

IF I SEEM FINE TO YOU

Here are a few things I need you to know...

There is a chance I look well to you

Maybe I'm sitting up, eating and chatting and I seem fine.

Maybe that doesn't fit the image you have in your head of someone who is too unwell to leave their house very often and definitely not what you may think someone should look like it they are too sick to leave their bed for days on end.

**WHEN
YOU
SEE ME**

JUST A SNAPSHOT

You are seeing a snapshot of a rare event in my life.

It is not representative of the quality of my life, the nature or severity of my illness any more than a brief moment of socialising represents what your life looks like day to day.

Please don't ask me to prove how sick I am to believe me.

BOXING IT ALL UP

I don't have symptom free days anymore.

So that I can try to enjoy this time with you, I have boxed up my symptoms.

Try to remember the last time you had the flu, even though your whole body was screaming at you, the aches, pains and nausea can be temporarily pushed aside or bearable...but only temporarily.

WHY BOX IT UP

An invisible illness is extremely daunting and exhausting to explain to others.

Revealing the true extent of my illness can leave me feeling vulnerable and exposed.

I also know everyone is going through something, so I often box up my symptoms to make space for what you might be going through.

SUPER SMALL BEFORE

My life has to be super small in the days or weeks leading up to our get together.

To stay out of the crash zone I have to think about everything from meal prep to showering, and do them very incrementally or let most things go undone.

That means I'm mostly bedridden so that it's possible to box things up and spend some time upright and talking.

UNBOXING

After the exertion of an outing or socialising I don't have the energy to box up my symptoms or I may have hit the wall in a way that makes it impossible to box it up or push through.

I have entered the crash zone.

This is the bit you won't see, where I lie in a dark room, with as little stimuli as possible.

SUPER SMALL AFTER

I always hope the joy is high and the price is low but that is rarely the case.

Even if I am lucky enough that all my symptoms do not flare too badly, my life will still need to be super small again in order to recover.

I will not be seeing anyone again for a while.

**THAT'S JUST THE SYMPTOMS
PART...**

UNFORTUNATELY, THERE IS MORE.

**EVEN ON
A LOW
SYMPTOM
DAY**

There is still the bone crushing fatigue

Most people have to try to get through the day even though they may be feeling tired.

The thing is...I'm not just tired.

It's exhaustion, quite literally, on a cellular level. There is a heaviness and effort to every single movement as if gravity has been turned up and I'm walking in deep mud, carrying lead weights.

WE ARE ALL DIFFERENT

A chronic, complex, multi-system illness does what a chronic, complex, multi-system illness does.

The symptom severity, the triggers for a flare, when a crash happens and how long the crash lasts varies for everyone.

It's also a fluctuating illness, which means that things that might have been possible to do last month without too many consequences may not be this month.

JUST SO YOU KNOW

I appreciate you

I respect your time and that you are sharing it with me and I and appreciate the effort it took you to get here too.

I see you

I know you face many challenges too. None of it is easy. I'm hoping we can be a port in the storm for each other.

I only ask

Be curious about what life is like for me but understand its very personal and difficult to talk about.

Believe me

You may not witness how bad it gets for me but I'm hoping you will believe me.

IF YOU ARE INTERESTED

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