What's So Tough About Home Repairs, Maintenance And Construction?

It's not easy when you're living with a family member that has chemical injury.

by Michael and Judy Stouffer

Finding materials, techniques and equipment that are safe for the chemically injured is a difficult job. By its very nature, there are unanticipated and unavoidable delays. Gyrations that are undreamed of for the healthy are essential when remodeling a home for the chemically injured. Here are a few common examples of challenges that we know about or have run into ourselves that are outside of the experience of most healthy people. We've chosen to use some analogies with everyday experiences to help "make real" some of the challenges that these projects must address.

Issue #1: Nails don't come with an ingredients list the way that food does.

Analogy 1: Reading Food Labels.

There are at least half a million patents for chemicals granted by the U.S. Patent and Trademark Office. Each of these chemical inventions is "new, useful and unobvious", or it wouldn't have been granted a patent. Depending on how you count the number of chemicals covered, there are millions of chemicals described by these patents. In fact, there are over 370,000 different chemicals listed just in the National Library of Medicine's ChemIDplus database (http://chem.sis.nlm.nih.gov/chemidplus/chemidlite.jsp). If a person had sensitivities to only a handful of these chemicals, say one out of 1000, this would make the person sensitive to at least 370 chemicals in the ChemIDplus database and probably thousands more that aren't listed in the database. The hazards of each of these hundreds upon hundreds of chemicals must somehow be avoided by a person sensitive to them.

The analogy here might be like reading the ingredients list of your favorite food. Twinkies, for instance, contain a long list of chemical additives from "*Polysorbate 60*" to "*1H-Pyrazole-3-carboxylic acid, 4,5-dihydro-5-oxo-1-(4-sulfophenyl)-4-((4-sulfophenyl)azo)-, trisodium salt*" (FD&C Yellow No. 5). Some people can't tolerate certain food chemicals. Others can't tolerate certain natural food substances: anaphylactic reactions (possibly deadly) to peanuts and shellfish are examples of this. Reading the food labels is a time-consuming activity, but it's an essential everyday task for people with known food-based sensitivities.

The same is true for building materials, techniques and equipment for the chemically injured. "Reading the Labels" is a "must" for building a safe and healthy house for the chemically injured. Each item, from paint to nails to shingles to drip edge to flashing has the potential to contain or have been coated with dozens of modern chemicals. When you pick up a package of nails at a big box store, it doesn't list what it's made from. It takes time to contact manufacturers and get "ingredient lists." That information helps winnow out items that are made with a chemical that's a known problem for the chemically injured person. After that, however, the item still must be tested. There is always the possibility that the item might contain an "unlisted" chemical that is seriously unhealthy for the chemically injured person.

Issue #2: Resources are limited by what's known to work and already available, not by what's sitting on the shelf at the hardware store.

Analogy 2: The Apollo 13 rescue.

When you're in a spacecraft, you are limited to the materials and equipment that are on hand. You must think ahead, before launch, about what you are going to need. You can't just run out to the hardware store to buy something you've overlooked, once you're in space.

An incident in the movie *Apollo 13* involving a buildup of CO_2 inside the spacecraft illustrates this. Because of the change in operations on the disabled Apollo 13 spacecraft (the crew had to live in the lunar lander), the air became saturated with CO_2 gas, endangering the life of the crew. NASA engineers were given the task of creating a makeshift air filter with only a limited list of parts that were already onboard the spacecraft. There was no option of "running to the hardware store" to buy other parts. The engineers were successful, and saved the lives of the crew.

With construction for the chemically injured, initial plans most likely will require materials, techniques and equipment which cannot be tolerated by the chemically injured person. On the other hand, if you start to design with only a limited supply of materials and equipment (like with the Apollo 13 challenge), designs will likely not meet code or standards for acceptable workmanship, or the requirements of the homeowners themselves. The inevitable result is a design that goes back-and-forth between a wide number of alternatives, similar to traditional "cut-and-try" designs. Unlike most "cut-and-try" designs though, the number of "tries" is much, much larger because of the need to examine a greater number of alternatives to come up with a workable solution. The large number of alternatives needed to satisfy all of the requirements and constraints greatly increases the amount of planning involved in the project. The need to stop work-in-progress and re-assess the alternatives when snags occur, can also significantly increase the work effort and slow down the project.

Issue #3: Finding safe products isn't an easy or safe process

Analogy 3: Who wants to be Stuck with a Needle?

When we get to a snag in a maintenance or construction project, we just might be able to get around the problem with materials, techniques and equipment that we already have. Oftentimes though, something new is needed. There are thousands of products available at stores that can help in this case: nails, flashing, plastic, paints to name a few. But for the chemically injured, many of these are off-limits. Worse, it's difficult to know ahead of time which products are problematic and which are healthy. When there's no way to work around using new materials, techniques or equipment, these must be tested for health effects first.

Testing materials means exposing the chemically injured person to a potentially harmful substance. Testing for harmful substances then, might be likened to sticking yourself repeatedly with a needle, just to stay healthy. A diabetic may do this every day, with insulin injections, in order to remain relatively healthy. But for the chemically injured, the experience is more like sticking yourself with a needle and hoping that it doesn't result in the pain and slow healing of a bone marrow punch instead.

Remember also, that the chemically injured person is disabled in many ways, and most likely undergoing treatments of some sort. There may be long periods of time where the chemically injured person is simply unable to test at all because they are too ill to do so. Also, it's practically impossible to test more than one material at a time, because of the complexity of figuring out which one of multiple substances caused what kind of reaction. And, testing can't go on continuously month after month either, because of the deep weariness that develops from constantly "sticking yourself with a needle." The testing process, though necessary, is a major contribution to the apparent stop-and-start nature of construction for the chemically injured.

Issue #4: Testing new materials isn't the only thing happening - all sorts of other daily life activities must go on simultaneously

Analogy 4: Lessons learned from Aircraft Carrier Flight Decks.

We've already talked about intentional exposure to chemicals that accompanies the testing of new materials, techniques and equipment. However, in the ordinary course of living the chemically injured person is also exposed unintentionally to unhealthy chemicals. These unintentional exposures may be minor, requiring relatively short recovery times. Or they may be setbacks that take weeks or months of recovery. They may come from completely unforeseeable sources. Or they may come from changes in composition of existing products (batch-to-batch variations or new production techniques), contamination of the products in shipment, or from other known, but uncontrollable sources. Sometimes the source of the exposure can be easily contained, and sometimes there will be extensive cleanup of the offending substance.

The book "Managing the Unexpected" talks extensively about organizations that handle the unexpected well, or at least better than most. Crucial norms of thinking and acting are intentionally emphasized in these organization. Some of these norms are *mindfulness* at all times, *tracking small failures* (for instance, seeing near misses as failures with minor consequences, rather than successes), *resisting oversimplification*, *sensitivity to operations*, and *maintaining capabilities for resilience*. These norms help teams like aircraft carrier flight deck crews, fire fighting teams and nuclear power plant operators to respond to threats with flexibility, rather than rigidity. The book calls organizations that practice these principles Highly Reliable Organizations (HRO).

Households that accommodate the needs of the chemically injured need to keep operating, just like HROs, when there's an unexpected chemical exposure. The householders have ongoing needs for sleep, food, water and medication. Much like in combat, the household of a chemically injured person may suffer severe losses due to unexpected chemical exposures: lost time, lost money, lost health, lost property. But like HROs, resilient households take the time to build capabilities for resiliency, communicate thoroughly and in a timely fashion and track and correct even minor failures. This is especially true during times of relative calm. The time taken to hone skills and correct minor problems may seem like plodding to some, but it makes a critical difference when the unexpected strikes.

Issue #5: You call it a pah-tay-toe, I call it a poe-tah-to.

Analogy 5: "English as a Second Language".

Language for discussing chemical injury is often inconsistent and confusing. Manufacturers, regulators, consumers, industrial users, healthcare personnel, researchers, emergency workers, shills and conspiracy theorists all use different vocabularies. They have different perspectives, use different concepts and have different attitudes and directions. The resulting exchanges between these parties often seem like unintelligible gibberish.

Many American communities have mixed cultures, each with its own language. Generally, English is a common language, but not always. Movies sometimes portray the confusion that results from the "language barrier". Often times this isn't just a matter of failing to understand other people. The worst confusion comes about when people *think* that they're communicating well, but are using phrases and words that don't translate well. Often people come away from these situations believing that the "other parties" are stupid or acting in bad faith.

Similarly, when it comes to materials, techniques and equipment for the chemically injured, there is no common language for dealing with the issues. Even among contractors and suppliers who specialize in working with "chemically healthy" products, misunderstandings often arise. For instance, two chemicals (or chemical classes) that are used in detergents and some personal care products are sodium lauryl sulfate (SLS) and sodium laureth sulfate (SLES). A question

sometimes arises about these related chemicals: is sodium lauryl sulfate the same as sodium laureth sulfate? Unfortunately, the practical answer is "sometimes yes, sometimes no" even though these are technically different chemicals with different properties. This kind of confusion makes finding safe products very complicated. The resulting misspecifications, lost time, wasted materials and occasional lawsuits make the task of creating and maintaining healthy homes for the chemically injured an especially difficult and daunting challenge.

Putting it all together

We've discussed a few of the difficulties involved in the repair, maintenance and construction of homes for the chemically injured. This is by no means an exhaustive list of the challenges. Construction projects for the chemically injured are markedly different from projects for the healthy in our communities. We hope that the selection of challenges that we've discussed in this article helps you understand why this is so.