Luminus

Unpaid carers insight for the Joint Strategic Needs Assessment (JSNA) chapter

March 2025

Shining a light on what matters to people.

Unpaid carers insight for the JSNA chapter

Contents

About Luminus

Luminus is a Surrey based independent community interest company which exists to empower people to have their voices heard. We are an enterprise driven by social value, that invests in the local community. We help organisations provide equity of access, and the best services possible, through the inclusive involvement of local people. Our vision is to create a society where everyone's voice is heard so we all receive the support we need for our wellbeing.

About Giving Carers a Voice

Giving Carers a Voice listens to the experiences of carers (of all ages) to ensure their views are heard in the design and delivery of the services they use. If people look after anyone who couldn't manage without their help, they are a carer.

Introduction

Surrey County Council (SCC) asked us to help facilitate carer insight and input into the development of the new Joint Strategic Needs Assessment (JSNA) chapter for all age unpaid carers. The aim was to identify key groups of carers (across all ages) to understand what works well and where there are unmet needs. SCC identified 4 key groups for us to explore. These were: young carers, young adult carers, parent carers and adult carers.

We began by conducting a desk-based analysis of the experiences which we have gathered from carers through our engagement since 2022. This desk-based research included experiences from **2,143** carers and **311** young carers. We then categorised the experiences into topline themes with sub themes sitting underneath. We identified which themes were specific to key groups and which were overarching themes for all unpaid carers. Following this, we conducted a series of **21** events and spoke to **186** unpaid carers during December 2024 to February 2025. These events included carers from all the key groups, to check the themes resonated with them, identify the unmet need, and document any other challenges or additional unmet needs they may be facing not already included in the themes.

Places visited to speak to unpaid carers during December 2024 – February 2025:

- Hale Youth Club
- Action for Carers Epsom hub
- Action for Carers Godalming hub
- Surrey Youth Focus Community in Practice neurodiversity event
- Age Concern Banstead dementia carers group
- Rare dementia support group
- Boxgrove Primary School
- Hermitage Infant School
- East Surrey autism, ADHD and neurodiversity support group

- Mytchett memory group
- Action for Carers Leatherhead hub
- Surrey and Borders Partnership (SABP) mental health carers forum with Action for Carers Guildford
- Action for Carers Banstead hub
- Farnham hospital
- NE Hants and Farnham mental health forum
- Action for Carers Cranleigh hub
- Heathside School
- Glebelands School
- St Peters Primary School
- Guildford Hongkongers event
- SABP older persons network meeting.

The findings of the desk-based research and the discussions with carers have been collated into this report, with first person quotes, to be shared with Surrey County Council and stakeholders in the development of the JSNA chapter.

Summary by age group

This table provides a brief summary of the themes for each age group of unpaid carers. More detail and lived experience is given in the themed chapters that follow.

Adult carers	Parent carers
Not being identified as a carer or reluctance to be labelled	Struggle to get support because of no diagnosis or late diagnosis of child's condition
Lack of knowledge and training for professionals	Not referred to professionals with specialist knowledge in child's condition
Not being involved in decisions about the cared for	Need single case worker who can advocate from birth to adulthood
Insufficient tailored support services and information	Difficulty accessing statutory help e.g. Education Health and Care Plans (EHCP)
Impact of caring on their own wellbeing and emotional health	Feeling blamed and shamed for the behaviour of their cared for
Difficulty getting a caring /life balance	Impact on wellbeing and emotional health not supported
	Difficulty getting a caring /life balance
	Lack of support and respite services

Young adult carers	Young carers
No communication of carer responsibilities as they transition to young adults	Not identified from a young age
No tailored or relevant information	Insufficient tailored and local support groups
Difficult to identify the young adult carers in further education settings	Difficulty balancing school and caring responsibilities
	Lack of understanding from professionals and teaching staff
	Isolation and loneliness (feeling they are alone)

Main findings

This report has been compiled to inform the Joint Strategic Needs Assessment for unpaid carers. Through our engagement activity we have identified 4 key themes within the findings. Within each theme there are separate subtopics. In the findings we have provided lived experience quotes and labelled these by the main unpaid carer groups we have considered: adult carers, parent carers, young adult carers and young carers. Some themes are cross-cutting all groups of carer, but in other cases the narrative details the different experiences for each group where relevant.

Theme 1: Knowledge and understanding

There are 5 key areas within the overarching theme of knowledge and understanding. The themes focus on carers reporting that professionals and people working within health, social care and related services have little or no understanding about the role of unpaid carers; that standard services are not meeting needs; there is little understanding of the impact of being a carer; failures to identify carers; and not consulting carers in decisions about their cared for.

1.1 Understanding by professionals

Adult and parent carers felt that they were not listened to even though they are often caring 24/7 and are best placed to advise on health and care issues. In some cases, health and social care professionals are only advising the cared for person of doctor or hospital appointments even though they lack capacity or are too ill to be able to respond.

> "Professionals do not understand what we are coping with on a daily basis. The onus is always on the carer to just carry on caring but there is no support from services."
> **Adult carer**

There is general frustration that information is not shared between services, helping to make services more person-centred and joined up.

> "Why don't all the health services connect and share information? It would make life much easier for the cared for and the carer."
> **Adult carer**

> "As a carer of someone with severe mental health problems, when you are in dire straits you don't have the capacity to reach out and phone people… I just don't understand why nobody talks to each other. Services are not joined up. People don't reach out to you."
> **Parent carer**

People also reported that services sometimes lacked understanding about the condition of the cared for and did not show respect or sometimes even acknowledge the carer.

> "The way that mental health services treat carers is appalling. They think that they are specialist, but they are not. More specialism is needed within the mental health teams to deal with all different types of conditions. They all require different approaches and treatments."
> **Adult carer**

Both adult and parent carers mentioned the difficulty of getting their cared for to appointments because of their poor health and/or behaviours.

> "Management and support of the conditions is what we need. Also home visits for those who cannot manage to get out to where the consultations are held. It's so stressful for me too. Getting him there and then managing his behaviour while he is there and then [the service] assuming that someone who requires a carer due to extremely poor health such as advanced dementia needs treatment, but sometimes it's about the management of their condition."
> **Adult carer**

> "He needs to see the consultant tomorrow. I don't know how we will get him there. I haven't seen him for 2 weeks as he is in such a bad state he doesn't want to see me. He doesn't want to see anyone. He isn't eating or looking after himself. He won't go out, he is frightened."
> **Parent carer**

Parent carers reported that they are often feel blamed for the behaviour of their children who require care and that general understanding by professionals and wider society would be helpful. Some parent carers reported that they have been told to keep quiet and back off

during medical appointments with the implication they are causing trouble. Some even reported being threatened with their child being taken away. This is particularly with children with Pathological Demand Avoidance (PDA) as the carers we spoke to felt professionals do not understand the condition and parents are accused of abuse.

> "So many parents are blamed for their children's behaviour as professionals don't understand their condition. Not all autistic children/parents have the same traits. The professionals need to be specialists in autism/ADHD/PDA. Otherwise, they simply do not understand the child or the parent."
> **Parent carer**

> "It's all very stressful and frustrating. We're carers for our son who has autism and ADHD. Every day when I go to school, the teachers are waiting for me to complain about this or that, and to tell me he's been naughty. Every day when I collect him I feel so judged."
> **Parent carer**

Being blamed for their child's behaviour is deeply traumatising for parent carers. Proper training needs to be given to all professionals working with families who are neurodiverse. This includes teachers, teaching assistants and social workers. A good example is the Oliver McGowan training and having training delivered by people with lived experiences is good practice.

This parent carer explains the benefit of appropriate health care approaches and the importance of getting a diagnosis.

> "Having a diagnosis was so helpful for my son. He could understand why he was feeling like he was and why he behaved like he did. His mental health was really suffering before as he couldn't make sense of how he was. The sooner you get a diagnosis the better. They can understand why they feel like they do. It also meant that we found groups for him and he didn't feel isolated. At school he was always the odd one out. Now he is with his own 'tribe' and flourishing."
> **Parent carer with own needs**

Many adult and parent carers have their own health conditions and managing these while managing those of the cared for can be very challenging. Early diagnosis can help a carer to cope with caring responsibilities better.

> "Now I have the diagnosis, I find that my friends and family are more understanding. Getting a diagnosis in my thirties was life changing. I'd battled with my mental health all my life. I have learnt acceptance for myself."
> **Carer with own needs**

1.2 Appropriateness of standard services

Adult carers feel the primary care standard approach to cared for and their carers as being inadequate and not meeting needs.

> "My husband does get called once a year and gets a 20-minute check-up appointment with the doctor. It's a waste of time though. He says I'm fine and they accept that and don't ask any questions. Why don't they ask me?"
> **Adult carer**

Carers reported that there are a number of shortcomings and failures in the annual assessment provision as indicated below and also frustration that unpaid carers are not consulted about the care of the person they are caring for.

> "You're supposed to have a yearly care assessment with the GP for yourself and your cared for. But it's a real battle to get either. They just don't happen automatically. I had to write to the Practice Manager of my mum's practice as they wanted to do her assessment over the phone. You can't do an assessment over the phone with someone who has dementia. They then called her to go into her appointment without me. She can't do these things alone. I just can't battle anymore. The GPs then focus on the physical aspect and they don't look at her mental situation. I do feel that I am not included in this assessment. Why don't they ask me? I'm her carer."
> **Adult carer**

Generally, carers feel they are not listened to by health and social care professionals.

> "Professionals should listen to carers more. We are caring 24/7 and know what's best for them."
> **Adult carer**

The next comment relates specifically to dementia, but our engagement team often hear that carers are not informed about general health conditions that develop in their cared for and are left to try and find out for themselves.

> "There really should be something in place when someone gets diagnosed with dementia to help guide you on further. There is nothing."
> **Adult carer**

> "We aren't given any training to look after and cope with our very mentally ill children. As carers we are just left to get on with it. I don't have the knowledge about the medication they are on, the side effects, what to expect. Nobody ever explained any of this to me. Even now after caring all these years, training would

be helpful. Things like what triggers certain behaviours and how to de-escalate them."
Parent carer

1.3 The impact of being a carer

Carers feel that there is a lack of understanding about the impact on daily living, wellbeing and emotional strain from the pressures of being an unpaid carer. The lack of understanding is compounded by the feelings of guilt and sometimes failure for carers when they are not coping well and need to put themselves first. This applies to all age groups.

"Being a carer is just exhausting. I have no fight left. I feel that services just wait for you to be in crisis before you can get any help. You really have to be a carer and live it to really understand the impact."
Adult carer

"It's ongoing, overwhelming and goes on for years. As carers we are just left to cope on our own. You can't get away from it. I just want to get my life back."
Adult carer

"My older brother has autism… It would help if others knew what young carers have to put up with and maybe they'd be nicer to us when we get frustrated because we're tired."
Young carer

"People say I should be proud of being a young carer, and I don't think they understand what it's like. I like to help my brother but it's exhausting and I shouldn't have to put up with his moods."
Young carer

"I am a young carer for my dad. It's not easy, but I try hard to do what he needs me to do. It would be better if people asked how I am and if they can help me. I wish people were nicer and everything wasn't rushed. I've asked for help and the teacher told me they didn't have time to talk."
Young carer

Particular pressures exist for carers who care for adults or children with severe cognitive, mental and physical health conditions.

"That is what is lacking - specialists in dementia. If someone could come and speak to him at home where he is in his familiar environment, it would be far better and less stressful for him and me as his carer."
Adult carer

> "I'm a carer for my husband who has anxiety and depression… I can't work anymore… I have nothing now. Life is a struggle… I wake up in the night panicking and stressing. I am struggling. I can't carry on like this for much longer. My mental health is suffering hugely and I can't cope."
> **Adult carer**

> "Being a carer for someone with dementia, it's like having a child again."
> **Adult carer**

For carers across all groups there is a perceived gap in services to meet their own needs. They need training or advocacy to be properly equipped to cope, adequate support services, and processes to ensure their own health does not deteriorate.

> "We are all untrained, we don't get a break, and we don't get looked at and checked over."
> **Adult carer**

1.4 Identifying carers

All unpaid carers need to be identified as such even if they choose not to be described as a carer. Some people, particularly parent carers and partners or close family of people being cared for, may not want to be called a carer but should be identified as such as soon as possible as it is a pathway to getting support.

> "I hate the word carer and I won't use it. I'm her husband and partner. I don't like that label."
> **Adult carer with own needs**

Others see using 'carer' to describe themselves as a way of getting help and support.

> "I don't mind using the word carer if it opens doors to support me and my husband. It's just a word and if you're refusing to recognise yourself as a carer, it means that you're missing out on things you're entitled to."
> **Adult carer with own needs**

However, identifying the caring role someone is carrying out is critical to getting the correct support they need. It is also imperative that identifying people in unpaid carer roles is done as soon as possible and not left until the carer is in crisis.

> "I think schools need to think carer when you first start a school and not wait until something happens… I remember when my son started school, the teachers just said he was naughty. How is that useful to me as a mum? It's just not. It would have been helpful to get information and advice about being a carer. Parents

know when they have a child who is different from other kids. We know and we just need help."
Parent carer

"It's so important that [young carers] are identified and supported in schools and also taught what a young carer is so they can self-identify… There is a lot of pressure on [my child] above and beyond what other young people are doing especially at exam time."
Parent carer

This quote is from a young carer who is often distressed at school and requires additional reassurance. By identifying young carers such as this when they start school there is greater understanding and empathy and there is less chance that the young carer will be penalised for their differences.

"I'm six and my little sister who is four has cancer; she's had it since she was a baby. I help my mum and dad to care for her."
Young carer

A parent carer described a caring relationship developing between siblings at a very young age, so professionals need to be educated in the impact this may have as children grow up.

"My oldest child was born with complex health needs. He cannot manage without an oxygen tube, and he's nonverbal. My youngest daughter is 20 months old, and I would say that she is very intuitive to his needs. She comforts him when he's distressed, holds his hand, sits close to him, gives him cuddly toys and in her own way talks to him in a calming manner. She puts it back for him when his oxygen tube comes loose, which I guess she's learned to do from seeing us. I can see as she's getting older and more able, she's doing more for him. I worry because I don't want her to grow up thinking this will always be her role."
Parent carer

1.5 Not involving carers in care

It appears to be common practice to not consult with or involve unpaid carers when making decisions about the treatment or support a cared for person may require. It seems that patient confidentiality may be a barrier to finding the best solutions and consequently outcomes for cared for people when their carers are excluded.

"How can you assess a person with dementia in 10 minutes sat round a table. You need to speak to the carer, the person who lives with them day in day out. Carers should be entitled to have a say."
Adult carer

Excluding carers may lead to deterioration of someone's condition and in turn, impact the mental and physical health of their carer.

> "I had written to [his doctor] about my brother and additional support but never heard back. Not even an acknowledgement that they had received it. He's getting more and more isolated. He won't answer the door or phone and so I'm doing more and more."
> **Adult carer**

> "My son, who has severe mental health issues was recently sectioned,... and moved to another facility. There was no consultation with me as his carer. I had been to see him the day before and there was a ward round but no one mentioned it to me. I received a call at 10am on the morning to say that this was happening and no explanation why. It took me completely by surprise. I can drive but it's further for me and there was no consideration for how I could continue to visit. Luckily I can but it does make it more difficult as it's a longer journey for me."
> **Parent carer**

Adult and parent carers find communication from services often poor or inadequate, if they are included at all.

> "As a carer I have to chase everything up. It was up to me to contact the community mental health team. When I did eventually manage to get hold of them and they agreed to come and see and assess my son, they said they came to the house at the appointed time and we weren't there. I can assure you that we were. They then discharged him from the service as they said he didn't engage. But we were there but they blame the person and so we were back to square one."
> **Parent carer**

Knowledge and understanding – what's needed?

All carer groups:

- Knowledge and understanding about unpaid carers (by education, health and social care professionals).
- Co-designing and co-producing solutions with unpaid carers.
- Actively looking into the extent of caring responsibilities and any support that may be needed.
- Early diagnosis of carer health conditions.
- Referrals or access to specialist practitioners who can advise unpaid carers on complex conditions such as dementia, mental health conditions, autism etc. (to assist them in their caring responsibilities).
- Services for people who have barriers to leaving home.

- Personalised advice and support.
- Involvement of carers in hospital care and discharge processes.
- Consistency of care (retaining same professional or clinician) for neurodivergent people or those with cognitive impairments.

Parent carers:

- Knowledge about families who are not neurotypical. This should include teachers, teaching assistants and social workers.
- Prompt diagnosis of cared for children.

Theme 2: Emotional Wellbeing

This theme highlights how being an unpaid carer impacts the emotional wellbeing of people. It looks at 5 areas including the range of services available, access to respite care, accessing carer's assessments, early diagnosis of people who need care and the transition from children to adult services.

2.1 Support services

Carers from each of the carer groups told us that support services for unpaid carers are few and far between and that they have to be at crisis point before they can access them. Adult carers expressed the need for consistent and comprehensive support services that are available across the county and not just in ad hoc areas. Funding is also an issue when services disappear because of funding cuts. Finding appropriate services is also a barrier to accessing support.

> "You feel so alone and you're led to believe that you're the only family who have these challenges. Then you go onto Facebook yourself and you find help and realise that you're not. Coming to this group is wonderful. I don't feel so alone and I have got some great advice and support for myself here. I had to find them myself, no one helped me or directed me to them."
> **Parent carer**

One couple have been caring all their parent years for their daughter (in her 50s now) who has complex needs. The parents had never been told about Action for Carers Surrey and signposted to them for support. The mother now has dementia and so her husband has become the unpaid carer for both his wife and daughter and would not have been aware of support available unless we had engaged with him.

Young carers reported that there were insufficient activities for them and that they are often too far away for them to be able to access them.

"My son is part of Surrey Young Carers but there are not enough regular activities and events for him. He would like to make friends with other children who are in the same situation. He thinks that he is the only one with a brother with autism spectrum disorder (ASD). Knowing that there are others like him who have a sibling with ASD, is really helpful."
Parent carer on behalf of young carer

"My youngest has additional needs and my eldest is a young carer. I don't feel there is enough help for young carers. Everything is about the parents. She is registered with Surrey Young Carers but can never get onto any of their activities. A weekly group would help more because she gets very anxious and if she got to know people she would feel better."
Parent carer on behalf of a young carer

"It would help me to have a young carer group in my school. I could have a break with other young carers, talk to teachers and other young carers about what it's like."
Young carer

"I would like to have a young carers group in school, it would help me to talk to an adult about what it's like at home."
Young carer

Many of the carers (from all carer groups) we spoke to experience considerable stress and anxiety as part of the enormous responsibility of caring for someone who is not well. They rarely have support, training or guidance. Many also become isolated because they do not have time to maintain their own hobbies, work or relationships. Often, unpaid carers become exhausted and experience symptoms of physical and mental breakdowns. Unpaid carers say they need individual one-to-one support to help them through the difficult times and this should be specific to their challenges as an unpaid carer and not just standard counselling or medication for anxiety or depression.

Young carers, in particular, need regular, consistently available local groups. Young carers do not have the life knowledge to realise that they are not alone and bringing them together with other young people in similar caring situations is critical to their wellbeing. Parents want their child to make friends with other young carers in similar situations in the hope that over time they will build friendships and feel comfortable enough to share their caring role and how this impacts them. One parent told us that they struggled to find a carers group for their child with caring responsibilities as there are few groups for this age group and when they did find one it was a long way to travel so they could not always attend.

""I have 2 boys with ASD and ADHD… The parents at his school have formed a group… So all the children are neurodiverse and we all understand each other. As

parents we also support each other and I find this very useful. He likes these groups and outings."
Parent carer

"My school has a young carer group and our teachers are really nice. They get what being a young carer is about and help us do our best."
Young carer

As part of the engagement activities, we visited a number of carer groups. Many at the group were on anti-depressants and were having counselling to cope with their caring responsibilities. Many had given up work due to caring responsibilities, even though work was in itself a positive thing in their lives. Even though some are accessing day and respite care, the 24/7 nature of being an unpaid carer means people cannot maintain a normal working life.

"I'm giving up my job now as it's just become too much. Although he is in day care and we have respite through Crossroads Care Surrey, I work those days, so although I'm not with him, I'm still working, so it's not really a break. I never get a break and I'm just exhausted with it all. Something had to give and it's my job."
Adult carer

Some expressed that they felt they were becoming a 'monster' from the strain, some others said work was their only relief and were determined to try and continue working. Carers feel they are ignored. They feel that everyone in the family should be supported as, if the person being cared for is still at home, it affects everyone in the family.

"It's a partnership and we should all be looked after. What would happen if you didn't have anyone? You'd be in a home."
Adult carer

"My parents won't accept help from anyone other than family and now [the family] are all getting fed up with it and it's all being left with me. I've got my own family to look after and I work, so how do I prioritise everything and everyone? It's getting really tricky and I'm finding it hard."
Adult carer

Many support services (groups) are too short. By the time the carer gets them there, it's time to go back. The carers are also required to provide transport which takes more time and energy from their respite opportunity.

"My parents both go to a group on a Friday and I spend the morning getting them there, then go to work, then collect them. I'm becoming quite resentful of this as I want my Fridays back."
Adult carer

Carers reported feeling relief when their cared for were moved to residential care as they could get some of their time back, although this feeling is often accompanied with feelings of guilt. Many people access some support from small voluntary sector providers, but these are very dependent on volunteers and funding. The carers were concerned that some of these groups would be taken over by statutory services and the flexibility and appropriateness of them would disappear e.g. groups run in the evening by older volunteers.

Some people talked about isolation and loneliness.

> "I have been referred to a social prescriber as I was feeling isolated and lonely. I found it a very good experience. I hope that it stays. Unfortunately, I've found that many services that are useful and helpful suddenly disappear as they are just pilots or their funding ends."
> **Parent carer**

Some hope was shared about designing support services with carers.

> "I feel that more co production is being used by services, so hopefully they should consult the people who have actually used the service and see what we think."
> **Parent carer**

School is not suitable for some children but parent carers are not being given any advice or support to access either a specialist school or an alternative provision.

> "My child needs something other than school as all they are concerned about are getting his GCSEs and he's simply not well enough to do this. He's now refusing to go and I do think what is the point of pushing him towards these qualifications that will cause his mental health to deteriorate further. What will he use them for?"
> **Parent carer**

Many carers feel invisible.

> "It's ridiculous. Who takes care of the carers? Who even notices the carers?"
> **Adult carer**

Good practice example

We spoke to 2 carers from separate GP practices who had been rung by their practice recently to tell them about the Personal Health Budget (PHB). They hadn't known about it until then and were very happy to be able to have it. They both said that caring does take its toll on their own health and just having that phone call to recognise what they are doing and offering something free to them was just amazing. They said they usually have to battle for everything, and this was just a lovely thing to happen.

2.2 Respite care

Many carers are not aware of respite care as they are not signposted by social workers or other professionals. Carers that had tried to access respite care said that accessing respite care was difficult if the cared for person had behavioural issues and waiting times were very long.

> "I registered with Linkable and Challengers but was told there was a minimum 2 year waiting list. I also tried White Lodge but that was 2 years as well."
> **Parent carer**

> "A break is what we need. I can't remember the last time my husband and I went out on our own."
> **Parent carer**

> "I'm a carer for my adult son [in his 40s]. Of course we don't have respite care. How could we? There is nothing out there to support him, or us, and we can't go away and have a break. Being a carer of someone with severe mental health problems is a 24/7 job."
> **Parent carer**

> "Respite care is also a challenge. [They] have a long waiting list... It's so important for parents to have time to themselves and time to go out with the other children in the family. Everyone gets affected by the one who has the special needs. It's really difficult."
> **Parent carer**

> "I'm a carer for my son [in his 40s] with severe mental health issues… There is a huge gap for people like us wanting respite. We want a break but we can't find anybody who our son will trust and who he knows. Trust is the biggest issue and so many carers just don't stick around so how can we ever get respite care. We can't. And as we age, our friends who used to help us out sometimes are getting older too and it's just not possible."
> **Parent carer**

The PHB funding is helpful to unpaid carers so they can access other services which provide respite.

> "No, I don't get any respite but I got the £300 carer break. I'm going to use it for an annual swimming pass. That will be my break."
> **Parent carer**

2.3 Getting carer's assessments

Those people who had heard of and received a carer's assessment said it had not provided any outcome. They had not heard back and felt that if you are struggling along then there is no help available.

There is also concern that an annual assessment is not sufficient to support an unpaid carer when caring for someone with a complex condition.

> "When mum got her dementia diagnosis, I asked the mental health advisor what now? She said you get a yearly check-up. I looked at her and she said that's it and that is all they have to offer. You're on your own."
> **Adult carer**

2.4 Transition from children to adult services

Parent carers described the difficulties caused by the change from children's services to adult services and how this leads to things being overlooked.

> "When they are over 18, you have no say. He's going to all these different places but we don't know anything. This is why things fall through the gaps."
> **Parent carer**

> "There shouldn't be a hard stop at 18. There should be a transition for people identified as vulnerable. I think it should be a gradual transition. That would benefit both carers and the cared for... Now my child is over 18, I'm blocked out. I don't know what is going on. It's really, really hard for me. Having done everything for him for 10 years, I'm now blocked out. I don't think they realise how much of the hidden support that goes on to keep them [the cared for] fine."
> **Parent carer**

> "We look after our grandson he's [in his mid teens]. He is autistic and has learning disabilities... It's actually harder now from our perspective as he gets older. When he turns 16 he will get his own money via his own bank account and very soon he will be considered an adult and transition to adult services, when he is in fact not able to make those adult decisions."
> **Kinship carer**

> "Things need to change with regards to the transition from children to adult services. How can they say that our children with special needs are adults at 18? There needs to be some sort of different scenario for children like my son and for parents like me. Or at least some flexibility but there is nothing. We can't attend appointments with them, access records without it all being approved by the child. When they aren't engaging with services, the parent doesn't know. It's worse for

us now he's over 18 but it also costs the system more as I've needed more support as it's been more traumatic. If I had been involved then we would not have hit crisis point and I could have intervened so he stayed engaging with the services he needs."
Parent carer

"The challenge is that care needs don't stop once someone is over 18... Things are not joined up. [My son] now receives all the emails and all the letters as he is over 18. I am his registered carer but they no longer have to go through me... I just find now that he can decide if I am involved in his care or not. It is very difficult. I feel more helpless now than I did when he was a struggling little boy. He is a young vulnerable teenage adult who has enough of a grasp to think he knows and knows best."
Parent carer

Emotional wellbeing – what's needed?

All carer groups:

- Information about respite care.
- Quick access to respite care.
- Respite care that will take people with mental health and behavioural issues.
- Services to support unpaid carers as well as the cared for.
- Regular contact with unpaid carers to monitor wellbeing.
- Consistent offer across Surrey of the PHB for carers wellbeing, and other services other than counselling.

Theme 3: Caring and life balance

Across all unpaid carer groups there is a common theme of managing caring responsibilities with other aspects of life. Many adult and parent carers end up stopping work because of the overwhelming demands of caring. They also have less or no free time to maintain their own interests and people can become isolated and lonely. Young carers have considerable difficulty managing their school commitments and if this is not recognised then they can be penalised for this. As young carers transition into adulthood there is no provision for their carer responsibilities to be communicated to further education providers and they become difficult to identify and support. Finally, parent carers describe a lack of necessary support for young cared for people in school.

3.1 Balancing care with employment

Most parent and adult unpaid carers wanted to work as a change to their caring duties. Even those carers whose loved ones were now in residential care still felt they were caring. However, some had not been able to manage work with care responsibilities.

> "I have had to reduce my hours as it's exhausting juggling caring and trying to work. I didn't want to as work is my escape. My break from caring."
> **Adult carer**

Some were still working for their own benefit or financial need, however, many eventually have to stop.

> "I'm holding onto work as I need something for myself. I don't want to spend any more time caring."
> **Adult carer**

Parent carers reported needing to take unpaid leave for caring responsibilities.

> "I'm currently on unpaid leave to try and sort things out for my son. I can't afford to give up work and why should I?... Now I'm taking time off to try to appeal. If I had been given some help from someone who knew about this, I wouldn't be where I am now."
> **Parent carer**

Parent carers need more support so they can continue to work and not have to give up work to 'fight' the system to get help and support for their cared for children.

> "I've just given up my job as we get no help or support from the council at all. I'm burnt out and exhausted. I'm trying to plan for his future and make him more independent but It's all down to me to find things out and do the planning."
> **Parent carer**

Parent carers also say they want to be able to specify who comes into their home to assess their child. It's important to get the right person to ensure the family can talk openly and the correct support and advice is provided and arranged. Parent carers feel they might not have to fight and battle for things if the right support is there from the beginning.

3.2 Neglecting own health needs

Carers we met expressed concerns about what would happen to their cared for if they became ill and in the worst case if they had to be hospitalised for a period of time. They were not aware of what service could support in this situation and people have not considered a backup plan for this eventuality. One carer we spoke to was diagnosed with Chronic Obstructive Pulmonary Disease (COPD) and had developed a chest infection at Christmas. He

refused to go into hospital as he didn't want to leave his wife who he is the unpaid carer for. He said that if he had to, he would bring her with him. He, as the carer, didn't know about Crossroads Care Surrey and their emergency planning service.

3.3 Isolation and loneliness

All carers are susceptible to becoming isolated, having no personal relationships and losing their personal identity due to the demands on their time and energy of being a carer. This is particularly relevant for couples where one person develops a degenerative condition and no longer remembers the relationship they were in.

> "People came and asked how my husband was, how my son was but no one asked how I was as the carer. No one ever asks how I am."
> **Adult carer**

> "I look after my mum. I cannot do things and don't like leaving her. I worry about her when I'm not at home to look after her. We don't get to do things as a family anymore and I get lonely."
> **Young carer**

> "My mum has psychotic behaviour and paranoia, which affects me and friends can't come to my house."
> **Young carer**

Support groups and other community services can be important in combating the feeling of loneliness and isolation but the services need to be aware of the restrictions an unpaid carer will have.

> "Just before Christmas they were both ill and I had to constantly go to the GP surgery for them. It all got too much for me and I broke down."
> **Adult carer**

A range of support services and groups are needed including meet up groups, virtual chat and meet up forums and one-to-one talking support.

> "I have been living with this for such a long time and carrying on and carrying on so having time for me to have a 1 to 1 with someone was just what I needed. I found that going to support groups for carers wasn't really that helpful for me. I would listen to their problems and try to help them."
> **Adult carer**

> "Services have failed us. If they gave us the support we need for our children, then we wouldn't need to fight for everything which affects our mental health."
> **Parent carer**

"I'm paying for an advocate as my mum used to help me but she has died and so I have no one to help. I am neurodiverse myself, so I find attending meetings with professionals makes me very anxious. This has helped as they know the words to use and how to navigate the system for me. It's so confusing and all I want is what's best for my child."
Parent carer with their own needs

3.4 Balancing school with caring

Young carers have to maintain their school attendance, keep up with their homework and pass the necessary qualifications. The additional strain of caring can be extremely tiring and demanding of their time. School staff need to be aware of these pressures and find supportive mechanisms so these children are not penalised for their additional caring responsibilities.

"Homework is a worry for me. Some teachers understand that I'm a young carer and have a lot going on at home. Allowing extra time depends on the teacher. The same goes for when we're late… I suffer from anxiety and worry a lot about school… Having a young carers homework group would help, we can't always manage to do it at home because there are too many distractions. I was told that only SEND pupils are allowed extra help and young carers don't matter. There's no-one to talk to at school but I don't think they care about young carers and what we have to do at home and the problems we have."
Young carer

"I struggle when my brother is naughty and nasty to me. Sometimes I'm late for school because of him and I shouldn't have detention when it's not my fault. Teachers should ask if there's anything wrong and can they help, but they don't."
Young carer

"Sometimes I'm late for school and the teachers don't really understand what I've dealt with that morning and it isn't my fault."
Young carer

"Sometimes I struggle with my homework because I don't have a place to do it alone at home. I asked my teacher for help and more time to do my homework but I was told she was not interested in any more excuses, so I don't do it now. I don't have many friends because they don't understand why I'm moody. I'd like more time for my homework in school, friends and teachers who understand."
Young carer

3.5 Transition of young carers to young adult carers

When young carers transition from school to further education there is nothing communicated from their secondary school to indicate that they are young adult carers. It is up to them to self-identify and many have no idea that they are carers at all. As young adults many do not want to be seen as different from their peers so even if they are aware that they have caring responsibilities they are reluctant to declare these. Our engagement team has met with staff at Guildford College and Farnborough College and college staff have said they are finding it very difficult to identify young adult carers. We are working on a number of strategies with colleges to encourage young adult carers to identify themselves so support can be put in place. Ideas such as a flyer in welcome packs is being considered. Staff in the colleges we spoke to have identified a need for training about how to identify and support a young carer/young adult carer.

3.6 Cared for children in school

Parent carers feel schools are often not meeting the needs of cared for children. Some feel that statutory education services are failing parent carers and they feel they are left to cope alone. Parent carers describe being made to feel fear and shame because of a lack of understanding. Case workers would provide parent carers with a consistent advocate and supporter for their child's needs. This is especially important in neurodiverse families as consistency is vitally important.

> "My child isn't being believed by the teachers as to how his form teacher is behaving towards him. Even his friends say that they pick on him. His behaviour is going down as he is so unhappy there. I think the school are trying to push him to the point where his behaviour is so bad that they will exclude him. I just want some help. If he can't cope in primary school, how is he going to cope in secondary school? I'm just left with no help and support but just blame for his behaviour."
> **Parent carer**

Many parent carers experience stress and mental health difficulties when their cared for children are not appropriately supported in school and/or they cannot access support through specialist schooling or Education Health and Care Plans (EHCPs).

> "My child's school said that they can't meet his needs. This has gone back and forth and the school have put in for additional funding for him. They won't give him an EHCP as this would be legally binding and SCC don't want that. But I don't think the extra money (if they get it) will be spent on my son having a 1 to1, which is what he needs. They'll use the money to fund a teaching assistant who might not have ASD training and will help other children too. If he had an EHCP, 1 to 1 support would be written in and the school would have to comply and SCC would

have to fund it. Meanwhile, he's in an environment that is not meeting his need while the school and SCC argue about funding and giving him an EHCP."
Parent carer

Caring and life balance – what's needed?

All carer groups:

- Services that cover a range of needs including information, respite, temporary carer arrangements and emotional support for unpaid carers.
- Services to enable people to continue working.
- Access to health professionals for unpaid carers when they are concerned about their cared for.
- Guidance on contingency planning for unpaid carers so they are aware of short- and longer-term replacement care options.
- Information about the costs of emergency and respite carers, what support is available with these costs and options for paying.
- Proactive communication from health and social care services.
- Information about hospital discharge pathways for cared for.

Parent carers:

- Funding and statutory provision for cared for children in school. (Some suggested that case workers would be helpful).
- Knowledge to manage difficult behaviours in schools for education professionals.
- Choice and control of caring needs assessments so parent carers can be confident in the outcomes.
- Monitoring by mental health services to support people who are discharged to their families.

Young adult carers:

- Mechanism for recognising young carers when they transition into further education and become young adult carers.

Young carers:

- Supportive approaches in education to provide flexibility and support to young carers.
- Opportunities for young carers to form friendships with other young carers and establish a rapport with organisers of services.

Theme 4: Signposting and information

Across the previous 3 themes there have been many connections between the experiences of unpaid carers of all ages and a lack of information and accurate signposting from professionals.

Many carers we spoke to were unaware of their rights as an unpaid carer, the services available to them and how to get coping help when they need it. Those who had accessed help and support had often found out about this through informal networks and/or support groups. There appears to be a particular need for professionals to be equipped to be able to provide advice when unpaid carers reach out to them. This is made more complicated by unpaid carers of all ages not wanting to be identified as a carer or not realising that they are a carer.

One of the issues raised is that unpaid carers do not want to be inundated by generic leaflets; they want relevant and often personalised information. This would be through one-to-one person-led information services and ideally face to face.

> "Just give me one that is relevant to me and my situation. I just don't have the time to read through a big pile [of leaflets] to see what's relevant and useful to me."
> **Adult carer**

> "I find that I'm just overwhelmed with all the information that I'm given… Being a carer, I don't have that much free time."
> **Adult carer**

This barrier to accessing information may be worsened for carers who have their own needs as demonstrated by this parent carer.

> "My son was diagnosed with autism and then we were just left. They gave me some leaflets but I couldn't read them all as I have ADHD so just can't process all of that information. I feel abandoned and alone. Just diagnosed and told to get on with it."
> **Parent carer with own needs**

There are also access barriers including unpaid carers who do not speak English as their first language and those who are not digitally literate or connected.

> "It is difficult for people from our community who don't have English as their first language… They need these things explained to them… It's hard to translate these things sometimes and so you don't access the help/support. These are barriers. It's a shame. Why do we have to struggle and shout to get heard. Why can't things be easier for carers?"
> **Parent carer**

> "It really winds me up that everything is online or digital. We don't use the computer and I would find it difficult anyway as I'm partially sighted."
> **Adult carer with own needs**

Adult carers also need specialist information to support caring for people with degenerative conditions such as dementia and managing behavioural issues. This was also raised by parent carers with children with complex conditions who could not access care in some respite settings.

There are some necessary legal matters that many carers are faced with which can be particularly difficult to deal with in addition to the onset of caring responsibilities.

> "I care for both my mentally ill brother and my mother. They live together. My concerns are around how do I activate the power of attorney with someone who is mentally ill. Can they give consent?"
> **Adult carer**

Clear and accurate signposting to services is also crucial to avoid people incurring costs or making wasted journeys.

> "I had to pay for childcare to be here. I thought the carer practice advisor would be here. It wasn't clear from the newsletter that they only come occasionally. I thought that as this was called a hub, it would be a one stop shop with people here to help me and help me fill out forms and answer my questions. My time is very limited. This isn't helpful. The information I've been given is all very vague and not clear."
> **Parent carer**

> "You feel so alone and you're led to believe that you're the only family who have these challenges. Then you go onto Facebook yourself to find help and you realise that you're not. Coming to this group is wonderful. I don't feel so alone and I have got some great advice and support for myself here. I had to find them myself, no one helped me or directed me to them."
> **Parent carer**

Incorrect signposting can have detrimental effects not only for the unpaid carer but also for the cared for.

> "My son was wanting to do some voluntary work and was signposted to [name of service]. He then contacted them, only to be told that they don't do volunteering, only paid employment. It takes so long to get someone with mental health issues and severe anxiety to contact an organisation, only to be told they can't help. It really sets them back. Professionals should check where they're signposting to."
> **Parent carer**

Our engagement team has identified that information does not cater for young adult carers, as they turn 18 years old they only have access to information aimed at older adult carers and not information that is relevant and appealing to them.

Finally, in other themes we have described people giving up work through exhaustion and not being aware of respite services; people refusing hospital care because of fear about what will happen to their cared for; people having breakdowns because they were not aware of help and support; and people hating themselves and having feelings of failure because of unpaid caring responsibilities taking too much out of them. It is apparent that relevant information and accurate signposting could be helpful to many unpaid carers.

Signposting and information – what's needed?

All carer groups:

- Early identification of carers by professionals.
- Timely accurate and relevant information.
- Specialist information for carers of adults and children with behavioural issues.
- Personalised and one-to-one information e.g. face to face and telephone services.
- Support on rights and legal issues.

Young adult carers:

- Age appropriate information for young adult carers (rather than information produced for older adult carers).

Thank you

We would like to thank all the unpaid carers for sharing their experiences with us. We recognise their hard work and dedication to those they care for, and they value they bring to our community.

Contact us

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