

My Emergency Planning Worksheet For Maple Syrup Urine Disease (MSUD)



Even minor illnesses can quickly escalate into an emergency situation for people with MSUD, so it's important to be prepared. The front of this worksheet provides tips for managing an emergency situation, and the back can be filled out with personal health information.



It is vital that you contact your metabolic healthcare team at the first signs of illness or injury. Always follow your clinician's instructions without delay.

CALL YOUR CLINIC

Your clinician may instruct you to follow your Sick Day diet plan, which provides more calories and fluids than the Well Day diet plan. **Only make changes to diet and formula as instructed by your metabolic team.**

SICK DAY

Even though the Sick Day diet plan is designed to avoid hospitalizations, sometimes it is necessary to go to the hospital. It may be necessary to go to the emergency room if, for example, you or your loved one are unable to drink formula, are vomiting, or have a high fever. Follow your metabolic clinic's instructions. If you are unsure, it is safest to promptly go to the hospital.

GOING TO THE HOSPITAL

Be sure to bring all of these essential items when you go to the hospital.

Hospital checklist:

Remember to pack your **E D F A M** if going to the hospital

- Emergency Protocol Letter** signed by your doctor
- Diet Plans:** Sick Day and Well Day
- Formula:** 1-2 cans of your Sick Day and Well Day formulas (List below)

- Amino acids** and vitamin/mineral supplements _____

- Medications** _____

ARRIVING AT THE HOSPITAL

Immediately notify the hospital that you or your loved one has MSUD and show them your Emergency Protocol Letter signed by your doctor. If possible, let your metabolic clinic know that you are in the hospital.

Personal Health Information Summary for Maple Syrup Urine Disease (MSUD)



This worksheet can be used to help you stay organized and inform healthcare providers or caregivers of your or your loved one's important health information related to MSUD.

PATIENT INFORMATION

Patient Name: _____ Date of Birth: ____/____/____

Patient/ Guardian Phone: (_____) _____ - _____

Patient/ Guardian Email: _____

Guardian Name: _____

Relationship to Patient: _____

DIAGNOSES AND MANAGEMENT

Diagnoses:

Maple Syrup Urine Disease _____

ICD-10 code:

E71.10 _____

Metabolic formula(s): _____

Medications, amino acids, and supplements: _____

Drug or food allergies: _____

CARE TEAM

Metabolic clinic: _____

Metabolic physician: _____

Phone: (_____) _____ - _____

Other medical team(s) and contact details:
