

This resource provides suggestions for identifying high-need caregivers throughout your organization and engaging them with your program.

1. Sources of Program Referrals

Professionals across all areas of a health care organization interact with family caregivers. Staff should be equipped to identify caregivers in distress and to connect them with the supportive services offered by your program.

Department or Area	Opportunity for Referral
Hospitalists	Hospital-based clinicians can be trained to recognize signs of distress in family caregivers of hospitalized patients
Social Work	Social workers can serve as champions for the caregiver support program, helping to connect caregivers identified via inpatient encounters or in ambulatory settings
Volunteer Services	Volunteers often come into contact with caregivers and are well-positioned to identify those in need of support
Psychiatry	Psychiatry care teams may encounter caregivers in need of support through their work with patients receiving support for coping with serious illness
Palliative Care/Supportive Care	Palliative care teams play an essential role in caregiver communication and support, and can identify those in distress for referral to your program
Patient Representatives/Advocates	Distressed caregivers often reach out to patient advocates. Staff should be aware of your program and suggest support when appropriate
Dementia Care Services	Programs that support people living with dementia often include caregiver support and training. These staff can be trained to recognize signs of high distress and refer those in need of support to your program

Referrals can also happen outside of patient encounters in health care settings. For example:

- **Self-referral**, facilitated by the organization's website, advertising, and via word-of-mouth.
- **Social media** postings through your sponsoring organization or on your own professional pages can raise awareness of the caregiver support services you offer.

2. Screening and Triage

Depending on role and capacity of referring programs, the referring team can conduct their own distress screening and refer those in high need of support. If referring program are unable to conduct caregiver screenings, your support program should be prepared to screen caregivers and then triage them to appropriate support and services, ensuring that only those caregivers who require your level and type of care are enrolled (i.e., if the source of a caregiver's distress is concern about how to perform medical/nursing tasks, then referral to nursing – not your psychosocial care program – would be most appropriate).

Recommended caregiver distress screenings include:

- [FamilyStrong Distress Thermometer](#) is an adapted version of the National Comprehensive Cancer Network Distress Thermometer. It has been proven feasible and reliable for caregivers of patients with cancer and may be appropriate for caregivers of patients with other illnesses as well.
- [AMA Caregiver Self-Assessment](#) was developed to help physicians assess the stress-levels of family caregivers accompanying chronically ill older adult patients to their medical visits, tested for reliability and predictive of caregiver stress.
- [Zarit Burden Interview](#) measures the perceived burden of caregivers for patients with chronic illness, disability, or dementia. Note that perceived burden and distress may not fully correlate, but the Zarit is increasingly used to identify at-risk caregivers of those with dementia.
- [CancerSupportSource™-Caregiver](#) 33-item, web-based tool that measures distress in six areas. It serves as a screening and triage tool, as well as an intervention by immediately notifying respondents of local resources that address targeted drivers of distress in the screening. Note this is specific to oncology and has not yet been evaluated in other populations.

Using the FamilyStrong Distress Thermometer

If you are using the FamilyStrong Distress Thermometer, a score of 4 or greater and a problem identified should be explored further by asking:

- What happens that makes this a problem?
- When does this problem happen?
- How does the problem happen?
- Where does it happen?
- Who does the problem involve?
- What have you already tried to solve the problem?

Determining the appropriate cut-off for enrollment is an art, not a science. A higher cut-off may be necessary for caregiver support programs with limited capacity or with a very high rate of acceptance into the program.