

LIFE DURING A PANDEMIC

HEALTH AND WELLBEING

Introduction

Thank you to everyone who has contributed to being involved in our collective creative project to share your thoughts, experiences and opinions about life during the Coronavirus pandemic. The first edition received amazing feedback (see some examples below) and can still be accessed at this link: (https://rb.gy/97gldo). One of our Lay Leaders Hilary was also able to include the booklet in the weekly update for the West Yorkshire and Harrogate Health and Care Partnership.

For our second edition, we focused on **health and wellbeing** during the pandemic. We sent out a poster to encourage everyone from our involvement communities, the Yorkshire Quality and Safety Group (YSQR), Improvement Academy and Yorkshire and Humber Patient Safety Translational Research Centre (PSTRC) including;

- YQSR Patient Panel
- Yorkshire and Humber PSTRC Lay Leaders
- Yorkshire and Humber PSTRC Citizen Participation Group
- Improvement Academy Lay Fellows

This edition also includes reflections from Livi Joseph and Claire Marsh.

Thank you kindly for posting a hard copy. I have read it all. It is interesting reading, I feel I know everyone so much better having had an insight into their lives. The silence here is amazing, I can even hear my own thoughts. There are so many birds around, it is lovely to

hear the songs.!

Such an interesting and thought provoking read.
So honest and open!

It was very interesting to read the variety of responses in the 'first reflections booklet' and I will look forward to reading volume 2. There is much to think about given the effects of the current circumstances on society as a whole, as well as individuals.

David

My youngest is a Dr and currently working in Australia for two years, which I'm pleased about, as there are hardly any coronavirus cases there.We FaceTime every week and were planning to go out to visit this year but with the travel

restrictions that's pretty unlikely.



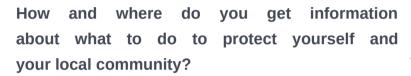


PLEASE TAKE CARE IF YOU ARE TOPPING UP YOUR VITAMIN D IN THIS BEAUTIFUL SPRING SUNSHINE



How are you looking after your own health and mental well-being?

I am looking after my health by wearing a face mask when I go outside ,also I am wearing gloves and a visor over my face. I am having a shower when i come in from outside and also I am eating alot of vegetables and healthy food. I am also looking after my wellbeing by doing exercise indoors and doing yoga.



I have been getting my information from nhs website, daily telegraph, daily mirror newspaper and the bbc news.

Any impacts on yours or your loved ones health?

There has just been the impact on my mother having to self isolate as she is over 60.health e.g. mental or physical? I think physically my mother is just feeling bored, but she has the moral support of family members around her.

Anything you are planning for your health or wellbeing for the next few days?

I am just planning to drink alot more water that is all

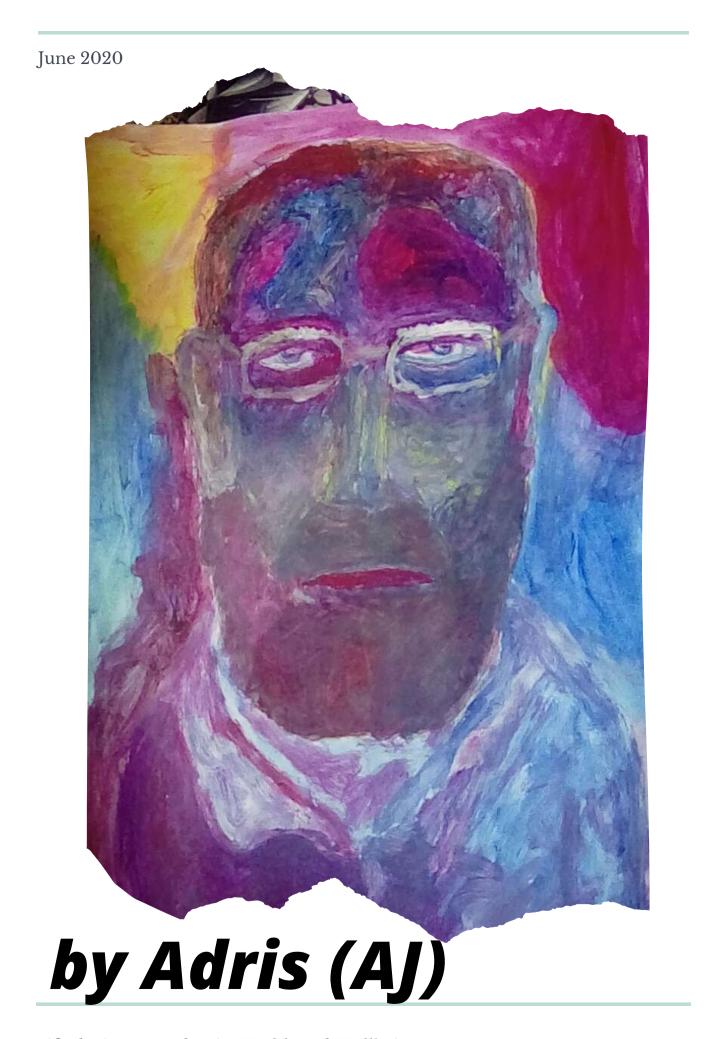












Marilyn



I am sat here wondering what I can add to my recent diary as I seemed to say then all that has been on my mind.

However, I am quite concerned with how a lot of people are quite blasé about the new rules. There have been lots of comments on Facebook about how the rules are being interpreted, and I am afraid that the example from above seems to have added to the problem.

We are going to carry on with the clapping as it is a way of neighbours getting together without breaking the rules as well as still showing our appreciation.

I think the biggest frustration for me now is my hair getting longer and more unmanageable by the day; so that tells me I am still ok with lockdown if that is my only worry.

The garden is now starting to show the changes we have made, and when all the flowers come out it will be gorgeous. The good weather is wonderful, it feels as if we are abroad, except there is still the housework etc to do!!

I am still busy with hobbies I normally have not time to do, also meetings on Zoom and Teams. I hope that we do not have too many meetings online when this is all over as I like the atmosphere at face to face meetings, it seems to encourage my brain to work in a creative manner.





We can see our son this week for the first time since early in the year as we can now see each other in our gardens if we are 2 metres apart. We need to choose a day when it is sunny and warm.

Just finish on another positive note my cousin is looking well, we saw her for the first time today from the other side of the gate and manged a short conversation.

I hope the next time we see her we will be able to stay longer.

I feel we have learnt a lot during lockdown about what is important in life.

Our health and family and friends must take a more prominent place in our lives and being hurried along and 'have no time to stand and stare'.

Both Peter and I have said that we are going to spend time visiting our own countryside instead of jetting off abroad. That is fine now because we are in Mediterranean weather, I might change my mind if we have a summer with weather like last year.





Ruminations on Lockdown:

To be honest lockdown has probably affected me less than a "normal" person.

I suspect most "normal" people are simply experiencing how life is for a lot of Autistic people.

The only things I've missed has been not being able to buy some things because most of retail is shut and haircuts! I'm starting to have a lot of sympathy with sheep and my Border Collie keeps trying to herd me into a pen.

If I've had any affects on my health it is because of the NHS going into Covid-19 only mode and things might have been missed. I know that A&E is still available but all outpatient appointments have been cancelled until god knows when.

So what is being missed as easy to treat now but will be much harder to treat once services are available again.

Philip

Margaret's Potted Diary Continues...

20th April 2020

I have just been through a very harrowing time. My son, who was OCD about protecting himself against Coronavirus contamination had been very ill in the two previous weeks. His health had gone downhill, high temperature, continuous coughing, difficulty breathing, talking and extreme pain in his lungs. His partner works in St James, Leeds so he had been given a test for the Coronavirus at the LGI on 14th April. He had to have a throat swab as his nose haemorrhages. The test came back negative and he was told he probably had a lung infection on 16th April but the throat swab test had over 35% false negatives.



Through Facetime I could see he was not well and coming in and out of consciousness. When I could, I talked him through the breathing exercises for Covid 19 and encouraged him to lie on his front. He was confused, looked awful and his breathing was laboured. The previous week he had written his will and final wishes and emailed me a copy – that was how bad he felt. The nights of 18th and 19th April were the worst, he was self-isolating in his own home but in his delirium he kept Facetime open, asking me to talk to him through the night. I did tell him that I would call 999 to get help to him if I could not keep him communicating with me. He was fearful of going to hospital and not seeing anyone ever again. It was harrowing and very worrying but somehow he got through both nights, whatever it was, thankfully. My heart goes out to those families who go through the crisis of a family member succumbing to the Coronavirus and the patient being alone.

21st April 2020

This morning we were both still wrecked but I insisted he showered and then rested back in bed. It did make him feel better but he was visibly grey with the effort.

Life during a pandemic: Health and Wellbeing

22nd April 2020 I told him he had to strip the bed. Remaking the bed was more complex and took hours but he did feel better getting into a fresh linen bed - exhausted. Each day he was managing to do just a little bit more but he had no focus or concentration, experiencing extreme fatigue as if hitting a wall of tiredness. This was 20 days after the first signs of symptoms, so much or testing negative and returning to work after 14 days.



The strange call

27th April 2020

Received a strange phone call. The young lady said she was checking up that I was maintaining Shielding. I said I did not know what she was talking about. Although she was very pleasant she started talking to me as if I was not quite there. (ageism and as if I was slightly senile).

You got the letter from the Government that you are extremely vulnerable": me "no"

"Have you been going out the house" me "yes"

"Oh dear where have you been going": me "into my garden"

I really thought it was someone winding me up or it was a scam.

""do you live on your own": me "no"

"oh who do you live with": me "my cat"

Further shift in the person's voice that she was dealing with someone who was not the full shilling.

"you must register with the number on the letter to get help": me "I do not have a letter"

"You are extremely vulnerable": me "what are the criteria of being vulnerable?"

"The Government have your records and you fall into the extremely vulnerable category, have you been going out in the streets": **me "No"**

Though I had a wild desire to float down my street in my nightdress, I realised that would not help my cause. More questions like DOB, postcode and can I get shopping or make my meals. Of course, I was skeptical and would not supply personal details. It ended with being told a letter from the Government would follow. I dialled 1471 to get the telephone number and then went online to check if the number was listed as a scammer.

I found out it was from the Government Shielding Office.

It was all rather confusing.

1st May 2020

My group shared their photos of the challenge to make a Maypole. It gave us a good laugh and illustrated how resourceful people can become. One person used a candle stick and potato, I used a mop, others used china figurines and another beautifully cut out children to dance round their Maypole.









7th May 2020

Receive a text, NHS Coronavirus Service. You have been identified as a person who may be of high risk of severe illness if you catch Coronavirus. You should get a letter from the NHS confirming this. You should Shield until 30th June 2020. Support is available. Please complete this short form. Opened up the link for the online form. First question have you received a letter from the Government. Well the answer was "no" nor did I fulfil any of the criteria listed so I could not register. Beginning to think I was living in a twilight zone. Phoned my GP Practice, when I finally got through, I explained and asked if they could they help. NO, we know nothing about it we have not submitted you as vulnerable. But my auto immune system is compromised, we do not issue letters was the response.

8th May 2020

Further text instructing me to eat and sleep separately from others – try telling my cat that! Use separate toilets and answer a telephone call from a given number. Tried the number – told they did not receive calls! Well it had said I was to accept a call from them. 8th May 2020 was also a new public holiday. VE Day- a Celebration.



I knew it was going to be a hard day as tears were rolling down my cheeks before 8am listening to Zoe Ball on Radio 2. The day continued like an emotional rollercoaster. The concert broadcasted at night was beautifully staged in front of Buckingham Palace,

but oh my goodness, the whole day pulled on our heart strings as we were reminded of the sacrifices made during World War 2 and the similarities to the number of people dying from the Coronavirus and the stalwart efforts made by all of the NHS and keyworkers getting supplies into place. If I was affected by the VE Celebrations. I knew it was going to have a damaging effect on many more people. And their mental health

9th May 2020 another text on how to receive prescriptions and wash my hands. Phoned the number, did I have a letter "no" response "sorry cannot help you."

10th May 2020 text instructing me to tell family, friends or employer that I was staying at home, talk to someone once a day, pack a single bag in case I developed symptoms of Coronavirus and had to go into hospital for an overnight stay. I told my cat, he was not interested.

11th May 2020 text informed me to ask family or friend to take my rubbish to the bins and walk any pets. I would like to see someone taking my cat for a walk! (I know they meant dogs) Check cupboards for food supplies and soap. Another website address for support or another telephone number to call for a friendly chat.

All excellent information and instructions but without the "letter" I was in no man's land and I was running out of cat food. My post arrived at 2pm on 11th and to my surprise there was a letter from Leeds City Council telling me I had been identified to Shield and in the letter it laid out the precautions I had to take and where to get help. Tried the online system to register, it would not work for my responses. I phoned up and got a very helpful man who registered me. I was told to register with my local authority volunteer help centre as I lived alone and they would help to get cat food.

13th May registered with the LCC Volunteer helpline and everything was put in place to collect my prescriptions and have a volunteer to shop for me with LCC billing me.

Later that day an email came in from Tesco informing me that I was registered for a priority shopping delivery. Everything fell into place and I felt so much better knowing I could get fresh bread and milk delivered to my door.

I noticed less traffic on email which initially felt like a blessing as I had felt bombarded by the amount of information coming through in addition to daily news updates on the Covid19 situation and the repetitive press questions that appeared to be enquiries to answers they actually already knew but just wanted the air time to ask them.

I contacted the group I run and told them that I thought VE Day actually made me feel awful, my actual words were "it was a real bummer". The response was overwhelming, members had thought that their mental health was damaged or very fragile and that they were not coping after VE Day. Members felt better sharing their thoughts and that they were not experiencing these feelings alone, repeatedly the word relief was expressed to be able to break their silence.







21st May 2020

Due to my delivery from Tesco's very late the previous night I was able to feed my cat and have a treat myself – a banana for my breakfast – delicious. The first one in 6 weeks. I made a chocolate Krispie cake and cheesy biscuits.

Although a significant birthday I spent the day very quietly. At 5pm my son rang and said he would come round to sit in the garden and talk. He duly arrived at 6.30pm having made me cupcakes. He sat at least 3 metres apart eating the cheesy biscuits and Krispie cake making up for his 6 weeks of incapacity.

I was delighted to see him and received a trowel, cactus solar lights, a big bunch of flowers and the promise of a celebration when I was released from shielding.

At 8pm the clap for the NHS started, we were treated to the sound of the neighbouring Sikhs who paraded around a Cul de Sac playing their drums. It sounded as if the whole area was out following them like the pied piper but I later learnt that BBC Look North were out filming them.



22nd May 2020

Should have gone off to Whitby for a booked extended break.

No travel plans possible for this year. Thankfully the weather has been good and I really appreciate being able to sit out in the garden though I can see the weeds actually growing in front of me. Great anticipation that next week we will have a resumption of our garden waste collection – but it will take a number of collections to clear the backlog. The things we have taken for granted.

23rd May 2020

Decide to ration exposure to the news and the daily briefings. A Yorkshire phrase that I have learnt "it does my head in" If it was an important issue, I would hear about it anyway. Received another text that despite the easing of lockdown I was to remain in Shielding until 30th June.

25th May 2020

I have been engaging in Zoom, MS Teams, What's App, Facetime and Google Hangout for meetings to continue engagement in NHS volunteering work/committees/ meetings. I even got my group to agree to try out Zoom to meet up. They were very nervous about the process and technology but everything went well. I have booked another Zoom to reveal our creative tasks that I set for the month of May. Carve/Sculpt a bar of soap and decorate a hat but not using a hat as the bases. I recommended a bucket or a colander and in fact I used a funnel and a lampshade as bases to make my hats.





31st May 2020

Yes I have cut out another 3 double sheets to make more bunting for the delayed wedding but have not made them up - yet. I have been madly quilting, finishing off what we call UFOs, unfinished projects, and making facemasks, expertly. Everything appears to be more complex to carry out and takes so much longer than first anticipated. I never get through everything I planned to do in a day.







I have become more emotional as the weeks roll on, more philosophical about life. I ask myself how I can mingle once I come out of Shielding, I have nightmares about finding a clean toilet and just thinking about a hot air hand dryer makes me cringe and recoil. Growing up I thought my mother irrational about keeping me away from crowds and public places if I should have a cold. She grew up as a child through Spanish Flu and though she never spoke of it (no one did) I can appreciate its impact affected her all through her life.

My son is still affected with fatigue, physical and mental, but he is gradually improving. He goes on walks but knows he is not up to a Park run, if they should be resumed. He is more adamant that I should be kept out of circulation as he says "you do not want to catch this Mum"

The only thing I know is how much we do not know and I think going forward we still have a lot to learn about Covid19, the economy and the shift in global dynamics.

Magaret

Claire

Reflections as we unlock.....



I have mainly enjoyed locking down in my small family unit of three - me, my husband and 13 year old son, all working from home.

My husband, a real nature lover, introduced us to his woodland friends and between us, we fed this Robin daily for many weeks. With more time (less commuting) I appreciated this and spent much more time with the birds on the Chevin and in the garden.

My son (also called Robin!)
brought me into his wonderful
world of music and got me
painting a music mural with him,
and helping him to entertain the
neighbours on those long
lockdown evenings....



All these things have been sources of strength, joy and positivity as I, like most people, have had things to worry about. For me this has mainly been my Mum with dementia in Teal Beck care home in my town.

Due to visitor restrictions. I've had to pull right back and just trust and hope that the home will cope and provide what she needs.

As lockdown eases and people rush to get back 'out there', I want attention to turn to what we can do for people like her, in care homes or vulnerable in their own homes, who could be cut off for a long time yet....can we really keep these people locked up so others can go out and about?

Is that really the plan?!

I have decided to take every opportunity to help keep the good parts of lockdown alive and build on what we learnt to be really important to us.

To me that means being a bit more creative than listening to Boris tell us to 'go out shopping'!

Gotta keep dreaming and spread the love. Simple really.

Claire





Walk or run, no gym, no swim

Walk with him, run without him?

Back and forth where can we go?

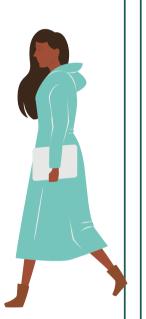
Walking round and round in circles

Thank goodness it is fine

Two metres apart- use the road!

Break the rules run early morning- walk in the evening? Even the solitary cat at 7am obeyed the social distancing!

Enlightenment Think – avoid the hills- the CANAL!



Walking-smiles

Walking- "hello's" exchanged

Walking-senses heightened- did you hear that bird?

Walking- even in the wind and rain

Walking- bud to bloom, blossom and leaf

Walking- ducklings and goslings- new life

Walking west head wind walk back east the wind transports you

Walking east head wind walk back west the wind transports you

Sun setting dazzles and delights

Once a week run-invigorating

Nine weeks times seven days times one hour of walking

enjoying- wellbeing



What will we do when lockdown released?
Will we continue our hourly, daily walks?
I would like to think so!











My life during this pandemic has spanned the spectrum between positive and negative - an uncontrollable wave of thoughts, feelings, and emotions, which has pushed me into new spaces of personal and professional growth.

Embracing uncertainty with a mixture of nostalgic and new communication solutions for example making phone calls, setting up video calls/ Zoom meetings, posting letters and sending wellbeing, food, or sweet treat packages.

Of course, for me, nothing beats seeing someone face to face and being able to take in all the non-verbal communication. As someone who is a nurturer, my initial energy started by finding out how everyone else was doing, supporting my family and friends. keeping in touch with involvement community and extending my support to community organisations I had been working with, support to their vulnerable clients.

Personally, local grassroots community organising and activism has been incredibly inspiring.

Mobilisation of collective action and community spirit to support and help each other has given me so much hope for what society can achieve after the pandemic.

It has enabled a larger community to experience (temporary) isolation, raised and increased awareness empathy towards some of the circumstances people have faced prior to the pandemic. The weight of bearing witness to the level of inequality in people's experiences of lockdown soon hit from my conversations with communities. People without gardens, with no access to/ poor quality internet, limited phone credit, with a lack of social support, no tv or radio, low food security, low job security etc. This virus has exposed and amplified the repercussions of societal inequalities that are yet to be addressed. We have so much to learn from these communities, especially

their strength and resilience in the face of uncertainty and challenge.



Questions of the importance of public involvement in research during a crisis has been extensively discussed on Twitter. With many of the major funding bodies diverting funds to put calls out for Covid 19 specific research and I think public involvement is particularly vital at this time.

We should be reflecting on how we can diversify our approaches to involvement and looking at our relationships and networks with community organisations.

Do current approaches for involvement ensure people from communities that are often seldom heard have equal access to support decision making in health research? And how do we ensure those that are disproportionally affected by the virus are aware of and



By the end of April my initial energy was depleted, destroyed by reports of BAME communities being disproportionally affected and dying at higher rates - the very community that includes my friends and family.

The blur between my identities as a professional working in health research and as a Black British 'Yorkshire Lass' with Grenadian heritage embedded in community organisations became harder to separate. I listened to reports of people from the Caribbean community that were in hospital and some concerning experiences of

healthcare services. In addition, I had the responsibility of signposting them to official guidance about the government's measures, to challenge misinformation spreading via Whatsapp and encourage people to call 111 or contact the GP even though they had a fear of catching Covid19.

Fear and uncertainty is definitely something I can understand, my feelings of uncertainty when entering the healthcare system have increased now, both for myself and my

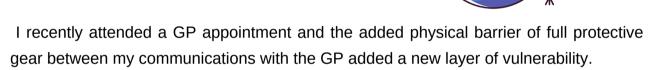
mother who has been recently diagnosed with cancer.

Can I keep attending appointments with her to be able to explain what the Doctor has said in a way she will understand?

How do we weigh up the risks of starting chemotherapy vs. the possibility of contracting Covid19?

What do I need to do to keep myself and the GP safe?

Should I sit down, stand up, stay further back, touch the door handle, wash my hands again?



The waiting room was no longer within the GP surgery it was outside, in the open and exposed. I can't begin to imagine how many people have avoided interacting with the healthcare system e.g. health screening appointments, new symptoms, routine appointments etc. Equally those that have had appointments delayed, are managing existing conditions or taking new/ existing medications.

Patient safety is so vital and the language of safety seems to be used in conversation now more than when I first started working in the Yorkshire and Humber Patient Safety Translational Research Centre. How do we continue the conversation of safety in healthcare, the community and at home beyond the pandemic?





These are all heavy topics, but embracing this uncertainty has lead me to reflect on my privileges, the things I have, the area I live in and people I take for granted.

My silver linings remind me that I am alive and need to make the most of this time. Life is uncertain and self-care is important.

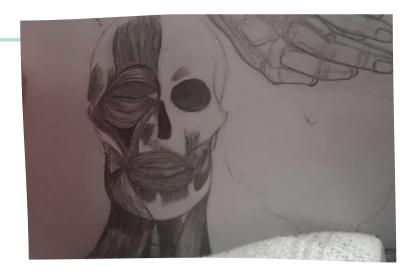
Constant calls with my family, drawing again, taking time to reconnect with nature and being able to read more has replenished my energy.

And I have been able to slow down, breath and develop my relationships with both research colleagues and involvement members in a way that the rush of life before the pandemic didn't allow space for.

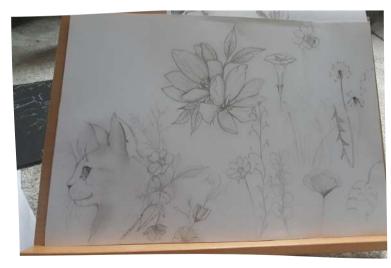
I have absolutely valued learning more about each and every one of you with this 'keeping in touch' booklet. Thank you for sharing a piece of yourself.

Sending love and light to you all xoxo











More ramblings re life during the pandemic lockdown: May 2020

Our day to day situation has not changed significantly since my first ramblings re life during the pandemic, at the end of April 2020, so they remain pertinent now, at the end of May 2020.

Life continues as it was then, with much the same restrictions, but obviously we accept the way life has to be, during the pandemic. We continue to enjoy time at home, seeing our daughter from a distance, when she brings our shopping. Days seem to meld into each other and it is not always obvious what day it is! We keep busy and we are never bored, for which we are thankful! The lovely weather has helped a great deal, as we have been working in the garden most days. I am thrilled with the dahlias that are growing from the tubers I dug up last autumn. We have become well acquainted with slugs, snails, vine weevils and cats! We don't have a cat, but neighbourhood cats seem to have adopted our garden – not because they like us! Unfortunately, they like the birds that frequent the garden!

There is nothing quite like a good stint in the garden for clearing one's head, and

'putting the world to rights' - if only!

Whilst we haven't put the world to rights

, we have had plenty of time to enjoy being

at home, and we have been able to make a difficult life choice that we were struggling to make. To move house or not to move house?, that was the question! We have reached the stage in life when we are weighing up the pros and cons of downsizing. Not easy! To cut a long story short, we accept that although it might be sensible to move, we are not yet ready to make that move.

We enjoy life where we are, even during the lockdown! So, we are staying put!



We have allowed technology to invade our space – up to a point! Our tech. 'know how' amounts to not very much! We plod along with the basics and we are just trying to get to grips with Windows 10, which is still relatively new to us. It is probably fair to say that we are not very adventurous when it comes to technology. But, oh dear! It seems that everyone is zooming, now that contact with other people is somewhat restricted. Zooming? We had never heard of it!

We didn't have the 'where withal' to zoom, and maybe we didn't want the hassle of having to learn? However,we were getting out of touch with groups with which we are involved, as actual meetings were, out of necessity, replaced by virtual meetings. Zoom! There was only one thing for it! We bought a camera / mic. for our p.c. We are not very proficient yet, but we are trying! If I am honest, I am pleased that we took the plunge, as we are back in the loop. Better still, we earned a brownie point from our tech. savvy grandson. That was a first!

A great deal of time has been taken up watching scheduled news programmes and Corona Newscasts, to which I have become addicted, temporarily I hope!

Why do I need to watch? I guess I am hoping to hear some snippets of information that will give us hope of some improvement in the covid situation and, generally in the 'state of the nation'. It seems that every time our leader addresses the nation, to inform us of important developments and advice, he causes a huge amount of confusion and concern. The apparent lack of cohesive planning within government, and lack of clarity in our leader's presentations to us, are quite worrying.



What are we supposed to do when we are being given conflicting information and advice from the very people who are meant to be leading the way through the pandemic, and managing it's effect on our lives and the economy of our country?

Whilst acknowledging the enormity of the task, what are we supposed to do if we have neither respect nor trust for our leader? So many people have made huge personal sacrifices to keep us safe, and to ease our lives by keeping vital services accessible, and so many families have endured so much pain during this pandemic.

It is just incredible and almost unbelievable! We could never have imagined the impact of the corona virus! It is anticipated that the brilliant professionals who are investing so much time and effort into the search for a vaccine, will succeed one day.

Hopefully sooner, rather than later.

Who knows?

"Hope is important, because it can make the present moment less difficult to bear. If we believe that tomorrow will be better, we can bear a hardship today"

'Thich Nhat Hanh'

Wendy

LIFE DURING A PANDEMIC

We are in a Global Metamorphous just as you think the caterpillar is dying it turns into a butterfly. Marilyn (Improvement Academy Lay Fellow)

Massive thank you for all the contributions and to everyone who has been involved. We hope you enjoyed this as much as we did!

Stay safe x

Booklet created and collated by Olivia Joseph and Claire Marsh in June 2020.



