

APPLYING FOR A CARE ACT ASSESSMENT FOR ADULTS WITH TOURETTE SYNDROME

TOURETTE SYNDROME (TS) IS RECOGNISED AS A DISABILITY AND IS PROTECTED UNDER THE EQUALITY ACT 2010. THIS MEANS THAT YOU MAY BE ENTITLED TO REASONABLE ADJUSTMENTS AND SUPPORT. SOME PEOPLE WITH TS STRUGGLE TO ACCESS SUPPORT. THIS FACTSHEET AIMS TO HELP YOU NAVIGATE THE CARE ACT ASSESSMENT, WHICH IS NEEDED TO ACCESS SOCIAL CARE IN ENGLAND.

DISCLAIMER

Care Act assessments can vary between local authorities. A TS diagnosis alone does not guarantee eligibility. It makes someone potentially eligible, but support is only provided if the condition has a significant impact on their daily life and wellbeing.

WHAT IS THE CARE ACT 2014?

The Care Act 2014 is the law that explains how adult social care works in England. It sets out:

- **Who can get support**
- **How your needs should be assessed**
- **What kind of help you may be entitled to**
- **Your rights to be involved in decisions about your care**

The Act aims to make sure adults with disabilities or long term conditions, including TS, can live safely, independently and with dignity.

HOW DOES THE CARE ACT ASSESSMENT WORK?

A Care Act assessment looks at **your needs, your daily life** and **what support would help you stay well.**

If you think you could benefit from additional support, the first step is to contact your local authority (council). If you are not sure about who your local authority is, you can find out using this link to the government website: www.gov.uk/apply-needs-assessment-social-services.

A local authority must assess you if there is a reason to think you may need care or support. You do **not** need a diagnosis

and your finances do **not** affect whether you can be assessed.

WHO CAN REQUEST AN ASSESSMENT?

- You
- A family member or friend
- A GP or health professional
- Anyone who is concerned about your wellbeing

There is a template at the end of this factsheet that you or your carer can use to help you write to the adult social care team at your local authority. →



HOW DOES THE CARE ACT ASSESSMENT WORK?

(CONTINUED)

WHAT SHOULD THE ASSESSMENT INCLUDE?

Care Act assessments are carried out by trained assessors and will involve a **person-centred conversation** about your needs and goals. They will discuss with you:

- How your condition affects your wellbeing, safety and independence
- Your views and the views of your carer or advocate (if you want them involved)
- What community support and practical help is currently available to you

ARE YOU ELIGIBLE FOR SUPPORT?

You may be eligible if:

1 Your needs come from a physical or mental impairment

This includes Tourette syndrome, ADHD, autism, OCD traits, anxiety or other neurodivergent conditions.

2 You are unable* to achieve two or more daily tasks, such as:

- Eating and preparing meals
- Washing, bathing or personal hygiene
- Using the toilet
- Dressing appropriately
- Keeping your home safe and clean
- Maintaining relationships
- Working, studying or volunteering
- Using community services
- Caring for a child

* 'Unable' includes needing help, taking much longer or experiencing distress or risk.

3 Your wellbeing is significantly affected

This may include your mental health, safety, independence or quality of life.



HOW DOES THIS APPLY TO TS?

TS can affect daily life in many ways, including:

- Motor or vocal tics that make tasks difficult
- Anxiety, OCD traits or executive dysfunction
- Sensory overload
- Social isolation or stigma
- Difficulty planning, organising or completing tasks

During your assessment, you can explain how TS affects:

- Cooking and eating
- Personal care
- Managing your home
- Going out safely
- Communicating with others
- Managing routines
- Emotional wellbeing

It's important to remember that TS symptoms can fluctuate and not all professionals understand the condition well. It may help to bring written examples of how TS affects you on 'good days' and 'bad days' to your assessment.

QUICK ELIGIBILITY CHECKLIST

Tick any that apply to you:

1

Step 1: Needs arise from a condition

- ☐ Tourette syndrome
- ☐ ADHD, autism, OCD traits, anxiety or sensory issues
- ☐ Condition affects daily functioning

2

Step 2: Difficulty with daily tasks

- ☐ Eating or preparing food
- ☐ Washing or hygiene
- ☐ Using the toilet
- ☐ Dressing
- ☐ Keeping your home safe
- ☐ Relationships
- ☐ Work, education or volunteering
- ☐ Using community services
- ☐ Caring for a child

3

Step 3: Impact on wellbeing

- ☐ Mental or physical health affected
- ☐ Risk of harm, neglect or isolation
- ☐ Reduced independence

If you have ticked at least one box from each of the three categories, you are likely to be eligible for support.

WHAT HAPPENS IF THE ASSESSMENT CONFIRMS YOU ARE ELIGIBLE FOR SUPPORT?



If you meet the criteria, the council must:

- 'If you meet the criteria, the council must: Create a **care and support plan** with you
- Explain your support options
- Review your plan regularly

The support you receive will depend on your needs and the plan may include:

- Help with daily tasks
- Support to access the community
- A personal assistant (PA) or support worker
- Help to manage routines and wellbeing
- Access to local services or groups

If you decide to use a **support worker** or **PA** to help with daily living, routines, community access or social support, the local authority must offer the option of direct payments if you want to employ your own PA. Direct payments mean payments made directly to you or to someone you choose, rather than having the local authority manage your support budget.

SAMPLE REFERRAL LETTER

You can copy and adapt the letter below if you want to write to your local authority to request a Care Act assessment for yourself or someone else. The text in red can be edited or deleted to personalise the letter and explain your individual needs.

Request for Care Act Assessment – [Full Name]

Dear Adult Social Care Team,

I am requesting a Care Act 2014 needs assessment for **[Full Name]**, an adult living with Tourette syndrome and associated neurodivergent traits. Their condition affects daily living and they may require support, including a support worker or personal assistant (PA).

Background: **[Name]**, aged **[Age]**, experiences motor and vocal tics, as well as challenges such as **[anxiety/sensory issues/executive dysfunction]**. These symptoms affect their ability to manage daily tasks and maintain wellbeing.

Areas of difficulty include:

- **[Personal care and hygiene]**
- **[Meal preparation and nutrition]**
- **[Keeping a safe home environment]**
- **[Accessing community services]**
- **[Managing emotional wellbeing and avoiding isolation]**

These difficulties meet the Care Act eligibility criteria.

Additional request[s]: A person centred approach that recognises the fluctuating nature of Tourette syndrome. **[Consideration of direct payments.]**

Please confirm receipt and advise on next steps.

Yours faithfully,

[Your Name]

[Relationship, if relevant]