

# Support for Stroke Survivors and Caregivers



You do not have to recover from your stroke by yourself. Your caregivers and support groups can help you heal both your mind and body. Below are several resources to help you and your support person(s) as you progress in your recovery and overcome any challenges you may encounter.

## **Social Work at Michigan Medicine**

A social worker is a specialist who helps patients, caregivers, and families cope with illness, treatment, financial and emotional challenges, and grief. They can meet with you and your family to ensure you have the right support systems to handle emotional and practical issues.

## **What services can a social worker provide?**

- Coordinate care and improve communication among patients, family members, and healthcare providers.
- Offer counseling to help patients and family members manage the emotional impact of diagnosis and treatment.
- Support to patients in expressing their needs, wishes, and care goals.
- Provide education and assistance with durable power of attorney (DPOA) for healthcare, advanced directives, and guardianship.
- Educate about Social Security Disability and employment leave.

- For more information on Social Security Disability Benefits After a Stroke visit this link: <https://tinyurl.com/tcjusw65>
- Help with understanding insurance coverage and benefits.
- Connect patients to resources that can reduce out of pocket costs.
- Provide information on lodging, transportation, and parking options.

### **How can I reach a social worker?**

- **Inpatient Social Work**

Ask your nurse or provider to contact social work for you, or you may call the Michigan Medicine Guest Assistance Program at **(800) 888-9825** Monday-Friday, 9:00am to 4:30pm.

- **Outpatient Social Work**

- Call the Michigan Medicine Guest Assistance Program at **(800) 888-9825**, Monday - Friday, 9:00 AM - 4:30 PM and ask for assistance
- If a patient of the Frankel Cardiovascular Center you can reach a social worker at **(734) 232-1559**

## **For the Caregivers**

### **Emotional Impact on Caregivers**

A stroke affects not only the patient but also everyone involved, including caregivers. Caregivers often face unexpected demands and added responsibilities, which can lead to stress. They must balance their caregiving duties with home and work life. While supporting your recovery, your family and friends need to manage their own needs and emotions. It's essential for them to take care of themselves both physically and emotionally.

**When supporting someone who has had a stroke, here are some ways a caregiver can help:**

- Help with physical tasks such as personal care, transportation, housework and managing meals
- Assist with managing financial, legal, and personal affairs
- Watch their behavior and make sure they are safe
- Coordinate health care follow-ups and manage medications
- Encourage the survivor to work on their recovery and become as independent as possible
- Provide emotional support to the stroke survivor

**Self-care ideas for the caregiver:**

- Make your health your priority! Eat a well-balanced diet, stay active, and get plenty of rest.
- Be patient- it is not unusual for your loved one to have good and bad days.
- Share your feelings with someone you trust.
- Build your personal support network. It is important to have a team of people who can help and support you.
- Ask for help if you feel overwhelmed. Be specific on how others can help you, do not try to do it all yourself.
- Talk to your family doctor if you have feelings that are concerning.
- Make yourself a priority. Do something you enjoy or find relaxing each day.

**As a caregiver, how do I know if I need help?**

Caregivers do a lot for others. The natural response of a caregiver is to put their own feelings and needs aside. This may work temporarily but over time, it can become difficult to maintain. As a result, caregivers may end up feeling physically and emotionally drained. Look for these signs of caregiver stress:

- You feel overwhelmed or worry all the time.
- You feel tired most of the time.

- You sleep too much or too little.
- You gain or lose weight.
- You get annoyed or angry easily.
- You lose interest in activities you used to enjoy.
- You often feel sad.
- You frequently have headaches or body aches.
- You misuse alcohol or drugs, including prescription medications.
- You miss your own medical appointments.

If you notice these signs, it may be time to ask for help.

### **What Resources are Available for Caregivers?**

Help may come from family, friends, your place of worship, government and non-profit organizations, and other community resources. Some examples of additional assistance for caregivers and stroke survivors include:

- **Adult Day Care:** A place where adults receive professional care and can socialize during the day.
- **Meals on Wheels:** A federally sponsored nutrition program that delivers home-cooked meals to people who are homebound on weekdays.
- **Respite Care:** Short-term relief for caregivers, available for a few hours, days or even weeks. This care can be provided at home, in a health care setting, or in adult day care centers.
- **Caregiver Support Groups:** Groups where caregivers can share experiences, get advice, build relationships, and learn healthy coping strategies. Some support groups allow stroke survivors and their caregivers to meet together to discuss shared experiences. Other groups may separate caregivers and stroke survivors to focus on topics and concerns specific to each group.
  - To find a support group near you:
    - Visit this link <https://www.stroke.org/en/stroke-support-group-finder>

- Call the Stroke Family Warmline **(888) 478-7653** between 9:30 a.m. and 6 p.m. EST Monday through Friday.
- To find an online support group, consider these options:
  - **The AARP Family Caregivers Discussion Group:** This is a private Facebook group you can join. Visit <https://www.facebook.com/groups/aarpfamilycaregivers/>
  - **The Caregiver Action Network:** They offer an online forum for caregivers. You can visit their forum at <https://www.caregiveraction.org/community>, or call their telephone help desk at **(855) 227-3640**
  - **The Eldercare Locator,** This is a service from the government's Administration for Community Living. It can help you find local services. Visit <https://eldercare.acl.gov/Public/Index.aspx> or call their hotline at **(800) 677-1116**.

## **What resources are available at Michigan Medicine?**

### **Michigan Medicine Support Services**

- **Michigan Medicine Brain Aneurysm Support Group**
  - This support group is for people with a diagnosis of brain aneurysm or arteriovenous malformations (both those who have suffered from rupture and those who have not).
  - Contact: Karissa Johnson, LMSW
    - Email: [MManeurysmSG@med.umich.edu](mailto:MManeurysmSG@med.umich.edu)
    - Phone: **(734) 803-1340**
  
- **Michigan Medicine Guest Assistance Program (GAP)**

The Guest Assistance Program (GAP) is part of the Department of Social Work and can help you with non-medical needs during your treatment at Michigan Medicine. Our team solves problems, researches community

resources, and helps coordinate various needs to ensure nothing prevents you from getting care.

GAP can connect you to resources that help meet social needs related to your medical care. These resources may be based on eligibility and include:

- Coordinating with government and community organizations
- Assistance with pharmacy prescriptions
- Help with costs for medications, supplies, and equipment
- Lodging assistance
- Meal assistance
- Transportation assistance
- Access to durable medical equipment and supplies
- Parking support
- Help with food insecurity

GAP is open Monday through Friday, 9 am - 4 pm. It is located at University Hospital Level 2, near the Gift Shop and Cashier's Office. For assistance, you can call GAP toll-free at **(800) 888-9825** or at **(734) 764-6893**. On weekends, a GAP staff member is available during the day. You can ask any hospital staff member to contact the GAP office for you.

- **Michigan Medicine MSupport Program**

This program offers financial assistance for medically necessary services provided by Michigan Medicine. You may qualify for this program if you:

- Do not have medical insurance
- Have insurance but cannot afford your out-of-pocket expenses
- Have insurance but require services not covered by your plan

Eligibility for MSupport is based on income, assets, Michigan residency and medical necessity

To apply for MSupport or explore other financial options, you can:

- Contact our financial counselors at (855) 855-0863 or (734) 615-0863 Monday-Friday, 8 am-4 pm
- Email them at [PFC-Counselors@med.umich.edu](mailto:PFC-Counselors@med.umich.edu)

- **Michigan Medicine Patient Financial Counseling**

If you have questions about billing and insurance, Michigan Medicine's Department of Patient Financial Counseling can help. Their financial counselors can explain financial assistance programs you might qualify for. They have created a handout titled "*Patient Financial Counseling: What is it?*" to help answer your financial questions related to your care at Michigan Medicine. You can view the handout using this link: [Patient Financial Counseling Handout](#). A copy of this handout is also included at the end of this chapter.

- **Michigan Medicine Peer Mentoring for Stroke Patients**

- Peer mentoring offers one-on-one support from individuals who have experienced similar health journeys. Our mentors are patients or caregivers who have been trained through the Michigan Medicine Peer Mentor Program. They understand what you're going through and are here to help.
- Our peer mentors share their experiences and listen to you and your caregivers. Participants find this one-on-one connection with someone who understands their situation extremely helpful.
- To learn more about the program:
  - See the flyer at the end of this chapter.
  - Contact: [UMstrokesupportgroup@med.umich.edu](mailto:UMstrokesupportgroup@med.umich.edu)

- **Michigan Medicine Stroke Support Group**
  - Michigan Medicine offers a stroke support group for stroke survivors, their families, and caregivers. This group offers an opportunity to support each other and build new friendships.
  - To learn more about the group:
    - See the flyer at the end of this chapter.
    - Contact: [UMstrokesupportgroup@med.umich.edu](mailto:UMstrokesupportgroup@med.umich.edu)
  
- **Michigan Medicine Turner Senior Wellness Program**
  - The Turner Senior Wellness Program at the Turner Resource Center is dedicated to enhancing the quality of life for older adults and their families. It offers a variety of high-quality, low-cost programs and resources focused on learning, health, and wellness.
  - For more information, you can:
    - Call (734) 998-9353
    - Visit their website: <https://tinyurl.com/mvj6v5xc>

## **Outside Resources for Patients and Caregivers**

- **2-1-1 Helpline**
  - The 2-1-1 helpline offers referrals to programs that can help with food, housing, financial assistance, utility help and more. This service is available 24 hours a day, every day of the year, throughout Michigan. If you need help finding resources in your area, simply dial **2-1-1** to speak with a representative.
  - For more information visit their website at: <https://www.211.org/>
  
- **American Stroke Association: Stroke Family Warmline**
  - The Stroke Family Warmline connects stroke survivors, their families and caregivers with a team member who can offer support, helpful



information or a listening ear. They can also help you find local support groups, which are important for stroke recovery.

- To reach them, call the Stroke Family Warmline at **(888)-478-7653** between 9:30 a.m. and 6 p.m. EST Monday through Friday.

- **Area Agencies on Aging Association of Michigan**

- Area of Agencies on Aging helps older adults and their caregivers connect to information and resources they need.
- To find your local Area Agency on Aging, visit their website at: [About | Area Agencies on Aging Association of Michigan \(4ami.org\)](http://4ami.org)

- **Department of Veterans Affairs (VA)**

Veterans who are experiencing stroke-related issues may qualify for additional benefits and resources through the Department of Veterans Affairs (VA). For more information, call the VA benefits hotline at **(800) 827-1000**.

- **Disability Network Michigan/Centers for Independent Living (CIL) Locator**

- Disability Network Michigan is dedicated to helping individuals with disabilities achieve full participation in their communities and lead self-sufficient lives. They connect you to a network of CIL to ensure you have the services and support needed to make informed decisions, maintain personal control over your own life, and participate fully in activities at work, home, and within the community.
- To find your local Disability Network/CIL visit: <https://dnmichigan.org/cils/>

- **Great Lakes Loan Closet Locator**

The Great Lakes Loan Closet Locator helps individuals find Loan Closets, which are programs that lend home medical equipment to those recovering

from illness or injury. They typically offer durable medical equipment (DME) such as wheelchairs, shower chairs, bedside commodes, walkers, crutches, canes, and high-rise toilet seats. Some may also have hospital beds or electric wheelchairs available..

- This website helps you find organizations that lend medical equipment for minimal or no cost.
- For more information, visit: <https://loan closets.org/michigan>

- **University of Michigan Aphasia Program (UMAP)**

- An intensive speech-language program designed to help individuals recover or develop new communication techniques after experiencing trauma to the language centers of the brain.
- Please note that there is a cost for this program and is not covered by insurance.
- To learn more, you can:
  - Call (734) 764-8440
  - Visit their website at <https://mari.umich.edu/ucll/umap>

- **University of Michigan Aphasia Program Aphasia Social Hours**

- This program offers Aphasia Social Hours, allowing individuals with aphasia to chat and connect with others who have the condition. These virtual social hours are free and take place from 4-5 p.m. (Eastern) on the first Thursday of each month.
- Registration is required to receive the Zoom link to join the conversation.
- For more information visit their website at <https://mari.umich.edu/ucll/umap/dates-rates>

- **Young Adult Stroke Survivors Support Group**
  - This support Group offers support for young adults who have experienced a stroke.
  - For more information, you can contact Susan Emery via email at [susan@circleofrights.org](mailto:susan@circleofrights.org) or visit their website at <https://www.stroke.org/en/stroke-groups/young-stroke-group>.

## **Additional Resources**

For more information, you can visit our online resources at <https://careguides.med.umich.edu/browse-by-medical-service/stroke>. You can also your healthcare team for one of these helpful handouts:

- Finances After Stroke Guide
- The Stroke Family Caregiver
- How Can I Support My Loved One?
- How Should I Communicate with Heart and Stroke Patients?
- What is Caregiver Burnout?
- 7 Practical Tips for Self-Care

**Identifying Your Own Supports:**

The activity below will help you find current and new support options. Use the checklist to choose supports you might want to use during your stroke recovery.

	Informal Supports		Formal Supports
<input type="checkbox"/>	Ask a family member, friend, or co-worker for help	<input type="checkbox"/>	Seek mental health counseling or therapy
<input type="checkbox"/>	Use a grocery or food delivery service	<input type="checkbox"/>	Attend a stroke support group
<input type="checkbox"/>	Set an alarm or timer	<input type="checkbox"/>	Connect with a peer mentor
<input type="checkbox"/>	Carpool to work	<input type="checkbox"/>	Call the Stroke Warmline for help
<input type="checkbox"/>	Connect with your religious or spiritual community	<input type="checkbox"/>	Participate in the Stroke Association’s Stroke Forum
		<input type="checkbox"/>	Attend an Aphasia Social Hour

Now think about your own support system. Can you identify additional supports that can help you in your recovery process?

<input type="checkbox"/>	
<input type="checkbox"/>	
<input type="checkbox"/>	
<input type="checkbox"/>	

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