

The majority of thyroid patients still suffering years on from diagnosis

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Diagnosis is only the start of a lengthy journey for the majority of thyroid disease patients, according to new research exploring people's experience of living with the condition.

Marking World Thyroid Day on 25 May, researchers at the University of Aberdeen have released the findings of a survey which shows that after waiting years to secure their diagnosis, more than 90% of adults still experience symptoms after receiving treatment.

One in 20 people in the UK have a thyroid problem, with women six times more likely to suffer from the condition than men. Posing serious implications for the physical, mental and [emotional life](#) of those affected, thyroid patients are at greater risk of experiencing long-term sick leave and impairment of working ability.

The team from the Business School's Centre for Labour Market Research worked with the British Thyroid Foundation, Thyroid UK, the Thyroid Trust, Thyroid Patients Advocacy UK, the Improve Thyroid Treatment Group and the charity Miscarriage Support (MISS) to circulate a survey across a UK-wide network of sufferers.

The study gathered data on almost 1,200 patients' experience from the onset of symptoms through diagnosis and treatment and beyond. In total, 95% of the respondents were women.

It found it takes an average of 4.5 years for a thyroid condition to be diagnosed, with this taking considerably longer for patients with hypothyroidism. In most cases (almost two thirds of respondents) it took multiple appointments and a worsening of the severity of symptoms before a diagnosis was made.

The gender of health professionals also seems to matter, with patients saying they felt more involved and empowered when diagnosis was made by a female consultant.

Even once treatment has started, a staggering 92% of patients still experience multiple symptoms, most commonly tiredness and slowness

(79%), cognitive deficits (64%), and muscle aches and weakness (62%).

Despite this, various aspects of everyday life improved after the start of treatment, with 46% people engaging in more [physical activities](#), 32% having a more active social life, 28% engaging more in active social/cultural/political activities, and 47% enjoying a more rewarding personal and/or family life.

Improvements across aspects of labor market engagement such as employment prospects, career and skill development opportunities post-treatment were however much more limited. Only around 10% of respondents reported positive change whereas for the majority of people (approx 60%) there was no improvement, and for the remaining (approx 30%), things even got worse.

Around three quarters (78%) of the respondents who were employed at the time of diagnosis informed their employer about their thyroid condition. In 23% of these cases, the employer did not appear to be sympathetic.

"The evidence that emerges from this survey confirms that thyroid diseases have serious implications for the life of patients, with adverse and long-lasting consequences on their well-being and their ability to engage with and interact with [social activities](#) and work long after they get a diagnosis," said Professor Alexandros Zangelidis.

"Patients on average do not feel they are being heard by the [medical profession](#) and do not feel empowered during their medical journey. Given it affects one in 20 people in the population, its impact should be much more prominently reflected in the Scottish and UK Government's women's health strategies," added Professor Catia Montagna.

The researchers have put forward a number of policy recommendations,

including a review of the effectiveness of treatment and the creation of a UK-wide thyroid taskforce to investigate how people with these dysfunctions can be better supported.

Increased awareness of healthcare professionals on women's health would also be beneficial, along with the development of workplace and HR policies on organizational approaches to thyroid disease and the support employees can expect to receive.

"Relatively little evidence exists about the impact of thyroid dysfunctions on the well-being and labor market outcomes of those affected," added Professor Catia Montagna. "This research makes it very clear that a more holistic approach is needed to inform relevant healthcare policy debates and initiatives."

Thyroid sufferer Natalie Guy, 48, from Bournemouth, said, "Looking back, for more than a decade I had classic thyroid symptoms such as [weight gain](#), digestive issues, puffy face, brain fog, hormone problems and heavy periods that were dismissed out of hand with patronizing comments such as 'eat more vegetables', 'take up jogging', 'it's laziness', 'it's all in your head' by my then GP and by a consultant.

"I hope this important research into the impact of thyroid disease, its effect on well-being and its financial impact is part of the catalyst for change. This lack of diagnosis and earlier treatment affects the social and economic well-being on the individual and society."

Julia Priestly, chief executive office of development at the British Thyroid Foundation, said, "We welcome this study which gives a detailed picture of key issues facing people with a thyroid condition; in particular around patients not feeling listened to nor involved in decisions around their treatment and care.

"The emphasis is now on patient organizations, medical professionals, policy makers and employers to work together to address these recommendations for helping people to live better with thyroid disease."

Louise Sellar, director at The Thyroid Trust, said, "This vital research highlights that [thyroid](#) patient voices have been overlooked for too long and the reasons why this needs to change."

Provided by University of Aberdeen

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