

No Limits – Edited Interview Transcripts

Shirley (Carer)

No Limits helps us, as carers, to know that special time that we call 'me time'.

My husband has got Alzheimers and is now in a home, but I'm still classed as a carer. I was asked if I wanted to come to No Limits to learn the computer, and I thought it'd be a marvellous idea because it'd let me into this world. I've enjoyed it. The social side of it is really good because it makes you feel more of a person and not ostracised when you're caring for someone. You feel alone when you're doing that all of the time. It gets you out of your situation and into life, I think.

Me time is very important. Like I said, you feel as if you're on your own when you're a carer. You're doing that 24/7 and it's hard. You need time out. I believe that No Limits has done a wonderful job – it enables us to be a person.

My husband used to wander. You'd lose him for several hours, and he'd disappear all over Yeovil. You'd really be panicking. Eventually, because he got aggressive, they took him into the home.

No Limits is different to other services as there's more get up and go here. There's computers and other things besides. I think that it builds your confidence, which you lose when you're caring. I used to think 'Oh, there's my life. It's gone down round the corner'. You're out of touch with everything. No Limits is a bolt hold for you to get to.

The open day was lovely. We laughed constantly. It's heartbreaking that a few strangers didn't come in because we know the benefits of it.

When I first started caring, it was a lonely process. Then, gradually, I found out things. I learnt a lot after my husband went into a home, and I say I wish I'd have known that earlier. Other carers are missing out on such a lot. I think they don't get involved in things, and then they're on their own. I don't know where you can spread the word, but we have talked about putting leaflets in doctors surgeries and libraries.

Hazel (Carer)

I come to No Limits for 'me time', but also to keep up with computers and live in this generation where everything is computerised. To hopefully ... well ... fit in.

I'm not an official carer. I don't know if I let my hair down, one day to somebody who passed on the information. I got a telephone call from No Limits asking if I would like to join the group. I can along and found out it was perfect for me because it gives me 'me time' and I can also use the computers to save time. I use this extra time in the house and the home, which I virtually run along now because of my husband's heart condition.

I enjoy the social side of coming to No Limits. We laugh a lot, and that's good. When we go out, after a session with No Limits, we feel good. We totally forget our situation when we're here.

Just before I left home, I wanted to say goodbye to my husband. I called out 'Bye John' and there was no reply. So I start searching around the house. I try the toilets, and then I went in to the garage. He wasn't anywhere, and I was thinking 'where can I go next?'. And I'm calling out, and getting a little bit agitated and tight. Then suddenly a voice came in from around the sideway, and he'd gone there to do something. When a carer you're working on strings all the time, and they're tight. When you come here the strings all slack off.

I feel that I never thought of myself as a carer. The first day I came here, someone said to me 'are you a carer?' and I thought 'where am I? I'm in the wrong place. I'm not a carer!'. Then, after I'd been here for a while I wondered who I'd let my hair down to and said that maybe things were getting on top of me a bit. I got that telephone call out of the blue, and I wouldn't be here now if that hadn't happened. I had no idea that anything like this existed. So I think that even recognising yourself in the position you hold is difficult. Somebody somewhere should say, when your husband goes into hospital, 'how do you manage?'. I'm not grumbling about the hospital, they've been wonderful, but I don't know how you find out that you're a carer in my position.

I went to the day conference. They gave us a programme for balancing our caring with our life. Instead of putting of your eggs in one basket and just trying to be a carer, you balance the scales with other things. I must admit that when I sat down and saw the scales I thought 'oh I've got an awful lot of things that side', but when he finished he told me that that side should have things in it. He made me feel that I wasn't being selfish. It made me feel less greedy. There are other things I might want to do, and I sometimes think 'oh, maybe I shouldn't go'. This made me feel that yes, I should go.

I like the mechanism that they use here. I have been to computer classes before, and they were all for people who were going back to work or going into business. They wanted you to type out a whole page and swap the setting around. Well, I've never worked in the office and I'd never touched a keyboard. I used to get two or three paragraphs done and the rest of the class had already done the next piece. I got left behind and found that I wasn't gaining anything. Here, we work at our own pace. I did the first course with headphones on and at the end of six weeks I had it off perfectly. I could do all the tests and I even did the tests again to get the score better. That was wonderful for me, to be left to my own speed rather than trying to keep up with a class of people much younger than myself, that were going in a different direction to myself.

I think there needs to be a plan, somehow, to make a loudspeaker of some description to let people know what's going on. I don't who can do this as the welfare people have enough to do, and the hospitals have enough to do.

Jackie (Carer and Carers Assessment Worker)

I'm a carer, and I'm also a carers assessment worker in the mental health field. I visit carers to assess their needs that are not being met, and try to develop resources to meet these needs.

No Limits, to me, has been a safe place to be able to come to know. You know that they're not judging you. They are encouraging, and offer lots of training options that are not beyond people's thoughts, capabilities or potential.

I understood that Denise and Sam were opening up a No Limits project around carers needs. We ending up calling it the Carer's Hub. They invited carers to come along and have a voice, and also offered a lot of training. I felt it was a very valuable resource, and introduced carers to it. I tried to get my carers to go to college, or on a computer course, but they felt quite intimidated with regards to the college and the process of the computer courses. Whereas here they come and feel comfortable. It's not an a, b, c, d course. They will show you what you want to know.

No Limits doesn't feel as if it's statutory. It feels comfortable, friendly and safe. It doesn't feel as if it's targeting, like some other places do. Even if only four people want to do something, they will try their utmost to do it.

I've accessed the City and Guilds Learning for Living course, and I'm doing that as a pilot for myself to sell it to other carers. As I'm not a technical minded person, I feel that if I can do it anybody can do it. Going through that course has given me a lot of confidence and a lot of insight into my skills that I didn't really have before. To put it in perspective, I was looking at

the course papers last night and I was reading some of the stuff I put on paper and I started crying. My husband says 'what's this about?'

(more to come)

Maya (Carer)

(first part of interview still to come)

No Limits is giving me three things. First – freedom. Second thing – knowledge. Third thing – encouragement to do the things I want to do.

Since daughter hasn't been well since 1995. She's since married and had the children (they are now 7 and 8) and I've been looking after them. Social services, they all knew it but no one ever supported me or asked me what my need was. I didn't really know what I needed, and what I could have asked from anyone else. Now I realise that I never had any support from any side, and I'm feeling cross. Now when I'm talking, I don't stop. My feelings are coming out and I'm thinking if I had all those things perhaps it would not have been so bad.

Through No Limits, I'm learning how much I should have had in the past. I am cross about those people who should be giving me support. They knew I was a carer and they all knew I was looking after two babies. Social services wanted to give my daughter help, but she wasn't ready. They were making her do this and that, but because she was ill she wasn't able to keep up some appointments. I didn't know about these. If I had a little knowledge, and someone communicated with me, I would be supporting her that way. To me, they wasted a lot of money.

Social services switch off from me. They are only dealing with my daughter because their job was with her. They don't realise that I am the one caring for her.

We had a meeting in Bath, with the national health people, and asked them questions. I tried to tell them this. That the Carers Network have supported me, and they took me for a few days away for respite. If the doctors understood, it would not be so hard for me.

English is not my first language. I learnt English in school. I did try to go, a few times, to college to do things. I started a few courses in a community project. I had to stop because my daughter was ill. I started another course, but I had to stop because my son-in-law was ill. These things stop me doing whatever I want to do.

But at No Limits I am doing it at my own pace. I do not have to do certain times. If I am not able to come I tell them. They don't mind.

I think the people here, they care for you. It's the caring. I think that sort of caring, I haven't had it before. Understanding.

Denise (Project Manager)

No Limits is about listening to carers, and responding to their needs. It's about giving them a voice,

I think that we have been really successful in overcoming the barriers. We are a small organisation, working against the odds. Initially we were on the outside trying to make a difference. We have worked hard to gain acceptance and acknowledgement of what we are doing.

We have developed an employers pack, which contains a job description for true carers representation. It's a knowledge pack, and it enables carers to come to the table as equals.

We ran a 6 week Christmas card making class. It sounds simplistic, but so many people signed up to it. It's important that people don't have to come to us to talk about caring. They can escape for a while.

We won an award for 'Opening Doors To Adult Learning', for working with people that are 'hard to reach'. A number of our group have achieved a level 2 qualification.

We joined the Skills For Care project late, in the last year of the pilot site funding, and were awarded 2 years of continuation funding. At the end of the first years our project changed dramatically. We initially were about Somerset carers having a voice, but didn't choose our words well and felt blocked by others. So we continued to work, but needed to communicate. We produced some work, and people thought 'wow'.

We consulted with Somerset Carers, asking them what gaps they had in their support. They wanted their own website, but unfortunately this didn't happen. They wanted a crisis worker and a helpline, but there weren't the resources for it. No one else was listening.

When we got continuation funding, we sat down with Skills For Care and discussed where we were at with the project.

We interviewed Carers Representatives and asked them 'How did you get here?', and 'What support do you get?'. We found that they no support in their role, and that they mostly represent themselves. In consultation with stakeholders (carers, managers etc) we came up with the idea of True Carers Representation. This is similar to a union representative, needing proper infrastructure. The employers pack should properly induct the carer to their role (including information on policies).

We hold quite a lot of events (not meetings). We hosted a large conference (of 80 people) to start to work up what was needed to be a carers representative. It involved a good range of stakeholders, including carers, service users, carers workers and senior managers. We wrote a report about whatever that audience said. They said what was needed was to develop True Representation. We then put together a skeleton job description.

We ran café style workshops to develop the job description and person specifications.

We developed a training pack and knowledge set, which takes people through the skills they develop (including communication, confidentiality and report writing). All carers in this training have a personal development file. We ran this from 11 – 3pm to flexible to carers needs.

For example, a retired judge didn't need carers training, but wanted to learn how to use PowerPoint. It's about identifying needs and identifying learning opportunities. It's about finding ways to give carers and equal platform.

Initially we tried to reach out directly to carers to give them a true voice, bypassing workers. Now, in hindsight, I would have explained more about what were doing with workers.

We tried hard to reach other employers outside of Health & Social Care. We ran breakfast mornings and awareness-raising sessions, but these didn't truly achieve what we wanted them to. We did get some people, and raise some awareness but ...

No Limits started the Carers Training Network. We still don't know how to reach unknown carers. To me it's tragic, and shows there's another piece of work to be done. We could try raising awareness with milkmen and postmen, to reach people before their loved one is admitted into residential care. How do you ask the right questions? It's only the tip of the iceberg.

Before starting this job, I didn't realise how passionate I would feel about carers' rights.