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Website provides ‘day in the life’ stories of service users

Donna Kemp reports on an online resource that helps people to tell of their experiences

The ‘A Day in the Life’ website was the inspiration for this edition of Mental Health Nursing’s focus on a day in the life of mental health nurses.

The website provides a snapshot of what it is like to be a person with mental health difficulties in the 21st century. You can find it at https://dayinthelifemh.org.uk.

Currently in its first year, the project has been made possible with the support of Public Health England and is curated by Social Spider, a community interest company.

Behind Social Spider are Mark Brown and David Floyd. Mark is prolific on Twitter (@oneinfour), commenting on mental health and social action. He speaks at conferences about mental health, social media and innovation and is leading on several national workstreams.

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This ultimately builds a library of people’s experiences, painting a picture of what it is like to live with mental health difficulties – what helps to make life better and what makes it worse.

There are guidelines for writing, which includes considering their own and other people’s confidentiality, not disclosing sensitive information and writing generally about specifics – for example ‘a nurse’, ‘my local community team’.

Further safeguards are in place as content is approved before publication, and any content contrary to the Equality Act is deemed inappropriate.

The writing guidance is thorough and written in plain English, and it encourages people to participate and seems to have got the balance right between ‘do it’ and ‘don’t do it’.

Searching the website is straightforward as the content of people’s diaries are put into themes of health, people, things we do, home life, services, where we live, money, stigma and work.

Within these you can then search for reports that are positive, negative or neutral.

So taking a peek at ‘services’, an example of negative was: ‘I am desperately disappointed in the NHS. I know it’s not their fault but the waiting list to see a psychiatrist to review my medications is three months. ‘I’m also on a waiting list for DBT but I don’t even know how long that will take.

‘I have to wait for my temporary care co-ordinator to tell me (I don’t have a permanent care co-ordinator yet... But am on the waiting list! I’m sure you can start to see the pattern’.

Conversely, an example of positive was: ‘But now, I am in the mood for listening. I have discussed treatment options, and specifically lithium therapy, with my ever-patient care co-ordinator and with the NHS consultant who will oversee the change of medication.’

Drawing out a concrete positive took more reading of diaries than it did for finding negative content. That said, the diaries are not a catalogue of negatives – they are reflective and descriptive.

My impression of the diaries is that they hold very personal accounts, not only of that day but of life generally.

The brief is met. This is a library of people’s experiences. But it is more than that. People have seized the opportunity to share their thoughts and feelings, hopes and dreams through writing.

This is an example of where contributors have created something unique and collectively it has exceeded its brief.

What can we learn from this as nurses? Well, there are some standout observations:

• As nurses we should do this more – sharing what we experience, what we do and how we do it is useful. It promotes reflection and supports shared learning and development.
• The themes identified (health, people, things we do, home life, services, where we live, money, stigma and work) give us a clear ‘heads up’ as to what is important to people and as such can guide us in engaging with people.
• As nurses, we should note this as an example of how being radical can yield results, bring awareness to an issue or simply amplify a voice.
• If you find yourself professionally conflicted, submerged in your organisational mire, defending boundaries of services, and rationing health, then read a diary or two and remind yourself of the people you serve. This will help you to maintain your professional and personal focus. MHN

Donna Kemp is the care programme approach development manager at Leeds and York Partnership NHS Foundation Trust.