

August 21, 2018
(August Letter)

Dear Samantha,

I thought it was time to tell you about my “new body”.

After living for about a year and a half with myeloma and the various types of side-effects that my treatment creates, I realized that I am now living in a new body – much like the characters in “Altered Carbon” where people would take on other people’s bodies, then have to learn how to use them.

Over my 74 years of experience, I learned a great deal about how my body works. Bump it hard and it bruises. Ice the bruise and it goes away in a few days. Eat junk food and it grows fat. Exercise and it gets stronger. Similarly, I learned how to interpret various symptoms and take action that would reduce any negative effects they anticipated. A muscle ache can be reduced by a RICE approach. A headache calls for rest and relaxation. An infection requires antibiotics. With all that experience, the relationships among actions, symptoms, and remedies seemed rather straightforward.

But that was with my “old body”.

Since my diagnosis of myeloma and the subsequent regime of treatment, I have discovered a new set of symptoms, different interpretations of the old ones, and new treatments to deal with them. It’s like I am now living in a “new body” with a different set of operating principles that require new learning and adjustments on my part.

One of the first times I came to this realization, was when I got a kink in my back near my shoulder blade. In my old body this just indicated a sprained muscle. I got out an ice pack and proceeded to go through the RICE routine. I figured that it had occurred while riding my bike.

However, the problem did not go away for a few days, and when some sores developed on my side, I realized that I had developed a case of shingles. The sore back was the beginning sign of the shingles, not a sprain.

The shingles was probably due to my reduced immune system as a result of my myeloma and the medication I was taking. A round of anti-viral treatment cleared up the shingles, but the experience got me thinking about the many other ways in which I am living in a new body.

Under my old body, if I got pins and needles or reduced sensitivity in my feet or hands, I would just move around a bit because it was likely a result of blocked circulation or nerves. Under my new body, the reduced sensitivity in my feet and hands is a result of the cancer medication I am taking (Revleimid or Lenalidomide). It interferes with the transfer of nutrients to nerves so that the long sensory nerves in my legs and arms start to die off. This means that in my new body I feel like I am walking on sand.

In my old body, if I bumped into a chair or other piece of furniture I may get a bruise, but in most cases it will be sore for a short while and I would soon forget about it. In my new body, even a small bump is likely to produce a bruise and as often as not, I will find that I am bleeding as well.

This is because the skin in my legs and arms has become much thinner. Old age will have this effect as the middle part of the skin gets thinner, but in my case it is aggravated by my medication as well. For example, I take a bit of aspirin each day to thin my blood and it means that I bleed easier – and the steroid medication I take as part of my myeloma regime makes the skin thinner. Thus, once again, my new body is one that will continue to include “paper skin” as one of its features.

My new body is also different in many other ways. It can't walk as far, it is not as strong, and it tires more easily. In my old body, I would just get into an exercise regime to build up my strength and stamina, but in my new body, this has not been as effective. Perhaps this is just a case of not continuing my exercises long enough – or perhaps doing the wrong exercises, but in any case, it requires the discovery of the new body requirements and limitations.

I remember getting a lesson on my new body limitations when I was busy working on our garage door last fall. I spent some time installing a new board along the top edge while standing on a stool. I was tired, but under my old body regime, this was not unexpected so I just pushed through it to get the job done. Having finally finished, I stepped down off the stool to start the cleanup part of the job, but was surprised to find that my legs – instead of bounding through the step-down – just kept bending, until I found myself lying on the garage floor! The resistance I had come to expect in my old body just seemed to disappear!

These experiences made me think of the times that changes occurred in my old body – like when I would put on weight, have more limited flexibility, or lose some strength. In my old body, I could rectify it by changing my diet, reactivating an exercise regime, or learning a new physical skill. Even if I did not do it, I believed that this was possible and that my old body would respond accordingly.

This new body transformation seems to be different. Like with the kink in my back, the relationship between the old body symptoms and causes has shifted. My efforts at exercise have an impact, but not as quick or in the same way. Like restoring an old car, the parts will never be exactly the same as the original version.

My expectation is that I will be operating in my new body for the rest of my life so I might as well try to figure out the way it works. After 74 years of learning how the old body worked, I now have to shift gears to learn about the new one. That is why it has been so much fun to go through the diagnosis procedure when a new surprise emerges.

The latest one is the emergence of swollen feet. In the old body, this has been very rare – and inevitably linked to standing or sitting still for a long time – especially in the heat. Putting them up or cooling them off cleared up the problem quickly. In my new body, the old treatments are much more limited. Given my new body's constant walking on sand feature, this also complicates the swelling, its diagnosis, and treatment. That is why I have enjoyed the process of exploring the other possible causes – like medication and myeloma – to determine whether my old remedies need adaptation and what this might be.

The diagnosis more often comes back to the issue of the myeloma and medication. This means the range of solutions often gets smaller. Like with the walking on sand feature of my new body, I am left with the choice of living with the effects or stop the medications. For me this is a choice between walking on sand or dying, so the choice is clear – and I turn to accepting my new body and continue with the adventure it provides as new aspects of its surprising function emerge.

As a result, my life has changed to include new types of exercise, a regular regime of drugs, compression stockings, shoe inserts, visual checks of my feet rather than reliance on nerves alone, a stash of band-aids in my pouch, and lots more naps. I expect there will be plenty of other accommodations to come as I adjust to the idiosyncrasies of my new body.

Love,