

The disease that's so difficult to pin down

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If you get lupus, it could be a long time before you realise what it is. The disease mimics the symptoms of so many others that diagnosis is tricky even for specialists — and nightmarish for sufferers. **BEN WEST** explains

ONE of the few things worse than your doctor reaching a diagnosis you don't want to hear is when your doctor fails to reach a diagnosis at all. It's a situation with which lupus sufferers are all too familiar. The auto-immune disease, a kind of self-allergy causing inflammation of connective tissue, currently takes about two-and-a-half years — and a roomful of specialists — before it is identified.

In its most serious form, systemic lupus erythematosus, it can be life-threatening and affects many systems of the body, including the brain, joints and kidneys. Symptoms can include extreme fatigue, muscle aches, joint pains and anaemia, and result in the destruction of vital organs. It affects nine times as many women as men, usually women of childbearing age.

The main problem of diagnosis is that the symptoms of lupus mimic those of other diseases, such as multiple sclerosis and rheumatoid arthritis. To complicate things further, the condition can affect patients very differently. New symptoms can come

and go, which can make patients think it's all in their mind and lead them to be labelled hypochondriacs.

"The disease is more common than multiple sclerosis and leukaemia, so it's amazing how little it is known," says Dr Graham Hughes, of the lupus clinic at St Thomas' Hospital. "It's much more well known in America." Dr Hughes is one of the world's leading lupus specialists and has a syndrome linked to the disease named after him. The clinic, Europe's first unit devoted to lupus, is handling more than 2,500 cases.

As there is no single test for lupus, doctors look for symptoms from a wide-ranging list that includes weight loss, fever, a cough, rashes, hair loss, depression and convulsions. Although there is no cure, treatment — with steroids, anti-malarials, non-steroidal anti-inflammatory agents and other drugs — has improved greatly in the last 20 years.

"The increasing awareness among doctors and the public has had a major impact," Dr Hughes says. "Fewer GPs and specialists are missing cases than before."

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