

## **Nan's Story**

Jeanette Thompson, March 2013

Nan was 95 years of age when her daughter first heard about self directed support. Nan was registered blind, deaf and had pernicious anaemia. She was also very fragile. At that time, Nan was starting to feel like a burden to her family, something she really struggled with. She had always been the centre of the family and had supported everyone else and kept them strong. At 95 she felt like her body was giving up on her and that she could no longer do the things she wanted to do or had always been able to do. More importantly she could no longer be the support to her family that she wanted to be. When talking to her about this she said she often cried but didn't want her daughter to worry about her so she always said everything was fine, demonstrating her absolute strength of character.

### **The first personal budget in Sheffield**

The timing of Nan telling her daughter all was not fine coincided with the start of the work in Sheffield to put in place self directed support. This meant that the opportunity was there for Nan to have support that was designed to work for her rather than the respite or day care she had previously been told about. Nan was clear that being placed in group settings where she needed to 'trouble' or ask people for support, such as to go to the toilet, was not for her. She wanted to stay at home where she felt safe and loved.

Nan was part of the very first group of people to start planning to have a personal budget in Sheffield; in fact she became the first person to have one. She came to an event where everyone in the room was planning what they wanted their support to be like. The start of this process was to describe who you are as a person. This is crucially important when planning with someone as it is the start of a logical journey to understanding what support someone might want to keep them safe and help them to live their life.

### **Telling her story**

Nan told everyone about all the things she had done as a child and as she grew up and became a mum, a grandma and a great gran! She told everyone about the time she went to the pictures when her dad thought she was somewhere else; how as a child she were in awe of the village bobby; about meeting her husband, having her children, losing children, taking in other kids that were struggling and the challenges some of her family members had. Most of all she told us about the love for her family and for life that she had. As she told the story Niki (her support planner) was drawing and writing this up on a huge graphic. At the end of the session the graphic was full of stories, anecdotes and information about Nan. She was thrilled, if not a bit overawed that people had spent time listening to her story and writing it up. She was amazed to see her life story on paper in front of her. She was even more impressed when she realised it was hers to keep and she could take it home.

### **Choosing a personal assistant**

Nan had a simple support plan; she did not want the earth, she never did. She wanted a personal assistant to support her, to help her garden and grow tomatoes, to help her wash up, re-cover her sofa, to visit her brother and sister and to visit the places that she had grown up in. Nan found a wonderful PA, Rachael. Rachael has supported Nan

brilliantly for the last 4 years. She has become a part of the family. She has helped Nan to wash, when her daughter found this particularly difficult, she has taken her to visit relatives and all her favourite old places, amongst many other things.

### **Support for the whole family**

Rachael has also been an amazing support for the whole family and particularly for Anita (Nan's daughter), when Anita has had challenges in supporting her mum, such as when she broke her arm. Rachael has stepped in and been flexible about the support she offered (paid via Nan's contingency). Equally, when Anita and her husband were about to have their first holiday together as a couple in many years I was stunned but pleased when I got a call (whilst I was on holiday) telling me that they were all going; Anita, Tony, Nan and Rachael. At that time I felt respite breaks was about being away from the person and was initially a little worried. But as a family they all went to the same place, did their own thing during the day and got together on an evening over dinner. It was a fabulous break for all concerned; they had a break from the routine and chores of everyday life and got time to enjoy each other's company. Even more importantly Nan started telling everyone she came into contact with that they needed some of this 'self directed support stuff' and when they thought it was just a freebie from the local authority, she corrected them - very firmly.

### **A pioneer for self directed support**

When she was not quite so poorly, Nan used to do conference presentations for us. We videoed one of these; the experience of hearing her talk to a room full of people, knowing many of them were sceptics, was inspiring. Particularly when she told the room full of social workers that if she were well enough she would be knocking on the door of every older person in Sheffield telling them all about self directed support, but as she couldn't, she expected everyone in the room to do the same. She was a powerful lady who inspired lots of people to do something wonderful for the people around them.

### **Flexibility and control**

Nan had a budget for over 4 years. In that time her needs changed and her budget increased, but she continued to be supported at home by her family and Rachael. This and the flexibility to support her kept Nan safe for a long time, when she had urine infections and has been singing and marching 24 hours a day Anita has flexed the budget as much as she could, often not as much as she needed. When Nan went into hospital, Anita worked tirelessly to get her home as soon as possible and was able to use Nan's personal budget to help make that happen.

During the last 4 years Nan's brother passed away. Nan was distraught by this but remained steadfast and determined not to give up, as she had to tell lots more people about self directed support and personal budgets. Anita has said on more than one occasion that this kept Nan alive at a very difficult time.

### **The legacy of a great lady**

Recent years saw Nan become increasingly frail and ill. The last few months were particularly challenging as Nan went in and out of hospital with a range of difficulties. She was also singing constantly, 24 hours a day, week in week out, all her favourite oldies. Singing like this was almost her signature when she was particularly ill and is

one of the things I will always remember about her when I think of her and her family. Nan passed away three weeks ago, just a month before the end of the programme that she has been such an advocate for and such a symbol of inspiration. She died peacefully and when she was ready to, at the age of 99.

Today (12.3.13) was her funeral and people from the self directed support team attended the service. The vicar read out her support plan as part of her eulogy; he described Nan as a pioneer and said that she had left a legacy for the whole of Sheffield thanks to her work with personal budgets. He said that he was delighted that because of self directed support he was able to do something he had never been able to do before - tell people about the person's life in their own words. He also expressed thanks to the team on behalf of the family for helping Nan to stay independent to the very end.

Self directed support gave Nan her freedom and independence to the end of her life, a gift greater than any other. But it also gave those of us who knew her the opportunity to know an amazing and inspirational lady. She has helped to keep me grounded with what is important while I have been working to implement self directed support in Sheffield.

## **Wayne's Story**

March 2013

**Wayne is 32 years old and from Sheffield. He has a rare degenerative disease that took 13 years to diagnose. He is also half way through his second year of a social work degree, hoping to graduate in summer 2014.**

**Wayne has been through the self directed support process; he wrote his own support plan and has had his support in place since April 2012. He went through his assessment stage with a student social worker called Laura. This is his story.**

### **Great social worker; great assessment**

I started the process at the back end of 2011 with Laura; she managed to do my assessment with me from start to finish. We ended up meeting three times, a couple of hours each time. It was more than I expected, but it worked great. She got everything; she got it coming from myself, from the social perspective and from my nurse's perspective as well. So when her assessment came back it was really good. Laura came and explained all about the indicative budget, about how it could be spent, how it could work. She informed me, she were really good!

### **Choosing to plan on my own**

She told me that I could get someone in to do me support planning; she gave me all the options, but I did actually choose to do it myself, which I think actually should be encouraged a bit more. I know its staffing and time, but if people have got capacity and they are able to, I think it's giving people more sense of achievement, and saving

money from their indicative budget. And you know where it's coming from; the person that's living with that disability and knows how it works.

Laura emailed me all tools; it was very daunting. Mine took from September to January, and the process was very detailed but that worked great for me; it helped me doing my course on top of it, and that's why I wanted to do it [on my own]. I had more input and it were more of a choice; I understood what I were asking for and why. I got a lot of insight through the assessment, 'cause it's you talking through the questions. It really did work well for me that way.

### **Some challenges along the way**

So, we got the indicative budget, then I did me support plan, and I spent it! Easy! They gave me this amount of money to spend, and I've managed to spend it; I've showed you how I'm gonna spend it, when it's gonna be spent, how it's gonna be spent, detailed it all to the T, but then they came back to me and said it's not all there for spending.

So that made it more difficult, I had to go back and reassess everything, so that were a bit disheartening and a bit disempowering. I'd spent all that time, that effort; its not that it were difficult, but it were very time consuming, to sit and do it properly. I got more quotes, got this and got that, got things reduced, and juggled it all, and then it went back again.

### **Choosing the support, making the changes, getting it agreed**

I'd gone through every outcome, used things from the toolkit, got some ideas from that, and I knew roughly what I needed to change. For my one off payments for example, I was struggling with me kitchen because I couldn't bend and get into me fridge [or oven] so I designed it [but] we had to cut [the cost] down, which is fair enough. I'd worked out how my PA could support me and how that could be implemented. Other one off payments like a mobility scooter, to help me round uni, things like that.

But then there are examples that say some people had put down a weekend break and pay a PA to take them; so I put down for £700 a long weekend break to go to a caravan park with my PA. I had got a big thing for my enjoying/achieve outcome that I wanted to meet: to have a bit more of a social life, to be able to get out with a bit more support. My mobility scooter were one of those things; [the holiday] was just another way to meet that need. But the [duty] social worker came back to me saying you can't be putting this money down for holidays.

Don't get me wrong though, they gave me some ideas, perhaps that, for my university friends, [who give me support] I could gift them a meadowhall voucher to say thank you. So they gave me some good advice that way.

In the end, we did manage to agree it. At the time, there were times when I were fff... flipped off! It were a back and forth thing. Towards the end of it, of the support planning stage, I were thinking has this all been worth it? And it has, now looking back in hindsight.

### **Challenges at the Financial Assessment stage**

It were all working well when the financial assessment came through. Laura told me about it at the beginning but they didn't get in touch with me till I were about half way through the support plan. When they did the assessment, the support plan was in place. When it came back, they told me that I owed them x amount of 100s of pounds, plus I had to pay £75 a week. I were like, hold on a minute...

Well, it were an error, but I had to argue with them, and I don't like arguing at the best of times. In the end they [realised] they'd counted two lots of money along the way which meant I were paying too much, so in the end it came back that I'm paying £14 a week towards it. Originally they'd said £75...!

That were a frustrating time and I remember getting really upset about that. They don't explained it in layman's terms, I couldn't understand what I were paying and why I were paying it, and they couldn't really explain it either! It were a nightmare!

But... how much difference my kitchen has made to my life... I can access things independently without having to rely on someone to get into fridge. I can't do a full shop, but if I get a few bits I can put them in the fridge, whereas before I couldn't get down to it. That has made a big difference to my life.

### **Choosing to have a personal assistant**

I am quite independent, but if am going places I do like to make sure I'm with someone, just in case I do fall. My PA, he's my mate, he's a big guy and he can just help me up. We've lived together for a long time. He works full time but in the morning it's great when he gives me that support. I am needing more support each time; putting socks on is a nightmare. You don't want to ask for help [so] it just gives me that way of saying thank you, here's a bit of cash now put me shoes and socks on! Its them little things that make all the difference, and stop the isolation. It's not much, but it's nice. I've got a contingency that I can use to pay my PA too.

I manage the money myself. I struggled to start – spending a lot of time on the phone with HMRC. But I've got all the tools on the computer so I do do it, its not TOO bad...!

Laura gave me good advice and did her research. With Jason, my PA, it works wonderful, I'm so glad that I am able to do that. There's no power imbalance. He knows that he's appreciated, and I appreciate what he's doing. Me and Jason live together and most of my needs are around the house but if I do want to go out or go away I can feel confident because he's there to support me if I need it.

### **Looking back and moving forward**

[Having a personal budget] has given me more confidence, more independence, more control; I'm more positive about everything. I feel confident that with [my friends] being with me at uni they can support me and Jason's there at home. I know they don't want owt for it, I wouldn't, but it is nice that I can do that. If something was to happen, you will get that support from someone and it's nice to be able to say thank you. I put some of my money into a contingency and I'm so glad I did, giving me even more flexibility. If Jason is away, I have a friend down the road who can help me and I can thank them using my contingency.

I'm in my 2<sup>nd</sup> year; I'm doing the course full time, and it has been a hard slog, I am looking forward to the summer but I know two weeks in I'll be bored, I've kept myself really busy. Perhaps before, this all started, I were just sat about feeling sorry for myself, I look back 7, 8 years, I was fed up; so it has changed, getting my diagnosis, Occupational Therapists that are interested, getting a personal budget; its giving you the confidence and the empowerment to get out and do things, giving someone a purpose; it'll keep you going longer. I think it's critically important.

It's never going to be 100% perfect but there have been dramatic changes over the past few years; it's got to be worth it.

### **Supporting others**

Now in my role [as a social work student] I can explain things in layman's terms, I'm not an academic or anything, I'm an activist. I can explain the whole process and the benefits and I can give them real examples of how it can work for them and how they can chose things that will really make a difference for them.

I think we need to encourage people to plan for themselves – I know it's difficult to get that time, and there's always an element of support but encouraging people to do their own plans, people will get more understanding of the process and get the confidence from that. It's not about doing things for people, its empowering people to be able to do what works. Everyone's different; someone with the same disease as me, their needs will be totally different but so will what they want to get out of life, what they want to do, what they want to achieve.

### **Pushing the limits**

Some people do these courses and want to get on a career path; it's not about that for me, it's about personal goals, get onto the course, get through uni. I'm not bothered about money, as long as I've got a bit of cash in my pocket to have a drink at the end of the week I don't mind.

It's a learning process and I'm getting there. I'm happy where I am and I will say that part of that is due to this [having a personal budget]. It is well well worth it; bit stressful some of the time, but nowt's ever going to be perfect. You know, it's a complex system and its complex people you're dealing with. It can work. Negatives at the time are frustrating but it is definitely worth it. There are stressful bits but you can pay someone to help you if you do want it.

If I'd done it differently I might not have met my exact needs and learnt exactly what I needed. Doing it myself, I could really push the limits.