

Delirium Voices: The experience of delirium captured in zines **Contents**

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Introduction

"The human species thinks in metaphors and learns through stories" Mary Catherine Bateson (Anthropologist)

"Storytelling is an important communications tool for us. It can capture people's attention, and hopefully provoke them to think differently about an issue. We use storytelling as a way of encouraging people to delve deeper into the evidence about what works and doesn't to improve health and health care" Catherine Irving, (Director of Communications, Health Foundation)

About this eBook:

The power of personal voice to move hearts and minds is recognised by eminent figures across a wide range of sectors. To bring about change and new understanding, there is nothing more powerful than the authentic experiences of the individual. To create this eBook, Oldham Libraries and Dementia United, part of Greater Manchester's Integrated Care Partnership, brought together people with lived experience of delirium, for a professionally facilitated zine workshop to help them find their creative voice. The hope is that their creations will help raise awareness of the reality of delirium, motivating a more person-centred understanding of this wide-spread condition.

About Dementia United:

Dementia United is Greater Manchester's Integrated Care Partnership programme for dementia. They work alongside clinicians, charities, localities, professionals, those living with dementia, families, friends and care partners to make the region the best place to live if you have or are caring for someone with dementia.

Dementia United in collaboration with a wide range of partners and stakeholders, including people with lived experience, have been working to improve the detection, assessment and management of delirium. This has involved the development of a public facing delirium leaflet, which Dementia United commissioned the translation in to 10 languages, all accessible through our toolkit webpage: https://dementia-united.org.uk/delirium-community-toolkit.

About Delirium:

Delirium is a condition which causes a short-term confused state and develops over hours and days. It causes short term problems with memory, concentration, attention and personality. It occurs when a person is medically unwell and can be caused by several things, such as infections, pain or constipation. People living with dementia are more likely to experience delirium. People may go on to develop delirium, whether they are in hospital, in a care home or living at home.

Why does identifying delirium early matter?

Where delirium is not detected and treated, people's outcomes are much poorer. Delirium can lead to increased hospitalisation and readmission, increased likelihood of placement in a care home and can make the symptoms of dementia worse. Prevention, early detection, standardised assessment and treatment all improve these outcomes.

Why zines?:

Zines have a long illustrious history of giving voice to the disenfranchised. It is the medium of social activism. It is the publication format for people who have something to say. As a mixed-media format, zines also suit all abilities and inclinations. Whilst the compact 8-page print makes for easy circulation and reproducibility.

Why a delirium Zine workshop?

We were keen to explore how to capture people's lived experience of delirium; be that as someone who has experienced an episode of delirium directly, or as a family member or healthcare professional who has supported others through episodes. As Dementia United had already been working in partnership with library services in Oldham, as part of raising awareness about delirium, we commissioned Oldham Libraries, who have experience of running zine workshops, to support with hosting a delirium zine workshop with our lived experience members. It was important for the workshop to be hosted in the library, a safe, welcoming community space, that encourages and enables creativity. Moreover, through the library service's eBooks platform, the resultant publication is available for people to discover, borrow and read, freely and easily, thereby further raising awareness about delirium. The Delirium Zine workshop took place on 1 July 2022, with a facilitator to assist with the creation of the resource we have collated here.







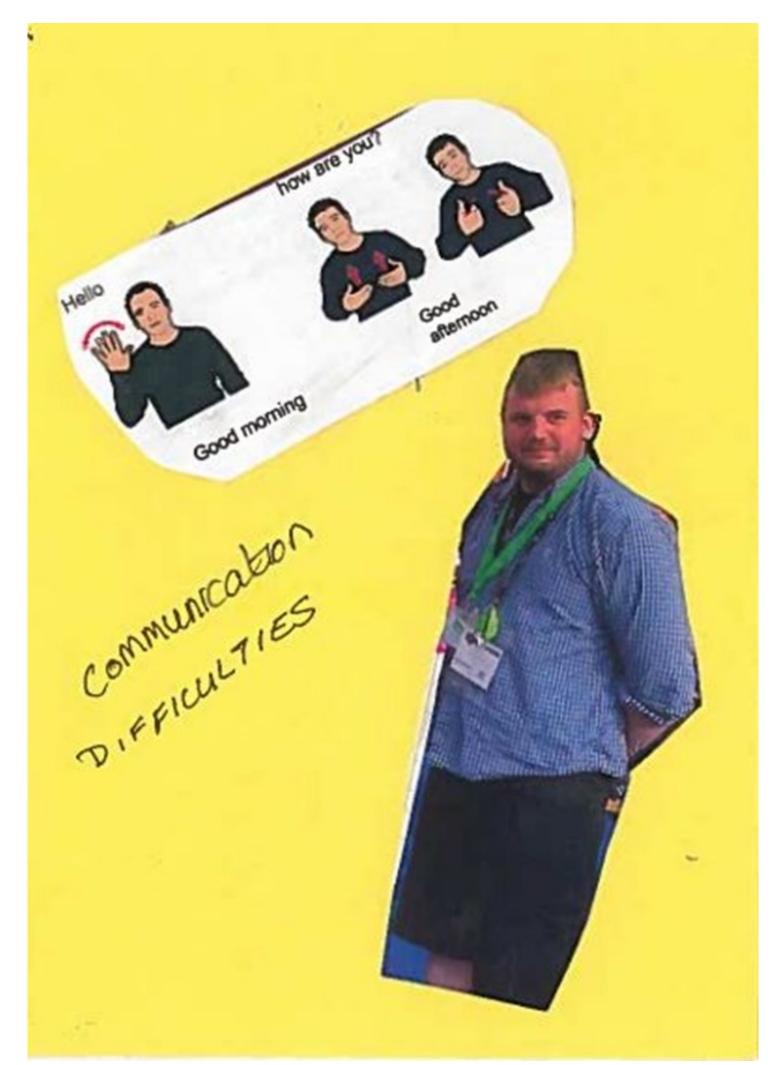
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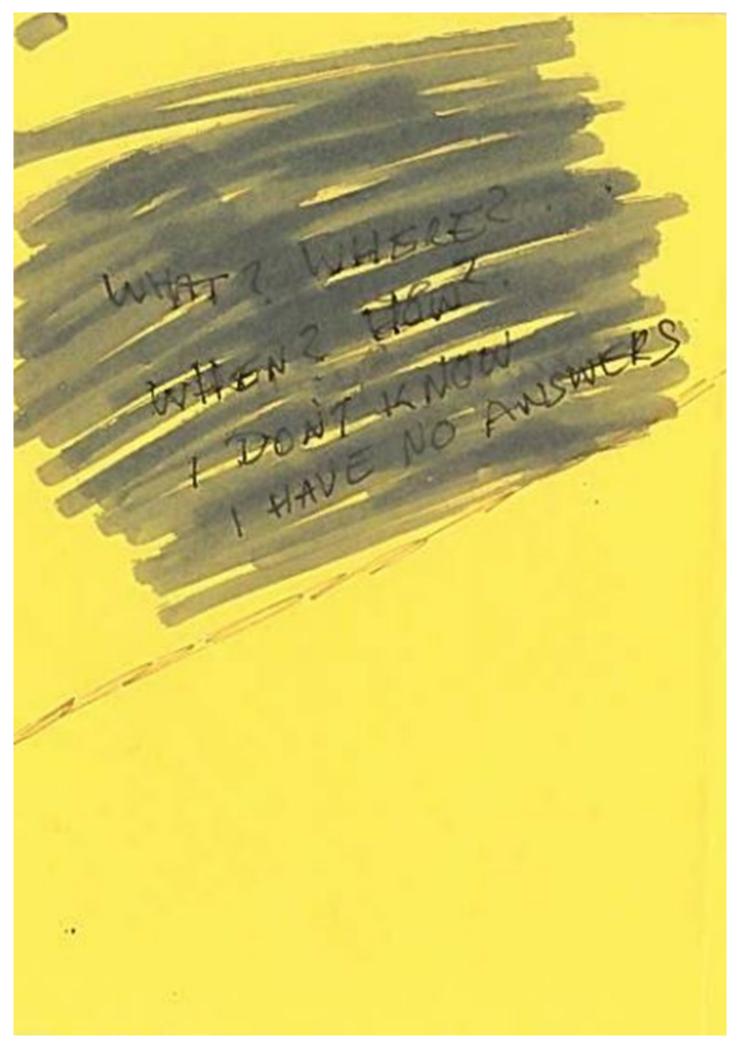
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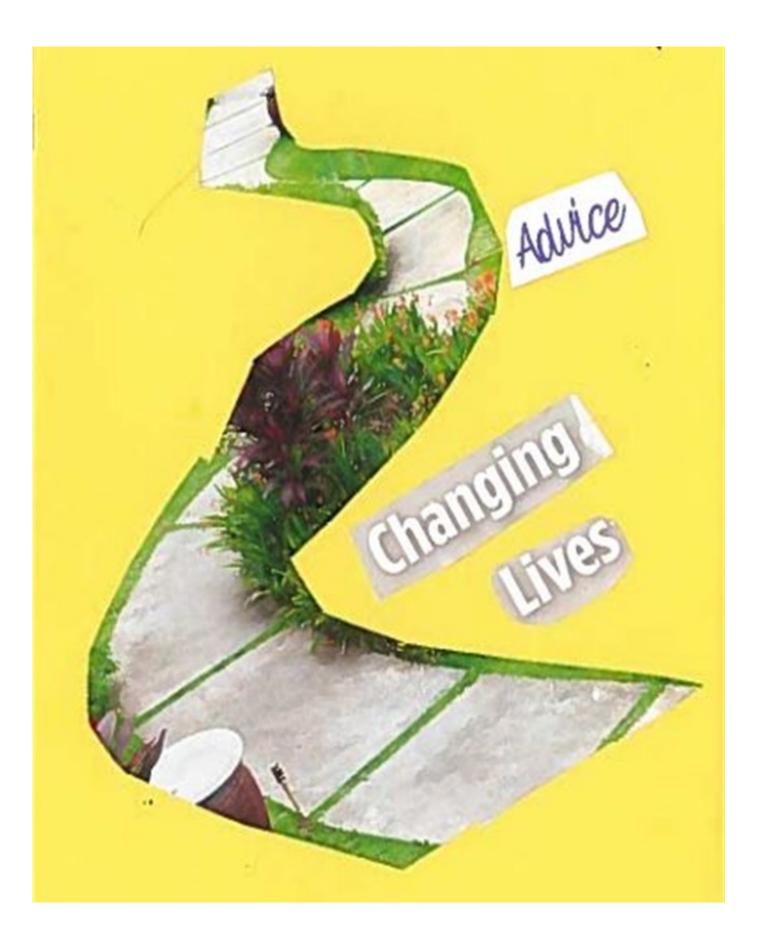


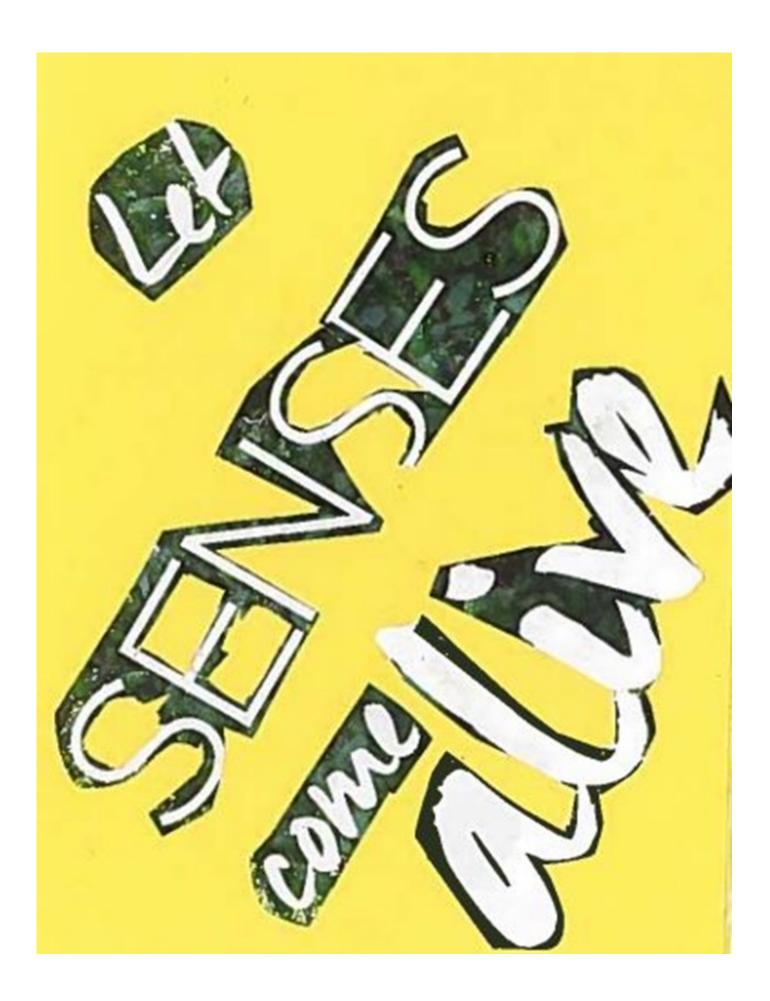


NOT ABLE TO TALK ABOUT MY HUSBAND John unless he is aware of the conversation and the person people in Ealking too.

SOME reople asume that it 15 another stage of demention and don't reduce it isn't always there.

IT Caw come and go

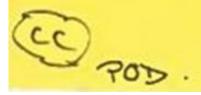


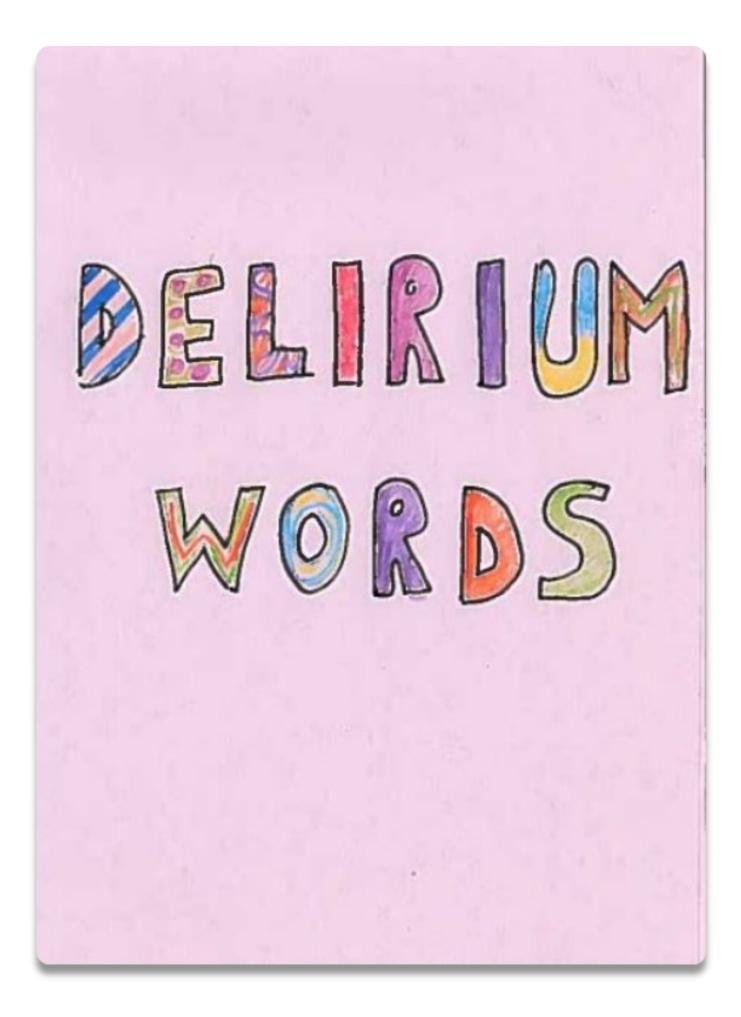


Having a vurj Good Support System that includes my family + friends

Being able to share my cancerns with others who

care.

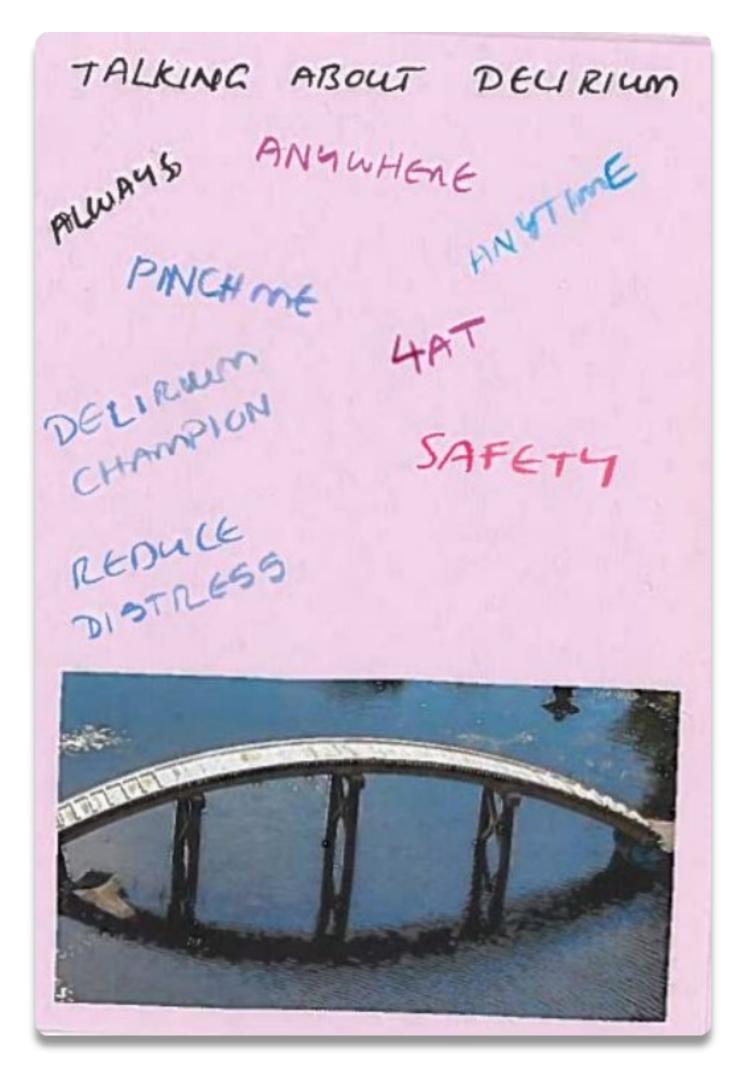








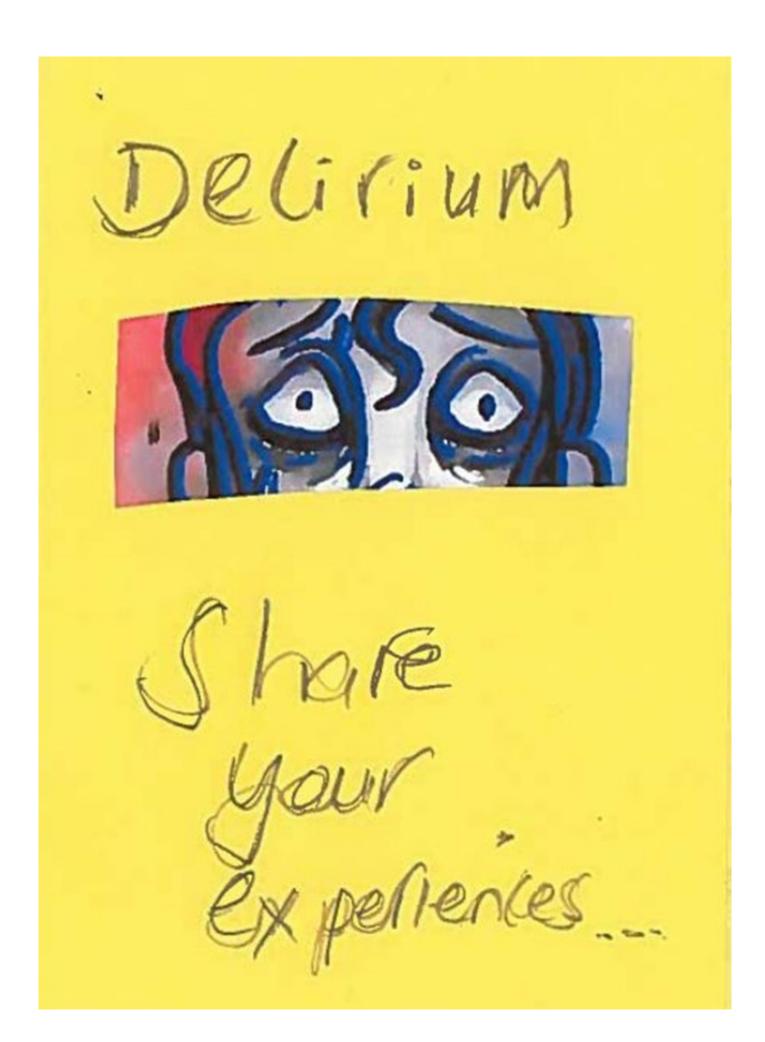
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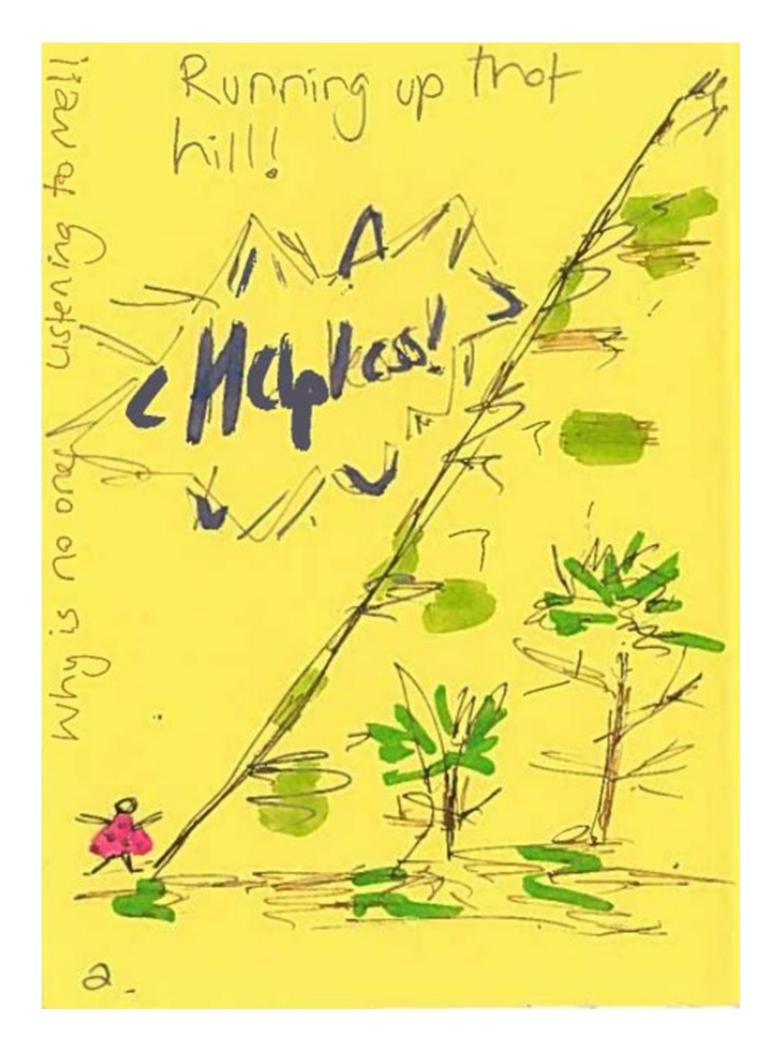


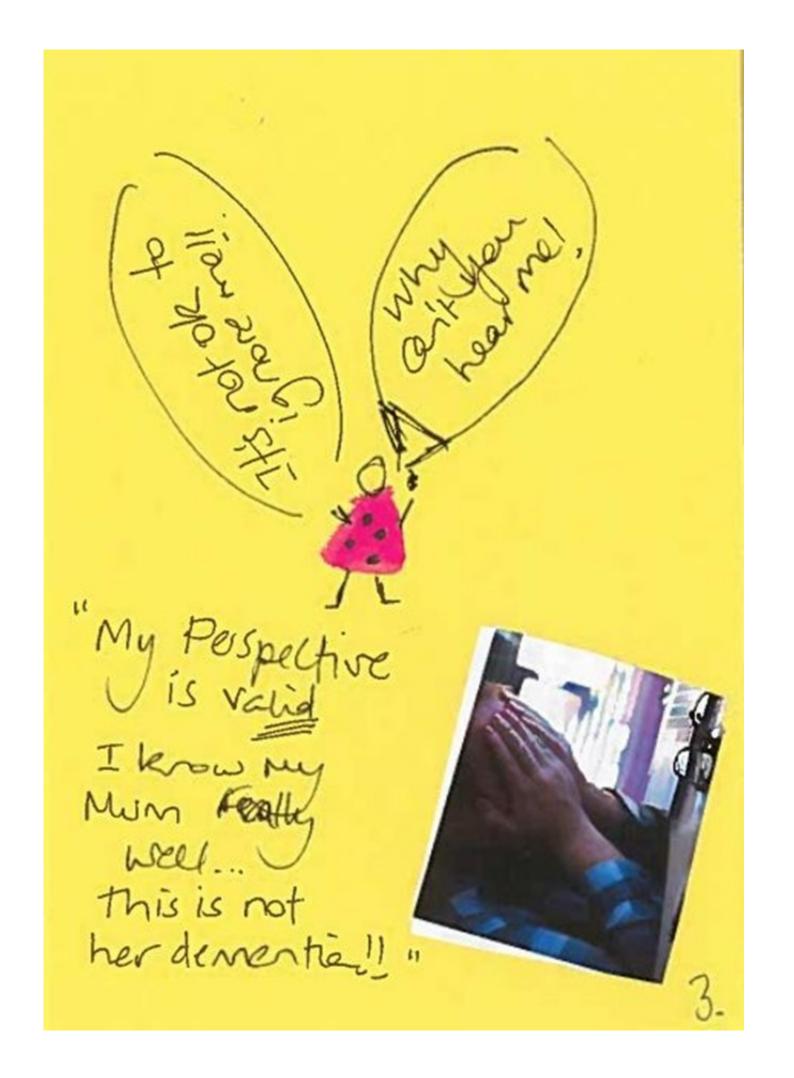
SHARE TO SUPPORT It is common. we can help you ! You can help your relative. Its really important we try and prevent this happening ayain. It you are seeing things that are hightening, you are safe . No- one is trying to hunt you ! will Look AFTER YOU. ÜE

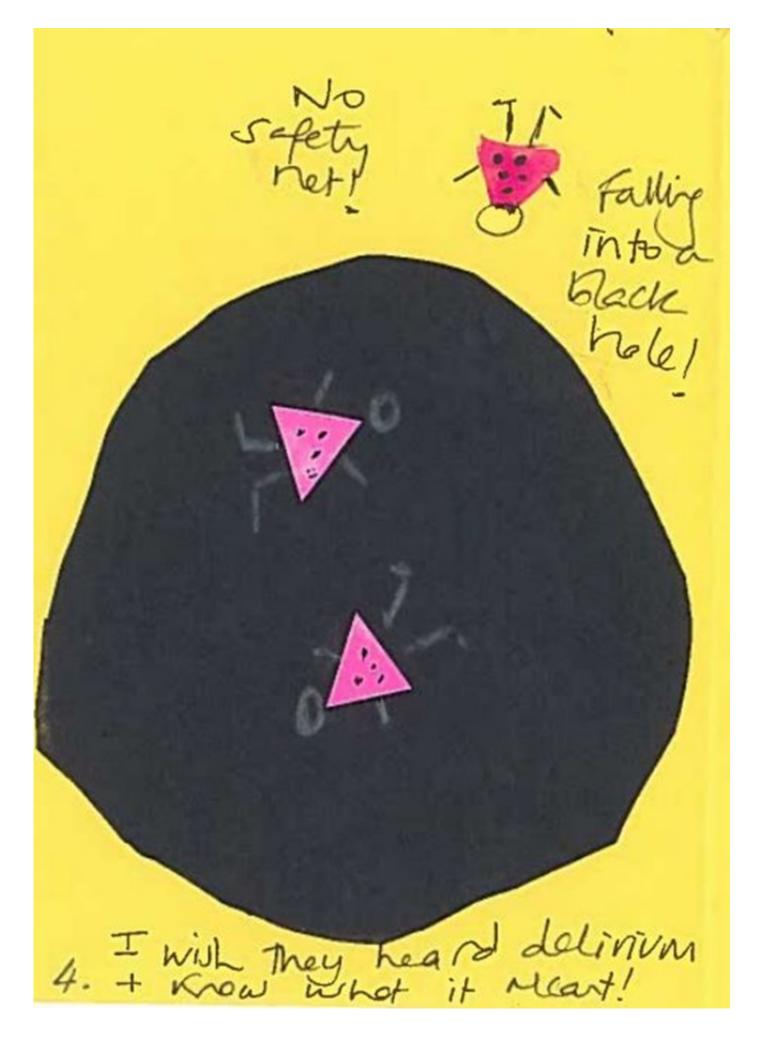
SHARE TO INFORM Delinium is serious Delirium is real. You patient could have a delinum learn how to help yar papert Good delmun good care Help with eating, drinking, glassis, heavy and and bonds Lister to your panus and relations









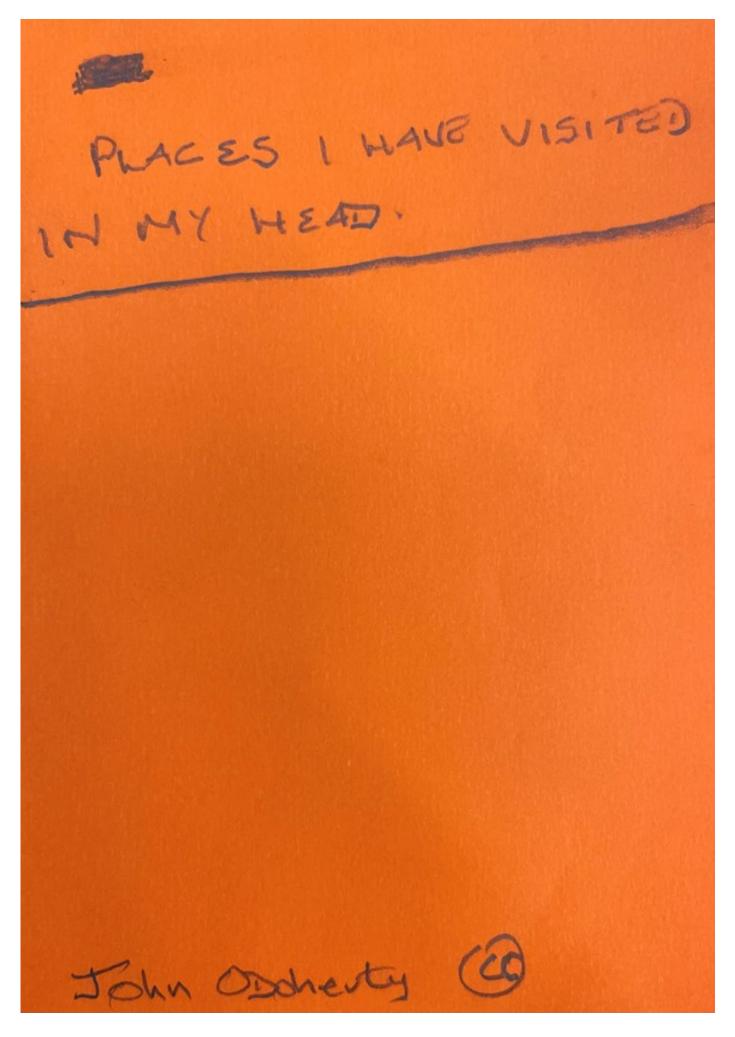


TABOOS JOOR 1- It's deverte 2. The hallughatters delusies will remain 3. The person & family feel invisible whilst it's have so the dar't Knoki who to turn to talk about iF. 4. It's depression - as They are sad, not catty and drinking S. It's not delining as they are still confused

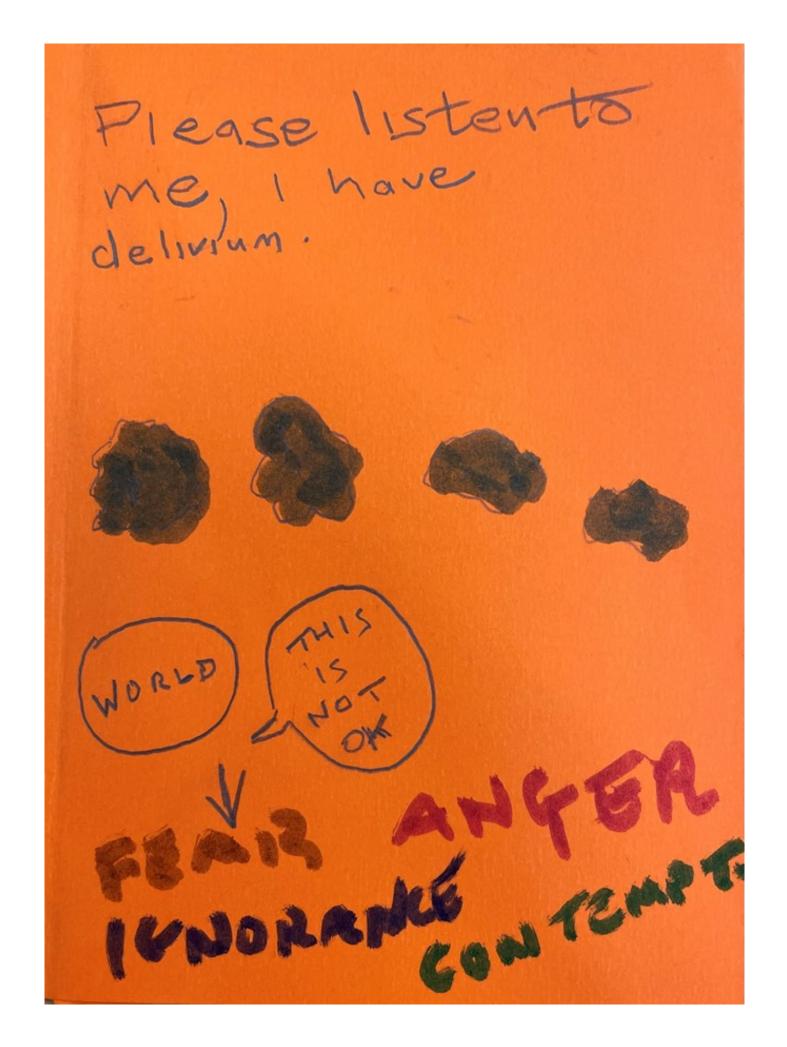


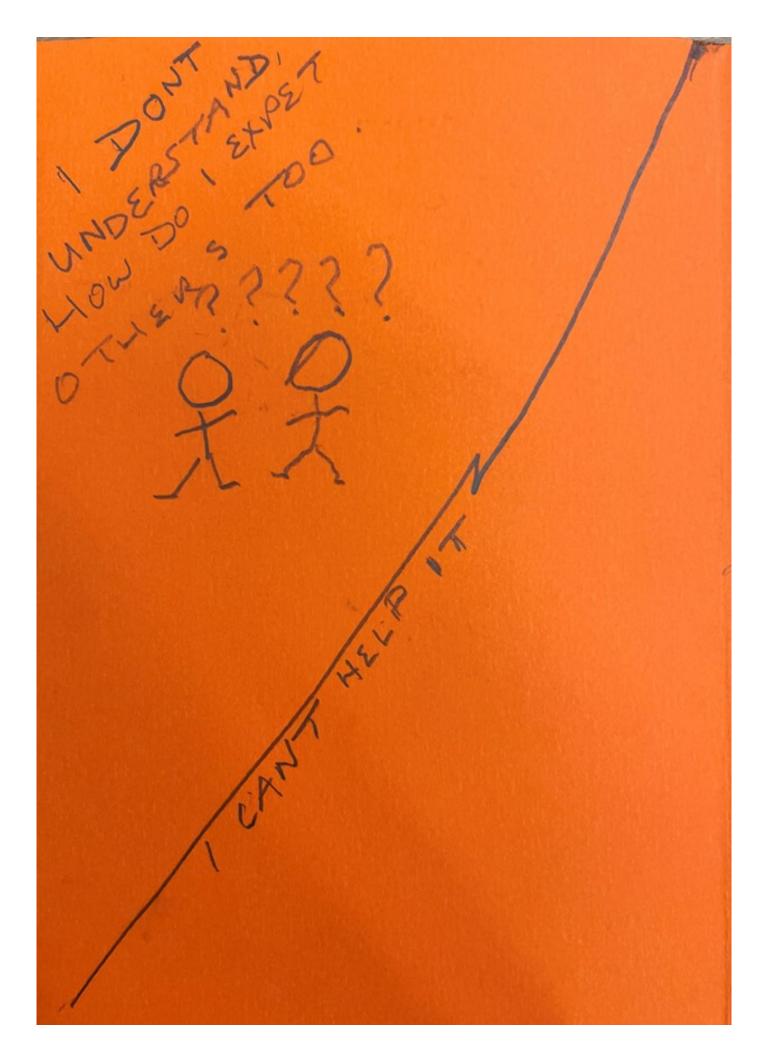
Tou Can't get depression in a few days! It's detrim -+ back T- Shift to be wearing on 7.













SMARE TO SUPPORT IT'S DELIRIUM IT'S NOT YOU YOU ARE NOT BAD YOU HAVE BEEN 1LL. - DONT FEAR SHARING YOUR EXPERTISNEE. HELP PEOPLE KNOW.

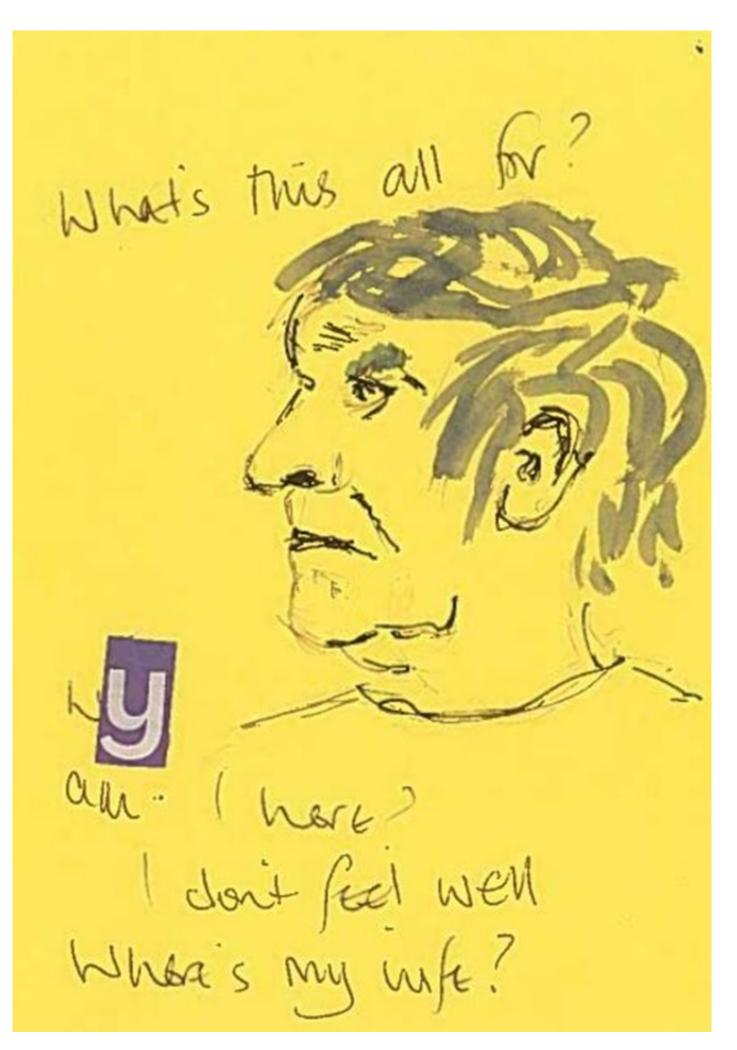
WHAT WOULD YOU TELL MEALTRLAKE STAFF. DONT BE AVER A.D. LEARN FROM ME. VI LIAVE BEEN TO A WORLD YOU CHN NEVER IMAGINE BUT I CAN HELP YOU SEE IT THROUGH MY MINDS EYE.

LIVING WELL - WHAT Have YOU LEARNT. 210 BE CONFIDENT V - TRUST OTHERS TO LISTEN. = YOU ARE THE PERSON NOT THE DELIRIUM

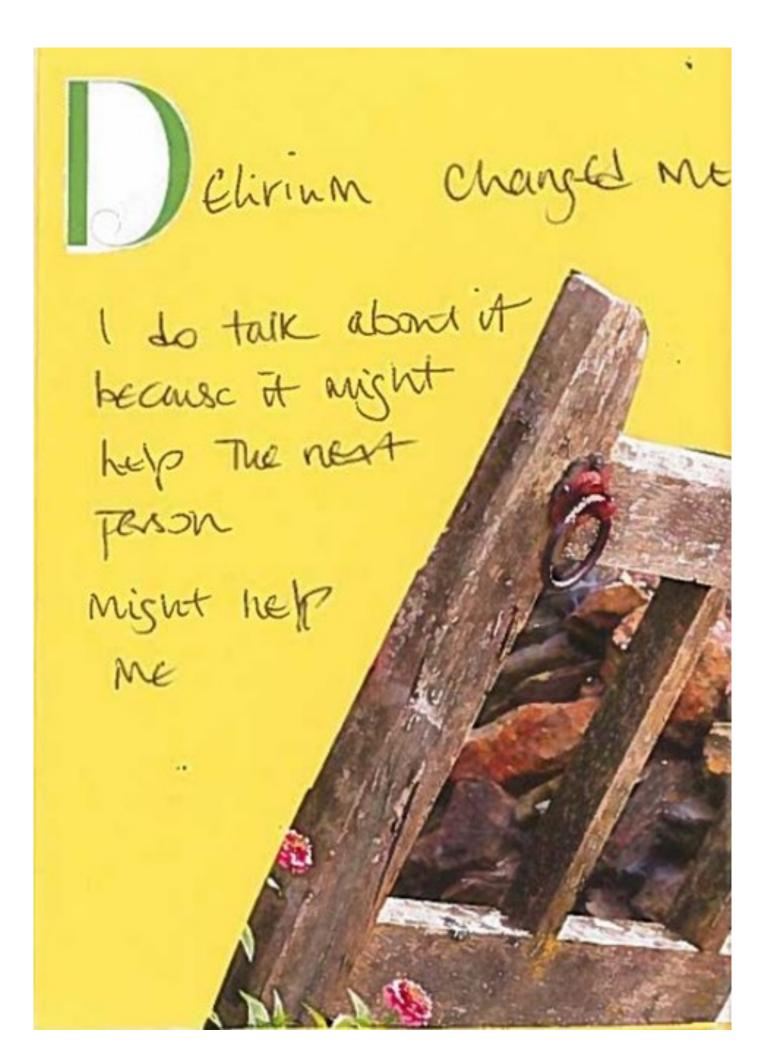
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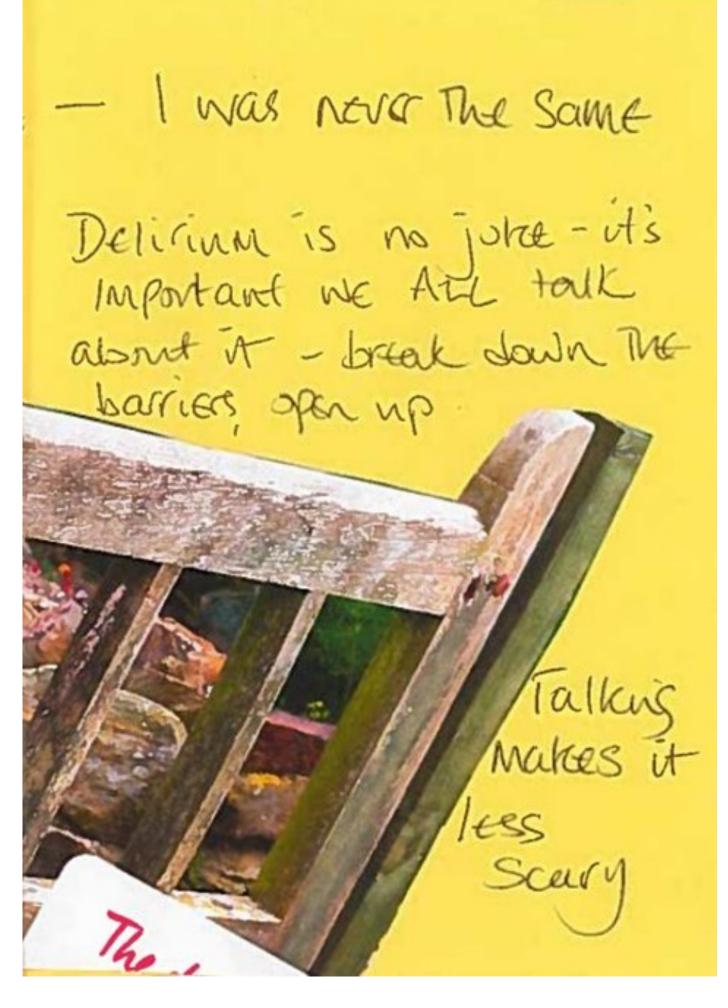






Doctors - hospital and Gis Nurses, tICAs must ask about Confusion and Must Lista What because Someon has demontia dean + Mean They don't Know what's not happening.





If Can be tracted It will get better Try not to worry, we're look after yon lodey is ~~~ you are It is ... oclock Produes. 2022

Annotated Zines

Prompts:

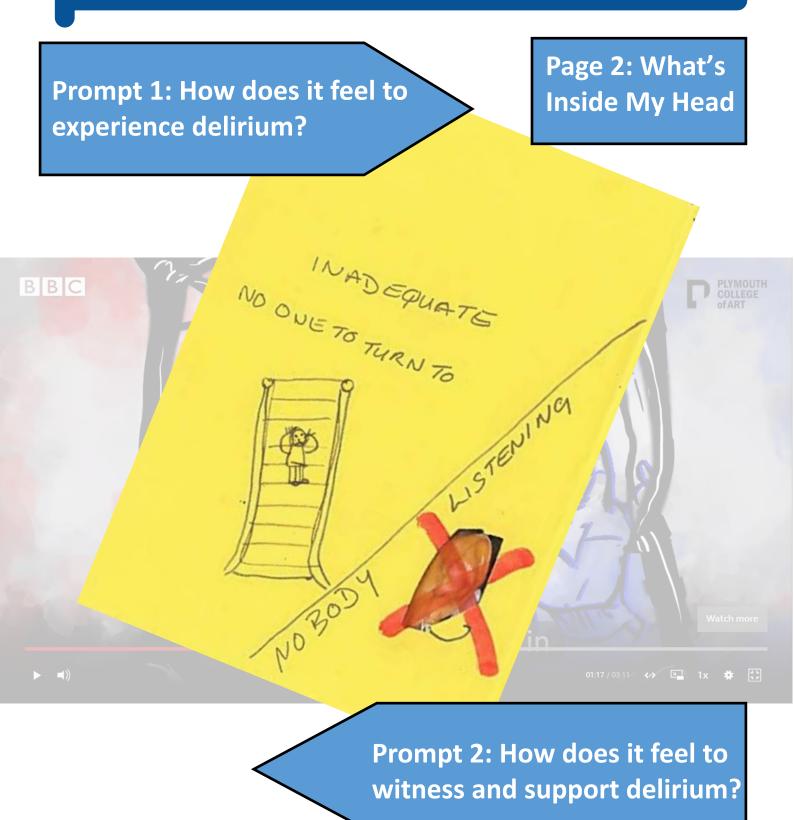
The zines contained here in were created in response to a series of prompts. This methodology enables people to find form to how they would like to express themselves, either by responding to the prompts directly, or because the prompts provoked an alternative chain-of-thought. Prompts are an opening question, an example from another person, that may or may not resonate with an individual, or even just a thought shared. Some participants enjoyed responding very directly to the prompts, others found their voices in different ways. There was no obligation for participants to refer to the prompts directly, as each unique zine was their sole creative property to build as they wished.

What Follows:

What follows is the annotated version of the Delirium Awareness Workshop Zines, contained in the previous section. The annotations offer more insight into the prompts provided for each page and some additional comments from participants, about their Zines.

Delirium Community Toolkit:

There are also a number of annotations that refer to the Delirium Community Toolkit created by Dementia United as part of a wider programme of work aiming to raise awareness and improve outcomes for people experiencing delirium. You can access the full toolkit on the Dementia United website: <u>https://dementia-united.org.uk/delirium-community-toolkit/</u>.



https://www.youtube.com/watch?v=JrK5zZC1rbw

Prompt 1: Have you had to tell anyone that "this is not ok"?

Hello

Page 3: This is Not OK!

Prompt 2: Have you had to fight for the recognition/ response that your delirium experience needed?

Communicates Difficult TIES

ION BIE YOU

Good morning

https://www.youtube.com/watch?v=t1djSyhHyew&t=6s

Prompt 1: Have you had an experience where someone misunderstood your condition/ experience? Page 4: Misunderstood Me

USTRIC

Prompt 2: Why do you think this happened?

Prompt 3: What would you like to say to them?

Small Pleasures by Clare Chambers, P251-253

Prompt 1: Who do you talk to about your delirium experiences? Page 5: Talking About Delirium

Prompt 2: Do you feel free to talk about it or not? NOT ABLE TO TALK ABOUT MY HUSBAND John UNLESS he is aware of the conversation and the person people im Ealking too.

People assume that it is another stage of demention and doit realise it isn't always there.

IT Caw come and go

Prompt 3: What do you think are the taboos around delirium that might be stopping these conversations?

hane

Advice

Page 6: Share to Support

Prompt 1: What would you want to tell someone with a new delirium diagnosis, for themselves or a loved one?

Page 7 Share to Inform

Prompt 1: What would you tell healthcare staff about experiences of delirium?

"Never really considered how distressing this could be previously"

(Emergency Department practitioner)

"It is really powerful to get a patient's and carer's experience of delirium"

(Emergency Department practitioner)

÷

Page 8 Living Well

Having a vury Good support System that includes my family + friends

Being able to share my cancerns with others who care.

cc

POD .

Prompt 1: What have you learned that helps you live well with your delirium experiences?

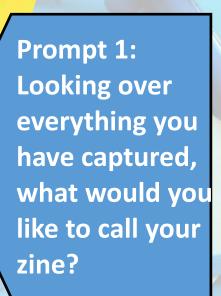
WELCOME

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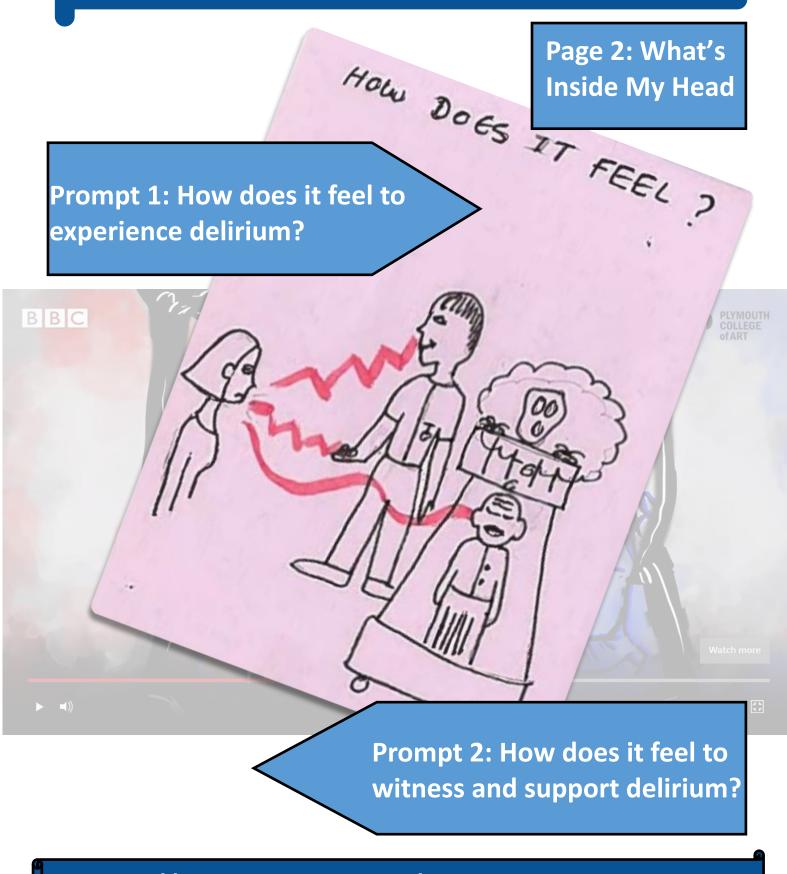
MY WORLD

Page 1

Title



Annotated — Delirium Words



https://www.youtube.com/watch?v=JrK5zZC1rbw

Annotated— **Delirium Words**

Prompt 1: Have you had to tell anyone that "this is not ok"?

Page 3: This is Not OK!

Prompt 2:

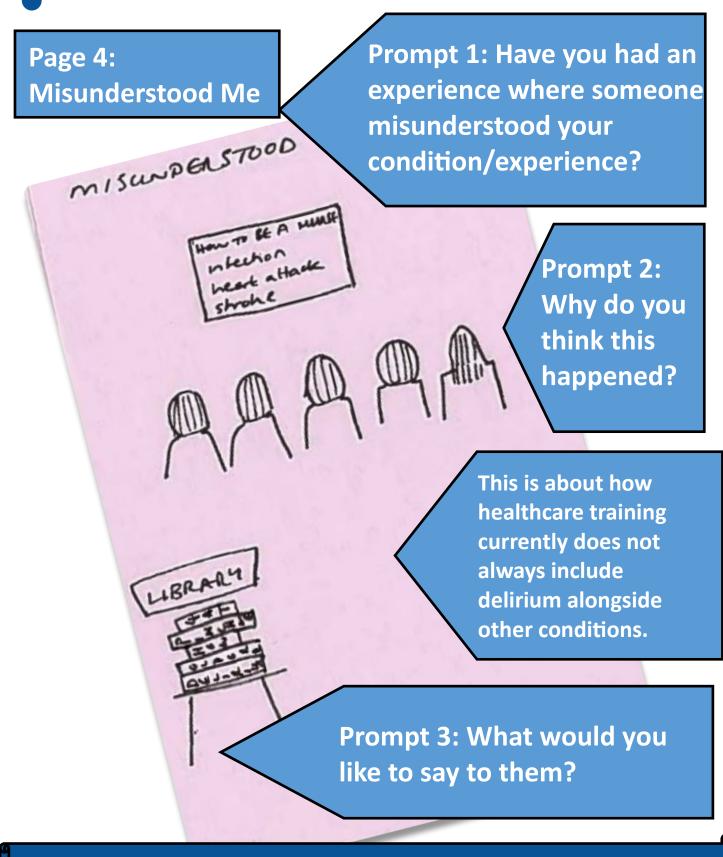
Have you had to fight for the recognition/ response that your delirium experience needed?

This page was created by a healthcare professional trying to capture how it feels raising delirium awareness with other competing conditions.



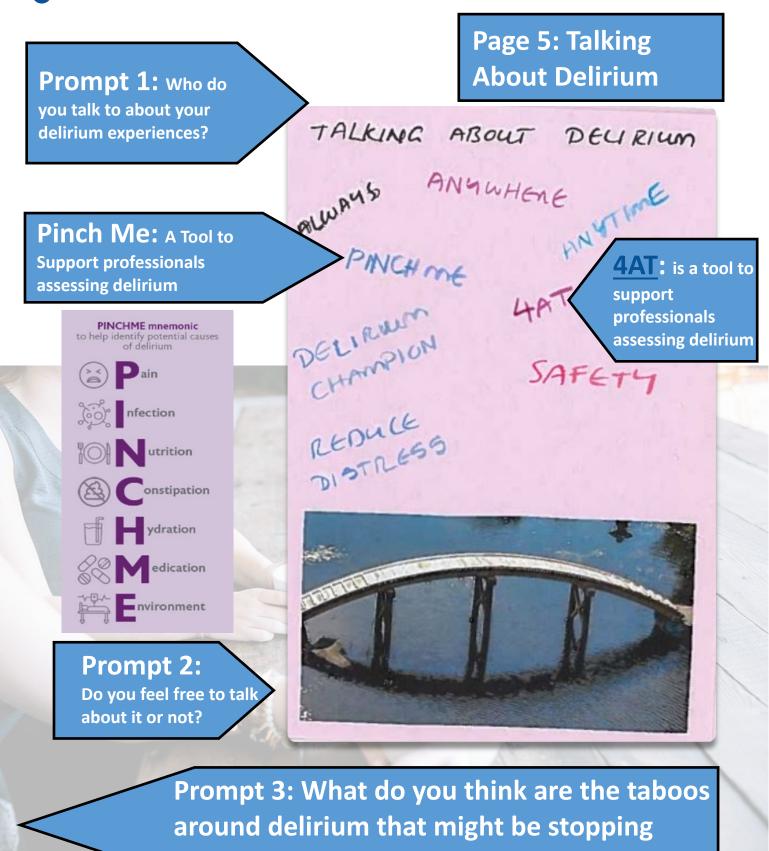
https://www.youtube.com/watch?v=t1djSyhHyew&t=6s

Annotated—**Delirium Words**



Small Pleasures by Clare Chambers, P251-253

Annotated—**Delirium Words**



these conversations?

Annotated — Delirium Words

Completed by a Healthcare Professional

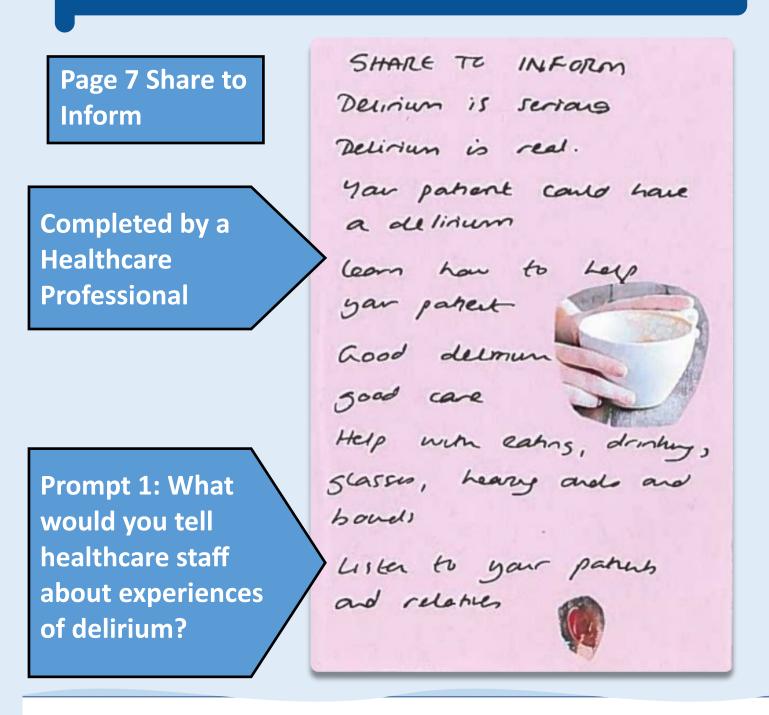
SHARE TO SUPPORT ' It is common. We can help you ! You can help you ! You can help your relative. Its really important we try and prevent this happening ayain. It you are seeing things that are hightening, you are safe . No- one is trying to hurt you !

WE WILL LOOK AFTER YOU.



Prompt 1: What would you want to tell someone with a new delirium diagnosis, for themselves or a loved one?

Annotated— **Delirium Words**



"Never really considered how distressing this could be previously"

(Emergency Department practitioner)

"It is really powerful to get a patient's and carer's experience of delirium" (Emergency Department practitioner)

Annotated — Delirium Words

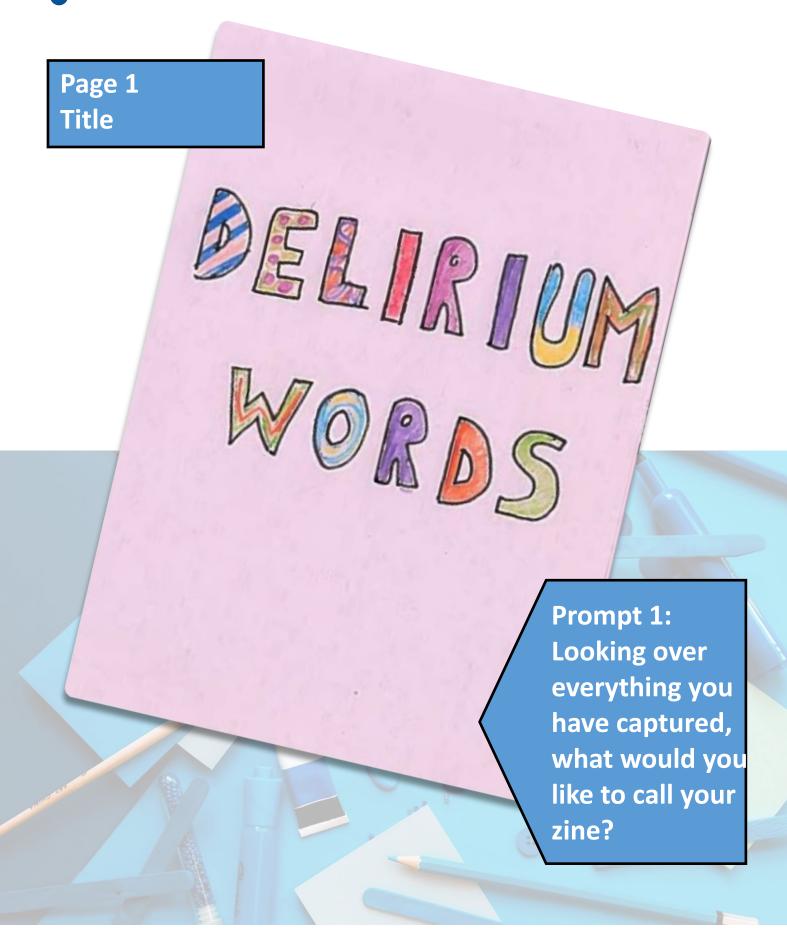
Emma Lordy @

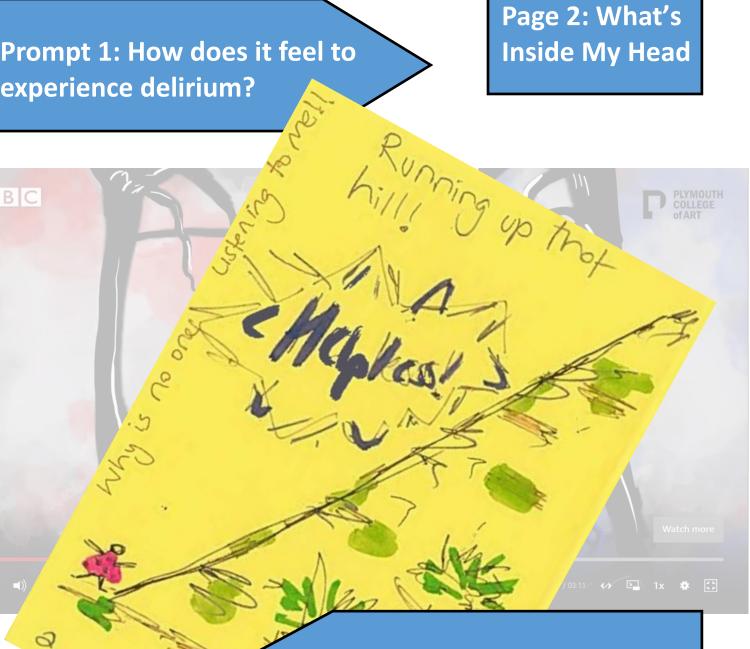
LIVING WELL



Prompt 1: What have you learned that helps you live well with your delirium experiences?

Annotated—**Delirium Words**





Prompt 2: How does it feel to witness and support delirium?

https://www.youtube.com/watch?v=JrK5zZC1rbw

Prompt 1: Have you had to tell anyone that "this is not ok"?

Page 3: This is Not OK!

Prompt 2: Have you had to fight for the recognition/ response that your delirium experience needed?

this is not her dementie!! " 3-

https://www.youtube.com/watch?v=t1djSyhHyew&t=6s

NO

+ WILL They heard delinion + Know what it Marth

Prompt 1: Have you had an experience where someone misunderstood your condition/ experience? Page 4: Misunderstood Me

Prompt 2: Why do you think this happened?

Prompt 3: What would you like to say to them?

Small Pleasures by Clare Chambers, P251-253

TABOOS

1- It's dementio

2. The hallugnations

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who to turn to

are sad, not eating

and drinkin

S. It's not deliv

about it.

3. The person & family

Invisibil

4. It's depression - as they

Prompt 1: Who do you talk to about your delirium experiences?

> Prompt 2: Do you feel free to talk about it or not?

Page 5: Talking About Delirium

Prompt 3: What do you think are the taboos around delirium that might be stopping these conversations?

S

Page 6: Share to Support

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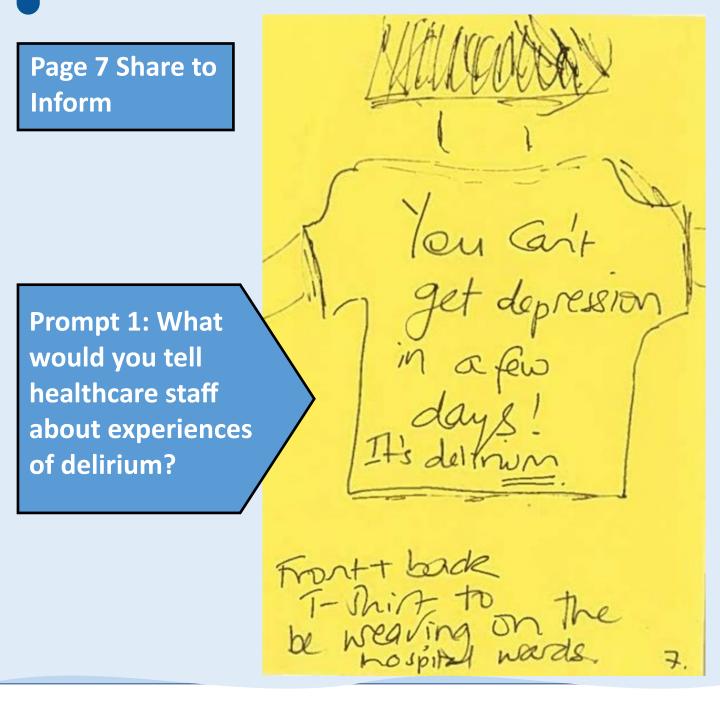
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otalone

Person

Someone

Prompt 1: What would you want to tell someone with a new delirium diagnosis, for themselves or a loved one?



"Never really considered how distressing this could be previously"

(Emergency Department practitioner)

"It is really powerful to get a patient's and carer's experience of delirium"

(Emergency Department practitioner)

HIP. CC

Page 8 Living Well

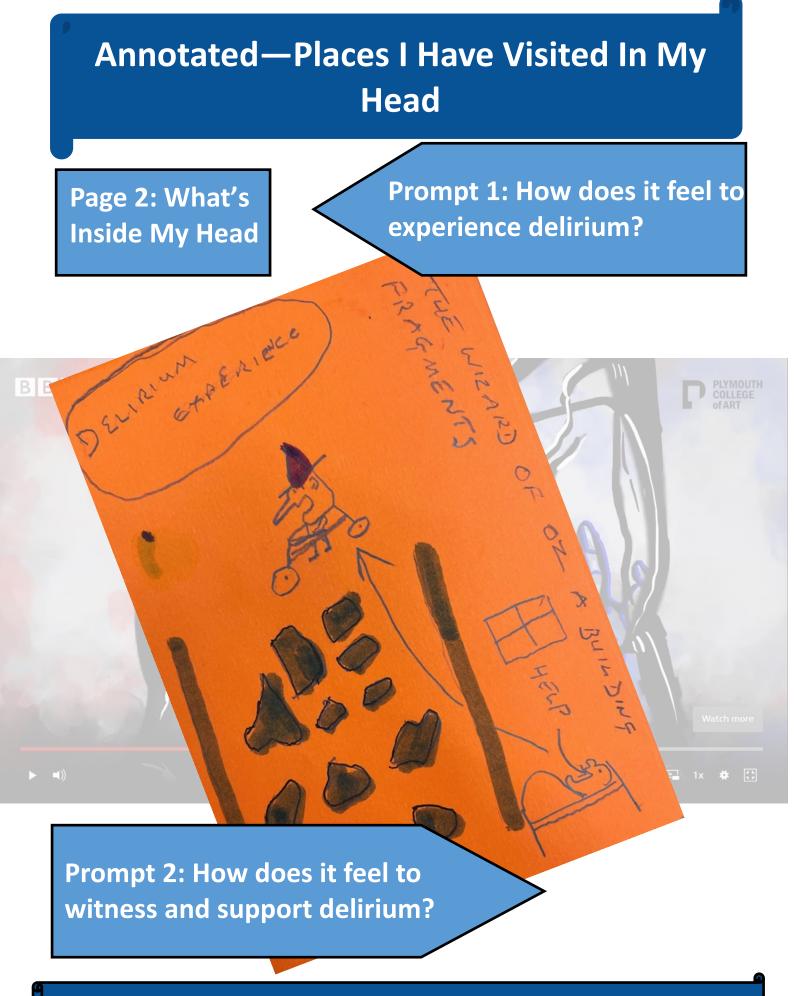
8.

Prompt 1: What have you learned that helps you live well with your delirium experiences?

elirium



Prompt 1: Looking over everything you have captured, what would you like to call your zine?



https://www.youtube.com/watch?v=JrK5zZC1rbw

Annotated—Places I Have Visited In My Head

Prompt 1: Have you had to tell anyone that "this is not ok"?

Prompt 2:

Have you had

to fight for the

recognition/

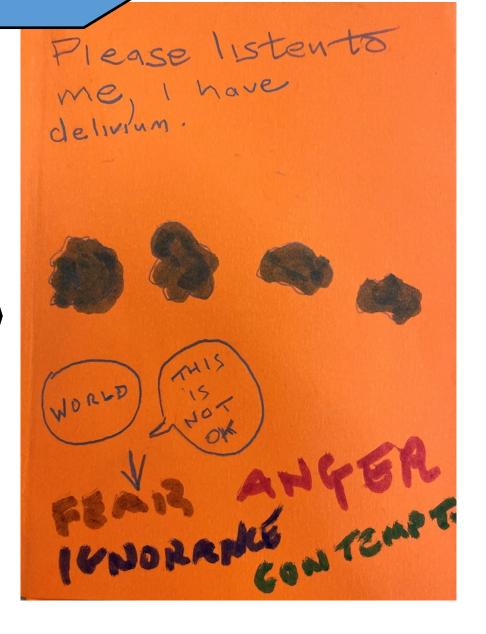
response that

your delirium

experience

needed?

Page 3: This is Not OK!



https://www.youtube.com/watch?v=t1djSyhHyew&t=6s

Annotated—Places I Have Visited In My Head

Prompt 1: Have you had an experience where someone misunderstood your condition/ experience? Page 4: Misunderstood Me

001

Prompt 2: Why do you think this happened?

Prompt 3: What would you like to say to them?

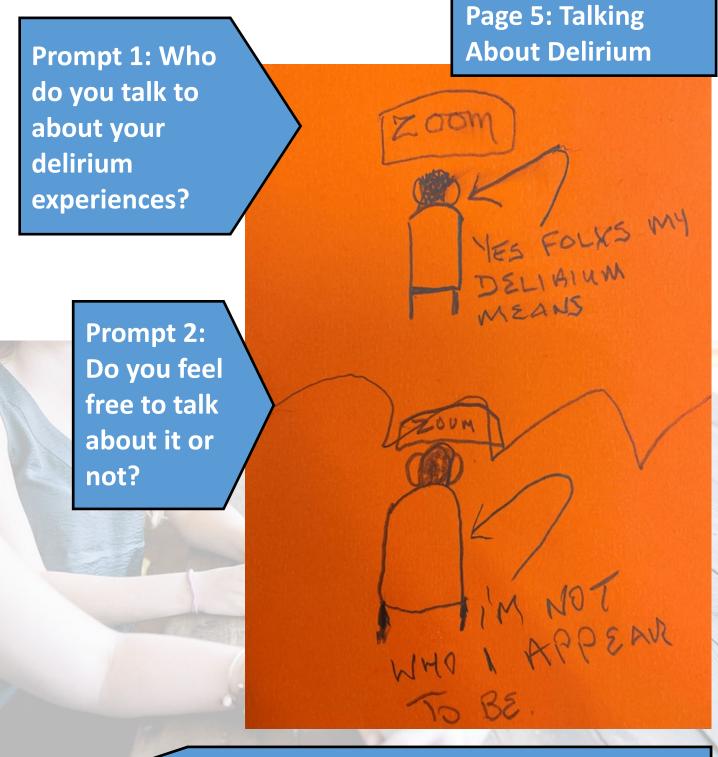
UNDERSTAND,

SiA

IT

Small Pleasures by Clare Chambers, P251-253

THELP



Prompt 3: What do you think are the taboos around delirium that might be stopping these conversations?

SMARE TO SUPPORT

Page 6: Share to Support

YOU ARE NOT BAD YOU HAVE BEEN ILL.

IT'S DELIRIUM

IT'S NOT YOU

Prompt 1: What would you want to tell someone with a new delirium diagnosis, for themselves or a loved one? DON'T FEAR SHARING YOUR EXPERIENCE HELP PEOPLE KNOW

Page 7 Share to Inform

Prompt 1: What would you tell healthcare staff about experiences of delirium?

THAT WOULD YOU TELL EALTACANE STAFF TBE AID LE M ME. HAVE BEEN TO A WORLD YOU CHN NEVER IMAGINE BUT I CAN HELP YOU SEE IT THROUGH MY MINDS EYE.

"Never really considered how distressing this could be previously"

(Emergency Department practitioner)

"It is really powerful to get a patient's and carer's experience of delirium" (Emergency Department practitioner)

HAVE

LIVING WELL - WHAT YOU LEARNT.

= TRUST OTHERS LISTEN.

= YOU ARE THE PERSON

NOT THE DELIRIUM

TO BE CONFIDENT

Page 8 **Living Well**

> Prompt 1: What have you learned that helps you live well with your delirium experiences?

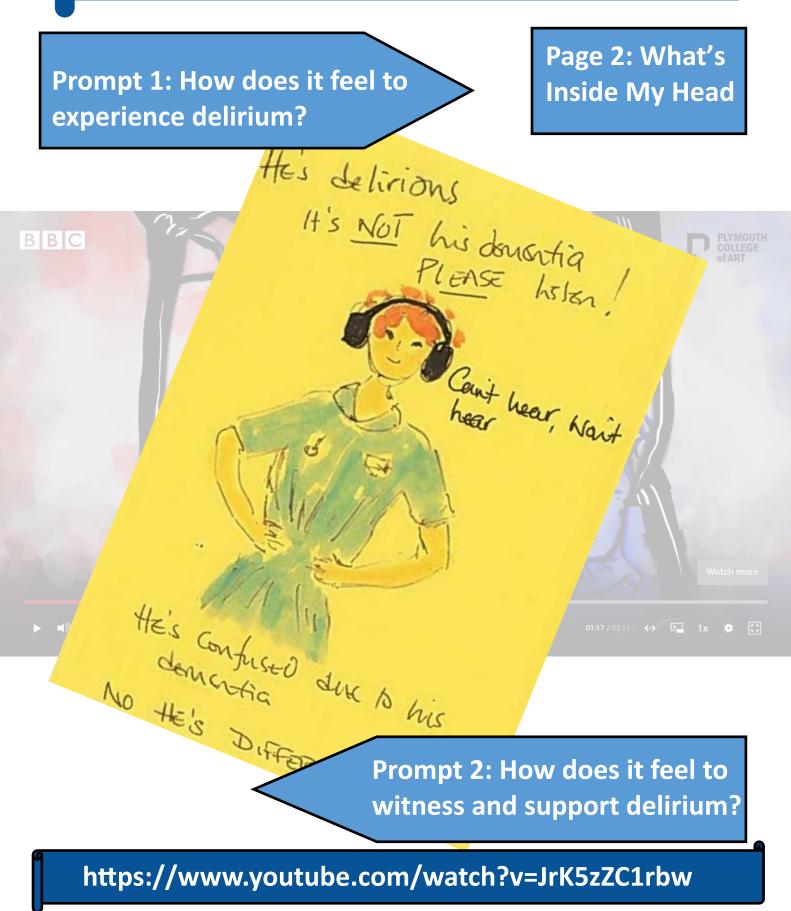
Page 1 Title

PLACES I HAVE VISITED IN MY HEAD.

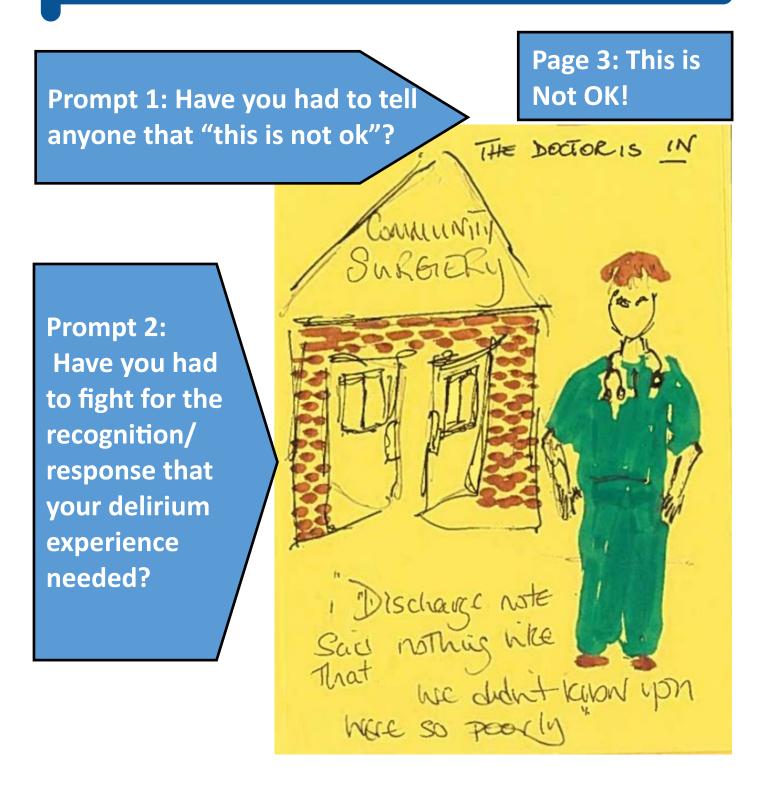
John Oddherty

Prompt 1: Looking over everything you have captured, what would you like to call your zine?

Annotated—Me and Delirium



Annotated —Me and Delirium



https://www.youtube.com/watch?v=t1djSyhHyew&t=6s

Annotated — Me and Delirium

Prompt 1: Have you had an experience where someone misunderstood your condition/ experience? What's this all

Page 4: Misunderstood Me

Prompt 2: Why do you think this happened?

Prompt 3: What would you like to say to them?

am ! here? I don't feel well Whea's my infe? Small Pleasures by Clare Chambers, P251-253

Annotated — Me and Delirium

Prompt 1: Who do you talk to about your delirium experiences? Page 5: Talking About Delirium

Prompt 2: Do you feel free to talk about it or not? Must ask about Confision and Mist Lister. Just because someone has donathe someone has donathe doch t mean They doi know what's Mis happening.

Doctors - hospital

and Gis

NURSES, HICAS

Prompt 3: What do you think are the taboos around delirium that might be stopping these conversations?

Annotated— Me and Delirium

Page 6: Share to Support

Prompt 1: What would you want to tell someone with a new delirium diagnosis, for themselves or a loved one?

Elirium changed me to talk about it because it might help The next Terson might help ME

Annotated — Me and Delirium

Page 7 Share to Inform I was never The same

Delirium is no juke - it's Important we ALL talk about it - break down The barriers open up

Prompt 1: What would you tell healthcare staff about experiences of delirium?

"Never really considered how distressing this could be previously"

(Emergency Department practitioner)

Talking

Makes

Scar

"It is really powerful to get a patient's and carer's experience of delirium"

(Emergency Department practitioner)

Annotated— Me and Delirium

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Annotated— Me and Delirium

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Page 1

Title

Prompt 1: Looking over everything you have captured, what would you like to call your zine?

Participant Comments and Evaluation



Participant Quotes:

- . "It was fun and very therapeutic"
- "Enables revisioning of an experience"
- . "It was a very effective way of representing our experiences"
- "I took away a sense of wellbeing"
- . *"I felt that I am not alone on my journey of delirium"*
- "Zines have the power to get people talking"
- "Delirium leaves a mark that needs to be talked about"

Evaluation Form Responses (01/07/22):

Participants: 5 (people with lived experience and professionals)

How would you rate your experience – quotes as below 100% of attendees rated it is as Very good

"Relaxed and engaging" "Encourages creativity"

What will you take away from the workshop – quotes as below

"It was fun and very therapeutic" "Encourages creativity" "Enables revisioning of an experience" It was a very effective way of representing our experiences The value of hearing from others, sharing lived experiences in a safe space I took away a sense of wellbeing I felt that I am not alone on my journey of delirium I feel I would be able to support my family member, with concerns and fears if there were any further episodes of delirium in the future Zines have the power to get people talking Delirium leaves a mark that needs to be talked about

Did you find you were able to participate as you had wanted - quotes as below

Yes – 100% Much more than I expected I knew my views and opinions were taken fully on board

What did we miss? What if anything would you have liked us to have done differently? Quotes as below

I don't think you missed anything More attendees More magazines and resources – 3 attendees mentioned Were the venue and facilities suitable Yes – 100% Other – positive feedback about the facilitator's engagement with us all For a moment or two Jean was quite dumbfounded, speechless with outrage.

'A man? On the ward? Why didn't you call out or say something?'

Her mother gave a scornful laugh. 'No one would believe me... Anyway, then there was a sort of fire drill, and we all had to get up and go outside in the rain in our nothingness. What a performance,' She chuckled to herself at the memory.

Jean looked around at the other occupants of the ward – comatose, heavily bandaged, intubated or otherwise immobilised – and caught up at last.

'Goodness. Quite a night then.'

'l'll say.'

All the same, she felt obliged to mention her mother's remarks to the matron before she left.

'She seems a little confused.'

'They all get like that. It's the diamorphine.'

Jean smiled, not altogether reassured.

Extract from Small Pleasures By Clare Chambers

ISBN, 978-1-4746-1390-3

Publishers: Weidenfeld and Nicolson

Pp251-253

'She though she'd been interfered with. By a man.' Matron shook her head. 'She also thinks Queen Mary is in the bed opposite.'

'It must be so distressing – perhaps she'd be better off without the diamorphine.'

Matron looked at her over her glasses. 'You only say that because you are not in pain.'

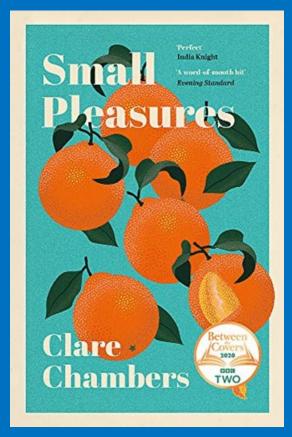
[...]

'The sister on duty expressed surprise when Jean Mentioned her concerns. From their point of view Mrs Swinney was an ideal patient – placid and untroublesome, grateful for small attentions, where others were restless and obstreperous.

'but she is not herself,' Jean protested. 'She was perfectly sane when she arrived. Now she hardly knows who I am.'

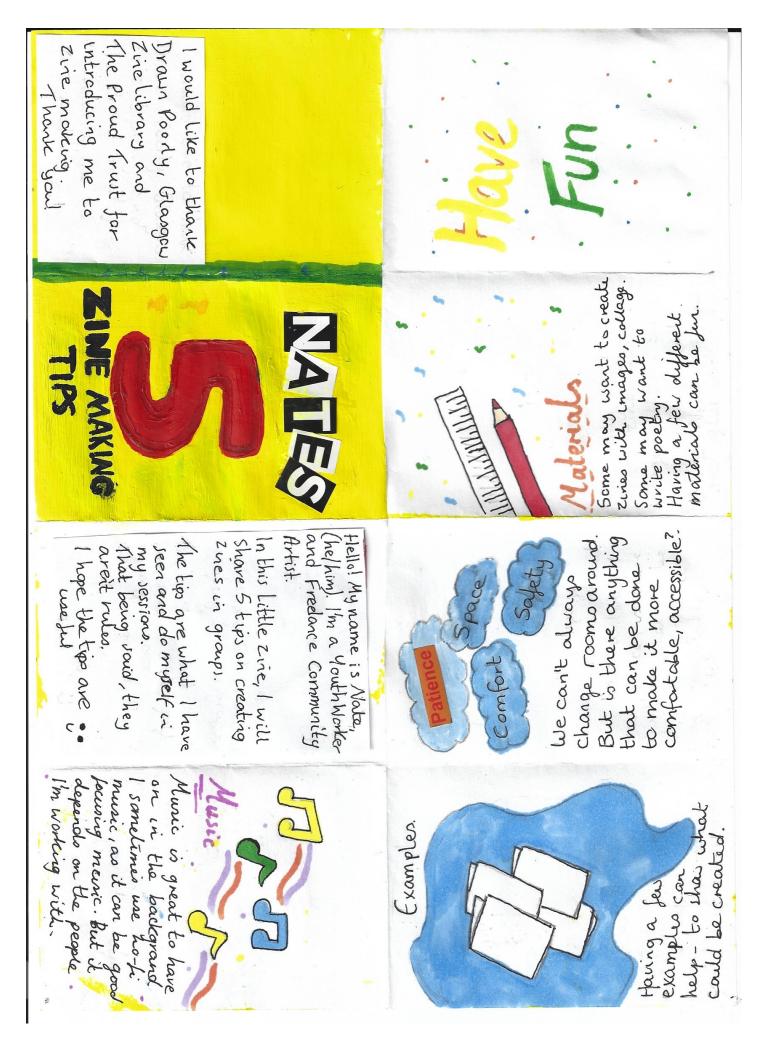
She remembered with shame her previous irritation with her mother's irksome habits and predictable conversations. What trivial dissatisfactions these now seemed.

Sister looked disappointed. There was a hint of reproach in her voice. 'I'll tell the doctor what you've told me. But we're all really pleased with her progress.'



How To Run a Delirium Zine Workshop Some Top Tips

- 1. **A3 Paper** an A3 paper folds perfectly to make a palm-sized zine. You can find how-to-fold-a-zine instructions online. It is best to get in plenty of practice before the day of your workshop. (You can also colour-code your A3 paper if you wish to track which participants were patients, healthcare professionals, family members—although bear in mind that these may not be mutually exclusive categories).
- 2. **Provide lots of materials** magazines, coloured paper, pens, pencils, sticky tape... the resource material options are near infinite, but try to ensure that you have plenty in stock for your event.
- 3. **Have a Facilitator** If you can afford a professional facilitator to run your event, that is great, but even if you cannot, the main thing is to have someone whose job it is to gently nudge things along and encourage participation.
- 4. **Use Prompts**—8 blank pages can feel like an intimidating void without a starting point, prepare some meaningful prompt questions or ideas to help people start creating (see annotated zines section of this eBook, for the prompts we used).
- 5. Allow people to find their own voice—providing prompts aims to get the creativity flowing, but if people want to ignore them and do their own thing, that is all good too.
- 6. **Provide travel support**—your target audience may have additional access requirements. Provide clear travel information and, if budget allows, consider paying for direct transportation for participants who find travelling to new locations challenging, such as those with more advanced dementia.
- 7. **Provide refreshments**—creativity thrives when all bodily needs are met, aim for a comfortable, welcoming space with refreshments provided.
- 8. **Creative Commons** in order to use the resultant zines in support of other people ,with direct or indirect lived experience of Delirium, invite participants to mark their zines with a cc, to indicate that it is under a Creative Commons public copyright licence, which allows other people to share, use and build upon a work.





WHAT IS DELIRIUM?

Information on how to recognise delirium and what to do about it

You are being provided with this leaflet because you are either at higher risk of developing delirium, you have a current delirium, or your loved one has experienced delirium.





What is delirium?

Delirium is a common condition. People with delirium may have trouble thinking and remembering, may feel frightened or upset, see or hear things which are not there. It can come on over hours or days. It is not a permanent illness.

What causes delirium?

There are many things that can trigger a person to develop delirium. These are called underlying illnesses, for example: pain, infections, not eating or drinking enough, constipation and side effects of medicines.

Who can get delirium?

People can develop delirium anywhere such as in hospital, care homes and living at home.

It is more common for people who:



Are aged over 65 years.

Experience cognitive impairment or dementia or had delirium before.

Have had recent surgery, for example for a broken hip.

Have many medical conditions, or sight or hearing loss.

How to spot delirium?

To reduce the possible impact of delirium it's important to spot the signs as early as possible that someone is developing it.

The behaviour of a person with delirium will change quickly, over hours or days. If you spot any of these signs **speak to a doctor or a nurse**.

They may be restless and agitated.

They may be withdrawn and drowsy.

They might not know where they are.

They might not recognise friends and family.

They might not be able to hold a conversation.

They may see or hear things which aren't there, or be suspicious of people around them.

How to help someone with delirium

The following things help somebody with delirium feel better and get well.

X Encourage to at regularly, little and often if they are not eating 3 meals a day.



TOT Encourage them to wear their glasses if they have these **and hearing aids**.



* Encourage exercise and getting up out of bed.

Make sure they get a good night's sleep.



Encourage going to the toilet regularly, to avoid becoming constipated.

Ask a doctor or pharmacist to check if they are taking multiple medicines, or in pain.

Explain where they are, if they are in an unfamiliar place, write things to help with remembering.



Use things they know such as photographs to chat with them. Encourage them to engage in activities and hobbies that they like.



Use clocks and newspapers to remind them of the date and time. **Getting Better**

Getting better

Most people do recover. As we treat the underlying illness, the person will slowly come back to their normal self. They might struggle with day-to-day things for a few days or weeks.

Someone who has had delirium once is more likely to get it again. Make sure you do everything in the list above to reduce the risk of them getting delirium again. Remember to **speak to a doctor or nurse**, if you spot the signs of delirium.

Some people have symptoms which never go away. If they still have problems with thinking or remembering things after several months, speak to a doctor or a nurse.

Further information

Dementia United have a longer version of this leaflet, which can be accessed via the website <u>www.dementia-united.org.uk</u>

Organisations which support those with delirium also help people living with dementia, who are at higher risk of developing delirium:

Age UK: Information and resources on frailty and delirium: <u>https://www.ageuk.org.uk/our-impact/policy-research/frailty-in-older-people/common-conditions-frailty</u> You can also call the Age UK Advice Line on 0800 678 1602

Dementia UK: Dementia UK provides specialist dementia support for families. Their delirium booklet can be downloaded from <u>www.dementiauk.org</u>. They also have a helpline: 0800 888 667

If you want to get in touch with us in Dementia United - Email: <u>gmhscp.dementiaunited@nhs.net</u>

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