000, up by 30% from a decade earlier (U. S. Department of State, 2017c). Again, by continent and the three highest country rates, in 2016 the U.S. Department of State (2017a) documented immigrants came from:

- Africa: Nigeria, Ethiopia, and Ghana
- Asia: China (mainland and Taiwan), Philippines, and India
- Europe: Ukraine, Albania, and Great Britain/Northern Ireland
- North America: Mexico, Dominican Republic, and Haiti
- Oceania: Australia, Fiji, and New Zealand
- South America: Colombia, Ecuador, and Peru

Either among the permanent or transitory population living in or migrating through the U.S., accidental events or incidences occur that could impact a single person or a cohort of individuals from any culture. With the accelerating diversity of the U.S., the probability that a life care planner will have increased multicultural or cross-cultural experiences in practice is likely. The numbers depicting the tremendous diversity of just two slices of the population (religion and ethnicity) clearly illustrate how under studied this topic is in the field of life care planning. It is time for the literature to start addressing the different facets, issues, and considerations of culture.

### **Purpose of the Study**

The purpose of the study was to answer the question: What experiences have life care planners had with culture in life care planning services? This question was designed to collect data to understand some of the broad multicultural and international experiences of life care planners to contribute to the understanding, advancement, and practice of multicultural and cross-cultural considerations in the field.

### **Methodology**

The question this research sought to examine is exploratory in nature because it seeks to study something we know little about. Exploratory research necessitates a qualitative research design (Marshall & Rossman, 2016) that empirically generates initial themes for areas of further study. Whereas quantitative data measures information with

numbers, qualitative data measures it with words. For quantitative research to be meaningful, it must rest upon empirically-based themes that typically derive from qualitative research or theories.

Therefore, in spring 2016 an online qualitative survey was developed and disseminated through a variety of online professional listservs where life care planners typically participate including the Care Planner Network, American Association of Nurse Life Care Planners, and International Association of Rehabilitation Professionals/Life Care Planning Section. The purpose of the survey was to minimize respondent burden by collecting data in a brief five-minute survey administered over four weeks specific to the desired research question.

Instrumentation disclosed and informed respondents of their voluntary participation in the anonymous survey, and included three qualitative questions:

1. Over the last three years, please estimate the number of life care plans you completed in the following categories: Multicultural [definition provided], Cross-cultural [definition provided]
2. Please describe up to three differences that you found in developing life care plans where there were multicultural or cross-cultural considerations.
3. If you performed a life care plan cross-culturally, please identify in what country(ies) and/or subculture(s) within that country.

The instrument also collected demographic data about the respondent's credentials specific to life care planning, years of experience, and primary geographical region of practice.

### **Data Analysis Procedures**

Coding of the qualitative data was the method of analysis for the responses received to the survey. Because most of the responses were short phrases or sentences, and not long narratives or paragraphs, there was no need to go beyond exploratory coding (Saldaña, 2009) to greater depths of first or second cycle coding. Themes easily emerging from the collected data and, in some themes, being repeated across the respondents.

### **Results**

A total of 26 responses were received. While in quantitative research, a power analysis is used to estimate a sample size sufficient to ensure a degree of confidence in the data, in qualitative research the metric is data saturation (Glaser & Strauss, 1967) where additional data do not contribute more themes or information to the analysis. Therefore, sample size in qualitative research bases itself not on the *quantity* of the responses, but the *quality* and depth of those responses resulting in the repetition of concepts and themes based on a constant comparison coding of the narrative. Of all responses, 22 were complete in all sections of qualitative survey and analyzed, while four terminated the survey prematurely and were discarded from the data analysis. The respondents were experienced, with the largest

group having between 11-20 years of life care planning experience (40.90%), followed by 21-30 years of experience (27.27%). New entrants into life care planning, those with fewer than 10 years of experience, represented the third largest group of respondents (18.18%), while those with the most experience, (over 31 years) represented the smallest group (13.65%).

Although the survey was disseminated to sources across multiple professions, including dissemination to life care planners outside the U.S., respondents were only U.S.-based. The largest group of respondents were from the South Atlantic and Mid-Atlantic region (n=4, 18.18% each), followed by the Midwest/West North Central, West South Central, and Mountain areas (n=3, 13.64% each). The last two areas of respondents were from the Midwest/East North Central and Pacific regions (n=2, 9.09% each). One respondent (4.54%) indicated being from an Other region rather than choosing the geographic selections on the survey (U.S., Canada, and Ireland), but did not specify from where. There were no respondents from New England, East South Central, U.S. Territories areas, or from outside the U.S.

With respect to credentials, the most common certification was that of the Certified Life Care Planner (n=13, 59.09%) held by half the respondents, followed by the Certified Nurse Life Care Planner (n=6, 27.27%). Two life care planners indicated the Certified Case Manager was their primary credential specific to life care planning (9.09%). Each of the following received a response (4.55%): CAPS, CDMS, CRRN, LNCC, and LNCPC. Totals do not add to 100% because some respondents held multiple credentials.

#### **Content Analysis of the Data**

Respondents identified developing 162 life care plans in the past three years (2013 to 2016) where the evaluatee came from a different culture than the planner's and multicultural or cross-cultural issues were a consideration during the development of the life care plan. Those who provided life care planning services internationally during that period noted these to be in the following countries: Australia, Brazil, Cambodia, Costa Rica, Cuba, England/UK, Germany, Honduras, India, Italy, Japan, Laos, Mexico, Pakistan, Peru, Russia, and South Africa. Two respondents reported developing life care plans in the Caribbean, but did not specify the countries served.

The study clustered into three thematic categories: 1) common considerations whether the case was developed nationally or cross-culturally; 2) themes more prevalent in a multicultural environment; and 3) themes more prevalent in a cross-cultural environment. The respondents seemed to identify culture mainly from ethnic and religious perspectives.

#### **Among Group Themes**

The three areas that seemed as equally widespread nationally and internationally were: communication; access/use of medical, mental health, or related care; and the role of the family. Each of these three themes reached the

level of data saturation.

#### **Communication**

More than half of the respondents identified communication issues as being the predominant multicultural consideration in life care planning. Many these respondents merely identified language differences as a barrier, while others provided greater detail as to how language affected communication and other considerations in the life care plan, (e.g., discussing bowel, bladder, or sexual issues). The more detailed responses identified language barriers affecting the evaluatee's ability to access care or the "difficulty in expressing needs to [the] healthcare provider."

#### **Access/Use of Medical, Mental Health, or Related Care**

Access to the required or recommended services outlined in a life care plan was considered a common ground theme for those performing life care plans nationally or internationally. Comments mainly clustered in areas of healthcare being different in the evaluatee's home country from what is considered mainstream in the U.S. Life care planners described evaluatees using nontraditional medications or differing "attitudes toward medicine/aggressive treatment." With therapies, one life care planner cited the "role of alternative modalities" while another noted "religious components to therapeutic modalities." Use of recommended services stipulated in the life care plan was also noted as an area of difference. Some respondents reported a lack of or unwillingness to follow through on life care plan recommendations as a concern. With respect to durable medical equipment or assistive technology, particularly if there is a stigma associated with the item, the evaluatee may not use the recommendation, or the item may not be available in the same form (or at all) in another country. How the evaluatee or the family perceives mental health or psychological services may also affect the use of those services.

#### **Role of the Family**

Family support and care of the evaluatee and input into the plan were identified about as frequently as the other two common themes relevant to multicultural and international issues in life care planning. Statements such as, "very strong family units" summarize the tone of the experiences of many life care planners. Differences in "attitudes toward family members caring for patient versus paid help" or the client having a "large family or caretakers and did not want outside help" were identified as areas of attention, while other respondents bluntly stated that the evaluatee only wanted the family to provide care. The long-term care of the evaluatee by family members as well as "geographic preferences of/for families" driving the decision-making for life care plans were areas for assessment.

#### **Within Group Differences**

Beyond the common themes among both multicultural and cross-cultural places of practice, there emerged distinctive themes within each area.

### **Multicultural Issues in Life Care Planning**

Two other areas stood out as significant in multicultural situations: Housing and Other. Each of these areas did not reach data saturation.

#### **Housing**

The “pre-injury housing arrangement” was cited by one life care planner as an important area of assessment. Other life care planners were specific to a single cultural unit making statements like, “Hispanic multi-family homes.”

#### **Other**

A variety of other single responses provided insight to a mix of themes ranging from attitudes to beliefs or affects. Sometimes the evaluatee was described as “more dependent and passive.” Other times, the level of the evaluatee’s education was posited as an area of concern. The cultural difference in the evaluatee’s expectations and coping style received mention by one life care planner; another respondent cited the “reverence for aged.” Yet, other life care planners simply provided single-word responses such as “beliefs,” “psychosocial,” or “shame.”

### **Cross-Cultural Issues in Life Care Planning**

Cross-cultural experiences of life care planners were identified in the following thematic areas: Cost Resources, Society, Legal, Providers, and Referral Source Education. Data saturation was reached only in the Cost Resources theme.

#### **Cost resource**

The main consideration for those performing life care plans internationally was the practical ability to obtain costs for the life care plan items, particularly in societies where socialized medicine covered many recommendations. Also, identified as a challenge were “differing healthcare delivery systems,” presumably presenting challenges to valuing or measuring the costs of the needed care.

#### **Society**

Overarching the international life care plan development is the understanding of community or societal priorities that may be different in a country of service than what may be the norm in the life care planner’s home country.

#### **Legal**

Within a society, attention to the “laws of the particular country/nation” was noted by a life care planner as the most prominent issue in developing a life care plan in a cross-cultural setting. Another respondent succinctly stated, “differences in the legal gestalt affecting service provision.” From a more practical standpoint, one respondent described the need to understand the legal mandates governing such practices as disclosure and informed consent, which is a common in practice in the U.S.

#### **Providers**

Research within the country of service can be challenged by the unfamiliarity of those providing care to the evaluatee as to the purpose of a life care plan. Education of these providers as to life care planning as well as providing their care recommendations within the more-probable-than-not

threshold was mentioned in the responses. Other respondents identified that the systems for delivery of care, such as therapies, were sometimes different or involved a variety of providers different from what the life care planner may be accustomed.

### **Referral source education**

Lastly, educating the referral source about the need and value of a face-to-face evaluation and home visit as is common when providing life care planning services in the U.S. country was identified as an area of challenge.

### **Discussion and Implications**

This introductory research exploring the multicultural and cross-cultural experiences of life care planners resulted in three main themes. In communication, life care planners need not only to make provisions to understand the evaluatee’s language, but also the intent of what is being communicated and its implications for the development and delivery of a valid life care plan. Training to help life care planners develop better and more effective methods of communication in a multicultural or international setting by educational or professional organizations could help increase life care planner competencies and resources in this regard.

Many respondents expressed concern about the evaluatees’ access to or use of recommended or alternate healthcare services, resources, or technology. Life care planners may need to learn how to navigate the divergence between the recommendations of the mainstream or consulting medical provider and the behaviors dictated by the evaluatee’s culture. This may determine the need for a creative approach to care to remain within the practitioner’s standard of care, to avoid harm to the evaluatee, but also respect the evaluatee’s culture and wishes.

Family was the third theme that arose consistently in both multicultural and cross-cultural life care planning areas. The predominant mention was the family’s participation in the care of the evaluatee, and often the rejection of care by a non-family member. Whether addressing attendant care, or other issues, considering the role of the family may become more significant in some cases, or in some countries. Awareness of the level of the family’s role and involvement may provide insights to the life care planner. For multicultural life care planning, other considerations identified included evaluatee housing, education, or societal attitudes.

Those recently developing life care plans cross-culturally identified by respondents as having been completed in the recent past appear to be developed in countries with very different legal, societal, and healthcare systems than exist in the U.S. Comparative literature that includes some legal and cultural differences in the development of life care plans in the U.S. and Canada has begun to appear in the literature (Phillips, 2016). Barros-Bailey (2017) recommends several competency topics that could be helpful to the life care planner, such as



understanding if the society is individualistic or collective. Whereas an evaluatee from an individualistic society may respond favorably to life care plan recommendations with a goal of promoting independence, those from a collective society may not respond in the same way. Understanding someone's level of acculturation or enculturation may also be important as it may influence how much the individual identifies with his or her dominant cultural values and the appropriateness of the life care plan recommendations or the probability the advice would be implemented. Just like in the U.S. where it is important to understand the jurisdiction where the life care plan is being developed, this recommendation is no different if the venue is in a different country. A variety of authoritative resources exist that life care planners can use to obtain essential information about a country (e.g., World Bank, U.S. Central Intelligence Agency country reports, U.S. Department of State, embassies of the foreign government). Research regarding those main sources of societal, legal, health and other country profiles could be an important area for study.

In performing services in an international arena, the life care planner may need to take on a greater role as an educator. Those providing services to be incorporated into the life care plan may not know what it is or its purpose and contents, and may need to learn of its use as a tool in someone's current and future care. Referral sources may not always understand or appreciate the importance of adhering to the same evaluation tenets and principals of life care planning across borders as would be expected in the U.S., such as a face-to-face home visits with the evaluatee in the country of ultimate residence. Lastly, life care planners reported that finding the sources for determining costs was a practical challenge when preparing a life care plan in another country. Obviously, life care plans are being regularly developed that include associated costs in the home country, and examining the resources used by those preparing the plans could benefit life care planners in the future who may be tasked with the same or similar assignment.

#### **Future Research**

Exploratory research is meant to start the discussion on a topic about which there is little known. Because the method requires a qualitative research design, the number of respondents is less of a concern than the quality of responses. In the areas that were common across both multicultural and cross-cultural life care planning practices, data saturation occurred. This was also the case in the cost areas of the international life care planning themes. Each of these themes that emerged intra- and inter-geographically merits substantially more detailed study. Greater depth in each of the themes would be best applied by the practitioner if tools, theories, or methods were offered.

Further, although a cursory review of case law revealed cross-cultural cases spanning a period of 20 years, an area for future research could be the examination of those cases as to the issues addressed by the courts, and resulting

decisions.

Valuable to the development of any life care plan are reliable and valid resources. Research projects, directed by those life care planners who regularly work with evaluatees in multicultural or cross-cultural environments, could develop a list of resources (e.g. evaluation instruments, costs). The rate of immigrant and non-immigrant mobility into the U.S. from Mexico, China, and India suggests these may be the countries to be researched first with respect to themes identified in this study.

This research was directed towards the life care planner's experience. Almost tacit in their description of those experiences was an underlying question as to the ethical dilemmas in these environments. Therefore, research about the ethical quandaries encountered by life care planners engaged in multicultural and cross-cultural practice along with resources to help the resolution of those dilemmas could enhance professional development of life care planners.

Lastly, methodological frameworks help us conceptualize a case and guide our clinical decision making. Caragonne (2016) developed the first known model for those working cross-culturally in life care planning involving nine stages. Further research on the application of her model, or the use of other new or existing content, process, or hybrid models, could engage the profession in making the issues of our experiences the stimulus for our innovation.

#### **References**

- Aggarao, Jr. v. MOL Ship Management Company, LTD., 675 F. 3d 255 (2012).
- Banuelos v. Secretary of the Department of Health and Human Services, U.S. Cl. Ct., 89-25V (1990).
- Barros-Bailey, M. (2017). Cultural considerations for life care planning. In D. Berens & R. O. Weed (Eds.), *Life care planning and case management handbook* (4th ed.). Boca Raton, FL: CRC Press. Manuscript submitted for publication.
- Caragonne, P. (2016). Life care planning in Mexico and Latin America. *Journal of Nurse Life Care Planning*, 16(3), 18-23.
- Cosby, M. F. (2016). Cultural considerations for life care planners: Religious traditions and health beliefs. *Journal of Nurse Life Care Planning*, 16(3), 13-17.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Aldine Publishing Company.
- International Academy of Life Care Planners (2015). *Standards of practice for life care planners* (3rd ed.). Glenview, IL: International Association of Rehabilitation Professionals (IARP).
- Martinez v. P.J.'s Lumber, Inc., et al., Cal. App. A120846 (2009).
- Marshall, C., & Rossman, G. B. (2016). *Designing qualitative research* (6th ed.). Thousand Oaks, CA: SAGE.
- Neulicht, A. T., Riddick-Grisham, S., & Goodrich, W. R.

- (2010). Life care planning survey 2009: Process, methods, and protocols. *Journal of Life Care Planning*, 9(4), 131-200.
- Neulicht, A. T., Riddick-Grisham, S., Hinton, L., Costantini, P. A., Thomas, R., & Goodrich, B. (2002). Life care planning survey 2009: Process, methods, and protocols. *Journal of Life Care Planning*, 1(2), 97-148.
- Phillips, K. (2016). A comparison of Canadian and U.S. life care planning. *Journal of Nurse Life Care Planning*, 16(3), 23-28.
- Preston, K., Pomeranz, J., & Walker, C. (2008). Life care planning Summit 2008 proceedings. *Journal of Life Care Planning*, 7(2), 49-60.
- Royal Caribbean Cruises, LTD v. Cox, Fla, App 2246 (2011).
- Saldaña, J. (2009). *The coding manual for qualitative researchers*. Thousand Oaks, CA: SAGE.
- U.S. Census. (2011). *2010 census show's America's diversity*. Retrieved May 7, 2017 from [https://www.census.gov/newsroom/releases/archives/2010\\_census/cb11-cn125.html](https://www.census.gov/newsroom/releases/archives/2010_census/cb11-cn125.html)
- U.S. Census. (2017a). *Population*. Retrieved May 7, 2011 from <https://www.census.gov/topics/population.html>
- U.S. Census. (2017b). *Population and housing unit estimates tables*. Retrieved May 7, 2017 from <https://www.census.gov/programs-surveys/popest/data/tables.2008.html>
- U.S. Census. (2017c). *Self-described religious identification of adult population: 1990, 2001, and 2008*. Retrieved from <https://www.census.gov/library/publications/2011/compendia/statab/131ed/population.html>
- U.S. Department of State, Bureau of Consular Affairs. (2017a). *Immigrant visas issued at foreign service posts*. Retrieved from <https://travel.state.gov/content/dam/visas/Statistics/AnnualReports/FY2016AnnualReport/FY16AnnualReport-TableXIV.pdf>
- U.S. Department of State, Bureau of Consular Affairs. (2017b). *Immigrant visas issued at foreign service posts*. Retrieved from <https://travel.state.gov/content/dam/visas/Statistics/AnnualReports/FY2016AnnualReport/FY16AnnualReport-TableIII.pdf>
- U.S. Department of State, Bureau of Consular Affairs. (2017c). *Nonimmigrant visas issued by nationality*. Retrieved from <https://travel.state.gov/content/dam/visas/Statistics/AnnualReports/FY2016AnnualReport/FY16AnnualReport-TableXVIII.pdf>

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# Eliciting Rehabilitation Recommendations During Forensic Life Care Plan Consultations

*Michael Shahnasarian, Ph.D.*

## **Abstract**

A life care plan—a product of expert analysis and a roadmap to identify lifelong rehabilitation interventions for a person with disabilities—typically requires multidisciplinary input. Through research and by consulting with treating professionals and presumably knowledgeable experts, life care planners assemble information about the person with a disability's presenting problems and appropriate recommendations for present and future care. Difficulties with the information exchange, however, can complicate and even derail a life care planner's efforts. Discussed herein are reasons these communications can go awry, and suggestions to facilitate interactions with life care plan contributors. Additionally, ethical and practice standards associated with eliciting life care plan recommendations are discussed.

## **Eliciting Rehabilitation Recommendations During Forensic Life Care Plan Consultations**

When determining recommendations beyond their qualifications to independently prescribe, life care planners rely on qualified allied professionals (i.e., contributors to a life care plan) for assistance (International Academy of Life Care Planners, 2015; Pomeranz, Yu, & Robinson, 2014; Weed, 2004). Full contributor cooperation facilitates preparation of a comprehensive life care plan capable of withstanding the scrutiny imposed by interested parties—namely, attorneys, opposing experts, economists, insurance adjusters, judges, and triers of fact; however, this collaboration is sometimes elusive. Further complicating the life care planner's task are ethical and standards of practice concerns that can make obtaining comprehensive recommendations and managing communications with contributors challenging.

A life care plan contributor is a professional with whom a life care planner consults to elicit treatment recommendations. Qualified contributors have knowledge of an individual's presenting problems, history, and recent status, and possess expertise necessary to propose and prescribe appropriate rehabilitation interventions. The knowledge necessary to provide life care plan input can be gained via reviewing pertinent records, rendering treatment, conducting an examination(s), research, and expertise achieved through professional experiences.

This article explores reasons undergirding barriers to secure contribution cooperation. Prospective contributors' reluctance—conscious and/or unconscious—to collaborate with a consultation can be complex, and insight and sensitivity to these factors can dismantle barriers that life care planners encounter. Additionally, preemptive measures a life care planner can employ to facilitate a life care planning

consultation are discussed, along with ethical and practice standards considerations.

## **Barriers to Securing Contributor Cooperation**

Major barriers that life care planners encounter during efforts to secure contributor recommendations include contributor inhibition about participating in consultations in which litigation is pending, contributors' preoccupation with other work at hand, and requirements for compensation to cooperate. These barriers are discussed in more detail below.

## **Inhibition about Participating in Litigation-Related Consultations**

A hint that litigation, with its adversarial trappings, accompanies a pending consultation can inhibit a prospective contributor from engaging in a life care planner's efforts to extract present and future treatment protocols. Related attenuating factors include lack of financial incentive to fully cooperate and a perception that risk or even liability looms.

A case's litigation status should have no effect on the treatment recommendations that a contributor specifies, and a patient's reasonable and necessary rehabilitation needs should be communicated straightforwardly. The reality, however, is that contributors' real or perceived threats to consenting to a life care planner's consultation in a litigated case can greatly affect their behaviors when approached to provide life care plan recommendations.

Merely knowing that a case is in litigation can cause a prospective contributor to run for the proverbial hills. Consenting to a consultation in this context, from the frame of reference of apprehensive contributors, portends exposure of them to unwelcome, nonproductive, and potentially adverse experiences. These experiences can range from the need to encumber expenses via hiring counsel, potentially being subpoenaed to provide unwelcome and uncompensated deposition and trial testimony (with concomitant submission to potential scrutiny associated with having one's diagnoses, treatment, and billing publicly reviewed and subject to critique), to lost practice income. Life care planning consultations with treating healthcare providers tend to be particularly unwelcome in cases involving medical malpractice, where, by extension, a prospective contributor may be implicitly linked to accusations of wrongdoing.

Frankly, considering the above, who could fault a prospective contributor's reticence to engage a life care planner's request for a consultation? Yet, juxtaposed is the contributor's conundrum that a healthcare provider's obligation is to unabashedly specify treatment that a patient is reasonably expected to require.

Full disclosure should be made when contributors

question a life care planner's involvement in a patient's litigation (International Academy of Life Care Planners, 2015). If a prospective contributor asks, for example, whether a consultation is being initiated for reasons related to litigation, or who is employing the life care planner, provide straightforward answers. Deceit for sake of obtaining the necessary information to complete a life care plan is never justified.

How a life care planner responds to inquiries of the types posed above can determine a consultation's fate. A candid, disarming explanation along the lines of the following can preserve an exchange that could implode if a prospective contributor becomes too inhibited to cooperate:

*I became involved in patient Y's case to assess future treatment she is reasonably expected to require. That is the reason for my consult with you. I reviewed your treatment notes and know from my examination of her that she remains under your care. Yes, her case is in litigation and future care needs are at issue. My role in her case is to promote efforts to settle it by determining her future rehabilitation needs and identifying the associated costs; hence, my conference with you.*

In cases where counsel representing a defendant retains a life care planner, the life care planner rarely has access to the plaintiff's treating healthcare providers. Only with consent of plaintiff's counsel, which is often prohibitive in securing, should these types of consultations occur.

When retained by defense counsel, other retained defense experts are aware that a case is in litigation and, since the same lawyer retained both experts, are typically more accessible and accommodating in providing life care plan consultations. In these instances, consultations can be further facilitated by requests that the lawyer(s) who retained the experts inform each other about their respective involvement in the case and request cooperation with expert consultations.

#### **Contributors' Lack of Priority in Providing Life Care Consultations and/or Being Too Busy**

Although obtaining comprehensive treatment recommendations is of paramount importance to a life care planner, others may not share this perspective. In fact, some find the consultation burdensome and interfering with their routine, daily business such as patient care.

Contributors' busy schedules and professional demands apart from a case at hand can challenge a life care planner's efforts to secure comprehensive recommendations. Innate in presenting a completed life care plan is the assumption that its contributors provided sufficient time and effort to fully assess the present and future needs that a life care plan's subject will require; however, this is not always the case.

Additionally, life care planners should be mindful that many healthcare professionals do not share a life care planner's perspective regarding long-term needs assessment and planning. Surgeons, for example, tend to focus on short-term issues such as discerning pending invasive treatment options and intervening to relieve a patient's current

symptoms. After an acute postoperative follow-up period, they discharge their patients and often have nominal, if any, subsequent contact with them. This near-term perspective can cause the surgeon to focus on acute care needs, lending to less expansive recommendations—including probable future needs arising, for instance, secondary to a progression of pathologies—that a life care planner should attempt to elicit.

Life care planners who encounter significant difficulty arranging consults with busy practitioners have a Plan B option: They can pursue a consultation with a member of the practitioner's staff. In many cases, physician assistants, nurse practitioners, therapists, nurses, and other medical staff members are more accessible and approachable in evaluating treatment recommendations. A life care planner can begin the process of identifying treatment needs and protocols from these individuals and, later, as the life care plan evolves, seek supplemental input and approval from the elusive contributor.

#### **Requirement to be Compensated**

Some healthcare providers require payment in advance before consenting to a consultation. The life care planner has little, if any, recourse in this situation other than to forego the consultation or request that the life care plan referral source provide the requested payment; this should be decided by the referral source. Alternately, the life care planner can absorb the cost and defer it to the referral source.

#### **Preemptive Measures to Facilitate Quality Contributor Input**

Life care planners can optimize the window of opportunity that avails during a contributor consultation by adequately preparing for the event, and then conducting it efficiently and thoroughly. Life Care Planning Consensus and Majority Statements suggest reliance on medical/ allied health professional opinions, review of evidenced-based research and practice guidelines, as well as multidisciplinary consultation (Johnson, 2015; Preston & Johnson, 2012). A life care plan's quality depends to a large part on its author's skill in eliciting recommendations, which necessitates collaborative contributor input (International Academy of Life Care Planners, 2015). A discussion on preemptive measures that a life care planner can employ to facilitate the consultation follows.

#### **Preparing for the Consultation**

Requesting and scheduling contributor appointments via the practitioner's staff facilitates establishing a professional rapport necessary to accomplish a consultation's objectives. During the scheduling call, explain your role in identifying rehabilitation needs, specify details about the reason for the consultation, and estimate its duration. This courtesy demonstrates sensitivity and consideration for the contributor's schedule, and allows the contributor to allocate sufficient time for the consultation. It also provides an opportunity for the contributor to begin focusing on the task at hand.



Many prospective contributors look askance at cold calls—contacts initiated without any forewarning or opportunity for preparation—for life care plan input. These unanticipated and sometimes unwelcome communications can cast a negative undertone, which is counterproductive to the collaborative interaction a consultation requires. Strained communications with an irritated contributor who is, deprived of an opportunity to prepare for the interaction, may result in a cursory or otherwise less than comprehensive analyses that a life care planner seeks.

While coordinating a consultation, and in deference to a prospective contributor, the life care planner should propose alternatives to traditional work hour schedules. A contributor may prefer afterhours or weekend times to a midday work interruption. This preference is most often the case among practitioners with routinized schedules and/or high-volume practices in which interruptions cause adverse scheduling repercussions, such as those maintained by many primary care physicians.

Life care planners should anticipate that a prospective contributor, when a treating healthcare professional, will require a signed client authorization form before a consultation. In some cases, sending this document before your request for a consultation can be facilitative. This, among other things, formalizes the process, forewarns the contributor about an impending interactive contact, and signals the need to prepare for a communication with an allied professional.

Unless counsel representing a plaintiff consents, life care planners retained by defense counsel should not request that plaintiffs sign authorization forms allowing permission to speak with their healthcare providers. Likewise, when serving as an expert witness who was retained by defense counsel, life care planners should refrain from independently contacting a plaintiff's treating healthcare providers unless plaintiff's counsel grants permission, which rarely occurs.

Prepare major questions you plan to ask contributors in advance. This preparation enables you to focus on pertinent, complex treatment nuances, and facilitates a perception of you as knowledgeable, professional, and respectful of the contributor's time. Ensure you have all your intended areas of inquiry formulated before initiating a consultation. Reviewing relevant literature and becoming familiar with current treatment standards and protocols specific to the disabling problem(s) in question can facilitate your efforts.

Additionally, before beginning your consult, be aware of any treatment recommendations the contributor has made in office notes, evaluation reports, deposition testimony, or other documents. This requires you to request documents of this sort from your referral source, before your consultation, and to review them thoroughly.

Preparation for a consultation should include research into technical areas related to the types of recommendations you may elicit. If, for example, consulting with a wound care specialist about future care required due to a stage-4

decubitus ulcer, a basic understanding of debridement and flap procedures will enhance your communications and enable you to pose probing questions likely to glean information necessary to fully elicit recommendations, knowledge of potential complications, and the like. Standard IV.2 of the Standards of Practice for Life Care Planners (International Academy of Life Care Planners, 2015, p. 8) states, "The life care planner must have skill and knowledge in understanding the healthcare needs addressed in a life care plan." This standard further addresses the necessity to conduct consultations to obtain information about healthcare needs that are new or unfamiliar. Consistent with this Standard, Consensus and Majority Statements derived from Life Care Planning Summits held between 2000 and 2015, suggest reliance upon evidence-based research for recommendations in life care plans (Johnson, 2015; Preston & Johnson, 2012).

### **Conducting the Consultation**

Imposing a basic structure while conversing with a contributor can greatly facilitate the synergistic information exchange that hallmarks an effective life care plan consultation (Pomeranz, Yu, & Robinson, 2014; Shahnasarian, 2015; Weed, 2004). Life care planners should approach the contributor consultation with both preconceived, evaluatee-specific questions and a mental template configured to elicit rehabilitation recommendations. The template should include areas inherent to a life care plan, such as residential options, skilled care requirements, recurrent evaluations and therapies, pharmacy needs, durable medical equipment, and prospective future procedures. A dialogue to elicit this information could proceed as follows:

*Good morning, Dr. X. I very much appreciate you taking the time to consult with me about YYY. I am preparing a treatment plan for YYY, and I wanted to include your input. When did you last examine him? Please bear with me while I ask you a few questions about going forward. Let's start with routine office visits. How often do you recommend following-up with YYY? In reviewing your last two office notes, I learned that you have been seeing YYY at quarterly intervals. Do you anticipate any change in this frequency – let's say in the next 2 to 3 years? What about treatment modalities? What do you foresee in this area? Physical therapy, for example?*

The dialogue will evolve as information about a client's treatment needs are identified and processed. Additionally, the life care planner can enrich the information exchange by asking questions about rehabilitation interventions the contributor may not have considered, and/or providing supplemental information about a patient's course, which may be unknown to the contributor. For example, during a consult with a pain management specialist about a candidate for a spinal cord stimulator, prefacing your conversation by referencing the practitioner's last treatment record and your knowledge of that history helps to establish a common denominator to proceed with questioning and obtain specific

treatment recommendations. Questions thereafter likely would include timing of a trial implant and potential permanent implant, supplemental pain management modalities, maintenance including battery changes, and contingency interventions for events ranging from the migration of device leads to failure to realize sufficient pain relief.

Contributors are apt to become annoyed with multiple follow-up queries from a life care planner, especially for reasons that include failure to initially pose seminal questions, and inefficiently or incompletely culling required information during an initial consultation. Questions perceived as trivial, common sense, or of relatively little significance in the case management of a person with a disability—for example, asking an oncology urologist about a leg bag replacement schedule for an end stage individual—can also raise this ire.

It is in the best interests of both the contributor and life care planner to accomplish consultation objectives as completely as possible during the initial contact. Complex cases, such as those involving multisystem disabling conditions with anticipated degenerative courses, may require more than one consult.

At the conclusion of a consultation, good practice dictates advising contributors that, as a professional courtesy and to ensure accurate and full understanding of specified protocols, you will provide a copy of your completed life care plan. Beyond a professional courtesy, inviting contributors to make adjustments on further review serves as a quality control measure to safeguard and often help defend

a life care plan, thereby maintaining its integrity.

For a myriad of reasons ranging from litigation-related concerns to practice operations management issues, a prospective contributor may insist that a life care planner's questions be addressed only in writing; when this happens, the life care planner should acquiesce. Assuming the input is well conceived—even though not provided ideally with opportunities to review and process it in a professional, interactive manner—the life care planner and client can benefit from every scintilla of emergent earnest input.

Figure 1 presents sample questions posed to an orthopedic surgeon. Note the specificity and level of detail the questions pursue. When reduced to communicating in writing, a life care planner is prohibited from inquiring about things such as contingencies associated with treatment outcomes and potential complications.

Interactive consultations enable a life care planner to pose follow-up questions and clarify recommendations proffered in writing. For this reason—along with the probative, collaborative, and synergistic value inherent in allied professionals' consultations—interactive life care planning communications are preferred over rote questions that are devoid of evaluatee-specific details aimed to facilitate a life care plan's customization. If the contributor's penchant, however, is to respond to written questions, the life care planner's recourse is to submit to this preference. This does not diminish the quality of the contributor's input.

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Figure 1. Sample Written Questions to Elicit Life Care Plan Recommendations.

**Re: JJJ**  
**DOB: 10/25/87**

**Questions for Dr. N for future care needs of Ms. J**

What current and future diagnostic evaluations (e.g., CT scan, X-rays, MRIs) do you recommend for Ms. J because of injuries she sustained in her February 17, 2015, motor vehicle accident? Please specify schedules of any recurrent and serial diagnostic evaluations now and over the remainder of Ms. J's life.

(Note: After each set of questions, allow sufficient space for responses, approximately 9 lines.)

What current and future treatment do you recommend for Ms. J (e.g., PT, OT, exercise program) because of injuries she sustained in her February 17, 2015, motor vehicle accident? Please specify treatment protocols including the frequency and duration of each protocol, both now and in the future.

How frequently do you believe Ms. J will require follow-up visits with you or another orthopedic surgeon because of injuries she sustained in her February 17, 2015, motor vehicle accident? Please consider present and future protocols.

Do you believe that Ms. J would benefit from consultations and/or treatment with other specialists (e.g., pain management, neuropsychologist, orthopedic surgeon) because of injuries she sustained in her February 17, 2015, motor vehicle accident? Please specify specialists, along with frequency of office visits.

Do you believe that Ms. J will most likely require ongoing prescriptions of medications because of injuries she sustained in her February 17, 2015, motor vehicle accident? Please delineate present and future prescriptions including name of medication, reason for prescription, dosage, and duration.

Are injections anticipated for Ms. J because of injuries she sustained in her February 17, 2015, motor vehicle accident? If so, please specify the type, number, and locale, along with an anticipated administration schedule – both now and in the future. Please also specify whether any injections will need to be administered in a specialized facility.

Do you have any recommendations for current and/or future durable medical equipment for Ms. J because of injuries she sustained in her February 17, 2015, motor vehicle accident? Please consider current and future needs over Ms. J lifespan, indicating when the need for different types of durable medical equipment is anticipated.

What, if any, future surgeries will be required for Ms. J because of injuries she sustained in her February 17, 2015, motor vehicle accident? Please specify the procedure(s), time frame, and postoperative care protocols.

Will Ms. J require physical therapy or other specified treatment after each projected surgery, if any, because of injuries she sustained in her February 17, 2015, motor vehicle accident? Please specify treatment protocols.

Are there any other rehabilitation recommendations that you have for Ms. J as you consider her medical future course because of injuries she sustained in her February 17, 2015, motor vehicle accident? Please specify treatment protocols including when interventions are anticipated.

### Ethical and Practice Standards Considerations

Life care planners have a duty to develop and present comprehensive, unbiased life care plans, regardless of whether defense or plaintiff counsel retained them (International Academy of Life Care Planners, 2015). The Code of Ethics for Life Care Planners, included in the *Standards of Practice for Life Care Planners*, states:

*The life care planner is expected to accurately represent any information received for a particular case. Recommendations are to have medical, rehabilitation, psychological, and case management foundations with appropriate medical specialist and treatment team collaboration when possible, with support from medical recommendations, clinical practice guidelines, and other current literature (p. 6).*

Falling short of this standard for whatever reason, including insufficient input from a contributor beyond the life care planner's control, obligates practitioners to make recommendation deficiencies known.

Diplomacy and professionalism apply in making representations about difficulties that the life care planner encountered while attempting to enlist contributor compliance. Instead of testifying, for example, "Dr. Smith did not return any of the three scheduled calls I placed," an alternative is to state:

*I had difficulty in my efforts to consult with Dr. Smith. I look forward to receiving any input she may have to offer and defer to her area of expertise for potential adjustments in the life care plan I prepared. In the interim, I applied my best effort to interpret her treatment plan from my review of her records.*

A life care planner can assemble a life care plan devoid of a contributor's direct input by referencing available indirect contributor sources—namely, available reports, office notes, and testimony. These sources can be further used to make reasonable extrapolations about ongoing recommendations based on reviews of historical consumption rates and prognoses. A person with quadriplegia, for example, who attained maximum medical improvement and continues to use assorted durable medical equipment can reasonably be expected to have similar ongoing equipment needs.

In some cases, regardless of a life care planner's best efforts, full or partial contributor cooperation is untenable. The life care planner in these instances should alert the referral source about irregularities, deficiencies, and any other anomalies that make the life care plan less than complete and final, if this is the case. Such notification will educate involved parties of the life care planner's effort to obtain cooperation and how lack of cooperation may have impacted the plan.

Life care planners who encounter difficulties with contributor cooperation should explore alternatives necessary to complete their work in compliance with practice standards. Options available include requesting the lawyer referral

source intervene by impressing on the contributor the importance of the life care plan consultation, thereby encouraging the elusive contributor to comply. If this effort fails, another option is to refer the evaluatee to another specialist with expertise akin to the noncompliant contributor for a second opinion. This individual would then become an alternate, presumably equally qualified contributor, whom the life care planner could approach to elicit relevant recommendations.

Yet another option includes enlisting assistance from the evaluatee; when retained by plaintiff's counsel, a life care planner can request this aid. In the context of an established patient/healthcare provider relationship, a request from the plaintiff/evaluatee to the treating healthcare provider/contributor to comply with a life care planning consultation sometimes provides the nudge necessary to facilitate the process.

### Summary

A life care planner's consultation with qualified contributors can greatly facilitate the process necessary to assess lifelong rehabilitation needs that a person with a disability can reasonably be expected to require. At a superficial level, the task of eliciting life care plan recommendations from contributors can appear simple and straightforward, especially when framed during adverse cross-examination.

My experience with cross-examining lawyers has included flippant barbs such as, "So, all you did was have a 10-minute chat with Dr. X, and you wrote down what he speculated the plaintiff needed – correct?" Questions of this sort are calculated on multiple levels to demean and undermine the life care planner.

The above interrogation's tenor implies the applied methodology lacked rigor and science, and does not require any expertise beyond calling a healthcare provider and acting as a scribe—tasks most laypeople and, likely, jurors in attendance could perform without any advanced training or credentialing, and without charging fees customary of those that credentialed life care planners bill. This latter innuendo aims to further impeach the life care planner as a for-hire instrument of the retaining lawyer, beholden to undeserved monetary self-gain.

Contrarily, consultations with life care plan contributors are complex and multifaceted. The life care planner's responsibility includes discretely, yet poignantly punctuating—especially when challenged—the intricacies and expertise fundamental to ensure a life care plan's integrity has been applied, along with the underlying science required to develop it.

Above all, despite the underbelly of the adversarial context in which life care plan experts are pitted against those presumably at odds with their efforts and product under development, the practitioner must at all times apply relevant practice standards. A life care planner's understanding of the

internecine dynamics operating in matters involving their work can help to preserve their credibility and contribution to the judicial process (Shahnasarian, 2001; 2009; 2015).

### References

- International Academy of Life Care Planners (2015). *Standards of practice for life care planners* (3rd ed.). Glenview, IL: International Association of Rehabilitation Professionals (IARP).
- Johnson, C.B. (2015). Consensus and Majority Statements Derived from Life Care Planning Summits Held in 2000, 2002, 2004, 2006, 2008, 2010, 2012 and 2015. *Journal of Life Care Planning*, 13(4), 35-38.
- Pomeranz, J., Yu, N., & Robinson, R. H. (2014). Introduction to life care planning. In R. Robinson (Ed.), *Foundations of forensic vocational rehabilitation* (pp. 391–399). New York, NY: Springer Publishing Company
- Preston, K. & Johnson, C. (2012). Consensus and Majority Statements Derived from Life Care Planning Summits Held in 2000, 2002, 2004, 2006, 2008, 2010, and 2012. *Journal of Life Care Planning*, 11(2), 9-14.
- Shahnasarian, M. (2001). *Assessment of earning capacity*. Tucson, AZ: Lawyers & Judges Publishing Company, Inc.
- Shahnasarian, M. (2009). The litigation process and the truth: Meditations of a forensic expert. *The Rehabilitation Professional*, 17, 207–209.
- Shahnasarian, M. (2015). *Assessment of Earning Capacity* (4th ed.). Tucson, AZ: Lawyers & Judges Publishing Company, Inc.
- Weed, R. O. (Ed.). (2004). *Life care planning and case management handbook* (2nd ed.). Boca Raton, FL: CRC Press

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# The Opioid Epidemic and Its Effect on Life Care Planning

*Melissa Jones Wilkins, Ph.D., CRC, Amanda Connell, M.S., CRC and Sandra Bullins, M.S., CRC*

## The Opioid Epidemic and Its Effect on Life Care Planning

Every day in the United States, 91 people die from an opioid overdose, either from prescription opioids or heroin (Centers for Disease Control and Prevention, 2016). The number of American deaths, as well as the amount of prescription opioids sold in the United States, have both quadrupled since 1999 (CDC, 2016). As more than 183,000 people died between 1999 to 2015 in the U.S. from overdoses related to prescription opioids, over prescribing of medication and overuse of opioids has been deemed an epidemic (CDC, 2016). This epidemic has brought attention to the need for changes to the CDC's guidelines for prescribing opioids for chronic pain, prompted states to create additional laws related to substance abuse, and has driven research to be conducted about future changes that must occur for responsible treatment of chronic pain.

This article is the first of a two-part series of articles intended to educate life care planners about changing pain management policies and practices in America. These changes have resulted in large part from the opioid epidemic in America. These changes, in turn, will affect how life care planners outline chronic pain management in their life care plans. This article will outline proposed changes in policies in the treatment of chronic pain and the second article will outline changes in chronic pain management practices. This information may be of assistance to life care planners when developing plans of care for individuals with pain or other conditions which have historically been treated with opioids.

## What is Chronic Pain

Chronic pain is defined as a persistent and unpleasant sense of discomfort that has lasted longer than twelve weeks (Arneric, Laird, Chappell, & Kennedy, 2014; Singh, 2017). According to the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), it is estimated that approximately 35% of Americans (50 million people) experience some element of chronic pain (American Pain Society [APS], 2015). Chronic pain, also referred to as chronic pain syndrome, can be one of the most difficult conditions to diagnose due to the variance in body and organ systems involved, but it differs from acute pain in the aspects of length and receptiveness to treatments (American Pain Society, 2015; Arneric, Laird, Chappell, & Kennedy, 2014; Fiore, Nelson, & Tosti, 2014; Singh, 2017).

Chronic pain is linked to a wide variety of medical conditions including but not limited to: diabetes, fibromyalgia, arthritis, migraines, orthopedic injury, and trauma (Arneric et al., 2014; APS, 2015; Fiore et al., 2014;

Singh, 2017). The effects of chronic pain reach further than just the physical manifestation experienced by the individual (Arneric et al., 2014; Fiore et al., 2014). Chronic pain affects not only the individual, but other outside factors as well including employment, relationships, and many activities of daily living (e.g. personal care needs, walking, shopping, preparing a meal) (Arneric et al., 2014; Singh, 2017).

As with any chronic illness or disability, the vast expanse of treatments and therapies have had their successes and failures (Fiore et al., 2014). In the area of chronic pain, treatments have included both pharmacological (e.g. medications) and nonpharmacological (e.g. massage, yoga, counseling, meditation, exercise and transcutaneous electrical nerve stimulation [TENS] units) (Arneric et al., 2014; Fiore et al., 2014; Singh, 2017).

## American Medical Association Standards

In the last several years, the American Medical Association (AMA) issued statements to several federal level committees within the U.S. government regarding the growing opioid epidemic (AMA, 2015a; AMA 2015b; AMA, 2016). In their letter to the House Committee on Energy and Commerce, the AMA stated there was no doubt that prescription opioid abuse/misuse had reached the level of epidemic to the United States. The AMA recognized that as it became more difficult for those addicted to opiates to obtain opiates through their usual means, many turned to heroin to satisfy their addiction (AMA, 2015). The increased rate of prescription opioid abuse is intertwined in the growing rate of heroin use, as misuse of prescription opioids has been found to be a significant risk factor for heroin use (Compton, Jones & Baldwin, 2016). They further stated that they are continuously working to create new training for physicians in opiate abuse recognition and are using several screening devices to determine a patient's addiction potential.

The American Medical Association has also discussed increasing the use of naloxone availability. Naloxone is a medication that binds to opioid receptors that can reverse or block the effects of other opioids (National Institute of Drug Abuse [NIDA], 2016). This aids in restoring normal respiration very quickly to a person whose breathing has stopped or is dangerously slow because of an overdose of opioids. It is delivered through a nasal spray or injection. Naloxone can be purchased at some pharmacies, such as CVS and Walgreens, without a prescription in the following states: Ohio, Arkansas, California, Minnesota, Mississippi, Montana, New Jersey, North Dakota, Pennsylvania, South Carolina, Tennessee, Utah, and Wisconsin (NIDA, 2016). The AMA has also discussed how to increase access to

naloxone by police, fire and EMT personnel (and even the public). There has also been discussion of the need for introducing “Good Samaritan” laws so that those administering naloxone in the event of an overdose, do not pay for their assistance as if they had committed a crime (AMA, 2015).

The American Medical Association has created a task force to promulgate the ideas of Prescription Drug Monitoring Programs with the goal of adding to physician knowledge about prescribing practices for opioids (AMA, 2015). The task force is comprised of 20+ states and some medical associations. They have developed a Providers' Clinical Support System for Opioid Therapies that contains free physician educational materials related to opioid use and misuse (AMA, 2015b).

In his letter to Thomas Frieden, the CDC director at the time, James L. Madara, the Executive Vice President and CEO of the AMA made 12 recommendations to the CDC during the commenting phase of the proposed guidelines. In the letter's closing Dr. Madara wrote:

We sincerely hope that CDC will seize the opportunity to align itself with other ongoing efforts designed to foster a balanced, public health-based approach to improving pain management practices while minimizing the diversion of controlled substances, reducing unintentional overdoses and deaths from opioid analgesics, and supporting improved access to treatment for patients with substance use disorders (AMA, 2016).

The AMA continues to write letters such as these to state government officials and federal committees and organizations such as the FDA with the fervent hope that some of their recommendations will alter the long-standing upward trend of opiate overdose deaths.

#### **State Efforts**

Between 2006 and 2012, states created 81 laws related to substance abuse for both prescription drug abuse and illegal substance use (Meara et al., 2016). By 2012, all states had at least one type of law, with Florida, Tennessee, and Vermont having the most intensive legislative activity (Meara et al., 2016). Since that time, state legislation and educational progress has continued to increase, however, many states are still lagging. A 2016 report by the National Safety Council examined state progress and categorized the states in “Making Progress”, “Lagging Behind” or “Failing” based on evaluation of efforts in six indicators: Mandatory Prescriber Education, Opioid Prescribing Guidelines, Eliminating Pill Mills, Prescription Drug Monitoring Programs (PDMPs), Increased Access to Naloxone, and Availability of Opioid Use Disorder (OUD) Treatment (National Safety Council [NSC], 2016). The three states scoring the lowest (meeting zero indicators) included Michigan, Missouri, and Nebraska. The states scoring the highest (meeting 5 of the indicators) were Kentucky, New Mexico, Tennessee, and Vermont. However, by 2016, there were no states that had met all six

indicators (NSC, 2016).

As of April 2017, there are more than 750 newly filed bills and resolutions for state legislation of prescription drugs (National Conference of State Legislation, 2017). In 2017, 70 bills have been enacted in 24 states (NCSL, 2017). The states that have enacted the most bills so far in 2017 include Virginia (16), Arkansas (6), Utah (5), Arizona (4), District of Columbia (4), Montana (4), and West Virginia (4) (NCSL, 2017).

#### **Future Changes to Chronic Pain Treatment Education and Standardized Instruction**

One of the most common areas where change is necessary is in the education and training of medical students, residents, and even prescribing physicians who work in clinic or emergency room settings (Khidir & Weiner, 2016). Currently, medical students and residents do not get a uniform education on evidence-based practices of assessing a patient's drug-seeking behavior or evaluating if the individual is a good candidate for opioid treatment. Having standardized instruction in all teaching hospitals and training sites for doctors would be beneficial to improve clinician knowledge of how to effectively manage patient's pain, change prescribing practices that may reduce the over prescribing of opioid medication, and ultimately benefit patient health (Karon, 2017; Pearson, Eldrige, Moeschler, & Hooten, 2016; Rosenblum, Marsch, Joseph & Portenoy, 2008).

Information campaigns that target clinics in areas with higher incidences of opioid overdose and/or deaths have been shown to be effective in reducing the number of deaths from overdose (Hawk, Vaca & D'Onofrio, 2015; Kattan et al., 2016). Kattan et al. (2016) surveyed 1,069 health care providers following a 2-month campaign in New York City about opioid analgesic prescribing. They also compared prescribing data from the 3-month period before the campaign with two sequential three-month periods following the campaign. The information campaign focused on three ideas: (1) that acute pain patients be given enough opioid pain medication for only three days, (2) professionals were to refrain from prescribing opioid medications to patients with chronic pain not associated with cancer and (3) professionals stop prescribing high dosages of opioids (Kattan et al., 2016). The researchers found that after this type of campaign, the overall prescribing rate decreased (Kattan et al., 2016).

#### **New Medications**

Because of the continued high rates of abuse of prescription opioids, the United States Food and Drug Administration (FDA) considers the development of abuse-deterrent opioids to be a priority. This has led to the development of seven new drugs that have met the FDA's new criteria for abuse-deterency, with each of them being extended-release formularies (Pezalla et al., 2017). One in particular, Oxycodone DETERx®, is the first extended-



release (ER) opioid that makes it possible for the medication to be crushed or chewed. It can also be administered in several ways, including through feeding tubes and sprinkled on food. This separates it from all other current ER opioids and makes it less likely to be abused, because the slower release of medication is maintained, even when the medication chewed or crushed. This takes away the more rapid drug high that abusers are able to get from current oral ER opioids due to their large opioid load.

### Screening Tools

To help mitigate the high rates of opioid abuse, the Food and Drug Administration (FDA) now requires a comprehensive screening and documentation of assessment. Appropriate screening tools are now being used as part of the comprehensive screening. One such screening tool is the Opioid Abuse Risk Screener (OARS). The OARS is comprised of 43 items and is self-administered using an iPad or other tablet (InteraSolutions, 2015). It takes an estimated 15 minutes to complete and then an immediate summary report is sent to the physician. It is recommended that this be completed before the patient meets with the practitioner to allow practitioners to assess the risk of abuse prior to consulting with the patient (Henrie-Barrus, Averill, Sudweeks, Averill, & Mota, 2016; InteraSolutions, 2015). Along with the OARS, other assessment tools can be utilized by practitioners and patients to screen for substance abuse. The National Institute on Drug Abuse provides a chart of evidence-based screening tools with directions on what type of substance each screening tool should be used for, the appropriate patient age, and how the tool is administered.

### Conclusion/ Implications for Life Care Planners

As life care planners are frequently called upon to address issues of chronic pain, it is important to be knowledgeable of recent research about pain practices, outcomes of chronic pain treatment, as well as the current best practices (Stewart, Jakubowicz, Beard, Cyphers, & Turner, 2016). It is also important for life care planners to be able to differentiate between patients that are abusing opioid medication and those taking it safely as prescribed for pain management. Life care planners can help ensure the safety of clients by ensuring that appropriate recommendations for pain management programs are included in the life care plan. Such a program would be broad-based with pharmacologic approaches including anti-inflammatories, muscle relaxants, antidepressants, and/or neuroleptics combined with the use of topical compounded creams, supplements, and modalities including physical therapies and/or electrical stimulation. The goal such a program is to effectively manage pain and when used in combination, these medications and therapies should also reduce reliance upon opioids. Based upon information above, an additional item to be considered by the life care planner is medication such as Narcan, to be used in the event of an overdose. This would also necessitate inclusion of

family or caregiver education about how to administer this medication.

As mandated in the Consensus and Majority Statements Derived from Life Care Planning Summits, a “review of evidence-based research, review of clinical practice guidelines, medical records, medical and multidisciplinary consultation, and evaluation/assessment of evaluatee/family are recognized as best practice sources that provide foundation in Life Care Plans” (Johnson, 2015, p.37). In addition to being best practices in life care planning, having a working knowledge of the recent state laws and AMA standards will also allow for better communication between life care planners and physicians involved in life care plan development. This knowledge will enable the life care planner to fully understand the context of pain management treatment and properly communicate about the items necessary to effectively manage a pain condition. The second of this two-part article series will address additional changes in pain management techniques with accompanying recommendations for life care planners.

### References

- American Medical Association (2016). Letter Re: Docket No. CDC-2015-0112; *Proposed Guideline for Prescribing Opioids for Chronic Pain*. Retrieved from: <http://www.painmed.org/files/ama-letter-to-cdc-proposed-2016-guidelines-for-prescribing.pdf>
- American Medical Association (2015a). Statement of the American Medical Association to the Committee on Energy & Commerce Subcommittee on Oversight and Investigations United States House of Representatives Re: “*Combating the opioid abuse epidemic: Professional and academic perspectives*”. Retrieved from: <http://docs.house.gov/meetings/IF/IF02/20150423/103367/HHRG-114-IF02-Wstate-HarrisP-20150423.pdf>
- American Medical Association (2015b). *Task force to reduce opioid abuse*. Retrieved from: <https://www.ama-assn.org/delivering-care/task-force-reduce-opioid-abuse>
- American Pain Society. (2015). *NIH study shows prevalence of chronic or severe pain in U.S. adults*. Retrieved from <http://americanpainsociety.org/about-us/press-room/nih-study-shows-prevalence-of-chronic-or-severe-pain-in-u-s-adults>
- Arneric, S. P., Laird, J. M. A., Chappell, A. S., & Kennedy, J. D. (2014). Tailoring chronic pain treatments for the elderly: Are we prepared for the challenge? *Drug Discovery Today*, 19(1), 8. Doi: 10.1016/j.drudis.2013.08.017
- Centers for Disease Control and Prevention. (2016). Wide-ranging online data for epidemiologic research (WONDER). Atlanta, GA: CDC, *National Center for Health Statistics*. Retrieved from <http://wonder.cdc.gov>.
- Compton, W.M., Jones, C.M., & Baldwin, G.T. (2016). Relationship between nonmedical prescription-opioid use

- and heroin use. *The New England Journal of Medicine*, 374, 154–63.
- Fiore, R., Nelson, R., & Tosti, E. (2014). The use of yoga, meditation, mantram, and mindfulness to enhance coping in veterans with PTSD. *Therapeutic Recreation Journal*, 48(4), 337-340 4p.
- Governor's Cabinet Opiate Action Team (2016). *Expanding Ohio's opioid prescribing guidelines*. Retrieved from: <http://mha.ohio.gov/Portals/0/Acute%20Prescribe%20Guidelines%20FINAL%20PRINT.pdf>
- Gufin, J. (2016). Oxycodone DETERx®: A novel abuse-deterrent, extended-release analgesic option for the treatment of patients with chronic pain. *Pain and Therapy*, 5, 171-186. doi:10.1007/s40122-016-0062-1
- Hawk, K. F., Vaca, F. E., & D'Onofrio, G. (2015). Reducing Fatal Opioid Overdose: Prevention, Treatment and Harm Reduction Strategies. *The Yale Journal of Biology and Medicine*, 88(3), 235-245.
- Henrie-Barrus, P., Averill, L. A., Sudweeks, R. R., Averill, C. L., & Mota, N. (2016). Development and preliminary validation of the Opioid Abuse Risk Screener. *Health Psychology Open*, 1-12. doi:10.1177/2055102916648995
- InteraSolutions. (2015). Opioid abuse & risk screener (OARS). *InteraSolutions*. Retrieved from <http://interasolutions.com/opioid-abuse-risk-screener-oars/>
- Johnson, C. (2015). Consensus and majority statements derived from Life Care Planning Summits held in 2000, 2002, 2004, 2006, 2008, 2010, 2012 and 2015. *Journal of Life Care Planning*, 13(4), 35-38.
- Jones, C. M., Campopiano, M., Baldwin, G., & McCance-Katz, E. (2015). National and state treatment need and capacity for opioid agonist medication-assisted treatment. *American Journal of Public Health*, 105(8), e55-e63. doi:10.2105/AJPH.2015.302664
- Karon, A. (2017). Medical schools respond to the opioid epidemic. *ACP Internist*. Retrieved from <https://acpinternist.org/archives/2017/01/opioids-medical-education.htm>.
- Kattan, J. A., Tuazon, E., Dowell, D., Vo, L., Starrels, J. L., Jones, C. M., & Kunins, H. V. (2016). Public health detailing—a successful strategy to promote judicious opioid analgesic prescribing. *American Journal of Public Health*, 106(8), 1430-1438. doi:10.2105/AJPH.2016.303274
- Khidir, H. & Weiner, S. G. (2016). A call for better opioid prescribing training and education. *Western Journal of Emergency Medicine*, 17(6), 686-689. doi:10.5811/westjem.2016.8.31204
- Lim, J. K., Bratberg, J. P., Davis, C. S., Green, T. C., & Walley, A. Y. (2016). Prescribe to prevent: Overdose prevention and naloxone rescue kits for prescribers and pharmacists. *Journal of Addiction Medicine*, 10(5), 300-308. doi:10.1097/ADM.0000000000000223
- Meara, E., Horwitz, J., Powell, W., McClelland, L., Zhou, W., O'Malley, A., & Morden, N. (2016). State legal restrictions and prescription-opioid use among disabled adults. *New England Journal of Medicine*, 375(1), 44-53. doi: 10.1056/NEJMs1514387
- National Conference of State Legislation. (2017). Prescription drug state database. *National Conference of State Legislation*. Retrieved from <http://www.ncsl.org/research/health/prescription-drug-statenet-database.aspx>
- National Institute of Drug Abuse. (2016). Chart of evidence-based screening tools for adults and adolescents. *National Institute of Drug Abuse*. Retrieved from <https://www.drugabuse.gov/nidamed-medical-health-professionals/tool-resources-your-practice/screening-assessment-drug-testing-resources/chart-evidence-based-screening-tools-adults>
- National Institute of Drug Abuse. (2016). Opioid overdose reversal with naloxone. *National Institute of Drug Abuse*. Retrieved from <https://www.drugabuse.gov/related-topics/opioid-overdose-reversal-naloxone-narcan-evzio>.
- National Safety Council. (2019) Prescription nation 2016. *National Safety Council*. Retrieved from <http://www.nsc.org/RxDrugOverdoseDocuments/Prescription-Nation-2016-American-Drug-Epidemic.pdf>
- Pearson, A. C., Eldridge, J. S., Moeschler, S. M., & Hooten, W. M. (2016). Opioids for chronic pain: a knowledge assessment of nonpain specialty providers. *Journal of Pain Research*, 9, 129.
- Pezalla, E. J., Rosen, D., Erensen, J. G., Haddox, J. D., & Mayne, T. J. (2017). Secular trends in opioid prescribing in the USA. *Journal of Pain Research*, 10, 383-387. <http://dx.doi.org/10.2147/JPR.S129553>
- Rosenblum, A., Marsch, L. A., Joseph, H., & Portenoy, R. K. (2008). Opioids and the treatment of chronic pain: controversies, current status, and future directions. *Experimental and Clinical Psychopharmacology*, 16(5), 405.
- Singh, M. (2017) Chronic pain syndrome: Practice essentials, etiology, patient education. Retrieved from <http://emedicine.medscape.com/article/310834-overview>
- Stewart, D.E, Jakubowicz, B., Beard, K., Cyphers, G., & Turner, D.V. (2016). Revisiting chronic pain in the life care plan. *Journal of Life Care Planning*, 14(2), 39-45.
- Traynor, K. (2014). Rhode Island's opioid epidemic response features collaborative practice model. *American Journal of Health-System Pharmacy*, 71(16), 1328-1332. <https://doi.org/10.2146/news140057>
- Traynor, K. (2016). Thoughtful pain management looks beyond opioids, CDC says. *American Journal of Health-Systems Pharmacy*, 73(9), e116-e117. Retrieved from: <https://doi.org/10.2146/news160027>
- Traynor, K. (2016). Opioid control law in Vermont addresses provider status for pharmacists. *American Journal of Health-System Pharmacy* 73(12), 1024-1026. <https://doi.org/10.2146news160044>
- Traynor, K. (2016). Maine enacts statewide limits on opioid prescribing. *American Journal of Health-System*

Pharmacy 73(10), 854-856.  
<https://doi.org/10.2146/news160038>

U. S. Department of Health and Human Services Centers for Disease Control (2016). Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report: CDC guidelines for prescribing opioids for chronic pain-United States, 2016. Retrieved from: <https://www.cdc.gov/media/modules/dpk/2016/dpk-pod/rr6501e1er-ebook.pdf>

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# The Inclusion of Cannabinoids and Medicinal Marijuana as a Treatment Option for Individuals with Disabilities in Life Care Plans

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## Abstract

With the growth in popularity of marijuana as a legitimate form of treatment in the United States, the inclusion of it as a viable treatment option for individuals with a number of disabilities and chronic illnesses has become evident to life care planners. The utilization of marijuana and its related products, unlike other medical services and medication, is complicated by the conflicting ideals outlined in state and federal legislation as well as the variations among the laws in each individual state. The use of these products, coupled with having to navigate the guidelines governing their use, can create challenging situations through which care planners and their clients must transverse. To obtain information about how life care planners in the United States are incorporating these products in their current plans, interviews were conducted with four life care planners in states where marijuana is legal in some form. This article will explore how life care planners are addressing the needs of their clients by including marijuana in life care plans when appropriate; it will also include a basic overview of the pharmacological properties of marijuana and provide a brief summary of disorders commonly by treated by medicinal marijuana and included in state medicinal marijuana laws.

## The Inclusion of Cannabinoids and Medicinal Marijuana as a Treatment Option for Individuals with Disabilities in Life Care Plans

Over the last 15 years, the American economy has seen the growth of legal sales of marijuana and its related products. As of 2017, largely as a result of consumer demands, medicinal marijuana has been made legal in 29 states and the District of Columbia (ProCon.org, 2017). These states include Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Hawaii, Illinois, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oregon, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia. Sixteen additional states have cannabidiol-specific (CBD) marijuana laws (Norml, 2017) including Alabama, Florida, Georgia, Indiana, Iowa, Kentucky, Mississippi, Missouri, North Carolina, Oklahoma, South Carolina, Tennessee, Utah, Wisconsin, and Wyoming. Several states have laws which permit the recreational use of marijuana (i.e., Alaska, California, Nevada, Colorado, Maine,

Massachusetts, Oregon, and Washington).

Life Care Planners are responsible for preparing a concise plan for current and future medical and rehabilitation goods and services for individuals with disabilities along with the associated costs for these items. Life care planners work with individuals with various disabilities and are charged with understanding not only the symptoms of the disabilities but also the treatment protocols for the disabilities, which are typically evolving as a result of medical research and changing policies. Life care planning Standards of Practice note that in their practice, life care planners rely on “state-of-the-art knowledge and resources” (International Academy of Life Care Planners, 2015, p.34). One treatment option that is considered novel and emerging is medical marijuana. For life care planners to make an informed recommendation for the inclusion of medicinal marijuana and its related products in a life care plan, an understanding of the basic pharmacology of the plant’s active ingredients should be obtained as well as an understanding of its impact on the brain and body.

## The Pharmacology of Marijuana

Cannabis, the species to which marijuana belongs, contains more than 400 chemicals and approximately 60 of these chemicals are cannabinoids. Marijuana is defined as dried cannabis flowers, and its primary cannabinoid is  $\Delta^9$ -tetrahydrocannabinol (THC) (Appendino, Chianese, & Tagliatela-Scafati, 2011), which was isolated in 1964 by Raphael Mechoulam. This discovery led to a better understanding of marijuana’s psychoactive and medicinal properties. While THC is the cannabinoid that produces marijuana’s desired psychoactive effects, very little is present in its natural state. The precursor to THC,  $\Delta^9$ -tetrahydrocannabinolic acid (THCA), which has no psychoactive active properties and is found in fresh plants, is converted into THC via a decarboxylation process. When heated, THCA releases a carboxyl group and carbon dioxide thus converting THCA into psychotropically active THC (Dussy, Hamberg, Luginbühl, Schwerzmann, & Briellmann, 2005). As such, marijuana must be exposed to heat via smoking, vaporizing, cooking, etc. to create THC (Baker, Taylor, & Gough, 2011; Eichler et al., 2012; Hazekamp et al., 2006). THC is easily decomposed when exposed to air, heat, or light; therefore, storage in “amber silicate glassware” prevents or slows down this process (Sharma, Murthy, & Bharath, 2012, p. 150). Once THCA is converted to THC, it



is then metabolized, or broken down, by enzymes in the liver producing two primary metabolites, 11-hydroxy- $\Delta^9$ -carboxytetrahydrocannabinol (11-OH-THC) and 11-nor-9-carboxy- $\Delta^9$ -tetrahydrocannabinol (THCCOOH) (Sharma, Murthy, & Bharath, 2012). THC is stored in the fatty tissues of the body and its metabolites can be re-released into the body for days or even weeks depending upon the amount and the length of time used (Sharma, Murthy, & Bharath, 2012).

A second cannabinoid noted for its special properties is cannabidiol (CBD). Like THC, CBD is produced via a decarboxylation process when cannabidiolic acid (CBDA) is converted to CBD utilizing heat. Once metabolized by the liver, several metabolites are formed with 7-hydroxy-CBD and CBD-7-oic acid being the most prominent (Hanus, Tchilibon, Ponde, Breuer, Fride, & Mechoulam, 2005). While CBD is not psychoactive like THC, it boasts numerous pharmacological benefits.

### Cannabinoid Receptors

The brain and body are able to respond to the psychoactive and/or medicinal properties of THC and CBD by means of receptors. Receptors are sites on cells that help to send signals throughout the body using chemical messengers such as neurotransmitters (e.g., dopamine and serotonin) (Heiss & Herholz, 2017; National Institute on Drug Abuse [NIDA], 2012). The characteristic effects of THC and CBD result because their chemical structure is similar to that of endogenous neurotransmitters (NIDA, 2017a), which are naturally occurring chemicals in the body. Seven endogenous cannabinoid neurotransmitters have been identified, with anandamide, which is a Sanskrit word meaning “extreme delight,” being the most common. THC and CBD act through two main cannabinoid receptors, CB1 and CB2. CB1 receptors are located mostly throughout the central nervous system (brain and spinal cord) and are primarily concentrated in areas of the brain associated with movement coordination, memory, and cognition (Herkenham et al., 1990). CB1 receptors are targets when treating conditions that impact movement such as Parkinson’s disease, Huntington’s disease, Wilson’s disease (dystonia), and Tourette Syndrome (Kluger, Triolo, Jones, & Jankovic, 2015; Moghaddam, Khodayar, Abarghouei, & Ardestani, 2010). CB2 receptors are found primarily in immune cells (Ameri, 1999; Cabral & Griffin-Thomas, 2009; Pertwee, 2008). CB2 receptors have been identified as the target for medications, including medicinal marijuana, that treat conditions where chronic pain and/or inflammation (e.g., cancer, rheumatoid arthritis, atherosclerosis) are the primary symptoms or for neurodegenerative conditions (e.g., multiple sclerosis, Lou Gehrig’s disease, Huntington’s disease) (Dhopeshwarkar & Mackie, 2014; Ehrhart et al., 2005). Issues associated with movement and chronic pain are primary symptoms of numerous conditions; therefore, determining the appropriate use of THC and CBD so that both CB1 and CB2 receptors are engaged is best. This can be

accomplished through the use of specific cannabis species or through the production of cannabis hybrids.

### Cannabis Species and Hybrids

There are three species of cannabis: *Cannabis sativa* L., *Cannabis indica*, and *Cannabis ruderalis*. *Cannabis sativa*, which grows as long narrow leaves on plants that average 5 to 13 feet high, has higher levels of THC (NIDA, 2017b). Psychological and physiological characteristic effects of *C. sativa* include “euphoria, analgesia, sedation, memory and cognitive impairment, appetite stimulation, and anti-emesis” (El-Alfy et al., 2010, p. 434). *C. sativa* is generally preferred for the enhancement of euphoria and energy (Pearce, Mitsouras, & Irizarry, 2014). Broad, deep green leaves are characteristic of *Cannabis indica*, which tends to have lower levels of THC but higher levels of cannabidiol (CBD) (Alghamin & Almirall, 2003; Amar, 2006; Medical Genomics, 2014). *C. indica*’s psychological and physiological effects include reduced pain, sedation, and sleep (Pearce, Mitsouras, & Irizarry, 2014). *Cannabis ruderalis*, also known as “weedy hemp,” produces varied sized leaves and possess few desired properties making it less likely to be utilized for recreational or medicinal purposes. Cannabis hybrids, which result from cross-pollination of any of the three species, allow growers to produce plants that have varying amounts of both THC or CBD, which can be used to treat a number of conditions. It is important to note that cannabis is the species; it is how the plant is classified and distinguished from other living organisms. When discussing its medicinal properties, however, the term medicinal marijuana is used as opposed to cannabis.

### Cannabinoids and Medicinal Marijuana

The primary active compound, THC, and CBD are the two cannabinoids that have undergone the most extensive research trials and have the most promising associated treatment outcomes. The therapeutic effects of marijuana vary depending upon the strain and the different concentrations of THC and CBD. Dronabinol (Marinol®) and nabilone (Cesamet®), synthetic replicas of THC, are the only two cannabinoid-containing medications approved by the US Food and Drug Administration (FDA), and both are considered controlled substances. Both of these medications are used as an antiemetic to treat nausea and vomiting associated with cancer treatment; dronabinol is also used to treat wasting illness, which is characterized by decreased appetite and excessive weight loss among individuals with HIV/AIDS (Hill, 2015). Dronabinol (a light-yellow oil administered in 2.5 mg, 5 mg, or 10 mg soft gelatin capsules) has an onset of action of 0.5-1 hour, and its effects last upwards to 4-6 hours (FDA, 2004; May & Glode, 2016). Nabilone is an off-white crystalline powder administered in 1 mg capsules, has an onset of action of 1 to 1.5 hours, and the duration of action lasts anywhere from 8 to 12 hours (Ware, Daeninck, and Maida, 2008). Other forms of treatment

utilizing THC are not considered cannabinoids, but fall under the category of “medicinal marijuana”.

Marijuana is considered a Schedule I drug by the Food and Drug Administration (FDA) indicating that it has no accepted medical use and has a high potential for abuse and dependence. As such, marijuana cannot be prescribed, but can only be recommended or certified by a physician to treat disorders outlined by state laws. It is also important to note that because marijuana is deemed illegal, it cannot be purchased at a federally regulated pharmacy; as such, it is generally bought and sold at state-regulated dispensaries or cultivated in personal residences as allowed by law.

While there are obvious medicinal benefits associated with its use, the various ways in which marijuana can be ingested is considered a bonus as well in that it increases the likelihood of identifying a dosing mechanism that optimizes the alleviation of symptoms. Most medications come in only one dosage form (e.g., the cannabinoids dronabinol and nabilone in capsule form); however, medicinal marijuana can be consumed through various mediums including smoking, ingesting edibles (e.g., brownies, candy, tea), consuming concentrates (e.g., wax, oil, shatter), dabbing (concentrates heated, vaporized, and inhaled), and via CBD oils (Stockburger, 2016). It is noted that the effects of smoking or vaping marijuana are different from that of consuming edibles or concentrates. These forms of ingestion have been identified as effective ways to administer THC and/or CBD for a number of chronic illnesses and disorders including, but not limited to neurodegenerative conditions, neuromuscular conditions, autoimmune disorders, chronic pain, and psychiatric disabilities.

**Neurodegenerative conditions.** “Neurodegenerative diseases represent a large group of neurological disorders with heterogeneous clinical and pathological expressions affecting specific...neurons; they arise for unknown reasons and progress in a relentless manner” (Przedbroski, Vila, & Jackson-Lewis, 2003, p. 3). These disorders are characterized by loss of nervous system functioning because of neuronal (nerve cell) death in the brain, they are irreversible, incurable, and debilitating, and they cause problems with movement and cognitive functioning. Medicinal marijuana is noted to have neuroprotective and antioxidant factors that help to slow down the progression of these disorders by preventing the release of enzymes that might destroy neurons (Rossi, Bernardi, & Centonze, 2010). Individuals with Alzheimer’s disease have shown improvement in overall symptomology when using marijuana. The primary active ingredient, THC, blocks the production of enzymes that destroy key areas of the brain (Eubanks et al., 2006). Eubanks et al. (2006) found that THC was superior in the treatment of Alzheimer’s disease symptoms when compared to other currently approved medications. Studies utilizing THC as a form of treatment for those with Parkinson’s disease demonstrated an increase in neuronal protective effects of THC (Carroll, Zeissler, Hanemann, & Zajick, 2012; Garcia-Arencibia et al.,

2007). Other studies on neurodegenerative conditions demonstrate similar effects: amyotrophic lateral sclerosis (Lou Gherig’s disease) (Rossi, Bernardi, & Centonze, 2010; Shoemaker, Seely, Reed, Crow, & Prather, 2006); multiple sclerosis (Pryce, Riddal, Selwood, Giovannoni, & Baker, 2015; Rossi, Bernardi, & Centonze, 2010), and glaucoma (Carins, Baldrige, & Kelly, 2016; Tomida, Pertwee, & Azuara-Blanco, 2004).

**Neuromuscular disorders.** The term neuromuscular disorder is a wide encompassing term used to describe conditions that impair muscle functioning. These disorders are characterized by a weakening and eventual disintegration of the muscle. While neurodegenerative disorders affect nerve cells in the brain, neuromuscular disorders impact the nerve cells leading to muscles within the periphery of the body such as the arms and legs. As with neurodegenerative disorders, medicinal marijuana has the potential to slow the progression of damage to these cells and alleviate many of the associated symptoms. Muscular dystrophy is a genetic disorder that results in the progressive degenerative of nerves leading to the muscles; it is commonly characterized by pain and fatigue. Medicinal marijuana has been shown to reduce muscle spasms and significantly improve pain and discomfort when compared to other forms of treatment (Baker et al., 2000; Woodhams, Sagar, Burston, & Chapman, 2015).

**Autoimmune disorders.** The immune system, where the majority of CB2 receptors are located, is responsible for defending and protecting the body against foreign substances. When an unknown antigen (e.g., bacteria, virus) enters the body, the immune system forms antibodies that attack and destroy it. As such, the antigen-antibody reaction is the basis of the immunity (Falvo, 2014). In autoimmune disorders, the body recognizes itself as foreign, and an antigen, and responds by synthesizing antibodies for attack. Studies conducted utilizing medicinal marijuana for autoimmune conditions have demonstrated positive effects such as: decrease in inflammation and osteoclastogenesis in patients with rheumatoid arthritis (Fukuda et al., 2014; Gui, Tong, Qu, Mao, & Dai, 2015); significant reduction of pain and stiffness and increased relaxation, somnolence, and feelings of well-being among individuals with fibromyalgia (Fiz, Durán, Capellà, Carbonell, & Farré, 2011); and improved clinical benefits (e.g., reduction in abdominal pain, cramping, and diarrhea) among those with Crohn’s disease and irritable bowel syndrome (Schicho & Storr, 2014).

**Chronic pain conditions.** According to the National Institute of Health (2011) chronic pain is defined as any pain lasting 12 weeks or more, oftentimes persisting for months or longer. Medicinal marijuana has proven effective in alleviating the symptoms associated with chronic pain and neuropathic pain. Aggarwal et al. (2009) report that individuals with chronic pain conditions such as myofascial pain syndrome, neuropathic pain, discogenic back pain, osteoarthritis, diabetic neuropathy, central pain syndrome, phantom pain, spinal cord injury, fibromyalgia, rheumatoid

arthritis, HIV neuropathy, visceral pain and malignant pain all experienced significant pain alleviation when using medicinal marijuana.

Cancer is a condition that causes numerous complications and the side effects from medications used to treat this disorder can result in additional problems. Pain is a common characteristic of cancer as well as nausea, vomiting, and decreased appetite. Cannabis sativa, which has high rates of THC, has proven effective in decreasing the nausea and vomiting associated with treatment, and it has been shown to produce proteins that kill the cancer cells (Machado Rocha, Stéfano, de Cássia Háiek, Rosa Oliveira, & da Silveira, 2008; Prowles et al., 2005). CBD, which is more prevalent in *Cannabis indica*, inhibits tumor growth (Ramer et al., 2012; Russo & Guy, 2006).

**Psychiatric disabilities.** Numerous studies note the positive effects of marijuana on psychiatric disorders such as a reduction in post-traumatic stress disorder (PTSD) symptom severity and nightmares and an improvement in sleep quality (Greer, Grob, & Halberstadt, 2014; Roitman, Mechoulam, Cooper-Kazaz, & Shalev, 2014). Other studies note a decrease in anxiety and depression symptoms (Walsh et al., 2013). Dronabinol, synthetic THC, was found effective in significantly increasing weight gain among participants with anorexia (Andries, Frystyk, Flyuvjerg, & Støving, 2013). Other studies related to other conditions that impact appetite noted marked increases in weight gain among those with wasting illness associated with cancer, cachexia, and HIV/AIDS (Argilés, Lopez-Soriana, & Busquets, 2008; Woolridge, Barton, Samuel, Osorio, & Dougherty, 2005).

### **How to Include Medicinal Marijuana in Life Care Plans**

When including medicinal marijuana and related products in a life care plan, it is treated methodologically like any other medication. Upon review of medical records, use of medicinal marijuana and its related products may be noted in a client's medical records depending upon the jurisdiction and acceptance in the medical community. Historical usage may be corroborated or disclosed in the personal interview. Like all medications, inquiry is made about pre- and post-injury use of medicinal marijuana products. If there is use of these items prior to the injury, this is noted and only the difference in use is potentially included in the life care plan. If the individual resides in an area where the medicinal marijuana use is not documented in medical records, the interview may be the sole source of information about the type of administration (e.g. oil, lotion, edible), dose and frequency of use of these products.

To determine whether to include these products in a life care plan, the first step that life care planners take is to determine the legality of the substance in the geographic area of the client. Because laws governing the legality of these products are rapidly changing, this step is critical. Medicinal marijuana, and its derivative cannabidiol, is now used in some form in over 40 states and the District of Columbia

(Norml, 2017; Procon.org, 2017). State laws govern factors including who can receive marijuana for medicinal purposes, the amount a person can possess, who can recommend or certify marijuana for medicinal purposes, as well as who can grow it and distribute it. One resource identified as a potential tool for life care planners to use in researching what medical conditions can be treated with marijuana in each state is the National Council of State Legislatures website, <http://www.ncsl.org/research/health/state-medical-marijuana-laws.aspx>.

Once the legality of the product is established, consideration of how to include the medicinal marijuana product in the life care plan occurs. As established by Life Care Planning Standards of Practice (International Academy of Life Care Planners, 2015) and Consensus and Majority Statements (Johnson, 2015), collaboration with medical professionals is undertaken by the life care planner; this is where the discussion of the use of medicinal marijuana and related products will ensue. Various medical professionals including neurologists, physiatrists, and family practice physicians may recommend use of these products based upon their familiarity with a specific diagnosis. However, the products are not usually prescribed by these individuals. Rather, marijuana dispensaries typically have physicians whose practice it is to evaluate patients for the use of cannabis products. Therefore, if a medical foundation is required for the use of medicinal marijuana and related products in the life care plan, either a treatment team member must be familiar with its use for treatment of the disability-related symptoms or a physician with such training may be consulted. Based upon interviews with life care planners throughout the country, typically dispensary-affiliated physicians are not consulted in the preparation of the life care plan. However, treatment team members often recommend the products based upon familiarity with the literature, reports by the patient of symptom relief, and/or reduction in consumption of other products (including opioids) with the introduction of medicinal marijuana products. While most practicing physicians were not formally trained in cannabis use or dosing, many are educating themselves, sometimes through their patients, of the science of cannabis use.

Once a medical foundation is established for inclusion of the medicinal marijuana product(s), research is performed by the life care planner to determine historical usage patterns and cost of the products. The most common way to establish historical usage patterns is by examination of receipts, as one would with other medications or supplies included in the life care plan. This may also be a way to document the cost of the medicinal marijuana products being used. In some areas, dispensaries can be contacted for information about product pricing. Some life care planners report obtaining information online or by telephone from the company providing the product to the individual. No life care planners who were interviewed for this research reported these products being covered by health insurance, so it is likely that the individual



is incurring these costs through private pay. In some states where medicinal and recreational marijuana are both legal, the cost for medicinal marijuana is less than recreational marijuana. Life care planners report seeing monthly cost of medicinal marijuana related products from \$100-\$1600 per month, depending upon the number of products used, the frequency of use and the dose of the products being consumed.

Unlike other medications, there are not specific dosing recommendations indicated for medicinal marijuana, making it difficult to determine what an appropriate dose for any disorder or condition may be. Additionally, considerations for potency and route of administration must be made. Unlike the traditional restrictions on number of pills dispensed or the number of refills allowed, an individual may purchase lotions, creams and edible products without such limits. Without specific dosing guidance from a physician, the life care planner may be faced with the determination of how to schedule long-term use of the medicinal marijuana related product. One method may be to continue the individual's current usage pattern into the future. Again, this determination may be addressed during collaboration and consultation with healthcare practitioners involved in the person's care. When these decisions are made, medicinal marijuana and related products are typically included in the life care plan tables section entitled "Medications."

In some cases, if the individual is consuming or using medicinal marijuana or a related product, ancillary services will be required that may be included in other parts of the life care plan. For example, in Georgia where possession of low THC oil is legal for certain medical conditions, individuals using this product are required to see a physician four times per year to maintain a "Low THC oil registry" card. The card, which is recommended by a physician for a patient with certain conditions, is issued by the State of Georgia. It is not a prescription for the THC product, but allows the person to legally possess 20 fluid ounces of low THC oil, a medicinal marijuana related product. In these cases, the required physician office services would be included in the "Future Medical Care- Routine" section of the life care plan.

Like the low THC oil, medicinal marijuana related products may be used to treat a range of disabilities for which life care planners create plans. Life care planners report inclusion of these products for diagnoses including chronic pain, phantom pain, seizure disorder, and nausea and report inclusion of the products in both pediatric and adult life care plans. Some of the diagnoses for which medicinal marijuana is currently used are discussed above.

### **Discussion and Implications**

As life care planners practice in all states as well as internationally, there are differences in how they approach the inclusion of cannabinoids and medicinal marijuana in their life care plans, largely depending upon the laws governing the product in their state. Unlike other items to be included in

the life care plan, this product primarily remains illegal in the eyes of the United States government. While it may be appropriate for the life care planner to include cannabinoids and medicinal marijuana products in the life care plan to be presented in a state court where the products are legal, it may not be included in cases that are to be presented in a federal court. For each life care plan, the life care planning professional must investigate the legality of the products as a first step in determining if the product can be included as a life care plan recommendation. As widespread, legal, use of these products is relatively recent, understanding a juror's (or trier of fact) perceptions of these products will be an interesting phenomenon to document and is a suggested area of future research in life care planning.

While navigating the conflicting state and federal laws is difficult for the life care planner in and of itself, other challenges mentioned by life care planners include: 1) how a family might travel across state lines or internationally with these products; 2) how to handle cannabinoid or medicinal marijuana use when transitioning from a pediatric to adult healthcare team; 3) how small hospital or medical centers approach the use of these products; and 4) how to determine when to terminate the use of the substance in the life care plan. These are all valid concerns and will require much forethought and proactive planning. The decision to add these products to a life care plan must take into consideration numerous mitigating factors all of which lead to the success of the plan or a lack thereof. Because of this, knowledge of marijuana's pharmacology, its impact on the brain and body, and its success in treating chronic conditions and disorders is paramount, along with understanding the unique needs and circumstances of each client.

Even though life care planners have medical backgrounds or training, very few, if any, life care planners have received training in areas related to medicinal marijuana. Most medical schools, in fact, do not provide training as part of their curriculum. Therefore, as a profession, life care planners are often educating themselves about the properties of marijuana and its usefulness in treating disability-related symptoms. This is an area where ongoing research in the life care planning field should be focused. Additional research allows for a better understanding of marijuana's exact mechanism of action in treating disabilities and other chronic conditions, and it creates an opportunity to develop specific guidelines pertaining to dosing, both of which are important for both life care planners and their clients. As states continue to legalize marijuana for medicinal use and research continues to show the benefits of its use, opportunities for large-scale projects may materialize followed by opportunities for further training and advancement of the field of life care planning.

### **References**

Alghanim, H., & Almirall, J. (2003). Development of microsatellite markers in *Cannabis sativa* for DNA typing

- and genetic relatedness analyses. *Analytical and Bioanalytical Chemistry*, 376(8), 1225-1233.
- Aggarwal, S., Carter, G., Sullivan, M., ZumBrunnen, C., Morrill, R., & Mayer, J. (2009). Characteristics of patients with chronic pain assessing treatment with medical cannabis in Washington State. *Journal of Opioid Management*, 5(5), 257-286.
- Amar, M. (2006). Cannabinoids in medicine: A review of their therapeutic potential. *Journal of Ethnopharmacology*, 105, 1-25.
- Ameri, A. (1999). The effects of cannabinoids on the brain. *Progress in Neurobiology*, 58, 315-348.
- Andries, A., Frystyk, J., Flyuvjerg, A., & Støving, R. (2013). Dronabinol in severe, enduring anorexia nervosa: A randomized controlled trial. *International Journal of Eating Disorders*, 47(1), 18-23. doi: 10.1002/eat.22173
- Appendino, G., Chianese, G., & Tagliatalata-Scafati, O. (2011). Cannabinoids: Occurrence and medicinal chemistry. *Current Medicinal Chemistry*, 18, 1085-1099
- Argilés, J., Lopez-Soriana, F., & Busquets, S. (2008). Novel approaches to the treatment of cachexia. *Drug Discovery Today*, 13(1-2), 73-78. doi: <http://doi.org/10.1016/j.drudis.2007.10.008>
- Baker, D., Pryce, G., Croxford, J.L., Brown, P., Pertwee, R.G., Huffman, J.W., and Layward, L. (2000). Cannabinoids control spasticity and tremor in a multiple sclerosis model. *Nature*, 404(6773), 84-87
- Baker, P., Taylor, B., & Gough, T. (2011). The tetrahydrocannabinol and tetrahydrocannabinolic acid content of cannabis products. *Journal of Pharmacy and Pharmacology*, 33(1), 369-372.
- Cabral, G., & Griffin-Thomas, L. (2009). Emerging role of CB2 cannabinoid receptor in immune regulation and therapeutic prospects. *Expert Reviews in Molecular Medicine*, 11(e3). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2768535/>
- Carins, E., Baldridge, W., & Kelly, M. (2016). The endocannabinoid system as a therapeutic target in glaucoma. *Neural Plasticity*, 2016. Retrieved from <http://eds.a.ebscohost.com/ehost/pdfviewer/pdfviewer?sid=e61c45d2-b80b-4eba-8da6-2efca62d8599%40sessionmgr4009&vid=8&hid=4205>
- Carroll, C., Zeissler, M., Hanemann, C., & Zajicek, J. (2012).  $\Delta^9$ -tetrahydrocannabinol ( $\Delta^9$ -THC) exerts a direct neuroprotective effect in a human cell culture model of Parkinson's disease. *Neuropathological and Applied Neurobiology*, 38(6), 535-547.
- Dhopeswarkar, A. & Mackie, K. (2014). CB2 receptors as a therapeutic target – What does the future hold? *Molecular Pharmacology*, 86(4), 430-437.
- Dussy, F., Hamberg, C., Luginbühl, M., Schwerzmann, T., & Briellmann, T. (2005). Isolation of  $\Delta^9$ -THCCA-A from hemp and analytical aspects concerning the determination of  $\Delta^9$ -THC in cannabis products. *Forensic Science International*, 149, 3-10.
- Ehrhart, J., Obregon, D., Mori, T., Hou, H., Sun, N., Bai, Y., & Shytle, R. (2005) Stimulation of cannabinoid receptor 2 (CB2) suppresses microglial activation. *Journal of Neuroinflammation*, 2(29). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1352348/pdf/1742-2094-2-29.pdf>
- Eichler, Spinedi, L., Unfer-Gruwiler, S., Bodmer, M., Surber, C. & Drewe, J. (2012). Heat exposure of Cannabis sativa extracts affect the pharmacokinetic and metabolic profile in healthy male subjects. *Planta Medica*, 78(7), 686-691.
- El-Alfy, A., Ivey, K., Robinson, K., Ahmed, S., Radwan, M., Slade, D. & Ross, S. (2010). Antidepressant-like effects of  $\Delta^9$ -tetrahydrocannabinol and other cannabinoids isolated from *Cannabis sativa* L. *Pharmacology, Biochemistry and Behavior*, 95, 434-442.
- Eubanks, L., Rogers, C., Beuschler IV, A., Koob, G., Olson, A., Dickerson, T., & Janda, K. (2006). A molecular link between the active component of marijuana and Alzheimer's disease pathology. *Molecular Pharmacology*, 3(6), 773-777.
- Falvo, D. (2014). *Medical and psychosocial aspects of chronic illness and disability* (5th ed.). Burlington, MA: Jones & Bartlett Learning.
- Fiz, J., Durán, M., Capellà, D., Carbonell, J., Farré, M. (2011). Cannabis use in patients with fibromyalgia: Effect on symptoms relief and health-related quality of life. *PLOS One*, 6(4), e18440. Retrieved from <http://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0018440&type=printable>
- Food and Drug Administration. (2004). *Marinol*®. Retrieved from <https://www.fda.gov/ohrms/dockets/dockets/05n0479/05N-0479-emc0004-04.pdf>
- Fukuda, S., Kohsaka, H., Takayasu, A., Yokoyama, W., Miyabe, C., Miyabe, Y. & Nanki, T. (2015). Cannabinoid receptor 2 as a potential therapeutic target in rheumatoid arthritis. *BMC Musculoskeletal Disorders*, 15, 275- 284.
- Garcia-Arencibia, M., Gonzalez, S., de Lago, E., Ramos, J., Mechoulam, R., Fernandez-Ruiz, J. (2007). Evaluation of the neuroprotective effects of cannabis in a rat model of Parkinson's disease: Importance of antioxidants and cannabinoid receptor-independent properties. *Brain Research*, 1134, 162-170.
- Greer, G., Grob, C., & Halberstandt, A. (2014). PTSD symptoms reports of patients evaluated for the New Mexico medical cannabis program. *Journal of Psychoactive Drugs*, 46(1), 73-77. doi: <http://dx.doi.org/10.1080/02791072.2013.873843>
- Gui, H., Tong, Q., Qu, W., Mao, C., & Dai, S. (2015). The endocannabinoid system and its therapeutic implications for rheumatoid arthritis. *International Immunopharmacology*, 26(1), 86-91.
- Hanus, L., Tchilibon, S., Ponde, D., Bueuer, A., Fride, E., & Mechoulam, R. (2005). Enantiomeric cannabidiol derivatives: Synthesis and binding to cannabinoid

- receptors. *Organic & Biomolecular Chemistry*, 3, 1116-1123.
- Hazekamp, A., Ruhaak, R., Zuurman, L., van Gerven, J., & Verpoorte, R. (2006). Evaluation of a vaporizing device (Volcano®) for the pulmonary administration of tetrahydrocannabinol. *Journal of Pharmaceutical Sciences*, 95(6), 1308-1317.
- Heiss, W., & Herholz, K. (2017). Brain receptor imaging. *Journal of Nuclear Medicine*, 47(2), 302-312.
- Herkenham, M., Lynn, A., Little, M., Johnson, M., Melvin, L., de Costa, B., & Rice, K. (1990). Cannabinoid receptor localization in brain. *Proceedings of the National Academy of Sciences of the United States*, 87(5), 1932-1936.
- Hill, K. (2015). Medical marijuana for treatment of chronic pain and other medical and psychiatric problems: A clinical review. *Journal of the American Medical Association*, 313(24), 2474-2483.
- International Academy of Life Care Planners (2015). *Standards of practice for life care planners* (3rd ed.). Glenview, IL: International Association of Rehabilitation Professionals (IARP).
- Johnson, C. (2015). Consensus and majority statements derived from life care planning summits held in 2000, 2002, 2004, 2006, 2008, 2010, 2012 and 2015. *Journal of Life Care Planning*, 13(4), 35-38.
- Kluger, B., Triolo, P., Jones, W., Jankovic, J. (2015). The therapeutic potential of cannabinoids for movement disorders. *Movement Disorders*, 30(3), 313-327
- Lusk, S., Paul, T., & Wilson, R. (2015). The potential impact of the legalization and decriminalization of marijuana on the vocational rehabilitation process. Why the buzz? *Journal of Applied Rehabilitation Counseling*, 46(2), 3-12.
- May, M., & Gode, A. (2016). Dronabinol or chemotherapy-induced nausea and vomiting unresponsive to antiemetics. *Cancer Management and Research*, 8, 49-55.
- Machado Rocha, F., Stéfano, S., de Cássia Háiek, R. Rosa Oliveira, L., & da Silveira, D. (2008). Therapeutic use of Cannabis sativa on chemotherapy-induced nausea and vomiting among cancer patients: Systematic review and meta-analysis. *European Journal of Cancer Care*, 17(5), 431-443.
- Medical Genomics. (2014). Cannabis overview page. Retrieved from <http://www.medicinalgenomics.com/resources/cannabis/>
- Moghaddam, H., Khodayar, M., Abarghouei, S., & Ardestani, M. (2010). Evaluation of the role of striatal cannabinoid CB1 receptors on movement activity of parkinsonian rats induced by reserpine. *Saudi Pharmaceutical Journal*, 18(4), 207-215.
- National Institute of Health. (2011). *Chronic pain: Symptoms, diagnosis, & treatment*. Retrieved from <https://medlineplus.gov/magazine/issues/spring11/articles/spring11pg5-6.html>
- National Institute on Drug Abuse. (2012). *Drugs, brains, and behavior: The science of addiction*. Retrieved from <https://www.drugabuse.gov/publications/drugs-brains-behavior-science-addiction/drugs-brain>
- National Institute on Drug Abuse. (2017a). *How does marijuana produce its effects?* Retrieved from <https://www.drugabuse.gov/publications/research-reports/marijuana/how-does-marijuana-produce-its-effects>
- National Institute on Drug Abuse. (2017b). *Marijuana*. Retrieved from <https://www.drugabuse.gov/publications/drugfacts/marijuana>
- Norml. (2017). *Medical marijuana*. Retrieved from <http://norml.org/states>
- Pearce, D., Mitsouras, K., & Irizarry, K. (2014). Discriminating the effects of Cannabis sativa and Cannabis indica: A web survey of medical cannabis users. *The Journal of Alternative and Complementary Medicine*, 20(10), 7878-791.
- Pertwee, R. (2008). The diverse CB1 and CB2 receptor pharmacology of three plant cannabinoids.  $\Delta^9$ -tetrahydrocannabinol, cannabidiol, and  $\Delta^9$ -tetrahydrocannabivarin. *British Journal of Pharmacology*, 153(2), 199-215.
- Prowels, T., te Poele, R., Shamash, J., Chaplin, T., Propper, D., Joel, S. & Liu, W. (2005). Cannabis-induced cytotoxicity leukemic cell lines: The role of the cannabinoid receptors and the MAPK pathway. *Blood*, 105, 1214-1221.
- ProCon.org. (2017). *29 legal medical marijuana states and DC: Laws, fees, and possession limits*. Retrieved from <http://medicalmarijuana.procon.org/view.resource.php?resourceID=000881>
- Pryce, G., Riddall, D., Selwood, D., Giovannoni, G., & Baker, D. (2015). Neuroprotection in experimental autoimmune encephalomyelitis and progressive multiple sclerosis by cannabis-based cannabinoids. *Journal of Neuroimmune Pharmacology*, 10(2), 281-292.
- Przedborski, S., Vila, M., & Jackson-Lewis, V. (2003). Series introduction. Neurodegeneration: What it is and where are we? *The Journal of Clinical Investigation*, 111(1), 3-10.
- Ramer, R., Bublitz, K., Freimuth, N., Merkord, J., Rhode, H., & Hinz, B. (2012). Cannabidiol inhibits lung cancer cell invasion and metastasis via intercellular adhesion molecule-1. *The Journal of the Federation of American Societies for Experimental Biology*, 26(4), 1535-1548. doi: 10.1096/fj.11-198184
- Roitman, P., Mechoulam, R., Cooper-Kazaz, R., & Shalev, A. (2014). Preliminary, open-label, pilot study of add-on oral  $\Delta^9$ -tetrahydrocannabinol on chronic post-traumatic stress disorder. *Clinical Drug Investigation*, 34(8), 587-591.
- Rossi, S., Bernardi, G., & Centonze, D. (2010). The endocannabinoid system in the inflammatory and neurodegenerative progresses of multiple sclerosis and of amyotrophic lateral sclerosis. *Experimental Neurology*, 224(1), 92-102.
- Russo, E. & Guy, G. (2006). A tale of two cannabinoids: The therapeutic rationale for combining tetrahydrocannabinol and

- cannabidiol. *Medical Hypotheses*, 66(2), 234-246.
- Schicho, R., & Storr, M. (2014). Cannabis finds its way into treatment of Crohn's disease. *Pharmacology*, 93, 1-3.
- Sharma, P., Murthy, P., & Bharath, M. (2012). Chemistry, metabolism, and toxicology of cannabis: Clinical implications. *Iranian Journal of Psychiatry*, 7(4), 149-156.
- Shoemaker, J., Seely, K., Reed, R., Crow, J., & Prather, P. (2006). The CB2 cannabinoid agonist AM-1241 prolongs survival in a transgenic mouse model of amyotrophic lateral sclerosis when initiated at symptom onset. *Journal of Neurochemistry*, 101(1), 87-98.
- Stockburger, S. (2016). Forms of administration of cannabis and their efficacy. *Journal of Pain Management (Special Issue: Cannabis)*, 9(4), 381-386.
- Tomida, I., Pertwee, R., & Azuara-blanco, A. (2004). Cannabinoids and glaucoma. *British Journal of Ophthalmology*, 88(5), 708-713.
- Walsh, Z., Callaway, R., Belle-Isle, L., Capler, R., Kay, R., Lucas, P. & Holtzman, S. (2013). Cannabis for therapeutic purposes: patient characteristics, access and reasons for use. *International Journal of Drug Policy*, 24(6), 511-516.
- Ware, M., Daeninck, P., & Maida, V. (2008). A review of nabilone in the treatment of chemotherapy-induced nausea and vomiting. *Therapeutics and Clinical Risk Management*, 4(1), 99-107.
- Woodhams, S., Sagar, D., Burston, J., and Chapman, V. (2015). The role of the endocannabinoid system in pain. *Handbook of Experimental Pharmacology*, 227, 119-143.
- Woolridge, E., Barton, S., Samuel, J., Osorio, J., & Dougherty, A. (2005). Cannabis use in HIV for pain and other medical symptoms. *Journal of Pain and Symptom Management*, 29(4), 358-367.

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# Life Care Planning in a Country with For-Profit Medicine

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## Overview of Life Care Planning Methodology

The multi-disciplined specialty in life care planning has thrived over the last several decades. The reasons for the growth include the demand in litigation and other venues, the formation of the International Academy of Life Care Planners (IALCP) with its established standards of practice and ethics, and the growing body of empirical research devoted to the profession. Since the 1993 *Daubert vs. Merrell Pharmaceuticals* decision that placed all experts on notice regarding the need for expert opinions to be based on generally accepted methodology and supported by one's peers, it is imperative that life care planners offer supported opinions (Field, 2000). Prior to the Daubert decision, expert witnesses could provide opinions based on their education, training and experience without necessarily having a consensus of professional opinions.

Through the years, the profession of life care planning has developed both an accepted methodology and scope of practice for life care planners. These have emerged from research included in textbooks, journal articles and from the multiple symposia held by the International Academy of Life Care Planners. The Academy has produced Consensus and Majority Statements with noteworthy statements related to standards and methodology including, life care planners shall: (#55) utilize research for recommendations; (#56) consider the integrity of the data; (#65) utilize adequate medical and other data for opinions; and, properly inject personal expertise (#73) (Johnson, 2015, p. 36-37). In preparing our plans, life care planners often walk a fine line regarding providing opinions based upon sound medical data yet remaining within our area of expertise to do so, which is also required by our guiding documents.

One area, however, that can be confusing to the trier of fact in litigation, is how two opposing life care planners assessing the same evaluatee can at times be millions of dollars apart in their overall future care costs (Marini, 2012; Ysasi, Marini, Antol, Maxwell, & Kerwin, 2016). Marini (2012) offered one explanation for large differing (opposing) expert cost assessments being that some life care planners add in the costs of potential complications that are possible, but not medically probable within a degree of certainty. This article explores additional possible explanations for large cost differences, including the variation in costs found in the US healthcare system, particularly when compared to other countries. We also address the prevalence of healthcare goods and services in the US healthcare system and the issue of determining medical necessity of surgeries. Finally, implications to life care planning are addressed through presentation of an anonymous case scenario presented from

the second author's life care planning experience.

## Cost of Medical Care in the United States

Despite attempts to slow the costs of healthcare in the United States (US), costs topped over \$2 trillion in 2005, \$3 trillion by 2014, and are projected to top over \$5 trillion by 2022 (Munro, 2014). Kane (2012) reported that the US spent an average of \$8,233 per year per person on healthcare in 2010 and in 2014 approximately \$9,086 per year per person (Squires & Anderson, 2015) making up approximately 18% of the Gross Domestic Product (GDP). In contrast, the Organization of Cooperation and Economic Development (OCED), which is made up of 34 developed countries, reported the average annual healthcare expenditure of \$3,268 per person, almost two-thirds less the US average. Mahar (2006) compared healthcare cost differentials between the US and other countries, noting that the US spends 50% more than Switzerland, 85% more than Germany and Canada, and twice as much as the Netherlands, United Kingdom, and Australia, with approximately 30% of US healthcare dollars being paid to hospitals.

Kane (2012) noted that the average hospital stay cost in the US was \$18,000, compared to the next highest countries of Canada, the Netherlands, and Japan whose hospital stays ranged from \$4,000 – \$6,000. Tokin (2012) also noted the drastic differences in the cost of the same surgery in different hospitals within one state, even some that were only miles away from each other. In his research, Tokin cited a California study of 19,000 patients who underwent uncomplicated appendicitis surgery with costs ranging from \$1,529 to \$182,955 across hospitals. Squires and Anderson (2015) reported that the average cost of a coronary bypass surgery in 2013 averaged \$75,345 in the US, while Australia reported the second-highest cost for the same surgery at \$42,130.

While the United States ranked the higher in healthcare costs than 195 other countries in the world, it ranked lowest in performance (among 11 industrialized countries) regarding health care quality, efficiency, access to care, equity, and healthy lives (The Commonwealth Fund, 2014). Among the 195 countries, the US ranks 37th in overall mortality rates. It does, however, rank fourth regarding quality healthcare (but only for those with insurance), but last in quality for those with poor or no health insurance. Mahar (2006) concludes that "while more healthcare equals more profits, it does not necessarily lead to better health." (p. xix).

The United States remains one of only a few industrialized countries without universal healthcare. Critics of universal health care argue that there will be the negative

financial implications for patients, the government, and businesses with universal healthcare and that the marketplace competition in the US system provides the highest quality healthcare (Mahar, 2006). Recent comments made by Warren Buffett to CEOs of American companies provide a different perspective. Sorkin (2017) cites Warren Buffett's May 2017 comments regarding rising healthcare costs where he cautioned CEOs that the major problem for retaining company profits is the financial burden of rising healthcare costs for employers. Buffett noted the alarming rise in healthcare costs related to HMOs, hospitals, doctor's visits, prescriptions, medical devices, and insurance companies that have driven the Gross Domestic Product from 5% over 50 years ago to its current 17%, with much of that cost being absorbed by employers. Corporate America pays more for healthcare than any other country's businesses, where American corporations spend over \$12,500 annually to cover a family of four, up 54% from 2005 (Sorkin, 2017).

In addition to differences in costs of services among US healthcare providers, there are also noteworthy differences in consumption of healthcare services between US residents and residents of other countries. Kane (2012) notes that the US spends significantly more on diagnostic testing and prescription medications than any of the 34 developed countries, a finding similarly reported by Squires and Anderson (2015). Squires and Anderson (2015) found that Americans consume more prescription drugs (average 2.2 each), nearly twice the amount of prescription medication than citizens of other industrialized countries. This rate of medication of prescription has been linked to the epidemic in opioid related overdoses and deaths in the US, with the Center for Disease Control (2016) reporting approximately 33,000 annual American deaths from prescriptions. At this rate of 78-91 deaths per day, this is a 72% increase in opioid related overdose deaths from 2014 to 2015 (CDC, 2016; Leonard, 2016).

Mahar (2006) in her book *Money Driven Medicine: The Real Reason Health Care Costs So Much*, suggests several reasons for the high cost of medicine in the United States including unnecessary diagnostic testing and/or surgeries, entanglement with pharmaceutical companies and device makers, and the differences between for-profit and not-for-profit hospitals. Overall, noteworthy healthcare differences between the US and other countries begs the question; are Americans simply more unhealthy than other nations or is the American free-market healthcare system a factor in our outcomes?

### Determining Medical Necessity

Waddell (1987), over 30 years ago, noted that lumbar disc surgeries have a medical basis in only 1% of patients seen by surgeons, yet he noted in 1987 approximately 400,000 such surgeries were performed. Weber (1983) found that patients who are recommended for a second similar surgery are twice as likely to have that surgery fail, and if a

third or more lumbar surgery is required, the likelihood of it failing to relieve the patient's pain four to 10 times higher. Waddell (1987, p. 636) adds "In an extensive review of the treatment outcomes data, there is no evidence that any treatment for low back pain is better than a combination of the natural history and the placebo effect." Weber (1983) similarly reported that patients who underwent a lumbar surgery, were no better off in having their pain reduced than a control group with the same lumbar diagnosis/symptoms who were treated conservatively, at a four and 10-year follow-up.

Similar to Weber's (1983) findings regarding lumbar surgery, Harris, Mulford, Solomon, van Gelder, and Young (2005, as cited in Franklin, Wickizer, Coe, & Fulton-Kehoe, 2015) found that patient recovery from lumbar surgery was far worse when compared to those with similar lumbar issues who did not have surgery. In a sample of patients with chronic low back pain who underwent lumbar surgery, 66% were still disabled while 23% underwent a second lumbar surgery (Chou et al., 2009). The success of thoracic outlet syndrome surgeries was also studied with 21% of those who underwent surgery complaining of greater neurological problems after the surgery (Franklin, Fulton-Kehoe, Bradley, & Smith-Weller, 2000). The authors reported poor outcomes for those who had the surgery versus those who did not have surgery (Franklin, Fulton-Kehoe, Bradley, & Smith-Weller, 2000).

### Case Scenario

*The second author is a certified life care planner with 17 years of life care planning experience who was asked by defense counsel to review a case involving an individual who reported cervical and lumbar disc herniations as a result of a motor vehicle crash. The life care planner was asked about the reasonableness of a plaintiff physician life care plan (PLCP). A review of records revealed that the individual participated in 6 to 12 months of typical conservative treatment (e.g. chiropractic care, physical therapy, ultrasound) then received epidural steroid injections to the cervical and lumbar spine. Finally, one treating surgeon performed a cervical laminectomy, discectomy and fusion, and a second treating surgeon performed the same surgery for the lumbar herniation. Neither treating surgeon indicated in any medical records that their respective surgery failed, nor did they note the need for ongoing treatment.*

*After the plaintiff's physician life care planner performed an IME, a life care plan was developed without the individual consulting treating or other related professionals for future medical care recommendations. The PLCP recommended: a) lifelong or almost lifelong related physician visits; b) periodic MRI, x-ray, CT scans; c) the cost of second-level cervical and lumbar surgery as medically probable; d) ancillary physical therapy; e) lifelong or near lifelong NSAIDs, antidepressants, opiates and analgesics; f) continued epidural steroid injections; and, g) lifelong maid*

services, and other minor items.

*During this assignment, the second author consulted with defendant's retained orthopedic surgeon. The surgeon indicated that when these surgeries are successful (as the medical records in this case appeared to indicate), the patient will require a short-term comprehensive physical and/or occupational therapy to be followed by a home exercise program. The surgeon opined that there would be no justification for lifelong care unless some other intervening event had occurred.*

### **Case Analysis**

In opining about the reasonableness of the plaintiff physician life care plan, this life care planner consulted life care planning standards of practice. The 2015 Standards of Practice for Life Care Planners (International Association of Rehabilitation Professionals [IARP], 2015, p. 6) states that "the life care plan is a collaborative document among various parties, when possible" and that life care planners evaluate literature and use appropriate research findings when developing a life care plan.

In addition to the IALCP Standards of Practice for life care planners, the American Academy of Physician Life Care Planners (AAPLCP) have their own Standards of Practice and ethics (AAPLCP, n.d.). Under Standard 2D, physician life care planners endeavor to discover and consider (among other things), documented opinions from the subject's treating physicians. Standard 3A notes that physician life care planners seek collaboration with other experts whenever necessary and practicable. Standard 3D notes that physician life care planners formulate medical opinions by considering all prospective, medically probable effects of a subject's impairments while 3E notes that physician life care planners formulate opinions regarding probable duration of care based upon published, peer-reviewed methods and standards.

In this case, there was divergence from life care planning standards of practice by not conducting consultation with treatment team members. Despite no treating surgeon recommending future lifelong treatment, the PLCP included this treatment, without citing relevant research or recommendation from a treating professional. In addition, prior life care planning research has noted less than half of physician life care planners surveyed reported consulting treating physicians for recommendations or utilizing empirically based research to develop their life care plans (Ysasi et al., 2016). Reliance upon published data assisted this life care planner in reaching conclusion about the reasonableness of the life care plan.

### **Implications for Life Care Planners**

Life Care Planning Standards of Practice and Majority and Consensus Statements indicate that life care planners come from different disciplines and should remain within our scope of practice. Despite our background differences, there is a vast body of literature stating how life care plans should

be developed (Deutsch & Raffa, 1981; International Academy of Life Care Planners, 2015; Weed & Berens, 2010). It is critical that life care planners adhere to these methods, which have been documented for 30 years, even as the healthcare systems in which we practice have become increasingly complex. Our practice recommends collaboration with various professionals in the development of our plans. When conducting this consultation/collaboration, our standards cite that we should be knowledgeable of the relevant literature including outcomes and evidence-based practices.

Life Care Planning Consensus and Majority Statements (2015) suggest that life care planners use research for recommendations, but that we also consider the integrity of data (Johnson, 2015). Perhaps understanding how the US healthcare system compares to other developed countries in terms of costs and number of procedures as well as the rate of medications and diagnostic studies prescribed, will help inform our base of information. We work in a system where there are opposing medical experts, psychologists, psychiatrists, etc. who are retained on either side who often proffer differing opinions about the same injured party (Marini, 2012; Ysasi et al., 2016). Yet our guiding documents, including Consensus and Majority Statements provide guidance for our professional practices in situations where we are confronted with divergent opinions (Johnson, 2015).

It behooves all life care planners to be familiar with evidence-based research, including understanding "optimal outcomes achievable for particular injuries" when collaborating with treating or IME physicians in life care plan development (Johnson, 2015, p. 35). Life care planners are not simply scribes to physicians, but a group of professionals with years of research and directives agreed upon by our profession, available for our use. We should not underestimate our value, skills, knowledge, and capabilities to assist physicians in providing their recommendations, particularly when we suspect their recommendations are not fully supported in the literature. If recommendations are inconsistent with our understanding of the literature, we should engage in a dialogue with the life care plan contributors. Our Consensus and Majority Statements address this issue stating, "Life Care Planners shall methodically handle divergent opinions" (Johnson, 2014, p. 37). The second author has observed in his practice that one way that life care planners handle discordant opinions is by creating different projection options or scenarios for the trier of fact to decide.

Overall, the United States has the costliest healthcare system of all industrialized countries, with few market regulations (Mahar, 2006; Squires & Anderson, 2015). It behooves all life care planners to do their research on specific disabilities, particularly prevalence statistics of secondary complications. The more knowledgeable life care planners are about specific disabilities, the more capable we are when



collaborating with the healthcare team regarding the future medical care needs of our clients.

## References

- American Academy of Physician Life Care Planners (n.d.). *Standards of practice*. Retrieved from <http://www.aaplcp.org/about/practice-standards.aspx>.
- Centers for Disease Control and Prevention. (2016). Wide-ranging online data for epidemiologic research (WONDER). Atlanta, GA: CDC, *National Center for Health Statistics*. Retrieved from <http://wonder.cdc.gov>
- Chou, R., Baisden, E.J., Resnick, D.K., Shaffer, W.O., & Loeser, J.D. (2009). Surgery for low back pain: A review of the evidence for an American pain society clinical practice guideline. *Spine*, 34, 1094-1109.
- Deutsch, P. & Raffa, E. (1981). *Damages in Tort Actions*, (Vol. 8). New York: Matthew Bender.
- Field, T. (2000). *A resource for the rehabilitation consultant on the Daubert and Kumho rulings*. Athens, GA: E & F Publication.
- Franklin, G.M., Fulton-Kehoe, D., Bradley, C., & Smith-Weller, T. (2000). Outcome of surgery for thoracic outlet syndrome in Washington State Workers` Compensation. *Neurology*, 54, 1252-1257.
- Franklin, G.M., Wickizer, T.M., Coe, N.B., & Fulton-Kehoe, D. (2015). Workers` Compensation: Poor quality health care and the growing disability problem in the United States. *American Journal of Industrial Medicine*, 58, 245-251.
- International Academy of Life Care Planners (2015). *Standards of practice for life care planners* (3rd ed.). Glenview, IL: International Association of Rehabilitation Professionals (IARP).
- Johnson, C. B. (2015). Consensus and majority statements derived from life care planning summits held in 2000, 2002, 2004, 2006, 2008, 2010, 2012 and 2015. *Journal of Life Care Planning*, 13 (4), 35-38.
- Kane, J. (2012). Health Cost: How the US compares with other countries. Retrieved from <http://www.pbs.org/newshour/rundown/health-costs-how-the-us-compares-with-other-countries/>
- Leonard, K. (2016). Illicit opioids drive increase in US overdose deaths. *U.S. News & World Report*. Retrieved from <http://www.usnews.com/news/daminate/articles/2016-12-16/illicit-opioids-drive-increase-in-drug-overdose-deaths>
- Mahar, M. (2006). *Money driven medicine*. HarperCollins: New York.
- Marini, I. (2012). Practical matters: Possibility versus probability. *Journal of Life Care Planning*, 10 (4), 45-47.
- Munro, D. (2014). Annual US healthcare spending hits \$3.8 trillion dollars. Retrieved from <https://www.forbes.com/sites/danmunro/2014/02/02/annual-u-s-healthcare-spending-hits-3-8-trillion/#4ae733da76a9>
- Sorkin, A. R. (2017). Forget taxes, Warren Buffett says. The real problem is healthcare. *The New York Times*. Retrieved from [https://www.nytimes.com/2017/05/08/business/dealbook/09dealbook-sorkin-warren-buffett.html?smprod=nytcore-iphone&smid=nytcore-iphone-share&\\_r=0](https://www.nytimes.com/2017/05/08/business/dealbook/09dealbook-sorkin-warren-buffett.html?smprod=nytcore-iphone&smid=nytcore-iphone-share&_r=0)
- Squires, D. & Anderson, C. (2015). U.S. Health Care from a Global Perspective: Spending, Use of Services, Prices, and Health in 13 Countries. Retrieved from: <http://www.commonwealthfund.org/publications/issue-briefs/2015/oct/us-health-care-from-a-global-perspective>
- Standards of Practice for Life Care Planners (2015). International Academy of Life Care Planners retrieved from [http://higherlogicdownload.s3.amazonaws.com/REHABPRO/4225bec9-0568-4efd-b613-0709a1684d21/UploadedImages/Standards\\_of\\_Practice\\_for\\_Life\\_Care\\_Planners\\_Third\\_Edition.pdf](http://higherlogicdownload.s3.amazonaws.com/REHABPRO/4225bec9-0568-4efd-b613-0709a1684d21/UploadedImages/Standards_of_Practice_for_Life_Care_Planners_Third_Edition.pdf)
- The Commonwealth Fund (2014). US health system ranks last among 11 industrialized countries on measures of access, equity, quality, efficiency, and healthy lives. Retrieved from <http://www.commonwealthfund.org/publications/press-releases/2014/jun/us-health-system-ranks-last>
- Token, C. (2012). Patients in the dark on medical costs, study finds. Retrieved from <http://abcnews.go.com/Health/medical-costs-vary-wildly-hospital-hospital-study/story?id=16196700>
- Waddell, G. (1987). A new clinical model for the treatment of low back pain. *Spine*, 12, 632-634.
- Weber, H. (1983). Lumbar disc herniation: A controlled, prospective study with 10 years of observation. *Spine*, 8, 131- 140.
- Weed, R. O. & Berens, D. E. (2010). *Life Care Planning and Case Management Handbook* (3rd Ed.), New York: CRC Press.
- Ysasi, N. A., Marini, I., Antol, D. L., Maxwell, K., & Kerwin, S. (2016). A comparison of physiatrists life care planners versus non-life care planner physiatrists professional opinions regarding secondary complications of spinal cord injury. *Journal of Life Care Planning*, 14(1), 3-23.

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# Trauma and Stress Related Disorders: Relevance to DSM-5 and Life Care Planning

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## Abstract

Research posits that people with disabilities are at greater risk of experiencing events that could precipitate the development of trauma symptoms when compared to people without disabilities (Hassouneh-Phillips & Curry, 2002). This information places life care planners in a strategic position to assist this potentially vulnerable population. This article provides a definition of trauma, information about populations at risk for acquiring trauma- and stress-related disorders, and clinical features of disorders listed under the new DSM-5 trauma and stress-related disorders section. Psychosocial and vocational aspects of trauma- and stressor-related disorders are also presented. Finally, implications for life care planners are discussed. A review of six sexual trauma case studies with recommendations follow a discussion of the new DSM-5 definitions and criteria for trauma and stress-related disorders.

Since 2013, when the *Diagnostic and Statistical Manual of Mental Disorders-5* (DSM-5) recognized and listed trauma and stress-related disorders as a specific category, there has been heightened interest in trauma and trauma-related symptomatology (American Psychiatric Association, 2013; Jones & Cureton, 2014; Nemeroff et al., 2013). In 2015, individuals 12 years of age and older in the United States experienced an estimated 5 million violent victimizations (i.e., rape or sexual assault, robbery, aggravated assault, or simple assault) (United States Department of Justice, 2016). Between 2005 and 2010, the majority of these violent injuries were caused by loved ones or acquaintances with over 60 percent occurring within the home by assailants known to the victim (Harrell, 2012). While the current rate of violent victimization declined over previous years, these assaults still result in considerable physical, emotional, social, and economic consequences (Truman & Planty, 2012). Living through traumatic events can change the way individuals view themselves and the world around them because the traumatic event is outside the individual's normal realm of experience and overwhelms the individual's usual psychological defenses.

It is important for life care planners to recognize when a client is experiencing symptoms of a psychiatric disorder following a traumatic experience. Such recognition is critical for developing a treatment plan that addresses the trauma, and the resulting mental health symptoms. Understanding the changes in the current *Diagnostic and Statistical Manual of Mental Disorders-5* (DSM-5) will assist life care planners with proper identification, referral, and treatment options for their clients.

## Definition of Trauma

Trauma is now defined as exposure to actual or threatened death, serious injury, or sexual violence in one or more of four ways: (a) directly experiencing the event; (b) witnessing, in person, the event occurring to others; (c) learning that such an event happened to a close family member or friend; and (d) experiencing repeated or extreme exposure to aversive details of such events, such as with first responders (APA, 2013). This definition differs from the previous versions of the DSM, by specifying examples of experiencing or witnessing a traumatic event and by being explicit about if the event was experienced directly or indirectly. The new definition also eliminated such events as the unexpected death of a family member or close friend due to natural causes, as well as indirect non-professional "... exposure through electronic media, television, movies, or pictures" (APA, 2013). Consequences of the changes in definition include an individual losing a claim for damages based solely upon indirect involvement in the traumatic event, for example, watching a traumatic event on television.

Trauma can occur in a single incident or become a chronic presence. Violent acts and trauma cause millions of people to suffer injuries that lead to long-term disabilities with a significant proportion of disabilities being caused by injuries resulting from traffic crashes, falls, acts of violence, and war and conflict (World Health Organization, 2014). Estimates propose that up to one quarter of disabilities around the world may be the product of injuries and violence (WHO, 2014). Individuals for whom life care plans are developed may have incurred physical injuries as a result of a traumatic event. Conversely, injuries may be psychological in nature and these injuries may co-exist with physical injuries or in the case of sexual assault or similar trauma, the psychological injuries may persist long after the physical injuries have healed. An individual's ability to cope with violence or trauma is moderated by individual and contextual factors, including social support, cognitive functioning, personality variables, behavioral capacities, preexisting psychological conditions, and the duration and intensity of the trauma (Coursol, Lewis & Garrity, 2001; Strauser, Lustig, Cogdak & Uruk, 2006). When life care planners become involved in a case, they will likely learn, through reviewing medical records, interviewing the evaluatee or through interviewing family members, the effects that trauma may continue to have on the individual as a result of the disabling event.

## Populations at Risk

Research has consistently reported that individuals with

disabilities, women and children, and elderly individuals are at a much greater risk of overall physical, sexual, and emotional abuse (Hines, Malley-Morrison, & Dutton, 2013; Jones et al., 2012; Plummer & Findley, 2012; Stalker & McArthur, 2012). In regard to domestic violence, 1 in 15 children are exposed each year, and 1 in 3 women have been victims of physical violence by an intimate partner in their lifetime (National Coalition Against Domestic Violence, 2015). A recent study reported that 7.6%-10% of elderly individuals experienced abuse within the past year (Lifespan of Greater Rochester, Inc., Weill Cornell Medical Center of Cornell University & New York City Department for the Aging, 2011). It is also reported that individuals with developmental disabilities are 4 to 10 times more likely to become victims of crimes than individuals without a disability (Tyiska, 1998). While individuals with disabilities cannot be viewed as a monolithic group, this population in general may have characteristics that lead to increased victimization of domestic abuse and bullying, such as dependency on others for caregiving, limited mobility or communication, and possible social isolation (Blake et al. 2014; Hines, Malley-Morrison, & Dutton, 2013; Jones et al., 2012; Plummer & Findley, 2012; Stalker & McArthur, 2012). This is certainly something that life care planners should consider when developing plans for individuals with limitations in cognition. When developing facility care options in a life care plan, this fact should be strongly considered to ensure that such placement does not lead to further injury.

Many times, individuals with severe disabilities are placed in long-term care settings that make them particularly vulnerable to violent victimization (Iversen, Kilvik, Malmedal, 2015). Unfortunately, advocates report that crimes against these populations often go unreported (Frohman & Didi, 2015; National Research Council, 2003; Office for Victims of Crime, n.d.). Many reasons explain this underreporting: mobility or communication barriers, fear of losing needed services, feelings of shame and self-blame, ignorance of the justice system, or if the perpetrator is a family member or primary caregiver. The high incidences of abuse by caregivers have prompted some researchers to promote the expansion of the definition of domestic violence to include paid caregivers (Lightfoot & Williams, 2009).

#### **DSM-5 Trauma and Stress- Related Disorders**

*The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)* is the standard classification of mental disorders used by mental health providers in the United States (APA, 2013). It contains a listing of diagnostic criteria for every psychiatric disorder recognized by the United States healthcare system. The DSM-5 is the most contemporary system available in the United States to rehabilitation counselors and other clinicians in making distinctions between normal life variations and more serious psychiatric symptoms. A DSM-5 diagnosis also assists with

accountability, record keeping, treatment planning, and communication with other helping professionals.

In the DSM-5, disorders which are precipitated by specific stressful and potentially traumatic events are included in a new diagnostic category, "Trauma and Stress-Related Disorders" (APA, 2013). Friedman et al., (2015) assert that there is heuristic value in grouping this set of disorders in a specific stress-related category because it enables clinicians to differentiate among normal (non-pathological) distress, from acute, diffuse clinically elevated stress reactions indicative of Adjustment Disorders, as well as more severe and chronic psychopathology (including Posttraumatic Stress Disorder). Disorders listed under the new trauma and stress-related disorders section include Reactive Attachment Disorder, Disinhibited Social Engagement Disorder, Other Specified Trauma- and Stressor-Related Disorder, Unspecified Trauma- and Stressor-Related Disorder, Adjustment Disorders, Acute Stress Disorder, and Posttraumatic Stress Disorder (APA, 2013). The definition, common causes, treatment, and psychosocial/vocational aspects of each disorder are provided.

#### **Reactive Attachment Disorder and Disinhibited Social Engagement Disorder**

The DSM-5 eliminated the diagnostic group, "Disorders Usually First Diagnosed In Infancy, Childhood, or Adolescence", in which Reactive Attachment Disorder had been placed. Unlike other stress disorders, which may arise at any age and may originate from a single event, Reactive Attachment Disorder and Disinhibited Social Engagement Disorders must originate during the early developmental period (i.e., prior to the age of 5) and must involve a pattern of social neglect, rather than a single traumatic incident (APA, 2013). Like the trauma associated with Posttraumatic Stress Disorder (PTSD) the stressors that precipitate Reactive Attachment Disorder and Disinhibited Social Engagement Disorder must be serious and extreme. The earliest time period both disorders can be diagnosed is "a developmental level of at least 9 months" (APA, 2013, p. 266, 269).

Reactive Attachment Disorder is defined as a lack of ability to form affectional bonds with other people and a pattern of markedly disturbed social relationships (Broderick & Blewitt, 2010). There are two types of Reactive Attachment Disorder: inhibited and disinhibited. Follan and McNamara (2013) characterized inhibited type as being withdrawn, hypervigilant, or having contradictory responses, and disinhibited type as indiscriminate sociability, over-friendliness, diffuse attachments, aggression, and problems with peers.

Disinhibited Social Engagement Disorder is an alternative diagnosis for children who manifest symptoms, prior to the age of two, that are mainly associated with the disinhibited type of Reactive Attachment Disorder. The American Psychiatric Association reports that Disinhibited Social Engagement Disorder closely resembles Attention

Deficit Hyperactivity Disorder (ADHD). However, the two disorders differ in important ways, including correlates, course, and response to intervention. The *DSM-5* cautions that the indiscriminate sociability of youngsters who meet the criteria for Disinhibited Social Engagement Disorder is not due primarily to impulsiveness (as is the case in attention deficit hyperactivity disorder), but is mainly a function of the child's socially disinhibited behavior.

### **Other Specified Trauma- and Stressor-Related Disorder and Unspecified Trauma- and Stressor-Related Disorder**

The *DSM-5* description states that symptoms that cause clinically significant distress or impaired functioning predominate, but do not fully meet the criteria for another disorder go into the Other Specified Trauma- and Stressor-Related Disorder category. Unspecified Trauma- and Stressor-Related Disorder is a temporary diagnosis for settings such as an emergency room where there is insufficient information to give a complete diagnosis.

### **Adjustment Disorders**

Adjustment Disorder is a stress-related, short-term, non-psychotic disturbance with symptoms including low mood, sadness, worry, anxiety, insomnia, and poor concentration. The definition of Adjustment Disorder is emotional or behavioral symptoms developing within three months of the onset of the stressor(s) plus either or both of: (1) marked distress that is out of proportion to the severity or intensity of the stressor, even when external context and cultural factors that might influence symptom severity and presentation are taken into account and/or (2) significant impairment in social, occupational, or other areas of functioning (APA, 2013). After the termination of the stressor (or its consequences), the symptoms persist for no longer than an additional six months. As the term Adjustment Disorder implies, symptoms develop when the person is responding to a particular event or situation, for example a loss, a problem in a close relationship, an unwanted move, a disappointment, or a failure. Medical illness or injury may also be a trigger for a diagnosis of adjustment disorder.

### **Acute Stress Disorder**

Acute Stress Disorder, is a psychiatric condition that is characterized by acute stress responses that could last anywhere from two days to four weeks following the traumatizing life event. A diagnosis of Acute Stress Disorder requires that a person experience a traumatizing life event, experience an intense emotional reaction to this event, and also experience a specific constellation of symptoms that cause impairment or distress (Shelvin, Hyland, & Elklit, 2014). For a diagnosis of Acute Stress Disorder in the *DSM-5*, qualifying events must now be explicit as to whether they were experienced directly, witnessed, or experienced indirectly. Also, the *DSM-IV* Criterion A2 regarding the subjective reaction to the traumatic event (i.e., "the person's

response involved intense fear, helplessness, or horror" (APA, 1994 pp.427-8) has been eliminated. Based upon evidence that acute posttraumatic reactions are heterogeneous and that the *DSM-IV*'s emphasis on dissociative symptoms was overly restrictive, individuals may meet diagnostic criteria in *DSM-5* for acute stress disorder if they exhibit any 9 of 14 listed symptoms within the following five categories: intrusion, negative mood, dissociation, avoidance, and arousal.

### **Posttraumatic Stress Disorder (PTSD)**

Previously grouped under anxiety disorders, Posttraumatic Stress Disorder was reclassified in the *DSM-5* to a trauma- and stressor-related disorder based on a common etiology (i.e. exposure to a traumatic event), rather than symptoms (Friedman et al., 2011). The *DSM-5* specifies examples of experiencing or witnessing a traumatic event, such as sexual assault or a recurring exposure that could apply to police officers or first responders. It also requires being explicit about how the event was experienced (i.e., directly or indirectly). The *DSM-5* definition rules out such events as the unexpected death of a family or close friend due to natural causes, as well as indirect non-professional exposure through media sources (i.e., television, movies, or pictures).

Post-traumatic stress disorder (PTSD) can develop after a very stressful, frightening event, or after a prolonged traumatic experience. Types of events that can lead to PTSD include combat exposure, childhood neglect, physical abuse, sexual assault, physical attack, being threatened with a weapon, natural disaster, mugging, robbery, car accident, plane crash, torture, kidnapping, life-threatening medical diagnosis, terrorist attack, and other extreme or life-threatening events (Brown, Burnette, & Cerulli, 2015; Frame & Morrison, 2001; Mayo, 2017; National Institute of Mental Health, 2017)). While both genders can experience traumatic events, statistically the traumatic events most often associated with PTSD in men are rape, combat exposure, childhood neglect, and childhood physical abuse (Nebraska Department of Veterans' Affairs, 2007). For women, the traumatic events are most likely to be rape, sexual molestation, physical attack, being threatened with a weapon, and childhood physical abuse (NDVA, 2007).

Two subtypes of PTSD have also been added: the preschool subtype (PTSD in children younger than six) and the dissociative subtype (PTSD with prominent dissociative symptoms). The most common causes of PTSD in young children are maltreatment and witnessing intimate partner violence (IPV). If the trauma involves the primary caregiver as either the perpetrator, (as in maltreatment cases), or the victim, (as in IPV), it can be particularly damaging to the mental health of the child, likely because of the central role of the caregiver in the child's early development (Scheeringa & Zeanah, 2001). The second PTSD subtype, Dissociative subtype, is diagnosed when PTSD is seen with prominent

dissociative symptoms including be either experiences of feeling detached from one's own mind or body, or experiences in which the world seems unreal, dreamlike, or distorted. The dissociative subtype is applicable to individuals who meet the criteria for PTSD and experience additional depersonalization and derealization symptoms.

### **Psychosocial and Vocational Aspects of Trauma**

A traumatic event may impact an individual's life and can result in significant impairment in social, occupational or academic functioning (APA, 2013). Individuals often cannot function as well as they could before the traumatic event occurred (Friedman, 2015). As a result of trauma, survivors may experience difficulties with self-esteem, assertiveness, anxiety, trust, guilt, and decision making (Strauser, Lustig, Cogdal, & Uruk, 2005).

Traumatic events that occur in childhood can have a lasting impact on their future. For example, while Reactive Attachment Disorder is a major psychosocial disorder of childhood, it is increasingly understood to produce short- and long-term relationship, health, and social consequences for children (Follan & McNamara, 2013). The complications of Reactive Attachment Disorder can continue into adolescence and later adulthood, causing a number of long-term negative effects. Some of these effects may include: poor self-esteem, academic problems, delinquent or antisocial behavior, anger problems, anxiety, inappropriate sexual behaviors, depression, constant problems with coworkers or peers, substance and alcohol addiction, unemployment or frequent job changes (Allen, 2015; Kenny, Blacker, & Allerton, 2014; Millward, Kennedy, Towson, & Minnis, 2006; Minnis, 2003; Zelechowski et al., 2013).

One aspect of the individual's function that may be affected by trauma is one's ability to engage in vocational/work activities with PTSD being linked with lower income, lower educational success and absenteeism from work (APA, 2013). Over time, untreated and undertreated individuals who have developed psychological disorders due to a traumatic event are especially susceptible to a deterioration of personal and work relationships and to the development of substance abuse or dependence. Some examples of problems associated with the workplace for those who have experienced traumatic events are: memory problems, lack of concentration, difficulty retaining information, feelings of fear or anxiety, physical problems, poor interactions with coworkers, unreasonable reactions to situations that trigger memories, absenteeism, interruptions if the employee is still in an abusive relationship, trouble staying awake, and panic attacks (Flannery, 1995; Pagotto et. al, 2015; Schnyder, Moergeli, Klaghofer, & Buddeberg, 2014). In a 2005 study of trauma survivors, Strauser et al. (2005) found a significant relationship between higher levels of trauma symptoms and higher levels of dysfunctional career thoughts and lower levels of work personality, and vocational identity. A correlation was found between trauma symptoms and career

thoughts, indicating that as trauma symptoms increase, so does the level of dysfunctional career thoughts (Strauser, et al., 2005). As a result, the trauma survivor's career goals, interests, personality, and talents become unclear and unstable. The authors propose that this finding supports the notion that trauma symptoms inhibit cognitive functions related to the development of a solid vocational identity (such as possessing clear vocational values, interests, and awareness of one's basic needs) and may interfere with the implementation of career goals (Strauser, et al., 2005).

### **Implications for Life Care Planners**

It is important for life care planners to recognize when a client is experiencing a trauma induced disorder and assist them with seeking treatment. As a life care planner, it is imperative to address these symptoms in the life care plan to ensure adequate treatment of trauma and stress related disorders. Weed and Berens (2010), in the section entitled life care planning for mental illness (p.584), provide a life care plan checklist for mental illness that can serve as a guide for developing life care plans for individuals with mental health diagnoses. The American Psychiatric Association (APA) has also published practice guidelines for diagnoses including Major Depressive Disorder (APA, 2010c), PTSD/ Acute Stress Disorder (APA, 2010a), Bipolar Disorder (APA, 2010b) and Substance Use Disorders (APA, 2010d). Each of these can be consulted both for treatment planning purposes and may serve as a foundation for collaborating with professionals in the life care plan development process. The most common traumatic stress diagnoses seen by life care planners are likely Adjustment Disorders and Post-Traumatic Stress Disorder. These may be the primary presenting diagnoses or they may be co-morbid conditions existing with a physical injury/ illness. The DSM-5 notes, "Adjustment disorders are common accompaniments of medical illness and may be the major psychological response to a medical disorder (APA, 2013, p. 289).

Adjustment disorders are reported to be the most common diagnoses in a hospital consultation setting (APA, 2013). Adjustment disorders necessitate treatment, likely in areas of counseling, anti-depressant or anxiolytic medications, with necessary medical management. Areas of the life care plan most relevant to treatment for an adjustment disorder include: Projected evaluations, projected therapeutic modalities, future medical care, medications and potentially hospitalizations. Due to the nature of an adjustment disorder, once the stress has been terminated, symptoms would not be expected to persist for more than six months (APA, 2013).

By contrast, a client with a diagnosis of PTSD may have longer-term healthcare needs. Again, areas of the life care plan that would likely be considered include: Projected evaluations, projected therapeutic modalities, future medical care, medications and potentially hospitalizations. A review of the Practice Guidelines for PTSD was conducted with the authors concluding that psychotherapy was found to have a



significant beneficial effect on PTSD diagnosed in veterans, female assault victims and victims of other traumatic events (APA, 2010). Additional cognitive-behavioral interventions including systematic desensitization, progressive muscle relaxation, breathing exercises, as well as modalities including biofeedback, group therapy, imagery rehearsal, eye movement desensitization and reprocessing (EMDR) and exposure therapy are all discussed in the Practice Guidelines. For each modality, accompanying research findings are provided, some of which report treatment frequency and duration. This review of relevant research may be helpful in developing or supporting life care plan recommendations. For PTSD, Practice Guidelines also discuss the use of antidepressant medication including SSRIs, noting that they are the “most extensively studied medications in PTSD treatment research” (APA, 2010a, p. 63) with both sertraline (Zoloft) and paroxetine (Paxil) receiving approval of the United States Food and Drug Administration for PTSD symptom treatment. They report that SSRIs have been found more effective than placebo in multiple studies, reducing PTSD symptoms and improving social and occupational functioning. The Guidelines note that patients will generally need to continue the medication for symptom control. Discussion of other medications including benzodiazepines, monoamine oxidase inhibitors (MAOIs), tricyclic and other antidepressants, as well as effectiveness research regarding each class of medication is included in the Guidelines.

#### **Life Care Planning Case Study**

For demonstration of developing life care plans for trauma-related diagnoses, a review of six (6) cases from the second author’s case load was made. In these cases, diagnoses found in the medical records included PTSD, adjustment disorder, depression, anxiety, and in one case, bipolar disorder following trauma. In these cases, the cause of the trauma was sexual abuse/ assault with two subjects reporting both sexual and physical abuse. Ages of the individuals ranges from 15 to 51 with two male victims and four female victims. Each of the individuals had achieved less than a high school diploma at the time of referral. Two were employed after the assault and three reported psychological symptoms and/ or treatment prior to the alleged abuse. Demographic data is summarized in Table 1 below.

**Table 1: Case Study Demographics**

<u>Age</u>	<u>Gender</u>	<u>Education</u>	<u>Employment</u>	<u>Pre-Event Diagnosis</u>
21	Female	<HS	No	No
21	Female	<HS	Post Only	No
21	Male	<HS	Pre/Post	Yes
19	Male	<HS	Pre/Post	Yes
15	Female	<HS	No	Yes
51	Female	<HS	Pre only	No

Consistent with life care planning methodology (Johnson, 2015; Preston & Johnson, 2012; Weed & Berens,

2010) a review of medical records was conducted that revealed DSM-IV diagnoses of adjustment disorder with anxiety and depression, post-traumatic stress disorder, depression, substance abuse and bipolar disorder. In terms of the DSM-5, PTSD and adjustment disorder would both be classified in the DSM-5 in the chapter entitled Trauma and Stressor Related Disorders (APA, 2013, 265-290). Bipolar disorder would be classified in the DSM-5 in the chapter entitled Bipolar and Related Disorders (APA, 2013, 123-154). Substance abuse would be classified in section II of the DSM-5 in the chapter entitled Substance-Related and Addictive Disorders (APA, 2013, 481-590). Anxiety would be classified in the DSM-5 in the chapter entitled Anxiety Disorders (APA, 2013, 189-233). Depression would be classified in section II of the DSM-5 in the chapter entitled Depressive Disorders (APA, 2013, 155-188).

Following review of medical records and client interviews, collaboration meetings were held with individuals involved in evaluation and/ or treatment of the individual. These professionals were most often psychiatrists, with one subject receiving care from both a psychiatrist and licensed clinical social worker (LCSW) and one from a psychologist and general practitioner. Based upon consultation with mental health professionals, life care plans were developed outlining treatment recommendations. A summary of treatment recommendations is below in Table 2.



Table 2. Life Care Planning Treatment Recommendations – Sexual Trauma

Client	Traumatic Event	Diagnosis	Life Care Plan Contributor	Recommendations
21 yo female	Sexual/ Physical Abuse	Adjustment disorder with anxiety/ depression; Post Traumatic Stress Disorder (PTSD)	Psychiatrist	One psychiatric eval through LE; Cognitive-Behavioral therapy (CBT) 48 sessions for 6 years; SSRI daily for 2 years; Psychiatrist visit 4/year for 2 years
21 yo female	Sexual/ Physical Abuse	PTSD, Depression, Anxiety	Psychiatrist	Psychiatric eval (1); CBT 48 sessions for 6 years; SSRI daily for 2 years; Psychiatrist visit 4/year for 2 years
21 yo male	Sexual Abuse	PTSD, Depression, Substance Abuse	Psychiatrist	Psychiatrist 4/yr for 5 years; 5 CBT evals through LE; Vocational rehabilitation services; SSRI for 5 years; 1 inpatient psychiatric hospitalization through LE
19 yo male	Sexual Abuse	PTSD, Bipolar Disorder	Psychiatrist	Psychiatrist visits 4 year for LE; 5 CBT evals through LE; Vocational rehabilitation services Assault Survivor group; CBT sessions 12-20 sessions/ year for 5 years; Family counseling 12-20 sessions for 5 years; SSRI for 5 years; Lithium or similar medication through LE; Laboratory monitoring yearly through LE; Inpatient psychiatric hospitalizations every 5 years through LE
15 yo female	Sexual Abuse	PTSD, Depression	Psychiatrist Social Worker (LCSW)	Psychiatrist 4/yr through LE; CBT weekly for 3 years then 10 occurrences of 27 sessions; SSRI LE; 1 Inpatient psychiatric hospitalization; Assault Survivor group; Art/Music therapy 4/mo for 8 years; Family therapy 24 sessions/ yr for 2 years; Vocational rehabilitation services
51 yo female	Sexual Assault	PTSD, Depression	General Practitioner Psychologist	GP visits 2/yr through LE; CBT weekly for one year/then 2 per month through LE; Support Group; SNRI through LE; Benzodiazepine through LE; Antidepressant through LE; Inpatient psychiatric hospitalizations PRN

The most common recommendations for future treatment of trauma-related injuries included use of anti-depressant medication and cognitive behavioral therapy, which were recommended in every case. It is noted that the frequency and duration of these services, varied, depending upon the symptomatology of the individual. Six of the seven cases included follow-up with a psychiatrist and in one case, this was performed by a general practitioner. The most common schedule of psychiatric follow up was four (4) visits per year for a period of 2-5 years in three cases and through life expectancy (LE) in two cases. Recommendations seen in three of the six cases included vocational rehabilitation services and inpatient psychiatric hospitalizations. Recommendations seen less frequently included family therapy (2 of 6 cases) and sexual assault survivor group (2 of 6 cases), art/ music therapy, use of lithium and laboratory monitoring seen in only one (1) of six (6) cases.

As can be seen, many of the future treatment recommendations were consistent with the American Psychiatric Association's Practice Guidelines. These included SSRIs and cognitive-behavioral treatment. Due to the holistic nature of the life care plan, additional recommendations including vocational rehabilitation services, family therapy and art/music therapy were found in this group of life care plans. These types of recommendations find support based upon the vocational disruption noted by Strauser et. al (2005) and also in the DSM-5 itself (APA, 2013). Because the life care plan is a comprehensive document designed to address facets of care that are not strictly medical, review of all relevant research should be made to inform the plan of care for individuals who have sustained trauma-related injuries.

### Summary

Understanding the specifics of trauma disorders is important for the life care planner, as trauma is a leading cause of disability both in the United States and abroad. Prior to the DSM-5, previous versions of the *Diagnostic and Statistical Manuals* did not provide a trauma-specific diagnostic category. The most recent version, however, includes a trauma and stressor-related disorders section where PTSD and adjustment disorders can be found. A review of DSM-5 diagnostic criteria will provide the life care planner guidance in the individual's diagnosis and prognostic factors and help the practitioner better understand the impact of the disorder on a person's functioning.

In preparation of the life care plan, various sources of research should be consulted. Research is available addressing the impact on both psychosocial and vocational outcomes for individuals with these trauma-related disorders. Review of the American Psychiatric Association's *Practice Guideline for the Treatment of Patients with Acute Stress Disorder and Posttraumatic Stress Disorder* is one source of information for life care planners to obtain research-based practice recommendations. These may serve as a basis for

recommendations when preparing life care plans for individuals who have experienced traumatic events or they may help inform the life care planner about treatment options to be discussed when collaborating with professionals in life care plan development. This important element in the life care plan should be addressed whether it is the presenting problem or a comorbid diagnosis.

### References

- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, D.C., American Psychiatric Press.
- American Psychiatric Association. (2010a). Practice guidelines for the treatment of patients with acute stress disorder and posttraumatic stress disorder. *American Psychiatric Association*. Retrieved from [https://psychiatryonline.org/pb/assets/raw/sitewide/practice\\_guidelines/guidelines/acutestressdisorderptsd.pdf](https://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/acutestressdisorderptsd.pdf)
- American Psychiatric Association. (2010b). Practice guidelines for the treatment of patients with bipolar disorder. *American Psychiatric Association*. Retrieved from [https://psychiatryonline.org/pb/assets/raw/sitewide/practice\\_guidelines/guidelines/bipolar.pdf](https://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/bipolar.pdf)
- American Psychiatric Association. (2010c). Practice guidelines for the treatment of patients with major depressive disorder. *American Psychiatric Association*. Retrieved from [https://psychiatryonline.org/pb/assets/raw/sitewide/practice\\_guidelines/guidelines/mdd.pdf](https://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/mdd.pdf)
- American Psychiatric Association. (2010d). Practice guidelines for the treatment of patients with substance use disorders. *American Psychiatric Association*. Retrieved from [https://psychiatryonline.org/pb/assets/raw/sitewide/practice\\_guidelines/guidelines/substanceuse.pdf](https://psychiatryonline.org/pb/assets/raw/sitewide/practice_guidelines/guidelines/substanceuse.pdf)
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing
- Blake, J. J., Kim, E. S., Lund, E. M., Zhou, Q., Kwok, O. M., & Benz, M. R. (2014). Predictors of bully victimization in students with disabilities in a longitudinal examination using a national data set. *Journal of Disability Policy Studies*, doi:1044207314539012.
- Broderick, P. C., & Blewitt, P. (2010). *The life span: Human development for helping professionals*. Boston: Pearson.
- Brown, J., Burnette, M. L., & Cerulli, C. (2015). Correlations between sexual abuse histories, perceived danger, and PTSD among intimate partner violence victims. *Journal of Interpersonal Violence*, 30(15), 2709-2725.
- Coursol, D. H., Lewis, J., & Garrity, L. (2001). Career development of trauma survivors: Expectations about counseling and career maturity. *Journal of Employment Counseling*, 38(3), 134.
- Follan, M., & McNamara, M. (2013). A fragile bond: Adoptive parents' experiences of caring for children with a diagnosis of reactive attachment disorder. *Journal of Clinical Nursing*, 23,1076-1085.

- Flannery Jr, R. B. (1995). *Post-traumatic stress disorder*. New York City, NY: Lantern Books.
- Frame, L., & Morrison, A. P. (2001). Causes of posttraumatic stress disorder in psychotic patients. *Archives of General Psychiatry*, 58(3), 305-306.
- Friedman, M. J., Resick, P. A., Bryant, R. A., Strain, J., Horowitz, M., & Spiegel, D. (2011). Classification of trauma and stressor-related disorders in DSM-5. *Depression and Anxiety*, 28(9), 737-749. doi:10.1002/da.20845
- Friedman, M. J. (2015). Strategies for Acute Stress Reactions and Acute Stress Disorder (ASD). In *Posttraumatic and Acute Stress Disorders* (pp. 115-135). Springer International Publishing.
- Frohman, C., & Didi, A. (2015). Preventing violence against women and girls with disabilities: Integrating a human rights perspective. *Women*. Retrieved from [http://wwda.org.au/wp-content/uploads/2013/12/Think-Piece\\_WWD.pdf](http://wwda.org.au/wp-content/uploads/2013/12/Think-Piece_WWD.pdf)
- Harrell E. (2012). Violent victimization committed by strangers, 1993-2010. *Bureau of Justice Statistics Special Report*. Washington, DC: U.S. Department of Justice.
- Hassouneh-Phillips, D., & Curry, M. A. (2002). Abuse of women with disabilities state of the science. *Rehabilitation Counseling Bulletin*, 45(2), 96-104.
- Hines, D. A., Malley-Morrison, K., & Dutton, L. B. (2013). *Family violence in the United States: Defining, understanding, and combating abuse* (2nd ed.). Thousand Oaks, CA, US: Sage Publications, Inc.
- Iversen, M. H., Kilvik, A., & Malmedal, W. (2015). Sexual Abuse of Older Residents in Nursing Homes: A Focus Group Interview of Nursing Home Staff. *Nursing Research & Practice*, 20151-6. doi:10.1155/2015/71640
- Johnson, C.B. (2015). Consensus and majority statements derived from life care planning summits held in 2000, 2002, 2004, 2006, 2008, 2010, 2012 and 2015. *Journal of Life Care Planning*, 13(4), 35-38.
- Jones, L., Bellis, M. A., Wood, S., Hughes, K., McCoy, E., Eckley, L., Bates, G., Mikton, C., Shakespeare, T., & Officer, A. (2012). Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies. *The Lancet*, 380(9845), 899-907.
- Jones, L. K., & Cureton, J. L. (2014). Trauma redefined in the DSM-5: Rationale and implications for counseling practice. *The Professional Counselor*, 4(3), 257-271.
- Kenny, D. T., Blacker, S., & Allerton, M. (2014). Reculer Pour Mieux Sauter: A review of attachment and other developmental processes inherent in identified risk factors for juvenile delinquency and juvenile offending. *Laws*, 3(3), 439-468.
- Lifespan of Greater Rochester, Inc., Weill Cornell Medical Center of Cornell University & New York City Department for the Aging. (2011). Under the radar: New York state elder abuse prevalence study. *Lifespan of Greater Rochester, Inc., Weill Cornell Medical Center of Cornell University & New York City Department for the Aging*. Retrieved from <http://ocfs.ny.gov/main/reports/Under%20the%20Radar%202005%2012%2011%20final%20Oreport.pdf>
- Lightfoot, E., & Williams, O. (2009). The intersection of disability, diversity, and domestic violence: Results of national focus groups. *Journal of Aggression, Maltreatment & Trauma*, 18(2), 133-152.
- Mayo Clinic Staff (2017). Post-traumatic stress disorder (PTSD). *Mayo Foundation for Medical Education and Research*. Retrieved from <http://www.mayoclinic.org/diseases-conditions/post-traumatic-stress-disorder/symptoms-causes/dxc-20308550>
- Millward, R., Kennedy, E., Towlson, K., & Minnis, H. (2006). Reactive attachment disorder in looked-after children. *Emotional & Behavioural Difficulties*, 11(4), 273-279.
- Minnis, H. (2003). Reactive attachment disorder: The missing link in the causation of social exclusion? *International Journal of Mental Health Promotion*, 5(4), 42-46.
- National Coalition Against Domestic Violence. (2015). *Statistics*. Retrieved from <http://www.ncadv.org/learn/statistics>
- National Institute of Mental Health. (2017). Post-Traumatic Stress Disorder. National Institute of Mental Health. Retrieved from <https://www.nimh.nih.gov/health/topics/post-traumatic-stress-disorder-ptsd/index.shtml>
- National Research Council. (2003) Elder mistreatment: Abuse, neglect and exploitation in an aging America. Washington, D.C.: The National Academies Press.
- Nebraska Department of Veterans' Affairs. (2007). Posttraumatic Stress Disorder. Nebraska Department of Veterans' Affairs. Retrieved from <http://www.ptsd.ne.gov/what-is-ptsd.html>
- Nemeroff, C. B., Weinberger, D., Rutter, M., MacMillan, H. L., Bryant, R. A., Wessely, S., & Malhi, G. S. (2013). DSM-5: A collection of psychiatrist views on the changes, controversies, and future directions. *BMC Medicine*, 11(1), 202.
- Office for Victims of Crime. (n.d.) Multidisciplinary response to crime victims with disabilities. *Office of Justice Programs*. Retrieved from <https://www.ovc.gov/pubs/victimswithdisabilities/communityguide/comm-print.html>
- Pagotto, L. F., Mendlowicz, M. V., Coutinho, E. S. F., Figueira, I., Luz, M. P., Araujo, A. X., & Berger, W. (2015). The impact of posttraumatic symptoms and comorbid mental disorders on the health-related quality of life in treatment-seeking PTSD patients. *Comprehensive Psychiatry*, 58, 68-73.
- Plummer, S. B., & Findley, P. A. (2012). Women with disabilities' experience with physical and sexual abuse

- review of the literature and implications for the field. *Trauma, Violence, & Abuse*, 13(1), 15-29.
- Preston, K. & Johnson, C. (2012). Consensus and majority statements derived from life care planning summits held in 2000, 2002, 2004, 2006, 2008, 2010 and 2012. *Journal of Life Care Planning*, 11(2), 9-14.
- Scheeringa, M. S., & Zeanah, C. H. (2001). A relational perspective on PTSD in early childhood. *Journal of Traumatic Stress*, 14, 799-815. doi:10.1023/A:1013002507972.
- Schnyder, U., Moergeli, H., Klaghofer, R., & Buddeberg, C. (2014). Incidence and prediction of posttraumatic stress disorder symptoms in severely injured accident victims. *American Journal of Psychiatry*.
- Shevlin, M., Hyland, P., & Elklit, A. (2014). Different profiles of acute stress disorder differentially predict posttraumatic stress disorder in a large sample of female victims of sexual trauma. *Psychological Assessment*, 26, 1155-1161. doi: <http://dx.doi.org/10.1037/a0037272>
- Stalker, K., & McArthur, K. (2012). Child abuse, child protection and disabled children: A review of recent research. *Child Abuse Review*, 21(1), 24-40.
- Strauser, D. R., Lustig, D. C., Cogdal, P. A., & Uruk, A. Ç. (2006). Trauma symptoms: Relationship with career thoughts, vocational identity, and developmental work personality. *The Career Development Quarterly*, 54(4), 346-360.
- Truman, J. L., & Planty, M. (2012). Criminal victimization in the United States, 2011. *Bureau of Justice Statistics Office of Justice Programs*, Washington, DC.
- Tyiska, C. G. (1998). Working with victims of crime with disabilities. *US Department of Justice, Office of Justice Programs, Office for Victims of Crime*.
- U.S. Department of Justice (2016). *Criminal victimization, 2015*. Retrieved from <https://www.bjs.gov/content/pub/pdf/cv15.pdf>
- Weed, R.O. & Berens, D.E. (2010). *Life care planning and case management handbook*, (3rd edition). Boca Raton: CRC Press.
- World Health Organization. (2014). Injuries and violence: The facts 2014. *World Health Organization*. Retrieved from <http://www.who.int/iris/handle/10665/149798#sthash.orTUv3TT.dpuf>
- Zelechowski, A. D., Sharma, R., Beserra, K., Miguel, J. L., DeMarco, M., & Spinazzola, J. (2013). Traumatized youth in residential treatment settings: prevalence, clinical presentation, treatment, and policy implications. *Journal of Family Violence*, 28(7), 639-652.
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## Ethics Interface

Nancy Mitchell

### Dilemma

I recently was retained by a plaintiff attorney and completed a life care plan for his client. I just received a report written by the defense life care planner viciously attacking my plan. This has happened many times with the same life care planner. When does the criticism of another person's work cross the line? At what point is this unprofessional or unethical?

### Response

Life care planners come from individual primary health care/disability backgrounds. In those employment situations, someone is not hired specifically to analyze our work. It can be painful and even embarrassing to have our work critiqued in a written and public forum. However, a boundary is crossed when the life care planner is attacked rather than the work or methodology. Such statements can be considered disparaging remarks.

It is helpful to review the definition of disparaging remarks from the glossary of the CRCC Code of Ethics: "public statements that degrade, belittle, minimize, defame, demean, humiliate, or scorn individuals or groups of individuals. These differ from critiques, which are intended to provide comparisons of thoughts, ideas, methods, work products, or conclusions. If statements criticize the individual as a person, their character or intellect, or are based on incorrect information or fictional claims, these are considered disparaging remarks."

Criticism of our work can be a challenge but it is something life care planners must learn to accept as an inevitable part of the work. Life care planners can minimize criticism by using well-established and accepted methodology, staying within their scope of practice, and using consistency as they develop life care plans. A life care planner retained to critique another's life care plan must be mindful that critiques should be focused on the work, the methodology, and conclusions of the opposing life care planner rather than a personal attack about the value of the person. A life care planner who violates these principles can be reported for an ethical breach to the certifying organization.

### Relevant Organizational Standards

From the Certification of Disability Management Specialists (2015)

RPC 3.02 – Indirect Service Provision

When serving as case consultants or expert witnesses, certifiants shall provide unbiased, objective opinions.

From the International Academy of Life Care Planners (2015)

Ethical

5. Life care planners are professionals, from varying educational backgrounds, who maintain professional conduct when addressing opposing life care plan consultants. Life care plan consultants should focus upon methodology of plan development, supporting documentation for recommendations and plan content.

From the International Commission on Health Care Certification. (2015).

Principle 1 - Professional and Legal Standards

*ICHCC certifiants shall behave in legal, ethical, and professional manner in the conduct of their profession, maintaining the integrity of the Code of the Professional Ethics and avoiding any behavior which would cause harm to other entities and/or individuals*

R1.1 ICHCC Certifiants shall obey the laws and statutes in the legal jurisdiction in which they practice and are subject to disciplinary action for any violation to the extent that such violation suggests the likelihood of professional misconduct.

R1.4 ICHCC Certifiants shall not engage in any acts or omission of a dishonest, deceitful, or fraudulent nature in the conduct of their professional activities.

R1.5 ICHCC Certifiants shall understand and abide by the Principles and Rules of Professional Conducts, which are prescribed in the *Code of Professional Ethics*.

R 1.6 ICHCC Certifiants shall not advocate, sanction, participate in, and cause to be accomplished, otherwise carry out through another, or condone any act, which the ICHCC Certifiants are prohibited from performing by the *Code of Professional Ethics*.

Principle 4 - Professional Relationships

*ICHCC Certifiants shall act with integrity in their relationships with colleagues, other organizations, agencies, institutions, referral sources and other professions as to facilitate the contributions of all specialists.*

R4.5 ICHCC Certifiants shall not discuss with evaluatee and/or referral source reputations and/or competency of colleagues in a disparaging manner, nor will they provide judgments to the evaluatees regarding quality and appropriateness of treatment they may have received from other professionals.

R4.8 ICHCC Certifiants possessing knowledge of any rule violation of this Code of Professional Ethics is obligated to

reveal information to the International Commission on Health Care Certification unless the information is protected by law.

From the AANLCP- Code of Ethics 2015  
Ethics Guideline

3. The nurse life care planner incorporates high standards of professional conduct through the continuum of the nurse life care planning services.

The nurse life care planner demonstrates honesty, integrity, responsibility, accountability, timeliness and respect for human dignity.

The nurse life care planner will not knowingly engage in unethical or unlawful activities nor will they knowingly misrepresent their background or credentials, or promote personal interests for personal gain.

The nurse life care planner remains objective and does not impose individual values on others.

5. The nurse life care planner assumes responsibility and accountability for all actions, opinions, recommendations, and commitments.

The nurse life care planner assumes accountability for his/her life care plan, as well as their actions, opinions and decisions.

The nurse life care planner relies upon his/her specialized education, body of knowledge, level of competence and experience when accepting and completing an assignment.

The nurse life care planner's professional services are delivered in a competent, concise and timely manner.

6. The Nurse Life Care Planner provides professional services with objectivity. The nurse life care planner demonstrates critical thinking in decisions, recommendations and opinions. All functions of the nurse life care planner are void of personal opinion, prejudice and conflict of interest or any such other consideration that could interfere with or influence objectivity, performance or outcome.

## References

- American Association of Nurse Life Care Planners. (2014). *Nurse life care planning scope and standards of practice*. Salt Lake City, UT: Author.
- Certification of Disability Management Specialists Commission. (2015). *CDMS Code of professional*

*conduct*. Retrieved from [http://www.cdms.org/uploads/files/CDMS\\_Code\\_of\\_Professional\\_Conduct.pdf](http://www.cdms.org/uploads/files/CDMS_Code_of_Professional_Conduct.pdf)

International Commission on Health Care Certification. (2015). *Standards and examination guidelines*. Retrieved from [http://www.ichcc.org/PDFs/ICHCC\\_Standards\\_andGuidelines.pdf](http://www.ichcc.org/PDFs/ICHCC_Standards_andGuidelines.pdf)

Commission on Rehabilitation Counselor Certification. (2010). *Code of professional ethics for rehabilitation counselors*. Schaumburg, IL: Author. Retrieved from <http://www.crcrcertification.com/>

International Academy of Life Care Planners. (2015). *Standards of practice for life care planners* (3rd ed.). International Academy of Life Care Planners, The Life Care Planning Section of the Association of Rehabilitation Professionals. Retrieved from [http://www.rehabpro.org/sections/ialcp/life-care-planning/standards/ialcpSOP\\_pdf](http://www.rehabpro.org/sections/ialcp/life-care-planning/standards/ialcpSOP_pdf)

This column is the collaborative effort of Nancy Mitchell, Mary Barros-Bailey, Sherry Latham, Bobbi Dominick, and Ann Neulicht. The author is grateful for their editorial support, wisdom, and collective experience.

The column is meant to be an educational forum for life care planners. It is not designed to offer an authoritative opinion from the editor or editorial board of the *Journal of Life Care Planning*, the board of the International Academy of Life Care Planners, or the board of its parent organization, the International Association of Rehabilitation Professionals, nor is this column designed to represent or replace official opinions from the certifying body or other organizations associated with the practice of life care planning.

## Questions

**1. In forensic practice, criticizing the opposing life care planner is:**

- a) allowed.
- b) expected.
- c) disparaging.
- d) methodological.

**2. Methodology in the development of a life care plane is a source for an ethical:**

- a) critique of the work product.
- b) attack by an opposing life care planner.
- c) fierce public opposition.
- d) criticism of the work product.

**3. Using a well-established methodology in the development of a life care plan invites:**

- a) demeaning statements.
- b) protection.
- c) criticism.
- d) disparaging remarks.

**4. Comparisons of thoughts, ideas, methods, work products, or conclusions:**

- a) have no place in life care planning.
- b) are unwarranted.
- c) are unethical.
- d) are expected in forensic practice critiques.

**5. In forensic practice, critiquing the work product of an opposing expert is:**

- a) allowed.
- b) unruly.
- c) disparaging.
- d) unethical.

**6. Life care planners should not discuss with the plaintiff the in a manner.**

- a) opposing expert, collegial
- b) opposing expert, disparaging
- c) colleague, beneficent
- d) colleague, collegial

**7. The ICHCC requires certified life care planners to:**

- a) advocate for the retaining party.
- b) act in their own self-interest.
- c) advocate for the plaintiff.
- d) act with integrity in relationships with colleagues.

**8. Public statements that minimize or demean an individual or group are:**

- a) critiques.
- b) criticisms.
- c) factual.
- d) inconclusive.

**9. When receiving repeated vicious attacks from the same life care planner on a variety of your life care plans, as a life care planner you should:**

- a) file an ethical complaint with the appropriate professional board or organizations.
- b) discuss this fact with the retaining party, but not otherwise act.
- c) react with the same vicious criticisms.
- d) tell other colleagues about the life care planner's behavior.

**10. Life care planners remain and in their critique of the opposing expert's work product.**

- a) unbiased, skewed.
- b) unbiased, critical
- c) objective, critical
- d) objective, unbiased



# Guidelines for Authors

## Purpose and Objectives

The *Journal of Life Care Planning* publishes refereed education and research materials relevant to the practice and processes of life care planning. The specific objectives of the Journal are as follows:

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- Provide a forum for the debate and discussion of practice issues.
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