

# Health

## I know how lucky I am to still be alive

■ **MEDICAL** experts believe a powerful pain-relief drug can be derived from cone snails' venom, which appears to act as an analgesic on humans. Researchers are currently

working to produce a version that can be taken orally as the only similar drug available at the moment must be injected into the patient's spine.

By Alan Shaw

**BERYL JONES is an exceptional woman.**

Only 5% of patients with cholangiocarcinoma — bile duct cancer, or CC — survive for more than 12 months, but Beryl is sitting pretty six years on from her diagnosis.

And the Burscough-based gran, originally from mid-Wales, knows just how lucky she is.

"It was my golden wedding this year, and seeing it was my aim when I was diagnosed.

"I did — and it was brilliant," says Beryl, who's 67.

"I had a top surgeon, Mr Malik, at Aintree Hospital, and his words to me were: 'I think I've removed it all, just go and live your life.'

"But for that first 12 months, it was very difficult for me to accept that it had gone," adds Beryl.

"It was mentally horrendous for me. I was really well looked after and got all the support I needed, but I was just sitting there waiting for the worst to happen.

"I went to my GP and asked if he had anyone else on his list with this, and he said just one and that they're not here any more.

"If I could have found a survivor, it would have helped me enormously.

"But I couldn't find any

support group before I came across the Alan Morement Memorial Fund (AMMF) a couple of years later.

"I was listening to Radio Merseyside one morning and this chap started talking about losing his wife at an early age to a rare condition, cholangiocarcinoma. I almost fell out of bed!

"They mentioned the AMMF, the UK's only CC charity.

"So now, I've got someone at the end of the phone, I can speak to other people who've had this — I'm more positive, I'm not alone, and it's wonderful.

"It's turned from all negative to how lucky I am. And I'm very, very lucky and living my life to the full.

"Put it this way, I saw a GP a couple of years after my operation and when I told him what I'd had, he said: 'I've never seen anyone alive with that!'

At least Beryl's doc had heard of the disease.

She didn't receive a definitive diagnosis until after her surgery and she reveals: "Even Mr Malik didn't know what it was, it was only when he took it out that he could confirm it was CC.

"The first surgeon I saw told me I had them completely baffled — there seemed to be no cancer in my body and they couldn't find anything that would cause this mass on my liver.

"When I was first told what it was, I thought they'd made up a fancy name.

"Unfortunately, I went onto the internet to find out things and didn't like what I read.

"I know I shouldn't have, but I just wanted information and couldn't get it anywhere else — how did I get it, why did I get it, what could I have done to prevent it?

"Every answer was: 'We don't know, it's very rare.'



"They don't know what causes it or anything about it, and that's what was so scary.

"I'm fortunate that I had a very early diagnosis. The first signs in my case were feeling

## Frightening statistics of Britain's

WITH murder, it's said 80% of victims know their killer, writes Alan Shaw.

With cholangiocarcinoma, the vast majority of victims have never heard of it.

That's despite it claiming more lives than cervical cancer, more than 1,800 in the UK last year alone.

Helen Morement (pictured) set up the Alan Morement Memorial Foundation (AMMF), the UK's only CC charity, following her husband's death in 2000.

And she reveals: "When Alan was diagnosed, we'd never heard of it.

"It really is the Cinderella of cancers. It's in the corner, neglected.

"It's one of those diseases that certainly isn't glamorous, it doesn't capture people's imagination unless you're an affected family.

"And yet the incidence is increasing enormously.

"The statistics show it's a disease that strikes the over-60s, but I know a girl who's 29 and stage 4, and we're regularly getting people in their late 20s and 30s.

"There needs to be a lot more research done, but the hot spots are in more rural areas, very often in areas of high agricultural land use, so one wonders."

Cholangiocarcinoma's

mortality rate is so shocking, I honestly thought there was a digit missing.

Much of that is due it being very difficult to detect.

It's caused by the natural flow of bile to the intestines being blocked.

This is bad for the body, as it flows back into the tissues and blood causing symptoms including itchy skin, reduced appetite and later jaundice.

The danger lies in the fact that these symptoms at first seem trivial.



"Long time, no see!"

Only when I laugh



"... and how long have you had this pane, Mr Figgis?"



"I left the toilet seat up once too often!"