

Ipsos MORI



# **Norfolk Dementia Services Study**

Draft Report for NHS Norfolk

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# **Executive Summary**

# Executive Summary

Speaking directly to service users highlights the wide variety of factors which can influence the well being and quality of life of people with dementia and their carers. The following chapters explore these factors in detail, looking at individual experiences discussed over the course of interviewing. A brief overview of some of the key points is provided here for reference.

- The needs of service users and carers vary widely according to their own personality and character traits. While some carers are confident in accessing services and finding out information, others struggle to communicate their needs.
- Social and community support groups are a very popular and highly valued service. They are seen as a vital opportunity for carers to share information and advice, as well as providing a safe and comfortable environment where service users can participate in a range of cognitive therapies.
- Such groups play different roles, depending on their format and structure. For instance, sessions which cater to carers and service users are often easier to access, as carers do not need to arrange for somebody to take over their caring responsibilities. On the other hand, carers-only groups, while more difficult to arrange, can provide more in the way of respite and more opportunity for carers to share information and learn from visiting experts.
- Carers do not necessarily *expect* a great deal of support from health services beyond diagnosis and ensuring that the service user is on the correct medication. They often see dementia as more of a social care rather than medical concern.
- Carers often report receiving priority treatment from healthcare services to allow them to continue in their caring role and such consideration is clearly appreciated. However, some carers feel that more collaboration and communication is required between service providers to ensure that such practises become standard procedure.
- Carers currently struggle to find the respite care that they need. There is often insufficient opportunity for them to relax from the stresses and strains that their roles place upon them. Nearly all the carers we spoke with explained that they were unable to plan for the future as they struggled to find time and energy to look beyond the daily pressures that they face.
- The levels of information and knowledge that carers have varies considerably, with some becoming experts on dementia and others having minimal understanding of the condition. Personal experience and advice from other carers are seen as a vital source of information, particularly as dementia can be manifested in such a variety of ways.
- The financial aspects of caring for somebody with dementia are of concern to all the participants taking part in the research. The demands on carers' time means that it is difficult for them to investigate what benefits or advice is available. Because of this many carers did not know what benefits they were entitled to. Even those that did were often

unsure about whether they or their partners would be entitled to support in finding and funding care and accommodation in future.

# **Chapter 1: Introduction**

# Chapter 1: Introduction

This chapter starts with an introduction giving the research background, aims and context. We then describe the methodology used, and detail the interviews that took place.

## 1.1 Research objectives

Dementia transforms the lives of service users and their carers, affecting the way they live on a day to day basis, their relationships and their self image. Most of the carers we spoke to described themselves as carers first and foremost before touching on any other aspect of their lives, indicating that many people feel defined by the illness or caring role.

While dementia dominates the lives of all those we interviewed, this is not to say that all participants live similar lives. Those with dementia have been affected in a number of different ways, in terms of how it affects their behaviour, their needs and their medication. In most cases carers explained that the person they cared for had been dramatically changed by their dementia. This in turn alters the relationships between carers and those they care for, particularly when carers feel that the person they are caring for is “no longer there”.

While healthcare professionals are perhaps all-too familiar with this phenomenon, we feel that it is worth re-iterating here, as this consideration influenced the research project from the outset and influenced all aspects of our approach, from recruitment and interviewing to analysis and reporting. The complexity and variety of ways in which dementia can affect service users and carers, and the extent to which it impacts on their lives, suggests an in-depth qualitative approach to the research programme.

This research aims to discover more about the totality of the experiences of local service users and carers and to assess their attitudes towards dementia support services in Norfolk. We adopted an investigative qualitative approach to develop a deep and detailed understanding of the lives of service users and carers in Norfolk, the challenges they face, and a consideration of the support services they use (and don't use) and how they could be adapted to best suit their needs. This chapter introduces the research and methodology while the research findings are available in the next three chapters of the research.

- In Chapter 2 the findings are examined thematically with a consideration of the wider factors that influence the quality of life that service users and carers have.
- Chapter 3 includes six case studies illustrating the variety of different needs that carers and service users have, and looking at the different

‘journeys’ that service users and carers are taking from diagnosis to using end of life services.

- Chapter 4 considers the implications of our research and includes some recommendations on how service improvements could best adapt to the variety of needs that service users and carers have in Norfolk.

## 1.2 National and Local Context

The National Dementia Strategy and implementation plan sets out how the Department of Health plans to support delivery of a clear pathway for improving support for people with dementia, their carers and their families. The Implementation Plan is not prescriptive and there is room for the NHS and Local Authority areas to develop services according to the needs and resources of the area.

NHS Norfolk is currently working with partners from the public, third, voluntary and community sectors to redesign and put in place an overarching strategy to meet the needs of the population who have, or are caring for someone who has dementia. The aging population in the UK is a widely reported phenomenon. As of 2006, 11.3 million UK residents were above pensionable age and 2.7 million aged over 80<sup>1</sup>. This general trend is even more pronounced in Norfolk, where the proportion of people aged over 85 is expected to increase by almost 100% by 2029<sup>2</sup>. Norfolk is clearly making dementia care a priority for the future, with several initiatives to support these services being announced recently. These include a pilot project designed to support people once diagnosed and to support earlier diagnosis, and funding for a Dementia Intensive Care Unit at Julian Hospital in Norwich.

## 1.3 Methodology

### 1.3.1 Challenges

The vulnerability of service users and carers created some real challenges for this research project. In particular the research methodology had to:

- ensure that the welfare of participants remained of the highest priority;
- involve participants in the research process as much as possible;
- allow carers and service users to take part as much as they were able; and
- obtain full consent before each interview and throughout the interview process.

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<sup>1</sup> ONS Population projections 2007

<sup>2</sup> Ibid.

A key concern from the outset was that the research fitted around the needs of participants. Caring for someone with dementia is a full-time occupation and many carers have established daily schedules in order to cope with the demands on their time. Moreover, some service users are uncomfortable in unfamiliar surroundings or with meeting new people.

### 1.3.2 Recruitment

In light of these facts, recruitment for this research was carried out through local dementia support services and charities. We agreed a broad quota with NHS Norfolk regarding the types of people to approach and designed the sample to include those in early, mid and late stages of dementia. However, we were also mindful of the challenges of locating participants ethically (we did not consider it ethical to telephone or write to a list of patients obtained through GPs for example) and so our recruitment procedure emphasised the importance of the voluntary involvement of participants and interviews were arranged to fit in their usual routines.

We were unable to interview anybody with early onset dementia. This was because nobody attending the clinics fitted this criterion, and those who had been recently diagnosed had been diagnosed late (when the dementia was already fairly developed).

Ipsos MORI moderators attended the support groups and conducted interviews and groups on site while also asking participants who were able if they could take part in more detailed depth interviews.

We interviewed people using **discussion groups**, in **depth interviews**, and **more informal interviews** and **mini-groups** with participants while they were at the support groups. In order to build up a rapport and put participants at their ease, interviewing was carried out face-to-face wherever possible. This approach also enabled interviewers to observe body language and to see first-hand how service users, carers and practitioners interact. Where it was more convenient for carers, this approach was supplemented by telephone depth interviews. The recruitment and arrangements for these were conducted face-to-face at a carers' café or equivalent, allowing the interviewer to meet the participant and explain about the research in person prior to carrying out the interview (usually carried out a few days later).

Interviewing took place between October and November 2009 and each interview session was carefully selected to ensure that urban and rural communities were involved.

### 1.3.3 Discussion groups

The discussion groups allowed some higher level discussions of the shared experiences that carers have, their needs and their assessments of where services are catering for their needs, and where improvements are needed. Discussion groups tend to naturally lead to more consensual discussions and allowed the participants to consider how services affected people from a

number of different circumstances. Participants are less inclined to share some of their more personal experiences, and these were discussed instead in the depth interviews.

#### **1.3.4 Informal interviews**

Informal interviews took place in conjunction with regular community groups and carer support services already attended by services users and carers, to fit in with the demands of their schedule and to cause as little disruption as possible to regular routines. Many of the service users we interviewed discussed their condition and thoughts in short, informal interviews either on their own or in small groups. Most service users were unable to discuss their conditions or the services they used in any detail, but could talk about the events they were attending and their day to day lives.

#### **1.3.5 In depth interviews**

In depth interviews were conducted on the telephone and in participants' homes. We listened to carers' and service users' stories from the period when they first noticed there was something wrong, through to diagnosis and up to the present day. By visiting people's homes and observing their behaviour we could learn a great deal about the challenges that they have. For example, how often they needed to watch their partners, and how they managed day to day chores.

Some participants preferred to be interviewed over the telephone. The advantage of this is that the interviews are more convenient. For example, participants do not feel under pressure to get dressed first, and feel more comfortable about re-booking an interview if they are busy.

The discussion guide used in all of our interviews is enclosed in the appendices.

## 1.4 Participant Profile

Over the course of fieldwork, interviewers attended a series of dementia support drop-in centres and carers' cafés, speaking to service users, carers, co-ordinators and practitioners. Where appropriate, these sessions were followed up by individual depth interviews with carers. The following table provides a detailed breakdown of the interviews which took place.

In total we spoke to around thirty participants.

<b>Interviews: October-November 2009</b>			
<b>Wroxly Music, Pabulum Café</b>	Group interview with six carers	Depth interview with two volunteers	Informal interviews with five carers, two former carers and a number of service users with moderate and more advanced dementia
<b>Wymondham Pabulum Café</b>	Group interview with three full-time carers and three service-users whose conditions ranged from 'mild' to 'advanced'	Depth interview with full-time carer/café volunteer who described her husband's condition as 'moderate'	Depth interview with full-time carer who described his wife's condition as 'acute'
<b>Fakenham Carers Café</b>	Depth interview with part-time carer who described his father-in-law's condition as 'moderate'	Depth interview with full-time carer who described his wife's condition as 'moderate'	Depth interview with full-time carer who described her husband's condition as 'very advanced'
<b>In home depth interviews</b>	Two depth interviews with carers and service users. The service users were unable to take a very active part in the interviews as their dementia was too advanced.		
<b>Telephone depth interviews</b>	Depth interview with full-time carer based in Norwich area, who described his wife's condition as 'advanced'		Two depth interviews with carers based in Norwich area

## 1.5 Acknowledgements

Ipsos MORI would like to thank Laura McCartney-Gray for her assistance throughout this project. We would also like to thank all the service users, carers, volunteers and co-ordinators for taking the time to participate in this research.

## 1.6 Publication of the data

As with all our studies, these findings are subject to our Standard Terms & Conditions of Contract. Any press release or publication of the findings of this survey requires the advance approval of Ipsos MORI. This would only be refused on the grounds of inaccuracy or misinterpretation of the findings.

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# **Chapter 2: Main Findings**

## Chapter 2: Main Findings

This chapter examines the different factors that influence quality of life for people with dementia and their carers. The chapter begins with a summary of the factors or themes that have emerged through the interviews and groups with carers and service users, and the observations made in the interviews.

The different factors are then explored individually in more detail.

Throughout the chapter we consider the relevance of these factors to service users and carers in Norfolk. In the final chapter we consider how NHS Norfolk and its partner agencies should best respond to the challenges they present.

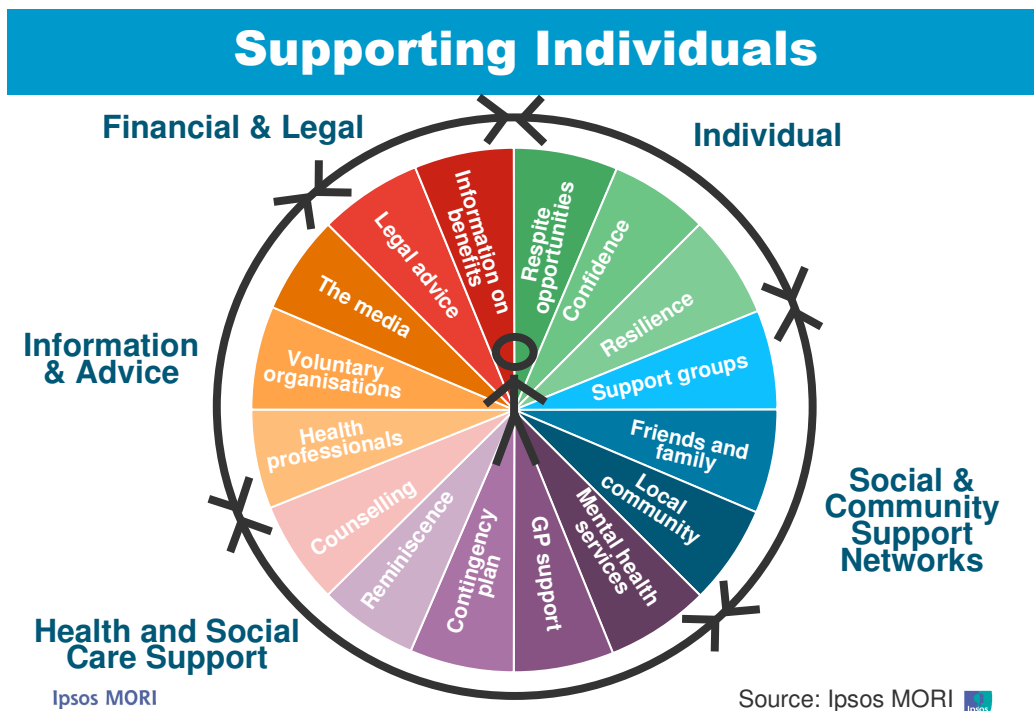
### 2.1 A thematic approach

Not only does dementia affect all aspects of our participants' lives, but it also affects them in different ways. Each of the individuals which we spoke to in the course of this research has had different experiences of the condition and its effects and different experiences of support services in their local area. Moreover, each has developed their own strategies to address the challenges they face.

To help make sense of the variety of responses and the range of topics covered over the course of interviewing we have developed a conceptual framework based upon a series of broad themes, each of which groups together related issues and topics. These are:

- Individual characteristics of the service users and carers;
- The social and community support networks available to them;
- The healthcare services which they encounter in their treatment;
- Sources of information and advice available to service user and carers;
- and
- Long-term financial and legal planning.

The following diagram illustrates the themes and outlines some of the specific issues relevant to each. The themes inter-relate, and our analysis of each in turn helps to draw out common factors and identify key issues for providing dementia support services in future.



Subsequent sections of the report will deal with each of these themes in turn, illustrating them with examples from interviews and providing case studies of individual service users and carers where appropriate.

## 2.2 Individual characteristics of service users and carers

### **Summary:**

The needs of service users and carers vary widely according to their own personality and character traits. While some carers are able to access services and find out information, others struggle to communicate their needs.

An exploration of the individual qualities observed in participants is largely a study of their personal resilience. Having the confidence to ask for help, the sense of entitlement required to ‘shout up’ and the knowledge of where to go can make a big difference. Many of those we spoke to were very proactive about staying informed and finding out about the services available. Indeed, some said that it was important to them to understand as much about the condition as possible as it helped to provide a sense of purpose and, to a limited extent, control.

**“You feel that you’ve always got to be doing something, even though there’s so little that can be done”**

There is also an acknowledgement on the part of some participants, that some carers are not able to make full use of the services that are available, either because they are unaware of them, or struggle to communicate their needs.

**“You’ve got to speak up...make yourself heard. It’s fine for people like us because we will shout if we’re not getting the services we need, but if you’re quieter and don’t make a fuss you can miss out”**

Service users also have different personalities, and different symptoms. In particular, service users could be roughly categorised according to whether they were more active and energetic or more passive and lethargic. Carers suggest that people with dementia who have more energy tend to be more difficult to look after because they may need more attention, and to be more likely to wonder off. Some carers explain that those they care for can be reluctant to go out and attend groups (such as cafés and carer’s groups) or services such as the GPs. That can be a barrier to carers and service users accessing services. In cases like this staff can really help people to access services.

**“The nurse was constantly phoning and asking us to go. [My wife] did not want to go to the meeting and eventually I said to the nurse that we will come... I said [to my wife] we would go and if you don’t like it we will go home. She loved it”**

Staff at the service users’ cafés explained that such a service is not ideal for everybody has some people do not like being sociable and would rather stay at home. In these cases home visits can help carers and service users. Different types of groups can help different people, for example some carers

and service users may prefer organised activities such as singing, or exercise, while others may just want to sit and talk.

Carers and service users will respond to situations differently and will develop their own ways of coping with circumstances. However, highlighting these different attitudes helps to demonstrate the complexity of the situation and demonstrates that the obstacles that service users and carers face go beyond issues of resourcing, finding and logistics. It is clearly important to take such considerations into account when designing services to ensure that they are easily accessible to all, regardless of individual circumstances. Such concerns are clearly reflected in the steps that Norfolk health and social care services as a whole are taking to ensure a more personalised approach to care provision.

## 2.3 Social and community support networks

### **Summary:**

Social and community support groups are a very popular and highly valued service, seen as a vital opportunity for carers to share information and advice, as well as providing a safe and comfortable environment where service users can have access to treatment.

Groups where carers and service users both attend are easier for people to get to as carers do not need to arrange for somebody to take over their caring responsibilities. On the other hand, carers-only groups, while more difficult to arrange, can provide more in the way of respite. There is also more opportunity for carers to share information and learn from visiting experts.

Most of the service users we contacted during the course of this study rely on family and friends as their primary care workers. In fact, in nearly all instances the person responsible for attending to their day-to-day needs was a spouse. Obviously this bond was hugely important to the carers that we spoke to, but it also has implications for the future of long-term care. As one carer pointed out, there are concerns that in future the state won't be able to rely on next of kin to provide care, given the declining marriage rates and increased divorce rates among younger generations<sup>3</sup>.

Community groups also play a huge role in supporting both service users and carers. Drop-in sessions such as Carers' Cafés and Pabulum clearly provide a very valuable service in terms of providing information and advice on services.

**"The Carer's Cafe provides information and advice on local services and the chance to meet other carers who understand what you're going through"**

Many people we interviewed regularly attended several such sessions to make use of a range of services and facilities; often travelling long distances to do so, particularly in more rural areas.

**"There are two groups in North Norfolk and I go to both. There is also a carer's meeting. This means that I get a group a week and a carer's group every month"**

We visited drop-in sessions aimed specifically at carers, as well as cafés for both carers and service users to attend. The services provided by these

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<sup>3</sup> Conversely, another carer remarked that many male carers of a certain age struggled with day-to-day activities such as cooking and cleaning, whereas younger couples were perhaps more likely to have shared such responsibilities from an early age.

centres tend to vary depending on the requirements and interests of those who attend, as well as by the resources available.

**"They think hard about what's going to be most useful for the people who use the service and change what's on offer to suit them"**

However, all of the sessions we attended offered some formal or informal information and advice on healthcare, adult social services, local support groups and voluntary organisations. Some offered regular visits from representatives of such organisations and regular talks on related topics, ranging from reminiscence work to advice on medication. Some sessions also offered additional therapies such as hand massage and counselling services. Some of the session organisers that we spoke with had experience in running other forms of community care centres, others had trained as social work or had been full-time carers themselves. Similarly, many of the volunteers at these sessions were currently carers, or had some experience of being carers in the past.

What was clear from observing the sessions was what an important role they play in the lives of service users and carers by providing easily accessible, community based advice and support in a convenient, comfortable and familiar environment.

**"If it is the day of the [café] she is always really excited about that"**

In addition, these centres play an equally important social role; giving carers and service users the opportunity to talk about and share their experiences. Carers were particularly positive about the benefits of talking to people with shared experiences and who can empathise with their own situation.

**"It's good to know that there are people (there) who can understand what you're going through"**

Carers found particular value in discussing the emotional experiences they go through as carers. For example, in one group they discussed the different ways in which they could manage to cope when their partner asked to go home to, or phone their dead parents. One carer explained this could get really upsetting.

**"She always says is this [home]? Is it just down the road? Can we go home? This goes on and on and on for hours. No matter what I say it won't stop and in the middle of the night"**

Several participants explained how difficult it is dealing with the aftermath of an argument or distressful incident with the person they are caring for. While the carer remembers what had happened and is still wound up, the person with dementia quickly forgets and consequently does not understand when their partner is upset or angry.

**“She started changing her clothes even though she already had some out and ready ... she got the colours all mixed up and I said we have to go. Well she got a bit stroppy with me. I drove off in silence and she forgot all about it ... She says “why are you getting angry with me”**

Another common experience is that those with dementia forget their carers or the relationship they had with them

**“I was on one knee feeding her and thought it was like proposing. I said, “Will you marry me”, and she said “No”. She had just forgotten”**  
**“[After she had woken up in the night] she said “Are you supposed to be in my bed? Where’s mum?”**

Many carers told us that the day-to-day demands of their role severely limit (and in some cases preclude) the opportunity to meet and interact with friends. Importantly, these groups are informal, social and free of the stigma that some carers perceived in public settings. In some cases carers continued to attend the groups either as volunteers or participants after the person they cared for had died.

Staff say that due to their high level of collaboration with local councils, healthcare providers and voluntary organisations, these community groups are able to provide a wide range of services in an efficient and cost-effective format. These sessions are held in the local community (often relying on local volunteers and fundraisers) which means that they can grow organically through word-of-mouth or via their direct involvement with local community life.

## 2.4 Healthcare services

### **Summary:**

Carers do not necessarily *expect* a great deal of support from health services beyond diagnosis and ensuring that the service user is on the correct medication. They often see dementia as more of a social care rather than medical concern. Many believe that service providers are not sufficiently joined up.

Carers often report receiving priority treatment from healthcare services to allow them to continue in their caring role.

Carers currently struggle to find the respite care that they need. There is often insufficient respite for them to relax from the stresses that they face. Nearly all the carers we spoke with explained that they were unable to plan for the future as they never had enough time, energy and support.

The fact that dementia is degenerative and not curable obviously has key implications for the way that service users and carers view health care services. Many expressed scepticism over the role that NHS can have in providing treatment in light of this and this may be a reason why service users and carers are sometimes uncertain about the services which are available to them. It seems that at least part of this scepticism is linked to individual attitudes towards specific services. For instance, one participant said that they felt 'reassured' by the visits that they had received from a psychiatric nurse, but they did not necessarily see such visits as a 'medical' service and found it hard to assess any health benefits they had derived from them.

Those that do have regular contacts with healthcare services are divided in their opinion of the quality of advice and support that they have received. For example, while some were very positive about their relationship with their GPs and spoke highly of the service they receive, others felt that more could be done to provide guidance and information following diagnosis. These mixed views indicate that services vary from area and area and from unit to unit.

**"My local GP was very good at assessing our need and directing us to the correct services"**

**"The diagnosis was very abrupt. There was no real effort to guide you towards help"**

This ambiguity is mirrored by the attitudes of service users and carers to medication. Some of the people we spoke with have a thorough knowledge of the drugs that are used to medicate dementia, their uses and their side-effects. On the other hand, some of those we interviewed struggled to name the medication that they were taking or administering, let alone their affects or associated contra-indications. Though this may indicate that more could be done to explain the use of drugs in the treatment of dementia, many carers acknowledged that it is difficult to know what effects a course of medication is

having, and what changes in the behaviour of the service user are caused by the condition itself. The situation is further complicated by the fact that many people with dementia and their carers also have other health or mobility issues.

Recent years have seen a shift in the debate on dementia treatment, with signs that in future there will be less of a focus in medication and a greater emphasis on early diagnosis so that patients can benefit from a wider range of treatments. This is a major strand of Norfolk's new dementia strategy and the conversations that we had with service users and carers during the course of this research highlight the relevance of these new measures.

Many of the service users we encountered during this research had been diagnosed with dementia a long time ago and the few who had been diagnosed relatively recently had exhibited symptoms for many years. Many spoke of early symptoms which they dismissed as aberrations in otherwise healthy behaviour ('part of getting older') and it is only with hindsight after diagnosis that they identified such behaviour as early manifestations of the condition. The fact that many had not consulted their doctors until reaching 'a crisis point' underlines the difficulties involved in securing an early diagnosis. The situation is further complicated by the fact that the condition itself can cause some patients to deny, or simply forget, that they have it. This in turn can make it difficult for carers to persuade them to seek help, take medication or consent to see health workers.

Positively, most of the participants explained that GPs worked to make sure that diagnosis happened as quickly as possible as soon as they were aware there could be a problem. Several service users had been diagnosed quickly due to their GPs pro-active approach in asking about their health when they were seeing the doctor for another problem.

**“We went to the doctor about something else, and he asked her if she could help her with anything and she said well my memory is going but I think it's my age. He said I would give you a test. We were in the Julian Hospital in a few weeks. They did thorough tests... they caught it very early. The doctor came to see us. He said she was the earliest patient he had who he could give tablets to. This made a difference.”**

One carer explained that quick diagnosis was less helpful for forms of dementia where there are no available types of medication. He explained that for vascular dementia it might be better to not recognise the dementia immediately as “there is nothing you can do”.

Some carers called for more signposting to support services following diagnosis, and complained about the lack of referrals between health services in the public sector and advice agencies in the third sector. Although there was an acknowledgment among some that data confidentiality played a part in this situation, service users and carers clearly feel that more can be done to improve matters.

**“When you get diagnosed, they should go: ‘Here. Here’s where you can go to find out more’...But that doesn’t seem to happen.”**

**“The doctors should refer you to the charities. I know there is a big gap between the National Health Service and the charities”**

One carer suggested that a check list should be introduced so that nurses are aware of all the different forms of help that carers and people with dementia may need, and are told where they might be available.

**“I can’t see why they don’t have a just a simple check list. The practice nurse should have a check list for Alzheimer’s. Have you dealt with this, this and this?”**

In fact, the need for local healthcare services to ‘join the dots’ and to ‘work together more closely’ was a theme of many interviews. The benefits of doing so were highlighted by the example of one carer who described how they were given priority treatment for their own health issues so that they could continue to care for their spouse. They pointed out that this was only possible because their GP was aware of their role as a carer and appreciated the difficulties of arranging contingency care while they were unwell. Indeed, many carers spoke of the difficulties that their own health issues presented, and several felt that the demands that caring had placed upon them had damaged their own well-being. This in turn underlines the importance of respite services to enable carers themselves to take a break from the relentless demands of their role. Respite care is often seen as the urgent need to have some time alone, and rest physically and emotionally. This need is rarely if ever met and this affects the health of carers.

Most carers we spoke to were aware of the respite care available through Crossroads<sup>4</sup>, which were universally seen as a very valuable service. However, high demand and limited resources were widely acknowledged to be an issue and some carers admitted that they saw respite care as a ‘last resort’.

Carers without close family members to rely on found it particularly hard to arrange respite care. Moreover, carers with families remarked that their relationship with their family had changed because their families are visiting to provide respite rather than as family. Arranging respite care is also clearly a major difficulty for those looking after someone who is prone to aggressive or inappropriate behaviour, or whose physical size or weight makes it particularly hard to care for.

In the most extreme cases, respite services struggle to manage the behaviour of service users – it is these cases where the carer is under most pressure from demands of caring for partner and yet also when it is most difficult to find

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4 A charitable organisation which provides respite support for carers and their families via a national network of local charities. Adult Social Services is a major funder in Norfolk.

any other agency with the skills and facilities to step in effectively. In these cases, carers are forced back onto their own resources once more until another 'crisis point is reached'. In such circumstances carers expressed frustration at doing so much to be independent and self-sufficient and then not being able to access services when most required. Conversely, other carers described themselves as 'lucky', because the person they looked after was relatively passive and their behaviour much easier to cope with.

## 2.5 Information, Advice and Training

### **Summary:**

The levels of information and knowledge that carers have varies considerably, with some becoming experts on dementia and others having minimal understanding of the condition. Personal experience and the suggestions from others are also a vital resource, particularly as dementia can be manifested in such a variety of ways.

We have already seen the important role that GP practices and other healthcare services have as a source of information about dementia and the services available to support people whose lives are affected by it. However, there seems to be a great deal of variety in how much patients know and understand, and while some carers say that they have received a great deal of information from local health services, others say that they were not sure where to turn to. Some people felt that ‘you have to be quite loud and pushy’ to get the services that are available, whereas people who are less assertive can often miss out or not realise that there is support out there.

Newsletters from agencies such as the Alzheimer’s Society are also widely cited as important sources of up-to-date and reliable information, while community cafés and drop-in centres are also an invaluable forum for carers to discuss their experiences and to share information and advice. Often this advice covers practical issues such as how to lift a partner who is unable to turn themselves in bed or ways of reassuring them by talking to them about a familiar topic. Perhaps the most important support available at these sessions comes from empathising with other carers.

Some carers had been on different training courses lasting between six and twelve weeks. They heard about these courses through their mental health treatment. All those that had attended them all reported that they were extremely beneficial, particularly at the early stages. They mentioned receiving legal and financial advice and learning about medical aspects of Alzheimer’s.

**“It was a series of 12 weeks every Thursday... I didn’t even know what Alzheimer’s meant before then. If I hadn’t have gone I wouldn’t have known. All sorts of people attended. Nurses, police... and then the powers that be ran out of money”**

What also became apparent over the course of this research was the expertise that carers themselves demonstrate in meeting and anticipating the needs of those they care for. Many of the carers that we spoke to husbands or wives who had been looking after their partners for many years, during which time they had developed an incredibly deep understanding of their needs.

**“It’s like being a parent; you have to work it out for yourself”**

Of course such an understanding also carries with it a huge emotional commitment to the looked after person, which can mean that some carers sometimes find it difficult to give objective information about their experiences. Similarly, one carer who had arranged respite care for three hours a week described how they usually spent the first hour explaining their partners needs and how best to cope with them.

## 2.6 Financial & Legal Planning

### **Summary:**

The financial aspects of caring for somebody with dementia were of concern to all the participants taking part in the research. The demands on carers' time means that it is difficult for them to investigate what benefits or advice is available. Because of this many carers did not know what benefits they were entitled to. Even those that did were often unsure about whether they or their partners would be entitled to support in finding and funding care and accommodation in future.

Most of the carers we spoke to had some financial and legal concerns, either in the short term (receiving the correct benefits, and support), and in the longer term (funding care homes, and organising Wills and other legal documents).

Carers mentioned receiving a number of benefits and different types of financial support. Many carers received attendance allowance, carers allowance and reduced council tax. Other's mentioned receiving support to help with their heating, and aids (such as rails) to help their partner's mobility around the home.

Many carers were confused about the financial benefits that they should have access to. Among those who do feel informed, the Citizen's Advice Bureau (CAB) was cited as good source of information, as was the Alzheimer's Society and Age Concern, which also offers in-home assessments. However, though advice is available, some people are unaware that they may be eligible for help, indicating that more guidance to point people towards these sources of advice would be beneficial.

Participants in one Pabulum group explained that the group had been vital in informing them about the benefits they should have been on.

**“And that's us in an organisation [Pabulum], that we are pleased to be in, but then there's lots of people without who are not in that. My sister ... [won't join an organisation like Pabulum] and nobody will tell her [about benefits] nobody will come to see her and talk to her.”**

Even when carers are told about the benefits they should be receiving, they may still need support completing the forms correctly. For example, one carer explained that he was refused Attendance Allowance when he had applied without the help and support of Age Concern. It was only once he had had support filling it in that the benefit had come through.

**“I tried for [Attendance Allowance] a couple of occasions and it was refused. Then [somebody from Pabulum] came. She came round the house and helped me fill it out.**

One of the younger carers (caring for his mother in law) find out about the benefits he could receive through the internet. This may become an increasingly popular method of accessing information over time.

The carers that we spoke to say that their role makes such demands on their time that they find it incredibly hard to find the time and energy to plan ahead. Again and again carers talked of 'taking each day as it comes'. Clearly such pressures are not conducive to long-term planning, so it is perhaps unsurprising that so few of those we spoke to had given detailed thought to planning for the future.

Some carers also expressed frustration over the current means-tested approach to providing home care and accommodation. There was a perception among some that it is better off not to have any savings and thereby be eligible to receive financial support than to have assets and be forced to sell them to pay for treatment and accommodation. Added to this is the fear of what happens when the money runs out. Such concerns are clearly a source of worry to many of the carers we spoke to, and yet without the time to access information about the options available, they do not have the opportunity to pre-empt events by putting support structures in place in advance.

# **Chapter 3: Case Studies**

## Chapter 3: Case Studies

### **Chapter summary:**

This chapter includes six case studies considering the experiences and opinions of service users and their carers in depth. The participant's real names have not been used to preserve their anonymity.

Each case study includes a brief summary of the key factors described in our conceptual framework that influence (either positively or negatively) carers and service users' ability to have the highest possible quality of life. We have adopted a traffic light system that can be used to quickly reference where the supports and barriers are to maximising service users and their carers' wellbeing. Green indicates that the carer and service user have no major difficulties or barriers in a particular area and red indicates significant difficulties.

The case studies themselves explore the particular journeys that service users and carers have been on, and their thoughts about where improvements can be made. They give a flavour of the variety of different circumstances that affect different people.

## Case Study 1: John and Jane

### Summary:

This case study highlights the importance of respite care, particularly for those without wider family support and for cases where those with dementia are less active and difficult to manage.

Although John has received valuable information and advice, the lack of respite care means he is struggling to plan for the future.

Individual	Social & Communal	Health and social care	Information & Advice	Financial & Legal
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**Individual:** John is able to access services and find out what help is available. The lack of available respite care means that he is often too tired to plan for the future.

**Social & Communal:** John and Jane do not have family and friends available to help them. They do however receive support from Crossroads and regularly attend two Pabulum Cafés.

**Healthcare:** Jane has received excellent help and the medications that she uses have really helped her. The reminiscence classes that she had helped John and Jane at the time.

**Information & Advice:** John receives advice through the Cafés he attends. He also uses a number of sources such as the Alzheimer’s Society to find out about dementia and dementia services.

**Financial & Legal:** John has a good understanding of the benefits he should be on. He does not have enough time to fully explore the longer term financial and legal issues he would face if he went on holiday or if his wife had to go to a home.

### Background:

John is 80 years old and has been married to his wife Jane for 50 years. He works as her sole carer, because he has no family or friends who could help him in his supporting role. He receives three hours of respite in his home a week. He has had a hip replacement and may need another one. He was extremely tired and stressed in the interview, and sometimes struggled to collect his thoughts (partly because he was constantly keeping an eye on his wife). He had only slept a few hours because Jane had wet the bed the night before.

Jane has fairly severe dementia. Her short term memory now lasts for only a minute or two at the most. She was diagnosed ten years ago with dementia.

Since then she has been given medication to slow down the development of the condition. This has worked to some extent although John now believes that the medication has stopped working. The reason that she is still using it may be that withdrawal would cause more harm than continuing with the medication. She was unaware of what was going on for a lot of the time, but was still able to get some benefit from the music played at the Pabulum session that she attended. Her dementia was too severe for her to be interviewed about her condition, but she did enjoy talking in general terms about her childhood. She has quite a lot of energy and is now incontinent. For that reason, John cannot leave her alone for any length of time. This is probably the greatest difficulty he faces.

## Medical Care

Jane realised that her memory was going before the dementia was very advanced and she decided to go to the GP herself. John reports that she was diagnosed very quickly, and received a very good service from the NHS. She had six monthly visits from qualified staff. They were primarily concerned with the medical aspects of the dementia in particular whether or not she was on the right amount of medication.

He believes his wife was given the medication she needs – and that it has made a significant difference in allowing her to live for such a long time with the condition. He is concerned that in the future patients will not receive the medication that they need.

**“[NICE] now say they should only give the tablets when the disease has reached the middle stages. That is absolutely ridiculous. The whole point is fending off the process as soon as you know about it.”**

John has a good understanding of dementia and dementia services. His understanding largely comes from reading articles from the Alzheimer’s Society.

## Pabulum Café and support groups

John expects the NHS to primarily offer medical support, and sees other forms of help as more to do with the social services. He knows that there is an NHS Carers Group but he is unable to access this as there are insufficient resources at Crossroads for somebody to look after his wife. In his experience NHS staff have not given him advice about where to find out information or support. All the advice he has received has been through the voluntary sector.

He does go to two Pabulum Cafés (run by Age Concern) which give him the opportunity to talk to other carers. He attends both sessions with his wife, the advantage of which is that he can attend them without the need for a support worker. However, he feels that he is not able to totally relax at the groups as he has to continue caring for his wife.

**“You don’t get to run away from the problem. You are always aware that they are there. I can’t get away for more than [20 minutes] unless I am aware that there is somebody there dedicated to the patient [Jane].”**

He has heard from another carer that there is another similar community Café available nearby and he would like to join that if there is space available. In his experience the quality of the sessions that he visits has declined in the last ten years due to lack of funding. In the past the groups that he visited employed a mental health helper who conducted a series of reminiscence sessions based on issues such as going to the seaside and shopping. She also brought information about things like getting your council tax reduced, how to contact Crossroads. They also had a solicitor to come in on one day to give advice. He believes that current services are of a poorer quality due to a reduction in the funding available.

### Reminiscence classes

John has used reminiscence classes at a Pabulum Café session. He explained that they were only of use to his wife in the very early stages of dementia. They did help him to understand dementia better and prepare for the deterioration of his wife’s condition. He suggested that the classes were of a great help at the time and provided interest to his wife when she could still remember her childhood.

**“What pabulum did was ideal. Going to seaside was about going to the seaside in the 1950’s or 1940’s.”**

He feels that their use is limited in the later stages, and there also needs to be some investment in respite for the carer, which is vital to the middle and later stages of the condition.

### Respite care

John explained that his single greatest need is to receive additional respite care. He currently receives three hours care once a week. This time is reduced by the need to prepare for the Crossroads carer support worker. In this time he tried to go to a café in town so he can quietly read for a few hours, sometimes however he has to use the time for shopping or other jobs.

He explained that this is insufficient as he constantly has to stay alert and keep an eye on his wife. During the interview he constantly had to stop talking to make sure that his wife was alright. This need meant that at times he found it difficult to concentrate on the conversation. He explained that he was scared of leaving his wife for a moment as she would get in to trouble if left alone for any period of time.

**“It’s unbelievably stressful you never get away from it. Never. I’ll go and hang out that sheet [on the washing line] and come back and a problem will have erupted.”**

When asked how much respite time he needed, he suggested that three respite periods a week would make a tremendous difference to his health.

At the present time his respite time is insufficient to manage any long term planning. He explained that he would like to take a holiday, but has not had time to plan for the holiday in terms of organising the holiday itself, the care that his wife will need while he is away, and the financial planning needed to pay for his wife's care during that time. He feels perfectly capable of planning these things but he does not have the time or energy to manage it. This means that he is living day by day rather than developing coping strategies that could make things more manageable for him in the longer term.

## Case Study 2: Bert and Brenda

### Summary:

For Bert it is important that services are local and that he can talk to people he is familiar with. This case study stresses the importance of continuity of care for some, and the role that Pabulum Cafés and similar community groups can have in joining up services to make them more accessible.

<b>Individual</b>	<b>Social &amp; Communal</b>	<b>Health and social care</b>	<b>Information &amp; Advice</b>	<b>Financial &amp; Legal</b>
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**Individual:** Bert makes use of a limited number of local services to access information and support. He is relatively mobile, but is more comfortable using services which he is familiar with.

**Social & Communal:** Bert and Brenda have a daughter who lives nearby who visits regularly. She has made arrangements with her employer for her to be available at short notice, should either Bert or Brenda require her assistance.

**Healthcare:** Bert says that he has had very little support from healthcare services, but admits that Brenda dislikes visits from health workers and can be uncooperative when it comes to following medical advice.

**Information & Advice:** Bert regularly attends a carers' café and relies on the practitioners there for information and advice as and when he needs it.

**Financial & Legal:** Bert has a good understanding of the benefits available to him as a full-time carer, but admits that he has done little in the way of long-term planning as he is still coming to terms with his wife's condition.

### Background:

Bert cares for his wife Brenda, who was diagnosed with dementia 4 years ago. He regularly attends a monthly carers' café which takes place just down the road from his home and occasionally drives to a local village to take part in a community support group. The couple have lived in the local neighbourhood for 20 years and both still has close links with the community and friends nearby. They are both able to make occasional trips to the local pub together, though these trips have become rarer as Brenda's condition has deteriorated. They also have family members who are based in the area – their daughter works 15 minutes drive away and has arranged with her employer to be able to leave work at short notice if necessary.

## Medical Care

Bert feels that he has little contact with local health services, except nurses who attend the carers' café.

**“I go straight to her. They're always here and they all know me”**

Consequently he relies on a few individuals for support and advice. In our interview he was initially dismissive of the role that health service currently plays in helping them. However, he later explained that he finds it hard to make use of the health services as Brenda is often uncooperative or refuses help. He therefore tends to find it easier to make use of those services which are accessible through channels that he is familiar with and which suit his lifestyle and needs (i.e. local, relatively informal and in familiar surroundings).

## Community support groups

Bert is very positive about the support groups that he attends. As well as appreciating the opportunity to speak to healthcare professionals in an informal environment, he relishes the social aspects of the sessions and is well known to the regular attendees.

**“It gives you a chance to get away from it for a while. Gives you a bit of time to yourself.”**

However, it's also clear that he continues to worry about Brenda while he is at the session and is concerned about her welfare all the time that he is away from her. The fact that the centre is close to his home is very important to him in this respect, as is the relationship that he has with the Crossroads carer who comes to look after Brenda while he is away.

## The future

Bert seems to have found a reliable support network in his local area. He is familiar with the volunteers and health workers at the carers' café and seems comfortable and confident in this environment. However, he expresses uncertainty about the future and sees himself and Brenda relying more and more heavily on their daughter for respite care as they grow older. He is however determined to continue caring for Brenda and living relatively independently for the foreseeable future.

## Case Study 3: Mark and Barbara

### Summary:

Mark's mental health problems means that he is less able to access information and services, as he has less energy than others, and is less confident about demanding support. Despite his partner having had dementia for ten years they are only just starting to receive the support they need. The case study highlights the importance of sign posting and actively encouraging people to use services particularly with more vulnerable groups.

<b>Individual</b>	<b>Social &amp; Communal</b>	<b>Health and social care</b>	<b>Information &amp; Advice</b>	<b>Financial &amp; Legal</b>
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**Individual:** Mark finds it very difficult to care for Barbara because of his depression and agoraphobia. He is not confident about contacting service providers, and his depression is a barrier to longer term management and planning.

**Social & Communal:** Mark and Barbara have now started attending a community Café for service users and carers. Mark believes that he will be able to use the clinic to meet people and access information. Unfortunately his depression and agoraphobia are a barrier to him attending.

**Healthcare:** Mark has little understanding of the healthcare needs of Barbara and of what medication she is on. His own mental health is a barrier to him being able to care for Barbara the way he would like to.

**Information & Advice:** In the past Mark has not had much access to information and advice. However, this is improving now that he has started to attend a Pabulum Café.

**Financial & Legal:** Again, Mark's access to financial and legal information is improving now that he attends a Pabulum Café.

### Background:

Mark suffers from depression and agoraphobia, and his wife Barbara has Alzheimer's. He suggests that the depression began thirty years ago when he was involved in a legal dispute with his neighbours that have continued to this day. He has had agoraphobia for the past five years. He has some help from a psychiatric nurse but it has not been very effective.

**"I don't have no interest in anything in life, apart from my wife. My wife she takes my time, and I sit around the rest of the day. I used to be**

**involved in quite a few things – I was a member and chairman of quite a few associations but I don't have any interests these days."**

Like all the sole carers we spoke to his caring role dominates his life. He is concerned that his mental health condition is a major barrier to him providing his wife with the care that he feels that she needs. His mental health problems make him very lethargic and he finds it difficult to manage jobs such as cooking and washing. Shopping is particularly difficult because of his agoraphobia.

**"I am doing the best I can but I just can't look after her the way I want to look after her."**

His agoraphobia also means that he finds it difficult to use facilities and support services, as he cannot easily leave the house. To some extent the organisers have adopted to this problem by phoning him on the day of the meetings, and this has helped him to attend. While he finds caring difficult; he feels that his love for his wife and his role as a carer are helping him to keep coping with his condition.

**"If it wasn't for my wife's condition then I wouldn't want to be living"**

Barbara now has fairly advanced dementia, and has had dementia symptoms for the past ten years. She is now on medication for her symptoms but Mark does not know what medication she is on and has little understanding about what the medication does. Barbara's dementia means that she is fairly passive and "*not very demanding in any way*". This means that in some ways she is easier to look after than some of the other people with dementia who we met and talked to.

Mark first realised his wife might have dementia when she started walking off alone when he left her at a car park. They spoke to their GP, who was "very understanding" and referred Barbara to a psychiatrist, who in turn was quick to diagnose his wife with dementia. Mark described the day that her Alzheimer's was confirmed as the "*blackest day of my life*". One reason for this was that his father had already had dementia, for this reason he had some understanding about what was likely to happen. Mark was already a member of the Alzheimer's society when his wife was diagnosed.

When asked whether services could have been improved Mark suggested that he could have been given more information at the early stages of diagnosis. Despite Barbara having dementia for ten years he has only recently been in contact with his local carers' Café. In general, has not actively looked for support services (probably because of his depression). One example of this is that he knows that the local Alzheimer's society group may be running some services, but he has not contacted them to find out what services are available. He would like support organisations to contact him directly.

## Support and funding

Mark feels that dementia is not adequately funded, and is not seen as a priority by ordinary people, by health care workers, and by those commissioning services. He believes that ordinary people would understand dementia better if there were more stories about it.

**“You mention cancer and everybody drops everything [to help] and there is fundraising... service [providers] don’t have time or money.”**

He feels that more face to face support would make a significant impact on his and his wife’s condition. This is particularly important as he does not get out of the house, and is not able to talk to people much. At the Pabulum Café he did not talk to many people, or take a very active part in the activities.

**“I would like a more regular visit from the psychiatric nurse. They can only spend so much time on each patient. It’s a lack of staff ... It would really help if I could talk to somebody about my problems”.**

He would also like somebody to visit to see his wife. At the moment he explains that there is no regular support for her from a dementia specialist. He explained that she was on the wrong medication for a long time. He believes that with more face to face contact this problem would have been identified earlier.

## Carers’ Cafés and Crossroads

He has only recently started to attend Pabulum Café (and has just attended a few sessions). He feels that these helps to inform carers about what help is available. Since attending he says that he has realised that other carers have a greater understanding about the help that is available (such as financial support and advice). Age Concern have been involved in helping him to get in touch with other services, and it seems that he has recently started finding out about services such as Crossroads.

It is extremely difficult for him to attend the Pabulum Café sessions, due to his agoraphobia and staff working there explained that they found it a struggle to persuade him to attend.

He suggests that the Crossroads service would be unsuitable for him as he finds it very difficult to leave the house. It would be better if he could receive respite by somebody taking his wife out to a care service. He has been told about a course that is coming up and Crossroads have said they might be able to give him the support he needs to attend.

## Case Study 4: Anne and Peter

### Summary:

Anne has had very negative experiences of healthcare services. Although she is confident and independent she has not had the support, advice and information that she needs in her caring role.

Individual	Social & Communal	Health and social care	Information & Advice	Financial & Legal
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**Individual:** Anne is very independent and is proactive about seeking out advice about the condition and the services available to support carers.

**Social & Communal:** Anne attends carers' cafés whenever she is able, usually about once a week. She also has a nearby neighbour who cares for someone with mobility problems, whom she regularly turns to for support and advice.

**Healthcare:** Anne is very positive about the support she has received from her local GP. However, she feels frustrated by the number of obstacles she's had to overcome to access reliable respite care.

**Information & Advice:** Anne makes full use of the information available at her local carer's café, but she feels that more could be done to provide advice about training, respite care and planning for the future when dementia is first diagnosed.

**Financial & Legal:** Anne has found it difficult to find time to plan for the future due to the daily demands she faces as a full-time carer.

### Background:

Anne is a full-time carer for her husband Peter, whose dementia is at an advanced stage. Each month she travels to a nearby village to attend a monthly carers' café. She and Peter also occasionally attend a referrals-only day care centre when she is able to arrange transport. She was keen to take part in an interview as she feels reticent and about discussing her experiences with the rest of the group, in case they demoralise those whose cases are relatively less developed.

### Medical Care

Peter was diagnosed with dementia in 2004 and Anne has assumed the responsibilities of full-time carer, slowly learning how to cope with all aspects

of her husband's condition from how to turn him in bed to how to reassure him when he becomes disoriented or alarmed. In general Anne manages to take care of Peter's day-to-day needs, but at a routine check up at her local GP, it became clear the demands of his condition have started to have an impact on her own health. Having been diagnosed with very high blood pressure, Anne was advised to look into respite care to enable her to take a break. However she found it incredibly hard to find suitable accommodation that could cater to his requirements. When she was able to arrange for a care home to look after Peter for a weekend, she was soon called by them as they said that they could not control her husband.

**“If they can't look after him for an afternoon, how do they imagine that I cope every single day?”**

She similarly feels 'very frustrated' by social services who were unable to find a suitable place for Peter to be cared for while she was in hospital for an operation, despite having been given plenty of advance warning. In light of these experiences, she adamantly believes that there should be more resources available so that support services can step in to provide care when a regular carer is unable to do so.

## Case Study 5: Fred and Joan

### Summary:

In general, Fred and Joan have had access to very good services. This case study illustrates the way in which Pabulum Cafés and similar groups can really help both carers and service users. In particular a pro-active enquiry from the doctor on Joan's health meant that she was diagnosed quickly.

On the other hand, a lack of legal and financial advice has meant that Fred has missed out on benefits that could have really helped his quality of life.

Individual	Social & Communal	Health and social care	Information & Advice	Financial & Legal
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**Individual:** Fred and Joan are both fairly extravert, and seem to be confident around people. Fred feels that he has good access to services where he lives.

**Social & Communal:** They have no family in Norfolk but they do have a number of friends. Fred is very involved in the local community, and is in contact with a number of people through veteran's organisations. He is on the committee of a number of societies, including voluntary groups and this has meant that he has a good knowledge of what services are available locally. Fred and Joan attend two weekly groups for carers and service users. In addition, their family have also been able to provide occasional respite care.

**Healthcare:** Fred reports receiving excellent healthcare locally both for himself and for Joan.

**Information & Advice:** In common with a number of other carers, Fred uses the Alzheimer's society magazine as a key source of information. He has also had access to the Carers Supporters Group.

**Financial & Legal:** Fred and Joan now have now had access to legal and financial advice and are on all the benefits that they should be on. Unfortunately they were not told about the benefits available to them for a long time and consequently missed out on support for three years.

### Background:

Fred and Joan have been married for over fifty years. Joan has had Alzheimer's for at least nine years. She now forgets most things very quickly but she still remembers music and songs. She enjoys Wroxy Music and looks forward to it. Joan needs a lot of support as she is energetic and Fred worries about leaving her on her own. Fred described the emotional difficulties of being married to somebody with Alzheimer's. One of the more distressing things is that Joan regularly forgets that they are married to each other.

**“She sometimes comes to the kitchen when I cook and asks whether I will marry her. ...you have to have a good sense of humour”**

The carers at the sessions we attended discussed some of the things that their partners forgot and the emotional consequences of being married to somebody who is losing their memory. Sharing these stories (and laughing about them) was clearly very important to the carers attending the groups, and they were the first things to be discussed when the carers attended the group.

## Diagnosis

Joan was diagnosed with dementia after Fred's doctor asked him how she was getting along. He explained that she was forgetting things, but assumed it was just part of an aging process. Fred's doctor responded very quickly and Joan was soon given an ECG scan, and diagnosed with dementia. At this stage Fred was introduced to carers support for a six week course.

**“We are living in a very good part of Norfolk where we are getting every kind of attention we ask for”**

He has also had support from a social worker who helped them to get a stair lift and smoke alarms. He employs a gardener as he no longer has time to cut the grass. He also has to ask people like hair dressers to visit him as it is difficult for him to get out. He does find his role as a carer tiring as he has to spend most of his time making sure that Joan is alright.

**“I sleep very lightly... you are always listening out to see if anything is wrong”**

He manages his time around her, and will get more done on days that she is tired and sleeping. On other days it is more difficult. On a number of occasions he has found her packing her bag to go back home to her parents. Fred explains that you learn how to manage this kind of event through experience and by sharing information and experiences with other carers.

**“You don't [argue with her] you just say “sit down and I'll make you a coffee” and then I go back to the bag and put everything back where it should be”**

Fred uses the Crossroads service regularly so that he can have some regular respite. Somebody comes round once a week so that he gets some time off. He likes to watch a film, go round the shops or go for a pint with a friend. They have also supported him when he has had to go to hospital for his knee and hernia operations. He also has friends who are helping him out with shopping and other jobs.

## Financial advice

Fred did not get any advice from healthcare and social care professionals about the benefits and allowances that he and Joan were entitled to. He eventually found out about the benefits from a discussion with a member of the Alzheimer's Society. He argues that somebody should have told him about this at an earlier stage, particularly as he lost out on three years of benefits.

## Pabulum Café and community support groups

When they were first told about Pabulum Café they were sceptical as they thought it would be too old fashioned. Both Fred and Joan now enjoy attending the sessions, and Joan particularly enjoys listening to music.

**“If it is the club on – she gets quite excited about that. She likes music and still knows the new tunes as well as the old ones”**

## Case Study 6: Ian and Sarah

### Summary:

Ian has also had some very positive experiences with the services that he has used. In particular he values the fact that healthcare providers have prioritised his own health so he can continue in his caring role.

Individual	Social & Communal	Health and social care	Information & Advice	Financial & Legal
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**Individual:** Ian is confident in accessing services and finding out about dementia.

**Social & Communal:** Ian has more support than some of the carers we interviewed. He attends several carer support groups. He has family in England and abroad who help to support him when they can – however they cannot come over that often as they live far away. He also regularly meets a friend who is also a carer. Sarah also has a sister who has been of some help; however she is now a carer herself.

**Healthcare:** Sarah has severe dementia. She has not always been given the most suitable medication. Ian did not suggest that this was the fault of any healthcare staff. Ian has had a few health problems but has been prioritised by the NHS so that he can continue with his caring role. They have worked hard to ensure that she is looked after when ever he has any problems.

**Information & Advice:** Ian is now very knowledgeable about dementia. He has learnt a lot about the condition from the Alzheimer's' Society and medical science magazines. He also has a good knowledge about the support services that are available in the area. He attended a course for carers at the Julian Hospital which he found invaluable.

**Financial & Legal:** Ian has been given financial and legal advice through a carers' scheme run through the Julian Hospital.

### Background:

Ian is 87 years old. He came to Norfolk to retire and so does not have any family in the area. Never the less he has some friends, including a friend whose partner also has dementia who he sees fairly regularly. He is interested in gardening. He looks after Sarah and manages all the housework.

Sarah has fairly advanced dementia, and has very little memory at all. She has had dementia for about 13 years. Her symptoms are that she is fairly immobile most of the time. This affects the activities that they can manage.

She is however very quiet which means that she does not need a great deal of attention from Ian. This means that the emotional side of caring for somebody who “isn’t really there” is more draining for him than the physical side of looking after her.

## Diagnosis

It took some time for Sarah to be diagnosed with Alzheimer’s. Her first symptom was that she had tried to say something to Ian and had not been able to speak. She was originally treated for epilepsy for the first few years. Eventually she was diagnosed in Australia, and this was confirmed in England. She had a few problems getting on the right medication. The medication was changed after Ian asked for a review. The medication had strong side effects and she slept all the time. After stopping the medication her condition briefly seemed to improve and then started to deteriorate again. Sarah is now very lethargic and is asleep for most of the time. This means that Ian does not find the job of looking after Sarah as difficult as other carers.

**“I have to say once I have got her up and washed her and fed her. She’s quiet ‘til lunchtime.”**

## Information and support

Ian has found out about dementia through a wide range of sources. He explained that the Alzheimer’s Society magazine had been invaluable. He also benefitted from a course that was available at the Julian Hospital.

**“The Julian Hospital offered a six week course for carers. They helped with the financial stuff and solicitors and that sort of thing... So I am aware of all that. I am not sure if others are.”**

Another way of gathering information is through the attendance of a Pabulum Café and an aromatherapy massage group. He values the opportunities to meet other people and share advice and information with other carers. Ian feels that Sarah and he do not get many opportunities to meet other people as it is difficult for Sarah to go out anywhere with her mobility problems.

**“We tend to be somewhat isolated. We can’t get out to people. People can come out to us.”**

Ian has had several health problems recently where he has had to go to hospital (for example he has had a hip replacement and a hernia operation). He has found the health services very responsive both in terms of prioritising him as a carer and in terms of working to ensure that somebody is available to look after Sarah when he is in hospital. This is particularly important as it gives peace of mind.

**“I have unfortunately had to go to hospital a lot recently and they [Crossroads] have always been around to help me out... I can't really find fault with the service”**