

What to Do When the Diagnosis is “Dementia”

When a person receives a diagnosis of a dementia-causing illness, it can be scary and overwhelming for both the person and for his or her family. However, there are resources and supports available to help you and your family through this process. There are also steps that you can take now to make a plan for the future.

Learn more about what the diagnosis means:

Start by contacting Southern Maine Agency on Aging at 1-800-427-7411 or 396-6500 to speak with a Resource Specialist in the Family Caregiver Support Program. We can meet with individuals or family groups to discuss resources, planning, and caregiver support. We offer classes and caregiver support groups at various locations in southern Maine. You can also contact the Maine Alzheimer’s Association at 1-800-272-3900 for more information about any type of dementia.

Make sure that your legal affairs are in order:

It is a good idea for all adults to set up a health care power of attorney (POA) and complete an Advance Directive form to express their wishes about future medical care. The Advance Directive forms can be found on line or through SMAA. People with a dementia diagnosis may also wish to talk to an elder law attorney and set up a financial power of attorney in the event that they are no longer able to make their own financial decisions.

Look at your financial picture:

Now is the time to gather information about available income and assets that can be used to pay for in-home and/or facility care. It is important not to give or sign away any assets without consulting with an attorney first, due to the 5-year look back period for Long-term Care MaineCare (see below for more information.) If the person with dementia has long-term care insurance, find out what it covers and what documentation is necessary to activate the coverage. If the person is a veteran or the widow of a veteran, contact the Veterans’ Administration at 1-800-

827-1000 to find out about potential benefits. People diagnosed with early-onset dementia (before age 65) may be eligible for immediate Social Security disability benefits, so call the Social Security Administration at 1-800-772-1213 if this applies.

Start Long Term Care Planning:

Obtain a list of long term care facilities from the Southern Maine Agency on Aging (SMAA) and consider making an appointment to discuss care options. Get a comparison checklist from SMAA, and begin to visit facilities as early as possible. Place the person's name on several waiting lists for facilities, especially if the person will need funding assistance through MaineCare (Medicaid) to pay for long-term care in a facility. Be aware that Medicare is federal health insurance, and it does NOT pay for long-term facility care. It may pay for a short-term rehabilitation stay in a skilled facility if it is determined to be medically necessary by a physician and the person meets other requirements

Consider Obtaining Care for the Person with Dementia:

Respite care is short-term care for the person with dementia, which can provide much needed relief for the primary caregiver. Caregivers should consider asking family members and friends to help. SMAA can also provide referrals for in-home non-medical care, adult day programs, and short-term overnight care in a facility, as well as guidance and problem-solving help with making a respite plan.

Planning Ahead When the Diagnosis is Dementia:

If you are caring for a person with a dementia diagnosis who does not have the financial resources to pay privately for in-home or facility care, there are state-funded programs designed to help- **but they often have long waiting lists, so it is very important to be proactive and plan ahead.**

People who are able to pay for their own home care may hire help privately or use an agency. SMAA can provide a list of non-medical home care agencies, and a checklist of questions to ask when hiring a private provider or an agency. The

State of Maine has a contract with an agency called **Maximus** (formerly Kepro/Change Healthcare/Goold Health Systems-1-833-525-5784) to assess a person's abilities and care needs whenever state funds are requested for in-home or facility care. Maximus does a screening over the phone and may then send a nurse to do an in-home MED assessment. Generally speaking, a person must need assistance with at least one "Activity of Daily Living" (bathing, dressing, toileting, etc.) for Maximus to do an assessment. There may be a wait to receive an assessment for home care through Maximus depending on funding availability.

An assessment through Maximus is required for all admissions to nursing facilities (private pay or MaineCare) and for most admissions to assisted living facilities as well. Maximus generally will not do an assessment for a person to go into a facility unless the facility has a current or anticipated opening, so it is important for families to work with facilities regarding the timing of the assessment.

When someone is going into a long-term care facility and needs assistance to pay for care, the person must submit a **Long-term Care (LTC) MaineCare application** to their local Department of Health and Human Services. DHHS may request up to 5 years' worth of financial records to determine that nothing of value has been given away or transferred. A transfer of assets may result in a penalty period for MaineCare. Generally speaking, a single person's assets must be below \$10,000 in order to qualify for LTC MaineCare. DHHS may determine that a spouse can keep some of the jointly-held assets to be able to continue to live in the community after the person goes into a facility. It can be very helpful to consult with an elder law attorney early in this process, as MaineCare rules are complex and change periodically.

If a person receives assistance through the MaineCare program during his or her lifetime, the state of Maine may make an Estate Recovery claim against his or her estate after he or she passes away. Maine Legal Services for the Elderly (www.mainelse.org; 1-800-750-5353) has useful information about Estate Recovery and other considerations when applying for LTC MaineCare.

Please call the Family Caregiver Support Program at 1-800-427-7411 or 396-6500 to discuss resource options and start planning for the future.

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