

State of Suffolk: Carers

Since this report was produced, the 2021 Census data has been released. It should be in conjunction with reports published on the Healthy Suffolk website (<https://www.healthysuffolk.org.uk/joint-strategic-needs-assessment/suffolk-census-2021>), particularly the section on [Health, disability and unpaid care - 2021 Census Suffolk summary](#)

If you only read 5 things...

- At least one in 10 carers across Suffolk are aged 75 and over, with 13% of carers in West Suffolk CCG being in this age group
- The number of unpaid carers aged 65 and over in Suffolk is forecast to increase by 37.7% between 2017 and 2035, slightly below the national increase of 39.2%
- 3 in 5 carers have a long-term health condition compared to half of non-carers. For young carers aged 16-24 years, 45% have a long-term health condition compared to 30% of non-carers in the same age group
- When asked about their physical and mental health, adult carers in Suffolk were more likely to report negative outcomes compared to the regional and national averages
- Social isolation is a problem for carers in Suffolk. A quarter of adult carers in the county say they do not have as much social contact as they would like.

Why are carers important in Suffolk?

Caring for relatives and friends when they are in need is a challenge that many people will face at some point. When a family member or friend experiences ill-health, it has the potential to change lives forever and can have a profound and lasting effect on the health and wellbeing of family members who look after them. The support offered by carers is one of the most valuable assets within our communities. Without the input of carers, the formal care system would be likely to collapse¹.

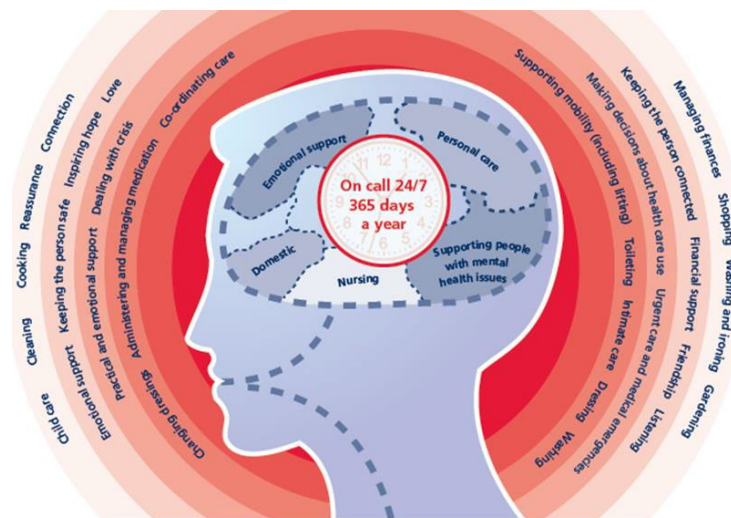
Carers UK estimate that there are 6.5 million unpaid carers in the UK who contribute £132 billion of unpaid care per year². DEMOS, which is a cross party think-tank and independent educational charity, believe the figures to be even higher, estimating the number of unpaid carers as closer to 8 million and the value of the informal care economy to be £139 billion³. DEMOS suggest that a Carers' Covenant – a settlement between the state and informal carers – is necessary because government policy has not reflected what it perceives to be '*one of the biggest demographic shifts in recent British history*'.

There are several descriptions of the term 'carer' but currently no single, agreed definition. The 2014 Suffolk Carer's Needs Assessment used the '*Commissioning for Carers*' definition^{4,5}:

'A Carer spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems'.

The type of support a carer may provide will vary according to the needs of the individual that they are caring for (Figure 1). This support can range from helping with day to day tasks such as cooking, dressing, and administering and managing medication, to less regular but equally vital tasks such as shopping, gardening and managing finances. A carer also provides friendship, emotional support and social interaction to the person they are caring for, as well as keeping them safe and being on hand to deal with emergencies. In this way carers help the person they care for to remain independent and live the life they choose.

Figure 1. Types of support that carers contribute



Source: ¹

The pressure of providing such comprehensive assistance can lead to carer stress, and potentially breakdown; in these circumstances the demand on the health and care system can come from *both* the person being cared for – who is now without support to lead an independent life – and the carer themselves, who may require mental and emotional support as their caring responsibilities impact upon their own quality of life. Having no carer and carer stress are major influences on admissions to long-term residential and nursing care, with an estimated 38% of such admissions attributed to carer stress, and a further 8% resulting from family breakdown, which includes the loss of the carer⁶.

The 2018 GP Patient Survey found that carers providing round the clock care are more than twice as likely to be in bad health as non-carers⁷. Other findings of this survey include:

- A higher proportion of carers have a long-term health condition compared non-carers (61% v 50%).
- The difference is more pronounced among younger people aged 16-24 years, with 45% of carers having a long-term health condition compared to 30% of non-carers
- Long term back and mobility problems are caused by long term physical stress from moving and handling without the right equipment or training.

The 2016/17 Survey of Adult Carers found that⁸:

- More than half of carers (58.7%) said they had general feelings of stress because of their caring responsibilities, and 23.3% had developed their own health conditions
- Almost 2 in 3 carers (64%) reported difficulty getting a good night's sleep
- 4 in 10 carers (43.4%) said they had suffered with depression because of their caring role

The potential consequences of these negative effects can be as extreme as the carer having to give up work, stop caring or go into hospital themselves. This can be exacerbated by carers not attending their own medical check-ups through lack of time or delaying treatment because of caring responsibilities. Carers providing more than 50 hours of care a week and carers aged 65+ were both more likely to report that caring has had a worsening effect on their own physical health. This finding is of importance because of the anticipated change in the demographic profile of the population. The estimated number of people aged 65+ in England is expected to increase by 40.7% between 2017 and 2035, with the number of unpaid carers of the same age expected to rise by a similar amount 39.2%⁹. By 2035, there are expected to be almost two million unpaid carers aged 65 and over¹⁰.

The term 'sandwich carers' refers to individuals whose caring responsibilities include looking after both children and sick or disabled older relatives. It is estimated that 3% of the UK population (1.3 million people) have this 'twin responsibility' as a consequence of increasing life expectancy and women having their first child at an older age¹¹. The report suggests that 'sandwich carers' are more likely to report symptoms of mental ill-health, feel less satisfied with life and struggle financially compared with the general population.

Projections suggest that the number of people aged 65 and over who provide unpaid care in Suffolk will increase between 2019 and 2035, from 25,300 to 33,700 (an increase of 33%).^[10] Over the same period, the number of people aged 65 and over who are unable to manage at least one self-care activity on their own will increase from 60,900 to 91,000 (a rise of 49%).^[10]

Carer's allowance recipients

In August 2018, there were nearly 8,400 individuals in receipt of carer's allowance in Suffolk, of whom 3 in 4 were female.^[15] This represents a small subset (11%) of the unpaid carers identified in the 2011 census. Possible reasons for the small number of individuals receiving carer's allowance include the stringent eligibility criteria for both the carer and the cared for person.

Eligibility for carer's allowance is complex, with a large proportion of unpaid carers not meeting the criteria. The person being cared for must be in receipt of a benefit related to their need, such as Attendance Allowance. This means that most carers' allowances are claimed by people caring for those with more severe needs rather than older people whose needs do not qualify them for the relevant benefits. Among other criteria related to the unpaid carer, they must spend at least 35 hours a week caring and earn a maximum of £110 per week (excluding pension payments).

Young carers

The identification of young carers and young adult carers can be difficult and often takes place in different settings to that of the adult unpaid carer population¹². Nationally, there are estimated to be 700,000 carers aged under 18 who care for a family member or friend that is ill, disabled or who misuses drugs and/or alcohol. Young carers who provide 50 or more hours of care a week are five times more likely to report their health as 'not good'¹³.

It can be difficult for young carers to access support because of their circumstances and the demands of their caring role. For example, they may need to make an appointment without the support of a parent or older person to help them, or there may be no one available for them to call on to cover care provision for their family member or friend. Their caring responsibilities can lead to tiredness, worry, stress and isolation, and can also be a risk factor in terms of their mental health. Caring responsibilities can also impact on other areas of life, such as educational attainment, employment, personal and social life.

Where young carers' physical and/or mental health is at risk, and/or their life opportunities reduced (perhaps as a consequence of poor educational attainment and employment options), the longer-term impacts on their lives may include their own need for care provision.

What is the local picture?

Demographics

Demographic information about carers in Suffolk is available from two key sources, the GP Patient Survey 2018 and the 2011 Census^{7,14}. The GP Patient Survey is less comprehensive than the 2011 Census but more up to date. This section includes a summary of demographic information from both data sources.

The GP Patient Survey shows that more than half of carers across Suffolk are female, and more than 9 in 10 are of White Ethnic origin. Percentages are shown in the table below to allow meaningful comparison to be made between Suffolk CCGs and England.

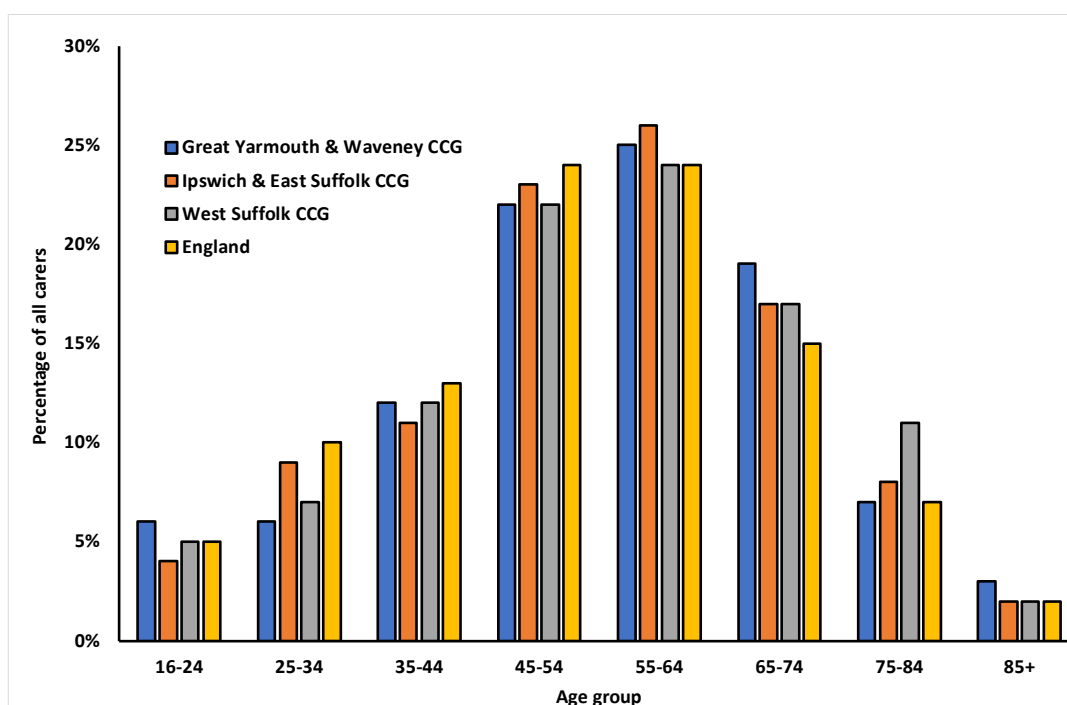
Table 1: Demographics of carers across Suffolk and England, 2018

	Percentage of unpaid carers		
	Male	Female	White ethnic origin
Great Yarmouth & Waveney CCG	46%	54%	92%
Ipswich & East Suffolk CCG	42%	58%	95%
West Suffolk CCG	42%	58%	95%
England	44%	56%	84%

Source: ⁷

The age distribution of carers in Suffolk is shown in Figure 2 below. In 2018, almost half of all carers in Suffolk CCGs and England were aged between 45 and 64 years. A relatively small but notable proportion of carers, at least 1 in 10, were aged 75+⁷. The highest proportion of carers aged 75+ were found in West Suffolk CCG (13%).

Figure 2: Proportion of all carers by age group and area, Suffolk CCGs, England, 2018



Source: ⁷

Data on carers at district and ward level is available from the 2011 Census¹⁴. The 2011 Census identified 77,745 unpaid carers in Suffolk, representing 10.7% of the county's total population (compared to 10.2% in the East of England and England as a whole). Across the districts/boroughs in Suffolk, the proportion of the population who provide unpaid care varies from 8.3% in Forest Heath to 11.9% in Suffolk Coastal.

The proportion of people providing unpaid care varies by ward in Suffolk, with Felixstowe East in Suffolk Coastal having the largest percentage of unpaid carers in 2011 (16.3%) and Red Lodge in Forest Heath the lowest (5.7%). Higher percentages of unpaid carers were recorded in wards in the North-East of the county (for example in the Leiston and Aldeburgh areas) and in parts of Lowestoft. The wards in the North-West of the county (around Brandon and Lakenheath) had the lowest percentage of unpaid carers in 2011.

In Suffolk, just over 4,700 young people aged under 25 identified themselves as unpaid carers in the 2011 census (4,713; 4.1% of all carers in Suffolk). Almost a third (31.8%) of these were aged under 16 (1,497; 1.9% of all carers in Suffolk). One in ten carers aged under 25 provided 50 or more hours of unpaid care (495; 10.5%).

In Suffolk more than a third (37.7%) of unpaid carers were aged 65+, although this varies across the districts/boroughs from 27.1% in Waveney to 47.7% in Forest Heath. Two thirds (66.3%) of all unpaid carers across the county provided under 20 hours of care a week and almost a quarter (22.1%) provided 50+ hours of care (ranging from 19.1% in Mid Suffolk to 27.4% in Waveney).

By 2038, Suffolk's population is expected to increase by 8.6% to 823,500⁹. The number of people aged 80+ is projected to rise by more than 40,000 people during this time period (a percentage increase of 81.9%). There are many implications of this significant demographic change. There will be an increase in the number of people requiring care and a corresponding rise in demand for carers to look after these individuals.

Projections suggest that the number of people aged 65 and over who provide unpaid care in Suffolk will increase between 2019 and 2035, from 25,300 to 33,700 (an increase of 33%).^[10] Over the same period, the number of people aged 65 and over who are unable to manage at least one self-care activity on their own will increase from 60,900 to 91,000 (a rise of 49%).^[10]

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In August 2018, there were nearly 8,400 individuals in receipt of carer's allowance in Suffolk, of whom 3 in 4 were female.^[15] This represents a small subset (11%) of the unpaid carers identified in the 2011 census. Possible reasons for the small number of individuals receiving carer's allowance include the stringent eligibility criteria for both the carer and the cared for person.

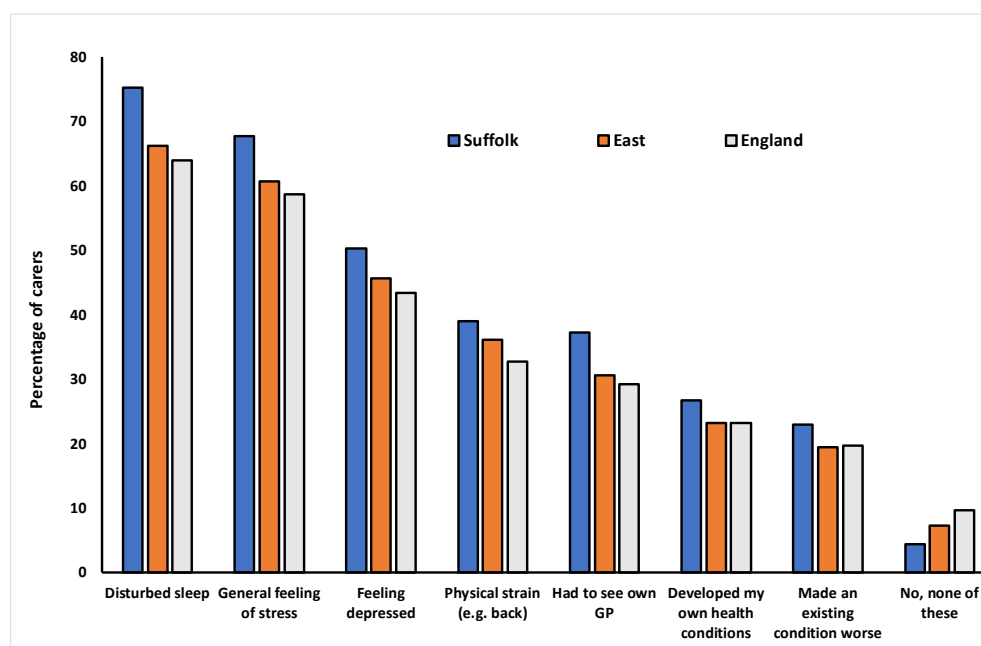
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Carer health

Young carers providing 50+ hours of care a week are five times more likely to report that their health is 'not good'. There is evidence that young carers have significant levels of mental ill health need that are not being addressed¹³.

The 2016/17 Survey of Adult Carers asked respondents *'In the last 12 months, has your health been affected by your caring role in the ways listed below?'*⁸. In Suffolk, a higher proportion of carers reported that their health had been negatively affected by their caring role compared to the East of England and England as a whole (Figure 3). The most commonly reported effects of being a carer were disturbed sleep, general feelings of stress and feeling depressed.

Figure 3. Ways that caring has impacted on the carer's health, Suffolk, East of England and England, 2016/17



Source: ⁸

Another consequence of having caring responsibilities can be social isolation, with carers often experiencing little or no free time to see family, friends or undertake activities of their own choosing and for their own benefit. In Suffolk, social isolation amongst adult carers is worse than the national average, with only 1 in 4 adult carers (24.9%) stating that they had as much social contact as they would like, compared to 1 in 3 (35.5%) across England. In the East of England, only Hertfordshire had a lower percentage than Suffolk.

How do local policies and services account for carers?

The provision of Carer's Assessments is a statutory requirement for local authorities. A number of organisations across Suffolk provide services to carers in Suffolk, although these are not listed here.

In Suffolk, Carers Assessments are currently provided by Suffolk Family Carers and Suffolk County Council. There is a review currently underway, involving family carer representatives and various organisations, to review the accessibility and effectiveness of the present provision in relation to advice, information, assessment and support for family carers.

The overall aims and priorities within this review are to:

- Increase the early identification and awareness of family carers.
- Improve the ease of family carers accessing timely, relevant and appropriate information and support.
- Increase awareness of and access to timely carers assessments.
- Ensure that there is appropriate support available for family carers to sustain their wellbeing and resilience to continue their caring role.
- Ensure a clearer and less fragmented offer across statutory organisations for carers across all ages, with jointly commissioned services and support where appropriate.

A multi-agency steering group has been set up, led by Adult Community Services (SCC) and which includes representation from

- Family Carers
- Children and Young People's Directorate, Suffolk County Council
- Norfolk and Suffolk Foundation Trust
- Ipswich and East Clinical Commissioning Group
- West Suffolk Clinical Commissioning Group, and
- Great Yarmouth and Waveney Clinical Commissioning Group.

Work undertaken by the steering group has included identifying and mapping the existing commissioned support for Family Carers and co-designing a survey, looking to obtain views from Family Carers around what is working well and what is working less well in relation to the current provision.

More information regarding the proposed timeframe for this review can be found in the Supporting Family Carers in Suffolk Equality Impact Assessment¹⁵.

There are a number of local charities and voluntary organisations that provide information, advice and support to Carers:

- **Suffolk Family Carers** is an established charity, which helps family carers of all ages across Suffolk get the support they need to live fuller lives. This includes providing access to an Online Community where carers can chat to other family carers, share information, advice and support each other. Find out more at: <https://suffolkfamilycarers.org/>
- **Suffolk Carers Matter** provides health information for carers, as well as local news items and details of local activities such as free art workshops. Find out more at: <https://www.suffolkcarersmatter.org.uk/>

Further information

A Suffolk Carers Needs Assessment was published by Suffolk County Council in October 2014⁴. The needs assessment can be accessed here: <https://www.healthysuffolk.org.uk/uploads/16-Dec-2014-Family-Carers-Needs-Assessment-final.pdf>

Public Health Suffolk also published a Young Carers and Young Adult Carers Needs Assessment in December 2015¹², which can be accessed here: <https://www.healthysuffolk.org.uk/uploads/20150104Young-Carers-Supplementary-Reportfinal.pdf>

Charities Age UK, Carers Trust and Carers UK are national charities who provide advice and support:

Age UK: <https://www.ageuk.org.uk/>

Carers Trust: <https://carers.org/>

Carers UK: <https://www.carersuk.org/>

References

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