

# **“I can’t make them accept help”**

**The experience of unpaid carers managing care refusal**



# Contents

Contents.....	1
About Healthwatch .....	2
Why this project? .....	2
Methodology .....	4
Our recommendations and next steps.....	4
The impact of unpaid caring.....	7
Rejecting care.....	8
Rejecting engaging with services.....	12
Carers not being involved in decision making.....	14
Sectioning and lack of control for unpaid carers .....	17
The cost of caring.....	18
Self-neglecting behaviour.....	20
Lasting power of attorney.....	21
Respite care.....	22
Support available for unpaid carers.....	23
Appendices .....	25

# About Healthwatch

Healthwatch is the independent voice of health and social care service users. We listen to peoples' experiences of health and social care services to feedback how to improve them.

Healthwatch uses your feedback to better understand the challenges facing the NHS and other care providers and we make sure your experiences improve health and care for everyone – locally and nationally. We can also help you to get the information and advice you need to make the right decisions for you and to get the support you deserve.

## Why this project?

### Purpose and objectives

- The 2021 census found that there are around 5.8 million unpaid carers in the UK.
- It is estimated that carers provide £182 billion worth of care each year across the UK.

Source: [www.carersuk.org/policy-and-research/key-facts-and-figures/](https://www.carersuk.org/policy-and-research/key-facts-and-figures/)

- The purpose of this project is to better understand the experiences of unpaid carers across BANES, Swindon and Wiltshire (BSW) when someone they are caring for refuses to accept help that could benefit them. It is based off the experiences we heard from carers at engagement events.
- Our project got lots of additional responses which cover the general experiences of carers in BSW, so we have written another report to go alongside this one.

### We will focus on:

- What it is like to access health and social care on behalf of someone else.
- What happens when someone refuses to accept help that a carer has got for them.
- The overall impact of caring on a carers mental and physical health and if they feel there is suitable support to help them.
- To understand the role other organisations (e.g.: carers centres) play in supporting carers.

### **Support for this project:**

We were thankful for having support from a number of organisations in this project:

- Avon and Wiltshire Mental Health Partnership (AWP)
- Carers Together Wiltshire
- BANES Parent Carer Forum
- BANES Carers Centre
- Swindon Carers Centre
- Wiltshire Parent Carer Council
- Age UK Wiltshire
- Swindon SEND Families Voice
- Three Chequers Medical Practice
- Forward Carers
- Bath Alzheimer's Society
- Alzheimer's Society Dementia support service
- Youth Action Wiltshire
- Wiltshire Council
- BSW Carers Forum

In addition, we were able to attend several carer support groups / coffee mornings which are listed here:

- KS2 carers meeting (BANES)
- Swindon Carers Centre meeting
- Carers voice meeting (BANES carers centre)
- Trowbridge carers café (Carers together Wiltshire)
- Salisbury carers café (Carers together Wiltshire)
- Devizes parent carer café (Carers together Wiltshire)
- Pewsey carers café (Carers together Wiltshire)
- Care 'n' share café BANES (AWP)

# Methodology

Details of the demographics of the respondents and where the people who completed the survey are available in appendix 1.

Our research took place between January 2025 and May 2025 and is summarised in this table:

Research	Number of responses	Additional information
Survey and carers cafes	127	Survey was available online and as a paper version.
Interviews	4	Interviews took place in BANES (1 interview) and Swindon (3 interviews). These were 1-to-1 conversations about carers experiences and were informal.
Focus groups	1	This focus group was online with 2 cares in BANES.

# Our recommendations and next steps

Based on the findings from our research, we have outlined key recommendations and proposed next steps.

## 1. Enhancing Respite Support

**Issue:** Carers often receive short or inflexible respite periods that do not allow for proper rest or recovery.

**Recommendation:** Local authorities should consider extending the duration and flexibility of respite care services to better accommodate the full cycle of a carer’s needs – preparation, rest, and reintegration.

### Next Steps:

- Conduct a survey of carers to assess current respite usage and unmet needs.
- Pilot extended respite models in one locality.
- Collaborate with care providers to introduce flexible scheduling options.



## 2. Improving Accessibility of Support Services

**Issue:** Many carers are unable to attend in-person support due to their responsibilities.

**Recommendation:** Expand digital access to carer support services to ensure inclusivity.

### Next Steps:

Audit current digital offerings and identify gaps.  
Develop or enhance online platforms for peer support, counselling, and training.  
Promote digital services through GP practices and community hubs.

## 3. Diversifying Support Activities

**Issue:** Support services often lack variety and do not always meet the needs of carers who attend them. For example, it was reported lots of activities are often geared towards female carers (e.g. having nails painted etc)

**Recommendation:** Services should review the availability of support activities to ensure a broad range of support is available for a wide range of carers (such as male carers)

### Next Steps:

Engage carers in co-designing activity programmes.  
Partner with local organisations to offer varied sessions (e.g. fitness, tech, DIY, creative arts) and review effectiveness.

## 4. Providing Legal Guidance

**Issue:** Carers often lack access to legal information and support.

**Recommendation:** Improve access to legal information and practical support around Power of Attorney and related tools for services who support carers.

### Next Steps:

Partner with legal aid organisations to offer free clinics or webinars.  
Create accessible guides and toolkits for carers.  
Train support staff to signpost legal resources effectively.

## 5. Raising Awareness of the Carer Role

**Issue:** Many individuals do not recognise themselves as carers and miss out on support.

**Recommendation:** Launch a public awareness campaign through the BSW Integrated Care Board and the third sector.

### Next Steps:

Develop campaign materials (social media, posters, radio).  
Target outreach through GP surgeries, pharmacies, schools, and workplaces.  
Include real-life stories to illustrate the diversity of carer roles.

## 6. Standardising Emergency Care Protocols

**Issue:** Inconsistent application of emergency care protocols – particularly during mental health sectioning – across Bath and North East Somerset, Swindon, and Wiltshire (BSW) has led to unequal treatment of carers. Reports indicate that outdated assumptions (e.g. prioritising older parents over primary carers) may influence decisions, resulting in exclusion of key carers from critical processes.

**Recommendation:** Review and harmonise emergency care protocols across Bath and North East Somerset, Swindon, and Wiltshire.

### Next Steps:

Further investigate the frequency of this issue and how widespread it is.

If required, create a working group with BSW ICB, Avon and Wiltshire Mental Health Partnership, third sector and carer representatives to:

- Audit current protocols and identify inconsistencies.
- Draft and pilot a unified protocol with clear carer inclusion criteria.

## 7. A More Nuanced Approach to Safeguarding and Carer Involvement

**Issue:** Current safeguarding protocols can unintentionally exclude carers from participating in medical decisions, even when they are the primary source of support and advocacy for the individual.

**Recommendation:** Review of safeguarding policies to ensure carers are not excluded without clear justification.

### Next Steps:

Review case studies where carers were excluded.

Update safeguarding guidance to include carer advocacy roles.

Train staff on balancing protection with inclusion.

## 8. Mandatory Training for Local Authorities and Enforcement Bodies

**Issue:** Frontline staff often lack training in supporting neurodivergent individuals and those with learning disabilities.

**Recommendation:** Make **Oliver McGowan Mandatory Training** or similar training available for all public-facing staff. This includes groups like Police officers, social workers, Emergency responders and Local authority staff who interact with vulnerable individuals. Consider developing training that is specific to different public facing roles in order to be equipped to support neurodivergent individuals.

### Next Steps:

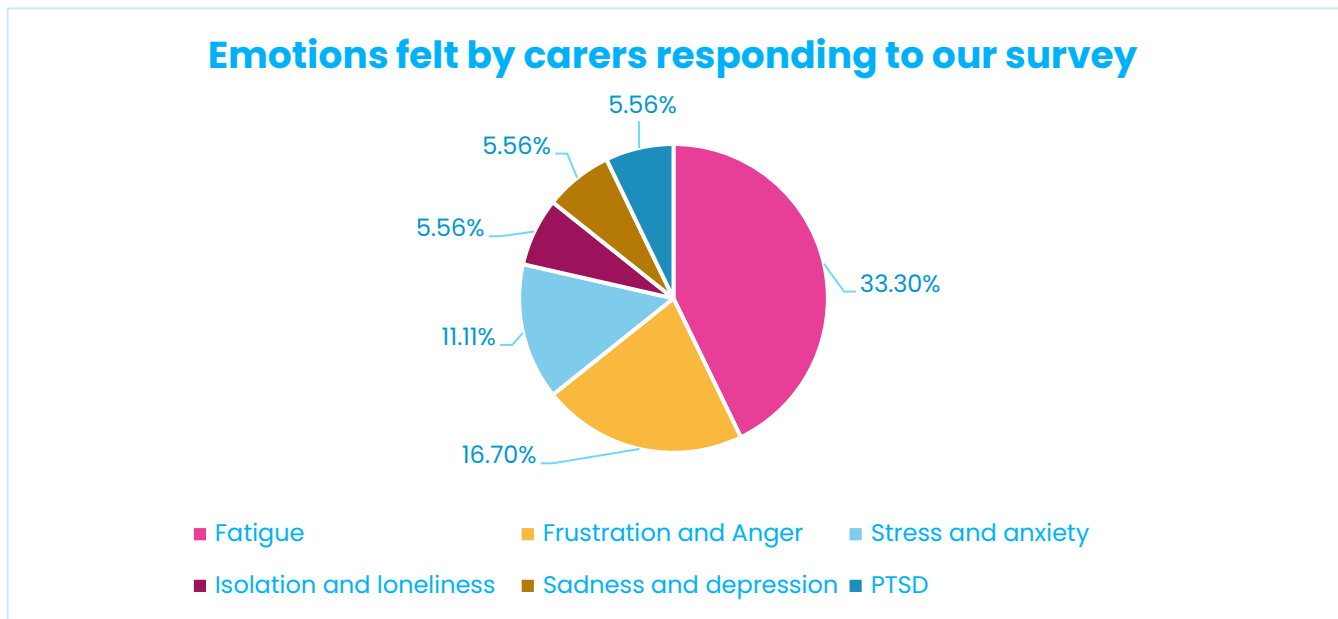
Map current training coverage across BSW.

Develop role-specific modules for police, social workers, emergency responders, etc.

Monitor uptake and impact through feedback and service outcomes.

# The impact of unpaid caring

92% of respondents to our survey said they felt overwhelmed because of their caring role.



Carers described needing to have their phone on alert all the time, always needing a full tank of petrol in their car and always being prepared to drop things they are doing to support the person they care for.

**"No break, on alert all the time, struggle to get NHS appointments. Cannot get out of the house many days as unable to leave my daughter, cannot meet people or attend appointments for myself as caring for daughters."**

Carers also described giving up hobbies or opportunities to socialise so that the person they care for would not be alone.

**"I have had to give up the two things I enjoyed most – playing bowls and my season ticket at Bath Rugby. I have my own health issues (I am 83) and am often tired."**

Carers also reported feeling a duty to care as there is no one else who is willing to.



"My needs come last. There is no one to take care of things if I stop. It just gets worse."

Carers have no sense of identity as they have lost it to the role of caring for someone else.

"I don't have time for me, I have lost my identity."

Carers told us they do not have control over their own lives and felt they exist to care for the person.

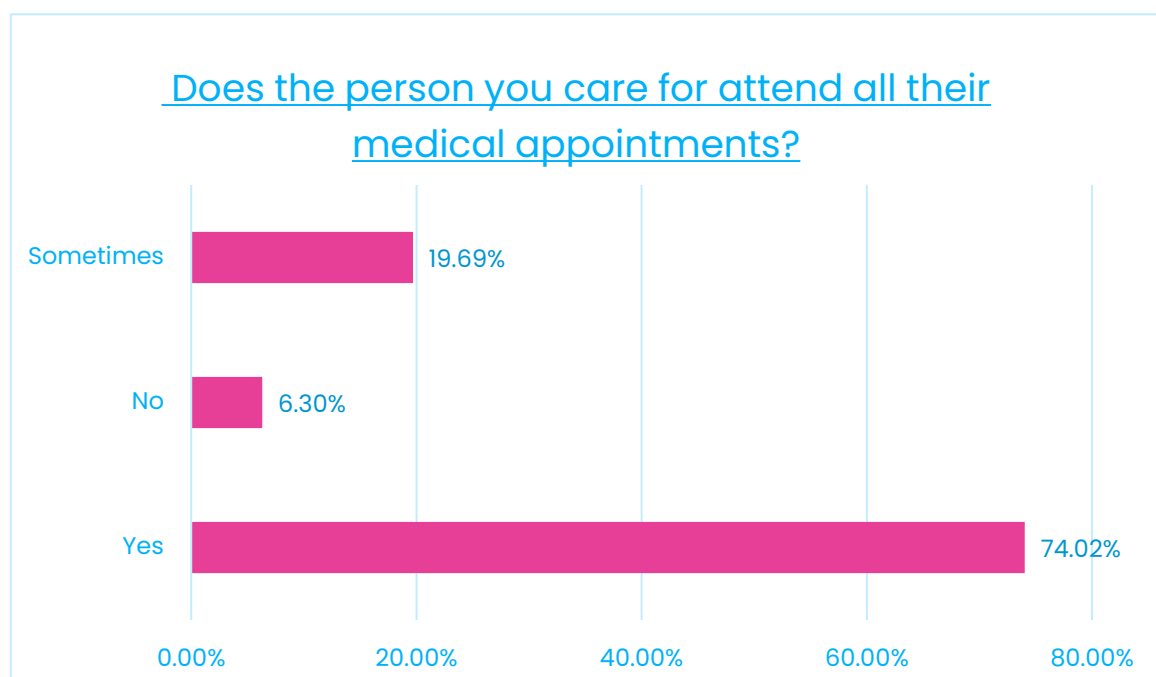
# Rejecting care

## Rejecting attending appointments

19.7% of respondents said the person they care for **only sometimes** attends all their appointments.

6.3% of respondents said the person they care for **does not** attend all their appointments.

74.02% of respondents said the person they care for **does** attend all their appointments.



## Why don't people attend their appointments?

"They don't want to engage with some mental health teams, either because they refuse to believe they are sick, or because they don't like the professional or feel the professional doesn't listen to them or like them."

- In some cases, people don't attend appointments because of negative past experiences.

---

"They feel too unwell and do not think the outcome is worth the effort".

---

- Other times, people are physically unable to attend their appointments.

---

"My husband is housebound, so it is difficult for him to attend."

---

- Other people may not attend because they find it anxious to be in a medical environment or around medical professionals.

---

"Because he gets too low or anxious and lacks motivation to look after himself"

---

## Reasons for not attending appointments: lack of flexibility in care

Many carers reported that someone might refuse to go to an appointment but would accept help from a GP at home.

However, in lots of cases, the GP will not do home visits, so the person misses out on receiving care.

Other carers told us that sometimes the times of appointments are not suitable and so they end up being missed.

## How this affects the carer

These problems fall on the carer to solve.

---

"I am blamed by the GP if he does not attend his appointments"

---

Carers also reported a lack of flexibility from call handlers that mean the person they care for does not always get the help they need



"Just last week, he was living with us not feeling well. His awful morning cough and sickness did not stop. I called 111 in the morning he had been coughing badly for 1 hour. He wouldn't speak to them. He stopped then it started again. Refusing help. By 7pm he agreed to calling 111. It took 4 'if you want this button press x' when we reached a person she said I need to ask questions some are irrelevant. My son refused to continue talking. The 111 person said I could not continue on his behalf as he hadn't given consent. He wouldn't go to hospital in the car with me. 2 hours later I called 999. He was assigned category 1 as they could hear him wheezing and coughing in the background. I was asked to get a defibrillator. They arrived very quickly, put him on oxygen - his levels were dangerously low. If 111 had accepted my request that he had been triggered because of autism and I would continue for him this awful emergency could have been avoided."



Carers report finding the process of accessing care on behalf of someone else exhausting.

"I had a seizure due to stress. It is stressful enough to be an unpaid, untrained carer but the majority of the stress comes from:

Trying to book appointments, trying to get medication changes, changes not communicated to pharmacy, medication not in stock, endless form filling for assessments, forms for benefits, council be unhelpful, chasing appointments."

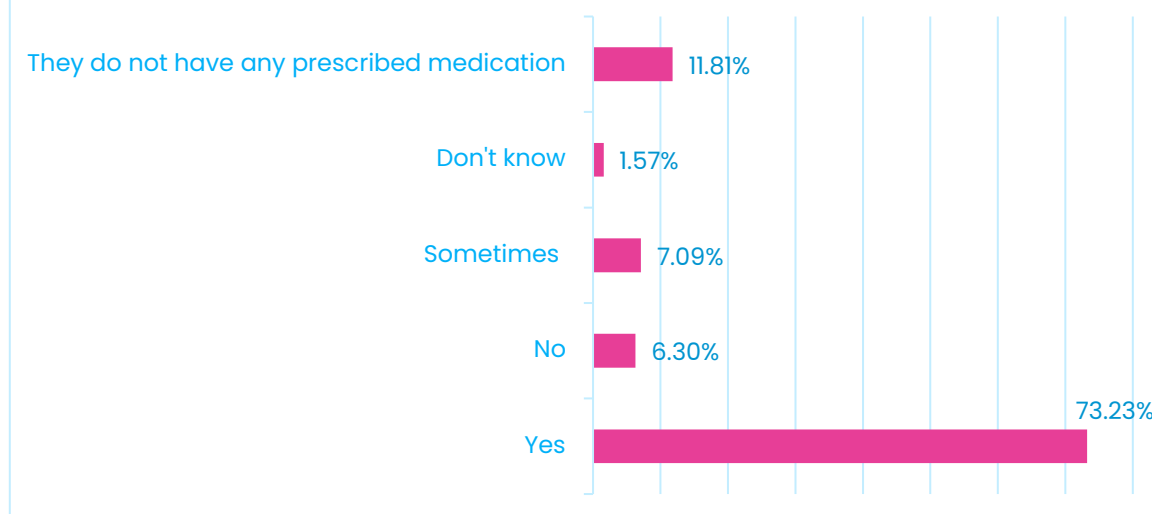
## Rejecting taking medication

7% of respondents said that the person they care for **only sometimes** takes all their prescribed medication.

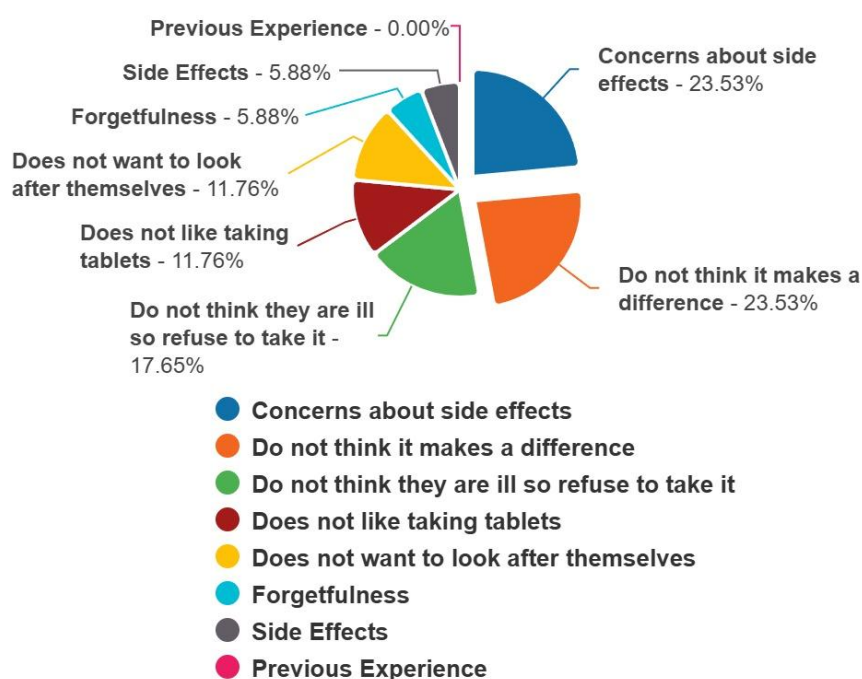
6.30% of respondents said that the person they care for **does not** take all their prescribed medication

73.23% of respondents said that the person they care for **does not** take all their prescribed medication

## Does the person you care for take all their prescribed medication?



## Why people don't always take their medication



- Carers reported that the person they care for does not always take medication because they are worried about the side effects or have had unpleasant side effects before

---

"Decide they feel better, concerned about accessing repeat medication, frightened of what will happen to his mind and body."

---

- Other carers reported that the person does not always take medication because they do not believe they are ill or do not want to feel better.

---

“They don't believe they are sick. Or they take it all at once because they want to stop feeling.”

---

- Some carers also told us it is due to practical issues that the person does not always take their medication, such as forgetfulness or not liking to take pills.

---

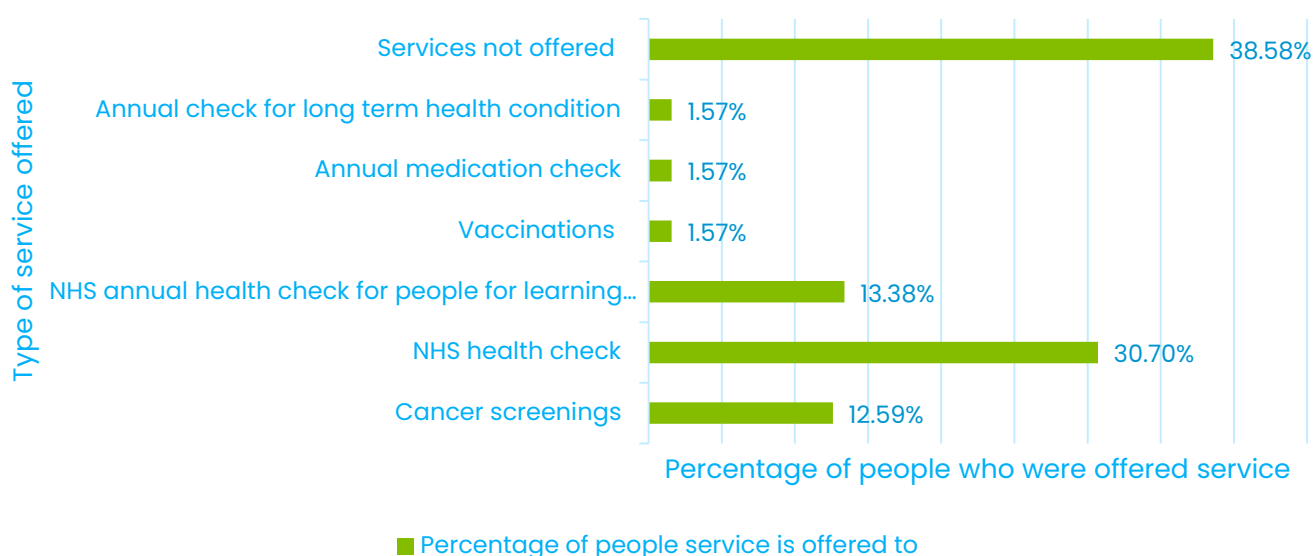
“Gets mixed up and needs to know what they are taking.”

---

## Rejecting engaging with services

In our survey, some carers reported that the person they care for refuses to engage with services that could be useful for them.

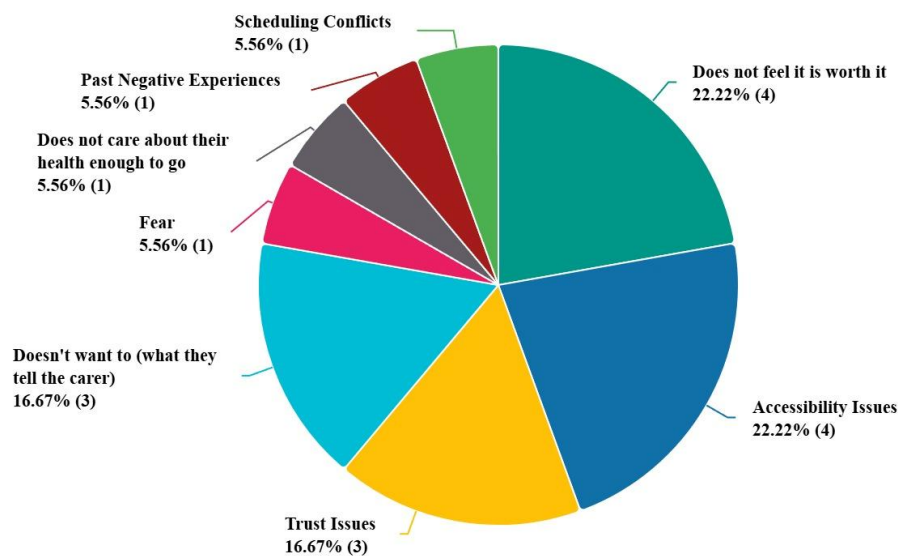
Services offered to people (data from our survey)



- 64.38% of carers said the person they care for **does** take up the services they were offered.
- 15.07% of carers said the person they care for **does not** take up the services they are offered
- 20.55% of carers said the person they care for only **sometimes** accepts these services

**In cases where services were reported as not being offered, it is also possible that these services are available but are not advertised so people are not aware of them.**

**Why don't people use services they are offered?**



The main reasons given by carers for people not taking up services they are offered is 'not feeling it is worth it' and 'accessibility issues'.

This shows that this issue is not a simple rejection of care but is actually far more complex.

Many people may not be aware of the benefits of using services such as an NHS health check, while other people may have issues with accessing the services (e.g.: being bed bound and not being able to do the check at home)

### **The impact of not using services that are offered**

- People with serious mental illness (SMI) have higher rates of premature deaths compared to the rest of the population
- The majority of these deaths are caused by preventable illnesses.

### **Rate of premature deaths among adults with SMI in 2021 – 23.**

- England: 110.8 people per 100,000



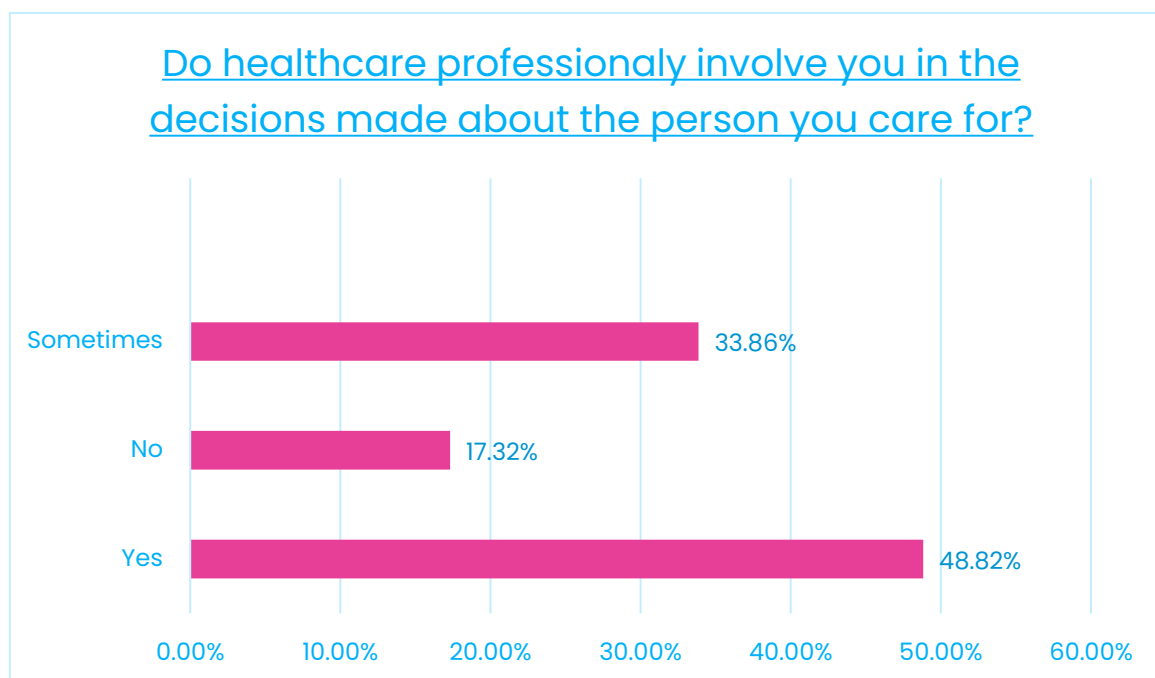
- BANES: 69.1 people per 100,000
- Swindon: 89.0 people per 100,000
- Wiltshire: 67.0 people per 100,000

Source:

<https://fingertips.phe.org.uk/search/premature%20mortality%20rates#page/4/gid/1/pat/6/ati/502/are/E06000054/iid/93581/age/181/sex/4/cat/-1/ctp/1/yr/3/cid/4/tbm/1/page-options/tre-do-0>

# Carers not being involved in decision making

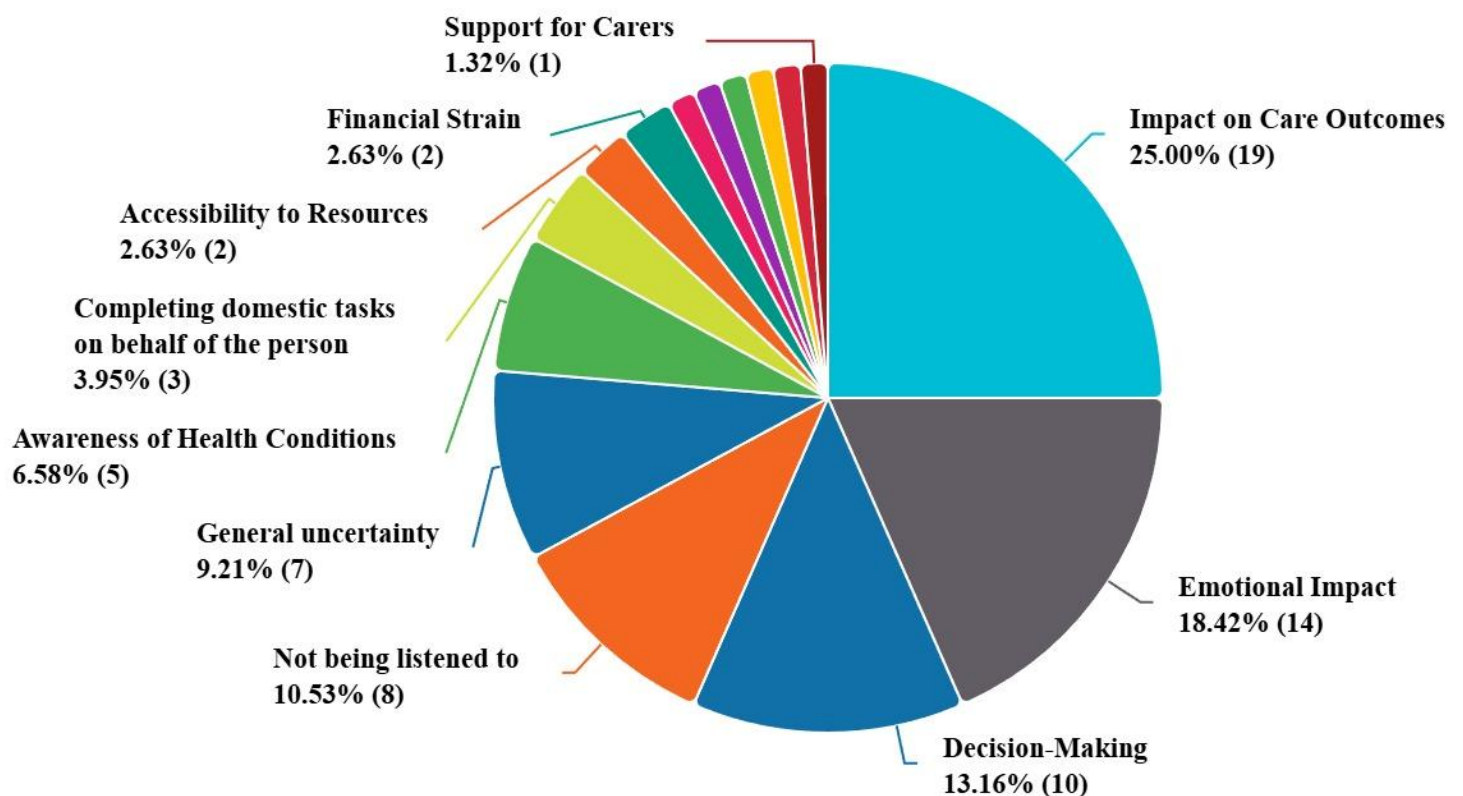
- 33.86% of respondents told us they were **sometimes** involved in decisions made about the person they care for
- 17.32% of respondents said they **were not** involved in decisions made about the person the care for
- 48.82% of respondents told us they **were** involved in decisions made about the person they care for



## The impacts of not being involved in the person's care

- 18.42% reported an emotional impact of not being involved in the person's care.
- 25% said not being involved had an impact on the care outcomes of the person, the majority said these impacts were negative.

These are all the reported impacts of not being involved in care from our survey:



The most common words used to describe the impacts of not being involved in decision making by unpaid carers:



## Safeguarding through the eyes of carers

- Carers acknowledge that confidentiality serves a purpose in safeguarding people but feel that often it negatively impacts the health outcomes of the person they are caring for.

"They don't contact me /won't usually ask me for my input because of 'confidentiality', even though she lives in my house and her health affects me."

- Carers told us that being excluded from conversations about the person they care for makes them feel unsupported by the systems and professionals that are meant to help them.

"I feel extremely frustrated and concerned that the medical profession does not have a full picture... He has refused consent... This then limits the kind of support he is offered."

"It is extremely difficult to navigate coordinating support now our daughter is over 18... support has been extremely limited and disjointed."

- Carers also told us that their experience and knowing the needs of the person would make them valuable resources, but confidentiality means they cannot be involved

"I feel the professionals are making decisions without having the full picture. I am the Expert by Experience in Caring for my husband and should be used as a valuable resource."

### Case study

One carer told us about their experience of safeguarding and how it negatively impacts their ability to carry out their caring role.

- The carer told us that although healthcare professionals do not share personal information about the person they care for, they often ask the carer to share similar personal information with them.
- They told us they understand why safeguarding rules exist, but feel healthcare professionals and other authorities lack an understanding of the carer role and the importance of knowing what is going on.
- In some cases, the carer told us that they have been kept in the dark so much that they are not aware the person they care for has been in any kind of trouble. This has been due to safeguarding procedures.

"The police are no help – they don't understand autism."

The full case study is available in Appendix 2.

# Sectioning and lack of control for unpaid carers

### What is sectioning?

Sectioning is when someone is kept in hospital under the Mental Health Act (1983). This is done because the person poses a risk to themselves or others.

Source: NHS website: <https://www.nhs.uk/mental-health/social-care-and-your-rights/mental-health-and-the-law/mental-health-act/>

Carers reported that sectioning often leads to a lot of control being taken away from unpaid carers.

This experience starts when the person is sectioned and continues right the way through to discharge (this is more often the case of people with a severe mental illness)

- Carers reported that the way the person is sectioned can be damaging for their mental health. In one case, a person was sectioned by police who were not sufficiently trained in dealing with someone with mental health issues. This left the person with a fear of police.
- Carers also reported that sometimes the person they care for was sent far away from their home. In one case, a person was sent to Harrogate, Yorkshire when they lived in Swindon.
- When someone is discharged, carers reported feeling that there was a lack of support from services in transitioning back to normal life.

---

“There’s no care plan when he leaves. He goes from 24/7 supervision to nothing.”

---

- Carers also reported not being listened to by healthcare professionals when someone they care for has been sectioned or is in hospital.
- Some carers reported that they were not allowed to be part of conversations around the care of the person because they were the younger of the two parents caring for the person., despite being registered as their care.
- There was a disparity in where this happened. Some carers reported this happening to them while others did not. There was no consistency of different policies across all the stories we heard.

---

“Because I am younger than my husband I was shut out from meetings about their care”

---

- Some carers even told us that people can be discharged from sectioning as homeless and with no care plan, so it is then up to the carer to pick up the pieces.
- Carers told us that services know that the carer will be there to help, so do not do everything they can to support someone in discharging them.

# The cost of caring

Carers told us they had been financially impacted by their caring role.

“One cannot earn from other roles when caring 24/7 and when this goes on for a decade it's utterly depleting to an ordinary family.”

### **Financial impact of caring on the carer**

- In some cases, carers told us they had to quit their job or move house to care for the person.

“I had to quit my job to care for him full time.”

### **Carers and lack of financial control**

- Some unpaid carers also told us they spent a lot of their money on the person they care for, even if the person receives benefits.
- This means that unpaid carers then do not have enough money to support themselves or live comfortably.
- Because the person they are caring for is over 18, they are told that they can spend their money how they like.

“I don't have enough money to do what I want ... and that impacts on my health and mental health.”

- In other cases, it is up to unpaid carers to cover bills for things that the person needs, leaving them in financially stressful situations.

### **Financial support**

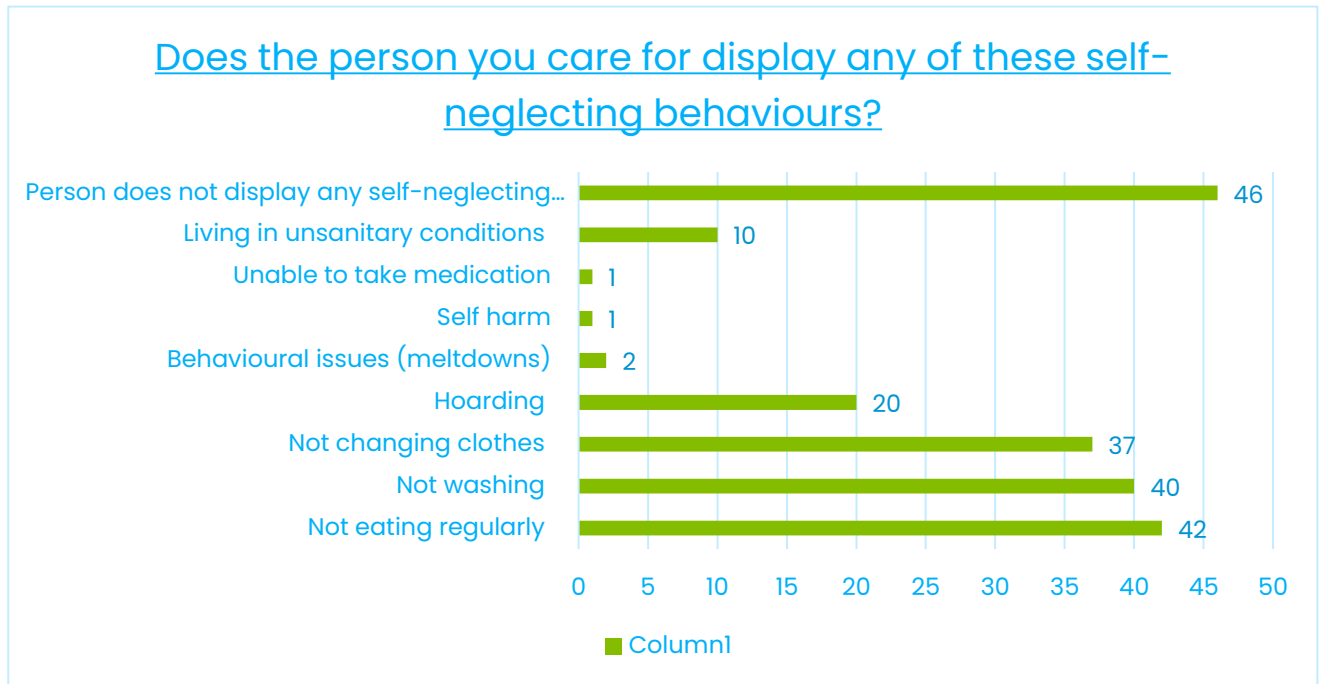
- Carers told us that support allowances are not always enough to keep up with the cost of caring for someone full time.

“I worry a lot about money, personally, I live on the breadline, carers allowance and universal credit simply do not cover the increasing bills.”



# Self-neglecting behaviour

What carers told us:



- Carers told us that it is because of them that the person they care for does not engage in more self-neglecting behaviours

---

If he was not living at home with me, it would be a lot worse"

---

- Carers often take on more roles than just helping with medical issues. They are involved in cleaning, food shopping and ensuring the person is looking after themselves.

"I [am] expected to sort everything out – (he hoard's) and re decorate etc... I have redecorated his current flat we have put in new carpets (that are always being cleaned as he insisted they must be white)."

"Always responsible for physical activities of daily living, such as shopping, driving, housework, meal prep.

# Lasting power of attorney

## What is lasting power of attorney?

In our survey we were particularly interested in health and welfare lasting power of attorney (LPA) and money and property LPA.

Lasting Power of Attorney (LPA) is a legal document that allows a person (called the donor) to appoint one or more people (called attorneys) to make decisions on their behalf if they lose the mental capacity to do so themselves.

There are two types of LPA:

### Health and Welfare LPA –

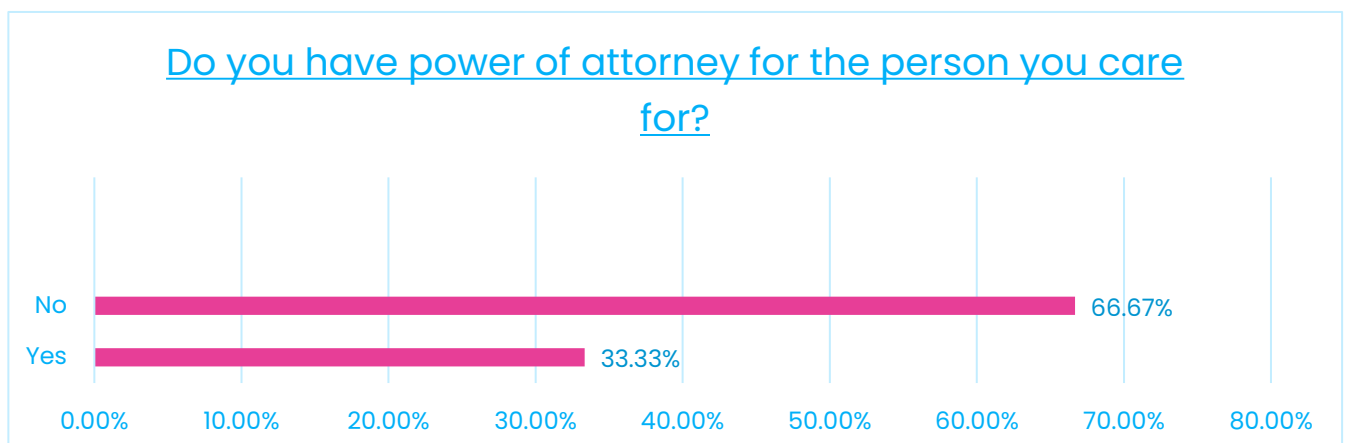
- This allows the attorney to make decisions about: daily routine (e.g. washing, dressing, eating), medical care, (such as moving into a care home and life-sustaining treatment).
- This type can only be used when the donor is unable to make their own decisions.

### Property and Financial Affairs LPA

- This allows the attorney to manage: bank or building society accounts, bills and expenses, benefits or pensions, and buying and selling property.
- This type can be used as soon as it's registered, with the donor's permission.

[Make, register or end a lasting power of attorney: Overview – GOV.UK](#)

From our survey:



- The carers we spoke to who have power of attorney said it has been very useful in being able to be involved in the care of the person they are looking after.
- Some carers have lasting power of attorney for medical decisions, while others may also have it for financial decisions too.

---

“It has been very useful for me, and I think it something that should be more widely spoken about.”

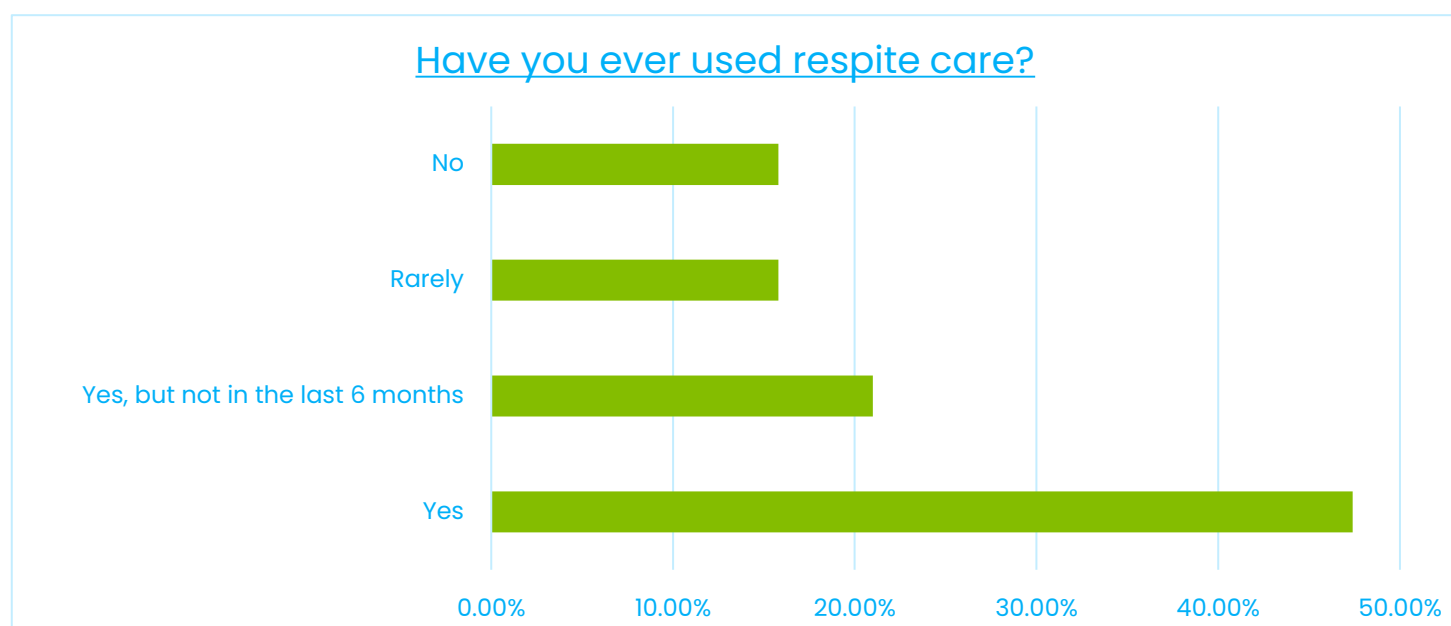
---

# Respite care

## What is respite care?

Respite care is designed to give carers a break from their role by giving them some time to themselves while someone else takes over caring for the person. It can range from a few hours with someone sitting with the person to being able to go on a holiday while the person stays in a care home.

We asked carers if they had ever used respite care:



For those who have not used respite care, these were the reasons given for not

using it:

- The cost
- The cared-for person has refused it
- The carer did not qualify for it

For those who did use respite care, it reported by some that it was not always a full rest from caring.

“By the time I have convinced them to accept the respite completed the handover chat and gotten ready and managed to leave the house I might only have an hour or two before I have to go back.”.

## Support available for unpaid carers

- Carers told us they use their local Carers Centre for advice and support.
- Carers also told us they found carers cafes useful in meeting other carers with similar experiences for advice and a chance to socialise.

“KS2 group has been welcoming; a place of understanding. I have also benefitted from a small number of kind church friends.”

“All the help and support comes from voluntary organisations.”

“It’s really hard to not feel overwhelmed and alone. The local peer support groups and carers centre are vital in helping me feel valued and not alone.”

- However, there are some cases where carers are not able to attend carers cafes as they cannot leave the person they are caring for.

"Often carers cafes are not accessible because I'm at home, caring, which is just as well as I'm often so tired I don't have the energy for anything else."

- Some carers told us that local organisations helped them as they had limited support from local authorities.

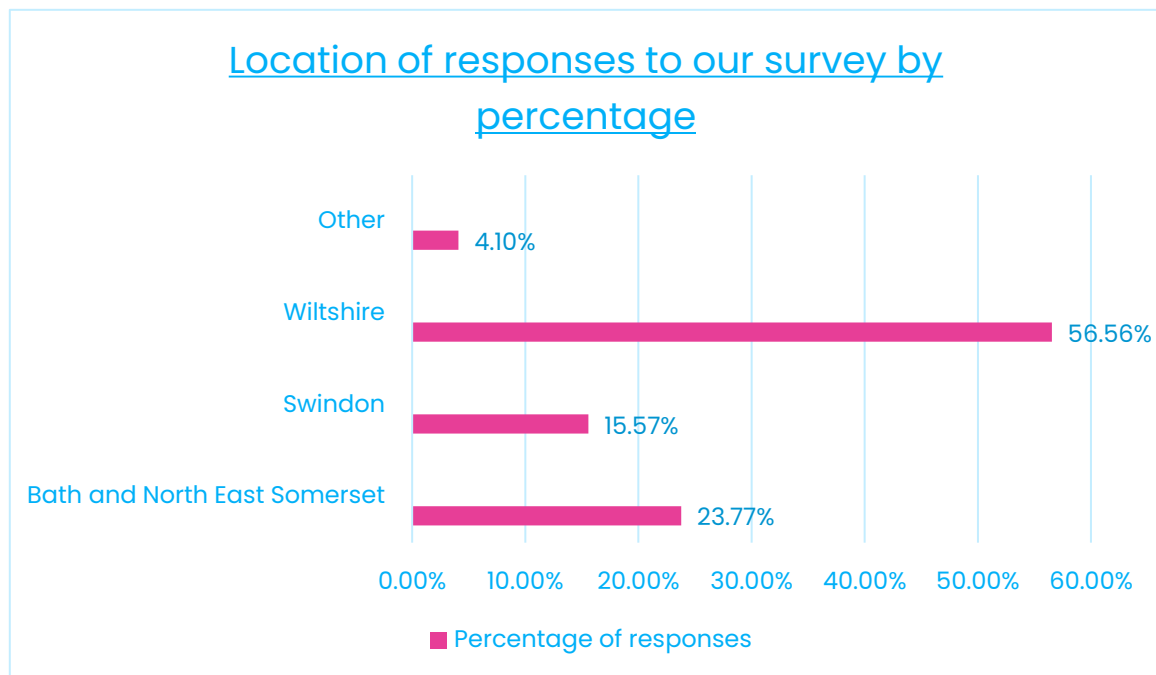
"The only respite I'm offered are through charities. Social services and Wiltshire council have absolutely no facilities or respite centres suitable."

# Appendices

## Appendix 1: The picture of caring in our survey

### The carers who completed our survey

- Our survey focused on carers caring for people over the age of 18 so that our scope was not too wide. It is worth noting that we had many more responses that were from parent carers of someone under the age of 18 (17 responses).
- Our survey was also limited to people living within Bath and North East Somerset Swindon and Wiltshire (BSW).
- The majority of responses to the survey came from Wiltshire. We have tried to balance this by holding our interviews in Swindon and Bath and North East Somerset (BANES).



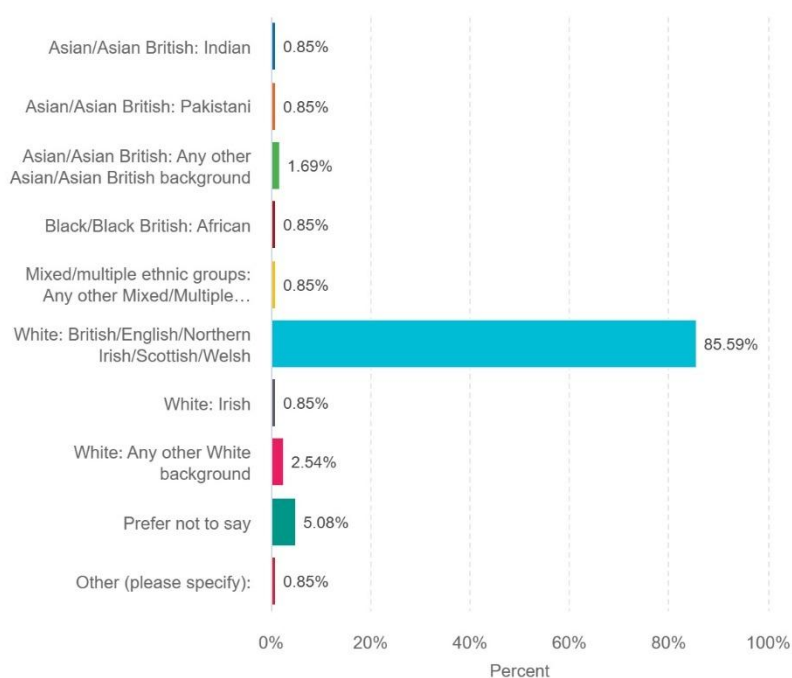
Survey responses that were not from BANES, Swindon or Wiltshire came from:

- Dorset (2 responses)
- Hampshire (1 response)
- North Somerset (1 response)

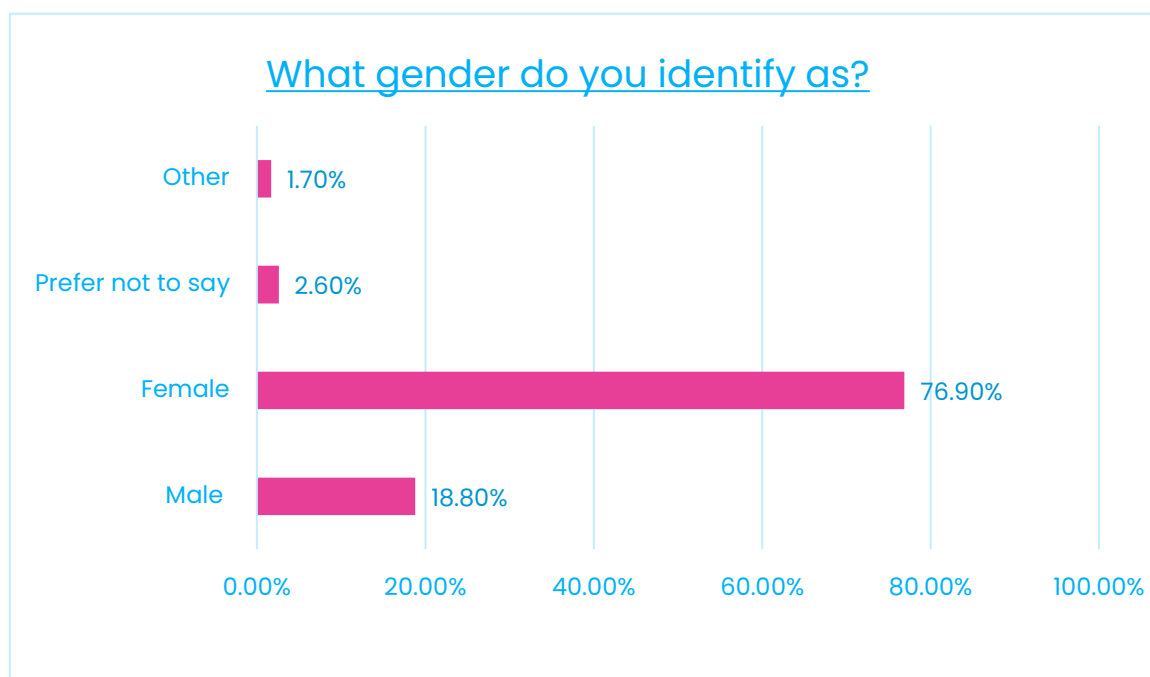


## Ethnicity of carers

- 85.6% of respondents to our survey were White British / Northern Irish / Welsh / Scottish.
- Those who described their ethnicity as other stated their ethnicity to be white British.
- Opposite is a full breakdown of all the ethnicities of carers who responded to our survey:

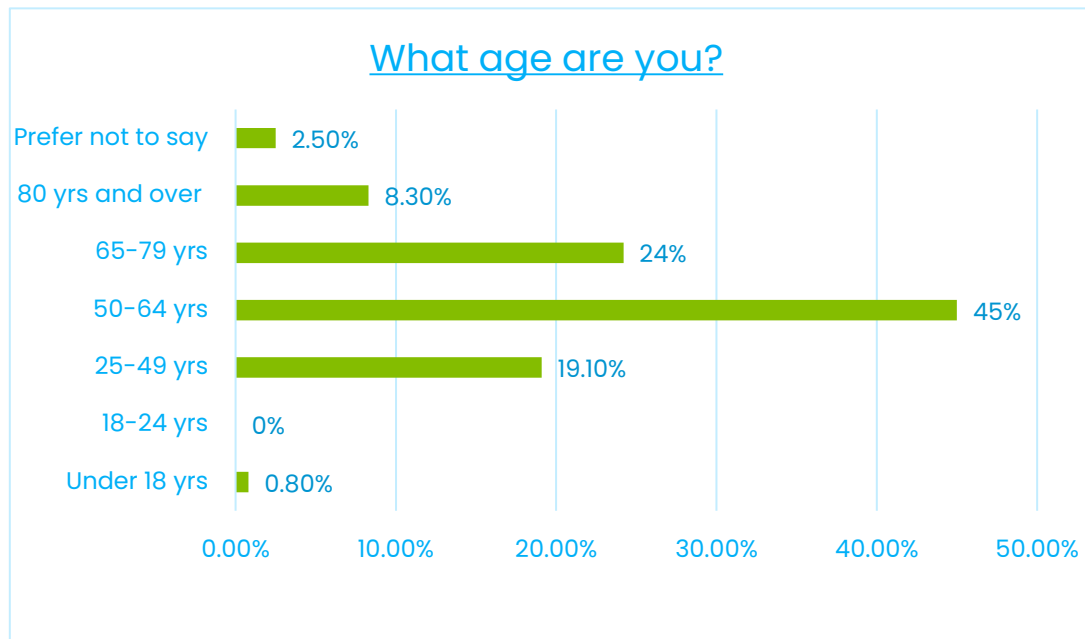


- Most carers who responded to our survey were female.
- However, we have included sections on the unique experience of male carers in this report and our second report on carers' experiences in BSW.



## Age of carers

- Nearly half (45%) of the carers who responded to our survey said they were aged 50–64.



## People that are being cared for:

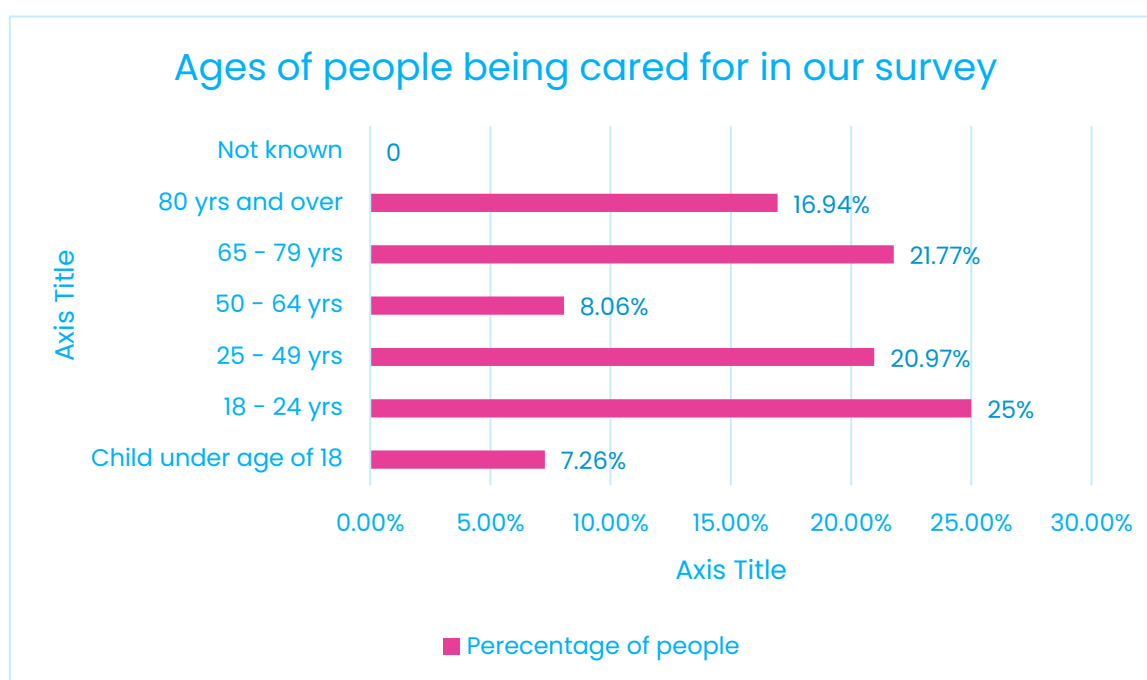
Our survey showed that carers are caring for people with a wide range of conditions that often co-exist. This accounts for the total number of people with a condition being higher than the overall number of responses to the survey.

Name of condition	Number of people
Person with a physical disability or mobility issues	26
Person with learning disabilities	23
Person with serious mental illness	21
Person with dementia or Alzheimer's disease	16
Person with another long-term health condition	14
Autism	12
ADHD	6
Addiction	4
Terminal illness	3

Cerebral Palsy	1
Epilepsy	1
Anxiety	1
Borderline personality disorder	1
Eating disorder	1
Diabetes	1
TOTAL	131

### Age of person being cared for

There was a lot of diversity in the ages of the people being cared for across BSW.



### Relationship to the person

- 92% of respondents said the person they care for is a family member.
- 74.5% of respondents said the person they care for lives at home with them.
- Lots of respondents said they care for someone because they are family and they have a duty to do so.

## Appendix 2: A case study of a carer in B&NES

### Overview

- This carer has been caring for their child in Bath and North East Somerset for the past 30 years who has autism and other mental health issues.
- The person does not live with the carer but is with them most of the time. The carer has had to turn down work opportunities to be there for the person they care for.

### The invisibility and isolation of the carer role

The carer is often excluded from the decision-making process and is ignored by professionals, despite their central role in the person's daily life.

"I'm rarely asked for my opinion by clinicians."

"Confidentiality is always used as the reason for not being involved – and this is the case for all other carers I know."

"They ask me for personal info about the person but won't tell me anything in return."

### Constant state of crisis and hypervigilance

The carer lives in a near-permanent state of readiness, anticipating regular emergencies without external support.

"I always have to keep my phone charged and a full tank of petrol in case something happens."

"There's an emergency at least once a week."

"There have been occasions where I've been out all night looking for them."

"Crisis lines just tell me to ring the police – but the police don't know how to deal with autism."

### Systematic barriers to accessing support

Legal and healthcare systems often fail to support the carer, especially since the person being cared for is an adult

The carer feels that healthcare professionals use things like confidentiality to their advantage by asking the carer for personal information about the person but will not tell them any information they deem to be sensitive.

"The police are no help – they don't understand autism."

"Because they're over 18, I'm told they can spend their money however they want – even if it means I have to pay for food."

"I don't feel like any of these organisations actually listen to what carers want."

"Professionals just blame me if they miss appointments."

### **The mental and physical impact of caring**

The carer experiences lots of physical and emotional effects as the result of long-term caregiving with very limited support.

"I feel mentally exhausted – like there's never a true picture of what's going on."

"Sometimes I have to just shut myself off for a few days."

"It's all-consuming – it's what I'm thinking about all the time."

"I have psoriasis and heart arrhythmia – it's all stress-related."

"I also care for other family members and support other carers – it's too much to contain."

### **Suggested recommendations from the carer**

The carer argues for a more tailored and effective system of support that respect the realities of caring for someone with complex needs

"There needs to be a crisis line for carers – one that actually responds and doesn't just signpost."

"I understand they're an adult, but there should be better options for emergencies."

"Professionals need proper training around conditions like autism."

"It feels like no one's actually listening to carers."

## **Appendix 3: Survey questions**

View or download appendix 3 on our website: [www.healthwatchwiltshire.co.uk/i-cant-make-them-accept-help-experience-unpaid-carers-managing-care-refusal](http://www.healthwatchwiltshire.co.uk/i-cant-make-them-accept-help-experience-unpaid-carers-managing-care-refusal)

If you need this information in an alternative format, please email [info@healthwatchwiltshire.co.uk](mailto:info@healthwatchwiltshire.co.uk) or call 01225 434218.



# healthwatch Wiltshire

Healthwatch Wiltshire  
C/O Independent Living Centre  
St George's Rd  
Semington  
BA14 6JQ

[www.healthwatchwiltshire.co.uk](http://www.healthwatchwiltshire.co.uk)

t: 01225 434218

e: [info@healthwatchwiltshire.co.uk](mailto:info@healthwatchwiltshire.co.uk)

f [Facebook.com/HealthwatchWiltshire](https://www.facebook.com/HealthwatchWiltshire)

X @HWWilts