Edinburgh Community Voices

Experiences of Treatment and Support for Physical Health Issues:

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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332 Leith Walk, Edinburgh, EH6 5BR
www.advocard.org.uk
collectiveadvocacy@advocard.org.uk

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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 Treatment and Support for Physical Health Issues

The aim of this research was not to make a judgment about physical health care in Edinburgh.

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 issues raised and to improve the care that people receive for their physical health.

If you would like to be involved in what Edinburgh Community Voices do next with this piece of work or would like to be kept up to date, please contact Becky Leach (AdvoCard Community Collective Advocacy Development Worker):

collectiveadvocacy@advocard.org.uk
AdvoCard, 332 Leith Walk, Edinburgh, EH6 5BR, 0131 554 5307.

How We Did the Peer Research

The research was open to anyone who lives in Edinburgh 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

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.

We said to the people filling in the questionnaire that we needed them to answer the first two questions, however they could choose which of the remaining questions they wanted to answer.

When we put together the report, we were not able to include any responses where the person answered the questions in relation to treatment and support for mental health issues rather than physical health issues (of which we received four). This was because the responses were not relevant to the questions being asked and the issue we were looking into.

These are the questions we asked:

1. Please tell us a little bit about the condition or symptoms you sought help or received care for.

2. Who was or is involved in your care? E.g. GP, consultant, practice nurse, physiotherapist. Please do not give names.

3. Are there any aspects of your care that you were happy with? Please give details.

4. Are there any aspects of your care that you weren’t happy or were less happy with? Please give details.

5. Was there anything that made it easier or harder for you to get help? If yes, please give details.

6. Do you feel that you were treated differently because of your mental health diagnosis? If yes, please give details.

7. Do you feel that you were listened to and that your views were taken into account in the decisions made about your care? If yes or no, please say why.

8. Is there anything that would have made your care better for you?

9. Are there any wider changes that could be made to improve the care that people with lived experience of mental health issues receive for physical health issues?

Summary

We heard from 14 people.

They told us about a range of conditions and symptoms they sought help or received treatment for.

A range of professionals were involved in their care or treatment, including GPs, nurses, consultants, physiotherapists and occupational therapists. For some people, mental health professionals were involved as well as physical health professionals at some point in their care.

Things people were happy with included:

- Being listened to, believed, treated with respect and taken seriously
- Being treated with compassion / staff being kind and caring
- Adjustments being made to make it easier to attend appointments
- Tests organised quickly
- Thorough investigations into symptoms
- Physical health professionals and mental health professionals being in regular contact

Things people were not happy with included:

- Their physical health being ignored
- The impact of their physical health issues not being recognised
- Delay in referral for tests
- Delay in diagnosis
- Issues with how GP appointments are arranged
- Issues with how GP appointments are carried out
- No discussions of side effects of physical health medication
- Required adjustments not being made

- Lack of communication between physical health professionals and mental health professionals
- Physical health needs not being met for inpatients in the Royal Edinburgh Hospital

Most of the things that people told us made it easier to get help were related to appointments with their GP, either because they find it easy to get an appointment, because of how their GP carries out appointments or things their GP does, or because of other services their GP practice provides.

Some people felt that they were treated differently in a bad way. Some felt that they were treated differently and that this was in a good way, they got the extra help or adjustments that they needed. Some people felt that they were not treated differently and that this was not right, that there were adjustments that should have been made. Others felt that they were not treated differently and that this was good because their mental health diagnosis did not affect the standard of service they received and they were not stigmatised against.

Some people did feel listened to, some people felt listened to in part and some people did not feel listened to at all.

These are the things that people told us would have made their care better for them:

- A home visit by an occupational therapist to assess their physical health needs
- Greater integration and interdisciplinary working between NHS departments
- Offering acupuncture and massage
- Their whole life looked at not just their physical health
- A key worker
- Physical health services not discriminating on the basis of mental illness
- Alternative treatment options offered
- More recognition of impact of physical health medication side effects
- Having had more social support, e.g. a friend to help them when unwell

These are the wider changes they identified which could be made to improve the care that people with lived experience of mental health issues receive for physical health issues.

- Listen to, believe and help us
- Don’t dismiss physical health
- More funding for improving physical healthcare for people with mental health issues
- Encourage people with mental health issues to take part in screening programmes (e.g. cancer screening)
- A mobile triage service within Community Mental Health Services
- Don’t prevent people from joining the Pain Management Programme because of a severe mental health diagnosis
- One key person responsible for prescribing pain and psychiatric medication
- Greater team working between GP, physio, psychiatry, psychology, neurological services, with key lead
- Believe that the pain is real and not all in someone’s head
- A key worker, volunteer or advocate
- More training on mental health for medical staff in general hospitals
- More consistency and awareness of staff, both mental health and physical health

Our Findings

Please tell us a little bit about the condition or symptoms you sought help or received care for

These are the conditions or symptoms the people who responded sought help for:

- Shoulder pain, family related cholesterol and heart disease.
- Stopped periods and high prolactin levels.
- Difficulty hearing and not taking up opportunities for cancer screening because motivation to do so is affected by mental health condition.
- Knee problems, weight loss, persistent dry cough.
- Chronic back pain, dating back more than 25 years, first ten of which was suggested as psychosomatic when walking around with herniated disc, thereafter neuropathic pain and three lumbar surgeries.
- Heart problems and type 2 diabetes.
- Type 2 diabetes
- Extreme back pain leading to operation for ruptured disk in lower back. Falls and balance issues leading to private referrals to physio for foot, ankle and leg pain and frozen shoulder. Now walk with stick and very unsteady outside. Difficulty using public transport.
- Asthma and fibromyalgia.
- Missed and irregular periods.

- General concern over heart and chest pain.

- Secondary breast cancer.

- Severe kidney infection.

- One person specified their mental health condition in their answer to this question, but did not describe their physical condition or symptoms. However, the other answers indicated that the physical health issue was chronic pain / ongoing problems with pain.

Who was or is involved in your care?

These are the professionals that people told us were involved in their care:

- GP
- Practice nurse
- Audiologist
- Community physiotherapy service
- Physiotherapy
- Private physiotherapist
- Consultant
- Consultant orthopaedic surgeon
- Pain Management Programme at Astley Ainslie
- Pain Clinic
- Pain consultant
- Spinal consultant
- Neurologist

- Oncologist
- Specialist nurse
- Occupational therapist
- Psychiatrists
- Psychiatrist at REH
- Junior doctors at REH
- Nursing staff at REH
- CMHT Psychiatrist
- Psychiatric consultant
- CPN
- Psychotherapist

You will notice that these are not just physical health care professionals. For many of the people who responded, a mental health professional was involved in their care at some point. For instance, where someone needed help with their physical health while receiving treatment for their mental health as an inpatient in the Royal Edinburgh Hospital, where somebody's CPN supported them to get help, or where somebody's oncologist and psychiatrist kept in regular contact to minimise any medication interactions.

Are there any aspects of your care that you were happy with?

Some people had things that they were happy with about their care and did not have anything that they were not happy with. Some people had things that they were happy with but also things that they were not happy with. Some people did not have anything that they were happy with and only things they were not happy with.

For some people, being listened to, believed, respected and taken seriously is what meant that they were happy with their care.

For instance, one person said:

> ‘My current GP is pretty good. She actually listens to me and believes me unlike previous ones.’

Another person in reply to this question simply responded:

> ‘Generally given respect.’

Being taken seriously and also treated with compassion was highlighted by one person:

> ‘To be honest, I was treated compassionately and taken seriously.’

Another person, who had been referred to audiology because of difficulties with their hearing, talked about how the staff at the department were kind and caring and made accommodations to make it easier for them to make it to their appointment:

> ‘The audiology department was very concerned when I explained I could not make an appointment one day because I was too distressed to use the bus to get to my appointment. They were very, very kind and made me an appointment more at a time to suit me. They then also contacted me on the day of the appointment to make sure I was feeling well enough to attend. They were really caring and helpful.’

Another person talked about being treated kindly and not being treated differently to anybody else. This person had a severe kidney infection and had to have the kidney removed. They said of the doctors and nurses that looked after them that:

> ‘They were very good with me, I don’t think they treated me any different to anybody else. I was happy with that. My aftercare was very thorough.’

Some people talked about being happy that tests had been organised quickly. One person was an inpatient in the Royal Edinburgh Hospital when they needed tests because of stopped periods and high prolactin levels. They told us:

> ‘Tests were organised very quickly and I was taken by nursing staff to where the tests were to take place.’

They also said:

> ‘I was happy that they seemed keen to cover all the bases to rule things out and were thorough in their investigations.’

Another person, who had missed and irregular periods, told us:

> ‘I did receive blood tests and was sent for an ultrasound reasonably quick.’

One person, who has secondary breast cancer, told us that were happy about the communication between their oncologist and their psychiatrist:

> ‘My oncologist and psychiatrist are in regular contact. The oncologist made sure that the drugs for side effects from cancer treatment didn’t react with my bipolar medication.’

One person told us that they were happy with the fact that their GP is ‘happy to prescribe products available over the counter, e.g. Voltarol gel’.

Are there any aspects of your care that you weren’t happy or were less happy with?

Some people felt that their physical health was ignored.

One person was concerned that they weren’t getting the physical health checks that they needed and felt that his was because of their mental health issues. They told us:

> ‘Since diagnosed with mental health problems, it seems my physical health is ignored. I’m over 50 with family heart disease issues yet never get routine tests even though I’m in the surgery every month.’

Another person, who had issues of knee problems, weight loss, and persistent dry cough, told us that they felt that their GP did not recognise the impact of their physical health issues:

> ‘I’m not sure my GP realises how stiff my knees become, and how this impacts upon my everyday activities. For example, I have difficulty with sitting down and getting up again, especially when using the toilet. It’s also becoming especially difficult to access my flat.’

That person also felt that there was a delay in referral for tests that they needed:

> ‘It took the best part of a year before my GP referred me for an X-ray in relation to my chest or knees. It turned out I had a bacterial chest infection. I feel this could have been identified sooner.’

Several people had issues concerning how their GPs conducted appointments.

One person was not happy that their old GP would not listen to more than one symptom per appointment.

Another person was not happy about how difficult it is for them to get an appointment with their GP, having to reveal personal information to reception to get an appointment on the same day and the lack of time their GP has for each appointment.

Issues of side effects of medication prescribed or medication interactions were raised by some people.

One person told us:

> ‘No discussion about side effects of the medications I was prescribed - and no discussion about what the possible interactions with medication I was already on (for mental health conditions) either.’

They also told us:

> ‘The medication made me too ill to do anything and I lost my job because I was always off sick. I could not get any help from anyone about this.’

One person, who was receiving chemotherapy for secondary breast cancer, told us:

> ‘Outpatient chemotherapy nurses gave me anti sickness medication that did react with my psychiatric meds despite repeatedly [telling them] until I mentioned it to the oncologist and he emailed them.’

This person also told us about nurses not making required adjustments they needed when they were receiving treatment as an inpatient:

> ‘While an inpatient the consultant advised that I should have a single room due to my anxiety in the hospital environment. I overheard nurses being rude about this and remained in a four bedded ward. However the next time I was an inpatient on the same ward I did immediately get a single room.’

Lack of communication between professionals was an issue raised by two people.

One person had extreme back pain which led to an operation for a ruptured disk in their lower back.

They told us:

> ‘The lack of communication between the surgical consultant and the psychiatrist in the Western General and my psychiatrist in the Royal Edinburgh Hospital about my bipolar condition led to me becoming manic and admitted to the REH for two months. In my view this could have been avoided.’

Another person talked about not being happy about ‘having to repeat information to each healthcare professional.’

They also highlighted the:

> ‘Lack of multidisciplinary approach / interaction between different parts of the NHS.’

Two people talked about their physical health not having been looked after or physical health needs not being met when they were in the Royal Edinburgh Hospital (REH) or were an inpatient in a similar hospital.

One person said:

> ‘I would like to say that physical health issues were not very well addressed while I was in the Royal Ed. I know of people whose physical health was not looked after at all well in the hospital.’

Another person had problems with chronic back pain. They were in hospital (they did not specify if this was the REH or a similar hospital elsewhere) and told us:

> ‘For 12 nights I was boarded out to a different ward so did not have anywhere during the day where I could go to lie down to get some relief.’

That person also told us about aspects of their ongoing care that they were not happy with:

> ‘Non diagnosis prior to becoming paralysed, continued prescription of opiates including fentanyl and morphine, no help from GP when I decided to go cold turkey two years ago. Now refused referral to Glasgow Centre for Integrative Care who take holistic approach.’

One person has type 2 diabetes. They were diagnosed in February 2018 but the consultant who gave them the diagnosis told them that they had probably had it for a long time. It was only diagnosed after they became very unwell and had an ‘attack’. They tried to get help from their GP practice, but, they told us,

> ‘It took a rather pleasant NHS lady doctor to say I’ve got an appointment for you at the new Royal Infirmary. The practice had nothing to do with that, they disposed of me. They sent me home on the Friday and I can’t remember the Friday. I put a complaint in, I told my GP about it and she wasn’t happy about what happened.’

One person was concerned about missed and irregular periods. They told us that they were not happy about the following aspects of their care:

> ‘I wasn’t really given a particular reason for the problem, other than stress, and even then, it wasn’t followed up or seen as a big deal, despite not having my period for over 8 months (to which I was told that it was normal) and another time having my period for a month.’

One person raised the issue that they have missed out on cancer screening opportunities because their mental health condition has affected their motivation to take up those opportunities:

> ‘I have not taken the opportunities offered for cancer screening because I don’t see the point given my mental health condition.’

They told us that no one has noticed or offered help:

> ‘So many screening opportunities are passing me by and no one is noticing. So I have no one to talk to about how my low mood is making me feel that I don’t care if I have cancer.. I just want to die anyway.’

Was there anything that made it easier or harder for you to get the help you needed?

Some people talked about the things that made it easier.

For some people this was about things that their GP or their GP practice did.

One person had concern over heart and chest pain. Their GP and a consultant at the Royal Infirmary of Edinburgh were involved in their care. They told us:

> ‘I had a good GP who referred me.’

Another person talked about how organised their GP practice is and how nice the staff are and the difference that makes:

> ‘In my present surgery, all of it runs like clockwork - that makes it easier. I was onto them this morning about something and they were very nice and they were able to give me an appointment this week at the time I wanted.’

Another person told us:

> ‘My GP is very easy to access, as same day appointments are available twice each day, as well as bookable appointments several weeks ahead.’

They also said:

> ‘He is also happy for me to go with a ‘shopping list’ and does not insist on one appointment per issue as I understand some do. He is happy for me to attend as often as I need to, and always gives me permission to revisit him as and when I need to. However, he doesn’t always remember previous conversations and can contradict advice he had given previously - especially in relation to ongoing issues.’

They also told us that the GP practice ‘offer regular physical health screenings to people who are being treated for mental health issues, including those treated elsewhere.’

One person told us that ‘an excellent CPN from the NE Community Mental Health Team’ made it easier for them to get the help they needed.

One person highlighted the difference it can make if you have someone who can go with you to appointments:

> ‘Taking in a significant other can help. Being alone means it’s easier to dismiss you.’

The person who has secondary breast cancer told us that something that made it easier to get help was that:

> ‘My GP asked me come in to discuss all my medical needs going forward after the cancer diagnosis.’

However,

> ‘I wasn’t offered the yearly physical review for my bipolar the year before which might have shown up cancer symptoms earlier and avoided a terminal diagnosis.’

One person told us that a lack of adjustments made for their lack of mobility caused by chronic back pain made it harder for them to get help as there was a:

> ‘Lack of online support when my condition started.’

One person told us:

> ‘PTSD about going to the doctor for help made it more difficult.’

Do you feel that you were treated differently because of your mental health diagnosis?

We had a mix of responses to this question.

Some people felt that they were treated differently and that this was in a bad way. Some felt that they were treated differently and that this was appropriate, they got the extra help or adjustments that they needed.

Some people felt that they were not treated differently and that this was not right, that there were adjustments that should have been made.

Others felt that they were not treated differently and that this was good because their mental health diagnosis did not affect the standard of service they received and they were not stigmatised against.

Some people had a mix of experiences and some people were not sure.

One person told us that they felt that their symptoms were attributed to their mental health diagnosis:

> ‘At times. It felt like my ‘diagnosis’ was the reason I was having my issues and I was having to push for tests to rule different possibilities out.’

One person, who said that they had ‘had quite a lot of psychosomatic symptoms’ in the past, told us:

> ‘Although my current GP has never openly suggested any of my physical symptoms could be psychosomatic, it does appear that may be his first assumption regarding my knees and other joint issues - at least if his delays in considering future investigation is anything to go by.’

Two people felt that they were prevented from accessing physical health services which would have helped them because of their mental health.

One of them was prevented from joining a Pain Management Programme because they have a severe mental health diagnosis.

Another had their referral to the Chronic Fatigue Syndrome Clinic refused because of their mental health. They told us:

> ‘My referral to the Chronic Fatigue Syndrome Clinic was refused because of my mental health and current mental health treatment. Apparently you can’t be treated for physical and mental health stuff at the same time.’

One person told us that they do not think that they were treated differently because of their mental health diagnosis and they do not think that this is a good thing. They said:

> ‘I think prescribers need to think about the mental health of their patients and how drugs might interact with each other.’

One person had a mix of experiences.   This was the person who has secondary breast cancer. They told us:

> ‘Yes but in the main this has been an appropriate sharing of information and offers of support. However the cancer diagnosis didn’t have any impact over the length of time on the clinical psychology waiting list. I was given appointments with a specialist psychologist in cancer but felt that she didn’t have the breadth of knowledge required. The psychologist I am now seeing in the mental health team also has a background in pain management and long term conditions and has been very good.’

One person told us that they had been treated differently in one place and that this was good. This was the person who had received extra support from the audiology department because of their mental health issues. However they also felt that they had not been treated differently when it came to uptake of opportunities for cancer screening because no extra support has been offered or adjustments have been made to address the barrier they face. They told us:

> ‘It’s all being left up to me and I am too lowly motivated to do it.’

Two people were not sure if they were treated differently because of their mental health diagnosis.

One person told us:

> ‘Not sure, now having spent six months in hospital with Major Depressive Disorder beginning to feel doctors not recognising the link between my mood and constant pain.’

The other person said:

> ‘It’s difficult to tell.’

Do you feel that you were listened to and that your views were taken into account in the decisions made about your care?

Some people did feel listened to, some people felt listened to in part and some people did not feel listened to at all.

One person told us that they are never asked about their physical health during the consultation with their GP.

One person said that they would not know what questions they should ask.

One person, who has chronic back pain, told us that they are the one who knows best how to deal with a flare up but their wishes as to this treatment are not respected:

> ‘I am the one who knows how to best deal with a flare up but now that I have kicked opiates for two years trying to get a prescription for diazepam or dihydrocodeine is impossible.’

One person told us that they felt listened to at times. They were concerned about missed and irregular periods and this was listened to, they were ‘given tests and asked to come back for follow ups’. However, one time, they said:

> ‘I felt I was being judged for not wanting to take contraceptives to regulate my period, which I stated clearly I didn’t want, and it felt like, because I said ‘no’ that there were no other options offered.’

One person felt that they were not listened to by the ‘nursing / managing practitioner’ at their GP practice when they submitted a complaint about how they had been treated by the GP practice when they had become unwell, and that ‘she tried to fob it off’. However, the person did feel that their GP listened to them and that they were listened to in the hospital.

One person told us that in general they feel that they have been listened to. However, they said, ‘it isn’t holistic enough.’

One person, who had stopped periods and high prolactin levels, was happy that their views were acted upon. They said:

> 'Yes, because it turned out that one of the likely causes was my medication and my views at wanting to reduce these medicines was listened to and acted upon.'

One person had general concern over heart and chest pain. Their GP and a consultant were involved in their care. They told us that they were taken seriously and seen as competent:

> 'I was treated sympathetically and as a competent, responsible adult.'

One person told us that they do feel that they were listened to however they have had an advantage from their work that they think has made a difference. They said:

> 'Yes, but having worked in advocacy and third sector for nearly 30 years, I think this has given me an advantage in knowing how to find out information and also prepare for consultations. It is much harder doing it for yourself than others though!'

The person who has fibromyalgia and whose referral to the Chronic Fatigue Syndrome Clinic was not accepted told us that they had not been listened to in relation to treatment for their fibromyalgia:

> 'At least not by the CFS clinic. My GP, psychiatrist and psychotherapist have done more for me than the CFS clinic has.'

Is there anything that would have made your care better for you?

One person, who has knee problems, told us:

> ‘I think I need a home visit by an OT, to assess my physical needs in terms of sitting and standing, use of the toilet etc., and to arrange any adaptations that would make my daily living easier. My GP seems totally oblivious of this need I even get PIP points on the strength of it!’

One person told us that ‘greater integration and interdisciplinary working between NHS departments’ would have made their care better for them.

One person, who has chronic pain, told us that what would have made their care better for them was:

> ‘Offering me acupuncture or massage which I know helps to cope with flare ups.’

One person would have wanted their whole life to have been looked at:

> ‘Having my whole life looked at not just my physical health issues cause maybe I would still have my job if I hadn’t had to take medication that made me so ill.’

One person told us that having a ‘key worker’ would have made their care better for them.

The person who has fibromyalgia and whose referral to the Chronic Fatigue Syndrome Clinic was not accepted told us that what would have made their care better for them was:

> ‘If the CFS Clinic didn’t discriminate on the basis of mental illness.’

One person, who had missed and irregular periods, told us that what would have made their care better would have been to have been offered ‘alternative options’ to contraceptives, which they did not want to take, and ‘to be asked if I understood the reasons for my period problems’.

The person who has secondary breast cancer told us that would have made their care better would have been:

> ‘More recognition of the anxiety caused by gaining weight as a result of both treatments and support in tackling this.’

The person who has type 2 diabetes and became unwell when they were still not diagnosed, became very unwell while they were at home. They told us that what would have made things better for them would have been having had more social support, a friend that could have helped them, and not being isolated. They said:

> ‘Knowing that someone would have been in the house when the attack was really bad, having had a friend that could have helped me that evening would have been more than appropriate. That’s where the isolation comes in from mental health, that’s not good for anyone.’

Are there any wider changes that could be made to improve the care that people with lived experience of issues receive for physical health issues?

One person was pessimistic about the prospect about changes being made. They told us:

> ‘People with a mental health diagnosis are too much of a problem for the system to make the effort to make it work for them.’

However, other people had ideas for changes that could make a difference. This is what they told us.

> ‘People need to listen to us, believe us and help us. It is possible to have both physical and mental health problems together.’

> ‘Not to dismiss physical health and treat me only as mentally ill given the huge correlations between them.’

> ‘More funding could go into improving physical healthcare for people with mental health issues, because a lot of people with mental health issues have many various physical needs.’

> ‘I really think more needs to be done to ensure that people with mental health issues are encouraged to partake in pro-active screening programmes. It seems to me that to leave participation up to someone who is already feeling low and worthless is a failure of responsibility.’

‘It would probably help if some kind of mobile triage service could be arranged within community mental health services, where people could get advice or reassurance on the appropriateness of approaching their GP, and/or what services their GP could help them access.’

‘More training on mental health for medical staff in General Hospitals would help.’

‘Not to be prevented from joining the Pain Management Programme because of severe mental health diagnosis. One key person responsible for administering all pain and psychiatric medication and liaising with other healthcare professionals if required. Greater team working between GP, physio, psychiatry, psychology, neurological services - key lead (CPN?) would be helpful. Acknowledgment of difficulties and interaction between pain and mental health distincts this group’s needs from others.’

‘Believe that the pain is real and not all in someone’s head… there was a physical cause for my pain which was not detected until an MRI scan was done. If having to be an inpatient in a mental health setting, make sure that physical health needs are met.’

‘More consistency and awareness of staff in both environments (part of CPD training perhaps).I think it depends on the professionals involved (different GPs and consultants have been better or worse now and in the past, in terms of awareness and communication with each other).’

Conclusion

Not everybody’s experience is the same, different people have different needs and different views about what they would want their care to look like and what wider changes should be made.

There are some things that are clear however and these are:

- People care about their physical health. It is important to them.

- For many people, their physical and their mental health are linked, they’re not two separate things, the one affects the other.

- Change is possible, it can and should be made. There are already examples of good practice and good work happening that people have told us about here. It might need more investment, it might take a concerted effort from some professionals to change how they do things, but it is possible and achievable.

- People with lived experience of mental health issues are experts precisely because of their experience. They know what their needs are and what will help them. Any change should be led by them, by their views and their ideas, if it is to be successful, if it is to meet their needs and if it is to uphold their rights.

If you would like to be involved in what Edinburgh Community Voices do next with this piece of work or would like to be kept up to date, please contact Becky Leach (AdvoCard Community Collective Advocacy Development Worker):

collectiveadvocacy@advocard.org.uk,
AdvoCard, 332 Leith Walk, Edinburgh, EH6 5BR, 0131 554 5307.

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a city-wide advocacy project

AdvoCard

for users of mental health services