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Foreword

Caring for someone with a chronic illness like MS can be deeply satisfying. Partners, family, and friends can be drawn more closely together when they meet the challenges. But caregiving can also be physically and emotionally exhausting, especially for the person who is the primary caregiver. That person is most often a partner or spouse, but can also be a child, parent, or friend.

There are a wide range of caregiving activities, just as there is a wide range of abilities and disabilities among people with MS. Someone giving care to a person who has relatively few functional difficulties may be helping with injections of a disease-modifying drug and offering support in dealing with the medical team. Someone caring for a person with a more severe level of disability may be involved in daily activities like toileting, dressing, transferring, and feeding, as well as medical treatments. This booklet provides an overview of the issues that caregivers in most kinds of situations might face.

Those caring for someone who is newly diagnosed, or who has little disability may want to concentrate only on those sections relevant to their particular situation. The resource section at the end is a good starting place for those who want more in-depth information or specific kinds of support.
Throughout this booklet, the term *caregiver* is used to refer to the person primarily responsible for providing daily care to a person with MS. It may help to remember that the person giving care and the person receiving care are in this together. This booklet sometimes refers to them as *carepartners*. MS doesn’t change the fact that important relationships are always a two-way street. The person with disabilities may need a great deal of assistance, but the needs and concerns of both partners must be addressed if the relationship is to remain healthy.
PART I: Practical Decisions

Most people with MS do not develop such severe disability that they require full-time, long-term care. But since there is no way to predict who will develop severe disability, it is wise to make contingency plans. This means investigating the kinds and costs of local long-term care options before a crisis occurs.

Financial and life planning

Financial and life planning for continued financial stability are essential and should be undertaken early. The process of long-term planning will help the carepartners feel more secure about their well-being, regardless of what the future brings. A book titled Adapting: Financial Planning for a Life with Multiple Sclerosis is available at nationalmssociety.org/FinancialPlanning or from your chapter.

Life planning includes an investigation of income tax issues, protecting existing assets, saving for future financial needs, and end-of-life planning. People should seek advice about insurance, employment rights, and state assistance, and discuss all options.

Carepartners need to understand the coverage provided by their medical insurance, including Medicare, Social Security benefits, and available private disability...
insurance. Some people may qualify for state programs such as public assistance, food stamps, or Medicaid. Hospital or clinic social workers are good resources for information regarding these programs.

Carepartners also need a clear understanding of the Americans with Disabilities Act (ADA) and other legislation that provide protections concerning housing, transportation, recreation, and employment. A booklet outlining the basics of the ADA is available from the National MS Society.

Since each person’s situation is unique and the laws pertaining to legal and financial issues vary from state to state, it is wise to seek the advice of professional financial planners and “elder law” attorneys who specialize in disability-related law. Professionals can help sort through available options and explain the possible legal and tax consequences of various choices.

Advance medical directives preserve a person’s right to accept or reject medical treatment. They are essential tools for maintaining personal control in the event of incapacitating illness or disability. Medical directives come in two forms. Both are needed for complete protection: (1) a living will, in which the person outlines specific treatment guidelines to be followed by health-care providers; (2) a health care proxy in which the person designates a trusted individual to make medical decisions if the person is unable to do so. Advance directive requirements, like other legal and financial issues, vary from state to state. They should be written
with the help of an attorney who is familiar with the relevant state laws. An attorney is not needed for advance directives naming a health care proxy.

**What level of care is needed?**

Evaluating care needs should also be a joint effort. Ask your medical team to assess what treatments, adaptations, and other changes are necessary. For some, training in self-administering medical treatments, advice on coping with fatigue and occasional relapses, and some long-range financial planning will suffice. For others, at-home care is the best option. And sometimes a nursing home or assisted living center is the better choice for all concerned.
It’s important to be realistic about what the person with MS needs, and what the caregiver can provide in terms of time, kinds of care, and financial responsibility. This is more easily said than done. Making changes—whether small or large—can be enormously difficult. Coming to terms with chronic illness and disability takes time and strength. Rational decision making can be sidetracked by anger, guilt, grief, confusion, or shame. Carepartners can benefit from speaking with a therapist, counselor, or other person outside the situation to get a clearer perspective.

Don’t be afraid to ask for help. The cost of not asking for help may be very high for everyone involved.

**At-home care**

Even people with a significant level of disability can live at home successfully. There are usually a number of solutions to practical problems. For example, someone who cannot transfer from wheelchair to bed or bath can be moved using the proper kind of lift. People with disabilities can be more independent when a home has wide doorways and grab bars. When the caregiver works full-time and the person with MS needs some aid and companionship during the day, adult day care may be an option. Caregiver burnout can be avoided when the carepartners make use of respite care, friends, and support groups.
Other care options

Providing care at home will be impossible for some people. There are different kinds of live-in facilities, including assisted living, nursing homes, and cooperative care housing. Deciding what kind of facility is best will depend on individual needs and financial resources available.

The cost of care

All care options cost money—a situation that often coincides with a drop in the income earned by the person with MS. Researching possible resources begins with asking questions. Start with the staff at your chapter of the Society or with a social worker at your hospital, social agency, or MS clinic.

Resources include local public agencies for people with disabilities such as independent living centers and agencies for senior citizens. (They often serve younger people with disabilities.) Some states have long-term care and/or personal-care assistant programs for people who are not otherwise eligible for Medicaid. Research the national organizations listed in the Resources section beginning on page 28 as well.
CARING AT HOME

Adapting for safety, accessibility, and comfort

Adaptations can increase safety, accessibility, and comfort for everyone. But before deciding to make major home renovations, ask a doctor for a referral to an occupational therapist (OT) for a home visit. OTs can suggest ways to keep the person with MS as independent as possible, ensure safety, and reduce the physical strain on the caregiver. Ramps, widened doorways, and renovations in the kitchen
and bath can often solve accessibility problems. Not all changes involve major expense. The National MS Society has information about practical, low-cost modifications and can provide referrals to appropriate resources.

Sometimes the best choice involves moving to more accessible housing. Moving to a place that is near public transportation, stores, and other public facilities can give a person with disabilities more choices. It might also make it easier to hire necessary help.

**Flexible roles**

Changes are not confined to doorways or light switches. Relationships are affected as well. People with severe MS lose independence. Caregivers have to take on more responsibilities. This shift can be a source of tremendous anxiety.

Inevitably, the caregiver and the person with MS will have different perspectives about the same issue—about adaptations, about medication side effects, or how best to schedule hired help. It might help to remember that MS affects everyone involved, but it affects everyone differently.

MS is extremely changeable and unpredictable. People experience attacks and remissions, loss and recovery or partial recovery of abilities. One day a person with MS can dress alone, the next day the person can’t. The caregiver has to take and then give back responsibility for tasks all the time.
Carepartners will need to rethink who does each task necessary for the smooth running of the household. For example:

- Household tasks such as general cleaning, shopping, cooking, laundry, child care, and transportation.
- Care-related tasks such as dressing, bathing, eating, toileting, exercising, transportation, doctor visits, and taking medication.
- Daily activities such as work, recreation, entertainment, exercise, hobbies, private time, and religious activities.

Plan to re-evaluate task assignments as needs and circumstances change. And make sure to schedule personal time for everyone in the household.

**Helping with daily activities**

If a task seems impossibly difficult or stressful, there is probably an easier way to do it. The medical team can provide tips and techniques for bathing, dressing, toileting, and safe transfers. Other caregivers and the National MS Society are also good sources of advice and tips.

**Roles and gender differences**

Women and men who act as caregivers face the same day-to-day responsibilities, frustrations, and satisfactions. However, women caregivers may feel more comfortable than men caregivers, since caregiving has traditionally been viewed as a more feminine role.
Studies have found that many men who are caregivers report difficulty in discussing their problems and are more likely to repress emotional reactions. They find it more difficult to ask for help and many do not use the resources available to caregivers. On the other hand, some men are more willing to participate in social and recreational activities that contribute to their overall well-being.

Some women are better at expressing their feelings and accessing supportive networks. But women caregivers are more likely to neglect their own health, and their need for outside activities. They tend to report more physical and emotional ailments than their male counterparts.
When a child is a caregiver

Sometimes children assume major household and personal care responsibilities when a parent has disability due to MS. This is more likely to occur in single-parent households. While it is positive for children to take on household responsibilities, their needs must be carefully balanced with the amount and level of caregiving they are expected to do.
Children are not equipped to handle the stress of being a primary caregiver. They should never be responsible for a parent’s medical treatments or daily functions such as toileting. Children under 10 can certainly handle some household chores. Young teenagers can take on more responsibility, but they also need to spend some time with their peers. Older teenagers and young adults may be competent caregivers, but they should not be expected to undertake long-term primary care. They have their own futures to attend to.

When a parent is a caregiver

The return of an adult child to the home can be stressful for both the parents and the adult child. Often, this homecoming reproduces the earlier struggles that occurred before the child became independent. Parents probably have house rules that they want to have respected. But the adult child needs to be treated as an adult, and some house rules may presume the wrong kind of dependence.

As parents age, providing care will become more difficult. In time, one or both parents may become ill and require care themselves. Alternative care plans and living arrangements should be discussed with the adult child well before such a crisis occurs.

Family and friends

Family and friends can be crucial members in a network of assistance but caregivers often report that
it’s hard to actually get their help. The first step is to tell friends and family that their help is needed and welcomed. Friends often worry that offering help might seem intrusive, especially when it looks as if things are being handled well.

Keep a list of projects, errands, and services that friends could do. Then, the next time someone offers to help in some way, it will be easy to oblige them. Give people specific, time-limited tasks. Asking a friend or relative to come by on Saturday for 3 hours in the afternoon so the caregiver can run errands is going to be more successful than asking them to stop by when they have a moment.

**Hiring help**

People with disabilities need most help with daily care. Unfortunately, this kind of help is generally not covered by insurance plans. Unless one of the carepartners has a long-term care insurance policy with a home care provision, paid care will be limited to what the family can afford.

Doctors often refer to specific professional nurses and therapist agencies. However, home care aides and domestic assistants are hired by the carepartners. Hiring capable, reliable and trustworthy help will be easier if the needs and concerns of the person receiving care are discussed in advance. The person with MS should always be part of the interview process.
Other caregivers, the health-care team, and the National MS Society can be of help in locating reliable agencies that screen and refer potential candidates.

Neighborhood teenagers are an underused source of low-cost help. Some schools require community service, and many teenagers would like part-time work. Ask the honors program advisor at the local public high school for names of interested students. Be willing to write recommendation letters for students who work for you and be ready to teach them something about MS and disability. Be prepared to pay at least the minimum wage.

**Safety and security**

Leaving a person with significant disabilities home alone can be a frightening proposition for both partners. Advance planning and adaptation of the home can decrease these worries. Accessible peepholes in the front door, portable telephones with speed dial, automatic door openers, and “life-net” call systems that summon help in an emergency may provide security.

If there is no secure way to leave a person with a severe disability home alone, then don’t do it! You must find help or alternatives.
Medical issues

Management of MS and its symptoms will be easier if everyone involved learns as much about the disease as possible. For general information, contact the National MS Society. To get the best information about an individual, caregivers should rely first on the person with MS, and then on that person’s medical professionals.

The health-care team and symptom management

Many MS symptoms can be controlled by medications, management techniques, and rehabilitative therapies. The health-care team can advise carepartners about diet and routines that will regularize toileting and sleep habits. Although MS can not yet be cured, symptoms can be managed.
For some people, the most frightening aspect of giving care to someone with a chronic disease is being responsible for treatments. This may involve keeping track of medications, administering injectable drugs, or performing intermittent urinary catheterization.

Caregivers can and should make appointments with health-care professionals to get information, advice, and training. Treatment plans can fail if the caregiver does not know the medical staff, does not understand why and how a procedure is done, or gets instructions that are impossible to carry out. If there are problems with carrying out a medical or treatment procedure, contact the health-care team and arrange for a follow-up training session. With proper training and a little experience, most caregivers end up feeling confident about this part of their role.

**It isn’t always MS**

Both the person with MS and the caregiver need to remember that having MS doesn’t protect anyone from the normal ills that can affect us. This is especially important for people with MS who see a neurologist for their medical care. Specialists may not suggest routine, preventive health exams like Pap smears or prostate exams. Type “Preventive Care Recommendations for Adults with MS” in the Society Web site search box or ask your chapter for a printed copy of this important document.
PART II: Emotional Support

Handling stress and caregiver burnout

Providing emotional support and physical care to someone with MS is often deeply satisfying, but it is sometimes distressing, and now and then simply overwhelming. The strain of balancing employment, child-rearing, increased responsibilities in the home, and the care of the ill person may lead to feelings of martyrdom, anger, and guilt.

One of the biggest mistakes caregivers make is thinking that they can—and should—handle everything alone. The best way to avoid burnout is to have the practical and emotional support of other people. Sharing problems with others not only relieves stress, but can give new perspectives on problems.

“Why doesn’t anyone ask how I am?”

It is easy to feel invisible. Everyone’s attention goes to the person with MS and no one seems to understand what the caregiver is going through. Many caregivers say no one even asks. Mental health experts say it’s not wise to let feelings of neglect build up. Caregivers need to speak up and tell other people what they need and how they feel.

If this seems like disloyalty to a partner or family member, or a caregiver fears being labeled a
complainer, reach out to support groups, religious advisors, or mental health counselors to learn constructive communication techniques.

Take care of the caregiver

Many caregivers neglect their own physical health, too. They ignore their ailments and neglect preventive health measures like exercise, diet, and regular medical examinations.

Many caregivers do not get 7 hours of sleep a night. If sleep is regularly disrupted because the person with MS wakes in the night needing help with toileting or physical problems, discuss the problems with a health-care professional.

The person with MS needs a healthy caregiver. Both partners need uninterrupted sleep.
Outside activities

Researchers report that the emotional stress of caring has little to do with the physical condition of the person with MS or the length of time the person has been ill. Emotional stress seems more related to how “trapped” caregivers feel in their situation. This, in turn, seems to be closely related to the satisfaction they have in their personal and social relationships, and the amount of time available to pursue their own interests and activities.

Successful caregivers don’t give up enjoyable activities. Many organizations have respite care programs. Other family members are often willing—even pleased—to spend time with the person with MS. It may be possible to arrange respite care on a regular basis. Keep a list of people to ask on an occasional basis as well.
TWO-WAY COMMUNICATION

Many emotional stresses are the result of poor communication. The caregiver should be able to discuss concerns and fears openly; the person receiving care isn’t the only one who needs emotional support. Although collaboration isn’t always easy or possible, working out long-term plans and goals together will help both carepartners to feel more secure.

The emotional and cognitive symptoms of MS are often more distressing than the physical changes. If memory loss, problems with problem solving, mood swings, or depression are interfering with open communication or disrupting daily activities, consult a health-care professional.

Effective ways to acknowledge feelings

Ignoring a problem will not make it disappear. Anger, grief, and fear soon become guilt, numbness, and resentment. Some people find that talking about their concerns happens more easily when they schedule a regular time for conversation. Taking time out to collect feelings before presenting them for discussion will make it easier to speak clearly and calmly.

Handling unpredictability

Living with MS means expecting the unexpected, making backup plans, and focusing on what can be done rather
than what can’t. The unpredictability of MS can be very stressful, but it can be managed.

When making plans for outings, for example, always include extra time for travel. Calling ahead to check out bathroom facilities and entrance-ways is wise. Buildings are not always accessible, even when they say they are. Don’t make plans too complicated. And when plans fall through, have an alternative ready. If the night out is impossible, order in pizza.

A list of backup people who can be contacted for help at short notice is also useful.

**Dependency and isolation**

Fear of dependency and isolation are common in the families of the chronically ill. The person with MS is increasingly dependent on the carepartner, and the carepartner needs others for respite and support. Many caregivers feel shame about being dependent on others. As a result, many don’t ask for the help that they need. Anxieties are greatly reduced for carepartners who are able to develop personal and social support.

**Anger**

Anger is a common carepartner emotion. The situation feels—and is—unfair. Hurtful words might be spoken during a difficult task, doors might be slammed during a disagreement, shouting in frustration sometimes replaces conversation. Anger and frustration must be addressed
and healthy outlets developed before angry encounters become physically or emotionally abusive.

**Avoiding abuse**

Abusive behavior is never acceptable. But tensions can mount in the most loving of families. While circumstances that produce frustration and anger are often unavoidable, an emotionally damaging or physically aggressive response is not okay. If tensions are mounting, call for a time-out, and call for help.

Physical abuse usually begins in the context of giving or getting personal help—the caregiver might be too rough during dressing or grooming. The person with MS might scratch a carepartner during a transfer. Once anger and frustration reach this level, abuse by either partner may become frequent.

The dangers of physical abuse are obvious, but emotional abuse is also unhealthy and damaging. Continued humiliation, harsh criticism, or manipulative behaviors can undermine the self esteem of either partner.

Family and social groups may provide support and counsel. Therapists and marriage counselors can help partners work out problems. The National MS Society can offer local referrals.

The majority of carepartners never experience such levels of distress or become abusive. However, separation, divorce, or a nursing home are healthier options than a corrosive relationship.
SEX AND INTIMACY

Carepartners who are also spouses or partners usually face changes in their sexual relationship. These changes can have physical or emotional causes. MS can interfere with both sex drive and function. Problems can include decreased vaginal lubrication, numbness or painful sensations, decreased libido, erectile dysfunction, or problems reaching orgasm.

MS fatigue can interfere with sexual activity. Spasticity or incontinence problems can negatively affect sexual desire. Most of these symptoms can be managed, so it is a good idea to seek the help of a health-care professional.

In addition to MS-related functional problems, changes in roles may change the sexual relationship. Caregivers feel that they are performing a parental role, rather than being a lover or spouse, and this can dampen intimacy.

Sexuality does not have to disappear. Partners might begin by discussing what they find most rewarding about their intimate relationship. Many preconceived ideas of what sex should be prevent the satisfaction of actual needs and pleasures. Discussion could lead to the discovery of more imaginative sexual behaviors.

Open and honest communication about sexual needs and pleasures without fear of ridicule or embarrassment is the crucial first step. Counseling with a sex therapist can be helpful in this process.
SELF-HELP GROUPS

Self-help groups can provide an outlet for emotions and a source of much needed practical information. All National MS Society chapters have affiliated self-help groups for people with MS, and many have groups for caregivers as well. Religious and spiritual communities often provide support and guidance.

Many carepartners say it is difficult to find time to attend group meetings. They want to use their limited time for other things. The benefits of a group might be obtained through the Internet. There are many useful online caregiver chat groups.
PART III: Resources

Books


Contains chapters on topics ranging from emotional and cognitive issues, to sexuality and intimacy, to life planning.


Focuses on medical issues and treatment, with chapters on financial planning, insurance, and occupational therapy.


A practical guide to caregiving, from activities of daily living to emergency situations. Includes many illustrations.
Lots of basic information for caregivers.

A comprehensive guide to working with doctors and lawyers, making choices about employment and income, MS and your job, disability and other federal benefits, insurance issues, dealing with taxes, family law, handling debts, and getting around with MS.

**Ordering books**
For all books from Demos Medical Publishing, call 800-532-8663. Books with no ordering information can be found in bookstores or from major Web booksellers.
Caregiver support

Caregiver.com

www.caregiver.com

- Maintains one of the most visited caregiver sites on the Internet.
- Publishes *Today’s Caregiver Magazine*.
- Provides links to many resources such as government and nonprofit agencies.

Today’s Caregiver Magazine

6365 Taft St., Suite 3003
Hollywood, FL 33024
Tel: 800-829-2734

www.caregiver.com/magazine

- A bi-monthly caregiver magazine.

National Family Caregivers Association

10400 Connecticut Ave., Suite 500
Kensington, MD 20895
Tel: 800-896-3650

www.thefamilycaregiver.org
email: info@thefamilycaregiver.org

Free member benefits include the following:
- Take Care!, a quarterly newsletter.
- *The Resourceful Caregiver*, a useful guide to resources.
- A support hotline.
The Well Spouse Association
63 West Main Street, Suite H
Freehold, NJ 07728
Tel: 800-838-0879
www.wellspouse.org
email: info@wellspouse.org
- Publishes Mainstay, a quarterly newsletter.
- Provides networking/local support groups.

Adaptations, equipment and accessibility

ABLEDATA
8630 Fenton St., Suite 930
Silver Spring, MD 20910
Tel: 800-227-0216; TTY: 301-608-8912
www.abledata.com
email: abledata@orcmacro.com
- A database of over 29,000 products that can be searched by type or topic.

American Academy of Orthopedic Surgeons
6300 N. River Road
Rosemont, IL 60018
Tel: 800-346-AAOS (800-346-2267)
www.aaos.org
- Offers a free booklet on lifting procedures for home-based carers called “Lift It Safe”.


To order, contact:
Meeting Life’s Challenges
9042 AspenGrove Lane
Madison, WI 53717
Tel: 608-824-0403
www.meetinglifeschallenges.com
e-mail: help@meetinglifeschallenges.com

- A guide to dressing for people with disabilities plus over 100 resources for custom clothing.

National Council on Independent Living
1710 Rhode Island Ave. NW 5th floor
Washington, DC 20036
Tel: 202-207-0334 (voice)
Tel: 202-207-0340 (tty)
www.ncil.org
e-mail: ncil@ncil.org

- Refers callers to local independent living centers.
- Offers publications and advice related to disability issues.
- Advocates for policy changes.
National Rehabilitation Information Center for Independence
4200 Forbes Blvd., Suite 202
Lanham, MD 20706
Tel: 800-346-2742
www.naric.com
email: naricinfo@heitechservices.com
- A database of research information about assistive technology and rehabilitation.

ProductABILITY
www.tenten.mb.ca
- Supplies information about adaptivetechnology.

Home care agencies/hiring help

National Association for Home Care and Hospice
228 Seventh Street, SE
Washington, DC 20003
Tel: 202-547-7424
www.nahc.org
- Provides referrals to state associations, which can refer callers to local agencies.

Hiring Help at Home
A fact sheet from the National MS Society.
Call 1-800-344-4687 to order.
Tel: 888-860-7244

Information on recruitment, interviewing, reference checking, training, being a good manager, maintaining a good working and personal relationship, problems that might arise and how best to solve them, service dogs, assistive technology, and tax responsibilities. Contains sample forms and letters.

Someone Who Cares: A Guide to Hiring an In-Home Caregiver

32 page pamphlet. Free—$3.50 shipping and handling.
The Center for Applied Gerontology, Council for Jewish Elderly, 3003 W. Touhy Ave., Chicago, IL 60645.
Tel: 773-508-1073
www.cje.net
email: tasha.sykes@cje.net

A comprehensive and practical guide to hiring your own home care.
Assisted living facilities and nursing homes

American Health Care Association
National Center for Assisted Living
1201 L Street, NW
Washington, DC 20005
Tel: 202-842-4444
www.ahca.org
- Provides consumer information on services, financing, public policy, nursing facilities, assisted living and subacute care.

American Association of Homes & Services for the Aging
2519 Connecticut Avenue, NW
Washington, DC 20008
Tel: 202-783-2255
www.aahsa.org
- Provides information on not-for-profit nursing homes, senior housing facilities, assisted living and community services.

Assisted Living Federation of America
1650 King St. Ste 602
Alexandria, VA 22314-2747
Tel: 703-894-1805
www.alfa.org
- Offers referrals to local facilities listed by state.
Respite services

ARCH National Respite Locator Service
800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514-2204
Tel: 919-490-5577
www.respitelocator.org
- Provides caregivers with contact information on respite services in their area.

Eldercare Locator
National Association of Area Agencies on Aging
Tel: 800-677-1116
www.eldercare.gov
- Supplies information about many eldercare issues, including respite care.
- Provides referrals to local respite programs and area agencies on aging.

United Way
701 N. Fairfax St.
Alexandria, VA 22314
Tel: 2-1-1
www.unitedway.org
- Supplies referrals to local United Way offices.
The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience, and expert opinion, but do not represent individual therapeutic recommendations or prescription. For specific information and advice, consult your personal physician.

The Society publishes many other pamphlets and articles about various aspects of MS. To ask for these, or for other information, call the National MS Society at 1-800-344-4867.

All our publications are on our Web site, along with handouts called “Basic Facts” on various topics. For a list, click the bar on our home page called “Library.” If you have no access to the Internet, just call your chapter and ask for a copy of the latest Publications List.

Some of our popular pamphlets include:

- Managing Progressive MS
- So You Have Progressive MS?
- Hiring Help at Home: The Basic Facts
- Managing MS Through Rehabilitation
- At Home with MS: Adapting Your Environment
MS STOPS PEOPLE FROM MOVING.

WE EXIST TO MAKE SURE IT DOESN’T.

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