



The Fog of Support

An inquiry into the provision of respite care and carers assessments for people affected by dementia.





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Foreword

At the time of writing in August 2020, the COVID-19 pandemic has been devastating for people affected by dementia. More than one quarter of all COVID-19 deaths in England and Wales have been people with dementia and dementia has been the most common pre-existing health condition of people dying from the virusⁱ. There have also been more than 5,500 dementia deaths above what would be considered normal for this time of yearⁱⁱ.

This report, and the research from which it draws, was collated before the outbreak of the COVID-19 pandemic. As such, the particular challenges that the pandemic has introduced, and the changes to practice adopted as a result have not been addressed within this report. It explores the issues in the context of the legislative and practical frameworks that existed before the pandemic.

Towards the beginning of the pandemic, the Coronavirus Act was introduced which allowed councils to suspend elements of the Care Act – the Act which encapsulates many of the rights and entitlements of carers. While this was a sensible precaution to mitigate the risk of social care being overwhelmed if the impact of the pandemic was particularly acute, we cannot allow it to become the new normal.

Many carers of people living with dementia have now spent more than three months in lockdown with the person they care for. During that time many will have received no assessment of their needs, no respite care and limited outside contact. Since lockdown began, Alzheimer's Society volunteers have now made more than 90,000 companion calls to people with dementia to try and ease the isolation that lockdown can bring. A further 11,000 welfare calls have also been made by our dementia advisers to those with more specific needs.

Alzheimer's Society was founded in 1979 by a small group of current and former carers of people

living with dementia. Since then, current and former carers have been integral to everything we do. But charity alone cannot meet the needs of carers of people with dementia.

Supporting and caring for someone living with dementia can be positive and rewarding, but it can also be very challenging. Currently, there are around 700,000 informal carers of people with dementia in the UK¹. Research also shows informal carers of people with dementia, who provide care in the community, are saving the NHS an estimated £11 billion per year². Carers of people living with dementia are often older people, have their own mental or physical health issues, and shoulder significant costs of providing that care out of their own pocket.

Carers do a superb job. And often they are keen to continue to provide that support. As a society we have recognised that the state has a role to play in providing extra support to them to ensure

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ⁱ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/analysisofdeathregistrationsnotinvolvingcoronaviruscovid19englandandwales28december2019to1may2020/technicalannex#main-points>

ⁱⁱ IBID

they can continue to fulfil those roles, or ensure there are appropriate safeguards in place if they are no longer able.

But we mustn't take carers for granted. Supportive words are welcome, but these must be backed by action and appropriate funding to sustain that action.

The Care Act 2014, and the Social Services and Well-Being Act in Wales, sets a strong foundation for support for carers, but to date this has not been fully implemented due to a lack of funding from central government, with innovation at a local level further hampered because of poor and inconsistent data collection.

The Acts also set minimum standards that must be met. We must remember that these standards are

the floor, not the ceiling. Across the pages of this report you will read the voices and experiences of real carers and real people living with dementia. You will also read about some of the innovative work that is being led by local authorities, a sector that is often unfairly maligned and misunderstood.

As far as possible, we have sought to be positive and constructive in this report. We have set out a series of recommendations which we think will lead to better outcomes for people affected by dementia, but are also achievable within limited budgets.

To have picked up this report you clearly share a passion with me to ensure that people affected by dementia are able to live as well as possible with the condition; for that, I thank you. We can only do this together.



Kate Lee

Kate Lee
Chief Executive
Alzheimer's Society
#UnitedAgainstDementia



Acknowledgements

This report could not have been written without the contributions of carers and people living with dementia, and the professionals who dedicate their time to providing support to these people. We are extremely grateful to the time they have all given in contributing to this work, and particularly to those people from Salisbury, Halifax, and Colwyn Bay whose resilience is truly inspirational.

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Ethics and data protection

Contact with directors and senior leaders in adults services was preceded by approval from the research committee of the Association of Directors of Adults' Social Services. Further additional guidance and peer review was attained from Innovations in Dementia, who helped to shape the process and materials for the workshops with carers and people living with dementia. Informed prior consent was collected from all workshop attendees and as a conditional cover page for all online surveys.

All data was anonymised during the transcription / data processing stages, and no identifiable information is presented in this reporting. However, there is some identifiability at a regional level due to the varying nature of social care, and the information provided consensually by directors and senior leaders in local authorities.

Where local case studies are provided, interviewees gave permission for this during interviews.



Executive summary and summary of recommendations

Dementia is a complex and progressive condition which occurs when the brain is damaged by diseases (such as Alzheimer's disease) or a series of strokes. The symptoms of dementia can include memory loss and difficulties with thinking, problem-solving, language and physical function. The specific symptoms that someone experiences will depend on the parts of their brain that are damaged and the underlying cause of their dementia.

Across England and Wales, there are an estimated 820,000 people living with dementia, with this number set to increase to 1.4 million in 2040³. While those in the early stages of the condition can often live well with limited support, as the disease progresses they may become increasingly reliant on formal (paid) care workers or informal (unpaid, e.g. family, friends) carers to support them to live well. This extra support might be needed at any stage of the dementia pathway, depending on individuals' ability to manage, but those with the most severe symptoms will be in particular need of significant extra care. Currently, approximately 85% of people in England and Wales who are living with dementia have moderate or severe dementia.

Caring for someone living with dementia can be both rewarding and challenging. Carers might experience a range of difficult emotions and may have to make significant decisions on behalf of the person they care for and their own mental and physical health can also be affected. Carers can also find providing care very rewarding but need effective support to enable them to continue caring. The different types of dementia affect people in different ways and at different ages. This, in turn, means the experience of carers of people with dementia can be equally varied.

Carers may not always recognise themselves as such, wish to be associated with the role, or recognise the associated language as applying to them. We must be sensitive and adapt our approach and language appropriately.

This report reviews the support available to informal carers of people with dementia, with specific attention being given to carers' assessments (or "check ins"³) and the provision of short breaks for carers⁴.

The legislative framework for the provision of this support is broadly fit for purpose and so this report has focussed on the role that local government can play as it seeks continuous improvement. However, to successfully deliver services, local government is reliant on sufficient funding and quality data, which national government must deliver.

The support available for carers

The complex nature of both dementia and the health and social care system creates a context whereby carers are often expected to be proactive in seeking an assessment of their needs and subsequent support. The post-diagnostic support pathway can be challenging to navigate and often the onus is on people with dementia and carers to identify appropriate support services. This is particularly challenging given the responsibilities carers face and the pressures they are under. The need for carers to identify themselves and actively seek support is a barrier to local areas fully supporting their carer populations. In addition, post-diagnostic support is often provided by a diverse range of service providers with different levels of funding; for example, some will be voluntary organisations and others will be statutory health or social services.

³ Many carers have told us that the term 'assessments' has negative connotations, suggesting the quality of the support they provide is that which is being assessed. While legislation refers to "carers' assessments" we recommend councils work with carers to identify the most appropriate wording. We have included a suggestion here.

⁴ We have chosen to use the description 'short breaks for carers' instead of 'respite care' or 'replacement care' as we recognise there are negative connotations with the latter two descriptions which may imply the person living with dementia is a burden or that their carer – who may be a loved one – is replaceable.

In the case of caring for someone living with dementia, there are added complexities which may make it harder to identify carers and provide support. People with dementia can have a range of co-morbidities and with healthcare systems typically organised around single conditions, people who have multiple conditions often receive uncoordinated care. For example, shortages of appropriate types of breaks for carers mean that people with care and support needs are left to reject unsuitable support, carers may feel guilty about leaving the person they care for, and it is challenging to find suitable arrangements which can be booked in advance.

Methodology

Evidence for this research was collected from a range of sources, including via desk-based research, a survey of Directors of Adult Social Care, a request to local authorities for data, interviews with senior leaders and commissioners in adult social care, a survey of professionals, a survey of carers, and workshops held in England and Wales with people living with dementia and carers.

A more detailed methodological note can be found in the appendices of the report.

Our findings

There is a reported lack of available services that enable carers of people living with dementia to take a break from caring. Positive support is reported by some (such as that provided by local charities, and the use of community resources); however both professionals and carers report difficulty in finding care provision which suits the needs of people living with dementia, and this in turn prevents carers from arranging breaks for themselves.

The experience of carer assessments reported by carers is mixed; however this research confirms findings in the wider literature that only a minority of carers have received an assessment of their needs. Furthermore, these assessments were not always experienced positively, with negative experiences being linked to assessments that were conducted over the telephone and/or did not seem personalised to the individual circumstances of the carer.

The nature of providing short breaks for carers is challenging from a legislative perspective and at a practice level, particularly where support may be delivered to a person living with dementia but is intended primarily for the benefit of the person caring for them. Some evidence highlighted situations where this was the case, as well as situations where the person with dementia may have different wishes to the person caring for them in terms of replacement care.

Limitations in national data for carers

National data on carers and specific conditions are limited and cannot be disaggregated to provide a clear view of publicly funded support for carers of people living with dementia. Furthermore, national data sets do not contain good quality information related to short breaks for carers.

Limitations on national data reporting requirements appear to cascade down to a local level. Most local authorities who engaged with this research were unable to provide numbers related to support for carers of people living with dementia. Those councils which had more detailed information indicated that this was due to reporting arrangements with third party providers of carer support services and / or dementia support services for purposes of contract monitoring.



‘People with dementia can have a range of co-morbidities and with healthcare systems typically organised around single conditions, people who have multiple conditions often received uncoordinated care.’



Recommendations

Carers of people with dementia do a vital job, often in very trying circumstances. The care they provide can be difficult and can take both a physical and emotional toll. While carers are often hugely dedicated and deliver their care with love, sensitivity and warmth, they are not just the sum of their caring responsibilities. Carers are people in their own right, with their own physical and emotional needs, with their own ambitions and talents, and with their own obligations. It is important to ensure that carers supporting someone living with dementia can also continue to live their own lives as fully as possible, as set out in the ambitions of the Care Act 2014. The Act has huge potential to support all carers, in particular with assessing carers' needs – via

carers' assessments – and providing them with information, advice and support. However, this can only happen with appropriate levels of funding from the Westminster and Welsh governments.

The solutions to providing quality support to carers can vary, however based on the evidence we have collected, the people and organisations we have spoken to, and the best practice we have looked at, we have arrived at a set of recommendations which we have described below. We have grouped these recommendations under five main themes which, if appropriately considered, can have a significant and positive impact on the support for carers and, ultimately, the people with dementia they care for.

Policies and planning

Achieving continued positive outcomes for people affected by dementia requires systemic change and firm, public commitments and targets to affecting that change.

1. Councils should ensure their Health and Wellbeing Strategies recognise carers as a specific group to receive targeted advice and support to maintain their own health, particularly in relation to smoking, diet and mental health.
2. Councils, working alongside their NHS partners, should offer psychological support to carers (e.g. START – see case study).
3. Councils should ensure all staff delivering short breaks for carers or carers' assessments are trained to at least Tier 2 of the NHS-backed Dementia Training Standards Framework (Known in Wales as the Goodwork Framework).
4. Councils should ensure that their case recording systems provide for 'dementia' to be used as a searchable category, while also recording the different types of dementia.
5. Councils must proactively offer carers assessments to people when they are identified as carers, rather than wait for a request for an assessment.
6. Councils should ensure newly-identified carers are contacted to recognise them as such within 4 weeks. That communication should include information on how to access a carer's assessment. If a carer's assessment is not taken up, the person with caring responsibilities should be reminded of the offer at least annually.
7. Recognising the progressive nature of dementia, and therefore the progressive nature of caring responsibilities, councils should ensure that carers' assessments of carers of people living with dementia are provided at least annually, with the opportunity for more regular reviews if appropriate to circumstances. These assessments should also consider emergency planning if the carer were to unexpectedly no longer provide care (for example, through illness).
8. Councils should ensure records for carers are collected individually, with a link to the records of the person they care for.
9. Councils should ensure that carers strategies set out clear and ambitious targets and plans for increasing the identification of carers.
10. Current and former carers, as well as people living with dementia, should be actively consulted or included at key stages of the commissioning cycle, including the service design and service evaluation stages.

In partnership

There are many effective support services available for people affected by dementia, however we know that there are some rarer forms of dementia, or smaller population groups affected, who might require specialist support. To ensure these people are effectively served, neighbouring authorities or clinical commissioning groups should explore how they can work together, taking account of current and projected future needs.

- 11.** Working with neighbouring authorities or commissioning groups and the NHS, councils should ensure particular language, communication or cultural needs are met. This should take account of projected future population trends and needs.
- 12.** Working with neighbouring authorities or commissioning groups and the NHS, councils should ensure sufficient support for younger carers or those with young-onset dementia. This should take account of projected future population trends and needs.
- 13.** Working with local services, charities and businesses, councils should develop a local offer for carers outlining their statutory entitlements as carers, as well as any additional local provision (e.g. discounts). (See Local Offer for Care Leavers guidance).

Organisational culture

People who work in health and social care enter the profession because they are compassionate, caring people. This compassion should be complemented by rules and regulations, not hampered by them. However, much of the way carers of people living with dementia experience the support they receive cannot be defined in policies or legislation and is down to the culture in which professionals operate.

- 14.** Councils should ensure that carers' assessments take a strengths-based approach, focussing on the positive aspects of carers' practice, while also acknowledging the areas in which they might need extra support or advice. These assessments should recognise the specific needs of those caring for people living with dementia.
- 15.** Councils should ensure that those undertaking carers' assessments are skilled in active listening techniques.
- 16.** Councils and providers, including the NHS, should regularly review their use of language in policy and practice. The choice of language can have powerful implications for carers, particularly in relation to feelings of guilt they might have. For example, rather than talking about 'if' you need a short break from your caring responsibilities, instead talk about 'when'; or rather than talking about "carers' assessments" refer to them as "check ins".

Practical

Carers of people with dementia can spend upwards of 36 hours a week providing care, with this time likely to increase as the condition progresses. Health and social care services should make it as easy as possible for carers of people living with dementia to access the support they need.

- 17.** Councils should ensure that carers' assessments are provided in person. Where a telephone assessment is unavoidable, or preferred by the carer, a follow up face-to-face meeting should always be offered.
- 18.** Councils should encourage and promote peer support groups for carers of people living with dementia to help them build social connections and mitigate feelings of captivity, whilst also providing an opportunity to share knowledge, experiences and expertise. Such groups could operate virtually or in more informal settings, such as coffee shops or libraries.
- 19.** Councils should provide a straightforward method of booking overnight care in advance, to allow carers to be able to manage when they can have a break from their caring responsibilities.

National government

While this report has primarily focussed on the part that local authorities and local partners can play, national governments also have a crucial role in enabling these changes. While a consistent approach to service delivery may not be appropriate due to differing needs in local areas, a consistent approach is required across the countries to enable local authorities to usefully measure and compare performance.

- 20.** National governments in England and Wales should require public health bodies to collect local authority and health authority-level data on:
 - a.** Number of carers assessments offered and number taken up, with the reason for their caring responsibility (e.g. the condition(s) of the person they care for) also recorded.
 - b.** The number of short breaks for carers provided recorded, including the type of break. Parallel codes should be used for financial spend and the volume of support provided to enable comparisons of unit prices for support.



1

Introduction

The presentation of dementia is varied and the needs of people experiencing dementia can vary dramatically. This could include physical needs and disability, risks to personal safety, as well as detrimental psychological effects. Accordingly, there is no one-size-fits-all approach to supporting people living with dementia.

Carers are a crucial component of the support systems for people living with dementia. The Carers Trust estimate⁴ that there are seven million carers in the UK, with approximately 770,000 of those caring for someone living with dementia.

National legislation, the *Care Act (England) 2014* and the *Social Services and Wellbeing (Wales) Act 2014*, determine how adult social services in England and Wales⁵ respectively offer support to people with care and support needs, and the carers who provide unpaid care for them. Whilst the eligibility criteria in Wales and the eligibility criteria covering England is the same for authorities working across each of the respective nations, there is variation across both nations in the support available locally. This is in part because local authorities have a duty to consider a person's needs and wellbeing. This is in part because local authorities have a duty to consider a person's needs and wellbeing. Under the Act a person's wellbeing is a broad concept and one in which people are viewed as best placed to judge themselves. This can lead to a degree of local flexibility in the support and services delivered which is intended to enable local authorities to work in a flexible way to meet people's individual needs. These local variations have, anecdotally, been reported by some as a 'postcode lottery', where care and support from local government services is not always consistent^{5,6}.

As well as providing guidance and requirements for local authorities on support for people with needs, the *Care Act 2014* and the *Social Services and Wellbeing (Wales) Act 2014* also set out the way that local authorities must engage with carers. This includes the rights of carers to receive an assessment of their needs, as well as information and support to enable them to continue caring and leading their own lives. In addition to the two Acts, the National Institute for Health and Care Excellence (NICE) have also produced guidelines to inform work in identifying, assessing and supporting carers (National Institute of Health and Care Excellence, 2020). Though not dementia specific, these guidelines make recommendations to local services and

commissioners relevant to this report, including around the local provision of replacement care services and the responsibility of health and social care practitioners to “regularly discuss with carers the value of having a break from their caring role” (NG150; 1.5.2).

This piece of research, conducted by Research in Practice and commissioned by Alzheimer's Society, aims to explore this support for carers in further detail. It explores the individual stories of people living with the condition and their carers, as well as the way that local areas are offering them support. It also explores the national data related to social care for people living with dementia, and the wider literature. Key lines of enquiry for this research include:

- Understanding local practice in identifying carers and undertaking carer's assessments.
- The local offering and uptake for carer support, including respite (or 'replacement') care across local authorities.
- Dementia-specific frameworks and practice in local areas.
- Outcomes for carers of people living with dementia as a result of respite and other support.

770,000



The Carers Trust estimate⁴ that there are seven million carers in the UK, with approximately 770,000 of those caring for someone living with dementia.

⁵ Legislation in Scotland for carers (The Carers Act 2016) is distinct from the situation in England and Wales and is outside of the scope of this research

1.2 Definitions

Definition of 'carer'

'Carer' means an adult who provides or intends to provide care for another adult (an 'adult needing care'); but not under virtue of a contract or as voluntary work, unless the local authority considers them a carer.

- Care Act 2014 (10.3)
- Social Services and Well-being Act 2014 (3.1)

Definition of young-onset dementia

People with dementia whose symptoms started before they were 65 are often described as 'younger people with dementia' or as having young-onset dementia.

The age of 65 is used because it is the age at which people traditionally retired. However, this is an artificial cut-off point without any biological significance.

The symptoms of dementia are not determined by a person's age, but younger people often have different needs, and require some different support. Different types of dementia may also be more common in younger people than older people.

Definition of early-onset dementia

Early-onset dementia refers to the early stages of the condition, at whatever age and whether they have received a formal diagnosis or not. Those in the early stages of the condition can often live well with limited support.

Definition of 'meeting needs'

The *Care Act 2014* (8.1) and *Social Services and Wellbeing Act 2014* (34.2) state that any of the following may **"meet the needs"** of carers or adults with care and support needs, and might be arranged by the local authority, provided directly, or indirectly via direct payments:

- Accommodation in a care home or in premises of some other type;
- Care and support at home or in the community;
- Counselling and other types of social work;
- Goods and facilities;
- Information, advice and advocacy.

Definition of respite / replacement care

Respite (or 'replacement') care is defined as taking a break from caring, whilst the cared-for person is looked after through alternative arrangements. These arrangements can take a variety of forms, varying by length of respite and type of provision. Any of the following may be considered respite care:

■ Day support services in the home environment:

- Sitting services
- Befriending services
- Paid carers
- Support from friends and family

■ Day support services in a secondary environment:

- Day centres
- Voluntary and community services
- Day breaks in a care home

■ Overnight support at home:

- Live-in carers
- Domiciliary care

■ Overnight support in a secondary environment:

- Short-term stays in a care home
- Shared living arrangements (i.e. Shared Lives)

■ Changes in caring context:

- Taking a holiday

It is important to note that the terms 'respite' or 'replacement' care may not be how carers and people with care and support needs refer to these arrangements. For the purpose of this research, caution was taken over how these arrangements were termed, and were often referred to as **'taking a break from caring responsibilities'**.

1.2 Statutory responsibilities of local authorities

Where it appears that there is a possibility a carer may need support, the *Care Act 2014* and the *Social Services and Wellbeing Act 2014* stipulate that local authorities must undertake an assessment of carers' needs, wants, and their ability and willingness to provide care now and in the future.

Although there are nuanced differences between legal requirements for local authorities in England and Wales, the legislative wordings are broadly similar on many key points (**Table 1**).

Table 1: Mapping of Acts: England and Wales

| Requirement | Care Act 2014 (England) section | Social Services and Well-being Act 2014 (Wales) section |
|---|---------------------------------|---|
| Carers should receive an assessment of their needs and wants where the local authority has reason to believe they are in need of support. | 10 (1) | 24 (1) |
| Assessments should occur regardless of financial situation of the person being cared for and person providing care. | 10 (4) | 24 (3) |
| Assessments should consider the carers capacity and willingness to provide care now and in the future. | 10 (5) | 24 (4) |
| Assessments should consider what carers want from their own lives. | 10 (5) | 24 (4) |
| Assessments should consider whether the carer is working and wishes to work in the future. | 10 (6) | 24 (5) |
| Assessments should look for appropriateness of provision of support from local authority, services, and the local community. | 10 (8) | 24 (5) |
| Regardless of a financial assessment, local authorities may provide support to carers free of charge at their own discretion. | 20 (9) | 35 (4) 66 (1) |
| Local authorities must identify whether eligible support to a carer should be charged to the carer or the adult with support needs based on the provision. Financial assessments of this support should be related to the person charge is levied on. i.e. Support for a carer, charged to the person with support needs, should relate to a financial assessment of the adult with support needs. | 17 (3) 17 (4) | 60 (5) 69 (1) |
| Where the local authority is not required to provide support, it must provide reasons for this and advice and information to support the carer. | 24 (2) | 32 (1) |
| If a local authority is unable to meet the needs of a carer through the provision of care and support, but it is required to do so, it must identify some alternative arrangement. | 20 (8) | 44 (3) |

1.3 Local, regional, and national variation

Both Acts provide some flexibility for local areas in terms of the exact ways in which they conduct assessments of care and support needs, assess financial circumstances, and how they meet any identified care and support needs (Care Act 2014, 125(1)).

The *Social Services & Wellbeing Act 2014 (Wales)* suggests that local authorities may make their own definitions of what circumstances they might carry out a needs assessment. For instance, in section 30:

‘[Regulations] may, for example, specify [...] the circumstances in which a local authority [...] may refuse to comply with a request for a review of an assessment, and [...] may not refuse to do so.’

And:

‘[Regulations may also specify] the way in which an assessment is to be carried out, by whom and when.’

Similar provisions are made in the *Care Act 2014 (England)* in section 12:

‘Regulations [on needs and carers assessments] may, in particular [...] specify steps that the local authority must take for the purpose of ensuring that the assessment is carried out in an appropriate and proportionate manner’

And:

‘[Regulations may] specify circumstances in which the local authority must, before carrying out the assessment or when doing so, consult a person who has expertise in a specified matter or is of such other description as is specified’

Both Acts make several further recommendations related to regulations which might guide the assessment of and support for carers; however neither Act references individual conditions (such as dementia).

In light of this flexibility in the wording of both Acts, it is understandable that carer identification, carer assessment practice, and the type and quality of provision for carers would develop distinctly across local authorities in England and Wales based on local practice.



About 40% of family carers of people with dementia have clinically significant depression or anxiety.



1.4 Literature review

1.4.1 The key numbers

It's estimated that unpaid care accounts for 45% of the total economic cost of dementia in the UK, and valued this at £15.7 billion. In 2014 it was estimated that approximately 700,000 people were providing informal or unpaid care for 850,000 people living with dementia in the UK⁸; and further estimates echo this approximation⁹.

In a recent report, Carers UK (2019) called on the next government to make caring a new 'protected characteristic' under the Equality Act 2010, and to increase provision to this significant population. The report cites evidence that by the time they reach age 46, women have a 50:50 chance of having been a carer; and that men have the same 50:50 chance by age 57¹⁰.

MODEM, a longitudinal study of 300 pairs of carers and people living with dementia over a one-year period, is looking at the needs of people living with dementia and their carers, with a view to predicting future need in the context of a rising care population¹¹. The team estimated that there are 690,000 people living with dementia in England, with total care costs of £24.2 billion, with 42% of this (£10.1) billion attributable to unpaid care. Furthermore, of the total social care costs (£10.2 billion), 60% of these (£6.2 billion) are met

by people living with dementia and their carers¹². In the cohort, the estimated average number of unpaid care hours provided was between 71 and 105 hours per week (depending on the method used to calculate).

IDEAL is a longitudinal study of living well with dementia, led by the Centre for Research in Ageing and Cognitive Health at the University of Exeter and funded by Alzheimer's Society. The study's large population size (beginning with 1547 people in 2014) offered additional valuable insight into the nature of unpaid care for people living with dementia, such as that carers are taking on approximately 75% of the associated costs, that their average caring time is 36 hours a week, and that carers experience high levels of loneliness¹³.

About 40% of family carers of people with dementia have clinically significant depression or anxiety¹⁴. A carer's psychological health can predict a breakdown in care and therefore the need for the person with dementia to move into a care home, thus improving carers' psychological health and ensuring they receive adequate support may delay the need for placement in a care home.

£15.7 billion

A pink outline icon of a person standing, with a pink circle containing a pound symbol (£) positioned next to their lower right leg.

It's estimated that unpaid care accounts for 45% of the total economic cost of dementia in the UK, and valued this at £15.7 billion.

850k+

A pink outline icon of a person standing.

In 2014 it was estimated that approximately 700,000 people were providing informal or unpaid care for 850,000 people living with dementia in the UK.

1.4.2 The impact of caring

The IDEAL project also highlighted some key challenges faced by carers of people living with dementia, particularly in terms of wellbeing and resilience¹⁵, and drew a link between carers' coping mechanisms and resilience, and the quality of life for carers and people they cared for.^{16,17}

Caring for someone living with dementia can be extremely difficult, and carers may experience varying levels of stress, effects on wellbeing, and grief. Chan and colleagues¹⁸ demonstrated that grief is a central part of caring for someone living with dementia, but that the impact varied and could also include anticipatory grief as the disease progressed, coupled with other complex emotions such as guilt and anger related to the condition and person living with it. Further studies¹⁹ also highlight the importance of protective factors such as resilience in the wellbeing of carers, and suggest that interventions which aim to develop these factors would provide valuable support for carers.

The IDEAL study found that carers who felt there was little the person with dementia could do to control the effects of the condition reported higher levels of stress and lower wellbeing. Conversely, the belief that there were things the person with dementia could do to manage their condition was linked to improved wellbeing.²⁰



Caring for someone living with dementia can be extremely difficult, and carers may experience varying levels of stress, effects on wellbeing, and grief.

In addition to this, the IDEAL study found that when carers are not confident in their caring role, it has a negative impact on their well-being.²¹ Existing research also shows that identifying positive aspects of caregiving can have a positive influence on the caregiving experience.²² This suggests providing interventions that improve carers' confidence in their role and help them identify positive aspects of their role could also improve the wellbeing of carers and those they care for.

The IDEAL study found it may be helpful to focus on enabling carers to cultivate positive emotions, rather than trying to decrease the sense of burden, which is more difficult to change. These emotions may include:

- satisfaction with the role
- emotional rewards
- personal growth
- competence and mastery and relationship gains with the person they care for.²³

Quinn et al.²⁴ notes research highlighting interventions focused on reducing caregiving burden have insignificant effects. The research indicates interventions that target modifiable factors, such as caregivers' beliefs about competency or their appraisals of positive aspects of caregiving, may be more feasible.²⁵ Quinn also highlights that a focus on positive aspects of caregiving would enable a 'strengths perspective' or capabilities approach and that interventions focused on problem-solving can help improve feelings of caregiving competence.²⁶

Thus, providing carers with a greater understanding of dementia and strategies to manage the effects of dementia, and helping carers to feel more confident in their role and identify positive aspects of their role, can all help improve carers wellbeing. A carers' assessment may be an appropriate means to reinforce positive messages and recognise a carers positive contributions. Quinn et al. notes research which shows that understanding the role of positive aspects of care may help healthcare professionals validate caregivers' feelings and experiences.²⁷



The significant psychological symptoms family carers of people with dementia experience have been found to be more common among carers who are older, female, live with the recipient of care. They report greater carer burdens and care for a person with a greater amount of neuropsychiatric symptoms.

However, the psychological symptoms are unrelated to the severity of dementia.²⁸ Other studies have found carers of people with fronto-temporal dementia and Lewy body dementia experience greater care giving burden than carers for people with Alzheimer's disease.²⁹ Moreover, South Asian groups, who often feel more culturally obliged to provide care but are not necessarily as willing to provide emotional and nursing care compared to White British carers, have been shown to have lower levels of confidence in their role and perceive higher levels of burden and depression in themselves.³⁰

The form of support carers require also differs. Alzheimer's Society research has found that Black, Asian and Minority Ethnic (BAME) groups and those with English as an additional language were more likely to use BAME led groups or services and found the need for interventions to be more culturally sensitive, including the use of interpreters.³¹ In the same way that dementia – and its different forms – affect people in different ways, carers of people living with the condition face unique challenges and have differing needs.

Effectively supporting carers is both important to the carer themselves and the local authority. Wellbeing support forms a fundamental part of the way a local authority can enable carers to continue providing care for someone with dementia.

The IDEAL study found that a carer's psychological health is most strongly linked to their ability to live well.³² Research suggests 40% of carers of people with dementia have clinically significant depression or anxiety. This has been shown to be unrelated to the severity of dementia³³, which suggests that if carers have the right support with their mental health, it could improve their wellbeing and enable them to better cope with their caring responsibilities as the condition progresses. A carer's psychological health can predict a breakdown in care and therefore the need for the person with dementia to move into a care home, thus improving carers' psychological health and ensuring they receive adequate support may delay the need for placement in a care home³⁴.

Although there is some emerging evidence surrounding new approaches to strengthening carer support (such as online and remote support^{35, 36, 37}), these approaches need to be balanced with what carers say they want, and their specific needs and desires around taking a break from caring responsibilities to focus on their own lives and wellbeing.



Active listening

Active listening is a technique to ensure that we hear what people are really saying. It's important that carers are listened to – actively – before solutions or support is offered or discussed.

Feeling as though you have been listened to and understood – even if the other person hasn't agreed with you – can have a powerful impact on the speaker's personal wellbeing. Equally, it can ensure messages conveyed are accurately understood and helps draw out key details.

While training programmes on active listening are available, often it can be successfully applied by utilising greater self-awareness.

Set out below are some of the key principles of active listening:

A Actively listen. Make eye contact, keep an open posture, and don't be distracted by electronic devices or whatever else might be happening around you. Focus on the person who is talking to you. Often while another person is speaking we spend that time thinking about what we would say in response or what points we want to get across; don't do this. Focus on what the person is saying to you.

R Respond and repeat. Acknowledge what the person is saying to you and repeat it back to them in your own words – without judgement – to check your understanding. Allow the speaker time to finish what they are saying before you do respond. Repeat key words back to them and seek to identify any feelings behind the facts presented.

E Be empathic. You don't need to agree with what the person is saying, but try and understand how they are experiencing things. They may be really struggling with something that you might consider to be straightforward, but their struggle is real and is having a negative impact on them. Recognise how they might be experiencing difficulties or successes.

1.4.3 Carer entitlements

The case for supporting carers is clear; however in reality this support may not be realised as much as it should or could be. In a 2019 conference summarising the Caregiving HOPE study results¹⁰, it was highlighted that there is no nationally representative, longitudinal dataset where people living with dementia and their carers can be identified and are followed up regularly. This was also identified by carers in one of the workshops conducted in this research (see page 50).

Some literature suggests that less than one third of carers receive the assessments they are entitled to under the Care Act³⁸. Evidence also suggests that local authority support for carers may be reducing in real terms. A recent analysis of NHS Digital data by the King's Fund (including from the Adult Social Care Financial Return) highlighted reductions in gross expenditure on support for carers and the number of carers assessed and/or supported^{39, 40}; although provision of 'information and advice' may be increasing. These findings should be treated with some caution due to the nature of the data used, as discussed further in the analysis of national data in this report, (see page 25).

One of the challenges faced by those seeking to support carers, and to carers themselves, may be the complexity of being in a caring role and the nature of how this develops. In their report 'Missing out: the identification challenge', Carers UK noted that over half of carers took a year or longer to recognise that they were in a caring role⁴¹. Further research by Carers UK has highlighted that, of those surveyed in their State of Caring 2019 review, only 15% had received or paid for a break from caring, and 11% had used a day centre⁴².

As noted above, there may also be variance geographically in how well carers are identified and supported. A report by the Carers Trust⁴³ cites evidence from 148 GP practices, highlighting the high level of regional variance in the identification of

carers by GPs. However, there is also evidence of local areas seeking to overcome barriers to the identification of carers who may require support, including a service of volunteers based in GP practices across Bristol and South Gloucestershire⁴⁴.

Another important factor to note is that of 'hidden' groups within the wider dementia and carer populations. Most people in the MODEM study cohort and IDEAL cohort were White British, and generally the evidence related to carers and people living with dementia is similar, posing questions as to how well evidence truly represents the national population, and whether there are gaps in understanding hidden needs. Similarly, in the Carers UK State of Caring 2019 report, only 5% described their ethnicity as black or minority ethnic (England and Wales 2011 Census data indicated that 19.5% of the population were from ethnic minorities). The 'Caregiving HOPE' study⁴⁵ from the University of Bradford explored concepts such as willingness to care and feelings of obligation in South Asian (Pakistani, Indian and Bangladeshi) families. The study identified that many people felt a cultural obligation to provide care, and that this was often coupled with different views of dementia and ways to provide care. There were also indications that cultural differences could impact on the mental wellbeing of South Asian carers.

As noted by Livingstone et al.⁴⁶, whilst UK policy recognises that psychological therapy for carers of family members with dementia should be a key component of high quality dementia care, resources for implementation are not available, partly as effective therapies have only been delivered by highly trained clinical psychologists, with little evidence on cost-effectiveness.⁴⁷ However, evidence-based interventions exist that have been shown to improve carers' psychological health and be cost-effective. One example is StrAtegies for RelaTives (START), developed by University College London, which consists of one to one support to help carers develop coping strategies to manage behavioural symptoms. This intervention has demonstrated impact with users, helping to reduce depression and anxiety among carers. It is also cost-effective⁴⁸ and the positive impact has been found among carers six years after the intervention was initially

completed.⁴⁹ Carers assessments provide an opportunity to signpost carers to START. Done well, assessments can also have a positive psychological benefit in themselves by providing the carer with the opportunity to feel listened to and understood. The assessment can provide carers with opportunities to develop, or maintain, social connections, through, for example, group activities and team sports. The assessment can also provide a carer with respite from caring responsibilities, which can be used to spend time with the person they care for and with family and friends, outside of the caring environment.

1.4.5 Summary of literature

The literature related to support for carers of people living with dementia is relatively limited. Though many of the themes emerging from wider literature on carers in general will be applicable for this group, there are additional complexities related to supporting carers who support someone living with dementia (such as the feelings of grief and guilt highlighted above) which present further challenges to services with responsibilities to support carers.

Against the backdrop of local variance in services, gaps in provision, and the challenges faced in identifying carers of people living with dementia, there is a high likelihood of carers falling through the gap. Indeed, the evidence from wider literature suggests that this may be the case. Furthermore, the complex nature of caring for someone, and current systems for supporting carers may create a situation where carers need to be proactive in seeking support from local authorities, rather than services seeking out carers and offering them a range of support. This is not to say that local authorities aren't working to address these barriers (see the results section below); however this is particularly concerning as a system 'default' when considering that, post-diagnosis, carers will be under a great deal of pressure and stress in managing their own lives and providing care, and may not be able to seek support for themselves.

This research seeks to strengthen the literature specific to people living with dementia and their carers, exploring the national and local context in services, as well as hearing from people with lived experience.

2

Results

This chapter reviews and analyses a range of qualitative and quantitative data that has been collected over the course of this inquiry. This data should not be considered in isolation, but alongside all other findings and evidence detailed in this report.



Methodological note

National data sets, the Adult Social Care Financial Return (ASC-FR), Adult Social Care Outcomes Framework (ASCOF) and Short and Long Term collection (SALT), provide top-level local authority data related to annual social care provision and spending.

Although these data returns provide some detail as to how local authorities are meeting their care and support responsibilities, the ability to draw conclusions related to specific care populations (such as people living with dementia and their carers) is limited.

A scoping exercise as part of this research has explored the variables in these datasets, and highlighted those fields which might relate to carers of people living with dementia. The key tables identified are listed below, and details can be found in the appendices (Data mapping – national data).

- Gross Current Expenditure on other (not long or short term) social care, by primary support reason
- Support provided to carers during the year, by type of support provided
- Support provided to carers during the year, by type of support provided and age band
- Summary figures regarding Adult Social Care activity and finance
- Gross Current Expenditure on long and short term care combined, by age band and primary support reason
- Support provided to carers during the year, by age band
- The proportion of carers who receive direct payments

2.1 National data

Public Health England's Dementia Intelligence Network (DIN) took a huge step forward in collating and presenting dementia-related data in 2016 when it introduced a new 'dementia profile' on its Fingertips tool. This tool has proved invaluable, however there remains limitations in national data as it relates to dementia, particularly in regard to carers of people with dementia. These limitations mean opportunities to measure impact, value for money and performance are equally constrained. Where data does exist, there are significant variations across the country which gives the indication that coding of spend or provision is inconsistent.

It is clear from the analysis of guidance documents (see appendix: Data mapping – national data) that no sub-categories allow for exploration of spending on individual conditions or groups of carers. Furthermore, the guidance for completion of these returns is not entirely prescriptive, and different areas may not complete the returns uniformly.

Combined, this means that the generally available data does not provide a truly accurate picture of spending on carers, and certainly does not enable clear differentiation between carers of different conditions such as dementia.

Nonetheless, this research has gathered data for the identified fields for the past two financial years (2017-18 and 2018-19) from SALT, ASC-FR, and ASCOF, and further explored spending on carers across England.

The key points of these analyses are summarised below.

- Spending associated with carers can be identified in ASC-FR table 44 and the absolute number of units in table 45. However, spending is further split by type. As such, respite care could fall under different categories of spending. For instance:
 - Befriending or sitting services could be categorised as 'Support for social isolation/other'.

- Replacement care arrangements might be classified as direct/part direct payments to carers; however this will be different in the case of short-term stays in residential care (which is classified as support to the person with care needs, rather than the carer; again, this cannot be disaggregated in the SALT return).
- Any information or advice to carers (e.g. on how to arrange respite) will likely be classified as 'Information and Early Intervention).
- Any assessment of a carer and their need for support is classified as 'Social Care Activities'; which also captures a range of other expenditure not related to assessment.

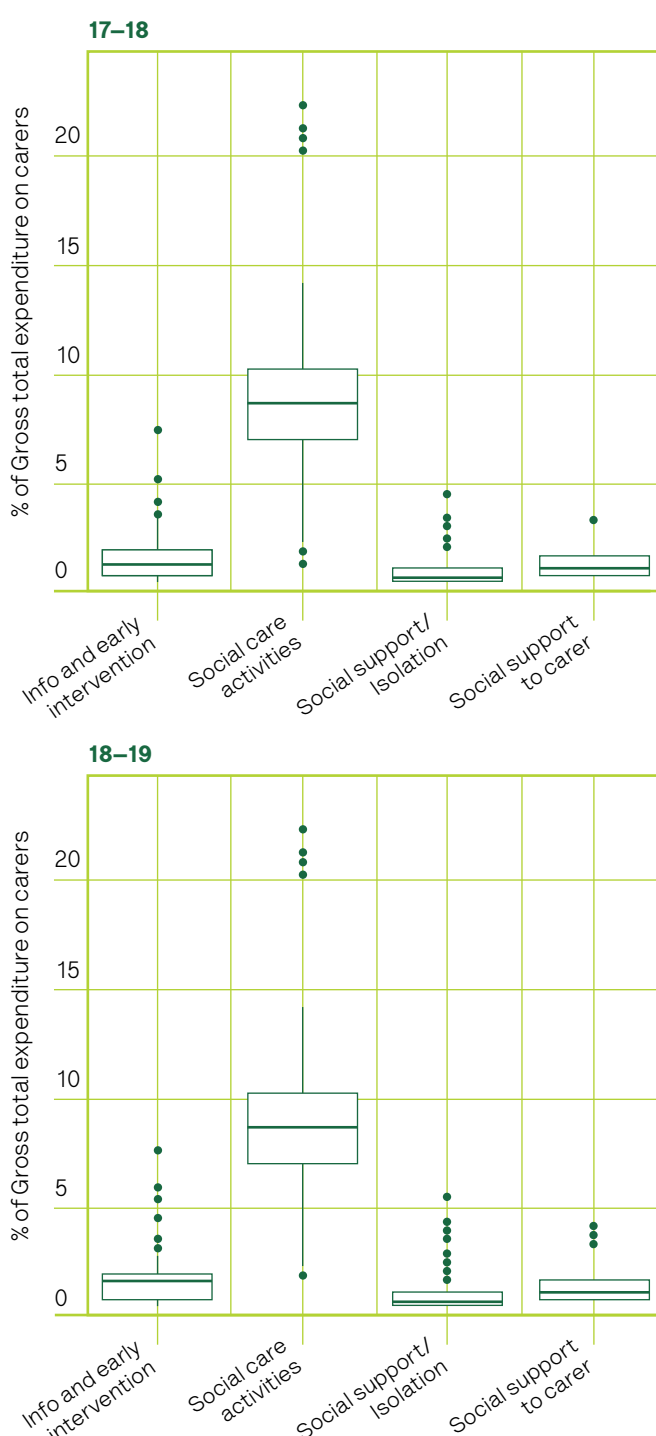
Figure 1 shows variance on spending on carers for English local authorities. This indicates the average spend as a proportion (%) of gross total expenditure for the authority (to help normalise for variance in the local population and demand). The figure indicates that spending is relatively stable over time, however that there is some degree of local variation, particularly in 'Social care activities', which make up between 2-25% of total spend. This variance in spending may partly be explained by differences in local recording practice, which cannot be seen in the data. Nonetheless, it may also suggest that local areas differ in the amount they are spending on carer assessments, which fall under this category.

In **Figure 2**, the boxplot shows variance in the quantity of provision, normalised by calculating as a proportion (%) of the total number of carers supported in the year. Note on the y-axis that in some areas the proportion is 100, which could be due to multiple support happening for individuals (e.g. multiple direct payments made). As such, totals could add up to greater than 100%.

ASC-FR categories limit the granularity of information available, and thus the conclusions that can be made regarding support for carers. For instance, support for carers involving respite care can be considered short-term care arrangement, support for isolation, and could be counted under a direct payment, part-direct payment, or within other categories.

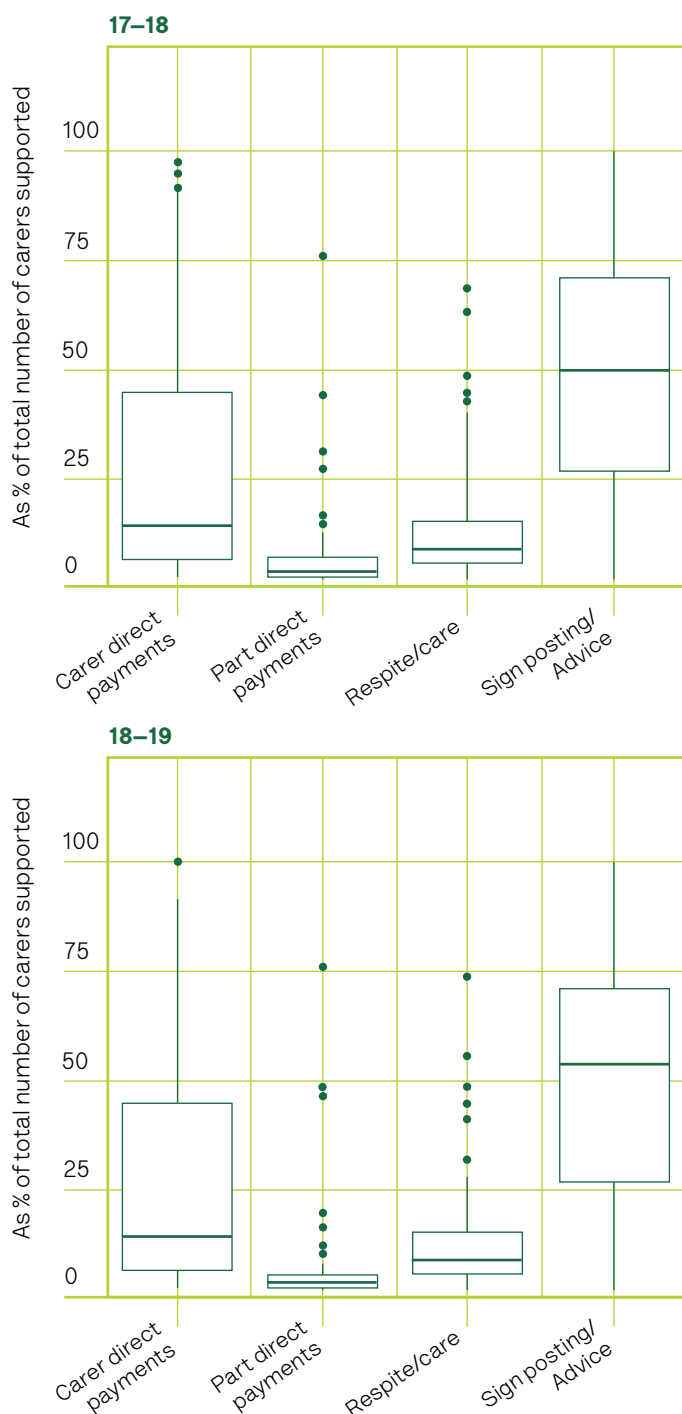
As such, it cannot be concluded with any level of confidence whether unit costs for respite care (i.e. £000s spent per unit of respite care) vary between individual areas. Furthermore, carer assessments are wrapped up within the umbrella of 'Social Care Activities', which can include a large volume of other work. So although the variance in spending as a proportion of budget shown above is clear, it is not clear whether this is representative of carer assessments on their own.

Figure 1: Variance in local spending on carers
All English LAs, 2017–2019



Data from ASC-FR 2017-18 and 2018-19 summary data: NHS Digital

Figure 2: Variance in local provisions to carers
All English LAs, 2017–2019



Data from ASC-FR 2017-18 and 2018-19 summary data: NHS Digital

One area which is slightly simpler to explore is 'Information and Early Intervention' for carers which has its own category in both overall spend and volume of support. However, there is also a large volume of anomalous values which might indicate imperfect data rather than extreme spending on this type of support (**Figure 3**).

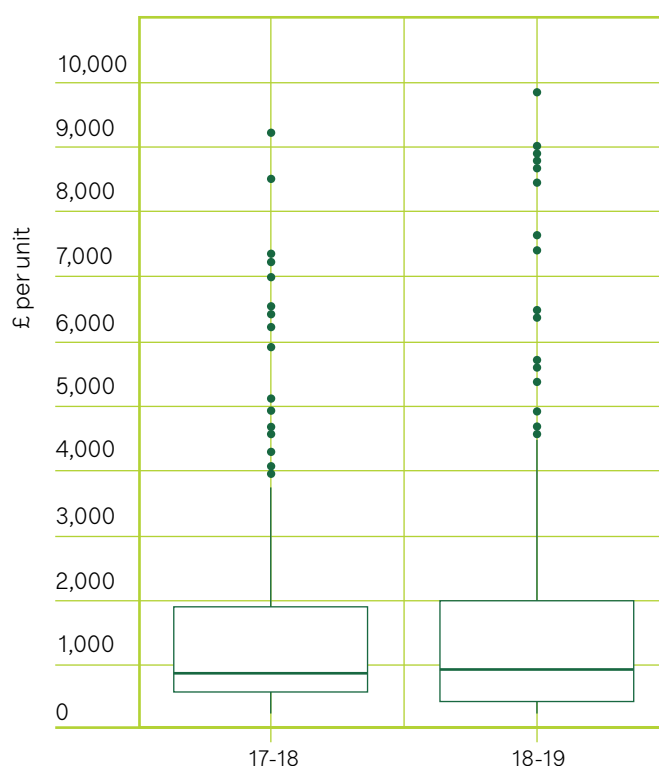
In summary, an analysis of publicly available, national datasets highlights the gaps in both

recording and reporting for support for carers and respite care in particular. Moreover, evidence of support and spending for particular conditions is also not possible within national reporting, since conditions are grouped within overarching categories and by primary condition (which does not clearly show when multiple needs are present).

At present, national reporting allows for some comparison of support for carers between local authorities at a very high level, and some further data analysis, as documented here, can further expand this. However, some large scale changes in reporting are necessary if local areas are to be compared in terms of specific forms of spending (such as on carer assessments) and provision, and to further understand spending and provision for particular conditions such as dementia.

In light of these limitations in national data, the next phase of data collection relates to requests for individual local data and further narrative from local authorities related to provision for carers of people living with dementia. This involved a survey of Directors of Adults' Services, followed by a request for additional specific data related to respite care for people living with dementia.

Figure 3: Estimated spend per unit of information support/advice
All English LAs, 2017–2019



Data from ASC-FR 2017-18 and 2018-19 summary data: NHS Digital

2.2 Survey of Directors

Those living with dementia, and those who care for them, are often balancing other medical conditions alongside their dementia. With limited medical interventions available for dementia, those affected by the condition are often those who derive the greatest benefit from greater integration of health and social care services. Directors of Adult Services noted that a strong local dementia strategy – whether alongside health and social care integration or not – can also set a firm framework for the provision of care and support for those affected by the condition. There are currently 820,000 living with dementia in England and Wales, which is set to increase to 1.4 million by 2040, meaning the necessity of a considered, strategic approach will only increase. We also heard concerns from Directors of Adult Services about the limited provision of support for those living with young-onset dementia and the need to recognise carers and those they care for as connected, but each having their own distinct needs.

Just over half (60%) of respondents reported that their LA had a local strategy related to carers of people living with dementia.



Methodological note

Survey invitations were sent to 154 directors and senior leaders via email. A total of 26 completed responses were received, representing **24 English local authorities and one CCG (also in England)**. Two responses were received from the same local authority; answers were consistent across both respondents and where figures have been reported below, only one of these responses is included. All respondents were strategic leads, predominantly in commissioning, along with partnership managers and directors.

Comments noted that the LAs had existing or forthcoming dementia (n = 12) and carers (n = 14) strategies. While no respondents reported joint strategies, where links were provided, many dementia strategies also considered the needs of carers and vice versa.

Respondents were asked what they would consider 'respite' care in their area (**Figure 4**), with results suggesting a variety of options can be considered as respite care, in line with definitions above; however there was some level of variance in this at a local level. Additional comments reinforced this, with 'carers break', 'replacement care', 'sitting service' and 'Direct Payments' all mentioned.

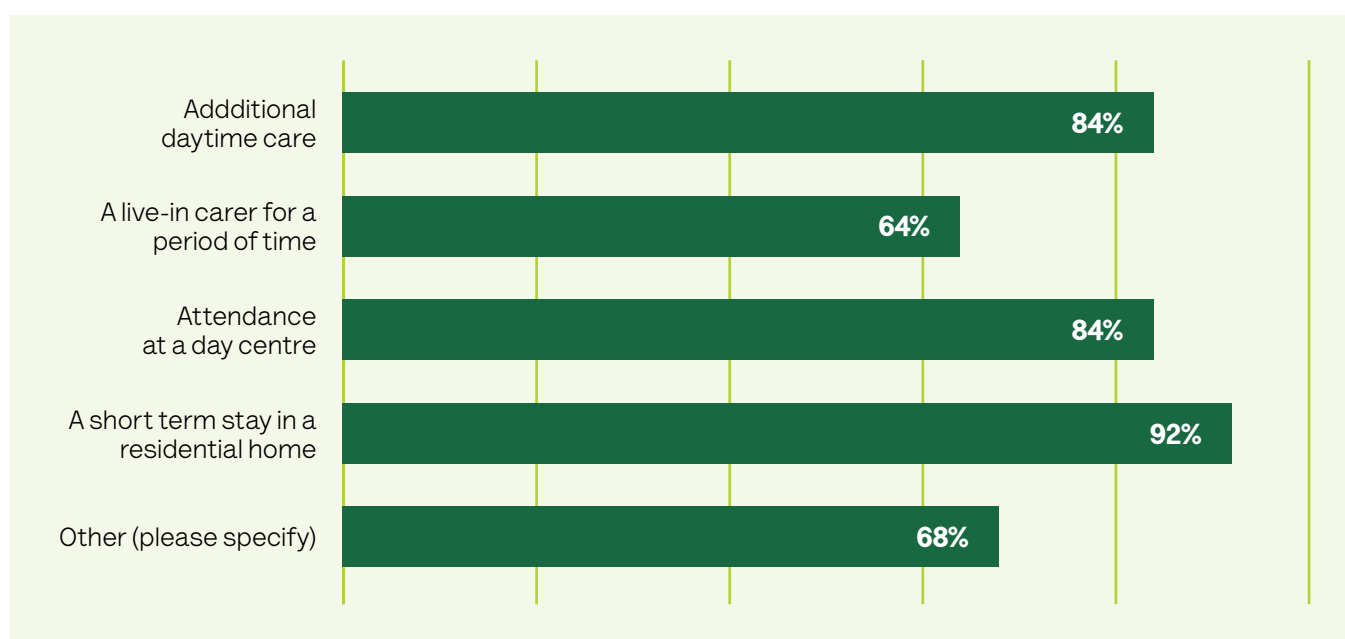
When asked for any other comments about local definitions of respite care, five people noted how their authority takes a **person-centred approach to care**, two mentioned extending **Shared Lives** provision to include dementia care, and three advised that they use the term 'breaks' ('short breaks' or 'carer's breaks') rather than 'respite'.

Most respondents reported having **local outcome targets related to carer assessments (67%) and carer wellbeing (58%)**; however only a third reported having targets related to the provision of respite care (33%).

Approximately a third (36%) of respondents reported targets / performance indicators specific to dementia and carers of people living with dementia. Where these indicators were listed, they included specific targets, such as 'number of carers receiving a service' and 'measures of improvements to wellbeing', as well as more general targets such as 'people know what support is available' and 'people are supported to live well and care for their loved ones'.

When asked about the approach taken for assessments of carers of people living with dementia, it was generally noted that there was **no specific approach**, with comments highlighting a person-centred (n = 4), needs-based (n = 3) approach to assessments, rather than focusing on conditions.

Figure 4: What do you consider 'respite' care in your area?



The majority of respondents stated that financial reporting included the proportion of budgetary spend on respite care for carers (64% 'yes', 12% 'not sure' and 24% 'no'), although it **typically did not include the specific proportion for carers of people living with dementia (12% saying 'yes' overall).**

When asked for examples of best practice, examples of respite services were given (n = 8), including 'provision of additional support at home', '2-3 weeks respite for carers' and 'dementia friendly features' in lodges used for carer's breaks. Five people also referenced a specialist carer's hub or service, while four described how peer-support/activity groups were valued in their areas.

Finally, respondents noted any specific challenges related to supporting carers of people living with dementia. Challenges around provision of appropriate respite placements were mentioned most frequently (n = 11), particularly in terms of securing places with private providers which were considered appropriate for people living with dementia. This included where carers or people living with dementia were not comfortable with the respite care on offer, the availability of appropriate sitting services, and the ability to pre-book breaks in advance to enable carers to plan their breaks. Comments also **noted a lack of provision for specific needs such as young onset dementia.**

Identification of carers was also raised as an issue (n = 6), with some respondents noting carers who might not self-identify can be difficult to engage with and support. In addition, four people noted further challenges engaging with carers, potentially because of concerns about leaving the person they care for with someone else. There were also three people who mentioned difficulties identifying people living with dementia and / or their carers due to **dementia not being a searchable category on their case recording system.**

Some local strategies for dementia contain a reference to carers and ways to support these, and several respondents in the Directors survey reported linking performance measures to these strategies, such as Kirklees⁵⁰:

'Supporting carers to enable people to be supported at home, for example, through the provision of appropriate advice, information, respite care, education and peer support'
(Kirklees Council, 2015)



However, in certain strategic approaches, acknowledgement of risks to carers' excessively referred to carers and people living with dementia as a single entity, rather than treating these two (or more) people as individuals, with individual needs and wishes. The danger of excessive use of 'people-with-dementia-and-their-carers' is that meeting the needs of one is assumed to be supportive of both. However, the literature and research above highlights the importance of treating carers as individual people, and supporting them as such.

As part of this survey, respondents were asked for contacts in their authority who might be able to provide specific information about data regarding current budget and delivery of support for carers. These contacts were approached by email and presented with a template to complete to provide this further information. This is described further in the next section.

“

‘The danger of excessive use of ‘people-with-dementia-and-their-carers’ is that meeting the needs of one is assumed to be supportive of both.’

2.3 Request for local data

Local authorities are only required to collect limited data as it relates to dementia and their carers, meaning any data that is collected is usually due to a local determination to do so. This inconsistency in collection has meant that councils and CCGs struggle to understand their performance compared to others'. However, we found that where there was a commissioning impetus, quality data was able to be collected, suggesting that imposing a requirement for collection would be both feasible and beneficial.

A total of 11 responses were received to a data request to respondents of the survey of Directors. Of these, 10 were from local authorities and provided data from 2018 – 2019, and one was from a health and care partnership between the local authority and NHS, providing data from 2019.

The information received varied greatly across authorities, potentially due to different recording methods and systems. For many authorities, information in several areas was unknown and it was noted by some that the condition of dementia is not recorded 'in a structured way', echoing comments from the survey of directors and strategic leads.

Most areas were not able to provide clear data related to the number of people living with dementia and carers in their area. Furthermore, this data was limited for many in terms of the carer population and in-care population more widely, with some citing census data and area population data. For those able to provide a number for people living with dementia, (n = 6), most were citing SALT / ASC-FR figures and referencing the 'memory and cognition' or 'health condition' figures rather than local dementia-specific figures. Where figures were given, two people noted that the figures they provided were for those receiving 'support with memory and cognition', which could include support needs besides dementia. One respondent noted that dementia is recorded as a health condition on their assessments/reviews.

While most respondents were able to provide a figure for the total number of carer assessments conducted (n = 9), fewer had access to figures for the number of assessments where dementia is the primary condition. There was a large variance in the number of assessments reported, which did not appear related to local authority size (mean = 1778.2, range = 5072 – 224, sd = 1759.8).

For those providing carer assessment volume, several cited the SALT return data (LTS003), which equates this number to 'carers receiving carer-specific support'. A cross reference of these figures to the publicly available SALT returns also found that many figures did not match the cited figure; however it was not clear why there were differences in these reported figures.

Some local authorities who outsource carer assessments to third parties had clearer figures related to the number of assessments completed, possibly due to performance and contract monitoring for these arrangements. This was explored further in interviews with local authorities (next section).

There was also no specific data on the total spend on carers assessments or reviews, or for people where dementia is the primary condition. The only local authority able to provide a figure cited the value of the contract with the third party organisation who completes the assessments.

Similarly, the information respondents were able to provide about spend was mostly incomplete, often due to the nature of recording formats. One local authority noted difficulties due to respite care being recorded 'in the name of the carer'. Those that provided estimates, or exact figures, again varied greatly (mean = £543,290, range = £11,000,000 – £78,000, sd = £987,536). Only one local authority provided a detailed summary of respite care by provider (broken down by respite, day care, and sitting services).

Ten respondents were unable to provide figures on the total spend on respite care for carers of people living with dementia, though one was able to provide a half-year estimate.

For those providing information about spending on carers, this was similar to reported ASC-FR figures, which wrap carer support into several categories, and do not differentiate by type of support or specific condition.

The absence of detailed data here suggests that local authorities do not have access to data at a more detailed level than the publicly reported datasets, even at a Director/commissioner level. Furthermore, the current reporting framework significantly inhibits an assessment of local spending and provision which would enable appropriate assessment of whether local authorities are meeting their responsibilities.

Some specific issues with the current data were raised by respondents, some examples of this are provided:

“Dementia could be recorded as a mental health or cognitive condition.”

“We are often not kept updated when someone is no longer a carer – our systems can only assume that carers are carers until we are informed otherwise.”

“In terms of recording people with dementia, there are occasions where people have been recorded with different Primary Support Reasons, such as Mental Health or Learning Disability rather than Support with Memory and Cognition. Where we can identify this we can make changes to the data.”

Overall, outside of mandatory data returns, systems for recording data vary across authorities. Respondents proposed some changes to recording systems as a potential solution to this:

“If we wish to better understand the support received by people with dementia and their carers, it would be helpful if a specific reporting framework was introduced to capture the information required. This may include a requirement to identify if dementia is a secondary rather than a primary condition.”

“If it were possible to collate information on specific health conditions such as dementia it would enable us to more accurately predict the need for future support such as respite, direct payments and homecare services which can manage complex needs.”

“Data on carers is focused on the person as a carer. To successfully identify people with dementia and their carers, there needs to be a direct link between the two based on an acknowledged relationship (which may not always be the case); plus, a mechanism to capture this link, and ensure it is updated as relationships change.”

“

‘We are often not kept updated when someone is no longer a carer – our systems can only assume that carers are carers until we are informed otherwise.’

2.4 Interviews with Directors/Commissioners

Identifying and providing support to carers can be challenging, but this can be doubly so when the carers don't recognise themselves as such. For many who provide care, it is not a specific responsibility but "just something they do" as a partner, friend or neighbour. Equally, while those who might be living with dementia may be reticent to receive a diagnosis, those providing care may also be reticent to be categorised as a carer due to a fear of losing their own identity or having expectations projected on to them. For carers to feel listened to and understood, they also require the professionals they interact with to have some understanding of dementia and therefore the ups and downs they are experiencing in their specific caring role.



Methodological note

Local authorities who had completed the survey of senior leaders, and who had contributed evidence via the request for data, were invited to provide additional evidence via a short telephone interview. Four people accepted this invitation to interview. Their professional positions varied, but the majority were in senior management positions in commissioning teams, with responsibility over support for carers and/or dementia services.

2.4.1 Key themes

One interviewee noted that although on paper and in legislation carers have equal rights, this may still not be the case in reality. Across all interviews, there was a sense that local authorities have identified the challenges with supporting carers and many have consulted with them directly as part of their commissioning; but the task of identifying and supporting carers was restricted by available funding and wider issues around the integration of health and social care. One person highlighted the complexity surrounding separate health and social care budgets, particularly in the case of people living with dementia, where social care was funding preventative work to minimise the impact of health conditions.

One key area of focus was in the identification of carers locally. The way in which local authorities were addressing this varied (Case Study 1); however the difficulty in promoting local offers to carers was present in several areas, particularly for carers who were working or who weren't aware of existing support. There was a variance in the use of online tools, with some taking an online, self-assessment approach, and others with more focus on services identifying carers (such as through training GPs).

Areas have distinct ways of accessing performance and monitoring information about carer assessments and provision of support. In places where external contracts are used in the provision of assessments, contract monitoring appears to be a key part of this (Case Study 2). In other locations, the way in which carers are engaged (e.g. through online portals) can offer an additional means of monitoring the carer population in the area. However, these systems are localised and distinct, and joining these data to develop a national picture of carer provision would be challenging. One person also noted that their local CCG may have a much more detailed view of dementia prevalence via their dementia register⁵¹; however that this was not joined with social care data (e.g. carer assessments).

Data reported via national frameworks is limited and doesn't allow for the understanding of specific populations, which affects the data that is captured locally. One interviewee noted how, due to the way that national reporting was structured, there had never been a drive to improve local information management systems accordingly. This way of reporting resulted in a gap between what was known about local care (and carer) populations and what was needed to make evidence-informed commissioning decisions.

Interviewees also noted how local and national data may not truly capture the full extent of support for carers, particularly in terms of respite, due to how support is recorded and coded. For instance, in one area the interviewee noted how any support that was delivered to the cared-for person, even if purely to provide respite for a carer, would be recorded as care for the individual. Without a clear record which links a carer to an individual receiving care, it would be impossible to identify this as respite within the data. The only way to identify it would be through looking at individual case file data.

The view of how distinct dementia was from other conditions was not always clear. Some interviewees noted that assessment and provision was personalised, therefore condition was not recorded on data management/in reporting. Also, that this is complicated where people have multiple conditions and the way that dementia is classified as a cognitive/mental health condition (rather than distinct) for the purpose of national data reporting. Furthermore, the nature of support was considered to complicate reporting on this matter. For instance, if support was considered primarily for ageing or physical disability, dementia may not be captured. Interviewees were asked about the local availability of respite services for people living with dementia. There was variation in whether interviewees saw local capacity as limited. Some reported a general challenge with service capacity for supporting people with mental health conditions, whilst others reported relatively good capacity and suspected that this may be related to the higher number of retired people in their local population and private provision which reflected this.

One interviewee gave examples of how their service had overcome a complex situation where a person living with dementia had chosen not to pay for support out of their personal budget, when the support was to enable their carer to take a break. The local authority were able to use the carer's budget to pay for support for the cared for person instead. This was considered a particularly complicated situation which did not arise often, and it was dealt with carefully and individually by the local authority.

The link between diagnosis of dementia and support for carers was discussed. One interviewee highlighted that their carer support service was providing training for GPs to support the identification of carers and onward referral at the point of diagnosis (of dementia and other conditions). This was seen as one of many possible ways that carers could be better identified. However, it was also noted that diagnosis was not typically the point that caring begins, and that diagnosis is only one part of the local responsibility to identify carers.

As well as the key themes identified above, there were some examples of good practice identified by interviewees which highlight differing approaches to supporting carers in their area. Local areas gave permission to use these case studies in this reporting.



'It was also noted that diagnosis was not typically the point that caring begins.'



Best practice example

Carer Resource Information Support Programme (CRISP) – Bournemouth, Christchurch and Poole (BCP Council)

BCP run the Carer Resource Information Support Programme (CRISP) service for carers in the local area. This is joined with the wider Dorset area. The online portal (crispweb.org) provides a clear route to providing details of individuals' caring situation and a welcome pack with information for carers.

On the landing page for the crispweb.org website, the main image and call-to-action clearly helps people identify as carers and encourages them to sign up for support, information, and local discounts (such as health and leisure services, at cafés and restaurants, on home services such as cleaning and repairs, and for a variety of local retailers).

This local discount card for carers to receive money off local services and shops is central to the BCP approach, which they have used as a promotional tool to successfully identify and engage local carers.

The CRISP portal and discount card sign-up process has allowed BCP and Dorset to gather greater detail about the local carer population, including those who may not necessarily come into contact with the local authority through traditional means. This enables better and more accurate assessment of the number of local carers, and the types of conditions of the people they are caring for. It also serves as a tool for the council identifying carers to conduct carer assessments, a means to share information and advice to the local carer population, and a way to organise emergency support schemes for carers, and respite care (such as the use of local beach huts and holiday lodges).

BCP report being able to use CRISP to access more detailed information about carers of people living with dementia, which in turn guides their approach to providing additional information, advice, and support.



www.crispweb.org/home.aspx
www.mycarerscard.co.uk/



Best practice example

Identifying and assessing carers Nottingham City Council (NCC)

NCC has a contract with Carers Trust, who deliver their Nottinghamshire Carers Hub and the Carer Respite contracts. These arrangements are jointly commissioned between NCC, Nottinghamshire County Council, and the NHS via the local area Better Care Fund.

A former commissioning cycle in Nottingham identified the need to support carers at varying levels of need, including people who did not meet certain thresholds for support. Carers Trust is contracted to conduct assessments of individual carers, to make decisions related to carer support needs on a person-by-person basis, and the provision of respite which could be up to 100 hours across a 12-week period. This contract includes a budget for the provision of this respite and the responsibility for allocating it based on individual needs.

The nature of this external contract and related monitoring arrangements has enabled NCC to see a more detailed level of information than is

present in some other areas, particularly around the volume and type of carer assessments being conducted and provision of respite care for carers. For instance, the contract provider is responsible for collecting detailed data related to people supported, the reasons they require support, and how resources have been used to support them. As such, NCC is able to generate a clearer picture of local support for carers than might be seen in routine reporting data.



www.carerstrustem.org/hub

www.nottinghamshire.gov.uk/care/health-and-wellbeing/health-and-wellbeing-board/better-care-fund



2.5 Carers survey

An online survey was open for the month of November 2019 which asked carers of people living with dementia in England and Wales about their experiences and any support they receive to take a break from caring. The survey was promoted by Research in Practice for Adults and Alzheimer's Society, through newsletters, emails and social media.

Filter questions were used to ensure respondents met the eligibility criteria. A summary of these filters is displayed in the **Table 3**. The data presented in this section relate to the 319 people who went on to complete the survey after exclusion criteria were applied.

Table 3: Filtering criteria for carer survey

| Criteria | n | % |
|---|------------|------------|
| Total responses | 404 | 100% |
| Do you live in England or Wales? | 351 | 87% |
| Are over 18 years old? | 403 | 99.8% |
| Do you currently provide care and support for someone living with dementia? | 369 | 91% |
| Total respondents meeting eligibility criteria | 319 | 79% |

The complexity of the health and social care policy framework can often be equally, and needlessly, as complex to navigate for those it exists to serve. The longitudinal MODEM study found that carers of people with dementia who are also working full or part time typically provide 36 hours of care each week, while those not employed or working fewer hours than part time typically provide 77 hours of care per week. Providing care for those with dementia can be extremely difficult and time consuming, meaning accessing any extra care and support should be as straightforward and accessible as possible – regardless of the policy complexities that may lie behind those services. Carers often found their responsibilities increased as the dementia of those they care for progresses, highlighting the necessity for their needs to also be regularly reviewed as well as those they care for.

Of the 319 filtered respondents, 90.6% of people reported that dementia was the main reason for the care and support they provide, while 9.4% (n = 30) reported 'no'; comments suggested support was provided for various other reasons such as osteoporosis, stroke and older age. Ten people (33%) referenced their familial relationship as the main reason for providing care (e.g. "We've been together 47 years and cared for him one way or another all that time. Not about to stop now."). This was primarily those caring for their spouse/partner (n = 7) and parent (n = 3).

Respondents reported providing care on average 62.14 hours per week (SD = 56.39) which is slightly lower than the MODEM study (see literature review). Not surprisingly, there appeared to be variations in time spent caring by employment status; those who report being employed full – or part-time provided an average of 36 hours of care (SD = 38.03, range = 1 – 168, n = 150), while those who reported their employment status as something other than full- or part-time employed provided care for an average of 77 hours a week (SD = 58.5, range = 1 – 168, n = 223).

2.5.1 Respondents' demographics

Respondents from across England and Wales completed the survey, with numbers ranging from 12 in the Eastern region to 53 in the South East (Table 4); respondents represented 123 different local authorities in England and Wales.

Table 4: Respondents' regions

| Region | n | % |
|--------------------|----|-----|
| North East | 27 | 8% |
| North West | 47 | 15% |
| West Midlands | 38 | 12% |
| East Midlands | 47 | 15% |
| Eastern region | 12 | 4% |
| London | 19 | 6% |
| South East | 53 | 17% |
| South West | 30 | 9% |
| Yorkshire & Humber | 23 | 7% |
| Wales | 23 | 7% |

The age range of respondents in the present survey is similarly distributed to the overall figures for carers in England⁵². Although, of all carers, those over 85 are more likely to be carers of people living with dementia⁵³, suggesting the present sample might be slightly younger than the average carer of someone living with dementia (Table 5).

Table 5: Age range of respondents

| Age | n | % |
|-------|-----|-----|
| 18-30 | 4 | 1% |
| 31-40 | 18 | 6% |
| 41-50 | 62 | 20% |
| 51-60 | 114 | 36% |
| 61-70 | 68 | 22% |
| 71-80 | 37 | 12% |
| 81+ | 11 | 4% |

In respect of ethnicity, 95% of respondents described themselves as White British, with under 1% describing themselves as White Irish (0.97%), other White background (0.65%), Indian (0.65%), Pakistani (0.65%) or White and Asian (0.32%). This suggests an underrepresentation of carers from minority ethnic backgrounds, who are thought to make up around 10% of the caring population in England⁵⁴.

Respondents were mostly female (84%), suggesting an underrepresentation of male carers; across the UK, it is thought 58% of carers (Carers UK, 2019a) and 60 to 70% of carers of people living with dementia are female⁵⁵.

Respondents most frequently reported being retired (32%), while 24% were part-time employed and 24% full-time employed. This suggests 48% of respondents were in paid employment, compared to figures from Carers UK where 39%⁵⁶ of respondents reported being in employment, again suggesting that the present sample might over represent younger people. This might be due to the sampling methods used, as the survey was promoted through digital means, in particular social media.

2.5.2 Demographics of people living with dementia

Information about people living with dementia was completed by their carers.

All people living with dementia were 51 or over, the age distribution is summarised below:

- 51-60 (3%, n = 11)
- 61-70 (13%, n = 42)
- 71-80 (37%, n = 116)
- 81+ (47%, n = 148).

91% were described as White British, 5% as White Irish, 1% any other White background, 1% as Indian and 1% as Pakistani, with less than 1% described as White and Black Caribbean or Caribbean.

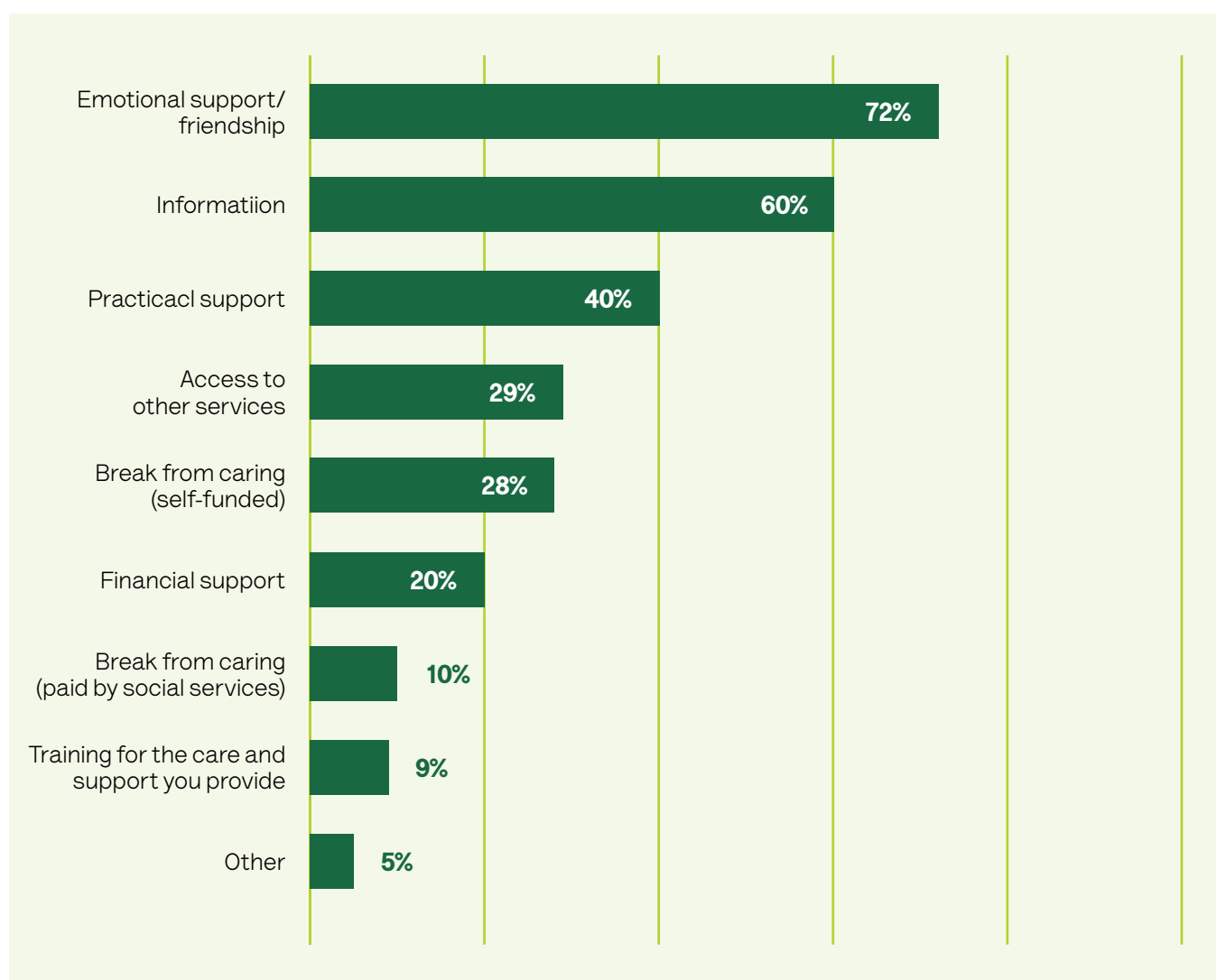
In respect of gender, 58% were female and 40% male, five people commented that they cared for more than one person, in particular both parents.

The person living with dementia was most often the parent (57%) or spouse / partner (33%) of the person providing care.

2.5.3 Support received

Figure 5 displays the types of support respondents had received from others. The majority of respondents reported receiving emotional support/friendship (72%) and information (60%) from others. Less frequently reported was training to help with the care and support they provided (9%) and a break from caring paid for by social services (10%). There were 21 people (7%) who reported receiving no support at all.

Figure 5: As a carer, please indicate the types of support you have received from others



A number of respondents chose to provide additional information to this question (n = 105). The open text answers gave a rich narrative overview of experience of carers. Two broad themes emerged; a lack of support and the financial implications of caring.

Respondents reported feeling that they lacked support (n = 33), with the most common concern being that there was a lack of support to know how to access help and information and which resulted in a need to be proactive to find help (n = 14).

“ For those who don’t know it’s a complicated and long process and for some people who are worn out it’s impossible to fight through the fog of support.

Respondents reported feeling ‘I have no support I’m doing this on my own’ and that support was only available at crisis point or after prolonged time delays (n = 8). In particular a lack of emotional support was raised (n = 3).

The impact of caring without support or respite was noted by respondents as a cause of their own ill health and comments noted that their ill health, disabilities or age did not seem to be accounted for (n = 5).

Specific mention was made by carers who were trying to juggle work alongside caring responsibilities (n = 8) with one respondent explaining

“ In reality, the practical support is non-existent. My personal and professional life is on hold, my mental health is suffering [...].

A smaller group of respondents (n = 4) explained that the provision of good support provides peace of mind and is very much appreciated.

The second main theme from respondents’ comments involved the financial implications of caring. Most frequently, the costs of caring were noted (n = 9) with comments including the financial implications of working reduced hours on income and pension contributions for carers of working age, the challenges of meeting the costs of respite care for those required to self-fund and the complexity of navigating the benefits system.

Some respondents able to pay for care using their own funds, attendance allowance or personal budgets, benefited from being able to access respite care to allow for friendships to be maintained or to attend social activities (n = 4).

Challenges faced by carers unable to access support because of the wishes of the person living with dementia were addressed by a number of respondents (n = 9). When help or support was declined, some carers were able to negotiate support that was acceptable to the person living with dementia for example, respite care in their home rather than a residential setting, whilst other carers remained unable to access any respite support. The following response highlights this challenge:

“ I get very little support even though I have had a triple heart bypass and am unwell myself... I have tried to get my husband into respite to give me a rest but because he says no his social worker says it’s his human rights, my human rights are not relevant. Caring for my husband is making my health deteriorate.

This comment also makes a link between a lack of help and individuals required to self-fund. This connection was explicitly stated by others (n = 7) across the survey.

“ From diagnosis I feel that you are on your own to find any information especially if you are self-funded.

A desire for continuity of support rather than short term input was expressed in the open text comments (n = 2) as it would improve services to carers and those living with dementia and help both to feel supported.

Finally, a loss of identity was explicitly referenced by one respondent in powerful terms:

“ I am no longer classed as a person, when they come to my home and keep calling me a Carer. I could go bananas.

Respondents indicated who provided them with support (**Table 6**); this was received from friends / family most often (85%), with support from professionals (32%), charities (22%) and social services (20%) reported less frequently. Respondents reportedly received support from community groups least often (12%).

Table 6: Frequency of support source by the type of support people report receiving

| Type of support people have received | n (type support)* | Where people have received support | | | | | |
|--|-------------------|------------------------------------|-----------------|-------------------------------------|-----------------|-----------|------------------|
| | | Friends or family | A support Group | Professionals Such as GP/clinicians | Social services | Charities | Community Groups |
| Emotional support/ friendship | 218 | 201 | 43 | 68 | 39 | 51 | 28 |
| Practical support | 123 | 110 | 31 | 54 | 31 | 33 | 22 |
| Information | 181 | 146 | 41 | 68 | 31 | 58 | 26 |
| Training to help with the care and support you provide | 26 | 22 | 9 | 15 | 9 | 4 | 4 |
| Financial support | 61 | 58 | 11 | 26 | 19 | 20 | 8 |
| Access to other services | 87 | 75 | 28 | 42 | 28 | 36 | 19 |
| Break from caring (self-funded) | 85 | 76 | 23 | 32 | 21 | 22 | 12 |
| Break from caring (paid for by social services) | 29 | 24 | 9 | 15 | 17 | 13 | 2 |

* People could receive support from multiple sources, so total support by type may not equal the sum of all sources of support

Respondents' comments regarding support from health and social care services were mixed, with both positive (n = 3) and negative experiences recalled (n = 6). There was concern that support was only available once crisis point had been reached (n = 2) and that processes to access support are bureaucratic (n = 1). Support via charities was frequently cited (n = 20) often in very positive terms:

“ My Admiral Nurse at the time was a god send and I knew she would always be at the end of the phone for me.

A quarter of these comments regarding support from charities mentioned the benefits of being able to access online or telephone support which had flexible access times (though note previous caveats regarding the sample favouring those who are engaged with online technologies).

One respondent noted the challenge of accessing appropriate support for a man whose first language was not English and specifically of the lack of male carers in this context.

Three respondents made direct reference to feeling that there is a disparity between the support available for people living with dementia compared with those with a cancer diagnosis. This disparity was noted in both professional support and provision as well as support provided by friends and family. One respondent commented:

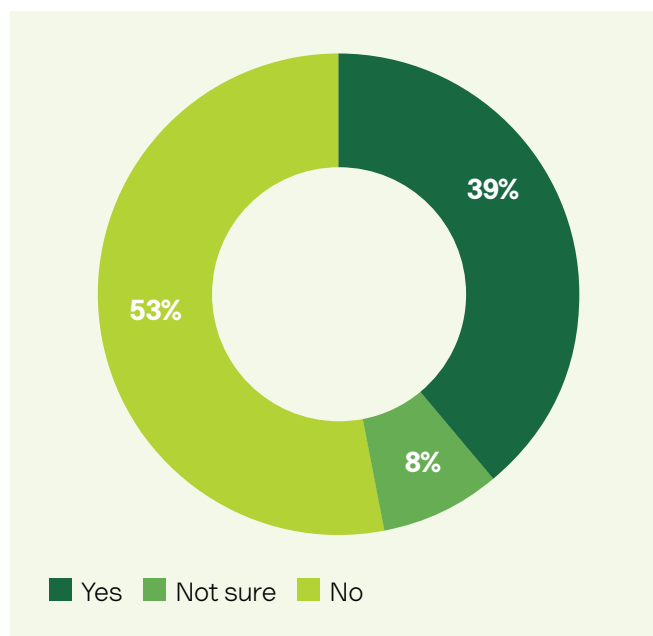
“

‘I am amazed how little support is available – having had a mother die of cancer and now helping an elderly Father with Alzheimer’s – the difference in support is huge.’

2.5.4 Carers assessments

Overall, 39% of respondents have had a carer assessment, with 8% who were unsure and 53% having not had one (Figure 6).

Figure 6: Have you had a carer assessment?



For the 53% who had not had an assessment (Figure 6), this was due to not having been offered one (47%), other reasons (22%), such as not knowing / complications with the process or not being the main carer. Sixteen percent reported not being aware of carer assessments, while 4% reported having been told they were not eligible for one. Some of those people who indicated that they had not had an assessment highlighted the length of time waiting for an assessment (n = 7) and the high thresholds required to receive support (n = 8).

In particular, remarks were made around the need to repeat assessments to take account of changes in circumstances or the person living with dementia's needs (n = 3) and the distressing nature of having an assessment (n = 3) when it is felt that the likelihood of support being available is slim.

Reviewing results by region (**Table 7**), those from Wales reported having had a carers assessment most frequently (52%), compared with the North

East, Eastern region and South West (all 33%) where a lower proportion of people reported having had a carers assessment.

Table 7: Carers assessments by region

| Region | Yes | Not sure | No |
|-----------------------------|-----|----------|-----|
| North East (n = 27) | 33% | 15% | 52% |
| North West (n = 47) | 34% | 6% | 60% |
| West Midlands (n = 38) | 37% | 8% | 55% |
| East Midlands (n = 47) | 38% | 2% | 60% |
| Eastern region (n = 12) | 33% | 8% | 58% |
| London (n = 19) | 37% | 5% | 58% |
| South East (n = 53) | 47% | 6% | 47% |
| South West (n = 30) | 33% | 17% | 50% |
| Yorkshire & Humber (n = 23) | 43% | 4% | 52% |
| Wales (n = 23) | 52% | 13% | 35% |

Those who reported receiving a carer assessment rated their experience of the assessment from 0 to 10, based on how well they were listened to, how well they felt their needs were identified, and how well their situation was understood. Participants again reported a full range of experiences, with

overall averages between 5 and 6 for each question (**Table 8**). Those in Wales provided more positive ratings than those in England, with less variation in scores across individuals, although the small sample size of respondents from Wales should be noted

Table 8: Rating of carer assessment by region

| | Overall (n =125) | | | England (n = 113) | | | Wales (n = 12) | | |
|---|------------------|------|-------|-------------------|------|-------|----------------|------|-------|
| | Mean | SD | Range | Mean | SD | Range | Mean | SD | Range |
| How well you were listened to | 5.74 | 2.88 | 0–10 | 5.61 | 2.96 | 0–10 | 7 | 1.65 | 5–9 |
| How well they identified your needs | 5.26 | 2.88 | 0–10 | 5.12 | 2.94 | 0–10 | 6.5 | 1.83 | 3–9 |
| How much they understood your situation | 5.04 | 3.04 | 0–10 | 4.88 | 3.12 | 0–10 | 6.5 | 1.88 | 3–9 |

2.5.6 Taking a break from caring

Respondents were asked if adult social care had supported them to have a break from providing care. Overall, 13% of people had been supported to have a break, 2% were not sure and 85% had not

been supported to have a break. Those in Wales were also most likely to have been supported by adult social care to take a break from caring (30%), compared to 0% (Eastern region) to 20% (South West) in England (**Table 9**).

Table 9: Support to take a break from caring by region

| Region | Yes | Not sure | No |
|-----------------------------|-----|----------|------|
| North East (n = 27) | 11% | 0% | 89% |
| North West (n = 47) | 9% | 2% | 89% |
| West Midlands (n = 38) | 8% | 0% | 92% |
| East Midlands (n = 47) | 11% | 2% | 87% |
| Eastern region (n = 12) | 0% | 0% | 100% |
| London (n = 19) | 11% | 5% | 84% |
| South East (n = 53) | 15% | 2% | 83% |
| South West (n = 30) | 20% | 0% | 80% |
| Yorkshire & Humber (n = 23) | 17% | 9% | 74% |
| Wales (n = 23) | 30% | 4% | 65% |

For those who had been supported to take a break from caring, the arrangement reported most frequently was for the person living with dementia to stay in a care home for a short while (36%). Other options included someone providing residential care and support during the day (24%) and the person living with dementia spending time in a day centre (19%). Other arrangements (19%) included evening visits and increased support from an alternative carer. One person highlighted a gap in provision, noting that it “*was dreadful as there are no homes for younger people with dementia.*”

Breaks were most frequently funded by social care (60%), followed by self-funded care (43%; respondents were able to select more than one source of funding). Open text comments included that social care funding did not necessarily cover the full cost of a week in a residential home requiring partially self-funding, even for those who were entitled to full funding. Reports of the quality of this care varied from ‘very good’ to ‘very bad’, although care was most frequently reported to be ‘quite good’ (43%).

Figure 7: How have you used the time away from your caring responsibilities?

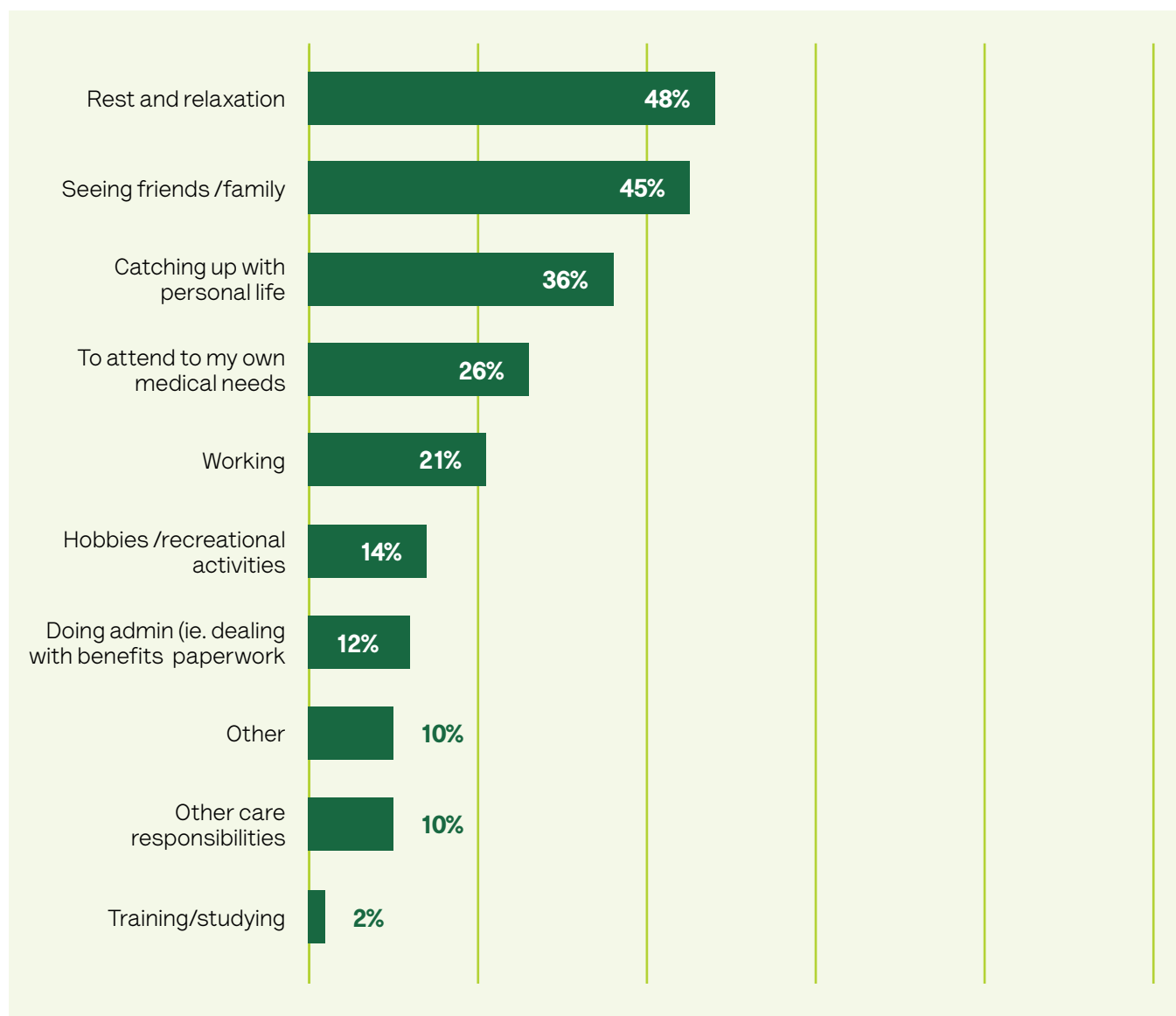


Figure 7 displays how time away from caring was used. Respondents were most likely to use this time for rest and relaxation (48%) and seeing friends and family (45%), and least likely to spend time training / studying (2%). Whilst others (10%) used the break away from caring to fulfil other care responsibilities, such as spending time with children, highlighting the complexity of some carers' responsibilities.

Overall, the majority of people (60%) felt 'mostly positive' about having breaks from their caring responsibilities, however 12% felt mostly or entirely negative. Where answers were explained ($n = 17$), respondents raised concerns around the quality of care ($n = 4$), feelings of guilt / not wanting to leave the person they care for ($n = 4$) for example:

“ Breaks are essential, but given the poor quality of care available I am left feeling anxious and concerned about husband's well-being when I'm away.

Other concerns included issues with the complexity of arrangements (n =3) and feeling that the length of replacement care was too short (n = 3). Comments also acknowledged that carers face an emotional challenge having had a break to return to caring.

The majority of respondents (79%) reported that they would like to take further breaks from caring in the future, while 14% were unsure and 7% did not want to take further breaks. In particular, the inability to book respite care in advance and the challenges of navigating the process to agree dates was noted as a specific barrier to taking breaks in the future, as the following quotes illustrate:

“A week isn’t enough also you cannot book in advance so a lot of stress beforehand by the time you get the rest you are exhausted.”

“It’s an incredibly bureaucratic process to agree dates with NHS via Social Services to confirm funding and to only then be able to arrange actual care.”

Other comments highlighted the need for a break, with many noting the difficulties in taking one, whether due to having ‘no other family to take over’.

The survey of carers highlighted some of the key challenges faced by people caring for someone living with dementia, including the high levels of stress and grief associated with caring, barriers to accessing support, and where people have often been left feeling alone in providing care and support. The majority of people responding hadn’t received a carer’s assessment, despite self-identifying as a carer. This was often due to not being offered one. In terms of respite, very few had been supported by social care to take a break from caring, self-funded arrangements were much more common.



2.6 Survey of professionals

While emergencies can never be predicted, they can be planned for at both a strategic and individual level. Individual care plans and carers assessments should all consider arrangements for emergency provision, for example if a carer was to become unwell themselves, while there should also be sufficient capacity and mapping of alternative provision locally. This would not only reduce stress and anxiety for those receiving and providing the support, but should also reduce the associated extra costs of crisis support. More consistent, lower level support to carers that increases their knowledge of dementia and helps them to manage their own wellbeing also has the potential to prevent crises or reduce their impact.

The majority (94%, n = 47) of respondents worked in local authority adult social services, 4% (n = 2) in the third sector and 2% (n = 1) in the NHS.

Respondents were primarily social workers (38%, n = 19), with other roles including advanced/senior practitioner/consultant social worker (12%, n = 6) and other social care staff (10%, n = 5). The remaining respondents were from a range of backgrounds including community worker (6%, n = 3), occupational therapist (4%, n = 2) and commissioner (4%, n = 2).

Table 10: Region of respondents to professionals' survey

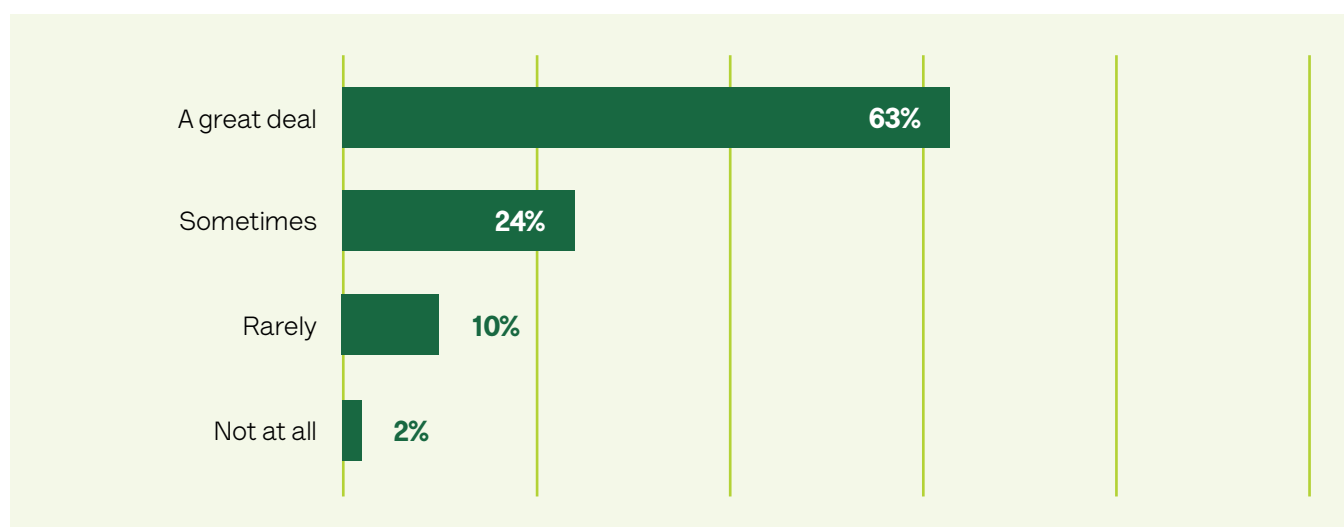
| Region | n | % |
|--------------------|----|-----|
| North East | 0 | 0% |
| North West | 12 | 24% |
| West Midlands | 0 | 0% |
| East Midlands | 1 | 2% |
| Eastern region | 2 | 4% |
| London | 10 | 20% |
| South East | 8 | 16% |
| South West | 14 | 28% |
| Yorkshire & Humber | 2 | 4% |
| Wales | 1 | 2% |



Methodological note

A survey for professionals working in adult social care in England and Wales was live between December 2019 and January 2020, and a total of 50 responses were received in this time. **Table 10** displays the regional distribution of respondents.

Figure 8: Does your work involve direct contact with people living with dementia and their carers?



Most respondents' work involved direct contact with people living with dementia and their carers 'a great deal' or 'sometimes' (87%, n = 43; Figure 8).

A slightly smaller majority reported that their work involved conducting assessments of carers 'a great deal' or 'sometimes' (66%, n = 31), with 8% (n = 4) conducting assessments 'rarely' and 26% (n = 12) 'not at all'.

Considering local provision, 82% reported specific support for carers of people living with dementia, such as services provided directly by local authorities including carers assessments, respite services and providing information and guidance to carers as well as signposting or referral to services provided by charities or other agencies.

The majority of respondents (68%, n = 30) reported a local strategy for carers of people living with dementia however there was a degree of uncertainty with some respondents reporting they were unsure and less than a third (30%, n = 15) specifying details of their local strategy or services. Some areas clearly have a specific strategy for carers of people living with dementia whilst in others this is included within a wider carer's strategy.

Table 11: What do you consider 'respite' care in your area?

| Option | n | % |
|---|----|-----|
| Additional daytime care | 40 | 82% |
| A live-in carer for a period of time | 21 | 43% |
| Attendance at a day centre | 41 | 84% |
| A short term stay in a residential home | 46 | 94% |
| Other (please specify): | 11 | 22% |

A short term stay in a residential home, attendance at a day centre and additional daytime care were all considered 'respite' care (94%, 84% and 82%, respectively). Fewer people (43%, n = 21) considered a live-in carer to be 'respite' care. Eleven people specified other types of care which included Shared Lives (n = 3) and sitting services (n = 2). One respondent noted that all of respite services given in the table 11 above existed but 'they were not always available'.

When asked 'Is there anything else you would like to tell us related to your local definition of respite care?' the most frequent comments related to a lack of capacity regarding both residential and day respite services (n = 9). Respondents reported this results in emergency respite care being necessary (n = 4) and the associated costs of respite care, both to local authorities and carers or the person living with dementia (n = 3). There were four people who suggested further planning and action is needed to avoid the use of emergency respite care with two comments focusing on the need for creative solutions or alternatives to residential or day-care services.

Most respondents supported carers of people living with dementia to take breaks from caring 'a great deal' or 'sometimes' (68%, n = 34). There were six people (12%) who answered 'rarely' and 10 people (20%) responding 'not at all' or 'not applicable to my work'.

Respite / replacement care was provided through direct provision of care most frequently (40%, n = 19), with 17% (n = 8) reporting signposting to voluntary / community services and 15% (n = 7) personal budgets. No respondents reported using vouchers in their area.

The main challenges to providing support to carers was considered to be funding (n = 18) and problems with capacity and a lack of availability of support (n = 20). Other challenges included the concerns of carers regarding accessing support (n = 8) and resistance of the person living with dementia to having additional care or support (n = 3).

When asked to give examples of good practice, responses focused upon providing services that met both the needs of the carer and the person living with dementia. Activity groups including fitness, singing and a dementia café were mentioned. Respite services that accounted for the needs of both carers and the person living with dementia included services that provided respite care at weekends or for longer hours to allow carers to work and sitting services at home. Other examples included joint working and information sharing between health and social care services (n = 2) and processes which allow regular reviews with carers and a contact telephone line for carers to access support services.

When asked about opportunities to improve the wellbeing of carers of people living with dementia, respondents' replies most frequently involved three key themes.

- The need for greater capacity in the respite services available (n = 11) including day services, sitting services and longer respite breaks.
- The need for greater education, training and information for carers (n = 10) on a range of topics including on dementia itself and their own wellbeing.
- The need to focus upon carer wellbeing by providing regular, planned and ongoing services (n = 9). This was considered an opportunity to support carers wellbeing and simultaneously offered the potential to avoid or delay more costly, emergency interventions being necessary (n = 9).



Methodological note

Three focus groups were held with dementia and carer groups in England and Wales. One each in Northern and Southern England and one in North Wales during December 2019. The focus groups ran for two hours with a short break in the middle. Each group had between six and eight attendees (plus facilitators). Each group had a mixture of people living with dementia and carers. In some groups, the people living with dementia chose not to have their carer present in the focus group.

The focus groups followed a topic guide and were structured as follows:

- Welcome, introductions, confirming willingness to participate and consent.
- Discussing understanding of carer assessments and respite support.
- Exploring caring responsibilities and personal circumstances.
- Exploring personal experiences of carer support and respite.
- Exploring challenges in accessing support and respite and potential improvements.

In each focus group, there was a degree of flexibility in how conversations were guided based on group preferences. For instance, each group was offered the opportunity to divide into smaller groups to discuss their experiences of respite due to the potentially sensitive nature of this (see methodology in appendix); however, none of the groups expressed a desire to split their group.

2.7 Focus groups

Carers of people with dementia must often straddle the divide between GPs, memory clinics, support services, and social care, often acting as the connecting point between services in the absence of formalised joint working. The necessity to fulfil this complex role, alongside existing feelings of guilt, a lack of understanding of available support, and their actual caring obligations, can act as a barrier to accessing those services. As part of carers' assessments, one of the challenges carers found in seeking to access support was that there was an expectation of prior knowledge; they found they were often asked what support they wanted without being given any indication of the kind of support that might be available. Participants in our focus groups noted that where commissioned as part of memory clinics, occupational therapists can be invaluable to carers and those they care for, providing practical care management advice, sharing knowledge and providing warm introductions to other forms of support.

2.7.1 Sources of support

Although experiences of support varied greatly, there was a general consensus between participants in all three groups that they had experienced a lack of support from statutory agencies. Many participants described feeling alone after diagnosis due to a lack of support and signposting, some referencing long gaps between a diagnosis and any subsequent contact from social care.

The groups highlighted the differences in diagnosis, support and treatment between dementia and other physical / health conditions such as cancer.

“ What I find is you're very left alone. I can't understand why if somebody's got dementia, they're treated completely different from somebody who's got cancer.

People also described how support felt fragmented, with agencies not effectively communicating with each other, resulting in people having to repeatedly answer ‘the same questions time and time again’, and even within the same agency people might have to repeat themselves when reengaging:

“ Then after six months, you’re on the back burner. So when you get another crisis or something else happens, you have to go back to the beginning.

One participant felt the experience of being diagnosed could be improved if GPs automatically notified relevant agencies (e.g. social services, council tax, benefits) as soon as the diagnosis was received.

One person with experience providing care to someone with dementia described how they experienced social services’ involvement as being done ‘to’ and not ‘with’, describing how when meetings were arranged, it felt as though the decisions had already been made by professionals without family involvement. There was general agreement that when professionals had personal experience with dementia, this strengthened the relationships and the degree of understanding and empathy increased.

As well as support from social workers, one attendee described their experiences with an occupational therapist, two years after the initial diagnosis, feeling that of all the professionals worked with, occupational therapists were ‘*the only people that really helped me*’. This support was considered invaluable and it was suggested that connecting someone with an occupational therapist at the point of diagnosis could be beneficial to other people in their situation.

There was also positivity about the support received from charities, particularly Alzheimer’s Society and Age UK (though it should be noted that the present focus groups were arranged with support from Alzheimer’s Society). There was also some praise for the dementia support provided by the emergency services and hospitals in Wales, with suggestions that staff in these agencies had received specific training around dementia and were particularly supportive and understanding.

“ If you’re in hospital, on your name board at the back, there’s a butterfly, so that people know that that person has got dementia. Which I think is a good thing.

“ I ring 111, and the police has been, and the ambulance has been. I said ‘I’m sorry to call you out’ and they said ‘we’re here, doesn’t matter, if you want us, we’re here. We’re used to dementia patients’.

Where carers had access to additional support, this was often from family living locally or, in some cases, from neighbours. Some attendees described losing friends through their lack of understanding, both of dementia itself and the levels of care and planning necessary when making arrangements:

“ We were always used to people coming or going, you do lose [friends], because they don’t understand or they get embarrassed.

The contrast of public understanding between dementia and other physical / health conditions was again highlighted. Attendees felt that there was an assumption that families will be willing and able to provide support, with social services offering nothing until crisis point. There were also concerns over a lack of back-up, with people worrying what would happen if they were no longer able to provide care.

An element of luck was thought to play a part in the support and information people receive. Conversations with other carers and prior knowledge of the system were felt to be particularly supportive in the absence of a coordinated approach to support from local services and related information / signposting. Charities and support groups were also considered vital for finding out about available support and navigating the process.

“Often something will happen and I will think its fine. A, I’m fairly articulate, B, I can drive, C, I’ve got this bit of information, what happens to those that haven’t?”

A few participants reported having more positive experiences engaging with local services, including social workers, occupational therapists, health services, and charities. However, in almost all of these cases, they reported high levels of personal resilience and organisation, citing their own determination to access support. Furthermore, those who had successfully navigated local authority support indicated that their own backgrounds in nursing, local council work, social care, or administrative roles played a significant part in their ability to achieve positive outcomes for themselves and the person they cared for.

2.7.2 Experiences of adult social care and carer’s assessments

Where participants had made contact with adult social care, attendees described long waits between the initial contact, being allocated a social worker and actually receiving support. Even in crisis situations, some reported waiting for months before support was forthcoming (“*You can be at crisis, but there’s nobody that can help you immediately*”). Once adult social care had made contact, experiences were mixed, with some describing the support positively and others feeling there was room for improvement. One participant in North Wales reported a quick and successful engagement from the local area following their request for support:

“I have to say that within three weeks of that first phone call, the whole thing for direct payment was set up. It was extraordinary.”

A small number of attendees had had a carer’s assessment. There was a sense from some who had that the assessment was not particularly useful, with the process feeling prescriptive and consisting of form filling; attendees generally felt that little came from the assessments, and there were few reports of subsequent signposting. In addition, carers’ wellbeing was not always fully explored, with many attendees not being asked about their employment or educational aspirations.

A number of those who attended the focus groups self-funded the replacement care and some felt that once their financial situation became clear, social services were not particularly interested in helping, both in terms of support provision and signposting.

“As far as I’m concerned, the assessment on the patient, if we call it the patient, is a waste of time. Because once that magic £23,000, whatever it is comes out, they’re not interested, they couldn’t care less.”

Where people had received assessments, there were some suggestions for potential improvements. There was consensus that when it came to assessments, it was preferable for these to take place in person rather than by phone. It was raised that vital information can be missed over the phone, and meeting in person can offer valuable insights into how someone might be coping (e.g. *‘when they come out, they can see the state of you as a carer for a start’*).

One carer described being busy, attending many local support groups, however they felt that being actively involved in these groups gave social services the view that they were coping, when this might not be the case (*‘I feel that because we go to so many different things [...] I feel that they think I’m coping.’*). This person had their own on-going health needs and described how the council was aware of these needs, which might mean they were unable to provide care for brief periods, however allowances did not appear to be made for this.

In all three of the groups, people providing care explained how social workers might ask them ‘what do you want?’ or ‘what were you expecting?’ during an assessment. More than one person highlighted that they wanted to know what might be available from local services, rather than being asked to put suggestions forward themselves.

“ I was asked ‘what do you want?’ And I thought ‘I don’t know what I want, I’m waiting for you to tell me what’s available’. And it was only because I had this friend [with professional experience]. And she was the one that sort of gave me that information that I was able to formulate something that I wanted [...] But a lot of people wouldn’t be able to walk into that room and say ‘this is what I want’.



“

‘I was asked ‘what do you want?’ And I thought ‘I don’t know what I want, I’m waiting for you to tell me what’s available.’

Many respondents also felt that there were few considerations around circumstances changing as dementia progressed; it was raised that if someone were assessed as not needing support at one point, a very different picture might emerge a year later. Some people suggested scheduling regular reviews might support with this. On the whole, services were considered 'reactive' rather than 'proactive'.

One person living with young onset dementia described how services were designed around older adults, and situated under 'older people', which might not be appropriate for those with young onset dementia:

“ [...] so you could have dementia in your 30s and you'll be expected to be cared for or supported by the same system that's designed around the needs of your grandparents.

While it was felt essential to ensure emergency support / back up plans were created, only some participants had been encouraged to do this. There were also examples of these plans not being carried out. One carer described preparing a detailed emergency backup plan to enable them to go for a surgical procedure at the local hospital. However, when the surgery appointment was received, the arrangements were not followed through and only through last minute arrangements with the family could the procedure go ahead.

While experiences varied greatly across individuals and regions, the most positive report of a carer's assessment came from someone living in Wales. This person described an informal, person-centred conversation in their home, where enquires were made about their individual needs and aspirations for work and hobbies. Support was then provided quickly, with a follow-up phone call.

“ I got a phone call back the same afternoon to say I needed a carer's assessment and somebody would contact me. I thought 'well that'll happen whenever'. Within, I think by the end of the week, somebody had phoned me and arranged to see us at home. That was actually fine. We just had a chat. It was a full assessment, clearly, but it was very informal and very pleasant.

2.7.3 Taking a break from caring

Carers' understanding of respite or replacement breaks differed to some degree. Several had taken breaks in the past, and some had regular arrangements in place to enable them to carry out errands during the week. Most of those who had taken longer breaks (more than one night) reported self-funding these arrangements. Charity / community groups were a significant part of the daytime respite arrangements that carers had in place, however this is potentially biased in this sample due to the way focus groups had been arranged.

Some attendees discussed barriers to taking a break from caring such as feelings of guilt (e.g. *'and half of you wants that break yet the other half is that feeling of awful guilt'*). In some cases this guilt was exacerbated by the person they were caring for commenting that they want to spend time together, and might not want to be supported by anyone else. Logistical difficulties were evident, for example challenges in booking overnight care in advance was raised, which caused booking a holiday extremely challenging.

“ And the respite I really need for next year, there are two long distance walks, one in England, one in India. It's really important to me that I'm able to get that respite. Whether I have to pay for it or whatever is immaterial [...] It's actually being able to book in advance that's the real problem.



The duration of alternative care was an issue for some, noting they might only receive support for an hour and *'what can I do for an hour? [...] You can't really go out the house much and do anything.'* An overnight break was thought to bring additional concerns around adjustments to new circumstances and routines; similarly there was thought to be a lack of concern about the reaction of the person with dementia to unfamiliar people and places. Attendees also spoke of anxiety around breaks, of watching the clock and worrying about how the person they care for is. Concerns were also raised about the quality of the care provided, with some people feeling that they are best placed to care for their loved ones.

“ Because I’ve got to be back within a certain time. So you’re clockwatching. You can’t relax.

“ He doesn’t want to go and if he goes in for respite he packs his case every night, ready to come home.

Across the focus groups a mixed picture emerges, varying both by local authority and individual circumstances. Participants describe a degree of luck, with many people finding out about support

through avenues besides social services, such as other carers or their own prior knowledge. There were also clear gaps in how carers had experienced the early stages of dementia and becoming a carer, with not all carers receiving or being offered a carer assessment; and a lack of continued assessment as the dementia of the person they cared for progressed.

However, there were also examples of good practice, where attendees described receiving prompt, person-centred assessments, which supported them to live as they choose. Although the sample was limited geographically, this was more evident in the Welsh local authority than the English areas.

Finally, it should be noted again that these focus groups only represent the views and experiences of a small number of people living with dementia and carers. There are clear gaps in the demographics of carers represented in these groups, which in part may be due to the way in which focus groups were organised. For instance, there were very few carers under the age of 50 present, and very few who were in full-time employment. Furthermore, there were no carers or people living with dementia in the groups who were not first-language English, or from ethnic minority backgrounds.

3

Discussion of findings

This research set out to explore support for carers of people living with dementia, capturing the individual stories of people living with the condition and their carers, as well as the way that local areas are offering them support.

The evidence collected and considered includes local and national data, surveys, focus groups and interviews with people living with dementia and their carers, as well as those working in a professional capacity, either directly or through overseeing and commissioning services.

People from across England and Wales have provided their views, and whilst the legislation differs between the two countries, the guidance for local authorities is broadly the same. And although a degree of variability is to be expected between individual experiences of care and support (due to the differing circumstances of people affected by dementia and their carers), the evidence across this project suggests that, in fact, there is a much larger geographical variation in the experience of carers of people living with dementia across England and Wales.

An inconsistent approach

At a national and local level, reporting and recording systems appear very limited in the view of dementia and dementia care provided by social services. National reporting frameworks (ASC-FR, SALT & ASCOF) capture a limited view of support in terms of quantity and spending, with support for carers often wrapped up in broader categories, and support for dementia grouped within general cognitive or other health conditions. As such, it is impossible to assess the national picture of carer assessments and respite support for carers of people living with dementia. Furthermore, this gap in monitoring data is seen at a local level as well, with very few local areas spoken to able to provide details on their spending and provision for carers of people living with dementia. Where more detail can be provided, this is often due to local commissioning arrangements, and local authorities and providers have developed their own systems to record provision as opposed to a joined-up approach across regions and services.

From the point of initial diagnosis, many people in the focus groups and surveys reported feeling alone in their journey. People in the focus groups and carer survey reflected on the differences in provision for someone with dementia compared to someone with cancer, and there was a sense of disbelief that the level of support could vary so much. Where support was received, some felt

services did not communicate effectively and people were asked to repeat their stories when meeting new professionals. It was also reported that local data could not be disaggregated by condition, causing difficulties when investigating, for example, the number of assessments for carers of people living with dementia. Analysis of national data and requests for data from local authorities further confirmed this, highlighting the gaps in recording and reporting for individual conditions and carer-specific support and spending. Furthermore, some local leaders highlighted how this restriction on national data reporting cascades down to limitations at a local level. It was not just those who worked at a strategic level who noted the limitations on data either; in one focus group a carer noted how there should be clear communication from the point the person he cared for received a diagnosis to all other relevant services. Some of the evidence presented highlights how some areas are strengthening local practice in identifying carers in GP surgeries; however, there is still no joined up approach in capturing and acting upon data related to carers and people they care for.

Responses from the carer survey suggested that where people are receiving support, this is overwhelmingly from friends and family, with far fewer in receipt of support from social services. Although this family-based support is undoubtedly a positive for those reporting it, this also raises the question of how to ensure those who might not have friends and family locally receive appropriate support.



Where support was received, some felt services did not communicate effectively and people were asked to repeat their stories when meeting new professionals.

Carers described a degree of luck around their support and interactions with social services. There were instances of people signposted by other carers as opposed to professionals, which could somewhat explain the differences in awareness and services accessed. Some focus group attendees suggested that while they might have experience of completing forms or knowledge of how services are run, others without these skills and knowledge might struggle to navigate the system, creating a gap where those who struggle to coordinate their own support are the ones who end up missing out. Professionals also identified potential barriers, noting those who were persistent or at crisis were more likely to receive respite.

A majority of carers from both focus groups and the carer survey had not received a carer's assessment, though the picture was more positive in Wales. The majority of those who had not been assessed reported they had not been offered one. One potential reason for this might be found in the professionals' survey, with people from local authorities describing challenges in identifying carers. Likewise, health professionals were felt to not always identify carers at diagnosis. Although the number of carer assessments could not be seen in national datasets, analysis of social care data highlights a large amount of variance in spending at local and regional level within related spending categories, which suggests carer assessments may not be carried out consistently between areas. Local leaders and commissioners also identified challenges in identifying carers; however some areas gave examples of how their commissioning was addressing this, and alternative approaches to tackling the challenge.

Professionals described taking a person-centred approach to assessments. Typically, it was reported that local authorities had separate dementia and carer strategies, which considered carers of people living with dementia. However, there was also feedback that the diagnosis was not as relevant as the individual support that was put in place at an individual level. Although this is a positive approach in terms of person-centred care, it does also pose a challenge for a higher level of understanding of how local areas are

meeting the needs of particular care populations, and assessing local demand for services. And at an individual level, carers reported on multiple occasions that they felt dementia was treated differently to other conditions such as cancer, suggesting that this person-centred approach may not be translating into practice. Furthermore, the evidence from carers who attended focus groups and responded to the survey indicated that assessments often felt impersonal and limited in their understanding of individual circumstances. Some people wanted to be offered options for support rather than being asked to suggest options for themselves without any prior understanding of what was available. Again, the available national and local datasets do not allow for further exploration of carer assessments and the satisfaction of those receiving them, so although many local areas highlight their person-centred approaches in assessment, it is not clear whether this is translating into practice.

The impact of support

The experiences of those who had received a carers' assessment were mixed. There was again the sense that assessments undertaken in Wales might be more personalised than in England (albeit within a small sample), querying the needs, wants and aspirations of the person providing care. This contrasted with participants in one local authority who described assessments being conducted by telephone, which was felt to be insufficient to capture the full experiences of the carer. A further example of good practice was provided in Wales, where an assessment which focused on the circumstances and wishes of the carer was arranged promptly, with effective support initiated soon after initial contact. Crucially, this individual received a follow-up call, from the same professional, a year later to review whether their situation had changed. Conversely, there were some instances of additional challenges for people in Wales; for example, conversations after the focus group provided anecdotal evidence of Welsh speakers experiencing delays in receiving support whilst a Welsh speaking professional was located.

Other challenges were also evident, with a number of people feeling they had to initiate the contact and describing the council's approach as 'reactive' rather than 'proactive'. In some cases further communication was not forthcoming and carers had to make further contact to receive a response. Some people also felt that once it was determined the individual would be self-funding, there was a lack of interest with little further support or signposting from the local authority.

A small proportion of people had been supported by social services to take a break from caring; this was seen in focus groups and the survey, where in many regions over 80% of people had not had social services support to take a break. There was general agreement amongst professionals over what constituted respite, with a short term stay in a residential home recognised as respite most frequently and a live-in carer least frequently. This was also reflected in the experiences described in focus groups, with most breaks occurring in day centres/residential homes.

Of those who did have a break, this time was used for a range of reasons including engaging in personal hobbies such as walking and leisure activities, pursuing other roles (e.g. as a councillor or chaplain), to attending to their own medical needs. There were also difficulties described where carers needed to attend hospital appointments; other family members provided the replacement care, though this was often due to lack of contact or availability of council provision. These discussions also raised issues with emergency support plans; while most people had not been supported to arrange these, there was an example of a plan which had been arranged, but was not actioned when needs arose.

Various other complications were raised, resulting in reluctance or inability to take a break from caring. Availability of appropriate support was an obstacle, with provision for those with young onset dementia and the ability to book overnight care in advance noted as particularly challenging.

Even within some focus groups, carers were quizzing each other over experiences with local providers, seeking recommendations against a backdrop of limited options and availability.

A complex condition coupled with a complex support system

A further challenge was the guilt that carers described, both in the survey responses and focus groups. This guilt was also recognised in the survey of strategic leaders, who noted potential difficulties identifying and engaging carers and carers' concerns about leaving the person they care for with someone else. Despite the challenges, a large majority of carers expressed a wish to take breaks in the future, a view which was echoed in professionals' comments about the importance of breaks in maintaining carers' health.

Across all evidence strands there was a sense that the complexity of dementia as a condition, coupled with the complexity of the pre-existing system, creates a significant challenge to delivering appropriate support to carers. On an individual level, the carers, professionals, commissioners, and senior leaders spoken to in this research were all trying to improve the lives of people living with dementia. However, barriers are faced in the form of shortfalls in communication between services, routine data collection and sharing, local budgets and professional capacity, and the availability of respite services suitable for people living with dementia.

80%



In many regions over 80% of people had not had social services support to take a break.

4

Conclusion and key findings



Carers in many areas are expected to be proactive in seeking an assessment of their needs and subsequent support, potentially leading to large gaps in care and support:

- Although the *Care Act (England) 2014* and *Social Services & Wellbeing (Wales) Act 2014* require with local authorities to identify and consider the needs of carers, there is still the chance of:
 - (1) Not identifying carers due to them being in hidden populations; and
 - (2) Not identifying, assessing, and supporting carers if they do not appear to be actively engaging with the local authority (which may be due to the complexity of their situation rather than not wanting or needing support).
- Local authority professionals report challenges identifying carers when they are not aware of where someone has become a carer.
- Carers may have many reasons for not having the time or capacity to proactively seek support (not least of which their caring responsibilities). Those carers who are still working (or studying), or who do not have English as a first-language, may struggle even further with accessing support. Furthermore, people may not identify themselves as carers and not seek support.
- Accessing assessment, care and support as a carer may include a large amount of administrative work on the part of the carer; and some carers reported that even when they took steps to access support, it wasn't available.
- The system itself further widens the gap, with a mix of health and social care systems, different patient pathways in the diagnosis phase of dementia, and a mix of public and private providers of services. In this context, sharing information is inhibited, such as between GPs, memory clinics, social care, and the third sector.

There is a lack of dementia-appropriate services which can be accessed by carers, people living with dementia, and local authorities:

- Carers, professionals, and senior leaders engaging with this research reported a lack of places in respite / care providers which are appropriate for people living with dementia, meaning that arrangement of short-term or last-minute residential places to enable carers to have breaks is limited.
- Charity providers (not commissioned by local authorities) appear to be filling some gaps and providing well-received support (though note above the potential bias in the samples within this research); however this may again be limited / variable between areas.
- Although limited evidence was available, and other more focused research is cited in the literature review above, this research also highlights potential gaps for people requiring Non-English speaking support and people with loss of their second language (e.g. for people whose first language is Welsh).
- Gaps were identified for people with young onset dementia, and it was noted that care placements were primarily linked to services for older people.
- Gaps in appropriate short term support inhibit the ability of carers to plan for and take breaks from their caring responsibilities.

The provision of respite and the nature of 'choice' is complex. A person living with dementia may not wish for additional support; however the carer may still want or need a break.

- Carers involved in this research addressed the complex feelings of guilt associated with respite and replacement care, particularly when the person they care for was not happy with the arrangements. It may be that people living with dementia face more difficulties with finding suitable care arrangements than people with other types of care and support needs.
- There can be challenges for carers and professionals when there is a difference in views between the carer and the person receiving care. For instance, if the carer would like to take a break from caring, but the person receiving care declines support.

Carer assessments are variable at a local level, and there is room for improvements in local approaches to this:

- At times, assessments were felt to be impersonal. Telephone contact which occurred long after the point that caring commenced and was reported, as well as difficult conversations managed badly. Those who had received assessments in person reported more positive experiences. There were also positive experiences reported from alternative assessments or contact (such as from charities and occupational therapists).
- People and organisations carrying out carer assessments should note that caring often began before a diagnosis, so even conducting an assessment soon after diagnosis might still not feel 'timely' to the carer.
- Some carers reported feelings of a loss of identity; being seen as a carer rather than their own person, which is also seen in assessments. Not many people in the sample reported feeling that assessments acknowledged their wishes related to work and personal life.
- Where assessments occurred, some reported challenges in knowing what to ask for in terms of support where open questions were asked. This is a complicated area, since flexibility is potentially a positive component of assessment; however carers reported wanting to hear some options of types of support, and what was available to them, rather than having to know in advance.
- Local systems for identifying and assessing carers varied greatly. Some areas appear to take an approach which prioritises online and self-assessment, which carers reported as not meeting their expectations. However, there were some examples of good local practice, such as the use of discount cards and benefits for registering as a carer.

Data at the national level is extremely limited in terms of what it says about respite care and dementia:

- National data frameworks do not adequately capture spending on carer assessments and respite care. These are either split across multiple categories or captured under wider umbrella categories. Disaggregating spending and quantity of provision is therefore impossible using these data sets and reports.
- Furthermore, dementia as a condition is not visible in the data, and the condition can be categorised under various headings. The absence of condition-specific recording at a local and national level is a barrier to accurate understanding of system pressures and the activity and efficiency of local authorities. Local authorities highlight that dementia may be captured as a cognitive condition, mental health condition, or hidden within other categories (such as physical conditions) when the primary support is not memory-related.
- These limitations in national frameworks appear to cascade downwards to local authority reporting, and very few areas can provide figures related to spending on carers, sub-populations of carers or on specific conditions such as dementia.
- There is also a discrepancy for some areas in terms of how data is recorded, with some large local variation which cannot easily be explained in terms of total spending or local population.
- Local authority leaders and commissioners confirmed these challenges, citing the structure of data returns and systems as limiting what was known about actual spending and provision for specific populations. One of the ways in which this could be improved is through a more detailed requirement in national data; however there are resource implications that require additional consideration when making any changes to reporting data.
- Local authorities who had external contracts in place with providers (i.e. those who had outsourced carer assessments and respite provision) appeared to have better reporting structures in place due to procurement and contract monitoring arrangements.
- There was a great variety in whether local areas had a dementia strategy, and very few reported performance targets related to dementia and carers which could provide a view of local provision in this area.



5

Methods

This mixed methods research combined the experience and views of carers and people living with dementia, professionals, and leaders in local authorities who provide support. The aim of this approach was to ensure evidence was reflective of the complexities of dementia care.

The methodology also acknowledges the potential for regional variation in the experiences of people living with dementia and their carers (as discussed above). Local authorities across England were invited to participate, and workshops were conducted in locations across England and Wales.

The following key lines of evidence are considered:

Surveys:

- A survey of strategic leaders in adult social services.
- A survey of professionals who work directly with carers.
- A survey of carers of people living with dementia.

Interviews/qualitative research:

- Interviews with a small sample of strategic leads in local authorities, exploring best practice and challenges.

- Facilitated workshops with carers and people living with dementia, discussing carer assessments and respite care, views of support for carers, and the associated impacts.

Data collation and analysis:

- Gathering key data related to allocation of care respite in local authorities via contact with local authority contacts, the strategic leader survey (above), and through national datasets.
- A review of the relevant literature via desk-based research.

The structure of questionnaires and further tools used in this research can be found in the project appendices. Further details on each of the key evidence collection channels is provided below (Table 2).

Table 2: Evidence collection framework

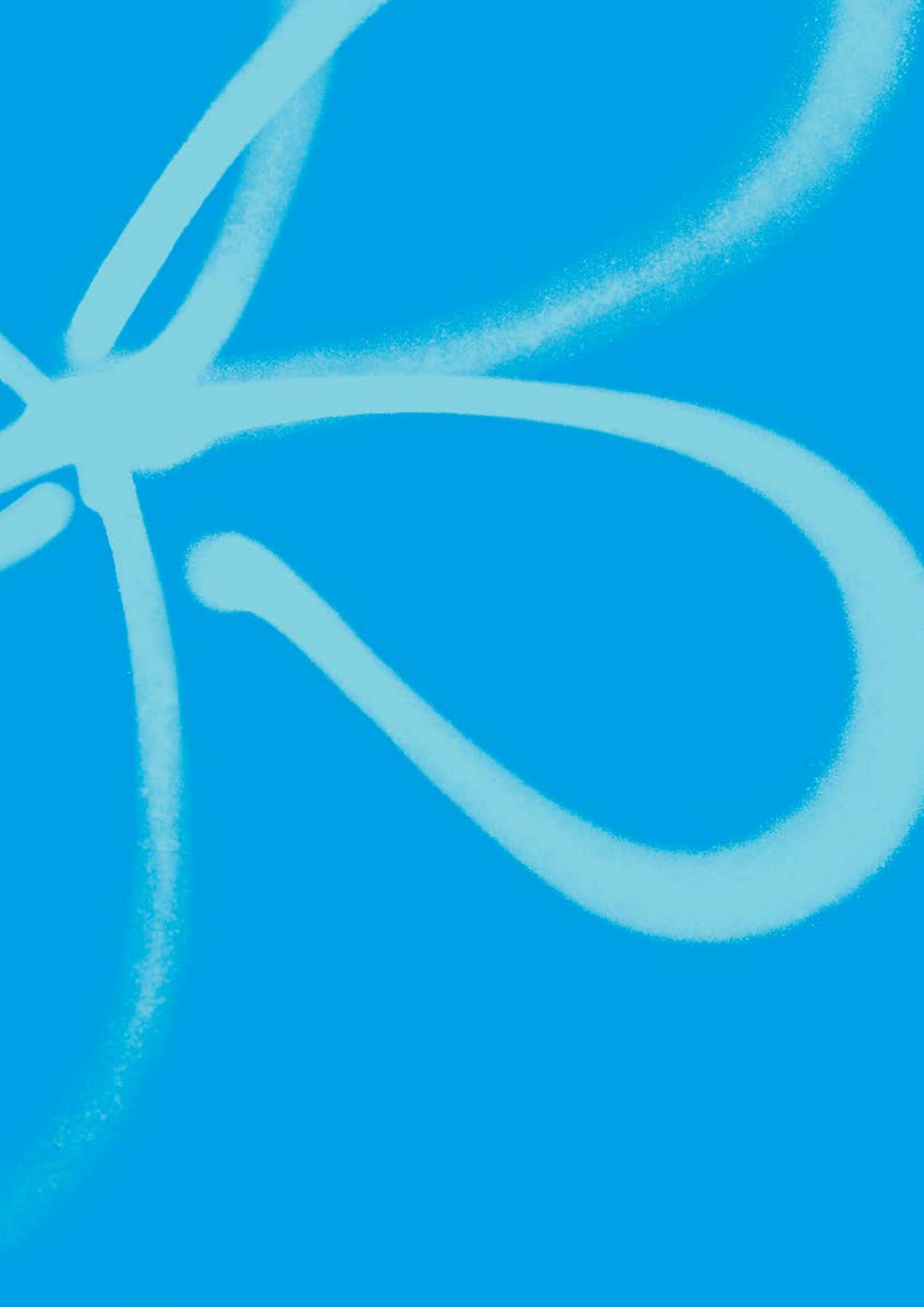
| Evidence collection | Methodology |
|------------------------------------|---|
| Survey of strategic leaders | <p>Directors of Adults' Services for local authorities across England were approached via the Association of Directors of Adults' Social Services (ADASS), Research in Practice's network of local authorities, and directly via email.</p> <p>The survey collected information related to local carer strategies, support for carers including carer assessments and respite, dementia-specific support, and the detail of local reporting related to these factors.</p> <p>Target response rate: 15 Directors/Assistant Directors/Relevant strategic lead.</p> <p>Actual response rate: 26 (173%)</p> |
| Survey of professionals | <p>An online survey, aimed at professionals who work directly with people with care and support needs including those in public or private services, but not those in unpaid or voluntary care roles. Distributed via Research in Practice's partner network, the PSW network, and Alzheimer's Society. Questions reflect the type of local care provided for carers of dementia, local understanding of</p> <p>Target response rate: 150 professionals</p> <p>Actual response rate: 50 professionals (33%)</p> |

| Evidence collection | Methodology |
|--|--|
| Survey of carers | <p>An online survey for people with experience of providing care and support for someone with dementia in England or Wales. The survey explored the type of care provided, experience of receiving a carer assessment and replacement or respite support, and carers' views on support available to them.</p> <p>Carers were identified via local authority partners, Research in Practice's partner network, through Alzheimer's society, and via social media.</p> <p>Target response rate: 150 carers Actual response rate: 404 (269%)</p> |
| Interviews with strategic leaders | <p>Interviews with key individuals from local authorities, identified via the strategic leader survey. Exploring the local approach for supporting carers and people living with dementia.</p> <p>Target number of participants: 5 Actual number of interviews: 4 (80%)</p> |
| Lived experience workshops | <p>Three workshops were delivered by Research in Practice in partnership with Alzheimer's Society's Dementia Voice network across the country. These workshops explored respite care from the view of both carers and people living with dementia. Conversations were guided to focus on key research questions.</p> <p>Workshop findings were recorded, and findings written up anonymously, highlighting key themes.</p> <p>Target number of participants: 30 (approximately 5 carers and 5 people living with dementia in each of the three workshops) Actual response rate: 22 (across three workshops) (73%)</p> |
| Request for data from local authorities | <p>Requesting specific service and finance data from local authorities related to carer assessments, support for carers of people living with dementia, and respite care.</p> <p>Target number of responses: 15 Actual response rate: 11 (73%)</p> |
| Desk-based research | <p>A rapid review of peer-reviewed journals and other relevant literature.</p> |

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