

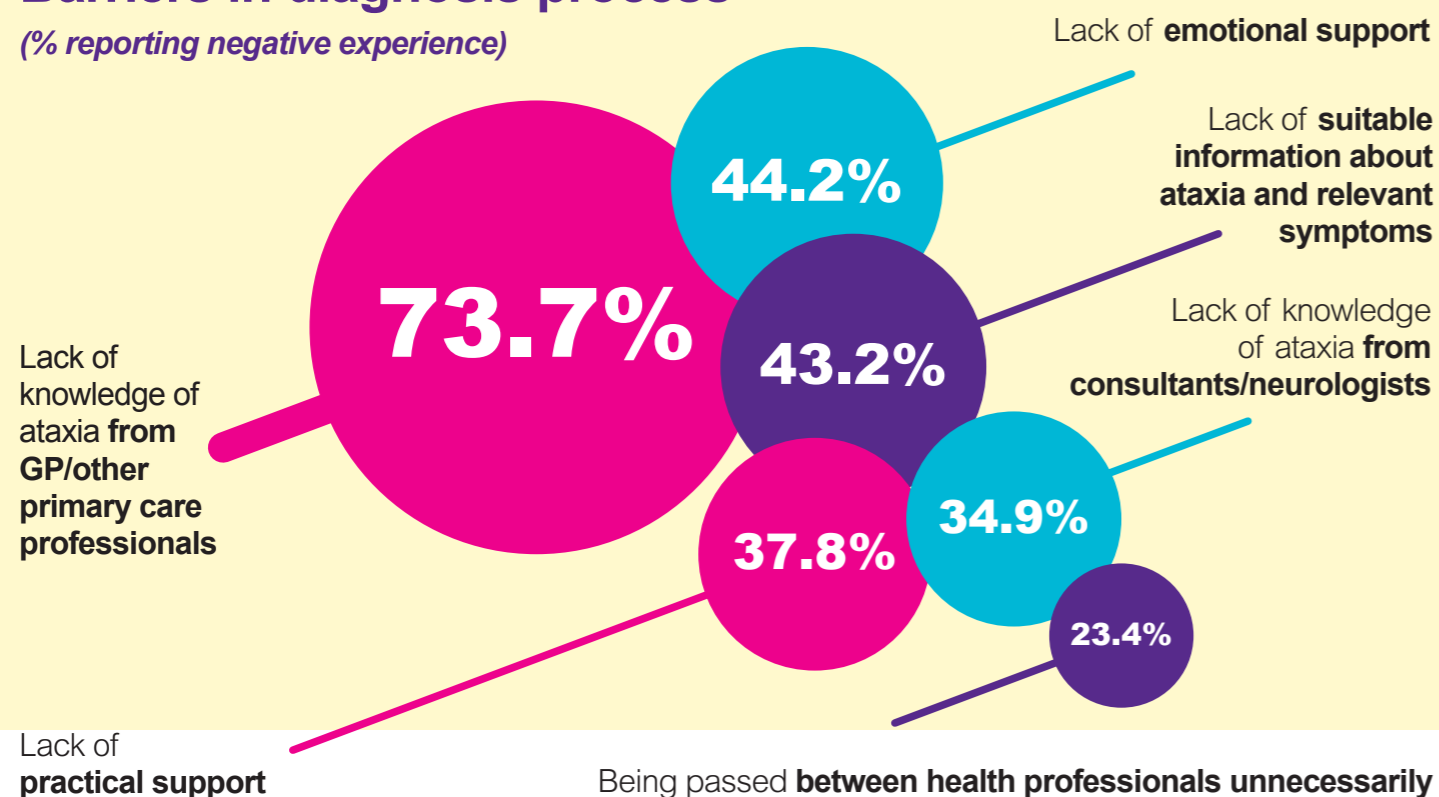
Ataxia UK 2021 survey: what you told us

In Spring 2021 Ataxia UK asked for the experiences of people living with ataxia and carers. The research comprised a survey for those living with ataxia and another for carers, we received a total of 314 surveys from people with ataxia.

This infographic covers an overview of the findings and, in the next issue of the Ataxia Magazine, you'll find an in-depth article covering our findings. Thank you to everyone who participated; your answers help Ataxia UK to work out our priorities and tailor our business strategy to empower and support the ataxia community.

Barriers in diagnosis process

(% reporting negative experience)



Impact on life

80.3% indicated that ataxia had an impact on their mobility outside of the home.

75.6% reported that ataxia had an impact on their ability to use public transport.

72.9% indicated that ataxia had a significant impact on their physical health and wellbeing.

71.7% had installed aids and adaptations.

70.0% indicated that ataxia had an impact on their mobility within the home.

61.8% felt that their current housing met most of their needs.

55.5% reported that ataxia had an impact on their ability to engage with friends outside their home.

51.5% specified the most significant impacts on relationships were with their spouse/partner.

Access to therapies and counselling

86.6% had accessed physiotherapy; **51.6%** reported that it met most of their needs.

56.7% had accessed speech therapy; **48.9%** reported that it met most of their needs.

16.6% had accessed counselling; **38.7%** noted that they could not access counselling or that the counselling support they did receive met none of their needs.

Dealing with issues at work (% reporting negative experience)

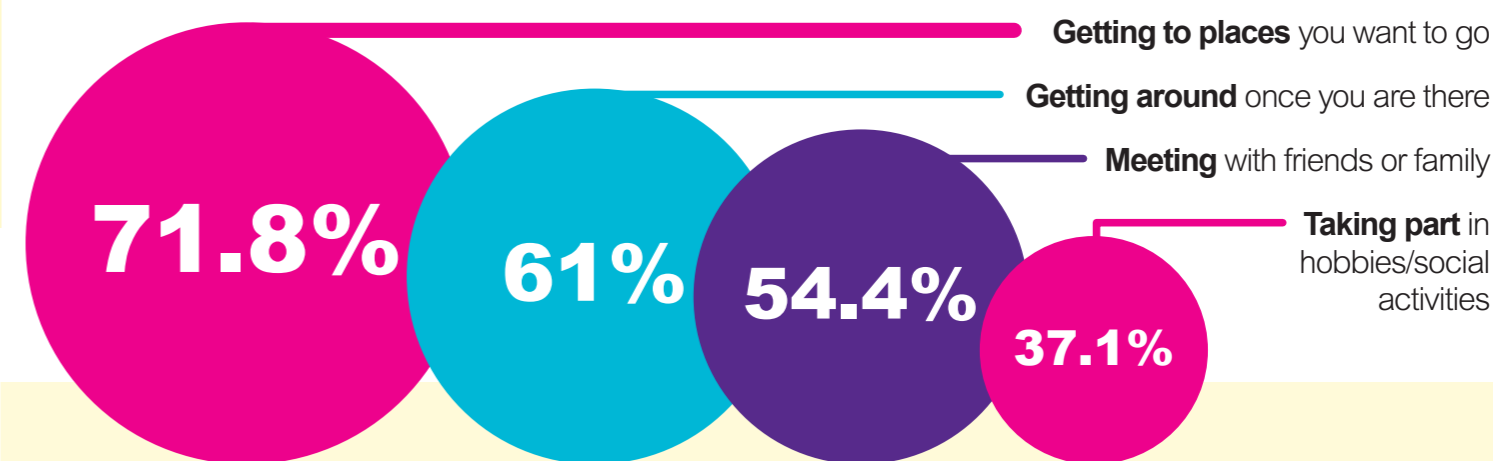
21.5% Negative employer attitudes

19% Issues with physical access at work

14.9% Negative colleague attitudes

11.3% Lack of reasonable adjustments

Informal care activities (% reporting getting help)



Formal care activities (% reporting getting paid help)

