

THE LOW DOSE IMMUNOTHERAPY HANDBOOK

**Recipes and Lifestyle
Advice for Patients on
LDA and EPD Treatment**

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The History of Low Dose Immunotherapy

In the 1960s, Dr. S. Popper in England serendipitously discovered that when he injected his patients with what he thought was the enzyme hyaluronidase in an attempt to treat their nasal polyps, their inhalant allergies disappeared. When he was unable to reproduce the same results later, he determined that it was actually a contaminant in the first batch of hyaluronidase, the enzyme beta-glucuronidase, that was responsible for the phenomenon. After his untimely death, his colleague Dr. Len McEwen developed injections of very low doses of allergens combined with beta-glucuronidase which he dubbed Enzyme Potentiated Desensitization, or EPD.

EPD was used in the United States under an Investigational Review Board in the 1990s. When the IRB expired, delays were encountered in the submission of an Investigational New Drug (IND) proposal with the FDA. As a result, the FDA banned EPD treatment in the United States in April 2001. An IND application was submitted in the fall of 2001, but bureaucratic difficulties plagued the IND trial. Therefore, an American-made injection based on the same principle as EPD was developed.

The American-made injection is compounded in a licensed American pharmacy from American-made antigens manufactured in FDA approved laboratories. The antigens used are the same as in conventional allergy desensitization shots, but in very low concentrations. These injections are called LDA for Low Dose Allergens. In addition to common allergens, LDA contains uniquely American antigens which are not present in EPD such as cottonwood, sage, mountain juniper, some New World evergreens, American perfumes, avocados and other “American” foods, etc. American patients have had very good results with LDA, possibly because it is custom-made for the needs of American allergy patients rather than having been developed for the allergic exposures of the British. The author of this book has had better results with LDA than EPD, perhaps due to the more complete coverage of American antigens.

How to Live with Low Dose Immunotherapy

Being a low dose immunotherapy patient can take some getting used to. Every few months it may seem like your whole life is disrupted by your treatment. However, the good health you will enjoy after a few shots makes up for the inconvenience.

Low dose immunotherapy patients participate actively in their treatment by making necessary lifestyle and dietary modifications around the time of their injections. Your doctor and his staff will instruct you about “the rules” and their individual application to you. Your doctor should also give you a copy of the *Patient Instruction Book* (“the pink book”) to clarify the rules. Read this book very carefully several times, and ask your doctor or his staff any questions you have about the instructions in the book and how they apply to you. The two most helpful comments I heard from my doctor about the rules were, “The more you can do, the better off you will be,” and “Be careful, but not paranoid.”

Some low dose immunotherapy patients experience anxiety because they are afraid that they will, through forgetfulness or ignorance, neglect to keep one or more of the rules. Being organized, which is covered in the third chapter of this book, can help you not to forget anything and allay this anxiety. If you do accidentally break one of the rules, ask your doctor or his staff about it. Most of the time, unless a medication that adversely affects the shot is taken, these small diversions from the protocol do not cause major problems.

The application of the rules in the patient instruction book is an individual matter. For example, the book says that eczema patients may have difficulty avoiding creams and lotions and encourages them to discuss a way around this rule with their doctors. If you have eczema, your individual needs and sensitivities may change how the rules are applied for you. Your doctor also may vary how the rules apply to you with other medical conditions and in consideration of the severity of your allergies. The length of time you must avoid various substances before and after a shot may vary from person to

person. The “Timetable for LDA” in recent editions of the pink book indicates this variability by using X’s on the days when everyone should avoid a substance and using parentheses on the days for which you should ask your doctor if you need to avoid that substance.

Non-medical rules issues should also be discussed with your doctor. For example, when I started treatment I was concerned about having to avoid laundry detergent for a few days at shot time because my younger son was a five-year-old then and he liked to change his shirt every time he got a speck of food on it. I asked my doctor if I could use my usual brand of unscented hypoallergenic laundry products, and he said, “Yes.” (Please ask your doctor which laundry detergents are acceptable for you as this can vary with your level of chemical sensitivity). Discuss any questions or concerns you have about the rules with your doctor. Both the patient instruction book and this book were written with the most sensitive patients in mind.

Low dose immunotherapy is not a quick, easy cure for your allergies and you may have ups and downs in how you feel as your treatment progresses. The patient instruction book says “Do not be discouraged if...” in more than one place, but each time I was in one of those situations, I found that I was discouraged. Reassurances from my doctor and his staff that how I was feeling was normal for the stage of treatment I was in were very helpful. Call your doctor's office if you have concerns. They may be able to help, and if what you are feeling is not normal, they should know.

Another help for discouragement is having a friend, hopefully one who is a positive person and is a few shots ahead of you in treatment, with whom to correspond or talk to on the phone. Hearing that your friend actually did survive the “downs” and went on to reach new “ups” will make you feel better mentally immediately while you patiently wait to feel better physically.

Perhaps the best way to cope with discouragement is to prepare for it in advance. When we put so much effort into our treatments, we want to get better immediately, but for many patients, it takes time to achieve good results, especially with food allergies and chemical sensitivities. Knowing this in advance will help. Also, even the best

shots wear off, especially in the early stages of your treatment. When my son took his first shot at age eleven and was able to eat everything without having eczema problems two weeks after his shot, I warned him that it might not last until his next shot. Then our doctor told him the same thing. He asked me, “Why do you guys keep telling me that?” I replied, “So if or when it happens, you won't be upset.” When it happened, he was able to cope much better than some adults do.

Finally, keep your eyes on the goal of good health and the times when you will feel better. About the time my son started low dose immunotherapy treatment, we regularly listened to a radio station that played his favorite songs while riding in the car. There was one song which we heard occasionally; we turned up the volume whenever it came on because its message was meaningful to us as low dose immunotherapy patients:

“I can see clearly now; the rain is gone,
Gone are the obstacles that were in my way.
Here is the rainbow I've been waiting for,
It's gonna be a bright, bright, sunshiny day.”

Look forward to and enjoy the sunshine of relief from your allergies!

Getting Organized

Trying to follow the rules in the patient instruction book can be daunting, especially when you first start treatment. If you are organized, you will find it easier to remember and follow the rules and to prepare in advance for some of the circumstances that may arise in the course of your treatments. Also, since many patients must travel to get their injections, organization helps make the trip go more smoothly.

Some patients may experience hypersensitivity or a lack of energy after their shots. If you are among this group, it is helpful to plan your schedule around the times when you may not be in top condition. Before your shot, cook and freeze the food you and your family will need the week or so after your shot. Shop ahead of time for items you will need during the period when you may be hypersensitive. Plan your work schedule to avoid exposures as much as possible. Stay home as much as possible during your hypersensitive period, and have plenty of old books, videos, correspondence, paperwork, or needlework to keep you occupied during this time.

If you travel to get your shot, preparing food to take along on the trip is very important. This is not the time to try to find a restaurant that has something you can eat after you reach your destination! Marge Jones, editor of the *Mastering Food Allergies* newsletter, cooks ground lamb and sweet potatoes and freezes them in small, one-serving-sized jars for her trip. One patient I know who stays overnight when she and her family get their shots takes along a crock pot and ingredients to make stew when they arrive at their motel. (See the crock pot stew recipe on page 22). Suggestions for other foods you may want to take on your trip are listed on page 15.

Chemically sensitive patients should plan ahead for chemical challenges such as restrooms that they may encounter while traveling. In order to avoid using scented soaps in restrooms, take wet wash cloths in plastic bags with you and use them to wash your hands after you leave the restroom. (This also will minimize the time you spend

in the restroom). Be sure to provide your traveling companions with unscented soap to use in the restroom so they don't carry a perfume scent back to you on their hands after a rest stop.

If you must spend the night away from home when you get your shot, finding an acceptable place to stay can be a challenge especially if you are chemically sensitive. Ask your doctor for suggestions for where to stay. When you go to the city where you will take your shots for your initial office visit and testing, stay in one of the places your doctor suggests, and check out the other places if you are having problems where you are staying. Many motels and hotels will make special arrangements to clean your room with Bon Ami™ or baking soda and air it out before you arrive if you ask them to.

I have found it very helpful to have a “To Do List” to help me get organized and remember what I need to do before each shot. A sample of this list follows below. Many items on the list may not apply to you, and the list may not include things that you *do* need to do. This list is just given as an example for drawing up your own list which will help you to be organized, get everything done, and not worry that you have forgotten something.

SAMPLE “TO DO LIST”

4 to 6 weeks before your shot:

Order any special foods you need for your shot. (See “Sources,” pages 77 to 78 and 82, for suppliers of game meat, tuber flours, etc).

Order gloves, soaps, cleaning supplies, and supplements. (See “Sources,” pages 80 and 81).

Make any necessary travel arrangements or reservations.

Gather materials and supplies for reading, letter writing, needlework, etc. if you plan to stay home and do such projects after your shot.

If you would like to read a new book and are chemically sensitive, ask your doctor how long before your shot it needs to out-gas.

Shot-Time Diet Baked Goods

The basic shot-time diet does not include any grains but it does include starchy foods that can be used as bread and cereal substitutes. One of the most important practical questions I asked as I prepared for my first shot was whether Special Foods' cassava and white sweet potato flours and baking powders would be allowed on the shot-time diet. When the answer was "Yes," I had bread! (See ordering information for Special Foods on page 82).

Foods from Special Foods are expensive, so you may wish to live on vegetables, lamb, rabbit, venison, and fish around the time of your shot. However, if you are allergic to the shot-time diet meats, foods from Special Foods and the fresh starchy tubers they are made from may give you something substantial to eat. Also, tapioca flour (also called tapioca starch or tapioca starch flour) is not expensive, so you can use the tapioca wafers, below, to add some crunch to the basic diet whatever your budget is.

Tapioca Wafers

These wafers add a starchy food to the shot-time diet for a reasonable price but can be challenging to make. They are affected by weather, humidity, variations in the flour, and the type of baking sheets used. If your wafers come out too hard to chew easily, try microwaving them for a few seconds or dunking them in boiling water or rhubarb tea.

1¼ cups tapioca flour
¼ teaspoon sea salt
½ cup plus or minus 1 tablespoon bottled water

Combine the flour and salt in a bowl. Stir in about ¾ cup of the water. The dough is difficult to mix; you may have to stir it and then let it rest a few seconds, then stir and let it rest, etc. Add the remaining 1 to 3 tablespoons of water one tablespoon at a time until the

About the Very Mixed Diet

There are two situations in which the very mixed diet (VMD) – a formal system of eating a little bit of a lot of foods at each meal – can be helpful to low dose immunotherapy patients. The first is when patients “unmask” or experience symptoms due their body’s rapid shift in response to their second or third shots or sometimes later shots. The second situation is when a very mixed diet is required to control post-shot hypersensitivity symptoms.

If your doctor suspects you are unmasking, he or she may give you a handout about Dr. McEwen’s VMD which explains how it works as well as giving the formulas for the food mixtures Dr. McEwen prescribes for his unmasking patients to eat. If you do not have the handout, a little explanation here might be helpful.

The basic principle behind the VMD is that for every allergen, there is a particular dose of the allergen that causes the maximum reaction. A larger dose, especially if it is eaten at four or five day intervals in a rotation diet, will not cause symptoms. (Thus, foods that we consider our safest foods because we eat them on a rotation diet without problems are not actually foods that we are not allergic to). If one were to graph the strength of an allergic reaction versus the dose of the allergen, the graph would be a curve with a high point in the middle and low points (no symptoms) at both the high and low ends of the dosage scale. On a rotation diet, we are eating an amount of the food that is “above” the peak of the tolerance curve. As treatment progresses, the curve shifts to the right. Now the amount of food we were eating without symptoms is in the part of the curve that is the highest on the strength of the reaction. Thus, the solution is to eat on the other end of the curve – to eat foods in very small quantities. In order to get enough to eat, you will need to eat several to many foods at each meal (I was told that nine was the minimum number) in very small amounts. As the shot “ripens” or, for some patients, with subsequent shots., the reaction high point of the tolerance curve moves farther toward the high end of the dosage

scale, and normal-sized servings of the food will be tolerated without causing symptoms once again.

For any allergen – inhalant, food, or chemical – LDA or EPD treatment does not eliminate your allergy to that substance. What it does is make the dosage required to provoke a reaction 10 to 1000 times higher than the dosage that caused symptoms before the patient began taking low dose immunotherapy shots.

The VMD, as it was originally developed by Dr. Len McEwen, is based on a specific set of fairly common foods. Many EPD and LDA patients I have talked to who have been put on the VMD by their doctors react to one of more of the standard VMD mixtures. The grain mixture is usually the most problematic, followed by the meat mixture. Therefore, these patients must find other “safe” foods to substitute for the foods they are reacting to in the standard mixtures, or they may need to “start from scratch” and eat many rare or exotic foods that they have not eaten much in the past in 1 teaspoon to 1 tablespoon amounts at each meal. Thus, they are following the principles of the VMD rather than the specific details of Dr. McEwen’s VMD. For more about this type of VMD, see the next chapter.

Using the VMD for unmasking is a balancing act, and the balance can change from day to day as your shot ripens or wanes. However, with subsequent shots, you should reach a stable place. In the meantime, do not get discouraged. Do not be concerned if you cannot follow Dr. McEwen’s VMD as written, or even the VMD that seemed to work for you a few days ago without reaction. If you can add more foods, thus eating each food in smaller quantities, that is one way to improve your tolerance for the VMD. Another variation on the VMD that may lessen your reactions is Dr. Shrader’s “crazy rotation” which is described in the LDA patient instruction book. It is basically having at least three sets of at least nine foods, and eating one set of foods in VMD quantities for all meals on day one, the second set on day 2, and the third set on day 3 of your crazy rotation cycle.

For more tips on using the VMD and for improving your tolerance for it, see pages 46 and 70 to 71.

Your Personal Very Mixed Diet

This chapter contains ideas that you can use as a springboard for devising your own personalized VMD. Be sure to discuss these ideas with your doctor before implementing them.

I have used a personalized “exotic” VMD for a few weeks around my shots (not including the critical three days, during which I use a glycerin solution) for years as a way to deal with post-shot hypersensitivity. Because I may begin reacting to a formerly “safe” food after using it at shot time for several shots, and also because the foods I eat are so exotic that I can’t buy more easily on the spur of the moment, I never mix the foods. Instead, I put a small (less than 1 tablespoon) amount of each separate food on a plate, cover it with paper towel, and microwave it to make my meals. By eating this way, if I seem to be reacting to my meals, I can remove foods one at a time until I find the offending food. Then all that is wasted is that one food, not everything I was planning to eat.

This is a pretty boring way to eat, I admit. I have talked to satisfied VMD users who make crock pot stew using several types of game meat and a dozen or more vegetables. They eat this every day for every meal, but find it more appealing than small bits of food arranged separately on a plate.

The bottom line advice for those of you who are working out your own VMD or other around-shot-time diet (such as eating exotic, page 38) is two-fold: (1) Eat all foods in small quantities and eat as many foods as possible to avoid reactions and sensitizing to new foods, and (2) As Dr. Shrader told me years ago, “Do whatever works.” Each of us is an individual with unique allergies and reactions. You are the only one who can ferret out what foods might be causing you problems. Talk to your doctor (who might tell you “Do whatever works”) and then experiment, keeping the quantity of each food small, until you find what works best for you. Keep in mind that if you are using the VMD for unmasking, you WILL get through it sooner than you might think.

Notes and Tips

On leavening: Non-yeast baked goods are leavened by mixing an acid component, such as vitamin C crystals, with a basic component, such as baking soda. For three weeks after an injection, low dose immunotherapy patients must restrict their intake of vitamin C to 500 mg per day. Therefore, they must either keep track of how much vitamin C they are consuming in baked goods and stop eating them when they reach their vitamin C limit, or they should use a substitute acid component for leavening, such as cream of tartar, rhubarb concentrate, lemon juice, or lime juice (if tolerated).

To substitute cream of tartar for vitamin C powder or crystals, an approximate rule of thumb is to use 1 to 1½ times the amount of baking soda called for in the recipe. For example, if your recipe calls for 1 teaspoon baking soda and ¼ teaspoon vitamin C, use 1 teaspoon baking soda and 1 to 1½ teaspoons cream of tartar. Mix the cream of tartar with the dry ingredients. If the recipe contains fruit, slightly less cream of tartar may be required. Cream of tartar is highly purified potassium bitartrate crystals. It is made with a byproduct from wine-making. Because of its purity, it usually does not cause problems, but patients who are highly sensitive to grapes or brewer's yeast may want to keep its original source in mind and use rhubarb concentrate for the acid component of the leavening process instead.

To substitute rhubarb concentrate (recipe on page 36) or, if you are not allergic to citrus fruits, lemon juice or lime juice for vitamin C crystals, a rule of thumb is to use three times the amount of baking soda called for in the recipe. For example, if your recipe calls for 1 teaspoon baking soda and ¼ teaspoon vitamin C, use 1 teaspoon baking soda and 3 teaspoons rhubarb concentrate, lemon juice, or lime juice. Mix the rhubarb concentrate or lemon or lime juice with the liquid ingredients. The amount of other liquids may need to be decreased in the same amount as the liquid leavening that you add. If the recipe contains fruit, slightly less rhubarb concentrate, lemon juice, or lime juice may be required.

To use calcium phosphate for leavening, see pages 72 to 73.

On using fructose or glycerin rather than the shot-time diet: Patients who are sensitive to all or almost all of the foods on the shot-time diet may be advised by their doctors to use a fructose or glycerin solution rather than the shot-time diet around the time of their shot. Glycerin is metabolized like a fat and fructose is metabolized more slowly than other types of sugars, so they should not cause major swings in blood sugar levels like sugar can. My personal experience with using the fructose and glycerin solutions was that it is not as difficult as I had expected it to be. Mixing the fructose or glycerin with hot water may be more satisfying than drinking the solution cold. Or you can make “slush” by mixing ¼ cup of bottled water with 4 teaspoons fructose or glycerin in a food processor and adding a tray of bottled water ice cubes one at a time until all are finely blended. It is advisable to eat lightly when you return to eating after being on the fructose or glycerin.

On margarines that were used on the EPD diet: Two types of margarine, Granose™ and Tomor™, are allowed on the EPD diet. In the 1990s, Klaire Labs, the makers of Vital Life™ vitamins, imported Granose™ margarine from England for use by American EPD patients. After the FDA shut down EPD in 2001, Klaire Labs stopped importing it. When LDA became available, several small American companies looked into the possibility of importing Granose™ margarine again but found that they would have to import so much that they did not have the facilities to store it frozen until it was sold. However, there are distributors who will sell Tomor™ margarine in smaller quantities and it is possible that it could be imported by a small company in the future. Therefore, the recipes developed in the early 1990s which included the margarines which are acceptable on the EPD diet have been left in this book with options added for making the recipe without the margarine.

On keeping yourself from using lotions, cosmetics, etc. without thinking around the time of your shot: Keep a small brown bag in the cabinet under your kitchen and bathroom sinks. Before your shot, remove hand lotion, soaps, makeup, toothpaste, etc.

from their usual storage places and place them in the bag. After your shot, store your Magick Botanicals™ or Simple™ soap and shampoo, baking soda for brushing your teeth, etc. in the bag, where they will be all ready to go for your next shot.

On newspapers and glossy magazines: The evening of two days before our shot, we remove all newspapers and most magazines from our house. We put the TV schedule and any magazines that we do not want to throw away in well-sealed plastic bags.

On cleaning products: It is important to use the proper cleaning products and equipment when you clean before your shot. You are not helping yourself if you remove the dust and mold from your environment but leave toxic chemical residues in their place! Always use unscented products such as Bon Ami™ and SuperClean™ (see “Sources,” page 80) for general cleaning. To eliminate mold, use a citrus extract product such as NutriBiotic™ (“Sources,” page 80). You can dilute it 30-60 drops to 32 ounces water (or ¼ to ½ teaspoon NutriBiotic™ to 32 ounces water, rinsing the spoon into the water) in a spray bottle and use it to spray down showers, etc. To leave a stronger anti-fungal residue on the inside of your refrigerator, put several drops on a barely damp cloth and use that side of the cloth to wipe down the refrigerator walls. If you are allergic to dust, you may want to consider getting a vacuum cleaner which filters the air before returning it to your environment.

On garbage disposals: Garbage disposals are never completely free of bits of the food that has been ground in them. Bacteria and mold can easily use this food to support their growth, especially in warm climates or at a warm time of the year. Before your shot, see if there is a moldy smell after pouring boiling water in the disposal side of your sink. If you do detect this smell, or if your house is warm, clean your garbage disposal with natural cleaners in this way: First, mix some dish soap and warm water. Dip an old toothbrush in it and brush the back side of the rubber splash guard at the top of your garbage disposal. You may notice black “crud” on the toothbrush. If

so, rinse the toothbrush, dip it in the soap solution, and scrub the splash guard again, repeating until the toothbrush is clean after scrubbing. Cut a lemon in half. Throw a handful of baking soda and the cut lemon in the garbage disposal and grind them down.

On polishing furniture: I prefer to polish furniture with lemon oil during non-shot months, but if you feel you must use something on your furniture close to the time of your shot and your doctor allows you to, use an all-natural, non-petrochemical product like pure lemon oil. (See “Sources,” page 81).

Tips for improving your tolerance of the very mixed diet: When the very mixed diet is used to deal with “unmasking,” the amount of each food in the mixtures eaten is important. You may find that you react less if you eat several mini-meals of the very mixed diet per day rather than eating three more normal-sized meals. If you use a small dish for your mini-meals and it is fairly full, you won't get the feeling of being deprived that you may get from seeing very small amounts of several mixtures on a regular-sized dish. Also, the greater number of foods or VMD mixtures you eat per meal, the better you may feel.

If you find that you do not tolerate one of the mixtures, even in very small (1 teaspoon to 1 tablespoon) amounts, you may wish to experiment with the component ingredients. With your doctor's approval, try substituting another ingredient for the one(s) you suspect may be the greatest problem for you. (However, keep in mind that Dr. Shrader says that sometimes you may need to eat small amounts of your most problematic foods to feel better). For instance, although I was allergic to all of the meats in the VMD meat mixture, beef, chicken, and venison had been more major problems for me than rabbit, pork, and lamb. When I had trouble tolerating the meat mixture, in order to have at least four meats as the diet specifies, I used pork, lamb, rabbit, and turkey, and found that I could tolerate the mixture in small amounts. Another option for a meat mixture is to substitute four ground game meats, such as kangaroo, venison, antelope, and buffalo. Another “exotic” meat mixture I have used

after shots consists of a mixture of small pieces of cooked rattlesnake, alligator, and frog, which are good rolled in a mixed exotic tortilla. (See the tortilla recipe on page 47). For recipes for cooking snake, alligator, and frog, see *The Ultimate Food Allergy Cookbook and Survival Guide*. (For more information about this book, turn to the last few pages of this book). If the VMD grain mixture (page 52) or VMD flour mixture (page 51) is a problem for you, consider using the non-grain flour mixture on page 47.

Some patients make a crock pot stew of 20 to 30 of their safest vegetables and meats to eat for all of their meals after their shots. Another variation on the principles of the VMD is Dr. Shrader's "crazy rotation" which is described in the LDA patient instruction book and on page 45 of this book.

On skate and the VMD fish mixture: Although Dr. McEwen's VMD calls for skate in the fish mixture, it may be difficult or impossible for Americans to obtain skate for the VMD. In that case, with your doctor's approval, substitute a kind of fish that you do not suspect to be a major problem for you and/or that you have rarely eaten for the skate in the fish mixture.

On boning meats for the VMD: If you are using chicken or rabbit as part of your VMD meat mixture (page 53), you may be spending a lot of time boning meat. To simplify your work with chicken, call around to stores in your area; you might be able to find frozen ground chicken. If you are using rabbit, you may wish to just remove about 80% of the meat from the bones, and then bake the bones with a little water in a covered dish at 350°F for 1 to 1½ hours. Remove the rest of the meat from the bones after cooking and grind it in a food processor. Combine each 5 ounces of cooked ground rabbit with 8 ounces of each of the other meat you are using. Proceed with your recipes as if all of the meats were raw. If you are really pressed for time, you can cook the whole rabbit, remove all of the meat after cooking, grind it, and mix it with the other meats in 5 ounces cooked to 8 ounces raw proportion.

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