

# Symptom Assessment and Triage in the Last Days of Life

*Terminal Agitation, Pain and Respiratory Distress*

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# Outline

EOL Changes That Make Assessment and Management Challenging

Physiologic Changes at EOL and Effects on Medication Absorption

Terminal Restlessness and Terminal Agitation

Pain in the Last Days to Week

Opioid Induced Neurotoxicity

Respiratory Distress in the Last Days to Week

# EOL Changes Making Assessment and Management Challenging

## Patient LOC declining

- Loss of ability to self report
- Loss of oral route

## Caregivers are increasingly stressed and challenged

- Rapid changes in condition
- Decreased sleep for caregivers
- New arrival of family/friends who may not understand illness trajectory

# EOL Changes Making Assessment and Management Challenging

## Organ systems are shutting down

- Bowels, Kidneys, Liver, Brain
- Decreased tissue perfusion
- Dehydration and electrolyte imbalances

## Medications, routes, and doses changed frequently

- Hard to differentiate between a true symptom change vs.
  - medication absorption issues
  - changes in medications
  - toxicity

# Physiologic Changes at EOL and Effects on Medication Absorption

## Oral

- Slowed peristalsis, mesenteric hypo-perfusion, delayed gastric emptying decrease absorption<sup>1</sup>
- Altered consciousness and swallow reflexes increase risk for aspiration

## SL

- Most medications are poorly or not at all absorbed SL<sup>2</sup>
- SL medication may drip out of mouth

## SQ

- BP and cardiac output drop at EOL causing blood shunting to core and away from SQ tissue<sup>3</sup>
- Absorption can be erratic with cachexia, edema

# Physiologic Changes at EOL and Effects on Medication Absorption

## Suppository

- Dry rectum (dehydration and EOL medications) causes poor dissolving and dispersing<sup>4</sup>
  - Need 10ml free water to dissolve and disperse
- Stool can decrease absorption

## Intravenous

- absorption both 100% and immediate
- Fast elimination - frequent breakthrough dosing necessary

## Micro-enema

- Medications have necessary water to immediately disperse and absorb across mucosal membrane<sup>5</sup>
- Liquids absorbed even with solid stool
- Onset faster for palliative meds compared to oral, SL, Supp

Three Most  
Common and  
Distressing  
Symptoms

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Terminal  
Restlessness/Agitation

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Pain

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Respiratory Distress

# Terminal Restlessness and Agitation

## Terminal Restlessness/Agitation

- **Excessive restlessness or increased mental or physical activity in the last few days to weeks of life.**
  - Not a diagnosis - a symptom – multiple causes
  - Usually caused by Delirium
- **Incidence**
  - As many as 42-88% of patients experience in last week<sup>6</sup>
    - Over 90% of CA patients<sup>7,8</sup>
    - Increases exponentially as death approaches



# Terminal Restlessness vs Terminal Agitation

## Typical Behaviors for Restlessness

- Excessive arm and leg movements
- Wandering, repetitive movements
- Does not seem fearful - not at risk of harming self or others
- May have “nice” hallucinations, not scary

## Typical Behaviors for Agitation

- Hitting, biting, yelling, paranoia, delusions
- Fear, anger, rage
- Behaviors that could harm to self or others
- Constantly trying to escape, climbing out of bed

# Key Indicators of Advancement to Agitation

## Is the patient anxious or fearful?

- Ask patient, “Are you feeling afraid?”
- Do they look fearful?
- Are they making paranoid statements?
- Fearful delusions or hallucinations?
  
- If anxiety or fear present
  - Benzodiazepine may be indicated
  
- If paranoia or delusions present
  - neuroleptic may be indicated.

## Are they sleeping?

- Lack of sleep will lead to delirium
  
- Avoid benzodiazepines unless SOB or anxiety is present
  - Worsens disinhibition, disorientation and delirium
  
- First gen. neuroleptic at bedtime for sleep may be indicated
  - quetiapine and chlorpromazine
    - more sedating than haloperidol

# Terminal Restlessness Intervention and Teaching

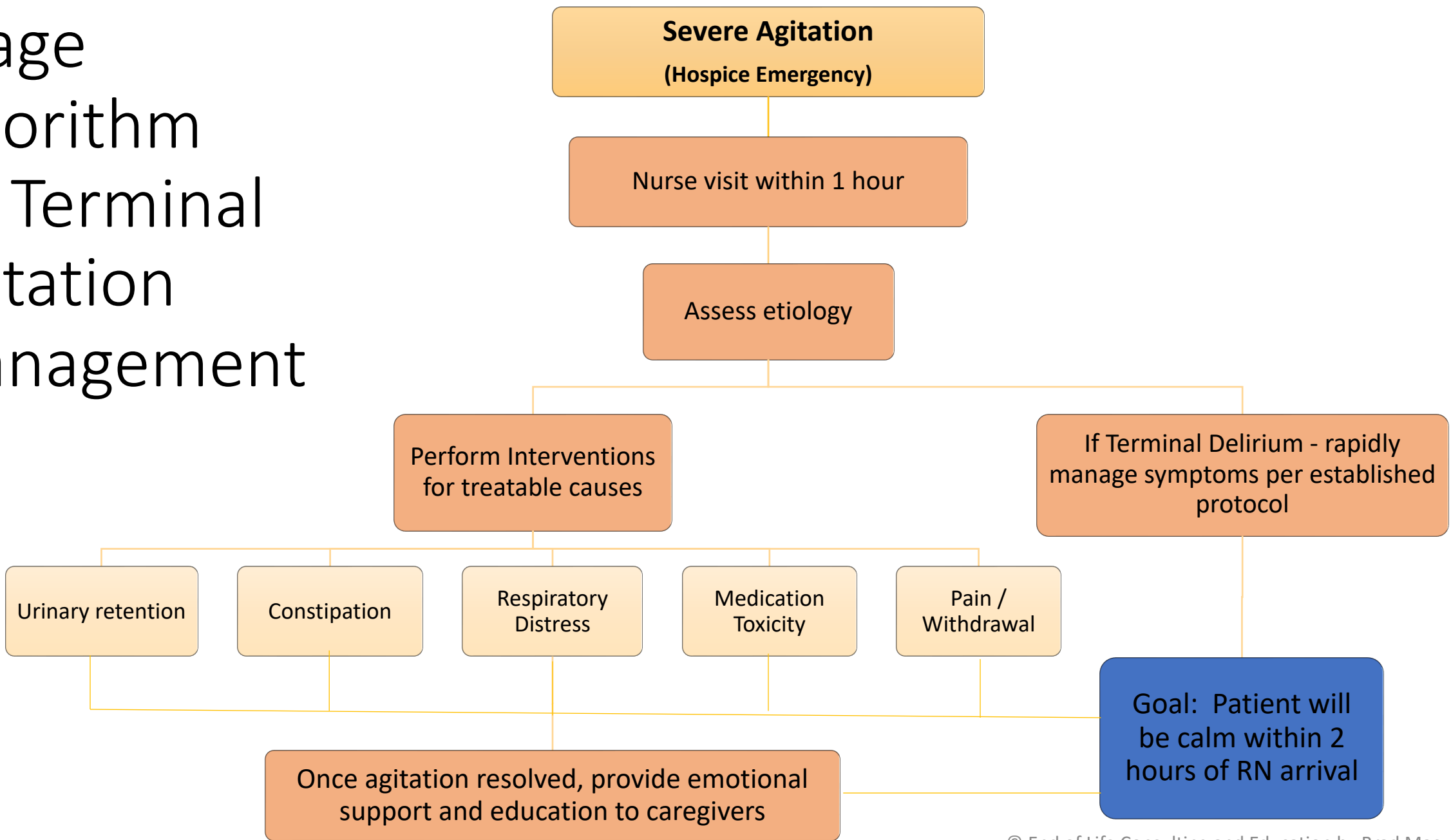
## Teaching

- restlessness is normal part of the process
- provide calm, quiet environment
- reorienting
- limit visitors to family and very close friends
- closely monitor to avoid progression to agitation
- call hospice if patient seems
  - fearful, paranoid, angry
  - unable to sleep
  - at risk of injuring self or others

## Intervention

- Visit by hospice RN within 24 hours to continue education, support and assessment

# Triage Algorithm for Terminal Agitation Management



# Treatable Causes for Terminal Agitation

## Urinary Retention

- When was the last time the patient urinated?
- Are kidneys working?
- Palpate bladder for fullness and discomfort
  - Place Urinary catheter only if needed

## Impaction/Constipation

- When did the patient last have a BM?
- If 3 days, RN should do rectal check
  - If hours left, a full disimpaction may be too uncomfortable

# Treatable Causes for Terminal Agitation

## Respiratory Distress (Hypoxia)

- Is the hospice DX Respiratory related?
- Is the patient breathing hard/fast?
- How does the breathing sound? Lung Sounds?
- O<sup>2</sup> Sat?
- Have they had respiratory distress in the past?

## Medication Toxicity

- Anticholinergics
  - NOTE: Atropine drops can be difficult to dose
- Opioids
  - too much / too little?
- Benzodiazepines (disinhibition)
- DC Other non-palliative medications

# Treatable Causes for Terminal Agitation

## Pain and/or Withdrawal

### History and Diagnosis

- Is pain likely with the diagnosis?
- Does patient have pain history?
- Has patient recently cut back opioids or adjuvants?

### Assessment

- Currently on an opioid?
  - Are they getting scheduled and BT doses?
- Is route of delivery oral/SL?
  - Are bowel sounds diminished?
  - Stomach distended?

## if pain is suspected, perform 1-hour test

- try opioid dose first via effective route (IV or ME)
- Give normal scheduled dose
- If no pain change after 1 hour, treat for agitated behavior directly

# Terminal Delirium

Acute change in mental status in the last days to weeks of life caused by an underlying physiological disturbance.<sup>4</sup>

## Hyperactive

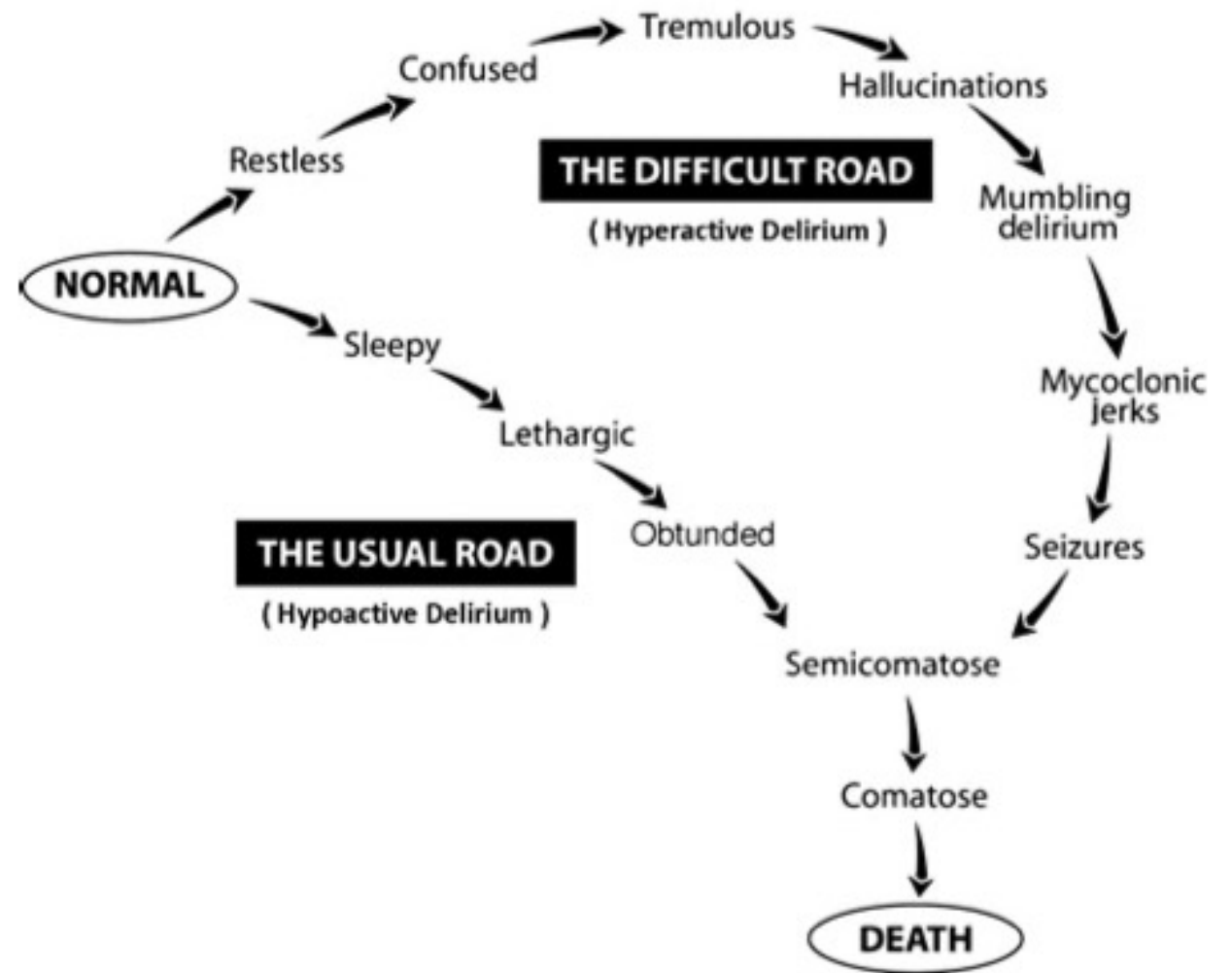
- restlessness, agitation, or aggression.

## Hypoactive

- withdrawn, quiet and sleepy.

## Mixed

- hyperactive and hypoactive symptoms.



From: Irwin SA, Pirrello RD, Hirst JM, Buckholz GT, Ferris FD. Clarifying delirium management: practical, evidenced-based, expert recommendations for clinical practice. J Palliat Med. 2013 Apr;16(4):423-35.



# Irreversible Terminal Delirium

## Causes for Delirium at EOL

- Metabolic
  - Organ shutdown at EOL
  - toxic metabolites (Ca, NH<sub>3</sub>, Medication metabolites)
  - dehydration
  - infection
- Can be exacerbated (but not caused) by psychological factors
  - existential fear, PTSD, fear of dying process
  - Family interaction/preparedness for death

# Treating “Irreversible” Delirium Symptomatically

Patients may only have minutes or hours...

- Every minute counts
- Families remember agitated death the rest of their life
- Prolonged agitation is extremely distressing for patient and caregivers

Treat as Quickly as Possible

- Plan to control within minutes to 2 hours
- Treat with rapid acting meds for quick titration (fast tmax)
- Give via route that assures rapid onset and low intra-subject variability
- Move quickly to the next line medication when therapy not successful

# Terminal Delirium Treatment Guidelines

## First Line Medications

### First-generation neuroleptic or benzodiazepine

- Currently no agreement which is better
- Recommend basing on behavior
- First Generation Neuroleptics\
  - Haloperidol, Quetiapine, Chlorpromazine
  - Agitation “of mind”
  - Calming, slowing
    - hallucinations, delusions, sleeplessness, disinhibition
- Benzodiazepines
  - Agitation “of body”
  - muscle tension, myoclonus, anxiety, fear, aggression
    - Sedating

## Switch to a sedative if;

- No results after two hours
- Potential harm to self or others
- Significant CG anxiety
  - Phenobarbital, Propofol

# Terminal Agitation / Delirium

## Non- Pharmacologic Interventions

- Provide education and support to families to decrease stress
  - If the family is calmer the patient will more likely be calm
- Teach
  - Quiet environment with low stimulation (avoid TV, background noise, etc.)
  - Limit visitors to family or very close friends
  - Limit visit length
  - Provide constant supervision (family should rotate)
  - Provide soft but adequate lighting
  - Pad on floor next to bed
  - Soft music or relaxation tape may help
    - be sure patient has history of liking this

# Pain

## Prevalence

- 47% of patients experience moderate or severe pain in the last month<sup>9</sup>
- 25% experience uncontrolled pain in last week of life, in spite of having access to opioids<sup>10</sup>
- 85 – 90% of patients could be pain free with proper use of knowledge and technology
  - 98 -99% could have pain controlled
  - The other 1 - 2% could be offered palliative sedation<sup>11</sup>

# Assessing Level of Pain

## Primary indicators of severe pain

- Constant grimace, clenched or trembling jaw, moaning, whimpering, screaming, vocalizing “ouch” constantly

## Primary indicators of mod. pain

- Fidgeting, guarding, occasional incidence of any of the above severe indicators, vocalizes “ouch” when moved

# Algorithm for Severe Pain

## Severe Pain

**7-10 (scale 0 to 10)**

- Considered a Hospice Emergency



Nurse visit after 1 hour of unsuccessful titration by phone

- For oral/SL, titrate q 1 hr
- Increase by 50% to 100%



Change routes from PO/SL after 1 to 2 hours if still severe

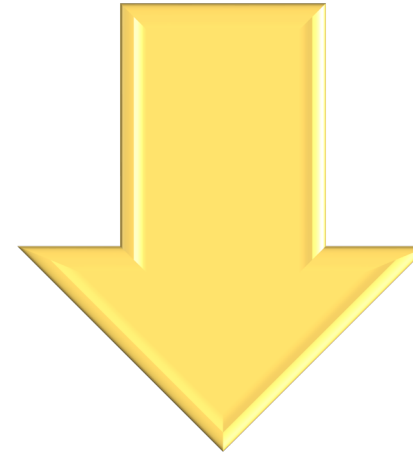
- IV or ME routes – fastest onset, best absorption, least variability
  - Can titrate q 30 minutes
- Consider starting/restarting adjuvants

## Pain in the Last Days to Week

**In last days of life, a sudden increase in pain is more likely due to;**

- **Not Enough Opioid**
- or
- **Too Much Opioid**

**as opposed to a disease related increase in pain.**



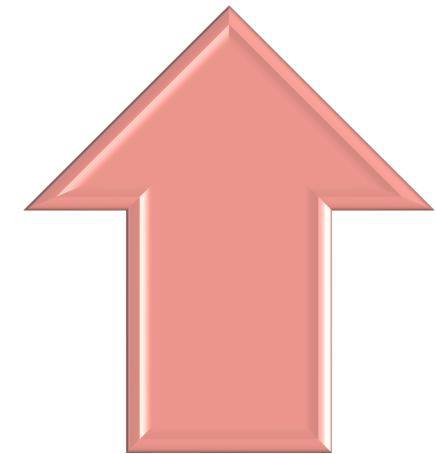
## Not Enough Opioid

- CGs not delivering the prescribed medication regime
- Medications not being absorbed properly



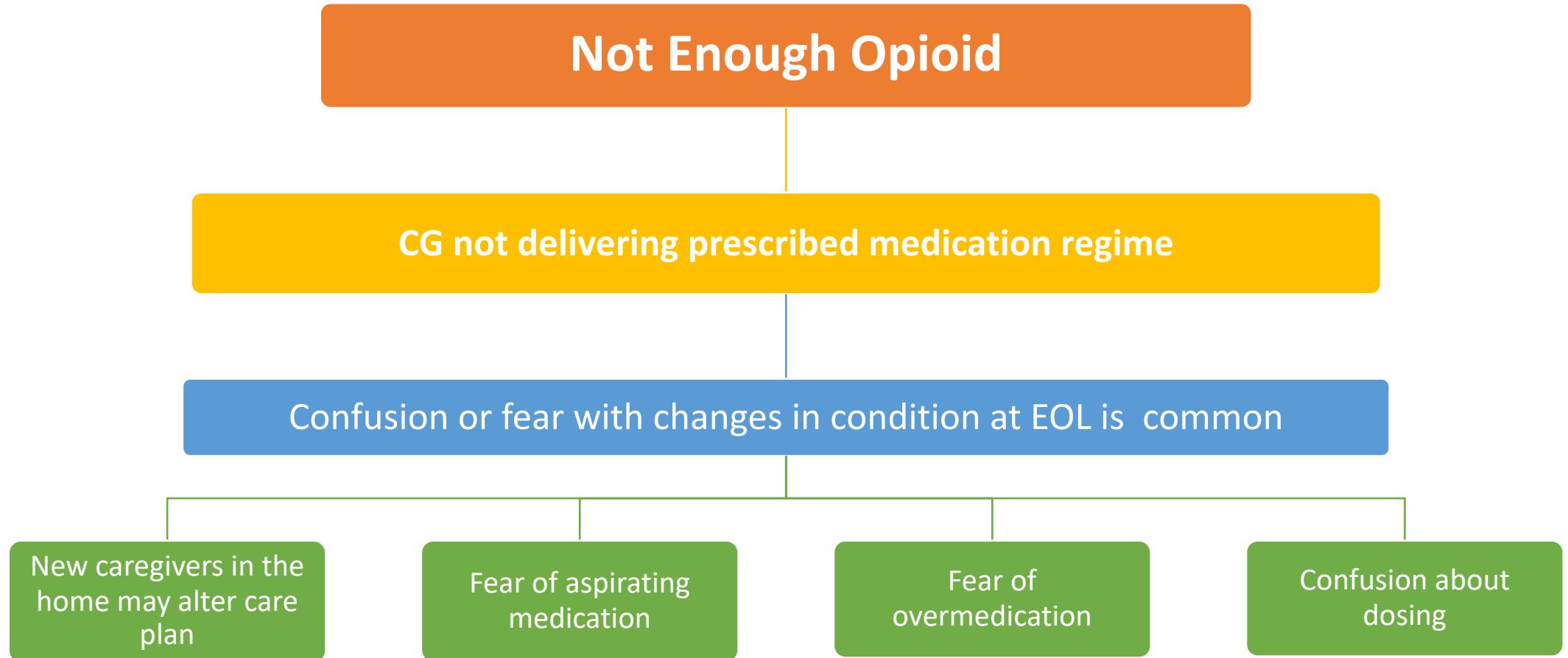
## Too Much Opioid

- Opioid Induced Neurotoxicity (OIN)

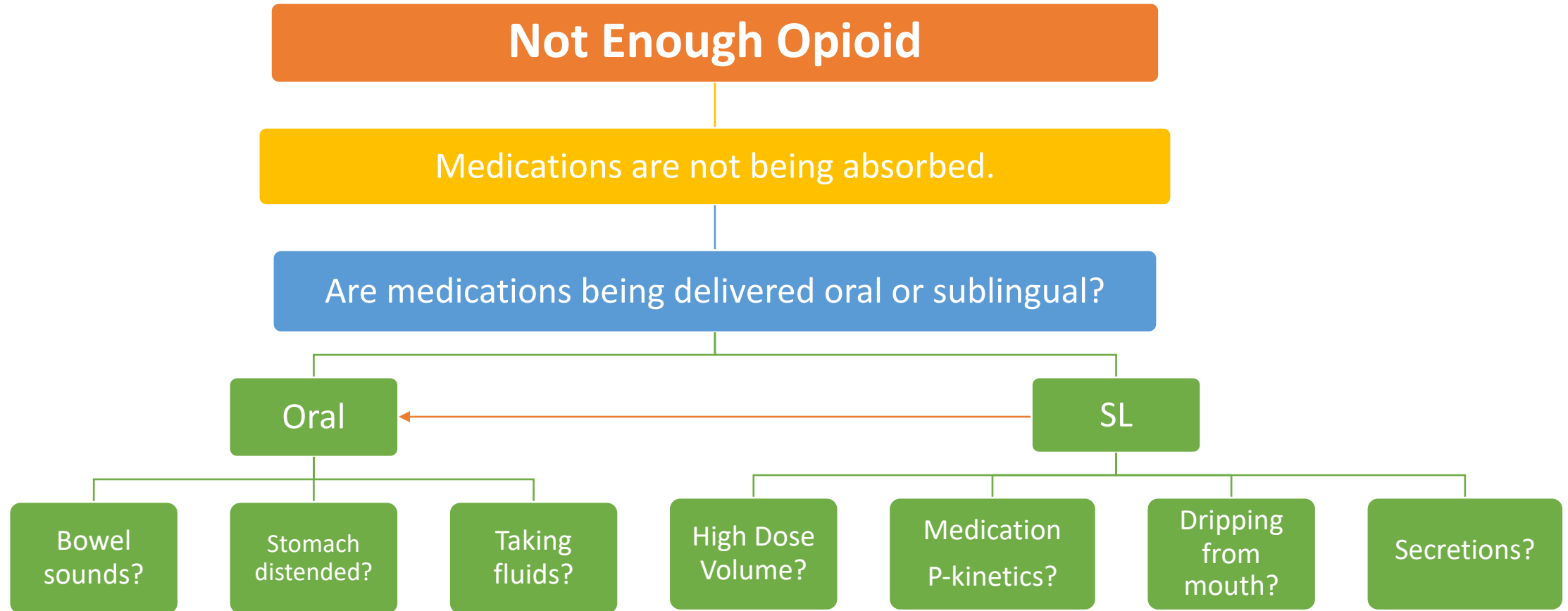




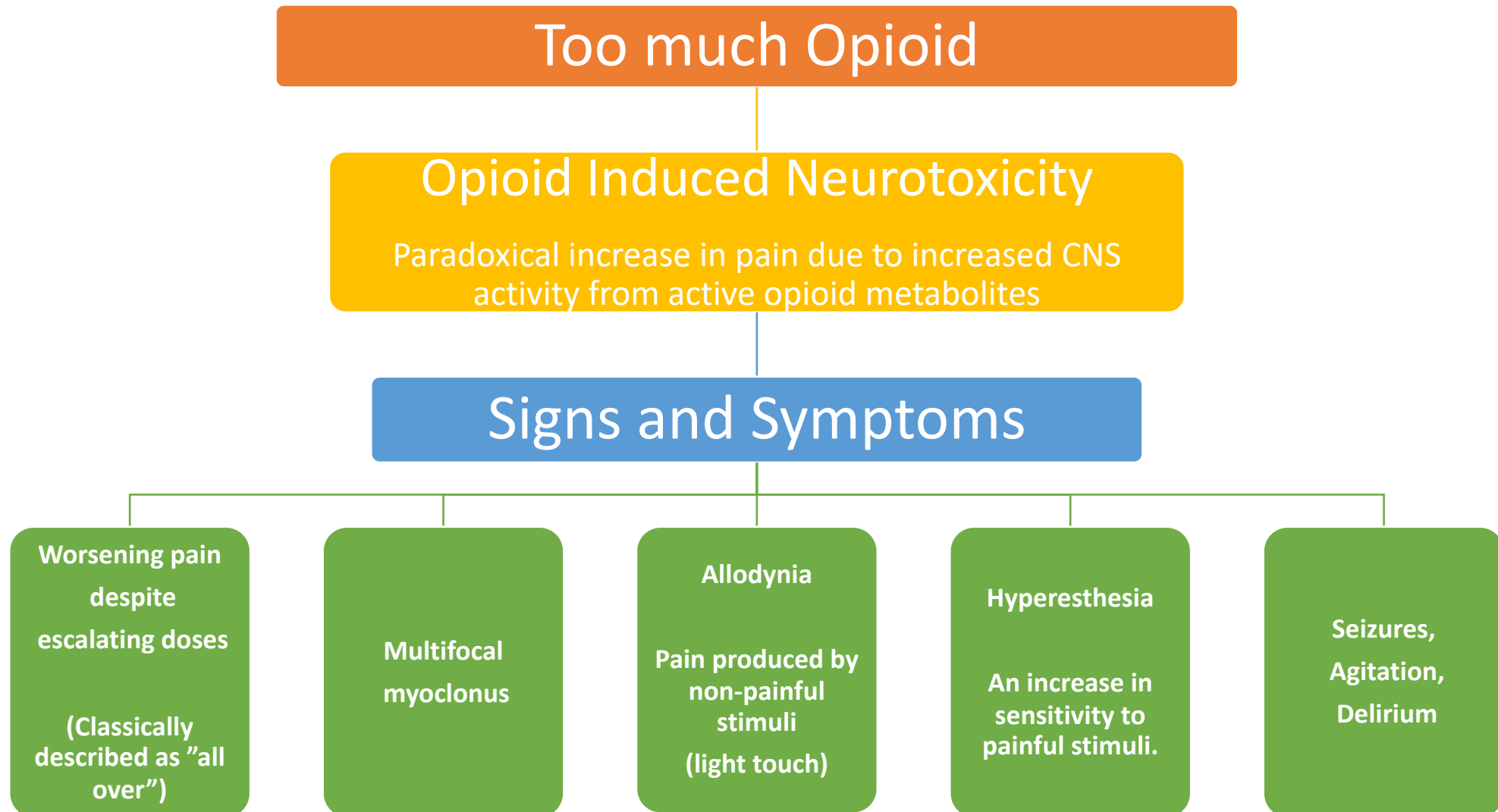
# Pain in the Last Week to Days



# Pain the the Last Week to Days



# Pain the the Last Week to Days



# Too much or too little?? – 1-hour test

If OIN is suspected AND pain or other symptoms are severe

RN, MD, NP visit

## Assessment

- Classic signs of OIN?
- Rapid escalation in both pain and dosing?
- 24-hour dose calculation

## Perform One-Hour test

Switch route to ME or IV

- Give normally scheduled opioid dose
- Monitor pain for 1 hour

Treat OIN if pain not improved

## OIN Treatment

- Hydration (ME,IV)
- Opioid rotation
- Adjuvants
- Opioid reduction

# Treating Opioid Induced Toxicity

## Hydration

- Give 100ml - tap water ME bolus
  - repeat every 2-4 hours until symptoms subside
- Give IV at 30-50/hr until symptoms subside
- At EOL may quickly solve issue without other interventions

## Opioid Rotation

- Switch to Equianalgesic dose of different opioid
  - Methadone
  - Hydromorphone

## Adjuvant Medications

- For myoclonus
  - Benzodiazepines
- For pain
  - NMDA agonists
    - Methadone,
    - Ketamine
- Anti-inflammatory
  - Dexamethasone,
  - NSAID
- For Seizures or sedation
  - Phenobarbital

## Decrease medication dose

- By as much as 75% of the morphine equivalent daily dose prior to OIN
- Riskier at EOL

# Respiratory Distress

## Incidence<sup>21</sup>

- prevalence of dyspnea is 50% to 70%, in CA patients
- 90% in patients with lung cancer.
- 90% of patients with severe lung disease
- 50% of heart failure patients
- intensity and prevalence increase in the last six months of life
- 90% during the last 3 days of life,

# Confirming Respiratory Distress

## Assessment: Physiological

- Resp Rate >30
- Heart rate not as good a parameter at EOL
- O<sup>2</sup> sat can help
- >93 = hypoxia
  - In 80s or below - treat as severe resp distress
  - CGs should avoid “sat watching”

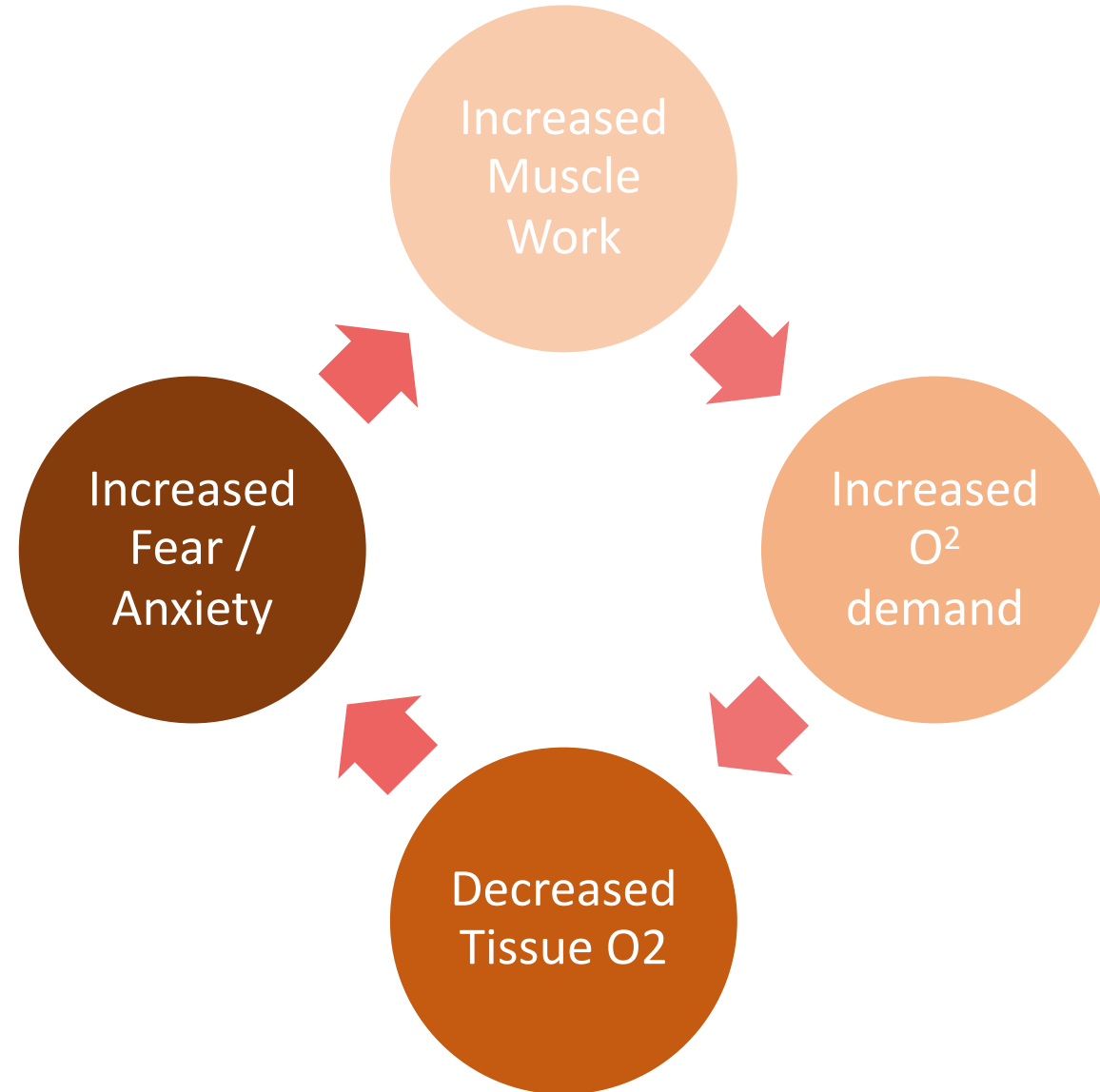
## Assessment: Physical

- Grunting, nasal flaring, paradoxical breathing
- use of accessory resp muscles
- look of fear

## Diagnosis and History

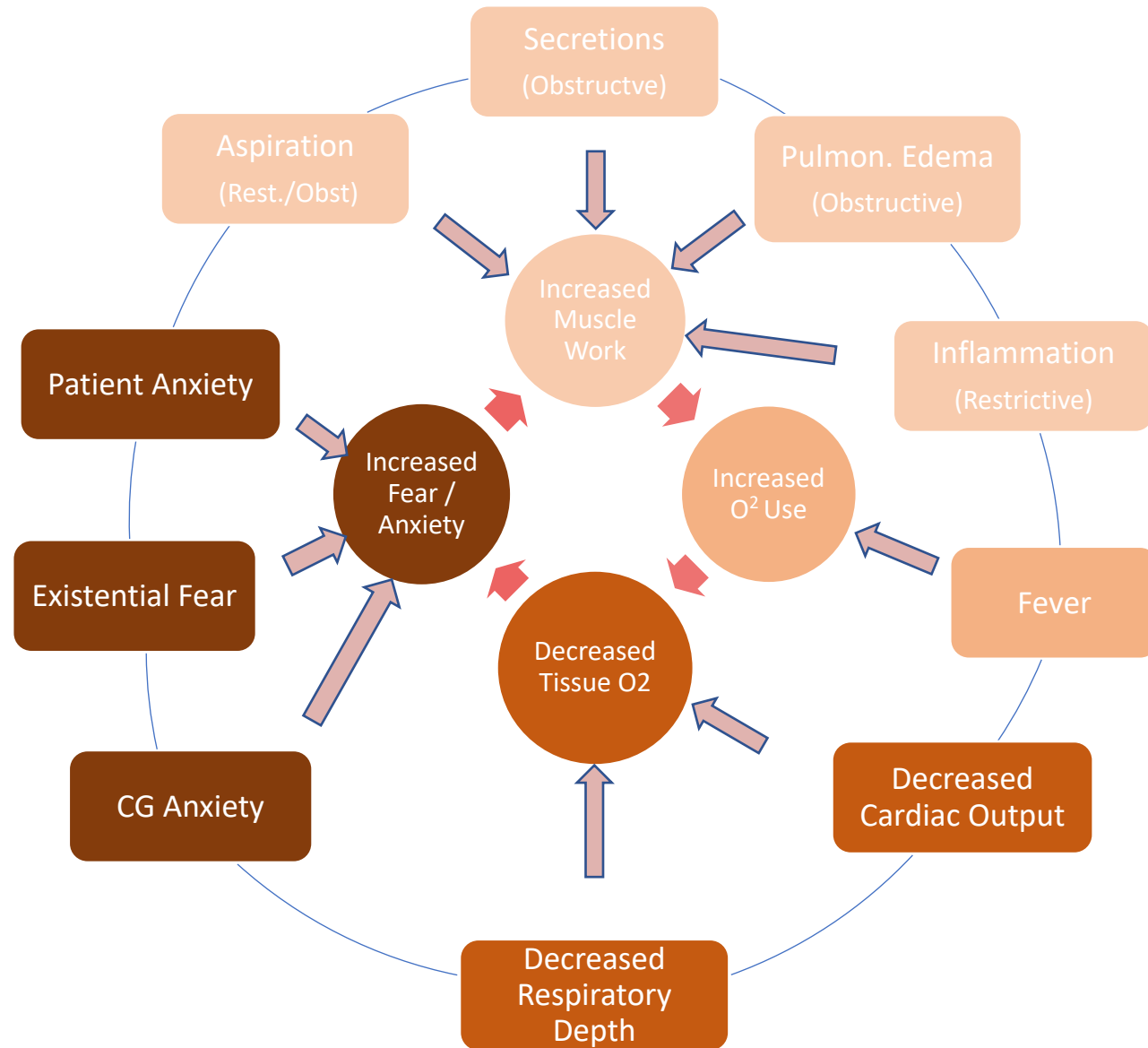
- Pulmonary fibrosis, lung CA, COPD, CHF, heart
- Has the patient had RD in the past?

# The Vicious Circle of Respiratory Distress





# End of Life Changes Feeding the Respiratory Vicious Circle



## Secretions/Aspiration/ Pulmonary Edema (obstructive)

- Proactively stop Oral/SL meds when
  - Volumes greater than 1ml
  - Signs of aspiration (coughing, wet respirations)
- Elevate HOB 30°
- Position on “bad” side
- Gentle oral suction
  - No deep suction
- **Meds to improve oxygenation**
  - Anticholinergics
  - Muscarinic Antagonist
    - Ipratropium / Albuterol Neb
- Diuretics
  - Oxygen
- **Meds for anxiety/fear/muscle relaxation**
  - Opioids
  - Benzodiazepines
- If above ineffective
  - Sedatives

## Inflammation (restrictive)

- Meds to improve oxygenation
  - Dexamethasone
  - Albuterol/Ipratropium via nebulizer
- Oxygen
- Meds for anxiety/fear/ muscle relaxation
  - Opioids
  - Benzodiazepines
- If above ineffective
  - Sedatives

## Decreased Cardiac Output

- Oxygen
- Elevate HOB
  
- Meds to increase cardiac output
  - CA channel and/or Beta blockers (can give ME)
  
- Meds for anxiety/fear/muscle relaxation
  - Opioids
  - Benzodiazepines
- If above ineffective
  - Sedatives

## Decreased Respiratory Depth

- Oxygen
- Elevate HOB
- Position on “bad” side
- Control other areas well
  
- Meds for anxiety/fear/muscle relaxation
  - Opioids
  - Benzodiazepines
- If above ineffective
  - Sedatives

## Existential Fear, CG Anxiety, Pt. Anxiety

- Teach Family
  - Pt. Reaction to Anxiety
  - Calm voices
  - Little background noises
  - No violent TV or political banter
- Quiet environment
- Limit visitors and length
- Is there a missing family member?
- Chaplain/MSW/Aide support
- Same team members
  
- Meds for Anxiety
  - Benzodiazepines

## Fever

- NSAIDS, ASA, Tylenol
  - ATC dosing to avoid chills/sweats
    - increases O<sup>2</sup> demand
- Light covers
- Temp controlled - (low 70s)

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