





## Acknowledgements

Acknowledgement and thanks firstly goes to the carers and young carers who took part in this research. They welcomed researchers into their homes and youth groups, giving considerable time and effort to the project and generously sharing their stories with us. The accounts they gave of caring for a loved one were very moving and thought provoking. Without the detailed insight into the lived experience of caring that each participant offered, this research would not have been possible.

Thanks goes to the Manager and Young Carer Co-ordinator of the organisation we recruited through. Both gave valuable advice and support at the beginning of the project, and facilitated the recruitment process to ensure it ran smoothly for the research team and participants.

Alan Russell from Wandering Minstrel Media filmed the interviews with the carers. His professionalism and sensitivity to the carers' experiences ensured that the process was a comfortable one for them.

Finally, the research steering group provided important advice and guidance throughout the project. Thanks to its members: Wendy Burt, Healthwatch Essex Strategic Body member and co-ordinator of the Essex Care Network; Susan McPherson, Senior Lecturer at the School of Health and Human Sciences, University of Essex; and Amy Young, Healthwatch Essex Youth Ambassador.

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## Executive summary

### Background

There are an estimated 145,000 people in Essex who provide unpaid care and support for someone (a family member or friend) on a daily basis. Carers play a vital role in supporting people who are frail, ill, or disabled. However, carers are particularly vulnerable to stress and breakdown (Essex County Council, 2015a). Whilst most of those providing care are older adults, caring is also something that is done by over 10,000 young carers who combine the role of supporting and caring for someone whilst completing their school work and forming relationships with their peers.

Preliminary Healthwatch Essex (HWE) research (Milne, 2014) highlighted the complexity of caring for a family member and the ways in which existing familial relationships shift as a result of the carer/cared-for dyad. The caring role, therefore, can result in changes in identity for the carer; this change is something that can impact upon their access to support services or their decision to continue caring. Previous research undertaken by HWE showed that carers play an important role in providing support, care and advocacy and that their needs and experiences are often overlooked by policy makers and health and social care providers (Corrigan *et al.*, Milnes, 2014)

In order to understand these complexities for carers in Essex, this research was designed to explore the everyday, lived experience of caring. Paying attention to the voices of carers is a key means of understanding the entanglement of relationships, identities, emotions and the experience of support and services.

This study responds to a 2013 HWE AGM motion to raise the profile of carers<sup>1</sup> needs (Penfold, 2013). Preliminary HWE research (Milne, 2014), along with the HWE Voice Network film featuring carers, highlighted the emotional, practical and financial challenges of caring and the need to place carers' voices at the centre of discussions about support provision. This study places the lived experience of carers at its centre, attending in particular to the day-to-day experience of caring and of formal and informal support provision. It is set in the context of important changes to UK social care provision outlined in the Care Act 2014.

HWE is an independent organisation committed to producing high quality research that explores people's lived experiences of health and social care services in Essex. Listening to the seldom heard voices of carers is a key aspect of our research strategy. In capturing and articulating people's experiences through in-depth qualitative research and outreach/public engagement projects, HWE hopes to positively influence the commissioning and delivery of health and social care in Essex.

## ***Methodology***

This study aimed to generate an in-depth understanding of the experience of caring for a friend or family member, rather than to offer a representative or

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<sup>1</sup> Throughout the report the term carer applies to: adult unpaid carers, young carer and unpaid carers below the age of 18. Young carer is defined as somebody who provides unpaid care for another person because of long-term physical or mental ill-health, disability, or problems relating to old age. This is based upon the definition used in the 2011 census and is sufficiently broad enough to encompass the full range of caring tasks that carers are engaged in.

wide-scale review of unpaid care in Essex. Therefore, to gather in-depth accounts of caring, we adopted a qualitative methodology. The views of adult and young carers were gathered using the following methods:

### *Audio diaries and video interviews*

- Seven carers completed a ten-minute audio diary entry, every day for a period of two weeks. They spoke about their day-to-day experiences of caring and of support services. This method allowed us to gather data that conveyed the daily aspects of care that are little understood by non-carers.
- Six of the seven adult carers agreed to take part in a one-to-one interview. Three of these took part in video interviews. During the interviews the carers were asked to tell the interviewer their story of being a carer. They were then asked follow-up questions based on their account. This approach allowed the carers to tell their story, reflecting on their experience of caring across time. It also enabled them to expand upon issues raised in their audio diaries.

### *Focus group*

- Four young carers took part in a focus group where they were asked about their experience of caring for a sibling. The focus group allowed the young carers to discuss their experiences with their peers in a relaxed and comfortable environment. They were able to direct the topic of discussion, with some guidance from the researchers facilitating the group.

## *Key findings*

The use of qualitative methods in the form of audio diaries, interviews and focus groups to explore carers' experiences of caring provided a rich, textured and in-depth insight into their everyday lived experience. Our research demonstrates that caring relationships are already embedded within an existing relationship, such as friendship or family and, as such, the experiences of being a carer are multi-layered and complex. Carers did not primarily identify themselves as carers but used the pre-existing relationship bond to define their identity.

Our participants' accounts highlighted the profound sense of love, care and commitment they felt towards the person they were caring for and it is such feelings that motivate and propel the decision to care. However, this was experienced alongside feelings of guilt, isolation, despondency and powerlessness - feelings that have a negative impact upon carers' own health and wellbeing. These emotional foundations of care influenced every decision made about caring for someone, including whether to continue caring full-time. These emotional aspects and the time taken up with caring also meant that carers had a tendency to prioritise the wellbeing of those they care for over their own needs and were therefore less likely to identify themselves as carers or to seek care, support and advice about their own welfare.

The emotional dimension of care cannot be separated from the experience of formal and informal support services. Whilst positive support that is delivered with understanding and empathy can have great benefit for carers, support systems, including the experience of carers' assessments, were often found to be unnecessarily bureaucratic and impersonal. This further compounded the feelings of isolation, despondency and powerlessness.

The study also highlighted contextual factors of the caring role, revealing how this is enacted in day-to-day activities, locations (at home and outside the home), in the context of daily rhythms, and in imagining and anticipating the future.

The young carers who took part in this research experienced a lack of understanding from friends and professionals and their experience of friendship, education and family life was characterised by a sense of being the ‘same but different’. Young carers groups were helpful to the young carers in our study. They provided them with a space to relax, socialise and study. The young carers in our research described not recognising themselves as such until a parent sought support on their behalf. They often felt unsure about who to talk to about being a young carer; whilst they wanted support they were also reluctant to draw attention to themselves and receive unwanted attention.

Whilst many of the study’s findings are common to both adult and young carers, we have summarised the main themes separately below.

### *Adult carers*

Three key areas emerged from the analysis of the audio diaries and interviews:

- The significance of emotions, relationships and care.
- The experience of formal and informal support services.
- Contextual factors of caring as experienced in physical **places** and **spaces** and at various **times** of the day.

## Emotions, relationships and care

Caring roles are embedded in relationships. Caring was often undertaken and continued because of a commitment to a pre-existing and reciprocal relationship. Every decision the carers made about care was born out of this relationship. For example, Harry, one of the participants, decided to care for his wife Jean at home because of a commitment to their marriage vows and viewed this as part of his role as Jean's husband.

Carers often described feeling guilty, isolated, despondent and powerless in their caring role. This created a stress point for carers who, although often committed to continue caring, did so at emotional cost to themselves.

## Formal and informal support services

The carers accessed a range of formal and informal support across time, both for themselves and on behalf of, or with, the care recipient. These included support groups, health and social care services, carers' assessments or carers' allowances, in addition to informal support from family, friends and Good Samaritans<sup>2</sup>. The carers also demonstrated a high level of expertise relating to both the condition and personal biographies of the people they cared for.

A contrast between formal support systems and informal support networks was evident in the accounts. Formal support systems were characterised by poor access, lack of continuity and often left carers feeling isolated and uncared for. These systems also failed to acknowledge and utilise carers' expertise. In contrast,

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<sup>2</sup> The term Good Samaritan is used, instead of stranger, to describe a person unknown to the carer, yet helpful and supportive of them. This is likely to be momentary and fleeting support.

successful support networks included professionals, family, friends and Good Samaritans who offered personalised, specific support, delivered with understanding and empathy.

### Spaces and temporalities of care

The audio diaries in particular offered a rich and detailed insight into the experiences of carers in the context of their everyday lives, highlighting the physical spaces and places where caring occurred, as well as the amount of time caring consumed. Caring took place across numerous private and public spaces, access to and experience of these impacted upon the carers' wellbeing. Private spaces, such as the home, can become professionalised when paid carers and other professionals are present. When paid care was regular and reliable it could be an effective means of support for carers. However, when it lacked continuity it could make the carer feel out of control in their own home and further undermine their emotional and physical wellbeing.

The use of public space illustrated how the needs of the carer cannot be separated from the needs of the care recipient. For example, poor wheelchair access meant that public space was experienced as unwelcoming and inaccessible for one carer and her son, who was a wheelchair user. Not only did poor access to public places impact negatively on the person being cared for, it was a source of daily frustration for carers when trying to access shops, eating out, holidays, days out and so on. Public attitudes can help ease some of these difficulties and frustrations. For example, one carer was able to elicit support from fellow coach travellers when taking his wife, who had dementia, on short breaks. However,

others experienced negative and unhelpful responses, which further added to a carer's sense of frustration and isolation.

Time emerged as an important feature for those participating in the audio diaries and interviews. Firstly, carers were engaged in care tasks 24-hours a day, seven days a week. This included the repetition of daily tasks, such as helping the care recipient wash and dress, assisting at mealtimes and the use of time alone to complete the administrative aspects of caring. Consequently, carers had very little time to pursue their own hobbies and interests. Secondly, the carers described their parallel lives, those lives they imagined they would have if they were not caring, which might involve enjoying more freedom in retirement or not having sole responsibility for domestic tasks. Finally, the carers imagined the future to different extents. Imagining future care arrangements was challenging because it inevitably involved thinking of a time when they were no longer able to continue caring, accompanied by a sense of foreboding and loss. Since support services were often, at best, just meeting a present need, professionals did not facilitate involving them in future planning. This inability to plan the future care needs of the person being cared for contributed to a carer's sense of disempowerment and further negated their independence and sense of wellbeing.

### *Young carers*

The analysis of the young carers focus group concentrated on their experience of feeling 'same, but different' to their peers. They discussed their experience of friends, school and family life and the ways in which this experience of difference impacted upon each of these. Whilst spending time with friends, completing homework and familial relationships were all recognisable experiences to young

people, for young carers these were filtered through their caring role. They felt that it was more difficult for them to socialise, to complete school work and to find quiet and calm places in the home, in comparison to their peers. The young carers also described their difference from their peers in positive terms, highlighting the knowledge and understanding they gained from their caring responsibilities.

The young carers felt that people needed to listen to them to really understand what it was like to be a carer, to appreciate that caring is an ongoing experience and that there are many different facets to the role. Young carer groups were pinpointed as places where they felt understood and did not have to explain themselves to others. They were important places for diminishing, albeit temporarily, their sense of difference.

## ***Recommendations***

Recommendations for practice have been divided into recommended improvements for existing schemes or policies and recommendations for new services and practices.

### ***Improving existing practice:***

- (1) **Personalised support:** support for carers should be personalised and targeted; offers of respite and other support are not always a suitable match for the carer's needs. Provision should take into account the holistic needs of the carer, care recipient and other significant people (i.e. family members). Carers should be enabled to access support that helps them meet their own particular needs and circumstances. This may include support

with domestic work, administrative tasks, specialist family holidays or more flexible respite care to allow carers to pursue other activities.

- (2) **Partners in care:** care providers and professionals must recognise that the carer's knowledge and expertise is an essential component of adopting a holistic approach to care and treatment. Shared information and understanding between carers and professionals has reciprocal benefits. Carers and care recipients should be viewed as partners in care and be involved in the co-production of service provision and be asked to road-test information sites, procedures such as carer's assessments and the accessibility of public spaces.
- (3) **Empathy and understanding:** carers need to trust the health and social care professionals who provide care. It is vital that they feel cared for and listened to throughout. Trust in health and social care services can be eroded by a series of instances and so practitioners must endeavour to ensure that every interaction with a professional is a positive one. It is particularly important that carers feel listened to and our research, which supports other research, shows that whilst carers play a vital role in caring for many of the vulnerable, elderly, ill and frail members in our society, their voices are often not heard or ignored by medical or healthcare professionals and those administering such services.
- (4) **Reduction in bureaucracy:** support systems (assessments, information seeking, etc.) need to be made more streamlined, less confusing and bureaucratic. They should be based upon principles of care, understanding, support and empathy to ensure that carers have a positive empowering

experience of seeking and accessing support. Developing a centralised cross agency system so carers do not have to repeat information to different service providers would make the process easier and less frustrating.

- (5) **Ease of access to information:** information about support and care services must be easily accessible and readily available to carers. The numerous professionals with whom they come into contact should have access to information to enable them to direct carers for support, and be proactive in doing so. Schemes such as Making Every Contact Count should be extended to focus specifically on carers' needs, to ensure that practitioners at every stage are supported in identifying and advising carers. Information such as that provided on the telephone by HWE's information services should be made available to all carers. The establishment of a new multi-organisational service, Supporting Carers in Essex, which has recently been commissioned by Essex County Council, should help with the provision of information, advice and support to carers across the County.
- (6) **Increase provision of young carer groups:** continued and increased support for young carers is essential. Support groups that offer a wide range of activities and opportunities to relax in a safe environment away from the home are particularly valued by young carers and are important for their present and future health and wellbeing. Raising awareness more generally amongst schoolteachers and pupils about the demands placed on young carers may also help to reduce the stigma many of them experience.

## *Developing new services and practice*

- (7) **Support at transitional periods:** targeted and personalised support is required at key points in the caring trajectory to help carers and care recipients navigate decisions and ensure continuity of care. Decisions about future care are complex and emotionally loaded. Likewise, transitions between care provision, such as from child and adolescent to adult services, is equally challenging. Given that carers are concerned about what will happen to the care recipient as and when their condition deteriorates, or if the carer him or herself is no longer capable of continuing to provide care due to ill health, support and open discussion should be provided. These interventions should occur in advance of the transition to ensure carers feel supported and that care provision is in place ahead of any transition. This is important, not only to facilitate a sense of carer control and independence but also to maintain carers' health and wellbeing.
- (8) **Tackling poor perceptions about residential care services in Essex:** care providers must identify and respond to the reasons for a lack of trust amongst carers' regarding the quality of care homes in Essex. Carers often have personal experience of poor quality care in care homes and this, coupled with negative media portrayals and a general reluctance for social services to promote care, leads to carers' negative views about such homes and feelings of guilt about them as a future option. However, many care homes provide a very good standard of care and, for many families, will be the best place option. It is essential to find ways of rebuilding carer confidence in these services, in consultation with carers and care recipients.

A lack of trust and negative experience of social care services, particularly residential care, can lead carers to continue to care, despite a negative impact on their own health and wellbeing.

- (9) **Advocacy:** independent advocates should be provided to offer information and support. This service should be routinely offered to carers from the outset and at regular intervals. This is particularly important where the person being cared for has a deteriorating condition, such as dementia, or where those undertaking the role are likely to be doing so for many years, as in the case of parents caring for grown-up children with long-term disabilities. It is crucial that the assessment process does not become another bureaucratic exercise, but that person-centred advocacy can be provided for carers throughout the care trajectory.
- (10) **Health and wellbeing:** GPs and their services should be directed to identify any carers known to them and should proactively seek out these patients and offer them regular health check-ups. Such services should signpost carers to local befriending services, such as Community Agents, who provide a network of agents and volunteers to support older people and informal carers to find and develop independent living solutions from within their local community.
- (11) **Good Samaritan scheme:** informal community support for carers should be facilitated and encouraged. Hairdressers, fellow holidaymakers and others can all enable carers to access public spaces with their family members. A scheme that encourages such Good Samaritans would involve accrediting local businesses whose employees receive training in disability awareness

and incorporate it into their customer service. In addition to ensuring that physical spaces are accessible and safe, it would also involve employees in developing augmentative and alternative communication skills and an understanding of the needs of both carer and care recipient. The scheme could be developed in collaboration with carers and care recipients.

- (12) **Support innovative voluntary sector schemes:** further strengthen the local voluntary sector to deliver innovative projects, such as the Community Agents scheme. This recently initiated scheme helps vulnerable older people and informal carers to identify, source and implement solutions to the issues they face, helping them to find support from within their own natural and community networks. Such schemes help to address loss of confidence, social isolation, and they empower and enable carers to gain a sense of control.
- (13) **Increase education about young carers:** trained workers should facilitate discussion groups in schools and youth groups about the experiences of young carers. This would aid young people's understanding of being a young carer without the young carers themselves having to lead the conversation, unless they felt able to do so.
- (14) **Talk to young carers about their needs:** young carer workers in schools and youth groups could facilitate conversations between young carers and other professionals about their support needs. This would give young carers control of who knows about their caring responsibilities and would ensure that they felt included and empowered.

## Introduction

This study responds to a 2013 HWE AGM motion to raise the profile of carers needs (Penfold, 2013). Preliminary HWE research (Milne, 2014), along with the HWE Voice Network film featuring carers, highlighted the emotional, practical and financial challenges of caring and the need to place carers' voices at the centre of discussions about support provision. This study places the lived experience of carers at its centre, attending in particular to the day-to-day experience of caring and of formal and informal support provision. It is set in the context of important changes to UK social care provision outlined in the Care Act 2014.

HWE is an independent organisation committed to producing high quality research that explores people's lived experiences of health and social care services in Essex. Listening to the seldom heard voices of carers is a key aspect of our research strategy. In capturing and articulating people's experiences through in-depth qualitative research and outreach/public engagement projects, HWE hopes to positively influence the commissioning and delivery of health and social care in Essex.

## Background

The 2011 census (White, 2013) identified approximately 5.8 million people providing unpaid care in the UK, this was almost 10% of the population<sup>3</sup> and a 10% increase since the 2001 census.<sup>4</sup> Carers UK have estimated that the national

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<sup>3</sup> Of this 10%, 6.5% provide care for between 1-19 hours per week; almost 1.4% provide care for 20-49 hours per week and 2.4% provide care for 50 or more hours per week.

<sup>4</sup> There were 600,000 more unpaid carers in 2011 compared with 2001; this growth is at a faster pace than the increase in population growth during this period in England and

economic value of carers' contributions is £119 billion annually (Buckner and Yeandle, 2011). In Essex specifically, Buckner and Yeandle reported a 12% increase in carer numbers between 2001 and 2011. There had been an increase in the number of young carers across all areas of England and Wales since the 2001 census (ONS, 2013a). The 2011 census identified 177,918 young carers in England and Wales (defined as 5-17 year olds), 54% of whom were girls and 46% boys.

According to the 2011 census over 10% Essex residents provided care to a family member, friend or neighbour, each making an estimated £2,426.80 annual economic contribution (Buckner and Yeandle, 2011). A county-wide Joint Strategic Needs Assessment (JSNA, 2013) estimated that 66% of Essex carers were caring for less than 19 hours per week, 12% providing care for between 20 and 49 hours per week and 22% for 50 or more hours per week. Adults who provided 50 hours or more of unpaid care tended to have worse health outcomes and were less likely to be in employment than their peers (Penfold, 2013). Almost half of Essex's carers were aged over 50, although, in a briefing paper prepared for the HWE Strategic Body, Penfold (2013) placed this figure at 60%. Two thirds of Essex carers were in paid employment and it was estimated that young carers made up 2.4% of the county's carer population (JSNA, 2013).

Between 2001 and 2011 a number of Essex districts, specifically Braintree, Maldon and Uttlesford, had an above average increase in the number of people caring for 20 or more hours per week (Penfold, 2013). Despite this increase, support for carers was found to be fragmented, with service provision patchy across the county (Penfold, 2013). A Carers' Survey of South East Essex was carried

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Wales. London was the only region with a decrease in the number of carers (ONS, 2013b).

out in 2011<sup>5</sup> (MG Consultancy, 2011) as part of a multi-faceted mapping exercise to develop new strategies for carer services. The survey found that services, when accessed, were generally well received, however, adult respondents reported financial barriers to accessing services and there was a concern that there were not enough services to ensure equal access for all. A need for information and advice on what support is available was also identified. Young carers highlighted the need for educational support and the continuation of young carers groups, which were generally found to be very helpful. Young carers also felt that more could be done by GPs and schools to identify young carers and provide services for them.

## **Prior research**

The emotional and physical challenges of caring, and the difficulties in accessing adequate support and information, are well documented (for example, Arksey and Hirst, 2005; Carduff *et al.*, 2014; Milne, 2014). Research indicates that carers report an increase in anxiety, depression and other mental health conditions, and in physical injuries or illness, such as back pain, as a result of their caring role (Brown and Mulley, 1997; Carers UK, 2015; Girgis *et al.*, 2013; Maher and Green, 2002; Schulz *et al.*, 1990). It is suggested that rates of anxiety and depression in carers often exceed that in care recipients (Girgis *et al.*, 2013).

A recent report by Carers UK (Carers UK, 2015) provided a snapshot of caring across the UK and illustrated the impact of caring upon carer health,

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<sup>5</sup> As a partnership project between Southend Carers Forum, Supporting Carers and Families Together, Crossroads Care and NHS South East Essex

finances and wellbeing. Amongst the 4,572 carers who completed the survey: a majority reported higher levels of stress, anxiety, depression and concern for relationships with family and friends as a result of their caring responsibilities; 48% of carers reported struggling financially and 40% wanted increased financial support for carers to be a government priority; 82% felt that caring had a negative impact on their health, 74% reported difficulties in sleeping and 76% were concerned for their future health; 29% asked the government to make practical support for carers a top priority.

Studies suggest that various factors influence the impact of caring upon the carer, including the relationship to the person being cared for, the level of dependency of the care recipient, and the resources and support available to both carer and care recipient (Berg *et al.*, 2005; McCullagh *et al.*, 2005; Suh *et al.*, 2005). Girgis *et al.* (2013), in a meta-analysis of studies with carers of people with cancer, found that a number of factors increased the risk of anxiety and depression in the carer. These included: being younger and female; living with the care recipient; having a poor relationship with the care recipient; lower levels of social support; and being unprepared for caregiving. Carers' experiences are, therefore, formed through various conditions.

Preliminary HWE research (Milne, 2014) highlighted the complexity of caring for a family member and the ways in which existing familial relationships shift as a result of the carer/cared-for dyad. The caring role can result in changes in identity for the carer and this change is something that can impact upon their access to support services or their decision to continue caring. One interviewee in this preliminary research, for example, described how her husband stated during the carers' assessment that he would always care for his son, because he was a father.

Here, the identity of carer is inextricably linked to the identity of father, perhaps making it even more difficult for the carer to state that they are in need of support, or that there may be a point when they are no longer able to care (Milne, 2014).

There are additional and specific pressures placed upon young carers. Research has suggested that, in comparison to their peers, young carers have poorer health and wellbeing, are unhappier, have an increased likelihood of being bullied and poorer educational aspirations (Butler and Astbury, 2005; Lloyd, 2013). McAndrew *et al.* (2012) found that young carers experienced support services as good in places, but lacking in consistency. Young carers also reported not being listened to by professionals and feeling undermined and ignored (McAndrew *et al.*, 2012). Barry (2011) found that, whilst young carers reported good familial relationships, they used friendships, school and support groups as a means of respite or freedom from the home. Young carer groups in particular offered opportunities to socialise, a release from responsibility and avenues of emotional support. However, the young carers in Barry's study also expressed a mistrust of professionals, possibly out of a desire to protect their family from interference. Condition-specific experience must be taken into account when addressing the needs of young carers; research with young carers of adults with Huntington's disease suggested that young carers need support services that offer specific and personalised instrumental (information and advice) and emotional support (Kavanaugh *et al.*, 2014).

This brief overview of the existing literature demonstrates that there are multiple facets to the caring role. The practical aspects of gaining access to health and social care services as a carer cannot be separated from the emotional

complexities of caring and the impact this has on relationships and identities. To understand these complexities for carers in Essex, this research used in-depth qualitative methods to explore the everyday, lived experience of caring. Paying attention to the voices of carers is a key means of understanding the entanglement of relationships, identities and emotions and the experience of support and services.

## *Policy*

The Care Act 2014, which applies to adult social care, came into force in April 2015 and signals a historic overhaul of the social care statute in England. The Care Act 2014 removes the requirement that carers need to be providing a ‘substantial amount of care on a regular basis’ to be entitled to an assessment. Local authorities are now required to undertake an assessment when a carer appears to have support needs of any level and to meet eligible need. For carers who do not meet eligibility, the local authority are required to provide written information and advice about what can be done to meet or reduce their needs. The Children and Families Act 2014 similarly gives young carers the right to an assessment on the appearance of need.

The Department of Health (DoH 2014) has identified four priority areas in relation to carers:

- Identification and recognition
- Realising and releasing potential
- A life alongside caring
- Supporting carers to stay healthy.

These priorities reflect a concern with supporting carers to care effectively and safely; to look after their own health and wellbeing; to partake in education and employment; and to have a fulfilling life outside of their caring responsibilities. Aspects of the Care Act 2014 received criticism from the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS). Both suggested that the money set aside to implement the changes was inadequate, as it is unclear how many carers will come forward for assessment.

Since the Carers and Disabled Children Act 2000 the right to an assessment of support needs that takes into consideration carer's health and wellbeing has been part of UK legislation. Both the Care Act 2014 and the Children and Families Act 2014 place further responsibilities on local authorities to support carers and young carers. However, whilst legislation attends to the health and wellbeing of carers, research suggest that carers experience isolation, a lack of recognition and support and are often unsure of their entitlements (Arksey and Hirst, 2005; Carduff *et al.*, 2014).

In response to the Care Act 2014, Essex County Council (ECC) has developed a new carers' strategy for the period 2015-2020. At the heart of the strategy is the intention to support carers of all ages to maintain health, wellbeing and life opportunities, and to recognise carers' expertise and ensure that they are considered 'partners in care'. The strategy involves developing existing services, conducting pilot schemes and developing new services for carers. This includes: an online information portal; befriending schemes and support networks; developing targeted age- or condition-specific support; focusing on the transition from young

to adult carer; and providing school link workers in every secondary school across Essex.

The strategy is based around four areas, firstly, community based and led activities that help carers find support and assistance within communities. Secondly, local first-stop services that provide and co-ordinate access to a range of support in each Clinical Commissioning Group area. Thirdly, social care assessments and support that ensure carers are assessed in line with the Care Act 2014. Finally, professional awareness and engagement that takes carers' contributions and support needs into consideration when commissioning services (ECC, 2015a). The strategy aims to prioritise carers' health and wellbeing, provide individualised support, facilitate independence, choice and control, and prevent problems by pre-empting need.

## ***Research aims***

This study aimed to capture the lived experience of carers in South Essex. Through audio diaries, video interviews and focus groups it sought to understand the day-to-day experience of caring and to provide some insight into the experience of formal and informal support provision. To bring carers' voices to the centre of the discussion about carer health and support needs it aimed to:

- Capture the lived experience of adult and young carers
- Understand the emotional aspects of caring
- Gain insight into the experience of formal and informal support networks.

This research is not intended to provide a comprehensive overview of carer support and related services across Essex. Rather, it is concerned with providing a

detailed picture of the daily lives of some carers and their experiences of caring, to capture depth rather than breadth of experience. This approach complements the broader, large-scale surveys already discussed, which usefully set this research in the context of caring in Essex and the UK more widely. As is discussed in the following section, a small sample size and qualitative approach were selected to meet this aim.

### ***Outcomes***

Our study findings raise awareness about the lived experiences of carers in Essex and provide recommendations for improving support services.

## Methodology

### *Exploring lived experience*

This research is concerned with gathering the lived experience of carers as a means of developing a deeper understanding of carers' everyday lives. Lived experience is a concept founded in the work of German philosopher Edmund Husserl. Phenomenology is the study of lived experience, concerned with exploring the world as it is lived, rather than categorising experience using fixed, binary thinking or abstract theory (van Manen, 1990). Researching lived experience involves the researcher engaging empathetically with participants' accounts to gain an understanding of the world as they experience it.

Narratives are an important part of exploring lived experience, as Max van Manen writes: 'aren't the most captivating stories exactly those which help us to understand better what is most common, most taken-for-granted, and what concerns us most ordinarily and directly?' (van Manen, 1990:19). Storytelling is a means of making sense of experience of the world (Lindseth and Norberg, 2004). Phenomenological research, therefore, is concerned with a close reading of individuals' stories about their lives.

Meeting this concern required an approach that was able to capture the intricacies of carers' day-to-day lives, shining light on experiences that are not always known about or understood. Qualitative methods are an effective means of capturing experience in this depth and so this study adopted a qualitative approach, using audio diaries, video interviewing and focus groups. Using multiple methods offered participants various means of articulating their experience, recognising that narratives are context specific and change their tone and focus

dependent on audience and mode of production. The chosen methodology is outlined here, the methodological choices, recruitment, sampling, ethical issues and the research's strengths and weaknesses, are described in detail in Appendix 1.

## **Methods**

The following methods were deployed:

- Audio diaries from seven adult carers
- Video interviews with six adult carers
- Focus group with four young carers.

### *Audio diaries*

Seven carers were given a digital audio recorder for a period of two weeks and asked to record daily entries for around ten minutes per day, documenting their thoughts, feelings and experiences of being a carer. The participants were offered guidelines for completing the diaries (Appendix 2), but it was emphasised that the participant could talk about whatever they felt was relevant. At the end of the two-week period the audio recorders were collected by the researcher and the entries transcribed by a transcription company.

### *Video interviews*

Following the completion of the audio diary stage of the study, the same participants were invited to a one-to-one video interview, although given the option of an audio interview if they preferred. All the interviews took place at the

participant's home. During the interviews the participants were asked to tell their story of being a carer. This approach allowed consideration of the participants' experience in its biographical context. In addition, it gave participants the opportunity to direct the content of the interview, allowing them to discuss experiences of caring that may be overlooked by a more structured interview schedule. Following this initial part of the interview, the participants were asked questions based upon their account, allowing the researcher to elicit more information about specific events. Finally, the researcher asked additional questions, if they had not already been discussed. These were based upon key areas of interest identified in collaboration with the steering group, which were: carer identity; support services; work and leisure (for a full interview schedule, see Appendix 3).<sup>6</sup>

### *Focus groups*

Four young carers participated in the focus group, which took place at the weekly young carers group they all attended. Snacks and drinks were provided to create a welcoming and relaxing atmosphere. Two researchers facilitated the group. To begin with they reiterated the aims of the research, discussed confidentiality and anonymity and gave an overview of the focus group structure. Group members, including the researchers, then introduced themselves and said one thing that they enjoyed doing or were interested in. This was designed to encourage the participants to contribute to the discussion.

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<sup>6</sup> This approach was based upon the Biographical Narrative Interpretive Method interview approach (Wengraf and Chamberlayne, 2006).

Following this icebreaker the group discussion was structured around the following questions:

- What does being carer mean?
- What does a typical day involve?
- Who helps you with your caring role?
- What should people know about being a young carer?

This design drew on recommendations for conducting focus groups with young people from Sinner *et al.* (2012). The questions were developed in consultation with the project steering group and the young carers' co-ordinator at the organisation the young carers attended.

## ***Participants***<sup>7</sup>

### ***Adult carers***

Seven carers were recruited for the study. All completed the audio diary and six agreed to be interviewed. Of these six, three chose to be video interviewed.

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<sup>7</sup> All participants have been given a pseudonym that is used throughout this report to ensure anonymity.

Name	Age	Ethnicity	Socio-economic class	Cares for	Care recipient age	Hours caring	Years caring
Alison	55	White English	-	Son	27	24/7	27 years
Debbie	64	White British	Middle class	Mother	92	24/7	-
Fred	71	British	-	Wife	72	24/7	-
Edel	73	Irish	-	Wife	75	24/7	-
Jen	59	White English	Working/ middle class	Son	21	24/7	21 years
Harry	74	English	-	Wife	72	24/7	2-3 years
Simon	48	White British	Middle class	Mother	81	24/7	2 years

Table 1: adult carer participants

As demonstrated in Table 1, there was some diversity in age of carer and care recipient, relationship to care recipient and the number of years caring. There was little diversity in self-defined ethnicity or time spent caring. Four of the seven carers decided to leave their socioeconomic status blank, therefore any diversity here is unclear. One of the key gaps in the sample was that of working carers; none of the carers interviewed were currently in full- or part-time paid employment. As a small scale, qualitative piece of research extensive diversity was not expected, it does, however, offer some directions for future study, as discussed later in the report.

Some of the carers provided more detailed descriptions of themselves and the person they cared for:

- Alison is 55 years old, a wife, mother and grandmother. She loves the theatre, reading, crosswords and spending time with family and friends. Her son Daniel is 27 years old. He loves being out with his friends and family. He enjoys the theatre, the soaps (such as Eastenders), football (supports Liverpool), music and drama
- Debbie is 64 years old and enjoys painting and spending time with her husband. She has cared full-time for her mother since she came to live with them in 2010. They had recently moved to the coast and enjoy living by the seaside
- Jen is 60 years old and enjoys reading, sewing and going to the cinema. Her son Tom is 21 years old and loves animals, drawing, going to theme parks and doing DIY jobs around the house and in the garden

- Harry is 74 years old and enjoys looking after his pigeons and working in his allotment. His wife Jean is 72 years old. She has always loved gardening, growing flowers in particular. Both Harry and Jean enjoy spending time with their family, who live nearby
- Simon is 48 years old and enjoys singing, reading and doing word searches. Simon's mother is 81 and likes watching television, doing jigsaws and crosswords.

### *Young carers*

Four young carers participated in the focus group.

Name	Age	Cares for
Abi	15	Brother
Geoff	13	Brother
Rosa	14	Sister
Steve	13	Sister

Table 2: young carer participants

The background information was less comprehensive for the young carers. At the young carers group the participants attended, they only shared information about their caring status if they chose to. To ensure that the young carers felt comfortable and safe in the focus group environment, particularly as they had not met with the researchers prior to the group taking place, we adopted this approach and did not ask them to provide extensive personal information before or

during the focus group. The young carers only shared information about their caring responsibilities with the researchers and each other if they chose to.

One of the young carer's questions during the group indicated that this more cautious approach was justified. Geoff asked numerous questions about the research aims, dissemination and our motivation as researchers. He was also very interested in who would listen to the recording or read the report. When reflecting on who he could or could not trust, he referred to the audio recorder:

Geoff: Like with that little thing.

Carly: With the recorder?

Geoff: Yes.

Carly: What do you mean? Do you-?

Geoff: Like when you take this away a bunch of people are going to be listening.

Carly: And are you sort of worried about who is listening to it?

Geoff: Not really. But it's just you never know.

Ofra: It's going to be us basically and maybe another colleague.

Geoff: Yes, but you never know.

Ofra: But then we write it up so yes.

Geoff: Someone might steal it and then find out where we are. (Laughter)

Carly: We are going to be really careful with it so they won't be left on the recorder which is important

(Focus group, l. 1266-1290)

Geoff asked numerous questions like this, although he laughed at his comments and at gentle teasing from the other young carers, his questions might have indicated a mistrust, suspicion or lack of clarity regarding the process. Incorporating conversations into the focus group, and prior to the study, about the aims of the study and use of the data was an important part of ensuring that the focus group provided a safe space for young carers to discuss their experiences.

The young carers gave the following descriptions of themselves during the focus group:

- Abi is 15 years old. She enjoys cooking and wants to be a chef when she is older
- Geoff is 13 years old. He likes food
- Rosa is 14 years old. She enjoys horse riding
- Steve is 13 years old. He likes playing on his Xbox and playing football.

## ***Analysis***

The data from the audio diaries, interviews and focus group were analysed using thematic analysis, which identified patterns and themes across the data. The audio diaries and interviews were analysed together while acknowledging the differences between the types of data. The focus group was analysed separately as data that offered insights into young carers' experiences.

## ***Ethics***

Ethical approval was sought from the Essex County Council Ethics Committee and awarded in December 2014. A number of steps were taken to ensure this research adhered to high ethical standards, as outlined in Appendix 1.

## ***Research team***

The study was carried out jointly by Dr. Carly Guest, Dr. Oonagh Corrigan and Dr. Ofra Koffman. The data collection was carried out by Dr. Carly Guest and Dr. Ofra Koffman and the data analysis by Dr. Carly Guest and Dr. Oonagh Corrigan.

A steering group was established to monitor progress and advise at every stage. It consisted of:

- Wendy Burt, Healthwatch Essex Strategic Body Member and co-ordinator of the Essex Carer Network
- Dr. Oonagh Corrigan, Commissioning and Research Manager, Healthwatch Essex
- Dr. Carly Guest, Research Associate, Healthwatch Essex
- Dr. Susan McPherson, Senior Lecturer, School of Health and Human Sciences, University of Essex
- Amy Young, Healthwatch Essex Youth Ambassador.

## Analysis: audio diaries and interviews

Across the audio diaries and interviews three themes were identified

- Relationships, emotions and care
- Formal and informal support services
- Spaces and temporalities of care.

Each theme was explored through a detailed discussion of the participants' experiences. This ensured that, whilst the analysis was grounded in the experiences of all the participants, the discussion of the themes offered a detailed and sensitive exploration of experience, thereby generating understanding and insight into the lived experience of caring.

### *Relationships, emotion and care*

'I love you. You're safe. I'm with you. I will never leave you on your own.' I tell her. (Harry, interview, l.1051-1053)

The carers who took part in the study all provided unpaid care for a family member. This relationship was central to the experience of caring; carers made decisions relating to care that were informed by and born out of pre-existing relationships. This section considers how the carer's relationship to the care recipient influences decisions made about care. It goes on to explore the deeply emotional element of the carers' experiences. In particular, the way emotions are made visible and managed through key moments of care and the feelings of guilt, isolation, despondency and powerlessness expressed in various ways by each of the carers. A tension emerged between the carer's commitment to caring and the challenging emotions that can characterise the caring experience. It is a tension

point that creates stress and requires sensitive and considered support.

### *Caring within relationships*

Relationships were central to the participants' accounts; their experiences of caring were embedded in a profound interconnectedness between themselves and the care recipient. Pre-existing understandings of what these relationships entailed infused the accounts and formed part of the carers' motivation for, and commitment to, caring. For example, Harry and Jean had been married for 52 years or, as he affectionately and poetically described it: 'two jail death sentences plus. 1963, married in that winter, three months of snow' (Harry, interview, l. 1076-1077). Harry began caring for Jean following a diagnosis of vascular dementia at the end of 2013. His understanding of and commitment to caring for Jean was embedded in the context of their marital relationship. The love and affection Harry and Jean had for each other was clear in his account of caring for her. Reflecting on their relationship he said:

'Cause, you know, she says, 'I love you,' and she said, 'You're super. I don't know what I'd do without you'. So I said, 'Well, we're married and that's it. You'd look after me, I look after you, until death us do part'. Then we have a cuddle and then everything's okay. (Harry, interview, l. 1063-1068)

In citing his marriage vow, 'until death us do part', Harry offered a context for his care of Jean. There was a reciprocal and mutual agreement that was being adhered to by Harry, one based on love, affection and commitment. It was not possible to separate the care Harry provided for Jean, nor Jean's receipt and appreciation of it, from their marital relationship. The roles of carer and care recipient were embedded in this relationship. Harry understood his role as carer

for Jean as being part of being her husband and adhering to the vows they took together.

This emotional and relational foundation of the caring experience revealed something of the reasons and motivations for undertaking care of a friend or family member. There were numerous examples of this across the audio diaries and interviews. For example, Jen, who cared for her son Tom, who has autism, described her care role as an extension of maternal care for her children. When asked how she felt about the term carer she responded:

I don't- I'm, I'm his mother. Mothers care ... I don't need to be, I mean, I know I'm his carer, but then, as I said, I cared for my daughters as well. (Jen, interview, l. 1208-1213)

Both Harry and Jen constructed their caring roles through familial relationships and their understanding of what these entailed. This relational context had emotional and practical implications for the carers. It was evident, for example, that decisions about how and when to use paid care were embedded in the carer/care recipient relationship. During the interview Harry contemplated a time in the future when full-time paid care for Jean might be necessary. However, he had rejected this option following her initial diagnosis, discussing this decision to care for Jean at home, he said:

But I'd hate her to have gone into a home because you just see them in there and they're just sitting around, you know, and she would just vegetate and I wouldn't want that. She's quite, she was quite capable of going out for a walk and coming back, all that sort of thing. And I thought, 'No, I can't have that. I can't have my loved one go there whilst I'm here on my own all the time'. (Harry, interview, l. 561-567)

Harry's reluctance for Jean to be in residential care was based on concerns about the adequacy of care and its impact on Jean's wellbeing, independence and autonomy - this was a concern expressed by many of the participants and considered later in this report. However, as we can see from Harry's comments, residential care for Jean would also mean a loss of companionship for him and so decisions about Jean's care were always intertwined with and influenced by their relationship. The terms Harry used to describe Jean throughout the audio diary and interviews - 'darling', 'my valentine', 'loved one' - foreground their husband/wife rather than their carer/care recipient relationship. It was through the marital relationship that the carer relationship was formed and understood and decisions were made about care.

This was also evident in Simon's account of caring for his mother, who was diagnosed with dementia following two strokes in 2013. Simon and his mother had a very close relationship and this bond was at the centre of Simon's decision making about his mother's care. Despite working under extreme pressure as her sole carer, with little other support and with health difficulties of his own, Simon was determined to care for his mother at home. His reasons for doing so centred, like Harry, around concerns about full-time paid care, but also because of a reciprocal care relationship:

But to reiterate really that mum is my mother. She looked after and cared for me all those years and I therefore feel and want to look after her the best that I possibly can, for as long as I possibly can. And that is indeed what I intend to do. (Simon, audio diary, 1263-1267)

Simon had a sense of responsibility and duty to care for his mother; it was a reciprocal care arrangement where Simon's care of his mother acknowledged her

care of him. As Marian Barnes (2012) suggests, drawing on a notion of reciprocity can bring a sense of autonomy, pride and purpose to the caring role. It was evident in Simon's account, and something he explicitly commented upon in his audio diaries that, despite the challenges of caring, it was also a role he enjoyed and one that offered him a sense of purpose:

I actually love looking after mum and I'm pleased that I'm able to do so. So I wouldn't want the view to get out that I'm finding it totally a burden, 'cause I'm not. Although, yes, it is difficult and yes it is most definitely tiring, but I don't really find it a burden and I wouldn't want to give the impression that I do. I love my mother and I, I don't see her as a burden in any way at all. (Simon, audio diary, l. 298-303)

And, reflecting on his feelings whilst she was in respite care:

I admit I'm, I'm missing her. I think also it's true to say that I feel that part of my sense of purpose in my life, at the moment, has gone for the week. 'Cause I've come to see that my sense of purpose really is to care for mum and to make sure she's okay and look after her all the time. (Simon, audio diary, l. 603-607)

Simon understood his care for his mother as founded in a gratitude and acknowledgement of the care she provided for him as a child. Understanding his care role as purposeful and taking pride in caring perhaps enabled Simon to manage the shift in their mother/son relationship. There was a profound sense of loss that Simon had to negotiate resulting from the onset of his mother's illness, which he expressed as:

We've always turned to each other for support, advice and help and so, of course, I've lost that. Erm, because sometimes if I ask mum something just straightforward, she hasn't got a clue what I'm talking about...So, I've lost that. So, that's gone. So, I've got nobody now that I can actually turn to and

say, 'Well, what would you do about this?' Or, 'What would you do about that?'. (Simon, interview, l.763-776)

This shift was something Simon continually re-negotiated in response to the changing manifestations of his mother's illness. The changing relationship dynamic, and subsequent shifts in Simon's identity, were illustrated through a story he told of giving his mother her mid-morning tea and biscuits:

But, now, it's sort of, I'm having to be the...the father figure, or mother figure, however you look at it, because she's very much the child and as the dementia gets worse and worse she becomes more and more of that child...Erm, for example, just a small thing, but it was something that struck me the other day. I mean she'd been doing it for a while but it just struck me the other day more than ever, I always give her tea and biscuits anytime between 10 and 11 o'clock in the morning, depending on a) when she's awake in the armchair and b) when she actually wants it. Erm, and the other day she'd eaten some of the biscuit and she said to me, 'Is it all right to eat the rest of it now?'...Erm, just like a little child would say to their parent...'Well, I've eaten that, but can I eat the rest of this now?' And different things like that, erm, and I thought, yes, it's completely reversed role now...Whereas when I was younger I would have said that to her...She's now turning round and saying that to me...And asking me if everything is all right...Erm, so, that's completely changed. So, I mean, I try and keep- sometimes you'd think there was nothing wrong with her...Erm, she has moments when she's perfectly okay and you would think there was nothing wrong. So, from that point of view I try and keep the mother and son relationship there because when she's like that I try to become the son again...And let her be the mother again. (Simon, interview, l. 791-846)

Simon's reflections on the changes in his relationship with his mother once again drew on an understanding of the reciprocity of care. Just as he would once look to his mother for advice, reassurance or permission, he now adopted that parenting role. The challenges of adjusting and responding to changes in relationship dynamics and the incorporation of caring responsibilities into an existing

relationship are highlighted by instances like the one Simon described. He managed this, in part, by reaffirming the *son* identity and enabling his mother to occupy her *mother* identity wherever possible. The reciprocal caring relationship was drawn upon and experienced in different ways by Simon; it was an explanation and motivation for his decision to care and something that signalled the loss of, and changes in, an existing relationship.

Both Harry and Simon demonstrated that a complex range of emotions, relationships and pre-existing kinship ties are brought to the caring role, forming and shaping the experience of and decisions made about care. Family histories and personal biographies were drawn upon to explain and manage changing relationships and shifts in identity.

To hear Harry talk about caring for his wife:

[https://www.youtube.com/watch?v=mOk\\_4\\_uSjWQ](https://www.youtube.com/watch?v=mOk_4_uSjWQ)

### *Emotional care*

The deeply relational dimension of unpaid care and the profound interconnectedness between carer and care recipient were evident in the carer's management and negotiation of their own and their family member's emotions throughout each day. The audio diaries and interviews illustrated how care is a fundamentally emotional experience and two aspects warrant highlighting here. Firstly, the ways in which the management of emotion became evident in key moments throughout the day, such as dressing, eating and so on. Secondly, the

emotional experience of guilt, isolation, despondency and powerlessness that can sit in tension with the commitment to care.

### *Visible emotion*

At particular times during the day, such as mealtimes or bedtimes, the challenges for carers of containing emotion became evident throughout the audio diaries and interviews. Fred, who cared for his wife Helen, who has dementia, described a particularly difficult mealtime during which Helen rejected the food he had cooked for her:

My patience is wearing thin. Then she just toyed with it when I gave it to her. I got fed up and I fed her the rhubarb, she was clearly...the rhubarb that, you know, she was clearly going to leave, she grimaced as though it was poison. Oh I get this from her, if she doesn't like something she grimaces and so on. (Fred, audio diary, l. 550-555)

At this stage during the meal Fred was feeding Helen the rhubarb she had been moving around the plate for some time. Fred, who had cooked the meal and encouraged Helen to eat, was now engaged in another practical caring task - that of feeding. He felt 'fed up', impatient and frustrated as he tried to care for Helen by feeding her whilst managing his own emotional response to her resistance. This is one of numerous points during the audio diary that Fred described mealtimes, which were key moments of care between them. Fred invested time and effort in cooking meals that were inviting and nutritious and Helen's reluctance to eat presented an ongoing challenge to him. As he described it:

I get fed up with this, I really do. Afterwards she asked me if I liked my dinner. I just saw red, I lost it. I can't remember exactly what I said. But I'm fed up trying to do my best to feed her nicely and this constant rejection...I said,

‘You know, if you don’t want something just say so. Don’t say you like something or you’ll have something and then not eat it or spit it out.’ (Fred, audio diary, l. 556-562)

But I really lost my cool with her and of course I felt rotten about it for the rest of the evening. (Fred, audio diary, l. 570-571)

And I feel so bad for losing my temper. I just, I hate food wastage and to see it annoys me. And I’ve got to learn, I’ve got to appreciate that her appetite is limited, her concentration span is limited, her cognitive ability is...limited...And I’ve been in tears trying to think how do I get through to her? (Fred, audio diary, l. 588-593)

Throughout the audio diaries Fred described the meals in detail, suggesting that they were significant occasions for him and his identity as carer. It is perhaps unsurprising, therefore, that it was at mealtimes that Fred’s frustrations were made most explicit. His feelings of rejection as Helen repeatedly refused to eat the meals he cooked were combined with frustration at her lack of communication.

The effort Fred invested in providing meals for Helen was testament to his commitment to caring for her; his frustrations were also produced through his own hatred of food waste. Helen’s tendency to ask for food that she then did not eat challenged Fred’s own sense of self. For Fred, accepting that Helen’s appetite, concentration and cognition were limited, as he reminded himself, required an acceptance that food might be wasted during mealtimes. He was not only having to control and manage his emotions at mealtimes, but also change his beliefs about what mealtimes should entail. The challenges of this shift were made visible through Fred’s loss of temper.

Fred almost immediately expressed guilt for losing his temper. He reminded himself of the challenges Helen faced as a means of managing and controlling his own emotions. Although he prioritised Helen's feelings, he also recognised and was sympathetic to his own:

And I'm thinking, 'I've got to say sorry to her.' Which, after I've given her a Fishermen's Friend and tucked her into bed and so on, and I say, 'I'm sorry I lost my temper' and 'You didn't lose your temper' she said. 'I did' I said, 'But I love you, I will look after you, but it's a long learning curve and I make mistakes' and...I suppose my tears weren't helped by the fact I've got a bit of a cold today. (Fred, audio diary, l. 601-608)

Fred's apology was again enacted around a caring act - he is settling Helen into bed for the night. During this intimate and tender moment Fred apologised for his loss of temper and offered love and reassurance to Helen. He was also forgiving of himself - reminding both himself and Helen that caring for her was a process and mistakes would be made. Whilst Fred initially admonished himself for losing his temper and prioritised Helen's feelings, he then realigned to the caring role with understanding and compassion for both himself and Helen.

To see Debbie talk about respite from caring, follow this link:

<https://www.youtube.com/watch?v=xEzDfi7QhAw>

### *Guilt, isolation, dependency and powerlessness*

Fred's account illustrated how caring is a highly emotional experience; the carers often expressed difficult and challenging emotions in the audio diaries and

interviews. Whilst all were committed to caring for their family members and expressed love for the people they cared for, feelings of guilt, isolation, despondency and powerlessness were also expressed. Caring emerged as a practice formed through these emotions; the act of care cannot be disentangled from the emotions it elicits.

Guilt was an emotion expressed by most of the carers. It was born out of a sense of not caring *properly*, or at the neglect of other relationships as the result of caring. Guilt was also a feeling that committed the carers to caring.

The experience of not caring ‘properly’ was illustrated through Debbie’s account. Debbie cared for her mother, who had dementia but was independent enough to be left alone for short periods of time. Debbie described an instance where her mother was home alone and Debbie was delayed in her return. As it grew dark, her mother could not remember how to turn the house lights on:

We got home at about seven-ish. Um, Mum was fine, not a problem at all, and she soon settled into her usual evening routine where she comes in and sits with us, and she went to bed at ten o’clock. I just feel so guilty about the fact that I hadn’t been able to plan in advance to make sure that she had enough cover. I should’ve known that this was gonna be a problem (Debbie, audio diary, l. 658-664)

Debbie admonished herself for not anticipating her late return and arranging adequate cover for her mother. Her experience of caring became laden with guilt; mistakes or oversights, even when out of her control, were illustrative of what she *should* have done in caring for her mother. Even though, as Debbie described, her mother was seemingly unaffected by the incident, the overriding emotion was one of guilt.

Debbie's feelings of guilt were echoed in Alison's account of caring for her 27-year-old son Daniel, who suffered brain damage at birth. Alison suggested that a guilt complex was an inevitable part of being a carer:

Daniel is always, always, always the very top of the list, and it, it makes you feel guilty because you love these other people just as much, but you can't give them the same attention because you've always got to consider somebody else first. And that is, is upsetting, and I, I can't see that there's any, any way round that. (Alison, audio diary, l. 1170-1176)

I think every carer lives with a guilt complex, because you can't split yourself into umpteen pieces. You can't be where you want to be when you, when you think that you need to be there, and that, that does make for some very hard choices at times (Alison, audio diary, l. 1184-1187)

Whilst Debbie expressed guilt for mistakes made in caring for her mother, Alison highlighted how the numerous demands made upon carers, and the inevitability of having to make choices and sacrifices, ignited guilt. Alison's account illustrated how the caring role is embedded in numerous relationships, but that the care of her son Daniel was always prioritised.

Both Debbie and Alison's experiences demonstrated the ways in which every aspect of the caring role was infused with emotion. Whether they perceived themselves as not caring well enough, or caring at the expense of other relationships, both women internalised this experience as guilt.

Guilt was also an experience that propelled care decisions. For example, Simon's reluctance to seek full-time residential care for his mother, despite the immense strain that caring placed upon him, was propelled, in part, by feelings of guilt.

And I sort of feel that about, even now, 18 months down the line I feel that it's too soon really to put her into a home and that I'm gonna feel extremely guilty. So I suppose in a way there's a bit of a selfish streak on my part, because I'm thinking, 'I don't wanna to feel guilty'. I couldn't cope with feeling guilty and feeling I've let mum down. (Simon, audio diary, l. 208-213)

Like many of the carers, Simon's perception and experience of care homes was a negative one and they were considered an unsatisfactory alternative to providing care at home. In part, Simon's decision to care for his mother at home was a means of managing or minimising the guilt he anticipated, should full-time residential care become necessary.

Debbie, Alison and Simon demonstrated the different ways in which guilt was experienced through the caring role. Guilt is a powerful dimension of the emotional experience of caring and is active in the decisions carers make about care provision. The guilt carers experience can propel their caring role, meaning that taking breaks from, or imagining a future without, caring responsibilities was challenging. This can then create the sense of isolation, despondency and powerlessness that was palpable across the audio diaries and interviews.

Simon, who cared for his mother and, as discussed, took pride and purpose in doing so, struggled with feelings of isolation. He had left his home and moved back to Essex to care for his mother, consequently leaving many friends and social groups. In addition, he could no longer take part in activities he was once heavily involved with. A lack of family or social support, or breaks from caring for his mother, compounded his feelings of isolation:

Erm, and because I'm not really seeing that much of anybody, I feel isolated and lonely. I've managed to get out today briefly though - on a Tuesday morning we always have a have a carer come and look after mum for a couple of hours, well three hours. (Simon, audio diary, l. 66-70)

For three hours a week a paid carer came to Simon's home, this was the only break from caring he received, except for short periods during the year that his mother spent in residential care homes for respite. Simon described how, whilst he tried to leave the house during this time, he was often too tired to do anything except sleep. Simon explicitly expressed feelings of isolation and loneliness and was the participant that reported the least social or relational support in caring. However, as sole or primary carers, all the carers conveyed a sense of isolation in their caring role.

Edel cared for her husband, who was disabled as the result of a hip operation. Her audio diary reflections illustrated the relationship between the isolation of being a sole carer and feelings of despondency:

Sometimes I feel very put on, because having to do everything myself and not having any help will sort of get you down every now and again. (Edel, audio diary, l. 119-121)

I'm sorry to moan at you. But I feel a lot of this is a bit too much. However, I'll get over it and it should be worth it in the end. (Edel, audio diary, l. 289-291)

Edel commented upon having to undertake the caring role herself, conveying a sense of isolation that left her feeling unhappy and overwhelmed. She minimised her own experiences, commenting that she felt down 'every now and then' and would 'get over it'. In doing so she reflected a tendency observed amongst carers to delegitimise their own feelings in favour of the person they care for (Girgis *et al.*, 2013 Carduff, 2014). In not valuing her own feelings opportunities for self-care

might be limited, as carers are less likely to access primary healthcare services when in need of support (Arksey and Hirst, 2005). Edel's isolation was compounded by a feeling of despondency; a sense that there was little opportunity to change and improve the situation for carers, which she expressed here:

I hope something on the recordings will be of help. I doubt it though, because I don't think there's much scope to do anything about people that are carers, even though they didn't know they were carers. But, erm, you do what you have to do and you get on with it. (Edel, audio diary, l. 335-339)

Edel's comments suggested a desire for change, but a scepticism about the possibility. This created a sense of powerlessness as the lack of opportunity for change left her with no choice other than to 'get on with it'.

Alison, who cared for her son Daniel, expressed a similar sentiment when reflecting on her experience of completing the audio diary:

And only doing this recording and really talking about it day in, day out I've realised how horrendously monotonous and boring my life really is, which has, has been hard and I have to say I, I do feel a little bit depressed about the whole thing now I've done this (Laughter). I think before I'd shut it all away in a little box and just said, 'Right, well, this is your lot. Make the best of it.' Which is obviously what I am doing and what I will continue to do. (Alison, audio diary, l. 1653-1659)

Alison described her day-to-day life as 'horrendously monotonous and boring' but, like Edel, expected to continue caring and 'make the best of it' with no hope of improvement or change. Alison's coping mechanism for managing her feelings was to shut them away, effectively ignoring their importance.

Feelings of guilt, isolation, despondency and powerlessness were expressed by the carers in various ways. They did not supersede the commitment they had to

caring, whether they anticipated doing so for the long or the short term. Nor did they negate the feelings of love, pride, purpose or companionship that were also experienced through caring. However, these emotional experiences of guilt, isolation, despondency and powerlessness had a significant effect on the carer's wellbeing and ability to continue caring.

To see Debbie talk about feelings of isolation, follow this link: [https://www.youtube.com/watch?v=\\_RJ27l9AQmk](https://www.youtube.com/watch?v=_RJ27l9AQmk)

### *Tensions in care*

Caring roles are embedded in existing relationships, not only that of carer and care recipient, but also encompassing and impacting upon relationships with friends and family. The carers in this study viewed their care role as part of their commitment to their relationship to the care recipient, whether as partner, parent or child. This, in some accounts, required the re-negotiation of relationships and the management of emotions. As shall be explored, it also impacted upon decisions regarding care provision and support services.

A tension arose in the accounts when the carers commitment to caring was combined with feelings of guilt, isolation, despondency and powerlessness. The conflict between a commitment to caring and the challenges the care role presented created a stress point in the carers' lives. This was the point at which

effective support was required to enable carers to recognise and respond to stress and be supported in making decisions about care.

Such feelings, although perhaps experienced as individual responses to personal circumstances, were not separable from the social context in which people care. They echoed the experiences of carers in numerous studies (Brown and Mulley, 1997; Carers UK, 2015; Girgis *et al.*, 2013; Maher and Green, 2002; Schulz *et al.*, 1990) and were a response to attempting to care for someone in a context that did not provide adequate support to either carer or care recipient.

The following section considers the different forms of support, both formal and informal, that carers draw upon, the features of successful and unsuccessful support and the ways in which carers develop expertise.

To hear Debbie talk about the frustrations of being a carer:

[https://www.youtube.com/watch?v=A-\\_1T1WDrJc](https://www.youtube.com/watch?v=A-_1T1WDrJc)

## **Support services**

Participants accessed health and/or social care support services with, or on behalf of, the person they cared for. There was also a wide range of informal (family/friend/Good Samaritan) support networks that facilitated the caring role. This section considers the formal and informal support and services accessed by the carers and some of the difficulties they experienced. Whilst positive interactions with professionals were helpful to carers, the difficulties in accessing services, a discontinuity of care and a negative perception and experience of

residential care in particular, were reported across the audio diaries and interviews.

Carers also accessed networks of informal support, including friends, family, acquaintances and Good Samaritans, and pursued hobbies and leisure activities. This support took different forms and was accessed in different ways, but was an important and effective means of enabling carers to continue in their role.

### *Formal support: carers' groups*

None of the carers accessed support services specifically for their own needs.

There were various reasons for this. Alison, for example, felt that carers' support groups would not offer her respite from caring from her son. She said:

I've always shied away from that, because I don't really want to go in and listen to other people's problems. Sorry that sounds really awful, (Laughter), but I don't. (Alison, interview, l. 826-828)

Erm, I just want, I...you want to go to something where you're actually forgetting about what you have to do. Because otherwise, if your whole sort of social life revolves around you going to support groups, that just makes it, every minute of every day, you're actually talking about caring...Instead of just being, walking in and, and I'm just Alison, I'm not Daniel's mum/carer/dogsbody basically. (Alison; interview, l. 835-845)

Rather than offering support, Alison felt that these groups further prioritised her carer identity, rather than allowing her to be 'just Alison'.

In contrast, Simon, who moved to Essex to live with and care for his mother following her stroke and had little local support, would have valued attending a support group, but had very restricted time and financial resources to enable him to do so:

I've often thought about the fact it would be so much easier if I could actually get out and go to a carers group. I know there are carers groups, but it's just not possible or practical for me to do so, erm, because unless it was extremely local and on a Thursday within the hours that I've got a bit of free time, I wouldn't be able to leave mum unless I've got a carer in or something like that and that would cost more money, obviously, which we would have to finance. So it, it isn't really possible. So I have thought about it before, but as I say, it's not just possible or practical. And then I also think, perhaps a bit selfishly...I've also thought that on a Thursday if, if they did one in the, in the time I was free on a Thursday, would I really want to give up the time that I have to myself. (Simon, audio diary, l. 624-640)

Although Simon anticipated that a support group would help him in managing his caring role - perhaps particularly because of his feelings of isolation - he still, like Alison, questioned whether this was how he would like to spend the little free time he had.

The caring role was, for all the carers interviewed, so all-consuming that time away from the person they cared for was often spent doing housework or administrative work relating to their caring role. For Alison, and to a lesser extent Simon, support groups were a continuation of that role. They may, however, be useful at different stages in the caring trajectory - Alison had cared for her son for many years, whilst Simon had started caring for his mother less than two years previously. Support groups might offer different things to each of them at different times.

The benefits of support groups were evident in Jen's account. She cared for her 21-year-old son Tom, who had autism, commenting:

I did join a group, and I've got friends now through that. Erm, but they were like a group of mums whose children all got on the same bus to go to their various places...And then I had a mutual friend who put me in contact with the

one who started this up. This is just a voluntary thing started by mums, and I think I've had more help from them. It's almost like a self-help group...Because we've all got different experiences. And then if someone finds something out, they pass that on to everybody. So that's how I've got a lot of information, just by, erm, a self-help group...And I think that's...Perhaps they need more help, self-help groups. Because my friend who started it, she did, erm, she got funding from somewhere...Which is really good. And you know, it meant that we could have like Christmas parties, with all our children together, and...Yeah, so, erm, that's where I've got most of the help. But that's going to sort of come to an end, because now, I mean, she's very ill, so...But I still see some of the mums when I go and pick Tom up from the centre, the day centre...But it, it's nothing, it's just quite informal, as such. There's nowhere really where I could go and get help, I don't think. (Jen, interview, l. 750-785)

Jen's experience of a support group was one through which she accessed information and developed friendships. Perhaps unlike Alison and, to a certain extent, Simon's perceptions of the groups, the friendships Jen formed meant that the group became a space with a broader remit than 'listening to other people's problems', as Alison had anticipated. The group provided a forum for information sharing and a space for socialising for both parents and children. The self-started community support group offered Jen guidance, information, help and friendship.

The value of this support network was in contrast to the support Jen was offered when Tom was a teenager. During this period Tom experienced extreme anxiety, which manifested in OCD and self-harm. Jen struggled to access support for Tom from the GP or mental health services. Social Services suggested increasing the respite support that Tom was already in receipt of:

And they said that's all they could do, was give us more respite. But that wasn't helping Tom and his problems. We didn't want him to be taken away from us, to give us respite, we just wanted him to be helped. (Jen, interview, l. 119-122)

I felt as if...Sometimes we, it was seen as we were the problem (Jen, interview, l. 382-383)

As Jen described it, there was a mismatch between the support offered and the support needed. Respite increased Tom's anxiety and made Jen feel that the family were the cause of his problems. The lack of personalised support solutions, in contrast to the positive experience of support the parent-led group provided, meant that Jen was left feeling frustrated and unsupported by more formal services during this period.

### *Formal support: finances*

The carers discussed a range of formal support services that they accessed. The experience of accessing financial support, for either themselves or the person they cared for, was one aspect. Fred, Jen and Alison described their different experiences of direct payments. Fred felt that the direct payments system was inadequate because of the poor quality of the services available:

Yeah, decent respite care is necessary. This direct payments system is, is not fit for purpose. It'd be much better if the local authority or the health service provided respite care for those who needed it. And employed sensible people, 'cause a number of the people who are employed by, erm, agencies and so on are not up to the job. (Fred, interview, l. 1274-1279)

In contrast, Jen valued the choice that direct payments afforded her, enabling her to find structured support for her son:

Jen: 'Cause instead of them providing, like the day centres, where you've got no choice, that's where your son will go, erm, they now give you more control of the money. So I get the money direct, and I choose where that money goes.

Carly: And is that, is that an improvement, do you think?

Jen: I think so, yes, because you've got more choice over...And you can find a place that you feel is more suitable.

Carly: Mmm, yeah. Yeah.

Jen: And it's, it's up to you what you spend the money on. I mean, some people don't send their, erm, offspring to places every day, but they employ personal assistants, carers, who take them out to places. But we already have that, a few hours, and I think that's enough. I felt Tom needed something a bit more structured, you know, and that seems to suit him. (Jen, interview, l. 871-899)

Alison used direct payments to provide day centre support for her son Daniel.

Whilst her experience of receiving direct payments was initially positive, the inflexibility of the system created problems for her:

The direct payments, erm, I knew somebody whose son was already going to the day centre that Daniel was looking at going to and then the, the staff at the day centre said, 'You need to call Social Services'. So I called Social Services at that - I had a specific thing that I was asking about. We then were contacted. They just took all our details and we had to wait for them to phone us back. They phoned us back, they came round. Initially, everything went brilliantly and we got the funding, I think it was in the September time. Unluckily for us, the day centre decided to put their prices up in January. So in my naivety, I phoned up the financial team at Essex County Council to say, 'Right, well you're sending us this money...and it's now gone up. So if I send you the letter, do you increase the money?' 'No, you have to be reassessed by Social Services.' So I phoned Social Services again, 'Oh no, well you've got to wait a year because you've only just started getting this.' So, so we had to take the hit financially. After a year I phone them up, asked to be reassessed, and explained the situation. 18 months after that phone call we actually had somebody come round to, to reassess Daniel. It wasn't an actual, erm, member of the main team; it was somebody who was doing freelance work because they were so behind with all their work. They came in, wrote the report, said, 'Yes, yes, yes, you need this money, you need this money'. We heard nothing for 12 months...then I got a phone call to say, 'Daniel hasn't been reassessed', I said, 'Well yes he has.'... 'Oh, not according to our records', I said, 'Well he

has', 'Oh well, anyway.' So she came out, this lady, and er...they'd gone through their files, and they'd found the report that this freelance person had done, but it had never been acted upon. So we, we went nearly three years, taking the hit of the rise in the funding, for Daniel to go. Erm, the new lady that I had was brilliant, she went ballistic, she whacked it through. In the blink of an eye, we suddenly had what we should've had. (Alison, interview, l. 574-611)

The bureaucracy and inefficiency of the direct payments system had financial implications for Alison. Alison moved back and forth, making numerous phone calls and speaking to various people in order to both establish and resolve the situation. She powerfully conveyed the work involved in accessing support and the challenges of dealing with various agencies. As with many of the carers' experiences, effective professionals eventually helped Alison resolve the funding problems, but only following a period that generated financial and emotional costs.

Fred, Jen and Alison's experiences of direct payments were mixed, but Jen's positive experience was the result of having access to services that provided the support her son required. Both Fred and Alison reported problematic experiences that were the result of either a lack of quality service provision, or failures in the system. They illustrated the precariousness of effective service provision for care recipients and the implications this had for carers.

The main benefit for carers is the Carers Allowance. It is currently (2015/2016) £62.10 per week. Carers must be over 16 and not in full-time education and must care for someone who receives a qualifying benefit for over 35 hours per week. Carers must also earn £110 (following deductions) per week or less. Both Debbie and Harry referred to the lack of financial support they received as carers:

Mum's in receipt of Attendance Allowance, and that's the only benefit we could actually apply for because Mum has savings and I'm on pension; so is my husband. So, it appears that once you get to pensionable age you're not, um, applicable for any other sort of Carer's Allowance or anything, despite the fact that we're still caring for her in exactly the same way as we were when we were...before we reached retirement age. (Debbie, audio diary, l. 121-128)

And we get- she gets an allowance, so much a year, and, touch wood, they [Essex County Council] haven't- didn't cut back on it...So she's got the money, 'cause that's what pays for that and everything else. So, touch wood, I'm lucky there, but I, I get nought. (Harry, interview, l. 360-365)

Neither Debbie nor Harry qualified for carer's allowance. Debbie noted the change in benefits, but not caring circumstances, as a result of her retirement. Whilst Harry later stated that he did not expect payment and was very positive about the services his wife received, he also suggested that any future residential care his wife needed should be at a reduced rate in recognition of the care he had provided.

Alison, who did receive carers' allowance, reflected on the disparity between the money she received and the work she did:

So, the respite care that I get actually means that I actually get four days a year where I don't actually see Daniel at all, and out of 365 that means 361 days a year I either get Daniel up, or put him to bed, or both. So, considering what Carer's Allowance is, I think I'm decidedly underpaid. (Alison, audio diary, l. 625-629)

The financial implications of caring are numerous, varied and often hidden. For example, caring responsibilities can mean that carers are unable to work, have to work part-time or are unable to accept additional work or promotion opportunities. This was something experienced by both Jen and Alison. The cost of

equipment is often also met by the carer; both Harry and Alison referred to equipment they purchased privately, either because of a lack of adequate support for the maintenance of the equipment, or because they were not informed that the items were available to them at no cost. Harry described buying personal care items for his wife that he was not informed he could actually receive for no payment. It was only as a result of his daughter's research that he stopped paying for the items privately.

Other indirect, hidden costs of caring include patterns of socialising that caring for someone can impose, for example, hosting meetings or evenings with friends so the carer can easily attend. This was something described by both Fred and Alison. Simon gave an example of having to choose alternative buying and delivery options for a new sofa because of being unable to leave the house and visit the showroom. All these aspects of being a carer cost in time and money; these form the smaller, unseen implications of caring that are little understood by those not in a caring role. As Alison explained:

Everything to do with, with being disabled is expensive. Equipment is expensive. Everything is expensive. Respite care's expensive. Carers are expensive. But nobody gives you any extra money, not really. (Alison, interview. l. 372-375)

To see Harry talk about financial support, follow this link:

<https://www.youtube.com/watch?v=DPHUyppYySM>

## *Formal support: carers' assessments*

Fred and Simon both expressed frustration with the process of carers' assessments.

The carer's assessment's a waste of space. I've had carer's assessments. At first, they were tick-box exercises, you know. The last one I had that I know of was with a Carer Link worker and it was a conversation. And basically came and said, 'you really ought to have direct payments Fred'. And this is about the only thing that comes out of it, you know...obviously it's an assessment in order to get these direct payments renewed, but you just fill in the forms...because there's a difference between assessing the needs of a carer...and the resources that are available to meet those needs. (Fred, interview. l. 1371-1393)

Simon: Well, you had a carer's assessment when, when we were beneath the threshold. We then had a carer's assessment. Erm, mum had an assessment and I had an assessment at that point.

Carly: Mm. And did anything...?

Simon: So they gave me a bit more help and support then. Erm, but even there, there was complications. I mean I won't go into here, but things weren't as straightforward as they should have been. (Laughter) Erm, which made it more frustrating for me than it needed to be. But, as I say, initially I was, sort of told, 'Right, well, we can't help you cause you're above the threshold. You need to do this, this and this yourself.' Erm, and it's just, sort of, knowing where to turn to and how to get that sorted. (Simon, interview, l. 1333-1365)

Both Fred and Simon found the carers' assessment exercise a difficult, frustrating and unsupported process, even when it did result in help for them. Fred dismissed the assessment as a bureaucratic, tick-box exercise that did not benefit carers. He expressed scepticism at the value of the assessments by questioning the availability of resources to carry out the recommendations. Whilst Simon did receive support as a result of the assessment, it was a complicated process and his account highlighted another form of isolation experienced by the carers, that of

feeling alone in the face of bureaucracy. Both Fred and Simon were left feeling despondent or confused about access to and availability of help and support following the assessment.

Of the support carers did receive, they reported feeling frustrated with the challenges of identifying and accessing this support and the discontinuity of care and highlighted the impact of interactions with professionals. Positive interactions where the carer feels cared for and listened to can make a significant difference to their wellbeing. In contrast, encounters with professionals that leave carers feeling dismissed and ignored can slowly erode their trust in services.

### *Formal support: access to and (dis)continuity of care*

In accessing support for the care recipient, some of the carers reported difficulties in finding information, in knowing which agencies to speak to, or of not receiving quick and efficient services. The transition between services often resulted in the loss of good service provision or support.

For example, Alison reported that her son Daniel received a good level of support when he was in full-time education. During this period Daniel had access to professional support, including from occupational therapists, physiotherapists and speech therapists. Alison had confidence in the support he received during this time:

The occupational therapists within the school were sorting out all his wheelchairs, making sure he had the right seating. They would go with him to appointments, so that you knew he was getting exactly what he needed (Alison, interview, l. 19-23)

At 17, Daniel left Essex to go to college and had to be registered in another county for all his health and social care services. When he returned home during the college holidays, Alison struggled to access the services he required:

They just didn't want to know, because they said, 'Well, technically he's not living here'. But he was living here. He, I mean, you know, eight weeks in the summer, he was here, but they didn't want to know. (Alison, interview, l. 44-45)

And when Daniel moved home permanently, Alison reported difficulties in knowing how to contact the relevant organisations:

That's when I came up against a lot of problems, when he came back, and there's no one central number that you can ring that can put you into contact with a named person in each of the other organisations, to get him back on the books (Alison, interview, l. 48-51)

As a result of the difficulties Alison faced in accessing support for Daniel, who required a range of specialist equipment, she decided to privately fund his equipment:

And we ended up, luckily, because we were in a financial position that we could, creating our home and sorting out his equipment, and we paid for everything privately and we don't actually have anything from, erm, services now, because we just didn't feel that the back-up was there to help us, and so I just had to go it alone really. (Alison, interview, l. 52-57)

Alison's account highlighted the difficulties in negotiating and accessing adequate support, particularly during transitions between services. Like many of the participants, Alison was frustrated by the lack of centralised and personalised services that would help her provide care for Daniel. Describing what good services would look like Alison said:

Instead of being passed pillar to post all the time and ending up hanging up half the time because you just can't get the information that you want, that you need. Being disabled is a very personal thing, but you're just classed as a number on a form, and there should be much more personal help with the caring side of it, instead of coming under a category. (Alison, interview, l. 1227-1223)

Alison highlighted two important points here that were echoed across the interviews: the challenges of accessing information; and the impersonal experience of support.

Many of the carers, when they first started caring, had little direction in learning about the support needs of the person they were caring for. The carers sought information from various sources, including the Internet, professionals, friends and family, but, as Alison indicated, they all felt there was no systematic means of finding out information. Again, this reinforced the sense of isolation often felt by the carers, in this instance isolation from adequate information, which makes the caring role so challenging.

Gaining access to information or good services often happened by chance, or was contingent on good relationships with professionals or friends who passed on information. For example, Simon received information from his mother's ex-colleague about where to access support for her. Reflecting on what kind of things would help him care for his mother he said:

I think other things really would be a bit more signposting of what's out there and where you go for them. (Simon, interview, l. 1221-1222)

Erm, and so somebody that she [Simon's mother] used to work with, when we went there one time to the day centre that she now goes to, erm, they came out and saw her and they actually said to me, 'Do you know there's this available and that available?' And I said, 'No, I had no idea'. So, they gave me

some information and details of what was actually out there, available. I mean, things like getting the mattress, erm, that she now sleeps on...I didn't know where I had to go for that, but that was the district nurses. I was hoping to approach them and say, 'Well I think mum really could do with, with a different mattress'...And different things like that. Those initial days, or initial weeks, would be really helpful. (Simon, interview, l. 1227-1246)

Here, Simon described finding out about essential aspects of his mother's care, such as a specialist mattress, only because of a chance meeting with his mother's ex-colleague, who directed him to the day centre. Gaining information about where and how to access support was often contingent on existing connections, knowledge or skill.

As Simon suggested, the initial days and weeks, when advice and guidance are most needed and the carer is perhaps least able to seek out information, is the point at which the information is difficult to find and is dependent on individual networks. Key transitional points - for Alison and Jen, their sons' transition from child and adolescent to adult services, and for Simon, the transition from hospital to home care - are particular times when additional and targeted support, guidance and direction are required.

Alongside the lack of access or information, a discontinuity of care was often experienced. Carers reported seeing different care professionals, or having a poor follow-up on the progression of the care recipients' illness. Fred, whose wife Helen had experienced mental health issues for many years, commented on their experience of psychiatric services:

It wasn't long before the psychiatrist said that he was moving on...and I found that difficult to accept. Well I wrote to him and say, well, you know, 'It would be helpful if, you know, Helen had the same psychiatrist.' But the follow-up

was nil, zilch, you know, you're just left on your own. (Fred, audio diary, l. 2016-2020)

A more recent experience of a lack of support and continuity of care was articulated by Debbie, who cared for her mother:

There has been no NHS assessment of her since (2010), so I only know what I'm observing; I have no clinical knowledge of how her disease is progressing. Um, we have no clinical over-...Uh, no clinician beyond the GP; we have no clinician actually observing what's going on. Um, all of the support that we get is reliant very much on charities; people like Essex Cares, and the Alzheimer's Society, and, uh, Caring for Carers are our support mechanism. Um, there is no formal assessment. (Debbie, audio diary, l. 907-914)

Debbie's mother had had no medical check-ups since 2010. They accessed support from charitable organisations and Debbie relied on her own observations of her mother's condition as a means of charting its progress.

Both Fred and Debbie's experiences left them feeling isolated and poorly supported by services. They were unable to develop productive relationships with health professionals or, in Debbie's example, receive information about illness progression. The lack of access to or (dis)continuity of care can disrupt or minimise opportunities for the effective support of both the carer and care recipient. This experience reinforces the sense of isolation, despondency and powerlessness in the caring role.

To see Debbie talk about residential care, follow this link:

<https://www.youtube.com/watch?v=nBU-Dk6U6JI>

## *Informal support: professional interactions*

The quality of interactions with professionals had a significant impact on carer experiences. Positive encounters with support services occurred when professionals offered specific, personalised advice that was delivered with empathy. These encounters may appear small or inconsequential, but were meaningful in the day-to-day lives of the carers. For example, Edel reflected on the experience of caring for her husband and commented on a visit from a paid carer:

It's very hard having to do everything yourself and have no help at all. But funny enough, the carer that came this morning actually asked me how I felt, which is most unusual, because nobody ever seems to, to wonder how you're doing or how you feel or anything else. So it was nice to be asked. She was a very nice girl. (Edel, audio diary, l. 56-61)

Edel described the strain of caring for her husband with little help or support. Although the carer's question did not change the material conditions of Edel's caring role, it did bring her experience into focus and offered her emotional support and recognition of the challenges she faced. Such day-to-day interactions are important when considering the sense of isolation that many carers report (Arksey and Hirst, 2005; Carers UK, 2015; Carduff *et al.*, 2014) and the impact of caring upon carers' mental health (Girgis *et al.*, 2013). The pressures and strains of caring were expressed by Edel in a later diary entry:

But, erm, it gets me down now and again having to do everything. I get very depressed on occasions. But on the whole I'm not too bad. So it's just- nobody seems to care how you feel. It's all, you know, how does my husband feel? And how is he coping? But no one seems to ask how you're coping. (Edel, audio diary, l. 152-156)

The impact of caring on Edel's mental health was evident. In part she attributed her occasional feelings of depression to the sense that no one cared about her own experiences or feelings. There was a sense of invisibility and of the carer's needs and feelings being relegated or forgotten in favour of the care recipient's. The conversation with the paid carer made Edel feel cared for and acknowledged, it was a seemingly simple and everyday conversation that went some way to alleviating her sense of not being cared for. Carers often delegitimise their own feelings and needs in favour of the care recipient's and professionals can assist in compensating for this through questions about the carer's wellbeing during routine interactions.

Positive interactions with professionals were ones where the carers felt listened to, where their concerns were acted upon and they were given time and space to talk about their lives. Jen described her positive interactions with the staff at the day centre attended by her son Tom:

And also, they're very supportive there as well, the, like the carers there, you know, I know if I've got any problems with Tom, or... You know, they're always sort of willing to listen. And they're always looking at ways of, erm, making life easier for us, and thinking of ways of giving, you know, the people they care for a nicer life. (Jen, interview, l. 732-737)

Jen described staff that were not only supportive of Tom and his needs, but who also considered the needs of the carers.

Fred, who cared for his wife Helen, similarly received support from professionals primarily involved with Helen's care. He referred to the community psychiatric nurse who supported his wife following her suicide attempt:

Deven is a community psychiatric nurse. He came in and he saw the smoke coming out of my ears. He was absolutely brilliant. If anybody deserved a gong Deven did. Time was of no importance to Deven. He would sit there for an hour, hour and a half perhaps. He's got the gift of the gab as well. (Fred, interview, l. 231-236)

Deven recognised Fred's frustration and the strain of supporting his wife, he offered Fred time and understanding and in doing so was able to support Fred in supporting Helen.

Whilst all the participants described interactions with professionals across different services and time periods - for example, Fred was describing an experience that had taken place years previously - they all remembered positive interactions as being the ones where they felt listened to and cared for.

Conversely, negative interactions were characterised by feelings of dismissal or of being ignored. Fred described his experience of visiting psychiatrists:

And, er, the person you're probably seeing is a trainee or a junior doctor, you know, and he or she opens the file and says, 'What medication you on?' And I say, (Laughter) 'Surely it's written in the file'. And, you know, you've got 20 minutes of awkward conversation, because as the carer you shut up, because you've gotta let there be, erm, a conversation between patient and, and doctor. And, and, 'How have you been Helen?' And, er, 'Very well, ' (Laughter) she says, you know. And eventually you get a chance to have your say or you feel that you've gotta jump in, but you know, it, it might be six months since you've last seen a doctor. And you think, 'What is there to tell? There's so many things'...And where do you begin? And so many of them just don't have people skills...you know? They'd probably be happier in a lab and you, you know you get the feeling that you're not a human being, you're a lab specimen. (Fred, interview, l. 522-541)

Fred's experience of attending psychiatric appointments with his wife conveyed a lack of attention to the details of her medical history, a dismissal of the carer's

input or experience and inadequate social skills. The experience led to a feeling of being a dehumanised and viewed as a 'lab specimen', a sharp contrast to the positive experiences described. Both positive and negative interactions with professionals illustrated the power and importance of attentive listening, empathy and care that ensure carers feel valued and supported.

### *Informal support: family and friends*

Whilst the audio diaries illustrated that all the carers adopted primary responsibility for daily caring tasks, these were performed in the context of homes with other resident or non-resident family members or friends facilitating and supporting the care work. This might take the form of the presence of another person available to assist with caring tasks in the home, or to allow the carer to go out.

Networks of family and friends provide support to the carer in various ways. This support shifts in type and intensity across time. Simon, Fred, Edel and Harry all lived alone with the person they cared for, whilst Jen, Alison and Debbie lived with partners, but were the primary carer. The proximity of family members and the nature of their relationship impacted upon the type of support provided. For example, Alison, who was separated from Daniel's father and lived with her second husband, described what was needed for her to 'nip to the shops':

If Daniel is at home and you wanna nip up to the shops, you've either gotta take him with you, or, if my husband's here, ask him if he'd just keep an eye on him, or you've gotta load him up in the car or, or get him ready to walk.  
(Alison, audio diary, l. 988-991)

Although Alison remained Daniel's primary carer, her husband supported her in this role. Alison also had two other adult sons who lived in their own homes and provided reliable but more ad hoc support. For example, when Alison needed hospital care her sons provided care for Daniel. However, the availability of family care is often relied upon by formal support services; Alison described a scheme for providing emergency care for Daniel in such circumstances:

We did have this instance last year where I was rushed into hospital, and Daniel's brothers basically took over. For six weeks in total. Erm, and I was given a phone number to ring by the social worker, who assessed Daniel for his direct payments, and I contacted them, and they sent me through a load of forms, and I've read it, and I've got to talk to my other two sons about it because it just seems it's a bit pointless really. (Alison, interview, l. 742-749)

It's supposed to be for emergency care and it says if I'm taken ill or anything, or rushed into hospital, then this action plan comes into being. And they've got all this information recorded. But initially they ask you to give, erm, it was two or three phone numbers of family who could possibly step in...Okay, well that's not exactly what I call emergency, because I'm quite capable of doing that myself (Alison, interview, l. 745-760)

In this instance, it was assumed that family members were available and willing to provide care in the absence of the main carer. This assumption did not take into account either the availability of family carers, or the consideration of family relationships in the provision of care. In trying to arrange emergency care Alison was attempting to relieve her sons of caring responsibilities by ensuring that adequate, formal emergency care was in place. However, the emergency care system was similarly reliant on family support and redirected Alison to this.

Depending upon family members can cause additional stress or anxiety for carers, as Alison described:

Daniel's two brothers are very close to Daniel, and I would hate it for something to happen to me and then feel that they wanted to step in and look after him, because then it would really affect their lives, and that's not what you want for your kids, and I, I, I do worry about that on a daily basis. (Alison, audio diary, l. 1108-1112)

And, and it is hard because you want- when you've got other children as well, you want to help them out as much as you can, and, and you can't because I have to put Daniel first every time. And it's like putting one brother's needs- one son's needs over another son's needs. And, and sometimes that, that can be really, really, really difficult, but there's not a lot you can do about it. (Alison, audio diary, l. 186-191)

The reliance on family support, even when willingly provided, has ramifications for family relationships and carer wellbeing. Accessing family support is, as Alison demonstrated, a complex negotiation of family relationships and needs.

When family support is less readily available it is similarly difficult to manage. For example, Simon had a sister and a niece living locally who, when Simon moved home to care for his mother, had committed to supporting him by caring for her one or two days per week. This support did not fully materialise, leaving Simon feeling frustrated and disappointed, whilst also acknowledging his sister's own family commitments. When Simon did receive support from his sister or niece he took responsibility for co-ordinating that support, meaning that the additional support became another task for Simon to manage as part of his caring role:

For example if I've got a doctor's appointment or something like that she will, nine times out of ten, if I beg enough (Laughter) she will come over and look after mum then. (Simon, interview, l. 350-353)

Accessing family support is complex and requires the negotiation of family relationships. The complexities of family life and the various emotional ties and relationships that pre-exist care do not evaporate, indeed are perhaps heightened, in a caring context.

Family members also offered important emotional and moral support to the carers, often in the form of advice, concern and care. For example, Harry's family gathering offered him the opportunity to relax and lift his spirits after a tiring and stressful period:

Oh hello. Yes, I feel a bit relaxed and happy today, because it's our granddaughter's birthday. She's 24 today and only lives across the road...Took Jean over, my wife, and everything seemed okay. (Harry, audio diary, l. 10-12)

When Harry's wife Jean started leaving the house unattended, his children assisted him in finding innovative solutions to help him keep her safe:

And in the end, erm, I think my son or, or my daughter, they found out about a tracker [...] So, erm, it's a little tracker, I change that now every two days and slip it in the side- er, the end pocket of her handbag. She doesn't realise that's there. And when it's flashing, my two children, if she does a bunk, then they can track her. (Harry, interview, l. 156-157; 164-167)

Similarly, Jen received support and validation from her father when he complimented her son. His comments reassured and instilled confidence in her:

Erm, but my dad just laughed and he said, 'Oh no, he's adorable'. So I, I must be doing something right but, erm, for people to think that he's doing okay. (Jen, audio diary, l. 387-389)

The participants' experiences of caring can only be understood as enacted within a complex network of relationships that included the care recipient, family members

and friends. Caring is a practice that is embedded in these relationships and so is experienced through a range of kinship ties and emotions. As already discussed, this can elicit guilt, can be a point of worry or stress, and can generate more care work. When effective, it can also provide invaluable support and guidance to the primary carer.

To see Harry talk about family support, follow this link:

<https://www.youtube.com/watch?v=ggPqBrwGDYw>

### *Informal support: acquaintances and Good Samaritans*

Carers also drew upon a wider network of acquaintances and Good Samaritans to help them continue in their care role. This support was sometimes invited or anticipated, but was often spontaneous. Fred, for example, had a number of hobbies and interests, however, attending meetings could be difficult because of his caring responsibilities. Pursuing his interests was made possible because his wife was able to accompany him to meetings and other attendees welcomed her:

People are very kind to her at these meetings, you know. They'll say hello to her and so on. And I've encouraged her to engage in conversations. And sometimes she does. (Fred, interview, l. 430-436)

Similarly, interactions with acquaintances and Good Samaritans allowed Debbie to attend a local coffee morning with her mother:

After lunch I took her with me this afternoon; we have a coffee afternoon in the village, and she came up and sat and had a cup of tea and some cake. And

I was quite pleased, actually, because whilst she was there one of the other ladies who's there who also has, um, Alzheimer's - um, not quite as old as Mum but has a similar diagnosis - they sat together and they seemed to be chatting. And that's the first time since we've moved and I've been taking her out to this coffee afternoon that she's actually conversed with somebody, so I was quite, I was quite pleased to see that, really. (Debbie, audio diary, l. 878-888)

In this instance it was another woman with a diagnosis of Alzheimer's who provided Debbie's mother with conversation and companionship, allowing Debbie and her mother to engage in social activities.

The support of acquaintances and Good Samaritan assisted the carers in accessing and supporting the people they care for in public spaces, but also helped the care recipient to retain some independence. For example, on two occasions during the audio diaries Debbie described taking her mother to her weekly hair appointment:

I dropped in the hairdressers and I left her there whilst I took the opportunity to go and get a...grab us a bit of shopping from Morrisons, and when I went back to the hairdressers she was in a very confused state, standing up and wandering round the hairdressers looking for me, which, uh, hasn't actually happened in the hairdressers before. So, I reassured her, put her mind at rest, settled her down, and then said I'd wait for her to have her hair done. (Debbie, audio diary, l. 69-77)

We took her out, or I took her out, this afternoon to go to the hairdressers to have her hair done, and I left her in the hairdressers whilst I went and did some shopping. When I got back, the hairdresser reported that they'd had quite a laugh with her; she'd been quite chatty today, so that was good. (Debbie, audio diary, l. 797-801)

On both occasions Debbie was able to leave her mother at the hairdressers and do her weekly grocery shopping. The hairdresser was able to let Debbie know how her

mother had coped with the appointment. The support of the hairdresser enabled both Debbie and her mother to continue with these activities.

Harry similarly described how the support of Good Samaritans allowed him and his wife to continue taking regular holidays. Harry used the same holiday company to ensure his wife was familiar with the hotel and location. During the coach journey, fellow holidaymakers assisted him in supporting his wife to, amongst other things, use public toilet facilities and so ensure she did not wander off alone:

Yeah, well, then if she was to wander off, er, we're in company- they would say, 'Where you going?' 'I'm going to the toilet'. One of them would go with her. Yeah...Er, every time. Even when we did a stop, if it wasn't a, a disabled toilet, they would, er, make sure, like, where we stop when we take over the full-time driver, and she goes in there 'cause it's quite busy, er, one of them would go in with her to make sure that...make sure that, er, she's alright and comes out. (Harry, interview, l. 1129-1144)

Harry used the support of the people around him to ensure that he and Jean were able to continue going on holiday. He suggested that there had been an increased understanding of dementia and a related reduction in stigma, making it easier for people with dementia and their carers to access services and support in the community.

Both Debbie and Harry demonstrated the networks of informal support that enable carers to care. Their positive experiences were in contrast to some of the systemic barriers the carers experienced in accessing services and, as we shall see in the final section, public spaces. It was also in contrast to the stigma that some of the young carers who took part in this research experienced when in public with their siblings.

## *Informal support: hobbies and leisure time*

All the carers were limited in their opportunities to pursue hobbies, interests, education, work or other leisure time, although each reported the benefits of being able to do so. Personal interests offered carers time away from caring, something that was infrequent for all of them.

Harry, for example, kept pigeons and had done so for many years. The physical space of the pigeon loft, in Harry and Jean's back garden, provided Harry with a space to express his emotions when his wife first became ill:

Yeah. Well...obviously I broke down several times. I rang my daughter, even down the pigeon loft. I just went down there and cried my eyes out...'cause I just couldn't believe what was happening. (Harry, interview, l. 146-149)

Caring for his pigeons had helped Harry process grief when his brother had died as a teenager:

I took pigeons when I lost my brother. I was 18. I lost him at 17. And we did everything together, and when that happened I was just left floundering and, er...I just took a liking to pigeons and carried on from there. That's what got me out and about, socialising, etc. So that's how I got into it and got the bug. (Harry, interview, l. 1364-1369)

Keeping pigeons provided Harry with both a private and social space in which to manage and process his emotions. Their significance to his emotional life cannot be overstated, having offered him support following his brother's death and his wife's diagnosis. This was something recognised by his son when he stressed the importance of Harry continuing with his hobby:

Well, my, my son said to both my daughters, 'Don't talk dad out of not having his pigeons...because that's the thing that's going to keep him going when things get bad' (Harry, interview, l. 1288-1290)

However, doing so was increasingly difficult as Jean frequently left the house alone when Harry was in his pigeon loft. Harry used several strategies to manage this, including putting an alarm on the front door and a tracker in his wife's handbag, in case she left the house. He also explained where he was and asked her not to go out whilst he was away:

I say, 'Look, you're there. I'm going down the pigeon loft. Don't do a bunk, please, because it's cold out there and it's raining', because she would. She would've just...and she- but she hasn't now. So- now she said, 'I won't do that. I'll be here, dear. I know where you are'. (Harry, interview, l. 1054-1058)

As Jean's illness progressed it was increasingly difficult for Harry to pursue the hobby that provided him with time to himself and emotional support.

Jen similarly experienced restrictions on her access to non-caring activities. She discussed studying for a degree with the Open University whilst her son was younger. She reflected on the challenges of studying whilst caring for her son:

I mean, the times I used to have to do, erm, my essays, with Tom almost like sitting on my shoulder, and sort of leaning on me...It was very difficult. It would've been better if I could've been somewhere else, and gone to lectures, and...And it is quite a solitary thing, really, learning at home...Whereas I would have preferred to have more of a, meet people and have more of a social life. (Jen, interview, l. 995-1008)

Jen offered a striking image of studying with her son physically leaning on her. This physical occupation of Jen's space was a fitting metaphor for the space that caring for Tom occupied in her life. Whilst Harry was attempting to continue with a hobby

that preceded Jean's illness, Jen's educational choices were shaped by her caring responsibilities. She chose a course of study that she could complete over a longer period of time and via distance learning, thereby making studying a more solitary experience than she would have liked.

Both Harry and Jen illustrated how carers' free time is shaped around their caring responsibilities. They were not able to engage in their interests without considering the impact on the care recipient. Being able to engage in a hobby requires managing and anticipating the support that the care recipient needs in the carer's absence. Pursuing non-caring activities therefore requires additional care work.

Importantly, leisure time enabled carers to sustain and develop other relationships. For example, Debbie and her husband Rob had a boat moored at a local sailing club. Maintaining the boat provided them with the opportunity to spend time alone together:

Rob wanted to go and, um, check on something at the boat...at the sailing club, so we went to the sailing club and then we took the opportunity to pop into the pub for a drink before we came back for lunchtime. (Debbie, audio diary, l. 443-446)

Edel described going for a meal with her friends and its positive impact:

And I've just got in from my Indian meal. It was absolutely delicious. It was lovely to get out and talk to different people and see different faces. (Edel, audio diary, l. 91-93)

So I think I'll have to go out a bit more often. Maybe I'll relax a bit more and I won't get so uptight and frustrated with everything to do. (Edel, audio diary, l. 117-119)

Whilst the benefits of pursuing other interests were clear for carers' emotional and mental wellbeing, the practicalities of doing so were complex. When asked what was needed to allow him to have time away from caring Fred said:

Oh, decent respite...But local authority just doesn't have the resources. When, when they say that in all these documents, these are what the politicians, an aspiration. I'm very, even with the community psychiatric nurses, I think there's only about two of them available for the area...Erm, but enabling you to pursue education or, or work (Laughter) (Fred, interview, l. 1027; 1062-1066; 1070-1071)

Fred was sceptical that resources were available for carers to engage in their own interests. He experienced a contrast between what was promised by politicians and the delivery of those promises, describing political discourse regarding carers as 'aspirational'. In Fred's experience support was scarce and the notion of supporting carers to pursue activities outside of caring was laughable.

Jen offered a similar account of inadequate social care and support. When asked what would have enabled her to study full-time and attend lectures she said:

I think someone picking up the slack, the overlap. School finishing or whatever. And then that little gap where you just can't get back in time. That's what stopped me doing so many things. (Jen, interview, l. 1053-1056)

Erm, you know, wherever he goes, he's only there for a few hours a day. Well, it's about six hours maximum. But it doesn't always coincide with the real world, and real life, and what you would like to do. (Jen, interview, l. 1030-1033)

The need for respite care for carers to pursue other interests and the lack of flexibility of this respite, also means that it is very difficult for carers to have a

spontaneous social life. This was illustrated by Alison, who cared for her son Daniel:

I mean, the old adage, especially round Christmas time, is I always say is he has a much better social life than I do because I'm spending my time driving him to and from his social events, his parties, meeting his friends. And then one of my friends might phone up and say, 'Ooh, can you - ?' and I go, 'Well I can't because I've got to take Daniel here, I've got to take Daniel there', or, or 'Daniel is at home that day so I can't come'. And if you, if you want to have anybody come in to sit with him while you go out, if you, if you bring in a paid carer, it's the financial side of it all the time. (Alison, audio diary, l. 83-93)

In supporting Daniel to have a full and active social life, Alison sacrificed her own. Fred, Jen and Alison's comments reflected the ways in which the timing of paid care or additional support did not always fit with the needs of the recipient. Carers' access to paid or unpaid support did not encompass the flexibility or idiosyncrasy of people's lives to enable them to easily pursue non-caring activities. When combined with the financial implications of paid care, these carers each reported forgoing social, leisure or work activities because of their caring responsibilities.

To see Debbie talk about going on holiday, follow this link:

[https://www.youtube.com/watch?v=A-\\_1T1WDrJc](https://www.youtube.com/watch?v=A-_1T1WDrJc)

## *Carer knowledge and expertise*

As discussed, intimate and emotional relationships were at the foundation of the caring roles undertaken by the participants. These relationships brought an intimate knowledge of the person being cared for into focus. It influenced the ways carers developed knowledge of their family member's needs, impacted upon their access to and choices of paid care and resulted in a wide range of expertise.

Fred emphasised the importance of equipping carers with condition specific knowledge as an essential part of helping them care. He also emphasised the expertise carers possess that professionals can draw upon:

You know, if, if carers are informed then it puts them in a much stronger position. And therefore also, they're all- able to feedback much better to psychiatrists and nurses....Carers are there 24 hours a day, seven days a week. Psychiatrists might see somebody for 20 minutes, once every third blue moon.  
(Fred, interview, l. 1176-1184)

Fred described a reciprocal benefit to acknowledging carers' expertise and supporting them in developing it. Giving carers better condition specific information not only assists carers in their role but also enables them to communicate effectively with professionals. Carers are able to bridge the gap between the condition specific care provided by professionals and the intimate and personal knowledge of the care recipient and their needs. In doing so they are able to assist professionals in responding to both the condition *and* the person, and facilitate genuine co-production of care and shared decision making. When professionals work in partnership with carers they can draw upon their knowledge to facilitate a whole-person approach to care.

Carers' expertise is developed in different ways. It emerges both from the intimate knowledge of the person they are caring for - their likes and dislikes, opinions, intricacies of communication, biography and life experience - and from the necessity of developing the condition specific knowledge required to care. This might be developed through positive support from professionals, or through a lack of adequate support. For example, Alison's struggle to find adequate support for her son's equipment needs once he left compulsory education, resulted in her not only buying his equipment privately, but also developing the expertise required to maintain it where possible:

So every piece of equipment that Daniel has got now is owned privately, and I have to use the knowledge that I've gained over the years, when I had the back-up from the occupational therapists through his school, I've put that into sorting out his wheelchairs now. (Alison, interview, l. 58-62)

12 months later we were still waiting for him to be reassessed. We were in a financial position that we could look at private wheelchairs, and that's exactly what we did. We went to a local company and the, erm, the people there were prepared to work, altering backs, adding belts, altering footplates, to our specific needs, because I knew basically what Daniel needed. (Alison, audio diary, l. 477-482)

Both me and my husband have got quite adept at using the old spanners and replacing stuff. So as soon as we got Daniel home, out of his chair, old lap belt off, new lap belt on, get it in the right position and then, so that nobody can alter the right position, I actually sew the two pieces of fabric together so that the tension on the belt cannot be moved, ensuring that anybody who hoists him, hoists him properly back into his chair. (Alison, audio diary, l. 1214-1220)

Alison's account illustrated the range of caring tasks that required the development of expertise, in this case a very practical task, but one that was

central to ensuring Daniel's wellbeing and independence. Alison also demonstrated the various ways in which expertise was developed. She drew upon knowledge acquired when she felt well supported by professionals and transferred this to manage a period where she received less adequate support.

Alison and her husband developed the skills to maintain Daniel's wheelchair over time and used their knowledge of Daniel's preferred seating position to ensure the wheelchair was tailored to his needs. In doing so they also indirectly managed the professional care that Daniel received from day centre staff. By adjusting his seat belt to ensure it would only close when Daniel was seated correctly, they used their knowledge and expertise to continue caring for Daniel even when not performing the tasks themselves. Alison's expertise was developed out of her personal knowledge of Daniel and his needs, as well as her experiences of professional support.

Working closely with professionals can offer carers a means of developing expertise and utilising this in their caring role. The paid carers working with Harry's wife Jean also supported Harry in learning how to cook, thereby helping him adjust to his new responsibility for the domestic tasks his wife once performed. He referred to learning to cook a Christmas cake with the support of Liz, a paid carer:

Liz comes in on a Friday for two hours. Yeah. And she was the one that taught me. She said, 'I'll help you', and she did. It turned out right. (Laughter) It turned out better than hers actually. (Laughter) (Harry, interview, l. 862-869)

Harry's pride in his achievement was evident in his comments and illustrated how positive support provided by professionals can assist carers in numerous ways.

Jean's carers also enabled Harry to develop the communication skills required to support Jean:

And, er, I learnt a lot through her (Liz), and Carol as well, on how to interact with her mood and...get her out of it and make her realise everything's alright. (Harry, interview, l. 1049-1051)

Jean's carers helped Harry to develop the skills to care for Jean, but also to manage the transition in their relationship that required Harry to adopt a different role; taking on the domestic tasks that Jean used to have responsibility for and developing a different style of communication. In developing his expertise through good working relationships with professionals, Harry felt supported and was given the confidence to care for Jean.

Where carers feel that their opinions are not listened to, or their needs understood by professionals, they can feel unsupported and frustrated. Jen, who cared for her son Tom, described two instances where her own knowledge of Tom's condition was not being listened to. The first was during the period she was trying to get Tom diagnosed with autism, when he was attending an assessment centre whose staff agreed with Jen that Tom had autism:

We knew, or we guessed that Tom was autistic when he was really quite young, and erm...But then that's when the fights began with, I suppose, the caring organisations out there. Erm, it took us a long time to get him actually diagnosed as autistic. (Jen, interview, l. 9-14)

I think they [Tom's assessment centre staff] were as frustrated as us, and it was the, erm, the health service. 'Cause they were education. It was the health service, the consultants at the hospital, who didn't seem to want to make, erm, a diagnosis, they didn't want to commit. (Jen, interview, l. 556-559)

So there was the anger, there, with the medical profession, and especially the reluctance of the hospital to diagnose him. Because without that diagnosis, he wouldn't get his, erm, certificate of special educational needs, and he wouldn't, he'd have ended up having to go to the mainstream school. And we were getting very close to the age when he should have started school. In fact, yeah, he should have started the mainstream school. But without that certificate, he wouldn't be able to go to the special school, and that's where we wanted him to go. (Jen, interview, l. 587-597)

Jen described feeling frustrated with the hospital consultants for not committing to a diagnosis. Her own knowledge of her son and her concern that he receive the right kind of support for his needs, fuelled the anger at the consultant's reluctance to diagnose him. As Tom's mother, Jen adopted a holistic view of Tom's care needs; her wish for a timely diagnosis of autism was, in part, motivated by the implications of his educational provision. Her experience of the healthcare services during this period were characterised by frustration and anger as her knowledge and expertise of both Tom's condition and the implications of a delayed diagnosis, were not fully taken into account.

Carers not only develop knowledge and expertise through their caring role, but also bring a knowledge of their family member's personal biographies to the caring relationship. As discussed, the intimate and personal relationship the carer has with the care recipient informs every decision made about their care. For example, Simon's knowledge of his mother's views on care homes was a barrier to making a decision to obtain full-time residential care for her:

I know or knew mum's views on going into a home because we'd had a discussion about 18 months prior to this happening...I was home and something was on the television, a programme, that, erm, and there was a home in it and we sort of, it prompted a discussion really. So I knew that she didn't want to go into one unless she absolutely had to. (Simon, interview, l. 70-72; 76-83)

Simon brought a knowledge of his mother to the caring relationship and this impacted upon the decisions he made about her care. It is a dimension of caring that is distinct from, yet encompasses, professional care. So, whilst clinicians may offer expert opinions or advice about an individual's care, this is only one aspect of a wider and much more complex process of decision making, which is based upon knowledge of both the person and the condition.

Importantly, when considering the impact of caring upon carers' wellbeing, one of the implications of carer knowledge and expertise is that, as Simon demonstrated, it can be difficult or stressful for the carer to consider using extensive paid care. Consequently, carers often described taking on care roles themselves rather than using paid care. Simon commented that his mother would not want to go into residential care unless she 'absolutely had to'. Based on this knowledge Simon was determined to continue caring for his mother, despite the considerable impact on his own wellbeing. His audio diaries and interviews conveyed the profound challenges he faced in caring for his mother, including a lack of sleep, rarely being able to leave the house and suffering from symptoms of depression and anxiety.

The question of when someone *has* to receive residential care is ambiguous. For Simon, who approached the question from a relational perspective, the answer was dependent on his knowledge of his mother's wishes, rather than consideration for his own wellbeing. To support carers in making decisions about care at crucial transitional points, professionals must attempt to understand the factors that influence carers' decision making.

A mistrust of professional care as a result of negative past experiences is another factor in carers making the decision to provide the majority of care, using

their own knowledge and expertise. Recalling a time that her son Daniel was admitted to hospital and had an infection that was not cared for properly by hospital staff, Alison commented:

And all these sort of instances make me lose...total faith and, and have no trust in professionals, unless I know them really well and keep, keep a check on them. And if I'm there keeping a check on them, then I might as well be doing it myself, which is what usually happens. (Alison, audio diary, l. 662-666)

Importantly, Alison's comments suggested that she did once have faith in professionals, but a series of negative experiences eroded this trust and necessitated her closely monitoring the professional care that Daniel received, ultimately undertaking the care herself. Alison illustrated the ways in which trust can be eroded gradually through a series of negative experiences. In doing so she drew attention to the importance of every professional care interaction building and maintaining trust with carers and care recipients.

The audio diaries and interviews suggest that one area in which trust has been significantly eroded is residential social care. Debbie, who cared for her mother who has dementia, articulated some of the concerns expressed by many of the participants:

Sometimes this caring lark is quite frustrating, when Mum could go into a care home and we would then be free to have our own time, but I can't put Mum in a care home, because I've been lots of them and they really are not suitable places. I would not put anybody into a care home at the moment. The, the level of care is very doubtful and Mum is quite settled and happy where she is with us at the moment. Um, it's frustrating and it's a tie, and it means we can't do necessarily what we would want to do, but we are trying to work our way...Our life, trying to work our life out so that we can get the best out of both worlds, both for us and for Mum. (Debbie, audio diary, l. 136-146)

Debbie's experience of visiting residential care homes did not instil her with the confidence to consider them as a viable alternative to caring for her mother at home, despite the restrictions caring placed on her own life. Her decision to care for her mother was, in part, formed through the lack of trust she had in residential social care, feeling that she was able to provide a more settled and effective care environment for her at home.

Debbie's perception and experience of residential care was echoed across the data, highlighting a need for social care services to explore the reasons for this lack of trust and to begin the process of responding to and rebuilding it. This is not because residential care should or would be the choice for everyone, but that a lack of trust can close down the options for people making decisions about their own or a family members' care. Consequently, individuals may choose to undertake care roles, or continue to care, due to a perceived lack of viable alternatives.

To hear Harry talk about becoming a carer, follow this link:

<https://www.youtube.com/watch?v=ZnlZbgCOfxc>

### *Support systems versus support networks*

The carers drew on different types of formal and informal support, finding different aspects useful. An apparent distinction emerged between support systems and support networks. Support systems, characterised by poor access and lack of continuity of care, often created barriers to effective care and left the

carers feeling isolated and uncared for. These barriers included: lack of information; time-consuming exercises such as carers' assessments; delays in diagnosis; lack of follow-up; negative experience and perception of residential care homes; and a mismatch between need and service provision.

Support networks offered personalised, specific support delivered with understanding and empathy. These might include positive interactions with individual professionals, encounters with acquaintances and Good Samaritans, and need-specific support groups. The challenge in supporting carers is to ensure that support systems adopt some of those support network characteristics that help carers in a personalised and specific manner.

## *Spaces and temporalities of care*

The lived experience of caring is conducted through space and time. The audio diaries in particular offered a rich and detailed insight into the different ways in which space and time were experienced.

### *Caring spaces*

All the participants in this study lived with the person they cared for. Caring took place across numerous public and private spaces, with the boundaries between them blurred in various ways.

Harry and Fred's accounts have already illustrated how access to public space and activities was facilitated by the practical support of acquaintances and Good Samaritans and by an increased understanding and decreased stigma towards people with dementia. Alison, Jen and Edel's experiences of public space were more problematic.

During the period of the audio diary, Edel and her husband Martin were having a new kitchen fitted. This is something that caused a lot of disruption to the home, but that Edel was excited about. During the kitchen fitting they had limited cooking facilities, as Edel described:

Most of the cooking this week will be done in the microwave. I've already put a load of dinners in the freezer. Everyone keeps saying, 'Why don't you eat out?' But unfortunately my husband doesn't feel he can go out. So we're stuck in. We will have a take-away at least one night. So hopefully that'll help. (Edel, audio diary, l. 273-277)

The inaccessibility of public space for Edel's husband, who had limited mobility and could no longer drive, meant that they were 'stuck' in the house. During this period this was more of a challenge because of the limited cooking facilities.

This short anecdote illustrates how space is experienced in different ways by carer and care recipient. The assumption that Edel and Martin could simply eat out when their home was less functional or comfortable, ignored the additional accessibility and mobility issues experienced by Martin and, consequently, Edel. The caring role, which involved Edel cooking meals for Martin, temporarily became more complex during this period, because of the lack of accessibility, mobility and independent transport. Consequently, Edel, alongside Martin, experienced a shrinking of their world and a retreat into a private space.

The significance of effective and accessible transport in enabling carers and care recipients to access public space cannot be underestimated. Edel's account also illustrated the interaction between the home environment and public space; changes in the home made the inaccessibility of public space an even starker reality for Edel and contributed to her feeling 'stuck' in her own home and

exacerbating some of the pressures of caring. An event that is seemingly unrelated to caring can have wider implications for the day-to-day lives of carers.

The inaccessibility of public space was also a barrier to leaving the home for Alison and her son Daniel. She described the experience of going to the cinema or theatre:

You go to a cinema and you have to sit at the front, right underneath the screen. Now, you're in a wheelchair with a solid back. Now, if you're a person sitting in one of the seats, you slide down so that you can tilt your head back. If you're in a wheelchair with a solid back, how can you tilt your head back to look at the screen? You go to a theatre and they run the wheelchairs - a local theatre at Southend, they run the wheelchairs at this angle down the side, and they ram them in so that there is not enough space. The wheels get caught on one another and you end up having to turn the chair so in fact the person sitting in the chair is not actually looking at the stage. They're looking into the audience and then they've got to twist (Alison, interview, l. 253-265)

This is a clear example of how the needs of the carer cannot be separated from the needs of the care recipient. Alison's ability to fully access public space with Daniel was dependent on wheelchair accessibility. Alison described being unable to move around shop aisles, eat in restaurants, go on holiday or even attend her sister's wedding, because of the lack of adequate provision and facilities. Alison's description of her son's theatre experience conveyed the extreme physical discomfort and the consequent closing down of public space that was created by the lack of detailed consideration to accessibility. It highlighted the need for regular checks and comprehensive consultation with intended users of the space. In this instance, had Daniel and Alison been asked to trial the seating arrangements, the lack of accessibility would have immediately been made apparent.

Whilst Alison described the inaccessibility of public space, other accounts illustrated how the private space of the home can be similarly oppressive and difficult to manage. Simon, who moved into his mother's home to care for her following her stroke two years previously, found that she was increasingly dependent on him and anxious in his absence. He found it difficult to leave the room without her calling for him and, in the previous months, had slept on the floor of her bedroom whilst she held his hand:

I now have to actually sleep in her room with her, on the mattress on the floor. And she wants to hold my hand all night. So, if she wakes up and I'm not holding her hand then she'll wake me up just to hold her hand...Erm, so, of course that's very, very difficult. (Laughter) (Simon, interview, l. 163-172)

Simon had very few breaks from caring for his mother, even when sleeping. His use of his private space was dominated by his caring responsibilities. For example, his movement around his home was negotiated through his mother's anxiety:

It took me most of the afternoon to get the washing up from lunchtime done, because every time I went into the kitchen she would want me back in the lounge with her. So that's just one example. But there's, there's other examples as well. For example, I wasn't able to put the rubbish out today, 'cause she didn't want me to go outside. Erm, not even to put the rubbish out. (Simon, audio diary, l. 364-370)

Simon's home, and his occupation of it, was a caring space. He had few opportunities for breaks from caring for his mother because of the lack of familial support and the financial cost of paid care. Simon's mother's anxiety made it very difficult for Simon to leave the room, even for very short periods of time.

Simon's account powerfully conveyed how his own life was restricted in line with his mother's illness. In caring for his mother Simon was restricted in his use of

space - very rarely being able to leave the home - and experienced interrupted sleep. His description of his experience of their home illustrated the ways in which caring is a role that penetrates every aspect of the carer's life, including how they move around and access public and private spaces.

All the care recipients, except Alison's son Daniel and Jen's son Tom, received some form of paid care in their own home. This was usually in the form of paid carers performing personal care. The receipt of paid care in the home illustrates the blurring of private and public spaces; the private space is professionalised as it is both a home and a workspace, or a space in between. This has different implications for the carer's experience of their own homes. For example, Edel described a morning visit from a paid carer in an audio diary entry:

This morning I got up round about eight o'clock and got a cup of tea ready and gave my husband his breakfast. And I thought I'd wait until the carers had been to have my shower. But at twenty to eleven I had to go up and have my shower anyway. And it meant leaving the front door open on the catch, which I don't like doing. (Edel, audio diary, l. 93-99)

Edel's own morning routine was, to a certain extent, determined by the timetable of paid care. Although she intended to wait to shower until after paid carers had arrived she decided, presumably because of their late arrival, to shower beforehand. As a consequence, she had to leave the door on the latch because her husband was unable to open it himself. Her home became a less secure space because she had to make it accessible to the paid carers. The boundaries between public and private, personal and professional became blurred through this act of leaving the door on the latch.

In contrast to the sense of insecurity that the carer's late arrival provoked, carers paid for privately, who arrived at the same time each week allowed Edel the opportunity to relax in her morning routine:

It was nice to know that the carer, which we pay for, comes at the same time every Monday. She comes at 9:30. So it meant I could take my time getting up, make a cup of tea, give my husband his breakfast and I waited 'til she got here to go up in the shower, which means I could have a nice relaxed shower. (Edel, audio diary, l. 125-130)

This experience of paid care afforded Edel and Martin more choice and control. In this instance, where Edel could rely on the regularity of paid care, the incorporation of the professional space into the private afforded Edel a real break from caring. The successful incorporation of paid care into the home can offer the opportunity to experience the home as more than a caring space.

To see Alison talk about accessing public spaces, follow this link: <https://www.youtube.com/watch?v=1ly-LqCCBDo>

### *Temporalities of care*

The audio diaries in particular offered insight into the multiple temporalities of care; the carers experienced time in different ways. The three aspects of their temporal experience outlined here is that of: the repetitive and relentless experience of 24/7 care; the experience of parallel lives, expressed by all the carers; and notions of future time and concerns about future care.

## 24/7 care

When asked how many hours per week they spent caring, all the carers stated 24 hours per day, seven days a week. Simon's account of being woken during the night by his mother powerfully conveys what 24/7 care meant to the carers' day-to-day lived experiences.

One aspect of 24/7 care, conveyed in the audio diaries in particular, was the repetition of daily tasks, in particular personal care and domestic work. Across the audio diaries Fred referred to helping his wife Helen get properly washed and dressed in the morning. A number of extracts are reproduced here to give a sense of the daily repetition of this task:

Helen appeared around about half past nine, washed, ha-ha, and dressed.  
(Fred, audio diary, l. 163-164)

Erm, I think discovered that she's, although she's washed, sorry, although she's dressed, ha-ha-ha, she's still wearing her pyjama trousers underneath her trousers. (Fred, audio diary, l. 190-192)

I went down and had my breakfast and at quarter past nine I got her out of bed, supervised all the washing and dressed her. Of course during all of this she says why am I taking her pyjamas off? (Laughter) 'To get you washed and dressed.' (Fred, audio diary, l. 366-371)

I got Helen up. Got her washed and dressed (Fred, audio diary, l. 852-853)

Then I would've helped her get dressed and washed (Fred, audio diary, l. 1021)

Anyway, Helen came down, dressed and washed. And I assumed that she'd still got her pyjamas on underneath her clothes. And I said, 'Have you got your jim-jams on underneath those?' She said, 'Yeah.' But she hadn't, she'd actually got those off and she'd washed...which was good, you know, I doubted at first whether she had washed but she said she did so I have to believe her. (Fred, audio diary, l. 1712-1718)

Ah...Helen came down, dressed, over her pyjamas. I asked if she'd washed, she said, 'Yes.' I repeated the question shortly afterwards, yes she had had a wash. So I accepted that. I got her to scrub her teeth after she had breakfast. (Fred, audio diary, l. 2357-2360)

Fred's description of the task varied each day, but each description illustrated that checking Helen was washed and dressed properly was a repetitive activity that required monitoring. Fred's expression of 'ha-ha', indicating that Helen was not actually properly dressed when she said she was, to his need to repeat the question, double check and, on occasion, wash and dress her himself, illustrate how the routine of washing and dressing - an everyday and common-place activity - became a daily challenge that required Fred's ongoing vigilance and care. Despite Helen still being able to wash and dress herself, the activity needed checking and monitoring to ensure that it was done properly. Fred's account illustrated the relentless and repetitive aspects of caring for someone full-time, even when there are aspects of self-care the care recipient can perform themselves.

This ongoing and repetitive aspect of care was conveyed in Alison's account of caring for her son Daniel. Daniel's favourite evening activity was watching soap operas and he had control of the television each evening from 6.30pm until 9pm. During this time, despite Daniel being occupied, Alison was not able to relax, but was 'up and down' ensuring that Daniel was comfortable:

Erm, he's settled down to watch his, his programmes and, again, (Laughter) the same old boring routine. I will be jumping up and down, chocolate, crisps, biscuits, drink and then putting him to bed at 10 o'clock. (Alison, audio diary, l. 1230-1233)

Like Fred, Alison conveyed the ongoing, repetitive nature of everyday care. Fred and Alison's accounts were examples of the aspects of care that are little known or

understood by those not in a caring role. Despite the seemingly small and everyday nature of tasks, such as those that Fred and Alison described, they are time-consuming; these are the smaller tasks that ensure the care recipient is happy, comfortable and healthy, but that can dominate the carer's time. These smaller, everyday acts of care illustrate the ways in which caring can be experienced as a 24/7 occupation.

24/7 care is also demonstrated by the work that carers do when they are not with the person they care for. The magnitude of paperwork, advocacy, housework and other tasks that fill the carers' time was evident in the accounts. For example, Harry considered increasing Jean's attendance at the day centre to two days a week, to enable him to perform the necessary administrative tasks of caring for her:

I'm thinking of doing another day because it would give me more of a break, for the simple reason it gives me a chan- like what- sometimes I have to catch up on all the paperwork, letters and things like that regarding her medication and what shopping, everything, you know. I'm the housewife, so it's reversed. (Harry, interview, l. 295-300)

This respite care did not, therefore, offer Harry time to relax or pursue his own interests, but created more time for him to complete tasks relating to caring for Jean. His account illustrated that caring does not cease when the carer is not physically with the care recipient, which is an important dimension of 24/7 care. The carers each expressed the ongoing, repetitive and relentless nature of care. It is unsurprising that they also relayed feelings of isolation, despondency and powerlessness.

To see Alison talk about 24/7 care, follow this link:

<https://www.youtube.com/watch?v=RuwJRTy8OgM>

### Parallel lives

Another striking temporal experience expressed by all the carers was the notion of parallel lives. Carers used the experiences of peers, their own expectations of their life course, and social scripts, to compare their lives as carers to what they could or 'should' have been doing at that time of their lives. For example, Edel reflected on how she had anticipated spending her retirement:

I just feel the same sort of, more or less, a housekeeper, sort of maid doing everything at...I was looking forward to retirement when we could do things between us, but unfortunately it hasn't transpired. I have to do everything myself. (Edel, audio diary, l. 179-183)

Edel had anticipated that the domestic work would have been split between herself and her husband following their retirement. Her husband's care needs meant that Edel continued to take responsibility for the domestic work. She experienced herself as a 'housekeeper' or 'maid', in contrast to her imagined retirement that would have relieved her from some of these tasks.

Both Jen and Alison, who cared for their sons, considered the contrast between their expectations of having children, which included a time when their children became more independent and required less care, and their actual experience:

You know, it's never stopped. 'Cause you do get to a certain level- when you've got children, you never stop worrying about them...But you don't have as much input in their lives, you know, they're independent. But with Tom, that's never stopped. (Jen, interview, l. 177-184)

When you, when you have your kids, you don't expect this to be, to be happening. We didn't know that Daniel was gonna be like this; this was...uh, the brain damage was caused at birth, so there was no reason up until that point that you could foresee that your life was going to be so different, and I do sometimes feel that, um...my life, my personal life, ended the day Daniel was born, because from that point on my whole life revolved - and still revolves - around considering his needs. And people don't, don't think that; they don't realise that. (Alison, audio diary, l. 974-982)

Alison in particular expressed the loss of a personal life she experienced as a result of Daniel's brain damage. This experience or expression of loss, either of a previous or anticipated life trajectory, was expressed by a number of the carers. For example, Simon reflected on his decision to leave his home and return to Essex to care for his mother:

I'd been living there nearly 14 years, erm, to living here with mum in the flat. 'Cause I thought well I'll have to, I'll have to become her full-time carer and look after her so that she can remain in the flat. So, that's what I did. I left X. I left my life behind there. (Simon, interview, l. 96-100)

Alison and Simon had different experiences of care, but both expressed a sense of loss of a parallel or previous life as a result of their caring responsibilities. The carers' perceptions of a previous or imagined parallel life highlighted the sacrifices they made as carers. The love and commitment the carers expressed for the person they cared for was often interwoven with an experience of loss.

## Future lives

All the carers expressed concerns about the future for the person they cared for and their caring role. Each had made plans for the future to different extents.

Alison, for example, had put a long-term care plan in place. Her son Daniel owned the family home, bought with compensation he received, providing him with a home that could accommodate paid carers if necessary. However, despite this apparent security, the future still provoked fear and anxiety for Alison. She recalled playing a 'Mr and Mrs'-style board game with friends:

And one of the questions that my husband was asked of me is: 'what is your wife's greatest fear?' And he had to write down the answer, and then when it was opened up he'd written down 'That she dies before Daniel does,' and that is exactly right; that is my biggest, biggest fear (Alison, audio diary, l. 1101-1106)

Despite a well-developed plan for Daniel's future care, imagining a time where she was no longer able to provide care for Daniel was a frightening experience for Alison. Elsewhere, Alison expressed both her own and Daniel's feelings of intrusion and discomfort at the thought of having paid carers in the home. This discomfort, coupled with negative experiences of social care in the past, were barriers to imagining a time when full-time paid care would be something they felt comfortable with.

For others, the future was more uncertain in practical ways. Jen, when asked about contingency plans should she be unable to care for her son Tom for some reason, replied:

Well, I wouldn't be able to get him...Because I drive him everywhere. I wouldn't be able to get him anywhere, would I? And he would find that very unsettling, because he's got his routine, and, and he knows that he should be going, going out to X. This is something that I really should think about, you know, what would I do? (Jen, interview, l. 1104-1109)

Fred's response to a similar question illustrated how the carers found it difficult to imagine not caring:

If it's only flu I'd get on with things. If it's a twisted ankle I'd get on with things. But if I had to go into hospital...Erm, then I think the boys would arrange something...Erm, what exactly I know not. (Laughter) Yeah. Yeah, it's something I don't dwell on. (Fred, interview, l. 1244-1254)

The carers found it difficult to consider questions about the future, or about no longer being able to care. The emotional and familial context of care meant that decisions about the future were, in some ways, questions about separation in some form from the person they were caring for. It involved imagining a future without or distanced from their family member. This was compounded by fears expressed about the quality and availability of paid care, either within or outside the home. This was expressed by Alison and Jen when discussing the future of caring for their sons:

And you read so much in the papers about carers, erm, taking things, doing things, that I'm not very happy about it. I think if we get to that stage where Daniel does need somebody like that, we will employ somebody privately and, and have them live in, but it will hopefully be somebody that we know, so that we can feel safe in going out and leaving Daniel with that person in the house and know that everything in the house is, is safe and secure. (Alison, interview, l. 103-110)

There just aren't enough facilities in place for the future, for people like Tom. And we shouldn't have to send them miles and miles and miles away...Because we're okay now, we can get to him. We need to be able to get to him. But in the future, I mean, things change, don't they. I mean, what if I couldn't drive any more?...How would I get to see him? (Jen, interview, l. 351-359)

Alison and Jen expressed concerns about future care that were exacerbated by the inaccessibility or poor quality of paid care. Jen emphasised this point in email correspondence following the interview:

What I probably would like to emphasise more than anything is my fear for Tom's future and my real concern that there will not be a good enough level of service to provide the care he needs and deserves, that's why I am willing to care for him myself for as long as I can, regardless of the restrictions on my life. (Jen, email correspondence, 15/07/2015)

Jen's comments illustrated the impact of a lack of trust in and good experience of residential care, this mistrust compounded her fear for Tom's future. Jen was concerned that good quality full-time care would not be available for her son, she was therefore determined to care for Tom for as long as possible, regardless of the impact on her own life.

Negative perceptions or experiences of paid care have a profound impact on decisions regarding both short and long-term care and cause carers concern and anxiety about the future. The relational and emotional context of care means that imagining the future and making decisions about future care are incredibly complex processes that involve navigating the availability and quality of service, whilst placing the wellbeing of the care recipient at the forefront of the decision-making process. This process has emotional and financial costs that need to be

understood and accounted for when supporting carers in making decisions about future care.

### *Making space and time for care*

Paying attention to the spaces and temporalities of care provides an insight into the detailed lived experiences of carers. The discussion here highlights how the boundaries between public and private space are blurred, particularly when homes become professionalised spaces through the presence of paid carers. The lack of accessibility to public spaces can reflect a lack of attention to detail in accessibility planning, as well as highlighting the importance of accessible transport in facilitating access to public space. Simon's account of his home illustrated how the care role also influenced the experience of private spaces and carers may need assistance in creating a home space that can both accommodate care and provide some respite.

The carers experienced time in different ways, the audio diaries conveyed the relentless, ongoing, experience of 24/7 care. The interviews allowed the carers to reflect on broader temporal experiences of parallel lives and future time. Importantly, the carers powerfully expressed the true meaning of 24/7 care; even if not actively engaged in a specific care task, carers are engaged in their caring role, which requires vigilance, empathy, awareness and planning at all times.

When discussing the experiences of carers, and assessing carers' needs, caring is often defined by the number of hours spent caring. However, these carers demonstrated that care is not a temporally bound activity - the caring role exceeds temporal definitions, or is experienced through multiple temporalities.

## Analysis: young carers' focus group

The analysis of the young carers' focus group firstly considers how the group defined young carers. It then explores three sites across which the young carers examined their caring role:

- Friendships, hobbies and social life
- Education and learning
- Family life

These sites were characterised by a sense of young carers being the 'same, but different', this provides the final theme under discussion.

### *What does it mean to be a young carer?*

The group's discussion of what it meant to be a carer illustrated the range of activities and responsibilities they undertook as young carers, as the following extract highlights:

Geoff: Like, to go out of the way for, like, who you care for.

Steve: You would find information about, like, stuff.

Geoff: What's going on.

Steve: Yes. Stuff.

Carly: Okay.

Ofra: So what sort of information, about services or...?

Steve: Like stuff, like people to go to, what to do.

Geoff: And just in case, like an emergency and you had to know who to call to find out-

Carly: Right, so you kind of need to know quite a lot of stuff I guess.

Geoff: Yes.

Abi: Yes.

Rosa: Yes.

Abi: Erm, assist them like going out or something like that so, and help them with like, erm, like sorting their money out, especially if they're like, erm, like younger or older because sometimes people don't really have like a good understanding of money and that. It's like helping them with that. Erm, cleaning. We do a lot of cleaning. I'm sure we all agree. (Laughter)

(Focus group, l. 220-250)

The group demonstrated the range of activities involved in caring, including information seeking, emergency care, financial and social support and domestic work. The tasks described involved direct support of their sibling, including, as Abi described, assisting in their use and understanding of money. They also described more generalised support, including cleaning and tasks within the family home. Through these different types of care the young people adopted different positions within the family that afforded them knowledge and responsibility. Whereas cleaning, for example, might function as a task that teaches shared responsibility in families with no additional care needs, within a family where young people are adopting caring responsibilities, such tasks become a necessity.

The young carers listed a range of tasks they undertook, but there was some ambivalence or confusion about the label 'young carer'. As expressed by Steve:

Steve: I didn't really understand, I still don't really understand, like, a 'young carer'. Like if you said to describe a young carer I'll know what it is, but I wouldn't necessarily say who, like, what people could you describe would be a young carer if this was to happen. It would just be, I understand it, but I don't understand it.

(Focus group, l. 1585-1590)

Who can identify, or be identified, as a young carer was confusing for Steve. His comments perhaps reflect the ambiguity or often hidden nature of unpaid care,

where the wide range of tasks and, in particular, the emotional or social support given often go unrecognised. Following this comment, the group went on to consider the distinguishing features of being a young carer:

Steve: Erm, I think, well if you're like, say it this way it's basically, a young carer is someone who helps somebody but that could be like, it has to be a special someone.

Geoff: It has to be like someone related to you.

Steve: It's like, say like your little sister fell over it wouldn't be classed as a young carer helping her.

Geoff: That's called like-

Steve: Just helping her.

Geoff: Yes.

Steve: It would have to be something, but you would do exactly the same thing as that. It's just nothing's changed, it's just different.

Carly: Yes.

Steve: Like you wouldn't put a plaster on a bruise.

Carly: So it's not like a one-off thing?

Steve: Yes. It's like an all the time thing.

Carly: Yes.

Steve: Yes.

(Focus group, l. 1594-1622)

Geoff and Steve agreed that, whilst many of the tasks that young carers might perform in caring for someone were shared by non-carers, it was the ongoing aspect of the experience, coupled with the care recipient having additional needs, which distinguished them as young carers.

Interestingly, Geoff also emphasised the relational aspect of being a young carer. Whilst not all carers or young carers are caring for a family member, like the adult carers, relationships were an important factor in the young carers' experiences. When asked to describe what a young carer does, Geoff's immediate response was 'to go out of the way for, like, who you care for' (l. 220). In common

with the experience of the adult carers, Geoff's comment brought relationships and care to the centre of the caring experience. When asked to expand on what he meant by the comment, Geoff used the example of his sibling's performance in a play to illustrate his point:

Geoff: Like, if you, say if you was going to do something and then say if like if you are going to care for something you need to go, if they want you to go to their performance and you want to go out I would, like, go to their performance instead of, like, going out.

Carly: Right.

Geoff: Because if, like, going out, I can do that any time, but then if I'm gonna go watch a play or something I just go watch that, because it's like a one time thing.

(Focus group, l. 263-273)

To 'go out the way' for the person they cared for involved a level of sacrifice. In this instance Geoff forwent pursuing his own interests in favour of supporting his sibling. Although this sacrifice was viewed as an inevitable aspect of being a young carer, and in Geoff's description was embedded in the care he had for that person, it was not always an easy experience. When asked how situations like this felt, the group indicated that going out of the way for the person they cared for, and the sacrifices this could entail, could result in feelings of missing out, social exclusion and embarrassment for the young carers. The implications of caring are wider reaching than having extra responsibilities at home. Caring impacts on the young carers' social lives, education and general wellbeing. Before considering their experience of feeling the same, but different to their peers this analysis will consider the impact on friendships, hobbies and social life; education and learning; and family life.

## *Friendships, hobbies and social life*

Abi, Geoff and Steve indicated some of the pressures that caring placed on their friendships. Some of the group felt that their friends had a lack of understanding or recognition of their care role:

Abi: They just sort of think, 'Oh, yes.' Like you see like all the programmes like all the people that like, on like Children in Need and stuff like that, all the young carers that do so much and you think, 'Oh everyone's got it that bad.' And then that like your friends sort of like will show you, 'Oh she's not a young carer because she doesn't have it as bad as that person on that TV programme we saw' or-

Geoff: But maybe you do.

Abi: Yes.

Geoff: But they just don't recognise that you do.

Abi: Yes.

Geoff: Because they won't understand what you are going through.

Steve: Or how serious it actually is.

Abi: Yes.

Ofra: And did you try sometimes to speak to some of the closer friends and explain how you feel maybe, I don't know, they don't want to hear or?

Geoff: I think it's like, not like they don't want to hear. I think it's just that they don't understand what you are trying to say to them.

Abi: Yes.

Steve: It's not something you can just sit down and talk to somebody, kind of thing.

(Focus group, l. 397-429)

Abi, Geoff and Steve described their friends' lack of understanding and recognition of their caring role. This was compounded by the challenge of talking to friends about being a young carer, particularly when they had pre-conceived ideas about what it might entail.

Although talking to friends was a difficult prospect for the young carers, Geoff and Abi felt that it was necessary to create a real understanding of their experiences. When asked what they would like to say to their friends about being a young carer, Geoff responded:

Geoff: Tell them actually to listen.

Carly: Yes. You'd want them to listen?

Geoff: Yes.

Abi: For them to shadow you for a day.

Geoff: And to like understand, like to go into your shoes and feel, if they can like going through what we're going through.

(Focus group, l. 528-537)

Geoff and Abi both felt that if their friends were able to both listen and experience first-hand what it was like to be a young carer, they would develop more empathy for their position. The young carers struggled to fully explain their experiences to an audience that they often found to be lacking in understanding. This impacted upon how they interacted and socialised with friends, Abi, for example, would spend time at friends' houses, rather than invite them to her own. Geoff described being selective in which friends to invite into his home, inviting only close friends who had some understanding of the situation. Whilst Abi and Geoff described not being able to talk to friends about their caring responsibilities and feeling limited in whom they could invite to their home, Rosa, who was close in age to her sibling, felt that all her friends knew about her situation:

Ofra: What about you Rosa? Is it the same kind of experience that you've had with your friends or?

Rosa: Kind of, but most of my friends kind of knew because like, erm, I'm like a similar age to my sister and so I've always been at school with her so, like everyone knows.

Carly: Yes. And how does that, does that, how does that feel to you, do you think?

Rosa: It can be quite annoying because she's always there.

(Focus group, l. 493-503)

Rosa's friendships were similarly impacted upon by her caring role, but in contrast to Abi and Geoff it was the visibility of her sister and her friends' awareness of her needs that made Rosa feel intruded upon at times.

Trust and understanding were important factors in supportive friendships.

When discussing whom they could look to for support, Rosa said:

Rosa: Erm, well I'd probably talk to my family probably but I have a friend and she, erm, I think she, I think her sister has some kind of special needs or something so I can talk to her because she understands.

(Focus Group, l. 1328-1331)

Rosa's friend, who she felt had a good understanding because of her own personal experience, was someone that she would turn to for support. Friendships then, when characterised by understanding, can be important sources of support for young carers.

Abi, Geoff and Rosa all illustrated the ways in which their friendships were experienced and negotiated in relation to their caring responsibilities. This presented an additional challenge to young teenagers who, during this period, experienced changing patterns of friendship and socialising (Weller, 2007), and for whom friendship was an important factor in wellbeing and happiness (Bagwell *et al.*, 2015).

The young carers also experienced a lack of understanding and judgement in their interactions with strangers. Geoff and Steve discussed the responses of strangers to their siblings' behaviour in public places:

Geoff: If my brother doesn't get, like, what he wants he just goes off in a tantrum.

Carly: Right.

Abi: You know.

Carly: So what does that, if that happens kind of when you are out and about or you've gone, I don't know, to the park somewhere, or what, how does that feel when there are other people around?

Geoff: Like you kind of want to hide away. You don't want to show your face to them. You just want to like-

Steve: You don't want to get embarrassed.

Geoff: Like, it might sound weird, but you just don't want to be with them. 'Cause like it could be like embarrassing with other people around all saying, 'Oh, look at that.' And then you're just like, you just want to disappear and stuff.

Ofra: Do you have things that you usually say or explain or do you come up with something you sort of say when you have to explain to people, or you just try and avoid the-?

Geoff: No, it's like something happens, we'll sort it out and then just walk away, down something like that, get out of there quick. There's nothing really you can just say like, we're at a mall like Asda or something, like so you are going around with people just looking at you and talking to them about it and stuff.

Steve: Everybody would just be staring, like if they're having a tantrum in, like, Asda, everybody would be just staring at them. You can't tell everybody like, what like problems he's got wrong with him or anything.

(Focus group, l. 885-920)

Geoff described a feeling of not wanting to be with his brother when he was having a tantrum in public. The sense that people were watching and talking about his brother made him feel like he wanted to disappear. Steve similarly described wanting to avoid embarrassment in such situations. Both had an acute awareness of being talked about and stared at in public, but felt powerless in approaching

strangers and talking to them about their sibling's behaviour. Instead, Geoff described leaving the situation as quickly as possible.

Geoff and Steve's experiences demonstrate how stigma is enacted in interactions between strangers; the stares and whispers that Geoff and Steve described illustrate perhaps a lack of awareness and understanding of the care recipient's behaviour, but also a lack of sensitivity to the experiences and feelings of the carers. These factors make the young carers experiences of spending time with and caring for their siblings more challenging, instigating feelings of wanting to escape, rather than spending time with family as a fulfilling and an enjoyable experience.

At the beginning of the group the young carers introduced themselves by telling the group about their interests and hobbies. For any young person the ability to pursue hobbies is likely to be contingent on financial and practical support from parents or guardians. None of the carers talked specifically about their caring role preventing them from pursuing hobbies, in fact Steve, when describing his weekend, said:

Steve: Erm, well it's like, I like to go to sleep but I can't really do that because I have like football training in the morning and I have to wake up like at the same time. And then on Saturday I have a match so I have to wake up at the same time as, like, always, so there's no time for me to just have a lay-in but, no, nothing's changed really. It's just busy, stuff, but if it's called off then it's happy days. Stay indoors.

(Focus group, l. 819-825)

Steve's weekends were filled with football practice and matches. When asked to describe his weekend he did not indicate that his caring role impinged on pursuing his hobbies. Similarly, neither Geoff, nor Rosa nor Abi made specific reference to

their caring responsibilities in their descriptions of their weekends. That the young carers were being asked to describe their typical weekend and in doing so did not make specific reference to caring responsibilities, or indicate that caring interrupted their hobbies, perhaps reflected how these responsibilities were normalised in their day-to-day lives. For example, Abi's response to the question was:

Abi: Erm, it's usually just, erm, like revision and then like do some jobs like walk the dog, cook, wash up and, erm, sometimes I make dinner, erm, but my mum usually does a roast on a Sunday so, I don't have to do it because, I just like cooking so I just do it.

(Focus group, l. 810-814)

Each of these activities may, or may not, have been considered part of her caring role. In her discussion of what a carer does Abi made particular reference to the level of domestic work she did. However, her description illustrated how caring responsibilities can be incorporated into everyday life - they are routine and normal, rather than extraordinary, and so become a taken for granted part of young carers' experiences. When asked to reflect more explicitly on how it felt to, as Geoff commented when discussing what a young carer does, miss out on their own social life to support their sibling, the group reflected more directly on the impact caring had on their lives:

Abi: You feel like you're missing out because if all your group of friends are going out, especially if it's like a big group, you feel like you're missing something. And like sometimes they ask like, 'Why can't you go out?' And you're just like, 'Oh I have to go and do this' or 'I have to stay indoors and look after this person' or whatever.

Steve: It's kind of like embarrassing. Like your mates coming and like 'Oh let's do this' and I'm like, 'I can't do that.'

(Focus group, l. 288-300)

Both Abi and Steve discussed times that their caring responsibilities disrupted their social activities and the feelings of exclusion and embarrassment this elicited. They described having to stay indoors because of their caring responsibilities, rather than spending time with friends. Explaining the reasons for this to their friends was, as discussed, challenging and resulted in feelings of embarrassment.

The contrast between the young carers accounts of their weekends and their elaboration on a more specific comment about what it meant to be a young carer, illustrated how care became part of the unquestioned everyday. As will be considered later in this report, the young carers discussed feeling the same, but different in relation to their peers. Their account demonstrated how they experienced and imagined their lives in this way; their caring role came into view at different times in their discussion. Whilst it was not explicitly present in their accounts of the everyday, when reflecting on their relationships with peers and the feelings of embarrassment that can characterise these, it came to the forefront.

The levels of support and understanding that these young carers received from friends, acquaintances and strangers impacted upon their engagement in hobbies and social activities. Feeling misunderstood, judged or embarrassed led some of these young carers to avoid inviting friends into their home, or talking to friends about their caring responsibilities. Similarly, strangers' reactions to their siblings could make them feel uncomfortable in public spaces. However, friends that offered understanding, such as the one described by Rosa, had an important role in offering support to young carers. Supporting young carers in talking to their peers about their experiences, as well as a more general education for young people about disability and caring, could help young carers foster, develop and sustain a supportive friendship network.

## *Education and learning*

All the young carers were still in full-time education and much of their discussion centred on the interaction between their caring responsibilities and their educational experiences. Two particular experiences stood out in the discussion: homework; and interactions with and attitudes, knowledge and support of teachers.

Two issues were raised relating to homework. Firstly, the young carers sometimes struggled to find a good environment to do their homework, with the home environment experienced as noisy and busy. Abi, for example, often did her homework or revision at the young carers' group she attended:

Carly: And Abi you talked about doing some homework, doing some revision here?

Abi: Yes. Erm, like cause it's not really quiet and obviously it's never quiet here either, but like it's a lot quieter than it is at home because either like someone's either watching the telly or someone's like arguing or someone's like crying or whatever but...I tend to not take any notice it's just normal, sometimes you just block it out. You sit there and you think, 'Yes, whatever. Just get on with it.'

(Focus group, l. 709-715)

For Abi, the busyness of the home environment made it difficult to focus on her homework. The young carers' group offered her a space to do so and was an important respite from caring. Both Rosa and Geoff created this space for themselves in the home, using their bedrooms as study spaces.

Secondly, the young carers found it difficult to explain to teachers the reasons for handing in their homework late. The group discussed why it would be helpful for their teachers to be aware of their caring responsibilities:

Abi: Because homework and stuff, sometimes it's late because you don't have time to do it, like, because you are always doing something else. And they are like, 'Oh well where's your homework?' And you're like, you're just like, make something silly up like-

Steve: Like the dog ate it or something.

Abi: No not that. It's just too easy to guess. But like, 'Oh I didn't feel well last night' or whatever, so.

Carly: So it's quite hard to kind of say, 'I didn't do my homework because this was happening at home'?

Abi: Yes.

Geoff: Yes.

(Focus group, l. 640-655)

The young carers not only found it difficult to complete homework because of their caring responsibilities, but also struggled to explain to teachers *why* they had not completed it. Consequently, they made excuses to their teachers rather than discuss their situation with them and so, potentially, missed out on accessing understanding and support.

The young carers did not disclose their status to many teachers. When asked if they told teachers at school about their caring responsibilities they said:

Steve: Not really.

Geoff: I often think that most of the teachers who understand-

Abi: The only person that knows is my form tutor because-

Geoff: I don't think any of my teachers know.

Abi: The only other person is my counsellor, but she doesn't, she's not allowed to tell anyone anything so obviously she's not going to go and stuff and be like, 'Oh yes that person's a young carer. She does this and this happened this week in her life' and stuff like that, so.

(Focus group, l. 576-587)

Beyond teachers and other professionals who worked closely with Abi - her form tutor and school counsellor - staff were not generally aware of the young carers'

caring responsibilities. Whilst this afforded a sense of trust and privacy - Abi knew that her counsellor was not going to disclose information about her to other staff members - it could also create difficulties in accessing support and understanding with issues such as incomplete homework, as described above. The lack of disclosure to teachers can prevent the young carers developing positive relationships with professionals who might be able to offer them support. This was evidenced by Steve's discussion of the 'person on the phone', who was the only school professional who knew about his caring responsibilities:

Steve: I think that the only person is like the person who is on the phone.

Because like, you need like, you can't just get someone to call you out of school. You need a reason for like, you barely ever see them, so.

Carly: So you barely ever see the person? So what would happen if you need to leave school?

Geoff: Like they will ring up and then they'll be like, 'Blah, blah, blah. Then this happened and this.' I'll go like 'Okay then.' They call the teacher who's there to say that, 'Geoff has to leave' I'll then go to there and then they'll say, 'Okay, wait here. Someone's here to pick you up.' And then-

Steve: And then you just go.

Geoff: For like a dentist appointment or something like that, but more other things.

Steve: In depth.

Carly: So do you mean there's somebody who takes that call who kind of knows about the situation, but you don't really see them or know who they are?

Geoff: No. Like I see them but you like, you never know who it is, like a mystery.

Carly: And how does that feel to kind of know that there's somebody who sort of knows about what might be going on, but you don't necessarily talk to them?

Geoff: I don't think like that anyone actually realises that this happens.

There's someone that knows like everything. Like, (Laughter) That they know everything.

Ofra: The teachers are not told? They're just told-

Geoff: No just that he has to come here at this time and stuff like that. Not really told the whole thing.

(Focus group, l. 589-628)

Steve and Geoff are, presumably, referring to a school administrator who relays messages to their teachers, should they need to leave school for any reason. Although Steve and Geoff knew this person existed and was aware of their caring responsibilities, they did not know specifically who they were. Geoff described their identity as a 'mystery'; his comments perhaps overstated the anonymity of the individual - he relayed being directed to 'stand over there' by them when waiting to be picked up - but, more importantly, they were experienced as anonymous and mysterious. Geoff and Steve gave a sense of the partial invisibility of young carers in the school environment, where some professionals are aware of their caring responsibilities, whilst others are not, without this always being clear to the young carers themselves.

The young carers did not experience teachers and other school staff as particularly helpful or having an awareness of their caring responsibilities. However, when discussing how they became aware of the support group they all attended, it was clear that teachers directed their parents to additional support services:

Rosa: The, like, special needs, or whatever, teacher at my school told my mum about it and then like my mum found out about it.

(Focus group, l. 1472-1473)

Geoff: Erm, well I was coming home from school and I see my mum going down the road, because our school's at the end of the road. I said, 'Wait. Is that my mum?' And she went, 'Hello.' And I went, 'What are you doing?' And she went to the school to ask the Deputy Head about what is going on and they said about this, like Young Carers and I was like, 'Oh alright then. Yes I'll look into it.' And I looked into it and I'm here and stuff.

(Focus group, l. 1493-1499)

Rosa and Geoff had both previously stated that their teachers were not aware of their caring responsibilities, however, for both it was teachers who recommended the support group to their mothers. What was important here was not the question of whether teachers were or were not aware of the young carers, but that the group did not *feel* that they were. It was significant that the conversations detailed above took place between a parent and teacher; both Rosa and Geoff gave accounts of being talked about, rather than talked to.

Disclosure in the young carers' school environment is a difficult and complex decision. The young carers did not express a desire for all teachers to know about their role, in fact, at one point during the discussion Steve explicitly stated that he would prefer that teachers did not know he was a young carer. A conversation between Geoff, Steve and Abi offered an insight into the reasons for this:

Ofra: Do you think, what would you like, if you could change things what would you like? Would you like the teachers to do something? What?

Geoff: There's nothing really that the teachers can do.

Abi: Like maybe change. Like if they were like, if they actually got, not, no they don't understand if they upset that person.

Geoff: If they went on like a course about all of it and then they can do something about it if it happens.

Carly: So if they maybe had a bit more training to sort of understand?

Geoff: If they had a bit more understanding of like the surroundings that they are actually in.

Steve: Yes but if you wanted to change everything you would have to stop it from happening. Cause if you tell like a bunch of people, that's all they're going to be talking about.

Geoff: It's going to be like the big thing that they're going to be talking about.

Carly: So like drawing attention to you?

Geoff: Yes, it might draw attention to like, and you can also get bullied because of that as well.

(Focus group, l. 1213-1239)

Here the young carers suggested that teachers were unable to change their situation and might in fact make it more difficult by generating unwanted attention. Teachers were also perceived as having a lack of understanding or knowledge to enable them to support young carers. There are clearly benefits to teachers being more aware of young carers, to aid understanding of the impact upon their studies, to direct young carers to services where appropriate. However, disclosure needs to be managed sensitively and with the young carer involved. This would ensure trust and understanding and avoid the air of mystery and secrecy described by Steve and Geoff.

## *Family life*

All the young carers cared in a family environment. They did not speak in detail about their families, or caring roles in relation to them, during the focus group. This perhaps reflected both a teenager's focus on friendships and school and a reluctance to discuss personal information in a group setting. However, three experiences relating to family life stood out in the discussion. Firstly, and already suggested in the discussion of socialising and homework, it was sometimes difficult

for the young carers to find space at home away from caring responsibilities. Secondly, they expressed feelings of protection when discussing their relationships with their siblings. Finally, adults provided a gateway to support services and positive interactions with other professionals.

As indicated by the discussion of homework, the family home was not always an easy environment for the young carers. Abi described the home environment:

Abi: Because I don't really concentrate at home because there is so much going on around me that I can't. It's like people like screaming and shouting. Or not screaming and shouting but like-

Geoff: Disturbing you.

Abi: Yes. You can't never get a quiet place. There's always someone talking.  
(Focus group, l. 203-211)

The young carers found ways of creating a space for themselves amidst the busyness of family life. Abi, for example, got up early in the morning, before other family members:

Abi: I leave before anyone else is awake in my house.

Carly: Oh do you?

Abi: Yes. So I sort of get up and it's all quiet so it's actually really nice. I just like, I get up, I'll wake up at about 6am, get up, just like walk around to do whatever. I have a shower, erm, then I will leave about 7.40am get to school at 8am

(Focus group, l. 751-758)

Steve used his bedroom to forge a private space in the home. His account of doing his homework in his bedroom illustrated the importance of enabling young carers to have their own spaces where possible:

Carly: So do you, is the kind of the homework thing, how, where do you actually do your homework? Is that-?

Geoff: Like in my room.

Carly: You do it in your room?

Steve: Like somewhere quiet and away from everything that's, something that hasn't changed because of this.

Carly: Like a place that hasn't changed?

Steve: Yes, like, where like, say like memories of stuff.

Carly: Okay.

Steve: Somewhere like that, or something like that.

Carly: So somewhere that feels...Where would that be?

Geoff: Like safe.

Carly: That feels safe.

Geoff: I don't know, like your room or something and stuff.

(Focus group, l. 681-704)

Steve sought out a safe space that not only afforded him the peace and quiet to do his homework, but that also remained unchanged by his caring role. Steve's comments and his experiences of friendships and education demonstrated the emotional impact of being a young carer. The young carers not only engaged in physical or practical care tasks, such as domestic work or financial support, but also offered their siblings emotional and social support. Having his own physical space offered Steve temporary respite from the practical and emotional task of caring. His bedroom enabled him to return to a place unchanged by caring and manage the impact of providing such support on his own wellbeing.

The emotional and social support provided by young carers was evident in the group's discussion of their relationship with their siblings. The young carers adopted a protective role towards their siblings; in particular, they discussed how difficult it was to witness their siblings being bullied or struggling with social interactions:

Abi: I felt really bad for him because he used to get circled by a group of girls and they used to push him around in the circle and the teachers just stood there and watched.

Geoff: They didn't do anything?

Abi: Yes, they just didn't do anything. They just watched and sort of like as if to say, 'We don't care.' And I felt that in that surrounding that they just did not understand and stuff like that, so. Yes, it was quite sad and hard to see my brother go through that pain and be treated like that.

Geoff: It's hard to like, it's hard to actually see someone like your brother go through like something. Like if they get bullied in school it's hard, you just want to go over there and stop it but then everybody's crowding round of them and you can't like get through to like stop it.

Carly: It sounds very difficult.

Geoff: It is.

(Focus group, l. 1107-1128)

Abi and Geoff felt protective, yet helpless, when witnessing their brothers being bullied. Abi's helplessness was compounded by the inaction of teachers. This was one example of how care infused family relationships and everyday life. In these instances Abi and Geoff were caring for their siblings, despite being unable to offer any practical support; their feelings of hurt and protectiveness were illustrative of a general awareness of care recipients' needs at all times. As illustrated by the adult carers' accounts, care cannot be restricted to specific tasks or time periods. The young carers all adopted a caring role, even when not actively engaged in self-evident caring tasks.

The unquestioned nature of care can make it difficult for young people to recognise themselves as carers and so access the support they might require. All the young carers in this group said that they did not view themselves as such until they were invited to attend the support group that they were recruited through for

this study. This also makes understanding and explaining their position to others more challenging.

Steve: And they don't know about it. Like when I started I was like, 'What is this?' and then now I understand that-

Geoff: Because when you are like young you don't really understand, like the issues but when you like get older and older you get some more of an understanding.

Carly: Yes. So have you all been caring for quite a long time or is it quite a new thing?

Abi: A long time.

Carly: Yes. That you feel like as you've got older you've kind of understood a bit more.

Steve: Yes, understood a bit more.

(Focus group, l. 330-345)

In ensuring that young carers are able to recognise themselves as such and so access appropriate support, adults can act as gatekeepers to services. This was demonstrated by Rosa and Geoff when discussing how they first found out about the young carers group they both attended. Abi's mum also found out about the service and during the process Abi identified herself as a young carer:

Abi: Erm, I think I was just, my mum was looking online for things to do and I think she typed in like 'young carers' or something like that and it came up. So she sort of rang up and was just like, 'Oh like my daughter cares for her brother who has special needs and that, like would she pass as a young carer?'

(Focus group, l. 1480-1484)

Abi: I think I just sort of like realised when my mum like referred me to The Young Carers I was like, 'Oh I'm a young carer am I?'

(Focus group, 1534-1536)

Geoff similarly came to understand himself as a young carer through conversations with his mother:

Geoff: I didn't fully understand what it was all about until like my mum told me.

Abi and Geoff demonstrated how adults, and parents in particular, can assist young carers in accessing support and identifying themselves as young carers, thereby opening up opportunities for them to discuss the challenges of being such. The earlier discussion suggested that it was important these conversations take place with young carers, rather than about them. Offering young carers a means of articulating their experiences can facilitate both access to support services and, potentially, a means of explaining their care role to friends and teachers.

Time spent outside the family home offers young carers respite from their caring responsibilities. In particular, the young carers discussed the value of attending the young carers' group:

Abi: Yes and, erm, we've sort of like, I hate to say this but it's like gone loads downhill, like we've lost so much funding, erm, but we used to go on lots of trips to Butlins and stuff like that and stay like for the weekend. Erm, used to do like shows and stuff and now it's more, like, in here.

Geoff: It's like more compact.

Abi: Yes. But we're all in one space doing the same thing. And whereas before you could do whatever you wanted. You could go upstairs, you could go downstairs. You can watch a film or you could just chill. It's changed quite a lot I think.

Carly: Changed quite a lot.

Abi: Yes.

Carly: What about, have you all been coming here for the same amount of time?

Geoff: No. I've been coming a little less than Abi. I mean she started in March.

Steve: I started before her (Rosa).

Rosa: Yes. I started a couple of weeks ago.

Carly: Oh did you? So you're really new to the group? And what kind of, erm, what do you sort of enjoy doing while you're here? Are there particular sort of activities or...?

Geoff: Erm

Abi: Just chilling really. You don't get to do that at home so just chill. And just talk to people.

Geoff: And it's like random what we do. Like one week we'll do something like art and another one we just stuff, different stuff.

Steve: Sitting down. (Laughter)

Carly: You had a film night the other night?

Steve: Yes.

Abi: Yes. I sat and did revision.

(Focus group, l. 143-186)

Abi and Geoff, who had attended the group for a number of years, both noted the changes they had experienced there. Reductions in funding resulted in fewer off-site activities and a smaller choice of activities. Despite the changes, Steve, Geoff and Abi each valued a space to 'chill', to talk to other young carers and engage in different activities. Steve and Geoff later contrasted their experience of the young carers group and other spaces, with being at home:

Carly: Are there any other kind of things or people that particularly helped at times that have been more difficult, or is there anything?

Geoff: Erm, it's probably not necessarily people but it's like a group.

Carly: Okay.

Geoff: Like you go somewhere with a group and it kind of makes you forget about everything. When you come home it's just kind of normal because you've forgotten about most of it.

Steve: But then when you see the person you like remember again.

Geoff: You're like, 'Oh yes.'

Ofra: So what group do you go to? You were talking about this group or another?

Geoff: Yes some of like this group are like your friends when you go out and you-

Steve: When you go out with your friends and that and you come home and you forget and then you see the person it's like, 'Oh yes.' You remember again.

(Focus group, l. 1430-1441)

The young carers' group and the friends Steve and Geoff made there, provided a space away from home and their caring responsibilities. It offered a place to forget about being a young carer during difficult periods. Considering the lack of understanding they had from friendships outside the group, the young carers group may have been, paradoxically, a place where they could temporarily forget about being a young carer.

These young carers experienced family life in different ways. They both gave and received care through their relationships with siblings and parents. They used places in and outside the home to create a space for themselves away from caring. The young carers' group offered the opportunity to do this, in contrast to the young carers' experiences of their friendship groups.

### *Same, but different*

In their discussion of their family life the young carers illustrated their experience of being same but different. When asked what they would like other people to know about being a young carer, Abi and Steve responded with:

Abi: We're just the same as everyone else but just, our lives are sort of like different. Like when everyone else is like we have more like sort of responsibilities.

Steve: Responsibility. Yes.

Abi: The other people don't really realise that we have to like-

Steve: They don't understand what we have to go through.

(Focus group, l. 1653-1661)

The young carers' discussion of friendships, education and family life can be characterised by this sense of being the same, but different. Spending time with friends, completing homework and complex relationships with siblings, are all recognisable experiences to non-carers. However, for young carers there are additional facets to these experiences that mark them out as different. A young carers' group serves an important function in diminishing this sense of difference, albeit temporarily.

Abi and Steve pinpointed responsibility as one of the experiences that marked them out as different from their peers. Developing a sense of responsibility and the important skills and knowledge that accompanied it, were considered one of the positive aspects of being a young carer.

Steve: You have to take more responsibility for the other person as well as yourself.

Ofra: Okay.

Steve: Like, for like a job or something if you were, if something happened and you already had experience for this, for doing more stuff and then you can become better.

Carly: So do you think that you, do you mean that sort of having, helping care for somebody-

Steve: Can make you better in your future and that.

Carly: Right, okay.

Steve: Like say for cleaning, whereas like you learn how to work the washing machine and stuff. And then like if you like, if that didn't happen to you when you're like 20 or 30 you'd-

Geoff: And you live by yourself you have no idea how to do it

(Focus group, l. 1045-1065)

Steve and Geoff valued the skills they had developed through caring and anticipated their use in future personal and professional lives. They appreciated this particular difference from their peers and compared themselves positively to

peers who will grow up without domestic skills, such as cleaning or operating a washing machine. Caring offered these boys a source of pride and confidence in their abilities. They saw a value in skills that may well be dismissed by other teenagers. This particular difference from their peers was seen as a very positive and useful one.

The experience of being different from their peers is not, therefore, always viewed as negative. However, these differences require consideration and understanding to ensure that young carers can be fully supported.

### *Making a difference for young carers*

When asked what would be required to make the experience of being a young carer easier, Steve and Geoff emphasised that people needed to listen to young carers to really understand their experiences:

Steve: That people listen.

Carly: That people listen? Which people?

Steve: Everybody.

Geoff: Make it better? Erm, not like, I don't really know because like-

Steve: It's always going to be there on your mind, like of incidents that's happened. And when you're like doing stuff at school it can like pop up in an instant and then they can't really forget about it. Because it's like something that you can't forget.

(Focus group, l. 2101-2114)

Steve reflected on the inescapability of being a young carer. It was not something he could easily forget and, even when not actively engaged in a care activity, his care role still infiltrated every area of his life, such as school in this example.

The young carers also emphasised the need for a greater understanding of the intricacies of their experiences:

Abi: [That] they sort of like understand that it's not just, like, a one time thingy, it's only happens for six months, it's like going to happen, like, for as long as like, it's going to be forever. For, like, just all the time, so it's not always a one-off thing.

Geoff: It's like a lifetime thing.

Abi: Yes it's like a big recurring thing.

Ofra: So you mean that the teachers understand, or your parents understand?

Abi: Stuff like that yes.

Ofra: Teachers, friends. Anyone else? Anyone else that needs understanding do you think or...?

Geoff: Some doctors if they don't understand it. That is like necessarily their job but they don't, it's like maths, you have to understand mainly the main thing but there's all these little things on the side that you could understand.

Carly: So there's always more to know?

Geoff: Yes.

(Focus group, l. 2129-2154)

Abi and Geoff highlighted particularly the ongoing, recurring nature of being a young carer. Both in terms of time - caring is a lifelong experience - and in the extent of caring responsibilities, of which there was always 'more to know' and for friends, family and professionals to understand.

The young carers who took part in this focus group relayed their experiences of being a young carer with friends, at school and in the family home. Across each of these sites they felt being a young carer marked them out as same but different. Everyday teenage experiences, such as socialising, studying and spending time with family, were experienced through the prism of being a young carer. A perceived lack of understanding made spending time with friends difficult and careful consideration was given to who to invite into the family home, or speak to about their caring role. Some of the group felt that talking to professionals, such as teachers, risked drawing attention to themselves and so excuses were made for

occurrences such as late homework. The role of young carer therefore had implications for significant areas of the teenagers' lives.

# Findings, recommendations and conclusions

## Findings

### Overview

This research illustrates the enormous challenges of providing care for a friend or family member. The participants' accounts brought a profound sense of love, care and commitment to the fore; feelings that motivated and propelled the decision to care. However, this was experienced alongside feelings of guilt, isolation, despondency and powerlessness - feelings that have a negative impact upon carers' own health and wellbeing. These emotional foundations of care influence every decision that is made about caring for someone, including whether to continue caring full-time.

As discussed by Priestley (2015), when policies are based upon a dichotomous carer/care recipient identity, the relational aspect of care remains invisible. This approach fails to attend to the negotiations that take place between carer and care recipient regarding decisions about care (Girgis *et al.*, 2013) and assumes the care recipient's lack of autonomy (Priestley, 2015). Caring relationships are already embedded within an existing relationship, such as friendship or family, so the experience of being a carer is multi-layered and complex. Our research supports the argument that policies relating to caring must be able to accommodate the complexities of the relationship between carer and care recipient (Priestley, 2015; Henderson and Forbat, 2002).

The emotional dimension of care cannot be separated from the experience of formal and informal support services, or the accessibility of private and public

spaces. Whilst positive support that is delivered with understanding and empathy can have great benefit for carers, formal support systems, including the experience of carers' assessments, are often found to be unnecessarily bureaucratic and impersonal, further compounding the feelings of isolation, despondency and powerlessness.

The importance of positive and easily accessible health and social care support that genuinely facilitates care and enables carers to pursue hobbies and other activities, cannot be overstated. In a meta-synthesis of research relating to carers of people with depression, Priestley identified a 'cyclical psychosocial process' (Priestley, 2015: 33) in which carers make sense of depression, experience changes in family dynamics, overcome challenges, adapt and move forward. In order to move forward, carers need to retain an identity separate from being a carer and be able to pursue employment, hobbies or other activities unrelated to caring. This is influenced by external challenges, such as accessing support and encountering stigma - experiences reflected in the accounts of carers and young carers in our study.

Both our research and prior studies suggest that carers are not in receipt of adequate support. Despite an apparent increase in emotional and physical support needs, carers' use of GPs and other primary health services does not necessarily increase when they undertake a caring role; access to and use of primary care services depends upon the carer's location in the caregiving trajectory, and other factors such as gender (Arksey and Hirst, 2005). In addition, carers experience a range of difficulties in accessing services as a result of a lack of information, reactive services that do not actively seek to identify carers, inadequate organisation and delivery of services (appointment inflexibility, etc.) and a lack of

recognition of the legitimacy of carer needs (Arksey and Hirst, 2005; Carduff *et al.*, 2014). This is perhaps confounded by a tendency for carers to minimise their own experiences and needs in favour of the person they are caring for (Girgis, 2013; Milne, 2014), particularly as the caring demands upon them increase (Carduff, 2014).

Young carers have specific needs that must be considered when developing support services. The young carers who took part in this research experienced a lack of understanding from friends and professionals and their experience of friendship, education and family life was characterised by a sense of being the same but different. In other research, young carers highlighted the need for educational support, in addition to young carers groups, which were considered to be very useful. Young carers felt that more could be done by both GPs and schools to identify carers and provide services for them (MG Consultancy, 2011).

The young carers in our research described not recognising themselves as such until a parent sought support on their behalf. This echoes research that pinpointed difficulties in identifying young carers (Smyth *et al.*, 2011). Smyth *et al.* (2011) argued that the process of recognising young carers was complicated by societal expectations regarding caregiving, where young people are expected to be the recipients, rather than providers, of care. It has also been suggested that young carers might be silenced due to stigma or fear of being removed from their families (Rose and Cohen, 2010). Other research on carers has suggested that identifying as a carer is a gradual process, which may not necessarily have a clear beginning or end point (Girgis *et al.*, 2013). Individuals are often encouraged to name themselves as carers by health and social care professionals, rather than doing so independently (Carduff, 2014). Some studies suggest that many people

providing informal care do not identify themselves as carers at all (Heaton, 1999; Henderson and Forbat, 2002). Within a familial relationship in particular, caring may not be distinguished from everyday family practices (Smyth *et al.*, 2010).

### *Audio diaries and interviews*

Three themes emerged from the analysis of the lived experience of adult carers, generated through the audio diaries and interviews. Firstly, the significance of relationships and emotion to the lived experience of caring. Secondly, the experience of formal and informal support services. Finally, the importance of the spaces and temporalities of care. Although these are considered separately in the report, the analysis illustrated a profound interconnectedness, where one aspect cannot be separated from another. The list of key findings reflects this interconnectedness:

- (1) The lived experience of care and decisions made about this care are intimately linked to, and understood within, existing relationships. Carers expressed a commitment to caring and made decisions about care that were located within their understanding and experience of their relationship to the care recipient.
- (2) There was a tension between the commitment and (sometimes ambiguous) desire to care, and the experience of guilt, isolation, despondency and powerlessness that caring evoked. This tension formed a stress point for carers.
- (3) The emotional experience of caring cannot be understood in isolation from the use of formal and informal support services. The carers had all experienced challenges in accessing support, receiving adequate

information and feeling frustrated by bureaucracy. Poor experience of services and support can create the feelings of isolation, despondency and powerlessness described by the carers.

- (4) There is a distinction between support systems and support networks. Support systems are often characterised by poor access, a lack of continuity and are experienced as barriers to, rather than facilitators of, effective care and support. Support networks are often comprised of people - professionals, family, friends, acquaintances and Good Samaritans - who acknowledge the importance of the carers' experience and offer personalised, specific and empathic support. Many of the carers reported positive experiences with individual professionals, but challenges in engaging with support services because of complicated or inefficient systems.
- (5) A negative perception and experience of care services, in particular residential care, informs the decisions carers and care recipients make about care. These decisions are also always understood through a knowledge and understanding of the care recipients' needs and wishes regarding care.
- (6) Carers have a wealth of knowledge and expertise relating to both the care recipient's life history and their condition. This knowledge is not always recognised by professionals, but, if it were, carers could bridge the gap between care of the condition and care of the person, enabling carers and professionals to provide whole-person care and support.
- (7) The line between public and private spaces is blurred, one key example of this is the professionalisation of the home when occupied by paid carers and

other professionals. This can alter the carer's experience and use of their own personal space.

- (8) A lack of attention and consultation with carers and care recipients can make public spaces inaccessible to carers and care recipients. Accessible and reliable transport is a key consideration in providing a bridge between private and public spaces.
- (9) Spaces are experienced through the prism of the caring role. Another essential consideration is creating a home environment that facilitates effective care whilst ensuring carers are not trapped by their home environment.
- (10) Carers experience time in multiple ways. The ongoing and relentless aspect of 24/7 care is characterised not only by the repetition of tasks and routine, but also by the ways in which care is enacted even when the care recipient is not present. The notion of parallel lives is an important temporal experience that places carers' lives in contrast to imagined lives or those of their peers. Concerns about the future are ever present and combined with concerns about adequate social care services.
- (11) Caring is an experience that cannot easily be temporally bound, but in the definitions, perceptions and assessment of care, time is a key factor. This can have implications for support provision.

### *Focus group*

The analysis of the young carers' focus group concentrated on the experience of being same but different and how this was manifest in friendships, school and family life. The following key findings highlight, in particular, the importance of

speaking *to* young carers, rather than *about* them, of facilitating understanding and acceptance amongst young carers and their peers and of the importance of young carers' groups.

- (1) Young carers often felt misunderstood by their friends and so were cautious about discussing their caring role with all but a few trusted friends. This impacted upon the ways in which the young carers felt able to socialise, for example going to friends' houses rather than inviting friends into their home.
- (2) The young carers were ambiguous about whether they would like teachers and other professionals to know more about their caring role. They worried that this would draw attention to them, but experienced a sense of confusion and mystery about who knew what information about them.
- (3) Young carers described instances of being talked *about* rather than *to* in relation to their caring role.
- (4) Young carer groups were important spaces that provided understanding, support, friendship and time away from the home.
- (5) The young carers experienced a reduction in the range and type of activities available to them at young carers' groups. For example, activities that the young carers enjoyed, such as off-site trips, were no longer available.

## ***Recommendations***

Recommendations for practice have been divided into recommended improvements to existing schemes or policies and recommendations for new services and practices.

## *Improving existing practice:*

- (1) **Personalised support:** support for carers should be personalised and targeted; offers of respite and other support are not always a suitable match for the carer's needs. Provision should take into account the holistic needs of the carer, care recipient and other significant people (i.e. family members). Carers should be enabled to access support that helps them meet their own particular needs and circumstances. This may include support with domestic work, administrative tasks, in accessing specialist family holidays or more flexible respite care to allow carers to pursue other activities.
- (2) **Partners in care:** care providers and professionals must recognise that the carer's knowledge and expertise is an essential component of adopting a holistic approach to care and treatment. Shared information and understanding between carers and professionals has reciprocal benefits. Carers and care recipients should be viewed as partners in care and be involved in the co-production of service provision and be asked to road-test information sites, procedures such as carer's assessments, and the accessibility of public spaces.
- (3) **Empathy and understanding:** carers need to trust the health and social care professionals who provide care. It is vital that they feel cared for and listened to throughout. Trust in health and social care services can be eroded by a series of instances and so practitioners must endeavour to ensure that every interaction with a professional is a positive one. It is particularly important that carers feel listened to and our research, which is

supported by other research, shows that whilst carers play a vital role in caring for many of the vulnerable, elderly, ill and frail members in our society, their voices are often not heard or ignored by professional medical or healthcare professionals and those administering such services.

- (4) **Reduction in bureaucracy:** support systems (assessments, information seeking, etc.) need to be made more streamlined, less confusing and bureaucratic. They should be based upon principles of care, understanding, support and empathy to ensure that carers have a positive empowering experience of seeking and accessing support. Developing a centralised cross agency system so carers do not have to repeat information to different service providers would make the process easier and less frustrating.
- (5) **Ease of access to information:** information about support and care services must be easily accessible and readily available to carers. The numerous professionals with whom they come into contact should know how and where to direct them for support and be proactive in doing so. Schemes such as Making Every Contact Count, should be extended to focus specifically on carers' needs, to ensure that practitioners at every stage are supported in identifying and advising carers. Information such as that provided on the telephone by HWE's information services should be made available to all carers.
- (6) **Increase provision of young carer groups:** continued and increased support for young carers is essential. Support groups that offer a wide range of activities and opportunities to relax in a safe environment away from the home are particularly valued by young carers and are important for their

present and future health and wellbeing. Raising awareness more generally amongst schoolteachers and pupils about the demands placed on young carers may also help to reduce the stigma many of them experience.

### *Developing new services and practice*

- (7) **Support at transitional periods:** targeted and personalised support is required at key points in the caring trajectory to help carers and care recipients navigate decisions and ensure continuity of care. Decisions about future care are complex and emotionally loaded. Likewise, transitions between care provision, such as from child and adolescent to adult services, is equally challenging. Given that carers are concerned about what will happen to the care recipient as and when their condition deteriorates, or if the carer him or herself is no longer capable of continuing to provide care due to ill health, support and open discussion should be provided. These interventions should occur in advance of the transition to ensure carers feel supported and that care provision is in place ahead of any transition. This is important, not only to facilitate a sense of carer control and independence but also to maintain carers' health and wellbeing.
- (8) **Tackling poor perceptions about residential care services in Essex:** care providers must identify and respond to the reasons for a lack of trust in carers' regarding the quality of care homes in Essex. Carers often have personal experience of poor quality care in care homes and this, coupled with negative media portrayals and a general reluctance for social services to promote care, leads to carers' negative views about such homes and feelings of guilt about them as a future option. However, many care homes

provide a very good standard of care and, for many families, will be the best place. Ways must be established to rebuild carer confidence in these services, in consultation with carers and care recipients. A lack of trust and negative experience of social care services, particularly residential care, can lead carers to continue to care, despite a negative impact on their own health and wellbeing.

- (9) **Advocacy:** independent advocates should be provided to offer information and support. This service should be routinely offered to carers from the outset and at regular intervals. This is particularly important where the person being cared for has a deteriorating condition, such as dementia, or where those undertaking the role are likely to be doing so for many years, as in the case of parents caring for grown-up children with long-term disabilities. It is crucial that the assessment process does not become another bureaucratic exercise, but that person-centred advocacy can be provided for carers throughout the care trajectory.
- (10) **Health and wellbeing:** GPs and their services should be directed to identify any carers known to them and should proactively seek out these patients and offer them regular health check-ups. Such services should signpost carers to local befriending services who provide a network of agents and volunteers to support older people and informal carers to find and develop independent living solutions from within their local community.
- (11) **Good Samaritan scheme:** informal community support for carers should be facilitated and encouraged. Hairdressers, fellow holidaymakers and others can all enable carers to access public spaces with their family members. A

scheme that encourages such Good Samaritans would involve accrediting local businesses whose employees receive training in disability awareness and incorporate it into their customer service. In addition to ensuring that physical spaces are accessible and safe, it would also involve employees in developing augmentative and alternative communication skills and an understanding of the needs of both carer and care recipient. The scheme could be developed in collaboration with carers and care recipients.

- (12) **Support innovative voluntary sector schemes:** further strengthen the local voluntary sector to deliver innovative projects, such as the Community Agents Essex scheme. This recently initiated scheme helps vulnerable older people and informal carers to identify, source and implement solutions to the issues they face, helping them to find support from within their own natural and community networks. Such schemes help to address loss of confidence, social isolation, and they empower and enable carers to gain a sense of control.
- (13) **Increase education about young carers:** trained workers should facilitate discussion groups in schools and youth groups about the experiences of young carers. This would aid young people's understanding of being a young carer without the young carers themselves having to lead the conversation, unless they felt able to do so.
- (14) **Talk to young carers about their needs:** young carer workers in schools and youth groups could facilitate conversations between young carers and other professionals about their support needs. This would give young carers control of who knows about their caring responsibilities and would ensure

that they felt included and empowered.

### *Recommendations for future research*

The chosen qualitative approach has been highly effective in generating insight into carers' lived experiences. We would recommend developing research that takes a similar approach to explore the experiences of some of those groups not included in this report. This includes working carers, non-resident carers, carers receiving no support and young carers caring for adults.

In addition, the findings of this research revealed some important directions for future study that relate to the experience of caring. Firstly, it would be useful to conduct research with a specific focus on the experience of carer's assessments and the carer's allowance. This could involve talking to carers across a period of time as they move through the assessment process. Secondly, research that focuses on transitional points in the care journey (i.e. from child and adolescent to adult services, or from home care to residential care), would offer important insights into the particular difficulties reported in receiving adequate support at these points. HWE is currently developing a piece of research that looks at the lived experience of negotiating the residential care maze, to commence in September 2015. Finally, the significance of space/place was apparent in the audio diaries, interviews and focus group. Future research could adopt methods that incorporate photo diaries and participant generated maps as a means of exploring in more detail the relationship between care and space/place.

## Conclusions

The provision of social care cannot be separated from the wellbeing of carers. A 2013 PSSRU discussion paper (Fernandez *et al.*, 2013) documented the changes in patterns of social care provision in England between 2005/6 and 2012/13. It identified a significant reduction in service provision, both in terms of the number of people receiving social care and the net expenditure on this care. This reduction was more significant in community provision than residential care. The three groups most affected by this reduction - older people, people with mental health problems and people with disabilities - make up the largest group of social care users.

The authors of the discussion paper suggest that some of this reduction, but by no means all, may be accounted for by the successful implantation of prevention and re-ablement schemes, or the shift in resources to individuals with the greatest need. However, the changes in provision are significantly greater than any change in local authority eligibility thresholds. The authors suggest that this indicates that implicit eligibility thresholds - meaning the interpretation of explicit thresholds - have altered. Another possible reason for the reduction in service provision is that fewer eligible people are receiving information and advice about support services. If, as the paper suggests, there has been a reduction in support services, but not necessarily in the numbers of people eligible for these services, then the responsibility of care is possibly being absorbed by unpaid carers.

In 2013 there was a projected rise of 22.8% over the following five years in Essex residents with social care needs, higher than the 19.2% projected across England (Penfold, 2013). There is a mismatch, therefore, between the reduction in services identified in the PSSRU discussion paper (Fernandez *et al.*, 2013) and the

increase in need (Penfold, 2013). Essex faces a significant challenge in meeting the ever growing demands for care and support and, according to a recent Essex County Council Report (2015b), is likely to face these pressures sooner than the rest of the country as a result of the county's demographic profile.

In recent years funding reductions nationally have had a dramatic impact on the delivery of social care services (LGA and ADASS, 2014). As reductions to welfare and social care funding continue, resources for both carers and care recipients are at risk. Service providers are working under increased pressure to deliver effective services, despite continued reductions in funding, and carers are likely to continue to absorb the impact of this reduction to social care provision. Ray James, the president of ADASS made a plea to the government to provide 'sustained and substantial' addition funds for the care and protection of older and vulnerable people. This is in anticipation of expected £1.1 billion budget cuts in 2015/16.

The impacts of austerity measures upon mental health and wellbeing have been well documented (Karanikolos *et al.*, 2013; McKee *et al.*, 2012; PAA, 2015). This includes the experience of isolation and loneliness and feeling trapped and powerless - experiences conveyed by the carers who participated in this research. Health services too have come under increasing strain in Essex, with a shortage of GPs negatively impacting upon the services for those living with complex long-term health care needs and their carers.

The voices of both adult and young carers in this research illustrated the impact of these changes. Unsurprisingly, carers expressed a scepticism that the measures put in place for carers in the Care Act 2014 will ever be realised.

There is a recognition in Essex, as elsewhere, that a greater integration of health and social care is required. Other new approaches - such as the Community Agents scheme, which provides a network of agents and volunteers to support older people and informal carers find and develop independent living solutions from within their local community - are already making an impact in providing valuable advice and support for carers in Essex. As the experiences of our participants in this study showed, much more is needed to support carers in the important role they play. This is not only a moral imperative, but it is also an economic one. As our research shows, caring is undertaken because of deep familial and emotional bonds. The true value of the care and support provided by carers cannot be fully be quantified, however, it is estimated that the economic annual value of the contribution made by carers in the UK equals that of the entire annual NHS budget (Buckner and Yeandle 2011). Where there are adequate support systems in place and where caring professionals and the community at large act with empathy, compassion and care, it can help facilitate the ongoing care that carers provide to those in their care and recognise the enormous contribution carers make to the people they care for and society at large.

The recommendations put forward in this report are founded in the experiences and concerns of the carers and young carers we spoke to. We hope that they will be considered in full and acted upon as a means of delivering comprehensive care and support to carers in Essex.

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# Appendices

## Appendix 1: methodology

### *Audio diaries*

Audio diaries have been used to research a number of areas within health and social care including: breastfeeding difficulties (Williamson, Leeming and Lyttle, 2012); young people and disability (Gibson *et al.*, 2013; Worth, 2009); people living with dementia (Bartlett, 2011); and experiences of healthcare professionals (Zwet *et al.*, 2014; Finnerty and Collington, 2013; Chan *et al.*, 2013). This method generates participant controlled data that can offer insights into the specificities and complexities of lived experience.

The use of audio diaries had a number of benefits for this study. Firstly, audio diaries are particularly effective for capturing participants' experiences in real time, allowing them to record their thoughts and feelings as they occurred (Elliot, 1997); this gave immediacy to the data that offered a contrast to the interviews. Secondly, considering the time pressures that many carers experience, this flexible form of data collection enables participants to contribute to the study at times that suit them. Thirdly, audio diaries offer a form of participant controlled data, ensuring that participants are active in the construction of their own narrative (Hislop *et al.*, 2005; Williamson *et al.*, 2012); this allowed them to highlight issues of particular relevance or concern, thereby offering real insight into their lived experience. Finally, in collecting the data on a daily basis across a two-week period, this method offered a rich and detailed account of lived experience across a sustained period of time (Williamson *et al.*, 2012).

## *Video interviews*

Video interviews provide a contrasting, although similarly rich, data set to audio diaries. A loosely structured approach begins with the participant's account and allows the interviewer to cover specific topics of interest, whilst making space for unexpected or new topics (Dunn, 2005). This gives the participant the time and space to talk about their experiences in a comprehensive and meaningful way, acknowledging the variety of individual experiences. Face-to-face interviews enable the interviewer to take account of the non-verbal communication and social cues from the interviewee (Opdenakker, 2006). By video-recording the interviews, the participant's body language and non-verbal communication can be taken into consideration. This is particularly important in research concerned with the lived experience of challenging and emotive topics. The expression of emotion is embodied and may be more forcefully and compellingly communicated through body language than the words. Using video interviews enabled us to explore this in more depth than audio interviews alone.

Three of the six interviewees chose to be video recorded. A professional camera operator accompanied the researcher to the interview. The camera equipment was set up in the participant's home and operated by the cameraman, who was present throughout the interview. Each participant was informed of the procedure beforehand, to ensure they were fully aware of what being video interviewed would involve.

## *Focus group*

Focus groups can provide an effective means of generating the discussion of challenging subjects and can foster a sense of shared experience. Krueger and

Casey (2000) recommend that focus group participants feel comfortable enough with one another to enable discussion. The young carers all knew each other, although were not so familiar with each other that shared experiences did not require elaboration through discussion. The use of a homogenous group is also recommended (Casey and Krueger, 1994) and this group were similar in age and shared the experience of caring for a sibling.

The focus group provides a different type of data to that from audio diaries and interviews. It is based on group interactions that can risk some participants dominating the discussion, whilst others remain quiet and is unlikely to generate accounts that convey the detail of lived experience (Kidd and Parshall 2000). However, focus groups can offer a useful means of generating discussion on potentially difficult topics in a supportive environment. The use of focus groups in this study ensured the voices of young carers were heard, whilst relieving any pressure or embarrassment that they may have felt in participating in audio diaries or video interviews, as discussed in the following section.

## *Recruitment and sampling*

### Recruitment

A targeted recruitment strategy was adopted for the study; carers and young carers were recruited through a carers' organisation based in South Essex. The manager of the organisation initially contacted members by letter and included an information sheet with details of the study (Appendix 4). The details of individuals interested in participating were passed on to the researchers, who made contact to discuss the study. Interested carers were given more detailed information and if they were still willing to participate, the researcher visited the carer in their own

home, when they were given the opportunity ask any questions before being given the digital audio recorder, background information questionnaire (Appendix 5) and consent form (Appendix 7). The researchers also attended one of the support groups at the organisation to invite attendees to participate, however, none of those chose to do so.

Initially, the young carers' co-ordinator at the carers' organisation assisted us in speaking to young carers about the study. However, it became clear after speaking to young carers that the audio diaries in particular were off-putting and that they felt they would feel embarrassed and self-conscious taking part. In order to involve young carers in the study we amended the proposal to incorporate a focus group. It was anticipated that speaking in a group with peers would be a more comfortable experience for them. Following this amendment four young carers decided to take part in the study and the young carer co-ordinator arranged a time and date for the focus group to take place.

The targeted recruitment strategy had a number of benefits. The carers' organisation is located in a town in South Essex. Osbourne<sup>8</sup> is a low-income area with an ageing population and is located in a part of Essex with a high percentage of carers (ONS, 2013). The lived experience of carers is therefore of particular relevance to residents in this town and enabled us to consider the data in this specific context. Whilst the chosen approach and methodology were not intended to elicit findings that can be generalised to all carers they covered our concern with the depth rather than breadth of experience. The focus of our recruitment in a specific area of Essex may offer some insight into experiences of unpaid care

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<sup>8</sup> The town name has been anonymised to protect the identity of the study's participants.

within and around the Osbourne area, which can be used as a springboard for further research. To date HWE have not conducted any research in South Essex; by focusing on carers in Osbourne we ensured that HWE research was listening to voices across Essex. The targeted recruitment strategy also meant that participants had support in place for the duration of and following the study, as all were already in contact with the carers' organisation.

### Sampling

The study adopted a purposive sampling approach (Given, 2008), specifically criterion sampling. Purposive sampling is a common technique within qualitative research, whereby strategic sampling decisions are made to ensure that the sample matches the research objectives (namely, to understand the lived experience of carers in South Essex). The sample sought was non-representative of either the general population or the carer population; the purpose of the study was not to generalise the results to the wider population. Criterion sampling seeks out a participant group that meets a certain criteria. For this study the broad category was carers living in South Essex, however, in order to ensure some diversity in caring experiences, we sought young carers, adult carers of younger people, carers of elderly people, working carers and a range of carer/care recipient relationships.

### *Ethics*

#### Confidentiality/anonymity

Participants were given pseudonyms that have been used throughout this report. Any identifying information (names, places, etc.) has been kept confidential and is

known only to the researchers. Confidentiality and anonymity is, however, compromised for participants who agreed to take part in the video interview. Selected video extracts used during the dissemination of the research, including extracts embedded in the electronic version of this report, have been approved by the participant. All participants were given the opportunity to take part in an audio only recorded interview, ensuring that they could participate whilst remaining anonymous.

### Participant welfare

This research asked people to share highly emotive, stressful and potentially distressing experiences. Therefore, we developed the following strategies for minimising participant distress, or supporting them should they become distressed before, during or after the study:

#### ***Before the study***

All potential participants were given as much information as possible about the reasons for the study and what participating would involve. They had the opportunity to discuss any concerns or ask any questions with the researcher before agreeing to participate. This ensured that participants were fully informed and prepared for the study, thereby minimising the chances of discomfort with the procedure.

#### ***During the study***

During the audio diary study participants were able to contact the research team with any questions or concerns. The researcher contacted them following the first week of the audio diary study to check on its progress. If any distress was

identified at this point, the participant would have been directed to appropriate avenues of support, including helplines (Samaritans, Carers UK), or the carers' organisation that all the participants were already in contact with. The carers' organisation we recruited through agreed that, should a participant become distressed during the data collection stages, they would be able to provide telephone support or a face-to-face visit, as appropriate.

It was made clear to the participant that if at any time during the audio diaries, interviews or focus group, they should become distressed they were free to withdraw from the study, or take a break if required. During the audio diary stage this may have involved taking a break from recording diaries for a day or more, or withdrawing from the study completely. During the interviews and focus group, this would involve pausing or terminating the recording equipment, offering the participant the opportunity to talk through their concerns without being recorded, or to take a break and leave the room before continuing with the interview. Alternatively, they may have decided to withdraw from the study entirely.

### ***Following the study***

Following completion of the audio diaries, the researcher met with the participants to collect the audio diaries, thank them for their participation and discuss their experience of the study. During this conversation, if the participant identified any distress or support needs, the researcher directed them to relevant agencies - as detailed above. Similarly, following the interviews and focus group the participants had the opportunity to raise any concerns or ask questions about the study in an unrecorded debriefing session with the researcher.

These strategies were designed to ensure that the participant felt informed and supported at every stage of the study, with the aim of minimising the potential for participant distress and successfully supporting participants should this occur.

### **Informed consent**

To obtain informed consent the research team endeavoured to give potential participants full and accurate information on the study before they decided to participate. This included both written information and face-to-face/telephone discussion of the study. All issues relating to anonymity, confidentiality and the right to withdraw were discussed with the participants in full, and the intentions for the dissemination of the data were made clear. Once these conversations had taken place the participant was asked to sign a consent form for the audio diary study (Appendix 7). The consent forms for the interviews were signed after the participants had decided to take part in this stage (Appendix 8). Although participants were made aware of the interviews at the beginning of the study, they did not have to commit to participating before the completion of the audio diary stage.

For young carers' participation consent was sought from both participant and their legal guardian. The young carers' co-ordinator facilitated this process. Both the young carers and their guardians had the opportunity to speak to a member of the research team if they had any concerns or questions, no one chose to do so. The young carers and guardians were asked to sign separate consent forms and both were required for the young carer to participate (Appendices 9 and 10).

## *Strengths and weaknesses*

There were a number of strengths and weaknesses to the project. A key strength was the carer-focused approach facilitated by the chosen methodology. The carers and young carers who participated in the study were given the opportunity to talk about their lives in great detail. Whilst methods such as surveys can gather the experiences of a large number of people, and in so doing offer a very useful overview of patterns of care, qualitative methods offer participants the space, time and means to share the detail of their story. The accounts that are generated through these methods are powerfully evocative and offer the opportunity to explore the complexities and messiness of lived experience. Adopting this approach enabled us to understand carers' experiences holistically and highlighted how experiences and perceptions of service provision cannot be separated from carers' life histories, relationships, emotions or the spaces and temporalities of care.

Another key strength of the study was the comprehensive ethical considerations. We were aware that we were asking carers to discuss highly emotive and often difficult aspects of their lives. Therefore it was essential that participants were fully informed about the procedure and had the opportunity to ask questions and express concerns at numerous points. Developing positive relationships with the carers was an essential element and this was made possible by having continuity of researcher between the different stages of the study. In the audio diaries and interviews, from first contact to final interview, the participants were in contact with the same researcher. For the focus group both researchers created a warm and welcoming environment for the young carers by providing refreshments and chatting with them before and after the focus group.

All participants were recruited through a carers' organisation they were already in contact with in some way: in receipt of paid care services; care recipient attending day centres; attending carer and young carer groups themselves. This approach ensured that the carers we spoke to had some form of support network in place. The organisation agreed that, if needed, they could provide additional support to participants if they experienced distress as a result of the study. This ensured that, in addition to information signposting, a comprehensive support package was in place if required.

The targeted recruitment strategy and the use of the carers' organisation as a recruitment tool was also one of the weaknesses of the study. Despite the ethical benefits of the approach, it did mean that the participants were all carers who were already in contact with services and support in some form. It did not include people who may not recognise themselves as carers or have knowledge of, or access to, support. This was a consideration in the design of the study, but the research team felt that, for an in-depth and small-scale study, ethical considerations and adequate support provision for participants should take precedence. This does not mean, however, that future research should not and could not adopt a different recruitment strategy to access carers who are not in contact with support services.

A small sample size is not considered a weakness for an in-depth, qualitative piece of research. However, whilst there was no expectation that the sample would be big or diverse enough to generalise to the wider carer population, there were some important voices missing from the sample. Firstly, there was little diversity in nationality or ethnicity, whilst this reflects the general demographics of the area it is important to highlight the absence of non-white voices. Secondly,

there were no working carers, although some of the carers had worked previously whilst caring, and no non-resident carers. In addition, there were no young carers of adults. Although a small sample is unlikely to show a wide diversity, these are key groups who were missing from the study.

## **Appendix 2: audio diary guidelines**

**Who cares for the carers? - capturing the lived experience of carers in South Essex**

### **Audio diary guidelines**

#### **How often should I record a diary entry?**

Aim for at least once a day for two weeks. You can do more than one entry a day if you'd like to. If you miss a day - don't worry, just carry on with the diary as normal the following day.

#### **How long should the diary entry last?**

Try and speak at least 10 minutes per day. If you would like to talk for longer - that's great! There is no upper time limit!

#### **When should I record a diary entry?**

At any time of day or night. You might get into a routine of making a recording at a specific time, or you might prefer to do it as and when you feel you have something you'd like to talk about. You can make a recording at any time and in any place.

#### **What should I include in the diary entry?**

Please start every entry with your name, the date and time. After this, you are free to talk about whatever comes to mind. We are interested in your thoughts and feelings in relation to your caring role. The following questions might help you think about what to say:

- What has happened today? (this can include anything, even events that seems 'everyday' or inconsequential)
- What has your caring role involved today?
- Have you had a good day, or a bad day?
- How are you feeling? How would you describe your emotions today?

- Who have you spoken to today?
- What activities have you done that relate to your caring role?
- What activities have you done today that don't relate to your caring role?
- What were your plans for today? Did today go as planned?
- Did anything unexpected happen?

We want to know about your day-to-day experience as a carer. There is no 'right' or 'wrong'. We want you to tell us what it is like being a carer and it is up to you to decide what that should include.

#### **What if the recorder breaks or I'm not sure how to use it?**

If you are having problems using the recorder have a look at the instructions given to you by Carly. If you still need help, call Carly on XXX and she can try and sort the problem out.

#### **What happens at the end of the two weeks?**

When the two weeks are over, Carly will contact you to arrange a convenient time to collect the recordings.

## Appendix 3: interview schedule

Can you tell me your story of being a carer?

*Participant gives initial account. Following this, ask them to expand on anything from this initial narrative, based on the notes taken and referring to the account they have given. Once they have responded to these follow-up questions use the following or similar (if necessary/appropriate):*

### Illness

- If you twisted your ankle tomorrow and couldn't move off the sofa, what would the day look like in relation to caring for...?

### Carer identities

- When did you first call yourself/recognise yourself as a carer?
  - o How do you feel about the term?
  - o Do you consider yourself to be a carer?

### Support services

- What types of support or services, no matter how big or small, would make your caring role easier/more manageable?

### Work and leisure

- You said that you enjoyed/worked as/spent time...what needs to be in place to enable you to do that?
- Would you like more time for (work or leisure activity they have mentioned)

## **Appendix 4: information sheet for audio diary and interviews**

**Who cares for the carers? - capturing the lived experience of carers in South Essex.**

### **Participant information sheet**

**Research Team:** Dr. Oonagh Corrigan & Dr. Carly Guest

**Contact:** Dr. Carly Guest **Tel:** XXX

**Email:** carly.guest@healthwatchessex.org.uk

Thank you for your interest in taking part in this Healthwatch Essex study. We want to hear the voices of unpaid carers in Essex and have designed this study to give you the chance to tell us about your experience of being a carer.

This information sheet outlines the aims and design of the study, and what taking part involves.

It is important that you feel comfortable with participating in this research and fully understand what this involves. We have tried to give as much information about the study in this information sheet. After reading this information sheet we encourage you to discuss the research and your role in it with Carly Guest.

#### **What is this study about?**

For this current study we want to hear about your experience of caring. This study aims to listen to carers' in-depth accounts of caring and bring their voices to the centre of discussion of carers' health and wellbeing needs.

#### **Outline of the study**

There are two stages to this study. The first is an audio diary study, the second a video interview. These are described separately below. Participating in stage one does not mean you are committed to participating in stage two.

##### *Stage one: audio diaries*

For this stage of the study you will be given an audio recorder for a period of two weeks. For these two weeks you will be asked to record your experiences, thoughts and feelings relating to your caring role for at least 5-10 minutes per day (or longer

if you decide to). At the end of the two weeks the researcher will contact you to arrange a time to collect the recorders and discuss your experience of completing the diaries. At this point you will be asked whether you would like to participate in the second stage of the study, described below.

### *Stage two: video interviews*

For this stage of the study you will be invited to attend a one-to-one interview to discuss your experiences further and talk in more detail about the types of support you would like, or already receive as a carer. We would like to video record this interview, but you can also be interviewed using only audio recording if you prefer. The interview can take place at a time and location convenient to you.

### **What will we do with the data?**

- The audio diaries and interviews will be transcribed.
- The recorded and transcribed data will be stored securely in a locked filing cabinet or password protected electronic file. This will be accessed by the research team only.
- Any identifying information we collect (names, dates, places etc) will be anonymised through the use of a pseudonym.
- We will analyse the data to further our understanding of carers experiences.
- We will write about the study in a research report that will be disseminated to carers and service providers.
- This report may contain anonymised quotes from your audio diary or interview - we will seek your permission to use these.
- We may use extracts from the video interviews for dissemination purposes, such as in presentations or on the Healthwatch Essex website. This will only happen with your consent.

### **Participant rights**

As a participant you have the right to:

- Confidentiality
  - Any identifying information, including names, dates, places, will remain confidential.
- Anonymity

- You have the right to remain anonymous through both stages of the study. This means that names and places will be replaced with a pseudonym in the transcription and reporting of the data.
- If you choose to take part in the video interview study your explicit permission will be obtained to use this video for dissemination purposes (for example, in presentations or on the Healthwatch Essex website).
- You can participate in this study and remain entirely anonymous - you do not have to agree to the use of the video data for these purposes.
- Withdraw from the data collection stages of the study
  - At any point during stage one and two you can take a break, or withdraw from the study completely.

### **What now?**

After reading through this information sheet please contact Carly to ask any questions. Alternatively you can ask Carol or Laura at Carers Choices to pass your contact details onto Carly and she will get in touch with you directly.

### **Who are we?**

Healthwatch Essex is an independent organisation committed to producing high quality research that explores patients' experiences of health and social care services in Essex. In capturing and articulating people's experiences through research and community engagement projects we can positively influence the commissioning and delivery of health and social care in Essex.

## ***Appendix 5: background information questionnaire (adult carers)***

**Who cares for the carers? - capturing the lived experience of carers in South Essex.**

**Background information questionnaire**

**Research Team: Dr. Oonagh Corrigan & Dr. Carly Guest**

**Contact: Carly Guest Tel: XXX**

**Email: XXX**

Thank you for your interest in taking part in this study. Please complete the questionnaire below. Any identifying information will be anonymised and the questionnaires will be kept in a locked cabinet accessed only by the research team.

Please state your:

- Name
- Age

How would you describe your:

- Gender:
- Ethnicity:
- Social Class:

Relating to your caring role:

- What is your relationship to the person you care for?
- How old is the person you care for?
- What is the gender of the person you care for?
- What is the ethnicity of the person you care for?
- What are the support needs of the person you care for?

- For how many hours per week do you undertake caring responsibilities?

#### Contact details

- Address
- Telephone number:
- Email address:
- What is your preferred method of communication?

## ***Appendix 6: information sheet for focus group***

**Who cares for the carers? - capturing the lived experience of carers in South Essex.**

### **Information sheet**

**Research Team:** Dr. Oonagh Corrigan & Dr. Carly Guest

**Contact:** Dr. Carly Guest **Tel:** XXX

**Email:** XXX

Thank you for your interest in taking part in this Healthwatch Essex study. We want to hear the voices of young carers in Essex and have designed this study to give you the chance to tell us about your experience of being a young carer. This information sheet outlines the aims and design of the study, and what taking part involves. It is important that you feel comfortable with participating in this research and fully understand what this involves. We have tried to give as much information as possible about the study in this information sheet. After reading this information sheet we encourage you to discuss the research and your role in it with Carly Guest.

### **What is this study about?**

For this current study we want to hear about your experience of caring. This study aims to listen to young carers' accounts of caring and bring their voices to the centre of discussion of carers' health and wellbeing needs.

### **Outline of the study**

We would like to gather the experiences of young carers through a focus group discussion with other young carers. The group will be asked to talk about their experiences of being a carer, through a discussion that will be guided by a leader. A member of the Carers' Choices young carers' group will also be present for the discussion.

## What will we do with the data?

- The discussion will be transcribed.
- Any identifying information we collect (names, dates, places etc) will be anonymised through the use of a pseudonym.
- We will write about the discussion in a research report that will be disseminated to carers and service providers.
- This report may contain anonymised quotes from the discussion.

## Participant rights

If you take part in this study you have the right to:

- Confidentiality
  - Any identifying information, including names, dates, places, will remain confidential.
- Anonymity
  - You have the right to remain anonymous through both stages of the study. This means that names and places will be replaced with a pseudonym in the transcription and reporting of the data.
- Withdraw from the data collection stages of the study
  - At any point during the focus group you can take a break, or withdraw from the study completely.

## What now?

After reading through this information sheet please contact Carly to ask any questions. Alternatively you can ask Laura from XXX to pass your contact details onto Carly and she will get in touch with you directly.

## Who are we?

Healthwatch Essex is an independent organisation committed to producing high quality research that explores patients' experiences of health and social care services in Essex. In capturing and articulating people's experiences through research and community engagement projects we can positively influence the commissioning and delivery of health and social care in Essex.

## Appendix 7: audio diary consent form

Who cares for the carers? - capturing the lived experience of carers in South Essex

Participant consent form

Stage one: audio diary study

Research Team: Dr. Oonagh Corrigan & Dr. Carly Guest

Contact: Dr Carly Guest Tel: XXX

Email: XXX

Thank you for agreeing to take part in this study. After reading the following statements and discussing them with the researcher, please sign and date this form.

- I am over 16 years of age.
- I have been informed of the aims, objectives and procedures of this research, outlined on the attached information sheet and willingly consent to participating.
- I have had the opportunity to discuss any questions or concerns I have about the study with the researcher and am satisfied with the response.
- I understand that a pseudonym will be used in the transcription, discussion and dissemination of the audio diary data to protect my anonymity.
- I consent to anonymised extracts from my data to be reproduced in publications, such as the research report, information sheets and journal articles.
- I understand that if I disclose information about an individual being at risk of harm, it may be necessary for the researcher to disclose this to the relevant organisations. I understand that the researcher will discuss this with me before taking further action.

Name of participant

Signature of participant

Date

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Name of researcher

Signature of researcher

Date

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## ***Appendix 8: video interview consent form***

**Who cares for the carers? - capturing the lived experience of carers in South Essex.**

**Participant consent form**

**Stage two: video interview study**

**Research Team: Dr. Oonagh Corrigan & Dr. Carly Guest**

**Contact: Dr Carly Guest Tel: XXX**

**Email: XXX**

Thank you for agreeing to be interviewed for this research. After reading the following statements and discussing them with the researcher, please sign and date this form.

- I am over 16 years of age.
- I have been informed of the aims, objectives and procedures of this research, outlined on the attached information sheet.
- I willingly consent to be interviewed/video interviewed (delete as applicable).
- I have had the opportunity to discuss any questions or concerns I have about the study with the researcher and am satisfied with the response.
- I understand that a pseudonym will be used in the transcription, discussion and dissemination of the interview data to protect my anonymity.
- I understand that HWE will securely store paper copies of data for 2 years only, electronic data will be stored for up to 10 years. The data will then be securely destroyed.

- I consent to anonymised extracts from my data to be reproduced in publications, including the research report, information sheets and journal articles.
- I consent/do not consent (delete as applicable) to video extracts from my interview being used as part of research dissemination, with my prior approval. This may include reproduction in presentations or on the HWE website.
- I understand that if I disclose information about an individual being at risk of harm, it may be necessary for the researcher to disclose this to the relevant organisations. I understand that the researcher will discuss this with me before taking further action.

Name of participant

Signature of participant

Date

Name of researcher

Signature of researcher

Date

## Appendix 9: young person focus group consent form

Who cares for the carers? - capturing the lived experience of carers in South Essex

Participant consent form

Focus group study

Research Team: Oonagh Corrigan, Carly Guest & Ofra Koffman

Contact: Carly Guest Tel: XXX

Email: XXX

Thank you for agreeing to take part in this study. After reading the following statements and discussing them with the researcher, please sign and date this form.

- I understand the aims of the study and would like to take part.
- I have been able to ask the researcher any questions about the study and am happy with the response.
- I understand that a different name to my own will be used throughout the study so that no one can recognise me.
- I consent to anonymised extracts from my data to be reproduced in publications, such as the research report, information sheets and journal articles.
- I understand that if I disclose information about an individual being at risk of harm, it may be necessary for the researcher to disclose this to the relevant organisations. I understand that the researcher will discuss this with me before taking further action.

Name of participant      Signature of participant      Date

Name of researcher      Signature of researcher      Date

# Appendix 10: parent or guardian focus group consent form

Who cares for the carers? - capturing the lived experience of carers in South Essex

Parent/legal guardian consent form

Focus group study

Research Team: Oonagh Corrigan, Carly Guest and Ofra Koffman

Contact: Dr Carly Guest Tel: XXX

Email: XXX

After reading the following statements, please sign and date this form.

- I am the parent/legal guardian of \_\_\_\_\_ and consent to participating in this study.
- I have been informed of the aims, objectives and procedures of this research, outlined on the attached information sheet.
- I have had the opportunity to discuss any questions or concerns I have about the study with the researcher and am satisfied with the response.
- I understand that a pseudonym will be used in the transcription, discussion and dissemination of the audio diary data.

Name of guardian

Signature of guardian

Date

Name of researcher

Signature of researcher

Date

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_





## Why not get in touch?



[www.healthwatchesessex.org.uk](http://www.healthwatchesessex.org.uk)



@HWEssex



/healthwatchesessex



[enquiries@healthwatchesessex.org.uk](mailto:enquiries@healthwatchesessex.org.uk)



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