

# **Examining support marshalling within an asynchronous online peer support forum for individuals affected by dementia.**

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## **Data sharing statement**

The data analysed during the current study are not publicly available nor are they available on request. Whilst the data is publicly available online, publication of the data could identify individual account holders and this was not approved by the ethics committee or from the Dementia Support Forum (who gave us permission to analyse forum posts).

## **Declaration of conflicting interests**

The authors declare that there is no conflict of interest.

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## **Ethics approval**

Ethical approval was granted by the University of Bournemouth Faculty of Science & Technology Research Ethics Committee (ethics id: 39602). Consent to analyse the forum posts was obtained from the Dementia Support Forum.

## **Abstract**

Online support communities may provide individuals affected by dementia opportunities for reciprocal peer support, however, the support marshalling strategies employed, and their success remain unclear.

Analysis of 100 randomly selected conversation threads from the Dementia Support Forum indicated that 29% (29/100) of opening posts included a direct support marshalling strategy (i.e. explicit support request) compared with 54% (54/100) labelled as indirect, with the remainder not seeking support. Within the direct marshalling posts, informational support was the most frequently requested (n=23), followed by network support (n=7), emotional support (n=5) and esteem support (n=1) with analysis of subsequent posts confirming that the types of support requested were present within responses. Regardless of whether a direct or indirect strategy was used, most posts received a response, typically on the same day. Other response facets were comparable, apart from thread duration with conversations elicited through a direct strategy being longer (M=39.71 vs 14.62 days).

**Keywords:** content analysis, internet, peer support, social support, Alzheimer, online communities, cognitive impairment

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## **Introduction**

Dementia is a pernicious global health concern, currently affecting around 55 million people worldwide with projections estimating an increase to 150 million by 2050 (GBD 2019 Dementia Forecasting Collaborators, 2022). The trajectory of dementia is often described across three stages: early, middle, and late. In later stages, individuals require extensive support for personal care and activities of daily living (Prizer and Zimmerman, 2018). In contrast, the earlier stages are marked by noticeable decline in instrumental activities of daily living, including using the telephone, meal preparation, shopping, household tasks, and handling medication (Pérès et al., 2008). These impairments can significantly encroach upon an individual's independence, impacting their confidence and ability to live well (Martyr et al., 2019).

While people with dementia can continue to find meaning and positivity in life (Wolverson et al., 2016), they often experience feelings of loss, depression, frustration, shame, and loneliness, as well as shifts in agency, social roles, and personal identity following diagnosis (e.g., Górska et al., 2018; Spreadbury and Kipps, 2019; Victor et al., 2020; Ward et al., 2022). The journey to obtaining a diagnosis is also fraught with challenges; those affected by dementia frequently report a lack of clear information, living with uncertainty throughout the pre- and post-diagnostic phases, and a reluctance to seek a diagnosis partly due to stigma (Roach et al., 2016; Campbell et al., 2016). Following diagnosis, individuals may struggle with assimilating and adjusting to their new reality, and experience a shrinking social world (Roach et al., 2016; Bjørkløf et al., 2019; Lishman et al., 2016). Accessing appropriate support services poses an additional challenge due to stigma, geographic limitations, specific dementia types (e.g., vascular, Lewy body, frontotemporal, Alzheimer's), financial constraints, lack of awareness, and cultural relevance (Giebel et al., 2021, 2023). Moreover, the progressive nature of dementia creates uncertainty and fear about the future, leading some to avoid seeking support or engaging in future care planning (Ashworth, 2020).

Considering these challenges, it is imperative that people with dementia have access to appropriate support. Peer support groups offer significant emotional and social benefits grounded in shared experience, fostering a sense of belonging and reciprocal support – an experience that stands in contrast from the support provided by professionals, who may adopt a medicalised view of the condition and where deficit is the focus (Keyes et al., 2016). Engaging in peer support enables people with dementia to re-establish their identities at a time of perceived loss and explore positive identities with the diagnosis (Clare et al., 2008; Talbot et al., 2021). Moreover, these groups play an important role in reducing isolation and loneliness, enhancing self-esteem and overall quality of life, and providing access to resources that enable a person to live well (Clarke et al., 2013; Keyes et al., 2016; Leung et al., 2015; Sullivan et al., 2022). However, face-to-face support groups are not accessible to all,

particularly those living in certain localities, with rare dementia sub-types, have caregiving responsibilities, or financial constraints (Giebel et al., 2021; Millenaar et al., 2016).

### *New opportunities for peer support in the digital era*

In recent years, peer support groups have been established both on the Internet as well as social media (e.g., Facebook) and have provided individuals new opportunities to connect with similar others. Often referred to as online communities, individuals impacted by dementia (e.g. patients, caregivers, family members), have an opportunity to come together online for the purpose of seeking information, advice, and support (e.g., Allen et al., 2016; Craig and Strivens, 2016; Gerritzen et al., 2022; Talbot et al., 2021; Ziebland & Wyke, 2012).

Whilst online communities can be underpinned by a range of platforms (e.g., Facebook groups, Zoom), asynchronous text-based forums have proven especially popular and may be helpful for individuals affected by dementia since they are available 24 hours per day, 7 days per week and members can take their time when writing messages, since there is no urgency to communicate (Idriss et al., 2009; Vilhauer et al., 2010). Therefore, participation in a dementia-specific online forum may be a means through which individuals affected by the condition may obtain much needed social support from similar others who truly understand what they are going through (Johnson et al., 2020; Talbot and Coulson, 2023).

Social support can be described as the experience or perception that one is loved and cared for by others, esteemed and valued, and part of a social network of mutual assistance and obligations (Wills, 1991). Social support may come from a range of individuals including a partner, relative, friend, co-worker, or members of a social network, as well as fellow members of an online community. Research over many decades has consistently demonstrated that social support may have multiple mental and physical health benefits (Cohen and Wills, 1985; Farr et al., 2021; House et al., 1988; Linkiewich et al., 2023). Within the context of asynchronous forums, social support is primarily enacted through text-based communication and there has been a growing body of research which has sought to identify and describe the types of social support exchanged between online community members (e.g., Mo and Coulson, 2008), yet dementia research in this area is limited to very few studies (Johnson et al., 2020; Talbot and Coulson, 2023). Four types of social support appear particularly relevant to online community settings: i) informational support provides advice, information, and/or facts relevant to an issue; ii) emotional support provides care and compassion to another individual and what they may be experiencing and serves to reduce the individual's negative affect; iii) esteem support helps an individual enhance how they feel about themselves; iv) network support involves individuals providing personal connections to the individual and makes them feel like they belong. In a meta-analytical review of 41 content analysis studies examining the provision of social support within online communities, Rains et al., (2015) reported that informational and emotional support were the most common types of support exchanged.

However, the strategies used by online community members to marshal social support as well as the extent to which they are successful remains unclear.

### *Strategies for marshalling social support within online communities*

According to the Social Support Activation Model (Barbee et al., 1993), behaviours to marshal social support may be considered along two dimensions: i) direct versus indirect elicitation and ii) verbal versus nonverbal elicitation. Within online community settings where communication is textual (i.e. the online equivalent to verbal), such as an asynchronous forum, a direct elicitation strategy may involve posting a message to ask a question about dementia medication, whereas an indirect strategy might involve expressing fear about a dementia diagnosis. Previous research has suggested that community members may ask direct questions to obtain informational support (Bambina, 2007) and that focussed questions are more effective in soliciting useful responses compared with open-ended ones (Burke et al., 2007). In contrast, indirect elicitation strategies are typically used when seeking emotional support, where individuals share their personal stories about their illness and emotional reactions to it (Bambina, 2007; Rodgers and Chen, 2005). Within the dementia context, little attention has been devoted to understanding the support marshalling strategies used by members of online communities except for one study focusing explicitly on social support requests (Johnson et al., 2020). In an analysis of original posts from an online forum for people with dementia, Johnson et al. (2020) found support seeking is a key activity for all users, with informational support activities being the most prevalent, followed by emotional support. However, the researchers did not analyse responses to original forum posts, thus limiting understandings of how the online community perceives and interacts with these posts. Furthermore, it is not clear whether direct elicitation strategies only yield informational support and indirect strategies only yield other types of support (e.g., emotional).

In considering the process of support marshalling, little attention has been given to understanding the consequences of either direct or indirect elicitation beyond the assessment of the type of support received. For example, Wang et al. (2015) employed a computer-assisted content analysis tool to analyse self-disclosure, question asking and support provision (as judged by the first response post) within an online cancer support community. Their findings suggested that self-disclosure was effective in eliciting emotional support, whereas question asking was effective in eliciting informational support. They concluded that the perception that individuals seek specific kinds of support influences the support they receive. Whilst this study is helpful in exploring the mechanisms through which social support may be elicited within an online community, there is a need to extend our examination of support marshalling strategies beyond the type of support provided. For example, there are other potentially relevant response facets which have yet to be fully explored within the literature. These include, but are not limited to: i) whether the first post receives a reply; ii) how soon the first post receives a reply; iii)

how many replies the first post receives; iv) the number of community members replying; v) the length of conversation.

Our work sits at the intersection of dementia online communities and wider conceptualisations of online support within health psychology. Whilst there is emerging literature on online forum usage among people with dementia (e.g., Johnson et al., 2020; Talbot and Coulson, 2023), we still know very little about how these online spaces are used, the support strategies employed by users, and the responses to support requests. Such research is valuable for informing future technological interventions aimed at supporting people with dementia. The current lack of understanding led us to our research questions:

### **Specific research questions:**

RQ 1: What types of support marshalling strategies do members of the ‘I have dementia’ sub-forum use to elicit support?

RQ 2: Where a direct form of support marshalling is evident, what type(s) of support are requested and what is the nature of this request?

RQ3: How do response facets differ depending on whether a direct or indirect support marshalling strategy is used?

### **Method**

#### *Data collection*

The data for this study comprised messages posted to the Alzheimer’s Society Dementia Support Forum (DSF; previously named Dementia Talking Point), which is a UK-based asynchronous discussion forum moderated by volunteers. It is a free to use, online community which seeks to support anyone who is affected by dementia (e.g. patients, caregivers, family members). The forum has more than 83,000 members, who have generated over 131,000 conversations containing approximately 1.9 million individual posts. Our study focussed on a specific sub-forum within the online community (‘I have dementia’) because we wanted to take a broad approach to the topic area and felt this sub-forum would offer many instances of support elicitation and response and would therefore be suitable to address our research questions.

Our approach to data retrieval was informed by the guidelines set out by Smedley and Coulson (2021), whereby each included conversation thread was selected using an online random number generator. From a pool of 1,678 threads within the sub-forum, 100 (approximately 6% at the time of retrieval) were selected for analysis, yielding a dataset of 863 individual messages (range 1 to 34 messages per thread) posted to the sub-forum between July 2009 and October 2021 and which was generated by 251 unique usernames. Our decision to sample 100 conversation threads was made after reviewing other studies undertaking similar analyses of user-generated content (e.g., Eades et al., 2020). Each

conversation thread within the dataset was downloaded as it appeared, including original formatting. As our dataset only included information that was present within the conversation thread, no detail on the socio-demographic or user characteristic of the 251 individuals who generated this content were available. However, through the analysis process, we were confident that both individuals living with dementia as well as caregivers (e.g. spouse) and other family members (e.g. adult children), were represented.

### *Analysis*

To address research question 1, our analysis began with a categorisation of the first post at the start of each conversation thread in our dataset according to whether it demonstrated: i) a direct request for social support; ii) an indirect request for social support or iii) whether the message did not make any request for social support (i.e., no request). Solicitation of social support was considered direct if the first post included an explicit articulation of a support need, such as through directly asking a question for assistance or input from the community (e.g., “What do others think?”, “What should I do now?” “Has anyone else experienced these symptoms?”). In contrast, first posts were considered indirect if the solicitation of support was evident but not expressed through a question (e.g., “This is all too confusing, I don’t know what to do”). These indirect requests were more subtle and involved the sharing of dementia-related experiences or feelings without directly asking for help. The final category (i.e., no request), comprised messages which were often not dementia-related (e.g., weather-related) and where no support request was evident either explicitly or implied. To classify posts, both authors independently coded each first post and then compared their classifications, with 97% agreement (n=97). In the few (n=3) instances of disagreement, discussion between the authors took place and it was quickly established that human error in the recording process accounted for the discrepancies and resolution was easily reached.

Next, in all instances where a direct support request was evident, the specific focus of that request for social support was identified and this addressed research question 2. However, we recognised that any support marshalling strategy could potentially seek more than one type of social support. Therefore, we coded every direct support marshalling first post in relation to four types of social support using an adapted version of Cutrona and Suhr’s (1992) widely used taxonomy of social support (see Table 1 for definition of each support category). Again, this was undertaken independently by both authors before comparing their classifications. Initial independent coding yielded 83% agreement (n=24) as to the combination of types of support being solicited. The remaining first posts (n=5) were discussed until agreement was reached. Within the firstposts coded as direct and provided there was sufficient data, we then undertook an inductive thematic analysis (Braun and Clarke, 2022) to explore the nature of the requests according to each type of support.

To address research question 3, we identified and described various response facets including: i) did the first post receive at least one reply (Yes/No); ii) how soon was the reply? (Same day, next day, two or more days); iii) number of replies; iv) how many people posted at least one reply; v) how long did the conversation last (number of days). In addition, we considered the extent to which the type of social support elicited directly was congruent with the type(s) of social support evident within the responses in the conversation thread. This was achieved by each author independently coding the congruence between the type(s) of support being directly elicited with the type(s) of support evident in all the other replies within the same conversation thread.

**Table 1.** Type of support solicitation and definition.

<b>Type of support</b>	<b>Definition</b>
Soliciting informational support	A post which seeks support in terms of ideas or advice, or referral to other sources of support, perspective, or seeks information, facts, or news about a situation or about skills required to address the situation.
Soliciting emotional support	A post which asks for support that conveys understanding, empathy, love, caring, encouragement, hope, confidence, or concern.
Soliciting esteem support	A post which seeks support that may say positive things about the person or enhance how the person may feel about their abilities and attributes. It may seek agreement with their perspective on the current situation or may serve to alleviate any feelings of guilt they have.
Soliciting network support	A post which seeks support in terms of being available or that others are available to them.

### *Ethical considerations*

Ethical approval for this study was obtained from the second author's home institution (ID: 29602). In preparing the application for ethical approval, issues of confidentiality, informed consent and privacy were central (British Psychological Society, 2021). Our attention focussed on the distinction between the 'private' and 'public' nature of the online domain, and we considered two key issues. Firstly, no registration was required to read messages posted to the sub-forum of interest (or the over-arching forum). Secondly, at the time of our application there were more than 72,000 community members. Therefore, considered together we concluded that the sub-forum of interest could reasonably be argued to be within the 'public domain' and consequently, informed consent would not be required. Beyond this, we took steps to ensure the confidentiality and privacy of members by ensuring no usernames were

reported in our results and no quotes could be traced back to the original conversation thread, sub-forum, or over-arching forum. As an additional safeguard, our proposed study methods and data collection procedures were offered to the administrative team supporting the forum of interest and written approval received.

## Results

### *Types of support marshalling strategies used by community members*

Our analysis of the first post at the start of each of the 100 conversation threads within our dataset indicated that 29/100 (29%) used a direct support marshalling strategy, whereas 54/100 (54%) used an indirect strategy. The remaining posts 17/100 (17%) were categorised as no request.

### *Types of support requested through direct support marshalling posts*

Analysis of the 29 direct support requests indicated that informational support requests (n=23) were by far the most common. Seven unique combinations of support requests were evident (see Table 2). The most common type of social support solicited through a direct marshalling first post was for informational support only. Next, though much fewer in number, were posts which solicited network support only. The remaining posts solicited various combinations of 2 or 3 types of support apart from a single post which solicited only emotional support.

**Table 2.** Types of support explicitly requested in direct first posts.

Combination Type	Informational	Emotional	Esteem	Network	No. of posts
1	Yes	No	No	No	18
2	No	No	No	Yes	5
3	Yes	Yes	No	No	2
4	Yes	Yes	No	Yes	1
5	No	Yes	No	No	1
6	Yes	Yes	Yes	No	1
7	Yes	No	No	Yes	1
	No. of posts = 23	No. of posts = 5	No. of posts = 1	No. of posts = 7	Total = 29 posts

### *Direct elicitation of informational support*

Our inductive thematic analysis of the twenty-three first posts categorised as seeking informational support generated four sub-themes: i) Understanding and managing symptoms; ii) Adjustment to diagnosis and life with dementia; iii) Effects of medication; iv) Engagement with health and social care services.

### Sub-theme 1: Understanding and managing symptoms

Some users of the forum described in their first post, the nature of the symptoms either they or someone they knew were experiencing. For some, they asked whether others were also experiencing specific symptoms and/or whether such symptoms were common in those living with dementia. For example, after being recently diagnosed with Alzheimer's disease, one forum user asked, "*I would like to know if those of you of experience of loved ones with dementia find they are increasingly intolerant of noise and people chattering non-stop?*". In other first posts, users described either new symptoms or a worsening of symptoms and sought information and advice from the forum about how to manage and cope with them.

### Sub-theme 2: Adjustment to diagnosis and life with dementia

Several users of the forum shared their recent experiences of being diagnosed with dementia within their first post. Across these messages, it was common to see users seek information and advice on how to react to the diagnosis and make sense of what it means for their life and future. As one user shared, "*Im just 53 and was diagnosed vascular dementia just 1 week ago, after 14 months of tests. The thing is I don't believe the doctors at the hospital that I have and also keep wondering if I heard them right! My partner was with me and he said that is what they said. They offered me a nurse for a couple of months, I dont know what for? I have to go back next month and start lots of new medication. But I cannot accept the diagnosis, is it me? or do others feel the same, any advice greatly appreciated, thank you.*"

### Sub-theme 3: Effects of medication

Questions which related to medications being taken by those with dementia focused on the experience of side effects and whether other forum users had experienced something similar. For example, one carer who used the forum posted, "*I have an 80 year old wife who has been prescribed Donezapil Hydrochloride. Upon reading the effects they can cause I wonder has anybody else experienced these, namely loss of appetite feeling nauseous all the time, tiredness and taste being affected.*"

### Sub-theme 4: Engagement with health and social care services

Some users had specific questions either about what to expect with regards tests and support from health professionals, for example "*Just a quick question, I had a neuropsychological assessment on 30th August this year i am still waiting to see a copy of the report. Is it normal for it to have taken so long?*", whilst others had questions about social care procedures.

### *Direct elicitation of network support*

Whilst the wish to connect with similar others was evident in all the first posts which sought network support, it was evident that there were a range of different circumstances driving the request. For

example, some described the challenges of having “*nobody to talk to*” whilst others simply said, “*I have dementia and needs to talk to someone*”. In other instances, the user had been diagnosed with a specific type of dementia and they sought contact with others with a similar diagnosis, “*So, any fellow LBD sufferers out there*”.

#### *Direct elicitation of emotional support*

Across the posts was the shared experience of coming to terms with the diagnosis of dementia and the subsequent emotional impact of this devastating news. As one user explained, “*Now the realisation has hit I have become tearful, withdrawn from friends and grieve for our future*”. The user continued to describe the emotional impact the life-changing and overwhelming nature of their diagnosis, and asked the question, “*When, if ever will I ever be able to not have this my head 24/7?*”.

#### *Responses to support marshalling strategies*

For both the direct and indirect marshalling strategies (see Table 3), nearly all first posts received a reply (97% vs 93% respectively) and inspection of the relevant timestamp for the first response posts indicated that most were on the same day as the initial first post (96% direct vs. 90% direct). For both categories of support marshalling first posts, the number of responses was comparable, as were the number of fellow community members who replied. However, there was a marked difference in the duration of the conversations with those initiated by a direct support marshalling request lasting approximately 40 days compared with approximately 15 days for indirect requests.

**Table 3.** Responses to first post messages by response time, volume, people, and duration.

<b>Type of support marshalling</b>	<b>Receive a reply (yes/no)?</b>	<b>How soon was the reply?</b>	<b>No. of replies (no. of posts)?</b>	<b>How many replied (no. of people)?</b>	<b>How long did the conversation last (days)?</b>
DIRECT	Yes = 28 (96.5%) No = 1	Same day = 27 Next day = 1	Range = 1 to 32 Mean = 9.36	Range = 1 to 15	Range = 1 to 493 Mean = 39.71
INDIRECT	Yes = 50 (92.6%) No = 4	Same day = 45 Next day = 3 2 or more = 2	Range = 1 to 33 Mean = 8.04	Range = 1 to 16	Range = 1 to 362 Mean = 14.62

#### *Congruence between direct support marshalling posts and subsequent replies*

Across the 29 first direct posts, a total of 36 requests for different types of support (see Table 2) were present. Our analysis of the replies posted by other community members in response to each of these 29 first direct posts indicated that, across all seven combinations of support requests (e.g., Combination 3: Seeks information and emotional support), members received the type(s) of support they requested

(see Supplemental Material Appendix A for the types of support provision with definition and examples).

## **Discussion**

The aim of this study was to explore the support marshalling strategies employed by members of a dementia-related asynchronous online peer support forum. Our analysis found that just under one-third of first posts employed a direct support marshalling strategy, compared with just over half employing an indirect strategy. According to the Social Support Activation Model (Barbee et al., 1993), direct support elicitation strategies may be used when seeking informational support compared with indirect strategies which are employed to seek emotional support. Within the present dataset, most first posts evidencing a direct support elicitation request did indeed seek informational support. In particular, the support seeking questions asked within the posts focussed on four key areas: i) understanding and managing symptoms; ii) adjustment to diagnosis and life events; iii) effects of medication and iv) engagement with health and care services. These findings resonate with previous literature which suggests members of dementia-related online communities may seek experiential information and advice from fellow members around the multiple impacts of a dementia diagnosis (Rodriquez, 2013; Talbot and Coulson, 2023). However, our findings also show that community members may engage in direct support marshalling strategies for other types of support and not just information. For example, in a smaller subset of posts coded as direct, members sought network, emotional and esteem support. Our findings are consistent with the Social Support Activation Model in that asking a direct question may be an effective way to solicit informational support. However, our findings serve as a cautionary note that informational support should not be considered the sole reason for employing a direct support marshalling strategy and that members of online forums may use a direct support marshalling strategy when seeking a range of different types of support.

Whilst previous research has tended to focus solely on the first reply post (Wang et al., 2015), our analysis considered all subsequent response posts within a conversation thread and a range of response facets. Our exploration of what might count as a response facet included whether a post received a reply, how soon the reply was posted, the number of replies, the number of people posting a reply and the duration of the conversation thread. Our findings suggest that regardless of the support marshalling strategy employed (i.e. direct or indirect), most support requests receive a reply, typically on the same day from multiple members over several days and weeks. Whilst the duration of the conversation thread was markedly longer for the direct support marshalling strategies, this appeared to be the result of a single outlier. Therefore, our study suggests that regardless of the strategy used, posts seeking support will normally receive replies. However, it can be argued that the congruence between the type of supported requested and that which is offered is a more important consideration, yet few studies have

considered this. Our findings offer an encouraging picture, suggesting that when a forum member seeks support from others, they will likely receive responses from other members which are consistent with the type(s) of support being requested.

Online forums for people with dementia, such as DSF, offer valuable pathways to peer support. This support can be particularly meaningful in fostering a collective sense of identity rooted in shared experiences (Clare et al., 2008), contrasting the support provided by professionals which may adopt an overly medicalised view and not fully address the needs of people with dementia (Keyes et al., 2016). For example, both people with dementia and their carers have reported feelings of anxiety and confusion stemming from unsupportive interactions with professionals, including insufficient emotional exploration of the impacts of diagnosis, poor rapport building, limited information provision, and inadequate checks of patient understanding (Dooley, Bailey, & McCabe, 2015; Yates et al., 2021). In contrast, research on synchronous online support shows that people with dementia often experience acceptance and understanding from their peers who can genuinely empathise with their situation (Gerritzen, McDermott, & Orell, 2023). Asynchronous peer support may offer additional benefits, such as enhanced anonymity which can be particularly valuable for people in stigmatised contexts (e.g., Andalibi, 2019; Talbot et al., 2022). Additionally, the less time-intensive nature and constant accessibility of asynchronous online support may contribute to its appeal. However, potential risks exist with asynchronous online support, including repeated exposure to negative experiences, miscommunication due to a lack of social cues, non-responses or delays in receiving responses, and misinformation (e.g., Attard & Coulson, 2012; Perkins et al., 2020; Talbot et al., 2023). These challenges and outcomes have yet to be thoroughly explored in the context of online forums for people with dementia, highlighting a need for future research in this area. While our research demonstrates the promising potential of online forums in facilitating peer support for people affected by dementia (e.g. patients, caregivers, family members), it is crucial that our findings do not overshadow the urgent need to invest in offline dementia services, particularly those facilitating peer support. As with other digital services, online forums may not be accessible, usable, or suitable for all people with dementia (see Caprioli et al., 2023; Giebel et al., 2021). Therefore, we recommend online forums serve as a complementary avenue for support, particularly for those with rarer diagnoses, those who do not live near others with dementia, and those who may be hesitant to disclose their diagnosis offline. Furthermore, it is essential that these online spaces are designed to be dementia-friendly to optimise social support provision and psychosocial outcomes, which may be achieved through improved design, intuitive navigation, and accessibility features. In future, organisations and designers of online forums could benefit from further collaboration with people affected by dementia to improve the usability of these online spaces so a wider range of people can benefit.

### *Strengths and limitations*

There are several strengths and limitations with the present study which should be considered when appraising the results. One key strength of this study is the fact that our analysis of the types of support marshalling strategies employed by community members considered all subsequent posts within the same conversation thread. This is an important issue since it acknowledges that there may be multiple people and responses provided to an individual seeking support. Whilst previous work has either not considered responses or focussed only on the first response post, our study adopts a more holistic approach by considering the entire conversation thread. That said, we acknowledge that no conversation is truly over, since members may post further replies at any time. Therefore, there may be further support provided by forum members in response to requests (either direct or indirect). In addition, whilst our analysis suggests that forum members received the specific types of support they request, future research may seek to undertake qualitative research and explore with those forum members who posted a request for support, whether they felt they had received helpful and relevant responses. Additionally, due to the methods employed in our research it was not possible to determine users' stage of dementia. Given the progressive nature of dementia, it is likely that support needs and engagement with online forums change over time. Future longitudinal research is required to gain a deeper understanding of the dynamics of online support exchanges as dementia progresses. Finally, while our study focused on the experiences of forum users, it is important to acknowledge the vital role forum moderators play in facilitating and shaping online support conversations, which were not directly explored in our study. Future research could engage with the perspectives of forum moderators to understand their experiences, challenges, and strategies for enhancing online support provision.

### *Conclusions*

The findings of the present study suggest that individuals affected by dementia who seek support online will receive timely and pertinent responses from fellow forum members. Furthermore, regardless of whether an individual is more explicit or implicit in their request, fellow members can accurately gauge which types of support are required and offer it accordingly. This understanding of 'support marshalling' expands conceptualisations of online support provision, which can be applied to other health contexts beyond dementia. Our findings provide insights for health and social care professionals, unpaid carers, and charity organisations to recognise and harness the value of online forums as complimentary support resources for people affected by dementia. By acknowledging and integrating online forums into their support frameworks, these stakeholders can amplify the availability of social support, ultimately enhancing the wellbeing of people affected by dementia.

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**Appendix A.** Type of support provision with definition and examples.

<b>Type of support</b>	<b>Definition</b>
Informational support provision	<p>A post which provides support in terms of ideas or advice, or referral to other sources of support, perspective, or seeks information, facts, or news about a situation or about skills required to address the situation.</p> <p><b>Example:</b> <i>“might you contact your Local Authority Adult Services and arrange an assessment of your care needs, as you have a right to this ... maybe write a list of the daily tasks you are finding more difficult to do for yourself, so you can give them an idea of the support you feel you need”</i></p>
Emotional support provision	<p>A post which provides support that conveys understanding, empathy, love, caring, encouragement, hope, confidence, or concern.</p> <p><b>Example:</b> <i>“I’m really sorry you are going through this: I will be thinking of you and wish you well.”</i></p>
Esteem support provision	<p>A post which provides support that may say positive things about the person or enhance how the person may feel about their abilities and attributes. It may seek agreement with their perspective on the current situation or may serve to alleviate any feelings of guilt they have.</p> <p><b>Example:</b> <i>“It must be very difficult in the first few weeks after diagnosis.”</i></p>
Network support provision	<p>A post which provides support in terms of being available or that others are available to them.</p> <p><b>Example:</b> <i>“a warm welcome from me too..there are members here who also have a diagnosis, so there are others on TP in a similar situation to you..do write here with whatever is on your mind - feel free to chat about anything - members are generous in sharing their experiences and knowledge to help each other”</i></p>

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