Quality of life.

People seem to throw that phrase around as if it means the same thing to everyone. It's actually a multi-layered concept. When you throw in the complications of chronic disease and how it effects everyone differently – well, then you've got a fine mess on your hands!

Well-meaning physicians have no way of understanding what is truly happening to us when the only filters they have to view us are through the results of labs and tests – which sometimes look normal at a surface level.

We're finding it necessary to come up with our own scale of what quality of life means to us. It's also a way of dealing, concretely, with the fact that our quality of life will never go back to what it was in pre-diagnosis days. There's a lot of grief that comes up with that. But then, we have an objective way to look at what we do have and how to communicate clearly with our physicians so they understand, on some level, what we're going through.

I think things can get so jumbled when we talk with healthcare workers. We carry all of the grief and disappointment at the limitations of our new level of health into our appointments. It's either that, or, we minimize the effects of chronic illness so everyone stays in a state of denial, including ourselves. Either way – there is a lack of clarity about what our lives are truly like, therefore mitigating the help that we so desperately need to attain a better QOl!

If you would like to take an objective look at what your quality of life is in this new part of your life's journey – please join us on our livestream.

As always, we see you, we hear you – because we ARE you.