

Neurological Alliance of Scotland (NAoS) members meeting 2nd April

This was the Neurological Alliance's first virtual members meeting, and there were 14 members who joined. We discussed the general issues we were facing in light of the coronavirus. In summary these were;

Information and issues for our clients

- As yet the CSO letters for neurology had not been issued. This was causing anxiety for those who were unclear if they fell into the 'extremely vulnerable' group and should therefore be self-isolating.
 - Gerard Gahagan from Scottish Government joined the call and indicated that these letters were expected soon, with a timescale to be published publically. They were currently interrogating the data so that only specific people would get the letter, rather than the more 'blanket approach'. Members' requested that this letter also be shared with them so that they can produce FAQ's for their helplines/support services.
 - While on the call the Scottish Government's latest advice for those with neurological conditions was sent out. This is also on NAOs website <https://www.scottishneurological.org.uk/news-resources/>
- Third sector therapy providers had stopped providing face to face therapies (in line with Government guidance) but some were providing virtual clinical therapies via phone or video conferencing services such as 'Near Me'.
- Anxiety-many members had seen a huge rise in the level of anxiety of their clients. These included concerns about;
 - getting medicines (both now but actually also with the interruption to the supply chain from China and Italy for example)
 - having access to condition specific service when so many staff are being deployed.
 - How will conditions progress longer term when therapies are not being received.
 - How to get food and other essentials when self-isolating if the support network isn't in place.

Organisational Issues

Income

Unsurprisingly the main issue that our members are facing are significant drops in projected income. This is due to the complete postponement of community fundraising (Edinburgh marathon etc.).

Some organisations had started to put staff on furlough leave through the Government's job retention scheme and others were exploring this as an option. While only currently available short term, this may offer some significant savings, depending on how many staff are impacted. Other organisations had also started redeploying staff to cope with increase traffic to helplines etc.

It was also raised that restricted funding (from trusts etc.) needed to be reallocated but there were major restrictions around this. In particular, that staff employed through restricted funding could not be put on furlough leave. This was causing an issue for some members. It was agreed that NAOs would have a discussion with SCVO about possibly influencing this.

RESPONSE: New guidance on the job retention scheme has just been issued but unfortunately this doesn't offer clarification on this issue. I've spoken to SCVO who are working with their equivalents across the UK to get the clarification we need. I'll keep you all posted!

Some members had or were planning to apply for the Scottish Government's Third Sector Resilience Fund. However, concerns were raised about the equity of this fund. There was a concern that organisations who were not on the brink of collapse, because they had good financial checks in place such as a robust reserves policy, would not be prioritised. It was discussed that a good financial position at the moment meant the ability to survive for 3 months, while the likely implications of coronavirus will extend well beyond this which makes most of our members vulnerable. NAS will also raise this with SCVO.

RESPONSE: SCVO have a lot of information about funding the sector through the coronavirus. This is very much an ongoing priority for them, so keep an eye on the website; <https://scvo.org.uk/support/coronavirus/funding/the-voluntary-sector-and-coronavirus>

Members discussed if there was a way to quantify the financial impact on the sector to demonstrate just now devastating this is for third sector.

Risk to services for people with neurological conditions

Members discussed the current risk to neurological services, with many members reporting that their condition specific nurses had already been redeployed. So there was an immediate concern, but also longer term how likely those posts were to resume their substantive roles.

Discharge plans-there was a concern amongst members that the emergency Covid-19 legislation that was passed cause major risk to those being discharged from hospital. Local authorities do not have the same duty to provide care, which means that people may be being quickly discharged without an appropriate care structure in place.

The issue of coronavirus testing was also raised. Members felt that as well as NHS staff, carers working the community should also be being tested, and those in the voluntary sector providing services.

Members who were also research funders raised the issues of delayed clinical trials. While the membership reflected that this is wholly appropriate at the moment, there are longer term implications for treatment development for those with neurological conditions.

There was also a concern for members who provide benefits support that this is incredibly difficult to administer virtually, as so much of DWP is paper based. There was also a concern that DWP were prioritising universal credit applications which had significantly increased, and that this will impact on those applying for other benefits (such as PIP).

How we influence/engage politically

We also discussed the very real challenge of engaging politically at the moment, or influencing on the issues that matter to the neurological communities we serve (as detailed above). While we know that health and social care services and local and national government are under extraordinary pressures due to the coronavirus pandemic, people with neurological conditions do still a level of treatment and care. We can appreciate that no service improvement is likely at the moment, but there is a question of what do we put in place in the meantime.

NAoS will speak to colleagues in Neurological Alliance England/Wales/NI to explore how we can ensure that our voices are still heard and services don't dramatically deteriorate long term.

Members' great ideas!

- ✓ Some members who provide therapies were now doing this virtually through tele or video link up.
- ✓ One member was using zoom to host a UK wide volunteer link up
- ✓ Some members were providing 'virtual' events, including condition specific information webinars and more informal chat sessions.
- ✓ Many members had provided condition specific information, which has been shared on the NAOs website.
- ✓ Some members were using secure desktop programmes to help people complete their DWP paperwork.
- ✓ One member explained that they were gathering data on their clients who had coronavirus and monitoring how they were being infected.