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HOSPICE PATIENT AND FAMILY EDUCATION AND TRAINING

AMYOTROPHIC LATERAL SCLEROSIS (ALS)

What is Amyotrophic Lateral Sclerosis (ALS)?

Amyotrophic Lateral Sclerosis (ALS), often referred to as Lou Gehrig's disease, is a progressive neurodegenerative disorder that affects nerve cells in the brain and spinal cord. Over time, these motor neurons gradually break down, leading to muscle weakness and atrophy. ALS can impact various aspects of daily life, including mobility, speech, swallowing, and eventually, breathing.

What are the Signs and Symptoms of ALS?

Individuals with ALS may experience a range of symptoms, including:

Symptoms:

- Muscle weakness, twitching, or cramping
- Difficulty with coordination and fine motor skills
- Gradual loss of muscle mass
- Difficulty speaking or slurred speech
- Difficulty swallowing (dysphagia)
- Tight or stiff muscles
- Fatigue and tiredness
- Emotional changes, such as mood swings or depression

Signs:

- Loss of voluntary muscle control
- Difficulty walking or maintaining balance
- Increased risk of falls
- Involuntary muscle contractions (spasticity)
- Changes in facial expressions

What potential factors can cause Heart Failure?

The exact cause of ALS is not fully understood, and it may result from a combination of genetic and environmental factors. Some potential factors include:

- Genetic mutations (familial ALS)
- Environmental factors, such as exposure to certain toxins
- Abnormal protein aggregations in the motor neurons
- Immune system dysfunction

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What can be done for the person with ALS?

While there is currently no cure for ALS, supportive care and hospice services can enhance the quality of life for individuals and their families facing this challenging condition. Here are some considerations:

- Ensure the patient receives comprehensive care from a multidisciplinary team, including physicians, nurses, physical therapists, occupational therapists, and respiratory therapists.
- Promote a comfortable and accessible living environment to accommodate changing mobility needs.
- Implement assistive devices and technologies to aid communication, mobility, and daily activities.
- Provide emotional support and counselling for both the patient and their family members.
- Encourage proper nutrition and hydration, considering potential challenges with swallowing.
- Assist with managing symptoms such as pain, muscle spasms, and respiratory issues.
- Educate the patient and their family about advanced care planning and end-of-life decisions.

It is essential for patients and their families to maintain open communication with the hospice and palliative care team, promptly reporting any changes in symptoms or concerns. Additionally, seeking support from ALS-specific organizations can provide valuable resources and community connections during this challenging journey.