

# Voices of Carers during the COVID-19 Pandemic: Messages for the future of unpaid caring in Wales



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## 1. Executive Summary

*Unpaid carers are the backbone of the health and social care system in Wales and across the United Kingdom. The economic value of the tasks performed by unpaid carers on behalf of partners, parents, children, relatives, friends and neighbours in Wales is worth more than the entire budget spent by the Welsh Government on health and social care each year.*

During the COVID-19 pandemic, the responsibilities of unpaid carers have increased considerably. There are more unpaid carers than ever before, and most of those who provided unpaid care before the pandemic are now spending more time on providing care for another person. Despite the vital contributions they make on a day-to-day basis, unpaid carers are poorly recognised in public discussions of health and social care and have felt overlooked during the pandemic, in contrast to professional health and social care workers, whose efforts have received greater recognition.

Prior to the COVID-19 pandemic, we knew that, although caring for another person can bring fulfilment and strengthen relationships, becoming a carer can often come with difficult personal consequences. People may not immediately realise that they have become a carer and therefore miss out on vital practical support, and may not know

about welfare benefits to which they are entitled. Many carers suffer from loneliness and isolation, face financial difficulties if they are unable to work alongside their caring role, and suffer worse outcomes in terms of physical and mental health. Those who do work often find that they have difficulty in balancing their caring responsibilities with their job, while younger adult carers may also find that their educational and career choices are restricted by their caring responsibilities. During old age, many unpaid carers fulfil caring responsibilities while also managing their own health conditions. The difficulties carers face have been exacerbated by the social distancing measures necessary to manage the pandemic, which have resulted in many community services being paused, reduced the amount of help available from relatives and friends, and cut unpaid carers off from their usual networks of support.

The Social Services and Well-being (Wales) Act 2014 affords all unpaid carers the right to an assessment, and to services if they are assessed as being eligible. Many carers, however, continue to feel that their needs are not considered in the care planning process and have difficulty in accessing support. Per capita reductions to social care service budgets ongoing since the financial crisis of 2008 have had a direct impact on unpaid carers as well as on the people who use those services.

This study aimed to explore the experiences of unpaid adult carers across Wales during the COVID-19

pandemic. We carried out in-depth interviews, via video link or telephone, with a total of 47 participants, aged from 15 to 85 years. This work has helped to highlight the extent of the challenges faced by carers prior to the pandemic, the nature of carers' experiences during the pandemic, and what their hopes and concerns are for the future. The messages from this research will help services to understand how to improve support to ensure that unpaid carers' roles and responsibilities are sustainable and that their well-being is prioritised and protected.

## 1.1. Key findings and recommendations

Our research highlighted a number of key themes, which relate both to unpaid carers' experiences and needs before the COVID-19 pandemic and to the impact of the pandemic on their living conditions and well-being.

### 1.1.1. Identities and relationships

Becoming an unpaid carer can have a profound impact on the relationship between the carer and the person cared-for. Because caring responsibilities often come about as a response to the needs of a loved one, performing care is often regarded by unpaid carers initially as the normal action of a family member or friend, meaning that developing and recognising a distinct identity as a carer is a complex and gradual process. Maintaining a positive relationship between the carer and person cared-for can be challenging, but is essential to the sustainability of the care arrangements.

#### Key findings

##### Life before the pandemic as an unpaid carer:

- Unpaid carers may not recognise their status or identify as carers until they reach a crisis point, meaning that they are often struggling before they ask for help (See Section 4.1.1).
- Maintaining a healthy relationship between the carer and the person cared-for is vital for the sustainability of a caring role. Most carers are driven by love and/or a sense of duty, yet they may also experience powerful feelings of frustration, or of being trapped and having no choice about fulfilling their responsibilities (4.1.2).
- Caring can complicate family dynamics to a point

that they can become problematic and drive tensions in relationships, for example when roles of parent and child are reversed (4.1.2).

- Shared times of pleasure and enjoyment between the carer and the person cared-for are important for maintaining the relationship between the carer and person cared-for. Carers often feel as if they are treated as instruments of care when their needs are being assessed, but care takes place within a human relationship that must be nurtured and maintained (4.1.2).
- Caring can produce positive benefits for some carers, particularly for younger carers who reported a greater sense of confidence and self-efficacy from their experience (4.1.3).

##### How the COVID-19 pandemic has affected unpaid carer experiences:

- The COVID-19 pandemic has enabled some carers to feel as though they are 'stepping off the treadmill', allowing them more time to relax with the person cared-for, yet for others the loss of respite, personal space, activities or external support has had a negative effect on relationships that risks making the caring arrangements unworkable (4.1.2).

##### The impact on the COVID-19 pandemic on unpaid carer well-being:

- Many carers have felt overlooked during the pandemic and have felt a sense of injustice over the focus on paid health and social care workers by politicians and the media (4.1.1).
- Many caring relationships have deteriorated during the pandemic, with a negative effect on well-being for both carers and the people they care for (4.1.2).

#### Opportunities for action

- Unpaid carers often do not realise that they can be identified as carers until they have been doing the role for a considerable time and therefore do not ask for help until they reach a crisis. There is a need to ensure that carers can access support from the beginning of their caring role.
- Both carers and people who are cared-for need support in coming to terms with the changes in their relationships and in maintaining positive

relationships. It is important to consider not only overcoming problems, but also ensuring opportunities for shared enjoyment.

- In many cases, the conditions of the pandemic have placed additional strain on relationships between carers and people cared-for. Additional support may be required to address these difficulties in the coming months.

## Recommendations

- Targeted promotion of carer identification at points of interaction between services and carers, especially General Practitioners (GPs) and secondary health services. This should be led by professionals to overcome the barriers to carers' self-identifying. The Making Every Contact Count (MECC) approach could be used to guide this improvement.
- Organisations with which carers may have contact should review all published service promotional materials to ensure that inclusive language is used, i.e., language that does not require a person to self-identify as a 'carer' to appreciate its relevance to them.
- The impact of caring on relationships and support to sustain relational well-being should be attended to in carer assessments. Short-term therapeutic work may be useful to support the carer and person cared-for in understanding and managing the transition into a caring relationship. It may be necessary to develop a model of intervention by social services that could be offered as part of a care plan following a carer assessment, drawing upon systems theory, solution-focused therapy and family therapy.
- Post-pandemic carer assessments should attend particularly to how social distancing has impacted personal relationships as well as social and practical support networks, and identify where an elevated risk to carer well-being has occurred as a result of reduced social support during the pandemic, offering intervention where appropriate.

## 1.1.2. Health and well-being

Caring responsibilities can have a profound impact on both the lifestyle and future life choices of unpaid carers. The challenging nature of many caring roles, the restrictions on their personal freedoms and social isolation are all a threat to carers' well-being. Neglecting the well-being of unpaid carers increases the risk of the breakdown of care arrangements and, therefore, a greater need for funded social care services for the person cared-for. Despite the aims of the Social Services and Well-being (Wales) Act 2014, the Welsh Government's Strategy for Unpaid Carers and the long-term plan for health and social care, set out in the *Healthier Wales* strategy document, carers continue to suffer profound detriment to their well-being due to unmet needs related to the stresses of their caring roles. Although we asked interviewees directly about their physical health, this was not a matter that many chose to discuss in detail. We would anticipate, however, that quantitative research with a larger sample might highlight inequalities in this area.

### Key findings

#### Life before the pandemic as an unpaid carer:

- Many carers experience increased stress and adverse impacts on their mental health due to their caring responsibilities (See Section 4.2.1).
- Caring for another person can mean living with significant levels of uncertainty and fear, for example, about the progression of disease or their loved one's suffering increasing (4.2.1).
- Loneliness and social isolation were common difficulties before the pandemic for many unpaid carers. Weaker social networks emerged as being linked with poorer mental health (4.2.2).
- The conditions in which some carers live would, in other situations, be understood as a breach of their human rights. For example, the number of hours of care performed and the risk of personal harm due to lifting or being assaulted (in the case of loved ones with illnesses or disabilities that impact on behaviour), would not be acceptable in a place of work (4.2.3).

#### How the COVID-19 pandemic has affected unpaid carer experiences:

- Carers have felt physically cut off from important sources of support, such as friends and family members (4.2.2).



- The pandemic has further restricted carers' fundamental freedoms – for example, the need to protect 'shielding' loved ones has sometimes meant that carers have not been able to participate in normal family life (4.2.3).

### **The impact on the COVID-19 pandemic on unpaid carer well-being:**

- Levels of stress, anxiety and depression have increased for many during the pandemic. Fear of the cared-for person becoming infected with COVID-19 has been an added pressure here (4.2.1).
- Feelings of loneliness and isolation have been greatly exacerbated by the pandemic, leading to a substantial increase in mental health concerns (4.2.1).

### **Opportunities for action**

- Carers suffer from considerable stress and many note a negative impact on their mental health. Improvements are needed in the services offered to carers to ensure that their caring role is sustainable and that proactive support is available in situations in which their health and well-being are at risk. The recovery period as the country emerges from the pandemic represents an opportunity to find new ways to support carers.
- Loneliness and isolation are common experiences for carers. Many need support to build social connections and to find ways to engage with support from their wider social networks and communities.
- Some carers experience living and caring conditions that breach their human rights. These exacerbate both their stress and isolation. Such situations need to be identified and addressed promptly. It is vital that all carers are able to have time to relax and pursue their own interests.
- Carers live with a considerable amount of fear related to managing the health and well-being of the person cared-for. They need to feel supported by professionals in managing their responsibilities.
- The conditions of the pandemic have impacted negatively on many carers' mental health and well-being, and it is important that professionals recognise and identify those most at risk of crisis.

## **Recommendations**

- Gaps in social support groups should be identified by local authorities and health boards and targeted with new or expanded third sector or statutory services.
- Young adult carer groups with dedicated support workers should be made available locally and promoted to all carers under the age of 25 in Wales.
- Carer assessments should be used as an opportunity to collaboratively consider whether the demands that caring places on a carer are reasonable in relation to their human rights, and what statutory or third sector services can do to mitigate potential harm where carers are willing to accept detriment to their rights.
- Third sector services would be well-placed to offer specialised counselling for carers, free of charge, to address existing harms to carer mental health. This should be given high priority during recovery from the pandemic.

### **1.1.3. Employment, education and finances**

Many unpaid carers value engaging in paid work outside their caring responsibilities. This can enhance carers' well-being by offering a break from caring, boosting self-esteem, and providing an opportunity to socialise independently. Similarly, education is of high importance, especially to younger carers, both for their social development and for their future career development. Many unpaid carers suffer financially because of reduced access to employment and career opportunities. This can compound other threats to their well-being.

### **Key findings**

#### **Life before the pandemic as an unpaid carer:**

- Paid employment outside the home is often of great value to carer well-being and financial stability (See Section 4.3.1).
- Younger adult carers feel that their choices around education and career are much reduced by their caring responsibilities (4.3.2).

- Often, caring has a substantial impact on personal finances, and this was particularly pronounced for single carers who had no partner to boost their household income (4.3.3).
- Many carers find the amount they are paid through Carers Allowance inadequate and feel demeaned that their responsibilities are valued so poorly within the benefits system (4.3.3).
- Specialist school attendance and support is a key part of managing life well for most people caring for their disabled or ill children (4.3.4).

#### **How the COVID-19 pandemic has affected unpaid carer experiences (4.3.4):**

- Increased levels of working from home during the COVID-19 pandemic have been welcomed by many carers for providing additional flexibility, though some have missed having the workplace as an area in which they have a break from caring and can socialise.
- For parents of disabled children, the closure of schools and need to cope with home-schooling have been particularly challenging.
- Unpaid carers already experiencing financial precarity have found that their financial worries increased during the pandemic, especially as having all the family in the home at all times has increased household costs.

#### **The impact on the COVID-19 pandemic on unpaid carer well-being (4.3.4):**

- Stress levels have increased for many due to increased financial precarity.
- While some have appreciated the opportunity to be at home more, some have found that being required to be at home more with the person cared-for has been difficult.

#### **Opportunities for action**

- Carers value flexibility and understanding from their employers, but individual experiences vary greatly. There is a need for greater consistency across all sectors to ensure that unpaid carers who work feel able to manage their caring role alongside their job.
- Many younger participants reported that their schools did not recognise or support them as young carers. Schools, colleges and universities all

need to be proactive in identifying and supporting young carers, with clear and visible policies in place.

- Schools are particularly important for supporting parents of disabled children and consideration should be given for services to support families while schools are closed.
- Many carers suffer financially because of their caring responsibilities and feel that Carers Allowance is an inadequate provision. Consideration is needed as to how the financial disadvantages suffered by many unpaid carers can be better mitigated.

#### **Recommendations**

- A review of employer guidance and legislation around support for unpaid carers should be carried out to ensure that they are best supported into work. This should focus on the issues of 'carer's leave' (paid and/or unpaid) and employer acceptance of requests for flexible working hours wherever possible (with justifications when refused). This work could draw upon the spirit and structures underpinning the Welsh Government's Fair Work and Social Partnership agendas.
- The recommendation in the Welsh Government's Strategy for Unpaid Carers that all schools should have a lead member of staff for young carers should be made mandatory.
- Universities should lead efforts to identify students who are unpaid carers and offer both social and academic support. This should be publicised on university websites to allow unpaid carers to make informed choices regarding their higher education, and be made accountable through named staff members adopting a 'carer support' role.
- An investigation into the sustainability of Carers Allowance to support low-income carers should be initiated, to include identification of appropriate means-testing for further support. While this is a UK-wide issue, there is potential in Wales to offer additional economic and in-kind supports to financially vulnerable carers in receipt of Carers Allowance which should be considered (for example, free gym memberships; vouchers for various products or services; discounted leisure activities).

### 1.1.4. Services and systems

Despite provisions in the Social Services and Well-being (Wales) Act 2014 to enhance recognition and support for carers, there is still a lack of focus on the well-being of unpaid carers in social care planning by local authorities and health boards. Services have not yet adapted sufficiently to focus on making caring more sustainable or on preventing carers from reaching crisis point. There is a continuing need to improve co-production between professionals and carers and to enhance the voice of carers in both the planning and delivery of services. Services must pay more attention to the well-being and human rights of carers.

#### Key findings

##### Life before the pandemic as an unpaid carer:

- Many carers found the experience of being assessed for support by local authorities unsatisfactory and feel that they are not recognised, understood or prioritised in social care planning. Concerningly, many interviewees reported that professionals have not asked them about their needs or experiences as carers (Sections 4.4.1 and 4.4.3).
- Much of carers' time can be spent chasing services and attempting to contact the right people to obtain support and provision for the person they care for (4.4.2).
- Provision of support by third sector organisations is highly valued and helps to make caring more sustainable for many. For younger adult carers, groups that enable peer support to develop were reported to be particularly important (4.4.4).
- Flexibility in the arrangement of services, both for the person cared-for and the carer, is an important factor in unpaid carers' satisfaction with the services they receive. The use of direct payments (and private resources for more affluent individuals or families) was indicated by some as a means of acquiring the flexible services most needed (4.4.5).

##### How the COVID-19 pandemic has affected unpaid carer experiences:

- Time spent chasing services has increased during the pandemic as services have become even less accessible (4.4.2).
- Access to carers' groups during the pandemic has generally been remote – via video calling. This has been appreciated by carers, yet most felt that being able to meet in person provides a better experience (4.4.4).

##### The impact on the COVID-19 pandemic on unpaid carer well-being:

- The inaccessibility of services and limitations on support has led to greater stress and feelings of abandonment and invisibility (4.4.1).
- The rapid adaptation of young adult carer support groups has supported the well-being of this group despite challenges (4.4.4).

#### Opportunities for action

- Services and information for carers need to be more easily identifiable and accessible.
- Unpaid carers need to feel recognised and respected by professionals at all times in their interactions with them.
- Assessments for health and social care services need to focus more on the needs of the carers, rather than focusing solely on how the needs of the person cared-for are met.
- Local carer centres were highly valued by many of our participants, yet the services provided varied across different areas. There is a need to ensure that all carers have access to support in their local area. This is particularly important for younger carers.



## Recommendations

- Local authorities and health boards need to ensure that they actively and proactively identify carers across all their areas of service. A national register of carers might be a useful tool in ensuring that carers are visible to services, so that interventions to promote their health and well-being can be more easily directed to them.
- Regional Unpaid Carers Teams should be established in each area of Wales – these should take a multi-agency approach with representatives from social care, health, and education. These should be available for direct unpaid carer enquiries.
- A mapping of local support groups and other third sector services across Wales is needed to identify where gaps exist, and funding identified to ensure that all unpaid carers have equitable access regardless of location. This information should be gathered in an online hub alongside contacts and locations. This would ideally be provided through a national third sector organisation.
- In the event of future crises similar to the COVID-19 pandemic, a governmental consultation group of diverse carers should be immediately established to consult on policy and practice in relation to their support. Additionally, an outreach programme should be planned and implemented where need arises to ensure that carers do not feel a sense of abandonment during any future lockdown conditions.
- Regarding future vaccination schedules, unpaid carers should be equal in priority to the person cared-for.
- Schools providing care for disabled children should be consulted regarding their provision during COVID-19 and their views obtained as to whether it would be reasonable to expand their available places to sustain disabled children's education in the event of future pandemic conditions.

## Conclusion

Unpaid carers are central to care planning under the Social Services and Well-being (Wales) Act 2014 and in the Welsh Government's long-term plan for health and social care, set out in the Healthier Wales strategy document. Despite their importance in meeting the care and support needs of so many individuals, and the enormous economic value of the tasks they carry out, they continue to suffer detriment to their own well-being because of their caring responsibilities. The COVID-19 pandemic has highlighted the extent to which the health and social care systems rely on unpaid carers, who are too often poorly recognised or supported by statutory services. During the pandemic, many unpaid carers' stress, anxiety and isolation have been exacerbated and rapid remedial action is now needed for those reaching crisis point.

Further consideration needs to be given to mitigating the social and economic inequalities that too often arise from caring for another person. It is essential, therefore, that health and social care services develop their understanding of carers' experiences and needs, and adapt to ensure that caring for loved ones is sustainable for individuals and families. Unpaid carers need to be recognised and supported, with specialised, flexible services available to them locally. The findings of this study suggest that, to date, the provisions of the Social Services and Well-being (Wales) Act 2014, and the Welsh Government's Strategy for Unpaid Carers, have not produced the required changes in approaches to working with and supporting unpaid carers by health and social care services. A cultural shift is needed within statutory social services and health services, especially in relation to NHS Continuing Healthcare funding, where the availability of an unpaid carer is too frequently treated as a justification for withholding services for the person cared-for. Where unpaid carers are relied upon to meet the care needs of another person, local authorities must prioritise the carer's well-being and human rights.



## 2. Introduction

*In this study, we aim to explore the future of unpaid carers in Wales, based on interviews with citizens in Wales currently fulfilling such roles.*

The recent Public Health Wales (PHW) Health Impact Assessment identified unpaid carers as a specific group vulnerable to the direct and indirect impact of COVID-19<sup>1</sup>. Increased stress and anxiety and exposure to the virus amongst carers were raised as concerns by a number of those interviewed. A survey amongst carers aged under 18 and young adult carers in the UK found that over half reported increased time caring for others since COVID-19, 58% of young carers and 64% of young adult carers spending on average ten hours a week more on their caring responsibilities<sup>2</sup>. The wider impact of COVID-19 on unpaid carers has been highlighted in a letter from the Wales Carers Alliance to the Welsh Government, which points out reductions in support and care planning from statutory services and confusion about the status of unpaid carers with regards to social distancing measures and stay-at-home mandates<sup>3</sup>.

Despite the contribution of unpaid carers to population health in Wales, there is a lack of understanding of the true extent and diversity of unpaid carers, no routinely available data to understand the impact of caring on their own health and mental well-being, nor the longer-term impact of caring on educational outcomes and employment

prospects. Such information is needed to help inform action to reduce the harms within the *Welsh Government's Recovery Plan, Leading Wales Out of the Coronavirus Pandemic*<sup>4</sup>, and also to inform the longer-term aspirations within the national Well-being of Future Generations (Wales) Act 2015 and the Social Services and Well-Being (Wales) Act 2014. The Wales Centre for Public Policy have identified the role of informal carers and support needs and issues arising from COVID-19, as an area of interest to Welsh Government and public bodies in Wales, and a potential area for future programmes of work<sup>5</sup>. This report has therefore been undertaken in order to understand the concerns of and support for unpaid carers in Wales, and the impact of the COVID-19 pandemic on carers themselves and their ability to care for others. The findings presented in Chapter 4 provide valuable insights into the experiences of unpaid carers in Wales during a pandemic, but also highlight longstanding challenges faced by unpaid carers and gaps in support across the health and social care, and wider public systems.

This research was funded by Public Health Wales and developed in collaboration with the Research & Evaluation Division, Knowledge Directorate.

### 2.1. Who are unpaid carers?

Under the Social Services and Well-being (Wales) Act 2014, an unpaid carer is understood as an adult or child

who provides care to another person who would not be able to cope without their support, whether due to physical illness, disability, mental illness or addiction. Carers may provide practical support, including housework, shopping and transportation, personal care, including washing, toileting and support with medical treatment (e.g., taking medication, managing dressings), and/or emotional support. People can become carers at any time in their lives and may find themselves responsible for the welfare of a partner, a parent, a disabled child, a relative, a friend or a neighbour with little or no prior preparation. This study focuses on adult carers, aged 16+ (though one participant was aged 15 at the time of interview). We recognise that children who care are a distinct group, and their needs are beyond the scope of this report.

According to the 2011 census, there were over 370,000 unpaid carers in Wales, and it is likely that this figure has increased significantly over the past ten years, with Social Care Wales suggesting that 12% of the Welsh population should be classed as carers<sup>6</sup>. According to the UK census, 58% of carers overall are female and 42% are male<sup>7</sup>. However, gender differences reverse in higher age groups. Among the 75–84 age group, half of carers are male and in the 85+ age group, 59% of carers are male. Almost three out of five carers are aged 50 and over, while 1 in 5 people aged 50–69 in the UK are carers<sup>8</sup>.

The contribution made by unpaid carers is of considerable economic value, estimated to be worth around £8.1 billion annually in Wales<sup>9</sup> – a figure higher than the annual budget allocated for health and social care by the Welsh Government. As the ageing population of wealthy countries such as the UK continues to grow, it is likely that the number of people providing unpaid care will also continue to rise<sup>10</sup>, especially in countries that favour care at home over residential or communal forms of care. The Welsh government's long-term plan for health and social care, which emphasises a community-based approach to the delivery of services, contains an implicit reliance on unpaid carers to support people at home<sup>11</sup>.

## 2.2. The impact of caring on carers

A carer's stage of life can be a considerable influence on their experiences of caring. For example, caring responsibilities can have a marked influence on the choices and events of early adulthood such as

education, career direction, forming partnerships and beginning a family<sup>12,13</sup> or can influence decisions about the retirement plans of those caring later in working life. Carers in old age themselves often must cope with their own health issues while undertaking considerable caring labour on behalf of another and may struggle to access services due to digital exclusion and social isolation<sup>14</sup>.

Providing care to another person can be a rewarding part of life<sup>15</sup>, providing a sense of accomplishment, and can lead to fulfilling relationships between the carer and the person cared-for<sup>16</sup>. Yet being an unpaid carer can also bring with it a number of hardships and undesired consequences. In 2019, Carers Wales found that unpaid carers in Wales express significantly less happiness and satisfaction with life, and report twice as much anxiety as the general population<sup>17</sup>. International evidence suggests that providing unpaid care can result in carers scoring significantly lower in measures related to health and quality of life<sup>18–21</sup>. Carers from minority ethnic communities in the UK face additional challenges related to language, cultural barriers and stereotypes, all of which can make it more difficult for them to access services to protect or enhance their well-being<sup>22</sup>.

Carers are more likely than the general population to have limited access to employment opportunities, with Carers UK finding that 38% of carers report giving up work due to their caring responsibilities, 18% report reducing their working hours due to caring, 12% report taking a less senior job or missing out on promotion and 17% report that although they work the same hours, their job is negatively affected by their caring role (due to e.g. fatigue, lateness or stress)<sup>23</sup>. Consequently, carers suffer financially due to lost earnings and reduced ability to save for the future. Carers UK found that 39% of carers overall report that they are struggling to make ends meet, rising to 53% for those claiming Carers Allowance. Because women tend to become carers at a younger age, they are disproportionately affected by the negative financial consequences of caring, with 67% of Carers Allowance claimants being female<sup>24</sup>.

## 2.3. Support for unpaid carers

The Social Services and Well-being Act (Wales) 2014 places unpaid carers at the centre of social care provision, recognising their vital role in meeting the needs of people who are affected by illness and



disability. Two key principles of the Act have particular relevance to carers: prevention/early intervention and co-production. The Act gives unpaid carers an entitlement to be assessed by their local authority for services to support their well-being, regardless of whether the person for whom they care is receiving local authority services. In addition to their entitlement to have their eligible needs met by local authorities, carers also have the right to be provided with information about their entitlements and about community services that may be appropriate for them to access. It is vital that carers can receive services prior to experiencing a state of crisis and that they are included in the planning of services for the individual for whom they care (with their consent).

The recently updated *Welsh Strategy for Unpaid Carers*<sup>25</sup> identifies four key priorities:

1. Identifying and valuing unpaid carers
2. Providing information, advice and support
3. Supporting unpaid carers' lives alongside caring
4. Supporting unpaid carers in work and education

Similarly, the National Institute for Health and Care Excellence's guidelines on supporting adult carers<sup>26</sup> emphasise the importance of identifying carers and providing information, advice and support. As services continue to develop to meet the needs of carers, it will be important to ensure that priorities are shared and that carers receive a consistent message about their centrality from both health and social care providers.

Despite the ambitions behind the legislation and policies related to unpaid carers, Carers Wales found that, in the year to March 2020, only 28% of carers had a carer's assessment or review of their assessment in the last 12 months<sup>27</sup>. Five years after the Social Services and Well-being (Wales) Act 2014 was first implemented, there remain considerable challenges to ensure that services in Wales recognise and support unpaid carers effectively.

## 2.4. Caring in the time of COVID-19

Carers UK have identified that unpaid carers have been particularly vulnerable to the direct and indirect impacts of COVID-19, suffering a sustained period of increased levels of stress and anxiety, and exposure to the virus<sup>28</sup>. 81% of carers report that they are providing more care since the beginning of

the pandemic, and 78% report that the needs of the person for whom they care have increased. 64% of carers also said that they have not been able to have breaks from caring, and that their mental health has declined during the pandemic<sup>29</sup>. At a time in which the contribution of people in paid caring roles has been widely acknowledged by politicians and the media, many unpaid carers felt that their vital contribution was overlooked. Carers UK<sup>30</sup> estimated that the value of care provided by unpaid carers in Wales between March and November 2020 alone amounted to £8.4 billion, which is indicative of a substantial amount of care provided, yet unpaid carers face burnout due to exhaustion and mental health difficulties brought about by the situation and a lack of support.

## 2.5. Rationale for this study

The unprecedented situation brought about by COVID-19 highlights once more the enormous contribution made by unpaid carers in Wales, and represents an opportunity to examine their experiences in-depth. This research study set out to explore the following questions:

1. What were carers' lives like before the pandemic began?
2. How has COVID-19 impacted on the lived experiences of carers and the roles they undertake?
3. What has the impact of COVID-19 been on carers' well-being?

Answers to these questions will assist in identifying key messages about the needs of unpaid carers in the future and the provision of services to support and promote their well-being, enabling recommendations to be made about the development and provision of services by statutory and third sector agencies.



## 3. Methodology

### 3.1 Research design

In order to address the research questions, this study needed to capture the narratives and personal interpretations of unpaid carers in their own words, therefore a qualitative interview approach was determined as the most appropriate research method. We applied a semi-structured approach to interviews to enable participants to guide the researchers to matters which they felt were of personal importance to them, whilst ensuring that we captured data on the critical issues pertinent to the study research questions. This design was also a responsible approach to interviewing where we knew that the content of interviews was likely to be highly emotional for participants, as it allowed researchers to maintain a high level of reflexivity and flexibility throughout interviews to protect the well-being of participants during data generation. A target of 40–50 interviews, that accommodated individual targets representing a range of identified carer characteristics, experiences, and demographics, was set as the maximum feasible within the study timeframe, and of a minimum number that would allow the researchers to capture diverse carer voices within each target population. The research team consisted of two lead investigators and two research assistants, one of whom was able to conduct interviews in Welsh.

To develop our methods co-productively with people with lived experience of caring, we engaged in a

consultation process before data generation began. We developed a draft interview guide based on the aims and suggested areas of the research tender and our own knowledge of the field. This guide was shared and revised in consultation with the research team and Public Health Wales, before being distributed to Carers Trust Wales and Carers Wales for stakeholder consultation. These organisations shared the interview guide with their own carer groups and we received feedback through this process, which we incorporated to produce the final interview guide.

### 3.2 Sample

47 participants were recruited from a variety of age groups and we achieved representation from all regions across Wales. The sample characteristics are detailed in Appendix A.

### 3.3 Recruitment and consent

Initial recruitment was conducted through circulating our project information to relevant organisations and individuals to disseminate on our behalf, and via social media. Interested individuals were directed to a weblink including information about the study and a consent form, or to contact the Principal Investigator by telephone. Where initial response rates were lower than anticipated from particular groups, we took more

targeted steps to publicise the study with those groups, including translating materials into other languages, and approached gatekeepers to aid our recruitment.

All individual characteristic targets were met apart from self-identified Black, Asian and Minority Ethnicity (BAME) carers. Despite efforts in targeted recruitment, we were unable to achieve the 10% representation of BAME carers desired, with 4% of participants self-identifying as belonging to non-white ethnic groups. As this under-representation became apparent approximately halfway through the data collection process, we approached three specific organisations with BAME carer contacts to aid us in targeted recruitment and distributed our recruitment materials into Somali and Arabic for Yemeni participants (both ethnicities with substantial representation in South Wales). However we still failed to recruit any participants through these methods. Based on this experience and the advice of gatekeepers, we believe that studies seeking to include representation from these groups should have a longer lead-in time with co-production included from study initiation to acknowledge the specific needs and value that they offer to knowledge around unpaid caring, and to mitigate potential distrust between researchers and minority ethnic communities in Wales. We would also acknowledge that the social distancing requirements in place at the time of data collection inhibited our ability to engage with communities and build trust.

Informed consent was received from all participants.

### 3.4 Interviewing process

Due to the COVID-9 pandemic and public health response all interviews took place remotely via online video call software or telephone, based on participant choice. Participants were asked to find a private location for their interviews wherever possible to protect confidentiality. Young adult carers were invited to participate via small group interviews if they wished, and several accepted this offer, with the result that four interviews in pairs took place in this age group. Interview length was targeted at 60 minutes. In practice, interview length ranged from 30–90 minutes, with an average time of 60 minutes. Interviews took place starting 20<sup>th</sup> January 2021 and concluded on 1<sup>st</sup> April 2021.

### 3.5 Topic guides

Participants were asked questions about their experience and views relating to the following areas to generate data that could inform the research questions:

- Relationships with the person they cared-for: how the participant became a carer and how they feel about their identity as a carer;
- Support and sustainability of caring: the practicalities of caring and the services received and required to make it sustainable;
- The personal impact of caring on the participant: Finance and employment; education; mental health; physical health;
- The impact of COVID-19 and the future of carer support in Wales.

Researchers were encouraged to ask additional ad hoc questions on these subjects to produce greater richness and breadth of data where they felt appropriate during interviews.

### 3.6 Data generation and analysis

Interviews were audio recorded and transcribed in full. Each researcher anonymised their own interviews and undertook initial coding before sharing within the team. We used a preliminary thematic coding framework based on the study research questions alongside a reflexive approach to coding, allowing for emergent themes to be identified and attended to as they arose in participant narratives. This reflexive approach generated a final coding framework of 18 themes, ranging across relationships with people and organisations, emotional and physical well-being, identities, feelings about the future, social support, and financial circumstances. Each researcher was asked to write a short summary of each their participants and the points of discussion covered within interviews to accompany each transcript, which were circulated around the team, enabling all project researchers to gain a rich understanding of the dataset generated.

When approximately half the interviews were completed and coded, the research leads judged that we had reached coding saturation and the research team met to discuss the data included within each code thus far. At this meeting the primary themes structuring the findings shared here began to take shape.



Once interviewing and initial coding was complete, each researcher's dataset was reviewed by the study leads, who compared the coded data and wrote summaries of each theme to reflect participant views and experiences, and to identify links between the themes. Extensive participant quotations were supplied to support and detail the theme summaries, which were then further refined through ad hoc research team discussion. Finally, a research team meeting took place prior to writing the report where the key themes were identified and discussed among three team members (with one researcher being unavailable at this time), ensuring that all were in agreement about the content and points made within each theme. This discussion formed the basis of this report.

### 3.7 Ethics

In order to preserve confidentiality, all names used in this report are pseudonyms.

The study was approved by the Cardiff University School of Social Sciences Research Ethics Committee in December 2020 (reference number SREC/4042).

During data generation researchers were encouraged to work responsively to participant narratives and emotion, and were permitted to omit questions where they judged them to be potentially distressing to the participant or inappropriate given their circumstances (one example being: asking a parent-carer about their future as a carer when their child had a terminal illness). Interviews were ended with a non-recorded participant de-brief where researchers checked with participants how they had found the interview and offered them the opportunity to discuss their emotional response, to allow them to express themselves freely and enable the team to signpost appropriate support organisations and phone numbers (supplied to us by Carers Trust Wales), which were offered to many participants.

Informal de-briefing took place within the research team where any interviews were particularly emotive.

### 3.8 Limitations

As with most qualitative research, the relatively small sample size means that generalisations based on our findings cannot be made in the same manner as would be the case for a larger quantitative study. The restrictions on social contact at the time of data collection meant that we were limited to recruiting unpaid carers who had either direct contact with support organisations or access to social media. This meant that some groups were under-represented, including people from minority ethnic backgrounds and older people. We note that the experiences of carers who are children and young people are distinct and warrant further investigation, which was not within the remit of this study. Interviewing via video technology or telephone meant that it was more difficult for interviewers to establish rapport and read body language, although we felt that this effect was usually mitigated by our participants' enthusiasm to tell their stories.



## 4. Findings

### 4.1. Identities and Relationships

#### Key findings

##### Life before the pandemic as an unpaid carer:

- Unpaid carers may not recognise their status or identify as carers until they reach a crisis point, meaning that they are often struggling before they ask for help (See Section 4.1.1).
- Maintaining a healthy relationship between the carer and the person cared-for is vital for the sustainability of a caring role. Most carers are driven by love and/or a sense of duty, yet they may also experience powerful feelings of frustration, or of being trapped and having no choice about fulfilling their responsibilities (4.1.2).
- Caring can complicate family dynamics to a point that they can become problematic and drive tensions in relationships, for example when roles of parent and child are reversed (4.1.2).
- Shared times of pleasure and enjoyment between the carer and the person cared-for are important for maintaining the relationship between the carer and person cared-for. Carers often feel as if they are treated as instruments of care when their needs are being assessed, but care takes place within a human relationship that must be nurtured and maintained (4.1.2).

- Caring can produce positive benefits for some carers, particularly for younger carers who reported a greater sense of confidence and self-efficacy from their experience (4.1.3).

##### How the COVID-19 pandemic has affected unpaid carer experiences:

- The COVID-19 pandemic has enabled some carers to feel as though they are 'stepping off the treadmill', allowing them more time to relax with the person cared-for, yet for others the loss of respite, personal space, activities or external support has had a negative effect on relationships that risks making the caring arrangements unworkable (4.1.2).

##### The impact on the COVID-19 pandemic on unpaid carer well-being:

- Many carers have felt overlooked during the pandemic and have felt a sense of injustice over the focus on paid health and social care workers by politicians and the media (4.1.1).
- Many caring relationships have deteriorated during the pandemic, with a negative effect on well-being for both carers and the people they care for (4.1.2).

### 4.1.1. Identity and becoming a carer: A gradual and complex process

Many people reported fulfilling the caring role for a considerable amount of time before they started to identify as carers (or were recognised as being so by a professional). This was particularly the case for people who care for someone with dementia or someone in advanced old age, as the caring tasks first required tended to be low level and resembled things that people would do for their loved ones without questioning.

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*I didn't think I was a carer, I was his wife, you know I'm of the age where if one thing goes wrong, we've been married nearly 66 years, if one thing goes wrong with one the other one picks it up.*

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– Clara, age group 80+, carer for her husband

Providing practical or emotional support to each other is an intrinsic part of family and friendship, and it can therefore be difficult for people to distinguish at what point the balance shifts from the commonplace kindnesses of everyday life into a relationship of responsibility and dependency. There are times, however, when a medical diagnosis enables a carer to recognise that they have already been fulfilling the role of carer for some considerable time.

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*...Before she was diagnosed with Alzheimer's, my mum suffered with depression pretty much all of my life. So even though... until she had Alzheimer's, I never really thought of myself as a carer but I kind of was even before then, to be honest.*

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– Jenna, age group 50–64, carer for her mother

A challenge that arises from the subtlety of the transition between ordinary support and the development of dependence upon a carer, is that it is not uncommon for unpaid carers to reach a crisis point before seeking help.

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*It was becoming sort of 24-7 because what happened, because of her problems and her diagnosis, her body clock had changed. And by that, I mean she was sleeping all day, but she was wide awake all night. So I wasn't getting any sleep because I had to be with her in the day to make sure she didn't hurt herself, but when we went to bed at night, she was up all-night shouting and screaming because of the dementia.*

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– Peter, age group 65–79, carer for his wife

Peter went on to describe the feeling of “burning out” before he had even contacted social services to ask for help, due to the intensity of the caring work he needed to do to look after his wife, and the lack of sleep. Progressive conditions make it challenging for carers to identify the point at which their role should be recognised, with the result that they remain hidden from services that might be able to help them until they reach a crisis point in which they feel compelled to seek support.



Parents of disabled children discussed a particularly complex orientation towards the status of 'carer'. Lindsey noted the tension between ordinary parenting and meeting the extra needs of her child as a carer.

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*I think there is a big difference in being Mia's parents and being her carer. There's different things that I need to look at. I can't always be that fun mum that wrap you up and playing with you and keeping you in cotton wool, that type of thing because I also need to care for you to keep you safe over and above what somebody else your age would be and I might pull you away from the playground because I can see that the fatigue is going to bring on a seizure with you and that's my caring hat on whereas as a mum, I'd love you to play for hours and hours with your friends but I know what the impact's going to be... It's difficult.*

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– Lindsey, age group 26–49, carer for her son

Lindsey tied her realisation of being a carer to her gradual understanding and acceptance of how serious her daughter's condition was, and how it would affect her life. This emerged in her narrative as a doubling of loss: the huge changes and adaptation that would need to occur in her own life to accommodate her daughter's needs, but also the loss of the future she imagined for her daughter. This emerged in other forms in several other parents' narratives, suggesting that this is a common experience for parents of disabled children.

### **Impact of COVID-19**

Most of the carers we spoke to did not feel that their wider community supported them or recognised them prior to the pandemic and felt that there is a general lack of understanding of how much unpaid carers do. If anything, this feeling has been exacerbated by the pandemic. There were no reports of extra assistance being provided through locally developed COVID support groups and some even felt that increased recognition of paid health and social care workers brought their own lack of public acknowledgement into more focus.

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*You know, there's been a lot of clapping for the NHS and, you know – belatedly – a kind of recognition of what care staff in care homes do. It took a long time to even get them recognised but carers who are unpaid, I don't think the public in general or politicians understand just how much they do and, you know, no thanks is being given.*

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– Jenna, age group 50–64, carer for her mother

### **4.1.2. Relationships: A balance between love, duty and frustration**

The relationship between the carer and the person cared-for is an important and complex part of the carer's identity. For many carers, a prominent theme was the love they shared with the person cared-for, particularly when this was a child or partner. The commitment of carers to the person cared-for is often driven by this love, and the relationship between the two is not simply one of dependence and responsibility, but of mutually shared affection and commitment.

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*He's a pleasure to look after... and I never want anyone to think that my son is a burden... I'm really careful that I don't send out a message like that, however difficult it is... Because he's so sweet, he has such a nice personality, he's lovely.*

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– Angharad, age group 50–64, carer for her son

Spousal relationships are associated with a particularly strong loyalty from the carer towards the person cared-for, that manifests in anxiety over the thought of separation and resistance to services that would separate them. Indeed, Clara made the point that respite for a carer should not necessarily mean spending time away from the person cared-for – some carers would also like the opportunity to spend time with the person without needing to attend to their care.

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*We don't like being apart but any sort of respite they want to give, it's always take the patient in one direction and the carer in the other but when you've been married nearly 66 years, you are no good like that, you're only one good one between you. What I would like is somewhere we could both go together and have a holiday together and I could be waited on for a week and I could have food put in front of me.*

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– Clara, age group 80+, carer for her husband

While love was prominent in many carers' discussions of their relationships with the person cared-for, there were also some complex feelings. Valerie spoke of the mixed emotions and thoughts she has towards her parents, both of whom suffer from dementia.

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*I still have lovely cuddles with my mum and dad, and they tell me they love me, they both can still do that, which is lovely. Other times I truly hate them for messing up my life, if that doesn't sound too terrible, and I wish they were dead...*

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– Valerie, age group 26–49, carer for her parents

Valerie was clearly not being literal when she said this, but was expressing the unsettling recognition that caring responsibilities, particularly for older people, will cease once the person cared-for passes away, and while the loss of that relationship will be difficult, the cessation of caring responsibilities may ultimately come as a relief.

In addition, there were several instances reported where either the nature of a person's condition or the impact of their situation led to tensions and conflict between them and their carer. Carers found this distressing and acknowledged that these circumstances put unsustainable pressure on their relationship, regardless of how much love or closeness was felt between them.

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*Unfortunately things have got that bad that the doctors have put her on antidepressants because she'd lash out at me. She'd throw things at me if she didn't get her own way, it's the frustration... and I sort of feel guilty... she's my world, to be honest with you... I can get on her nerves, she can get on my nerves, we can clash. But we can be the closest unit you could ever think of really.*

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– Luke, age group 26–49, carer for his mother

Where carers spoke with less warmth of the person they care for, there was nonetheless a strong and uncompromising sense of duty, but this was often accompanied by a sense that there were no other acceptable options available so carers felt trapped in their position.

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*I'm doing this because I don't want to have any regrets and I want to know that I've done everything that I can, which I am doing and, you know, I have done, but God, it's a cost.*

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– Valerie, age group 50–64, carer for her parents

In addition to feeling trapped by their sense of familial obligation, some carers spoke of their own frustration at feeling taken-for-granted by the person for whom they care.

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*...This is horrible to say and I'm, you know, mum and Auntie Lorna would say differently, but I do feel quite unappreciated.*

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– Judy, age group 50–64, carer for her mother and aunt

As was noted above, time spent enjoyably with the person cared-for is an important sustaining experience for many carers, and where the person cared-for is not able to show their appreciation or connect emotionally with the carer, this can be detrimental to the carer's self-esteem.

A common experience discussed by many carers was how caring changes the relationship between the parties involved. Of particular significance in this regard was the way people who care for their parents note the role reversal.

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*I think she gets annoyed with me sometimes in that I can act quite maternal towards her. You know, I'll do the sort of 'Have you done so and so? Have you done that?' these kinds of things and there is a very weird power dynamic.*

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– Natalie, age group 26–49, carer for her mother



Younger adult carers who noted this role reversal when caring for their parents expressed an added sadness that they were missing out on having their parent fulfil what they considered to be a usual parenting role.

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*I miss my dad, because when I was younger, ... he could take me out, drive with me, take me to school... things like that I miss. And he is a bit sad that I have to take care of him instead of him taking care of me, in a way.*

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– Sion, age group 15–25, carer for his father

Struggles with changing relationship dynamics, complex feelings towards the person cared-for, and experiencing guilt despite doing so much for that person, illustrate that carers may struggle to understand and come to terms with the ways in which caring responsibilities impact on their relationships with the person cared-for. Whether through a predominant sense of mutual affection or a sense of duty, the relationship between the carer and the person cared-for is often marked by loyalty and a sense of obligation. This can lead carers to push themselves to their limits in order to meet that person's needs. Spending 'down time' with the person cared-for, rather than every interaction being focused on a particular caring activity, is important for some carers, enabling a sense of emotional reciprocity and closeness that builds the resilience of the relationship to the demands of caring for both people. Without this reciprocity being nurtured and sustained, with the aid of external support where necessary, there is a risk that a carer's love for the person they care for could lead to them feeling that that love is being exploited within the social care system.



### Impact of COVID-19

There appear to be two main ways in which the pandemic has impacted on the relationships between carers and the person cared-for. Spending more time together has meant that some carers feel they have become closer to the person cared-for, even though they acknowledge that this has been a difficult process at times, in which conflicts and frustrations have had to be worked through.

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*It's nice that we're all together more and we do get on. We have our moments obviously, like me and Mike are not getting much time on our own because everybody's home but then you know we've got to see the benefits of it as well.*

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– Nancy, age group 26–49, carer for her husband

These are significant findings, because they remind us of how important it is for carers and the person cared-for to be able to spend relaxing or fun time together. Carers' lives are very busy, and often involve struggling to fit in multiple tasks, which can mean that these shared moments are difficult to make time for.

For many, however, the impact of the pandemic has been negative, because the effect of the lockdowns has been to curtail some cared-for people's independence, resulting in increased reliance on the carer.

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*They have become more dependent because they can't leave the house. Before March she was popping out for her own shopping once a week... I know that I'm always going have to do her shopping, I know now, COVID, the whole bloody lockdown thing means now that Auntie Lorna has got no technological... bone in her body, you know, and I'm sure that I could get online and maybe get deliveries to her. That might be something I could do, but, you know, then she wouldn't see anybody. So I feel a bit trapped...*

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– Judy, age group 50–64, carer for her mother and aunt

An increased level of responsibility will be a permanent impact of the pandemic for some carers, and this may have a significant impact on the sustainability of their caring roles.

### 4.1.3. Positives of being a carer: Confidence, closeness, and strength

Carers were asked directly about what enjoyment or personal fulfilment they derive from their caring role. Some carers struggled to answer this question because the difficulties they faced appeared so overwhelming. However, many carers were able to identify aspects of caring that did bring them some pleasure or that they found positive. Some spoke of the satisfaction of seeing their loved one thriving due to their care.

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*Well, I know I'm making a huge difference. My mum you know, she was given six months to live five years ago. I'm not saying I'm entirely responsible for rolling back the clock, but, we do take huge care of her, both myself and my husband helps me, and it really means a lot to her, I know it does, because the alternative is to go into a care home, and she really, really values being in her own space at the moment. So, I know that I've made a difference to her quality of life for the last 10 years and that is fulfilling.*

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– Liz, age group 50–64, carer for her mother

The clearest benefits in this regard were often shared by parent carers, who took great fulfilment from seeing their children flourish and grow as people despite their conditions. Lindsey talked about her growth in confidence about her capacity to help her child, and reported that it made her feel she could do anything if she put her mind to it. Jayne felt fulfilled by her knowledge that her daughter could always rely on her, and that because of her care she had the ability, despite her condition to be “able to have a life, not just be there, alive”, finding a positive in the enhanced quality of life she had been able to provide for her. Ffion shared her sense of achievement and pride that her son had such a great personality and was a joy to be around.

For younger carers, feelings of personal efficacy, confidence, or resilience derived from being able to provide care were frequently mentioned.

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*I'd say I'm very resilient and that's a positive for me and I think that's come as a result of all of the responsibilities that I've had over the years... because of all of the shit in a way, I'm quite happy in general because I try to see the good stuff otherwise what's the point? Yeah, very mature, appreciative I'd say of small things. So yeah, a lot of positive things definitely.*

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– Helena, age group 15–25, carer for her brother



### Impact of COVID-19

While it is true that life during the pandemic has made it possible for some carers to spend more time relaxing with the person cared-for, it has been harder for some carers to partake with the person cared-for in activities that bring pleasure. The closure of leisure services, hospitality services and even public conveniences, and the need for many cared-for people to shield and therefore stay away from shops, have all had an impact in this regard.

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*...I've planned a few trips with him and before we set off we have to make sure, well where can go for a, where can we stop for a toilet break? What's open, where can we do it?*

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– Derek, age group 50–64, carer for his brother-in-law and neighbour

The reduction of opportunities for enjoyable time spent together outside of the home during the pandemic has brought carers' attention to the importance of spending pleasurable time together. Services for carers should not be thought about only in terms of time spent away from the person cared-for – it is vital that people who care and people who are cared-for have the opportunity to spend time sharing mutual enjoyment and experiencing other aspects of their relationship.

### Opportunities for action

- Unpaid carers often do not realise that they can be identified as carers until they have been doing the role for a considerable time and therefore do not ask for help until they reach a crisis. There is a need to ensure that carers can access support from the beginning of their caring role.
- Both carers and people who are cared-for need support in coming to terms with the changes in their relationships and in maintaining positive relationships. It is important to consider not only overcoming problems, but also ensuring opportunities for shared enjoyment.
- In many cases, the conditions of the pandemic have placed additional strain on relationships between carers and people cared-for. Additional support may be required to address these difficulties in the coming months.

## *A Carer's Story: Identity and relationships*

### **Angharad and the importance of shared enjoyment before and during the pandemic**

Angharad cares for her adult son, Joshua, who has a learning disability and profound physical impairments, including blindness, respiratory failure, and osteoporosis. Joshua is fed via a tube and is unable to communicate verbally. He requires expert care due to the risk of aspiration and bone breakages, which Angharad provides for him all the time except when she is in work (during which time he is supported through a package of care arranged by the NHS).

Angharad admits that her life is hard, especially as she does not receive very much support outside of the care package for meeting Joshua's needs while she is in work. She does, however, find a great deal of joy in caring for Joshua because she appreciates his sweet personality and gets so much pleasure from seeing him enjoy himself. For example, in between the lockdowns during 2020, Angharad and her sister managed to take Joshua to a safari park for a day out. Even though he wasn't able to see the animals, Angharad enjoyed being able to

describe where they were and what was happening and took great pleasure from seeing how alert and content he became. Joshua is not able to express his feelings verbally, but his body language gives clear indications of his reactions and seeing positive body language helps Angharad to feel that she is helping to create happy moments for her son. Trips out to town, or to events like concerts or shows, are also important to Angharad because they are times when she gets to see Joshua doing something age-appropriate, since he has missed many of the rites of passage that most teenagers and young adults go through, and will not be able to develop independence as most do as they grow up. Angharad feels a sense of satisfaction when she sees Joshua enjoying himself and finds that doing special activities together helps to keep her going. For Angharad, caring for Joshua means not just meeting his physical needs, but ensuring that he has positive enjoyment in his life that she gets to share with him. Knowing that Joshua is happy is as important to her as knowing that he is safe.

Doing activities and making special memories is especially challenging for both Angharad and Joshua because there are so few facilities appropriate to his needs outside the home. Going to concerts or shows can involve a long journey to another city, yet so few hotels have hoists or other specialist equipment that they often have to return home the same day. Angharad has found the pandemic particularly frustrating, because needing to shield Joshua has meant that his life has been more boring and has been a reminder to her of how important it is to make time to enjoy life together, to make special memories and to have things to look forward to.



## 4.2 Carers' health and well-being

### Key findings

#### Life before the pandemic as an unpaid carer:

- Many carers experience increased stress and adverse impacts on their mental health due to their caring responsibilities (See Section 4.2.1).
- Caring for another person can mean living with significant levels of uncertainty and fear, for example, about the progression of disease or their loved one's suffering increasing (4.2.1).
- Loneliness and social isolation were common difficulties before the pandemic for many unpaid carers. Weaker social networks emerged as being linked with poorer mental health (4.2.2).
- The conditions in which some carers live would, in other situations, be understood as a breach of their human rights. For example, the number of hours of care performed and the risk of personal harm due to lifting or being assaulted (in the case of loved ones with illnesses or disabilities that impact on behaviour), would not be acceptable in a place of work (4.2.3).

#### How the COVID-19 pandemic has affected unpaid carer experiences:

- Carers have felt physically cut off from important sources of support, such as friends and family members (4.2.2).
- The pandemic has further restricted carers' fundamental freedoms – for example, the need to protect 'shielding' loved ones has sometimes meant that carers have not been able to participate in normal family life (4.2.3).

#### The impact on the COVID-19 pandemic on unpaid carer well-being:

- Levels of stress, anxiety and depression have increased for many during the pandemic. Fear of the cared-for person's becoming infected with COVID-19 has been an added pressure here (4.2.1).
- Feelings of loneliness and isolation have been greatly exacerbated by the pandemic, leading to a substantial increase in mental health concerns (4.2.1).

### 4.2.1. Stress and mental health: The toll of constant vigilance

Unsurprisingly, stress was a recurring theme throughout most of the interviews. Several carers spoke about the impact of constant responsibility on their day-to-day lives and referred in particular to the need to be constantly on alert, whether to attend to the person's personal needs (e.g. fetching drinks, toileting) or to intervene if they began to do something dangerous due to confusion. Related to this was a frequent sense of lacking time alone, and feeling trapped in the situation.

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*You know, if I go out the back to have a cigarette or something, I can hear her. I have to stand and look through the window to make sure she's not trying to get up or whatever, but she'll be calling me and I'm thinking, 'God, just give me five – five – minutes just so I can just go and think about nothing and just stare at a brick wall for five minutes.'*

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– Alison, age group 50–64, carer for her mother

For some carers, the impact of caring does not only occur during the time spent directly providing support, but also dominates their thoughts at other times.



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*Yeah, I think subconsciously it's there, isn't it, and you... It's not a burden but it's something else that you always have to consider...*

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– Sandra, age group 50–64, carer for her father

This often promotes a feeling that, though they are doing the practical tasks that need doing, they are somehow failing in terms of providing a stimulating and enjoyable life for that person.

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*It never feels like you're doing the right thing or you're kind of getting it right. You always feel like 'is there something else I should be doing?' 'Am I getting this wrong?'*

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– Valerie, age group 50–64, carer for her parents

It is concerning that carers may experience such anxiety over doing the right thing, as this suggests that their self-esteem and sense of self-efficacy can be low despite the accomplishments brought about by their hard work, commitment and ingenuity.

Negative impacts on mental health are a potential impact of stress on carers' health, with many carers reporting the symptoms of anxiety and/or depression.

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*...It was awful – when I was doing the 24-7 stint, I was sinking like a stone. It was affecting my general health and it was affecting my mental health and I couldn't cope. I couldn't cope. And I admitted that immediately because there were some days – because of the stress and the anxiety and the worry – there were some days I didn't want to get out of bed, but I had no option.*

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– Peter, age group 65–80, carer for his wife

The stories carers told us suggest that caring is a role that can come to dominate all aspects of daily life, since thoughts turn to the person cared-for frequently, and there is less space for undertaking self-care. Parent carers and single carers tended to report worse mental health than other groups, which seemed linked to both their sense of isolation and their need to 'carry on' as the sole or primary emotional support for the person they care for. Carers often struggle to manage the balance between meeting their caring responsibilities and maintaining their own mental and physical health.

### Impact of COVID-19

Living through a pandemic with control measures unprecedented in the UK has been a stressful experience for most people. Many carers were enduring stress and mental health difficulties even before the pandemic, however, meaning that simply watching the situation unfold and going through the unsettling changes to daily life posed an additional challenge to people already in a fragile condition. A recurring theme was the fear of the person cared-for catching COVID-19.

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*...We were so worried, we thought (if they caught COVID) it would kill them within five minutes. So March, April, May, the kids and I took it in turns, we did a lot of the caring and all the nights between us, and then that nearly broke us.*

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– Valerie, age group 50–64, carer for her parents

While the pandemic naturally caused high levels of anxiety, especially in the earlier days of the pandemic, the realities of lockdowns and living with a person required to shield led to a feeling of boredom and entrapment more likely to provoke depressive feelings.

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*There's no escape from it. As soon as you wake up, you're on duty. As soon as- you know, even though he's asleep, sometimes if [Ben] has nightmares, I'm on duty all night. So there's no escaping it unless you physically remove yourself. And COVID has stopped that, you can't do it.*

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– Charlotte, age group 50–64, carer for her son

To manage stress and maintain mental health, carers need space to themselves and it is of concern that the pandemic situation has impacted on their ability to have this for such a considerable period of time. The lack of ability to 'take time out' for oneself during the pandemic, usually by going out of a home shared with a person cared-for to engage in exercise, social, or leisure activities, was cited by many participants as a particular strain on their stress levels and mental health. From these experiences, it is possible that some carers will be emerging from the pandemic less willing to continue caring at the same level that they did before, or that the quality of the care they are able to deliver will suffer due to a deterioration in relationships caused by 'being trapped together' for so long.

### 4.2.2 Isolation and loneliness: The critical importance of strong social support

Many carers recognised isolation and loneliness arising from their caring role, and where strong social support did exist, participants cited it as being a very important contribution to their well-being. Some interviewees expressed the desire not to 'burden' other people with their problems so tended not to speak to friends or family about negative things. Others had good longstanding friends who provided strong social support for them.

Sometimes these friendships were made through dedicated carer support groups and other times consisted of existing family and friend networks. Where they existed, they were invaluable to participants in managing their sense of isolation and loneliness.

Where social networks were weaker, this often linked to participants stating that they were struggling more with their mental health. Luke, for example, reported struggling generally with isolation, having been disowned by much of his family due to his sexuality and feeling that there are not many opportunities in make new friends in rural North Wales (which he characterises as quite socially conservative). He explained how his free time was heavily restricted by his care for his mother.

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*I've lost in touch with, with so many people ... my confidence is like at the bottom now. It's me and my mum and I try and battle for her, but never have the opportunity now to make time for me and I think that's before the pandemic as well really... it's been so isolating.... I'm not the person that I was because I think it's just emotionally taken it out of me really.*

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- Luke, age group 26-49, carer for his mother

Sometimes the nature of the condition of the person cared-for can bring about isolation. Amy, who struggles with social discomfort herself, has found that the nature of her son's disability (which includes severe autism) has isolated her further, as she feels his behaviour is too challenging for them to socialise with other parents together. She related how she has found solace in a social group for parents of autistic children but does not feel she has made very close friends through it. Now that her older son has become gravely ill she feels isolated from this group as well, as while they understand her challenges with an autistic child, they are not focused on supporting parents of children with serious illnesses. She felt that trying to build friendships would add more stress and demand more effort from her that she does not feel able to give.

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*It's been difficult to like go to parties, you know, with the other children and, and stuff like that. I tend to, if we get invited to anything I'm just like, oh no thank you, I'd rather not, 'cause it's just stressful, you know.*

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- Amy, age group 26-49, carer for two of her children

Particularly prominent among younger carers was a sense that caring cuts them off from important social relationships, since peers simply do not understand their lives, and may even feel afraid of facing the person for whom they care, or they just feel that their life is too different to their peers to share fully.

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*I've had some friends who are afraid of my dad because of his condition.*

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- Sion, age group 15-25, carer for his father

It should be noted that engagement with supported young adult carer groups provided a strong mitigation for isolation and loneliness with younger carers: this is discussed further in section 4.4.4.

Not only does caring have the potential to cause isolation and loneliness for younger adults through making them feel different to, and cut off from their peers, it can also interfere with the formation of romantic attachments.

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*It's hard for me to date people [laughs] who are my age now because they're really immature [laughter] like, compared to me. I'm, like, I'm thinking of the bills, I'm thinking of the food and shit and then they're, and they're thinking, 'I'm gonna play on my video game' [laughs] and I'm like, 'I don't want that.' I'm quite, I'm quite fortunate, I recently started dating someone who's also a carer. Lucky old me [laughs].*

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– Rachel, age group 15–25, carer for her father

Some carers hinted at social stigma associated with their caring responsibilities, with the sense that they did not want to talk about their caring with friends because of a fear of burdening them.

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*At first I found it really difficult [to talk about being a carer], because I don't know why but I find it really embarrassing. In a way almost like I was ashamed of it. I don't know why, but I was really, really ashamed of it...*

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– Alexa, age group 26–49, carer for her father



A particular situation in which loneliness is likely to occur is when a person is caring for a spouse with dementia. The dementia causes changes to the spouse's personality and identity, which means it can feel like the carer is no longer with the same person. Though there can still be moments of intimacy and warmth, Clara likened the experience of life with her husband in recent years to caring for a child, rather than having a relationship of mutual support. The earlier stages of the dementia can result in the couple's social circle shrinking significantly, which means that, as the condition progresses, the carer's support networks have already reduced.

Several carers referred to the loneliness of dealing with the significant responsibilities of keeping someone safe, and not feeling as though there is an adequate safety net should an emergency arise.



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*I'd like to feel less responsibility for them, like there was somebody else who was just as responsible as me, that I could, you know, just say, what shall we do about mum?*

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– Judy, age group 50–64, carer for her mother and aunt

Caring tends to cut people off from their potential networks of support, because of the time taken up carrying out caring duties, because of the way the person cared-for may respond in social situations and because of the impact of stress and worry on the carer. Many carers lack the opportunity to talk about their worries and fears and experience reduced access to social contact and support.

### **Impact of COVID-19**

The pandemic has particularly exacerbated carers' sense of loneliness and isolation, since many carers have reduced their social contacts with others in order to avoid transmitting the virus to the person they care for. Family members have reduced their visits to the carer and/or person cared-for, which not only means a loss of social contact, but also reduced help or respite for the carer.

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*I've got extended family on my mother's side who live nowhere near us, they all live in other parts of the country. And normally, under these circumstances, if we weren't under a pandemic, they would've been calling, they would've been coming down to visit their family including us – I've got cousins who live locally. So, yeah... in that sense that I've had no one else to give me respite. So, you know, whereas aunts and uncles might have called in and let me know. And I'd say, 'Oh brilliant. I'll go out for a couple of hours. You stay with mum, you know where everything is, just get on with it.' I haven't been able to do that.*

---

– Alison, age group 50–64, carer for her mother

Another way the pandemic increases loneliness and isolation can be seen in those who provide care to their loved ones while they are in residential care. Peter described the impact of being excluded from visiting his wife throughout the pandemic in emotive terms. His description of being able to see his wife through the window for the first time after five months away was particularly poignant.

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*Because of the lapse of time – the five months between March and August – she didn't have a clue who I was, and I had to stand outside her bedroom window and shout through her bedroom window. It's awful. It's absolutely heart-breaking. And many occasions I just broke down and I cried my eyes out whilst standing outside the care home and then had to come home after going through that trauma into an empty home and it was just devastating.*

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– Peter, age group 65–79, carer for his wife

### 4.2.3 Conditions of caring and human rights: An unsustainable burden for many

A matter that may compound the detriment to carers' mental health is that many carers' lifestyles would be seen to constitute breaches of their rights in other circumstances, resulting in lifestyles that would appear unsustainable. For example, employment law stipulates that people should be permitted rest breaks and their working hours should be limited, whereas some carers, particularly those who lived alone with the people or person they cared-for, described their responsibilities as spanning 24 hours a day, 7 days a week.

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*I have to be on call for those 110 hours a week, which is almost three times the legal maximum if I was actually working in a proper job!*

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– James, age group 26–49, carer for his grandparents

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*If you're like in a paid job you can clock off... you can go away, you can switch off. But with being a carer, sometimes it's 24/7... it's draining.*

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– Luke, age group 26–49, carer for his mother

In addition to breaching the working time directive, caring can also infringe carers' right to protection from physical and mental harm.

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*Your back – your back is where gets it. Then because you do it constantly, what you get when you go for help is if you don't stop doing it, we can't help because you keep doing the same damage. So, yeah, that's the biggest thing ... and I'm not big, and sometimes I feel like I'm wrestling with my son because of the medication he's on, he's pretty chunky, you know, he's physically bigger than he would be, I think, compared to our size.*

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– Angharad, age group 50–64, carer for her son

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*When you have to stand there and get punched, and get kicked, or get hit, or have your hair pulled, and you just have to stand there and take it, and you can't do anything about it. You know, I wouldn't let you punch me or kick me, you know, I'd report you to the police, but you can't do that with your own child, you don't want to do that to your own child, you know. So, that's the hard thing.*

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– Heather, age group 26–49, carer for her son

A few carers wryly noted that the restrictions on freedoms brought about by the COVID lockdowns are a normal part of life for many carers.

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*Carers knew what lockdown was before lockdown was a thing because...they couldn't go out whenever they wanted and do whatever they wanted, they had to stay inside...but we've been doing this most of our lives.*

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– Katy, age group 15–25, carer for her stepfather

For some, visits from care services only provide relief from a small proportion of the time in which they are 'on duty'.

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*When the lady from the local authority came in and we got Margaret up, Margaret went in the bathroom and she was cleaned, then the paperwork was done, that lady from the local authority had gone within half an hour. I still had 23 and a half hours to look after Margaret. I still had to give her medication, I still had to bath her, I still had to look after her, etcetera, etcetera, etcetera.*

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– Peter, age group 65–79, carer for his wife

Carers' liberty is restricted because they are unable to come and go as they please or take part in their own interests and leisure activities. For example, Clara described having only two hours of the day, when her husband first goes to bed, as private time in which to pursue interests such as reading, but finds herself so exhausted that she is not able to enjoy this time or make any real progress in her own interests.

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*You know, the whole of life is taken away from you and just because you have been thrust into that position, rights that you had before as an individual, you don't even ask for because you know if you insisted on your rights, the person you look after, would, their care would be diminished.*

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– Clara, age group 80+, carer for her husband

Caring responsibilities can also impact on people's right to family life, as they are unable to make time for other family members. As an extreme illustration of this, Alison described moving out of her own family home to care for her mother, and consequently having far less time to spend with her partner and children.

The amount of caring work some unpaid carers report carrying out on a daily basis, and the nature of risks to them in the course of providing care, would not be tolerated for paid care services and are likely to have a profound impact on carers' health and well-being.

### Impact of COVID-19

The pandemic has exacerbated the impact of caring on individual carers' rights, especially because of the need for many people who are cared-for to 'shield'. 'Shielding' to protect the person cared-for has meant that carers have had to cut themselves off, at least physically, from friends and networks of support, and has further reduced the extent to which carers are fully able to engage in family life. For example, Natalie was having her toddler nephew for overnight stays every week prior to the pandemic, but has not been able to see him at all for the past year due to fear of passing on COVID to her mother, who is particularly vulnerable.

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*I mean last time I phoned him he was showing me a picture of the two of us and cuddling it and kissing the phone... because he doesn't have language as a result of various developmental issues, I can't explain to him why I'm not seeing him and that's really hard. But equally it means I can't see him at all because I couldn't explain to him that I can't cuddle him and because he has been going to school as an extra... additional needs child the whole time it's just too much of a risk for mum.*

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– Natalie, age group 26–49, carer for her mother

Shielding has had a significant impact on carers and has further reduced their freedoms and enjoyment of aspects of life to which they are entitled within their human rights.

### 4.2.4 Living with uncertainties and fear: Daunting responsibilities

Fear was a common emotion expressed by carers for various reasons. Most common was the fear of the person they care for being hurt while they were looking after them and needing hospital treatment.

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*I was petrified that I'd do something wrong. I was petrified that she might fall. I was petrified that I may give her the wrong type of food or the incorrect medication because if something happened on my watch, the coroner at the inquest would be saying, 'Well, you gave her an overdose.' Or, 'Why were you giving her this medication?'*

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– Peter, age group 65–79, carer for his wife

The fears expressed by carers demonstrate the unpredictability that becomes a part of their everyday lives. Some carers described their fear of situations involving personal injury to the person they care for, where they anticipate being unable to help because of disparity in their size or strength.



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*If he had pulled me down with the times he was falling, if he'd pulled me down with him and I banged my head, you know, there would have been two of us not one to look after and I don't want us to go out like that because situations can be controlled.*

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– Clara, age group 80+, carer for her husband

For some carers, the anticipation of the cared-for person's deterioration and/or death also caused fear. This included anticipation of possible crisis and difficult decisions about residential care at some undetermined point in the future, as well as not knowing exactly what to do when death occurs.

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*What do I do when I go in and find my mother dead? Who do I phone? Because that's what I need to know, because that's what I'm hoping will happen.*

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– Judy, age group 50–64, carer for her mother and aunt

Carers live with fear because of the uncertainties caused by the health condition of the person cared-for and often lack anyone to reassure them about what help will be available when progressions of illnesses or conditions occur. Taboos concerning talking about death can be particularly difficult, since dealing with the immediate aftermath of death is not an everyday experience, and anticipation of this can increase carers' anxiety.

For parents of disabled children and spouses in particular, there was an additional fear of what might happen to the person cared-for if/when the carer dies and leaves the person cared-for behind.

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*So you know, she's a very immature, very vulnerable young lady, you know, functioning on probably about six years. And you know, at some point, I suppose I'm not going to be around to be there. I once had a discussion with a friend, vaguely similar, and he actually gave me a very good analogy, which is, if you've ever read The Lord of the Rings books, there's one bit in the book where there's a guy sitting with a cloak and he's a king or a ruler. And underneath the cloak, he then reveals he's wearing armour, and he's worn armour all the time, even though he's old, so that his body doesn't become weak. And that's the kind of thing that I put on every day, this sort of mental, metaphorical armour... to always be aware that that's the corner I'm fighting from, I think.*

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– Matt, age group 50–64, carer for his daughter

### Impact of COVID-19

For some carers, the sense of living with uncertainty has been exacerbated during the pandemic, especially because carers' access to hospitals and residential care settings has been much reduced, meaning that they have not been able to have contact with the person for whom they care. This was particularly a worry for people caring for people with reduced mental capacity, whether through learning disability or dementia. Alison, for example, was concerned about the impact of a stay in hospital on the progression of her mother's dementia, and what that might mean for her as a carer when she was eventually discharged.

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*The last time I saw her, which was two weeks before Christmas in hospital, I took my daughter with me – her granddaughter – and she didn't even recognise her. So I'm pretty dreading what I'm going to have coming home with her... I don't know what she's going to be like. I don't even know if she'll recognise me. So that's quite scary.*

---

– Alison, age group 50–64, carer for her mother

Similarly, the fear of the person for whom they care being hospitalised during the pandemic has weighed heavily on some carers – again, particularly those who care for people with dementia or reduced mental capacity. The COVID-19 pandemic has confronted many carers with increased awareness of the vulnerability of the person for whom they care and has meant that they have lived with considerable fear in the background of their daily lives.

### Opportunities for action

- Carers suffer from considerable stress and many note a negative impact on their mental health. Improvements are needed in the services offered to carers to ensure that their caring role is sustainable and that proactive support is available in situations in which their health and well-being is at risk. The recovery period as the country emerges from the pandemic represents an opportunity to find new ways to support carers.
- Loneliness and isolation are common experiences for carers. Many need support to build social connections and to find ways to engage with support from their wider social networks and communities.
- Some carers experience living and caring conditions that breach their human rights. These exacerbate both their stress and isolation. Such situations need to be identified and addressed promptly. It is vital that all carers are able to have time to relax and pursue their own interests.
- Carers live with a considerable amount of fear related to managing the health and well-being of the person cared-for. They need to feel supported by professionals in managing their responsibilities.
- The conditions of the pandemic have impacted negatively on many carers' mental health and well-being, and it is important that professionals recognise and identify those most at risk of crisis.

## 4.3 Employment, education and finances

### Key findings

#### Life before the pandemic as an unpaid carer:

- Paid employment outside the home is often of great value to carer well-being and financial stability (See Section 4.3.1).
- Younger adult carers feel that their choices around education and career are much reduced by their caring responsibilities (4.3.2).
- Often, caring has a substantial impact on personal finances, and this was particularly pronounced for single carers who had no partner to boost their household income (4.3.3).
- Many carers find the amount they are paid through Carers Allowance inadequate and feel demeaned that their responsibilities are valued so poorly within the benefits system (4.3.3).
- Specialist school attendance and support is a key part of managing life well for most people caring for their disabled or ill children (4.3.4).

#### How the COVID-19 pandemic has affected unpaid carer experiences:

- Increased levels of working from home during the COVID-19 pandemic have been welcomed

by many carers for providing additional flexibility, though some have missed having the workplace as an area in which they have a break from caring and can socialise.

- For parents of disabled children, the closure of schools and need to cope with home-schooling have been particularly challenging.
- Unpaid carers already experiencing financial precarity have found that their financial worries increased during the pandemic, especially as having all the family in the home at all times has increased household costs.

#### The impact on the COVID-19 pandemic on unpaid carer well-being:

- Stress levels have increased for many due to increased financial precarity.
- While some have appreciated the opportunity to be at home more, some have found that being required to be at home more with the person cared-for has been difficult.

### 4.3.1 Employment: Valuable but often compromised

Working is important to many carers because their responsibilities entail not only being present to provide care, but also to provide financially for their family or loved on. Where carers were able to work, they placed a high personal value on this – not only in terms of their own self-esteem and interest, but also, for example in Ffion's case, in affording them 'legitimate' time out of the house and away from caring responsibilities.

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*This sounds really awful, I'd be going to work just to have a break from Osian... because Osian's never going to not be at home, I'm always going to have to work around him, but I do need to, to work because I'm quite an intelligent woman, and sometimes you vegetate.*

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– Ffion, age group 50–64, carer for her son

Encouragingly, many carers spoke with warmth about their employer and appreciated the flexibility and understanding they had been given. These carers felt that this flexibility allowed them to carry on balancing work with caring and acknowledged a certain amount of emotional support provided through the workplace. It was important to these carers that their caring duties were understood and acknowledged by colleagues and managers.

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*You know, they're very supportive. If I need to go for an appointment or take him to a hospital appointment – because he's got a few hospital appointments – they're quite happy for me to juggle my hours for that.*

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– Sandra, age group 50–64, carer for her father

For others, however, the employer's understanding was more limited, and allowances appeared to be made only when a hospital admission occurred.

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*Yes, it's difficult because they don't realise how ... how much work it is, how difficult it is... So the comparisons you get, people try to make comparisons, and they're not even close. And there's no point in trying to explain either. So, no... they probably know 30% of what it is ... but they don't know the extra 70%, I'd say.*

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– Angharad, age group 50–64, carer for her son

In Deborah's case, her employer has been so inflexible in the past that she described having to use her annual leave or "skive" (as she put it) to take her father to hospital appointments or handle emergencies, leaving her feeling anxious and guilty, and diminishing her work satisfaction and trust in her employer.

Some carers recognised that their caring responsibilities have a direct impact on the extent to which they will be able to fulfil ambitions for their careers. Natalie is currently studying for her PhD, and her future in academia will be more challenging due to the fact that she cannot move away, or even commute very far, due to the responsibilities she has as a carer.

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*I very much used to aspire to an academic career that was quite high flying, whereas now my priority view is whether I could cope with it with the things that are in place, so you know that's quite a limitation. It's going to be a limitation when I look for jobs which I will admit, you know, I get very scared about sometimes because it's quite a constraint, but maybe it will all work out who knows?*

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– Natalie, age group 26–49, carer for her mother



Work is not only important as a source of income for carers, but also for identity, self-esteem and creating a space away from caring duties. Carers appreciate flexibility from employers and understanding of their situation and needs from managers and employers. The extent to which such flexibility and understanding is granted appears to be inconsistent, however, with the result that some carers can suffer in the workplace. Inevitably, some carers' career ambitions are limited by their caring duties.

### 4.3.2 Education: Inconsistent recognition and support

Recognition of carers in educational settings was inconsistent. Some younger carers mentioned the benefits both of flexibility and of their situation being understood in educational settings.

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*From school, from teachers in particular, I get emotional support, just little chats. I have extended deadlines and things like that give me more – I don't have as much freedom as my friends have, so they give me that extended time, so I can relax and do my work.*

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– Sion, age group 15–25, carer for his father

For many participants who started caring when they were still at school, however, the lack of recognition or support was problematic, even in situations in which the school was aware of the young person's caring responsibilities.

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*I remember one time I did get called out in school, like oh you're missing a lot of days... I think they started like, chasing me up on my attendance, but they never really asked about anything. Like, I did say I was going to appointments and stuff with my mum, but they never really pushed the whole, 'ah is there anything we can do to help you or anything?'...*

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– Nur, age group 15–25, carer for her mother



Similarly, Amelia recalled her mother being threatened with prosecution by the educational welfare officer because her caring responsibilities had impacted on her school attendance. Young carers' reduced school attendance often brings their situation to the attention of the school, yet it is concerning that the response is often to enact disciplinary measures, rather than to initiate support and signpost young people to services that can help.

Carers in education, or younger adult carers who had recently left education, mentioned the importance both of flexibility and of their situation being understood.

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*I remember telling the university and they did offer me extensions and stuff, so that was nice, that was kind of a relief in the end.*

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– Nur, age group 15–25, carer for her mother

Not all participants had positive experiences of support at university. Some found that, while their university knew they were a carer and promoted carer support services, in practice the help they needed was not forthcoming.

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*Everything's always stressful and it's very hard to study and I feel like my Uni haven't been very helpful, I mean my lecturers know I'm a carer, they know I can't always attend. Some of them I've asked them to record so I can catch up and they've said 'no' because otherwise people will just start not turning up and I said 'I don't have the choice, I would turn up if I could'.*

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– Katy, age group 15–25, carer for her step-father

For younger carers, caring responsibilities can have a profound effect on career prospects and future plans. Some reported that their ambitions had been curtailed by their caring responsibilities.

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*I want to do a post grad, and the thing is I am kind of thinking about what I want to do and then what I should do in terms of what support would my family need and you know, whether I'll be around and I shouldn't go too far and if I do how often do I have to come back. So, I have to think about everyone else while I'm also thinking about what I want to do.*

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– Helena, age group 15–25, carer for her brother

### **4.3.3 Finances: How caring exacerbates inequality**

We found great variation in our sample of carers between those who were financially struggling and had experienced problems severe enough either to bring substantial stress and difficulty, and in some cases to access emergency debt or bills support, and those who were coping or even thriving financially. What most distinguished these groups (although there were exceptions) was that those who were single and caring alone tended to be unable to work full-time and experienced greater financial difficulty, whereas those who were living with a partner included at least one partner who was able to work while also sharing some of the caring responsibilities, which led to less financial difficulty.

Some carers reflected that they were poorer because of their caring role. This was particularly the case for the carers who have given up work due to their responsibilities, many of whom expressed discontent with the low amount of money provided by Carers

Allowance. (At the time of this study Carers Allowance stands at a flat rate of £67.70 per week for those caring 35 hours per week or more on a low income, and is only available to those where the person they care for receives particular benefits\*).

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*We're not as bad as some people in this situation but, of course, it's very tight. We're living to the exact penny... My husband gets the Carers Allowance for his side of it but that's it then.*

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– Lindsey, age group 26–49, carer for her son

In addition to the day-to-day financial worries of those claiming Carers Allowance, there was also a sense that the low amount of the benefit, and the tight restrictions on when it can be claimed, impact on carers' sense of self-esteem and the degree to which they feel that their role is recognised and respected within society. Some carers called the amount they received “patronising” and “demeaning”, while others struggled with how any money they did earn could impact their Carer's Allowance.

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*Can I just say on that point, I get carers' allowance, and three weeks last year, I went over the, over the limit by about £12, and they took three weeks' money off me, and I thought that was disgusting. They took the three weeks' Carers Allowance off me because I went over the limit that you're allowed to work. And I thought god, you know, it wasn't like thousands. It was ridiculous. So, yeah, that upset me.*

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– Ffion, age group 50–64, carer for her son

Financial worries do not only affect those on Carers Allowance, however, as carers who are also in employment also had their stories of financial worries.

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*I could do with working full time. Your bills aren't lower because you're working full-time – part-time. So, no, it's a pain. It's a constant pain you know. And your pension, you know, I had to stop working for a while after my son was born, and that affects your pension. It affects someone's future, and nobody cares. You can't contribute to your pension pot, and it's just a pain.*

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– Angharad, age group 50–64, carer for her son

Some of the carers interviewed appeared to be reasonably affluent (and therefore unlikely to be eligible for services free of charge). It was striking how much these participants spoke about drawing from their personal financial resources to meet their caring responsibilities, such as private medical appointments, home modifications and improvements, and private support workers.

\* <https://www.gov.uk/carers-allowance> – correct as of 30-4-21

Those with access to moderate amounts of money found that money could be used up quickly by spending necessary for caring. Natalie described having been able to save some money while working in London during her 20s, but had to use up all of her savings to care for her mother when she needed nursing while living overseas. Luke, who cares full-time for his mother and could not work, had limited financial options due to his mother moving into his home, and his ownership of property assets.

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*I've given up work to look after mum... And, and because she's living with me I don't get any financial support for doing that. I own a couple of mortgaged buy-to-let properties. And because I've got them I'm ineligible for any support. So I'm looking after mum. She'll, she'll give me like money towards like food and that type of thing and like a contribution... but... it's not a wage... it works out about £40 a week like sort of spending power that I have left over... if mum had her own place she'd be eligible to claim other benefits and that.*

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- Luke, age group 26-49, carer for his mother



Carers who have private resources use them to meet their own needs and the needs of the person cared-for. Many carry on working but find their earning potential reduced due to their responsibilities, which impacts not only on their day-to-day lifestyle, but also on their planning and saving for retirement. Carers Allowance, which is only provided for those on an income below £128/week\*, does not provide enough for many carers to enjoy an acceptable quality of life. Where carers find their responsibilities make it difficult for them to seek employment to supplement their income, financial difficulty is a significant risk.

#### 4.3.4 Impact of COVID-19 control measures

##### *Working from home and being furloughed*

The pandemic has had a profound impact on the working life of many people over the past year, with a shift to working from home for some, and with many being furloughed due to the enforced closure of leisure and hospitality businesses. Unsurprisingly, some carers recognised furlough as helpful in reducing how busy they were, and felt that this had been beneficial to their well-being.

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*It helps me now that I am furloughed... If I was working, because I do nine hour shifts I, I really, you know, it's going to be really difficult when I go back to work.*

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- Judy, age group 50-64, carer for her mother and aunt

\* <https://www.gov.uk/carers-allowance/eligibility> - correct as of 30-4-21



Similarly, many carers have found working from home useful, because of the additional flexibility they feel that they have in fitting their work around providing care. For some carers, however, the loss of a work environment as a space away from their caring responsibilities has been problematic.

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*I'm trying to work from home and look after her, she doesn't always understand if I'm on like a Zoom call or a Teams... or whatever, she doesn't understand, so she'll start talking. And I'm like, 'Mum, I'm in work. 'No, you're not. You're sat at the dining room table.' [laughs] She doesn't quite understand that, you know, although I might be sitting here looking like I'm doing nothing, I am actually working. So the only time she really registers that I'm working is on the days where I used to actually go into my organisation for two days.*

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– Alison, age group 50–64, carer for her mother

Where the person cared-for has need for emotional support, as is often the case for people with dementia, mental illness and learning disabilities, home working is difficult to manage, because it is not always possible for the person cared-for to understand the boundaries required for working without distraction.

### **Further education at home**

Similar to those working from home, several young carers noted the impact of distractions on their engagement in education during the pandemic, as they tried to keep up with college or university work.

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*I have to try and calm my sister down obviously, like, it's very hard. Like, she hits, she punches, she gets physical, so then if I have to deal with that. It's the same now in my uni class, I'm not in uni, I can't just sit there and concentrate, if I hear something going on, I have to get up from my class. I've got to go and see what's happening and when I was in college I could actually engage more... before the pandemic I was able to engage more with my learning and get breaks, whereas now I can't.*

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– Seren, age group 15–25, carer for her sister

The issues raised here by Seren will be familiar to parents of school-aged children who have been working from home during the pandemic, however, given the under-recognition of young carers in many educational contexts, their distractions from their work may also not have been recognised to the same degree as parent carers during the pandemic.

### **Home-schooling**

For almost all the parents of school-aged children included in the sample, where they had to home-school their children for a significant period, this was a cause of stress, difficulty and tension. While such stress has arguably emerged with most parents during lockdown, it was clear that the additional needs and vulnerabilities of disabled and ill children heightened these difficulties and stresses, and in some cases led to a disengagement of

both child and parent from schooling. Parents of disabled and ill children reported a strong reliance on school not only to give them time to work or attend to other matters, but also as a form of respite from the practical and emotional toll that caring could take on them in the everyday.

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*Mia needs one-on-one attention constantly. It's not a case you can just leave her in another room and set some work for her. Because of her seizures and how they present, she needs to be almost sat next to a person so we can keep an eye on her. So when I was working, I found it significantly difficult and as much as my work tried to help, I was being paid to do a job as well as trying to keep my daughter safe in schooling. So, unfortunately, I think probably her education suffered...*

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– Lindsey, age group 26–49, carer for her daughter

Many parents described trials of home-schooling, but these emerged differently in each case. Lindsey's daughter experiences frequent seizures because of her condition, which the video-based learning tended to trigger, so this meant that she had to both limit her school interaction and watch her "like a hawk" to check for signs she might be about to have a seizure. Parents of autistic children struggled greatly with attempting to engage their children with learning activities. Heather found it very difficult to engage her son in learning as he was accustomed to a different style and environment within his supportive school. As her son can be violent and aggressive when he gets frustrated, she was inclined not to push too much with home-schooling as she knew it would aggravate him. Amy was experiencing similar problems with her son, who became angry and frustrated at home and she found it difficult to engage him in learning and manage his behaviour.

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*It's just extra stress when you're trying to do things and you've got him screaming in the background because he doesn't want to be at home. You know and he's hitting himself against the walls and stuff because he's frustrated, and it is stressful... parents aren't coping at home, school is key to everything.*

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– Amy, age group 26–49, carer for two of her children

Several parent carer participants in the study expressed frustration that they had not been allowed to access limited school 'hub' places during school closures, due to not being keyworkers, despite their children's conditions making home schooling so challenging. They argued forcefully that the conditions for taking up hub places in schools should have been assessed individually during closures to protect their child's well-being and education, and their own mental health. Ffion expressed disappointment at the lack of pastoral care offered by her son's college, saying that nobody had contacted them to check on how they were managing.

The challenges parent carers have experienced with home-schooling are a reminder of the importance of the relationship between the school, the disabled or ill child and their parents. Parents of disabled or ill children look to schools as a form of social support and have faced particular difficulties during periods of school closure.

### Increased financial precarity

Negative financial impact deriving from the pandemic was experienced by most carers in our study. This occurred through the forms of reduced household income due to furlough or job loss, and increased household expenditure due to having whole families spending all their time at home. Where carers have been struggling financially, the prospect of a reduced income due to going on furlough represents an impractical prospect.

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*I didn't ask for [furlough]. At the time, my husband was going to furlough himself. So the money side of it and the impact, we just wouldn't have been able to have managed. It's come to the point where he's actually lost his job now, so it's only me working full time. I think everyone... a lot of people are in the same boat. We're managing, it's okay but the option just wasn't there to be furloughed...*

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– Lindsey, age group 26–49, carer for her son

Meanwhile for people on benefits due to their caring role, who were already financially precarious, the increased cost of having the whole family at home proved unsustainable and led to people seeking emergency support of various forms.

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*[My husband's] got a credit card, a Visa, and we've [just been using] it because we got to the point where..., we just can't pay this. We didn't want to. It almost feels like a bit of a failure, but- and also everything's gone up.*

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– Ffion, age group 50–64, carer for her son

This illustrates how the financial difficulties carers encounter means that they are ill equipped to cope with contingencies or emergencies. A negative economic impact of the pandemic has been a widespread experience across the population, yet the prevalence of financial precarity for unpaid carers, and their frequent inability to be flexible in relation to employment opportunities leaves them particularly vulnerable in the face of unforeseen events.

### Opportunities for action

- Carers value flexibility and understanding from their employers, but individual experiences vary greatly. There is a need for greater consistency across all sectors to ensure that unpaid carers who work feel able to manage their caring role alongside their job.
- Many younger participants reported that their schools did not recognise or support them as young carers. Schools, colleges and universities all need to be proactive in identifying and supporting young carers, with clear and visible policies in place.
- Schools are particularly important for supporting parents of disabled children and consideration should be given for services to support families while schools are closed.
- Many carers suffer financially because of their caring responsibilities and feel that Carers Allowance is an inadequate provision. Consideration is needed as to how the financial disadvantages suffered by many unpaid carers can be better mitigated.

## *A Carer's Story: Managing employment and caring*

### **Deborah's juggling act**

Deborah, in her 40s, began caring for her father five years ago as his degenerative condition worsened. Deborah first realised she was a carer when she made the decision to reduce her working hours to part-time, in order to be able to do everything her father needed her to do. As an ambitious person with experience in her previous career, she feels that she could have progressed much further should she have stayed full-time in her previous career, but will now not be able to fulfil this promise. Part-time work was helpful in managing her caring responsibilities, however after being made redundant three years ago, Deborah had to accept a full-time unskilled job as there were no other opportunities available. She finds balancing these hours with her caring responsibilities 'horrendous', leaving her with no time to care for her own health and well-being.

Before the pandemic, Deborah found that she was struggling to cope with the stress of juggling caring with work. She asked her employer to support flexible hours so that she could take her father to appointments and deal with minor emergencies, however they were not receptive to this and refused her request. This meant that she would often have to surreptitiously take time out of working hours, leaving her feeling guilty and resentful towards her employer. Compounding her struggle is the fact that her employer does not offer carer's leave, so she usually uses up her annual leave allowance to care for her father. Feeling trapped and frustrated, suffering from huge anxiety, stress and exhaustion, Deborah was unsure what to do before the pandemic hit, and was on the verge of a mental breakdown.

The pandemic has made things considerably easier for Deborah. Because she now works from home, and her employer has become far more flexible around working hours, balancing her caring with her work has become more manageable. She has also had to visit her father less due to COVID lockdowns, which has eased the burden of care on her, but has had a negative impact on her father's health. Deborah fears her father's mental and physical health have deteriorated significantly over the pandemic. She is concerned that after the pandemic his care needs will be even more demanding, and that a return to regular office hours combined with this will place an unmanageable burden on her own mental health again. She is at a loss of what to do or who to turn to in order to help her navigate this change, feeling that as a working carer who doesn't live with the person she cares for, she is forgotten about by services that could support her.





## 4.4 Services and systems

### Key findings

#### Life before the pandemic as an unpaid carer:

- Many carers found the experience of being assessed for support by local authorities unsatisfactory and feel that they are not recognised, understood or prioritised in social care planning. Concerningly, many interviewees reported that professionals have not asked them about their needs or experiences as carers (Sections 4.4.1 and 4.4.3).
- Much of carers' time can be spent chasing services and attempting to contact the right people to obtain support and provision for the person they care for (4.4.2).
- Provision of support by third sector organisations is highly valued and helps to make caring more sustainable for many. For younger adult carers, groups that enable peer support to develop were reported to be particularly important (4.4.4).
- Flexibility in the arrangement of services, both for the person cared-for and the carer, is an important factor in unpaid carers' satisfaction with the services they receive. The use of direct payments (and private resources for more

affluent individuals or families) was indicated by some as a means of acquiring the flexible services most needed (4.4.5).

#### How the COVID-19 pandemic has affected unpaid carer experiences:

- Time spent chasing services has increased during the pandemic as services have become even less accessible (4.4.2).
- Access to carers' groups during the pandemic has generally been remote – via video calling. This has been appreciated by carers, yet most felt that being able to meet in person provides a better experience (4.4.4).

#### The impact on the COVID-19 pandemic on unpaid carer well-being:

- The inaccessibility of services and limitations on support have led to greater stress and feelings of abandonment and invisibility (4.4.1).
- The rapid adaptation of young adult carer support groups has supported the well-being of this group despite challenges (4.4.4).

### 4.4.1 Statutory service provision: Incomplete and frustratingly limited

Local authority assessment and support was almost universally perceived as inadequate, incomplete, and sometimes actively distressing in its delivery. In almost every case, participants found assessment at best unhelpful, and at worst, deeply upsetting.

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*I know about carer's assessments, but... and I've had a carer's assessment and at the end of the day what, what has it done for me? It's done very little for me.*

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– Deborah, age group 26–49, carer for her father

Throughout the interviews there was an overwhelming sense that local authority social services existed to safeguard budgets and reduce support wherever possible, and where support could be accessed, made it as difficult as possible to do so. Many felt that, if they appeared to be able to look after the person requiring care, social services saw that as an excuse to withdraw from involvement or to provide minimal provisions.

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*...Once I was deemed to be a fit and proper person to look after Margaret, a fit and proper person to give her medication, the social worker that was supposed to be looking after me – he said, ‘Well, yeah, you’re okay, Pete. No problem. You’re fit and proper. Bye.’*

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– Peter, age group 65–79, carer for his wife

Gail even described an insulting remark from a social worker when she asked for more assistance from her local authority:

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*I think that’s it, it’s that message that comes across all the time, that we should only be getting in contact with people if our need is urgent, and I think, well, it isn’t urgent, so I don’t ask! And I want to be made to feel like it’s okay to ask. It’s a bit like that social worker saying to me, you know, ‘Well, I appreciate you want to preserve your inheritance’ [laughs]. And I feel guilty enough asking for help without people making comments...*

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– Gail, age group 50–64, carer for her mother and daughter

As has been noted above, people often do not come to realise that they can be identified as carers until they have been undertaking considerable responsibilities for some time, at which point they may already have been experiencing considerable personal challenges. The feeling of not being able to ask for help, or not expecting that help will readily be given, contributes to carers’ sense of being isolated and devalued.



### Impact of COVID-19

Some services have had to reduce or withdraw during the pandemic, whether because of reductions in funding, staff unavailability. This often had a significant negative impact on the quality of life for both carers and the people they cared-for.

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*We had Admiral Nurses for three years. They were funded for three years and unfortunately, their funding went caput, and I found the Admiral Nurse was the only person that I genuinely felt supported by... And unfortunately, that service was taken away during the pandemic, which I think is unconscionable, to be honest, because, you know, I knew she supported people that were in, you know, far worse situations than me and I hate to think what's happened to them with her advice and support taken away from them.*

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- Jenna, age group 50-64, carer for her mother

A common complaint among our participants was that services took a lack of direct contact from carers as a sign that all was well, and therefore that services or support were not needed. As a result, some carers found that situations spiralled into crises because of the lack of preventative support.

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*We didn't get that much when it wasn't a pandemic. Don't get me wrong, the mental health services we've had, like, no help at all. But we'd at least have something from them, like, maybe once every two weeks they would come up, but since the pandemic we haven't seen them at all. And then, only when my sister, like, hits rock bottom and is a threat... they all just come running back, as if to just save their backs so they don't get sued or nothing.*

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- Seren, age group 15-25, carer for her sister

At a time when unpaid carers have experienced increased responsibility, increased stress and exacerbations of problems around loneliness, isolation and living with uncertainty, the withdrawal or limitation of statutory services proved problematic for many carers in the study. Carers already found it difficult to ask for help before the pandemic, and found that local authority services were not responsive to their needs. The impact of the pandemic has been that carers feel even more acutely that they are a low priority. Having low expectations of services increases the risk that carers will not seek the help they need.

### 4.4.2 Time spent chasing services: A maze without a map

A challenge that many interviewees mentioned in relation to time spent asking for services was a lack of information. Carers do not always find that information on how or where to find support (whether for themselves or the person cared-for) is readily available, and some have to spend time contacting different agencies to find out what they can do and whether they can help. Valerie memorably described the labyrinthine process of trying to book a physiotherapy appointment for example:

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*...I had to ring to the GP, the GP referred me to the physios and then somebody rang me and said, 'Oh no, I'm the wrong kind of physio, you need the community physio'. So like, three or four phone calls later, I stayed on a call thing for, I don't know, half an hour and in the end I got a recorded message that said, please don't leave a message here, please send us an email to this address. You know, I've done that so many times, whether it's for podiatry, opticians, chiropody, whatever.*

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– Valerie, age group 50–64, carer for her parents

Significantly, this was not a one-off irritation, but an experience that had been repeated for Valerie when trying to book a number of different services.

Some interviewees advised that they had learned over time that you have to 'learn to play the game' in order to get what you need, particularly from local authorities. Participants describe how time consuming and emotionally draining they found this, with some naming it as the most difficult thing about being a carer.

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*Now it's okay because now I know who I need to speak to, now I know the order, now I know how to queue, not queue-jump, but how, now I know how to jump over the person and know what they're actually going to be able to offer and think, 'There's no point even going there. Let's go to the next one up...'*

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– Heather, age group 26–49, carer for her son

An issue that arose for some parents of disabled or ill children was their belief that it was additionally difficult for them to acquire the services and support they needed because their child did not fit into one of the pre-determined eligibility criteria recognised by the local authority, falling in-between categories of need, and therefore it was harder to identify who to speak to or obtain authorisation for support.

The time spent ensuring that the cared-for person has the correct services does not necessarily end or pause when the person cared-for goes into hospital or residential care. Angharad, for example referred to the need to provide support and advocacy when her son goes into hospital as an inpatient, as he is liable to be admitted to a less appropriate ward due to erroneous assumptions about his medical condition caused by his having a naso-gastric tube. Similarly, Peter emphasised the important role he had in his wife's daily care in a residential home prior to the first lockdown.

An improvement to the complexity of navigating the social services system and getting the support carers need in a clearer, simplified way was often the first thing carers cited when we asked what would improve their lives as carers.



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*They need to get their departments talking to each other, and they all need to know. There needs to be one central person, and they all need to, to listen to each other. And I shouldn't be the one chasing around every department. They should.*

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- Ffion, age group 50-64, carer for her son

It is difficult for carers to negotiate the fragmented services provided by various third sector organisations, local authorities and health services. The substantial stress and frustration caused by the time they spent chasing services led many participants to describe a centralised hub or team to pursue and support carer enquiries as the primary development that could help improve their lives and well-being.

### **Impact of COVID-19**

Many describe how the challenge has grown since the start of the pandemic as resources are in even shorter supply and there are fewer people who answer the phone, or when they do find someone that can help them that person might be redeployed, absent through sickness or move jobs.

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*I'm phoning social services office and there's nobody answering the phones now ... Nobody's got any answers to me.... So I feel like I'm going round in circles, and nobody's got any answers to any of the questions I ask.*

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- Jayne, age group 26-49, carer for her mother

The pandemic has made pursuing communication with health and social care services a particular issue for carers whose loved one is in a hospital or residential home. Information does not come readily out of such institutions to the carers, who must spend time and energy tracking down information. In one case, Alison found that her mother had been moved to another hospital without her knowledge, and that many of her possessions had been left behind. This meant numerous telephone calls to track her mother down and to retrieve her possessions. As noted above, the lack of information contributes to the sense of worry and uncertainty that often dominates carers' stories. It also suggests a lack of partnership working between professionals and unpaid carers, which indicates that the aims of the Social Services and Well-being Act (Wales 2014) are not being fulfilled.

One aspect of health care provision that has worked well for some carers has been remote access to their GP, which simplifies getting medical attention for both the person cared-for and the carer, where necessary.

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*They've put in this new Ask My GP app. And if anything, it's better than the service we had before. So it's so prompt. It's so efficient. So I hope they keep that... certain things from the pandemic, I do hope they keep.*

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- Ffion, age group 50-64, carer for her son

One carer, however, expressed a more ambivalent attitude to accessing the GP remotely, despite the apparent success of this approach.

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*Well, you, you can't get a GP visit really. My mum, my mum hasn't seen a GP in probably a year now. So you have to deal with the GP over the phone all the time, so you have to kind of try and explain what's going on which isn't always easy, but in fact her skin cancer was diagnosed by me sending in pictures to the GP, and the GP sent that onto the hospital.*

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– Liz, age group 50–64, carer for her mother

While carers may find it convenient to access GPs remotely, it is important to bear in mind how isolated many carers are, and not to underestimate the need for reassurance and feeling as though they are part of a team with professionals who provide services. Caution would be advised in assuming that this would be something all carers would want to continue as the primary method of communication with medical professionals after the pandemic.

#### 4.4.3 Invisibility: Feeling undervalued by professionals

The impact of the partial and fragmented support for carers, and their difficulties in accessing and communicating with services, is that they feel undervalued and invisible. A common feeling among interviewees was being seen as an instrument of care for a person with eligible needs, rather than as a person in their own right. The feeling of being undervalued by service providers can be compounded by the impression that carers' expertise and involvement with the person cared-for is not acknowledged by professionals. Carers reported their frustration and resentment at the assumption that they will simply cope with the work they are doing because of the power of family obligation.

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*I mean, our local social services, my mum's social worker... their view of it is, well, if there's family around they can care for them. Not realising the impact upon that family is already given a lot for things in my life, already, do you know what I mean, to be my mum's carer, to make sure that she's always got somebody there, because they're not putting that safety net around us, do you know what I mean?*

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– Jayne, age group 26–49, carer for her mother

Participants sometimes raised points during their caring journey where professionals could have recognised them as carers and referred them for help but did not. For example, GP surgeries are required to keep a list of unpaid carers, yet more than one carer described difficulties when they approached their surgery for this purpose. Where carers reach out to services and find that they are not met with recognition, the impact on their mental health and self-esteem can be profound.

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*Looking on Carers UK website they say, oh get yourselves named as a carer with the GP. But I've tried to sort of get that three or four times and it, it sort of, it's not forthcoming... my confidence is at the bottom now.*

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- Luke, age group 26-49, carer for his mother

It was striking that many participants said that the research interview for this study was the first time that anyone had asked them about their needs and experiences as a carer, and many clearly found the process cathartic. This suggests a significant deficit in the services carers receive, and much improvement is needed in the way professionals address and communicate with carers.

### **Impact of COVID-19**

The pandemic has intensified many carers' feelings of being forgotten about or deprioritised by public services. Several interviewees mentioned the lower prioritisation of unpaid carers for vaccination as indicative of the extent to which they are undervalued within the social care system of Wales.

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*...Because you've got to keep that person safe you are essentially a vulnerable person and I think that's something that hasn't been recognised in the vaccine programme, is, you know if you're caring for someone vulnerable you are vulnerable, really, because, you know, giving something to someone you love that kills them is a pretty vulnerable position to be in.*

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- Natalie, age group 26-49, carer for her mother

When coupled with the above themes of isolation, loneliness, stress, and financial worries, this lack of official recognition for their importance symbolised by the vaccination schedule has solidified a sense of being 'invisible' and 'undervalued' for many carers.

### **4.4.4 Prominence of third sector as a source of support: A lifeline in difficult times**

Third sector support services were perceived much more positively than statutory services as being actively helpful and providing the bulk of support for those who were accessing them. Ffion and Amy, who both had disabled children, were particularly glowing in their reports of support from third sector organisations associated with particular medical conditions, who had offered them a wealth of practical and emotional support over the years.

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*We were allocated a support worker from, it was the Christian Lewis Trust at the time. We also had the support worker from the CLIC Sargent. And I've got to say, without those two people, we- I would never have coped. And we also had a lady from LATCH. But once Osian hit I think it was five years out of treatment, LATCH just stopped. ...but we definitely wouldn't have coped with-without those people.*

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- Ffion, age group 50-64, carer for her son

The availability of such organisations, the funding they receive and the services they can provide vary greatly, meaning that parent carers with similar levels of need can have unequal provision of support depending on the diagnosis of the person they are supporting. Matt and Angharad, who also have disabled children, mentioned the importance of specialist residential centres, such as schools and hospices that provide appropriate support (though the coverage of these is patchy and there is nothing for Angharad's child after he turns 25).

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*Oh, it's, it's great. It's amazing. I think that - I think that you could take everything else out of our lives, except for the hospice, they are the hands that catch you when you fall, in a way.*

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- Angharad, age group 50-64, carer for her son

However, Matt acknowledged that finding the right fit in identifying the most appropriate service is not always easy and can be a source of stress and worry.

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*...She went to a special visual impairment school that was probably her high point of her life, 'til she was 19. Then they had a kind of roadmap that a lot of them went to a specific college, which was fantastic, we visited it, it was great. And yet in the sort of few years between booking that, putting her name down and her going, it underwent a change and within two weeks, we knew it was the worst placement. ...the social worker then and our local authority put in a POVA [protection of vulnerable adults concern] at one point because we were that concerned. That's when she changed... she changed a tiny little bit, it was... because she was a happy person, and this was awful. And so we ended up going every weekend from where we live a few hours' drive to England, just to check on them. And then we made a decision after about, was it half a term, maybe a term, that we... with the social worker, she was going to... we withdrew her.*

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- Matt, age group 50-64, carer for his daughter

Finding a good fit in terms of specialised services inevitably involves some trial and error, and this process places a great deal of responsibility on carers to advocate on behalf of the person cared-for.

Many carers mentioned the importance to them of support groups run in local carers' centres or by local carer support services, which offer a chance to meet and share peer support, expressing that this helped to relieve the social isolation they might otherwise feel.

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*I've not really got friends, if that makes sense. I've got like that group, which is my only like friends, and then I've got family and my family's great. So they are like my friends as well, but it is only those two groups, the family and that autism group.*

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– Amy, age group 26–49, carer for two of her children

The advice carers received through dedicated workers was also frequently mentioned, and many carers felt that this helped to mitigate a deficit in the information and services that ought to be provided by local authorities.

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*I always feel that there are people, I don't want to name names, but at the Carer Centre that I can ring and have a chat to if I'm particularly low or particularly anxious about something I need advice on.*

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– Frank, age group 65–79, carer for his wife

Young adult carers who participated in dedicated groups spoke about the exclusion they often felt amongst their peers, and how important it was to have somewhere to go where they felt understood.

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*I don't think I could have dealt as well as I did at home if it wasn't for the Young Adult Carers group. I mean, it really was a lifesaver because it's just something you know you can rant to them; you know you can play games, it's something to look forward to every week. It's really nice.*

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– Katy, age group 15–25, carer for her stepfather

In some cases, this had led to friendships that were of great importance to younger carers in making their life as carers feel sustainable.

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*...We didn't have to say a word about what had happened over the two weeks, we didn't have to say anything. Most of us would just look at each other and we'd know if something was going on.*

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– Rachel, age group 15–25, carer for her father



Some carers did identify barriers to participating in support groups, however. Valerie would have liked to attend an informal carers support group but her life was so busy managing her business and her parents' care that she had no idea how she could fit it into her days. Heather, also a working carer who felt too busy to attend a carer group, could not see the value of making "polite chit chat" with other people when her free time was so limited (she was more concerned about developing suitable activities to occupy and socialise her children, which were of limited supply locally). James did attend a carer support group but was frustrated in the lack of practical help it offered and felt it was a patronising form of support for people, like him, who were in desperate need of practical intervention. It is possible that age is a factor in how useful carer groups are, since older carers' reactions to carer groups were mixed, whereas all of the young adult carers we spoke to valued them highly.

Some carers were unsure of what support was available for them, and when asked, said that they had not been in touch with Carers Trust or Carers Wales to find out more about potential local resources.

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*Sometimes, it's just that offloading, talking and you're not on your own. That type of support... even prior to the pandemic, I haven't found anything that really sort of fits that side of it. I mean there are groups that are national groups and you can do things over the phones and things like that, which is great but sometimes you just need a face-to-face sit down with people.*

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- Lindsey, age group 26-49, carer for her son

Carers particularly valued services that were local to them, that offered a physical setting that they can visit. While national helplines may be helpful for providing information, carers want support to be available within their community.



### Impact of COVID-19

During the pandemic, third sector services have continued to operate, but have mostly moved online. For most services, carers did not raise this as a particular issue, most being accepting of the current circumstances. In relation to social and support groups, the change in delivery was much more keenly felt. Many young adult carers missed the opportunity to meet in person, though they did emphasise the value of staying connected through platforms such as Zoom and WhatsApp. Dedicated centres for young adult carers were discussed with warmth by participants for how well they had adapted to pandemic conditions and moved support to remote methods.

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*There's a WhatsApp group where we get given information by the project workers, so [the support worker] will message and say 'ah, quiz tonight or game tonight' or whatever.... It's youth club and we get to decide what we want to do... We have a couple of chats with a couple of the like some of the other young carers, the ones that we're closest with, we have chats, we speak to them privately but yeah, I think the YMCA are doing everything they can to sort of support us. They've got Fitbits that will be in scheme with Fitbits so we have three calls with them a week, we get set challenges.*

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– Sam, age group 15–25, carer for his partner

Despite this, there was often regret shared that online groups were not as helpful as in-person meetings and services, though there was understanding that this could not be helped.

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*We used to have young adult carer meet-ups, where we'd literally just leave everything at the front door and just be kids again. And she's right, we don't have that anymore, and a lot of YACs (Young Adult Carers) needed that. And yeah, okay we got the zoom but it's not the same because it's still going on in the background. So, it's, I know for other YACs it's a struggle.*

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– Louise, age group 15–25, carer for her mother

Many reflected that third sector organisations adapted to the lockdown conditions and used technology to attempt to continue to offer support to carers, yet it was also clear that carers valued being able to meet in-person wherever possible. This demonstrates the importance of locally based services that are designed to meet the needs of carers in situ, with a physical space for meeting up. Some carers (though not all) value the opportunity to meet others who are in a similar situation to them.



### ***Opportunities for action***

- Services and information for carers need to be more easily identifiable and accessible.
- Unpaid carers need to feel recognised and respected by professionals at all times in their interactions with them.
- Assessments for health and social care services need to focus more on the needs of the carers, rather than focusing solely on how the needs of the person cared-for are met.
- Local carer centres were highly valued by many of our participants, yet the services provided varied across different areas. There is a need to ensure that all carers have access to support in their local area. This is particularly important for younger carers.





## 5. Summary and recommendations

*This study set out to examine the nature of unpaid carers' experiences before the pandemic, the impact of COVID-19 on their experiences of caring and the effects of these experiences on their well-being. Our findings indicate that unpaid carers were already experiencing a range of challenges and that their difficulties have often been exacerbated by the pandemic.*

### 5.1. What were carers' lives like before the pandemic began?

Becoming a carer can be a complex and gradual process, which means that many carers do not recognise their identity as a carer until they reach a crisis and seek help from health or social care services. Most carers are driven by a sense of love or duty, yet there can also be powerful feelings of being 'trapped', having a lack of choice, and frustration with the person cared-for. Entering into a caring role has profound implications for the relationship between the carer and the person cared-for, which can complicate family dynamics; for example, when the parent/child roles are reversed. It is important that the carer and the person cared-for share times of mutual enjoyment and pleasure, since these can enhance

their relationship and make the caring arrangement more sustainable. Many carers in our study reflected on the importance of their caring relationship and some noted a sense of achievement and self-efficacy derived from their caring role.

Despite their commitment to the person cared-for, and some positive experiences, most carers reported that they suffer from stress because of their caring role, and that their mental health suffers as a result. For many, social isolation and loneliness were long-standing problems before the COVID-19 pandemic began, with a few wryly noting that they had been experiencing lockdown as a normal feature of life as a carer for some considerable time. Importantly, those with weaker social networks tended to report poorer mental health.

The impacts on carers' well-being were made worse in some cases by living and caring conditions that might be understood in other situations as breaches of human rights – for example, the number of hours spent caring each week, or exposure to the risk of physical harm due to lifting or being assaulted (in the case of loved ones with illnesses/disabilities that impact on their behaviour). Furthermore, most carers live with a constant level of fear and uncertainty, for example related to the progression of their loved one's condition and the possibility of their greater suffering in the future.

Many unpaid carers value engaging in paid work outside their caring responsibilities. This can enhance carers' well-being by offering a break from caring, boosting self-esteem, and providing an opportunity to socialise independently. The experiences our interviewees reported with regards to support from employers for managing their caring responsibilities alongside their work were mixed. Many carers shared examples of flexibility and understanding from employers and colleagues, for which they were grateful, yet others indicated that their needs were not understood and that very few allowances were made to accommodate their caring responsibilities. Several acknowledged that being a carer has impacted on their career plans, since they are restricted both in the hours they can work and how far from home they can travel or live. This was particularly a concern for younger carers.

Just as responses of employers to unpaid carers were mixed, carers' experiences of education varied greatly. Many younger carers reported that they were not identified as young carers by their schools, despite recalling events that could have provided an opportunity for schools to discuss the support they might have needed and to refer them onto other agencies for support. Where carers in education did receive some flexibility, for example through university policies, they valued the flexibility and time allowances that were made for them, however such policies did not always bear out in practice for our participants.

Many carers in our study reported that they had suffered financially as a result of their responsibilities and role. Several were experiencing financial crisis or unsustainable economic detriment before the pandemic. A handful of more affluent carers reported that they spend considerable amounts from their own personal resources to meet the needs of the person cared-for, while those with moderate amounts of money had stories of finding that their resources were quickly used up upon becoming a carer. Some carers reported that they were obliged to work fewer hours or even give up work to be able to care and that they had suffered financially as a result. Several expressed resentment at the low value of Carers Allowance and its narrow eligibility criteria.

It was disheartening to hear from many carers that their experiences of being assessed for support from local authority social services were poor. They

generally reported that they feel unrecognised and undervalued by professionals, and struggle to secure any meaningful support. By contrast, many spoke highly of voluntary sector services aimed at supporting carers, especially when carer centres were available in their locality.

## **5.2. How has COVID-19 impacted on the lived experiences of carers and the roles they undertake?**

Unpaid carers have felt overlooked during the pandemic, since politicians and the media have focused on the contributions made by paid health and social care workers. This sense of injustice is unfortunate in the context of the extraordinary level of sacrifice many unpaid carers have made, since they have increased the amount of care they have been providing while decreasing the time spent pursuing their own well-being and interests.

Social distancing measures have meant that many carers have been cut off from their usual avenues of support – for example, relatives have been unable to visit and children have been unable to go to school. This has meant that carers have had less time to themselves and have had more responsibilities for performing caring tasks daily. An aspect of the pandemic control measures that has had a particular impact on carers has been the advice for the most vulnerable to 'shield'. For carers, the need to shield their vulnerable loved one has often meant that their own fundamental freedoms have been curtailed even further than was the case before the pandemic. A particular source of frustration during January and February was that unpaid carers were not prioritised for vaccination as early as paid workers or their vulnerable loved ones.

Many unpaid carers who work welcomed increased opportunities to work from home, since this provides more flexibility for fitting in their caring responsibilities. Some, however, reported missing the workplace as a space away from caring and said that they found it difficult to work at home while also providing care. This was also the case for younger carers in education, many of whom regretted that they were unable to escape distractions when attempting to follow lessons or lectures at home. Those experiencing financial precarity (around a fifth of our sample) indicated that



the pandemic has brought about additional challenges, since household running costs have increased with everybody at home most of the time.

Unpaid carers have found that health and social care services have been harder to access during the pandemic, though some have seen benefits from accessing health care remotely. Third sector organisations have continued to provide vital support and have shown impressive adaptability by switching to remote forms of communication. While this has been appreciated by carers, however, there was a general sense that meeting in person is preferable and, therefore, that having services based in the local area is essential.

### **5.3. What has the impact of COVID-19 been on carers' well-being?**

Some carers reported that the COVID-19 pandemic, and the control measures imposed in response, had prompted them to spend more time relaxing with the person cared-for, which had been beneficial for their relationships and had reminded them of the importance of times of shared enjoyment. For others, however, the loss of time away from the person cared-for, personal space and activities to enhance their own well-being (e.g. the closure of gyms) had led to increased feelings of tension and frustration that may have a long-term impact on the sustainability of their caring role.

The increase in carers' responsibilities and the loss of avenues of support or respite have meant that carers have experienced additional levels of stress and loneliness as a result of the pandemic, leading in turn to further detriment to their mental health. The fear of their vulnerable loved one becoming infected with COVID-19 has been a further source of anxiety for many, as have increased financial pressures. Meanwhile, the decreased visibility and availability of statutory services has left many carers feeling invisible and abandoned.

In the short term, carers have responded to the emergency conditions of the pandemic with fortitude and stoicism, but this has been undertaken at great personal cost. The longer carers are expected to cope without enhanced support, the more likely it is that their living and caring conditions will come to feel unsustainable, resulting in crisis or their withdrawal from caring. As was noted above, unpaid carers were already experiencing considerable challenges to their well-being before the pandemic began. The combination of additional caring tasks and responsibilities, increased stress, loneliness and anxiety should be seen as an early warning marker to policy makers, services and professionals. As a matter of priority, carers must receive improved recognition and support in Wales, beginning with a comprehensive post-pandemic improvement plan to address the detriment to their interests and well-being that they have suffered.

## 5.4. Recommendations

### 5.4.1. Addressing barriers to identifying carers

The identification of carers across society needs improvement within medical, educational, social care, and employment settings. Medical professionals are often best placed to identify carers, including administrative staff where they are public-facing, yet many carers reported that clear opportunities to offer recognition and support were missed at GPs surgeries and hospitals. Carer identification could be substantially improved if medical staff were proactively identifying who is providing care unpaid and offering signposting to services that can support them. A review of support for young carers and young adult carers would be apt to generate improvements in this sector, since our study identified inconsistency in the extent to which educational institutions identify and provide support for younger carers.

Language used in support and guidance materials can sometimes be obstructive to helping unpaid carers find the help they need. Many carers in our study reported that they did not initially personally identify with the term 'carer', resulting in missed opportunities to access services that could help them. Services providing information for carers should therefore avoid relying on the term 'carer' in publicity materials aimed at carers and instead should identify the activities carers do.

#### Action points

- Targeted promotion of carer identification at points of interaction between services and carers, especially GPs and secondary health services. This should be led by professionals to overcome the barriers to carers self-identifying. The Making every contact count (MECC) approach could be used to guide this improvement.
- Organisations with which carers may have contact should review all published service promotional materials to ensure that inclusive language is used, i.e., language that does not require a person to self-identify as a 'carer' to appreciate its relevance to them.
- Local authorities and health boards need to ensure that they actively and proactively identify carers across all their areas of service. A national register of carers might be a useful tool in ensuring that carers are visible to services, so that interventions to promote their health and well-being can be more easily directed to them.

### 5.4.2. Supporting relationships between the carer and the person cared-for

The importance of maintaining positive relationships between the carer and the person cared-for is vital for the sustainability of caring at an individual level. Services for carers therefore need to focus not only on problems, but also on promoting positive interactions and shared pleasure. Spending quality time together is beneficial for both carer and the person cared-for. Opportunities to enjoy activities or relaxation together should be reviewed in carer assessments and included in social care planning. Short-term therapeutic work may also be useful to support the carer and person cared-for in understanding and managing the transition into a caring relationship. It may be necessary to develop a model of intervention by social services that could be offered as part of a care plan following a carer assessment, drawing upon on systems theory, solution-focused therapy, and family therapy.

#### Action points

- The impact of caring on relationships and support to sustain relational well-being should be attended to in carer assessments. Short-term therapeutic work may be useful to support the carer and person cared-for in understanding and managing the transition into a caring relationship.
- Post-pandemic carer assessments should attend particularly to how social distancing has impacted personal relationships as well as social and practical support networks, and identify where an elevated risk to carer well-being has occurred as a result of reduced social support during the pandemic, offering intervention where appropriate.

### 5.4.3. Reducing social isolation and loneliness

Carers in our study consistently reported that carer assessments were unsatisfactory and felt that social workers were not interested in supporting them if it was apparent that they were competent enough to meet their loved-one's care needs. Much more attention needs to be paid in carer assessments to ensuring that carers are not cut off from social support networks and to assisting them to identify sources of help that will make fulfilling their roles sustainable in the long term.

Some mid-life and older carers benefited from support groups with a social element, while others who did not know of one operating locally desired to join one. On the other hand, some working carers whose time was already overstretched were not interested in the idea, as they did not feel they had time to engage with a group. Therefore, while we recommend that carer support groups continue to be prioritised as a method of offering support to carers, this would not necessarily be helpful to all.

For young adult carers, however, experiences of dedicated support groups and centres were universally extremely positive, particularly for the opportunities

to socialise with other young people who understood their circumstances. It is clear that such groups offer substantial value and we recommend that every effort be made to ensure that all identified young adult carers have access to such groups. It is worth noting that young carers projects have dedicated support workers, whereas this may not be the case for older adult groups. It is possible that this role is what makes young adult carer groups so successful, so this could be considered for wider implementation with older adult groups.

#### Action points

- Gaps in social support groups should be identified by local authorities and health boards and targeted with new or expanded third sector or statutory services.
- Young adult carer groups with dedicated support workers should be made available locally and promoted to all carers under the age of 25 in Wales.

### 5.4.4. Addressing carers' stress and anxiety

Participants who discussed carer assessments with us were disappointed at how little the professional focused on their own well-being and support needs, feeling that assessments they had experienced exclusively focused on the needs of the person cared-for. This led to feeling devalued, invisible, exploited, and disillusioned. Carer assessment processes within local authorities should be reviewed to ensure that they adequately cover the well-being and support needs of unpaid carers themselves, and that this assessment is meaningful in that it produces genuine provision to support those needs.

While it is important to have policies that prevent stress and anxiety from becoming problematic for carers, in the context of increased mental health issues brought about during the pandemic, it is also essential to address problems that are currently

occurring. Many carers are suffering moderate to severe negative impacts on their mental health due in part or in full to their caring role and its associated challenges, effects that have been exacerbated by the COVID-19 pandemic. It is important to note that many carers also adopt an identity that accommodates being the 'helper' rather than the 'helped', leading them to dismiss their own mental health concerns. A free or heavily discounted counselling service (according to financial status) should be actively promoted to carers to mitigate harms to their mental health. This would ideally be run by a third sector organisation as they commanded a higher level of trust for participants in this study than local authorities. This would have offered significant benefit during the pandemic were it available.

Single people who care alone in our study were often those suffering the greatest detriment to their finances, their mental health, their stress levels and their leisure time, due to their lack of immediate family support. Their lives often appeared to be completely taken over by their caring role to the extent that the situation was unsustainable. This was particularly the case with single carers taking care of multiple people. Additional support needs to be implemented for single carers to protect their well-being. This could come in several forms: a boost to Carers Allowance based on household income; additional external support offered to ensure leisure time is available; carer assessments focusing on immediate support networks to identify those most at risk of isolation and loneliness; and better signposting to social support groups.

### Action points

- Carer assessments should be used as an opportunity to consider collaboratively whether the demands that caring places on a carer are reasonable in relation to their human rights, and what statutory or third sector services can do to mitigate potential harm where carers are willing to accept detriment to their rights.
- Third sector services would be well-placed to offer specialised counselling for carers free of charge to address existing harms to carer mental health. This should be given high priority during recovery from the pandemic.

## 5.4.5. Enhancing carers' access to information and support

Many carers are unsure of what services are available, what benefits they might be entitled to, what their rights are, and how best to support their own well-being while caring. When they do become aware of what services are available, they usually find the process of accessing them to be a substantial source of stress and a significant demand on their time.

Information and resources on these areas should be more clearly disseminated at a local level, ideally during the carer assessment process to ensure full coverage of all identified carers. Carers would significantly benefit from a specialised advisory and support team in each region to reduce the time they spend chasing services and help them understand what they are and are not entitled to. This team would support carers in navigating the various agencies, organisations and services who can offer them support, reducing confusion and anxiety. Ideally this team would be able to take on some of the tasks of chasing and coordinating services for caring to reduce the time carers have to spend doing this. As services were under further pressure during the pandemic, such a team would have helped to continue delivering the standard of service that carers need to help them care effectively.

Carer preparedness would be greatly improved by locally delivered carer training sessions for new

carers to attend to know what to expect, allowing them to gain knowledge, ask questions, and feel visible to, and cared-for by, statutory services. This could be connected to the regional statutory carers team outlined above. Carers need to feel that they have people to turn to, since coping alone with their responsibilities can increase their sense of isolation.

### Action points

- Local authorities need to review how local carers obtain information and guidance regarding the services they require for the person they care for, with the aim of simplifying processes and enhancing clarity of information.
- Regional Unpaid Carers Teams should be established in each area of Wales – these should take a multi-agency approach with representatives from social care, health, and education.
- A mapping of local support groups and other third sector services across Wales is needed to identify where gaps exist. This information should be gathered in an online hub alongside contacts and locations. This would ideally be provided through a national third sector organisation. Funding should be identified to ensure that all unpaid carers have equitable access regardless of location.

## 5.4.6. Policies to support carers in employment and education

Unpaid carers in employment were significantly affected by their working conditions and the support their employer offered for carers. Where employers were understanding and offered clear benefits like carer leave and flexible hours, this offered substantial benefit to carers in terms of reduced stress levels and a sense of recognition and social value. However, these benefits are not universally offered and working carers whose employers did not make an active offer of support felt resentful and undervalued for their contribution, with some expressing that they were unsure they would be able to continue caring after the pandemic. Enshrining reasonable flexibility and carer leave days in employment legislation would offer clear benefits to working carers and make the continuing blend of working and caring more sustainable. Incentivising good practice by employers, through recognition schemes, would also be of value. In the context of Brexit, in which employee rights may be reduced, it will be important to advocate for protection and enhanced support for unpaid carers.

Support in education was greatly valued when delivered well, however inconsistency here means that many younger carers do not feel supported to achieve. When support is delivered, it is often patchy, with individual staff implementing institutional guidance in different ways, or not at all. All educational institutions should have a written strategy regarding identifying and supporting unpaid carers that carers in education can refer to in order to understand what support they should expect. Schools, colleges, and universities should have a named member of staff responsible for identifying and supporting young people with caring responsibilities; this person should be promoted as a point of contact should the institution's policies not be adhered to by any staff member.

### Action points

- A review of employer guidance and legislation around support for unpaid carers should be carried out to ensure that they are best supported into work. This should focus on the issues of 'carer leave' (paid and/or unpaid) and employer acceptance of requests for flexible working hours wherever possible (with justifications when refused). This work could draw upon the spirit and structures underpinning the Welsh Government's Fair Work and Social Partnership agendas.
- The recommendation in the Welsh Government's Strategy for Unpaid Carers that all schools should have a lead member of staff for young carers should be made mandatory.
- Universities should lead efforts to identify students who are unpaid carers and offer both social and academic support. This should be publicised on university websites to allow unpaid carers to make informed choices regarding their higher education, and be made accountable through named staff members adopting a 'carer support' role.



### 5.4.7. Addressing financial disadvantage and inequality

Financial problems linked to caring and limitations on paid employment were prominent within this study. There was a clear need emerging from our data that Carers Allowance should be a more personalised benefit accounting for individual circumstances. A governmental review of Carers Allowance is much needed to ensure that carers do not fall into financial crisis as a result of their caring responsibilities. Two central factors to consider in this review, based on our data, include:

- a) The number of hours per week that a carer needs to be immediately available for caring tasks ('on standby') and thus unavailable for work outside the home.
- b) The carer's annual household income

This would provide significant help to prevent carers from facing financial difficulties due to their caring role.

#### Action point

- An investigation into the sustainability of Carers Allowance to support low-income carers should be initiated, to include identification of appropriate means-testing for further support. While this is a UK-wide issue, there is potential in Wales to offer additional economic and in-kind supports to financially vulnerable carers in receipt of Carers Allowance which should be considered (for example, free gym memberships; vouchers for various products or services; discounted leisure activities).

### 5.4.8. Responding to future emergencies

Most carers in our study felt that their needs and well-being had been overlooked during the COVID-19 pandemic, placing substantial strain on their mental health and capacity to give high quality care. It is possible that other pandemics may occur in the future, or other emergencies requiring measures that will impact on carers. To ensure that unpaid carers are not overlooked in future public health crises, carer groups should be consulted with in crisis planning at the highest level. Some measures that might have been helpful during the COVID-19 pandemic would include additional support for families of disabled children (e.g. easier access to childcare 'hubs'); earlier priority for vaccination and outreach from statutory services to assess whether additional support was needed. Should these recommendations be implemented in the event of similar future crises, the resilience of the carer population to the associated challenges will be improved.

Our research has indicated that many unpaid carers were under enormous strain before the pandemic began. Addressing longer-standing issues, such as identification processes, pathways to support services, access to mental health support, and financial precarity, will also ensure that carers are better placed to withstand future emergencies.

#### Action points

- In the event of future crises like the COVID-19 pandemic, a governmental consultation group of diverse carers should be immediately established to consult on policy and practice in relation to their support. Additionally, an outreach programme should be planned and implemented where need arises to ensure that carers do not feel a sense of abandonment during any future lockdown conditions.
- Regarding future vaccination schedules, unpaid carers should be equal in priority to the person cared-for.
- Schools providing care for disabled children should be consulted regarding their provision during COVID-19 and their views obtained as to whether it would be reasonable to expand their available places to sustain disabled children's education in the event of future pandemic conditions.

## 5.5. Conclusion

Unpaid carers are central to care planning under the Social Services and Well-being (Wales) Act 2014 and in the Welsh Government's long-term plan for health and social care as set out in the Healthier Wales strategy. Despite their importance in meeting the care and support needs of so many individuals, and the enormous economic value of the tasks they carry out, they continue to suffer detriment to their own well-being because of their caring responsibilities. The COVID-19 pandemic has highlighted the extent to which the health and social care systems rely on unpaid carers, who are too often poorly recognised or supported by statutory services. During the pandemic, many unpaid carers' stress, anxiety and isolation have been exacerbated and rapid remedial action is now needed for those reaching crisis point.

As the ageing population of Wales continues to increase, the role of unpaid carers becomes even more significant. Further consideration needs to be given to mitigating the social and economic inequalities that too often arise from caring for another person. It is essential, therefore, that health and social care services develop their understanding of carers' experiences and

needs, and adapt to ensure that caring for loved ones is sustainable for individuals and families. Unpaid carers need to be recognised and supported, with specialised, flexible services available to them locally. The findings of this study suggest that, to date, the provisions of the Social Services and Well-being (Wales) Act 2014 and the Welsh Government's Strategy for Unpaid Carers have not produced the required changes in approaches to working with and supporting unpaid carers by health and social care services. A cultural shift is needed within statutory social services services and health services, especially in relation to NHS Continuing Healthcare funding, where the availability of an unpaid carer is too frequently treated as a justification for withholding services for the person cared-for. Where unpaid carers are relied upon to meet the care needs of another person, services must prioritise the carer's well-being and human rights.

Caring is a normal part of human experience and the ability to provide care to loved ones safely and without personal detriment should be considered a citizenship right, recognised by all institutions and employers throughout Wales.



# Appendices

## A. Sample

Category	Number	Percentage
<b>Age group</b>		
15–25	13	28%
26–49	12	26%
50–64	17	36%
65–80+	5	9%
<b>Gender</b>		
Female	34	72%
Male	13	28%
<b>Carer characteristics<sup>‡</sup></b>		
Welsh speaker	*	*%
BAME	*	*%
Disabled/ill carer	6	13%
LGBTQIA+	6	13%
Working carer	21	45%
Low income	12	26%
Rural dwelling	12	26%
Caring for multiple people	15	32%
In education	8	17%
<b>Cared-for by interviewee<sup>§</sup></b>		
Parent	25	53%
Sibling	6	11%
Child	11	23%
Relative	8	17%
Partner/spouse	8	17%
Carer and cared-for person live together	33	70%
<b>Care need<sup>**</sup></b>		
Physical disability	24	51%
Physical illness	10	21%
Learning disability	9	19%
Mental illness	12	26%
Dementia	12	26%
Old age	8	17%
Disabled child	5	11%
Palliative	*	*%
Addiction	*	*%

\* Denotes a value <5

<sup>‡</sup> Interviewees often fell into more than one category

<sup>§</sup> Interviewees sometimes cared for more than one person

<sup>\*\*</sup> Often the person cared-for had more than one care need

## B. Research Team

### **Principal investigator: Dr Dan Burrows**

Former social worker with experience in working with children with long-term illnesses and disabilities.

### **Co-investigator: Dr Jen Lyttleton-Smith**

Sociologist specialising in research into children's social care and Welsh social policy, with previous experience of research with young carers.

### **Research assistant: Ms Lucy Sheehan**

Registered social worker, currently working on a PhD investigating child protection social work.

### **Research assistant: Dr Siôn Jones**

Sociologist and bilingual Welsh language researcher.

### **Consultant: Ms Faaiza Bashir**

Policy officer at Carers Trust Wales.



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