

## BURDENSOME SYMPTOMS IN THE LAST 12 MONTHS OF LIFE

End of life symptoms are **burdensome** if they cause physical, psychological, social or spiritual distress. The extent of burden is a function of

- each symptom's frequency, severity and duration
- each person's distress, bother and difficulty in tolerating the symptom

Burdensome symptoms that we can measure using the RAI-MDS 2.0 are:

Symptom	Definition
<b>Communication difficulties</b>	<i>Resident rarely or never making self-understood during the last seven days. At best, understanding is limited to staff interpretation of highly individual, resident-specific sounds or body language (e.g. indicated presence of pain or need to toilet).</i>
<b>Constipation</b>	<i>In the last 14 days, the resident passes two or fewer bowel movements per week, or strains more than one out of four times when having a bowel movement.</i>
<b>Delirium</b>	<i>New onset or worsening during the last seven days of any one of these behavioral signs: a. easily distracted (e.g. difficulty paying attention, or gets sidetracked); b. periods of altered perception or awareness of surroundings (e.g. moves lips or talks to someone not present, believes he/she is somewhere else, or confuses night and day); c. episodes of disorganized speech (e.g. speech is incoherent, nonsensical, irrelevant, or rambling from subject to subject; or loses train of thought); d. periods of restlessness (e.g. fidgeting or picking at skin, clothing, napkins, etc.; frequent position changes; or repetitive physical movements or calling out); e. periods of lethargy (e.g. sluggishness, staring into space; difficult to arouse; or little body movement); and f. mental function varies over the course of the day (e.g. sometimes better, sometimes worse; or behaviors sometimes present, sometimes not).</i>
<b>Depressive symptoms</b>	<i>Defined as the Depression Rating Scale (DRS) <math>\geq 3</math>. It is based on the observation of seven behavioral patterns in the last 30 days. They include: a. making negative statements, b. persistent anger with self/others, c. expression of unrealistic fears, d. repetitive health complaints, e. repetitive anxious complaints/concerns, f. sad/pained/worried facial expressions, and g. crying/tearfulness. When one behavior is observed up to five days a week, a score of 1 is given; when the behavior is observed daily or almost daily, a score of 2 is given. Thus, the DRS can range from 0 to 14.</i>
<b>Eating problems</b>	<i>During the last seven days, inability to chew food easily and without pain or difficulties, regardless of cause (e.g. resident uses ill-fitting dentures, or has a neurologically impaired chewing mechanism, or has temporomandibular joint pain, or a painful tooth). Or dysphagia (e.g. frequent choking and coughing when eating or drinking, holding food in mouth for prolonged periods of time, or excessive drooling)</i>
<b>Edema</b>	<i>During the last seven days, excessive accumulation of fluid in tissues, either localized or systemic (generalized). It includes all types of edema (e.g. dependent, pulmonary, and pitting).</i>
<b>Falls</b>	<i>In the past 30 days, any unintentional change in position where the resident ends up on the floor, ground or other lower level.</i>
<b>Fecal incontinence</b>	<i>In the last 14 days, a lack of control of bowel movement (despite scheduled toileting plans, continence training programs, and/or use of appliances) occurs at least once a week.</i>

<b>Infections</b>	<i>Any one (or more) of antibiotic resistant infection, cellulitis, clostridium difficile, conjunctivitis, HIV infection, pneumonia, respiratory infection, septicemia, sexually transmitted diseases, tuberculosis, urinary tract infection, viral hepatitis, and/or wound infection.</i>
<b>Pain</b>	<i>Presented during the last seven days, any type of physical pain or discomfort in any part of the body, localized or generalized, acute or chronic, at rest or with movement, that is either daily and/or of worst possible intensity.</i>
<b>Pressure ulcers</b>	<i>Any lesion caused by pressure resulting in damage of underlying tissues (also known as bedsore or decubitus ulcer) during the last seven days that is at Stage 2, 3, or 4. Stage 2 ulcer is a partial thickness loss of skin layers that presents clinically as an abrasion, blister, or shallow crater. Stage 3 ulcer is a full thickness of skin is lost, exposing the subcutaneous tissues; presents as a deep crater with or without undermining adjacent tissue. Stage 4 ulcer is a full thickness of skin and subcutaneous tissue is lost, exposing muscle or bone.</i>
<b>Responsive behaviors</b>	<i>Any of these behavior symptoms during the last seven days: wandering, verbally abusive behavior, physically abusive behavior, socially inappropriate behavior, and resists care.</i>
<b>Dyspnea</b>	<i>During the last seven days, difficulty breathing (dyspnea) occurring at rest, with activity, or in response to illness or anxiety.</i>
<b>Urinary incontinence</b>	<i>In the last 14 days, a lack of control of bladder function (despite scheduled toileting plans, continence training programs, and/or use of appliances) occurs at least once a week.</i>
<b>Weight loss</b>	<i>Weight loss of 5% or more in last 30 days, or 10% or more in the last 180 days.</i>