The Parkinson's NSW Guide to Effective Online Support Group Meetings and Chat Groups

Introduction

Online health communities (OHC) have grown at a rapid rate over the past two decades and are predicted to expand further over the next few years.

The online exchange of information and knowledge is fast becoming a valuable way for people to connect within communities, communicate and find support across many health issues and topics.

The outbreak of Coronavirus (COVID-19) – declared a pandemic in March 2020 – has brought about profound social and economic consequences where public freedoms are being restricted as part of infection control measures.

Over the past two years Parkinson's NSW has been transitioning its Support Groups to OHCs through the introduction of:
- **Online support group meetings**
- **Online discussion/chat groups**

The success of OHCs is explained by three principles:

- Focusing on the needs of users, having a shared community purpose and goals
- Encouraging adherence to on-line etiquette, purpose, protocols, and codes of behaviour
- Facilitators of the group encourage discussions and reward members

OHCs are cost-effective, available 24 hours a day, do not have geographical barriers and are particularly useful for people living in regional and rural areas.

OHCs reduce the need for travel, provide for more accessibility, younger people are more likely to attend, and they offer the ability to have more homogenous types of Support Groups – for example focused on supporting younger people, caregivers, newly diagnosed, and women or men.

Friendships and relationships are formed online as participants gain a further understanding of technology and themselves.

OHCs enhance communication between patients and health professionals while supporting the coordination of care across traditional practices – something that does not happen naturally in busy practices.

Internet rates in Australia support future development of online support groups as more and more people are accessing the internet.

Your safety online

Using technology such as computers and smartphones comes with some risks.

However, don't fear or avoid technology – with common sense and some helpful tips, these risks can be managed to ensure your online safety.

Technology can open up new ways of communicating and having fun with your nearest and dearest – without being face-to-face.

Here are nine ways you can relate well with others, while protecting your privacy and guarding against scams (fraud) while online:

1. Choose strong passwords

Some web sites and all accounts for online applications require a log-in – a space provided where you must type in a password or code.

For optimum security, choose a unique password that only you would know. Use special characters and symbols and consider using longer words strung together.

Do not share your password information by email or social media and avoid entering your password unless you recognise the website you are visiting.

Here are some tips on [choosing a strong password](#).

2. Use Google for safe searching online

When searching for information, a company, product or person online, don't simply use an address that someone has sent you.

Instead, use [Google](#) to search for what you want. You don't need to know a web address – Google is a widely used and trusted search engine that provides safe and trusted answers to any question you may have online.

It can help you find products and services, order home deliveries, look up the latest news, and troubleshoot any technical issues you may face while online.

3. Install and keep antivirus software up to date

If you don't already have antivirus software installed on your computer, it is important to download and install it for your online safety.

There are many free downloads available [here](#).

These can protect your device from hackers or malicious viruses and software.

A hacker is a person who tries to gain unauthorised access to your computer programs. A computer virus is a type of malicious code or program written to alter the way a computer operates.

It is designed to spread from one computer to another. A virus operates by inserting or attaching itself to a legitimate program or document. In the process, a virus can cause damage such as harming the computer's system software by corrupting or destroying data.

Once you have installed antivirus tools, they run in the background on your computer. You don't have to do anything more than occasionally update them.

They will give you an automatic alert if they detect an issue, and they usually quarantine viruses so they cannot damage your computer or phone. You can then browse the internet while feeling a more secure.

4. Don't reply to emails from people you don't know

There are scammers (fraudsters) who send alluring emails to try to steal personal information.

You can avoid these cyber criminals by [choosing not to open or reply to any emails](#) from people you don't know. Remember: if something seems too good to be true, it probably is.

Most Australian banks, insurance companies, online shops and other companies have a policy of not asking you to share personal information by email.

So, if you receive an email pretending to be from your bank asking for your account number for example, it will not be a legitimate request.

The same caution should apply to telephone calls supposedly coming from your bank, the Australian Tax Office, Centrelink, etc. They have a policy of not asking for personal details over the phone – particularly account numbers or passwords.

If you are suspicious of a phone call, text message, email or online activity, the first place to visit is [Scamwatch](#).

Scamwatch is a web site run by the Australian Competition and Consumer Commission (ACCC) and provides information to consumers and small business about how to recognise, avoid and report scams.

5. Be careful when you click on a link or attachment

Before you click on a link in an email or download an attachment**,** [make sure you confirm the identity of the sender](#).

If the email came from someone you know, it is likely safe to open the link or attachment. However, it's always best to use caution when handling anything unknown on the internet.

It will always be safe to open a link or attachment from Parkinson's NSW.

6. Avoid oversharing on social media

Social media (for example Facebook) is intended for communicating with others but do be selective about the information you share.

Personal information such as your passwords, account numbers, phone number, and address should never be shared on a public forum or with strangers online. Also be careful of anything you share about people you know. It is best to first ask them for permission to do so.

7. Follow online etiquette

There are a few unspoken rules that social media users follow.

For example, writing with the caps lock turned on is generally interpreted as shouting. Emojis and other images can also have their own meanings, so it's best to research an unknown symbol before using it on social media or any other website.

An emoji is small digital image or icon used to express an idea or emotion like this:

🙂

8. Change your smartphone settings for easy reading

If you find that text size on the screen of your smartphone is too small, you can change your settings to increase the size and adjust the screen brightness. Find out how to change them here.

9. Add contacts to your smartphone for family and friends

Your phone allows you to store saved contact information for your family and friends, so you no longer have to type in or remember each person's phone number.

Read through your phone's instructions on how to add a contact to your phone, whether you use an Android or an iPhone. Android phones include brands like Samsung, Huawei and Sony, and iPhone is an Apple product.

Here's how to add contacts to your Android phone. Here's how to add contacts to your Apple iPhone.

Benefits of online Support Group meetings and chat groups

The purposes of PNSW Support Groups are:

- Provide a forum for Support Group participants to learn and support one another
- Help promote and further the purpose of Parkinson's NSW
- Increase the effectiveness of communications between Parkinson's NSW, its Members and Support Group participants

The appropriate use of technology can help all involved to fulfill these purposes – offering flexibility of timing, overcoming distance and becoming a bridge between people during social isolation.

Tips on effective online meetings and chat groups

Introduce yourself

When you first enter the Online Support Group or chat 'room', treat it like a physical room and introduce yourself.

At first the session leader (usually the Support Group Leader) may have all participants on mute. This is nothing personal; it is just a practical way of preventing people from talking over one another until some structure is established for the virtual meeting.

When you have the opportunity to speak, you may like to give your first name – or choose to be known by a nickname you have created for this purpose. It's your choice.

Be guided by the Support Group or chat group leader

There will always be a Support Group Leader, or someone nominated in their place leading the online meeting or chat group.

The role of the Leader is to provide support and guidance for the online session, to ensure the guidelines for participation are understood and followed by all, and to ensure that the Online Support Group or chat group is a safe place for all users.

Respect other users

Open and honest communication is encouraged within the Online Support Group or chat group, but always be aware of how your words may impact others.

Please be patient and kind with other users and try to respect other individuals' opinions, statements, ideas, and shared story or experiences – even when they may be quite different to your own.

One person speaks at a time

Each person should be allowed to speak free from interruptions and side conversations. Please also be respectful of conversational space and try not to dominate the conversation.

Some people may have issues with their voice and speaking can be difficult.

One of the great things about being online is that you can type what you want to say. Ensure that the people who are typing can have their comments included in the conversation.

'Headline' your comments

Say the most important part of your comment first. Try to keep your contribution brief and to the point.

Respect confidentiality and privacy

Respect everyone's privacy. Being part of a Support Group (whether in real life or online) requires mutual trust. Authentic, expressive discussions make Groups great, but may also be sensitive and private.

Above all, remember 'what is said in the meeting stays in the meeting'.

This is the essential principle of confidentiality in any peer-support group or chat group and must be respected by all participants.

Offer support, not advice

The Online Support Group or chat group is a space where – if you want to – you can provide really valuable support to other people who have experienced similar issues to you.

However, remember that you are there to provide support not advice.

Everyone's experience of Parkinson's disease is unique. What worked for you will not automatically work for someone else, no matter how similar their experience may sound to yours.

The most helpful thing you can do is speak personally – "what worked for me" – and let others decide for themselves if it might work for them too.

Differences of opinion are OK

We are all entitled to our own points of view. Be kind and courteous, we're all in this together to create a welcoming environment. Let's treat everyone with respect.

Healthy debates are natural, but kindness is required.

It's also OK not to share

People do not always need to actively participate. Much can be gained by just listening – particularly if you are new to this.

Also do not share content that is self-promotion, spam or irrelevant links. Only share information that is evidence-based – in other words, information that comes from a credible source or a professionally qualified person

The Group or chat leader may interrupt you

This is nothing personal; it is sometimes necessary to keep the session on track.

Online behaviour

As in face-to-face Support Group meetings or conversations, Online Support Group and chat group behaviour is guided by the Parkinson's NSW Support Group Guidelines and Parkinson's NSW Support Group Charter, both of which are found within the *Support Group Manual* which has been issued to every Group.

Specific online behaviours to avoid include:

- Not posting any statement which you know is false, inaccurate, misleading, defamatory, libellous, or in violation of any law.

- Not posting statements, asking questions or using language which may be construed as offensive, harassing, threatening, abusive or invasive of a person's privacy.

- Not posting any statement that may be construed as discriminatory on the basis of race, gender, sexual orientation, religion or any other form of illegal discrimination.

If you have any queries, concerns or require further information relating to this Guide, please contact:

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