

Introduction

Nidotherapy was introduced more than 20 years ago as a form of treatment for those with chronic persistent mental illness, who had failed to respond to standard therapies. If you read this sentence again it sounds like many other alleged breakthroughs that we hear so often about in the media; so often that we can disregard them. We use superlatives so often that when we are really looking for superlatives, there are no words to choose.

Hence rather than using complicated Greco-Latin words that run so rapidly into clichés we think the best way to get the essential point of nidotherapy over is to hear from a patient who has been involved with this treatment for over 20 years and who now regards herself as the best she has ever been in terms of her health. We also hear how she has educated us along the way.

She does not mind us giving her name, but as we have known her with two names over the course of the last 26 years we will only use one of them, Anthea.

Anthea's Case

Anthea was studying an art degree in Amsterdam when she became acutely ill with a form of schizophrenic illness. She was only 21, on her own in a strange country, and her subsequent pattern of treatment was typical of those with schizophrenia. Before we move on we would like you to reflect on what exactly is this pattern of treatment. Oddly enough, the treatment of schizophrenia with drugs, the standard method of management, is still regarded as one of the most positive advances in psychiatry in the twentieth century. Often dubbed the 'psychopharmacological revolution' it gave rise to the notion that all mental illness, in time, could be treated, cured, or corrected, whatever verb you care to choose, by giving the appropriate drug. In the words of Heinz Lehmann, one of the first psychiatrists to use chlorpromazine, the first antipsychotic drug, in the 1950s, this group of drugs 'served as the "Rosetta stone" for the hieroglyphs of mental disease symptoms and opened new avenues for the development of mental neuroscience' (Lehmann, 1993). The follow-up is more gloomy. We are still looking for a new Champollion to decipher the Rosetta stone of neuroscience; 60 years after the first use of chlorpromazine, neuroscience has spectacularly failed to explain schizophrenia or the reason why these drugs help some people and do nothing for others, and in a small group, even make them worse.

The psychopharmacological revolution has ended in stalemate (Tyrer, 2012) and this was realised by Anthea quite early on, without needing to look at any psychiatric literature, during the course of the management of her own case. Put in a nutshell, we as psychiatrists can treat the positive symptoms of schizophrenia effectively with (antipsychotic) drugs, but only at the expense of a range of unpleasant side-effects. Far too

often we maintain that our patients are *clinically* better when they feel physically worse. The nasty little term, ‘risk-benefit ratio’, now used so often in medicine, gives a spurious pointer of accuracy to the choice of treatment, but in the case of schizophrenia the risk-benefit ratio is so often negative for the patient (i.e., the positives of symptom reduction are far outweighed by a raft of negatives, including cloying sedation, abnormal movements, increasing appetite and weight gain, and sexual incompetence). For the doctor, and indeed for society, the gains may seem to be greater, as on most occasions the patient can be kept out of hospital and not cause disturbance to society by unusual behaviour, and these particular gains are normally achieved with drug treatment.

But this only applies to positive symptoms. The so-called negative symptoms of schizophrenia, apathy, disinterest, lack of motivation and persistence, do not really respond well to drug treatment but do better with different forms of psychotherapy, such as cognitive behaviour therapy (Sensky et al., 2000). The more diffuse system of care called the recovery model, which is clinically understandable but a problem to evaluate, has now been introduced to give more hope to those who have illnesses like schizophrenia and have no prospect of remaining well without drugs (Leamy et al., 2016).

But we must not deliver a picture of unadulterated gloom. A large number of patients with schizophrenia respond well to medication and can also continue to remain well by taking a level of dosage of antipsychotic drugs that prevents the more severe side-effects from emerging and allows a reasonable quality of life. Nevertheless, in both the acute and chronic treatment of schizophrenia there remains a very large minority of patients who do not like the standard treatment for their condition, will do a lot to try and avoid receiving it, and are constantly having to receive this treatment against their will. Here we have the hinterland of nidotherapy.

Anthea was one of these patients. She found taking treatment intolerable, fought consistently against it at every opportunity, and when left to her own devices (i.e., not under compulsory treatment), she stopped all her drugs entirely. It is perhaps predictable what happened next, but we will leave Anthea to explain this in her own words.

This was just the start of a series of admissions, starting in Amsterdam and then back in England. Since that first admission 32 years ago I have had over 20 admissions, all of them in the 15 years after my first one, and all compulsory ones, and each giving me a diagnosis of schizophrenia or something silly on the road to manic-depression called schizoaffective disorder. Psychiatrists can never make up their mind over diagnosis – they could abolish it. On every occasion I have had drugs that have made me fat, burned my skin, blurred my vision, and fundamentally rotted my soul. So, the first thing I did when taken off my section was to starve myself back to a normal weight.

It is worth breaking off at this point to emphasise that the treatment that Anthea received was entirely proper, and in the language of today, evidence-based. Every doctor she saw sang from the same schizophrenia hymn sheet. ‘Anthea, you have a schizophrenic illness. The only proven treatment for this, at least in the acute phase, is medication. You must take this medication otherwise you will not get better, and if you stop it after you get better you will relapse.’

Now Anthea regarded the drugs that she had been prescribed as poison. This word may be an exaggeration, but to her the damage it was doing to her body could not be interpreted in any other way. But there was not one single advocate to advance the cause and so she continued to tackle this illness in the same confrontational way that she had

started. Every time she was admitted it was under a compulsory order, continued drug treatment was only maintained under compulsion, and as soon as she was discharged from hospital she stopped treatment. (Nowadays, she almost certainly would have been put under a community treatment order with one of the conditions being that she took her medication on discharge.) Anthea made it very clear to us that if a community treatment order had been imposed on her she would either have emigrated or committed suicide. Fortunately she got better before this order was introduced. (Incidentally this apparent advance has been shown to have no positive effects on outcome despite increasing the duration of compulsory treatment 22-fold (Burns et al., 2013).)

So before we return to Anthea's story it is worth thinking how any of us would have felt under the same circumstances after a set of repeated admissions to hospital, no evidence of any change in policy or treatment, and a continued battering ram of insistence that (poisonous) drugs were the only answer when it came to treatment. Add to this a sense of being alone in a hostile world. If we absorb all these features does it really surprise you that suicide rates are so high in schizophrenia?

We Return to Anthea:

What changed? 23 years ago I was visited by a psychiatrist and psychologist who worked together in a community mental health team.

They came out of the blue and at first I ignored them, as I was convinced they were going to section me again, as had all the other psychiatrists in the previous 10 years. Nobody had ever come to see me at home to talk to me. So I did not let them in. But they kept on coming round and talking through the letterbox – one had a very loud voice – and saying they only wanted to talk about my problem. Eventually I let them in and they explained they were not connected directly with the hospital, but had been asked to make an assessment because I was always bouncing back into hospital and they wanted to see if they could help. As I expected, after they saw me, the psychiatrist, who was a bit of an odd bod, tried to persuade me to take a very small dose of medication. But I wouldn't. I told him that as far as I was concerned it was poison and I would not be taking it under any circumstances, unless I was forced to take it in hospital.

We continued like this for some time, but he kept on visiting and eventually I persuaded him to let me try without medication. He can tell the rest of the story.

The Perspective of the Consultant Psychiatrist (PT)

I first met Anthea in 1990. She was referred to an early intervention team where I was working, and which had been set up to promote community psychiatry and also help people who in the euphemistic mantra of the time were 'difficult to engage'. She had repeatedly failed to keep appointments in the out-patient clinic at the hospital and no contact could be established with her. On looking through her past records it appeared that she had severe psychotic episodes invariably leading to hospital admission, and during these she exhibited a combination of excitement and manic symptoms, including stripping off her clothes and being generally disinhibited, and schizophrenic ones, paranoid delusions about the IRA, and the conviction that people were plotting against her. Admissions had occurred almost annually in the last 17 years, first of all when she was living in a rural area, and latterly in an urban one. Each admission followed a familiar pattern. She was

admitted to hospital under a section of the Mental Health Act, usually with the police in attendance, and, once admitted, was passively cooperative with treatment with antipsychotic drugs given intramuscularly or orally. She disclosed very little about herself and the psychiatrists treating her were uncertain to what extent she had improved or whether she was still ill and deluded. After each discharge she was given out-patient appointments but always failed to attend.

My First Contact with Anthea

So when I, and our team psychologist, went to see her we knew it would not be an easy meeting, and we wrote a gentle letter reassuring her of our good intentions and telling her the time and date of our appointment. I was accompanied by a psychologist to her flat in a Victorian block, a typical grey Bayswater building, its appearance was broken only by the flash of bright orange curtains drawn across the window on the first floor.

We knocked on the front door but there was no answer. We left and returned again the following week, and the week after, and continued to see only the orange curtains, which by now seemed to be making a statement of their own. Eventually, after another visit, and a few shouts through the letter-box, Anthea came to the door. She was highly nervous at first, but after being reassured that we were not going to take her immediately to hospital against her will, she invited us into her flat, entertained us to tea, and showed us her collection of tropical fish, who periodically were taken to have a swim in her bath when the aquarium was being cleaned.

But this was just the social component of the visit. She also made it abundantly clear to us that she was not going to take any medication for her symptoms, as most of the time she was quite well and, in any case, the drugs she had received in the past had ‘played havoc with her hormones’.

I subsequently visited on my own to try and work out a drug regime that involved very low doses of antipsychotic medication as I was convinced from her history that this was the only way of preventing relapse and further admissions to hospital. But Anthea was having nothing of this, and even the option of having medication in her flat to be taken at the first signs of relapse was rejected out of hand.

Eventually I gave up and asked Anthea if she had another solution to prevent the inevitable cycle of recurrent admissions. She replied quite simply, ‘I’ll cooperate with you provided you don’t give me medication.’ Now, as a well-trained psychiatrist following evidence-based principles, I knew, or at least thought I knew, that the acute positive symptoms of psychosis were best treated by antipsychotic drugs, and there was no other option.

Taking the Plunge

In finding a way out of the dilemma I employed nidotherapy for the first time. Of course, I had no idea what it was, but because I had completely run out of ideas when it came to all standard therapies, I had to look around for other options. What was abundantly clear was that Anthea was not ill at present. She was sparky and lively, had none of the so-called negative symptoms of schizophrenia, had good self-care and leisure activities, and seemed to be living a satisfactory and happy life. Her regular visits to St Paul’s Cathedral also told me she was getting succour from religion; this may have been true but she also told me she fancied the organist ‘something rotten’.

So at one level it was incongruous to try to argue with her that she had to take medication. There are some people with schizophrenia who seem to get slightly less competent after each episode of illness, so in retrospect the course of illness seems to proceed slowly downhill. But Anthea was clearly not in this group. Despite having dozens of episodes of illness none had left a negative mark.

So I looked around desperately for some type of intervention that would fit in with what Anthea wanted. At this point I was struggling towards one of the core principles of nidotherapy – ‘do not make any plans without the full cooperation of the patient’. Anthea may have been wrong in thinking all the drug she had been given constituted poison, but I was not going to change her mind, and she had had many years to reconsider her verdict since she first became ill.

The First Glimpse of Systematic Environmental Options

It was then I considered the possibility of environmental options. Was there any way of maintaining Anthea at home in her very stable setting and avoiding the awfulness of compulsory admission and forcible administration of drugs? At first I had no idea what the answer was and decided to go on seeing Anthea, not so much as a patient but as a fellow human being with a problem that I might be able to solve in some way.

My clinical team, a novel and radical one called the Early Intervention Service (before the names was taken up elsewhere), supported me in this plan. At this point I must take issue again with those who say that nidotherapy is what good psychiatrists practise all the time. I do not think that I have this wrong, but I am sure that at this point most community mental health teams would have either been rejected by Anthea, or would have developed some form of crisis intervention plan to deal with the next time that Anthea had a psychotic episode. They would not have continued to see her and apparently condoned her continued refusal to take medication.

What eventually transpired was a plan to preserve every aspect of her positive environment – her flat, her tropical fish, her striking orange curtains (I always thought this was linked to the happy time in Amsterdam before she became ill), and her magnificent library – and keep this away from the psychotic one when she became ill. At these times everybody was perceived as hostile or needlessly interfering in her life, and of course once she was in this environmental mode admission to hospital soon followed.

Was there any way of proceeding without medication? I just had to go on talking with Anthea and hoping to find some clues. What became clear in these discussions, and looking at her past notes from a mental hospital in Somerset, was that her episodes of psychosis, although very severe in terms of her symptoms and behaviour, did not seem to be long-lasting, and the hypothesis developed in my mind that for most of the time she spent in hospital she was probably well. It was only her ingrained suspiciousness and hostility to all things psychopharmacological gave the impression that she still had the residual symptoms of psychosis.

A Treatment Plan

So this allowed the development of a new treatment plan, supported by colleagues at our Early Intervention Service. At the first sign of psychosis, something she was able to detect a day or so before it burst into its florid manifestations, she would go to ground, as it were, stay in her flat at all times and ensure she had enough food to batten down for a few days,

without venturing into the community. A few people, including our service, could be informed about the relapse but we would just monitor events without intervening.

What happened? Well, it worked. In the last 24 years Anthea only had two admissions to hospital for a total of 7 days compared with an admission of several months almost annually in the previous 15 years, and all this has been achieved without any medication at any time, apart from a few days when in hospital. She has also become an established mosaic artist with her own studio. Just to ensure that any relapses are dealt with according to the long-term plan we have established, she carries round a letter from me – which could now be regarded as an advance directive – which outlines her case history, her preferences for treatment, and her wish if admitted to hospital to be discharged as soon as possible.

This account contains all the elements of nidotherapy and they will be identified and clarified in the following chapters. But there is one question we would like to ask at this point to those who regard nidotherapy as an activity psychiatrists practise all the time. Would you have treated Anthea in this way?

And when my good colleagues, Ani and Ani (2007), say that we are all nidotherapists now, would they too have treated Anthea similarly? The answer to this question is probably ‘no’, but you may be persuaded that the answer should be ‘yes’ after you have read the rest of this book.