

Carers' Chronicles

Convenient transport and easy access to buildings
Services that respond when circumstances change
Information and advice about money • Support and help with the practical things
Choice, getting services that are right for you • Prompt diagnosis and treatment

Being listened to and respected

Easy access to information and advice at times which suit
Looking after carers' well-being • Friends and families who keep
Communities that are welcoming • Help with keeping up old interests
Information about carers' entitlements in lots of ordinary places
Getting a holiday • Good quality services
Good care for your physical health needs
Advice on keeping well and active

Carers' Chronicles

The way it is and signposts for the future

This report has been produced for

- People with dementia and their carers
- Angus Council
- Dundee Council
- Perth and Kinross Council
- Voluntary organisations
- NHS Tayside.

Thank you to all the carers who contributed to this project.

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Section 1: About this project

NHS Tayside and the local authorities in the areas it serves – Perth and Kinross, Dundee and Angus Councils – wanted to find out about the experiences of people who have dementia and their carers.

There are many ways through which people with dementia and their carers can and do contribute their experiences and views as feedback to people who provide services.

This project describes what carers said through a diary which they kept about their contact with services. People kept diaries for 2-4 weeks in early 2006. They told us about themselves and the person they cared for, and then noted what happened each day.

Design of the project

This was a joint project involving NHS Tayside, the three local authorities, the Dementia Services Development Centre and Outside the Box Development Support. The project was based on the Health Champions project, where Outside the Box had worked with carers of people with learning disabilities in Ayrshire to identify their experiences of health services and their suggestions for how services could best suit people with disabilities and their carers. Gathering information and reflections through diaries completed by participants is a well-established social research method and is a rich source of qualitative information. The design of the Tayside project was informed by the experience of the people involved in the Ayrshire project – we kept the parts that had worked and followed their suggestions of ways to improve the method.

All the people who completed the diaries volunteered to do this in response to advertisements. In the information we gave out about the diary project, the term 'memory difficulties' was used, rather than dementia.

Two people acted as links for the people completing the diaries. This meant that people taking part could ask someone questions at any time about the project or the services they receive, or just talk over any matter that concerned them. One of the link people was a volunteer with the Public Partnership Group (the health service patient and public involvement project) who is also the carer of someone with dementia. The second link person was the Managed Care Network Dementia

Project Worker: the Managed Care Network is a way of linking services together to improve the quality of care.

The questions in the diary were developed by Sylvia Cox at the Dementia Services Development Centre, based on the original Health Champions diaries. The list of questions is included at the end of this report.

We tried the diaries with just a couple of people to start off with, and this pilot showed that two weeks was long enough to cover a range of services and situations, and was a manageable period for the people completing the diaries.

The people taking part in the main project were asked to keep the diaries for 4 weeks. Some people stopped earlier – for example, because the carer or the person with dementia was unwell, or when the pattern of services and the well-being of the people involved were steady and the carer felt that little was changing from day to day.

17 diaries were returned from the two stages of the study, describing the care for 18 people. The people who contributed came from all 3 Council areas.

Benefits and limitations of the approach

We chose this approach because it has several benefits.

- The people who complete the diaries have control over what they record – they can include as little or as much detail as they want.
- It lets people note their contact with the full range of services they use – health, social work, private care and voluntary organisations.
- It shows how the services interact.
- People can also describe the support from friends and family, which tends to get missed from surveys that focus only on formal services.
- People can describe factual points – such as whether the person delivering the service arrived on time and the outcome for the person receiving care.
- They can also describe their feelings about the day, or about previous experiences which this has reminded them about, if they want.
- We supplied sheets of stickers with smiley and sad faces, ticks and crosses etc – so it was easy for people who found writing

difficult to also use the diaries or if people wanted to use this to convey how they felt.

- The diaries were designed to be used by the family carers and by the people with memory problems, if they chose to do this. The diaries could also be used by several family carers if this suited the family.

We are aware that this approach has some limitations, and these need to be borne in mind when people are reading this report.

- The number of people completing the diaries is small.
- The people who took part are not necessarily representative of all the people who receive services, or of people who have dementia and their carers.

This project complements and adds to the other sources of information we have from people who have dementia and their carers. In particular, it adds to the information that has been gathered as part of the mapping exercise carried out by the MCN Dementia Project Worker. It will contribute to planning of health and social care services in Perth and Kinross, Dundee and Angus. In particular, it will form part of the on-going development of the Dementia Integrated Care Pathway. The project has also started to explore the potential of this use of diaries completed by family carers to enhance the ways we involve people with dementia and their carers in planning delivery of the care and services they receive.

Several of the people who took part in the project told their link person or wrote in the diary that they had found keeping the diary helpful. For example, a few people were facing a difficult decision around the care for the person with dementia, and used the diary for listing the relative advantages and disadvantages of the options. Some people used the diary to record their thanks to services. One of the people who was being cared for died during the project. A few weeks later her relative filled in the pages for the days following her death.

Arrangements were made to return the diaries to the people concerned once the report was written, if they wished this. The other diaries were destroyed, as agreed with the participants at the outset.

"Doing this bit has been very therapeutic as I've got rid of a lot of anger."

"Oh dear! I'm thinking about it all! Thank you for inviting me to keep a diary."

"We appreciate the help from all areas we have received since my husband's health problems arose. Thank you all."

Content of the report

The following sections describe what the family carers told us in their diaries. The direct quotes from the diaries are in italics, while the text paragraphs summarise the points made by several family carers.

The final section of the report is a list of questions, to help people in various roles reflect on how the experience of these families can help you to deliver or plan for effective ways to support all people with dementia and their relatives as part of their communities.

The report was written by Anne Connor of Outside the Box Development Support. The carers who took part, people involved in the Managed Care Network and from the Dementia Services Development Centre read the draft report: this final report includes their comments and suggestions.

Section 2: About the people

The relationships

- 11 diaries were kept by wives caring for their husbands.
- 2 were kept by husbands caring for their wives.
- 2 were kept by a daughter caring for her mother.
- 1 was kept by a son caring for his mother.
- 1 was kept by a daughter caring for both her parents.

The ages of the people with dementia ranged from early 50s to mid 90s. The people who were their carers ranged in age from early 40s to mid 80s.

Some of the people with dementia had other health problems as well, and the person caring for them had been doing so for several years before they began having memory problems.

Several people were also caring for other relatives within their extended family, or were supporting younger family members through a difficult time.

About the people who had dementia

The carers gave us a lot of information about the people for whom they cared.

The people were spouses, parents and often grandparents, and most still had contact with good friends. Some of these relationships were still very important, both for the person who had dementia and for the other people around them. For many people, some or most of their family – sons and daughters or siblings and their families – lived a distance away.

Some of the carers described how the person with dementia was a source of support for them and emphasised that it was still very much a two-way relationship. The person who was caring for both her parents described how they looked out for each other and gave each other practical and emotional support.

Some of the people had lived through significant bereavements or other losses in their lives, and the distress around these events was affecting them today.

The people who had the memory problems had considerable achievements in their personal and professional lives. Some of the carers described how their relatives' achievements were continuing to make an impact in the world – such as buildings or structures they had built or designed, teachers who were proud of the pupils they had taught.

Many of the people had worked hard through their lives to look after their families. Sometimes the carer mentioned this as a reason why it was important for them, and other members of the family, to be there for the person with dementia now.

"We didn't have much money, but the children were always beautifully turned out. She made all the family's clothes. "

"He worked for many years in [factory] and when that closed he did whatever jobs he could until he started at [another factory]. He worked hard to look after his family."

"She was an infant headmistress and loved teaching."

"He served in the Ministry of Defence Police."

"He was a very competent engineer and supervised the building of the two biggest tankers ever built in the UK."

"It was always a happy house."

"She was always there for us when we were children and long after we had left home. Now it is my turn to be there for her."

"During the war he was with the convoys crossing the North Atlantic and then in Burma."

"She worked with the Enigma project during the war!"

The carers also described the hobbies and skills that had been important to the person – belonging to choirs, being a talented amateur artist, and playing sports. Some people still enjoyed these activities and found them comforting.

"She loves singing along to tapes of the hymns she sang as she was growing up."

"He has always worked with his hands – woodworking, fixing children's bikes. He did this well into his 80s."

"We enjoy walking together and playing table tennis."

"She was always baking and made wonderful jam."

"She baked every day and she was entertaining her friends and cooking for them every week (in her early 90s) until her fall a few years ago."

The carers often commented on how so few people in the person's life today knew about what they had contributed. They also noted how the person did not always remember or understand what they had achieved, which was a source of sadness for the carer. Several women thought that their husband was frustrated about activities at which he had excelled but could no longer do.

They described the person's personality – whether they were outgoing, or quiet. Again, they noted that even when other people asked what the person had been interested in, they usually didn't take account of the ways this interest had involved other people.

For one person, it mattered a great deal that some of the people caring for her did not appreciate that certain things distressed her. This had a significant bearing on how her well-being varied from day-to-day.

"He was never one for the company of other people."

"She was always very sociable, loves other people's company."

"He always enjoyed the company of children, explaining how things worked, letting them learn how to look after plants. He misses our grandchildren."

The people who had memory problems also often had other health problems, and sometimes this was a major worry for the carers. Many of the health problems were of types experienced by many people of their age, such as mobility problems, heart and respiratory conditions and Parkinson's disease. Two people have cancer. For some people, these other health problems posed significant limits on what the person was able to do or required careful monitoring. The carers described how the treatment for these conditions, or an illness such as a bladder

infection or getting a cold, could have consequences for the person's mood or general well-being, or for the way they responded to medication.

For a few people, the carer thought that frustration around not being able to be as active as before following a fall or illness was at least as significant in the person's mental well-being as their dementia. Other people wrote about the person seeming depressed as a consequence of the dementia and its impact on what they could do. It wasn't clear whether the person with dementia and the carer had discussed this with a doctor.

"The frustration comes from her mobility being so limited. She doesn't know what day it is. But then, every day is the same for her now. "

Most of the people with memory loss lived with the person who was caring for them. The couple who both had memory problems lived together at home, 3 people lived alone, and one person was currently living in hospital but his wife was trying to get him home.

The carers described the types of care each person with dementia needed. There was a wide variation in the levels and types of help people needed with personal care, for example. However, almost everyone referred to the supervision that people needed, or the need to have someone near by.

About the carers

People told us about what they had done before they retired or had stopped working to look after their relative, and about the hobbies and sports they had enjoyed. Most of the carers described how they had few contacts now with friends as they no longer had the time or energy for these activities.

"I loved cooking, baking and making jam."

"I am a low handicap golfer, but have had to give this up."

"I miss the friendships as much as the enjoyment I gained from these interests."

"I feel as if I haven't spent any proper time with my children in weeks."

Several people were still working and were juggling their job, the care for the person with dementia, looking after the domestic arrangements in their parent's house as well as in their own, and other personal and family responsibilities. They described how they had to change the days and times they worked to fit about the available care from day care or home carers, and how little flexibility this gave if there was an unexpected change at either end. During the diary period 2 people were taking a week's leave to take their parent who had dementia to hospital appointments and sort out domestic arrangements, such as getting an appliance repaired.

"I got home after 1 am, as I did ironing and emptied and reloaded dishwasher before leaving mum's. I was behind as I'd been unwell during the week and had been out with a friend for a couple of hours."

Several of the carers had significant health problems of their own. Sometimes this meant they were worrying about the implications of possible or emerging serious illness for them and the effect this would have on the care for their relative. For one couple, there were as many contacts with health services recorded in the diary for the person who did not have dementia.

Even a small period of being unwell, such as getting a cold or a virus, could knock the care arrangements out for a week or so.

"We are both so tired with this virus. I just want to sleep, and [husband's] days are all upside down. He kept asking if I was all right. Bless him, he realised something was wrong with me."

Support from family and friends

Some people had family and friends living nearby while others did not. Some families had spent many years living and working abroad, for example, or had moved to the area when they retired.

The people who had memory loss and their carers were receiving support from a wide range of family – daughters and sons, their partners or spouses, their children (the person with dementia's grandchildren) and extended family.

The carers often described how extended family supported both themselves and the person with dementia, even though they did not live nearby. Some of these people also had their own health problems, or were also caring for other people.

"My sons, even though they live over 100 miles away."

"My daughter visits regularly to give practical help and support. She works and is also looking after her husband's parents."

"My son is always there at the end of the phone."

"My son granny-sat again and I got into town with a friend for shopping for a little while."

"My brother was round today, looking at what we can do for respite in the summer."

"Hair-do night with my cousin's daughter, who comes every week. She is an angel!!"

Some people had valuable support from friends and neighbours. But some people noted that their friends were also elderly and had their own health problems.

"My neighbours are very good at visiting."

"All my neighbours have offered help, day or night. We haven't needed this so far, but I know they are there if a crisis ever arose."

Almost everyone either mentioned that they had fewer contacts now with friends than before, or contrasted the occasions when a social situation happened during the diary period with the day-to-day pattern of the person with dementia seeing only their family carer, care staff and other people who attended day care.

"I check 1471 on the phone. She has received no calls since I rang yesterday. No-one calls these days. Double glazing salesmen are welcome!!"

Contact between the person with dementia and the carer

People usually recorded each day how the person with dementia was doing – if they were in good spirits, content, agitated, anxious. The carers who lived apart from their relatives spoke to the person or saw them every day.

People wrote about their feelings for the person – how the day-to-day care could be frustrating and tiring, how they worried about the person, how they loved them.

"I love the old sausage so much."

There were also situations where relationships had come under a strain. Some people's friends and neighbours had drifted away. Sometimes the main carer or other family members had found it difficult to respond to the person's changed behaviour at times.

"She has become very demanding and possessive of my time."

"He is anxious if I am out of his sight. Sometimes I find this a real strain and then feel guilty."

"The visits when it is laughs rather than sobbing are so much easier."

"Since his illness things have changed dramatically for my husband. He has changed in attitude and gone from being easy going to short-tempered. It can be hard to cope with."

"After 4 good days on the trot, she was very confused and grumpy tonight... The main problem was she was having a day when she was realising for sure she can't remember things and with this constantly in her head hence the worry and frustration and thinking she will be put away."

"It just seems to be a week for complaints."

"She must have asked the same question 30 times this evening."

"He was up and dressed again at 5.35 this morning, looking for the fish van which comes at 9.30."

Looking ahead

Some carers noted their concerns for the future – knowing that the person's condition would deteriorate, or worrying that services might not be able to cope or be reliable.

"In many ways we are so blessed. This is now our sixth year and I am so aware things are going to be much worse."

"The loss of short-term memory will never get any better and although it is frustrating for me I know that when Mother sits for lengthy periods actually realising that she can't remember things, this turns into extreme worry for her."

Help in a crisis

The diary asked the carers to whom they would turn for help in a crisis.

The 2 main sources were family and friends, and the GP and/or Community Nurse.

Some people distinguished between a major and a less serious crisis, and how urgent the matter was likely to be – so, for example, calling on the GP and neighbours immediately, and then getting on-going help with a serious matter from family.

Source of help in a crisis	Frequency: of 16 responses
Neighbours, friends	7
Family	5
GP/medical practice	7
Community Nurse	6
Community alarm	2
Warden or manager at housing complex	2
Carers' visitor	2
NHS 24	1
Private carer whom the person with dementia already knows	1
Contact at hospital	1
Link person at day care	1
Person's care manager	1
No-one comes to mind	1

1 person: no response

Section 3: Experience of getting access to services

How it feels

The people who took part in the pilot project told us about their experience around getting access to services – what happened and what it felt like. We then added this as a specific question in the diary for the people participating in the main project.

Those people who were caring for someone who also had other health problems – sometimes for some time before the memory problems were identified – linked together the overall services and support that they and their relative received.

Some people were receiving few or no care services. Sometimes this seemed to be because the person with dementia was still quite well, and the family were satisfied with this.

"We've always been self reliant. She is responding well to the medication and we are getting on with things quite well."

For some of the families, there was a gap in getting advice and help to prepare for the future or deal with problems that were coming up now, such as advice about financial matters.

Some families were getting services now, but it had taken many years to achieve this. For some people, the problem had been around identifying what was happening for the person with dementia – for example, when someone began not to drive or stopped doing other activities which were becoming difficult, but did not tell other people what he was experiencing. In some cases, it appeared that treatment or the consequences of a physical illness or injury had been the initial focus.

For other families, the person had been given their diagnosis but did not have access to other services. Some people described having effectively no services for several years after a diagnosis of dementia.

The carers commented on the difficult times when they didn't know that help could be available. For some people, this had put a significant pressure on the carers' own health. Several people noted the financial implications when someone had to give up work, and how important it is to get advice about entitlement to welfare benefits.

"We didn't know we could get help or what to ask for."

"We barely get by on the money we receive."

"I'm not sure what services are available."

"When I enquired about various services I have never received any information or feed back."

"My husband was diagnosed with Alzheimer's in 2001, and we are no better off with help, advice or services now than we were then."

"If only there had been information then about what was available years ago – the stress and sleepless nights, the crying and frustration, the horrible helplessness, the 'who do I turn to' feelings might never have been."

"We didn't get help until years later, when I was becoming ill too, that my sister-in-law got the doctor, and it started from there."

"I think the Government should have more information leaflets in Post Offices etc, advising carers on what help they can get and where to get it."

At the beginning

Several people described in detail the incident that had led them or the person with dementia to realise that something was wrong, and commented on how their GP or other staff had responded. For other people it was a gradual realisation that something had changed for the person.

Whether the realisation was sudden or gradual, the response they received during their first contact with services was important. Positive aspects were when staff understood it was difficult for the person and carer, when they took concerns seriously, when they made referrals for tests or assessment and followed up if these were slow, and when they answered questions.

"I was visited by a very nice young woman. She arranged everything from then on."

"Our GP was very understanding and explained everything to us."

Some people described the problems they had in getting a diagnosis – for example, they might be referred to a series of doctors and specialists, with little feedback along the way. For some families the difficulties had been in getting the information from the person with dementia when she was attending clinics on her own.

"Nothing seemed to happen for 2 years. Eventually we asked to see a different doctor, and things moved from that point. The care now is very good."

"It took us a while to feel that we were getting anywhere with regards to a diagnosis. The specialist we saw was distant, didn't seem to understand our worries. Our GP was very understanding – the only one who suggested this early on that it looked like dementia."

"Everything seemed uncoordinated between GP, hospitals and specialists, placing a great deal of stress on both of us. Now that we have the specialist and the support we need everything seems better. I just wished it had been more co-ordinated to save us all the stress and anxiety."

Some people and their family carers got advice on how to keep well.

"Visit from community nurse. Chat about general health, fitness and events/outings and experiences since last visit. A pleasant, useful day."

Some people were still looking for information about the person's condition several years after they had a diagnosis of dementia.

"I wish that doctors had the time to have the listening and patience of [community nurse]. For example, I'd like to know if x-rays and scans show up in any detail which parts of [husband's] brain are affected. Why is he so good at table tennis and so hopeless about wheres and whens? Is there any relationship between diabetes and dementia around what he eats? There seems to be a link with what he eats and his moods. Why does he sleep so much? Is it really just boredom? I'd like to make him less bored. But maybe it is not boredom, maybe he needs a lot of sleep."

Once people had a diagnosis, their experiences around access to a package of support services varied. This went smoothly for some families – services were in place quickly and the type of services worked well for that person and their family. Other people came up against more difficulties, including delays in getting assessments, delays in the delivery of services and poor or variable quality of services.

When things change

People described how the level and pattern of the person's needs and of services changes. For some people, this was – or had been – a distressing time for both the carer and the person with dementia. Some people had found the response from services helpful – the practical arrangements changed and staff were understanding about how it was embarrassing for someone to now need help with personal care, for example, and but their attitude made this ok. For other people, the strain of frequent requests for a review or assessment, waiting for the new service to start, or problems with the quality of care made the situation more stressful.

For some families, the person's health had changed during or just before the diary period and the carer recorded the day-to-day events as they happened.

For example, one person became incontinent. His wife struggled to cope with the practical aspects of giving him a clean set of clothes to change into at the day centre. She also struggled with the sudden increase in washing. There was no mention in the diary of anyone giving her advice on this, or asking how she or her husband felt about what was happening to him.

Several carers discussed increasing or changing the pattern of day care or home care with the key person with whom they worked, and that person took it on from there.

One person noted asking the community nurse about more help. Five days later she recorded:

"Letter confirming help with washing and dressing 3 days a week from [following week]" (and a smiley face sticker).

When a carer did need to get the pattern of services changed, it could take frequent phone calls over several weeks.

One carer recorded every day that she had been trying to phone for an assessment as her husband's needs were changing:

"phoned again, left message, still no answer."

Some days she just wrote 'no services' and put in a sad face sticker.

Some people were looking for a change to the timing rather than the level of services. The person's daily pattern – usually when they were alert or tired – had changed. It was good when the carer could get the pattern of daytime services changed easily to have more benefit for the person and for themselves. Other times, services responded that it might just be a temporary change, or that it was best to stick with the existing package. Carers noted that this might be a temporary situation, but still found it put a significant strain on how they were coping.

Carers also commented on the response to a request for home adaptations, such as installing a stair lift or shower. The main problem was the length of time taken for all the steps to be completed: for an assessment to be done; then for visits by an Occupational Therapist and Council workmen; then confirmation that the Council will pay for the adaptation; then it finally getting installed.

"The biggest set back is that it takes too long, since most carers will wait until really desperate before asking for things."

Several people described having particular difficulties getting a care package to enable their relative to come home from hospital. For one person this had delayed the person's return home for over a year, while for others the delay had been several months. In each case, the person with dementia's confidence and abilities had declined markedly as they waited.

For some people, the suggestion that the pattern of services should change came from the services rather than from the family. A few people found this helpful – the person now needed more support, but the carer had not wanted to ask for more or did not expect that anything more would be available.

The potential change that caused most concern was when the person was thought to be too ill or frail for day care. Some people were told that the day centres were intended for people with a certain pattern of

needs, which the person no longer fitted. But the family carers knew that the person still gained other benefits, such as the company of other people. There was also the worry around the potential impact for the carer.

The accounts in the diaries all pointed to the benefits when a specific alternative – different pattern or levels of services – was described at the time when the possible change to the existing pattern was raised by staff.

People having their say

Several carers described how they and their relative talked over options about changes to services, and discussed the services that were helpful or less useful. They had frequent conversations, and the carer usually felt that if the person was consistently making the same points, or having the same reactions, this was confirmation of what they really felt. For a few people, this was contrasted with an assessment by someone whom the person with dementia did not know, or a one-off conversation.

"They asked her what she wanted to do and she said go home. But what she means is be at home with me. And I can't always be here during the day."

However, even when people had explained what they felt, there were some problems getting access to combinations of services other than fairly standard packages.

"My comments get slightly pushed over or misinterpreted."

"The [worker] made suggestions in good faith, but they would not have helped our situation. I don't mean to be stubborn or ungrateful."

"They don't seem to listen. Maybe I am not expressing myself clearly enough to them."

"The staff make assumptions about my mum. They provide what they judge is required and don't give her choice."

"One service should not be able to make changes with no regard for the views of the other people involved in someone's care and who know the person."

"They said that this is the service given to people with his condition. But I want what is right for him."

"Talk to mum as a person. Give her a chance to answer for herself (even if she often can't). The questions can be directed at me but made to appear that it's to mum."

"Treat us both with respect."

In contrast, some carers noted how the staff at a service continually checked how things were going and made suggestions about care and services.

"The staff [at the day hospital] keep me up to date on [wife's] illness. They get in touch with me to enquire how she is getting on at home and how I am coping."

Section 4: Features of services

The main themes and features of services which carers think are important

- *attitudes of staff*
- *range of services*
- *match between services and the person's needs*
- *awareness of the needs of people with dementia*
- *consistency and continuity*
- *communication*
- *transport*
- *practical help*
- *benefits from the services*
- *maintaining existing relationships and activities*
- *support for the carer*

Attitudes of staff

Carers often commented on the attitudes and behaviour of the people who delivered the services or who had a co-ordinating role and were the link to other sources of information and services.

Several people described how it had been difficult at first – for the family carer to share the caring tasks/role and accept they needed help, and for the person with dementia to accept the care from other people. The carers often praised people who had helped them through this stage.

They particularly praised staff who are good at engaging with the person who has dementia. They also commented on people who did not respect the person with dementia.

"He was agitated before she came, but the home carer put him at ease even though it was a different lady from our regular carer. The rest of the day was good from that point on."

"We both like coming here. The atmosphere is so friendly."

"Everyone at this clinic is friendly. The receptionist makes us feel welcome and the porter asked us how we were." At another clinic

the following day: *"the nurse said hello to me but did not look at mum. I felt angry and embarrassed as I knew mum had noticed the slight."*

"Some of the home carers talk about mum as if she weren't there or does not understand. 'She was very difficult today...etc', or 'she was a good/bad girl today.' Mum is in a bad mood when she feels she is being spoken about, especially if she's being talked about as if she were a child. She pulls a face behind the carer's back. This particular lady means well, but mum understands her and just finds her irritating."

People wrote about how the attitude of the care workers made a difference when they were finding the caring difficult.

"They are all helpful, especially when my spirits are low and the same simple tasks become a burden."

Carers praised staff whom they could talk to about options around care for the person with dementia – for example, asking what might be possible, talking over whether a change would be a good idea or not. Short, frequent contacts and ease of getting in touch with the worker were described as good features of services.

"I have been thinking of a home help for a couple of weeks. It was very useful being able to discuss the situation with someone else who was able to offer practical help."

"I like these visits [from community nurse]: they are good for instilling 'does it really matter?' and helping me gain a new perspective. And it is nice getting a bit of encouragement whether it is deserved or not."

"Visit from community nurse. We enjoy these visits as any problems can be talked about and solved with him. He is a very approachable person and easy to talk to."

The encounters each day showed the importance of all the people involved in services, and how their attitudes and behaviour have an impact.

"The volunteer drivers and ambulance patient transport drivers are our friends now."

"The men who come to collect [husband] in the morning are very cheery, polite and considerate."

"Met the Meals on Wheels lady today – very friendly with a nice manner."

The attitudes that were most frequently described as unhelpful were when staff did not listen and when people with dementia – and sometimes older people more generally – were not treated with respect.

"He always liked to be neat, with clothes that co-ordinate – navy cardigan with navy trousers. It distresses us both when some of the home carers put him in the first clothes that come to hand. They all know how he likes to be dressed."

For some families, the problem appeared to be the attitudes of staff in services to older people. There were examples of people being expected to walk or push a wheelchair a distance, and no recognition of the circumstances of carers who were also elderly or unwell.

Carers felt they were expected to do things which were embarrassing for the person with dementia – such as a son being expected to take a urine sample from his mother. Several carers commented about the attitude of some people towards people with dementia or to older people generally – as if their dignity no longer mattered.

Some people found it very difficult to get home visits from GPs, and thought that other older people would appreciate home visits too.

Range of care services

People wrote about the range of services they received. Some families were using mostly home care or mostly day care services, but several people wrote about how it was helpful when the home care services and day care services linked together. They also described good care at hospital – clinics and inpatient care.

People also wrote about the community services that helped with day-to-day living. For example, one person mentioned the good response time from the community alarm team when her relative had a fall a while back – she was feeling secure that help will be available quickly, so it is a good service even when it isn't being used.

"Meals on wheels were an instant hit. It is good value for such convenience and another contact during the days when she is at home."

Match between services and that person's needs

One of the aspects carers valued was when the type of service was well suited to that person's needs and preferences. Sometimes the timing and pattern of services was an important aspect – for example, care workers coming in early in the morning when the person was more confused and needed help with personal care, or day activities that gave the person a routine that was familiar to him.

"Having the carer in the mornings to help with dressing etc has made a great difference for both of us."

Sometimes the timing of services no longer suited the person's needs. Some people were content during the day but became anxious or aggressive in the evening. That was the time when the carer sometimes wanted some extra help – but all the services they received were concentrated in day hours. Periods when someone was agitated or active in the evening had a series of knock-on effects: the carer didn't get to bed and was tired next day; the person was tired and sleepy in the mornings so didn't get the benefit of daytime activities, which made him more anxious that evening.

Some people with dementia and their carers were struggling when the form of service offered did not suit them – for example, when someone who preferred to be on his own was attending a day centre because this was the only service available or offered.

"Each day he says doesn't see the point. He doesn't enjoy these activities. He does enjoy the food, though."

Sometimes the mismatch around services was that some staff assumed that the carer and person with dementia did not still enjoy each other's company and want to be together, and so planned for services to have a significant respite element.

It was suggested that a volunteer be found to do an activity with the person with dementia *"when I thought I had made the point that it was one of our favourite together things."*

Awareness about needs of people with dementia

Most of the carers had a lot of confidence in the skills and experience of the staff and volunteers in the various services.

"The care staff understand that she needs to have her medication regularly."

Some carers were concerned that the staff in services did not understand enough about the needs of people with dementia. The main worries were around care workers and volunteers not understanding the importance of ensuring that the person with dementia was eating and drinking, and around medication.

"Both the morning and evening tablets were left on the kitchen table. She did not have her medication, which leads to her being much more anxious. And if she had taken both tablets at once the consequences would not be good. Possibly a new worker who does not realise that someone with dementia cannot remember to help herself."

There were situations when the person became agitated or more confused as result of getting dehydrated or low blood sugar. Some carers found they had to keep explaining to the care workers that they needed to encourage the person with dementia to drink and eat, or to sit with the person and have something to eat themselves.

"Care workers have said it is her choice not to eat."

"She had not eaten the food left out for her. So I made some toast and tea and we sat together and enjoyed it. She must have been quite hungry."

Another concern for a few people was that some day services tended to assume that all people with memory problems were the same and that the same kinds of activities would work for them.

A more frequent concern was the interaction of care for various conditions. Some people were finding that the care for the person's physical health problems did not take account of their memory problems.

"I feel that if he were to have more physio with the therapist, instead of given a book and told to do exercises at home with a renewal every 3 months, would be more beneficial to a person who has little or no short-term memory or concentration to read."

Consistency and continuity

Most of the carers highlighted the benefits when the services were consistent and reliable.

People who were getting home care all mentioned the importance of a team of carers – continuity, knowing who is coming the following week, being able to rely on the service and the individuals.

"There is a team of five and they really brighten my day with their care and support."

"I can't stress enough how important it is to have the same person with her because of her illness. She doesn't get upset and I can relax knowing everything is OK."

"Carer off sick, and none of the other workers know mum. So I had to do it. One of the few nights I had arranged to see friends for a meal. At least I managed a coffee."

"Relief – this week it is a carer whom I know and more importantly who knows Mum and whom Mum seems to remember. She will call me if anything is wrong..... Mum is socialising much better. Her mood improvement is palpable."

It also mattered for day services.

"She needs to see familiar faces."

Carers described the benefits for the person with dementia of being with someone they know and trust. This was often staff, but also included other people like someone who helped with cleaning and household chores.

"Usual banter with the carers."

There were examples of a service sending someone who was not the usual care worker, but when they got on well with the person it was that care worker who came until the regular care worker returned.

Carers liked to know what the arrangements were for the following week – who the care worker would be, and confirmation of timings when there were some variations around this. It was good when they had the information, and people were anxious when they still did not have confirmation the Friday of the previous week.

Another situation that arose during the diary periods which affected the consistency of the support people received was day services getting cancelled.

"The service is frequently cancelled for training days, which is a great loss for people who attend regularly."

"Closing the day centre over the holiday periods was a big problem over the past few weeks."

Communication

Communication between services and the carer, between services and the person with dementia, and between services involving several organisations or staff was a frequent theme in the diaries.

People tended not to comment when day-to-day communication was going well, unless it was something out of the usual routine. They did write about the frustrations and worries when things were not going so well.

"They phoned to say the transport was running late, which I appreciated. It saves him sitting by the door and getting anxious."

Carers appreciated services that are linked to other services or when one service made the arrangements for access to another. One example was day service staff arranging for the appointment with an NHS podiatry service for the days when the person with dementia is at the day service and staff or volunteers can help.

The people whose carers took part in the diary project included people who lived alone and relied on a range of services. Here, the communication between services was a crucial part of the quality and

effectiveness of the services. Carers noted when the communication was good as well as when there were difficulties.

"The home carers had put everything in the book, so I knew mum was ok."

"She hadn't eaten again today, which is a worry. The home carers left me a note of what they had tried and when in the book as usual."

"We keep an A4 diary in the kitchen – have done for 3 years – and the 'regulars' write a mini-report about food, drink, tablets. Everyone can read it and it means I can talk to her about what she did each day. The doctors, if need be, have a complete set of 'patient notes', and everyone can keep absolutely up to date from visit to visit. As it is A4, the diary is harder to misplace. Handovers from carer to carer are much easier."

For one person, staff from services provided or organised by social work recorded their visits in a log book – which was helpful and had benefits for the quality of the care given to the person with dementia and in the reassurance for her family carers. But the NHS staff did not use this log book.

Communication with the person who has dementia was an important part of all services. A positive aspect was when staff took time to get to know the person.

Family carers valued good communication, including prompt responses to questions.

"The fact that they got back to me so quickly has had a positive effect on my outlook regarding future services and the ability to cope with future challenges."

There were many instances of workers not returning phone calls and/or carers relying on people who are difficult to get hold of, which mattered a lot when that person is the gateway to other services.

"Only negative thing was that due to social worker's being available 9-5, my phone calls have to be at work when it is difficult to talk freely. Whereas the Alzheimer's outreach worker calls me at home after 6pm, which is much better."

"No phone call."

For each of next few days: *"phoned again and left message, still no response."*

People did note difficulties in getting information from or about different aspects of services or the person's care. Several people found it difficult to get answers to questions when one worker referred them to someone else, and that person also referred them on.

Sometimes the communication problems were with general NHS services, such as dentists or other hospital services. There were also a few examples of carers who had not been told about a change in the health of the person with dementia. In one case, it was about a serious health condition other than the dementia: the person had been told, but not his wife.

There were a few instances of health care or social work staff visiting people, but the other staff involved in their care and the family carer did not know who they were or why they were there.

"It's confusing for my mum and for me."

Transport

Getting to and from services, usually day services or clinics, was important. If the transport is good and the travelling is easy, that makes the visit a pleasure. Positive aspects of transport and access were it arriving on time, a helpful driver, and a clean and comfortable car. It helped if someone rang to tell the carer when the car or ambulance was running late.

Reliable transport was also reassuring for the carer, and gives them a longer break.

"She was picked up by the bus at 9.05. With this pick up time she is not having to sit and wait therefore she does not get agitated."

The most frequent difficulty with transport to day services was when it was late. On these days, the person with dementia and the carer were anxious and delays caused problems when someone needed help to go to the bathroom.

A few carers noted problems with the type of transport that was provided.

"It was a small cramped car which causes discomfort to someone who has painful joints and back and has mobility difficulties. It is worse if sharing with another person, walking aids, etc."

The carers also described visits to places where they had to provide the transport. The most frequent difficulty was finding parking. Aspects which were difficult included getting the person into the car, getting parked near enough to the venue and then again when picking the person up, and having to help a frail older person walk along a busy street without getting anxious. It was worse in poor weather.

This made the visit more difficult – for example, arriving late so the person was late for a clinic appointment, or was distressed and less able to cope with whatever was happening at the clinic. One person described how stressed she got – it took away the respite benefit for her, although her husband enjoyed the visits.

"Having transport provided to the Centre – even one way would help."

"No hitches except for car parking. Fortunately, we had left 25 minutes for finding a parking space and then for the possible walk. We needed the time. I (the driver) couldn't just leave him at the door. I had to be where he was."

"It didn't feel safe as I pushed the wheelchair through all the parked cars."

Practical help

The carers described various services, or the things which workers provided such as aids and adaptations or advice on coping with the person's condition or its consequences, as valuable forms of practical help.

A few people had significant mobility problems. Access to a loan of a wheelchair or getting a stair lift installed at home made life much easier.

"Today was a happy outing arranged by our son. The wheelchair allows activities where some distance has to be covered."

"The stair lift is a new addition, but like the walk-in shower is a massive difference to being able to cope."

The impact of relatively small practical pieces of equipment or advice could have a substantial benefit for the person with dementia and for the carer.

One person needed to stay close to his wife and had started having panic attacks when his wife went out for even a short while and he could not find her. His wife was finding the situation more of a strain. The community nurse gave them a notice board for the back door a few days later. The first day, the carer noted that it did not seem to be a help. But a few days later she wrote:

"Today I went out shopping on my own. I wrote up on the board where I was, what to take for lunch, reminder about pills that were left out and when I would be back. He said that it gave him a sense of security and he seemed to be ok when I got back."

Several carers mentioned difficulties in getting help with personal care, especially bathing.

"My daughter comes on her day off to help me with bathing her father. It isn't ideal."

Food was a worry for several carers – getting the person to eat, the struggle around finding food that the person likes, and the day-to-day hassle of cooking and shopping when time is short or the person needs a lot of attention. Some people used the diary to record what they had offered the person each day during a difficult period.

"His lack of appetite is unusual. Trying to encourage him but end up feeding him. Not keen to drink tea or coffee, have changed to juicy drinks. I'm a bit fed up cooking and wasting food. (The birds are eating well though.)"

There were no notes in the diaries of anyone getting advice from staff about what could help the person with eating and drinking, or having the chance to swap notes with other carers.

The other practical aspect of coping which several carers mentioned was laundry. Getting clothes and bedclothes washed, and especially

getting items to cleaners, was a problem – the time needed when this was a daily occurrence was considerable and for some people it caused worries about the expense. There were times when the staff from services contributed to extra work, while other staff helped.

"I found items that should have been left to soak in with the rest of the laundry. Too tired to sort it tonight."

"The catheter and the night bag were not securely attached by the home carer, but we didn't notice the extent of the leak until bed time tonight. It caused [person] a lot of discomfort as well as the extra washing and expense of the duvet going to the laundry."
Next day: *"[one of the other care workers] took the duvet to the laundry – went out of her way to help."*

Benefits from the services

The carers described the benefits their relatives gained from the services. The points that were mentioned most often were stimulation, company and good food (without the carer having to cook or shop). Friendships with other people at day centres were important for a few people.

"When [wife] is at the centre, she is in company and enjoys herself."

"She is always happy there."

The evening after a lady had a first visit from a befriender:
"She told me about the really nice young lass who brought lovely biscuits, and they had a cup of tea and biscuits and a chat. ... All in all, she was in good form tonight."

Maintaining existing relationships and activities

People valued services, but also valued the time they had alone and with family and friends.

What was good about today?

"It was just the 2 of us. A nice quiet day in watching sports on the telly, like we always used to do at the weekend."

"A pleasant time with the family."

After a couple of days with discussions about services that had been difficult for both the person with dementia and the carer:
"A walk in the sun cheered us up."

Sometimes the carer noted ways in which services helped these activities to happen, such as the loan of the wheelchair.

People valued social outings – for example, watching carpet bowls, which could give people the chance to meet up with friends and be a break from routine – where there were benefits for both the carer and the person with dementia. So services that helped make these shared activities happen were valued.

The carers also valued ordinary community places where both people were welcome – such as going to a church service.

"Today we attended a funeral, and being in the company of old friends and neighbours helped both of us."

"[Husband] decided we should go to church today. He enjoyed the fellowship at the service and as we tucked into tea and biscuits afterwards. A good day."

Places where the person who had memory problems or other disabilities was welcome were important. As with care services, this was often linked to the attitude of the people involved. One example was the owner of a local coffee shop who made a lady who had difficulties with eating and drinking especially welcome.

Some of the services that people were looking for are mainstream or commercial services, rather than health and social care responses.

"I often read a little wistfully of activity holidays. It would be good to know [husband] was being looked after whilst I participated (for example, painting or a craft) in the mornings, say, and then we'd do joint things the rest of the day. We'd pay, if it wasn't run too extravagantly."

Support for the carer

Days when the carer could talk to someone – such as a community nurse, Carers' Visitor, a neighbour or a friend – were always described as good days or good services. Sometimes the person came to them, sometimes there was someone else with the person with dementia and the carer could get out for a short while.

"Alzheimer support group meeting for carers. Idea is to support each other through coping as carers. Got some advice on benefits and discussed some of the behavioural problems we have experienced over the last month or so. Good group discussions, find the interaction with other carers very helpful."

"It helps me feel better about coping. Got some good advice about asking family for help and support."

At other times, the carers mentioned that they were lonely or had few other people to help them.

"It has been the first time in a long while I'd let things get to me!!! I'm not very happy with myself."

"I feel a bit down today. Don't know why."

"I am feeling trapped. I don't have a life of my own. Someone popping in just to check that things were ok would make it easier."

"I felt very lonely today."

Summing up

These final two quotes were each written on the last day of the diary periods.

"Everything is running well this week. Tablets taken, kitchen and bathrooms clean, bedroom tidy, etc. Fresh food prepared and mum's doing crosswords, listening to music. The 'regulars' have coaxed her out of bed, so she gets a little exercise rather than lying in bed all day. Private carer is trying to take her out. Homecare worker brings in mum's favourite home made soup to tempt her to eat. This is exactly the kind of companionship and care that is so desperately needed.

Because all carers know mum well and work so well together, her mood is completely changed to much more positive, open and communicative. She is smiling, settled, has eaten well and her conversation is much more coherent. Anxiety has subsided dramatically."

"Life is a routine for carers, and that's what we need with some help along the way, because it means the person you're caring for is OK.

But, it takes a long, often tearful time to reach and accept that situation. Because you give up your life, your FREEDOM. Its 24 hours a day. This is my 16th year of ups and downs and regrets along the way. But she'll be 96 years young in June. Bless her."

Section 5: What would have made it easier?

There were two sources of information in the diaries about things that could make life easier for the person with dementia and their family carers.

At the introduction, people were asked ' Do you ever say if only there was available?' Only 3 of the 17 people did not suggest something.

"Nothing. We are happy to be self-reliant."

At each daily entry, the carer also had the opportunity to suggest things that would have made that day or that contact with services easier.

This is the combined list from the carers' experiences.

Someone to talk to

- someone to talk to
- someone who asks how the carer is doing
- advice when the carer is not sure what to do – for example, when the person isn't eating, or is sleeping a lot.

Information about services and about financial help

- transparent information relating to social services – eligibility, financial aspects
- financial help for family carers who have to give up work
- information about welfare benefits, impact on pension, etc.

The range of respite and how available it is in practice

- a sitter for a few hours
- someone to sit in for an overnight
- respite that can be booked in advance, so we can plan ahead
- respite that you don't have to pay for
- good quality respite care
- live-in temporary carer – respite at home
- assisted holidays so the person with dementia and family carer can go away together.

How services are co-ordinated and access to them

- one focal person reaching across health and social care
- someone who can be reached outside office hours

The quality and type of services

- reinstating the previous system of a small number of regular home carer workers
- more frequent access to the podiatry service.

Help with maintaining community connections

- outings with volunteers for people on their own or with their family carer.

Practical day to day caring

- help with difficulties in getting a bath for someone with dementia
- all drivers of volunteer cars should be provided with mobile phones.

Money

- information about entitlement to welfare benefits
- advice about pensions for the carers who are still working.

"I can't afford both respite and the holiday/break for me."

"I find the financial aspects of being a carer a constant worry."

The person's own family circumstances

- family living nearer.

Section 6: Questions raised by the carers' experiences

For people who manage or work in services that support people with dementia

- Do the experiences described here resonate with your knowledge of your services?
- Do you know what the circumstances and views are of the people who use your services and of their families?
- Are there staff with skills and experience who could help people with dementia and their families to have a better quality of life, who are not yet in touch with this group? Could they give some advice and back-up to the staff and volunteers?
- Do the staff and volunteers in your services have enough confidence and advice to support people who have dementia? Would they welcome extra training? How will you make sure that this includes opportunities to learn from the people who live with dementia?
- Are there practical things you could do that would make life easier for the people who use your services and for their family carers?
- How will you ask the people who use your services and their families for their ideas?
- Could you give advice and information to people in the local community, so they can continue to support and welcome people who have dementia and their families?

For the people who have responsibility for overall strategies and resources

- How do the policies and services to which you are contributing help support people who have dementia and their family carers?
- Are mainstream health and social care services that are used by everyone remembering to take account of people who have dementia?
- Would staff welcome some training and advice? How will you make sure that this includes learning from the experience of people who live with dementia?
- How can the arrangements for co-ordinating between and across services work well for people who have dementia and their families?
- Are there strong enough links between services that provide care and support and the sources of information about money?
- How are you investing in the capacity of communities to include and support people as they and their relatives develop dementia or become frail?

For people in community settings – employers, churches, community groups, local shops and so on

- How can you continue to make members of your community welcome when they or someone in their family has dementia?
- Would you welcome advice and information, to help people feel more confident? If so, can you approach a service in your area and ask them for some contacts to get a discussion started?
- Are there people in your organisation or community who would be willing to take on volunteer support roles? One example could be as befrienders for people who have dementia, to help them keep up as much of their interests and skills for as long as possible. Another might be as a befriender for someone who is a carer and has lost contact with old friends. Or could you provide some of the practical help such as transport and help with lifting, so a couple can continue to go out and enjoy being together and doing ordinary things?
- If you are an employer, can you offer flexible work opportunities to people who are family carers?

For people who want to hear the views of service users

- Are there aspects of this approach – using a diary – which you can use alongside other ways of gathering people's views about services generally? Could this work for people in other situations or who have other health problems?
- How are you making sure that you can listen to what each person and their family is saying about the support that will be right for them?
- Are there aspects of this approach that could be useful when the support for someone is being reviewed, to make sure that services continue to reflect their needs and choices?

The feedback from the people who participated in the diary project was that the diaries were easy to use. Some people found them useful when they wanted to reflect on what had happened over a few weeks.

One suggestion is that a carer of someone with dementia could be invited to use the diary for a few weeks in the run up to a review, to let them record the pattern of the person's needs, how services are working out and so on.

They can involve the person with dementia and other members of the family if this suits the family.

They could discuss the diary with someone, such as a friend or a worker they know, if they find this helpful in preparing for the review.

They can refer to the diary at the review if they want to.

The document is theirs. They can keep it to refer to a few months later, or destroy it.

Annex 1: Headings in diaries

Introductory section:

Please tell us a bit about yourself

Please tell us a bit about the person you care for

Are you a:

- family member?
- friend?
- carer?

Is there more than one carer? If they are going to write in the diary too, please tell us a bit about them.

Is there anything you would like to tell us about the services that are important for you and the person you care for?

Who would you turn to for help in a crisis?

Do you ever say to yourself: 'If only there was.....available?'
If so, please tell us what this help is:

Is there anything else you would like to add about what happened before you got services?

For each day:

Tell us about your experience of help you received at home or at a clinic or other place.

Was there an arranged time:

- yes
- no

If it was late, how late?

What was good about the service/visit?

Anything not so good?

What effect did this have on the person/family?

What would have made it easier for you?

Any other comments?