

Keira's story

Keira is 17 and currently doing very well after a 10 year struggle with an eating disorder and difficulties related to her PDA profile not being understood or supported by health and social care. Her story illustrates the life-changing impact when professionals adapt their practice to be person-centred and PDA-friendly. Sharon Donaldson, director of the specialist eating disorder unit where Keira was an in-patient, also shares how she and her team worked with Keira and her family to develop the personalised, holistic approach which was so key to achieving a successful outcome, and is now being shared with others as an example of best practice.

TRIGGER WARNING: this case study contains information about eating disorders and distressed behaviours (including self-harm) and mention of suicidal intent.

Please note that Keira's name has been changed to protect her identity

Keira was first seen by CAMHS age 5 because of the distressed behaviours she was exhibiting, including self-harm and meltdowns. Her behaviour was attributed to 'naughtiness' and her parents were sent on a parenting course. However, two years later Keira was diagnosed with autism and ODD - a diagnosis that was subsequently revised to a PDA profile of autism. She was excluded from school aged 9 and referred back to CAMHS, where once again she was discharged after the standard approaches (which were all that could be offered) proved unsuccessful. A specialist educational placement was recommended, and a year later Keira started at the National Autistic Society Robert Ogden School which has inclusive learning 'hubs' for pupils with a PDA profile (Keira still attends today).

Over the next few years, Keira was referred on several occasions for specialist input in relation to regurgitation/rumination problems, germ anxieties, anxiety, self-harm and sleeping difficulties. On each occasion, standard approaches were tried and failed, leaving Keira and her family distressed and disillusioned that her needs weren't being understood or supported.

Keira had longstanding difficulties with rumination (involuntary regurgitation of recently swallowed food back into the mouth), which worsened when she was anxious, and she began to lose weight. With investigations and tests proving inconclusive, Keira's parents realised that she had an eating disorder. Keira restricted her food intake considerably and became increasingly unwell. Both Keira and her parents were worried that the 'gold standard' approach for treating eating disorders was very demand-heavy and wouldn't be accessible for her. Keira was informed by several healthcare professionals that if she wasn't able to increase her calorie intake she risked being sectioned, admitted to hospital and fed forcibly. This understandably felt very

threatening to Keira, and her anxiety increased to the point that she was felt to be at risk of suicide.

After a short stay in a children's hospital, aged 14, Keira's paediatrician acknowledged that the standard methods weren't working for her, and allowed her to return home on the agreement that she would keep up a regime based on therapeutic nutritional drinks. For a short time this was successful, but Keira was unable to sustain her intake. Over the next few months, a specialist healthcare and support package was requested and agreed to, but nothing was ever put in place. Keira's conditioned yo-yoed, with each promise of tailored support her mood and intake improved, and with each disappointment they dipped, eventually resulting in another hospital admission.

Keira spent two months in hospital, being fed via a pump and naso-gastric tube. She was promised a move to a suitable unit that would take account of her needs and use a person-centred approach, but was once again let down and told that she would have to go to whichever mental health unit had space and follow the standard eating disorder model. Despite the director of the proposed unit agreeing that they were unable to meet Keira's needs, her Mum was threatened with child protection proceedings if they didn't accept the place. Undaunted, Keira's Mum raised the prospect of launching a judicial review into the failure to meet Keira's needs.

At this point, the newly opened Ellern Mede facility in Rotherham was suggested - the Ellern Mede Group had extensive experience of developing bespoke packages of care for patients with eating disorders, with two established hospitals in the London region. From the very first phone call Keira's parents felt that they had found somewhere that would finally be able to help their now 15 year old daughter.

At this point, Sharon Donaldson, Service Director of Ellern Mede North Region, picks up Keira's story ...

“It was clear from reading Keira's initial referral letter that we'd need to think very carefully about how to meet her needs. We held a lot of pre-admission meetings, several of which included Keira's paediatrician. The unorthodox approach that she had taken (which was absolutely essential in order to prevent further deterioration, but in terms of conventional eating disorder guidelines was highly unusual), together with Keira's detailed PDA diagnostic report, gave us the platform to do things very differently and, most importantly, to gain Keira's trust.

At Ellern Mede we often make adaptations to treatment because our service is for people for whom standard approaches haven't resulted in any recovery, so we're used to thinking out of the box and looking at different ways to engage.

Listening to and building a trusting relationship with Keira was the vital first step, especially as she had such little faith in healthcare professionals based on her experience to date. Our starting point was to ensure that everyone who had any dealings with Keira – from cleaners to consultants – had PDA training from someone who Keira had total confidence in: the assistant head at Keira's school, Jilly Davis. This was a rolling training programme, with many sessions delivered over the time that Keira was with us, to ensure that all new staff members were fully up to speed. Jilly explained that initially a PDA young person may only trust one person, and there was indeed one particular healthcare assistant who Keira really bonded with and who went the extra mile to support her. Over

time, as we earned her trust and Keira could see that we were doing our utmost to help her, Keira was able to work with a wider team.

We learned from the training that Keira needed a sense of control in order to feel safe. This meant doing some things that went against normally sacrosanct eating disorder protocols, such as allowing Keira to set the pace of how her calories were increased, letting her choose which staff members to work with and giving her much more time and flexibility both nutritionally and therapeutically. As a clinical team, we kept the focus on the end goal rather than focusing too much on how we got there. This meant we could work in a collaborative and negotiative way with Keira, with lots of input from her Mum and Jilly.

Another significant learning point from the training was that a change in phraseology makes a huge difference. I remember one conversation with Keira that really crystallised how difficult things were for her: she said “I want to drink. I know I need it. But I can’t unless you tell me I have to. But if you do that then it’s a demand and then I can’t do it.” It was really important to help the team understand that they needed to find a way to tell Keira she had to do things, but in a PDA-friendly way.

We did this by reducing the perception of demands. For instance, we’d only focus on one priority at a time so that it felt less overwhelming, or we’d link what was needed to Keira’s interests so that there was a reason to do things that was more meaningful for her. For example, Keira loves to dance and when there was a need to do some physio we discussed building muscles and strength to enable her to be fit and safe enough to dance again and assured her that we could arrange for her to have some dance lessons at the unit with her former teacher. As part of this we didn’t rush things, we just ‘planted a seed’ and enabled Keira the time to process and reflect on what we’d discussed and reach her own conclusions. The dance sessions really gave Keira the impetus to recover, and gradually as she got stronger and needed more space she was allowed out to work with her teacher at the dance studio on a 1:1 basis. Just five days after leaving the unit she achieved a merit in her level 3 ballet exam. Another approach we developed with Keira was to disguise or share demands or make them more fun. So to help her develop diaphragmatic breathing techniques needed to help control her rumination, for instance, we learned opera together.

Honesty was also always the best policy with Keira, as the complex combination of anorexia and PDA was something we all had to work through with some degree of trial and error. I was very open with Keira and said things like “It’s my job to get you well and get you home, but I don’t know exactly how we’ll go about it!” or “Normally we’d do X but I don’t think it would be helpful in your case, so how about we try Y?”. We had many round table discussions with Keira’s Mum and Jilly about how to make both nutritional and therapeutic interventions, such as DBT, more PDA-friendly.

We also established that giving Keira the facts in quite scientific and visual ways was helpful, for instance when she was anxious about increasing the pump speed by 5ml per minute we showed her a teaspoon to help her understand how small this amount actually was.

The biggest challenge was getting other healthcare professionals on board with the highly personalised and very unconventional approach we were taking with Keira. It required a huge mindset shift! It helped that, as lead clinician and with a strong reputation in my

area of expertise, I felt very engaged with Keira and was absolutely determined that we were doing the right thing. Support and regular supervision/welfare sessions with the staff team was also a top priority. I put together a phrase sheet for staff on what to say and what not to say, and our lead autism nurse put together an A4 leaflet to help new or agency staff. The better Keira did, the more others came on board and the team felt proud and committed to the course we were taking.

There were also many meetings with external professionals who didn't accept PDA as a valid diagnostic formulation. I was fairly robust and took the approach that we needed to focus on needs not 'labels' and that arguing the point would prevent them from being able to access and support Keira.

We're all delighted with the fantastic progress Keira has made and continues to make. Our team feels confident in working with a PDA person again, and our approach is being shared with others as an example of best practice."

Keira was discharged from Ellern Mede after 14 months, initially continuing as a day patient before her care was transferred back to the community (with the local CAMHS eating disorder team now adopting the same approach as the Ellern Mede hospital), and remains well 9 months on. She is back at school and continuing to dance, and has been asked by several organisations to help train professionals on PDA and eating disorders, as an expert by experience. Keira is also thinking about her plans for the future, maybe running her own dance school or studying psychology so that she can help others. The professionals involved in Keira's journey also report positive outcomes as a result of the skills and knowledge they built in adapting their practice to be more person-centred, informed by PDA-friendly approaches.