

# Ask The Experts

**QUESTION:** My friend in Hawaii has spinal muscular atrophy, Type 3 (SMA3), uses a ventilator, and is in a motorized wheelchair. Her husband is her sole caregiver since they have no insurance or money for private care. She is not old enough for Medicare and his income (on paper) does not qualify them for Medicaid. How do other ventilator users obtain attendant care?

**ANSWER:** Deshae Lott, [deshaelott@hotmail.com](mailto:deshaelott@hotmail.com)

Your friend's situation sounds quite familiar to me. There are a few things I can suggest, though none of them offers an immediate resolution to this difficult and depressing situation that I, too, have faced and do face.

First, SMA3 should qualify her for SSI (Supplemental Security Income) or, if she has paid into Social Security for 10-plus years of work, for SSDI (Social Security Disability Income). Signing up for Medicare, despite a wait, eventually will alleviate some health care expenses. This will and can supplement any other insurance she has and reduce the burden of medical expenses that Medicare approves, which will not be hourly skilled long-term caregiving, but still will help with overall finances so that more funds of her own can be directed into caregiver costs.

Second, they should check with the state Medicaid office or an independent living center to see if there are any waiver programs for caregiving. These services often have long wait lists. I've been waiting on a list in Louisiana since 2004; however, if I am alive when my slot opens, perhaps within two to three years, that program will begin to assist us tremendously. After the 1999 Olmstead decision, which ruled that Title II of the Americans with Disabilities Act prohibits the unnecessary institutionalization of persons with disabilities, most states have initiated such programs. Some states have a much swifter service record than Louisiana.

Third, check into a special needs trust. The rules vary state-to-state. However, this is a way the government allows you to receive its benefits (or remain eligible to stay on wait lists for services) but also to have a means to supplement your care costs for things the government does not cover. Such a trust can fund medical expenses not already covered by other means (private insurance, Medicare, and/or state Medicaid insurance) but cannot fund basic daily living expenses (housing, food, clothing) that SSI or SSDI and other government assistance programs are designed to support.

The trust requires using a specialized attorney, and that can cost \$1,500 to \$7,000 – a considerable expense. However, if there are friends or relatives who have an interest in supporting your

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friend's health costs, it's vital to have a trust. Direct gifts to the individual are forbidden if one is to receive or to qualify for government support. But gifts can be given to a trust. The caveat is that neither she nor her husband can serve as trustee. They will need a trusted friend, relative or a bank representative to serve, and this may involve financial compensation for their time. So, this is an option, but again it has its limits.

I have had to cultivate a peace with the high cost of my life. This entailed a grief process, but in the end, I looked at the facts straight on, knowing mostly I'd be facing Hobson's choices. It's humbling to wish to be self-reliant and then to conclude that a vast array of a community's resources will be required to sustain one's life.





Finding peace with this daunting situation has been a matter of deciding whether I feel purposeful in staying embodied, and – as a person of faith – whether I feel it is God’s will that I do so. As long as I can say “yes” to purpose and a sense that God still wishes my soul to inhabit its current physical form, then I opt to do the best I can. It involves re-enthusing one’s self for and re-committing to the journey each day. And then I problem-solve and navigate my dynamics as best I can, step by step.

Please let me know if you have questions about what I’ve shared. I am not fully informed about various state regulations or specific situations, but I can share more of my experience.

**ANSWER: Audrey King, king.aj@rogers.com**

If you lived in the province of Ontario, Canada, and are considered “competent” (able to hire, fire, manage, direct and pay your attendants in accordance with Ontario’s Employment Standards and Regulations), you qualify for Direct Funding. Funding for up to six hours a day at \$15 per hour is deposited directly to you by the Ministry of Health and Long-Term Care. If you use a ventilator 24/7 you may be granted nine or more hours per day. You would become an employer or “self manager” and would be expected to take on the responsibilities and liabilities entailed as well as keep records and provide a quarterly report to the government (via your local center for independent living).

In addition to “hours” there are also provisions for contingency situations and an option for flat-rate overnight situations. This is very low – \$30 to \$50 – and is based on the premise that somebody sleeps over just to be “on call” if needed. Many significantly disabled ventilator-assisted people have found this program sufficient to establish a successful “live-in” caregiver situation. The great thing is the flexibility and choice in choosing your own attendants, in how and where and when you use these hours and what you can train them to do for you, e.g., any routine procedure like suctioning and catheterization and/or driving. The down side is the small size of the program and the lengthy waiting list. Approximately 500 people are still waiting to get on to the program.

Alternatively, you would be eligible to receive up to a maximum of 14 hours per week from your local Community Care Access Centre. This medically assessed service is only for personal care, simple meal assistance and to tidy up your home. You are likely to receive care from a variety of workers and at times not necessarily convenient to you. Also, the service is usually burdened with policies and procedures that limit you further, e.g., no nail cutting, registered nurse (RN) must train the worker in using your lift, two workers must be present during lift transfers, only RNs can do “invasive” procedures such as suctioning, catheterization, injections and medications. ▲

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**Audrey King, PhD**, is an instructor, researcher and advocate on disability issues at university, government and community levels. A psychologist by profession, she played a key role in establishing Ontario’s attendant services – supportive housing, outreach services and the Direct Funding program. King, a ventilator user who was disabled by polio at age 9, has used purchased attendant support for the last 25 years.