

Take Meds Faithfully

It's often referred to as the nation's "other drug problem." A surprisingly large number of people who are prescribed a medicine – including for a chronic illness – do not take it as directed by their doctor or pharmacist. Some people never fill the prescription. Some quit taking a drug before they are supposed to. Others forget to take doses. And some people take much less or more of a medicine than they should.

This lack of "adherence" or "compliance" – as doctors refer to it – is a substantial medical problem of its own. It causes unnecessary hospitalizations and suffering, hundreds of thousands of premature deaths per year, and tens of billions of dollars in preventable health care costs.

Doctors and drug companies (who have a large financial stake in the matter) have been trying to tackle the problem for decades. But studies show little progress. The consensus now is that it is a much more complex problem than previously appreciated, having to do mostly with hard-to-change human behaviors and fear of, or the experience of, medication side effects. Money also plays a big role: millions of people everyday are unable to take their medicines as directed because they simply can't afford them.

This brief gives you: (a) some background on the problem; (b) advice on how to talk to your doctor and pharmacist about your drugs; and (c) how and why to become a more responsible patient if you take medicines regularly.

BACKGROUND

While there is no overall statistic on how many adults who get a prescription fail to take it as requested by their doctor, most studies indicate that the number is around 45 to 55 percent. But in one recent large-scale survey of almost 77,000 adults, fully three-quarters who got a prescription in the previous 12 months admitted that they had not filled a prescription, skipped a dose, forgotten to take a drug, or taken less than the recommended amount.

Of most concern are people with chronic diseases. For example, one major study of the medical records of 17,000 people who had had a heart attack found that only about 45 percent were still taking a drug called a

beta-blocker one year after the attack. Beta-blockers substantially lower the risk of another heart attack and death and are generally prescribed to all heart attack victims. One surprising

finding from the study was that only 70 percent were taking a beta-blocker 30 days after their attack – indicating that 30 percent either never filled the initial subscription or stopped taking it very early.

Another recent study of people diagnosed with coronary artery disease (clogged arteries) found that only about 40 percent were faithfully taking three drugs now widely recommended for all such patients: a beta-blocker, a statin to lower cholesterol, and a type of drug called an ACE Inhibitor.

Other studies have found that from 25 percent to half of people with high blood pressure, high cholesterol, or diabetes stop taking their medicines as directed within a year or so.

People with mental health conditions are also highly prone to non-compliance. A recent study by researchers at the University of California, San Diego found that only 40 percent of schizophrenics were following their drug treatment regimen.



WHY IT MATTERS

The consequences of drug “non-compliance” can be serious. In one of the most thorough studies to date – of 31,455 heart attack survivors aged 66 or older – those who did not take their cholesterol-lowering drugs as advised, or stopped taking them, had a 25 percent higher rate of death after just two and a half years. In the same study, those who did not take beta-blockers as advised had about a 10 percent greater risk of death.

In the UC San Diego study referred to above, 35 percent of people with schizophrenia who did not adhere to their medicines had to be hospitalized compared to 14 percent who took their medicines as directed.

Big numbers get tossed around about the financial impact of non-compliance – in prolonged illness, extra medical costs, and worker absenteeism. The number often put forth by drug companies is \$100 billion per year. But, in truth, it’s very difficult to precisely assess the financial impact. There is little doubt it is substantial.

The three main reasons people don’t take medicines as directed are cost, side effects, and a perceived lack of benefit from the drug.

In a 2006 survey of 1,001 adults aged 50 and older by *Consumer Reports Best Buy Drugs*, 14 percent reported not filling a prescription because of cost and 15 percent said they had skipped doses because of the drug’s expense. One quarter were non-compliant due to side effects and 20 percent because they didn’t think the drug was doing any good.

Also relevant, nearly half of respondents reported having at least one experience where they asked their doctor to switch a medicine for cost-related reasons.

A study published in 2004 in the *American Journal of Public Health* and

based on surveys of 4,264 people over age 50 with at least one chronic disease found similar results: 18 percent reported cutting back on their medicines because of cost and 14 percent reported using less medicine every month than their doctor had prescribed.

In the most recent data on this issue, reported in August 2007, one in five seniors enrolled in Medicare (Part D) drug benefit plans had not filled or had

delayed filling a prescription due to cost in 2006. The finding was based on a survey of 16,000 seniors.

ENTRENCHED BEHAVIORS

Two other recent surveys – one of almost 77,000 adults and the other of 1,000 adults – focused more on the behavioral or “attitudinal” reasons

WHAT SOCIETY AND THE HEALTH SYSTEM COULD DO

Actions and changes that could help enhance drug compliance:

- No co-pays or cost-sharing (under insurance plans) on low-cost generic medicines deemed important for disease control and prevention, such as drugs to treat high blood pressure, high cholesterol, and diabetes.
- Adjustment of cost-sharing based on ability to pay and health risk. For example, heart attack victims could get drugs to prevent another attack at very low cost or no cost.
- Discount programs for consumers who renew their prescriptions on time.
- More and better outreach services to help get people who can not afford their medicines enrolled in pharmacy assistance programs.
- Toll-free telephone help lines to respond to questions about medication use, side effects, and interactions – staffed by pharmacists.
- More routine use and wider acceptance of mail-order prescriptions for people with chronic diseases. Mail order makes it easier to get refills every 90 days.
- Closer monitoring of refills by pharmacy benefit managers (PBMs), with follow-up of people who do not get refills on time.
- Calls or emails from your doctor’s office, pharmacist, or pharmacy benefit manager following up on your use of a drug, any side effects or problems, and reminding you when it’s time to get a refill.
- More use of special “pharmacy care” programs that help people with multiple chronic conditions manage their complex pharmacy needs. Studies have shown such programs highly successful in enhancing compliance.
- Daily emails, cell phone or PDA (personal digital assistant) text reminders to take your medicines as directed. (Some analysts think this might be overkill but in one survey 28 percent of consumers thought it was a good idea.)
- Wider use of electronic prescription pills boxes and reminder devices that can tell you when to take your medicines.

behind non-compliance. In the smaller survey, fear of side effects was widespread: 70 percent said they were “very concerned” about the side effects of taking prescription medicines on a long-term basis. In the larger survey, 30 percent reported not taking their medicines as prescribed for behavioral reasons. Among these were:

- I didn’t think I needed the medicine.
- I didn’t think the medicine was helping me.
- My symptoms went away.
- I felt better.
- I felt sick from taking the medicine.

Surveys also consistently find that a quarter to half of people who do not take their medicines as prescribed do *not* inform their doctors.

Doctors agree on the scope of the problem, and on the reasons people don’t take their drugs as prescribed. In one survey, 71 percent of doctors agreed with the statement, “my patients can not pay for all their medicines.” Sixty-two percent agreed that “my patients are taking so many medicines that it’s hard for them to take all of them properly.” And 26 percent

agreed with the statement, “my patients think they know better than I do what’s good for them.”

Non-compliance is also substantially due to the fact that many chronic conditions have no or few symptoms. In such cases, taking a pill everyday that may have side effects can actually seem like an irrational thing to do.

The two most often-cited examples are high blood pressure and high cholesterol. Unlike pain, asthma, allergies, or depression, most people with either condition would not even notice the effects of skipping doses or not taking their pills. And the affects of not taking the medicine would not be evident until they had a heart attack or stroke.

As doctors frequently complain, telling a patient this is one thing. But making them change their behavior if they experience side effects from a drug or can’t afford it is a quite another matter.

BECOMING MORE RESPONSIBLE

Taking your medicines as directed may be one of the most important health decisions in your life. It may spare you

discomfort, pain, disability, and unnecessary health care expenses. And it may prolong your life – in some cases for many years.

There is a lot that society and the health care system can and should do to address the compliance problem – especially as it pertains to the cost of drugs. (See the box on page 2.) But behavior change on the part of consumers/patients (and doctors) is critical.

The most important change is to get into the firm habit of:

- Having a full discussion with your doctor and/or pharmacist about any and all drugs you are taking – what they do, how critical they are to your short- and long-term health, how to take them, the side effects they may cause, and how to cope with any side effects. If your doctor seems rushed or reluctant to talk about these issues, ask him or her if you can set up an appointment devoted to understanding your medicines better and airing concerns.
- Contacting your doctor or doctor’s office if you experience side effects that are not tolerable, can not afford your medicines as prescribed, or are having trouble taking your medicines as prescribed.

On the cost front, your doctor and pharmacist may be able to substitute a less expensive medicine – a generic, for example – that will work just as well. If a less expensive drug is not an option, most pharmaceutical companies have assistance plans that will supply the drug for free or subsidize its cost for people with low and modest incomes. (See our brief titled “Prescription Drug Assistant Programs” at www.CRBESTBUYDRUGS.org.)

Be aware, though, that numerous studies have consistently shown that doc-



tors do not take the cost of medicines or a patient's insurance coverage into account when prescribing. In fact, they are often reluctant to bring financial issues up at all. As a result, it falls to you to do so.

Don't be reluctant. Ask yourself: would I rather be embarrassed to tell a doctor that I can't afford a drug or risk my health because I can't bring it up?

Also, be honest and open with your doctor about any fears you have and any lifestyle issues that could be obstacles to taking a drug as prescribed. As the survey results discussed above show, most people fear side effects. If your doctor and pharmacist know you are especially fearful about this, they can work with you to deal with the problem – for example, by calling periodically to check up on you.

We advise making a written list of issues to discuss with your doctor at every office visit. This should include an accounting of problems you have had in the past or have now with your medicines. Keep track of side effects in writing, too. The few hours a month you might spend making such notes will go a long way to making your visits with your doctor more productive. (More doctors these days are also open to email consults, which is a good way to report drug side effects.)

Most importantly, every doctor you see should be aware of *all* the medicines you take. Drug interactions have become a common and serious problem as more people (and especially seniors) take multiple medicines for chronic conditions. And this problem goes hand-in-hand with lack of compliance. As drug interactions raise the risk of side effects, people stop taking or cut back on one or more of their medicines.

Be sure to talk to your doctor about cultural issues as well if you are a member of a minority group. This has emerged as a serious impediment to drug compliance. For example, surveys show widespread stigmatization of people with mental illnesses among Latin Americans. This leads many in the Latino community to shun the drug treatment of depression, schizophrenia, and other psychiatric disorders.

GET WRITTEN INFORMATION – AND READ IT!

Talking with your doctor is critical, but we strongly advise also taking the time (it doesn't take long!) to read about your medicines, and especially the side effects they may cause.

This is much easier today. A wealth of information on prescription drugs is on

the Internet, just a few clicks away. The FDA Web site (FDA.gov) is a valuable primary source, as are medlineplus.gov and CRBestBuyDrugs.org. Advice: skip the "sponsored links" on most major search engine drug pages; these are mostly drug company-funded.

Unfortunately, doctors don't usually hand out written information on the drugs they prescribe. Pharmacists do, and reading that material is important. But it is not as helpful as it should be. That's because it is in part controlled by drug companies (which tend to underplay possible side effects) and also may not be as up to date as information you can obtain on the Internet.

Pill books – at books stores everywhere and many pharmacies, too – are a tried and true source of information. Take care to purchase one that has been published or updated in the last year or two. Even then, we advise supplementing information in books with information from Web sites.

Finally, new gizmos to help you take your medicines are proliferating. Electronic pill reminder devices are available at most large pharmacies and electronics stores. These are essentially elaborate alarms that can be programmed to let you know when it's time to take each pill. Some come attached to actual pill containers. Most cost in the range of \$30 to \$50. The Web site www.e-pill.com offers links to a range of these products.

We have not formally vetted electronic pill reminders and can not say whether they are helpful or not. Certainly, such devices would *not* be useful if you don't regularly use electronic devices, or have a disability that would prevent you from using one. In that case, a plain old non-electronic plastic pill box may work just as well.

THE SHOPPER'S GUIDE TO PRESCRIPTION DRUGS SERIES

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