



Hospital to Home: Matthew

Acknowledgements

Matthew Dolton and Jayne Leeson (authors), Katie Seymour (portraits and design).

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Foreword

Whilst working with Matthew on this book, I have come to know him as a thoughtful and considerate individual, who is cheeky and optimistic, who needs some support to navigate every day events. As this support was lacking in his childhood and youth, Matthew found himself misunderstood and walking an unstable path, where the consequences of being inadequately supported resulted in him losing all freedoms for approximately 16 years of his life. Had Matthew been appropriately supported earlier, by a team who understood him, his thought processes, and communication style, there is no doubt in my mind that he would have been spared many of those years in hospital.

Matthew's unwavering resilience towards the difficult situations he has found himself in is something that I find remarkable. Although he remembers vividly the 16 years he spent deprived of his liberty in hospital settings, he now looks back through a lens of positivity and uses the lessons of his past constructively, with an understanding and an appreciation that he is now in control of shaping his future.

Although previously Matthew had poor support, and was moved from hospital to hospital as a result, for the past few years he has been able to successfully navigate changes in his life in part because of the support of the professionals around him. The support provided by his key worker, Asa, enables Matthew to engage with every day life experiences with renewed confidence. Matthew himself acknowledges that this support is important as his key worker gives him a safe space in which to test out communication strategies and to interact with new faces. Without this safe space, Matthew may well still be misunderstood by people he meets in his life. This support enables Matthew to have an ordinary life.

When I first proposed the possibility of this book to Matthew, he was very keen that his experiences were shared, so that they could be used by others who were facing similar difficulties, as well as by professionals who could learn from his journey. He reflected on using the term 'Asperger's' in the book and decided that although this is a term used less today, we would use it throughout the narrative as he believes its annoying that labels and diagnoses change.

In contrast to many individuals who have found themselves stuck in the hospital system, Matthew's perspective is strikingly optimistic: for all the pain he endured during this time, he believes that his final hospital placement was in fact necessary, as it enabled him to feel better about himself and stabilise his reactions to everyday life experiences. He equally believes that support from the hospital during his teenage years would have been beneficial, rather than being left on his own, unsupported, to fend for himself in the community.

Jayne Leeson MBE

Changing Our Lives CEO



Matthew is a joyful individual who has a dry sense of humour and is fun to be around. He is caring and helpful, honest and tells you things straight.

After being buffeted from hospital to hospital - including a medium secure, as well as locked and open rehabilitation units - over a period of 16 years, Matthew now lives in supported living.

The teenage years

Matthew lived at home with his mom and dad in his early childhood, but as things were difficult there, he was taken into foster care aged 10. Over the next 7 years, Matthew lived with 5 different foster carers but each of these broke down as he struggled to cope emotionally, and from about age 15, he started to commit petty crimes. As a result he had little, if any, stability, moving from home to home. Matthew was not diagnosed with Asperger's until 17, so there was no support tailored to his needs during these years.

"If someone or something annoyed me, I didn't know how to react well. I would react by damaging a car or breaking a window or threatening the person. This was my reaction at the time. I know now that it's wrong, but it's the way I coped when I was younger."

As relationships with foster carers broke down, Matthew found himself sent to a children's home for a while, and then on to a residential sixth form college. Still unhappy, Matthew threatened to burn the college down and was expelled.

Then, for a short time when he was 17, Matthew moved into a flat on his own with staff coming in to support him. Matthew was not old enough to sign for his own tenancy at this time, so the council put arrangements in place so he could legally stay in the flat with paid carers. Matthew found it very difficult to cope, with carers being with him 24 hours a day, and as a result his behaviour got worse.

"I hated this. I hated having staff around me all the time so I went to my neighbour and harassed and threatened them. I knew what I was doing but I was so upset at the time and I wasn't thinking straight. I found it difficult to control myself."

When Matthew was living in the flat, he had a remote control hovercraft, as he has always loved gadgets and transport. However, when the hovercraft broke and he lost the receipt, the shop wouldn't exchange it. Matthew, who needs to have situations resolved and finds open ended circumstances very difficult to deal with, began to think of a way to resolve the problem. He had a toy gun which looked real, and so he decided that a solution would be to take the toy gun to a local golf course and demand money from them so he could buy himself another hovercraft. He thought he would leave the broken hovercraft with the golf course so that they could take it to the toy shop and sort it out. If he had the money from the golf course, it made sense to him that he would be able to buy another remote control hovercraft.

This incident, which in Matthew's mind was logical at the time, led to him being arrested and placed in prison on remand for a month. His former foster carers found out that he was in prison and offered him a bail address, and so Matthew left the prison and went to live with them. At sentencing, Matthew was given a probation order and a 6 month curfew from 7pm until 7am. However, after living with his foster carers for only a short time, he began to struggle with the thoughts in his head and how to engage with the world around him, and so he fell into a pattern of committing crimes, being drunk and disorderly and generally, in Matthew's words, being "*out of control*".

"I had a pretend gun and I threatened people with it and I threatened to bomb places. I wasn't going to do any of those things. I didn't want to hurt anyone. At the time my head was so messed up, so this was the way I thought. Looking back on it now I can see that it's completely illogical and not a good way to behave. I wasn't on any medication at the time and I just couldn't cope. I felt really unstable."

Although upon going to court Matthew was only given a probation order, Matthew now wishes that he had been given the support of a hospital as he felt this would have made him more stable. Reflecting back, Matthew feels let down at this point in his life, arguing that hospital would have been the right place for him.

Whilst on the probation order, living with his foster carers, Matthew's behaviour was repetitive and predictable as he would commit crimes and get into trouble with the police on average twice a week. All of this time, Matthew was not on any form of medication and had no psychological support.

"When I was in court two doctors said there is no need to put me on a hospital order and that I wouldn't cope in the prison population. On reflection, hospital would've been good for me at this stage. I feel they let me down by not sending me to hospital. Giving me the curfew was a real punishment because the one thing I really love doing is going out."

“What I needed at this point was not punishment, I needed help.”

"I strongly feel that all the time I spent in the community really struggling, I would've been better off spending in hospital being sectioned. I should've been sectioned in order to help me many years earlier. All of this behaviour was me saying something is wrong, but I was just left to behave illegally and violently when I could've been in hospital getting to the root of the real problem."

The hospital years

The first hospital

As a result of this continued behaviour, Matthew, aged 17, eventually found himself sent miles away from home to a locked ward on a Section 3 of the Mental Health Act. In the locked ward, Matthew remembers feeling very unwell and violent most of the time. The doctors tried him on different types of medication but they simply didn't work. After a while, Matthew remembers being taken off the medication altogether and he started becoming distressed again, which led to him hitting people.

A residential care home

After about a year on the locked ward, Matthew was moved to a residential care home with the same provider as the hospital. At this point, it was still the case that he was not on the right medication, and he continued to feel out of control most of the time.

Back to the locked ward and seclusion

After a few short months, he then went back to the locked ward, again with the same provider. Matthew describes this time as one of the lowest points in his life: he was kept in seclusion under the observation of 2 staff, who were stationed outside his door at all times. He was told that he needed to be in seclusion until he made the transition to a medium secure unit.

At this point Matthew tried to hang himself as he didn't think that life was worth living.

Medium secure

When Matthew was sent to the medium secure unit in London - once again miles away from his family - he found himself on a ward with people who had committed murder. He was there for about a year. Matthew found this whole experience incredibly traumatic.





"It was horrible being on the ward with murderers and really violent people. This shouldn't happen. You should be kept separate from these people. I knew there were murderers on the ward because they talked about who they had killed. There was one guy who used to beat me up and I was really scared. I had my own room but you couldn't have a lock on it, so you couldn't keep yourself safe from other people. Once a patient came into my room and started punching me and I shouted for help. Another patient came in and he struggled to get the other guy off me but when he did get him off me, he gave him a really good beating to teach him a lesson."

Matthew remained in the medium secure unit for a year.
The memories of frustration and powerlessness are still vivid in his mind.

"People always have to wait, especially in medium secure places.

You wait for psychiatrists and psychologists. I know there are only so many of them but there are not a lot compared to the numbers of patients.

As psychology is part of treatment and without this you can't get out, it's annoying to wait.

This made me frustrated.

Why should we be detained longer than we need to be?

Why don't they hire more staff?

I felt powerless in this situation."



Matthew remembers a regime of negative reinforcement and punishment.

“‘If you don’t do the treatment, you will stay in until you do, and you won’t be able to have your Section 117 leave.’ This is what staff used to say to me. If you hit someone, the staff came into the room with their pink gloves on and they would ping those gloves, and then put all of your things in a black bag. They would say, ‘you can have your things back when you behave’. They gave your things back to you one thing per week when you were good. They also used Section 117 leave as a punishment.

This was wrong. Hospital is not a punishment.

It should be about treatment and support.

If staff punish you for doing something wrong, it shows you two wrongs make a right. It tells you if you do something wrong, people do awful things back to you. So patients learn this is a way to behave.

People say its like prison but its not. You are there for treatment. It should not be punishment; its treatment.”

Low secure hospital

After his time in the medium secure setting, Matthew was moved to a low secure hospital in London. This hospital was the last hospital Matthew ever lived in. Although Matthew didn't want to be in hospital at the time and remembers he did not want the support of the psychology service, he now reflects that it's the best place he ever went to. Whilst in this hospital a professor in psychiatry worked with him and Matthew remembers thinking:

"When I knew I had a professor and not a consultant I thought I'm never getting out of here but I was really wrong. This professor sorted out my meds and before I knew it I had unescorted leave. I was able to get the bus into town. I just couldn't believe it. I was only allowed to go to a certain place but it was really great. The first time I went out I thought there might be an incident where I get myself into trouble, but there wasn't. I made such great progress and I was really grateful to the professor. I was in a terrible state years ago, assaulting people, but the hospital made me a new person."

Moving into his own place

As Matthew was gradually getting better, plans were made for him to move out. Matthew's social worker and community learning disability nurse worked with the hospital staff to ensure a smooth and supported transition. Mem, the community learning disability nurse reflects on how Matthew was supported doing this period:

*"We looked at the Matthew situation in a different way to try and fit a community service around him in a bespoke way, rather than him having to fit into a rigid community service."*¹

Matthew was supported to view a range of properties and Mem says he was clear about how he wanted the support to look:

*"Matthew was consistently saying he wanted to maintain as much of his independence as possible but have the support 24 hours a day if needed for emotional and practical support."*²

1 Changing Our Lives (2020), *Resetting the Narrative: What Learning Disability Nursing Means to Me*, p. 19.

2 Ibid.

Staff within the hospital were also supportive of Matthew moving into his own place.

"The hospital was helpful to me when I was moving out. They said I didn't need a community treatment order as they trusted me to stick to my meds voluntarily. They helped me move out and I did this gradually over several weekends - I stayed at nan's every month, and also at mom and dad's, and gradually I became more confident and so did the doctors. They even had a leaving party for me. A couple of the staff also kept in touch with me for the short term to make sure I was ok."



Although a placement was found in the area where Matthew wanted to live, 4 days before he was due to move the placement fell through. However, as Matthew had made such progress by this stage and as he had support from hospital staff, his community learning disability nurse and others around him, he managed his emotional reaction to this set back well and his mental health did not decline.

As this placement had fallen through Matthew asked to stay with his parents until he could find a home of his own. The community and in-patient team worked together to support him to do this, and although he lived with his parents during this time he was still a patient at the specialist hospital, which acted as a safety net in case it was necessary.

After a while living with his parents, a supported living property in the Isle of Wight was found opposite a residential care home. This was felt to be ideal for Matthew as it enabled him to be independent, while at the same time there was 24/7 backup. Professional support was put in place via Section 117 of the Mental Health Act, which provided aftercare and support in case Matthew needed it.

However, no sooner had Matthew moved in than the Covid-19 pandemic occurred and lockdown caused Matthew, like many in the wider community, to feel anxious. As a result during some of the lockdown he chose to live with his parents on the mainland, rather than remain on the Isle of Wight. During this time he continued to access the support of professional teams via Zoom and telephone calls.

"I didn't like the lockdown. Nothing was open and I felt cut off on the Isle of Wight. I like to go out and so to begin with I ignored some of the rules and I went out. I would have struggled otherwise. I just couldn't cope with it. Good thing was I didn't react like I would have done years ago. I didn't do anything illegal. My learning disability nurse helped me as she said, because I have Asperger's, I could go out."



My life now



Moving to a new home

Although Matthew liked his first flat, he decided to move in early 2022, because he felt isolated on the island and felt he lived too far away from his parents; he wanted to be able to hop on a bus and pop around to see them.

Matthew now lives in a supported living flat nearby. He is enjoying the responsibility of living on his own, with his budgie called Bobby. Matthew has a team of around 8 staff who support him to navigate situations he may find difficult and assist him where he needs it with everyday tasks.

Matthew is taking control of his own life as he has casual work as an Uber Eats courier, delivering food on his pedal bike. He also has a provisional driving licence and is saving up for driving lessons.

"I love my bike. I like the sensation of a push bike. I also like picking food up and dropping it off."



Earning money enables Matthew to buy gadgets; these play a big part in his life. He has a scanner which enables him to listen on marine, aircraft and civil bands.

"I like listening to what's going on. It's exciting to hear what's happening."

Matthew also has a drone which he enjoys flying - even if it crashes a lot! He carries his scanner, drone, battery charger, power bank, tablet and other bits and pieces with him when he goes out.

"I like to carry them around with me because they bring me comfort."

One of the most important aspects of Matthew's life now is his ability to navigate situations and emotions he would have previously struggled with. Matthew now reacts calmly to situations and benefits greatly from self-determination.



"I make my own decisions because I like to make my own choices because I know what I like. If someone tells me what to do, I might not like what they choose.

I think people should have a say.

It's my life, not theirs.

My life is much better now than in hospital. My life is totally good. I don't get into trouble with people anymore.

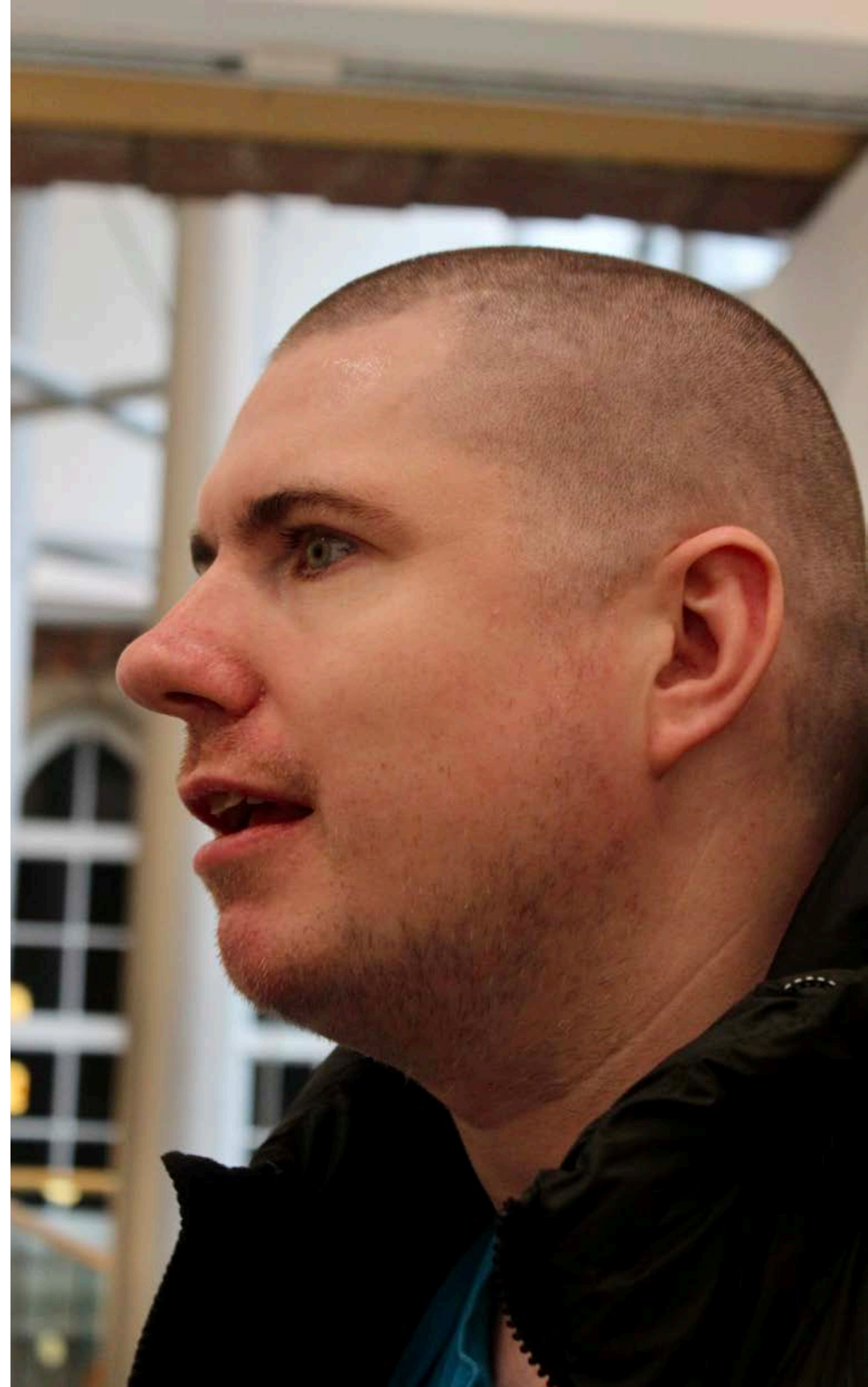
The most trouble I get in these days is setting the fire alarm off accidentally by cooking sausages at 2am. I was really hungry and fancied some sausages but I never thought to put the extractor fan on. I wasn't the most popular bunny! I didn't know whether to laugh or be embarrassed."

Having Asperger's

Matthew was diagnosed with Asperger's when he was 17 after he got into trouble with the police when his remote control hovercraft broke. Over the last few years Matthew has reflected a lot about having the diagnosis of Asperger's, and has been supported with ways to manage his anxiety, thought processes and communication style.

He looks back on his younger self now and realises that although the solutions he was putting in place were logical in his mind then, they were decisions that resulted in him getting into trouble, which is something he never wanted nor intended.

"When I have a problem now I talk to staff and to family. I've learnt that I need to talk to people before I do things. I'm also older now and this probably makes a big difference."



Matthew has a good understanding of how Asperger's affects his life and he manages this with support from staff.

"It means my mind works differently to other people's. I get jokes sometimes but sometimes I don't. I am learning gradually to understand some jokes. I have to do things in a certain way and I like certain routines.

There are some things I don't like the feel of. For example, when I smoke my vape, I bought one with a metal mouth piece on but I had it changed to plastic because I didn't like the feel of the metal.

I like the last word, the last say. I like things to come to a definite conclusion. I don't like things to be unresolved."

Talking to Matthew during the writing this book and discussing that Asperger's is a term not used much any more, Matthew reflects that he still likes to use this term.

"Why do the doctors keep changing it? It's confusing to people? Do the doctors do it to be confusing?"

The importance of skilled support

Over the early years, not having good support around Matthew left him incredibly vulnerable. Arguably, if Matthew had a diagnosis earlier and there had been more support in the community, some of the circumstances Matthew found himself in - particularly those which led to him being in prison and then in hospital - could well have been avoided. Working with his current key worker, Asa, while writing this book, the benefits of skilled support were apparent, as Matthew is now understood and supported through clear boundaries and appropriate challenge. An example of this is that Matthew can get anxious at times, speaks loudly and finds it difficult to bring his conversation to an end. Liking to have the last word, he is well aware that this can annoy people and may get him into trouble with others, but supported by Asa he is managing this:

"I am very friendly but I can talk too much. I don't mean to get on people's nerves and I know I can speak loud and I find it difficult to know when to stop talking. Asa, my key worker, reminds me to speak quietly. This helps me as I do speak loud but don't really know I'm doing it. My voice gets louder and I need someone to remind me to be quiet.

I'm also learning to understand sarcasm and Asa is working with me on this."

Asa takes a positive approach to supporting Matthew with his communication style:

“Matthew’s communication is part of him. It’s part of his Asperger’s. We are all human and we can all annoy people.”

Watching Matthew and Asa’s interactions it’s clear that Asa acts as a navigator, informing Matthew about aspects of social and emotional situations he may find hard to comprehend. This has the effect on Matthew of making him feel safe:

“Asa makes me feel safe. When I am out with him, he supports me to keep safe and not get into any trouble. He tells me the truth. He gets my jokes but tells me if I am not funny. This is good.”



Asa is also encouraging Matthew to achieve all he can:

"When I think I need help with something, Asa pushes me to my full capabilities and this calms me down. I know I can do things."



**No one is too disabled,
or too affected by
mental health difficulties,
to lead an ordinary life**

Changing Our Lives

Tel: 0300 302 0770

Email: ask@changingourlives.org

Web: www.changingourlives.org

Twitter: [@positive_lives](https://twitter.com/positive_lives)

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