COVID-19 may have put the world on pause, but vision loss continues.

By Avril Daly, CEO, Retina International

The COVID-19 pandemic has changed the world.

This is a phrase we have heard many times in the past ten months - in many languages, across all continents. There is truth to it; many people have changed the way they live, and have learned a lot about themselves and how they fit into the world around them. The world may have changed, for now, but will these changes be permanent? Or will they be transient - and in one year will we be back to the old normal? We hope, of course, that what we perceive as good changes remain - but one person’s definition of good may not be the same for another.

All of society has had to face significant challenges at every stage of the COVID-19 pandemic: from the first phase and associated lockdown - which was a shock to all of our systems both personally and professionally - to the second, and now third and perhaps most concerning phase. At the time of writing, most of society is back where it was in March 2020; at home, filling the days with work, trying to be educators to children, and to be supportive to older relatives and friends. All the while, we are attempting to remain connected through a dozen different online applications, and wondering what normal used to be.

The COVID-19 pandemic has presented very specific and unique challenges to the vision impaired community. Through our studies on the impact of COVID-19 for the retina community, Retina International has learned about the lived experiences of those affected by all forms of retinal degeneration. The results gave us pause for thought, and in some cases the personal statements that came from the surveys were concerning. These studies will be published in the coming weeks, but as we support the Retina Action Call to Action on the theme of Wellbeing and
Inclusion, we are eager to share some of our learnings and experiences with you, our members and stakeholders.

The requirements of social distancing have made it difficult for people living with vision impairments to leave the home environment. It has become harder to rely on others to provide assistance when going outside for shopping and for exercise. Vision impaired people and those providing assistance to them by linking arms for safety and guidance as they walk in parks and on public pavements, were on the receiving end of finger pointing, and unfortunately in some cases, verbal abuse. Accusations of “breaking the rules” have arisen in cases where it is not obvious a person has a vision impairment, and therefore needs someone to assist them in order to leave the home.

Restrictions forced the world indoors and inward. However, much heralded advances in online communication and conferencing tools meant that the outside world could now be connected with easily “at the touch of a button”. Through our devices, communities could stay in touch and reach out to those living on all corners of the globe, including those living alone, for conversation, work, shopping and leisure. The statement of 2020 was “you are on mute”, as we were all learning how to use these tools better. Once we got the general idea of it, these systems would be so easy to navigate - or so we were told.

This has not been the reality for many living with a vision impairment, in particular those living alone. Online conferencing services are not fully accessible; while some are better than others, simple things like magnifying a screen can hide mute buttons and camera buttons. Chat boxes also are not accessible for most. This is a major issue for the vision impaired community who must rely on these online conferencing systems for work and for personal connectivity. In a working environment, chat boxes brought a change to the way meetings take place. Participants in meetings and webinars can add notes, thoughts and suggestions, all live, providing an opportunity for a more robust discussion and exchange of information.

For a person living with a vision impairment, chat boxes mean further isolation. We are removed from the live discussion, but are welcome to read the notes after the meeting has ended. Nobody likes to complain too much, to be perceived as difficult, so in many cases the person with a vision impairment says nothing. This is not inclusion. This is not accessibility for all.

As a person living with a vision impairment, I have participated in many ‘live’ events during this period. Some have been just fine, but others have been disastrous. The back end of online event platforms is often different to what the participant sees. They can show slides the size of a postage stamp (or not at all), and there are different interfaces with different buttons that you are not sure what do with. I am fortunate; I have a circle of colleagues who live with vision impairments, who have experienced similar challenges, I can call upon them to get tips on how to do better the next time. I have sighted colleagues who I can ask to help and make it easier for me - which I appreciate greatly. I know I will never be able to fully use these platforms, but I can participate, and I have support at my disposal. As I say, I am fortunate.
Working from home has proven a success for many, but from the surveys carried out by Retina International and other members of the community at large, it is clear that adapting to an online world has not been easy and has certainly not been for everyone. Many people with a vision impairment live alone, especially those with conditions of the ageing retina. They are not “online” all of the time and find the platforms challenging. When they do use them, and encounter a challenge, they feel they have no one to ask for help. Some don’t wish to “cause a fuss” or “be a burden” by asking for help. Many people with vision impairments live in regions where broadband is weak and connectivity is poor. Some don’t have the newest version of an operating system to allow them to connect. Many have not been trained on digital devices, or even own a computer. These individuals cannot use online platforms to carry out their leisure activities, shop, or connect with family and friends. They are further isolated; they are not included.

Retina International has learned from its surveys that those receiving treatment for Age-related Macular Degeneration (AMD) and Diabetic Retinopathy (DR) were particularly impacted during the pandemic. Many appointments were cancelled. Where clinics continued, despite assurance of safety measures, older patients were fearful of attendance in case they contacted COVID-19. Retina International received statements saying “I am afraid to take public transport”, “I don’t want to have to touch a handrail on my journey to a clinic”, “I don’t want to wait for hours in a waiting room with other people”, and “My husband can’t come to the appointment with me”. These are real and understandable fears for a group who know they are classed as vulnerable. People who for the first time were experiencing visual disturbances lost critical time as they too were fearful of attending a clinical setting. Vision has been lost.

Efforts are now being made in some countries to move appointments for those attending clinics to an online service. While this is important to consider, and may alleviate the burden of travel on patients and those who support and care for them, it must be remembered that many of those affected are not connected to digital platforms. Others have expressed a preference to meet with their clinician face-to-face. It is important to support the progress that is being made in Digital Health, while acknowledging that it will need very specific considerations.

The digital divide is real and is not going to change overnight. We must understand this when developing new tools and services for this community, especially now the COVID-19 pandemic has put the possibilities of Digital Health in sharp focus. The potential of Digital Health for the vision impaired community is enormous, with new applications that can help us with everyday tasks and really make a difference. Home monitoring devices and wearable technologies that can feedback information to clinicians mean that if another crisis occurs, symptoms can be monitored at home, and so patients do not have to attend hospital settings. This has huge potential for clinical trials also. To develop these technological possibilities effectively, patients must be included in the development and design from concept to delivery.

Two recognized symptoms of COVID-19 are a loss of taste and a loss of smell. Evidence of these symptoms enduring is emerging along with published papers on the detrimental impact of COVID-19 on the retina. As a society we are only learning of the lasting effects of this virus. The
community is concerned and is calling for people living with retinal degenerations to be prioritised in the roll out of vaccinations against COVID-19.

We have learned through Retina International’s surveys, and those of our partners and stakeholders, that the retina is not considered a public health priority in a crisis. We have learned that we must work together to find ways to bring patients receiving treatment back to the clinic in safety and with confidence. We have learned that there is a significant issue to address in order to make every day platforms accessible to the vision impaired. We have learned there is a digital divide that must be recognized, and must be considered as we develop digital health care now and into the future. We have learned that the vision impaired community, young and old, regardless of geography, have faced very real isolation during the COVID-19 pandemic that has affected their wellbeing.

This prolonged isolation has impacted the physical and mental health of our community and as a society we must find ways to improve services and access to ensure this community is fully included in all aspects of society for better wellbeing, health outcomes and indeed economic realities.

Those who make decisions on the delivery of health care services must engage with patient communities and professional societies to understand the lessons we have all learned throughout this period and apply these learnings. There is an opportunity to build back better, and it should not be missed. And so we encourage you, our members and stakeholders, to support the Retina Action Call to Action. To encourage your politicians and decision makers to listen, to learn, and to work with us as we lead the change needed to promote inclusion and wellbeing for all.

Avril Daly

Retina International

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