

Coping with change: an interview with Paula Johnston, an adult with autism

Paula Johnston and Sue Hatton

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Editorial comment

This article is a transcript of an interview between Paula Johnston, an adult with autism, and Sue Hatton, training officer for autism west midlands, on the topic of change. It starts with general comments from Paula about change and then Sue poses questions to Paula on different aspects of change. The interview illustrates that Paula often has a similar emotional reaction to us when a plan is changed (eg disappointment; anger; uncertainty; fear), but whereas most of us would have a range of options and strategies to manage and cope with change that we could call into play, Paula sometimes has no alternative but to act out her emotions and often becomes very distressed. However, over time she has worked out a way of managing some of the changes that occur – often by doing something very similar to that which was planned. The message for practitioners and parents is to enable and facilitate individuals with autism to devise coping strategies that will work for them when the unexpected happens.

Those who want to read more about Paula's life can read a book Sue and Paula wrote together, published by BILD in 2003, and entitled, *Conversations in autism*.

Introduction

I find comfort in eating the same food every day, or the same food I ate last time I was in a similar situation, or wearing the same clothes I wore somewhere where I had felt relaxed. I find it comforting wearing them again without washing them in the interval.

My husband and I have started to go to a pub in King's Heath, to celebrate anniversaries. When I go out for a meal, to feel comfortable and reasonably sure of not panicking or having a tantrum, I like to go to the same place, sit at the same table and have the same meal. But this pub in King's Heath was a new place. The first time I went to that pub, I saw something on the menu I thought I would like, but because it was a new place, instead I had the same meal I usually have in the places I am used to: baked potato and cheese. The second time we went there, I sat at the same table, and had the same meal again. I still thought about the new meal I would like to try, but was not ready to change yet. Next time we go there, if I can get the same table, I think I could try the new meal, but if someone else is sitting at that table and I have to sit somewhere else, I will have to have the old familiar meal, baked potato and cheese.

For some time I have been taking drinks based on milk, for example; instant chocolate, cappuccino etc. My husband was drinking lemon and ginger tea. He said it was very nice, and invited me to taste it. But I couldn't face it. I had been having instant hot chocolate drink with ginger, and muffins with lemon curd for supper recently, so the lemon and ginger tea shouldn't have been too much of a change taste wise. But there seemed to be an insurmountable barrier. I just couldn't bring myself to taste it. I hate water anyway. I never drink it straight from the tap. And I hate getting wet in the rain or washing my hair or my body.

When sitting in a bath or standing in the rain at a bus stop, the thought comes to me that if there were too many experiences like this, life wouldn't be worth living!

I remember being terrified when my mother had her hair permed about twice a year. She would go from someone with collar length straight; brown dyed hair to someone with short curly grey hair. Her facial features would seem so much bigger. Her teeth seemed to stick out like a horse's. When she came near me I would scream and scream; 'You're not my mother.'

Interview

Sue: *When a plan changes can you tell us what that makes you feel like inside?*

Paula: I feel afraid. Like, 'What will happen now? What will I do now? What will other people do now? Will I understand what is going to happen instead of what was supposed to happen? Will I be able to do what I need to do now, as I would have been able to if things hadn't changed?'

Here is an example of a change of plan, which caused me to become very upset and violent. Before that I had been quite peaceful, and had been having very few real tantrums. One of the reasons for my relative calmness was that I had been studying Buddhism by distance learning. I was just about keeping up with the course and was reasonably on course for my second essay deadline. Life seemed to be quite sorted out. It's something like this; first I do this and then I do that, afterwards I do that, like everything seems to be under control. Then my husband said we had to go to London. So all this dread started to play on my mind, as I realised that my studies, so carefully planned, would be disrupted.

Whereas before I could see this well ordered plan, now I could see only darkness, nothingness. Everything was out of my control now, and had become very threatening. I had about three weeks to wait for this trip, and my tension grew and grew, until it reached unbearable proportions. On the day before we travelled, as my husband went on and on about the people we would be meeting and so on, I punched him on the head, shoulders and chest, and kicked him in the legs. He was sitting down at the time. I continued until I finally lay sobbing on the floor. Next day I was off to London. My mood did not improve, until I got some time to myself in a big branch of Waterstones, where I bought some books, including an enormous anthology on my all-time favourite subject, consciousness. When we returned home I was still tensed up, and had some more tantrums, but these did not end in violence.

Sue: *Are there any small transitions that bother you, like when you move from one room to another, or moving from inside your house to the outside.*

Paula: Yes, I feel disorientated. The house next door, which was on my left, when I was in one room, may now be on my right when I go into the other room, which I find bewildering. If I sat and thought it out, it would probably make sense to me, but when it's actually happening, it's surprising, not what I would expect. It's like stepping through the looking glass.

Sue: *If you are affected by these smaller transitions and changes in what way are you affected?*

Paula: Well, I can easily get lost. At the time of writing this, my husband Fred is in hospital. He's in a men's room with four beds. This is the confusing layout. On the left of the corridor, (or on the right, depending on whether you are leaving or arriving), there is the men's room, and ahead of it, (or behind it), there is a unisex toilet.

On the opposite side of the corridor is a women's room, and an identical unisex toilet. Quite often, after using one of these toilets, I find myself in the women's room. It's not that I am thinking about something else. It just feels right to take that direction. Or when I've been sitting in the ward sitting room with Fred, and we go to his room to pick something up and bring it back to the sitting room, when he leaves the bed room to return to the sitting room, if he goes first, I will think he is going the wrong way. If I go first, I will just continue in the same direction that I had been going in to get to the bedroom, and go even further away from the sitting room. Fred has to turn me round. It seems like my mind doesn't change very easily.

It can get so fixed in the pattern of repeating a negative phrase over and over for hours. Fortunately nowadays, using this knowledge, I can replace the negative phrase with a positive one associated with my special interest, and my mind will soon start to rehearse this instead, and I will be calmer. Similarly, when there is a change of plan, part of my mind seems to want to continue as if there had been no change. But a change of plan involves so much, just about every aspect of life for the immediate future, that it can be just too much for me to cope with. That's why I try to do something similar to the plan that has been cancelled, so I can avoid getting upset. I give an example of this later.

Sue: *Can you share with us some examples of plans that have had to change and what your response was? One example might be the time you were not able to go to your Thai Cookery class.*

Paula: Buddhism had become my special interest. I went to a Buddhist temple, where all the monks and most of the people who attended were from Thailand. All the ladies brought food for the monks, and I wanted to do the same. So, to learn to cook Thai food was just about the most important thing in the world for me then. I enrolled for a Thai cookery class at my local college of further education, but when the course started, my husband was too ill to be left. I was unable to attend the class. Therefore during the time when I knew the first cookery session was going on, I began to tantrum. I banged my head against the wall. I sobbed for about three-quarters of an hour until I could hardly breathe. My head was throbbing and I lay exhausted on the floor.

Sue: *For many people changing their clothes is not an issue, but I know that you much prefer to wear the same clothes. Can you tell us why you prefer this, and how it makes you feel when you have to change your clothes?*

Paula: I find having to change my clothes quite threatening, and, when I do have to change them, I then calculate how many days I can wear them for, 3, 4 maybe 5 before I have to do this again, and that prospect relaxes me a bit. It takes me so long to get comfortable. However, in the pursuit of a special interest, like attending a class or other function in a Buddhist temple, I can transcend this dread, and change into something clean and even bathe before it. Then after that event, especially if it has been ecstatic, as it quite often is if associated with a special interest, I will continue to wear those clothes again and again without washing them, for the sense of security this gives me. But if I have to change my clothes for no reason than that I am itching, I dread that because they won't feel right. They will be cold and stiff, and hard and unfamiliar, and if other things have had to change that day as well, I may get upset. So when I give a talk, like today, I will wear something I have worn before, in a more familiar environment, no not having washed it since then.

Sue: *Changes in what you eat can be an issue for you. Can you tell us about the food you prefer to eat now?*

Paula: Because of my need to eat the same thing every day, which happens to have been cheese pie, or quiche, or something else based on cheese, for many years, my cholesterol level has consequently gone very high. My doctor is very reluctant to put me on medication for lowering it, as I don't have any of the other associated risk factors, such as, obesity, high blood pressure, smoking, etc. So, instead, she has made me an appointment with a nutritionist, who may no doubt make suggestions, but can not give me the ability to implement them and change my habits. I have tried to deal with the problem myself, by attempting to introduce tinned fish and beans and lentils as alternatives to cheese. While I have enjoyed building a collection in the cupboard, of all the different varieties of tinned fish, for

example in spicy tomato sauce, in curry sauce, and all the varieties of Sainsbury's tinned bean curries, to actually eat them is a rather more difficult matter. The hurdle seems insurmountable; I have managed it about twice on days when all the other variables of my day have been relatively unchanged up to lunchtime. Then I can manage a controlled change. But if other things have changed I am afraid I need the security of my cheese pie, like for example today.

Sue: *When you were young and living with your mother, how did you react to the different food that she gave you to eat?*

Paula: Meal times were a problem. I particularly remember a horrible meal of rib stew, full of tiny bones, which my mother unsuccessfully tried to get me to eat. However, I would eat chips. I remember day after day eating a plate of chips with tomato sauce, brown sauce and vinegar. I could sometimes be persuaded to eat an egg with them. Fortunately I lived near the primary school and had lunch at home.

When I went to secondary school, which was quite far away, I continued to have chips for lunch. The school canteen provided a memorably inedible lunch of vegetable roll with the cellophane still on the edge, followed by semolina with currants in it, so I had to find a way round this. I got free dinner tickets, as my mum was on the social security. Pupils who were not on social security had to pay one shilling, which equalled twelve pence, for a dinner ticket. Therefore I placed myself outside the canteen door and offered my free dinner ticket at the knockdown price of nine or ten pence. I almost always made enough for a plate of chips in the local cafe, out of bounds of course, but I had to have the chips.

Then when I was a young teenager, my mum took me to some neighbour's house for a meal. It was salad with cheddar cheese. I really liked it. 'What's that I asked?' 'Cheese', the neighbour replied. 'Why did you never give me this?' I asked my mother. 'I didn't think you would like it', my mother answered, perhaps not surprisingly. So, after that it was cheese all the way. I had to be taken up town to try all the different varieties of cheese, Danish blue, Camembert; nothing could be left out of my research. I remembered in my twenties, sitting in a cafe on a hot summer's day eating a roll with cheese. The cheese was all cracking and oily looking. 'I don't know how you can eat cheese on a hot day like this', a girl opposite me commented. I was thinking, 'I wouldn't know how I could eat anything else'. I have occasionally eaten other things, like rice and spicy beans every day for lunch. But these deviations have been relatively short lived, and I have returned to cheese. So it's not surprising, that although I don't eat much in quantity, my cholesterol is high!

Sue: *What kinds of things help you to eat a variety of foods now?*

Paula: Well, obviously if the food is connected to my special interest, as for example, when I was attending a Thai Buddhist Temple, the Thai ladies all brought food for the monks, which is a very important aspect of being a Buddhist, a way of making merit etc. I wanted to be able to do that too, and to do it as successfully as the Thai ladies did. Therefore I realised, it was not enough to try to follow recipes, I was going to have to eat the Thai food that other Buddhists had brought for the monks, to find out how it should taste whenever I would try to prepare it for the monks. So I found myself trying a great variety of foods, when I was at the temple, in the pursuit of my special interest. When I no longer attended that temple, I have reverted to cheese pies or quiche every day.

Sue: *You have a structured routine to help you to go to bed and sleep well at night. Can you tell us a bit about this routine and how you feel if it is disrupted?*

Paula: By 12.15. I need to start getting ready for bed as it takes quite a while and I need to be in bed by 1am. I always sleep between 1am and 6am. If I go to bed earlier than 1am, or get up later than 6am, I would inevitably wake up during the night, and not be able to get back to sleep, as my mind would cyclically repeat some negative phrase. To get rid of that I would need to get up and have something to drink and read something, and then because I had taken a drink, I would need to get up again during the night to pass water, and my sleep would be disturbed. I don't see the point of being up and about during the night which is the coldest, darkest time of the 24 hours, so I do everything I can to make sure I am asleep between the hours of 1am and 6am. I achieve this by:

- restricting my sleep each night to five hours.
- fluid restriction, especially no more than $\frac{1}{4}$ of a cup of fluid after 7pm
- wearing earplugs in bed so no noise can disturb me.
- emptying my bladder carefully before getting into bed.

So at 12.15 I go to pass water. Then I put the kettle on for my first hot water bottle. While this is boiling, I change into my night-clothes and pass water again. Then I fill the first hot water bottle, and put it into my bed, also bringing upstairs any money I have on the ground floor. Then I come downstairs and put on the kettle for my second hot water bottle.

While the kettle is boiling, I clean my teeth and pass water again. Then I fill my second hot water bottle and put it up in my bed. Then I come downstairs again and make sure everything is unplugged, and the gas and lights are switched off, and I pass water again. By now it is about 12.55. and so I go upstairs and get into bed, hopefully to sleep through until 6am.

On one occasion, my preparations for going to bed were disrupted. When I went upstairs to put one of my hot water bottles in my bed, my husband who is usually fast asleep, drugged by a sleeping tablet, heard me and called me into his room, to tell me that he couldn't sleep. I went in but I didn't know what to do. I didn't want to stay in his room. It is very cold and unpleasant. I wouldn't be able to read there. I would be bored, and besides I couldn't help him to sleep. I just started to shout; 'I don't know what to do. What do I do now? I can't cope.' and other words to that effect. One other night he actually came into my room, and woke me up in the early hours, when I was already asleep, to tell me that he couldn't sleep. I began to scream and cry.

Then I called the emergency out of hours doctor service. I was still screaming and crying. The doctor inquired about my situation, so I told her I couldn't cope any more with looking after my husband and his collection of papers. The emergency doctor didn't come out, but she reported my call to my GP next day. It was taken seriously enough for the rehab team from the local psychiatric hospital to come out very soon with a view to clearing the house of rubbish. What they hadn't realised was that what had upset me so much, was not so much the house being filled with paper rubbish, but having my sleep disturbed. When we were first married, and used to sleep together, I had no proper routine at all and I had lots of tantrums. For example, once when I was trying to sleep, my husband started to ask me a long list of questions about my mother, who I didn't get on very well with. I began to scream and cry, and then I socked him on the jaw. He said I had broken his eardrum, which was an exaggeration.

Sue: *We live in a world where changes do happen, and though these are difficult for you, you seem much better at coping with it now that you are older. What have you done to help yourself to cope with change?*

Paula: Yes – life probably does change a lot for other people, but my routines stay pretty much the same. I don't have a mobile phone, as I have no one I want to contact. I have no digital camera. I don't even use an ordinary one. I have no-one to photograph. I don't have satellite TV. I'm not interested. I'm not out at work. I stay home and look after my husband and go a couple of times a week to a Buddhist temple. But even within these limitations, unexpected changes do sometimes happen.

I've found that one way to deal with this is to minimise the change, by trying to replicate what should have happened. For example, about once a week, I go to a Buddhist temple with another woman, to do voluntary work in the library. But occasionally she calls me on the very morning we are supposed to go there to say that she can't make it, which means I can't go either. I can't adjust to that very well. I've made a lot of preparations for the day out. I've found clothes that match, I've packed my bag, I've even had a bath, and my mind is full of ideas to do with the library work. So, if she calls to cancel, to avoid having a tantrum, I just continue on, as I would have. I go for the same bus, but instead of getting off at the temple, I stay on a bit longer, and get off at the central reference library. I go to the comparative religions department, and ask for some rare out of print books on Buddhism to be brought for me from the archives, and I find something interesting to photocopy from them, to take home with me. So what I end up doing will not really be too different from what I had prepared myself to do anyway.