

Real Pandemic Diaries

About Pandemic Diaries

Over the last 6 months, Real has been running a storytelling project, funded by the London Community Response Fund. The aim of the project was to create a safe platform for disabled people to share their experiences of the pandemic and lockdown.

The project has achieved 4 outcomes:

- **Health and wellbeing**

Sharing experiences has had a therapeutic value for our members.

- **Record social history**

Disabled people's experiences historically have been lost or forgotten, so it has been really important to capture them during the pandemic as a testament to what has happened. We have linked up with the Local History Library to showcase these stories as part of their collection.

- **Feedback to Council and other statutory bodies**

Testimonies will help the Council and other statutory bodies to better understand the experience of disabled people throughout the pandemic and may inform policy decisions.

- **Safeguarding and Referral**

Supporting disabled people to tell their stories about how they are experiencing the pandemic, has also allowed Real to identify any immediate safeguarding and referral issues.

In this document, we have brought together a beautiful selection of poems, stories, and art created by our disabled members and staff which expresses how the pandemic has made them feel.

1.

Ms Pandemic - Art of Idleness

The Corona Pandemic has created disaster, turbulence and havoc the world over. Social-distancing, Isolation, Quarantine and lock-down are the buzz phrases of the era.

But this Ms. Pandemic has given us a rare opportunity to pause and ponder; to wait and relax and wait patiently for every minute to pass. There is no need to have the account of time. Do everything (or nothing) at your own speed.

This has provided me with a new branch of Art: The Art of Idleness. “My day and night myself I make, whenever I sleep or play.”

I can postpone all my activities indefinitely but Nature’s call.

I had planned to write an inspiring poem or an interesting article on Ms. Pandemic. But I left it pending for the last moment and still waiting for that last moment. In fact I have forgotten the count of time. Watches still tick, clock still strike. But they denote nothing. Past, present and future have shrunk together into one unending moment.

“They also serve who stand and wait.” So, I am serving by practising the ART OF IDLENESS.

By Mahendra Rastogi

2.

The mechanism of getting to one place to the other. That mode of transportation that I used to depend on has been heavily reduced. I’m always getting emails saying don’t travel on such times. The state is dictating where I should go and when I should go. Before it was travel whenever you want to travel but now the state is imposing an order on you saying no you can’t. Where you were talking about depression and the clouds being your metaphor for depression, for me I don’t know what sign I would be. For me that would be my depression as its internal not external. Before the pandemic we took the buses and tubes for granted. Because they aren’t there in the same ways we want them to be, its like they’re not there. Not only have they become paralysed, we have become paralysed too as a nation. This has made us zombies. When I mean zombies I mean we are even afraid to touch each other. When things do get better, I think we are duty bound to get out there and thank our key workers. When I say get out there I mean promptly get out there and stop all this criticism for a day or two. We owe it to them as an engagement project and a user led organisation to positively do something. We must do something as we do owe a debt of gratitude to everyone attempting to keep us safe so we must do that in whatever way we can. We must incorporate this into the stories project in some shape or form. We must at least record a message or something to our local hospital and just to record our thanks and gratitude we must do that otherwise history will never forgive us.

By Faiz Rehman

(This is a transcribe from a Local Voices Meeting - a network of disabled people in Tower Hamlets that influence local issues that affect disabled people and people with long term health conditions in the Borough)

3.

This whole thing with covid-19 is a disaster. People like us we are friendly people. We like to help people and help others. I choose to go to 2 old ladies. They can't even speak any English and they can't phone anyone. I used to make some food also and do some shopping to see them and now I just have to phone them. I can't even go so I miss everything. I can't wait till things get better soon and we can do how much we were doing before. Thank god I can still drive as all of my friends can't. When things start getting bad, I just drive to them. I sit in my car as I am not good with my legs and I ask them to stand next to their door so I spend 5- 10 minutes and if they need something like sometimes, they can't carry heavy stuff, so I did that too. I can't wait till things get better. Sometimes as people are a bit far away then suddenly, they disappear. So I lost one friend then somebody said we didn't hear about that friend. Thank god I spoke to her on the phone and she's very ill. I can't do anything its not in my hands god will help everyone and us. We can't do anything. Its not in our hands.

By Jagir Kaur

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4.

A lot of things were destroyed. We had everything before that pandemic. I was going to Tower Projects, I was going swimming, working at the council at mulberry place everything and Core Projects when they were opening at Aldgate East. That was my day to day life and it was before the pandemic and It was destroyed because of the pandemic. I also went hydro and trampolining rebound. That was my day to day life. I got the invite to do it and started to really feel the benefits of being me. Then that went and it went online, it makes sense to have something like this online to continue our health. Then to not see that person face to face that's much harder. Like someone on your telephone you don't know what that voice is. I'm glad about this platform as I know the face and who I'm speaking.

By Samantha Walker

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5.

Unity over division

So much divide
Will be humanities demise
Lies lies lies
We need to unite
Deceit and deception
The manipulation and dejection
Where is humanities connectedness?
So speak your truth
Own your truth
Stand in your truth
And most of all
Embody love and unity
Let it echo through your veins
Through your soul
United we stand
Divided we fall

By Anonymous

6.

Art of Losing

The art of losing may not be hard to master,
But losing me would be a disaster.
I am in the smile of your lips
And in the unshed tears of your eyes.
In the pleasing giggle of your laughter
And in the silent sob of your cry.
Coy of my existence you might be,
You cannot lose me.
I am in the music of your voice,
In the croon of your choice.
In the melancholy of your pain,

In bliss of your gain,
In the moment of your sorrow, in the time of your glee,
You cannot lose me.
In every drop of your blood,
In every beat of your heart,
In your memory in your brain,
In the train of your thought,
I am in your epic, in your story,
You cannot lose me.
I am answer of your prayer,
Your intimate desire,
Your fascinating admiration
And your burgeoning aspire.
Love me, cuddle me,
Kiss me and own me.
You can't lose me,
You shan't lose me.
Do not forget me, do not lose me.

By Mahendra Rastogi

7.

I went to the fridge. I slightly opened the door. I felt some hope. I could eat some more. Then I saw my son. He smiled at me in a dazy fashion 'Daddy what are you doing?'. I replied 'I don't know. When will this crazy world be free from this.

Note from the Writer: This poem is about my providing for my child. The fridge is a space of possibility. When it's full, it's hopeful. When it's empty, it's about hunger. This situation has made things so inadequate on the one hand but on the other hand I am able to help my son which I never thought possible.

By Faiz Rehman

8.

I felt sad, I didn't have a tablet, a
laptop or internet
Mixed messaging
I felt happy like my teddy bear when I
got online

By Samantha Walker

9.

Lockdown made me feel like a droopy plastic bag being blown around on the wind of Corona. We were pebbles on a beach absorbing the waves together. As we clapped for those closest to the shore. Our Frontline Workers.

By Jo Turner-Attwell

10.

What am I?
But two things.
One and the same.
I climb I fall back I climb I fall back I climb I fall back
What am I?

Note from the Writer: The session lead had asked to me to write about an object, I chose a smooth bowl. The metaphor being hope and the fight to maintain it

By Rob Johnson

11.

Going Nowhere Slowly

We're in a time lapse it seems
Time is standing still
Routine is out the window
It prompts the question
What is this all about?
What is this for?
Where are we going?
Where is the next destination from here
Time is moving so fast yet so slow
And I don't know where I'm going anymore
I need to put the breaks on
And simply breath

By anonymous

12.

I went into lockdown with a complex mix of neuro, mobility and mental health issues. I lean heavily on NHS support both medically and for occupational

health. I do live independently, alone and without Council social care provision. Early into lockdown, I was designated Clinically Extremely Vulnerable and, like anyone else in that category, was given advice on the few reasons that I should emerge from home. With limited access to resources and no local support network, everything became much more difficult, missed medical appointments, access to transport, drugs, food etc. I ended up getting Council food parcels for which I was grateful, despite the limited and unvarying nature. Minimal fresh, fibre and protein content but it was better than nothing. Then delivery became sporadic, though no one could tell me why. In the end I was forced to emerge and take my chances in Tesco's. From the point of medical support, the normal raft of review appointments with consultants, routines tests have all ceased. Some of them were important, some not so. None of them happened. The NHS keeps claiming it was still open for regular business was not the case! On the plus side, living alone gives me full control of my home environment. During lockdown, I became aware of how many people would try to gain access – meter readers, checking the dodgy cladding, updating the router, the list goes on and on. They all get told the same response – no one gets in here without a Court Order. Maybe not even then. Ultimately they all acquiesced to this, I do like a good scrap so we're slightly disappointed in some instances!

By Rob Johnson

13.

One staff member has PTSD from a road accident which caused a mobility impairment. COVID 19 created delays in getting access to the appropriate medical footwear, which has created a risk of skin breakdown. This could cause medical issues for the staff member further down the line by creating pressure sores. The pressure of COVID 19 on the NHS has also meant that more time has been spent chasing referrals. In addition to receiving phone calls for unexpected medical appointments during the work day, because letters have not been sent out when they should have. The staff member's PTSD is triggered by feeling out of control. The unpredictability of necessary medical care has created feelings of being out of control and triggered the staff members PTSD. This has in turn triggered feelings of overwhelm and fatigue.

By Jo Turner-Attwell

14.

A grandfather had been living in a residential care home in Tower Hamlets for some years. He used to go out by himself for a walk to the shops, and to spend time in the communal lounge watching TV or chatting to other resi-

dents. Staff closed the lounge, requiring residents to stay in their own rooms. This was reduced to sitting immobile for long periods, and consequently developed a serious pressure sore, which became infected. The family decided to take him from the residential home to stay with themselves. Sadly, despite their best care, the infection spread, and the man died in August.

By Anonymous

15.

Young woman with mental health condition was living in a hostel near Hackney Road. Was on the housing list and offered a flat in Whitechapel Road during Covid19 and given a date by the hostel when she should leave. She couldn't make contact with his support worker who was self isolating and wasn't capable of moving by herself. She was lucky to have a friend who organised everything but the flat wasn't in a ready state to be moved into (no heating) so she was camping whilst electricity was fixed etc.

By Anonymous

16.

Social Isolation during pandemic of an elderly disabled man who uses an electric wheelchair. Lives on 4th floor and relies on the lift that sometimes breaks down. When it breaks down he can't get his food shopping. He has no mobile or computer because he was hacked once and he is nervous about it happening again. He relies on his landline. During Covid19 he has found it difficult to get through to council and his housing association when needed. Hangs on phone sometimes for up to 7-10 minutes then gives up. He has found a local community centre during Covid 19 helpful with food parcels and also they gave a gift.

By Anonymous

17.

A young man who grew up outside London, with a history of eating disorders and self-harm. After about 10 years in NHS mental health institutions, he was discharged to live with her parents in September 2019. The pressure of isolation during the lockdown got to him and he began self-harming again, after which he was hospitalized again in April. Things have spiraled downhill since

By Anonymous