

9 April 2020

STIR CRAZY

Quarantine is doing a number on my family. For one thing there is the problem of getting everyone to stay in place. The position of Dog Walker has acquired the utmost prestige and I'm still not used to seeing my husband and children fight for the privilege of doing a chore.

We have fallen back on the old family holiday standbys – board games, bad movies etc – and those of us whom the COVID crisis has made even more busy are of course able to stave off the cabin fever via work.

At a time like this, with so much going on, I think it is interesting to reflect on how differently we handle life's anomalies.

What I can say is that 'Free Time' can be treacherous. From speaking to people who experience long-term hospital stays, the secret is to fill the gaps. Dress well as often as you can, even if you know you won't be leaving the house. Set goals and make your time work for you. Fill that empty space.

Understandably, a lot of us have our minds on health issues right now, but that too can be constructive or destructive. Remember to reward yourself for little victories and to only make plans for what you can handle. If a long period of quarantine is too much to think about then just focus on the next couple of days or even the next few hours.

I'm reminding many of you of what you already know. Compared to the population at large the CF community has a much better handle on isolation, just like we had a better handle on Social Distancing and germ hygiene.

I for one plan on re-discovering my passion for yoga and cooking. Meanwhile the family dog is re-discovering its passion for sustained physical exercise.

Here are a few CF-friendly Links to help organise your Quarantine mindset ...

<https://perxhealth.app.link/xCbKVnxbsR>

<https://beamfeelgood.com/onDemand/list/cystic-fibrosis>

<https://cfa.padlokt.com/my-account/login>

And here are some links to CF surveys ... we really need your input.

Sibstars

Parent questionnaire: https://unsw.au1.qualtrics.com/jfe/form/SV_enT5tEw09kaB2zb

Sibling questionnaire: https://unsw.au1.qualtrics.com/jfe/form/SV_bw41VNfgp5TBfY9

Hayley Kimball on Procedural Anxiety

<https://bit.ly/2SCIWld> - **NOW CLOSED**

ACI Models of Care:

<https://gars.cec.health.nsw.gov.au/Survey?i=3408a1e2-19f9-4f6a-9449-49715e0acf5c&d=c0955fa1-7c73-44b8-a117-f1802407e9e5>

Earn while in isolation and improve the patient experience and information provided by Pharma. If you are selected for an interview in Stage 2 it will be done in the safety and comfort of your own home

<https://www.surveymonkey.com/r/VertexCF> (paid)

Kind regards

A handwritten signature in cursive script that reads "Nettie Burke".

Nettie Burke, CEO

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