

# Developing the 'Understanding Psychosis' workbook

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&

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(with help from service users and staff at Fromeside)

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# Plan for the session

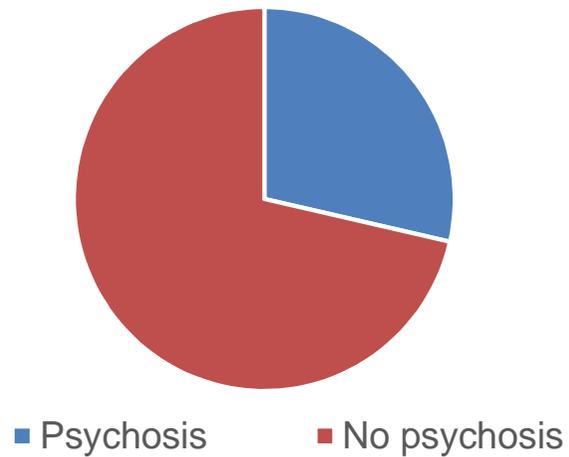
- Why we did this project
- How we did it
- What people have told us about it
- Next steps.....

# Prevalence of psychosis in LD/ASD populations

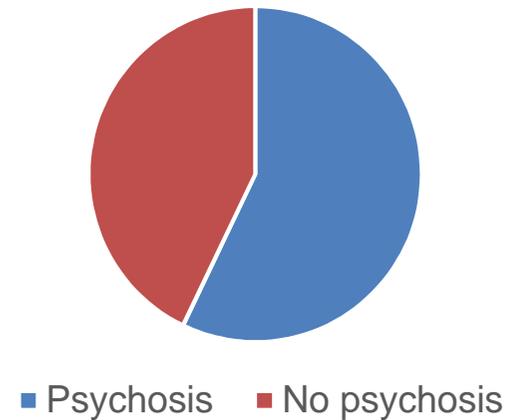
- Challenges in collecting accurate data.
- Systematic review from 2016 showed rates of schizophrenia at least 3 times higher for people with learning disabilities, than the general population (Aman, Naeem, Farooq & Ayub)
- Meta-analysis from 2018 showed co-occurrence of schizophrenia in nearly 6% of people with autism spectrum disorders without learning disability (Marin et al).

# Prevalence of psychosis in service users under the FIND Team

People with Learning Disabilities



People with Autism Spectrum Disorders without Learning Disability



# The impact of psychosis on individuals within secure services

- Links to risk (e.g. command hallucinations, paranoid ideation, disinhibition, impulsivity)
- Limiting ability to engage in risk focused work
- Impact on QoL, social inclusion

# NICE guidelines re psychosocial interventions for schizophrenia

- CBT
- Family interventions
- Arts psychotherapy
- Peer support
- Self-management programmes including information and advice on:
  - psychosis and schizophrenia
  - effective use of medication
  - identifying and managing symptoms
  - accessing mental health and other support services
  - coping with stress and other problems
  - what to do in a crisis
  - building a social support network
  - preventing relapse and setting personal recovery goals.

# Does psychoeducation help?

## **Systematic review: Brief psycho-education for schizophrenia** (Zhao et al., 2015)

- Significant improvements in concordance with medication in the short and medium term
- Reduced rates of relapse in the medium term
- ?improvements in mental state
- ?improvement in QoL and social functioning

## **Systematic review: Psycho-education for schizophrenia** (Xia et al., 2011)

- Significant improvements in concordance with medication in the short, medium and long term
- Reduced rates of relapse and readmission
- Improved social and global functioning and QoL
- Better satisfaction with mental health services

# Psychoeducation for people with LD & ASD with psychosis

Increase in knowledge about psychosis  
Crowley et al., 2008

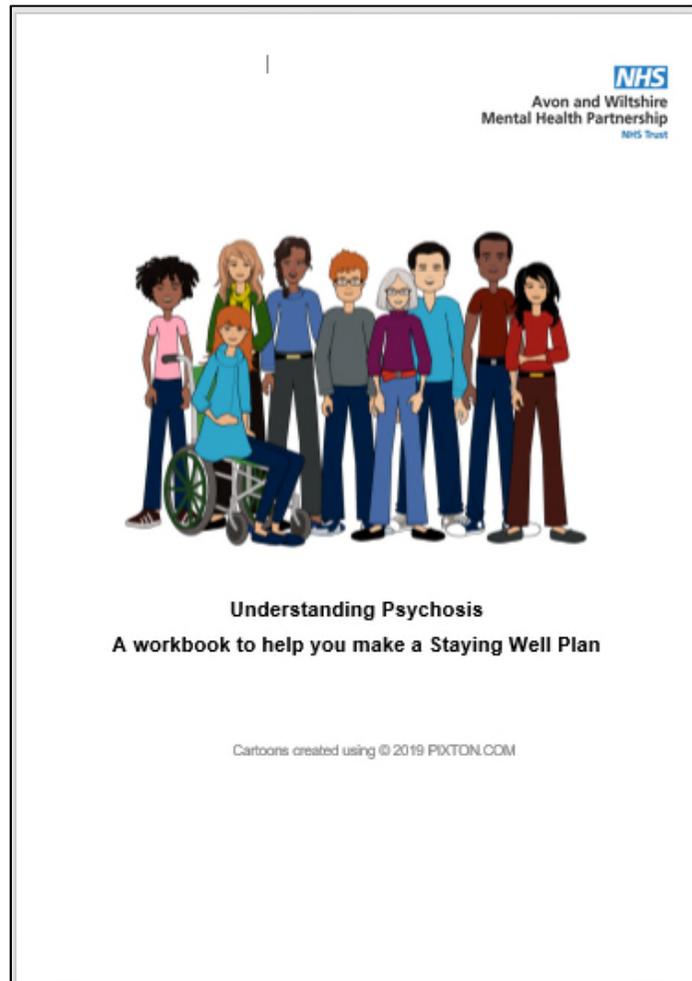
Positive feedback, developed 'Staying Well  
Plans' still being used several years later  
Douds et al 2014

Positive feedback  
Ashworth et al 2016

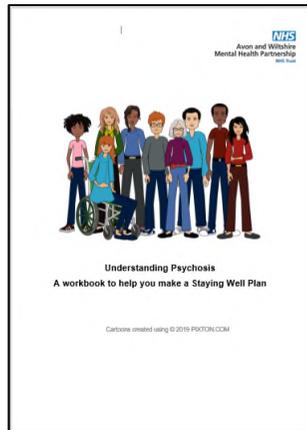
# Challenges of providing psychoeducation to people with LD/ASD in secure services

- Heterogeneous condition
- Complicated, abstract concepts
- Difficulties with:
  - Expressive/receptive communication
  - Concentration
  - Distressing/difficult content
  - Stigma
  - Lack of insight
  - Lack of perceived benefit
  - Previous negative experiences of therapeutic interventions

# The 'Understanding Psychosis Workbook'



# What's in it?



## A workbook



## Sorting cards:

110 acute symptoms cards

54 early warning signs cards

33 trigger cards

# Developed through:

- A literature search
- MDT discussions
- Discussions with service users
- Asking service users for their 'tips'
- Feedback from service users and clinicians who have used it



*Supported by an Avon and Wiltshire Mental Health Partnership NHS Trust  
'Bright Ideas' grant*

# Aims of the workbook

To develop a free resource for any clinicians working with people with cognitive/communication difficulties who experience psychosis, providing:

- Comprehensive, accessible information about psychosis
- Simple, concrete explanations of complex concepts
- Clear examples of experiences that could be embarrassing/emotionally challenging to raise
- Stories of recovery to normalise and instil hope
- Activities to build a relapse prevention plan ('Staying Well Plan')
- Sorting cards to help concentration & engagement

# Where has it been piloted so far?

- Specialist LD/ASD medium secure services
- Mainstream medium & low secure services
- Assessment and treatment unit
- Forensic community learning disabilities team
- Community learning disabilities teams
- Adult community mental health team
- Inpatient child and adolescent services

<b>1</b>	<b>Introduction</b>
<b>2</b>	A story of recovery
<b>3</b>	What are hallucinations?
<b>4</b>	How does psychosis affect people's thinking?
<b>5</b>	How does psychosis affect people's behaviour?
<b>6</b>	<i>Activity: What was it like when you were unwell?</i>
<b>7</b>	How long does psychosis last?
<b>8</b>	<i>Activity: More about you</i>
<b>9</b>	NICE guidelines for psychosis
<b>10</b>	Tips for dealing with voices and other problems
<b>11</b>	<i>Activity: What helps you when you are unwell?</i>
<b>12</b>	What causes psychosis?
<b>13</b>	<i>Activity: Dealing with triggers</i>

<b>14</b>	Things you can do to stay well
<b>15</b>	<i>Activity: What could help you stay well?</i>
<b>16</b>	Medication
<b>17</b>	<i>Activity: Information about your medication</i>
<b>18</b>	Early warning signs
<b>19</b>	<i>Activity: Your early warning signs</i>
<b>20</b>	Drugs and psychosis
<b>21</b>	Planning for if you need to go to hospital
<b>22</b>	<i>Activity: Making a plan for if you need to go to hospital</i>
<b>23</b>	Making a Staying Well Plan
<b>24</b>	Where to get more information

# A story of recovery\*

\*very condensed version



This is a story about Matt.

He has experienced psychosis.



Matt left college when he was 18.

He got a job at a supermarket.



Matt found the job really hard.

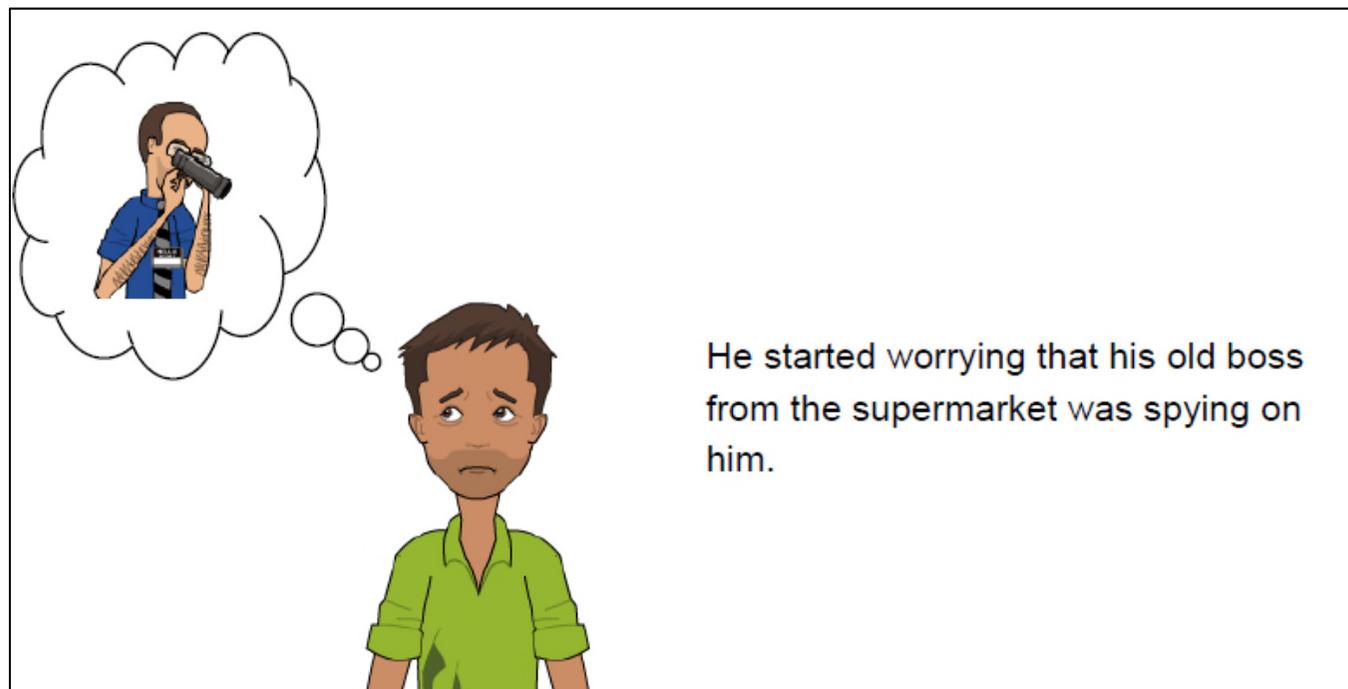
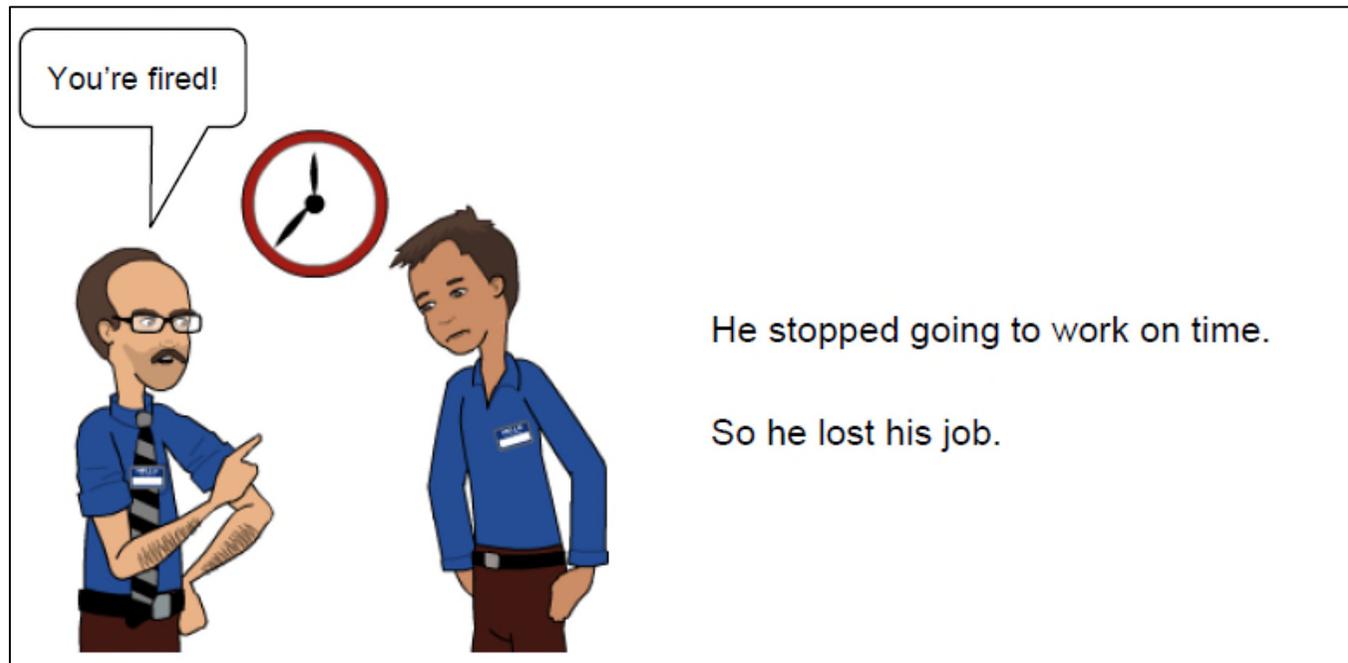
He kept making mistakes.

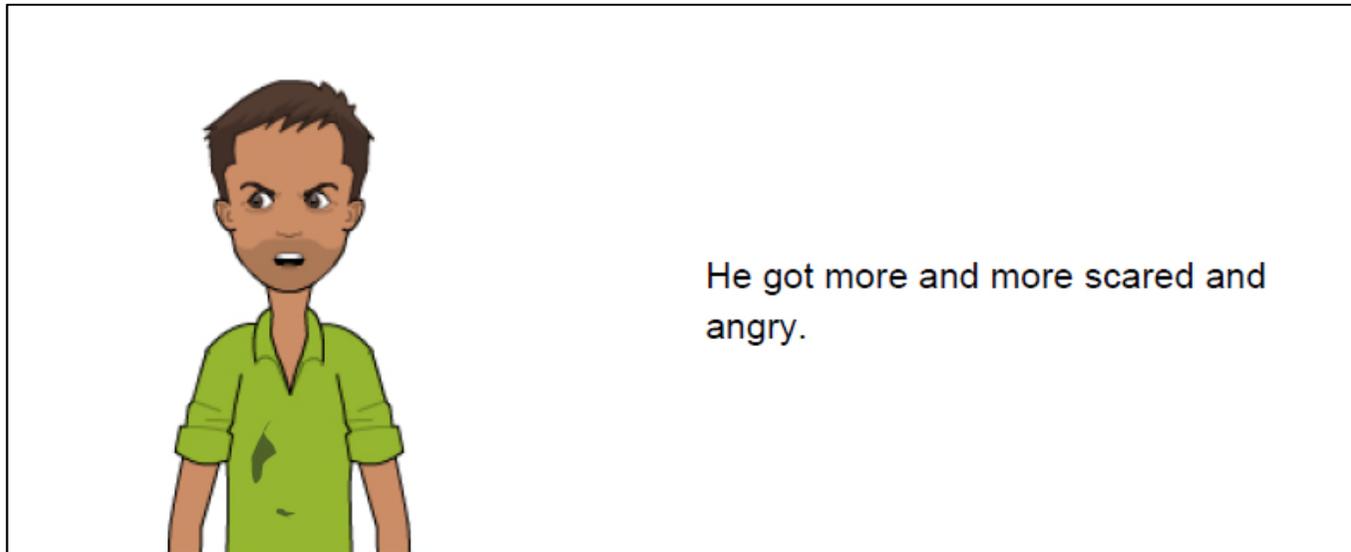
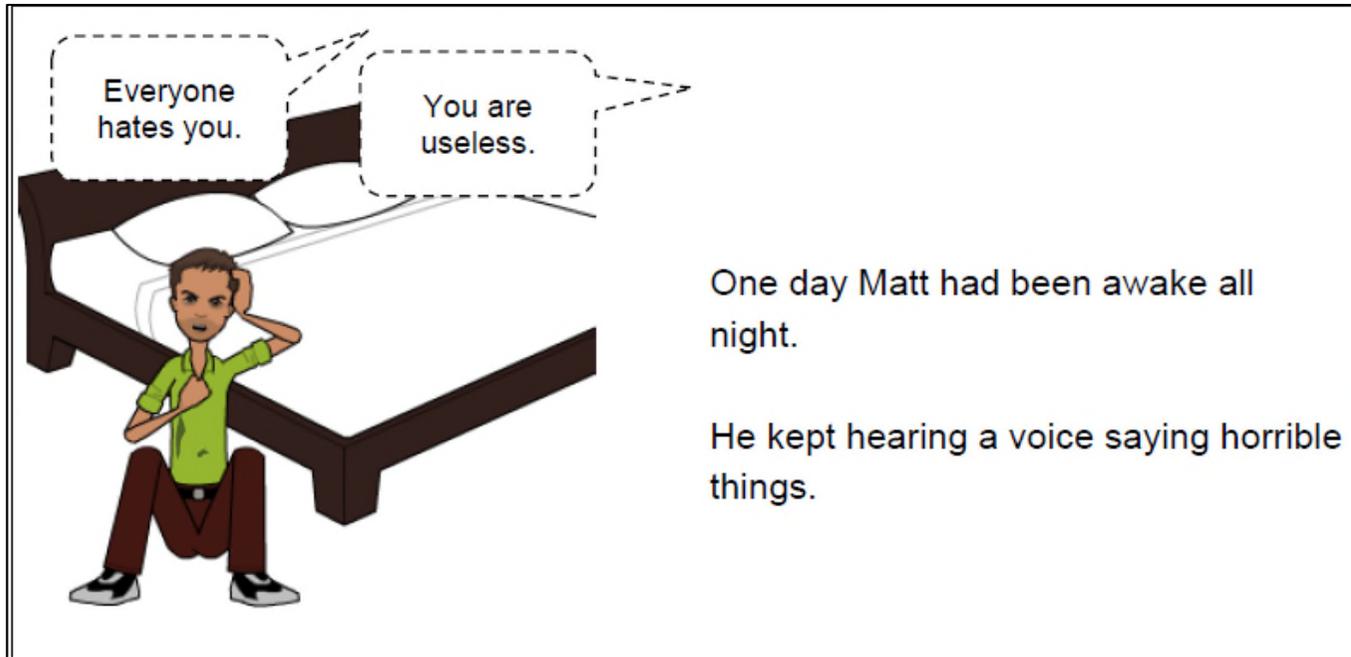
People at work teased him.



Matt felt very stressed.

He started smoking cannabis to help  
him calm down.



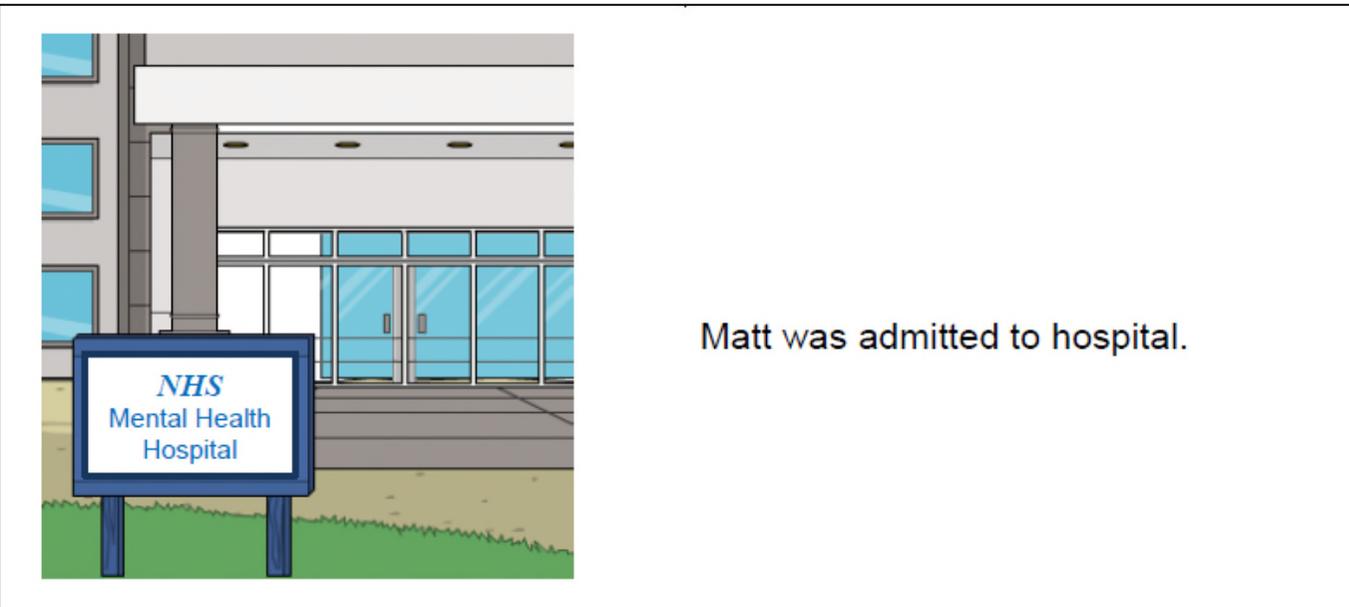




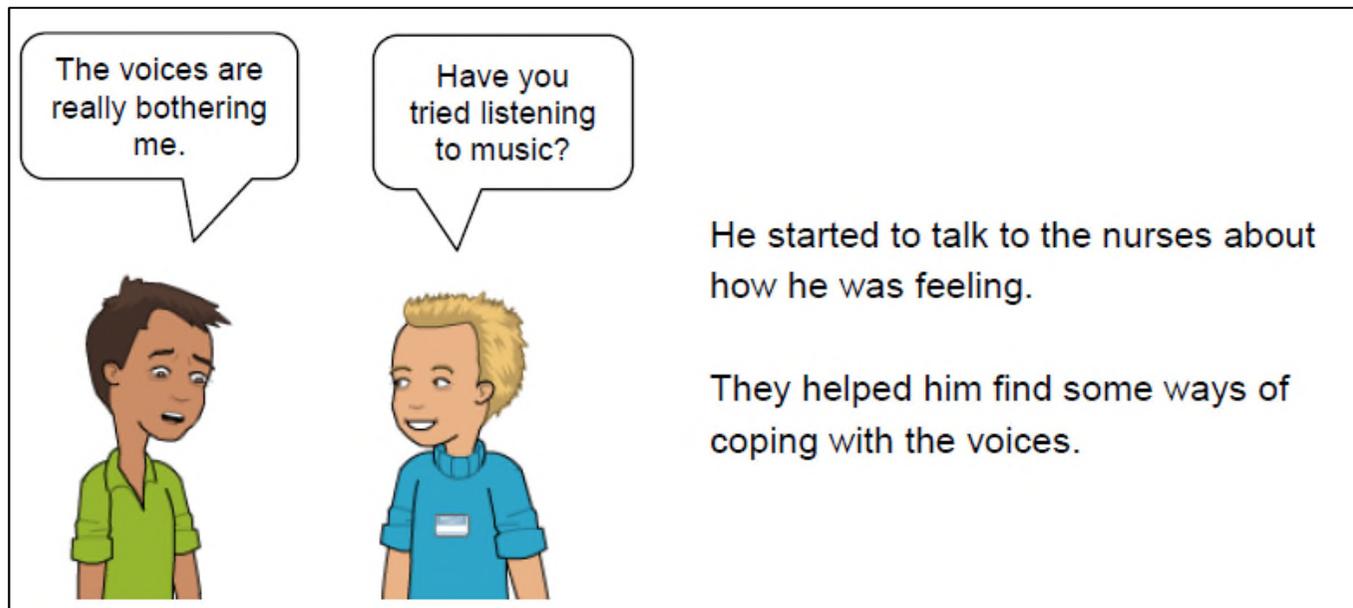
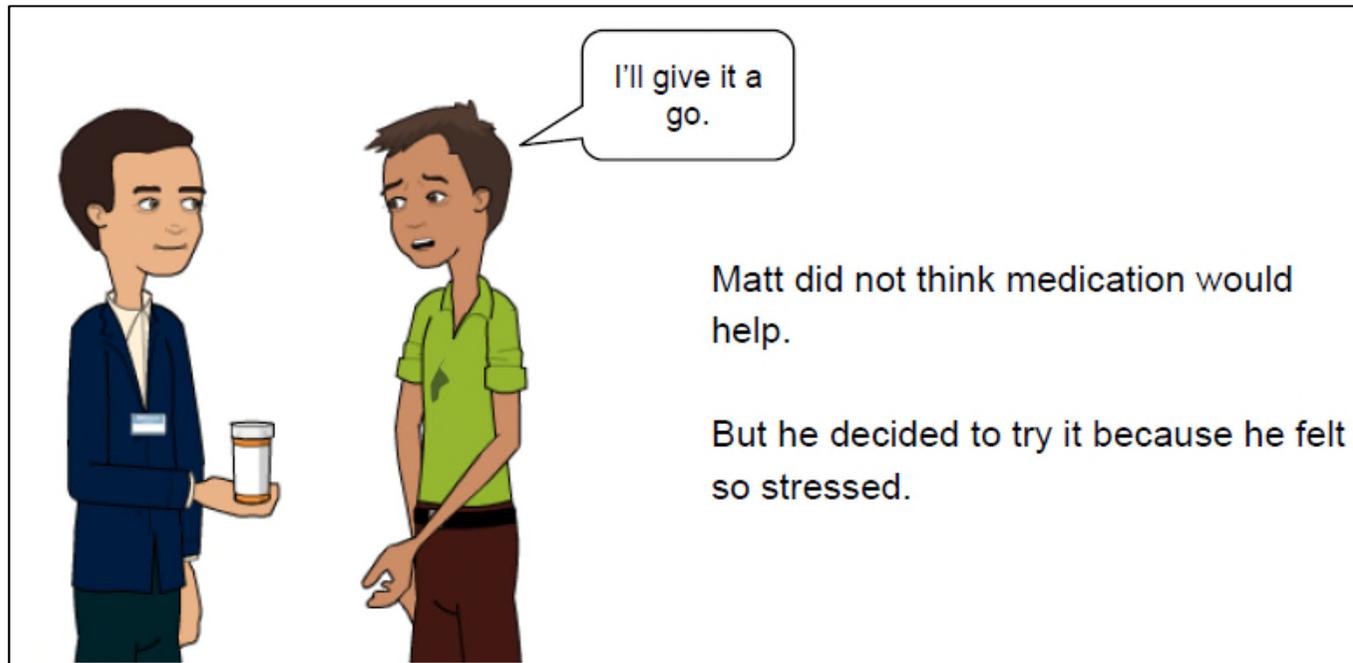
He went downstairs shouting.

He got a knife from the kitchen and threatened to stab himself.

He wanted his boss to leave him alone.



Matt was admitted to hospital.



Sometimes I have nightmares about my stepdad.



Matt talked to a psychologist.

They talked about difficult things that happened in the past.

They talked about how to manage upsetting thoughts and feelings.

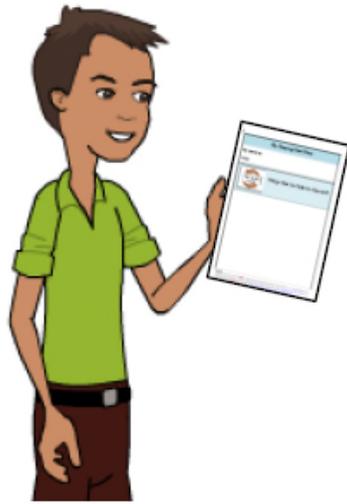


Matt worked with his OT.

They worked on his personal care.

He joined a gardening group.

He started cooking again.



Matt's named nurse helped him make a Staying Well Plan.



After a while he was ready to leave hospital.

He moved into a supported flat.



## Comments from clinicians

“The story aspect really helped him relate to material and appreciate how it might apply to him.”

“Matt’s story was also really useful to go through early on as the service user identified a number of similarities himself with his own story.”

“The story of recovery was also very helpful as it normalised his experiences.”



## Comments from service users

*What did you like best?*

“Story about Matt – [had] psychosis like me.”

“Matt's story was quite good.”

# Sorting cards

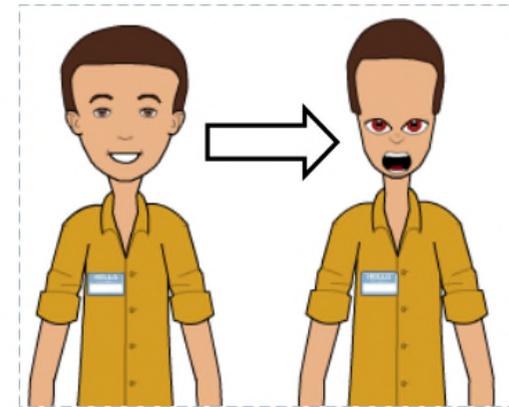
**Acute symptoms**



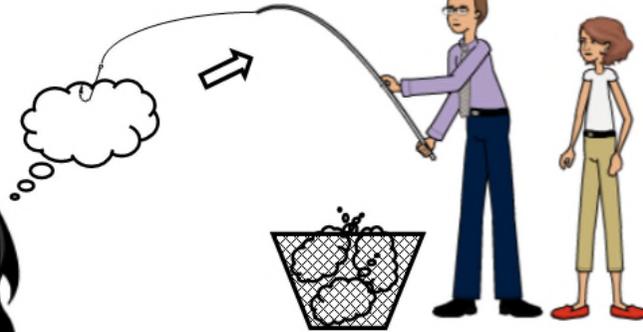
If you tell anyone about us we will kill you.

You will die...

I heard voices that told me that something bad would happen if I told anyone about the voices.



I saw people's faces change shape.



It felt like other people were stealing my thoughts.

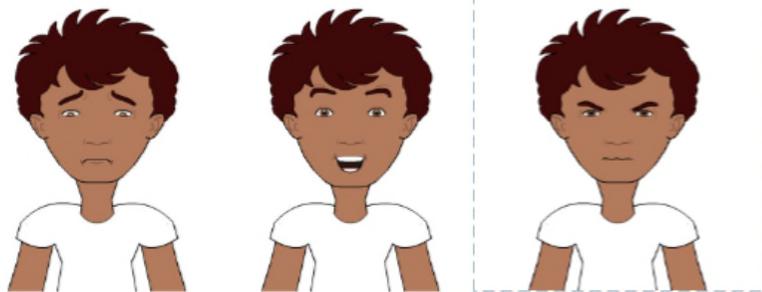


Would you like a burger?



I thought that people were trying to poison me.

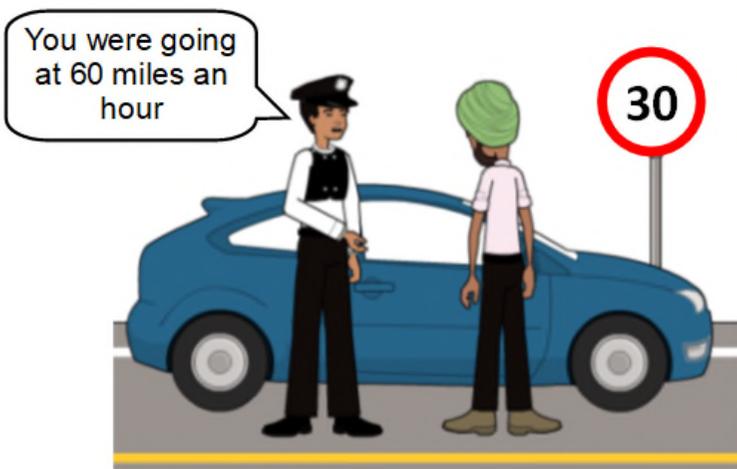
# Early warning signs



I had mood swings.



I had problems sleeping.



I did risky things, like drive too fast.



I did not want to speak to people.

# Triggers



Using drugs.



Money problems.



Going to prison.



Not taking my medication.



# Comments from clinicians

“The images on the cards.. were well thought out, comprehensive, covered all symptoms or experiences that I wanted to discuss and above all they proved accessible when other resources did not.”

“Usually the SU is fairly guarded and dismissive about his symptoms so this was a really helpful activity to say things out loud and openly acknowledge that they had experienced these symptoms previously, was a step forward.”

“I think may have helped with shame and internal stigma that he experienced as gave the impression that these are symptoms that other people also experience, understandable reactions etc.”

“Helpful as kept him engaged - cards with clear pictures and sentences were accessible despite the distress he was experiencing.”

“The service user enjoyed the sorting cards as I think they felt like it was part of a game.”



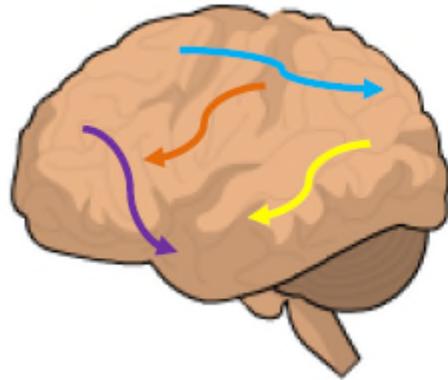
## Comments from service users

“I liked the sorting cards because it made it a bit easier to think about different symptoms I had.”

“The cards helped, I like when I look at the pictures.”

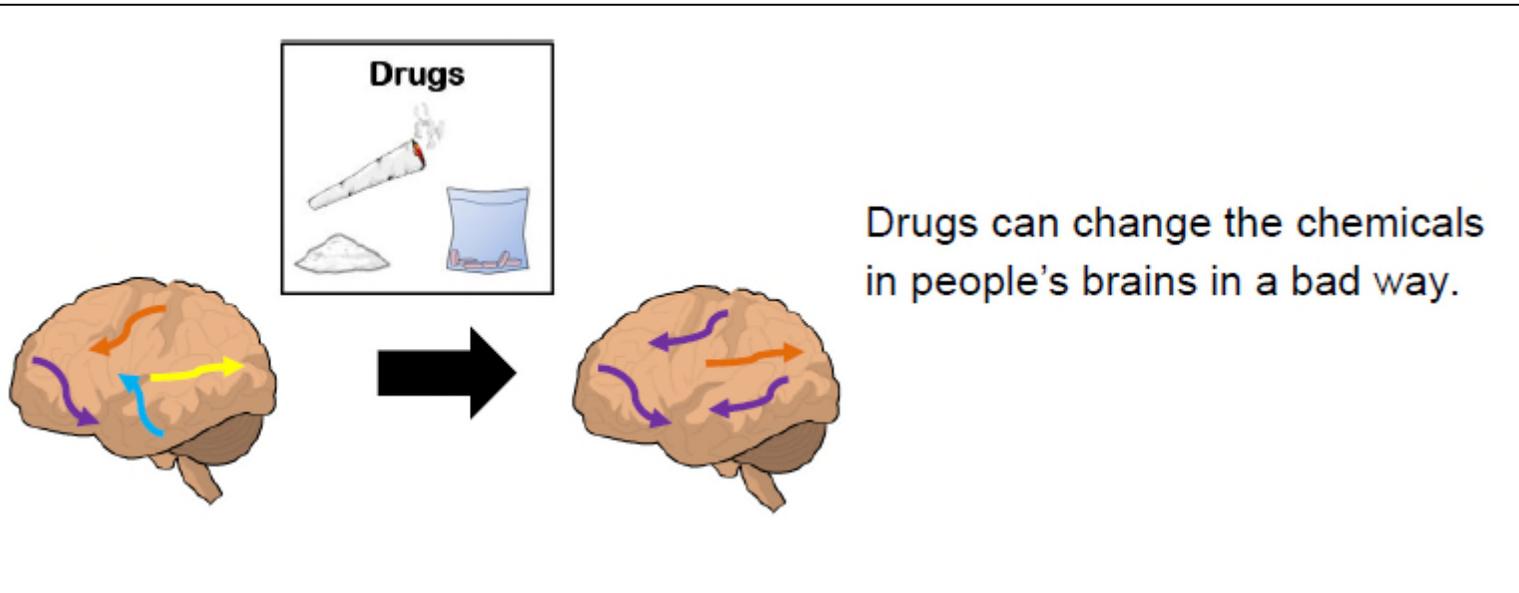
“I would like the cards to show people if I am struggling to talk about this.”

# An example from the main workbook: Extracts from 'Drugs & psychosis'

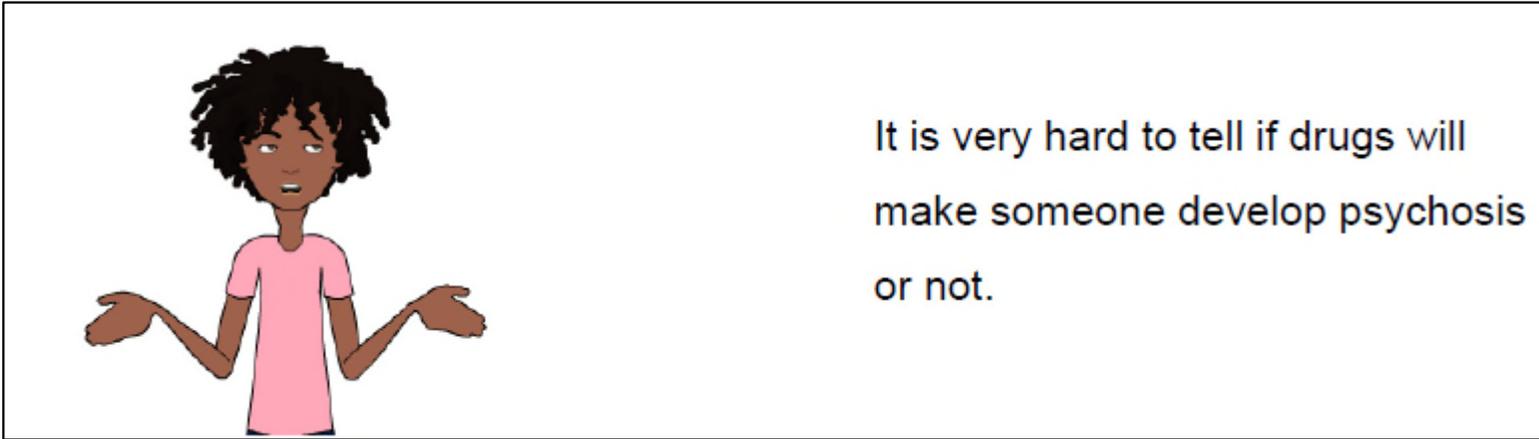
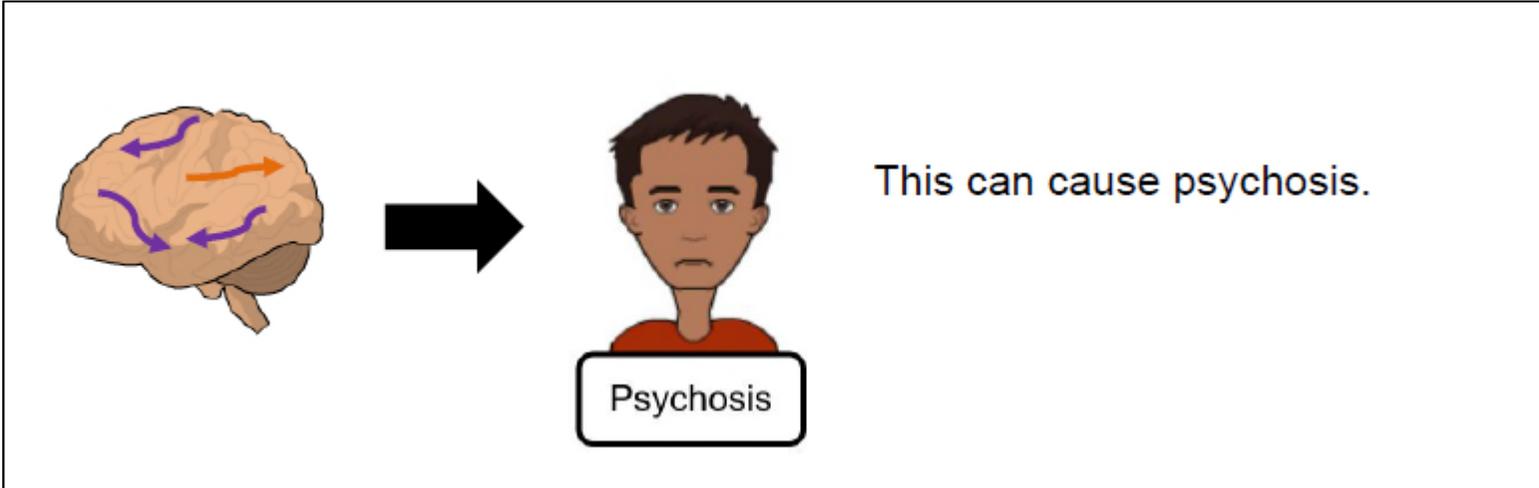


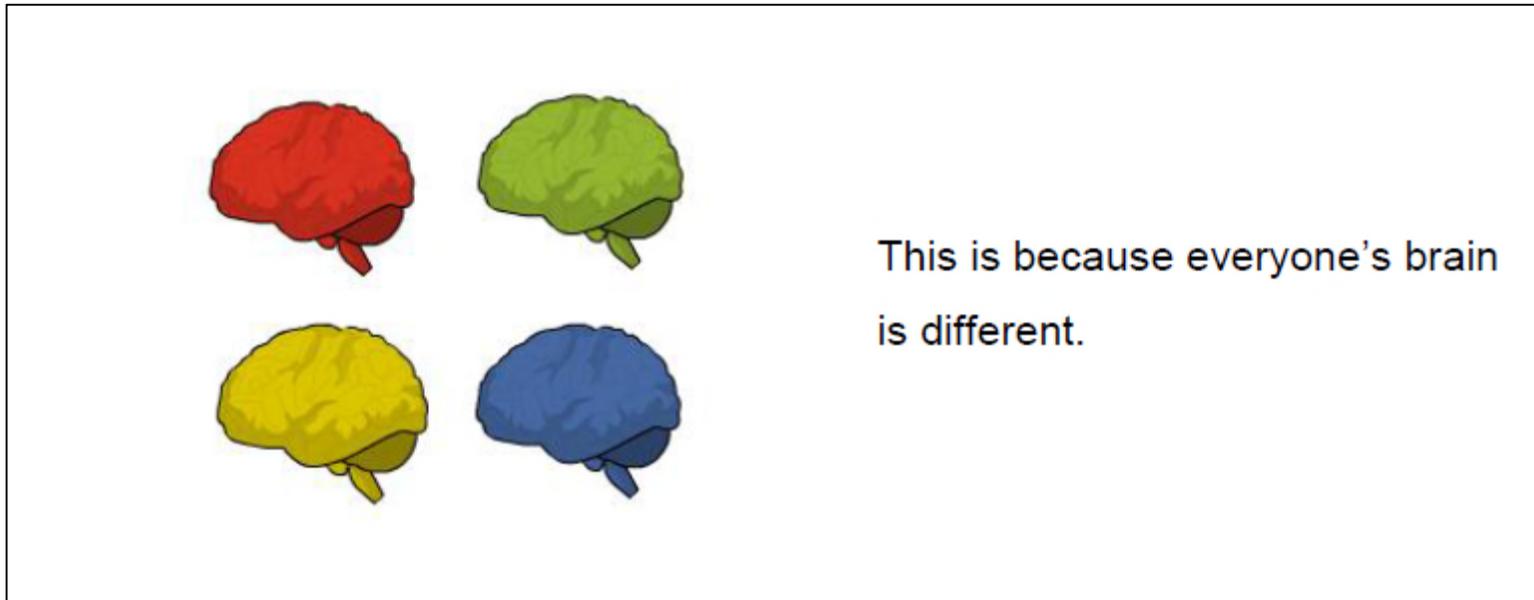
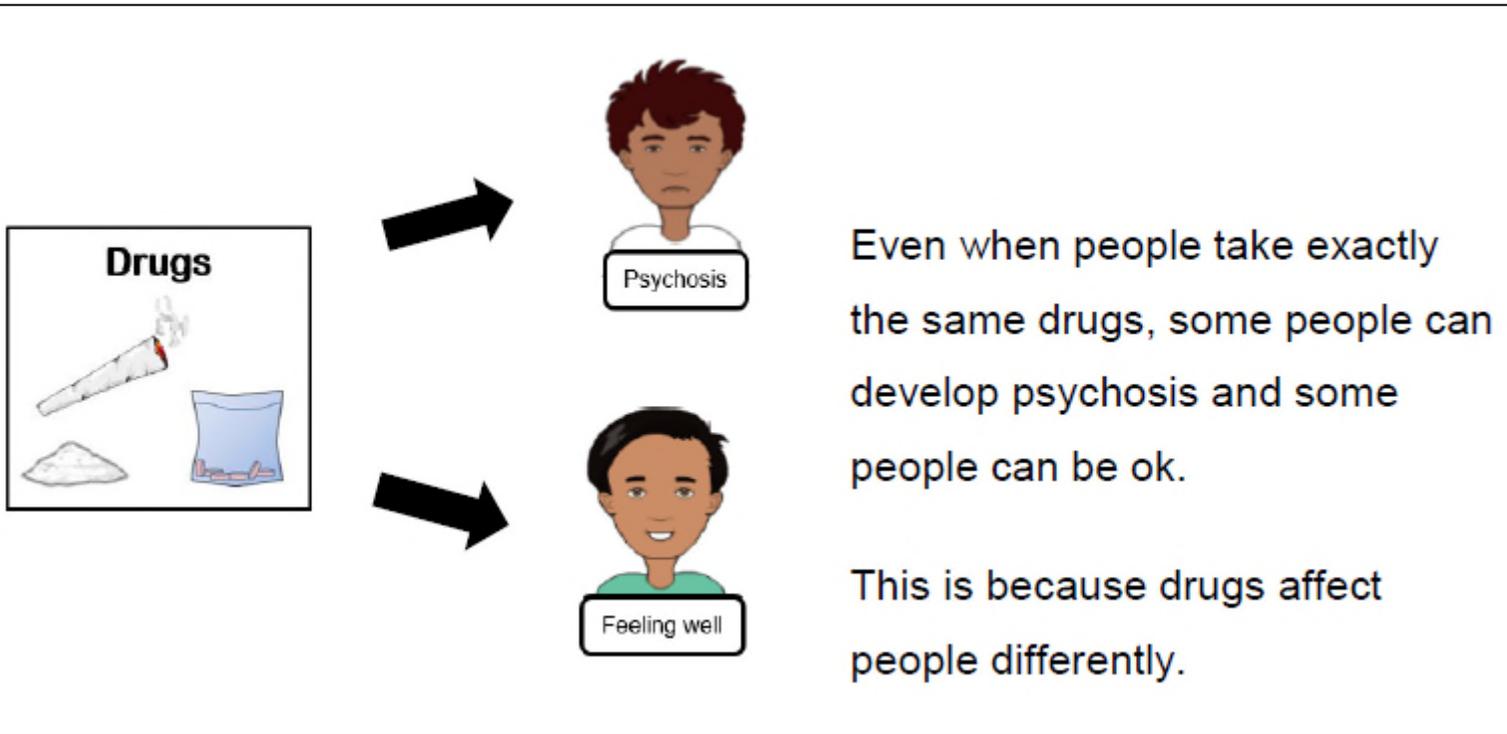
Everyone has chemicals in their brains that make it work.

The chemicals pass messages around the brain.



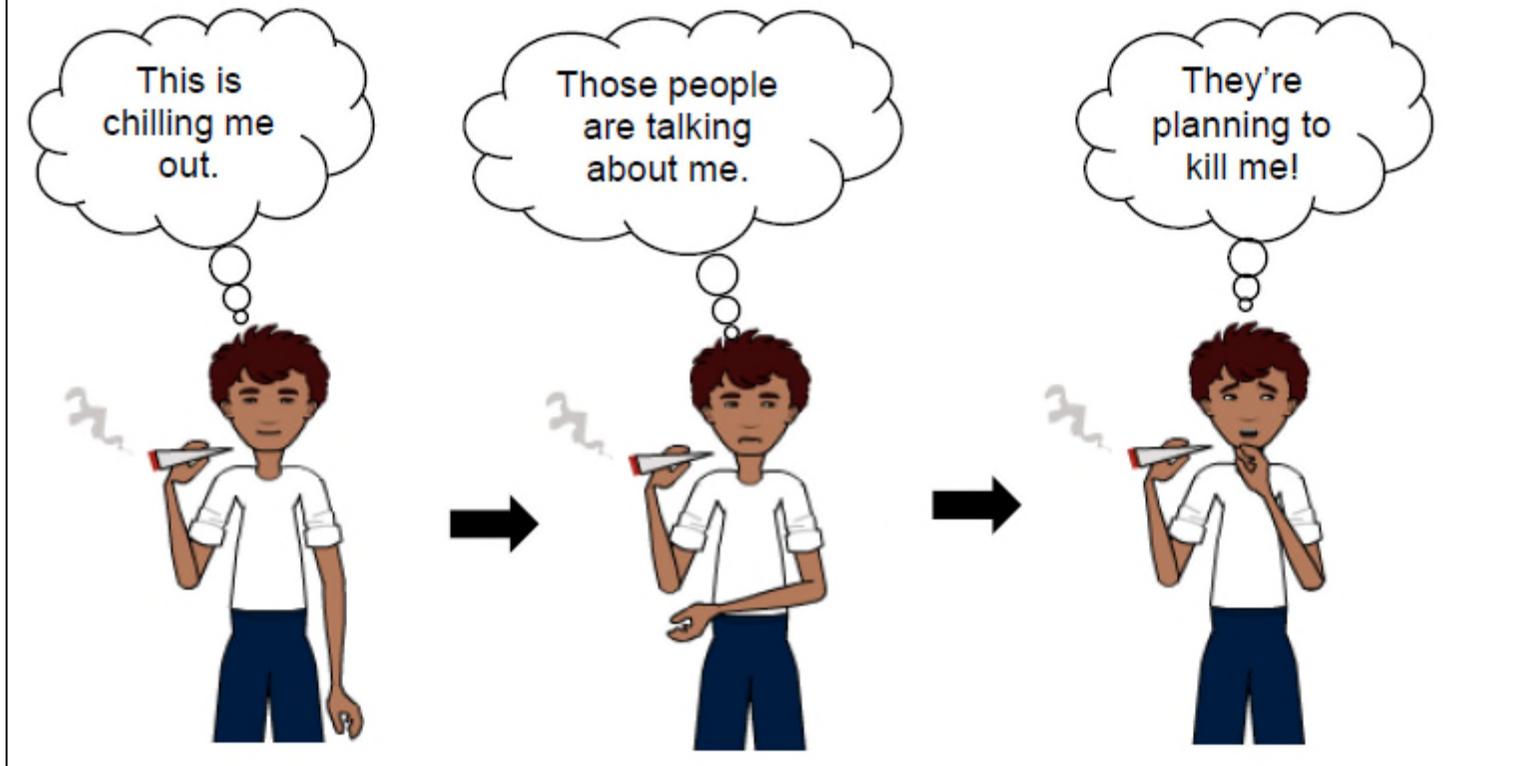
Drugs can change the chemicals in people's brains in a bad way.





Even if people feel ok when they start using cannabis, it can make them more and more paranoid.

It can slowly make people psychotic.





# General comments from clinicians

“...the triggers section helped them to make links between things they find stressful in life and their experiences of voices.”

“the clear instructions about drugs seemed to resonate with him. Pictures were extremely helpful as they were often literal and concrete.”

“I particularly liked that the workbook is divided into distinct sections, which can be used independently as this allows for the clinician to tailor the information according to the needs of each service user.”

“The patient took pride in creating a workbook and plan to share with others - increased engagement with looking after her own mental health.”

“The SU was also paranoid and providing him with more detailed or complex info appeared to increase this paranoia. Providing him with information which he could engage with and understand appeared to help a more trusting therapeutic relationship.”



# General comments from service users

“I would recommend people to make a stay well plan because it will help them”.

“They are easy to look at and give you lots of support. It made me think more about other people's experiences of psychosis and there were some symptoms and experiences that I didn't realise before were linked to my psychosis.”

“I know what to do now if I get unwell.”

“I am happy I completed it.”

“I think the book really helps me. When I get a bit of psychosis and all that schizophrenia I go through the book and it really helps me.”

# Outstanding comments/suggestions

- Issues around suggestibility
- Difficulty generalising from specific examples
- Emphasis on medication
- Emphasis on a 'medical model'
- Lack of information regarding alcohol
- Long
- Need for more activities
- Sorting cards for risk factors for psychosis/coping strategies



# Other ways to use the materials?

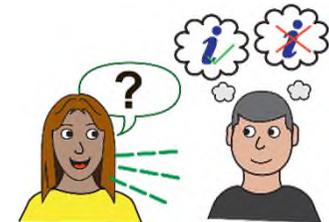
- Flashcards to communicate symptoms to carers
- Monitoring of psychotic symptoms
- Gaining a better understanding of service users' mental health
- Working with interpreters
- Information for carers

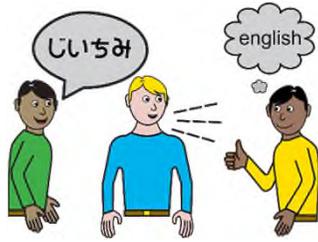
# Understanding service users' experiences

15 out of 17 clinicians said that using the workbook helped them gain a better understanding of the service users' experiences and how to support them.

“The sections on symptoms yielded interesting insights into what the patient experiences in a way that a regular consultation does not. E.g. ‘I experience...[x,y,z]..too’ or ‘I get that’

“The cards enabled me to realise that the client was dissociating for long periods... so we were able to work on this during the intervention. I may not have realised that she was experiencing this otherwise.”

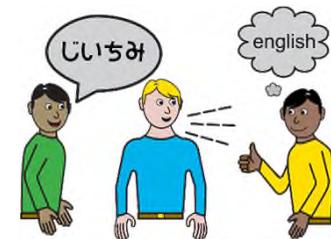




# Working with interpreters

“The client spoke Farsi (Persian) and in sessions, it was sometimes not possible for the interpreter to convey a word for a specific symptom or experience because it did not exist in Farsi. The client and translator both reported that mental health problems were rarely openly discussed in the client’s culture of origin. Translation of existing written UK psychoeducation materials proved somewhat inaccessible to the client for the same reason – because some psychotic experiences did not have known words or concepts in Farsi. Of the limited written materials that had been translated into Farsi, a number appeared outdated or medicalised when back translated into English by the interpreter.”

“The visual materials, particularly the images on the sorting cards were a significant help because they provided a talking point from which the client and I could co-construct the meaning within the picture together. I could talk to the client via the translator whilst we looked at the image. This seemed to help the client to map on her own experiences. She was able to explain both the similarities and differences between what was happening for the person on the card and herself.”



# Working with carers

“The mainstream literature that we were using was based around the diagnosis, as opposed to the symptoms of psychosis and the experiences that people experience. The literature was very wordy and focused on a medical model explanation.... Carers spoke about how they felt like it wasn't for them. Carers struggled with the literature particularly if English was not their first language or if they had struggled with reading and writing at school.”





“The Carers in my caseload have relatives who have been diagnosed with psychosis for years, however they have never had anyone explain to them what psychosis is. The explanation was clear, appealing, colourful easy to read and relevant. Carers commented on how the images were multi-cultural and for all age groups.

The workbook was fantastic. It was easy to read and the symptoms were clear with an easy to follow format. We have used leaflets in the past that Carers have found patronising and child-like, or ... extremely complicated and wordy with no clear examples.”

# Interested in taking part?

Contact us: [Awp.secureservicesFINDTeam@nhs.net](mailto:Awp.secureservicesFINDTeam@nhs.net)

Thank you for listening!