healthwatch Wiltshire

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the heart of social inclusion

Guiding Hands: enabling parent carers to get the help they need

Neighbourhood health and wellbeing insights – June 2026

Contents

Thank you

We would like to thank the following for their help with our research:

- Jo Hiller-Culley, Carer Support Co-ordinator (Parent Carer Lead), Carers Together Wiltshire
- Stuart Hall, Director of Wiltshire Parent Carers Councils (WPCC)
- All of our respondents who bravely shared their stories

Summary

Parent carers play a crucial but often unrecognised role in supporting their children with additional needs. However, many do not realise they are parent carers or have the knowledge of what support is available to them.

Our research found that families need more practical support to navigate the complexities of the health, education and benefit system.

They also require more emotional support to maintain their resilience and manage the emotional strain.

Parent carers want a partnership approach with professionals, but these relationships are often poor.

Parent carers feel supported by two key organisations, with Carers Together Wiltshire running the cafés/groups and the Wiltshire Parent Carer Council providing support. Our recommendations include:

- Launching an awareness campaign
- Strengthening the parent carer groups
- Establishing a parent carer companion role
- Improving access to core advice

Parent carers play a critical role supporting their cared for family members. However, they need Guiding Hands to give them access to essential information and navigate the complexities of the wider care and support system.

See the appendix on page 17 for stories of lived experience from parent carers.

About Healthwatch

Healthwatch Wiltshire is your independent, health and social care champion. We listen to people's experiences, amplify their voices, and make sure decision-makers understand what matters to communities. Our role is to ensure that the design and delivery of health and care reflects the needs of the people it serves.

About this research

We undertook the following research:

Research type	Information	Number of people
Focus groups	Devizes (x2) Trowbridge Virtual	45
Conversations with professionals	Wiltshire Parent Carer Council (WPCC) Carers Together Wiltshire Local Offer (Wiltshire)	3
1-2-1 interviews	Parent carers	5
	TOTAL	53

These methods were chosen to ensure we heard from parent carers in settings that felt natural to them. Using both group discussions and one-to-one interviews enabled us to capture a wide range of experiences from those new to caring, to families who have been navigating services for many years. This approach provided a fuller and more accurate picture of the challenges they face.

Context

The Care Trust defines a carer as: 'anyone who cares, unpaid, for a friend or family member [of any age] due to illness, disability, a mental health problem or an addiction'.[1] There are at least 5.8 million carers in the UK.

Care UK explains that:

> "Carers are holding families together, enabling those they care for to get the most out of life, making an enormous contribution to society and saving the economy billions of pounds."[2]

We are focusing in this report on 'parent carers', who care for young people between 0-25yrs. Wiltshire Parent Carer Council has more than 4000 members who care for young people.[3]

There are laws and national guidance that recognise this crucial role and calls for parent carers to be treated as partners when drawing up health, education and social care plans. This includes:

- Children and Families Act (2014)
- Care Act (2014)
- SEND Code of Practice

Lord Darzi, in his 2024 report said that the NHS and social care are "in serious trouble", facing chronic underfunding, staff shortages and long waiting lists.

This situation harms the health and wellbeing of parent carers.

- Caring responsibilities means the majority (62%) of parents/partners have to give up a paid job or reduce hours. On average these parents have lost £21,000 of income per year.
- Over half (54%) of parent carers have received treatment from their GP for depression, anxiety or stress.

These national challenges were mirrored locally, with parent carers in Wiltshire describing similar pressures around navigating services and accessing support. Our research indicates that parent carers have to "fight the system" to get support.

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[1] https://carers.org/about-caring/about-caring

[2] https://www.carersuk.org/about-us/why-were-here/

[3] https://www.wiltshireparentcarercouncil.co.uk/en/Who_we_are

Co-produced recommendations

The following recommendations have been developed based on the insights and ideas shared by contributors to this report

1. Awareness campaign

Rationale

At the beginning of their 'journey', a significant majority of participants did not realise that they were parent carers. This meant that, even if there was support available to them, they were not aware of these services.

We therefore recommend that the Council (supported by the ICB, schools and GP surgeries) run an awareness campaign targetting both parents and professionals.

Purpose – raise awareness that

- Caring for someone with additional needs (whether diagnosed or not) may make you a parent carer.
- Parent carers are entitled to support
- Professionals can help put them on the patient pathway to support

KPIs – collect data to measure success of awareness campaign

- More parents self-identify at an earlier stage
- Professionals (e.g. teachers, GPs) routinely refer them
- There is earlier access to help (e.g. benefits, EHCP)
- Stress/isolation etc. is reduced
- Increased community care – e.g. numbers at parent carer cafés

Engagement tools

- A Parent Carer Card (ie a leaflet) given to all parents at first referral: "are you a parent carer?" explaining role and signposting to resources.
- Minizines

- Social media videos – very short, pushed locally
- Signposting at school gates
- Annual session by professionals run at school
- Professional drop-in sessions
- A flag on GP primary health records e.g. “significant carer responsibilities”.
- Training for professionals (e.g. GPs, nurses, hospital liaison team, social worker, teachers, paediatricians) to ask: “do you feel you are taking on extra caring responsibilities that impact your daily life?”. This is similar to midwives asking about domestic abuse at every meeting – i.e. it is embedded in the conversations.

2. Parent carer cafés

What carers told us

All the parent carers we spoke to found the carer cafés to be a lifeline. Carers describe these spaces as places that ease loneliness, provide emotional reassurance, and foster a warm, supportive community. They’d like cafés to include more practical advice and clear next steps, such as expert-led sessions, advocacy training, and peer mentoring. Flexibility matters having online access and recorded sessions would help those who can’t attend in person.

What would make the ideal café?

- Expert Sessions: SEND officers, CAMHS reps, and benefits advisors giving advice directly.
- Interactive Workshops & Resources: Practical tips and signposting to services and grants.
- Advocacy Training: Short, easy sessions to help carers feel confident in meetings.
- Hybrid Access: Recorded sessions for those who can’t attend in person for local drop-in sessions with experts.
- Peer Mentoring: Experienced carers supporting newcomers (volunteers).
- We recommend increasing the number of Parent Carer Groups across Wiltshire, noting that Carers Together Wiltshire are contracted by Wiltshire Council to run these sessions, and that WPCC volunteers currently attend the Devizes and Salisbury cafés as parent carers, so any future joint-delivery model would need to be explored carefully.
- We expect to engage stakeholders to ensure that any future developments are realistic, appropriately resourced, and aligned with existing contracts and capacity.

Knowledge

This section is about the knowledge that parent carers have (or should have) at the start of their 'parent carer' pathway. We are looking at the period between when they first recognise that they need support, up to the point of diagnosis of their cared-for person. One parent carer told us that she felt the information she needed was hidden from her: "everything is behind a cloud."

Not identifying as a parent carer

At the start of the journey, we heard that many parents do not realise they are a parent carer due to a lack of clear information. As a result, they often view themselves simply as "managing" their child's needs rather than recognising their caring role. This leads to missed support early on, leaving families isolated and unaware of the services available to them.

Lack of knowledge about conditions pre-diagnosis

Some parent carers did not realise their children might have mental health conditions due to limited awareness and understanding of mental health disorders. As a result, diagnoses were often delayed, making it harder to access appropriate support and sometimes leading to traumatic experiences, including bullying at school. Behaviours such as difficulty concentrating were often seen as personality traits rather than signs of underlying needs. Autism was also widely misunderstood, with some families even asking, "Is that a disease?"

Waiting for diagnosis

We heard waiting times for diagnosis often leave parents searching for information on their own, which can be unhelpful. Without a confirmed condition, they risk focusing on the wrong issues or following misleading advice. This uncertainty adds stress and highlights the need for clearer interim guidance and trusted resources.

> "There's a risk that when you're searching for information without a diagnosis, you end up searching for the wrong thing."

Information received at diagnosis

We heard that at the point of diagnosis, parents often receive limited or outdated information. Diagnosis letters rarely include signposting to support groups or practical resources, leaving families unsure where to turn. This lack of timely guidance delays access to help and increases feelings of isolation at a critical stage. One parent told us: “I only just found out about this group; there was nothing about support for parent carers in the library.”

Websites

There are a variety of websites that include information for parent carers. These include the websites of WPCC, SENDIS (Wiltshire SEND Advice and Information), the Local Offer, and Wiltshire Council. However, our respondents raised that these sites were difficult to use. One respondent said: “I felt overwhelmed by the amount of information”. We were told that both the Local Offer and the WPCC website are being revamped to make them clearer and easier for families to use, but many parent carers still reported challenges in finding what they need.

Other information

We heard from parents that useful leaflets are rarely available in schools unless they ask for them, which means many carers miss out on important information or support.

Deputyship

A parent carer is a parent who looks after a child with additional needs, whilst deputyship is a legal role that gives the parent the formal authority to make these decisions. A deputyship is when a parent carer is legally appointed by the Court of Protection to make important decisions for a young person over 16yrs olds, who cannot make those decisions themselves, usually about money, health or daily welfare.

Knowledge about legal status of parent carer

Some parent carers have limited awareness of deputyship. They may be unsure whether they can hold the role themselves or how it differs from other responsibilities. It is crucial to apply for deputyship before age 16, ideally when the child is 15, to ensure finances can be managed appropriately

> “The parent isn’t listened to. They don’t listen to me and I’m an expert witness.”

Knowledge about first steps of practical support

Parents told us that early awareness of practical steps such as applying for extra support at school is vital. Many said they only learn about these processes later, which delays access to the right support and increases stress. Clear guidance at the very start of the pathway helps families prepare, reduces confusion, and ensures children receive timely help.

Knowledge about parent carer groups

Parent carers felt that opportunities to connect with other parent carers needed to be pushed more widely and that additional groups should be created. Much of the current communication happens through word of mouth, leaving many families unaware of available support.

Practical support

This section is about the practial support that parent carers need to manage the health, education and benefit system.

EHCP and Health Plans

An Education, Health and Care Plan (EHCP) is a legal document that outlines a child or young person's special educational needs and the support they must receive.

A Health Plan sets out a young person's medical needs and how professionals should manage their health, such as medication, treatments and emergency procedures. For children who do not have an EHCP, schools may also use SEND support plans to record their additional needs and the adjustments required to help them access learning. These plans ensure that children with SEND receive appropriate support even without a statutory EHCP.

Practical support for education (nursery & school)

Parents told us they valued EHCPs and Health Plans and recognised their importance. However, many felt they carried the full burden of gathering evidence and navigating the process on their own. They told us the process was complex and poorly explained, with little guidance from schools or professionals. Families frequently felt unsupported and unsure how to secure the right help.

Practical support for diagnosis

Parent carers noted that children showing traits across several conditions may not meet thresholds for support. Partial scores across multiple areas are often overlooked, while full criteria for one condition is required. This narrow approach leaves families struggling to access help despite significant combined difficulties. One example we heard was a child who had both Autism and ADHD traits.

Carer’s Allowance

Carer’s allowance is a financial benefit for people who spend a lot of time caring for someone who needs significant support. It helps recognise the unpaid care that they provide and offers some financial relief. This support can make it easier for parent carers to balance their own needs while continuing their caring role.

Practical support to get benefits

Parents stressed the importance of financial help like Carer’s Allowance but found the process confusing. They often had to research eligibility themselves with little guidance from professionals. Families felt clearer information and more accessible applications were needed to ensure carers received the support they deserve.

Practical aspects for group attendance

Families noted barriers such as travel costs, inconvenient locations, and lack of disability access to attending a parent carer group. Without affordable, accessible venues and transport, many struggle to attend and risk being excluded.

Respite

Many of our respondents expressed their need to have respite from their caring role. However, some told us that they didn’t know where this support could come from. Others expressed concern that another carer or organisation wouldn’t be able to look after their child safely.

Many parent carers told us they urgently need respite but often don’t know where to find it or how to access it. Others said that even when respite is available, they feel anxious using it because they’re unsure whether staff understand their child’s specific routines, communication needs, or medical requirements. This lack of confidence means many families go without a meaningful break, even when they’re exhausted and in need of support.

> “We just need some respite. The load is exhausting.”

Emotional support

This section is about the emotions that parent carers need help to manage. We are including this section beause this is what reduces the resilience of parent carers and therefore prevents them from fulfilling their role.

Fear

Parents expressed deep anxieties about the future, often asking *"What happens when I die? Who will care for my child?"* These fears highlight the lack of clear long-term planning and support structures, leaving families uncertain about who will step in when they are no longer able to provide care.

Self-care

Many parents felt drained by complex systems and constant demands, which left little time or energy to look after themselves. They described cancelling their own GP appointments or neglecting personal health because their child's needs always came first. This pattern of self-neglect shows how the caring role can erode wellbeing over time.

Comfort

Parents expressed a need for someone to walk alongside them, not necessarily medically trained but to guide, listen, and provide support. They valued genuine human contact over online resources, as this offered reassurance and reduced feelings of isolation.

Isolation

Parents described feeling alone and solely responsible for their child's care. With little shared support, this created emotional strain and reinforced a sense of exclusion from community life. Many highlighted the need for stronger peer connections and practical help to reduce isolation.

Blame

Parents felt strongly that they were blamed for their child's challenges, including behaviour, school attendance, medication, and allergies. This sense of blame added to the pressure and stress they already faced in their caring role.

Not listened to

Parent carers told us of their sense of frustration because they didn't feel "heard". Teachers made them feel "to blame" for their child's misbehaviour in class. We heard one mother told us how frustrated she was when benefit payments were redirected from her to her son, even though she felt her son did not have the ability to manage these funds. She told us "there are no checks, I have no voice, and no control". The lack of agency left them frustrated, powerless, and anxious, reinforcing the sense that their voices were not valued.

Barriers to attending groups

Some are put off from attending parent carer groups in case they are judged as doing a bad job with the person they care for. This fear of criticism or being misunderstood creates anxiety and discourages them from seeking peer support, leaving them more isolated.

> “It’s so overwhelming.”

Relationships

This section is about the relationships parent carers have with health, education & benefit professionals.

Consistency, trust and social workers

Parents emphasised that “consistency of care” and “building trust” are critical. Positive relationships relied on reliability, with some professionals described as “a diamond in the rough.” Parents also spoke about the stigma surrounding social worker involvement, often feeling it suggested they were “doing something wrong.” Parent carers explained that frequent changes including several newly qualified social workers in a short space of time, disrupted continuity and added to their frustration.

Schools & EHCPs

Parents reported doing extensive work on EHCPs only to find their notes excluded. Professionals often wrote overly positive statements like “he’s taking small steps in the right direction” or “let’s celebrate little steps,” even when parents felt things were worsening. One parent said that without their input, the school would describe their child as “a superhero.”

Peer Support Groups

Parents said there was virtually no support outside peer groups, which provided a reliable place to offload, share experiences, access signposting, and connect with others. Many had attended for years, even as organisations changed.

CAMHS and AMHS

The Child and Adolescent Mental Health Services (CAMHS) supports children and young people up to the age of 18, and sometimes up to the age of 25 for particularly complex situations. Most young people transition to receive support from Adult Mental Health Services on their 18th birthday.

When their young person is under the age of 18, the parent is legally responsible for them. The parent carer is described by this legal term: "the person with parental responsibility". At a practical level, this means that the parent carer must be consulted by CAMHS and other professionals working with the child – for example, the school or doctor.

At the child's 18th birthday, the responsibility (in most cases) reverts back to the young person. This means there is no legal requirement for Adult Mental Health Services and other professionals to involve the parent carer.

Knowledge about bridging the gap difficulties

Most parent carers told us that they found the transition from CAMHS to Adult Mental Health Services difficult to manage. This is because, overnight, they lose some or all of their involvement in the decisions reached by the authorities. They also had concerns about the benefit system. When their child is under the age of 18, the benefits go directly to the parent carer. When their child turns 18, the funds are immediately redireccted to the young person. This change happens even if the young person remains dependent on the parent carer.

GPs, consent and early identification

Parents felt unheard and not treated as the "expert witness." GP consent rules limited involvement, even when parents were the primary carers. One parent only discovered their first child had autism when a midwife visiting their second child noticed it, highlighting inconsistent early recognition.

Empathy, history and proactivity

Parents wanted professionals to acknowledge when difficulties actually began, often years earlier. They stressed that carers did not choose this role and received no training. Parents said "you've got to find it; the support doesn't find you," with support varying widely between GP practices.

Holistic working and joined up thinking

Parents wanted professionals to be more holistic and avoid working in isolation. Many worked separately, each doing "their own little bit." One physio was praised for looking beyond a single issue and offering signposting. Parents said there was "no joined up thinking" and stressed that professionals must recognise the parent carer as the expert.

Locality differences and human contact

One family moved counties to access more holistic care. Many felt services relied too heavily on online or virtual platforms, reducing in-person support and making trust harder to build.

Parent carer group experiences

Parents praised local groups for listening, emotional support, connection, and signposting. One parent described attending two sessions: staying quiet in the first, then sharing challenges in the second and receiving meaningful help. The group reduced pressure, responded quickly, and even helped arrange GP support.

> "Even when I feel like it's all a bit much or I don't want to go anywhere, every time I attend a parent carer group online or in person I feel glad I did. Nothing feels as reassuring as chatting with someone who 'gets it'."

Stakeholder response

Wiltshire Parent Carer Council

The Wiltshire Parent Carer Council (WPCC) is grateful to the parent carers who shared their experiences with Healthwatch Wiltshire to help inform this report. Many of the findings reflect what families tell us every day, and it is encouraging to see the vital and demanding role that parent carers play in supporting their children recognised and highlighted throughout this report.

We recognise that navigating health, education and SEND systems can be challenging, daunting and confusing, and we hope this report helps raise awareness that the WPCC is here to support families of children and young people with SEND across Wiltshire.

We particularly welcome the recommendations to increase awareness of the parent carer role and to improve awareness of, and signposting to, practical information, advice and support for families. These recommendations align closely with the WPCC's commitment to ensuring that parent carers are recognised, valued and treated as equal partners in decisions affecting their children and young people.

The WPCC remains committed to ensuring that parent carers are recognised, valued and supported, and will continue to work with families and partners, including Healthwatch Wiltshire, the Local Authority and the ICB to amplify parent carer voices and improve outcomes for children and young people with SEND, and their families across Wiltshire.

Last word

Parent carers carry extraordinary responsibilities that often go unseen. To remain resilient, they need guidance to direct them to the knowledge, practical and emotional support available.

Healthwatch Wiltshire will share these findings with local decision-makers to help Improve support for parent carers in Wiltshire.

Appendix: My life

My life as a parent carer

In this report, we have woven the voices of parent carers into our analysis. We conclude by presenting their voices on their own. The purpose of these first-hand stories is to give the reader a visceral sense of what it's like to be a parent carer, day-to-day. They were gathered through one-to-one interviews. Some details have been changed to ensure that the parent carers cannot be identified.

Story 1: Constant anxiety

The themes of this story are constant vigilance and fear.

My son Leo is nine. He's autistic and full of energy, but he doesn't understand danger. He'll run off without warning, climb things he shouldn't, and head straight for busy roads if I don't stop him. That means I'm always watching. I don't mean casually watching. I mean proper watching. My eyes are always on him, even when I'm smiling and trying to look normal.

School says they understand, but staff change all the time. One person gets Leo, the next doesn't. I've had phone calls saying he ran out of class or disappeared from the playground. One time, no one noticed for several minutes. I felt sick. I keep explaining what he needs, over and over. I've written lists, gone to meetings, begged them to stick to the plan. Still, it feels like if I'm not there, it's only a matter of time before something goes wrong.

At home, it doesn't stop. I sleep lightly in case he wakes and goes off somewhere. I don't relax in parks or shops — and I'm always checking the exits. My body is tense all the time. I'm exhausted, but I can't let my guard down. If I do, and something happens, that's on me.

I love my son more than anything. But living like this — constantly on edge, constantly responsible — wears you down. I'm not just parenting. I'm preventing disaster, every single day, mostly on my own.

Story 2: Constant battle

The themes of this story are diagnostic delay and battling the system.

My daughter Megan is now 23, but we knew something wasn't right when she was very little. We were told to wait. Then to wait again. "She'll grow out of it." "Let's see how she gets on." Years passed with no diagnosis, no real help. In the meantime, things got harder. Her anxiety grew. School became a nightmare. Home life was constant firefighting.

By the time we finally got a diagnosis, everything was already in crisis. Instead of early help, we were handed leaflets and told to join waiting lists. I felt like I was always chasing, always explaining, always one step behind. Every delay made things worse, but no one seemed to join the dots.

As Megan got older, the system became colder. Forms, assessments, thresholds. I was suddenly treated like I was part of the problem, not the person holding everything together. Support was reduced because she didn’t tick the right boxes, even though nothing had changed at home. I was still doing the care. I was still managing the meltdowns, the appointments, the money worries.

I’m angry — not because I want special treatment, but because if someone had listened earlier, our lives could have been very different. Instead, I’m stuck fighting a system that reacts too late, asks too much, and somehow still expects me to cope.

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