Section 1: Important Contacts

In this section:

- Physician Contact Information
- Patient Support Team and Support Team Contact
- Emergency Room (ER) Plan

How to use this section:

- Keep important phone numbers and other contact information together
- This section will help caregivers communicate with each other and the patient’s medical team

Notes:
<table>
<thead>
<tr>
<th>Name of Contact</th>
<th>Specialty (MD, PA, RA, Social Worker)</th>
<th>Phone</th>
<th>Office Address</th>
<th>Email</th>
<th>Notes</th>
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Patient Support

Teams can include several people who are all important for the patient’s care. Your team may include some or all of the following people. Consider assigning specific roles to people who want to help. On the back of this page, keep track of their names, phone numbers and email addresses.

**Primary Care Manager/Emergency Contact:** This person is number one and in charge of hands-on, day-to-day care and arrangements for the patient, often speaking or working on the patient’s behalf. This person is often an adult child, spouse, partner, or close relative or friend.

**Secondary Care Manager:** This person can help the Primary Care Manager by lightening the load, providing breaks, and preventing burnout.

**Medical Power of Attorney:** This person makes health-care decisions for the patient if the patient is unable to make them for himself/herself.

**Drivers:** Drivers take a patient to clinic or laboratory appointments on time. Adult children, relatives, neighbors, friends, or church/community volunteers can all be helpful as drivers.

**Pharmacist:** A person who can take charge of medications at home. Primary Care Managers usually do this, but a helper can organize medications, make schedules, fill and pick-up prescriptions, and be sure the patient has been taking medications as directed.

**Comedian:** Assign someone the job of making people laugh. Children and teens, friends and family can bring smiles and laughter to a patient visit, assisting in recovery.

**Cooks and Special Helpers:** Grocery shopping and meals can be split between people who want to help. Others can assist with laundry, housecleaning, yard work, and pet care.

**Exercise Buddies:** Family members, teens, neighbors, or friends are great candidates for exercise buddies. With doctor approval, they can walk or exercise with the patient and provide motivation.

**Spiritual Caregiver:** A Spiritual Caregiver is a great listener and someone who is somewhat removed from the immediate situation. Their main job is to listen, not to advise.
## Patient Support Team/Emergency Contacts

See previous page of a description of each role.

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<thead>
<tr>
<th>Role</th>
<th>Name</th>
<th>Phone</th>
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<td>Primary Care Manager/Emergency Contact</td>
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[www.amyloidosis.org](http://www.amyloidosis.org)
Emergency Room (ER) Plan

At some point during treatment, you or your loved one may need emergency care. Talk to members of the healthcare team in advance about what to do in emergency situations. The following signs and/or symptoms may require a trip to the emergency room:

- Fever of 100.4° F or higher
- Change in mental status or confusion
- Difficulty breathing
- Trouble swallowing
- New or increased pain
- Uncontrollable nausea, vomiting, or diarrhea; these symptoms can lead to dangerous dehydration.
- Bleeding
- Rash or swelling in arms or legs

Ask members of the healthcare team this question: What signs and/or symptoms require a trip to the emergency room? Either list them below or highlight the signs and symptoms in the list above.

Emergency Contact Person on the Healthcare Team

Name: ____________________________________________

Phone Number(s): ____________________________________________

Email: ____________________________________________

Notes: ____________________________________________

After-Hours Contact:

Name: ____________________________________________

Phone Number(s): ____________________________________________

Email: ____________________________________________

Notes: ____________________________________________
Nearest Emergency Room (ER)

Where is the closest emergency room? The emergency room at your treatment center may not be the one nearest to you. In an emergency situation, minutes can make a difference so it’s important to know the location of the closest emergency room.

Upon arrival, let the ER staff know that your loved one is a patient with a compromised immunity. Ask for a face mask for him or her if one is not provided.

Hospital Name: ________________________________

Phone Numbers: ________________________________

Address: ________________________________

Directions: ________________________________

Emergency Bag

Have a bag packed for you and your loved one so that you are ready to leave immediately in an emergency situation. The prepacked bag should include the following items:

- Copies of necessary medical records
- Copies of insurance ID cards
- List of all current medications
- Phone charger
- Toothbrush
- Change of clothes
- Jacket or small blanket for cold hospital rooms
- Snacks, such as protein or granola bars
- Water bottles

Before you leave, don’t forget to also include

- Medications in prescription bottles, if possible
- Your own daily medications
Childcare

If you or your loved one have children, have a plan in place for childcare. You may want to consider both an immediate and a longer-term plan. For example, if you have to go to the emergency room, can your neighbor stay with your children until a family member arrives?

Name:

Phone Numbers:

Email:

Notes:

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Pet Care

If you or your loved one have pets, you may want to consider asking a neighbor to check in on them during an emergency situation. Give a trusted neighbor a spare key, in advance, in case a trip to the emergency room lasts for more than a few hours.

Name:

Phone Number(s):

Email:

Notes:

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Designated Point Person

Pick a family member or friend to act as a point person who will take messages and provide updates during an emergency situation. You will likely be focused on getting your loved one the care they need, so instead of fielding calls from concerned family and friends, designate someone else to be your point person, so you only have to update one person.

Name:

Phone Number(s):

Email:

Notes: