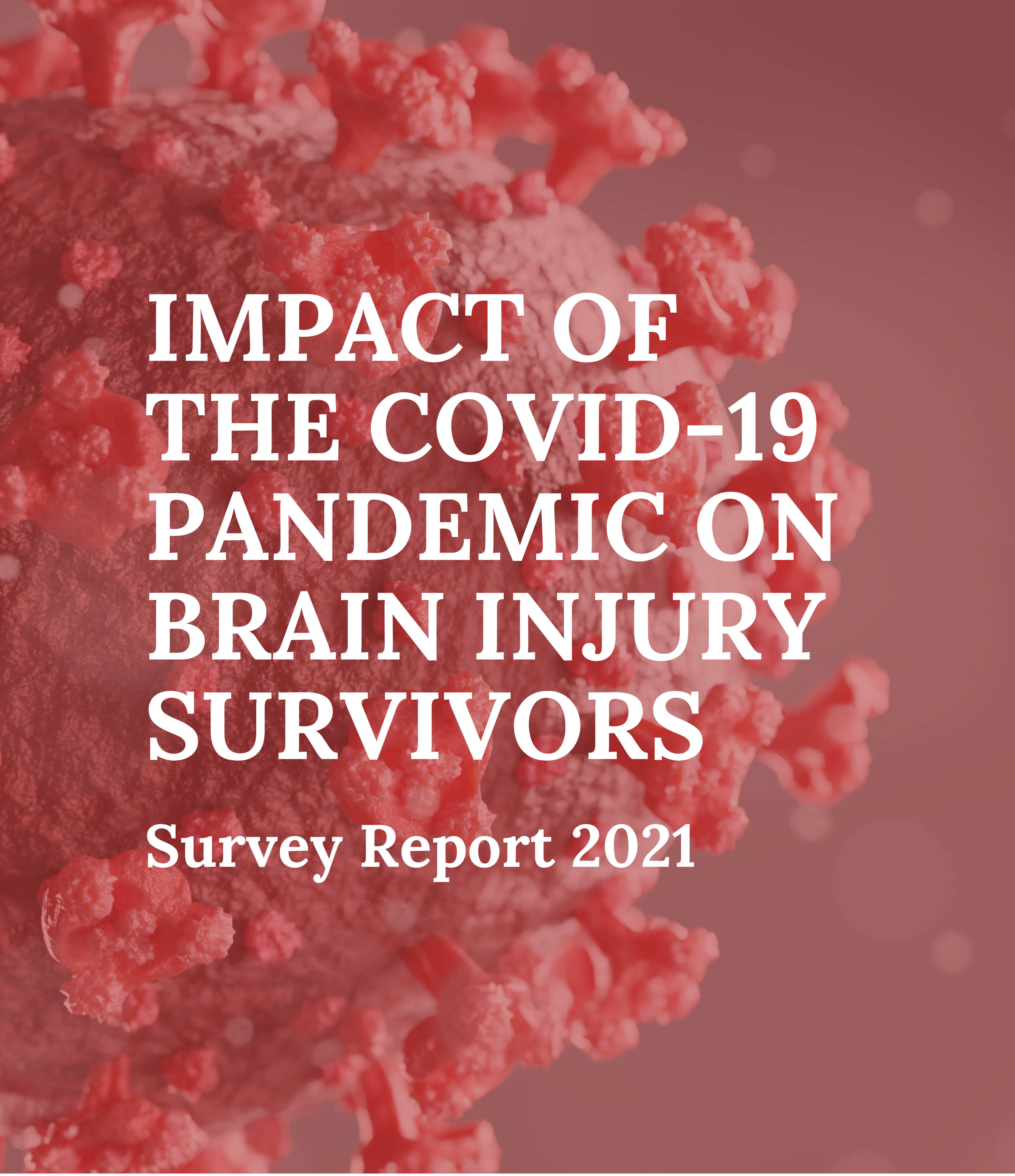

IMPACT OF THE COVID-19 PANDEMIC ON BRAIN INJURY SURVIVORS

Survey Report 2021

BRAIN INJURY CANADA | LÉSION CÉRÉBRALE CANADA

www.braininjurycanada.ca

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Introduction

In the winter of 2021, Brain Injury Canada launched a survey for brain injury survivors. The purpose of the survey was to:

- Check in with individuals one year into the pandemic to learn about how they had been coping
- Determine if there had been any challenges experienced as a result of the pandemic with respect to accessing services
- Assess which programs and/or supports had been beneficial throughout the past year
- Identify key recommendations for actions that could be taken to ensure future support for brain injury survivors across Canada

It is important to note that while many individual comments have been received, this report primarily highlights the shared experiences and themes that have been expressed throughout the survey at large. The information provided is intended as a representative overview of brain injury survivors across the country. The findings represent 135 individual survey responses.

It must also be noted that some individuals were not able to complete this survey because it was in an online format. We acknowledge those who chose not to participate in this survey, and we thank those who have brought this to our attention.

While this report may not capture each unique circumstance that has been experienced by brain injury survivors this past year, we want to be sure that the conversation continues. With this in mind, should you wish to add your voice, or share your story, it can be submitted to info@braininjurycanada.ca. Please provide your name and be sure that your story is at least 300 words. As it may be posted on www.braininjurycanada.ca, stories may be edited for grammar and spelling.

The findings of this survey support the key data and information received in the spring of 2021 from a survey that was completed by Canadian brain injury associations. These associations reported a range of conditions that directly impacted their interactions with their clients over the course of the pandemic, including:

- Reduced face-to-face contact and/or hands-on support
- Service delivery interruptions; modifications; suspension or cancellations
- Moving of programs and support services to remote online/virtual platforms, with Zoom becoming a primary technology for service delivery

With the information from associations and individuals now coming together, Brain Injury Canada is seeking ways to ensure that the brain injury community at large can continue to thrive and support one another. To the best possible extent, it is our aim to address the key gaps that are being identified in order to ensure equitable and accessible care, treatment and support for brain injury survivors in the future.

Demographic information

A total of 135 survey responses have been received from across Canada.

Responses were received from those who live in cities (94); towns (21); and in rural areas (19).

Some respondents chose to skip certain questions. However, given the volume of feedback received, all information provided is viewed as representative of the brain injury survivor community.

Unfortunately there were no responses from Yukon, Northwest Territories, Nunavut or Prince Edward Island despite best efforts to disseminate survey(s) to these regions.

Summary of findings

It is clear that this past year has had an impact on individuals who are coping with a brain injury during the pandemic. Overall, the obstacles listed below are shared by the majority of survey participants. These include:

- Reduced access to care, treatment and support
- Increased isolation
- Emotional distress
- Deterioration of mental health
- Rising rates of depression and anxiety
- Online/virtual service delivery creating challenges for many
- Individuals who are struggling and losing ground; feeling overwhelmed
- Survivors finding it difficult to maintain positivity

At the same time, it is important to note that a number of individuals have reported that they have been coping relatively well and that they have been able to maintain services and make new connections throughout the past year.

Brain Injury Canada appreciates that individuals were willing to participate in this survey and to commit the time and the thought required to provide valuable feedback in order to help others by:

- Providing suggestions for services and activities to help others, and given the unique circumstances, acknowledging that one-size does not fit all

- Demonstrating a willingness to learn about available resources and to try out new programs

- Applying resiliency and perseverance as individuals strive to adjust to new and/or changing conditions and to find new ways of coping

Emotional indicators & changes in mental health status

Overall, the top five emotions experienced during the first year of the pandemic included:

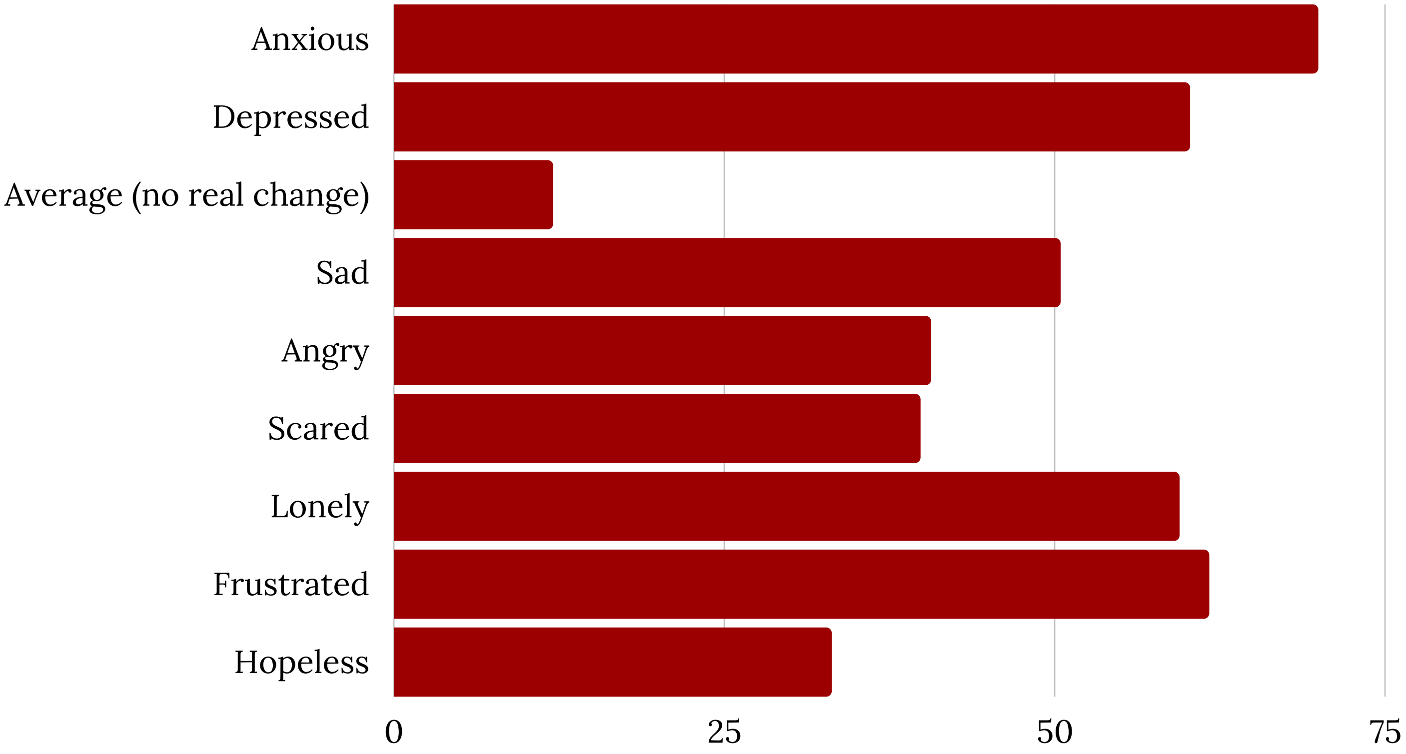
- Anxiety (93) 69.92%
- Frustration (82) 61.65%
- Depression (80) 60.15%
- Loneliness (79) 59.40%
- Sadness (67) 50.38%

Additionally, 33.08% of respondents reported feelings of hopelessness. This is a worrying trend as we know that some people have lost ground with their recovery over the past year. These conditions are also compounded by the isolation that has occurred, leading individuals to cite a range of mental health challenges with which they are coping.

When asked about how their mental health had been affected during the pandemic, 27 respondents indicated that their mental health has not been negatively affected. Some reported that they were enjoying the break from everyday pressures to socialize and to maintain the energy levels required to keep up with pre-pandemic routines and commitments.

For the remaining 100+ respondents, individuals overwhelmingly reported significant declines in their mental health. The effects of this are far-reaching, as those who are involved in the care of an individual coping with a brain injury continue to seek out ways to provide meaningful connections and support.

Increase in emotions during the pandemic



Mental health impacts

- Don't want to get out of bed, suicidal some of the time
- I have become depressed and feel isolated from my brain injury support group
- Much lower mood
- It's been real work to keep the depression at bay
- Impacted severely
- Moderately to severely affected with a dramatic increase in all brain injury symptoms.
- Major decline. I cannot return to the level of function I once maintained
- Pre-existing depression and anxiety have worsened
- More isolation has meant more depression and therefor more drinking and over eating

Emotions

- All emotions more intense, increased symptoms – intensity and frequency
- Two reports of suicidal thoughts
- Lashing out with people I come in contact with.
- Disassociation happening more
- A sense of terrible "what is my purpose"
- Irritable
- Non trusting; protective; hyper-vigilant
- No fun things to look forward to
- Bewilderment
- Isolation; trapped in your brain then trapped in isolation = double isolation
- A certain "lazy-natured" way in pattern with feeling more hopeless
- Worried about finances and/or access to job opportunities

Coping with emotions

Over the course of the pandemic, individuals have been applying a range of strategies to help cope with the increasing frequency and intensity of emotions that are being experienced.

It is important to note that while some brain injury services have been reduced, a range of life events have continued throughout the pandemic. In some cases, these events have compounded the already existing emotional challenges being experienced.

It is acknowledged that people across the country have suffered loss and uncertainty during this time. From the loss of family members and the loss of trusted companion animals to job loss and other significant life events, people are requiring real-time support, which is often not readily available.

Some examples of this include needing to take critical steps which require additional effort and attention on the part of the individual. For example:

- Making trips to urgent care to receive assessment and support
- New medication requirements
- Medication adjustments to help with anxiety and/or depression
- Requiring the services of a counsellor; psychologist; psychiatrist; or psychotherapist
- Requiring support from a crisis line or the distress centre
- Seeking out urgent legal and/or other professional advice and support
- Contacting general practitioners for referral to community services
- Continuing with physiotherapy
- Access to peer support groups
- Seeking out support services on their own

While many are doing their best to take the actions required to stabilize their emotions, some have reported that it is not sustainable, and that they are finding it difficult to maintain the momentum required to remain positive and move forward.

The majority of respondents have had to make concerted and intentional efforts to help improve their deteriorating emotional well-being. For some this has been possible. For others it remains a work in progress. One thing is certain: as individuals are seeking ways to find services and/or support, it is critical that they can have access to healthy coping options.

The majority of steps individuals are taking can be categorized into groups. Some examples of these are provided in this report.

How individuals are coping with their emotions

Nature

- Gardening
- Being outside daily
- Listening to nature
- Outdoor activities
- Being with companion animals
- Sunlight & fresh air
- Going to the park
- Bird watching

Exercise

- Walking
- Yoga
- Riding a bike
- Working out
- Fitness class
- Kickboxing
- Running

Self-Care

- Faith & spiritual practices
- Sleep
- Solitary activities
- Turn off the news
- Maintaining a routine
- Meditation
- Light therapy
- Practicing patience
- Eating well
- Staying connected with others via zoom or phone calls
- Think positive and be positive
- Cleaning & organizing
- Maintaining rehabilitation

Hobbies & Connecting

- Music therapy
- Art class
- Listening to and playing music
- Singing
- Colouring
- Painting
- Puzzles
- TV
- Cooking
- Talking
- Joining online groups
- Staying connected with others via zoom or phone calls
- Reading
- Crafting
- Car rides
- Helping others
- Family support

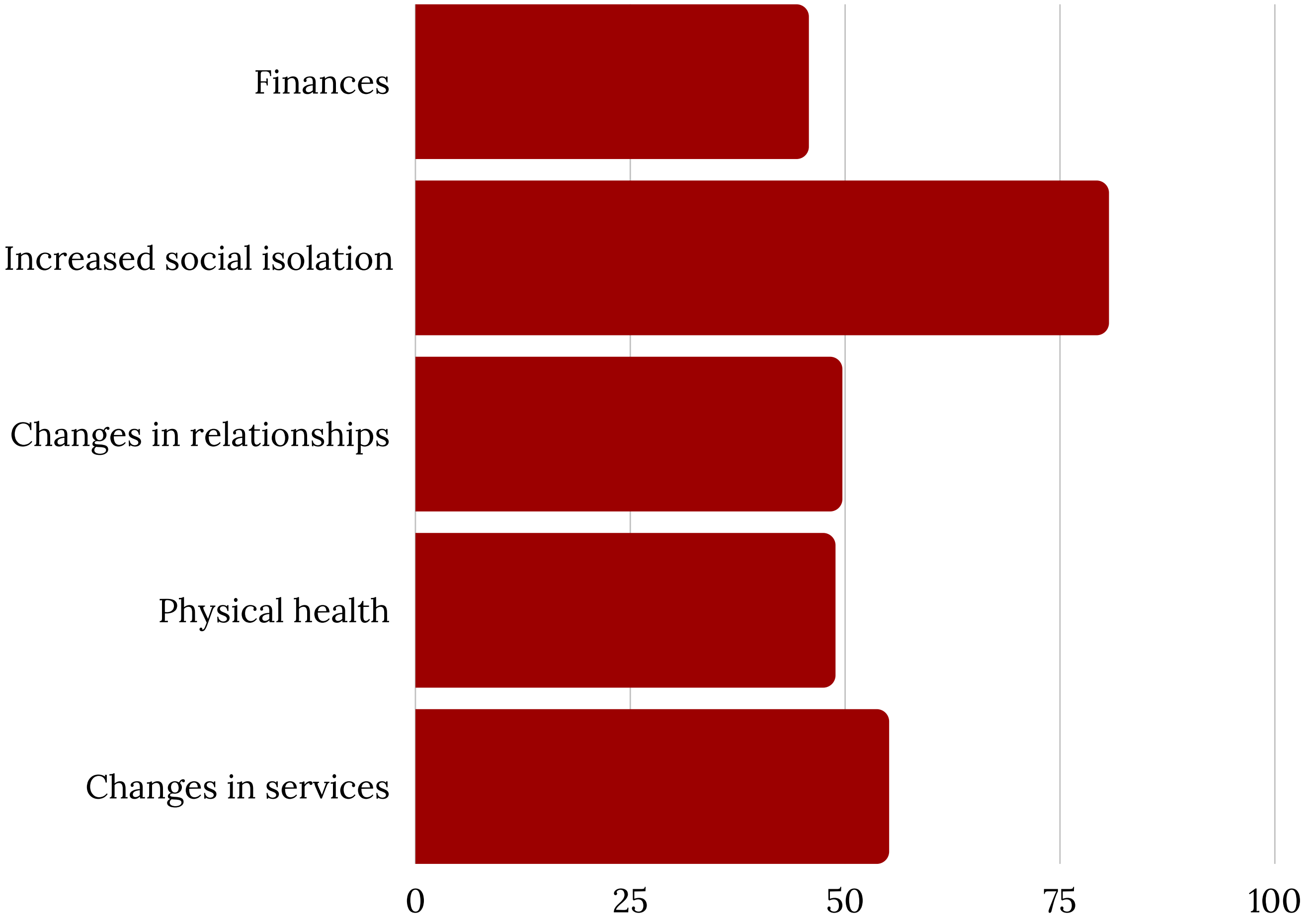
Situations that contributed to changes in mental health

Given the reports of increasing challenges around emotional and mental health, it was important to identify some of the conditions that were contributing to deteriorating levels of well-being. Overall, out of 129 responses, the top 3 reasons cited were:

1. Increased social isolation (104) 80.62%
2. Changes in services (71) 55.04%
3. Changes in relationships, including spouse, partner, children, family and friends. (64) 49.61%

The graph below provides additional contributors

Situations that contributed to changes in mental health



Increased social isolation and changes in relationships

Apart from the benefits of a particular service, for many individuals the routine of accessing in-person services has become an integral part of the recovery process. Going to appointments not only allows for social interaction: it also provides much needed structure to the day. At the same time, it helps to build confidence and maintain momentum as individuals access care, treatment and support.

Losing these vital links and the opportunities for individuals to see progress and to be encouraged by others – and to encourage others themselves - leaves immeasurable gaps that are becoming difficult to overcome.

The strain that the pandemic has had on relationships is also a significant factor. Individuals are struggling to find the energy required to foster, maintain and meaningfully participate in those relationships closest to them. This includes spouses; partners; children; family; and friends.

Under typical circumstances, coping with a brain injury and striving to maintain relationships can take a toll. Given the added layers of increased social isolation; changes in services and support; and uncertainty about the future, the impacts are being experienced in different ways.

Emotional responses are becoming more prevalent and reports of feelings of loneliness, sadness and depression are on the rise.

Respondents also provided details about other changes that are being experienced and why their mental health is being negatively affected. Some of these examples are provided on the following table.

Summary examples of changes in mental health
Narrative responses

Situations = changes in mental health

- Forced computer interactions and demands to perform virtually. Worldwide expectation that everyone can and must slog through exhausting on screen programs, then typing (like this survey, instead of paper)
- The technical requirements to move treatments on-line as well as banking and shopping and government services
- Termination of all organized fitness programs which I previously and regularly participated in.
- Job loss
- Cannot go out to enjoy visits; dancing, movies
- Assumptions from others = it's business as usual for me because I have a brain injury and am isolated anyway
- Life events continue = difficult to attend medical appointments; have other procedures done; find a needed lawyer; begin treatment
- Longer wait lists for counselling
- Loss of other supports from volunteer organizations that provide rides to appointments; small home repairs and cleaning

Impact some changes have had

- I am feeling like I want to hurl this keyboard across the room
- Feeling forgotten about
- Isolated
- Struggling to find support
- Life is less fun
- Not just social isolation, physical isolation as well
- I have no desire in eating. I spend isolation in my room most of the day
- Increased body & nerve pain
- Things take longer/seem harder to achieve results
- Worry for others
- Delays can mean a further deterioration to overall health
- Less happiness; connection and fulfilment
- Feeling awkward with new zoom groups, do not know the participants

Services or activities inaccessible due to pandemic

Similar to most Canadians, various programs, services, social gatherings and activities have either been interrupted; modified; paused or cancelled altogether. For many brain injury survivors, there is no adequate Plan B for social interaction; physical activity; medical treatments and support; emotional and mental health counselling; or in-class activities. Along with this, many reports of cancelled medical support appointments have also been received. The following are some examples provided:

- Limited access to a Case Manager. Cannot see a doctor/harder by phone. Not able to attend drop-in programs for social and cognitive stimulation. After 5 live sessions, had to leave a 6 month coping program that I waited 1.5 years to get into because virtual was too demanding. Still not coping well at all
- Due to the risk involved with close contact neglecting health by not regularly visiting dentist; eye specialist and other health care providers
- Massage therapy, physical therapy, was on the list for an OT but that program has closed.
- Not able to access physiotherapy, in person psychology sessions; brain injury neuro-rehab out-patient services
- Any type of counselling
- Cannot see family doctor; had t.i.a.'s; saw doctor at ER then once to a t.i.a.clinic in the last 10 months
- Occupational therapy and group in person learning
- Regular appointments for massage, chiropractor, acupuncture for pain management and nervous system regulation
- As a hearing impaired person with a brain injury, could not access in person counselling nor hearing instrument care
- Not able to get a massage or physiotherapy for a long time which set back my recovery quite a bit. Level of pain has increased; headaches; dizziness and fuzzy thinking increased in intensity and frequency

These concurrent challenges are having a direct effect on how individuals are coping. Dealing with the level of additional energy and effort that is required to access these services, or to attempt to arrange alternate care has become challenging, not to mention directly contributing to increasing levels of frustration, anxiety and uncertainty.

The following table provides some examples of the services and/or activities that could not be accessed during the pandemic. While some of these activities may now include an online component, many remain difficult to access and/or do not compare favorably to in-person.

Inaccessible during pandemic

- Swimming
- Church community
- Family gatherings
- Shopping/browsing various stores
- Library
- Fly a plane
- Face to face conversations
- Work
- The gym
- Dancing; social groups
- Concerts
- Volunteer work with horses and children
- Ping pong
- In class yoga
- Group counselling
- Any type of counselling or therapy
- Community centre events and volunteering
- Baseball
- Travel
- Dining out
- Theatre
- Alternative health care providers
- Pool rehabilitation activities
- Pickle ball
- Sewing classes
- Audiology clinic and speech therapy
- Personal trainer
- Job searching
- In person photography class
- Various winter sports
- Festivals or conferences
- Working in an office

Individual impacts

- Going out shopping or to a restaurant has always taken a lot of energy, but now, with everything we have to be careful with, it takes even more energy. I tend not to go out, except for walks
- I used to be a social butterfly, always on the go, but now if not for grocery shopping I don’t come out of the house
- Church, gathering with friends, doing exercise class by phone instead of in person, all social aspects of life amounting to none
- Many if not all of my activities have been disrupted or inaccessible for a period of time at different stages of the pandemic – including healthcare I require
- Spontaneous meetings and visits no longer possible
- Disconnection from family; friends and colleagues
- Emotional and social isolation
- Loss of routine
- Missing extended family

Changed interactions with brain injury associations/service providers

Of the 122 who answered the question "How did moving programming online change interactions with brain injury associations/service providers?", 31 respondents reported that their interactions remained the same or worked out well for them overall. The remainder experienced a range of challenges and online difficulties identified on page 12 of this report.

Some individuals reported strengthened connections as people came together online, others greatly appreciated the opportunity to continue their support services virtually. One of the benefits cited was less fatigue and logistical difficulties of having to travel, and making it easier to access programming overall.

In addition to the information provided on page 12, this illustrates the divide between those that can successfully migrate to an online program versus those who cannot.

There were many pros and cons highlighted throughout the responses to this question and thoughtful reasoning when people were trying to determine which approach might be the best for them in the future.

A sample of responses:

I enjoyed most of the online and really would enjoy continued classes that way. Previously the commute, the time and costs associated with attending in person would limit the amount I could attend. However, online classes require that everyone have an understanding of how to use the platform. Too many times there were sound issues; background noise from viewers.

I used to volunteer facilitating a mindfulness meditation group in person with up to 15 participants per session. This was moved online to an 8 week program with a waiting list and was given by another person. I really miss this group as we had formed a community of practice doing that together since 2016. I can't wait to go back. I am aware that many have visual symptoms related to brain injury (Post Traumatic Vision Syndrome) and that they cannot look at a screen without getting overwhelmed and exhausted, never mind the concentration and memory that basic computer use required. I know they will not be filling out this survey for those reasons so I am letting you know about this.

I really dislike that each separate support group has its own separate website. Some have done an excellent job of designing their websites, and the list of resources is deep. Others are very thin on resources so I go to the websites of associations in other cities. It's too much to seek out the information I need on multiple sites.

Changed interactions with brain injury associations

Respondents also shared the following comments:

- Less or no contact
- No transition time to on-line
- Not easy to access
- No hands on help
- Reduced – programs next to nil
- Hurt my progress
- Screen time provoked symptoms so did not participate
- On a wait list – zero support
- Had privacy concerns
- Can’t handle a bunch of people on zoom – mentally exhausting and confusing
- Fewer programs to access
- Not acceptable/not same treatment
- Many appointments cancelled
- Less personalized and less comprehensive
- Music therapy did not work
- Easier but zero connection or hugs
- Range of visual issues reported = screen intolerance
- Worse overall/less effective
- Hard of hearing = overwhelming
- Not getting much out of it so stopped attending

When individuals were asked if they used services or programs of brain injury associations or service providers outside of their community as a result of programming being available online – Q9:

- 33.08% (44) responded that they did
- 66.92% (89) responded that they did not

Of interest is that some survivors were able to find new sources of support by finding resources and programming beyond the traditional locations that they would normally access.

Additionally, some were not aware that this was an option and as a result of participating in this survey they were able to do some research and locate various services and support outside of their local area.

In general, the supporting information received for this question reflected the earlier reported challenges with accessing services on-line. Following is a sampling of the pros and cons reported:

- Yes, attended a Facebook group support group
- As my screen time tolerance improved, I took part in a program
- Watched videos/webinars from various organizations
- They have been a lifesaver
- Finally, I had an intake just before the first lockdown and then felt “forgotten” … I’m still waiting
- With difficulty with the onset of symptoms
- There are no programs in my community
- Cannot use zoom/anything on-line – need in person
- ABI and computer do not work well for me
- I tried to
- Although this is happening - it is not the same as being in the same room together

Changes in services & service delivery models

As a direct result of the pandemic, many of the service delivery options have been moved to virtual/online models. One year on, we were interested in learning about the preferences for continuing online services after the pandemic, and what shape this might take in the future. With increased social isolation being identified as a significant challenge, along with a series of changes to the level of services available over the past year.

- 9.92% (13) survey participants prefer services and programs be held virtually after the pandemic
- 32.06% (42) survey participants stated that they did not want services and programs to be held virtually at all
- 58.02% (76) highlighted the benefits of a hybrid service model with a combination of in-person and virtual program delivery

Support for remote/virtual platform

- The groups I've been a part of have had people from different parts of Canada and the USA. I've really enjoyed them – and from the comfort of my own home.
- Some changes are positive.
- I have become attached to the virtual services and would love to continue working with them.
- I think this has proven counselling & phone meetings and online sessions can happen – no need to force disabled people to travel to all non-physical exam type appointments.
- Having the choice is really nice.
- I can't drive – so much easier for my support people for transportation.

Challenge with remote/virtual platform

- The face to face and group interaction is what matters most in terms of my well-being. There just isn't the same connect with virtual
- In-person services are important for rehabilitation. It's difficult to re-enter society when it can easily be avoided by having everything on-line
- Zoom programs are great & convenient but we also need the social interaction
- Meeting with people face to face is imperative for mental health
- I'm not alone in saying it's frustrating
- We need both
- Online for quick appointments. In person for more serious appointments

Given the range of comments received, and that 76 respondents highlighted the benefits of a hybrid service model, it’s clear that a shift in how people are now thinking about accessing treatment and support is taking place.

Many of the comments agree that remote/online has been valuable during the pandemic – yet at the same time – when thinking more long-term, there is hesitation as online and remote service delivery models have been challenging for many to access. One end result is the understanding that this is not an either/or proposition.

At this stage, it appears that the hybrid model would allow for a certain level of on-going in-person contact and treatment, while at the same time ensure that clients can access other forms of programming and support on-line and/or over the phone.

In addition to this, some online services, including training and education; webinars; workbooks; research results; and accessing resources can happen in the person's own time. This self-paced learning definitely has its place when considering online options.

It’s important to note that while hybrid models may bring about some balance between in person and online services, the conditions required to ensure equal access to care, treatment and support, along with quality program development, would need to be carefully reviewed at both the individual and the association level. Some future planning questions to consider may include, but not be limited to:

1. Are there any assumptions we are making that may not be accurate?

2. How can we guarantee privacy and confidentiality in an online setting?

3. Are there any policies that we may need to develop and/or modify to address new service delivery models?

4. Do we have the expertise required for developing appropriate long-term online supports, resources and/or programs?

5. What, if any, risks might be involved for the client and/or the service provider?

6. How many clients have access to the technology required to ensure dependable and consistent connections to services, including for example: reliable computer; laptop or tablet; internet; broadband; high-speed; phone; other?)

7. To what extent would access to technology and/or the ability of the individual on-line create a barrier to participation?

8. Are we willing to accept any number of clients to this new arrangement. Conversely, are we willing to leave anyone behind?

9. Are we able to invite survivors from other catchment areas to join our online programs? What might this mean to our human and financial resources?

10. What programs and/or support services would translate well to an on-line delivery model?

11. What programs and/or support services must remain delivered in-person?

12. What can realistically be done to support others who cannot access a hybrid model?

13. What has been working well during the pandemic? How can we build on this?

14. What challenges have we had to overcome during the pandemic? How can we build on this?

15. What are the strengths/weaknesses/opportunities/threats of moving to a hybrid model?

16. Is it possible to identify a pilot project where a hybrid service delivery model is implemented - with follow-up milestones put in place in order to review; assess and adjust as may be required to meet the needs?

With a range of service delivery preferences being expressed, it will be important to take a collaborative approach to determine which programs and supports would make the most sense to move online long-term, and what services would be most suited to in-person delivery.

In considering this, it is important to acknowledge that one size will not fit all. Because survivors experience brain injury differently, with a broad and diverse range of realities and factors having a direct effect on the continuum of recovery and care, treatment and support, there is an opportunity to imagine what this might look like from all sides concerned.

The questions above can help to begin the discussions, while at the same time serve as a reminder about the broad implications of moving towards a more permanent hybrid service delivery model.

Services or programs found to be helpful during the pandemic?

When asked about what services or programs helped the most during the pandemic, 103 responses were received. Given that various provinces were in different stages of "lock-down" and under certain restrictions at different times throughout the year, some of these services have been accessed as follows, with the majority being remote/online as the pandemic continued.

- In-person
- Remote/online/video calls
- Phone calls
- One-on-one support
- Group support

Overall, there were consistent and multiple reports about the following services or programs being the most helpful:

- Support groups over Zoom, including peer support and educational programs; webinars and watching videos about brain injury recovery and coping

- Counselling services

- Wellness programs including mindfulness; meditation, yoga, accessing podcasts, and gentle exercise

- Phone and video calls with General Practitioners

- Various on-going medical and/or professional support including functional neurologist; chiropractor, neuro-psychologist; rehab group; neuro-feedback, equine therapy; psychotherapy; occupational therapy; eye specialist specific to concussion; virtual OT for walking assistance and regaining strength; able to access help regarding anxiety; and justice and health services

- Any services/programs related to social and mental health, wellness, and connection, including social programs and coffee chats; drop in centre; guided group coping sessions; family; listening to music and the radio; attending online concerts; art class; arts and crafts; attending a men's group; cooking class; and an opportunity to talk on a sensitive level

- Support services for shopping and home delivery

- Access to and delivery of food support

- Volunteering and helping others

- Attending on-line church; participating as part of a spiritual group

Services or programs not helpful during the pandemic

When asked about what services or programs were not helpful, 81 responses were received. As previously reported, a range of challenges were described, centering primarily around technology and the isolating aspects of the pandemic overall, as well as the inability to access previous services.

These included:

- Zoom issues including technical set up; visual challenges; cognitive fatigue; background noises and overall reduced services contributing to lack of connections and isolation
- On-line technical issues
- Delayed services/treatments and everything moved on-line
- Places there to help have literally lost me and no one has helped me to connect to the new group.
- Lack of contact – very difficult to contact Case Manager; not answering messages.
- Lack of access to medical/hands on therapy
- Virtual appointments for my brain injury that I felt should have been in person (post craniotomy) and return to work assessment
- Difficulty filling out forms
- Being surpassed physically by previous contacts and being left behind
- Long questionnaires
- Lack of support
- People so impatient
- Confusion! Service providers were confused/added to my confusion which was overwhelming
- Remember that many with a brain injury cannot follow long conversations with many details – most get lost and suffer overload
- Don't want to hear negative stuff
- Music therapy
- Anything complicated
- New vs old website
- Only having phone contact
- Silence
- Delay and inadequacy in financial assistance
- Things that cost more money to attend
- Everything!
- Husband home from work all the time
- Lack of exercise
- On-line options
- Expectations of performance on-line and that we all know the basics and that someone with a brain injury can field hundreds of e-mails or that people are either able to access services visually or audio – not an either or – some are both, and some people change entirely after a brain injury

- OT not that helpful – took 8 months to get it set up – ended up figuring out a lot of it by myself
- Just sharing vs. being proactive and having something concrete to help yourself
- Feeling incompetent when accessing services with others involved who are talking down to me
- Every ABI client has different deficits and each person progresses at a different pace – so “dumbing down” the material to appeal to the broad base, made learning much slower
- Shutting everything down. Expecting survivors suffering from PTVS to go on-line
- Overlooking the necessary mental energy, visual skills, concentration and memory, eye-hand coordination to be able to use a basic computer
- Failure to recognize that many with a brain injury are being left behind since they are unable to partake in zoom/on-line activities
- Everything went on-line, physical doors were shut, felt like being pushed away again
- Hearing, knowing others who share same obstacles, experience, knowing you are not alone

Advice on coping with increased isolation

Throughout the pandemic individuals have been coping with increased isolation. When asked for advice on coping that could be shared with others, we received an abundance of comprehensive and thoughtful responses, for which we are grateful. Overall, the range of coping mechanisms can be grouped together as follows:

- Contact with others and reaching out
- Exercise and being outdoors in nature
- Healthy habits and healthy living
- Positive reinforcement
- Creative pursuits and hands-on activities
- Help from & for others
- Educational and learning pursuits
- Apps & technology
- Therapy and support

Resources participants would likely use if made available for free online

The good news is that there is a high level of self-awareness among this group. While they are aware of the challenges and have been experiencing the impacts, both the statistical data and the narrative responses indicate that individuals are coming to terms with how they are feeling and what they are experiencing. That said, it is clear that some are doing better than others. With that in mind, when asked what supports would be of the greatest value, 60.16% (74) responded that mental health supports are urgently required at this time. This would include creating the conditions to enhance mental health and wellness overall; input from experts; guided meditation; yoga, and physical exercises.

Changes in services & service delivery models

60.98% (75) respondents indicated that having the ability to access government programs and subsidies would be of value. Moreover, having a range of these programs and subsidies coordinated in one place and provided in plain language to describe eligibility and application criteria would be valuable. 25.20% (31) participants provided additional options. Please refer to the following table for further detail, along with the full graph for this section on page 25.

Suggestions for Free Resources

- Virtual assessments
- Addressing safety issues
- Ability to conference with GP and/or other specialists
- Something that is light and fun that doesn't feel like therapy
- More contact with others in the same boat
- Peer support on-line
- Clearinghouse for resources available locally/in the community
- Art therapy
- How to talk to family and friends about brain injury
- Vocational training to assist in becoming a productive member of society again
- Help with applying for disability pension/assistance
- Tai chi or Qi Gong on-line or at home
- How to plan grocery orders and budget
- Any knowledge from how to cope with your new limitations to how to rediscover yourself
- Regular classes for family, friends and public on how to live with a brain injury person, including the fact that it is an invisible disability and what that might mean
- Needs to be non-online PDF and word documents available
- Legal support on-line
- Speech therapy; cognitive/memory exercises

Additonal Comments

- When in a deep depression anything physical is impossible; meditation was just horrible

- How to interact without a computer

- Revive social etiquette

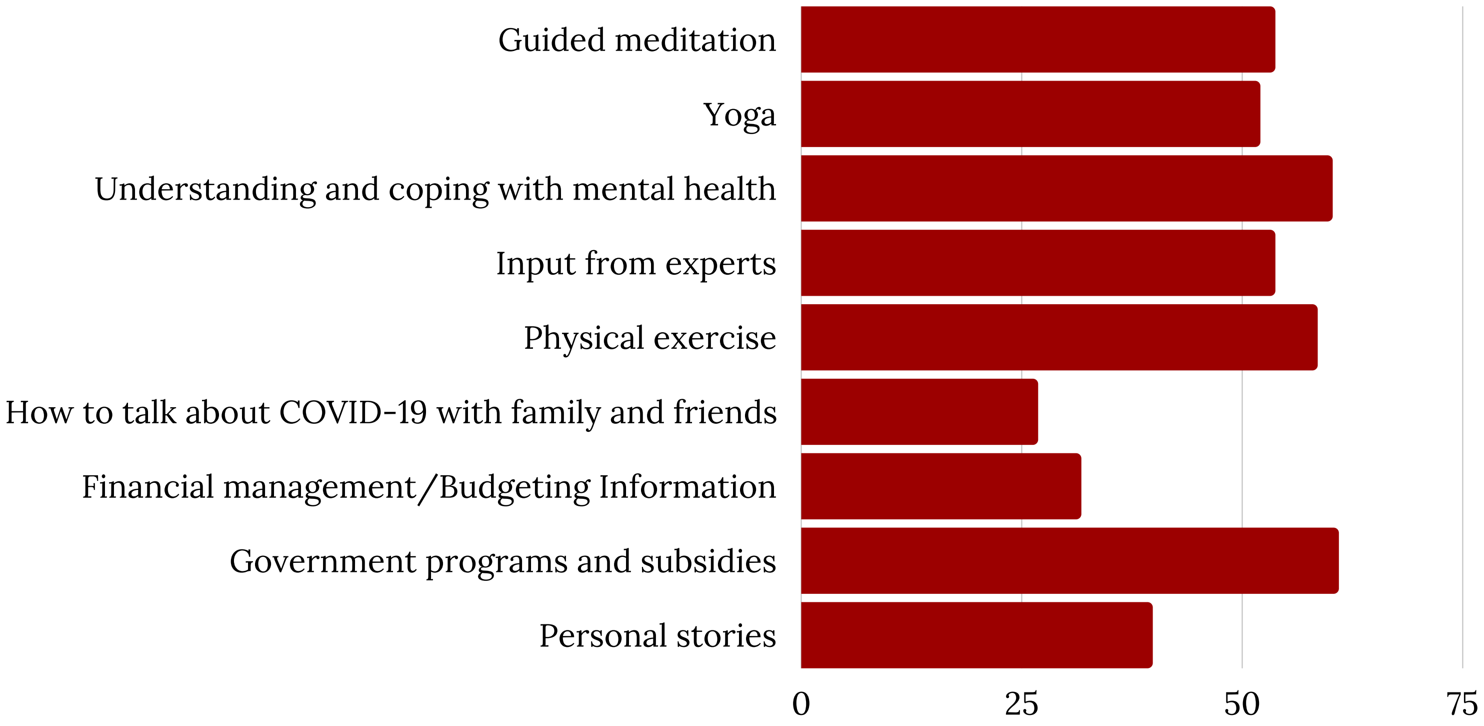
- Physical exercises would have to be chair based

- Review peer support leaders versus a trained group leader and be sure of their suitability = provide proper training for them

- Several comments regarding challenges with on-line access overall received

The following graph provides the resources that most would choose to access if they were made available free on-line.

What kind of resources would you be likely to use if they were made available to you for free online?



When reviewing the responses to this survey, it is evident that some individuals are coping better than others. Based on the feedback received, this may be due to:

- Some having a high degree of confidence, ability, and preference for accessing online services;
- Being able to ward off some of the isolation that many are feeling;
- Perhaps being further along in their recovery; and
- Being able to maintain a good degree of emotional and mental health overall

Regardless of the reasons, it is reassuring to know that despite the pandemic, some brain injury survivors have continued to remain connected and have been relatively well throughout.

The above said, the majority of brain injury survivors who responded to this survey have reported a range of obstacles and challenges throughout the pandemic. Behind the statistics, people are struggling to overcome isolation, and to maintain their physical, emotional and mental health.

Given the nature and range of symptoms experienced from a brain injury, combined with other emerging factors, there is a high rate of anxiety and tendency towards depression in a large sub-set of survivors. It's difficult to quantify this.

With over 100 people reporting a continuum of deteriorating mental health – ranging from mild to moderate to severe depression – to the point of suicidal thoughts – we must ensure that meaningful and reliable supports are in place now and into the future.

We cannot know with certainty when this pandemic will end. What we do know with certainty is when that day comes we must be prepared and have the appropriate resources to:

- Welcome back clients and support those who have lost ground and have had their services interrupted; modified; suspended or cancelled altogether
- Provide holistic and client centered programming and support
- Carry out assessments for existing and new clients
- Resume programs and support services in real-time
- Respond to the needs on the ever increasing wait lists
- Ensure that the structures are in place for meaningful collaboration and program development
- Find, reach out to and support the most vulnerable
- Review peer support and other engagement opportunities

For many survey participants, online and virtual platforms cannot take the place of in-person service delivery. Both the data and the narrative responses clearly support the need for a return to some form of in-person programming.

With this in mind, given the increasing levels of isolation being experienced because of the propensity towards remote online services, some have expressed frustration with the assumptions being made that online services can be readily accessed.

How might we respond to this?

- Seek ways to balance out individual needs with the services that are now available
- Consider that even though online is an option, is it the best option overall?
- While the programs may be available online, to what extent are they being accessed?
- How can we measure if those who are attending the programs are actually gaining something from it?
- Acknowledge that social and physical isolation is real, and so too are the preferences of some to not want to engage online. How can we ensure that we are reaching these individuals?
- What are the cumulative effects as a result of lack of access and inequities?
- How can we build bridges between individuals and the supports required?
- Is it possible to measure recovery loss during this time and find ways to increase participation?

It was also conveyed that during this time, those who cannot use screens and/or various technical applications are being left even further behind as paper-based resources are decreasing. This is a valid concern, and it further demonstrates the divide that is taking place between those who can access online services, those who cannot, and those who prefer in-person. Whether related to brain injury services or through other institutional practices, there appears to be a widening gap taking place.

As existing clients lose ground, there are also others who are joining the wait lists and embarking on their pursuit to find adequate resources and support. In order to respond to this, it will be important to:

- Ensure that the brain injury community has sufficient capacity with both human and financial resources available to respond to the needs
- Re-engage with clients and service providers
- Re-assess current clients when required, and provide assessments for new clients
- Understand and respond to the increasing levels of depression and mental health challenges being identified, by implementing emotional and mental health supports, including wellness checks
- Develop inclusive care, treatment and support options that take into consideration newly emerging emotional and mental health needs
- Address the growing back-log for services and waiting lists and develop realistic paths forward for same
- Carefully consider which services should be migrated to an on-line delivery model

It’s through individuals with brain injury that we can learn the most. From sharing successes and challenges experienced over this past year, to providing suggestions for services and activities to help others, we appreciate the valuable contributions that have been made to this survey.

As we continue to highlight the shared experiences and collectively move forward, these contributions will ensure the brain injury community is in a stronger position to respond to both the current and emerging needs that have been identified.