

## **Survey of Adult Carers Experience – Peterborough – Published June 2022**

### **Introduction**

Every two years NHS Digital, the analytics function in Department of Health and Social Care, directs Local Authorities to conduct a national survey of adult carers. The previous survey took place in the Autumn of 2018. The survey due in Autumn 2020 was postponed due to Covid and in fact took place Autumn 2021. The results were published nationally in late June 2022.

We sent out 361 Surveys in the autumn of 2021, and received back 163 responses, a response rate of 45%. This was much higher response rate than for the survey undertaken in 2018, which had a response rate of 37%. Part of the reason for the changes throughout the survey was due to the timing of the survey during the pandemic, and the impact this was still having on carers at that time.

A questionnaire template was provided by NHS Digital. The questionnaire is divided into six sections:

1. Section 1: About the person you care for
2. Section 2: About your needs and experiences of support
3. Section 3: The impact of caring and your quality of life
4. Section 4: Information and advice quality
5. Section 5: Arrangement of support and services in the last 12 months
6. Section 6: About yourself

### **Executive summary**

The carer's survey results provide important insights into the lived experience of people who provide unpaid care for others. The analysis presented below sets this out in the context of the shift in responses between the 2018 and 2021 surveys and against responses in the wider Eastern region. The information is valuable but also challenging to interpret for two key reasons.

Firstly, the extraordinary covid situation has prevailed through much of the intervening period between the current and previous surveys and has undoubtedly impacted in carers in many and varied ways.

Secondly, we have made a significant change to how we engage with carers since 2018. We have moved away from a one size fits all model of undertaking carers assessments and reviews as a way of understanding what our carers need. This is in acknowledgement that most often a lengthy assessment is not what carers want. As a result, the majority of interactions with carers are now in the form of conversations, often with externally contracted partners, which can lead to a wider variety of outcomes. This could be linking a carer in to support networks in their local community, or providing information and advice. Some carers do go on to receive a full assessment, but this number is much reduced and more likely to occur when someone is caring for a working age adult. While we believe this is a better way of interacting with carers it has impacted on the group contacted for their responses to this survey, with a large shift in the sample away from people who are caring for older people and towards people caring for working age adults.






Some key findings from the detailed of the survey set out in this report are listed below:

- Fewer carers had received formal assessments as result of our deliberate shift towards more nuanced conversations. **14.8%** of carers had been joint assessed or reviewed with the person they cared for, down from **36%** in 2018. However, **58.2%** had received a separate carers assessment, up from **52%**. **27%** had not had either an assessment or a review within the year, up from **12%**
- **9.2%** had a mental health problem or illness, (down from **10.3%** in 2018). Nationally there was a growth in carers disclosing a mental health problem or illness climbing from **16.3%** in 2018 to **19.8%** in 2021 so Peterborough differs significantly from the national picture in this respect.
- Satisfaction with services received by the cared for person improved overall. Those who were either extremely, very satisfied or quite satisfied rose from **54.6%** to **59.9%**. There was a marked decrease was in those that said they had not received any support at all, which was down from **25.7%** to **14%**
- Health impacts of being in a caring role had worsened in nearly all areas, particularly in the areas of feeling depressed, disturbed sleep, general feeling of stress and making an existing condition worse.
- A higher percentage of respondents had been caring for the person they cared for 20 years or more, **15.6%** in 2018 and **19.9%** in 2021. Nationally the percentage caring for over 20 years, was the largest group of respondents, at **24.5%**. This is likely to reflect a move towards a larger cohort of working age adults being supported by Adult Social Care.
- **23.2%** of carers stated that they did not receive and support during the pandemic, this was much lower than the **45.5%** nationally
- There was a significant decrease in how carers reported their sense of having control over how they spent their time, being able to engage in things they enjoyed outside of their caring role and being socially connected.

Results from the survey will be used to inform the forthcoming refresh of the Carer’s Strategy which is being co-produced with people with lived experience and in collaboration with our health colleagues.

### Links to the national Adult Social Care Outcomes Framework (ASCOF).

The national survey of adult carers provides valuable local insight into carers and their experiences, but it also feeds a number of national indicators within the Adult Social Care Outcomes Framework. The table below gives the results for Peterborough, compared to the results for the region overall.

ASCOF carer experience indicator	2016	2018	2022	Change	2022 Region
Carers quality of life (high is good)	7.8	7.4	6.8		7.3
Carers with as much social contact as they would like	33.2%	32.2%	21.3%		28.8%
Overall satisfaction of carers with social services	38.1%	39.8%	40.7%		35.4%
Proportion of carers who report that they have been included or consulted.	71.2%	67.7%	60%		65.4%
Carers who find it easy to find information about services	N/A	63.6%	56.3%		55.6%

Prior to the pandemic in the national results for the quality of life indicator was 7.5, the national position for this indicator for 2021 has not yet been published as it is a weighted blend of a number of measures from the survey.

## Who were the carers?

### Demographics

The demography of the carers known to the Council has always been predominantly female, however the 2021 survey a slightly higher percentage of male carers responding, rising from 33.1% in 2018 to 39.3% in 2021. Nationally the respondents in 2021 were 30% male and 70% female. The biggest groups of carers were aged 55-64 (23.3%) and 75-84 (23%) with next biggest group being those aged 65-74 (20%), these age bands were also the biggest across the country. The carers in the sample were predominantly white British, 79.6%, nationally this was higher at 78.7%, the next largest ethnicity was Asian / Asian British at 6.3%.

### Employment

**63.8%** of carers responding were retired, a decrease from **67.4%** in 2018, and much lower than the 81.9% responding nationally. **21.3%** are employed / self-employed full time or part time, increase on the 17% in 2018. **4.4%** were doing voluntary work, a decrease on 7.2% in 2018. **23.1%** were not in paid employment, an increase on 21.4% in 2018.

**19.7%** indicated that they were not in employment because of their caring responsibilities, this was an increase on **17.8%** in 2018 and might well be a reflect of the impact of Covid.

**11.2%** stated they were in paid employment and felt supported by their employer, (up from 7% in the previous survey)

Thinking about combining your paid work and caring responsibilities, which of the following statements best describes your current situation?	2018	2021	England
I am not in paid employment because of my caring responsibilities.	17.8%	19.7%	21.4%
I am not in paid employment for other reasons (e.g. retired)	65.8%	61.8%	54.7%
I am in paid employment and feel supported by my employer	7%	11.2%	11.7%
I am in paid employment but don't feel supported by my employer	2.6%	2.0%	4%
I do not need support from my employer to combine my responsibilities	2.3%	0.7%	3.6%
I am self-employed and able to balance my responsibilities	2.9%	2.0%	2.9%
I am self-employed and unable to balance my responsibilities	1.5%	2.6%	1.7%

### Comment from carer

I am self employed BECAUSE I can manage a limited amount of work to balance caring duties - BUT - I can't work enough to support myself/family as I would of if I were able to work more. It's not an either/or, it's an enforced situation not a decision based on choice













### Health

Only **33.6%** of carers declared themselves to have no health condition or disability, a decrease from **36.7%** in 2018. **27.6%** of carers stated that they have a long-standing illness (less than **30%** in the 2018 survey). **27.6%** had a physical impairment or disability (more than the **22.7%** in 2018), **21.1%** had sight or hearing loss (slightly up from 20% in 2018), **9.2%** had a mental health problem or illness, (down from **10.3%** in 2018) **1.3%** had a learning disability (lower than **2.7%** in 2018).

Nationally there was a growth in carers disclosing a mental health problem or illness climbing from **16.3%** in 2018 to **19.8%** in 2021, Peterborough is therefore notable for both the lower levels declared the direction of travel, from **10.3%** to **9.2%**. Nationally the proportion declaring

no health condition or disability was higher than Peterborough at **57.5%** and had only reduced marginally from the **57.6%** in 2018.

Impact of caring on the carers health, the table below illustrates the carers responses to how they felt their caring role had impacted on their health, with responses from 2018 shown as a comparison. Health impacts had worsened in nearly all areas, notable increases were reported in respect of feeling depressed, disturbed sleep, general feeling of stress and making an existing condition worse.

Impact on health	2018	2021	Change
Feeling tired	78.6%	79.2%	
Feeling depressed	42.5%	50.3%	
Loss of appetite	13.7%	10.7%	
Disturbed sleep	65.2%	73%	
General feeling of stress	52.4%	71.7%	
Physical strain (e.g. back)	31.9%	39%	
Short tempered / irritable	39.3%	42.8%	
Had to see own GP	25.4%	25.2%	
Developed my own health condition	23.6%	23.9%	
Made an existing condition worse	18.8%	32.7%	
Other	2.3%	1.9%	
No, none of these	9.1%	2.5%	

### Comments from carers

My wife ..... suffering from mild vascular dementia which creates very stressful times. I am taking medication for stress but my mental state is being stretched on occasions. After 14 years as a full time carer and 84 years of age this is stretching my ability to look after my wife, home, garden etc

I have my own problems health wise. I am also visually impaired and find it difficult to cope at times. I also get very tired. I am not sure what help I can get - not just a matter of time out.

### Caring arrangements

**78.8%** of carers lived with the person they were caring for, down slightly from **84.2%** in 2018.

A higher percentage of respondents had been caring for the person they cared for 20 years or more, **15.6%** in 2018 and **19.9%** in 2021. Nationally the percentage caring for over 20 years, was the largest group of respondents, at 24.5% In 2018 the largest % of respondents had been caring for between 3 and 5 years at **23.6%**, by 2021 this group had dropped to **14.9%**, with the largest group now being those who have been caring for between 5-10 years at **20.5%**

The majority of respondents, **54.4%**, care for someone for 100 or more hours a week, and this percentage had increased since 2018 (**51.3%**). This was also the most frequent response nationally at **36.4%**. There was a comparatively even split between other caring hour ranges, with the next most common being 35-49 hours per week at **9.5%**, an increase from **3.4%** in 2018.

In relation to the type of care provided, the highest results were for 'other practical help' (**98.8%**) slightly above the **94%** in 2018, and 'keeping an eye on them to see if they are all right' (**93.8 %**) down marginally on **94%** in 2018. Next common were helping with dealing with care services and benefits, and giving medicines, both reported by **90.1%** of respondents in 2021. Helping with paperwork or financial matters at **87.7%** was also common. **80.9%** provided personal care, an increase from **71.6%** in 2018. The % providing physical help was down slightly from **61.2%** in 2018 to **56.8%** in 2021.

### Who were they caring for?

In both 2018 and 2021 the largest age groups cared for were aged 75-84, (**34.7%** in 2018 and **31.3%** in 2021) and 85+ (**27.2%** in 2018 and **25.2%** in 2021). There was a growth the % cared for aged 25 –34 (**3.1%** to **5.5%**) and 35-44 (**3.1%-5.5%**)

How old is the person you care for?	2018	2021	England
18-24	3.6%	3.7%	6%
25-34	3.1%	5.5%	6.9%
35-44	3.1%	5.5%	5.7%
45-54	5.8%	4.3%	6.6%
55-64	6.9%	8.0%	8.9%
65-74	15.6%	16.6%	14.3%
75-84	34.7%	31.3%	25.8%
85+	27.2%	25.2%	25.8%

The most common reason for the cared for person requiring support was due to a physical disability. This was the same in 2018, however the percentage has decreased from **57.1%** to **54.4%**. The main growth was in those caring for someone with dementia, which increased from **41.2%** to **46.8%**. The percentage with a learning disability or difficulty, also increased from **12.7%** to **13.9%**. The most notable reduction was in those with a long-standing illness, reducing from **42.7%** to **31%** and problems connected with ageing, reducing from **40.1%** to **33.5%**.

### Carers support

**14.8%** of carers had been joint assessed or reviewed with the person they cared for, down from **36%** in 2018. **58.2%** had received a separate carers assessment, up from **52%**. **27%** had not had either an assessment or a review within the year, up from **12%** and reflecting the move toward lighter touch carer's conversations.

**53.9%** had received information, advice or signposting to universal services, an increase from **41.6%** in 2018. **68.2%** had received some form of breaks service, either planned in in an emergency, up from **45.7 %** in 2018. **20.4%** reporting having had support from a carers group in the last 12 months, up from **19.4%** in 2018. Those using equipment or housing adaptations was down slightly from **56.3%** in 2018 to **54.6%** in 2021, whilst those accessing a Lifeline alarm was up from **39.9%** to **43%**.

Support services accessed in the last 12 months	2021
Information, advice or signposting to universal services	53.9%
Emergency breaks service	13.7%
Overnight (24 hour +) breaks service	11.9%
A break service for less that 24 hours / sitting service	42.7%









Personal assistant	14.3%
Home care	29.6%
Day centre	17.4%
Equipment / adaptation to the home	54.6%
Lifeline	43%

## Carers experience – Headline results.

### Improvements from the Previous Survey were as follows:

**Overall satisfaction with services received by the cared for person.** - The percentage who were “extremely satisfied” dropped slightly from **10.8%** in 2018 to **8.3%** in 2021. However, the percentage who were “very satisfied” increased notably from **18.7%** in 2018 to **26.8%** in 2021. The percentage who were “quite satisfied” decreased from **25.1%** to **24.8%**. The percentages who were quite dissatisfied (**5.1%**), and very/extremely dissatisfied (**5.1%**) increased. The marked decrease was in those that said they had not received any support at all, which was down from **25.7%** to **14%**

How we compare

Overall how satisfied or dissatisfied are you with the support of services you and the person you care for have received?	National	Peterborough compared to England	Change since 2018
We haven't received any support from social services in the last 12 months	28.6%	14%	
I am extremely satisfied	9.6%	8.3% Worse	
I am very satisfied	16.3%	26.8% Better	
I am quite satisfied	21.6%	24.8% Better	
I am neither satisfied or dissatisfied	12.3%	15.9%	
I am quite dissatisfied	5.6%	5.1% Better	
I am very dissatisfied	2.7%	1.3% Better	
I am extremely dissatisfied	3.3%	3.8% Worse	

## Comments from carers

I am happy with the care/information provided by Peterborough Social Services and feel fortunate to live in the area.

ASC has been extremely helpful over the last 14 years that I have been a carer for my disabled wife. More recently to provide a replacement carer during the time our regular private carer was in hospital ..... Also providing me respite time to take my disabled wife out to her regular gym work and shopping 5 hours/week.

Very happy with the service. Since \*\*\*\*\* has been our daughter's social worker the service outstanding 100%.

Passed from one agency/department to another. Mental Health Team indicated that it was NOT their job to provide help when needed during a crisis and was told to contact hospital A & E or Police.






I love my role as a carer, it gives me great pleasure and fulfilment in providing care to someone. I would like more pads made available to the person I care for and for an easier way to contact the GP. Ambulance services need to be informed and district nurses contact times to be shortened and regular review to take place.

When social services initially visited the help and advice regarding aids to assist with caring were first class ie. grab rails, door alarm, Lifeline etc. However, recently I have been frustrated by meetings being cancelled at the last minute and the constant requests for filling in assessment forms.

The system is not joined up making it confusing and difficult for the carer to navigate. If I had 2 mins to calm down and have some time, it would probably not feel quite so bad, but I don't. It is always up to the carer to keep things on track, pull the right agencies together, keep them communicating etc. etc. so, the carer is always under pressure.






**Access to information and advice** – A higher percentage of carers had sought information and advice in 2021 than in 2018. In 2018 **42.8%** of carers said they had not tried to find information and advice in 2021 this reduced to only **21.7%**. An increased percentage stated that they found it very easy to find information and advice, up from **7.8%** in 2018 to **8.7%** in 2021. An increased percentage stated that they found information and advice fairly easy to find **28.6%** in 2018 and **35.4%** in 2021. However, a higher percentage found it difficult to find, up from **13.9%** in 2018 to **24.2%** in 2021. There was also an increase in the percentage who found it very difficult to find, up from **6.9%** in 2018 to **9.9%** in 2021.

How we compare

In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits.	National	Peterborough compared to England	Change since 2018
I have not tried to find information or advice in the last 12 months	34.7%	21.7% Better	
Very easy to find	9.1%	8.7% Worse	
Fairly easy to find	28.6%	35.4% Better	
Fairly difficult to find	17.8%	24.2% Worse	
Very difficult to find	9.7%	9.9% Worse	

**Helpfulness of information and advice** – The percentage stating that information and advice had been very helpful remained the same at **18.1%** for both surveys. The percentage of those finding it quite helpful, rose from **30.3%** in 2018 to **36.3%** in 2021. Those finding it quite unhelpful rose from **6.1%** to **7.5%**, and those finding it very unhelpful also rose from **3.2%** to **4.4%**.

## How we compare

In the last 12 months, how helpful has the information and advice you received been?	National	Peterborough compared to England	Change since 2018
I have not tried to find information or advice in the last 12 months	37%	33.8% Better	
Very helpful	17.7%	18.1% Better	
Quite helpful	35.5%	36.3% Better	
Quite unhelpful	6.8%	7.5% Worse	
Very unhelpful	3%	4.4% Worse	






### Comments from carers

DISABILITY /PETERBOROUGH - have also been most helpful providing a grocery delivery service during the pandemic. Also helping me get Attendance Allowance. Also providing a clothes ironing service and advice on travel insurance companies who specialise in insurance for disabled patients.

Nobody has contacted me approx. 2 and 1/2 years when a man rang to ask me if i still needed carers trust. My reply was yes - they are my only lifeline and I told him I was struggling - I have heard nothing else. Carers Trust not delivering the hours arranged. Poor/no communication with any dementia services after diagnosis at the memory clinic.

As a carer I feel I have been very much left on to 'get on with it'. There is no proactive contact to check on to see that everything is OK, especially during these past 12 months. Even after testing for COVID19 there was no communication to ask if we needed support. I have managed to find sources of help and support for myself but anyone older, with no experience or access to the internet would struggle.

**Carers feeling consulted with** – Questions in relation to carers engagement with care and support planning for the person they supported were more positive. The proportion who had not been aware of any discussions in the last 12 months had decreased from **35.2%** in 2018 to **26.3%** in 2021. However, the proportion of carers who said they were always involved or consulted had decreased slightly from **26.4%** to **24.4%** with the percentage who stated that they were usually involved rising from **17.5%** to **19.9%**. However, the percentage who only sometimes felt involved or consulted had also risen from **17.2%** to **22.4%** and the percentage who never felt involved or consulted had risen from **3.7%** to **7.1%**.

In the last 12 months, do you feel you have been involved or consulted as much as you want to be, in discussions about the support provided to the person you care for?	National	Peterborough compared to England	Change since 2018
There have been no discussions that I am aware of, in the last 12 months	36.1%	26.3% Better	
I always felt involved or consulted	22.6%	24.4% Better	
I usually felt involved or consulted	18.9%	19.9% Better	
I sometimes felt involved or consulted	16.6%	22.4% Worse	
I never felt involved or consulted	5.8%	5.9% Worse	






Difficult to get people to understand how we had become close to breaking point. No one would accept we couldn't provide the level of care needed and just accepted my parents word they could manage. lack of appreciation for our concerns regarding their safety when we weren't available. When we needed emergency support it took 3 days

Additional information - the assembly and assorting of certain groups within the hospital discharge and social services team, effectively erased the audit trail from hospital discharge to assess. When I tried to establish who was responsible for each decision in the above chain I was completely 'fobbed off'. This is my main reason for my sense of utter dissatisfaction.

**Areas where results have worsened from the previous survey were as follows:**

**Being able to spend time doing the things I value or enjoy** – The percentage who said they were able to spend their time as they want, doing things they value or enjoy went down from **16.8%** to **10.3%**. More carers said that they could do some of the things they value or enjoy with their time but not enough, up from **68.9%** in 2018 to **71.2%** in 2021. More carers stated that they did not do anything they value or enjoy with their time up from **14.2%** in 2018 to **18.5%** in 2021.

How we compare

Which of these best describes how you spend your time	National	Peterborough compared to England	Change since 2018
I am able to spend time as I want doing the things I value or enjoy	16.2%	10.3% <b>Worse</b>	
I do some of the things I value or enjoy with my time but not enough	65.4%	71.2% <b>Worse</b>	
I do not do anything I value or enjoy with my time	18.3%	18.5% <b>Worse</b>	




**Comments from carers**

Council made thing harder than usual and clubs were stopped. This meant that I was caring 24hours for my wife. We bought in nursing staff to allow me to go shopping etc. and this gave me a break. it also allowed me to go to hospital/GP visits as my own health has declined during this time. We may have been able to choose another route other than a care home(permanently) if we could at the time of had regular respite care. However, we appreciate that these were unprecedented times.

Telephone access to the representative allocated to us isn't easy. I waited I hour in a queue to leave a simple question that took a week to answer. I run my own business and juggling Mum's needs of appointments is difficult. The time I have is precious and I get stressed by feeling I am letting her down by not being able to spend the time (unnecessarily long) to organise for her e.g. It took me 5 hours of my day just making appointments for her care.

**Having control over daily life** – The percentage having as much control over their daily life as they wanted reduced from **21.5%** to **16.4%**, with those stating they had some control also reducing from **64.1%** to **61%** and those feeling they had no control rising from **14.4%** to **22.6%**

## How we compare

Which of the following statements best describes how much control you have over your daily life?	National	Peterborough compared to England	Change since 2018
I have as much control over my daily life as I want	22.1%	16.4% <b>Worse</b>	
I have some control over my daily life but not enough	62.1%	61% <b>Worse</b>	
I have no control over my daily life	15.7%	22.6% <b>Worse</b>	




## Comments from carers

As for the support available for the person I care for, considering his age, options are very limited. He is too old for some activities and too young for others. There are no day centre/activities geared for the 'middle aged' group. This put additional pressure on me as a carer, working full time and responsible for managing the home, finances etc, as well as providing support and activities to retrieve the boredom and keep his mind and body active.

I have been waiting over a year for my husband to get the help to move into a suitable property so he is not stuck in his bedroom and so he can use his wheelchair I bought him because wheelchair services won't give us one until we moved. Can't get any more help from OT till we move




**Looking after myself** – In respect of getting enough sleep or eating well less carers stated that they felt they looked after themselves, reducing from **55.2%** to **39.4%**. There was an increase in the percentage saying they only sometimes looked after themselves well enough, **28.9%** in 2018 to **37.4%** in 2021 and those that stated they were neglecting themselves **15.9%** in 2018 to **23.2%** in 2021.

## How we compare

Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?	National	Peterborough compared to England	Change since 2018
I look after myself	49.2%	39.4% <b>Worse</b>	
Sometimes I look after myself well enough	31.4%	37.4% <b>Worse</b>	
I feel I am neglecting myself	19.5%	23.2% <b>Worse</b>	




**Personal safety** – The percentage of carers with no worries about their personal safety decreased from **79.3%** to **77%**. A larger percentage than previously had some worries about their personal safety **18.7%** in 2018 and **22.4%** in 2021, although there was a decrease in the small percentage who were extremely worried about their personal safety **2%** in 2018 and **0.6%** in 2021.

## How we compare

Thinking about your personal safety, which statement best describes your present situation?	National	Peterborough compared to England	Change since 2018
I have no worries about my personal safety	80.5%	77% Worse	
I have some worries about my personal safety	17.4%	22.4% Worse	
I am extremely worried about my personal safety	2%	0.6% Better	

**Social contact** – A smaller percentage of carers felt they had as much social contact as they wanted with people they liked down from **32.2%** to **21.3%**. There was an increase in the percentage who had some social contact but not enough from **44.9%** up to **53.1%**. There was also an increase in the percentage stating that they had little social contact and felt socially isolated, up from **22.9%** to **25.6%**

## How we compare




Thinking about how much social contact you've had with people you like, which statement best describes your social situation?	National	Peterborough compared to England	Change since 2018
I have as much contact as I want with people I like	28%	21.3% Worse	
I have some social contact with people but not enough	51.1%	53.1% Worse	
I have little social contact with people and feel socially isolated.	20.9%	25.6% Worse	

## Comment from carer

My husband has been spinal cord injured for 30 years. His condition has deteriorated so that he receives NHS continuing Healthcare Funding. He receives a 4 hours per day Care Package, supplied by an excellent local agency. As he is not helped by Social Services I have almost no contact/support. COVID 19 has left me more isolated than ever as it has been very hard to meet with friends and impossible to get to church. Please get me on the register so someone knows I exist. Even quarterly contact would be helpful.

**Encouragement and support in the caring role** - There was a reduction in the percentage of carers stating they had encouragement and support in their role as carer from **33.4%** in 2018 to **28.3%** in 2021. A higher percentage felt they had some encouragement and support but not enough, up from **45.5%** to **53.5%**. Less carers proportionately felt they had no encouragement and support however, down from **21%** to **18.2%**

## How we compare

Thinking about encouragement and support in your caring role, which statement best describes your present situation?	National	Peterborough compared to England	Change since 2018
I feel I have encouragement and support.	31.5%	28.3% <b>Worse</b>	
I feel I have some encouragement and support but not enough	45.8%	53.5% <b>Worse</b>	
I feel I have no encouragement or support.	22.8%	18.2% <b>Better</b>	

## Comments from carers

I have to say that employing a private carer for 1 hour in the morning for 6 days and an ASC help in paying for our carer taking my wife out for 5 hours a week is very gratefully appreciated.

My husband went into \*\*\*\*\* Care Home in January. I didn't really want him to go into care but he had got so difficult to care for I couldn't cope anymore. He has continuous NHS funding with one-to-one care. The Social Services were very helpful, I got respite care for Patrick whenever I asked. the sitting service was very good.





I think I am very fortunate to have a fantastic neighbour who has helped more than I can say. Furthermore the professional carer I have for three hours on two afternoons each week is also fantastic and a great help.

As we all know there is a vast shortage of labour including carers. Although social services allow me to be supported for some 16 hours per month the carer company (although extremely good) cannot provide cover for all these allowed hours.

It is difficult to know who will fund what. People will not visit due to the pandemic, even after restrictions have been lifted. Too many assessment forms are asked for with no one visiting in person. The services from GP and social services don't seem to be joined up




**Caring for others** – Carers responding to the 2021 survey were more likely to also having caring responsibilities for someone else, with those stating they didn't have caring responsibilities for anyone else dropping from **70.5%** to **51.4%**. The percentage stating that they cared for someone else and always had time to care for them increased from **14.2%** to **20%**. Those stating they only sometimes had enough time to care for other people rose from **12.2%** to **22.9%**. Those stating they never had time to care for other people nearly doubled from **3.1%** to **5.7%**.

## How we compare

Thinking about the other people you have caring responsibilities for, which of the following best describes your current situation.	National	Peterborough compared to England	Change since 2018
I don't have caring responsibilities for anyone else	55.5%	51.4%	
I always have enough time to care for them	17.6%	20% Better	
I sometimes have enough time to care for them	21.4.8%	22.9% Worse	
I never have enough time to care for them	5.5%	5.7% Worse	

**Financial difficulties** – The percentage of carers reporting no financial difficulties caused by their caring role in the last 12 months decreased slightly from **59.8%** in 2018 to **59.2%** in 2021. Those responding that they had faced a financial impact to some extent had increased marginally from **32.4%** to **32.5%**. Those reporting a lot of financial difficulties had also increased slightly from **7.8%** to **8.3%**

## How we compare

In the last 12 months, has caring caused you financial difficulties?	National	Peterborough compared to England	Change since 2018
No financial difficulties	57.2%	59.2% Better	
Yes, to some extent	34.1%	32.5% Worse	
Yes, a lot	8.8%	8.3% Better	

## Experience of Covid 19

The national survey in 2021 also asked four questions specific to the Covid 19 pandemic.

**Satisfaction with the support you received from social services during the pandemic** – **23.2%** of carers stated that they did not receive and support during the pandemic this was much lower than the **45.5%** nationally who stated that they had not received any support. **8.4%** were extremely satisfied with the support their received during the pandemic, **12.9%** very satisfied and **24.5%** quite satisfied. **6.5%** were extremely unsatisfied, **4.5%** very dissatisfied and **3.9%** quite dissatisfied.

## How we compare

Thinking about your experiences during the pandemic, how satisfied or dissatisfied are you with the support of services you and the person you care for have received?	National	Peterborough compared to England
We didn't receive any support from social services during the pandemic	45.5%	23.2% Better
I am extremely satisfied	7.6%	8.4% Better
I am very satisfied	10.8%	12.9% Better
I am quite satisfied	15.3%	24.5% Better
I am neither satisfied or dissatisfied	11.6%	12.9%
I am quite dissatisfied	3.7%	3.9% Worse
I am very dissatisfied	2.1%	4.5% Worse
I am extremely dissatisfied	3.3%	6.5% Worse

**Social contact during the pandemic** – Only a small percentage of respondents, **11.5%**, felt they had as much social contact with people as they wanted during the pandemic, this was markedly lower than the **17.8%** nationally. **40.8%** of respondents had felt socially isolated, slightly lower than the national percentage or **41.2%**. The largest percentage, **47.8%**, said that they had some social contact but not enough.

How we compare

Thinking about how much social contact you've had with people during the pandemic, which statement best describes your social situation?	National	Peterborough compared to England
I had as much contact as I want with people I like	17.8%	11.5% <b>Worse</b>
I had some social contact with people but not enough	41%	47.8% <b>Worse</b>
I had little social contact with people and felt socially isolated.	41.2%	40.8% <b>Better</b>

**Personal safety during the pandemic** – the majority of carers, **66.5%** stated that they had no worries about their personal safety during the pandemic, although this was lower than the **71.5%** nationally. **6.3%** were extremely worried about personal safety, slightly better but similar to the **6.6%** nationally.

Thinking about your personal safety during the pandemic, which statement best describes how you felt?	National	Peterborough compared to England
I had no worries about my personal safety	71.5%	66.5% <b>Worse</b>
I had some worries about my personal safety	21.9%	27.32% <b>Worse</b>
I was extremely worried about my personal safety	6.6%	6.7% <b>Worse</b>

**Feeling consulted and involved during the pandemic.** **42.2%** of carers felt there had been no discussion that they were aware of during the pandemic, lower than the **51.5%** stating this nationally. Where there had been discussions higher percentages had felt involved or consulted.

How we compare

Thinking about your experiences during the pandemic, did you feel you were involved or consulted as much as you want to be, in discussions about the support provided to the person you care for?	National	Peterborough compared to England
There have been no discussions that I am aware of, during the pandemic	51.5%	42.2% <b>Better</b>
I always felt involved or consulted	14.8%	18.2% <b>Better</b>
I usually felt involved or consulted	13.9%	19.5% <b>Better</b>
I sometimes felt involved or consulted	12.5%	11.7% <b>Better</b>
I never felt involved or consulted	7.4%	8.4% <b>Worse</b>

## Comments from carers

My husband waited 21 months for life-saving surgery at Stoke Mandeville - before the pandemic, it would have been 2 - 4 weeks. The specialist beds were taken for COVID 19 patients. It was utterly terrifying. He is safe now and well but we still cannot access local hospital care as required. I am exhausted and depressed because I have had to make all the decisions concerning his care. Our GP's have been amazing. He's still got another 6 months to wait for a specialist bed for bowel surgery - 24 months all told. We had a fight to get him vaccinated due to government/NHS cock ups

During the last 2 years because of the COVID I have not had any break from my caring role or any respite break at all, as I was very worried about my daughter catching COVID so I rang SS if I can have my elder daughter, if she could have her for the weekend so I can have a break, but the person I spoke to said she took my details and somebody will contact me. But nobody rang me back.

As my son was classed as extremely vulnerable, I cancelled all respite care to ensure his safety. My mental state suffered severely as my only release was a 45-minute walk with him daily. I was supported by my youngest son who was home from university. It was agreed he could supply a sleep night for me once a week. My son struggles with changes in routine and was very frustrated by our lack of contact with the outside world. I was also supported by friends who did my shopping and prescription pickups. I was frustrated that I was not vaccinated at the same time as my son, as the consequences of me being ill would have been catastrophic and this in turn affected my mental health.

I felt very alone caring for my mother during COVID, it was frightening time as I knew I needed to remain well to care for her. getting food deliveries was hard until one store placed us on priority - the Wansford Surgery was really supportive. The manager of Caring Crew knew I was struggling after the duration of caring, alone during COVID and repeated broken nights. The kindly arranged one sleep in carer a week. I just sobbed with relief to know the responsibility was for one night, not mine and I could sleep and relax

Whilst help and support was needed earlier, we did not feel comfortable in asking what was available to us until we had had both of our vaccines. Support for my husband was sorted very quickly, for which were grateful. My carers assessment took 13 weeks to get a response to, with little support available to me as we pay for care

## Local Questions

In addition to the prescribed national questions Local Authorities are able to choose additional questions from a list of approved questions, where they think these may add value. In collaboration with members of the Carer's Partnership Board the following local questions were selected.

**Have you found it easy or difficult to get the support or services you need as a carer in the last 12 months? The services may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services**

Response	Percentage
I did not need any support or services in the last 12 months	20.1%
Very easy	10.4%
Quite easy	31.8%
Quite difficult	26.0%
Very difficult	11.7%

**Q6C If you found it difficult to get the support or services you needed as a carer in the last 12 months, please tell us why and what we can do to make it easier for you)**

This was a free text box and a selection of responses have been included:

My comment is not about me, but about all of those carers who are 'dropped in the deep end' when their loved one is suddenly discharged from hospital and sent home to be looked after by a member of the family acting as a part time or permanent carer. From my experience your lifestyle changes completely - you are 'in the dark' as to what help you can access and you don't know what questions to ask. You are given certain information before the patient leaves hospital, but the information is not 'taken in' because your attention is focused on your loved one. The same can be said about the City Council who visits you at home. You are bombarded with help and information, but at a vulnerable time, so only 10% of the information is retained. There needs to be someone who regularly visits the home and talks to the carer about problems and benefits available. The visits could diminish in time as the carer becomes more knowledgeable.

I didn't always know about services available to me. Sometimes I've found out about help through the Alzheimers Society and their support workers. I would like it if ASC would check upon me from time to time as it's been particularly hard for me as mum deteriorates.

The hardest part was that before support became easy to obtain, my Dad had to reach a crisis point and not be safe in his home anymore. More support to plan earlier would have been helpful.

Provide disabled parking amenity/amenities. As a carer I am also severely disabled. I can only walk or shuffle 5 yards at a time

There are no day care facilities available at a weekend that we can access for my husband and help to give me a rest. I cannot be the only carer working full time who would find a facility like this invaluable.

**How is your health in general?**

Response	Percentage
Very Good	6.9%
Good	26.3%
Fair	49.4%
Bad	16.3%
Very Bad	1.3%



**What do you use to find information and advice about support, services or benefits?**

<b>Response</b>	<b>Percentage</b>
Internet	51%
Family and friends	41.9%
Telephone helpline	14.2%
Leaflets / newsletter	20%
Advice from a voluntary of community group	21.3%
Advice from a professional	20.6%
Other	10.3%
Not applicable	7.7%

This page is intentionally left blank