

An interview with medical rights champion Lynn McAfee

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LYNN MC AFEE is three weeks old, and her parents are panicking. Why has she gained so much weight and grown so long? Her large mother has already spent many painful years of her life battling her weight, and she doesn't want the same for her child. So it's off to the pediatrician's office.



The rest of McAfee's childhood continues much the same. She is either dieting or feeling guilty about not dieting. She is occupied either by a search for "illicit food" or by efforts to distract herself from hunger.

She is a fat little girl, and very physically active, running around the neighborhood like all the other kids. But unlike the other kids, food is an issue in her childhood home, and McAfee feels punished because she's fat. She also feels as if there's something wrong with her. Once, because of all the doctor appointments, someone asks McAfee if she is sick. "Well, yes," says the little girl, "because I'm fat."

MC AFEE'S PARENTS spare no expense in their effort to help her become thin. But nothing works. When she is six or seven, her pediatrician starts her on "cocktails" of rainbow-colored amphetamines. The combinations of dangerous medications make her feel crazy, but at least she loses weight. Every few months, she is taken off the pills because she develops a tolerance to them. Back comes the weight because of "rebound hunger": an urgent need to eat constantly after she stops the pills.

By the age of ten, McAfee is fatter than ever, even though her mother prepares healthy, balanced meals. As she approaches her teen years, McAfee becomes more desperate to lose weight. She tries everything: liquid diets, the gelatin diet, the safflower oil diet, the same-thing-every-day diet, the diabetic diet, the only-one-color-of-food-a-day diet, only fruit, counting carbohydrates, five

hundred calories a day, shots, Ayds candy, hypnosis, relentless exercise, and diet groups.

When the diets repeatedly fail the teenaged McAfee, it is *she* who feels like a failure.

She tries to kill herself.

It doesn't work. But something else happens. After the botched suicide attempt, Lynn McAfee realizes that she wants to live, even if she is going to be fat.

AT FOURTEEN, near-tragedy strikes again for McAfee when she almost dies from a ruptured appendix, undiagnosed until almost too late because she's afraid to visit the family doctor about the pain. On her last visit before her appendix burst, he said to her, "Look at you. You look like a G-d gorilla. Look at your thighs. Look at your belly."

MC AFEE is fifteen years old, eating two hardboiled eggs and two stalks of celery a day and a case of diet soda a week. She's taking lots and lots of Adipex (phentermine). McAfee's doctor knows she's taking much more than the recommended dose, but he reassures her that they'll worry about side effects when she gets thin.

But McAfee develops a tolerance to this drug, too. Despite the despair and almost incessant crying she experiences every time she stops taking medication, she decides that it's time to lose weight without them. "Without the pills, I got hungry like normal people," she says, "and ate like normal people, which was death to me. My body was so messed up from years of starvation and pill taking that if I went over a thousand calories a day, I gained a pound."

McAfee experiences a huge rebound weight hike once she discontinues her medication for the last time. She says, "There's not much worse for self-esteem than weight regain."

Enter psychotherapy.

By the time she starts seeing a therapist, McAfee is twenty-one and believes she is the "fattest, ugliest thing that ever lived." Refusing to treat McAfee unless she goes on a diet, the therapist devotes their sessions to flipping through

magazines to look for the hair, clothing, and makeup styles that are "appropriate" for McAfee while she's still fat. The therapist also insists that McAfee cut her hair, because, she advises, fat people really shouldn't wear their hair long.

The therapist places McAfee on a diet and makes her report her weight loss every week. But McAfee is noncompliant. Strangely, for the first time in her life, McAfee is unable to diet.

Along with the inability to diet comes a revelation. She has been living her life almost entirely in the future: "When I lose this weight, I'll get that job, take that vacation, find that man, go to that concert, let myself buy nice clothes, and like my body."

McAfee realizes that weight loss is probably not feasible, so she vows to feel good about herself nonetheless. She teaches herself to accept her body and to love it by retraining her aesthetics. "I decided to be as healthy as I could, no matter what my weight. It's the best I could do, and it's the least we all deserve.

IT'S 1970. McAfee lands a job in a medical library, fetching books for doctors. The job stirs up her lifelong curiosity about the medical aspects of obesity and her frustration with the lack of answers she's gotten to all her questions about her body and the way it functions. All around her is the material she needs to begin her research. "I thought one of those medical journals had the secret in it," she says.

But what she discovers is another secret, which only fuels her sense that she's been betrayed by the medical profession: since 1958, the failure rate of diets has been more than 95 percent. She is shocked that the researchers knew all this time that diets don't work, and she waits for the information to be disclosed.

But her waiting is in vain.

She asks a doctor why figures on the failure rate of diets haven't been divulged. His response to her is that no one wants to discourage people from dieting.

It's absurd, she thinks, to suggest that people do what is clearly impossible. She is incensed. "I spent my childhood and adolescence feeling like the lowest form of life because I couldn't do something as 'simple' as lose weight and keep it off." The bad news she's learned about dieting sets her free, because it puts her

in touch with all the rage she feels toward the sizeist society that has abused her.

In 1973, McAfee moves to Los Angeles and finds a group that has broken away from the local chapter of the National Association to Aid Fat Americans (NAAFA, now titled the National Association to Advance Fat Acceptance) and calls itself the Fat Underground. FU, its initials, signified, she says, the group's contempt for "thin" society.

Lynn McAfee is now Lynn Mabel-Lois, having replaced her surname with her mother's and maternal grandmother's first names as a sign of her feminist identity.

In 1970s confrontational style, the FU pickets and marches; invades diet group meetings, confronting the instructors about the diets' failure rates; disrupts and takes over university lectures and seminars; and speaks at political rallies. The FU make their presence and their objectives quite clear.

Still an activist, Mabel-Lois leaves Los Angeles a few years later. She continues the work on her own, and then she joins NAAFA. But soon she leaves NAAFA, along with NAAFA founders Bill Fabrey, Nancy Summers, and Paula and Neil Dachis, to form the Council on Size & Weight Discrimination (CSWD). The members of the CSWD seek to influence public opinion and policy on behalf of larger individuals through public testimony, letter-writing campaigns, and participation in national task forces and committees.

"When I was in the Fat Underground, I thought that if I just told the world they were wrong and showed them how they'd hurt us, things would change. They didn't. When I was in NAAFA, I thought that if I could help fat people feel better about themselves, feel more entitled to a better life, things would change. They didn't. So I decided to downscale my expectations. I realized that I had expected the world to move too fast, to go from A to Z in one or two short leaps. Through the council, I decided to concentrate on moving people from A to B.

"I've always operated on the principle that people aren't crazy: even doctors, even obesity researchers, and even the FDA. They have reasons for doing what they do, and for believing what they believe, and they believe that the reasons are good and logical ones. The reasons may not always be apparent to us, but there is an internal logic to what people say and do. We all have a responsibility as communicators to try to find the other person's underlying logic and

understand and respect it. When I locate that internal logic, then I can critique it. We can dialogue about what we perceive as reality, not just yell at each other or each think the other is crazy."

Through the years and the struggles to improve life for the large, McAfee has become far more concerned with finding the truth than with changing other people.

HERE ARE A FEW OF HER TRUTHS:

1. I get to exist as I am, fat or thin, healthy or sick, without apology.
2. There is currently no way to make fat people thin.
3. The evidence of the biological superiority of extreme thinness is contro-versial and weak at best.
4. Evidence that most people can be healthy and not disabled at very high weights is also not there.
5. Thin people are not superior, nor are fat people. We are simply different. Our bodies and our experiences in society are different.
6. There are no helpful stereotypes.

These truths are the foundation for McAfee's work as director of the Medical Advocacy Project for the Council on Size & Weight Discrimination. In that capacity, she attends meetings of the National Institutes of Health (NIH) Task Force on Obesity Prevention and Treatment and their consensus panels. She goes to the annual conventions of the obesity research organization North American Association for the Study of Obesity (NAASO) and the American Society for Clinical Nutrition. "Many times I can't stop what I see as wrong or harmful to us, but I believe that at least raising issues may make change easier in the future." One tangible consequence of McAfee's involvement is the NIH publication, of a pamphlet on exercise for supersize people. (See "[Medical Activism Resources](#)", which is compiled by Lynn McAfee.)

Through the Medical Advocacy Project, McAfee is reaching not only government agencies but also pharmaceutical companies and the general public. When Knoll Pharmaceuticals asked her to coteach a size-acceptance seminar for five hundred of their employees, McAfee persuaded them to refrain from using "before and after" pictures in their advertising. Knoll has since stated that it is considering taking a public stand against size prejudice in its ads.

McAfee published a two-part article on medical discrimination in the May and July 1998 issues of BBW entitled "Health Care Horror Stories." She also appeared in the fall 1998 PBS documentary by Antony Thomas on weight, which looked at current research as well as the theories and activities of people in the fat-acceptance community.

McAfee was invited to join a Federal Trade Commission (FTC) committee to develop voluntary business guidelines for weight-loss programs such as Weight Watchers and Jenny Craig. "The diet program folks are nervous about this. They're afraid they'll be out of business if people see the true costs of the programs. For example, Jenny Craig advertises twenty pounds for \$20. But if you buy everything you need to follow through with the program, it costs you over \$1000.

"People who are fat are desperate to be as thin as possible to avoid social prejudice and gain social privilege. The problem we face is that the behavior of many physicians and weight-loss programs has been so unscrupulous that we doubt they have either the ability or desire to assess the risks to some people in some cases.

"This project has been quite an experience for me. At the first meeting of the Voluntary Guidelines Committee, I sat at a table with the FTC and all the big diet program companies. We argued for three solid hours about whether to disclose the educational or professional backgrounds of company representatives who work with consumers. To this day, I have no idea what their objections really were."

WE ALL KNOW that myths and stereotypes about fat people abound. According to McAfee, the medical profession is responsible for inventing as well as maintaining many of the misconceptions that lead to the mistreatment of fat individuals. One misconception is that all our bodies are the same: that we all experience hunger and satiety in the same way and have the same metabolic processes. Thus if someone is thin, the assumption is that she has more discipline. McAfee explains, "Scientists now know that this is not true, yet this myth continues to be an important basis for size prejudice and discrimination."

Such untruths persist because of society's unwillingness to let go of archaic beliefs. For instance, many people think, despite mounting evidence to the

contrary, "that all large people are on the verge of death, simply because of their size." Other popular stereotypes by the medical establishment that have seeped their way into public opinion: all fat people have various psychological disturbances and develop diabetes, hypertension, heart trouble, and hemorrhoids. Fat women are infertile, give birth to deformed babies, and have irregular or no menstrual periods. And, McAfee adds, "My own personal favorite is that we're never sexually active and therefore don't need birth control.

"Like the majority of others in our society, health care professionals hold beliefs that express our culture's contempt for fat people. We are seen as intrinsically unhealthy. It's gotten so oppressive that it seems as if thin people are presented as the healthy master race and fat people are the sick, inferior race."

This is evident from the horror stories McAfee tells of in her *BBW* article. Here are a few examples:

A twenty-two-year-old woman is raped. While waiting for treatment in the emergency room, she hears two doctors arguing about who has to examine her "fat, disgusting body" and joking about whether her genitals are as fat as the rest of her. "People seem to feel," says McAfee, "that they have permission to act as though we are invisible and without feelings."

A woman's gynecologist palpates her abdomen so hard that it becomes uncomfortable for her. His response: "Well, if you weren't so damn fat, this wouldn't hurt. This is your problem, not mine!"

A child reports that her pediatrician threatened her the last time she was there: "You're too fat. If you don't lose weight, I'm going to put you in the hospital."

One woman reports that her fertility specialist is a bit confused. First he tells her that having a baby at her size would be irresponsible, that she is "far too big" to safely carry a baby, and that she should use birth control until she loses at least one hundred pounds. Then he says that she can't possibly ovulate at her size and will not even be able to get pregnant until she loses weight.

"We are told that we have our ailments because we are fat and that if we lose weight, our medical problems will disappear. While weight loss may help many conditions, we are sometimes given diet advice instead of the testing or treatments we need."

This substandard health care, McAfee believes, contributes to the higher mortality rates of larger people.

Another contributor to mortality rates is avoidance of health care. When large patients (especially women) are verbally attacked by their doctors, they simply stop going for examinations or treatment. McAfee says, "We are forced to suffer severe verbal abuse from angry and contemptuous physicians who seem to blame every condition we have on obesity. This abuse ranges from 'Take this medicine with food, which shouldn't be a problem for you,' to stopping a patient's young son on the street and telling him, 'Your mother is going to die' because she wouldn't go on a liquid diet, to telling a woman during a bungled gynecology exam, 'Well, probably no man would touch you, anyway.'"

McAfee recalls, "I've been yelled at and told I was subhuman many times. What's interesting about this is that at a certain point, it all becomes totally internalized. Even if a nurse or doctor doesn't say anything, the scale becomes the judge, which is one of the reasons fat people avoid medical treatment."

According to David B. Allison, Ph.D., a noted obesity researcher and assistant professor at Columbia University whom McAfee quotes in her *BBW* article, research indicates that women larger than a certain size are less likely to receive certain kinds of preventive health care. He says, "Some of this may have to do with the direct results of discrimination on the part of health care providers, and some of it may have to do with the discomfort of large women with seeking medical care in general or certain medical procedures in particular."

McAfee says that it is imperative that the medical profession begin to realize the part it plays in supporting and promoting society's prejudices. It's also imperative that researchers and health care professionals stop blaming the victims.

"Medical prejudice is something many of us encounter in our lives. How we handle it can make the difference between life and death. Both sides have to be involved in solving the problem. The medical profession has to study the problem and find ways of educating physicians and other health care workers. Women of size have to become aware that the problem is a social one, not a personal one, and continue to seek, and insist on, good health care."

In her statement given to the National Institutes of Health panel on methods for voluntary weight loss and control in 1992, McAfee spoke of her amazement at the inconsistency between knowledge and practice in the field of obesity

research. "We know that diets don't work, yet we continue to prescribe them and act as if there is only one cause of obesity, only one path this so-called disease can take, and only one treatment."

That was 1992. Today, diets still breed at a furious rate and continue to fail their devotees. Says McAfee, "Body size is not about dieting. It's about understanding individually who we are, where we come from environmentally, what our genetic potentials are, and our basic biology. How do we manage who we are in ways that make us happy and comfortable? For many of us, that's not ever going to involve dieting."

"I've gotten in touch with my issues around nutrition. The whole concept of nutrition was perpetrated on me by the diet industry. I've had to learn to give my body what it needs, not deny my body. That is something new for me. My growing-up years were about taking away from my body. Now, nutrition is not at all about cutting out foods, but about adding foods that my body needs. If I care about myself as a person and I want to take care of myself, I will give my body what it needs, not take away things that other people think I don't need."

When Redux and fen-phen came out, they were all the rage. Now, we find that the drugs have injured the health of many of their users, in some cases irreversibly. In the Council on Size & Weight Discrimination's statement to the public about its legal suit against the FDA to stop the sale of Redux and fen-phen based on insufficient testing of the drugs, McAfee wrote, "Fat people in this country often live very painful lives. We face the effects of prejudice and discrimination because of the size of our bodies. Most of the sales of these drugs have been to people who were seeking to escape this prejudice by whatever means necessary. I often receive mail from people who tell me they don't care if these drugs kill them, as long as they can be thinner, even for a while."

Why aren't the diet drugs working? According to McAfee, some are very outdated—though the current market hype might lead us to believe that they're new—and some have only a temporary effect. "The older drugs, which are more than twenty-five years old, work on the dopamine model. The body develops a tolerance to them and overcomes them. The newer drugs—the serotonin reuptake inhibitors like Zoloft and Prozac—have an anorectic effect in the beginning, but as soon as your body's weight maintenance mechanism kicks in, it overcomes the drug's weight-loss effect. We admit that we don't understand the basic mechanisms involved in obesity, yet we continue to develop drugs based on our imperfect knowledge and on our stereotypes about fat people and how we eat."

One of the personal truths that McAfee holds most dear is that there is no helpful stereotype, no matter where it comes from. After years of addressing the stereotypes that society at large holds about fat people, she is now asking the fat community to examine the stereotypes that we hold about our own. "We act as if all fat people are healthy and eating in healthy ways. We act as if there are no diseases or disorders we are subject to as fat people.

"On the other hand, in the public's mind, all fat people have eating disorders. *Fat* and *compulsive overeating* have become synonymous. It has long been a fight of mine to get the medical profession to see that, for some people, genetics have dictated that we have a certain body size, and that the amount we eat is appropriate to our size: it is not overeating."

Nor is obesity a disease, says McAfee. "The medical profession sees obesity as a disease. I see it as a made-up word. In the Fat Underground, we used to say, 'Dieting is the cure that doesn't work for the disease that doesn't exist.' Would I say that there are some people who have a disease or defect? Yes. But do I, just because I'm fat? No. My cholesterol is low, I have no diabetes. Not everyone who's fat has a disease. Obesity in itself is not an illness."

Neither is it a mental disorder, McAfee says, reflecting on her experiences with psychotherapy. "For many of us, therapists are just another way our culture enforces its standards of acceptable body size. I was taught early in life that because I was fat, I was mentally ill. The all-knowing therapist could help me understand why I was so aberrant, so willful as to want to eat."

So what is the truth when it comes to fatness?

"There are three aspects of being fat: genetics, basic biology, and environment. Genetics is the background. For instance, I probably would not be fat in a starving country, but I might be among the last to die of malnutrition. For people who are fat because of basic biology, when they lose weight, their bodies do everything to gain it back. As for environment, ask yourself if you grew up in a family that withheld food. That would make food much more important to you than it should have been. Or were you force fed? These environmental influences can have varying effects on what and how much we eat."

Despite the efforts of the size-acceptance movement to downplay the health risks of being supersize, McAfee has come forth about her problems with both sleep apnea, a disorder in which the sufferer stops breathing at times during

sleep and is thus fatigued during waking hours, and with obesity hypoventilation syndrome, a problem with exhaling. It has become difficult to breathe when she moves around a lot or has to stand to give lectures. She explains, "While some thin people do get this, the vast majority of people who have these problems are fat. Originally, I went to a pulmonary specialist who told me, 'Things don't work right. You have to lose a hundred pounds, at least, or you'll die.' That was it. He didn't even give me the name of the condition. I had to do my own research. When I found out that sleep apnea was associated with the hypoventilation problem, I decided to get my sleep apnea fixed. I had to work on my HMO to pay for it, which they did, and that's when I went to Virginia to the hospital-based program that I knew from my research would give me unprejudiced health care. Unfortunately, that program is no longer in existence.

"When I was told that the only thing I could do for the hypoventilation syndrome was to lose weight, I knew that it was a death sentence. Telling me that all I have to do is lose one hundred pounds and keep it off is the same thing as telling me that I'm going to die and there's nothing to be done. There was no way for me to lose one hundred pounds and keep it off. I knew that from my life. I knew that from the research I'd done on obesity. To me, that's just like saying, Go home and die. And that's what happens to a lot of people: they go home to a very long, slow death."

After her many years of involvement with size-acceptance and medical activism, and after working so diligently to dispel the myths and stereotypes that abound when it comes to fatness and illness, you might think that McAfee would have balked at the suggestion that she had a physical disorder associated with obesity. "It didn't bother me to find out that my obesity was causing some physical problems, because I'm aware that a lot of things are associated with obesity. I'm not going to feel ashamed about not being in perfect health. Why should I be defensive about this? Why should I be ashamed?"

McAfee was also dismayed to find out several years ago that she has an eating disorder. "I stopped pretending that I ate the exact amount of food my body needed, and realized that I ate a lot of food. I also found that I didn't make the food choices that I would have liked to make. I came to really understand the effect that my history of dieting had on my choices. When I realized all this, I really began to mourn for my past. I looked at it differently. Instead of fighting my weight and being defensive about it, I really mourned the person I could have been. For the dying I had done. For the life that I had had, and the easier life I *could* have had. I really got angry about the extent of the damage that had been done to me. Undoing diet damage is like telling a rape victim that

everything will be all right. Everything will *never* be all right again. I will never be the person I would have been if I hadn't spent all those years dieting. I can never go back and undo that damage: it's not possible. The best I can hope to do is manage that damage a little bit."

McAfee's discovery that she has an eating disorder came about when she checked into the hospital program to help her lose the small amount of weight that might improve her sleep and breathing conditions. "For the first time in my life, I was in a medical setting that was free of fat phobia and fat prejudice. This positive atmosphere enabled me to stop fighting the 'compulsive overeating' stereotype and look at the truth about myself, rather than relying on what others said about me. What I learned in my five weeks in a program that included anorexic and bulimic women and men is that my eating disorder is a function of the dieting oppression I suffered as a child. Anorexic and bulimic people are also responding to our fatphobic culture, and they understand that our struggle and theirs are tied. In a sense, my eating disorder was as appropriate a response as I could have had to my living situation. I have a disordered relationship to food as a result of the cultural overlay that's been put on me as a fat woman."

In a speech at the 1992 NAAFA convention, McAfee talked about a girl she met while in the hospital. "Her name is Brandy and she is twelve years old. She is a beautiful, sweet, loving fat girl who is harassed at home and at school because of her size. The staff told her that she is okay the way she is and that she should never diet again. She was taught to accept herself and to feel good about who she is, regardless of what she weighs. I cried for the little girl in *me* who never heard that she was okay, for the little girl who spent her life feeling like a failure no matter how much she accomplished, because she couldn't get thin. When I look at all the scars I have on my mind, body, and soul from a childhood of dieting, I vow not to let another generation of fat children suffer in silence."

McAfee asks us, "Do our childhood scars have to doom us to a second-rate life? Do we have to accept the stereotypes of a world that thinks we are all unhealthy binge eaters? Do we have to accept the size-acceptance rhetoric that says we are all healthy?"

For most of us, she says, the truth can be found somewhere between the two extremes. And it is only when we find our own truth that we can truly begin to define ourselves and set a course toward health and happiness. It is only then that we will have the strength to demand the medical care we need, to feel good about taking care of our nutritional needs, to give up any fears or guilt we have

about eating, and to be as strong and powerful as we need to be to succeed as individuals and as a movement."

IT'S 1998. Recent studies by obesity researchers reveal that most fat people with uncomplicated obesity do not live longer if they lose weight. Still, the latest balloon of weight-loss "magic" has been released, and it floats above the U.S. public: a new diet drug called Meridia. Just as news of the new drug arrives on the scene, another news report claims that there are 25 percent more "overweight" adults than was previously counted. The diet industry and medical profession are no longer using height and weight charts, but are now turning to a new system for determining "ideal" weight: the body mass index (BMI), which yields an increase in the number of those who are termed overweight adults.

Where is Lynn McAfee in all this?

In her early activist days, she was most interested in saying what she believed and getting her principles out to the world. Now, though, she's more interested in hearing what other people have to say. How is what they say different from what she believes? she asks herself. Then she asks herself, What is right and what is wrong with both belief systems? "Then," she says, "I try to find ways to move our 'opponent' just an inch along the continuum toward what I see as the truth, or perhaps a new version of the truth that is an amalgam of the information to which we all have access."

What she wants is movement. "Movement and change," she says, "no matter how small." ©

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www.radiancemagazine.com/issues/1999/med_act_resources.html

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