

## CASE REPORTS

# Advance care planning in same-sex couples

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## ABSTRACT

Advance care planning (ACP) is a process in which an individual's goals, desires, and preferences regarding health care during a serious illness or end of life are explored by the clinician through conversations with the patient and their families. ACP is underutilized among same-sex couples. In our case report we describe a same-sex couple who did not have an ACP. The gap in current practice is primarily due to provider discomfort or unfamiliarity in discussing end of life care issues especially in same-sex couples. If not remedied, this could negatively impact the physical and emotional health in this vulnerable population leading to health disparities.

**Key Words:** Advance care planning (ACP), Same-sex couples, Men who have sex with men (MSM)

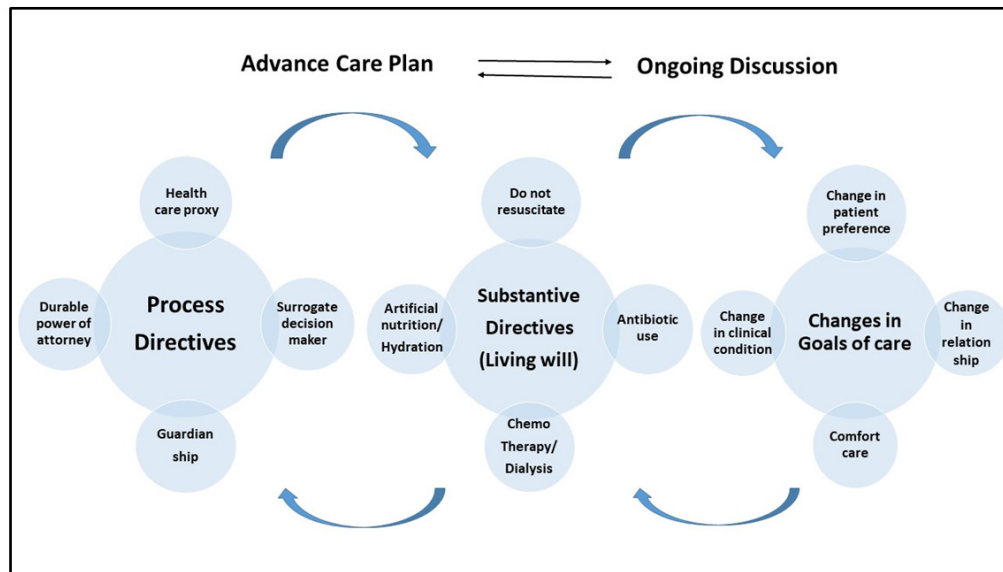
## 1. INTRODUCTION

A terminal medical illness or severe injury could place an individual in a situation where they are unable to make medical decisions for themselves. Advanced care planning (ACP) involves learning about the types of healthcare decisions that might need to be made, considering these decisions ahead of time, and letting others know about these preferences often in the form of an advance directive (AD).<sup>[1]</sup> The term "AD" is used to denote a written document that addresses future medical care of an individual. The two major forms of AD (see Figure 1) are process directives (i.e., health care proxy, durable power of attorney) and substantive directives (i.e., living will). Some ADs may contain both forms. Completing an AD can extend patient autonomy if they lose decision making capacity. However, completing an AD alone is insufficient and has several limitations including the inability to accurately predict the future and the possibility of individual's preferences changing over time.<sup>[2]</sup> Therefore, recent

focus within medical education and clinical practice has been on the implementation of ACP.

ACP is a process in which an individual's goals, desires, and preferences are explored by the clinician through conversations with the patient and their families.<sup>[3-5]</sup> ACP is a dynamic process that evolves as an individual experiences serious illness and as their condition changes over time. There are several barriers to completing ACP: lack of awareness, patient and provider denial of death and dying, conflict between choosing palliative care and aggressive care at end of life, racial, ethnic, and gender orientation differences in preferences at end of life.<sup>[6,7]</sup> Mitigating these barriers and incorporating patient's wishes in the form of AD can effectively extend patient autonomy especially if the patient loses decision making capacity, and alleviate stress on next of kin.<sup>[8]</sup> In this case report, we discuss ACP in the context of a same-sex couple who faced some of these barriers, and share some practice recommendations to mitigate these barriers.

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**Figure 1.** Advance care planning and its components

## 2. CASE PRESENTATION

DB is a 49-year-old male with Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease. He currently receives nutrition through a percutaneous endoscopic gastrostomy (PEG) tube and is dependent on a ventilator for breathing. He attempts to communicate with a Tobii eye tracker, but most days he is too weak to move his eyes in order to effectively operate the device. DB's disease has progressed to the point where he is now completely bedbound and resides at home with his male partner, JT, on whom he is dependent for all his activities of daily living.

DB and JT are a same-sex couple who have been together for nearly 24 years. Eight years ago, DB developed speech problems and other vague symptoms such as fatigue and difficulty swallowing. He underwent multiple assessments by different specialists and extensive investigations over a period of several months. In 2011, he was diagnosed with bulbar-onset ALS. In 2013, he developed trouble with chewing and swallowing and subsequently started losing weight rapidly. DB and JT contemplated getting a PEG tube for nutritional supplementation and eventually decided to have it placed. Two years later, DB developed worsening breathing problems and his neurologist recommended that he get a bi-pap for use at night. He became increasingly dependent on the BiPAP (Bilevel Positive Airway Pressure) and eventually needed tracheostomy and ventilator support. DB continued to experience progressive voluntary muscle weakness and became increasingly dependent upon his gaze tracker to communicate. Some days, DB appears tearful and makes subtle expressions that imitate grimaces. It is difficult to discern if these emotions are the result of physical or emotional pain.

JT continues to face daily uncertainty with regards to what DB would want for himself as he feels that DB is "locked in" and currently has a poor quality of life.

DB and JT are highly educated and both of their families fully support their relationship. They have considered getting married, but since it was not legal in the state in which they lived in at that time, they did not actively pursue marriage. JT recalled that he felt the need to "contract" everything for legal purposes. As such, the couple obtained a will for their estate and also designated each other as power of attorney for health care. While this is a form of advance directive, they did not possess a comprehensive ACP.

## 3. ACP IN SAME-SEX COUPLES

ACP is underutilized within the general population with only one third of adults expressing their wishes in the form of an AD.<sup>[9]</sup> Such healthcare discussions may be even more crucial to complete in same-sex couples as the default state medical decision-making laws may not recognize same-sex relationships and therefore not extend the surrogate decision making capacity to a same-sex spouse or partner.<sup>[10]</sup>

Same-sex couples represent one special subset with a particular need for discussion regarding ACP.<sup>[11]</sup> Same-sex couples and their families face unique challenges in a health care system that does not always recognize or respect their relationship. Same-sex couples frequently face negative attitudes while seeking medical treatment for physical and emotional health.<sup>[11]</sup> Men who have sex with men (MSM) make up about 4% of the male population in the United States.<sup>[12,13]</sup> This fraction of the population is subjected to a disproportion-

ate amount of medical disparities that place them at increased risk for chronic disease, untreated psychiatric illnesses, and lack of appropriate health screenings.<sup>[12,13]</sup> Same-sex couples may be hesitant to disclose their sexual orientation for fear of being met with judgment or disapproval.<sup>[12,13]</sup> There-

fore, this population is at increased risk to healthcare inequalities secondary to provider discomfort or unfamiliarity in discussing end of life care issues with same-sex spouses or loved ones.<sup>[13,14]</sup>

**Table 1.** Key practice recommendations for ACP in same-sex couples

Components	Strategies
Clinical education	ACP clinical simulation workshop using standardized patients (including diverse population) for medical students
	Optional self-directed clinical modules on LGBTQ healthcare issues through inter-professional education (IPE) curriculum
Clinical practice	Conversation with patients with terminal illness or advancing age during office visit
	Assess for ACP during hospitalization
	EMR templates for ACP
	Readdress ACP when patient’s condition changes
	Assess the gender orientation and relationship status
	Create a LGBTQ friendly environment in the clinic
	Register in LGBTQ provider network

**4. DISCUSSION**

JT developed sepsis secondary to pneumonia, and became unresponsive. He also developed pressure sores and frequently appeared to be in distress. DB felt torn as he was convinced JT would not like to live like this. After much deliberation, DB made the decision to stop peg nutrition and withdraw ventilator support. This was done at their home with support from hospice chaplain and social worker. JT passed peacefully shortly after withdrawing ventilator support. We have summarized some practice recommendations (see Table 1) here based on our experience in caring for JT and DB.

Clinicians must to be educated about the difference between AD and ACP.<sup>[14]</sup> Medical students must to be aware of the terminology and process of completing ACP. This can be effectively taught through clinical simulation with standardized patients. Residents and practicing clinicians have to address these issues ideally at the point of diagnosis of serious medical illness and routinely for geriatric patients with multiple medical problems. Hospitalists should determine whether their patients have an ACP and if not, initiate a discussion and encourage completion of an ACP. Social workers and case managers can help coordinate this process. Standardized templates for ACP need to be incorporated into the patient chart within electronic medical records for easy access.<sup>[15]</sup> To increase provider awareness, optional self-directed clinical modules on lesbian, gay, bisexual, transgender (LGBTQ) healthcare issues should be made available through academic institution’s inter-professional education (IPE) curriculum.

Clinicians must be willing to readdress ACP when the pa-

tient’s condition changes. In DB’s case, when his condition deteriorated and he needed a PEG tube for nutritional support and BiPAP for respiratory support, DB and JT experienced a decision-making dilemma. PEG nutrition and ventilatory support are medical interventions which can be initiated and stopped based on patient’s individual preferences. Many clinicians are uncomfortable with readdressing patient needs in light of changing medical condition, which can be further complicated by provider experience in caring for diverse populations. Engaging a palliative care physician in co-managing such patients could alleviate the associated challenges in these situations.

Diverse populations such as same-sex couples have certain societal challenges that need to be respected while addressing ACP.<sup>[12,13]</sup> Until recently, Homosexuality and transgender identity were listed as psychological disorders and long history of stigmatization, discrimination and abuse exists in this population, predisposing them to significantly higher risk of anxiety, depression, posttraumatic stress disorder and suicidality.<sup>[11]</sup> Clinicians need to be aware that same-sex couples may have reservations regarding disclosing their relationship status. Provider attitudes towards the partners or spouses of same-sex patients can drastically affect the quality of care that patients receive. For each clinical encounter, clinicians need to ask about relationship status such as married, single or partnered along with need for initiating conversation about ACP.<sup>[11,12]</sup> Clinicians need to be sensitive and respectful about a patient’s gender orientation and partner status. Creating a same-sex friendly environment through facilitated training may help assuage patients’ stress while creating an

environment that fosters open discussion of healthcare concerns of diverse population. Providers can display equality symbols, pink triangles, or rainbow flags in offices, online media, and in printed brochures to indicate that they welcome same-sex patients. Furthermore, providers may register with a LGBTQ provider network such as Gay & Lesbian Medical Association (GLMA) and elect to be listed on an electronic provider directory that can easily be accessed from an online search. These techniques enhance the provider's visibility and may help to establish trust with same-sex couples, who may have been hesitant to seek services secondary to distrust or discomfort with the healthcare system.

## 5. CONCLUSION

In a changing health care environment with focus on patient centered medical care, addressing ACP could ensure high quality care focused on individual preferences, especially in same-sex couples.

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## CONFLICTS OF INTEREST DISCLOSURE

The authors have declared no conflicts of interest.

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