ST. FRANCIS 24/7 CALL CENTER: (321) 269-4240

St. Francis REFLECTIONS® Hospice
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Amyotrophic Lateral Sclerosis (ALS)

ALS is a progressive neurodegenerative disease that affects motor neurons, leading to muscle weakness, atrophy, and eventual paralysis.

Common Symptoms:

Symptoms may differ from person to person

- **Early signs include:**
  - Muscle twitching
  - Weakness in the arms or legs
  - Difficulty speaking or swallowing
- **As the disease progresses:**
  - Patients may lose the ability to move, speak, or breathe independently

Causes:

Potential causes:

- The exact cause is not known, though genetic mutations and environmental factors may play a role. Familial ALS has a genetic component.

Hospice Considerations:

No cure for ALS exists. Treatments aim to slow progression and manage symptoms. Certain medications may be used to extend survival slightly and improve function.

- **Advanced Disease:** When the patient is in the advanced stages of ALS, with significant loss of mobility, communication, and respiratory function.
- **End-of-Life Symptoms:** When managing symptoms such as severe muscle weakness, respiratory distress, and difficulty with feeding becomes complex.
- **Comfort Care:** When the focus is on providing comfort and support, rather than extending life through medical interventions.

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Symptom Management Tips:

- **Respiratory Support:** Non-invasive ventilation (i.e. BiPAP) helps with breathing difficulties. Ensure frequent monitoring for signs of respiratory distress.
- **Swallowing:** Use of feeding tubes (percutaneous endoscopic gastrostomy) to ensure adequate nutrition and prevent aspiration.
- **Mobility:** Assistive devices like wheelchairs, and home modifications to enhance mobility and safety.
- **Comfort:** Manage pain and muscle spasticity with appropriate medications and therapies.

How to Help:

- **Patient Tips:**
  - **Conserve Energy:** Prioritize essential activities and rest between them to prevent exhaustion.
  - **Assistive Devices:** Use mobility aids, communication tools, and non-invasive ventilation as needed to maintain independence.
  - **Plan for Future Needs:** Discuss advanced care preferences early, including respiratory support or feeding tubes.

- **Caregiver Tips:**
  - **Emotional Support:** Encourage open discussions about care preferences and fears while offering emotional reassurance.
  - **Mobility Support:** Assist with transfers and ensure the home is safe and accessible with ramps or lift chairs.
  - **Caregiver Resilience:** Caring for someone with ALS can be taxing; seek respite care and support groups for yourself.

St. Francis Reflections is always available to assist with any questions or concerns 24/7

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