



Cavernoma Alliance UK Members' Survey Analysis 2020

Executive Summary

Cavernoma Alliance UK (CAUK) carried out a survey of its members in December 2020 and January 2021 in order to evaluate the effectiveness of their support programmes and to investigate the challenges faced by members living with cavernoma. 178 responses were received, 72% of whom were adults with diagnosed cavernomas.

Findings showed that published information (blogs, website, leaflets and newsletters) was the most used support service since March 2020 and the introduction of Covid-19 restrictions. These materials were used by 73% of respondents and were rated very highly, particularly concerning the quality of the new CAUK website and the trustworthy nature of the resources. Social media (particularly Facebook pages) and webinar/Zoom events were also popular. It was clear that members valued the psychosocial support offered by these platforms as well as the sharing of scientific and medical progress for cavernoma. As a result, members have suggested that future CAUK events are simultaneously held as face to face and virtual meetings, allowing fully inclusive access.

Although all support services were seen to be positive in supporting the wellbeing of members, CaverFamilies activities were viewed as the most supportive. All respondents agreed that the programme provides excellent support and events for children, siblings and their parents/carers. Understanding of the factors that have made CaverFamilies such a success may inform CAUK's other programmes, particularly CaverBuddies.

Conclusions could only be drawn about the experience of adults living with cavernomas because there were insufficient responses from children and young people. Further discussion with these cohorts may help to ensure their needs are well understood. For adults, it was clear that the most significant symptoms associated with cavernomas were tiredness/fatigue and sensory difficulties including numbness and sight and hearing impairments. However, members overwhelmingly reported that psychosocial difficulties posed them the most problems in daily life. This supports the findings of previous surveys indicating that worry about the future, low mood and feeling helpless were the most frequent challenges affecting these adults. Carers were also surveyed, most of whom were parents or spouses/partners. Unsurprisingly, the most frequent support offered was full time emotional and social care, which most typically reduced carers' opportunities for additional social interaction. Understanding these challenges can inform the way in which CAUK supports all of its members, and the focus of forums, meetings and publications.

Overall, this members' survey has revealed a strong community of CAUK members who value the support they are offered and agree that this improves their wellbeing. They are grateful that advice and information is trustworthy and supported by scientific and medical evidence. For many CAUK is seen as a 'lifeline'.

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Context

Cavernoma Alliance UK (CAUK) is a registered charity founded in 2005 to support those affected by cavernoma, including family, carers and friends. The charity also aims to raise awareness of cavernoma amongst the medical community; as a rare disease it is often misdiagnosed. CAUK also supports research into treatments and a cure for cavernoma.

CAUK carry out regular surveys following events and usually a large survey every two years (the last survey was in October 2019). In the past these have mainly been qualitative making it difficult to extrapolate the overall or average views of members. This feedback has provided excellent information to improve specific projects but is less useful when trying to summarise members' views and experiences.

This survey had two aims by investigating the views of CAUK's members.

- Objective 1: To evaluate the effectiveness of the support provided by CAUK to its members. In particular, analysis of the support provided since the beginning of the Covid-19 pandemic. The findings are expected to inform future support plans for CAUK members.
- Objective 2: To gain further insight into the experiences of members (including children, young people and carers) to better understand the difficulties faced as a result of cavernoma. These findings will help to illustrate fundraising bids and also shape the support given to members.

Methodology

This survey was created with senior leaders at CAUK and used Google Forms to gain responses by members. The survey link was sent to members by email and placed on CAUK's social media pages. It was estimated that the survey would take 20-30 minutes to complete online. There was no option to complete the survey in another format. A total of 178 responses were received (6.4% of membership) between 10 December 2020 and 13 January 2021. All respondents had completed at least one section of the survey. Their distribution can be seen below:

Table One: Completion of the survey by membership type

Member	Total Responses	Percentage of Responses (%)
Adult with a cavernoma	128	72
Carer of someone with a cavernoma	20	11
Adult with a cavernoma that has been removed	15	8
Completed on behalf of a child with a cavernoma	6	3
Parent/Grandparent of an adult child with a cavernoma	5	3
Young person with a cavernoma	2	1
Adult previously misdiagnosed as having cavernoma	2	1
Supporter	1	1

Findings

Overall Support From CAUK

Figure One: Support Accessed by Members Before Covid-19 Restrictions

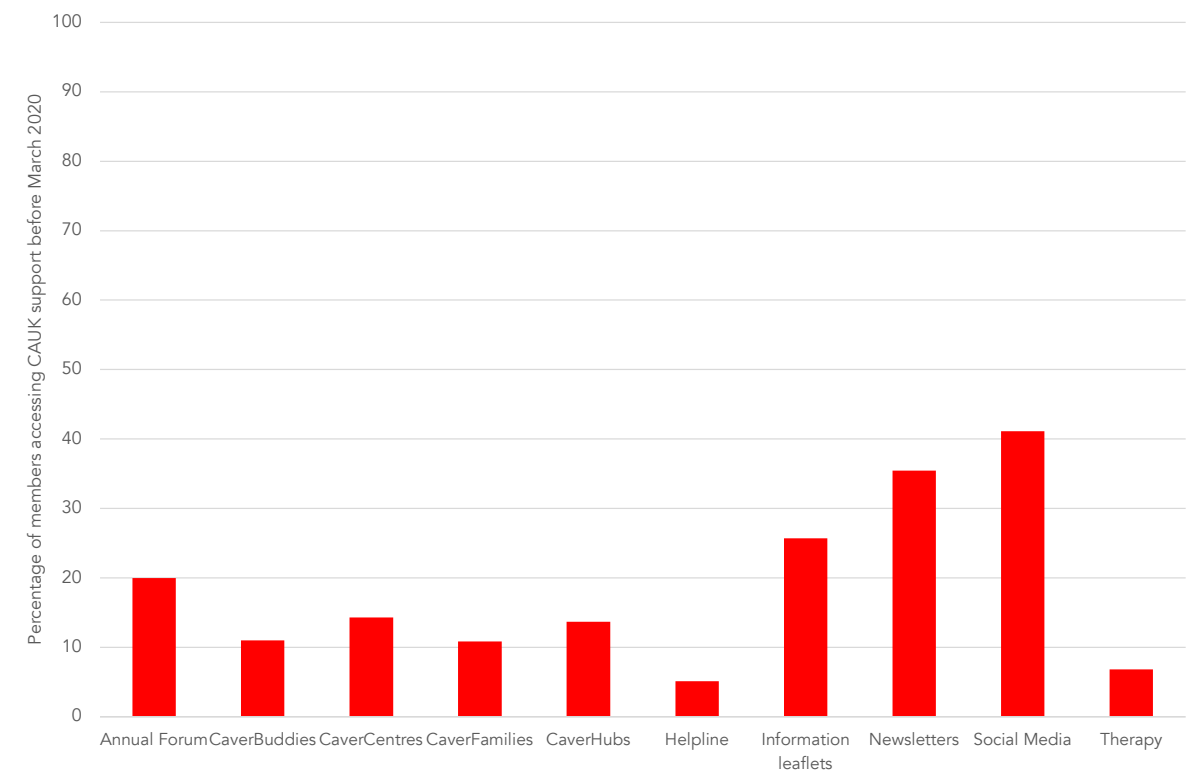
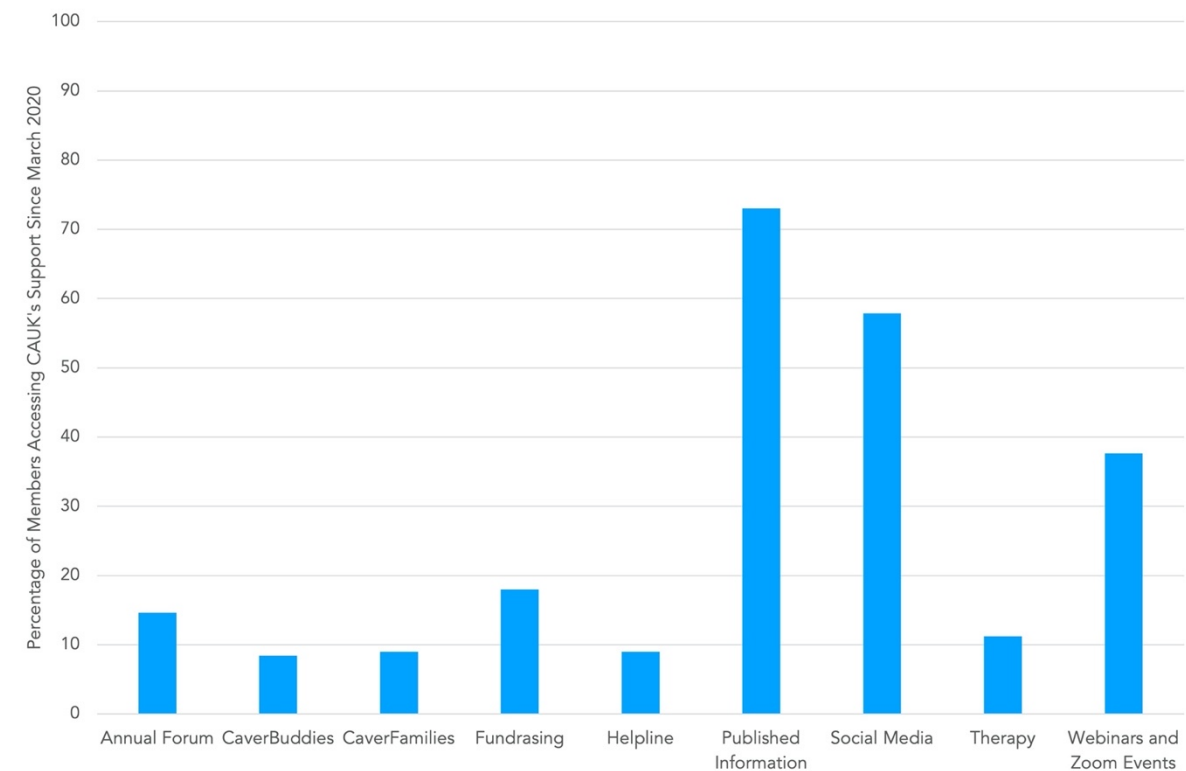


Figure Two: Support Accessed by Members from March 2020



Overall engagement in support from CAUK increased following the introduction of Covid-19 restrictions, particularly with the use of social media and published information. Webinars and Zoom events increased in popularity compared to physical meetings such as CaverHubs and CaverFamilies. This could be because members had more time to spend online, although it is likely to be because online events were easy to access for the majority of members. Use of the helpline and therapy also increased over this time, whilst comments suggest that the increase in access to published information is due to greater use of the new CAUK website.

"I feel part of a community rather than alone with this condition."

Helpline

A helpline is available for members between 10am and 4pm Monday to Friday and its use remained constant during the pandemic. Although only 9% of respondents said that they used the helpline, their enthusiasm for the support it offers showed that it is a valuable resource for some. One member wrote:

"The helpline is a godsend. The team are really lovely and will go above and beyond to do all they can to help. From providing a listening ear, organising therapy sessions, organising events and providing us with so much knowledge. We no longer feel alone we are a part of a family and they have helped us to form life-long friendships."

Figure Three identifies that members feel that the helpline is fit for purpose and offers the support needed, with over 90% of users stating that it is easy to contact and over 80% stating that the helpline offers appropriate support. However, a minority of respondents wanted greater access to the helpline, with one member saying, "Sometimes difficult to get through."

Social Media

CAUK uses Twitter, Facebook and Instagram to share its work and to allow members to interact with one another as well as the charity. The use of each platform can be seen below:

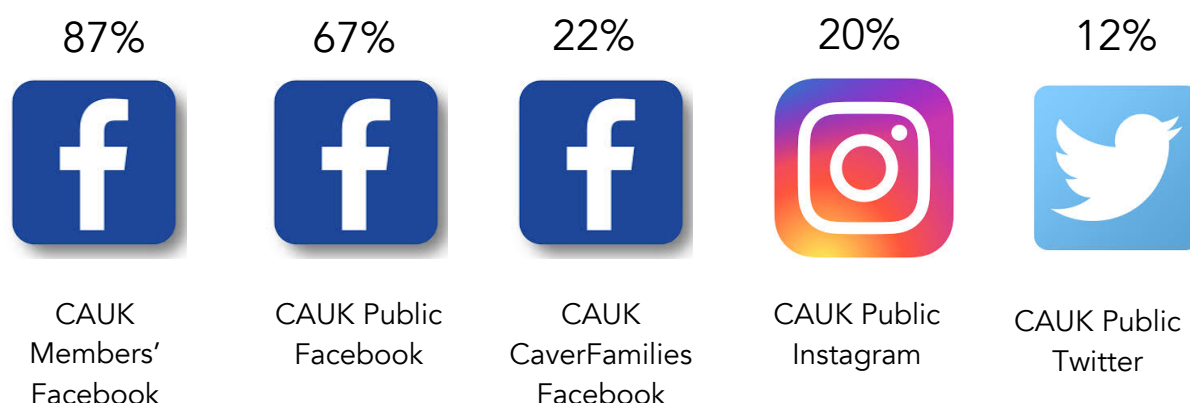


Figure Three: Members' Views of Helpline Support from March 2020

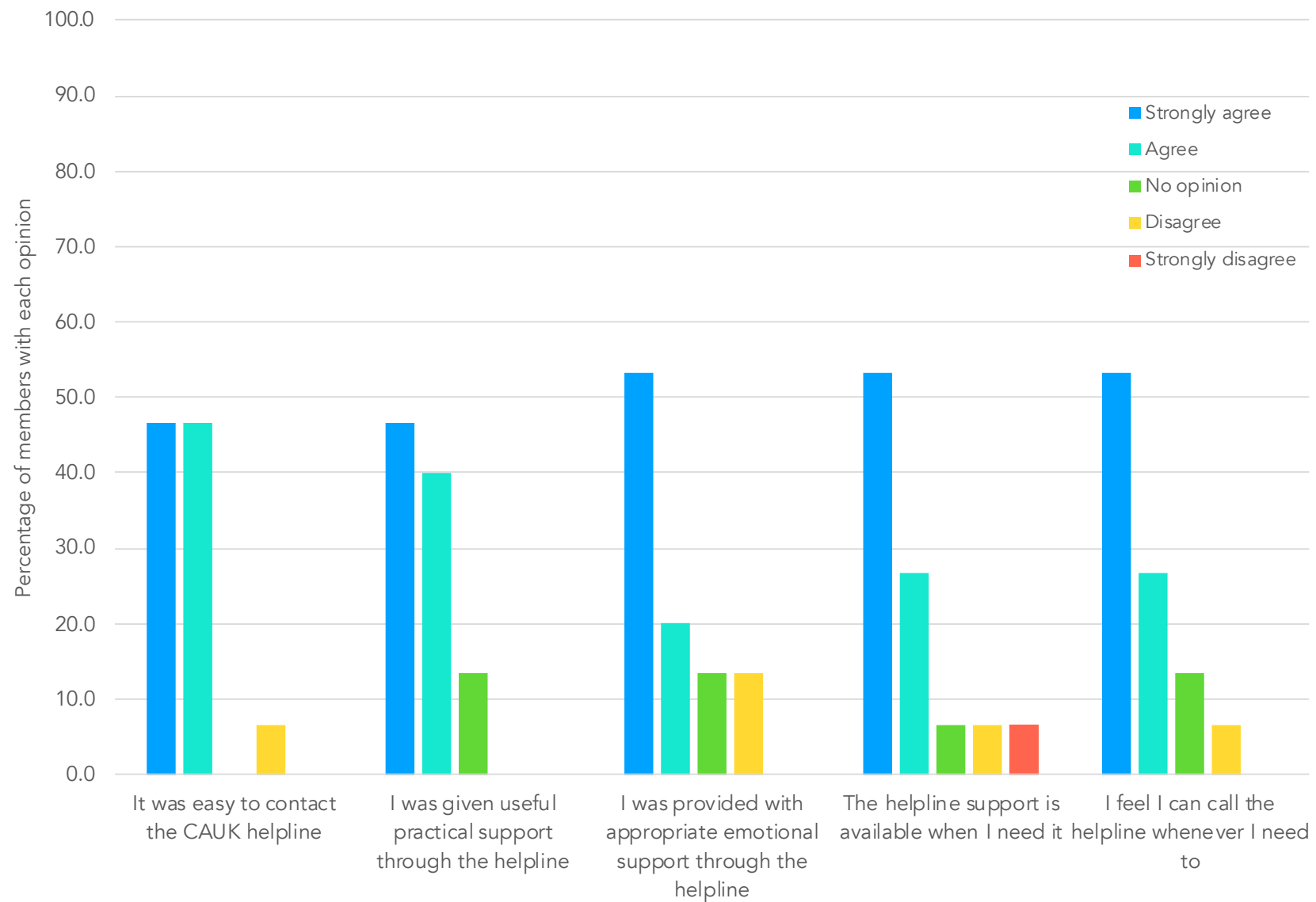
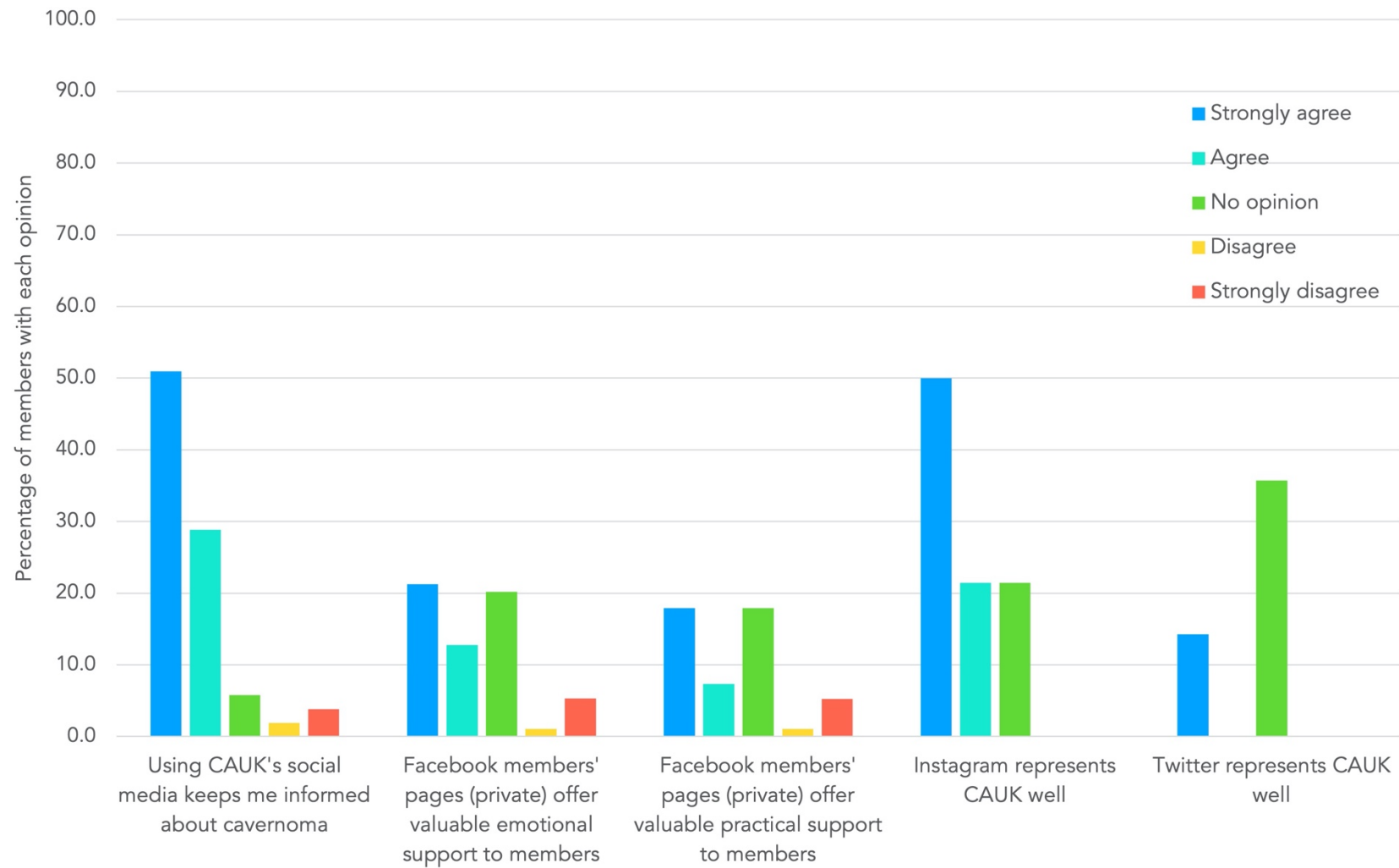


Figure Four: Members' Views of CAUK's Social Media from March 2020



Social media is one of the most used support methods used by members, with Facebook being far more popular than Twitter and Instagram. Although the majority of members felt that Facebook offers some support to members, (see Figure Four) there were many comments provided about how it could be improved, including:

- More stories about members journeys.
- [An improvement could be made] by using the alt text on Instagram so a description of the photo is available for visually impaired/blind people.
- I would like to see ways in which you can increase the engagement of members of the page. I see a lot coming from CAUK but less so from the members.
- Moderation could perhaps be used better to avoid misleading or incorrect information from being shared.
- More positive stories. I have found some stories worrying which have increased my own anxieties.
- People with knowledgeable information from the charity answer queries and questions online.
- Sometimes medics are given a very negative view which is not helpful or possibly fair. Some posts are potentially alarming for the newly diagnosed. Hopefully someone is monitoring the site and is aware of this. Some posts of holidays etc are irrelevant. Keep on with the facts and research information.

"CAUK's social media sites are a lifeline for us... when we need a bit of advice, information or are just facing a particularly difficult time."

CaverFamilies

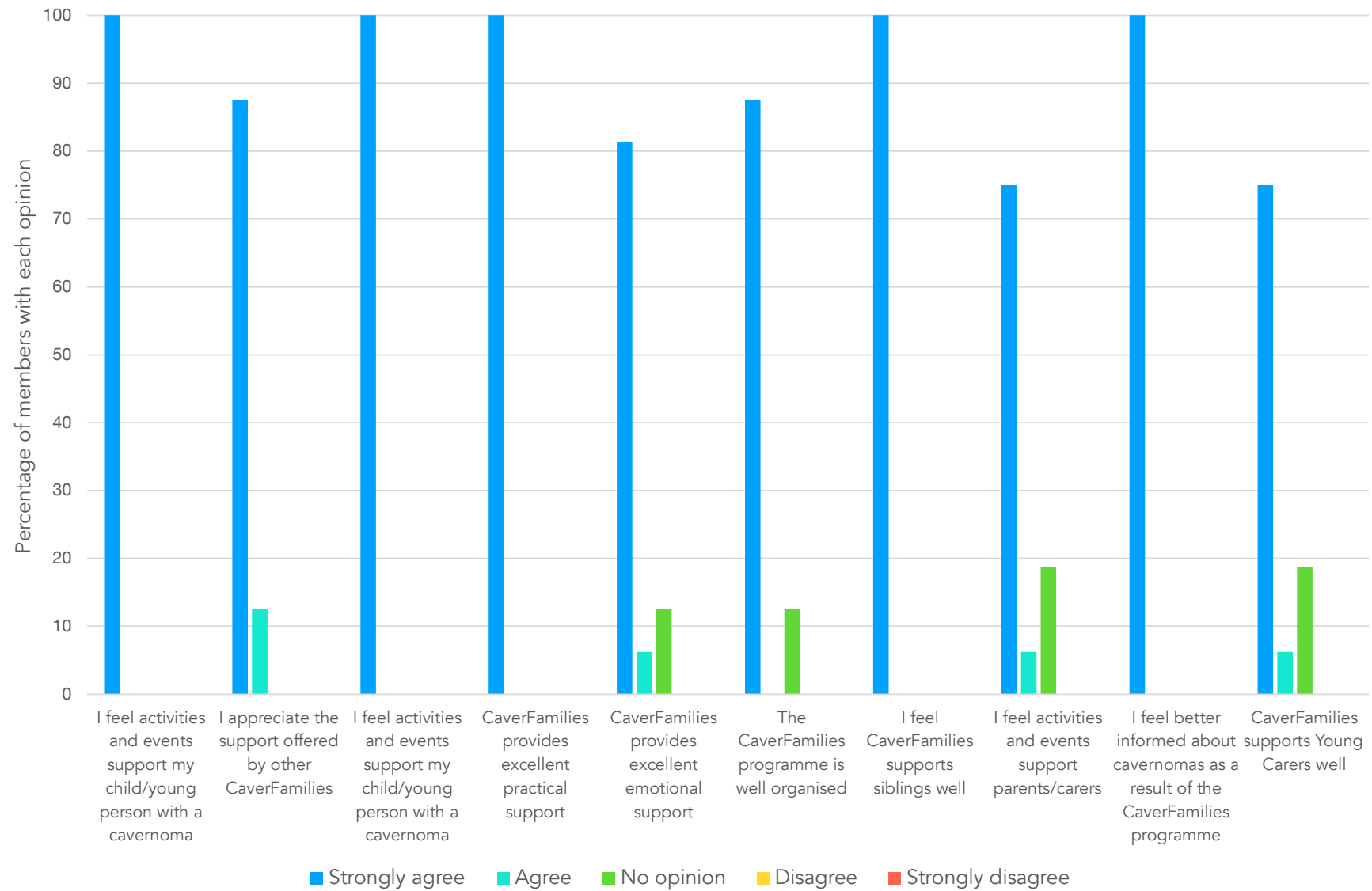
CaverFamilies are members who have a child with cavernoma and includes parents/carers, siblings and children with cavernomas. CAUK organises specific activities and events for young people, children and their families. Since Covid-19 regulations were implemented, these have had to be held virtually.

Table Two: Participation in CaverFamily Events and Activities Since March 2020

CaverFamily Activity	Percentage of CaverFamilies who Participated
CaverFamily specific Zoom meetings	69
CaverFamilies Virtual Day(s)	44
CaverFamily specific therapy	38
Helpline	6
Social media support	69
Support with school or college	31

Although uptake in CaverFamily activities is limited, it should be noted that many CaverFamilies also receive support and participate with CAUK's mainstream activities. However, the praise for CaverFamily specific support was overwhelmingly positive, as can be seen in Figure Five.

Figure Five: Members' Views of CAUK's CaverFamilies Programme from March 2020



"Caverfamilies are a support for the whole family. Living with cavernoma or supporting someone with cavernoma can sometimes be lonely, as the condition is relatively rare, lockdown can really heighten this and CAUK have been amazing at reaching out to their members and letting them know they are not alone. I couldn't make any suggestions that would improve what CAUK do - they always have and continue to do an outstanding job at supporting their members and families."

CaverBuddies

The CaverBuddies programme provides peer support to members. Co-Buddies are trained to offer informed support, advice and guidance to buddies. Often, a CaverBuddy is a new member who has recently been diagnosed with a cavernoma. Only 10% of respondents were involved in the CaverBuddy programme with 80% stating they were CaverBuddies and 20% being Co-Buddies.

Figure Six shows that CaverBuddies were very positive about their experience of the programme, showing that it provides both emotional and practical support. However, the experience of Co-Buddies was less positive where comments showed that the matching and training process had not worked effectively. It seems that when a CaverBuddy has been trained and matched to a Co-Buddy, the programme works well and provides members with excellent support. However, there is a need to ensure that the training and matching process are effective.

Published Information

CAUK publishes information for members in a variety of formats. New members receive an information pack in the post whilst a new website provides in depth information for members, clinicians and the public. A blog is posted that discusses medical advancements in cavernoma whilst newsletters are regularly emailed to members. This formal dissemination of information is complemented by informal posts on social media (see above). The methods used by members are shown below:

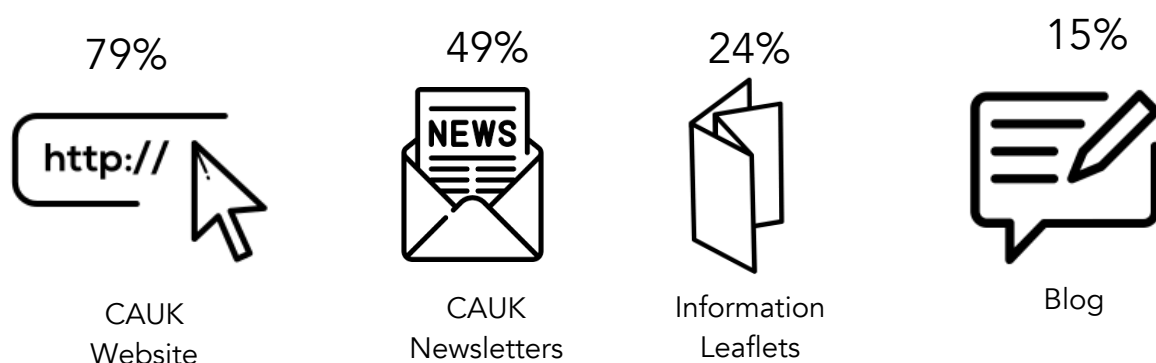


Figure Six: Members' Views of the CaverBuddies Programme from March 2020

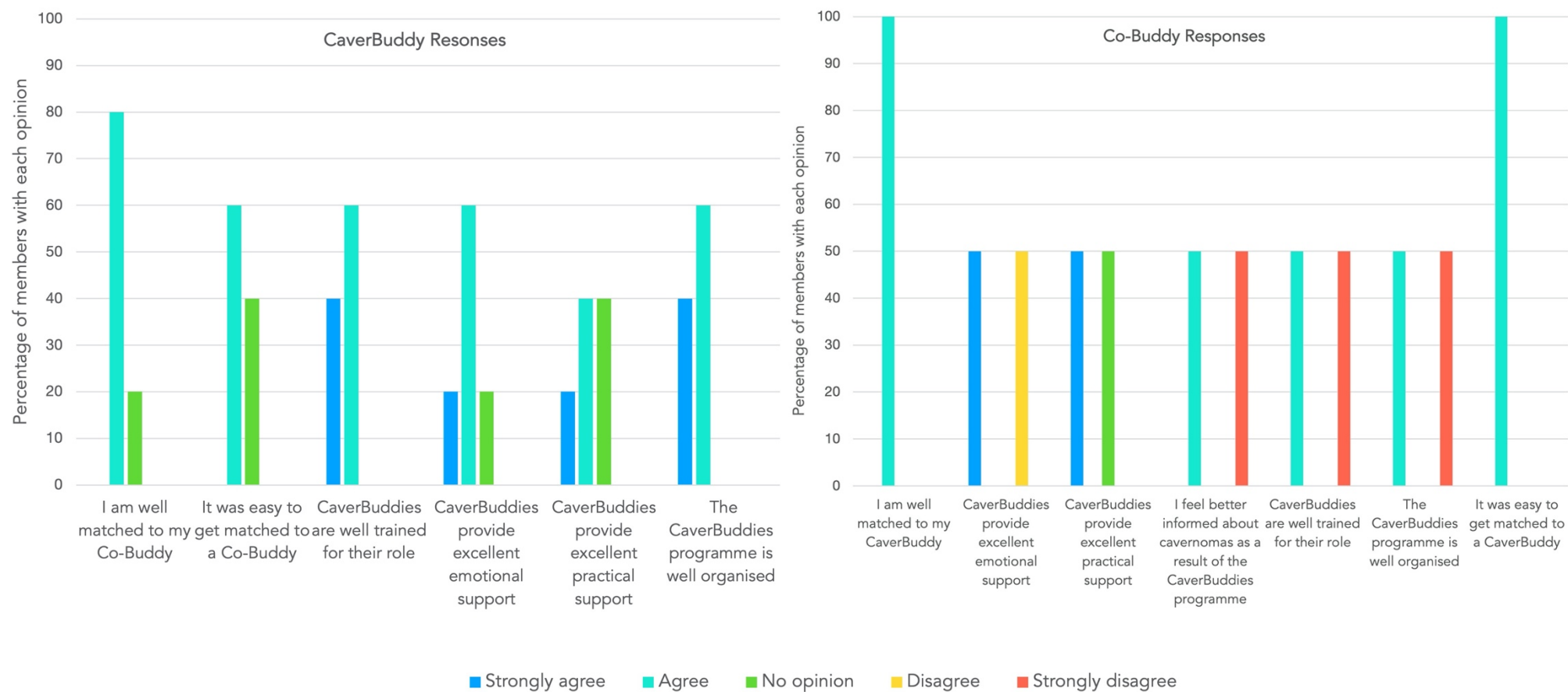
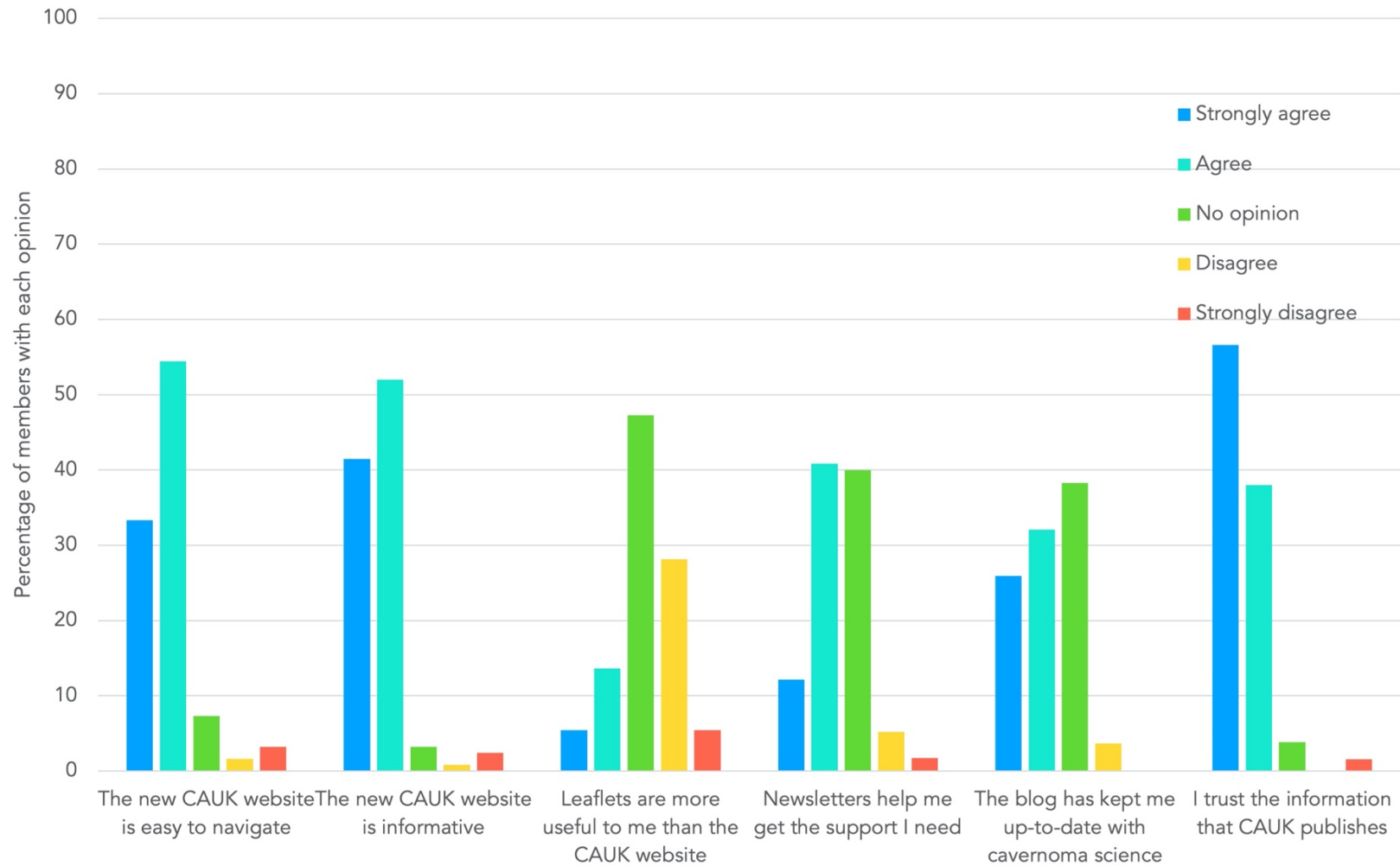


Figure Seven: Members' Views of the CAUK's Published Information from March 2020



"CAUK have provided us with so much valuable information, much more than what we can get from our doctors and hospitals."

Figure Seven shows very positive views by members towards published information. Although information leaflets were viewed as less useful than other media, comments explained that on first joining CAUK these leaflets were invaluable, particularly in explaining cavernoma to family and GPs. There was much praise for the new website, it was seen as 'really easy to navigate' whilst a

member commented that they 'really value the knowledge of the clinicians and experts collaborating with CAUK'. A few comments offered improvements to the publications including:

- More information on spinal cavernoma
- Creating a young people's magazine
- Ensuring the information remains up to date.

Zoom Meetings and Webinars

CAUK developed Zoom meetings and webinars to replace many of the face-to-face activities that were restricted by Covid regulations. This has evolved into a regular programme of events that include five distinct online meetings. 38% of members engaged in these online sessions with CaverHubs talks being the most popular.

Table Three: Participation in Online Events by Online Users Since March 2020

Online Activity	Percentage of online users who engaged in the activity
CaverHubs (talks from a clinician)	46
Virtual Cafes and Chats	43
Cavernoma Science Webinars	42
Members' Stories	29
CaverCentres (regional meetings)	13

The lower popularity of CaverCentre meetings may be due to the fewer events of this kind. They are dependent on the activity of regional groups, where some areas of the UK are not yet represented.

Figure Eight shows that in line with feedback on published information, CaverHubs are highly valued by members. 92% of members felt that these sessions helped them to learn more about cavernomas. Furthermore, members' comments explained that Zoom meetings have helped them keep connected during a time of loneliness under Covid restrictions. Many requested that virtual meetings continue alongside face-to-face meetings when rules allow. They highlighted that this would allow them to choose

"Talking to people who understand is the best therapy – thank you for providing this breathing space and support."

Figure Eight: Members' Views of Zoom Meetings and Webinars from March 2020

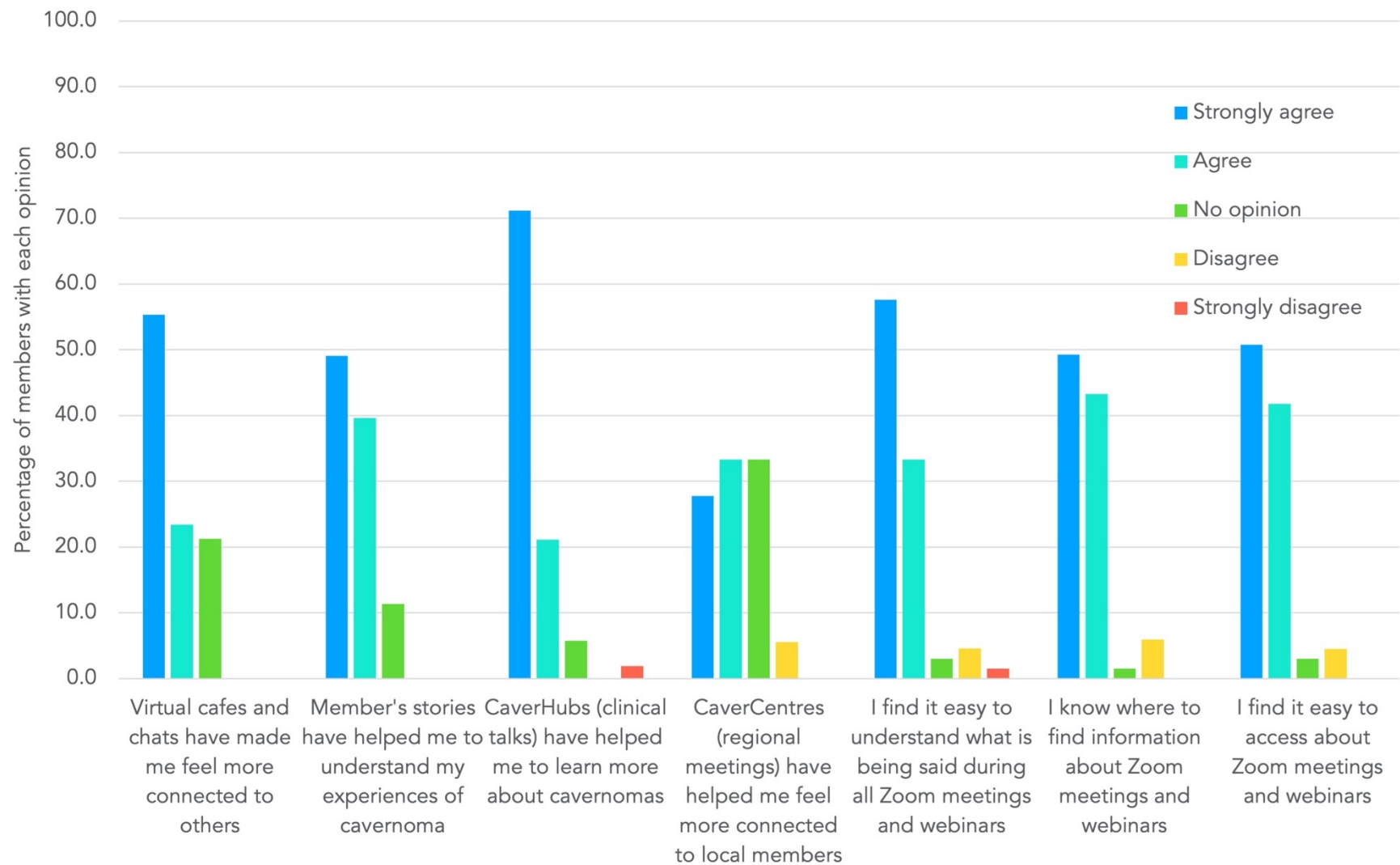
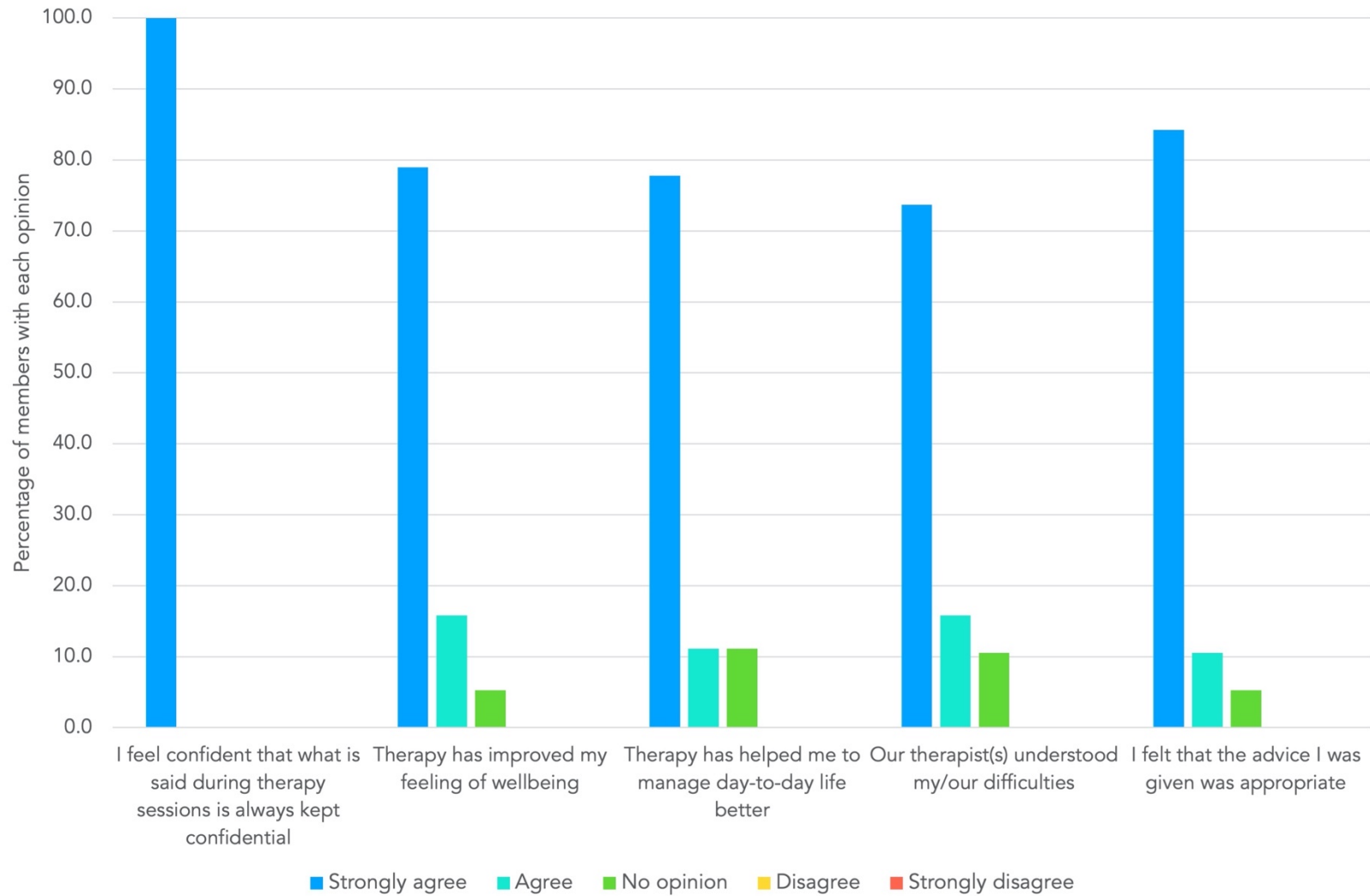


Figure Nine: Members' Views of Psychological Therapy Provided by CAUK from March 2020



how to attend, particularly when they may find travel or leaving home challenging. For example, a member wrote,

"Zoom meetings are critical for me to participate. When things get back to "normal" I would hope that the Zoom function is continued, even if some of the participants are "face to face". I know that it is the only way I can try and be an active participant and I believe that there are others at distance who would be in the same position."

A number of members commented that the timing of the Zoom meetings meant that they were unable to access them, either because of disability or because members are working. Nonetheless the overall feeling about these sessions is summarised by the member who said, "These have been asset to CAUK, hope you continue to run [them].".

Therapy

CAUK have recently extended their programme of psychological therapy to members. This is a free service and is offered to members, carers and families who are finding the diagnosis and/or symptoms of a cavernoma challenging. Only 12% of respondents had received therapy through CAUK since March 2020. Of these the majority (62%) participated in group therapy, 33% in personal therapy and only one respondent had received family therapy. The quality of this support was seen to be exceptionally high (see Figure Nine) with all participants feeling it was a trustworthy service, that improved their wellbeing and provided appropriate advice.

"Without therapy I would be totally lost."

Comments from members who engaged in therapy were wholly positive, whilst they also made a number of suggestions, including:

- Could the therapists do some general webinar sessions? Blogs?
- Members of the group therapy that I attended all wanted to stay in contact and continue to support each other. It would be great to be offered a follow up one-off session to check in with the therapists.

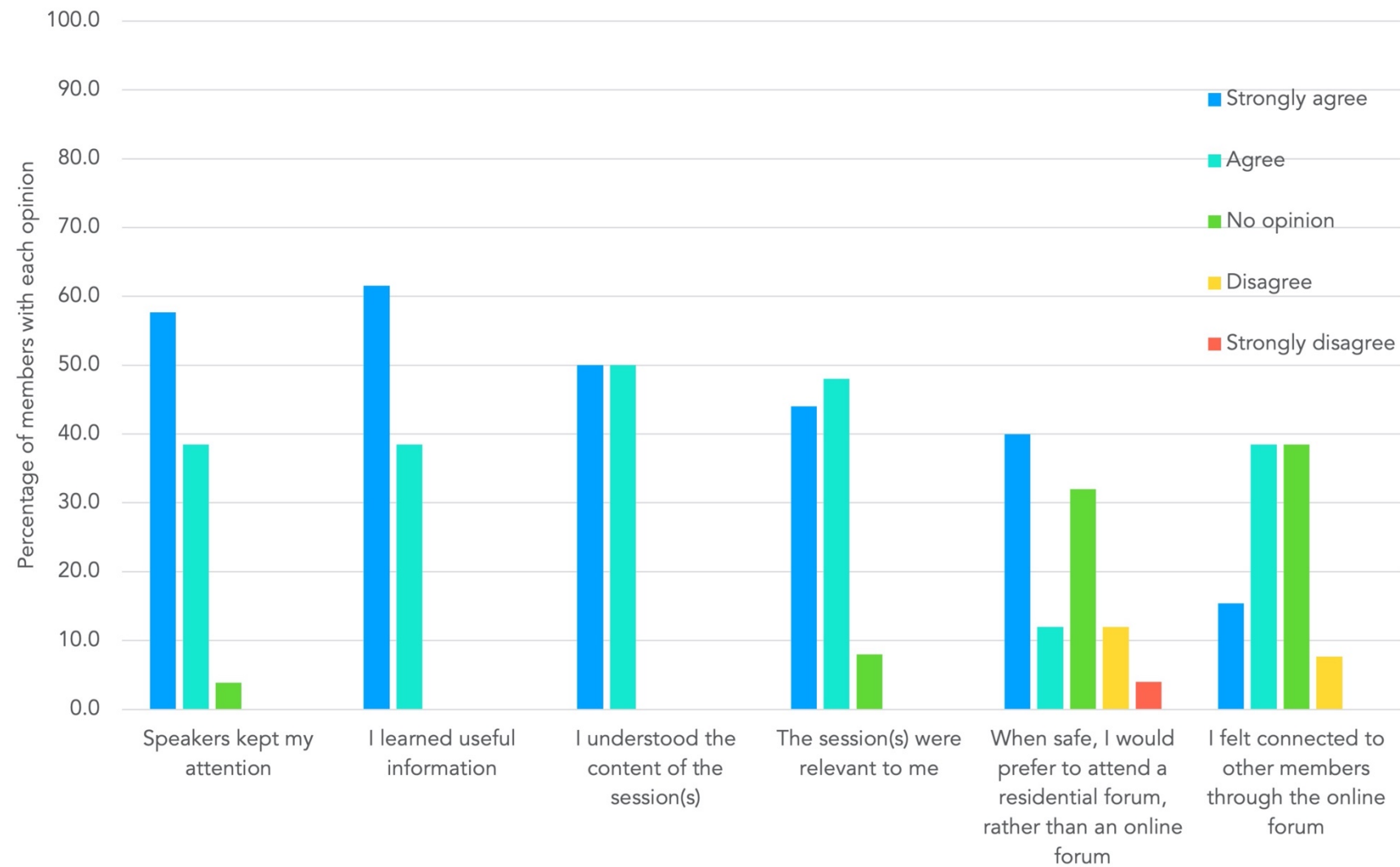
Annual Forum

Until 2020, CAUK's Annual Forum has been a face-to-face residential event where members, clinicians and scientists host presentations, workshops and seminars. In May 2020, this became an online event using Zoom to deliver presentations from five speakers.

"The richness of speaker blended with members' ability to ask questions seems to be one of the ways CAUK is different from other cavernoma charities."

Members attended these sessions in the same numbers, with some engaging in all five events and others in just one. Fewer members attended these events compared to the event in 2019, but the overall view of the quality of the sessions was excellent (see Figure Ten).

Figure Ten: Members' Views of CAUK's Annual Forum Held in May 2020

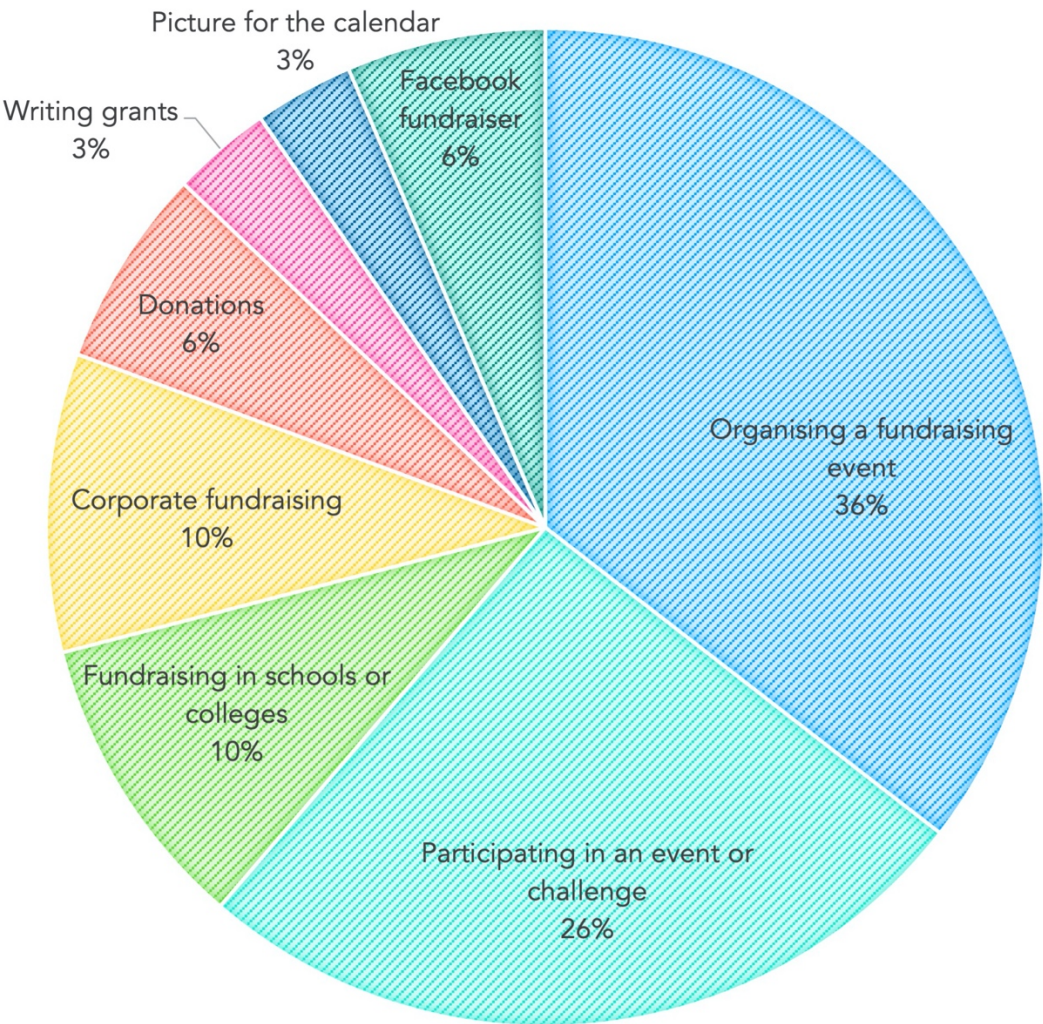


There were mixed opinions about whether the Annual Forum should be held online in the future. Comments showed that members valued the ability to access the sessions from home, making it fully accessible, whilst others missed the opportunity to network and meet other members. There seemed to be a consensus that a mixed approach could be taken in the future – a residential event with sessions streamed online.

Fundraising

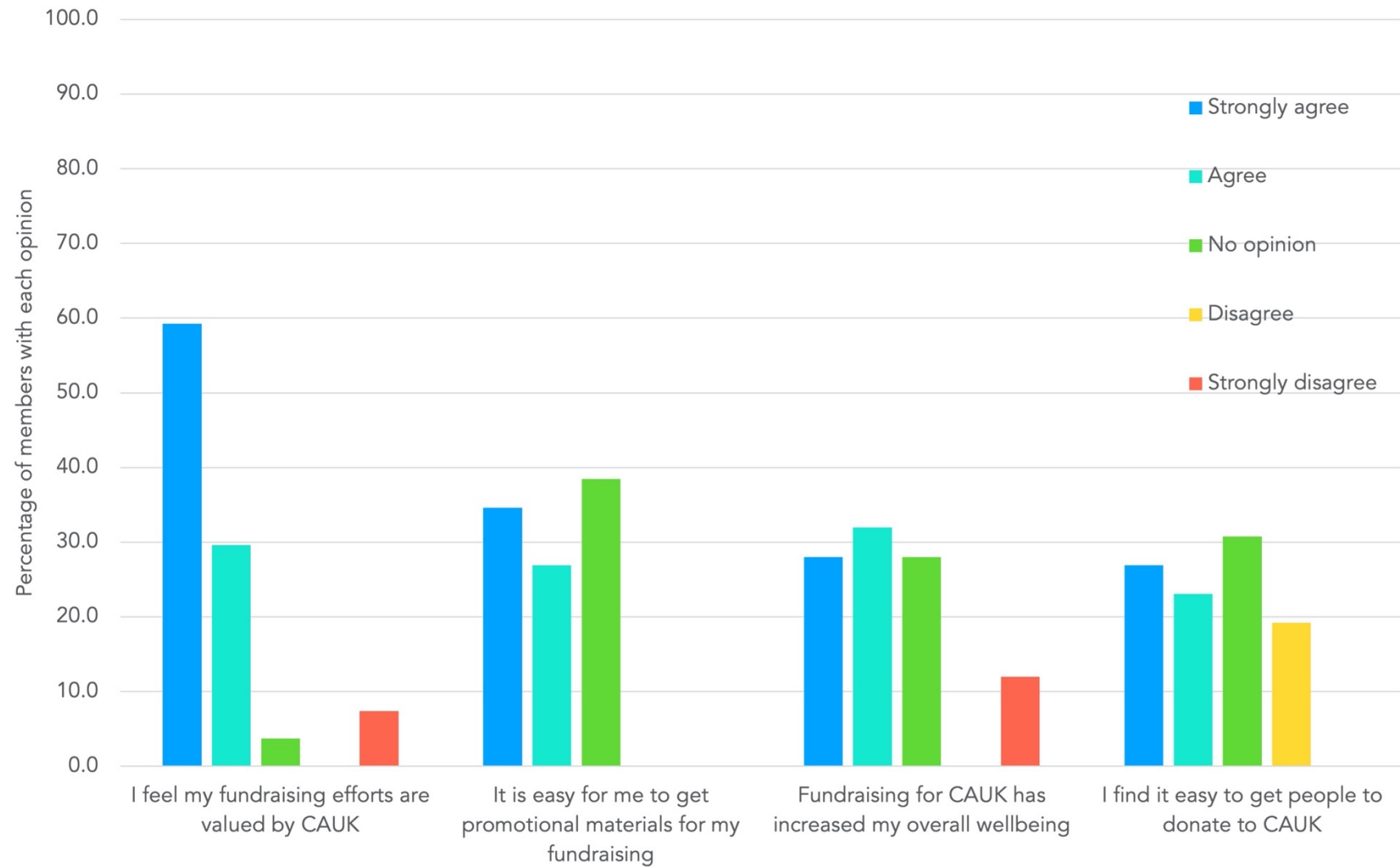
Fundraising opportunities were severely reduced as a result of Covid restrictions affecting events. Nonetheless 18% of respondents had been involved in fundraising after March 2020, the majority of whom organised events.

Figure Eleven: Members’ Involvement in Fundraising from March 2020



Although overall views of fundraising for CAUK were positive, some members indicated that they found this challenging. Suggestions were made that fundraising packs could be purchased, at a discount, from the CAUK shop whilst it was also suggested that (local) fundraising volunteers might help others to organise profitable events.

Figure Twelve: Members' Views of Fundraising from May 2020



Members' Experiences

All members gave information about their experience as a member of CAUK. This included their experience of living with a cavernoma or caring for someone with a cavernoma. Analysis showed that those living with cavernoma experienced similar symptoms (see Figure Thirteen) with tiredness and fatigue being the most common (55% of respondents with cavernoma) followed by bleeds (50%) and sensory difficulties (47%) including impaired hearing, vision or numbness. There seems little difference between the symptoms experienced by adults and those by children and young people, although a greater sample of younger members would be needed to investigate this further.

Members also shared the positive outcomes from living with a cavernoma. These were wide-ranging, but analysis of the comments showed that psychological changes were the most prevalent. These are paraphrased below, in order of their frequency in comments

Most common



- Made me appreciate life, not taking things for granted
- The people I've met; being part of a community
- A greater appreciation/understanding of disabilities
- Being happy and living for the moment
- Able to offer support to others with cavernoma.
- CAUK's support and advice
- Explained my symptoms
- Allowed me to evaluate my beliefs/opinions/life

Carers indicated the roles that they carry out in looking after someone living with a cavernoma. This showed that emotional and social support were the most common ways in which they helped (see Figure Fourteen). Carers were unanimously parents (65%) of adults or children with cavernoma, or a partner or spouse (35%). Of these carers, two-thirds said that they cared for someone full-time. As with other members, carers explained that their role had positive psychological effects such as valuing time spent together and becoming closer to others. However, carers also identified that their role brought about challenges, with the greatest being reduced social activity:

"Seeing my son grow up and thrive at school is very rewarding."

Table Four: Challenges Faced by Carers

Challenges	Percentage of Carers Experience Each Challenge
Reduced social activity	41
Poor mental health	30
Poor physical health	19
Financial difficulties	7
Extra strain on other family members	4

Figure Thirteen: Symptoms Experienced by Members Living with Cavernoma

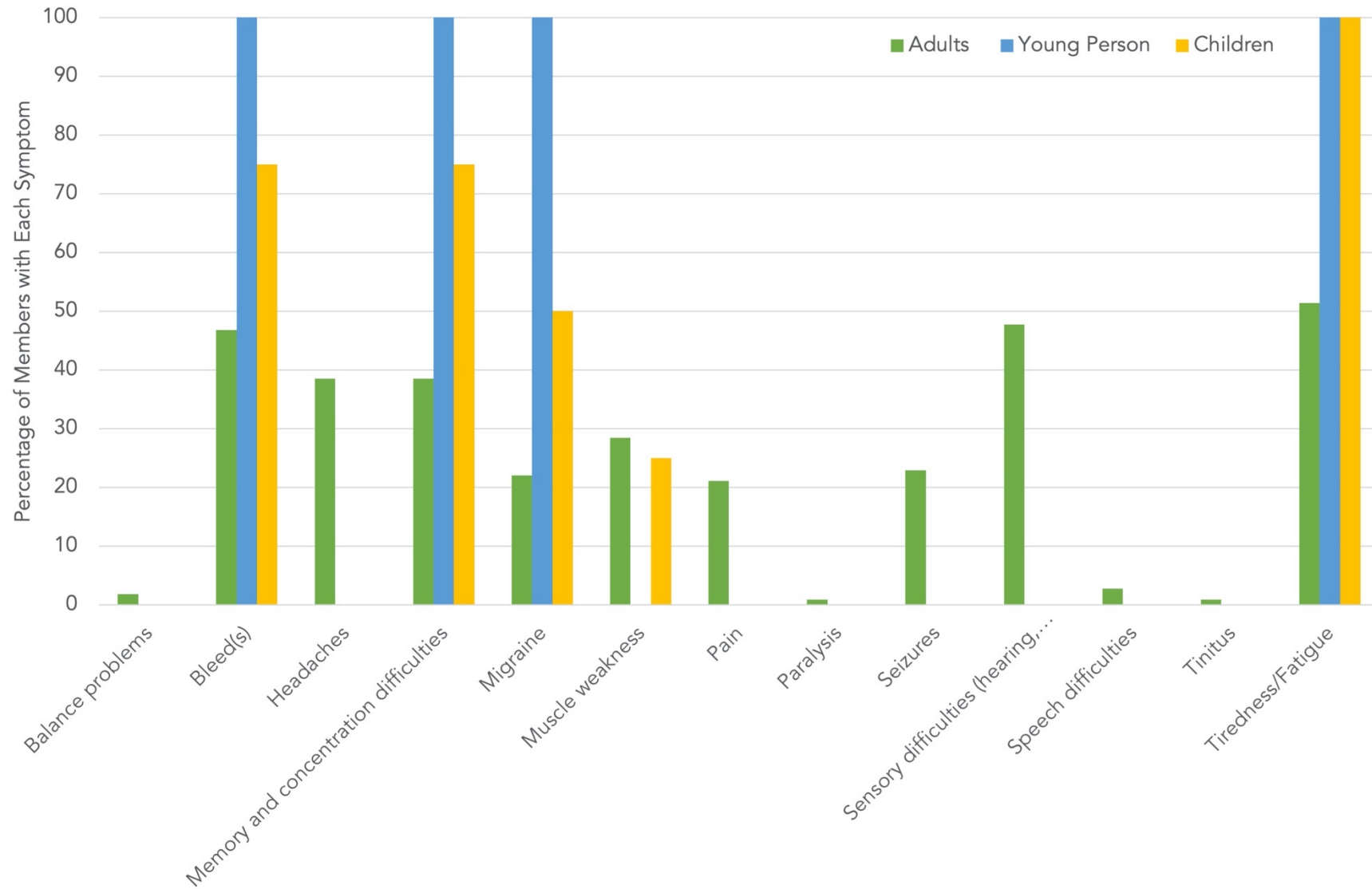
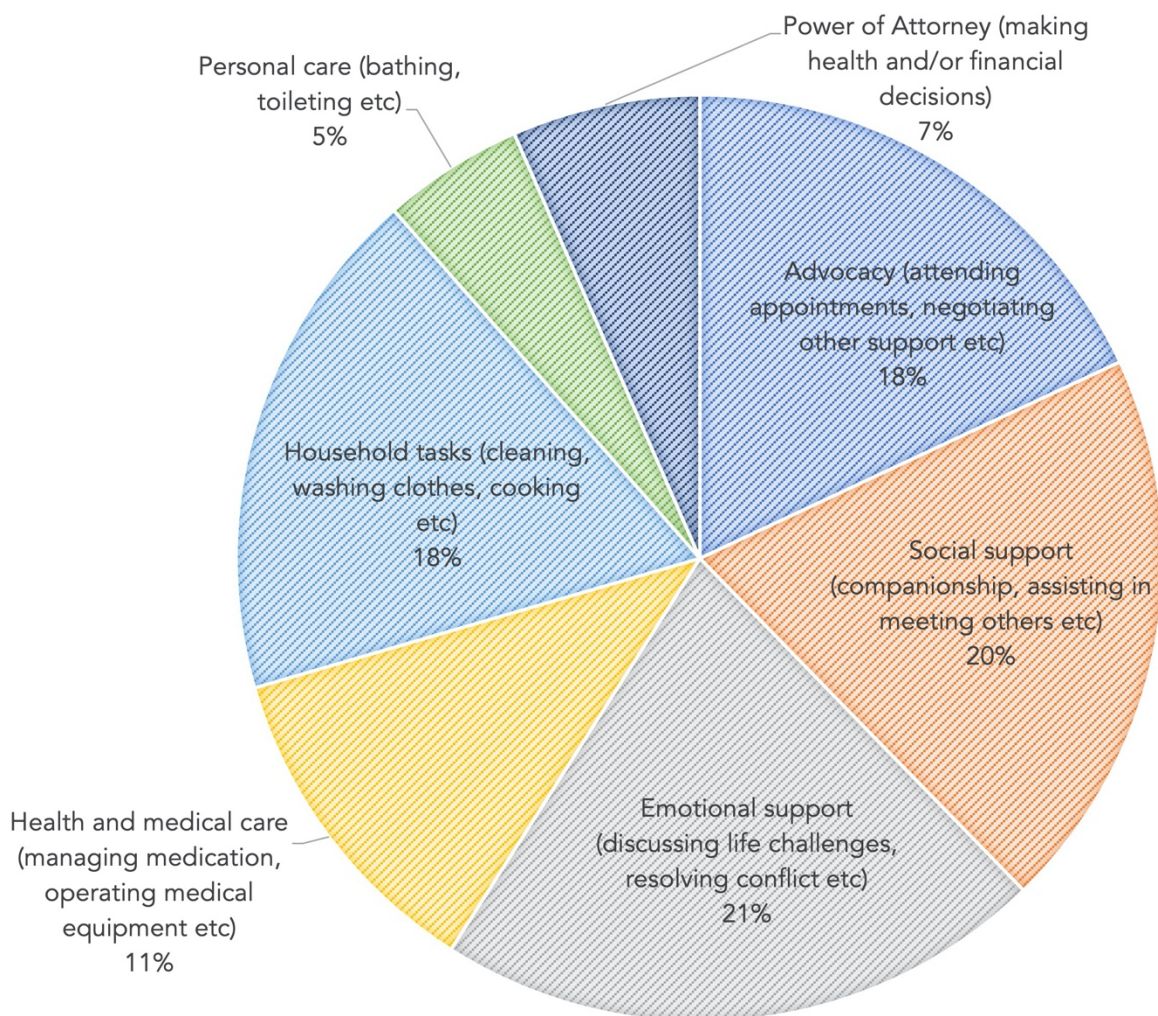


Figure Fourteen: Roles Carried Out By Carers



Members living with cavernoma also identified the most significant challenges affecting their lives as a result of their cavernoma. These challenges were different for children and young people, compared to adults. For children and young people, the most significant challenges were coping with schoolwork and controlling emotions (see Figure Fifteen). However, of all the challenges faced, tiredness was viewed to have the greatest impact on children's lives.

Emotional effects were also seen as the most common challenges for adults living with cavernoma. 44% of respondents indicated that they worry about the future, whilst 35% experience low mood. As with children, coping with work was identified as a problem for adults, although there were less difficulties concerning friendships and prejudice. Once again, worry about the future was identified as having the greatest negative impact on members lives, closely followed by controlling emotions and holding down a job.

Figure Fifteen: Challenges Experienced by Children and Young People Living with Cavernoma

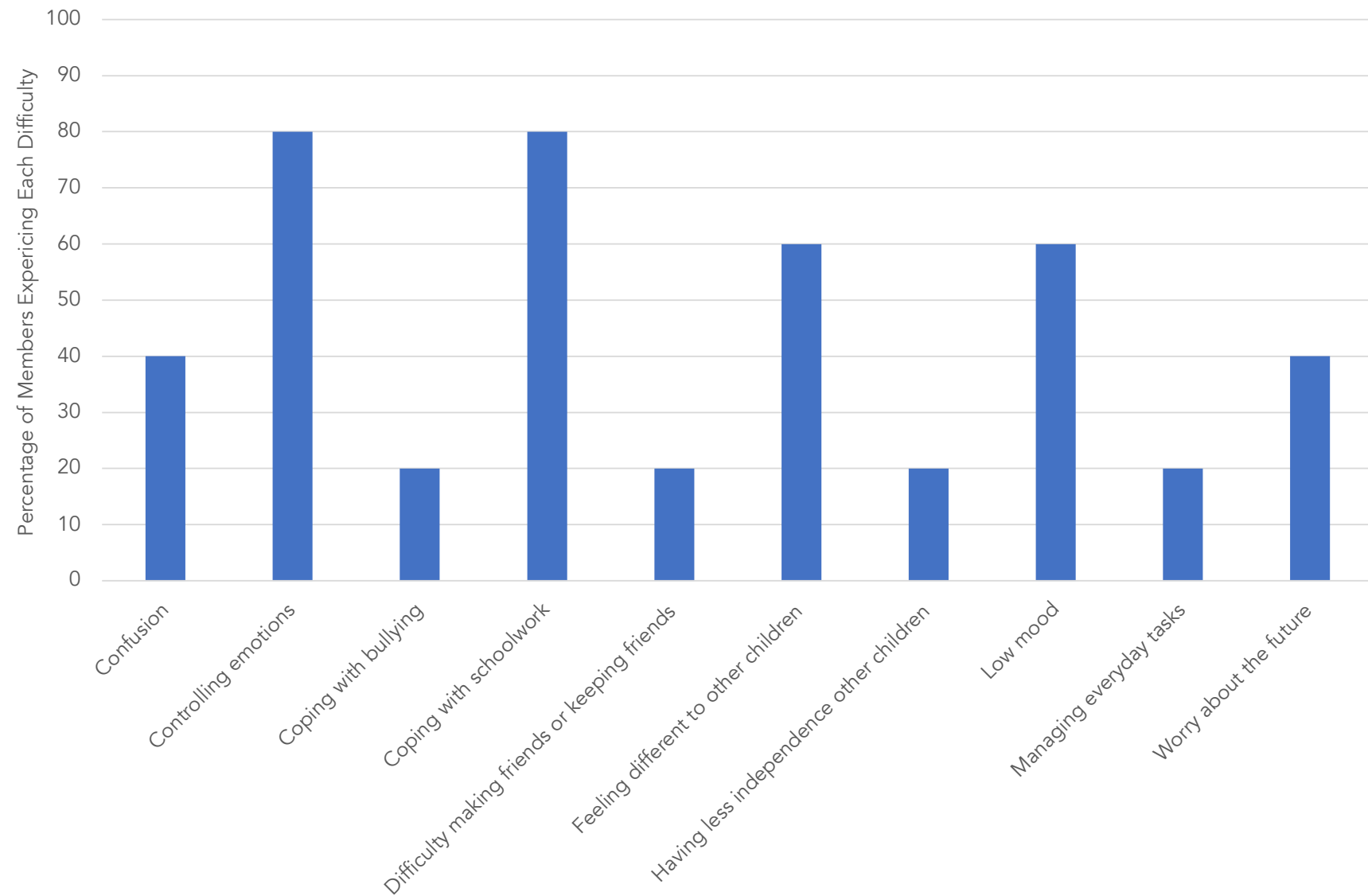
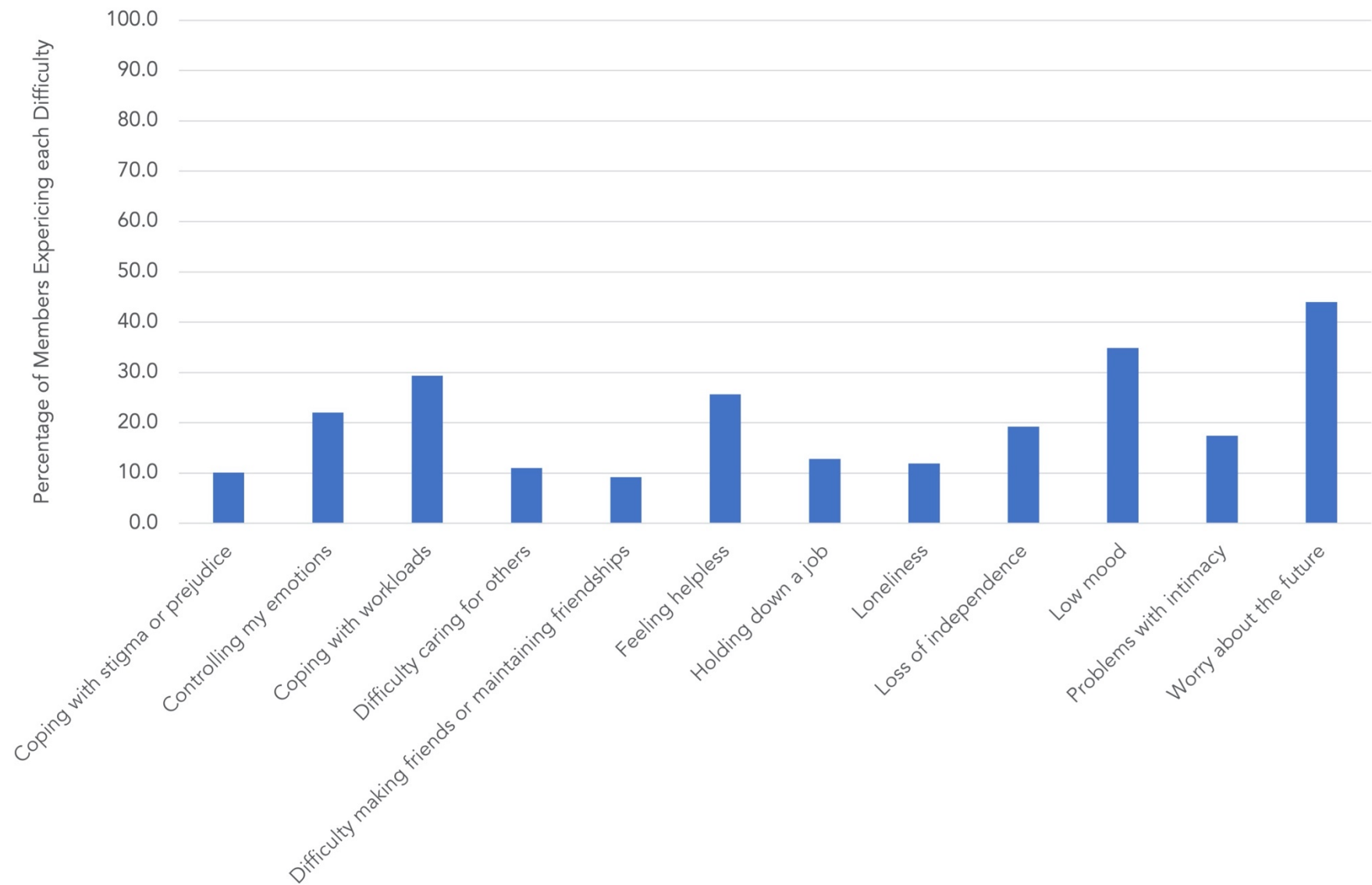


Figure Sixteen: Challenges Experienced by Adults Living with Cavernoma



Most common challenges
faced by adults with
cavernomas



- Worry about the future
- Controlling emotions
- Holding down a job
- Loss of independence
- Feeling helpless
- Low mood
- Tiredness/fatigue
- Caring for others
- Seizures
- Not being able to drive

Cavernoma Alliance UK

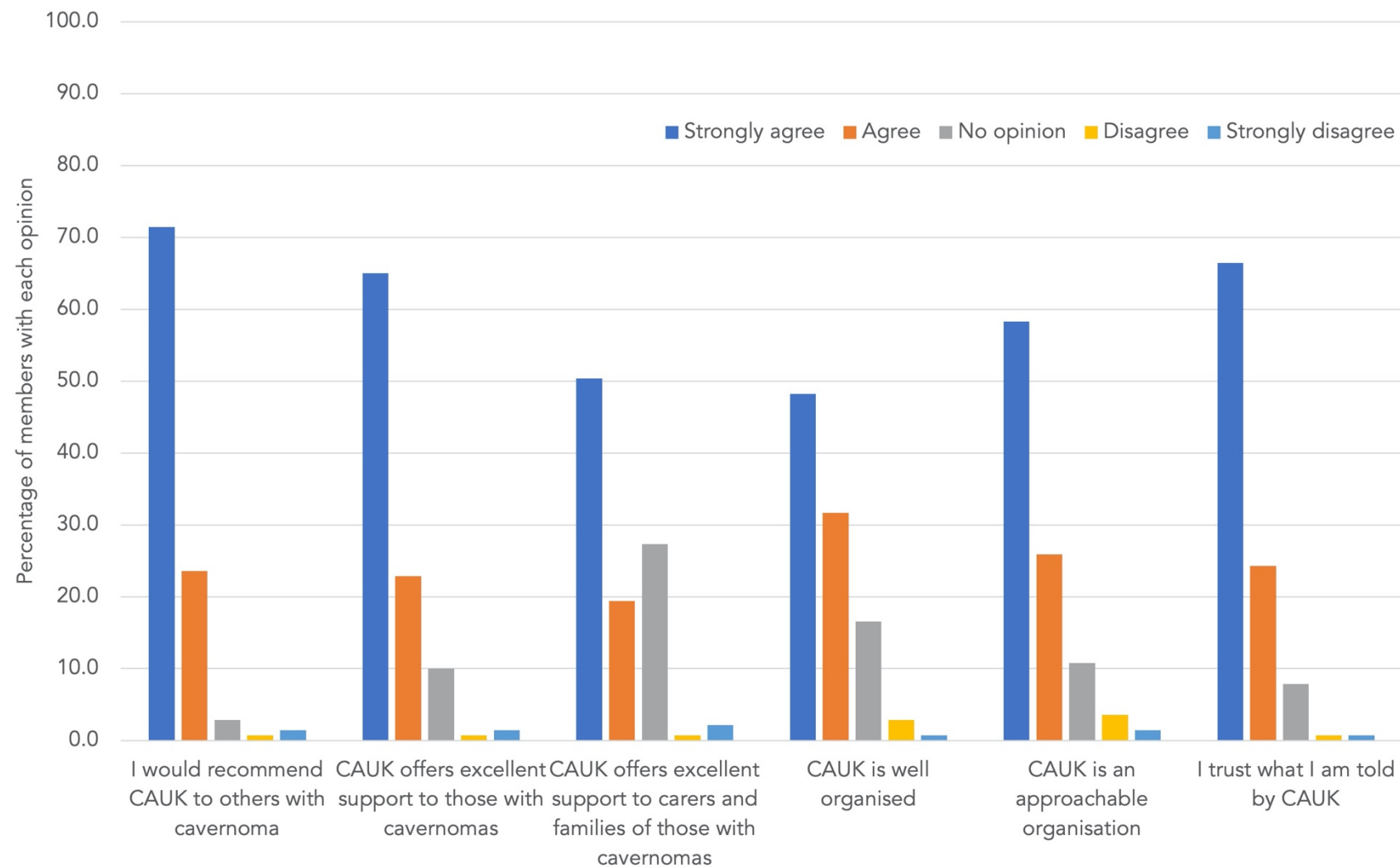
Members were asked to evaluate the role of CAUK with respect to the charity's mission, 'To work to find a cure for cavernoma, improving treatment and supporting those affected by cavernoma along the way.' The charity's core values were also investigated:

- Empowering
- Inclusive
- Informative
- Trustworthy
- Confidential
- Approachable

Members' views were overwhelmingly positive about the role of CAUK and its ability to meet their needs. Figure Seventeen reflects these attitudes, showing that 95% of respondents would recommend CAUK to others with Cavernoma. All the comments made about the charity were positive, with some members offering ideas for how the organisation could develop its support further.

"Thank you for all you have done and continue to do to support our family. Our lives would be very different and much more difficult without the support of CAUK."

Figure Seventeen: Members' Views of CAUK



Suggestions for Development

Appendix A lists all the comments made by respondents with respect to the range of support programmes offered by CAUK.

Conclusion

This survey was developed to meet two objectives:

- Objective 1: To evaluate the effectiveness of the support provided by CAUK to its members. In particular, analysis of the support provided since the beginning of the Covid-19 pandemic. The findings are expected to inform future support plans for CAUK members.
- Objective 2: To gain further insight into the experiences of members (including children, young people and carers) to better understand the difficulties faced as a result of cavernoma. These findings will help to illustrate fundraising bids and also shape the support given to members.

Objective One

Every aspect of support offered by CAUK was rated positively by members.

Overwhelmingly, comments supported CAUK's work and offered positive suggestions for developing services further. It is clear from the findings that the support programmes meet the needs of members who responded, however, it would be prudent to investigate the views of those who did not complete the survey. These members are less likely to be engaged with CAUK activities and may have different opinions about the support that is offered. Nonetheless, CAUK should be commended for providing programmes that obviously provide trustworthy information; psychosocial support; and opportunities for members to connect and gain a sense of belonging to a caring and valued community.

Objective Two

A wide body of evidence was gained about adult members' experiences of living with cavernomas. It is clear that the emotional effects of living with cavernoma pose the greatest difficulty for adult members. To this end, it seems that CAUK's support programmes are well matched to the needs of its members. However, there were very limited responses from children, young people and carers and therefore less evidence concerning their challenges and needs. It would seem appropriate to attempt further consultation with these groups to ensure services are tailored to their needs.

Overall, this survey has revealed a strong community of CAUK members who value the support they are offered and agree that this improves their wellbeing. They are grateful that advice and information is trustworthy and supported by scientific and medical evidence. CAUK is not viewed as a faceless organisation, but one where its employees care about members and want to make a lasting contribution to improving their lives.

Appendix A: Members' Comments

Overall Comments

- Access for personal alarm system for those who live alone with Cavernoma and more awareness given to GPs, health care professionals and also DWP and other related services and organisations. Also, ID bracelet or card to hold on person should a bleed/seizure take place.
- Any further comments would be best addressed directly to the CAUK team
- CAUK plainly is limited in the ability to support International groups. However it would be great to be able to utilise some of the expertise here in Australia (and perhaps elsewhere). Caverbuddy programmes and general information will help.
- Don't know how I'd get through this without CAUK.
- During Covid-19 many of the webinars were held during the day which I was unable to attend due to working
- Group meetings once safe enough to do so.
- Have seen great improvements in support offered to members since joining the organisation almost 10 years ago
- Help with DVLA - current....
- I enjoy reading the information and other people's views on living & dealing with cavernomas. I feel part of a community rather than alone with this condition
- I sometimes feel that CAUK is more concerned with children than adults.
- I think there are probably some members who would like to volunteer/help to support others, to do bits of work that that they see - or you see - is needed. Some are not sure how to approach. Some don't know yet they are needed!
- I'm finding it hard to reach out for support, due to loss of confidence and on-going symptoms since my stroke and diagnosis. It may have helped if I could have requested a phone call, as I still find it hard to access information due to brain damage.
- I'll likely make contact very soon for advice and help/support regarding my personal situation and ongoing difficulties in accessing relevant professional medical care.
- Keen fundraiser with my daughter Hannah Thompson so we will always play a part in this. I missed a bit in caverfamilies section I pressed next by mistake. I wanted to add some ideas:
 - 1) A residential for young adults only so they can all connect, share experiences and make friends and just be themselves without parents or younger children present.
 - 2) Work Shops
 - 3) Get the young adults to create a leaflet based on their experiences for sharing with the medical professionals at Hospitals etc as medics don't explain things in a way a child or young person would understand.
 - 4) Day Trips Out - Families to contribute towards the cost.
 - 5) Get the young adults to create a monthly or quarterly magazine for young people with Quizzes, puzzles, jokes and cartoon strip. Etc This could even be sold.
 - 6) Create a Caverfamilies Family Favourites Recipe Book. This can be sold to raise funds.
 - 7) Family Fun Day,.
 - 8) Sports Day.

9) It's a knockout.

10) Charity Ball.

- Local meet ups for children with cavernomas would be very useful. We don't know families in the midlands with cavernomas
- More information about latest scientific and clinical developments in an accessible way.
- Neurologists having more info on the condition
- Not aware of meetings etc in central Scotland
- Only thank you - for all you have done and continue to do to support our family. Our lives would be very different and much more difficult without the support of CAUK
- Please continue with the zoom meetings until the Covid restrictions [end].
- Please keep up the good work
- Thank you for everything you do for us, it really is a great charity :)
- Thank you so much all of you XXXXXXXXXX
- Thank you, it would be brilliant if it were possible to extend some of your services more internationally. I know funding limits this and please keep the zooms going they're brilliant

Helpline Comments

- Sometimes difficult to get through
- The helpline is a godsend. The team are really lovely and will go above and beyond to do all they can to help. From providing a listening ear, organising therapy sessions, organising events and providing us with so much knowledge. We no longer feel alone we are a part of a family and they have helped us to form lifelong friendships.

Social Media Comments

- By using the alt text on Instagram so a description of the photo is available for visually impaired/blind people.
- CAUK's social media sites are a life line for us normally when we need a bit of advice, information or are just facing a particularly difficult time. Through Covid and lockdown this has become even more valuable, being the only space to talk to people who understand and receive support through such a challenging time.
- Facebook is excellent
- I am satisfied with the sites' information
- I check Cavernoma social media and websites almost if not daily to welcome new members, to check for updates and to see if there's anything I can assist anyone with. The social media groups are really useful and help people not to feel so isolated and alone. I remember the very first time I accessed the Facebook support group it was early hours of the morning and I got talking to a couple of really lovely members who welcomed me and helped me massively by sharing their experiences with me. There's always someone willing to listen and support you. I can't comment on Twitter as I don't really use it. I will make a point of having a look though.
- I find it useful to understand other people's experiences, thoughts and emotions to help me look after and understand my adult daughter who has cavernoma.
- I love how welcoming the private group is and how brilliant and supportive everyone is.

- It has picked up in recent months. I would like to see ways in which you can increase the engagement of members of the page. I see a lot coming from CAUK but less so from the members.
- Keep on with the facts and research information
- Loving the support group on Facebook
- Moderation could perhaps be used better to avoid misleading or incorrect information from being shared.
- More positive stories. I have found some stories worrying which have increased my own anxieties.
- More stories about members journeys
- People with knowledgeable information from the charity answer queries and questions online
- Sometimes Medics are given a very negative view which is not helpful or possibly fair. Some posts are potentially alarming for the newly diagnosed. Hopefully someone is monitoring the site and is aware of this. Some posts of holidays etc are irrelevant.
- Sometimes, I feel very overwhelmed reading the post of the private Facebook group. My cavernoma is asymptomatic and reading about the stories of other people whose cavernoma is severely impacting their lives increases my anxiety and fear. So, I mainly use it to ask questions and provide support. I really value the members' knowledge and advice on how to live with cavernoma. Since I was diagnosed in 2019, I have been dealing with anxiety and panic attacks and during the first weeks after my bleeding I would go to ER quite frequently and my therapist advised me to stop reading the group. I have learnt now how to use the group in a more positive, as a source of valuable information.
- The social media is so important. You can get so much advice just from the website. There is always someone happy to talk if you need it.
- They are good and active from members which is good
- Useful and supportive
- When my son had his first bleed and diagnosis of a Cavernoma in his brainstem I felt alone but I've found some comfort with other families who know exactly what you've been through and are there to support each other
- Would like a way to search topics covered in Facebook members' pages. Often see same sort of conversations coming up and would find it useful to refer back to threads.
- You've already improved it all so much... esp website. Can't think of more right now

CaverFamilies Comments

- An organised kids zoom event for kids to link up
- Caver families has become a major part of our life. It is a massive part of our support. We don't know how we would have coped in some difficult situations over the years.
- Caverfamilies are a support for the whole family. Living with Cavernoma or supporting someone with Cavernoma can sometimes be lonely, as the condition is relatively rare, lockdown can really heighten this and CAUK have been amazing at reaching out to their members and letting them know they are not alone. I couldn't make any suggestions that would improve what CAUK do - they always have and continue to do an outstanding job at supporting their members and families

- CaverFamilies is a great way for parents to understand other peoples experiences with the effect of Cavernoma. The children love to mix with other children who understand the fear of having this disease and also mixing with children from across the country and feel like they are a member of a special club.
- Just getting involved now after being diagnosed in Aug
- This year's been hard for everyone but kids and young adults still need hospital visits for treatment and assessments and I've found that caverfamilies has been invaluable during this hard year for support and advice for eachother.

CaverBuddies Comments

- I have been matched but I am not trained
- I have not yet been matched to a co-buddy. I started my training but didn't hear anything after the last session.
- I think the caverbuddy scheme is a great support for those effected by cavernoma
- My caver buddy was matched quickly. She was positive & helped me see it wasn't all doom & gloom.
- The training is helpful. Does new members pack forefront the opportunity to talk to someone?
- Unfair to say as I helped train them!

Published Information Comments

- All good! (sorry -not that helpful !)
- CAUK have provided us with so much valuable information, much more than what we can get from our doctors and hospitals.
- Great new look and having up to date information is fantastic.
- I just prefer information online
- I really value the knowledge of the clinicians and experts collaborating with CAUK. CAUK was determinant in helping me to choose a hospital for check-ups and monitoring my cavernoma.
- I think it a good idea to keep published material available to new members
- I think the leaflets are very useful to help doctors and family members understand. The scientific articles in the blog are very interesting and keep me up to date on scientific information.
- I usually find the information I need and the answers to questions.
- I was very interested in the link between stomach acid & Cavernoma
- Improved information on Spinal cavernoma
- On the whole excellent.
- Really, really have benefitted from this over the years. Don't know what I would have done without it, the printed material and the website and e-material also. Please keep it up and up-to-date. It's a fantastic resource, even if I haven't used it as much in the past months (apart from keeping up with the science, which was new to me, and looking at some of the information booklets).
- The new website is great and really easy to navigate and the newsletters are always a good read too. I had an idea about making a young people's monthly/quarterly

magazine full of information but with less jargon. Also containing crossword puzzles, joke corner, comic strip all created by our talented young people.

- Useful
- Useful I have only just been diagnosed with a Cavernoma that has bled.
- Usually clear and concise

Zoom Meeting and Webinar Comments

- As I (and others) live remotely from the UK, it is essential for me to have Zoom as part of the meetings. Even if a meeting is held face to face I would be grateful if it could be held over Zoom as well.
- Email reminders are very helpful
- extremely helpful, please continue these informative clinical sessions after the end of the pandemic
- Have been a member for several years but have welcomed the opportunity to re-connect with the charity since lockdown. You've put on a full programme of varied and interesting webinars and through one of these I learnt that you were offering therapy for carers of those with a cavernoma which I was unaware of until that point. As a result I am now in regular contact with other carers which is fantastic. Also being at home during the pandemic has meant that I've had the chance to attend webinars held during daytime weekday hours. Going forward I personally am interested in occasional talks by professionals, updates in research and hearing member stories as every member's experience is unique.
- Have them during evenings. As people work during the day, are missing out
- How could we attract a larger, more diverse membership/audience? Advertise differently? Different times, approaches...? I like the morning time slot, so am keen to keep it, but recognise its limitations for working people, parents. Topics for talks: clinical and non-clinical: widen the scope perhaps to cover psychosocial, creative responses, and where appropriate open these to wider public? I'm not sure, just trying out ideas.
- I have had problems with zoom meetings ie finding various menu's but it could be as I am on a tablet rather than iPad
- I have LOVED the Zoom meetings. Please keep them going when any normality returns
- I think some of my favourite ones are the virtual cafe and chats and they're such a great way to make contact and connect with others with cavs
- I'm never around at right time so important I can access meeting or talks at any time
- It would be nice to talk more often - like twice a month - also as perhaps not every session is possible to attend.
- Skeptical at first, I warmed to this way of working.
- Sometimes it is a challenge to find the link to the meeting i.e. finding the email!
- Talking to people who understand is the best therapy – thank you for providing this breathing space and support.
- The Zoom caverfamilies catch-ups are great it gives you an opportunity to talk about anything you like Cavernoma related or not. It's really helped with mental well being especially during covid 19. Members stories are also very interesting and they help you to understand how Cavernoma effect people differently. I absolutely love listening to others stories.

- The Zoom meetings are useful if travelling is a problem and it would be good if they could continue after we return to normal alongside actual events like the annual conference for this reason.
- These have been an asset to CAUK, hope you continue to run.
- They are usually at 11am and due to being severely disabled I cannot be up and ready by this time. I have missed out on most zoom meetings/webinars for this reason. It has been disappointing that I have missed them, especially the regional meeting because I would have liked to have been a part of that. The ones that I have attended have been great though, so I hope that if any are done in the future at a later time, I will be able to attend
- Vary the hours so that more people can come. Evenings for some more of the webinars
- Zoom meetings are critical for me to participate. When things get back to "normal" I would hope that the Zoom function is continued, even if some of the participants are "face to face". I know that it is the only way I can try and be an active participant and I believe that there are others at distance who would be in the same position.

Therapy Comments

- Could the therapists do some general webinar sessions? Blogs?
- Made us realise how lucky we have been
- Members of the group therapy that I attended all wanted to stay in contact and continue to support each other. It would be great to be offered a follow up one-off session to check in with the therapists.
- Robyn was extremely helpful and informative and I am looking forward to my future sessions. I love that they are not at set times and that you have 4 sessions and can spread these out as far as you like
- The therapists are excellent they were a lifeline to me and my son during lockdown.
- The therapy services are absolutely amazing and in my opinion there's no need to improve on them just continue all that you're doing and make them available as much as possible for all to access as and when the need arises. Robyn is amazing and she's so lovely. She can make anyone talk and get them to really open up. She's caring, understanding and very passionate about her role and she listens and empathises but never judges you.
- Without therapy I would be totally lost
- Your plans as far as I know sound good. The peer support group I participated in was helpful beyond my expectation. I really didn't expect it to be more than the 'usual' coffee morning with a twist, but it wasn't. I don't know if it is sustainable, but this might be an option for future.

Annual Forum Comments

- I had never been to an annual forum before so was really looking forward to attending this year however Covid 19 put a stop to it. The online forum was very good and very informative. My husband and I got a lot out of it. I do not have an opinion whether online is better than residential really as I would attend either. The only thing is you're

more connected with other members at a residential and you can spend time getting to know people. Online it's harder.

- I think there are advantages to both, and I would welcome the opportunities to meet other members in an in-person setting, but it has been very helpful to be able to access the Annual Forum virtually from my home as I was still recovering from the fatigue of a bleed and would have found the journey to a residential too tiring. Perhaps the ideal situation would be if the forum could be held as an in-person event, but with real-time virtual access for those who are unable to physically attend, so that they can also be part of Q&As and discussions.
- I'm not sure about whether we should have future Forum virtually or on site! There are benefits to each: wider accessibility (the former), more intimate with the benefit of networking and friendship building (the latter)
- If have residential out online as well
- If there is a residential also having the speakers online at the same time would be good as being able to attend can change at the last minute. A good summary of each talk before and time to send in questions in advance is always useful
- Partner with cavernoma is wheelchair user so travelling for residential forum not always easy and can be expensive. Online means it is fully inclusive but I can see the value of attending a real conference and meeting people in person.
- Some way to interact in like break out rooms might be nice, or another way to connect with others and process the information learnt in the sessions. Especially the neurofatigue one would have been interesting to have an interactive session associated.
- The richness of speaker blended with members' ability to ask questions seems to be one of the ways CAUK is different from other cavernoma charities.
- Was well run but I missed the physical interaction although I think an element of this would be beneficial every year that a physical meeting is held

Fundraising Comments

- CAUK were supportive and appreciative of our fundraising event. We were offered everything we needed and more to make our event a success.
- I have lots of fundraising ideas from sponsored walk/run other sponsored events. Dance a thon, bake sales, raffles, Tombola, charity stall at a free, car boot sale, garage sale, lottery bonus ball, brave the shave, quiz nights, race night, pamper night a psychic night just to name a few.
- Ready made fundraising packs to be ordered at discount from the shop. More help available to advertise local fundraising. Local fundraising volunteers may be helpful