NOTTINGHAMSHIRE JOINT STRATEGIC NEEDS ASSESSMENT

Carers

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Executive summary

Introduction

A person is a carer if they provide unpaid support to a family member, neighbour or friend. The person could need support because they are ill, frail, disabled, experiencing mental health issues or using drugs or alcohol.

The Care Act 2014 defines a carer as "an adult who provides or intends to provide care for another adult" and "A carer is someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally, or through a voluntary organisation".

The Children and Families Act 2014 defines a young carer as "a person under 18 who provides or intends to provide care for another person".

The Children's and Families Act 2014 also defines a parent carer as "a person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility".

A carer doesn't necessarily have to live with the person they care for to be a carer - some carers don't live in the same town or city as the person they care for, but their lives are still affected by their caring role. Anyone can become a carer, and often caring responsibilities for a family member, loved one, friend or neighbour can arise unexpectedly.

Unpaid carers are crucial for providing care and support to those vulnerable and in need in our society. However, their caring role may impact significantly on their psychological and physical wellbeing and these in turn will determine the sustainability of their caring role.

This Chapter provides an insight into the prevalence of carers living in Nottinghamshire. Using a variety of data sources, it explores areas of carer need including physical and psychological health, employment and financial support. This chapter also gives an overview of current service provision and assets.

Prevalence

Nationally the 2021 Census data relating to unpaid carers shows a decrease in the overall total number of unpaid carers; down from 6.3 million to 5 million, a reduction of 1.3 million. This means that around 9% of the population are providing unpaid care. This may however be due to many people not recognising themselves as carers with Carers UK reporting that half of all carers (51%) took a year or more to recognise their caring role and a third taking over 3 years¹. Carers UK instead estimate that 10.6 million, or one in five people, are an unpaid carer in the UK. Despite the overall reported fall in the total number of carers, those carers providing 50 hours or more unpaid care has increased by 7%. Nationally 120,000 young carers between five and seventeen are reported in the England census data. The number of young adults aged 18 to 24 providing between 20 to 49 hours of unpaid care per week has risen from 43,950 in the 2011 census, to 71,120 in 2021. Over the period 2010-2020, every year, 4.3 million people became unpaid carers².

¹ Carers UK State of Caring Report 2022

² Carers UK

Locally, the 2021 Census data regarding carers, despite the impact of COVID-19 and estimates by Carers UK, shows that there has been an overall decrease in the number of carers in the previous decade by 8,526 across Nottinghamshire County. The latest census estimated that 41,649 carers providing between 1-19 hours of care per week – down by 15,777 since the 2011 Census. However, those carers providing over 50 hours of care per week has increased by 2,819 from 21,680 to 24,499.

Unmet need and gaps

From feedback received from carers it is clear that there are additional requirements to support both working carers and parent-carers. Parent-carers in particular report being unsure regarding where their parenting role ends and their caring role begins and therefore find it difficult to access support in their own right. The new Carers Hub service are able to provide support to parent-carers but further work is required to ensure that all areas are aware of this service offer so that carers are able to access the support provided.

The State of Caring Report (2019) states that "providing support for carers, especially those looking to stay in, or return to, paid work is essential if women are to be able to participate fully in the economy and live a life free from poverty in older age". The report also states that "increasing numbers of employers are recognising the importance of supporting carers in their workforce to continue working, so they can retain talented staff rather than incurring the costs of recruiting and retraining new employees". It is important therefore that we work with provider services, including statutory services, to ensure that provision of support is available and accessible to carers who work.

Additionally, whilst the data shows that the vast majority of carers in Nottinghamshire are white there is a danger that this may lead to carers from ethnic minority backgrounds not receiving the support they need or being engaged in coproduction activities to ensure that services meet their needs. The new Carers Hub service has been specifically tasked with broadening support to all communities as part of the new contract.

Recommendations for consideration

	Recommendation	Lead(s)
1	Review and streamline the provision of short breaks	Nottinghamshire County
	for carers to ensure a range of options are available	Council Integrated Strategic
	for those who require them. Educate staff to enable	Commissioning
	effective commissioning of available short breaks.	
2	Ensure carers needs and the caring situation is considered throughout all aspects of social care provision through whole family assessments to move away from silo working and ensure that the needs of the whole family (including the carer) are met in the most appropriate way. As part of this keeping carers informed about outcomes and next steps through feedback.	Principal Social Worker



2	Monte proportional and the second state of the	Nottinghamakina Carreta
3	Work proactively with the assistive technology work	Nottinghamshire County
	programme to ensure carer needs are encapsulated	Council Integrated Strategic
	in equipment specifications (e.g. the need for	Commissioning
	alternative monitoring for people with dementia to	
	provide a break for the carer or the use of electronic	
	reminder services for medications and appointments	
	to free up carer time/reduce visits)	
4	Develop a single point of access for carers so that	Carers Hub Service
	they are aware of where to go for information and	
	advice without being overwhelmed with information	
5	Support carers to plan for the future including a	Carers Hub Service
	change in their needs as well as those for the	
	person they are caring for. This will involve early	
	conversations with carers to plan for future changes	
6	and contingency planning for emergency situations	Company Husb Compiler Marrows
6	Ensure easily accessible information and advice	Carers Hub Service through
	(including support and finance) is available when it	coproduction activity
	is required including out of standard office hours.	
	This will need to be supported by face-to-face	
	support and connecting to services rather than	
	signposting.	
7	Support young carers as they transition from	Carers Hub Service and
	children to adult services to ensure that they	Young Carers Support
	continue to receive support whilst maximising their	Service
	potential to take up educational, employment and	
	social opportunities.	
8	Develop support for parent-carers specific to their	Carers Hub Service in
	caring role.	coproduction with parent-
	g	carers
9	Review the current young carers assessment tool to	Integrated Strategic
	bring in line with strength-based approaches and	Commissioning, Children
	ensure that support provided achieves the	and Families Service and
	appropriate outcomes for the young carers	
	appropriate outcomes for the young carers	Operational teams in
		coproduction with young
40		people and families
10	Ensure carers are identified and offered support at	All system partners and
	the earliest opportunity including through schools	commissioned services
	and primary care to prevent a crisis from occurring	
11	Ensure that carers needs in relation to Severe	All partners
	Multiple Disadvantage are recognised as part of the	
	assessment and whole family process utilising a	
	multidisciplinary approach to support people within	
	this group and prevent self-neglect. Improve data	
	recording to determine impact of this area on carers and inform future service and support planning.	
12	Ensure that carers have equal access to support in	All system partners and
'-	a way that is suitable and appropriate for them and	commissioned services
	,	



their family needs. This will include carers who may not have English as their first language (including BSL), carers from ethnic minority backgrounds, support that is appropriate to religious needs or those who find it difficult to access statutory services during office hours due to work commitments.



Full JSNA report

Notable changes from previous JSNA

Since the previous JSNA a new census has been carried out providing updated information regarding carers, their demographics and who they are caring for. This intelligence provides up-to-date information regarding carers and their needs to support them in their caring role.

The Covid-19 pandemic has also significantly impacted on carers and learning from this will be used to support carers in the future.

What do we know?

1. Who is at risk and why?

A person is a carer if they provide unpaid support to a family member, neighbour or friend. The person could need support because they are ill, frail, disabled, experiencing mental health issues or using drugs or alcohol.

The support provided could be:

- washing and dressing
- shopping and food preparation
- helping with laundry or housework
- keeping someone company
- helping someone take medication
- emotional support or help managing difficult behaviour
- keeping an 'eye' on someone to make sure they are safe.

People are still carers if they:

- don't live with the person they care for
- are not the only person providing care to someone
- are caring for more than one person
- are not related to the person they care for.

A carer may be a spouse, a friend or neighbour. Carers may often have multiple caring roles as well as additional responsibilities. For example a person may be caring for a spouse, providing childcare for grandchildren, helping a neighbour with their shopping as well as maintaining paid employment.

The Care Act 2014 defines a carer as "an adult who provides or intends to provide care for another adult" and "A carer is someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally, or through a voluntary organisation".



The Children and Families Act 2014 defines a young carer as "a person under 18 who provides or intends to provide care for another person".

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A carer doesn't necessarily have to live with the person they care for to be a carer - some carers don't live in the same town or city as the person they care for, but their lives are still affected by their caring role. Anyone can become a carer, and often caring responsibilities for a family member, loved one, friend or neighbour can arise unexpectedly.

Unpaid carers are crucial for providing care and support to those vulnerable and in need in our society. However their caring role may impact significantly on their psychological and physical wellbeing and these in turn will determine the sustainability of their caring role.

Covid-19 led to an increase in carers who provided support for the first time with "almost <u>one third (32%)</u> [of carers] mentioned giving help to someone who they did not help previously"³. These people may not identify themselves as carers and indeed many other carers can often fail to recognise their caring role. It is important that the needs of all caring groups are captured and their needs assessed to ensure they are supported to maintain their caring role alongside their own health and wellbeing.

1.1. National picture

Nationally the 2021 Census data relating to unpaid carers shows a decrease in the overall total number of unpaid carers; down from 6.3 million to 5 million, a reduction of 1.3 million. This means that around 9% of the population are providing unpaid care. This may however be due to many people not recognising themselves as carers with Carers UK reporting that half of all carers (51%) took a year or more to recognise their caring role and a third taking over 3 years⁴. Carers UK instead estimate that 10.6 million, or one in five people, are an unpaid carer in the UK. Despite the overall reported fall in the total number of carers, those carers providing 50 hours or more unpaid care has increased by 7%. Nationally 120,000 young carers between five and seventeen are reported in the England census data. The number of young adults aged 18 to 24 providing between 20 to 49 hours of unpaid care per week has risen from 43,950 in the 2011 census, to 71,120 in 2021. Over the period 2010-2020, every year, 4.3 million people became unpaid carers⁵.

Unpaid carers are crucial for providing care and support to those vulnerable and in need in our society. However their caring role may impact significantly on their own psychological and physical wellbeing and these in turn will determine the sustainability of their caring role.

Census 2021 data shows that nationally there is a 152,000 increase in the number of carers providing 50 or more hours care/week over last decade. This also indicates that the 'health gap' between carers who are providing over 50 hours or more per week of unpaid care compared to non-carers is equivalent to losing 18 days of full health each year. The data

³ Office for National Statistics

⁴ Carers UK <u>State of Caring Report 2022</u>

⁵ Carers UK



suggests that many carers are doing more, but at the detriment to their own health and wellbeing. The data also shows that the highest percentage of people providing unpaid care are in the most deprived areas in England, compared with the least deprived areas.

The 2021 Census reported 120,000 young carers (aged five to 17) in England however Carers Trust and others think there is significant under-reporting with some studies suggesting the figure is as high as 700,000 UK-wide. On average, young carers are caring for three years before being identified and have poorer physical and mental health compared to their peers.

The Carers Trust Survey⁶ found that more than half of young carers and young adult carers (51%) reported that they care for 20-49 hours each week. 56% of young carers and young adult carers said the time they spend caring has increased in the last years, and 47% now care for more people than they used to. 44% 'always' or 'usually' feel stressed because of being a young carers or young adult carer, and 27% either 'never' or 'not often' feel they get enough sleep. One in three young carers and young adult carers (37%) said the NHS did not understand their needs as an unpaid carer either 'very well' or 'at all'. Support for their mental health was one of the top priorities identified by young carers and young adult carers.

Nationally, women make up 59% of carers and more women are providing high intensity care when they would otherwise expect to be in paid work. 41% of people who became new carers between 2010 and 2020 were people aged 46-65⁷. The State of Caring report (2022) shows that many carers feel forced to give up work to carry out their caring role and many can find it difficult to return to the workforce after having a substantial break to support the person they are caring for. The State of Caring report 2022 shows that 75% of carers worry about managing to juggle work and care going forward⁸.

Carers UK estimate that the value of unpaid care provided in £193 billion a year, exceeding the budget of the NHS⁹. Surrey County Council carried out some modelling of what it would mean if they failed to support their carers effectively. They found that if just 10% of the 13,000 carers they supported each year required alternative support for the people they care for it would cost them an additional £14.7 million each year¹⁰.

"The impact of caring is not just dictated by the number of hours of care provided. If a carer is working full-time, combining caring with looking after young children, or having to travel long distances to provide care, then even having to provide a few hours of care a week can have a serious impact on their life" Carers UK Carers Survey 2022 found that 74% of carers care for one person, 19% care for 2 people, 4% care for 3 people and 2% care for 4 people or more 12.

According to 2021 census data around 2.5 million people are carrying out their caring role alongside paid employment however many of these (around 600 people every day) will give up work as caring demands and pressures mean that maintaining employment is unfeasible. Carers Allowance will then become their main source of income and is currently set at

⁶ Carers Trust Survey 2023

⁷ Carers UK

⁸ Carers UK State of Caring Report 2022

⁹ Carers UK

¹⁰ Economic Case for Local Investment in Carer Support

¹¹ Carers UK <u>Policy briefing August 2019</u>, page 3

¹² Carers UK State of Caring Report 2022



£81.90 per week (for those providing a minimum of 35 hours of care per week). This reduction in income can have a significant impact on the health and wellbeing of individuals as discussed at 1.11.

Many carers may also have caring responsibilities for more than one individual compounding some of the pressures they feel. Further the Carers Survey 2022 reports that 31% of carers have been caring for 15 years or more, 14% for 10-14 years and 23% for 5-9 years¹³.

One of the key things that carers say will assist them to maintain their caring role is the availability of a break. The Carers at Breaking Point report (2019) found that "69% of carers said that a carers break had had a positive impact with their health and wellbeing improving as a result"¹⁴. The State of Caring report shows that just over 40% of carers said that they had not taken a break from their caring role in the last year¹⁵. When asked what they would like to do with their break carers said:

- Taking part in hobbies and leisure (63%)
- Spending time with other family and friends (52%)
- Catching up on sleep (50%)
- Pampering themselves (38%)
- Completing practical tasks (37%)
- Attending their own medical appointments (33%)
- Studying or attending training (22%)¹⁶

Many carers report facing difficulties in getting NHS treatment with 34% of respondents to the State of Caring report waiting for specialist treatment of assessment for over a year. 67% of those waiting for treatment said that this was having a negative impact on their physical or mental health.

In the State of Caring report the highest level of carers' needs were reported among carers with mental health needs of their own, among carers from Asian/British Asian Communities, carers under the age of 64 and among those caring for 15-20 years. The vast majority of carers in the country are not in touch with social services.

1.2 Who are carers supporting?

The Office of National Statistics article <u>Living longer: caring in later working life</u> suggests that "the type of person being cared for largely determines both the level of caring intensity, and whether they live with the caregiver" Caring for parents and caring for grandchildren are both likely to involve few hours of caring and carers are less likely to live with the person they are caring for. However "a child requiring care from parents" who are aged 50+ "is likely to be an adult child with a disability, which both prevents them from living independently (73% of children receiving informal care live with their caregiver) and requires intensive levels of care (63% care for 35 or more hours per week)" For those caring for a spouse "the intensity of care associated with [this] is more evenly distributed than for other types of care"

¹³ Carers UK State of Caring Report 2022

¹⁴ Carers UK (2019) Carers at Breaking Point, page 6

¹⁵ Carers UK State of Caring Report 2022

¹⁶ Carers UK (2019) Carers at Breaking Point, page 8

¹⁷ Office of National Statistics (2019) Living longer: caring in later working life, page 8

¹⁸ Office of National Statistics (2019) Living longer: caring in later working life, page 9

¹⁹ Office of National Statistics (2019) Living longer: caring in later working life, page 9



There is still a stigmatisation of drug and alcohol use and mental illness that may mean that carers are not coming forward to access support²⁰.

People caring for those with dementia can often experience their own set of challenges. "As the illness progresses the caregiving burden grows, and the relationship with the care recipient becomes increasingly strained, often resulting in communication problems and conflicts. Social isolation follows. Eventually, many dementia carers need professional help from care services and rely on them to an increasing extent"²¹.

1.3 Carers and gender

As mentioned above 59% of carers are female and 41% are male. "The percentage of carers who are female rises to 60% for those who are caring for 50 hours or more a week"²². Caring responsibilities tend to affect men and women at different times with women being more likely to care in middle age and therefore having to balance work with caring responsibilities – almost one in four of female workers and one in six of male workers²³.

Research by the office of national statistics suggests that when a care need arises it is typically the wife (rather than the husband) who will provide it however when it is the wife who requires care there is often nobody other than the husband who can do this. Male carers are therefore more likely than women to care for a spouse²⁴. According to Care UK "women have a 50:50 chance of providing care by the time they are 59 compared with men who have the same chance by the time they are 75 years old"²⁵. Women are also more likely to juggle multiple caring roles. Almost one third (29%) of female carers provide care for multiple types of people²⁶ and women are much more likely to be sandwich carers (those who care for both sick, disabled or older relatives and dependent children). As a result women are much more likely to give up work in order to care²⁷.

Male carers often seek help differently to female carers tending to focus on "functional tasks and refraining from showing emotions, this despite reporting similar carer burden"²⁸. Study findings also suggest that "opportunities for social interactions gradually 'dwindled' due to a reluctance by older male care-givers to leave their spouse/partner at home alone, to accept offer of help or respite, or to attend social events without their spouse/partner"²⁹.

1.4 Carers and age

²⁰ " Chan, C.K., A. Barnard, and Y.N. Ng, *Who Are Our Support Networks?*" A Qualitative Study of Informal Support for Carers, Journal of Social Service Research, 2021. **47**(2): p. 265-275.

²¹ Oxford Brookes University (2019) <u>Nottinghamshire County Council: Reducing Older People's Need for Care – Exploring risk factors for loss of independence</u>, page 18

²² Carers UK (2015) The importance of Carer's Allowance: Recognising and supporting family care cited in Carers UK Policy briefing August 2019, page 5

²³ Carers UK Policy briefing August 2019, page 5

²⁴ Office of National Statistics (2019) Living longer: caring in later working life

²⁵ Carers UK <u>Policy briefing August 2019</u>, page 5

²⁶ Office of National Statistics (2019) Living longer: caring in later working life

²⁷ Carers UK Policy briefing August 2019, page 4

²⁸ Poisson, Vincent O et al. *A mixed method study exploring gender differences in dementia caregiving*. Dementia (London, England), 14713012231201595. 23 Sep. 2023,

²⁹ Fee, A., S. McIlfatrick, and A. Ryan 'The care circle consists of me.' Loneliness and social isolation for older male spousal care-givers. A qualitative study, Ageing & Society, 2023. **43**(3): p. 706-723.



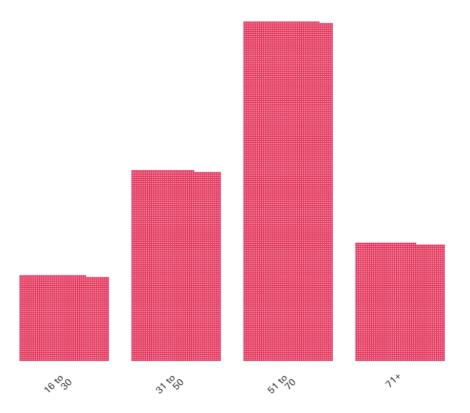


Chart 1: Provision of unpaid care by age group, UK Source: The Health Foundation 2023

The number of carers aged over 65 is increasing more rapidly than the general carers population which is inline with overall population changes and this happens there will be an increased need for informal care and also an increased need for older people to stay in work longer³⁰. The increasing state retirement age is also leading to more people needed to juggle work.

As the UK population gets older, an increasing number of workers are providing care towards the end of their working life for family members. One in four older female workers, and one in eight older male workers, have caring responsibilities³¹. As people are living longer they are increasingly likely to have a living parent and/or a grandchild and provide informal care for both. Nearly three in five carers in England and Wales are aged 50 year and over and one in five people aged 50 to 69 years are informal carers. There is an increasing prevalence of 'sandwich carers' (2.4 million in the UK) – those looking after young children at the same time as caring for older parents. It can also be used much more broadly to describe a variety of multiple caring responsibilities for people in different generations.

Overall, parents are the most common recipient of care by those of older working ages. People caring for parents are more likely to be in work than people caring for any other type of person³².

³⁰ Office of National Statistics (2019) <u>Living longer: caring in later working life</u>

³¹ Office of National Statistics (2019) <u>Living longer: caring in later working life</u>

³² Office of National Statistics (2019) Living longer: caring in later working life



1.4.1 Young carers

The 2021 Census reported 120,000 young carers (aged five to 17) in England however Carers Trust and others think there is significant under-reporting with some <u>studies</u> suggesting the figure is as high as 700,000 UK-wide. On average, young carers are caring for three years before being identified. <u>Multiple research studies</u> have found that young carers have poorer physical mental health, compared to their peers- but more research is needed. <u>The COVID Social Mobility and Opportunities Study</u> found young carers are more likely to report psychological distress, self-harm and make attempts on their life and the <u>According to the Me-We Young Carers project</u> found that about three in ten adolescent young carers in the UK think about self-harming, and more than ten per cent contemplate harming others.

The Children's Society report that as many as 800,000 young carers, aged 5-17, care for an adult in England. However some studies suggest that this number could be closer to 3 million children who "live in households with a disabled family member but not all of these will have caring responsibilities"³³. According to Carers UK "the vast majority are providing under 20 hours of care a week, however thousands provide even higher levels"³⁴. This difference means that there is variance in how caring responsibilities impact upon the young person. "There is a big difference between a child helping parents to bathe a disabled brother or sister and being the sole support for a lone parent with a severe mental health condition"³⁵.

1.5 Carers and ethnicity

The Carers Trust report showed that only 19% of unpaid carers from Black, Asian and minority ethic communities said they felt listed to by the UK government compared to 39% of white unpaid carers³⁶. The report also shows that people from ethnic minority backgrounds received less support having had to find information for themselves and being unaware of any support they were able to receive. A lower percentage of ethnic minority carers said they received any statutory services than white carers³⁷.

1.6 Carers and health

According to the Care UK report those providing high levels of care are twice as likely to be permanently sick or disabled with carers reporting that caring results in a "negative and often long-lasting impact on their physical and mental health"³⁸. In 2019 the GP Patient Survey found that carers are more likely to report having a long-term condition or disability themselves compared to the general population (63% vs 51%)³⁹ and the NHS Information Centre Survey of Carers in Households reported that 27% of carers were in receipt of benefits due to their own health⁴⁰. Carer ill health is also a factor in whether or not carers

³³ Becker, Dearden and Aldridge (2001) 'Children's labour of love? Young carers and care work' in 'Hidden Hands: International perspectives on children's work and labour' cited in Carers UK <u>Policy briefing August 2019</u>

³⁴ Carers UK Policy briefing August 2019, page 4

³⁵ Carers UK Policy briefing August 2019, page 4

³⁶ Carers Trust, September 2023 <u>Adult Carer Survey Report 2023: "Unpaid carers are not unsung heroes. We are forgotten, neglected and burnt out"</u>

³⁷ Carers Trust, September 2023 <u>Adult Carer Survey Report 2023: "Unpaid carers are not unsung heroes. We are forgotten, neglected and burnt out"</u>

³⁸ Carers UK Policy briefing August 2019, page 6

³⁹ NHS England (2019) <u>GP Patient Survey 2019</u>

⁴⁰ NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009-2010



are likely to be in paid employment (18% of disabled carers compared to 33% of non-disabled carers) or whether the carer was likely to give up work (61% of disabled carers compared to 52%). Further carers who themselves have long-term conditions are more likely to be in debt and report their financial situation as affecting their health⁴¹. Although the causes of long-term conditions in carers are varied Carers UK report that:

- 72% of carers responding to the survey said they had suffered mental ill health as a result of caring.
- 61% said they had suffered physical ill health as a result of caring
- 8 in 10 people caring for a loved one said they have felt lonely or socially isolated.⁴²

Increasing hours of care often results in the general health of carers deteriorating incrementally. Unpaid carers who provide high levels of care for sick, or disabled relatives and friends, are more than twice as likely to suffer from poor health compared to people without caring responsibilities, with nearly 21 percent of carers providing over 50 hours of care, in poor health compared to nearly 11 percent of the non-carer population⁴³.

Caring responsibilities can have an adverse impact on the physical and mental health, education and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes. These in turn can affect a carer's effectiveness and lead to the admission of the cared for person to hospital or residential care⁴⁴. The State of Caring Report (2019) states that "when asked how they expect their quality of life to change over the next year, 11% of carers said they expected it to get better, 45% expected it to get worse and 44% expected it to stay the same"⁴⁵.

Carers attribute their health risk to a lack of support, with 64 percent citing a lack of practical support⁴⁶.

The Carers Survey 2018-2019 reported that "60.6% of carers reported that caring had caused them feelings of stress, compared with 58.7% in 2016-17. This was a significant increase" The percentage of carers who reported feeling depressed increased from 43.4% to 45.1% and those reporting feeling tired rose from 77.6% from 76%. 66% said they experienced disturbed sleep, an increase from 64%.

Oxford Brookes University report that "as the intensity of a caring role increases, so the mental and physical health of the person doing that caring often decreases" They state that "informal carers are 2.5 times more likely to experience psychological distress than non-carers; working carers are two to three times more likely to suffer poor health than those without caregiving responsibilities" 24.5% of carers compared to 19.6% of non-carers report a score of 4 or above on the General Health Questionnaire which looks at screen

⁴¹ Carers UK (2016) State of Caring

⁴² Carers UK

⁴³ Carers UK (2004) <u>In Poor Health: the impact of caring on health</u>

⁴⁴ Department of Health (2012) Assessment, eligibility and portability for care users and carers

⁴⁵ Carers UK (2019) State of Caring Report, page 5

⁴⁶ Carers UK (2012) In Sickness and In Health

⁴⁷ NHS Digital (2019) Survey of Adult Carers in England, 2018-19 guidance for local authorities

⁴⁸ Oxford Brookes University (2019) <u>Nottinghamshire County Council: Reducing Older People's Need for Care – Exploring risk factors for loss of independence</u>, page 17

⁴⁹ Oxford Brookes University (2019) <u>Nottinghamshire County Council: Reducing Older People's Need for Care – Exploring risk factors for loss of independence</u>, page 17



individuals for minor psychiatric disorders in the general population. This score indicates that carers are more likely to experience mild or moderate anxiety or depression than those who are not carrying out a caring role⁵⁰. Interestingly, the scores do not directly correlate to the amount of caring hours provided:

Hours spent caring	GHQ Score ¹		
	0 to 3	4 to 12	
0 to 4	82.5%	17.6%	
5 to 9	77.6%	22.4%	
10 to 19	77.8%	22.2%	
20 to 34	67.2%	32.8%	
35 to 49	68.7%	31.3%	
50 to 99	70.2%	29.9%	
100+	66.8%	33.2%	
Average	77%	23%	

Table 3: General Health Questionnaire scores by hours of care provided Source: Office of National Statistics (2020) Characteristics of unpaid carers

Carers also report that the impact on their health continues after their caring role has ended with a third (35%) of former carers stating that their mental health had got worse since their caring role ended, 20% said they were struggling to make ends meet and 35% saying that their financial situation had got worse since caring ended. Former carers also said that more support would have been beneficial when their caring role ended, including support with bereavement and support with resuming paid employment⁵¹.

1.7 Access to healthcare

According to the Carers UK policy briefing (2019) the impact of caring on health is "often exacerbated by carers being unable to find time for medical check-ups or treatment, with two in five carers saying that they were forced to put off treatment because of their caring responsibilities"⁵².

Macmillan report that 70 percent of carers come into contact with health professionals, yet health professionals only identify one in ten carers with GPs, more specifically, only identifying 7 percent⁵³. Further 66 percent of carers feel that healthcare staff don't help to signpost them to relevant information or support, and when information is given, it comes from charities and support groups.⁵⁴

Carers Trust report that 36% of people disagreed or strongly disagreed that the NHS understands their caring responsibilities⁵⁵.

⁵⁰ Office of National Statistics (2020) Characteristics of unpaid carers

⁵¹ Carers UK, August 2023 <u>The experiences of former carers</u>

⁵² Carers UK (2012) In Sickness and In Health cited in Carers UK Policy briefing August 2019, page 11

⁵³ Macmillan (2013) Briefing on Carers Issues

⁵⁴ NHS England Commitment for Carers: Report of the findings and outcomes

⁵⁵ Carers Trust, September 2023 <u>Adult Carer Survey Report 2023: "Unpaid carers are not unsung heroes. We</u> are forgotten, neglected and burnt out"



1.8 Utilisation of technology and adaptations to support the caring role

The State of Caring Report (2019) found that:

- 19% of carers who said that they used technology used remote monitoring and alerts such as motion sensors, falls detectors, personal alarms or GPS trackers
- 12% use medication management tools
- 8% use environmental monitoring such as heating and lighting, door video systems or smart appliances
- 13% use monitoring for blood pressure, blood glucose and heart rate monitors
- 4% of carers use apps for things such as pain management, mood management and care coordination.

Research has found that "carers can ... benefit significantly from the provision of home adaptations – reducing their care giving hours by up to 60%" ⁵⁶.

The 2019 State of Caring Report asked carers about the use of technology to support their caring role. 79% of respondents said they used some form of technology with 88% using it as a source of information and 44% using it as some form of communication or online support.

Research shows that "many carers are realising the benefits of everyday technology to help deliver care" However, "many barriers to digital technology use remain, including a lack of ongoing technology support" but the support of t

1.9 Social isolation

One of the key concerns for many carers is the impact their caring role has on their relationships with friends and family and the feelings of social isolation this can lead to. Such feelings can have a significant impact on the mental wellbeing of carers.

The article <u>Living longer: caring in later working life</u> from the Office of National Statistics reports that "for men, loneliness is far lower for workers than non-workers, regardless of whether they provide care"⁵⁹. Men who give up work to fulfil their caring role are therefore more likely to report feelings of loneliness and social isolation than their female counterparts. It is thought that this may be because men generally work full-time throughout their careers whereas women are more likely to work part-time, have wider social networks and may have had a break when raising families.

1.10 Physical activity

⁵⁶ Oxford Brookes University (2019) <u>Nottinghamshire County Council: Reducing Older People's Need for Care – Exploring risk factors for loss of independence</u>, page 69

⁵⁷ Egan, Kieren J et al. *Understanding Current Needs and Future Expectations of Informal Caregivers for Technology to Support Health and Well-being: National Survey Study*. JMIR Aging. 2022, . **5**(1): e15413.

⁵⁸ Egan, Kieren J et al. *Understanding Current Needs and Future Expectations of Informal Caregivers for Technology to Support Health and Well-being: National Survey Study*. JMIR Aging. 2022, . **5**(1): e15413.

⁵⁹ Office of National Statistics (2019) Living longer; caring in later working life, page 10



Whilst research shows that exercise can be an effective health-promotion strategy to improve the physical and mental health of informal care givers⁶⁰⁶¹ many carers (81%) report that "they are not able to do as much physical exercise as they'd like to do"⁶². Physical activity can have a huge impact on mental as well as physical health. Taking part in physical activities can also help to reduce loneliness and social isolation.

1.11 Key inequalities

Carers experience a range of difficulties as a result of their caring role including mental and physical health concerns, social isolation and lowered social functioning, and increased mortality as a result of mental or emotional distress, especially in more elderly carers. The Government White Paper 'Healthy lives, healthy people' highlights carers as a group who experience health inequalities.

Carers can also end up as patients or requiring care and support, therefore it is important to provide adequate support to enable carers to maintain their own health whilst providing care. However the State of Caring Report 2019 found that only 21% of carers either buy or receive support. The type of support carers say they have purchased are:

- Equipment 48%
- Help from friends or family 31%
- Technology (e.g. alarms, sensors or remote monitoring to help with caring) 26%
- Practical support from care workers 26%
- Motability vehicle 21%
- Carers break 15%
- Day centre 11%
- Help with household chores 11%
- Help managing or coordinating care 4%⁶³

68% of carers report using their own money to purchase this support, 6% reduced the amount of care because of increased costs and 5% reduced the amount of care as the personal budget for the person no longer covered it.

82% of carers said the impact of caring on their physical and mental health would be a challenge over the coming year, an increase from 77% last year and 54% of carers said their physical health had suffered, and 22% said that caring had caused them injuries⁶⁴.

One of the key inequalities faced by carers is financial. Families often fund care costs, equipment, higher energy and laundry bills etc. all at a time when the carer may have given up paid employment to carry out their caring role. Carers UK (2019) report that 22% of carers live in poverty compared to a national figure of 16% and that these poverty levels

⁶⁰ Prieto-Prieto, J., et al., *Effects of a Home-Based Exercise Program on Health-Related Quality of Life and Physical Fitness in Dementia Caregivers: A Randomized Controlled Trial,* International journal of environmental research and public health, 2022, 19(15)

⁶¹Madruga, M., et al., *Effects of a home-based exercise program on mental health for caregivers of relatives with dementia: a randomized controlled trial*, International psychogeriatrics, 2021. **33**(4): p. 359-372

⁶² Carers UK (2019) State of Caring Report, page 22

⁶³ Carers UK (2019) State of Caring Report, page 8

⁶⁴ Carers UK (2023) State of Caring Report, page 8

⁶⁵ Carers UK Policy briefing August 2019, page 9



are higher in the working age population. Further 39% of carers say that "they are struggling to make ends meet, and over two thirds report that they regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for"⁶⁶. Carers UK report that "caring can come as a shock and families, unprepared for the impact on their work and household bills"⁶⁷, something which is likely to be increasingly the case during current COVID-19 measures. These financial difficulties can often worse as the person being cared for lives in the same household and has also had to give up work due to their ill health. The State of Caring Report (2019) found that of those struggling financially:

- 44% are relying on their savings
- 36% are using credit cards
- 33% are using their bank account overdraft
- 15% are in arrears with their utility bills
- 9% are in arrears with their mortgage or rent

Additionally

- 81% of carers report cutting back on luxuries
- 47% have had to cut back on essentials like food and heating
- 77% have cut back on hobbies
- 64% have cut back on seeing friends and family
- 14% have cut back on support services to help with caring
- 6% of those struggling have used foodbanks
- 3% have used payday loans

In addition to the financial difficulties already faced by cares the cost of living crisis has led to "exacerbated inequalities" for caring and in accessing support services⁶⁸.

The Public Health England 2021 *Caring as a social determinant of health* shows that the majority of care recipients of unpaid care are older parents and partners and that changes in the make up of the population estimate that the number of dependent older people in the UK will increase by 113% by 2051. The report states that the "support provided by carers is often physically and emotionally demanding, with consequences for the carers own health and wellbeing"⁶⁹. The main findings of the study were that:

- There is mounting evidence that unpaid caring should be considered a social determinant of health.
- carers experience poor physical and mental health but also have unmet care needs themselves.
- different groups of carers may have different support needs.
- a lack of clear and robust evidence about how best to support people caring for older populations, and gaps in evidence on key outcomes⁷⁰.

⁶⁶ Carers UK (2019) The State of Caring, page9

⁶⁷Carers UK (2019) Policy briefing, page 10

⁶⁸ Giebel, Clarissa and Heath, Bronte, A 3-UK-nation survey on dementia and the cost of living crisis: contributions of gender and ethnicity on struggling to pay for social care, Aging & Mental Health, Apr 07,2023. 1-6

⁶⁹ Public Health England, 19 March 2021 Caring as a social determinant of health: review of evidence

⁷⁰ Public Health England, 19 March 2021 Caring as a social determinant of health: review of evidence



1.12 Employment

Around 5 million people are carrying out their caring role alongside paid employment (approximately 1 in 7 of the UK workforce) however many of these (around 600 people every day) will give up work as caring demands and pressures mean that maintaining employment is unfeasible. Additionally, 2 million report having reduced their working hours due to caring responsibilities. According to the Carers UK Policy Briefing (August 2019) "carers managing to juggle work and care describe having to forgo promotion or miss job opportunities because they cannot increase working hours or move to take up a new position" Figures obtained by the Office of National Statistics show that 52% of carers are in employment and that the number of people in paid employment decreases in relation to the amount of time spent in the caring role:

Hours	Economic Activity				
spent caring	In Employment	Unemployed	Inactive	Total	
0 to 4	64.4	2.1	33.4	100.00	
5 to 9	63.5	2.8	33.7	100.00	
10 to 19	57.5	3.1	39.4	100.00	
20 to 34	51.6	3.5	44.9	100.00	
35 to 49	33.2	6.5	60.3	100.00	
50 to 99	28.6	1.7	69.6	100.00	
100+	16.2	2.3	81.5	100.00	
Total	51.9	2.8	45.3	100.00	

Table 4: Economic Activity of Carers by Hours of Care Provided Source: Office of National Statistics (2020) Characteristics of unpaid carers

This impact on employment also has financial consequences which can lead to poorer health outcomes for both the carer and cared for. 1 in 3 report having seen a drop of £20,000 per year as a result of caring responsibilities⁷². In addition to the financial impact of stopping work is the effect on loneliness and subsequent mental health difficulties. Going to work can often provide a welcome break for carers and help them to retain social connections. The recent move to home working as a result of COVID-19 has also seen similar impacts.

The impact of giving up work to provide care can have long term repercussions. Those who have a break from their careers to undertake their caring role may experience "a loss of skills, knowledge, experience and confidence making returning to work when caring ends extremely challenging"⁷³.

People in their 40's-60s are more likely to caring out caring responsibilities than at any other time thereby coinciding with what is usually the peak of a person's career. However older workers will increasingly have caring responsibilities both for carers, grandchildren and other family members. Older workers who are women are far more likely than men to work part-time, and women who are carers are much more likely to combine work alongside their

⁷¹ Carers UK (2019) Policy briefing, page 14

⁷² Carers UK (2014) Caring and Family Finances Inquiry UK Report

⁷³ Carers UK (2019) Policy briefing, page 14



caring role than men who are carers.. Almost two-thirds (62%) of women in employment work part-time compared with less than one-quarter (24%) of men⁷⁴.

Studies have shown that both men and women who have had periods of unemployment and/or worked part-time in the past are more likely to provide care⁷⁵. Research has also shown that those who have caring responsibilities are more likely to be in low-skilled, administrative or service-oriented jobs⁷⁶. This research also showed that whilst in many cases the amount of time a person has available to work is directly affected by their caring role and vice versa there are a significant number of people who are working full time alongside a full caring week. According to the report "21% of people are providing 35 hours of care or more per week were in full-time work over the three years to 2013/2014"⁷⁷. Further "the loss of earnings, savings and pension contributions can mean carers face long-term financial hardship into retirement"⁷⁸.

Almost two-thirds (64%) of people caring for parents are in work⁷⁹. The need for care for parents is likely to increase as the age of the population increases. As such people in their 50's and 60's will increasingly likely to have living parents who may develop care needs⁸⁰. High levels of employment for people who care for parents may be possible due to the relatively low number of hours people spend caring for a parent⁸¹ however when those who gave up employment or reduced their working hours were asked about the reason most stated that it was due to "problems accessing suitable care services"⁸². Many of the issues relate to the inflexibility of the services to fit with working hours, the unsuitability of support to meet the needs of the person they are caring for, the unreliability of support which can lead to difficulties with employment or that the cost of care is too expensive⁸³. There are however additional barriers with 40% of carers saying that "the person they care for is unwilling to accept replacement care"⁸⁴.

There are particular difficulties faced by working carers which include "lack of time, restricted opening hours, excessive stress and resulting health problems, family conflicts, work-related conflicts and financial pressures"⁸⁵.

1.13 Carer assessments

The Carers Trust report that under half of unpaid carers (43%) said that in the last year, they had an assessment, review or reassessment of their needs as an unpaid carer⁸⁶.

⁷⁴ Office of National Statistics (2019) Living longer: caring in later working life

⁷⁵ Office of National Statistics (2019) <u>Living longer: caring in later working life</u>

⁷⁶ New Policy Institute (2016) Informal carers and poverty in the UK cited in Carers UK (2019) Policy briefing

⁷⁷ New Policy Institute (2016) Informal carers and poverty in the UK cited in Carers UK (2019) Policy briefing

⁷⁸ Carers UK (2019) Policy briefing, page 14

⁷⁹ Office of National Statistics (2019) <u>Living longer: caring in later working life</u>

⁸⁰ Office of National Statistics (2019) <u>Living longer: caring in later working life</u>

⁸¹ Office of National Statistics (2019) Living longer: caring in later working life

⁸² Carers UK (2019) Policy briefing, page 14

⁸³ Carers UK (2019) Policy briefing, page 14

⁸⁴ Carers UK (2019) Carers at Breaking Point, page 10

⁸⁵ Oxford Brookes University (2019) <u>Nottinghamshire County Council: Reducing Older People's Need for Care – Exploring risk factors for loss of independence</u>, page 17

⁸⁶ Carers Trust, September 2023 <u>Adult Carer Survey Report 2023: "Unpaid carers are not unsung heroes. We</u> are forgotten, neglected and burnt out"



1.14 Carer breaks

Respite day care interventions are effective in reducing caregiver stress and depression in family carers of vulnerable older adults (with dementia, mental health problems, physically frail)⁸⁷. However a 2023 Carers Trust report that only 32% of carers said they could access a break from their caring role whenever they needed⁸⁸.

A meta-analysis of caregiver interventions found respite/day care interventions to be effective in reducing caregiver depression in family carers of vulnerable older adults (with dementia, mental health problems or who were physically frail).⁸⁹

A two year study to investigate value/effectiveness in three models of day care services for physically frail older people drew its findings from a qualitative analysis of the views and experiences of service users and professionals, together with information relating to costs. settings were compared: i) Social Services funded day centre for older people with mixed physical and mental disabilities, with a goal to provide social activity and carer relief; ii) an NHS outreach service for older people with complex rehabilitation needs, and iii) a traditional, purpose-built NHS day hospital. The indicators of 'value' used collectively describe the aspects of the service which were most valued by the main stakeholders i.e. day care attendees, their carers and the service providers. This approach overcame problems of the usual definitions of effectiveness as implied by outcomes measurement questionnaires and problems of inconsistency in goal setting and review. The key features of value were rated on a five point scale ranging from very low to very high. day centre scored as follows:

- Very high:
 - social interaction
 - friendly environment
 - o carer relief
 - person centred involvement in decision-making
- High:
 - o maintenance of independence
 - o positive framing of life
- Median:
 - o home focused
- Low:

⁸⁷ Age UK (2011) Effectiveness of day services: Summary of research evidence, page 5

⁸⁸ Carers Trust, September 2023 <u>Adult Carer Survey Report 2023: "Unpaid carers are not unsung heroes. We are forgotten, neglected and burnt out"</u>

⁸⁹ Age UK (2011) Effectiveness of day services: Summary of research evidence, page 15



o mobility health-care screening⁹⁰

Carers value breaks for a wide range of reasons – practical, emotional, social and psychological. For some, the break has value beyond the allotted time: 'to look forward to a break has the same effect as the break itself'. It's important to think about whole family approaches and breaks as 'a break from the caring routine', not just time away from the person. Some carers prefer a break that is about being with the person they care for, or as a whole family, but not having to do all the caring. Breaks can play a vital preventive role, sustaining the caring relationship and preventing carer stress, crisis and breakdown. There are key points where, if practical support and information had been provided, the impact of caring may be reduced. Breaks can reduce loneliness and isolation, enabling the carer (and the person they care for) to stay connected to family, friends and things they enjoy⁹¹.

When asked what type of breaks they wanted carers said:

"More choice and control for carers over the type of break they take. Everyone's needs, preferences and situations are different, so carers want a range of breaks available. Flexibility and a mix of settings are important – residential, in the home, out of the home, day services with good activities, for example"92.

1.15 Impact of Covid-19

Covid-19 and it's resultant lockdowns had a huge impact on carers, particularly as support services and respite options became unavailable and many more carers took on the caring role for the first time. During the pandemic there is evidence that carers who are "lesbian, gay and bisexual carers were more likely to be struggling financially, more anxious about their current financial situation, more likely to feel lonely, more likely to have poorer mental health and less likely to access certain services"⁹³. Additionally during the pandemic "parents with disabled children consistently experienced significantly lower levels of mental wellbeing, and higher levels of social isolation, anxiety and stress, compared with the general population"⁹⁴.

1.16 Impact of the caring role

⁹⁰ Powell, J, Bray, J, Roberts, H, Goddard, A and Smith, E, Goal negotiation with older people in three care settings, Health and Social Care in the Community 8(6), 380-389 60 and Powell, J and Roberts, H, Identifying "value" in day care provision for older people, The Journal of the Royal Society for the Promotion of Health, Sept 2002, Vol 122, No. 3

⁹¹ SCIE

⁹² SCII

⁹³Carers UK, September 2022 <u>The experiences of lesbian, gay and bisexual carers during and beyond the COVID-19 pandemic</u>

⁹⁴ Disabled Children's Partnership, July 2022, <u>Unseen and Unheard The impact of the Covid-19 pandemic on</u> disabled children and their families from black and Asian ethnic minority backgrounds



The Carers Trust Report 2023 reveals that 45% of carers feel that they don't get enough support, while 41% have seen their caring hours rocket in the past year⁹⁵. The report also highlights how women, those from poorer backgrounds, carers from Black, Asian and minority ethnic communities, LGBT+ carers and older unpaid carers experience additional barriers to support.

2. Size of the issue locally

2.1. Estimated total population who are carers

The 2021 Census data regarding carers, despite the impact of COVID-19 and estimates by Carers UK, the figures from this census shows that there has been an overall decrease in the number of carers in the previous decade by 8,526 across Nottinghamshire County. The latest census estimated that 41,649 carers providing between 1-19 hours of care per week – down by 15,777 since the 2011 Census. However, those carers providing over 50 hours of care per week has increased by 2,819 from 21,680 to 24,499.

The 2021 Census data highlights two district areas of Nottinghamshire that are ranked second and third highest in England, with the largest proportion of residents aged 5 years and over who provide any amount of unpaid care. These are Ashfield (11.6%) and Mansfield (11.5%).

In addition to the above, the percentage of the population who said they carry out caring tasks in Nottinghamshire (10.0%) is higher than the England average of 8.3%. There are approximately 6,000 carers in contact with Nottinghamshire County Council and 1800 with the Carers Hub (commissioned service). Carers assessments are undertaken for carers aged 6-96 years following a three-tiered conversation that aims to meet the carers need in the most timely and appropriate way possible. This may be signposting carers to other sources of support such as a condition specific charitable organisation, referring to services for training, making referrals to the Benefits Team or signposting to a support group. Should these be unsuitable or not meet the presenting need a carers assessment will be offered.

A breakdown of the support provided to carers following contact with the Council between April and December 2023 can be seen in the table below:

Age Band	Direct payment		Informatio advic		No direct	support	Total carers
	No. of	%	No. of	%	No. of	%	
	carers		carers		carers		
Under	336	61.88%	52	9.58%	155	28.55%	543
18							
18-64	510	47.44%	138	12.84%	427	39.72%	1075
65-84	238	36.17%	101	15.35%	319	48.48%	658

⁹⁵ Carers Trust, September 2023 <u>Adult Carer Survey Report 2023: "Unpaid carers are not unsung heroes. We</u> are forgotten, neglected and burnt out"



85 and	31	26.05%	20	16.81%	68	57.14%	119
over							
Total	1115	46.56%	311	12.99%	969	40.46%	2395

Table 1: Breakdown of support provided to carers in Nottinghamshire following contact with Nottinghamshire County Council (April-December 2023)

2.2 Who is being cared for

As at national level the type of care being provided locally is varied depending on the needs of the individual being cared for. The greatest impacts of caring are often due to the amount of time spent in the caring role and the condition of the person being cared for. Table 2 below shows the split of primary support needs for the people carers are supporting who contacted the Carers Hub between October 2022 and September 2023. As can be seen approximately 36% of the caring population provide care to someone with memory or cognition needs.

Cared for primary support need	Percentage of carers
Physical – personal care support	8.24%
Physical – access and mobility	23.23%
Mental health support	9.06%
Social – substance misuse support	0.27%
Social – social isolation/other support	0.14%
Support with memory and cognition	35.69%
Learning disability support	5.38%
Sensory support dual impairment (visual	0%
and hearing)	
Sensory support for visual impairment	0.27%
Sensory support for hearing impairment	0%
Unknown	17.71%

Table 2 Percentage primary support needs of people with carers taken from Census 2021 data

2.3 Carers and gender

The Census 2021 data shows that in Nottinghamshire 59% of carers are female and 41% are male. These figures are in line with the national averages.

2.4 Age

As can be seen in the table below the highest rate of caring is carried out by those aged 50 to 64. This is likely due to this age bracket providing support to ageing parents with the second highest category being those aged 65 and over. When broken down further the majority of carers in Nottinghamshire are female aged 25-64 (42%) and are still likely to be working (either full or part -time) whilst providing care for both older relatives and children. These multiple roles may lead to physical and mental ill health if support is unavailable and/or women ceasing paid employment to fulfil their caring role.



Age	Number	Percentage
15 years and under	1126	1.37%
16 to 24	3692	4.50%
25 to 34	6868	8.38%
35 to 49	17642	21.52%
50 to 64	32190	39.26%
65 and over	20472	24.97%

Table 3 Nottinghamshire carers by age taken from Census 2021 data

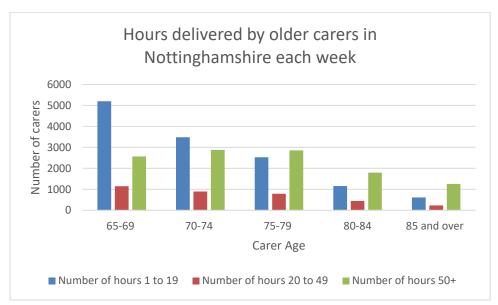


Figure 1 Hours of care provided by older adults in Nottinghamshire Source: POPPI December 2023

As can be seen from the chart above the majority of people aged 65-69 are providing relatively fewer hours of care per week than adults aged 70+. It is likely that this is due to people beginning to care for elderly parents at this time with fewer hours of care required. However, as people age they are more likely to care for partners or for people with increased care needs thereby increasing the amount of support required. This group of people are also getting older and are therefore likely to be at increased risk themselves from long-term conditions, injuries associated with caring or beginning to require support in their own right.

2.5 Ethnicity

Nottinghamshire has a relatively low proportion of carers from minority ethnic communities (4.5% compared to the national average of 15%) and this can be seen reflected in the figures below taken from the 2021 Census.

Ethnicity	Percentage of carers in Nottinghamshire	Percentage of carers nationally
Asian/Asian British	2.07%	7.23%
Black/Black British	0.84%	3.06%



Mixed or multiple ethnic	1.11%	1.82%
groups		
Other ethnic group	0.47%	1.64%
White	95.50%	86.24%

Table 4 Ethnicity of carers in Nottinghamshire taken from Census 2021 data

2.6 Health issues

In the 2021 Census carers reported on their own health. Whilst 71% of carers reported their health and being very good or good 29% said that their health was either fair or bad.

Reported health	Percentage of Nottinghamshire carers	Percentage of carers nationally
Very good or good health	70.79%	71.95%
Fair health	21.88%	20.86%
Bad or very bad health	7.33%	7.19%

Table 5 Nottinghamshire carers self-reported health taken from Census 2021 data

The Adult Social Care Outcomes Framework (ASCOF) 2021-22 reports that Nottinghamshire carers rated their quality of life in 2021/22 as 7.0 compared to an East Midlands average of 7.1 and a national average of 7.3. Carers also report having less social contact than they would like with a local percentage of 22.7 saying they had as much social contact as they would like versus an East Midlands average of 26.6% and a national average of 28%.

2.7 Employment

The 2021 Census revealed that over 50% of the caring population in Nottinghamshire are in employment with a further 2% being in full time education and therefore juggling their caring role alongside other demanding responsibilities.

Employment status	Percentage of	Percentage of carers
	Nottinghamshire carers	nationally
Employed	50.38%	49.76%
Unemployed	46.06%	45.55%
Students	2.19%	3.01%
Does not apply	1.37%	1.68%

Table 6 Number and percentage of Nottinghamshire carers in employment taken from Census 2021 data

2.8 Risk factors

We know that effective support for carers is a key factor in maximising independence and that that Carer breakdown is a key factor in the use of both short term and long-term care.

2.9 Future projections



In line with national figures projections for Nottingham and Nottinghamshire show an anticipated increase in people aged over 65 carrying out caring roles over the next 15 years. The anticipated increase is approximately 30% (just under the England average expected increase of 34%). As the number of older carers increases it is likely that they will have their own support needs that will need to be considered alongside their willingness and ability to carry out their caring role. Support for them will be of great importance to ensure that carer breakdown does not occur leading to more costly (and sometimes least appropriate) other forms of care.

Numbers of carers are likely to increase due to:

- an ageing population
- an increase in the number of people living with a limiting lifelong illness or disability
- changes in family life
- increased numbers of single-member households
- geographical dispersion within families
- increased awareness of young carers (in 2023 Carers UK estimated there to be 800,000 young carers in the UK)
- more children qualifying as a young carer, following the implementation of the Young Carers (Needs Assessment) Regulations 2015.

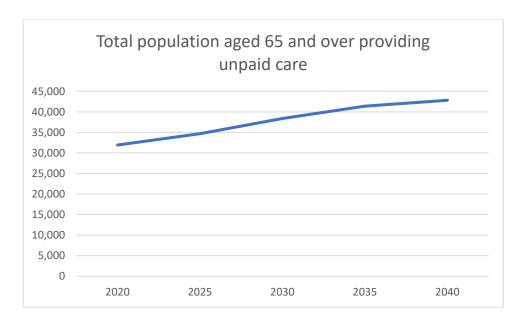


Figure 2: Projected increase in older adults providing care in Nottingham and Nottinghamshire to 2040

Source: POPPI February 2023, national prevalence model applied to ONS population predictions

3. Targets and performance



In line with Nottinghamshire County Council's conversational approach the target for carers is to resolve needs as quickly as possible (early resolution) so that support can be provided before crisis point and in a timely manner. In most cases this will involve information, advice and connecting to existing sources of support. For those where this is not a suitable solution, or who have greater needs, a carers assessment will be offered. For carers who have a carers assessment there are three outcomes:

- 1. Not eligible for paid support carers will be provided with information for alternative sources of support.
- 2. Require immediate one-off support this may be the provision of a piece of equipment for example to assist with their caring role
- 3. Ongoing support required these carers will require on-going paid for support to help them to maintain their caring role.

Carers who are eligible for support following assessment may also be entitled to short-breaks.

In order to achieve the aims of the early conversation approach the Carers Hub are supporting carers to meet their needs at an early stage through a range of support mechanisms which has led to a reduction in the number of carers going on to require a statutory carers assessment as can be seen in the graph below:

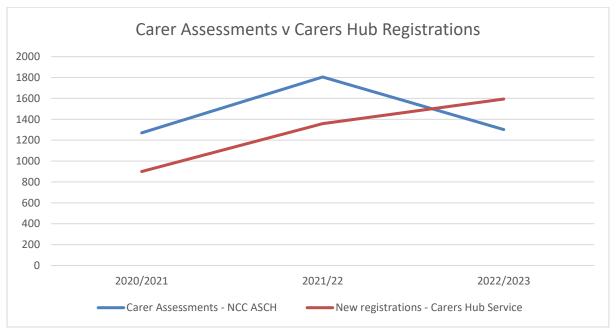


Figure 3: Number of carers assessments and Carers Hub registrations

This graph shows that as the number of new registrations with the Carers Hub has increased the number of carers requiring statutory assessments has decreased meaning that carers are supported through early intervention and community support.

The Adult Social Care Outcomes Framework (ASCOF) measures how well care and support services achieve outcomes which matter most to people. Nottinghamshire scores lower than the East Midlands average for the 2021/22 report as can be seen in the table below:

为	Nottinghamshire Health & Wellbeing Board

	East Midlands	Nottinghamshire
Proportion of carers who reported that they have as much social contact as they would like	26.6	22.7
Carer reported quality of life	7.1	7.0
score		

Table 7 Adult Social Care Outcomes Frameworks scores 2021/22

From this data it is clear that more support is required to enable carers to participate in social contact.

4. Current activity, service provision and assets

4.1 Adult social care

The primary support route for carers in Nottinghamshire is via the Carers Hub where carers are assessed for their needs and supported at the earliest opportunity to prevent a crisis from occurring. Where carers require additional or ongoing support carers will be referred to Adult Social Care for a statutory carers assessment.

Between April 2023 and November 2023 Adult Social Care have carried out 1560 carers assessments and have supported carers to access a range of services as shown in the table below.

	Adult Carers Direct Payment	Personal Health Budget	Regular Direct Payment	Young Carers Direct Payment
Total Carers	838	238	2	340

Table 8 Types of support received by Nottinghamshire carers April 2023 to November 2023

As can be seen the majority have carers have their needs met via a personal budget.

4.2 Commissioned services

Carers services have been recently recommissioned with new services commencing in October 2023. The new service specifications were coproduced with carers to ensure that services were available to meet their needs. Available data is from the previous service offer.

4.2.1 Carers Hub

The Carers Hub service is designed to be the first point of contact for all carers across Nottingham City and Nottinghamshire County. The Hub offers information, advice and connecting to other sources of support as well as running a series of support groups, carrying out an assessment of carer needs, supporting carers to think about the future and contingency plan, supporting mindfulness and wellbeing and working with the Young Carers Service and Adult and Children's social care to support carers as they move from children's to adult's services. The Hub also provides support to GP practices and social care to help with the early identification of carers and distribute a grant to support independent groups and organisations that support carers in their local communities. Additionally, the Carers Hub continues to



support Carers once their caring role has changed or ended to provide ongoing support. Between April 2018 and March 2022, a total of 4,989 carers registered to receive information, advice and support from the Carers Hub service in Nottinghamshire. During this four year period an average 1,247 carers were identified each year. Of these, 86% of carers are from a white British background, with less than only 5% of carers identified being from a Black, Asian and Minority ethnic background. Out of the seven districts and boroughs in the county, most carers registered were from the Ashfield district at 16%, the lowest being the Bassetlaw district at 10.9%. The remaining five districts and boroughs were between 11% and 15%. Carers accessing the service who live outside of the county (but provide care to a carer who lives in the county) is 4.9%. The age group of carers who accessed support the most is the 55-64 age range (late working age), with approximately 70% of those carers being female.

The top three most frequently reported conditions of the cared-for person are support with memory and cognition at 30% followed by physical access and mobility at 27% and personal care support at 16%.

4.2.2 Young Carers Support services

The Young Carers service supports young carers from 5-18 and works closely with the Carers Hub to support young carers as they transition to adult services. The Young Carers Hub carries out an assessment of carers needs, provides one-to-one support, group based support and activities and support to families. The service also supports carers to contingency plan and supports the work of health and social care to inform best practice. The Young Carers service also works closely with schools to support them to identify young carers and provide training around young carer support needs. From the period April 2018 and March 2022, the Young Carer Support service identified and registered 562 young carers. The service provided access to age-appropriate activities, support groups and one-to-one support to those registered carers. On average, 141 young carers were identified over this period. Most young carers (approximately 24%) were from the Ashfield area. Most young carers were from the age 9-13 age group (53.7%), followed by age 14-17 age group (32.9%). Nearly 61% of young carers in Nottinghamshire identified as female, with the remaining 39% of young carers identifying as male.

4.2.3 Carers Engagement and Promotion

The Engagement and Promotion Service supports organisations and communities to become carer friendly. They work with a range of employers to ensure carer-friendly workforces and recruitment practices and undertake consultation activities on behalf of the Council. The Engagement and Promotion Service also supports Carers Space which supports coproduction across the County. Since December 2019, the Carers Engagement and promotion service was commissioned to promote the awareness and interests of carers within employers, public facing organisations, GP practices, schools (for young carers) and encourage carer engagement and consultation activities and participation in the county. Contact with 30 employers was made with 5 signed up to a 'Carers Pledge', 61 GP Practices signed a 'Carers Pledge', and 78 GP Carer Awareness training sessions provided. A total of 54 schools engaged with the service, with 42 schools working towards a schools award. The number of carers taking part on consultations was 140.

4.3 Carers support groups

Around the county are several support groups with various focuses. For example some are generalist carers groups whereas others are condition specific, focus on supporting people from specific ethnic backgrounds, for those of specific ages (or supporting people who are)



or are locality based. Groups may provide a source of companionship assisting to reduce social isolation whereas others may focus on providing more practical support and information and advice to help with the caring role. Some groups are specifically for carers whereas others are for carers and the people they care for. A full list of local support groups can be found on the NottsHelpYourself website.

4.4 Carer Involvement Groups

There are a number of carers involvement groups and support groups that operate around Nottinghamshire. Some are run independently and others have support from the local Community and Voluntary Service, Nottinghamshire County Council's Coproduction Team and/or the Carers Engagement and Promotion Service. The groups meet to provide support, information and advice, share good practice and often feed into Council and ICB commissioning activities. Information regarding engagement groups and opportunities can be found on the Carers Space website.

4.5 Carers Breaks

A carers break (also known as respite) is a break from the normal routine of caring. It is planned in advance and is not the result of an emergency or crisis in the home, or because of illness e.g. hospitalisation of the carer. Usually the carer is having a break from caring, but there may be some circumstances where the person being supported needs a break from the caring situation (even if the carer is not asking for a break). This could also count as a planned short break. The Carers UK State of Caring Report (2019) recommends that Local Authorities and the NHS "provide funding and choice of quality services to enable carers to take the breaks they need" and that "a choice of appropriate and good quality care must be available or carers cannot get the breaks they need for their own health and wellbeing" ⁹⁶.

Planned short break services are:

- focused on prevention; they will be designed to help people to stay at home, sustaining caring relationships and preventing crises
- designed to avoid social isolation for carers, so that they are not housebound by their caring role.
- provided as part of a coordinated programme to prepare people for a transition to full time formal care and support, where and when appropriate for each person

People and carers assessed as eligible for planned short break services will be offered a personal budget for provision of planned short breaks. The budget will be determined as part of the support planning. This can be taken as a managed service or direct payment but cannot be spent on any other form of service unless that is to give the carer an agreed additional break (e.g. extra day service).

4.5.1 NHS Short Breaks

⁹⁶ Carers UK (2019) State of Caring Report, page 27



Locally, the Nottingham and Nottinghamshire ICB fund planned short breaks for carers. These are available to carers who are registered with a GP in Nottinghamshire and are commissioned in the carers name.

4.5.2 NCC Short breaks for service users

Nottinghamshire County Council are able to provide additional short breaks for those who are eligible where this is the most appropriate solution to meet the needs of the carer and the person they care for. These short breaks are commissioned in the name of the person accessing support.

4.5.3 Carers respite service

Short breaks are also available for carers who may not have had their needs assessed or their needs (or those of the person they support) do not meet eligibility criteria. The Carers Respite Service is able to offer 12 hours of replacement care over an 8 week period to support carers when they require a break.

4.5.4 Admiral Nurses

Along with ICS partners Nottinghamshire County Council are funding three Admiral Nurses to provide support to people with dementia and their carers. The Nurses provide specialist, ongoing support as required.

4.6 NottsHelpYourself

NottsHelpYourself is a countywide website to provide information, advice and signpost to Nottinghamshire residents. There is an area dedicated to <u>Carers</u> on the website to provide information regarding available benefits and financial support, support groups and much more.

4.7 Other forms of support

Other forms of support may include:

- Support groups for carers or to support them with the condition of the person they care for
- Access to health and leisure activities, sometimes at a reduced rate
- One to one support and guidance
- Direct payments for the carer to meet their assessed outcomes

We also work with a number of organisations and services to:

- Identify carers at an early stage in GP practices and schools
- Work with GP practices and schools to help them provide appropriate support once carers have been identified
- Engage with carers to improve services and provision of support
- Develop carer friendly communities and services

5. Local Views



5.1 Strategy Development

Over the past two years Nottinghamshire County Council have been working closely with carers to coproduce the Nottingham and Nottinghamshire All Age Carers Strategy. As part of the development carers were consulted on their views regarding the support they receive and that of the person they care for. A group of carers then went on to form part of the coproduction group that produced the strategy. Several common themes were identified as part of this work including:

- Accessing the right support for the cared for person
- Access to relevant and appropriate information, advice and guidance
- Access to short breaks or replacement care to get a break from caring
- Support for carer health and wellbeing both mental and physical
- Being listened to and being able to access good communication and information from health and social care providers

Following the broader consultation a group of carers worked with Nottingham and Nottinghamshire Councils and the ICB to produce some 'l' and 'we' statements for what good care should look like. These included carers being identified at the earliest opportunity and information and support being provided when people require it as well as support to understand what a carer is. Carers want the right to an assessment of their needs and to tell their story once and they want to feel valued and listened to.

Carers want their needs and the needs of their families to be considered so that the impact on everyone can be recognised and carers stated that they need access to a range of respite options depending on their needs and circumstances.

Carers want to feel connected to other carers, sharing their experience and they want to be given a voice in making decisions regarding the person they are caring for. Carers want their wellbeing to be prioritised as well as that of the person they are caring for and to be seen as more than a caring, living a balanced life outside of their caring role.

Carers want to be able to take up education, employment and volunteering opportunities without their caring role impacting on these opportunities. Carers also noted the importance of being recognised and supported as a carer even after their caring role has ended or changed and to be supported to plan for these changes.

5.2 The Big Conversation

During February and March 2023 Adult Social Care held The <u>Big Conversation</u> to ask people who use social care and their carers about the vision, the challenges, and what they want in the future. 542 people and carers with lived experience got involved and shared their experiences and ideas. During these events carers shared the challenge of working from home if they were also caring for someone at home or if carers came in to provide support



and many people shared the financial challenges of being a carer and the impact on their home life.

Many people talked about the personal pressures of caring, and the impact on their health and wellbeing. Many people shared the need for a break. Some people talked positively about the support they receive. People talked about 'small things making a big difference', giving examples of individuals with a personal touch who visited and helped, especially over Covid. People shared negative experiences of arranging or having a carer assessment. Many people said they did not get support and others mentioned gaps in support for carers. People said that physical support is offered but not emotional and social support. People also spoke about the importance of peer support.

Some people talked about the lack of consistency of social workers and other advisers, and the real challenges this raised. Whilst some people talked about family and friends and how supportive they are many others said they felt lonely or isolated and that their caring role had impacted on their social and work life and connections. People also talked about the lack of time to meet people and do the things they enjoyed in communities and spaces that were welcoming.

People shared their concern about the future of the person they care for 'when something happens to me' and of their fear of 'doing something wrong'. Carers of people with dementia shared fears for the safety of the person.

Whilst most people felt they had the right information, many people did talk about information being unavailable or hard to find and that they were unable to talk to a person when they needed to. People also mentioned a lack of information about breaks from caring and respite.

People also said they need more help to understand money and benefits including around charging for care.

5.3 JSNA focus group

A group of carers met with commissioners to talk about their experience of being a carer and what could be improved to support them further. Carers talked about how sometimes carers do not see themselves as carers and therefore don't seek support. People also raised concerns about not being seen as a carer if they don't live with the person they are caring for. Concerns were also raised regarding carers not being recognised if they were still working or that caring was their chosen 'job'.

Just as with The Big Conversation carers stated the importance of face-to-face support and that they wanted to feel listened to and valued. Carers often felt that they were being thought of as 'a pain' but that they are just wanting the best for the person they are support. There were also some concerns regarding a lack of follow up from social care which means that people don't always know what has taken place as a result of their assessment



particularly if they are placed on a waiting list for additional support. Carers also raised that the language used by professionals needs to be understandable and explanations provided. Carers also felt that social care staff need to have an understanding of the condition they are supporting and that this is unique to each person.

People told us that they don't know what is available or how to access services or support. Sometimes people can receive too much information which can be overwhelming and that they need the right information for their own needs. It can take a lot of time and energy and work out systems in order to get support which can often be a barrier. Carers also felt that they did not know about services until they reached a point of crisis however knowing about these in advance could have prevented this. Examples of this were financial support and housing.

Carers stated that access to services can often be problematic with services mainly operating 9-5 during the week when many carers also work. Care and support assessments often do not take into account things such as the number of appointments a person might need to attend which has an impact on work for the carer. Carers also felt their was no help with benefits or how to claim the support they were entitled to. Carers said that they needed a single point of contact and a named person to help them navigate services. This didn't necessarily need to be a social worker but could be someone from the Carers Hub or other services. Carers also felt that they many people don't know that they have the right to an assessment or where to get one from.

Parent carers in particular report falling through the gap in terms of accessing assessments and support as it is often difficult to tell what is parenting and what is caring. Carers felt that thresholds for mental health services can sometimes be too high when providing support at an earlier stage could be beneficial and prevent an escalation in needs. Again, carers also reported wanting to be included in decisions about the person they care for and to be valued in this, including being given notice of when meetings were happening.

6. Evidence of what works

6.1 National Strategic Drivers

6.1.1 Efficient and Effective Interventions

These documents provide guidance for professionals working with carers in Local Authorities implementing the Care Act 2014. They bring together a summary of the key sections of the statutory guidance relating to carers with existing good practice and effective operating models from across the country that can help:

- General responsibilities and universal services
- First contact, identifying needs and assessment
- Person-centred care and support planning
- Integration and partnership working



The guidance focuses on promoting wellbeing and independence and suggests that it is "vital that the care and support system intervenes early to support individuals, helps people retain or regain their skills and confidence, and prevents need or delays deterioration wherever possible" The guidance also lists results from the ADASS Carers Leads Survey and one of the findings from this was that digital is an area of growth.

The guidance outlines effective components of carers assessments and states that it needs to include "the outcomes that the carer wants to achieve in their daily life, their activities beyond their caring responsibilities, and the impact of caring on those activities". A whole family approach should be taken to assessments and support planning that takes "a holistic view of the person's needs and to identify how the adult's needs for care and support impact on family members or others in their support network" as well as taking into account any external sources of support such as community networks. It also talks about the need to look at the impact on any child or young people that may appear to be involved in care and that particular attention should be taken at transition to adult's services. The guides suggest that using this whole family approach "can be key to maximising the impact of resources and identifying opportunities to support carers" Assessments should take into account the impact of the caring role not the number of hours or the diagnosis of the person being cared for.

6.1.2 Universal Personalised Care: Implementing the Comprehensive Model

The 2019 NHS England paper Universal Personalised Care: Implementing the Comprehensive Model includes "moves towards joint health and social care assessments and care planning, carers' personal health budgets, more personalised outcomes from Continuing Health Care and Care Programme Approach Assessments and wider use of social prescribing" 101. The Continuing Healthcare guidance also places joint responsibility on health and social care to identify carers.

6.1.3 Commissioning for Carers Principles

The Commissioning for Carers Principles focus on key actions that are most likely to achieve the best outcomes. It is designed to help commissioners consider current commissioning practices with regards to carers and how this could be improved. The document provides a simple self-assessment questionnaire as well as supplementary questions to help trigger conversations and stimulate ideas.

The Commissioning for Carers Principles help identify different approaches for adaptation or adoption to fit with local priorities and engage through the whole commissioning cycle. The simple checklist for each principle is an easy way to identify what already exists or to highlight areas that need further support and possible investment. The 10 principles are:

- Principle 1, Think Carer, Think Family; Make Every Contact Count
- Principle 2, Support what works for carers, share and learn from others
- Principle 3, Right care, right time, right place for carers
- Principle 4, Measure what matters to carers
- Principle 5, Support for carers depends on partnership working

⁹⁷ Directors of Adult Social Services (ADASS) <u>General responsibilities and universal services</u>, page 4

⁹⁸ Directors of Adult Social Services (ADASS) <u>First contact, identifying needs and assessment</u>, page 4

⁹⁹ Directors of Adult Social Services (ADASS) <u>First contact, identifying needs and assessment</u>, page 5

¹⁰⁰ Directors of Adult Social Services (ADASS) First contact, identifying needs and assessment, page 7

¹⁰¹ Carers UK (2019) The NHS and Carers Rights



- Principle 6, Leadership for carers at all levels
- Principle 7, Train staff to identify and support carers
- Principle 8, Prioritise carers' health and wellbeing
- Principle 9, Invest in carers to sustain and save
- Principle 10, Support carers to access local resources

6.1.4 NICE guidance - Supporting adult carers

This guideline covers support for adults (aged 18 and over) who provide unpaid care for anyone aged 16 or over with health or social care needs. It aims to improve the lives of carers by helping health and social care practitioners identify people who are caring for someone and give them the right information and support. It covers carers' assessments, practical, emotional and social support and training, and support for carers providing end of life care.

The guideline includes recommendations on:

- information and support for carers
- identifying carers
- carers' assessments
- helping carers stay in, enter or return to work, education and training
- social and community support for carers
- training to provide care and support
- psychological and emotional support for carers
- support during changes to the caring role and during end of life care

6.1.5 <u>NICE guidance - Dementia: assessment, management and support for people living with dementia and their carers</u>

This guideline covers diagnosing and managing dementia (including Alzheimer's disease). It aims to improve care by making recommendations on training staff and helping carers to support people living with dementia.

This guideline includes recommendations on:

- involving people living with dementia in decisions about their care
- assessment and diagnosis
- interventions to promote cognition, independence and wellbeing
- pharmacological interventions
- managing non-cognitive symptoms
- supporting carers
- staff training and education

6.1.6 The Care Act 2014

The Care Act 2014 places duties on statutory agencies with relation to carers and the people they care for. Duties include:

- Wellbeing duty
- Prevention duty
- Duty to provide information and advice



- Assessment
- Eligibility
- Duty to meet care and support
- · Charging and financial assessment
- · Care and support planning
- Continuity of care
- Duty to promote diversity and quality in provision of services
- Paying for care
- Delegating duties
- Transition
- Safeguarding

The Care Act 2014 requires local authorities to "adopt a whole system, whole council, whole-family approach, co-ordinating services and support around the person and their family and considering the impact of the care needs of an adult on their family, including children" ¹⁰².

6.1.7 Children and Families Act

The Children and Families Act (2014) "extended the right to a needs assessment to all young carers, regardless of who they care for or the type of care provided. This means that when a child is identified as a young carer, the needs of everyone in the family will be considered, triggering both children's and adult's support services" 103. The Act removes the requirement for such carers to be providing "a substantial amount of care on a regular basis" in order to be assessed and requires local authorities to assess on the appearance of need as well as on request. The Act also requires local authorities to consider the wellbeing of the carer in line with the Care Act.

6.1.8 NHS Long-Term Plan

The NHS Long-Term Plan makes commitments to carers to assist them with their caring role and to ensure that their health and wellbeing needs are met. the plan states "carers should not have to deal with emergencies on their own. We will ensure that more carers understand the out-of-hours options that are available to them and have appropriate back-up support in place for when they need it"104. It makes a commitment to supporting 100,000 carers to have contingency planning conversations in case of carer emergency to ensure appropriate alternative arrangements could be put in place. This work has accelerated due to the COVID-19 pandemic with many people having been contacted by the Local Authority to carry out advanced planning should the carer not be able to fulfil their usual role.

The Plan commits to better recognition and support for carers through the introduction of best practice quality marks for primary care. Additionally "the NHS will roll out 'top tips' for general practice which have been developed by Young Carers, which include access to preventive health and social prescribing, and timely referral to local support services"¹⁰⁵. Principal Five also makes a commitment to improving technologies "where patients and carers can better manage their health and condition"¹⁰⁶.

¹⁰² NHS England (2016) An integrated approach to identifying and assessing Carer health and wellbeing, page 7

¹⁰³ Department of Health and Social Care (2018) Carers Action Plan 2018-2020: Supporting carers today, page 7

¹⁰⁴ NHS England (2019) The NHS Long Term Plan, page 42

¹⁰⁵ NHS England (2019) The NHS Long Term Plan, page 43

¹⁰⁶ NHS England (2019) The NHS Long Term Plan, page 9



6.1.9 Carer's Breaks: guidance for commissioners and providers

The Guidance outlines how "health and social care commissioners and providers can expand and improve regular breaks for family and friends who care for other adults"¹⁰⁷. There are two guides: one for <u>adult carers</u> and one for <u>young carers</u>. The guidance for adult carers focuses on best practice for supporting adult carers with breaks and respite. The one for young carers covers guidance about providing breaks and respite for young carers and young adult carers.

6.1.10 Supporting carers in general practice: a framework of quality markers

Supporting carers in general practice: a framework of quality markers (2019) builds on the provision NHS England work *Commitment to Carers* and outlines practical steps GP practices can take to support carers at a local practice level, clinical commissioning group (CCG) level, as a Primary Care Network (PCN) or as an Integrated Care System (ICS). The quality markers consist of a series of questions that practices can use to assess themselves along with a list of practical suggestions for each. The quality markers ask a general practice to identify six things:

- How the practice identifies and registers carers
- How the practice uses it's carer's register to support holistic carer health and wellbeing needs
- How the practice organises itself to understand and respond to the needs of carers
- How the practice makes it easier for carers to access its services
- How the practice communicates with, involves and informs its carers
- How the practice promotes a carer-friendly culture¹⁰⁸

6.1.11 <u>A connected society: A strategy for tackling loneliness – laying the foundations for change</u>

The Strategy looks at what can be done to design in support for social relationships into a changing society and recognising the crucial role of local authorities in this. It looks at changes that can be made in organisations, infrastructure and culture. The aim is for loneliness to be recognised and acted on without sigma and shame.

The strategy has three overarching goals:

- 1. A commitment to improving the evidence base so that the causes of loneliness are understood along with its impacts and what works to tackle it
- 2. To embed loneliness as a consideration across government policy, recognising the wide range of factors that exacerbate feelings of loneliness and support people's wellbeing and resilience
- 3. Build a national conversation on loneliness to raise awareness of its impacts and to help tackle stigma.

In the wake of COVID-19 and the social distancing measures that have been put in place to tackle it, this strategy is increasingly relevant. One of the areas looked at within the strategy is digital solutions to tackle loneliness.

¹⁰⁷ Department of Health and Social Care (2019) Carers Action Plan 1-year Progress Tracker, page 11

¹⁰⁸ NHS England (2019) Supporting carers in general practice: a framework of quality markers



6.1.12 An integrated approach to identifying and assessing carer health and wellbeing

This paper addresses changes to the way in which Carer health and wellbeing need is identified, assessed, and supported as a result of changes made by the Care Act 2014 and the Children and Families Act 2014. It is, essentially, a resource to help promote working together between Adult Social Care services, NHS commissioners and providers, and third sector organisations that support Carers, of all ages, with a specific focus on developing an integrated approach to the identification, assessment and support of Carers and their families across health and social care.

6.1.13 Employment support for carers

The Report sets out how to better support carers to stay in or enter employment. Having flexibility over when, where or how a job is done can be a critical factor in carers' ability to juggle care and work. The report suggests that any employee can benefit from flexibility and so too can employers. The right to request flexible working only kicks in after six months of continuous employment. But more carers could be encouraged to enter the workforce if they could request such arrangements from day one. The Report recommends amending the Flexible Working Regulations 2014 to ensure a day one right to request flexible working for all employees. Additionally supporting carers during times of difficulty is beneficial to carers and employers alike. Too many carers are currently forced to use annual leave or sick days to fulfil caring responsibilities.

6.1.14 Build Back Better: Our Plan for Health and Social Care

Build Back Better: Our Plan for Health and Social Care highlighted the important role carers have in providing support to their loved ones and made a commitment to "ensure that the 5.4 million unpaid carers have the support, advice and respite they need, fulfilling the goals of the Care Act".

6.1.15 People at the Heart of Care: Adult Social Care Reform

The Government white paper People at the Heart of Care: Adult Social Care Reform sets out a 10-year vision for how people will experience care and support in England. It highlights three key core strands specifically relating to improving support to unpaid carers as part of the new vision in reforming social care. The three core strands are:

- i. working with the sector to kick-start a change in the services provided to support unpaid carers. Supported by £25m over three years to identify and test a range of new and existing interventions that support carers
- ii. identifying, recognising and involving unpaid carers
- iii. supporting the economic and social participation of unpaid carers

6.2 Local strategic drivers

6.2.1 Supporting Adults in Nottinghamshire, Our Adult Health and Social Care

Strategy Nottinghamshire's Adult Social Care Strategy and outlines the guiding principles of Adult Social Care. The focus is on promoting people's independence so that they can live more fulfilled enjoyable lives with strong links to their local



community. It makes a commitment to make it as easy to access as possible to ensure people get the right support, at the right time and in the right place.

- **The Nottinghamshire Plan** sets out the Council's plans for the next ten years to make a 'healthy, prosperous and greener future for everyone'. Of particular relevance to carers are the first two commitments:
 - Helping our people live healthier and more independent lives
 - Supporting communities and families
- 6.2.3 The <u>Integrated Care Strategy 2023-27</u> brings together partner organisations from across health and care with a renewed focus on providing joined up services and improving the lives of all people who live and work in the city and county. The strategy has a focus on carers as well as the people accessing services throughout including "Recognising carers of all ages at the earliest opportunity, and ensuring that appropriate person-centred support is in place following a needs-led, strengths based and personalised conversation" and aims to increase in the proportion of carers who reported that they had as much social contact as they would like and an increase in carer reported quality of life score.

The ICS highlights appropriate support is needed for carers within the following ambition aims:

- Our people are resilient and have good health and wellbeing.
- Our people with care and support needs and their carers have good quality of life.
- Our system has a sustainable infrastructure.
- **6.2.4** The <u>Nottingham and Nottinghamshire Joint Carers Strategy 2023-2028</u> was coproduced with carers and contains the following principles:
 - To work in a way that is tailored to each carer to meet their needs and support their health and wellbeing and maintain their independence
 - To reduce isolation and health inequalities by improving access to carers who are 'seldom heard' or who are from ethnic minority groups
 - To ensure carers have a voice, that they are listened to and are treated with respect as expert partners in carer support
 - To improve the lives of all carers by everyone working together
 - To identify and support carers as early as possible
 - To provide the right support across the health and social care system to meet the needs of all carers and the people they care for by delivery high quality services
 - To make the best use of available resources in supporting carers across the health and social care system

As well as the above principles carers developed a number of 'l' statements to highlight the things that were important to them and these must be reflected accordingly by each service:

- I want to be able to access information and support when I need it
- I would like support at first contact to understand my situation



- I would like help to understand what a carer is
- I would like information or training to support me at the time I need it, for it to be easily accessible, meets my needs and accessible whoever I make contact with
- I want the right to a carers assessment
- I would like to tell my story once and then agree when I will have further conversations to explain my situation so my needs can be best met
- I want to feel valued and listened to
- I want my needs and the needs of my family to be considered and appropriate support provided recognising the impact on all of us
- I can access information and support when I need it
- I should be able to access different types of bespoke flexible and timely respite to meet my needs
- I want to be able to share my experiences with other carers in ways that are accessible to me face-to-face, virtual or otherwise
- I want to be involved in decisions affecting my cared for at all stages and by all professionals/services involved
- I want to be able to feel safe and supported in my caring role, as well as knowing the person I'm caring for is also safe and well looked after
- I want to be seen as more than a carer and have opportunities to live a balanced life outside of my caring role
- I want to be able to take up education, employment and volunteering opportunities
 offered to me, professionally and personally, without my caring role impacting on
 these opportunities
- I need support to prepare me for a time when my caring role reduces or ceases

7. What is on the horizon?

The <u>Carer's Leave Bill</u> received royal assent on 24 May 2023, introducing a statutory entitlement to five days unpaid carers leave per calendar year, for employees that are providing or arranging care.

According to the <u>Equality Act 2010</u>, <u>discrimination by association</u> would mean that someone was treated less favourably than someone else because they were caring for an elderly or disabled person. Carers UK are working towards having carers included as a <u>protected</u> characteristic.

Carers are facing increasing pressures due to cost of living, even for those carers who are able to continue in their employment. This is exacerbated by increasing care costs for those they are caring for.

7.1 Projected service use

The Institute of Public Care publish <u>POPPI</u>, a tool originally developed for the Department of Health to provide population data and future predictions of social care need by local authority.

National data shows that the largest expected increase in carer numbers are in those over 65 in line with general population increases. With the largest increase being in those aged



over 85 (an expected increase of (81%). As more people are living longer they are likely to do so with one or more long-term health conditions and therefore require support from their children who will fall into this age group.

Older adults predicted to be carers	2020	2025	2030	2035
65-69	8655	9395 (9%)	10837 (25%)	10912 (26%)
70-74	7607	7021 (-8%)	7671 (1%)	8860 (16%)
75-79	5122	6325 (23%)	5900 (15%)	6502 (27%)
80-84	3176	3783 (19%)	4732 (49%)	4481 (41%)
85+	1997	2307 (16%)	2824 (41%)	3613 (81%)
Total	26557	28831 (9%)	31964 (20%)	34368 (29%)

Table 8: Projected increase in older people delivering care to 2035 Source: POPPI June 2020, national prevalence model applied to ONS population projections

POPPI estimates also show that the greatest increase will be in those providing more than 50 hours of care per week (32%).

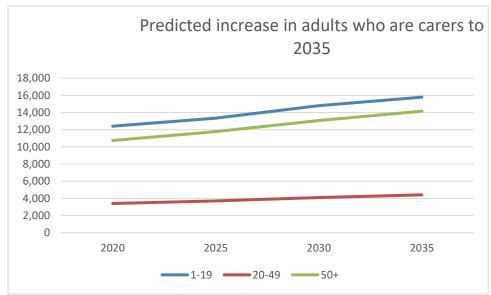


Figure 3: Predicted increase in adults who are carers to 2035 by hours of care delivered each week

Source: POPPI June 2020, national prevalence model applied to ONS population projections

Around the County the expected increase varies with Broxtowe predicted to have the lowest growth at 22% to 2035. Ashfield, Mansfield and Newark and Sherwood are expected to have higher increases (35%, 33% and 32% respectively).



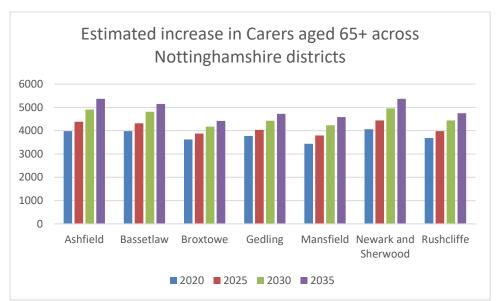


Figure 4: Estimated increase in carers aged 65+ across Nottinghamshire districts to 2035

Source: POPPI June 2020, national prevalence model applied to ONS population projections

7.2 Whole family, strengths-based assessments

The Adult Social Care Department of Nottinghamshire County Council is moving towards whole family, strength-based assessments. New carers assessments were launched in 2021 that were strength-based and further work is now being carried out to integrate these with whole family assessments.

7.3 Employment

The All-Age Carers Strategy 2023-2028 has access to employment as an area of focus to support carers either back into work or to maintain their current role if they have one. There are many benefits to carers in having paid employment both financial and psychological.

7.4 Primary Care Networks

Primary Care Networks are a move to provide more proactive care to patients in line with the NHS Long Term Plan. They aim to enable greater provision of proactive, personalised, coordinated and more integrated health and social care. Practices have begun working together and with community, mental health, social care, pharmacy, hospital and voluntary services in their local areas in primary care networks. One of the key changes brought about by this model is the use of place-based commissioning to support local communities.

What does this tell us?

8. Unmet needs and service gaps



From feedback received from carers it is clear that there are additional requirements to support both working carers and parent-carers. Parent-carers in particular report being unsure regarding where their parenting role ends and their caring role begins and therefore find it difficult to access support in their own right. The new Carers Hub service are able to provide support to parent-carers but further work is required to ensure that all areas are aware of this service offer so that carers are able to access the support provided.

The State of Caring Report (2019) states that "providing support for carers, especially those looking to stay in, or return to, paid work, is essential if women are able to be able to participate fully in the economy and live a life free from poverty in older age". The report also states that "increasing numbers of employers are recognising the importance of supporting carers in their workforce to continue working, so they can retain talented staff rather than incurring the costs of recruiting and retraining new employees". It is important therefore that we work with provider services, including statutory services, to ensure that provision of support is available and accessible to carers who work.

Additionally, whilst the data shows that the vast majority of carers in Nottinghamshire are white there is a danger that this may lead to carers from minority ethnic communities not receiving the support they need or being engaged in coproduction activities to ensure that services meet their needs. The new Carers Hub service has been specifically tasked with broadening support to all communities as part of the new contract.

9. Knowledge gaps

Available research is limited around the impact of the current cost of living crisis on carers and further support may be required as evidence emerges. Locally information will be gathered via the commissioned services, Carers Space and other coproduction routes.

Parent carer needs are also under-represented in the research however this is an emerging need locally and further knowledge is required to ensure that parent carers are to be supported in the most appropriate way.

Additional information is also required regarding the need of ethnic minority carers around the county to ensure that their needs are met by both commissioned and support services.

Additionally, the research in section 1 of this report shows a significant impact on the mental health and wellbeing of carers once their caring role has ended and additional information is required to understand how to support people as their caring role changes or ends.

Severe multiple disadvantage is a way of describing the lived experience of people whose current circumstances have been strongly shaped by deprivation, trauma, and abuse – often leading to experiences of homelessness, mental ill-health, domestic abuse/sexual violence, harmful use of drugs and alcohol, and perhaps contact with the criminal justice system. These



exposures and experiences often leave people vulnerable to some of the worst health and wellbeing of any group in Nottinghamshire and carers may be at risk of these as well as the person they are caring for.

It is difficult to accurately estimate the numbers of people that experience severe multiple disadvantage for various reasons. Firstly, there is no single universally adopted definition of severe multiple disadvantage, therefore different studies or estimates use different definitions. In many cases, services are difficult to access for those experiencing severe multiple disadvantage, meaning people are not present in service-use data. For this reason the number of carers impacted by severe multiple disadvantage is unknown.

What should we do next?

10. Recommendations for consideration

	Recommendation	Lead(s)
1	Review and streamline the provision of short breaks	Nottinghamshire County
	for carers to ensure a range of options are available	Council Integrated Strategic
	for those who require them. Educate staff to enable	Commissioning
	effective commissioning of available short breaks.	
2	Ensure carers needs and the caring situation is	Principal Social Worker
	considered throughout all aspects of social care	
	provision through whole family assessments to	
	move away from silo working and ensure that the	
	needs of the whole family (including the carer) are	
	met in the most appropriate way. As part of this	
	keeping carers informed about outcomes and next	
	steps through feedback.	
3	Work proactively with the assistive technology work	Nottinghamshire County
	programme to ensure carer needs are encapsulated	Council Integrated Strategic
	in equipment specifications (e.g. the need for	Commissioning
	alternative monitoring for people with dementia to	
	provide a break for the carer or the use of electronic	
	reminder services for medications and appointments	
	to free up carer time/reduce visits)	
4	Develop a single point of access for carers so that	Carers Hub Service
	they are aware of where to go for information and	
	advice without being overwhelmed with information	
5	Support carers to plan for the future including a	Carers Hub Service
	change in their needs as well as those for the	
	person they are caring for. This will involve early	
	conversations with carers to plan for future changes	
	and contingency planning for emergency situations	



6	Ensure easily accessible information and advice (including support and finance) is available when it is required including out of standard office hours. This will need to be supported by face-to-face support and connecting to services rather than signposting.	Carers Hub Service through coproduction activity
7	Support young carers as they transition from children to adult services to ensure that they continue to receive support whilst maximising their potential to take up educational, employment and social opportunities.	Carers Hub Service and Young Carers Support Service
8	Develop support for Parent Carers specific to their caring role.	Carers Hub Service in coproduction with Parent Carers
9	Review the current young carers assessment tool to bring in line with strength-based approaches and ensure that support provided achieves the appropriate outcomes for the young carers	Integrated Strategic Commissioning, Children and Families Service and Operational teams in coproduction with young people and families
10	Ensure carers are identified and offered support at the earliest opportunity including through schools and primary care to prevent a crisis from occurring	All system partners and commissioned services
11	Ensure that carers needs in relation to Severe Multiple Disadvantage are recognised as part of the assessment and whole family process utilising a multidisciplinary approach to support people within this group and prevent self-neglect. Improve data recording to determine impact of this area on carers and inform future service and support planning.	All partners
12	Ensure that carers have equal access to support in a way that is suitable and appropriate for them and their family needs. This will include carers who may not have English as their first language (including BSL), carers from ethnic minority backgrounds, support that is appropriate to religious needs or those who find it difficult to access statutory services during office hours due to work commitments.	All system partners and commissioned services

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