

Information for Clients awaiting full assessment of Autism

This Session Contain information about:

- The Wait for assessment (useful info and services for now)
- The formal diagnosis: experiences
- What is involved in the assessment and services that exist after assessment

The Wait

- The wait does vary a little bit and is updated monthly on the web site [Autism Spectrum Disorder \(asd\) Service \(yourhealthcare.org\)](https://yourhealthcare.org):

Who we are	Our team	What we do	ASD assessment waitlist
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This month we got **24** new referrals.
At the moment there are **527** people on the waitlist for assessment.
We are currently seeing people who were referred in **July 2021**.

Related Diagnoses

- ADHD; if you think you might have ADHD but you are not diagnosed this can be part of your Autism Assessment if you live in Kingston only.
- Please let us know if this is the case and we can plan a joint assessment.
- In Richmond, there is a separate ADHD service provision and a link to this service is here: [Service detail - Website \(swlstg.nhs.uk\)](http://swlstg.nhs.uk)

The Assessment

- The majority of the assessments take place at Hollyfield house in Surbiton:



The Assessment

- The assessment always involves two people, one of whom will be always be a Clinical Psychologist.
- The assessment involves an interview about your history. Often this is given by someone who knows you very well when you were young- like a parent, but if that is not possible then some people provide the history themselves, and sometimes old school reports or baby books are helpful.
- The assessment also involves a meeting with you, which is quite interactive and practical.
- These assessment are called the ADOS-2 and the ADI-R and they are related to diagnostic criteria for Autism. For more information: [all audiences \(autism.org.uk\)](http://allaudiences.autism.org.uk)

The Assessment

A majority of assessments are now done as a one day assessment.

That means a busy day, but is more straight forward in terms of taking time off work, and it means that you usually can meet with both clinicians in the morning to talk through the plan for the day, and at the end of the day to talk through the outcome(s)- so there is very little waiting to know the outcome.

If you don't have someone to give some early history on your behalf the one day structure may be too much and people are usually people are offered two slots then, one of which can be online. -Usually these will be quite close together (within a few weeks).

The Report

Within two weeks of your assessment you will receive a draft report, in addition to a shareable summary statement which is a proof of diagnosis not containing extensive personal information.

People have the chance to review the report and any factual corrections are addressed.

When the report is agreed, and with your consent the report is shared with your GP.

Following a diagnosis: work

- Disclosing diagnosis is an individual choice and different for everyone
- If your diagnosis is disclosed, it is a legal requirement for employers to make reasonable adjustments. Some employers will ask for proof of diagnosis.
- Reasonable adjustments at work- who makes these?
 1. You can list them and discuss with your employer
 2. You can seek support from your HR/inclusion officer- if one is in place [Asking for reasonable adjustments \(autism.org.uk\)](https://www.autism.org.uk)
 3. YHC- we support with this post diagnosis

Information about PIP/Benefits/transport

- There are dozens of different benefits which are individually assessed. Summary in link below
- <https://www.autism.org.uk/advice-and-guidance/topics/benefits-and-money/benefits/benefits-you-can-get/benefits-for-autistic-adults>
- In our experience, there are times when having a diagnosis can help with accessing benefits for people who need them.
- If needed we can provide a letter to PIP in relation to your needs following a diagnosis. Some GP's will do the same.

Supportive social opportunities in Kingston and Richmond

There are numerous social groups which may/may not suit every individual. Not all of these require a diagnosis and some links are below:

<https://creativyouthcharity.org/fusebox/>

- <https://www.bubbleclub.org/>
- www.kingstoneco-op.org.uk
- <https://www.ruils.co.uk>
- <https://www.doseofnature.co.uk>

Parenting (support and community)

- www.expresscis.org.uk offers a range of family support for the for a wide range of circumstance including: preschool-teens-siblings-girls-mums-dads-counselling-legal advice-demand avoidance
- <http://www.richmondnas.org/> the national autistic society -Richmond branch support
- **The Autism and Sensory Parenting Podcast** Candice Curtis

Housing: useful links

- <https://www.gov.uk/housing-and-universal-credit>
- <https://www.kingston.gov.uk/housing-options-advice#js-menu>
- <https://www.rhp.org.uk/>
- <https://www.spearlondon.org/>
- Kingston Council offers support through Older Vulnerable people Team for those 55 years of age plus- individual support with applying to housing/bids etc
- Resettlement and support team offers the same for 18-54 year olds age
- Richmond Advice and Information (RAID) offer a similar service
- YHC can provide supportive letters towards your housing post diagnosis

Autism and Women

-We are increasingly aware that women have a different experience, do often present differently, have some different vulnerabilities

-We do now have more women being referred than men, and from a sample of 30 recent assessments, women were not less likely to be recognised- so in that sense we are now better at picking up on female presentations. We do sometimes use a questionnaire designed to capture masking (the CAT-Q); if we suspect people are masking to the extent that we can't pick up symptoms (often we can). If you'd like to try the CAT Q you can find it here:[Embrace Autism | The ultimate autism resource \(embrace-autism.com\)](https://embrace-autism.com)

Diagnosis (vs self ID) Pros and cons

- Pros of formal diagnosis

For some people, there is an experience of increased understanding and acceptance- both of self and from others

Often the diagnosis makes sense of other labels/diagnoses and difficulties experienced over many years

Diagnosis be very validating; some people can change their lives and environments based on a new understanding, that is not now about changing themselves. A diagnosis can be impactful on sense of identity and this might often mean, doing or wanting do some things differently. Some times it means wanting to ask other people to do some things differently as well

Diagnosis does give access to some specific services (both individuals and families eg. Carers centres)

Diagnosis can be helpful re PIP etc. and can increase understanding and recognition from DWP or other services

Diagnosis Pros and cons 2

Difficulties following diagnosis - what people have told us

It is not uncommon to people to experience some feelings of grief following a late diagnosis:

'Im 67 now and my diagnosis made me look back at my life in a way that I felt less comfortable and proud of- I wished I hadn't done it at this stage'

Often however, the grief is linked to a sense of increased understanding and the wish that this had happened sooner.

Sometimes following diagnosis people feel distress at the outcome of disclosure; or experience discrimination:

'[someone else] told me to get a diagnosis, and now when we disagree everything gets put down to my Autism'

Several people have raised the concern with us that a diagnosis on their medical record impacts/ has impacted on their ability to emigrate and work abroad*- [Dehumanization: Archaic Immigration Policies Against Individuals with Disabilities | CANDLELIGHT \(utoronto.ca\)](#)

Other Useful Information

- Sensory Inputs [Sensory differences \(autism.org.uk\)](https://www.autism.org.uk); www.sensorydirect.com
- Burnout and Overwhelm-[Understanding autistic burnout \(autism.org.uk\)](https://www.autism.org.uk)
- Connection and the Double empathy problem: [The double empathy problem \(autism.org.uk\)](https://www.autism.org.uk)
- Right to choose; [Your choices in the NHS - NHS \(www.nhs.uk\)](http://www.nhs.uk)
- Assistance animals; [What is an Autism Assistance Dog?](https://www.autism.org.uk)

Your Health Care Services Post Diagnosis

- Social Prescribing/ Care Co-ordination
- Generic Social prescribing is offered by some GP surgeries on an ongoing basis, but in the service we are now piloting an Autism specific service aimed to improve access to community activities/events/individual hobbies/support around making calls/applications/college and courses/GP and other health appointments
- Autism Care Coordination – help with navigating care support/prevention of hospital admissions/care planning and monitoring/providing advice, education and information to clients and their network team

Your Health Care Services Post Diagnosis

- Post diagnostic groups are offered as an opportunity for people to learn from one another, and to exploring the symptoms of and impact of Autism in a supportive group setting
- Groups are offered in person or on line and at the moment there is also a women's group, and a group for supporters and family members
- Family Therapy: We have recently started offering families the opportunity to access a family/systemic therapy clinic which is focussed of neurodiversity in families and is around recognising and supporting family interaction in neurodiverse families

Some Other Resources

- There are hundreds of informative **podcasts** and **books** on the subject of Autism. While they are very much to individual taste those below have been particularly recommended by people who have accessed this service:
- **The Autism Podcast- David Gray Hammond**
- **Reframing Autism Podcast- Angelique Joy**
- **Autism in the Adult- Theresa M.Regan**

Books

The Autistic Brain- Temple Grandin

Camouflage- Sarah Bargiela

Strong Female Character- Fern Brady

Thank you