# National Survey Evaluating the Impact of
# **Tourette's and Tic Disorders in Australia**

# impact
## FOR TOURETTE'S

## Summary of Results
## **June 2025**

The KIDS RESEARCH INSTITUTE AUSTRALIA

UNSW SYDNEY

THE UNIVERSITY OF WESTERN AUSTRALIA

TOURETTE SYNDROME ASSOCIATION OF AUSTRALIA INC.

## ACKNOWLEDGEMENTS

First and foremost, we want to express our deepest gratitude to everyone who participated in this survey. This journey has been, and continues to be, a long and difficult road. This survey was initiated by the Tourette and tic disorder community, driven by the hope of shedding light on the critical and unmet needs of those living with tic disorders. We believe these valuable and informative results have the power to initiate meaningful change.

Working together with the team on this project is the Tourette Syndrome Association of Australia, the national peak body supporting people with Tourette Syndrome and tic disorders and their families. From the very start, you have stood by us, offering your guidance and expertise every step of the way. We thank you for your partnership on this journey and for the critical work that you do to support this community.

We also want to extend our heartfelt thanks to the community members who contributed to the steering committees, helping to shape and refine the research questions and offering essential recommendation based on lived experiences. We are especially thankful to those who participated in research interviews, sharing their personal mental health journeys to further deepen our understanding of the experiences faced by Australians living with tics.

Lastly, we would like to acknowledge the health services across Australia whose support has been invaluable to this work.

Thank you all for your dedication, your time, and your commitments to making a difference in the lives of those living with tic disorders.

## SUGGESTED CITATION

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impact
FOR
TOURETTE'S

# What's in this report?

Survey Sections

## WELCOME

**TOURETTE SYNDROME**
**ASSOCIATION OF AUSTRALIA**

The Tourette Syndrome Association of Australia is a charitable organisation established in 1989 with the mission to support individuals affected by Tourette Syndrome and to raise awareness of the disorder among medical professionals, public services, and the wider community. Tourette Syndrome is a chronic neurological disorder characterised by involuntary vocalisations and motor movements, known as tics. It affects approximately 1% of school-aged children, with 1 in 4 children experiencing lifelong symptoms. Despite its prevalence, Tourette Syndrome remains under-recognised, often overlooked or misdiagnosed.

Unfortunately, many individuals with Tourette Syndrome go through life without receiving an accurate diagnosis, leaving them without the appropriate support. Furthermore, people living with Tourette Syndrome often face discrimination in various areas of life, such as education, housing, and employment, due to a lack of understanding and recognition of their symptoms by teachers, healthcare providers, and employers. The Tourette Syndrome Association of Australia is committed to increasing awareness of the disorder and addressing the significant gaps in diagnosis and treatment. One of our primary goals is to establish a standardised diagnostic framework and treatment pathway for Tourette Syndrome across Australia.

In partnership with researchers on the Impact for Tourette's study, we have gained valuable insights into the challenges, sacrifices, financial burdens, and emotional stresses experienced by individuals affected by tic disorders and their families. This research brings these issues into focus, underscoring the urgent need for changes in policy and practice to ensure that individuals with Tourette Syndrome receive the support and recognition they deserve.

We call for a national commitment to improve diagnostic pathways, increase funding for evidence-based treatments, and enhance training for educators, healthcare providers, and employers. By implementing these changes, we can create a more supportive environment for individuals with Tourette Syndrome, reducing the barriers they face and enabling them to lead full, productive lives.

I thank you for taking the time to read this report. Let us work together to drive meaningful changes that will improve the lives of people with Tourette Syndrome and other tic disorders across Australia.

Yours sincerely,

Mandy Maysey

President

# GLOSSARY

## Abbreviations used in this report

| | |
|---|---|
| **ADHD:** | Attention Deficit Hyperactivity Disorder |
| **APA:** | American Psychological Association |
| **ASD:** | Autism Spectrum Disorder |
| **CBIT:** | Comprehensive Behavioural Intervention for Tics |
| **DSM:** | Diagnostic Statistical Manual of Mental Disorders |
| **ERP:** | Exposure and Response Prevention |
| **FND:** | Functional Neurological Disorder |
| **ICD:** | International Classification of Diseases |
| **MOVES:** | Motor tic, Obsessions and compulsions, Vocal tic Evaluation Survey |
| **NDIS:** | National Disability Insurance Scheme |
| **OCD:** | Obsessive Compulsive Disorder |
| **WHOQOL-BREF:** | World Health Organisation Quality of Life tool |

# DEFINITIONS

## Terms used in this report

**Activities of daily living:** the basic and daily self-care tasks a person needs to function independently (e.g., bathing, dressing, eating, toileting).

**Caregiver:** a person who supports others (children or adults) with additional needs.

**Complex tics:** elaborate and more complex patterns of involuntary movements and sounds that a person makes.

**Discrimination:** the unfair treatment of individuals or groups based on negative social attitudes or stereotypes.

**Motor tics:** sudden, repetitive, involuntary movements or actions that a person makes.

**Quality of life:** a person's overall wellbeing, including their physical health, mental state, social relationships, and ability to participate in daily activities.

**Respondent:** a person who completed the current survey.

**Simple tics:** brief involuntary movements and sounds that a person makes.

**Stakeholder:** a person who is attached to the current research project by way of their lived experience or the practical implications that survey outcomes represent for their lives.

**Steering committee:** a stakeholder group consisting of people with lived experience with tic conditions, healthcare professionals, and researchers who collaborate in determining the current research project's conduct.

**Stigma:** negative social attitudes or stereotypes that lead to prejudice against a person or group based on characteristics like disability, mental health, or cultural judgements.

**Tics:** presentation of unintentional muscle movements or vocalisations.

**Vocal tics:** sudden, repetitive, involuntary sounds that a person makes. Also referred to as phonic tics.

## Content Warning

The content of this report shares the lived experiences of people with tic disorders and their families. Some of the material presented may be difficult to engage with or be distressing to read.

If you experience distress or need to talk to someone, help is available. The following supports are available in Australia:

- **Lifeline:** 13 11 14 (24/7 support for people experiencing emotional distress) or chat online: https://www.lifeline.org.au/crisis-chat/
- **Beyond Blue:** 1300 22 4636 (support for mental health, including anxiety and depression)
- **Kids Helpline:** 1800 55 1800 (support for children and young people)
- **Headspace:** 1800 650 890 (support for young people aged 12-25 years) or chat online: https://www.headspace.org.au
- **Suicide Call Back Service:** 1300 659 467 (support for anyone affected by suicide)

These services are confidential and available 24/7.

This report presents findings from the **2024 Impact for Tourette's Survey**, containing key recommendations to help improve the lives of those impact by Tourette Syndrome and other tic disorders. The findings are relevant to individuals with tic disorders, their caregivers, medical and allied health professionals who support diagnosis and treatment, and teachers and employers who play an integral role in supporting their needs in educational and professional settings.

**Impact for Tourette's is the first national survey of its kind in Australia,** carefully designed to capture a comprehensive understanding of the difficulties faced by individuals living with tic disorders and their families. The areas explored include the diagnosis journey, the daily functional challenges of living with tics, and the varied experiences with available treatments and therapies. We also sought to understand obstacles faced in education and employment, as well as accompanying financial strains. Equally important were the emotional and social struggles experienced by individuals, and how these factors impact quality of life. This survey is a step towards amplifying the voices of those affected, providing a first critical step towards shedding light on a commonly misunderstood and stigmatised group.

Whilst the primary aim of this national survey was to highlight the magnitude of issues surrounding people with Tourette Syndrome and other tic disorders in Australia, a core component was the inclusion of voices from people within the tic community. Community members were an integral part of this journey, sharing their unique perspectives from the very beginning—shaping the survey design and questions, influencing the development of the research questions, and contributing to the writing of the final report. Their input has been truly invaluable. It was through their voices that we were able to ensure that the lived experiences of people with tics were authentically represented in this report and develop community-informed recommendations that will directly address the unmet needs that were uncovered. Their voices are at the heart of this work.

The responses from this national survey of 206 individuals from around Australia highlight that people with tic disorders and their families experience enormous challenges, in the uncertain pathways to diagnosis and treatment, poor recognition of tic disorders as a disability, unsupported educational difficulties, significant barriers to work and employment opportunities, and extreme mental health concerns.

**Key findings from this survey include:**

- 1 in 4 people waited more than 2 years to receive a tic disorder diagnosis.
- One third of respondents were not recommended any services or intervention options following diagnosis.
- Only 40% of respondents reported that their experiences with services and treatment had been positive, with many feeling unsupported and under-served.
- Over 80% of people experience tics every single day, with many reporting that these often cause emotional distress and physical pain.
- 2 out of 3 people had sustained injuries due to their tics.
- 3 out of 4 people had been ridiculed or bullied by other students at school,

while almost a third faced similar treatment from teachers.

- 3 out of 4 caregivers of children felt educators had very little knowledge and understanding of tic conditions.
- 2 out of 5 adults unable to work reported that the severity of their tics prevented them from working, leading to financial strain and limited workforce participation.
- 1 in 4 caregivers rated their child's quality of life as poor or very poor and 90% of caregivers felt that tics had a moderate to extreme impact on their child's mental health.
- 47% of caregivers reported that their child had expressed thoughts of ending their own life and 1 in 10 children had attempted suicide.
- Almost half of children with tics fell in the clinical range for depression.
- 1 in 4 adults rated their quality of life as poor or very poor and 86% felt that their tics had a moderate to extreme impact on their mental health.
- 71% of adults experienced thoughts about ending their own life and 1 in 4 had attempted suicide.
- More than half of caregivers reported that caring for a person with a tic condition had a high-extreme impact on their own mental health.

Based on the findings of the Impact for Tourette's Survey, and the priority areas identified by respondents, the following **key recommendations** were developed in collaboration with community consultation groups:

- That government funding be provided to develop a National Clinical Guideline for the diagnosis and treatment of tic disorders, designed for use by clinical and allied health professionals and to provide awareness and guidance to consumers and the community.
- As part of the capacity building component of the National Disability Insurance Scheme (NDIS), funding should be allocated to develop a suite of resources and training programs aimed at raising awareness and improving understanding of tic disorders among key stakeholders, including:
  - Key government decision makers
  - General practitioners, psychologists and other healthcare professionals
  - Educators and school staff
  - Employers
- Adjust the NDIS policy settings within the National Disability Insurance Agency (NDIA) to ensure that individuals with tic disorders are appropriately assessed, with those experiencing substantially reduced functional capacity receiving appropriate funding and support.
- Include targeted funding in the NDIS Foundational Supports program for services that enhance support for individuals with tic disorders and their families.
- Targeted funding be provided, beyond the NDIS' Foundational Supports Program, for mental health and emotional wellbeing services for individuals with tic disorders and their families.
- That State and Territory Departments of Education develop clear standards for accommodations and supports for students with tic disorders, ensuring equitable access to education and provide support at the local school level for these to be implemented.
- That major medical and research funding bodies, including the National Health and Medical Research Council and Medical Research Futures Fund, invest in research dedicated to innovative treatments and care pathways for tic disorders. This could be facilitated through a National Centre of Excellence in this field.

Unintentional muscle movements or vocalisations, known as ***tics***, are a common phenomenon occurring in 1 in 8 children between 5-6 years of age (Snider et al., 2002). For most children, these tics are subtle, often going unnoticed, and resolving quickly (<12 months). However, for 1 in 100 children, these tics will become prominent, progress in severity and frequency, and substantially impact their everyday life (Eapen & Usherwood, 2021). For around 75%, tics will present for a large portion of their childhood, reaching a peak severity somewhere between 10-12 years of age, before diminishing to milder presentations or remitting by adulthood (Bloch et al., 2006; Groth et al., 2017). For the remaining ~25% of individuals, their tics will be lifelong (Groth et al., 2017). It is estimated that there are 50,000 Australians living with a lifelong tic disorder.

Tic disorders appear in both the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR, APA, 2022) and the World Health Organisation's International Classification of Diseases (ICD-11, 2022). Tic disorders with an onset during the childhood period are classified into four diagnostic groups (see Figure 1).

While tic disorders commonly begin in childhood, they can also manifest in adulthood (Eapen et al., 2002). Known as Adult-Onset Tic Disorders, tics may appear on their own and sometimes part of a broader spectrum of symptoms linked to other neurological conditions, such as Functional Neurological Disorder (FND).

## Tic Presentation

Tics vary significantly in their presentation. Some tics are brief movements and sounds, involving minimal muscle engagement. Referred to as ***Simple Tics***, these include motor tics like blinking, facial grimacing, and head jerking, as well as vocal tics like sniffing, throat clearing, and grunting. Other tics are more elaborate patterns of movements and sounds. Referred to as ***Complex Tics***, these include motor tics like hitting objects or oneself, complex facial and head movements, and vocal tics like repeating words or phrases, including those that may be socially inappropriate.

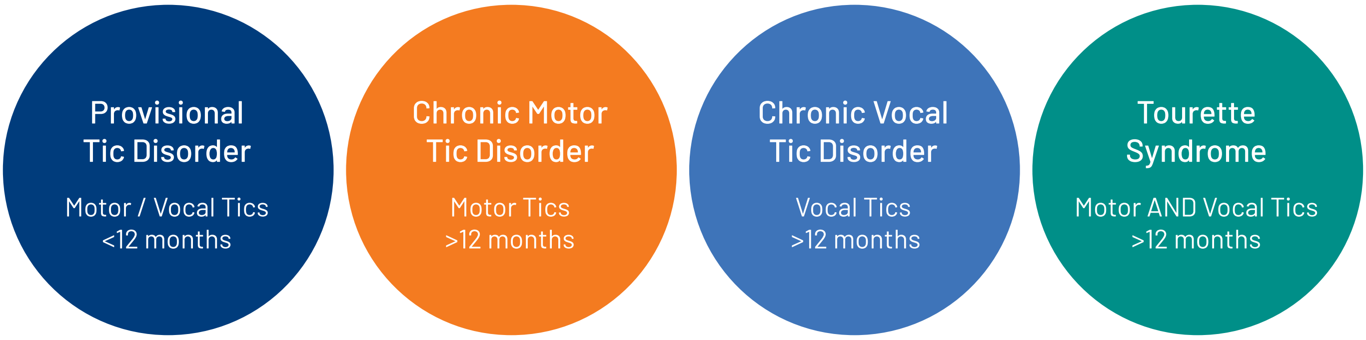

***Figure 1. Classification of Tic disorders during childhood***

The onset of tics can vary from person to person. For some, tics can appear in cycles, coming and going ('waxing and waning') with tic-free periods lasting anywhere from days to weeks to months. For others, tics remain more constant everyday experiences, with tic-free periods ranging from seconds to hours. Some people also experience random bursts of severe, sudden onset, continuous, and non-suppressible tics lasting minutes to several hours – known as tic attacks (Robinson & Hedderly, 2016). There is also variation in sensations experienced before a tic, referred to as a premonitory urge. Some people describe a sense of tension or discomfort that builds up, which is only relieved by the action of ticking. Others do not have this sensation, with tics emerging suddenly and without warning. While some people are able to suppress their tics, this often causes increased intensification of the urge to tic before eventually manifestation.

The impact of tics on a person's life varies considerably, influenced by factors such as their frequency, severity, and type, as well as how much they disrupt daily activities and social interactions. For some individuals, tics go largely unnoticed, having a minimal effect on their daily lives. However, tics can be severely disabling, especially when frequent and intense. Such tics can greatly hinder the ability to perform routine tasks, engage socially, learn in educational settings, and maintain employment, leading to considerable emotional and psychological distress. Additionally, the effort to manage or suppress tics can cause physical exhaustion and, in some cases, lead to injury or accidental harm.

Without appropriate support, the cumulative effects of experiencing tics can significantly impact individual's ability to lead a fulfilling and productive life.

## The Australian Context

In Australia, recognition and support for people with tic disorders and their families is significantly lacking (O'Hare et al., 2016). There are no standardised national guidelines outlining best practice for the assessment, diagnosis and/or treatment of tic disorders. As a result, substantial variability exists amongst clinical approaches delivered by clinicians and health services. There is also a shortage of specialised services, combined with many healthcare providers lacking essential knowledge and training, leading to limited and inconsistent support and care.

Tic disorders are not adequately recognised by organisations and government initiatives designed to assist people living with disability, such as the National Disability Insurance Scheme (NDIS). This lack of recognition may reflect misconceptions about the impact tics have on daily functioning along with the understanding that trajectories of tic disorders across an individual's lifetime can be unpredictable. However, tic disorders can be profoundly debilitating for some individuals, causing significant disruption on daily lives, and impacting opportunity and participation.

In addition to these healthcare challenges, individuals with tic disorders often face difficulties in education and employment. Schools and workplaces may not fully understand or accommodate their needs, impacting on academic performance and job stability.

Moreover, the general lack of awareness and misconceptions about tic disorders (e.g., people believing tic disorders only involves swearing), lead to discrimination and misunderstanding. These exacerbate social challenges and hinder access to necessary support. Increasing societal knowledge and awareness is essential for improving the understanding of tic disorders and creating a more inclusive environment.

The overall deficiency that exists in recognition, understanding, resources and support is currently impacting on the quality of life of Australian's living with tic disorders and their families.

This shortfall is affecting their ability to receive timely and effective treatment, thrive in educational and work environments, and engage fully in social and community activities. The lack of adequate support and awareness further exacerbates the challenges they face.

## Need for a National Survey

In Australia, the impact of tics and gaps in support remain largely unrecognised because comprehensive data collected at a national level does not exist. Such information is vitally important for highlighting the gaps in understanding, raising awareness, and supporting advocacy and policy development. By collecting and presenting data on the experiences and unmet needs of those affected, we can collectively work towards creating a brighter future for people living with tic disorders and their families.

## Impact for Tourette's

In August of 2023, a team of researchers met with four community consultation groups comprised of 23 people with lived experience of tic disorders. Together with these stakeholders, a national survey was developed and launched to evaluate the unmet needs of people with tic disorders.

Ethics approval for this project was received from the Human Research Ethics Committee at the University of Western Australia (Ethics 2023/ET000799). The survey was launched using REDCap over a 5-month period (early 2024) and promoted through a variety of social medial platforms (e.g., Facebook, Twitter), the Tourette Syndrome Association of Australia's website, and service providers around Australia.

The survey was distributed to three key groups of respondents:

1. caregivers of children (< 18 years) with a tic condition,
2. adults (>18 years) with a tic condition, and
3. caregivers/partners of adults (>18 years) with a tic condition.

Survey content was tailored according to each respondent group, but the survey broadly captured **7 Impact Domains** (Figure 2).

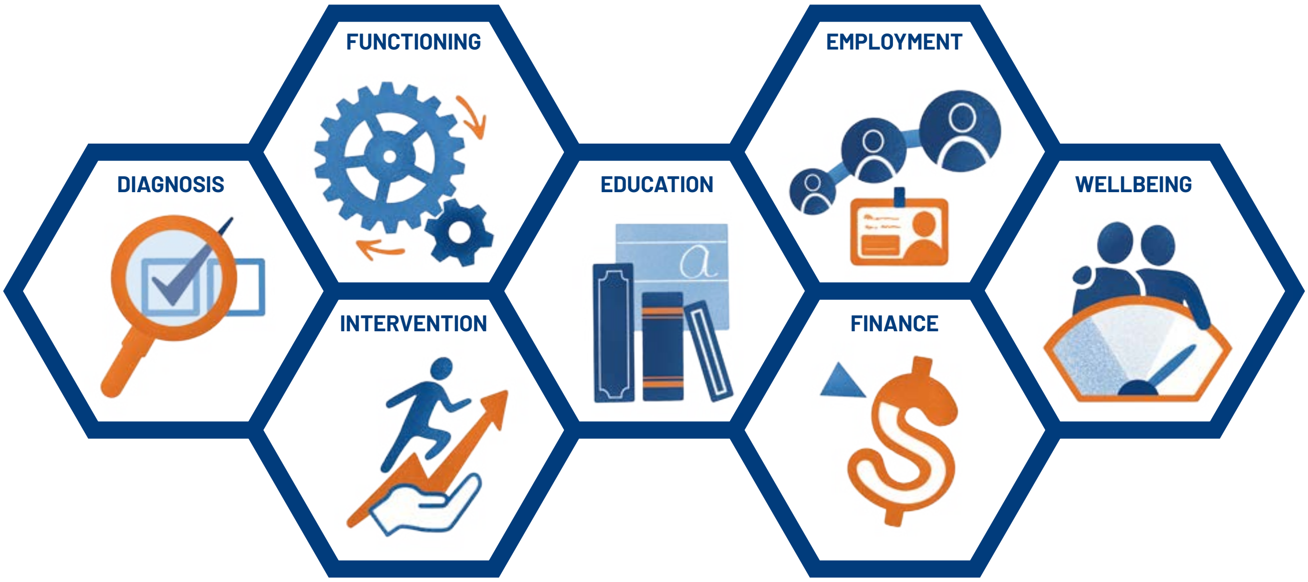

*Figure 2. Impact Domains*

The survey comprised several existing validated questionnaires assessing specific domains, as well as bespoke questions, informed by community and stakeholder input. Within each set of survey questions, free-text fields allowed for respondents to provide further information and elaborate on their responses. Across each domain, key findings are presented alongside quotes obtained from these free-text responses to provide further insight into the challenges encountered by the community.

Respondents also ranked **Priority Areas for Change**. This list was developed through community consultation, with respondents asked to rank their top 3 priority areas.

In addition to the national survey, a series of **Interviews** were conducted to explore the experiences and perspectives of young people and their caregivers regarding healthcare services, with a particular focus on mental health—a key area identified in the community consultation meetings that was not fully captured in the national survey. From August to December 2024, 13 young people with tics aged 8-24 years, along with 6 caregivers, participated in semi-structured interviews. These conversations provided in-depth insights into the healthcare experiences of individuals with tics, their views on health and mental healthcare services, and their recommendations for improving these. The findings from these interviews are integrated into the current report alongside the national survey results.

## Project Leads

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Researcher specialising in neurodevelopmental conditions impacting on motor function and has led national advocacy projects working to improve the awareness and support of movement disorders.

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## Research Coordinator

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## Funding

This project was supported through internal funding awards at The Kids Research Institute Australia, including a 2023 Julie Bishop Award and 2024 Embrace Award, to Dr Licari.

## Who took part in this survey?

Responses were obtained for **206 individuals from around Australia**. This included caregivers of 112 children (68% male, 32% female) and 17 adults (53% male, 47% female) with a tic condition, as well as 77 adults (29% male, 71% female) with a tic condition.

Given the potential for a survey being completed by an adult with a tic condition and also their caregiver, thereby duplicating responses, adult caregiver data was only included in the caregiver wellbeing section.

## State Location

Approximately one third of the participants were from New South Wales (32%), 20% from Queensland, 21% from Victoria, 9% from Western Australia, 9% from South Australia, 6% from Tasmania, 2% from the Australian Capital Territory and 0% from the Northern Territory (Figure 3).

Based on population sample size, New South Wales, Queensland, Western Australia and the Australian Capital Territory were well represented. South Australia and Tasmania were slightly over-represented, and Victoria and the Northern Territory were under-represented.

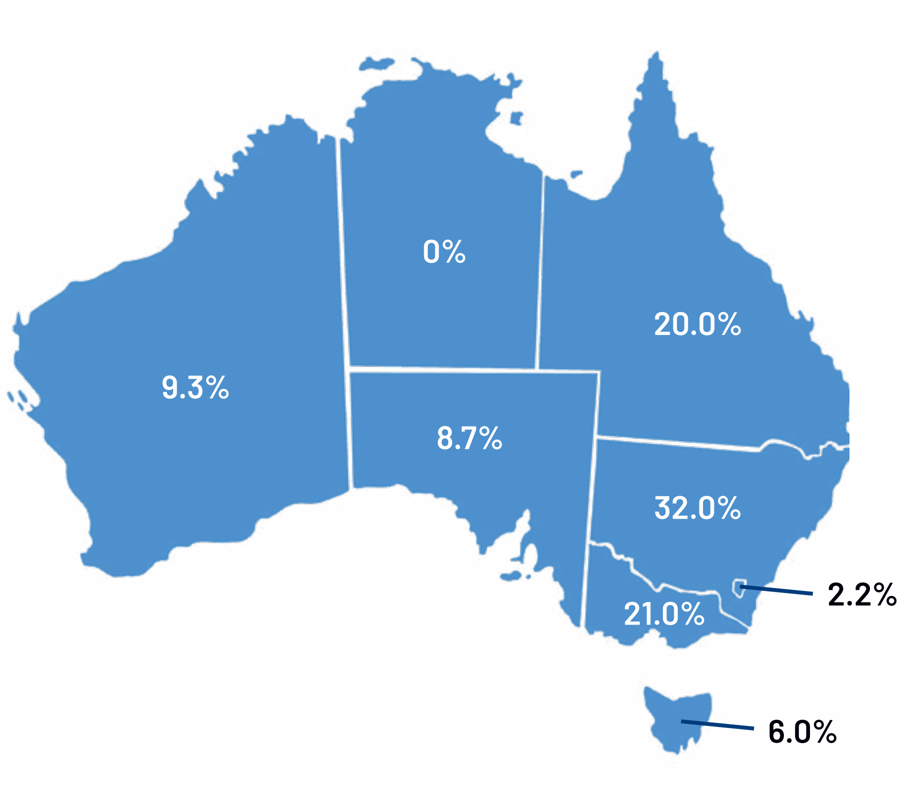

*Figure 3. Distribution of responses by state*

## Age Distribution

The majority of child caregivers were reporting on children and adolescents aged 10-14 and 15-19 years (Figure 4), while the majority of adults were in the 20-29 years age range.

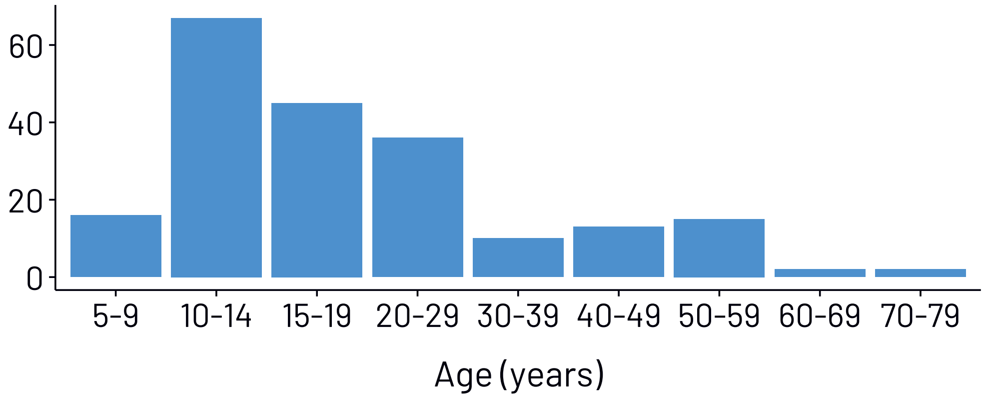

***Figure 4. Age distribution***

# Key Findings

Findings from the national survey were initially presented to community consultation and stakeholder groups. From these, **Key Findings** were identified. These are presented across the **7 Impact Domains** below.

## Diagnosis

Challenges in obtaining a diagnosis were highlighted across respondents, with one in four waiting more than two years to receive a diagnosis. Longest wait times were experienced when onset of tics occurred during adolescence, with wait times up to three years commonly reported.

Only two out of five people reported that obtaining a diagnosis was a positive experience. Challenges included lack of knowledge about tics and appropriate referral pathways amongst general medical professionals, along with limited access to and availability of specialists. Frustrations were also reported in the lack of information provided following diagnosis; 38% were not recommended any treatment or therapies following a diagnosis.

The Tourette Syndrome Association of Australia was reported as the main source of information and support following diagnosis.

## Function

Most children (89%) and adults (79%) experienced tics every day, with more than half of children and a third of adults experiencing tic free intervals of 5-10 minutes, at most.

Many children's (72%) and adult's (63%) tics impacted their everyday life, to a moderate degree. Tics frequently impacted ability to concentrate (64%), pay attention (52%), and learn (50%). Other frequently reported impacts of tics included sleep, such as the ability to go to sleep (53%) and overall sleep quality (50%), the ability to relax at home (49%), go out with family and friends (39%), and ability to verbally communicate (38%).

Four out of five children and adults had tics that caused physical pain, and two out of three reported sustaining injuries from their tics.

## Intervention

Only two out of five respondents reported positive benefits from accessing interventions for managing tics.

Over half had been prescribed medication (63%) and two thirds reported that their tics were either minimally or not controlled with medication. Side effects from medication were commonly reported, including drowsiness (57%), fatigue (42%), and low mood (41%).

Nearly three quarters of respondents (71%) reported seeing a mental health professional for psychological intervention; of these, most (91%) reported that their tics were either not or minimally controlled by these approaches. Many reported frustrations that the focus of psychological intervention was on symptoms perceived to exacerbate their tics (e.g. anxiety), rather than on practical strategies that could be used to manage tics themselves.

# Key Findings

## Education

Most respondents (75%) reported that tics had a moderate to extreme impact on experiences at school.

Common challenges at school included pressure to suppress tics (85%) and difficulty completing schoolwork (75%). Three out of four children had been ridiculed and bullied by other students, and almost a third had experienced similar treatment by their teachers.

Three out of four caregivers reported that educators had very little knowledge or understanding of tics and more than half felt accommodations provided in the education setting were inadequate for their child.

Almost two thirds of child caregivers were concerned about their child's ability to gain future employment because of their tics.

## Employment

More than half of adult respondents reported that their tics had a moderate to extreme impact on their employment opportunities. One in 10 adults were unemployed and not able to work because of the severity of their tics.

Most adults (82%) felt their employer had very little knowledge or understanding of tic conditions. Two thirds felt that they received very little support for their needs in the workplace and 42% had experienced discrimination in the workforce.

## Finance

Over a third of respondents were not satisfied with their financial situation, and one out of four adults with tics were having trouble meeting their basic needs.

Over half (51%) reported trouble covering the costs of managing their tic condition.

One in 20 reported receiving disability funding from the NDIS for their tic condition, with many of these reporting co-occurring disabilities (e.g. autism). Three out of four respondents who had applied for NDIS funding had their applications declined.

## Wellbeing

Nine in ten caregivers reported that their child's mental health was impacted by their tic condition. The quality of life for four out of five children was reported as below average, and many (44%) had elevated depression symptoms. Almost half of children experienced thoughts about ending their own life, a third engaged in self-harming behaviours, and one in 10 children had attempted suicide.

Most adults with tics (86%) reported that their mental health was impacted by their tic condition. One in four adults with tics reported below average quality of life, and all quality of life domains were well below population norms. Almost three out of four adults had thoughts about ending their own life, a third of these had these thoughts on a weekly basis. One in four adults had attempted suicide. Almost half of adults had engaged in self-harming behaviours and many adults (22%) reported self-harming on a weekly basis.

Three out of four caregivers reported current moderate to very high levels of stress. Over half of caregivers reported that caring for a person with a tic condition has a high to extreme impact on their own mental health.

# Key Recommendations

Based on the findings of the Impact for Tourette's survey and the priority areas identified by respondents, the following recommendations were developed in collaboration with community and stakeholder groups:

**Recommendation 1: That government funding be provided to develop a National Clinical Guideline for the diagnosis and treatment of tic disorders, designed for use by clinical and allied health professionals and to provide awareness and guidance to consumers and the community.**

***Outcomes:***

- Standardised, evidence-based care across the country, ensuring individuals with tic disorders receive the most effective and up-to-date treatment options.
- Improved diagnostic accuracy, leading to quicker identification of tic disorders and the implementation of timely interventions.
- Increased consistency in treatment plans, ensuring that all individuals, regardless of location, have access to high-quality care.
- Enhanced training and education for clinicians, empowering them with the tools and knowledge needed to treat tic disorders effectively.
- Greater training for psychologists to deliver evidence-based tic-specific interventions, such as Comprehensive Behavioural Intervention for Tics (CBIT) and Exposure and Response Prevention (ERP).

> *"People don't understand how much [tic disorders] impact daily life; being recognised as a disability would help with this and accessing support."*
>
> *– Child Caregiver*

**Recommendation 2: As part of the capacity building component of the National Disability Insurance Scheme (NDIS), funding should be allocated to develop a suite of resources and training programs aimed at raising awareness and improving understanding of tic disorders among key stakeholders, including:**

- **Key government decision makers**
- **General practitioners, psychologists and other healthcare professionals**
- **Educators and school staff**
- **Employers**

***Outcomes:***

- Stronger advocacy for policy changes, as decision-makers become more familiar with the challenges faced by individuals with tic disorders.

- Increased awareness and knowledge about tic disorders, leading to a more informed and compassionate response from key sectors of society.
- Reduced stigma surrounding tic disorders, fostering an inclusive environment for individuals affected by tics.
- Improved clinical support and treatment pathways, with general practitioners, psychologists and other healthcare professionals better equipped to guide individuals with tic disorders through a structured, evidence-based clinical pathway, ensuring timely intervention and appropriate care.
- Improved support for students with tic disorders and their families, with educators and school staff better equipped to provide necessary provisions in the classroom and facilitate their academic success.
- Workplace accommodations and support systems, as employers gain understanding of tic conditions, potentially reducing workplace discrimination.

> *"Life would be easier and I would feel less judged if those around me at least knew about [my tics]."*
>
> *– Adult with Tics*

### Recommendation 3: Adjust the NDIS policy settings within the National Disability Insurance Agency (NDIA) to ensure that individuals with tic disorders are appropriately assessed, with those experiencing substantially reduced functional capacity receiving appropriate funding and support.

***Outcomes:***

- Equitable access to support and services for individuals with tic disorders who experience substantial functional limitations, ensuring they are not overlooked in the NDIS process.
- Personalised care plans that address the unique needs of individuals with tic disorders, leading to more targeted interventions and better outcomes.
- Improved quality of life for individuals with tic disorders, as appropriate funding and services are directed toward managing and improving daily functioning.
- Decreased financial barriers for individuals and families affected by tic disorders, enabling them to access the resources they need for care and support.

# Key Recommendations

## Recommendation 4: Include targeted funding in the NDIS Foundational Supports program for services that enhance support for individuals with tic disorders and their families.

***Outcomes:***

- Increased availability of specialised services tailored to the unique needs of individuals with tic disorders, particularly in areas like mental health support and family counselling.
- Greater community engagement and peer support through organisations like Tourette Syndrome Association of Australia (TSAA), reducing isolation and fostering a sense of belonging.
- Enhanced service coordination, ensuring that families can access a comprehensive support network.
- Increased access to services for people located in non-metropolitan areas, either via telehealth or funding to access specialist metropolitan-based services.

## Recommendation 5: Targeted funding be provided, beyond the NDIS' Foundational Supports Program, for mental health and emotional wellbeing services for individuals with tic disorders and their families.

***Outcomes:***

- Greater access to mental health services given these are not included or provided through the NDIS Foundational Support Program.
- Additional financial assistance provided in addition to Medicare's Mental Health Plan to access ongoing and chronic mental health support.
- Greater provision of specialised mental health supports for caregivers of children and adults with tic conditions.

## Recommendation 6: That State and Territory Departments of Education develop clear standards for accommodations and supports for students with tic disorders, ensuring equitable access to education and provide support at the local school level for these to be implemented.

***Outcomes:***

- Better school staff training, ensuring that educators are equipped with the knowledge and skills to support students with tic disorders in inclusive environments.
- Increased academic success and engagement for students with tic disorders, as they receive the necessary accommodations to fully participate in the classroom.
- Improved social and emotional development for students with tic disorders, reducing bullying and increasing peer interactions.

> ***"Schools need better education for teaching staff to help assist students."***
>
> ***- Parent Caregiver***

# Key Recommendations

- A more inclusive educational system, where students with tic disorders are not marginalised or excluded, and are able to thrive alongside their peers.
- Long-term academic and professional success, as early and effective accommodations help students develop the skills needed for the future.

**Recommendation 7: That major medical and research funding bodies, including the National Health and Medical Research Council and Medical Research Futures Fund, invest in research dedicated to innovative treatments and care pathways for tic disorders. This could be facilitated through a National Centre of Excellence in this field.**

***Outcomes:***

- Advancement of scientific understanding of tic disorders, leading to the discovery of new treatments, therapies, and care pathways.
- Better treatment options as research explores innovative interventions, improving the quality of care for individuals with tic disorders.
- Increased investment in the field, attracting attention and resources from medical and research communities, which could lead to groundbreaking discoveries.
- Collaboration across disciplines, as a National Centre of Excellence fosters partnerships between clinicians, researchers, and organisations, accelerating innovation.

> ***"Medical treatment breakthroughs to decrease tics would be life changing."***
>
> ***– Child Caregiver***

- Enhanced quality of life for individuals with tic disorders, as evidence-based treatments improve symptom management and functional outcomes.
- Accelerated scientific understanding of tic disorders, leading to the discovery of new treatments, therapies, and care pathways.
- Improved quality of treatment options and care pathways, as research explores innovative interventions and solutions.
- Increased investment in the field, drawing attention and resources from medical and research communities, which could lead to groundbreaking discoveries.
- Increased cross-disciplinary collaboration through funding, such as a National Centre of Excellence, fostering partnerships between clinicians, researchers, and organisations, accelerating the pace of innovation.
- Enhanced quality of life for individuals with tic disorders, as evidence-based treatments improve symptom management and functional outcomes.

> ***"TS is still such a misunderstood condition and I would like to see more research undertaken."***
>
> ***- Adult with Tics***

# DIAGNOSIS

Tic disorders are a group of neurological conditions characterised by tics. Diagnosis is primarily clinical, based on the frequency, duration, and type of tics (APA, 2022). To be classified as a chronic tic disorder or Tourette's, the tics must occur for at least a year and must not be caused by other medical conditions. The diagnosis is often made by a healthcare professional such as a neurologist, psychiatrist, or paediatrician, who will evaluate the patient's medical history, conduct a physical examination, and assess the patterns of tics. Diagnosing tic disorders can be complex, as tics often fluctuate in both frequency and severity, sometimes improving and at other times worsening. This variability can make it challenging to fully capture the scope of the disorder during a single clinical visit. Despite these challenges, early and accurate diagnosis is critical for determining the most effective treatment and support for individuals with tic disorders.

Adding to the complexity of diagnosis is the high prevalence of co-occurring neurodevelopmental and neuropsychiatric conditions (Eapen et al., 2016; Hirschtritt et al., 2015). Attention deficit hyperactivity disorder (ADHD) is present in about 3 in every 4 individuals with a tic disorder, and obsessive-compulsive disorder (OCD) affects approximately 1 in every 2. Other common co-occurring conditions include learning difficulties (e.g., dyslexia, dysgraphia), autism spectrum disorder (ASD), anxiety, mood disorders, and behavioural conditions (e.g., oppositional defiant disorder, conduct disorder, rage attacks) (Eapen & Črnčec, 2009). The presence of co-occurring conditions can complicate the diagnosis, as clinicians must distinguish between symptoms that are primary to the tic disorder versus those stemming from coexisting conditions. For further information on the diagnostic process and the complexities involved, readers are encouraged to refer to Robertson et al. (2017).

A significant challenge in assessing and diagnosing tic disorders in Australia is the limited access to and availability of specialised professionals, making it difficult for people to access timely care (O'Hare et al., 2016). Clinicians may use varying approaches, assessments, or criteria to diagnose tic disorders, leading to disparities in how symptoms are evaluated and managed. This inconsistency can be frustrating for patients and their families, as it may result in delays in diagnosis, misdiagnosis, or the adoption of a treatment plan that is not well-suited to the patient's specific needs.

In the Impact for Tourette's survey, respondents answered questions in relation to age tics first appeared, age help was sought, age of diagnosis and family history of tic conditions. Questions were also asked in relation to the type of tic condition diagnosed, the specialty of the diagnosing professional, what intervention and therapies were recommended at diagnosis, and a rating of how positive the experience had been obtaining a diagnosis. Co-occurring conditions diagnosed and suspected, were also captured and reported. Results reported in this section include only data on caregivers reporting on their child and adults with tics (n=189). The data from caregivers reporting on an adult with tics has been excluded from this section to ensure individuals are not represented twice (i.e., adult reporting on themselves and as caregiver).

## Survey Findings

The average age of tic onset in children was 6.1 years of age (standard deviation ±3.1 years). The average age caregivers first sought help for their child's tics was 7.7 years. The average age of diagnosis was 8.9 years. The time between seeking help and obtaining a diagnosis varied, with 41% of children diagnosed within 12 months of seeking help, 33% diagnosed within 1-2 years, and 26% diagnosed after 2 years.

The average age of tic onset in adults was more variable (11.4 years + 8.6 years). 48% of adults reported initial tic onset during childhood (<10 years), 39% reported tic onset during adolescence (10-19 years), and 13% reported tic onset during adulthood (>20 years). Time between seeking help and diagnosis within the adult sample was largely dependent on the age of tic onset. Most adults with tic onset during childhood or during adulthood were diagnosed within 12 months of seeking help, but those with tic onset during adolescence were more likely to wait longer, with only one in four receiving a diagnosis within 12 months.

## Tic Disorder Diagnosis

88% of the sample had received a tic disorder diagnosis from a medical professional, with more children (96%) diagnosed than adults (76%). Those not diagnosed (8%), were either currently waiting to see a medical professional, had been dismissed by medical professionals without receiving an official diagnosis, reported challenges obtaining a diagnosis because onset had occurred in adulthood, were unable to afford the cost, were not sure how to obtain a diagnosis, along with perceived lack of benefit obtaining a formal diagnosis. There was also a small number of respondents who were unsure if they had received a diagnosis from a medical professional (4%).

Tourette syndrome was the most diagnosed tic disorder (Table 1). This was consistent amongst children in the sample (92%), adults with childhood onset of tics (onset <18 yrs, 85%), and adults experiencing onset of tics during adulthood (24%).

| Diagnosed tic condition | Child N = 112 | Adult, onset <18 yrs N = 60 | Adult, onset >18 yrs N = 17 | Overall N = 189 |
|---|---|---|---|---|
| Tourette syndrome | 103 (92%) | 51 (85%) | 4 (24%) | 158 (84%) |
| Chronic/persistent motor tic syndrome | 11 (9.8%) | 2 (3.3%) | 1 (5.9%) | 14 (7.4%) |
| Chronic/persistent vocal tic syndrome | 8 (7.1%) | 0 (0%) | 0 (0%) | 8 (4.2%) |
| Provisional tic disorder | 2 (1.8%) | 0 (0%) | 0 (0%) | 2 (1.1%) |

***Table 1. Type of tic disorder diagnosed within the sample***
*Note: Multiple diagnoses are presented in this table.*

> *"It was such a run around... I wish they tried helping me from day one of seeking help. It took well over a year for any treatment recommendations from my neurologists and I kept being told my tics were from anxiety and stress."*
>
> – Adult with Tics

> *"It took three years to diagnose Tourette's [ for my child ]. Symptoms were all there. Being given information and referrals to support groups or therapists that are experts would have helped."*
>
> – Child Caregiver

## Diagnosing Professional

Diagnosticians varied depending on age (Figure 5). Most children were diagnosed by a paediatrician (43%) or paediatric neurologist (36%). Most adults, particularly those with either adolescent or adult onset of tics, were diagnosed by a neurologist (53%) or psychiatrist (15%).

A proportion of respondents (16% of children, 21% of adults) reported needing to travel outside their city or state to see a medical professional to receive their diagnosis.

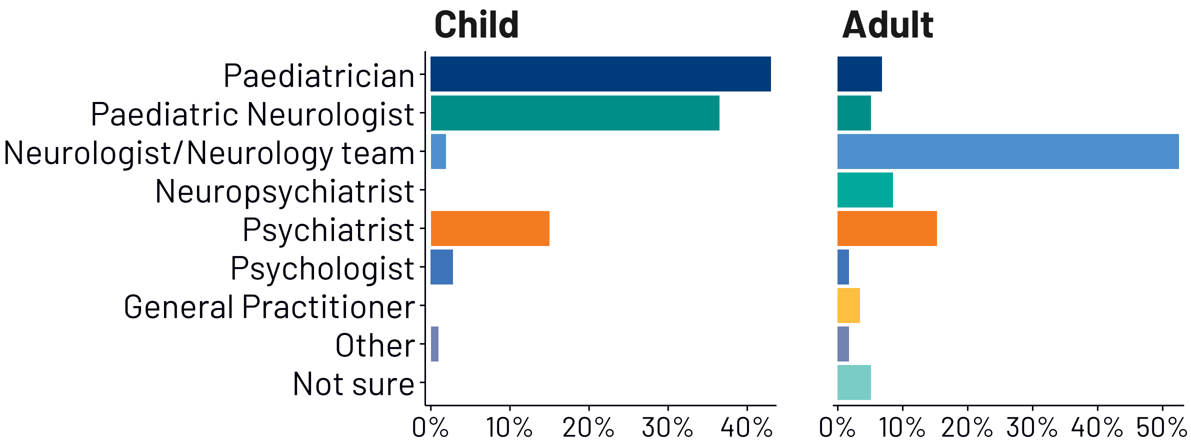

***Figure 5. Type of diagnostician by respondent type (caregiver of child or adult)***

*"The medical professionals said he was 'just putting it on' and didn't acknowledge the video evidence, and said 'oh but he's not doing any of that now'!"*

– Child Caregiver

*"A neurologist told me that since my tics aren't disrupting my life, there's no sense in getting a diagnosis and that my tics are probably because of anxiety."*

– Adult with Tics

*"There was very limited information given. No support or suggestions around therapies, management options or supports."*

– Child Caregiver

*"I was given a 2-page print out from Google and told to support the symptoms. The problem is, the symptoms were 15+ tics at a time and no support to draw on and no connection with anyone."*

– Child Caregiver

*"I would have liked to receive information about what the condition was, what the likely progress of the condition was, information about support groups to join. I would have like to not be the one to bring the DSM 5 diagnostic criteria to the doctor to beg for a diagnosis of TS."*

– Adult with Tics

A form of treatment was recommended at diagnosis for 61% of respondents (Figure 6). These recommendations included: prescribed medication (41%), psychological intervention (30%), allied health services (i.e., occupational therapy, physiotherapy, 14%), and alternative medication/therapy (i.e., supplements, 9%). Other recommendations included botox treatment (for musculoskeletal-related issues), sensory tools (e.g., stress balls), and exercise.

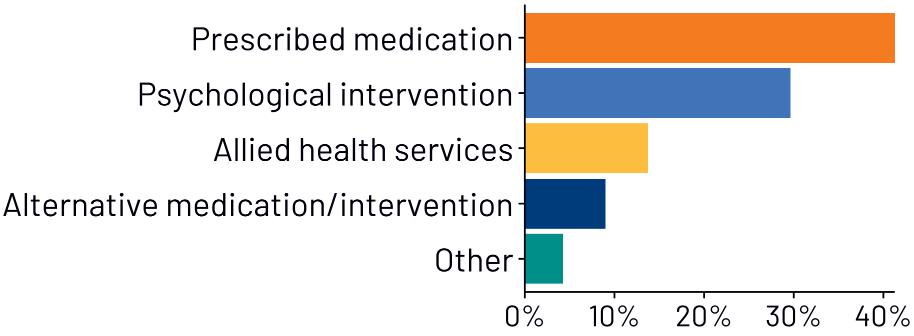

*Figure 6. Treatment recommended at diagnosis*

Respondents were asked to rate their experience of diagnosis on a 5-point Likert scale from extremely negative to extremely positive (Figure 7). A total of 39% of respondents reported that diagnosis of their tic disorder was either a somewhat or extremely positive experience, 27% reported that it was neither positive or negative (neutral), and 24% reported that it was a somewhat or extremely negative experience.

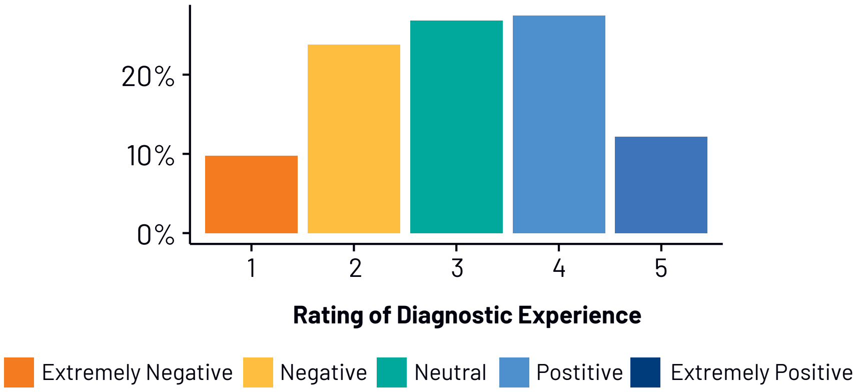

*Figure 7. Rating of diagnostic experience*

Negative diagnostic experiences were also highlighted in the **Healthcare Services Interviews**, with young people and their caregivers reporting challenges obtaining a diagnosis and difficulty navigating care pathways following diagnosis. In many cases, no information was provided by healthcare professionals following a diagnosis regarding appropriate therapies, local specialists, advocacy groups, or community programs. This left caregivers directionless and isolated, with appropriate resources only being identified through independent research, word of mouth, or chance.

> *"I remember when all my tics started. [The GP] told me to just try and be calm...that my tics were just anxiety and to listen to music, be calm, and do meditation."*
>
> – Child with Tics

> *“I think he was about nine or ten when they formally labelled it as Tourette's. But there was no sitting down at that point to say this is what Tourette's means, this is [the] information...there's an association you can seek advice from. There was none of that.”*
>
> – Child Caregiver

> *“I don't know how we would have got through this without the information we have accessed through the TSAA.”*
>
> – Child Caregiver

## Post-Diagnosis Sources of Information & Support

Respondents were asked what the sources of information and support they found helpful following diagnosis. The information and resources provided by the Tourette Syndrome Association of Australia (TSAA) online was the most frequently endorsed source of information. In addition to TSAA’s website, several respondents highlighted TSAA’s online support groups, tic camps, community meetings and online conference. Forty-nine percent of respondents specifically mentioned the value of TSAA resources and activities following diagnosis, highlighting the key role this organisation plays supporting people and families following diagnosis.

Other sources of information and support described by respondents included international organisations (Tourette’s Action UK, Tourette’s Association of America), Australian healthcare providers (The Children’s Hospital at Westmead, Sydney, The Royal Children’s Hospital’s tic clinic, Melbourne), scientific articles, books, podcasts, YouTube, TikTok, and lived experience from other people with tic conditions within the community.

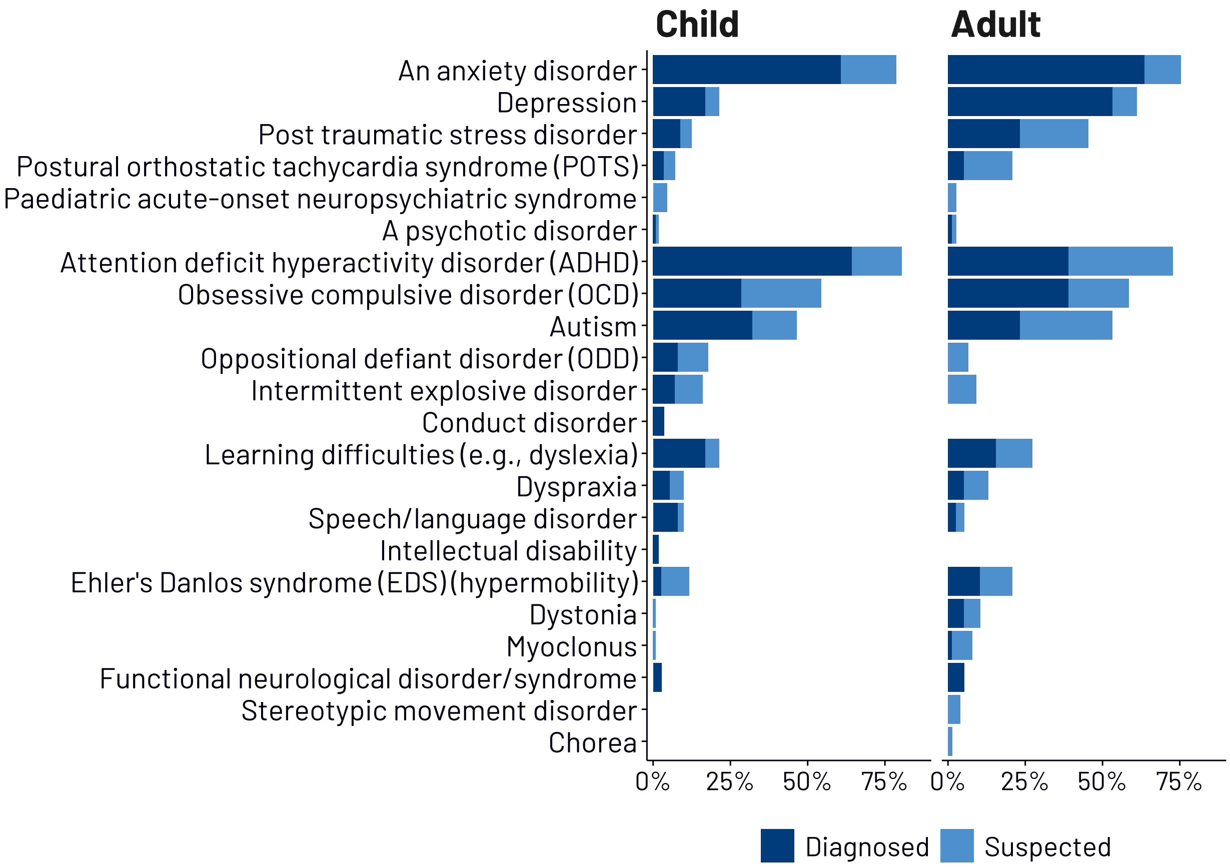

*Figure 8. Diagnosed and suspected co-occurring conditions*

## Co-occurring Conditions

Respondents were asked if they/their child was diagnosed (or suspected) with other neurodevelopmental disorders, obsessive compulsive disorder, depressive and anxiety disorders, personality disorders, and other medical conditions. The percentage of sample reporting a diagnosis or suspected diagnosis of co-occurring conditions is shown in Figure 8.

The most frequently reported co-occurring condition was an anxiety disorder, with 65% of the entire sample reporting a diagnosis and a further 14% suspecting. Other common co-occurring conditions were ADHD (59% diagnosed, 21% suspected), OCD (37% diagnosed, 23% suspected), depression (32% diagnosed, 5.5% suspected), and autism (29% diagnosed, 19% suspected).

About half (56% of adults, 54% of child caregivers) reported experiencing challenges seeking a diagnosis for these co-occurring conditions. The biggest challenge reported was difficulty getting general medical professionals to believe they had symptoms warranting specialist investigation for another condition. Other challenges included limited availability of specialists, specialists not accepting referrals due to the complexity of presentation (e.g., being a specialist in one area but not another), and cost.

> ***“The coordination between conditions is not understood or addressed by specialists. They only seem to specialise in one area.”***
>
> – Child Caregiver

> ***“There is no psychiatrist willing to see me for [an] adult ADHD assessment. Most only see children, don't take new patients or just reject my referrals.”***
>
> – Adult with Tics

# Diagnosis Recommendations

Respondents were asked what recommendations they would make to improve the diagnostic experience for tic disorders.

The **Top 5** most frequent responses included:

1. Increased recognition of tics by general medical professionals – not dismissing patients when tics are not present during medical consultation, or assume they are likely to resolve.
2. Increased knowledge of tic disorders by general medical professionals – know what tic disorders are, the diagnostic process, treatment/therapies, common co-occurring conditions.
3. Access to more specialist medical professionals – more specialists available to diagnose tic disorders and reduce wait times.
4. Specialist medical professionals providing patients with post-diagnosis information and supports – more information to be provided on how manage day-to-day life, treatments options, potential trajectories over time, what supports exist.
5. Increased time during medical consultations – to provide patients with the information and support they need to navigate life after diagnosis.

*"I think in an ideal world, we would have had some sort of opportunity to sit down after getting a diagnosis... Whether it's with the person making the diagnosis or someone from that team. Just someone to give you some more information about what it actually means."*

– Child Caregiver

*"It would have been helpful to be guided to resources or community groups."*

- Adult with Tics

*"In an ideal world there would be...a list of all the specialists that you can contact. I just feel like they're hidden, you know, like a needle in a haystack."*

– Child Caregiver

*"There needs to be more information and services available. I just got told, 'you have Tourette's syndrome, see you later'."*

– Adult with Tics

# FUNCTIONING

Tics can profoundly affect a person's life, influencing many areas of daily living. Their involuntary nature makes even simple tasks difficult, from social interactions to maintaining focus at school or work and managing physical activities (Conolea et al., 2013; Eapen et al., 2016). In structured settings, tics can disrupt concentration and productivity, adding unnecessary stress to already demanding situations. At home, tics impact the ability to perform routine activities, such as dressing, cooking, watching television, and even relaxing or engaging with family. They can disrupt sleep, further affecting quality of life.

Tics also pose a significant physical risk through injury and discomfort. Discomfort can be experienced as a direct consequence of the physical effort involved in motor tics, with muscle soreness, joint pain, and cramping being commonly experienced issues. Complex tics that involve self-injurious behaviour such as touching a hot stove or cutting oneself with sharp objects are also risk factors for physical discomfort, pain, and injury.

Respondents in the Impact for Tourette's survey were asked about both the frequency and severity of tics, comparing effects on a "best day" versus "worst day". Respondents were also asked to describe how their tics have changed over time. To explore the everyday impact of tics, respondents rated how their tics affected common tasks and activities; this list was developed through consultation with lived experience community members. Questions also asked about any physical pain or injuries sustained from their tics.

## Severity of Tics

Most respondents (89% of children, 79% of adults) currently experienced tics every day (see Table 2. Tic free intervals were reported between either 5 to 10 minutes (47% of children, 28% of adults) or up to 30 minutes at most (19% of children, 30% of adults).

| Current frequency that tics are experienced | Child<br>N = 101 | Adult<br>N = 67 | Overall<br>N = 168 |
|---|---|---|---|
| Everyday - tics present with tic free intervals 5 to 10 minutes at most | 47 (47%) | 19 (28%) | 66 (39%) |
| Everyday - tics present with tic free intervals up to 30 minutes | 19 (19%) | 20 (30%) | 39 (23%) |
| Everyday - tics present with tic free intervals as long as 3 hours not uncommon | 12 (12%) | 7 (10%) | 19 (11%) |
| Everyday - tics with long tic free intervals during the day | 12 (12%) | 7 (10%) | 19 (11%) |
| Fluctuating/waxing-waning (tics come and go with tic free periods days or weeks in between) | 5 (5.0%) | 8 (12%) | 13 (7.7%) |
| Other | 6 (5.9%) | 6 (9.0%) | 12 (7.1%) |

*Table 2. Frequency of tics experienced*

The Motor Tic, Obsessions and Compulsions, Vocal Tic Evaluation Survey (MOVES, Gaffney et al., 1994) was used to assess the severity of tics during mild (best day – when tics are at their minimum) and peak (worst day – when tics are at their maximum) tic periods, along with other co-occurring symptoms. This 20-item questionnaire is completed using a four-point Likert scale (0 = never, 1 = sometimes, 2 = often, 3 = always). The mean scores for both the best and worst days across the MOVES items are presented in Figure 9. On a 'worst day', 81% reported experienced parts of their body jerking either often or always, 81% experienced movements occurring when nervous, 78.5% made noises that could not be stopped, 73% made movements they could not control, and 71% experienced the same jerk or twitch over and over. While many of these were less severe on a good day, there were other tics with little variation in severity between a best and worst day. For example, a vocal tic like words coming out that cannot be stopped or controlled ranged from 43% 'often or always' on a best day and 49% on a worst day.

## Changes Over Time

Respondents were also asked to describe how their tics have changed over time. While 42% of children and 45% of adults reported that the frequency and/or severity of their tics had increased with age, a smaller proportion (12% of children, 16% of adults) reported that their tics decreased with age.

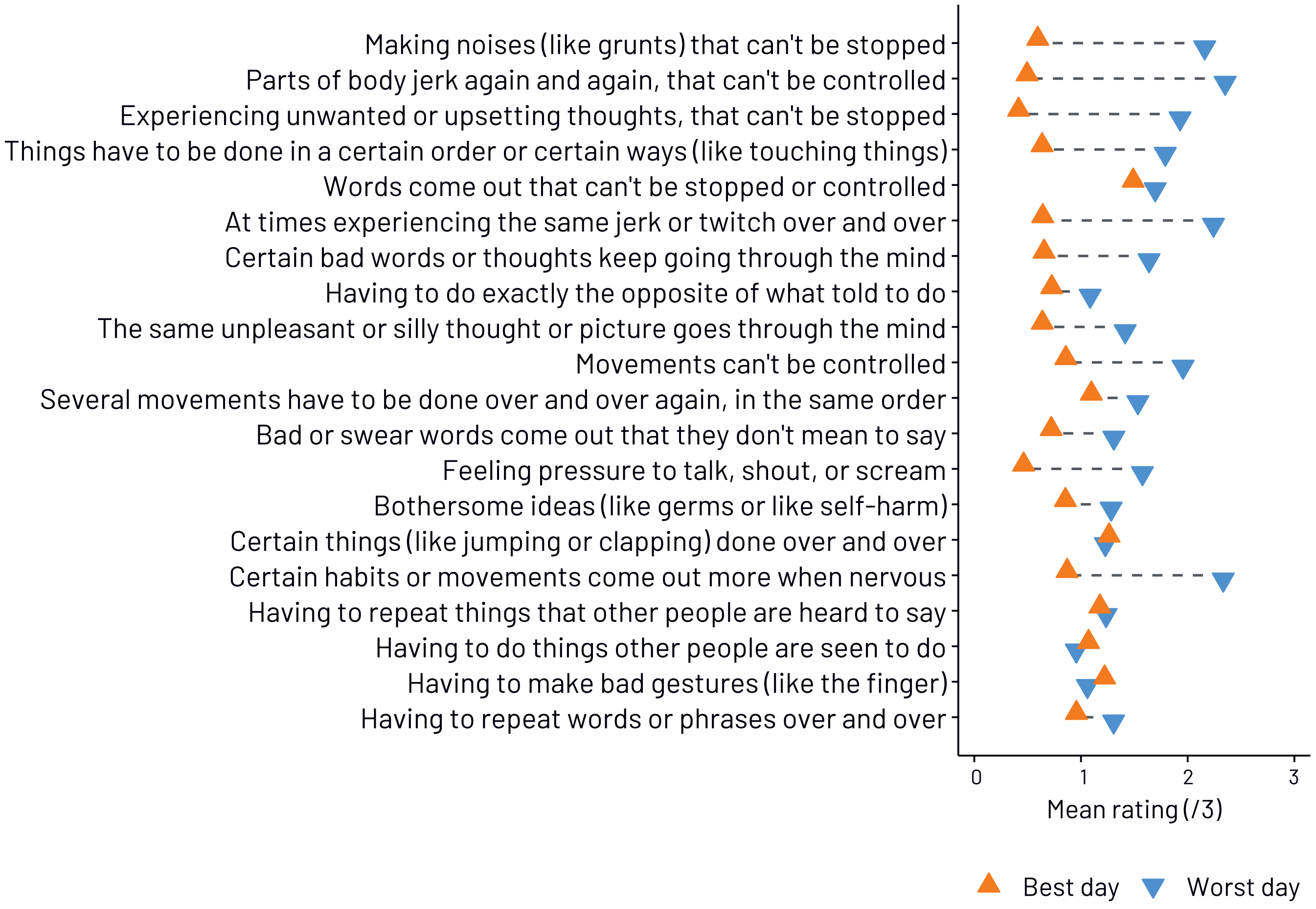

*Figure 9. MOVES data showing the severity of best and worst days*

*"[My tics] wax and wane over time, but they have definitely gotten worse as I've gotten older. They are constant, some days are worse than others."*

– Adult with Tics

*"The tics have progressively improved since diagnosis but [are] exacerbated in period of high stress, tiredness or emotion."*

– Child Caregiver

*"The vocal and motor tics are forever changing and adapting. They can be long- or short-term tics that come and go."*

– Child Caregiver

*"When first diagnosed, the tics were quite 'mild'... As we have moved through puberty, we have had a massive increase in all tics to the extent where he drops to the floor and looks like he's having a seizure, yelling out socially inappropriate content, hitting himself and sometimes others."*

– Child Caregiver

*"They started out quite based on vocal tics, now they are mostly physical. There was a major spike in severity in my late teens/early 20s where it affected my basic functioning such as speaking and walking."*

– Adult with Tics

Many children (46%) and adults (39%) reported no clear pattern in the presentation of their tics, sometimes experiencing frequent and complex tics and other times, milder and simpler tics, with no distinct trend in presentation over time.

## Impact on Daily Living

When asked to rate the overall impact of tics on daily living, 72% of child caregivers and 63% of adults reported tics having a moderate to extreme impact on day-to-day activities.

The impact of tics across specific day-to-day activities is presented in Figure 10. Caregivers of children reported that their child most often or always experienced difficulties with concentration (69%), paying attention (62%), and learning (60%). Adults also self-reported difficulty in paying attention (61%) and concentrating (58%). Close to half of caregivers of children and adult respondents reporting that relaxing at home (child 53%, adult 58%), going to sleep (child 57%, adult 49%), and sleep quality (child 57%, adult 44%) were either often or always impacted.

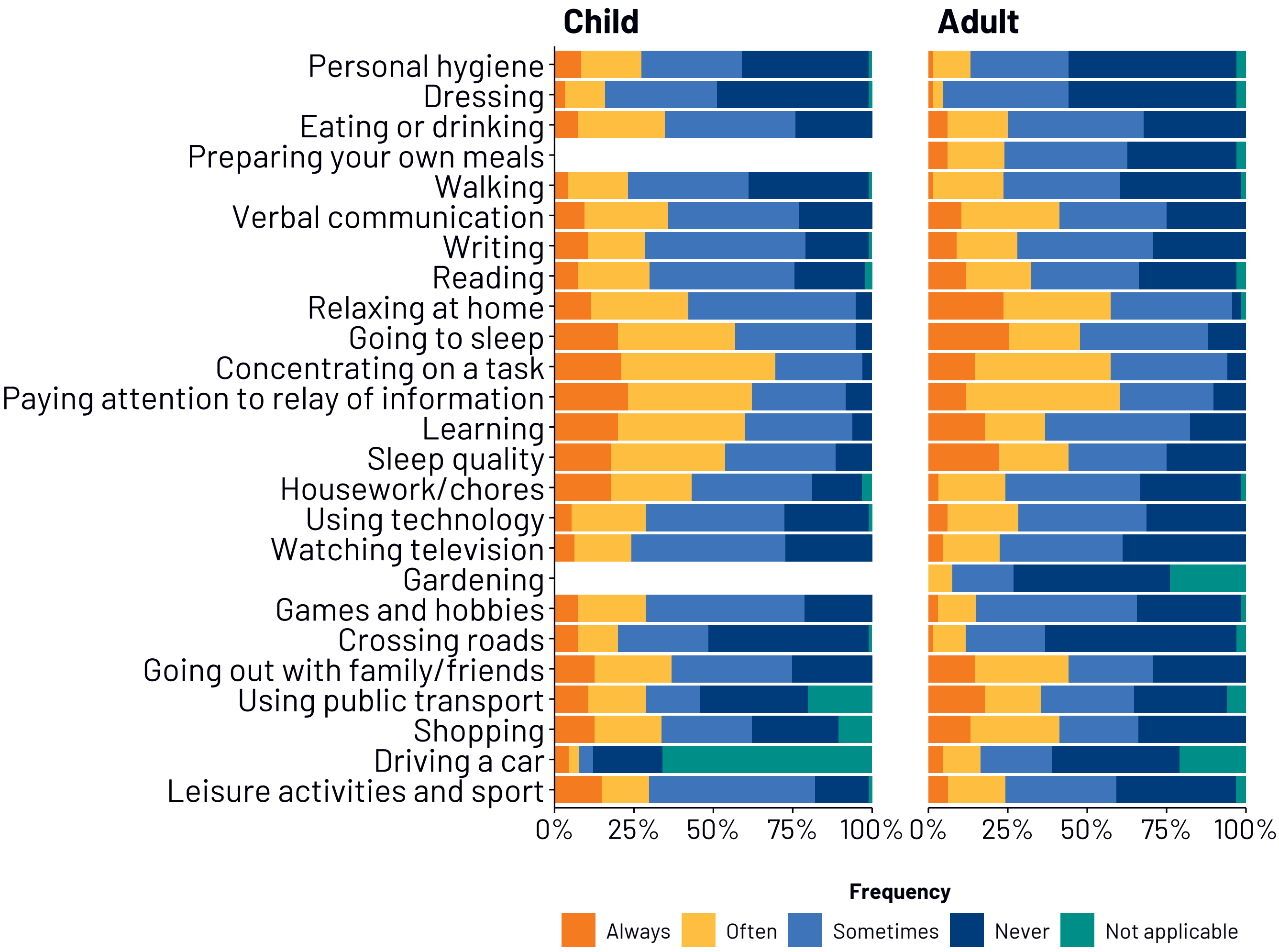

*Figure 10. Impact of tics on day-to-day activities*

> *“[Pain] limits my ability to be as fit and active as I'd like. I'm used to the pain, but it is intrusive and exhausting.”*
>
> – Adult with Tics

> *“Some of his more complex tics have caused physical discomfort, affecting his overall wellbeing and ability to engage in daily activities."*
>
> – Child Caregiver

> *“Pain stops my daughter from doing most things she enjoys. Her body is so deconditioned from lack of exercise and movement that this causes her more pain. She often feels like everything is hopeless and she doesn't want to go through this anymore.”*
>
> – Child Caregiver

## Pain and Injury

A large majority of respondents (85% of child caregivers, 86% of adults) reported that physical pain had been experienced as a direct result from tics. The types of tics that most frequently caused pain included head jerking or banging (59%), facial tics (51%), and shoulder shrugs (40%); Figure 11.

In open-text responses, when asked about the impacts that tic related pain has on their lives, both child caregivers (24%) and adult respondents (35%) reported that the most common issues were in enjoying activities of daily life due to fatigue, soreness, and injury-related anxiety.

Some (15% of child caregivers and 19% of adult respondents) indicated that tics caused persistent issues with pain, including muscle fatigue, sprains, and headaches.

Persistent, unrelenting pain caused frustration and overwhelm in 13% of children with tics.

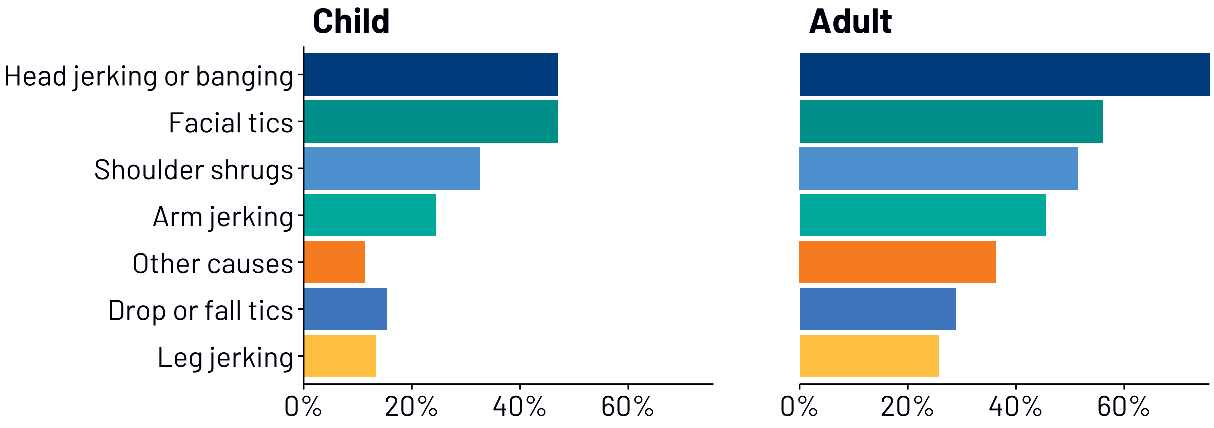

*Figure 11. Types of tics that cause pain*

> ***“He is constantly in pain somewhere each day. His head is sore, mainly the top part [ of ] his neck and shoulder joints, and head if he has been hitting his forehead really hard and repetitively. It's been the hardest thing to see my child go through.”***
>
> – Child Caregiver

> ***“Injuring and re-injuring is consistent throughout life which becomes very physically and mentally draining on top of the usual challenges of everyday living.”***
>
> – Adult with Tics

About two-thirds (68% child caregivers, 68% adults) of respondents reported that injuries had been incurred from tics. Pulled muscles were the most reported, followed by sprains, and whiplash (Figure 12). Other injuries included bruises, abrasions, cuts, headaches, and concussion.

Pain medication was regularly used by 31% of children and 34% of adults for pain associated with their tics.

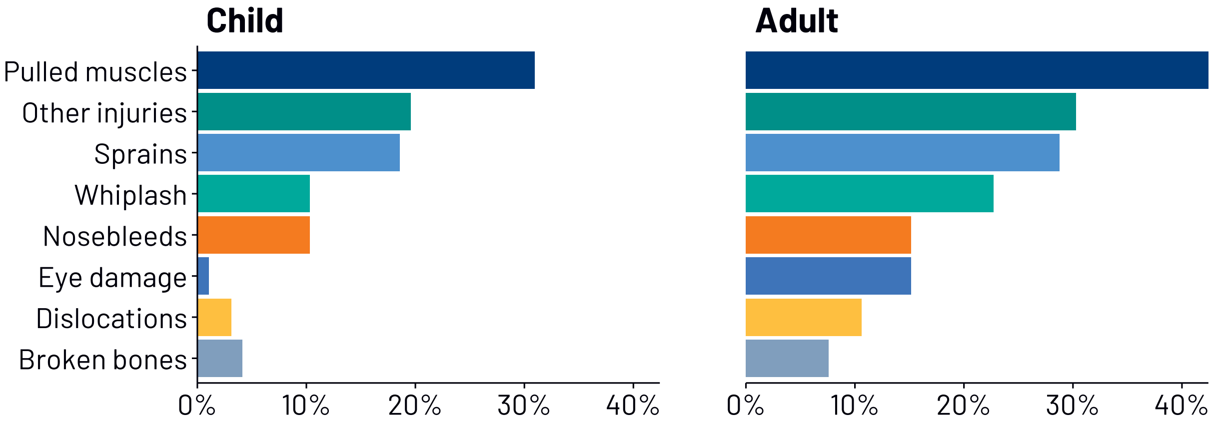

*Figure 12. Types of injuries*

> ***“It makes him cry with exhaustion and exasperation. All he wants is a break from it.”***
>
> – Child Caregiver

> ***“[ My child ] can get quite upset at the pain and not being able to stop themselves from further injury, even though they want to stop it.”***
>
> – Child Caregiver

# INTERVENTION

There are currently no national standards or clinical practice guidelines outlining recommended therapies or interventions following the diagnosis of a tic disorder. Further, the pathways for accessing or obtaining funding support for therapies and interventions are not standardised nor clear. This has left many individuals to navigate complex public health systems in isolation, often without guidance from the healthcare professional who provided their diagnosis. Fatigue in navigating such systems has forced many individuals with tic conditions to access services and interventions through the private health system, often at great personal financial expense.

Accessing services and intervention through the private healthcare system is also a challenge, especially for those living outside well-resourced areas. There is a dearth of Australian healthcare professionals who specialise in the treatment of tic conditions, with great disparity observed not only between rural and urban areas, but states and cities as well.

When available and accessed, treatments for tic disorders typically include prescribed medications, over the counter or alternative therapies, and psychological intervention. Prescribed medications are primarily aimed at reducing tic frequency and intensity, but they often come with the trade-off of increased side effects (e.g., drowsiness, fatigue, weight gain, changes in mood, depression). Alternative medications and therapies are also commonly sought to manage both tics and their secondary effects. Psychological intervention aims to improve control of tics while reducing their frequency and severity, and the negative emotions that can surround them.

Respondents were asked about access to prescribed medications, over the counter or alternative therapies, and psychological intervention. In addition, respondents were asked to rate how effective these therapies and interventions have been in reducing tics, along with side effects associated with medication use.

## Accessibility

Most respondents (88% of child caregivers, 75% of adult) sought or had accessed services or intervention for their tics. Over a third (39%) of child caregivers reported a delay between seeking and accessing services or intervention of between 6-12 months. Adult respondents, however, typically experienced a shorter delay between seeking and accessing services of less than 6 months (38%). Time to access intervention is presented in Figure 13.

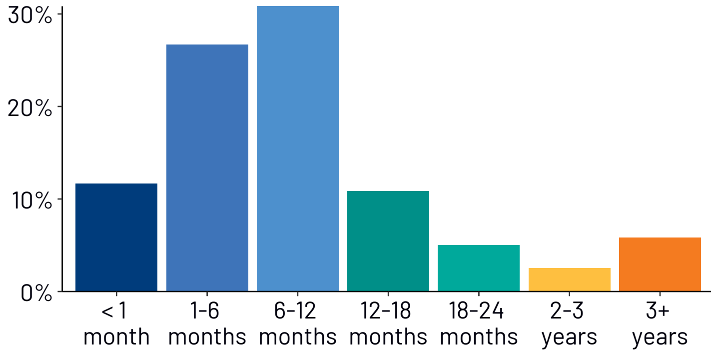

*Figure 13. Time to access intervention*

For those that had not accessed services or interventions (12% child caregivers, 25% adults), child caregivers reported issues in availability (50%), low awareness of services (30%), and the high associated costs (30%). Adult respondents, however, described a lack of perceived benefits associated with intervention (33%). Adult respondents also reported apprehension due to the side effects of medication (20%) and having other priorities getting in the way (20%).

One in four children and more than half of adults (58%) had accessed services or interventions through telehealth (i.e., phone or online consultations). Additionally, one in five individuals have travelled outside their city or state to access services or intervention.

## Prescribed Medications

64% of children and 58% of adults had been prescribed medication for reducing tics or symptoms that exacerbate tics. Clonidine (i.e., Catapres) was the most commonly accessed prescription medication. 29% of children and 18% of adults reported current use of Clonidine, with 23% and 38% having accessed it previously. Other commonly accessed prescription medications are listed in Figure 14.

57% of children and 65% of adults' tics were either not controlled or minimally controlled by prescribed medications (Figure 15). Only 11% of child caregivers and 17% of adult respondents felt tics were adequately or well controlled by prescription medications.

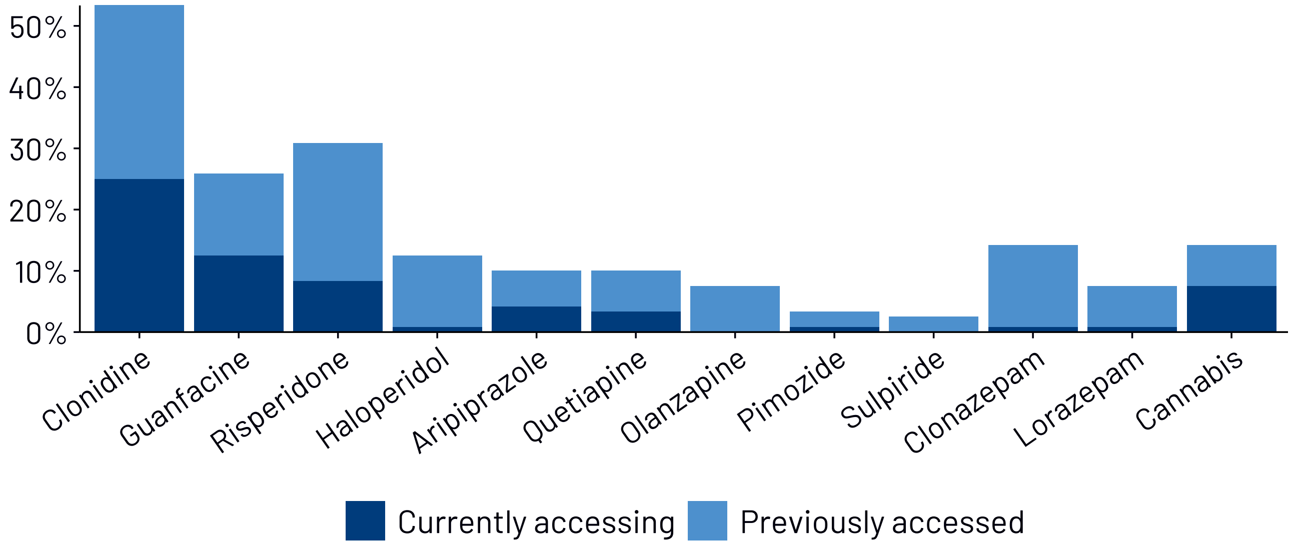

*Figure 14. Prescribed medications currently and previously accessed*

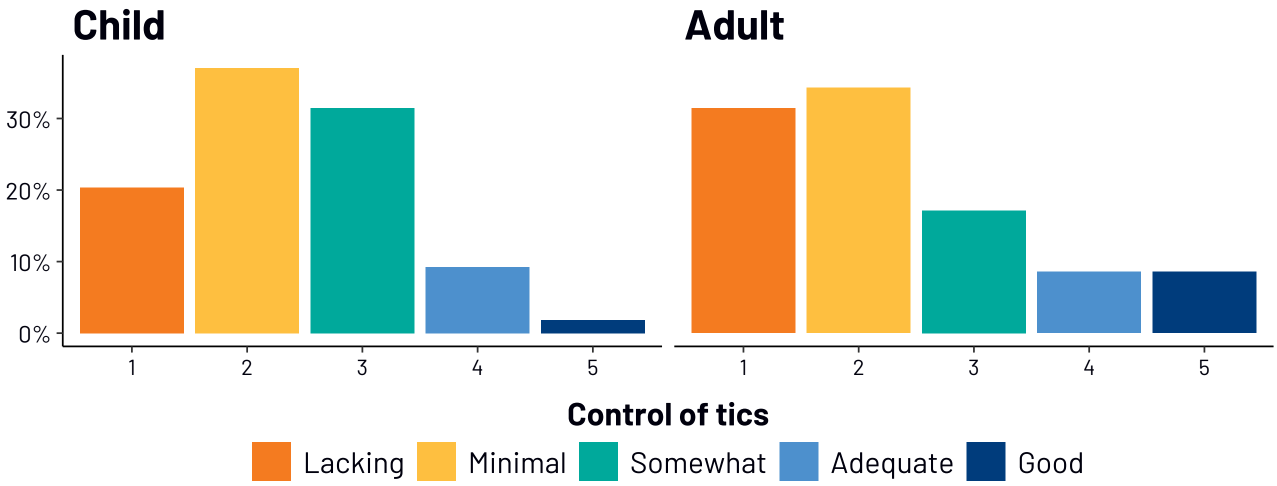

*Figure 15. Perceived effectiveness of prescribed medication on tics*

Child caregivers (51%) and adult respondents (67%) reported tiredness as the most commonly experienced side effect. Other commonly experienced side effects are listed in Figure 16. All were experienced at higher rates by adults than children.

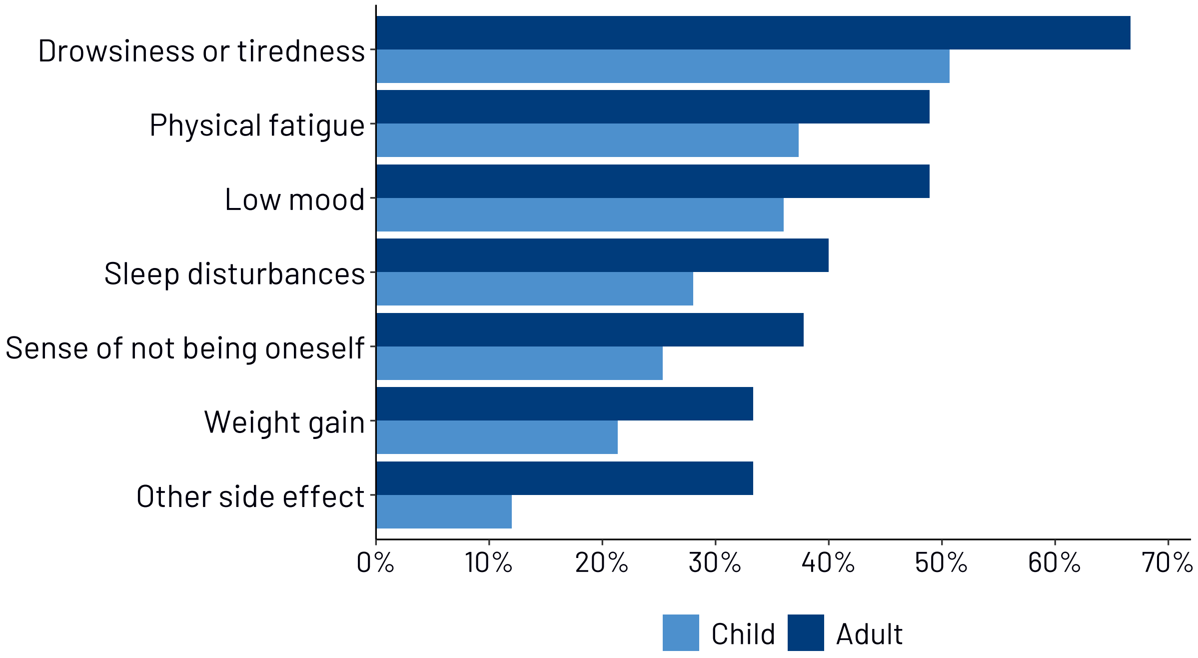

*Figure 16. Frequency of side effects from prescribed medication*

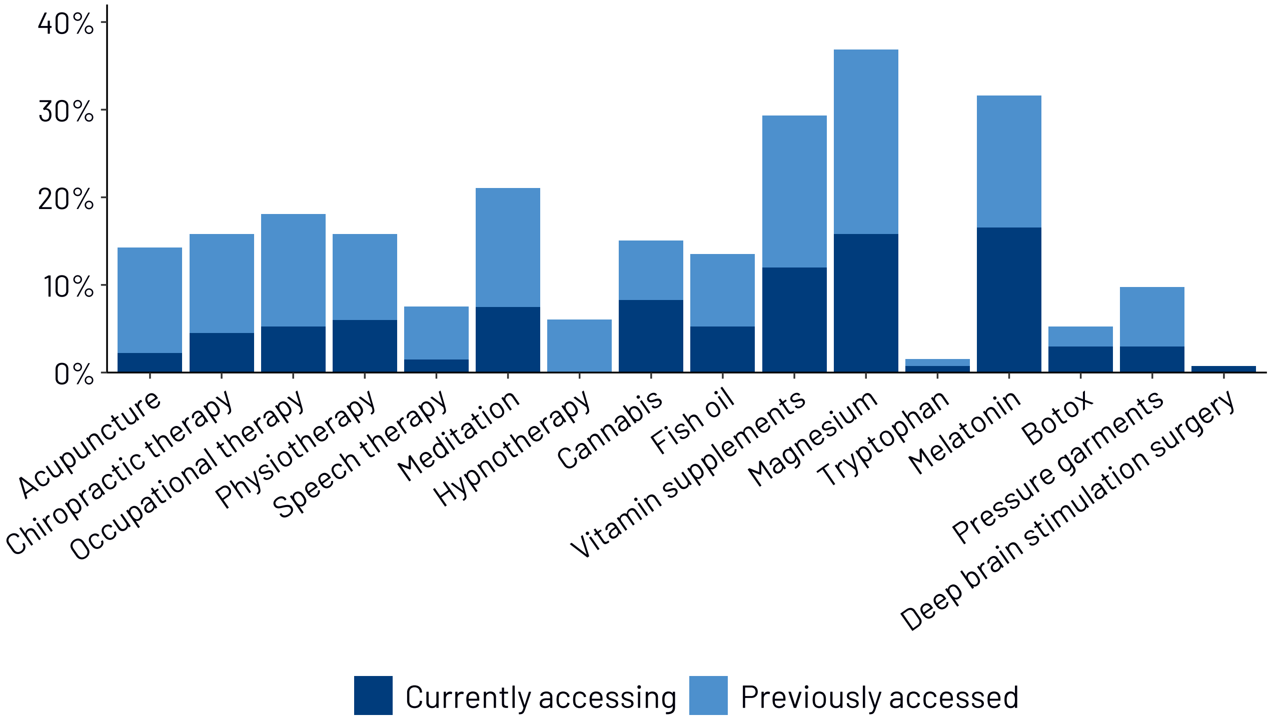

*Figure 17. Other treatments currently and previously accessed*

## Unprescribed Medications and Alternative Supplements, Treatments or Therapies

Unprescribed (i.e., over the counter) medications and alternative supplements, treatments, or therapies had been accessed by 46% of child caregivers and 48% of adult respondents. Of these, magnesium, melatonin, and broader vitamin supplements were the most reported. Current and previous access to other supplements, treatments and therapies is presented in Figure 17.

On average, other supplements, treatments, or therapies were reported to not control or only minimally control tics in 79% of children and 41% of adults (Figure 18). Adult respondents reported greater success with non-prescription medication, with 58% reporting their tics being somewhat to well controlled.

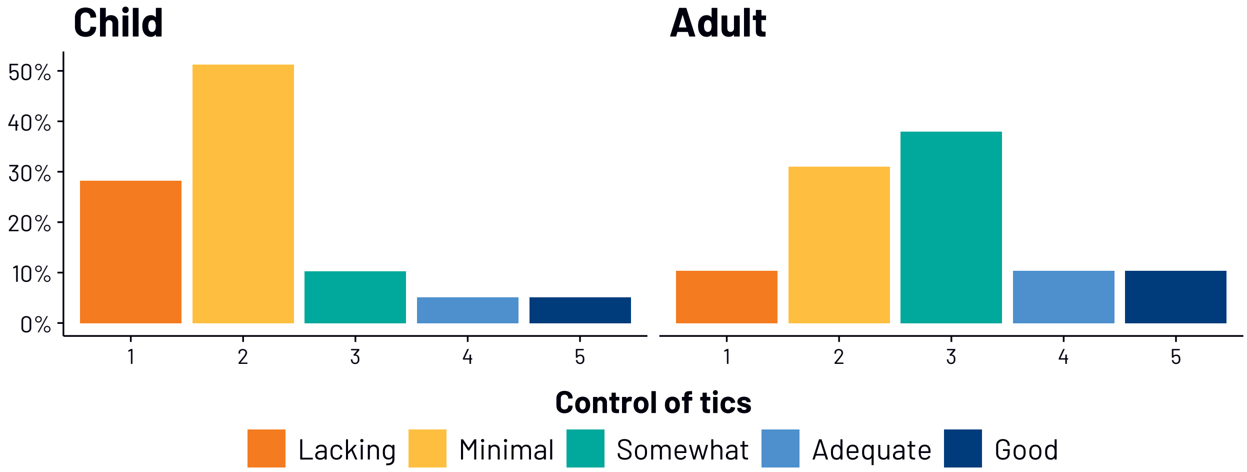

*Figure 18. Perceived effectiveness of other medical treatment on tics*

## Psychological Intervention

Psychological intervention had been accessed by 78% of children and 58% of adults. Whilst most people accessing psychological intervention were receiving therapy targeting symptoms associated with tics (i.e., stress, anxiety), tic-specific manualised approaches (e.g., CBIT), had been accessed by one in five people.

Psychological intervention was reported to have little or no effect on tic control in 80% of children and 77% of adults (Figure 19). However, this response was made for all forms of psychological intervention, both those targeting emotional symptoms associated with tic disorders and those specifically aimed at managing tics.

Open-ended responses indicated slightly more positive perspectives for those receiving tic-specific psychological intervention, with some challenges additionally highlighted relating to the complexity of suppression.

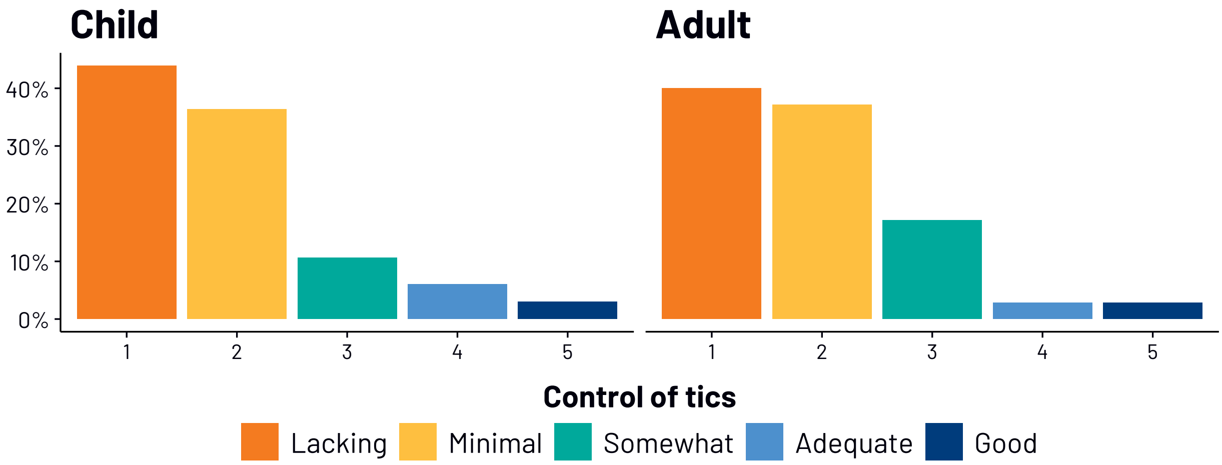

*Figure 19. Perceived effectiveness of psychological intervention on tics*

> *"The use of CBIT with a clinical psychologist has been extremely effective for my son in treating the tics that he has identified as the most troublesome for him."*
>
> – Caregiver respondent

> *"CBIT was good at being able to teach myself how to change specific tics, but it's tricky and not always possible."*
>
> – Adult respondent

> ***“I think one of the first issues was that a lot of those psychologists don’t actually have any practical knowledge or experience around Tourette’s. So, I kind of got the feeling at times that they were not really incorporating that into their treatment.”***
>
> - Adult with Tics

> ***“Being told to stop doing [my tic], that's not a useful strategy... You're telling someone to just stop something without telling them how to stop it or giving them stepping stones in working up to kind of blocking it out and things it was not helpful.”***
>
> - Adult with Tics

In **Health Experience Interviews**, many reported that psychologists and mental health professionals exhibited a general lack of knowledge about tics and tic conditions. Many felt that psychologists and mental health professionals were ill-equipped to incorporate appropriate tic-management strategies into their sessions.

When asked to rate their overall experience accessing interventions for tics, 32% of child caregivers and 49% of adult respondents reported that their overall experience of accessing services or intervention for tics as somewhat or extremely negative. Ratings of overall experiences are presented in Figure 20.

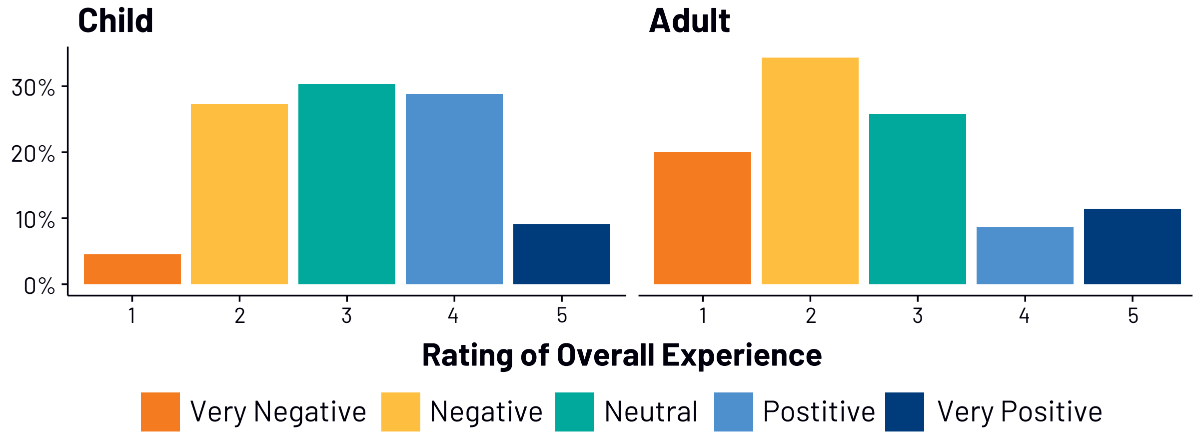

*Figure 20. Rating of overall experience accessing intervention for tics*

# Intervention Recommendations

Respondents were asked what recommendations they would like to make to improve people's experiences accessing interventions.

The **Top 5** most frequent responses included:

1. Access to more specialist healthcare professionals – ensuring easier access to interventions, particularly for adults and individuals living in rural areas.
2. Enhanced knowledge of tic disorders by medical and allied health professionals – to provide better information and support on available treatment and therapies, effectiveness and side effects.
3. Increased funding availability – financial support to ensure access to interventions and supports.
4. Stronger collaboration among healthcare professionals and the establishment of more tic clinics – promoting cooperation across specialties to improve patient care and treatment outcomes.
5. Broader access to treatment options – to expand the variety of available treatments and therapies.

***"There doesn't seem to be a clear medical field dedicated to supporting people with tics and to access this easily. We have tried to get our daughter medication and health practitioners have given her things for anxiety etc, but nothing specifically to stop the tics."***

– Child Caregiver

***"Tic clinics with centralised supports need to be created so practitioners can work together."***

– Child Caregiver

***"Have a centralised support system so that medical professionals can share knowledge and treatment ideas so that paediatricians, doctors, psychologists can work together following one plan."***

– Child Caregiver

***"Professionals need to know more about things we can try outside of medications and helpful strategies to know how to help with the tic related challenges like pain."***

– Adult with Tics

# EDUCATION

Educational settings can present significant challenges for young people with tics, not only because of the tics themselves – throwing objects, clenching fists, or damaging worksheets – but also due to the negative reactions from peers and teaching staff. Teasing and exclusion are common school experiences for young people with tics, with many receiving little to no support.

Many young people try to conceal their tics during the school day to avoid bullying and punishment. Common strategies include suppression (i.e., conscious and effortful reduction) and distraction (i.e., engaging in highly focused activities). While these methods may achieve temporary concealment, the mental and physical exhaustion from prolonged suppression makes it very difficult to complete schoolwork. In addition, bursts of tics or tic-attacks are more likely to occur upon returning home after suppressing throughout the school day.

Caregivers often find themselves in the role of advocates, working to educate schools about tic disorders and push for necessary accommodations, such as allowing their child to take breaks during class. Unfortunately, these efforts are frequently met with resistance, forcing many caregivers to move their child to different schools or even take on the responsibility of homeschooling.

To better understand these challenges, the Impact for Tourette's Survey asked caregivers of children with tics about their child's experiences in school. Adults with tic onset during childhood were asked about their experiences at school, technical/vocational training (e.g., TAFE), and university. Respondents were asked to identify challenges experienced in education and the types of supports or adjustments provided. Respondents were also asked how they responded to educational challenges (e.g., leaving/moving school or university) and for recommendations around how educational experiences can be improved for people with tics.

## Type of Education Attended

Approximately one third of children with tics were currently enrolled in primary school (30%). Fewer children (14%) had completed secondary school, as most had started but not yet completed it (56%). Highest level of education completed is presented in Figure 21.

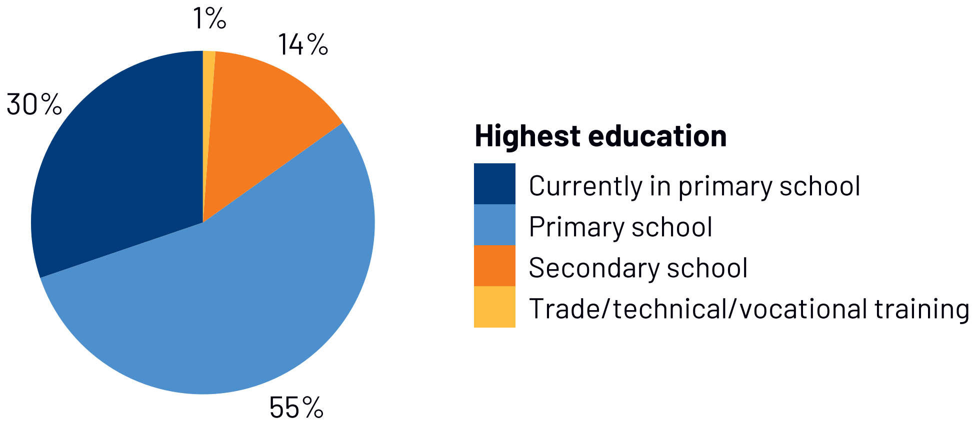

*Figure 21. Highest level of education completed by children <18 years in the sample*

About half of adult respondents (56%) had completed education beyond primary and secondary school. Approximately one in five (22%) adult respondents had completed secondary schooling as their highest level of education. Education and training completed by the adult sample are presented in Figure 22.

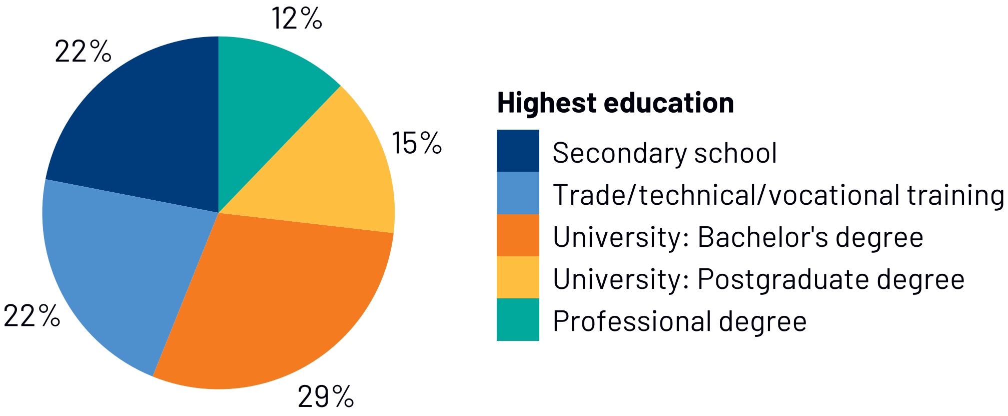

*Figure 22. Education and training completed by the adult sample*

## Primary and Secondary Education

For 79% of caregivers of children and 69% of adults, tics had a moderate to extreme impact on primary and secondary school experiences (Figure 23). Across all respondents, pressure to suppress tics (85%) and difficulty completing work (75%) emerged as the greatest challenge within primary and secondary schooling environments; Figure 24.

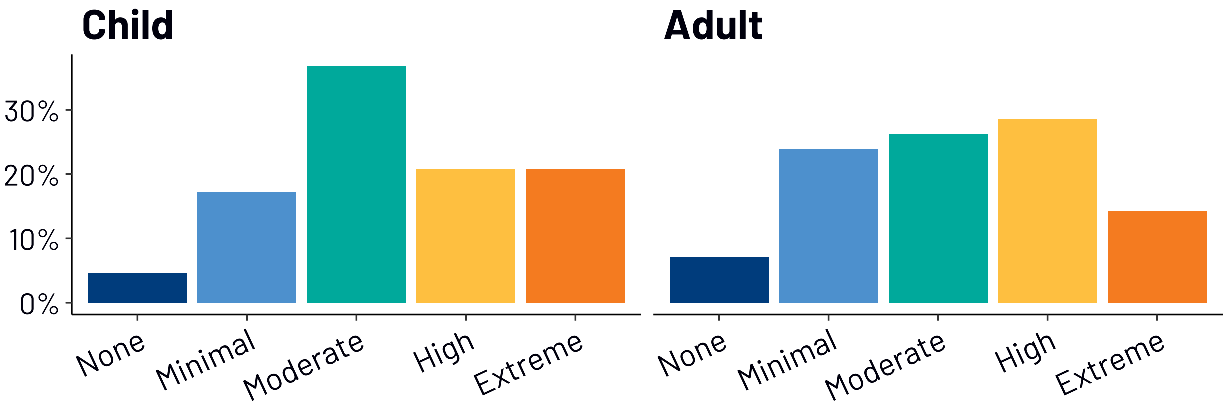

*Figure 23. Impact of tics in primary and secondary education for children and adults*

> *“I used a lot of energy and effort to suppress my tics at school which increased my difficulties with concentrating and processing issues. I fatigued a lot and would have tic blasts when I got home and let them out.”*
>
> – Adult with Tics

> *“When I went to school, nobody knew what Tourette’s was so I was ridiculed... It was living hell.”*
>
> – Adult with Tics

> *“I was kept in a classroom by myself away from friends and peers for two months because they 'couldn't figure out what to do' with me."*
>
> – Adult with Tics

> *“I was abused by teachers because of Tourette's. I also was humiliated in front of the class because of my Tourette’s."*
>
> – Adult with Tics

Respondents also reported experiencing unfair treatment by both students and teaching staff. Three out of every four (72%) had been ridiculed or bullied by other students. Almost one third (32%) had been ridiculed or bullied by their teacher.

In many cases, prolonged tic concealment was reported as a necessary strategy to avoid negative attention, but effortful suppression often distracted students from their schoolwork and led to built-up tics being released after returning home.

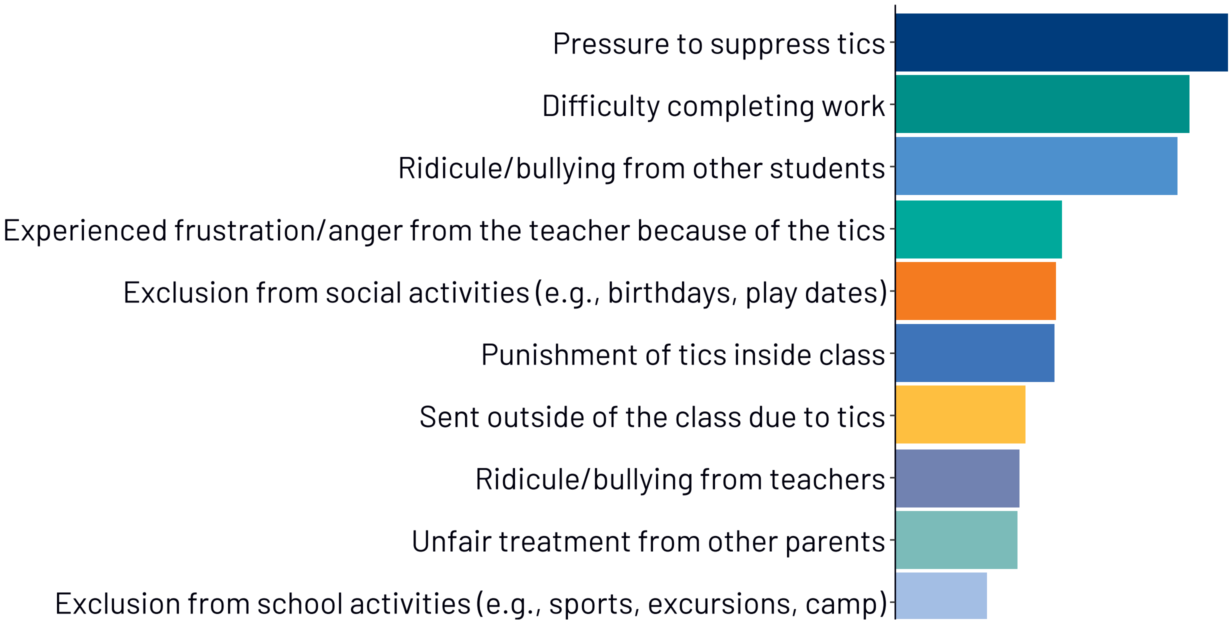

***Figure 24. Challenges experienced during primary and secondary education for both children and adults diagnosed in childhood***

> *"The impact got much more significant as Coprolalia developed. He is now a recluse, hates going out in public, and has an extremely difficult time at school. He has no friends and has no social interaction out of school."*
>
> – Child Caregiver

> *"Due to constantly trying to suppress my tics in class, I couldn't focus and having tics led to me not being able to make friends."*
>
> – Adult with Tics

In response to experiencing challenges in educational environments, 16% of respondents reported switching schools one or more times. Seventeen percent of caregivers had removed their child from mainstream education to pursue homeschooling. One in 20 reported leaving school before graduating secondary school.

Caregivers of children <18 years were asked if they were concerned about their child's ability to seek employment in the future. 62.5% of caregivers were concerned about their child's future employment opportunities. Of these caregivers, common concerns included facing potential discrimination in the workplace (44%), difficulty obtaining work (28%), and difficulty completing work (32%).

## Tertiary Education

For those adults who had experiences of tertiary education, 44% felt their tics had a moderate to extreme impact on their tertiary education (Figure 25). The types of challenges experienced in tertiary education settings are presented in Figure 26.

Similar to experiences in primary and secondary education, pressure to suppress tics (50%) and difficulty completing work (44%) were the most reported challenges.

> *"If the school had adequately trained staff and had good supports in place, had dealt with bullying, my child would still be in school."*
>
> – Child Caregiver

> *"My child left mainstream school to homeschool...We tried to return to high school but it was unsuccessful. He was coming home early every day distressed and tired from the almost-constant ticking."*
>
> – Child Caregiver

Seventeen percent of adults who had undergone or were undergoing tertiary education reported using online study modes over in-person education. This allowed respondents to avoid suppression and negative attention, although still a difficult undertaking for some. Other adults reported moving to a part-time study load to cope. One in five reported leaving a course before completion.

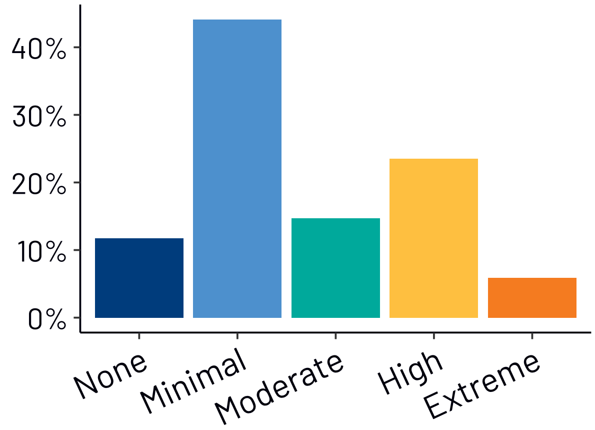

*Figure 25. Impact of tics on tertiary education for adults*

> *"As with high school it was hard as I felt I had to hide a part of myself and was afraid people would think I was crazy if they saw me tic and that that could interfere with my professional goals."*
>
> – Adult with Tics

> *"I find that I am unwilling to take on any more education out of fear of failure or having to be in a classroom, sitting for hours in pain supressing tics."*
>
> – Adult with Tics

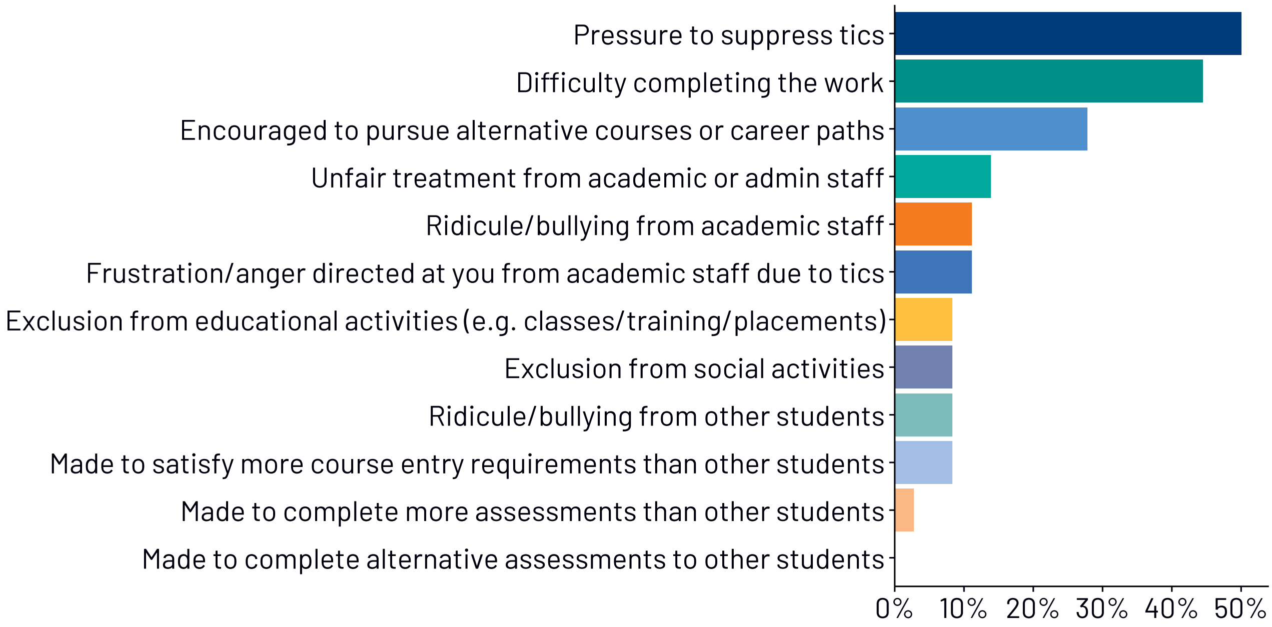

*Figure 26. Challenges experienced within tertiary education settings*

> *“Nothing in life with Tourette's has been as hard as dealing with schools.”*
>
> – Adult with Tics

> *“I found the lack of support and adjustments from his high school very poor. They lacked knowledge, patience and understanding around his needs. "*
>
> – Child Caregiver

## Educator Knowledge

Most child caregivers and adults with tics (77%) felt that educators had very little knowledge and understanding of tic conditions. Respondents emphasised that a lack of training or guidelines for teachers was primarily responsible for this issue. In secondary education, pressure to suppress tics (50%) and difficulty completing work (44%) were the most reported challenges.

Despite most respondents noting a lack of knowledge among teaching staff, some reflected that schools were open to learning about the needs of children with tics. However, the responsibility of advocating for change and education fell exclusively on caregivers.

> *“I need to constantly advocate and liaise with the school and that has worked well. If I didn't have the capacity to do this he would have suffered more.”*
>
> – Child Caregiver

## Accommodations and Support

In most cases, while some educational accommodations were available, many respondents felt these were inadequate. Forty-one percent of child caregivers and 64% of adults with tics felt that educational accommodations only provided some or little support.

The most common supports accommodations provided included:

1. Tic breaks during class
2. Exam/assessment accommodations (e.g., separate room, extra time, use of computers)
3. Provision of teacher aides

Many respondents commented that being given permission to leave the classroom to tic was very useful. Having an opportunity to tic away from others avoided the fatigue accumulated from suppression and concern about visibility with peers. However, some individuals also expressed concerns about drawing further attention to themselves, fearing they might be perceived as different if they left the classroom.

> ***"They have an exit pass to quickly leave the classroom when needed. Teachers have addressed the class and explained that a student has Tourette's and what it is. I think these have helped."***
>
> – Child Caregiver

Some respondents highlighted the advantages of flexible assessment conditions. In the context of exams, they appreciated being placed in a separate room where they could tic freely without the worry of disturbing others. However, a few expressed concerns about being seen as different when completing assessments outside the classroom.

Extra time for completing assessments and access to computers for handwritten tasks were also recognised as valuable accommodations.

Educational assistants were occasionally available for children with tics, although they were often unfamiliar with tic conditions and how to best provide support.

> ***"I was able to use a laptop to type my exams in year 12. It helped a lot as I was very bad with writing."***
>
> – Adult with Tics

> ***"She was able to take tests and timed assessment in a room by herself so tics do not distract others and so she doesn't feel pressure to suppress (and thus reduce her own focus)."***
>
> – Child Caregiver

# Education Recommendations

Respondents were asked what recommendations they would make to improve people's experiences access education.

The **Top 5** most frequent responses included:

1. Increased knowledge of tic disorders by educators – having an increased understanding about what tic conditions are, how they present, and what accommodations and support are necessary to create a supportive and inclusive learning environment for students.
2. Clear and consistent accommodations and supports – supports that are tailored to the needs of students.
3. Better resourcing of schools – resourcing includes the necessary tools, personnel, and supports to enable students with tic disorders to learn equitably.
4. Improved communication between schools and support networks – a coordinated approach to addressing the needs of students with tic disorders, providing consistent care and support across settings.
5. Education of other students – to promote understanding, reduce stigma, and foster a more inclusive and accepting school environment.

Respondents described the importance of increased education for teachers and students to improve the educational experience of students with tics. Many respondents noted the need for standardised materials that can be easily distributed and the benefit of having educational content delivered by a person with lived experience or expertise in tic conditions.

Of particular importance was ensuring the respectful treatment of students with tics. Given the extra accommodations required for students with tics, and commonly held misconceptions, it is important that teaching staff and students maintain a respectful relationship to facilitate self-advocacy and the access of supports.

> ***"Schools should have professionals come in to talk and educate them about Tourette's, how to support the student and how to ensure they don't miss out on education."***
>
> – Child Caregiver

> ***"The difference when educators are adequately trained and can see the person behind the disability is incredible."***
>
> – Child Caregiver

# EMPLOYMENT

Securing and maintaining employment can be challenging for individuals with tic disorders. When seeking job opportunities, several factors must be considered, including workplace safety (e.g., operating machinery or tools while experiencing tics), the work environment (e.g., suppressing tics in quiet office spaces), and the need for flexible working arrangements (e.g., regular tic breaks). In the process of obtaining employment, individuals with tics often face the difficult decision of whether to disclose their condition. This is particularly concerning, as employers who lack awareness or hold discriminatory views about tic disorders may be less inclined to hire someone with Tourette's after disclosure. Once employed, maintaining a job can be challenging depending on the workplace culture. Individuals with tics may be passed over for promotions, face social stigma (e.g., exclusion, bullying), and experience both physical and mental fatigue from the constant effort to suppress their tics.

Respondents answered questions about the setting in which they were currently employed (e.g., wage-employed, self-employed), reasons for not participating in the workforce (e.g., difficulties securing a job), and specific challenges encountered (e.g., denial of work or promotions, difficulties completing tasks, and lack of accommodations). Respondents were also asked to detail any accommodations provided by their employers to help manage tics in the workplace. Finally, respondents were asked to suggest ways to improve the process of seeking, obtaining, and maintaining employment for individuals with tic conditions.

## Employment Status

Nearly three quarters of adult respondents (71%) were either employed for wages (56%), self-employed (13%), or actively looking for work (2%). This rate of workforce participation is below the national averages for working age adults (81%; Australian Institute of Health and Welfare, 2023).

For adult respondents who were not in the workforce (29%), most were students or were retired (Figure 27).

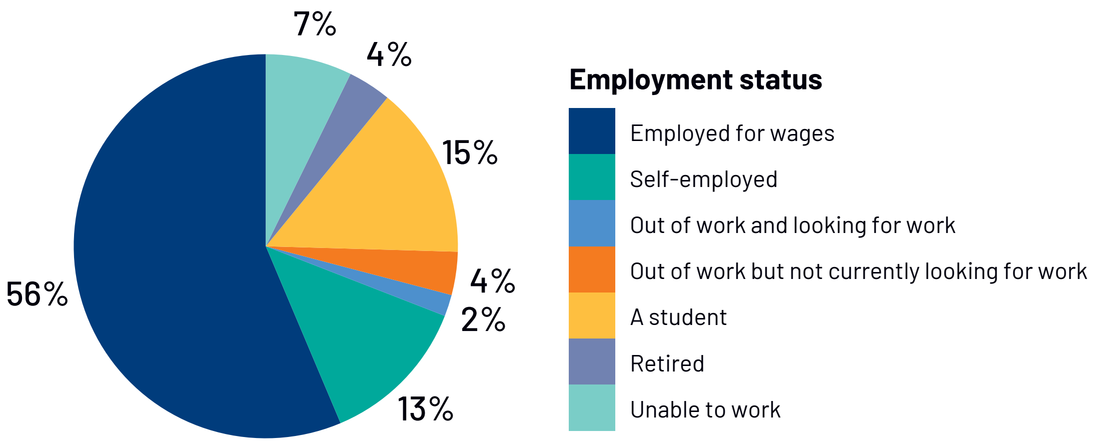

*Figure 27. Current employment status for adults with tics*

Roughly one in ten adults (11%) reported being either unable to work or unemployed and not actively seeking employment. The reasons for not participating in the labour force are shown in Figure 28. The most common reason for not engaging in the workforce was that the severity of their tics hindered their ability to work. Participants who selected 'other' noted challenges such as difficulty finding workplaces that offered necessary accommodations, or the physical fatigue or pain caused by their tics.

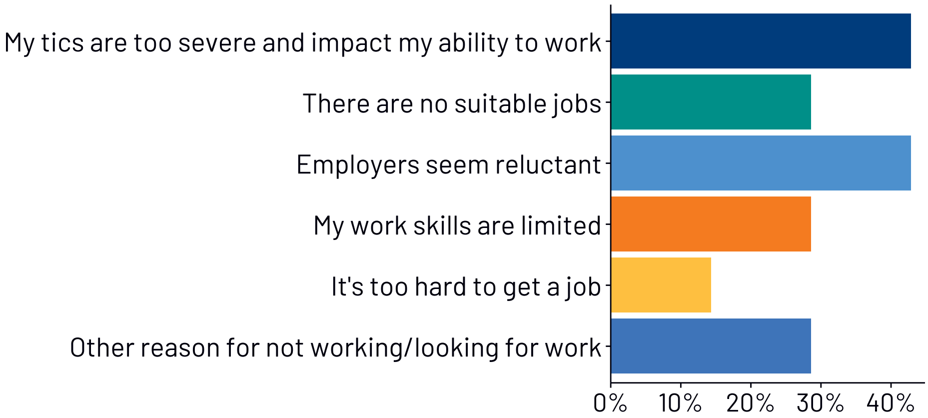

*Figure 28. Reasons for adults with tic disorder not participating in the labour force*

## Employment Challenges

Half of the adult respondents (52%) felt their tics had a moderate to extreme impact on their employment opportunities (Figure 29). Through open text responses, respondents described the key challenges they had experienced in the workplace. Commonly reported challenges included being denied work or promotions, difficulty completing work due to physical fatigue and pain, and having to seek employment in occupations that accommodate their tics (e.g., working from home).

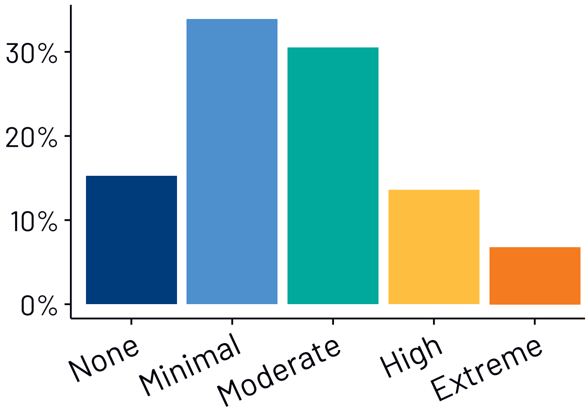

*Figure 29. Impact of tics on employment*

> ***“I have been overlooked for career development and jobs. My boss and others at work talk down to me, like I am not smart or capable.”***
>
> – Adult with Tics

> *“Given that tics increase during periods of stress, the idea of a job interview is really scary. Tics will inevitably increase in an interview- even though they may be less impactful in the actual job.”*
>
> – Adult Caregiver

> *“I suppress in interviews and work itself for fear on not getting the job or getting a reputation due to Tourette stigma that would stop me being promoted.”*
>
> - Adult with Tics

Two in five (42%) of adult respondents had experienced discrimination in the workplace. Most frequently, this was ridicule or bullying by co-workers and being overlooked for promotions (Figure 30).

Half of adult respondents felt the need to suppress their tics at work. The primary reasons for suppression included fear of judgment (38%) and the desire to reduce distractions (29%). Many adults reported significant pressure to suppress their tics in the workplace and concerns around disclosure. To avoid risking the loss of potential employment, many adults reported disclosing their tic disorder only after obtaining employment, rather than during interviews. Others, with less noticeable tics, chose never to disclose. Some individuals did not have the option to avoid disclosure, due to the severity of their tics.

Some adults did report openly disclosing their tic condition in job interviews, to assess attitudes towards neurodivergence and what accommodations were available. The outcomes of upfront disclosure were varied, with respondents reporting both favourable and unfavourable responses.

For some, self-employment was a favourable option, offering flexible working arrangements to suit individual needs.

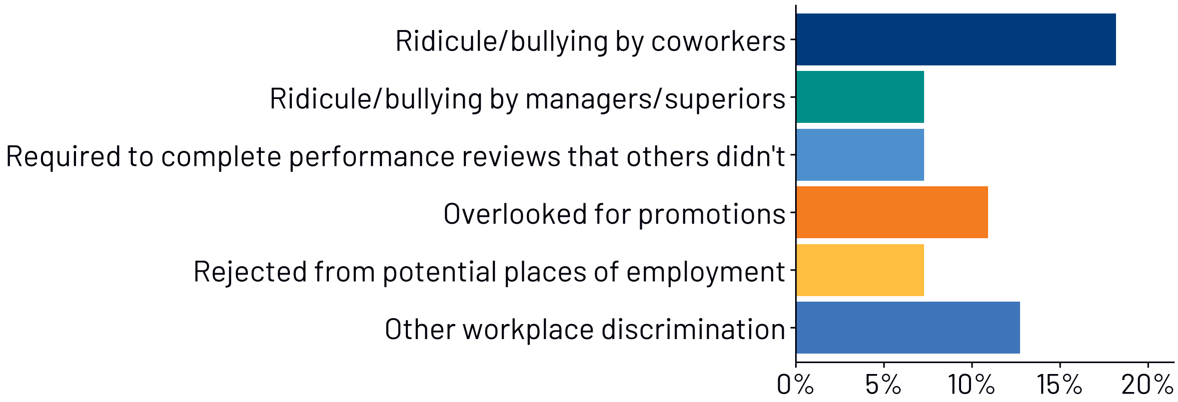

***Figure 30. Types of discrimination experienced in the workplace***

> *"I always mention the Tourette's and educate the employer that it's never been something that defines me. It is a challenge although it's not a reason for me to excel any less than the next person. I tell them I'll prove it in the job and the confidence is usually admired."*
>
> – Adult with Tics

> *"I always disclose my Tourette's during an interview, usually as a test on whether the employers are good people; I don't want to work for ableist people. I noticed that I was getting interviews and shortlisted every time, but many interviewers had a visible negative reaction about Tourette's and then didn't contact me."*
>
> – Adult with Tics

## Accommodations and Support

Adults reported that employers generally provided minimal consideration to their needs. When it comes to additional workplace support, most adults with tics (67%) reported receiving very little assistance. While 18.5% of adults reported receiving some support, only 15% indicated they received a significant amount. The most common accommodation reported was regular breaks to tic, though a few reported having access to safe spaces to tic or sensory accommodations (e.g. headphones or earplugs). Some adults also reported having regular check-ins with management to assess their comfort in the workplace.

# Employment Recommendations

Respondents were asked what recommendations they would make to improve people's experiences seeking, obtaining and maintaining employment.

The **Top 5** most frequent responses included:

1. Employers and colleagues receiving increased education and awareness about tic disorders – by understanding the nature of tics, their impact on individuals, and the accommodations needed.
2. Promoting an understanding and empathetic workplace culture – by encouraging open communication, reducing stigma, and fostering acceptance of neurodiversity.
3. Providing resources to all employees on safe disclosure of disability and their rights against discrimination – to empower individuals to make informed decisions about disclosure, understand their legal protections, and provide access to support they need without fear of bias or negative consequences.
4. Ensuring employers are compliant with the provision of reasonable accommodations in the workplace – to ensure a supportive and inclusive workplace. This may include flexible work hours, regular breaks, sensory accommodations, or designated spaces to manage tics.
5. Public awareness campaigns – to address misconceptions about tic disorders in the workplace and highlight the value individuals with tics (and disabilities more broadly) can bring to the workplace.

***"There needs to be increased awareness of tic disorders. It's really good that famous people like Lewis Capaldi have been open about their tics as it shows people that you can still do your job and achieve things in life. Too many people think tics indicate an intellectual disability."***

– Adult caregiver

***"Decreasing the stigma around tics to help employers not discriminate when hiring and help those with tics feel more comfortable in the workplace."***

– Adult with tics

***"There needs to be openness to learning about Tourette's. My employers are super supportive so it's been good."***

– Adult with tics

# FINANCE

Tic conditions impose a significant financial burden on both individuals living with tics and their caregivers. Currently, tic disorders are not adequately recognised as a disability in Australia, meaning there is little to no financial assistance available during the diagnostic process, in seeking interventions, or for obtaining functional supports (e.g., care workers, assistive technology). This lack of financial support often forces caregivers and adults with tic disorders to seek treatment through private clinics, often at considerable personal expense. Due to the high costs associated with private care, many necessary supports are simply out of reach.

Additional financial strains arise from more severe or complex tics, which can lead to injury or damage to household items. Because injuries are common, individuals with tics often require treatment from medical or allied health services (e.g., physiotherapy), which are typically not covered by the public health system. Furthermore, the frequent need to replace personal technology (e.g., phones, computers) and fragile household items (e.g., glassware) contributes to an ongoing financial burden.

The financial challenges of living with a tic disorder are further compounded by the difficulties individuals with tics and their caregivers face in seeking, obtaining, and maintaining employment. Discriminatory attitudes and physical fatigue often reduce work capacity for adults with tics, while caregivers are frequently unable to work due to the time demands of caring for someone with tics. These barriers result in reduced earning potential, which in turn limits access to necessary supports.

Respondents were asked to report household income levels and satisfaction with their current financial situation, including the ability to meet basic needs and cover the costs of services and intervention. Respondents were also asked to estimate the annual cost of treatment for their tics and any funding they had received to assist with these expenses.

## Household Income

Household incomes for child caregivers and adults with tics are presented in Figure 31. Household income for child caregivers were mostly between \$88,400-\$129,999 (34%), 130,000-\$181,999 (20%) and \$182,000+ (29%); the median family income in Australia in 2024 was \$108,524 (Australian Bureau of Statistics, 2024).

The spread of household income was slightly more varied for adults with tics, likely due to fewer households receiving a combined income; Figure 31. One in five adults were currently living below the poverty line (<\$500/week, Melbourne Institute Applied Economic & Social Research, 2024).

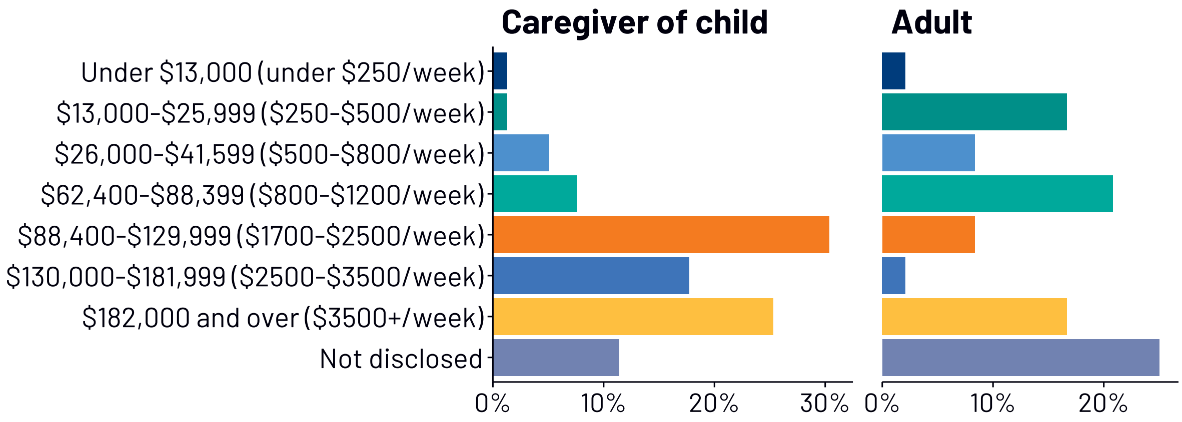

*Figure 31. Household income by child caregiver and adult respondents*

## Financial Burden

Estimated yearly costs in accessing services or intervention for tic conditions varied widely across both child caregivers and adults (Figure 32). About half of child caregivers reported an estimated annual out of pocket cost of more than $4000, with 18% reported costs exceeding >$10,000. Estimated costs for adults were slightly lower, with 10% reporting an annual spend of more than $10,000 and much more reporting they were unsure about how much they spent.

When asked about financial impact of caring for a child with tics (caregivers) or having a tic condition (adults), many reported not being satisfied across a range of financial indicators. The most frequently endorsed dissatisfaction ratings were for the adequacy of savings, current income, financial situation, ability to contribute to household income, and ability to cover therapy costs and treatment expenses for their tic condition (Figure 33).

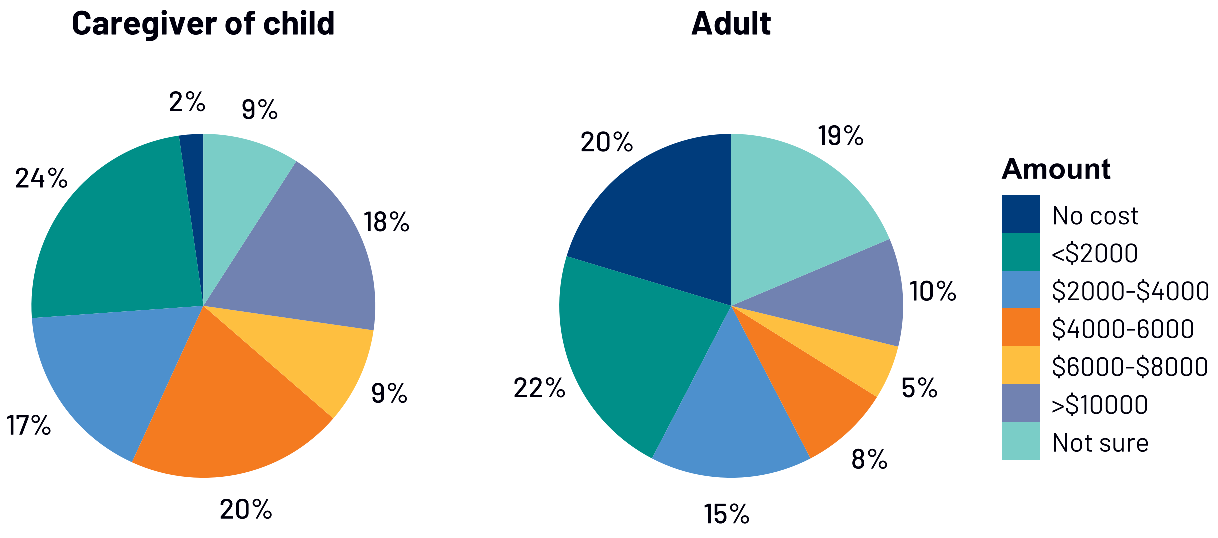

*Figure 32. Annual costs for accessing tic-related services or interventions*

> *“There is often a loss of income due to fatigue and loss of sleep or tic attacks which is hard to graph financially. Its near impossible to do a full week of work without making the condition worse.”*
>
> – Adult with tics

> *“I had to drop my capacity by a day a week due to the impact of my tics.”*
>
> – Adult with tics

> *“It's exhausting! $650 for one [paediatrician] visit, $349 for speech, wait lists exhausted, thousands for a "good school", isolated and no help, and no funding means no holidays or making memories together.”*
>
> – Child Caregiver

> *"There are so many additional costs that we have to cover for my son."*
>
> – Child Caregiver

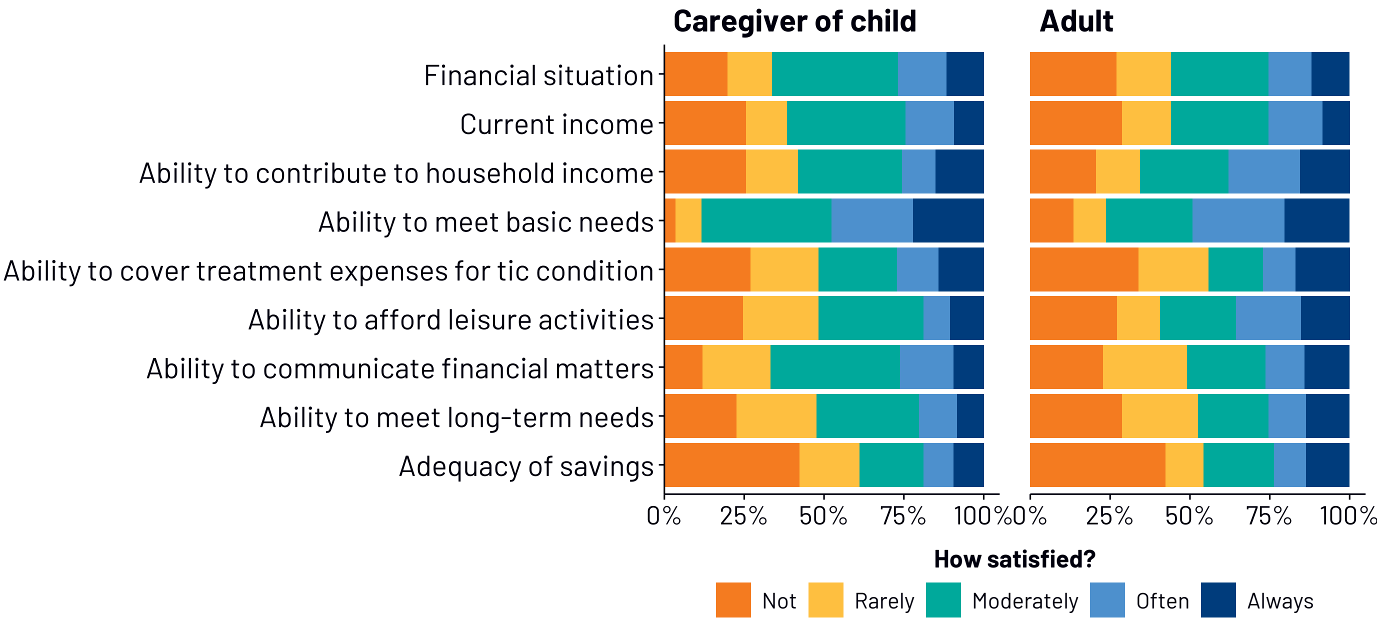

*Figure 33. Satisfaction with current financial situation*

## Access to Disability Funding

Access to disability funding supports from the Australian federal government to assist with the costs associated with therapies, interventions and to support daily living are presented in Figure 34.

Of the respondents that had applied for funding (46% children, 30% adults), a third of children and half of the adults had their applications declined. The majority of those with disability funding received it for other co-occurring medical conditions (i.e., autism, mental health conditions), with more than half (63% children, 56% adults) reporting that funding was used for tic-related treatment and care. A very small percentage of children and adults were successful in obtaining disability funding specifically for their tic disorder. The most reported funding sources were the NDIS and Centrelink.

More than half of respondents had not applied for disability-related funding. Whilst there were some who felt they did not need it (10% children, 23% adults), there were many who did not pursue funding due to the effort involved and the perceived high risk that their application would be declined.

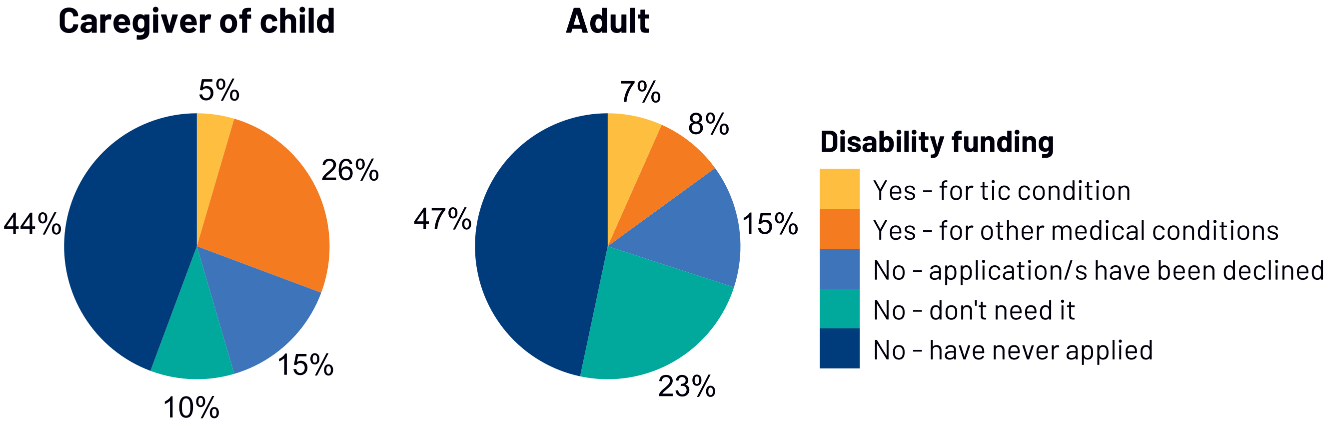

*Figure 34. Current access to disability funding for children and adults with tic disorders*

> ***"We get no funding and I have paid thousands for reports and assessments including functional capacity assessments... NDIS will not support us or acknowledge the impact it has on his mental health or functioning."***
>
> – Child Caregiver

> ***"We need to cover the costs of medication, allied therapy, psychology, but also things that will reduce the impacts of his tics, (i.e., boxing helmet, heat packs, wheelchairs). None of this is covered."***
>
> – Child Caregiver"

> ***"A lot of money was spent on needless doctors appointments in order to try and apply for NDIS funding, which was declined."***
>
> – Adult with tics

> ***"We've had to prioritise and sometimes forgo certain therapies or interventions, which has been heartbreaking for us as parents. We're constantly grappling with the knowledge that our child may not be receiving the comprehensive care they deserve due to financial constraints."***
>
> – Child Caregiver

# WELLBEING

People with tic disorders often face significant challenges that impact their wellbeing. These challenges can stem from the physical symptoms of tics, which may lead to social stigma, isolation, and difficulties in everyday functioning. Additionally, many individuals with tic disorders experience co-occurring mental health issues, such as anxiety and depression, which can further exacerbate their situation. Factors such as limited support from peers and family, difficulties in academic or work settings, and barriers to accessing appropriate care all contribute to the lower levels of life satisfaction and wellbeing. Understanding these factors is crucial for developing effective support and intervention strategies.

The Impact for Tourette's survey included a series of standardised questionnaires, along with targeted questions developed through our community consultation meetings. These were used to capture wellbeing, including the quality of life and mental health, of both children and adults with tic conditions, as well as the wellbeing of caregivers. Questionnaires for child caregivers included the Kidscreen-10 (Ravens-Sieberer et al., 2010) and the Mood and Feelings Questionnaire (MFQ; Angold et al., 1995). Adults with tics completed the World Health Organization Quality of Life, Brief Version (WHOQOL-BREF; WHO, 2012), a standardised assessment of quality of life across physical, psychological, social, and environmental domains. Questions around suicidality, self-harm, substance abuse, and disordered eating were also completed by all respondents. Experiences of stigma and discrimination were also examined, including experiences of judgement, harassment, and safety behaviours (e.g., social withdrawal).

Caregiver wellbeing was assessed using Kessler Psychological Distress Scale (K10; Kessler et al., 2002) and Caregiver Burden Inventory (CBI; Novak & Guest, 1989). These were completed by both caregivers of children (n=113) and a small sample of caregivers of adults with tic disorders (n=17).

## Children's Quality of Life

One in four caregivers rated their child's quality of life as poor or very poor; Figure 35.

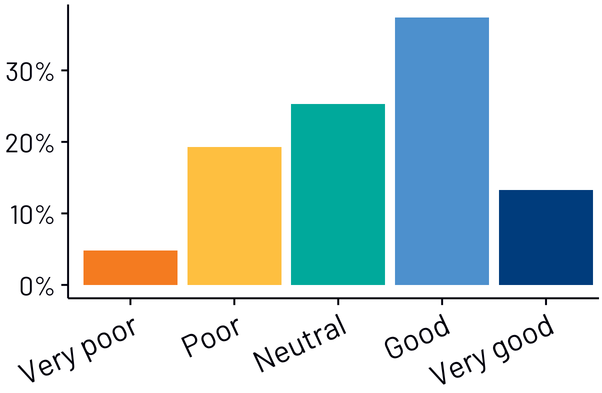

*Figure 35. Parental rating of quality of life*

Using the Kidscreen-10 (Figure 36), 82% of children were reported by caregivers as having below average health-related quality of life. Caregivers reported that their child had difficulty paying attention (41.5%) and difficulty getting on well at school (38%). One in four children were reported to be very or extremely sad and lonely.

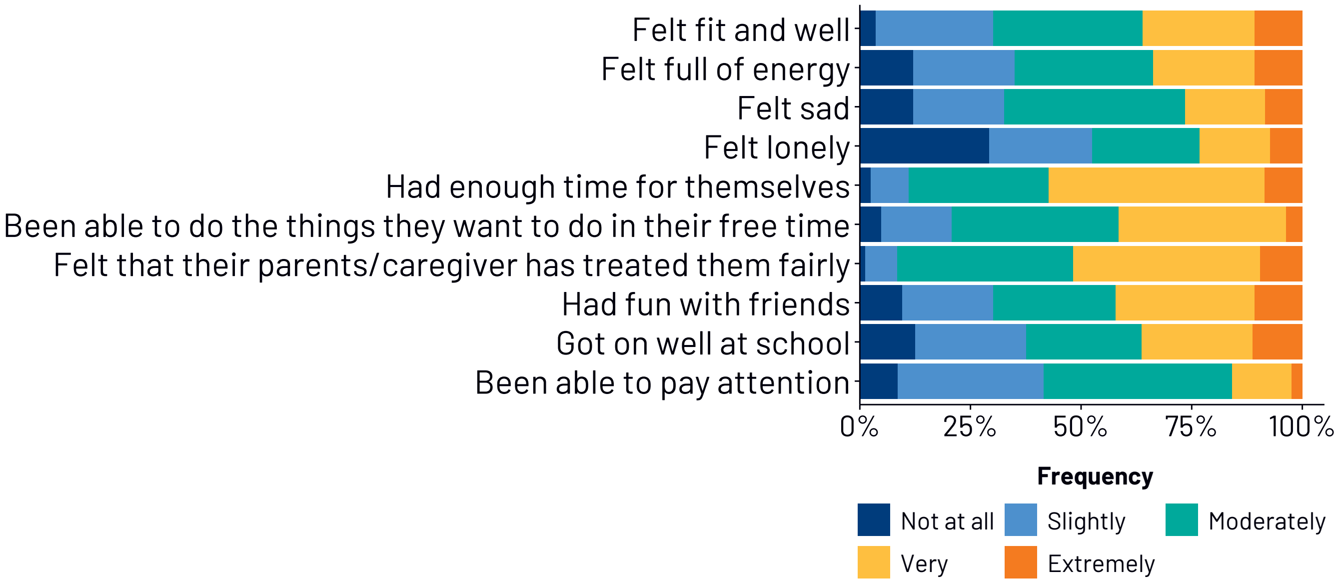

*Figure 36. Caregiver-reported quality of life in children with tic disorders*

## Discrimination and Stigma Experienced by Children

Discrimination and stigma emerged as a key issue for children with tics (Figure 37). 65% of caregivers reported that their child experienced moderate to extreme discrimination or stigma. This includes ridicule and bullying, exclusion from activities, unfair judgement, social exclusion, and stereotyping.

Many caregivers reported going out of their way or changing their daily routines to avoid subjecting their child to discriminatory attitudes or behaviours. This included:

- 26% of caregivers reported that they often or always avoided inviting new people over to their house
- 21% avoided taking their child to new locations
- 19% avoided taking their child to meet new people, and
- 17% avoided taking their child out in public.

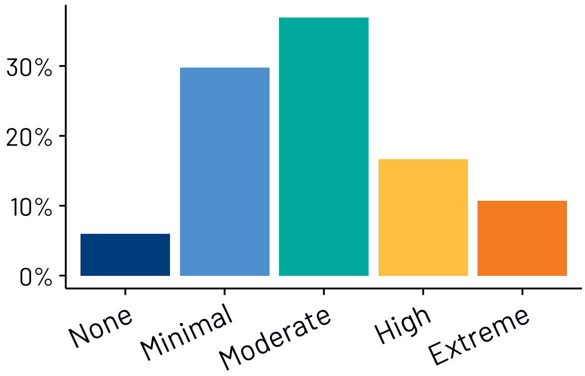

*Figure 37. Frequency of caregiver reported discrimination and stigma experienced by children*

Changes in caregiver behaviours to protect their child may be driven by caregiver's worries; 74% of caregivers often or always experienced concern that others would react poorly to their child's tics.

> *"I feel a sense of worry and sadness for my child most days about how his life will look as he gets older. There is such a stigma associated with Tourette's and it breaks my heart over and over to see how cruel people can be towards people living with this condition."*
>
> – Child Caregiver

## Anxiety and Depression Experienced by Children

Nine in ten child caregivers felt that tics had a moderate to extreme impact on their child's mental health (Figure 38a).

Thirty-six percent of caregivers rated their child's current mental health as poor or very poor (Figure 38b).

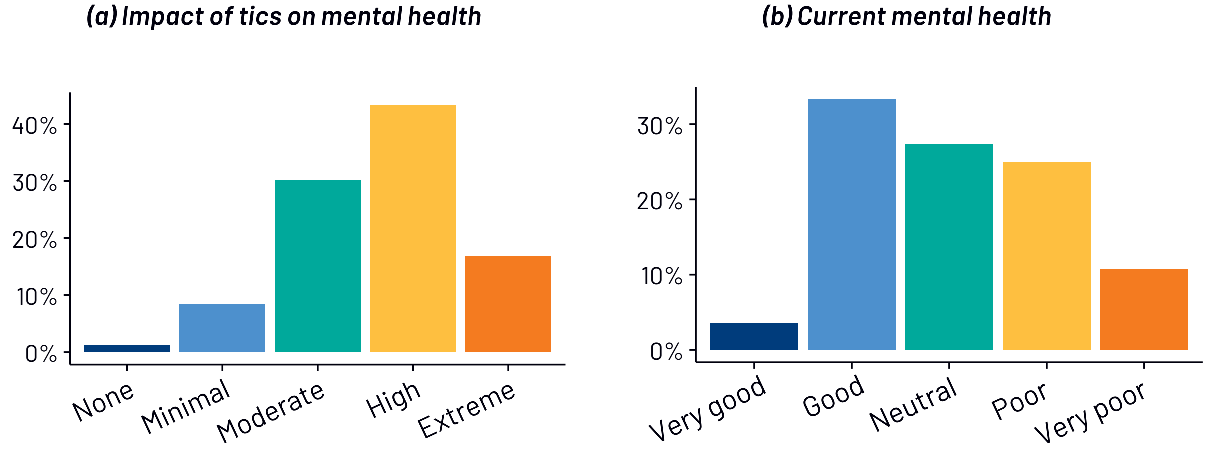

***Figure 38. Caregivers ratings of (a) the impact of tics on children's mental health and (b) children's current mental health***

> *"I used to actually hit myself to try and get me to stop doing this ... There'd be some nights where I'd be like crying, like, 'why, why do you keep doing this? Why aren't you normal'?"*
>
> – Child with Tics

> *"When they're bad, he gets very, very frustrated. He just screams with frustration. Internally, I think there's a feeling of "I hate tics", "why do I have them". All that sort of stuff."*
>
> – Child Caregiver

Experiences and concerns around anxiety emerged as a key driver for poor child mental health (Figure 39). More than half of the caregiver respondents reported that their child was often or always worried about approaching new people (58%), self-conscious (56%), and anxious when out in public (53%). 30% of caregivers also reported that their child was often or always worried about leaving the house.

Caregivers also reported that many children experienced depressive symptomology. A third of children reportedly often or always felt they were less valuable as a person, 29% felt isolated from everyone else, and 27% were unmotivated to do anything.

Half (54%) of caregivers reported their child was often or always frustrated with life.

Child caregivers also completed the mood and feelings questionnaire (MFQ, Angold et al., 1995), a standardised screening tool used for the assessment of depression in young people. Forty-four percent of children were identified at risk for depressive disorder. Approximately one quarter of caregivers reported their child felt as though they could never be as good as other kids (26%), hated themselves (25%), felt they were no good (24%), and felt miserable or unhappy (24%).

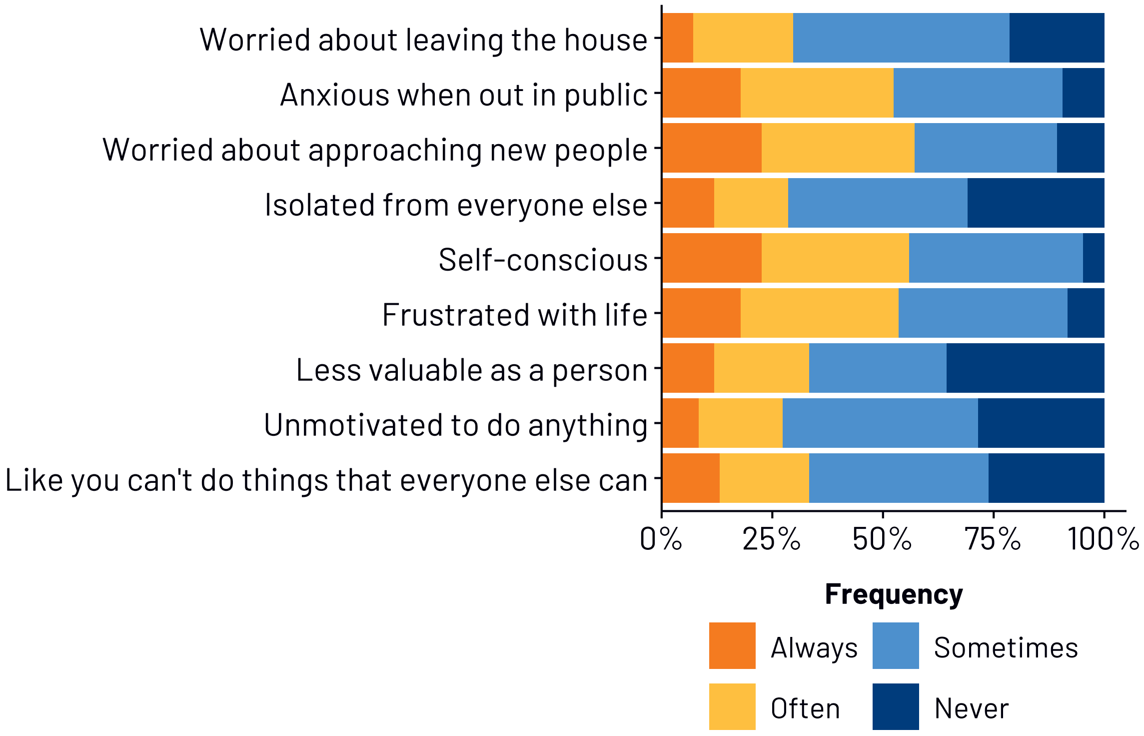

*Figure 39. Caregiver-reported mental health concerns for children with tic disorders*

## Suicide, Self-Harm, and Substance Abuse in Children

Behaviours relating to eating disorders, substance abuse, self-harm and suicide in children are presented in Figure 40. While just over 40% of child caregivers reported none of these behaviours in their child, for those who did, higher rates of all behaviours were reported compared to the general child population (Zubrick et al., 2016).

Almost half of all caregivers (47%) reported that their child had experienced thoughts about ending their own life.

Thirty-one percent of caregivers reported that their child had engaged in self-harming behaviours, almost four times higher than comparative national rates in children aged 12-17 years (Zubrick et al., 2016).

One in 10 children had attempted suicide; this is almost five times higher than national rates of Australian children (Zubrick et al., 2016).

23% of children engaged in disordered eating with a small proportion (2%) engaged in substance abuse behaviours.

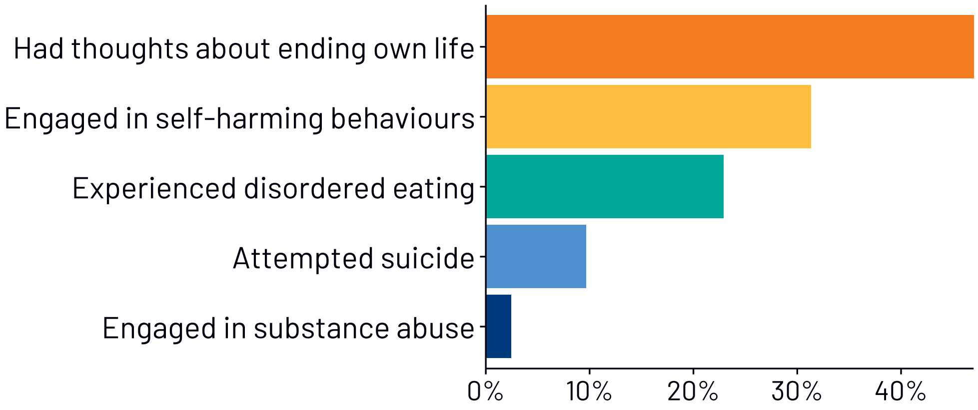

***Figure 40. Caregiver-reported suicidal thoughts and behaviours, eating disorders, and substance abuse in children***

> ***"On occasion he's expressed that he hates life, and he wants to die. I don't think he's ever expressed that in a state where he's really meant it. But I understand that that's just his way of sharing big feelings."***
>
> – Child Caregiver

> ***"He has so much to offer the world, so it is heartbreaking to watch him suffer to the extent that he doesn't want to be alive sometimes, or to see him hurt himself."***
>
> – Child Caregiver

## Adult Quality of Life

When asked to consider their overall health, comfort, and ability to participate in and enjoy life events, a quarter (25%) of adults with tics reported that their quality of life was poor or very poor (Figure 41).

Quality of life was further examined using the WHOQOL-BREF (World Health Organisation, 2004, Figure 42), a standardised assessment of quality of life across physical, psychological, social, and environmental domains. Responses are scaled to a 0-100 scale, where 0 represents the worst possible state of health and 100 represents the best.

Adult respondents reported below average quality of life on physical health (mean = 45), psychological wellbeing (mean = 42), social relationships (mean = 44), and environment (mean = 53) domains. Compared to representative Australian data, this is well below national averages on physical health (Australian mean = 74), psychological wellbeing (Australian mean = 72), social relationships (Australian mean = 73), and environment (Australian mean = 80) (West et al., 2023).

A key area impacting quality of life for adult respondents was sleep, with 61% reporting that they were dissatisfied with their sleep. Many also reported that they were dissatisfied with themselves (51%), their energy for daily life (51%), and capacity for work (48%).

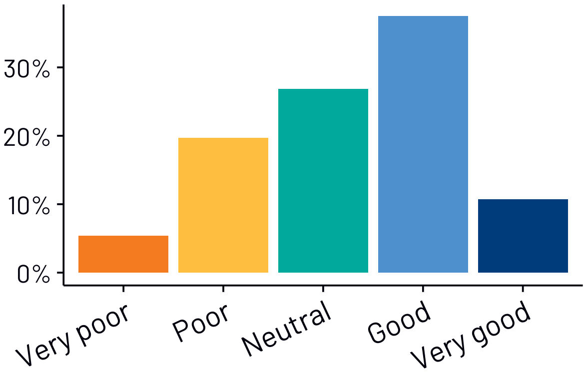

*Figure 41. Quality of life in adults with tic disorders*

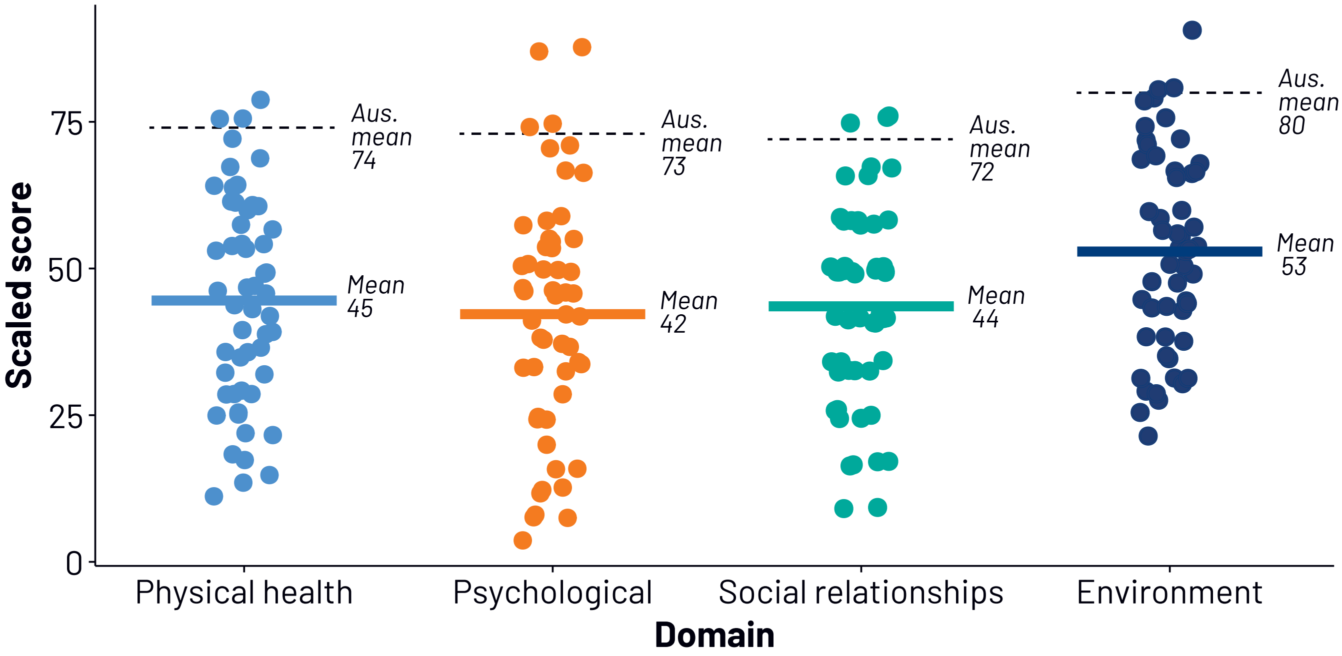

*Figure 42. Quality of life domains (WHOQOL-BREF) for adults with tic disorders*

## Discrimination and Stigma Experienced by Adults

Half of the adult respondents reported that they had experienced moderate to extreme stigma (Figure 43).

This stigma is reflected through the discriminatory actions and attitudes of others (Figure 44), with 34% reporting that they had been unfairly judged by others, 27% unfairly treated by family members, and 11% reported experiencing verbal harassment.

Many adults reported often or always fearing for their personal safety in public (25%) and engaging in safety behaviours such as suppressing their tics in public (87%). More than half avoided activities such as meeting new people (57%), and some avoided accessing public transportation (16%) and emergency services (11%).

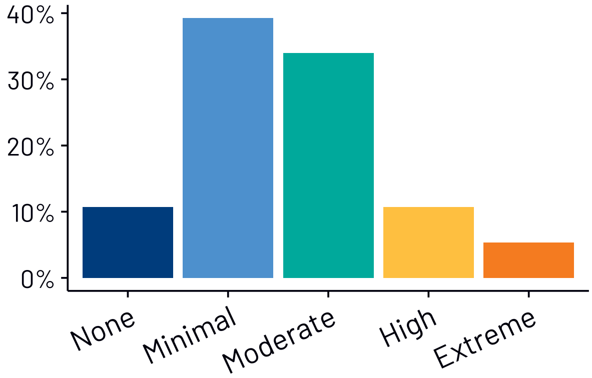

*Figure 43. Discrimination and stigma experienced by adults*

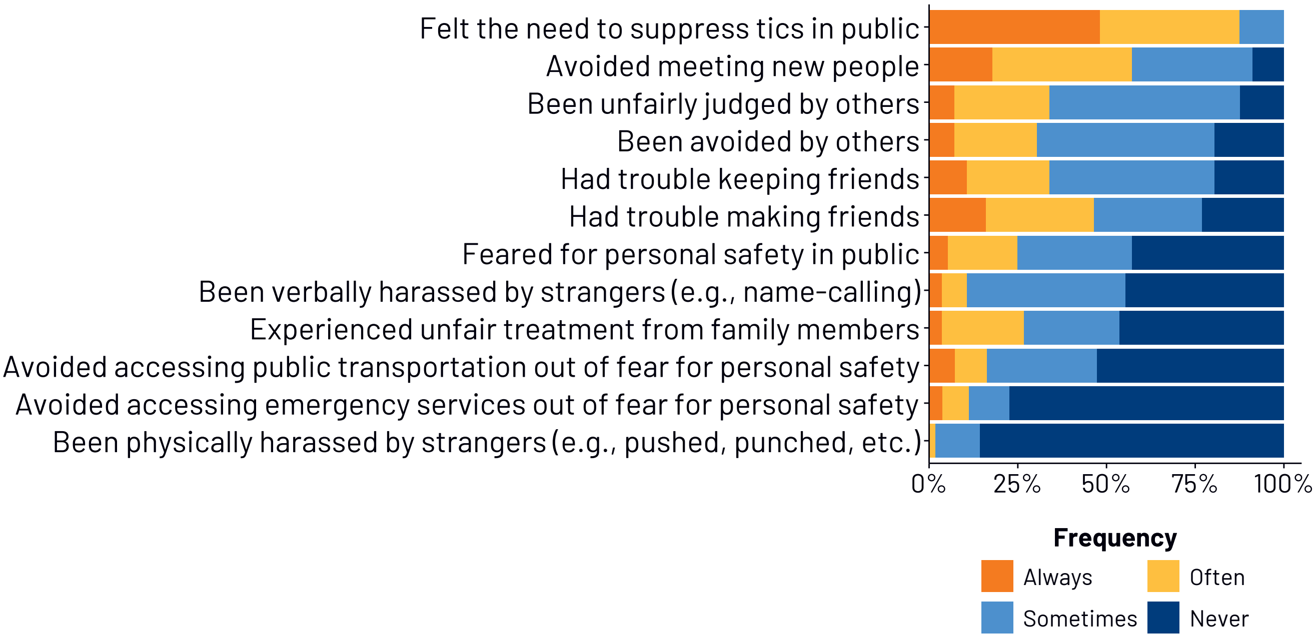

*Figure 44. Discriminatory actions and attitudes experienced*

> *“Hospitals and police assume that I am high on drugs or having a psychotic episode.”*
>
> – Adult with tics

> ***"I feel tics are not understood in society, people make fun of you as though it's a joke, do not understand that my head jerks are hurting me. I feel judged like I'm crazy and not fit to work and too much of a risk. I am embarrassed by my tics going out in public because of people's reactions. I have even had people speak to me slowly because she thought I was intellectually impaired."***
>
> – Adult with tics

## Anxiety and Depression Experienced by Adults

Similarly to children with tic disorders, 86% of adults felt that their tic condition had a moderate to extreme impact on their mental health (Figure 45a) and 36% of adults rated their current mental health as poor or very poor (Figure 45b).

Like children, anxiety emerged as a primary mental health concern for adults (Figure 46), with many reporting that they were often or always self-conscious (69%), anxious when out in public (58%), worried about approaching new people (53%), and worried about leaving the house (18%).

Depressive symptomology was also frequently reported by adult respondents. Many reported either often or always being frustrated with life (48%), feeling like they are unable do things everyone else can (43%), isolated (40%), less valuable as a person (32%), and unmotivated to do anything (32%).

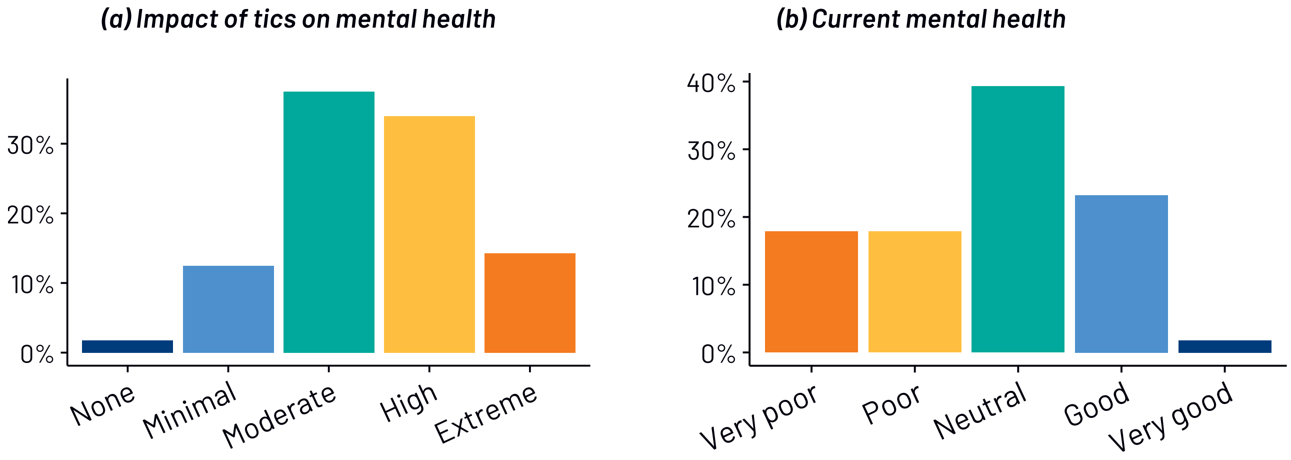

*Figure 45. Adult ratings of (a) the impact of tics on their mental health and (b) current mental health*

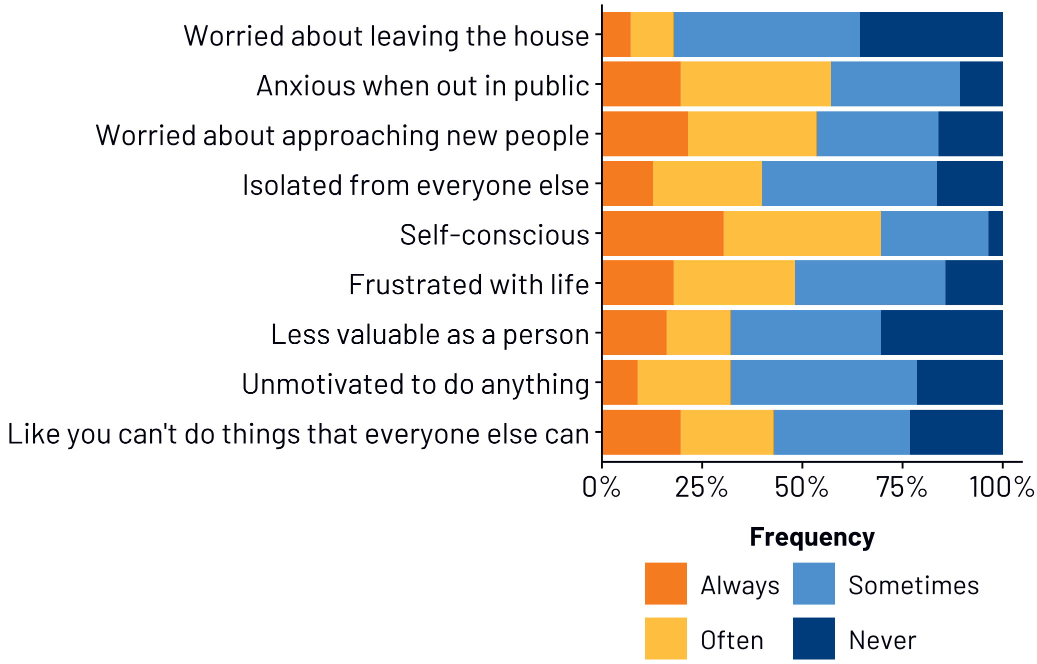

*Figure 46. Adult tic-related mental health concerns*

## Suicide, Self-Harm, and Substance Abuse in Adults

Disordered behaviours are presented in Figure 47. 71% of adult respondents reported having thoughts about ending their own life, with 38% experiencing suicidal thoughts on at least a weekly basis.

1 in 4 adults had attempted suicide. This attempted suicide rate is five times the national average reported in Australians aged 16-85 years (Australian Institute of Health and Welfare, 2023). On average, five suicide attempts had been made by adult respondents who reported having previously taken actions to end their own life.

45% of adult respondents reported engaging in self-harming behaviours. Of these individuals, 22.5% reported engaging in self-harming behaviours at least once per week.

More than one quarter of adult respondents reported engaging in substance abuse (29%). Alcohol (33%) and tobacco or nicotine products (25%) were the mostly commonly used substances, although the use of unprescribed behind-the-counter medication (19%) and illicit/illegal drugs (22%) was also common.

Disordered eating was reported by 41% of adult respondents, with binge-eating (44%), calorie restriction (42%), and purging behaviours (22%) being common.

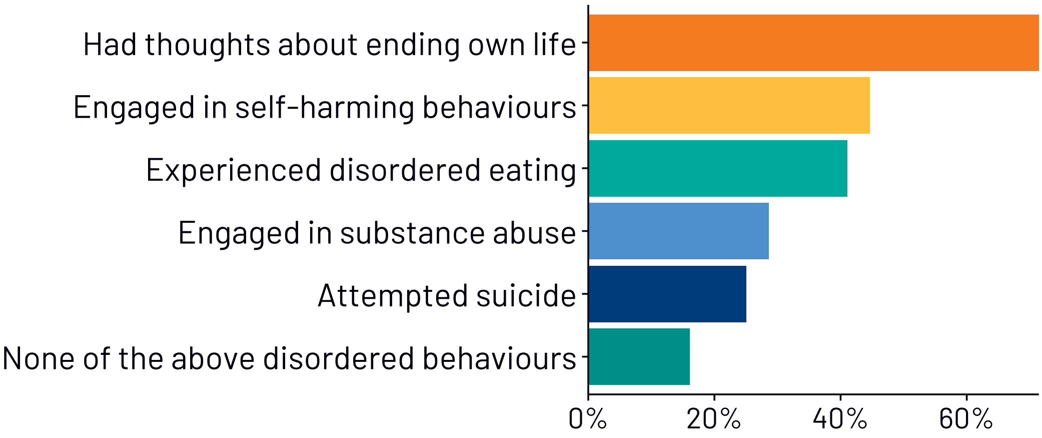

***Figure 47. Percentage of adults reporting suicidal thoughts and behaviours, or engaging in disordered eating or substance abuse***

> ***"I am grieving my life... I live in chronic pain and the tics are showing me just how badly I am deteriorating...It is very hard to live like this. Some days I just don't want to anymore. I am finding it harder and harder to hold on."***
>
> – Adult with Tics

> ***"I self-harmed once because I was like, I'm sick of this [censored]. I don't want to deal with it and maybe it will calm my ticks down. And surprise, it just led to more stress... When my tics got super-duper bad, I just wanted to feel like grounded and like real and in control."***
>
> – Adult with Tics

> *“Parenting a disabled person is exhausting...Tourette Syndrome affects the whole family and their ability to function normally, it puts a lot of pressure on all relationships in the family. It is socially isolating and it is very hard to keep friends.”*
>
> – Adult Caregiver

> *“As parents, we experience a range of emotions, from worry and stress about our child's future to feelings of helplessness when we can't alleviate their discomfort."*
>
> – Child Caregiver

> *“...the arguments, lack of help and understanding for my son by doctors, health professionals, educators, parents, friends, family have broken me both mentally and have impacted my health irreparably...I failed him. I couldn't get him or give him the help he needed.”*
>
> – Adult Caregiver

> *"The constant vigilance and advocacy required to ensure our child receives adequate support and understanding from others is exhausting.”*
>
> – Child Caregiver

## Caregiver Quality of Life and Mental Health

Caregivers were also asked about their own quality of life, to understand the psychosocial impacts of caring for a child or adult with tics. One in three caregivers reported that their quality of life was poor or very poor (Figure 48).

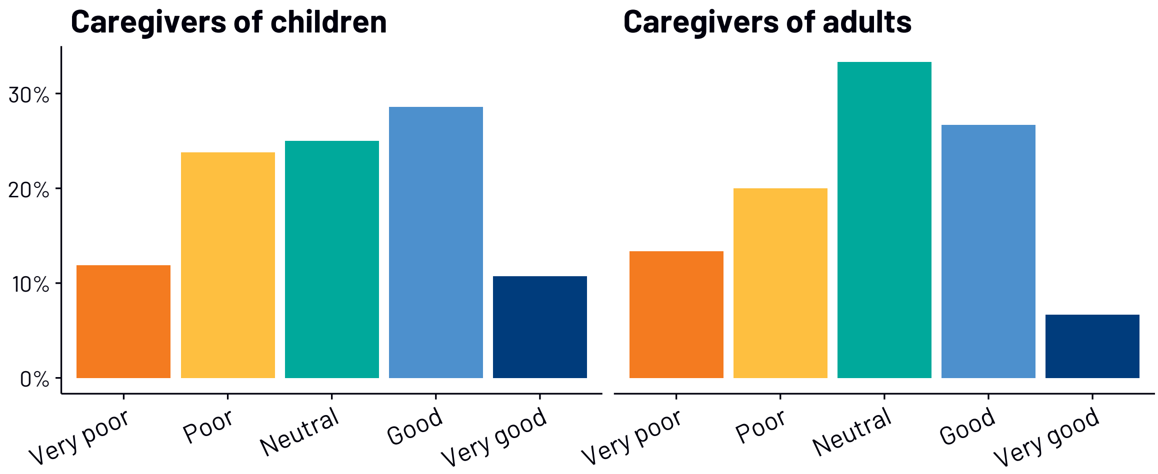

*Figure 48. Perceived effectiveness of other medical treatment on tics*

> *“You do ask yourself how did we end up here? You question everything you've ever done. Was I too lenient? Was I too hard? Did I not pay enough attention?”*
>
> – Adult Caregiver

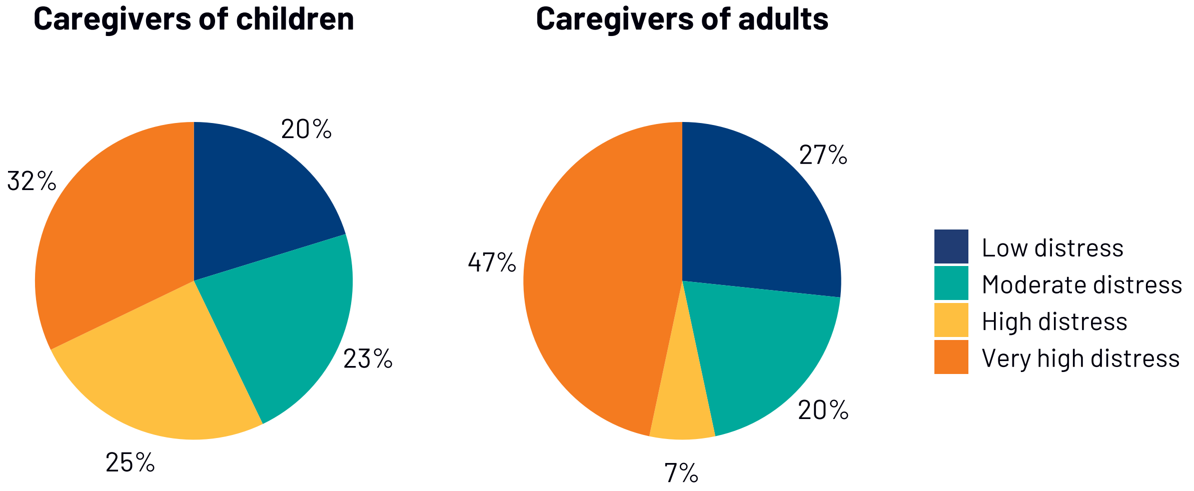

*Figure 49. Emotional distress experienced by caregivers*

Four in five child caregivers and 74% of adult caregivers experienced moderate to very high stress levels, as measured using the K10, a commonly employed measure of psychological distress in general practice; Figure 49. Child caregivers reported often or always feeling tired for no good reason (48%) and restless (20%).

Adult caregivers most often reported feeling tired for no good reason (47%) and depressed (47%).

48% of child caregivers and 60% of adult caregivers reported that caring for a person with a tic condition had a high or extreme impact on their mental health (Figure 50).

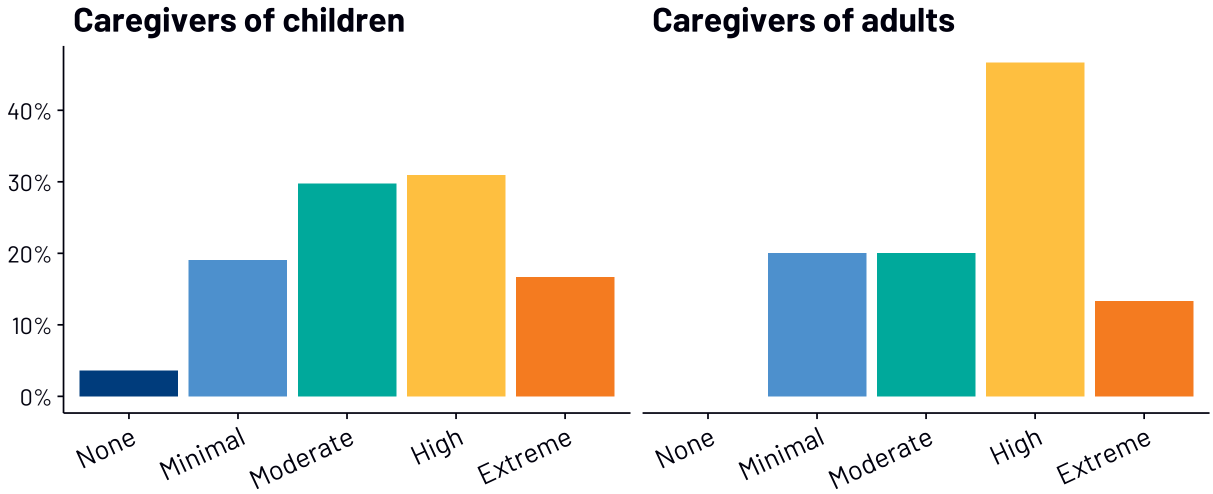

*Figure 50. Child and adult caregiver ratings of their own mental health*

## Caregiver Burden

Using a measure of caregiver burden (The Caregiver Burden Inventory [CBI]; Novak & Guest, 1989), 48% of child caregivers and 100% of adult caregivers were at risk of burnout. A further 12% of child caregivers were in need of respite.

The areas most impacted for caregivers included:

1. Care-receiver's dependence on caregiver
2. Caregiver not getting enough sleep
3. Caregiver feeling their health has suffered
4. Caregiver being physically tired
5. Caregiver helping the care-receiver to perform many daily tasks

When child caregivers were asked about the specific ways in which caring for a child with tics had impacted their family:

- 73% of caregivers reported experiencing emotional worry or concern
- 66% were concerned for their child's future
- 40% reported that their child's tic condition limited family activities
- 38% reported that their child's tic condition limited time for personal needs

***"People who don't live the TS life, just don't get that the impact could be so heavy! ...TS isn't just the same symptoms on repeat like some other things. You never know what you are going to get. So it's almost like having to be hypervigilant for every possible thing that could happen or during the time where tics might decrease, you are just waiting for when it kicks into gear again."***

– Child Caregiver

***"I work full time and then on top of that I feel like I almost have a second full time job in school advocacy and it's that part that affects me"***

- Child Caregiver

***"It can be really, really stressful. Not only stressful from managing the chaos and complexity at home, but stressful with the worry I constantly carry throughout the years for what's in store and who will they be when they're adults."***

– Child Caregiver

***I just want the best for them. It's hard to not worry about what driving will be like for someone who's impulsive. What job will he be able to get?"***

– Child Caregiver

## Prioritiy Areas Identified by the Community

Initial community and stakeholder meetings identified a range of priority areas that would help improve the lives of Australian's impacted by tic conditions and their families. Respondents were asked to rank their top three priority areas from this list. These priority areas are presented in Figure 51.

Improved recognition of tic conditions as a disability was ranked as a top three priority area by 53% of respondents. Respondents felt that improved recognition of tic conditions as a disability was important for improving awareness and validating the impact of tic conditions, increasing pathways to funding and support, and addressing misconceptions about tics.

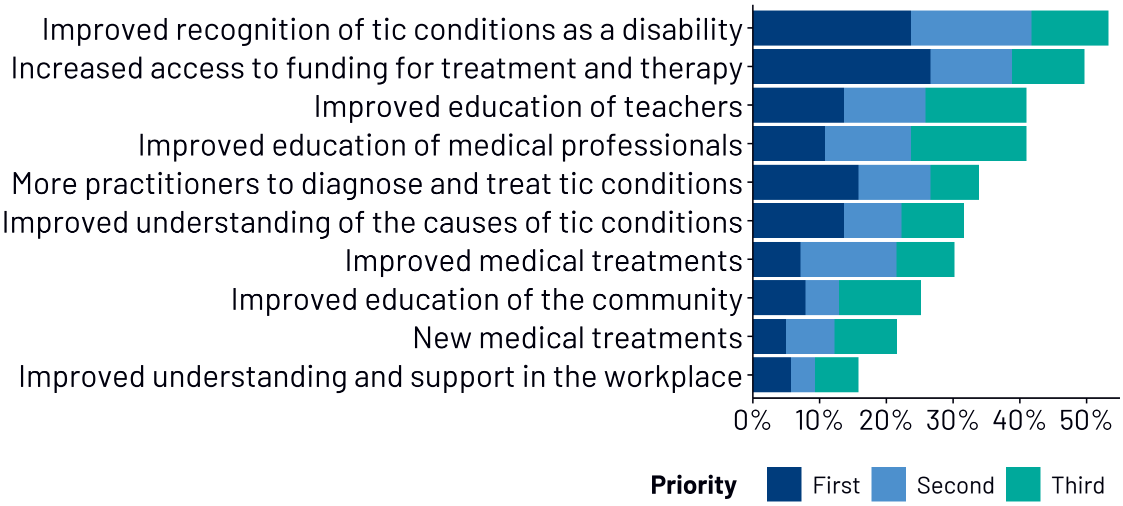

*Figure 51. Priority areas identified*

> *"Tics can be a very debilitating condition that does prevent a normal quality of life...we also need to make sure the support is around it medically, not enough of a focus is on this and it's because it's not recognised therefore the money doesn't follow it."*
>
> – Child Caregiver

> *"People are better at accepting diversity in gender, sexuality, culture, physical conditions such as those needing wheelchairs - BUT there is little acceptance of different behaviour - the more folks know about TS and tics the more people will think it's just part of the continuum of being human. "*
>
> – Adult caregiver

> *“I need funding to help me get the support I need to try and improve. I haven't had success with treatment so far and would like for there to be information and more options available for treatment for tic patients.”*
>
> – Adult with Tics

> *“Increased access to funding for treatment and therapy is crucial because it helps alleviate the financial burden on families affected by tic conditions. Many treatments and therapies, such as behavioural therapy and specialized interventions, can be costly, making them inaccessible to families with limited financial resources."*
>
> – Child Caregiver

Increased access to funding for treatment and therapy was ranked as a top 3 priority area by 50% of respondents. Open-ended responses indicated that increased funding was a priority area for change in the hopes that it would reduce financial burden for people with tic conditions and their families, increase access to the medication therapies, and increase the availability of therapeutic alternatives to medication.

Improved education of teachers was ranked in the top three priority area by 41% of all respondents. It was the highest ranked priority area by caregivers of children, ranked in the top three by 55% of child caregivers. Child caregivers reported that increased education of teachers would position teachers as important allies in advocating for and providing academic and social support, allow teachers to act as information pathways to the wider community, and reduce discrimination and bullying through increased understanding of tic conditions in the school setting.

> *“As kids spend so much of time in school, we need educators to be more aware so they are supported to provide better support themselves - you don't know what you don't know.”*
>
> – Child Caregiver

> *“The school system…is having a MAJOR impact on his health and wellbeing, and that of the whole family. Educating teachers would flow down to educating peers and other parents, leading to increased awareness in the community.”*
>
> – Child Caregiver

*“If more medical professionals were educated on tic conditions then diagnosis could occur sooner and support and education of other areas of our lives could happen at a younger age… It would also help inform and guide what supports are needed.”*

– Child Caregiver

*“The wait list to get a diagnosis are lengthy and once we had a diagnosis, there was no treatment on offer other than medication."*

– Child Caregiver

*“Improved education of medical professionals is essential to ensure accurate diagnosis, appropriate treatment, and effective management of tic disorders. Many healthcare professionals may have limited knowledge or understanding of tic conditions, leading to misdiagnosis or inadequate treatment. By providing comprehensive education and training on tic disorders, medical professionals can improve their ability to recognise and address these conditions, ultimately improving outcomes.”*

– Child Caregiver

Improved education of medical professionals was ranked as a top three priority area by 41% of respondents. Respondents felt that improved education of medical professionals was of particular importance to improve the standard of care in diagnosis and treatment, provide early identification, reduce negligent medical practices, and increase understanding that tic disorders are lifelong for some people.

More practitioners to diagnose and treat tic conditions was ranked as a priority area by 34% of survey respondents. Respondents felt that more practitioners would reduce wait times, improve the quality of care, and ensure that people with tic conditions receive the support and resources they need.

*“It will allow for better support for those struggling with tic disorders and their families, lessen the rates of mental health problems that having a tic disorder cause. Medical professionals have our lives in their hands, it is integral to our safety that they have correct knowledge on our tics and don't have stigma.”*

– Adult with Tics

The findings of this national Impact for Tourette's survey highlight the significant gaps in care for people living with tic conditions and their families. An urgent need for increased recognition of the disability associated with tic conditions has been prioritised by the community, along with improved access to healthcare and treatment, increased access to funding, improved access to mental health services, and improved knowledge and support within the education and employment sectors.

The findings from this survey presents a powerful opportunity for change. By collectively investing in the expansion of resources, education and research, we can ensure those with tic conditions are no longer overlooked and underserved.

It is now time to transform the way we approach diagnosing and managing tic disorders across the lifespan, to create a future where individuals receive the care and understanding they deserve.

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