Dementia in Virginia

Underdiagnosed, undercounted, undertreated: How a responsive dementia registry addresses this urgent issue

Alzheimer's and Related Diseases (ADRD) are shockingly underdiagnosed and diagnoses are undercounted in Virginia. Current projections from the CDC and others are not counting about one third of ADRD diagnoses.

Between 2020 and 2025 there will be an anticipated increase of 26.7% cases of Alzheimer's dementia in Virginia.

THE NEED FOR SPECIFIC DIAGNOSES

In order to receive effective treatment for ADRD, a specific diagnosis is needed. However, according to Virginia Memory Project (VMP) data, about 40% of people in Virginia diagnosed with ADRD are diagnosed with "unspecified dementia." This closes off a pathway for clinical trials, leaves us unable to address specified needs, and signals a bigger problem: that many practitioners aren't equipped to effectively diagnose these illnesses and provide optimal care.

WHY A RESPONSIVE DEMENTIA REGISTRY

A responsive, two pronged dementia registry is a key way to address dementia in Virginia. A responsive dementia registry will help anyone onto a pathway to care. Dynamically integrated into a continuum of programs, including connection to and training for providers, VMP is housed at the Virginia Center on Aging and serves as Virginia's dementia registry.

VMP automatically captures data previously unreported in ADRD diagnosis projections. VMP collects the data that was missed and provides a direct pathway to services – including for caregivers. VMP refers out to providers who are equipped to provide optimal care. This will continue to open opportunities for community partners, lawmakers and health professionals to create effective educational programs, delegate resources and become dementia capable.

COMMUNITY IDENTIFIED NEEDS

Currently, top Virginia service requests are for:
- Brain health education
- Memory monitoring
- Memory screening

VMP provides referrals for each of these.
Contact VMP by emailing rhodesas2@vcu.edu

HOW DOES THIS REGISTRY WORK?

In Virginia all insurance claims go into a database called the Virginia All Payer Claims Database. VMP automatically extracts all (de-identified) diagnoses of dementia and drugs prescribed for dementia along with basic demographics, like ZIP code, and analyzes this information for public health programming.

A responsive dementia registry will help anyone onto a pathway to care. Registry questions are based on the Behavioral Risk Factor Surveillance System (BRFSS) and your answers are reviewed by a social worker, who can provide resources and referrals to providers.

All are welcome
The more people of all types who enroll, the better the data. This self-enroll feature is building a comprehensive look at memory health and caregiving in Virginia.