

Caring by Love, not by Pay

Stories and Solutions from Unpaid Caregivers

THE WHITE PAPER



FOREWORD

This is the Grace Cares consultation on the needs of the unpaid caregiver. We assembled a representative sample in the national and local care community to discuss the challenges from the perspective of the people at the heart of the matter. We also looked at possible solutions to improve the unpaid caregiver community to address these challenges head on.

The solutions proposed are varied in their distribution of accountability. Some solutions require action from either / or national and local Governmental bodies encompassing Health & Social Care and other solutions are in the gift of local communities and Grace Cares itself.

Unpaid caregivers play a critical role in the UK's health and social care system. According to Carers UK, there are an estimated **5.7 million unpaid carers** providing care worth an estimated £132 billion a year - equivalent to a second NHS. Yet many of these caregivers remain under-recognised and under-supported. Research completed by the Carers Trust (2023) revealed that more than two thirds are unable to get a respite break from their caring role when needed.

In addition, over a third of unpaid caregivers don't think the NHS understands their caring responsibilities or provides adequate

support to them and only 38% say the Carer's Allowance is enough to make a meaningful difference to them.

In order to hear the voices from our local unpaid caregivers we produced and disseminated our own Grace Cares unpaid caregivers survey to gather information and experiences of the personal cost of unpaid caring. These include aspects of their emotional, psychological, financial and physical health. Additionally an in-person consultation was held with unpaid caregivers to share experiences and to allow a space for them to discuss and explore what support they might need to ease the pressure of caring on their daily lives.

Our participants included representatives from:

- People with lived experience of being both unpaid carers and care recipients
- The local and national unpaid caregiver community
- Previous customers who purchased equipment from Grace Cares
- Local health and social care professionals
- Voluntary and community organisations supporting carers
- Local Authority Adult Social Care leads
- NHS partners, including social prescribing teams
- Care home and domiciliary care providers



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THE CONSULTATION

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Recognition and Identity: How do Caregivers Feel About Their Identity and Degree of Recognition They Receive?

What can we do to Help?

What do we Know?

- People in an unpaid care-giving position do not always consider or identify themselves as 'carers', especially not at the start of the care journey.
- Without this recognition and acknowledgement it can make it difficult for them to access the support that is available.
- When people are positively identifying themselves as carers they report feeling their role is underestimated, misunderstood and undervalued.

What are the Issues?

- People feel **under appreciated by: Government** - Lack of meaningful recognition from the Government with insufficient funding and personal financial allowance for unpaid carers.

"We are not professionals, have no training for this role so have to learn as we go on. Every day is a new challenge."

- **Health and Social Care** - Lack of support creating feelings of isolation, confusion and helplessness. Lack of training in the caring role.
- **Society** - A sense that members of the community without caring experience have no awareness of those that do and the enormous impact it has on their daily lives.
- People feel **unsupported** in their caring role due to lack of training for what are often quite complex physical and mental medical conditions.
- People feel unsure about, or are unable to access, advice and support that might be available to them.

How can we Solve These Issues?

- Help to promote the role of the unpaid caregiver, in person across our local community and nationally via social media; **raising public awareness** and helping to support local and national charity initiatives to ensure the voices of unpaid carers are heard.
- work to establish an appropriate name for the role which would be widely accepted and

recognised by caregivers themselves.

- Provide a signposting service to support people to access available support according to individual needs.
- Continue to **build relationships** with local NHS, social care providers and community groups to champion the needs of the unpaid caregiver.
- Offer peer to peer support groups and provide forums to help foster a stronger identity.

"People don't realise how difficult it can be."

"There is no help out there for carers. You just have to get on with it."

"You feel completely on your own, no check ins from any supportive agencies you are expected to just get on with it."

"I'm on wife and mother duty. That's what you do. I love them, so I do it."

"How invisible it is, when your child 'masks' in the outside world, it means no one understands."

How Prevalent is the Damaging Emotional and Psychological Impact on Caregivers? How can we Help?

What do we Know?

- The role of the unpaid caregiver can be relentless, especially if someone is attempting this role without help.
- 56.4% of our survey respondents indicated they would like improved emotional and psychological support.
- Often people find themselves **'on call' 24 hours a day, 7 days a week**. Their own lives and priorities take a back seat, to allow the priorities of the person in need of care to take centre stage.
- This frequently has negative impacts on the emotional and psychological health of the caregiver
- Caregivers also report that they feel unable to make plans for their own lives as they live in a constant state of waiting for the next crisis.
- **Feelings of guilt** have been reported frequently. If the caregiver does take some time for self-care it can lead to further mental distress and anguish.
- Caregivers often describe the constant **'juggling act'** of balancing their own lives with the needs of the person they care for. This struggle can lead to burnout and exhaustion.



What are the Issues?

- Frequent feelings of **being overwhelmed and of exhaustion**.
- Feelings of guilt and remorse if self-care is prioritised.
- Feelings of guilt when resentment for the cared-for person arises.
- Feelings of grief for **loss of own identity** and a change in the roles between 'caregiver' and 'cared for'.
- **Loss of personal freedom** and focus on decisions made to prioritise the needs of the cared-for person.
- Worries for the future.
- Loss of the caregiver's social activities and leisure time leading to loneliness and isolation.

How can we Solve These Issues?

- **Counselling** - establish a database of evidence based professionally registered counselling services to enable signposting to relevant accredited counselling services. Approach local counselling services and invite them to support.
- **Peer support groups** - establish and then encourage self-run peer support groups for caregivers to share experiences and provide emotional support to ward off feelings of isolation and enable people to talk through the challenges.
- **Increased respite** opportunities to allow for short periods of self-care.
- **Signposting to services** to help with future planning e.g. Social Services, NHS, disease specific charities (PD / MS Society, Stroke Association etc).

Are Cared for People Sufficiently Supported by the Government and Health and Social Care?

What do we Know?

- Caregivers feel there is **not sufficient support** for those being cared for at home by relatives, friends or neighbours.
- Survey respondents have reported that at times they feel untrained and underqualified to provide the care that is needed.
- Caregivers feel there is not enough access to **affordable day care** opportunities or

activities for the cared for person which would help enrich their lives at the same time as offering brief respite for the caregiver.

- Caregivers feel **overwhelmed with caring** responsibilities and report they have neither the time nor energy to complete internet searches to seek help.

What are the Issues?

- Limited affordable day care or respite.
- **Lack of knowledge**, skills and training for the unpaid caregiver.
- **No proactive offer** of help from the NHS or Local Authority Social Care - caregivers are expected to research it themselves.
- Inadequate ongoing support from Health and Social Care.



How can we Solve These Issues?

- National and Local Government commitment to increased funding for adult day care and respite opportunities.
- Health and **social care delivered training**, both digital and face to face, to support unpaid caregivers to fulfil their role.
- Exploration of **local respite services** currently on offer and consideration of ways to expand these.
- More support to enable easier access to support available via drop in groups and collaboration with Social Prescribers.

Are Caregivers Aware of Support Services Available to Them?

What do we Know?

- Caregivers report they **feel frustration** at not being able to easily access support. Advice and information is disparate and held in different places making navigating the options difficult and time consuming.
- Caregivers lead busy and tiring lives leaving them little time to do their own research on what help could be available.
- During the consultation, many people spoke about **feeling isolated and frustrated**, saying that information, advice, and support are often difficult to find or access.
- Unpaid caregivers also reported that navigating online support directories was either cumbersome, too time consuming or

that they were unaware of them.

How can we Solve These Issues?

- Promotion and referral to social prescribing service to ensure signposting is easy to access, individualised and efficient.
- Provide **drop in events** for carers to provide chance for peer support and volunteer assisted signposting / research for carer support.
- Promotion of existing local directories and websites created to help people access support.

Promotion of local Government initiatives such as Staffordshire Together for Carers & First Contact Carers website (NHS + SCC).

What are the Issues?

- Caregivers failing to identify themselves as such and therefore not seeking support they are entitled to and that would benefit them.
- Lack of awareness of where to look for help.
- Caregivers lack time and energy to research the services and support on offer.
- Lack of easy access to advice around future planning and legal and financial affairs.
- Perceived lack of effective signposting available.
- Sense of abandonment felt by caregivers.

THE FUTURE OF THE UNPAID CAREGIVER ROLE

Some clear gaps in support for unpaid caregivers have emerged as a result of this consultation. Bringing together these recommendations reveals some clear issues that need to be better understood and failings that demand action at different levels of the care sector in order to ensure Care-Givers can continue to make their critical contributions

Requirement for Better Recognition of the Unpaid Caregiver Role, Locally and Nationally

54% of our survey respondents and the majority of participants in our face to face consultations felt that the role of the unpaid caregiver is **under-recognised**, both amongst the carers themselves and the wider public. This detail has a dual impact for the carers; firstly reduced access to available support and secondly feelings of isolation and frustration.

Actions / Future Considerations

- **Help to promote** the role of the unpaid caregiver, in person across our local community and nationally via social media; raising public awareness and helping to support local and national charity initiatives to ensure the voices of unpaid carers are heard.
- Work to establish **appropriate terminology** which would be widely accepted and recognised by caregivers themselves.

- Provide a sign posting service to support people to access available support according to individual needs.
- Continue to build relationships with local NHS, social care providers and community groups to champion the needs of the unpaid caregiver.
- Offer a peer support group to help foster a stronger identity and provide a forum for people to embed their identity as an unpaid caregiver.



Requirement for improved Emotional and Psychological Support for Unpaid Caregivers

53.2% of survey respondents and the vast majority of face to face consultation participants voiced their need for **improved emotional and psychological support** in relation to the psychological strain and mental health deterioration they have experienced as a direct

result of their caring role.

Actions / Future Considerations

- **Counselling** - establish a database of evidence based professionally registered counselling services to enable sign posting to relevant accredited counselling services. Approach local counselling services and invite them to support.
- **Peer support groups** - establish and then encourage self-run peer support groups for caregivers to share experiences and provide emotional support to ward off feelings of isolation and enable people to talk through their challenges.
- Increased respite opportunities to allow for short periods of self-care.
- Signposting to services to help with future planning e.g. Social Services, NHS, disease specific charities (PD / MS Society, Stroke Organisation etc).

Requirement for Improved Support for the Cared-for Person

51.6% of our survey respondents and participants in our face to face consultations felt that improved support for the 'cared-for' person was essential to enable them to continue their role.

Respondents expressed a need of training in caring for people with increasingly complex health conditions, but were unaware of how to access such training and desired better access to healthcare support for the cared-for person.

Actions / Future Considerations

- Government commitment to increased funding for adult day care and respite opportunities.
- Health and social care delivered training to support unpaid caregivers to fulfill their role to the best of their ability.
- Exploration of local respite services currently on offer and consideration of ways to expand these.
- More support to enable easier access to support available via drop in groups and collaboration with Social Prescribers.

Requirement for Improved Access to Support that is Already Available

Our survey revealed that 78.2% of caregivers were either unaware or unsure of what local support was available to them and 76.4% reported either little or no awareness of how to access that support.

Actions / Future Considerations

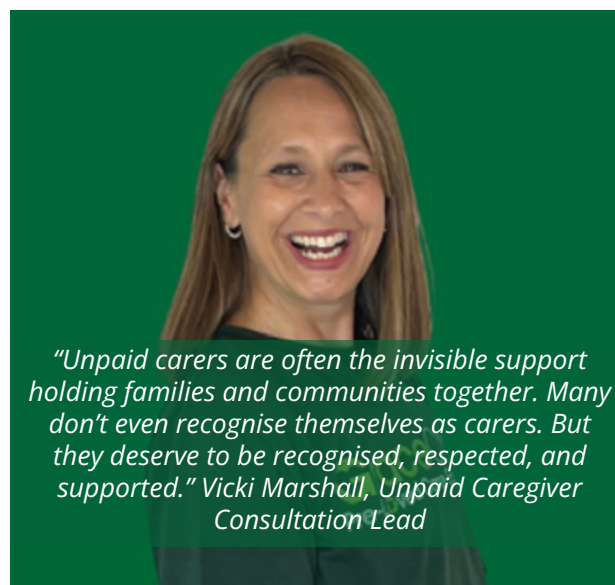
- Promotion and referral to social prescribing services to ensure signposting is easy to access, individualised and efficient.
- Provide a regular drop in event for carers to provide chance for peer support and volunteer assisted signposting / research for carer support.

- Promotion of Local Authority and charitable websites such as Staffordshire Connects (directory of community activities in the area).
- Promotion of Local Authority and Local Charitable websites such as Staffordshire Together for Carers & First Contact Carers website (NHS + Staffordshire County Council)

WHAT HAPPENS NEXT?

Now that the results of the consultation have been published, we're keen to work with our partners in health and social care, as well as charities and community support groups, to explore what we at Grace Cares can offer to help improve the lives of unpaid caregivers.

We also welcome the opportunity to engage with more local authorities and central government representatives.



ACKNOWLEDGEMENTS

This paper was developed following consultation discussions and survey responses collected throughout June 2025, with support from **Ontex International** and **Grace Cares CIC**.

The caregivers consultation and resulting white paper would not have been possible without the generous contributions of all those involved. We extend our sincere thanks and respect to everyone who took part, including more than 60 unpaid caregivers from both local and national communities.

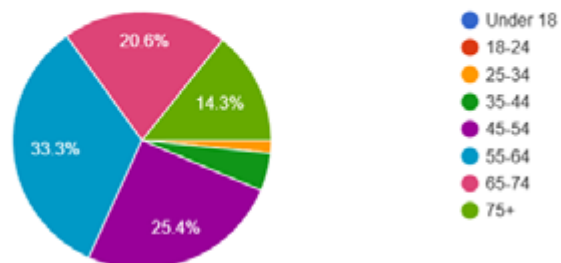
Their openness, honesty, and willingness to share their experiences and ideas for change have been deeply appreciated. They are a true inspiration to us all.

APPENDICES

STATISTICS AND RESULTS FROM UNPAID CARER SURVEY

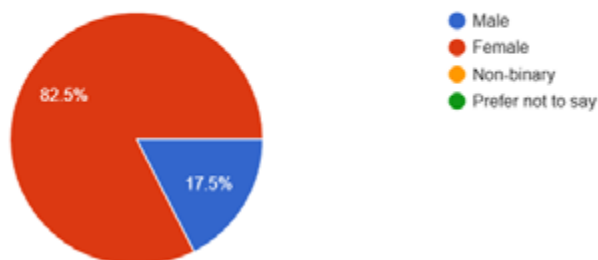
1. What is your age range?

63 responses



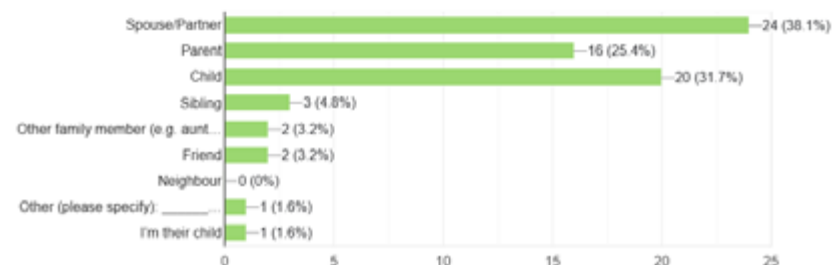
2. What is your gender?

63 responses



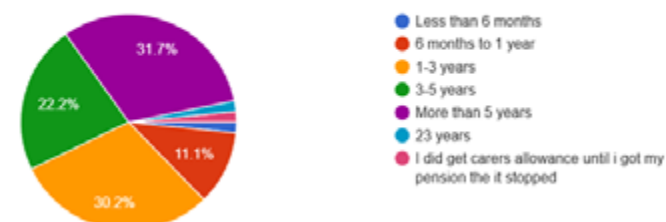
3. Which of the following best describes your relationship to the person you care for? (Select all that apply)

63 responses



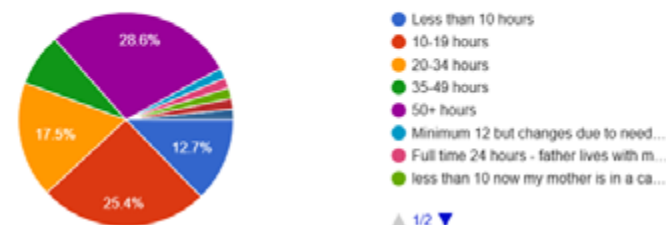
4. How long have you been an unpaid carer?

63 responses



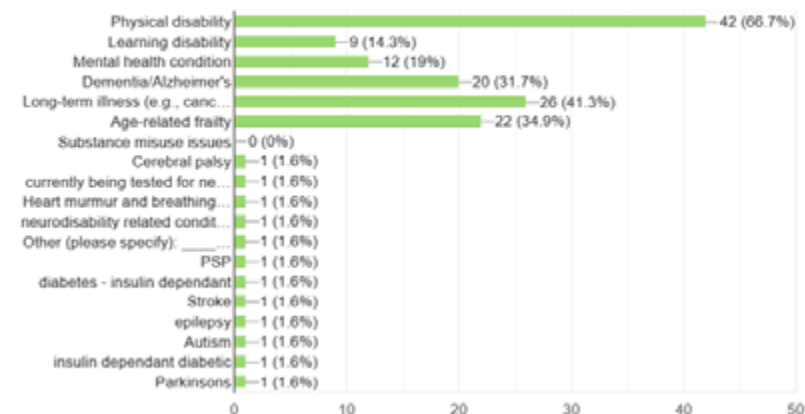
5. Approximately how many hours per week do you spend on caring responsibilities?

63 responses



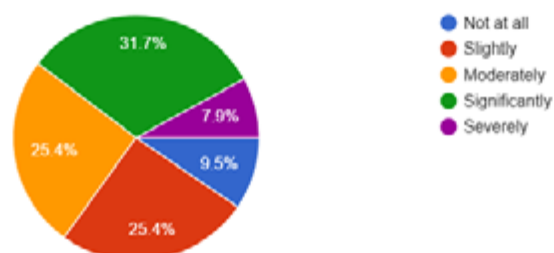
6. Does the person you care for have any of the following conditions? (Select all that apply)

63 responses



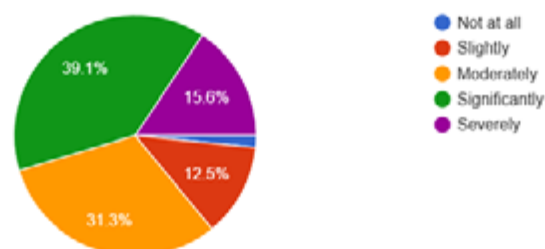
7. How much does your caring role impact your own physical health?

63 responses



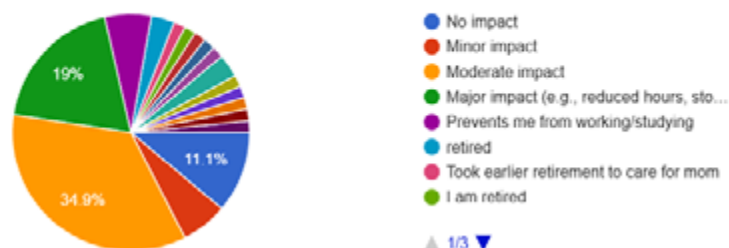
8. How much does your caring role impact your own mental and emotional well-being?

63 responses



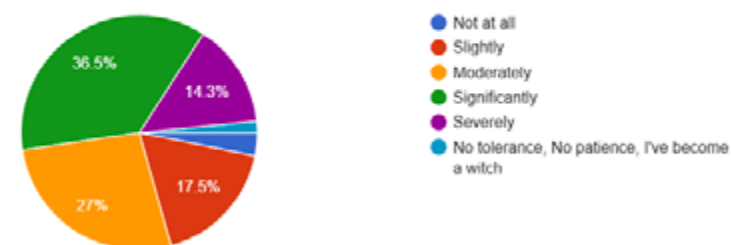
9. To what extent does your caring role affect your ability to work or study?

63 responses



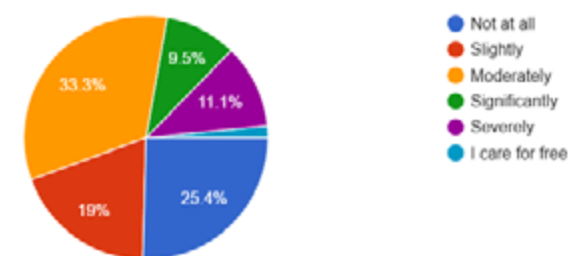
10. How much does your caring role affect your social life and relationships?

63 responses



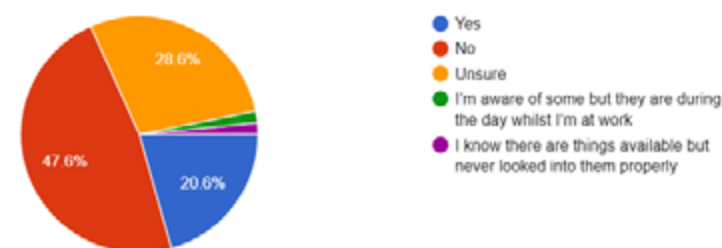
11. Do you feel financially impacted by your caring role?

63 responses



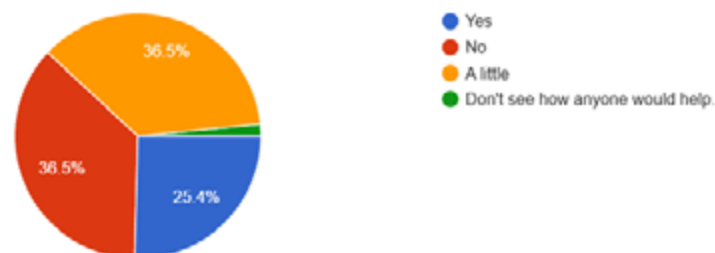
12. Are you aware of local support services available for unpaid carers?

63 responses



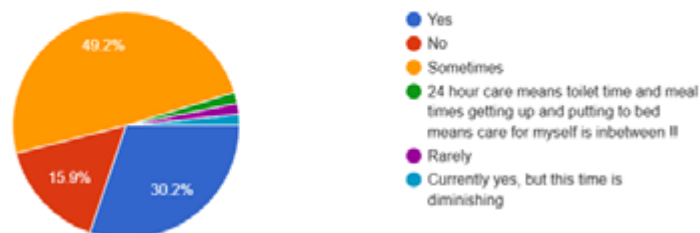
13. Are you aware of how to access information and guidance, including signposting, in relation to your caring role?

63 responses



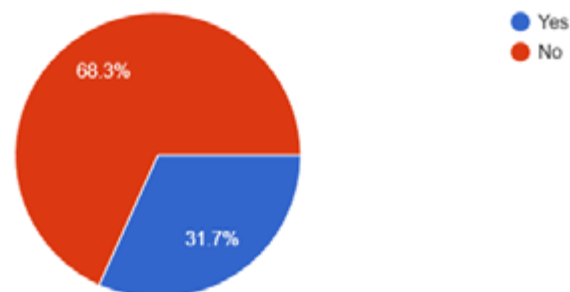
14. Do you have time for taking care of your self

63 responses



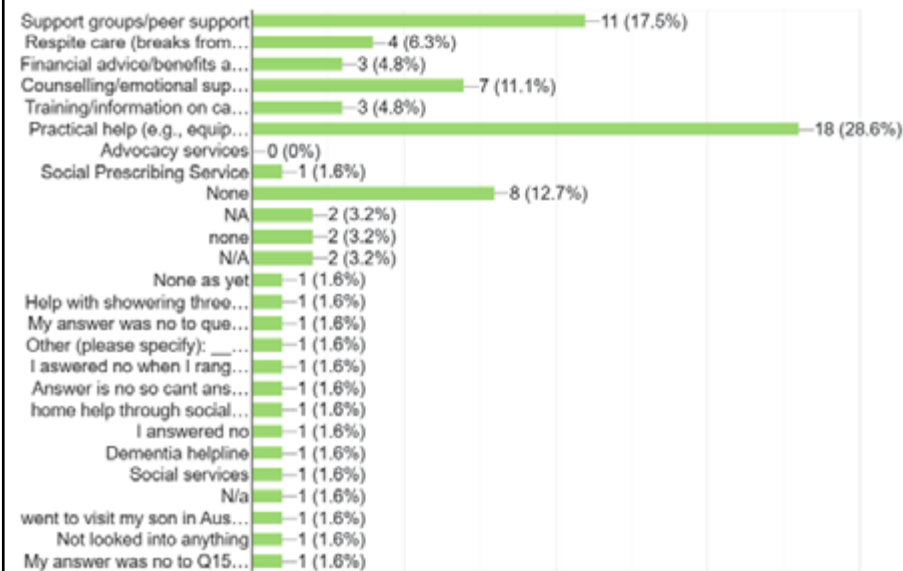
15. Have you ever accessed any support services for unpaid carers?

63 responses



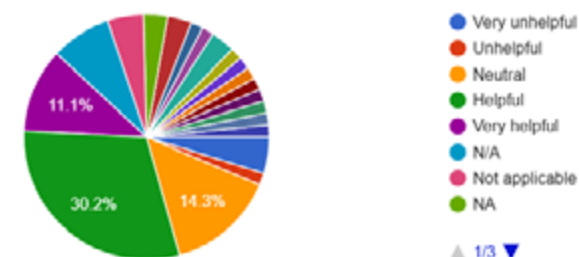
16. If yes, which of the following services have you accessed? (Select all that apply)

63 responses



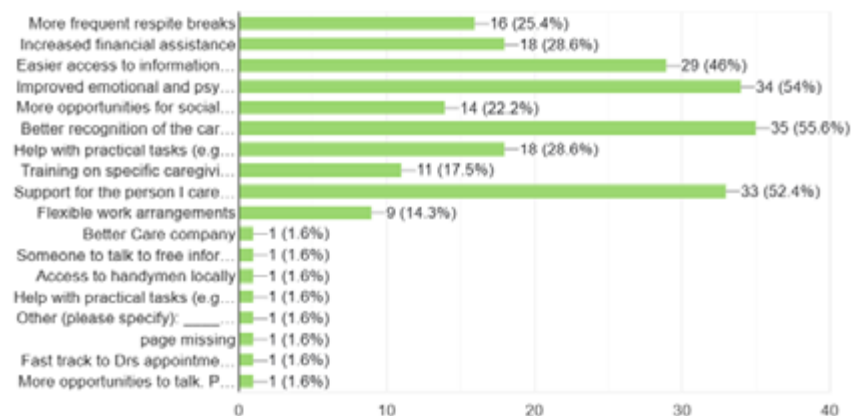
17. How helpful were these services? (if applicable, for each service you accessed)

63 responses



18. What additional support or resources would most help you in your caring role? (Select all that apply)

63 responses



"Partnering with Ontex has given us the opportunity to truly listen. This is about more than resources – it's about building a movement. We want unpaid carers to feel seen, valued, and supported, not left to carry the weight in silence."
 - Hannah Montgomery, Co-Founder of Grace Cares.

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- Caregivers feel there is not enough access to **affordable day care** opportunities or

activities for the cared for person which would help enrich their lives at the same time as offering brief respite for the caregiver.

- Caregivers feel **overwhelmed with caring** responsibilities and report they have neither the time nor energy to complete internet searches to seek help.

What are the Issues?

- Limited affordable day care or respite.
- **Lack of knowledge**, skills and training for the unpaid caregiver.
- **No proactive offer** of help from the NHS or Local Authority Social Care - caregivers are expected to research it themselves.
- Inadequate ongoing support from Health and Social Care.



How can we Solve These Issues?

- National and Local Government commitment to increased funding for adult day care and respite opportunities.
- Health and **social care delivered training**, both digital and face to face, to support unpaid caregivers to fulfil their role.
- Exploration of **local respite services** currently on offer and consideration of ways to expand these.
- More support to enable easier access to support available via drop in groups and collaboration with Social Prescribers.

Are Caregivers Aware of Support Services Available to Them?

What do we Know?

- Caregivers report they **feel frustration** at not being able to easily access support. Advice and information is disparate and held in different places making navigating the options difficult and time consuming.
- Caregivers lead busy and tiring lives leaving them little time to do their own research on what help could be available.
- During the consultation, many people spoke about **feeling isolated and frustrated**, saying that information, advice, and support are often difficult to find or access.
- Unpaid caregivers also reported that navigating online support directories was either cumbersome, too time consuming or

that they were unaware of them.

How can we Solve These Issues?

- Promotion and referral to social prescribing service to ensure signposting is easy to access, individualised and efficient.
- Provide **drop in events** for carers to provide chance for peer support and volunteer assisted signposting / research for carer support.
- Promotion of existing local directories and websites created to help people access support.

Promotion of local Government initiatives such as Staffordshire Together for Carers & First Contact Carers website (NHS + SCC).

What are the Issues?

- Caregivers failing to identify themselves as such and therefore not seeking support they are entitled to and that would benefit them.
- Lack of awareness of where to look for help.
- Caregivers lack time and energy to research the services and support on offer.
- Lack of easy access to advice around future planning and legal and financial affairs.
- Perceived lack of effective signposting available.
- Sense of abandonment felt by caregivers.

THE FUTURE OF THE UNPAID CAREGIVER ROLE

Some clear gaps in support for unpaid caregivers have emerged as a result of this consultation. Bringing together these recommendations reveals some clear issues that need to be better understood and failings that demand action at different levels of the care sector in order to ensure Care-Givers can continue to make their critical contributions

Requirement for Better Recognition of the Unpaid Caregiver Role, Locally and Nationally

54% of our survey respondents and the majority of participants in our face to face consultations felt that the role of the unpaid caregiver is **under-recognised**, both amongst the carers themselves and the wider public. This detail has a dual impact for the carers; firstly reduced access to available support and secondly feelings of isolation and frustration.

Actions / Future Considerations

- **Help to promote** the role of the unpaid caregiver, in person across our local community and nationally via social media; raising public awareness and helping to support local and national charity initiatives to ensure the voices of unpaid carers are heard.
- Work to establish **appropriate terminology** which would be widely accepted and recognised by caregivers themselves.

- Provide a sign posting service to support people to access available support according to individual needs.
- Continue to build relationships with local NHS, social care providers and community groups to champion the needs of the unpaid caregiver.
- Offer a peer support group to help foster a stronger identity and provide a forum for people to embed their identity as an unpaid caregiver.



Requirement for improved Emotional and Psychological Support for Unpaid Caregivers

53.2% of survey respondents and the vast majority of face to face consultation participants voiced their need for **improved emotional and psychological support** in relation to the psychological strain and mental health deterioration they have experienced as a direct

result of their caring role.

Actions / Future Considerations

- **Counselling** - establish a database of evidence based professionally registered counselling services to enable sign posting to relevant accredited counselling services. Approach local counselling services and invite them to support.
- **Peer support groups** - establish and then encourage self-run peer support groups for caregivers to share experiences and provide emotional support to ward off feelings of isolation and enable people to talk through their challenges.
- Increased respite opportunities to allow for short periods of self-care.
- Signposting to services to help with future planning e.g. Social Services, NHS, disease specific charities (PD / MS Society, Stroke Organisation etc).

Requirement for Improved Support for the Cared-for Person

51.6% of our survey respondents and participants in our face to face consultations felt that improved support for the 'cared-for' person was essential to enable them to continue their role.

Respondents expressed a need of training in caring for people with increasingly complex health conditions, but were unaware of how to access such training and desired better access to healthcare support for the cared-for person.

Actions / Future Considerations

- Government commitment to increased funding for adult day care and respite opportunities.
- Health and social care delivered training to support unpaid caregivers to fulfill their role to the best of their ability.
- Exploration of local respite services currently on offer and consideration of ways to expand these.
- More support to enable easier access to support available via drop in groups and collaboration with Social Prescribers.

Requirement for Improved Access to Support that is Already Available

Our survey revealed that 78.2% of caregivers were either unaware or unsure of what local support was available to them and 76.4% reported either little or no awareness of how to access that support.

Actions / Future Considerations

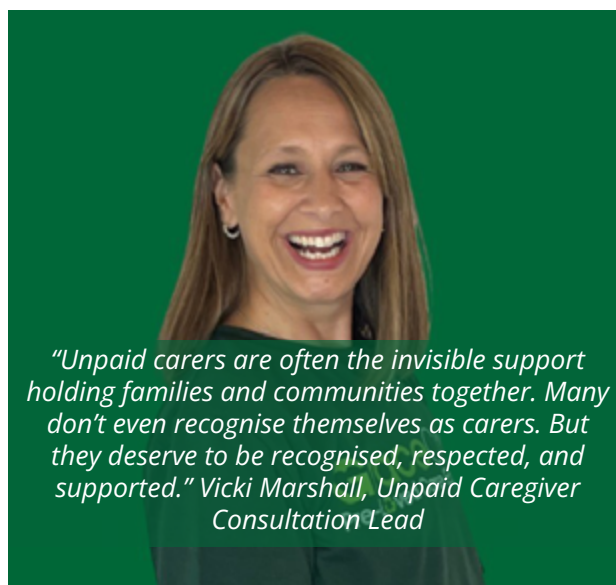
- Promotion and referral to social prescribing services to ensure signposting is easy to access, individualised and efficient.
- Provide a regular drop in event for carers to provide chance for peer support and volunteer assisted signposting / research for carer support.

- Promotion of Local Authority and charitable websites such as Staffordshire Connects (directory of community activities in the area).
- Promotion of Local Authority and Local Charitable websites such as Staffordshire Together for Carers & First Contact Carers website (NHS + Staffordshire County Council)

WHAT HAPPENS NEXT?

Now that the results of the consultation have been published, we're keen to work with our partners in health and social care, as well as charities and community support groups, to explore what we at Grace Cares can offer to help improve the lives of unpaid caregivers.

We also welcome the opportunity to engage with more local authorities and central government representatives.



ACKNOWLEDGEMENTS

This paper was developed following consultation discussions and survey responses collected throughout June 2025, with support from **Ontex International** and **Grace Cares CIC**.

The caregivers consultation and resulting white paper would not have been possible without the generous contributions of all those involved. We extend our sincere thanks and respect to everyone who took part, including more than 60 unpaid caregivers from both local and national communities.

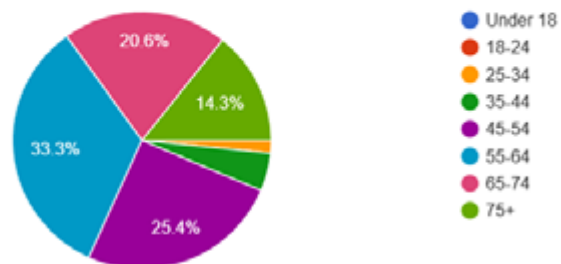
Their openness, honesty, and willingness to share their experiences and ideas for change have been deeply appreciated. They are a true inspiration to us all.

APPENDICES

STATISTICS AND RESULTS FROM UNPAID CARER SURVEY

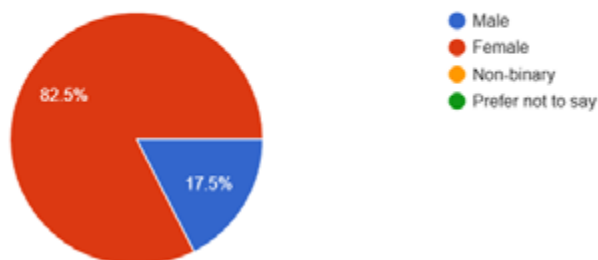
1. What is your age range?

63 responses



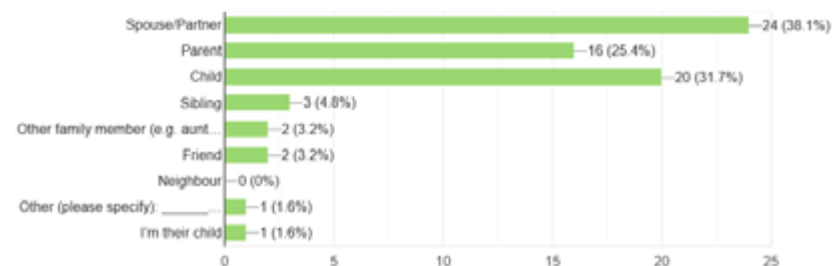
2. What is your gender?

63 responses



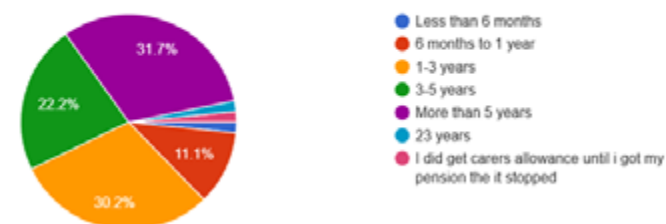
3. Which of the following best describes your relationship to the person you care for? (Select all that apply)

63 responses



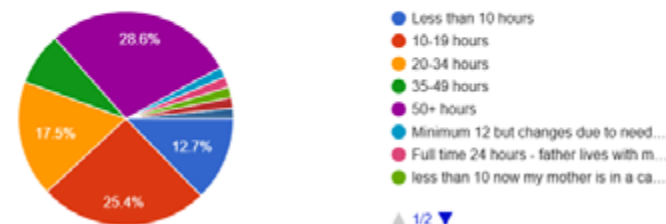
4. How long have you been an unpaid carer?

63 responses



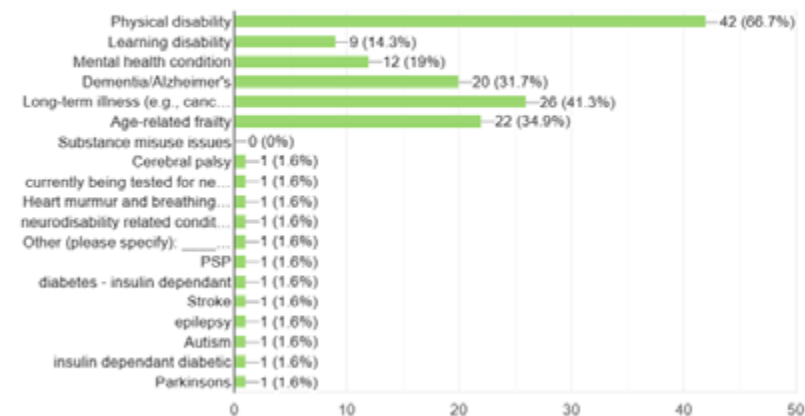
5. Approximately how many hours per week do you spend on caring responsibilities?

63 responses



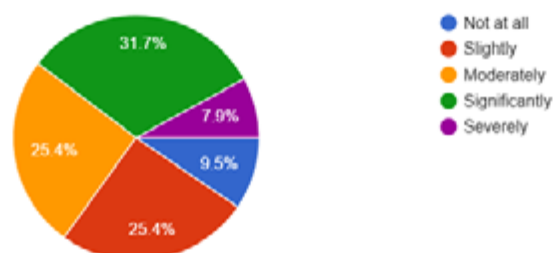
6. Does the person you care for have any of the following conditions? (Select all that apply)

63 responses



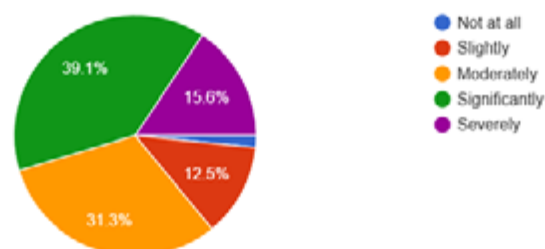
7. How much does your caring role impact your own physical health?

63 responses



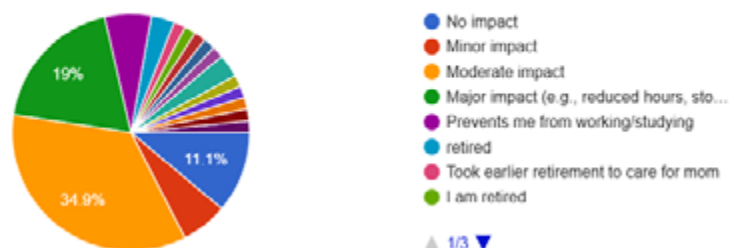
8. How much does your caring role impact your own mental and emotional well-being?

63 responses



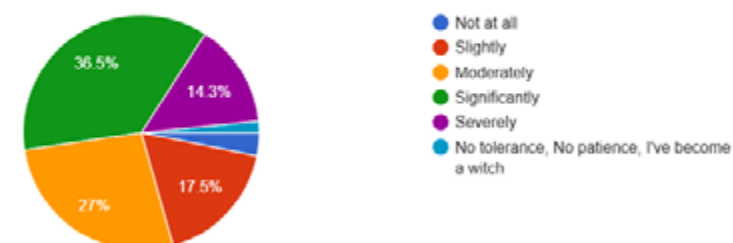
9. To what extent does your caring role affect your ability to work or study?

63 responses



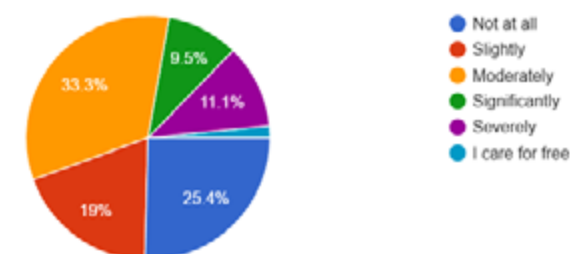
10. How much does your caring role affect your social life and relationships?

63 responses



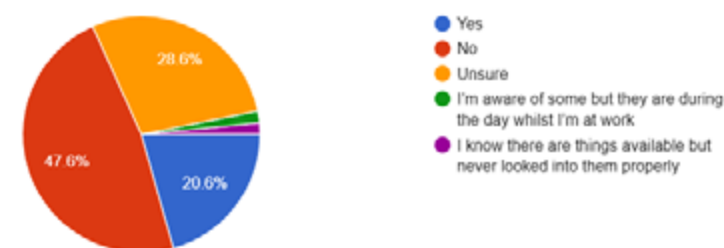
11. Do you feel financially impacted by your caring role?

63 responses



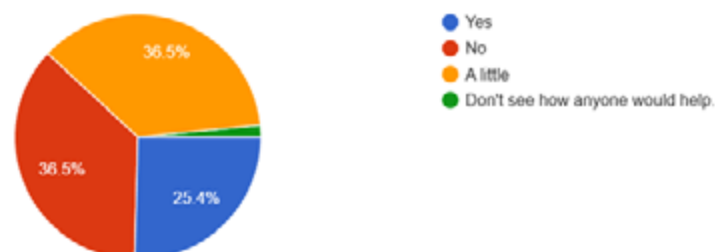
12. Are you aware of local support services available for unpaid carers?

63 responses



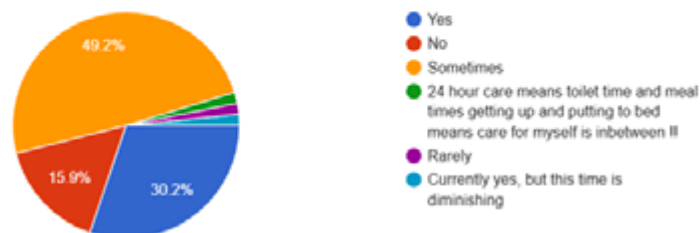
13. Are you aware of how to access information and guidance, including signposting, in relation to your caring role?

63 responses



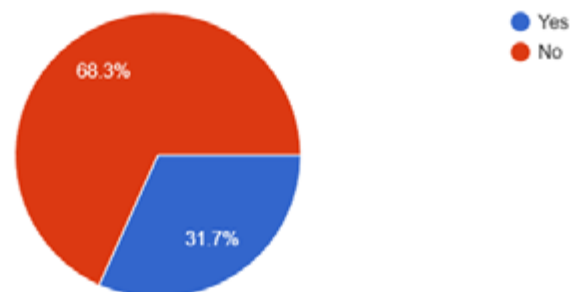
14. Do you have time for taking care of your self

63 responses



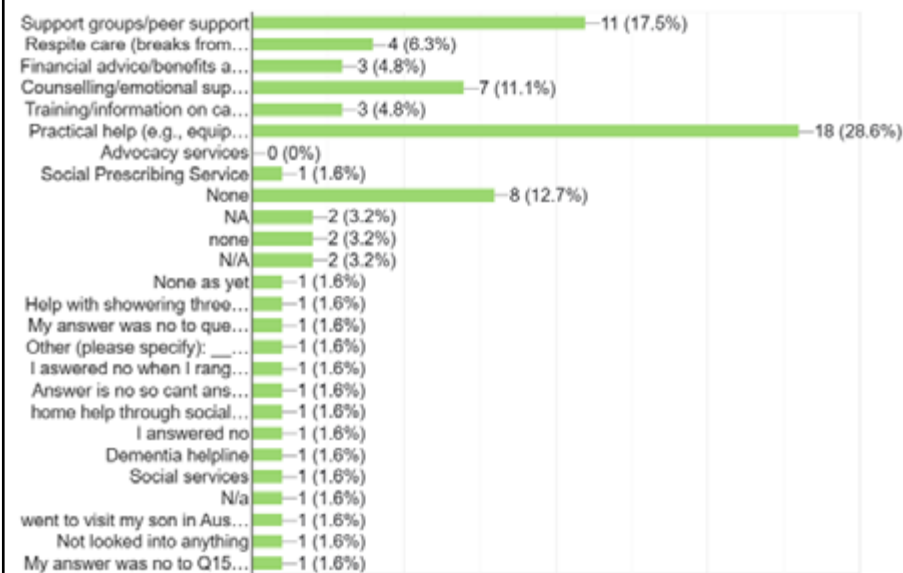
15. Have you ever accessed any support services for unpaid carers?

63 responses



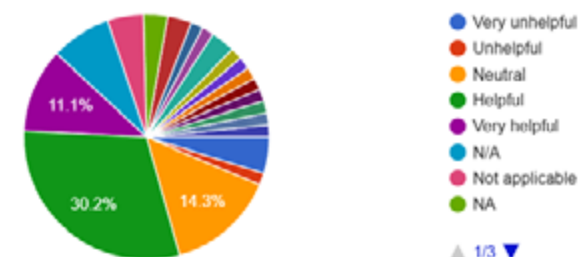
16. If yes, which of the following services have you accessed? (Select all that apply)

63 responses



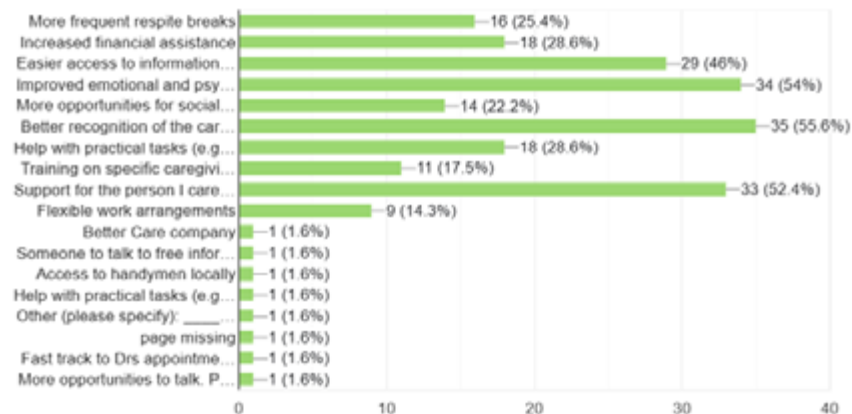
17. How helpful were these services? (If applicable, for each service you accessed)

63 responses



18. What additional support or resources would most help you in your caring role? (Select all that apply)

63 responses



"Partnering with Ontex has given us the opportunity to truly listen. This is about more than resources – it's about building a movement. We want unpaid carers to feel seen, valued, and supported, not left to carry the weight in silence."
 - Hannah Montgomery, Co-Founder of Grace Cares.