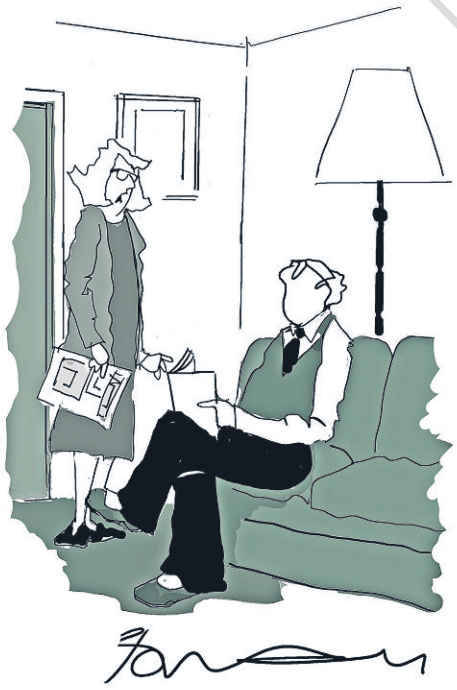

"Apart from performing the Heimlich manoeuvre, when was the last time you put your arms around me?"

Only when I laugh

"This obsession with Elvis Presley — I feel like I'm caught in a trap . . . !"

STEM cells taken from the umbilical cords of babies should be able to help people with heart failure.

An intravenous infusion of the cells brings about a "significant" improvement in the ability to pump blood, discovered researchers at Chile's University of the Andes.

Health

There's no cure for our Maddi's rare condition

By Alan Shaw

CARINA THURGOOD was faced with a parent's worst nightmare.

Her daughter Maddi had been diagnosed with a rare disease that affects fewer than 20 people across the world.

There's no cure, and Maddi's condition is so unusual, there wasn't even any funding for research into possible treatment.

So Carina did the only thing she could — she set up a charity to fund the research that could help her daughter herself.

"It's always horrible to be told your child is ill but usually the doctors can tell you what it is and how they'll treat it but not in Maddi's case," says Carina.

Maddi, now 15, is the only patient in the UK who has SPG15, a very rare and complex Hereditary Spastic Paraplegia (HSP).

HSPs are progressive lower-limb disorders characterised by a loss of neurons connecting the brain to the spinal cord.

SPG15 has other neurological symptoms which can affect speech and sight and cause mental impairment.

There is no treatment, but gene therapy aimed at replacing defective genes is being developed by Professor Mimoun Azzouz at the Sheffield Institute for Translational Neuroscience.

With this, therapeutic genes are transferred into the patient's cells by a deactivated virus.

Carina explains: "It's basically a very rare type of Motor Neurone Disease and because there are not that many people with it out there, it's not like there's been lots of funding gone into her particular type.

"She was originally diagnosed with Krabbe disease, and that was awful enough, but there was treatment available which was a bone-marrow transplant.

"But then we were told it wasn't Krabbe, it was SPG15, which is even more rare.

"The research isn't being done because they take a business-minded approach.

"With so few potential patients, the money just isn't there.

"Also, any help that is available is so specialised, it's incredibly expensive.

"In the US, we were originally going to have the bone-marrow transplant when they thought it was Krabbe, and it would have cost between $300,000 and $600,000.

"The Professor is very positive about what he's doing for Maddi.

"In his words: 'If this works, there are other conditions this should work for.'

"With SPG15, I'm raising funds for what's called the 'proof of concept'," adds Carina.

"If we raise £250,000, basically he's going to prove that this could work, after that, they're talking about another £1.5 million to take it to clinical trials.

"Before this happened, Maddi was just a normal girl growing up," reveals Carina.

"She didn't look like she had a problem at any time, we didn't look at her and think: 'Something isn't right.'

"She'd run about, she was really good at ice skating and from that to this is just living in an awful nightmare.

"The first symptom was Maddi suffering a collapsed ankle a couple of years ago.

"It was so minor, and from that to where she is now is just devastating for us.

"We know that we're living with a child who's not well and is progressively going to get worse.

"Because the condition's so rare, it took us a long time to get a definitive diagnosis for Maddi," adds Carina.

"When they thought it was Krabbe, she was in Great Ormond Street.

"They did a scan and could see she had some kind of progressive disease of the brain, but they just didn't know what.

"From that scan, it took another four months for them to say it was Krabbe, which was awful because we were called in to see the team and they said: 'Don't bring Maddi.'

"But after that, we went off to America to see a specialist who was pretty convinced it was Krabbe, but just wanted to rule out this one other disease it could possibly be — which is what she's got.

"We're not getting phone calls to say: 'Bring her to this hospital and we'll see what we can do.'

"We're getting literally nothing.

Drug resistance makes the fungus hard to treat.

Medics facing fight

MORE than 200 patients in England have been infected or contaminated with a drug-resistant fungus, writes Alan Shaw.

First found in Japan, British hospitals are now on the lookout for further cases and are putting in place measures to help control any further spread of Candida auris.

Authorities say in some cases, patients will have no symptoms, but the infection can cause serious bloodstream and wound infections, though so far, no UK patient has died from it.

The first UK case emerged in 2013, and infection rates have been going up though it remains rare.

Candida auris is hard to stop, as it's developed some drug resistance.