

Bedside Conversation 3 of 5 with Liz Crow as part of the *Bedding Out* performance
Thursday 11 April 2013 Noon

Liz: So welcome everybody following on Twitter. We're really pleased that you can join us live streaming from Bedding Out in Salisbury Arts Centre.

This is the third of five bedside conversations and this one's happening with me, Liz Crow, and with the fabulous Tweetmeister, Dawn Willis, who has been tweeting in the run up to Bedding Out and is continuing throughout the 48 hours. We're here on the bed and very, very pleased that you guys are joining us in the Twitter-sphere.

So please do pitch in with your questions and responses and ideas and comments as the conversation unfolds.

Bedding Out got underway 22 hours ago so we'll be continuing here for the next 26 hours. What I wanted to do was begin by telling you a little bit about the work.

Just before I do that, it's the reminder that you can participate on Twitter using #beddingout. But if you are watching us on the internet, and you're not on Twitter and you would like to join in via text, the text number is also on that page and Dawn will be able to pick up your comments and add them to the Twitter feed.

But just to give you some background to Bedding Out, how I come to be here in this very public space and a very busy café this morning, in my bed, Bedding Out really has come out of a dilemma that I've faced over many, many years in that what I found is that I live a life in two very separate parts.

There's the public self that goes out amongst people and tries to appear energetic and animated and happening. And then there is another side which is the private self which is the larger part of me where I spend most of my time at home, much of it lying down and a lot of it in bed.

But I learned very early on that that private self doesn't win friends and it doesn't win accolades. So I learned early to conceal it. And I've always done that very carefully. To the extent that I've realised in recent times that there are some people who have known me for 10 years and more and they actually don't realise that I'm ill.

That adds all sorts of complications to life because I can't take friendships as deeply as I want to if I don't trust them. But equally, my friends can't do right by me if they don't really know who I am.

But in a way, all of this is just a kind of personal and private conundrum. And it has had all sorts of compromises. But it's kind of worked for me for about 30 years.

But then events changed outside me. And that has changed everything. What has worked for all that time no longer works. Because the UK government has done a major overhaul of benefits, of the benefit system in the UK, and has introduced a whole lot of cuts that means suddenly, if I'm facing a system that judges me on what is visible, if I present my public self, that becomes used as evidence that I don't need support.

And so what I'm required to do instead is turn my life upside down and begin to parade that very private self as justification for state support.

But alongside that has been a campaign in the newspapers in which when they see the public version of ourselves, they label us as frauds and scroungers and that has had very direct effects on level of hate crime, which have soared.

So this has now gone from being my personal dilemma to something that is a knife edge. We are talking now about life and death. So that is why I came to do this project.

I first wanted to make visible this very hidden life and this very hidden community of people. But more than that, I wanted to begin to show that what a lot of people see as contradiction, private and public, what they label fraud, is actually just the complexity of real life. And that until we actually build that into the systems and into our judgement of other people and our relationships, then actually we can only have a world that discriminates hugely and even endangers disabled people.

So that's the background to the piece. I'm going to turn to Dawn now and I'm hoping that you guys will want to come into that on Twitter and let's start the conversation.

Dawn: We've got a question straightaway asking, "Do you think people fear the possibility of getting into discussing this? i.e., most people would rather avoid the topic"

Liz: I think that's true. I mean I don't think we live in a society that talks about these issues easily. And I suppose if we did talk about the issues easily, then there wouldn't be this dilemma that I'm talking about. I would find that I could be honest in my conversations.

In effect, I have been lying for 30 years. For good reason. Because the truth feels dangerous. But I think we're in a time where not to tell the truth places us in danger. So we need to get past the reluctance to talk about all of these issues. Illness, death and so on.

Dawn: By the way, we have lots and lots of questions coming in.

Liz: Fantastic.

Dawn: Please forgive me for being a bit slow.

Liz: And if there are questions we don't manage to address in this time, we will come back to them. Either Dawn will address some of them during the performance or I will come back to them after the performance. So bear with us if it takes a while to answer some of them.

Dawn: We have a question here from Kristina Veasey who asks, "How best do we support someone refusing to face the limitation of psychosis," which is a mental health question, "and where the ESA form depends on a medical model?"

Liz: Ah. The Medical Model, huh? If I could bring in some of your knowledge as well on there.

It's really difficult managing this Medical Model that is brought to us through these systems, because that's not how anybody lives their lives.

And so to manage the process of assessment, we have to become incredibly skilled at re-presenting ourselves. And the risk of re-presenting ourselves as helpless and hopeless and needy is that we start to believe that story about ourselves. So part of the question for me is how do we find ways of doing what is necessary in that system but regarding it as a performance we have to do. The returning to our true selves so that we maintain the strength that we have. Yet still get the resources we need.

Dawn: I guess, I think, with people with psychosis, they are going to need very highly specialised support and that is going to need to come from mental health professionals. Which, as we know, is very difficult to get at the moment because there's funding cuts. So there any answer to that question. Whether you're relying on the Medical Model, which people do kind of reject a lot of the time when they have a mental health condition. I don't know whether I can adequately answer that question.

Liz: I mean one change I do see is amongst campaigners, the approach is very widespread. So people who are directly tackling government, directly trying to change the public's minds and to get them informed.

But there's also a whole body of resources starting to exist. People advising each other and supporting each other.

I think maybe that is one of the key areas that actually the core is that we need to turn back

to ourselves. Not just us fighting our own corner, but as a community.

One of the things that I've noticed in the last three years, particularly through disabled people against the cuts, DPAC, and actually in lots of other groups, there's an incredible resource built up from people who have been through the assessment process. People with a whole variety of impairments feeding back what they have learned from that process. So that other people don't have to learn in quite such a hard way.

Maybe one of the things we need to do is keep building that resource and getting it out there.

On the website, there are some links, there are advice links, and there are also support links for people who need counselling to deal with what's happening with benefits, for people who are in a place of crisis. So do have a look at those resources if you think you need to pull on those. Or if you need somebody else who might.

Dawn: I'm a very quiet speaker. I'm a mouse behind a mouse. (Laughter)

"My PTSD," says Lisa, "means I have achieved great things publicly but they are not without a cost privately." Which I guess echoes what you said yesterday.

Liz: It's interesting because, yes, I very much have an impairment that has that same kind of pattern of you go out there and you try and come across as being strong and happening. And the strange thing is that the more you do that, and the less you acknowledge your impairment in public the heavier the bite-back afterwards. That there is always a cost to going out in public.

But if there's a way of integrating those two sides of self, actually it might be possible to do more for less payback. That's what I'm kind of experimenting with, I suppose, at the moment.

Dawn: Naomi says, "I've been told so many times by my consultant that my personality or character will conflict with my diagnosis of ME." That is a huge dilemma, isn't it?

Liz: Personality will conflict with my... Oh, as in they are a driven person?

Dawn: Yes, I would imagine that it means that they're quite – they can manage it and cope, or they can appear to cope. Like you discussed yesterday.

Liz: It's interesting, isn't it, how different impairments have different stereotypes attached to them? And that those stereotypes influence yet further how we are seen. And very often are used against us. So if somebody has ME and they happen to be a kind of energetic, go-getting person, that's held against them. Because they've brought it on themselves and they don't pace themselves. If somebody is a quieter, shyer person, then they're not helping themselves because they're not being energetic enough.

Actually, we have to find a way of being who we are, managing these really very complex situations, and somehow stop other people beating us up while we're doing it. (Laughter)

We've had a series of videos from people who have been following the Bedding Out Twitter feed showing their bed lives. And a number of those have been from people with ME. And in all of the videos the thing that has come across to me so strongly is that we are looking at a group of people who are dealing with a very, very tough situation. Yet in all of those people what came through to me was a tremendous strength of character. And a very deep compassion.

I look at that and actually that's the kind of world I want to live in. And I think it's really important that we don't apologise for who we are. We manage our lives as best we can.

Dawn: Thank you for being so patient, people.

There are floods.

Somebody said, "That's too loud in the café. You've got to tell them to shut up!"

(Laughter)

Liz: Hopefully, if people are struggling with the sound, they might be able to pick up on Marian's feed because she's live captioning as we go. So I hope that will support some of the sound, if that is problematic. And those captions will remain on the site afterwards so you will be able to go back and read those more slowly if that's useful.

Dawn: I've got one here from my daughter. That's nice. "Hello, mum, do you think Bedding Out is representing mental health adequately?" Hello daughter! (smiles and waves at what she thinks may be the camera)

In a word, I would like to just say, "Yes," but I don't think that is enough. Before I thought about coming here with Liz, I really had to consider whether it was going to. Because if it was all about physical disability and a bed. But I think that once I got into looking at the project, I thought I saw the bed as a more figurative image of how the personal-private self, as Liz has

explained, is very concealed. And in mental health, that doesn't mean you've gone to bed because you're mentally ill. But you can be equally imprisoned by the illness, imprisoned in your house, or within your lifestyle. And so, yes, I do think it hits home for any illness. The illness doesn't matter. The name of the illness doesn't matter; the effect is what is important.

But thank you for that.

Liz: Do you want to Tweet it?

Dawn: I'll Tweet it afterwards, because it's too long.

Liz: Just to add to that. A number of people have asked me what my impairment is. I'm very stubbornly not saying what it is. There is a reason for that. And I think if I say, "I've got X," then *Bedding Out* becomes about people with X. And it isn't.

What it's about is the fact that, as disabled people with a whole range of impairments, we have to edit ourselves. There are acceptable ways to appear in public. And very often, they don't fit what we really are. So we have to edit how we really are to become acceptable.

Then, very often, we have to recover from that in private because it takes such a toll.

Dawn: We had a question yesterday which I thought you might really like to hear.

"I really feel very disempowered." It comes from Kristina. "I can't think about anything else. Anxiety over reforms is all consuming. And I want to make a difference. But how?"

Liz: We're talking about how disempowered people feel going through this process. And yet in the midst of that, wanting to make a difference. How do we do that?

I went through ESA assessment last year. Then had nine months waiting for my tribunal. So I really, really understand that sense of disempowerment and the intense pressure and distress that comes with it.

I certainly found that an incredibly dark period to get through. And I know hundreds of thousands of other people are experiencing something very similar.

I suppose what's got me through is knowing that there are other people out there answering back. When I can, join in forces with them. Also doing this project it moves it away from just

me trying to survive, to doing something and it's the point at which I have a sense of 'doing something' that the whole thing becomes easier to handle.

One thing I think a lot of us could begin to do is to – there's a thing where everyone says, "Oh, everybody knows somebody who is cheating benefits." I don't. But everyone seems to know somebody who has been taken in by the lies about who we are and about the levels of fraud. I know people like that.

I think what we can start to try and do is talk to those people. Simple conversations. Face-to-face, via Twitter, via blogs, whatever medium is accessible to us. And when we can.

Just to try and pick up on the untruths that are out there and to tell a different kind of story.

The government puts great store in public opinion. And at the moment, public opinion is with them. It's really, really key that we change public opinion whenever we have the opportunity on whatever scale that we can do it. And to know that we're doing that collectively.

Dawn: A lot of people are saying, "A lot of things are more easily said than done when ill." I don't know if that needs an answer or it is just a fact, isn't it?

Liz: Yes, yes.

I think there's also something about all of us have times when we absolutely cannot be active. We need to allow ourselves and each other to have those times. So I've really noticed amongst campaigners, in groups of campaigners, that people move in and out and they pick up the slack for each other according to state of health at the time. I think that's what has made these groups as strong as they are. Because they are incorporating the way our bodies and our lives really are.

Dawn: (inaudible)... watching you.

Liz: (Laughter) Lovely.

Anything you can do to get the word out is fantastic. We start off with a circle around us of people who are already understanding these issues. But every single person on Twitter has access to so many other people that if you can keep getting the word out and using this to start that conversation, we will reach people who don't yet know about these issues. So please, do keep retweeting and pushing the project.

Dawn: “Complexities of disability aren’t recognised by the welfare system or even by doctors,” says Two Wolves. “How can we challenge this?”

Liz: I’ll answer the first bit first and remind me of the second part.

One of the things I’ve realised about the way that the benefits system is structured is that it’s based on a very narrow idea of impairment. So if you think of the classic Paralympian, somebody who has a typically structural impairment quantifiable, predictable, so they say yesterday as today as tomorrow, they are the kind of person this benefit system is built on. But the people who are most likely to need help, certainly from the out-of-work benefits, from ESA, are people with often invisible impairments, changeable impairments, unpredictable impairments.

So what we have is a system that actually is not capable of measuring bodies like ours. So the people who need that assistance most of all become the most likely to fall through the gaps. And that is what we’re facing.

And the second part?

Dawn: And the second part was, “How can we challenge it?”

Liz: How can we challenge it? That’s a really, really tough one within bureaucratic structures. Really tough.

In the long term, I think it’s about continuing to get our stories out there, to tell a different kind of story that reflects complexity. And that needs to sit within the much bigger campaign that is happening on not just benefits’ restructuring but on the whole cuts process that’s going on at the moment.

But in the meantime, we need to get through this as individuals. And it’s back to storytelling. It’s how we tell our story. And there are always multiple ways of telling the same story. Sometimes we have to represent parts of ourselves, rather than the whole of ourselves, in order to get what we need.

So, I’m trying to give an example here. In this scenario of benefits, we need to look to the days that are very, very difficult. In the rest of life, we might try and stress the things that we do and the things that we can do. When it comes to a benefits form, we need to change that around. We need to emphasise everything that we have difficulties with.

If those difficulties are only some of the time, we still need to make sure that that is there. We need to do the opposite of what we've been taught to do.

Dawn: It's like the opposite of living.

Liz: Yes, yes. It is, isn't it? It's the opposite of living. It's the opposite of who we want to be. But this is a game. A very cruel game. But is a game that has to be played in order for us to continue the lives that we prefer to lead.

And doing that can be a very demanding thing. An emotionally demanding thing to do. I think it's really important that we can call on each other, disabled people, in order to draw strength to do that. Then when we've done that process, shut off from it again and return to what you know of yourself.

One thing I think is quite useful is to make your impairment as visible as possible in those circumstances. Often a very difficult thing to do.

Two examples. I might wear the dark glasses that I often wear in private and sometimes I wear a mustard sweater because it makes me look much paler. That's really simple stuff. But think about how you present. Whatever your impairment, think about the image that you present and degrade your usual image for that time.

Dawn: How does that work with someone with mental health who for their own mental wellbeing it's important to look good. Are we meant to sit and rock in a corner to fit a stereotype?

Liz: I suppose that's why I say, 'time limited'.

Do you know, it's how to do it in a way that doesn't destroy your soul. If you have a medical appointment where so much of your future depends on it, that's time limited. And I do understand that not everybody can do this. But if there is a way to put personal support in place from your friends that kind of cheers you on and you do this as an act. You know for that moment you are an actor. Somehow try to separate it from who you really are.

Dawn: Acting your illness to fit a system.

Liz: Absolutely. At that moment, it's very consciously fitting a system. Know in your head that it is wrong. The system is wrong to put you in that position. But in that moment, it's doing it

for your future. So it's a temporary compromise.

If other people have other suggestions for how they manage this incredibly difficult process, please stick them on the Twitter feed. It would be really great to get ideas out there. And to remind ourselves that this is truth telling. It is not lying or fraud. This is telling the version of our lives, the aspects of our lives, that count within that system. That is something we have to do in order to manage our lives.

Dawn: A lot of people saying we shouldn't play that game because we're pandering to their ignorance and we'll change nothing.

Liz: Do you know, I really, really get that. I think in that instant, if you are one applicant and effectively your life depends on getting this at the extreme, you can't change that system in the making of your application. But if you can get through that process, and get your life back on track, then you're actually in a much stronger place to campaign for changes.

It's outside that assessment, that specific assessment place, that is where the power for change sits.

These are really, really difficult compromises. And other people will manage it in other ways. And we need to find the way that works for ourselves with least damage. Then when we can, go back outside and get on with that campaigning to change the system on a much bigger scale. For our own and for everybody else's.

Dawn: "Why are we treated, "Chris Evans says, "with such contempt?"

Liz: Wow!

It's a huge question and there's probably no simple answer. (Sighs) I think in recent times we have been seen to serve a purpose. The current government has an ideological agenda. We have become useful in that. To pursue that agenda, they have needed to turn public opinion against us.

The onslaught of the benefits cuts and the newspaper propaganda take a very serious toll that we need to fight against.

But I think it's also important somehow to hold on to the fact that there are also many, many good and compassionate people out there. Some of those people are already with us. And some of those people aren't yet speaking out. And some have been misled by the lies. But they are good people and we need to find a way to connect with them and have them as

allies.

I think we can probably take one more question and then we're actually out of time.

Dawn: I'll let you pick the last question.

Liz: I can't. I haven't my glasses on. I can't see! (Laughter)

Dawn: Somebody has backed up what you said about if you don't show your worst aspect when you're applying, you won't get help. Which is true. Sad but true at the moment.

Liz: Yes.

Dawn: What if you are someone who can't play that game, who is going to help those people?

Liz: You know, that's the million-dollar question. Because of course the people who most fall through the gaps are the ones who most need the help. People with learning difficulties, people with mental-health difficulties, people who are at their most ill are those likely to fall through the gaps.

Those of us campaigning need to continue to hold them very firmly in mind in what we're doing. There are people involved in DPAC, Disabled People Against the Cuts, and other groups, who will try and help support.

I think what we need to do is make those advocates much more visible and easier to call upon.

There is a terrible irony that, for me, when I'm at my most ill, I cannot represent myself. But when I can represent myself, I am not seen at most ill.

And in situations like that we need the very best advocates. Particularly from amongst disabled people who really understand what that means and how that life is lived so that they can convey it alongside us.

Dawn: There's one really quick one I think you'll really like. It's really quick. It has come from a lady called Fiona Art who says that she finds Anxiety really holds her back from getting out and doing things. "How did you overcome any anxiety, if you had any, about doing this?"

Liz: (Laughter) I had plenty. Thanks, Fiona. Yes.

I've been dreading this. But as with a lot of things, I realised that the anticipation is a lot more frightening than doing it. It's still very strange to know that there are people watching me here now. I can't say it's entirely comfortable. But I'm kind of glad I'm doing it. Now I'm here, there's a strength in doing it that actually means the next thing I do might not be so difficult.

But it is all the kind of 'what if' in the run up that is the thing that was most frightening of all.

There are still two conversations to come and 20-something hours. But so far, my fears haven't been realised. The feedback we're getting is that the work is actually doing something which is my greatest hope for it.

So I think sometimes maybe it's just going, "To hell with it! I am just going to do it anyway!" The worst is that I look really, really stupid. And I suppose I'll get over that. The best is that it might actually do something.

So I'm afraid we need to bring this Twitter conversation to a close now. This was the third of five conversations. It's been a really interesting one. And I suspect, with the backlog of questions and responses that Dawn's got, we could carry on for hours. We really will try and get back to those tweets over a period of time. So please do keep following the Twitter feed.

Our next conversation will be people gathered around the bed. That is at 3:15 this afternoon. So do join us on the internet for that, or in Salisbury, and the Twitter feed will continue throughout the next 48 hours. So please keep taking part in that.

And it has been fantastic to have your involvement. Thank you very, very much.

And thank you to Carol for interpreting, Dawn for tweeting and Marian for doing the captioning.

That's us. Thank you.

Thanks everyone.

Bedding Out created and performed by Liz Crow
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