



Who can help me?

Exploring the experiences of carers supporting people with a neurological condition in Lancashire.

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Executive Summary

This report details the findings of our project exploring unpaid carer's experiences of supporting someone with a neurological condition, including any support the carer received, whether the carer's individual needs were addressed, and whether their health and wellbeing had been affected as a result.

We spoke to **124** unpaid carers supporting someone with a neurological condition. We attended **25** community groups and conducted **27** case studies.

80% of carers in our study were registered as a carer with their GP. However, only 39% had received a carer's assessment.

The majority of carers received information about their partner/relative's diagnosis in a way they could understand. However, those who told us they did not felt there was a lot of information given at diagnosis but not once the condition had progressed. There was a lack of follow-up appointments, medical professionals showed a lack of compassion, and they were given no information on how to manage symptoms or best care for their loved one.

The most common form of support accessed by carers came from local organisations such as carers cafés and groups, followed by organisations for specific neurological conditions, Lancashire County Council Social Care Service, and Lancashire Carers Service.

The most common barrier to accessing support by carers was not

being offered any support and not knowing what support was available. Additional barriers included the individual with the neurological condition not wanting to access support, work commitments, finances and a lack of support offered by GPs.

The caring journey was described as exhausting, stressful and lonely. Caring responsibilities impacted mental and physical health as well as finances, social life and family relationships.

The majority of carers expressed a need for clearer guidance on what support is available to them and signposting to support. Continuity of care was also desired by carers as well as information about the progression of symptoms, financial advice and information about respite care.

These findings have informed a series of recommendations for the attention of Lancashire County Council, Lancashire and South Cumbria Integrated Care Board, Age UK Lancashire and Lancashire Carers Service to help improve the support offered to carers who are supporting people with a neurological condition.

Introduction

About Healthwatch Lancashire

Healthwatch Lancashire is the independent voice for Lancashire residents using local health and social care services.

Healthwatch Lancashire talks to people who use local NHS and social care services to hear about their experiences, identify what's working well and what could be done better so that services can improve.

Healthwatch Lancashire is here to:

- Provide information and signposting to local health and care services so that people get the support they need.
- Listen to views and gather feedback about health and social care services.
- Improve the quality of services by making sure service providers and decision makers listen to the views and use these to make services better.
- Encourage people running services to involve local people in changes to care.

Healthwatch uses people's feedback to better understand the challenges facing the NHS and other care providers and we make sure people's experiences improve health and care for everyone – locally and nationally. Healthwatch was established in April 2013 as part of the implementation of the Health and Social Care Act 2012.

Introduction

Over the last 18 months, whilst engaging with members of the public, we identified gaps in support for unpaid carers and family members supporting people with a neurological condition including Dementia, Parkinson's Disease, Multiple Sclerosis and Huntington's Disease.

The aim of this project was to understand the experiences of unpaid carers who support people with a neurological condition, including the support they receive/d as a carer (if any), whether their individual needs were addressed, and whether their health and wellbeing had been affected as a result.

Findings have informed a series of recommendations to influence change and improve experiences for carers for the attention of Lancashire County Council, Lancashire and South Cumbria Integrated Care Board, Age UK Lancashire and N-Compass. Areas of good practice have also been highlighted.

Disclaimer: At the time of this report, Lancashire County Council had recently published their Carers Strategy which includes how they support carers such as carers assessments, carers awareness briefings for professionals and their Carers Community Network. This report should be considered alongside this Carers Strategy.

Acknowledgements

Healthwatch Lancashire would like to thank all the people who shared their experiences with us for this project. We appreciate people sharing their poignant stories to help us drive improvements.

We would like to thank members of the steering group, including Lancashire Carers, MS society, Age UK Lancashire, Alzheimer's Society, and volunteers with lived experience who supported us with the planning and direction of the project, ensuring our project was co-produced with people with lived experience of caring responsibilities.

My experience of being a carer is a lonely one



The love for my darling husband is the motivating energy and driving force behind my devotion to caring for him – regardless of the total lack of support I've received.

My experience of being a carer is that it's a lonely one, and one that tests who you are at the soul level. I regularly go through a whole spectrum of emotions but know despite this all my caring for him and all associated tasks still has to be done – irrespective of how I feel or how much pain I may be in at any time. And because I love him so much, I'll continue to do this for as long as it takes.

I just wish that at the start, organisations and people would've simply been honest and told me from the outset that I'd be on my own, and I'd just have to find a way to cope and figure things out.



Methodology



124 people
engaged with



During March 2024 and April 2024, we engaged with 124 unpaid carers (those currently caring or who have cared for someone in the past 12 months) supporting people with a neurological condition, to understand their experiences and the support (if any) they received. We also asked carers if they felt their needs as a carer were addressed and whether their health and wellbeing had been affected as a result of their caring responsibilities.

A steering group was formed in the early planning stages of the project, which included people with lived experiences of caring responsibilities and stakeholders from Lancashire Carers Service, Age UK Lancashire, MS Society, Alzheimer's Society, Lancashire and South Cumbria Integrated Care Board. The steering group met four times, and also provided us with guidance on survey questions and engagement opportunities.

We engaged with carers by attending a range of carers support groups, general public engagements, face to face conversations, telephone calls, along with an online survey. The project was advertised through posters and leaflets which, with the support of the steering group, we distributed throughout Lancashire in community centres, local support organisations as well as through our social media channels, website and e-newsletter. The project was also promoted through local carers' support organisations, who advertised the project online and through word of mouth.

In total, we attended **25** community groups including carers cafes, neurological condition support groups and memory choirs. Discussions with carers were inputted through an online survey. We also conducted case studies with people who were happy to share their experiences in more detail.

Twenty seven case studies were conducted. These gave us a rich insight into carers' experiences, the effect caring has had on them, and what support they would have benefitted from.

25 community groups attended



27 case studies

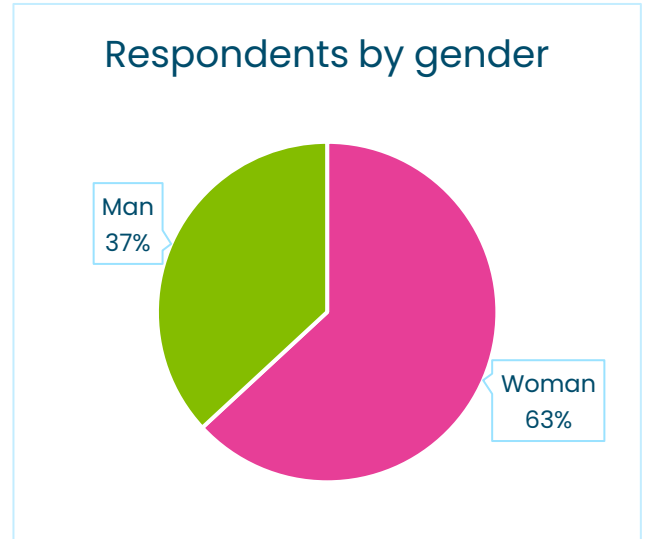
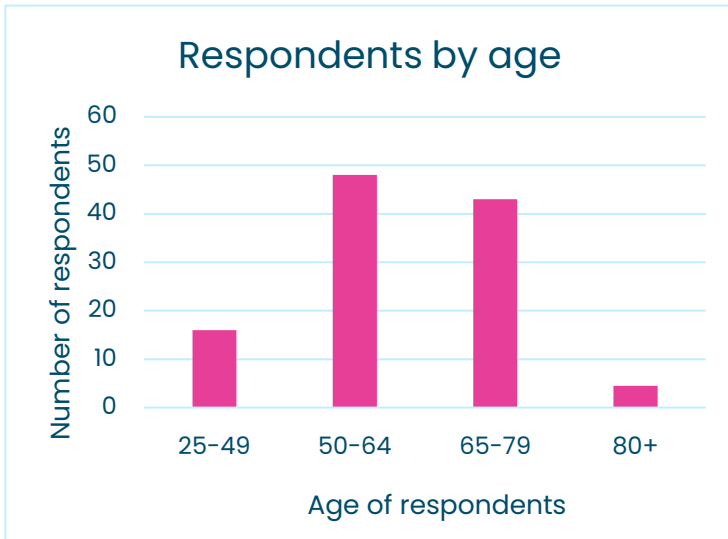
A promotional graphic for a survey. It features a photograph of an elderly man sitting in a chair, with a woman in a yellow jacket leaning over him. The text 'Who can help me?' is in a dark teal circle, followed by the question 'Do you support someone with a neurological condition?'. The 'healthwatch Lancashire' logo is in the top right. A QR code is in the bottom right with the text 'Scan the QR code to have your say'. A white circular arrow icon is at the bottom left of the teal circle.

Who can help me?
Do you support someone with a neurological condition?

healthwatch
Lancashire

Scan the QR code to have your say

Demographics



Ethnicity	Number of respondents
White British	110
White: Any other White background	4
Asian/Asian British: Pakistani	1
Black/Black British: African	1
Mixed/Multiple Ethnic Group: Any other Mixed/Multiple Ethnic group background	1
White Irish	1
Prefer not to say	4

Post code area	Number of respondents
PR (Preston)	60
LA (North Lancashire)	20
BB (Blackburn)	29
FY (Fylde and Wyre)	6

Employment Status

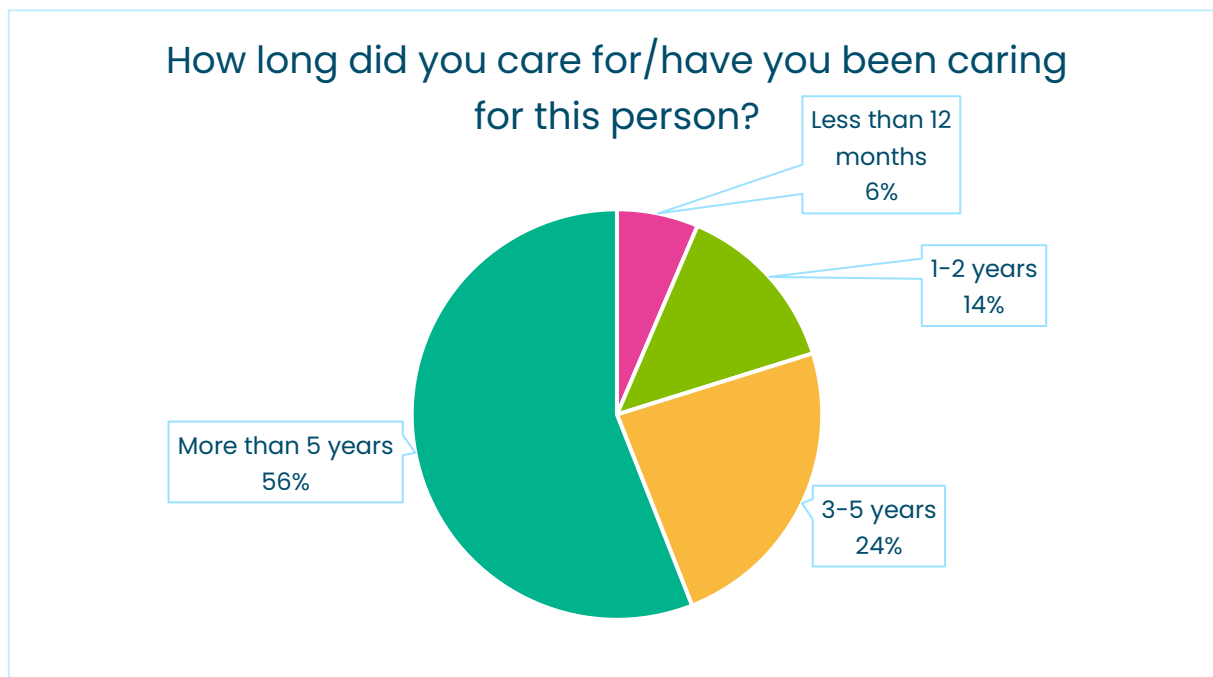
- 39% Retired
- 30% Caring responsibilities
- 16% Working part-time
- 12% Working full-time
- 2% Unable to work due to disability

Reported health of carer

- 30% High blood pressure
- 16% Physical or mobility impairment
- 11% Cardiovascular condition
- 10% Mental health condition

Findings

64% of carers were caring for their spouse/partner and 36% were caring for a family member. The length of time they had been caring for a partner/relative ranged from 6 months to 38 years. Most had been caring for more than 5 years, as shown in the graph below:



83% of individuals with a neurological condition had received a diagnosis

Those currently waiting for a diagnosis

Seventeen carers shared that they were currently waiting for a diagnosis for their loved one. Six carers shared that they had received no support so far.

"None. My wife has to fight and advocate for herself for 16 years, against a system that disbelieves, ignores, negates and neglects her"

The most commonly accessed form of support was from charity organisations including Age UK and Lancashire Carers. Two carers were receiving support from paid carers funded through the NHS and two carers had received support from their GP.

Registering as a carer with GP

80% of carers had registered as a carer with their GP

For those who had not registered as a carer with their GP, 50% did not know that they could do so. Two carers shared that they were next of kin/power of attorney and they did not know that registering as a carer was also an option.

Carers assessments

Only 39% of carers had received a carers assessment. For those who had received an assessment, 28% had received an annual review and 28% had not received any review on their assessment.

Receiving information about diagnosis

80% of carers received information about their loved one's diagnosis in a way that was easy to understand. For those who did not, the majority of carers shared their experience of when they received the diagnosis for their loved one and how they felt a lack of compassion from medical professionals. When receiving life-changing news, carers felt that they were not given enough information and were left to find support and information themselves.

Carers also said:

- There was a lot of information given in one go at diagnosis, which was hard to digest during a distressing time, and then they received no information or support following that.
- A lack of follow up appointments on progression of the condition offered/available.

"When given the Vascular Dementia diagnosis from the memory assessment service you were just discharged and pointed towards the Bay Information Hub. I was blindsided that there were no yearly/2 yearly follow-up option. I was just left to get on with it."

- Medical professionals stating there is "no cure", leaving carers feeling unsupported and overwhelmed
- No information given on how to manage symptoms of their loved one and other advice on how best to care for their loved one

"There was nothing about how to help them when things get difficult. My mother lashes out and it can be hard to work with her"

Several carers shared their experience of not being listened to, particularly during medical appointments regarding their loved one's symptoms.

"They didn't listen to me at the hospital and they kept him on medication which made him much worse. They finally took him off it and he became better but as a carer I didn't feel listened to."

No one knows about Huntington's Disease



People tend to focus on the person with the condition but its bigger than that, its probably worse for the carers.

My husband was diagnosed with Huntington's Disease 10 years ago. He started to decline with his memory and psychological elements. Things he could do yesterday he couldn't do today. He didn't disclose his symptoms to work and the likelihood of something happening at work was high. It's not uncommon for people with a Huntington's Disease diagnosis to not want to share it. A lot of issues get swept under the carpet.

As a carer, I would get thousands of calls a day from my husband of what he was going to do or not going to do. It was quite manipulative, he was under psychiatry and admitted to hospital as he wanted to end his life. Huntington's Disease is hereditary and he had seen it with his mum and how it affected her so knew what it was like.

I had no one to help me and speak to.

The only support we had which was guaranteed was the Huntington's Disease specialist nurse. Without her neither of us would be here to tell the story.

She only works 27 hours a week for the whole of the North West. At the time, she had 750 cases but she shared that there are 3x more people with Huntington's Disease who are undiagnosed. She always rings back and emails back. There is no other support available to help with self-harming support. Nothing has been easy.

I have had to fight for everything, I have had to meet with managers of care homes and the CCG in relation to funding.

There are no services for Huntington's Disease so they get put under the Mental Health umbrella. He does have Mental Health issues but one of the triggers of a Huntington's Disease patient is sound and so the Mental Health ward he was on was feeding his anger and issues, it made things worse. There is such a lack of understanding about Huntington's Disease.

The council will contact you from time to time about support but apart from that there was not enough support.

When you ask if anyone knows about Huntington's Disease, you are an educator not just a carer. No one knows a lot about it, there is such a lack of understanding of Huntington's Disease. When people see you out and about, they will say to him 'have you had too much to drink', you feel embarrassed because people misinterpret his symptoms. You find yourself withdrawn from social interaction, it can be isolating and draining, and you feel the pressure of having nowhere to go.

In relation to finances, I am a nurse so I know where to go for financial support. I am very lucky but even I struggled. Even just to fill a form out to describe his condition. When we went to apply for PIP we got told he had to

complete an assessment. I asked his HD nurse to help us who said 'you are not going for an assessment' and explained what the condition has no cure so an assessment is not appropriate. His symptoms were changing all the time. He might be able to do something but then an hour later he can't. Had I not had the nurse, I would have been under even more pressure.

The nearest support for me is Chorley and I live in Wigan (husband is now in Burscough). I still advocate for him even though he is in a care home. You actually have more responsibility, as you are never satisfied with where they are, you are constantly monitoring and observing. You never switch off as a carer, there is a lot of responsibility.

There should be more access to support services, but for everyone who takes on that role. There is nowhere advertised, it is always a battle you have to fight for everything you need. The journey is fragmented, there is no clear pathway.

The GPs know nothing about Huntington's Disease.

GPs should be raising awareness of different conditions which are less well-known, even through pop-ups in town centres. If people have a better understanding of the condition, it would help as people know what you are dealing with.

During our worst months, we had the HD nurse for her full 27 hours. There needs to be better funding. Her advice is so valuable and we still tap into her on a regular basis, 10 years later.



Support offered for carers

One hundred and thirteen carers shared what support they had either been signposted to or accessed. The most common form of support accessed by carers we spoke to was from friends and family local support organisations such as carers cafés and groups in which carers can attend with their loved one.

This was accessed by 28 (25%) carers. Further, 21 (19%) carers received support from organisations for specific neurological conditions including the Alzheimer's Society, Brainkind, Dementia UK, Parkinson's UK, Huntington's Disease Association and the MS Society.

"The Bay Information Hub has been a lifeline so has N-Compass especially the coffee and chats where you get to meet other carers and get more information from other carers and find out about other groups and activities."

Sixteen (14%) carers had received support from Lancashire County Council Social Care Service. This support included house adaptations, social workers, respite care and financial support.

Twenty-three (19%) carers had accessed support from The Lancashire Carers Service through N-Compass, and a further 6 (5%) accessed this support through Carer's Link. Positive feedback was received for these services for their understanding and signposting to further support including carer's assessments.

Other support accessed included support from Age UK (9), financial support (6), paid carers (4), district nurses (2), admiral nurses (2), hospice (2) and support from their employer (2).

Twenty-two (19%) carers had received no support to help with their caring responsibilities. Carers described how they were left to find support themselves which made them feel overwhelmed and stressed.

"We have had very little help. We were left on our own for ages and the problem I have is everything has to be done by telephone which takes ages. There is no help for finances and now they are means testing things I am worried I am going to be left without support financially."

We do need some more help

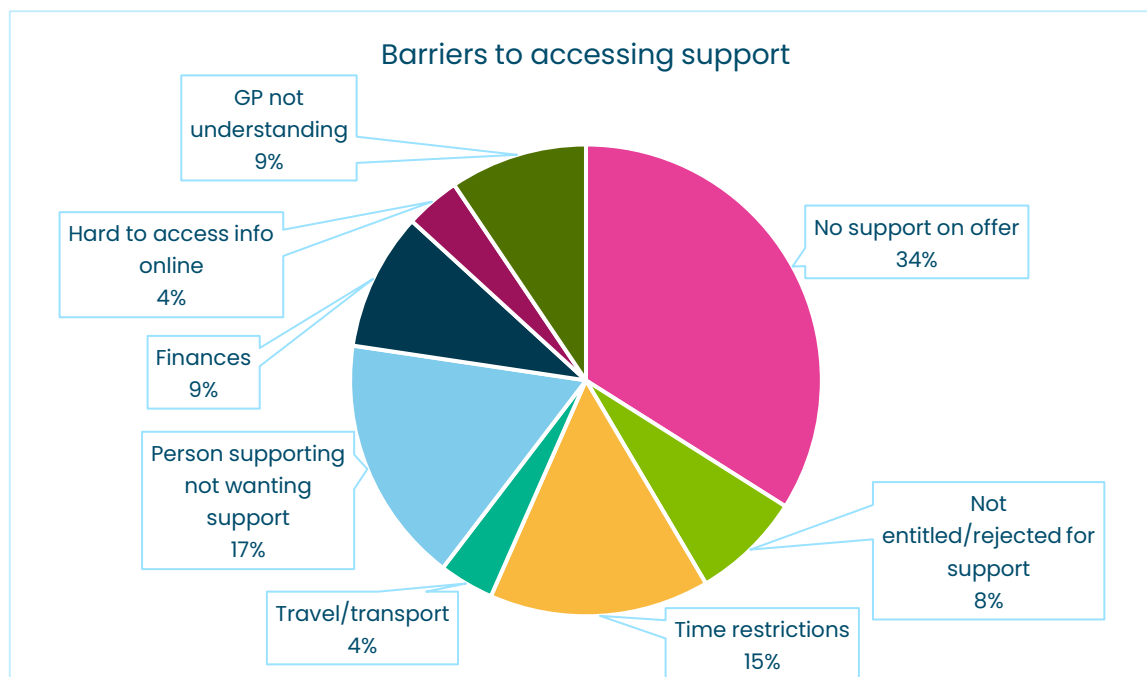


I don't think that I have been offered anything, every application that I complete I keep getting rejected. I have received some support from attending 'Singing for the Brain' which is ran by the Alzheimer's society, a couple of the women here have helped me or pointed me in the right direction some attended the council with me.

Adult social care visit once a year but I don't have a contact number and we do need some more help, especially with the cleaning. I have applied for attendance allowance and they have said I am not eligible as my wife currently doesn't need any help with cleaning herself. I have applied for a blue badge and night relief but they were also rejected.



Carers were asked if they experienced any barriers to accessing support. The most common barrier faced was not being offered any support, not knowing what support they were entitled to and/or having to look for information and support themselves.



Another common barrier to accessing support was due to the individual with the neurological condition not wanting to access support.

“My mother! She is fiercely independent and this has stopped us going further with support we’ve had care assessors who have helped but she’s stubborn and doesn’t want help off strangers.”

Carers also shared that due to work commitments, they do not have the time to search for support. This was also regarding accessing support groups, as the majority occur during the day in working hours making it difficult for carers with jobs to attend. Some carers suggested having support groups available in the evening and at weekends.

Other barriers included GPs offering little support and not understanding the carer’s situation and concerns. Finances were also a barrier as carers cannot afford to fund extra support needed.

Four carers explained that when they applied for support, they were told they were not eligible and their support request was rejected.

“Money [is a barrier]. My wife can’t get any extra care without paying. We get an hour and a half care support a week, even though I work full time and my wife needs care around the clock”



There is no follow up support offered once diagnosis is given



My mum was diagnosed with Alzheimer's and vascular dementia a few years ago. I have never had a carers assessment and only an assessment for my mum. It is a struggle at times as we have carers coming in but my mum doesn't always like them and this can be hard to deal with. I was told I was entitled to four weeks respite as a carer but when it came down to organising it, I found it very hard and got no support with it so I haven't used the respite.

I am aware of a company called dementia adventure where they support carers and their relatives to go on holiday for the week, this is very pricy and unfortunately, I can't afford to take my mum at the moment.

I have personally found that social worker follow up is appalling and there is no follow up support or care offered for carers once a diagnosis is given. I felt I was left to get on with it with no help or support and this became very difficult.

I personally think a timeline of support would be helpful, so we are aware what we are entitled to, when and by whom. I feel as carers we are kept in the dark most of the time and this can be very difficult as you don't know what is happening and when.

I have the peace of mind plan in case I ever have to go in to hospital and I had to use it a few months ago. I went into hospital for an appointment, and I rang them to tell them I would need to have some support for the next 24 hours as I have an emergency appointment and might have to stay in overnight. I told them that the door was unlocked and where the key was to lock up once they were in.

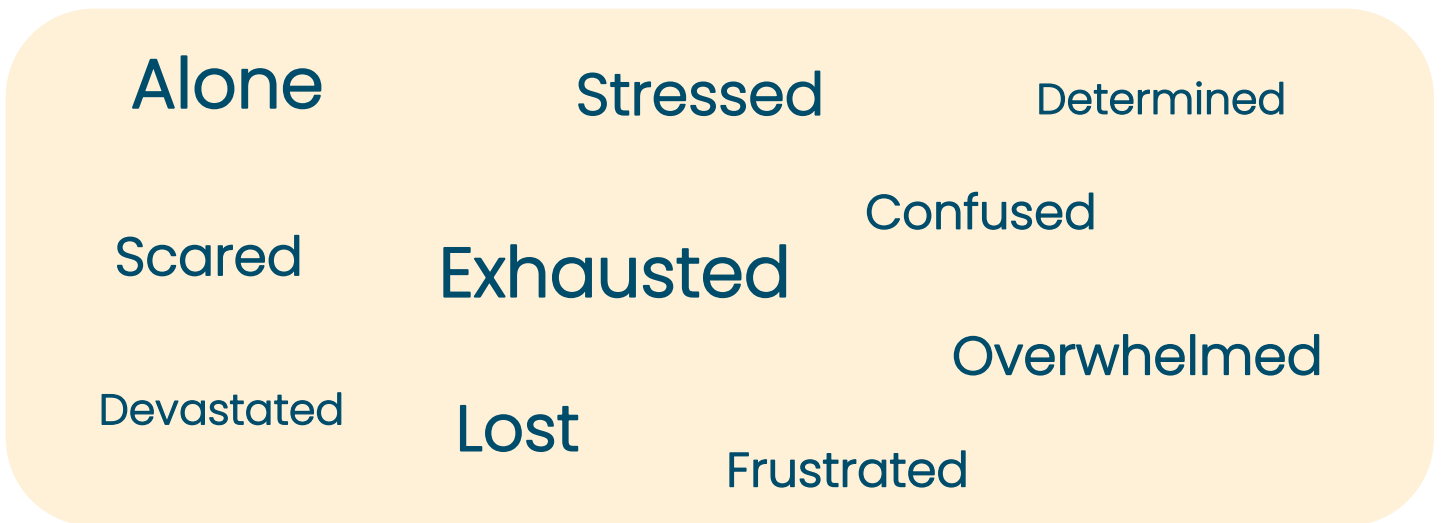
They turned up and tried to call me but as I was in the hospital, I didn't receive the call, unfortunately they called my relative who isn't allowed to see my mum and isn't allowed to be contacted and they spoke with him about how they couldn't access the house and that my mum was in the house alone.

When I eventually managed to call them back, they told me that they couldn't access the house, even though the door was unlocked and there was no reason for them not to get in. I have a camera in the main door anyway for safety with my mum and I looked at this and there was no sign they had even entered the door or even attempted the door.

When I got home I called the agency and asked them why no one had been out to my mum as now she had been on her own for hours with no support. They were using an outdated plan which wasn't even for my mum but for my dad who had passed away. This plan was over 7 years old and I was made aware that this document had been destroyed as we had made a new one for her and for safety reasons. I found the process really difficult when it should have been a calming experience for me when I was in hospital myself.



The caring journey



Carers expressed how their caring journey has impacted their health and wellbeing. The overwhelming response was feelings of exhaustion, stress and loneliness as they try to support their loved one through a life-changing experience; not knowing where to access support and focusing all their time and effort on caring responsibilities.

"I started as optimistic and strong, but now I feel tired, drained, sometimes angry, depressed with anxieties as there is no silver lining there is no cure. I'm watching the woman I love the most fall apart mentally and physically."

The impact of caring included physical and mental health deterioration as well as financial difficulties. Carers shared their experiences of "losing their freedom" and that they live "a very restricted life" due to caring duties being constant. Many carers also spoke about how their caring responsibilities affected their family dynamic and relationships. Carers did not have as much time to socialise and meet family and friends, and due to stresses, disagreements often occurred during families about the individual's condition and care.

"I feel lonely and that my life is just dementia."

One carer expressed how they felt their "life is not my own". Three carers shared that they had to quit employment to care for their loved one which impacted their financial position. Several carers also shared how they had to learn how to cook and do housework as it was their partner who had this role before their diagnosis.

"The last two years have been a nightmare and there are days I've just sat and cried - I feel totally abandoned."

You have your whole life taken from you in a matter of seconds



My husband was diagnosed with cancer and Parkinsons within a year of each other. I don't feel there is enough support for carers as I don't think they understand what is important to carers and just assume. My husband took care of the bills, car, passwords and house before he was diagnosed so the stress I felt when he was diagnosed as he began forgetting everything was hard.

When you are unwell as a carer you feel you can't be too unwell as you still have to care for your relative. They need you round the clock, and this means that illness is not always possible for me.

I feel as a carer you have your whole life taken from you in a matter of seconds, like going into town shopping, something so simple I now cant do as I've got to take my husband and it takes a lot of preparation to take him out and you can't do what you'd normally do.

I've been told so many times, go on holiday have a break, but it isn't a break when I take him away because he needs care all the time, so it actually makes it harder not being at home. I feel as a carer you feel a lot of guilt when you do leave them and you are constantly thinking of them and ringing them to see if they are ok.



Support needed

We asked carers what support they would have benefitted from and how this would have impacted them. The majority of respondents expressed a need for clear guidance on what support is available, what they are eligible for and signposting to local services. A few carers suggested being given a "checklist" of what they need to do and who they should contact when becoming a carer.

Continuity of care by having a named professional who they could contact if they had any concerns was also desired by carers. This was particularly important due to the progression of symptoms and the changing of symptoms.

"With my mum and her dementia, her condition kept changing and you have to keep up with it all. It would have been useful to have more consistent information or a check-in because things do change. We got loads of information at the start and then nothing."

Ten carers shared that they would have benefited from financial advice regarding what they could apply for. Nine carers shared that they wanted more information about the diagnosis their loved one had received including symptoms, progression of the condition and how best to care for them.

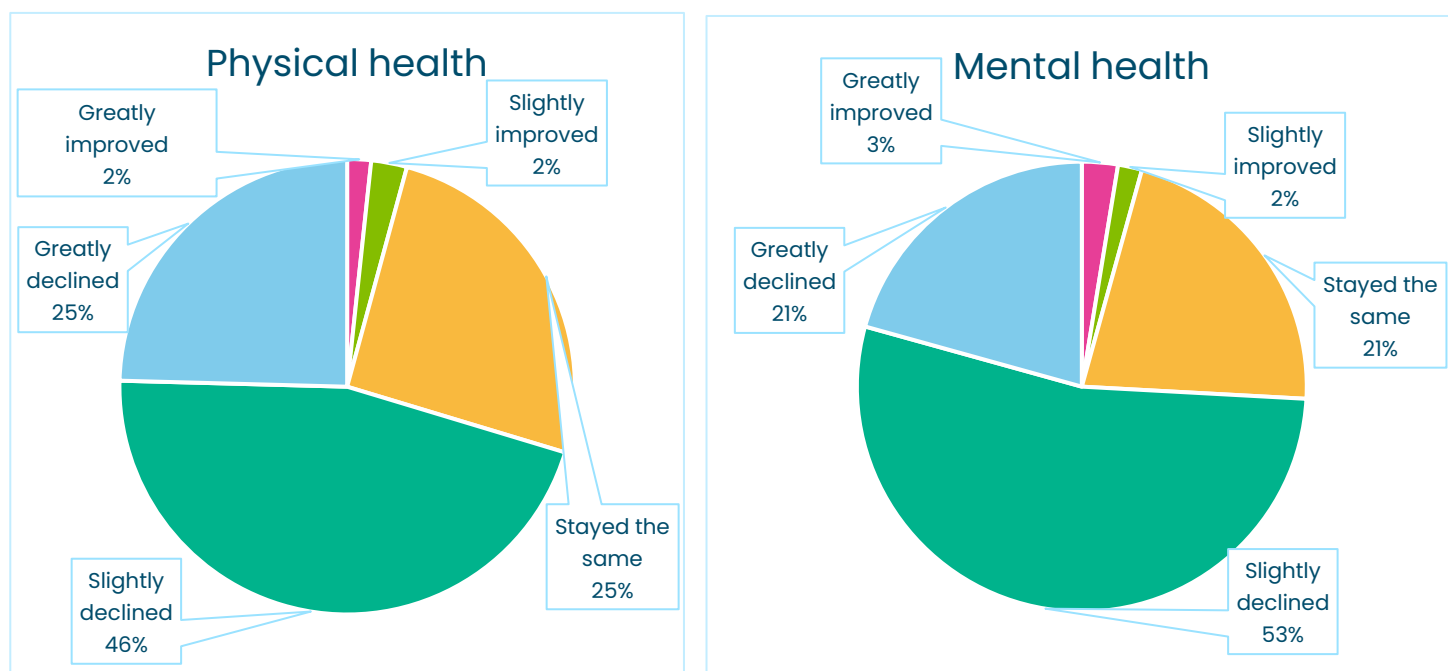
"More information rather than just a name of an illness for us to google, an idea of potential treatments, life effects etc as google is a scary place"

Other support carers would have benefited from included information on respite care (7), occupational therapy (2), and their GP being more proactive and understanding (3). Six carers said that “anything” would have been helpful as they had received no support.

Carers shared that if they had received this support, it would take the worry of caring away and would improve their mental health as they would be less stressed and more confident that their loved one was getting the support they needed. A few carers also expressed how they would feel appreciated as the impact of their caring responsibilities often go ignored or unheard.

“I wouldn’t be feeling so isolated, ignored and overlooked. It’d help me cope mentally, emotionally and physically.”

We also asked carers whether their physical and mental health had changed since taking on caring responsibilities. The responses can be seen in the graphs below which show that 71% of carers’ physical health had declined and 74% of carers’ mental health had declined.



As I get older so does the impact of caring on my body



I have been a carer for my husband who has Multiple Sclerosis for 15 years. My mental and physical health has slightly declined over the years and caring can be isolating. Washing, dressing and caring every day makes my back sore, my hands sore and I am tired especially when he needs help during the night as well as during the day. As I get older so does the impact of caring on my body.



I felt so alone as a carer



I have been looking after my parents for around 8 years now, my dad had dementia and my mum has Alzheimer's. I had to give up my full-time job as I couldn't manage working and caring at the same time.

I have never done anything like that before, so I had no way to know what to do or where to go for support. I didn't have a carers assessment early on and this only came later in the process.

I was given support from Marie Curie, my GP, the memory clinic, Alzheimer's society, mental health support and social services. I felt these didn't communicate very well though.

I was lucky enough that I had a friend in Marie Curie and they helped me with night respite so I could get some sleep and some support.

I then heard of Age UK through social services, and they helped me massively and helped me with day care so I could get some respite.

I wish I'd had this support a lot earlier as a lot of this came later in the journey. This was very overwhelming at first and I was just left at home with both of them and this was very hard.

When the district nurses came round, they were helpful with support and advice and I found dementia UK through them and they were very helpful and supported us with groups and coffee mornings.

I got support from the RNIB as he had a visual impairment and they were brilliant, but again this was very late in the journey, and I wish I'd known about it sooner.

My mental health declined as I'd been on my own for so long looking after him and I felt I hadn't looked after myself.

I feel that more support from the GP earlier on would have been massively helpful, a package would be helpful when diagnosed with all support services and groups in the area would be very helpful.

I also feel that carers aren't told about medication and that can be frustrating. They change their medication, and they don't tell you why or tell you what the medication will help with.

I felt so alone as a carer as I didn't have anyone or anything, I didn't realise till afterwards that my mental health was awful but because you just get on with it you don't realise that your health was deteriorating. You end up bringing family members into the situation and this can have a massive impact on them as well.



Conclusion

In conclusion, our project has highlighted the concerns, barriers and daily struggles faced by unpaid carers supporting someone with a neurological condition. Carers described their caring journey as exhausting, stressful and lonely, impacting their mental and physical health, finances, social life and relationships.

A large proportion of people registered themselves as a carer with their GP. Although a large proportion of people identified themselves as a carer with their GP, there was less awareness regarding carers assessments and the support people could access through this, with less than half of carers having undertaken this assessment.

Carers have the right to decide what they are willing and able to do as a carer¹. Under the Care Act 2014, carers are entitled to a carers assessment to discuss the support they need. Our findings have shown a need to raise awareness of carers assessments to ensure carers are receiving the help and support they need.

The most common forms of support came from local support organisations, Lancashire County Council Social Care Service, and Lancashire Carers Service. Positive feedback was received about the support organisations, particularly the Lancashire Carers Service.

Information

Positively, the majority of carers received information about their loved one's diagnosis in a way they could understand. However, some carers shared that although they received a lot of information at the time of diagnosis, this did not continue as the condition progressed. Carers also said that there was a lack of follow-up appointments, medical professionals showed a lack of compassion and there was no information on how to manage symptoms.

Barriers to support

The most common barrier to accessing support was not being offered any support and/or not understanding what support was available. Work commitments, finances and a lack of support from GPs were also common barriers.

Improvements needed

Carers expressed a need for clearer guidance on what support is available to them, continuity of care, and information and support on progression of symptoms and how best to care for their loved one, financial advice, and information about respite care.

¹ <https://www.richmondcarers.org/2022/11/22/know-your-rights-understanding-the-care-act-and-carers-rights/#:~:text=Carers%20have%20the%20right%20to%20determine%20what%20they%20are%20willing,life%20alongside%20a%20caring%20role.>

These findings have highlighted the struggles faced by unpaid carers who are unsure what support they can access and how they access such support, as well as a lack of compassion received by professionals. There is a clear need for better signposting of support available for carers.

Recommendations

Theme	Recommendation	Responsibility	Provider response
Promotion of services	Promote the Carers Community Network through social media and posters in community settings so carers can share experiences and stay informed of support for carers.	Lancashire County Council	This will be included as part of our Carer's communication plan under the new Carer's strategy.
	Encourage the promotion carers assessments in Primary Care settings through posters and leaflets to increase understanding and uptake. This could be through engaging with Primary Care Networks	Lancashire and South Cumbria Integrated Care Board	<ol style="list-style-type: none"> 1. Share posters, leaflets and other relevant information via GP intranet. 2. Share with PCN leads along with this report for sharing with PCNs.
	Create a 'fridge list' including key support organisations and contact details which can be provided to carers at memory assessment clinics and GP practices.	Healthwatch Lancashire in partnership with Age UK Lancashire	Completed. See page 23-24

Raising awareness	Increase public knowledge of the definition of an unpaid carer and their rights through social media and posters/leaflets in community settings	Lancashire County Council Healthwatch Lancashire	This will be included as part of our improved information, advice and guidance offer including new and improved LCC Carer's webpages that the public can access.
	Raise awareness of the symptoms of less understood neurological conditions such as Huntington's Disease through social media, posters and leaflets	Lancashire and South Cumbria Integrated Care Board	We will share information to help raise awareness of less understood neurological conditions (such as Huntington's Disease) on social media, and via any leaflets, posters and other material that is available to share.
	Investigate if there is any opportunity to provide training to carers around their rights under the Care Act to increase understanding of what they are entitled to	Lancashire County Council The Lancashire Carers Service (N-Compass)	This will be looked into in partnership with the Carer's service.

Role of the GP	Increase uptake of GPs attendance at Lancashire Carers Awareness Briefings (delivered by Lancashire Carers Service, N-Compass) to support carers with diagnosis and progression of condition.	Lancashire and South Cumbria Integrated Care Board to work with The Lancashire Carers Service (N-Compass)	Given GP workload it would be difficult for us to increase GP attendance at the briefings, however we can provide written briefings via the GP intranet and in communication with GP networks.
	Investigate the introduction of a carer champion network across Primary Care Networks who can provide advice and information to carers, as well as gaining peer support from other champions within the network.	Lancashire and South Cumbria Integrated Care Board	Our place-based engagement coordinators in the comms and engagement team) are developing our support for PPGs and as part of that support we will investigate if PPGs can identify any carers champions and support them through the PPG network support that we are developing. These link with PCNs.

Next Steps... Fridge List

Carer Support		
The Lancashire Carers Service	We provide information, advice and a wide range of specialist support services designed to help carers continue in their caring role for as long as they choose and reduce the impact the caring role can have on their own health and wellbeing.	0345 688 7113
Age UK Lancashire	Respite via Cognitive Stimulation Therapy (For people with dementia) and Day Services, as well as help from our Support at home service; cleaning, laundry, shopping, and companionship	0300 303 1234
Alzheimer's Society	Dementia information, advice, and strategies to help with day-to-day experiences for carers affected by any form of dementia; and group learning through the Carers Information and Support Programme	0333 150 3456
Carers Allowance Unit	If you spend at least 35 hours a week caring for someone with an illness or disability, you may be eligible for extra money called Carer's Allowance. Call for assistance with any Carers Allowance related queries.	0800 731 0297 Textphone: 0800 731 0317
Carers Help and Talk (CHAT) Line	Don't suffer in silence. All calls are answered by volunteers who can offer understanding with regards to the common challenges faced by carers. Available 24 hours a day, 7 days a week, 365 days a year.	0333 103 9747
NHS Carers Direct Helpline	Further information for carers and signposting to local sources of support in England.	0300 123 1053
Practical Support		
Adult Social Care (Lancashire County Council)	Support with social care needs including technology enabled care (e.g. pendants), daytime support, care at home, supported living/extra care housing, residential care, safeguarding as well as info regarding deprivation of liberty (DoLs).	0300 123 6720
Age UK Lancashire	Scams awareness, digital support, footcare, planning your retirement and will writing.	0300 303 1234
Care Navigators (Lancashire County Council)	Free and impartial service to anyone in Lancashire over the age of 18 looking for safe personal care services that match their needs and requirements. E.g. we can help you find short term care – for example to recover from an illness, surgery, or respite.	0300 123 6720

Benefits & Financial		
Age UK Lancashire	Our Information and Advice team can support with benefits, housing, and blue badge applications, including form filling.	0300 303 1234
Attendance Allowance Helpline	If you have a long-term illness or disability and you've reached State Pension age, you may be entitled to a benefit called Attendance Allowance. The helpline can provide assistance with any attendance allowance related queries.	0800 731 0122 Textphone: 0800 731 0317
Blue Badge Applications (Lancashire County Council)	The Blue Badge scheme helps people with severe mobility problems, park close to their destination. Call for assistance with any Blue Badge related queries.	0300 123 6736
Personal Independent Payment (PIP) Enquiries	Personal Independence Payment (PIP) can help with extra living costs if you have both a long-term physical or mental health condition or disability and experience difficulty doing certain everyday tasks or getting around because of your condition. You can get PIP even if you're working, have savings or are getting most other benefits.	0800 917 2222 Textphone: 0800 917 7777



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Next Steps... Fridge List

Advisory/Other Support

Citizens Advice Bureau (Lancashire)	Provide FREE confidential advice online, over the phone, and in person, whatever the problem, e.g. power of attorney.	01524 239 100
Healthwatch Lancashire	We are your local health and social care champion. From Chorley to Lancaster, and everywhere in between, we make sure NHS leaders and other decision makers hear your voice and use your feedback to improve care.	01524 239100
Independent Community Advocacy Network North (ICANN)	ICANN delivers Advocacy and information services across Lancashire. Help with form filling for PIP, UC50/ESA50, and Attendance Allowance.	01772 746 061
Lancashire Advocacy Hub	A free, independent, and confidential single point of contact for adults in Lancashire. If you are experiencing difficulties with, or need help with, your health and/or social care the Hub can help.	0330 0022 200

Wellbeing Support

Lancashire Care (NHS) Wellbeing & Mental Health Helpline	Freephone out of hours, person centered listening environment for people requiring emotional support in relation to their own wellbeing and mental health or that of someone they know.	0800 915 4640 Text 'Hello' to 07860 022 846
NHS 111 service (for non-emergencies)	If you think you need medical help right now, 111 online can tell you what to do next.	111

For further information about neurological conditions please visit The Neurological Alliance Website:

www.neural.org.uk

Additional Information

Alzheimer's Research	0300 111 5555
Alzheimer's Society	0333 150 3456
Brain Tumor Charity	0808 800 0004
Brainkind	01444 239123
Dementia Uk	0800 888 6678
Epilepsy	01494 601 400
Huntington's Disease	0151 441 5444
Lewy Body Society	0800 888 6678
Motor <u>Neurone</u> Disease	0808 802 6262
MS Society	0808 800 8000
Muscular Dystrophy	0800 652 6352
Parkinsons	0808 800 0303
Rare Dementia Support	020 3318 0243
Royal British Legion Admiral Nurse Service	0333 011 4311
Stroke	0303 3033 100



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healthwatch
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