

**HERTFORDSHIRE PSP & CBD SUPPORT & FRIENDSHIP GROUP**

**APRIL 2020**

How many times, for nearly 6 years, have I started my newsletters to you all with the now familiar format?

However, as we are all too uncomfortably aware, this dreadful global pandemic that has affected us all means that until further notice all meetings are suspended.

 But as the Queen said in her address to the nation and echoing Vera Lynn, “***We will meet again***”

**VENUE:** ***We know where***……..Redbourn Parish Centre

**DATE**: - ***We just don’t know when***……….??

**TIME**: - But we can still look forward to a Rendezvous in Redbourn when this wretched time has passed

So, I’m sending out the customary newsletter now so that we keep in touch and I hope nobody need feel abandoned. Coping with PSP or CSB is so stressful and can feel lonely at any time but never more so than now when contact with families and friends is so limited or even non-existent.

**RETROSPECTIVE:**

I feel so thankful that I returned from Australia when I did and before borders were closed and flights cancelled. I saw everyone I wanted to see, especially my elderly brother and other relatives, including a sister in law who is in a care home in Sydney and cannot receive any visitors now. Much as my family profess to love me dearly I think they could have had too much of a good thing had I been stranded there indefinitely and I’d have soon worn out my welcome! The lockdown situation there seems similar to here, as does the loo roll famine!

**KEEPING IN TOUCH** As some of you will be aware, over the past week or so I have been phoning as many of the people who regularly attend our meetings as I can to see how they are and I was greatly reassured to learn that so far, or certainly at the time when we spoke, all the individuals and families I contacted were safe and virus- free and supported for shopping etc. by family and carers. I hope that situation has continued. If I have missed anyone out I do apologise but please feel free to phone me for a chat if you wish. That goes, too, for those I have already spoken to. I have also notified the PSPA Helpline of those I’ve contacted so that they don’t duplicate the courtesy calls. The Helpline is very stretched at the moment as you can imagine but it is functioning.0300 0110 122

**COPING STRATEGIES?** Do you have any helpful coping strategies you’d like to share? Some of the group have been passing on hilarious videos. One member in particular seems to come up with new ones regularly. I don’t know where he gets them but I’ve asked him to keep them coming as they are helping to save my sanity…as is Classic FM which has become my refuge from the relentless barrage of bad news and grim statistics on mainstream media and I’ve had my fill of TV pictures of ICU units.

**Walking** a couple of miles (only once a day of course!) has been my escape from four walls. (after all, there are only so many cupboards you can tidy) but as the days pass I’ve become concerned about the increasing number of joggers who come barrelling towards me exuding an invisible cloud of flying sweat and huffy puffy breath droplets!.

**OTHER OBSERVATIONS**. Did you notice how quickly the supermarket booze shelves were stripped once the lockdown was announced? We may survive the corona virus only to end up a nation of alcoholics!

**There are several services I thought it would be worth reminding or updating you about:-**

**EXTRA SUPPORT FOR VULNERABLE ENERGY CUSTOMERS DURING POWER FAILURES** How dependent we all are on a functioning electricity supply for heating and power especially when we are caring for someone with a medical condition or who relies on medical equipment, or refrigerated medicines. There have been some worrying references to the possible interruption to power supplies if maintenace staff levels were affected by Covid -19 related staff absences so if you have not already registered with your energy supplier as a priority customer I suggest you do so. You are eligible if you :-

* are elderly
* **have a serious or chronic disease or a disability or you care for such a person**
* live in the London, the East or South East of England.

Registering will entitle you to receive extra support if you experience a power cut. For more informatiom go to[**https://www.ukpowernetworks.co.uk**](https://www.ukpowernetworks.co.uk) **or phone 0800 169 9970. Each energy company maintains its own Register.** In the event of a power cut you will have a priority number to call and a dedicated team who will contact you to keep you updated etc. I registered when caring for my late husband and am still on their records as I received an update just last week..

**BRITISH TELECOM TELEPHONE SPECIALIST CARE TEAM S**ome of you may recall my landline went AWOL last month. As result I discovered the Specialist Care Service offered by BT for “vulnerable “users. Initially it was going to take nearly a week for Openreach to deal with the fault until I lodged a complaint, online, explaining that I am aged 78, live alone and the outside door to my building 3 floors below is operated though my landline for a caller e.g. in a medical emergency, to contact me to request entry and for me to activate the door opening for them. This information made a huge differnece! BT were excellent! The fault was fixed that afternoon and I subsequently received a phone call from the engineer explaining the reason for the fault, several texts from BT confirming that it had been fixed and the following morning a phone call to see if I were satisfied and happy for my complaint to be closed. If you should be in a similar sitaution it is worth exploring this service.

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enquiries@beaconchc.co.uk **0345 548 03000**

**Beacon Continuing Healthcare** the not- for- profit agency who advise on how to obtain NHS Continuing Healthcare have issued a summary of major changes to the NHS Continuing Healthcare system which have been enacted by the coronavirus emergency legislation. The Coronavirus Act 2020 implemented several measures to protect the NHS frontline. These included changes to hospital discharge, the way that new or enhanced care packages are funded, and NHS Continuing Healthcare. Beacon will explain in detail what the changes mean for families who are in or may be entering the CHC system and also what you need to do during this time to ensure your right to fair assessment, review and care choices that can be exercised once the emergency period is over. Beacon’s services, both casework and their Free Information and Advice Service will remain fully operational during the corona emergency.

**COVID-19 SCAM WARNINGS FROM HERTFORDSHIRE POLICE**

While we may feel we’re under a sort of “house arrest” the scumbag scammers are still very active deploying new scams that take advantage of the current situation. I am constantly updated by Hertfordshire Police as part of Neighbourhood Watch .

Only follow up offers of help from trusted sources or websites you would normally use and register with your local Neighbouthood Watch scheme to be kept informed. The range of scams changes all the time.

** SUPPORT OUR PSPA**

More than ever our vital (but very small) charity needs our support at this time. You may have been aware, as I have, in recent days of the worrying news that charities and hospices are facing significant loss of income as the result of fundraising events having been stopped indefinitely. PSPA, in keeping with other charities, will be seriously affected by this . Large events such as the London Marathon as well as the very many smaller ones organised throughout the year by groups, families or individuals are a major source of the revenue which makes the essential information , support and research work of PSPA possible.

How can we help?

It occurred to me that some possible ways could be by:-

* setting up a direct debit or reviewing an exisiting one in favour of PSPA if you can afford it
* ensure you’re registed for Gift Aid so that your donations will be increased by 20% by HMRC
* as you’re likely to be doing more online shopping than previously why not sign up to one of the agencies that will pay a percentage of the value of your purchses to your nominated charity. These include.: https://smile.amazon.co.uk https://www.easyfundraising.org.uk https://www.giveasyoulive.com
* as we’re not likely to be spending as much as usual on outgoings such as petrol, meals out, entertainment etc. you might consider making a one- off donation

Let me assure you nobody at PSPA has asked me to put this request to you ….it’s entirely my idea and I am mindful that many of you will be facing hard times yourselves because of the appalling impact of the Covid-19 crisis on the econmy. I feel the utmost sympathy for anyone in that situation so these suggestions certainly do not apply to you.

Finally, we may not be able to meet…. for now ……but in the meantime if you just want to have a chat or get in touch either by phone or by email please don’t hesitate.

I’m off to do some washing- up now……I’m saving on Brillo pads these days as my hands are so rough from such frequent washing they can scour the saucepans by themselves without additional help!

I wish you all and your families a restful and, most of all, a healthy Easter

Kind regards

Maureen

Maureen Horne

Volunteer Co-ordinator Hertfordshire Local Group **gordeenhorne1@aol.com** **01582 763432 07772 774458**