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Meeting Minutes

Consultations for carers to share their views with external organisations

FOR FALKIRK CARERS

Consultation with April Shaw and Greig Inglis Researchers at the University of the West of Scotland.

Held on Friday 31 July 2026

at The Carers Centre, Falkirk

There were 11 people in attendance including Carers, presenters and staff.

Quick recap

This meeting focused on research that has been conducted by the University of the West of Scotland (UWS) Scottish Families Affected by Alcohol and Drugs (SFAD) and Carers Trust Scotland (CTS). The research began in 2025 and continued into 2026. The purpose of this research is outlined below.....

The aims of this research study are to:

1. Understand the lived experiences of carers who care for a person with substance use problems in Scotland.
2. Examine the gendered relations of caring in the context of the current economic and cultural environment.
3. Identify third sector funding and service provision in Scotland.
4. Inform the development of supports and interventions and local and national policy and practice.

The conversation

During the session Greig and April shared findings from their research, took comments from Carers and asked questions to discover if they had captured the right information and if anything was missing.

April and Greig thanked Carers in the room who have already contributed to the research, some of Falkirk's Carers have participated in conversations, interviews and meetings with

falkirk & clackmannanshire carerscentre

Meeting Minutes

Consultations for carers to share their views with external organisations

FOR FALKIRK CARERS

other professionals, their meaningful participation has helped to shape the next stages of this research.

April and Greig explained that the purpose of their visit today was to share information about the research project and ask Carers for their views on what needs to change. Greig and April explained that Carers views will be used to write the report and influence recommendations.

What the researchers did

15 online interviews with unpaid carers.

Half of the participants looked after an adult child, others looked after their spouse, partner or parent.
Participants had experience of looking after someone who uses alcohol, drugs or both.
We asked questions about:

1. *What is the day-to-day experience of caring?*
2. *What are the main challenges experienced by carers?*
3. *What is the impact on carers?*
4. *What support do carers currently receive?*

What the researchers discovered before today .....

The Journey of Care

- Carers described their experience as a **journey**.
- The day-to-day steps on the journey are **complex and challenging**. The **spectrum of responsibilities** ranged from managing mundane daily activities to responding to crises in their cared-for person's life.
- There was a **steep learning curve** for some carers, especially if they didn't have previous experience of addiction or substance use.
- The journey is **uncertain**, both day-to-day and longer term.
- A key turning point in the journey for some is **identifying as an unpaid carer.**

falkirk & clackmannanshire carerscentre

Meeting Minutes

Consultations for carers to share their views with external organisations

FOR FALKIRK CARERS

Stresses and Strain

- Caring places **financial, physical and emotional strain** on carers and their families.
- Some carers described a **loss of personal freedom**, and feeling like they had to be constantly available to respond to emergencies.
- Caring responsibilities can also **strain relationships** between carers and their cared for person, as well as the wider family unit.

Stigma

- People with substance use problems and their carers encounter **multiple forms of stigma**.
- **Negative attitudes, lack of understanding and social rejection** are experienced from services, health care providers and friends and family.

- **"Stigma by association"** can be a barrier to carers identifying themselves as such, opening up to others or accessing support. Stigma can be **isolating.**

Experience of Support

- The support received by carers and their cared for person was **highly variable.**
- Formal supports (e.g. drug and alcohol services) could be helpful, but people with substance use problems can also **"fall through the cracks"** leaving carers to **fill in the gaps.**
- **Carers want to be involved** in their cared for person's treatment, but there are often **barriers from services** that make this difficult.
- **Peer-support groups** are valued for providing a non-judgmental, understanding space

Greig pointed out that the main things that Carers discussed during interviews were the uncertainty from day to day, complex and challenging behaviours, the stress for Carers

falkirk & clackmannanshire carerscentre

Meeting Minutes

Consultations for carers to share their views with external organisations

FOR FALKIRK CARERS

having to manage complex health needs, responding to life crisis, overdose and medical emergencies.

April acknowledged that some of the interviewed Carers had prior experiences of supporting someone however for others this was a very new experiences and a "steep learning curve".
A key turning point for many of the interviewees was when they identified as an unpaid Carer. This identification was empowering for some of the interviewees and helped "open doors" to new services and supports.
Some Carers felt that they were "tied down" and commented that they had "lost their personal freedom". Many Carers felt a strain on their relationships with others with stigma impacting many relationships too.

Greig and April asked if there was anything missing from their research findings.....

Carers from Falkirk commented .....

- Emotional abuse, people don't want to talk about this, but they can be violent and emotionally and physically abusive.
- Yes, abuse is not talked about, again its that stigma, there can be real venom in the verbal abuse.
- People don't want to admit that abuse is happening.
- Its so difficult because one day they are saying to you they are cutting you out of their life as you are toxic to them, then they call the next day and ask for food or money.
- Services fall off when they are 15/16 do the services think that they have just outgrown their problem, because they haven't.
- Respite, what is that, we don't get a break.
- Carers neglect their own health and its not until your caring role ends that you realise this. Many Carers agreed with this comment.
- Yes, verbal abuse, they can be very very verbally abusive to me.
- We don't get Carers allowance (many Carers in the room and out with the room are upset about this).
- I work full time, I pay my tax, I don't get Carers allowance, how is that fair.

falkirk & clackmannanshire carerscentre

Meeting Minutes

Consultations for carers to share their views with external organisations

FOR FALKIRK CARERS

Greig explained that the full report will be finalised within the next few months, he shall share this with Sharlene who will share with Carers who attended on the day, if you did not attend and are interested to learn, more, please let Sharlene know.

More Carers Views and answers to the questions asked on the day are included below.

Carers Views/Suggestions/ Experiences.

- At the hospital they don't involve us yet it's us that need to take them home.
- At the hospital I have told them that I am an unpaid Carer and I know my rights, the difference in the way they treat you once you say this is unbelievable.
- More people need help to identify as a Carer, there needs to be more advertising, and professionals need to tell us too.
- I didn't know I was a Carer until I did my families my rights by SFAD, but not everyone does this course.
- Stigma is such a big thing, even in some Carers groups there are people their who make judgements, I tell them come and live a day in my life before you judge me, other Carers wouldn't do this though.
- The SFAD groups are so important, everyone there just gets it.
- I and many others have offered to volunteer to tell people at the hospital about the Carers Centre and SFAD, let them know that they are a Carer, we need training, but we are happy to do this.
- It's a constant worry; I always give them money and its for things like electricity.
- The stigma is terrible, you feel like what have I did wrong, why are they like this.

falkirk & clackmannanshire carerscentre

Meeting Minutes

Consultations for carers to share their views with external organisations

FOR FALKIRK CARERS

- Some of the mainstream Carer's groups make you feel like you are not as valued as others who have different caring roles.
- I went on holiday, and a serious incident happened, there was no one to deal with this, I was phoned and I worried until I got home.
- Many Carers commented that they care for more than one person and this causes additional challenges.
- Services don't get back to you, their children get removed and they are left with no help, again its left to us.
- If they are picked up during a mental health crisis and refuse to go to hospital the police bring them to me, to avoid them getting arrested, do you know the stress this causes, and the police can't tell me anything due to confidentiality.
- It took me a year to finally call SFAD for support as I just wasn't ready for this.
- There are barriers to accessing many supports when you work full time.
- Most services are 9-5 caring doesn't stop at 5pm on a Friday night.
- I have to take them to their appointments as they don't drive, also nobody thinks about the digital barriers how are they expected to get online to book an appointment when they don't have access to online, again this falls to us.
- You "hit a brick wall" and "become numb to it all".
- When they were really ill, nobody told me at the hospital, it was too late when we found out how ill they were, it really wasn't good enough.
- Sometimes they manipulate you and make you feel guilty for going on holiday.
- The Carers café and SFAD groups are good, but I need something else, there is support that is missing. I need something to let all my anger out like axe throwing or one of them rooms you can smash up.

- I feel guilty when I have to put them out the house, but sometimes that's all I can do.

- They call me constantly when I am at work, I got counselling to help me to put boundaries in place, I had to pay for private counselling though (Sharlene explained that if Carers meet the eligibility criteria there is currently a counselling service provided at the Carers Centre).

- Why do the government get away with advertising gambling, gambling is an addiction too!

Questions and Answers from the room

1. **What support do unpaid carers of people with a drug or alcohol problem need?**
    - Social connection.
    - Medical staff sharing information when they can.
    - Better palliative care.
    - Carers need medical training, what to do.
    - Supports out with your area that you can access anonymously.
    - SFAD groups.
    - Things for people who work fulltime.
    - Understanding employers that allow time off work to attend support groups and information sessions.
    - Knowledge about the substances they are using, what it can do to them, how they might behave etc.
    - Al Anon is a good support.
    - Sharlene spoke about the need for a specific, individualised, planning document (completed with a qualified professional) which could support Carers with their cared for persons behaviours, eg if they can be violent

what to do, if they take an overdose who to contact, if the Carer needs training who can deliver this.

2. **How can drug and alcohol services specifically support carers?**

- Listen to family members.
- Introduce layers of consent, this has to be ongoing, this should be an opt out rather than an opt in (SFAD professional in the room).
- Specialist support workers for Carers in the hospital (there are no specialist drug/alcohol workers for Carers in the FV hospitals only the 2 Carers Centre support workers who will help any unpaid Carer).
- Schools supporting young Carers to be identified, discussion from Sharlene about Young Carer (YC) and Young Adult Carer (YAC) support workers in schools and SFAD comments about trying to work with local schools. Sharlene spoke about the Carer Champion programme and discussion led to YC/YAC not wanting a go to person for the stigma attached to this.
- Addiction teams identifying Carers.
- More knowledge about neurodiversity.

3. **What does "meaningful involvement" in treatment look like to you as a carer?**
    - Keep us informed throughout their journey as this is ours too.
    - Communication.
    - Having the knowledge of what the treatment plan is so we can help.
    - Acknowledge the information that we tell you.
    - I feel listened to and involved, and this really helps me.
    - Staff knowing that you are their Carer.
    - Permanent staff in GP's would help.
    - Getting a GP appointment, would help.
    - GP's having appointments to give.

- Less part-time GPs.
- Not being stigmatised, being seen as part of the solution not part of the problem.
- Kinship Carers both formal and informal having rights.
- MAT standard's required for alcohol and other drugs.

4. **How can we help people to identify themselves as carers and raise awareness of their rights?**

    - Tick box at the GP surgery detailing what an unpaid Carer is (e.g. if you care for..... you are also known as an unpaid Carer, please contact .... support services).
    - SFAD staff letting all Carers know they are in an unpaid caring role as soon as they register.
    - More advertising of what an unpaid Carer is, volunteers could do this.
    - Ask everyone in A and E when they arrive.

5. **What would help to reduce the stigma that carers might experiences from services or in the community?**

    - Information sharing
    - Advertisements for Carers Centre being broad as often its old people and that doesn't help.
    - Put it on cigarette packets

falkirk & clackmannanshire carerscentre

Meeting Minutes

Consultations for carers to share their views with external organisations

FOR FALKIRK CARERS