

Keeping psychologically well during COVID-19 when you have a neurological condition

Challenging and Uncertain Time

We are all in the middle of a really challenging and uncertain time, with COVID-19 having changed so many aspects of our everyday lives over a very short space of time. Regardless of whether you have a neurological condition or not, it is normal that you might feel stressed, anxious or fearful about all the changes and uncertainty that COVID19 has brought with it.

The Department of Psychology from St Vincent's Hospital Group (SVHG) has online resources for managing psychological well-being for all SVHG patients. You can see all the patient resources available here:

<https://www.stvincents.ie/psychology-for-patients/>

Remember there is no right or wrong way to feel- how you feel is how you feel, and that's ok. Everyone's response and reactions are unique. And feelings may change day to day or even several times a day. Some people may take all these changes in their stride and others may really struggle to cope.

Common Feelings

- You might feel a fear for your own or others' health
- You might also have feelings of frustration, worry, irritability or disbelief
- Some people may feel that aspects of the situation are unfair
- You might be feeling angry at others behaviour
- Sadness and loneliness at isolation from others
- You might have feelings of disgust about the idea of contamination
- Shame about spreading the virus
- Guilt about feeling like you are "not doing enough"
- Despair about "when will this end?"
- You might be feeling numb or detached
- Or you might be feeling a mixture of all of these feelings or none of them





Changes in your Everyday Life

- **You are likely to be spending a lot more time on your own at home without the help of structures, services, routines and activities.** We know that routine can be very important to some people living with the long-term effects of a neurological condition, with social isolation often exacerbating the behavioural, emotional and psychological effects of neurological conditions.
- Your usual **health appointments may be delivered in a different way**, such as by telephone or video link, and you may not be able to access your regular services in the same way as previously. You might be getting used to not meeting with your regular health care professionals face to face.
- For some people, having less to do might mean there might be more time for **worrying or thinking** about the impact of your condition also.
- Or you might be having to get used to spending a lot more time at home with other family, with a lot more noise and distractions and you might find this challenging if you are **sensitive to noise** and hustle and bustle. This might mean that you might feel particularly **irritable or frustrated** and this might make relationships difficult or tense at home. Social isolation can also put great strain on families, particularly if people at home are unwell.
- You might also have some questions about **vulnerability and risk** in relation to COVID 19. For example, if you are taking some disease modifying medication for MS, you might be worried about the impact of this on your immune system.

Neurological Conditions and Information about Covid-19

If you have a neurological condition, such as an acquired brain injury, dementia, epilepsy, MS, or Parkinson's, some people may be finding it:

- **Difficult to process and remember** the information that is being talked about in relation to COVID19.
- You might be feeling a real sense of **information overload**. This might make it hard for you to be clear about how you can follow the guidelines and keep up with all the changes and updates.
- With all this extra information to process, you might be feeling **very fatigued and overwhelmed**.
- With changes and interruptions in your normal daily life, you might be feeling more **confused and disoriented** than before and this might be making you feel more anxious or worried.
- If you have some difficulties with your **memory or planning**, you may worry about keeping track of your medication with a change in routine



What might help?

At a basic practical and health level

- ✓ If you need grocery items, or medication, you can either order these online or ask for family, friends or neighbours to pick them up for you. Local authorities and community organizations have set up helplines for all vulnerable persons where requests can be made for supports such as medication/grocery collection, transport to essential medical appointments, meals on wheels, social supports, and Garda related matters.
- ✓ Know who is in your support system and who you can ask for help.
- ✓ Make sure all your medication supply is ordered in advance. Speak to your pharmacists by telephone to make a plan for ordering and getting your prescriptions filled.
- ✓ If you have any exacerbation in seizures or symptoms, contact your specialist team (e.g. Epilepsy nurse, MS nurse, Parkinson's Nurse, GP or Neurology team).
- ✓ Do not make changes to your medications – if you have concerns talk to your GP or Neurology Team.
- ✓ If you have a phone or virtual consult with someone from your healthcare team, try and prepare in advance by writing down questions, making sure you have a quiet space at the scheduled time or having someone else there to hear the information with you.
- ✓ **It is really important that if you are experiencing medical symptoms to get medical assistance, call your GP, or in an emergency go to your local Emergency Department. Don't delay because of COVID 19.**

What might help to process and remember information and guidelines

- ✓ Get clear, easy to follow summaries from reputable sources (For example, from the HSE, or an organization you are linked with).
- ✓ Ask someone you live with or someone you can speak with by phone to clarify any questions you have.
- ✓ Keep some information available to you so you can check it again- maybe stick it up somewhere.
- ✓ Write down questions you have for checking when you get to speak with someone.
- ✓ You might find it helpful to check the day and date every morning, (ask someone or hear it from the radio or TV for example) and perhaps write it up somewhere that you can see it to keep track of time.
- ✓ Make a checklist every day to keep track of important activities, like taking medication. Ask someone you live with or someone you can speak to by phone to give you regular reminders.





What might help to deal with Anxiety and other emotions

- ✓ Try to do some things that you enjoy and that might help you relax
- ✓ Routine- keep a normal daily routine as much as possible, adapted to restrictions nationally. Get up and get dressed, eat meals at your usual times
- ✓ Stop and take some slow, deep breaths, every now and again. This helps to manage stress, worry, and anxiety in the moment. It activates your frontal lobes, and you are likely to feel better able to concentrate and think. Relaxation breathing, such as breathing in for a count of 4 and out for a count of 8.
- ✓ Sleep hygiene- keep the same time to go to sleep, try not to use phones or screens in bed, keep a notebook to write down worries and thoughts if you find your mind is racing.
- ✓ Limit your alcohol intake and limit caffeine (stimulants)- this can increase feelings of anxiety and irritability
- ✓ Connect and contact- It is important at this time to reach out to others and keep connected. We understand that it can be hard being physically distant from family members and loved ones but we can remain emotionally close to them by telephone, skype, online. Keep in touch – telephone, video calls, email, and internet. Have conversations with other people daily if possible, and try and talk about things other than COVID 19.
- ✓ Avoid over-checking the news. Try to limit news and social media if you notice you are checking your phone a lot. Using this time to check in with how you are feeling instead. What thoughts are there? How am I doing?
- ✓ Practise being present in the moment. Some people like to practise- mindfulness, or listen to a brief meditation. Others like to activate their senses by noticing what you can see, hear, touch, taste and smell around you.
- ✓ Exercise and keep active- walking, stretching, use online home programmes (e.g. yoga, fitness classes).
- ✓ Talk to someone about how you are feeling
- ✓ Connect with nature. It can be really reassuring to notice evidence of new growth and renewal all around. If you don't have a garden, it's not so easy, but other options include planting seeds, tending to house-plants, feeding birds out the window.

How you can feel more energized, creative or useful while staying at home

- When do you feel most useful, energised or creative? Something that gives you a sense of purpose, achievement and feeling in control.
- Examples: - Providing advice or sharing wisdom with others - Cooking or baking - Tidying or cleaning your home - Working in your garden if you have one - Completing a puzzle - Doing an online course - Playing a musical instrument - Writing a diary, memoir or letter - Putting old photos into an album - Making a list of things you are thankful for

How can you feel more at ease while staying at home

- When do you feel most at ease?
- Examples:- Talking with family or friends - Eating a nice meal - Offering comfort to others - Looking after a pet - Listening to your favourite music - Watching your favourite TV shows - Having a warm bath - Looking through family pictures - Painting - Sitting out in your garden or balcony if you have one- Reading the paper or a good book- listening to an audio book or radio



For Family members or carers

- This is likely to be an extra challenging time for family members also, so remember to look after yourself.
- Some ways to help the impact of cognitive impairment include providing written or visual prompts (e.g., picture of hand washing at sinks), frequent reassurance, and supporting and maintaining routine and consistency (as far as possible). Perhaps support the person with cognitive difficulties to make the most of virtual or telephone health care consults. Ask for help from local voluntary services for things like picking up medication or shopping.

Resources for Family Members or Carers:

- www.carealliance.ie 01 874 7776 – Support for carers and families
- www.familycarers.ie
- **SVHG Relative Support** service for Inpatients and family members to stay in touch:
01 – 221 4009 or 01 - 221 5045
Monday-Friday 8am-8pm, Saturday and Sunday 10-4pm

Further resources:

Department of Psychology SVHG online resources for keeping psychologically well for SVHG Patients:

<https://www.stvincents.ie/psychology-for-patients>

There are also resources and support from specific services – try helplines or check for updates online that may have particular tips that could be helpful for you.

For example, MS Ireland, Epilepsy Ireland, ABII, Headway, Irish Heart Foundation, Irish Wheelchair Association, Parkinson's Association of Ireland, Migraine Association of Ireland.

If you feel your mood is not improving and it is impacting on your day to day functioning you should seek additional support from your GP who will discuss treatment options with you





Helpful links and resources

Some other helpful links that you might be able to contact:

Alone:

www.alone.ie /0818 222 024 – supports for older people

Mental Health Ireland:

www.mentalhealthireland.ie – 01 2841166 – Mental health support resources

Wheel:

www.wheel.ie- 01 4548727 Community Champions and community support

Aware:

www.aware.ie Telephone (Freephone) 1800 80 48 48

Samaritans Ireland:

www.samaritans.org/ireland/samaritans-ireland/

Telephone (Freephone): 116123, 24 hrs

Websites for specific neurological conditions with Covid-19 support:

<https://www.ms-society.ie/coronavirus-covid-19>

<https://alzheimer.ie/about-us/coronavirus-covid-19-update/>

<https://headway.ie/2020/04/useful-supports-during-covid-19-outbreak/>

<https://parkinsons.ie/TheCoronavirusAndParkinsons>

<https://www.abiireland.ie/coping-with-covid-anxiety/>

<https://www.epilepsy.ie/content/coronavirus-epilepsy-updated>

<https://irishheart.ie/news/coronavirus-mental-health-difficulties-common/>

<https://www.huntingtons.ie/COVID-19-Information>

<https://www.diabetes.ie/covid-19-questions-answers/>

<https://migraine.ie/2020/03/access-to-neurology-services-and-covid-19/>

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