

Early Intervention in Psychosis (EIP)

Understanding systems: Engaging with Families

Engaging with the family and/or carer of someone experiencing psychosis is a key part of providing an Early Intervention in Psychosis service. This case study draws on learning from pathfinder sites and families working with them at NHS Tayside and NHS Dumfries and Galloway.

How are EIP services developing in Scotland?

There are currently two pathfinder EIP sites in development in Scotland, alongside an established ESTEEM service in NHS Greater Glasgow and Clyde. A brief overview of pathfinder progress is given below, with a detailed overview of progress over the past year available in the [Phase 2 progress report 2022-23](#).

NHS Tayside

- Hub model, City centre location in Dundee
- Open for 8 months and accepting referrals from secondary care mental health services

NHS Dumfries and Galloway

- Bespoke model, Rural location
- Open for 10 months and accepting referrals from secondary care mental health services

“ The level of service surprised me. I didn’t realise how much support I would have been given ”

Person with lived experience of psychosis, NHS Tayside

Method

This case study shares the learning from engaging with families of people experiencing a first episode of psychosis (FEP). Data was gathered via: interviews with family members of people with lived experience of psychosis, including a peer-to-peer interview supported by the Carers Trust; written feedback from people with lived experience; and conversations with EIP team leads.

Learning points

A number of themes were identified through listening to EIP team lead's experiences of engaging with families, and feedback from families and people with lived experience of psychosis.

Meet with the family as early as possible

- Both pathfinder sites emphasised the importance of family involvement as part of assessment to gather corroborative information and engage with them as active agents in care and treatment.
- The first appointment with the family is primarily about getting to know them and the person with psychosis. Acknowledging their experiences of psychosis and contact with NHS services so far, and identifying what they think their needs are and how the service can help builds trust.
- Family knowledge is valuable, for example asking when they noticed changes in their loved one's behaviour, what they were, and what they were like growing up helps to identify duration of untreated psychosis (DUP) and other needs such as neurodevelopmental or long standing anxiety. This information can help identify appropriate support needs early on.



"We first got into contact with the EIP prior to being discharged from hospital. This was a great way of getting to know the EIP team and made the process much easier of being transferred to their care after being discharged"

Person with lived experience of psychosis, NHS Tayside

Supporting the family is supporting the person



- Families often had concerns for a while and been struggling for a period of time, or they may have been involved in different services before EIP and they've not felt listened to.
- At times both sites met with the family altogether, the person experiencing psychosis and with family members on their own.
- Having a member of the EIP supporting the carer, who isn't also the key worker, can provide greater flexibility to meet carer needs - especially where multiple family members are needing intensive support or where having a single source of support could create complexity or conflict.
- Both NHS Dumfries and NHS Tayside have an 'open telephone' policy where family can phone at any point during working hours (9-5 weekdays) to seek advice or call in a crisis.

"Having this service is incredible for the family. Our queries are answered so fast [...] it becomes less of a burden on us since we have resources readily available, instead of us googling and guessing what's the right approach and potentially negatively impacting [the person]"

Family member of person with psychosis, NHS Tayside

Use a Person centered approach



- Support is as individualized to each family and responsive to each family's needs.
- Consider prior experience of mental health services; cultural understanding of mental health; balance and pace of support and interventions – some families might be hyper-vigilant, some not concerned about things they should be.
- Working with the family, wherever they are now. One of the EIPs is currently supporting the father of someone who experienced psychosis whilst the family were on holiday in Scotland. The service know the person will not go through the full service, but the key worker meets up with the person's father on the hospital site to support him, as well as the person experiencing psychosis.

"In terms of our approach with families, it's very flexible, just like the model for anybody really. We don't say 'we'll do this, this and this with the family' - it's very much what the family are coming to us with"

Team Leader, NHS D&G

Assessment, review and crisis support

- Every person accepted on to the caseload at both sites is given information that involving families is routine part of care and treatment.
- A developmental history and timeline of symptoms are completed as a routine. This is typically within the first 2 weeks of meeting the person, ideally face-to-face at the family's home, and can be prior to the person's discharge from hospital.
- Family input is invited at 12 week review meetings.
- No issues have been experienced getting families involved, as families are driven by the focus on the person getting better
- Crisis support is offered by both pathfinder sites between the hours of 9am – 5pm on weekdays. Crisis support outside of these times is provided by the Crisis team, this is via NHS24 at Tayside.

"Of particular benefit is building open and trusting relationships that a family can have with the service outside of the person's appointments. The family/carer has a separate avenue of support without the complexities or conflict of a key worker role"

Team Leader, NHS Tayside

Family psycho-education

- Psychoeducation is a key part of supporting a family experiencing FEP. Family education sessions have helped to encourage a shared understanding between family members. Examples include:
 - Mental health awareness; challenging stigma; identification of triggers; boundary setting; goal setting; staying well work; early warning signs card sorts and generally building up a tool kit and strategies for coping with symptoms.
- NHS Dumfries and Galloway are developing psychoeducational modules to be worked through with families when most relevant to them. These are being developed with family members of people currently within the service and the local lived experience group. This group are keen to develop their own module on carer support, in collaboration with the Carer's Trust.
- Support has also been offered to improve communication within the family and conflict resolution.
- Where no family in the UK (e.g: international students) friends/flatmates have also been offered psycho-education sessions.

"Colleagues ask and I say that [my family member] has psychosis. I'm like you know what I'm just gonna say, and they go 'wow'. But before [working with the EIP] I didn't say, I didn't want to say. Now I say "don't judge""

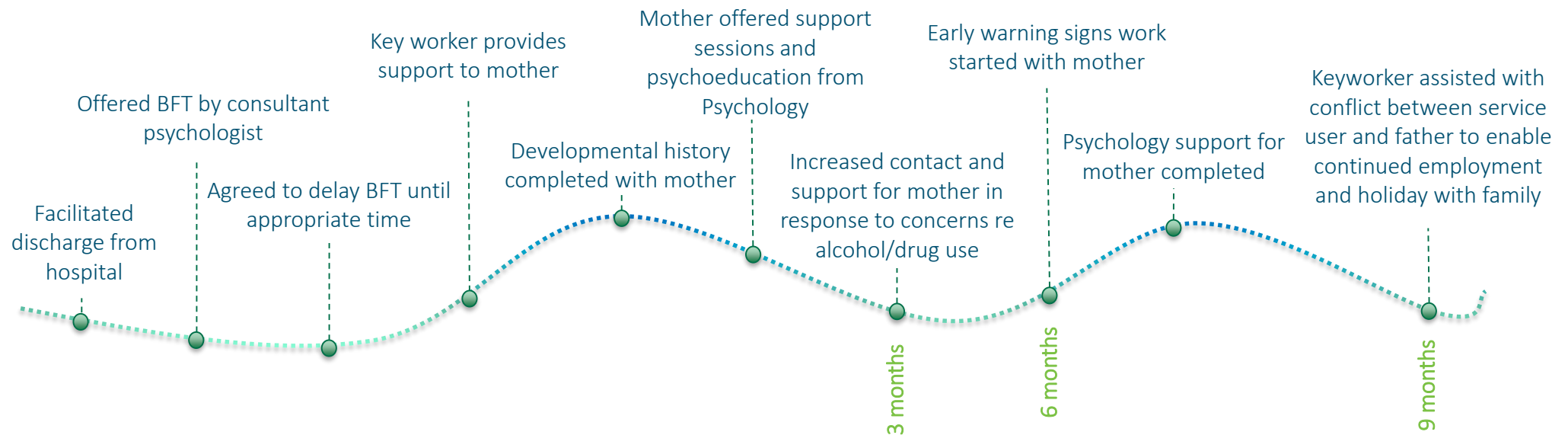
Family member of person with lived experience of psychosis, NHS Tayside

Carer support

- Both sites emphasised the importance of offering the family time on their own to talk as well as working with the whole family together.
- External carer support is offered to all families, the uptake for this isn't very high – possibly because families receive a lot of support from the EIP service itself.
- Families often do not consider formal 'carer' support relevant to them. It is, however, a carer's right to be identified by the service. An example of how this is challenged is by querying with the family ***"Is this the amount of support a family member would typically expect to provide to a young person?"***, and reflecting on whether they think they provide more than this.
- NHS Dumfries and Galloway are in the process of compiling a directory of support available across the region for carers. This is one of the ways that the service can support carers as the service develops and may not be able to provide the same level of direct support to carers. A family and carer group, similar to NHS Greater Glasgow and Clyde ESTEEM EIP, is being considered.
- NHS Dumfries and Galloway EIP are developing a training package for the wider community directorate. This is being developed around carer experiences and feedback from families within the EIP service.
- Young carer referrals have been made to support siblings, even when they are not primary carers.

Case study 1 - NHS Dumfries and Galloway

Below is an example of family specific contact and support offered to a single family, who have had contact with the EIP for 10 months. Most of the planned contact occurs within the first few months, led by the needs of the family. The family are typically contacted within the first 2 weeks of accepting a person experiencing psychosis onto the caseload. This is ideally done face-to-face but may be telephone contact. An assessment with the family is done at this point.



"It's probably my favourite thing to do in the first couple of months with the carer [...] families get a lot from it because it shows how interested we are in their loved one. We want to know everything about them, not just in terms of last year in terms of prodromal symptoms [...] families get quite animated, telling us all the anecdotes. It's been really nice doing that kind of work, and that's gonna build a lot of engagement"

Team Lead, NHS Dumfries and Galloway

"[my support] was quite structured but it was also based on what I needed to get from the service. I have to say I didn't have a clue, but [Psychologist] was really good at being able to eke out what it was that we needed as a family."

I think as a family and I think everybody would agree is a lot of guilt involved like you think it's something you've done wrong or what could you have done is stop it. Do you know? But they were very good at putting that in perspective"

Family member of person with lived experience of psychosis, NHS Dumfries and Galloway

Case study 2 – CONNECT, NHS Tayside



I know I can phone EIP and someone will come out and see [us]. It's good that I've got that support myself. They're really good at looking after the whole family [...] they involved me from the start and asked about the impact on the family

Family member of person with psychosis, NHS Tayside

Having this service is incredible for the family. Our queries are answered incredibly fast [...] it becomes less of a burden on us since we have resources readily available, instead of us googling and guessing what's the right approach and potentially negatively impacting [the person]

Family member of person with psychosis, NHS Tayside

“When someone is being supported by CONNECT EIP there is an assessment of family/carer needs to see what support can be offered to them. This is always person centred and dependent on the individual needs of the family/carer. The support required may be evident at first contact but can equally take time to tease out. Family dynamics and the stress/challenges faced, not only from supporting the person but also around other areas of their life, are also considered in suggesting supports available. Support from within the team is always considered as well as what support there may be available and appropriate from other agencies (eg Dundee Carers).

For this family as we developed a relationship, we could see that the person's Mum was the main carer/support not only for the person being supported by Connect, but also for others within and outside of the household. We positioned support on an individual and holistic basis for the Mum which was agreeable. We decided as a team it would be beneficial for the family support to be made available from a different team member to the key worker to allow for a safe space to share individual concerns, thoughts and feelings.

A loose contract of how the support would take place was agreed at the first meeting, with the view to change timings or type of supports offered as and when required. Some sessions are around reaffirming and reassuring that everything she does is appropriate, with some other suggestions for how to respond as and when appropriate. Current sessions are monthly with the opportunity to increase or decrease as led by the Mum. We also have an open telephone policy where she can phone at any point to update us of any changes in symptoms or seek advice.

So far this has been received positively by both the person on the caseload and the Mum. The Mum is able to speak openly about any challenges, concerns or indeed any positive progress without her family member present and that person then doesn't need to feel uncomfortable with two people speaking about them in their presence. It provides a safe space for everyone to receive appropriate support defined by them.

During these sessions other support for individual family members has been identified and a referral has been made to young carers in Dundee for a sibling.”

Team lead, CONNECT

Learning from Feedback

Both sites are collecting and using feedback continuously to inform the delivery of the EIP and other services. NHS Dumfries and Galloway are promoting the use of CareOpinion to gather and respond to feedback, as well as local verbal feedback, with established internal processes for this.

NHS Tayside are developing a feedback board within the EIP team hub to receive and display feedback along with the actions taken as a result of feedback. Feedback gathered for the purpose of the case study has also been taken back to boards and will be used to inform future quality improvement work. Current improvement based on feedback includes:

- **Available information on carer support in referring services.** NHS Dumfries and Galloway are developing training on carers support for the community mental health directorate, alongside the Carers Trust. Carer stories and experiences are central to this training.
- **Development of crisis support for first episode psychosis.** There is ongoing work developing out of hours crisis support within NHS Dumfries and Galloway. The team are using feedback from families to prompt further development of training for Crisis team on first episode psychosis and the support the EIP provide. The crisis team are also piloting the directorate carer support training. Home based treatment is offered as a favourable alternative to admission for FEP, this is more likely to be successful where there is good family support.
- **Early identification and referral of first episode psychosis.** Psychologists within the NHS Dumfries and Galloway EIP attend a weekly handover meeting on the acute wards, to identify people with FEP early on in their admission and facilitate early discharge. This presence on the wards builds on existing good relationships with psychiatrists.

“I feel we’re kept in the loop, whereas the ward was awfully closed off. I only found out in the tribunal that [person with psychosis] had advocacy” Family member of person with psychosis, NHS Tayside

“I wasn't in a good place, and it's not about me, it's about [person with psychosis], but it wasn't by then. I just had so much stress affected everything, so I think like just having someone here to talk to and put my thoughts into perspective and say well actually. You know, it's not your fault [...] to put it into quite clear terms for me, that was just invaluable.” Family member of person with psychosis, NHS Dumfries and Galloway

“We've got an action plan, so we know what to do now in these situations. If it happens again it's clear, and it's good because it helps us feel a bit more relaxed that if this was to happen again, we can lift the phone and say, right, you know, and there's someone that's going to listen and not just be like ‘we need to wait till the wheels come off the bus before we can get involved’ when the wheels have come off the bus and more by the end” Family member of person with psychosis, NHS Dumfries and Galloway

“Without the EIP we would be in a different place, [person with psychosis] wouldn't be as stable [...] and I can't help think what if we'd have got help at 15. Would we be where we are now? What if the EIP had picked them up, rather than the police?” Family member of person with psychosis, NHS Tayside

Useful resources

- [Carers Trust in Scotland](#)
- [Care Information Scotland](#)
- [Help for Carers, Change MENTAL HEALTH](#)
- [Dumfries and Galloway Carers Centre](#)
- [Dundee Carers Centre](#)
- [Information for brothers and sisters, Esteem, NHS GGC](#)
- [CareOpinion: NHS Dumfries and Galloway EIP](#)
- [CEIM Experience Improvement Model for Health and Social Care](#)

Acknowledgements

The content of this case study was gathered from conversations with:

- Family members of people with experience of psychosis, NHS Dumfries and Galloway
- Team lead, NHS Dumfries and Galloway
- Person with lived experience of psychosis, NHS Tayside
- Family members of person with experience of psychosis, NHS Tayside
- Team lead, NHS Tayside
- Key worker, NHS Tayside

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We would like to thank everyone for sharing their experiences with us.

Keep in touch



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