PATIENT PICTURE

Name _____

Address _____

_____

_____

Email _____ Phone _____

Emergency Contact _____ Phone _____

Emergency Contact _____ Phone _____

INSURANCE INFORMATION

PRIMARY INSURANCE/HEALTH PLAN

Insurance Company _____

Insurance Number _____

Group Number _____

Policy Holder _____

Relationship to Patient _____

Employer's Name _____

Employer's Address _____

City _____ State _____ Zip _____

Phone _____ Fax _____

Special Instructions _____

_____

SECONDARY INSURANCE/HEALTH PLAN

Insurance Company _____

Insurance Number _____

Group Number _____

Policy Holder _____

Relationship to Patient _____

Employer's Name _____

Employer's Address _____

City _____ State _____ Zip _____

Phone _____ Fax _____

Special Instructions _____

_____

Patient's Name _____

IMPORTANT PEOPLE IN MY LIFE

FAMILY MEMBERS:

Name	Relationship	Contact Information

FRIENDS:

Name	Relationship	Contact Information

PETS:

Name	Type of Animal

Patient's Name _____

MY HEALTHCARE TEAM

PRIMARY CARE PHYSICIAN

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

_____

NEUROLOGIST

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

_____

Patient's Name _____

MY HEALTHCARE TEAM

SURGEON

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

_____

PULMONOLOGIST

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

_____

Patient's Name _____

MY HEALTHCARE TEAM

CASE MANAGER/SOCIAL WORKER

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

_____

ALS ASSOCIATION CHAPTER LIAISON

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

_____

Patient's Name _____

MY HEALTHCARE TEAM

OTHER MEMBERS OF MY HEALTH CARE TEAM:

(For example, Nurses, Social Workers, Physical Therapists, DME, etc.)

Profession _____

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

_____

OTHER MEMBERS OF MY HEALTH CARE TEAM:

(For example, Nurses, Social Workers, Physical Therapists, DME, etc.)

Profession _____

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

Patient's Name _____

MY HEALTHCARE TEAM

OTHER MEMBERS OF MY HEALTH CARE TEAM:

(For example, Nurses, Social Workers, Physical Therapists, DME, etc.)

Profession _____

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

_____

OTHER MEMBERS OF MY HEALTH CARE TEAM:

(For example, Nurses, Social Workers, Physical Therapists, DME, etc.)

Profession _____

Name _____

Address _____

City, State, Zip _____

Telephone _____

Email _____

Notes _____

_____

_____

_____

Patient's Name _____

MY CURRENT MEDICATIONS

Brand Name	Generic Name	Dosage & Frequency	Purpose	When Begun	How Long Used	Special Instructions

Patient's Name _____

KEY INFORMATION FOR MEDICAL STAFF

Patient Name _____ Birth Date _____

Information on this form last updated _____

I attend the ALS Clinic at _____

Contact information for ALS Clinic _____

IMPORTANT! My caregiver(s) and I are extremely knowledgeable about my condition, treatment needs, and equipment. Please work with us.

Authorization to Speak with Caregiver(s)

I need my caregiver(s) to be with me during my entire treatment and ***I authorize you to consult with my caregiver(s)*** *(family, friend or home health personnel)* with no privacy or timeframe restrictions.

Caregiver Name _____ Phone _____

Caregiver Name _____ Phone _____

Caregiver Name _____ Phone _____

Patient Signature/Verbal/Other _____ Date _____

HOW I COMMUNICATE

- ○ Speech
- ○ In Writing
- ○ Via Speaking Device
- ○ Via My Caregiver
- ○ Via Letter Board
- ○ Other _____

Patient's Name _____

IMPORTANT!

- ○ **I have advance directives in place.**
- ○ **I use noninvasive ventilation.** If intubation or a tracheostomy is proposed, please consult me, my caregiver, and/or my physician.

  My current settings are: _____
- ○ **I have a tracheostomy.** It is critical that you consult me/my caregivers regarding the details of my routine.
- ○ **I have a gastric feeding tube.** It is critical that you consult me/my caregivers regarding the details of my routine.
- ○ **Other** _____

HEALTH PROFESSIONALS

PHYSICIAN

Name _____ Specialty _____

Comments _____

Phone _____ Date _____

PHYSICIAN

Name _____ Specialty _____

Comments _____

Phone _____ Date _____

PHYSICIAN

Name _____ Specialty _____

Comments _____

Phone _____ Date _____

CURRENT TREATMENTS

Oxygen: I require supplemental oxygen ○ Never ○ Always ○ Part Time

CAUTION! Providing oxygen to me may have dire consequences!
Oxygen used alone may mask or accelerate acute respiratory failure in neuromuscular patients. The response to low oxygen levels must be to increase ventilatory support and secretion management, **NOT** simply to administer oxygen.

Positioning: ***Laying*** me on my back may be difficult for me because of the possibility of CO2 retention due to diaphragmatic weakness, and aspiration due to poor ability to protect my airway. I may be able to lie on my back if I'm using a BPAP or non-invasive mechanical ventilation.

My best positions are _____

Anesthesia/Sedation:
Avoid anesthetics, narcotics or muscle relaxants unless absolutely necessary and with ability to rapidly assist ventilation non-invasively or invasively (if needed).

I can tolerate _____

I've had negative reactions to _____

CAUTION! Anything that depresses respiration must be used with great caution.

MY ALLERGIES

_____

_____

_____

_____

Patient's Name _____

MY TYPICAL VITALS

(These can change during ventilation and position change.)

Blood pressure _____ Vital Capacity _____ % Oxygen Saturation _____

Peak Cough Flow _____ Negative Inspiratory Force _____

Respiratory Rate _____

Other _____

MY EQUIPMENT

I prefer to use my home equipment. If use of home device is not feasible, hospital's equivalent is second best.

For Ventilation

I require breathing assistance for _____ hrs/day and _____ hrs/night, or

Other _____

My breathing machines/ventilators include _____

Type and Model _____

Manufacturer _____

Settings

Mode ○ Assist Control ○ Pressure Support/BPAP ○ SIMV (combination)

Tidal Volume _____ Backup Rate _____ EPAP _____ IPAP _____

PEEP _____ Oxygen _____

Inspiratory Time _____ Sensitivity _____

Low Pressure Limit _____ High Pressure Limit _____

Other _____

Patient's Name _____

MY INTERFACE(S) for access to my breathing machine/ventilator include

○ Nasal Mask ○ Nasal Pillows ○ Trach Tube (See detail below.)

○ Face Mask ○ Mouthpiece ○ Custom-made Mask

Model _____ Size _____ Manufacturer _____

Model _____ Size _____ Manufacturer _____

Model _____ Size _____ Manufacturer _____

Tracheostomy Tube details

Fenestrated? ○ Yes ○ No

Cuffed? ○ Yes ○ No

If yes, inflation is: Day @ _____ cc Night@ _____ cc

FOR SECRETION MANAGEMENT, the most effective methods for me are

○ CoughAssist® – Inhalation _____ Exhalation _____ # Breaths _____

○ Suctioning – Depth _____ Frequency _____ Catheter Size _____

○ Postural Drainage – Method _____

○ Bagging _____

○ Percussor – Locations _____ Times/Minutes _____

Medications used for secretion management

Medication: _____ Dose _____ Frequency _____

Medication: _____ Dose _____ Frequency _____

Medication: _____ Dose _____ Frequency _____

For Feeding/Nutrition, I use _____

_____

_____

My Bowel Routine is _____

Patient's Name _____

GENERAL INFORMATION FOR EMERGENCY ROOM AND HOSPITAL STAFF ON ALS

Diagnosis of ALS (Amyotrophic Lateral Sclerosis) or Motor Neuron Disease or Lou Gehrig's Disease

COMMUNICATION

Slurred communication due to tongue/soft palate atrophy can be mistaken for alcohol (ETOH) intoxication, drug use, deafness, or limited cognitive abilities.

Listeners need to be patient and wait while an ALS patient communicates using an adaptive device or alternative method. Do not guess/state words ahead of time.

A person living with ALS should not be isolated from their caregiver during emergencies. A family member or caregiver should be in attendance to assist with communication issues as needed.

- Talk directly to the ALS patient, not around them. Repeat back to ensure understanding. Even though their communication output is impaired, their input is not.
- If the patient has difficulty with normal speech for relaying care needs, assess the need for Augmentative Communication Devices (ACD) or methods for communicating.
- At a minimum, establish what the patient utilizes for conveying Yes and No answers and make a chart conveying this to other health care providers. Place this at the head of the bed or on the room messaging board.

MEDICATIONS

Avoid paralytic, general anesthetics, narcotics or muscle relaxants unless absolutely necessary. If used, the ability to rapidly assist ventilation non-invasively or invasively should be available.

Check to see if the patient has an enteral feeding tube that may affect how medications are administered.

RESPIRATORY

ALS patients have restrictive respiratory compromise and the use of O2 is not normally needed unless the patient is in the end stages of ALS or has another pulmonary diagnosis. Oxygen alone may raise CO2 levels and cause toxicity. A noninvasive ventilatory device (e.g. BPAP, noninvasive mechanical ventilation) is usually needed instead. Ventilation is critical.

Most patients cannot tolerate to be flat once they have a need for a noninvasive ventilatory device and may easily aspirate if made to lay flat without using the device.

- Does the patient have a pre-existing tracheostomy.
- Assess what type of respiratory device the patient has at home - suction, cough assist, noninvasive mechanical ventilation or BPAP
- Collect and document respiratory device parameters used in home setting. Using the patient's home ventilator is optimum.

RESPIRATORY (CONTINUED)

- Determine what last forced vital capacity (FVC) and negative inspiratory force (NIF) were at the ALS clinic for comparison to current respiratory testing.
- Sialorrhea (excess saliva) can be a major complaint for ALS patients and can interfere with good oral hygiene and compromise respiratory status. Establish what medications the patient is on to get "oral dryness" and plan a suctioning routine to provide optimal comfort and respiratory clearance.
- Stopping sialorrhea anticholinergic medications abruptly may make for an anxious patient.
- Patients are at high risk for silent and overt aspiration pneumonia due to the epiglottal flap muscles ceasing to work and liquids leaking into the lungs. The head of bed should be up at 45 degree angle.
- A cough assist and/or non-invasive mechanical ventilation may be very valuable. If not available, please use the patient's device and consider having the patient's family or caregivers help with use.

POSITIONING/MOBILITY

Impaired **whole** body mobility with alteration in comfort and potential for injury

- If the patient has loss of mobility and movement due to atrophied muscles, joints can be misaligned and uncomfortable – use good supportive positioning techniques to neck and all extremities.
- Establish what type of supports or aids for daily living the person utilizes (e.g. eating utensils, neck braces, arm supports, ankle-foot orthosis (AFO), power wheel chair).
- Be aware that ALS patients continue to feel pain and have all their senses intact. It is a motor problem, not sensory.
- If the patient is a full lift, or requires Hoyer lift at home, establish with home caregivers the best technique for transferring the patient. A high back split sling (due to neck weakness and back muscle wasting) may be very useful.
- If a person with ALS has a power wheelchair outfitted with many positional changes, consider letting the patient stay in the chair for certain outpatient circumstances and procedures.

ADVANCE MEDICAL DIRECTIVES (AMD)

- Assess if the patient has AMDs on file or a copy in their ALS Clinic, or treating physician, chart for placement in the current medical record.
- If long term ventilation is being considered, pre-surgical education on tracheostomy and mechanical ventilation care should be completed.
- If the patient has desires for the donation of their brain/body to ALS research, please alert appropriate hospital personnel.

COGNITION AND EMOTION

- Some neurology patients with certain neurodegenerative conditions have PBA (Pseudo Bulbar Affect) which is inappropriate and excessive laughter/crying. Medication is available for this.
- A small percentage of patients have frontotemporal dementia (FTD) or cognitive impairment which may include poor judgment, difficulty in decision-making, or inability to plan.

LAB WORK

- If the patient is on riluzole (Rilutek), realize this medication may cause neutropenia and liver function abnormalities.

NUTRITION

- Document accurate weight and compare to pre-illness weight.
- Consult registered dietician (RD) for nutrition review.
- Establish if the patient is eating normally. If they are, assess if choking is a frequent occurrence and the length of time it takes them to eat. Encourage Chin-Tuck swallowing for safety.
- The most difficult thing to swallow is water or thin liquids. Soft diet with moistened foods or using thickeners helps.
- If patient already has gastric feeding tube, establish type, document and assess if current tube is in need of change for optimal functioning. Confirm optimal positioning of patient e.g. the head of the bed should be up at all times.
- If the patient is nauseated with their gastric feeding tube and indicates the need to vomit– decompress or aspirate stomach contents ASAP prior to prevent aspiration as their tracheal flap may not be functioning properly.
- Due to the difficulty to toilet with impaired mobility, many ALS patients dehydrate to reduce their need for using the bathroom. Assess and encourage adequate intake.

ELIMINATION

- ALS patients have progressive impaired mobility which alters their ability to acquire normal position for bowel/bladder. Assess their activity level and provide necessary toileting equipment. Implement a bowel program early to prevent constipation issues.

DISCHARGE PLANNING/SOCIAL SERVICES

- ALS patients require a large amount of diverse durable medical equipment (DME) and medical supplies. Inquire in detail about equipment needs and type. All DME companies are not familiar with ALS requirements. Re-admissions may occur due to lack of equipment or supplies – it is in the details (e.g. does the Hoyer lift fit under their bed?).

DISCHARGE PLANNING/SOCIAL SERVICES (CONTINUED)

- Inquire with Home Health (HH) or Hospice agencies on their knowledge with ALS patients.
- Establish if their insurance policy has the benefit of a Case Management (CM) Program. If so, relay this benefit to the family so they have the opportunity to enroll in the CM program and assist them with making this benefit connection with exchange of names/ telephone numbers.
- An educated caregiver should be trained and established for assuming peg care and complex ventilation equipment prior to discharge. Start education early and involve the ALS Clinic Nurse, or other provider, as requested, for long term education.
- Contact the durable medical equipment or home health provider to visit prior to any surgical event to arrange the ordering of equipment and supplies so as not to delay discharge.
- Assess caregiver/family capabilities and anticipate care requirements and set up in-home assistance as needed. Determine the availability of caregivers for each 24 hour period. A primary caregiver may have difficulty providing 24 hour care without sleep and respite.
- Arranging for resources with insurance prior to discharge gives the best long term support impact for ALS families.
- Consider having an interdisciplinary planning discharge conference on patients who have recently undergone tracheostomy to assure all medical, neurology, pulmonary and the ALS Clinic nurse, or treating physician, are appropriately involved for follow up and long term care.

SOCIAL CHALLENGES

- Slurred communication may be due to tongue/soft palate atrophy and can be mistaken for alcohol (ETOH) intoxication, deafness or limited cognitive abilities.
- Listeners need to be patient and wait while an ALS patient communicates with a device or alternative method. Do not guess/state words ahead of time.
- Talk directly to the ALS patient, not around them. Even though their communication output is impaired, their input is not.

REFERRALS

- If patient has a motor neuron disease (MND e.g. ALS, PLS, PBP) and has not been seen in a clinic specializing in ALS, inquire with the patient and family if a referral to an ALS clinic and the ALS Association local chapter (or other ALS organization) is appropriate.
- If the patient has been seen at an ALS Care Clinic – notify Center Coordinator for Clinic or inquire with patient if they want the ALS Clinic nurse to visit.
- Notify the ALS Care Clinic MD Director or following neurologist/internist if patient is admitted.