

## **An exploration of the experience of using calendar reminders for people with dementia and family carers**

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## **Abstract**

People with dementia and family carers often use calendars to support time orientation to maintain routine. However, little is known about the use of calendars as a compensatory strategy. This study examines the experience and practicalities of using calendar reminders from the perspective of people with dementia and family carers. Six dyads were recruited and interviewed at home. Interpretative Phenomenological Analysis was used to develop a narrative interpreted from an occupational therapy perspective. The themes were reflected on during two subsequent focus groups. Findings suggested that calendars are used either intensively as external memory records or more casually and randomly for reassurance. The familiarity and location of the calendar and its utility to the person with dementia and carer, all contribute to its efficacy. For carers the experience of supporting calendar reminders encompasses practical, cognitive and emotional effort. There was little awareness amongst participants of electronic assistive technology.

## **Keywords**

Keywords: *Calendars, carers, dementia, time orientation, assistive technology*

## **Introduction**

Knowing what is happening and when, can be a cause of anxiety for people with dementia and their carers (Sweep 1998, Enable Project 2001, Topo et al 2007).

Calendars are a familiar tool often used by carers to remind about and encourage participation and engagement in daily life. Yet little evidence exists about whether they work or how best to utilise them for people living with dementia.

### *Dementia and time orientation*

Being orientated in time is reliant on the connection of disparate neural systems such as those of memory, attention and sense of time. Disorientation in time is commonly experienced by people with dementia, who have difficulty in knowing what time it is, measuring time or distinguishing between day and night. Time orientation is recognised and rated as an important issue by both people with dementia and carers (Topo et al 2007). Continuing to follow daily routines can become increasingly problematical. Routine and social occupations are intrinsically linked to knowing the day and time of day (Mirando-Costello, Woods and Orell 2010). Being occupied is fundamental to health and well-being and central to the human experience (Keilhofner and Posatery-Burke 1980, Law 1998). This paradigm of linking occupation to wellbeing is encapsulated in clinical advice to people with dementia to stay active and engaged (NICE 2008, Alzheimer's Society 2013). Family carers are key to maintaining this engagement which is crucial to enable a person with dementia to stay at home for longer (Milligan et al 2011).

### *Calendars reminders*

Paper calendars, diaries, written notes and Assistive Technology (AT) such as electronic orientation displays are widely used by carers to address issues with time orientation and to facilitate daily routines (Nygard and Johansson 2001, Topo et al 2007, Cahill, Macijauskiene, Nygard, Faulkner and Hagen 2007, Torrington 2009, Harris and Evans 2014). Professionals like Occupational Therapists (Swinson et al 2016) and Community Psychiatric Nurses (Crosse, Broomfield, Davies and Evans 2008) advise on orientation strategies and devices however in practice little robust evidence exists to support these interventions for dementia (Greenway, Duncan and Smith 2013, Parr and Down 2013)

Technology presents new opportunities to automate calendar reminders to support engagement in activity. There are examples of electronic AT specifically designed for time management such as the “Forget Me Not Calendar” (Holthe, Hagan and Bjerneby 1999) evaluated as part of the Enabling Technologies for People with Dementia (ENABLE) project (2001) and the “Day Clock” (Boyd, Evans and Harris 2016) which displays information in a format easier for people with dementia to intuitively understand.

Government policy recognises that technology could play a role in supporting people living with dementia in daily living (Kings Fund 2009-2012, European Dementia Research Agenda 2011) but despite this and the demand for clinical advice on orientation strategies and devices; very little research has been published directly on the subject of using calendar reminders.

The ENABLE Project (Topo et al 2007, Cahill et al 2007) loaned 50 electronic calendars to participants with dementia, reviewing just 22 at six months. The conclusions were that using a compensatory aid was effective but often relied on the carer prompting the person with dementia to use the calendar (Cahill et al 2007). This study had difficulties with recruitment and retention attributed to participant and professional lack of motivation to use AT.

Greenaway et al (2013) used a paper diary and Imbeault et al (2013) an electronic organiser in studies that demonstrated some efficacy but relied on extensive training. The cost of providing training programmes alongside AT interventions is unaffordable and impracticable as the number of people living with dementia in the United Kingdom rises to two million by 2050 (Alzheimer's Society Infographic 2014)

More evidence is needed on how to optimise the use of calendar reminders so they are effective for people with dementia; supporting them to know what is happening, when and prolonging their engagement in everyday routine occupations. Carers are reported as being very influential in the selection and use of compensatory AT (Topo et al 2007, Olssen, Engstrom, Skovdahl and Lampic 2011, Rosenburg and Nygard 2012, Lindqvist, Nygard and Borrell 2013) Therefore understanding of the carer's perspective is important.

Recognition of both the requirements of people with dementia and carers for calendar reminders is necessary to inform the design of future AT and is vital to delivering an inclusive, iterative, user centred design approach (Nygard 2008, Orpwood 2009, Van den Heuval et al 2012) that will deliver evidence based AT.

This study is an investigation into the detailed experience of people with dementia and carers using calendar reminders in the home setting. The objective being to

determine what factors contribute to the effective use of calendar reminders for this user group in order to inform guidance and identify requirements to underpin design of future calendar reminders for people living with dementia.

## **Methodology**

This was a qualitative feasibility study from a naturalist paradigm using Interpretative Phenomenological Analysis (IPA). IPA is informed by the philosophies of phenomenology, the study of human experience, hermeneutics, the method and purpose of interpretation, and idiopathy, how an experience is understood from the perspective of particular people in a particular context (Smith, Flowers and Larkin 2009). In this case, the objective was to understand the micro detail of the lived experience of creating and receiving calendar reminders. The research question was *“How do people living with dementia and family carers use calendar reminders?”*

This study looks at the dual experience of a person with dementia and a carer (Smith, Flowers and Osborn 1997). In IPA the researcher is engaged in a double hermeneutic where the participants share their experience and the researcher also makes sense of their account by self-conscious and systematic analysis (Smith et al 2009). IPA's person centred philosophy is compatible with the researcher's holistic and person centred perspective as an Occupational Therapist. (Cronin-Davis, Butler and Mayers 2009, Clarke 2009). Wilding and Whiteford (2005) suggest IPA can be a tool to explore “rich, multifaceted, intangible and dynamic phenomena such as being, occupation and everyday aspects of life”

## **Ethical considerations**

As this study involved adults with dementia approval was sought and granted by the University of Southampton Ethics Committee (Ethics ID:16804). Adhering to the

principles of the Mental Capacity Act (Code of Practice 2005). All participants had capacity to consent.

### *Method of data collection*

Six interviews followed by two focus groups were conducted. Focus groups are unusual in IPA. Usually a small sample of participants make sense of their own personal experiences. As the objective for this study was to determine practical requirements for calendar reminders; the focus groups presented an opportunity to further explore and reflect understanding of pragmatic themes with a broader sample.

### *Recruitment*

Purposive sampling was used to recruit six dyads living in the South of England, who met the following criteria: A carer providing support with calendar reminders and a participant with mild cognitive impairment (MCI) or dementia receiving support with calendar reminders. The inclusion criteria were broad as less than 50% of people with dementia have a formal diagnosis (Alzheimer's Society 2016). Excluded were persons with mental health or severe sensory impairments that precluded participation in interviews or focus groups or those who were unable to communicate in English. The study was advertised using publicity flyers distributed by two local voluntary support groups for carers and people with dementia. Following interest, if respondents met the inclusion criteria, a detailed information sheet was provided requesting basic demographic and optional descriptive information on their situation (Table 1).

## *Interviews*

Personal interviews were carried out by the researcher (NE) in the participants' homes. The Pool Activity Level (PAL) Occupational Profiling Instrument (Pool 2012) was completed by the carer as a surrogate measure to categorise the cognitive level of functioning of the sample. All participants and carers were interviewed separately and together, except for one dyad who were only interviewed together as there was a lack of opportunity to record a private interview. Recorded interview time for each dyad varied between 25 minutes and 52 minutes. Participants were encouraged to share how they used their calendar and invited to express views about reminder systems. A log identifying weekly events was completed. Photographs were taken to illustrate relevant detail of reminders like location, the amount of content and medium of delivery i.e. book, board etc.

## *Focus groups*

On completion of the interviews two focus groups were organised in order to present themes for further discussion. The first focus group was advertised to an existing voluntary group, and was attended by two participants with dementia and four carers who consented to join the study. The second focus group was recruited from the original sample of interviewees and was composed of three carers and two participants with dementia. Both sessions were an hour long and audio recorded to allow review. The focus groups were facilitated by the researcher and a colleague acted as an observer and took notes.

A field log book was kept by the researcher to supplement the audio recording. A low value voucher was given to participants to acknowledge their contribution and compensate for any incidental expenses.



## *Sample*

Of the six dyads, four were mother and daughter, one was mother-in-law and daughter-in-law and one was a husband and wife. All carers were female. Three participants were diagnosed with Alzheimer's disease, one with Alzheimer's disease and vascular dementia, two with mild cognitive impairment. All participants were in their eighties or nineties apart from one participant who was fifty and had a diagnosis of secondary progressive multiple sclerosis with visual, hearing and mild cognitive impairment. Multiple Sclerosis is classified as a rarer cause of dementia (Alzheimer's Society 2016, Devere 2011). Five participants were rated at the PAL "Planned" level. This represents a level of functioning where tasks can be completed but guidance to problem solve may be required. One participant was at the "Exploratory" activity level where completing activity can be challenging and staged directions are necessary. Five dyads represented a homogeneous group (Table 1).

<b>Table 1. Sample group</b>				
<b>Participant dyad as relationship (age)</b>	<b>Diagnosis</b>	<b>Living arrangements</b>	<b>Description in carer's own words supplied on expression of interest form prior to interview <i>Tell us a bit about yourselves (As a carer how much care do you provide?)</i></b>	<b>PAL score</b>
A Mother (83) and daughter(62)	Alzheimer's disease	In own home (17 miles apart)	<i>As a carer I manage the finances, house maintenance, garden, shopping. I remind her of all her calendar events on a daily basis.</i>	Planned 8 (8010)
B Mother (85) and daughter (57) and son in law	Alzheimer's disease	Linked annexe to main house	<i>She has her own bedroom, lounge, bathroom and kitchen/diner. She can no longer cook for herself. She can bathe and dress with support. Her life is managed by daughter and son in law who organise carers, links with outside agencies, shopping, cooking, meals, drugs, garden, washing, transport to appointments, doctor, hospital, chiropodist etc.</i>	Planned 6 (6210)
C Mother (90) and daughter (59)	Alzheimer's disease	In ground floor warden controlled flat (2.2 miles apart)	<i>Daughter organises everything financial. Daughter organises her private carers who call every morning to encourage food and drink and the taking of medication. Daughter takes her mother out to lunch 6 days a week to encourage eating. Mother attends two Alzheimer's clubs per week. Daughter writes everything on mother's kitchen calendar but would be very surprised if she ever refers to it. <b>Seems that ROUTINE IS EVERYTHING!</b></i>	Planned 9 (9000)
D Husband (50) and wife (48)	Secondary progressive multiple sclerosis Mild cognitive impairment Visual impairment Mild hearing impairment	In own home	<i>Wife is full time carer. We have a carer come for an hour each morning to get him up and approximately 3 hours sitting a week otherwise wife provides all the care, financial and housekeeping.</i>	Exploratory 3 (2322)
E Mother in law (85) and daughter in law (59)	Alzheimer's and vascular dementia	In son and daughter in law's home	<i>We live together with my husband who works from home. Mother in law usually manages her own personal care with a little instruction. Daughter in law helps with clothing choices etc. Mother in law is not able to help herself to any food or drink but has a good appetite when it is provided.</i>	Planned 5 (5400)
F Mother(85) and daughter (58)	Mild cognitive impairment	In her own home (over 60 miles/ 2 hour car journey)	<i>Daughter visits every 7-10 days and stay 1-2 days Care provided (do encourage / supervise) Shopping, house cleaning , financial affairs, making appointments (e.g. doctors, hairdresser) and providing transport</i>	Planned 9 (9000)
Note: PAL= Poole Activity Level (total score of 9 shown in domains of Planned/Exploratory/Sensory/Reflex levels of ability). Dyads shown as person with dementia and carer.				

## *Analysis*

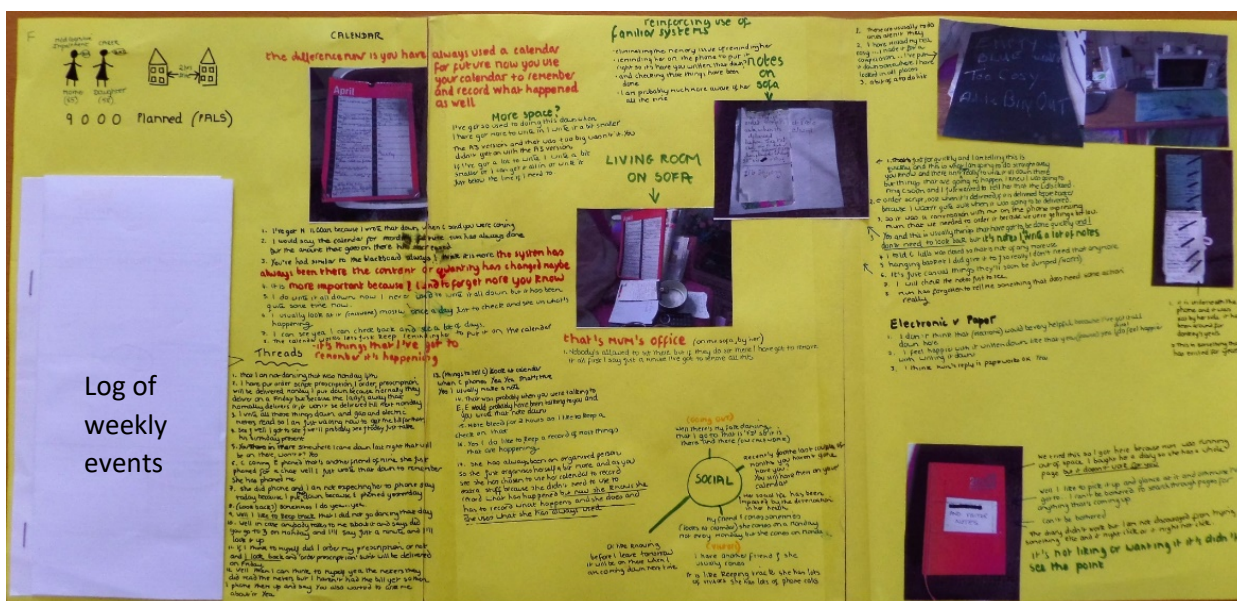
IPA recognises an interpretative process( Smith, Flowers and Larkin 2009). This analysis is from an occupational therapy perspective. The model of Human Occupation recognises the need for human occupation encapsulated as activities of daily living, play and productivity (Keilhofner 2008). Occupation is determined by individual volition (motivation), habituation (patterns and routines) and performance capacity as well as the physical and socio cultural environment. This represents a person centred and holistic stance. The researcher is an Occupational Therapist and reflected in her field log book that she is the same generation as the carers in this study and also has a personal experience of aging. Focus to the analysis has been brought by a continuous process of reflection with impartial mentors from a range of backgrounds including a social scientist, clinical psychologist and engineers.

## *Analytic Process*

The audio recordings of the interviews were listened to by the researcher and verbatim transcripts created and repeatedly read. Initial noting revealed clusters of topics that were organised into initial themes.

To gain deeper insight, collages were created using the weekly log, photographs and quotes to give a visual overview of the experience for each dyad (Figure 1).

Figure 1. Example of collage



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This visual encapsulation of each interview transcript has been a useful medium to maintain the hermeneutic connection with the perspective of the individual case whilst facilitating the identification and interpretation of patterns across the data set. Initial themes were refined into emergent themes which were presented to the focus groups. Additional data was then incorporated into the analysis to develop four superordinate themes with subthemes (Table 2) and a Master table of themes (Table 3).

Table 2. Initial themes refined to emergent themes and developed into superordinate themes and subthemes

<b>Initial themes</b>	<b>Emergent themes</b>	<b>Superordinate themes and subthemes</b>
1. <i>Recognises and uses a reminder system</i> <i>Knows a means of reminder is there (location, material object)</i>	1. <i>Calendars are a guide to knowing what is happening and what has happened for people with memory difficulties</i>	1. <i>Changes in utility and connection to calendar reminders</i>
		<i>i. Reliant on calendar reminders</i> <i>ii. Reassured by calendar reminders</i>
2. <i>Knowing what day it is and what is happening</i>	2. <i>The calendar and how we use it is familiar and unique to us</i>	2. <i>Customisation of calendar reminders</i>
3. <i>Who is the content for and does the reminder system work?</i>	3. <i>Who does the reminder work for?</i>	<i>i. Calendars are personal material objects</i> <i>ii. A calendar reminder needs to be familiar</i> <i>iii. A calendar reminder has to have utility to the person with dementia and their primary carer</i> <i>iv. Location must be a key place</i>
4. <i>Carer's aims and perspectives</i>	4. <i>Remembering someone else's calendar as well as your own is hard work</i>	3. <i>The experience of supporting calendar reminders</i>
		<i>i. Practical and cognitive effort required to support calendar reminders</i> <i>ii. Emotional effort required to support calendar reminders</i>
5. <i>Views on electronic AT</i>	5. <i>To use or not to use electronic technology</i>	4. <i>The role for assistive technology in delivering calendar reminders</i>
		<i>i. Little expectation of assistive technology</i> <i>ii. Paper or electronic is not relevant – does it work?</i>

<b>Table 3. Master table of themes</b>
<b>KEY: Participant dyads A to F Participant (P) Carer (C) Focus Group (FG1,FG2)</b>
<p><b>1. Changes in utility and connection to calendar reminders</b></p> <p><i>Reliant on calendar reminders</i></p> <p>AP I couldn't live without a calendar could I?            EP I think oh yes that's coming up today oh yes            FP It is more important because I tend to forget more you know            FG2 <i>Carer</i> People are so keen to have a calendar the worry.... (<i>Participant</i> finishes sentence) of what's happening</p> <p><i>Reassured by calendar reminders</i></p> <p>AC You are concerned with what is happening on the day            BC If we tell her someone is coming or she is going out then at least in her mind it is a bit more of a routine            CP It is mostly habit now that things happen mostly everyday            DP I do not plan my events they all happen off the top of my head on the day            EP It seems to be settled it is about the same each week            FG1 <i>Carer</i>- I fill out the calendar and tell him about events            FG2 <i>Carer</i>- X finds it backs up the information</p> <p><b>2. Customisation of calendar reminders</b></p> <p><i>Calendars are personal material objects</i></p> <p>AP The pictures are lovely to look at everyday            BC Bit jokey Friday FRYday if we have fish and chips            CP I have always used a calendar like that            EC She calls it my sheet            FC The A3 version was too big wasn't it?            FG1 <i>Carer</i>- Calendar with magnetic marker to show day            FG2 <i>Carer</i>- Using a paper calendar because she always has</p> <p><i>A calendar reminder needs to be familiar</i></p> <p>AP Well when something crops up or if someone phones me and says they are coming to visit I will put it on the table so and so will be coming that day and when they have gone I will throw it away            BC She did like to write on the whiteboard it used to make her laugh            CP Seventeenth yes well I read the newspaper because everyday I keep up to date the seventeenth so we are there the seventeenth and tomorrow is ..            DC If I put an alarm on his ipad he would know he has to be awake and then it will be easier for me to get him up But I didn't think it works? It works (<i>Participant</i>)            EP It is about the same each week and I think oh yes I like that            FC This is something that has existed for years            FG1 <i>Carer</i> When he comes downstairs he moves the paperclip to today we have been doing that now and it works C</p> <p><i>A calendar reminder has to have utility for the person with dementia and their carer</i></p> <p>AP If C says I'll be down so and so I look at the day C will be down today            BC If we wrote it on the board she followed instructions            CP You usually do that C so that I am not getting mixed up in what week it is and things            DP She is in charge of the calendar. It is the realisation knowing that I can be the best I can be but with the help of somebody else P            EC If it gives them any feeling of self-respect it must be worth it            FC The calendar works let's just keep reminding her to put it on the calendar</p>

FG2 The schedule I own so P knows what is going on because I am the one that has the knowledge it works well for us C

*Location must be a key place*

AP Every day to see what's going on and for the date so I have got to get the calendar out P

BC She wouldn't know what day it is once she has moved out of the bathroom

CP Well there is a calendar this is my calendar to know what is going on yes (brought from the kitchen by Carer)

DP I would like it on my phone

EP It's written down I have sort of got a piece of paper, a book of something

FC That's mum's office (on the sofa by her)

FG1 Carer It's easy you pass it near door at the bottom of the stairs

FG2 Carer It has to be presented to her rather than go and look for it

### **3. The experience of supporting calendar reminders**

*Practical and cognitive effort required to support calendar reminders*

AC Because I come here once a week I think if I ever forgot whereas with the month I can write the month down when I am coming and I just find it easier for myself

BC It is our responsibility to remember things not hers

CC The what's it's in the detail this is why I am so tired

DC I've got my Filofax and I put it all in there and lists I am a big lists person

EC I am beginning to think I should do a daily one (SCHEDULE). Really that's a lot more work to actually do one every night and make sure it is by her bed for first thing in the morning

FC I will check to see if Mum has forgotten to tell me something that does need some action really

FG1 Carer Thinking for two people you can forget things

FG2 Carer There are certain things I check she has put on the calendar so I am holding in my mind a skeleton calendar

*Emotional effort required to support calendar reminders*

AC I should have written him a note to let them know that things were in hand because X had to phone me and say that you were poorly and I had to explain to him that we were organising an x ray and then he had to phone Y to put his mind at rest.

BC Driving me mad her not knowing the day

CC Every day I write myself lists and work my way through them because I have so much to remember and my memory you know I am nearly sixty

DC I find his memory loss most irritating I can deal with the physical stuff and the you know it's the what are we doing and how are we doing it and speaking and him saying the same things I find it infuriating but it has got to be done. So sometimes I say I just don't know

EC I get stressed because we are going to be late

FC I am probably much more aware of her all the time as opposed to oh I haven't talked to her for a while its kinda there all the time

FG1 Carer Changes are tricky to manage

FG2 Carer You don't talk like you have a memory problem (note- disability not always recognisable)

### **4. The role for assistive technology in delivering calendar reminders**

*Little expectation of assistive technology*

B I don't know to be honest. Mum showed no interest in them.

*Paper or electronic is not relevant – does it work?*

AC I could use electronic communication but I think it would have to be very simple that we could all use

BC It's a bit over the top isn't it

CC I see technology as being it would involve me more

DP It would be very useful to me for example it would be like an electronic diary I press the button and then it would give my itinerary

DC I hate being the tech person C

EC She is quite open to electrical she will look at my iPad

FC I don't think that would be very helpful because I have got it all down here (ON PAPER)

FG1 Carer I'm just a technophobe

FG2 Carer We are all different

## Findings

These findings show that people with dementia use calendars as a compensatory strategy. Calendar use can be either intense, acting as an external memory record of what has happened and what is going to happen; or casual, primarily to reassure about what is happening when. The material object of the calendar itself, its overall familiarity, the measure of utility to person with dementia and carer and location are all factors that contribute to whether using a calendar works or not. Carers provide practical help that involves cognitive effort and is emotionally challenging. There is little awareness that calendars are being used as compensatory aids or any expectation of adaptive calendars. These findings are now explored in further detail. Participants (people living with dementia) are identified as AP to FP and carers AC to FC (Table 1). Focus groups are FG1 and FG2.

### *Changes in utility and connection to calendar reminders.*

All participants were using calendar reminders. Participants AP and FP were reliant on using a calendar as a framework to support independent living. For BP, CP, DP and EP the calendar reminders provided by family carers were used as a means of reassurance.



### *Reliant on calendar reminders*

Participant A recognised her own dependency and strong connection to her calendar.

*“I couldn’t live without a calendar could I?” AP*

She saw her calendar as a friend.

*“My friend this is”*

The content was crucially important to her.

*“This is my life”*

This increasing dependency and change in calendar use is also described by FC.

*“The difference now is you have always used a calendar for the future now you use your calendar to remember and record what has happened as well” FC*

FP explains how this works.

*“Well I like to keep track that I did not go dancing that day. Well in case anybody talks to me about it and says did you go to X on Monday and I’ll say just a minute and look it up” FP*

These threads of information are meaningful and link to valued social interactions and essential tasks like managing prescriptions.

*“If I think to myself did I order my prescription or not and I look back and “order prescription” (Note written on calendar) but it will be delivered on Friday (Another Note written on calendar)” FP*

### *Reassured by calendar reminders*

Participants BP, CP, DP and EP used their calendar for reassurance. They were living more in the moment and expressed a sense of life just happening.

*“It is mostly habit now that things happen mostly everyday” CP*

CP describes how routine happens.

*“She is good with routine but that is because everybody’s carting her off to a routine.*

*We are the routine, I suppose.” CP*

Information on what was happening was offered even though events were just happening, organised by others.

*“It is about the same each week and I think, oh yes, I like that” EP*

Information was often reiterated by telephone or in person. There was acknowledgement of interdependency.

*“You usually do that don’t you C? (write on the calendar) so that I am not getting mixed up in what week it is and things” CP*

Participants AP with a PAL planned score of 8 and FP with a score of 9 could actively use a calendar. At a Planned level, activities can be completed but some guidance might be needed. CP also had a Planned score of 9 but as her daughter was in daily contact she trusted and relied on the familiarity of the routine and reminders from others. Her lack of need for, connection to, or ability to use the paper calendar was evident during the interview and acknowledged by her daughter.

*“I write this on her calendar every month but I doubt she looks at it” CC*

BP, DP and EP all lived with family and had lower planned scores. They did not actively use a calendar but did reference it for reassurance. For BP and EP their functioning was starting to be exploratory so any benefit from a calendar was more by chance. EP was able to connect to a source of information, although not able to

name the daily schedule, she did know it was available, helpful and that she happened on it by her bed, or on the table.

*“Anyway it’s written down. I have got a piece of paper, a book or something” EP*

The carers of BP provided daily calendar reminders but were doubtful over whether they worked, intermittent success was recognised where the reminder had demonstrated some utility for their relative.

DP’s PAL score has been excluded from this comparison as his score was influenced by his visual and physical impairments related to Multiple Sclerosis so is not comparable to the PAL scores of the other participants (Table 1).

#### *Customisation of calendar reminders*

All the calendars had been customised. Consideration had been given to the material object itself, its overall familiarity, the measure of utility to person with dementia and carer and the location of the calendar. These aspects are now reported on.

#### *Calendars are personal material objects*

Personal connection was evident in the calendars chosen. Often they were gifts and of a preferred design and size repeatedly used over years. Changing a calendar to a diary did not work for Participants F.

*“We tried this so I got here because mum was running out of space (on her calendar)*

*I bought her a diary so she has a whole page but it doesn’t work for you. FC*

*Well I like to pick it up and glance at it and otherwise I’ve got to. I can’t be bothered to search through pages for a thing that’s coming up FP*

Even changing the size of the calendar did not work.

*“The A3 version was too big wasn’t it? You didn’t get on with the A3 version” FC*

This personal aspect extended to family photographs and how the calendar was used. For participants B writing on the memo board was humorous.

*“Bit jokey. Friday. FRYDAY if we have fish and chips” BC*

#### *A calendar reminder needs to be familiar*

Utilising a reminder system requires a systematic routine.

*“ Well when something crops up or if someone phones me and says they are coming to visit I will put it on the table So and so will be coming that day and when they have gone I will throw it away” AP*

This also resonated with a focus group participant.

*“When he comes downstairs he moves the paperclip (on the calendar) to today, we have been doing that now and it works” FG1*

Reminders were presented and used in familiar ways.

*“This is something that has existed for years” FC* commenting on her mother’s system of calendar, notes and memo board.

#### *A calendar reminder has to have utility for the person with dementia and their carer*

As this condition progresses what was useful can require adaptation. Carers for CP discuss this.

*“It would be interesting if we took it away (the memo board) if she would even notice.” BC1*

*“We have just got into a routine of doing it haven’t we?” BC2*

Utility was judged by a system that worked.

*“The calendar works let’s just keep reminding her to put it on the calendar” FC*

Outcomes were not always tangible and could relate to a need felt by the carer to ensure the dignity of the person they are caring for.

*“If it gives them any feeling of self-respect it must be worth it” EC*

There was a clear sense of partnership and trust, an acknowledgement of a state of interdependence, a word used repeatedly by Participant D, who described interdependence as

*“It is the realisation knowing you are never going to be the person you used to be, fit and able and completely free to do what you want when you want. It is the realisation knowing that I can be the best I can be but with the help of someone else” DP*

*“Yes the acknowledgement” DC*

Sometimes the calendar was about a network of communications, which could work well.

*“They (organisation) must have put it there themselves. I didn’t and they organised it because they pick mum up and bring mum back” AC*

Utility is having clarity about who the reminder is for and using only information pertinent to the person with dementia.

*“Separate calendar each as some things are not needed by the person with memory problems” FG1*

Use of familiar phrases was also helpful.

*“There were certain phrases that we’ve noticed she links onto like she remembers that DH is up the hill. Usually we say DH and she will look confused and then I’ll say up the hill” EC*

Social visitors or going out, required preparation to be ready so there was a driver to know that acted as an anchor even for BP, CP and EP who were using calendar reminders primarily for reassurance. CP talked repeatedly about tea in the communal lounge which she joins daily and enjoys.

*“When it gets to 10 to 3 I go in the lounge and I join them for a cup of tea.” CP*

Knowing the core events that are important to people with dementia is useful in order to target reminders that are more likely to be used.

#### *Location must be a key place*

The location of the calendar should be meaningful to the person with dementia so they know where to find information. For FP she had “mum’s office” on her sofa. The place mattered to her.

*“Nobody’s allowed to sit there, but if they do sit there I have got to remove it all first. I say just a minute I’ve got to remove all this.” FP*

Where a calendar is being used for reassurance it needs to be somewhere it will be come across. This was the case for EP who had copies of her schedule by her bed, on the table and by her chair.

This was also described during FG2 as

*“It has to be presented to her rather than go and look for it”*

For CP the traditional location of the calendar in the kitchen did not work as it was unlikely that CP would come across it. Familiar places that are visually encountered acted as information points.

Customisation of the object itself, familiarity and fit to the routine, utility and value to the person with dementia and carer, clarity of purpose and location were all described as requirements of an effective calendar system.

### *The experience of supporting calendar reminders*

Carers recruited were all actively supporting calendar reminders. They describe this task as needing practical, cognitive and emotional effort. Supporting calendar reminders seems trivial but it was apparent from the interviews that it was crucial to supporting someone with dementia to maintain their daily routine.

### *Practical and cognitive effort required to support calendar reminders*

The practical effort involved is visually represented by C's daughter extensive to do list.

*"The what's it's in the detail this is why I am so tired" CC*

The amount and level of detail can be challenging.

*"Thinking for two people you can forget things" FG1*

Another illustration was provided by FG2

*"There are certain things I check she has put on the calendar so I am holding in my mind a skeleton calendar" FG2*

Coping with multiple calendars is part of family life but caring for an adult with dementia can be at a stage of life linked to age related memory loss. C's daughter explains

*“Every day I write myself lists and work my way through them because I have so much to remember and my memory you know I am nearly sixty” CC*

Caring for adults brings responsibilities.

*“It is our responsibility to remember things not hers” BC*

Defining boundaries and respectfulness of the person with dementia was acknowledged as challenging. There was a sense “checking” to ensure her mother’s wellbeing for FC.

*“I will check to see if mum has forgotten to tell me something that does need some action really” ..... “behind the scenes rather than openly” FC*

The practical effort is also a factor.

*“I am beginning to think I should do a daily one (Schedule). Really that’s a lot more work to do actually one every night and make sure it is by her bed first thing in the morning” EC*

Stress and extra effort was created when the system was not used or didn’t work. AC did not leave a note to say she had taken her mother to the Doctor, AC then complained of being unwell to another family member and this causes a series of extra communications.

*“I should have written him a note to let them know that things were in hand because X had to phone me and say that you were poorly and I had to explain to him that we were organising an X-ray and then he had to phone Y to put his mind at rest” AC*

#### *Emotional effort to support calendar reminders*

Emotional effort was described.



*“I find his memory loss most irritating. I can deal with the physical stuff and the, you know it’s what are we doing and how are we doing it and speaking and him saying the same things. I find it infuriating but it has got to be done. So sometimes I just say I don’t know” DC*

FP’s daughter described heightened consciousness.

*“I am probably much more aware of her all the time as opposed to oh I haven’t talked to her for a while its kinda there all the time.” FC*

### *The role for assistive technology in delivering calendar reminders*

There was an absence of comment about technology indicating low awareness of AT. We all use memory aids like calendars, notes etc. but there was little expectation of any adaptive calendars paper or electronic specifically to meet the needs of people with dementia.

### *Little expectation of assistive technology*

This was summed up by CC, who had by chance seen AT at an Independent Living Centre.

*“I don’t know to be honest – mum showed little interest in them” BC*

### *Paper or electronic is not relevant- does it work?*

Familiarity and utility to the person with dementia and their carer was more important than whether it was a paper or electronic calendar.

*“I don’t think that would be very helpful because I have got it all down here (ON PAPER) I do feel happier with writing it down” FP*

DP was younger and the only positive voice about technology.

*“It would be very useful to me for example it would be like an electronic diary I press the button and then it would give my itinerary” DP*

His wife was less enthusiastic

*“It will just be you have got to do this and set reminders and change reminders.. I don’t mind doing it once” DC*

She elaborated:

*“I hate being the tech person” DC*

This underlines how the views of the carer are integral and there needs to be reconciliation of both user and carer needs within the design of solutions.

Technology was seen as an option for those more familiar with it, in future. Carers were willing and able to engage with technology but were adamant that it needed to be easy to use. Masking technology in a more familiar user interface was discussed in FG2.

*“Technology helping people who don’t realise they are using technology” FG2*

## **Discussion**

NICE clinical guidance (National Institute for Clinical Excellence QS30), dementia friendly design (Kings Fund, Dementia Services Development Centre 2012) and the findings of the ENABLE project (2007) suggest the use of and design of products to support time orientation can enable people to live well with dementia. In this study calendars were used by all the dyads as everyday objects although actual usage was adaptive and compensatory. There was very little or no expectation to use adaptive calendars, paper or electronic designed specifically to meet the needs of people with dementia.

This study reports adaptive typologies of use. Calendars were intensively relied on by participants to externalise and store information. This concept of an “extended

mind” where information is externalised in the environment and used to drive cognitive processes is described by Clarke and Chalmers (1998). It is also recognised as behaviour by Nygard and Johansson (2001). As dementia progresses this reliance on externalism diminishes and calendars are used more passively and randomly for reassurance. Better description and recognition of these typologies and how the progression of dementia changes the use of calendars is pertinent to guiding carers and people living with dementia to adapt their calendar reminder systems to support this reliance or to provide reassurance.

Recommendations on how to use a calendar as a compensatory strategy should encourage personalisation and customisation. Reminders need to be familiar and have inherent utility to the person with dementia, as well as being practicable for the carer. Recognition of what information is meaningful to the person with dementia and ensuring it is familiar and available all contributed as to whether calendars were effective as reminder systems for these dyads. This requirement for a personalised solution, which takes account of the lived experience, rather than just a technological led solution is pertinent and an approach that needs to inform guidance and inclusive design (Astell 2014, Gibson et al 2015).

Participants demonstrated inventiveness in customising calendar reminders.

Greenhalgh et al (2013) describes bricolage as the ability to holistically understand needs and meet them by utilising or adapting the familiar. If users’ abilities and needs are not understood and bricolage is absent, there can be frustration, wasted effort and lost potential for autonomy. When abilities and needs are well understood bricolage can be used to develop effective calendar reminders. This was evident especially for AP, EP and FP, and in the past for BP, CP and DP. Clinicians have a role to facilitate this process of bricolage.

Participants in this study recognised the input of family carers and acknowledged a state of interdependence rather than independence (Zwijssen, Alistair, Niemeijer, Cees and Hertogh 2011). Interdependency describes family care for people with dementia, who due to the progressive and debilitating nature of the condition find themselves increasingly dependent on others. Interdependency has implications for carers in the practical, cognitive and emotional effort involved to support cognition. In this research study, the participants represented were all motivated carers interested in optimising their use of reminders so their sharing of feelings of stress and tiredness suggest that this is an important issue to report.

### **Limitations**

This study is limited in involving only interviews with dyads with female carers so the views of male carers were not explored. Interest was primarily from family carers looking after parents. Couples may more easily share calendars, although the couple represented in the study expressed similar experiences to family carers. A weakness of the IPA method is that the richness and depth of analysis can be diluted by the focus on individual cases and across cases during analysis (Braun and Clark 2013). Social and cultural context has not been addressed by this study. Communication during the interviews was influenced by the researcher's being a stranger; repeated visits to develop a trusting relationship over a longer timeframe might have enriched the data.

### **Conclusions**

This study reports how calendars are used as compensatory tools to sustain autonomy and support routines for people with dementia. The illustration of

typologies of use and the meaningful customisation of calendar reminder systems are detailed in this paper.

Better understanding of these factors is relevant to practitioners to guide orientation strategies and are key requirements to inform the design of adaptive paper or electronic calendars that could better meet the needs of both the person with dementia and carer.

There needs to be wider recognition that effective use of calendar reminders is dependent on family carers and better understanding of the emotional, practical and cognitive effort required to support calendar reminders.

Calendar reminders that can address the requirements of people with dementia and carers to scaffold time orientation and engagement in routines could appear to be a trivial intervention but if more effective calendars can be set up or designed specifically for people with dementia; this is a low cost intervention that could contribute to delivering clinical and government policy to enable people to maintain their routines for longer and live well with dementia (Department of Health 2009, NICE 2013).

### **Funding acknowledgement**

National Institute for Health Research Masters Programme

Designability Charitable Funding

### **Acknowledgements**

The author wishes to thank all the participants who took part in the interviews and focus groups, local dementia support groups, university mentors and colleagues.

### **Declaration of conflicting interests**

The Authors declare that there is no conflict of interest.

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### List of abbreviations

Assistive Technology	AT
ENABLE	Enabling technologies for people with dementia
Interpretative Phenomenological Analysis	IPA
Mild Cognitive Impairment	MCI
Pool Activity Level	PAL

### Author biographies

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Nina Evans is an experienced clinical practitioner with a strong service delivery background in community occupational therapy and as an independent living centre therapist. She has worked in the NHS, local authority and voluntary sector. Nina is a specialist in Assistive Technology. As an occupational therapist her role at Designability ([www.designability.org.uk](http://www.designability.org.uk)) since 2001 has been to enable design by involving users in feasibility and evaluation studies to establish user requirements that are innovative and inclusive. Nina has substantial experience of involving people with dementia and carers in research and development programmes. Projects have included development of smart home technology, the Day Clock and the Memory Technology Library. She is currently involved in research on using technology to support task sequencing and the design of a sensory cushion.

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Dr Lesley Collier is a Senior Lecturer within the Faculty of Health Sciences (FoHS), University of Southampton. She is an Occupational Therapist with a research interest in sensory and information processing in adults with cognitive impairment. Lesley has a particular interest in facilitating meaningful activity for people with

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