

Ymchwiliad i effaith Covid-19, a'r modd y mae'n cael ei reoli, ar iechyd a gofal cymdeithasol yng Nghymru  
Inquiry into the impact of the Covid-19 outbreak, and its management, on health and social care in Wales  
Ymateb gan unigolyn  
Response from an individual

I am writing, in a private capacity, in response to the Health, Social Care and Sport Committee's consultation & inquiry into the Covid-19 outbreak in Wales.

These are some of my thoughts on the impact of the outbreak, and its management on, health and social care services in Wales:

1. "The Welsh Government supports and encourages everyone to download and use the Novel Coronavirus (COVID-19) Symptom Study app,"

I did download the app and used it twice before I discontinued use and deleted the app from my phone. The reason I decided not to use it are because I have several health conditions resulting in symptoms that could be mistaken for Covid symptoms and there was no means by which to explain that the symptoms being experienced were normal symptoms of an ongoing condition completely unconnected to Covid. For example 2 of my conditions are ME, Fibromyalgia & IBS, the symptoms of which include headaches, muzzy head/lightheaded, muscle aches and pains, extreme fatigue, stomach pain, tinnitus, general feeling of being unwell/coming down with something. Thus my entries instead of symptom tracking covid symptoms could be just tracking my ME/fibro symptoms. Impossible to know if it's covid or normal M.E. It would therefore give a very unrealistic picture for the purposes of trying to track Covid symptoms.

If lots of other people with similar conditions are taking part, then the results may not be very reliable for the purpose of the app/tracking covid symptoms.

2. Testing. Are unpaid carers critical front line/critical workers too especially as they are effectively keeping people out of care, nursing homes & hospitals by being full time unpaid carers. I believe that they should be able to be tested as well.

Unpaid carer's, in some areas, are given an iCareCard and are apparently treated as 'key workers' in supermarkets on production of the card.

Is unclear whether we are in fact recognised as key workers or whether we will be entitled to testing.

3. Also regarding the £500 given to paid care workers, I think it should also be given to unpaid carers. During the Covid 19 crisis – even more strain is put upon unpaid carers. I am an unpaid carer to my mother who is nearly 93 and has dementia. Respite breaks were hard enough to get before the Covid crisis. Now of course a break of any length of time is impossible. This is creating an incredible additional strain and negatively effective both physical and mental health.

I can only hope that provision of respite breaks will be reinstated as soon as the crisis is over.

4. Difficulties with length of time to get letter extremely vulnerable and being able to get on line supermarket delivery slots. I found out by chance myself that Mum (92 with dementia & other health issues) is classed as extremely vulnerable & should have received a letter. I rang the GP and he sent a letter, received on Monday 11th May 2020 but there was no information about how to get in the supermarket list for priority delivery slots.

On Friday 15th May 2020, I received a telephone call from the county council about myself being on the extremely vulnerable register. I explained that I had not received a letter and that I was still having great difficulty getting supermarket deliveries. I explained about my mother's and my dietary needs, (between us allergies, intolerances (including wheat), diabetes, and eating needs arising from cancer treatment). This means that it is very difficult for other people to do out shopping for us, so the suggestion of volunteers doing our shopping would be problematic. I explained that the single thing that I need is to get on the priority lists for deliveries, but no-one seems to be able to tell me how to achieve this.

However, the outcome was that I would get a food delivery box – this would contain wheat & other items we may be able to have so I will need to be careful to check the ingredients as they could not cater for special dietary needs! By the end of the call I was exhausted so just accepted the offer of the food box.

This is some 9 weeks after being advised by the government to self-isolate due to being vulnerable. I find this incredulous – what a waste and all I need is help getting on the priority delivery lists.

So getting shopping has been and still is a nightmare. It's still just pure luck when I have managed to get a delivery slot and causes stress and frustration.

5. I understand that there are 5 new methods/treatments being trialled in Wales. However, I notice that IV Vitamin C is not among. I have read a lot of reports and evidence based articles about the benefits and positive outcomes of using high dose IV Vitamin C.

Also HBOT has been proved to be a positive treatment for a number of conditions, including those requiring addition oxygen levels to reach the cells. a local Newtown company has offered to provide hyperbaric chambers to assist patients in their recovery of Covid 19.

I feel that both the above methods would prove beneficial and I hope these treatments can be seriously considered by the Welsh Parliament.

“Our vision is to provide hyperbaric oxygen therapy as an accepted and proven alternative therapy to assist in the recovery process and alleviate the pressure on the NHS by treating patients in a series of alternative clinics and locations.”

“HBOT is an innovative and specialised oxygen treatment that enhances the body's natural healing processes by inhalation of oxygen in a total body chamber, where atmospheric pressure is controlled. This allows the body to absorb greater amounts of oxygen into the bloodstream.”

References:

<https://www.mediwales.com/news/welsh-firm-aims-to-launch-therapy-that-could-treat-covid-19-patients/>

<https://www.countytimes.co.uk/news/18405364.coronavirus-newtown-cellpath-founders-oxygen-chamber-plan/>

<http://orthomolecular.org/resources/omns/?fbclid=IwAR0ZHnGclaQ4TAKS26x1hGQuOhMlOygbSaEih9sEMleTltQX71sgVjmNCSO>

### **Additional information – 28 May 2020**

The government food boxes do not help those with medical dietary needs - many vulnerable people have special dietary needs

The tick box system the local authorities use to support vulnerable people (it was clear the officer was reading from a script and could not cope with my answers which didn't fit in with a clear yes or no,) is too rigid and cannot take account of variations. While this might make statistic analysis easier, it is also likely to render the data unreliable.

Since my submission, I did indeed receive a food box. The volunteer did not knock but just left it on the doorstep which I found after s/he had driven away. This meant that I was not given the opportunity to ask the volunteer about providing foods that are safe for me and my mother as the officer at the council had informed me I should do.

This is not a criticism of the officer, but of the system that she was required to use – follow a script, use the tick box form - and she had clearly been given no/little training or sufficient information about provision/procedures for people who do not fit.

The box contained mainly wheat products and some high sugar products. Both my mother and I are wheat intolerant (the consumption of wheat causing us both varying painful and debilitating effects) and my mother is diabetic which is controlled with diet.

As most of the contents of the box were of no use to me or my mother, I donated it to the food bank. The person from the food bank informed me that the government's food boxes do not allow for any special diets necessary as a result of medical conditions.

This seems absolutely ludicrous to me. The people the food boxes are intended for are people who are extremely vulnerable due to medical conditions. Many elderly people and younger people with chronic conditions have special dietary needs.

It really does appear to be more of a tick box exercise. And that the tick box form that council officers are given to use must be very rigid and not allow for any variations.

A few days after the phone call from the local council, a volunteer organisation telephoned me as she had received a referral for me because I have no food. This misunderstanding arose because the council officer asked me whether I had food for a week. My reply was yes and no. I explained that I have enough tins of things like soup, beans, etc but I would run out of things like bread (wheat-free) & eggs in a day or two and had no fresh vegetables in.

I also explained to the volunteer organisation about dietary needs and again emphasised that the one simple thing that would help me is to get on the priority delivery slots. She was going to find out for me and get back to me. I'm still waiting.

Why is it so hard to get a priority delivery slot and why doesn't anyone know how to get on one?

So, in my case at least (but I'm sure I'm not the only one) the tick box 'support' system no doubt recorded another success - another statistic that a food box was delivered to a vulnerable person without recording that the contents of the box were useless, did not meet needs and would make the vulnerable person ill if they ate the food.

Thank you very much for the opportunity to make my views heard.

#### **Additional information – 29 May 2020**

I have one more very important point that I forgot to include with my submission for the above consultation.

Not being able to have any respite during self-isolation/lockdown is having a significant and far-reaching impact.

I am a full-time carer for my 92 year old mother who has dementia. Before lockdown, it was extremely difficult, time-consuming and frustrating to obtain respite care for my mother so I could have a break. It was very hit and miss and several much needed breaks had to be cancelled, including simple weekends to go and stay with my son. Now of course there is no respite at all. This is putting an enormous strain on me as a carer (I have several debilitating health conditions myself) and it's affecting my physical and mental health.

While I'm hoping that the absence of any respite is a temporary, I am not optimistic (given the previous difficulties) that respite will be reinstated and that suitable respite will be available for my mother after lockdown is over. I fear it will be a while before care homes open up again for respite provision. I changed a foreign package holiday from March to September this year (my own decision due to the risks of going abroad that were just coming out at that time). And care homes stopped taking respite residents in March as well. However, I will not be able to go in September if there is no respite provision for my mother and I will have to cancel the holiday. Travel insurance will not cover for a cancelled holiday for reasons of lack of alternative care provision, so I will lose around £600.

The uncertainty of respite, not being able to get regular respite breaks and the inordinate amount of time and effort trying to obtain the few respite breaks has caused frustration and stress in the past and I fear that this is likely to be even worse after the Covid crisis is over.

I sincerely hope that local authorities will prioritise providing suitable respite care after the crisis is over, so to ease the burden on unpaid carers and enable them to have a much needed break. After all local authorities much have saved a considerable amount of money during since March by not funding respite care.