



Self-advocacy and Health Care for Older Adults with Mental Illnesses

Why is self-advocacy important?

Mary Ellen Copeland, recovery author, educator and advocate, says, "The number one reason [for self-advocacy] is that I'm the only person who has to live my life. Nobody else can know what I really need."

It is especially important to advocate for yourself to get the best health care. The Agency for Healthcare Research and Quality (AHRQ) recommends partnering with your doctor and communicating openly and honestly. A good doctor is interested in what you have to say; the more information that you provide, the more likely that your doctor can make an accurate diagnosis and provide appropriate treatment.

Due to cost-containing insurance regulations, it is not unusual to have only a 15-minute visit with your primary care doctor. Older patients often require more time than this. Effective communication with your physician can help you make the most out of a short office visit, however.

Self-advocacy, older adults and mental illness:

Approximately one in five Americans experience mental health problems, and older adults are no different. The most common mental disorders are anxiety and depression; others include dementia and other neurodegenerative disorders, bipolar disorder, schizophrenia and alcohol abuse.

Without proper diagnosis and treatment, mental illnesses are likely to become worse. In addition, untreated mental illnesses can lead to many other problems in older adults. These problems include impairment in the ability to live independently, impaired cognitive functioning, and increased disability and mortality. For these reasons it is important to understand and acknowledge symptoms and discuss them with your physician.

Appropriate treatment, such as medication, therapy and counseling, can help improve psychiatric symptoms. The physician may also recommend a mental health professional, such as a geriatric psychiatrist.

Unfortunately, older people may have more difficulty seeking help from a mental health professional due to physical frailty, transportation difficulties, costs, isolation, stigma, fears of hospitalization, and loss of independence.

Miscommunication with your doctor:

There are many reasons for miscommunication with your doctor, including cultural differences as well as a misinterpretation of symptoms.

In addition, older people, particularly men, tend to underreport symptoms that may be associated with a mental illness. This makes it even more difficult for the primary care physician to diagnose and treat the illness.

For example, although the American Association of Geriatric Psychiatry (AAGP) notes that recent research shows a correlation between chronic pain and major depression among the geriatric population, many primary care physicians and older adults may not be aware of this. Doctors and patients may incorrectly assume that pain and sadness are normal characteristics of aging, and older adults may not mention such symptoms to their doctors.

Tips for advocating with your doctor:

On the day of your appointment:

- Write a list of questions to discuss with your doctor; write down answers as you discuss them.
- Bring a trusted friend or family member for support and assistance.
- Bring all your medications -- including over-the-counter medications, vitamins and herbal supplements -- to show your doctor. Bring a list of these substances to put in your chart.
- Report any changes in diet, exercise, mood, sleep, family, job, etc.
- BE HONEST. Never hide anything from your doctor because you are only hurting yourself.





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Be specific when presenting a problem to your doctor:

- When did the problem begin?
- What is the frequency of the problem?
- How would you describe the physical symptoms of the problem?
- Rate the severity of the problem (scale of 1 to 10, with 10 the worst).
- When does the problem occur? Any specific patterns (after meals, only at night, etc.)?
- Are the symptoms recurring? (Have you experienced this problem in the past?)

If you are given a specific diagnosis:

- Make sure you understand the diagnosis and possible treatments and outcomes.
- Know what lifestyle changes need to be made.
- Know common symptoms associated with the illness.
- Ask what tests will be performed and what the results of the tests could mean.
- What are the signs that your condition is improving? Worsening?
- Ask how you can learn more about your diagnosis.
- Always make sure to review what was discussed at the end of your appointment.

Important post-diagnosis information:

Communication and self-advocacy should not end once a physician has made a diagnosis and prescribed treatment. In some cases, a prescribed treatment may not be working; following up with the physician is important to ensure effective care.

Resources and Internet Sites:

American Association for Geriatric Psychiatry

“Age Discrimination in the Health Care System” (written testimony). <http://www.aagponline.org/advocacy/testimony.asp?viewfull=17>

AARP: Checkups and Prevention: “How To Talk To Your Doctor”. http://www.aarp.org/health/staying_healthy/prevention/a2003-03-13-talkdr.html

“Depression in Older Persons” http://www.nami.org/Content/ContentGroups/Hotline1/Depression_In_Older_Persons.htm

The National Mental Health Association Fact Sheets

Dialogue For Recovery. <http://www.nmha.org/pbedu/dialogueforrecovery/index.cfm>

Anxiety and Depression. <http://www.nmha.org/infoctr/factsheets/index.cfm>.

Psychiatric Illness in Older Adults. http://www.medem.com/MedLB/article_detailb.cfm?article_ID=ZZZSDCGUACC&sub_cat=62.

References:

Copeland, Mary Ellen. *Living without Depression and Manic Depression*. Oakland: New Harbinger, 1994.

O’Connor, Daniel W.; Rosewarne, Richard; Bruce, Ann. “Depression in Primary Care 1: Elderly Patients’ Disclosure of Depressive Symptoms to Their Doctors.” *International Psychogeriatrics* (2001). 13 (3) 359-365.

O’Connor, Daniel W.; Rosewarne, Richard; Bruce, Ann. “Depression in Primary Care 2: General Practitioners’ Recognition of Major Depression in Elderly Patients.” *International Psychogeriatrics* (2001). 13 (3) 367-374.

Quick Tips -- When Talking With Your Doctor. AHRQ Publication No. 01-0040a, May 2002. Agency for Healthcare and Quality, Rockville, MD <http://www.ahrq.gov/CONSUMER/quicktips/doctalk.htm>

RestoringtheInnerSelf: A New Psychiatry Emerges, Albeit Slowly, to Aid Older Persons Grappling with Stresses. <http://www.aarp.org/bulletin/yourhealth/Articles/a2003-07-29-innerself.html>

Van Citters, Aricca D.; Bartels, Stephen J. “A Systematic Review of the Effectiveness of Community-Based Mental Health Outreach Services for Older Adults.” *Psychiatric Services* (November 2004). 55 (11) 1237-1249.

