



Experiences of unpaid carers of engaging with mental health services in Edinburgh – Briefing One

Support for carers in Edinburgh



INTRODUCTION

This briefing summarises findings from research to identify the views of unpaid carers who care for a person using mental health services in Edinburgh. The research is part of a Thrive Edinburgh funded project led by VOCAL to promote carer engagement in mental health services.

The research focused on carer involvement in shaping the care of the person they care for, and how well supported they felt as carers. Fieldwork took place during June – September 2021 with 70 carers participating. A range of approaches were used to obtain carer views, including focus groups, one-to-one interviews and a survey. All names were changed to protect identity. Similarly, no individual service is highlighted. Carer feedback is therefore generalised when discussing services and professionals. [The full report can be accessed here.](#)

FINDINGS

Carers chose to take part in the research, meaning the findings are not representative of all carers supporting a person with a mental health condition.

Just over two-thirds of the 70 respondents (68%) had been caring for more than three years, with over half (54%) caring for five or more years. In terms of caring relationship, the largest category of respondents was parent carers (42%) mostly caring for an adult child, with the second most common category being carers caring for a sibling (12%).

Four main themes were identified:

- **CHALLENGING CIRCUMSTANCES OF CARERS**
- **POOR ATTITUDES AND ACCOUNTABILITY OF PROFESSIONALS**
- **LACK OF CARER RECOGNITION AND INVOLVEMENT**
- **THE POWER OF GOOD SUPPORT AND ENGAGEMENT**



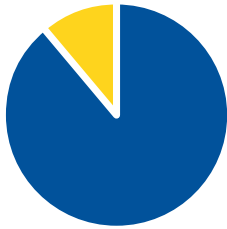
CHALLENGING CIRCUMSTANCES OF CARERS

The first theme centres on challenges faced by those caring for a person with a mental health condition. These can be categorised into two main areas, challenges related to the caring role and challenges associated with accessing carer support.

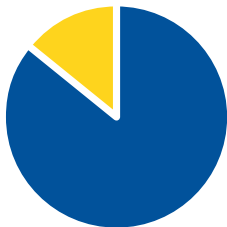
Challenges often started at the point of diagnosis, when carers were not only struggling to cope with symptoms of the person they cared for, but also found themselves in an alien landscape of conditions, services, medications and treatments. Many carers were not signposted for support for many years, and those who had received support felt it could be improved.

Despite the complexities of caring for someone with a mental health condition, and the impact this has on carers, many respondents felt professionals did not take carers' situations into account, which may partially account for the reported lack of referrals to carer support services.

“
I have only recently been informed of a support service for carers even though I have been caring for a person with a mental health condition for a number of years. I feel my role as a carer and the strain it has put on me has not really been taken into consideration.
”



- An overwhelming majority (89%) of carers felt the carer support and information they received could be improved.



- More than four fifths (86%) felt they had never, or only sometimes, been given sufficient information and support from professionals to manage risks associated with the person they care for.



- Over half (57%) reported a need for more support to help them manage risk related to the person they care for's condition.



POOR ATTITUDES AND SERVICE ACCOUNTABILITY

This theme covered issues regarding carers' perceptions of services and professionals lacking accountability. These included a view that services and professionals avoided taking responsibility and did not treat them with dignity or respect. This led to them feeling they were being 'fobbed off', neglected or treated like a nuisance.

- Of those who reported negative experiences with mental health professionals, over half (52%) felt professionals had not taken their caring role seriously and were not interested in them, or what they had to say. They did not feel treated as equal partners in the delivery of care.
- Many carers reported a strong sense of feeling distanced from mental health professionals and of feeling judged, abandoned or ignored by them. Some felt they had not been treated respectfully.
- Service boundaries appeared to compound this feeling of distance and lack of accountability. Issues relating to discharge arrangements were mentioned by some carers, who felt improvements could be made to ease the transition between hospital and community.
- Some found services could be inflexible and inaccessible. Working carers found it difficult to attend meetings during the day but were not offered alternatives. Carers reported challenges surrounding how to access crisis services for the person they cared for.



Exasperated. Desperate. Completely unsupported. I am infuriated at the lack of clarity on how to access services or what you can expect them to provide and putting all responsibility back on to informal carers and seriously ill individuals.

They look at discharge in a physical sense, any additional support required, but do not think about how the loved one is to adapt/cope with managing a person with mental health issues in their household.

The current system assumes you have all the time in the world – that you have three hours to wait to see somebody for an appointment and the difficulty for working carers is they are rushing from A to B. Because if they are not working, they are supporting somebody and if they are not doing that they are working.



LACK OF CARER RECOGNITION AND INVOLVEMENT

The third key theme relates to those described above. Many carers mentioned the impact of caring for someone with a mental illness, especially if they felt unknowledgeable about mental illness and its treatment. The majority felt strongly they could have been better supported whilst undertaking this challenging role.

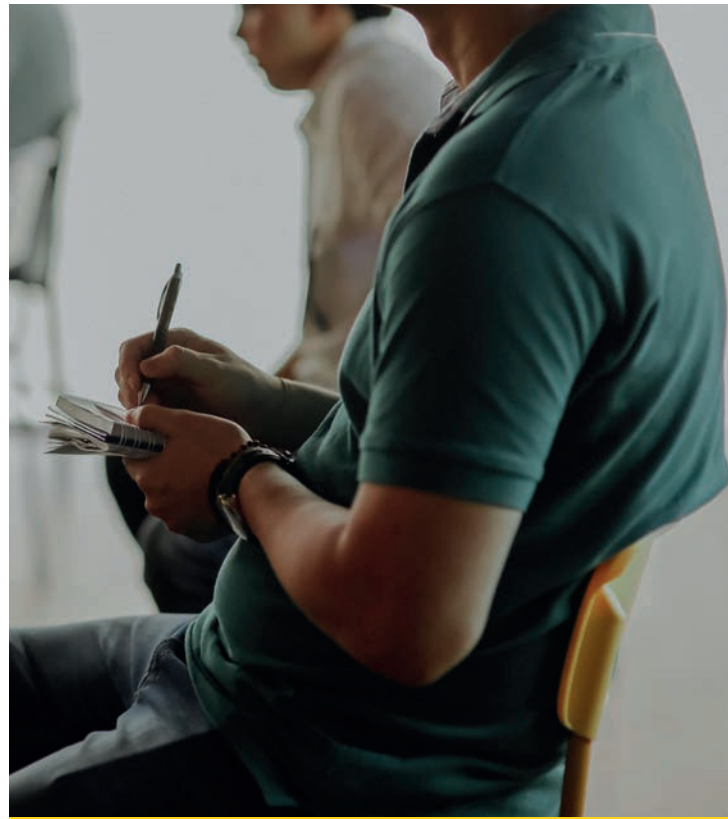
Carers described the impact of the lack of professional recognition of their caring role. They reported professionals had a poor understanding of what the role entailed, the impact it had, and were unaware how best to support them. Almost all respondents shared something in this theme.

“
There was no support for me really – around that time I ended up having a month off work as it was all a bit too much really.
”

- Almost all respondents felt professionals had not valued them and underestimated the caring role and its impact on carers. This led to a decline in their own mental health (to a significant degree for some), mostly due to providing care for someone presenting with high level needs without sufficient training or advice and support.

“
Without including the person that cares for them most often you will be doing a disservice to both parties. This should include medication changes, changes in staffing, final decision making on care planning etc.
”

- Nearly two-thirds (61%) felt professionals did not seek to engage them in the care, treatment and recovery of the person with a mental health condition. Possible reasons included confidentiality barriers, the person receiving care being the sole focus and a lack of carer awareness.





THE POWER OF GOOD SUPPORT AND ENGAGEMENT

The final theme consisted of positive feedback given about professionals and teams, as well as ideas for what good carer support should look like. Although positive experiences were less frequently mentioned than negative, where these had been experienced, the difference it had made to carers' lives was noticeable.

- Praise was mostly offered for individuals and teams rather than wider aspects, such as service or system approaches. Some carers felt 'lucky' to have received good support from a mental health professional, suggesting carers were aware their experience was unusual.
- Carers welcomed support when they found it, and experienced the benefits of being linked to dedicated carer support services which they valued.
- Most carers (90%) would like professionals to treat them with more respect, compassion and honesty. Some also wanted professionals to be more aware of how daunting carers found their services.
- Many carers would like professionals to treat them as equal partners in care, with 88% citing the need for improved, regular communication between professionals and carers.
- Several carers described how they would like to see improved integration of services. A significant minority of carers described the need for whole system change involving cultural transformation of the approach to carer engagement within mental health services, and many liked the idea of a 'hub' or 'one-stop shop' model where they could receive all the support needed.

“
I am really lucky with his psychiatrist... I can phone her up if I am worried about X... and tell her what is happening and she can say “yes let's get him in”, so that's sort of indirect support for me, just knowing I can speak to her.
”

“
desired, not actual experience
A service which takes into consideration the stresses and upsets of caring for a person with a mental health condition. Including carers even when it seems that this takes longer to achieve... as it will result in making things easier to manage in the long run both for the person receiving the service and the person caring.
”



CONCLUSION AND RECOMMENDATIONS

It is hoped this research, which took place as Thrive Edinburgh, the new mental health collaborative (services working together), becomes established, will help shape future service and system improvements in the area of carer support and engagement. The findings are largely critical of how mental health services engage with carers. Whilst this might be partially due to the self-selecting nature of carers that participated, carers made an articulate and often impassioned case for improved carer identification, support and engagement.

Based on these findings, the authors make the following recommendations:

- Strengthen carers' rights approaches at all levels (service, team and professional), including the ability to seek redress where rights are not met.
- Promote cultural change through professional development activities to ensure carers are treated as equal partners in the delivery of care and provided with sufficient knowledge to enable them to provide effective care.
- Encourage mental health professionals to identify and refer carers for support at the earliest opportunity. Mental health professionals should have an awareness of why such support is necessary.
- Improve carer engagement in hospital discharge (a legal requirement). Carers should be better supported during the transition from hospital to home.

We look forward to working with carers and mental health services in Edinburgh as part of our project to improve carer identification, support and engagement.

GET IN TOUCH

We would love to hear from you!

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