

**FAST FACTS AND CONCEPTS #451**

**PALLIATIVE SEDATION IN THE HOME SETTING**

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**Background** It is not uncommon for patients in the last days to weeks of life to experience severe physical distress from pain, delirium, or dyspnea refractory to usual palliative interventions. In these circumstances, sedatives may be prescribed to relieve suffering by reducing the patient's awareness or even rendering them unconscious. While a variety of terms have been used to describe this practice (e.g., controlled sedation, terminal sedation, continuous deep sedation), palliative sedation (PS) is the most utilized (1,2). For the purposes of this *Fast Fact*, we will utilize PS to refer to the rapid induction of sedation typically via the regular administration of a sedative. Major medical groups support the use of PS in patients who are imminently dying and experiencing suffering that is intolerable or unresponsive to other interventions (3-5). However, considering the potential controversies involved, a careful interdisciplinary (IDT) review is recommended before initiating PS (3-5). PS most often occurs in carefully monitored settings such as a hospital or general inpatient hospice unit (GIPU) (see *Fast Facts* 106 and 107). Yet, GIPUs are not widely available in many areas and many patients and/or their families have strong preferences to remain at home when dying. This *Fast Fact* will discuss the unique considerations behind PS in the home setting.

**Patient factors in home PS** PS in general may be appropriate for patients whose targeted symptom(s) has been refractory to other means of palliation; when prognosis is very short (e.g., days to short weeks), and/or there is not time to try more usual palliative interventions. The patient's symptoms may be secondary to a range of terminal diagnoses; however, PS has been most studied in patients with cancer (6-8). If appropriate, counsel families on the option of admission to a GIPU or hospital for the round the clock monitoring and support. However, if a home setting is desired for PS, then involvement of a robust, interdisciplinary palliative care and/or a hospice care team is strongly recommended.

**Decision-making** As in all cases in which PS is being considered, consult other IDT members (spiritual care, pharmacy, social work, nursing, referring clinician) to ensure the home care team is on the same page. In addition, consider a second opinion from a trusted colleague and/or ethics committee as available to ensure more usual effective palliative interventions have not been missed. An information visit with the family should occur about home PS. Families should be made aware that PS would not be prescribed with the intent to hasten death but rather in attempt to better control refractory symptoms (7). Clinicians should establish the anticipated duration of PS with families – whether it will be intermittent (e.g., stopped once a specific symptom has resolved or time has lapsed) or continuous until death occurs. If not completed, an out-of-hospital “do not resuscitate” or POLST form should be in place.

**Preparation** The medication route for PS at home varies by the patient's condition. Scheduled use of rectal or enteral medications via an established feeding tube can be considered for many benzodiazepines and barbiturates. Phenobarbital is one commonly utilized rectal sedative. For patients in which rectal or enteral routes are not feasible, the parenteral use of pentobarbital, chlorpromazine, diazepam, lorazepam, and propofol (dosing as outlined in *Fast Facts* #107) have been described for home PS. Unless a patient already has an established IV port or central line (e.g., Mediport or PICC line) a subcutaneous (SC) route is often used via a Huber needle or a butterfly needle for continuous infusions. Consultation with a clinical pharmacist is recommended for determining the best route of delivery and agent in the home. The most studied medication for home PS is parenteral midazolam (6,8,9). It is a benzodiazepine with a relatively short half-life that can be administered SC or via an IV. One systematic review found that 97% of patients achieved successful PS with initial doses of 1 mg/hr, titrated to sedation with usual total daily parenteral doses of less than 100 mg (8). Maintaining reliable access is crucial to home PS being managed via a parenteral route. If an IV route is used, supplies should be available to convert to SC administration promptly. Pumps should be checked daily for adequate supply of medication and reordered with plenty of time to prevent the pump from running out of medication. Caregivers and family members should be taught on how to manage an infusion pump in case of need. For patients on opioid therapy, opioids should be continued along with the sedation medication to prevent discomfort from opioid withdrawal. Indwelling urinary catheters often are used for the duration of home PS.

**Initiation:** Medication selection, route, and dosing should be prescribed by a physician, nurse practitioner or physician assistant; however, it is best if the prescribing clinician confers with the pharmacist and bedside nurse beforehand. A continuous care level of nursing support is recommended by either hospice, home health, or a private duty nursing until consistent dosing of the medication is reached. The use of a validated assessment form, such as the Richmond Agitation-Sedation Scale (RASS Scale), allows home care staff to monitor the change in the patient's level of consciousness using shared language (10). A RASS score between -1 and -4 is usually targeted; however, the broader goal is to provide the least amount of sedation to control the targeted symptom(s). Additional clinical signs to monitor include changes in breathing patterns (e.g., abrupt apnea, heavy snoring), signs of neuroexcitatory effects (e.g., myoclonus, allodynia) for patients on concomitant opioids, and the families perceived level of patient comfort. Nurses should contact the prescribing clinician if the prescribed dosing is not meeting the patient's comfort and overall care needs.

**Ongoing personal care during PS:** Eye care and oral care are important to support ongoing dignity during PS. Repositioning is recommended to prevent skin failure. Careful attention to the emotional concerns and needs of the family and IDT is crucial. Families and caregivers may question their decision at times or feel isolated at home; hence extra support from chaplaincy and social work is common.

**Prognosis and bereavement:** The average duration of PS prior to death is 3 days in the published literature, however, prognosis must always be individualized (8,11). Given the significant symptom burden and distress leading up to the decision to proceed with PS, bereavement support is a priority. In addition, the IDT may need to debrief the event to avoid moral residue.

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