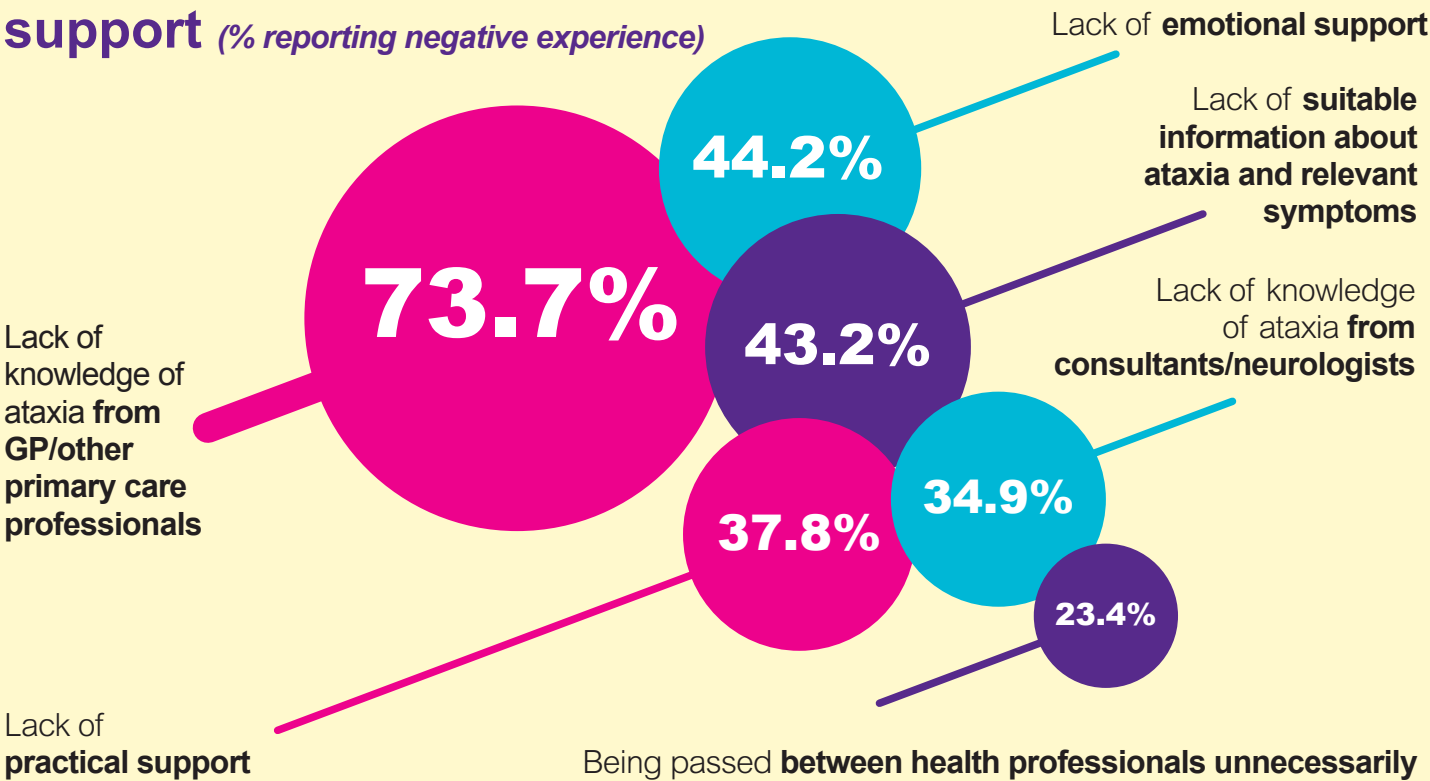


Ataxia UK 2021 survey: what you told us

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.

The following infographics covers an overview of the 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 & subsequent support (% reporting negative experience)



Impact on life

- 80.3% indicated that ataxia had a significant impact on their mobility outside of the home.
- 75.6% reported that ataxia had a significant 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.

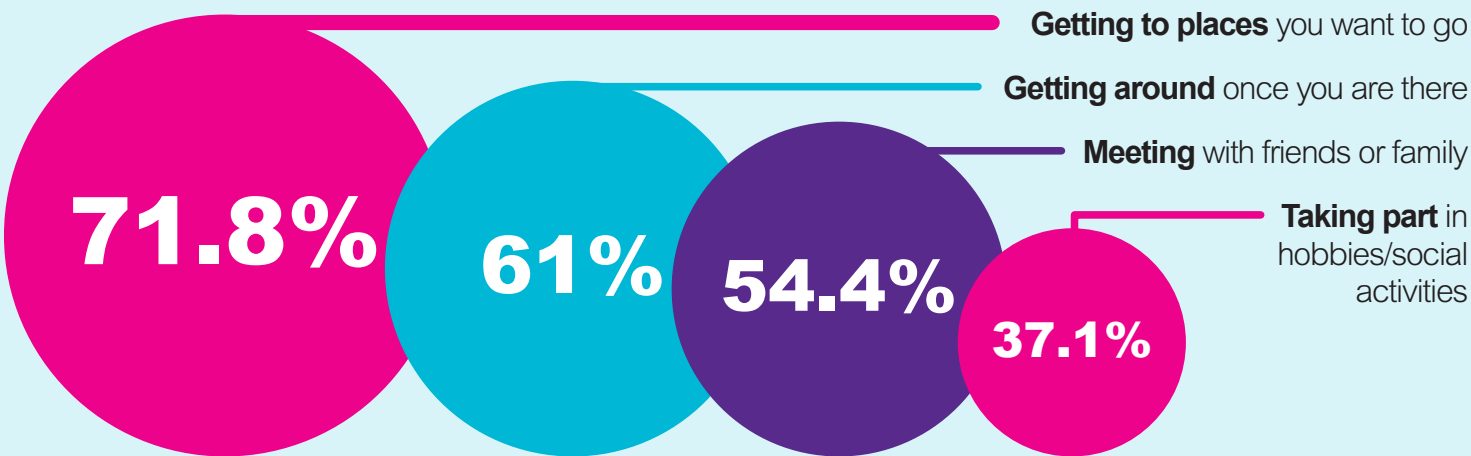
Access to therapies and counselling

- 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.

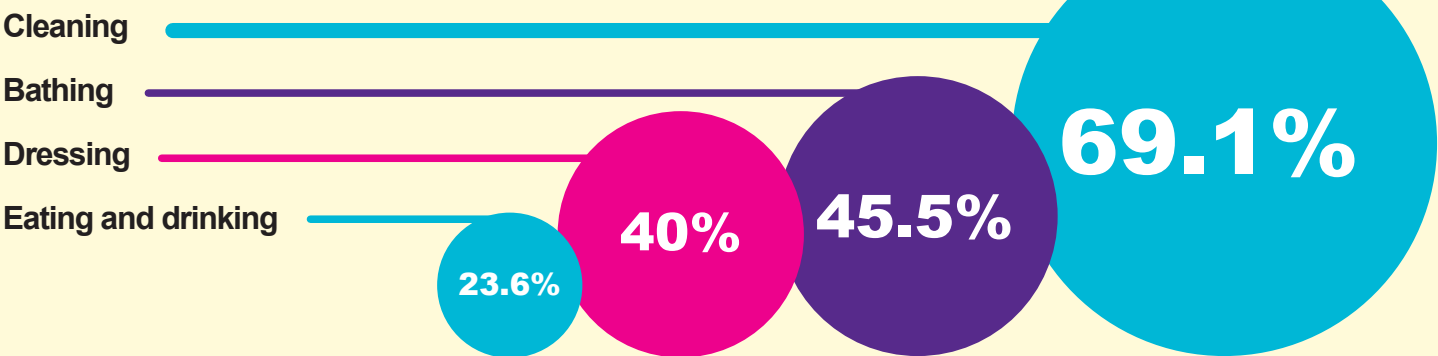
Dealing with issues at work (% reporting negative experience)



Informal care activities (% reporting getting help)



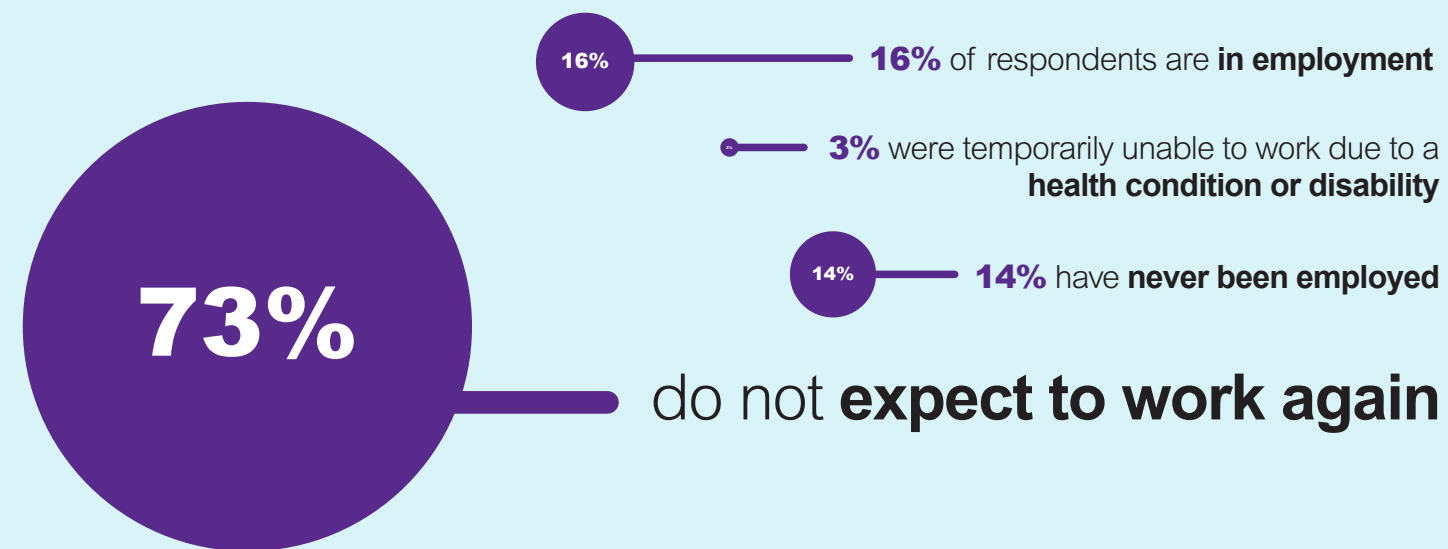
Formal care activities (% reporting getting paid help)



Employment experiences for those affected by ataxia

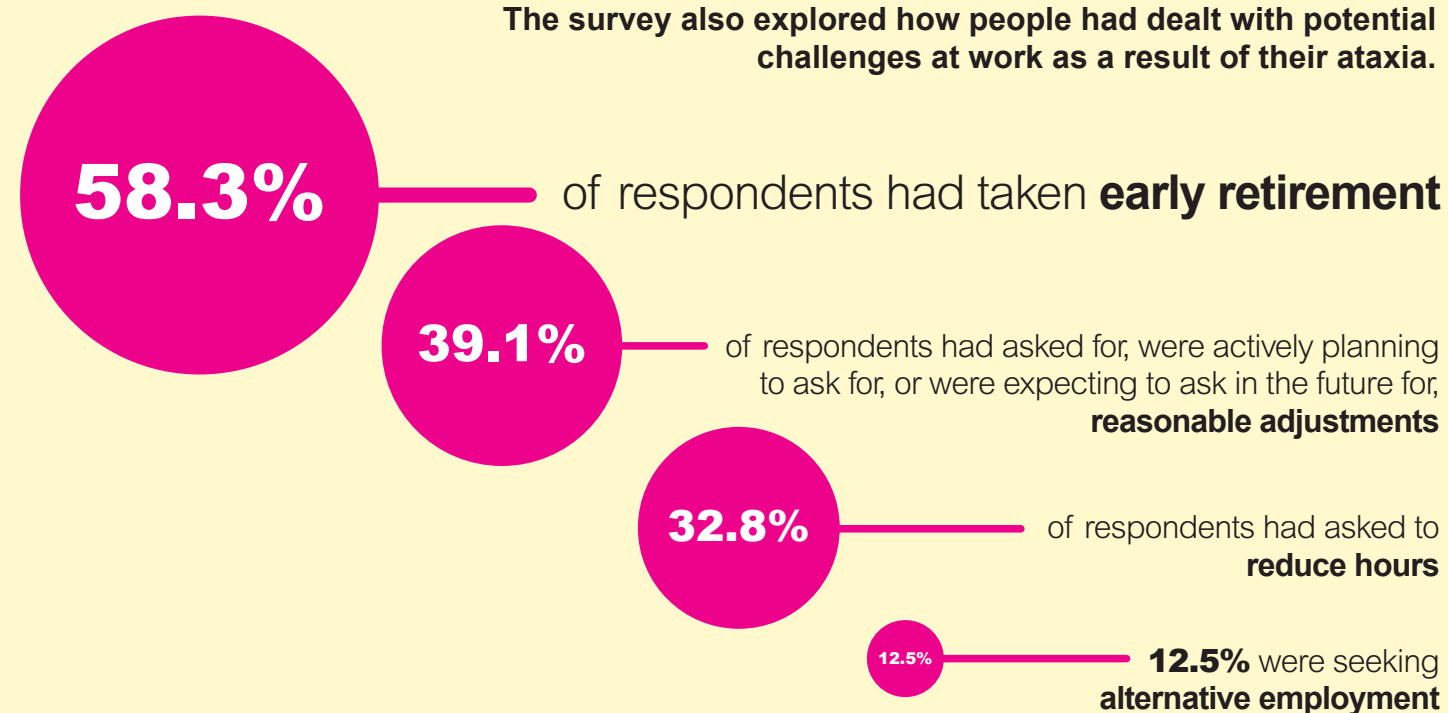
Let's now look specifically at experiences around employment for those affected by ataxia.

Employment experiences for those affected by ataxia

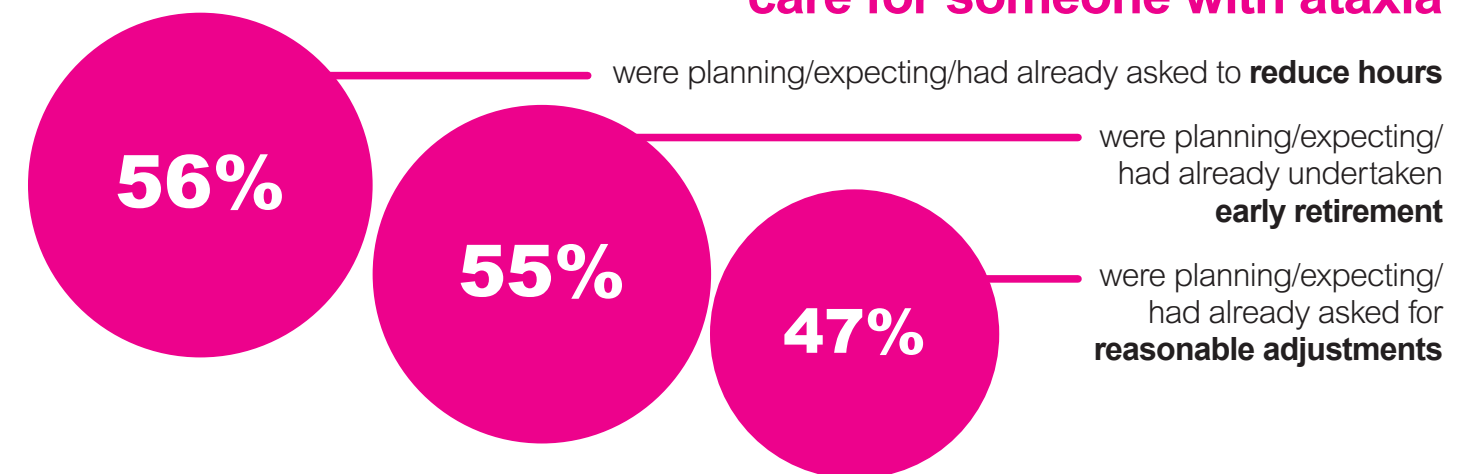


Dealing with issues at work from respondents with ataxia

The survey also explored how people had dealt with potential challenges at work as a result of their ataxia.



Employment experiences of those who care for someone with ataxia

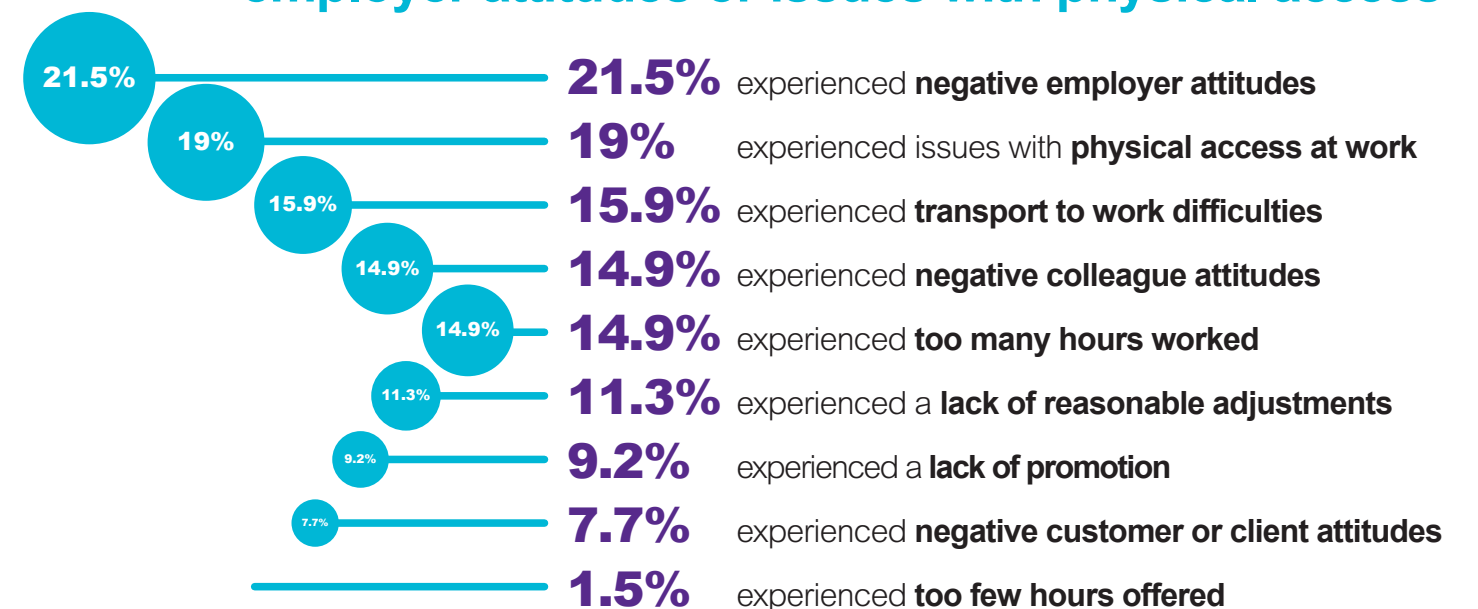


1 in 10 to nearly a quarter

of respondents had experienced:

- Negative **employer attitudes**
- Issues with **access to work**
- **Transport to work** issues
- Negative **colleague attitudes**
- Too many **hours worked**
- Lack of **reasonable adjustments**

Around **1 in 5** respondents had experienced negative employer attitudes or issues with physical access



Our advocacy service can support people with employment issues. The first thing we will always try to do is provide information relating to the specific issue. Then if the person needs support to use that information, we'll either find that support for them or provide 1-2-1 support ourselves as much as we are able to. Contact our advocacy service via the Ataxia UK Helpline on **0800 995 6037** or help@ataxia.org.uk. Open Monday to Thursday 10.30am-2.30pm.


Access to Information, Advice & Support


On these final two pages, we focus on your experiences accessing information, advice and support.


Emotional Support

The figures below focus on the views of participants who had accessed advice from the range of sources, and the proportion who had found the emotional support to be important, very important or vital.

Finding source of emotional support vital / very important / important

	Ataxia UK Helpline	72.5%
	Engagement with Ataxia UK branch/support group	65.2%
	Engagement with Ataxia UK online group	59.6%
	Involvement with Ataxia UK event	57.1%

	Consultation with NHS - secondary care	74.7%
	Consultation with NHS - primary care	70.6%

	Other voluntary organisation	72.7%
	Health Unlocked Ataxia Forum	54.1%

Those respondents who did access emotional support from these sources were more likely than not to find that support at least important. They were most likely to find consultation with NHS secondary care important, almost three quarters doing so, with just under three quarters of respondents feeling the same about emotional support from other voluntary organisations, or from Ataxia UK’s Helpline. Over seven out of ten of these respondents found consultations with primary care professionals important, and nearly two thirds of those engaging with the branch/support group did.


Generally speaking, respondents were more likely to need information than advice, and more likely to need advice than emotional support.





Information Support

The figures below focus on the views of participants who had used information from a range of sources, and the proportion who had found such information important, very important or vital.

Finding sources of information vital / very important / important

	Ataxia UK website	78.7%
	Ataxia UK Magazine	70.7%
	Ataxia UK Helpline	66.7%
	Engagement with Ataxia UK branch/support group	60.5%
	Engagement with Ataxia UK online group	58.7%

	Consultation with NHS - secondary care	79.7%
	Consultation with NHS - primary care	71.1%
	NHS Website	52.0%

	Other voluntary organisation	61.5%
	Health Unlocked Ataxia Forum	60.8%
	Other voluntary sector website	56.3%

This set of responses suggest that where respondents have accessed information from a given source, they are more likely than not to find it of considerable importance to them. This is particularly the case for the Ataxia UK website and magazine.