Healthwatch Bath and North East Somerset | Healthwatch Swindon | Healthwatch Wiltshire

The strain of unpaid caring

The voices of unpaid carers across BathNES, Swindon and Wiltshire

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About Healthwatch

Healthwatch is the independent voice of the patient. 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 purpose of this project is to better understand the experiences of unpaid carers across BANES, Swindon and Wiltshire (BSW).
- Our aim is to make recommendations based on the feedback to improve the experiences of unpaid carers.

The outcomes of our project

- Throughout our project, we gathered a lot of insights that gave us a deeper understanding of the experiences of unpaid carers across BSW.
- This report brings together all of the data we captured to ensure that the voices of unpaid carers are fully represented and heard.

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 a number of 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

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

1. Physical health and wellbeing

Issue: Carers are at risk of physical injury because of the physical demands of their role, but stress related injuries may not be the focus during GP health-checks.

Recommendations: Encourage GP surgeries to screen for stress-related injuries and promote training on safe physical care techniques.

Next steps:

- Work with local NHS bodies to integrate carer-specific checks into GP appointments.
- Collaborate with physiotherapists and occupational therapists to deliver regular training sessions on safe lifting and mobility support.

2. Support for wider family

Issue: It is not just the carers who are affected by their role, but also wider family who watch what happens at home and in healthcare settings.

Recommendations: Increase support and awareness for family of people being cared for.

Next steps

- Create safe spaces for siblings to share their experiences and receive age-appropriate support.
- Produce accessible materials (videos, guides, workshops) to help extended family members understand the carer’s role and the impact of caring on themselves.

3. Recognise the unique challenges faced by ‘sandwich carers’

Issue: Those caring for both older and younger generations simultaneously face even greater challenges when trying to meet meets that vary from person to person. Although lots of these carers exist, the issues they face are not widely researched or spoken about.

Recommendation: Increase the visibility and awareness of the challenges faced by sandwich carers to help distinguish their needs and issues from other carers.

Next steps

- Include a specific category for multi-generational carers in carer assessments and data collection to ensure their needs are visible and understood.
- Create peer support groups and counselling services specifically for sandwich carers to address burnout, identity loss, and emotional fatigue.
- Launch an awareness campaign to highlight the specific challenges faced by sandwich carers.

4. Carer isolation

Issue: Carers often experience high levels of isolation and loneliness.

Recommendation: Recognise and acknowledge the significance of loneliness in the carer experience and try to reduce this feeling among carers through support and planning.

Next steps:

- Provide structured support for future planning, including legal, financial, and care transition advice, to reduce anxiety about what happens if the carer can no longer provide care.
- Ensure loneliness is more routinely assessed in carer support plans and assessments.

5. Financial support

Issue: Many carers are unaware of the financial support available to them, including grants for home adaptations and essential equipment.

Recommendation: Improve the visibility and accessibility of financial support information through local authorities and carer organisations.

Next steps:

- Create a centralised, easy-to-navigate online resource hub.

- Distribute printed materials through GP surgeries, libraries, and community centres.

6. Recognition

Issue: Carers often feel undervalued and unacknowledged by health and social care professionals

Recommendation: Increase formal recognition of carers by GP surgeries and local authorities to validate their role and contribution.

Next steps:

- Review carer identification protocols in GP practices.
- Launch awareness campaigns to highlight the role of unpaid carers and promote carer-friendly services.

7. Mental and emotional support

Issue: Carers often experience co-dependency, grief and emotional strain, particularly after the loss of the person they care for. Male carers experience more feelings of isolation and are less likely to seek traditional forms of support.

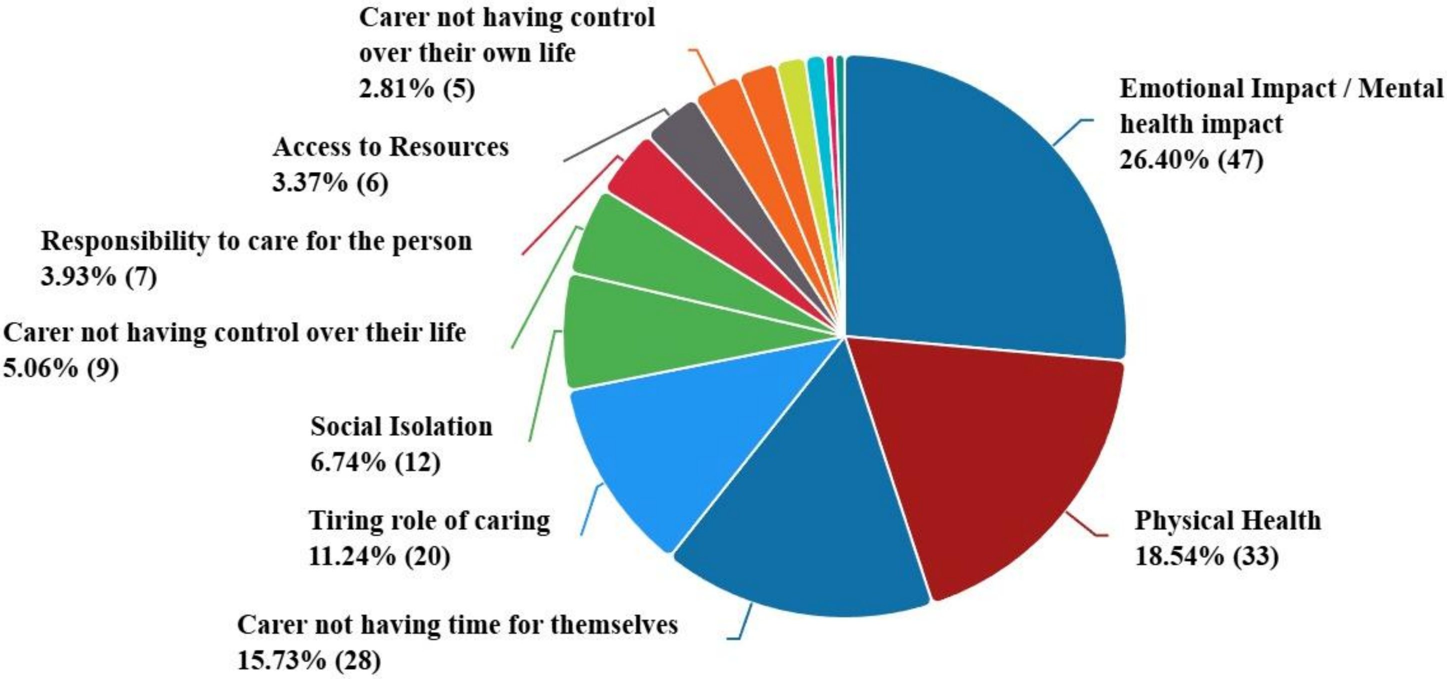
Recommendations: Develop targeted emotional support interventions, including more male focused support groups that use activity-based engagement.

Next steps

- Partner with mental health services and local charities to design tailored support programmes.
- Try new male focused support groups in existing carer networks.

The emotional impact of caring

In our survey, 26.4% of carers reported emotional and mental health being impacted on the most from their caring role.



- 82% of carers reported feeling overwhelmed because of their caring role.
- 58% of carers said they experienced low moods because of their caring role.
- 85% of carers felt stressed because of their caring role.
- 71% of carers said they felt anxious because of their caring role.

- Many carers reported that they always have their phone on full volume, with some even setting special ringtones so they know if the person they are caring for is calling them.

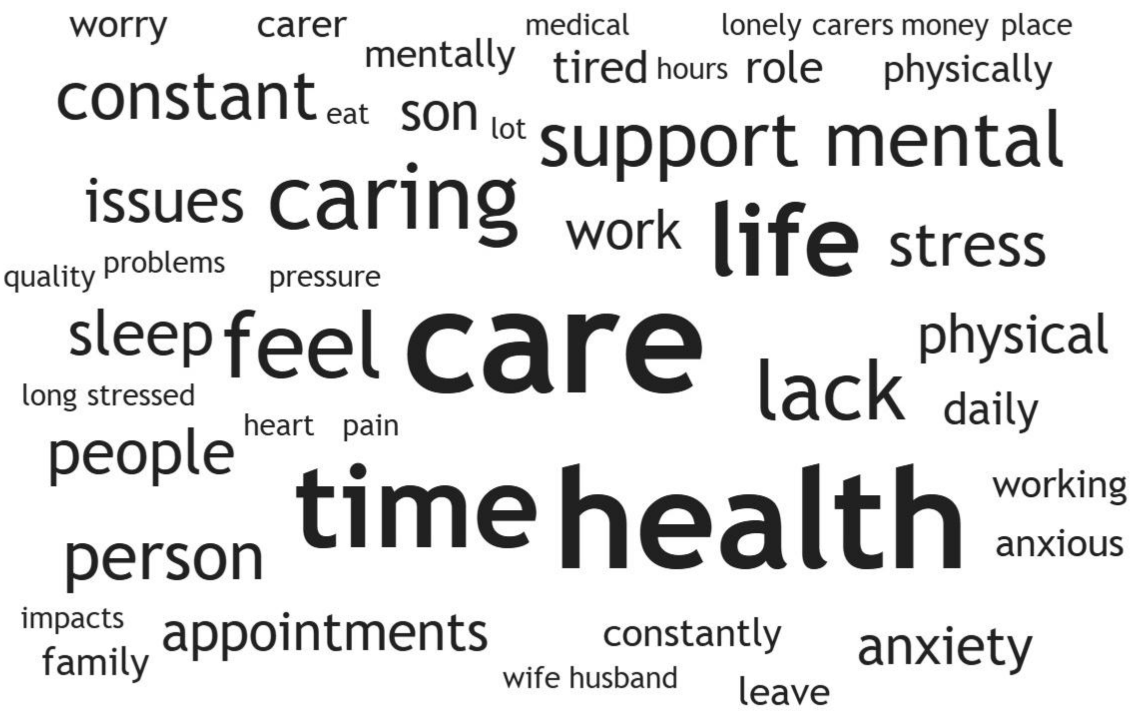
  Other carers reported not being able to do all the things they want to because they cannot leave the person alone.

> “It limits my life, in terms of work and leisure. It is quite depressing.”

> "My son needs constant support in most areas of his life, it's overwhelming and very draining."

> "It impacts me in every way. I mostly feel overwhelmed, sad, and lonely."

This word cloud shows the main responses when asked how caring affects carers:



Hypervigilance and caring

Carers also told us that they often had to be very aware of the person they were caring for in order to protect them.

This constant need to be aware of what is going on or if the person is safe means that carers experience a lot of worry and anxiety constantly.

> "So worried about him and keeping him safe."

> “Constant worry, sometimes mild panic attacks.”

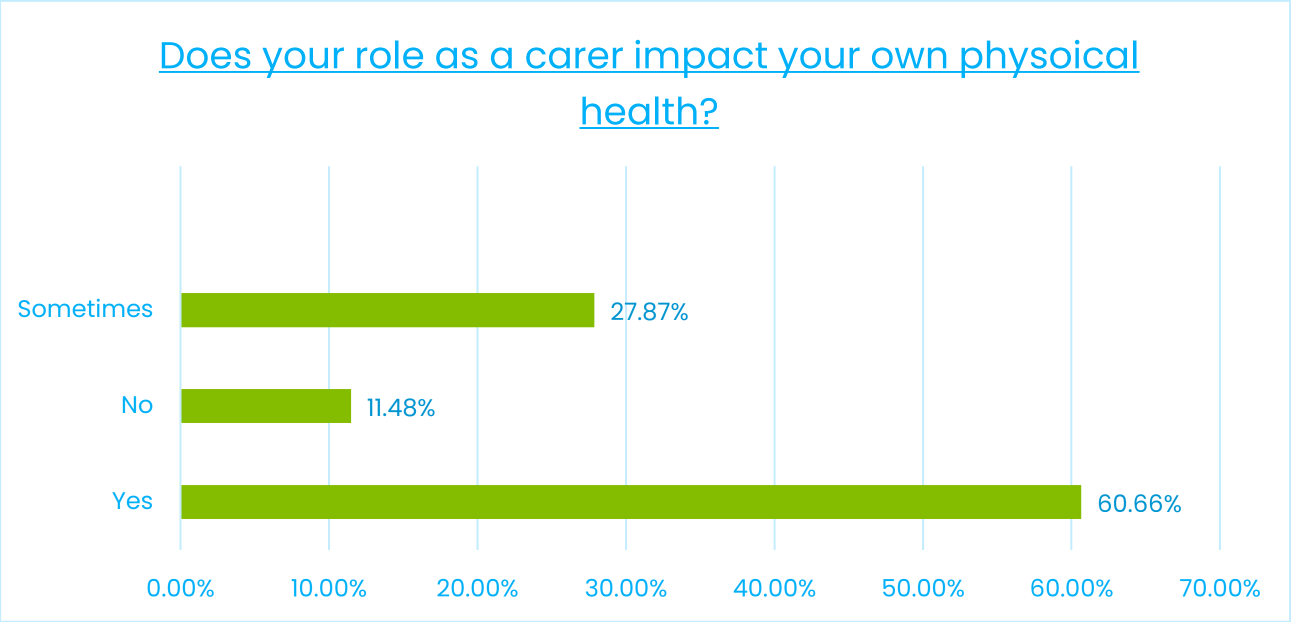
> “Constant worry. She is healthy and does things without my knowledge such as the washing machine to wash small batches of clothing, turns off light / power switches (e.g.: fridge, dishwasher when working).”

> “My partner has difficulty walking and the constant worry is she will fall when we are out.”

> “Left without enough info to care for loved one safely. Causes a lot of stress. Worry for loved ones safety.”

The physical impact of caring

60.66% of carers said they experienced physical impacts because of caring.



These are the reported physical impacts of caring from our survey:

Physical impacts	Number of carers reporting physical impact
Heart attack	1
Fatigue	17
Blood pressure	3
Stomach issues	1
Flare ups of existing chronic conditions	5
Joint pain / arthritis	9

Physical effects of caring range from fatigue to having serious incidents such as heart attacks.

> "Strength is low sometimes, takes me at least twice as long to do some things. Own your pain is greater cos you care more for others than oneself."

Carers also reported developing long term conditions because of caring for long periods of time.

> "I have psoriasis as a result of caring for so long."

> "Lifting has resulted in hamstring and back issues."

Carers told us that even with serious physical health problems, they still have to continue looking after the person they care for.

> "I have my own serious medical conditions. These take second place to my caring roles. When I had open heart surgery I was told I could not undertake any caring role during my recovery. However, I was not given my support and had to continue with my caring role during recovery."

Co-dependency in caring

- Carers have told us there is a co-dependent relationship between carer and the person being care for.
- When a person spends so much of their life looking after someone else, they become dependent on that person to give them purpose.

"When the person you care for passes away, it's like your life ends too."

- Carers that we spoke to told us they needed the person just as much the person needed them as all their identity had been consumed by their role of caring.
- This also comes from the loss of independence that many carers experience.

Co-dependency resulting in enabling behaviour

- Carers often feel they enable behaviours (e.g., drug use, spending) out of love and fear for the person they care for.

"I've paid for their drugs before because I know if they get it elsewhere, it might be cut with something worse."

- This co-dependency can also have detrimental effects when the person being cared for becomes sick or passes away.

"My life is done now that they gone."

Carers not caring for themselves

- Carers told us they often did not have the time or the energy to look after themselves or do things that are important for them.
- This included missing appointments, taking days off work, and sometimes even missing surgeries they need.

> “The need to take days off for regular treatments and appointments means I need to be more organised with my workload as I'm missing days I should be working.”

> “Really hard to attend medical appointments myself. Have turned down operations I need due to lack of support.”

> “Difficulty in fitting life around caring role. Back, knees, hips issues from lifting etc. Lack of time to look after myself.”

> ”As we both get older my carer role becomes harder as my wife needs more care. I have been a full time carer for my wife for 18 years and each year it gets harder.”

- This issue is very prevalent across the cohort of carers we heard from. Over 15% of respondents told us they did not have the time to access care for themselves.
- From this information, it is clear why so many carers have physical and mental health issues of their own which are not properly dealt with.

Carers and lack of control over their own lives

- Carers told us they feel as though they do not have any control over their life and therefore do not have the ability to look after themselves as well as the person they care for.
- This is because the needs of the person they care for always come first.

"Not having time for myself or not thinking about myself as the care of my wife is a higher priority."

"I can no longer come and go as I used to without ensuring his safety first, my life choices are secondary."

"Limits time for myself. Cannot always make sure I am ok."

"I accept that I need to reach out if I feel I need more help. Sometimes there just isn't the time to organise additional support."

"Huge impacts on my health - high blood pressure caused by stress, want to get out to exercise but caring means I am unable to. "

"I struggle to find the opportunity to relax and reduce stress and completely lack any time for creative self-expression."

Social isolation and caring

Isolation from non-carers

- Carers told us that their role made them feel isolated from the outside world.
- Some carers described feeling that they cannot relate to people who are not also carers.

> “It’s like you have nothing to say to people who aren’t carers. Their kids are growing up, moving out. Yours isn’t.”

Isolation and feelings of grief

- With these feelings of isolation, carers also reported that they experienced feelings of grief

> It is like you are grieving the life you could have had if you were not a carer for someone”

Loss of personal identity

- Some carers also told us that a key part of feeling isolated from others is that people only see them as carers.

> “People don’t see you as a person, only as a carer. That is really isolating”

Isolation and not taking care of oneself

- Carers also told us that they did not tell people about how they were feeling as they do not feel their feelings and experiences are as important as the person they are caring for.

> “They asked me if I was feeling depressed and I said no, even though I am.”

Isolation and fear for the future

- Lots of carers told us they worry a lot about who will care for the person if they are unable to, especially if they do not have a wider support network.

> "Always concerned that I'm ill or injured who would care for him, as all our family are miles away."

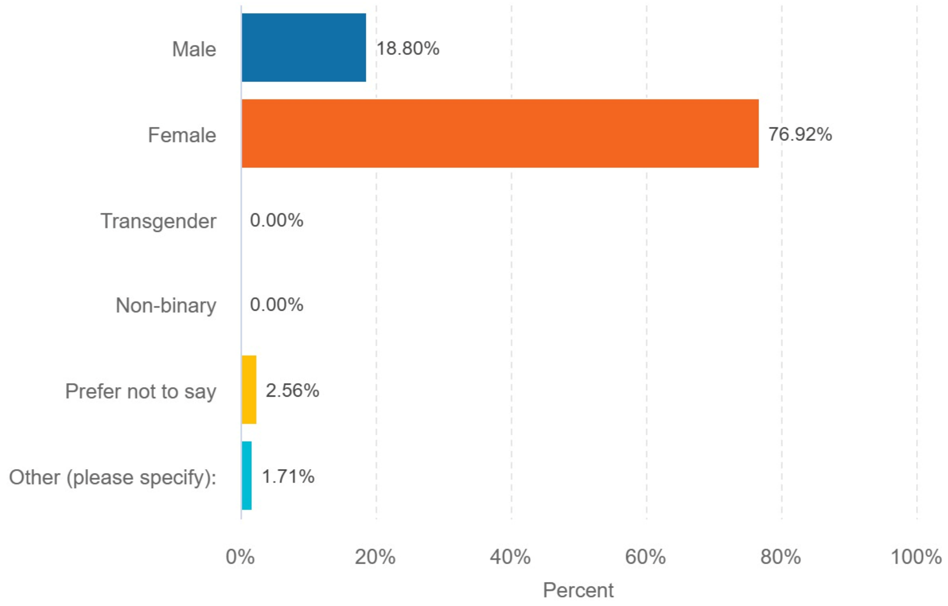
- Carers reported anxiety for the long-term outcomes of the person they care for, such as when the carer passes away.

> "Anxiety about what happens next/what will happen when we are gone."

> "Sometimes find it difficult to sleep as I can be worried about long-term outcomes."

Male carers and isolation

- Most responses to our survey were from female carers
- However, male carers told us they experience a lot of loneliness, even when around other carers.



- We were told that men being carers contradicted with traditional views of men being the breadwinner and women being the one to stay at home.

"When people think 'carer', they don't think of someone like me – they think of women."

- Men also told us that they felt isolated due to a lock of support networks that women might be more likely to have
- Men also felt that support groups for carers were often more geared towards women by design (e.g. focusing on talking rather than activities)

"Men don't talk like women do. We just don't have those friendships that stick around."

- This is not necessarily the case for all male carers, but it is what we were told by some of the male carers we spoke to.

The financial impact of unpaid caring

Lots of unpaid carers told us they had been financially impacted by their role.

Financial strain and lack of support

Carers told us they spent a lot of money on support for the person they care for as they are unable to get the money through grants:

> "Tried to get a disabled facilities grant for a stairlift and to altern the bathroom … so that has basically left us to get loans to cover these things, which we are now struggling to pay off. We will never see any of that money again."

"I have spent my own money and I have been on minimum wage for years I support him as much as I can but sometimes I have to buy him food which means I cannot actually buy what I would like."

Complex financial support systems

Other carers told us they had issues with the carers allowance and the difficulty in navigating the complex system

"I have had problems with overpayment of carers allowance - a system that is very unfair and difficult to navigate on top of caring (our son requires 24hr care 1:1 and we are certainly saving the state thousands of pounds)."

"I think it most unfair that the carers allowance is cut off once you get state pension."

Impact of caring on relationships

Impact on family relationships

- Some carers told us that caring put emotional strains on other members of their family, including relatives and siblings of the person they care for and the carer themselves.
- Carers told us that sometimes there are strains in family relationships as other family members cannot understand that for the carer, the person they care for has to always come first.

"It's not just me — everyone in the family lives this too."

Impact on sibling relationships

- Carers of children told us that their other children have had to watch their sibling be sectioned or in medical facilities.

> “My other child has had to visit psychiatric hospitals and watch sectioning happen. They’ve seen things no one should.”

Impact on marital relationships

- Some carers also told us that caring had put strains on their marital relationships.

> “My ex-wife never accepted the diagnosis which was part of the reason we separated.”

Impact on carer / care relationship

- Carers sometimes feel the relationship they have with the person they care for is one sided.

> “It’s very hard to love someone so much and for the relationship to feel so one sided.

The experiences of ‘sandwich carers’

Some carers told us they are caring for both older and younger generations in their family.

The effects of caring for more than one person

Carers told us they felt they were being stretched too far when caring for multiple people with differing needs

> “Exhausted as caring for two people. One younger person with disabilities one older person who is 89.”

> “It's difficult being a full-time carer for a child with complex medical issues and well as being a carer for an elderly parent you get no time for yourself and it feels like you are constantly being pulled in two directions.”

- Carers told us about the difficulty of caring for people with different ages and how this can feel like losing a sense of personal identity.

Juggling caring with other commitments

Carers are often also working age so are maintaining having a paid job as well as unpaid caring.

> “It affects everything in life especially as I'm caring for 3 people with medical needs and additional needs whilst trying to hold down a job to support them all and pay the bills.”

> “I do not time to get help as I also work and care for a family along with supporting my Dad.”

Why do people care?

Caring out of love

- Carers told us they care for the person because of their love for them.

> “But love my hubby therefore would not ever not care for him.”

> “It is often tough and can be thankless but I do it because I love her and don’t want her to be admitted to a hospital!”

Sense of duty to care

- Other carers told us they care because they have a responsibility to do so – whether it be as a partner or as a parent.

> “[…] we have and do it as our duty as parents.”

> “It's what I gave my word to do 63 years to do!”

Caring out of necessity

- Some carers also told us they care because they are the only ones around to do it. Without them, the person would not have any support.

> “However, if I am ill there is no one to take over.”

> “If I am unwell, who else is going to do it?”

- It is worth mentioning many of these reasons for caring are likely to overlap, especially when caring for a spouse or family member.
- In addition, many carers told us they do not see what they do for their loved one as ‘caring’, but rather they see it as being a mother, father, wife, husband etc.

What support do carers get?

Carers told us about the different types of support they use to help them cope with their responsibilities.

This word cloud shows the general responses we got from carers about the support they use.

Some carers use their local Carers Centre to get support:

> “The local peer support groups and carers centre are vital in helping me feel valued and not alone. Others are feeling the same and by sharing it helps immensely.”
>
> “Still worry a lot so carers coffee is great.”
>
> “Attend KS2 Bath support group and did a carers course with them a while back which was excellent.”

Other carers told us they attend other groups that are not associated with caring:

> “Keep calm and carry on! Walking with my club and swimming.”

We were also told that carers help to organise support groups and raise awareness, too.

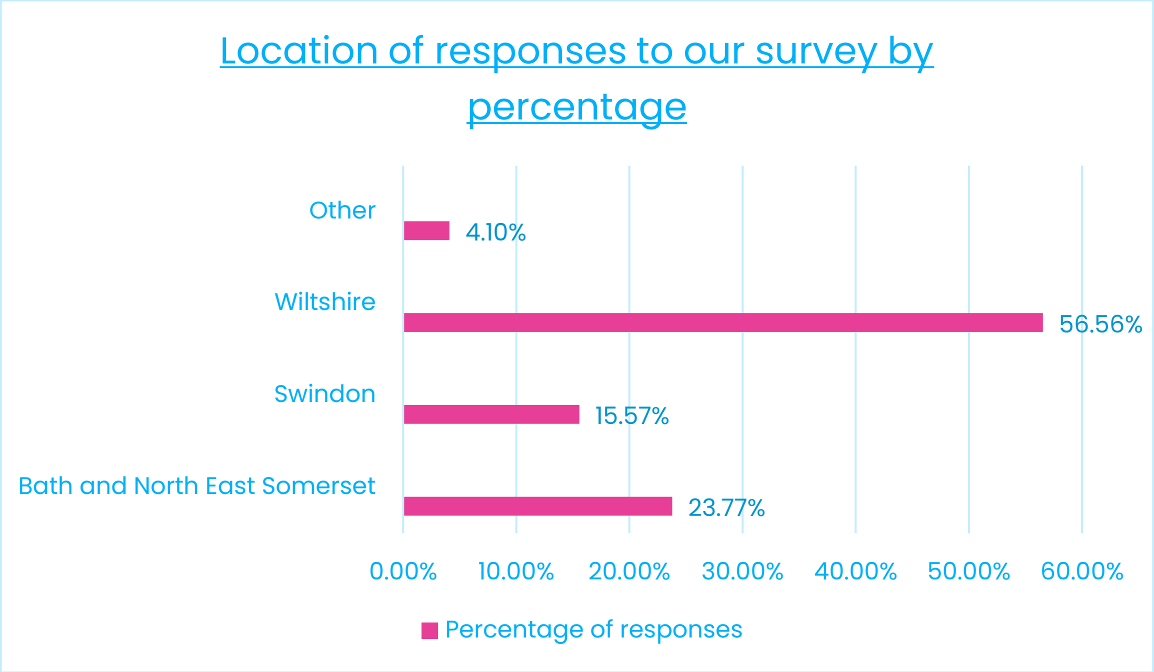
> "We attend an Alzheimer's course with others. I've organised an art group lead by Lighting Up. We pro-actively spread the word about dementia through talks, media and volunteering."

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).

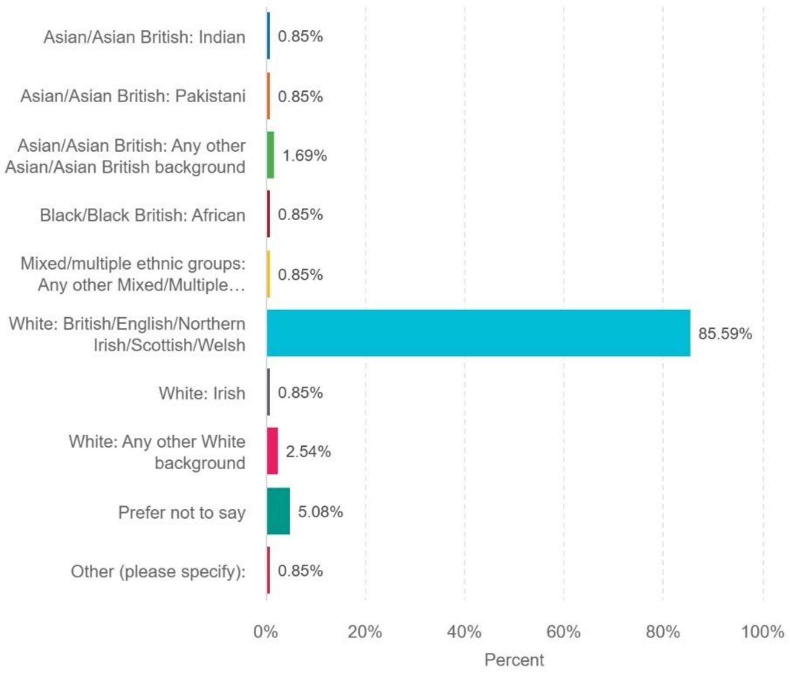


Survey responses that were not from BANES, Swindon or Wiltshire came from:

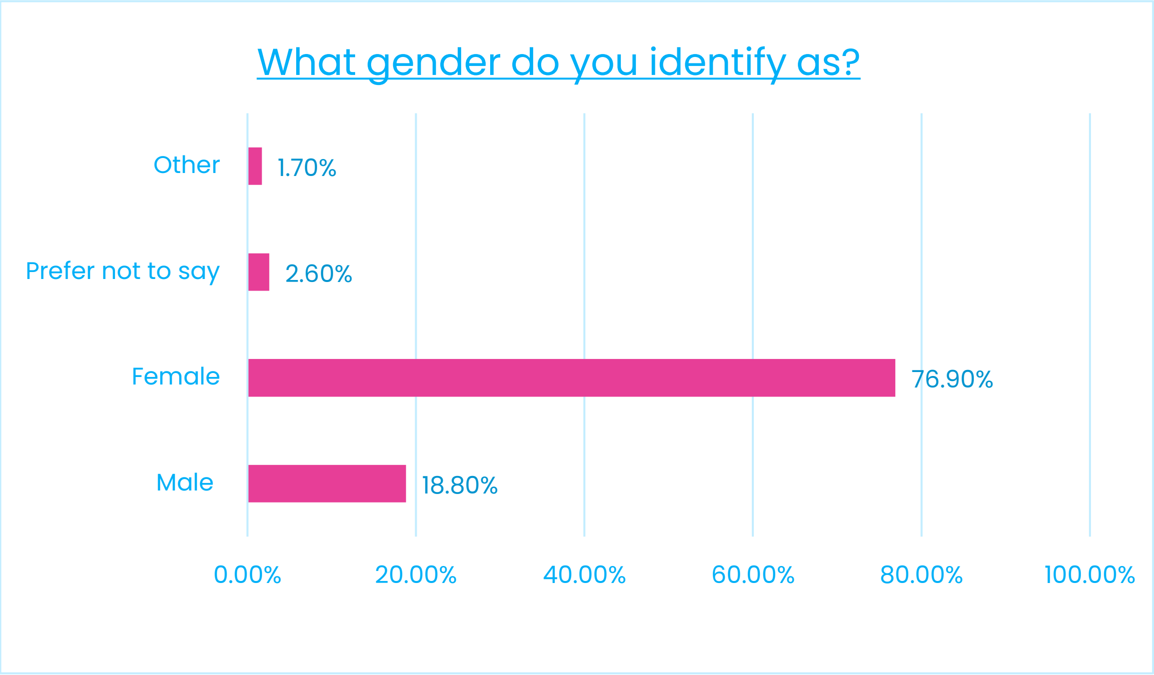
- Dorset (2 responses)
- Hampshire (1 response)
- North Somerset (1 response)

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:

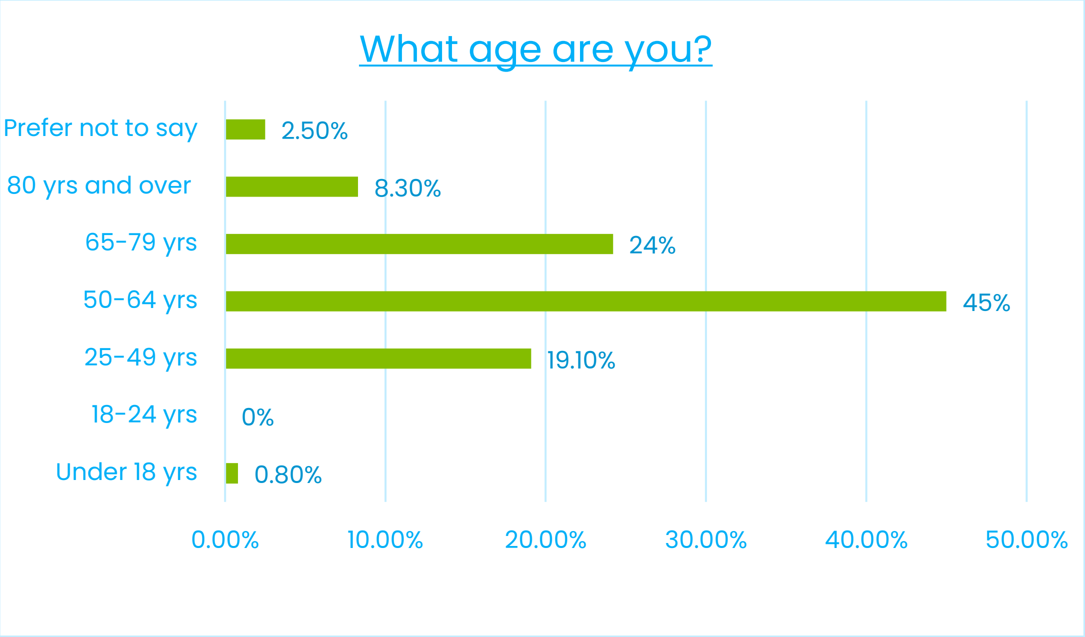


- Most carers who responded to our survey were female.
- However, we have included sections on the unique experience of male carers in this report and our second report on carers' experiences in BSW.



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:

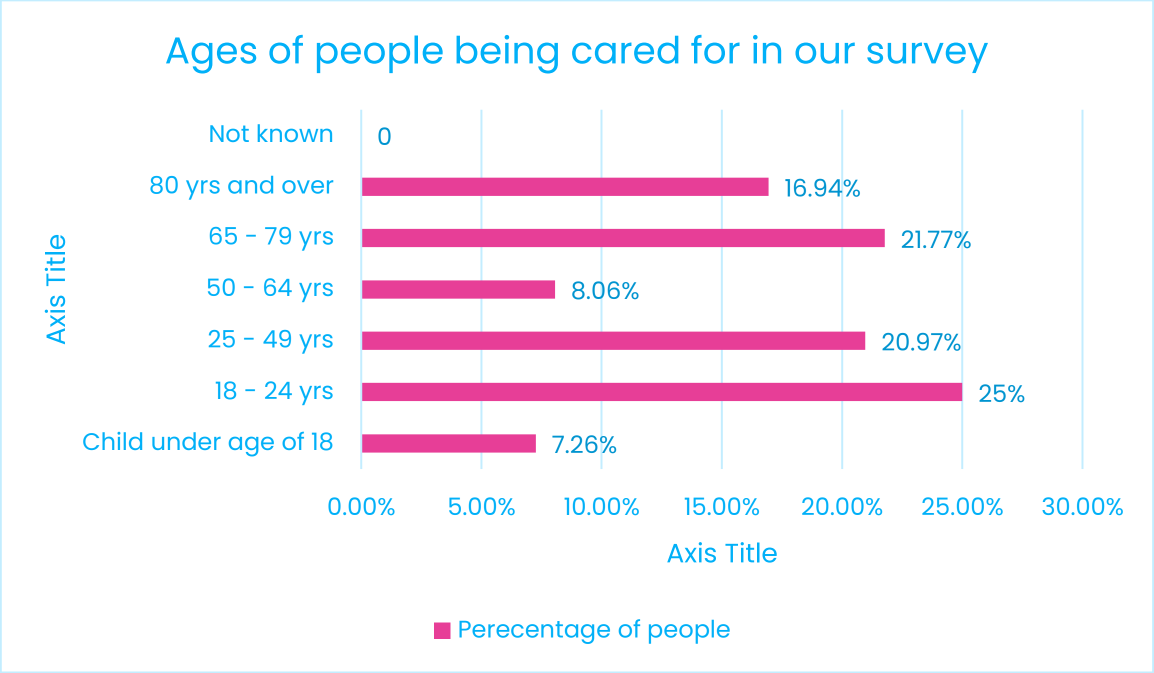
Our survey showed that carers are caring for people with a wide range of conditions that often co-exist. This accounts for the total number of people with a condition being higher than the overall number of responses to the survey.

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: Survey questions

View or download appendix 2 on our website:
www.healthwatchwiltshire.co.uk/strain-unpaid-caring-voices-unpaid-carers-across-bathnes-swindon-and-wiltshire

If you need this information in an alternative format, please email info@healthwatchwilthsire.co.uk or call 01225 434218.

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