NEURO KEY
An Alliance supporting people
with neurological conditions

TARDIVE DYSKINESIA

A neurological movement disorder

‘Unlocking minds and opening doors’

Open Door series by Neuro Key

Contents

Foreword

‘Tardive Dyskinesia (TD) is a movement disorder characterized by uncontrollable, abnormal and repetitive movements of the face, torso, and/or other body parts.’[1]

TD is a progressive, iatrogenic (medication-induced) condition that worsens over time. It is caused by prolonged use of an older generation of neuroleptics or anti-psychotic treatments that block dopamine receptors in the brain, commonly prescribed to treat mental disorders such as schizophrenia, bipolar disorder or acute depression. In individuals with TD, the treatments are thought to result in irregular dopamine signalling in a region of the brain that controls movement in the same way Parkinson’s disease is caused by the loss of dopamine-producing nerve cells in the brain.

TD is a neurological condition, not metabolic, skeletal or muscular but manifests as a movement disorder like Multiple Sclerosis, Functional Neurological Disorder, Dystonia, Parkinson’s, essential tremor, restless legs syndrome, Muscular Dystrophy or Ataxia. However, where people with Parkinson’s have difficulty moving at all, people with TD have extensive involuntary muscle movements or jerking which means TD has a similar impact on a person’s daily management to those people living with Dystonia. TD is physically and cognitively disabling and potentially life-threatening.

The poor professional understanding of TD has caused considerable difficulties for partners, parents or family members trying to secure an appropriate care pathway for their loved ones. These narratives and contributed outcomes could underwrite a system-wide reset for Mental Health services with the aim of addressing poor knowledge and preventing people sliding into early, aggravated disability.

The Mental Health Act Code of Practice requires that patient, family and carers’ choice is taken into consideration when making decisions about where a patient should be placed. It also requires that every effort is made to place a person as close to home as possible.

Neuro Key fosters collaborative working partnerships to sustain a high customer service focus. Where possible, we close the gaps in local, regional and national knowledge to encourage creative problem-solving and efficiencies by reducing risk of crisis and harm. We strive for excellence with agreed standards and outcomes.

Our ‘Open Door’ series of resources has been developed to acknowledge the challenges of living with a neurological disorder that is misunderstood, subject to media-driven or political myths and is neither prevalent nor the focus of publicity campaigns. The following stories are narratives of lived experiences of individuals or parent caregivers supporting people with a neurological disability.

We have adopted fictional names to protect their identities.

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[1] https://www.ninds.nih.gov/health-information/disorders/tardive-dyskinesia

Edith’s story

I emigrated to South Africa (SA) in 1972, my youngest son was 12 years old, perfectly healthy. At the age of 19, he was beaten up by SA Police.

He was transported in the boot of a car, kept in a cell overnight and brought home suffering from severe Post Traumatic Stress (PTS). He could not stay in SA and returned to the UK. At this time, my husband and I managed an hotel and we needed to stay for another 4 years. My son returned to the UK on his own and had no support.

When I returned to the UK in 1989, he was a patient of the regional Mental Health Trust and diagnosed with schizophrenia. Even then, I questioned the diagnosis as there had not been any investigation into the background issue in SA or concern for his welfare and needs.

My son lived in independent accommodation for ten years and was treated for schizophrenia. I have the documentation to prove my son was diagnosed with Tardive Dyskinesia (TD) in 2013 by two clinical experts, Dr Neil Kerry and Dr Gill. However, my son has now been in a wheelchair for over twenty years because no-one will deliver an appropriate care plan. Over that time, I tried and tried to have an investigation into the harm caused by Clozapine.

> ‘Our lives have been nothing to the Mental Health services. As a mother, I have had my heart ripped out’.

In 2016, my son was discharged from Mental Health services, living with me until July 2023 when he became very ill. The GP, Dr Kishore had refused to prescribe my son a particular neuroleptic anymore and although I asked what I was supposed to do, no-one was interested in helping. I did some research and took on a slow withdrawal of the medication which took a year and eight months. I was left to deal with circumstances that only medical supervision should have controlled. As the medication is very addictive, my son went into severe withdrawal and became an in-patient in a Mental Health hospital. Extremely ill and weak, my son was put back on the very medication he had proved metabolically resistant to in 2013.

Since August 2023, I have been blamed for my son’s mental health, cognitive impairment and disability. He has been refused a second opinion, refused the cytochrome P450 polymorphisms blood test that would prove his body resists the medication which causes medically proven disability. Under the instructions of Social Care and a Mental Health Consultant, the Care Home have placed my son under a Deprivation of Liberty (DOLs) order to stop me taking my son out or getting a second opinion. I was even threatened with the Police if I attempted to take my son for a neurology appointment for a Tardive Dyskinesia assessment. Likewise, occupational therapy, mental health capacity, counselling or even getting regular fresh air have all been refused. This is inhumane and little more than a punishment.

I have lived with a very high level of stress due to the poor knowledge of NHS professionals, failing to understand they are not trained to know about the medications. I am elderly, I live in fear at what would happen to my son if I passed away. I have been publicly maligned, insulted and my rights as a carer have been ignored.

> They should not be denying a person a second opinion just because it goes against what they assume.

In our case, my son is deteriorating. I have sent complaints across every sector, the Integrated Care Board, the Mental Health Trust, the NHS, Social Work England, the General Medical Council, Care Quality Commission, the Parliamentary Ombudsman and my son's Care home desperately trying to get someone to listen. I do not understand how they ignore the evidence so readily. I have had the Mental Health Act quoted to me continually as their reasoning, but I do not understand why this means my son is not entitled to specialist or medical support.

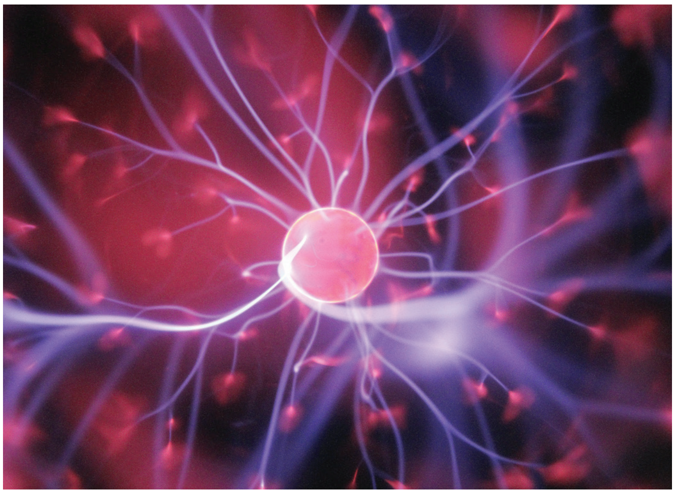
The system drowns you in paperwork hoping you won't bother or will give up getting something better for our families. One document will specify my son does not have capacity and is under a DOLs order and another document will describe he has capacity enough to be interviewed and answer leading questions that suit the public sector storyline. Surely, that is not fair or reasonable?

> What kind of system is this, where people think they are not accountable for harm?

My son has cognitive impairments due to the TD but the Care Home staff ignore and blame him for his dishevelled state and poor hygiene. I referred to them repeatedly that my son had a toe infection but they wouldn't call a doctor without permission from the Consultant.

Recently, Dr Rippon gave a report after reviewing my son's medical records for a forthcoming Tribunal. The doctor said my son's legs seemed weak due to a longstanding 'perception' by me and that TD was simply functional, not neurological. It was not clear if the doctor had any specialist knowledge but she defined my son as not having TD yet, my son was diagnosed in 2013. My eldest son has videoed the leg tremors. They have attributed these to anxiety and tried to blame me for causing that.

Public Services do not work with carers to understand when something happens that they know nothing about. They must be ready to learn new information and use their skill to make decisions, not persecute the carer and cause an immense amount of stress. I have been subject to verbal abuse by care home staff and even a social worker swore at me. I feel lucky to be alive.



All I did was ask for some help when my son was taken to hospital and 2½ years later, I am in the middle of a terrifying ordeal that is caused by their ignorance, not mine. The Solicitors letter from the Borough Council denying my legal right to a second opinion, showed me that services protect themselves first, not the people they are employed to serve. Duty of care in our case has vanished.

> 'It is unethical for a psychiatrist to offer a professional opinion unless he or she has conducted an examination and has been granted proper authorisation for such a statement' (National Library of Medicine – Goldwater Rule)

Despite the Goldwater Rule, the mental health Consultant claimed in a HM Courts and Tribunal (HMCT) report that I was mentally ill, intimating that I was the problem for my son. The Tribunal supported removal of my Lasting Power of Attorney. I was blamed for my son's incapacity. I was made to feel I was a criminal who had failed my son for telling the truth. It is obvious my son is in a toxic state having been put back on Risperidone that his medical data proves he should not be on.

I have had my 'nearest relative' status removed and the Council are now my son's guardians as they believe I am a threat to my son for my 'views' on his medications and TD. I have probably filed a cabinet worth of evidence to them and they still consider me the problem. With repeated attempts by social workers and the care home made to isolate me from my son, I have to ask permission to visit. It costs me £40 for a taxi to get from my home to the Care home and back but I do not live that far away, the road access is difficult. What happened to the Mental Health Act code that says care should be as close to home as possible?

When I can visit, I have to see to my son's hygiene, change of clothes and welfare because the Care home staff consider my son has capacity to refuse help so they don't bother. There have been several incidences where he had not changed his clothes for days which led to the toe infection. On other days, he lives in pyjamas and staff ignore him.

Me and my son have done absolutely nothing wrong.

I consider my case an extensive cover-up and the NHS and Mental Health services should be held accountable.

It is a disgrace that I offer evidence which is then weaponised against me, accusations are made about us to deny second opinions or even get basic medical care.

My abiding sadness is that once TD is evident there is no turning the clock back, the damage is done, causing increasing disability for life. I spend my days looking for ways to get someone to listen to the facts, read the evidence and offer my son some overdue quality of life.

Denise's story

My Son, Antidepressants, Antipsychotics and the Pharmacogenetic Gap

My son was often bullied at school for being a "boffin." He became depressed and was prescribed several antidepressants; eventually, the GP started Prozac. When he didn't feel better, the dose was doubled. Seventy-two hours later he was awake all night, appearing to talk to someone in his bedroom. Then he tore downstairs, screaming about God, heaven, hell, and the devil. I hid behind a door and dialled 999, terrified. Curiously, a glass of orange juice helped him settle before the police and ambulance arrived. That was our first full-blown psychotic crisis.

Diagnosis, revolving doors, and side effects

On the mental health ward, a psychiatrist diagnosed schizophrenia and replaced Prozac with an antipsychotic. Over the next five years my son was prescribed a variety of antipsychotics alongside benzodiazepines and hypnotics. Nothing seemed to work; he was discharged and readmitted many times. Each crisis was described as a "relapse," reinforcing the label.

Once, a voice told him to "drive to heaven." Police found my car straddling a moorland hairpin bend and he was taken to A&E. As we drove him to the now-familiar ward he asked me, "Am I schizophrenic?"

After starting antipsychotics, my son developed facial and leg twitches and drooled in his sleep until the pillow was soaked. Our NHS psychiatrist denied a link with the antipsychotic, yet a private neurologist later diagnosed Tardive Dyskinesia and recommended stopping antipsychotics - advice the NHS psychiatrist refused.

Over time he was restless, irritable and could not tolerate perceived disrespect. I learned this cluster—an urge to pace, internal jitters—is called akathisia, a known antipsychotic side effect that can look like "the illness" itself. The iatrogenic akathisia was attributed to the anxiety of schizophrenia. When he had extrapyramidal symptoms, he was instructed by the nurse to "control" his shaking hands; he could, but for only about a minute with extreme concentration - implying it was "all in the mind". He also experienced symptoms consistent with neuroleptic malignant syndrome, weight gain, shortness of breath, profound sedation, urinary incontinence, heartburn, blurred vision, protruding eyes, loss of hand to mouth coordination and emotional lability. One evening he walked off the ward and came home. I phoned to inform staff, police arrived, handcuffed him in his bedroom and took him back.

All he had wanted was to sleep in his own bed.

"Treatment-resistant," clozapine, and a lost adulthood

After he was aggressive to a nurse who had rebuked him, my son was moved to an intensive treatment unit and labelled "treatment-resistant." Clozapine was commenced and titrated up. He regressed to a toddler-like state; I took in his childhood teddy for comfort.

His pulse raced at 140 beats per minute and the psychiatrist said the rate was normal. I begged the GP to intervene; an echocardiogram was arranged, but in his regressed state my son refused. I asked a nurse about side effects. She first said her job was to dispense medication. When I asked what she thought as a person, she softened and said she would not want to watch her son suffer like this.

He took teddy to bed with him and in the bath. And this was my son who had started a chemistry degree.

At one point the unit told my son did not want to see me or his dad. I feared he could be transferred to a long-term unit without our knowing where he had been placed. This would be the final cutting off point from us being involved in his care. After two weeks I argued that he was delusional and could not give informed decisions. Visits were restored. Eventually, the "plan" was a year in secure rehabilitation before discharge. I pointed out he had not been at home for two years; after brief escorted visits, he was allowed a weekend at home and finally discharged.

He had lost everyday judgement: I had to remind him to stop at kerb to wait for traffic to pass

The price was heavy. Though utterly compliant, he became breathless walking uphill, could not use public transport, bank, phone or computer and was totally dependent on our care. He slept eighteen hours a day and snoozed in the afternoon.

Tapering, withdrawal, and small gains

To improve his quality of life, he attempted to reduce his clozapine dose. We didn't understand then that because he was dependent on antipsychotics, he was vulnerable to withdrawal-related - or "tardive" psychosis if dose reductions were too fast. Over several years, he very slowly removed about half the dose. He slept less, stopping pacing up and down the garden, could sit still to watch television and went on trips with us to walk in the countryside.

A lay-carer's crash course in pharmacogenetics (PGx)

In simple terms, if you're an extensive metaboliser (EM) for the pathway a drug uses, the dose can be therapeutic. If you're a poor (PM) or intermediate (IM) metaboliser, the same dose may lead to chronic toxicity.

Given these drugs target the dopamine receptors in the brain, it is not surprising that people who cannot metabolise them efficiently may show behavioural extremes. I also read that signs and symptoms of neuroleptic malignant syndrome overlap with organophosphate poisoning. These connections, made sense of what I was reading.

What are called "side effects" can in fact be toxic effects, many mimicking Parkinsonian symptoms.

Testing confirmed a mismatch—and revealed interaction risks

I asked my son's outpatient psychiatrist to order a genetic test. Though unfamiliar with pharmacogenetics, he agreed to a blood test being taken at the GP and together with a list of medications and the private fee was sent to DxS Systems.

Results: my son is a PM for CYP2D6 and an IM for CYP2C19. Further testing showed reduced expression of the serotonin transporter. Because Prozac is primarily metabolised via CYP2D6 and CYP2C9, and to a lesser degree through CYP2C19 and CYP3A4 it also involves the serotonin transporter. It became crystal clear that his first psychotic episode followed the increase dose of Prozac which he could not metabolise efficiently.

I learned that common medicines can inhibit or induce these pathways. An inhibitor can raise drug levels and worsen toxicity; an inducer can drop levels, provoking withdrawal-like reactions that can be mistaken for relapse.

Knowledge of my son's CYP450 status helped us avoid a hospital admission when he was prescribed lansoprazole for nightly heart burn and vomiting. Two weeks later he began to experience psychotic symptoms. Lansoprazole involves CYP2C19 metabolism – his weak pathway.

> When lansoprazole was replaced with 'Gaviscon' his psychotic symptoms ameliorated

Another example when he complained of chest pain, I took him to A&E. Suspecting a pulmonary embolism, I asked the hospital pharmacist which anticoagulant would be safer alongside clozapine given his genetic profile. She said it wasn't 'rocket science' and recommended rivaroxaban, not warfarin. The consultant initially prescribed warfarin but switched to rivaroxaban after speaking with the pharmacy. I felt so relieved: a drug choice that took his profile into account.

System gaps—and why they matter

In my experience, pharmacists understand pharmacogenetics; many doctors do not. Before testing, one psychiatrist suggested he must be a "fast metaboliser," which would imply clozapine would leave his body too quickly and therefore was ineffective. Yet, raising doses only escalated toxicity for him.

> Beyond individual clinicians, The NHS psychiatric system seems largely oblivious to pharmacogenetics.

I was disappointed that pharmacogenetics was omitted from the DH **New Ways of Working in Mental Health Medicines Management: A guide for service users, carers and health and social care practitioners.** DH also rejected pharmacogenetics from **New Ways Working for Pharmacists and Allied Health Professionals**. NICE, which is sponsored by the DHSC, provides national guidance and advice to improve health and social care, attributing the safety of medicines to the MHRA. MHRA shares new drug-gene interaction with NICE, but isn't responsible for NICE publications.

The lines of responsibility seem blurred.

The Royal College of Psychiatrists has acknowledged people with certain CYP variants may be more likely to experience adverse effects—including suicidality and aggression—yet has also stated genotyping would not be cost-effective and citing gaps in evidence, do not currently recommend routine testing for psychiatric drugs. Meanwhile, the BNF (co-published by the Royal Pharmaceutical Society and the British Medical Association) guides safe and effective use of medicine, while the General Medical Council describes pharmacogenetics as outside their remit because it is a "biomedical science degree". The International Society of Pharmacogenomics recommend four or more hours of pharmacogenetics education at UK medical schools, but only a few include the subject. The European Medicines Agency (EMA) now requires new medicines to specify dosing by genotype, yet for older drugs the default dose effectively assumes EMs, leaving those with variants to trial and error.

Since it is now over twenty years since the previous pharmacogenetic test, I requested a further test for my son from the NHS. This was refused because 'NICE' do not recommend it for schizophrenia. Currently, with further clozapine tapering, my son is sleeping less, alert during the day and has resumed walks in the countryside.

Pharmacogenetics is used in oncology to assess drug efficacy and to reduce serious adverse reactions; it is also practiced for other drug treatments: kidney transplants, rheumatoid arthritis, HIV infections, epilepsy and antiplatelet therapy following ischaemic stroke. In these medical physical situations, all NHS patients have personalised medication care.

> I believe psychiatric patients deserve the same personalised care, particularly those who are legally sectioned

Where my son is now and what helps

My son is understandably traumatised by years on wards and drugs he was legally forced to take and which for him, proved toxic. He rarely meets new professionals unless introduced by someone he trusts; a charity support worker helped us connect with a new social worker. He has no friends and can't live independently; I provide daily care. In public he still looks incredibly vulnerable. Lately, he's been constipated and more fatigued, sleeping longer and often dozing during the day. He refuses trips out and going walking, he says he is tired. I suspect age-related changes in CYP function may be part of this and another pharmacogenetic test may be necessary. He is tapering Clozapine again. One practical help is a simple grounding technique called Pre-therapy – from humanistic Person-centred practice. For instance, using orange juice during that first crisis re-anchored him in shared reality.

> He has rung me from wards in the past to say, "Please come and ground me, the nurses don't know what to do."

Unfortunately, Improving Access to Psychological Therapy (IAPT) /Cognitive Behaviour Therapy (CBT) services have dismissed this humanistic approach for people who have impaired psychological contact.

My son's life in the psychiatric system has been directed, controlled and so domineering that any vestige of self-empowerment has been scuppered. He is like an empty shell and yet within there, remains a hidden pearl: the person he truly is.

> I don't blame individual doctors for knowledge they were never taught, but patients and their families shouldn't carry the cost of that gap.

Conclusion: the key we nearly missed

Where am I in all this?

My ask is simple.

Haunted by his cry across a ward: "Help me, Dad, help me, Dad". Many a time I've walked to the woods at dawn and shouted into the trees, heart broken by the needless suffering my son has been forced to endure through sectioning and beyond.

For my son, pharmacogenetics was the key we nearly missed. If we can build an NHS system that asks, "Can this person metabolise this drug?" before prescribing let alone concluding "this person is treatment-resistant," we will spare countless families what ours has lived through.

Make pharmacogenetic testing and guidance part of standard practice prior to psychiatric prescribing

Nationally, place development of an up-to-date guidance where clinicians look first, in the British National Formulary (BNF).

Any medical patient, legally sectioned or not deserve legal protection for safe prescribing. When systems ignore foreseeable harms, it feels like institutional negligence.

Tina’s story

My vulnerable adult daughter moved with me to a new area. We immediately registered with a new GP that her Depot injection was due the following week. The injection is a long-acting, slow-release medication designed to release drugs, primarily used for antipsychotics to manage mental health symptoms or as a contraceptive.

> I visited Urgent care but to cut an awful story short, my daughter was sectioned under the Mental Health Act instead of facilitating continuation of treatment.

I could not get the treatment continued, was referred to Family Planning by mistake leaving her without the depot and withdrawing quickly.

That was over 5 years ago.

There followed tribunal after tribunal and renewal of the section notice and I was subjected to an ongoing investigation to remove my Lasting Power of Attorney (LPA). In addition, there was an ongoing County Court case for displacement of the nearest relative (NR) on the grounds of unsuitability. This proceeded to exclude me and concluded in displacement with my other daughter who then had a breakdown herself only for me to become NR again.

There was the most restrictive supervision in place with no leave, 2-1 escorted and staying within the grounds, not with family. The new appointed Doctor allowed a bit of leave for a short period. During this short period of time, I took my daughter to have an MRI scan which is what she constantly wanted but was denied where we used to live. The scans were not normal and showed cavernoma/lesions that needed further investigation and then the seizures started.

The family were not informed of the seizures and leave was granted for my daughter to come home where a seizure occurred lasting several hours. She was delirious and could not remain still for a minute. The leave period had ended and she was due to go back to the ward. Since the seizure, she has not been allowed more home leave.

THE CHALLENGE

I shared the private scans with the Cavernoma Allianz and a scientist and team researching Alzheimer’s and Parkinsons. I requested referral to a Neurologist and other specialists that had been denied at the previous hospital under the same Trust. The mental health team reluctantly backed down to allow a Neurologist referral but would not reveal details. I was given the details of the Neurologist by my daughter who even shared the appointment arranged in January 2024. She was not taken to the appointment. I turned up and presented the Neurologist with the private scans he refused to give comment on. That prompted the Trust to offer an MRI scan under a Tesla 1.5 scanner. That was said to be normal.

I then went to some lengths to get all the past scans which were not normal and showed something in the images needing further investigation.

Then came the referral to somewhere else where they have a Tesla 3 scanner. First of all, this was not booked correctly and they booked a Tesla 1.5 instead. I pointed out the appointment was arranged and done in a rushed, shambolic manner. No sooner had my daughter arrived, she was made to go under the scanner and could not complete the scans because she was too stressed after a 50-mile journey. This was further compounded by the 48 hr EEG not even being arranged. Instead, the Mental Health service filmed my daughter against her wishes. This prompted a series of capacity assessments (5 in total) all stating she had no capacity apart from the one they wanted her to have capacity for i.e. the filming. They claimed that the filming could alleviate the need for having to make a 100-mile round trip, tests would be properly done locally and my daughter could be extensively observed and monitored.

> She was rushed back to our home town in transport when they knew that I had arrived to support her

There was the fear of her breaking head equipment but my daughter said that, provided she could be supported by a family member she would not sabotage equipment at all.

The tests could not be finalised. Also, because the service had no information whatsoever and did not even know my daughter was sectioned, I brought all the past scans and documents to give to them. It was clear that the Trust had purposefully obstructed past appointments to see the Neurologist, cancelling them or stating they knew nothing about the appointments. We needed the scan to be a success because it was crucial to my daughter's health and welfare yet it was as though they did not want her to undergo the correct tests. Other requests for Endocrinology, Oncology etc were being ignored.

I then complained and having exhausted the complaints procedure had no choice but to seek judicial solutions. I did not wish to challenge matters within a new area but found I had to defend myself in a court case lasting months where my character and that of my daughter was made to look bad. Capacity has been hugely relied upon and manipulated against me to get their way, making decisions on everything in terms of my daughter's 'best interest'. Naturally, the Council backed the Mental Health Trust and at one point, even the Police were called and visits sometimes refused.

SOLUTION

My complaints procedure became exhausted so there was only one solution and that is litigation since every complaint found in their favour and some of it is totally malicious. It seems as if my efforts to get my daughter some appropriate care has been used as an illusory 'stick' to beat me with. It is pointless also turning to CQC when those at Board levels such as CEO and Director of Operations work for Mental Health services as Special Advisor/Executive Reviewers. There is massive conflict of interest at Board level.

There is only one solution that can only be achieved legally and that is a week's stay 50-miles away to undergo extensive tests and have the MRI done under a Tesla 3 scanner followed by 48 hr EEG and interleukin 6 Tests plus Endocrinology and interleukin 1 test, immunology and oncology as there was a cancer scare and someone died under the local Tesla 1.5 scanner, they did not detect the cancer in time.

IMPACT

In November 2024, my visit was going nicely for the most part. I tried to reassure my daughter that matters were progressing well before court now and hopefully directions would be made soon. She said she often cried at night because she was so unhappy and felt so much in pain. I asked what would make her happy and she said to come home and to see her cat. I then commented to those supervising and reporting on my visit that I hoped they include this in their notes.

I told my daughter about a recent meeting, she mentioned she had expressed her wish to come home to see her cat. I then gave her papers she is quite entitled to see. It was at this point that my visit turned sour. One of those supervising pressed the alarm button and out of nowhere came at least six members of staff. I was surrounded (mobbed) by all of them.

> Mobbing is a form of persistent, humiliating, and intimidating behaviour. It is contrary to the Protection from Harassment Act 1997

One of the staff supervising tried to snatch papers I gave to my daughter. My first thoughts were was there anyone at all left on the ward to care for the other patients whilst so many were standing there in the foyer? I have no doubt the objective aimed at me was to intimidate, threaten and bully which I have become quite accustomed to.

I stated that I would report any member of staff who snatched/took away the paperwork from my daughter that she was quite entitled to see. I had returned to the table to pick up my mobile phone half expecting the Police to be called out again but as I noticed some had name badges, I mentioned aloud the names of those I noticed, the Senior Healthcare Support Manager, the Ward Manager and a supervisor. I was in full view of CCTV – close to reception and stated that I was not afraid or intimidated by any of them. It was mostly the same people that have reacted this way before on three other occasions during my visits.

I am pleased that my daughter kept her cool and did not react to this situation. The whole experience was undignified, degrading and unpleasant but this sums up how I have been treated for so long now by so-called ‘Professionals’. The reception area was quite empty at the time apart from practically all of the ward staff standing within the foyer.

I have since written an account of what happened and I have sent it to both courts.

Who are these people that evidence or facts don’t touch the sides?

There has been a terrible waste of money with their attitude to the scans and transport rushing my daughter plus money wasted because of legal challenges on both sides. I feel so let down by ignorance. The impact on my daughter’s health has been tremendous as she is deprived of fresh air, exercise and she is self-harming, let alone uncontrolled seizures.

My daughter was diagnosed with Tardive Dyskinesia (TD) in 2014 in our former area by a Neurologist. Described as mild but nevertheless, was identified all those years ago.

> Being cut out of everything I can only rely upon my daughter telling me what is going on as nothing is shared.

In the last A&E report in November 2023, my daughter was said to be suffering from Oculogyric crisis (OGC) a rare, acute dystonic reaction involving the extraocular muscles and often triggered by dopamine receptor-blocking drugs like antipsychotics. OGC is most commonly described as the involuntary upward deviation of both eyes due to spasms and increased tone in the muscles of the eye. OGC is classified as a rare subtype of Tardive Dyskinesia.

The Doctor admitted that the cause was unknown but my daughter had a seizure which lasted from 1.00 pm until 7.30 pm, her body cold and clammy, her blood pressure was sky high.

I have tried to have extensive tests done. I consider untreated seizures a horrible risk for my daughter but nothing will be allowed by the Mental Health team. I am no longer considered the nearest relative and cannot influence medical care. It is a hopeless situation which in turn impacts upon my health as a parent and my daughter's health through worry at the deprivation of a legal right to essential physical health tests and referrals.

> They think that by revoking my POA they have won.

I am hoping I will get an in-person hearing where I can present more evidence. Whilst this next Tribunal case is about revoking my POA, I have an additional case coming up about treatment and pathology, in fact everything the lower Court had no jurisdiction to oversee.

The Trust are now in special measures and a senior responsible officer has been appointed. I am challenging treatment under Martha's rule. We should not have to live like this, its inhumane and breaches our basic rights. Launched in 2024, Martha's Rule is a patient safety initiative enabling patients, families and carers to request an urgent, independent review if they are concerned a patient's condition is rapidly worsening and not being acted upon.

A life in the day...

Since our last contact, I've been imprisoned for sending false information. I've not had access to appropriate healthcare. I've not been able to see a GP at all.

They just blame it on diabetes neuropathy and refuse to help me. Like many typical neuroleptic drugs, why don't they know that they potentially worsen glucose control, which can negatively affect anyone with diabetes?

They've been lied to as well and no-one will listen.

I have a diagnosed movement disorder called Tardive Dystonia. I've seen specialist neurologists who confirm non-axonopathic peripheral nerve hyperexcitability. I have no nerve damage, it's neurological not metabolic.

Things that keep happening to me;

- I stop breathing
- I was heavily bleeding from my rectum three years ago and again a year ago
- I have intermittent severe abdominal pains and it hurts to poo
- I have mild bilateral plural effusions
- I have an l4/5 disc tear and bulge causing intermittent Cauda Equina syndrome symptoms (loss of bowels, sexual function, sciatica)
- I have severe muscle spasms all over my body

I have chronic and disabling neurological symptoms which include pain, tiredness, exhaustion, stiff muscles and muscle contractions which started about 8 years ago when I was treated with Quetiapine. My life is not my own and the lack of understanding is causing me a huge problem.

I think my side effects are because no-one thinks about the proper dose of medications that take your full medical situation into account. I mean they don't care that you have other things and just go ahead and make a prescription. I am really angry at the damage they have caused me because someone should have known better. I really worry that this is all my life is from here.

Could you look at my case and speak with safeguarding and explain my neurological diagnosis to them? My anger is being misinterpreted as aggression against them.

Following this contact explaining a defined period of medication toxicity, this person was referred to physiotherapy by the GP but exercise made the symptoms worse. The person was desperate with suicide ideation and Adult Social Care were unresponsive to needs.

Using this information, Neuro Key made an urgent referral to the Mental Health service. The beneficiary has not been heard from since.

Learning outcomes

	Be able to;	Relevant for
1	Offer pharmacogenetics (PGx) testing before initiating antidepressants/antipsychotics	Primary Care, GP, NHS, Social Care and Mental Health practitioners
2	Listen to the caregivers	Primary Care, GP, NHS, Social Care and Mental Health practitioners
3	Provide PGx testing for all patients referred to or in Mental Health services	Community Treatment Orders and those detained under Section 3 of the Mental Health Act.
4	Teach PGx across medical training programmes. Assess era of older medications, type and length of time for therapeutic efficacy	NHS Trusts, Mental Health, in-service specialist training Continuing Professional Development (CPD)
5	Actively consult with pharmacists to maximise therapeutic benefit	Investigate drug–gene and drug>drug interactions by medical prescribers
6	Upgrade informed consent	Must include potential drug–gene issues, toxicity risks in poor and intermediate metabolism patients and initiate safer tapering options on treatment plans
7	Integrate the legal requirements on pharma-cogenomic guidance and testing into the British National Formulary (BNF)	Mental Health prescribers - Initiate clear EM/IM/PM dose ranges plus emphasis on long term harm of toxicity levels
8	Instigate reporting of medication serum levels on medical records within one week of death	Coroners reporting on deaths attributed to suicide in Mental Health patients
9	Strengthen the lines of communication, guidance and safety for medical care of Mental Health patients	DHSC, Medicines and Healthcare products Regulatory Agency (MHRA) and NICE
10	Review the power of influence exerted by Pharmaceutical Companies	DHSC, Medicines and Healthcare products Regulatory Agency (MHRA) and NICE

What can we learn from these narratives?

How can services respond more appropriately?

How should caregivers be heard?

Information resources

- **A European perspective on tardive dyskinesia; European Neuropsychopharmacology ; Volume 104, March 2026, 112740**

https://www.sciencedirect.com/science/article/pii/S0924977X25008041

Abstract

The clinical presentation of Tardive Dyskinesia (TD) comprises involuntary hyperkinetic movements of the face, trunk, and extremities that can severely impair patients' quality of life. Despite advances in antipsychotic treatment options, TD remains prevalent, with estimates suggesting that in Europe, approximately 22% of patients treated with antipsychotics (regardless of drug subclass) have TD.

The research underscores the necessity for further scrutiny to explain the impact of TD on patient outcomes and to develop effective management strategies to address the complexities of TD within the health care landscape.

Neurologists are central to the effective management of movement disorders such as TD.

- **The clinical effectiveness and cost-effectiveness of testing for cytochrome P450 polymorphisms in patients with schizophrenia treated with antipsychotics: a systematic review and economic evaluation (2010)**

N Fleeman, C McLeod, A Bagust, S Beale, A Boland, Y Dundar, A Jorgensen, K Payne, M Pirmohamed, S Pushpakom, T Walley, P de Warren-Penny, R Dickson

PMID: 20031087; DOI: 10.3310/hta14030

Abstract

To determine whether testing for cytochrome P450 (CYP) polymorphisms in adults entering antipsychotic treatment for schizophrenia leads to improvement in outcomes, is useful in medical, personal or public health decision-making, and is a cost-effective use of health-care resources.

There is a lack of clinical utility and economic studies and due to the unsuitability of published schizophrenia models, no model was developed.

- **International Journal of Neuroscience**

Suicidal Behaviour and Tardive Dyskinesia, (2009) 57:3-4, 269-271, DOI: 10.3109/00207459109150701 https://doi.org/10.3109/00207459109150701

https://www.tandfonline.com/doi/pdf/10.3109/00207459109150701

Significant correlation between depression, suicide attempts and involuntary movements of limb-axial TD.

- **New Tardive Dyskinesia Data at Psych Congress 2024 from the IMPACT-TD Registry, Revealing Differences in Patient Experience Based on Underlying Psychiatric Condition**

IMPACT-TD Registry, the largest study evaluating holistic effects of Tardive Dyskinesia (TD), highlights that there is a high burden of TD on quality of life regardless of a person's underlying mental health condition. Registry revealed fewer patients with psychotic disorders (36%) received TD diagnoses compared to those with mood disorders (50%)

https://www.tevausa.com/news-and-media/press-releases/teva-presents-new-tardive-dyskinesia-data-at-psych-congress-2024-from-the-impact-td-registry-revealing-d/

- **Treatment emergent violence to self and others; a literature review of neuropsychiatric adverse reactions for antidepressant and neuroleptic psychiatric drugs and general medications (2019)**

Clarke, C SRN, SCM, MSSCH, MBChA., Evans, J MCSP. Grad Dip Phys., Brogan, K MD

Mental health drugs can trigger reactions that mimic symptoms of mental health conditions such as delusions, hallucinations, mania and akathisia. These in turn can trigger violence, suicide and homicide.

https://pubmed.ncbi.nlm.nih.gov/31370036/

- **Precision psychiatry roadmap: towards a biology-informed framework for mental disorders**

Kas, M.J.H., Penninx, B.W.J.H., Knudsen, G.M. et al. Precision psychiatry roadmap: towards a biology-informed framework for mental disorders. Mol Psychiatry 30, 3846–3855 (2025). https://doi.org/10.1038/s41380-025-03070-5

In clinical research and drug development, diagnostic categories are used as enrolment criteria for clinical trials and to inform prescribing information for the appropriate use of therapeutic interventions. However, like other neuropsychiatric diseases, mental disorders arise from the biology of the brain and its bidirectional interaction with the environment. Current classification systems do not reflect this knowledge.

Global stakeholders must align research efforts to work toward integrating symptomatic, biological, and behavioural information into the definition of mental disorders to advance the development of effective treatments. The European College of Neuropsychopharmacology (ECNP), following the 2024 New Frontiers Meeting, is coordinating a global initiative to design and implement a Precision Psychiatry Roadmap.

https://www.nature.com/articles/s41380-025-03070-5

- **Dystonia UK**

hhttps://www.dystonia.org.uk/pages/faqs/category/tardive-dystoniattps://pubmed.ncbi.nlm.nih.gov/31370036/

- **MIND**

https://www.mind.org.uk/information-support/types-of-mental-health-problems/tardive-dyskinesia-td/

Neuro Key February 2026

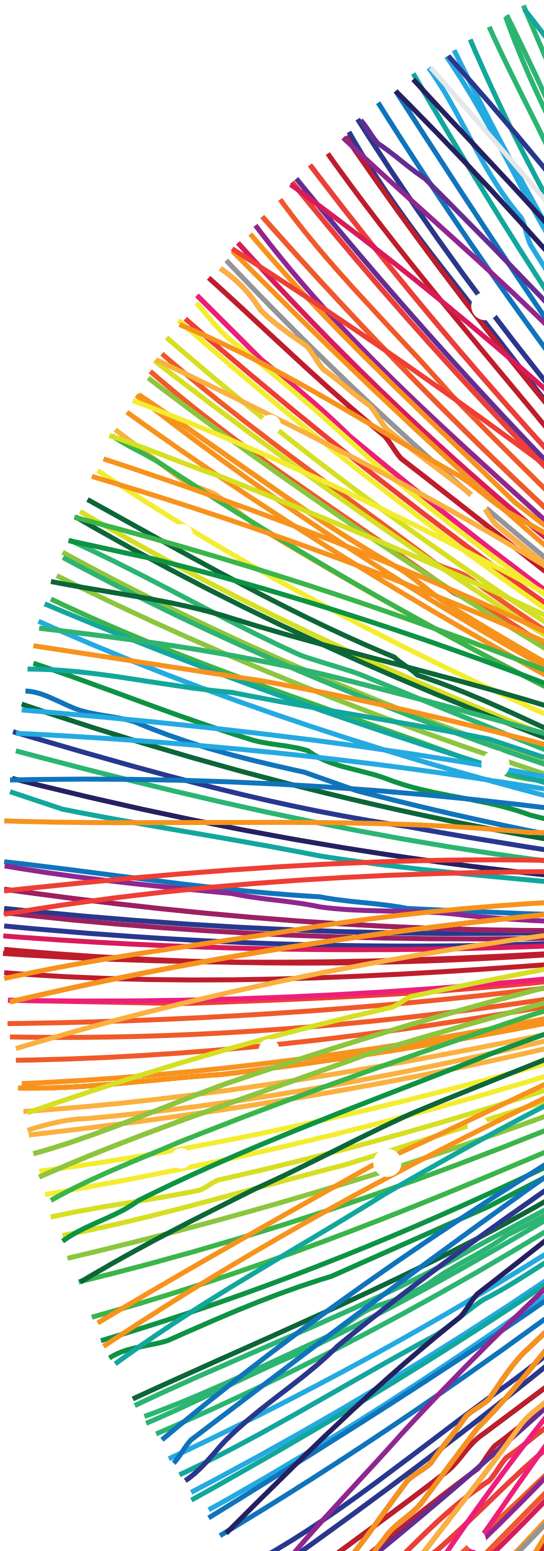
Notes

NEURO KEY

An Alliance supporting people
with neurological conditions

In the spirit of creative commons, our Open Door series is collectively created with the lived experience of participants to share expertise and ultimately, benefit the whole neuro community.

If this resource has been useful for you, we would appreciate a donation to help keep the work going.



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