Paying for Home Care

For most families living with ALS, in-home care becomes a necessity at some point. The expenses associated with in-home help can add up quickly. Public insurance plans (such as original Medicare and Medicaid) and private insurance plans (such as Medicare Advantage, an employer’s health insurance plan, or long-term care insurance) may help to cover some of the costs associated with in-home help, but most of the financial burden is usually borne by the family.

**Medicare**

Medicare is a federally funded insurance plan that provides health insurance to people 65 years and older, as well as to younger people with certain disabilities and conditions (including ALS). People with ALS are automatically enrolled in the Medicare program as soon as they begin to receive disability benefits from Social Security or the Railroad Retirement Board. You can choose to get your Medicare health insurance coverage through either original Medicare (Medicare Parts A and B) or a Medicare Advantage plan (Medicare Part C). Original Medicare is administered directly through the federal government, whereas Medicare Advantage plans are administered by private insurance companies that provide Medicare benefits (and usually additional benefits as well).

With both original Medicare and Medicare Advantage plans, you will usually be required to pay **premiums** (monthly fees paid to the insurer), a **deductible** (a set amount of money that you must pay out of pocket before the insurance kicks in), and **co-payments or co-insurance** (a fixed amount of money that you pay at the time you receive the service). With original Medicare, there is no annual limit to the amount of money that you could pay out of pocket for premiums, deductibles, and co-payments or co-insurance, but with Medicare Advantage plans, the total amount of money that you are responsible for paying out of pocket is usually capped annually. Some people with original Medicare opt to purchase a Medigap (supplemental insurance) policy to offset some of these out-of-pocket costs, but eligibility to purchase a Medigap policy varies according to state. In some states, only people 65 years and older are eligible to purchase a Medigap policy. Also, if you participate in a Medicare Advantage plan, you cannot purchase a Medigap policy.

Many people think that Medicare will cover the majority of their home health care costs, but in fact, Medicare only pays for home health care on a short-term and intermittent basis, and only
when the help is deemed medically necessary. That means, for example, that Medicare will not pay for:

- Round-the-clock care.
- Homemaker services (such as help with laundry, cleaning, or grocery shopping).
- Personal care services (such as help with bathing, dressing, or using the toilet) when these are the only services that you need.
- Meal delivery services.

**Medicaid**

Medicaid is a federally funded and state-regulated insurance plan designed to help people with low incomes pay for health care, as well as those with higher incomes whose medical costs exceed a certain percentage of their income. The federal government sets standards for care, but the individual state determines what services are covered. As a result, the home care services covered under Medicaid are different in each state. Additionally, most states offer more than one Medicaid program, so home care benefits provided through Medicaid also depend on which plan you are enrolled in. In most states, the Medicaid state plan (sometimes called “regular Medicaid”) will pay for personal care services in addition to skilled care services. Some states also offer “waivers” that are designed to keep people out of long-term care facilities and in their homes for as long as possible, since providing care in the home is more cost-efficient than providing care in a long-term care setting.

It is possible to receive benefits under both Medicare and Medicaid. This is called “dual eligibility.” Medicaid pays only after Medicare and private insurance plans have paid for covered services.

**Veterans Health Administration**

The U.S. Department of Veterans Affairs administers the health care benefits program for veterans. ALS is a service-connected condition, which means that when a veteran who served at least 90 continuous days on active duty is diagnosed with ALS, the ALS is presumed to have been caused by his or her military service. In the VA health care program, covered health care benefits and their associated costs are determined by the veteran’s enrollment priority group; veterans with ALS are classified as enrollment priority group 1. Home health care benefits through the VA health care program include skilled care services on a short-term basis, as well as personal care services and homemaker services.

**Private insurance**

Many people have health insurance that is provided through an employer’s plan or a privately purchased plan. Policies typically cover medically necessary home health care services on a short-term and intermittent basis, but coverage varies according to the individual policy.
Long-term care insurance

Long-term care insurance is a specific type of private insurance policy that can be purchased to offset future costs associated with long-term health care (that is, care that is needed on a daily basis over an extended period of time). Long-term care policies typically cover skilled care as well as personal care services in a variety of settings, including the home. However, if you did not have a long-term care insurance policy before you were diagnosed with ALS, it is unlikely that you will be able to purchase one after your diagnosis.

Private Pay

Many families pay for home health care services using their own income or savings. For example, when insurance does not pay for assistance with personal care, you may decide to pay for the services of a home health aide on your own. If you are working with an agency to obtain services that are not covered by insurance, ask about the agency’s willingness to negotiate service rates or set up a payment plan.

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Bibliography


