

Enhancing Support for Neurodiverse Individuals with Cancer within the Macmillan Information and Support Service

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Background to the Project

In 2024, a neurodivergent cancer patient highlighted a lack of support tailored to both cancer and neurodivergence.
A scoping exercise confirmed this gap within NUH and nationally.

The worldwide prevalence for neurodivergence is estimated to be **15% to 20%.**

(UK Parliamentary Office of Science and Technology)

It is estimated that **1:7** people in the UK are neurodivergent.

(The University of Edinburgh, 2024)

Neurodivergent individuals are protected by the Equality Act 2010.



‘Individuals with autism and autism spectrum disorder (ASD) represent an underserved population that encounters obstacles to receiving best practice of many types of medical care, including access to cancer screening and treatment. These obstacles may stem from limitations of the treating professionals or agency as well as challenges related to the ASD diagnosis’.

(Rochelle Strenger, MD; Howard Safran, MD; and Cooper Woodard, PhD, BCBA, 2020)



Project Aim

To enhance the knowledge and skills of Macmillan Professionals within Nottingham's Macmillan Information and Support Service, enabling them to provide effective information and support for neurodiverse individuals living with cancer.

Project Objectives

- Improve the skillset of the Macmillan Information and Support Service Staff.
- Develop evidence-based resources for neurodivergent individuals.
- Increase support for NUH cancer patients who identify as neurodiverse.
- Implement neurodiversity training across NUH's Cancer Workforce.

Methodology

Extensive
literature
review.

Collaborated
with NUH
teams.

Contacted
neurodiversity
charities.

Liaised with
research
leads.

Actions

- Sourced training for NUH's Cancer workforce.
- Developed a neurodiversity information pack.
- Implemented evidence-based resources for professionals.

Actions

- Developed a library of fidget aids, lanyards and ear defenders.
- Staff surveyed to measure knowledge and skills.
- Disseminated service improvement information trust wide.

Resources Implemented



Results

Staff Survey achieved 100% response rate, with all respondents reporting an increase in knowledge and confidence following training.

Evidence-based resources implemented to provide effective information for neurodiverse individuals living with cancer.

Library of sustainable aids developed:
Fidget aids
Ear defenders
Sunflower lanyards



Results

Positive feedback
received from NUH
Cancer Workforce.

Project presented to
Nottinghamshire's
Health Information
Forum.

Service user feedback
collected anecdotally
with positive
responses.

Funding secured for
the purchase of
resources to support
initiative.

Conclusion

- Initial feedback from both staff and service users has been positive, though rigorous data collection tools require implementation.
- Limited time and resources caused delays to training.
- As a result of positive outcomes from the training, roll out to wider NUH workforce should be explored.
- Dissemination of the project within NUH positively impacted the uptake of information and resources.



Next Steps

- Improve data collection tools to record and analyse engagement with the MI&SS from people who identify as neurodiverse.
- Roll out neurodiversity information packs and resources throughout NUH.
- Disseminate the Service's ability to support the neurodiverse community more widely.
- Develop a sustainability plan for the resources and aids.
- Expand the information and support available for neurodiverse carers.
- Produce a leaflet for neurodiverse individuals living with and beyond cancer.

