ALS Patient Emergency Information

Emergency Medical Services/Emergency Room Information

SHORTNESS OF BREATH ……..OXYGEN and ALS

- **Oxygen given alone may depress respiratory drive in ALS, causing elevated CO2, leading to respiratory failure.** Often lungs are healthy, but respiratory muscles including the diaphragm, may be weak.
- If shortness of breath or low oxygen saturation (SpO2) is present, may use supplemental O2 with close monitoring of patient.
- **Use pulse oximetry and capnography for monitoring.**
- Non-invasive ventilation (i.e. Bipap™ or Trilogy™) **or bag-valve-mask assisted breathing** should be used to expel CO2 and increase SpO2. **CPAP is contraindicated as it may increase the work of breathing.**
- Bleeding in oxygen to non-invasive ventilator is best for adding oxygen, thereby increasing SpO2 while keeping CO2 down.

VENTILATION

- Non-invasive ventilation may help avoid the necessity of invasive ventilation. **Note: Weaning/extubation is often difficult or impossible once invasive ventilation is initiated.**
- If patient is on non-invasive ventilation at home, **bring equipment, tubing and mask and use enroute as required.** The caregiver will know how to use it and may better understand speech while wearing it. **If possible, caregiver should accompany patient on the ambulance.**
- If using ambulance or hospital non-invasive ventilator, consider beginning use at same settings as home equipment to start, then titrate.
- If new to non-invasive ventilation, therapy might be started with beginning pressures of 10/5 and backup respiratory rate of 10 via mask, then titrate as needed for efficacy.
- If using a BIPAP™ instead of Trilogy™, be aware that pressure support will not self-adjust for changes in body position and that patient may be at risk of aerophagia leading to increased dyspnea.

AVOIDANCE OF MEDICATIONS CAUSING RESPIRATORY DEPRESSION

- When possible, avoid paralytic or general anesthetics, narcotics, muscle relaxants or other sedation unless patient is on non-invasive ventilator support with a back-up rate as these medications may dangerously decrease respiratory drive.
- **If meds must be used, the ability to rapidly assist ventilation should be available.**

ORTHOPNEA

- Lying supine may cause SOB due to respiratory muscle weakness, perhaps resulting in CO2 retention and low SpO2.
- If lying flat is necessary, wearing non-invasive ventilator (i.e. Bipap™, Trilogy™) would likely help breathing. If patient has excessive secretions, protection of airway should be monitored.

AIRWAY PROTECTION

- Aspiration is a danger and may be the cause of SOB. Many patients have decreased ability to protect their airway.
- Have a suction machine available and set up, oral secretions may be excessive.
- If available, a Cough Assist (insufflator/exsufflator) is preferable to suction as it can more forcefully "pull" secretions and mucous plugs out of the airway.
- If a gastrostomy tube is in place, consider using for administration of "oral" medications, as appropriate.
- Swallowing may be compromised, evaluate prior to PO intake. Patient/caregiver may have prior recommendations.

COMMUNICATION

- Dysarthria is common including slurring, slowness, inability to speak at all. Do NOT assume alcohol or drug use.
- Speak in a normal voice and **allow time to communicate**. Yes/no questions may be best. Speech boards, paper and pencil, and other devices may be utilized.
- Avoid separating patient from caregiver, they are knowledgeable about speech, treatment needs and equipment.
- If possible, allow caregiver to be present during interventions to assure appropriate handling and communication.
- **If patient is left alone, ensure they have call system that they can use.** Many patients cannot push a button, consider alternative system, for example pillow, tent or microlight switch for use with head or other body part.

TRANSFERS AND POSITIONING

- Use caution moving; muscles may be atrophied or stiff and range of motion limited. Do not lift by the arms if weakness/atrophy present as this may lead to shoulder dislocation.
- Gait may be unsteady from ALS, take precautions as needed. When mild-moderate assistance is needed, suggest using a gait belt which will give greater support without injuring weak shoulder girdle.