

What makes for good recovery focussed care coordination?

Key to quotes: C = Carer

SU = Service User

PR = Professional

1. Listening and responding

'Because they actually listen...they actually look at you and listen and make you feel like they're listening and care. That's what it is. They know how important it is to get it right.' SU106

Listening to both the service user and the family might appear to be common sense and expected to happen as routine practice. When effective listening takes place it makes a difference to how people feel about their relationship with their care coordinator. Unfortunately, this is not always the case.

'if she [CPN] could see a problem with [my wife] she would there and then phone the doctors; 'I want an appointment'... That was great but now people just seem to be if you don't mind me saying ticking boxes.' C09

When it is a tick box exercise people tell us that it doesn't work well as they don't feel valued. Professionals' time can be hijacked by a wide range of issues and pressures. However, if you as the care coordinator are not able to respond to the service user and their family member in a timely and constructive manner, then this leads to feelings of being let down and disillusionment with services.

Where it works well, the benefits are evident in the relationship that is established between the care coordinator, the service user and their family.

'I've always been listened to and I felt they've worked with me, they've valued what, you know, what my opinions are, I've not been pushed into anything. I've not been treated as someone who hasn't got anything to give in my recovery or anything like that. No, I just sort of feel I've been involved in every step of the way with them all.' SU113

Listening and working collaboratively supports service users to recognise their own strengths and capabilities on their recovery journey.

2. Sharing perceptions of recovery

'[the staff member] sees recovery different from what I see it as.' SU41

Service users, professionals and family members are likely to have a variety of understandings about recovery. Such differences need to be highlighted and can be helpful in generating discussion about the care coordination process and how it can be recovery focussed.

Service users might, for example, be looking for medication to 'fix' them, their family members expecting a return to a previous level of functioning, and professionals looking to support the management of symptoms and setting new goals. Understanding the individual meaning of recovery for those involved provides a platform for discussion in order to establish personal hope and aspirations. This may involve engaging in difficult conversations with both the service user and as appropriate their family member.

'What I do now, if I meet somebody for the first time, I'll always say: "Look, I won't be with you forever. This piece of work that I'm going to do with you is going to be time limited. You know, I'm not going to come next week and say: Right, you know, you've got four weeks and that'll be it, bye-bye. You know, I'm not going to change your life; I'm not going to change your diagnosis, I can't do that, but I'm going to help you to cope with it, you know?'" PR11

Setting out clear expectations about the direction of travel requires honest and transparent discussions with the service user and their family members from the outset. Such discussion challenges traditional ideas of being in services for life and encourages a focus on moving forward out of services and seeing this in a positive light. These discussions need to take place at an appropriate time in the recovery journey. They can be very difficult, but should not be avoided as they will ultimately support the recovery process.

Information and explanation about what care coordination is, the service that can be realistically provided, clarity about the roles of the professionals involved, transparency around timescales and clear recovery focussed goals are central to good practice.

3. Having a recovery and wellness focus

'Like, the first time we actually had a full meeting at that... It was, like, the first time. The first time I had met them. They had started talking about recovery, and I'm thinking, "Are you mad? I've only been here for 5 minutes and you're talking about recovery already.' SU152

It is important that everybody works together with a recovery focus from the outset. Whilst it can be difficult, the research shows that working in this way results in an approach to care coordination that can make a real difference to the service user journey. It is not just about having an end goal in mind but as importantly it is about agreeing a way of working together that is collaborative and built on mutual respect.

'So the whole point of you working with someone, you know, it's identifying what recovery journey they're working on and we're agreeing together, collaboratively I suppose, what we're aiming for.' PR01

Working with the service user and the carer in this way may seem like common sense, but doing it well requires an attention to your own assumptions about both recovery and care coordination. Reflecting on how perceptions of power and expertise influence the interactions that are taking place.

One service user was encouraged to write a Wellness, Recovery Action Plan (WRAP) which gave her a greater sense of control and being an equal partner in her recovery.

it didn't work, being in the same place for years and years and years and I thought: Right, it's time to take control. They obviously can't put us right; I've got a huge part to play in this, so I felt, for the first time as if I'm in a more powerful position, or at least have equal powers, instead of the power imbalance that there's always been. SU146

Care coordination was shown to work well, when WRAP was part of the process as this ensured that conversations were empowering for the service user and recovery orientated.

Using WRAP as a tool within the care coordination process supports:

- forward planning for times of crisis;
- recognition of triggers for times when someone is unwell
- taking responsibility for personal wellness.

Service users reported that it is most effective when it is completed together rather than on their own. It also helps the care coordinator to understand the service user's priorities. While it may not suit everyone WRAP allows a focus on recovery and wellness from the perspective of the service user to be included in care coordination from the start.

'I had a WRAP plan. A wellness, recovery action plan. Which highlights my triggers, early warning signs. It tells you what steps I need to take to hopefully prevent things breaking down. It has a crisis plan section. And I would hope that that would be used. And that I would use that in planning for my future care.' SU125

Practitioners need to be clear about how tools like WRAP and care coordination work together. It should not lead to duplication of work if it is to be effective.

Other tools people talked about that are useful in supporting wellness - stress and vulnerability bucket link to diagram or web link e.g. link to <http://www.tevv.nhs.uk/Our-services1/Trustwide-services/Early-intervention-in-psychosis-teams/The-stress-and-vulnerability-bucket/>

4. Including and educating family and supporters

'I do feel that I've moved on from somebody who got distressed and panicked by crisis... to someone who has some understanding and education. And I feel empowered and more in control because of that. So I think I'm in a better place than I was'. C44

Family members and friends don't always see themselves as carers, they view themselves as wives, husbands, mothers or fathers, people who are there 24/7. This can mean that people muddle through difficult times and see asking for support as something that is shameful or they are afraid to ask for help. Carers often feel as though they are telling tales about their family member who is unwell. All of these issues can lead to carers remaining silent or feeling that their voices are seldom heard within the care coordination process.

'It's a mixed bag because you worry that you're letting the person down if you get help too soon. So you tend to try and support them at home because you know that deep...Or I felt that deep down she didn't want to go into hospital. And I felt like I was letting her down to go by going to get professional help.' C44

The language that is used by the care coordinator needs to acknowledge the carer's wider role, acknowledging them in their own right. Carers can become ill themselves, sometimes they have difficulty accepting support and sometime there is no support available for them. Professionals need to recognise the stresses that carers are under and respond accordingly.

Family members generally felt excluded from the care coordination process. They felt that their experience was disregarded and that opportunities to support a recovery focussed pathway within the family setting were missed. It is essential to know and understand the life of the service user, who is in it and who can positively support their recovery journey. This can be mapped out with the service user and their family.

Where care coordination worked well, education was central to the family member's experience. This was either face to face with a professional or through a carers support network.

Carers need to be responded to as individuals, there is no one size fits all. What works for one person may not work for someone else.

Carers value an effective communication process which includes:

- Sharing knowledge and information and discussing things together.
- Signposting to services that are able to offer support
- Guidance on how to move on from being stuck themselves
- Guidance as to how they can best support recovery

Several carers tell us that feeling valued for their experience leads to good care coordination

'We worked as a team; she valued me as a carer. She has not seen me as interfering...she knows I have good experience.' C43

For carers it is important to:

- Know what is happening;
- Feel that the care coordinator sees the service user in the context of their whole life and part of a network of family and supporters;
- Be assured that attention is paid to the little things e.g. making practical phone calls and being available for advice

Often carers reported that they are not included; this leads to frustration and disappointment with the service that is provided. They feel unsupported and left to get on with the job, affecting their own sense of wellbeing.

'I feel as though I'm pushed out, but then when anything goes wrong, I mean, they're saying to me "Oh well, she could do this; she could do that" I think: Aye, she could do a lot of things, but you haven't got her 24/7.' C14

As family members, carers often have valuable insights about the person they support and make a long term commitment. Without appropriate guidance and help from services they can struggle to manage their own health and support the recovery journey of their family member.

Sometimes carers feel frustrated about the inconsistent way they are treated, on the one hand they are not fully included in care coordination and yet on the other they are expected to take responsibility in a crisis.

5. Knowing the boundaries of confidentiality

'Yeah. [CPN] has always been really good with me anyway. Like, he hasn't done anything without my consent. Like, if he's going to make a decision, he always comes to me first and asks about things.' SU133

Some service users do not want their family members to know what is happening for them but this can change over the course of their illness. Many carers would like to be more involved, but find that there are many barriers to their inclusion.

'[Carers] have a right to know, because sometimes when they discharge people, they just discharge them back home and to say to a family "Well, you're not entitled to any information about your loved one. Oh, P.S. We're discharging him on Friday back into your care", that's setting the carer up to fail and the service user up to fail... This is what that service user needs. Now, carer, what do you need? Because you have rights in your own right.' C35

Clarity is needed for the service user and their family about what information can be shared and what is confidential. For staff getting this balance can be challenging. Understanding a service user's

views about the sharing of information is not a one off event but a dynamic process that requires negotiation and checking. Its success depends on the wellness of the service user and the willingness of all concerned to listen and engage in an honest and open dialogue.

'I do see... carers wanting information or wanting to tell you something and, you know, saying "I can't talk to you because so and so won't let us talk to you". Well you can always listen, I say. As long as you don't give any confidential information away, you can listen. Er, it's very frustrating to be a carer and people will say "I knew this was going to happen and I told you this was going to happen and nobody listened to me and..."'. Some of that will be retrospective, I know, and maybe not accurate, but it's really important.' PR02

6. Recognising when you are stuck, what to do about it and preventing it from happening

6.1 Recognising when you are stuck

Service users, their families and professionals can become stuck and not be able to move on or facilitate others to move forward in their recovery journey. Traditionally people have remained stuck in services and not been able to move on to the new stage in their recovery journey.

'when we've looked more closely at what's happening, there isn't a plan; there isn't a comprehensive plan. There's no goals; there's no... there's not really a kind of sense that they're collaboratively working towards something...It's not a recovery focussed plan and they're not recovering and both parties are stuck. The service user is stuck and certainly not gaining anything, but actually, the professional's stuck. Erm, they've lost the focus.' PR01

Being aware that all parties can become stuck is important, but this is less likely if there are clear goals and that it involves a willingness to recognise when things aren't working, a willingness to change and talk about doing things differently.

'they actually discussed things with us and talked to us. They didn't talk at us; they talked with us and like when the psychiatrist was changing my medication, he actually explained why he was doing that and why it was important, because I'd been on the same stuff for like, umpty-two years and it obviously wasn't working'. SU146

Historically, mental health services have perpetuated practices of paternalism and being risk averse, which is encouraged by the current blame culture. This can make it difficult for professionals to encourage risk taking or acknowledge when they have got something 'wrong'.

'You have to allow people to develop, you have to allow people to take risks – but it can feel pretty scary if somebody's vulnerable and certainly the clinicians feel they'll get hung, drawn and quartered if something goes wrong.' PR08

Working together to develop an understanding of the risks and opportunities on the recovery journey allows for a recognition that professionals won't always get it right, but it is about everyone taking risks and having honest conversations about what is happening and what needs to happen to move forward.

6.2 What helps people to become 'unstuck?'

Moving from being stuck to becoming unstuck can be a difficult and challenging process for everyone involved. Both service users and staff recognised the importance of having open and honest conversations to facilitate this process.

'Good care coordination... is being able to negotiate a relationship where the person can say what they think and you can, as a worker, you can make mistakes, and get it wrong, because there is that trust and respect ...' PR06

Staff member PR01 in the section above talked about other strategies that can help people become unstuck. These include reflecting on practice in order to stop and recognise what is happening, then work collaboratively to refocus goals and set a new direction.

I like them to be straight talking and very honest and open and I don't like things being done behind like closed doors or without my knowledge and they're aware of that, so they're very straight with me, whether I like it or I don't like it, at the time, I'll always go away and think about it, SU140

Service users recognise that they also have an active part to play in the process of becoming unstuck:

I think it wasn't until I began to realise: instead of things being done to me, I had to take an active part and that's when the shift happened. SU146

Recognising that individually, as a family or together as professional and service user you are stuck or are becoming stuck is the first step in making positive decisions about moving forward. It is a learning curve for everyone and it isn't always easy to move out of a place where "I/we have always done it this way....".

Even when people recognise that they are stuck, change may be resisted as it involves uncomfortable adjustment to traditional ways of doing things. Introducing a different perspective through learning and education opportunities and peer support can help facilitate this process. In order to then move forward, service users, family member and professionals need to take responsibility and act based on a new understanding of the situation.

Understanding ourselves and our actions is important for everyone and being asked searching questions to illuminate this helps to understand why we are stuck and how we move forwards.

'She was absolutely fantastic and she made a massive impact on me life because we just got to the core of a really big issue just by doing that time line...' if it wasn't for the way she worked with me and she was very approachable and very engaging, [she] just asked really good probing questions that no one had even scratched the surface of in the past. SU131

Admitting to being stuck is not always easy requiring a level of awareness and honesty to make the first step of asking for support. Fostering a culture of learning together as staff as well as learning together with the service user leads to a co production and sharing of knowledge that is potentially more powerful and more effective.

Things that help people to become unstuck:

- Working together/ collaborating
- Having honest conversations together
- Reflecting together on what is happening
- Taking responsibility and playing an active part
- Asking or getting someone to ask probing questions
- Having clear meaningful goals

6.3 Not becoming stuck in the first place

6.3.1 Taking positive risks and personal responsibility

The section above illustrates that the attitudes of the service user, family and professionals can all contribute to people becoming stuck. Family members recognise that focussing on what people are unable to do (deficit model) and protecting them from potentially challenging situations can actually have a detrimental effect.

'I think there has been a lot of cossetting in mental health and I think you know, we should be working on people's confidence; we should be working on people's self-belief; we should be helping them to identify their strengths, so we can build on them, because how do you build confidence if you keep on doing the things that's within your comfort zone?' C35

Actively facilitating people to move forward in a gradual way is important in supporting people on their on their recovery journey. It may not always be welcomed; however, this research has shown that supporting people to step outside of their comfort zone can lead to a positive experience and engaging with daily life.

'I think that's what my care coordinators do with me. Put me at risk. Because I said, like, I didn't want to travel on public transport. But now I've got a concessionary travel pass and I do that. It's fine.' SU145

Taking positive risk was not well understood by service users, carers or professionals. It was also viewed as difficult to do because traditionally mental health services have been set up to minimise risk. In order for people to step outside their comfort zone our research showed that levels of personal responsibility need to be discussed, negotiated and mutually agreed in response to risk. People told us that having and taking responsibility is central to the recovery journey and consideration needs to be given to how some responsibilities might be maintained through times of being unwell.

'You're responsible for yourself and we're responsible for helping you to make the best of your life and overcome your problems. I think we are far too quick to take responsibility away from service users. I can't see how recovery can happen without them taking it back...' PR08

6.3.2 Facilitating not fixing

'I felt involved in the process, it wasn't just her sitting and saying this is what I can do and this is what the service is going to provide, it was about 'look, what do you want''. SU126

they supported me all the time. They... They gave me... They signposted me to what I needed to be looking at and... When I saw them, they would ask how I was getting on. But, still, they didn't do everything for me, because that wouldn't have helped. SU125

Service users told us that when care coordination was recovery focussed, the care coordinator took a step back and became a facilitator of the recovery journey. This differs from the traditional expectations of professionals as a fixer of symptoms.

People who were making steps towards recovery recognised in retrospect that they needed to take responsibility and not have everything done for them, even though this may have been easier at the time. Everyone was working together with recovery in mind.

6.3.3 Signposting to information and peer support

Service users and carers told us that a key part of facilitating recovery was being signposted to services that could offer peer support

'hen I became well enough I did start getting involved in some local services ...where they deliver support and education for service users... so I have started like doing a bit of peer support.' SU126

Professionals play an important role in signposting both service users and carers to services which offer peer support and educational opportunities. Sharing stories and hearing about other people's recovery journey gave people personal hope and encouragement about their own recovery. For

some people their positive experiences in peer support led to a more formal volunteering role offering peer support to others.

'that would be brilliant if you could get a database of people who are interested in talking to each other about their stresses in their life to do with, and whether they have had success, that's the most important thing.' C33

Peer support groups did not suit everyone so the care coordinator, service user and or the carer need to work together to determine what will work best for the individual.

Providing people with information about both mental illness seen as an important part of supporting recovery for both service users and their families.

'I was told when I was diagnosed that it was very, very important that my close friends and family were very boned up about [mental illness] and how they should support me in times of mania and depression and also times of being well but not too well that I tip into mania.'
SU104

Service users told us that information that is provided should be accessible to them and that care coordinators need to check that it is understood. Professionals suggested that the information could be used more effectively to establish clearer expectations of care coordination and the care coordinator.

You know, I think there's a lot of information we can give to people up front, which will, I guess, help manage their expectations; patients and carers about what care coordination is; how long someone is likely to be care coordinated for and what goals will be identified and aimed for. I think there's a lot of information that we can give that we're not giving now.'
PR04

7. Recovery can be possible through care coordination

When care coordination works well and is recovery focussed, everyone is willing to learn from each other and recognises the contribution that each person can make. Professionals want the best for the service user and carer, but sometimes this doesn't happen. Everyone means well, but sometimes they are ill-informed. Recovery focussed care coordination is not about coming up with the right answers, but about a commitment to working and learning together.

'I just feel as if, like, everybody is just wanting the best for me, you know. And that... they're all working for me and... And trying to... Trying to make me to the best I can be, you know. So it's... It's working well, like. It's champion.' SU148