

Families Experiences of Attending a Digesting Science Event to Learn about Multiple Sclerosis

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Context

There are approximately 26,000 children in the UK with a parent with Multiple Sclerosis (MS)¹. Parents with MS need support to have conversations about MS with their children². Digesting Science is a series of educational activities which explain several aspects of MS for families affected by MS³.

Objective

To understand families' experiences of attending a Digesting Science event.

Design & Methods

Digesting Science events were held across the UK and internationally with

support from various partner organisations. At the end of events, families completed an evaluation form asking about their experience of attending the event and responses were thematically analysed.

Results

Over 90 events were run from 2013-2024 for families affected by MS.

Families appreciated the opportunity to take part in fun activities together and learnt a lot from the event. Parents with MS highlighted the events as an invaluable opportunity to meet other parents with MS and their families. The events facilitated

learning and conversations about MS in a non-scary way and parents felt that it would enable them to have further conversations with their children about MS. Families also reported having a better understanding of the experiences of the family member with MS and how it affects them.

Conclusion

Families report that Digesting Science is fun for the whole family to attend, enabling families to come together and supporting learning and understanding in a practical and positive way.



Having fun as a family

"really appreciate getting together & family learning time"

"I loved seeing my family take part in activities together"



Meeting other people like me

"how common my difficulties are, that I'm not on my own"

"good for kids to see other families with same issues"

Digesting Science

Themes



Supporting difficult conversations

"[child] will now ask more questions to me about my MS"

"more able to discuss condition together as a family no longer 'taboo'"



Understanding and empathy

"I hope [my children] will have a bit more empathy and understanding when I'm fatigued and having a bad day"

"My family said they have learnt what it feels like to have MS"

