

Speak Up

“If we all do  
a little it will  
add up to a lot.”

—Helen Keller



NATIONAL FAMILY CAREGIVERS ASSOCIATION

Empowering family caregivers

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Building community

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Speaking up authentically with the  
voice of experience

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Advocating for the well being of family  
caregivers and their loved ones

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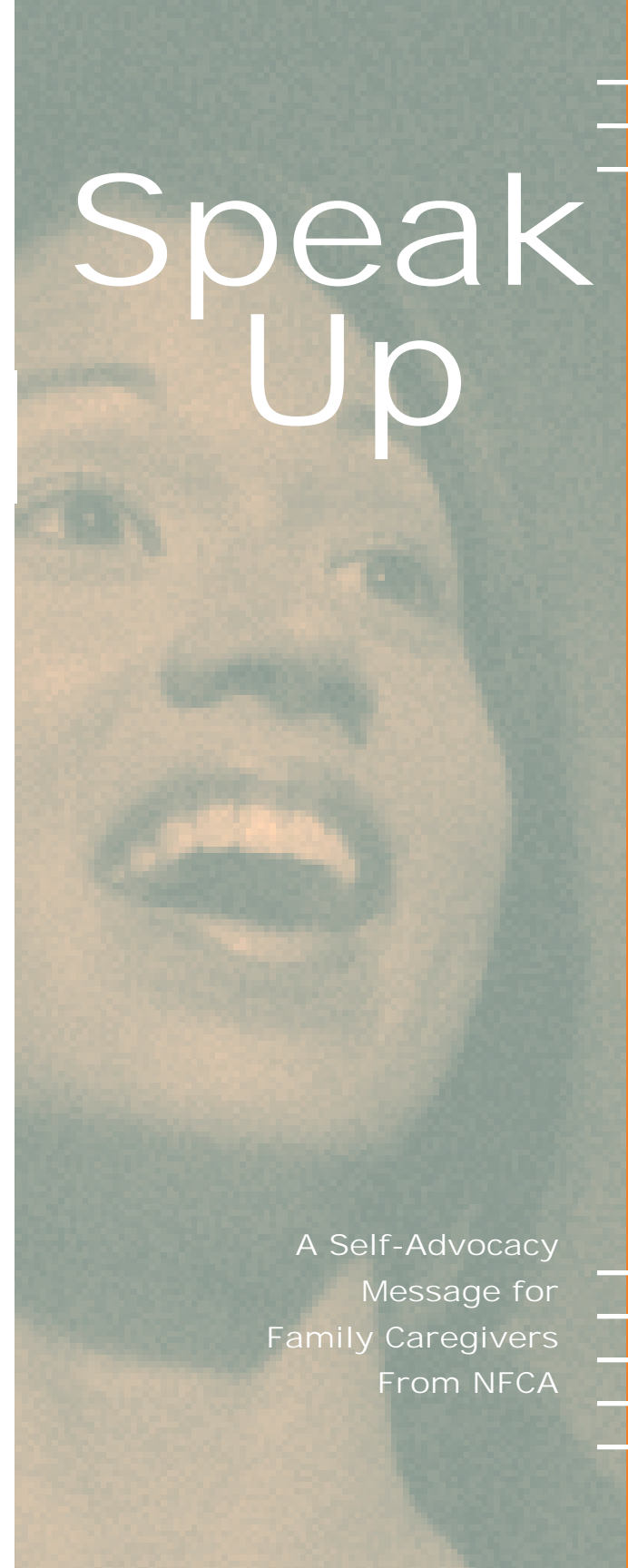
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Speak  
Up



A Self-Advocacy  
Message for  
Family Caregivers  
From NFCA

## What Does It Mean to Speak Up?

On the simplest level, it's about raising the sound of our voice so others can better hear us. Speaking up is how we solve problems. It's how we learn. It's how we educate. It's how we bring about change.

During the course of a typical day, we probably all speak up quite a bit. When it comes to family caregiving, however, many of us tend to be very quiet. We don't tell our children that we need help caring for their dad. We don't tell our boss that we need a more flexible schedule. We don't speak up to question a doctor when our gut tells us we should.

Speaking up tends to be hard for family caregivers because we are on uncertain ground. We question our knowledge and our actions and we don't get to talk with other family caregivers all that much to boost our confidence. We don't tend to think that maybe the difficulties we face have nothing to do with our own actions but, rather, with the fact that we really are swimming upstream as we try to make life better and easier for our loved ones and ourselves.

How do we Speak Up, on behalf of ourselves, our loved ones, and all family caregivers? How do we get more of what we need without coming across as difficult?

- We need to come from a place of confidence, to say to ourselves, "I can do this."

- We need to come from a place of anger — not too much, as that can be counterproductive, but just enough to say, "I'm not going to take this anymore," or, "I'm not going to do this anymore."
- We need to come from a place of knowledge so we can speak with some authority.
- We need to believe that speaking up for our rights is critical if we, and our loved ones, are going to journey down the crooked path of caregiving without tripping and falling each time we turn a corner.

Here are some tips and suggestions to help you Speak Up for respect, for support, for information, for help, and for the rights of all family caregivers.

### 1. Believe in Yourself

If you believe in yourself, you can Speak Up by making active choices that are in your own best interests, including:

- Self-identifying as a family caregiver
- Recognizing your strengths and acknowledging your limitations
- Learning to say "no"
- Commanding respect from healthcare providers

### 2. Protect Your Health by Speaking Up for Your Right to

- A good night's sleep
- A respite holiday
- Time and energy to exercise
- Regular checkups to ensure that if something is wrong you catch it early
- A life of your own apart from caregiving

### 3. Reach Out for Help

- Recognition that family caregiving is more than a one-person job
- Care coordinator services to help you navigate the confusing pathways of our health and social support systems and ensure continuity of your loved one's care
- Financial assistance so you can purchase help in the marketplace
- Community-based supports designed to help caregiving families
- Regular respite opportunities

### 4. Speak Up for Your Right And the Rights of All Family Caregivers

- Speak up for adequate education and training in the skills you will need as a family caregiver
- Speak up for affordable health insurance if you are not getting it through your employer
- Speak up for financial support to protect you from impoverishment in your later years
- Speak up for annual assessments of your own needs and the means for meeting them



Helen Keller, a woman who, despite blindness and deafness, became one of the most inspirational people of our age and a noted public spokesperson for the dignity of the disabled, said: "If we all do a little it will add up to a lot." There are more than 50 million family caregivers in America; that adds up to a lot of voices.