

Complex Case Management: A Trustees' and Family Members' Guide

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Introduction: Family Members' Fears and Concerns

Very few of us have experience navigating the oftentimes confusing world of helping a loved one get help for living with mental illness or substance abuse, much less navigating the world of managed care and insurance. When your loved one needs mental health or substance abuse treatment, it usually is a time of high stress for the family and the patient. Family members may experience a variety of feelings such as fear of the unknown, anxiety about how to get the loved one help, anger or frustration at being in the situation (often not talked about), and worries about financing the treatment. These are normal reactions to an unusual situation.

Trustees' Concerns

Trustees also have a number of concerns and stressors related to the care of their members and employees. It is not an everyday occurrence; however, when a family member feels they need help with the healthcare system they may call a trustee for help. This creates stress for the trustee as it is not their area of expertise. The trustee then has to call the broker, the third party administrator (TPA) or the managed care vendor (MINES) directly to determine if the family member is receiving the appropriate level of care and is in fact, getting good care. This further becomes complicated because of confidentiality laws at the state and federal levels, plus the HIPAA privacy laws: case managers legally must have signed releases unless there is an imminent danger to the patient, someone else or the patient is gravely disabled. There are ways to speak in generalities about similar cases, however, it is less frustrating for the trustees if releases are signed and everyone can speak openly. Then there are trustees who do not want to get involved as they simply want the benefit administered as it was designed to be. This requires trust and communication by all parties.

Expectations from Family and Trustees

Sometimes family members or trustees have received past treatment for substance abuse or mental health issues and may have a strong opinion as to how the treatment should go. For example, if they had success with a 30-day inpatient program for alcoholism or substance abuse, they may be comparing their successful experiences to the patient's care even though the two situations may be clinically dissimilar. If this occurs, it is important to have a discussion with the family member's case manager about treatment and levels of care.

Scientific and Evidence-Based Practice

MINES makes every effort to match your loved one's care with the best treatment based on the existing scientific and evidenced-based practice. As in any area of health care, research is ongoing and new treatments are constantly emerging. That being said, every person has their own unique set of symptoms that vary in frequency, intensity and duration, plus other complicating elements even though they may have the same diagnosis as another patient. Your loved one's treatment team and the case managers do everything they can to take all of the symptoms into consideration.

Hospitalization and the Continuum of Care

MINES is committed to authorizing the most appropriate level of care in the least restrictive manner while being a good steward of your loved one's benefits. This is important for a number of reasons. If your loved one can be treated through outpatient, intensive outpatient or even partial care, they can still work, live at home, go to school and maintain their life. This is important for all of us. If the patient needs hospitalization, it is because they are in danger of harming themselves (imminent intention, has means, has plans, and cannot contract for safety), is going to harm someone else (same criteria), or is gravely disabled (psychotic in some way such as hearing voices, paranoid or a variety of other conditions). In the case of substance abuse, the patient has to have failed an intensive outpatient program or be in a social situation where they cannot maintain their initial detoxification and sobriety. Hospitalization is designed to stabilize the patient, provide intensive psychotherapy, medication (or both), and have them return home as soon as they are able with a good aftercare treatment plan. Unfortunately, for many mental illnesses there may be recurrences (e.g., depression, anxiety disorders, psychotic disorders, etc.). Substance abuse disorders often have 2-3 relapses before the patient may have extended periods of sobriety. This is important to keep in mind because the family is usually the first to notice early signs of a recurrence of relapse and can alert the therapy team so that adjustments can be made without the need for hospitalization.

What Happens When it's Complicated?

Many times your loved one will only be in the hospital for a few days. Sometimes their condition is more complicated and longer stays are necessary. Complications can range from having multiple conditions such as depression and substance abuse, to having a history of emotional, physical or sexual abuse that had not been disclosed nor addressed in therapy before (other "secrets" such as gambling problems and "sexual" addiction (this is not a diagnosis, but certainly can be a problem) can also be a factor.

Medication trials are exactly that: trial and error. Not every person responds well to anti-depressant medications, anti-anxiety medications or psychotic medications, therefore first time and repeated experiments are needed. In the meantime, the patient is still suffering as along with the family. Family members will be worried and concerned if their loved one's condition is complicated - this is understandable and expected. Communication lines with the treatment team and case manager must stay open and available. The case manager's job is to oversee the treatment, figuratively hold the family members' hand, and keep working toward a good outcome.

Why is it Complicated?

The situation your loved is in may be complicated due to differences in brain chemistry, trauma history, multiple diagnoses, late stage substance abuse damage to their brain, head injuries, side effects of the medications, poor fit with the facility therapy team, and other factors. It is not unusual for the therapy team and the case manager to ask for a second opinion when your loved one's recovery is not progressing as everyone expected.

Complex Cases and the Course of Therapy

Unfortunately, there is no good road map for the family when your loved one's situation is complicated. A better picture is being lost in the wilderness for a number of days or weeks. What is meant by this is that

treatment starts by having them in a safe place such as the hospital. The loved one has a diagnosis and the therapy team starts with that as the beginning. Then the loved one does not respond to the usual course of treatment or even gets worse. Now the treatment team and the case manager have to reassess your loved one, come up with the next medication or psychotherapy intervention and see how that works. There may be improvement in some areas and not others. The assessment and treatment plan is redone again with either improvement or not. This cycle can occur a number of times due to the factors mentioned above regarding why a loved one's situation is complicated. In rare cases, sometimes your loved one does not get better and then long term care options are considered. Thus it feels like wandering through the wilderness and therefore having your case manager as guide can reduce the family's stress regarding the uncertainty

Patient's Ability to Report their Symptoms and History Reliably

Sometimes the patient does not give the same information to their family as they do to their treatment team and this happens for a number of reasons that may include secrets they have not told you or anyone about until they got to the hospital, problems with memory due to their illness or substance abuse, or their perceptions of an event. The point is, you may understand their illness one way and the treatment team may have a different perception. This is why it is important for you to be involved as a family with the treatment team so you can all be on the same page.

What is the role of the Case Manager?

MINES has experience with parents who had to take out second mortgages because a facility unnecessarily told them their teenager needed to be in the hospital, when in fact, their child had no symptoms that warranted such a level of treatment. These parents had no case manager working as their advocate, and that led to superfluous spending. Also, there are substance abuse treatment facilities that have been promoting 60-90-day inpatient stays in the last year. On the surface of it, you may say, "Well, that makes sense; because the loved one has an additional month or two to stay sober while in the facility." Unfortunately, there is no scientific evidence to-date that supports the idea that longer inpatient stays equal longer periods of sobriety. In fact, the main difference in outcome between intensive outpatient treatment and inpatient 30-day substance abuse treatment was \$15,000 and no significant change in outcome, with only a few exceptions.

Your case manager is there to support and guide you and your loved one. Your case manager does not get paid more money by denying service or benefit authorization. If either happens, it is because the treatment was not indicated or was inappropriate and they will help you get the level of treatment needed or the authorization was denied because of the benefit structure, or some other problem that arose with the provider, eligibility or other concern.

You have the right to appeal any decision by the case manager, if after discussing it with them you do not agree with the treatment team and the case manager's professional opinion regarding your loved one. This is a rare event, however, it is important that you know you have the option. The case manager will help through the appeal process as well because it is important that you have confidence in the treatment process.

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What is the Case Manager Doing?

The case manager is in daily contact with your loved one's treatment team. The case manager is reviewing progress, symptom change, treatment interventions, setting up discharge planning, asking for second opinions if necessary and communicating with you as frequently as you need after the appropriate releases are signed.

What Happens If We Run Out of Benefits?

This can happen if a case is very complicated with no progress. Running out of benefits will become a less common event now that the mental health parity law is being phased in for various benefit plans. However, in the case that it looks like a lifetime maximum may be exhausted by your loved one's care, the case manager will help you arrange for public sector funding and support. You and your loved one will not be left alone in the process of figuring this out.

Family Therapy

Even though your loved one has the illness, the entire family is affected and can be a primary source of support in the loved one's recovery. We highly recommend that you and the rest of your family be involved in family therapy as part of the overall treatment process.

Family Resources Such as Al-Anon and NAMI

If your loved one has a substance abuse disorder, we hope you will get involved in Al-Anon. This is a free community support group for family members of alcoholics or addicts. If your loved one has a chronic mental illness, there are a number of specialty diagnosis support groups that your case manager can help you find. In the meantime, www.nami.org may be a useful starting point.

Ongoing Case Management

If your loved one has a complicated mental health or substance abuse illness, you can expect some recurrences or relapses. This is a predictable course of these types of illnesses. In the case of children or adolescents with complex illnesses, we are going to be part of your life in raising them. We want you to feel comfortable staying in touch with your case manager, keeping them apprised of how the aftercare treatment is going and partnering with your case manager as we work our way through the wilderness together.