PACC
Championing your voice
Parent Carer Council
Shropshire

Carers Week 2026

“Building Carer Friendly Communities”

To build Carer friendly communities we **must** understand the lives of those within it.

Research from Birmingham University highlighted that

41% of Parent Carers had thought about suicide

less than **half** had ever told anyone or sought help.

We regularly hear from Parent Carers and Family Carers they fear.......

- Judgement
- Stigma
- Being blamed

Most parent carers never tell anyone about their thoughts of suicide and homicide, fearing judgement and stigma, and worrying that their child will be taken away. Those who have sought help say the response is rarely helpful. A prescription for antidepressants or a referral to a support group does little to address the underlying problem: a lack of support for, and respite from, the caring role.

The wellbeing of parent carers is heavily impacted by **the constant demands of caregiving, ongoing stress, and the struggle to balance a care role with personal needs**. Major influences include social isolation, financial strain, systemic navigation, and physical health, all of which directly affect a carer's long-term sustainability.

- Having to start from the beginning every time you meet a new practitioner.
- Fear of judgement, blame, lack of understanding.
- Lack of holiday clubs, support, suitable provision so they get a break
- Financial stress- impact on work due to carng role.
- Having to chase emails, plans, follow up phone calls.
- Feeling so alone- a lack of meaningful support.
- Worrying about the future
- The struggle to balance the role of caring with personal needs- Parent Carers often cannot prioritise their own needs.

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Understanding the Role of Parent Carers

Parent Carers are experts in their child's needs, strengths, communication, behaviours, preferences and daily experiences. They often hold information that no single professional or service can access.

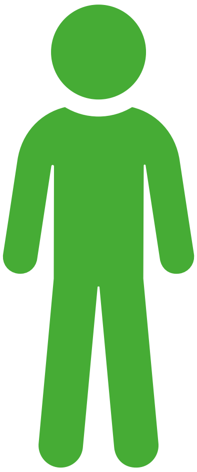
Building effective partnerships with parent carers is essential to achieving positive outcomes for children and young people with SEND.

Many Hats!

Many Parent Carers are managing:

- Multiple appointments across education, health and social care
- Complex care needs at home
- Sleep deprivation and caring responsibilities
- Employment challenges or reduced working hours
- Financial pressures
- Emotional stress associated with navigating services
- Advocacy and coordination of support

We are often told that Parent/ Family Carers are made to feel they are just like any other parent......Actually, being a Parent Carer means they are also.......



Emotional Anchor

Advocate for their child

Domestic Manager

Cleaner

Wife/ Husband

Employee

Proof reader

Coordinator of services

Rights Advocate

Record keeper

Trainer of support staff and professionals unfamiliar with their child

Employer of PA

Meeting attendee and contributor

Crisis manager when support breaks down

Social Facilitator

Household Manager

Emotional support for their child and wider family

Account keeper

Call handler

Cook

Researcher of legislation, policy and entitlements

Care Coordinator

System Navigator

Financial Administrator

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What have Parent/ Family Carers told us they **Need** From Practitioners?

Listen and Value Expertise
Parent Carers know their child best. Their knowledge should be treated as evidence alongside professional observations.

Communicate CLEARLY
Avoid jargon, explain processes, explain timescales, provide information in writing, be **clear** about next steps.

Take a person centred approach and Co-produce
Parent Carers should be involved in decision-making rather than informed of decisions after they have been made.

Understand the Impact of Delays
Delays in assessment, decision-making or service provision can have significant consequences for the child and family and prevent support from taking place.

Accountability
Taking accountability when things go wrong, and not making excuses of staff shortages and other priorities. Recognise- Apologise- Remove the barriers - End parental blame and system generated trauma.

What does good look like?

- Practitioners treat parent carers as equal partners and the expert in their child's life.
- Practitioners assume positive intent.
- Practitioners acknowledge lived experience.
- Practitioners are transparent about limitations and decision-making.
- Practitioners follow through on agreed actions.
- Practitioners ensure the child's and family's voice is reflected accurately in assessments and plans.
- Practitioners consider the wellbeing of the whole family.
- System leaders are visible and accessible to the local SEND community

The psychological impact of prolonged caregiving, repeated crises, sleep deprivation, and years of fighting for support can produce trauma responses that deserve recognition and support.

Parent Carer burnout is a state of physical, mental and emotional exhaustion caused by the ongoing demands of caring for a child or young person with additional needs, often alongside navigating complex systems and services.
Unlike short-term stress, burnout can develop over months or years and may affect a parent's ability to cope with everyday tasks, engage with services, maintain employment, or support their own wellbeing.

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Systems Generated Trauma is the harm caused by the policies and practices of the public services that disabled children and their families are forced to navigate. While often unintentional, this harm stems from deep-rooted problems that turn the act of seeking help into an ordeal.

The parents we spoke to told us that instead of receiving help, they face a relentless, hostile, and bureaucratic fight for basic support. They are met with disbelief, repeated assessments, and processes that leave them feeling blamed or broken. This report is a call to action. It demands accountability. It demands change. We must be brave enough to confront the truth, and bold enough to act.

READ MORE

What do families tell us when things work well?

My heart sings when I see her achieve something I wasn't expecting or didn't think she could do. she's fearless and determined and just gets on with it all despite it being harder for her. She's cheeky and has a fabulous grin. She is defying expectations of teachers and us. She LOVES maths and numbers. She can't talk but she can read (that blew my mind at first!). She has a great sense of humour and is funny.
PACC- Mad, Sad, Glad Report (2025).

It was such a relief to have activities planned which were fun but also relaxed and having supportive friendly faces when we arrived helped take the stress out of a trip out of the house!! Really grateful for the healthy lives programme and the difference it's made to my family's summer holidays.
PACC's Healthy Lives Programme Feedback (2025).

When talking to other SEN parents, it's clear ours is one of the easier cases by a country mile. Parents actually rely on Abi. Sometimes they have no idea how to proceed, who to email, contact or chase to get answers. Abi is a lifeline she speaks on our behalf with knowledge and heart. We all know that nothing comes easily for those parents with SEN children, their day to day lives and their futures are a constant worry and just getting them their basic needs (like a decent educational setting) is a constant fight and struggle. People in positions like Abi, should be valued and looked after. They make real differences to the lives of the vulnerable and their families.
PACC PFA Navigator Service Impact Report (2025).

Reassurance that we can start to plan for the future, even if it is as simple as contacting social work team to add his name to the list for PfA social worker. Highlighting healthy lives project provides a life line for school holidays and for building relationships with other young people of similar age and for parent carers to support each other on the journey.
Community Navigator Service (2026).

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Making Shropshire a great place for SEND families to thrive and have the same opportunities as everyone else.