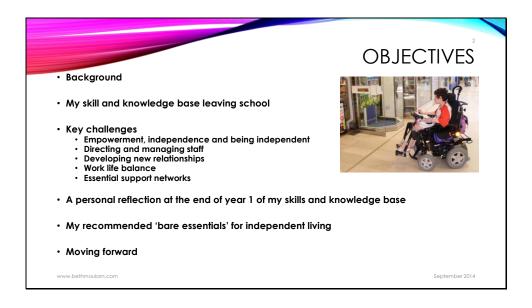


This paper is based on my personal experience. I started at University in 2013. My experiences have led me, to question if I was sufficiently prepared for the challenge.



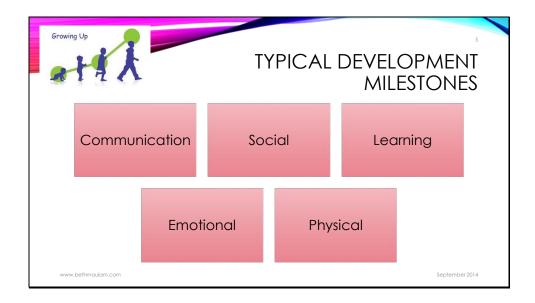
It has been a challenging year. One of academic success, and many social care challenges. This is a personal reflection of what I know now, and what I wish I had known then. With my action plan moving forward. My aim is to make others wanting to live independently think about these challenges and anticipate what they might need to plan for.



As background, I went to mainstream playgroup and primary school. I started mainstream secondary school before I moved in 2007 to a local authority special boarding school. A year ago, I moved into halls, I had already had several years being away from home during the week. I had experience of directing personal assistants, and care staff at school. I started in halls with 24 hour agency support. The fact I now have my own directly employed and dedicated support team, tells you it has been a year of change.



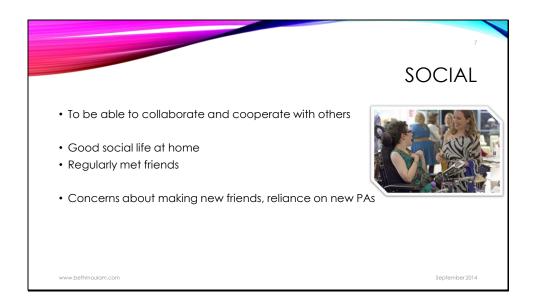
My family, and I, had done a lot of planning. I thought I was in good shape 12 months ago, to begin this new stage of my life. I considered my personal and more general skills, knowledge and experience up to the job in hand. Even though I knew it would be a tough first year, with a lot to learn.



To help me reflect, I looked at the typical development milestones for all young adults. This covers communication, social, learning, emotional and physical skills. What I have done in the coming slides is broken these into the competencies expected. What I felt I could do a year ago, and any concerns at that time.



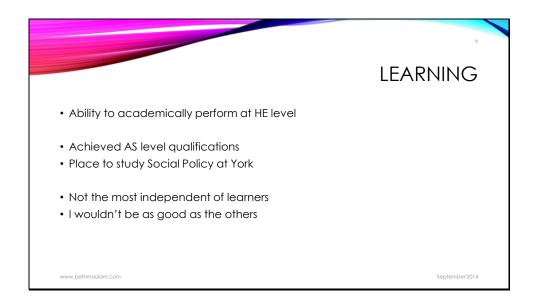
The right to communicate is essential for us all. To be able to convey our needs, wants and desires. I knew I was a good functional communicator. I am very resourceful in getting my message across. But I was also concerned I would be meeting many new people. Most of whom had no experience of people who use AAC, and might not be patient with me.



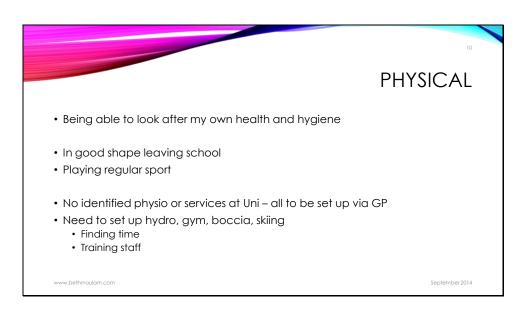
Socially, everyone needs to be able to cooperate and collaborate with others. I felt this wouldn't be a problem having been at boarding school, and having my own support staff at weekends and in the holidays. I have always had a good social life, regularly meeting friends from school, at boccia and in my local community. The challenge would be making people understand that I was no different to them. I was aware I would be completely reliant on a new team of personal assistants. This would be, I knew, tiring, and at times frustrating, whilst they learned their job, and the boundaries, between being a formal employee and a relaxed companion.



Emotionally, all young adults need to be able to cope with change, control impulses, manage anger and resolve conflict. I had had plenty of change in the past, and done a lot of planning for my move. I felt I could manage my emotions well and had rarely had to deal with conflict. I was used at school to a good support team and I had a counsellor I saw weekly. However, I had some concerns as I was leaving my friends and family behind and would have a new support team, and would need to find a new counsellor.



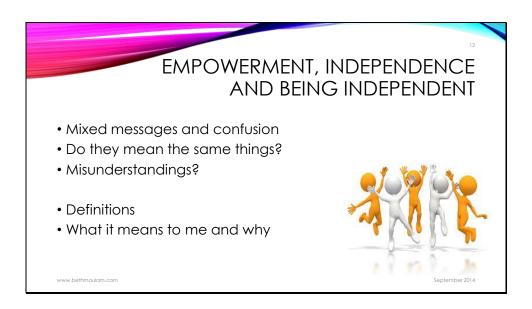
Going off to uni means being able to learn at an appropriate level. I had the qualifications and a place to study Social Policy on the extended degree. This meant 'someone' believed in me, not least myself. However, coming from a special school, where I had always had 1 to 1 support, I knew I was not the most independent of learners. I was also worried I might not be as good as the others, for lots of reasons. From speed of my communication, needing academic support, my slow reading, and just generally as things take longer for me.



Physically those leaving home need to be competent to look after themselves. I knew I was in good shape, that I could direct staff, and I was, and still am, an active sports woman. The communication challenge for my physical well being would be to meet and establish relationships with the university doctor, therapists and set up the physical programmes I needed. These are things over and above what most other students need to do.



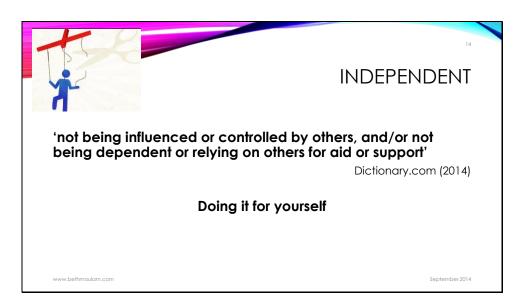
In summary, I felt good. Yet a little apprehensive, as I knew this was an enormous leap into the future, by leaving home.



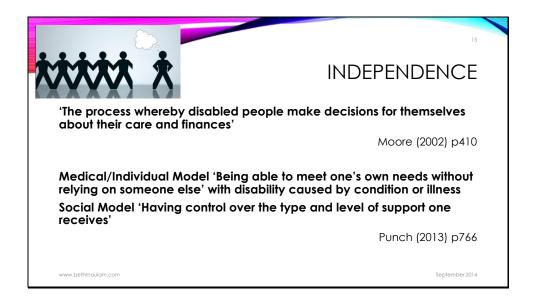
Almost immediately I started university it was clear different people had different ideas about empowerment, independence and being independent. There were some incredibly supportive people, but a small minority with views, such as. I was at uni so should be able to do everything myself. There was a lot of confusion so I spent some time researching this. Here is what I've found.



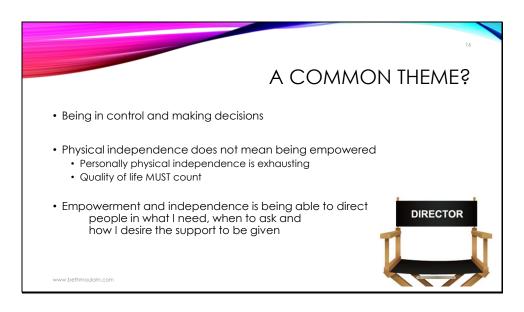
Moore said, empowerment is. A movement that encourages individuals to take more control of their own welfare and treatment, either by forming a partnership with professionals, or by seeking more appropriate representation of their rights and needs. This means actively involving people in making their own decisions.



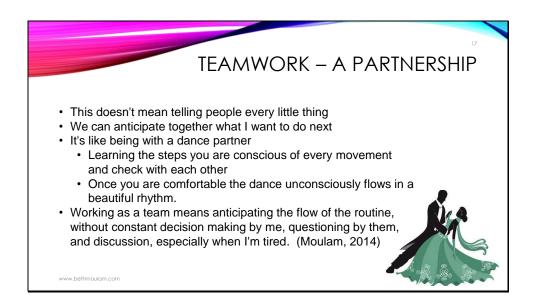
In contrast. The dictionary tells us. Independence is not being influenced or controlled by others, and or not being dependent, or relying on others, for aid or support. This means. Doing it for yourself.



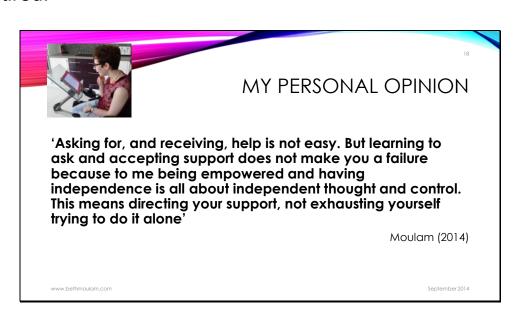
Moore in 2002, said independence was about disabled people making their own decisions about care and their finances. More recently, Punch has used the social model to explain the meaning of independence, as having control of the type and level of support you need.



There is a common theme across these 3 definitions. This theme is being empowered, being independent, and independence, is being in control and making decisions. I can agree with this. Being physically independent doesn't mean being empowered. Just because you can dress yourself, it doesn't mean you have the skills to direct your own support. To me being empowered, and independent, is directing people in what you need, what to ask for support and how you would like that support to be given.



Directing others is a skill. This doesn't mean I have to tell people every little thing I need, working with a personal assistant is a form of teamwork. If I need to do the same thing, at the same time every day, we can anticipate together what I want to do next, as it's what I always do, for example, bedtime routines. It's like being with a dance partner. While you learn the steps you are conscious of every movement, and check with each other. Once you are comfortable the dance unconsciously flows in a beautiful rhythm. Working as a team, with good staff who facilitate, and support my needs, means us both anticipating the flow of the routine, without constant decision making, questioning and discussion, especially when I'm tired.



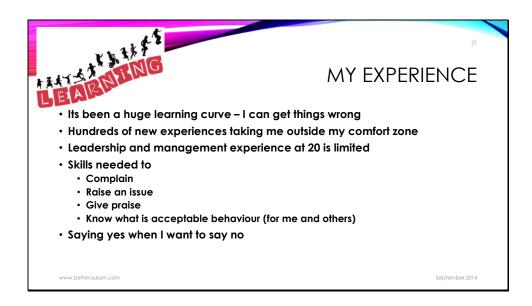
In my humble opinion, I know that, asking for, and receiving help, is not easy. But learning to ask, and accepting support, does not make you a failure, because to me, being empowered, and having independence, is all about independent thought and control. This means, directing your support, not exhausting yourself trying to do it alone.



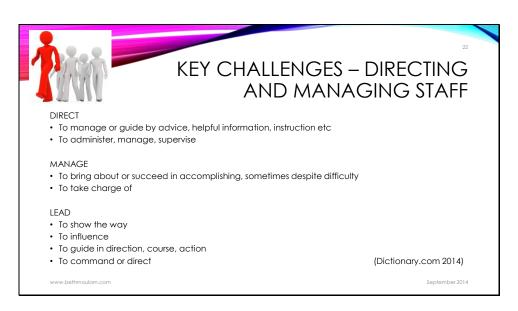
Many students moving away from home experience the same challenges. Feeling homesick and alone, missing friends or a pet. Needing suddenly to look after themselves. Learning new ways of working, and having to make new friends. I know people who have phoned or skype home daily for weeks. Some lost weight or piled it on by not eating well. And, some ran out of money in the first few weeks of term. In addition to these normal student challenges I have had a few other things to contend with.



I've had the typical student emotions and experiences. I've felt physically and mentally tired, completely frazzled. Not just from the new life style, but also having to direct a brand new team 24 hours a day. If I wake at night I have to be able to tell them what I need, so I have to be awake. The team all work shifts and so everyone has had to learn every part of my daily routine. In the first term I didn't get any academic work done on an evening as they were focussed on cooking me a meal, helping me eat, getting me showered and into bed. In the second term I agreed to a ready meal on an evening to free up some time but it's not been easy. Everything takes me longer so my free time has been work focused. In January the G P signed me off and told me to do no work. I had worked every day apart from Christmas day and boxing day and was exhausted.



Year one has been a huge learning curve. I can easily, and often have, got things wrong. I've had literally hundreds of new and sometimes fantastic experiences. And sometimes scary experiences that take me outside my comfort zone. These are not things I anticipated or planned for. I know now I have had limited leadership and management experience. Not many people aged 20 have the knowledge and skills to run a team. And I have definitely been learning on the job.



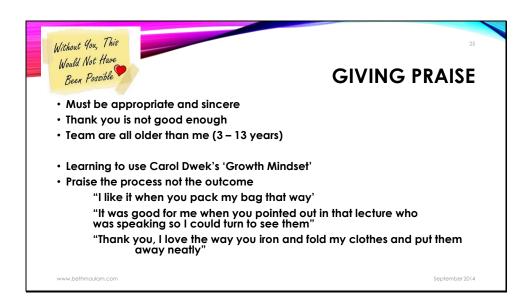
A huge challenge has been directing staff. I need to show the way, guide and influence. This means trying to set an example in how I behave. I need to take charge, instruct and even when it's difficult, be successful. The starting point, is making sure my own team know I am determined, that I need to succeed, and based on this year's experience, know that I am in charge, even if I make mistakes. This doesn't mean we don't talk. I expect to share experiences, discuss opportunities, and options, and enjoy being together.



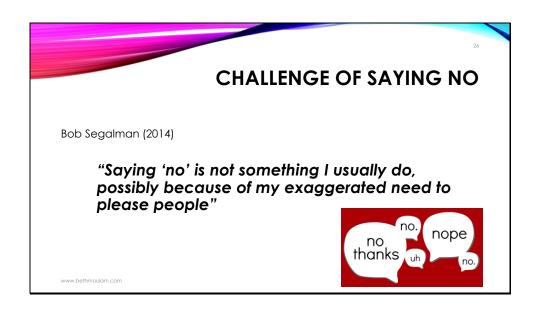
Since I was at school when I need to raise an issue, I often find myself writing an email, because it is less confrontational. Something in writing is usually taken more seriously, although it risks being more formal if people don't understand this is easiest for me. Making a complaint means I need to find an appropriate scribe. I had an issue this last year, where I couldn't use any of my team to scribe. Without a suitable recording system I was in a situation where I continued to feel at risk. Luckily, I have just been assessed for eye gaze, for recording, so this should stop this happening again.



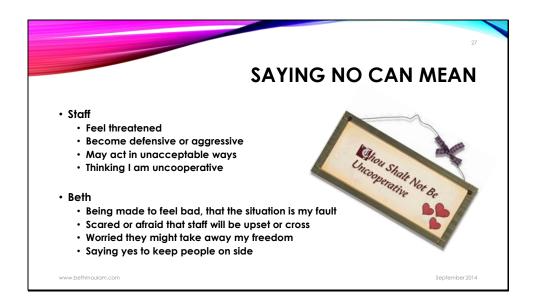
We all know tone of voice and AAC don't go together. When using AAC, being diplomatic is key. Using the right words are vital, as I don't want to be seen as rude. Even my natural speech can sometimes make me seem abrupt, because of my dysarthria. This means I worry about upsetting my team. I have been working on phrasing things in a way that is less confrontational. For example, making more of an appeal for help, and asking for their support, before I raise the issue.



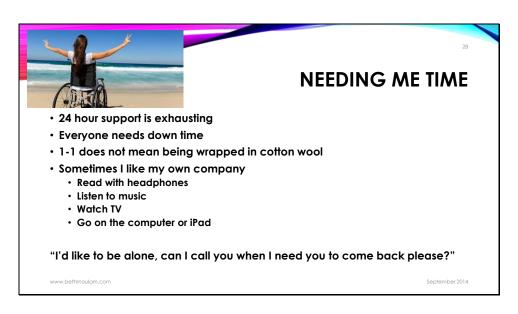
Because of my course, my team are all graduates, so they are older than me. They work hard, and sometimes saying thank you is not enough. Saying more can feel awkward. I heard about Carol Dwek, and the growth mindset, in relation to my sports coaching. I have found it easier to praise the process, rather than the outcome. Saying 'I like it when you do that' gets better results than 'well. done' and makes us all feel good.



There is research showing people with complex needs often smile at staff, and say yes, when they would like to say no. Bob Segalman, who uses AAC, and lives in America has said, 'saying 'no' is not something I usually do, possibly because of my exaggerated need to please people'. I can identify with this. I need staff to want to be with me, so even if I am not happy I won't show it easily. It is sometimes easier to go with the flow than say no!



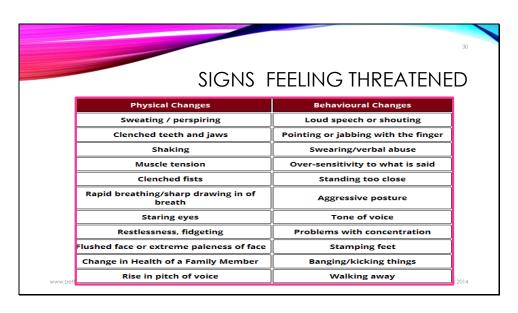
I've found saying no, or don't, means staff can feel threatened. So in turn they can act inappropriately. It is funny that they think I am uncooperative if I don't want to do things their way. I never thought I was vulnerable, or at risk. This year has shown me that others can make me out to be the culprit. Saying yes does help keep people on side, but, we all have the right to choice.



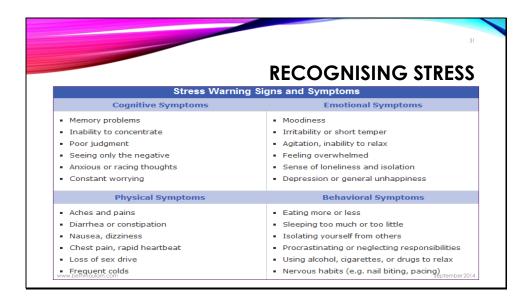
As I said before, having people around 24 hours a day is testing and exhausting. Yes, I do need 1 to 1 help, but I also need down time to myself. I'm often happy to read, watch a DVD, use my iPad or listen to music. Sometimes I prefer to be alone, sometimes I like my Personal assistant to be companionable and just sit quietly with me. Getting the space I need means I have had to learn to send staff off to do a job, which is easier than telling them to go to their room nicely. Then wait to be called to come back.



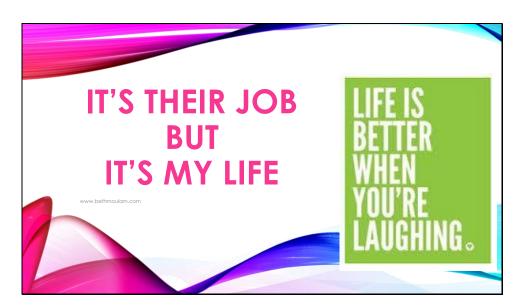
I mentioned before, acceptable behaviour. At school the staff were well trained and supervised. There were never any real incidents. What I have had to learn is the detail of what is in a job description. The agency guidelines, statutory information and whether it is reasonable to be black, and white, when life is often in the middle. I've also had to learn that when I am uncomfortable with my own, or someone else's behaviour, there is probably an issue. By knowing the signs of acceptable behaviour I am learning how to deal with situations.



If someone is threatened, or upset, then they often show it, without realising. By knowing that if someone sighs a lot, or shouts, or flushes, or clenches their jaw, there could be a problem. Then I know I need to raise the issue to avoid it escalating. But likewise, I also need to understand the difference between threatening behaviour, and someone who is enthusiastic, but unaware their actions invade my private space. There are the protocols for working with someone disabled, knowing that making us look up, or standing over someone, or leaning in too close, can be intimidating unintentionally.



I have a condition triggered by stress. This year I have experienced new problems, and so I have had to recognise the cause, and how to deal with them. I have always been a worry wort. But this year when things were tricky I became moody, short tempered and felt over whelmed. I also retreated to sleeping all the time when I went home, as I couldn't sleep in halls. At times I felt physically sick and didn't want to get up or eat. With better knowledge of myself I know I need to take action.



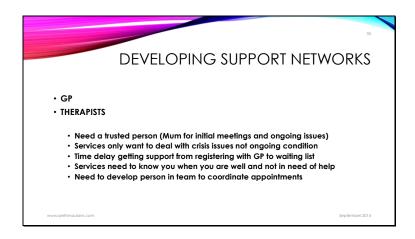
This year has reinforced the importance of employing great staff who want to be with me. It may be their job, but it is my life. I need to live, love and laugh.



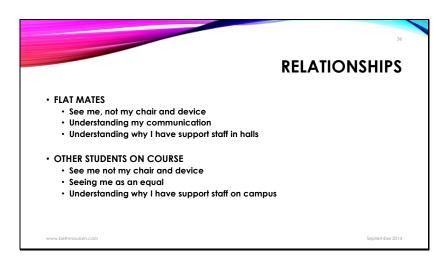
People have always been important to me. Again this year I have learned the value of good relationships. When things went wrong I had a core of very good people around me who continued to make my life worthwhile. There is the old saying that no one is an island. How true. Everyone needs a helping hand, I just need an army of them.



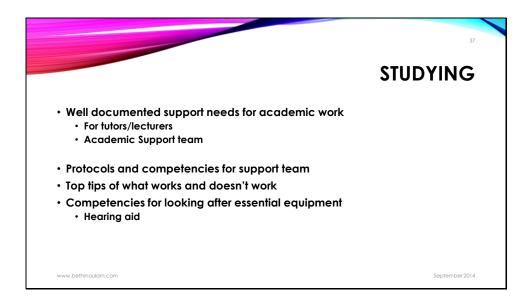
I ended last year with, I think, a good relationship with the course team. I also know the value of a great rapport with my academic support team. Last year I left the academic support team to find this out over time, but they all need to see me, as, me, from the first day so they have high expectations of me. It is important they understand it takes longer to communicate because of how I need to output using the Lightwriter. I have always known I was a visual learner and have learned even more this summer about my learning style. I will be sharing this with the course team in the first week to make sure they can facilitate me. Throughout last year the university support team was great, providing me with a safety net to fall back on when things needed sorting.



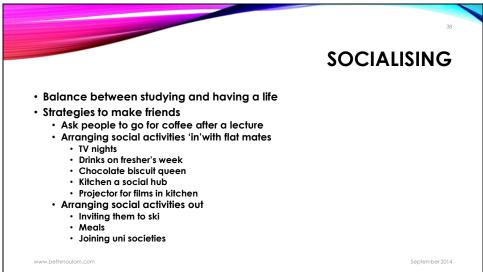
All students moving to university have to change their GP. For most people it is just a case of signing up and then going in if they are under the weather. I have had a great relationship with my GP surgery at home since I was born. They knew everything about me, the receptionists knew I needed a double appointment. The nurses knew about my condition and even trainee doctors were told about what I needed. To get new therapists I had to first register with the GP and then wait for referrals. I wasn't allowed to register for services, or have referrals, until I was actually on campus. Mum came with me to see the doctor and they agreed to make the referrals to physio, O T and speech. They sent me back to the university for counselling. Some referrals took longer than others which resulted in me having to find other ways of doing things. Mum has remained my coordinator for medical things as I haven't had someone in my team who can do this, yet.



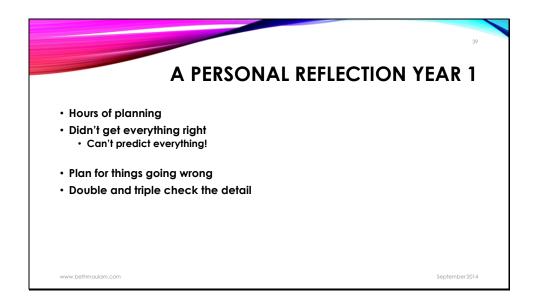
Relationships with other students are really important. I need people to see me, and not my chair or my device. Unfortunately that hasn't always happened. People need to get to know my communication and see me as an equal. I can't demand this, but I need people to understand why I need extra support in halls and around the campus. I can understand it's hard for my flat mates having a stream of people in and out of the flat who are working for me. On the course and in my life generally my team are there to support me medically, as well as, academically. But they are not there to over protect me. It is just life that my team are very obvious. Other students get note takers who sit at the back of the room, mentors they meet on campus, scribes who they work with in the library. The difference is I always has someone alongside me.



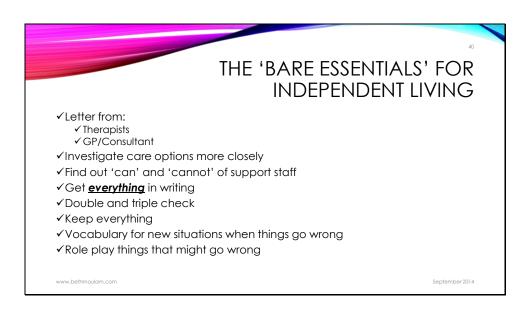
I need well documented protocols for academic tutors and lecturers. My support team need training in how I work and not just general academic training. This year I will have one single team who work with me 52 weeks of the year around the clock. This will take away the issues of not having academic support on an evening or weekend if I have work to do. It also means everyone in my team is trained to do the whole job and not just parts of it. We have nearly finished 5 days of tailored training for the team in how to support me. This has included scribing, note taking, my communication, study support, library support, carrying out research, and much more including looking after all my equipment. After last year, I need everyone to work in the same way, not to have to spend my time re briefing people when a shift changes.



Year one was gruelling. I did not do any socialising, at all. Apart from a few coffees and one night out at Christmas, and one at the end of the year, I worked the whole time. This year I have a very different plan. I intend to work hard but make time to enjoy myself, and definitely have time for sport.



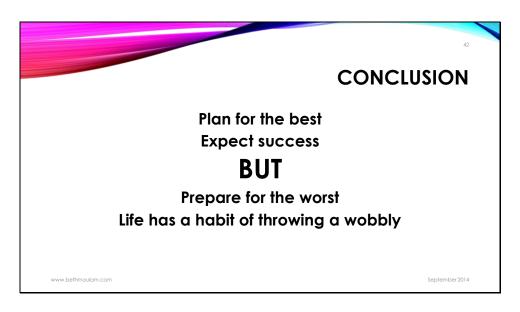
On reflection last year I did hours and hours of planning with my family. We had lists of lists, yet unfortunately, I didn't get everything right. I know I couldn't have predicted everything. But we planned for things to work smoothly and go well. What we didn't plan for were situations going wrong. From communication breakdowns, to low expectations, and delays getting health support. Moving forward I know the importance of planning for the things that might not work so well, as well as, those things that will.



I have come up with a list of my bare essentials for anyone going into independent living. Some are uni specific, and some only apply if you change your GP. First get letters from everyone who supports you that are detailed and up to date. Second investigate fully your care options. I fell into the trap of assuming what the university recommended would be right for me. With whatever option you choose, fully understand their protocols, of what they will and won't do. Get everything in writing and don't just double check, triple check it. Keep all the paperwork in case you need to go back. Plan for situations to go wrong. That means have the appropriate vocabulary on your device.



With my own team I do both formal, and informal interviews, there is a training programme which ensures everything is taught by someone expert, like Mum, or someone who has worked with me well for months. There is also formal training on key aspects of support, like supporting me doing presentations and academic work. We have written our own course, and the feedback has been good so far. I am aiming this year to have some quick wins with the academic team, and with my flat mates, this will be supported by my speech and language therapist to give them the opportunity to ask questions they may not feel comfortable asking me. I now want more training on being assertive, handling conflict and leadership.



I am a planner, so I plan for the best and aim to be successful. Now I know I need to also prepare for the worst because no one knows when life will throw a wobbly at you. If you asked me today if I knew then what I know now would I have not tried to do it? The answer is that I am stubborn and determined. I have learned and grown in many ways and I am better able to handle situations because of what has happened. I would definitely still have done it!