Edinburgh Community Voices

Experiences of
Side Effects of
Mental Health Medication:

A Peer Research Project

EDINBURGH
COMMUNITY
VOICES

a city-wide advocacy project
AdvoCard
for users of mental health services

Edinburgh Community Voices is a collective advocacy group for people in the community in Edinburgh who have lived experience of mental health issues. Edinburgh Community Voices is facilitated and supported by AdvoCard Community Collective Advocacy.

We would like to say a big thank you to everybody who responded to the research, to the steering group and to the peer researchers.

A large print version is available on our website or by contacting us as below.

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Introduction

At the end of 2016, Edinburgh Community Voices carried out a survey to hear from people who have lived experience of mental health issues about what's important to them when it comes to improving their physical health.

Following on from this, we set up a steering group of people with lived experience to discuss how to address the issues raised. The group decided that they wanted to do some peer research to hear more about people's experiences of and views about two of the issues – side effects of mental health medication and treatment and support for physical health issues.

Peer research is research which is directed and carried out by people who have lived experience of the issue which the research is looking at.

The steering group did the initial planning of the research, including how we would carry out the research and what questions we would ask. The later stages of the research, including finalising the planning and analysing the results, were carried out by two peer researchers (both members of the steering group), together with one of the AdvoCard Community Collective Advocacy Workers.

Michelle Howieson was one of the peer researchers. The other peer researcher preferred to remain anonymous.

We ran the two peer research projects at the same time but have published the reports separately.

Experiences of Side Effects of Mental Health Medication

The aim of this research was not to make a judgment about whether or not medication should be used to treat mental health issues.

We carried out the research to hear from people about their experiences, to get these down on paper, to identify any common issues, and to hear from them about what they think needs to be done to address the issue of medication side effects.

This report does not mark the end of this piece of work. We plan to hold one or more events with people with lived experience of mental health issues to discuss the results of the peer research, what action they think needs to be taken to address this issue and what our next steps should be.

If you would like to get involved, please contact Becky Leach (AdvoCard Community Collective Advocacy Development Worker):

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How We Did the Peer Research

The research was open to anyone who lives in Edinburgh and who has lived experience of mental health issues.

We decided to use a questionnaire to hear from people rather than carrying out interviews. This was so that we could hear from as many people as possible, as some people would find it difficult to get out of the house to make it to an interview. It also gave people the opportunity to reflect on their response and to make sure that they were happy with it before submitting.

We gave people four different ways that they could respond to the research to make it easier for them to take part:

- Online using online survey tool ‘smartsurvey’
- In a word document sent to us by email
- By filling in a printed questionnaire
- Meeting up face to face so that we could help them to fill it in

(All four of these methods for responding were used by research participants.)

Responses were open for submission between September and December 2018.

Full information was provided about what was involved in taking part in the research and how the contributions would be used so that people could make an informed decision about taking part.

These are the questions we asked:

1. Please tell us a little bit about the side effects you have had. For instance, what they are and how long or how often you had or have had them.

2. What impact have the side effects had?

3. Have you been given any support to help with the side effects? Or is there anything you found helpful?

4. Do you feel that you were given the information you needed about potential side effects? If yes or no, please say why.

5. Do you feel that you have been listened to and that your views have been taken into account in decisions about your medication? If yes or no, please say why.

6. Is there anything you would have liked to have been done differently? Please give details.

7. Are there any wider changes that could be made to address the issue of medication side effects?

Summary

We heard from 22 people.

They told us about a wide range of side effects that they had experienced.

They told us that the side effects had an impact in different areas of their lives. These included but were not limited to a negative impact on:

- Physical health
- Mood and mental health
- Self-esteem
- Ability to work
- Relationships and social life
- Ability to exercise / levels of physical activity

People had different experiences when it came to how much support they received to help them with the side effects. Some people did receive support but many did not.

Some people felt that they were given the information they needed about potential side effects, however some people felt that they were not given enough information and some people were not given any information.

Some people told us that they were listened to, some people told us that they were listened to in part and some people told us that they were not listened to at all.

In answer to our questions about support and information given and being listened to, some people told us that it depends on the doctor - they had had good experiences with some doctors and bad experiences with others.

These are the things that people would have liked to have been done differently:

- To have had more information
- A longer appointment time when the medication was prescribed
- More support from the doctor

- A support group with other people who had experienced side effects
- To have been listened to
- To have had their concerns and their side effects taken more seriously
- There to have been more understanding of the impact
- The likely impact of the medication to have been taken into account when the medication was prescribed
- Options other than medication, including counselling
- To see a counsellor or psychologist first before being offered medication
- Not to have been given medication
- Option of different medication
- To have received an accurate diagnosis in the first place

When we asked if there were any wider changes that could be made to address the issue of medication side effects, these are the ideas that people gave us:

- More research into medication with fewer side effects
- More alternatives to medication
- Increased investment in talking therapies
- People to be given more information about side effects
- More support given to people to help them deal with side effects
- When someone is given medication when they are receiving treatment for their mental health in hospital, include side effects in their Patient Care Plan
- Minimum dose prescribed for shortest time
- A check-in with the GP to review the benefits of the medication against the side effects
- The NHS no longer prescribing drugs which are likely to have a negative impact on a person's wellbeing and self-esteem
- More acknowledgment of impact of side effects
- More understanding and sympathy
- Training for non-mental health doctors and nurses

Our Findings

What were the side effects?

People told us about a wide range of different side effects. Some of these related to their physical health, some of them related to their mental health and some of them related to things like memory and concentration.

The medications which people told us that the side effects came from included antidepressants, anti-anxiety medication, mood stabilisers and antipsychotics. One person experienced side effects as the result of electroconvulsive therapy (ECT) which although it is not a medication is a treatment that was prescribed for a mental health condition.

Medications were prescribed by GPs and psychiatrists. One person had side effects from medication that they were given whilst receiving treatment for their mental health in hospital.

The number of side effects that each person had ranged from one to ten. The average number of side effects per person was five.

These are the side effects that people told us about:

Dry mouth

Dry eyes

Blocked salivary glands

Twitches of leg and mouth

Parkinsonian side effects

Benign tremor

Tardive dyskinesia

Facial twitches

Tiredness

Lethargy

Feeling sluggish and dopey in the morning

Feeling very sleepy

Half awake / half asleep ‘dreamy state’

Very vivid dreams

Increased insomnia

Restlessness of limbs leading to insomnia

Sleeplessness

Suicidal urges

Dissociated feelings

Very flat feeling and very little motivation or emotional response

Impact on motivation

Severe depression

Severe anxiety

Severe panic attacks

Very tense and agitated

Increase in addictions – smoking, alcohol

Vivid visions

Urticarial – generalised itch (though person was not sure if this was a side effect)

Nausea

Vomiting

Gum shrinkage

Pain due to depot injection in upper arm and buttocks and blood tests.

IBS

Bowel problems

Diarrhoea

Incontinence

Constipation

Freezing of limbs leading to falling over when feet spasm

Weight gain

Weight gain due to food cravings and increased appetite

Low metabolism then underactive thyroid then weight gain (9 stone 14 to nearly 13 stone in six months). Also Type 2 diabetes but not sure if this was due to medication.

Clumsiness

Drowsiness

Confusion

Poor concentration

Problems with memory

Memory loss

Brain fog

Feeling heavy in the mind

Unable to think clearly / think straight

Poor cognitive function

Increased blood pressure and pulse

Balance problems and other gross neurological problems

Joint problems i.e. arthritis spondylosis

Bilateral glaucoma and visual acumen distortion

Drooling

Vomiting and electric shock type feelings in your head when coming off a medication

Sweating

Slurred speech

What impact have the side effects had?

One person told us that the side effects did not have an impact for them.

However, for everybody else the side effects did have an impact, and for many people this impact was considerable.

For some, the impact the side effects had was in one area of their life. For others, the side effects had an impact in different areas of their life.

These are the ways people told us the side effects had an impact for them.

Impact on mood and mental health

For some people, the side effects had an impact on their mood and mental health.

One person told us that they experienced side effects of suicidal urges and dissociated feelings, as well as increased insomnia, lethargy and nausea. They said that these side effects made them feel ‘more vulnerable and at risk’.

Another person described the side effects they experienced as leaving them feeling:

> ‘pretty low and suicidal because I don’t really see the point of living when I am not really able to do much. Sometimes I go for very many days without being bothered to have a shower or eat properly or get myself dressed even. This is all very debilitating and makes me feel like just giving up completely.’

Another person decided to stop taking their medication on their own in order to test their view that it had made their health worse. They told us:

> ‘Coming off [the medication] unaided meant the most crippling anxiety and depression I have ever had.’

One person told us that the visions they experienced as side effects caused them distress.

Other people experienced distress as the result of physical side effects. For instance, one person told us that the facial twitches they experienced ‘caused me great distress and made me very self-conscious’.

For one person, the physical side effects they experienced affected their ability to work, to go to their yoga class, to get out and about and to meet friends, and this had a subsequent impact on their mood:

> ‘When dealing with the very worst side effects going onto or coming off psychiatric medicine, the physical side effects of nausea, vomiting, dizziness and sleepiness mean that I have missed out on work and countless activities that I would normally do to help my mood, such as going to yoga class and getting out and about and meeting friends. So the physical side effects then have a negative impact on my mood, I am unable to do the things that I know help.’

Self-esteem

Many people told us about the impact of side effects on their self-esteem and confidence.

For some people, weight gain had a big impact on how they feel about themselves and how they look.

One person said:

> ‘Weight problems have caused very low self-image and very low self-esteem. I really hide from looking in mirrors, I don’t like my reflection at all. Self-esteem and self-image are main parts of your overall wellbeing.’

It is not just weight gain that can affect your self-image. One person described feeling that they ‘appear drug induced to others’ if they are not wearing make-up or if they have taken greater amounts of medication, and they feel self-conscious about that.

Other people talked about feeling self-conscious because of facial twitches or twitches in other parts of their body.

One person told us:

> ‘Friends thought I was peculiar because I had the twitches’.

Another person told us that they have found a Parkinsonian side effect to be ‘very stressful and embarrassing’.

One person told us about the impact on their self-esteem of side effects of memory loss, poor concentration and ‘an inability to think straight’ which they experienced as a result of ECT (Electroconvulsive Therapy). They told us:

> ‘Lack of memory has increased my feelings of low self-esteem….why can’t I remember my phone number which I have had for 25 years? Not being able to plan a route in my head as to how to get from A to B, constantly having to check that I have everything I need when leaving the house, needing to write everything down rather than rely on my own memory, feeling stupid for closing my eyes when I’m speaking to try and focus on what it is I need to say.’

Your feeling of connection to self can also be affected by side effects like these. One person, who experienced side effects of brain fog, tiredness, ‘feeling very heavy in the mind’, and being unable to think clearly, said of the impact these side effects had that: ‘I was tired for months and felt quite disconnected from myself.’ This person also felt that their ability to make ‘wise judgments’ was affected.

Lowered self-esteem also came about where side effects had an impact in other areas of people's lives as you will see.

Ability to work

Some people told us that their ability to work was affected by the side effects they experienced.

Tiredness was a key factor for some people. One person told us 'a job would be impossible because of my tiredness'.

Another person told us about the impact that drowsiness and confusion had upon the quality of their work. 'Eventually', they said, 'I was unable to take my medication as prescribed because they made me too drowsy to be able to function at work during the day'.

Another person had to reduce their work from full time to part time. They told us that their self-confidence has suffered as a result.

Another person said that while they are still able to remain in work:

> 'Sick absences from work lead to increased stress as HR often get involved in not very helpful ways if a "trigger point" of x number days off sick per year is reached, and prolonged absences result in half pay, then zero pay, which adds to financial pressures'.

The impact on a person's ability to work can have a secondary impact on their financial stability and housing situation. One person had to stop working altogether because of the side effects they experienced as they became too ill to do their job. They told us:

> 'Currently I am only on Employment Support Allowance. I face the loss of my home, since I live alone and I am a sole mortgage holder on my flat. I am facing having my gas and electricity supply cut off.'

Another person talked about the long-term impact on their ability to work:

> ‘Quite apart from the life-sentence nature of the stigma of the diagnosis making it impossible to hold down jobs or even obtain jobs, the side effects of medication do the same.’

Impact on relationships and social life

Several people talked about the impact of side effects on their relationships and social life.

Tiredness, lethargy, sleepiness, low motivation, nausea and vomiting and dizziness were all mentioned by people as having affected their ability to go out, meet their friends and socialise.

Exercise and physical activity

Some people talked about side effects having an impact on their levels of physical activity or making it difficult for them to exercise.

One person had to stop swimming because of a distended gut, IBS and getting cramp.

Another person talked about the impact of weight gain: an increase of five stone meant that they went from being ‘an athletic young man of reasonable fitness and agility’ to walking being their only form of exercise.

Another person talked about not being able to go to their yoga class due to side effects of nausea, vomiting, dizziness and sleepiness.

Increased risk and delayed diagnosis of breast cancer

One person told us about a very specific impact that the side effects they experienced had for them:

> ‘I think that the subsequent weight gain increased my risk of breast cancer and wasn’t taken seriously enough by my previous psychiatrist or one of the GPs in my current practice despite me continuing to express concern. I also didn’t seek help for cancer symptoms at an early enough stage for it to be cured as I put the symptoms (particularly the tiredness and feeling sick) down to side effects of psychiatric medication.’

Lost independence

One person told us about the impact on their independence of side effects which included bowel problems, joint problems, balance problems, tardive dyskinesia and bilateral glaucoma.

They said:

> ‘These side effects have rendered me unable to weight-bear and walk, to see, to feel and touch, unable to be free from pain. Distress generally. Totally dependent on others, which to me is an anathema.’

They also told us that following colorectal surgery, which they had to undergo because of the side effects, they were unable to return to their flat in the community,

> ‘where I had lived as a proactive and interactive member, much respected and much valued. My life fell apart. I lost my family, my cat, my flat, my independence, but most of all my raison d’être and liberty. So as a woman of 65 I felt my life had ended.’

Impact of side effects affecting sexual function

One person had side effects of erectile problems and retrograde ejaculation. This is what they told us about the impact of these side effects:

> ‘I have found that prolonged use of these drugs has had a permanent negative effect upon my sexual function. This in turn has a negative effect upon my self-confidence and self-esteem; and as a single gay man it increases my sense of isolation, as I feel I can offer little of what prospective partners might expect of me. It also forces me to out myself in terms of my mental health issues as I feel I need to explain to prospective partners I am using [mental health medication] much earlier than I might otherwise prefer.’

Other kinds of impact

Some people told us that they stopped taking the medication that they were on because of the side effects they experienced. One person told us that they became ‘very unwell as a result’.

One person has had to be very cautious with their diet because of IBS. They also now have to wear an upper plate because of gum shrinkage.

One person told us that they:

> ‘have quite a serious set of addictions now, that must be almost constantly kept at bay’.

One person told us that the side effects:

> ‘threaten to shorten my life and blight my life-expectancy’.

For one person the weight gain affected their menstrual cycle.

Some people had to take extra medication in order to counteract side effects, including high blood pressure and tremor.

One person had to have surgery to their salivary duct after their salivary glands became blocked.

Some impact but happy overall

One person told us that although their side effects did have an impact, on balance they are happy that they have taken the medication:

> ‘The urticaria is a bit of an issue but generally not too much of a problem. The benign tremor is quite noticeable now and more annoying. At the same time I do believe [the medication] has really helped me to keep my head above the water over the years. It may well have saved my life. I do not have any other significant side effects from [the medication] that I know of, so I feel relatively fortunate, especially considering the list of possible side effects I had to consider before starting on it.’

What support has been given to help with the side effects? / Is there anything they found helpful?

Some of the people we heard from told us that they have not been given any support.

One person told us that it was ‘just the little leaflet that was in the box’. They said that:

> ‘That’s all, I wish I could have had more. Perhaps people thought that they weren’t particularly bad and that’s why they didn’t give me more support, but they were a nuisance.’

Some people talked about being given extra medication to try to counteract the side effects.

Others talked about their original medication dosage being adjusted or the doctor giving them a different medication.

One person described receiving their depot injection less frequently as a ‘positive step’.

Not everyone has been happy with or followed their doctor’s recommendations.

One person told us:

> ‘Support was offered, but I chose to stop [the medication] on my own and test my view that they had made my health worse. I wanted to come off them as quickly as I could without phased withdrawal and the doctor’s advice.’

They also said that:

> ‘the NHS support such as the Stress Control course (evening classes) was useful in particular. Unfortunately much of the support on offer was either too late or I had already read the information for myself.’

One person felt that their psychiatrist had been ‘heavy handed’ with their medication and they would have preferred to have been offered other options or other medication.

One person highlighted the difference it made when their GP listened to them, validated their experience and involved them in their care. They told us:

> ‘At first, my GP was really good as I came back saying I had a twitchy hand and she validated my experiences and really asked me if I wanted to continue to which I said yes (mainly because she was a good GP who listened). She guided me through upping the dosage slowly until I felt okay. Unfortunately, over time and having moved to a different surgery, the compassionate care I received was no more.’

Another person’s experience was the opposite of being validated, listened to and involved in their care. They said:

> ‘At the beginning of my treatment, we were not even told that the strange feelings we were experiencing were side effects and how to deal with them. Latterly, when I was developing my neurological problems in the community, I was not taken as credible and my problems were considered to be purely of a mental basis.’

Some people talked about things that they have found to be helpful in dealing with their side effects. These are:

- Exercise (including swimming and walking)
- Complimentary therapies
- Meditation
- Caffeine
- Allowing plenty of time to get ready in the morning
- Pacing yourself / avoiding anything social or physical when on greater amounts of medication
- Resting when tired

- Getting a daily nap
- Getting plenty of sleep
- Eating regularly / eating carbohydrates to control the nausea

One person was given advice by their psychiatrist to do 50 minutes of exercise per day – they said that this helped with weight gain and with their mood and they felt that it was an easy target for them to achieve.

Another person took part in a University of Edinburgh physical exercise study for people with their condition. They said that this was helpful in encouraging them to walk more and that 'this was because the young woman responsible for the study had very good interpersonal skills with people or participants'.

One person talked about meditation being helpful. However, they told us:

> 'This is help that I have had to seek out on my own because there is not one psychiatrist that I have ever known that has helped me with my side effects. They are very reluctant about giving out any sort of information to their patients about their side effects.'

Were they given the information they needed about potential side effects?

Most people told us that they had not been given the information they needed about potential side effects.

These are some of the things that people told us:

> 'No. I would like it, it was remiss of the powers that be to not give me that information.'

> ‘Never, never, never. And I go back many years.’

> ‘No. I’ve been on at least seven medications and all have risky suicidal ideation and physical side effects but feel left alone to trial these.’

> ‘I wasn’t made aware that one of the side effects could be a lowering of overall mood.’

> ‘Not from the doctors, I had to read up on this myself.’

> ‘No. Especially not re addiction, increasing tolerance meaning having to take more to get same effect and likelihood of having difficulties coming off meds.’

> ‘Whilst in hospital I was not given any info about any of the drugs that were administered and at least three different types were tried.’

> ‘Not when I was given [the medications] I was unaware that I might get visions.’

For one person the lack of information about potential side effects had a very specific impact. One of their side effects was blocked salivary glands and they needed to have surgery. But because they did not know that this was a potential side effect it was ‘a shock and frightening’ when it happened. Fortunately the oral surgery department at St John’s Hospital were ‘wonderful’ and were aware that this was a side effect of the medication.

One person was given information sheets to read, but, they said,

> ‘I don’t know if that information is necessarily what is required to make an informed decision. I mean the potential side effects of any psychiatric medication are pretty scary! And sometimes you feel so awful mentally that you are willing to try virtually anything if there is a chance it will help.’

Another person said:

> ‘I was told that [the medication] would ‘make me eat cakes’ but not given any support in addressing this.’

Some people did feel that they had the information they needed, or at least some of the information. This is what they said:

> ‘Yes. CPN told me. She said watch what I eat.’

> ‘Way back in 1998, yes I was given adequate information to make an informed decision.’

> ‘Yes on prescription info leaflets. Also on Bipolar Scotland website.’

> ‘Kind of. There are so many side effects that my GP at the time couldn’t go through them all but made me aware that there may be some and to tell her if I get any.’

One person has had different experiences over time:

> ‘Initially I was told to take the medication without any warning about side effects. I don’t know why not. Obviously they didn’t want me to know. In my most recent stay in mental hospital, being more savvy, I requested information about side effects of medication I was given and they complied. Again, I don’t know why they complied. Maybe they saw I was longer in the tooth. Perhaps they were beginning to wonder about the legality of administering drugs with severe side effects.’

Did they feel that they were listened to and that their views were taken into account in the decisions about their medication?

We had a variety of different responses to this question. Some people told us that they were listened to, some people told us that they were listened to in part, and other people told us that they were not listened to at all.

For some people, they felt that the psychiatrist’s views or preferences about medication affected whether or not they were listened to.

For instance, one person said:

> ‘I do not feel like I have been listened to in the past at all. Psychiatry is too interested in the drugs that they dole out to people more than I think how they would like to help their patients.’

Another person told us:

> ‘When I asked to be taken off the first medication I was taken off it and the psychiatrist put me on his favourite one.’

Another person told us that they did feel that they were listened to, however the psychiatrist ‘I felt was very meds heavy’.

One person told us that their experience, knowledge and insight into their condition was not recognised. They said:

> ‘I am still not being listened to. My experience and knowledge of my condition is very great. I studied medicine also and I never stopped learning throughout my life. I have massive capability for being objective in my insight and observation.’

Several people mentioned being told to keep taking the medication when they expressed concerns.

For instance, one person said:

> ‘I tend to find that most doctors and psychiatrists are quite unsympathetic and just tell me to keep taking the medication until my body gets used to it, or in the case of withdrawal to come off it more slowly.’

Some people told us that they felt that their views were overlooked or ignored when they have raised concerns about how side effects were having an impact on their wellbeing or have said that they don’t want to take a medication because it would affect their wellbeing.

One person, who had experienced side effects affecting sexual function, which had a major impact on their wellbeing, told us that:

> ‘It seems to me that I am expected to just take the pills and stop complaining, irrespective of how negatively they impact upon my overall wellbeing. Such side effects seem to be swept aside as unimportant.’

They also told us that:

> ‘A friend who uses mental health services within the Irish Republic and who has experienced similar side effects was offered a number of alternative drugs as soon as he highlighted the problem to his doctors; whereas this seems not to be the case in Edinburgh.’

Another person told us:

> ‘I think attention has been paid only in the most severe outcomes of taking a drug e.g. when I had a mini-stroke or heart-palpitations. Obviously I prefer medication with minimal side effects but I feel this view is being overlooked in my current position.’

Another person said:

> ‘I had one psychiatrist who was very keen for me to take [a particular medication], but I always resisted because they interact with a range of food stuffs including cheese, tofu and wine (basically anything fermented can be really harmful). I said no, because the thought of not being able to have cheese on my pasta felt too much, when depression had already cost me so much. But I felt my view on this was really looked down on and not seen as valid.’

One person told us that they felt that they were not listened to when they expressed concerns about the impact on their work and day-to-day life:

> ‘I felt like I wasn’t listened to when I said that I didn’t want to take the medication because it was impacting on my work. I felt that the doctors didn’t care that the medications were making many parts of my day-to-day life difficult for me, and I was told to carry on taking them even though I wasn’t experiencing any benefits.’

One person raised the issue of the lack of continuity in a therapeutic relationship with a psychiatrist:

> ‘Since discharge from hospital 10 weeks ago I have only seen a psychiatrist three times, the first left after the first two appointments so no therapeutic relationship and the second is a locum only here until December.’

They also told us that they ‘have strong feelings of not wanting to put any medications into my body unless absolutely necessary’. They have asked for a holistic approach to be taken to their condition and for a referral to the Glasgow Centre for Integrative Care but have been told that there is no funding for this.

One person, who stopped taking their medication three times because of side effects that included weight gain and tiredness and became very unwell as a result, told us that:

> ‘just being told to take it by psychiatrists without exploring and offering support around why I stopped it was not helpful.’

One person told us that they are ‘never given time’.

Another person similarly told us:

> ‘I have never been given sufficient time by my doctor to express my wishes sufficiently, at least not to her any way’.

Another person told us that they do not really feel they were listened to:

> ‘as if the medication makes me tired there is nothing much the doctor can do other than try me on something else, I feel like a guinea pig.’

One person felt that they were listened to by a GP who was compassionate and who validated their experiences. But other GPs, since then, they said, ‘I feel have judged me for taking the initiative to change medication and lower the dosage’.

One person said that they were listened to at first and received extra medication to help with the side effects. But since then they haven’t been listened to:

> ‘No one really wants to hear about or help me deal with this lowness of mood and spirit.’

One person said that they felt listened to in terms of having their medication changed several times. However, they do not feel that they ‘have received any support in creating a plan to come off meds, GPs seem reluctant to get involved or don’t have time’.

Of the people who said that they do feel that they were listened to and their views were taken into account, these are the things they told us -

One person said:

> ‘Doctors know best so leave it to them. So far so good.’

Another person said:

> ‘On the whole, yes. GPs and psychiatrists have been fine.’

Another person said:

> ‘Yes now because I’ve become an expert by experience in mental health.’

Things they would have liked to have been done differently

Some people told us that they would have liked to have been told more about potential side effects.

One person said:

> ‘Perhaps when I came off the second lot and was put onto my present lot, perhaps in the hospital they could have told me more. They treat people like idiots.’

Another person said:

> ‘In 1983, my initial 8 minute talk with a psychiatrist was not nearly long enough and there was no discussion of how [the medication] might affect me physically.’

One person said that they would have liked more information up front about addiction, tolerance and support available to amend or come off the medication.

Both information and support were mentioned by one person. They said that:

> ‘There should be support groups and better information from the doctor about how these medications can affect people. There should also be professionals supporting people with the different side effects in order to help people realise that it may be the medication that is making them feel a certain way.’

Similarly to this, another person said:

> ‘I’d like to have been given the opportunity to speak to people who had experienced similar side effects.’

Some people told us that they would have liked to have been listened to.

One person said:

> ‘I should have liked to have been listened to but not only listened to.. heard.’

Other people talked about wanting both their concerns to be taken more seriously and the side effects themselves to be taken more seriously.

One person said:

> ‘I would like someone to take these ongoing side effects more seriously. At least talk to me about them… are they usual? Is there some other drug I could try?’

Some people would have liked there to be more understanding of the impact of the side effects they experienced or continue to experience.

One person said:

> ‘I think a bit more understanding from doctors and psychiatrists about the impact of negative side effects would be helpful, rather than the attitude of ‘oh just keep taking them’. If I am feeling physically ill because of side effects, then that has a negative impact on my mental wellbeing, and prevents me from engaging in work and social activities that help to keep me stable.’

One person told us that they would have preferred the likely impact the side effects of the medication (erectile problems and retrograde ejaculation) would have for them to have been taken into account when the medication was prescribed:

> ‘I would like to be assessed and treated in a more holistic manner. For example, before deciding whether I should be prescribed [a particular medication], an assessment could have been made on the likely impact that such sexual side effects could have upon me and my lifestyle.’

Some people told us that they would have preferred to have had options other than medication.

One person said:

> ‘I would have liked to have seen a counsellor or psychologist first before I was put into the hands of psychiatry and their dirty drugs.’

Another person said:

> ‘I would like to have never agreed to try [the medication] in the first place. All I wanted was counselling, as it turns out that was all I needed.’

Another person said:

> ‘I would rather not have received medication. I would have preferred almost any other form of therapy. I have found advocacy beneficial; I have profited from peer support; I enjoy art, music and creative writing; I have developed my own coping strategies and receive a lot of help from my friends and family.’

One person said that they would have preferred to have been ‘weaned off their drugs in a manner that would have made me less dependent on them’.

For one person getting an accurate diagnosis in the first place before medication was prescribed is what they would have wanted to happen. They told us:

> ‘I would have liked to have been properly treated for depression by a doctor, not, as a result of incompetence (arguably), been treated for psychosis.’

Some people said they would have liked to have had the option of different medication.

Some people said that they would have liked to have had earlier or more frequent reviews of the medication to check things like the dosage and how well the medication is working, potentially comparing the effectiveness of the medication against the side effects experienced.

One person said that there is not anything they would have liked to have been done differently:

> ‘I have been pleased with my level of care from the NHS and on one occasion, a private consultant psychiatrist.’

Ideas for wider changes that would address the issue of mental health medication side effects

Some people talked about wanting there to be more research into new medication that would have fewer side effects, with several people saying that they would want there to be both more research and more alternatives to medication.

One person told us that more ‘people friendly’ medications should be used.

One person told us that while more research needs to be done, ‘mainly alternative treatments to medication are desirable’, saying that ‘the drug companies have a lot to answer for. Many of their products make matters worse for mental health sufferers.’

Another person highlighted both ‘further research for new and better medication’ and ‘quicker access to talking therapies as an alternative or to enable a reduction in the medication required’.

One person, in their response to the previous question, highlighted the needed for increased investment in talking therapies:

> ‘I would like to see huge investment in talking therapies so that everyone can get it, regardless of financial circumstances.’

One person told us that what was needed was ‘more options for alternatives’.

Similarly to the question before, one wider change identified was for people to be given more information about potential side effects.

One person suggested that this information could warn people about potential side effects and advise them about what to do if they get them.

Another person told us that people should be given enough information by their doctor to make an informed decision.

One person suggested there being more support available for people to help them deal with the impact of their side effects:

> ‘Having more support (rather than less as has been the case). I need some sort of (stress-free) structure to help me overcome my complete lack of motivation to do anything.’

Some people had suggestions for how medication is prescribed and for follow up care.

One person told us:

> ‘The minimum required dose for the shortest time should always be prescribed.’

Another person suggested having check-ins with the GP:

> ‘to measure the benefits of the medication and to measure the intensity of side effects’.

One person suggested that if you are receiving treatment in hospital your patient care plan should include matters relating to your medication:

> ‘so that concerns can be raised with nursing staff as well as consultants who are too busy to see you more than once a week. When a patient complains of side effects they should be recorded and if a patients asks for more monitoring, e.g. please take my blood pressure because I have a headache and can see flashing lights, then the nursing staff should oblige and listen to the patient.’

One person argued that certain medications should not be prescribed at all if they are known to have particular side effects:

> ‘In the modern society in which we live, with attendant challenges such as the rise in obesity related illnesses and soaring numbers of people reporting historic and current sexual abuse and violence resulting in severe trauma-related illnesses; the NHS should no longer use drugs that are known to have common side effects that include significant weight gain and/or sexual or genital functional impairment, or any other symptoms that are likely to have a negative impact upon the physical wellbeing, self-image and self-confidence of patients.’

That person also proposed changes to the legal definitions of Disability Discrimination, Assault and Homophobia.

One person told us that there should be more acknowledgement of the impact of side effects of medication, both individual medications and combinations of different medication. This was ‘especially in relation to fit notes, support letters to DWP, and correspondence with other healthcare professionals without a background in medicine’.

One person wanted to see changes made to address the issue of medication side effects both for ‘older people in the system’ and ‘younger people going into the system’. They also told us:

> ‘All in all, I would like to see changes in psychiatry on medication and their side effects. We’re people just like anyone else and we don’t need to be bullied in any form or fashion.’

Some people wanted to see general changes in the attitude of doctors and how they treat people.

For instance, one person said,

> ‘I think doctors and anyone prescribing the drugs should have a decent understanding of and a degree of sympathy around the likely side effects. I think that it should be possible to have a conversation with them around the side effects of the medication and whether the positive impact of the medication is outweighed by the negative side effects, without this somehow being viewed as you the patient being un-cooperative. At the end of the day it is our bodies and we should be able to say with confidence if something makes us feel ill and discuss other potential options rather than being told to put up with it.’

One person told us that:

> ‘mental health nurses need to realise that physical symptoms are not just dreamed up through hallucinatory or delusional experience’.

They also said that there should be training for non-mental health nurses and doctors ‘so that they realise that mental health patients can suffer as much physically as any other patients’.

Conclusion

Not everybody's experiences were the same and people have different ideas about how to address the issue of medication side effects.

However, there are some things that are clear:

- Side effects of mental health are having a negative impact in people's lives, in some cases a significant impact.
- Action needs to be taken to address this issue.
- There is no one size fits all solution as different people have different needs and different preferences for the treatment and care that they wish to receive.

People with lived experience of mental health issues are experts precisely because of their experience. The great insight shown by the people who responded to our research is evidence to that, as is the long list of ideas they came up with for wider changes which could address the issue of medication side effects.

This report does not mark the end of this piece of work. We plan to hold one or more events with people with lived experience of mental health issues to discuss the results of the peer research, what action they think needs to be taken to address the issue and what our next steps should be.

If you would like to get involved, please contact us at collectiveadvocacy@advocard.org.uk, AdvoCard, 332 Leith Walk, Edinburgh, EH6 5BR, 0131 554 5307.

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