



Nobody teaches you how to be a patient

The lived experiences of
neurodivergent, disabled and
chronically ill trans people

Edited by Moss Pepe

Written by neurodivergent, disabled and chronically ill trans people
for neurodivergent, disabled and chronically ill trans people



Nobody teaches you how to be a patient

This resource was written and produced by neurodivergent, disabled and chronically ill trans and non-binary people living in the UK. It aims to highlight the strategies that we employ to overcome the additional barriers we face in accessing care, as well as draw attention to those challenges.

All people deserve full and equal access to healthcare services, but this is not always the reality. People's identities enter the GP's office with them, and this can disadvantage their care. TransActual's 2021 Trans Lives Survey found that 70% of respondents experienced transphobia when trying to access non trans-specific healthcare services. In addition to this, 60%

of disabled respondents reported experiencing ableism when accessing trans-specific healthcare. This means that neurodivergent, disabled, D/deaf, and chronically ill trans and non-binary people have their access to care negatively impacted on multiple fronts. Furthermore, Black trans people and trans People of Colour reported experiencing ableism and transphobia in medical settings more frequently than white trans people did.

While we fight for better treatment in healthcare settings for trans people and for a better future, we hope that the lived experiences and resources in this collection can help individuals now. This collection is intended to aid people as they navigate these (often hostile) systems and try to overcome some of the barriers to accessing care in their lives.

These collected pieces demonstrate that different people take different approaches to the challenges of accessing appropriate care, and that different solutions can work in different situations. We hope that this collection will help readers to think through the difficulties they may face in accessing medical, mental health and trans related services, and that reading these pieces might help people to find potential solutions to the problems they face.

Finally, we would like to thank everyone who took part in this project for their openness and generosity in sharing their experiences, and for their invaluable advice and perspectives. We'd also like to thank the National Lottery Community Fund for funding this resource. Their funding meant that we could pay everyone who contributed to the project.

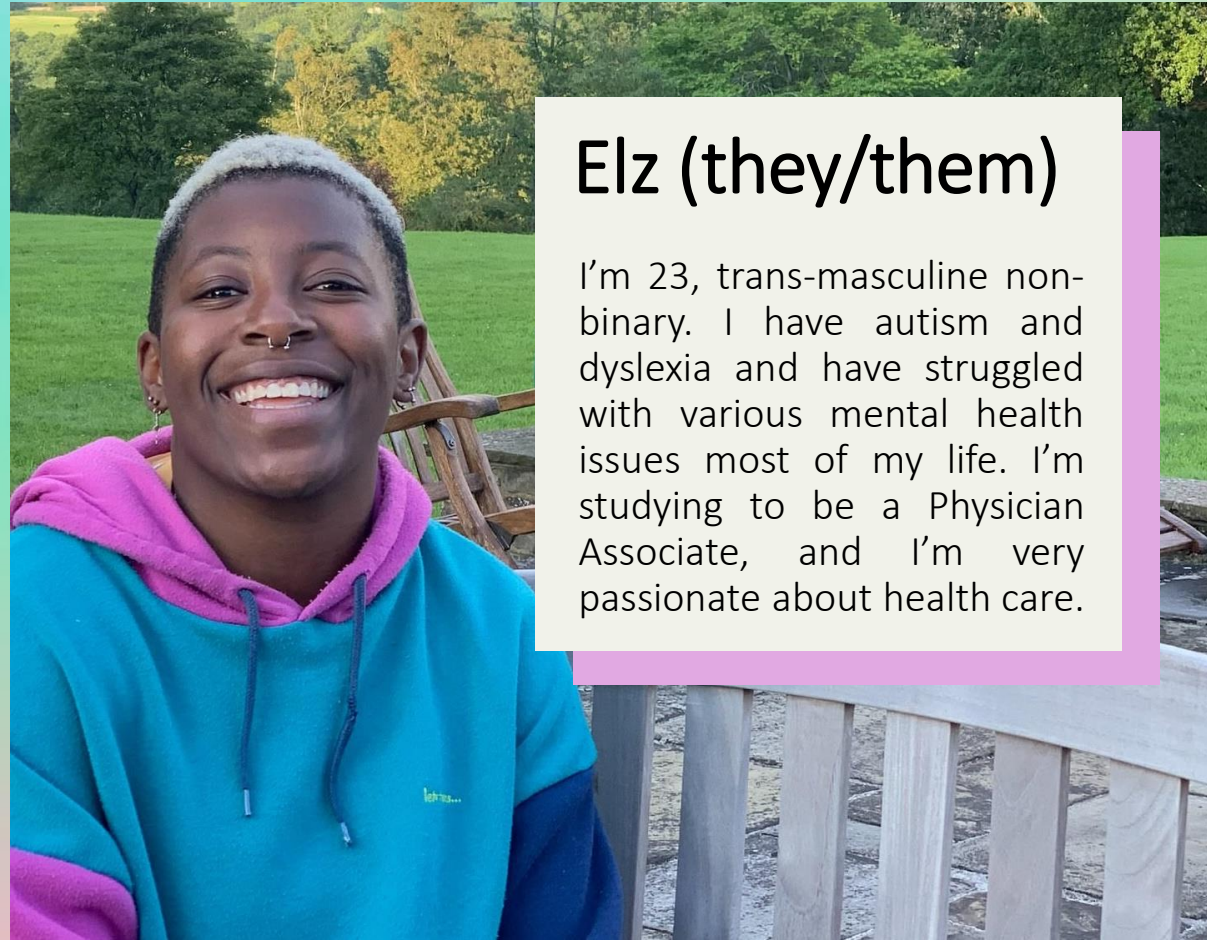


Content warning: this resource makes reference to experiences of ableism, transphobia, dysphoria, eating disorders and suicidal ideation.

Overcome the barriers: ten top tips

- 1 You are an expert in your lived experience.**
You know your body, your mental wellbeing, and what is normal for you. Keep this in mind at appointments so that you can confidently express when you need help with something, or when something is wrong.
- 2 Make a plan.**
Go into healthcare appointments with an idea of what you want to get out of them. Doctors won't always ask the right questions, so try to prepare to express what you need from them.
- 3 Write notes to bring to medical appointments.**
Writing notes can help clarify what you want or need from an appointment. Not having to keep everything in your head can make appointments less stressful. You can also show these notes to the doctor or health practitioner if you are finding it hard to communicate in other ways.
- 4 Consider bringing someone you trust with you.**
Important appointments can be a lot less daunting if you bring a friend, carer or advocate, who can help with emotional support, act as a witness to what is being said and intervene if necessary.
- 5 Ask for what you need.**
It's so important to be able to ask for what you need from a doctor. Try to figure out the way that you're most comfortable expressing yourself, whether on your own or with the help of someone else.

- 6 Keep records of your care.**
It can be useful to keep your own records so that you can track any referrals, appointments, changes in medication or dosages, and other treatments. This can also help you monitor what is and is not working for you.
- 7 See if you can change what isn't working.**
If you're facing barriers to receiving care, it's sometimes best to see if there is anything you can change. Perhaps seeing a different GP at your practice or changing GP surgery altogether might suit your access needs better. Services like PALS (Patient Advice and Liaison Services) can also help you make a complaint or advocate for you when things go wrong.
- 8 Join online or in-person support groups.**
There are lots of peer support groups that can offer practical and emotional support. Knowing others who have faced similar challenges can be comforting, and hearing about others' experiences can help too.
- 9 Charities can offer help.**
There may be charities in your area or nationally who can help you access additional help and support with a variety of things, such as applying for specific benefits, free or low-cost therapies, advocacy, support groups and more.
- 10 Do your research.**
Knowing your rights, relevant information about your illness, condition or disability, and what to expect from referrals can help you to feel empowered in appointments. You can also bring printouts or notes to show doctors.



Elz (they/them)

I'm 23, trans-masculine non-binary. I have autism and dyslexia and have struggled with various mental health issues most of my life. I'm studying to be a Physician Associate, and I'm very passionate about health care.

My whole life I have always felt different, especially when it came to my sexuality, gender, and emotions. I have been 'diagnosed' with general anxiety disorder, depression, OCD, borderline personality disorder, and PTSD, which was confusing to me. I have been to different kinds of therapies, but none of them seemed to help, and the anti-depressants I was on didn't seem to have much effect. I tried explaining to many doctors, "I still feel rubbish, something's not right," but due to all these labels on my records, they said it was just poor mental health. I never really got anywhere with any of the help offered, so I was just left suffering and getting worse. I felt hopeless.

As a 3rd year Psychology student at university, I happened to study a bit about autism. I resonated with a lot of the information and case studies I read about autism. It felt very familiar, but I was 21 at the time and I thought surely, I would have known by now if I had autism? Surely my family and

friends would have noticed something when I was younger? I read more about how people assigned female at birth were less likely to get diagnosed due to different presentations of autism. After two years of not getting any help, I read so much about autism, specifically autism and gender that I was almost confident that I might have autism. I went to see a GP. I came prepared with notes of all my symptoms and how I had been throughout my life, and I asked if I could start the process of getting a diagnosis. My GP was kind, she listened to me, agreed with me, and instantly referred me for an autism assessment.

I now have a new fantastic GP who is trans and takes a special interest in endocrinology. He has made my transition and my journey on testosterone very smooth, but not all health care professionals are like him. I recently made an appointment to start some

new contraception, and the doctor said that he did not know about testosterone and transitioning, so he couldn't prescribe me anything, which left me very frustrated and annoyed since I had waited two weeks for that appointment. I then had to call up for another appointment to see if anyone else could prescribe me contraception. I had to do my own research about interactions between medications, in case they too didn't know about testosterone and trans health.

A lot of health care professionals say don't google your symptoms and I agree and disagree with that. I think no one teaches you how to be a patient, or how to advocate for yourself. It's important to know yourself and your body and even do a bit of research before you go to an appointment. There are many websites that explain things simply. This allows you to have more informed conversations with health care professionals or even challenge them if you think they should / should not be doing the things they are doing.

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Holly (she/they)

My name is Holly, my pronouns are she/they. I am a 36-year-old person who has been suffering from ME/CFS for the past 25 years, and in the last year, Long Covid. This chronic illness affects my ability to exert any physical energy, so my hobbies are a bit limited. I really enjoy escapism as I don't have energy to do much in the real world, so I enjoy playing computer games, reading books and watching films full of energy.

Like many trans people, I have faced a healthcare system that is discriminatory when it comes to access to healthcare. The maximum waiting time for NHS appointments is supposed to be 18 weeks, yet the GIC waiting time for me has been 3 years and counting. Additionally, as a disabled person my access to healthcare is further limited. My ability to walk anywhere, even before Long Covid, was already limited due to my ME/CFS. Every time I exerted any energy, it cost me a lot. If I went past my energy limits, I crashed and became bed bound for anywhere between a couple of days to weeks. People with more severe ME/CFS are bed bound for life. I think, like with ME/CFS, some GPs don't take trans healthcare seriously. I was not allowed medication or blood tests through my GP, but luckily, I found an NHS clinic called CliniQ that could offer me help. Sadly, it came at the cost of my health as it meant travelling for hours into London, which resulted in me crashing for days or weeks afterwards. The only way I could overcome

Getting Covid completely disrupted my trans healthcare. I couldn't get out of bed, let alone go into London to receive treatment.

aware, however, that I'm lucky to live near a big city with these resources that others in the rest of the country do not have access to.

Things have sadly got worse with Long Covid, my energy limits have completely dwindled, and now I can't walk more than 15 minutes without being completely wiped. Getting Covid also completely disrupted my trans healthcare. I couldn't get out of bed, let alone go into London to receive treatment. I don't believe anyone should pay for good healthcare, but like a lot of other trans people, I've found that private healthcare companies have been a lifeline. They gave me the option to receive medication through the post, as well as the ability to do home blood tests via kits they can send to your door. Being disabled, my access to work is limited, and I would say now I

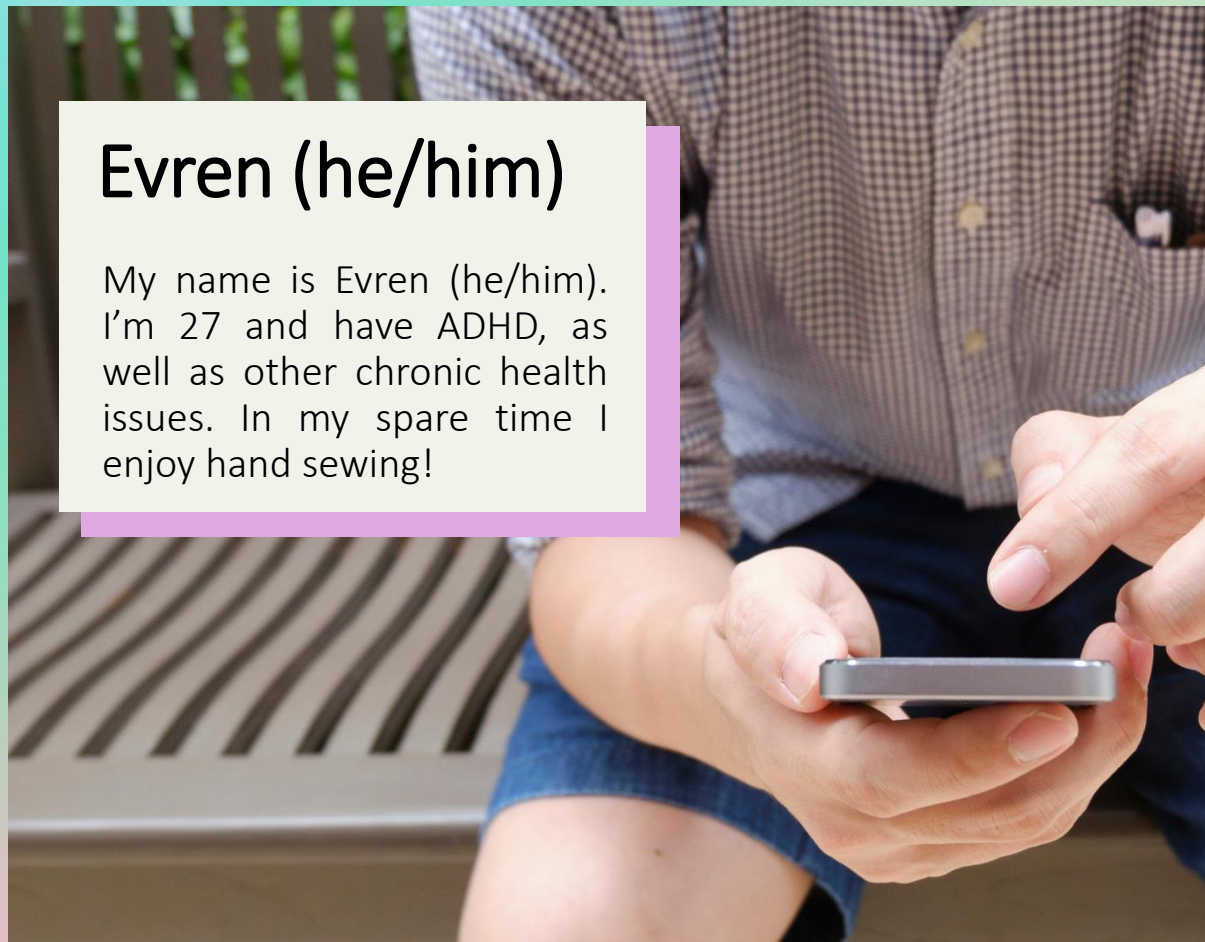
have Long Covid, finding work to fit around my disability is impossible. I am very lucky to have a loving partner who has a good enough job to support me and my healthcare costs. I really hope in the future that trans healthcare is free, fair and available to everybody and people won't have to spend years waiting for it.

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this was to limit my exertions as much as possible, so as to hopefully limit the toll it would put on my energy limits. I did this by finding transport with seating, making sure I could have the ability to sit and rest for a while after any walking and taking food with me for energy. I am

Evren (he/him)

My name is Evren (he/him). I'm 27 and have ADHD, as well as other chronic health issues. In my spare time I enjoy hand sewing!



I have had issues for over a decade related to gender care at the GP level, as well as mental health support, physical support for my chronic ill health and asthma. I've also had transphobia related problems on the administrative side of things, in terms of having my medical records lost, healthcare needs ignored because of 'trans broken arm' syndrome (when healthcare providers assume that all medical issues are a result of a person being trans), and also in accessing healthcare whilst unstably housed.

I've been faced with issues accessing healthcare for over a decade; whether trans related, mental health support, physical support for chronic illnesses or day to day stuff. I've had my medical records lost. I've had requests for care ignored, backtracked on, or outright denied. I've had tests rejected for incongruous gender markers. I've had threats to take away my HRT. I've had my fair share of 'trans broken arm' syndrome, and

I've been lied to by healthcare professionals at multiple levels. A lot of this will either be familiar to trans readers or even something they've experienced themselves, which is a sad indictment of an NHS I and many others agree is institutionally transphobic.

Despite all of these issues, I've been mostly able to access the care I've needed – save those services, like transmasculine bottom surgery, that have been unavailable for a period of time and are now severely delayed – thanks to some advocacy skills I've picked up, as well as a lot of help.


Things that I've found helpful:

Knowing your rights: Having the relevant legislation and NHS regulations easily accessible – maybe as notes I take to appointments – has helped me feel secure and confident even when dealing with potential access barriers.

Peer support: Dealing with GIC visits and other care difficulties can sometimes seem designed just to be hurtful. I credit my support networks for helping me to stay calm amidst intrusive questions and offensive comments from providers. A friendly support group chat, with boundaries to avoid burnout, is great for sharing the mental, emotional, and administrative load!

Advocacy: Sometimes self and peer advocacy alone doesn't cut it. When my GP refused to provide a gender marker letter for my passport and I was faced with not being able to leave the country in time for a job, QueerCare's intervention worked wonders to cut through the frustration when my own complaint was ignored. Peer support is great, but more 'official' help can work in similar ways to having a union rep, and I really recommend it!

A friendly support group chat, with boundaries to avoid burnout, is great for sharing the mental, emotional, and administrative load!

A portrait of Fey, a young person with long, dark, curly hair, wearing a teal turtleneck sweater and a necklace with a white pendant. They are looking slightly to the right of the camera. The background is dark with some green leaves and orange flowers visible.

Fey (they/them)

I am 23, non-binary, pansexual and I have autism, depression, and OCD. I work in a café, and am doing a master's in sexuality and gender studies. Frogs are my favourite animal.

The invalidation of the trans autistic experience is perhaps the most pervasive barrier during my transition. Before I had the language to articulate what it meant to be non-binary, I tried explaining my gender dysphoria to my GP. Whilst she was initially receptive, as I tried to explain how I was neither male or female her conclusion was incredibly invalidating. “Not to dismiss what you’ve said”, she said, “but because you’re autistic, it might just be that you’re confused.” I left feeling both unheard and as if I had wasted her time.

Through my local charity organisation, however, I found a counsellor who first opened my eyes to the possibilities of genderfluidity. At uni, I found other non-binary people who showed me that there is another option. It was the communities and found families I chose that worked to undo the pervasive and damaging ideologies from professionals who used gatekeeping and transmedicalism to dissuade me from transition.

Being read as an autistic postpubescent boy on the cusp of manhood seeped its way into discrimination in other forms of healthcare. Despite displaying many of the symptoms of anorexia and being an outpatient with the NHS eating disorder clinic, the closest diagnosis I got from a psychiatric professional was that I have “eating problems”. He specifically avoided using terminology that would legitimate my eating disorder. When I tried to express the ways it might be gender related, he shot me down immediately. I cannot forget the accusatory way he said to me, “you think by not eating you can avoid growing up and accepting your identity as a man”.

Once again, the intersections between being a trans & autistic person couldn't be clearer. My experience was trenchantly invalidated because under the cisgender and neurotypical gaze, we are drained of any agency, autonomy or say in who we are.

Thankfully, with the support of my other trans friends and my student loan, I found the means to begin oestrogen and laser hair removal. There were, however, issues with being pushed down a binary transition pathway. My endocrinologist assumed he would be treating me like a trans woman, despite telling him my pronouns were they/them. I had to reiterate multiple times that because I am non-binary, the body I want isn't a trans woman's body. This surprised him, but he agreed to start me on a half the typical dosage after some negotiation. I also refused to take T-blockers, and I am now eight months on oestrogen monotherapy! While the effects are slow, I couldn't be happier with the results, and I am so grateful I didn't succumb to the expectations of others.

If you are non-binary, don't let yourself be binarized by others. Especially not those who refuse to see us for who we are. I know many people who feel they have to pretend to be binary trans because they think this is the only acceptable way to access hormones. While being treated with legitimacy and validity is rare in a medical field and legal system that doesn't recognise us, there are those who will listen. And it couldn't be more liberating.

Oliver (he/him)

Oliver (he/him) I'm a 31-year-old non-binary trans man. I am autistic, schizoaffective, have Tourette's, and multiple other neurodivergent conditions. I also have chronic pain and chronic illnesses. I am a manual wheelchair user, and an AAC (Augmentative and Alternative Communication) user. In my spare time, I enjoy history and going to the theatre.



I was admitted to a private psychiatric hospital as an NHS patient, in a psychotic episode. As a wheelchair user, the bathroom in my room was not accessible, and therefore I was unable to shower for 6 weeks. The fact that I was unable to shower due to being a wheelchair user, made me feel forgotten and not even thought about. The ward staff referred me to the hospital occupational therapist (OT) and physiotherapist. With the support of the OT and physio, we were able to make the bathroom accessible, so that I was able to shower eventually with the support of one of the ward support workers. The fact that I was able to have a shower helped me somewhat as I was able to be clean and not smell, this helped with my mental health.

I use a manual wheelchair due to Tourette's Syndrome, and I am often met with disbelief when I tell people why I use a wheelchair. When I registered at my current GP practice, I was

very anxious about how the staff would react to my being a wheelchair user, however the staff have been great. I was not met with shock or disbelief, just staff who instead listened to me. This has helped to reduce my anxiety when going to see my GP, and therefore I am much more likely to visit the GP when needed.

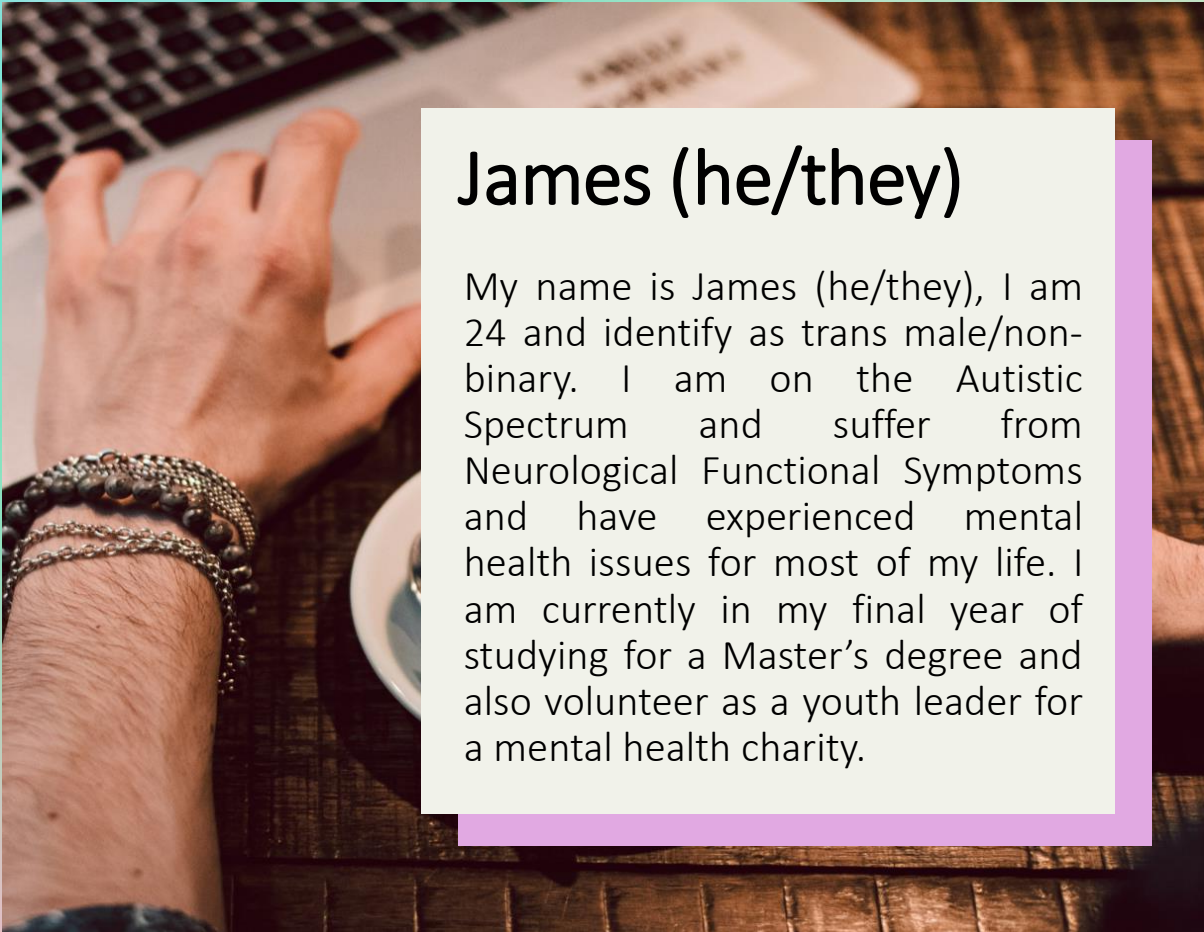
I carry 'Stickman Communication' cards with me, which I can show to professionals and explain quickly that I use AAC.

As an AAC user, I have had many experiences where healthcare professionals ignore me or refuse to engage with me. To help with this I carry 'Stickman Communication' cards with me, which I can show to professionals and explain quickly that I use AAC. This

has reduced the amount of professionals who refuse to engage with me.

When I was first referred for top surgery, I saw my surgeon and received a date for surgery. However, a few months before my surgery date, I was sectioned under the mental health act, and was in a psychiatric hospital for several months, including when my surgery date was due. My surgery was cancelled due to me being sectioned. I was obviously very upset and distressed about this. When discharged from hospital, I worked with my community psychiatrist and community mental health team to prove to the gender clinic and surgeon that top surgery would be a positive thing for my mental health. A few years after it was cancelled, I was able to have top surgery.

What I have learnt through my experiences as a disabled trans person is to work out what I need to say before going to medical appointments. I try to plan and write down things in advance, this helps my anxiety and means that I do not forget what I needed to say, and important things are not missed. It also means that, if written down on paper, I can give the healthcare professional a copy of the list straight away, which means it can be put in my notes and saved.



James (he/they)

My name is James (he/they), I am 24 and identify as trans male/non-binary. I am on the Autistic Spectrum and suffer from Neurological Functional Symptoms and have experienced mental health issues for most of my life. I am currently in my final year of studying for a Master's degree and also volunteer as a youth leader for a mental health charity.

I had been with the GIC for a while, and it was finally time for the appointment to get my prescription for testosterone, so I could start medically transitioning. I'd suffered from mental health problems for the majority of my life and, like many others, not being able to start hormone replacement therapy had had an added impact on my mental well-being.

What ended up happening in the appointment was confusing. After discussing the side effects of starting hormones and the physician agreeing to start me on them, I was then told that I should freeze my eggs. I explained that I wasn't comfortable freezing my eggs, that I had never wanted biological children due to personal and genetic health conditions, amongst other reasons. The physician insisted that it would 'be a waste of good genes' and that he would refer me to a local fertility clinic, that he would be 'very disappointed' if I did not go through with it. He also put a note in the letter back to my GP

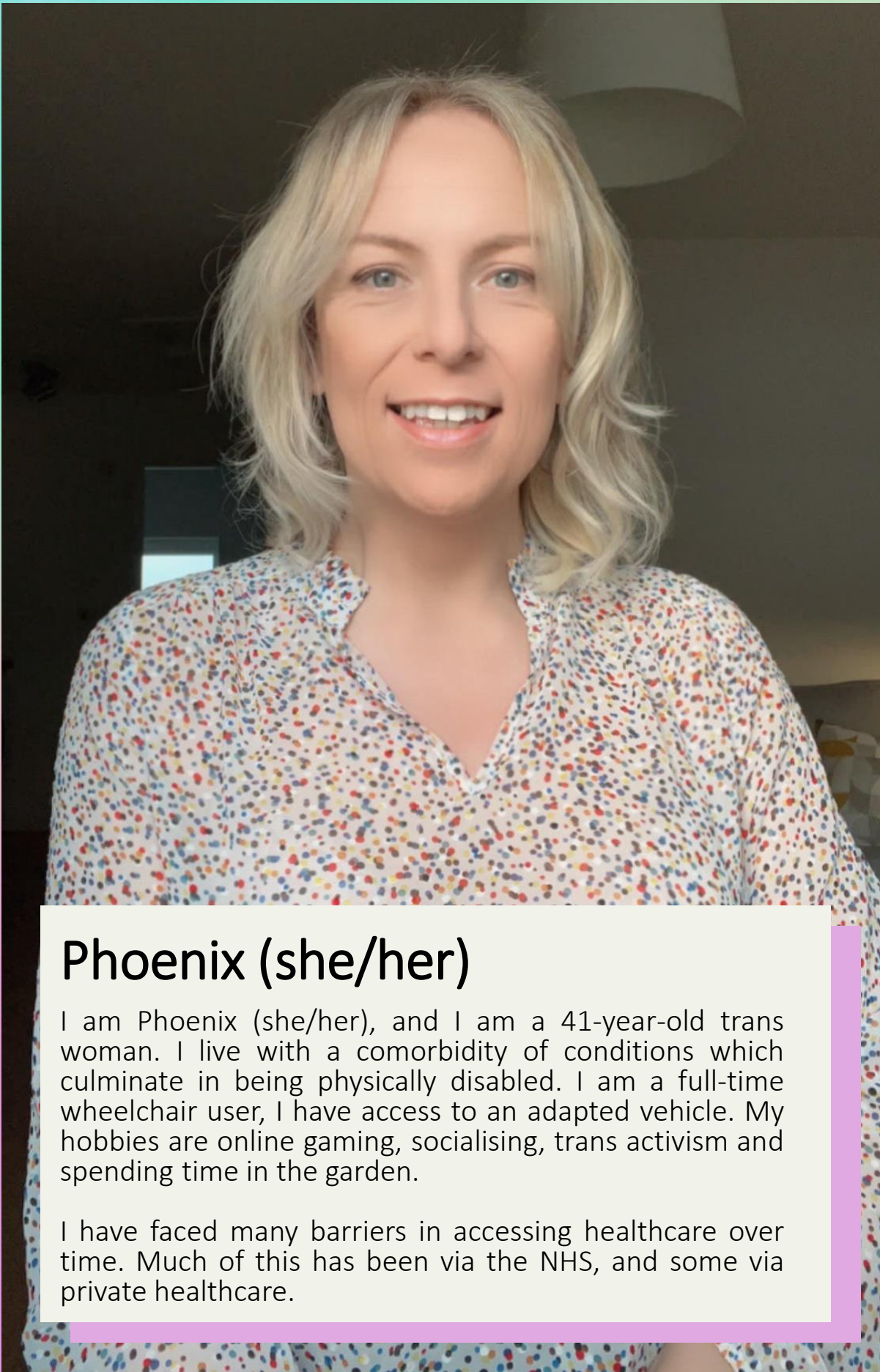
that he wished for me to have my eggs frozen before starting hormones.

Unfortunately, that didn't end up being the only problem trying to start hormones. My mental health continued to decline and after a couple of months I had still not heard from the GIC. I ended up calling the GIC and was repeatedly told that the letter-writing process could take up to or over six months, despite the letter having been dictated during my appointment. After talking to both my psychiatrist and my GP, I eventually called PALS (Patient Advice and Liaison Service).

PALS ended up being lifesaving in the end. After speaking – and crying – to them, about the wait time for the letter to be written up and the personal urgency of starting hormones (having been told by the physician that I should be able to start before University, but this becoming increasingly unlikely), as well as the opinions of the psychiatrist and GP, they got in contact with the GIC to enquire why the wait for a letter was so long.

After a combination of having a letter sent to the GIC by my psychiatrist and PALS putting pressure on the GIC, they eventually expedited sending the letter to my GP. Once the GP received the letter, I was able to talk to them about not wanting to freeze my eggs, especially if it was going to prolong my start to hormones – not to mention the months it would take to come off of my medication for my mental health as well as the months on oestrogen that would surely take a toll. Luckily, my GP agreed. She felt it was sexist and old fashioned that it was expected that I freeze my eggs and decided to ignore the 'request' that hormones not be started till I have my eggs frozen.

In the end I started testosterone before I started University. Without the combined support of PALS, my psychiatrist and the GP I doubt this would have been the case.



Phoenix (she/her)

I am Phoenix (she/her), and I am a 41-year-old trans woman. I live with a comorbidity of conditions which culminate in being physically disabled. I am a full-time wheelchair user, I have access to an adapted vehicle. My hobbies are online gaming, socialising, trans activism and spending time in the garden.

I have faced many barriers in accessing healthcare over time. Much of this has been via the NHS, and some via private healthcare.

I have encountered access issues just trying to physically gain access to my GP surgery. The GP provided in my local town offers 2 disabled parking bays outside. However, neither bay is for wheelchair use, and so does not have the space next to them to be able to get into/out of the car into a wheelchair. I knew they had limited trans health care experience as well. I realised I had to find a new, accessible GP to overcome these issues.

I changed GP surgery to a health centre that is 5 miles further away but offers local nearby parking where the use of the disability badge is possible. After visiting, I did some research to gain information. I discovered they had better knowledge of dealing with trans patients, and what that may entail. Parking is street-side, this is often also full due to the limited number of places and proximity to the busy shopping centre. It is pot luck whether, once I arrive, I will be able to park, transfer to my wheelchair, and head into the GP health centre at all. This was a risk worth taking for the confidence I felt in them moving forwards with my trans specific healthcare needs.

I was originally part of the many years long queue for accessing the GIC. However, I am extremely lucky to have been included as part of a pilot scheme for gender identity services. The clinic that I am in is simply outstanding. The staff and the service are absolutely brilliant, and, from the very beginning, I have felt listened to, heard, and dealt with in the very best ways.

It is, however, based an hour away by car. This would increase up to anything near the 2 or 3 hour mark if done by public transport (with wheelchair access). Once again, the clinic itself does not have disabled parking, and so I have to use a local multi story car park. This has only ONE disabled bay, and charges approximately £4 an hour. It is then a draining and painful manoeuvre to get through the local busy streets, across a major city road, and up and down the steep inclines to reach the clinic. Although this makes the process long, tiring, painful, costly, and has a long knock-on effect, it is essential for advancing forwards with my trans healthcare needs, due to the lack of any local services.

Troy (he/him)

I'm a 28 year old trans man and I have type 1 diabetes, I'm also blind in one eye. I work as a rope access technician. I'm about to complete my PhD in trans history, and in my spare time I enjoy conservation volunteering.



I've lived with type 1 diabetes for several years and have a lot of expertise about how to manage it in a way that feels livable. However, in clinical settings, my experience is often dismissed by doctors who assume they know better. For example, people with type 1 are advised to keep their blood glucose between 4-9mmol/l. If you dip under 4, you become disoriented and confused. My job is risky and I'm often responsible for the safety of others at height, so I sometimes make the choice to run my blood glucose above 9, in order to avoid accidentally going low and becoming unsafe at work. I receive a lot of pushback on this from clinicians, despite the fact that my blood glucose averages out at a healthy level. Doctors threaten to withhold access to vital technologies, like my continuous blood glucose sensor, unless I comply with their preferred clinical management of my diabetes. In an ideal world I wouldn't have to intentionally run my blood high, but I need the work, and I would probably be let go if I tried to get a break every time my

blood went low, so I don't feel I have much choice.

I've had the most success navigating healthcare barriers by engaging in a lot of self-advocacy work.

I go to appointments with a clear written plan of what I want to say and ask.

I stay up-to-date on medical research about type 1, new insulins, new management technologies, etc, so that I can offer relevant alternatives to my doctors' one-size-fits-all approach. When I am prescribed new medications I keep a journal of side-effects to show my consultant. I go to appointments with a clear written plan of what I want to say and ask. While I know that I deserve healthcare that supports the life I actually lead, and try to be assertive about things that I can't compromise on, I've learned to pick my battles, especially when it comes to being kicked off a service I need access to.

In terms of trans-specific healthcare, I spent years waiting for NHS appointments; it was a tough time. I was fortunate to have the option of getting top surgery privately because I couldn't wait any more, but it was very expensive. Now I'm back on the NHS, I dread the dehumanizing questions the GIC ask me, the never-ending loops of administrative bureaucracy, and the way my bloodwork always seems to go "missing" right before I need my shot. I've been waiting for bottom surgery, but learned this year that the NHS has not renewed my surgical team's contract; I do not know how or when I will be able to get surgery.

My best trans healthcare tip is: meet other trans people, support them, and allow them to support you. Accessing healthcare in a hostile environment is exhausting but having a care web of people with similar experiences will help build your resilience, knowledge, resources and ability to self-advocate.



Sage (they/he)

My name is Sage (they/he), I'm a 26-year-old Black, neurodivergent, nonbinary lesbian. I'm a freelance social media creative working for POC + queer centred orgs, and in my spare time, you can find me watching TikToks or reading.

18-year-old me was excited to start uni, but the transition from home life to being independent was overwhelming. This soon led to me experiencing suicidal ideation, executive dysfunction, and frequent panic attacks which made me fall behind in uni, as well as struggle to keep part time employment. I felt like an alien trapped in a world that wasn't built for me and there was no way out. This was amplified by the lack of support provided by my uni.

I didn't understand why I was feeling like this, so I decided to see my GP. Unfortunately, I was discharged from the CAHMS (Child and Adolescent Mental Health Services) for missing an appointment. In defeat, I didn't attempt to access their services again. My mental health soon spiralled, so I desperately tried to get an assessment with my new GP, as I had stopped going to my lectures. I was prescribed antidepressants that didn't work and had counselling that was

unhelpful due to the counsellor's lack of understanding of anti-Black racism and misogyny.

I then came across the term "ADHD." I never understood the condition before, so I decided to research it and realised the traits fit me to a tee. I already knew I was dyslexic, dyspraxic and dyscalculic, so this felt like the missing puzzle piece.

For years I tried to receive a diagnosis for ADHD, but I was told by doctors that there's no point because the waiting lists were so long, and even when I was persistent they were still reluctant to refer me to adult ADHD services.

I was even misdiagnosed with borderline personality disorder when I came out as non-binary – which I believe was due to stigma against my sexuality and gender identity. When I requested a name change with my GP, they became hostile towards me. I felt that this new diagnosis and revealing myself as trans had affected my level of care.

I took matters into my own hands and sought private treatment as I could no longer deal with being chronically disorganised, feeling scatter-brained and unable to keep up with simple daily tasks such as laundry and cooking. The high costs meant I needed to crowdfund in my community to be able to afford treatment. The support I received was unbelievable – when a community comes together it really can be life-changing. I was able to gather the costs I needed for treatment and carry on with my life.

When I needed assistance with transitioning, I decided to turn to my community again, as I no longer trust doctors. I received a binder through G(end)er Swap's free binder program, which has been a massive weight off my shoulders (no pun intended) whilst I remain on the GIC's waiting list for top surgery.

I'm currently awaiting an autism assessment but have been able to manage my conditions with the support of other neurodivergent trans people and online resources.

Gage (they/them)

My name is Gage (they/them), and I am a 24 year old non-binary trans masculine person. I have autism, a cyclic mood disorder, and autoimmune Grave's disease. I work as a research scientist and play lead guitar in a band in my spare time.



The first barrier I faced being trans was over my use of contraceptives to suppress my periods. I had been doing this for years, but during a regular check-up a nurse decided that, due to my health issues, I was too high risk to take the oestrogen-based pill. I was upset and tried to explain that I couldn't deal with having periods and being on a less reliable birth control pill, but she did not seem to understand. I was told as I was gay, I did not need to be concerned about birth control, that my issues with periods were likely due to past trauma or autism, and that I shouldn't want to compromise my health. I was unable to properly explain my situation. When I left, she said I could come back in 6 months and we could reassess if I was still struggling. I was scared and upset that I might have to experience 6 months of regular periods and was hurt that she couldn't understand how traumatic that was.

After this experience, I changed doctors' surgeries and went in

to ask for the contraceptive implant instead, as I had heard it could work for period suppression. This worked for a year before I had another period, and I was scared when I asked for help that I wouldn't be taken seriously again. However, when I visited the doctor I made sure to communicate from the start how traumatic the situation was for a transgender person. The doctor was understanding and agreed to help me find a combination of contraceptives that were safe for my body but also suppressed my periods. Being open from the start of the appointment about the emotional side of my request made it easier for me to communicate, something that can be hard being autistic, instead of trying to find the right words to say after I was already upset.

Being open also helped with a barrier that I was expecting to face, but did not turn out to be an issue. As I have a history of severe mental health issues, I was concerned that when I spoke to the GIC they would turn me down or request that I attend a second appointment for another opinion. However, I was honest about my past, as well as the steps I had taken to overcome it. I was also clear about what I was doing currently to maintain my mental health, and my plans for what I would do if it was ever a problem again (such as visiting a therapist and reaching out to my support network). I believe showing the doctors that I was aware and proactive about any issues, both physically and mentally, lead to an easy referral for hormones.

Overall, I am glad I was able to navigate difficult situations in which mental health, physical health and being transgender were interplaying by being confident to share my issues and what I needed early on in my interactions with doctors. Showing I was self-aware about the barriers I might face and that I had taken steps to try and resolve things as much as I could made the doctors much more cooperative and allowed me to progress in my transition.



Moss (he/him)

I'm Moss (he/him) and I have been living with Long Covid (Post Covid Syndrome) for almost two years. I'm a part-time PhD student, and in my spare time, I enjoy reading, painting, and hanging out with my dog.

When I first became unwell with Covid-19 in March of 2020, there was no understanding of Long Covid. This, coupled with the fact that many GP surgeries were triaging Covid patients to 111, meant that I struggled to get any care at all in the early stages of my illness. Once it became clear that I wasn't getting any better, as several doctors had told me I would, it was challenging to get referrals, as there were no Long Covid Clinics or effective pathways in Scotland.

During this time, I realised that it was vital to have a sympathetic GP. I tried speaking to a number of different doctors at my GP surgery until I found one who was well-informed, easy to talk to and understood the enormous impact Long Covid was having on my day-to-day life. During the period when my illness was at its most acute, I ensured I always spoke to the same doctor and I asked for regular appointments so that she could keep track of my illness progression. I also

prepared for doctor's appointments by making lists of questions, logging my symptoms and keeping track of the effects of the medications I was taking. Interactions with medical professionals have gradually become easier as doctors are now more aware of Long Covid and some of the protocols for testing and caring for patients.

With regards to trans healthcare, hormone shortages a few years ago made finding pharmacies that either stocked or could get hold of testosterone very challenging. I often found pharmacies would accept my prescription, then be unable to fill it. At the time, I found a national Facebook group for trans men and non-binary people, which was an invaluable source of information. They explained why the shortages were happening and gave telephone numbers for the manufacturers of the product. When I phoned them, they explained how long they believed the shortage would last. I also found out that a particular franchise of pharmacies had the most reliable stock, and I would call every branch in my vicinity until I found one that was able to fill my prescription. Although this was quite tiresome and inconvenient, I managed to fill every prescription I needed during that period.

Personally, I've found accessing healthcare for Long Covid far more challenging than I had found getting trans related care before (though I am aware that my experiences with the GIC were very likely made easier due being white and middle class). Being ill with an under-researched, chronic condition has come

I ensured I always spoke to the same doctor and I asked for regular appointments so that she could keep track of my illness progression.

with lots of new challenges. It is also often difficult to know whether being trans is affecting my level of care. In general, I've found that doctors don't always ask the right questions, and I've needed to learn to be more proactive in knowing what I want from an appointment and then directly voicing it.

Tink (they/he)

I'm Tink and I'm a theatre maker and performer, an advocate, a human rights campaigner and a loving parent. I'm a gender rebel that uses they/them or he/him pronouns. I was diagnosed with bipolar disorder in my 30s and was also later diagnosed as autistic.



I knew I was trans as a child and my mum was supportive, but we didn't have the language for it back then. My mum understood that my gender presentation was an intrinsic part of who I was, and it wasn't a big deal at home. I knew I wasn't a girl, but school and the wider society thought differently. Lots of things got in the way of me starting a medical transition.

When my daughter was young, I experienced a period of psychosis as a result of stress and the exhaustion of her not sleeping through a single night for 6 years. I was diagnosed as bipolar and went on lithium to treat it. Because of my diagnosis, I was nervous about talking to my GP about other things. I definitely felt like I couldn't talk to any of my GPs about transitioning.

As I got older, I began to feel more able to embrace my gender fluidity. Self-medicating with testosterone felt like part of that

process for me. I wanted to know how it would make me feel, and I'm glad I did because it felt right. Looking back, I feel like taking testosterone without having my blood tests monitored was a bit self-neglectful.

My daughter was diagnosed as autistic as a teenager, and it caused me to recognise my own autistic traits. When I spoke to the professionals involved in assessing my daughter, they agreed that it would be worth me seeking an assessment for myself too. They were trialling a new type of assessment and they spoke to the people in my life that I'm close to (with my permission, of course). I was 46 when I was diagnosed as autistic. When I looked at the medical report and reflections on my childhood, I recognised a lot about my gender as well as things related to being autistic. It made me think: Who are you? Where do you want to go from here?

I got on well with the occupational therapist involved in my autism diagnosis. He felt like someone I could approach, so I messaged him about my gender and told him that I was embarrassed to approach my GP. The occupational therapist was really supportive. His support was empowering – he recognised where I needed support and where he could step back. Not only did he write to my GP for me, he worked with my GP to write a referral to the GIC.

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My GIC is one of the pilot projects and I've found them to be very supportive. There was no judgement about having self-medded, about my mental health, or about being autistic. Even during the pandemic, they've done their best to accommodate me. I feel like I can ring them and tell them if I'm struggling. They

I'm glad that I was confident enough to ask for someone else to take my blood. The other nurse helps me to stay calm and it makes things a lot easier.

understood that I needed the changes from testosterone to happen slowly so that I could adjust to them. The team have supported me to transition at my own pace – including pausing testosterone and then switching to gel instead of injections.

When I was on lithium. I had to have lots of blood tests and was often left bruised from the needles. As a result, this has made me anxious about blood tests and needles. I need a lot of patience from the person taking blood and their support to help me stay calm. One of the nurses wasn't able to show me that patience, and it caused my anxiety to increase even further. I'm glad that I was confident enough to ask for someone else to take my blood. The other nurse helps me to stay calm and it makes things a lot easier.

These are just some of the barriers to healthcare that I've faced, but the thing that helped me was finding healthcare professionals that I felt comfortable to talk to and asking them for their support. It's important for trans people to remember that we're a community and that support is out there. It can be so useful to talk things through with a trans friend or even get them to go to an appointment with you.

You'll find a range of healthcare focussed information and resources on TransActual's website. Visit www.transactual.org.uk/healthcare

Sources of support and further information



56T is a London based service which offers a range of trans specific services including sexual health screening, cervical cancer screening, counselling, hormone monitoring and administration of hormone injections (if you have a UK prescription).

Website: www.dean.st/trans-non-binary

Phone: 020 3315 5656



Black Beetle Health offer a range of resources specifically focussed on LGBTQ+ Black people and People of Colour.

Website: www.blackbeetlehealth.co.uk



Black Trans Foundation offer a therapy fund for UK based Black trans and non-binary people.

Website:

opencollective.com/blacktransfoundation



Clinic T are Brighton based and offer STI testing and treatment, support with hormones (if you have a UK prescription), contraception, cervical cytology, vaccination, support and signposting.

Website:

brightonsexualhealth.com/service/clinic-t

Phone: 01273 523388 (9:15 - 4:30, Monday to Friday)



CliniQ is a London based service which offers a variety of trans specific services including counselling, mentoring, hormone injections and monitoring, cervical cancer screening and sexual health screening.

Website: cliniq.org.uk



Deaf Rainbow have a range of resources for D/deaf trans people, including information on your rights to an interpreter at medical appointments.

Website: deafrainbowuk.org.uk/trans



G(end)er Swap is a clothing outreach organisation that supports trans and gender non-conforming people to access clothes and community.

Website: genderswap.org



LGBT Health and Wellbeing are a Scottish service who offer a number of support services including a helpline which can be accessed by phone, email or webchat.

Website: www.lgbthealth.org.uk

Email: helpline@lgbthealth.org.uk

Phone: 0300 123 2525 (12-9pm on Tuesdays and Wednesdays and 1-6pm on Thursdays and Sundays)



LGBT Foundation offer a range of support services, including a helpline and wellbeing resources.

Website: lgbt.foundation

Email: helpline@lgbt.foundation

Phone: 0345 3 30 30 30 (9am – 9pm weekdays)



Live Through This is a cancer support and advocacy charity for LGBTIQ+ people affected by cancer.

Website: livethroughthis.co.uk



MindLine Trans+ is a national trans mental health support line. Support is available by phone.

Website: bristolmind.org.uk/help-and-counselling/mindline-transplus

Phone: 0300 330 5468 (8pm – midnight on Mondays, Wednesdays and Fridays)



The Rainbow Project works to improve the mental health and wellbeing of LGBTQIA+ people in Northern Ireland. Their website has details of the support that they can offer.

Website: www.rainbow-project.org

Email: info@rainbow-project.org

Phone: 028 9031 9030



Regard is a national organization for LGBTQI disabled people and can provide information, advice and support.

Website: regard.org.uk



QueerCare is a transfeminist autonomous care organisation, providing training, support and advocacy for trans and queer people.

Website: queercare.network



Spectra offer a range of trans specific services including mentoring, counselling, support groups and health advocacy.

Website: spectra-london.org.uk/trans-services



Switchboard are an LGBT+ specific helpline open 10am until 10pm every day. You can phone them, e-mail them or use their web chat function.

Website: switchboard.lgbt

Email: chris@switchboard.lgbt

Phone: 0300 330 0630



Transgender NI offer a range of Northern Ireland specific information, including details of local support services.

Website: transgenderni.org.uk



Trans Health Hub Brighton works in partnership with The Clare Project to help trans people to understand their rights relating to healthcare.

Website:

www.brightonhealthandwellbeingcentre.co.uk/endorsed-external-links/trans-health-hub



Trans Support Service is a counselling and support service for people living in Liverpool, Sefton and Knowsley.

Website: www.merseycare.nhs.uk/our-services/liverpool/sexual-health/trans-support-service-tss

Email: tss.merseycare@nhs.net

Phone: 0151 317 8581



TranzWiki is a directory of trans focussed organisations. Visit TransWiki to find a local trans support group.

Website: www.gires.org.uk/tranzwiki



Umbrella Cymru offer a range of support for LGBTQ+ people in Wales. You can contact them by phone, by online chat, via their website, or by e-mail.

Website: www.umbrellacymru.co.uk

Email: info@umbrellacymru.co.uk

Phone: 0300 302 3670

About TransActual

TransActual UK was founded by a group of British trans people in 2017 as a response to increasing press hostility, transphobia and misinformation. We are run by the trans community, with the trans community, for the trans community.

In June 2020 we expanded our scope and remit to:

- share reliable information about trans people's lives and about trans rights in the UK, as well as dispelling common myths
- amplify the voices of trans people so that the wider world may hear the experiences of a wide range of trans men, trans women and non-binary people
- educate people about trans people's lives and the issues we face
- advocate for trans people
- empower trans people to bring about change in their lives and in the community

We are working to improve:

1. Trans people's experiences of **healthcare**.
2. Legal **recognition** & protections for trans people.
3. Improved media representation of trans people and an **end to press transphobia**.

Find out more: www.transactual.org.uk