

A Useful Tool for Monitoring ADHD Treatment

by Keath Low, MA

WHEN LIZ BAKER'S SON WAS SIX YEARS OLD, she started keeping notes in a diary to track his behavior. She initially used these notes to determine how diet might be impacting his behaviors. "I recorded what he ate and drank and how his behavior changed or didn't change," says Baker, who continued using a diary when her son was first diagnosed with ADHD and placed on medication two years later.

"I wrote everything down—dates, times, name of medication, dosage, his behavior, different side effects, whether he was feeling lethargic or agitated, and so forth," she recalls.

It took quite a bit of time and a change to a new psychiatrist to find the best medication regime for her son. "I changed doctors a year later, when my son was nine, and was able to give him all of the information about the different medications we had tried," she says. "He found that history very helpful." Baker's now fifteen-year-old son has made significant gains over the

years, and the core symptoms of his ADHD are being well managed.

Monitoring medication over time

"We do know that children's response to medication often changes over time and that a medication or dose that was quite effective at managing a child's symptoms initially may not continue to be as effective," says David Rabiner, PhD, associate research professor of psychology and neuroscience at Duke University. "Probably the best evidence for this is from the MTA study [Multimodal Treatment Study of Children with ADHD], where children in the medication arms of that study began with a carefully conducted placebo-controlled trial to identify the optimal dose and medication for each child. Within three months into the maintenance period over half of the children already required a change in their medication and less than twenty percent continued on the same medication and dosage throughout the entire thirteen-month period," Rabiner explains. "This tell us that even when extreme care is taken to start children on a medication regime that is effective in managing their symptoms, it is likely that adjustments will need to be made to continue to optimize the management of ADHD symptoms."

Rabiner notes that in the absence of ongoing monitoring in some kind of systematic way, parents and physicians will be less likely to have the information needed to gauge whether the medication and the child's symptoms are continuing to be managed well. As a result, there are likely many children who are maintained on a medication program that may not be providing as much benefit to them as might be possible.

Keath Low, MA, is the ADHD Guide for About.com.



In partnership with your doctor

Jackie Morrison started using a medication diary in March of this year after she was diagnosed with hypothyroidism and ADHD. "I knew I needed to track my symptoms and responses to make sure which medication I was reacting to," says Morrison, who uses a "little pink journal" to document her information. "It works like a diary. I write the date on top, list the dosage and time I take medication, and I write a narrative of reactions I have noticed in the day: Did I daydream more

than usual? Did my thoughts seem spazzy?" She continues, "I write it in a way that a clinician can read—sort of like playing my own therapist and taking note of the experiences with respect to memory, cognition, task performance, etc."

Morrison also highlights any physical sensations she experiences, such as anxiety, rapid heart rate, or nervousness and jots down the times she feels them. "When I see my doctor I have a list of the pattern of my reactions," she explains. "The diary helps me to know which symptoms to report to my healthcare providers."

Morrison admits that she initially used the diary because she wanted proof for herself that the stimulant medication she was taking was making a difference. It has. "The diary has been especially helpful because when I meet with my psychiatrist we have been able to make the right adjustments accordingly," she says. "I have a doctor in whom I feel very confident for management of my ADD." An additional bonus that Morrison has found in using the diary is being able to identify and address with her psychologist and ADHD coach the challenges in her life that the medication is not able to address.

David Goodman, MD, is an assistant professor of psychiatry at Johns Hopkins University School of Medicine and director of the Adult Attention Deficit Disorder Center of Maryland. He notes that a medication diary can be very helpful in tracking a patient's adherence to medication, duration of action (when the person notices the medication wearing off and information about how they notice it wearing off), daily frequency of symptoms, and whether or not there are any noticeable side effects. The diary should also include any change in medications or dose. If there is some consideration for elevated blood pressure or pulse, the individual can check this periodically at home and enter it into the diary. Tracking cigarette and caffeine intake can also be helpful. Providing this information to one's physician facilitates a tailored approach to one's treatment. Goodman emphasizes that the system for documenting this information needs to be relatively easy, straightforward, and take less than three to five minutes to complete.

Robert B. Christian, MD, clinical assistant professor of pediatrics and psychiatry at the University of North Carolina at Chapel Hill School of Medicine, agrees that the system needs to be convenient. Parents—especially parents of children with ADHD—have a lot of competing demands and responsibilities. Keeping the diary system simple can help keep the momentum on gathering information. "Physicians who are attempting to make decisions regarding medications and behavioral benefits and side effects suffer from a lack of quality data from which to make decisions about medication changes," says Christian. "A diary from parents or adults charting ADHD symptoms and side effects, especially during the months of treatment initiation, is a big bonus for clinicians."

Parents are the key partners in the management plan as sources of information and as the child's primary caregiver, notes Christian, but physicians need to have information from teachers and other relevant school staff, as well, in order to make the most informed decisions about treatment. "We really need better and more web-based systems to allow for the secure and efficient flow of information between all three groups," he says. Until these are readily available, however, a well-kept diary from parents can be an important tool to help monitor and guide treatment.

Behavior rating scales completed by teachers and other communication from a child's school can be incorporated into the information a parent brings to the physician. Rabiner's ADHD Monitoring System is one such helpful tool that provides an easy and systematic way to monitor how a child with ADHD is doing at school. Parents can print out a copy of the monitoring form online at helpforadhd.com/monitor.pdf.

Medication management is an ongoing process

"I think that one of the limitations with how medication is sometimes prescribed is that parents are not necessarily aware that it can take time to identify the most helpful medication and dose for their child," says Rabiner. "And, as was clear from the MTA Study, even when this is carefully done the ongoing impact of medication may fluctuate and adjustments to the child's medication may need to be made."

"When parents are not aware of this, they can get discouraged when the effectiveness of their child's medication appears to decline after several months," Rabiner cautions. "Because many parents can be ambivalent about putting their child on medication to begin with, when they feel it is not working as well it can lead them to discontinue medication prematurely." This same pattern frequently occurs in adults with ADHD who become frustrated with their medication.

For medication to provide the optimal benefit that it can in helping to manage the core ADHD symptoms, there is an ongoing need to monitor, fine-tune, and make adjustments along the way. If parents of children with ADHD, as well as adults with ADHD, are made more aware of this process from the beginning, they will be less likely to become discouraged and discontinue medication.

Liz Baker's son will be off to college soon. The process of keeping a diary has been very beneficial—not only for guiding treatment, but also by increasing her son's awareness about how he feels at different times

and the important skill of communicating those feelings clearly and effectively to his doctor—all skills his mother has modeled for him through the use of a medication diary. "Over the years, he seems to have developed a good sense of self-awareness about how he

feels and whether or not he may be suffering from a side effect of a new medication," says Baker.

"As he's rapidly grown, we've had to either adjust the dosage or change to a new medication altogether, which is always a risky business," she explains. "Sometimes a higher dosage will be too much or a new medication can cause complications and uncomfortable side effects." Baker concludes, "He's very articulate when speaking to the doctor about any issues or side effects he may have, which inspires a lot of confidence in all of us about his ability to maintain his own care when he leaves home to go to college." O

What to track in your medication diary

- name of medication
- > dosage, time taken
- > duration of action
- > symptoms, behaviors
- > narrative of reactions, physical sensations
- > noticeable side effects
- > other concerns (such as blood pressure, pulse) if need to record is indicated