STROKE SURVIVOR 2 SURVIVOR PROGRAM

Stroke Survivor 2 Survivor (SS2S) program is a collaboration between the American Stroke Association (ASA) and Stroke Survivors Empowering Each Other (SSEEEO). Both organizations share a desire to improve the health and quality of life of stroke survivors and their caregivers. Having a stroke is often traumatic and isolating, and this program ensures that survivors and caregivers know they are not alone. It is our goal together to make the SS2S program available nationwide.

Over 9 million U.S. adults are stroke survivors and estimates show that about 795,000 Americans experience a stroke each year. Research has found that the vast majority (87%) of stroke survivors experience unmet needs, including in secondary stroke prevention and engagement in social and daily activities.

ABOUT THE PROGRAM

SS2S is a telephone-based post-stroke peer support program that facilitates stroke recovery, providing survivors with greater access to resources and increasing social support. Calls come from stroke survivor and stroke caregiver volunteers with special training and are overseen by a local hospital on-site coordinator.

PILOT FINDINGS

- Piloted at 17 sites throughout the U.S.
- Reached more than 1,000 newly discharged stroke survivors and caregivers
- Commonly identified issues faced by survivor participants were fatigue, memory/cognitive issues, and physical and mental challenges

<table>
<thead>
<tr>
<th>Issue</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Fatigue</td>
<td>33.3%</td>
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<tr>
<td>Memory or cognitive issues</td>
<td>18%</td>
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<tr>
<td>Other physical or mental difficulties</td>
<td>13.4%</td>
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<tr>
<td>Emotional disturbances</td>
<td>11.2%</td>
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<tr>
<td>Depression</td>
<td>9.4%</td>
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<tr>
<td>Attending stroke group</td>
<td>9.2%</td>
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N=822
Participants who completed the expanded pilot post-participation survey identified “helped” and “hopeful” as the terms that best described their experience with the SS2S program.

- Sixty percent would recommend participating in the SS2S program to others
- Fifty-nine percent reported that their participation helped with the challenges they faced

Additionally, volunteers and on-site coordinators implementing SS2S see its value, with 100% of on-site coordinator survey respondents indicating they plan to continue implementing SS2S. Their appreciation for and the impact of SS2S can be heard in their own words:

**SS2S Volunteer, New Hampshire**

“Being a volunteer of the SS2S is by far the most rewarding thing I am a part of. It has also helped me in my healing journey. ... Being able to communicate effectively and actively listening to reinforce my support for the stroke survivor has been essential. Many stroke survivors are pleasantly surprised when they receive the initial outreach. As the weeks go on, you form a connection to really reinforce the support.”

**Stroke Coordinator, Colorado**

“SS2S is a wonderful program. Starting the demonstration study at the tail end of the COVID pandemic when so many stroke support groups had been suspended, it was an invaluable resource to our new stroke patients. The program allowed the survivors and their families to open [up] in a way they do not with the clinical staff. Our [volunteer] was able to break through walls when she shared her story of waking up and not being able to speak more than three words. ... It allowed patients to feel less isolated and more hopeful.”

**GOALS OF THE PROGRAM**

1. Increase adherence to follow-up appointments
2. Educate stroke survivors on the need for treatment compliance to reduce risk of stroke recurrence
3. Provide program volunteers an opportunity to give back as part of their stroke recovery journey
4. Improve access to health care, social support, self-management tools and skills and other resources
5. Help health care facilities meet patient support and outreach requirements for certification
THE PROGRAM PROCESS

• Before stroke survivors’ discharge from a care facility, a stroke coordinator, other health care professional or peer visitor invites them (and their caregivers) to enroll in the program
• Enrollment forms are shared with trained volunteer(s)
• Volunteers contact the participants about four times over two months post-discharge, taking notes using provided forms, and send relevant stroke recovery resources to participants
• Volunteers or designated facility staff call participants one month after their final participation call to conduct a participation survey
• Volunteers or on-site coordinators submit aggregate data regarding calls to the ASA at least monthly

FOR MORE INFORMATION

• Webpage: stroke.org/SS2S
• Email: SS2S@heart.org
• Recorded info session: bit.ly/3Vx8KRO