

April e-news

Dear CGD Society member,

Welcome to our April edition of our newsletter.

In light of the current situation with the Coronavirus, this update will focus on the support we have been recently providing to the CGD community.

These are unprecedented times for us all. The outbreak of the Coronavirus (COVID-19) has led to much uncertainty and a change in the way we live our daily lives.

We are aware of the impact this will have on individuals, families, carers and carriers affected by CGD. The number of enquiries from concerned or worried members has significantly increased over the last few weeks. We would like to reiterate that we understand and are here to help, offer advice or support wherever and however we can. We have created a [dedicated page on our website offering the latest advice on COVID-19](#) along with emotional support information and ideas for us all to do while we are staying home or are having to self-isolate.

Although we are a very small team here, we are working as hard as we can to keep responding to our email and telephone help line or to provide you with the latest medical advice from our wonderful medical team and other recognised bodies like WHO (World Health Organisation), UKPIN and PIDUK. We'll be updating our website, social media channels and our newsletters to offer a listening ear when you may feel overwhelmed. We'll make sure that although we are all practising social distancing physically, that communication flows and our community still remains connected.

Each case of CGD is very different. Depending on your medical history and medication you may be given specific advice regarding self-isolation or you may need to follow government guidelines. We must all, including our overseas community, practise social distancing. Our CGD Society Clinical Nurse Specialist, Helen, is working hard to contact our members to give specific advice where needed. However, we should all be practising the social distancing protocol and only leaving your home for your once a day exercise and to shop for essentials for yourself or those classed as vulnerable.

This can all have an impact on our mental health, especially those who have been advised to self-isolate. You may feel a little lonely, frustrated, anxious and worried which is understandable and normal in these uncertain times. Missing family and friends can also be difficult and lead to feelings of depression.

Unfortunately, our charity does not currently offer a psychological support service (although this is something we are currently researching – both from a programme and funding perspective as we would love to offer this to our members). The good news is that there are some truly wonderful groups, projects and services out there who are specialised in this very area. We've listed a few of them on our dedicated COVID-19 page on our website. They offer online and [practical ways to look after you and your mental health](#) in this testing times.

Please do monitor our website for [updates on the COVID-19 epidemic](#) or our social media pages.

Stay safe, keep well and we will get through this together.

Best wishes,

Claire, Adelle, Susan, Helen and trustees



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