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## **Oxfordshire County Council**

# **Support to the Early Intervention and Prevention Services for Older People and Vulnerable Adults Programme**

## **Report on Study of Care Pathways**

**March 2010**

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## Report on study of Care Pathways

### 1 Introduction

As part of its Support to the Early Intervention and Prevention Services for Older People and Vulnerable Adults programme, Oxfordshire County Council engaged the Institute of Public Care to work in partnership on a study of the care pathways of older people moving into a care home. The aim of the research has been to identify the critical characteristics, circumstances and events which lead to a care home admission in order to provide appropriate services to prevent or delay such an admission.

This paper presents an analysis of:

- A file audit conducted on a sample of files of people admitted to care homes in 2008-2009.
- A number of qualitative interviews with older people who had been admitted, their informal carers and care managers.

### 2 Methods

The project combined a quantitative and qualitative approach. In the first phase, an analysis of 115 admissions in the City and West Oxfordshire areas was carried out. However, an additional nine admissions from South Oxfordshire were included by error in the file audit; these have been included in this analysis, although excluded in Section 8.3 when the two main areas are compared. Nine additional 'threshold' admissions were excluded, ie, self-funders who transferred into the care system when their funds fell below the threshold for eligibility for local authority funded care. The aim was to obtain data on a quarter of all admissions across the county over the last year.

It should be noted that the quality of file data depends on the approach of individual staff to recording the data and this obviously creates varying degrees of bias. For example, information prior to admission to a care home may emphasise the severity of an older person's situation in order to ensure that they are considered eligible for admission.

A comparison of data from SWIFT and ESCR indicates that there was greater recording of which services were received by people in ESCR than in SWIFT. For this reason, the analysis of the file audit data is based on the ESCR data where available<sup>1</sup>.

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<sup>1</sup> Both SWIFT and the Electronic Social Care Record (ESCR) are IT based systems which record relevant information on social care clients. ESCR has more detailed information.

The second phase of the study focussed on interviewing a sample of the 115 older people admitted to a care home in 2008-2009, their informal main carers where available, and care managers. A total of 21 interviews, including seven older people, eight carers and eight care managers, were carried out. There were three cases where the carers of older people with dementia were interviewed. The completed interviews were transcribed and an analysis of the transcripts carried out using qualitative data analysis software. This was triangulated with the data from the file audit.

Older people and their carers were asked about circumstances and experiences prior to entering a care home, including: the previous living arrangements of the older person; their health and need for care in the four to five years leading up to admission; the circumstances around the decision to go into care; and whether there were any services or support that they felt could have enabled them to continue living in their own home for longer. This phase of the project also included mapping timelines for the older people who were interviewed to visually demonstrate their pathway into care.

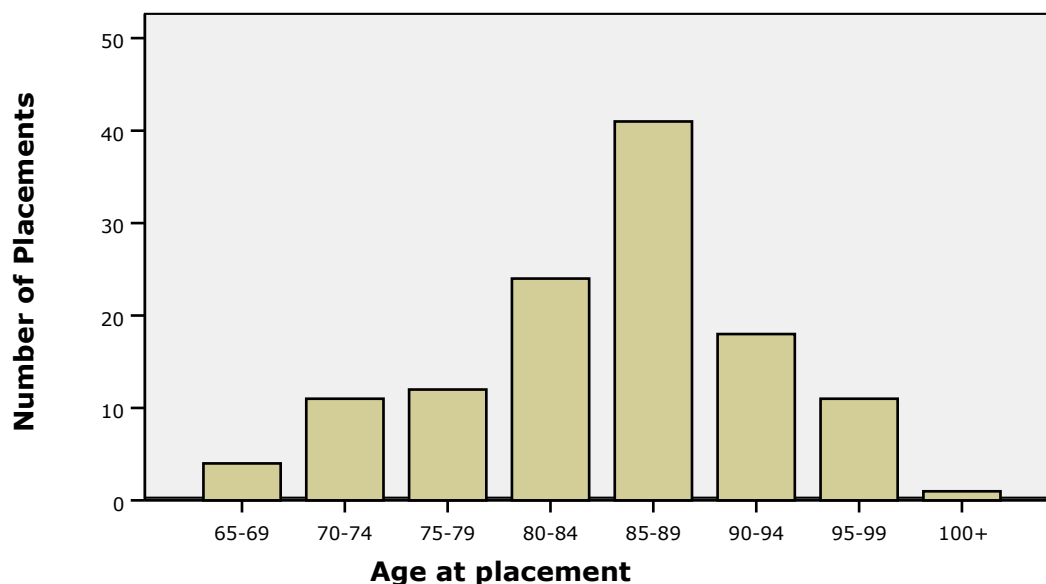
We are very grateful to the older people, carers and care managers who took part in the interviews for their contribution to the project.

The findings from the first two elements of the study are combined where appropriate in the sections below, and the timelines are attached as an appendix.

### 3 Profile

The median age at placement was 85.0 years old with a range from 65 to 103.

**Figure 1 Number of placements by age**



The great majority of people going into care were White British (97.5%) and nearly three-quarters (71%) were female. This is similar to the profile of older

people in Oxfordshire, particularly those aged 85 and above, and identical in terms of gender to an earlier national study based on 1995-1996 data<sup>2</sup>.

Prior to admission, more than three out of five older people aged 75 and over (63%) had been living alone, whilst 19% lived with a spouse or partner and 19% with another family member. In comparison, less than 50% of people aged 75 and over are estimated to live alone in Oxfordshire, reflecting in part a younger age profile. It is not known whether the higher proportion of older people living alone who are admitted to a care home reflects their higher age profile or indicates a greater likelihood to be admitted to a care home. However, a national study<sup>3</sup> of care home admissions in 2001 found 70% of people admitted to a care home, and 52% of people admitted to a nursing home lived alone.

More than two-thirds (70%) had been living in their own home, with 22% coming from sheltered housing, and 8% from their son or daughter's home. There may be scope to reduce the relatively high proportion of people moving to care homes from sheltered housing with greater provision of extra care housing as an alternative to sheltered housing. Bebbington et al (2001) reported 6% of admissions were people coming from sheltered housing.

#### **4 Predisposing conditions**

A number of conditions were identified among those being admitted:

Urinary incontinence	45%
Dementia	40%
Bowel incontinence	34%
Depression	25%
Visual impairment	21%
Stroke	19%
Diabetes	17%
COPD	6%
Learning disability	2%

Bebbington et al (2001)<sup>4</sup> found similar rates of dementia (38%) and stroke (21%), but lower levels of incontinence (29%), depression (13%), and visual impairment (10%) and a higher level for arthritis (32%) in their study of admissions to care homes.

More than half of those in the audit had multiple health problems at the time of admission: 56% with three or more conditions. Common combinations included: dementia and incontinence (19%); depression (17%); dementia and stroke (10%); and dementia and diabetes (9%). It is possible that there has been under-recording of the full range of health problems experienced by those in the audit.

The interviews also revealed that all of the older people in the sample had experienced multiple health problems in the years leading up to their admission.

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<sup>2</sup> Bebbington A, Darton R & Netten A (2001) *Care Homes for Older People, Volume 2 Admissions, Needs and Outcomes, The 1995/96 National Longitudinal Survey of Publicly-Funded Admissions*, Kent: PSSRU.

<sup>3</sup> Bebbington A, Darton R & Netten A (2001) op.cit.

<sup>4</sup> Bebbington A, Darton R & Netten A (2001) op.cit.

These included: stroke and associated disability, incontinence and UTIs, dementia, cancer, visual impairment and depression. In several cases, people were living with the consequences of a health condition from many years ago, eg, a stroke in 1987. A picture of the range of health problems and the timeline is attached as an appendix.

*He had the stroke in '95. But that limited his movement on his right side and you know I suppose getting older as well, he struggled getting around a bit more, then he got diagnosed with prostate cancer...And he had to have a catheter fitted and he gets quite prone to infection and he had falls and things.*  
Carer of Mr H

*When she was admitted to the Fulbrook she had a chest infection, a UTI, her diabetes was ridiculously unstable. So add that to the dementia, it all blew up.*  
Care Manager 3

Limited mobility was also common among those being admitted: at least 56% had some difficulty in walking; and 11% were unable to walk. Arthritis was noted in 9% of cases.

The levels of ill-health appear are well above national prevalence rates for incontinence, dementia and stroke. However, prevalence data from directly comparable age groups is rarely available. Twenty per cent of men and 25% of women aged 85 and above in the general population are estimated to have dementia<sup>5</sup>; and between 10% and 20% of the population aged 65 and over is estimated to be incontinent in the general population (prevalence data for higher age groups are not available)<sup>6</sup>. Levels of depression may also be higher than levels in the general population: between 10 and 15% of the population aged 65 and above were estimated to have depression in a study published in 1996<sup>7</sup>. Five per cent of men and 3% of women aged 75 and over report strokes<sup>8</sup>; and visual impairment is reported by 12% of people aged 75 and above<sup>9</sup>.

#### **4.1 Continence**

Incontinence was a common characteristic of those admitted to a care home: 51% of the sample in the file audit experienced some kind of incontinence. Four of those interviewed had become incontinent prior to admission and it is clearly an influential driver towards care. This may be in terms of the condition itself leading to people concluding that they cannot remain in their own homes but also through secondary factors eg the stress incontinence puts on carers, its

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<sup>5</sup> Alzheimers Society (2007) Dementia UK: A report into the prevalence and cost of dementia prepared by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the Institute of Psychiatry at King's College London.

<sup>6</sup> Department of Health (2000) Good Practice in Continence Services, London: Department of Health.

<sup>7</sup> Baldwin, R. (1996) 'Depressive Illness', in Jacoby, R. and Oppenheimer, C. (eds) Psychiatry in the Elderly, Oxford University Press.

<sup>8</sup> Office of National Statistics, 2004/05 General Household Survey, General health and use of health services, Table 7.15 Chronic sickness: rate per 1000 reporting selected longstanding conditions, by sex and age, National Statistics.

<sup>9</sup> Charles, N (2006) 'The number of people in the UK with a visual impairment: the use of research evidence and official statistics to estimate and describe the size of the visually impaired population', RNIB.

apparent link to urinary tract infections (UTIs) and falls, or people restricting their mobility because of anxiety about their continence. A couple of care managers commented on the significance of incontinence:

*There is one particular couple we get that the wife is the primary carer and she consistently says, oh I can't cope my husband has got to go in permanent care. And the trigger for her is the fact that he has problems with his catheter now that is just one thing that just tips her over.*

Care Manager 4

*Interviewer: The incontinence issue must have been really hard for you to deal with at home.*

*Carer: It was terrible, it was terrible.*

*Interviewer: And awfully distressing for her I imagine?*

*Carer: And it was. I suppose towards the end I'd got to the stage where I sort of resented it really, because the British Legion gave us an electronic bed for her, so that was nice, but it was just sponge, it was ruined and that was every morning. Mum was buying her own incontinence pads, because the doctor, we didn't even realise we could get them on prescription right up until probably 6 or 7 months before she came in here, before she went to hospital.*

Carer of Mrs C

*Some care homes appeared to have been able to tackle incontinence problems which had not been addressed in the community or in hospital:*

*In a lot of cases, when clients come from hospital to nursing homes, they come with catheters and all sorts of things that they quite possibly don't really need, but quite often they are given them at hospital because it's easier. Maybe I shouldn't say that but the general feeling is that it's easier to manage so they are given catheters and all sorts of things that take away their independence, take away their dignity and most of them don't want and don't actually need.*

Care Manager 7

UTIs were mentioned as a factor linked to falls:

*Carer of Mrs D: But the paramedics kept coming because she kept having urinary tract infections. One after the other. She used to drink a lot and that's what they thought was causing a lot of this.*

*Interviewer: The falls?*

*Carer: Yes.*

*UTI's is a biggie. We get lots of people coming in with urine infections.... But of course with a UTI quite often comes confusion, disorientation and falls.*

Care Manager 1

The relationship between continence and night care services was mentioned by several care managers.

*If you think for the sake of going to the toilet once, you go into a home, leave your own home, possibly your husband just for that reason. Until we realise that complex care does not stop at 9pm, I can't see how we can ever stop people going into homes unnecessarily.*

Care Manager 3

*Night care needs to be seriously considered because that is one of the big things they will always ask. Do they call out at night, do they sleep through the night, are they continent at night, because if they are not then the carers put them to bed at 9 at night and they don't come in till 9 in the morning their skin is severely compromised.*

*Care Manager 1*

## **4.2 Dementia**

Dementia was the other condition common to a high proportion of those admitted to a care home. It was also an important factor mentioned in the interviews, although for ethical and practical reasons, people with dementia were not themselves interviewed. Carers mentioned concerns about the behaviour of those they had cared for with dementia in terms of wandering (particularly at night) and aggression. These concerns were echoed by care managers:

*Yeah, he did get support but it is very difficult with dementia because the times that you need support are the times that are unpredictable. So someone went in everyday and the carers were great, they would pop in the morning and if she didn't want to know in the morning they would come back at lunch time and get her up and dressed and all those things. But he said sometimes I might need help at 4 o'clock in the morning, it might be 6 o'clock in the morning it might be midnight it might be not all day at all we'd be fine. No matter how much help you put in there for him it wouldn't have made any difference.*

*Care Manager 4*

*A lot of our clients have cognitive impairment to some degree and quite often it's that that makes them unsafe rather than their physical abilities or inabilities and this lady's dementia made her unsafe to be at home because, you know, we can't keep sending somebody home who is pulling out their catheter and a high risk to themselves really and I know that from reading back at my notes her son and her daughter were very distressed and really struggling to hold the whole thing together.*

*Care Manager 1*

## **4.3 Falls**

The data indicated that more than one-quarter (26%) of people had fallen requiring a hospital admission in the last 12 months; whilst 18% had a recorded fall although this had not resulted in a hospital admission in the last 12 months. There was a small overlap between these two groups (3%)

Falls were mentioned by several interviewees and there appeared to be a possible link with incontinence. The unpredictability of falls and concerns about frail elderly relatives falling while on their own were a common concern for carers.

*Interviewer: Do you think there's anything that could have been done to support him better at home?*

*Carer of Mr H: I don't think so, I think everything was being done, I think it was just purely dad with his falls and his safety issue and I don't think anything else could have been done. He had the alarm, he had the carers coming in, but I*

*mean he could have just fallen and laid there and not been able to reach his alarm because of the position he was in - he usually kept it in his pocket, his pyjama pocket for example, his shirt pocket you know - and broken a limb or something. I mean I turned up one day and he was just laid on the floor. He hadn't been able to press his alarm because he was in such an awkward position.*

Interviewer: *So what would you say was the main reason that you came into a care home?*

Older Person – Mrs C: *Mainly because my daughter didn't want to come home from work and find me on the floor. That's what she's frightened of.*

Interviewer: *She was worried about you falling?*

Older Person: *Yes*

Interviewer: *Were you living on your own?*

Older Person – Mr H: *Yes, that's where the trouble arose. I mean the Council got me a lovely little bungalow, but I had two or three falls and they weren't happy about me being on my own.*

*She can't stand, she can't walk and I didn't want that. I used to work in London, before mum came in here and I'd very often get a phone call, I've fallen or I've this or that, so really it's just for her own safety. I couldn't keep thinking about her constantly when I was at work all day.*

*Carer of Mrs C*

#### **4.4 Depression**

A quarter of those admitted to a care home (in the file audit) had suffered from depression. Mental health problems were mentioned in some of the interviews as factors contributing to the older person's admission to a care home.

Bereavement and isolation had in a couple of cases resulted in depression:

*He had that [depression] years and years and years, he had depression but I think it got, well it did get worse when my step-mum became quite poorly so that put strain on dad because he was caring for her at Swindon.*

*Carer of Mr H*

Isolation and lack of social contact was mentioned in a number of instances as a factor which contributed to an older person's deteriorating health and well-being:

*...the other big one that I find that people tend to go into long-term care that aren't hospital admissions, a lot of it is isolation, is loneliness, is feeling vulnerable and at risk and especially during the winter months.*

*Care Manager 7*

*I think she felt quite isolated at night in the flat. I think if there had been a warden there she would have been...but even now I think they are finding that she doesn't sleep very well, and they make her a cup of tea in the night and that sort of thing. And I think if somebody could have been on hand at night she may have been different..*

*Carer of Mrs D*

Social isolation was sometimes due to disability, for example, as a result of visual impairment, one older man stopped going out:

*'He wouldn't go out. He was frightened and so he got very isolated and although they had a community room at [sheltered housing scheme], because of the dark nights and that, he wasn't going to go; you know he didn't go so most days the only person he saw would be the warden, the lady who came to put him to bed, the one who came in the morning. So that was the only people he ever spoke to.'*

*Carer of Mr H*

Most people depended on their family and formal carers for social contact and only one older person had received a befriending service. One care manager commented on the waiting list for befriending services and, in particular a lack of any service in Chipping Norton.

#### **4.5 Stroke**

One in five of those admitted to a care home had previously a stroke. From the interviews it became apparent that a higher number had also had strokes sometime in the past than had previously been recorded, which had resulted in a degree of disability:

Older Person – Mrs G: *I had my stroke in 1987 I believe or '89, one or the other. Interviewer: And did that leave you with some disability?*

Older Person: *Yes I have. I can't use my left hand and my left side. It affected all of my left side. My eyesight is not that good on my left side either.*

Other older people interviewed had more recent mini-strokes or transient ischemic attacks (TIAs) which were also thought to have led to falls.

#### **4.6 Meals and nutrition**

Concerns about cooking and nutrition were mentioned in some interviews, such as neglecting to eat properly and inability to cook safely. In some cases this was the result of dementia, and in others due to disability:

*I had Heart to Heart and they used to come in and put my dinners in the microwave and the girls were very good there, but they couldn't stay long and after that I was on my own and I just found it difficult to make a cup of tea or anything safely.*

*Older Person – Mrs D*

*And what he used to do is he'd boil a big saucepan of potatoes up, a huge saucepan, dish himself up a few and then he'd leave the rest, but then the next day he'd put some more water in and put some more fresh potatoes in... the same with the peas, frozen peas. He kept topping them, topping them, topping them. The spam he wouldn't put in the fridge. He didn't like anything cold so he wouldn't put it in the fridge. He'd leave it on the side. Oh it's a wonder he wasn't poisoned.*

*Carer of Mr B*

Daughter: *Prior to all of the traumas of the last year say, prior to that when mum's sight was deteriorating to the point that she couldn't be left, you haven't cooked anything for a long time have you?*

Mother: *Oh I couldn't*

Daughter: *We had a little time when you set fire.*

*Joint interview – Carer and Older Person – Mrs F*

## 5 Mainstream services

### 5.1 Adult Social care

Prior to admission to a care home, at least 84% of older people had received social care to help them live at home, including 50% who had received intensive home care, ie, more than 10 hours of home care or 6 or more visits a week. However, this also means that 50% of those admitted had not been receiving an intensive care package prior to admission. Of the smaller sample that were interviewed all had been receiving a care package prior to admission.

From the audit the proportion of different types of social care people were receiving is set out below:

Personal care (eg, getting up, going to bed, getting dressed, washing and using the toilet)	62%
Home care/home help (eg, like laundry, shopping and essential cleaning around the home)	54%
Meals	46%
Equipment	35%
Day care	25%
Overnight respite away from home	22%
Telecare (including pendant alarm)	17%
Professional support	6%
Direct payments	3%

Sixteen people (13%) had received intermediate care, (however, it is not certain that the intermediate care figures are accurate, as some people may only have been recorded on NHS records which were not examined as compared to the ESC record).

One person was recorded as having received re-ablement services; and two people were recorded as having received falls services. One person had come from extra care housing.

There were both positive and negative comments about the support provided by social care staff. Some staff were praised for their helpfulness:

*I think it's worked really well for dad and I think the support he got before he went into the care home and I think where he is, is excellent.*

*Carer of Mr H*

*I don't think you can fault the JR really, I haven't been able to, and we can't really fault the social services or the council up here. I am telling you compared to Kent these look after their elderly people beautifully.*

*Carer of Mrs D*

However, there were also comments about the shortness of visits by care staff, and a lack of responsiveness. For example: comments by carers were not followed up by the care staff; care staff came and went too quickly.

*Yes, that's right. I didn't want anything else, that was all I wanted, just come in, concentrate on mum. They did have some really nice people that used to come, because mum had a 45 minute slot, but what would happen is if they came in and she didn't want anything to eat there used to be one of them that would sit with her and talk to her and that was as good as anything else. But we then had a letter saying they were cutting her time down because she didn't need any help with anything and they cut her down to a 15 minute slot.*

Carer of Mrs C

*I had Heart to Heart and they used to come in and put my dinners in the microwave and the girls were very good there, but they couldn't stay long and after that I was on my own.*

Older Person – Mrs D

Delays in accessing services were a source of frustration and concern for some:

*It was me that had to get him into the memory clinic, get him in to the doctors and get care for him and social workers out and it was like hitting your head against a brick wall...it was just like hitting my head against a brick wall to get any help. I just couldn't. I went to the memory clinic and that was months and months and months before anything was done from that.*

Carer of Mr B

*So care packages, you know, you make your referral through social services, they are put on the allocation list and who knows when it is going to get allocated and similarly with respite superficially it might not seem critical but the woman who, you know is struggling at 90 years old, we need swift action, we don't need them to sit, I mean I know it is really difficult for them to manage. But I suppose we are coming from that really acute perspective where we need things to happen swiftly.*

Care Manager 4

Continuity was also mentioned as an issue both by service users and care managers:

*I had lots of lovely people coming and going but you'd ring them the next time and I'd say oh can I speak to so and so. Oh she's not dealing with the case now. It's been handed on to so and so and so you'd ring so and so. Oh it's in the system at the moment. We haven't allocated it to anybody. You'll have to see a duty manager. It hasn't been allocated to a person and of course nobody knew anything.*

Carer of Mr B

*Because of how we work now, we go in do what we need to do and then we close them & CPN's are doing the same. So, if this person goes into a crisis, the chances of someone who does know them well and who would be able to establish if it is a crisis, the chances of it being that person are quite slim.*

Care Manager 3

One older person had six different care managers or social workers, partly as a result of admission to two different hospitals and alterations in her care package, over a period of six months.

## 5.2 Primary Care Trust

Comments about GPs were varied. One carer said that it was the GP who finally asked her if she was coping and got her some support, and another commented:

*Well I sort of got moral support from doctors and things like that, they were very, very good, at [doctors surgery], you know offered help, they were all, if there was ever a problem I could you know get in contact with them, health wise, they would get me in or see dad or whatever so they were very good.*

*Carer of Mr H*

However, there were also negative comments, for example, criticism of one GP's perceived reluctance to prescribe dementia drugs because of the cost. One carer thought that their GP was *uninterested* in the *small things to do with dementia* such as lack of personal hygiene.

Care managers also had mixed views about primary care staff. One commented that doctors and district nurses had an expectation that: *social workers can just put them [older people in crisis] into homes.*

The staff providing the case management service in West Oxford which uses the combined predictive model to identify patients at risk of admission to hospital reported that only a small number of the people which they are dealing with appear on SWIFT records.

## 5.3 Acute Sector

More than three-fifths (61%) of people in the file audit were admitted from hospital. Where information was recorded, nearly two-fifths (39%) had been in hospital for 8 weeks or more prior to admission. The national study by Bebbington et al (2001)<sup>10</sup> found only 10% of those admitted to a care home had been in hospital for 8 weeks or more prior to admission. The higher figure for Oxfordshire may be due to higher need thresholds for admission to a care home now in operation, but there may be local factors at play, such as policies and procedures around hospital discharge.

Nearly one-fifth (18%) of people admitted to a care home were known to have been in hospital in the last 12 months (excluding the time immediately before admission to the care home).

Most of those covered by the interviews were admitted to a care home directly from hospital, often after a protracted stay. In some cases, it appears that admission to hospital was the first time that the older person's health problems (such as dementia) were properly assessed and diagnosed: in other words, hospital provided an opportunity to assess the whole person. Some carers commented on the pressure on beds leading to prematurely early discharges:

*The most stressful time that my sister and I had was when she [mother] used to go into the JR and they kept her in. All they wanted to do was get rid of her really quickly. Which I can understand because this is...they couldn't wait to get rid of her and sometimes they sent her home and she was back in the next day.*

*Carer of Mrs D*

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<sup>10</sup> Bebbington A, Darton R & Netten A (2001) op.cit.

There was praise from some interviewees for the hospital social workers and the support they provided:

Interviewer: *Did the social worker talk through the process of being admitted to Madely Park and helped with that?*

Carer: *Yeah, they were wonderful.*

*Carer of Mrs D*

#### **5.4 Housing, adaptations and equipment**

Where information about housing was available, in nearly one-third of cases (30%) the person's current housing was not seen as appropriate. The reasons cited include: four first floor flats without a lift; and four others with stairs to, or inside, the accommodation; five lacked downstairs toilets.

From the accounts provided in the interviews, greater availability of extra care housing could have delayed admission to a care home, by meeting the needs of couples and people with dementia.

At least 12% of people in the audit had received adaptations to their homes although the audit does not indicate how long these adaptations had been in place and hence whether they had been cost effective in delaying an admission.

A number of people had received more minor adaptations, such as rails which they had found helpful. One carer illustrated how the provision of aids had helped her mother to continue to live independently following a lengthy period in hospital:

*She eventually returned home where adaptations had been done: a walk-in shower and a stair lift, and she and her husband had managed very effectively with minimal practical support from [her non-resident informal carers]*

*Notes of interview with Carer of Mrs I*

*I think they [Social Care] did really well, I mean they helped, they put rails in and things like that, they adapted the bathroom, put the walk-in shower in, you know they came and checked what he needed in the home, ...cause you know he had a stroke so he had limited movement. They were excellent; yeah I was really pleased with that.*

*Carer of Mr H*

Adaptations and appropriate housing (ie accessible) appear to have extended the ability of some older people to live independently, although without information on costs and the length of time that an adaptation delayed admission, it is not possible to assess cost effectiveness. Some equipment may have a perverse effect on mobility by reinforcing anxiety about falling in that people become dependent on aids and adaptations being present rather than in recovering greater balance and mobility. There was also a concern that people were sometimes supplied aids and equipment that were not always appropriate to their needs:

*You end up with these patients, they will open the door and they have got 3 different walkers, they have got 2 different walking frame, they have got a*

*disused toilet seat and they have got this mountain of stuff haven't they, they just don't want, they just don't use.*

Care Manager 4

## **5.5 Voluntary sector**

There was no mention of the voluntary sector in the interviews apart from help provided to one older person by Help the Aged and Age Concern:

*Help the Aged got in contact with Dad and they were able to, I think it was initially for a year, a lady would come. I think it's once every two weeks, X, her name is, and she would offer to take Dad out, or she would sit with him for a couple of hours or, they could watch TV together or she could chat, just chat to him about things, and a couple of times she's taken him out just to go to a pub or round the little villages you know and he enjoyed that and she still does pop in and see him.*

Carer of Mr H

The interviews highlighted unmet demand for befriending services, for example:

Care Manager 7: *There is Age Concern but they have a waiting list.*

Interviewer: *For the Day Centre?*

Care Manager: *No, for the befriending service and the problem with that is that when they do eventually get round to seeing someone, they only tend to go for a year because obviously the list is growing behind them all the time.*

## **6 Specialist services**

### **6.1 Falls services**

More than two-fifths (41%) of those admitted to a care home had fallen in the last twelve months. However, from the files, only two people were recorded as having been seen by the falls services although a third person had been offered the service but been unable to get transport to the falls clinic which resulted in her not attending.

Both the people who had been seen by the falls service valued its intervention although it appeared to have a limited long term impact.

Carer of Mrs F: *And after that, after going to the falls clinic, you gained a bit more confidence actually in moving about.*

Older Person – Mrs F: *Yes, I think I'm still learning to be very, very conscious of what my movements are. I think it took away the, whatever it is, the fall did it. I'm not so confident, even though I think I am. I'm terrified of having a fall.*

Carer: *So just to bring you up to date, that was at the beginning of 2008 you were attending the falls clinic for the appointed number of sessions and then you were signed off and then a period of stability really, but then Autumn last year you had another series of falls.*

### **6.2 Continence service**

There were no references in the audit and nobody described at interview the Oxfordshire continence service despite incontinence being a common condition among those covered by the interviews and in the file audit. One interviewee

mentioned that it was only shortly before the person they were caring for was admitted to residential care that they discovered that continence pads were available on prescription. The lack of night services to assist people to go to the toilet was also mentioned by care managers:

*Incontinence is an issue, so I said really the problem is night time. There is a night service but it's rare it has availability, so I rang agencies because we will not fund any part of night care apart from our night service which finishes at 3 o'clock. I think this lady needs an assessment to see how she sleeps, how does she fall out of bed, is it the loo, what is it? She didn't used to do it before so why is she doing it now, she's got a UTI, she doesn't drink enough.*

Care Manager 3

### **6.3 Telecare**

There was little mention of telecare, and experiences of its usefulness were mixed, depending in part on the availability of informal carers to respond, and the reluctance of some older people to disturb them:

*When I had a fall and had to ring the buzzer, it went through to an office, I don't know, it was up North or somewhere and they used to ring my son in law and my elder daughter that lived in Clanfield, and they used to come over and of course it was in the middle of the night and it wasn't fair to keep waking them in the night. I thought if something else could be done we'd do it, so that's what we decided.*

Older Person – Mrs D

*Even though I had alarms put on his door, I still had to get downstairs out of my door to see where he was going.*

Carer of Mr E

However, one care manager provided a striking example of how telecare had enabled a client to continue to live in her own home in spite of poor eyesight and advanced dementia:

*Certainly I've got a client in Chipping Norton, a lady who is soon to be 101 years old. She has very restricted sight so very impaired vision, little bit on the deaf side, bless her, very advanced dementia. She is still able to get around and they have had to put a stair gate to stop her going up the stairs. They have had to move her bed downstairs but we've put sensors in, I think we've put a seat sensor in so that if she gets out of her seat and doesn't return to her seat within a certain time it will go off. I think there is a bed sensor and I can't remember whether we put room sensors in or it might just be that she's got the Falls Cliff to go on her hip and that has worked extremely well, and those things have probably helped to keep that lady in her home.*

Care Manager 7

## **7 Informal care**

More than three-quarters of the audit sample (82%) had received informal care in the shape of help with daily tasks; and a smaller percentage (30%) of the total had received informal personal care from family or friends. The main informal carers prior to admission were sons or daughters (59%), followed by

partners (14%) and other family members (14%) of those receiving informal care.

More than one-third (37%) had family members living in Oxfordshire, although the closeness of informal carers and the frequency of the care provided varied.

Of those who received informal care, in 12% of cases, the carer had fallen ill or died in the last 12 months. From the small numbers where the recent death of a carer was recorded, it is not possible to assess the extent to which carer breakdown was a major factor in admission to a care home. However, the low percentage is surprising given the perceived importance of informal carers in supporting people at home and other evidence from the audit (eg, people living with someone less likely to be admitted from hospital) and indicates there may be other factors at play.

### **7.1 Burden of care**

Many carers had provided large amounts of informal care while working and bringing up their own families. The interviews highlighted the impact of caring on carers' health, income and family relationships. Carers spoke of the strain and practical difficulties which caring created:

*On a Sunday morning I got a phone call and I'd only just finished a ten hour shift at work and I had to spend all day at Banbury hospital with him, so it was causing a bit of strain all round. I think Dad realised that it was not just him, it was affecting me as well.*

*Carer of Mr H*

*To be honest, doing a bit of washing and ironing, but it's not that part of it, it's the mental stress is very, very difficult: trying to organise things and when other people you've organised and planned things, and other people do things that changes it all, and messes it all up it drives you insane. You know, you'd go and pick his medication up in it's box, dosset box or whatever it was called and a tablet had been missed or something, and you've got to start again, and go and get it all sorted, it's Friday and you've got to go to work, and you know it's things like that that would be awkward, so I don't have any of that now so it's lovely.*

*Carer of Mr H*

### **7.2 Support**

There were a variety of views about the amount of support provided to carers. One carer mentioned the value of *good information* and *a kind word*. Some carers felt that they had been provided with a lot of help, and some older people had been receiving as many as four visits a day from paid carers along with informal care. Others thought that the support offered had not been appropriate to their needs or sufficiently practical:

*I was offered support as a carer but only through a group which I did not want. I didn't want to sit and listen to everybody else's troubles as I felt my brother and I were only just about coping and we had enough on our plates.*

*Carer of Mrs I*

*I was offered support, I was told there was a support group but I never took it up, I found I just was rushing around too much to go to them. But I was happy to do what I was doing, I mean the carers would have done the cleaning and things like that but I just felt I was happier knowing that I had done it myself and that dad's washing was done, not properly, I don't mean they wouldn't do it properly.*

*Carer of Mr H*

*I needed good information and a 'kind word' from time to time. I didn't know what the implications were of my mother having dementia and it would have been really helpful to have someone to give advice, talk through options, and prepare me for what might happen in the future in terms of the progression of the disease.*

*Carer of Mrs I*

Respite care was something that one carer mentioned as a form of support that would have been useful, and this was echoed by care managers:

*My husband and I couldn't go away or anything without making sure that somebody was there to look after mum and I did make enquiries about relief care, but that was not easy to arrange. I mean that's something that I think it would be nice for people*

*Carer of Mrs F*

*As a service user that would have been something that would have been really helpful to me, to have easy access to respite care.*

*Carer of Mrs F*

*I believe many carers would benefit from more regular breaks and for it to be more flexible.*

*Care Manager 6*

It was not always clear that a carer's assessment had been carried out.

### **7.3 Information**

A number of carers commented on the lack of information available to them: for example, the availability of accessible respite care and continence pads. Carers had not always been told the diagnosis or prognosis of the person they were caring for:

*I can't actually remember anyone saying to me yes he has got Alzheimer's*

*Carer of Mr B*

Interviewer: *Did anybody ever come to talk through to you that he has Dementia?*

Carer of Mr E: *No, I don't know if he's got Dementia or Alzheimer's or what he's got. I just know that they scan him every so often to see what part of his brain is dying. Every time he has another one of these TIA's it seems to take him down another step of the ladder.*

And they were often lacking information about what services were available and where to get help:

*The trouble is you don't know, no one gives you a book and says this is what you can ask for or whatever and it wasn't until really I was at my wit's end, took her to the doctors because of her weight more than anything and like I say [the GP] just turned around to me and said how are you doing, how are you coping and I said I'm not, it's really hard.*

*Carer of Mrs C*

*I've never gone through it. I don't know what's available and what's not. If you was in the system and I'd done it for somebody else, like another time, I'd be a lot wiser but at that point no I had no idea what was available and so.*

*Carer of Mr B*

## **8 Exploring key variables**

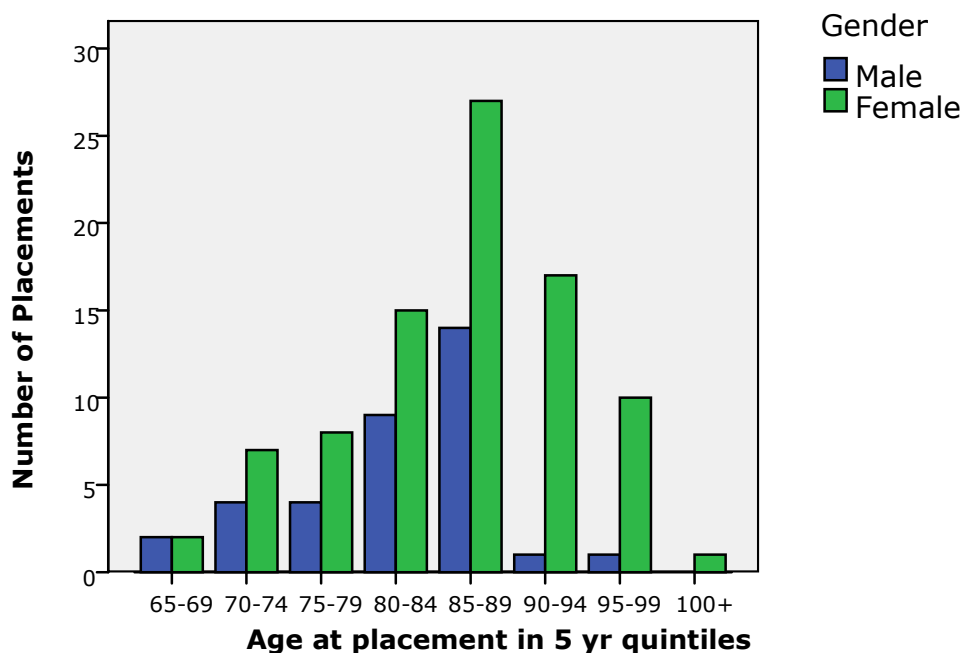
### **8.1 Gender**

Men appeared to be likely to be admitted to care at an earlier age than women: 54% of men were under 85 years old compared with 36% of women (see Figure 2). About one-third of both men, and of women, went into residential care; and two-thirds into nursing care for older people. This appears to correspond with the findings of other studies which have found that: older men without partners are more likely to live in residential care despite lower levels of disability than lone older women<sup>11</sup>. The implication is that they are admitted when they are less dependent.

While women were a little more likely than men to have been living alone (66% compared to 60%) or with another family member (19% compared to 13%) prior to going into a care; men were more likely than women to have been living with their partner (27% compared with 15%) prior to admission to care. Men were also more likely than women to have been cared for by their partner prior to going into care (17% compared with 10%) but much less likely to have been cared for by a son or daughter (34% compared with 51%).

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<sup>11</sup> Arber S, Davidson K & Ginn J, eds. (2003) *Gender and ageing – changing roles and relationships*, Maidenhead, Open University Press.  
Tinker A (1997) *Older people in modern society*, 4<sup>th</sup> edn., London, Longman.

**Figure 2: Number of placements by age and gender**

A small proportion of women were living in their son or daughter's home (8%) prior to admission, unlike any of the men. Overall, women were slightly more likely than men to have had an unpaid carer prior to admission to a care home and to have received unpaid personal care (see Table 1). This may be linked to the finding that a higher proportion of women than men had family living in Oxfordshire (41% compared with 26%). However, an analysis of those with local family and their access to informal care indicates that the gender difference, although slightly reduced, was also present among those with local family. Gender appears to be a key driver in access to informal care.

**Table 1**

Type of unpaid care provided	Men	Women
Help with daily tasks	78%	83%
Help with personal care	19%	35%

An equal proportion of men and women had lost their main carer through death or ill-health in the last 12 months.

A higher percentage of women (53%) were receiving intensive home care prior to admission than men (37%) reflecting the higher percentage of women in the sample who lived alone. When analysed in terms of household type, it appears that 82% of men living alone received an intensive care package compared with 76% of women on their own. There may therefore be a need to increase the availability of intensive care packages to women who live on their own.

However, slicing the data differently indicates that while less than 10% of men receiving an intensive care package also received unpaid personal care, more than 20% of women with intensive packages also received unpaid personal care. It may be that a smaller proportion of women on their own receive intensive home care because they have greater access to informal personal care.

Differences between men and women in terms of service use may reflect in part the higher proportion of men who lived with and were cared for by their partner prior to admission (see Table 2).

**Table 2**

<b>Previous services received</b>	<b>Men</b>	<b>Women</b>
Personal care	49%	63%
Home care/home help	54%	54%
Equipment	26%	43%
Meals	37%	46%
Day care	31%	21%
Overnight respite away from home	11%	26%
Telecare	6%	13%
Professional support	6%	7%
Direct payments	9%	2%

There were differences between men and women in terms of their health before admission to care which may in part reflect different prevalence rates for some conditions, but may also reflect differences in the factors that predispose people to admission (see Table 3). The greatest difference between men and women was in the proportion with dementia. However, the overall rank order is similar for both genders.

Among the men with a predisposing condition, there were higher proportions aged below 85 than among women with a predisposing condition, most notably stroke which is more common among men in general.

**Table 3**

<b>Predisposing condition</b>	<b>Men</b>	<b>Women</b>
Urinary incontinence	43%	46%
Dementia	34%	44%
Bowel incontinence	29%	36%
Depression	26%	24%
Stroke	26%	17%
Visual impairment	23%	18%

<b>Predisposing condition</b>	<b>Men</b>	<b>Women</b>
Diabetes	23%	14%
COPD	3%	6%
Learning disability	3%	1%

Women were more likely than men to have had a fall requiring hospital admission in the last 12 months, although men were more likely than women to have had a fall that did not require hospital admission in the last 12 months.

In terms of mobility, men appeared more mobile than women at admission to care: 20% of men were able to walk without difficulty compared with 13% of women, and only 4% were not able to walk at all compared with 17% of women.

Women were more likely than men to have been admitted directly from hospital (64% compared with 51%) and to have been in hospital before in the last 12 months (21% compared with 11%), but less likely to have received intermediate care (10% compared with 20%) and (in the 35 cases where information was recorded) less likely to have been in hospital for 8 weeks or more prior to admission (33% compared with 67%).

## **8.2 People who live alone**

This section and the following ones present the findings of the file audit analysed by two key variables, specifically: people who live alone and area.

People who live alone were (not surprisingly) less likely to have an unpaid carer than those who live with a partner or other family members (77% compared with 88%) prior to admission. Less than four-fifths (79%) of people on their own received unpaid help with daily tasks compared with 93% of those who live with others. The difference was most marked in terms of personal care: 15% of people who lived alone had unpaid help with personal care compared with 59% of those who lived with others before going into care. This indicates the important role of unpaid resident carers in providing personal care. Thus, better and/or increased support to resident carers to provide care may play a critical role in delaying or preventing admission to care. However, the death or illness of a carer was not a major factor in the 12 months prior to admission.

Correspondingly, people who lived alone receive more formal care services: 90% were helped to live at home compared with 71% of those who lived with others; and 62% received intensive home care compared with 34% of those living with others before admission to care.

Apart from respite care, older people on their own were much more likely to have received different formal care services than people who lived with a partner or other family members (see Table 4).

**Table 4**

<b>Previous services received</b>	<b>Lived alone</b>	<b>Lived with others</b>
Personal care	70%	46%
Home care/home help	62%	49%
Equipment	44%	33%
Meals	59%	24%
Day care	21%	24%
Overnight respite away from home	15%	32%
Telecare	12%	7%
Professional support	8%	7%
Direct payments	3%	7%

Older people on their own were much more likely to have been admitted from hospital (73% compared with 46% of those living with others), but less likely to have been in intermediate care (12% compared with 17% of those living with others). More investigation needs to be done on the provision of intermediate care. If further investigation confirms this finding, there may be scope to reduce admissions to care of people on their own by providing more support to enable them to return home after time in hospital.

There was little noticeable difference between these two groups in terms of whether or not they had been in hospital prior to admission in the last 12 months, or been in hospital for 8 weeks or more prior to admission to care.

Table 5 indicates the lower prevalence of a number of predisposing conditions among those living alone and suggests that they are going into care with a lower level of health need, at least with respect to incontinence and depression.

**Table 5**

<b>Predisposing condition</b>	<b>Lived alone</b>	<b>Lived with others</b>
Urinary incontinence	42%	51%
Dementia	42%	41%
Bowel incontinence	32%	44%
Depression	25%	32%
Stroke	21%	22%
Visual impairment	21%	20%
Diabetes	16%	20%
COPD	5%	7%

In terms of mobility, people who lived alone prior to admission, appear to have had better mobility than those who lived with others: 90% of people on their own were able to walk *even* if it was with difficulty, compared with 81% of those living with others.

People on their own appear more than twice as likely to have had a fall requiring hospital treatment in the last 12 months, prior to going into care, than other older people (33% compared with 15%). This may reflect the concerns of non-resident informal carers about the risks of future falls which was highlighted in the interviews.

Other noticeable differences between people living alone and others were that those on their own were less likely to have lost their informal carer in the last 12 months (5% compared with 17%); and also less likely to have family living locally (30% compared with 49%). People living on their own also went into care at a slightly later (*sic*) age than those living with others: 62% of people on their own had gone into care at age 85 or above compared with 56% of those living with others.

However, while 69% of people living alone were admitted to nursing care home, 94% of those who were married or living with a partner went into a nursing care home. The numbers are small, but this appears to indicate that people who live with a partner are likely to manage to live independently until they require nursing care.

The majority of the older people interviewed had been living on their own prior to admission, and all except one went into residential care from hospital. In the majority of cases where someone had been living alone prior to admission to care, this was since being bereaved. All those covered by the interviews were receiving varying levels of formal care prior to admission, and most had had informal carers, usually daughters.

### **8.3 Geographical difference**

Roughly equal numbers of older people were admitted to care from West Oxfordshire (55) and Oxford City (60). For the analysis of area, the nine admissions from South Oxfordshire were excluded. There were differences in both the profile of the older people going into care and their use of services between the two areas. For example, the profile of older people going into care is slightly younger in the City compared with West Oxfordshire (45% of people admitted to care from the City were under 85 years old compared with 38% of those from West Oxfordshire).

Overall, older people in West Oxfordshire appeared to be receiving more formal care services *and* more informal care than older people in the City prior to admission (see Table 6). Differences in the proportions receiving a meals service and telecare services are most striking, especially as the telecare visiting service is available in the City but not in West Oxfordshire. In West Oxfordshire, 55% had received intensive home care compared with 45% in the City, prior to going into care; 82% had received help to live at home in West Oxfordshire compared with 85% in the City.

**Table 6**

<b>Previous services received</b>	<b>West Oxon</b>	<b>City</b>
Personal care	67%	57%
Home care/home help	53%	55%
Equipment	31%	38%
Meals	56%	37%
Day care	24%	27%
Overnight respite away from home	24%	20%
Telecare	22%	2%
Professional support	13%	3%
Direct payments	2%	3%

In West Oxfordshire, 84% of people had an unpaid carer compared with 73% in the City: 89% received help with daily tasks and 38% had help with personal care compared with 75% receiving help with daily tasks and 22% help with personal care in the City.

For some health conditions, the proportions were similar in both West Oxfordshire and the City, but there were some significant differences in terms of depression, incontinence and visual impairment (see Table 7). With the exception of dementia, there were higher levels of ill-health among the people in West Oxfordshire who were admitted to a care home than in the City.

**Table 7**

<b>Predisposing condition</b>	<b>West Oxon</b>	<b>City</b>
Urinary incontinence	56%	35%
Dementia	38%	42%
Bowel incontinence	40%	28%
Depression	36%	15%
Stroke	24%	15%
Visual impairment	36%	7%
Diabetes	18%	17%
COPD	7%	5%

Older people admitted to care in West Oxfordshire also appeared to have lower levels of mobility than those in the City: 16% could not walk compared with 9% in the City.

The use of health services by older people prior to admission to care appears lower in West Oxfordshire than in the City: 44% had spent more than 8 weeks in

hospital prior to going into care compared with 50% in the City; 11% had been in hospital in the last 12 months compared with 22% in the City; and 18% had had a fall requiring hospital admission in the last 12 months compared with 33% in the City. This may partly reflect the proximity and accessibility of health services in the two areas, as well as differences in the kind of provision available.

Older people in the City were more likely to have been admitted directly from hospital (65% compared with 56% in West Oxfordshire); but less likely to have received intermediate care (8% compared with 18% in West Oxfordshire).

Overall, people in West Oxfordshire experienced worse health prior to admission to care than in the City, had received more social care and informal care, and made less call on acute NHS services. Clearly there are marked differences between the two areas. This variation is puzzling, it may reflect different recording practices, but equally it may indicate different thresholds for admission to a care home in the two areas, with a higher level of need required in West Oxfordshire.

## **9 Conclusion**

### **9.1 Characteristics**

All the older people covered by the interviews had followed fairly complex pathways into care. 84% of those admitted to care homes in 2008-2009 were already known to social care services and receiving a service. However, 50% were not getting an intensive care package. This was confirmed by the interviews.

Key characteristics identified were the proportion of women (71%), people who live alone (64%), aged 85 and over (58%), with difficulty in walking (56%), urinary incontinence (45%), bowel incontinence (34%), dementia (40%), experiencing a fall in the last 12 months (41%) and admitted from hospital (61%).

There were variations between men and women in the file audit data: men received fewer formal care services than women, eg, personal care (49% compared with 63%); men who lived alone were more likely to receive intensive care than single women; and men were admitted to care homes at a younger age. The figures are potentially contradictory but suggest that informal, mainly female, carers play a key role in supporting older men to live at home and could benefit from more support. They were an important element of the total care provided to people.

There were also marked differences between people who lived alone and those who did not. People living alone received more formal care services than those living with others and went into care with lower rates of ill-health, but at a later age. The data raise questions about whether eligibility criteria are applied differently according to gender and household type.

In many cases deteriorating health and well-being had begun with a stroke or a bereavement. In those cases, where the older person did not have dementia, falls and incontinence or UTIs were recurring themes. Stroke looked to be less common from the file audit although the interviews revealed it as an unrecorded factor which had occurred earlier along some people's care pathway.

Although not available from the file audit, the impression combined with the number of people living alone is that social isolation and depression are underlying conditions influencing progression along the pathway to care.

Inappropriate or inaccessible housing was an issue for more than one quarter of older people admitted to a care home.

All of the three people covered by the interviews with dementia were living alone, but were all receiving support from non-resident family members. Carer's stress was exacerbated by lack of information and appropriate support.

## 9.2 Services

There was a surprisingly limited take-up of intermediate care and telecare recorded in the social care files.

Investigation of the reasons for the high proportion of admissions from hospital is needed. It may reflect the greater frailty of people going into care homes, or discharge practices, or some other factor in operation. For example, 73% of people living alone were admitted from hospital compared with 46% of those living with others.

Falls, incontinence and dementia are some of the most common characteristics experienced by those being admitted to a care home. While the falls service was mentioned by some interviewees, there was no mention of the continence service. Services which can reduce falls and fear of falling; and services which can manage or treat incontinence are likely to delay or prevent admission to a care home.

Limited mobility indicates that re-ablement and intensive work to support mobilisation may also help to reduce or delay admission to care homes in Oxfordshire.

The transfer of care from hospital is a concern where people are discharged with medical issues that affect their health and well-being, such as incontinence, that were already present or that developed during the admission, unresolved.

Delays in receiving a service, the shortness of some visits and consistency in who provided care were all negative factors listed by service users.

## 10 Comment

Overall it may be felt that the decision to admit to a care home is inevitable by the time a service user has reached that point along the care pathway. Indeed, the small sample of older people interviewed mainly felt there was an inevitability about where they had ended up.

However a number of issues stand out from the research which indicates that such a course may not have been inevitable:

- The number of people who were not receiving intensive care prior to admission.
- The limited use and application of specialist services despite the relevance of older people's conditions.
- The lack of earlier follow up to falls and strokes.

Combined with the above is the number of people that suffered from a range of conditions but rarely received a holistic service to address all the factors potentially propelling them towards a high intensity care outcome. Equally, the conclusions underline the inter-relatedness of health and social care, addressing one without the other is unlikely to lead to successful outcomes.

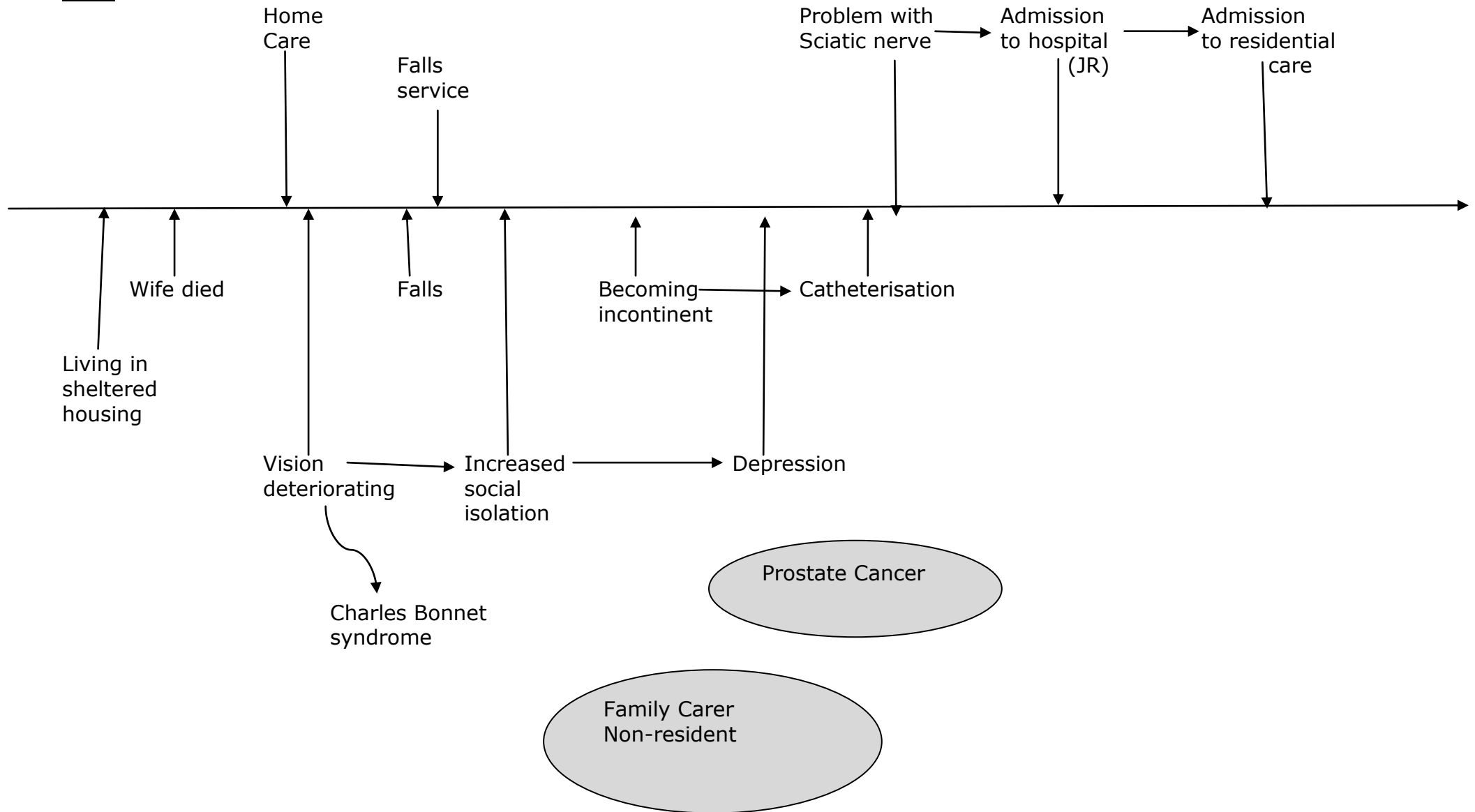
In conclusion, the file audit and interviews have provided important information about the care pathways of older people moving into a care home and raised many questions. The results have indicated areas for the development of future services which may help to prevent or delay the admission of older people to a care home.

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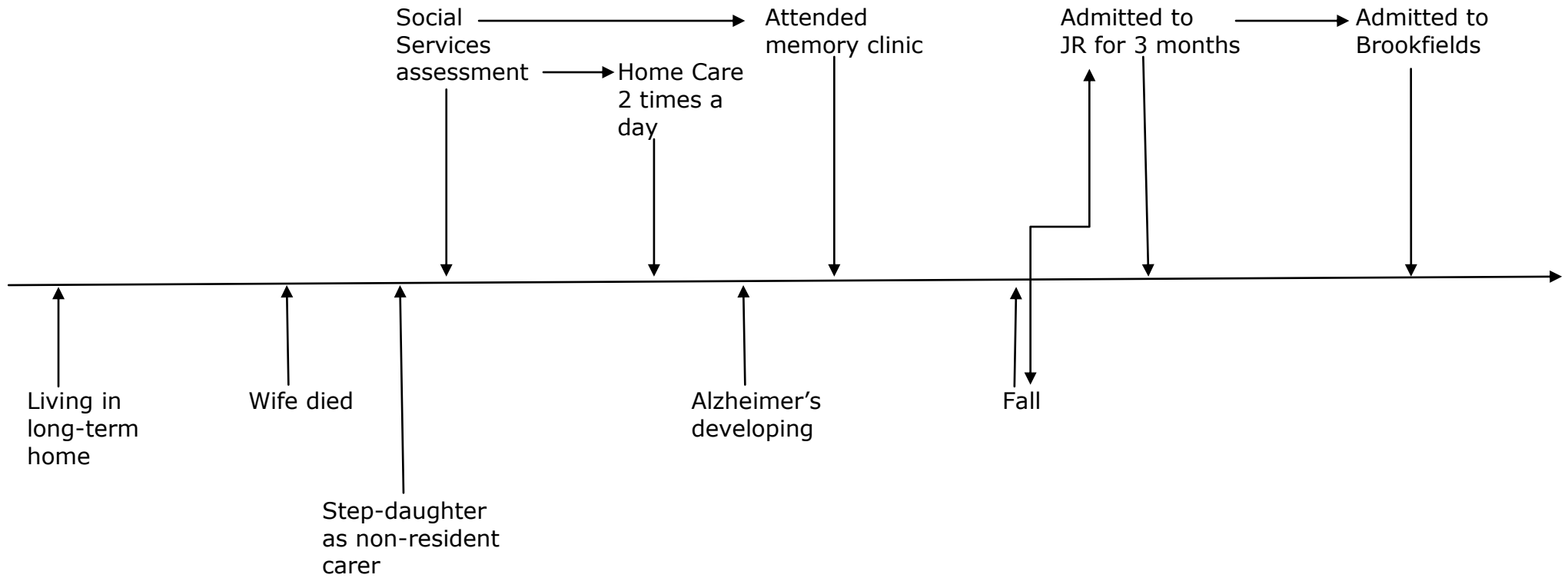
## **Appendix A:**

# **Timelines of Individual Pathways to Care**

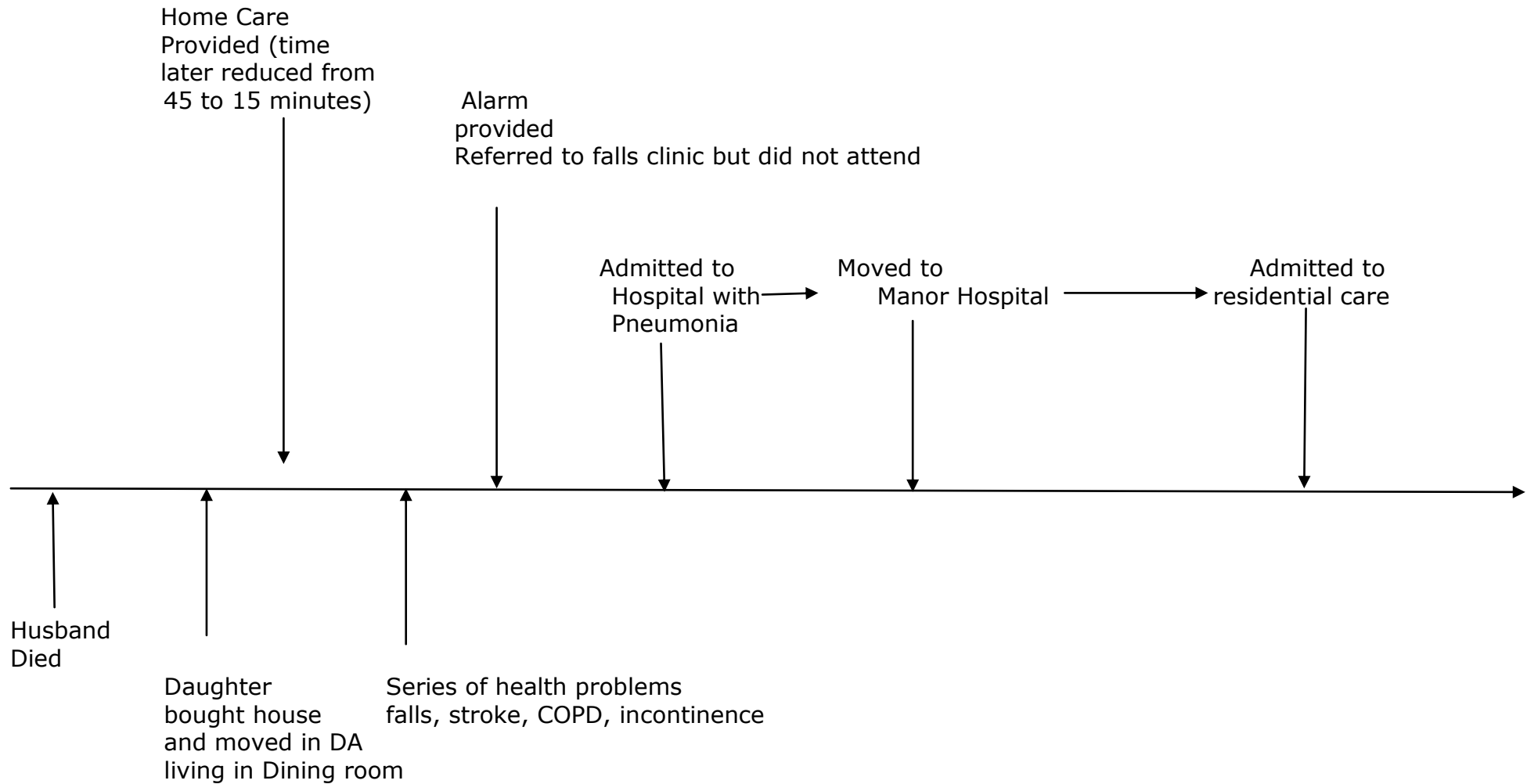
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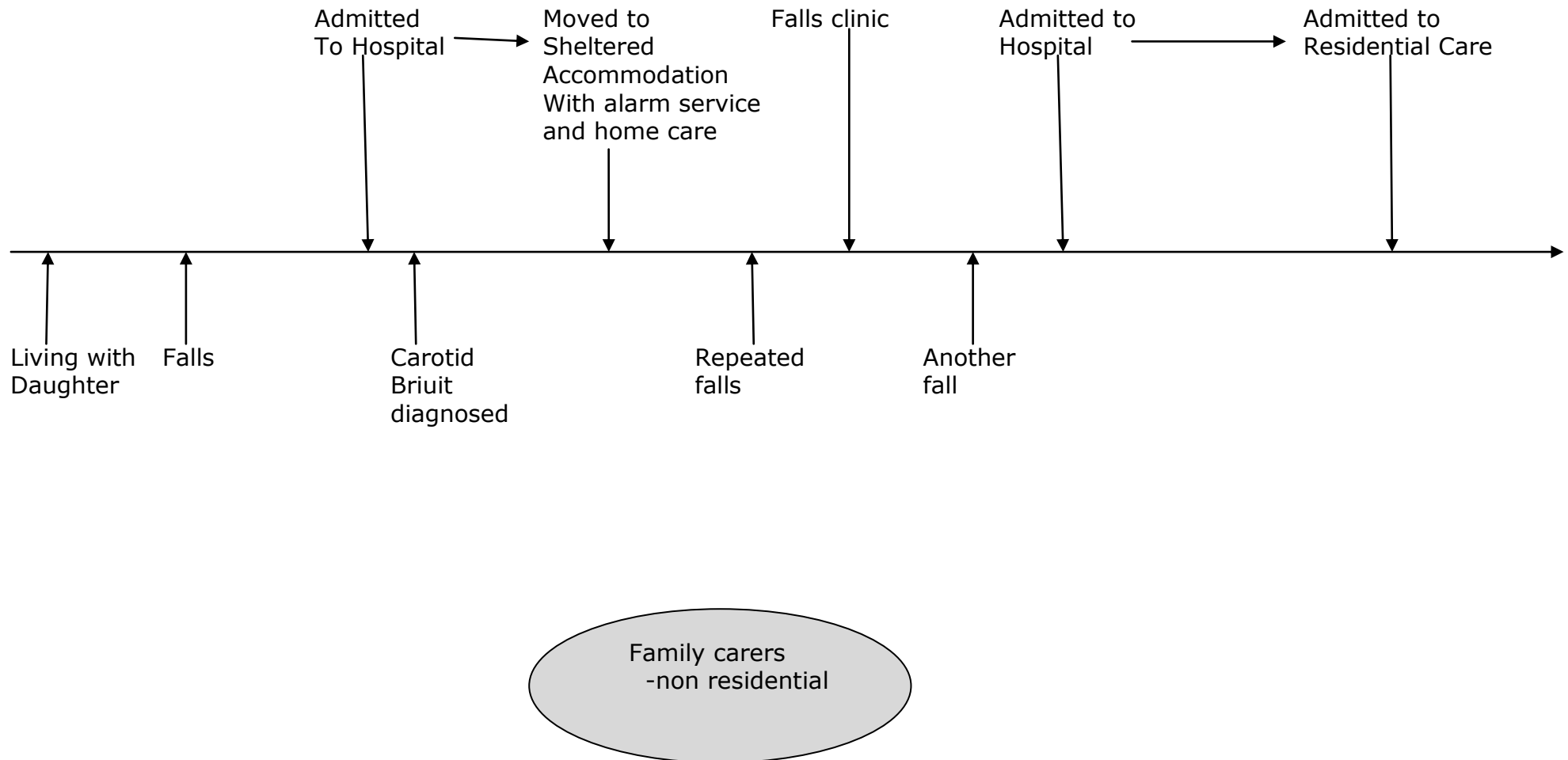
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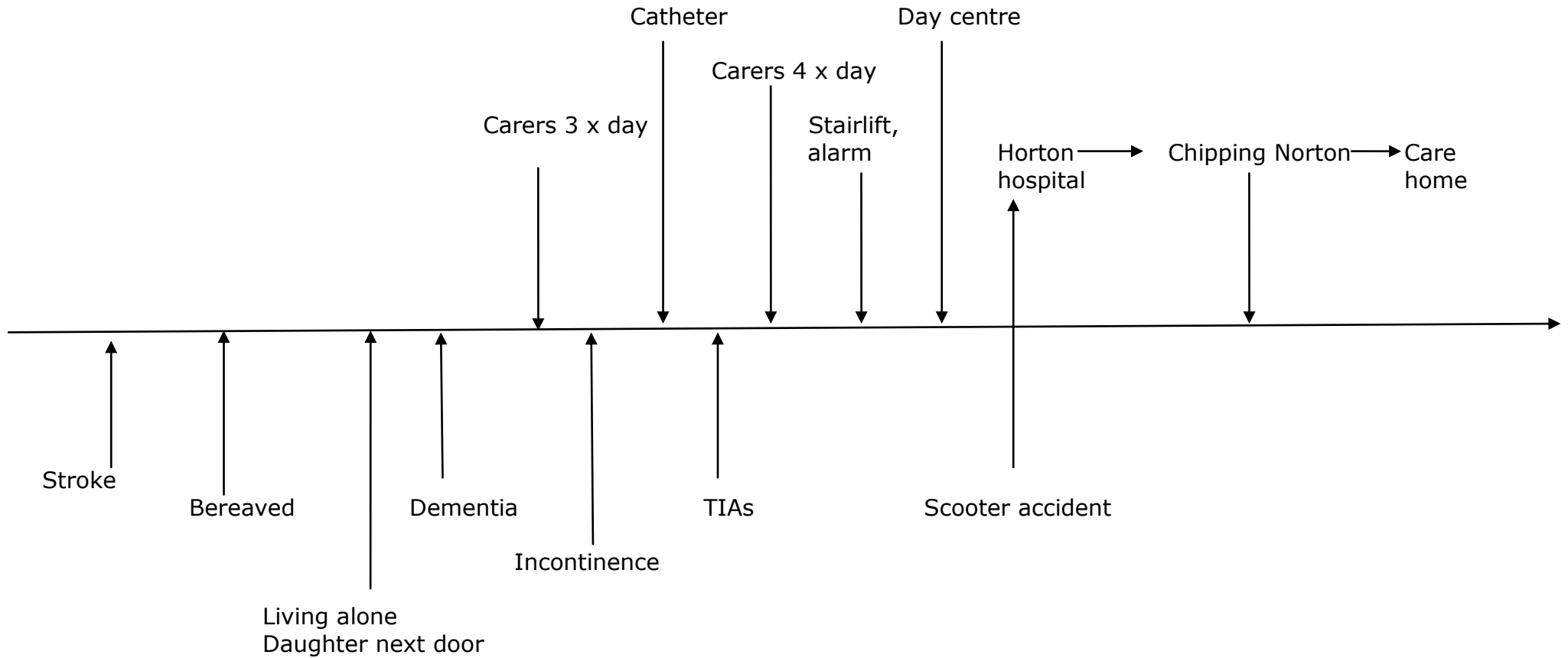
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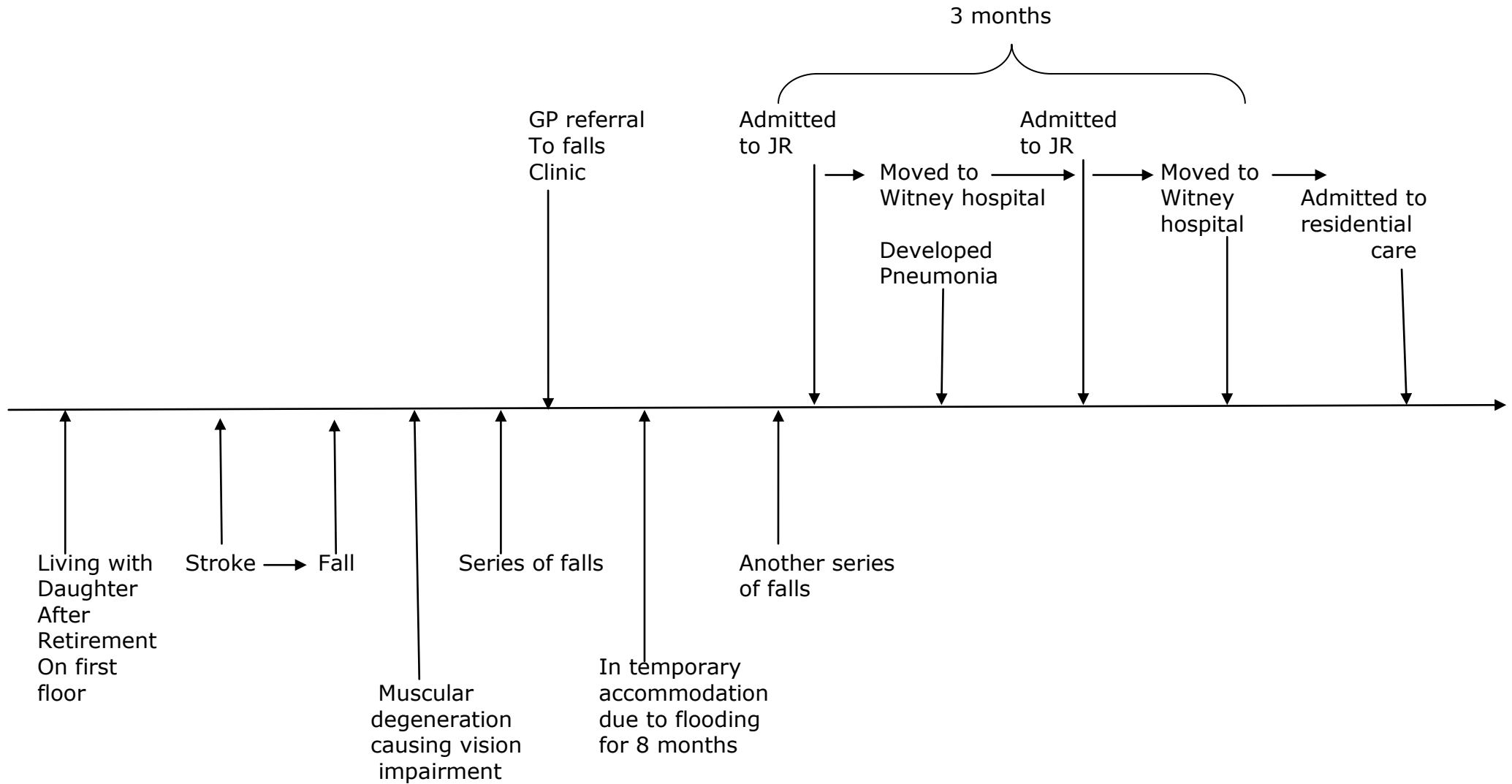
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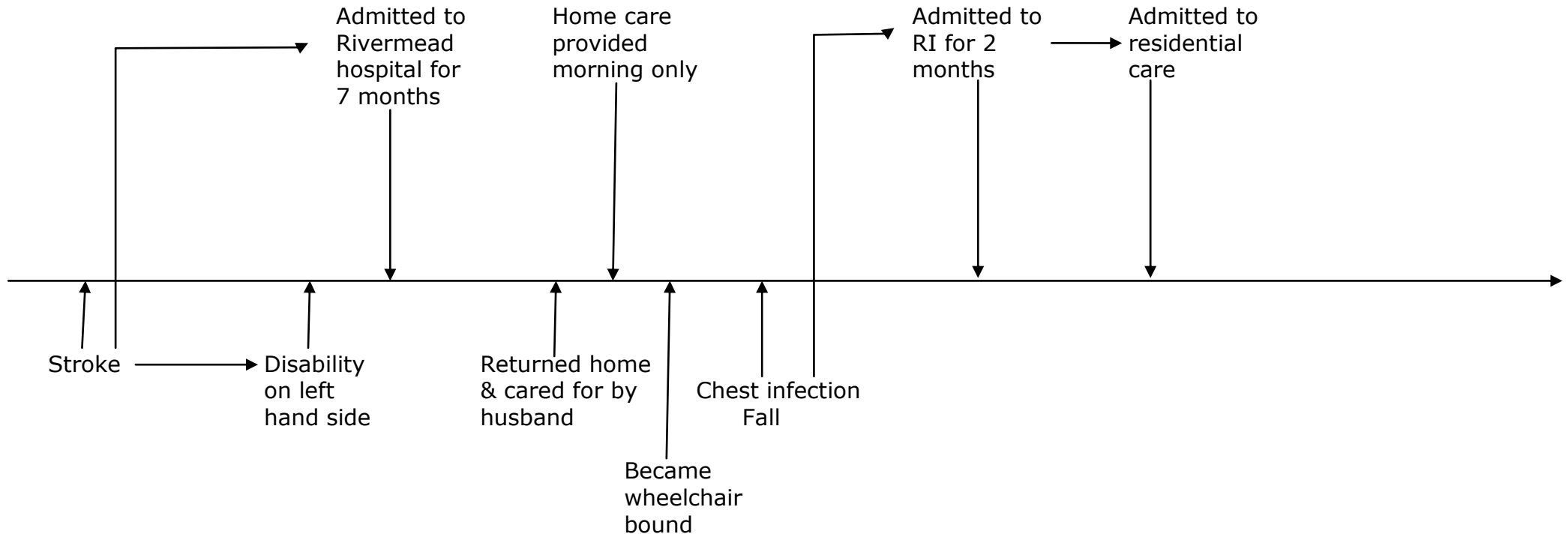
**Mr E**



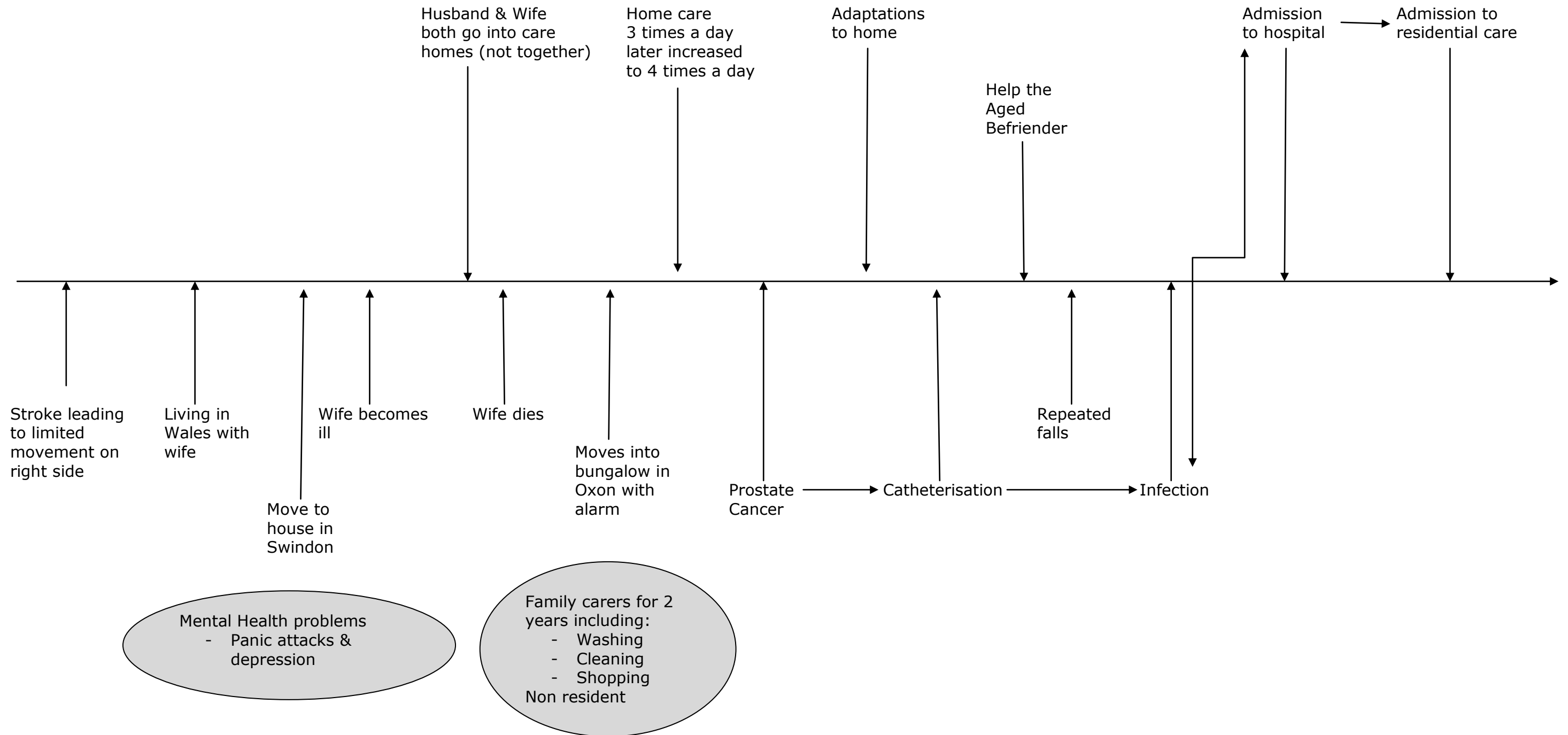
**Mrs F**



**Mrs G**



**Mr H**



**Mrs I**

