

# Young ME sufferers feel forgotten

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Being diagnosed with chronic fatigue syndrome would be a challenge for anyone. Although, it might be particularly difficult for adolescents who should be out and about with their peers.

"Their condition has a dramatic impact on their lives. Missing out on school, friends, and leisure-time activities makes them feel excluded, and many find it painful to think that the world carries on without them."

Anette Winger has conducted in-depth interviews with 18 Norwegian adolescents aged between 12 and 18 diagnosed with chronic fatigue syndrome (CFS/ME). The interviews provided her with unique insights into how this condition affects adolescents.

She is a PhD candidate at the Department of Nursing at Oslo and Akershus University College (HiOA).

## The symptoms

It is estimated that 600 persons under 18 years have been diagnosed with chronic fatigue syndrome in Norway.

The main symptom is a constant feeling of fatigue. Other symptoms are impaired memory, poorer concentration, sore throats, muscle and joint pains, headaches, and problems sleeping.

We still don't know what causes ME.

## A vulnerable phase

Having the condition means that the young people spend more time at home with their parents and less time with friends.

"They develop a sense of standing on the outside while everyone else gets on with their lives. These young people harbour a deep sense of loss of their old life, and feel like strangers in their own body. Although they occasionally attend school, they still feel excluded," says Winger.

Winger's study shows that the young people were worried about, and preoccupied with, the consequences of their condition. They expressed feelings of being different and forgotten.

"I think it must be particularly difficult for adolescents to have ME, because they are in such a vulnerable phase of life when a lot of things are happening, and they just want to be like everyone else. They miss out on the usual arenas where young people meet because their condition forces them to stay home," says Winger.

## More reflective

An additional burden for these young people was the realisation that health personnel, parents, friends and teachers did not believe that they were sick.

"We must believe in these young people. Good cooperation is dependent on believing them when they say they are sick," Winger says.

She thinks that public health nurses working in the school health service can play a key role in identifying the condition at an early stage.

"They have the trust of young people and are used to talking to them. The threshold for approaching the public health nurse is often low."

Winger emphasizes the importance of listening to young people and of finding out what is best for each individual.

"Despite the many challenges young people face, they are resourceful: they can envisage a future without illness and can nurture hopes and dreams for getting an education and finding a job."

In many ways they are more mature and more reflective than their friends.

"We must bolster their positive thoughts about getting well," she says.

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