



Talking Point User Survey 2018

**“I can give personal testimony to the positive difference Talking Point has offered me since caring for my mother who has a diagnosis of Alzheimer's. At any time of the day or night (and often at night when I am alone with my thoughts and feelings), there is a source of advice and support - this is a unique selling point.”*

**“Would always recommend it as most of the time it was the only world that I felt I belonged where other people understood what my life was really like.”*

*** Comments from our service users**

Executive Summary

Talking Point is Alzheimer's Society's online community offering peer support to people with dementia, carers and their families.

Summary of 2018

In February 2018, we ran a user testing project with people who were unfamiliar with Talking Point. We identified a number of ways to improve people's experience when joining the community, searching and posting messages.

We launched a new forum for people dealing with dementia and cancer, in partnership with an academic researcher. The forum will initially run for 6 months and will offer tailored information and Q&As with experts in dementia and cancer.

We continued to offer monthly Expert Q&A events on topics including eating and drinking, Lasting Powers of Attorney and loneliness and isolation. Talking Point members were asked for feedback on a government proposal to extend Blue Badges to people with dementia. In July 2018, the government extended the eligibility.

About the survey

We carry out the Talking Point survey on an annual basis. This year's survey was open from mid-December 2018 closing at the end of January 2019, and was completed by 613 service users*.

The survey was promoted via emails in December and January, and by announcements in the community in December and January. The survey was also promoted via the Society's social media channels.

We've seen improvements across all satisfaction and impact measures with many totals over 90%. Given the changes made to Talking Point's functionality and design this year, we are pleased to an increase in positive feedback. We are disappointed to see lower numbers of responses from men and people from BAME backgrounds.

The next Talking Point survey will be carried out in November 2019.

***Total membership of Talking Point on 31 December 2018 was 65,563.**

Key findings

How satisfied are users with the Talking Point service?

- **92.5%** of respondents agree or strongly agree that Talking Point was a helpful source of information about dementia. *(This figure was 90% last year, a 2.5% change. This change has been continuously increasing from 2017.)*
- **92%** of respondents said they would be likely or very likely to recommend the service to others. *(This figure was 87% last year, a 5% increase.)*
- **76.8%** of respondents agree or strongly agree that Talking Point offers support and information that they couldn't find anywhere else. *(This figure was 73% last year, a 3.8% increase.)*
- **78.6%** of respondents agree or strongly agree that they found Talking Point easy to use. *(This was 74% last year, a 4.6% increase.)*

What is the impact of the service?

- **78.4%** of respondents agree or strongly agree that Talking Point helped them feel less isolated. *(This figure was 73% last year, a 5.4% increase)*
- **93%** of respondents stated that they either got practical tips to help care for someone with dementia, felt less isolated, got answers to questions about dementia, learned more about living with dementia, or felt better to cope with their situations because of Talking Point.

“To be part of a group of people who were in a similar situation helped remove a feeling of isolation. Whilst learning of other people’s problems and experiences to benefit me, in sharing my experiences with others it gave my mind a lift at low times and also provided another outlet for concern or frustration.

I used the site on a very regular basis and saw it as a friend and something I didn't want to lose.”

Who uses the service?

- **79%** of respondents are female. **20%** are male.
(Last year, 77% of respondents were female, and 22% were male.)
- **37.2%** of respondents are between 55 and 64 years of age, and **16.5%** are between 45 and 54. **27.6%** are between 65 and 74 years of age, **10.9%** between 75 and 84, and **2.8%** are between 35 and 44.
(Last year, 41% of respondents were between 55 and 64; 19% were between 45 and 54; 22% between 65 and 74 years of age, 10% between 75 and 84, and 4% between 35 and 44).
- **85.5%** of respondents describe themselves as White British and **8.6%** as 'White: Other'. Of the remaining respondents, **2.6%** prefer not to state their ethnic group, **0.5%** describe themselves as Asian, **0.7%** describe themselves as Mixed, and **1.5%** describe themselves as Black.
(Last year, 85% described themselves as White British and 7% as 'White: Other'. 3% preferred not to state their ethnic group, 1% described themselves as Asian, and 1% described themselves as Black).
- **37%** of respondents describe themselves as a carer; **32%** describe themselves as a relative of a person with dementia; **15%** as 'former carers' and **3%** as a person with dementia.
(Last year, 31% of respondents were carers; 33% were relatives of a person with dementia; 14% were former carers and 5% had a dementia diagnosis)
- **86%** of respondents are members of Talking Point; **9%** are not members and **5%** are not sure
(Last year, 75% were members of Talking Point; 16% were non-members and 9% were not sure.)

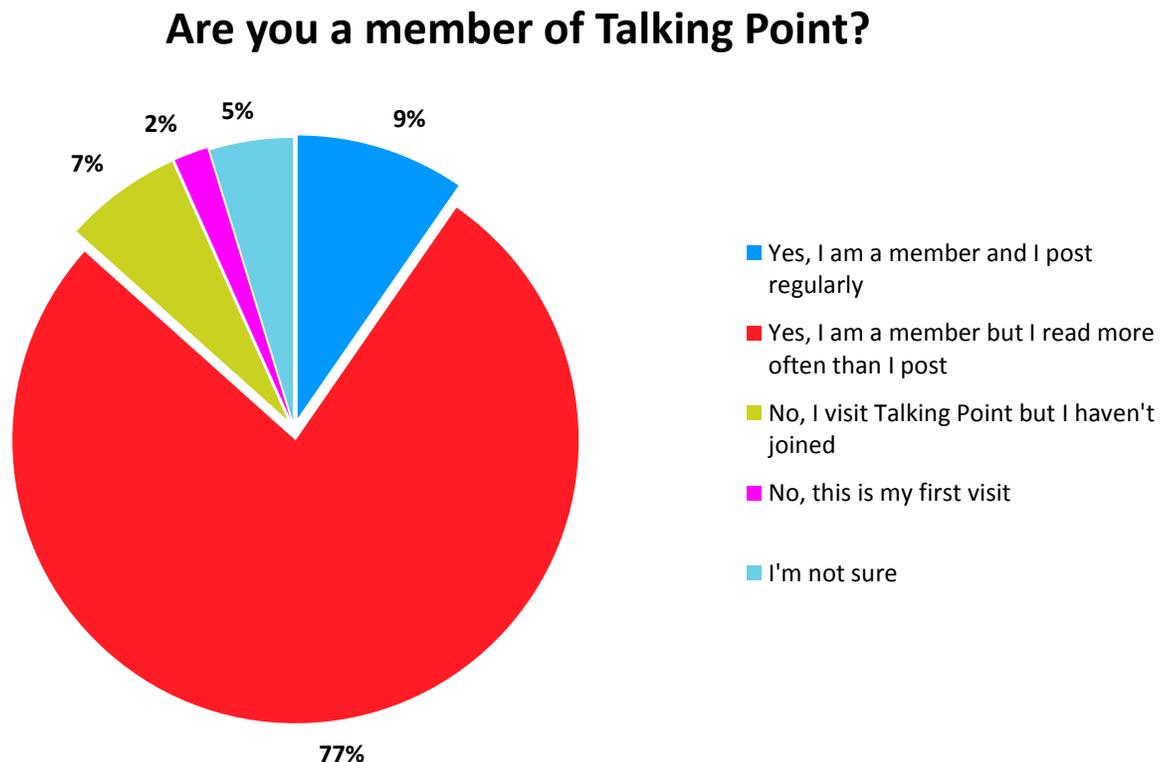
Question 1 – Are you a member of Talking Point?

This year the majority of responses are from members of Talking Point. According to the data, 77% of respondents read more often than they post while 9% of respondents post regularly.

This year there was a significant increase in members (85%) compared to last year (75%). This may be due to the fact that the survey was advertised in the Dementia Talking Point monthly update, which would reach current members of Talking Point instead of new users. Interestingly, there has also been a decrease in the amount of respondents who post regularly (9%) compared to last year (11%).

For non-member respondents, 7% have visited Talking Point while 2% were visiting for the first time. 5% were unsure of their member status.

(Note: anyone can access Talking Point for information, but only registered members are permitted to post messages on the community).



Question 2 – Which one of the following statements best describes you?

The majority of survey respondents identify themselves as carers (37%) and relatives (32%) of people with dementia. This is different from last year, when more respondents identified themselves as relatives (33%) instead of carers (31%), suggesting that this year has seen a significant increase in people who identify as carers completing the survey.

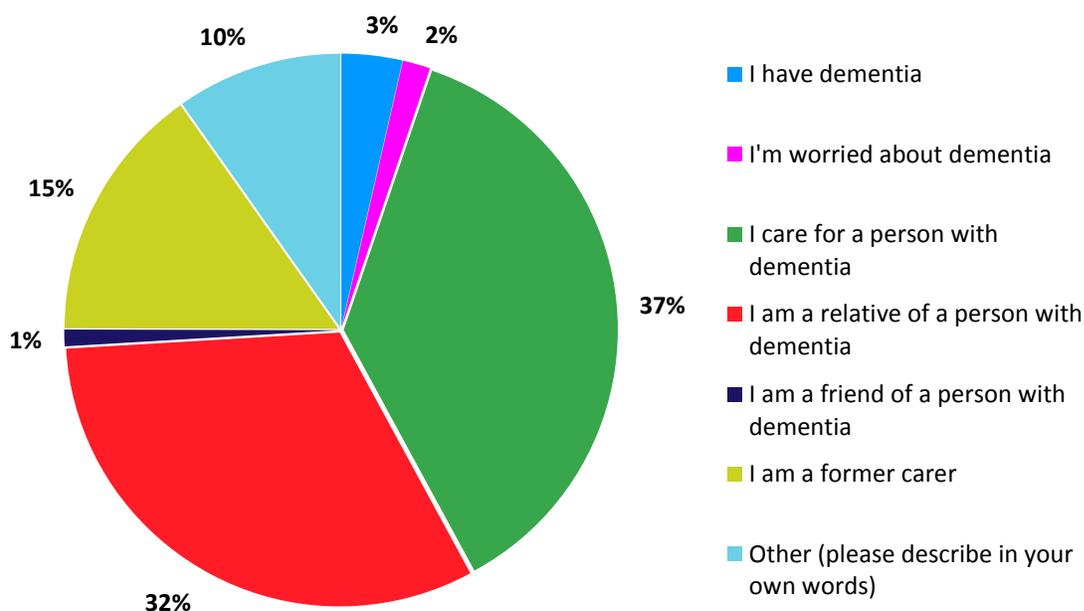
Similar to last year, the third/fourth largest categories were 'former carers' (15%) and people who responded 'other' (10%).

Respondents who have dementia decreased from 5% last year to 3%. Those who were worried about dementia decreased slightly from 3% to 2%. Those who were a friend of a person with dementia stayed constant at 1%.

Respondents who picked 'other' constitute 10% of the responses. Out of the 49 responses in this category:

- 19 are a relative or spouse of a person with dementia who have since passed away
- 12 are spouses of a person with dementia
- 8 work with people with dementia or volunteered for Alzheimer's Society
- 3 fit at least 2 descriptions from the survey (e.g. relative or spouse of a person with dementia while being worried about their own memory)
- 3 have cognitive impairment or experience early symptoms of dementia
- 3 share the care for a person with dementia

Which of the following statements best describes you?



Question 3 – What first brought you to Talking Point?

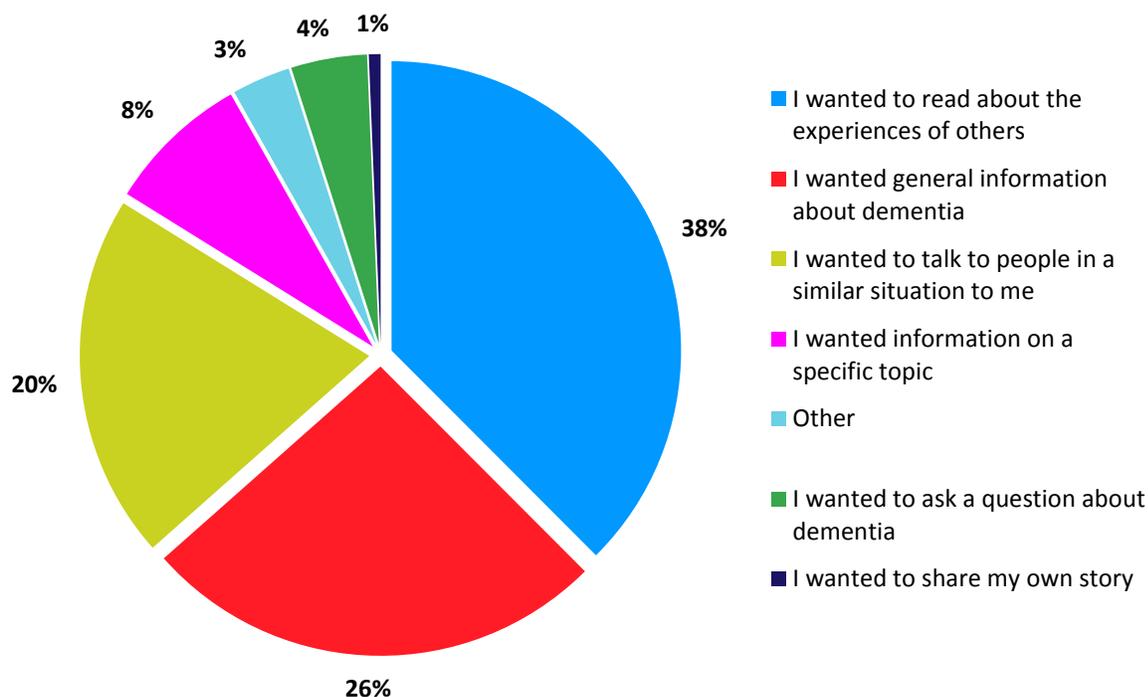
Similar to last year, the majority of users come to Talking Point because they want to read about the experiences of others (38%), want general information about dementia (26%), or want to talk to people in similar situations (20%).

This year there were 5% more respondents who wanted to read about the experiences of others compared to last year (33%).

Those who responded with 'Other' also decreased from 6% last year to 3% this year. Out of those 16 responses:

- 4 stated that they are either looking for emotional support or help managing situations related to dementia
- 4 stated that they want to learn more about dementia
- 2 stated that they want to do research on dementia or stay updated
- 2 have dementia or symptoms of dementia and were looking for general information or support
- 2 stated that they came to Talking Point due to a mixture of the above reasons
- 2 stated they were referred by someone else

What first brought you to Talking Point?



Question 4 – Please tell us how Talking Point helped you. You can tick any of the statements below that apply:

A total of 1,811 responses were recorded in this multiple choice question by 613 respondents. This equates to an average of 2.95 statements ticked by each respondent, which is higher than last year (2.5).

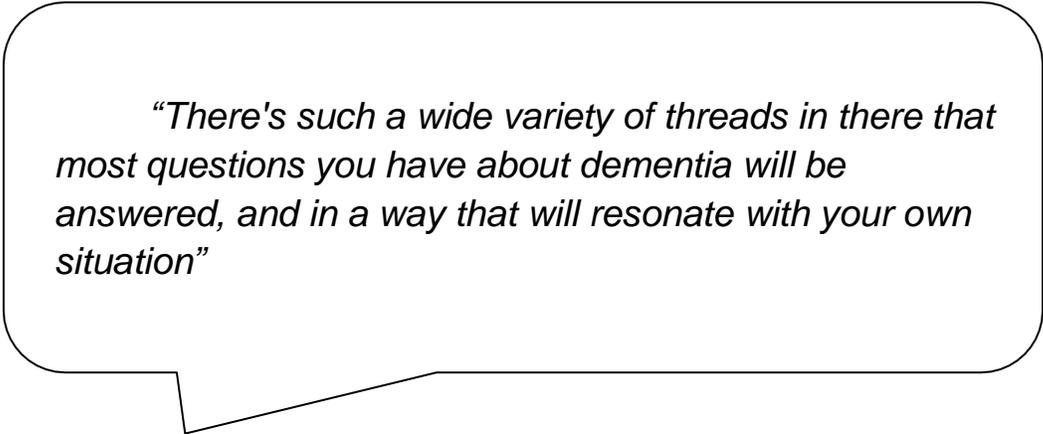
This suggests that Talking Point has helped the respondents in several different ways. According to the data, most respondents stated that the service has helped them:

- Get practical tips to help care for someone with dementia (306 responses)
- Feel less isolated (299 people)
- Get answers to questions about dementia (277 people)
- Learn more about what it's like to live with dementia (252 people)
- Feel better able to cope with their situation (227 people)

This ranking is consistent with last year's even though the number of responses for each statement is higher.

The least selected statement was 'I have been able to get better support put in place' (93 people). This is possibly due to difficulties with arranging care and support outside of the Talking Point service. However, this statistic is proportionally higher compared to last year. (Last year this statement made up 3.9% of the total amount of responses while this year it makes up 5% of the responses.)

Additionally, this year's ranking of the ticked options is identical to last year's even though the number of respondents and responses has increased. This suggests that even with more people responding to the survey this year, the ways in which the service helps users is consistent.

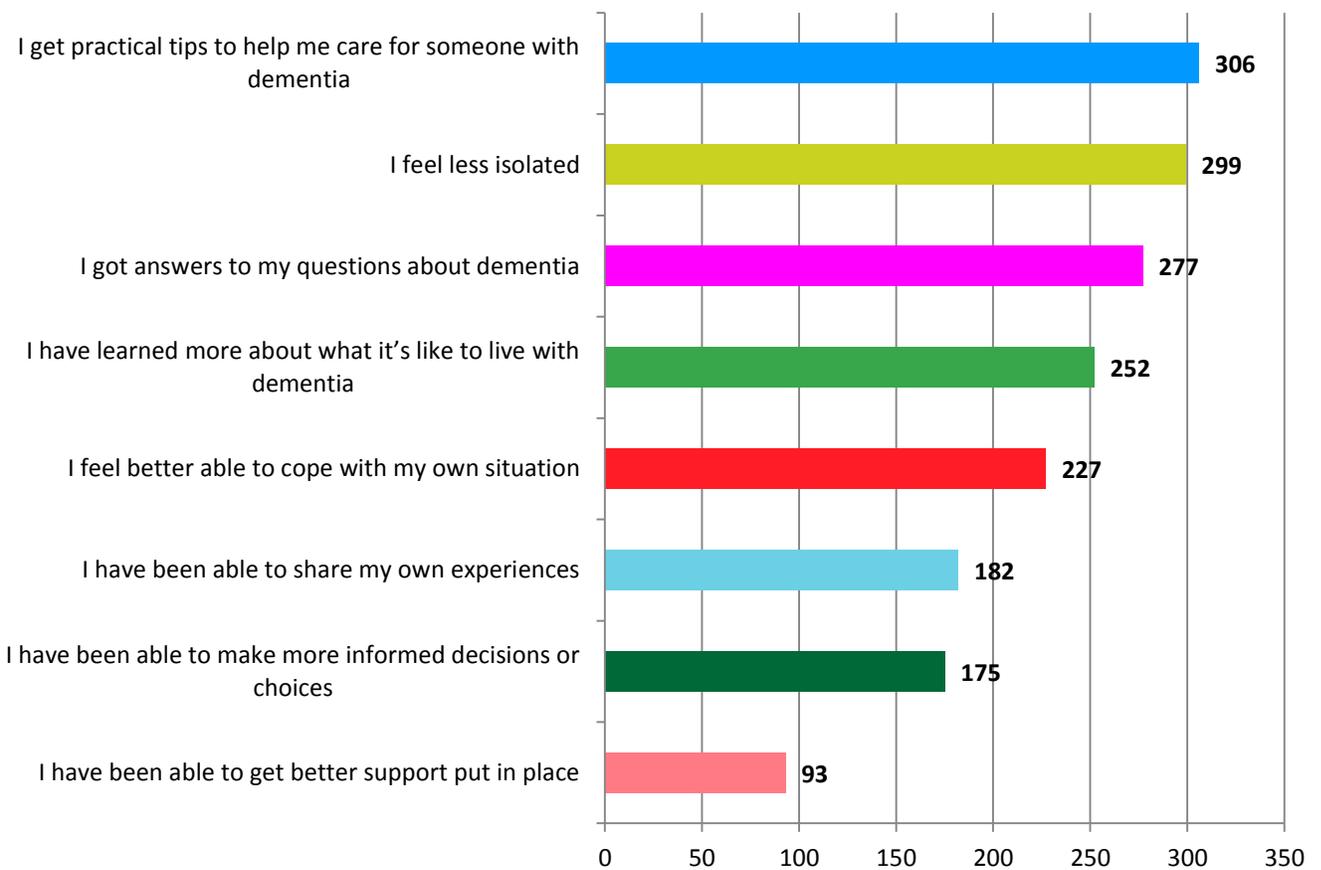


“There's such a wide variety of threads in there that most questions you have about dementia will be answered, and in a way that will resonate with your own situation”

Out of the 40 respondents who selected 'Other':

- 13 stated that Talking Point has yet to help them in any of the ways listed. 2 users attributed this to technical difficulties while the rest explained that they had not found the information they desired from Talking Point.
- 9 stated that they were able to get social and emotional support that alleviated their feelings of guilt and isolation. One respondent highlighted the importance of emotional support after bereavement.
- 9 stated that they were comforted by the experiences of others and received valuable insight
- 9 stated that they have not used Talking Point enough to thoroughly answer this question

Please tell us how Talking Point helped you



Question 5: Please share some examples of how Talking Point has helped you.

400 respondents shared specific examples of how Talking Point has helped them.

Many respondents stated that reading about other peoples' experiences with dementia helped them cope. Some stated that reading these experiences alleviated their feelings of isolation and provided emotional support.

"Reading that others have the same fears or worries, seeing the incredibly supportive environment that the forums have and the genuine responses that people post to each other, it's invaluable and not the sort of support you could find in a 'professional' context."

"I feel I am less isolated and frightened in facing the years ahead. I feel I am a part of this community that understands and lives with the disease. I appreciate others sharing very detailed daily and practical issues facing carers and sufferers. "

"The most important thing for me was finding that I wasn't alone in feeling lost, confused and helpless in trying to care for my late mum - suddenly I found a whole community of friendly, supportive people who knew exactly what I was going through and who were keen to offer practical advice and unending kindness. Information elsewhere - even from the Alzheimer's Society itself - is often quite generic, but Talking Point gets down to the detailed nitty gritty and also provides a safe and non-judgemental place for much-needed 'ranting'. Almost a year after my mum's death, I still visit Talking Point almost every day, to see how others are doing and occasionally to offer a bit of help if I can in return. For me, Talking Point was a life-saver."

Many respondents valued the community aspect of Talking Point, sometimes stating that they enjoyed sharing their own stories and helping others in the community.

"I look after my Mum who has dementia. Sometimes I feel very isolated and it is a great comfort to share stories with people in a similar position to me. They totally understand what I am going through as they are experiencing the same things or have done in the past. Just to have someone say they know just how I am feeling can take a great weight off my shoulders. We can laugh and cry together even though we have never met."

"When struggling with a bad situation or trying to deal with a new issue or just having a bad day, I have either posted and got supportive replies, or found other people in the same sort of situation, which makes life just a bit easier"

"When I have been at my lowest the wonderful friends on TP helped me so much. Sometimes their advice has been a huge help in getting a problem solved or helping me see things more clearly. Where to get the equipment that is needed not only at a good price, but also for quick delivery. I also like to think that I have helped other people. And perhaps more than anything, the empathy and sympathy of people that understand what it is like to be a carer."

Many respondents valued the information and advice received from the Talking Point community. Some pointed out that the advice from Talking Point was different to other sources because it came from people with real experiences with dementia.

“Helped me to understand how a person with dementia’s mind works and was able to be more empathetic to their own terrible ordeal on a daily basis. I have read practical advice on dealing with different challenging behaviours and have learnt a lot.”

“For someone who knew next to nothing about dementia, Talking Point was an absolute treasure when I found it. It has been a great resource from the time my husband was first diagnosed, through each stage - and now, following his death, it still provides support as I try to move forward. In time I became one of those able to offer support to others. That is the beauty of TP - it is a safe and non-judgmental place where users find strength and understanding through shared experiences.”

Some respondents are healthcare professionals who said that Talking Point provided important information and support for both their patients and themselves.

“As an Admiral Nurse I point the family carers I support in the direction of Talking Point (particularly if they aren’t in a position to attend support groups) so they don’t feel so isolated and if they need to ask specific questions.”

“Talking Point has helped me understand many problems that my clients have living with their dementia. It has answered a lot of questions that I have about dementia and helped me learn a lot more about the disease and how carers cope.”

“I care for both my father who was diagnosed with Alzheimer’s last year and my mother who is a wheelchair user. They both have multiple co-morbidities. I feel incredibly isolated at times and unfortunately the NHD and its staff let us down on a regular basis. Were I not a healthcare professional myself, and were I not able to share my experiences with others in a similar position, my mental health would suffer far more than it is at present and I would be unable to fight for the basic standards of care that my parents deserve.”

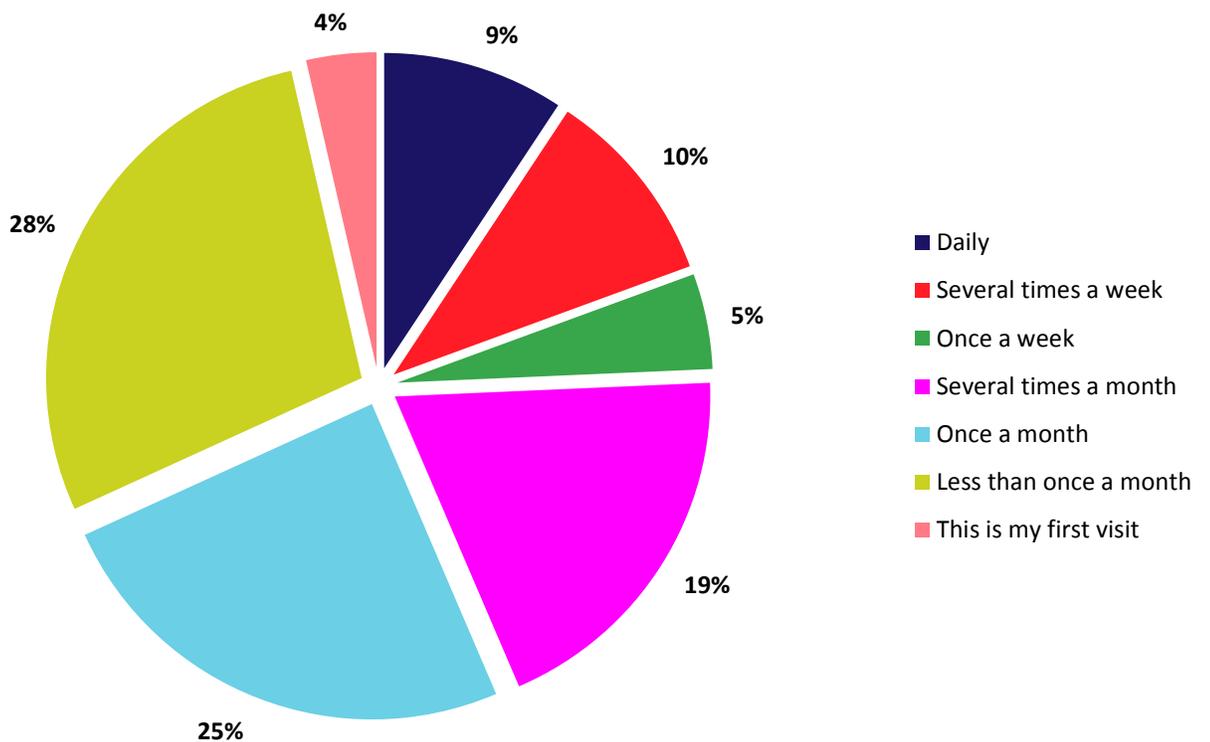
Question 6 – How often do you visit Talking Point?

Similar to last year, most respondents stated that they visited Talking Point less than once a month, although this statistic has decreased from 33% last year to 28% this year. Respondents who visited once a month increased from 20% last year to 25% this year.

Interestingly, those who visited the community daily decreased from 12% to 9% while those who visited once a week increased from 3% to 5%. Those who visited several times a week stayed constant at 10%. This suggests that this year's respondents are more active in terms of visiting at least once a week, but not more often than that.

Respondents who were visiting Talking Point for the first time during the time of the survey decreased significantly from 14% last year to 4% this year. This suggests that compared to last year, there are fewer new users responding to the survey.

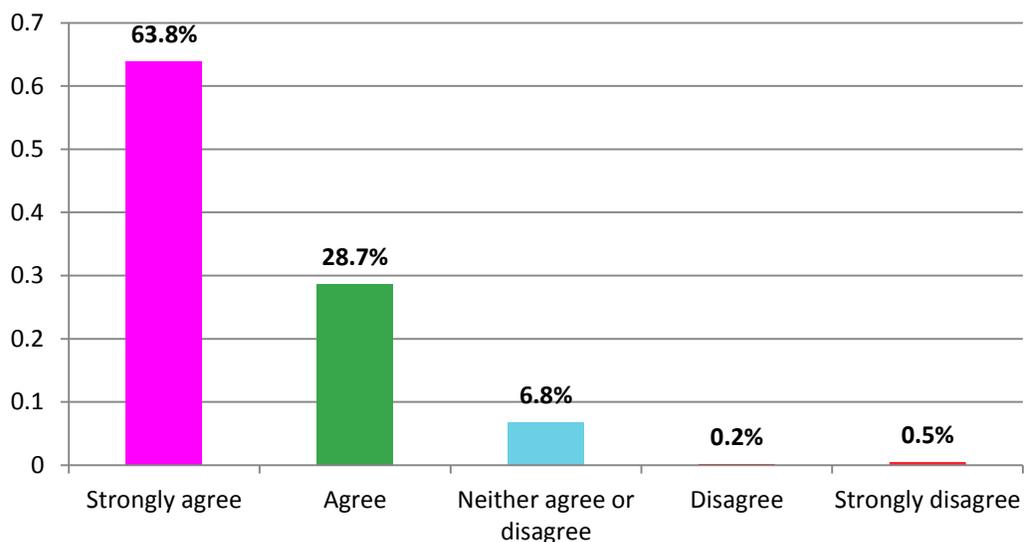
How often do you visit Talking Point?



Question 7 – Please tell us if you agree or disagree with the following statements and Question 8 – Please tell us more about your responses to these statements:

This question asked how much respondents agreed or disagreed with the following four statements:

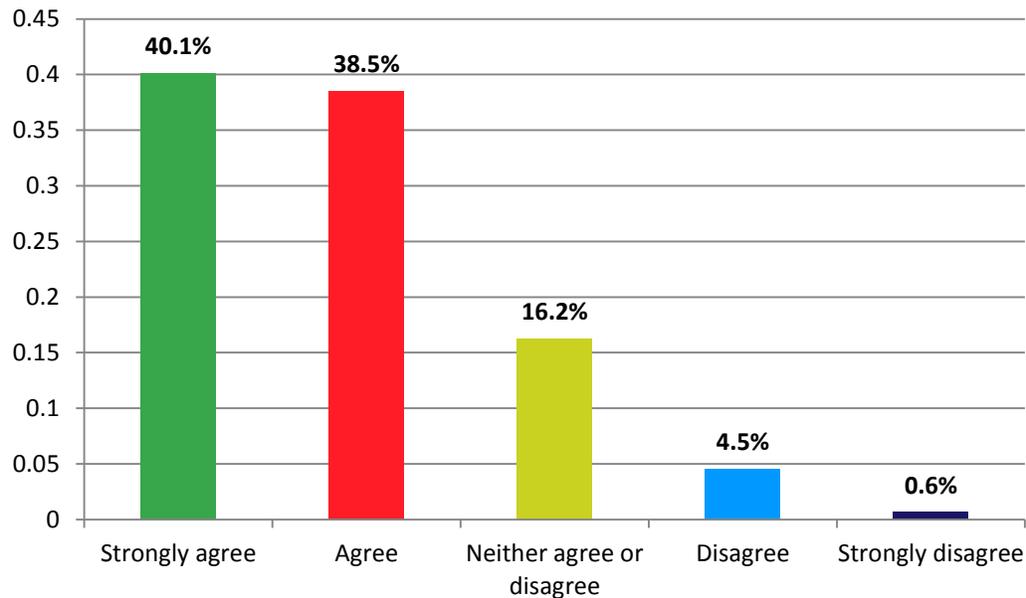
Talking Point is a source of helpful information about dementia



Generally, respondents find Talking Point to be a good source of information about dementia, with only 0.7% disagreeing with this statement. This is an improvement on last year, where 2% disagreed with the statement. Overall the responses are more positive this year. There is a 6.4% increase in the percentage of respondents who strongly agreed with this statement compared to last year.

“It's only by seeing people I've come to know and reading about their situation in depth that I feel I've come to understand the problem of dementia more. Information is available on the internet in dribs and drabs, not in the connected way as it is on TP.”

I find Talking Point easy to use

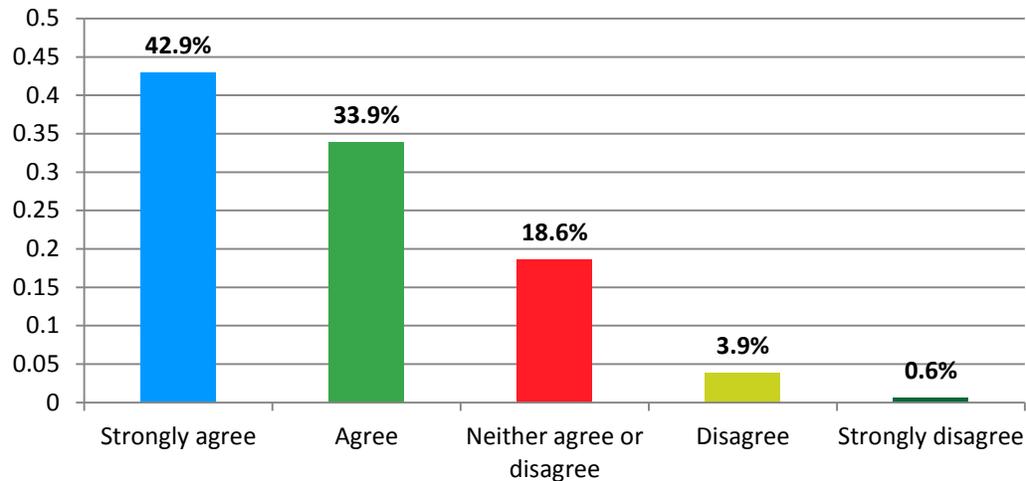


Most respondents find Talking Point easy to use, with only 5.1% disagreeing with this statement. Like the previous question, this is a decrease from last year, when 9% of respondents disagreed with this statement.

“Personally, I find talking things over on Talking Point is easier than joining support groups where I would have to sit and listen until the session ended even if I felt I'd had enough.

Talking Point allows me to dip in and out for 10 mins and then get back to my own life. I also find that if a certain subject is depressing me further, I don't have to stay with it, I can switch to a more up-beat post.”

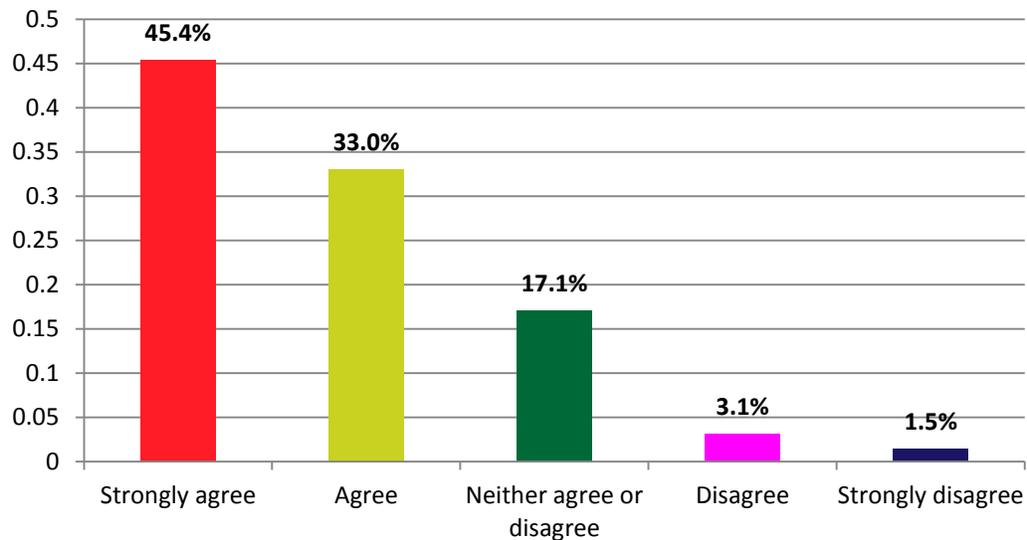
Talking Point offers support and information that I couldn't find anywhere else



The majority of respondents (76.8%) agreed that Talking Point was a good source of information and support that would be difficult to find elsewhere. This is a slight increase from last year, when 73.1% agreed with the statement

“Talking Point members gave me all the answers I needed, all the support I needed, and I know beyond doubt that without the community I would not have been the Carer I am proud to say I was.”

Because of Talking Point, I feel connected to others, and less isolated



Many respondents stated that they felt connected to others, and less isolated. This year 78.4% agreed with this statement compared to last year, when 73% agreed to this statement. Overall this year's responses to all 4 statements have been consistently more positive compared to last year.

"It's the personal experiences of others that really helps the most. We laugh at funny but not so funny things they do and can relate and join in conversations.

You feel more connected to other people, especially if there is no transportation or access to communication. Most times we have to give 24/7 care, therefore not allowing us to communicate with others. TP is our way of meeting people. Nobody feels guilty saying how they feel because nobody knows who you are."

Some respondents shared constructive criticism of the service.

Some felt that the service was difficult to access or navigate:

“When I first joined in 2015, it was easy to access but now I find it confusing and this colours my wish to visit often. I prefer the security but wish it was more straightforward to dip in and out.”

“Finding information is difficult because of the lack of effective indexing. I know that the information is there and that others have experienced the same problems I have, but it is still extremely difficult to find”

“It's basically a good website. The only downside is that I feel it's split up too much, so for example someone who has a loved one with dementia may have good advice that someone caring for someone with dementia may find useful, but they may not see it due to how the forum is separated.”

Some respondents, while acknowledging the usefulness of the service, also highlighted that it was emotionally depressing to read through some posts on the site.

“I haven't really learned a great deal from the site, and sometimes felt upset or a bit depressed reading what others post, so haven't accessed it too much. Also not really into 'social media/online type of sharing, so it wasn't really for me. I also only go online using an old iPhone so it's probably not the best way to access the site.”

A few also noted that it felt difficult to connect to people on an online platform.

“It's useful hearing about others' experiences. I don't feel connected to others through TP but that's me rather than the forum. As someone elsewhere once said, electronic communication is no substitute for human interaction.”

Question 9 – What kind of discussions on Talking Point are you most interested in?

This is a new question that was added this year due to interest in what Talking Point members are most interested in discussing. This question was only open to respondents who stated that they were a member of Talking Point in Question 1. Based on 461 responses, the kinds of discussions members were most interested in include:

Coping and dealing with dementia throughout the different stages of the disease as well as the behavioural changes that come with it (108 responses)

“How to ‘manage’ the situation of caring for someone at home’ - at various stages of the progression of their dementia.”

“Anything that was relevant at that particular time. Dementia is a fluid disease and even if I read something that isn't relevant at that time, it somehow stays in my mind and I can look it up when it is relevant.”

Tips, shared experiences, and advice regarding caring, care homes, and financial and legal issues (148 responses)

“Any discussions with fellow carers. Sharing their experiences is most helpful.”

“Now that Dad's in a care home I am interested in 'invisibles' and legal and financial situations.”

The emotional impact of dementia and finding a balance between caring and having a personal life. (48 responses)

“Ways of managing to maintain a life whilst caring for someone and sharing negative feelings. Too often carers are made out to be some sort of saint and we don't all fall into that category.”

“Practical ways to overcome problems e.g. distraction when confronted and repeated questioning. How people deal with negative emotions. I will always remember the lady who briefly goes into the garage, turns on the car radio and blasts away any negativity, and then back into the house to start again.”

News and updates about dementia or a specific disease for research purposes (40 responses)

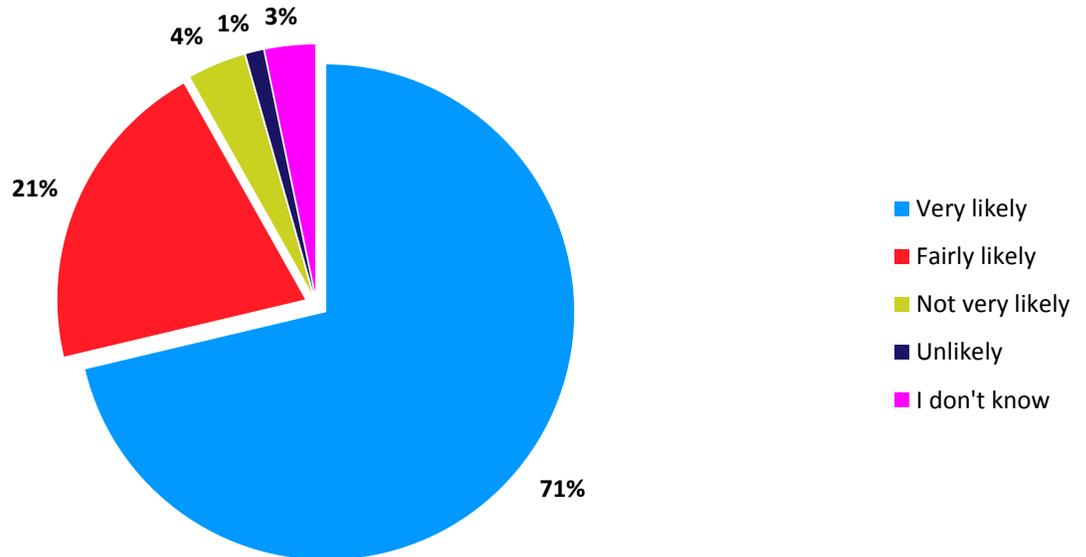
“Up to date developments of how people are coping in 2019 as compared to 4 or 5 years ago”

A significant amount of responses (54) also stated that they enjoyed the variety of discussions on Talking Point.

“All sorts, I came on here for a specific query but actually other people have questions that I then am keen to share my knowledge on to help them. I think it's great that there is such a varied amount of questions and knowledge to share.”

Question 10 - How likely is it that you would recommend Talking Point to others?

How likely is it that you would recommend Talking Point to others?



Like last year, responses have been predominantly positive.

Overall, the majority of respondents (91%) stated that they would recommend Talking Point to others. This is an increase from last year, when 87% stated that they would recommend the service.

Out of the 91%, 71% stated that they'd be very likely to recommend Talking Point while 21% stated that they'd be fairly likely to recommend Talking Point. Both statistics have increased since last year.

Those who stated that they were not likely to recommend the service decreased from 6% to 5%. Respondents who were uncertain made up 3% of the sample, a significant decrease from 7% last year.

Question 11 - Please tell us why you would or would not recommend Talking Point.

Most responses to this question were positive and stated that they have already recommended or would recommend Talking Point to others. The responses explained the reasons behind these statements and provided insight into what users found most useful about the service.

Some respondents stated that they have already recommended Talking Point to someone.

“I already have recommended Talking Point to others because I find it really helps to see others going through similar hardships and because there is so much support and useful information on there.”

“Talking Point has helped me deal with many of the problems caused by dementia and to understand that I am not alone. I have already recommended Talking Point to the wife of my best friend, who has been recently diagnosed with dementia.”

Some respondents explained that they would recommend Talking Point for its wealth of information about dementia.

“I have regularly pointed people in the direction of the website as it is beneficial for those who want more information. There is a lot of informed and useful information and reading available that can help others cope with numerous situations such as care home, contact with professionals etc.”

“I would recommend Talking Point because it is a one-stop place for information and engaging with others in similar circumstances.”

Some respondents explained that they would recommend Talking Point for the emotional support it provides.

“It simply is a much needed resource and support for carers of people with dementia who seem to be largely ignored and expected to put up with their expected carer role by social services.”

“It's a lifeline to many people trying to cope. There aren't often any easy answers, but at least you can let off steam to others who know exactly what it's like.”

Some respondents explained that they would recommend Talking Point for the community and the ability to share experiences with others free of judgement.

“There is nothing out there that comes even close to giving the same level of understanding and support.”

“In some cases it is the only place that really understands what living with a person with dementia is like. In the real world, nobody who does not experience it for more than an hour or two can believe the difficulties”

Many respondents praised Talking Point for being available and active 24/7.

“Talking Point provides meaningful help and support 24/7. This makes a real difference between coping and not coping even in a crisis. Talking Point offers information on wide ranging subjects related to dementia.”

“Always someone at any time of day or night to hear you and give you some support, or tell you where to get the information you need to make situation as good as you can.”

Some respondents were uncertain because they either have not used the service enough, or had no one to recommend it to.

“It would depend what type of person it was. Quite a few, like me, don't really go much for this on-line sharing stuff.”

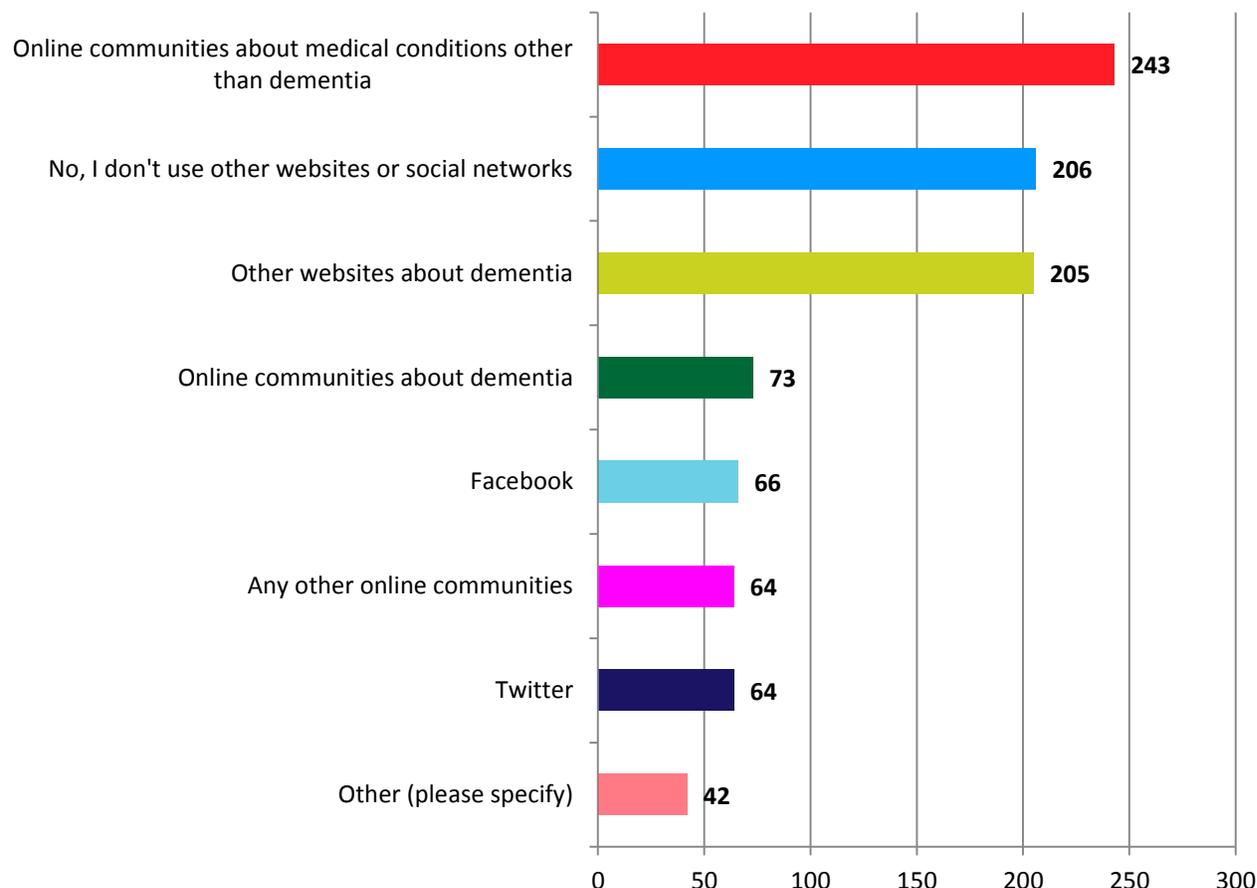
“I don't know anyone to recommend it to.”

A minority of respondents stated that they would not recommend Talking Point due to technical difficulties with the site and negativity in some posts.

“I find that people are only interested in those with difficult stories. They don't want to hear anything positive and it is really difficult to find anything positive.”

Question 12 - Do you use any other websites or social networks? (Tick any that apply)

Do you use any other websites or social networks?



There were 963 responses to this question out of 613 respondents, meaning that on average, each respondent ticked 1.6 options.

The majority of respondents (25%) stated that they use online communities about medical conditions other than dementia. This is different from last year, when Facebook was the most popular social network used by survey respondents.

Out of the 42 respondents who answered “Other”, the following websites were mentioned:

- Social media websites and applications such as LinkedIn, Instagram, Tumblr, Pinterest, Discord, and WhatsApp
- Forums and networks related to personal hobbies or work
- Charities and organisations such as AgeUK
- Health and health research websites
- Sites focused on providing information to carers, such as Carers UK

Question 13 - If so, please tell us more about the other online support forum(s) or websites that you use.

There were 218 written responses with a variety of answers.

Some respondents did use social media websites (usually Facebook) for dementia-related discussions. Most mentioned that they were part of Facebook support groups with people in similar situations to themselves.

Some explained that they use other websites for information on dementia or other diseases. Many specified that they use both Talking Point and these websites for information.

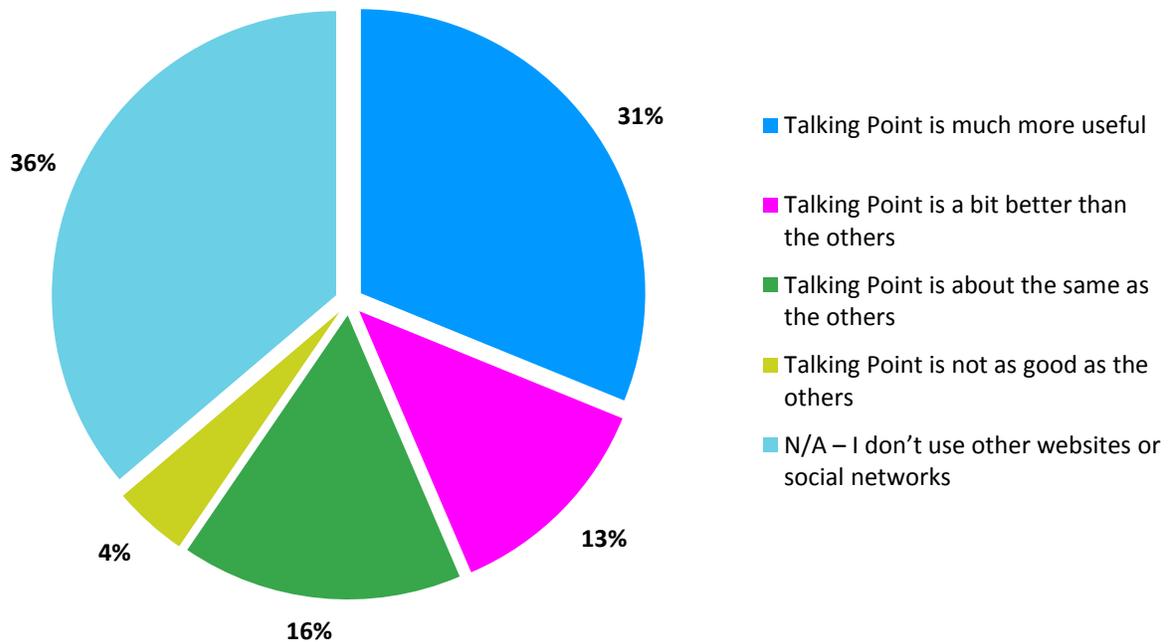
Some respondents explained that they used social media websites (usually Facebook and Twitter) for social reasons. Many specified that they used Talking Point for dementia-related support and information and used social media websites for reasons unrelated to dementia.

Some respondents explained that they use other websites for their personal hobbies and interests that are unrelated to dementia.

A few also explained that they like to casually browse other websites with no specific purpose, such as Googling for general topics of interest.

Question 14 - How does Talking Point compare to these other online communities or websites?

How does Talking Point compare to these other online communities or websites?



This year, 44% of respondent stated that Talking Point was better than the other online communities they were using. This is a slight increase from last year (43%).

Respondents who felt that Talking Point is about the same as the others increased from 14% last year to 16% this year.

The majority (36%) of respondents stated that they do not use other websites or social networks beside Talking Point, which is consistent with last year's statistics.

Only 4% of respondents stated that Talking Point is not as good as other social networks they use. This is a slight decrease from last year, when 6% responded with this option.

Question 15 - Please tell us more about your answer to the above question.

There were 227 written responses to this question. Many respondents explained that Talking Point was not comparable to other websites as they served different purposes and found this question difficult to answer.

Some respondents explained that Talking Point felt more personal and emotionally supportive compared to other websites

“I find it is more useful as you can interact with people in similar situations who genuinely want to help others as they know how difficult it is and this is affecting so many people now.”

“I feel that Talking Point is real, real people discussing real problems and sharing their experiences.”

Some respondents explained that Talking Point was more relevant for dementia and dementia-related topics that couldn't be found on other social networks and websites.

“Talking Point is second to none when it comes to support and advice for people caring for those with dementia. My other websites deal with completely different subjects”

“For dementia-related information, Talking Point is the most useful. I use other websites/networks chiefly for other purposes, but they can sometimes be a useful source of information and/or a way of sharing information (for example, when fundraising for the Memory Walk).”

Some respondents stated that Talking Point is the only place they feel comfortable to share their experiences with dementia.

“I don't use any other website about dementia. I don't want other people (friends) to know about the personal struggles of my family in that level of intimate detail online. Talking Point allows me that anonymity.”

“I feel that Talking Point is a separate community where I can open up and discuss my situation in total confidence.”

Question 16 - Are there any ways that you think Talking Point could be improved?

There are 306 written responses to this question. Most respondents (172) either stated that the service didn't need any improvements, or could not think of any improvements. Some respondents (21) also stated that they had not used Talking Point enough to provide any helpful suggestions for this question.

Some (50) respondents wanted the website to be easier and more intuitive to use. They highlighted their difficulties searching, posting, and logging in to the website.

"Talking Point is less easy to use because of the way the message boards are set up. Not so easy to get back into a conversation where one left off."

"Make it more basic and easier to navigate around and post as a lot of older people are not very computer savvy."

"The search function could be better; it's quite difficult to find information about something specific."

Some (7) suggested adding a "like" or "thanks" button to posts as a quick way to acknowledge posts without writing a response.

"I think you could have a like button as they have on Facebook so you can acknowledge a post without having to type in a response."

"A 'thank you' choice you can click on to show you appreciated what a post says."

Some (9) respondents asked for more information about certain topics.

“Up to date research trial findings, outcomes, and implications for practice/care.”

“I have done a lot of dementia training and although it goes into dementia, how it happens and a little of what to expect, it shows you videos of people in the early stages and coping. It doesn't show how severe it can get and it can be very traumatic as I have experienced.”

A few also (3) suggested easier access to more dementia-related resources through Talking Point, such as flow charts, guides, and factsheets.

“You could make the helpline and factsheets more accessible from the forum, maybe as a separate forum // thread heading.”

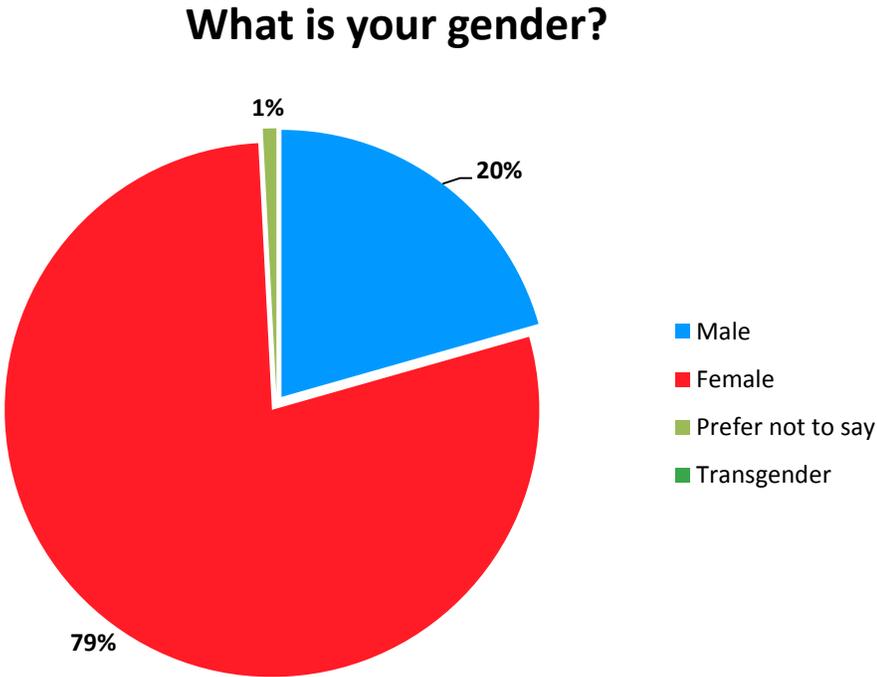
“A flow chart: you have been diagnosed, here is what to do next, AA, POA, wills, council tax reduction, assessment of needs, carers assessment, find out what groups you can access locally, and so on.”

Other suggestions included:

- Advertising the service more (2)
- Bringing back the mobile app (2)
- Email alerts for posts (2)
- Adding a section only for positive topics (2)
- Live chat feature (2)
- More responsiveness from moderators (2)

Question 17 - What is your gender?

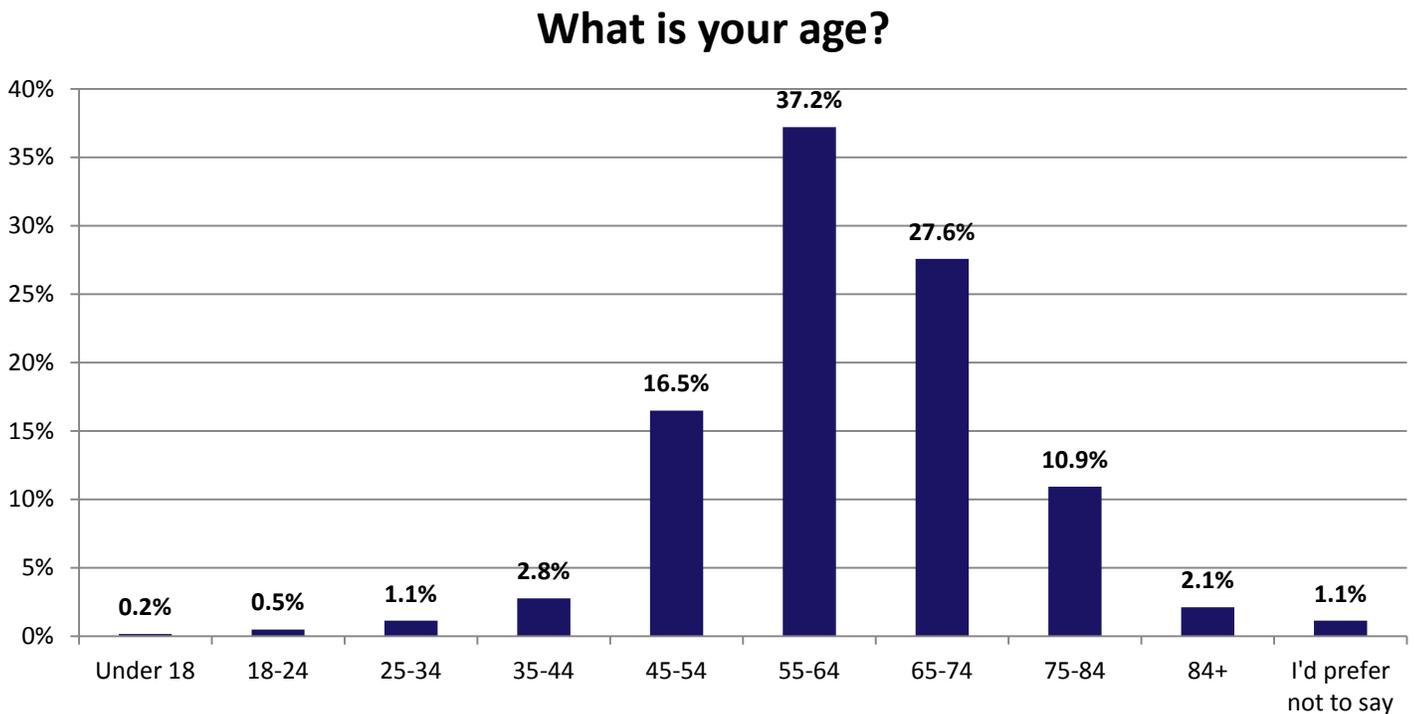
Similar to previous years, most survey respondents were female, which constitute 79% of respondents (a slight increase from 77% last year). Male respondents have shown a slight decrease from 22% last year to 20% this year. The remaining 1% chose to not state their gender.



Question 18 - What is your age?

Like last year, the most prevalent age group for respondents is 55-64, which decreased from 41.1% last year to 37.2%. Respondents aged 45-54 also decreased from 18.8% last year to 16.5% this year.

The most significant change this year was the increase of respondents aged 65-74, with an increase of over 5% compared to last year.

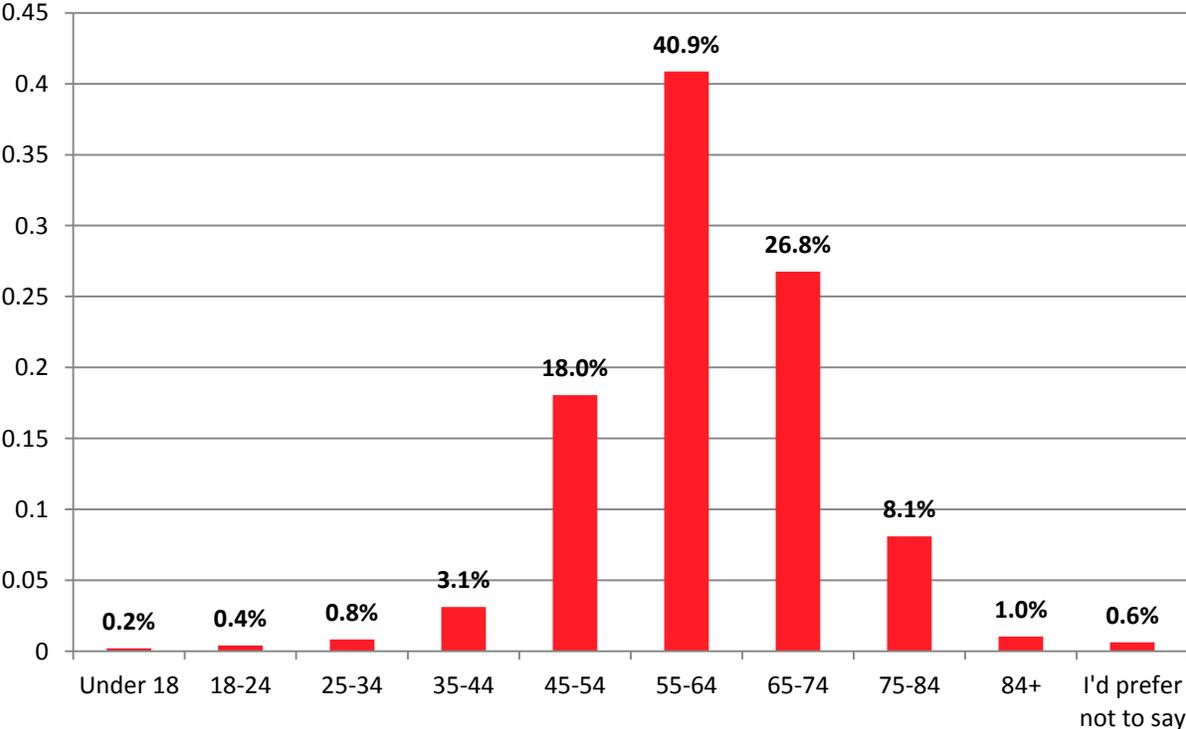


Female respondents

Age trends may differ according to sex of the respondent. When looking at **female respondents**, which made up 79% of the responses, the trends look similar to the overall results.

Significantly more respondents are in the 55-64 (40.9%) age group compared to others. More female respondents are in the 45-54 (18%) age group compared to the overall average. Interestingly, fewer females (26.8%) were in the 65-74 age group compared to the total sample, suggesting that more females are concentrated in the 55-64 age group while more males are in the later age groups.

What is your age? (Female respondents)



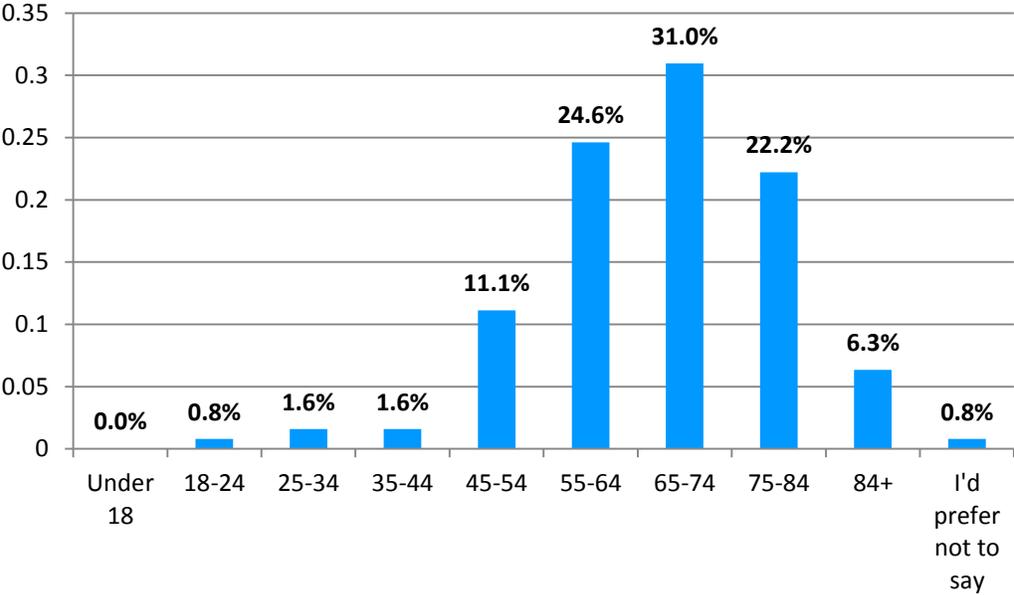
Male respondents

Results for **male respondents** are similar to last year's results.

Due to a smaller sample size, there is greater variation when compared to females. This year, most male respondents are aged 65-74 (31%), which is significantly different from last year, when most were aged 55-64. Age groups above 74 also increased compared to last year.

Male respondents aged 35-44 also dropped from 3.3% last year to 1.6%. Overall this year's male respondents are more widely spread across age groups compared to last year.

What is your age? (Male respondents)



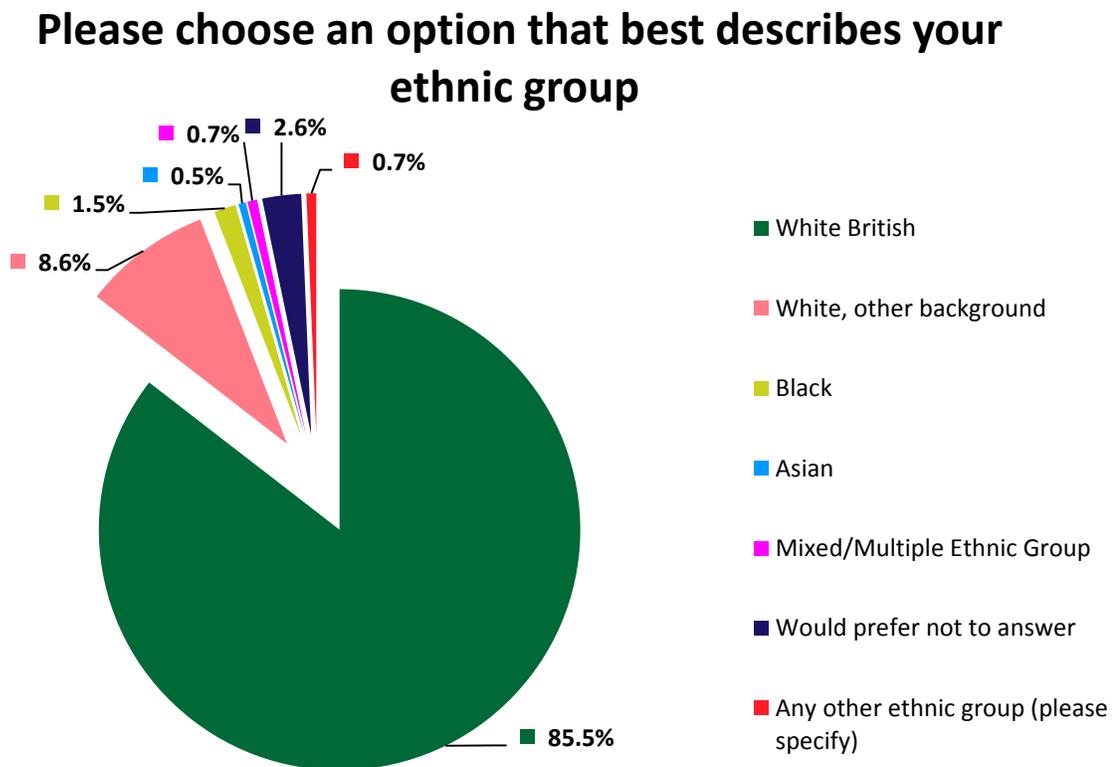
Comparing between male and female respondents:

Male respondents are more evenly distributed between 3 age groups (55-64; 65-74; 75-84), whereas female respondents are more clustered in the age group 55-64. Both sexes have low percentages of respondents aged 44 and under.

Question 19 - Please choose an option that best describes your ethnic group.

85.5% of the respondents identify themselves as White British, which is almost identical to last year's statistic (85%). However, those identifying as "White, other background" increased from 7% to 8.6%. There is also a slight increase in those identifying as Black (1.5%) and Mixed (0.7%). Compared to last year, more respond

Of the remaining respondents, 7% (same as last year) identify as 'White: Other' and 1% identify as Black. This year there are 1% respondents that identify as Asian. 3% of respondents preferred not to answer this question.



Conclusion

This year, we've seen improvements across all satisfaction and impact measures with many totals over 90%. Given the changes made to Talking Point's functionality and design this year, it is very satisfying to see an increase in positive feedback.

Members have responded positively to the new forum for people affected by dementia and cancer and this could provide a helpful rationale to provide ways for members to connect around specific topics or situations. In December 2018, we started to add 'topic' tags to selected threads and will extend this feature in 2019.

There are a number of areas for improvement and development:

We are disappointed to see lower numbers of responses this year from people with dementia, men and people from Black, Asian or other Minority Ethnic (BAME) backgrounds. We are researching ways to **encourage participation from under-represented groups** on Talking Point in 2019.

Members have asked for **email alerts and for a more intuitive design** on the community, making it easier to **find information on specific topics**. A small number of members mentioned re-introducing an app which they felt would **improve user experience on a smartphone**. A small number of members mentioned a 'like' or 'thanks' button, but this idea did not perform well in testing.

Some members suggested **making it easier to find the Helpline, Factsheets and other Alzheimer's Society content** and services on Talking Point. Other members specifically mentioned **information about what to expect** at each stage of dementia, particularly at the later stages which they feel is not represented well.

As we saw in previous years, members wanted the service to be **promoted more regularly**. In early 2019, we ran two promotional campaigns on Facebook and Twitter to raise awareness of Talking Point and will plan further activity in the future. We are also participating in activity which will equip Alzheimer's Society employees to promote the service.

Serena Snoad
Online Community Manager
Alzheimer's Society
June 2019

Acknowledgements

Alzheimer's Society would like to thank Anran Yu, a graduate of University College London (UCL) for completing data analysis and producing this report.

This report was coordinated by Harriet Dew, Online Community Coordinator. It was approved by Serena Snoad, Online Community Manager, who also provided the executive summary and conclusion.

NB All quotes included in this report are from survey respondents and have been edited solely to summarise or remove errors.