



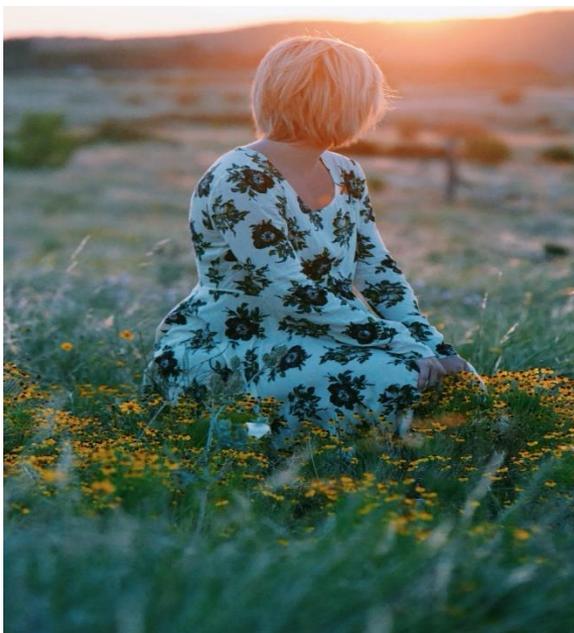
# Bridging the gap for patients with antibiotic resistant infections

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**Patient Support Officer**  
**Antibiotic Research UK**

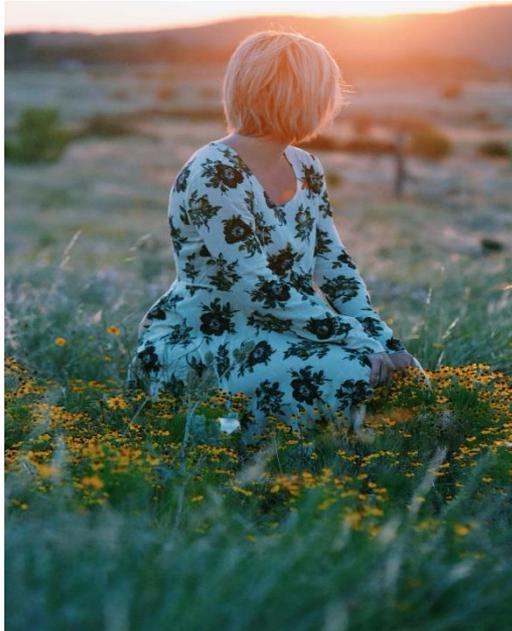




# Who are these patients?



# Sharon's story



- Ongoing health problems including recurring UTIs
- Self-diagnosed sepsis in A&E
- IV antibiotics for septic shock
- Told “you’ve got ESBL *E coli*”
- No explanation, no information, no support, no after-care
- Returned home scared
- Contacted PSO at ANTRUK

*“I was terrified I was dying..... After 3 weeks in hospital they told me ‘You’ve got ESBL *E coli*’. I had no idea what this was and didn’t know why I had to be put in isolation. No one explained anything to me.”*



# Nina's story



- Gallbladder removed - developed ongoing infection
- 4 days IV antibiotics for septicaemia
- Rotating regime of 3 antibiotics now
- “Only 5 antibiotics left to treat this infection”
- Admitted to hospital every 6-9 months
- Antibiotics took longer to work last time

“I would really like to know what the future holds. But no one seems to know or understand if I will always have these infections or what might happen. I feel I have had this wakeup call, that life is too short not to make the most of each day now.

I didn't know about antibiotic resistance before my illness, but now I want to play my part in making a difference.”

# 8 Months of Bridge Building.....



**8 days per month**



**Provide a one stop shop for information online**



**Identify gaps in current provision**



**Single point of contact for support**

# 8 Months of Bridge Building.....



**Written patient information resources for hospitals, doctors**



**Talk to the public and patient groups**



**Procedures to protect sensitive patient programme**



**Liaising with other medical charities with patient facing progs**

# Leaflet for patients and healthcare staff



<https://www.antibioticresearch.org.uk/find-support/>



**Antibiotic RESEARCH UK**



# Website information

<https://www.antibioticresearch.org.uk/find-support/>

Find Support - Details of how to contact the Patient Support Officer

Support for Individuals

Urinary tract infections

Skin and soft tissue infections

Respiratory tract infections - in progress

Sexually transmitted infections - in progress

Bloodstream infections- in progress

Patient Stories

# What do patients ask?



My sister was diagnosed with haemophilus influenza. She has been put on the same antibiotic over 6-7 months and no better. Please recommend an expert on superbugs

Will resistance build up to one specific antibiotic or all? I really think about this often and am really worried

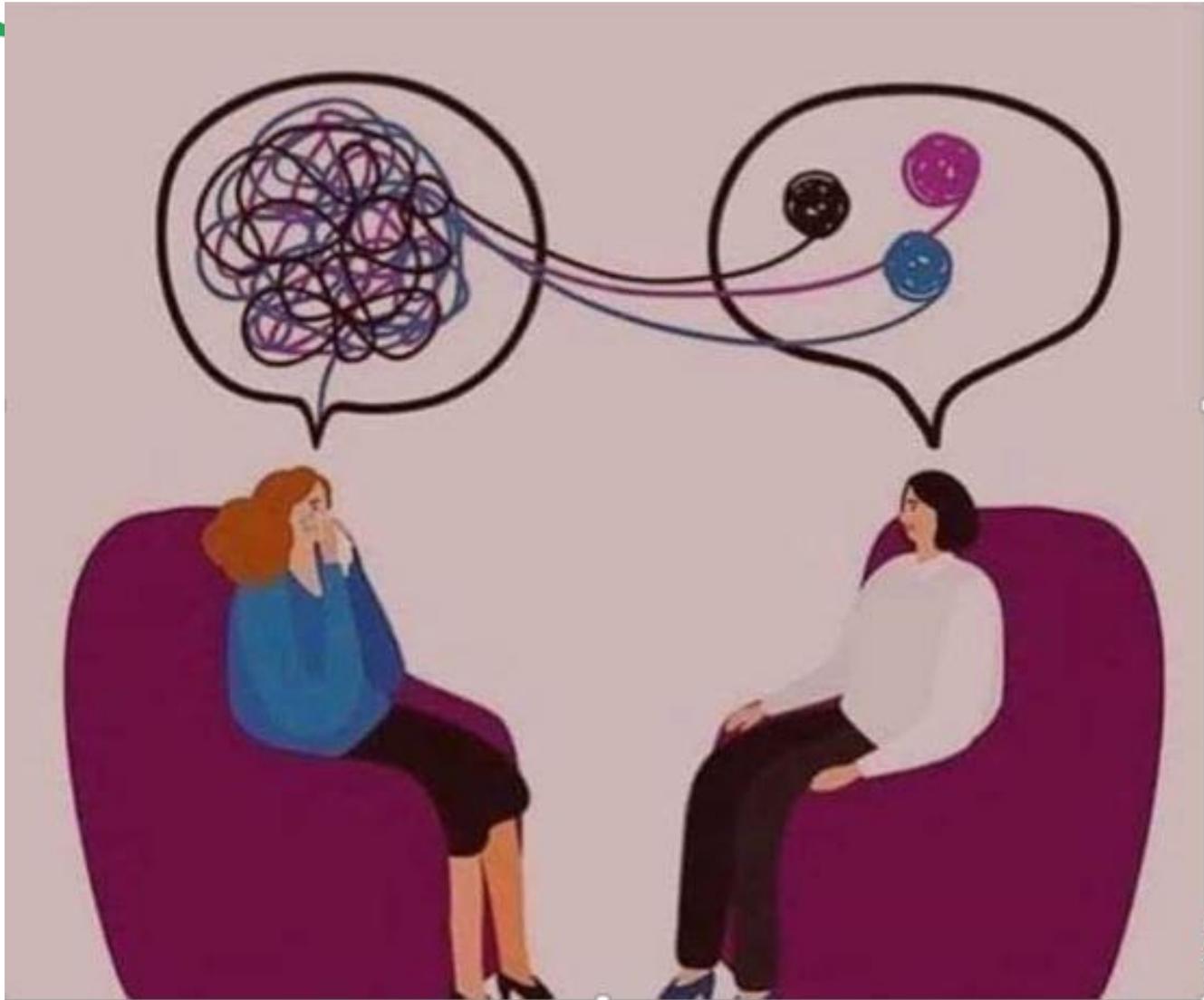
We had never heard of ESBL Klebsiella; despite googling. We've been unable to find answers to our questions.

Does having to have four different antibiotics to treat pneumonia count as antibiotic resistance?

I have a persistent UTI caused by Citrobacter koseri, contracted during surgery which resulted in sepsis. I'm in pain and plagued with worry. Can I speak to you?

My father has suffered from several attacks of *Klebsiella Pneumonia* and any support would be highly appreciated





**Sometimes we need someone to simply be there. Not to fix anything, or to do anything in particular, but just to let us feel that we are cared for and supported.**

- Unknown



fb/david avocado wolfe



# What patients have said.....

It's great to have someone to talk to at long last, I have been ill for 9 years.

Thank you. The information is very helpful .. it mentions almost all of my symptoms.

Thanks so much for your help....I haven't had the time to do a lot of research myself.

I got the newsletter yesterday.... you really are making such a difference in what you do not just for me but for many more I'm sure.

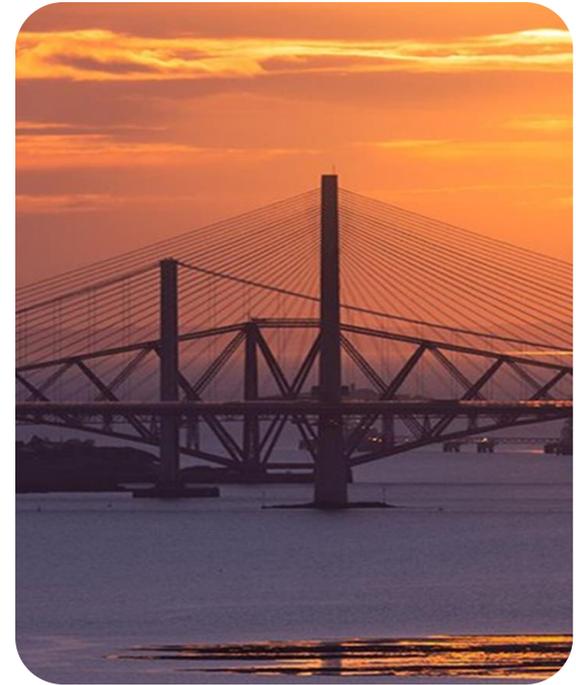
Thank you getting back to me and for really listening. It means a lot.

I have just read everyone's stories and feel relieved to know I'm not the only one going through what I'm feeling and some very similar stories I can relate to. This means so much... thank you!



# The next phase of bridge building.....

- Provide online support group
- Pilot face to face support group
- Library of patient stories
- Workshop for clinicians and patients together
- Continue to build written info – patient leaflets and website info
- Continue to raise awareness through talks





# Jordan White's story

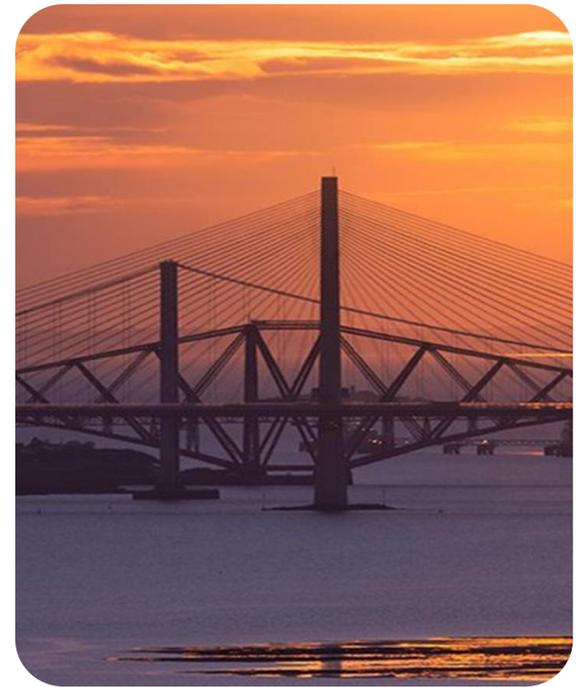
- Professional footballer at Wrexham FC
- Couldn't move legs during night
- Attended A&E several times that week
- Called 999 as listless and feverish
- IV antibiotics for bloodstream infection
- Operation to drain abscess
- Off pitch for 6 months
- Family shaken by experience
- Scoring goals again for Inverness Caley Thistle FC
- So grateful the antibiotics worked!





*“The “i” in illness is isolation,  
and the crucial letters in  
wellness are “we”.*

*(Anonymous)*



# Thank you for listening.....



[patient.support@antibioticresearch.org.uk](mailto:patient.support@antibioticresearch.org.uk)

<https://www.antibioticresearch.org.uk/find-support/>

