

***parkinson's jam***

***(on discovering the music and diagnosis of sangeeta michael berardi)***

i'm telling you man parkinson's fucking sucks  
you gotta live with it though no matter how it breaks you down  
live with it yeh because yeh that's the only way to get up  
after a night of mad thrashing night terrors dystonic contractions  
tremor waves under-the-skin  
anxiety pacing in the belly-cage  
nervous chatter goading the amygdala  
man that shit is hard to take  
even with carbidopa-levodopa pharma-jazz

parkinson's is rough! maybe not as rough as als or god knows what  
other progressive degenerative neurological disorder  
might kick its ass suffering-wise parkinson's is a bitch for sure  
often includes paralyzing fatigue rigidity sometimes dementia  
i'm telling you man it's a goddam disease can take you  
all the way down take you out make you wish you were already dead

but most of us figure it out  
by which i mean most of us figure out how to make a life  
by which i mean make a life *anyway* meaning *regardless despite*  
symptomatic multiplicity duplicity which varies hour-to-hour day-to-day  
our bodies are unreliable our brains undependable we must  
discover invent hammer-out instigate *work-arounds*—

and we get *backup* man i'm telling you  
parkies gotta get good backup! recruit folks who will help  
with our needs when we have trouble helping ourselves  
lebron his entourage got nothing on me my team of care-partners  
all mine except professional medical players join my team for free  
outta love for me not for money-and-fame of which i got none

and parkinson's aint pretty nor sexy not graceful nor easy to watch  
nobody will ever see me get over it so it hurts everyone i love  
surges out in waves of pain pounds everyone who loves me  
hits hard without mercy—

i'm telling you man parkinson's cuts nobody slack  
and you can't *fight* it  
i mean you can't take it on like a battle  
that warrior shit only makes it worse for me anyway  
like those so-called chinese finger-traps we used to call handcuffs

the harder you fight the tighter its grip  
so i don't war with it  
i don't get in the ring like some heavyweight knockout puncher  
i accept it  
yup for real  
honestly  
parkinson's is part of me  
part of me i gotta find  
some way to love  
because love is  
the only way—

hahaha don't get me wrong i'm no dalai lama saint gandhi  
i got hate for parkinson's some days it pisses me off  
i wanna wipe it the fuck out!  
get it outta my body altogether!  
but i'm not that suicidal (yet) see what i mean?

i take it in like an abandoned child provide care it needs  
care *i* need  
so we can make some kinda life together  
for better always for worse because  
that's what "progressive" means it's part of the deal—

i'm telling you man *that's* the hardest thing of all  
to care for myself the way i'd care for any of my beloveds  
the care we need me and parkinson's together —

when it works it's worth it totally worth it  
even now especially now after all these years—