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An insight into local people suffering from Fibromyalgia

Healthwatch Leicestershire were made aware in January 2016 that local services for people with Fibromyalgia are not meeting their needs.

Today they launch 'It's not in my head' report at Leicestershire County Council Health and Wellbeing Board. The report details the findings from their recent survey of local people suffering from Fibromyalgia.

Fibromyalgia is a chronic and debilitating condition that causes pain all over the body. It is difficult to diagnose because the symptoms vary and fluctuate and sometimes this can be mistakenly attributed to another condition.

What emerges clearly from the findings of Healthwatch Leicestershire report is that Fibromyalgia impacts on a person's day-to-day living and has a long-term impact on their quality of life.

The survey launched in September 2016, received a total of 950 responses from people all over the UK with just under 300 people responding from Leicester, Leicestershire and Rutland (LLR).

Fibromyalgia is largely a diagnosis of exclusion, it can take time to carry out tests and receive the results to rule out other conditions.

- **89% of LLR respondents lived with the symptoms of Fibromyalgia for 2 to 20 years before a proper diagnosis was made.**
- **47% of LLR respondents were finally diagnosed with the disease by a Rheumatologist.**
- **Over half of LLR respondents who were diagnosed by the NHS, were not offered any information on Fibromyalgia.**

Whilst the findings regarding GP services seemed to be positive, experience of secondary services was less favourable. The majority of individuals from LLR reported that non-specialist hospital staff do not have much knowledge of or understand Fibromyalgia. Healthwatch received a number of qualitative comments from individuals across LLR stating that, doctors and

medical staff in hospitals do not see Fibromyalgia as a “real thing” and their symptoms are dismissed.

“Most hospital A&E doctors simply laugh at the suspected fibromyalgia- to them it’s a made- up condition”

Female, 16-24, Hinckley & Bosworth

“A lot of health care staff don’t understand and a lot of the times when I explain I have Fibromyalgia it gets brushed off as if it wasn’t a real health issue.”

Female, 25-34, North West Leicestershire

Healthwatch Leicestershire will present the report to other local stakeholders responsible for commissioning and providing local services. In the report, they recommend 5 simple and practical steps that can be taken to make life easier for Fibromyalgia sufferers and their families.

Healthwatch Leicestershire worked closely with The Shuttlewood Clarke Foundation Fibromyalgia Friends Together Group throughout this project. Kathleen Wass a representative from the group commented;

“We’re pleased Healthwatch are raising awareness of Fibromyalgia and are working to improve the services for people living with the disease.

Following a meeting with a representative from the local NHS, facilitated by Healthwatch, we have produced our top 10 tips for living with fibromyalgia which is to be circulated to 28,000 people including 12,000 health professionals; this will certainly help to raise awareness of Fibromyalgia.”

To download a copy of the report ‘It’s not in my head!’ visit www.healthwatchleicestershire.co.uk.

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Notes to Editors

About Healthwatch Leicestershire

Healthwatch Leicestershire is an independent consumer champion for health and social care in Leicestershire. The organisation helps to shape and improve local health and social care in our community. Healthwatch Leicestershire is part of the Healthwatch national network, established by the Government to ensure local patients and users have a greater input to shaping and designing local services.

About Healthwatch England

Healthwatch England is the independent consumer champion for health and social care in England. The organisation has independent statutory powers, as stated in the Health and Social Care Act 2012, to ensure the consumers’ voice is heard and best practice is delivered

in health and social care nationally. Healthwatch is also focused on providing leadership, guidance and support to the development of the Healthwatch network. To find out more please go to www.healthwatch.co.uk.