



Negotiating the Care Maze:

The process of decision-making when a family member or friend needs full-time social care

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We wish to extend our heartfelt thanks to the individuals who shared their often painful stories of arranging care for a loved one for this study. They recounted emotionally and physically exhausting experiences, some of which had not yet come to an end, and as researchers we felt honoured to be able to capture them for this project.

Many of the participants told us they agreed to share their experience in the hope that it would make the experience of negotiating the care maze easier for others - we do too.

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1. Healthwatch Essex

This research has been conducted by Healthwatch Essex (HWE), an independent organisation with responsibilities under the Health and Social Care Act (2012) to provide a voice for the people of Essex with regard to health and social care services. Our research team conducts high quality research on the 'lived experience' of patients, citizens and social-care users, aiming to inform improvements in local health and social care provision.



Studying the 'lived experience' involves the detailed examination of participants' 'lifeworlds', their experiences of a particular phenomenon, how they make sense of these experiences and the meanings they attach to them. It is premised on the philosophical understanding that a proper scientific understanding of the social world cannot be undertaken by merely collecting 'objective facts', but that research needs to engage in a deep and empathetic way with the individuals involved in an attempt to get as close as possible to the everyday world as they experience it. It is the lived experience that reflects and determines people's confidence and trust in the healthcare system, undoubtedly contributing to their overall physical health and emotional well-being, and to their assessment of how the NHS and social care function in meeting their needs.

2. Background

When a person is no longer able to be cared for at home, this decision (and the practical steps this entails) will often involve a relative or friend. Relatives and/or friends are usually very involved in either supporting the decision and, in some cases, where the person needing care lacks mental capacity, in making the decision. The study reported here sought to better understand people's 'lived experience' during this decision-making process. Decisions about what kind of residential care a person requires hinge on a number of different factors, including:

- Consideration of the wishes of the person being cared for/needing care
- The ability of the person needing care to make a decision (i.e. the status of their mental capacity)
- The timing of the decision (given the likelihood that the person needing care will have been in decline over a period of time and may already be in receipt of formal and informal care)
- The financial cost of residential care
- The availability and suitability of care homes
- The opinions, experiences and wishes of other family members/informal carers
- Access to relevant information and support.

Such decisions are complex. Accessing relevant information can be difficult and decisions are further

informed by assessments carried out by health and social care experts. The local authority is obliged to carry out a needs assessment process when they become aware that someone may be in need of social care and support. If a person has been assessed and fulfils certain criteria that indicate that she or he has ongoing healthcare (rather than social care) needs, then the provision of healthcare is usually the responsibility of the NHS. The number of health and social care providers too has expanded exponentially in recent years, and while this may facilitate increased choice, it adds to the complexity of decision-making. Additionally, because most people who move into a care home do so as a result of a crisis, there is often little time for preparation or planning (National Development Team for Inclusion, 2009).



Given that these complex and time pressured decisions involve practical and inevitable emotional issues, it is important to understand how relatives/friends negotiate their way through the process. The study reported here intends to better understand people's 'lived experience' of this complex process. HWE has a particular interest in this issue as our previous research shows that informal carers (relatives or friends of someone being cared for) play an important role in providing support, care and advocacy for patients, and that their needs and experiences are often overlooked by policy makers and health and social care providers (*Corrigan et al, 2014 and Guest et al, 2015*).

3. Methods

This research was undertaken by a team comprising HWE employees and volunteers under the tutorage of external consultant, Professor Gayle Letherby, and the Research & Commissioning Manager at HWE, Dr Oonagh Corrigan. The group first convened in January 2015 at the beginning of a six month training programme focusing on auto/biographical approaches to research¹. This approach informed the research process (research design, fieldwork, analysis) of the research reported here.

We adopted a two-interview approach. First interviews were semi-structured and researchers were concerned with an exploration of respondents' experience of arranging care for a friend or relative. The second interviews were led by the respondents. In a discussion between the researcher and the respondent prior to the second interview, the respondent decided on the structure of the interview and the focus of the discussion – this was sometimes supplemented by looking at photographs or relevant paperwork. Such a methodological approach enabled respondents to contextualise the discussion with their own perspective and on their own terms (Liamputtong, 2007).

Qualitative methods, such as in-depth interviews, focus on the 'experiential', founded on the belief that the best way to find out about people is to let them 'speak for themselves' (Stanley and Wise, 1993). The use of qualitative

research is also seen by some as a way of giving respondents more control over the research process.

Following the anonymization of the transcripts (which took place in the HWE office) all transcripts were transcribed verbatim by a transcription agency.

Analysis took place as an ongoing part of the fieldwork process. In diaries and in research team meetings members shared their experiences and what they felt they had learnt from the interviews. From the transcripts we created a 'pen portrait' for each respondent and these were then discussed by the team for accuracy and in terms of their substantive significance. We then applied a thematic analysis to the data, acknowledging the influence of the researcher but aiming to edit and select data to best represent the experiences and concerns of the respondents (*Braun and Clarke, 2006*).

In addition to producing 'pen portraits' of service users and generating narrative quotes we (the research team) produced a set of 'I/They Poems', incorporating some or all of the "I/she/he/we" statements made in interviews. These poems, found as a collection called 'Negotiating the Care Maze in Poetry' at www.healthwatchessex.org.uk/our-reports, emerge from the transcripts of the interviews between the researcher and the respondent, and help to capture some of the intensity of the experience. Here we are adapting what Natasha Mauthner and Andrea Doucet (1998) called the 'Voice Centred Regional Method', an approach that acknowledges that selves are interrelated through a web of psychological and social complexity. This analytical approach became a primary means of giving authenticity to the voices of respondents (and researchers) in this project.



1 Across the humanities and social sciences there has been a growing recognition in the last thirty plus years of the value of auto/biography for exploring the lived experience of individuals. The specific use of 'auto/biography' as a linguistic device is employed to illustrate the elision between categories – such as self/other, public/private, and immediacy/memory – that are normally considered separate and distinct from one another. In sociology in particular auto/biography has proved especially useful in providing insight into areas of life that, while no less social in nature, are nevertheless difficult to access or research. See bibliography for resources.

4. Ethics

Ethical approval for the project was sought and obtained from the Research Governance Group at Essex County Council and the ethics application, participant information sheet, and consent form, are available in Appendix One.

We know, however, that ethics is not just a one-off process and are aware of the benefits of taking ethical issues seriously throughout the life of a research project, and consequently took great care to remind respondents at regular intervals that their involvement was entirely voluntary and could cease as soon as they wanted it to. All respondents saw the process through to the end, indeed a few of them said that they welcomed the opportunity to reflect on their experiences and put them towards helping to make changes for others.



5. Auto/Biographical Pen Portraits

In order to better introduce each respondent and their story what follows is a pen portrait of each of them. Their stories are prefaced with a couple of quotations from the interview that are indicative of the respondent's particular experience and relevant to the key themes and issues more generally.

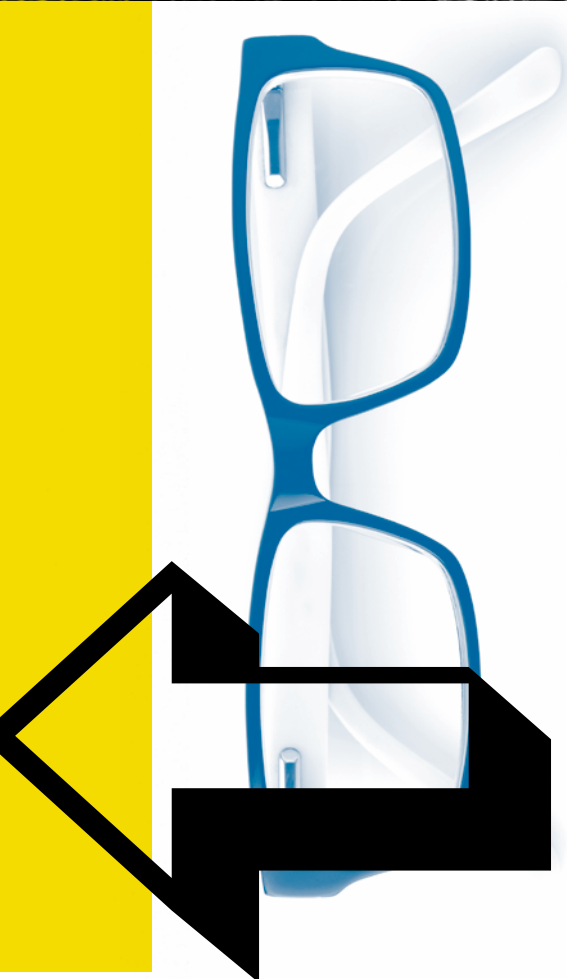


5.1 Joanna

'I guess in our modern society we are so shielded from all this stuff until it happens to our own - well, even if you're in healthcare, but until it happens to your own family, we're not talking about it a lot until ...'



'I AM SO ENVIOUS OF MY HUSBAND BECAUSE HE CAN HAVE A CONVERSATION WITH HIS MOTHER.'



Joanna's mother is 87 and her father is 90. Until February 2015 they lived independently in the house they had lived in for 50 years. Joanna's mother began to have problems with her memory and cognitive functioning about four years ago and dementia was diagnosed about three years ago. Joanna's mother's physical health also deteriorated and she suffered a cardiac incident and a number of falls. In addition to worrying about her mother Joanna and her two brothers were also worried about their father who was, as Joanna describes, 'hanging on by the skin of his teeth.'

Joanna's mother was a nurse specialist in the early '70s. She was also a Justice of the Peace and a school governor. Joanna describes her mother as an articulate, competent and confident woman who cared deeply about her husband and her family. She also cared about her appearance. Joanna says that dementia has 'stolen' the things that were important to her mother.

Joanna's mother is currently in a dementia specialist facility, having been for a time in a general care home which was unable to fully cater to her needs. Prior to this, she was hospitalised abroad during a stay with Joanna's brother Adrian. The family considered a nursing home place near to where Adrian lived but decided against it . . . not least because of the poor conditions. Joanna's mother and father do not qualify for financial help for their care needs.

Joanna and Adrian have lasting power of attorney over their parents' health and finance. In the document Joanna's parents both signed to say that they don't wish for any active measures to prolong their lives.





'MY POOR MUM. SHE CAN'T SEE ANYWAY, AND SHE WAS SAYING, "WHAT DOES THAT MEAN, MAGGIE? WHAT DOES THAT MEAN?" I DON'T THINK THE PROFESSIONALS ALWAYS REALISE QUITE HOW STRESSFUL IT IS FOR PEOPLE.'



5.2 Maggie

‘Some are better trained than others, but, at the same time, they’re following their guidelines. They’re working to their timescales, which might not be yours and, again, most of this is office hours.’



Maggie's mother was 91 when she was diagnosed with multiple myeloma (cancer of the bone marrow). This was in June 2013. She also had macular degeneration and was registered blind. Maggie's mother died in March 2014 aged 92. Nearing the end of her life and in hospital it was suggested that a nursing home would be the best place to care for her. The family agreed to this but knew that their mother would be reluctant and would rather return to her home in a sheltered housing facility. Mixed messages from medical staff upset and confused the family and delayed the application for

funding support. Securing funding and finding a nursing home in a suitable location and condition was largely Maggie's responsibility. During the interviews Maggie stated several times that despite considering herself to be 'relatively switched on and articulate', she 'couldn't believe' how difficult the process of negotiating care was.

Maggie's mother was originally from Ireland and most of Maggie's family still live there. Maggie described her mum as having a strong spirit and 'a good, long life' adding that 'it was only that last year that was grim'.

5.3 Angie

‘For me, I was faced with both seeing the difficulties of my mother and the difficulties of my dad.’ ‘I’m not paying £1000 a week for this sort of thing to happen.’

Angie’s mother was diagnosed with vascular dementia about six years ago. Following a fall approximately a year and a half ago, it became impossible for her to live on her own. She was divorced from Angie’s father (and her second husband is deceased) but Angie’s father remained in contact to the extent that he visited her every day.



'PART OF THE DECISION WAS ALSO FROM WORD OF MOUTH.'

Following her fall Angie's mother moved into Angie's father's house and eventually they moved together back into Angie's mother's bungalow. By this time Angie's father was providing 24 hour care and becoming very tired himself. Respite support financed by Social Services helped for a while but the rules around how this money could be spent seemed fairly inflexible. Angie herself suffers from multiple sclerosis which affected the support she could provide her parents. Despite this, her father was very reluctant to consider a nursing home for Angie's mother.

Angie was very dissatisfied with the first nursing home her mother lived in and she found looking for an alternative stressful and upsetting. Things are better now as her mother is in a home with 'caring' staff and plenty of 'stimulation'. This facility is close to Angie's father's home. In addition to paying the nursing home fees Angie and her father pay for someone from the Alzheimer's Society to visit Angie's mum twice a week.

Angie's mother has a 'living will' although Angie has doubts as to the practical value of this.

Angie finds the whole experience very hard, particularly as an only child. She described the paperwork as 'overwhelming', the guilt she felt as 'horrendous' and as a result of this said that she had 'cried buckets'.



5.4 Mark



'IT'S A MINEFIELD. WHEN YOU'RE FIRST DEALING WITH SOMEBODY WHO'S GOT THE ISSUES THAT PAULA HAD GOT, YOU HAVE AS MUCH TROUBLE WITH THE SYSTEM AS YOU DO WITH THE ACTUAL PERSON. IT'S REALLY COMPLICATED.'

‘This is all paperwork. Her age assessment, risk assessment. All kinds of things. All this kind of stuff. All to do with the paperwork. Because I was her advocate, I was given it all and I’ve got loads of it. I’m sure there’s a lot more stuff as well.’

Mark describes his wife, Paula, as a chronic alcoholic. Paula is 53 years of age and she and Mark have been together for 10 years or so. Mark says that from what he can gather from family and friends, Paula has been an alcoholic for many, many years. Mark had previously initiated divorce proceedings but stalled when this led to Paula drinking even more. Paula’s erratic behaviour included her reporting him to the police and putting herself in financial, physical and sexual danger. Paula was sectioned under the Mental Health Act three times and eventually put under a Deprivation of Liberty Order. In December 2014 Mark found an appropriate care home in the South West of England and Paula accepted a placement there.

Things are much better now. Paula is alcohol free, although she suffers some permanent brain damage from her drinking. Mark is now worried that Paula is ‘institutionalised’ and is concerned about how she might be best integrated back into everyday life.





5.5 Phil

‘All in all it’s been a journey. I think I’m quite happy with the decisions we’ve made, but a lot of it has just been more by luck than judgement.’

Phil's father is 84 and has been married to Phil's mum for 59 years. Having left school at 14 he worked in industry for 35 years, rising to a senior position and retiring at 60. Phil's father drank and smoked heavily, which Phil thinks might be relevant to his dementia which was diagnosed around his 80th birthday. Phil describes his father as a 'very strong character' with 'no self-doubt'. He 'ruled the roost' within the family, but Phil also describes him as a 'good father' to him and his two siblings.



'...NEITHER THE CLINICAL PSYCHOLOGIST NOR THE CONSULTANT NEUROLOGIST, NEITHER OF THEM ACTUALLY SAID TO DAD THAT "WE THINK YOU'VE GOT ALZHEIMER'S"... IT WAS ONLY IN THE WRITTEN MATERIAL THAT IT SAID, "THE RESULTS ARE SUGGESTIVE OF AN ALZHEIMER'S PATHOLOGY". WE WERE SORT OF LEFT TO READ IT AND UNDERSTAND ...'



Phil's dad's condition began to deteriorate about 18 months to two years after diagnosis and caring for him began to take its 'toll' on Phil's mum. Phil's cousin moved in to help but Phil's dad soon became increasingly vague and he began to develop 'bizarre habits'. He lost all interest in TV and alcohol, and 'forgot' how to smoke. He also started getting up and going to bed at different times of the day and night (and getting agitated when other family members did not do likewise). The family

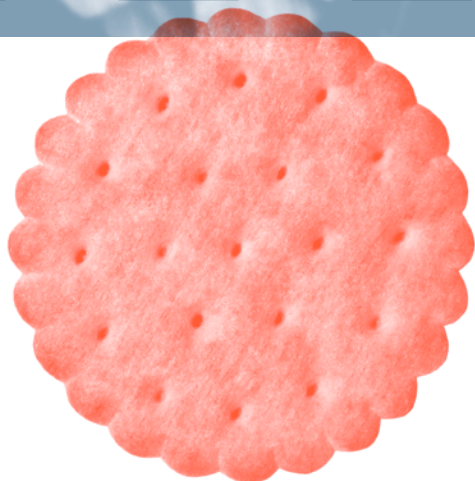
discussed the possibility of a live-in carer and modifications to the family home but further deterioration made a care home the only option. After a fairly extensive search Phil and his siblings found a couple of care homes they were comfortable with.

The whole experience has had a significant financial impact on the family, so much so that Phil's mother may have to move to a smaller property fairly shortly.

5.6 Jayne

‘To this day, it makes me sad that, even then, he just put his arm around me and said, “Don’t fret.”’





‘IT JUST MAKES YOU WONDER, DOESN'T IT, THAT IF YOU HADN'T PICKED UP THE PHONE TO THE ALZHEIMER'S ASSOCIATION, WHAT WOULD THIS JOURNEY HAVE BEEN LIKE? WOULD IT HAVE BEEN HARDER?’

In 2011, Jayne's father was diagnosed with vascular dementia. Jayne's mother, who is 83, was finding it increasingly hard to cope with his care, and so Jayne's parents moved to Essex in 2014 so that she could help support them. Soon after the move, the family reached crisis point, as Jayne's father's mobility decreased and he was admitted to hospital following several falls. Jayne and her mother had been considering options for her father such as part-time or live-in care, but at this point it became obvious that nursing home care was required. However, the hospital wanted to discharge Jayne's father before the family had found a placement for him.

Jayne talked about the rush to find a care placement for her father, and wondered how this difficult process might be even harder for someone who did not have the knowledge about Care Quality Commission reports, and so on. She also found the Alzheimer's Society very helpful.

Jayne's father died in 2014. Jayne spoke about the importance of knowing a person's history when providing their care. For example, she described her father as someone who loved the countryside, which explained an incident in the care home where he had rearranged the furniture in his room as he thought he was camping.

‘You're looking at these places and with the best will in the world, nothing can replace the one-to-one care that he has had in his own home. So anything else was going to be second best and it takes you a long time ...’

6.0 Themes and issues

6.1 The 'maze as metaphor'

Prior to undertaking the interviews, based on evidence (*National Development Team for Inclusion, 2009; Essex Joint Strategic Needs Assessment, 2003*) and previous HWE research on the experiences of carers in Essex (2015) we identified the pathway(s) to negotiating residential care for a family member or friend as a 'maze'. This was confirmed by the data. Maggie even commented on the appropriateness of the title: 'Your title about negotiating the care maze. I didn't believe how difficult it could be, and I think I'm relatively switched on and articulate, and I'm willing to fight my corner. I just couldn't believe how much fighting you had to do.'



6.0 Themes and issues

6.1 The 'maze as metaphor'



Attention to Maggie's account demonstrated this further, particularly her reference to a lack of information concerning the complex process of admission to a care home and the frustration surrounding this. Also clear is the time it takes when negotiating care for a relative or friend, and the need for significant research:

When I got home [on Tuesday]. . . I went on the internet. I Googled 'continuing healthcare fast-track', all these things, to find out what was happening, because it makes it sound as if it will be organised for you. What we didn't want to happen was that we would just get a phone call from somebody, saying, 'There's a place in a nursing home on the other side of [place name]. Your mother can be moved there.' We wanted it to be somewhere that Mum liked the idea of and that we could still get to and visit her easily.

We Googled more on this, and all of the information on the internet and all the national guidelines were saying . . . given the nature of the needs, this time period should preferably not exceed 48 hours from receipt of the completed fast-track pathway tool. So it's all geared up to be immediate, but nothing happened at all . . .

Thursday, having Googled all of that and thinking, 'What's going to be happening?' I spent Thursday morning, Googled, and found 6 care homes within a 30-mile radius of where we live and then just got on the phone and started ringing them . . . And that takes hours, because you need to speak to the manager.

'The manager's not in. Ring back later.'

This illustrates the frustration involved in knowing who to contact and how to identify and speak to the person who can help. In the course of her research, Maggie discovered that the type of care required outside of the hospital determines how it is paid for. NHS continuing healthcare (CHC) is provided free of charge as long as the need is assessed by the hospital². Whereas local authority help with the cost of residential care (not medical) is means-tested. In this financial assessment the local authority take into account income and assets of the person needing care³.

So you're ringing up and they say: 'Ooh, we might have a vacancy.' 'It will be fast-track CHC [continuing healthcare] funding.' 'Oh, no. Sorry. We don't have any vacancies.'

Maggie's mum needed CHC and when the care home realised this they said they didn't have a place for her after all. This could be because they didn't have the expertise, or it might be that they don't think they'll receive as much money from a CHC patient as from one that needs social care. Another aspect of arranging care that requires clarification.

Fair enough. It's a seller's market, because they're all privately run . . . I had two others booked in for Friday to go and look at, but

² <http://www.nhs.uk/conditions/social-care-and-support-guide/pages/nhs-continuing-care.aspx>

³ <http://www.nhs.uk/conditions/social-care-and-support-guide/pages/care-homes.aspx>

6.0 Themes and issues

6.1 The 'maze as metaphor'

Thursday morning, I rang [care home name], which is the one just up here in [place name]. Somebody had died on the Tuesday night, so they said they did have a room available in their nursing sector, because that was the other thing. When I was Googling, I had to Google 'nursing' and 'end-of-life care', because not all of the homes do that.

So I went up and saw it on the Thursday, and the manager . . . It was absolutely perfect and the woman said, 'Yes. It should be fine.' They did accept CHC funding, but they would need to send somebody to assess her from the home . . .

(MAGGIE)

Angie described feeling confused and overwhelmed by the maze-like process of finding residential care for her mum, whilst also caring for her dad who was distressed.

Most of our participants considered themselves to be capable, professional people, some with skills and experience relevant to making decisions about their loved one's care, for example Phil was an accountant, and yet they commented that even they found the system difficult to navigate. Jayne's account also demonstrates how knowledge of the system (which of course, many people do not have) makes a complex system a little easier to navigate:

The other problem was we were then under pressure because Dad had these episodes for, like, two or three days and then he'd sort of rally round again . . . The nurse came up to us and said, 'Yes, [he's] doing really well. We should be able to discharge him tomorrow.' We said, 'No, you can't.'

I think that, to them, came as a bit of a shock but I have a sister-in-law who used to work for the NHS and I'd done quite a bit of research, as well. She said, 'If they put pressure on you to discharge him, unless they've got a care plan and they have assessed where he is going back to and made sure that it's safe for him to be there, they can't discharge him.'

So we said, 'No, you can't discharge him because you haven't assessed where he's going and we know that we can't cope with him in the home environment anymore. We just haven't got the ability. If he loses his legs and he can't move, there's nothing we can do about it'.

Hospital staff are often under significant pressure to discharge patients from hospital as soon as an acute episode of ill health has been treated (Healthwatch Essex, 2016), but Jayne's account highlights the confrontation and conflict that occurs when the family don't feel able to take care for the person at home and haven't yet found suitable residential care for them. Rather than leaving



the organisation of her dad's care to the hospital, Jayne and her family wanted to exercise some choice and control over what happened to her dad next. Her account suggests a lack of trust in the hospital staff to get the best possible outcome for her dad, and that someone in a less knowledgeable and informed position would have struggled even more:

She [the nurse] looked a bit shell-shocked. 'Oh. So, what are you doing?' I said, 'We're looking for care homes.' 'How long is that going to take?' 'As long as it takes.' I said . . .

I'd done an awful lot of the searching on the internet because I was able to, but anybody who can't do that, if they haven't got a relative that can get an overall picture, I dread to think where we would have been. Because I was also able to look up all the CQC reports for all the homes, so I ruled out one or two without even going, and one of them was a local one. (JAYNE)

6.0 Themes and issues

6.2 Identity and change

6.2.1 Loss of identity

Previous research has indicated that illness, particularly degenerative conditions, can cause a loss of identity. This identity loss is related to both our understanding of physical and psychological selves and our memories and so forth, as well as in our relation to other people, meaning that other people increasingly lose their ability to recognise us in our unique character (*Gillies B. & Johnston G., 2004*). This certainly chimes with how our respondents tended to speak of the change in their loved ones' identities. They wanted us to know something of the identity of the person who needed care and to give a holistic account of the person because, for many, including Jayne, they felt the illness their loved one was experiencing or had experienced had diminished or even replaced their individual identity. Jayne, for example, told us that her father loved the countryside and hated towns and cities; that he went from working as a draughtsman (because he had a love of technical drawing) to mechanical engineer after years and years at night school, and worked in the Air Training Corps. He got his glider's licence and loved swimming. Joanna described her mum as an 'articulate, competent, confident woman, and Maggie similarly described her mum as an intelligent woman who needed to be involved. All of our participants were keen to impress the fullness of their relative's life and identity that somehow seemed diminished when their illness took hold.

The loss of identity can be experienced by the individual on entry to residential care when one is removed from the familiar and the familial:

I made sure she had a front room and it faced a fountain, they had ducks there and she would see people coming and going but, of course, that doesn't replace freedom . . . The place is beautiful but, really, what does that actually mean to her? It means that we do our best, it means the most to us but that's not really what she wants. She wants her family, she wants the people she knows around her, she wants a familiar environment but we're not able to provide that . . .

(ANGIE)

As further attention to Angie's account demonstrates, the loss of identity for the loved person going into care can lead to feeling of guilt for the one(s) negotiating/organising care:

I don't know what the best solution is because, quite honestly, at the time of putting somebody in it is so overwhelming. The guilt is horrendous. How can we be doing this to somebody that we know very well doesn't want to go in . . . It's not like you're taking their rights away . . . [but] at the same time, who by choice wants to be, on the whole, in a home? . . . Especially when you've got a case of dementia where they're not even understanding what's being done. You're the one that's making that decision.



6.0 Themes and issues

6.2 Identity and change

6.2.2 Coping with change

It was apparent from our interviews with participants that the change involved in arranging care for a loved one can often be extremely stressful for families, particularly if the medical management of their condition leads to further or different problems:

I remember being extremely upset when she had a very bad fall and had haemorrhaging, and being told that they were removing the blood thinner that she was taking. The reason she was taking that, I think,

was to prevent strokes and, since vascular dementia is all about mini strokes, I just couldn't get my head around that because they were setting her up for a major problem. I wasn't going to let this go. I did understand on one hand. I think it was the first time I was, actually, faced with the medical decisions as in between a rock and a hard place.
(ANGIE)

Sometimes respondents (and their

families) felt some responsibility for the medical management of their family member:

... He was on Diazepam, we were never quite sure whether we should be upping the dose or lowering the dose ... Diazepam is a sedative, it supposedly calms you down, but then that would make him lethargic at certain times ... then he'd be quite aggressive when he woke up. His mobility was starting to be effected as well. It was only later



6.0 Themes and issues

6.2 Identity and change

6.2.2 Coping with change

actually when he went into the home, and they replaced Diazepam with an alternative drug with less sedative properties, that we realised that the Diazepam had probably been affecting his mobility. **(PHIL)**

There is some evidence of the individual who is in need of care ignoring or downplaying the worsening of their condition (because he or she does not want to enter residential care), as Maggie's account demonstrates:

So it wasn't that she was in denial; she knew how desperately ill she was, but she didn't want to face up to it . . . In December . . . we were already having to look at changing the domiciliary carers, because the carers coming in couldn't visit late at night. She was getting to the stage where she couldn't get into bed by herself at night, but was determined to keep doing it, because she didn't want to go into a home.

She knew that when she went into a home, that really would be the last stage. So we talked amongst the family and we decided to tell her a white lie, so we said, 'Obviously, Mum, you can see how ill you are. There are problems with the carers. If you go into a nursing home for a few weeks, it will build your strength up again, and then we'll look at it again after that.' **(MAGGIE)**

From previous research into the lived experience of carers in south Essex (*Healthwatch Essex, 2015*), we know that caring roles are deeply embedded in relationship. Maggie's account gives us some insight into the depth and enormity of the emotional strain associated with learning that her mother's condition would continue to deteriorate, and needing to somehow communicate this to her mother. She continues to detail how difficult it was to talk to her mother about her needs because this essentially meant 'forcing' her mother to accept the seriousness of her condition:

Then, because of the forms that they have to do to get CHC fast-track funding for this care, the doctor said that the patient has to be involved in the decision. So Mum actually had to say that she knew what she was signing up to. That she knew that she was going into a nursing home and that was going to be the end of the road.

. . . So it was a very, very difficult meeting, because the doctor was telling her, basically, that she was dying and that this would be the best place for her to be cared for. I can see why the patient has to be involved in decisions, but Mum was desperately ill. We'd spun this little story for her and thought she would at least talk about it. When we saw her on the Thursday/Friday of that week and we explained it all to her, she'd thought that, actually, 'Yes. I think that's a good idea, at least for a couple of weeks. That sounds really good.' **(MAGGIE).**



6.0 Themes and issues

6.3 The stigma of care/the stigma of the condition

Respondents sometimes spoke of awareness of societal stigma associated with ill health, which can lead to the person organising care bearing a sense of shame relating to the condition of their relative. This is especially the case when the person needing care was experiencing mental ill-health, which seemingly discourages some people from accessing services designed to support them. For example:

I don't think support groups are the answer because I think a lot of people deal with this on their own and there's so much shame associated with certainly dementia and also acknowledging that you're not coping, that people won't do it. My father won't access support groups. I have arranged counselling, but I don't tell him that it's counselling.

Certainly for a long time even with my background I referred to my mother as having memory problems ... To start using the term dementia was actually quite difficult for me.

Also if I happen to see anything about it that really does make me feel quite, 'Gosh that is what my mother has got.' I think a lot of it is breaking down the stigma of this disease. (JOANNA)

As Jayne explains, stigma is sometimes related to ignorance, and can occur because dementia, for example, is at times invisible and changeable:

It's very frustrating and I had a bit of sympathy with that because I have fibromyalgia and nobody can see that, either. Especially when I was younger, because it was diagnosed in my 30s, people don't expect you to have problems at that sort of age. They think, 'Oh, yes. Young, fit person. She's fine.' Either that or you tell them one day that you're having a bad day ... The next time that you can do something, they'll say, 'Oh, you look alright now, then.'

There was also some discussion of the stigma associated with the accessing of residential care. Maggie, for example, felt that others expected her to care for her mother at home, and that there was an inference that she'd let her mother down by organising residential care:

It's difficult, isn't it? People never mean these things to sound the way they do, but several other acquaintances were [saying], 'we managed to keep him at home right until the last minute. We were so pleased that we could do that,' as if somehow you are letting them

down if they have to go into a nursing home. (MAGGIE)

Carers often describe feeling guilty, isolated, and powerless in their caring role (Healthwatch Essex 2015). Angie concurred that some of the guilt or sense of failure one can feel when making the decision to put a loved one in a home comes from long-standing deeply-embedded cultural beliefs about how relatives should be cared for:

I think a lot of this comes down to partly the upbringing but partly also your internal working model. How you feel, as you grew up or your expectations of the future, was that I would never have my parents in a home. My role as a daughter was such that when they needed help they should come and live with me.

But the reality of Maggie's mother's deteriorating condition was such that Maggie could not provide the care she needed – and there was perhaps a lack of understanding about this on the part of her relatives:

My Irish relatives particularly, they were full of this, sort of, 'Oh, well, could she not go and stay with you or [name]?' That's my sister. She couldn't because particularly in that last stage, they were coming in, basically, to turn her every three hours. She couldn't actually move herself in the bed properly. She was on much stronger medication by then and she needed nursing care. Where would I have put her in here? (MAGGIE)



6.0 Themes and issues

6.4 Continuity of care

Respondents referred to the lack of continuity of care. They described a sense that separate health and care providers did not communicate with one another, and communication within organisations also seemed to be lacking. This often led to a feeling that care was disjointed, and relatives were left to deal with the consequences.

For example, Maggie had to ‘manage’ the carer support her mum received whilst still living at home, by leaving instructions for them to follow because it wasn’t the same carer who came every time. She was also frustrated when, having convinced (with the help of the doctor) her mother that she needed to move into residential care, this was disrupted by the involvement of other hospital staff:

In the meantime, these two – I can’t remember the team they were from – came round when we weren’t there and said to Mum, ‘Well, do you want to go into a nursing home or would you like to go home?’
(MAGGIE)

Support for Mark was limited because of the need to work within the rules or ‘by the book’. Although there appeared to be a fairly quick response when Paula was in crisis, Paula needed longer-term consistent support to get better. But Mark describes the painful cycle they would find themselves in when that support was missing:

There is a crisis team, apparently. When she was admitted to A&E on one occasion . . . she was kept in overnight, and they said they would call the crisis team out . . . You think, ‘Oh, a crisis team . . . That’s great. Somebody is going to come out and help sort things out’ . . . [but] they discharged her the following day, because by then she was sober, and she could talk reasonably well, I said, ‘Well, what happened to the crisis team?’ She said, ‘Well, they

never came.’ When I queried it with the services they said, ‘Well, they never came because the crisis was over.’ Yes, can you believe it? . . . The fact that she had been in A&E for, at this time, seven or eight separate occasions, I mean that’s a crisis in itself . . . and you just sort of lose confidence in them. You just think to yourself, ‘Well, you just get what you’re going to get.’



6.0 Themes and issues

6.5 Assessing and experiencing residential care

6.5.1 Cost of care

The cost of care and/or the complexity of funding is another significant concern, as this interaction between Joanna and Michelle (interviewer) indicates:

JOANNA: The cost was enormous, there's no two ways about it. My father was able to fund it privately, but the cost of this place is phenomenal and I think he is concerned about it.

MICHELLE [INTERVIEWER]: How does it work if you do decide that we've run out of money to afford this, then the NHS kicks in and the NHS facilities?

JOANNA: It's not going to happen for a very long time, but it's going to deplete everything.

MICHELLE: So that would be the concern of the long-term, is what it means to his finances?

JOANNA: Yes, his quality of life. When Mum was admitted to the [name of nursing home], the clinical commissioning group for [name of district] were contacted to make an assessment of her and apparently they went in and assessed her as not needing nursing care, so, as such, they won't make any contribution to her care . . . I discovered that they had not actually seen her, they'd done it on the basis of her nursing records. So I questioned it . . . Because as far as I was concerned, my mother needed prompting and support and guidance and supervision for all activities of daily living and that I struggled to understand how they could come to that conclusion.



They emailed me back and said that they'd come to the conclusion based on the nursing record that yes, while she needed support and prompting and supervision, her needs were not complex nursing needs because she didn't require medication, she had no complex wound, she didn't require catheter care or anything like that and, as such, it wasn't considered a nursing need, so they weren't liable for it. I think that's just disgraceful.

Others spoke of not knowing what, if any, financial help might be available to them:

I've learned a lot more about it since, but that's the funding for people who have health problems

which require care, rather than like Mum had before. She had carers coming in, but it wouldn't have qualified her for the NHS CHC [Continuing Health Care], but this fast-track is for people like Mum near the end of their lives needing nursing home care. Basically, the NHS picks up the bill for the nursing home, which was obviously an issue, because Mum didn't have that much money. So it's a way of making sure that they're cared for properly without having to mortgage whatever to try and get it sorted out. **(MAGGIE)**

6.0 Themes and issues

6.5 Assessing and experiencing residential care

6.5.1 Cost of care

And yet as Phil's account highlights here again the messages can be confused, making the whole process harder:

In terms of identifying the financial help available, it is really quite complex. Although we were entitled to receive 'attendance allowance' for my father, we weren't in the end deemed eligible to receive means-tested support from social services.

When I look back on it, all of these things took time to get through and [there were] hurdles to jump over, but when you talk about it in retrospect, we kind of went through a process. You just jump over the hurdles as they present themselves really, I suppose, I think that's probably what most people do. You suddenly realise, 'Oh yes I haven't really thought about that, what are we going to do about that and where do I go for help?' It's not always clear where you go for help as well.



A key decision we took, while dad was still of sound mind, was to get his consent to my mother and I having power of attorney over his financial affairs and also over his health and welfare affairs. This proved to be a huge help when trying to jump the hurdles we faced. (PHIL)

The result for Phil and his family, as for others, is not just a financial burden but a negative impact on the lifestyle of others, in this case especially on Phil's mother:

To pay for his care home we talked about taking out an annuity, what they call an end of life annuity – it's whereby you put a sum of money into an investment and that pays you an amount of money to pay the care home fees for the rest of that person's life, but they are very expensive so we didn't go down that route. We released some equity from the property in the end ... and that will tide us over for the next few years.

After that we will need to find somewhere smaller for my mother because once this equity that we've released has run out, then we can't really release any more equity

from the property because the compound interest will be too high. (PHIL)

These extracts from Phil's account above also reveal language that is, perhaps, new and unknown for some people – 'attendance allowance', 'power of attorney', 'annuity', 'equity', 'compound interest', and so forth. Phil is a qualified and experienced accountant so understands a lot of it, but for many people such issues are likely to be difficult to understand.

Finally, the following extract from Phil's interview suggests the necessity of weighing up the cost of care with the quality of it, and that a higher price does not always mean better care:

... we went to about half a dozen in the end ... One of them I think had only been open for about six months. The two most expensive and most palatial were about £1,500/1,600 a week ... We thought about it, but concluded, having looked at the overall package and having spoken to other people too, that just because it's fantastic surroundings doesn't necessarily mean you'll get the best care ... (PHIL)

Which leads us to ...

6.0 Themes and issues

6.5 Assessing and experiencing residential care

6.5.2 Quality of care

Ensuring good conditions in residential care is a key concern for those who have the responsibility of organising and negotiating care. Our previous research indicated that carers had a lack of confidence in the quality of care homes in Essex, perceiving the care given as poor quality (Healthwatch Essex, 2015). Angie was one of the respondents who spoke of the need for 'on the ground' research:

We wouldn't make an appointment. We would just walk in the door as I'd read that was a good way to do it . . . The residents had just had lunch, there was still the smell of lunch in the air and they were . . . lined up around the wall of this on their seats next to each other . . . nobody talking to anybody . . . just the living dead, pretty much. I saw that and I thought, 'My god, is that what I'm putting my mother in for?' (ANGIE)

Similarly, Phil said:

Some were better than others. There was one home that we went to where we thought the staff didn't look that interested . . . [Another] particular home we didn't think that the cleanliness of the place and the attitude of the staff was all it could have been – let's just put it like that . . . We just wouldn't have been comfortable putting him in either of these homes.

This one [the home he is in] the staff are really good. It's run well, by a good manager; she is strong and she will make sure there's no nonsense. He's got a care plan there which they ask us to review regularly. (PHIL)

Joanna's mother was originally in a nursing home overseas. She said: **There was no dignity, there was no privacy . . . I was absolutely shattered by it. It was like going back . . . 30 or 40 years in the UK. It was so lacking in insight and lacking in dignity, that we were just horrified . . . (JOANNA)**

However, judging from Angie's experience, it seems that bad conditions and poor care are also evident in UK residential care:

She has diabetes and this particular day that I'd gone there, she'd had also an accident, just urine. I found her in the nappy and the pad and I completely flipped because nobody had told me that this is what had happened.

It's the first time she'd ever been incontinent. Anybody can have an accident, especially if they're not telling her, 'Do you want to go to the toilet?' or reminding her. She's in a strange place and she doesn't know where the loos are and isn't mobile enough to get to the loos and do it herself.

The first person to put her in a pad told me that they were going to leave her to get used to the pad. I'm not paying £1000 a week for this sort of thing to happen. Not only that, she also wasn't dressed properly. The trousers weren't matching the top. £1000 a week, I think we can expect top and trousers to match.

When I walked in to complain and got to see this assistant manager, because the main manager was away . . . just looked at me. I told her verbally what I was complaining about, plus the total lack of diabetes care. They were producing puddings for her [and] when we told them she's got diabetes and was telling them, 'No, take it away', the guy was telling me, 'Okay, if you don't want those, we can give you ice cream'. (ANGIE)

This extract points to the fact that even after she'd arranged for her mum, Angie's caring role still continued; it wasn't over. This was the case for most of our participants. Angie's account also suggests that even the experience of complaining can be complicated:

It showed that there was clearly no evidence of any diabetic knowledge. She took extensive notes and then told me, 'If you want to make this an official complaint, put it in writing'. I thought, "What have I just spent 15 minutes, 20 minutes telling you and now you're telling me to put it in writing?" I went to the reception and I said, 'I want the top man's name of this and give me his email as well, I'm complaining to him'.

Immediately it got referred to somebody or other who dealt with complaints at the next level . . . [I] ended up with a letter from them not even apologising, just acknowledging that the diabetes care is now better because they've all been trained and they don't know what happened about the incident with the pad. (ANGIE)

6.0 Themes and issues

6.5 Assessing and experiencing residential care

6.5.2 Quality of care

Angie's mother is now in a different residential setting which, although cheaper, provides more personalised care (echoing Phil's point that higher prices and nicer surroundings and facilities do not necessarily mean better care):

This home is run primarily by Romanians and they are the sweetest people to their clients . . . They say, 'We treat them like they're our parents' . . . [They seem] very much of the view that it's a privilege to work with these people because they're senior . . . When you hear that sort of thing, you know that they're in good hands. **(PHIL)**

However, the conditions are still not ideal:

There's less staffing at this home, which means they're a bit more pressurised, however, they're doing what they can. My dad is there for my mum all the time, as I said, so she is getting one-to-one stimulation from him, maybe not them. It would be a different story if he wasn't there because she would vegetate. **(ANGIE)**



6.0 Themes and issues

6.5 Assessing and experiencing residential care

6.5.2 Quality of care



This points again to the fact that once care has been arranged, that doesn't mean the end of the caring role for family members.

For Mark's wife Paula, the needs are somewhat different, and Mark is concerned about the lack of support for Paula's reintegration into the community:

... She needs time to readjust from being in a totally protected environment where she can't do anything. She's not allowed out by herself at all under any circumstances. It's like a prison, actually. To be back in the community, it's quite a major leap.

So, that's where we're at now. Now that she's been without alcohol for the best part of two years, she's absolutely a new person and you just wouldn't recognise her as being the same person as before. So, it's been a howling success, no doubt about it, but I still can't ignore the fact that her human rights are not really being addressed ... At the age of 53, she just can't be kept in there indefinitely. It's just not on. **(MARK)**

For some respondents, protesting about inadequate care and support was hampered by the fact that the person needing care did not want to complain, perhaps because they didn't want to cause a fuss, but sometimes for fear that they would actually receive poorer care as a result:

When she had the carers coming in, twice, the late evening carer didn't turn up, and there was an emergency number that I was almost told off for using ... When I rang up, first the care provider, and then the council to complain about it, the response was, 'Well, you'd be surprised, really, how often that happens.' The carer was meant to have been there at 7:00pm that evening. She [Maggie's mother] didn't ring me until 9:30pm because she kept thinking, 'They'll be here. They'll be here,' so she hadn't had her medication.

Then, when I got there, I said, 'Right. Well, I'm going to ring them up and find out.' 'Oh, no, no, no. Don't make a fuss. I don't want to trouble them,' partly because it's a generation that doesn't like to make a fuss, and because they don't want the carers to take it out on them. **(MAGGIE)**

6.0 Themes and issues

6.6 The hard work of the journey

It is clear from the data that all stages of the journey – from the beginnings of a person needing some form of care to supporting/managing residential care – is hard work for all involved: physically, intellectually, emotionally, and financially. Attention to Angie's account demonstrates her concern about the toll on her father whilst supporting her mother, as well as concern for her mother's needs:

I was in the position where I was having to fight with him to convince him that, 'Look, we need help'. I couldn't do it because of my illnesses and my family situation. He wasn't sleeping, basically, and that was starting to really affect him mentally... He desperately needed help and she was too much, almost, you could call her a burden really. It's not a very pleasant way to put it... The home we chose, though, initially, they did a day care arrangement once a week. We heard about that through the Alzheimer's Society... It was from eleven until four, which is five hours. It's good but, of course, that's a commitment to make sure she's at the other side of town as well. I would be, basically, going to get her and then crossing back on myself to go out the other end to drop her and then vice-versa.
(ANGIE)

Angie also spoke of the emotional impact on her father and of her own distress and feelings of responsibility: **He didn't want to lose my mum... It was very hard for him and I could see that. I'm an only child so I don't have any siblings or anything like that to help shoulder some of the responsibility so it was totally on my shoulders... I cried buckets.**



As far as emotionally goes, it was extremely hard, both from dealing with him [Angie's Dad] and seeing his pain but his pain was expressed as aggression towards me as if I was almost being heartless and that sort of thing.

Phil, his siblings, and cousin supported his mother in caring for his father as much as they were able to, but Phil feels that there was still a considerable physical and emotional burden on his mother: **[Dad was] getting short tempered, agitated, confused, you know, all these sorts of things as you can imagine... We got into the habit actually of taking him out most evenings down the pub for an hour**

to give my mum a break... There were some times when he wouldn't take his tablets... and we'd have to get him into bed. It took us quite a while to get him into his pyjamas and into bed, then half an hour later he'd get out of bed and start putting his clothes back on again. You'd think 'Bloody hell, all that hassle'.

You can imagine it was taking a particular toll on my mum because she was there all the time, so we started to explore all sorts of options, including asking local charity workers to come in and spend some time with him which they did for a few hours a week, giving my mum some limited respite.

I think mum felt she was finding it tough but she didn't want to give in. I think it's fair to say... she had quite a hard life with my dad... she always played second fiddle to him. Nevertheless there was a certain loyalty there I suppose and she didn't want to give in and put him in a home unless she had to. **(PHIL)**

Of course whilst all this is going on the rest of one's life responsibilities are not put on hold, as Joanna's experience demonstrates:

[My husband] and I are fully aware that I'm so embroiled in everything that he needs to physically take me away on occasions... and say, 'I'm your husband and I need you.' He's very good at doing that, in that he does it when he needs to.

6.0 Themes and issues

6.6 The hard work of the journey



6.0 Themes and issues

6.6 The hard work of the journey

But it is difficult because my father no longer has a wife. He no longer has that relationship and he uses me as his surrogate wife, in a number of different ways. My husband needs me as his wife, and I'm torn between the two of them a lot. (Joanna)

When asked if she received any support Angie said:
Nothing from professionals.

I could talk to my husband a bit about it but nobody could share the burden or the responsibility that I felt that I had to get this right. I wasn't getting it right because I didn't want her [Angie's mum] in the home.

I have high fatigue and I just couldn't cope. I knew I wasn't in a position that I could have her on my own. We had explored every other option and that [a care home] was the last one we wanted to really explore. (ANGIE)

And even then it was difficult for Angie to leave her mum:

I think I can honestly say the most emotional part of this was on the visits to the homes. I had seen [name of care home] and, as I said to you, I couldn't leave her. From signing all the papers, we were out of the door as quick as we possibly could be and I kept her with me for about eight hours until I felt I better get her back there or they'll be ringing the police or something. (ANGIE)

Maggie expressed gratitude to her husband for supporting her in making the decision:

My husband was just absolutely great. He and I were geographically closest, and he said, 'That has to happen. There isn't any other way that we can look after her. (MAGGIE)

Sharing the burden and the decision making was a constant in Phil's account:

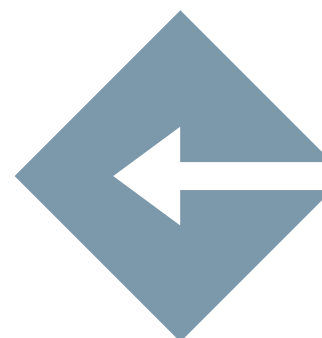
I think he [dad] held it all together [at Christmas] because he was in an environment, my brother and sister and their families were all there, so I think he kind of held it together with help from my mum. Then after Christmas he went downhill quite rapidly and it was then that we started to look at care homes. My brother and sister and I, we looked at a number of care homes local to us, and we also looked at the Care Quality Commission Reports, all these sorts of things to see what they were like . . . (PHIL)

The usefulness of a mentor/buddy was also mentioned by some:

You know what I think might be helpful, and I say this because I have a friend who is, their parent isn't that bad yet but they're thinking about it among her siblings. We got talking about it and I said, 'If you like, my mum's a resident in this home, I'll take you and you can visit my mum, you'll be my guest and you'll get to see the home without having someone escorting you around as a sales pitch or something to see the place and be natural' . . . and she fed back to me that she found that extremely helpful because it raised something that she wouldn't have been aware of or thought of.

When you're new to it it's an overwhelming thing. Some group of people that can be tapped into when people are making these decisions who've been there, done that . . . Who aren't affiliated with a home on a professional basis, only because they have a loved one in the home or in any other home . . . Somebody they can chat to, a buddy, somebody they can chat to who understands, who will empathise with them . . . Yes, GP or maybe something just as a local community volunteer thing . . .

(ANGIE)



6.0 Themes and issues

6.7 Politics, empowerment and agency

Respondents spoke of their attempts to ensure that others have an easier experience than they themselves have had:

... This sounds awfully patronising and it's not meant to be, but because of what I've been through, I'm actually able to help other people, a couple of other friends who've got something similar.

(JOANNA)

I've been working with the social services website people and their CHC team ... There's more information in that, because I worked with their website ... They've set out all the things that, again, would have been a godsend to find out what I needed to do ...

Maggie continues:

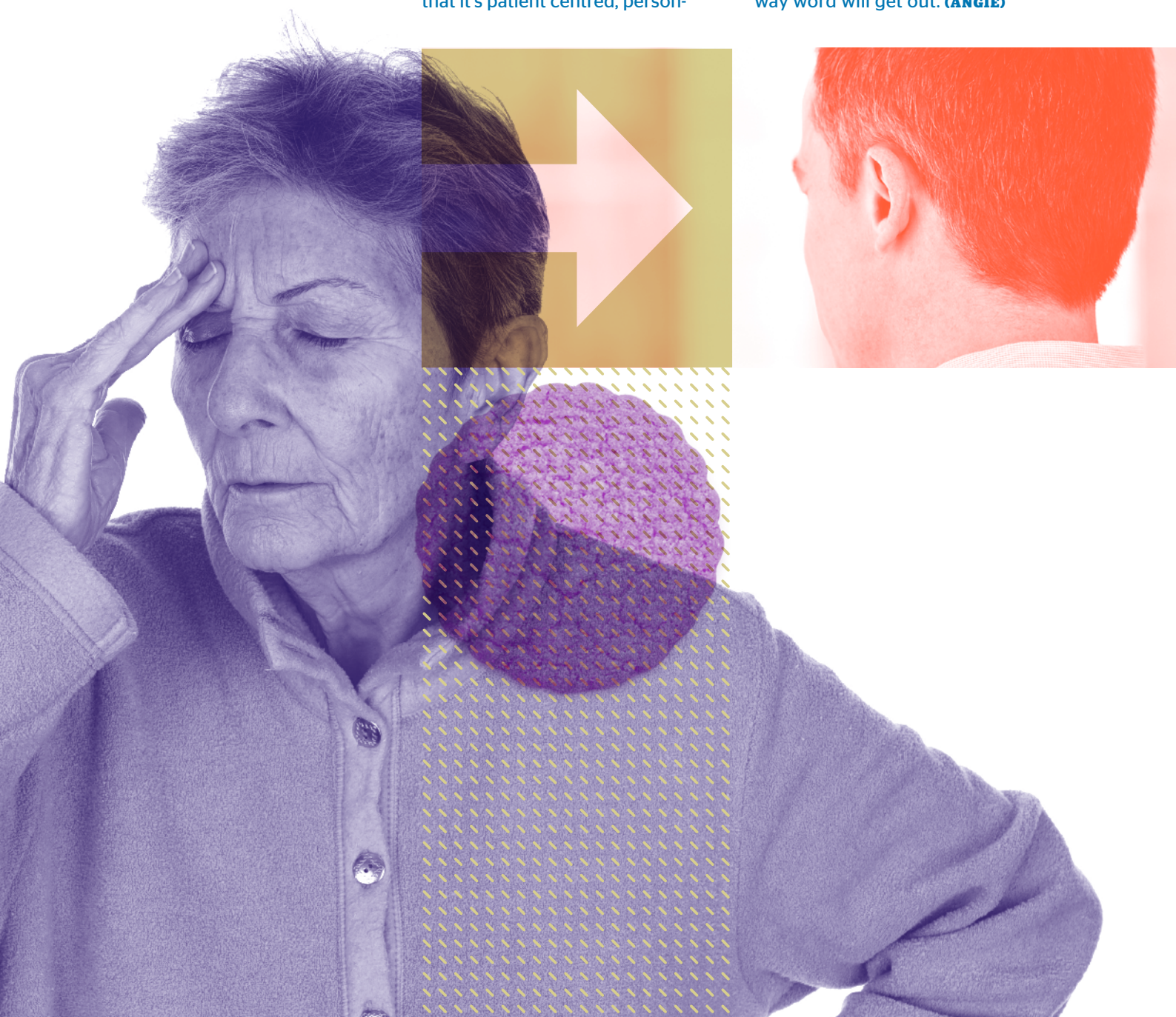
I would still advise people to do their own research and their own work on it ... All the national guidelines stress that it's patient centred, person-

centred, but I think it comes down to cost and availability ... sadly that's the case. **(MAGGIE)**

For some, the motivation to be involved in the research was the hope that it would help others who found themselves in a similar situation.

... If it can be of help to others ...

I'm really thankful that the likes of you and this organisation are doing these things because that's the only way word will get out. **(ANGIE)**



7. Discussion

'I guess in our modern society we are so shielded from all this stuff until it happens to our own- well, even you're in healthcare, but until it happens to your own family, we're not talking about it a lot until ...'

(JOANNA)

It is evident from our participants' accounts that organising and negotiating full time residential care for a family member or friend is often an emotional and distressing experience. In addition to dealing with the practical aspects of arranging care, our participants spoke of the emotional impact of seeing their relatives deteriorate and losing a sense of the identity they had before. Adjusting to changes in their capabilities and personalities was very difficult. Not only this, but participants spoke of the guilt they felt when they realised that full time residential care was the only option. Participants reported a cultural stigma associated with organising such care for a family member or friend rather than finding some way to care for them in their or another family member's home. Such a multitude of emotions can make arranging care for someone an emotionally tiring and challenging task.

What came across very strongly is the difficulty participants faced in finding information and guidance to help them make the right decisions. The language used in the documentation, particularly around finance, is not 'people-friendly'; it can be exclusive and confusing. Furthermore, the responsibility for who will pay for residential care is difficult to comprehend. Complications are encountered by many of those seeking long term residential care insofar as the distinction between people's eligibility for NHS funding in the form of continuing healthcare (CHC) funding for residential nursing or care home places that provides free NHS nursing care, and social care funding which is means tested and will often mean that people have to pay for some, and in some cases all, of their care, is far from clear. There is no single authoritative source of information to support people in discerning what those requiring longer term residential care may be entitled to. The NHS Choices website provides some information about the eligibility criteria for those seeking CHC funding⁴. Other organisations such as Age UK and Independent Age provide related information.

However, our Information Service at HWE report that this issue is one that receives regular call enquiries from relatives seeking information. Furthermore, research from the consumer organisation Which? (<http://www.carehome.co.uk/news/article.cfm/id/1571727/which-exposes-postcode-lottery>) reveals a postcode lottery for care funding, with local authorities in the south paying much more for long-term care compared to the north. Maggie's account of being told there was a place at a nursing (or care) home for her mother, and then when she told them it would be NHS-funded continuing healthcare the nursing home realised they would not receive as much money and they reneged on the offer of a place, shows just one way this distinction can negatively impact patients and their families/carers.

⁴ See: <http://www.nhs.uk/conditions/social-care-and-support-guide/pages/nhs-continuing-care.aspx#eligibility>

Financial implications and decisions were raised as a challenging area to navigate. Participants spoke of the stress they faced working out how they were going to pay for the care their relative needed and for some, Phil for example, this did not diminish over time as the impact of paying for ongoing care can have ongoing consequences for the family. Phil also made the salient point that more expensive, better equipped homes do not necessarily provide better care. And our participants told us that it was less the surroundings and facilities, and more the attention, compassion and dedication of the carers that was most important.

A number of our respondents suggested that they had to do a lot of research themselves, and, again, that the information found was not always easy to understand. They also suggested that the decisions they needed to make seemed to benefit from the professional knowledge some of our participants had, which, of course, many people do not. A couple of our respondents commented that they did not know quite how they would have coped without this 'insider' knowledge. Joanna and Maggie have since

been able to pass on the benefit of their experience to others – and Phil commented that a lot of the useful information you gather along the journey is by word of mouth from friends and colleagues who've been through it already – rather than via formal channels of support and information.



8. Concluding thoughts and recommendations

What came across very strongly is that organising care for a family member really does feel like navigating one's way through a maze. It is fraught with wrong turns and obstacles, and an almost complete lack of guidance. There are conflicts and battles all the way along too; those organising care often feel as if they have to fight to get the person-centred care their relatives deserve.

It's clear from participants' accounts of arranging care for their family member that obtaining easy-to-understand information is difficult. Better signposting is needed, as is the more stream-lined co-ordination of services. The need to negotiate the 'care maze' is becoming increasingly common as our elderly, frail population grows, so we would recommend any work to reduce the obstacles that make the work of the journey harder. Forward planning, perhaps instigated by GPs and service providers, even just by providing relevant information and signposting, would help reduce the frantic nature of arranging care when the time comes.

People's experiences of transition into full time care would be improved by the integration of health and social care delivery and budgets – because



patients and their loved ones/carers do not experience health and social care needs as discrete entities. As we have pointed out in previous research (*Healthwatch Essex, 2015*), carers need to be viewed as partners in care because as we've noted in this report, often they are the glue that smooths the patient's transition from one service to another.

Our participants' accounts also suggested a lack of support for the family care-givers themselves, the people negotiating the care maze for their relative. They may not identify themselves as a 'carer', but they are performing a caring role and thus should be able to access timely and effective support. This has been a common finding across all our work to uncover the experiences of carers in Essex.

Ultimately, despite all of the commitment and hard work, it can still feel like you are not doing enough:

You're looking at these places and with the best will in the world, nothing can replace the one-to-one care that he has had in his own home . . . We had to realise that it was going to be a difficult decision and no matter what we found, it was never going to seem as good, that it was never going to seem as good enough for our dad, your mum's husband. (JAYNE)

Thus, is it extremely important to be aware of, and provide support for, the experience of informal carers/ supporters/the significant others of individuals in need of residential care.

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Auto/Biography Publications

Some pieces outlining and arguing for (and occasionally against) an auto/biographical approach:

Cotterill, P. and Letherby, G. (1993) 'Weaving Stories: Personal Auto/Biographies in Feminist Research', *Sociology* 27(1): 67 – 79.

Delamont, S. (2009) 'The only honest thing: autoethnography, reflexivity and small crises in fieldwork' *Ethnography and Education*. 4 (1): 51 – 63.

Erben, M. (ed.) (1998) *Biography and Education: A Reader*. London: Falmer Press.

Evans, M. (1993) 'Reading Lives: How the Personal Might be Social' *Sociology* 27(1): 5 – 14

Letherby G. Scott, J. and Williams, M. (2013) *Objectivity and Subjectivity in Social Research* London: Sage (especially Chapter Five)

Mills, C. W. (1959) *The Sociological Imagination*. London: Penguin.

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A few examples of auto/biography in practice:

Davidson, D. (2011) 'Reflections on Doing Research Grounded in My Experience of Perinatal Loss: From Auto.Biography to Autoethnography', *Sociological Research Online*, 16 (1): www.socresonline.org.uk/16/1/6.html.

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