Breathless

If you’re sick and tired of being sick and tired, check for anemia -- it’s easy to treat.

March 1, 1999 By Lark Lands, PhD

Just combing my hair was enough exertion to make my heart pound and leave me literally gasping for breath," says Kiyoshi Kuromiya, a Philadelphia treatment activist and February/March 1996 *POZ* coverboy. His weakness and fatigue made standing in the bank teller’s line out of the question. “I’d have to sit on the floor while waiting,” he recalls. A trip to mile-high Denver last July was the final breathtaking straw that led Kuromiya to an emergency room.

Was the diagnosis some rare, new lung infection, unsuspected by even this very knowledgeable PWA? No -- it was just plain old-fashioned anemia, a red blood cell condition experienced by more than three-quarters of those with clinical AIDS, and by about a quarter of those with less-advanced HIV disease. Unsettling statistics when you consider that a 1998 study of more than 3,200 people with HIV found that regardless of CD4 count, the risk of death was substantially higher for those with anemia. Researchers also found that recovery from anemia by whatever means significantly lowered that risk.

Unfortunately, anemia -- indicated by decreased hemoglobin or hematocrit -- too often goes untreated. That can mean needless symptoms -- fatigue, weakness, heart palpitations and shortness of breath -- and the reduced quality of life they bring. But be warned: Anemia may be present without these obvious symptoms, yet it may still create such problems as increased drug toxicity and reduced capacity for work and exercise.

The widespread lack of treatment for anemia disturbs Ronald Mitsuyasu, MD, director of UCLA’s Center for Clinical AIDS Research and Education. “The importance of treating severe anemia in advanced-stage patients is clear to all who manage patients with HIV,” he says. “What’s less often appreciated is the importance of correcting the mild to moderate degrees of anemia that may greatly impact patients with less advanced HIV disease.” He theorizes that many physicians concentrate on what they see as more pressing medical issues -- like reducing viral loads or treating opportunistic infections -- making treatment of moderate anemia seem relatively unimportant. And, he says, “Quality of life is not considered by all physicians.”

Mitsuyasu lists multiple treatable causes of anemia. They include fearsome opportunistic diseases (*Mycobacterium avium* complex [MAC], tuberculosis, parvovirus B-19 and lymphoma, among others), deficiencies of vitamin B-12, folic acid or iron, and HIV itself. For women, blood loss during menstrual periods can add to the problem. In addition, many drugs used commonly by PWAs

suppress bone marrow function and thus may cause anemia. Included are AZT, ganciclovir, sulfa antibiotics, alpha interferon, hydroxyurea, pyrimethamine, pentamidine and various cancer chemotherapies. In order to pinpoint needed treatments, careful identification of all contributing causes is a must.

Unfortunately, this can be trickier than it sounds. Some conditions can be difficult to diagnose. Labs may sometimes miss less common infections like parvovirus B-19. And nutrient deficiencies often go unnoticed because of doctors' lack of nutritional training, the inadequacy of blood tests or simply because such deficiency tests are not run. Larry Lyle, DO, an osteopathic physician with a large HIV practice in San Diego, has found that for some patients who experience the classic fatigue and weakness symptoms of anemia, treatment with B-12 injections and adequate folic acid (800 micrograms per day, given orally) have yielded impressive symptomatic improvement -- even when the initial blood test for B-12 showed adequate levels. And Lyle notes that B-12 deficiency can cause anemia-type symptoms that precede the appearance of red blood cell abnormalities. Researchers have noted that B-12 deficiency, although present in large numbers of people with HIV, may not show up with standard blood tests and does not always cause red blood cell changes.

Lyle's solution: "I look for all the possible causes of anemia, treat what I find, and then, if addressing other causes is insufficient to fully correct fatigue and weakness, I give B-12 and folic acid." He says that patients often bounce back with impressive returns of energy and feelings of well-being. Mitsuyasu also urges addressing all treatable causes of anemia (including substituting for problematic drugs where possible), but says, "In the majority of patients in the HAART era, no specific cause of anemia is found." Since HIV itself can impair the production of red blood cells, he emphasizes the need for effective antiretroviral therapy in anyone experiencing anemia.

Of course, this is a catch-22: Although suppressing HIV can sometimes result in improved red blood cell production, anti-HIV drugs are a frequent cause of anemia. For Kuromiya, the path to breathlessness began when, seeking to intensify his antiretroviral regimen, he added hydroxyurea to an AZT-containing combo. Since both of these drugs can suppress the bone marrow -- the place where the oxygen-carrying red blood cells are made -- it only took three weeks for his debilitating symptoms to appear. His hemoglobin and hematocrit dropped from the normal range to severely low readings.

This led to Kuromiya being hooked up for a quick transfusion of three units of blood, followed by long-term treatment with erythropoietin (EPO), a protein normally produced by the kidneys that promotes the production of red blood cells and that is often low in people with HIV. Injections of genetically engineered human EPO, scientifically termed Epoetin alfa (Ortho Biotech's Procrit and Amgen's Epogen), usually given three times per week (by self-injection, if desired), often result in resolution of anemia within four to eight weeks.

And that can mean a major improvement in quality of life, including marked improvements in energy and the ability to work. For Kuromiya, it means being able to carry on his demanding lifestyle as a treatment activist and journalist. "When my hemoglobin was in the toilet, I couldn't even walk 50 feet without resting," he says. "Keeping my counts normalized with Procrit has given

me back the energy and endurance I need to do my work."

EPO's effectiveness makes it Mitsuyasu's preferred treatment for all but the most severe cases of anemia. Although transfusions are sometimes necessary with severe and symptomatic anemia, he cites many reasons why they are problematic for PWAs. "Transfused blood can reduce immune responses by white blood cells, decrease production of the cytokines used for immune cell communication, and decrease activity of two immune system components, natural killer cells and monocytes," he says. "In addition, transfusion reactions, iron overload or transmission of blood-borne infections can occur." As if that's not enough, studies have shown increases in viral load after infusion of as little as one unit of blood (see "Bad Blood," *POZ*, May 1997).

EPO has been found to have none of these side effects, although it may cause a temporary rash. And note: For those with uncontrolled high blood pressure, it is advised that the blood pressure be controlled before beginning EPO; for those with inadequate kidney function, it is important to monitor blood pressure during treatment. With prolonged use, vitamin supplementation -- especially of folic acid and iron -- may be needed. And the drug's effectiveness may be blocked by opportunistic infections that involve the bone marrow, such as, most commonly, disseminated MAC. Luckily, EPO does generally work well for medication-induced bone marrow suppression.

The only likely downside of EPO is the huge hole it makes in the wallet of anyone who must pay for it. Depending on dosage and schedule, costs can run from $360 to $840 per week. (EPO is generally reimbursed by either private insurers or Medicaid, and both firms marketing the drug offer limited patient assistance programs.) One path to a potential price slash -- the 1997 University of California discovery of a protein that may significantly reduce the drug's needed dosage -- has so far been blocked because Amgen, the holder of several EPO patents, has declined the university's offer to license the invention.

Overall, though, EPO's safety, lack of side effects and ease of administration, especially when compared to the lengthy time required for blood transfusions, makes Mitsuyasu surprised that it's not used more often. "Even in those with mild to moderate anemia," he says, "erythropoietin may be given one to three times per week to maintain hemoglobin and hematocrit in the normal range, thus improving energy levels." According to Mitsuyasu, the bottom line is simple: "The appropriate use of this drug will undoubtedly allow HIV patients to live more active lives."

Kuromiya is an enthusiastic convert to the cause of heightened vigilance. "Oxygen starvation wasn't exactly the Rocky Mountain high I had in mind, and it definitely isn't something you'd ever want to experience," he says. "Always check for anemia -- especially if you've added drugs that whack the bone marrow -- and treat it quickly. Reserve your hard breathing for more fun activities."

HOW TO ID ANEMIA

Two blood tests tell all

Below-normal readings on either of two blood tests -- hemoglobin or hematocrit -- can indicate

anemia. (Note that normal values may vary from lab to lab.) Physicians strongly urge anemia screening as part of standard quarterly lab workups.

Hemoglobin (Hgb) is the iron-containing protein that bonds with oxygen, allowing the red blood cells to transport it through the body. In men, the normal range for Hgb is 14 to 18 grams per deciliter; in women, 12 to 16 g/dl. Any Hgb measurement below 10 is considered severe anemia, while readings of 10 to 14 g/dl in men or 10 to 12 g/dl in women indicate moderate anemia.

Hematocrit (HCT, also called Packed Cell Volume, or PCV) measures the portion of blood volume made up by red blood cells. In men, the normal values are 40 percent to 54 percent; in women, 37 percent to 47 percent. HCT readings below 35 percent in men or 30 percent in women indicate severe anemia, while readings of 35 percent to 40 percent in men or 30 percent to 37 percent in women indicate moderate anemia.

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