

Briefing on pause to referrals for endocrine treatments for under 18s from the Sandyford Young Person's Gender Service 23rd April 2024

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The Equality Network is a leading Scottish LGBTI equality and human rights charity. Scottish Trans is the project of the Equality Network focusing on the equality, human rights and inclusion of trans people.

We want every child or young person to get the individualised care that's right for them at the time that's right for them. We don't think this decision will make that possible.

Background

The Sandyford Young Person's Gender Service is the only specialist gender identity service in Scotland that provides care to children and young people experiencing uncertainty or distress around their gender identity.

They announced on 18th April 2024¹ that they would no longer be referring under 18s to paediatric endocrinology as part of the pathway – which means people using the service will no longer be prescribed puberty blockers (which pause pubertal changes), nor will 16 or 17 year olds be prescribed testosterone or oestrogen (which have masculinising or feminising effects on secondary sexual characteristics).

This follows a similar announcement by NHS England made last month on puberty blockers. It indeed goes further than the NHS England position by stopping referrals for testosterone and oestrogen for 16 and 17 year olds. These decisions (in both England and now Scotland) have been taken in large part due to the publication of a NICE review into the evidence base on puberty blockers², and the publication of the Cass review, which was a wide-ranging review into the provision of gender identity services for children and young people in England³.

Before this announcement, puberty blockers and/or testosterone or oestrogen (depending on what was appropriate) would be prescribed to a small number of young people per year, after extensive psychological assessment, that included the child or young person's family.

¹ <https://www.sandyford.scot/sexual-health-services/gender-service-at-sandyford/gender-young-people-service/>

² <https://www.england.nhs.uk/publication/clinical-policy-puberty-suppressing-hormones/>

³ https://cass.independent-review.uk/wp-content/uploads/2024/04/CassReview_Final.pdf

Between 2016 and 2023, 71 young people were prescribed puberty blockers after accessing the Sandyford Young Person's Service⁴, which we understand is a very small percentage of the number of patients who accessed their service.

The service has confirmed that there are 43 young people under 18 who are currently, and who will continue to be, prescribed either puberty blockers or gender affirming hormones. There are around 600,000 children and young people aged 10-19 in Scotland. Before this pause, the referral to endocrine treatments of children and young people was always a choice for an extremely small number of people, after significant and lengthy assessment.

On 17th April Dr Hilary Cass met with The Kite Trust, alongside other LGBT+ support organisations in England. They asked her questions that young people and families had following the release of her report. This is how they summarise what Dr Hilary Cass said about puberty blockers and gender affirming hormones:

"The Cass Review Report does not conclude that puberty suppressing hormones are an unsafe treatment. The report supports a research study being implemented to allow pre-pubertal children to have a pathway to accessing this treatment in a timely way and with suitable follow up and data collection, to provide the highest quality of evidence for the ongoing use of puberty suppressing hormones as a treatment for gender dysphoria...

...The Cass Review Report recommends that a different approach is needed, with puberty suppressing hormones and gender affirming hormones being available to young people at different ages and developmental stages alongside a wider range of gender affirming healthcare based on individual need." (our emphasis added)

<https://thekitetrust.org.uk/our-statement-in-response-to-the-cass-review-report/>

The need for more research

We agree that more evidence on trans children and young people's health outcomes is needed, and would support any efforts to conduct collaborative, ethical research that could improve treatment options and outcomes.

We note that both the NHS England interim service specification for specialist gender incongruence services for children and young people⁵, and the Sandyford announcement, refer to the possibility that children and young people will continue to be prescribed puberty blockers as part of a research protocol. Yet as far as we are aware this research protocol does not yet exist, and there is no information about its intended design.

Approach to endocrine treatments for children and young people internationally

The decisions in England and Scotland to stop endocrine referrals for under 18s also means that our services are not aligned with practice in a range of other countries.

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https://www.whatdotheyknow.com/request/gender_dysphoria_service_at_sand/response/2518992/attach/3/FOI%20Request%2019994%20Response.pdf?cookie_passthrough=1

⁵ <https://www.england.nhs.uk/publication/interim-service-specification-for-specialist-gender-incongruence-services-for-children-and-young-people/>

Healthcare practitioners in Canada⁶, Australia⁷ and New Zealand⁸ have reacted to the Cass report explaining that they continue to be of the view that evidence supports the use of endocrine treatments for some children and young people.

Austria, Germany and Switzerland also jointly published an updated clinical pathway last month, and will continue to prescribe endocrine treatments for some children and young people⁹. They considered the NICE evidence review but concluded that puberty blockers should still be one possible treatment option.

Ensuring every child and young person can access the care they need

We are very concerned that the decision to place a universal pause on referrals for endocrine treatments for under 18s will result in some children and young people not being able to access the care that is right for them, at the time that is right for them.

NHS England, NHS Greater Glasgow and Clyde and Dr Hilary Cass all seem to agree that endocrine treatments may be the right thing for some children and young people, despite recommending a change in policy. A number of countries continue to provide endocrine treatments for trans children and young people where appropriate for that individual, on the basis of the same evidence available here.

We have spoken to families supporting young people to access gender identity services, and to people who have used the young person's service, who tell us that being trans, living true to themselves, and accessing endocrine treatment as part of that, were all positive, hopeful, joyful things.

Yet the position in Scotland is now, indefinitely, that no child or young person will be able to access endocrine treatments.

We call on MSPs to urge the Scottish Government and NHS to urgently prioritise resourcing high quality, ethical research that means that no child or young person in Scotland is denied the care they need.

⁶ <https://www.cbc.ca/news/health/puberty-blockers-review-1.7172920>

⁷ <https://www.theguardian.com/australia-news/2024/apr/20/england-nhs-dr-hilary-cass-review-transgender-healthcare-impact-australia>

⁸ <https://www.nzherald.co.nz/nz/nz-government-wont-say-if-it-will-follow-uks-move-to-ban-routine-use-of-puberty-blockers-as-treatment-for-trans-youth/XM4LR3XIVZF2JAKJU74OOELSOU/>

⁹ <https://www.sciencemediacenter.de/alle-angebote/press-briefing/details/news/awmf-leitlinie-zu-geschlechtsinkongruenz-und-dysphorie-im-kindes-und-jugendalter/>