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Feeling down and understanding depression

We are two people with learning disabilities who are lifelong friends. Recently we were asked to take part in Learning Disability Today with other members of the Tuesday Group to talk about depression, our experiences of mental health and things you can do to help you stay well. This article is about the day and some of the things we took part in. We wanted to go to the LD Today event to meet other people with learning disabilities, their families and friends as well as staff who support them. It also gives us a chance to talk about our work in the Tuesday Group. The Tuesday Group is made up of people with learning disabilities and others without learning disabilities who come together to work together to support us and make people more aware and campaign.

During the day, we took part in several activities. The first was to record a video where we answered questions on our mental health. This is to go on YouTube and help people who wasn't at the conference to understand about depression. The second activity we did was to talk to people in the health zone about depression and what we can do to help ourselves in this situation. This was like a chat where people talked about their experiences and what helps them. Our final activity was to do a talk about feeling down in front of a lot of people with our colleagues at the Tuesday Group Eddie and Christine, and with Steve also supporting us at the front of the audience.

Our talk started with Eddie telling people all about depression and mental health problems we how we can recognise them. We joined in and after we spoke Christine finished the talk. Here is what we said.

Depression and mental health problems

Not everyone who has depression experiences the same things. Some may find it hard to sleep but others might not want to get out of bed. What everyone has though is feeling sad and can't enjoy themselves. It also lasts for a long time over weeks. For some people with learning disabilities it can be hard to describe their feelings. Some people may not understand the words or know something is wrong with them that they can need help with. Sometimes people supporting them do not understand about mental health and say the problems are due to the person's learning disabilities or they are just upset and should just learn to cope.

Next we told people about our experiences of depression. Depression feels like a dark cloud above your head which you can't get rid of. It stops you doing things like going to work or enjoying doing things like talking and mixing with people. Sometimes it is difficult to get to sleep and it can also make you anxious. This can get worse when people do not understand. Some people have lost their jobs because of mental health problems because people haven't understood or felt that the person doesn't care and are just lazy.

Learning disabilities and mental health problems

People with learning disabilities are more at risk of mental health problems for many reasons. They are more likely to have:

- little money
- other people telling them what to do and making decisions for them
- few friends
- opportunities to do activities that others enjoy
- long term health problems and disabilities
- physical problems due to self-neglect e.g. poor dental hygiene, diet
- people who can support them

- experience abuse from others in the community such as school children or people pestering for money
- less chance of getting a job or going to college
- problems with support staff who we like and leave which makes us upset
- support workers who tell us to wait and talk to the next shift

Getting help for mental health problems can be hard

When people with learning disabilities go to get help for mental health problems it can be a bad experience. Here are some of the experiences that people we have had and people have told us about:

- The people who support them do not know the person or what they have been going through
- The Dr or receptionist will ignore the person with learning disabilities and will talk only to the person supporting them
- One person was shouted at for not going to see the Dr when his name come up in the screen. The receptionist did not know he could not read
- Sometimes it is difficult to understand what the Dr is asking the person or remember how long things have been going on
- Some people feel they are not listened to or being rushed and that the Dr doesn't understand about their learning disabilities

What can we do to help ourselves?

One of the ways that can help avoid these problems is to be prepared. We next talked with Eddie and Christine about things people with learning disabilities can do to help ourselves and our mental health. We have both helped to write guides for people on guided self-help (the SAINT) (Chaplin et al, 2014) and the Feeling Down Guide (Christine K Burke, 2014).

Using these has helped us when we have felt depressed and anxious and to understand

about depression and anxiety. A lot of ideas in these books we knew about from the Tuesday Group meetings where we talked about helping our mental health and practiced how to cope in situations we found difficult.

One of the things we talked about was to not to wait until we had problems, but to write a plan about staying healthy. Looking after mental health is as important as looking after our physical health. If you don't look after yourself or get help when you need to then your feelings can get worse and lead to mental health problems. There are several ways we can do this which are in the picture (see figure 1) from the Feeling Down Guide we helped to write.

ENTER FIGURE 1 AROUND HERE

Another thing that helped was an idea from when we used the SAINT, which was doing a diary. It is good to write a diary not only when we feel down but all the time and to talk about the positive things and what we have enjoyed. The Diary lets us write down our feelings and things we have done to help ourselves to cope. These are called coping strategies. The diary can help us when we go to get help as the Dr can see how long we have been feeling depressed or anxious and what we have tried to do to help ourselves and if this has worked. Sometimes things we try to do might not help us and makes us feel worse. Especially if we can't concentrate or find it hard to enjoy ourselves. This is why it is different sometimes to try different things. When we helped to write the SAINT we took part in groups to listen to people about what helped them cope with mental health problems. The list below is from the focus group we took part in and the top ideas that people with learning disabilities felt were helpful:

- Speak to someone you know this can include
 - Going for a check up
 - talk to key worker
 - see a counsellor
- Speak to someone outside your team you trust. This can include
 - the Samaritans
 - family and friends
 - someone who can give you time
- Socialise and going out. This can include
 - day trips
 - going to the pub
 - going to a disco or club
 - Watch TV or DVD
- Listen to music
- Keep busy. This can include
 - job hunting
 - go to classes
 - use the computer
 - do things round the house
 - go shopping

- Do exercises. This includes sports and activities such as walking
- Relax and rest. This can include
 - using a stress ball
 - doing breathing exercises
 - aromatherapy
 - scented candles
 - get some fresh air
- Do hobbies. This can include
 - stamp collecting
 - puzzles
 - traveling on buses
- Other ideas we had were reading, comforter such as cuddle a teddy, play games, go to Church, Temple or Mosque or any other religious place of worship or read a holy book

It is also important when supporting people is to let the person choose what to do. Not everyone can do or will like doing everything on the list. Some might find them boring and can even make them feel more stressed if they don't enjoy them or like doing them. Other focus groups who did the research also came up with different ideas in their lists like gardening and drawing and colouring. It is important to help the person find what they might enjoy and what is good for them.

Another thing people can do to help their mental health is to talk about what things or situations they find difficult. We mentioned some of these earlier in the article. Sometimes it

is good to practice how we will handle things or what we will do in a situation in real life. We can practice what to do with others and play act or role play the situation. For example we can practice how to say No to strangers who ask for money. This is difficult in real life and to practice. If possible it is better to try and avoid the situation if you see someone you know who might pester or beg from you. You can go a different way or cross over the road at a different place so you don't see them. Another situation is going on a bus when children are going to or coming home from school. This makes a lot of people with learning disabilities anxious as some of the groups of children can be cruel and call us horrible names. Wherever possible we do not go on the bus at these times and even if we go with staff we still think people are talking about us or hear them making rude comments behind our backs to their friends. Sometimes life is not fair but it might keep you safe. Other people we talked to at the conference told us about what some organisations are doing to make things better for learning disabilities who are taking public. They help bus drivers to understand the issues and talk to people in schools, so hopefully one day things will be better and people would know more about people with learning disabilities.

What people do to help their mental and physical health should be a part of their Staying Healthy Plan. As well as telling people about what the plan is, to help people to understand how to do a plan we gave them an example of what a Staying Healthy Plan looks like (see Figure 2).

ENTER FIGURE 2 AROUND HERE

If people reading this article want to know more they can get more information about Staying Healthy Plans and feeling down from <https://www.mentalhealth.org.uk/learning-disabilities/publications/feeling-down-looking-after-my-mental-health/> (Link not working now).

The guide also provides information on:

- Part 1: What is mental health

- Part 2: How to keep yourself feeling well
- Part 3: What to do when you are worried about your mental health
- Part 4: Planning a visit to your GP
- Part 5: GP Information Pack

Final Thoughts

We would like to thank the Editors for letting us write this article and to Eddie Chaplin, Christine Burke and Steve Hardy who supported us to put what we said and our thoughts together. For those who support people with learning disabilities our message would be to listen and try to put yourself in our lives. Many of the things said to us can be hurtful and people say them without thinking. These things can make us feel bad about ourselves. One of the examples we told the conference of how a bad experience that is hurtful that became positive when someone stood up for us. When I moved house (Peter). I had to look for a new Church to go to. The Baptist church I go to now is good and the people there treat me well, include me and try to understand how they can help me if I need support. Before I found this Church which I feel a part of; I went to a Church where a lot of people ignored me and didn't seem to understand. Before I left one day I heard the Minister saying to another congregation member, "Why does Peter come? He can't be a Christian he can't even read the Bible". I was very upset and hurt by this, but the man he was talking to said to him. "It doesn't matter if Peter can read or not. He understands about Christianity and human kindness and you can see by his actions that he is a true Christian". Although I didn't trust the Minister this made me feel better and whatever people believe in there are good people out there who will help.

References

- 1) Chaplin, E, McCarthy, J, Hardy, S, Underwood, L, Spain, D, Cronin, P, Peyton, L and Henry, J (2014) The SAINT a Guided Self Help approach for people with intellectual disability, Pavilion Brighton.
- 2) Christin Burke, 2014, Feeling Down: Improving the mental health of people with learning disabilities. Foundation of People with Learning Disabilities, London.

My Staying Healthy Plan

Use the ideas in this part to think about how you can stay healthy.



Figure 1: My Staying Healthy Plan (FPLD 2014)

My Staying Healthy Plan - Example

What will you do?	When will you do it?	Who will help?
<p>1. Relax by going to a relaxation class</p> <p>2. Go out with friends for coffee</p> <p>3. Talk to my sister as it makes me feel less anxious when I talk to her</p> <p>4. Tidy my room. Open the window in the morning to let some fresh air in. Put an air freshener in the room. This will help me sleep better</p> <p>5. Go to the GP this week to talk about how I am feeling and about not sleeping.</p>	<p>1. Once a week</p> <p>2. Once a week</p> <p>3. Every evening</p> <p>4. Once a week</p> <p>5. This week</p>	<p>1. Jane will help me</p> <p>2. My friends</p> <p>3. My sister</p> <p>4. My support worker</p> <p>5. My sister</p>

Figure 2: A Staying Healthy Plan (FPLD 2014)