

# Caring, Sharing and Daring What About Advocacy?

By Kay Rittenhouse

Offering Hope:  
The Church's Role  
with Mental Illness



Advocacy for a loved one who has a mental illness can be expressed through myriad activities which engage us in response to issues surrounding mental illness. If we care for a loved one and commit to share as a support person we soon find ourselves daring to advocate for what that person needs. Following are some thoughts gathered from families as they struggle to meet daily challenges.

**Advocacy is unique for each person.** When a diagnosis is first received the response is disbelief and the desire is to explain it away. This is easy to do since our society does not have a general knowledge about mental illness as we do about cancer. It is also easy to deny the diagnosis because the illnesses frequently manifest themselves as bad behaviors which we assume teens and adults can control. My first step into advocacy was to learn about the illness which came to our

family. As a teacher I attended thousands of staff meetings, hundreds of lectures and dozens of conferences. None of them informed me about the symptoms and issues surrounding bipolar disorder. Part of what I learned was that I needed to let go of some of the myths being circulated. My new education came from National Institute for Mental Health, local hospitals and professionals, other families dealing with similar issues, lectures, workshops, books, brochures, videos, etc. At first I thought "How can I find time for any of these activities?" Once I began to understand the illness better my load actually became lighter.

**Our response to mental illness is never static.** It is different for each individual and in each situation. It is different as the illness cycles. When someone is manic the response cannot be the same as when someone is depressed. When someone has respite from the cycles he/she wants to continue activities as normally as possible. Support and advocacy are very different when a loved one has access to treatment and it is effective from when treatment is denied or the money to purchase it is gone. When the system of care has few gaps our

response is different from when legislation or program implementation leaves huge gaps. When we dare to advocate we dare to make continual assessment of what is needed and how best to meet those needs.

**Advocacy is a common, shared experience.** Once we determine to address what our loved one needs we find

much common ground with other families, faith communities and friends. We can join together for effective responses to a local facility, a religious group, a state or national legislature. We can work through an organization like the National Alliance on Mental Illness (NAMI) or the Mental Health Association. We can help organize more local, less structured groups and programs. I have found no better topic for ecumenical work. Mental illnesses come about equally to persons in all walks of life.

**Where does one start?** Anywhere! Advocacy is not a logical sequence of steps. Each person must find his/her own way. The natural place for me to

When trying to reach out to people I think of a gentle spring rain. There is no flooding, no lightning, no thunder ... just raindrops refreshing the plants and loosening the soil.

That's the job I see for those wanting to advocate for those who are living with mental illness. We need to gently encourage people to open their eyes, open their minds, open their hearts, and open their arms.

— Kay Rittenhouse

start was with education since that has been my field of study and since I knew so little about mental illnesses. Another natural place to start is response to a particular crisis such as when the food stamps are cut off or when the money has run out and your loved one must apply for a support program. Taking the first steps into advocacy is a time to be particularly sensitive to how your loved one is reacting to the challenges of dealing with a mental illness. Out of respect, only the person with the mental illness should “break the silence.” There is so much stigma and so much misunderstanding that persons with a mental illness fear losing their health insurance, their job, their children, their spouse, their friends, etc. There are many ways to advocate without advertising that mental illness has come to your family or to a particular person. However, it is a genuine emotional relief when the person with the illness and the family can share openly with trusted friends and groups. I think of a teacher who supported her husband silently for 25 years and experienced such relief when she joined a NAMI Family-to-Family class. I think of a woman who decided to “break the silence” with a trusted neighbor and friend only to find out that the neighbor had been dealing with an ill son for 13 years.

So, start anywhere that is comfortable for you. And then keep trying new ways to advocate as they are presented to you or as you develop the skills to accomplish them. Below are some activities persons have tried successfully.

**Quiet advocacy before you have “broken the silence”:** Educating yourself, planning programs with others in groups you have joined,

writing letters to legislators, attending workshops and conferences, requesting books for the local libraries or local schools, recognizing stigma and drawing attention to it.

**Personal, more vocal advocacy:** Monitoring state psychiatric facilities; speaking to groups such as doctors, nurses, elementary students, faith communities and civic groups; leading a support group; teaching a NAMI Family-to-Family class; visiting your legislators; sitting on boards and committees.

**Group advocacy:** Joining a structured march such as NAMIwalks, visiting legislators as a group, planning and carrying out programs of education and action, studying issues and deciding as a group how to address one of them, supporting a person with a mental illness to navigate the inadequate system of care.

The diagnosis of a mental illness for one you love comes like a thief in the night or like a bomb on your front porch. Suddenly your life is off balance. Many of the old supports are gone or not effective. Advocacy helps you and your loved one to regain balance. As you reach out to others and confront issues you in turn benefit. You are empowered. As a faith community we want to nurture the “tie that binds” as we share “each others woes” and we want to help generate the hope that supporting friends and effective advocacy brings.

***We dare because we first care and share!***

— *Kay Rittenhouse is a Family-to-Family educator for NAMI St. Louis Chapter.*