The Winding Road - Final Report

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April 2021

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Background

This is the final report of what has turned out to be an eighteen-month project. The first section refers to the Carer interviews only, and the second section refers to those with lived experience of mental ill health.

The SUN Network and Rethink Carer Support are to varying degrees voice organisations, helping people speak up about their experiences of health and social care. People's views are collected and reported in several different ways, and for The SUN Network in particular, this often takes the form of evaluating people's experience of a single service.

The Winding Road project goes beyond these more traditional approaches to start and finish with the service user wherever they are in their 'recovery journey' It is truly person-centered rather than service centered, in that it engages with a group of people with mental health conditions, and people who are carers of those with mental health conditions, and simply follows their journey over time. It recognizes that people and their families may or may not be receiving services at any given point and that from their point of view the journey of seeking help is just as big as the journey of using it.

The project has the following key characteristics:

- It is a joint effort between The SUN Network and Rethink Carer Support Cambridgeshire and Peterborough
- It has grown out of what people have been telling us about their experience of living with mental health conditions over the past 2 to 3 years, above all, that access to mental health services remains problematic
- It checks in with selected groups of people with mental health conditions and carers three times over an 18-month period
- It involves interviewees in various ways of feeding back results and suggesting actions
- It offers interviewees a chance to reflect on their situation over time in a structured way and to generate ideas for a way forward

Aims

The overall aims of the project are:

- To examine people's experience of mental health and mental health services over a one-year period. As a result of Covid-19, this period has been 18 months
- To explore whether people's mental health and ability to live life to the full improves during this period
- To cast some light on whether there is any correlation between people's mental health needs at a given point and the level of mental health services they are getting
- To compare perceptions of needs and services between people with mental health conditions and the separate group of carers
- To highlight gaps in services as well as positive factors in people's recovery thus informing local service development
- To offer people a chance to reflect on their progress or lack of it on three occasions, and to for them to feel that they are influencing service developments

The project has certain limitations. It does not claim to have selected samples of people with mental health conditions or carers that are representative of this whole population. It does not attempt to prove any causal relationships between people's levels of mental ill health at any given point and the presence or absence of services.

Rather, it aims to amplify people's experiences by presenting it in a new way, following people over time and presenting a combination of quantitative and qualitative data. The authors believe that individual experiences, accurately and sensitively reported, can be a vital source of learning for service providers whether or not they are typical of all.

Carers Report – Jonathan Wells

Method

20 carers of people with mental health conditions were identified using the mailing lists of Rethink and Making Space, together with some recruited via Cambridgeshire and Peterborough Foundation Trusts (CPFT) Cambridgeshire and Peterborough Assessing Managing and Enhancing Outcomes team (CAMEO) carer support group. These are **not** carers of the group of service users interviewed and reported on separately. The carers' interviews are about **their perspective on the situation of their loved ones.**

The carers were interviewed by Jonathan Wells in a setting of their choice. At stages 2 and 3 interviews were by phone or on zoom because of Covid restrictions. At the start people were told about the project as a whole and asked to commit to the three interviews over the full year (which turned out to be 16 months). It was explained that any information held would be kept confidentially and that any information included in reports would not be traceable to them. It was stated that direct quotes might be used in reports but would be unattributed.

A semi- structured interview was used in each case, using a standard questionnaire which reflects the issues that people have previously expressed as important to them. See Appendix 1. (An example of this is the equal weight given in the questionnaire to formal mental health services and to other factors in someone's life when looking into what might help). The same questionnaire was used for interviews with people with mental health conditions and with carers.
The interviews allowed space for interviewees to comment on any aspects of their loved one's overall situation or care that they felt was relevant.

Stage 1 interviews took place in August/September 2019, stage 2 in March/April 2020 and stage 3 in January 2021.

Characteristics of Subjects and Interviewees

At the start, the ages of the subjects ranged between 20 and 68, with the average age being 37. Eight of the 20 subjects were in their 20s.

The gender of the subjects was 13 Male, seven Female and 0 'Other'

The ethnicity of the subjects was one Asian, two Other European and 17 White British.

The sexuality of the subjects was one Bisexual, three Not Known, two Preferred Not to Say and 14 Heterosexual.

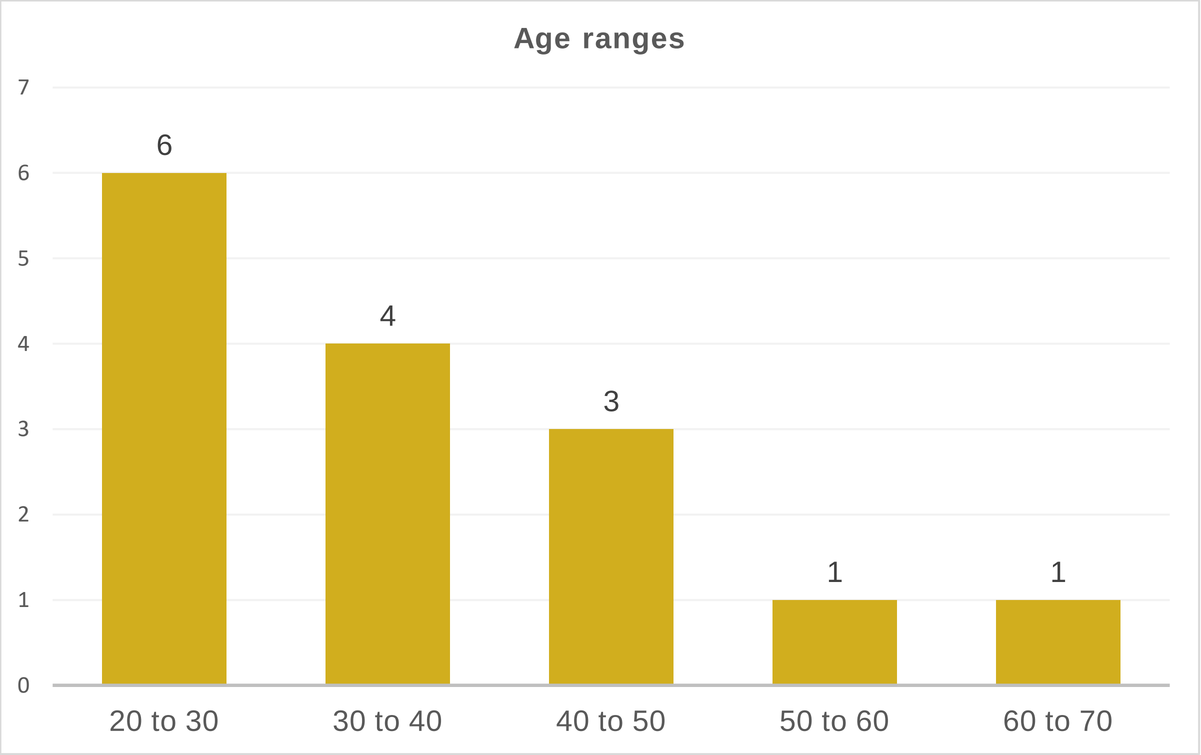
The geographical location of the family by District Council area was 12 Cambridge City, three South Cambs, one East Cambs, three Huntingdon and one Peterborough.

The mental health diagnoses were wide ranging. They included schizophrenia, other psychoses, bi-polar disorder, borderline personality disorder, socially avoidant personality disorder, agoraphobia, depression, anxiety, OCD, eating disorders, attention deficit hyperactivity disorder (ADHD), and autism spectrum disorder (ASD). Sometimes the interviewee was not sure if the diagnosis was tentative or definitive. In many cases the subject had more than one diagnosis, either in succession or at the same time.

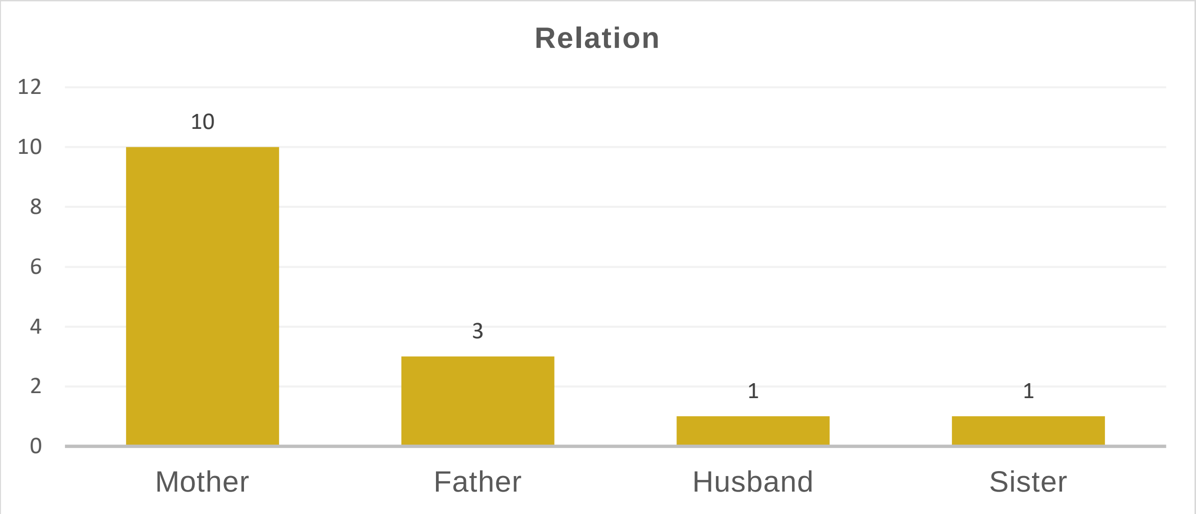
Amongst the carers, the primary interviewee was Male on five occasions and Female on 15. The primary interviewee was the Mother 13 times, Father three times, Husband twice, Wife once and Sister once.

At the end, the number of interviews had reduced from 20 to 15, so the group’s characteristics had slightly changed. The predominance of people with schizophrenia or borderline personality disorder had increased.

The age breakdown of the people with mental health conditions at the end was as follows:



At the end, the carer’s relationship to the person with a mental health condition was as follows:



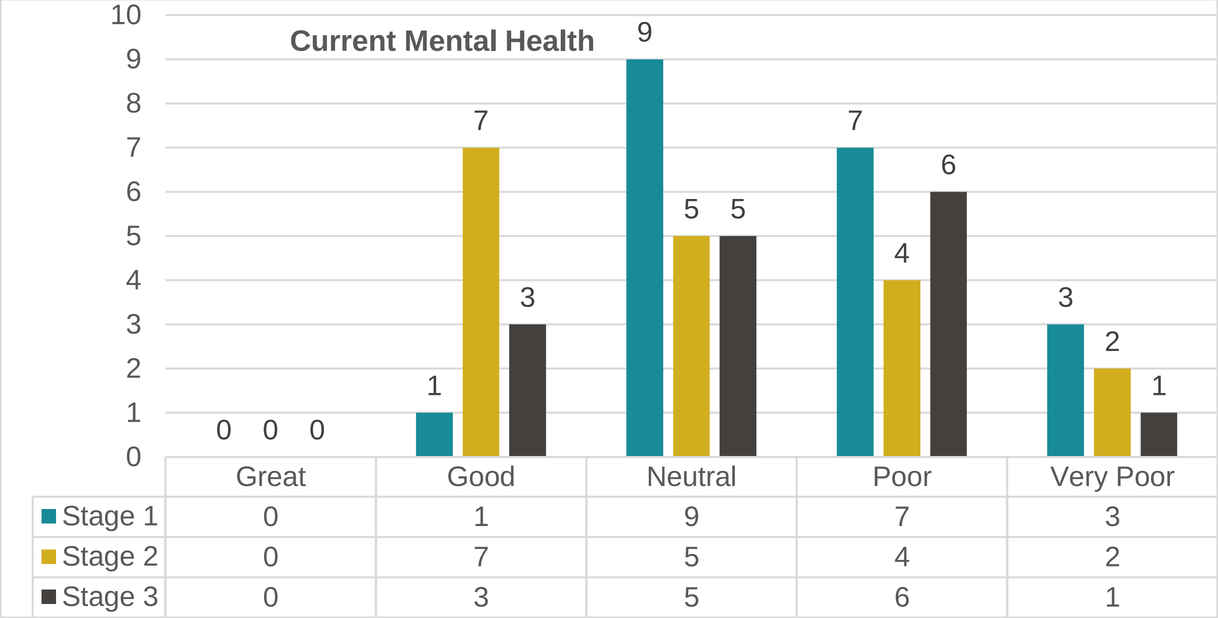
At the start, nine people were under the care of CPFT and 11 were not. At the end, nine were under the care of CPFT (Locality Team, CAMEO and Personality Disorder Community Service), and six were not.

Quantitative Data

This final report shows how over the 18 months, scores of the five questions about how the cared for person was getting on varied.

Current Mental Health

Carers were asked first to rate the current mental health of their loved one, focusing on symptoms, on a scale of:
Great, **Good**, **Neutral**, **Poor**, or **Very Poor**



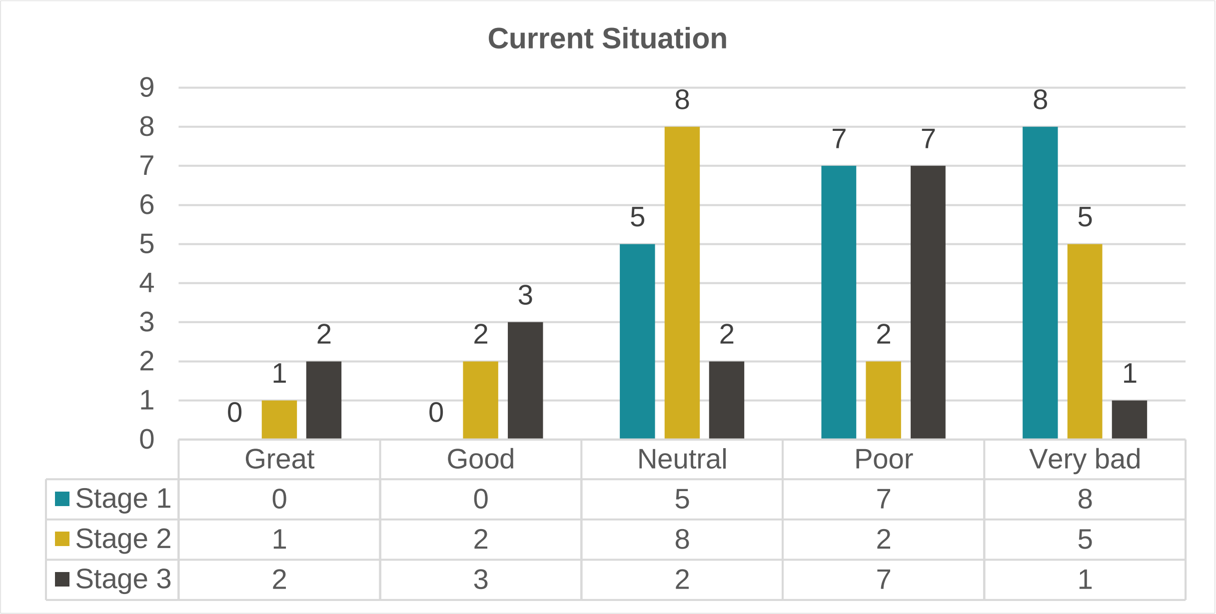
	Great	Good	Neutral	Poor	Very Poor
■ Stage 1	0	1	9	7	3
■ Stage 2	0	7	5	4	2
■ Stage 3	0	3	5	6	1

On current mental health, five of the 15 people rated better at the end, three worse and seven about the same. All of those who were ‘the same’ in their mental health from beginning to end had mental health as seen by their carer as ‘neutral’ or worse.

The person’s mental health tended to improve between September 2019 and April 2020, but tended to get worse somewhat between April 2020 and January 2021.

Current Situation

Carers were then asked to rate their loved one’s situation and to what extent they were living the life they wanted for themselves, on the following scale:
Great, **Good**, **Neutral**, **Poor**, **Very Poor**



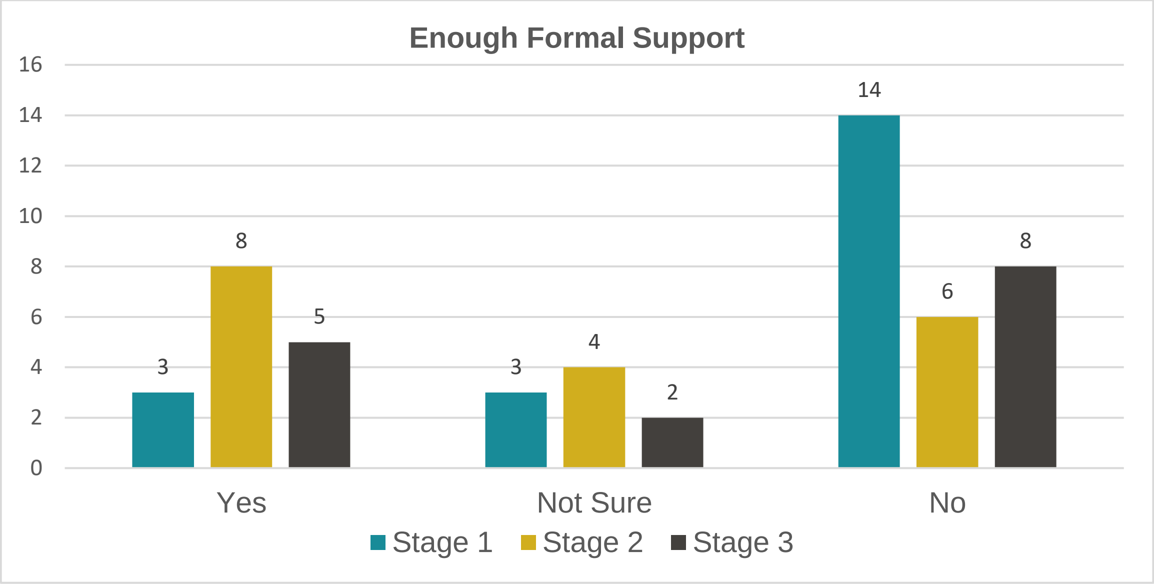
	Great	Good	Neutral	Poor	Very bad
■ Stage 1	0	0	5	7	8
■ Stage 2	1	2	8	2	5
■ Stage 3	2	3	2	7	1

On current situation, eight of the 15 people rated better at the end, two worse, and five the same.

The person’s social situation tended to improve between September 2019 and April 2020 but slipped back somewhat between April 2020 and January 2021.

Enough Formal Support

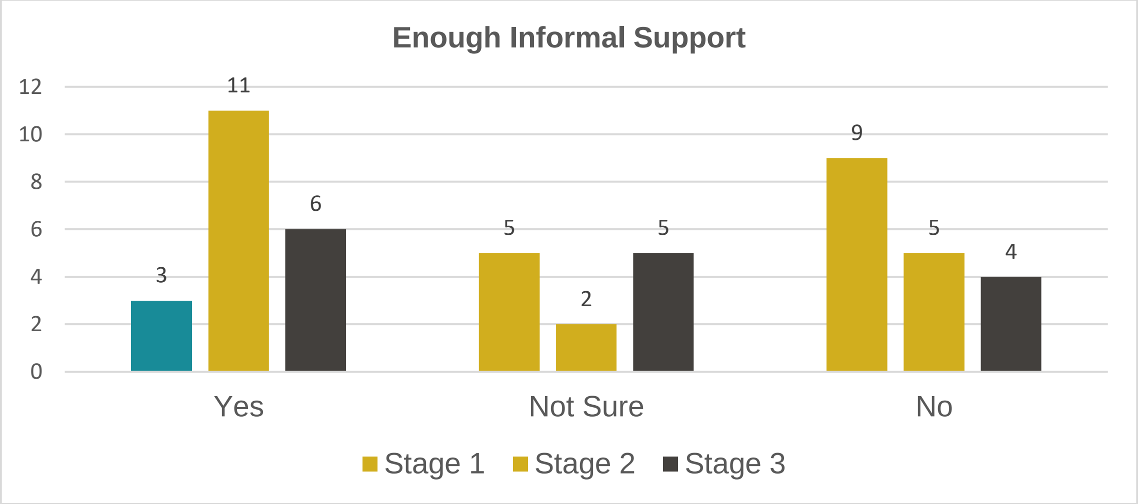
Then carers were asked whether the amount of publicly funded help their loved one was currently getting was enough. They were asked to rate this either **Yes**, **No** or **Not Sure**.



The carer's view on whether their loved one was getting enough help improved at first but then slipped back somewhat.

Enough Informal Support

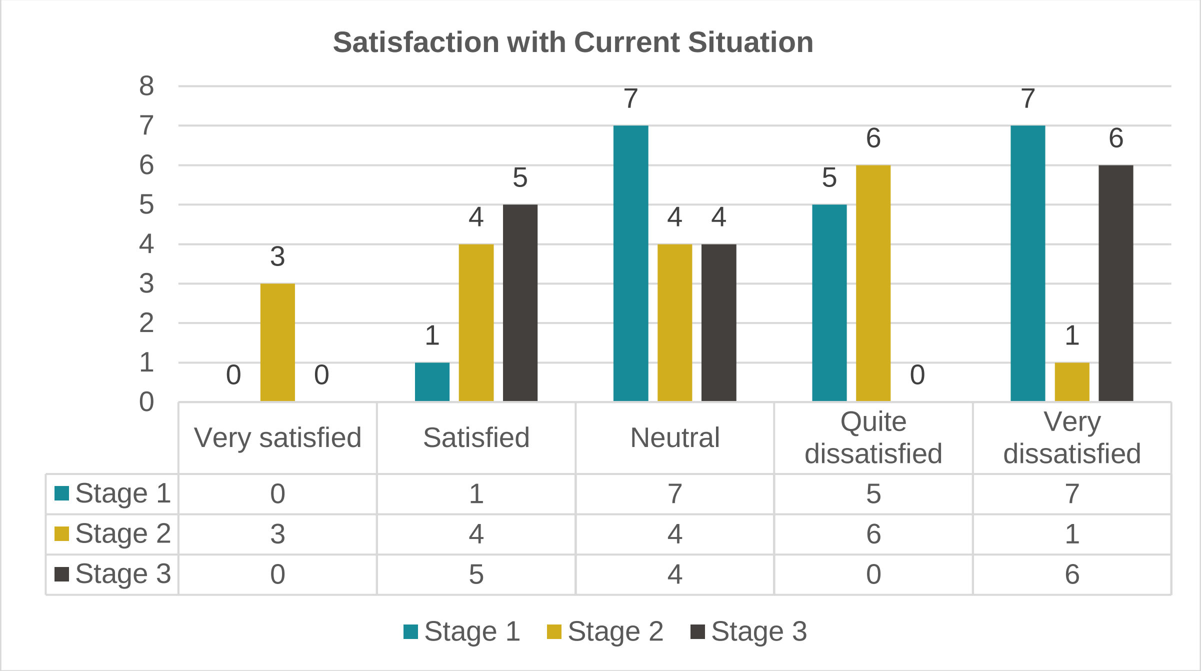
After this question, carers were asked whether they felt their loved one had enough support from other sources to enable them to progress on the same scale of **Yes**, **No** or **Not Sure**.



Again,the carer's view on whether their loved one was getting enough informal help improved at first but then slipped back somewhat.

Satisfaction of Current Situation

Finally, as a way of summing up, carers where asked to rate their level of satisfaction with the current situation for their loved one and themselves, on the following scale:
Great, **Good**, **Neutral**, **Poor**, or **Very Poor**



	Very satisfied	Satisfied	Neutral	Quite dissatisfied	Very dissatisfied
■ Stage 1	0	1	7	5	7
■ Stage 2	3	4	4	6	1
■ Stage 3	0	5	4	0	6

On carer satisfaction, five of the 15 rated better at the end, two worse and eight the same. Of these eight, it should be noted that for four, the carer's level of satisfaction was rated as 'very dissatisfied both at beginning and end.

Over the course of the project, the proportion of carers satisfied with the situation went from 5% (1 out of 20) to 22% (4 out of 18), to 33% (5 out of 15).

Qualitative Results

These results are reported through a selection of quotes from interview notes, so that the information is personalized and illustrates the range of individual experiences**.** Some are direct quotes, but many are lifted from interview notes.

Current Mental Health: Quotes and Notes

Stage 1 Interviews:

'I was given the impression that T currently is not troubled by psychotic features such as hallucinations or delusions, but that he is still strongly affected by other features of schizophrenia, such as a lack of motivation and concentration, and his thoughts and speech not flowing smoothly'

'His mood is rather flat. His behaviour is settled, and he has not been acutely unwell for a long time'

'Son tends to have acute psychotic symptoms all the time. For example he has a range of paranoid delusions and thinks neighbours are in touch with him telepathically'

'His wife seems relatively well at present in that her acute psychotic symptoms have largely gone'

‘At present she is relatively stable, but the situation remains tense because of the many relapses she has had in the past’

‘He is currently very stressed about a number of things. He has had a recent interview for Personal Independence Payment (PIP) which was terminated when he fell over. He is now awaiting a PIP interview…’

Mother and daughter have not spoken this week ‘which is a good sign’. The past few weeks have been fairly settled for C.

‘His mental health is variable. He is currently reasonably stable. He is not psychotic at present but can be unpredictable in his behaviour, and can be verbally aggressive’ She describes him as agoraphobic and says he doesn’t go out on his own.

‘When acutely psychotic he becomes very distressed, potentially suicidal and potentially a risk to others. This is not the situation at present, but six months ago it was’

‘J has never had a mental health diagnosis. However, since childhood he has showed signs of mental instability with consistent patterns of verbal aggression to others, failure to complete studies or hold down a job, self-neglect and dependence on others’

Y has been diagnosed also with anxiety, depression and socially avoidant personality disorder. He has poor sleep. I was told that he has not been out of the house for six years apart from when he took an overdose and the police found him.

‘L has been very psychotic about a year ago. He now seeks reassurance about things as if he is a little bit paranoid but is generally not acutely unwell. He won’t go out alone…’

Mrs N felt her daughter was ‘stable’ at present. The last crisis was about six weeks ago when M was depressed and expressed thoughts of self-harm.

‘He has just gone back to Uni. At present he seems disorganized, blank in manner and flat in mood. He seems passive and with little energy but is no longer acutely psychotic’

‘On top of the diagnosis of Aspergers made when he was 17, he now has the diagnosis of bipolar disorder. At present he tends to sleep till 7pm, and be up until around dawn. He often seems quite depressed at present, over-sedated and sluggish’

‘She gets anxious and depressed at times She lives at home with her parents and works from home …. which seems to suit her. So she is not doing too badly at the moment although the past has been very tough’

‘His mental health is changeable at present. He sometimes is in bed all day and is not at all energetic. He does not go out much and has previously had the label of ‘social anxiety’’

‘D is ‘relatively stable at present. He continues to hear voices which are “nasty” He is on clozapine (anti-psychotic medication) and an anti-depressant’

‘B has a diagnosis of Emotionally Unstable Personality Disorder (EUPD) She is just about coping at Uni so far this term but is very vulnerable there, giving other students money to look after her, being very impulsive creating crises and not always being honest with me (her mum) about what has happened’

Stage 2 Interviews:

‘She’s doing quite well. Her moods are not too bad. The sertraline is helping’

‘His mood is still quite variable – he was almost screaming at me today’

‘I have not seen him for two to three months – this is because I’m not well myself and cannot do any more. He seems reasonably content’

‘Her mood is generally better, but she has been more shaky and tearful in the past couple of weeks, mainly because of her boyfriend’

‘After eleven years of illness, he’s still not well and his life is limited in many ways’

‘She’s doing well – she is almost back to being a full person’

‘She has been feeling like crap (her words) since before Christmas’

‘He is doing better – he’s more open to friendship now’

Stage 3 Interviews:

‘In December he said: “I don’t want to be here anymore”‘

‘He hasn’t been outside the house for at least a year – apart from putting out the bins’

‘It’s good, He recognises his underlying issues’

‘My son still hears voices – he always will. His Obsessive Compulsive Disorder (OCD) is getting worse. He has a terrible life’

‘She’s doing well. She’s off her Community Treatment Order. She doesn’t agree she’s ill, but she takes her medicines. She has found the ability to show empathy again’

‘He is not the same person as we remember before. He has found his new normal. He has lost his sparkle and we wonder if he will ever get it back’

‘She seems less angry now, more settled’

‘Since I last saw you, she cut tendons in her arm and needed surgery. After that she was in a nursing home for eight to ten weeks before she went home again. There are an awful lot of agencies involved’

‘She is very lonely. When others are around, her OCD is better’

‘A few weeks ago he had a second breakdown. He was acutely psychotic, disoriented, violent and suicidal. He wasn’t admitted partly because of Covid. He had very good support from the Crisis Team and CAMEO’

‘Sometimes he’s normal, sometimes he just doesn’t take things in. He’s on another wavelength. He smokes too much and neglects himself’

‘He still hears abusive voices. He shouts at them. He drinks too much and has a very narrow way of life’

‘He was angry when the care co-ordinator said she was discharging him. He is taking more pride now in his flat and is interested in cooking. He said: ‘I didn’t know I was so good at cooking’’’

‘She stays in her room. She chats on social media. She is irritable and sad. She has lost four stone since she came home in March 2020. Her GP referred her to Personality Disorder Community Service (PDCS) but people called the Primary Care Mental Health (PCMH) team turned her down’

‘In December 2020 she got very unwell. She had been smoking a lot of weed and became angry and deluded thinking her house was bugged. She was nearly admitted to Fulbourn but didn’t go in because of Covid. The crisis team came out for two weeks’

Current Situation: Quotes and Notes

Stage 1 Interviews:

When we began to talk about living life to the full T and his parents agreed that this is just not happening.

‘T said ‘Old friends don’t come round anymore’ and ‘I don’t do much’’

‘Son often says he feels lonely and also that he has not achieved what he should have done in his adult life. His social life tends to revolve around other people with mental health conditions…’

‘She has no close friends. She sees more health professionals than family and friends. She is not employed and has no current hobbies’

‘R spends most of her time alone at home. When she goes out it is with me (carer)’

‘V’s life is very limited. She has had tragedies in her past which mean that it is hard for her to make friends and be accepted in her local community. Therefore she doesn’t go out alone’

C has no paid job at present. She is described as having driven a lot of people away.

‘Z does not go out much at all. He meditates, reads and writes a diary. He almost on purpose fails. He tries to make the world fit with him’

‘His chronic schizophrenia has led to him being isolated over the years and inclined to neglect himself’

Ms L acts as a sort of secretary, making appointments for him and checking his diary with him most days. He has no family involved apart from Ms L and no friends apart from the carer

He is very reliant on his mother. He does not have enjoyable rewarding things he does at present and has very little social life. His social life revolves around people at the hostel and in the homeless community. As far as mother knows he has no good trustworthy friends. He has no paid job nor meaningful occupation. ;He enjoys listening to music (Bob Dylan). He watches TV a lot'

It is easy to see that Y's situation is very bad and has been for several years. He simply does not go out. When his dog died he stopped eating and looking after himself and Mum was concerned about self-harm. A lot of the time she feels 'on the alert'

L has been getting out a bit helping with a building project. In the summer they had a happy family holiday, he gets on well with his aunt who joined them on holiday. He sometimes goes for long walks with his mum and/or dad. He is said to have a couple of friends but to be anxious about socializing.

M lives alone. Her mother lives not far away with her partner. M sees her mum two or three times per week. M does not have paid work and her mother doesn't know if she has things to do that she enjoys.

'Whilst he has some friends they are more often than not into drugs which is not good for him. He is nowhere near living the sort of life that he is capable of'

'He seems lonely and has no new friends. He was severely exploited by local criminals in 2018 which has made him wary of new acquaintances'

'He has no job and no close friends. He had a girlfriend this year, but they split up'

Mrs S feels D is a very long way from living life to the full. 'His biggest friend is me'

Because there is such a long history of disturbed behaviour by B, family relationships are naturally very strained at times. Mum still does a huge amount to support her daughter and to try to get her all the help she needs.

B is doing a photography degree. She enjoys this but is inclined to say she is useless. She has major financial problems at present having lost her PIP.

Stage 2 Interviews:

'It works that she lives on her own. I'm not far away and I drip feed information to her'

'I try to be alert to what he needs'

'She has some good friends, and I am still there for her'

‘He has gone back to school which is flexible and supportive. He works hard and is well motivated’

‘We’ve had some big problems but at the moment we have a lot of people around us who can help. They’ve stuck to their word as professionals’

‘We feel we are invaluable to him, as his family. His psychiatrist is totally accessible to us which makes all the difference’

‘He gets lonely but at least he has me’

Stage 3 Interviews:

‘He has friends online but not in real life. Maybe agoraphobia should be defined differently no’

‘We are all stuck at home obviously. I don’t get out on the trips that Social Services used to fund’

‘He misses his music lessons. He is getting overweight’

‘He’s getting on quite well at Uni now. He has a good group of students in his flat. We still wonder about drugs’

‘Although he has been very unwell, he has a very supportive extended family behind him, which is great’

‘I do less now – I’m quite old. I visit once a week and phone five days a week’

‘I have a great deal to do, and my health is not good. But there have been some good results lately in getting her the care she needs’

‘He plays games online but doesn’t really have online friends’

‘She still has no friends. She still lives alone and doesn’t go out much. She was not well enough to get many qualifications at school. She has no job. I keep in touch, but the rest of the family don’t understand’

‘He is isolated and overweight. Local youths have recently harassed him again’

‘I (mother) am carrying the situation. No-one else in the family supports her. I had a carers assessment and then quite a lot of practical help’

‘I haven’t been in touch with my daughter since before Christmas when she was very aggressive. I’ve had so much of this over the years, I just couldn’t take any more. Although I’m sure it was a cop out on my behalf. …. I’m broken inside’

Formal Support: Quotes and Notes

Stage 1 Interviews:

As a family they just wish they had someone with qualifications as a mental health professional to be in contact with as necessary.

Mrs B is grateful that CPFT ‘keep a fairly close track of how he is getting on’

‘On paper this looks like a lot of services, but B’s needs are so complex and her ability to use help constructively is so limited that it still seems inadequate’

He is very grateful for all the good care he and she have had in the past couple of years, from CAMEO and Mulberry 2 especially. As a carer he has felt closely involved in the care planning which is great. ‘CAMEO was fantastic’ However, he is aware that the Locality Team will be less accessible than CAMEO and offer less support to them both.

V has had some help from mental health services in the past but is getting none now. She became seen as someone who was hard to engage and Mr G now feels ‘they won’t touch her now’ (meaning CPFT). He feels her diagnosis of Borderline Personality Disorder (BPD) leads to her being excluded from services.

He says with reference to mental health services that ‘there’s an end to everything’ and that when you’ve had some help it then seems as if ‘you go to the bottom of the pile’ He says: ‘If you don’t fit in with the start and finish thing (meaning time limited services) then you get nothing’

P has no mental health support at present. He did until quite recently have a Community Psychiactric Nurse (CPN) from the older people’s mental health team of CPFT. He didn’t get on with her very well and felt she did not understand that he was on the autism disorder spectrum. They asked for a change of CPN and now have none. They wonder now if they were penalised for ‘being awkward’

C has been offered mental health services but has tended to turn down such offers saying she is OK. Mrs G doesn’t honestly know whether her daughter has had treatment from the CPFT Personality Disorder Community Services or not. ‘C is certainly getting no mental health support or treatment from CPFT at present’

Mrs H is glad that Z is under the care of CAMEO. Z has weekly visits from his care co-ordinator and they know who to contact in a crisis. They have phone contact with a family worker from the CAMEO team attached to them as carers.

Ms L believes that her brother’s main mental and physical health needs are being met by the NHS.

Mrs J feels that even though J is under the care of the Locality Team they have very little impact on his life. Because of negative experiences in the past they both struggle to have any trust or faith in what the service provides. This has led to J not wanting to engage with the service and then being indirectly threatened with discharge.

‘M has never had care or treatment from NHS mental health services and is not under the care of CPFT’

‘He has no relationship with his GP. He has never had social care despite being in a homeless hostel’

‘Y is currently getting no support or treatment from CPFT or any other mental health service such as CPSL Mind’

Y has been mentally unwell for around 10 years and there is a very long history of attempts to get help from MH services, mostly negative.

‘Mrs M can see that L is getting some good support and treatment from CAMEO. His care co-ordinator is ‘good and flexible’ She is pleased he will have this service if he needs it for three years.

‘M is under the CPFT Personality Disorder Community Service. ‘The Consultant Psychiatrist was good. The psychiatrist listened’

‘Generall,y he is happy with the provision: ‘They really have tried to meet his needs’’

E has support from the Locality Team. He is on medication although there have been errors with this at the pharmacy. He recognises that he has bipolar disorder. A psychiatrist who has known him for some time is still involved which provides some good continuity. He has had the same care co-ordinator for a year, and she does some of the tasks that Mr P previously did. Although these aspects of services are positive, Mr P feels their impact has been limited.

‘H has not had any treatment from CPFT. She is on anti-depressants prescribed by the GP. She seems to benefit because she has not spoken of suicide recently’

Q has been under the care of the Locality Team for over two years. He is on anti-depressants which he takes ‘on the whole’ He is having Cognitive Behavioural Therapy (CBT) which has not yet had much effect’

D has been under the care of CPFT for many years. The current psychiatrist sees D about once every three months but is also very much contactable by phone or email in between times. This is very much appreciated by Mrs W and their relationship with this doctor is clearly very positive.

‘It is difficult for B to use mental health services at present because she is moving between home and Uni. She is not actually getting any mental health care or treatment at present’

Stage 2 interviews:

‘We had to find new home care. This was sorted out quickly and he gets on very well with one of the new carers’

‘I have every admiration for the staff at the hostel’

‘He is still with CAMEO has a care co-ordinator and is on a mood stabiliser. He is doing well’

‘When she had the baby in December, she got some good support from the peri-natal mental health team. She still has a support worker’

‘He had intensive CBT from CAMEO which really helped’

‘He has been having some good CBT from the Locality Team’

‘The CPSL Mind worker phones her every day which is appreciated’

‘His care co-ordinator phones, and we know she is there if we need her’

‘He has a reablement worker who is helping him find voluntary sector things that might suit him’

‘He has still had no treatment for his agoraphobia because he cannot get out of the house!’

‘He is still on the books of the Locality Team, but we haven’t heard from his care co-ordinator since Covid. I don’t want to bother her’

‘She needs counselling but has a label of BPD so can’t get it’

Stage 3 interviews:

‘I realise he won’t get any help because he can’t leave the house’

‘I referred myself to Psychological Wellbeing Service (PWS). It has helped, gave me some techniques to use’

‘He’s still with CAMEO. The care co-ordinator keeps in touch remotely’

‘Being with the Locality Team now means a 15-minute phone call once every six months’

‘The good staff don’t stay. He’s not going to get better’

‘Aspire in Leeds have a very good Early Intervention in Psychosis Service’

‘He and we had wonderful back up from the Crisis Team’

‘CAMEO have just started a new family and friends group which is good’

‘He has a district nurse to give his depot (medication injection) and two home care agencies going in four days per week. Plus me’

‘PDCS have been very good. When there was mix up with her meds they sent them in a taxi. There is a good new psychiatrist at PDCS who is sympathetic. Staff have been superb. The Obesity Team is very good’

‘He has a care co-ordinator but she never sees him. He has seen a good new psychiatrist. He said: ‘She listened to what I had to say. She didn’t just talk at me. He had a support worker but he upset him by calling unannounced. He went to Cambridge Community Arts but couldn’t cope’

‘He’s no longer getting help from the Locality Team but we’ve been told we can get back in touch directly if we need to. They were trying to wind down their involvement for a long time’

‘She has BPD, she is severely depressed, she is having no life and says she wants Electroconvulsive Therapy (ECT). I am unwell and the atmosphere at home is extremely tense. And yet she is getting no help from CPFT. I just don’t understand it’

‘We’re completely stuck because she obviously needs therapy but won’t ask for it’

‘Things are much the same. He has his depot. He doesn’t need a CPN at the moment. There was a time when we though the Community Mental Health Team (CMHT) would get involved again because of the impact of his schizophrenia but when they heard methadone was involved they wouldn’t touch him’’

‘He has a CPN he uses Lifeline and attends the clozapine clinic. Last summer when he was in crisis a psychiatrist came out a couple of times. He also has an alcohol support worker. Apart from the lack of in-person contact the service is as good as I can reasonably expect’

Informal Support: Quotes and Notes

Stage 1 Interviews:

‘T has a very loyal family around him but not much apart from that’

K has some good friends, but they are a mixed blessing. His mum is very loyal to him, but the family is very divided in various ways.

‘She doesn’t really engage with her community which means chances to gain independence and develop skills and self-confidence rarely arise’

P has great support from his wife, but as a couple they are very isolated. They get some practical help from other family members but not a great deal of emotional support or understanding of what they are going through.

Mrs F said ‘I’m not always enough…’ meaning that she cannot always meet his needs and wants more care shared with the NHS.

Z is very well supported by his family including his stepfather.

M’s patterns of behaviour are very entrenched, and it is hard to see them changing dramatically. He remains very vulnerable and is a long way from living a fulfilled life. He is in a homeless hostel. He is supported by his mother who is in her 80s and no-one knows what will happen next.

She is glad the family are there for him (L), ‘We’re the only ones who know how he is’

Family support is good, as long as mum can ‘hang on in there’

Lots of informal support – family and friends – is available to M but he is still struggling to use it.

Father and son are very close but basically E’s life is still very limited, and he is not in a position to easily make friends and progress in his recovery journey.

Mrs Q feels H has some things going for her now. She is going out more with friends – shopping, eating drinking ice skating. The family are still intact after some very difficult times.

He has a great deal of support from his mum, but it is not at present enabling him to progress away from a very withdrawn and limited way of life.

D is well supported by his mother and brother, but this is not enough to enable him to lead a fuller life. D’s future is still a great worry for the family.

Stage 2 Interviews:

‘My daughter has me but that’s it. I’m totally on my own’

‘There are problems to sort out every day… the pharmacy is in disarray. It is nerve wracking for me’

‘As his family we are still there for him which we feel is hugely important. There have been lots of ups and downs and you never know what is coming next’

Stage 3 Interviews:

‘His life is still so limited. I am everything. I spend my whole life doing it, helping him. I do have lots of friends’

‘There’s a huge amount for me to organise. I am tired but resilient’

‘I do everything I can, but I’m worn out’

Satisfaction and Final Comments: Quotes and Notes

Stage 1 Interviews:

Mrs B also stated that she remains very concerned about the poor working relationships between mental health services (CPFT) and substance misuse services Change Grow Live (CGL) locally. Someone in her family has already suffered tragically because of this.

Mr C and his wife have grave concerns about how B will cope when they are no longer there for her.

Mrs F made the point that if mental health do not understand the autism spectrum, they can waste an awful lot of time trying to work with people in ways that simply won’t be successful.

The strains of dealing with C over the years have worn Mrs G down and she desperately needs more informal support for herself and psychological therapy which she has so far not been able to access.

Ms L is anxious about the future for her brother and herself.

'Parents are 'Frightened for him (L), when we're gone'

Mrs N has learnt to live on tenterhooks. She has had an incredibly tough and conflicted relationship with her daughter and cannot be sure that things will improve for her although the current situation is relatively stable.

'Good efforts to help, but little effectiveness'

Mrs R is very anxious sad and frustrated about her son's ongoing mental health problems and his very limited life'

'Other things that would help are:

- More resources like Lifecraft where people can get peer support and be accepted for who they are
- More expert help with PIP appeals and other Department of Work and Pensions (DWP) issues
- Free legal advice
- More chances for self-help and mutual support'

Stage 2 Interviews:

'Everything is in place'

'I feel in his own way he is coping for the first time. He seems to have got what he wanted in the end'

'I'm encouraged – things are more settled at the moment. But will that last?'

'Because there have been problems in the past, I see problems ahead'

'I don't want to see things regress'

'Being a carer can drag you down, but Making Space are great'

'It's still tough. In many ways it's wearing for me' (Carer is in her 70s)

Stage 3 Interviews:

'I try to keep everything normal'

'There are lots of good staff. The problems that arise are usually systemic'

Comments on Covid and 'In An Ideal World'

'Lockdown is a relief to him. The pressure is taken off'

'She self-isolates anyway'

'No difference – he doesn't go out anyway'

‘In some ways it’s made no difference because she doesn’t go out’

‘He does not understand the rules very well. For example, he still uses buses in Cambridge quite a lot’

‘She has an eating disorder and doesn’t use the phone so shopping at the moment can be a big problem’

‘Covid has made him more anxious about things like whether he will get his tablets. He has not wanted to bother mental health services. His mood is now low’

‘He doesn’t believe in the Coronavirus. He’s not deluded but he thinks it’s a conspiracy. He doesn’t do much anyway, so it hasn’t made a great difference’

‘We’re doing fine, the two of us. We love each other’s company, so it’s not really affecting us at all’

‘She has come home to live with us. She has been frightened and panicked and refused to go out at all’

‘It has been a very testing couple of months. I found it hard that I couldn’t attend my uncle’s funeral’

‘Covid is good for him. There are now no expectations, so he doesn’t get anxious. He gets on with his studies’

‘With Covid, he says ‘welcome to my world!’ It suits him’

‘Covid has suited him. He has done well with online learning’

‘He has been bored because of Covid. But today his care co-ordinator is visiting him at home which is good’

‘Nothing has changed for us. We were in a bubble before and still are’

‘Covid has been a blessing because it brought some help. No one has said ‘I can help you’ before’

‘He hasn’t heard from anyone at the Locality Team for quite a few weeks, but we haven’t pushed it’

‘She should have a social worker. By that I mean someone professionally qualified who can form a relationship with her, get to know her and help her access things like employment and the right accommodation. Plus, someone else in the same team to support me because I don’t know how long I can carry on sometimes’

‘As a carer I’ve finally managed to get 11 weeks of counselling through Mind which I found very helpful. It should be much easier to access counselling’

‘We are well off, but it should be possible for everyone to have a school for their loved one which is caring and responsible’

‘He faces big problems as a young adult finding his way into a decent social life, employment, living a rewarding life. To achieve this, he needs someone to get alongside him with professional knowledge and skills, for as long as it takes…. It doesn’t work if it’s Mum or Dad trying to take on this role’

‘Provide treatment for agoraphobia’

‘Let’s have staff who actually listen, who are accurate in what they record, who believe what we say and who do what they say they will do’

‘Psychological therapies should be more accessible and with top up sessions to stop people slipping back’

‘Everyone with a severe mental health condition should have a worker with the psychological skills to get to know them well and stick with them for as long as it takes.
‘My son needs someone to work with him energetically, to help him get out of a rut and be more active’

‘There should be more sympathy in society for people who are different. Too many people just don’t want to get involved’

‘Services are far too fragmented. Get rid of internal boundaries. Use digital more. Have staff who actually know what other services are available’

‘In an ideal world all community mental health services would be as good as an Early intervention to Psychosis (EIP)’

Things That Help in Lockdown:

‘She lost her job but found herself another job in a shop’

‘She enjoys talking with her friends online. She has always enjoyed this’

‘We play jokes on each other. We use humour. We’re used to being stuck together anyway. We love our dog’

‘He has a good support network online and does a lot of gaming’

‘I (carer) cried a lot last week. I feel trapped. I’m in a lot of pain from arthritis and can’t easily go out. I go into the garden for sanctuary’

‘I know it’s against the rules, but we allow one friend to visit him because this is so important to him’

‘He does lots of gaming online, has a routine and exercises in the garden’

‘He has a bit of routine – gets up late, does course work, takes the dog out’

‘He understands the virus and is coping OK’

‘We enjoy the one-hour exercise per day. As a carer I’m loving it because I no longer have to travel in my job’

‘She watches TV to distract herself’

‘She now has two dogs and loves walking them’

‘I write poems and songs and perform them. I go to the Quakers’

Discussion

Detailed interim reports after stage 1 and stage 2 have already been provided.

It needs to be stressed that although it may sometimes look like it this was not research. The carers who took part tended to have loved ones with severe mental illnesses such as schizophrenia, so they do not represent all people with mental health conditions. The small sample size means that there is no reason to assume that these results are representative of a wider population. There is also no reason to expect a correlation between what the carers said and what the service users said. They were not in the same families, and they were both small samples.

The big variable in this project was of course the arrival of Covid in our lives in March 2020 just before the stage 2 interviews. It is impossible to say overall what difference this made to the findings. A significant number of carers said that Covid actually hadn’t made much difference to their loved one who perhaps already lived a very isolated life.

It is always tempting to hope for strong consistent messages from surveys like this, but this is unrealistic. The various stories told by the project have a few aspects in common but mostly experiences differ. For example, Covid has been good for some people and disastrous for others.

What have we learnt?

The demographic data highlights the high proportion of females, usually mothers, in the sample, which is typical of well documented patterns of informal caring where the brunt is known to be borne by women. Other demographic data reflects biases in the sample – such as the lack of respondents from Peterborough and Fenland. This is regrettable and is a reminder to Rethink Carer Support that it needs to improve its reach.

There was no particular correlation found between the loved one’s mental health at a given point and the level of support and treatment they were getting.

The quotes and notes from interviews are considered the heart of the report. They include insights into the care received and what is most important to those ‘on the receiving end’ which should prompt reflection by the report’s readers.

Whilst caution is required in extracting messages from a limited set of interviews, some themes are outlined in the section below.

Conclusion

Carers reported their loved one's situation often improving significantly between the baseline interviews and stage 2.

The changes were as follows:

- Current mental health: one worse, nine better
- Current situation: one worse, 10 better
- Formal support: one worse, eight better
- Informal support: 0 worse, five better
- Overall satisfaction: one worse, 12 better

Sometimes improvements were linked to good quality care from CPFT, CPSL Mind or other agencies. Sometimes, life events such as a job or a new school, or less tangible factors such as learning from past mistakes or simply 'growing up' were stated as significant.

These encouraging signs were only sustained to a small degree at stage 3. This may be linked to the impact of Covid, but the evidence for this is not strong. It should also be remembered that the project's design meant people might have all sort of ups and downs between the 'snapshot' interviews spaced out over six-month periods.

Themes

Carers were often extremely grateful for the help their loved one was getting. Individual staff were often praised. But the system mental health staff operated within was often condemned as inadequate and incoherent. There were some very powerful stories of individuals in torment because of their mental health issues being repeatedly turned away from care and treatment, and at a loss to understand how this could be.

Carers would ideally like above all to have a professional who they knew well to get alongside their loved ones 'for as long as it takes' for them to lead a decent life. This response was common under the heading of 'In An Ideal World' Sometimes this was about the carer not wanting to feel totally unsupported in their role. But it was also about people with severe mental illness leading extremely limited and almost hopeless lives. There was an absence of anything resembling rehabilitation, with individuals lacking both the skills and the motivation to set goals for themselves and work towards them. Services often in the voluntary sector were sometimes available but this was experienced as patchy, with little outreach to help people engage. Social care was hardly ever mentioned and seemed invisible, (although interviewees might not be aware that services like CPSL Mind were social care funded).

For carers and their loved ones there were many instances of them being isolated within their own communities largely because of ignorance and stigma. There were some examples of people being harassed and discriminated against because of their mental health condition. This made 'living life to the full' very difficult. Some carers said that ideally everyone in their position should have a sympathetic family and friends, employer or school and community around them – creating a context within which they might flourish.

Overall carers reported significant stresses in their roles and a common sense of worry that their loved ones needed them too much and that alternative support was hard to find. They often worried about how their loved one would cope when they were no longer present, and many were being treated for depression.

They sometimes felt excluded or exploited by mental health professionals. There was a sense of an uneasy relationship with professionals, with a lot of unexpressed tensions about what a carer could reasonably be expected to do.

Recommendations arising from these themes are shown in the final section.

Acknowledgments

Partner agencies are thanked for their support of this project. Above all, my thanks go to all the 20 families who have taken part, subjecting themselves to up to 3 interviews over sixteen months that were sometimes very distressing. I know you have done this to make things better for your loved one, for yourselves and for those to come in the years ahead.

Thanks very much for all your support.
Jonathan Wells
February 2021

Lived Experience Report – Lois Sidney

Method

In 2019, The SUN Network had recruited 15 people currently living with mental health challenges to the project. These people were recruited through social media, our own SUN Network emailing list, chance conversations with people with lived experience whereby they were invited to join the project, or referrals from other services such as CPFT or Illuminate. These interviews are about their perspective on the situation of their own mental wellbeing and the support available for them at a time when it is needed. For stage 2 of the project we were able to speak with 12 people. At the beginning of stage 2, Covid-19 meant there were delays to this project as the immediacy of Covid-19 took precedence, and we were unable to speak with all 15 people.

The people with lived experience were interviewed by a member of The SUN Network team in a setting of their choice. Some of the interviews were face to face – socially distanced, and due to Covid-19, some were over the phone. It was explained that any information held would be kept confidentially and that any information included in reports would not be traceable to individuals. It was stated that direct quotes might be used in reports but would be unattributed.

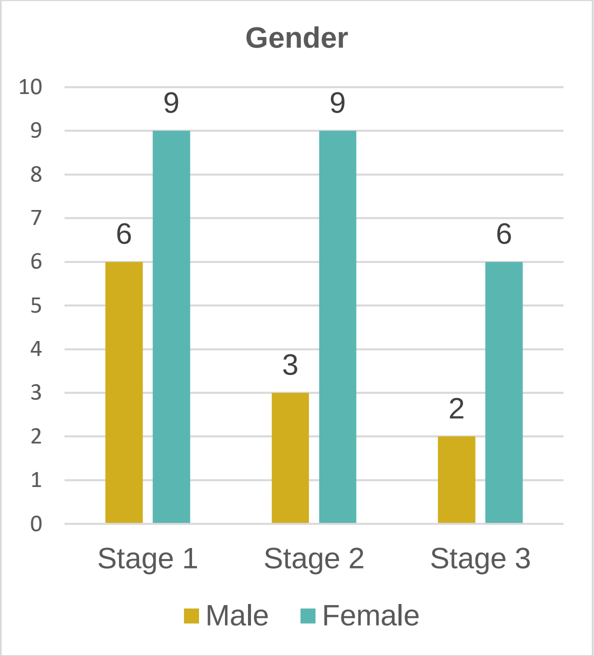
By stage three of the report, we were only able to speak with nine people.

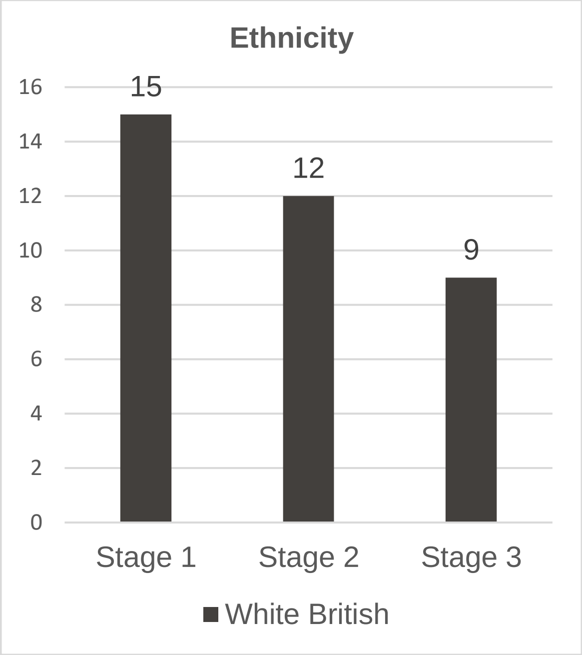
A semi- structured interview was used in each case, using a standard questionnaire which reflects the issues that people have previously expressed as important to them. (An example of this is the equal weight given in the questionnaire to formal mental health services and to other factors in someone’s life when looking into what might help). The same questionnaire was used for interviews with people with mental health conditions and with carers.

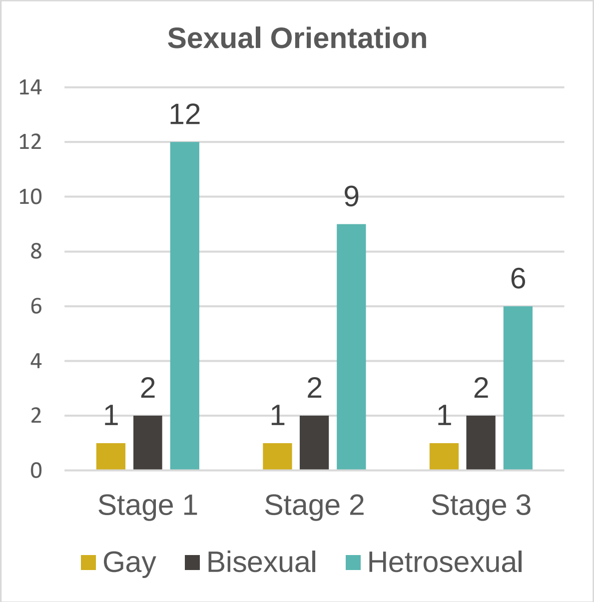
The interviews allowed space for interviewees to comment on any aspects of their overall situation or care that they felt was relevant.

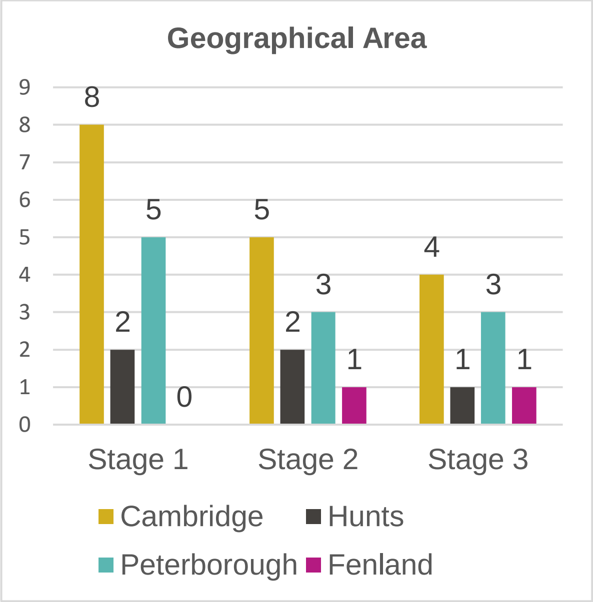
Characteristics of Interviewees

The ages of the participants ranged between 32 and 68 years old.





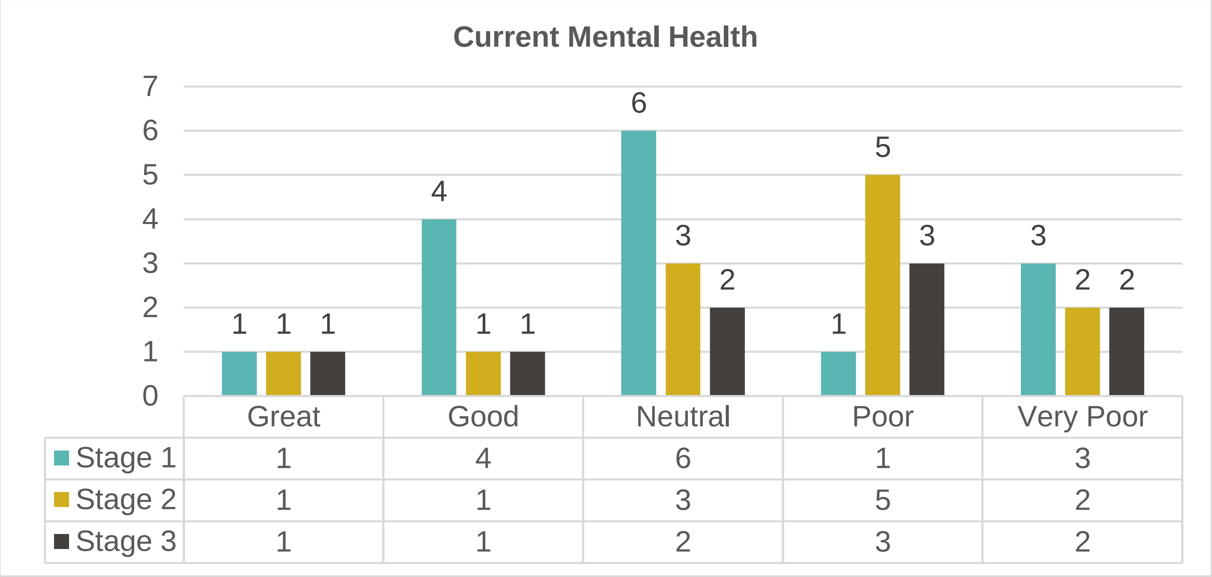




Quantitative data

Current Mental Health

Participants were asked first to rate their current mental health, focusing on symptoms, on the following scale:
Great, **Good**, **Neutra**l, **Poor**, or **Very Poor**

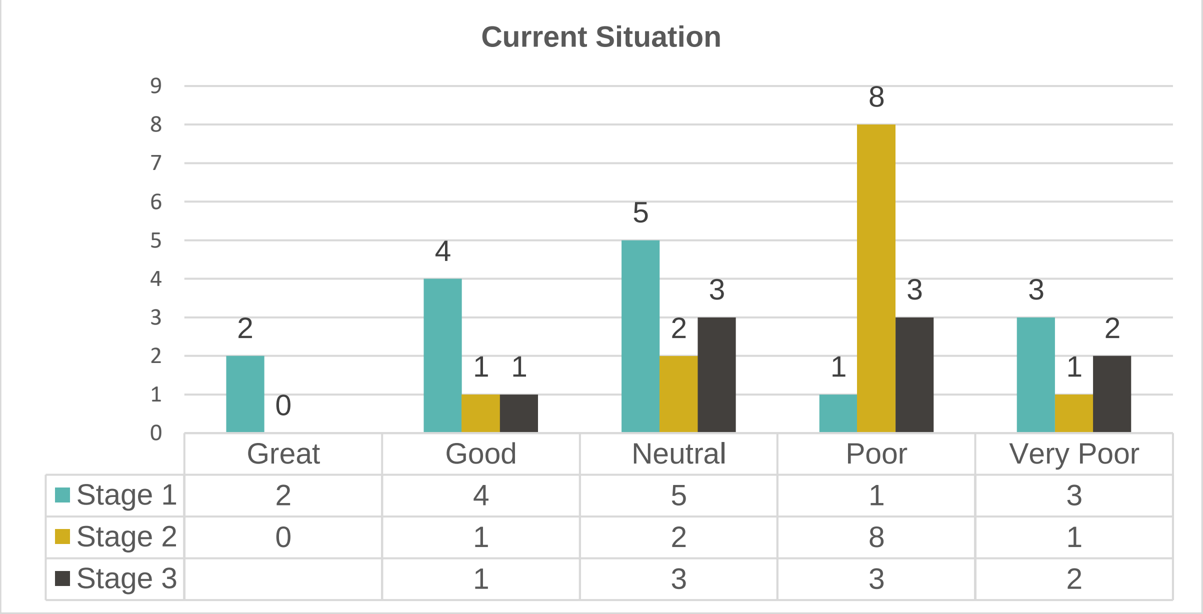


	Great	Good	Neutral	Poor	Very Poor
🟦 Stage 1	1	4	6	1	3
🟨 Stage 2	1	1	3	5	2
■ Stage 3	1	1	2	3	2

The data shows that over the course of the 18 months, only 1 person each time felt that their current mental health was great. The majority of responses ranged between neutral and very poor.

Current Situation

Participants were then asked to rate their situation and to what extent they were living the life they wanted for themselves on the following scale:
Great, **Good**, **Neutral**, **Poor**, or **Very Poor**

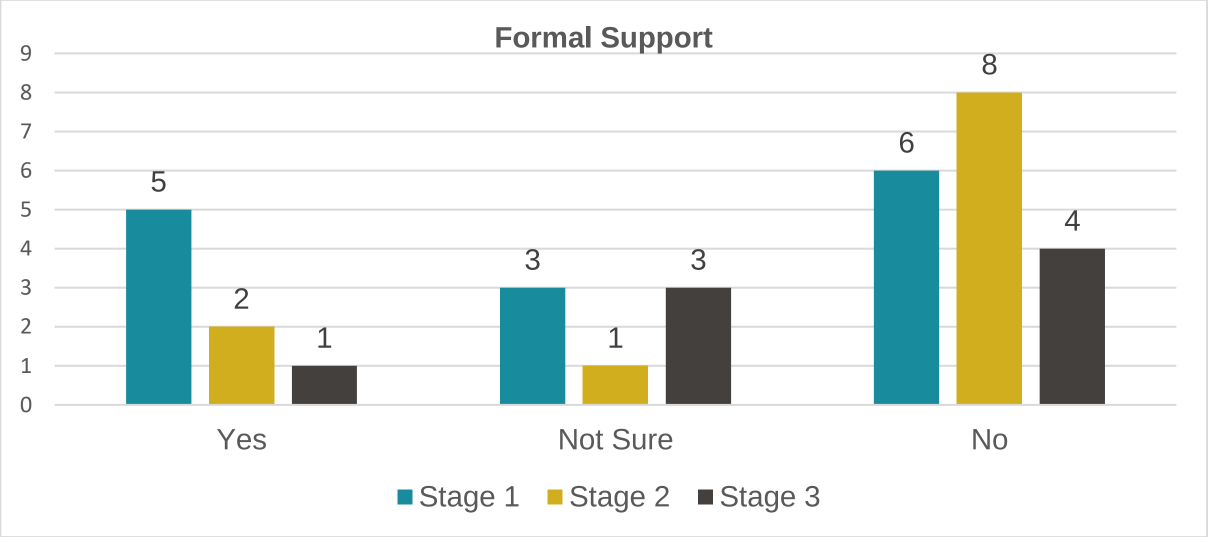


	Great	Good	Neutral	Poor	Very Poor
🟦 Stage 1	2	4	5	1	3
🟨 Stage 2	0	1	2	8	1
■ Stage 3		1	3	3	2

Throughout all three stages the majority of responses were neutral, poor and very poor which paralleled the responses for current mental health.

Enough Formal Support

Participants were asked whether the amount of publicly funded support they were currently getting was enough. They were asked to rate this either ‘**Yes**’, ‘**Not Sure’** or ‘**No**’.

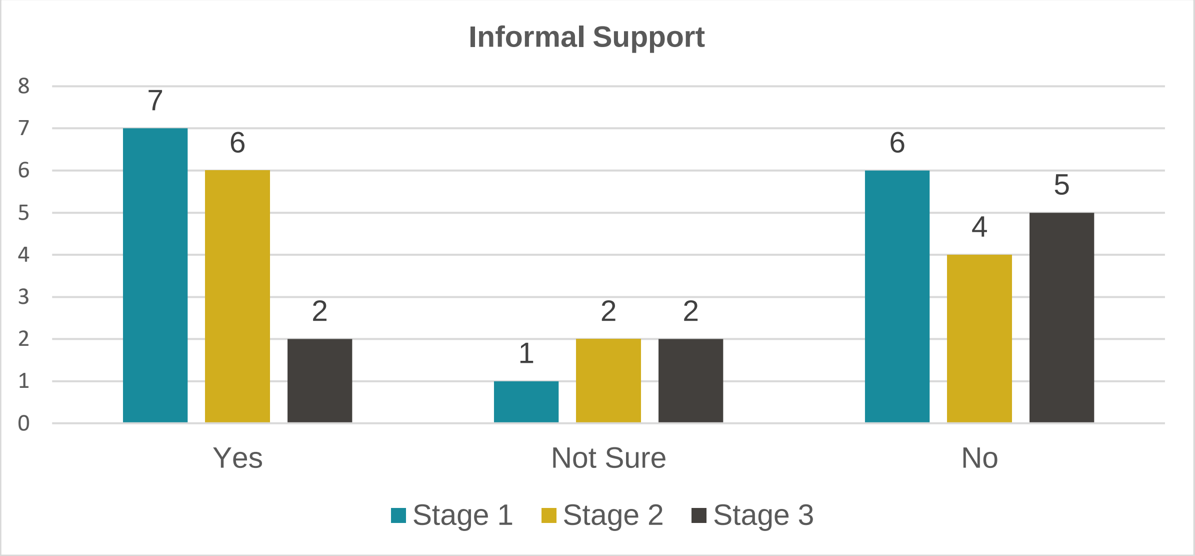


The majority of participants at every stage felt that they were not getting enough support from support services such as NHS (CPFT) and third sector. This was for reasons such as personality disorder diagnosis excluded them from accessing support, not knowing what was out there, or ‘bouncing’ around services without receiving support to the point where they had given up.

One participant felt this question was not applicable to them at any stage as they were not attempting to access services at all.

Enough Informal Support

After this question, participants were asked whether they felt they had enough support from other sources such as friends or family to enable them to progress.



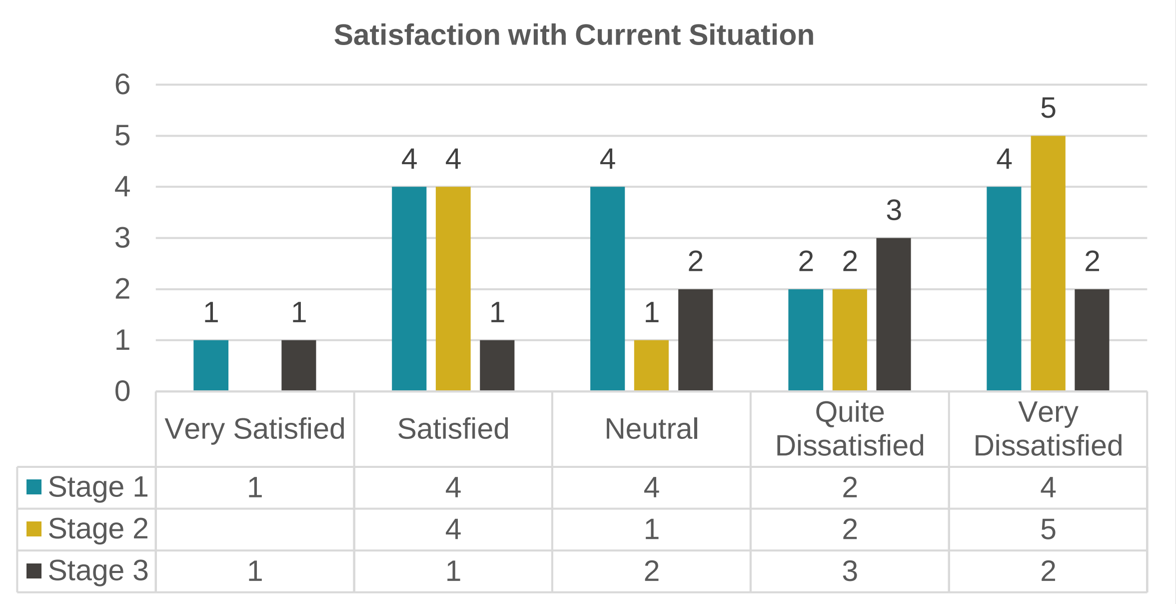
Participants were predominantly in two camps. Those that, in the absence of professional support had families and friends that filled that gap, and those that were reluctant to accept support from their family for fear of being a burden, or not wanting their families or friends to see how much they were struggling. Some also relied more on **either** family **or** friends so that they were not worrying certain people. All of the participants did not see it as their family's role to support their mental wellbeing.

The participants who felt that they were getting enough support tended to be ones that were in a fairly good place at the time of interview and were in employment and in a position to socialise with friends and family.

Satisfaction with Current Situation

Finally, as a way of summing up, participants were asked to rate their level of satisfaction with their current situation on the following scale:

Very Satisfied, Satisfied, Neutral, Quite Dissatisfied, or **Very Dissatisfied**


Satisfaction with Current Situation

	Very Satisfied	Satisfied	Neutral	Quite Dissatisfied	Very Dissatisfied
■ Stage 1	1	4	4	2	4
■ Stage 2		4	1	2	5
■ Stage 3	1	1	2	3	2

The majority of respondents over the three stages found their situation to be neutral or less satisfactory. A third of participants at stage 1 and 2 were satisfied or very satisfied. This dropped to just over a fifth in stage 3.

Qualitative Data

These results are reported through a selection of quotes from interview notes, so that the information is personalised and illustrates the range of individual experiences**.**

Current Mental Health

Stage 1:

‘At the moment I feel I am in a good place. I feel like life is moving forward positively, like I am getting my life back together. I have involvement projects coming up to look forward to, and hopefully, more things will come from them’

‘I feel quite happy, although I still have symptoms. I get very little psychosis at present which I am very happy with. This is controlled by medication and self-care’

‘Stable today, but this can vary day to day. Great fluctuations in mood. Still looking for help and support as I feel nothing is available to me. I would like targeted treatment’

‘I feel very isolated, but I don’t feel ready to engage with other support’

‘I feel very stable at the moment and I have done for a while. Feelings and moods are stable, and it is a relief to not have to put a mask on for the benefit of others. I feel I can be myself’

‘I use my own recovery tools. I have a book with who and what can help me with my mental health. Go out for walks. I feel I am now in a position where I can be supportive of others and offer something back’

‘I cannot maintain stability of mood, thoughts or feelings. I’ve only ever known poor mental health, and I waited 30 years for a diagnosis of Bipolar and BPD. Lack of understanding from friends, family and myself, and lack of support from services contributes. ‘’I feel like I am bobbing along, conscious that I am only just holding my stuff together. My anxiety is just about manageable. I feel like I am walking on a tightrope and it could go either way. Constantly feel on the cusp of tears. Feelings of anticipation of what will happen next. There is always something to sort or manage for other people. This feeling is my norm and I would like it to stop. I don’t feel I ever have had the time to give myself the time out to acknowledge what I feel and need’

‘Been on a two-year journey of trying to seek help and support. I feel very disappointed that there hasn’t been the help and support for me. It’s been a struggle to find a service that can help. Feel I have been trying to be strong, but recently that all collapsed. Moved from a different area to Cambs and was told all support had to start from the beginning. Not able to take meds due to not being able to get prescription renewed so feel in crisis’

‘Feel suicidal all the time’

‘I have chronic schizophrenia. At present I am getting on quite well. I occasionally hear voices, but they are not nasty ones. Sometimes, I’m not sure what is going on around me. I might still have some delusions…’

‘I’m anxious, but I feel empowered. My concentration is coming back after two years. I feel like I’ve come out of 2 ½ years of hell’

‘My mental health is really bad. A couple of weeks ago I was stood on the train tracks wanting to kill myself and ended up driving to A&E at PCH so I could try and see a psychiatrist. Because no-one will review me, I’ve not been on medication for several months and my mental health is significantly deteriorating’

‘I tend to struggle around my birthday and recently was feeling suicidal. I get really anxious’

‘Some good bits and some not very good. A good event was when I caught the train to Whittlesford and back – this gave me confidence. Not so good was when I was in McDonalds and began to wonder whether a group of teenagers were talking about me. I got a bit paranoid’

Stage 2:

‘I am generally down in mood and have some anxiety. Frequent crisis which is not supported every time. I feel I have been put off trying to access support from previous negative experiences. I haven’t been able to access services when I do approach them. Chronic suicidality is a constant feeling. I feel I am not receiving help at all’

‘My anxiety is very high. I don’t feel I am being of use and I feel I have no purpose. I am not sleeping well and have very little motivation. Covid-19 has definitely contributed towards these feelings. Things were quite positive before all this. I was volunteering a couple of days a week and that has stopped now’

‘My mental health is excellent. I feel very positive. I am looking forward to the future and I am just starting the process of looking for full time work’

‘When my mental health is good I have a zest for life. When my mental health is not good, it is hard to function, even to do the basics. I can have one good day, then five bad days. When I wake up in the morning, I never know how I am going to be – what the voice will be like. I can't plan too far ahead as I don't know how I will be. I am not able to be as sociable as I would like to be. I lose my ability to live normally. I wouldn't wish this on my worst enemy. I have done everything I can to help my mental health, but it is still hard'

'I'm managing to stay socially active. I am keeping my foot in the door of employment. I still have days that swing from feeling ok to feeling suicidal, the trigger can be anything. If I am not busy, my mental health is worse. I need to keep myself busy. I am at my happiest when I am out meeting people trying to help them'

'I can fluctuate between neutral and good on a daily basis. Good for me means I am able to do things. Engage with my children, do practical things around the house, and feel motivated. But there is always an underlying fear that it will come to an end. Neutral means I am just about functioning. I'll engage with the children but be constantly questioning myself and my abilities. I will be worrying that I am not doing enough or that I am not good enough'

'I have been feeling quite low. In turmoil but for unidentified reasons. I have been feeling exhausted. It doesn't seem to matter how much sleep I get I still feel tired and not able to keep up with the pace of life. I have been really unorganised, forgetting things a lot, not managing home admin and the running of the home. All this evokes feelings of anxiety and depression. When I am like this, I am fearful that things will get really bad again and what will I do and who do I turn to for help to get things back on track. I am not feeling anything at all at the moment. This scares me. I am upset and tearful a lot of the time. I feel that there are issues I cannot deal with, that I cannot face, and I wouldn't know where to go for help to help me deal with them'

'Things are pretty bad. I self-harmed a week ago and felt terribly anxious and worried about everything, phoned 111 option 2 but they were not a lot of help. I was told the Sanctuary would ring me, but they never did. I couldn't travel to the Sanctuary anyway. I am very agitated and paranoid about everyone and everything'

'It doesn't really feel poor and it doesn't really feel good either. I think this is due to the medication I am on (Quetiapine and Sertraline) as they make me feel quite numb, which gives the illusion I am coping but I'm not. I also split up from a ten-year relationship in the last few months that I had decided wasn't good for me so that has had a positive impact. I am on Quetiapine and sertraline as I phoned the GP who phoned the CPFT psych nurse, who spoke to the psychiatrist and then the news filtered back to me that they had changed my meds. I had a choice of two meds as I had tried one before. I didn't actually get to talk to anyone other than the GP. I am seeing a therapist at the GP's, however, it is only 6 sessions, so I am trying to spread them out over one a month, so I don't use them up too quickly. However, they are only 45 minutes long and by the time I explained what BPD was, the first session was gone. And sometime there is only one chair in the room which is the size of a cupboard and we have to take a chair from the waiting room. It's the blood test room so it is very clinical and very small. I feel really physically close to the therapist which I don't like'

'I feel I have no future, nothing to look forward to. I have lots of things to do but feel there is no point doing them. I am only carrying on for someone else. There is a plan, but it is wrapped up in rules and agreements with wife. I have lost all interest in everything. I feel very stressed, I don't sleep well, and I am very tired. Recently lost my mother, who was a support for me. I am over-spending. My finances are not good'

Stage 3:
‘I feel like my recovery has been consistent. I feel like life is good. Over the past 2 years I have gone form strength to strength. I am busy, I don’t feel overwhelmed. I am happy and proud to be a non-executive director of The SUN Network. I have responsibilities which keep me busy and are very rewarding.
I can receive 25 emails, they come in quick and fast but feel I can cope and deal with them’

‘I am good but during times of my menstrual cycle I feel vulnerable. I am aware this happens. I’m not feeling I need help at those times but being aware of why I feel like that really helps’

‘On negative days and when I’m feeling down, being honest about how I am feeling without blaming anyone helps move through those challenging days’

‘I am still affected day to day. Still have lots of negative thoughts that run through my mind constantly. Nothing really terrible – just worries that won’t go away. I go through phases of enjoying life and then not enjoying it’

‘I have a really extreme lack of motivation. I can sit on the sofa all day doing nothing. I get up and then I clock watch until I can go back to bed at around 7pm. Just so I can get another day over, and then I have to do it all again the next day. I am really fearful of everything opening up again. I feel anxious about the crowds. I feel resentful that this is how my life is. I wouldn’t mind if I die. I worry how my family would feel about that’

‘I feel worried about how I will cope when the world opens up again. I have got used to just being at home. I don’t want to go out’

‘I feel empty and woolly headed a lot of the time. I forget to look after myself. I can’t remember the last time I laughed. I am very comfortable at home not seeing anyone. I worry about money though. How I can afford to live and will my benefits be stopped. I hate how I feel, I’ve also put on weight which makes me feel bad about myself, but I don’t want to go outside so I don’t exercise’

‘I am really slow at everything. I try to think but it is too hard, and the thinking is too slow. I really have not been well at all. I would say I am in a bad place’

‘Everything feels like too much effort. I don’t have the energy to do much’

Current Situation

Stage 1:
I don’t know what else I need to do to get help’

‘I keep myself busy. I like to do karaoke and do this at a couple of places locally which I really enjoy. I now not working and I’m on benefits’

‘I set up a bipolar café two years ago and I attend that. I can be myself there, there is no judgement. I have my allotment which I love’

‘I have lived at my current address owned by a mental health housing provider for 12 years. I haven’t been acutely unwell for at least 15 years. I cook and clean for myself and manage my own finances. I get out of the house every day. I get bored sometimes and feel like I don't have enough friends. People I know tend to be other long-term mental health service users. I sometimes wish I had a paid job'

'I feel overwhelmed by the condition of my house, but don't feel like I have the capacity to start sorting it out. I used to have hobbies and interests, but due to physical and mental health, I no longer do anything. I feel I am trying to manage to much other stuff to focus on myself'

'Help is now in place but because it has taken so long, I had really hoped I would be further along in my recovery journey. I feel like my recovery has gone backwards. I want to just get my life back on track and start living, but this has all been delayed due to lack of support and care'

'I cancel events and personal meetings etc as I am unable to face it. I feel like I am only managing to keep together the basics…..work and the needs of my husband and children. I feel like I have to pretend to be ok whilst everyone around me falls apart, or I put on a front to family and friends. I really struggle with groups, not managing to make time for me. Huge anxiety about social situations. My work hours have changed, I used to work shifts which gave me alone time. Now I work 9-5 which means my free time is always looking after the needs of my family. My husband is a hoarder and the house has got on top of me'

'Because of self-education, I am developing an awareness of my behaviours, but because I am learning alone, I sometimes hit crisis and access crisis services. I feel forced to educate myself as no-one else will educate me on my condition (BPD)'

'I am now living my life to the full. I am able to drive again which has given me independence. My relationship with my daughter has improved. I am trusted more. I feel like my family is coming back together in a way that works for all of us. Moving from a drug den to a beautiful home has offered stability and comfort. I volunteer for the maintenance of a local nature area. I yarn bomb, leaving supportive recovery focused quotes. Crafting offers me a mindful practice. I eventually become able to recognize what strengths I already had. I am now a qualified peer support worker. I can finally begin to explore my world and find out what I am capable of doing. I trust how I feel about my emotions so am able to cautiously push the boundaries whilst understanding that I can't go too far too soon'

'Living each day to the full is very difficult as my mental health fluctuates so severely each day. I am in the best place I have ever been. I have felt debilitated by my illness and feel lonely and isolated. Having a dog helps'

'My recovery is turbulent. My partner has lost his job, nothing has changed for me since my diagnosis and I feel really demoralized as I can't get the help I feel I need. My ability to function is variable day to day. I don't go out, feel hopeless, angry, and I hide away. My husband takes care of the children and he suffers with his own mental health due to the situation'

'I feel ambitious and driven. I look after myself now and take care of things. I no longer have anxiety attacks. I am dealing with life and the little challenges I have to face'

'I do enjoy life, but after work, chores and self-care I feel there is not a lot of time left in the week. It feels like everything I am doing is just going through the motions. I don't feel free. I am scared of making changes and stepping out of my safe zone, and to be honest I don't even know what it is I really want. I don't feel a sense of possibility about the future, and everything has to be really planned. Life is good but it feels limited'

'Routine is important to me and I have quite a good weekly schedule at present. On Wednesdays I go trampolining which I'm good at. On Thursdays I do Kung Fu which helps him feel safer when I go out on my own. On Fridays I do badminton which I enjoy. I have some good friends but would like a partner. The diagnosis of Aspergers means that I have certain strengths. I am good at Maths and got a 2.2. degree at Anglia Ruskin in Maths and Chemistry. Unfortunately, I have not found a job that suits me'

Stage 2:
'I really want to move on from what is happening to me and what has been going for the past 5 years. I want to be able to be out there doing it, working, engaging in society, being normal. Not to be restricted by my Mental Health. I want to be recognised and valued for my contribution, at the moment that is not happening'

'I am not able to work and am about to lose my job. I have ongoing crisis situations, and nothing feels like it improves beyond a certain point. Corona has had an impact on my ability to live life and mental health services being shut down doesn't help. I feel distressed'

'I would Like to be able to function better. I would like to mix with people and not be so isolated. To Have a social life. Debilitates you to be able to so many things. Panic attacks and voices - Attempted suicide just wanted it to stop. The illness is so bad that suicide is the only thing you have left you can do. I don't have enough confidence left. I would like to Put Mental Illness on the map – be a representative for mental health. Especially for those who live with Paranoid Schizophrenia - People are really judgmental. I have to find ways to try and be normal - I'm a good actor – hide my debilitating condition to others. Would like to be able to speak more openly about it. More resources would help people stop slipping through the net'

'I am looking forward to things and being positive but there is an anxiety which very quickly builds, but I feel I have the skills to manage that and pull myself back. I am not doing all the things I would like to be doing at this moment in time'

'Again, I would rate myself between neutral and good depending on the day and time. For a long time now, things have felt hard work and a battle but due to a medication change I am feeling much more stable now. The most stable since my mental health deteriorated. I have always had an ambition to start my own business and at the end of march I launched a small craft business. Although I feel things are moving forward in a positive light, it is still really early days and I feel there is still a long way to go'

'I don't feel like I am managing. Feelings of frustration. Saying to myself, why don't you just get on with it and do it, but I am struggling to find the motivation. When I am in a good place I feel a lot more compassionate with myself. But when I feel like I do I get angry with myself. I just feel like I need time out – to be able to get back on top of things'

'I don't want to go out. I keep looking back rather than looking forward. Everything is hard work. I feel frustrated and get irritable very easily. The state of the house is overwhelming. I hate ageing. I am not coping with that very well. My lack of mobility, ailments'

‘Am finding it very difficult not being able to go out and physical contact with people. I miss my family and I have missed significant family events. I have not been able to do my voluntary work and this has been a huge part in my wellbeing along with meeting up with friends, who offer me support’

‘I am in receipt of PIP and my husband is my full-time carer. I have to get up and go and have to be pushed to wash, clean teeth, brush hair etc. I don’t like to leave the flat and am very paranoid of the outside world. I am living in a mental cocoon and my mental state is failing’

‘There is just no support. I finished the Mind PD group last year and have nothing. The group was really hard as it wasn’t facilitated well and the fact it was rolling, meant new group members joined and we had to keep re-covering ground that we had already covered and there was no psycho-education. The facilitators kept changing and that was unsettling. When I left, CPSL Mind did not ask me for feedback on the group. There is nothing for me. I get turned away from everything’

Stage 3:
‘Because of Covid it feels like I am only living my life to level number two. I don’t feel like I can live my life to the full due to lock down. I am doing all I can given the situation.
I feel like it hasn’t hit my mental health very hard, I have found the physical restriction more challenging - Being social, eating out, going to nice places, shopping, take my daughter out to nice places. I don’t like being in the house all the time and need to get.
Due to being able to attend so many meetings through the SUN Network I have managed to find myself a job, which has been my ultimate goal’

‘I haven’t eaten properly or cared about myself. I don’t even feel bored. I literally feel nothing and that scares me’

‘There are lots of areas where I do live life to the full, some areas I am satisfied with.
Socialising with friends is not happening as I would like it too. I miss swimming more than I thought I would. I was surprised by that. I try to walk instead but there are lots of people out and about and I don’t really like that’

‘It is what it is. What can I do about it? I can’t get any help as the GP surgery can’t help me and all appointments are over the phone and I don’t like that’

‘I feel like I am struggling all the time. Everything is foggy and unclear’

‘Who would I bother getting dressed for? I don’t care about myself. I don’t care about my house. I have zero motivation’

‘Although I am feeling well and good, I am frustrated by lockdown. When It began, I felt quite scared, but it has encouraged me to reconnect on Zoom with old friends from the past.
I have reconnected with people more. Although lock down has been difficult there have been benefits to it. There is an element of isolation, but I am used to being on my own and being in my own company, which has helped. I have met lots of nice people, the right people and I feel I have moved on a lot’

Enough Formal Support

Stage 1:

'I currently have enough support. I am accessing the GP. I was seeing a psychiatrist and had a CPN for a few years. I was offered psychology but turned it down. It would have been nice if someone had suggested it was a good idea for me to take this up as I didn't really realise at the time. I was drinking heavily and when I left the psychiatrist, I had to look for my own ways to stay well. GP looks at co-morbidity issues like smoking and weight and this actually helps. I see the GP once a year for 10 minutes and they say 'How are you?' and I don't even know where to begin to answer knowing that I only have 10 minutes so I don't answer'

'I am currently with the recovery coach service from being discharged from services. This has been a perfect way to ease me back into having no support. It has ensured that I have not gone for specialist mental health support to nothing. Having the recovery coach service has given me the opportunity to get involved with other things (The SUN Network, CPFT, Mind)'

'The continuity of care from the Locality team has been variable. I am aware of staffing issues but I saw 7 locum psychiatrists in a year. Getting into services wasn't easy and I had to not take no for an answer. GP eventually made the referral. My hospital admittance came from my care coordinator. Navigating mental health services was challenging and I needed the help of a friend. Discharge information was given verbally when I wasn't in a position to retain the information. Didn't know where to go after that to get help. I witnessed restraint in the hospital which was distressing. I felt it was a quick and easy option to control a situation'

'I have found my mental health deteriorated after the birth of my first child. I was under the care of the perinatal team and mental health services where I received a lot of support. I had a period of time in hospital and it was there that I received my Emotionally Unstable Personality Disorder (EUPD) diagnosis. Since then I have not been able to access any help. All mental health support has been denied. Referrals to Psychological Wellbeing Service (PWS) and Personality Disorder Community Service (PDCS) have been refused. I have had the opportunity to attend CPSL Mind's PD group. There is nothing out there that feels positive about PD. It doesn't look at the strengths of people with the diagnosis. I finally got a diagnosis after struggling half my life with my mental health only to find there was no help anyway. People have horrible views of people with PD'

'I feel I am getting the support I need through my CPN and support worker and I am very happy with the care I get. I have been in receipt of care for over 10 years now but feel I wouldn't be where I am now if I hadn't had that help for so long. I am worried about my care being reduced as I am not sure how I would cope'

'I am currently not involved with any services. I do need to engage with therapy at some point, but I don't feel ready at the moment. I want to explore my world a bit more and build up my resilience before I do that. I feel reengaging could bring emotional instability and I feel scared and concerned that I may not be able to access mental health support at the time I need it'

'I am not accessing any services at present. I don't feel the need to, and nor would I want to if I was offered. My experience of CPFT has not been good or helpful. I have been stigmatized and restrained in hospital which has created trauma. I felt my discharge process from hospital was rushed and I was not included in the process and was left with no after care or support. A new consultant came into Springbank and it felt like they wanted to clear out all the old patients. It took me two years to get back on my feet with several suicide attempts. If I needed help again, I would use the support network I have created for myself, not services'

‘I cannot access any services and the thought of becoming unwell is frightening to me, as I have no sense of identity and no idea of who I am if I don’t have BPD. My mental health needs are not being met as I fall into the too complex/not complex enough gap’

‘I don’t access any mental health support. I am on anti-depressants. I have had a Primary Care Mental Health (PCMH) referral and I am on the Choices counselling waiting list but they are long waiting lists. I have had various talking therapy sessions which I have paid for myself, but they have only been short and not specific to my needs, so they feel like they haven’t really helped at all. I feel I have not been able to access the right care at the right time’

‘Right now, yes, it feels like there is some support in place, but it has taken 2 years to get it. Although it is challenging, I understand that it will get better. Over the two years I have been doing my own research into what else can help as nothing came to fruition through the GP’

‘No services are in place any longer. My wife is doing her best, but it is not fair on her having to deal with everything on her own. I feel I have nothing other than NHS 111 option 2’

‘I am on medication that means I need a monthly blood test at Tenison Road for blood tests. I have a chance then to speak to a mental health nurse, but I don’t really bother. I see a psychiatrist once every 6 months but am thinking of asking for a new one as I feel pressured by this one to increase my medication and I don’t want to. I rarely see a GP. I see a Mind support worker for an hour a fortnight and I have to pay for this. I also attend a council funded badminton group which helps me feel I have achieved something’

‘I have used the Sanctuary. They saved my life. I am due to see a psychiatrist, but I have retold my story so many times as there is no consistency in staff’

‘I have disclosed to GP’s several times that I felt suicidal and was never told about NHS111 option 2, I found out about it elsewhere. (asked by SUN Network about various local services) I haven’t heard of The Sanctuary. Not aware of things like Recovery Coaches, Recovery college, CPSL Mind and have only just heard about IAPT (PWS) I don’t rate the services I have received as bad, but I had no idea of what other services were out there. I use the Samaritans a lot which is helpful’

‘I am pretty much aware of everything on offer, it’s just that none of them will see me. I seem to fit in between the gaps of different support. Too ill for one, not ill enough for another, the wrong type of ill for the third. I sometimes feel like the people who need the help most are the least likely to get it’

‘I am not getting help from mental health services but that’s OK, I don’t feel I need any. I am not getting help from social services either but am ok about that. I get some support via the voluntary sector. I call in at Lifecraft and used to use groups there, but I have noticed they are no longer available. I call in at the Edge café in Mill Road, Cambridge, I appreciate the breakfasts there. I enjoy an art class at the Edge café. I have been in touch with Russell Street social care resource for people with learning disabilities in Cambridge and hope they might help me find a job. More dynamic and consistent help into employment recognising my strengths in Maths would have been helpful (especially in Cambridge where such companies have proliferated in the past 10 to 15 years). I am on no medication and don’t need to be. I don’t often see my GP’

Stage 2:
‘I have been discharged from Life works. I miss this. Engaging with individuals with the same diagnosis and having the one to one session with a professional, really helped me manage my mental health. I’m finding managing my wellbeing more difficult by not having it there. The door to so many services is closed to me, because of my diagnosis. I have had to find other ways to help me manage my mental health. Although this is helpful it is not the same. I often end up being the one who supports others. Being part of a group to do arts and crafts has been a huge help to me but I am missing that at the moment due to Covid-19-19- 19’

‘I do call NHS 111 option 2 in a crisis, but I have to be in a crisis to get help, and even then I sometimes have to wait for a Sanctuary space not knowing if I will get one and waiting to find out is hard. If they could just send a text message letting you know that they are aware that you are on the list that would really help. The last time I didn’t get in, Glenn from Mind called me a couple of days later (tried to access Fri, called Monday) and I really appreciated that, It made me feel like I wasn’t forgotten. Other than that, I cannot access any other support. Just crisis support and that is only available sometimes’

‘I have previously been under the Older People Mental Health team, but support fell apart. I have recently been back in touch with them and waiting for an appointment. I don’t think there will be anything they can do. It is pointless really. I feel my MH journey has been very poor. I have been misdiagnosed with things, diagnosis changing and even feel like I have been mistreated. My multitude of medication has made things worse. But there has been a slight improvement with medication. A lot of the time I am told my medication is optional. If I feel like…then take this…’

‘I became unwell again in December. I booked an appointment with my GP but wasn’t seen until 17th Jan 2020. At this appointment I was referred to the PCMH Service. I am still waiting for that appointment. Because I didn’t get to see my GP when I needed to, I ended up at A&E and was seen by the Psychiatric Liaison team. They were a joke. As soon as they found out my diagnosis of PD I was treated completely differently. They made me feel like a child, talking to me in a patronising way. They treated me as my diagnosis not as an individual who was struggling at that moment in time. They said to me “I deal with people like you every day” they spoke to me like a child “sit here, take your coat off, look at me” I felt like I was in the head teachers office. I was referred onto the Crisis Team. They were really good and much improved since I last had them involved. A massive change in how they helped and communicated with you. They worked hard to offer me treatment, advice and guidance at how I could help myself right now and we worked together to find out what was needed. I felt better after their involvement. They were clear about what would happen next and checked if would be happy with that. I was referred back to my GP and my medication was changed. During this time, I was at the sanctuary. It was so nice they remembered me as I haven’t accessed in a long time. I came away feeling calm and reassured’

‘Medication - Medication review, 2 – 6 months Clozapine - Willingham Pharmacy with the doctors. Health Check - every 6 months. Psychiatrist – every 3 – 6 months. CPN - Sharon has been withdrawn – OT – Sarah - Gone – Help is now via the Mitchel - medication/bloods – support workers there but no more home visits. Did not get put in touch with other services. – only with Recovery college – recovery coach. – But didn’t feel I could engage, as it was too much of a leap to engage. I don’t know how to get back in. I’m under a 117 section - Treatment order. My support was Once a week, then every 2 weeks, then it went to once a month, but I was struggling so then went back to 2 weeks and now it is completely withdrawn. Told I am ‘well enough not to have the support’ It has been a very long journey with my MH health support and when you last interviewed me in September I had been discharged from all services. I had received quite a lot of help while my youngest child was under one but that ended and once I got my PD diagnosis all help seemed to cease. Since then I felt I was being passed around from pillar to post. I got confused with all the acronyms and thought PWS and PDCS were the same service and was constantly confused why PWS kept rejecting my application. I came to realise they were different and PWS didn’t accept PD diagnosis patients and I didn’t meet the threshold for PDCS. I was not in a positive place, but I did try and engage with Mind’s PD group sessions that they run. I started in Ely, then went to Cambridge and didn’t even manage getting to the Sawston group. Ely was just too far away for me. I found trying to park for the Cambridge session too stressful and by the time Sawston came up I just didn’t have the energy and motivation to go. It was also too far for me to get there. I have tried many doors for support, but none seem to be easily accessible or they remain shut. I eventually went private and paid for DBT sessions. I found the women lacked focus and structure and I didn’t know where it was going. I feel I am trying to engage, but just not getting anywhere. It has felt like a constant battle and fight and that is so hard when you feel you have nothing left and struggling to try and get through each hour, let alone a day. I have had huge problems with my medication. What should be sorted quickly has taken multiple visits, contacts and again just being passed around from person to person. I was prescribed one drug and because I had stopped taking it and then told to start it again during an appointment with the Psychiatrist, the Pharmacist wouldn’t prescribe it without authorisation from the Psychiatrist. They couldn’t call them and get that which meant I had to wait for another appointment with the GP then await an appointment for the PCMH team only a couple of weeks after initially seeing them. I felt it was completely ridiculous to have to continuously go through this process. Thankfully I have a good GP and they contacted the Psychiatrist to authorise it. I had a follow up appointment after all this with a new Psychiatrist and was prescribed a new medication. I was also prescribed an additional drug to help with my anxiety but once again when I went to collect my prescription the pharmacist said they couldn’t prescribe both together as they flagged up with a caution. So, it was then back to the psychiatrist, who informed me on their records it wasn’t flagged as a bad combination as it could cause serious side effects. Again, I just felt I was continuously being told different things by different people. No one seemed to know anything about each other’s role. The Pharmacist said that secondary MH teams know nothing about dispensing protocol, and it was always secondary MH teams saying things can be done when they can’t. It just creates false expectations and a lot of hard work to-ing and froing between the professional to get an answer. I am having to do the leg work. It was the Pharmacist that enquired whether I had had a physical health check and that should have been something that was done. I went for an initial assessment, but the practitioner didn’t seem to know what they were doing. The blood pressure cuff didn’t fit etc. I then was called in for another one, which was cancelled due to Covid-19. Eventually after all of this which had been going on since September last year I was finally put on some medication that seems to be working and told to take the other one as and when I felt I needed it. Which I haven’t as I have now lost faith in those that are meant to be keeping my health safe. All this uncertainty has just added to the anxiety. I feel more stable than I have done in a long time and feel hopeful’

‘I am not accessing any mental health services. The only things available to me would be if I were in a crisis, they would be 111 option 2, A&E, (where nothing would happen or the Sanctuary) I just have to try and find ways to self-manage. It always has to be extreme circumstances to get any help. There isn’t anything in between. I am on the waiting list for an Asperger’s assessment. I’m not thinking about that though in any detail’

‘I used to see a psychiatrist when I lived in Wisbech at Agenoria House. He retired and I moved, to elsewhere in the Fens (Cambs) they then said I do not come under their umbrella anymore. I need urgent care and desperately need to see a psychiatrist again. I also saw Mind for six weeks then that came to an end. I have pleaded with my GP, but she just put me onto PRISM (now PCMH) who said my needs are too high to be met. What??!!’

‘CPSL Mind have been good. They were the first to get in touch for groups online. I check the CPFT website for updates every single day. but no updates and I don’t understand why I can go to a hairdresser or a pub, but I can’t see a mental health professional, and no updates. I feel there has been no recognition of the impact of lockdown, just get told it’s unavoidable. I‘ve been begging for support and been totally ignored. I shut down and stop trying to engage and then I hit crisis’

‘I have a friend in Wisbech. That support relationship has changed to where I can now offer her support. Lived experience has helped me learn skills to give time for me. Research and planning help me manage my anxieties’

Stage 3:
‘I was getting help through the adult ED team before Christmas, just a brief intervention with some therapy. It ended abruptly without me being involved in the decision making. I found out on the day it was ending. I thought with the new pathway there would be improvements, but I don’t see that as an improvement. Eating still feels a challenge at the moment but don’t feel I’d like more support right now as having to do the extra work would be too much for me at the moment. I didn’t get the opportunity to share my thoughts about the discharge. I have been through it before with other services so I now know how to handle it’

‘I get told no-one can help me. They wouldn’t say that if I had a broken leg’

‘I get support from my GP at the moment and that’s all I really want right now. I’m sure more support would help but not sure what support would help. I was ok with lockdown to start with as everyone was missing out, not just me, but now I have anxiety around opening back up. I have isolated myself too much and only work has kept me in a routine which has made lockdown easier’

‘I can’t find support anywhere. If my GP was in a different place I could get into Exemplar. I’ve heard it has just what I need. Seems unfair that I can’t use it’

(Following a conversation about Exemplar) ‘’Exemplar? I didn’t know about that. That sounds like exactly what I need – I was told I needed DBT but that it isn’t available anywhere’

‘I feel the support is there. I have been offered an 18-month programme with Exemplar, but I don’t feel motivated to complete it. I feel now is not the right time. And what if I complete it and they say I’m cured and my benefits are affected? I won’t actually be cured. I still have huge anxiety about going out of the house. I use NHS 111 and the Sanctuary when I need it. I could access more but I don’t feel motivated. I have got too used to my own company through lockdown’

‘I thought I was getting help. I thought I was on a waiting list, but when I contacted them to ask where I was on the list, I wasn’t even on the waiting list anymore. They just said they couldn’t offer me anything at the moment because of Covid. I didn’t get told about anything else I could get instead. I had been waiting ages and now I feel back at the start. I am so down about that. It is a horrible feeling to think or hope you are going to get some support, only to find no-one cares and no-one is helping’

‘I am not receiving any statutory support, but my volunteer work is my medicine. I have to push myself to get involved and have things to do. I was attending Good Mood cafes online but have not felt the need to recently, as I am so busy. ‘

Enough Informal Support

Stage 1:
‘My family are supportive. I play golf twice a week with a friend who has mental health issues as well. I work as a volunteer one day a week which helps’

‘My friends are very supportive’ I have a poor support network. My girlfriend isn’t very supportive, she is pushing me to get a diagnosis. I also don’t want to burden people’

‘I do yoga and have my allotment. Also some really lovely friends and I have my sister’

‘There is only my wife, and she is already doing too much’

‘I have no support from family as I had to move to Cambridgeshire. I set up a mental health support group in St Neots and chat to others there. I have found support and empowerment with The SUN Network. I have had to find things for myself as nothing has been signposted to me’24 ‘only one friend and my husband know my story. I tried to tell my mother, but she denied it ever could have happened. I don’t like to burden people or ask for help’

‘My family are great, but they are not educated in my diagnosis (BPD) and don’t understand it or help me change. They can only support what they see right in front of them. Family and friends support should not be in place of having an actual service run by professionals. My family can’t always be there either. I can’t always be honest with them about how awful I feel (suicidal) as I don’t want to burden them with that’

‘I now have an amazing support network. People at the craft group I attend. My mum has been the person most dedicated to my recovery. My partner turned my life around and was the spark to a more positive recovery for me. My daughter is the center of my world and in the darkest moments has been what stopped me going too far. Although I no longer use diagnosis I was diagnosed with PD’

‘I have good support from my partner and their family. And support from friends and work’

‘I have good support from my family and the few friends I have’

‘I have great support from my family and husband. They have picked up the pieces. Family have given support when services haven’t. Although this is amazing, they are not qualified mental health specialists’

‘I have no family, and my friends are my safety net. They looked out for me when things were very bad. They acted on my behalf as I was completely shut down at my lowest point’

‘I access The Edge café which has helped me get close to others. My family are supportive, I have my mum and my sister who I can talk to. I have another sister that I meet socially. I wish I had more friends. I have good friends, but I would like to make more which I am doing slowly’

‘Happy where I live and appreciate the support of family and friends. I would like a partner’

Stage 2:
‘Despite the current situation I have had contact over the phone and via text messages with friends and family but a lot of these people either live a long way away or are shielding so I am still unable to connect with them’

‘I have my partner who is incredibly supportive but often feel I don’t want to burden him as he has his own MH to deal with. Friends are supportive but they don’t know the full extent of my MH or the whole story, so it is hard to completely confide in them. Friends just want to fix me, make it all better, but lack the acceptance of needs. I struggle to reach out for help. ‘I am lucky and have the support of my husband’

‘I have three friends that are all to do with MH. They are more valuable than all the friends I had in the past. Crime, drugs. I wanted more than that. If you want something and you try hard and more often than not you get it and if you don’t you tried. All depends on how much work you are willing to put into it. They don’t want anything from me not going to cause me any hassle. Not related to my past. Feel safe with them’

‘My friends and family are amazing. They have helped me the most, they are always there for me’

‘I am one of 4. They are supporting as much as they can, but it is not enough. With my mother passing and sorting out the will, things have got complicated. I am no longer in touch with friends’

‘My family are supportive, but I don’t want to burden them. It’s not their job. My parents are in their 70’s. I don’t want to worry them. I would like to make more friends as I only have one friend and I can’t put everything on her’

‘My husband is my full-time carer, so he is great and knows how to handle my splits (moods) which is great. I don’t have any friends as it has been too hard for me to maintain friendships. Before Covid-19 I saw my boys every fortnight but have not seen them in ages and it is distressing me a lot’

‘I don’t like family and friends to know how bad things are for me. I talk to a couple of friends to a degree, but I don’t want to worry them’

Stage 3:
‘I haven’t felt the need in the past six months to seek help. My social circle has increased, so there is more support through friends to help me through the bad days which are far and few between. Having that contact has made a difference’

‘I got a rescue dog, and I don’t know what I would do without him. He is the ONLY reason I go out of the house every day. Everything else I get delivered to the door’

‘My family are really great. We have spent many years working together to build and develop our relationship. It took a long time to stop being dishonest and it took a long time to have the courage to speak honestly. Saying what you feel, how you are, what you need, what you want, being able to share those dark thoughts. I feel I have neglected my friends recently but realised I needed to re-engage and make the effort’

My family support is better as they have had more time for conversations with lockdown. I don’t go to friends for support as they are not there for that. I feel more confident to talk to my family now’

‘I do have a great relationship with my family, and they would support me if I asked, but why should they. I wouldn’t ask them to treat me for cancer so why should they have to be unqualified mental health support?’

‘I get frustrated that my family are expected to look after me when I should be able to get professional mental health support. Why can’t I get help? Why? Why?’

‘I get enough support from friends who have had similar thoughts and feelings to mine. I do crafting with others’

‘’I’m not sure. I don’t like that there would be a dual relationship there as support/family member. How would I talk to my family about suicidal thoughts or no motivation? They wouldn’t understand really’

Satisfaction with Current Situation and Final Comments

Stage 1:

‘I don’t really have any friends. Or I attract friends that just use me or it’s one-sided. I support them and they don’t support me. I would really like some decent friends. I would like to be able to get some help from somewhere. Anyone who can understand how things are for me and how hard life is and really get how I am feeling. I wouldn’t wish this on anyone’

‘I’m ok. I take my meds and they seem to help. I would like more, but I don’t really know what I would like. I’m not satisfied but what else is there?’

‘No. I am not satisfied. I think there should be help out there for people like me. Why isn’t there? I don’t get it’

‘Parts of it I am happy with. Other parts I would like more. Then I feel guilty for wanting more and start having a go at myself in my head saying other people are worse than me, and I feel ungrateful’

‘Nope. Not satisfied.’

Stage 2:

I would like it if I could get my medication from the pharmacy in fewer trips. My medication works out every 14 days each medication, but I collect one every other week as they cross over. So I have to go out to the pharmacy every week. I would like to go less if I could’

‘I feel anxious about Covid and the help I get is on the phone now and it doesn’t feel the same. I would prefer to see someone face to face’

‘I don’t like to bother people at the moment. Covid makes me want to just stay at home and leave everyone to help those that need it more’

‘I am unhappy as I can’t do any of the things that made me feel happy and helped my mental health. I can’t see friends or family’

Stage 3:
‘I feel grateful for the good times, but there seems to be this block that stops me from enjoying life’

‘I wouldn’t mind if I died. I don’t enjoy life. I have been here before and know it will pass eventually but I don’t know when, and right now, I don’t care about anything’

‘Life is good but it won’t be great until I get back into full time employment which is my goal. I am happy with the increase in activity by being involved with the SUN Network, CCG and CPSL Mind’

‘I think for about a year and half it took me to find a job and I am now really pleased that I have found something and made a start to feel satisfied with life. The time of year makes lots of difference saying goodbye to the long winter. Coming out of lockdown I feel hopeful and there are opportunities to look forward to. They are the things that are making feel optimistic’

‘it would be good if I could get some DBT’

‘My family and friends keep me going. I feel guilty for relying on them and that stops me enjoying things. I feel like a burden’

‘I can’t seem to get any help. It’s hard to feel this way and not know if it will ever change’

‘Who would be happy if they felt this way all the time? I’m not satisfied with feeling this way’

‘I get knocked back for everything. I can’t go to the GP as there is nothing she can do. I can’t go to other services as they can’t do anything. I can’t get help anywhere’

Conclusion

In conclusion, although the numbers of participants decreased over the lifespan of the project, the themes remained consistent.

- People do not have a good knowledge of what support is out there. The SUN Network consistently signpost people to services they were not previously aware of. Unless people have accessed services and have a knowledge of the local Mental Health field, they do not know that CPFT are the local NHS mental health provider, or that CPSL Mind exists, and very little knowledge of other smaller providers
- Knowing where to look for help is also an issue. The first port of call is the GP surgery, when many services can be found and accessed online, The GP may or may not be knowledgeable around mental health and may or may not be aware of available services for their patient, and whether the patient is eligible for those services or not

- There are barriers to finding and accessing support, particularly for personality disorders.
- People are still treated as a diagnosis as opposed to a holistic person. A personality disorder or PTSD diagnosis tends to exclude people from accessing services as they ‘become’ ‘too complex’
- Gaps in services. There are still gaps for people to ‘bounce around’ in without receiving any support at all. This is down to lack of joined up working within services or a lack of knowledge within service staff. For example CPFT staff routinely advise people with personality disorder to refer to the CPFT Psychological Wellbeing Service, who do not work with people with a diagnosis of personality disorder
- It is also difficult to find the right support at the right time due to waiting lists or being referred or ‘bounced around’ services without being taken on. Covid has inevitably played a part in this. People report ‘giving up’ as they repeatedly tell their story to a new service only to get turned away for support
- There is an ongoing reliance on family and friends who operate as unpaid and unqualified carers in the absence of professional support
- Consistency of service. People are retelling their stories repeatedly due to either attempting to access numerous services and being turned away, not seeing the same person within one service twice, or communication between services or departments not at a level whereby notes can be shared or accessed by all relevant people
- Crisis care – people cannot access crisis care for as long as they would like, resulting in them feeling ‘dropped’ after the immediate intervention
- Diagnosis – people are trying to hide or change their diagnosis for fear of not being able to access services

Acknowledgement

A heartfelt thank you to all the participants who gave their time and a little piece of themselves for the greater good of improving mental health services for others. You are amazing.

Recommendations – Carers and Service Users:

- Co-produce all services, service literature, and service reviews and involve people with lived experience and carers at every opportunity
- Make sure the Peterborough Exemplar approach to community mental health services has the best possible impact and then roll it out across Cambridgeshire
- Improve communication of what mental health services exist and how they can be accessed – so that everyone including staff spends less time seeking resources
- Resist pressures to add new small and/or time limited services into the system; use people with lived experience to tell you whether a service is easily understood or not
- Deliver services that wherever possible provide holistic care rather than care based on single diagnoses such as BPD (or that exclude people on the basis of diagnosis)
- Ensure that all new opportunities to strengthen community mental health services include in their aims improving access
- Explore options for building services around care co-ordinators/connectors who can maintain relationships with patient and family over time and provide continuity of care
- Examine role, aims and impact of mental health social work

- Define what rehabilitation means for today’s people with severe mental illness and what level of priority it should be given
- Use of new roles e.g., social prescribers, and community connectors to raise understanding of mental health issues in their areas
- Continued training programmes in CPFT and voluntary organisations on best practice in carer engagement

Appendix 1 – Carer interview

1.	**Details**			
	initials			
	initials of cared for person			
	All sections below refer to the cared for person			
	Age		What gender identified with?	
	Ethnicity		Sexuality (Hetero/L/G/B/P/A /prefer not to say)	
	Location by district council		Peterborough Cambridge City Fenland Huntingdon East Cambs South Cambs Not Known	
2a.	**Current Mental Health (symptoms)**		Please rate current mental health on this scale: 5 – great 4 – good 3 - neutral 2 - poor 1 - very poor	
	Use your own words to say how they are at present:			
2b.	**Current Mental Health (recovery)**		Please rate their ability to live life to the full at present on this scale: 5 – great 4 – good 3 - neutral 2 – poor 1 - very poor	
	Use your own words to say what life is like for them at present:			

3a.	**Support – Mental Health Services**	Please rate whether they are getting enough support from mental health services (CPFT(NHS) CPSL Mind etc.) on this scale: Yes No Not Sure	
	Use your own words to say more about this:		
3b.	**Support - Other**	Please rate whether they are getting enough support from other sources (family, friends, other things to do) on this scale: Yes/ No/ Not Sure	
	Use your own words to say more about this:		
4.	**Satisfaction**	How satisfied are you with this situation – on this scale? 5 – very satisfied 4 – satisfied 3 – neutral 2 - quite dissatisfied 1 – very dissatisfied	
5	**Extra questions added for stage 2**		

	Covid In an Ideal World		
	interview no	date	Interviewer

Appendix 2 Interview – Lived Experience

The Winding Road – Questionnaire

1. Details	
Name: (initials)	
Age:	
What gender do you identify as?	
Ethnicity	
Sexuality	
Location	
2a. Current Mental Health (symptoms) Please rate your current mental health on this scale: 5 – great 4 – good 3 - neutral 2 - poor 1 - very bad	
Use your own words to say how your mental health is at present:	

2b. Current Mental Health (recovery)

Please rate your ability to live life to the full at present on this scale:
5 – great
4 – good
3 - neutral
2 – poor
1 - very bad

Use your own words to say what your life is like at present:

3a. Support – Mental Health Services

Please rate whether you are getting enough support from mental health services (CPFT(NHS) CPSL Mind, GP surgery etc.) on this scale:

Yes/No/Not Sure

Use our own words to say more about this:

3b. Support - Other
Please rate whether you are getting enough support from other sources (family, friends, other things to do) on this scale:
Yes/No/Not Sure

Use our own words to say more about this:

4. Satisfaction
How satisfied are you with this situation – on this scale?
5 – very satisfied
4 – satisfied
3 – neutral
2 - quite dissatisfied
1 – very dissatisfied

If there were no limits to what could be provided to support your mental health, what would you like?

interview number	1 2 3	date
initials of interviewer		