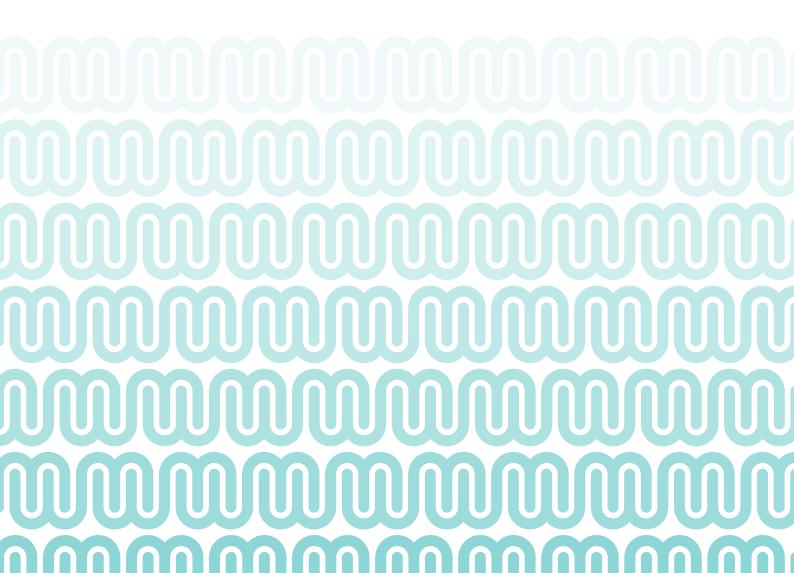


Service users and carers information



Care planning How people with lived experience and their friends and family want to be involved in developing care plans

What they should contain, what they should look like

Mental Welfare Commission for Scotland August 2019

The following paper reflects the voice, experience and opinions that people with lived experience (and 'carers') provided for the Commission around their work on Good Practice in care planning. It will inform our work and future reports on this subject but is not, in itself, an expression of the Commission's views on this area.

Service user and carer groups may want to use the stories and opinions gathered, but are requested not to state that they are an expression of the Commission's policy or opinion.

We are very grateful to all people with lived experience and their friends, relatives and/or carers who have contributed their experiences to this project. These are essential to the work we do and our philosophy of involvement and participation.

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Summary

What we were asking

We were consulting people about what they wanted in their care plans and how they wanted to be involved in drawing up care plans.

Who we asked

We met with 148 people in 14 focus groups from across Scotland. These meetings involved almost as many carers as people with lived experience of mental illness, and also included some people with dementia, autism and acquired brain injury.

What we found out

Most people had not seen their care plan, and very few people had been involved in creating one; but they did feel that they should have ownership, and a copy, or access to a copy, and help from an advocate or supporter to be involved.

Some people felt that they were best placed to write their own plan.

Some people were concerned that what's in a care plan is not always what they end up getting.

It should be multidisciplinary and electronically accessible to all appropriate staff.

It needs to be accurate.

It should contain information about:

- Who to contact, where to get information
- Who we are
- Safety and risk
- What we are like when we are ill and what we need
- How we are progressing
- Treatment plans
- Our views
- Our hopes and dreams
- Medication
- Discharge
- Respect
- Future happiness
- Relaxation
- Personal care
- Carers' views
- Culture
- Finances
- Activities
- Confidence
- Advocacy
- Allergies and health conditions
- Approach

- Children
- Religion
- History
- Crisis intervention
- Keeping well
- Recovery star
- Capacity
- Advance statements
- Assumptions of recovery.

Suggestions on format included including picture and photos, making it accessible, jargon-free, and individualised.

Some of the points about how to communicate with people with lived experience and involve them in their care plan included:

- Family involvement most people felt carers were an important part of the solution and discussion
- Respect and attitudes
- · Being listened to
- Being known/building relationships
- Being genuine
- Seeing the person
- Giving enough time
- The right body language
- More than a job.

Introduction

In 2018 the Engagement and Participation Officer was asked to find out from people with lived experience and their friends and family how they would like to be involved in care planning, what a care plan might look like and contain and any other issues to do with care plans.

This was to help inform the development of a Good Practice Guide being prepared by the Commission for 2019.

The meetings, prompted the submission of a paper by a person with lived experience of her opinions of care planning and provision, helped provide the basis of an introductory talk to a seminar on care planning in October of 2018 at which many of the issues were discussed by practitioners and some people with lived experience and their friends and family.

The notes of the meetings have now been compiled into this report of our consultation.

We carried out the consultation over the summer, autumn and winter of 2018 in:

- Aberdeen Aberdeen Carers Group
- Angus (Arbroath) Angus Voices
- Angus (Kirriemuir) Kirrie Connections
- Argyll (Mull) Mull Safe and Sound
- Argyll (Islay) Islay Link Club
- Dumfries and Galloway (Dumfries) UCI/Kaleidoscope
- Dundee Dundee SUN
- Edinburgh (Stafford centre) Edinburgh carers support group SIM
- Fife (Kickaldy) Bipolar Fife
- Glasgow (MaryHill) Restart
- Highland (Fort William) Lochaber HUG/ Cuthrum SIM
- Highland (Inverness) Bipolar Highland
- Highland (Skye, Broadford) Rag Tag n Textile
- Highland (Skye, Portree) Rag Tag n Textile

This involved 148 people, most of whom were people with lived experience of mental ill health; but we also involved almost as many friends and family (carers), some people with dementia and acquired brain injury, and a small number of workers (mainly advocacy workers).

Knowledge of care plans

It proved impractical to find out exactly how many people had a care plan, but it was very clear that most people had not seen their care plan, very few people had been asked to be involved in the creation of their care plan, and many people had very little idea of what a care plan was.

General comments about care planning

During our conversations people made some general comments about care plans in some way, a list of dos and don'ts.

These are listed according to how frequently they were mentioned.

Ownership and location

There was a very clear feeling that care plans are about people with lived experience and should belong to them, or, if not belong to them, then they should have their own copy which they can keep where they want, and certainly see whenever they want.

There was, however, some worry about what people might do with very personal information if they have a copy of their care plan but are not in a state to look after it.

They need to deliver

Some people said that sometimes they were involved in the creation of care plans and happy and relieved at what was in them, but that they did not end up getting what the care plan said it would do. If the care plan does not provide what it says it should, then people will lose faith in it.

"He has had that many people; nothing happens and they are repeating it again and again. They will never get him to participate in a care plan now. They need to get it right so that it doesn't happen again."

Help from advocacy

The support an advocate could provide when drawing up a care plan was remarked on and said to be valuable. Sometimes a supporter of some sort might also be helpful in involving people and helping them understand what is happening.

"You need to know the person a bit before first; I have autism and maybe need to have a supporter in the meeting or an advocate. Check that I understand at different points."

"Help to articulate what you want to say from an advocate; they are not judgemental, they don't tell you what to say."

Access

People said that it would be good if care plans could be accessed electronically by care and health professionals when they need to. This could include emergency

services and others. It was mentioned that sometimes health staff were not aware of important information in care plans that they should have been.

Lived experience contribution

A few people said that they had made major contributions to their care plans, and that they felt that in some circumstances they could be mainly, or entirely, written and constructed by the person with lived experience rather than the care professionals.

Review

People said there was a need to regularly review and update care plans.

"I asked to see my consultant as I hadn't seen him for two years, so they are going to get me an appointment with a new one. In these circumstances a care plan will be out of date."

Accuracy

People said that, if a care plan is to exist, then it needs to be accurate. A number of people commented on seeing inaccurate information in their care plans.

"It had information that had nothing to do with me, and which was untrue. It can be weird to see pre-ticked boxes."

"In my experience, whenever I have been discharged they have never spelt my name right, and have got my medication wrong, and I have had no follow up. You can feel abandoned."

When people do not participate

It was said that however good a care plan is, that if a person does not want to participate, or is not well enough to engage, then it will not be able to fulfil its purpose.

"You can have all the care plans in the world but if your relative will sign up to everything but not do anything they have signed up to, what is the purpose?"

Multidisciplinary

People said that these should be multidisciplinary documents.

What should be written in a care plan

The following table represents the information that people with lived experience, and family and friends, think should be contained in a care plan. The themes described start from the most frequently mentioned to the least frequent.

Who to contact, where to get information	People were keen to have a record of: who would need to be contacted on their behalf and about their care; who they have given permission to be contacted and informed about their treatment; and their views on confidentiality. They also wanted key organisations that provide, or might be able to provide, support to be included; and a record of people who could be contacted in order to add useful information concerning their care. They wanted information and addresses and contact details about next of kin, etc, to be included.
Who we are	People wanted a record of what sort of person they are when they are not ill, their quirks, likes and dislikes, what their lives are like, and how they cope at home.
Safety and risk	People wanted to be sure that they would be kept safe if necessary, but they also wanted to be asked about their views on risk, some people are keen to have as much freedom and autonomy as possible and others want to be sure that if they need to be protected that this will be done in a gentle and respectful way. They wanted these aspects of their care and their views on them recorded.
What we are like when we are ill and what we need	People wanted a record of what they are like when they are ill, what the triggers for their illness are, the sorts of things they worry about and need dealt with when they are ill, and elements of their home life needing taken care of, such as pets. They would also like notes of what they are and aren't able to do at such times, and how they are likely to behave. They also wanted a description of their illness and diagnosis.
How we are progressing	People wanted a record of what they wanted to achieve during their stay, or in their life, and what their goals are, from their point of view. They also wanted a record of, and measures to say, whether they were achieving their goals and recovering.
Treatment plans	People wanted a record of how they were going to be treated and how they themselves wanted to be treated. They wanted to be sure that the treatment was

individualised, and that the medical treatment did not obscure who they were and what they want. Our views People wanted to be able add their own personal information and statements to inform the care plan and people treating them. People wanted a section that detailed what their hopes, dreams, wishes and desires are. Medication People wanted a section about the medication they were taking which also detailed its effects and purpose, and their views about taking it, including any medication they felt didn't work well. Discharge People wanted details included about what would happen when they were discharged, and how it would be managed. They were especially keen to know who would visit them, where they would be referred to, and how it could be a positive experience. Respect People wanted the care plan to be written in such a way that it implied respect for them. Peuture happiness People wanted mention of things that would happen in the future that they could look forward to, and which would help them believe there is a possibility of recovery. Relaxation People wanted details of the sorts of things that help them relax and how this will be provided. Personal care People wanted mention of how they manage their personal hygiene and care, and how they want helped with this if necessary. Carers Views People wanted a section that detailed carers' views and knowledge and what their role is. Culture People felt that there may be aspects of the culture that they are part of that could usefully be recorded to make their care appropriate. Finances People wanted any problems with managing and arranging their finances and help that they may need recorded. Activities People wanted a record of the activities that they were doing, and what was available to them.		-
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Confidence	People wanted attention paid to the small things about life that improved such things as their confidence.
Advocacy	People wanted a record of if they had an advocate and who that was.
Allergies and health conditions	People wanted a record of any allergies or health conditions they have.
Approach	People wanted a record of the best way they should be approached in different situations.
Children	People wanted any relevant details about their children, and their needs regarding them, recorded.
Religion	People wanted a record of any religion that they followed.
History	People wanted some of their history to be recorded.
Crisis intervention	People wanted a record of what and who will help in crisis.
Keeping well	People wanted a record of the sorts of things that they do to keep themselves well.
Recovery star	This was mentioned for inclusion.
Capacity	People wanted a record as to whether they had capacity to make decisions.
Advance statements	People felt that many of the things they might put in an advance statement might appear in a care plan.
Assumptions of recovery	People wanted care plans to be written from a perspective that recovery is expected.

Presentation of care plans

The following are the ideas people had for the layout, structure and presentation of care plans written in the order of frequency with which they were mentioned. With the most frequent being the first mentioned.

Pictures and photos	People said that they would like a photo of themselves and maybe their family, so that people could recognise them. They also said it would be good to have some script around this describing their likes and dislikes, and themselves as people. They also felt that for some people, who struggle with reading, that pictures and drawings may be better ways of describing their care.
How we would like it	People said that they should be asked how they would like their care plan to be presented and that it should reflect those views.
Accessible and jargon free	People said that care plans should be written in a way that was easy to understand and contain a minimum of jargon. They should be simple and maybe written in sections and stages.
Individualised	People said that care plans should be person-centred and individualised.
Mind maps	People felt that mind maps, speech bubbles, diagrams and flow charts might all be good ways of presenting their care in a way they would understand.
All about me	People said that we should learn from the 'All about me' sections of care plans that are often used for people with learning disabilities or dementia. These should be at the front of the care plan, and have a photo of the person and a description of their likes dislikes.
informal	People said that formal and complicated care plans were intimidating and sometimes made them respond back in a formal way. They wanted care plans to be informally presented.
Clear and concise	People wanted care plans to be written in a clear and concise way.
Traffic lights system	People liked the traffic light system for recording risk.
Various formats	People said that different people had different needs for the way that their care plan is written; a professional

	may have a need for much more complex information about medication than a person with lived experience and therefore there may need to be different versions of care plans.
Not too clinical	People did not want overly clinical care plans.
What to do	Some people resented seeing instructions and lists of things that they needed to do and which had to happen, but couldn't think of an alternative.
Colour	People said that if someone wanted a care plan on pink paper, then they should have it on pink paper.

How staff should communicate with people with lived experience and their friends and family, and how this can encourage them to get involved in care planning

Most frequently mentioned

We discussed both communication and involvement but there were so many parallels to the conversations that they have been combined into the following section of this paper.

Those areas which were raised by seven to 27 people, and in four to 10 groups included, in order of frequency:

- Family involvement
- Respect and attitudes
- Being listened to
- Being known/building relationships
- Being genuine
- Seeing the person
- Giving enough time
- The right body language
- More than a job

Family involvement

Many people, especially family members, but also people with lived experience, talked of the value and need to involve carers in people's care, and in drawing up care plans. Some people with lived experience did comment on some family members intruding on their lives too much but, in the main, people felt carers were an important part of the solution and discussion.

"....then he told me the whole plot which made sense, but the first premise was wrong. From that it can all follow logically even though it seems crazy. He was relieved there was some logic.... I can tell the staff that this is not a good room for a CPA because he doesn't like a red room and so on. I can see the signs now. If people can take more time to understand what is going in in the person's head. If families could realise that they could play a bigger role in understanding, and helping staff understand. Staff often don't understand."

Carers often had detailed knowledge of people with lived experience in ways that professionals did not, and people felt that it was important to listen to them and their opinions.

"Talk to families and carers; often the person who is distressed will clam up if they are approached wrongly or will kick off. Family and friends can be needed at these times."

However, on some occasions family members felt that their contributions were dismissed and ignored, and that they were seen as part of the problem. On occasion confidentiality was ignored with harsh consequences.

- "....my experience and reality is that I am treated by the system as a problem getting in the way and 'leave it to the experts'. Part of it is the confidentiality, but they only get the picture which is the one that has erupted. Your ideas of what support and help the person needs, and what would help them recover themselves... are treated as though you are holding them back."
- "...the hospital won't talk to me... I spoke to them and they used it, and locked her up for longer as a result, and she was told it was me that told them. They needed an excuse to keep her longer. It was totally the wrong thing to do..."

Some carers had had good experiences, which often improved the longer they had to get to know professional staff. We also heard that in the treatment of people with dementia it was easier, and routine, to involve family and friends in ways that did not appear to always occur with people with a mental illness.

"I find the psychiatrist he is under will speak to me. Sometimes I feel they are trying to pacify me, but they do listen to me and do treat me well; they do try to explain, but I don't find it is always enough."

"...If they put a care plan in, it would be good if they update the carers to say if any progress has been made. You have to be pushy to be kept informed. They are pretty good now."

Respect and attitudes

People said that key to the involvement of people in their care plans is the way that staff communicate with them. They should convey respect and give people with lived experience dignity.

Sadly the majority of comments, from both carers and people with lived experience in this area, was that people expected to be patronised and dismissed, which did not give people a great desire to participate in their treatment.

"They talk to him like he was a six year old child."

"They should not bring out their diary as if to say 'let's stop talking."

"They should sit and listen and not just say 'This is what you need."

"...and she said 'We don't deal with this, you need to say what you want but I have an appointment in five minutes' he felt very let down."

"They should be civil whatever illness we have; they should remember we are human – they need to know we have feelings, and listen to what we say."

"They don't get compassion or empathy, and are made to feel like a fraud or a time waster."

Being listened to

People felt that key to involving them in their care and in providing treatment was taking the time to listen to the person. If people do not feel they are listened to, then it is hard for them to want to participate.

"I like to say not very much; if they talk too much you can get more distressed – sometimes you just need people to listen and be with you, and then talked to."

"If you feel you are not listened to, you get angry and frustrated and kick off, but they have got it wrong they need to see the distress."

Being known/building relationships

An important element of engagement occurs when people are able to take the time to get to know a person as a person, to spend time doing things they like with them, and seeing them as individuals. This is often much easier when someone has had some continuity in their care and know their helpers well.

"In hospital have something that reminds them that they are not just ill. My mum didn't feel she saw anyone. There were no activities, she was alone in her room and scared to go out: other people can be scary. Arts and gardening were only for people long term. She was there for three weeks; they need to learn who they are again. You can get conversation if people are doing things together, like knitting together and finding what the person likes – this can be how you make a care plan."

"They knew me well which made a big difference, as everyone is different."

Being genuine

Having people who are 'genuinely' there for them and who build a human connection can make it much easier to have conversation and discussion and participation.

"It is easier to speak to someone who gets what you are going through and has maybe been through it themselves. Not something that they have learned."

Seeing the person

People had a great need for staff to be able to see them as a person, to see behind the mask they sometimes put up and get to the 'real' them. They can struggle to communicate and be frightened of doing so and need people to reach out to them.

"That part where you say 'I am fine' and they instinctively know things are not right. I instinctively know what to say to get out of hospital. I know how to tick the boxes. You don't tell truth."

"You don't tell the truth; maybe it's guilt, or fear of opening up and not being able to stop, or being rejected, or worry that if I say I need help they will say I cannot look after my kids."

"To treat you like a normal person; they can speak to you like you are an alien. I had a nurse who spoke to me like a person – she was a breath of fresh air."

Giving enough time

In terms of both treatment and being willing to participate in care planning, people need time given to them. It can be hard to open up and trust a person, and this can be necessary if someone is to start an intimate conversation about their care.

- "...it takes six to eight weeks before you can really open up."
- "...there needs to be time, and no ultimatums. It can take weeks to build trust."
- "...he took time with me, and this has stopped me being admitted since then."

The right body language

The body language, expression, and posture of staff can play a big part in helping people decide whether to speak, or trust them to participate in their care. Equally the body language of some people with lived experience can be confusing, and may mean that people assume that they do not want to talk when in fact they do.

"Coming down to that person's level; taking their hand."

"My eye signals make people feel like I am not telling the truth – but I evade people's eyes so that they don't know how dreadful I feel."

"It's what people say to you: someone said 'You would never know you suffering depression because you are always smiling.""

More than a job

Another aspect of helping people want to participate and communicate is if they feel that the staff who are working with them do so because they want to, that this is not

just a job for them. People can be very sensitive and worried that they are seen more like commodities, getting beyond this anxiety can help build a relationship of trust.

"To not have it as their job. Some of them are, like, after ten minutes, looking at their watch and you know it is just their job, and it is, but it should also be a vocation, and that you are not just another patient."

"If I phone my doctor tomorrow in a mess I would see him the next day."

Less frequently mentioned

Areas of discussion around communication and participation raised less frequently (by between 7 and 4 people in 4 to 2 groups were:

- Compassion and empathy
- Reaching out
- Not being able to participate
- Confidentiality
- Being non judgemental
- Establishing trust
- Not being rushed or grilled
- Not being stereotyped

Compassion and empathy

People very much wanted a dignified and empathetic response when with their helpers. They feel this is important both for their treatment and in making them want to participate.

"What people really, really, want is a caring compassionate response; that should be in every practitioner's gift; they should go into the job for that reason."

Reaching out

One of the paradoxes of mental illness is that at the very point people need help, they can withdraw from help and need people to reach out them. They may need access to be made easy, for instance by email (which can be difficult in the NHS), or for people to seek them out. Often people lack the ability to come forward themselves, and need people to come to them.

"When we are ill we tend to curl up and hide away."

"When I was in, I was left for a week; I just couldn't talk. There was little effort made to include me and other patients."

"When I am in hospital, especially if I am on a downer, it would be really helpful if the named nurse would come and find me, rather than finding me as an inconvenience that they have to see – the lack of staff can be a huge problem – last time I had 15 minutes of named nurse time in ten days."

Not being able to participate

While talking about care planning, a number of people said that there are times when people would not be able to participate in drawing up care plans. This could be especially soon after admission to hospital. People said that in these circumstances, it may only be later on that they are able to participate in any meaningful way in their

care and care planning, and that sometimes, especially when they lack capacity, other people such as family may need to be involved.

"At that point you are not in the right frame of mind but when you are they should review it with you – a rough one on admission that they update later with you."

"You need it to happen while a person still has capacity but it will not always be the case and then it is important to engage with families: what do they like to do? What is their favourite thing?"

Being non judgemental

Important for communication, treatment and willingness to play a part in treatment is to be treated in a non-judgemental way by staff.

"Some you know that are really listening and you know that they are not judgemental and some are not."

Establishing trust

Underlying many of the wishes people have for when staff communicate with them, and try work alongside them, is establishing a sense of trust with them.

Not being rushed or grilled

People said that if they are to be expected to participate in care planning, then they need to be sure that they will not be hurried when answering questions, or feel like they are being interrogated.

Not being stereoptyped

Some people are used to being labelled and stereotyped, and certain behaviour and abilities expected because of their diagnosis. If staff wish people to want to participate in care planning, they need to guard against coming up with stereotypical assumptions about them.

"If you already have a diagnosis – they can stereotype – look at the whole person and the broader picture – look at why you are doing what you are doing."

Also mentioned

Other ways of helping people participate in care planning but mentioned by three people and less and in three groups and less are recorded below.

The environment that could be provided for people when helping them with care planning	 People wished to see a: Homely safe space that is private in which to participate. They did not want too many people involved and mainly preferred to work with just one person. They should feel safe and be made comfortable by being offered such things as a cup of tea.
Ideally staff would approach people in the following ways	 People would like to be approached with: Honesty. Patience. In a calm manner without stress being passed on. With gratitude and appreciation for the person's willingness to participate. They should be approachable, gentle and friendly. They should speak at the persons level, be interested and willing to share aspects of themselves.
What they should not do	 People wanted staff not to come with: Assumptions about them. Not to have a stigmatising attitude. Not to use jargon. Not to dismiss their opinions. Not to ask them to do things they are not able to do. To be aware of the tone of voice they are using. They should not give ultimatums. They should ensure note taking records lived experience and carer opinion as accurately as staff opinion. They should not see this as just procedure but a chance to make a difference. They shouldn't 'push too hard'.
What they should provide	People wanted to feel a sense of:

Continuity makes it much easier to participate. As a care plan develops it should be reviewed with the person with lived experience. • They should have a debrief afterwards to check how they are feeling. They should feel included in the process and feel they are working 'alongside'. They should be allowed to make mistakes. They should be presented with choices. They should get shown what is written as it develops. They should have breaks. They should have feedback about the effect the care plan has had. Staff should be aware People wanted staff to be aware that: that They can feel guilty about being there and a burden to the health service. • They can struggle to communicate and come up with the words they want. They can feel detached from the situation and find it hard to participate. They may have been denied help and find it hard to participate as a consequence. They may be used to being asked last when it appears that most decisions have been taken. They want staff to be trauma informed and to use this to influence their interactions. • That they are a part of a community and that this needs to be taken into account. They should understand the complexity of some of their situations and lives. Understand mental illness thoroughly. Know that they may feel great fear about what is happening due to past experiences. Things staff might like to People suggested that staff ask: do What their interests are. • Ask them how they want to be involved in a creating a care plan. • What their strengths are. How they like to be approached by staff.



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