

Explore the Issues Faced by Family Caregivers of Dementia Patients and Their Use of

Online Forums

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Declaration

This work is original and has not been submitted in relation to any other degree or qualification

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I would like to thank Dr. Liz Whelen for her support and assistance with this dissertation.

Supervisor Log

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To discuss ethics application and general premise of the research. Method of Thematic Analysis, research question, and selection of forums to be used for the data selection was discussed at this meeting.

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At this meeting the research was discussed more specifically. Content of each section was discussed and the research question itself was established. Supervisor gave advice on how to write each section, specifically the subsections needed in the methods section, and talked adding the forum posts used as appendices. Deadline was set for introduction draft.

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## Abstract

This qualitative study looks at the primary issues faced by dementia family caregivers and their uses of online forums. The previous literature finds that there are an array of psychological issues that are faced by dementia caregivers, including depression, anxiety, social isolation and psychological morbidity. The literature also analyses the potential causes of these problems. The research was conducted through the Thematic Analysis of 50 forum posts to interpret the content of what the caregivers were posting about in the forums and analyse how the caregivers made use of this platform. The results found three overarching themes to show the primary psychological problems that the caregivers were complaining of: anxiety, psychological morbidity and social isolation. The results also found two main reasons that the forums were being used, the need for help from others, and the desire for more knowledge on dementia. The causes that contribute to these issues are discussed in the present study, alongside the benefits and limitations of this method of research and the benefits of anonymity on online discussion forums. Ultimately, it is established that there is a need for more professional help to become available to dementia family caregivers and for further research into specific issues faced by forum users and the causes of these.

## Introduction

Dementia is a disease of the brain that has become increasingly more common in today's society, with a 2015 study claiming that 800,000 people in the UK suffer from dementia (Denning & Sandilyan, 2015). Dementia is progressive in nature, and affects many higher cortical functions such as memory, comprehension and thinking, often in a chronic way (Denning & Sandilyan, 2015). Advances in medical technology have contributed to people living longer in the modern day world; there has been an increase in the amount of people suffering from dementia, since the majority of cases of dementia occur in people over the age of 65 (Hutto Faria, 1998), therefore the impact of dementia on society has become more prominent. Despite this fact, there are many cases of dementia in younger people that contribute to the number of dementia sufferers, although these cases are not as common (Harvey, 2003). Due to the increasing numbers of people suffering from dementia, a demand has been created for people to take on the role of caregiver in order to assist those suffering from the disease.

Dahlberg, Demack & Bamba, (2007) looked at the amount of people in the UK population that had taken on a caregiver role and found that 10% of their sample of almost 2 million people were living as caregivers. This study also found that the amount of caregiving in different age groups can vary, with 45-59 being the age range where the most people are involved in the caregiver role, this often being the age when a person's parents would become elderly and therefore more likely to become ill due to their old age. The amount of people in caregiving roles also increases into old age, with spousal illness causing the role to become necessary. The present study aims to investigate the

psychological, physical and social consequences that are the result of living in a caregiving role. These consequences will be seen through data collected from online forums, where caregivers have voluntarily shared information on the circumstances, feelings and issues that they are facing. Firstly, the caregiving role will be looked at and the common issues faced by caregivers that have been highlighted in previous literature will be analysed. The benefits and limitations of the use of forums to look at these issues will then be discussed in this section.

The caregiving role is often taken on by a close family member to aid and support those suffering from illness, and as stated earlier, is becoming an increasingly more common role in UK society. Family caregiving is often considered very challenging and complex and people in the caregiving role tend to face many issues caused by a combination of factors relevant to their circumstances (Schulz & Martire, 2004). Family caregiving has become more common in modern day society than ever before, with people's lifespans extending significantly due to modern medicine, and therefore more elderly people needing care (Hutto Faria, 1998). Studies have shown that many of the issues reported by dementia caregivers are not problems that are specific to caregivers of dementia patients, finding that caregivers of people with many different illnesses, (such as cancer patients) face many of the same problems and feel a similar burden to dementia carers (Grunfeld, 2004). However, this study aims to discover whether the psychological effects on the caregivers of dementia patients are more significant due to the nature of the disease, and the personality changes and memory impairment that the disease causes. Studies have been shown to reflect on this; Ory, Hoffman, Yee, Tennstedt and Schulz, (1999) found that dementia caregivers spend significantly more hours a week

providing care than other caregivers, and are more likely to experience mental and physical health problems, and other life effecting problems such as family conflict.

George & Gwyther, (1986) researched the prominent problems that family caregivers of elderly dementia patients complain of. The researchers sent surveys out to carers on the mailing list of the Duke University Family Support Program and acquired responses from 510 dementia carers to self-assess their experiences as dementia caregivers. This study showed that the caregivers found that social isolation and mental health problems were the main issues faced, meanwhile financial and physical difficulties did not prove to be as prominent. However, a downfall of this study could be the fact that due to the researchers' reliance on the use of surveys, they are able to identify the mental health issues that the participants feel they suffer from, but are not able to gain an insight on the events and initial problems that have led these mental health issues to take hold. Many other studies on the subject have looked into the mental health and social problems faced by caregivers, focusing on levels of depression, anxiety and psychological morbidity that are often experienced by people in a caregiving role.

Psychological morbidity is a term often used when looking at the mental state of caregivers of dementia patients. To clarify, this is simply intended as a vague phrase to communicate the idea of general psychological ill-health. People can be viewed as being psychologically unhealthy regardless of their levels of depression or anxiety, allowing these issues to be analysed separately. Brodaty & Hadzi-Pavlovic, (1990) used a survey to collect information from caregivers involved in the Alzheimer's disease and Related Disorders Society and found that caregivers of dementia patients often experience psychological morbidity and social isolation without reporting high levels of depression

alongside this. However, as mentioned in regards to the George & Gwyther, (1986) study earlier, the use of surveys is unable to define the reasons for the problems that the participants have self-reported, only discovering the problems themselves. Therefore it could be argued that there are more effective ways to conduct research of this nature.

Challenging and defiant behaviour is a quality often found in people suffering from dementia, and the high-pressure and social isolation factors push many people into experiencing high levels of psychological morbidity when dealing particularly with dementia; studies have shown that the more unusual or disturbing the patient's behaviour is, the less help the caregiver receives from friends and family members, thus contributing to feelings of social isolation (Clyburn & Stones, 2000). Furthermore, studies have shown that psychological morbidity in carers can be directly linked to depression and challenging behaviour displayed by their patients (Brodaty & Luscombe, 1998). Mittelman, Roth, Haley & Zarit, (2004) found that regular appraisals of family caregivers and the patients that they care for have the ability to assist in the methods that the caregivers use to deal with the challenging behaviours displayed by the dementia sufferers. These appraisals had no effect on changing the behaviours of the patient yet had a large positive influence on the way in which the caregivers felt they were coping; this was due to the caregivers being able to gain an understanding of the behaviours and the nature of the illness through discussions with people who were knowledgeable about the subject on a regular basis. In agreement with the previous study mentioned, Arango Lasprilla, Moreno, Rogers & Francis (2009) showed evidence that psychological and emotional problems and feelings of caregiver burden are significantly influenced by behavioural and emotional issues that the patient displays rather than the challenge of the patient losing physical ability.

Depression is a significant problem faced by family caregivers to those suffering from dementia. It has been shown that closer relatives in the dementia caregiver role experience higher levels of stress and depression than distant relatives or friends in the same role (Coope et al., 1995). The depression and anxiety levels in caregivers can also be affected by the nature of the relationship, with differences between marital relationships and other forms of close relationships such as parent-child (Fitting, Rabins, Lucas & Eastham, 1986). It has been found in research on the subject (Morris, Morris & Britton, 1988) that members of marital couples with a higher level of intimacy prior to the dementia diagnosis of their partner experience less stress and lower levels of depression when in the caregiver role than those with lower levels of intimacy with their partner. However, those with a low level of intimacy in their marriage prior to the illness experienced higher levels of depression but reported less stress and strain than their previously more intimate counterparts. It could be concluded from this that the closer the relationship, the more likely it is that the caregiver will experience emotional and mental instability when taking on the caregiving role. This could be due to experiencing a form of grief of the person that they previously knew, or due to the general effects that being a family caregiver has on a person's life such as social isolation or a feeling of being trapped and losing one's independence.

Interestingly, (Samuelsson et al., 2001) found that husbands that had taken on the caregiver role noticed a change in personality as one of the first symptoms of dementia in their partner whereas other relatives noted memory loss first. This study also found that the husbands of the dementia patients felt that they experienced the largest burden out of all relatives asked, experiencing feelings of guilt and anger alongside others when placed in the caregiver role. These results imply that the husband-wife relationship is

uniquely different to other close family relationships in similar situations. Dahlberg, Demack & Bambra, (2007) found that fewer men are in the informal caregiving role in youth and middle age than women, whereas in old age (70+) it has been found that there is a majority of men caring for marital partners. When looking at female caregivers, there is a more even distribution of ages. It could be argued that this could be due to women being more likely to experience caregiving roles in life, due to maternal instinct and caring for children, and this could mean that men are further out of their comfort zone when taking on a caregiving role at a younger age than women. Chang and White-Means, (1991) hypothesised that more men take on the caregiving role at an older age due to elderly men being more willing to abandon gender roles than their younger counterparts. It has also been shown that with female caregivers, the younger the caregiver is the more resentful of their role they are in comparison to their older female counterparts (Fitting, Rabins, Lucas & Eastham, 1986). This could be attributed to feelings of frustration in the care giver, as it is not generally expected that a person would lose a substantial level of independence at an early age.

Research has suggested a significant difference in the experiences of carers of dementia patients depending on their gender. Many studies have shown that the burden and strain is more prominent in female carers than males (Fitting, Rabins, Lucas & Eastham, 1986), and this is often attributed to social expectations and gender roles in society (Morris, Morris, Davies & Woods 1991). This could be expanded upon by looking at female likeliness to be more open in admitting their struggles and strains than males, which also includes the pressures put on people by society's gender roles. In Borys & Perlman's (1985) study on loneliness, it was found that men generally experience higher levels of loneliness than women, but are less likely to admit it, due to the perception of

admitting feelings and weaknesses as being a feminine thing to do. Studies like these confirm that women may often be more likely to open up and ask others for help, or be more willing to admit defeat than men; this gender role bias could contribute to the majority of research showing that women suffer more than men when living in the caregiver role. The high levels of stress that are experienced in caregivers also have the potential to cause other problems in the caregivers' lives. There is evidence to suggest that high levels of stress can cause physical illnesses (Uchino, Smith, Holt-Lunstad, Campo & Reblin, n.d.) and these illnesses could be responsible for causing difficulties when caring for the dependent family member. It could be argued that relief of social isolation and an improved knowledge of how to deal with caring for their patient could help to relieve the stress and therefore symptoms causing these physical illnesses. Studies have shown that family caregivers have significantly more consultations with their doctors than other people (Brodaty & Luscombe, 1998) and this could be attributed to stress related illnesses.

A prominent issue faced by family caregivers is the issue of anticipatory grief; often people experience that they are beginning to grieve someone before they have died (Theut, Jordan, Ross & Deutsch, 1991). This is an issue particularly with dementia caregivers as people report experiencing the loss of the person that they felt they knew as personality changes start to affect their relationship with the person that they care for. Holley and Mast (2009) theorised that the anticipatory grief that is experienced in dementia caregivers is unique in comparison with the anticipatory grief that is experienced in caregivers of other illnesses (such as cancer) due to the progressive nature of dementia and the cognitive and physical deterioration that is experienced. Holley and Mast (2009) found in their study that feelings of anticipatory grief are often experienced

separately to other factors that are often prominent in caregivers such as depression, or challenging behaviour displayed by the patient. Studies have shown that feelings of anticipatory grief can have an effect on the functioning of caregivers, showing that the more intense the feelings of grief a caregiver is experiencing, the more likely they are to experience feelings of anger or frustration and to have an expectation for the person to be cared for away from the home (Walker & Pomeroy, 1997).

A way in which family caregivers could be able to seek relief from care commitments could be through the use of online forums. This could be a way in which a caregiver could reach out and seek help at any time, or simply just have a discussion with others who might understand their circumstances. These forums give people a way to anonymously submit comments and stories about their experiences, and seek advice and support from others in a similar position to themselves. These forums are interesting to look at from a research perspective, as they have the potential to show more raw and unfiltered perspectives on the caregiver role than could be found in other studies that may use more official sources such as questionnaires in which people may not be as honest about their experiences and also may not be given the same opportunity to explain the context of their situation in detail as they would on an online forum. An additional point on the benefits of the use of online forums could be that the anonymous nature of online forums allows people to express themselves freely and provides a particularly honest and real form of data that can be used in order to study the issues faced in the caregiving role (Tanis, Das & Fortgens-Sillmann, 2011). It has been argued that forums can generate a feeling of solidarity amongst people in similar positions to each other, with users offering support and advice to each other (Rodriquez, 2013). However, previous research has shown that forums tend to attract more female than

male users, with only 30% of the posts being from men (Hausner, Hajak & Spießl, 2008). This could help to define a possible limitation of the use of forums as research has implied that men feel less able to open up than women (Borys & Perlman 1985), and it could be expected that similar statistics to the 30% to 70% split could be seen through dementia forums as it has been seen through other forums. Therefore, forums may not be as effective as a form of relief to males as they are for females.

A quality of the use of forums that may separate it from other methods of data collection that could be used to conduct a study on this subject is anonymity. Forums provide an anonymity option for those using them that could be argued benefits the way in which people feel able to use them. Bertera & Littlefield (2003) conducted a study where students used online forums anonymously and reported on the effects that anonymity has on the way in which the forums are used. The study found that 54% of the participants of the study reported that anonymity improved honesty in the forum posts, with 60% reporting benefits in their relationships with fellow classmates through using the forum anonymously. Therefore, it could be assumed that the results of the present study may provide a more honest representation of the issues faced by the dementia family caregivers than could be otherwise achieved with different methods of data collection such questionnaires or interviews. On the other hand, studies have shown a negative reflection of the uses of anonymity in online forums in the form of cyberbullying (Moore, Nakano, Enomoto & Suda, 2012). Equally, as much as anonymity can cause there to be a positive increase in honesty and openness, Moore, Nakano, Enomoto & Suda (2012) have shown through their research that it can also cause people to feel more able to post aggressive or demeaning comments to others without fear of being identified.

Social isolation is a common problem faced by family caregivers, due to commitments at home being considered overwhelming. This can prevent caregivers from socialising externally to the home or being involved in other social activities (McKechnie, Barker & Stott, 2014). The problem of social isolation could be seen as being a particular issue for elderly caregivers with smaller social circles. Stoltz, Uden & Willman (2004) found in their study that family caregivers crave social interaction with peers for both social and educational purposes. This is a situation in which forums could be seen as being helpful, as forums create a social network of people that share a common experience. The forum network has been claimed to be a superior form of intervention than face to face meetings for people in the caregiving role, since they allow the caregiver to communicate with others and find a small social outlet from home; allowing them to not compromise with their caregiving commitments by doing so (Brennan, Moore & Smyth, 1992).

Studies have suggested (Graham, Ballard & Sham, 1997) that carers with a greater knowledge of dementia experience lower levels of depression and have lower expectations of those they care for given their knowledge of the condition. This in turn causes these caregivers to draw more positive comparisons from the people they care for than those who are less knowledgeable about the disease. Saad et al., (1995) also found that having a greater knowledge of the illness and having reduced expectations of what the people they care for are able to do or fully understand, were two factors that were inversely correlated with depression in caregivers. Therefore, it would be possible to draw the conclusion from the evidence found in these studies that the more knowledge a person has on dementia as a whole, the more understanding that person is able to be. Attempts have been made to find ways in which to reduce psychological stress in carers

of dementia patients. Brodaty & Gresham (1989) found that carers who have gone through a training programme to help them to try to gain a better understanding of the recommended ways to care for a person with dementia experienced lower levels of psychological stress and morbidity than they did previously. It could be argued that the use of forums and looking at the experiences of other people could assist in this, as the knowledge acquired from studying other people's experiences can contribute to changing the expectations that one has.

It has been shown through studies that support of dementia carers through the use of online forums can have a positive effect on levels of psychological morbidity, depression and anxiety that caregivers experience (Powell, Chiu & Eysenbach, 2008). McKechnie, Barker & Stott (2014) found through their analysis of the use of internet support forums by caregivers that the forums had a positive effect on those using them and very few negative effects were reported. This study showed that since using the online forums, the relationships between the carers and those being cared for improved, however, this study showed that the use of the forums had no significant effect on the anxiety or depression levels of those using them. Results from studies like these suggest that forums can be a useful aid for people in a caregiver role, particularly those in close family relationships with their patients. However, it is not a complete fix and other interventions are necessary to assist with all the psychological issues faced by caregivers.

A study by Marziali and Garcia (2011) compared experiences of caregivers in two different forms of online support groups, one being a chat forum and another being a video conference forum. The results from this study showed that the caregivers found the video conference intervention more effective than the chat intervention,

experiencing greater relief in mental health problems and lower levels of feelings of social isolation. This study reflects the idea that social interaction in person is more effective than social interaction through online chat. From this it can be hypothesised that as helpful as online forums can be perceived to be, a more intimate, personal form of support could be more helpful in attempting to resolve the issues faced by caregivers.

Alternatively, in a study conducted by (Kummervold et al., 2002) regarding online health forums about Norwegian mental health, it was found that 75% of participants stated that they felt more comfortable discussing personal problems using text based internet forums than they would when talking to another person face to face. This could be interpreted as a unique use of online forums for people in the family caregiver role to express their feelings and emotions more honestly than they would in face to face situations. This gives online forums an edge on other forms of support that could be an option to caregivers such as support groups where people may not be as honest about their thoughts and feelings than they otherwise would be.

It becomes evident while looking at the previous research on the subject of dementia family caregivers that the use of forums may be able to fill in gaps in research which other forms of data collection have not been able to fill. The use of questionnaires and surveys are usually limited as only specific questions are asked during these methods of research and therefore context, causes and explanations tend to get lost. When using interviews as the method in the studies on the subject, information and honest responses could also get lost, as a stranger may be conducting the interview, causing the participant to fear judgement and not be as open and honest as they might be on an anonymous online forum.

Overall, it seems from the evidence provided in the studies analysed that the best ways to provide support to family caregivers are by providing social support to reduce risks of feelings of social isolation, and also to expand the knowledge that the caregiver has on the disease in question. They can also benefit by learning recommended ways to deal with feelings of psychological morbidity and feelings of grief or challenging behaviours displayed by the patient. From looking at the self-reported experiences of caregivers it seems evident that online forums have the ability to increase opportunities for the caregiver to find support and to speak in an honest and frank way, through the benefits of anonymity. The benefits of forums have been seen to be prominent in a care context, and to explore this further a qualitative analysis of dementia caregiver's forum posts is undertaken in the present study to gain further insight of the issues experienced by dementia caregivers and the ways in which forums are used by people who are looking for support and advice.

## Methods

### **Participants and Materials**

The information used in the present study is from forum posts taken from two dementia discussion websites: <https://www.dementiaforum.org> and <https://forum.alzheimers.org.uk>. These posts were selected from within the time span of a year, between August 2017- August 2018. The participants' posts were selected on the basis of them being family caregivers to a relative who has lived at home while suffering from dementia. There is no discrimination on the age or sex of the participants or their relationship to the person being cared for (other than the requirement for a family relationship). On [dementiaforum.org](https://www.dementiaforum.org) the posts were selected from under the subheading "family and home caregivers" and on [forum.alzheimers.org.uk](https://forum.alzheimers.org.uk), under the subheading "I care for a person with dementia". All identifiable information has been anonymised to respect the privacy of those posting. If anybody posting has stated that they do not want their post to be used for research then their post has not been selected for use in the present study.

### **Analysis**

This research was conducted using the qualitative method of thematic analysis in order to identify patterns and themes in the forum data. Thematic analysis is often a method credited to Braun & Clarke, (2006) and consists of several phases of 'coding'. Braun and Clarke (2006) identified how thematic analysis can be used in qualitative research in the psychology field and identified the stages used to complete the method. These stages begin with the researcher familiarising themselves with the data and then identifying words and phrases that are relevant to the aim of the research. These codes are then

sorted into overarching themes that accurately represent the data, and the themes are defined into what they infer in regards to the study. Themes are chosen according to how relevant they are in regards to making meaningful contributions to the research kept in mind, and any gaps in the coding are to be explained and focussed upon. In the present study, the forum posts were reviewed and key words and phrases were identified. These key words and phrases were interpreted into many subthemes to define the feelings that the users of the forums were expressing through their posts. The subthemes were then grouped into over-arching themes just as the Braun and Clarke (2006) stages suggest and these overarching themes formed the results of the present study. This method has allowed several themes to be identified that can provide an insight on the experiences and struggles of family caregivers to dementia patients.

### **Reflexivity**

There could be many issues with reliability and honesty when using forum posts to conduct the present study. Due to the personal and intimate nature of the forum posts, it could be unlikely that the people posting would admit wrongdoings on their own part. In turn, it might be common for the person posting to paint themselves as a victim of their circumstances and attempt to gain sympathy from the other forum users. On the other hand it could be argued that forum data could be a more raw and genuine form of data than alternative data that can be used in this type of research. The individual's likeliness to express themselves honestly is greater through forum posts than other forms of data such as surveys or questionnaires due to the freedom that forums allow (Pendry & Salvatore, 2015). The fact that a person's anonymity can be preserved on a forum may allow them to be more open and honest than they otherwise would be, alongside the fact

that forum posts tend to be written by an individual on their own, without pressure from other people seeing what they are typing. However, despite this anonymity and room for honesty in the forum posts, the posts are usually relatively short and therefore full context is not given. This means that the posts could be interpreted in a different way to how they were intended as there is only a limited amount of information that the individual is able to share at once. In addition to this, it could be argued that forums are beneficial in comparison to other forms of data such as questionnaires as when answering a questionnaire, people are likely to look at their situation as a whole, whereas when using a forum, people are more likely to post in a reactive way to their current situation, causing there to be a more raw and relevant reaction to their situation and also making it easier to express emotion in this form.

In my personal experience as a family caregiver, I have found many of the issues found in the literature shown in the introduction of the present study to be accurate to my personal situation. During my time caring for my Father who suffered from dementia I experienced family feuds, social isolation, financial struggles and many symptoms of psychological morbidity. A prominent problem I faced when caring for my father was stress and the problems that this stress caused, I found myself struggling with my university work due to this, isolating myself from the people around me and becoming ill (suffering from shingles and other illnesses) during this time. It could be possible that my role as the researcher of this study could be tainted by my personal experience as my bias may lead me to empathise and relate the experiences of others to my own experiences. It is possible that these experiences have also caused me to be biased in my selection of the forum posts used, despite attempting to select posts purely because they are about a family member caring for someone with dementia.

## Results & Discussion

Through the process of thematic analysis, five main overarching themes were identified from the forum posts that were used as the data during the present study. These themes are: Psychological Morbidity, Expression of a need for help from others, Social isolation, The Desire for more Knowledge and lastly, Anxiety.

Table 1: shows the overarching themes that were identified from the data set and the smaller groups that were formed through the content that define these.

<b>Overarching Themes</b>	<b>Groups from Content</b>
<b>Psychological Morbidity</b>	Depressed, Upset, Miserable, Sad
<b>Anxiety</b>	Anxious, Worrying about being selfish, Worrying about wellbeing of person, Not knowing who can help, Asking questions
<b>Social Isolation</b>	Lonely, No time for socialising, Not wanting to burden family/friends, Exhausted/ tired
<b>Desire for more Knowledge</b>	Want to understand/learn, Continuous learning, Asking questions
<b>Expression of a Need for Help from Others</b>	Not coping, Complaints about lack of help, Not wanting to burden family/ friends, Not knowing who can help, Family conflict

The process of generating themes involved highlighting significant words and quotes throughout the data set and then grouping them together to find the content of the themes that have been identified in the present study. These five overarching themes create an interesting summary of the primary issues faced by the caregivers using the forums in question and also can be interpreted to give an insight into the main reasons that the forums are being used. From this it is possible to deduce ways in which caregivers might be able to be helped to reduce the negative psychological effects that the caregiving lifestyle can cause.

### **Psychological Morbidity**

Psychological Morbidity is the first overarching theme identified through analysing the forum posts. The content of this theme from the data set includes groups of phrases that are: feeling depressed, feeling sad, feeling upset and feeling miserable. The theme of Psychological Morbidity relates heavily to the literature previously mentioned in the present study that claims feelings of psychological morbidity are prominent in family caregivers of dementia patients. The content from the data that lead to Psychological Morbidity being identified as a main theme include groups that were formed by looking at several quotes that were found from the posts that were studied: "Every day I feel very sad and as though I have lost my Mum altogether" (Post 42) and "I'm sad, tired, drained, exhausted, fed up, angry, frustrated, ill, depressed, over sensitive, miserable and very sad" (Post 43) are examples of the forum users' displays of negative feelings and therefore, can these quotes can be used to define the theme of Psychological Morbidity.

When reviewing the forum posts, it becomes evident that many of the reports of sadness, anger and frustration that have been included in the bracket of psychological

morbidity are mentioned in relation to challenging behaviour being displayed by the person that the forum user cares for. This challenging behaviour includes aggression, refusal of help from others and the patient attempting to escape from the home. “She refuses all help and gets angry” (Post 24) is a quote from the forum posts that serves as an example of this challenging behaviour. This confirms the claims in the study by Brodaty & Luscombe (1998) mentioned previously, that suggested that challenging behaviour from dementia patients and the levels of psychological morbidity in their caregivers could be directly linked. However, it seems from the evidence shown in the forum posts that psychological morbidity could be detected and identified from most if not all of the forum posts used in the present study. It is the case when analysing the forum posts in the present study that these negative feelings are often expressed whether challenging behaviour is mentioned or not. Therefore, although challenging behaviour may be a contributing factor to psychological morbidity in caregivers, there seems to be more factors that contribute to this. These other factors could be identified through further focus in future research on the psychological morbidity of caregivers that could look into other causes of negative emotional feelings in caregivers of dementia patients and the reasons behind them.

### **Anxiety**

Anxiety is often mentioned in the forum posts, as people express their worries and concerns about their lives and the lives of the people that they care for. The content of this theme from the data includes worrying about being selfish, feelings of guilt, worrying about the wellbeing of the person that they are caring for and not wanting to burden family and friends. “I’ll just worry the whole time.” (post 40), “I still worry about

dad all the time” (post 28) and “I worry who will care for me when anything happens to him, and more importantly who will look after him if I’m not here?” (post 16) are three quotes from the forum posts that represent the concerns that the users express about what could happen to either them or the people around them, and show that anxiety should be considered a prominent issue in family caregivers of dementia patients.

Anxiety is an issue that is commonly mentioned in association with depression in the literature on the subject. In the present research, it was found that the forum users posted more about being worried about various aspects of their lives and the lives of those they were caring for than they mentioned feeling depressed. Depression was also identified as an important issue in itself that was mentioned throughout the data during the thematic analysis process – albeit a less prominent one. It was found in previous studies on the subject, that the closer the nature of the relationship between the caregiver and the person being cared for, the more anxiety and depression they experienced (Fitting, Rabins, Lucas & Eastham, 1986). This could be an option for further research on the subject, as the present study has only analysed the general problems that caregivers face when looking after a family member who suffers from dementia. However, it could be helpful to focus on the differences in the issues faced by caregivers in relation to the varying types of relationships that they are involved in with the person that they care for.

Additionally, it is important to recognise the distinction made in the present study between anxiety and psychological morbidity. It could be possible to include anxiety in the bracket of psychological morbidity, however it becomes clear from looking at the table above that the content of these two themes are easily separated. It becomes

evident with the content of the theme of Anxiety when looking at the forum posts in question that this theme becomes a significant issue in itself, and needs to be addressed separately. A clear pattern is created through identifying examples in the posts of people saying that they are worried about various aspects of their lives.

### **Social Isolation**

As stated in the above literature, social isolation is a significant problem regarding family caregivers to dementia patients and this is confirmed by social isolation being identified as an over-arching theme in the present study. The data content from the forum post analysis that supports this includes: feeling lonely, having no time for socialising, not wanting to burden family or friends and feeling tired. "I get resentful, tired and fed up of not having time for my family" (Post 40) and "I've pretty much cut myself off from people and feel so lonely" (Post 45) are both quotes that serve as examples of users of the forums expressing their feelings of social isolation. The forum users throughout the posts studied are often expressing that their care responsibilities prevent them from socialising in what is considered a normal way, and this shows clearly why Social Isolation is an important theme that is evident from the forum posts in question.

At this point in the summary of the subthemes, it becomes clear that there are subsections to the overarching themes that were found during the analysis of the forum posts. The previous three themes have identified issues in which the forum users suffer from due to their lifestyle as family dementia caregivers. Anxiety, Psychological Morbidity and Social Isolation are all psychological issues that the caregivers complain throughout the forum posts that they are suffering from, however, the next two themes represent a different interpretation of the forum posts. Needing Help from Others, and the Desire to

Learn are both themes that represent the main uses of the forum that were identified through the thematic analysis process. Therefore, the focus of the themes shifts from the issues that the forum users suffer with, to the ways in which they use to forums to try and combat these issues.

### **Needing Help From Others**

Needing help from others is the next prominent overarching theme that becomes a clear issue for the caregivers posting in the forums studied. This theme was established by recognising several groups that form the content of the theme; these include not coping, complaints about lack of help, not wanting to burden family or friends, and feeling tired. This expression of a need for help is mentioned often in the forum posts, with quotes such as "... I'm at a loss on how to manage or help him ..." (Post 31) and "It took having to call out the crisis team to help us cope with his hallucinations and the constant voices in his head telling him to kill himself" (post 30) are examples of the participants expressing their need for assistance. Alongside this, the ongoing trend throughout the forum users' posts asking other users for advice (posts 11, 12, 41, 48, 49, 50) helps to form the content that supports this overarching theme. The requests for advice from other users is interpreted in the present study as a cry for help, and a sign that the forum users are lacking help from both authorities accessible to them and people that they know personally. Therefore, the pattern of forum users asking other users for advice on where to find help or what to do can be used in order to define this overarching theme.

This overarching theme of a need for help from others could be interpreted as being the primary reason for people using the two dementia forums. Pendry & Salvatore,

(2015) confirmed in their study that a primary use for discussion forums is to seek a form of social support and information that may not be available to the forum user in their own social circle or community. Through looking at the forum posts included in the present study, there is a surprisingly small amount of posts that mention help that they have received from authorities in a positive light. Many of the mentions of external authorities involve complaints of a lack of assistance from these bodies, and this is also a common complaint of the users when mentioning other family members. "...their mismanagement of my husband's care so that I made a formal complaint" (Post 30) shows an example from the forum posts of somebody who feels discontent about the professional help that they have been receiving. From this it can be assumed that the users do not find the help that has been made available to them sufficient to fulfil their needs and give them relief from the other problems that they may be experiencing in the caregiving role. These different issues that may be relieved by external help are also outlined in the other overarching themes mentioned in the present study.

### **Need For Help From Others**

When looking at the data used in the present study, the overarching theme of the need for help from other people is common throughout the forum posts studied and is often mentioned hand in hand with people asking who they can turn to, or complaining of the lack of help that they have received off others. This theme and the theme of social isolation are two themes that can easily be linked together by establishing that people feeling alone and without sufficient help in their caregiver role is often the cause of the feelings of social isolation. A solution to this problem could be for more help to become available to those caring for a family member with dementia in the form of carers coming

into the home, or more options for respite. These additional forms of assistance would allow the family caregivers to have more freedom and time to ensure that they are being more socially active than they otherwise would be.

The desire for more knowledge of how to effectively care for a person with dementia seems to be a prominent reason for the use of online forums when looking at the literature written on the subject (Coulson, 2005) and this is no exception in the results of the present study. The overarching theme of the caregivers' desire to learn more about their role is found through the identified groupings of content that support this as a main theme. The groups of content identified include: wanting to understand, the idea of continuous learning curves and simply the fact that the majority of the forum posts studied include the caregiver asking other users of the forum questions. As mentioned when looking at previous overarching themes, asking for advice from other users is repeatedly shown in the forum posts, and displays a need that the users feel to learn from each other (posts 11, 12, 41, 48, 49, 50). Phrases such as "I ought to be able to understand" (post 39) and "I don't know what to do" (Post 1) could be interpreted to show the struggle that the users are feeling in their lack of knowledge of their role.

This theme could be mistaken as overlapping with the theme of 'needing help from others', and while defining both of these themes has included interpretation of much of the same content from the forum posts, they have very different meanings. The nature of the theme of wanting to develop further understanding of dementia and the dementia caregiver role is expressed through the forum posts by the participants explaining that they do not understand and wish that they could. This desire to learn is also shown by the users asking others to help extend their knowledge on the subject by

asking questions and asking for advice from them. However, the theme of needing help from others, while also being partly expressed through asking advice from people in similar situations to themselves, deals more with the need for physical help from others as a way to gain relief from the caregiving lifestyle rather than wanting to expand their knowledge on the subject of dementia. Therefore, in the present study, these two themes are distinguishable from each other, reflecting two separate uses of the dementia forums.

The benefit of education is a subject that is prominently focussed on in the literature on the subject of dementia caregivers and the problems that they face, and this desire to learn seems to be a common theme throughout the forum posts used in the present study. The study conducted by Saad et al., (1995) that identified that people with greater knowledge of dementia tended to have lower expectations of the people that they care for, established that caregivers with a greater understanding had a more understanding nature and therefore suffered less from psychological morbidity issues than others with a lesser knowledge of the illness. The forum posts show that there is a common desire of those in a dementia care giving role to develop greater understanding of the illness by them asking other users of the forum what advice they can give on the subject. Throughout the posts, users often discussed that they have asked professional bodies questions on how to care for the dementia sufferer (doctors, professional carers etc.) and this can be interpreted as the forum users asking these questions in the hope that a further understanding of dementia would help them to improve in their caregiving role; improving the life of the person they care for, and improving their own life at the same time.

The theme of social isolation could be easily linked to another overarching theme previously mentioned: the forum users expressing a need for help from others. The causes of social isolation could be seen as being the same reasons that cause the caregivers to not be able to reach out for help from others. The outcome of the study by Ory, Hoffman, Yee, Tennstedt and Schulz, (1999) was the conclusion that dementia caregivers spend significantly more hours a week in their care role than non-dementia carers. This could be interpreted to mean that this lack of spare time causes social isolation to be a significant issue in the dementia caregiving role in particular. It could be argued that the time consuming nature of the dementia caregiving role could be seen to prevent dementia caregivers from having the time to seek social support or spend the time looking for where they can find external assistance.

This social isolation factor can often cause caregivers to struggle with retaining close relationships well enough to feel as though they are able to ask those people for help and therefore these two themes can be linked (Cacioppo & Cacioppo, 2014). The experiences of social isolation also prevent caregivers from maintaining what would be considered as normal relationships with friends or family members that would usually allow them to have a break from their home life, which could potentially cause feelings of psychological morbidity or depression that are significant in the issues that dementia caregivers face daily. Research has confirmed the effects of loneliness and social isolation on mental health. In the study by Losada et al., (2012) it was established that when looking at a group of elderly Spanish people, loneliness had a significant effect on their mental health, with social isolation correlating with feelings of psychological morbidity, anxiety and depression.

Depression is a mental health issue that is frequently mentioned in the literature regarding the issues faced by dementia caregivers. However, in the present study there is little mention of depression in the forum posts analysed and therefore from the present study alone, depression appears to be a less prominent issue amongst dementia caregivers than it is otherwise claimed to be. This does not necessarily mean that depression should be ignored as a major factor in the present study and could potentially be detected from the quotes and phrases used to identify the overarching theme of psychological morbidity. Due to the nature of the forum posts, and the main uses of the forums- to ask others for help and expand knowledge on the dementia caregiver role, it may seem unlikely for forum users to mention serious psychological issues or clinically diagnosed mental health issues that they are suffering from. Forums are often used as a sounding board to speak about immediate reactions to situations and this causes raw emotions to often be expressed in the forum posts rather than general feelings and ongoing issues that the caregiver may be suffering from. It could be argued that questionnaires could be a better way to collect data on specific issues like depression due to serious mental health issues being a subject that may need to be identified through direct questions on the subject, rather than people freely talking on a forum.

In relation to this, a unique benefit of using forum posts as the data set for analysis is made clear through the way in which forums are often used. Forums are often utilised as a way to post something instantly that reflects a person's immediate feelings at that exact time. People often use forums as a way to get their thoughts and feelings out of their system after an event or while they are feeling distressed or down as a way to vent their feelings and relieve stress. Therefore, using forum posts in order to conduct the present study allows a unique insight into the lives of family caregivers that other

methods of research may not be able to recognise. When being interviewed, a participant may feel that they would be getting judged by the interviewer for what they are saying and may not be as honest when sat face to face with somebody as they would when typing their feelings onto a computer screen. Similarly, when using questionnaires to conduct research on the issues faced by family caregivers, these are unlikely to be filled out at a time when someone is feeling a high level of emotion and may ask general questions, concerning 'the last week' or 'the last year'. Therefore, the themes of the present study may be able to provide interesting information and a focus on different aspects of the lives of the participants than could be identified through other methods of research.

The role of social support is significant when looking at the use of online forums. The people using the forums in the present study often ask if others have experienced the same as they have and ask for validation for their feelings. The forums are also often used by people attempting to gain confirmation that what they are experiencing and feeling is normal, and experienced by others in similar situations. Coulson (2005) found during his research on online forums that people use forums to participate in a supportive network of people with similar experiences to find a form of social support that they are otherwise not able to find in their usual social circles. From studies such as Coulson's and the present study, it could be argued that forums are a very useful and unique method of gaining this sense of confirmation as by nature, forums are a large database of people who all have an experience in common. Many of the replies to these posts asking "is this normal?" were seen to be people attempting to comfort those posting. This idea of normality is often comforting to people in difficult situations and the social support received by those using online forums could be proved to be useful in

reducing the effects of many of the overarching themes that have been identified in the present study such as social isolation and feelings of anxiety (Powell, Chiu & Eysenbach, 2008).

When utilised properly, it is clear that the forums are used by many people as a way to reduce their feelings of social isolation by accessing opportunities of social support and through talking to other people that might be considered to be likely to understand the experience they are going through. However, this may be seen as a way for caregivers to experience an escape from their feelings of isolation, but cannot claim to totally reduce the feelings of social isolation experienced by caregivers of dementia patients. Marziali and Garcia (2011) found in their study that video forums had a greater effect on reducing mental health issues and feelings of social isolation than text forums, and from this it could be argued that face to face communication is more beneficial to those experiencing feelings of loneliness than other forms of communication- and therefore the existence of more video forums could be a step in the right direction for helping those in the dementia family caregiving role, particularly when leaving the house to meet others is not a viable option.

A prominent reason for the forum posts being used to express feelings and emotions so regularly could be due to the benefit of anonymity that the forums provide. Bertera & Littlefield (2003) have shown that the majority of students reviewing the effects of anonymity on online discussion forums found that being anonymous on forums increases the honesty of the posts and can also have other benefits including positive impacts on relationships with others that are using the forums (in the case of this study, the participants' own classmates). Research like this on the effects of anonymity confirms

one of the implications of the present study, that the cloak of anonymity provided in the forum posts causes there to be more honest and frank responses, where people are able to express their feelings and emotions without fear of judgement from others.

There are several limitations to the present study, despite the many benefits of the method used. Thematic analysis in itself is a very subjective method, meaning that other researchers could conduct exactly the same study on the same forum posts and achieve entirely different results; this is a common issue with this method of research (Guest, MacQueen & Namey 2012). The use of forum posts can bring many benefits such as the honesty, reflections of emotions and detail that forum users feel they can express under the cloak of anonymity, however the short length of most of the forum posts causes there to often be little context and the entire situation that the caregiver finds themselves in cannot be reflected through these short posts. Case studies would be the only other form of data that would be able to reflect the full picture of a caregivers' situation, and may be able to allow the researcher to gain a more in depth insight into the thoughts and feelings of the people involved. Additionally, an important limitation of the present study to note is that the use of forum posts restricts the participants to people who have access to the internet. This could exclude people in the older generation who do not own a computer or have internet access, or people without sufficient finances to afford this. Out of the people with internet access, this study also only takes into account people who are aware that forums are available to them, and that feel comfortable enough to use them. Therefore, the set of participants used in the present study is limited and may not be a fair representation of dementia caregivers in society.

A pattern found through the data set that was identified in the present study and was identified frequently throughout the forum posts was the theme of not coping. This was a phrase mentioned often throughout the forum posts which can be seen as being a significant problem for the forum users. This smaller theme was considered in the process of identifying the overarching themes as it is so frequently mentioned in the posts and is therefore significant in the identification of the feelings of the dementia caregiver forum users. However, the theme of not coping fits well into several of the overarching themes that were identified and is therefore seen as more of an underlying theme that can be used to identify many larger issues faced by the caregivers. The pattern of caregivers complaining that they cannot cope must be considered as a significant finding in the data set despite its role as a supporting theme. Perhaps further research would be able to conduct a similar piece of research to the present study in order to focus more heavily on the idea of not coping in dementia caregivers and the reasons behind this, and possible solutions.

Another pattern of content that is identified in the forum posts is the theme of family conflict. This theme is also identified in the literature (Ory, Hoffman, Yee, Tennstedt and Schulz, 1999) as a problem that is specifically prominent in dementia caregiving, as the amount of time that dementia caregivers have to spend caring for their patients makes it more likely that they are going to experience family conflict than other caregivers to non- dementia patients. Family conflict as a pattern in the data could be linked to the overarching theme of social isolation as often, family conflict can cause divides in the family that would isolate the caregiver further. The family issues experienced by the caregiver may also cause them to feel the need to seek help from others as they feel as though they are not able to call upon other family members. Family

conflict is a significant issue for family caregivers and can be seen as a major contributing factor to many more general issues that family dementia caregivers face on a daily basis.

## Conclusion

In conclusion, the overarching themes identified in the present study could be interpreted as a fair reflection of the problems faced by family caregivers of dementia patients, and these include social isolation, anxiety and psychological morbidity. These themes also identify some of the primary reasons that the caregivers use the dementia forums, including expression for a need for help from others and a desire for knowledge on dementia. The uses of the forums are reflected in the literature as ways in which the negative mental effects that the caregiving role can cause can be combatted, through the expansion of the individuals' knowledge on the subject and the increase in outside help.

Upon reflection on the analysis of the forum posts in the present study, it is apparent that the use of forums to explore the issues faced by family caregivers can provide a unique insight that is difficult to achieve with other forms of data. The informal nature of the forums and safety that the users feel from the benefit of the anonymity that the forums provide allow frank and honest entries from the forum users without fear of personal judgement from others. The users seem to feel able to admit their negative feelings about those they care for in a way that they may feel less able to do when they do not have this cloak of anonymity. Therefore, this form of data analysis can show a refreshing and honest reflection of the thoughts and feelings of dementia caregivers.

However, there are many options for future research on the subject of the issues faced by dementia family caregivers that could focus more heavily on many of the issues mentioned in the present study. Further research on the causes of psychological morbidity in dementia caregivers could be an example of this. Overall, it seems from the issues identified in the present study that dementia caregivers are calling out for more

accessible external help and information to assist them in what is an important and difficult role and the psychological issues that develop alongside this.

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Appendices**Appendix A**

Patterns found in forum posts used to identify overarching themes.

“not coping”	1, 17, 23, 33, 41, 50
Exhausted/ tired	1, 43, 25, 35,
Guilt	38, 44
lonely	45, 38,
depressed	39, 43, 45
anxious	45
Need help/ complaining of lack of	3, 5, 10, 24, 31, 38, 43
Family arguments/ feuds/ causing problems in family	19, 1, 8
Not wanting to burden family/friends	37, 45
Upset	27, 43, 25
Worrying about wellbeing of person	28, 16, 20, 35, 44
No time for socialising	34, 33, 8, 35
No Time for self	36, 8
Worrying about being selfish	16, 35, 37, 45,
Miserable	25, 43
Want to understand/ learn	12, 4, 40, 3, 5, 12, 15, 23, 4, 41
Continuous learning	38, 2
Not knowing who can help	1, 3, 4, 5, 12, 24, 43, 44

**Appendix B**

Forum posts analysed in present study:

1

June 24, 2018 at 6:14 pm

Hello

Both my elderly parents have dementia my father is 91 with advanced vascular dementia and my mother is 89 with mid stage Alzheimer’s

They moved 400 miles to me last year as my mum was not coping, I did not realise at that time she had Alzheimer's. We looked after them in my home for 10 weeks and we were exhausted Dad eventually had to be sectioned because of his moods. I eventually put them into a care home but at over £2,000 a week they would soon run out of money and Mum was extremely unhappy being on a locked floor and couldn't even get out for a walk. So I built an annexe onto my family home, and they moved on on 23/4/18 I have now had to get a live in carer, as I have my own medical issues and I run a business from home.

The stress I'm under is intolerable I am constantly on high alert as the live in carer can't deal with 2 she's young and more interested in her laptop mobile phone and a block 2 hour break, 3 times I've now found my mother wandering the streets at night, the intercom is constantly buzzed and I'm constantly texted by carers or my mother.

I don't know what to do, it's affecting my wellbeing, my marriage and my adult children. I feel like I can't just stick them back in a home it would be so callous, and they have paid for part of the annexe, my brother who is a "joint but several " poa just moved to the Isle of Man and leaves me to do everything and all he's interested in is their bank balance. I don't know where to turn and what to do, has anyone else has 2 parents with different levels of dementia

2

February 11, 2016 at 10:23 am

My husband of 30 years has been going off about 'leaving' every week. He has been diagnosed with Alzheimers 5 years back. Initially I was affected by it and would cry at

night. But in the past few years I've learnt to accept that it is part of the illness and even have some fun with it. Just last week, he brought up the issue of 'leaving' again, saying 'im gonna walk out the door and never come back. I've had enough'. (Wonder who is the one who has had enough) I responded, 'And where would you go'. He said 'New Zealand'. I asked why and that sparked a hour long discussion of New Zealand and everything else. The conversation did not stay coherent most of the time but it was funny how a seemingly hostile statement turned into a conversation starter.

3

January 24, 2018 at 10:54 pm

Hello!

I am very concerned about my father. He is in his sixties. It seems that he has always been on the "suspicious" side of things. However, past couple of months his behavior has dramatically changed, making me worried that he might be experiencing dementia. Some of what he is experiencing/expressing are thoughts of persecution/belief that people are against him, paranoia about people breaking into the house and stealing from him, incoherent speech at times (not all the time), strange behaviors (e.g. sniffing toilet paper, not sleeping at night and constantly looking out the windows), belief that people steal and return stolen/different items (e.g. his hammer was stolen and replaced by a different one), belief that my mom is unfaithful. Some things have happened to us in the recent past which prompted us to buy security cameras. However, he is now using the security cameras to spy on my mom inside the house! My dad is difficult to talk to: gets explosive

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and thinks everyone is against him when we express our concerns. Or worse yet, he thinks that he is in the right and that we are trying to make him seem mentally ill. I do not know how to bring it up with his doctor and I do not think he will do it himself.

Signs of dementia, mental illness or? I am desperate for help.

4

September 28, 2017 at 6:49 am

My parent was recently diagnosed with dementia, so I shifted back to take care of her. Now that I am more aware of her condition, I noticed that she does not eat often or eats very little. When I asked if she was hungry, she would often say 'no'. I can see that she is starting to lose weight, and I am getting more worried about her condition. Fortunately, she doesn't lose her temper or behave erratically, so this is the biggest challenge for me right now. How can I get her to eat more? How can I know if she is truly not hungry? I'm very new to caregiving, and would appreciate any feedback. Thank you.

5

February 19, 2018 at 10:56 pm

My mother is 97 years old. My mom hasn't seen a doctor since she was 50 years old and that was only because she was allergic to her lipstick. She doesn't take any medications, not even aspirin!. Starting 2012 I noticed that she was neglecting her chores, like cleaning her room or taking a shower as she used to do. She started hoarding and would get upset if I tried tidying up her closet. She can still hold a simple conversation but her logic sometimes worries me and I'm afraid to leave her home alone because she might

hurt herself or leave the house and get lost. She lived a clean life and I have never seen her in a negative mood. She refuses to go to be evaluated and I don't know how to handle her dementia without getting her upset.

My husband is 92 and is a different story. He is a WWII veteran, takes several medications and understands that he is gradually losing his mind. He is legally blind and in the past two years has gotten worse. He sits all day listening to old TV programs and can't hold a conversation. He is very agreeable and doesn't get excited when things don't go his way. The doctor prescribed an antidepressant and it seems to be working for him, at least he wants to go places and tries to start a conversation which I encourage him to do even though it doesn't make any sense.

I forgot! They both can still feed and clean themselves, hopefully this won't change soon.

As for now, I don't have any help at home and when I have to go do some errands I have to take them both with me. They both go to bed by 4:30 pm therefore I have the rest of the day for me but I can't leave the house. I love them both dearly but sometimes I feel like running away!!!! My healthcare provider suggested some sessions with a therapist but I can't afford the copayments.

6

April 3, 2018 at 5:46 pm

My biggest challenge as a caregiver is to remain calm during the times that my loved one goes through one of her daily mood swings. She is only 58 years old and has early onset dementia. When she's her normal self, she is friendly and agreeable. I don't think that

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she has ever met a stranger. That part of her personality has remained intact. Now she gets agitated and disagreeable when I try to get her to take a shower or if I try to see if she needs to have her underpants changed. She can really become irate and five minutes later she may have a crying spell and afterwards she seems to be okay again. Her mood can change instantly like Dr. Jekyll and Mr. Hyde. It's unbelievable to witness sometimes.

7

March 28, 2018 at 6:51 am

My mother has been suffering from dementia for the past 2 years. Although she has dementia, she is pretty healthy. Since she eats food, we don't have much worries regarding her physical health. I have heard a lot of people struggling hard to feed their parents who are suffering from dementia. Recently, she started playing with the soaps that are placed in the washrooms. She soaks the soap in the water and then pours the soapy water on the floor. Last day, I was about to slip and fall because of this soapy water on the floor but God saved me. Then my wife came up with the idea of wall soap dispenser. I also felt that as a good choice. What do you people think about it? Is there any chance she will be playing with those too?

8

November 6, 2017 at 3:55 am

Hi All, I am trying to out whether other caregivers have come across family with dementia that have a irrational or exaggerated fear of falling or of anticipated pain.

My granny has fallen twice and now whenever we lower or lift the bed she screams her lungs out that she is falling. There is tears in her eyes so to her it is a rational fear but to us it is irrational because she is in a bed and there is no risk of falling. her screams stop as soon as the bed stops moving and she behaves like nothing happened.

She also has the same issue with pain, her hip operation is probably still a little sore however she screams like she has lost the leg. We have had her checked out, x-rays doctors etc. It seems to be a psychological issue because just a touch results in a scream of pain. Even before we touch her, if she knows she will be touched in a sore spot, she screams that she is in pain. Her screams stop as soon as we stop touching her which indicates to us that if the pain is there, it's not really as intense as she makes out.

This is obviously tiring on our family because she startles everyone and we are afraid to do much which affects her mobility and leads to stiffness. We either leave it or push through with her screams ringing in our ears. I see people passing by look up at our window because she is that loud.

I would love to know if anyone has come across this and whether they tried any strategies to help manage this fear.

9

December 8, 2017 at 7:50 pm

I live with my nan whom I grew up with and am a full time carer for her. I love her lots but I have to say that it can be mentally draining. These days she is often not satisfied with what is on tv and will complain about it. Sometimes i will change many channels for her

55

but she gets frustrated. Sometimes she will switch between radio and tv for a very short time. My nan enjoys listening to her music and i put music on for her everyday. I feel like she could listen to her music most of the afternoon/evening, but i cannot take that. I was thinking of sorting out an i pod with music on for her so sometimes she can listen only to herself.

10

February 22, 2018 at 9:50 pm

Hi, my mom was diagnosed with Dementia at a younger age. She is still high functioning and it seems she now is concerned with independence and giving my father a hard time when he tries to help. We are having him start participating in a caregiver support group soon. I assume the independence is a big thing for dementia patients and therefore is very common. My father has tried to make sure she takes the medication daily but my mother has become very argumentative with him for checking on her with this, so he feels that she may not be taking the medication properly. I was wondering how other caregivers have gotten past this with their spouse? She just won't let him help and gets extremely angry at him when he tries. Any help would be greatly appreciated

11

September 25, 2017 at 6:07 pm

Bear with me as I am very new to this. My mom was diagnosed with frontal temporal dementia nearly 2 years ago when she was 59. Things have been progressing and my dad cares for her mainly but recently she is not sleeping/going to bed at all. She sits up all night but recently has been leaving the flat at 4am. More by luck dad has heard her but

he needs to rest. The other morning at 6:30 he was woken up by his door buzzer and it turned out to be mom stuck outside. Dad has been told that by law he cannot change his locks due to being a second floor flat. Can anyone offer any advice as to how we stop mom wanting to leave the property. Many thanks x

12

March 28, 2018 at 7:41 pm

Hi everyone,

My grandmother was just diagnosed with Dementia at the end of January and I am helping my single mother look for local resources and get advice. We had begun noticing changes a couple of years ago but my grandma has gotten much worse over the past half year. She is currently living at her home about 20 minutes away from ours. My grandfather passed away a couple of years ago so it is mostly just my mother and, to a lesser extent, my aunt caring for her.

Honestly, my mother is very overwhelmed right now between work, supporting my brother and I, and supporting my grandma. We really don't know what to expect or how to even get resources or advice. We are living in the suburbs of Philly btw. I want to help out my mom as much as possible and understand what needs to be done.

What are the things we should be doing right now for my mother? What are the things we will need to plan to do in the next couple of months and what should we expect?

Where should I go to get connected to resources (in PA)?

Anything advice or tips/resources would be extremely helpful!

13

Feb 18, 2018

A lot has happened with dad in the last 3 months. I suppose his brain has finally reached the point where there is nowhere for it to redirect to and he is so confused. The poor man, I should be sympathetic but I feel angry. I don't show him I'm annoyed, just put my game face on and carry on as normal.

"Normal" is now dad is incontinent but doesn't believe it. I admit I've had a wry smile at some of his excuses as to why he's wet!! He doesn't know day from night, which wouldn't bother me too much if it wasn't for the little walk he took at 2am the week before last. I dread going to see him. Yesterday I went at 2pm to see if he wanted to come for tea and he was making his breakfast. Tea, boiled eggs and toast with butter and jam. So he can obviously still feed himself.

I changed his wet bed, put his smelly pants and trousers (that he hasn't weed on) in the washer and I'll be going back shortly to do it again...

He doesn't shave anymore and because he's "not incontinent" he re-wears his clothes after he's dried them if I don't get them into the wash first. He can't smell. I can!!!!

I've given up drinking alcohol for a year because the stress of looking after dad was leading me to use it as a crutch, and I've put on 3 stone while I've been caring for him and my right knee is giving me gip again, an ongoing problem but not helped by the weight increase.

And just to add insult to injury both my daughters have fallen out so the atmosphere at home is grim.

Roll on Monday morning when they're at work and I get my day off!!!

Jul 31st 2018

[name] delusions/confabulations are getting more and more extreme - though Thank god, she isn't finding them upsetting and they are not stressing her out at all. But the sheer 'strangeness' and the absolute lack of logic behind them is breathtaking.

Just yesterday, we had her asking when her next exercise session was - you know, the one where she and the dog go to the gym!

We had her frantically looking for the 'Christmas Mobile phone' she had bought - she showed it to me, she said - the red one, that she is allowed to use to phone her brother at Christmas.

Last night she leapt out of her seat to go and 'clean that room'. What room? The one upstairs, where we play ten pin bowling, apparently - oldest daughter caught that one - I walked in to find [name] demanding that daughter accompany her up the stairs so she could SHOW her the bowling alley, and [name] then insisted that I went too. She went in every bed room, bathroom too - even opened the landing cupboard - but wasn't that worried when it couldn't be found.

This morning, she is worried about getting to her job at the theatre on time - the theatre where she wears the blue dress on the stage and there are horses

Because she isn't upset, then it doesn't worry or upset me, and its not stressful to deal with - but I am seriously puzzled by where on earth these odd ideas come from!

Dec 26, 2017

Not entirely down to the dementia, but something we could have done without! Found mum very pale and very clammy in her recliner yesterday afternoon. She was still able to stand for a transfer though so we went onto the commode and she had the largest bowel movement ever - first it was normal looking, but a lot of it, and then it was diarrhoea.

There was another bout of diarrhoea later. I was quite pleased that both had been dealt with on the commode so put her to bed and popped out quickly to get some food in - when I got back she'd had another bout in bed! I waited for the carer as I just didn't know where to start on my own, fortunately it was one of the very good ones and we got stuck in together, cleaned her up, washed her, changed her and changed the bed, all with her in it - would never have been able to do that on my own, or if I'd had to, it would have taken me hours. Thought all well, until this morning. I woke up around 6 and thought I'd better look in on mum - she had vomited in bed (thank goodness only a little, and to the side) and another bout of diarrhoea! Carer due in a few hours so I got her out, amazingly she could still stand, so I transferred her to the commode and cleaned her up, washed her, and then ... she vomited all over the clean clothes and all over the floor! Waited for carer then to help me do it all over again. More sickness and diarrhoea later, but now the flow seems to have subsided from both ends. I've only given her water, herbal tea and a salty clear soup today. I really hope tonight is quiet.

I think I know what caused the upset, but I need to see the GP again about the amount she stores in her bowel - it can't be healthy and it must be really uncomfortable for her, but unfortunately she doesn't seem able to tell me any more, though I keep a record so I know when something's due. I've tried prune juice and that doesn't seem to work well

enough to keep a regular movement through her bowel. I was using Lactulose morning and evening. Now, I don't really know how that worked, but just the fact that she had stored so much up, tells me that perhaps it wasn't working so well, or maybe I need to just give her a small dose, once a day. I took a photo of the commode pan so that I can show her doctor what comes out! I don't know whether an enema might be possible if I feel there's nothing coming out, or maybe I just need to keep trying different types of laxative in small dose, until I find something that keeps her regular. It's a real nightmare to manage! We eat a good, healthy diet - fish and chicken, vegetables, porridge/cornflakes/eggs for breakfast. I don't think I can really feed her more healthily, but can't seem to get her bowels working properly. She has no idea now if or when she has passed urine or had a bowel movement, and I am pretty sure she can no longer push it out. Poor mum.

16

Jun 26, 2018

Now we have the Alzheimer's diagnosis, at last, they have decided they won't medicate because of the health issues with his kidneys and bladder. We know that his upcoming surgery next month is likely to affect his dementia. I think the assumption is that he is in the early stages of dementia, but he does so many things that make me question if he is further down the line? And, where will we be post surgery? Things won't get better, they can only stay the same if we are lucky, but past experience tells me that he could deteriorate quite a lot.

It's just such a frightening worry.

So many things he just can't do, he can't work things out, he repeats things, he obsesses over things, his poor balance and mobility, his aggression when he looks like a different person, and quite honestly he scares me.

I spend my whole day, 7am to 10 pm looking after him, nights I'm on edge as he is urine incontinent and I never know what the morning brings.

I love him but I feel selfish. I worry who will care for me when anything happens to him, and more importantly who will look after him if I'm not here? I can't leave him for more than 2 hours, 3 maximum. And then I worry if he is ok.

What sort of life do either of us have?

There is no foreseeable future.... it all feels so bleak.

17

Jul 9, 2018

Mum was admitted to hospital 3 weeks ago - short version is that we couldn't wake her up, called paramedics and into hospital we went. Mum was initially being treated for dehydration, possible chest/uti infection. The weeks before being admitted she was eating and drinking less despite my attempts to feed her, walking with a frame had gone to shuffling and that was only to get her up out of bed or put her to bed at night, her carers were unable to persuade her to stand up in between those times. I would have said that at that point she was probably starting into the late stages of dementia (she has vascular).

In the 3 weeks that mum has been in hospital she has rapidly gone downhill to such a stage there have been many times that I expected (and wished for) a phone call to say

that she had passed away - she is hardly eating anything now and drinking even less, she has difficulty moving her arms, she is unable to talk and I'm not even sure if she knows who her family are. When I talk to her there is no reaction at all and the nurses are using a hoist to get her out of bed to sit in a chair and to hear her cry out is something I never want to hear again. The infection was a chest infection and that has cleared up, she has had a ct scan and that shows no or little change from the one she had in January and the doctors are now saying that as far as they are concerned she is "medically fit" for discharge. So we now have a decision to make and after discussing the whole situation with my brother (who lives with her but does next to nothing to help) I feel that we have no option but to start thinking about her going into a care home. This is now breaking my heart - I promised mum 3 years ago that she would never go into a home and I'm now breaking that promise. If this does happen will she understand where she is and know somewhere in her mind that I have done this to her? I have thought about her coming to live with us but I'm not sure I could cope 24 hours a day.

Do you think that mum is now coming to end of life or am I overthinking things- I just don't know, I've tried many times over that last 3 weeks just to hold her hand but there is no reaction, it isn't my mum who is sitting there just her body. God I wish she could just go to sleep and not wake up and if that sounds awful then I apologise, I want her suffering over

For anyone who has got this far, thank you for taking the time to read this

My dad is very ill with dementia. He sleeps most of the time, has some vague awareness of what is going on around him, but is mostly in some strange fantasy land from the past. He does recognise his children, still eats quite well, and is still just about mobile. He does have various other medical issues and we don't think he has long to go. The dementia came on quite slowly at first, maybe a year or two ago, but then he very rapidly deteriorated earlier this year. He was admitted to hospital from his residential home in February as he had really taken a turn for the worse and they could not cope. Also because a UTI was suspected, however, this was not the cause of his delirium. He ended up staying in hospital as the Residential Home would not take him back and in fact the hospital would not discharge him to there anyway. We had great difficulty finding a nursing home that would take him and the NHS finally found one for him after about 4 weeks in hospital. It's not the best, but it's good enough, and he has some carers who work really well with him. The problem is that it is very far from all 6 of his children - very far, but not impossible. He has been in the new home for just over two months now during which time his health has continued to deteriorate. Some of my siblings (there are 6 of us) have been looking for homes that are nearer and easier to get to, and have now found somewhere. What do people think about moving him again - it would be the third time this year...? Would the fact that he would get more frequent visits outweigh the fact that he will be confused and disoriented by the move? Or would it hasten him towards the end? I would really appreciate hearing what people think. Thank you.

19

Feb 19, 2018

The day of the Family Meeting

Day began with me calling SIL, married to OH brother who is the lawyer who drew of POA and our wills. Reminded her of the family meeting that night and wanted to give her the times. We meet at Son #1 house alone so OH won't see animosity, be embarrassed, or anything that would hurt him. We then go to my house and present a united front to OH. SIL said Brother had mentioned it but she would contact him. Later that morning I got a text saying he couldn't make the meeting and that OH "should be allowed to talk to a lawyer. I do not think that should be prevented. Also I feel you should include OH in any meeting about him. And I am not convinced that he has dementia. I provided That One the info on a lawyer." He could have slapped me in the face and it wouldn't have hurt that much. I became a basket case. I sent the benign response of "Thanks for your thoughts." Didn't add "You have just been removed from my life." Wife too.

Sent a children-wide text announcing time and date and the flack began among the SS (Sweet Sisters) and my two boys even threw some stuff right back at the Other One. Her rude text read "I will only attend meetings that dad attends and where the purpose of the meeting is shared. This the first I have heard that this meeting was scheduled and am unable to attend." L I A R. She had called Son #1 to discuss what was happening so he wrote back "You know the purpose" Son#2 wrote back "And ignored the request for your availability." She didn't stop "I will not attend meetings behind my dad's back. The purpose was not shared. I have heard guesses and assumptions from a few people." I wrote" Meeting beforehand was suggested by the social worker. It's nothing new. We did it last time to spare OH see animosity or ugliness within the family. We then presented a united front to him (U need a sitter). It was to protect him and his feeling that we hammer things out. So Other One you have attended a meeting behind his back before and I thought it was beneficial to everyone. U voiced no problem then and U did not

answer when a meeting date was requested. In fact, you never answer. Your husband suggested we reconvene 1-3 months to re-evaluate the situation. Texting is not the solution and neither is a phone in. I'm sorry for those who didn't understand. When can U meet Other One? Do we need to come to your town? We are meeting tonight and OH will be present against my better judgement."

And at the same time I was texts from That One, unaware there was a meeting. (She said she'd be in town Thursday.) Also, OH is telling her she doesn't need to stay (HE HAS Dementia!!) Said she wasn't on board with her dad not being in room, nothing to hide. I responded there were things being hidden (a lawyer being called to remove me from POA.) She ranted and raved so much! I said "Perhaps you can bring him home with you tonight?" Sassy reply "Well let's talk about that. What do you want to happen? He is always welcome to visit me but if you are looking for a permanent solution say it. Is that what you want to talk about tonight."

So that was my day before my evening meeting. I was a dishrag. I keep you angels in my head. I hope to write about the meeting later. This has been long enough.

20

Aug 20, 2018

Hi there my mum is 90 and has recently been registered blind (although has sufficient sight to cope for now).

She has carers 3 times a day to give her meds and check she is eating or offer food as it were. On recent visit she was telling of men at the door asking questions, but then goes on to talk about other stuff I know to be made up so that's a worry. Mum also gets things

in a loop and keeps repeating them I got her knitting just small squares but when I rang on my return home she had completely forgotten. I always ask her if she is lonely as my dad died last year and she says "I'm alright " we have a family member that lives closer and tries to do the doc appointments and shopping . Probably have read this loads of times before people but I feel better for writing it down any suggestions gratefully received.

21

Dec 26, 2017

We had a surprise visit this afternoon from a distant cousin, her husband and their small child (just under two). I was pleased to see them, but my heart sank a little as I immediately thought it would upset mum (new people, a small child, and noise). I warned them that mum would probably not know who they are and that she might be scared or anxious. After a bit of uncertainty from mum, she saw their child and her face immediately lit up. I don't think I've seen mum smile so much, for so long, in ages! They didn't stay long as they were passing en route to somewhere, but by the end of the visit, mum was stretching out her arms to hold the child. Unfortunately, the child didn't want to go into mum's arms, but mum didn't stop smiling all the time they were here.

I've read about mixing the elderly and children, and I think I've read somewhere about children going into dementia homes, but I saw the benefits in action here today! I suspect that after a while, and after enough screaming from the child, mum's mood would have changed, but it was nice while it lasted.

22

Apr 26, 2018

My 96 yr old FIL is very mobile, can walk around the house unaided, uses a stick on longer walks. He can sort all his personal hygiene and dress without any assistance at all.

However just lately we have noticed he is asking us to do more things for him. One day I helped him with his dentures and now he asks that I clean them and bring them to him....even after he's already been in the bathroom showering etc. He's now started asking my husband to shave him, which of course he has done fine every day.

If he asks, I say come with me and I'll show you where 'x' is but he flatly refuses and says he won't bother today. Sometimes I try to bargain and say, Ok I'll show you where 'x' is and you can do that while I make your tea or whatever. Again refusal.

He doesn't complaint that he doesn't know what to do, I know some can forget how things work. Some days he forgets that I've helped him with his dentures or finding his clothes and he manages perfectly well.

I don't want to be awkward and not help when he does need help, I think this latest behaviour is as if he can't be bothered or just plain lazy. If I do more for him, will he expect more and it will affect his mobility and cognitive behaviour too ? I've read that when people can do jobs and tasks for themselves it's good for their overall well being and sense of worth. Arrrggghhh I hate the evil dementia !!!

23

Mar 2, 2018

I've just had another call from the hospital to say my uncle has fallen by the side of his bed. Again.

The problem is that as he's unaware of his left side, he keels over really easily unless someone is with him and he has something to hold on to. Unfortunately, he's also unaware that he's unaware, so he doesn't ring the call button for help. He's agile enough to swing his legs over the side of the bed, but after that it's downhill.

What I'm wondering is how on earth a care home is going to be able to cope with this once he's discharged ? The hospital have him positioned right opposite the nurses' station so they can keep an eye on him, but if he has his own room, he's not going to be under that level of supervision. I know there are buzzer pads that can go by the side of the bed to alert staff once someone has tried to get out of bed, but that's not going to prevent a fall in the first place.

I'm sure this isn't a new problem, but really wondering does anyone know how it can be managed safely ?

24

Oct 22, 2017

Mum is now 4 years from Alzheimer's diagnosis and still living on her own. She has carers in every morning for an hour and meals on wheels every day. SS have assessed that she requires more visits but is unable to provide this service due to Mum's isolated location. The current carers are a private provider and SS have covered this as a managed service with us paying top-up fees as they cannot offer an alternative, they don't have capacity either.

Mum has not washed, cleaned her teeth or changed her clothes (jeans and a T-shirt) for many weeks/months, other than the occasional time the carers have been able to peel the T-shirt off and swap it. I'm not sure what she goes to sleep in or even if she gets into bed anymore. I can't stay there anymore as she has photos of 3 children (grand children) in the two spare beds who she talks to and looks after all the time.

She has developed cellulitis in her legs which for a second time have turned into sores and I am waiting to speak to her GP again.

Both myself, my sister and the carers have tried to sort a bath, wash her feet in a bowl of water, cut her toenails, put cream on her legs. She refuses all help and gets angry.

SS have suggested respite care to sort her legs out, but I know once she's moved she'll never get back home again. The only other suggestion was to move Mum to sheltered housing in another town where carers could get to, which would be a waste of time because the move would finish her off. Mum's wishes were to remain in her own home for as long as possible and that's what we're trying to do. But I just don't know what more help is available to her, and who to put pressure on. If the help was there, for example a nurse visiting to sort out her legs and feet, how do you make someone with dementia co-operate? She will end up in a care home before she's ready just because she won't let anyone help her and she's not looking after herself so medical problems will start occurring.

70

Mum is only 75 and physically fit and mobile. She's not on any medication anymore as she stopped taking it, but the GP has prescribed water tablets to help with the fluid in her legs which the carers are able to give her. She is going to need antibiotics again and with no afternoon visit there is no one to give her the medication other than once a day, which isn't sufficient. I live the other side of the country and my sister is not able to visit every day either. Anyone else with a similar experience?

25

Apr 18, 2018

I didn't take care of myself. Im 33 and completely let myself go. Im trying to come back from it now but its tough. I need a lot of dental work, traumatic few days in dentist, infection so lots of antibiotics. Feel so sick and tired. I will be getting partial dentures for the back I think. Not sure how good the front teeth are but will see how it goes. Ive other issues as well and alot contributed to how I let myself go but I just wanted to say mind yourself!! You deserve the best as well!!

My sister helps look after our mother so she's on duty these few days. Hoping to be better soon though. You feel so miserable that you let everyone down.

26

Oct 18, 2017

Dad has late stage Vascular Dementia and is almost 80 years of age - he has declined considerably in the past 6 months and a few weeks back suffered a major dip whereby his actions could not be explained and since then we are having sometimes daily incidences

where something has clearly happened, but he is not able to explain in words or sentences that make any sense what happened, but it is something concerning enough that he has either phoned me or pressed the alarm button on the system we installed as an extra precaution.

I therefore decided that rather than waiting for something more serious to happen, I would contact Adult Services to ask if Dad could be assessed with a view to possible respite care/short term stay in a care home as a starting point to his long term care. I thought respite or short term care to see how he adapted before any decision was made was a good starting point and presumed this was something I had to go through Adult Services for, because of his condition. We would be self funding, so it wasn't as if I was expecting his care to be paid for by the local authority.

I thought that was the right thing to do for his own safety and my piece of mind that he would be monitored 24/7, even if it was for just a couple of weeks, but apparently until such time as Dad agrees (which I can't see that ever happening as he won't accept any outside 'interference' as he calls it) we either have to continue as are, with Dad living at home on his own, with all the additional support measures I can put in place, or wait for a 'crisis' to occur whereby the need for his consent may no longer be applicable.

I don't think my Dad does not know what is best for him anymore - if he did then I wouldn't have to do half the things I do for him - he just follows the same daily routine whether it is a good day or a bad one but that doesn't detract from the fact I am not taking away any respect for him as a human being, all I am trying to do is what is best for his safety with the condition that he has so with the increasing day to day concerns that

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seem to be occurring, why is my request to keep him safer, deemed to be the wrong request to make as his carer??

27

Aug 19, 2018

My mum has had Alzheimers for nearly 15 years - she's over 90 now and in a CH. A few months ago she stopped recognising me and my two siblings. She gets very confused when I mention I am her daughter and repeatedly says 'How do you know you're my daughter?', 'It CAN'T be'. When I saw her this week, I was particularly upset and wasn't able to stay with her for long (even though I'd driven over 3 hours to see her).

I'm now wondering if it's best to pretend I am just another carer or a friend? The most I can do now is give her a few hugs and kisses, which always go down well. Any thoughts?

28

Sep 6, 2017

Well after my nice Friday off thanks to my husband, Saturday was not so good. I went to dad's house to sort him out (he's fine) and when I got home there is my husband sitting down with a black eye and pouring with sweat. Seems he passed out at the foot of the stairs while looking for his puffer because he had chest pains again. Took him to hospital where they admitted him (fourth time this year) with suspected heart problem. He is still in there and very fed up.

A very good friend of ours was in the same hospital with lung cancer, I saw him last week and they were trying to get him home as that was what he wanted. So on Saturday while in the hospital foyer I bumped into his wife and she suggested that I might go and see him

so I did. He was very very ill but I spoke to him and he could answer me. A couple of hours later and I bumped into her again as I was leaving and this time I went to see him to say goodbye, I think he could hear me but his breathing was not good. When I got home she phoned me to say he had died soon after. Feel so sad because he was a really good friend of ours, I told my husband this morning and he is sad too that our friend is gone. We are going to miss him very much. I am glad that I got to say goodbye to him though.

So I spent nearly all day today again at the hospital and my husband may have to have another angiogram tomorrow or he may get to have an implant that monitors his heart as they think he may have an electrical problem. I know, that is a new one to me too.

So back there tomorrow to see what is planned for him.

I have been a bit stronger this time and have dumped dad's care on to my brother. No notice, no choice in the matter but I can't do it at the moment. I still worry about dad all the time as I haven't seen him since yesterday morning so I will go to see him tomorrow at some point.

Just feeling a bit sorry for myself at the moment and need to write it down I suppose.

Jul 11, 2018

ive been trying to make things go smoothly for gran but all this chasing up and dealing with everything looking after my own family is too much.

Had a big problem with the care agency who didn't give meds over the weekend because they hadn't updated it on their system. Talked to the care agency 6 times and finally I've

managed to put the complaint through to the management team.

Was sorting out a certificate provider for the LPA. Paid 125 to gp to come down. Got a phone call to From practice manager to arrange a home visit and he was going to come down. One hour later in the middle of the meeting with care coordiater. I get a phone call from the practice manager saying the gps at our surgery no longer provide power of attorney certification and they are not legally bound to. You can get your refund and paperwork back....

I didn't know whether to laugh or cry. All these weeks I was Trying to get through to practice manager who only works tues and thurs, confirmed everything. Printed all the documents out £20 worth. Had a meeting with her Filled in consent form at surgery. Waited another week for gp to be available. He said he will do it. Paid the fee and arranged the meeting and now suddenly no gp wants to do it. I'm gonna go mad

30

Jul 12, 2017

My husband was awarded lower rate of PIPS care and mobility last year whilst we were still in the ever never ending process of trying to reach a diagnosis . It took having to call out the crisis team to help us cope with his hallucinations and the constant voices in his head telling him to kill himself ; and then their mismanagement of my husbands care so that I made a formal complaint, before the consultant reviewed his whole history and everything I had been telling them for nearly three years ( sleeping long periods of the day REM sleep patterns at night acting out his dreams , hallucinations , struggling to find words , balance problems , shuffling when he walked, etc etc.. ) he finally got his diagnosis of Lewy Body Dementia earlier this year . My initial feeling was to be cross that

we had wasted some of the precious time we had left together fighting for someone to acknowledge there was a problem , and myself doubting is it all in our minds . I notified DWOP of the change in circumstances (as advised) in May and was asked to fill in a form and return a form by JUNE 8th we are still waiting for a response ? How long have other people had to wait? And if they move him on to the higher level ( which we have been told by a different benefit department that he should be on .!) will they back pay it to when we notified them of the changes? I have so many more questions to ask about Lewy but they will wait for another post ! Thanks for 'listening'

[31](#)

Jul 25, 2018

After several bouts with some physical health issues as well as grief over a death in the family over the course of a year, my 62 year old father began to exhibit personality changes which were worrisome to say the least and which have gone on for many months. He became withdrawn emotionally, irritable and sad, unhappy with everything (literally, nothing' s good enough) and distrusting of everyone, he picked up smoking again (he quit when he had a heart attack a few years back), and most specifically he started to accuse my mom of having an affair and lovers behind his back which isnt true at all, my mom couldnt be further from that type of person.

He is now in a state where every few days he will bring it up and no matter what we say or try to logically reason with him or explain, he is convinced he is right and my mom is having all these affairs and demanding a lie detector test and phone records of hers. He

googles affair related things such as "signs they're cheating" etc. I've told him time again not to discuss this issue with me cause it bothers me, as their child, and he still does it. He's called my mom every name under the sun in front of me, as well as calling me all sorts of names. He has said he wants a DNA test to make sure we are his kids, cause he's not so certain with my mom being the promiscuous woman she is (lol). He checks her computer search history, and follows her around to check if shes on her phone around the house (he literally hides between trees and peeks through blinds). It's quite disturbing to watch, as his child, because he is not the person he was before.

From my research I noticed he does seem to be exhibiting a lot of symptoms of dementia of some sort, but he refuses to see a doctor for it and says we are the ones who need mental help. He has a heart condition but other than that has never had any mental health issues. So I'm at a loss on how to manage or help him, because I'm currently the one at home as his caregiver while my mom's at work, so I spend the most time around him. Does anyone have any advice? I'm desperate. Thank you.

32

Jul 24, 2018

My husband and I live with my parents, to help mum care for my dad as he has numerous health problems- including Vascular dementia. He has always been quite a 'grumpy' person, but he is getting increasingly angry/ short-tempered with my mum and it's not nice to watch, as it's not fair to her and it also seems to be grinding her down. I do understand that aggression is a symptom of dementia, but I don't know what to do.

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When he's shouting at her, do I stop him then and there and tell him to be nice?(Although I can only envisage it making him more angry). Or do I wait until he's more calm and try to talk to him about being nicer? (Although he doesn't seem to think he's being mean). Or just leave him to it?

33

Jul 22, 2018

Finding it impossible to cope with mother in law. She keeps going out and leaving the front door open. She crosses a busy road so we took her front door key home. The social worker told us it's illegal to do that but we did it for her safety. We live half an hour away but social worker thinks we should be with mother in law 24/7. Don't think that's fair as husband is ill and I care for him. He's his mothers only living relative so has no choice but to be with his mother as much as he can. Am I being selfish wanting some time with hubby ?

34

Jul 23, 2018

I look after both my parents my dad is late stages is wheelchair bound unable to speak and quite aggressive, my mum is early stages but won't get dianosed but has a lot of other issues too. As dad is house bound we are unable to leave the place , we have very little support and not for the want of trying but being out in the countryside it's difficult to find help.my morning starts at 4.30 am and I now finish at 7.15 pm my brother stays overnight with them but I'm just too shattered to go out and meet up with friends then.

35

May 30, 2018

Mum in Law is getting so bad now it is a worry to leave on own during the night, we have had some (episodes) as we call them, she now has a UTI, which is being blamed for her behavior, she has been so bad Rapid Response as been called in and they have given her wrap around care for 72hrs which we thought thank god some support, however yesterday she attacked the carer, when we got there she hit me this is not because she is angry it's because she keeps saying "you don't believe me " constantly that the doctor stole all her money and butchered her, its just never ending, shes in hospital now but very nervous about her being discharge.

36

Jun 6, 2018

So today is a bit of an anniversary for me. 9 years ago to the day I was told I had breast cancer. I'm glad to say I'm in remission and all is good. I like to mark the day by raising a glass of fizz to say I'm still here and winning the battle.

At the time of my diagnosis my Mum was a great support and was obviously very concerned about me. However, she was already showing signs of mild cognitive impairment even then. 9 years on and she sometimes doesn't realise that the woman sitting by her side is her daughter.

We've had a fairly good day today with Mum although she got very cross and stroppy when we asked her not to give the dogs any of her cake. She can't understand that some of what we eat isn't good for animals! It was also a bit of a trial getting her ready for bed.

She doesn't think she lives here and can't understand where my Dad is (he passed away in 2012) or where her parents or grandparents are. She also doesn't like me helping her get her nightclothes on but could never manage it herself. Fortunately I got Mum to bed at 9pm and while I was settling her my OH nipped round to the co-op and got a bottle of Prosecco. I'd said I fancied a drink but I'm sure he's not realised the significance of the day. So I've now had a couple of hours of me time. Not sure how many times I will get woken up on the night though!

It just seems a never ending battle of supporting the PWD. Us carers also have our issues and need support. Today especially I just feel like I need that extra bit of TLC and years ago I would have turned to my Mum and she would have been there for me.

37

Apr 10, 2018

Just been to the doctor as I feel it all too much. It has affected me at work and I have been signed off for a month plus put on tablets for stress. Compared to some people on here my problems with my Mom are insignificant. She can look after herself but needs help with doctors appointments, medication and financial help. My brother and me have got LPA's in place. The doctor thinks that I'm having trouble with acceptance of the situation. To an extent I think she is right. It is the intrusion into my life that I have trouble accepting. I sound selfish I know but having been made redundant 18 months ago I thought my life would never get back on track. I then found another job which I love and became a grandparent to a gorgeous girl, I thought my life was great. Then 9 months ago the process started getting my Mom diagnosed. Finally late January she was told she had early onset Alzheimer's. Since then it's been a continuous learning curve. Every week I

wonder if I'm doing enough/ not enough. Should I be concerned by slight changes in behaviour or just put it down to an off day. I tie myself in knots some days. My brother is a great support but like my Mom keeps his feeling to himself and talking to him is like getting blood out of a stone. I too am a bit like that and don't wish to burden my husband or children but they are good listeners. Reading other people's posts I realise I'm not the only one who feels like this but it's good to write it down and get it off your chest. A problem shared etc.

38

Jul 13, 2018

My mum has been given a diagnosis of Mild Cognitive Impairment after a series of dementia/memory tests. This means we are not able to access any of the dementia services locally, I understand that there are limited resources and these need to be prioritised so I am not unhappy about that at all. She is still forgetful and unable to cope with anything more than 1 thing at a time, which is what the Psychologist would happen. Physically she is wobbly as well, and is increasingly needing more care. We have lovely carers that go in daily and help. I am the only child and today I am just overwhelmed by the scale of what is ahead of me, knowing she will not get better but not knowing how long she has and how she will deteriorate and knowing that I am pretty much on my own. I know that I am lucky that mum has funds so we are not reliant on the poor overworked social care system. I know I am very lucky in many ways but today, well today is rubbish and I just wondered if anyone could send me a virtual hug with the understanding of all this and maybe being in the same place. This is such a lonely dark place to be whilst trying

to retain some sense of normality in my own life and not get buried under this along with the sense of guilt that I should somehow be doing more!

Thank you for reading if you have got this far, knowing there are others out there who are in similar boat does help a bit. Sorry if this sounds a bit wailing and self indulgent but I just needed to get it out and say help!!

39

Apr 13, 2018

Well, mum has been with us now for nearly four months. She has vascular dementia which was made worse by my dad's sudden death in March.

She came to live with my husband and I in our little 2 bedroomed house with only 1 bathroom.

Over the last few weeks Mum has stabilised a lot. She sundowns every day and is quite demanding and gets upset if things are not done exactly when she wants them done.

The problem, I think, is not her, it's me.

I am struggling to come to terms with her dementia and struggle to feel any emotion. I find it hard to be affectionate toward her as I have trouble separating my 'real' mum with the one who has dementia. The one who is selfish and nasty. Don't get me wrong, I am loving and kind, I just don't feel it inside.

My life has turned upside down. I no longer work. I'm with her all the time. My husband and I have no privacy. She hates to see us together and gets upset if we talk to each other.

All of her feelings I can understand. She has lost her husband and has had to move in with us. She feels she has no freedom. She wants to live alone. She wants to live back where she came from but it's 4 hours drive away so is not practical, plus she can't live alone. I do try to explain but she sees me in a negative light. She is so nice and gracious to my husband but irritated and grumpy with me. It hurts.

I do everything I can to make her life happy and comfortable but she is not happy.

I suggested going to a day centre but she doesn't want to. She has no interest in doing anything. When I suggest something or try to get her to do something with me she will say "I don't feel like it".

Every day I promise myself I will try harder but each day I fail. It is making me feel so depressed.

I feel for her, I really do but I'm struggling with this stranger in my house.

She wants to live in a care home but doesn't like the ones she can afford (with social funding). I'm not sure she even realises how it will be in a care home. She used to live in a warden assisted flat with my dad and I'm sure that's what she thinks of as a care home.

All this is making me feel rubbish as a person. I ought to be affectionate. I ought to be able to understand. Even after reading books about it I still struggle.

I ought to get a grip on this but don't seem able to do so.

Sorry for the rambling post. Thanks in advance to any who answer and thanks to those who have answered in the past.

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Jul 9, 2018

I don't post often but have found much support in others posts in the past when my father had dementia and now with my dear mum, who is 90 and has vascular dementia.

I work full time and have an 11 year old son as well as grown up daughters and a grandson. For the last 18 months I've been caring on an almost daily basis for my mum who still lives alone - albeit in the same town thank goodness. I go every day from work to prepare her evening meal as she has lost all ability to cook and prepare suitable meals for herself - she'd live on boiled eggs and dry bread otherwise. She can't even make a cup of tea now as she forgets to put the teabag in or the milk and she doesn't pour herself cold drinks unless I do it for her. I am an only child and she is very dependent on me for her emotional needs as much as physical. I also see her both days at the weekend - usually bringing her to me for lunch and then taking her shopping or to a garden centre etc, I manage her finances, her garden and have to keep an eye on her food hygiene. More recently I have to remind her to wash her outer clothes as she doesn't notice when they get grubby. She also struggles to make good choices - polo neck jumpers in 28C heatwave bless her.

The crunch is that sometimes this is all OK, but other times I get resentful, tired and fed up of not having time for my family - a whole day or being able to go straight home to my son after work etc. I'm also too scared to book a holiday as I know she will get anxious, fretful and I'll just worry the whole time.

Last week I saw my GP (her GP too) and she made a second request for a social services referral. Today they called. Asked lots of questions like, 'Is there any other family that can help' - No! 'Are you prepared to carry on doing the evening visits' - Yes but not every single day, I need time for myself too.

She said she'd talk to her manager and get back to me. So far so good....But...

I know my mum will HATE anyone else going in. I'm not sure how on earth I broach the subject with her without her thinking I've let her down. She gets very cross with me at times and is incredibly stubborn and independent. She doesn't think she needs help and thinks I fuss too much. She believes she eats/drinks well and she sulks if I don't visit. I know if I go away she will suddenly 'feel unwell' or become very moody/unhappy.

I feel like I'm letting her down - part of me thinks I need to just keep doing what I do but I can't be there in the day during the week and I am genuinely worried about her wellbeing with food and drink.

I'm sure others have felt this too and just wondered how you got through this stage without creating further drama and crisis??

Hi Everyone

I am currently caring for my 83 year old Dad who was diagnosed with Vascular Dementia last year. Dad still lives at home with Mum who has looked after Dad since his diagnosis 24/7. I am also Dads carer but not 24/7 due to having to earn a living, however I have recently had to reduce my work load as Mum is unable to care for Dad by herself as he has recently lost most of his mobility and has started to become aggressive towards her.

We are currently at the end of our tether and have had to involve Social Services as the pair of us are running on maybe 3/4 hours of sleep per day. Social Services originally offered to take Dad to a care home for a couple of weeks respite to give us a break however we refused as we have heard so many horror stories lately in the local press and from friends and relatives who have family members in care. However we have now come to the conclusion that we will have to accept their offer as we can longer cope on our own. Social Services are coming to visit us on Tuesday.

Our main problem at the moment is Dads lack of mobility , his nastiness and total lack of co operation. Our GP has prescribed a mild anti depressant with a sedative effect which has helped him to sleep for a few hours during the night, however it was only prescribed on Monday, so I expect the calming effects may take a bit longer to show.

I really don't know how to deal with things any more especially the nastiness and hatred he is showing towards Mum who has cared for him 24/7 which has also been very detrimental to her own health. I don't know what I expect you guys to say but I sort of just needed someone to rant to. I came across this forum whilst taking myself away from the situation for half an hour after just facing the aggression myself.

Dad has had 3 falls within the last 2 days and I really don't know if we can hold out until next Tuesday.

You guys all have my admiration as this is the most challenging and heartbreaking thing that I have had to deal with in my 40 years on earth.

86

Mum has been in respite for a week and I picked her up this morning and brought her home. On the way back I asked if she had enjoyed her stay but she didn't seem aware that she had been anywhere different to normal. She hasn't really given any sign that she knows who I am. I made small bite size sandwiches for lunch and she ate a tiny amount and gave the rest to the dogs. She's now nodded off on the settee next to me. I just feel very sad and as though I have lost my Mum altogether.

43

Jun 26, 2018

My GP didn't want to confirm or deny my mums lack of mental capacity.

He didn't know how we could do it either.

Where to go he did not know.

No help at all.

I've found during this tough road we travel, that you are on your own.

No help from the local authority, the living well with dementia team, no-one has helped us at all.

Mum has a property to sell so get on with it, shut up, pay up and sort it out yourself.

For £939 we have now proof that my lovely mum who has a terminal, progressive and disabling brain disease does not have the mental capacity to deal with her property sale or financial affairs.

Twenty minutes that's all it took.

Five minutes in conversation with mum that's all it took.

£939 that's all it took.

Today we were told that a room has become available in the care home of our choice.

Am I singing and dancing?

Am I happy?

No I am not.

I'm sad, tired, drained, exhausted, fed up, angry, frustrated, ill, depressed, over sensitive, miserable, and very sad sad sad, I lost my beloved dad suddenly in August, I lost my mum years ago to Alzheimer's and I'm losing her again and again and again an again.....

44

Jun 26, 2018

Why is it that whatever you do it is never good enough. Doesn't matter that you drop everything a couple of hours after you've got home from visiting and rush round as she's phoned to say she doesn't feel well or that you try to phone to say that the nurse will contact her later in the week and there's no answer, so you rush round again for the third time that day to find the phone is unplugged and she can't hear the other phone as she won't wear a hearing aid. So that was the evening choir practise missed.

Today I've been told that it's better that we don't see each other as I don't speak to her nicely and I obviously don't like her.

This was said as I arrived with a bag of shopping and was going to collect her pension as it's too hot to go out.

Great, as there's only me. No one else will visit (due to her negativity and attitude)

88

Feeling really worthless and useless, supposed to be going away for a few days and now don't know what to do.

45

Mar 29, 2018

Good morning

I've not posted for such a long time so feel guilty about my query and also that I'm being very selfish. Mum has been in a really good care home for almost 2 years now. She was admitted for a variety of health issues but was only diagnosed with mixed dementia 6 months after admission. I cannot fault her care and she still seems in a happy little world although she does say and believe the strangest things - my brother and I knew to expect this. I am so grateful for her care but I still struggle myself with all that's happened. I've pretty much cut myself off from people and feel so lonely, anxious and depressed. I dread what is ahead. I know so many of you are in a far worse position than I and I'm so sorry if my post seems selfish. I now live with my brother who is lovely but don't want to burden him further as I know he too is worried. I'm 61 but feel like a silly child revealing all this. Does anyone else out there feel like this? Thank you so much for your time.

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Jun 17, 2018

Mom was diagnosed with COPD last Monday, as well as Alzheimer's Dementia middle stages....she has been put on a strong anti biotic for the COPD, but I fear now she has a water infection too. Thursday we found out that she had lost the sight in her left eye to glaucoma and is on eye drops to save her right eye. All in a week, can things get

worse...of course they can.....the last 2 days have been very exhausting, she is seeing things, doesn't believe that where she lives is her home, thinks there is soil in the toilet pan, keep asking about her husband ( we lost dad last October ) which is understandable, seeing large lorries right up by the outside wall of the house, wanting to go back to her mom and dads ( they passed in the 80's ) and live where she grew up, she is very agitated, wandering of a night, the list goes on.....today has been the worst, especially for me, being Fathers Day, and he isn't here. I have shed so many tears since taking the role on of caring for mom....today has been the hardest, I didn't know wether to call the doctor and have mom admitted to hospital or weather the storm, have chosen the latter, but it will be a phone call to the doctors tomorrow.....still have nighttime to get through

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Jun 10, 2018

Still waiting for a room to become available for Mum in care home.

Psychiatrist needs to see mum again because she is not sure she lacks the mental capacity to sell her home or agree to us selling her home on her behalf which is holding up probate which in turn deems us unable to pay ch fees when they arise.

It's been a day of two parts. OH played golf am, I took mum out am. All fine and dandy then wham, as soon as we got home the tears the questions the questions the questions the tears the strops the strops, I want to swear.....I came home after our morning out and actually said to my husband, mum will be alright here won't she? What was I thinking, I am going crazy, and she is in and out of my bleep room still, I could scream.....OH and I are losing it, we've had enough, oh and ten mins before the SW

90

should have seen us on Thursday she rang to say she can't do an assessment for a 12 week disregard because mum has property and is living with family bleeeeeeeeeeep

48

Jun 6, 2018

My Mum has lived with me for the past 2 years since she got lost after walking to the local shops in the middle of the night. She was found in undergrowth 18 hours after leaving her house. Her memory has deteriorated slowly but surely since then. I now have problems getting her to bed every night. She does not recognise where she is and she does not recognise that I am her daughter. I understand that she thinks she is in a strange place and some strange woman is telling her she should go to bed. She is obviously tired but how do I convince her to go upstairs to her room and get ready for bed? Tonight was really difficult and she was determined that she would not go to bed. She thought my Dad was sitting next to her but he passed away over 6 years ago. She said she wouldn't leave him and I tried everything I could think of to convince her to go upstairs, including the white lie that my Dad had already gone up to bed. I try to see things from my Mum's point of view but sometimes I feel I'm at the end of my tether! Had anyone else experienced this and do they have any advice?

49

Jun 4, 2018

Hello all,

91

Thanks for all advice so far. I have been away on holiday for 2 weeks - oh what bliss! But now plunged back into looking after mum. She has a brain scan on 28th June which should determine dementia of some sort.

What I am concerned with at the moment is her personal cleanliness. She does have a bath every night - thank goodness - but she refuses to wash her hair and she does not know why. After 2 weeks she smells. How do I get around this?

She is also scratching below the waist (TMI I know!) but says there is nothing there, it's just habit after having sores on her tummy for a while which have mostly cleared up.

I have also bought one of those disposable nappy bins but just cannot get her to use it (she uses Tena lady pants) so she throws them in a normal bin which makes her bedroom smell.

No matter how many times I explain and show her what to do, she doesn't do it.

Any advice on personal hygiene would be great. Thank you.

50

May 31, 2018

Hello everyone

about to start caring for my uncle he has had memory loss since 2015 it's dementia /Alzheimer's now.

My Aunty lives with him but doesn't want to care for him she leaves him for a lot of the day on his own at the moment but he's starting to need more supervision now. He's at home all the time just watching tele At the moment he knows everyone is very placid . he

has breathing problems his speech is a bit slurred he can't remember short term things  
my Aunty leaves notes for him and can't walk far.

I have an active toddler that will be with me, what kind of routine do you all have that  
care? What can I do to help him as best I can?

Both aunt and uncle not driving and live in the middle of nowhere. They have no children.

Aunt can't cope with change very private doesn't want anyone to know anything. Both  
very good people would like to help them but extremely overwhelmed at the moment  
any advice appreciated .

**Staff / Office Use Only****DOPEC NUMBER:** *Click here to enter text.***Umbrella project DOPEC number (staff)** *Click here to enter text.***APPLICANT SURNAME** Bell

**APPLICANT:** UG  PGT  PGR  Staff

**REVIEW PROCESS:** Accelerated  Full

**APPLICATION STATUS:** New application  Major amendment  Resubmission

**APPLICATION FOR:** Dissertation  Teaching  Research & publication

**ATTENDANCE AT HEALTH & SAFETY BRIEFING:** Yes  No  N/A

**INCLUSION OF RISK ASSESSMENT FORM:** Yes  No  N/A

**NOTES ON THE ROLE AND FUNCTION OF THE DEPARTMENT OF PSYCHOLOGY ETHICS COMMITTEE.**

- All decisions of the committee are based on the application form and reviewers comments ONLY. Forms should be as detailed and clear as possible. Verbal discussions are not considered as part of the application or review process.
- The review process strictly adheres to the University of Chester Research Governance Handbook and the BPS Code of Ethics.
- The decision of the committee is final. If you are a UG, PGT or PGR student you should discuss the decision of the committee with your supervisor. If you are a member of staff you may contact the chair of the committee for further clarification.

Before completing the form researchers are expected to familiarise themselves with the regulatory codes and codes of conduct and ethics relevant to their areas of research, including those of relevant professional organisations and ensure that research which they propose is designed to comply with such codes.

Department of Psychology Ethical Approval for Research: Procedural Guidelines.

University of Chester Research Governance Handbook

[http://ganymede2.chester.ac.uk/view.php?title\\_id=522471](http://ganymede2.chester.ac.uk/view.php?title_id=522471)

BPS Code of Ethics

[http://www.bps.org.uk/system/files/Public%20files/bps\\_code\\_of\\_ethics\\_2009.pdf](http://www.bps.org.uk/system/files/Public%20files/bps_code_of_ethics_2009.pdf)

BPS Code of Human Research Ethics

[http://www.bps.org.uk/sites/default/files/documents/code\\_of\\_human\\_research\\_ethics.pdf](http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf)

BPS Guidelines for Internet-mediated Research

<http://www.bps.org.uk/system/files/Public%20files/inf206-guidelines-for-internet-mediated-research.pdf>

BPS Research Guidelines and Policy Documents

<http://www.bps.org.uk/publications/policy-and-guidelines/research-guidelines-policy-documents/research-guidelines-poli>

Any queries email: [n.davies@chester.ac.uk](mailto:n.davies@chester.ac.uk) or [psychology\\_ethics@chester.ac.uk](mailto:psychology_ethics@chester.ac.uk)

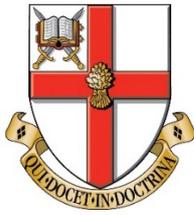
**CHECK LIST.**

**Please complete the form below indicating attached materials. Prior to submission supervisors must confirm that they have reviewed the application by completing the supervisors column.**

<i>Notes: Students to indicate where information is found, supervisor to confirm by ticking green column</i>	<u>Supervisor confirmation</u>	<u>Information sheet</u>	<u>Letter</u>	<u>Email</u>	<u>Email info. page</u>	<u>Consent Form</u>	<u>PowerPoint</u>	<u>N/A</u>
Brief details about the purpose of the study	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Contact details for further information	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Explanation of how and why participant has been chosen	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Notification that materials/interviews are not diagnostic tools/therapy or used for staff review/development purposes	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Explanation participation is voluntary	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Details of any incentives or compensation	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Details of how consent will be obtained	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
If research is observational, consent to being observed	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Details of procedure so participants are informed about what to expect	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Details of time commitments expected	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Details of any stimuli used	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Explanation of right to withdraw and right to withdraw procedure	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Option for omitting questions participant does not wish to answer	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Procedure regarding partially completed questionnaires or interviews	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
With interviews, information regarding time limit for withdrawal	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Details of any advantages and benefits of taking part	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Details of any disadvantages and risks of taking part	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Information that data will be treated with full confidentiality and that, if published, those data will not be identifiable as theirs	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Debriefing details	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Dissemination information	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						
Further information (relevant literature; support networks etc)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>						

**Supervisor Signature: Liz Whelen**

**Date :07/03/2018**



# University of Chester

DEPARTMENT OF PSYCHOLOGY  
APPLICATION TO  
DEPARTMENTAL ETHICS  
COMMITTEE

**WHEN COMPLETING THE FORM PLEASE REFER TO THE DOP ETHICS PROCEDURAL  
GUIDELINES HANDBOOK.**

**UG AND PGT STUDENTS CAN ACCESS A COPY ON THEIR RELEVANT MOODLE PAGE.**

**PGR AND STAFF SHOULD CONTACT [n.davies@chester.ac.uk](mailto:n.davies@chester.ac.uk) or  
[psychology\\_ethics@chester.ac.uk](mailto:psychology_ethics@chester.ac.uk)**

## 1. Working title of the study

*Notes: The title should be a single sentence*

A study on the effect of dementia on the family/carers supporting the diagnosed through online forums

## 2. Applicant name and contact details

*Notes: The primary applicant is the name of the person who has overall responsibility for the study. Include their appointment or position held and their qualifications. For studies where students and/or research assistants will undertake the research, the primary applicant is the student (UG, PGT, PGR) and supervisor is the co-applicant.*

Katherine Bell 1107704@chester.ac.uk

## 3. Co-applicants

*Notes: List the names of all researchers involved in the study. Include their appointment or position held and their qualifications*

Dr Liz Whelen, supervisor, senior lecturer

## 4. Start and end dates of the study

*Notes: The title should be a single sentence*

October 2017- September 2018

## 5. Is this project subject to external funding?

*Notes: Please provide details of the funding body, grant application and PI.*

N/A

## 6. Briefly describe the purpose and rationale of the research

*Notes: (Maximum 300 words). In writing the rationale make sure that the research proposed is grounded in relevant literature, and the hypotheses emerge from recent research and are logically structured.*

*If this application is for a PGR/Staff funded project please attach any detailed research proposals as appropriate.*

The purpose of the research is to identify the common problems faced by people who are living with or caring for somebody who is suffering from dementia. Dementia seems an interesting illness to focus on in this study due to the emotional nature of the disease and its effects on the sufferer and those around them. Mental deterioration may interestingly present more emotional issues for the family/carers than a disease with solely physical effects on the sufferer. The use of online forums to obtain data for the study should provide more honest and unfiltered results than face to face interviews due to a lesser inclination to hold back on an anonymous platform. This study will aim to discover the common issues faced by those supporting dementia sufferers and identify ongoing issues on the subject.

## 7a. Describe the methods and procedures of the study

*Notes: (Maximum 500 words) Attach any relevant material (questionnaires, supporting information etc.) as appendices and summarise them briefly here (e.g. Cognitive Failures Questionnaire: a standardised self-report measure on the frequency of everyday cognitive slips). Do not merely list the names of measures and/or their acronyms. Include information about any interventions, interview schedules, duration, order and frequency of assessments. It should be clear exactly what will happen to participants. If this is a media based study describe and list materials include links and sampling procedure.*

Data will be obtained through online forums and thematic analysis will be conducted to gain an insight on the thoughts and feelings of the carers and/or family members of people who are suffering with dementia. Online forums to be used are <https://www.dementiaforum.org> and/or <https://forum.alzheimers.org.uk> and these forum posts will be selected over roughly a month. Only forum posts from the last year will be used for analysis.

## 7b. Provide details of your contingency plan

*Notes: Please briefly describe your contingency plan. (100 words)*

The study will be undertaken through searching through forums using keywords such as “family” or “carer” in order to find submissions in which to search for common phrases or words amongst that portray the struggles faced by the participants. These will therefore be analysed and compared to identify what problems and commonly faced by people in this position.

## 8. Provide details of the previous experience of the procedures by the person conducting the study.

*Notes: Say who will be undertaking the procedures involved and what training and/or experience they have. If supervision is necessary, indicate who will provide it.*

Several qualitative studies that I have undertaken and teaching through the MSc Psychology Conversion Course at University of Chester. Dr. Liz Whelan will be supervising.

## 9. Describe the ethical issues raised by this study and discuss the measures taken to address them.

*Notes: Describe any discomfort or inconvenience that participants may experience. Include information about procedures that for some people could be physically stressful or might impact on the safety of participants, e.g. interviews, probing questions, noise levels, visual stimuli, equipment; or that for some people could be psychologically stressful, e.g. mood induction procedures, tasks with high failure rate, please include your distress protocol. Discuss any issues of anonymity and confidentiality as they relate to your study, refer to ethics handbook and guidance notes at the end of the form. If animal based include ethical issues relating to observation.*

All identifying factors present for the participants will be anonymised to protect the identities of those involved. If anyone has stated they do not wish their information to be used for research this will not be included and this is not an option on the sign up for the forum on the webpage.

## 10. Describe the participants of the study.

*Notes: Describe the groups of participants that will be recruited and the principal eligibility criteria and ineligibility criteria. Make clear how many participants you plan to recruit into the study in total.*

Participants have submitted forum entries on: <https://www.dementiaforum.org> and/or <https://forum.alzheimers.org.uk>

## 11. Describe the participant recruitment procedures for the study.

*Notes: Gives details of how potential participants will be identified or recruited, please list any social media platforms that you will use and the message. Include all other advertising materials (posters, emails, letters, verbal script etc.) as appendices and refer to them as appropriate. Describe any screening examinations. If it serves to explain the procedures better, include as an appendix a flow chart and refer to it.*

Participants will found on <https://www.dementiaforum.org> and/or <https://forum.alzheimers.org.uk>. Participant identifications will by anonymised. Posts will be analysed from the last year, over a two month time span.

## 12. Describe the procedures to obtain informed consent

*Notes: Describe when consent will be obtained. If consent is from **adult participants**, give details of who will take consent and how it will be done. If you plan to seek informed consent from **vulnerable groups** (e.g. people with learning difficulties, victims of crime), say how you will ensure that consent is voluntary and fully informed.*

*If you are recruiting **children or young adults** (aged under 18 years) specify the age-range of participants and describe the arrangements for seeking informed consent from a person with parental responsibility. If you intend to provide children under 16 with information about the study and seek agreement, outline how this process will vary according to their age and level of understanding.*

*How long will you allow potential participants to decide whether or not to take part?*

*What arrangements have been made for people who might not adequately understand*

*verbal explanations or written information given in English, or who have special communication needs?*

*If you are not obtaining consent, explain why not.*

Data will be taken from online forum submissions and therefore due to the voluntary public nature of the submission consent is not being obtained. The websites concerned have no option of information not be used for research on sign up and reminds people of forum etiquette / moderation if offensive information is posted. If anyone explicitly said they wanted the information not to be used for research purposes on the thread their data will not be used.

### **13. Will consent be written?**

Yes  No

*Notes: If **yes**, include a consent form as an appendix. If **no**, describe and justify an alternative procedure (verbal, electronic etc.) in the space below.*

*Guidance on how to draft Participant Information sheet and Consent form can be found on PS6001 Moodle space and in the Handbook.*

*[Click here to enter text.](#)*

### **14. Describe the information given to participants. Indicate if and why any information on procedures or purpose of the study will be withheld.**

*Notes: Include an Information Sheet that sets out the purpose of the study and what will be required of the participant as appendices and refer to it as appropriate. If any information is to be withheld, justify this decision. More than one Information Sheet may be necessary.*

No information given due to use of online forum data.

### **15. Indicate if any personally identifiable information is to be made available beyond the research team. (eg: a report to an organisation)**

*Notes: If so, indicate to whom and describe how confidentiality and anonymity will be maintained at all stages.*

N/A

### **16. Describe any payments, expenses or other benefits and inducements offered to participants.**

*Notes: Give details. If it is monetary say how much, how it will be paid and on what basis is the amount determined. Indicate RPS credits.*

N/A

**17. Describe the information about the investigation given to participants at the end of the study.**

*Notes: Give details of debriefings, ways of alleviating any distress that might be caused by the study and ways of dealing with any clinical problem that may arise relating to the focus of the study.*

N/A

**18. Describe data security arrangements for during and after the study.**

*Notes: Digital data stored on a computer requires compliance with the Data Protection Act; indicate if you have discussed this with your supervisor and describe any special circumstances that have been identified from that discussion. Say who will have access to participants' personal data and for how long personal data will be stored or accessed after the study has ended.*

All forum data will be anonymised and kept in password protected word files.

**SIGNATURES OF THE RESEARCH TEAM**

*Notes: The primary applicant and all co-applicants must sign and date the form. Scanned or electronic signatures are acceptable.*

Liz Whelen      Katherine Bell  
07/03/2018

**ETHICS COMMITTEE DATE**

Click here to enter a date.

**ACCEPTABLE**

You may now commence data collection subject to approval from any relevant external agencies.

**CHAIRS COMMENTS****Read and review all reviewers comments**

DATA COLLECTION IS **NOT** PERMISSABLE UNDER THE FOLLOWING 3 CONDITIONS. Please address the issues indicated.

**ACCEPTABLE SUBJECT TO SUBMISSION OF AMENDMENT FORM**

UG and PG students should discuss any recommendations with their supervisors.

**ACCEPTABLE SUBJECT TO CONDITIONS OF CHAIR**

Resubmit application for full review after addressing the issues described, ensuring you have indicated on the front page of the form that this is a resubmission.

**REVISE AND RESUBMIT**

Resubmit application for full review ensuring you have indicated on the front page of the form that this is a resubmission

**SIGNATURE:**

Click here to enter text.

