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A's Story

"You know, I love living here, I feel happier, I can relax. I can get back into living life again, and make my own choices with my team."

A's is a story of perseverance and the power of support in the home which has as its core the person, their specific needs and their aspirations for the future.

Prepared by: A, A's Mum and A's My Life Team Manager

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BACKGROUND

A is a person with autism who has spent a significant part of his teenage years and young adult life in hospital under a section of the Mental Health Act 1983.

While his family - and A himself - understood that he needed help with his mental health, there has always been a desire to achieve a stable and safe living environment outside institutionalised care where he could begin to build a life for himself, with support.

As A says himself, “being able to feel safe and calm and happy in the place you live is really important.”

Over three years ago, A’s mum began to work with local and regional healthcare professionals and institutions to plot a course for A to achieve his goal of living independently in his own home with support. It has been, as she puts it, an incredibly bumpy road, with plenty of challenges, disappointments and setbacks.

“Sometimes, all I’ve wanted was for A to have a Christmas in his own home’.

A’s mum got in touch with My Life Support after hearing about our success in helping other people transition from institutionalised care into community living with support.

Using partnership working, we all identified that finding the right accommodation and location for A would be crucial to the success of long-term, consistent care - and give him the best possible chance of staying out of costly institutionalised establishments in the future.

Everybody has preferences about where they want to live, but in A’s case they were particularly critical.

He needed to be far enough away from the places and triggers that had caused him problems in the past, but close enough to be able to feel supported by his family. He needed to be able to access and feel part of a local community - but in a specific way which would keep him safe and away from potential issues.

He would also need a home where he could have support from a local team who implicitly understood the challenges and potential benefits of that place.

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A’s mum and My Life then spent a number of months sourcing a quiet, semi-detached house in a semi-rural part of the North-West which met most of these criteria.

“It was the perfect house for A,” says his A’s Team Manager from My Life. “It was just the right size, we could create a caring, family atmosphere with our team while giving A the privacy and freedom he craved.

“The area felt secure, non-threatening and safe - and there was enough in the community nearby for A to take advantage of once he felt ready and confident.”

Finally, in March 2023, A moved in with a package from My Life Support which includes 2:1 support during the day and a waking night. He is shopping and cooking for himself, going on walks and expanding his horizons to match his interests in animals and gardening.

This is a story of someone for whom personalised care and support has been life-changing. It is the specific combination of house and the care package which has been fundamental to A’s wellbeing. It’s not a home that had to be adapted for his needs, but it’s a home that absolutely meets his needs.

As A’s mum says, eighteen months on:

“The difference you notice now is that he’s smiling. Honestly, if you look at him now, I can barely put into words how much he has changed for the better. I now have hope for his future. I can breathe.”



HOW MY LIFE HAS HELPED A

A had a late diagnosis of autism; while A's mum says that diagnosis would really have helped earlier in his life, at least now it allows people surrounding him to understand that he wasn't neurotypical - and gradually will enable A to understand himself, too.

A's mum had joined a peer support group (now closed) called FOMIS (Family of Mental Illness Support) where she first heard about My Life. When she was looking to build a package of support around A she got in touch with My Life's CEO Caroline Tomlinson.

"After that one phone call. I knew that My Life would be the right package," says A's mum. "I knew they would be consistent with their care and could adapt. I just felt everything Caroline said matched with my values, principles and understanding of personalised care."

“A was heavily involved in setting up that house and I think that's also made him proud of it - and himself.”

That first phone call, however, was in 2020. As a healthcare professional herself, A's mum had some understanding of the process necessary to discharge people into the community. Everyone involved with A knew that this next discharge needed to be right given he had been - as she puts it - "in a bit of a revolving door, constantly in and out of hospital."

The process of finding a house for A took a long time given his set of circumstances and needs. There were (and remain) a lot of risk factors which have to be taken into account when building A's package of support; understanding his needs was key to the whole idea and success of personalised care.

This was why it became a huge moment when a house was finally found for A that met the vast majority of his needs; away from a town centre but near enough to a local shop, a quiet area where he could feel safe and able to socialise if he wanted to, but also have his own privacy in and out of the home.

"He has his own bathroom, a personal area with his own privacy, and for this to work, it needed to feel like his home," says A's My Life Team Manager.

"A chose the colour scheme and the carpets," adds A's mum. "He was heavily involved in setting up that house and I think that's also made him proud of it - and himself."

A'S TEAM

Another reason this specific house works for A is that his team were specifically recruited for that place. Most live within five minutes - a deliberate decision so that they had an understanding of the local community. They knew the problem areas, the places to avoid, and the places that A would benefit from.

"You wouldn't get the specific, personalised support like that if you moved somewhere else," says A's My Life Team Manager.

"I remember when we sat down at the table to work his team out. I said it was very important that there was a strong female figure that worked on the team as well as someone who could be professional but act more like a peer or have similar interests. It was about emulating a normal family environment - because he'd not had that in hospital and he'd not made any valuable connections like that for years."

A's mum has noticed how beneficial this approach has been for A - in terms of his house being both a safe haven and a place that can act as a base for a greater depth of experience.

"The team have encouraged A to get out of the house," she says. "He's been institutionalised for seven or eight years - the last admission was three and a half years solid. But the team have drawn him out, taken him walking and to animal parks or sanctuaries; they've taken on board what A needs and they've got a massive understanding of him now which will only grow and develop. That local knowledge is just invaluable."

"He's got such a good relationship with the team in his house; he's had enough experience of care in the past to know that it can be a box ticking exercise, but with My Life staff he's formed real connections."

That extends to A having greater choice and control of what happens in his own home. At first he had to have a meal put in front of him - because that's what he was used to at hospital. But bit by bit, staff have engaged him to think about what he'd like; choosing ingredients, preparing meals himself and even growing it himself in the case of some of the vegetables.

"I've really enjoyed doing that, and the team are really welcoming, it's a nice, calm, happy house already," says A.

For a young man who had lost so much control in his own life, these are incredible developments.

CONSISTENT CARE DELIVERING LONG TERM OUTCOMES

A's My Life Team Manager says that one of the greatest achievements of A's first six months is that he feels secure. "Any change to that now would set him back massively," he says. "It would be like a further trauma."

"I once asked A what he would do in hospital. His answer was 'stare at the ceiling'. That's no way to live - and we've got him out of that state of mind."

Best of all, because of the security of the specific house he is in, A is naturally coming across potential opportunities to explore in the future. In the past, he wouldn't have been able to consider going to an animal sanctuary for example, let alone potentially volunteering at one. Yet those conversations are now being had.

He's talked, too, about having a dog of his own; this specific house allows pets. This process of slowly building confidence in himself means he knows he's getting well enough to think about caring for something or someone else.

I've seen such a change in A," says one of his personal assistants, Kelly. "We're not stopping in all day; we've encouraged him to go out more given he loves animals and is great with them too. We'll be pushing that with him a bit more because you can see how happy he is in that environment."

"I think his confidence is the thing I've seen grow a lot," adds another team member, Syed. "So where before going into a supermarket might have been really an anxious thing for him, we've made a lot of progress in that regard."

"He's really pushed himself, walking more, exercising more. It's amazing to see how much he's come on."

And while his CTO (Community Treatment Order) is currently quite restrictive, A is aware enough now not to break it; the relationships and trust he's built with his team over time in this specific house means he speaks honestly to his team about his actions and feelings and how we can help with coping strategies which he will try and implement.

That is clearly because he wants to stay where he is now mentally, physically and geographically.

WHAT A SAYS NOW

To start with, the best thing was my own bed! It was great to have my own place, have some freedom to do what I wanted and like to do - go out to some local shops, animal places, bird places. Then when I get back home I can chill out, listen to music. I feel happier and a lot better.

I feel like I'm getting my brain back to normal. I'm more aware of myself and my surroundings - and I feel healthier too. I'm eating a lot more vegetables, checking menus on the internet and then cooking them.

I feel supported, like I'm on the right path with my health, and I love living here because I can relax. There's not the stress of too many people around. I can get back into living life again, making my own choices. I am really proud of myself and how the last six months have gone. I am doing things now I wouldn't have been able to do six months ago - and that's because of the house I'm living in and the team around me.

WHAT A'S MUM SAYS NOW

There have been times where A has nearly given up on life. And that has been really difficult to watch. He didn't see a future; everything around him was negative. And while that's been happening, there have been jobs I've lost or not been able to do because my own life situation wasn't reliable; I was constantly having to deal with A's support failing. To be able to plan my own life with more assurance and stability now - to be a Mum again - is great.

He doesn't need me so much any more, but I know that's really good in the long run. I've been able to breathe. Let go of the reins. I'm not on my own, I'm not battling. I've never had that before - and if I have a problem I can work through it with My Life. I knew progress would be very slow. But I have hope for him again - obviously we've had a few blips, a couple of setbacks. But again, the team have worked through that and moved on; they're treating him as a human being rather than a patient and A's really responding to that.

Throughout this whole process, I've learned to manage my expectations. My only wish for A is that he's well and happy. In that house, he is. And that stability is a real victory as far as I'm concerned. He's got his life back.