

How 'dementia' can be beaten by a drain in your brain

By LISA BUCKINGHAM

WE ALL occasionally miss our footing. But when Carole Smith started tripping over more often, she started to worry.

'I'd be walking along quite happily, but then trip suddenly and fall flat on the floor,' says Carole, 74, from Henley-on-Thames, Oxon. 'I'd often bruise myself quite badly, but I never mentioned it to anyone. My walking had become more laboured and slower, too.'

There was another, more embarrassing problem. 'I just couldn't get to the toilet in time,' she says. 'It started ten years ago. I was so embarrassed and upset. I didn't tell anyone — not even my GP.'

Then in 2006, when she was 67, Carole tripped on a kerb while carrying some shopping home and broke her ribs.

'I was taken to hospital, badly bruised,' says the retired university administrator who is divorced with two grown-up children. 'After that, a team of six physios came to my house for a week.'

'I realised while they were there that the assumption was that dementia was setting in. They were quite patronising and started trying to tell me things like how to cross roads safely and how to step up kerbs, as though I'd forgotten how to do it.'

But as far as I was concerned, I still had all my marbles and was perfectly able to navigate around my house.'

THREE months after the physio, Carole went to her GP to seek an explanation. 'When I explained my symptoms, she asked to see me walk across the room. She commented on the fact that my gait was wide and I was unable to keep my knees near each other and said she wanted to refer me to a neurologist for further tests.'

Her GP told Carole she thought the problem was hydrocephalus — as it happened, she'd just been to a lecture on it and said the incontinence and the way Carole was walking and falling were classic signs.

Hydrocephalus is an abnormal increase of cerebrospinal fluid in the brain. When this fluid builds up it starts to affect the brain's function, causing symptoms such as gait disturbance (a wide, slow, shuffling gait with instability, particularly when

injury or after conditions such as stroke, brain haemorrhage, brain tumour or meningitis).

The condition is most common in people aged 60 or older and its trio of symptoms are also classic signs of other conditions, such as Alzheimer's or Parkinson's disease, so it often goes misdiagnosed.

Incredibly, it's estimated that 2 per cent of all people over 60 who've been diagnosed with dementia actually have normal pressure hydrocephalus, which equates to about 10,000 people in the UK.

'One study showed that NPH affects about five people per 100,000,' says Mr Edwards, 'which means we should be treating about 3,000 new cases a year. Instead, we're treating about 300.'

This means there could be thousands of people in the UK on drug treatments for dementia that aren't working.

With a proper diagnosis, the symptoms of this kind of hydrocephalus can be alleviated or reversed — people can walk normally again and recover from the memory loss and the

of people treated will get a good clinical improvement,' says Mr Edwards. 'Results vary from mild improvement up to total reversal of symptoms.'

Treatment most commonly involves inserting a shunt (a fine tube and valve) into the brain via a small hole in the skull during a 30-minute operation under general anaesthetic. The shunt drains the excess fluid from the brain and it is diverted into the bloodstream.

Patients usually undergo a lumbar drainage test first — here a fine needle is used to drain fluid from the brain and spine over two or three days to see if symptoms improve and confirm the diagnosis. If symptoms do improve, it's likely that a shunt would be successful.

Carole went into hospital a few weeks after she was diagnosed to have the fluid temporarily drained off.

'The result was instantaneous,' says Carole. 'I was in for three days having the fluid drained off through a small tube in my back.'

'At the end of the three days, the doctors asked me to try

Worrying symptoms: Carole Smith



stood up and practically ran across it. It was a tremendous feeling — I could walk fast and straight with absolute ease. It was a million miles from the slow, tortuous shuffling of before.'

The diagnosis confirmed, Carole was scheduled to have a shunt fitted. 'In the six months I waited, the symptoms returned as the fluid built up again, but I finally had the operation in April 2008.'

'I was in hospital for 24 hours and the effect was immediate — I could walk fast and straight once again and I stopped wetting myself.'

'All I had to show for the operation was a small incision and bald patch behind my left ear where they'd shaved my hair away to insert the shunt.'

'I lived symptom-free for more than a year, but unfortunately I started tripping up again during the second year. I went back to hospital and was told that the fluid had built up again, and I could have the shunt adjusted to drain off a higher volume of fluid, which was done in December last year.'

'That helped, though some further adjustment may be needed as I still have mild symptoms. It's still so much better than it was without the shunt though.'

Around 50 per cent of patients may experience some return of symptoms after a year, but for others the benefit can last several years.

'We can operate on anyone who is fit for surgery, whether they're 60 or 90 — it's never too late,' says Mr Edwards. 'A patient can have a shunt adjusted several times [although there is a limit] and the effects are not always permanent. But even if it gives someone a year or two of improved or reversed symptoms, it's worth it.'

BUT he stresses the need for better awareness and testing, so fewer people are misdiagnosed.

'If people present with dementia symptoms, they are often referred to a geriatrician, but they need to see a neurologist or neurosurgeon to undergo a lumbar drainage test. This is the best way to diagnose normal pressure hydrocephalus.'

For GPs and the public alike, there can be other indications to watch out for. 'For example, if a person has been diagnosed with

Picture: ALISTAIR HEAP

Drain in your brain

By LISA
BUCKINGHAM

W E ALL occasionally miss our footing. But when Carole Smith started tripping over more often, she started to worry.

'I'd be walking along quite happily, but then trip suddenly and fall flat on the floor,' says Carole, 74, from Henley-on-Thames, Oxon. 'I'd often bruise myself quite badly, but I never mentioned it to anyone. My walking had become more laboured and slower, too.'

There was another, more embarrassing problem. 'I just couldn't get to the toilet in time,' she says. 'It started ten years ago. I was so embarrassed and upset. I didn't tell anyone — not even my GP.'

Then in 2006, when she was 67, Carole slipped on a kerb while carrying some shopping home and broke her ribs.

'I was taken to hospital, badly bruised,' says the retired university administrator who is divorced with two grown-up children. 'After that, a team of six physios came to my house for a week.'

'I realised while they were there that the assumption was that dementia was setting in. They were quite patronising and started trying to tell me things like how to cross roads safely and how to step up kerbs, as though I'd forgotten how to do it.'

But as far as I was concerned, I still had all my marbles and was perfectly able to navigate around my house.'

T HREE months after the physio, Carole went to her GP to seek an explanation. 'When I explained symptoms, she asked to see me walk across the room. She commented on the fact that my gait was wide and I was unable to keep my knees near each other and said she wanted to refer me to a neurologist for further tests.'

Her GP told Carole she thought the problem was hydrocephalus as it happened, she'd just been to a lecture on it and said incontinence and the way she was walking and falling were classic signs.

Hydrocephalus is an abnormal increase of cerebrospinal fluid in the brain. When this fluid builds up, it starts to affect the brain's function, causing symptoms such as gait disturbance (a wide, slow, shuffling gait with headiness, particularly when turning); cognitive impairment such as memory loss, confusion and urinary incontinence.

'These three symptoms, the disturbance is the one that always appears,' says Richard Edwards, consultant neurosurgeon at Frenchay Hospital, Bristol. 'The cognitive problems and incontinence usually accompany it, but not always.'

Carole was diagnosed with normal pressure hydrocephalus (NPH), where the cause of the problem is unknown. Acquired hydrocephalus is caused by damage to the brain after a head

injury or after conditions such as stroke, brain haemorrhage, brain tumour or meningitis.

The condition is most common in people aged 60 or older and its trio of symptoms are also classic signs of other conditions, such as Alzheimer's or Parkinson's disease, so it often goes misdiagnosed.

Incredibly, it's estimated that 2 per cent of all people over 60 who've been diagnosed with dementia actually have normal pressure hydrocephalus, which equates to about 10,000 people in the UK.

'One study showed that NPH affects about five people per 100,000,' says Mr Edwards, 'which means we should be treating about 3,000 new cases a year. Instead, we're treating about 300.'

This means there could be thousands of people in the UK on drug treatments for dementia that aren't working.

With a proper diagnosis, the symptoms of this kind of hydrocephalus can be alleviated or reversed — people can walk normally again and recover from the memory loss and the incontinence. 'About 80 per cent

of people treated will get a good clinical improvement,' says Mr Edwards. 'Results vary from mild improvement up to total reversal of symptoms.'

Treatment most commonly involves inserting a shunt (a fine tube and valve) into the brain via a small hole in the skull during a 30-minute operation under general anaesthetic. The shunt drains the excess fluid from the brain and it is diverted into the bloodstream.

Patients usually undergo a lumbar drainage test first — here a fine needle is used to drain fluid from the brain and spine over two or three days to see if symptoms improve and confirm the diagnosis. If symptoms do improve, it's likely that a shunt would be successful.

Carole went into hospital a few weeks after she was diagnosed to have the fluid temporarily drained off.

'The result was instantaneous,' says Carole. 'I was in for three days having the fluid drained off through a small tube in my back.'

'At the end of the three days, the doctors asked me to try walking across the room and I

stood up and practically ran across it. It was a tremendous feeling — I could walk fast and straight with absolute ease. It was a million miles from the slow, tortuous shuffling of before.'

The diagnosis confirmed, Carole was scheduled to have a shunt fitted. 'In the six months I waited, the symptoms returned as the fluid built up again, but I finally had the operation in April 2008.'

'I was in hospital for 24 hours and the effect was immediate — I could walk fast and straight once again and I stopped wetting myself.'

'All I had to show for the operation was a small incision and bald patch behind my left ear where they'd shaved my hair away to insert the shunt.'

'I lived symptom-free for more than a year, but unfortunately I started tripping up again during the second year. I went back to hospital and was told that the fluid had built up again, and I could have the shunt adjusted to drain off a higher volume of fluid, which was done in December last year.'

'That helped, though some further adjustment may be needed as I still have mild symptoms. It's still so much better than it was without the shunt though.'

Around 50 per cent of patients may experience some return of symptoms after a year, but for others the benefit can last several years.

'We can operate on anyone who is fit for surgery, whether they're 60 or 90 — it's never too late,' says Mr Edwards. 'A patient can have a shunt adjusted several times [although there is a limit] and the effects are not always permanent. But even if it gives someone a year or two of improved or reversed symptoms, it's worth it.'

B UT he stresses the need for better awareness and testing, so fewer people are misdiagnosed.

'If people present with dementia symptoms, they are often referred to a geriatrician, but they need to see a neurologist or neurosurgeon to undergo a lumbar drainage test. This is the best way to diagnose normal pressure hydrocephalus.'

For GPs and the public alike, there can be other indications to watch out for. 'For example, if a person has been diagnosed with Parkinson's, but they're not responding to medication, then hydrocephalus should be considered,' says Mr Edwards.

Carole is thankful her GP spotted the signs so quickly. 'There was no identifiable cause for my condition, so I'll never know why I got it,' she says.

'I feel lucky, though, that I saw a doctor who was familiar with the condition or I could just have been left to deteriorate with a dementia diagnosis.'

■ **FOR more information on NPH, visit shinecharity.org.uk or call 01733 555988.**

Worrying symptoms: Carole Smith



Picture: ALISTAIR HEAP

TINY TWEAKS

AVOID drinking tea with meals. Most pre-menopausal women and girls are at risk of iron deficiency, and tea contains tannins, which can interfere with iron uptake from food. Wait an hour after food before enjoying a cup.

