



**EXPERIENCES OF CONSUMERS IN VULNERABLE CIRCUMSTANCES WITH DIFFERENT
LEGAL SERVICES PROVIDERS**

Consumers with dementia and carers of consumers with dementia

Qualitative Research Report

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CONTENTS

1. Executive Summary	3
2. Background and Research Objectives	7
3. Research Methodology and Sample	10
4. Main Findings	12
5. Conclusions	32

1. Executive Summary

In November 2016, the Legal Services Board (LSB) commissioned an independent research company, Research Works Limited, to conduct research to explore the experiences of consumers with dementia and consumers with mental health problems (and those caring for them) when accessing legal advice, as well as their experience of the advice itself.

This report details the research findings for people with dementia and those caring for them. (A separate report details the research findings for people with mental health problems and those caring for them). Both the executive summary and the report address each of the research objectives in turn (as quoted in each of the section headings).

1.1 What features of the legal services market are particularly relevant to those with dementia and those caring for people with dementia?

The research set out to explore the experiences of those using legal services providers for advice about any legal issue. It emerged that there was a clear cluster of relevant issues, all of which were either:

- associated with the experience of having dementia, namely: wills, lasting power of attorney and property issues;
- or, for a very small group, issues associated with the experience of being a carer for someone with dementia.

A majority sought advice from a solicitor, although a small group had used the online application service for lasting power of attorney¹, and another very small group had received advice and support from issue-specific third sector organisations. Individuals

¹ <https://www.gov.uk/power-of-attorney>

with early stage dementia (who were self-diagnosed²) accessed services without any support; individuals with later stage dementia accessed services with the support of their carer, which they very much welcomed.

1.2 What circumstances contribute to these individuals being vulnerable when purchasing legal services?

Individuals with early stage dementia were vulnerable when purchasing legal services because they felt that they were slower and less successful at processing and retaining information, which they found frustrating. As a result, this group felt that they needed additional communication from legal services providers: for clarity, for reassurance and to prompt them to complete tasks.

Individuals with later stage dementia were vulnerable when purchasing legal services due to symptoms which they and their carers described as including: confusion, memory loss, feeling uncomfortable in unfamiliar surroundings, and difficulty expressing themselves.

It was not just people with dementia who emerged as vulnerable when using legal services. There was a group of carers who were vulnerable, not only due to their caring role but due to other overlapping factors including: age, a lack of experience of using legal services and mental health problems (anxiety and depression).

More generally, all respondents (both carers and cared-for individuals) felt that their anxiety about purchasing legal services made them feel vulnerable. This included: anxiety about interacting with members of the legal profession, anxiety about their legal situation, and anxiety about the overall costs they might incur.

² Please see Appendix A for more information about why those who were 'self-diagnosed' were included in the sample.

Finally, all respondents (both carers and cared-for individuals) lacked experience of dealing with what they perceived were more complex legal issues. A lack of experience meant that respondents tended to accept the legal advice they were given, and also felt unable to judge whether the costs quoted were reasonable.

1.3 To what extent are the legal needs of those in the study being met?

Overall, the research evidence suggests that, with exceptions, respondents typically felt that their legal needs were being met. However, there were aspects of their experience which respondents felt had placed them at a disadvantage when accessing legal services. For example:

- Many felt that more could be done to communicate legal issues in plain English, as well as providing plain English written information before and after face-to-face consultations.
- Some complained about affordability, particularly the cost of a solicitor when completing applications for lasting power of attorney.

The exception was a very small group who felt dissatisfied with their experience of accessing help from a legal services provider. This group comprised much older respondents who appeared to lack an understanding of how legal processes work. This lack of understanding had led to disappointment (e.g. with the advice received, with the timescale for receiving a resolution).

1.4 What approaches could improve accessibility, service experience and outcomes?

Respondents across this sample were clear about how they would like interactions to be planned and conducted. They offered clear suggestions for what they would find helpful in future:

- Initial telephone contact to plan a face-to-face visit.
- Making clear information available before the meeting, so consumers have an opportunity to consider what they want to do.
- Proactively offering home visits from a person trained and experienced in dealing with individuals with dementia.
- Treating the individual with dementia with compassion, patience and respect and making adaptations to meet the individual's needs.
- Using plain English.
- Providing a written record of the meeting which consumers can refer to for reference and clarification, including any follow up actions for them to complete.

More broadly, respondents across this sample were clear about what they felt would help them access legal services in future. This included: offering a 'jargon-free' service, promoting 'dementia friendly' services, and being transparent about costs (particularly the cost options when applying for lasting power of attorney).

2. Background and Research Objectives

2.1 Background

The Legal Services Board (LSB)³ was set up to reform and modernise the legal services market in England and Wales in the interests of consumers, enhancing quality, ensuring value for money and improving access to justice across England and Wales. The LSB aims to achieve this by pursuing its regulatory objectives and providing regulatory oversight of the ten approved frontline regulators⁴, each of which have direct responsibility for the day-to-day regulation of the different types of lawyers.

The frontline regulators have various requirements in place, which mean that practitioners should be able to recognise and respond appropriately to vulnerability. In commissioning this work, the LSB's aim is to deliver research that is of practical benefit in informing frontline regulators' work, as well as help others to improve delivery of legal services to vulnerable consumers. It builds on previous research commissioned by the LSB and others with different groups of vulnerable consumers.

In November 2016, the LSB commissioned an independent research company, Research Works Limited, to conduct research to explore the experiences of consumers with dementia and consumers with mental health problems (and those caring for them) when accessing legal advice, as well as their experience of the advice itself. This report details the research findings for individuals with dementia and carers.

³ <http://www.legalservicesboard.org.uk/>

⁴ http://www.legalservicesboard.org.uk/can_we_help/approved_regulators/index.htm

About dementia

Dementia is an umbrella term for symptoms caused by different diseases (for example, Alzheimer's and vascular dementia), such as memory loss, confusion and personality change. It can affect anyone⁵.

Dementia is a growing issue. There are around 850,000 people in the UK with dementia (and two-thirds are women). It is estimated that by 2025, this number will have increased to around 1 million and by 2050 it is projected to exceed 2 million. The likelihood of developing dementia rises with age; one in three people over 65 will develop it, although over 40,000 under 65 are affected⁶. The Department of Health estimates that 59 per cent of people with dementia in England have a formal diagnosis. There are approximately 700,000 informal carers caring for loved ones, which is expected to rise to 1.7 million by 2050⁷.

As it affects a person's mental abilities, a person with dementia will usually need help from friends or relatives, including help with decision making. The NHS recommends to those who have just been diagnosed steps that may involve getting legal advice, for example, making a will and putting a lasting power of attorney in place⁸. The affected person may need adjustments to be made by a legal advisor to help them express their wishes clearly or to understand advice.

There is relatively little research with individuals with dementia (and their carers) about their experiences as consumers of goods and services, and none that we were aware of specifically in relation to legal services. This is also an area where limited quantitative data (for example, compared to mental health) is available. However,

⁵ <http://www.alzheimersresearchuk.org/about-dementia/facts-stats/>

⁶ <https://www.dementiastatistics.org/statistics/numbers-of-people-in-the-uk/>

⁷ <http://www.alzheimersresearchuk.org/about-dementia/facts-stats/10-things-you-need-to-know-about-prevalence/>

⁸ <http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-diagnosis-plan.aspx>

there has been recent work to support retailers to become more dementia friendly (as part of the Prime Minister's Challenge on Dementia⁹).

2.2 Research Objectives

The overarching objective of this research was to improve the LSB's understanding of how consumers with dementia (and those caring for them) experience legal services, as well as the impact of these vulnerabilities on obtaining legal advice. The research sought to answer the following research questions:

1. What, if any, features of the legal services market were particularly relevant to these vulnerable circumstances?
2. What circumstances contributed to these individuals being vulnerable when purchasing legal services?
3. Did these circumstances result in adverse outcomes when using lawyers, and if so how?
4. To what extent were the legal needs of those in the study being met?
5. Taking account of relevant existing/ongoing work and initiatives, what approaches could improve accessibility, service experience and outcomes?

The intention was to expand the available knowledge base for different types of vulnerability.

⁹ https://www.alzheimers.org.uk/download/downloads/id/3064/dementia_friendly_retail_guide.pdf

3. Research methodology and sample

Below is a summary of the research method and sample. A more detailed description of the sample and recruitment process is included in Appendix A.

3.1 *Method and sample*

The chosen methodology for this research was qualitative. It was conducted via a series of thirty individual and paired depth interviews. The qualitative methodology allowed for in-depth discussion of individuals' personal circumstances, experiences and attitudes.

The sample comprised 17 carers of people with dementia (depth interviews) and 13 individuals with dementia (paired depth interviews with carers). The rationale for including carers within our sample was that they have a unique role and perspective on seeking legal advice in partnership with individuals with dementia. Carers were key to the process of choosing and using legal services providers, either as a partner to the person with dementia or on behalf of the person with dementia.

All interviews were conducted in respondents' homes, and were of around one hour duration. In-home interviews provided a research setting which supported respondents' individual needs, and gave interviewees the time and space to engage with the topic in a familiar setting. Familiarity is an important factor for helping people with dementia feel comfortable.

3.2 *A note on methodology and ethics*

Qualitative samples are purposive and quota-driven in nature; they are designed to achieve specific outcomes. They therefore have no quantitative accuracy in terms of identifying proportions of populations holding stated views.

For these methodological reasons, it is not appropriate to present qualitative findings in terms of the numbers of respondents expressing certain views. We therefore describe the findings in qualitative terms, referring to groups within our sample (e.g. respondents who had tried and failed to use legal services) and giving a broad sense of the weight of views e.g. 'a majority' or 'a minority'.

The cases described in this report have not been independently verified, therefore this report describes respondents' experiences from their personal point-of-view.

Ethical considerations were identified and addressed in the design of both the recruitment and interview approach, with the support of relevant industry guidelines and best practice¹⁰.

The key principles on which our research design was based were:

- i) Taking reasonable precautions to ensure that participants were not harmed or adversely affected by the research activity
- ii) Informed consent
- iii) Voluntary participation
- iv) Participant anonymity
- v) Meeting individuals' needs

¹⁰ https://www.mrs.org.uk/standards/code_of_conduct,
<http://www.mrs.org.uk/pdf/MRS%20Researching%20Vulnerable%20Participants%20best%20practice%20note.pdf>

4. Main Findings

The report address each of the research objectives (described in section 2.2) in turn, as quoted in each of the section headings.

4.1 Which factors make a consumer vulnerable?

The Legal Services Consumer Panel has produced a guide¹¹ for legal services regulators setting out the individual risk factors for vulnerable people when accessing and using legal services, and describing permanent, fluctuating and short-term vulnerabilities. This is based on a relevant British Standard (BS18477).

From the list of individual risk factors set out on page 12 of that report, the factors most relevant to this sample group include:

- Age
- Inexperience
- Physical disability
- Health problems
- Being a carer

This research supports the finding that being a carer is a risk factor in itself. Our sample included carers with additional risk factors, including age, inexperience and mental health problems. Therefore it may not only be individuals with dementia who are vulnerable, but also their carers.

¹¹ *Recognising and Responding to Consumer Vulnerability: a Guide for Legal Services Regulators*. Legal Services Consumer Panel, October 2014

4.2 What are the barriers to accessing and successfully negotiating legal services?

- a) **All the difficulties associated with early stage dementia were barriers to successful interaction with legal services.** Within our sample, those who described themselves as having symptoms of early stage dementia were individuals who had diagnosed themselves. These respondents described themselves as typically slower and less successful at processing information. They reported having difficulty retaining information, and experienced frustration with these retention difficulties. As a result, this group felt that they needed prompting to conduct or complete tasks. They also felt that they had a strong need for regular feedback and communication, both for clarity and for reassurance:

'I'd like the advice to be a bit more user-friendly. Everything seems to be open to interpretation.' (Individual with dementia)

'I was forgetting things, I was getting frustrated or I don't know if it was just the way it was.' (Individual with dementia)

- b) **Equally, all the difficulties associated with later stage dementia were barriers to successful interactions with legal services providers.** The difficulties described by our sample included: confusion, memory loss, feeling uncomfortable in unfamiliar surroundings, and difficulty expressing oneself:

'She doesn't remember things and she has a hard time saying what she means. They were very good about that.' (Carer)

c) **More general anxieties about using legal services also constituted a barrier to engaging with legal services providers.** Anxiety tended to focus on three issues:

- i. anxiety about talking to professional legal people as well as the language they might use (as described in section 4.4.3);
- ii. anxiety about their legal situation: *'I'm afraid I'll end up in a nursing home and things won't be sorted out. He [the legal adviser] made me feel better.'* (Individual with dementia)

iii. and anxiety about costs:

Respondents were worried about the overall cost they would incur, particularly those on lower incomes and particularly when costs were quoted in excess of £200-300, which was usually when several issues were being dealt with concurrently (e.g. wills and lasting power of attorney). It was clear that respondents found it difficult to judge whether costs were reasonable, making judgements based on instinctive reactions:

'I did make enquiries by going through a solicitor for it [lasting power of attorney], but they were talking about something like £800 ...I know they go to college and all that, but I think that's a bit over the top.' (Carer)

'I don't know if I was shocked or not. But I was prepared to pay for it. I knew I was going to have to lay out a lot, but I wouldn't have wanted it done any other way than properly. The £1,500 was for everything [property put in sons' names, changes to wills and two applications for lasting power of attorney]. I don't know if that was reasonable or not, because I have nothing to gauge it by.' (Carer)

Costs associated with solicitors completing lasting power of attorney applications were perceived to be particularly problematic. As a result, younger, more internet experienced respondents opted to complete the application online. However this option was not perceived to be accessible to older, less internet experienced carers:

'I heard from someone else you can do it yourself ... She [the solicitor] showed me the form: my God, it's like a book. And even then they said it costs about £150 to do it ... No, I can't do that.' (Carer)

- d) **A lack of experience of using legal services:** for this sample, previous experience of legal issues was typically limited to matters such as conveyancing, divorce and wills. The issues currently faced (particularly those involving lasting power of attorney) were perceived to be more complicated than any previous personal experience (which came as a surprise to some). A lack of experience meant that respondents tended to accept the legal advice they were given, without question:

'I asked if there was a better way of doing things and he [the solicitor] talked about trusts and I said I didn't want to go down that route and to be honest I didn't quite understand about that. It's a bit more complicated and I said that I wanted to keep it simple, and he said, 'OK, let's just do this.'

(Carer)

4.3 What, if any, features of the legal services market are particularly relevant to those with dementia and those caring for individuals with dementia?

In this research we set out to explore *any* legal issues experienced by individuals with dementia and their carers, as well as legal issues specifically relating to dementia. It

emerged that our sample's experience of legal issues was closely associated with the experience of being diagnosed with dementia.

There was a clear cluster of relevant legal services: wills, lasting power of attorney and property (such as protecting an individual's interests with a view to care costs, or managing inheritance tax liability). These issues were often, but not always, dealt with concurrently. There was sometimes a degree of urgency about the need to seek legal help e.g. the need to organise lasting power of attorney while individuals with dementia still had the mental capacity to make their own decisions.

Individuals with dementia and their carers tended to seek the help of a solicitor. Solicitors were assumed to be the appropriate type of provider to consult regarding wills, lasting power of attorney and property issues. However, having consulted a solicitor regarding lasting power of attorney and heard the costs they would incur, some had decided to use the online application service¹² without a solicitor's help.

A small group had received information from issue-specific third sector organisations specialising in care and advice for older people. One respondent had completed their legal transaction exclusively with the help of a solicitor organised by an issue-specific third-sector organisation:

¹² <https://www.gov.uk/power-of-attorney>

'We saw the service in an article in a magazine. I thought it was a good idea. I went to their shop and there was a leaflet with information. I phoned and a man came out to see us. It's free. If you go to a solicitor it can cost £1,000.'

'He went through it all with us. It's a big book with all the implications. He explained all of it to us. He gave us this big envelope of stuff to read. It takes ages, but it's worth doing. It was very simple and very smooth. It cost £100 for each section and we made a donation as they didn't charge us. We were very happy with it.'

'He included my husband [who has dementia] in the conversation and he was able to follow it all.'

'He was brilliant. He knew his job and was obviously a specialist. I don't think he could have done any better.' (Carer)

There were also examples of carers seeking legal advice from solicitors because the issue involved them as carers (as well as a cared-for person who was unable to represent themselves). These issues were: being accused of fraudulently taking a cared-for person's money and being asked to pay the care fees on behalf of a cared-for person:

A local authority wanted to know how much money a respondent's uncle [who has dementia] has, in order to work out whether he needs to be contributing to his care costs.

'My mother and father have been put under so much pressure due to this and it is causing them immense stress and anxiety. They don't know what to do.'

'My first encounter with him [the solicitor] was on the phone. He offered me a free half hour service. He suggested I take my parents to see him. We were there just over an hour and he said, 'I'm not going to charge you.'

'He told them not to worry. It was as if he wanted to take the weight off their shoulders.' (Carer)

4.4 Approaches or techniques that consumers find useful in accessing legal services

Individuals with later stage dementia accessed services with the support of their carer. Carers were typically 'partners' in seeking legal advice, working in collaboration (as much as possible) with the cared-for person. Cared-for respondents explained that they were more confident and comfortable using legal services with the support of a trusted person. Mediation by a carer was universally perceived as having a positive effect on the experience.

Individuals with early stage dementia (who were self-diagnosed) accessed services without the support of friends or relatives, but typically felt that they needed additional reassurance from their solicitor.

4.4.1 Finding a solicitor

Choice of solicitor was largely determined by:

- a solicitor being previously consulted by the individual for another legal service (e.g. conveyancing or divorce); or
- a recommended solicitor, typically a word-of-mouth recommendation from a relative or friend or another source

'It's easier with people you know. If you get confused, it's easier.'

(Individual with dementia)

'Mum feels quite secure that her friends have used them and they are nice and everything.' (Carer)

'We went with a recommendation from a friend who said she [the solicitor] was lovely and understanding.' (Carer)

Local solicitors were very much prioritised, largely for convenience, and particularly because a home visit was a priority for most. Local firms were also more likely to be the subject of word-of-mouth recommendations. Smaller firms were preferred over larger since they were perceived as friendlier and less impersonal. This was a reassuring factor for many respondents who felt intimidated by the prospect of meeting a legal professional:

'There was a slight extra charge, maybe £100, for the home visits, but for the number of times she visited it seemed very reasonable.' (Carer)

'The solicitor was well known locally.' (Carer)

'I felt it was nice to use someone local. I needed them to do a home visit, which they did.' (Carer)

'I wanted a small firm. I feel I know who I'm dealing with.' (Individual with dementia)

All of the factors described above (using a 'known' solicitor, following a recommendation, using a local firm, using smaller firms) were ways in which carers tried to meet the needs of individuals with dementia. They felt that these factors were likely to 'protect' the individuals with dementia they cared for from an unsettling experience:

'I would say it was a very relaxed meeting. Some solicitors have very ostentatious surroundings, but this was just a tiny little family business, so it was quite nice and friendly and the girls in the office were friendly. We got offered a cup of tea or coffee. It was really nice.' (Carer)

Feeling comfortable when accessing legal services was equally important to individuals with dementia:

'He [the solicitor] was really good. I sat next to him and my wife sat opposite and he was really good to talk to. I was thinking, 'Oh I hope he's going to be OK', but within a short space of time he was quite 'you and I'.' (Individual with dementia)

'It was a big relief to know we were dealing with someone who understood what we were going through and had some patience.'
(Carer)

Some respondents expressed preferences for legal advisers with particular individual characteristics:

'I prefer to have a lady solicitor. I think they understand life better. More understanding.' (Individual with dementia)

'He was an older man, so you felt confident in his abilities as well.' (Carer)

It is worth noting that respondents reported using very few independent sources of information to help them find a solicitor other than limited Google search. Most respondents tended to conduct a very brief search prioritising local, small firms:

'I had a quick look on the internet, and chose the first one that was local to us.' (Carer)

Issue-specific third sector organisations were the only independent sources of advice that were consistently (but not frequently) used by carers in the sample. For a small group, it appeared that third sector organisations had raised awareness about the legal issues associated with a diagnosis of dementia. For example, one carer had been on a course run by a third sector organisation about looking after people with dementia which had prompted her to search for more information online. Another carer reported that she found out about lasting power of attorney from her mother-in-law who had been to a group run by another issue-specific third-sector organisation.

4.4.2 Initial contact with the solicitor

Carers tended to make contact with a solicitor first (sometimes using a 'free first half hour'), before setting up a face-to-face meeting with the cared-for person. There was good awareness of the option to use a free session amongst those accessing new solicitors (as opposed to using a familiar 'family' solicitor). As described in section 4.3, one respondent was delighted that his concerns were addressed within the free time he had been allocated.

This initial contact was perceived as useful for a number of reasons. It presented an opportunity for the carer to explain their situation and the circumstances of the cared-for person. It gave the solicitor an opportunity to ask questions about the nature of the cared-for person's difficulties and the services required. Finally, it

allowed both parties to agree on appropriate arrangements for a face-to-face meeting.

'We had a conversation on the phone before they came to visit. They didn't charge us for that.' (Carer)

By comparison, individuals with early stage dementia (who were self-diagnosed) did not take as much care about preparing to meet their solicitor. They did not divulge that they were experiencing symptoms of dementia, and their solicitors did not enquire about whether they had any particular needs. It was only during the process of dealing with their solicitor that their particular needs became apparent (e.g. difficulties understanding written information, need for reassurance regarding progress). These tended to be described as provider failings, rather than undisclosed and therefore unmet needs.

Although individuals with early stage dementia (who were self-diagnosed) tended not to identify their specific needs or preferences proactively when accessing help from a legal services provider, they were clear about their needs/preferences when prompted during the research interview:

'I find the spoken word better than the written word.' (Individual with dementia)

'Keeping the client informed is a big thing.' (Individual with dementia)

4.4.3 The main meeting

The most successful face-to-face meetings were conducted at home. This was the most reassuring arrangement for respondents with a formal diagnosis of dementia.

Solicitors who carried out a home visit were felt to have demonstrated an understanding of how unsettling it can be for someone with dementia to be asked to go into an unfamiliar environment, and to have understood the importance of people with dementia feeling calm, comfortable and in control:

'She was lovely. She treated mum with real compassion and respect. I think maybe she'd had experience of dealing with people like mum before.' (Carer)

'My mother-in-law is very hard of hearing and it's difficult to handle sensitive issues when you're shouting, but the solicitor handled it very well and still addressed her constantly throughout the meeting.' (Carer)

'I think because he visited us at home, it was more comfortable to talk to him. We felt more at ease.' (Carer)

Plain English was greatly appreciated by all respondents. There was a clear sense that legal jargon was intimidating and a potential barrier to understanding the remedies being suggested. Having the issues and solutions explained in 'layman's terms' was reassuring and respondents felt they were more part of the process when they understood what was required in simple terms:

'A lot of it was hard to understand. She had to explain everything to us more than once.' (Carer)

'He had a leaflet explaining it in layman's terms; that really helped. I find legal jargon very difficult.' (Individual with dementia)

Solicitors with good people skills were highly valued. A number of respondents expressed pleasant surprise that their solicitor had been easy to talk to and not intimidating. This reflects the initial apprehension felt by many respondents when contemplating using legal services. When one carer remarked that, "*She [the solicitor] was down-to-earth*", her husband, who has dementia, immediately agreed: "*That's the word, she were down-to-earth.*"

Due to retention difficulties, receiving written information after a meeting was considered important. This was the case not just for people with dementia, but often for carers too. The content and quality of information was also felt to be important; again, plain English and clarity were prioritised. Some respondents suggested that a simple document setting out what had been discussed would add value to the service received:

'It's just that once I've read something it's gone. If I haven't got something in front of me, how can I explain it to you?' (Individual with dementia)

'If they sent you a letter saying 'This is what we talked about', it would be helpful. Mum doesn't remember much of what happens, but if she sees something written down, it all comes back.' (Carer)

4.4.4 What does a successful meeting look like?

The ingredients for a successful meeting with someone with dementia (these criteria apply equally to a carer and cared-for person, those with a formal diagnosis and those who are self-diagnosed) included:

- **Building a rapport before turning to business**

- **Directing the conversation at the person with dementia, or including them in the conversation, rather than concentrating exclusively on the carer:** *'He came and spoke to both of us, so my wife felt included in it all. He asked her if she was OK with everything.'* (Carer)
- **Giving the cared-for person time to express themselves, and ensuring that their input is acknowledged:** *'The solicitor made sure my mum felt in charge.'* (Carer)
- **Bearing with emotional reactions, and showing tolerance and patience:** *'She was happy to repeat things and listen.'* (Carer)
- **Leaving behind key information in plain English and with a record of the issues discussed at the meeting:** *'If something is in writing, I can pick it up and look at it and do what I have to do then. I have a thing to put my pills in because sometimes I take two when I should only take one. So that's why I like things in writing.'* (Individual with dementia)
- **Giving people space to think during and after the conversation:** *'The solicitor left us for a few minutes so we could make sure we had covered everything. It was such a nice touch.'* (Carer)

4.5 Adverse outcomes: tried and failed

Most respondents reported feeling satisfied with the legal services they had received. However, a minority had tried and failed to access a legal provider, and another group felt dissatisfied with their experience.

4.5.1 Tried and failed to access a legal provider

Within this sample there were two examples of carers of individuals with dementia who also described themselves as experiencing symptoms of depression and anxiety.

These two female respondents had been put off dealing with legal services after poor initial experiences.

- In one case, a female carer felt overwhelmed by the response from the solicitor's firm she had approached. Firstly, she felt that the receptionist 'bombed' her with information and was focussed on getting her personal details (which she did not feel ready to provide): *'I don't think I was coping very well with information myself at that stage, let alone my mum, the state she was in ... It was just I felt she bombed me.'* Her first contact with the solicitor did not reassure her. She felt that he focussed on physical impairments (e.g. would her parents be able to get up the stairs) rather than the impairments associated with dementia. Finally, she felt that the cost was off-putting: £1,500 to complete two applications for lasting power of attorney.
- In another case, a female carer wanted to complain about the treatment her mother had received at a care home. She was recommended a firm of solicitors by someone at the care home where her mother was being cared for. She was told to 'log' her complaint, which she did; but when she contacted them she recalls she was told that their database had been wiped and so she needed to re-log the complaint. After several attempts, she gave up: *'It put me off from doing anything about anything until she died.'*

These examples suggest that an unsuccessful attempt to access legal advice can result in carers with mental health problems not pursuing the legal issue, rather than seeking help from another legal services provider. Clearly, carers expect legal services providers to recognise the needs of people with dementia, as well as their own needs i.e. their wish for support to pursue and complete their legal issue which may be affecting their own emotional well-being.

4.5.2 Dissatisfied with the experience

Two experiences suggest that a lack of understanding of legal advice and processes sometimes can lead to disappointment:

- In one case, an older carer is now unsure whether the advice she was given was appropriate: *'I went in again to see her [the solicitor] and I took our wills with me. She looked over them and due to my feelings of anxiousness that possibly things weren't covered as best they should be, she suggested we have them re-written. Although I felt then, yes, I understand it, I thought could she not have explained this to me without making another will? It cost us another three hundred and something pounds.'* In this example, the respondent acknowledges that her anxiety prompted the solicitor to re-write her will, but feels that she possibly needed more guidance about what she would gain for the additional cost.
- In another case, an older carer is unhappy with the service she has received from her solicitor, who she feels is taking too long to complete the lasting power of attorney process and not responding to her emails swiftly enough. She claims that the solicitor has experienced a bereavement and this may be the reason for the lack of response. However, she is considering whether to make a complaint when the case has been resolved.

More generally, respondents felt that they were unlikely to pursue a complaint, if they felt dissatisfied. This was a result of feeling that they were partly to blame for any perceived dissatisfaction (e.g. their perceived failure to understand or ask for clarification). In future, information in plain English about what to do if something goes wrong would need to include information about support available to those wanting to make a complaint e.g. advocacy organisations able to offer independent support to help individuals express their views and wishes.

4.6 Are the legal needs of this sample group being met?

Overall, this sample group largely felt that their legal needs had been met. Only a small group felt disappointed: individuals who had experienced problems in accessing and using legal services, and individuals who felt dissatisfied with their experience of accessing legal services (as discussed in section 4.5).

To help us address this objective, we have used the Legal Services Consumer Panel's consumer principles framework, which also forms part of its guidance document on consumer vulnerability¹³. The purpose of the framework is to provide a simple tool for regulators to help them think about the consumer interest in a structured way. It is based on a set of seven core principles that are commonly used by consumer organisations for working out how particular issues or policies are likely to affect consumers. Below we use this framework to analyse how our sample have accessed and used legal services.

- Can consumers access services in a timely, affordable and accessible manner?
- Do they receive the right advice?
- Is there a choice of suppliers?
- Do consumers have the right information to make choices?
- Are some consumers unfairly discriminated against?
- Can they access redress if something goes wrong?
- Do vulnerable consumers have a voice in shaping how legal services are delivered?

¹³ *Recognising and Responding to Consumer Vulnerability: a Guide for Legal Services Regulators*. Legal Services Consumer Panel, October 2014

4.6.1 Can consumers access services in a timely, affordable and accessible manner?

Most respondents felt that they were able to access legal services in a timely manner, although this involved extremely minimal time spent sourcing a provider. There were no complaints about the time taken for legal services providers to respond to their initial contact.

However, some complained about affordability, particularly the cost of a solicitor completing applications for lasting power of attorney. This resulted in some respondents deciding to complete applications for lasting power of attorney online. However, not all felt in a position to use this alternative channel. Even those who had completed the application online had found some aspects quite confusing:

'I found that the government website was quite self-explanatory, but I still don't understand it fully.' (Carer)

'I got the gist of what was being asked, but I found the bit about the mental capacity confusing. I remember thinking not everybody would have the same amount of understanding.' (Carer)

'A lot of those government forms are very easy to follow ... We were able to do it, but mum would have struggled. So if you have a family member to help you with it, it is fine.' (Carer)

None mentioned the option of being able to contact the Office of the Public Guardian with questions about the online service¹⁴.

¹⁴ <https://www.gov.uk/government/organisations/office-of-the-public-guardian>

A majority felt that their experience of accessing a solicitor had been extremely positive, particularly in terms of home visits and the manner in which solicitors engaged people with dementia. That said, many felt that more could be done in terms of communicating legal issues in plain English, as well as providing simple, written information after their face-to-face meeting.

4.6.2 Do they receive the right advice?

Given that the research data is based on respondents' perceptions, it is impossible to judge whether they received the 'right' advice. Certainly, none claimed to have experienced an adverse outcome based on the advice they had received. The only respondent who questioned the advice she had been given (as described in section 4.5.2) felt that she may have made a different decision, if she had realised the extent of the cost she would incur. That said, most reported that they had made decisions based on an understanding of the costs they would incur.

The research evidence suggests that both individuals with dementia and carers of individuals with dementia may be potentially vulnerable to receiving poor advice, given: limited capacity (amongst those with dementia) and limited appetite (amongst those caring for individuals with dementia) to weigh up different options, and reliance on one source of legal advice without seeking any alternative opinions or independent information.

4.6.3 Is there a choice of suppliers?

Overall, respondents felt that there was an adequate choice of suppliers. However, the evidence suggests that both individuals with dementia and carers of individuals with dementia were not taking full advantage of the range of providers available, notably from issue-specific third sector organisations as well as a broader range of solicitor firms and other types of legal services providers. The preference for small, local firms was a limiting factor in searching.

4.6.4 Do consumers have the right information to make choices?

Given finding 4.6.3, it is evident that respondents did not seek, or make use of, a full range of information on legal services providers. However, there is also evidence that respondents felt confused about the services on offer, particularly in relation to lasting power of attorney. Respondents did not perceive legal services providers as offering clear, simple information explaining what services were on offer to help them achieve lasting power of attorney.

Respondents felt that it would be extremely useful to make clear, written information about their legal issue available before meeting face-to-face, so that they would have an opportunity to consider what they wanted to do. They also felt that a written report of their meeting would be helpful, both for reference and clarification, as well as a record of any follow up actions for them to complete.

4.6.5 Are some vulnerable consumers unfairly discriminated against?

Most respondents felt that they had been treated fairly, and with understanding, by the solicitors they had dealt with. The evidence suggests that while individuals with dementia and carers of individuals with dementia did not feel actively discriminated against, they are at greater risk of vulnerability as consumers when accessing legal services providers and this requires providers to adapt their services to respond to their needs.

4.6.6 Can they access redress if something goes wrong?

There were no examples of respondents seeking redress against legal services providers, although (as described in section 4.5.2), one respondent was considering making a complaint once her case had been resolved. This finding reflects the generally high level of satisfaction across the sample group with the services received. However, as also described in section 4.5.2, the research also identified additional barriers that may mean this group of consumers is reluctant to complain, namely a

lack of confidence about complaining and a need for support in order to pursue a complaint.

4.6.7 Do vulnerable consumers have a voice in shaping how legal services are delivered?

Respondents typically felt that they did have a voice in shaping the service they received. Many carers of those with a formal diagnosis of dementia reported that they had been able to make arrangements to suit the cared for person. For example, those who wanted a home visit were typically able to arrange this, and in some cases, respondents reported that providers were proactive in asking if a home visit was preferred. However, there were cases when a home visit had not been requested, but would have been welcomed.

When asked about how legal services provision for people with dementia could be improved in future, many felt that more information (about costs, specialist services, home visits etc.) would help others to shape and receive a service appropriate to their needs.

5. Conclusions

Individuals with dementia were vulnerable when accessing legal services, as may be their carers.

- Individuals with early stage dementia were vulnerable when purchasing legal services because they felt that they were slower and less successful at processing and retaining information, which they found frustrating.
- Individuals with later stage dementia were vulnerable when purchasing legal services due to symptoms such as confusion, memory loss, feeling uncomfortable in unfamiliar surroundings, and difficulty expressing oneself.

- There was a group of carers who were also vulnerable, not only due to their caring role, but due to other overlapping factors including age, inexperience and mental health issues.
- More generally, all (carers and cared-for individuals) felt that anxiety about purchasing legal services made them feel vulnerable, as did a lack of experience of dealing with more complex legal issues (compared to commonly experienced legal issues which were perceived as relatively straightforward e.g. conveyancing).

Respondents across this sample were clear about how they would like interactions to be planned and conducted. They offered clear suggestions for what they would find helpful in future:

- Initial telephone contact to plan the face-to-face visit. This involves the carer being able to describe the cared-for person's needs and the solicitor being able to ask questions about the nature of the cared for person's difficulties, and the adaptations required.
- Making clear information about the legal issue available *before* the meeting, so consumers have an opportunity to consider what they want to do. This was particularly the case in relation to lasting power of attorney, which was widely seen as a complex and confusing area of law, particularly in terms of the options available and cost choices.
- Home visits, from a person trained and experienced in dealing with individuals with dementia.
- Treating the person with dementia with compassion, patience and respect and making adaptations to meet the individual's needs (e.g. building a rapport, including people with dementia in the conversation, giving people

with dementia time to express themselves, bearing with emotional reactions, and giving people time to think during and after the conversation);

- Using plain English.
- Providing a written record of the meeting that consumers can refer to for reference and clarification, including any follow up actions for them to complete.

More broadly, respondents across this sample were clear about what they felt would help them access legal services in future. This included: offering a 'jargon-free' service, promoting 'dementia friendly' services, and being transparent about costs (particularly the cost options when applying for lasting power of attorney).