

## **Dementia Talking Point User Survey 2021**

*\*“It is like having a refuge, a place where you can speak freely about how you are feeling. Doesn't matter what time it is, there is always a helpful or sympathetic reply, I felt less alone.”*

*\*“When I was a carer, I learnt so much from other members who were one step ahead of me in their caring roles. They were the ones who were often able to explain what was happening and offer pointers on how to manage it.”*

*\*“The people are so sympathetic and knowledgeable and non-judgmental. It has made a huge difference to me.”*

\*Speech bubbles in this report feature real comments from our service users

## **Executive summary**

Dementia Talking Point (known in this report as Talking Point) is Alzheimer's Society's online community service where anyone affected by dementia can receive support from other people in similar positions. It's open 24/7 every day.

### **Summary of 2021**

In May 2021, Alzheimer's Society launched a short film ahead of Dementia Action Week, as part of a bold and powerful campaign to expose the cracks in the social care system. We shared this film with the Talking Point community and gave members a chance to share their feedback. We got six pages of responses!

We welcomed two new volunteer hosts to the service team. Hosts welcome new members of Talking Point, point the way toward helpful information and sources of support, and help flag any issues on the community to moderators and employees.

We started work to connect with colleagues in Alzheimer's Society, running information webinars to increase understanding of Talking Point, answer questions, and encourage colleagues to help promote the online community to others.

Working with colleagues in Fundraising, we were able to secure People's Postcode Lottery funding so we could continue to offer high-quality, valuable peer support.

In July 2021, we surpassed 80,000 members –enough to fill the London Stadium!

### **About the survey**

We normally run our user survey on an annual basis, but we have been unable to run the survey since 2018, due to the COVID-19 pandemic. This is a shorter survey, asking fewer questions and including a question to gauge if the community was still helping people to cope with the pandemic.

The survey opened in mid-December 2021 and closed at the end of January 2022. This time, 506 people completed the survey. The survey was promoted through posts on the Talking Point online community, messages sent to all active members and our community email newsletter. This helped ensure a wide range of service users would have a chance to complete it.

**Total membership of Talking Point on 31 December 2021 was 82,429**

*“Christmas, New Year, birthdays and bank holidays when loneliness kicked in, all I needed to do was get online and find some comfort. Now whenever someone comes to me looking for advice, I always recommend your site.”*

## **Key findings**

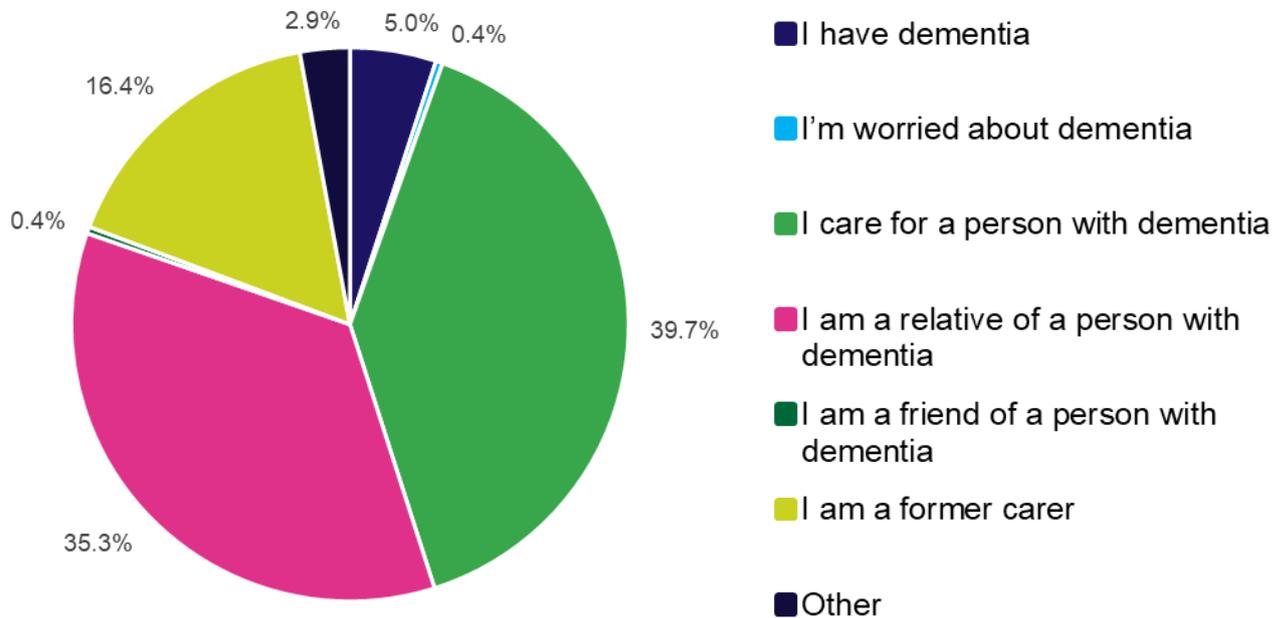
### **How satisfied are users with the Talking Point service and what is the impact of it?**

- 92.5% of respondents said they were very likely or fairly likely to recommend the service to others. *This figure was 92% in the last survey (2018) and 87% in 2017.*
- According to respondents, Talking Point helped most people with answers to questions about dementia (53.9% of respondents), feeling less isolated and more connected to others (53.2%) and allowing them to share their experiences and receive understanding from others (47.4%).
- In this year's survey, the most common themes we identified included: members "not feeling alone and feeling a sense of community", able to give "practical advice", enabled people to feel like they were "helping others", received "helpful advice and learned from other people's experiences".

### **Who uses the service?**

- 80.8% of respondents are female and 18.2% defined as male.  
*A slight change from 2018 where 79% of respondents defined as female.*
- 34.6% of respondents are aged between 55 and 64 years, 32.6% between 65 and 74 years, 13.6% are between 75 and 84 years and 13.4% between 45 and 54 years. Only 3.8% are aged 44 years or younger.  
*In the last survey 37.2% were aged between 55 and 64, 27.6% were aged between 65 and 74, 10.9% were aged between 75 and 84 and 16.5% were aged between 45 and 54.*
- 87.4% of respondents self-defined as White British, 5.3% as White, other background, 1.4% as Asian or Asian British, 1% as Black or Black British, 0.8% as Mixed/Multiple ethnic group, and 2.4% as any other ethnic group. 1.8% preferred not to answer the question.  
*In 2018 85.5% identified as White British, 8.6% identified as White other, 0.5% as Asian, 1.5% as Black, 0.7% as mixed 0.7% as any other ethnic group and 2.6% preferred not to answer the question.*
- 88.3% of respondents defined themselves as heterosexual or straight. 4.8% of respondents defined as gay, lesbian, bisexual, pansexual or asexual and 5.7% of respondents preferred not to answer the question.  
***This is the first-time sexuality has been asked in a Talking Point User Survey.***

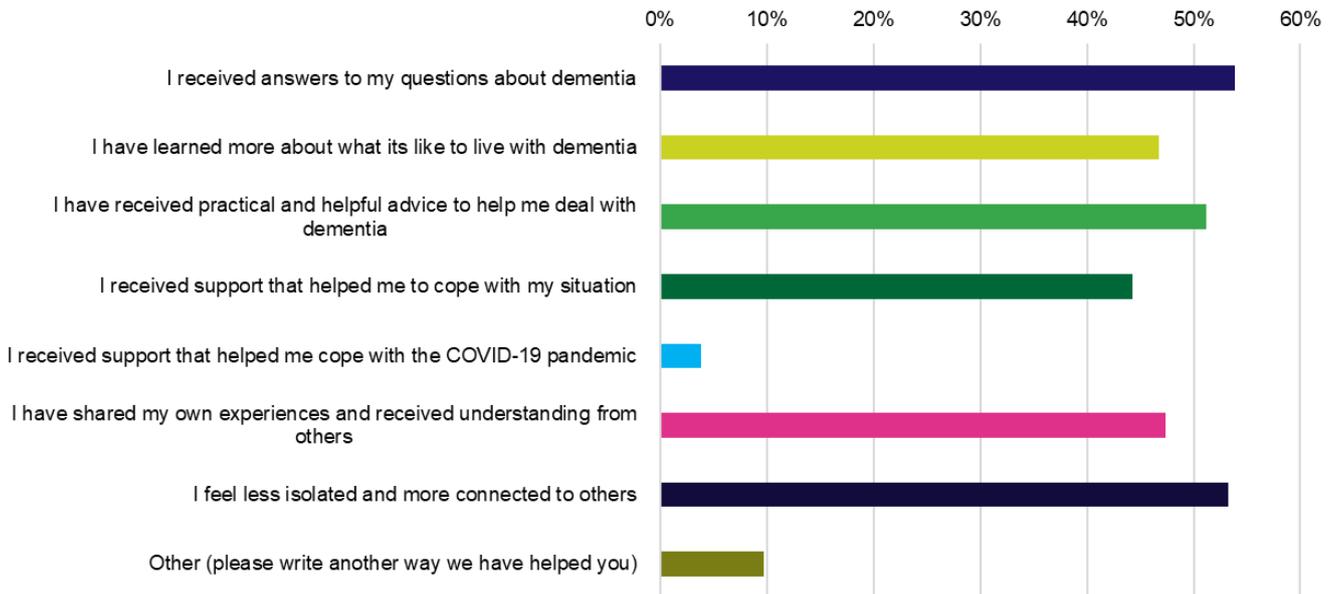
**Question 1 - Which of these statements apply to you?**



The most common response to this question were people caring for someone with dementia (39.7%) being a relative of someone with dementia (35.3%), being a former carer (16.4%) and having dementia themselves (5%). 8.9% (45) of the respondents originally answered other. 30 people gave a response that fitted into existing answer choices. This included 10 people who mentioned having a spouse or partner with dementia, so those responses were moved to the category of “I am a relative of a person with dementia”. After the 30 responses were moved to the relevant categories, this left 15 responses in the Other category or 2.9% of the total. Of the 15 responses:

- 10 people had a relative or loved one with dementia who had passed away.
- 3 people knew someone who could have dementia but didn't have a diagnosis.
- 2 people were professionals who worked with those with dementia.

**Question 2 - Please let us know how Talking Point has helped you. You can tick any of these statements that apply:**



1,527 responses were recorded for this question by 492 different respondents. This equates to an average of 3.10 statements agreed by each respondent.

The top three statements that participants selected were: I received answers to my questions about dementia (265 people, 53.9%), I feel less isolated and more connected to others (262 people, 53.3%), and I have received practical and helpful advice to help me deal with dementia (252 people, 51.2%).

Of the 48 people who selected other, there was a wide range of different answers. The most commonly occurring ones were:

- 11 felt they were too new to the service to answer the question
- 10 found reading other people's experiences helpful
- 8 said they didn't find Talking Point helpful
- 4 said they found the service helped them cope, feel less alone and reassured

While the number of people saying that had received support to help with the Covid-19 pandemic was relatively low (3.9%), this is likely because the survey was sent at the end of 2021 when most the impact of the pandemic had passed and there was less of a need for support around it.

*"I go to Talking Point when I'm feeling low and isolated...and it always helps"*

### **Question 3 - Please share some examples of how Talking Point has helped you.**

379 people answered this question giving a diverse range of ways Talking Point had helped them. These ranged from extremely specific ways to deal with certain government agencies, to helping people to better understand dementia.

A textual analysis of the responses gave four core themes:

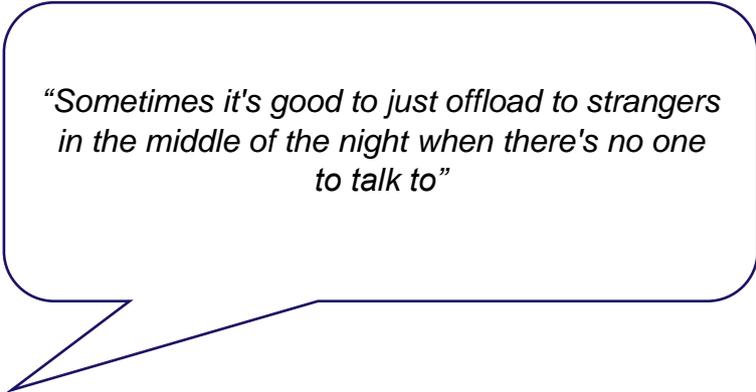
#### **Not feeling alone and feeling a sense of community**

A lot of people expressed how they felt less alone and felt a strong sense of community from connecting with others in a similar position with similar feelings.

*“Made me realise I am not alone, that there are thousands in my position”*

*“Isolated when caring for my husband. Talking Point made me feel connected to others with the same problems”*

*“Just understanding that I'm not alone and my frustrations are shared and understood makes it all easier to cope with”*



*“Sometimes it's good to just offload to strangers in the middle of the night when there's no one to talk to”*

#### **Practical advice**

A lot of respondents said they'd received practical advice from the community on a range of topics including issues with eating, hiding objects, knowing which organisations to contact, and dealing with incontinence.

*“At each step along the downward spiral of dementia, someone has been there before me and found a solution to share with others ... we learnt how to manage the practicalities of my mother's night time incontinence, followed by daytime incontinence.”*

*“You can seek advice, get phone numbers to ring, and even if they can't help you, they can point you in the right direction.”*

*“Talking point was a life saver – took me from knowing nothing at all about the problems to being able to cope and know what to expect.”*

## Being able to help others

Many members discussed that by being a member of the community, they got value from being able to support or help other people affected by dementia. People described a journey of moving from someone who primarily used Talking Point as a source of personal support to somebody who wanted to give back and give the same support that they had received to others.

*“I am now able to pass on my experience and help, having completed my journey”*

*“My primary reason for becoming active on Talking Point was to help others during the pandemic, when there were many new people asking for advice and support.”*

*“The opportunity to be able to help others with advice, factual information and support”*



*You feel support and members seem to genuinely care for one another. You feel like you are part of a community.*

## Helpful advice and learning from other people's experiences

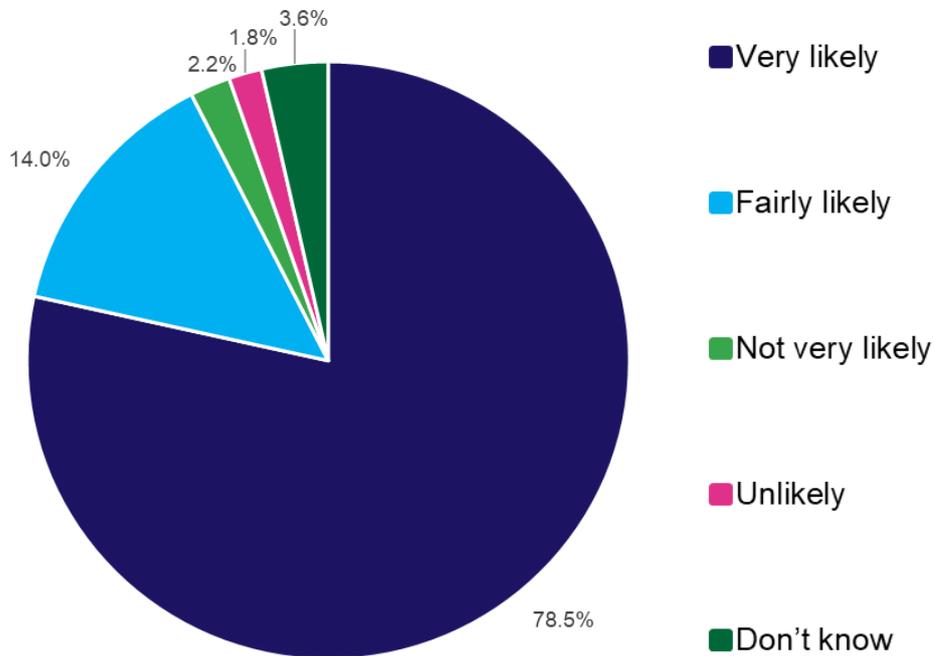
Another theme from respondents revealed that people received helpful general guidance in two ways - directly by people offering them advice on their own discussions, and indirectly by reading other people's experiences and learning how they reacted to different situations.

*“I have asked a few questions, during a time which has been very difficult to deal with ... I received nothing but support and helpful advice from people who know what they are talking about. Excellent.”*

*“Pose a question and you get the perspective of others in similar situations.”*

*“From reading posts from others, I have learned that my experience as a caregiver is not unique and that the behaviours of my partner who has dementia are not uncommon. A huge relief.”*

**Question 4 - How likely is it that you would recommend Talking Point to others?**



Similar to previous surveys, the response to this question has been predominantly positive, with 92.5% of respondents stating that they would recommend Talking Point to others.

This is a slight increase from a total of 92% in our 2018 survey and continues a trend from our 2017 survey where the total was 87%.

Of the 92.5%, 78.5% said they were very likely to recommend the service, a significant increase from the 71% who said this in 2018. 14% said they were fairly likely to recommend Talking Point which is a decrease from 21% in 2018.

The amount of people who said they were not very likely or unlikely to recommend Talking Point to others was only 4%, a decrease from 5% in 2018 and 6% in 2017. 3.6% stated they didn't know the answer to this question, a slight increase from 3% in 2018.

Overall, the responses to this question show an extremely positive trend for the service, with a greater percentage recommending the service compared to the last two surveys. It is worth noting that the highest response we have ever received to this question was 93% in 2015.

**Question 5 - Please tell us why you would or would not recommend Talking Point to others.**

There were 371 responses to this question, with 306 of the responses containing positive comments about the service.

Of the 65 people who did not share positive responses or recommendations, 15 had this view for practical reasons or rejected the nature of the question; saying they were too new to make a judgment, "*don't usually recommend anything to others*", or wouldn't recommend to family members for fear it would "*compromise my privacy*."

Other common reasons for not recommending the service were from people who found difficult to use (8 responses), found it frightening to read (6 responses), or disagreed with moderators or members of the community (5 responses).

Looking at the reasons people recommended Talking Point, there was significant overlap with the themes identified in question three of this survey report (*how Talking Point has helped you*). The three themes were as follows:

**Talking Point helps you feel less isolated and alone**

Many members shared how Talking Point allowed them to feel less alone and isolated in their situation by connecting others going through similar difficulties:

*"There are always members around and you are never totally alone when you have access to TP."*

*"To feel less isolated and speak to others who understand the experiences you go through from having been through it themselves. It's helped me realised others are struggling with the same issues."*

**It is a place to connect with others for support and to learn from their experiences with dementia.**

*"... recommend Talking Point for support and understanding. A chat in the tea room can give an amazing break from the world of caring even if just for half an hour"*

*"...having experienced caring for my dad, it's very reassuring to know that there are so many people out there like me who are struggling with the same sorts of things."*

*"I would recommend the site because it's informative, there are topics that help you see things from another perspective sometimes."*

## **Talking Point is a source of useful knowledge and information**

Members shared the positive benefits of practical and 'real life' advice:

*"Because people posting on here have real life knowledge of the illness. Doctors I've spoken to have no knowledge of 'hostess mode' or other issues."*

*"Sharing problems with carers who have encountered the same dilemmas brings answers and very often a light - bulb moment of "Oh, we haven't thought of doing it like that". Ordinary people just like us, not medically trained, but "learning on the job" and willing to pass on their experiences is a Godsend and builds confidence."*

*"I would recommend Talking Point because you are engaging with others in the same boat or maybe they had experienced the same thing that I had. I learned more about dementia on Talking Point than anywhere else. I got more information and useful advice than any pamphlet could give me .... a godsend for me."*

## **Recommending Talking Point**

Some members shared that they have recommended Talking Point to others:

*"I have already recommended Talking Point to a friend, whose partner has dementia, and she needed help to support him. I recommend it to others for practical help and support."*

*"I have already recommended Talking Point to two of my cousins whose parents have developed dementia. This is because they will find answers to their questions here from people who are going through/have been through similar experiences."*

*"I have been sure to send friends being newly exposed to dementia within their families the link to TP and to make sure they are fully aware of how much of a life saver it is."*

Additionally, survey respondents mentioned that Talking Point could be a useful resource to for someone without dementia, to allow them to learn more about the reality of the condition:

*"I'd also recommend it to people who do not live with dementia just to give them an inkling of the realities, there's more to dementia than losing your glasses! I would also recommend that every MP reads it regularly!"*

**Question 6 - How do you think we could make Talking Point a better community for people affected by dementia? We'd love to hear your suggestions on how we could make the community easier to use, more helpful, more welcoming and meet your needs in a better way.**

This question was answered by 283 people who provided a wide range of different responses. Most answers were from people saying that they were happy with the service and had no suggestions for improvement. Once these responses were removed and the rest of the responses were analysed, six key themes emerged.

**More advertising to promote Talking Point**

One of the most popular themes were from people who were happy with Talking Point but wanted the service to be advertised and promoted more widely. Members mentioned coming across Talking Point “*by chance*” or “*by accident*”. Members suggested it could be promoted on social media, at doctor’s surgeries, in the local media, and in handouts when a person with dementia receives a diagnosis.

*“I think Talking Point is a great asset for people affected by dementia. It just needs to be promoted more widely.”*

*“I think Talking Point should be advertised more in the media as it was only by chance I came across it!”*

*“Advertise widely on social media. Encourage people of all ages and ethnicities to get involved.”*

**New features for Talking Point**

Many respondents suggested new features for the online community. The most popular was asking for a like or thumbs up button, with one person saying “*I'd like to be allowed to leave a sign of appreciation without having to comment*”

Other suggestions included keyword searching, bringing back the app, being able to sign in with your fingerprint and password prompts.

*“A password prompt for those who cannot remember passwords.”*

*“It would be great if there was a Like button for posts. Quite often something chimes with me and I'd like to endorse it but not necessarily reply.”*

*“... when I first used [Talking Point] it was available as an app which was easy to use. I do struggle now so rarely use it anymore ... it would have been very helpful especially through these hard times. So if it was an app again that would be great.”*

## **Desire to communicate with experts**

Comments from respondents showed a desire to have a more experts providing information on Talking Point. People wanted to hear from medical experts as well as other professionals who could provide answers on more complex or difficult issues.

Survey respondents mentioned wanting webinar sessions or online meetings where experts could comment on issues and answer questions.

*“Would be good to have access to professionals from time to time for those questions that are harder/more difficult to find answers to.”*

*“It might be helpful if some medical people could sometimes contribute too.”*

*“I would very much like more professional input on some of the issues and/or why it is that certain issues manifest themselves, e.g. fixing (muscle) positions.”*

## **Improvements to make Talking Point easier to use**

A total of 27 respondents said they had previously been unsure on or confused by how to use some aspect of Talking Point

The area which caused the most confusion was knowing how to post or start a thread. Respondents said:

*“Can there be a simpler video instruction at the point of registering.”*

*“Make it easier to post a comment or initiate a thread- I learned by trial and error!”*

The other main difficulty was navigating the site and to find answers to the topics that you are interested in. Members said:

*“Just make the site easier to navigate. Maybe it's me but it's not user friendly at all”.*

*“Make it easier to navigate and find the things you are really looking for help with.”*

The other difficulty that occurred multiple times was with members struggling to remember their password which is needed to log in and use the community.

*“I have had problems logging in and being directed to the correct place.”*

## **Change the number of forums on Talking Point**

There was a divide of opinions between people who wanted more specific forums and some who found the number of forums confusing and wanted fewer of them.

Suggestions for new forums included one on what happens after caring (but not due to bereavement), and one for younger people caring for someone with dementia.

Some respondents mentioned wanting a “simplification of the different forums” and having “found the number of different forums confusing at times”.

*“Maybe less forums - it can get confusing knowing which one to use sometimes.”*

*“Maybe there is a need for fewer sub-forums or clearer guidance. It can be tricky sometimes when there are people posting who are having difficulties with their loved one with dementia and say things that might be hurtful to someone with dementia.”*

Several respondents wanted a greater social aspect to the community including suggestions for a “section where people could meet up” a “group where people could make friends” and a desire “to meet people in the same situation as me.”

*“Also, what about having different rooms, a room you can go into to have friendship groups outside Alzheimer’s, a hobbies room etc? Some carers might be really isolated and value forming online relationships like this”*

## **Include more information and resources**

Many members wanted to see more information and resources on Talking Point, including factsheets and summaries of topics. Respondents wanted more practical information like solutions to common problems and specific issues.

One respondent suggested:

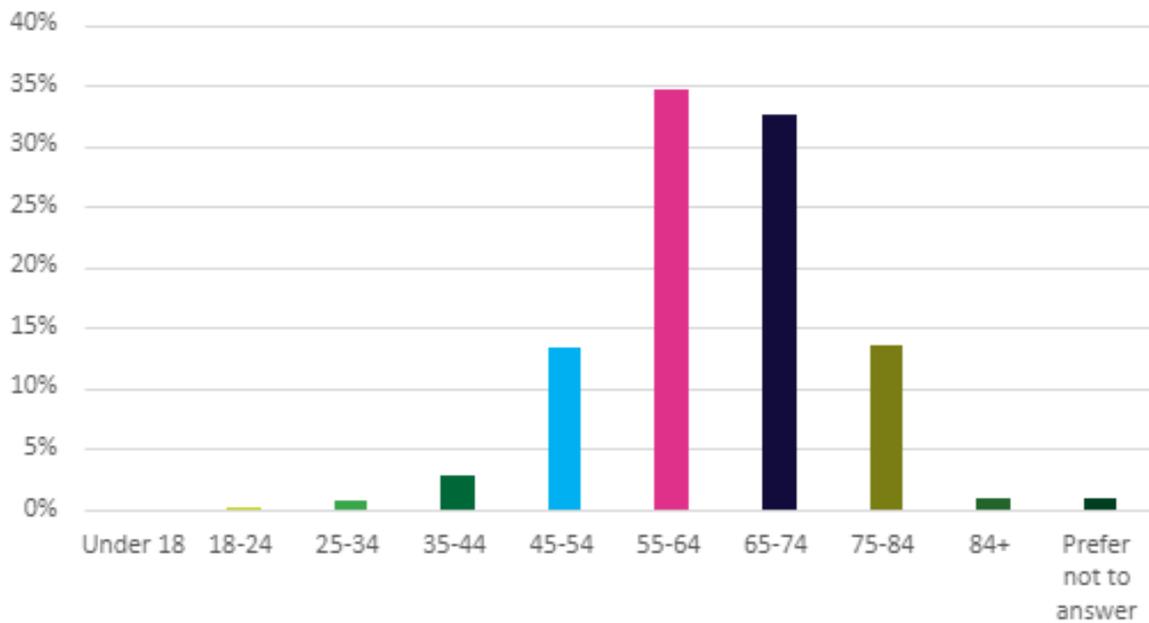
*“Maybe a resources section for links/documents? I'd like to post there some of the things that have been shared with me.”*

Other respondents wanted to see “Information on famous people and how they coped after diagnosis” and “some case histories which show helpful pathways.”

One person suggested including advice and resources for emergencies, saying:

*“I think a link to numbers and clear succinct advice for someone if having an emergency would be useful. A person seeking advice in the middle of a crisis does not want to wait for responses or trawl through threads.”*

### Question 7 - What is your age?



The most prevalent age group for respondents was 55-64 which was also the most prevalent age group in the surveys from 2018 and 2017. 34.6% of respondents were in aged 55-64, a slight decrease from the last survey when the total was 37.2%.

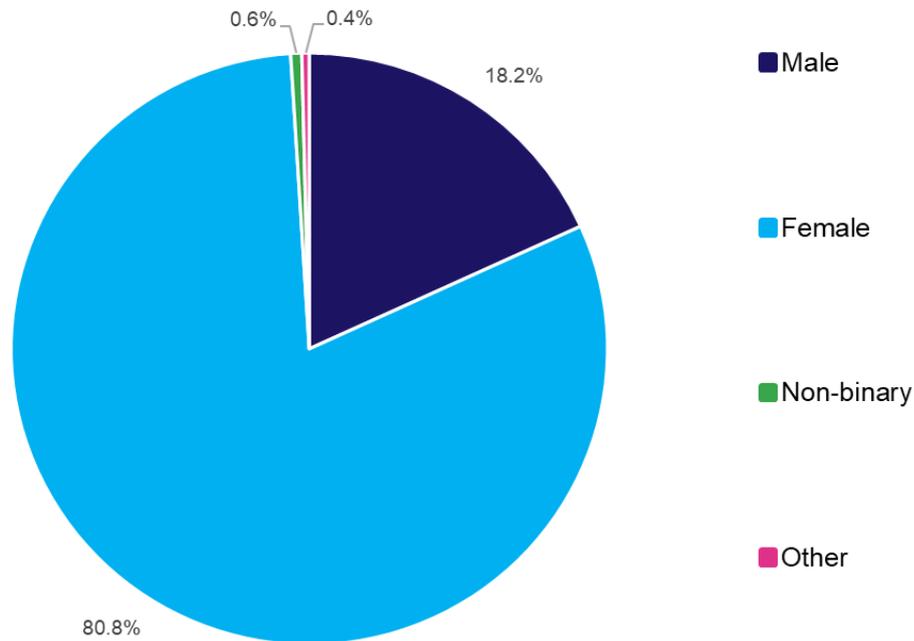
The second most prevalent age group was 65-74 with 32.6% of respondents, an increase from the 27.6% in the last survey.

The next most common age groups were 75-84 (with 13.6% of respondents) and 45-54 (with 13.4%).

A vast majority of respondents fitted into the four age groups mentioned above, with only 5.7% being younger than 45 or older than 84. Overall younger people are extremely underrepresented on the community with less than 1% being under 34.

This suggests that Talking Point may not be reaching enough young people and more efforts could be made to target this age group.

**Question 8 - What best describes your gender?**

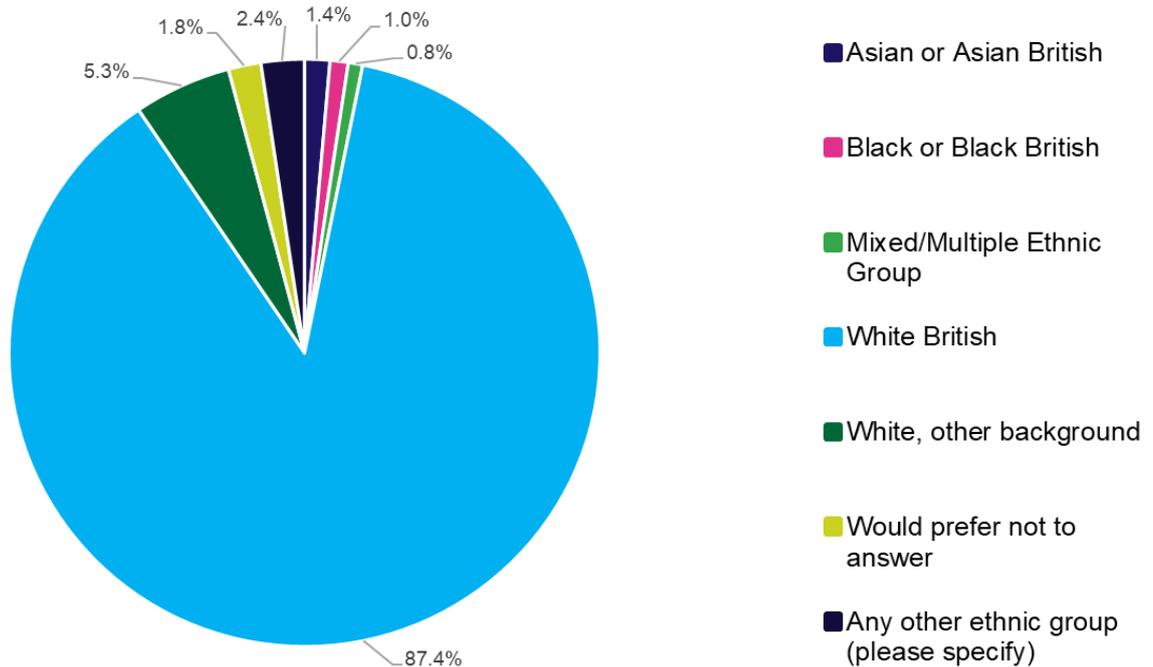


80.8% of respondents defined themselves as female, which is a similar total seen previously, with figures of 79% in 2018 and 77% in 2017.

18.2% of respondents defined as male (a slight decrease from 20% in 2018) and 0.6% defined as non-binary (an option provided for the **first time** this year). The remaining 0.4% of respondents selected other.

The community having a significant majority of female participants is in line with previous survey data. The average percentage of females over the last ten years of Talking Point User Surveys is 80%, with the lowest percentage of females during this time period still being the relatively high 76% (in 2016). This is comparable with other Alzheimer’s Society services which show a higher number of female users and potentially demonstrates a widespread issue with representation.

**Question 9 - Please choose an option that best describes your ethnic group**



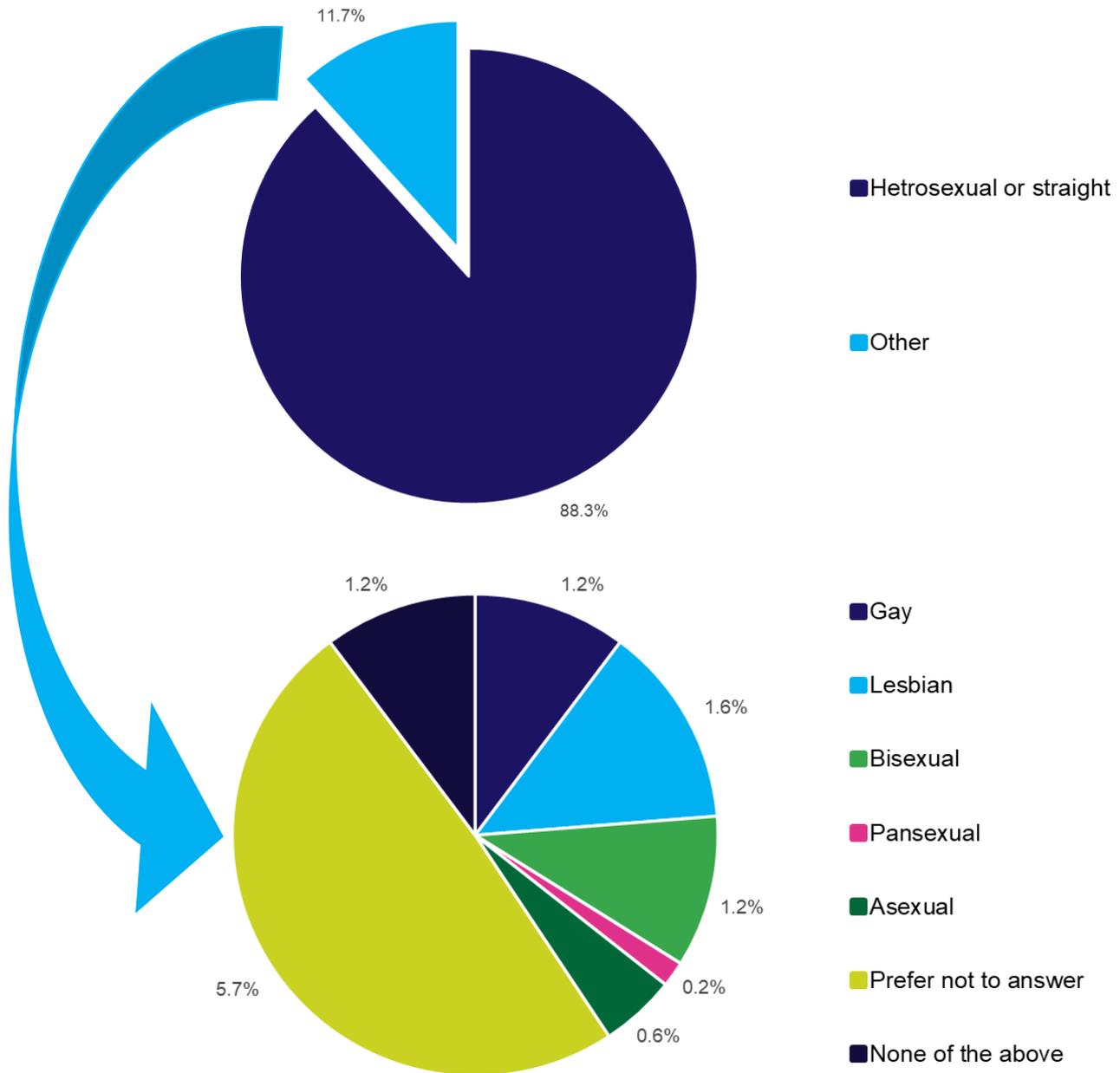
Talking Point continues to see a majority of survey respondents who identify as White British, a pattern that is also seen more widely in the demographic data across Alzheimer’s Society’s services.

87.4% of respondents identified as White British, a similar figure to the 2018 and 2017 survey (85.5 and 85%). 5.3% of respondents identified as “White, other background” a slight decrease from 2018 (where it was 8.6%).

There was also a slight decrease in people identifying as Black or Black British (going from 1.5% in 2018 to 1%) and an increase in those identifying as Asian or Asian British (going from 0.5% to 1.4%). However direct comparisons cannot be exactly made as the group labels have been slightly changed since 2018, previously just being Asian and Black and now being Asian or Asian British and Black or Black British.

The amount of people who defined as another not listed ethnic group increased from 0.7% in 2018 to 2.4%.

**Question 10 - What is your sexual orientation?**



To improve the readability of the data around sexuality it has been split into two pie charts, one showing the of respondents self-defined as “heterosexual or straight” and one which shows the breakdown of all other responses.

This was the **first time** a question about sexual orientation was asked in a Talking Point User Survey. Most respondents defined as “heterosexual or straight” (88%), 4.8% of respondents defined as gay, lesbian, bisexual, pansexual or asexual, and 5.7% of respondents preferred not to answer. Of the six people who selected “None of the above (please specify),” four took issue with the question being asked and two gave unclear answers.

## **Conclusion**

Members of the Talking Point community have faced many challenges and uncertainties due to the COVID-19 pandemic. It is reassuring to see strong evidence that Talking Point continues to provide high quality information and support, and a much-needed safe space for people affected by dementia. The word 'lifeline' appeared several times in survey feedback.

Talking Point, along with other services at Alzheimer's Society, needs to better support people who are not female, not white, and not heterosexual. In this report we included a question on sexual orientation so we can benchmark changes in who we are reaching and supporting as the service continues to develop. In 2021, we started a project to research the needs of LGBT+ people affected by dementia.

From our survey report, we can see that respondents want to see the Talking Point service advertised and promoted more widely. We will seek support from colleagues and partner organisations to increase our reach. Respondents also wanted access to experts and high quality information. We note requests for an improved experience in navigating and using the online community, and to revisit a mobile app. These survey responses will directly inform our service development plans.

The most positive survey result is from our Net Promoter Score remains at 92% of people who are very likely or fairly likely to recommend Talking Point to others. The number of people **very likely** to recommend the service increased significantly from 71% to 78.5%. It means a lot that the service is trusted and appreciated.

We continue to see evidence that the online community service supports people in at least three ways, proving the versatility and effectiveness of online peer support. Talking Point breaks down barriers of loneliness, connecting people who may otherwise be alone. The community provides practical advice on how to deal with the realities of dementia, answers questions, and gives helpful insight in what to expect.

It's difficult to choose a favourite insight, but it meant a lot to see so many respondents mention how much they valued being able to give back the support they received from the community by sharing insights and support with newer members. This virtuous cycle of giving and receiving support proves the longevity and strength of the supportive ethos of Talking Point. Peer support is incredibly powerful.

## **Acknowledgments**

The data analysis and production of this report was completed by Joseph O'Kelly, Online Community Assistant. It was approved by Serena Snoad, Online Community Manager who also provided the executive summary and conclusion. All quotes included in this report are taken from this year's survey respondents and have only been edited to summarise or remove errors.