

Dementia Carer Voices - What Matters to You Case Studies and Podcasts

Leanne Patrick, Student Nurse and Carer



Leanne is a first year mental health student nurse at Stirling University. Leanne and her partner are carers for their four year old daughter, Ella, who has autism. Listen to [Leanne's interview](#) with DCV Project Engagement Lead, Tommy Whitelaw, talking about her experience as a mother and carer navigating the health and social care system.

What Matters to Leanne and Ella?

When people see Ella as a sweet little four year old who loves princess dresses, dancing and music, and are able to see past the days when she isn't at her best and struggling. It's about seeing the value of the person, regardless of any condition they have.



Lorraine McGreevy, Carer



What Matters?

My family and friends matter to me, I love to read and can lose myself in a good book. We both love the garden and when Jimmy is having a good day we enjoy being there, we've passed this love on to our two granddaughters who both love being in the garden with us. We both love to go for walks but over the last couple of years we have not been able get out much as we like as Jimmy's illness has stopped this, but through it all Jimmy has a great sense of humor and we laugh a lot.

I go the art group and the craft group in the Carers Centre, I'm quite good at art and enjoy this. The Carers Centre has been a great asset for me over the years. I've been coming here since 1998. They have been a great source of strength for me, strength from staff and from the other carers who come here. The peer support has been essential for me, and has helped me to cope over the years. The Carers Centre provides emotional support, someone to talk to, and no judgement.

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Who Matters?

My husband, who is my soul mate, our three children, and two grandchildren. My husband proposed to me after 6 weeks, and we were married after 10 months. We recently celebrated our 34th wedding anniversary.

Jimmy has been diagnosed with several long term conditions, and I grieve for the man I married, and the life we had planned to share. I like to put up a strong front and I'm good at hiding the grief.

He does have good days and I'm reminded of the man I fell in love with, and with the support of my children, we have survived and we're still here. Despite all the hardships we've faced, I can honestly say we're still very much in love and that we're happy.

What Information do you need?

We moved to Scotland before we knew Jimmy was ill. It meant that I was removed from my family and friends when I needed them the most, had I known I wouldn't have moved. That's when I learnt the value of peer support.

I know I can come to the carers centre and get support, and when I'm having a really bad day they're only a phone call away. I don't feel like I can talk to Jimmy about how I feel because he already thinks he's let me down. I do get frustrated with his illness, but it's not his fault.

It's important to know that it's ok to be frustrated, and that took me years to realise. My GP has been great at helping ease that guilt, and I know I can talk to my GP for support when I need it.

Janice Dunn



We spoke to Janice at the South Ayrshire's Carer Centre, where she told us what matters to her, and her husband. Find out [what matters to her and George](#), in her own words.

What Matters?

Living with a progressive life limiting illness can be overwhelming, especially being a wife, mother and grandmother.

Sometimes my physical health impacts on my mental wellbeing when I worry about further down the road of my journey. How much I will miss my family, how will they cope without me, as I have always looked after their wellbeing, caring for them. I do take comfort in knowing that I have a very caring husband.

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As part of my home management I had to learn to pace myself, with my husband's encouragement these past years I am learning to see the positives, glass half full, live in the moment, and not put too much emphasis on the things I can no longer do.

I still like to take pride in my appearance, initially after my diagnosis I started to constantly wear sweatpants, then I thought this is not me. I can still dress for comfort and ease but not necessarily leisure wear. This helps me still be me, and I feel it is important to keep that identity.

I still enjoy listening to music, this helps me to relax, lift my mood, evoking lots of feel good memories. I like keeping in touch with friends, I try to keep smiling through the pain whilst making memories for my family in the process

Who Matters?

My family matter to me. I have been married for 33 years to my husband George, we met in our teens. We have two sons, plus three grandchildren. Stephen who is in his thirties and Ryan, who is nearly 16.

Ryan has autism, he is also registered partially sighted. Ryan's autism plus sensory difficulties impact on our lives, coupled with my own deteriorating health, diagnosed with COPD in my early forties, 8 years ago and then just over 2 years ago a further diagnosis of Fibromyalgia.

As I was once Ryan's main carer, the dynamic of our family has changed significantly, almost a role reversal. George has devoted his time to supporting me, plus caring for our son making sure his needs are continually being met to help him reach his potential. Nothing is too much trouble for him, this leaves him very little time for himself.

Although I love my husband dearly, I found asking for help difficult to deal with. Suddenly being the one in need of care and assistance, this hits you hard, more so when I need personal care. Both my conditions render me to easily become quite breathless and fatigued. I suffer from frequent exacerbations. My husband does his best to make me feel comfortable.

What Information do you need?

After initial diagnosis, the information I received was to help living with a long-term condition. My GP arranged for me to go on a 'co-creating health home management course'. I found this very useful for the early stages. As my disease has progressed with a continual decrease in lung function with poor reversibility I feel more information is needed with regard to possible difficult decisions that as a family we may face in the future; for example, if my husband would have access to support him to be able to care for me as long as possible at home whilst keeping me comfortable, advice on controlling my breathlessness, easing my symptoms and appropriate pain management.

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Unfortunately, I have read that for Chronic Obstructive Pulmonary Disease patients, would be less likely to be able to benefit from Palliative care due to the Trajectory and nature of the disease on each person individually.

Agnes Houston, MBE



Agnes [tells us](#) what matters to her and who matters.

What Matters to You?

I think peer support is everything. But the right peer support for the right people. That's why the alumni group is really good because we've all had a diagnosis for a long time, and we want to work with people with dementia who are recently diagnosed. We love doing it, it gives us a feeling of purpose because we've lost our job and we've got something to give, and if you give something back it makes you feel good.

It's also about peer support for the right people at the right time-and people will know what is right for them, because they talk with their feet. When I'm seeking peer support it's to enable me, and to get help and move forward. I don't want to go every second Monday and talk over the same old. I don't like the idea that dementia is being herded into ghettos like dementia cafes and things like that, I think it's appropriate for some people but it's certainly not for me. If I want a cup of coffee, I will go to a cafe. I have friends and they don't have dementia, and we meet at the gym. So don't think that a dementia cafe ticks everybody's box, it doesn't work that way.

Who matters to you?

My daughter Donna and my husband. Donna and I have always had a good relationship, and we've always been a mother-and-daughter type, but now dementia has taken that away. I'm often saying to her 'we need to have some time to ourselves', but unfortunately I live with dementia 24/7, I cannot wake up and say, 'today I'm not having dementia because I'm going to have mother-daughter time', so it affects everything. So how can you help it? You can't ban it from your life because it is what it is, and nobody thinks to appreciate that- and that is a tremendous loss. I think sometimes 'if only it was cancer we could possibly get counselling', we can get a nurse that would support us through our issues, but it's not there at the moment for us.

What information do you need?

I definitely think getting the message across that dementia is more than memory, dementia can and may bring about sensory challenges – where are you going to get help? what do you do?

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Sometimes you think everybody else is coping and you're the only one that isn't, so what's wrong with you? But when you go on Facebook or something like that, and someone says, 'I've had a bad day, and I just screamed in the toilet' and you think, 'Oh that's ok then.' It's permission to have somewhere to go and express your feelings that everything is not rosy and happy clappy. That's normal, they're ups and downs and I think that's why meeting with the alumni helps, we talk about our stories and the ALLIANCE allows you to tell the honest story. We don't want to reduce people to tears but you know, this is life. This is life with dementia, and I fall, and I have many hurts, and I cry, and what have you – that doesn't mean to say that I'm not living as well as I can. I do live as well as I can, but it's not blue sky all the way.

Donna Houston

What Matters to You?

I actively campaign as an unpaid carer. Although I don't think I've gotten to the point where I say 'my name is Donna, and I'm a carer' but when I'm campaigning I feel it's very important. If you're getting paid for something you're considered a valued member of society, but what I've seen and heard from other carers is if you give up your job, people ask 'what have you been doing? Why is there a gap in your CV?', and you reply, 'I cared for my mum' to which the response is 'but what else were you doing?' as if it had no value at all! That's why I emphasize 'unpaid care' because I don't think it is valued. The government knows that if we stopped, the world would grind to a halt. But they know we wouldn't do that because we love the person, and we care, you're a hostage to your heart. It's a bit of my identity, but you do have to try and have a life out with that.

Who matters to you?

My mum and dad. My mum has dementia, of the early onset Alzheimer's type, and about six years ago my dad was diagnosed with mixed vascular and Alzheimer's.

I struggled with the label 'unpaid carer' because it was just an extension of looking after my parents. I only recently thought of it as a caring role, as the caring aspect got bigger and things like just meeting mum for a coffee, grew to me considering if it would be suitable for mum, like 'is it a quiet place for a coffee, is there any obstacles because of her sensory problems?' that kind of thing. Caring for my parents had reached a level that it started to impact my job. I realised that I couldn't make a decision without considering my mum and dad's schedule. It all has to balance, if someone says, 'Can you do this for me?', I can't just say yes or no, I had to think what am I doing in relation to my parents.

What information do you need?

I haven't had any kind of formal support. There are places like dementia cafes, but it's not quite right for me. I would prefer one-on-one support. There are a couple of helplines, but I feel my problems aren't serious enough to call them. I would like a place where I can have a wee moan, where the service isn't for people who are in

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crisis, but I can talk about things like time management and logistics. That's the stressful part, the dementia is what it is, and mum and dad are doing as well as they can but it's just the logistics.

I would like to be able to stay anonymous, but that can be hard because of a lot of people know my mum, so there's that aspect of feeling disloyal. I just need a bit of a rant or a moan, to get it off my chest, because you are trying to present a happy face to the world. People don't see the negative side of what you're feeling and for someone to actually turn around and say, 'actually they're normal, it's normal to feel sad, it's normal to feel down' would be incredibly helpful and reassuring. You need someone to talk to, so that you can then pick yourself back up and start again the next day.

Listen to [Donna and Agnes](#) talk about what matters to them and their experiences of living with dementia.

Paula Smart, Carewatch Care Services



What Matters to You?

When I first started working at Carewatch as a carer I thought it was just home help and after going on a couple of calls I found I loved it, and by the end of the week it didn't feel like a job. I've always worked with people but not in that capacity, and I think that's what I liked, going into their home environment and how I could make a difference, and how something that we take for granted will help that person maintain their independence and stay in their own surroundings. That's why I still like going out and doing care now.

You do have to have a passion to want to care, it's not a job to just tide you over until you find what you want to do. There are people who are apprehensive and nervous when they first start, but I've got a gut feeling that they're going to be great, and they turn out to be fantastic. I've got a lot of care staff who say 'I wish I did this years ago!'

Who matters to you?

Well, I've got a family. I've got three children, two dogs, and I live with my long term partner who I've been with for over 25 years. I've worked with Carewatch for the last 14 years. I was a care worker for over 6 years in my local community, and then a training position came up which I've now been in for 8 years. My role has expanded quite a lot and probably I've felt it's something I've been able to do as my children got a bit older.

What information do you need?

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My role in the training and development team at Carewatch means I'm responsible for making sure all the care staff are trained, from new staff members to supervisors. It's important that we educate them to have an understanding of different conditions, and we work with lots of other agencies to make sure care staff have that knowledge. I still go and care myself because I feel it's the best way to know what I'm talking about when delivering training. But really the best people to tell you if the training is working are the people who receive our care, so it's important to find out what we're maybe not doing enough of, what we could do more of, and what we're doing well.

I remember when I first started working as a carer I didn't have any dementia training and at that point I didn't have anyone in my family that had dementia so I had very little understanding about what dementia was. I was very naïve, and remember going to see one lady, and she thought she knew me and that we were the same age. I didn't understand this, I managed the call fine but it frightened me a wee bit, and I think if I'd just had a bit of training on the different types of dementia, and how it can affect people I would have felt more comfortable, and could have made her feel more comfortable. I kept calm and blethered away to her like I do with everyone, and found out who she was. Maybe that was the best thing I could have done, but maybe in hindsight I would have gone in more relaxed if I'd known more about dementia. All those years ago there wasn't the same training as there is now, which is another reason why I enjoy the training that I do.

Listen to a [podcast of Paula](#) talking about what matters to her.

Suzy Webster

What matters to You?

That we can be supported to care for Mum at home for as long as possible.

Who matters to you?

My family taking a team approach to dementia care, and my friends who give me the respite I need.

Watch and find out what matters to [Suzy](#).

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Rogelio Arellano



Read what Rogelio of [Mindmate](#) has to say!

What Matters to You?

When I was growing up I always wanted to create something of my own, I had so many ideas and I wanted to make something that would help people. That's why I applied for a masters in Innovation Management at Strathclyde, so I could learn how to make an idea into something that would help people. Now I'm the CTO of Mindmate, an app which helps people living with dementia and their carers to live well.

Who matters to you?

My family, my grandparents were both very social people, they were always bringing people together, like at Christmas time. Christmas was the best time of the year because everyone gathered together and my grandparents made such a homely environment with all of my cousins and uncles, we all had nice time and good food. The day after Christmas we would get together again and it was a very warm environment. I have so many good memories with my grandparents.

When my grandad was diagnosed with Alzheimer's we pulled together as a family to care for him. He was very smart, he was a mining engineer and he always carried a calculator in his pocket. Sometimes I would take out pictures and we'd look at them together and he would tell me stories about them.

He had good days when we went to the cinema on the weekend. We'd drive into the city and my grandad would remember streets and start telling us stories because he recognised the outside environment. He really liked going to the movies and by the time we got home we had forgotten about the dementia, he had a smile on his face and would talk about the movie we had watched.

What information do you need?

It didn't occur to us to get outside help because we thought it was the family's responsibility to look after each other. In hindsight, getting extra support could have helped me prepare, and know how to deal with situations when my grandad was upset or confused.

I don't think Grandad understood what was happening to him. I think that he was living in a world where he was with us, but would also travel back to the past. He would never talk about it and just got on with his daily routine. He liked to garden so he was constantly outside doing stuff and he would go for walks around the house. I don't think he realised that at some point he would have no memories.

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I think that if I had known what was going to happen, I would have tried to do more of the things that my grandad liked and to be more open to getting advice from other people who have gone through this. I would have liked to have done more activities with him that he enjoyed, to have shared more moments with him- that would have been much better for myself.

Listen to a podcast of [Roger](#) talking about what matters to him.

James and his wife Maureen have taken part in our case studies, find out matters to them. [Listen](#) to what they have to tell us.

Read what Maureen and James have to say:

James McKillop

What Matters to You

Having a sense of humour is important to me. I've noticed people with a sense of humour seem to do better, whereas dour faces seem to deteriorate.

Being able to participate in society matters to me. Having the confidence to give presentations was something I didn't have before, but now I've travelled to places like Japan, Denmark, Beirut, Dominican Republic, Italy and all over the UK to talk about my experiences. It's important not to give up hope, you've got realise there's things that you can't do in your life any longer, maybe driving, but don't dwell on those. Dwell on what you can still do and enhance them. If there's something you've always wanted to do on your bucket list go ahead and do it.

You can still have a life after dementia, it's a different life, but if you've got the right attitude, you'll still enjoy life.

Who matters to you?

Maureen my wife and our four children. Maureen is my carer but I've got to watch what I do, I'm her carer in a way. I can hear warning bells and if I do know something is going to upset her or cause her alarm I try to be careful what I do. I made sure to buy her a valentine's day card!

What information do you need?

There was very little information available when I was diagnosed with dementia in 1999 when you were ushered out of the door and left to get on with it. Now people are more aware of dementia, there's more booklets and information around and in Scotland you get post-diagnosis support, but only if you live in an area where there's a trained LINK worker so it's a bit of postcode lottery.

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Usually when dementia comes knocking on the door and there's a couple, there's a reversal of the roles, whether its male or female. Whoever did the banking and made the financial decisions the other partner now has to take that on. We still discuss things and Maureen involves me in decisions. Any stimulation to keep my brain cells working, all the help I get is from Maureen, and from the stimulation of participating.

Maureen McKillop

What Matters to You?

I'm very involved in my church and I do a lot of things there, I've got a lot of good friends in the church. My husband James, who has vascular dementia, has now started joining in activities at the church although he doesn't attend services. He joins us for coffee and biscuits after the service and everyone is pleased to see him. We have Christmas fetes and all sorts of functions that he helps with.

I also go out with friends from church for a meal, we go out to the theatre quite often to see shows. I think it's important to maintain a balance of things that are just for you, for your own sanity.

Dementia is not the first thing I think of when I wake up in the morning, we're just ordinary people getting on with our lives and yes, he forgets things, he loses things, but it doesn't bother me the way it used to.

Who matters to you?

My family matter to me. My husband James, and our 4 children. When James was awarded with an MBE in 2011 for his voluntary work for people in Scotland with dementia, that was a real defining moment for me. It shows that life isn't over just because you get a diagnosis of dementia, you keep going and you can still do things

What information do you need?

When James began getting support I began to feel better myself. When he comes home now he's in a much better place which makes life a lot easier for me. Getting that help early helped us get into the position we are in now where I don't feel I need formal support. That's not to say I won't need it again in the future but for now I know we're alright.

As I was told at my carers' support group, you're human, it's alright to get angry. You can still get angry, just because your loved one has dementia. You've got to learn to live with dementia as well. It takes an awful long time to learn not to get angry all the time, that he's not doing it on purpose, it's things that he can't help. Dementia has made me a more compassionate and tolerant person.

For people who find it hard, especially for married couples, before James had a diagnosis we had hit rock bottom-we were at the point of divorce. When we found out he had dementia, that started to change my attitude to 'right he's not well, so how I need to deal with this?', and I think that's mainly what helped us through it, and just

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taking every day as it came, every day was a new day and just, trying to get on with it as best you can.

Listen to a podcast with [James and Maureen](#), discussing their experiences:

Tommy Whitelaw, UK Lead for Dementia Carer Voices



On the 6th June 2016, on National What Matters to You, we asked Dementia Carer Voices' UK Lead, Tommy Whitelaw, [to share his thoughts.](#)