



 Changing  
Our Lives

# Jenny Bennett



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# Foreword

Jenny's story shows us that with great support and good housing, people with learning disabilities are leading independent and valued lives in their local community.

Looking back over Jenny's life it's impossible to imagine what it must have been like to live for 19 years in a series of locked hospitals, not because she was ill but because she was born with a learning disability.

This was Jenny's story.

This was a reality for many people.

Fast forward to the present, Jenny's drive for independence and love of life has proved everyone wrong! There is no question about whether she can cope in her own home; she is in charge of her own life and loving every minute of it.

At the time of writing in 2020, there are approximately 2,200 autistic people and people with learning disabilities still in hospital. They are detained because they are seen as problematic, as diagnoses to be treated rather than human beings with human rights. Jenny's story shines a light on these injustices. Locking people up because they are different reinforces prejudices and false narratives about people not being able to be part of the community. These false narratives take hold and people begin to think it's normal that people with learning disabilities are excluded from society. This is one reason we tell stories such as Jenny's to show that we are all human and, all of us, with no exceptions, deserve a home, and an opportunity to create a life of our own choosing.

**Jayne Leeson MBE**  
**CEO**  
**Changing Our Lives**

# Chapter 1

## 19 years in an institution

When I was 17, I went to live in St Margaret's long stay hospital. This was a place where people with learning disabilities were sent to live; it was a hospital not a home. Before this, I lived in a children's home for 7 years.

St Margaret's was not a nice place, looking back to how I lived then is upsetting. No one there seemed to be happy; everyone used to moan or cry about the place. There were so many people there, you just couldn't have any personal space.

I remember everywhere being locked so you could not get out. I knew a few people who tried to escape but they were never successful. I will always remember the beautiful lake at the bottom of St Margaret's. We were never allowed to walk around the lake because we were told it was too dangerous.

St Margaret's was a place where no one had choices. I had to stick to a strict time schedule from the moment I woke up to the moment I went to bed. I remember the big clock in the main room that told the time of my daily routine. It was a boring place, every day was the same and there was no excitement. I had to eat at the same set meal times even if I was not hungry. The food was awful! I never had a choice of what food I had, I just got given it.

I used to stay in a shared dormitory with other women. I remember the dormitory always being cold, with lines of single beds and curtains on the windows. I never had a warm duvet like I have now, we used to have blankets and that was it. You could not choose who you lived with at that time so I was stuck with people I didn't like and they used to get on my nerves.

In the day I used to go to an activity room in St Margaret's where I did art and music. It was something to look forward to at the time, because when I was not doing music there was nothing to do, or you were just told to watch TV and that was boring. Everyone watched the same TV so I could not watch what I wanted.

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*Jenny is a very inspirational lady who has been on a remarkable journey. I've supported Jenny for about a year now and she welcomed me with open arms from the beginning. Jenny shared her experiences of being in St Margaret's and it was very emotional but now she is very independent and forever smiling. She is very happy to have her own home. She loves to go shopping and she loves her clothes. She has a loving family and always has a kind heart. I believe there are some people we are destined to meet and Jenny is one of those people!*

”

**Katie Reid, one of Jenny's staff members**

We were never allowed to go out to the shops when we wanted. We were always told what we were going to do. I used to get so angry because I couldn't do what I wanted to do! I used to play up because I thought it would help me to get out of there, but that never worked.

Sometimes I was put into the seclusion room. This was a bare room I was put into on my own, if I played up. I used to bang the door for them to let me out but they didn't! If I played up they would restrain me by holding me down and giving me an injection. This happened a lot in those days.

I remember on my 18th birthday I just stayed in my room. I can't remember now if I got birthday cards or a present. I can remember making myself a wooden key as a birthday present. Staff had the keys in the hospital. I never had my own key and I wanted one. I didn't celebrate my 18th birthday with friends because I didn't have friends there. I just made sure I kept myself to myself. Some people were not nice to me. I got a black eye from someone who lived there. The staff were nasty too.



The main thing I looked forward to was seeing my family. Sometimes they would come and pick me up and we would go out together which I really liked. They could not pop in to see me when they wanted to because they could only visit at certain times.

My family wasn't happy with me being at St Margaret's so my mom and my sister had a meeting with the staff and I got moved to a little cottage on the St Margaret's site where I lived with one other person when I was 21. I still didn't like it.

I didn't leave the hospital until I was 23. Then I was moved to another hospital, called an assessment and treatment centre, for a couple of years as I was told there was nowhere else for me to go. I also lived in a locked ward, where no one could get out.

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*I have known Jenny for over 5 years. She is a lovely person to be around. No matter what kind of day it is, she brings a smile to the place. It's all positive with Jenny!*

”

**Andrew Johnson, a volunteer from the  
Dorothy Parkes Centre in Smethwick**

I had my own room on the ward, but it didn't make a difference to living in the dormitory at St Margaret's, as people used to come and steal from me and mess up my room. Living with people I did not want to live with was the worst thing of all.

I used to be physically assaulted and have my personal objects stolen from my room. I hated it there and the food was disgusting.

After that I moved to a building in the community that was run by the hospital. This was called an NHS Campus.

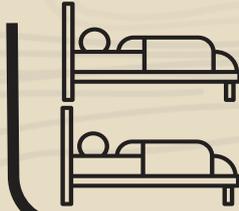
It looked like any other house in the street but I had hospital staff support me and they ran the home like a hospital. I lived there until I was 29!

So 19 years of my life was spent living in institutions! My life back then was not a happy time and it all seems to be a bit of a blur now.



# 19 years in an institution

When I was 10 years old I lived in a children's home.



I shared a bedroom and a bathroom with lots of other people. It didn't feel like mine.



I wasn't allowed pets.



When I was 17, I was moved to a locked ward in St Margaret's Hospital.



I couldn't go outside when I wanted.

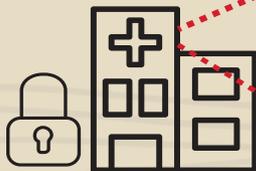
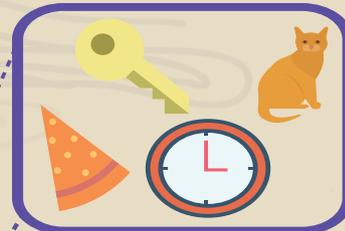


When I was 21, I was moved to a bungalow on the St Margaret's site.



I didn't choose what I ate at mealtimes, or when I ate.

When I was 22, I was moved back to St Margaret's and lived on a locked ward.



When I was 23, I was moved to a different locked ward.



I couldn't go to bed when I wanted.



Now I live in my own home. I have a key. I go outside when I want. I have a cat. I choose when to eat and when to sleep.

# Chapter 2

## A fresh start

When I moved out, my life completely turned around.

I still remember how I felt moving into my own home, a ground floor flat – I felt chuffed with myself.

I was a bit scared as it was a big step. I didn't know any of the bus routes but I worked it out and gradually every day became a bit more confident.

I was also really excited because now I got to spend my own money.





I really wanted to live on my own, but my mum wasn't too pleased with where I moved to. In the end she understood that this was the best thing for me. My mum can be very protective of me and does not realise how independent I can be.

She's only protective because she loves me so much, but this is my life now and I want to live it the way I want to. I see my mum and sister and we have a close relationship.

When I moved in I chose the decorations for my new flat and was over the moon that everything in it was mine. Living in my own home with a council tenancy meant I had freedom to do what I wanted to do when I wanted to do it. This was completely different for me as I was used to being told what to do, having certain times to do things and more than anything I hated not being in control of my own life.

Gradually over the first few months and years, I became more chilled and relaxed and I live my life to the full. I have lived in my home 18 years now and it is great.

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*I really enjoyed working with Jenny. I didn't see a lady with a disability. I saw a lady with the potential to be in control of her life but had never had the chance to do so. It was a highlight of my career to see how she took control and turned into the lady that no-one thought she could be.*

**Michelle Smith, who worked with Jenny when she moved into her own home and enabled her to recruit her own staff**

”

# Chapter 3

## What an ordinary life means to me

I think an ordinary life is having the chance to do all of the things most people take for granted.

Moving from the hospital, I don't take those things for granted.

In my own home I make my own choices, I eat what I want and go where I want. I see my family when I want.

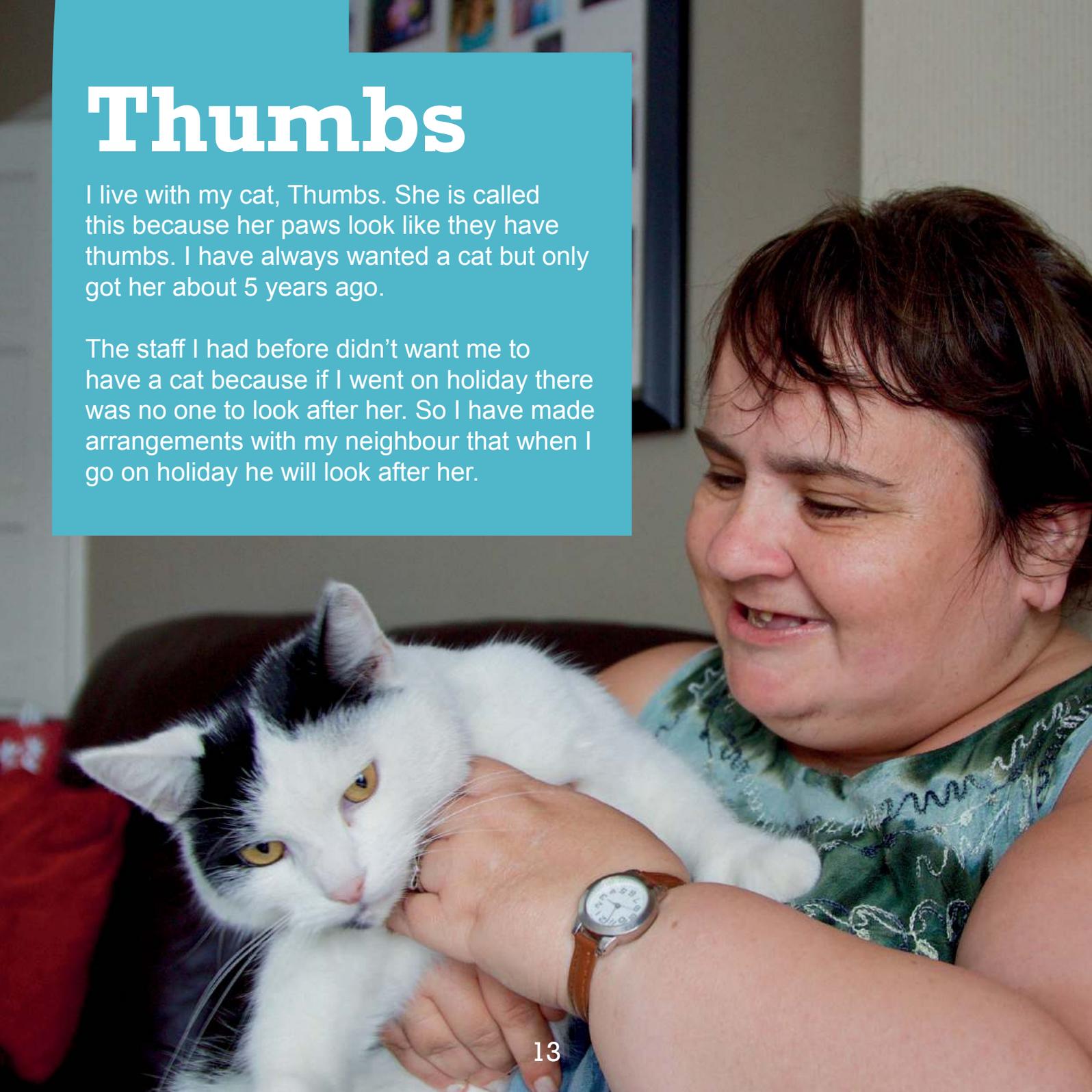
Now I am completely in control of my own life.



# Thumbs

I live with my cat, Thumbs. She is called this because her paws look like they have thumbs. I have always wanted a cat but only got her about 5 years ago.

The staff I had before didn't want me to have a cat because if I went on holiday there was no one to look after her. So I have made arrangements with my neighbour that when I go on holiday he will look after her.



# My own money

I look after my own money with support. This is something else that has changed in my life. It used to be difficult to get hold of my own money.

I used to have to bring receipts back for everything that I bought, even if it was a loaf of bread. I did not like this and I thought it was silly.

If I couldn't find my receipts then it would make me feel anxious and I thought I would get into trouble. This made me feel angry.

Now I now have money for each day and this works for me.





# Living vibrantly

I'm naturally creative. I love fashion and I have an eye for coordinating colours. I love shopping for new clothes and accessories to match, especially in Primark!

At home, I listen to music all the while. My favourite genres are pop music and 80s, and I particularly like Little Mix and Queen.

Recently, I went to see Strictly Come Dancing Live in Birmingham. I thought seeing Craig Revel Horwood in real life was *fab-u-lous!* He got the audience up and dancing; it was lots of fun. In 2020, I'm going to see it again - how exciting!

# Being part of the community

I live a full life and make sure that I am part of my community. This is really important to me, as I like to have friends and be out socialising, meeting different people.

I have a real interest in jewellery making and go once a week to a local community centre to a class. I love jewellery and you can often find me in the market buying new necklaces and rings but I also love to buy presents for people and often make jewellery to give as a present.

I love to go out as staying in can be really depressing. I like to see what's going on in the local area.

I also know lots of women in the community centre and also on the local markets stalls where I have shopped for years.





# Being independent

I've become much more independent in recent years. I'm much more confident when things in the house break. For instance, my outside light by my front door broke. This made it dangerous at night because I have steps into my home. I phoned the council and got them to come and fix it. I did this with no support from my staff, which I felt really good about.

I also organise all of my own health appointments. This is something people thought that I would never have done and I would have just asked the staff to do it for me. But I keep proving people wrong, which makes me smile!

I have my own front door key, I answer my own front door, I cook my own food, clean my own home and I am very independent now. Every decision about my home is my choice. I now have control of my own life and I love it!

I have come to learn that things go wrong in life - like being late or burning the dinner. I never had to deal with these small challenges as everything was done for me. If things like this happened to me before I would get upset and angry. I now know it's part of life and it happens to everyone.

I am confident in making complaints in all areas of my life. A while ago my neighbours were being really noisy and it used to make me annoyed, but with support from my staff I complained to the council and it got sorted out.

I travel independently to most places. Recently I started Slimming World and I have got to know lots of the people who go. I go to different supermarkets and meet my staff there instead of meeting them at home. I phone my staff and tell them to meet me at a shopping centre. This means that if I am out and about I don't have to come back home to go back out with my staff.

As I go out and about on my own, I have come across some challenges that I now deal with on my own.

I have been approached by a member of the public who asked me if I needed help carrying my shopping bags. I felt nervous and anxious about a man I did not know approaching me. I just carried on walking but I felt scared. So I decided to go to the police station to explain what had happened.

My staff have now given me a personal alarm and I have bells on my bag. I feel really proud that I was able to go and do this without support. I feel a lot more comfortable with my alarm now. Plus I even got a cheeky ride in the police car!



“ It’s lovely having Jenny in the group as she’s always so positive. She always really happy to see people and they are always happy to see her. She’s just one of the group like everyone else. She has come great conversations with the other ladies and always has great plans for being healthy. ”

**Mel, Slimming World Consultant**



# My own staff



I have a staff team that works around what I want, not what the company wants. I have staff work with me when I want them to. They work hours that suit my lifestyle best. I am glad that I can have flexible hours so I can do what I want to do.

I feel happier with my life now I am independent. I feel like I have more control over what happens in my life. I think I have changed now because I have had to. Before my staff just used to do it for me, I never had the chance to prove myself. They now realise that I can do things for myself and they push me more to become even more independent.

To make sure I have a staff team that I am happy with, I work closely with the company that supports me to recruit new staff. When I have new staff, they send out an advert and when the people come for interview they are matched to the people who use the service.

I have told them the type of person I want to support me. They have to be funny, bubbly and girly. They have to be happy to work with me and of course make a nice cup of coffee! I like my staff to have the same interests as me like going to the pub and shopping for girly things. I just love girly things!

Once a new staff member has been matched to me I will go and meet them and have the final say about whether they will work with me or not.

I used to have 105 support hours a week and I would have staff with me most of the time. I would still go out on my own and the staff would stay in my home. So an independent social worker came and did a review. She assessed me and she said I only needed 35 support hours. When I had a meeting about my hours getting changed I got very upset and angry and it took me a long time to get used to this change.

At the time I didn't understand that reducing my hours was for the best, it seemed like I could not live without the extra support. Looking back now, oh how I was wrong! From the reduction of my hours I have realised and proved to myself the strong independent woman I am. Not only did I prove this to myself but other people too.

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*Having staff with Jenny all of the time limited her. She got on well with her staff and they supported her to do things, but she didn't need all of that support. In a way it was stopping her finding out what she could do herself.*

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Diane, a member of staff who worked with Jenny for about 20 years







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

Changing Our Lives

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