

# *Medical Care of the Dying*

4<sup>th</sup> Edition

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## Confusion: Delirium and Dementia

Studies report that this symptom, which varies from mild to severe, occurs in 25–85% of patients with advanced cancer(7). Gagnon reported a prevalence of delirium in 52% of patients(8). On occasion, however, a few patients will remain coherent until within minutes or hours of death.

Lawlor et al(9) reported that, on admission to a palliative care unit, delirium was initially diagnosed in 42% of patients, and later developed in a further 45%, with 12% having no delirium at any point. Terminal delirium occurred in 88% of deaths.

### Confusion about Confusion

In a Cochrane collaborative review, delirium is stated to be a common disorder that often complicates treatment in patients with life-limiting disease. Delirium is described using a variety of terms such as agitation, acute confusional state, encephalopathy, organic mental disorders and terminal restlessness(10).

Chang(11), in an editorial entitled *The Confusion About Confusion*, also notes various terms that are used but have different meanings, including confusion, altered mental state, cognitive impairment, acute brain syndrome, restlessness, dementia and delirium.

Even then, 'confusion' could represent delirium, pain, a psychiatric condition, dysphasia, dementia or disorientation(12). 'Altered mental status' could be agitation or anger, coma, seizures or delusions(13). 'Delirium' and 'dementia' are more closely defined using DSM-IV or ICD-10 coding. The criteria



for delirium by DSM-IV are listed in Chapter 17 Psychosocial Care, and by ICD-10 is shown in Table 14.1(14).

Acute brain syndrome(15) was often previously used but delirium has now replaced it(16).

Dementia will be briefly discussed later but, in comparison to delirium, has the following characteristics:

- Often irreversible
- Consciousness level usually not affected
- Hallucinations not common
- Usually deterioration of all cognitive and intellectual functions

Delirium in dementia appears to have similar diagnostic criteria(17).

N.B. For the purposes of this book, delirium will generally be used in place of confusion, and dementia used as it implies.

## Etiology and Assessment of Delirium

Delirium is one of the most prevalent symptoms in palliative care and, since it may present in different shades of altered cognition, the routine use of screening instruments is recommended(18).

As with all symptoms, careful assessment is necessary in determining the etiology of confusion. Much can be gained by careful review of recent history, current medications and physical examination. Table 14.2 outlines the general causes of confusion in advanced disease.

Although the following data relates to a study (physicians, social workers)(11), Inouye et al report that hospice nurses have difficulty recognizing delirium, with a sensitivity of 18% (15–31%) but specificity of 95%(20). This means that they were accurate in knowing when delirium was not present, but significantly under-recognized it when

ICD-10 Diagnostic Guidelines for Delirium	
For a definite diagnosis, symptoms of mild or severe should be present in the following areas:	
<ul style="list-style-type: none"> <li>• Impairment of consciousness and attention</li> </ul>	<ul style="list-style-type: none"> <li>• On a continuum from clouding to coma</li> <li>• Reduced ability to direct, focus, sustain and shift attention</li> </ul>
<ul style="list-style-type: none"> <li>• Global disturbance of cognition</li> </ul>	<ul style="list-style-type: none"> <li>• Perceptual distortions, illusions and hallucinations, most often visual</li> <li>• Impairment of abstract thinking and comprehension, with or without delusions, but typically with some degree of incoherence</li> <li>• Impairment of immediate recall and of recent memory but with relatively intact remote memory</li> <li>• Disorientation for time as well as, in more severe cases, for place and person</li> </ul>
<ul style="list-style-type: none"> <li>• Psychomotor disturbances</li> </ul>	<ul style="list-style-type: none"> <li>• Hypo- or hyperactivity and unpredictable shifts from one to the other</li> <li>• Increased reaction time</li> <li>• Increased or decreased flow of speech</li> <li>• Enhanced startle reaction</li> </ul>
<ul style="list-style-type: none"> <li>• Disturbance of sleep-wake cycle</li> </ul>	<ul style="list-style-type: none"> <li>• Insomnia or, in severe cases, total sleep loss or reversal of the sleep-wake cycle</li> <li>• Daytime drowsiness</li> <li>• Nocturnal worsening of symptoms</li> <li>• Disturbing dreams or nightmares, which may continue as hallucinations after waking</li> </ul>
<ul style="list-style-type: none"> <li>• Emotional disturbances</li> </ul>	<ul style="list-style-type: none"> <li>• Examples - depression, anxiety or fear, irritability, euphoria, apathy or wondering perplexity</li> </ul>
<ul style="list-style-type: none"> <li>• The onset is usually rapid, the course diurnally fluctuating, and the total duration of the condition less than six months.</li> <li>• The above clinical picture is so characteristic that a fairly confident diagnosis of delirium can be made even if the underlying cause is not clearly established.</li> <li>• In addition to a history of an underlying physical or brain disease, evidence of cerebral dysfunction (e.g. EEG) may be required if the diagnosis is in doubt.</li> </ul>	
Includes: <ul style="list-style-type: none"> <li>• Acute brain syndrome</li> <li>• Acute confusional state</li> <li>• Acute infective psychosis</li> <li>• Acute organic reaction</li> </ul>	

Causes of Delirium	
<b>Physical Causes</b>	<ul style="list-style-type: none"> <li>• Tumor burden or location e.g. brain tumor</li> <li>• Infection, sepsis</li> <li>• Biochemical</li> <li>• Hypercalcemia</li> <li>• Uremia</li> <li>• Hepatic encephalopathy</li> <li>• Hypo- or hyperglycemia</li> <li>• Cardiorespiratory</li> <li>• Hypoxia</li> <li>• Hypercapnia</li> <li>• Cerebrovascular e.g. stroke(19)</li> <li>• Trauma</li> <li>• Hemorrhage</li> <li>• Subdural hematoma</li> <li>• General discomfort</li> </ul>
<b>Drug Effects</b>	<ul style="list-style-type: none"> <li>• Idiosyncratic</li> <li>• Drug accumulation</li> <li>• Physical decline, decreased renal or hepatic clearance</li> <li>• Accidental or intentional overdose</li> <li>• Drug withdrawal</li> <li>• Opioid</li> <li>• Alcohol</li> <li>• Other medications e.g. steroid</li> </ul>

**Table 14.2.** Causes of Delirium. M Downing

a patient was delirious. Four independent risk factors for under-recognition were identified: hypoactive delirium, age 80 years and older, vision impairment, and dementia. Under-recognition increased with the number of risk factors present: 2% (0 risk factors) – 6% (1 risk factor), 15% (2 risk factors), and 44% (3 or 4 risk factors). Patients with 3 or 4 risk factors had a 20-fold risk for under-recognition. Recognition of delirium can be enhanced with education in delirium features, cognitive assessment, and factors associated with poor recognition(20).

Any decision to carry out investigations must be weighed against the value which will be gained from the results and the expected improvement from treatment based on those tests, as well as the morbidity and 'usefulness' of pursuing investigations in a patient who may be deteriorating quickly and close to death.

### Assessment Tools

There are many possible assessment tools used for assessing cognitive and affective aspects of delirium(21,22), although usual medical and nursing assessments may have similar outcomes(23). Of those, several are more often used in palliative care.

One of the most widely used tools for assessing cognition is the Folstein Mini Mental State Exam (MMSE)(24,25), but it is not specific for delirium. The Delirium Rating Scale (DRS)(26,27) has value in screening and monitoring the severity of delirium(21), as has the Memorial Delirium Assessment Scale (MDAS)(28,29).

Screening tools, i.e. not for full assessment, which could be used in various settings include Confusion Assessment Method (CAM)(8,30-34) and Bedside Confusion Scale (BCS)(35). Even then, use of these without some training reduces their sensitivity(36). CAM assesses 10 areas: acute onset, inattention, disorganized thinking, altered level of consciousness, disorientation, memory impairment, perceptual disturbances, psychomotor agitation, psychomotor retardation and altered sleep-wake cycle. The CAM (short form) uses 4 factors: acute onset and fluctuating course, inattention, disorganized thinking and altered level of consciousness.

### Delirium Sub-types

Two types of delirium are of particular note as each is seen in end-of-life care(37). As the terms imply, hyperactive delirium involves an agitated, hyperalert stage, and hypoactive delirium involves being lethargic. Table 14.3 shows distinguishing characteristics.

Among older adults, especially those in long-term care situations, delirium may not appear to be very different from previous episodes observed when the resident experienced an infection, exacerbation of a chronic condition, anxiety, pain or adverse drug reactions. However, delirium at the end of life is usually multifactorial and exacerbated by the progressive multiple system failure.

Sandberg et al(38) reported that in the elderly, although episodes of delirium in general occur in the afternoon, evening or night, in fact 47% of the delirious patients in a residential facility had morning delirium. Further, nearly 26% were classified as having hypoactive, 30% as having hyperactive, and 42% as having mixed delirium(39).

Hypoactive delirium is often misdiagnosed in the elderly as depression or simply not recognized(40, 41).

The experience of delirium is highly distressful to most. In a recall study, Breitbart et al(42) found several important points:

- Patients who could recall delirium (about 53%) ranked their distress level at average 3.2 (scale 0–4) with delusions being the most distressful predictor
- Spouses/caregivers rated their distress at 3.75
- Nurses rated personal distress at 3.09 with symptom severity and perceptual disturbances as most distressful
- Patients with hypoactive delirium were just as distressed as those with hyperactive type
- They concluded stating the necessity for timely recognition and prompt treatment

Contrasting Features of Subtypes of Delirium		
Type	Hyperactive Delirium	Hypoactive Delirium
Symptoms	<ul style="list-style-type: none"> <li>• Hallucinations</li> <li>• Delusions</li> <li>• Hyperarousal</li> </ul>	<ul style="list-style-type: none"> <li>• Sleepy</li> <li>• Withdrawn</li> <li>• Slowed</li> </ul>
Examples	<ul style="list-style-type: none"> <li>• Withdrawal syndromes (e.g. benzodiazepines, alcohol)</li> </ul>	<ul style="list-style-type: none"> <li>• Encephalopathies (hepatic, metabolic)</li> <li>• Benzodiazepine toxicity</li> </ul>
Pathophysiology	<ul style="list-style-type: none"> <li>• Elevated or normal cerebral metabolism</li> <li>• EEG – fast or normal</li> <li>• Reduced activity in GABA systems</li> </ul>	<ul style="list-style-type: none"> <li>• Decreased global cerebral metabolism</li> <li>• EEG – diffuse slowing</li> <li>• Overstimulation of GABA systems</li> </ul>

**Table 14.3.** Contrasting Features of Subtypes of Delirium. From Handbook of Psychiatry in Palliative Medicine, edited by HM Chochinov, W Breitbart. With permission of Oxford University Press, Inc(37).

## Treatment

It is a major challenge to discern whether one should pursue investigations or not. If the cause could be identified easily, with minimal invasion and be readily treated with resulting improvement, then many would want this as this is a distressing symptom.

Physicians always face the dilemma of how aggressively to intervene in reversing delirium, and the following is a possible strategy(43):

- Identify the underlying cause (if possible) and assess its impact on the patient's quality of life
- Rank the distress of delirium in the context of the patient's overall symptom complex
- Assess the potential problems associated with correcting the underlying causes and consequent impact on quality of life (e.g. using IV line for antibiotics, and patient pulling out)
- Consider the advantages and disadvantages of intervention versus no intervention
- Discuss treatment options with the patient (if mild cognitive impairment) and the family to allow informed decision-making and ultimately the development of a consensus on the appropriate level of intervention

It is usually neither simple nor easy, and the causes are often multiple. When confronted with delirium in terminally ill or dying patients, health care professionals should always review a differential diagnosis and the likely factors involved. A firm diagnosis may only be attainable in less than half of cases(44). In the Lawlor study above(9) reversal of delirium was possible in 56% of first episodes, but only 26% if a subsequent delirium developed.

Factors associated with likely reversible delirium were:

- Opioid-induced neurotoxicity
- Psychoactive drugs
- Dehydration

Factors associated with irreversibility:

- Hypoxic encephalopathy
- Metabolic factors (e.g. hypercalcemia, hyponatremia, renal insufficiency)
- Non-respiratory infection

A valuable practical insight is that of a baseline vulnerability and superimposed precipitants. Age, mental status, multi-system impairment, decreased nutritional status and decreased functional status provide a precarious baseline. Any superimposed factor may then precipitate delirium, including medications, dehydration, infection, metabolic dysfunction or hypoxia.

The mortality rate in delirium varies of course by the etiology and patient condition, and varies from 10–65%(45).

### *Treatment Approaches*

Taking the above facts into consideration, there are three approaches to consider in management as follows. Each of these have pros and cons, requiring team and family input as noted.

Additionally, similar to the relationship of pain and total pain, delirium has the underlying disease factors precipitating delirium, but there can be superimposed many other features, including unresolved fears, anxiety or spiritual journey. Cultural aspects may also be involved and respect for these are required as discussed in Chapters 17 Psychosocial Care and 18 Cultural and Spiritual Care.

The three possible treatment approaches include the intent to reverse delirium, the intent to relieve with sedation and the intent to observe for the time being.

#### 1. Intent to Relieve by Reversal

In this approach, there is some likelihood of reversing delirium, particularly where the patient has a higher functional status.

Criteria for this include:

- Known patient wish for intervention where possible, even if chances are low
- If readily reversible
- If potentially reversible e.g. opioid neurotoxicity
- If not dying, i.e. earlier stages
- If dying, trial attempts – only if patient had wanted active treatments and reverse is likely; otherwise no. Treatment examples – hydration, O<sub>2</sub>, opioid rotation

With this approach, some investigations and treatments will be carried out depending on the identified causes. Examples include antibiotics,

hydration, bisphosphonates for hypercalcemia, oxygen, rotation of opioids, reduction or discontinuing of other offending drugs.

At the same time, low dose neuroleptics may be started. The aim is not to sedate, which may tip the situation to become irreversible, but rather to provide sufficient medication to reduce agitation. Therefore, one should use low-sedating neuroleptics and avoid anxiolytics as possible.

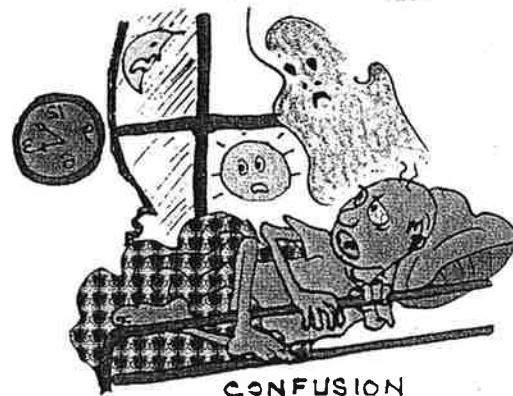
#### 2. Intent to Relieve by Sedation

Reversal may be unrealistic or unwanted. Latimer(46) used the term 'sedation as therapy' in recognizing that the goal may be reduction of severity of delirium via use of sedative medication.

Criteria for this approach include:

- If delirium unpleasant and/or worsening
- If patient did not want active treatment
- If treatment is futile or unlikely to improve delirium
- If conditions are unsafe for patient, family or staff e.g. wild agitation, violence

In this approach, neuroleptics ± anxiolytics are titrated in the usual manner to provide acceptable control. Most patients will respond to this. This is not palliative sedation per se, as that is intended only in severe refractory symptoms. Palliative sedation as a topic is discussed in Chapter 19 Death and Dying with its own criteria.



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### 3. Intent to Observe Delirium

There are occasional times when, in known imminently dying patients, the patient develops hallucinations, visions or physical movements which appear comforting(37), or at least not disturbing, and possibly have interpretable meaning to family. This usually occurs in a hypoactive delirium, with its quietness. Some view this mild restlessness, visions and voices as a meaningful journey for the patient, with symbolism in the patient. Callanan's book *Final Gifts* discusses such types of experiences wherein some family find comfort(47).

In these cases, it may be prudent to observe the patient, provide support to family, but be prepared to initiate sedative therapy if circumstances change to agitation. As Breitbart and Cohen(37) note, "such a 'wait and see' approach must, however, be tempered by the knowledge that a lethargic or hypoactive delirium may very quickly and unexpectedly become an agitated delirium that can threaten the serenity and safety of the patient, family and staff."

At the same time, in the study discussed above(42), patients with hypoactive delirium who survived recalled that they were highly distressed during delirium. Guidance by the temporary substitute decision-maker and other family, along with the palliative care team, is needed to determine the most appropriate course of management.

### *Other Treatment Measures for Delirium*

#### Provide Education and Support:

- Explanation (repeated) to patient, family and staff
- Stress that the patient is not going 'insane'
- There may be brief lucid periods for some meaningful interaction

#### Using More or Less Stimulation as Intervention:

Provide a safe and relaxing environment.

Patients with delirium need *LESS* stimulation:

- Quiet, well-lit room
- Minimal staff changes
- Repeated reassurance, explanation
- Calendars, clocks, observing sunshine, darkness, are helpful
- Contacts with fewer people
- Sedation as necessary

Patients with dementia need *MORE* stimulation, but **structured** so as not to further disorient:

- Constant reorientation to time, place
- Familiar and constant surroundings
- Sedation often worsens disorientation

#### Use of Relaxation Techniques

Some relaxation therapies may be helpful while others may worsen delirium. For example, massage, tub baths, gentle music, scripture, etc. may assist in calming the patient, while visualization or guided imagery can worsen hallucinations or deepen feelings of fear and dissociation from reality. Therefore, these need to be applied on an individual basis.



## Drug Therapy in Delirium

### Neuroleptics

Two classes of drugs can be used as indicated, neuroleptics and anxiolytics. Neuroleptic drugs are the standard and quite effective(48–50). There are the so-called 'conventional' and 'modern atypical' drugs with some being more sedating (e.g. chlorpromazine, methotrimeprazine, olanzapine) and others less so (e.g. haloperidol, quetiapine). Drugs in both categories are used for delirium management as discussed here, and also for intractable or refractory delirium as part of palliative sedation as discussed in Chapter 19 Death and Dying.

A Cochrane review(10) noted that evidence is scarce regarding this class of drugs in terminal care. Recognizing this limit, **haloperidol** is the most suitable drug therapy for the treatment of patients with delirium near the end of life. **Chlorpromazine** may be an acceptable alternative if a small risk of slight cognitive impairment is not a concern. This was based mainly on a study by Breitbart(51) but also with support from other case studies(52–56).

**Haloperidol** is generally considered the gold standard. It is a longer acting drug(48) which can be given PO, SC, IM or IV. In delirium, a suggested regimen is 0.5–1.5mg PO (mild), 1.5–5.0mg PO (severe) or 10mg SC or IV (very severe) [one report of up to 250mg/24hr(57)]. These doses may be repeated q30–60 minutes until alleviation (37,58). Once controlled, the maintenance dose suggested is 50% of amount to achieve control, usually between 1.5–20mg daily divided to 1–3 times daily. Typical doses in the first hour range from 0.5–20mg (45). Caution is needed in elderly patients who may need as little as 0.25–0.5mg q4h PRN(59), unless severe. **The parenteral dose should be 50% of the oral dose (48).** It does have a higher EPS profile and, if needed, benztropine is usually effective or lorazepam in selected cases where sedation is not an issue. Rare concerns are QT interval prolongation(59) or neuroleptic malignant syndrome(60).

Olanzapine is a newer atypical antipsychotic (61). It may be helpful where haloperidol is contraindicated(62). It has a low EPS profile but is more sedating. In one trial, 75% had complete response(63). Of those with poorer response, factors included age >70 years, history of dementia, central nervous system spread of cancer and hypoxia,

'hypoactive' delirium, and delirium of 'severe' intensity. Another reported value in the elderly who were non-responsive to other neuroleptics(64). There have been two case reports of opioid-induced delirium while on olanzapine, so its role in the multiple etiologies in palliative care remains unclear at present(65). Dosage is 2.5–10.0mg once to twice daily PO or by dissolvable wafer on the tongue(37) and also as injectable.

**Methotrimeprazine** is effective and used as an alternative to haloperidol(66,67). It is a higher sedation drug at doses of 15mg or above. It can be given PO, SC, IV as well as SL. Very low doses are used for nausea (0.5–2.5mg) but control of delirium usually requires 10–15mg for mild and up to 50mg for severe delirium. These may be given q4–8h initially, then less often once controlled(37).

**Quetiapine** may be an acceptable and safe alternative(68) but there is little evidence in the palliative field. Some have found it helpful at mean dosing of  $93 \pm 23$ mg/day(69) or mean dosing of  $44 \pm 30$ mg/day(70). Anecdotally, some have started at a low dose 6.25mg bid and increased as needed (71). For agitated dementia with delusions, an expert panel's first-line recommendation is an antipsychotic drug: risperidone (0.5–2.0 mg/day) was first line followed by quetiapine (50–150mg/day) and olanzapine (5.0–7.5mg/day) as high second-line options(72).

Other possible drugs are droperidol, risperidone, thioridazine or molindone.

In cases of *hypoactive delirium*, **methylphenidate** may be effective(73–75). Neuroleptics in low doses may also be effective alone(76) or in combination with methylphenidate in improving hypoactive delirium(77).

### Anxiolytics

Benzodiazepine drugs do not clear the sensorium or improve cognition(45), and should not be used for delirium unless as an adjunct to primary therapy with haloperidol or another neuroleptic(48). Lorazepam alone appears to be ineffective and is in fact associated with treatment-limiting adverse effects(78), but in combination may provide quicker and more effective control(78). Particular caution should be used in the elderly or those with hepatic failure.

The main role of this class is where haloperidol fails to control delirium, as in severe agitation or terminal restlessness. The goal in these cases is quiet

sedation only(38). In this situation, benzodiazepines give effective palliation of restlessness and, unlike haloperidol or other phenothiazines, do not exacerbate the existing tendency to myoclonus and convulsions(79).

**Lorazepam** is often used. It has an intermediate half-life, no active metabolites and several routes are available (SL, PO, SC, IV). Doses vary widely from 0.5mg to 5mg. In *mild* cases of delirium, it should be avoided as noted above or used on a PRN only basis for agitation until the neuroleptic provides overall control, especially if the goal is reversal of delirium.

In *severe* delirium with agitation and/or violent behavior, purposeful but hopefully temporary sedation is necessary, in which case both the neuroleptic and anxiolytic doses require escalation. Lorazepam may be 1–2–5mg SC q1h until control of agitation, then reduced as quickly as possible on a q4h basis.

**Midazolam** is also frequently used in delirium, but is more helpful for the restlessness aspect(79). In acute dosing, it is short-acting and rapidly effective. With longer-term infusion, the drug is widely redistributed and may result in prolonged effect(45). Initial dosing may be 5–10mg SC then 2–5mg SC PRN or by pump at 1–2–4mg/hr SC. Total daily doses have varied from 20–200mg/day(80,81).

In a review by Kehl(82), a number of studies demonstrated the effectiveness of other medications such as benzodiazepines (notably midazolam and lorazepam) or phenothiazines, either alone or in combinations. There is insufficient evidence to suggest that a single medication or class of medications is appropriate for terminal restlessness. There is a clear need for additional trials of neuroleptics, benzodiazepines, barbiturates and combination protocols to determine which protocols are the most effective and have the least side-effects(82).

### Other Drugs

**Propofol**, a short-acting anesthetic, could also be used. Suggested starting doses are 10mg IV bolus, then 10mg/hr(83), or 20mg stat then 10–70mg/hr(84, 85).

**Phenobarbital** may be helpful(86,76) or in combination if midazolam fails to provide adequate sedation(67,88) in refractory cases.

## Restlessness

### Terminology and Etiology

This term is variously used in health care and thus, is often unclear. It may be defined as(89): 1) inability to rest or relax or be still, 2) the quality of being ceaselessly moving or active, or 3) a feeling of agitation expressed in motion.

In the broader context of palliative care, there are several categories in which restlessness may be evident:

- **Physical** – pain, constipation, bladder retention, hypoxia, metabolic, organ failure, fever, etc.
- **Drug effect** – EPS akathisia, opioid-induced neurotoxicity, etc.
- **Psychosocial** – personal suffering, existential anguish, interpersonal conflict, spiritual journey, worry, grief, etc.
- **Psychiatric** – delirium of any cause, dementia, anxiety disorder, psychosis, etc.
- **Imminently dying** – any combination of above with altered, fluctuating and declining state of consciousness

Kehl(82) lists several terms used in the literature to describe the latter in dying patients, including terminal delirium, terminal restlessness, terminal agitation, terminal anguish and confusion at end-of-life.

As readily appreciated, each of these categories and sub-issues require assessment and, generally speaking, separate strategies for relief. Sometimes, however, the strategy is even 'not to relieve' per se, as this may reflect an important emotional process for the patient.

## Terminal Restlessness

In patients who are imminently dying, many factors come into play as noted above. The use of the phrase 'terminal restlessness' in this context includes any or all of those five categories for restlessness in general.

It varies from mild, almost unnoticeable, to extreme with agitation and bewilderment. There may be muscle twitching or jerks, fidgeting or tossing and turning, yelling, or moaning.

Keeping in mind that the journey from life through death is a path on which the patient has never been before, which may not even be desired, which may be occurring too soon, which might be different from what was anticipated, and is ultimately an isolated journey for that person alone, it then becomes more understandable that anyone might become somewhat restless at points through this process of decline near death.

Additionally, if fear or agitation is part of this uneasiness in the patient, it can be quickly transferred to the family and staff alike, and becomes part of the total pain and suffering picture discussed elsewhere in this book. In reviewing 72 articles for evidence in treatment of terminal restlessness, Kehl(82) notes that it has a very high frequency of occurrence and equally high degree of distress to the patient and family(54,87).

Management begins with assessment to rule out simple treatable causes, such as a distended bladder that may be easily treated with insertion of a Foley catheter. Psychosocial, relaxing and environmental supports are important. Review current drug profile to determine if any may be causing delirium and stop or adjust accordingly.

Use of neuroleptic or anxiolytics should be used as needed but not in excess of what is required as part of 'consequential sedation' noted in Chapter 19 Death and Dying. In severe agitation refractory to usual medications, consideration for use of palliative sedation may be necessary. The overall goal, however, is reduction of distress not total sedation, as some interaction of patient and family may be possible once the main agitation is controlled. Finding this balance is challenging and necessitates discussion with family and the palliative care team.

Delirium with terminal restlessness through to death can have negative impacts upon family members who are witness to this. A study by Brajtman identified several core themes that reflected

the participants' perceptions and experiences: the multidimensionality of suffering, the need for communication, feelings of ambivalence, the need for information and sensitivity and respect(90).

Brajtman(91) also studied palliative care team members who confronted several challenging and stressful issues surrounding the management of terminal restlessness that influenced their treatment decisions and relationships with families. Four themes reflected the participants' perceptions and experiences: suffering, maintaining control, feelings of ambivalence and valuing communication to reduce conflict. These findings suggest the need for comprehensive treatment plans to meet the special supportive and information needs of these families, specific supportive strategies for the professional caregivers and further studies to develop ethical criteria and evidence-based guidelines for the use of sedation in the management of terminal restlessness(91).

## Terminal or Palliative Sedation

This is briefly included here to encapsulate the complexity in use of words and treatment strategies for restlessness in dying. The term *palliative sedation* has generally come to replace terminal sedation or sedation for refractory symptoms at end-of-life as found in the literature. As Cherny and Portenoy(92) emphasize, it provides "a readiness to address pain and other intolerable symptoms as a medical and moral imperative"(93,94).

Palliative sedation is not physician assisted suicide. It has clear differences but misperceived similarities. A full discussion including a framework and management guideline for palliative sedation is found in Chapter 19 Death and Dying.

## Altered States of Consciousness

An obvious aspect of dying and death is the loss of consciousness. With cancer, this loss is usually a process involving changes over a period of time. In other diseases, it may be an event, not a process, such as with a stroke or cardiac arrest.

Loss of consciousness, either real or feared, is a critical aspect of who a person is, how they relate to their environment and those around them, and the extent of influence or control they have of themselves.

Although it may be intellectually accepted by patients that they are dying and will lose consciousness, most have great difficulty in letting go of their conscious awareness of life. Some will

be so fatigued from their disease and its limitations that 'going to sleep' becomes almost like paradise – they often die very quickly once they 'let go.'

For others, however, the inner drive to survive continues. Any impairment of consciousness creates a turbulent, restless phase through which they continually attempt to 'climb up out of.'

Assisting a patient and the family through this period truly requires art and compassion, as well as knowledge and skills in managing it.

The following section is adapted from the classical description of altered states of consciousness by Plum and Posner(125).

Common Physical Changes Approaching Death		
System	Areas to Discuss	Outcome
Respiratory	<ul style="list-style-type: none"> <li>Breathing patterns</li> <li>Periods of apnea</li> <li>Respiratory congestion</li> <li>Hemoptysis</li> </ul>	<ul style="list-style-type: none"> <li>Irregularities common; explain; reassure</li> <li>Reassure not dyspneic; if cluster breathing, death is closer</li> <li>Common; mild to severe; treat if occurs</li> <li>Very rare; reassure unless concern (Chapter 10 Respiratory)</li> </ul>
Neurological	<ul style="list-style-type: none"> <li>Conscious level</li> <li>Delirium, restlessness</li> <li>Twitching</li> <li>Seizures</li> </ul>	<ul style="list-style-type: none"> <li>Overall, will decrease to death</li> <li>Common; can treat</li> <li>Common; treat if moderate</li> <li>Rare unless prior seizures with brain tumor</li> </ul>
Gastrointestinal	<ul style="list-style-type: none"> <li>Food</li> <li>Fluid</li> <li>Risk of choking</li> <li>Medications</li> <li>Mouth care</li> </ul>	<ul style="list-style-type: none"> <li>Intake will become zero</li> <li>Intake will become zero</li> <li>Advice re swallowing, fluid, aspiration</li> <li>Which to stop, which routes; teach if family to give</li> <li>Important at all times</li> </ul>
Cardiovascular	<ul style="list-style-type: none"> <li>BP</li> <li>Heart rate</li> <li>Heart failure</li> <li>Pulmonary edema</li> <li>Arrhythmias</li> </ul>	<ul style="list-style-type: none"> <li>Will fall as part of dying process</li> <li>Often rapid and weak</li> <li>Common part of dying process</li> <li>Uncommon; treat if occur</li> <li>May occur (ventricular fibrillation or asystole at death)</li> </ul>
Skin	<ul style="list-style-type: none"> <li>Temperature</li> <li>Color</li> <li>Skin breakdown</li> </ul>	<ul style="list-style-type: none"> <li>Often cool; may be febrile</li> <li>Often pale; blue; mottled</li> <li>Minor at end OK; turning usually q4h</li> </ul>
Urinary	<ul style="list-style-type: none"> <li>Bladder</li> <li>Bowels</li> </ul>	<ul style="list-style-type: none"> <li>Incontinence common; pads, depends, catheter</li> <li>Bowel care stopped in last days; incontinence might occur</li> </ul>
Prognosis	<ul style="list-style-type: none"> <li>How long; when to call</li> </ul>	<ul style="list-style-type: none"> <li>Not know for sure, but provide some guidance</li> </ul>
At Death	<ul style="list-style-type: none"> <li>Do NOT call 911</li> <li>Pronounce death</li> </ul>	<ul style="list-style-type: none"> <li>Call phone numbers of nurse, physician; have DNR in place</li> <li>Requirements vary by province/state</li> </ul>

Table 19.6. Common Physical Changes Approaching Death. M Downing.

## 1. Consciousness

To be fully conscious is 'to be aware of one's self and the surrounding environment.'

There are two aspects to this:

1. Content – the sum of mental processes including the ability to discriminate among both the sensory inputs and the internal cognitive aspects
2. Arousal – a state of wakefulness or alertness to external and internal processes

## 2. Clouding of Consciousness

Clouding of consciousness is defined as 'a reduced state of wakefulness or awareness.' It occurs in several levels, and an individual patient may go through any or all of these as death approaches.

### a. Mild Clouding of Consciousness

For the terminal patient, fatigue and periods of drowsiness are not uncommon. After a period of rest, the patient regains and remains fully conscious.

In mild clouding of consciousness, however, several other features occur which may not be observed or appreciated by caregivers in the early part of this phase. These features include:

- Excitability and irritability which alternate with drowsiness
- Patient is startled by minor stimuli
- Easily distracted
- Misjudges sensory perceptions, especially visual
- Cannot think clearly or quickly
- These features may be intermittent and mistaken for anxiety

### b. Advanced or Subacute Confusional State

In this phase, the intensity and persistence of the symptoms is increased. The patient is 'confused.'

- Stimuli are more consistently misinterpreted
- Attention span is shortened
- The patient is bewildered and has difficulty following commands
- There is some disorientation to time and sometimes to place and person
- Memory is faulty
- Drowsiness is often prominent (may alternate with night-time agitation)
- There is some evidence that overall cerebral metabolism is reduced by up to 20%

### c. Delirium

The next level of consciousness is delirium, although many would combine confusional state above with this.

- Intensified disorientation, fear, irritability
- Misinterpretation of stimuli; often visual hallucinations
- Lucid periods which often alternate with delirium (while lucid, the patient may be afraid of mental failure, i.e. limited insight)
- Delusions are common
- Patient is often loud, talkative, offensive, suspicious, agitated

This is seen in opioid-induced neurotoxicity and toxic or metabolic states including poisoning, alcohol withdrawal, uremia, acute hepatic failure and severe systemic infections.

### d. Stupor

Stupor is defined as 'a state where the patient is unresponsive but briefly arousable, only during vigorous and repeated stimuli, and then immediately drifts back to unresponsiveness.' In this stage, the patient may moan or be briefly restless when being turned or when given skin care. Staff need to ascertain whether this moaning is due to insufficient pain control or simply being partially roused from a deeper level and is discussed later under 'Moaning and Furrowed Brow.'

### e. Coma

This is the true coma, defined as 'complete unarousable unresponsiveness' or ... 'the absence of any psychologically understandable response to external stimuli or inner need.'

This is exemplified in a patient who is breathing on his own but is totally unarousable by any physical stimulus such as pinching, heat or cold, yelling or sudden noise. There is no intake or ability of caregivers to detect any desire or need by the patient.

There are subsets of coma including the Minimally Conscious State (MCS), vegetative state and locked-in syndrome(126). These are more often seen as consequences of brain hemorrhage or injury. Figure 19.4 shows the variations in arousal and awareness among these.