


# Palliative Care and Legal Issues in Geriatric Psychiatry

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## ABSTRACT

There is an increased risk of debilitating illnesses that often have no curative treatment with aging. The mainstay of treatment in many such conditions is palliative care: a holistic approach focused on preventing and relieving physical, psychosocial, legal, ethical, and spiritual problems. It involves the facilitation of end-of-life care decisions aimed at relieving distress and improving quality of life. In this article, the authors discuss the role of mental health professionals in legal issues related to palliative care in the elderly around decision-making, right to autonomy, euthanasia, and advanced directive. The cognitive decline associated with aging and mental health issues in the palliative care setting of an individual such as dementia, depression, and hopelessness, and impact on the family members like burnout may influence the overall capacity of that individual to make decisions about their treatment. While an individual has a right to self-determination and autonomy, withholding or withdrawing treatment has many legal and ethical implications, more so in those with incapacity, especially in India due to the absence of uniform

legislation. The decision to withhold or withdraw treatment might be a restrictive choice due to limited options in a setting with a lack of palliative care options, poor psychosocial support, nonaddress of mental health issues, and lack of awareness. As the right to health is a constitutional right, and the right to mental health is legally binding under Section 18 of the Mental Health Care Act 2017, systematic efforts should be made to scale up services and reach out to those in need.

**Keywords:** Advanced directive, decision-making capacity, individual autonomy, palliative care

The interface of palliative care (PC) and psychiatry is crucial. Psychiatric issues in patients receiving PC are highly prevalent both due to the illness itself and its implications.<sup>1</sup> The progress made in PC in India is still primitive, albeit encouraging. Decision-making capacity, the autonomy of the individual, and State's responsibilities towards the individuals in need of PC have complex interaction and legal implications. The enigma of life and

death has attracted people from various backgrounds, including philosophers, psychologists, religious preachers, physicians, intellectuals, and writers alike. Alfred Tennyson quoted, "no life that breathes with human breath has ever truly longed for death." When one loses one's conceptual identity, the quality of life is sunk, and the sanctity of life is destroyed. Whose duty is it to uphold one's fundamental right to live with dignity? In this article, the authors discuss the role of mental health professionals in legal issues related to PC in the elderly around decision-making, right to autonomy, euthanasia, and advanced directive.

## Palliative Care

### What Is Palliative Care?

In life-threatening illnesses, PC is an approach to improve the quality of life of patients and their family members. This is achieved through prevention and relief of suffering through early identification, assessment, and treatment of pain and other problems that are either physical,

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psychosocial, legal, ethical, or spiritual.<sup>2</sup> PC affirms life and intends neither to hasten or postpone death. Cardiovascular diseases, malignancies, Parkinson's disease, severe mental illness, dementia, neurological diseases, chronic renal failure, and chronic infections are important indications for PC.<sup>2</sup>

## Need for PC: The Problem Statement

Worldwide, around 40 million people require PC each year.<sup>2</sup> There is substantial evidence to suggest that PC is integral and beneficial for end-of-life care. With the increasing geriatric population globally, the burden of life-threatening and debilitating disorders that require PC have also increased.<sup>2,3</sup> Around 70% of those in need of PC are constituted by those aged above 60 years.<sup>4,5</sup> Up to 50% of individuals receiving PC have co-existing mental health issues.<sup>6</sup> **Figure 1** describes the components and methods of providing PC. According to a survey done by WHO in 2019 across 194 member states, funding for PC was available only in 68% of the countries and only 40% of the countries were able to reach out to at least 50% of the population.<sup>7</sup> Merely 1%–2% of the people have access to PC or pain management in India.<sup>8</sup> India is a major exporter of the opioid to the rest of the world but treats less than 2% of its

patients who require opioid for the treatment of chronic and debilitating pain.<sup>8</sup> The demand for PC is increasing due to an increase in noncommunicable diseases; however, its availability is limited.<sup>3</sup>

## The Interface of PC and Psychiatry

Patients requiring PC are at an increased risk of psychiatric issues such as anxiety, depression, hopelessness, suicidal ideations, cognitive impairment, delirium, dementia, insomnia, decreased appetite, fear and uncertainty related to death, terminal restlessness, and agitation.<sup>9–11</sup> It is not just the patients, the caregivers who are under enduring stress also need PC.<sup>12</sup> Anticipatory grief, burnout, PTSD, unwillingness to accept reality, complicated grief, and chronic grief have been the issues recognized in the caregivers.<sup>13</sup>

The roles of a mental health professional in the PC setting are many. These are broadly divided into clinical and legal roles. Clinical roles would be to identify and address the mental health issues in the patient and the family members. Issues range from pain management, emotional and spiritual support, psychotherapy, and pharmacotherapy. One must judiciously use antidepressants, benzodiazepines, antipsychotics, opioid analgesics, and psychostimulants while providing PC. There are various

psychosocial interventions such as Existential Psychotherapy, Cognitive Behavior Therapy, Supportive Expressive Therapy, Meaning Centered Group Therapy, Individual Meaning Centered Group Therapy, Dignity Therapy, and Managing Cancer and Living Meaningfully (CALM) approaches. The general themes in therapy are related to generativity, continuity of self, role preservation, maintenance of pride, hopefulness, aftermath concerns, and care tenor.<sup>14</sup> A PC psychiatrist is also expected to have an educational role regarding mental health issues. The legal roles would be centered around capacity assessment for treatment decisions or other civil issues like testamentary capacity. The treatment-related decisions could center around specific issues like the decision to withhold treatment and the presence of a valid advanced directive if capacity is absent. This article primarily focuses on the legal aspects involved in PC in geriatric psychiatric settings.

## Barriers in Providing PC

Various barriers to PC development are a lack of clear policy, lack of specialists for a multispecialty team, lack of investment in health resources, lack of awareness, elderly neglect, financial constraints, lack of educational programs to teach PC, and a lack of pain-reducing medications.<sup>15</sup> This is further complicated when the individuals suffering from the illness lose their decision-making capacity related to treatment.

## Legal Aspects Involved in PC in the Geriatric Psychiatry Setting

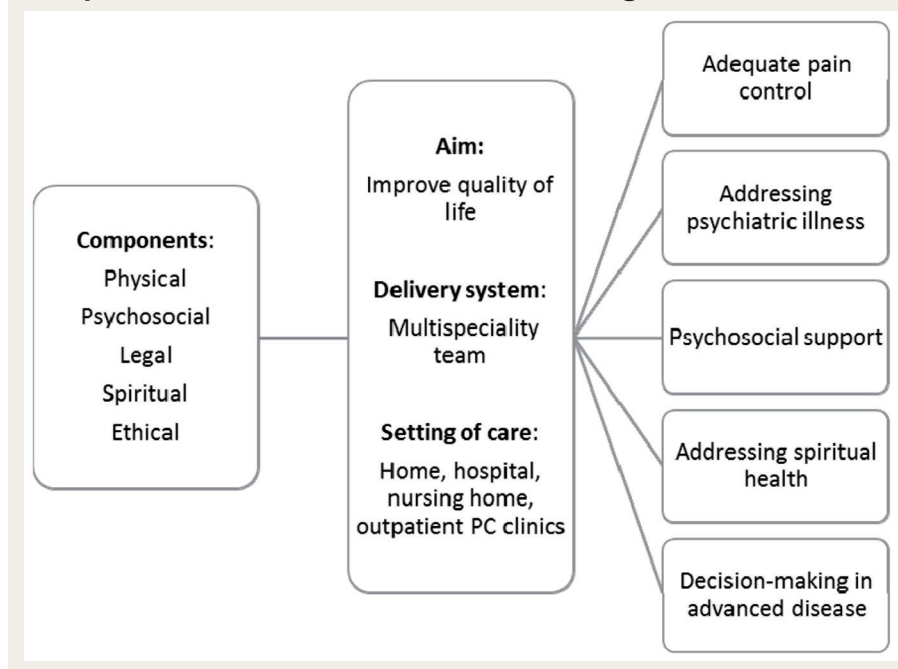
### Decision-Making and Capacity

Capacity assessment is instrumental in upholding the individual's autonomy and dignity to decide. This provides a means to mitigate potential harm that could arise from failing to intervene when cognitive deficits and other factors render a threat to the individual's well-being and decision-making capacity. Medical and psychiatric diagnoses contributing to incapacity need to be assessed.

There are broadly two conditions when a psychiatrist might be requested for capacity assessment: (a) When the

FIGURE 1.

### Components, Modes, and Methods of Providing PC



individual's primary condition that warrants PC is a severe form of mental illness like severe dementia, and (b) When the individual is receiving PC for a physical or neurological condition but has developed mental health issues like severe depression and hopelessness. The assessment would grossly include whether the individual can understand the information provided, appreciate and reason out the consequences of the decision made, and express their choice.<sup>16</sup> During the entire process, the individual's values should be upheld, and the reasons for making a particular decision should be explored.

Interventions that can enhance the capacity should be explored and implemented.

## Right to Self-Determination and Individual Autonomy

The right to self-determination and individual autonomy in health care decisions entails exercising choice in deciding for any particular treatment from available alternatives or opting for no treatment at all, thus resonating with the person's aspiration and values. However, to be autonomous, the patient should have the capacity to make decisions. In the absence of capacity, his wishes expressed in advance in the form of a Living Will or the wishes of a surrogate decision-maker would become important.

In 1990, the United States Congress enacted the Patient Self-Determination Act (PSDA), which acknowledged the patient's rights to either refuse or accept treatment.<sup>17</sup> As per the *Common Cause v. Union of India* (2018),<sup>18</sup> where the patient has already made a valid AD free from reasonable doubt and specifying how or not one wishes to be treated, such directive must be given effect.

## The Decision of Withholding or Withdrawing Treatment

Euthanasia is an intentional premature termination of another person's life either by direct intervention (active euthanasia) or by withholding life-prolonging measures and resources (passive euthanasia) either at the expressed or implied request of that person (voluntary euthanasia) or in the absence of such an approval or consent (nonvoluntary euthanasia).<sup>19</sup> A distinc-

tion should be made between euthanasia and Physician-Assisted Dying (PAD). In euthanasia, a physician or a third party administers it, while in PAD, it is the patient who does it, though, at the advice of the doctor.<sup>20</sup> The Netherlands was the first country in the world to decriminalize euthanasia under strict regulations.<sup>21</sup> Euthanasia and/or PAD have been legalized/decriminalized in various regions across the globe on various grounds like the right to die with dignity, the right to self-determination, and individual autonomy. This legalization varies between countries as a few allow passive euthanasia for minors with special laws (e.g.: Belgium) while few exclude minors (e.g.: Luxembourg), few allow assisted suicide that has led to "suicide tourism" (e.g.: Switzerland). Several countries do not have clear laws about euthanasia, although courts have passed landmark judgments in this regard (e.g.: India).

The right to live with dignity is a fundamental right, as per article 21 of the Indian Constitution. Would the right to die with dignity come within the fold of article 21? The Indian courts have taken varying viewpoints in this accord. Some courts have viewed it as a threat to the fundamental right to live, have clarified that the right to die should not be confused with the right to die an unnatural death curtailing the natural life span before the process of death has set in, while others have viewed it as a process of accelerating an otherwise slow and painful death to reduce the suffering. As per the Indian Penal Code (1860), terminating a person's life is a criminal offense under Section 302 (punishment for homicide).

With changes happening around the Netherlands, Belgium, and a few states in the United States, India too came up with the Euthanasia (Regulation) Bill (2002). However, this was rejected in Parliament. After that, several attempts to form legislation for euthanasia were made, which were in vain. India has only one legislation concerned with the end of life: The Human Organ Transplant Act (1994 and 2011), which validated the concept of brain death for the limited purposes of organ donation.<sup>22</sup> However, the landmark judgment of *Aruna Ramachandra Shanbaug v. Union of India* (2011)<sup>23</sup> revamped India's outlook on euthanasia. In *Aruna Ramachandra Shanbaug v. Union of India* (2011), an activist-journalist filed a petition under Article 32 of the Constitution requesting

passive euthanasia. The petitioner was a victim of sexual assault and had been in a permanent vegetative state (PVS) for 37 years. Although the petitioner did not get approval for passive euthanasia for various reasons, the Supreme Court, for the first time, laid clear guidelines for passive euthanasia, and approval from a High Court for passive euthanasia was made mandatory.

In 2018, the Supreme Court passed another landmark judgment, the *Common Cause v. Union of India*,<sup>18</sup> which reemphasized the right to die with dignity, legalized passive euthanasia, introduced the concept of Living Wills, and provided elaborate procedures to be followed to execute the AD. The *Common Cause v. Union of India* (2018) concluded that the right to die with dignity is a fundamental right enshrined under Article 21 of the Constitution. It also specifies that active euthanasia is not covered under the right to die with dignity. It recognized the right of an adult to have the mental capacity to make an informed decision to refuse medical treatment, including withdrawal from even life-saving devices.

In 2015, the End-of-Life Care in India Taskforce (ELICIT), a joint initiative of the Indian Society of Critical Care Medicine, the Indian Association of Palliative Care, and the Indian Academy of Neurology, was set up with the objectives of creating a comprehensive law, for end-of-life care, raising awareness about pertinent issues, and capacity building in providing end-of-life care.<sup>24</sup> This group drafted the End-of-Life Care Bill, 2019.<sup>25</sup>

**Table 1** summarizes the factors influencing advocacy of euthanasia. Although, right to die with dignity appears to be a fundamental right, executing this right might lead to serious repercussions and abuse. Various reservations expressed in legalizing euthanasia have been listed in **Table 2**.

## Advanced Directive

A person is entitled to execute an advanced medical directive when he ceases to have mental capacity. **Table 3** summarizes the guidelines proposed for the safeguards for executing an advance directive, as per the *Common Cause v. Union of India* (2018).<sup>18</sup> The procedure governs the withdrawal or withholding of life-sustaining treatment in two cases: one, where there is a valid AD, and second, where no AD exists, and the patient has lost decision-making

TABLE 1.

**The Factors Influencing Advocacy of Euthanasia**

1. **Perspectives of the patients receiving PC:** The right to choose when to end one's life, cognitive impairment, pain, anticipated pain, fear of indignity, the possibility of being a physical and financial burden on others, fear of loss of control, fear of frailty, the meaninglessness of life were common themes that emerged in support of euthanasia.<sup>25-26</sup>
2. **Caregiver burnout:** It is immense which takes forms of psychological, logistical, emotional, and financial distress.
3. **Advancement of technology:** Advancement of technology and facilities like artificial ventilatory support, even if one is in a persistent vegetative state has added to this complex situation.
4. **Perspectives of the community:** Various community studies done across the world have shown that public opinion favors euthanasia, and their opinion should be given due regard.<sup>27-28</sup>

TABLE 2.

**The Factors Influencing Nonadvocacy of Euthanasia**

1. The voluntary killing of a patient is against the Hippocratic Oath.
2. Legalizing voluntary killing could seriously impact the progress made in the PC services as was evident in Holland.<sup>29</sup>
3. The desire to die might be transient and a treatable cause of mental illness.
4. Quality of life has a lot of subjectivity and hence cannot be generalized and incorporated into a legal framework.
5. Good PC might improve the quality of life and allow the patient to lead a life with dignity.
6. Suffering depends on various factors and hence might be dynamic and fluctuating in nature.
7. Would the physician be certain while certifying that a patient is suffering from an ailment that is permanent and will progressively deteriorate the condition of the patient leading to death.
8. Spirituality and religion are known to provide meaningfulness to life and helps an individual to cope with stressful situations.
9. Good PC with high social support, availability of resources and pain medications are all known to improve the quality of life of an individual with a terminal illness.
10. Availability of a legislature could lead to its overutilization and premature decision to end the life of a terminally ill.

TABLE 3.

**Supreme Court Guidelines of the Safeguards for the Execution of an Advance Directive<sup>7</sup>**

1. Only adults more than 18 years of age having a sound mind and, in a position, to communicate, relate and comprehend the purpose and consequences of executing it.
2. This would also include persons with mental illness provided they are of sound mind at the time of executing an AD.
3. It should be free of coercion.
4. AD should have been executed with the notarized signature of the person executing it, in the presence of two adult witnesses, and should be countersigned by the jurisdictional Judicial Magistrate of First Class (JMFC).
5. The form should have a reaffirmation that the person executing it should have made an informed decision.
6. Only those ADs relating to the withdrawal or withholding of treatment are legally valid.
7. It mentions that the executor may revoke the instructions at any time.
8. It should specify the guardian who will be authorized to give consent consistent with the AD once the patient becomes incompetent.
9. In the case of multiple ADs, the latest one would be considered.
10. Assessment of incapacity before the AD can be enforced should be done as per the medical professional regulations (assistance from a panel of experts may be considered to make this decision).
11. The primary responsibility of implementing the AD would be on the medical institution from where the person is receiving the treatment.
12. If the concerned hospital refuses to execute the AD, the relative or the next friend may approach the jurisdictional high court seeking a writ against the hospital.
13. The high court would examine the validity and applicability of the AD in the given situation.
14. No hospital or doctor can be held liable for executing a valid AD.
15. An individual doctor may object to execute an AD on the grounds of religion and his fundamental right under Article 25 of the constitution. However, the hospital would still be under the obligation of executing the AD.

capacity; these have been described in **Figure 2**. However, the procedure laid down for both these scenarios is broadly identical. This procedure is tedious,

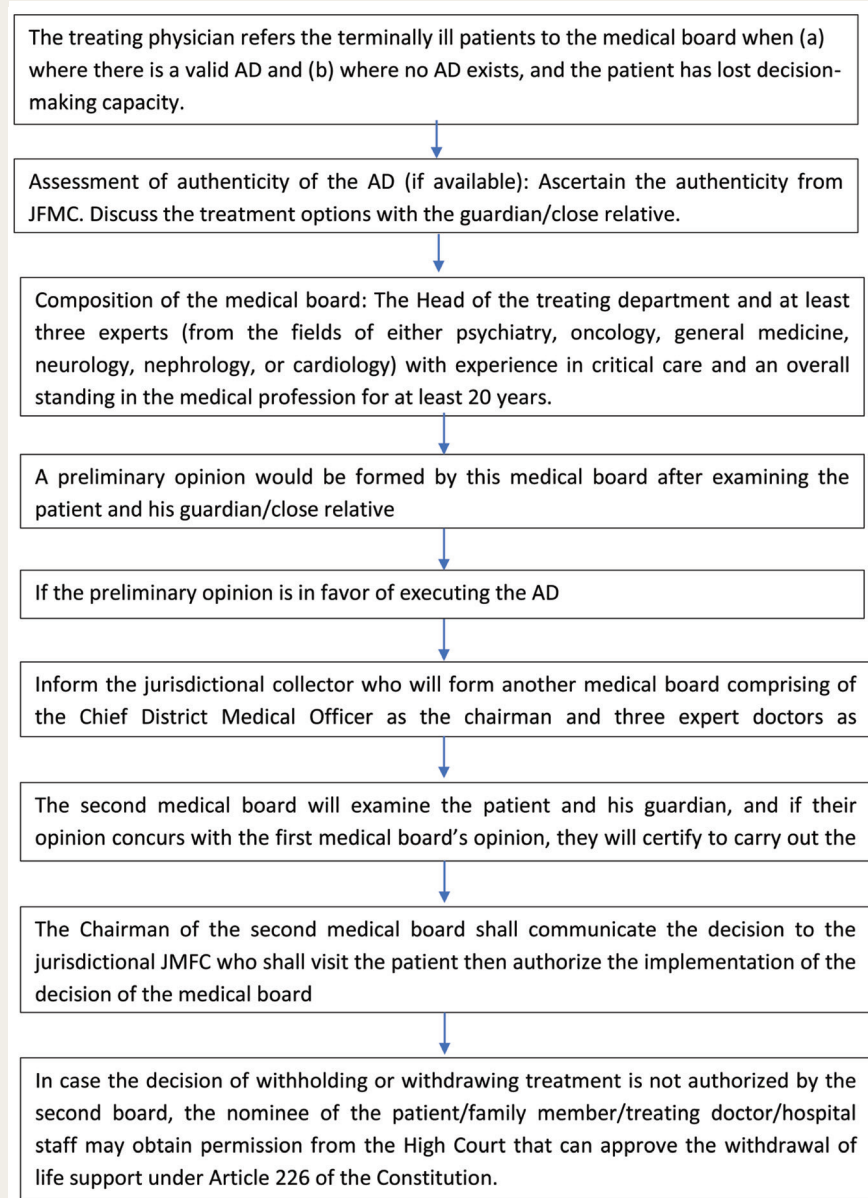
requires approval at three different stages from three different authorities. This procedure is well described for specific situations in the End-of-Life Care

Bill 2019. Additionally the Bill provides safeguards in the form of holding audits of such decisions by an “end-of-life care committee”.



FIGURE 2.

## Supreme Court Guidelines for Withholding or Withdrawal of Life-Sustaining Treatment<sup>8</sup>



## The Approach of a Mental Health Professional in a PC Setting in the Geriatric Population: A Legal Standing

There is a likelihood of unscrupulous utilization and referrals for requisition for withdrawal of treatment in the PC setting. Although this might not be a prevalent practice at present, this is being asserted due to the recent advances witnessed in the legal standing of end-of-life care such as the End-of-Life Care Bill<sup>25</sup> in India and

the landmark Supreme Court judgment of the *Common Causes vs. Union of India*<sup>18</sup> which has provided guidelines for withdrawal of treatment. Although these measures are provided to uphold the individual's rights during their end-of-life care, it could be misused if PC is not available and if the caregivers are unable to provide any form of care to the person requiring it. Therefore, it is important to take steps to ensure that the decision for withdrawal or withholding treatment is not merely driven due to the lack of availability of PC. Also, it would be imperative to have a psychiatrist on board. At the same time, a decision of passive

euthanasia is considered to rule out an underlying psychiatric condition such as depression that might be a driving factor for such a decision. **Figure 3** provides the proposed assessment approach of a psychiatrist for treatment refusal in PC setting. Every individual has the right to access mental healthcare and treatment from mental health services run or funded by the government under section 18 of the Mental Health Care Act, 2017.<sup>26</sup> Therefore, it is the State's responsibility to provide mental health treatment to every individual requiring PC. The authors strongly believe that withdrawal or withholding treatment should not be encouraged in the country. First, the country must scale up PC facilities and ensure that every measure is taken to provide better treatment to those in need.

## Summarizing the Role of a Mental Health Professional in the PC Setting

Mental health professionals play a crucial role in the PC setting for both patients and their family members. The roles have been summarized as follows:

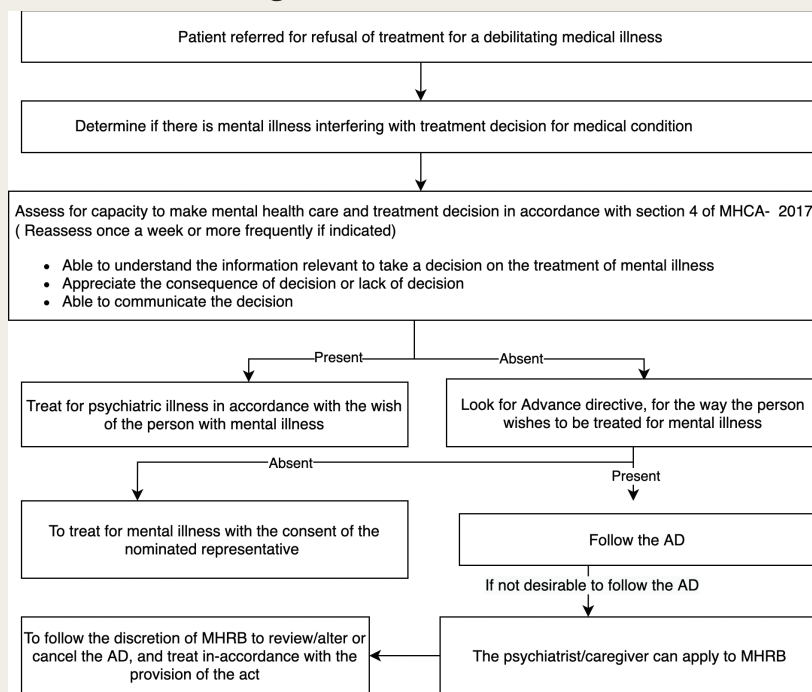
1. **Addressing and treating areas of suffering:** pain, physical suffering, fear of being a burden, mental health issues such as depression, anxiety, hopelessness, psychotic symptoms like the delusion of poverty or nihilism, etc.
2. **Making decisions and assessing capacity**
3. **Assessing the need of request for withdrawal of treatment:** Due to lack of resources and availability of PC, physical pain, mental health conditions, psychosocial factors such as lack of support, financial constraints, or spiritual
4. Upholding the **right to self-determination and individual autonomy**
5. **Reviewing advanced directive**
6. Ensuring that every effort is made to provide PC to individuals requiring it.

## Conclusion and Way Forward

Although India has made several strides towards addressing PC, there is still a long way to go. The uncertainty in the absence of uniform legislation to protect the rights of people with a terminal illness and the physicians caring for them is concerning. The decision to die

FIGURE 3.

### Proposed Assessment Approach of a Psychiatrist for Treatment Refusal in PC Setting



might be a socially restricting choice of the individual or his guardian due to a lack of options. The presence of mental illness should be viewed as a relative contraindication for passive euthanasia, and every effort should be made to treat the mental illness. We should fathom the need for PC and accordingly scale up the services. It is legally binding for the appropriate government to provide facilities for the treatment of mental health issues. As the right to health is a fundamental right in the ambit of the right to life, systematic efforts should be made to scale up the investment in health care.

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