

Edinburgh Community Voices

Improving Physical Health for People with Lived Experience of Mental Health Issues

Survey Results
March 2017



We would like to say a big thank you to everybody who responded to the survey and to the members of Edinburgh Community Voices who helped us to plan and write the survey.

Published by AdvoCard in 2017

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Large print version available on website

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Introduction

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

We did this so that we can push for their priorities, needs and views to be heard, taken into account and respected when service planners and providers in Edinburgh are looking at ways to improve physical health.

44 people responded. Here is what they told us.

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.

Summary

We asked people what was most important to them when it comes to improving their physical health, expecting that most people would have one or two main priorities.

However, out of 44 respondents, only 4 picked one aspect of their physical health in answer to this question, while 26 people picked four or more aspects.

For many of the people who responded, the different aspects of their physical health are interlinked, with one affecting the other, and this was a major reason for not identifying one main priority.

When it comes to improving the physical health of people who have lived experience of mental health issues, increasing life expectancy can often be the main focus.

However, for our respondents, improving or maintaining quality of life and wellbeing seem to be at least if not more important than extending life.

Many people want to be able to do the things that would help their physical health, like being more active, eating more healthily or reaching a healthy weight. But there are a number of barriers which make it much more difficult than is often presumed.

Some people feel hopeful about their physical health, while others feel more pessimistic.

Some people are already accessing the services which they feel would help them with their physical health, or otherwise have the help that they need, while others have identified things that would help them that they currently don't have or aren't able to access.

What's important?

	Most important	Also important
Becoming more active (doing exercise)	24	9
Becoming more active (getting out and about)	29	10
Drinking less alcohol	6	3
Eating more healthily	25	10
Getting the treatment or support you need for physical health issues	24	4
Having fewer side effects of medication	19	9
Having more energy / reducing fatigue	27	8
Reaching or maintaining a healthy weight	21	9
Reducing or managing physical pain	10	4
Reducing substance / drug use	1	0
Stopping smoking	2	0

Other things which are important

Most important

Access to sunshine holidays	1
Avoiding unnecessary OTT medications	1
Better treatment of mental health issues	1
Doing Alexander Technique (helps both mind and body)	1
Engaging in creative activities (e.g. music, writing, art)	1
Engaging with my community	1
Environmental Sensitivity Issues being properly addressed	1
Getting better sleep / addressing sleep disorder	3
Getting fresh air / being out in nature	3
Lamps designed to improve mood	1
Maintaining good relationships with friends and/or family	2
Not allowing others to upset or irritate you	1
Raising self-esteem	1
Relaxation and Meditation	1

Also important

Being able to hear and articulate	1
Better lifestyle	1

Things that help

- Support from other people, particularly others who are in the same situation
- Emotional support
- Services that meet your needs
- Attending drop-in services
- Safe spaces
- One to one support / somebody to help you identify goals and take small steps
- Mentoring
- Having groups and classes which you can attend
- Free activities or help with costs
- Green spaces
- Good relationship with GP and other health professionals.
- Being listened to and involved in your treatment.
- Reducing side effects of medication, as these affect other aspects of your physical health.
- Information about side effects, and support to help you manage them
- Better treatment for mental health issues (as these can impact on your physical health)

Things that make it more difficult

- Isolation
- Lack of support
- Helpful and supportive services / classes being cut
- Poverty or limited budget
- Lack of motivation (and not knowing how to improve motivation)
- Fear of public spaces or being out on your own
- Low mood, depression or anxiety
- Dealing with mental health issues uses up a lot of energy
- Side effects of medication
- Physical health issues not being seen as real or taken seriously
- Not getting the treatment you need for physical health issues
- Being judged or ignored by health professionals
- Lack of understanding
- Not enough time in GP appointments
- Not being able to show your ups and downs, physically, because they can be associated with your mental health condition

How we did the survey

We designed the survey with the help of members of Edinburgh Community Voices.

We did an online version of the survey and a paper version which people could fill in themselves or with help from others.

In the survey, we asked the following questions:

1. What is most important for you when it comes to improving your physical health?
2. Is there anything else that is important for you?
3. Is there anything that helps or would help you do or achieve these things?
4. Is there anything that makes it more difficult for you to do or achieve these things?

We had eleven options that respondents could select in answer to questions 1 and 2.

These were arranged in alphabetical order. Respondents also had the option to select 'other' and write in their own thing. Respondents could select as many or as few options as they liked. Respondents did not have to answer every question.

Our Findings

Physical health as a whole

Why is it important?

'My physical health means the most to me.'

'When I'm physically fit I feel better mentally.'

'My current situation with my physical health isn't really doing me any good, not only is it bad for me but other people are worried about it and this creates this problem of no confidence and uncertainty about the future.'

What helps?

- Being with other people in the same situation as me
- Being with other people with the same goals
- Group support
- Being part of a supportive community
- A holistic approach
- Feeling better about myself
- Better relationship with GP
- Attending drop-in services
- Participation in arts / arts therapy

‘More organised time and thought and deep consideration given about my physical health priorities, and real goals and achievements over a given period of time.’

‘Using the SEASONS service which is supported by friendly and helpful staff has opened my mind to a new world of information. I stumbled upon the group by chance. Creating other similar groups and making the general public aware of such services’ availability [could help other people].’

What makes it more difficult?

- Social isolation
- Social phobia
- Anxiety
- Depression
- Low mood
- Feelings of hopelessness
- Lack of motivation, and not knowing how to improve motivation
- Lack of support
- Lack of incentive
- Lack of plan / co-ordination
- Limited budget
- Poverty
- Side effects of medication

'My mental health definitely adversely affects my physical health – which then affects my mental health (I get more depressed at the state I am in) and so in a vicious cycle.'

'Being constantly stressed to hell and back by the DWP and Jobcentre with all their punitive crap that hinders instead of helping my recovery.'

'The general lifestyle challenges of managing multiple mental and physical health as it is very difficult to establish a regular routine.'

'I am sick of the focus on lose weight, do more exercise, stop smoking, important as they are, there is support for all of this but not for the complex psychological problems and coping with other things that I face.'

Becoming more active - Getting out and about / Doing more exercise

Why is it important?

'Getting out and about regularly is important for my mental health and wellbeing.'

'It is very important for me to try to improve the quality of my life as I begin to recover from severe illness, and activity, exercise and getting out and about are crucial for this.'

'Exercise and fresh air are vital to maintaining good physical and mental health.'

'I know that exercise and healthy eating both make me feel better. When I was first unwell, but before abuse / onset of trauma symptoms, I did exercise (swimming and badminton); plus badminton meant I met up with people. Although I was never very good at 'official' mindfulness exercises, I could swim mindfully so had additional mental health benefits.' [After having to stop exercising due to low energy, worsening mental health, and physical health issues:] *I felt that I even as I was following advice I was in a vicious circle – the lack of physical activity reducing mental health coping strategies / healthy behaviours; the lack of physical activity worsened physical health.'*

What helps?

- Regular exercise
- Exercise that is incorporated into daily life without needing to attend a gym or class.
- Getting exercise by walking
- A walking buddy
- Having friends/family who can go out with you
- Exercise both outdoors and in the gym / leisure centre / swimming pool
- Safe and gentle exercise
- Having a safe space for exercise
- Safe cycling routes
- Doing things together / people to exercise with

- Having a group or class to go to would help with motivation
- Exercise provision at a central location
- Help with motivation
- Support to attend
- Emotional and practical support and advice
- A befriending / buddying service - to get there / moral support / help me feel safe when there / help identify times when pool not busy / identify places to go / goals, what to focus on, small steps
- Childcare provided at classes
- Low cost activities / Help with costs
- Being able to book classes through an app
- No show charge means that you have to show up or lose money – helps with motivation
- Dedicated time with trainers
- Trainer/instructor – empathetic and encouraging / one to one support / help you move out of your comfort zone
- Safe / gentle exercise
- Classes which focus on stretching, mobility, and helping to avoid or resolve injury
- More GP prescribing for exercise
- Healthy Active Minds

- Edinburgh Leisure Community Access Programme
- Membership for multiple sites at Edinburgh Leisure
- Attending Redhall Walled Garden – can be physically active in the garden
- The growing community garden scene

‘For me, attending classes and/or scheduling a set time in each week to do a particular type of exercise makes it easier for me to do it, as it is part of my routine. Focussing on activities/classes that I enjoy helps to motivate me to exercise.’

‘In terms of exercise, Edinburgh Leisure’s Healthy Active Minds scheme has been of great help to me, getting me into the gym (where I had never been before) with an empathetic and encouraging instructor.’

‘Having some 1:1 time with someone to encourage me out of my comfort zone was helpful.’

‘Outlook courses quite often offer supported, free physical activity in small groups – introductions to the gym, walking groups, swimming, badminton – which is exceptionally helpful.’

What makes it more difficult?

- Many activities are too expensive
- Not enough free public tennis courts in Edinburgh
- No concessions on swimming lessons

- Leisure centres with the right facilities (e.g. badminton courts) can be quite far away
- Found accessing free gym membership hard
- The 4pm time restriction on the Get Active Pass – some people have illness or treatment which makes it difficult for them to use the facilities at earlier times
- Having children
- Chaotic spaces – cyclists, kids, dogs, joggers around
- Fear of public spaces / agoraphobia
- Fear of strangers
- Fear of walking on your own
- Fear of doing things on your own
- Being isolated (e.g. no longer having friends to play badminton with)
- One person lives in sheltered accommodation. She sees older people there struggle to get out because of mobility issues. She feels it is important to get out every day, and worries about not being able to when she's older.
- Lacking motivation to leave the flat
- Darkness and bad weather – make it harder to get out and about
- Bad road surfaces - makes it dangerous to cycle
- Hatred of 'gym and slim' culture / gyms full of 'narcissists'
- Would like to swim, but lack of self-confidence in body
- Mood / mental state

- Low energy levels / exhaustion / fatigue
- Lack of willpower
- Not receiving adequate treatment for physical health issues
- Can't do gardening due to aggravated hip injury
- Side effects of medication – e.g. lethargy, not enough energy and constipation
- Fear that activities will be skewed by assessors to deny benefits.
- Helpful and supportive classes being cut

'The low energy, low mood and low motivation which is part of my condition can make things like exercise or eating healthily very difficult. Darkness and bad weather can also make it harder to go out and about.'

'I panic and do housework instead of going out for a walk.'

'Apart from my own mental state, lethargy and lack of willpower, the main issues are cost and accessibility.'

'The city is noisy and dirty and the roads too full of traffic which is frequently aggressive towards cyclists.'

'The appallingly bad road surface in Edinburgh makes it dangerous to cycle in many places and cycling is very important for me to be able to get to places at a reasonable cost and also stay fit.'

'I need to be in a positive state of mind. I need to feel strong enough physically and mentally to engage in any physical activity. '

'I have a good talking relationship with my GP(s), but empathy doesn't mean action/treatment. When I suddenly stopped being able to climb the stairs to my flat due to breathlessness, and couldn't fit shoes on due to ankle swelling, the response was 'keep your feet up', and when my energy levels were so low that I couldn't keep myself warm, the response was 'graded exercise' (no explanation and impractical).'

Green space

Several people told us about the importance of green space and nature, for both their physical health and their mental health.

Green spaces are locations for outdoor exercise, for instance walking. But green space, nature and fresh air also important in themselves, they help your mental health and your mood.

'Getting out and about regularly is important for my mental health and wellbeing. Sometimes getting out of the city into the countryside is even more helpful.'

With gardening: *'you can improve your physical and mental health at the same time'*

'Quiet urban green space is vital for connecting with nature, calming anxiety and allowing exercise at low cost.'

'A lot of green space in the city was built on in the 1980s which has made the city more depressing and probably reduced air quality. Allowing infill building on green space is very unhelpful for mental health.'

Drinking less alcohol

Nine people said that drinking less alcohol is important, but only one person gave us more detail. They told us that it is difficult because wine at night seems like something to look forward to, but that emotional and practical support would help.

Eating more healthily

What helps?

- Eating regularly
- Someone to help you identify goals / what to focus on / small steps
- Planning meals ahead of time to discourage snacking and the use of 'quick' foods

What makes it more difficult?

- Low energy
- Low mood
- Low motivation

'I have the knowledge re: healthy eating but am currently unable to cook unsupervised or remember to eat regular meals.'

Getting the treatment or support you need for physical health issues

What helps?

- Support to attend appointments and clinics
- A sympathetic GP
- Better relationship with GP
- A GP who listens
- Being believed when you describe your symptoms

‘A good GP with a sense of humour and who gets that life is more complex than most GPs have believed.’

‘I find my monthly appointment with my GP practice nurse very helpful.’

What makes it more difficult?

- Not enough time with GP
- Mental health problems making it hard to communicate with doctors
- The GP only hearing the first part of what you’re saying
- Your physical symptoms being attributed to your mental health diagnosis
- Being judged

- Being ignored
- Dismissive and patronising GPs

'Because I am anxious and stressed, I cannot go to clinics and hospital appointments because I get too distressed unless I have support. I have no family and it is not something friends can do, so I don't go at all.'

'I have a difficulty believing the physical symptoms I experience are 'real' and feel like I'm wasting their time.'

'You're not allowed to show your ups and downs [physically], because they're then associated with your mental health condition'.'

Environmental Sensitivity Issues

One person has progressively increasing Environmental Sensitivity Issues. They feel that wider public education is required so that their health is not affected by cosmetics, deodorants, air fresheners and antibacterial sprays.

Side effects of medication

Why is it important?

- Side effects are devastating and humiliating
- Side effects can make it harder to do the things that would improve your physical health – for instance getting more exercise or reaching a healthy weight

‘I have real problems with medication because I find it too strong and my reactions to it are quite extreme.’

‘Side effects can have a massive impact on wellbeing and physical health, e.g. weight gain, kidney problems etc.’

‘My kidneys have been ruined by lithium. I am on dialysis and waiting for a transplant.’

‘Long term effects including, for example, IBS / mega colon, heart problems as well as tardive dyskinesia and related problems, can have a really negative impact on wellbeing.’

‘As I get older, the drugs have a longer effect on my physical wellbeing, making it more difficult for me to maintain a good quality of living (life). I would like to spend the rest of my life getting older as naturally as possible.’

‘Constipation can prevent you from going out and attending things, meaning that you have to take more medication – because you take medication.’

What helps?

- Information about side effects
- Being involved in your treatment
- No medication

'You need information about side effects and dialogue with the health professional to help you yourself manage the side effects, so that side effects are alleviated and ameliorated.'

'Psychiatric medication has long term effects on physical health and we should be told about these in the first place so we can make proper informed choices about what medication we choose to manage our mental health ... Focus should be on prevention and minimising our dependence on toxic harmful iatrogenic medication.'

'I think other people should have better support about their use of lithium and possible kidney problems. I think with young, deeply depressed people, medical staff should consider involving family as well as asking the patient if they want to come off lithium. If a person is deeply depressed it is difficult to look beyond this at future kidney problems. They cannot be relied upon to give a fully balanced view. Close family members who are trusted by the patient should be talked to with the patient. ... [Also:] A bit more common sense on the part of psychological services. My kidneys deteriorated over many years. There was plenty of time to make changes. I needed to know that there was an alternative to lithium that could be relied upon. Psychiatrists were too busy pointing out that alternatives might fail and watching their backs to make it possible for me to make a decision to come off lithium. This has landed me in big problems for life.'

'Being drug free, especially psychiatrically. ... With the help of my present consultant this may be possible.'

What makes it more difficult?

- Lack of information about side effects
- Withdrawal symptoms if you reduce/come off medication, especially if you've been on it for a long time
- Some people believe that there is nothing they can do about side effects, that they're stuck with them

'Get us off the blooming medical model that defines who we are physically.'

'If I come off medication, I will lose the benefit and experience withdrawal effects.'

'Medication has side effects, can't do anything about those.'

Having more energy / reducing fatigue

Why is it important?

- Lack of energy makes it hard to exercise or get out and about, even when you're motivated.
- It can also itself affect willpower and motivation, you can feel emotionally tired as well as physically tired.

'I don't have enough energy to keep up with my motivation.'

What helps?

- Not taking medication which has the side effect of fatigue
- Stopping smoking

What makes it more difficult?

- It's a common side effect of medication
- It's a symptom of physical health issues
- Not getting the support or treatment you need for physical health issues
- Lack of energy being attributed to problems with weight rather than an actual physical health condition
- Coping with mental health symptoms uses up a lot of energy
- Managing daily tasks can take up a lot of energy

Reaching or maintaining a healthy weight

Why is it important?

- It is linked to other things, for instance exercise, healthy eating and getting out and about

'I have in the past been very overweight – and then very underweight – so reaching a weight that is right for my size makes a big difference to my ability to do things, as well as raising my self-confidence and self-esteem.'

'As I am aging, I find that with the particular treatments/medications I am on I am struggling more and more to maintain a healthy weight. Weight gain is having an effect on my physical health and so is something I would like to improve.'

What helps?

- Reducing side effects of medication
- Planning meals in advance
- Exercise

What makes it more difficult?

- Side effects of medication
- Difficult to improve alongside managing mental health problems

Reducing or managing physical pain

Why is it important?

- Physical pain can make it difficult to do the things that help with both your health and your weight, for instance gardening and exercise

‘In order to participate in other sporting activities for developing fitness and social interaction, avoiding injury / recovering from injury is very important.’

What helps?

‘Stretching and mobility exercises that help avoid or resolve injury problems are very hard to do on your own, so classes are very beneficial. ... When I go to classes like Bodybalance this helps me improve back problems and also helps me do more stretching and mobility exercises outside of classes.’

What makes it more difficult?

- Lack of understanding by social work department
- Previous injury the doctor has been unable to treat
- Being judged

‘We are given the wrong medication for pain. If we claim we have pain, we are classified as malingerers, so we suffer our pain in silence.’

Stopping smoking

Why is it important?

- Stopping smoking has a positive impact on many of the other aspects of physical health

What helps?

- Mentoring
- More accessible smoking cessation support

'I would like different support in exchange for the cost free NRT. So some kind of mentoring might be ideal. A combination of planning, cheerleading, practical support and non-judgmental empathy.'

What makes it more difficult?

- If you feel worthless, the 'relief' of smoking is harder to resist

'When I stop, it is like a dam of suppressed emotional damage is released. For a while, my moods become more extreme.'

'Last time I tried [to access support], the pharmacist was patronising, dis-empowering, bureaucratic and non-neurodiverse friendly.'

Conclusion

The people who responded to our survey have a wide range of views and experiences. It is clear that there is no one size fits all approach for helping people with their physical health.

If people in Edinburgh who have mental health issues are to be able to improve their physical health, then there needs to be:

- Recognition of the different challenges and barriers that people face
- Support and services which listen to people, and which are flexible and meet people's needs as they define them
- More understanding and less judgment
- Proper involvement of people in the dialogue around and decisions regarding their treatment, including treatment for both physical health issues and mental health issues
- A city landscape and environment that supports both physical and mental health

If you are interested in working with us to make this happen, please get in touch.

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