



## Living with Disability

*Ann's story: academic perspective*

### **Jan Walmsley:**

My name is Jan Walmsley. I was the consultant commissioned to author units one and three of this course. Using a drama rather than a documentary, I suppose you could say its cheating in a way because you can structure the drama to say what you need it to say, but I wouldn't accept that it's cheating. Actually its using material based in research undertaken by Joyce Cavaye in 2002 into caring trajectories by families in Scotland, and we chose one of these families, we anonymised it; we took some liberties; we made things happen more quickly, or we created dramatic incidents and perhaps they'd been more mundane, but we actually followed this family's story from beginning to end and we wrote a drama around it. So it was something I felt very proud of doing actually. Ann and Angus have become part of the student sort of everyday conversation and that's what we meant to happen. That was our intention; lets give them something human to hold on to and that makes learning much easier.

One of the main points was that we wanted a course on Health and Social Care to start not with medical or technical ideas. We wanted it to start with, 'well what is caring actually like?' And most caring happens in families. Believe it or not about seventy-five per cent of people over ninety still live in private households, so there's most people, despite what we might think, still live in their families or supported by families and friends or independently if you like, well into the very advanced age. It means there are a lot of people doing caring jobs who aren't paid carers, who aren't qualified, who are friends or much more normally family, and we wanted students to recognise this. This tends to get forgotten. You know, you're working in a hospital or a residential home and that's what your reality is and you forget that actually most of the work is actually done somewhere else. Most of the job of caring is done by people who aren't paid and who aren't trained and who are sometimes struggling to discharge their responsibilities. So that was the reason we started with what used to be called informal care or caring in families.

Secondly we wanted to bring out the stresses and strains of caring. We wanted to bring to life the fact that caring is often about somebody you know and love, deteriorating, and you don't want to recognise that this is a problem. You don't want to recognise that maybe they're moving into really serious illness or death and so you struggle on and you fight on and you don't ask for help and this is the classic family trajectory, that you get, kind of slide into it without noticing, and that the way formal services respond can be enormously important for enabling those people to carry on or not. There, as in Ann's case, she's probably, she's quite young to be a carer, more carers are over fifty, but Ann is sort of struggling with both sides of the caring equation if you like, the older person and her daughter, and also trying to be a wife as well and be herself, and so there's this stress, stress and conflict of roles and competing demands on her which lead with Ann and with many people to possibly depression, ill-health, having to give up your job, financial problems, relationship problems, all sorts of consequences of having to focus on this person who is getting older and more disabled. At the same time we wanted to, I suppose, get people to empathise with what it feels like to be Angus, to be the person who is losing his grip on life, his ability to eat and go to the toilet by himself and the lack of dignity and frustration that that entails, so those were key issues that we were trying to bring out and as I say the, the other part was, we're moving in the later part of the drama to how do services respond to this, how can somebody in Ann's situation be supported in a way that enables her to carry on? I mean this is policy now. It's much more policy for governments to support carers than it is to put people in a expensive residential facility or to leave them in hospital for long periods. That's a) seen as not respectful of life and b) seen as very very expensive. We just can't afford it, so policy is, its about supporting people to care better, longer and

it often isn't carried out into practice as well as it might be.

They're often very slow to respond and that certainly comes out in the drama, and then there's the negotiation. You're letting somebody into our house. You've not been used to having somebody in your house, sort of having to make that their work place. And what do you expect of them? What do they expect of you? Can you ask them to do things or are they very constrained in what they can do? To what extent can they mould their behaviour to your needs and the needs of the person that needs care? So, those were all, all the learning points that we were quite keen to get into the drama.

You need to understand the system in order to help people access it and the system is quite complicated. There are a number of sort of hoops you have to jump through. One is getting an answer from your local adult social services or community care services, whatever. The second one is going through an assessment and if you aren't in a category that has a critical need because of funding restrictions you will find that very difficult. You may well be screened out from support from formal services unless you your situation is such that your caring situation is likely to break down unless something is done, so I think it's very important if you're in a sort of advocacy or friend or support role to help people understand that, but the other bit is that there's a lot of help around and founder carers group, and that was hugely helpful. She found a Parkinson's Disease Support Group. Almost all of these long-term conditions as they're called; Parkinson's, Motor Neurone Disease, Stroke, MS, have a network of support groups and they vary in their quality obviously but go out and find some other people you can share with and if you can, and a lot of solutions are private solutions. So the other party is thinking about what other resources are there around er if you can't access the system that, that local authorities operate?

I think the tension in this case study is that we wanted a happy-ish ending (laugh) and there aren't always quite such happy endings. I mean the care-worker that Angus and Ann get is really wonderful and responsive and very warm. Many care-workers are, some aren't, and one of the tensions for people who are home carers is that they're given a care plan. They have to work to a care plan, and the care plan is what their assist is needing. The family might want something different. This particular woman was quite skilled in negotiating that tension and managed to sort of adapt what she did in a way that the family found er more acceptable and enabled her to really become a support to the family.

The other bit is that I'm a great believer that stories are a great vehicle for learning and this case study should help students begin to use their own experience as learning vehicles. That's the other idea, still reflecting on what you see and do every day. One of the things that courses like this do is give students a language. They might feel things or think things but actually it gives them the language to put them into words that other people can understand, so this case study gives people the words of informal carer; it gives them knowledge about roles; it gives them insight into the words that research uses, burden, stress, those kinds of things, and it therefore enables them to begin to put their own experience into a bigger context and perhaps become more effective. Certainly one of the things almost all students say when they start this sort of study 'well I thought that before but I didn't know how to say it and I didn't know what was wrong' and that, and learning gives them the confidence to say 'actually I don't think we should be doing it like this because x y and z' so that's why I think stories help because it enables people to bring learning right into their own experience and from there you can travel a very long way.