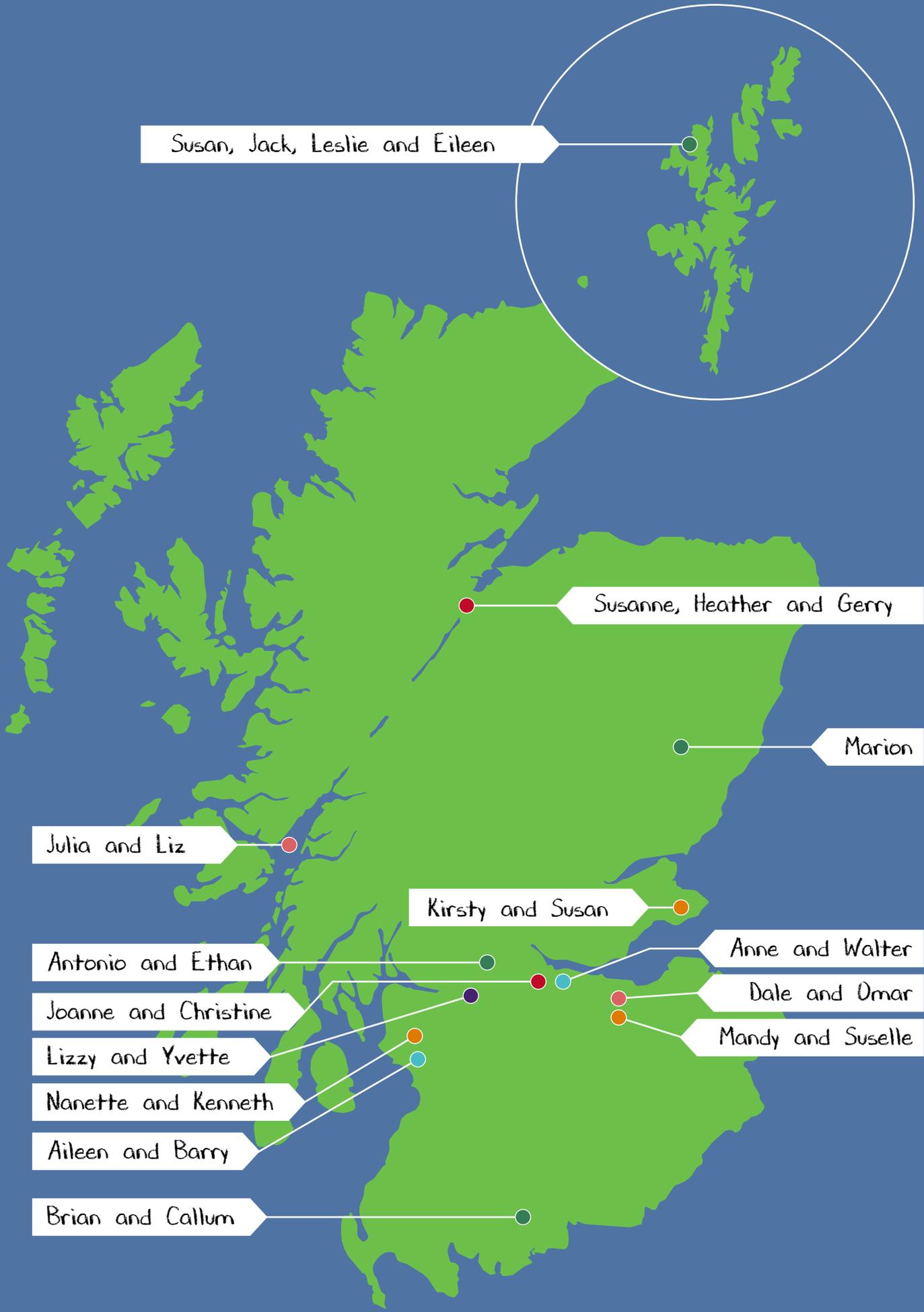




PAssport to Independent Living

Self-directed Support - our lives, our choices





Susan, Jack, Leslie and Eileen



Susanne, Heather and Gerry

Marion

Julia and Liz

Kirsty and Susan

Anne and Walter

Antonio and Ethan

Dale and Omar

Joanne and Christine

Mandy and Suselle

Lizzy and Yvette

Nanette and Kenneth

Aileen and Barry

Brian and Callum

Contents

Foreword.....	Page 4
What is SDS?.....	Page 5
Dale and Omar's story.....	Pages 6 - 9
Lizzy and Yvette's story	Pages 10 - 13
Mandy and Suselle's story	Pages 14 - 17
Brian and Callum's story	Pages 18 - 21
Susanne, Heather and Gerry's story	Pages 22 - 25
Susan, Jack, Leslie and Eileen's story	Pages 26 - 29
Aileen and Barry's story	Pages 30 - 33
Personal Assistant FAQ	Pages 34 - 35
Network & Open Badges	Pages 36 - 37
Nanette and Kenneth's story.....	Pages 38 - 41
Julia and Liz's story	Pages 42 - 45
Anne and Walter's story.....	Pages 46 - 49
Antonio and Ethan's story.....	Pages 50 - 53
Kirsty and Susan's story	Pages 54 - 57
Marion's story.....	Pages 58 - 61
Joanne and Christine's story.....	Pages 62 - 65
Acknowledgements.....	Pages 66 - 67



This collection of stories shines a light on a very special partnership. The relationship between a personal assistant and the person they support can take a thousand different forms, but at the heart of each is dignity, respect and collaboration.

Foreword

A PA can be a friend, a colleague, a helping hand – someone to enjoy things with, and help people achieve the things that matter to them.

This partnership goes both ways and personal assistants themselves find huge satisfaction in their work. The role is flexible, varied and every day is different – as you can see from the wide range of stories in this book. All the PAs featured here are enormously enthusiastic about their job and the difference they are making, day in and day out, to their employer.

Being supported by a PA enabled Suselle to travel the world; Barry to write published books; Walter to give back to his community, and many others to work, study and live in the way that suits them best.

This flexibility and focus on what is important to the person being supported is how we in Scotland have chosen to implement social care. It's called Self-directed Support, and it means that care and support fit around the person and the outcomes they have agreed with their social worker.

The PAs and supported people featured in these stories come from many different backgrounds and previous working lives, and I thank them for sharing their words in this way.

Aileen Campbell
Minister for Public Health and Sport

What is Self-directed Support?

“Self-directed Support enables people who are eligible for Social Work Services, to direct their support and to have an informed choice about how their support is provided.” <http://selfdirectedsupportscotland.org.uk>

Self-directed Support gives people the right to decide how much choice, control and responsibility they wish to take over their support arrangements.

People in receipt of Self-directed Support receive an individual budget. This budget is used to purchase the support they require. The Social Care (Self-directed Support) (Scotland) Act 2013 offers people the choice of four options as to how the support can be purchased and delivered.

1 A Direct Payment

The individual budget will be given to the person (or person authorised to act on their behalf) and they can purchase the service they need from a service provider or directly employ a personal assistant (PA).

2 An Individual Service Fund

The person can choose a service provider to provide their support and the local authority will arrange and pay for the service using the person's individual budget.

3 Service arranged by the Local Authority

The local authority will choose, arrange and pay for the services required, using the person's individual budget.

4 "Mix and Match"

The person can choose a combination of the options above.

Employing a Personal Assistant (PA)

If a person wishes to employ a PA then they must choose Option 1: A Direct Payment. Therefore if you are currently a PA or are in the process of being employed as a PA, your salary will be paid using your employer's Direct Payment.

Dale and Omar's Story



Dale (PA): In 2006, I had just completed a degree in sports coaching and was looking for a part time job to tide me over for a couple of months, when I saw Omar's advert. Ten years later, I'm still here!

I started working for Omar when he was a student at Edinburgh Napier University. I had no experience of supporting someone with a disability, but I did know what it was like to be at college – both the pressures and the social life!

□ Omar (PA Employer): Until university, my family had provided all my support so I had lived a rather sheltered life. When I was preparing to leave school there was no information available so I did not realise that I could receive practical support with my studies. During my first year at university, my mum had to attend with me to scribe. Although I have a warm relationship with my family and greatly appreciate their support, I wanted to be more independent and embrace all aspects of university life.

Things changed when I met the university disability adviser who helped me to apply for a grant from the Students Awards Agency for Scotland (SAAS) to employ someone. I was a bit nervous about employing someone and it took a while for me to arrange the interview with Dale, but we hit it off right away - over football!

"I value
being able to
support Omar
to live his
life as he
chooses"

Dale - PA



Seriously, I felt at ease with Dale as we were of a similar age and had the same outlook on life – sometimes you just have to go on instinct. By the time I started third year, Dale was working for me.

The SAAS grant covered the specific practical support with my studies, but I needed general support at other times too. The adviser had also told me about the Lothian Centre for Inclusive Living (LCIL) so I contacted them and with their help, I applied for Self-directed Support. I chose a direct payment because I wanted to be in control of my support and I used the direct payment to increase Dale's hours.

 Dale: On a day to day basis I support Omar with personal care, general domestic stuff, shopping, bill paying, etc. He employs a second PA for evenings and weekends. When I first started, Omar told me that when he was at school he received regular physiotherapy which had greatly helped his mobility. When the service ended, Omar's condition deteriorated and he was forced to use his wheelchair all the time. Due to the knowledge gained on my degree course, I was confident about developing exercise programmes for Omar, in conjunction with advice from a physiotherapist, and these are now part of our daily routine. As a result, Omar can now walk short distances around his home with support.



"Trust and
communication"

Omar - PA Employer

Omar: My first contact with LCIL was in 2006 to seek assistance. Now, 11 years later, I work there part time as an Independent Living Officer, providing others with the type of assistance that I received. Dale couldn't drive when he started working for me, but he took lessons, passed his test and now he drives me to and from work. Dale also assists me to travel to home visits, conduct PA training sessions and to carry out admin tasks, all related to my job - he is my 'hands' at work. In 2014, I moved into my own home. This was a huge transition for both me and my family. My parents were very supportive, but I know this was primarily because they have such trust in Dale's abilities and commitment.

Having PAs has literally changed my life. For me the two key words related

to working effectively with a PA are 'trust' and 'communication.' After ten years I would describe us as 'best mates' and we have a really close relationship. We do a lot of social things on my days off, from time to time I spend time with Dale's wife and children, and Dale spends time with my family. This kind of relationship may not suit everyone, but the reason it works is because Dale "gets it," as they say. I don't have to 'remind' him that I am the employer because we have a deep mutual trust and I know that he understands the PA/PA employer relationship through the quality of support he provides and by the way he respects my wishes - even if he doesn't always agree!

Dale: No two days are the same working with Omar and that variety is one of the things I enjoy most about being a PA. I also enjoy working and building a relationship with one person and I value being able to support Omar to live his life as he chooses. I get a great deal of satisfaction from that. It's not all plain sailing of course, there is the occasional 'niggle' but we don't let it fester. As Omar says, good communication is the key and I can honestly say we have hardly had a cross word in ten years. When I first started work with Omar, I must be honest and say that I felt reticent about how to relate to him, as I did not wish to inadvertently cause offence. However on one of my first days I heard him enjoying a joke with one of the university janitors, so I think the banter started from that moment!



Lizzy and Yvette's Story

Yvette (PA employer):

I am mum to six children, three of whom still live at home. My youngest two children, Anthony, 11 years and Kieren, 10 years, both have autism, but that is where the similarities end. They have very different personalities with very different needs.

My other son, Terrence, also has an impairment so family life can be exhausting and challenging.

I was not offered any support after the boys were first diagnosed so life was very difficult. Even something as simple as getting all the children ready and out to local nursery or to meet the school bus was a bit of a nightmare, particularly as Anthony and Kieren have no road sense and can run very quickly without warning. I couldn't chase after one and leave the others unattended! Also in the home the boys require very different strategies to keep them calm and Terrence, who has less complex needs, was becoming 'invisible' and was not receiving the attention he deserved.

Eventually, thanks to a very helpful local authority worker and after reading a booklet about Glasgow Centre for Inclusive Living's services, I applied for Self-directed Support and was awarded a direct payment for both Anthony and Kieren.

□ Lizzy (PA for Anthony): For the past nine years I have worked as a pupil support assistant in the school that Anthony and Kieren attend. I work on a one-to-one basis with Kieren, Anthony's



younger brother, but socialise with Anthony at school events. Prior to working in the school I completed an SVQ3 and HNC in Social Care. I am currently studying for a BA in Childhood and Youth Development because I love the work I do and I am committed to acquiring more skills.

Yvette: I decided to place an advert for a PA in Anthony's school because I thought that perhaps the staff might know of a student teacher interested in some additional work. I wanted someone with experience of working with children, but also someone young and energetic: you need to be with Anthony!

Lizzy: Having chatted to Yvette, I decide to apply. I was keen to develop my skills and experience and as I was already working with Kieren, I believed I would be able to fit into the family dynamic and provide some

consistency for Anthony. I felt I could use my knowledge to support him in settings outwith the school. Yvette and I did have some concerns that seeing me in a certain role at school and then a different role at home would be confusing for Anthony. We agreed that before I started I would prepare a 'social story' using pictures and simple language to help Anthony to understand my different roles. This worked well and Anthony accepts me in my role as PA. I work with Anthony for some hours after school during the week and for a few hours at weekends. My role is to encourage and support Anthony to develop his social skills, and to be able to engage with people beyond his close family circle. Anthony can very easily become overwhelmed by his environment and this increases his anxiety so we keep things simple and straightforward and make sure he knows what to expect. I will offer him



"I enjoy seeing
the different
sides to Anthony"

Lizzy - PA

a choice of two options based on the activities he likes to do and he picks. He loves swimming, cycling, all things 'trains,' being outdoors, going to the cinema and he loves a pub lunch! When we go for lunch, instead of me ordering for both of us, I encourage Anthony to tell the staff member what he would like to order. He has a couple of favourite places so the regulars know him and will greet him with perhaps a 'hello' and a smile. I encourage Anthony to respond with a greeting. When we go swimming, I place his clothes in the order he needs to put them on, then leave him to dress himself. Sometimes he calls for help and I end up calling instructions from the next door cubicle while trying to get myself dressed as quickly as I can! Yes these are small steps, but Yvette is very aware of the need for Anthony to become more independent of his family at a pace he can cope with. I also support Anthony

with his bedtime routine to give Yvette time to focus on the other children.

Yvette: A PA has to have patience, understanding and a genuine interest in the wellbeing of the person they are working for. I am inviting a PA into our home and they have to possess the sensitivity to fit in with my family's life, but most of all there has to be good communication, mutual trust and respect. I welcome suggestions from Lizzy about new activities or strategies and we discuss key issues like setting boundaries, but she respects that the final decision lies with me. I also expect everyone concerned to take a consistent approach with Anthony.

Lizzy: I enjoy seeing the different sides to Anthony in school and at home and being able to support him to deal with the variety of situations he faces. I also enjoy seeing a positive



"I would be able to provide some consistency for Anthony"

Lizzy - PA

difference in the other members of the family now that I am here to share the responsibilities of supporting Anthony. Yvette has just appointed a PA for Kieren and she is going to shadow my work with Anthony as part of her induction.

Working in the school and as a PA while studying for a degree is a challenge, but Yvette is very flexible and supportive. Recently I was worried about completing my final essay of the year on time. Yvette gave me the evening off so that I could complete it. In turn I am happy to adjust my hours for special events or to support Anthony on family outings. It's about 'give and take' on both sides.

Yvette: If you are thinking of becoming a PA, just do it! Having a PA to share the responsibilities of supporting Anthony has improved the quality of life for everyone in my family,

particularly Anthony. By using a person centred approach a PA looks after his physical, emotional and social needs, encouraging his choices, independence and fulfilment. Life is completely different now and I could never go back to the way things were before.

"If you are thinking about becoming a PA, just do it!"

Lizzy - PA



Mandy and Suselle's Story

Mandy (PA): Why did I become a PA? That's an interesting story. I have been in a wide variety of jobs in my life. I worked on market stalls, also in a chicken hatchery, then with an Indian family in their clothes shops and latterly, a bus driver.

"Suselle had a great spirit of adventure"

Mandy - PA

When I was a bus driver, the terminus was in St Andrews Square, Edinburgh. There was a canteen, but the banter could be a bit wearing to say the least, so I used to go to another bus company lounge to have a quiet break. One day I spoke to a young woman who was in the lounge and seemed a bit lost. Heather turned out to be an American student who was spending some time in the UK. She was due to meet a friend, but her bus had arrived late. We had a great conversation without even telling each other our names and then I left to go back to work. At the end of my shift there was a note waiting for me from Heather asking to meet again for coffee (which we did) and what became an enduring friendship developed. It turned out she was working as a PA in London! Once, when visiting her we spent time socialising with other PAs and their employers and I really enjoyed the atmosphere and great stories. This was my introduction to the disability movement. That was 24 years ago and for the past 23 years (until she passed away in July 2016) I was PA to Suselle. But what happened to Heather? We are still friends, the young man Heather was meeting all those years ago is now her



husband and with their two children, they live in Oban!

Suselle was working as a social worker and living with her mother when I started working for her. I was trained both by Suselle and her mother in how to best assist her with various tasks. Suselle was a great communicator, enabling me to learn quickly. I assisted her with household tasks, personal support, driving her to and from work and attending meetings, appointments, and social events. It is so important that as a PA you fit into the person's life and in my case I had to consider Suselle's mother as well as it was her home and I had to respect that. Whilst they both agreed employing PAs was the best way forward for Suselle, there were some challenges. I had to become very aware of boundaries and that sometimes I had to be 'invisible,' for example if Suselle and her mum

were having a disagreement, it was not appropriate for me to express an opinion or get involved.

I quickly learned that Suselle was a very independent woman, her work was very important to her and she was someone who was passionate about and involved in many things. One example of this was being asked to talk to third year social work students on a few occasions. We did a sort of double act: Suselle talking about independent living from an employer's point of view, and me from a PA's perspective. I really enjoyed being part of these conversations and got a great deal of satisfaction from being able to contribute.

In 2000 Suselle's health deteriorated and she required constant ventilation. Her support package had to be increased to cover the additional support required, including previous



"If I had the last 23 years over again, I wouldn't change a thing"

Mandy - PA

sleepover support having to be changed to waking night cover. At this point she required more PAs and I assisted Suselle to organise appropriate training, rotas, holiday cover, and associated paperwork.

Suselle had a great spirit of adventure. Over the years we travelled to nearly all the countries of Europe, mostly by car, due to the fact of Suselle being ventilated and having to take so much equipment, although to be honest travelling by car meant that you got to see a lot more of the real country, something both Suselle and I enjoyed. We worked well as a team. Suselle would plan the trip, where she wanted to go, what she wanted to see and

the route we would take. My part was to make sure we had everything with us that we would need, which became more as the years went on and especially after Suselle required ventilation. In an ideal world Suselle would have taken two PAs because she knew that all the driving and assisting was a lot for one person, but her funding didn't incorporate holidays! Prior to one trip a travel guidebook told us that "St Petersburg was not advisable for even the hardest of disabled travellers." Well, we drove 4,000 miles around the Baltic states, including St Petersburg, in 27 days. As Suselle said "Not advisable? Definitely advisable in my book."

Suselle possessed all the qualities required to be a good employer and looking back I really appreciate that more and more. She was clear that she wanted to live her life, her way, but she was always considerate, thoughtful and respectful towards her staff. A PA's job can be isolating even if there is a team, as you tend to work different shifts, and you are a bit like ships passing in the night. Suselle would make the effort to arrange occasional social outings, for example an afternoon tea, to bring us all together for a chat and a catch up. One of the things I liked most about working for Suselle was simply appreciating the person that she was and how she led her life, her values, her faith and what she had achieved. I also enjoyed the variety of the job. Things were never mundane with Suselle! I was introduced to so many new activities, experiences and thoughts that I sometimes look back and wonder who actually got the most from our working relationship.

Spending so much time together obviously meant that we became very close while still respecting boundaries and acknowledging that Suselle was my boss. Inevitably in such a close relationship we 'had our moments' as most people do, but for the most part we always seemed to be able to resolve them relatively quickly. My three key words for a successful PA /PA employer relationship are communication, communication, communication.

Last summer, nearing the end of her life, Suselle was hospitalised. The hospital staff could not have been kinder. All her PAs continued to support Suselle in hospital, leaving the nurses to provide the medical care. We worked well together with respect for each others' roles.

Since Suselle's passing I have mourned the loss of an employer, a friend and a way of life. But I have also had to look for new work whilst helping with Suselle's estate. Despite all of that, if I had the last 23 years over again, I wouldn't change a thing. I was privileged to work for an exceptional woman and I am going to leave the final words to Suselle.

"If you want a summary of life in my view, it would include the following:

- A passion for justice and equality
- A commitment to openness of communication and relationship building
- Kindness with a light touch"

Excerpt from a letter written by Suselle to be read at her funeral.

Suselle Boffey

16th September 1956 –
14th July 2016

Brian and Callum's Story

Brian (PA):

I have lived in the Dumfries area all my life and for 33 years I worked in a factory, until being made redundant in 2009. I had also been in the Territorial Army (TA) for 33 years as a cook and after my redundancy I was asked to stay on with the TA to help out with the younger recruits.

I eventually had to retire from the TA, but I wanted to keep active and use my skills to help in some way. I saw Callum's advert and thought I would give it a try. I was a bit nervous as I had no previous experience of this type of work, but I needn't have worried: Callum and I hit it off right away and I have now been working for him for the last four years.

Callum (PA employer): From the age of nine years I lived in the countryside outside Dumfries with my grandparents, traveling into Dumfries to school. These were very happy times and my grandparents really supported me. However during secondary school I began to think about what I wanted to do with my life in the longer term.

I had a great social worker who spent time listening to me and she inspired me to really think about what I wanted to do in the future. She helped me to apply for a direct payment and develop a plan for how I would use it. At first I used the direct payment to support me to go to a youth group twice a week and to go to a local respite resource. I had known one of the respite workers for a long time and I got on really well with her.

"Callum and
I hit it off
right away"

Brian - PA



Eventually I decided to stop going to the respite resource and instead I used my direct payment to pay for overnight stays in her family home. That's the beauty of direct payments, you can adapt the support to suit you.

Although I love my grandparents and appreciated my great upbringing, I wanted to be more independent and develop 'me' as a person. My grandparents moved to a small flat in Dumfries and by coincidence the ground floor flat below became available and that is where I now live. It allowed me to be independent, but still have their support if I needed it. In the past I had agency support but that was not fit for purpose. I now wanted to be in more control of my support and not have to keep repeating myself, telling different workers coming in and out what I wanted done. I felt that directly employing a PA was the way to go.

 **Brian (PA):** I work with Callum two evenings a week. I also work as a school crossing patrol man and I finish that job around 4pm so the hours fit in really well. The school is just round the corner from Callum's house so sometimes I pop in for a cup of tea and a chat before the afternoon shift. It's really good that we have developed the type of relationship where sometimes we can just be friends having a chat although during the hours I am working for Callum, I don't forget who's the boss!



"I wanted to be more independent"

Callum - PA Employer

My tasks are mainly cooking, general domestic tasks and supporting Callum to go out socialising, keep up with the family or perhaps just going to play a game of pool. It was difficult to begin with and I must admit that I wasn't very confident, but Callum was very clear about what he wanted and that helped. It also helps that we get on well and trust each other. Callum had agency support in the past and he felt that he was always having to fit in with the service's needs. I am here to do what he wants, when he wants and how he wants it done. I really enjoy being able to contribute to the life Callum has chosen and actually if I was a bit younger I would take on more PA work. Having said that, you are never too old to give PA work a try. Just think of the work and life skills you can bring to it!

 **Callum:** I have two other PAs: one who helps me during the day with general household tasks, bill paying, etc, and one who helps me with shopping once a week.

As well as being a PA employer I have contributed to the promotion of the Social Care (Self-directed Support) (Scotland) Act 2013. I was a member of the council's working group that designed and delivered training to social work staff, which required me to have a sound knowledge of the legislation. I have also been trained in customer service.

Being able to directly employ PAs is a fantastic thing and my life is a lot better as a result. However I, like most other PA employers, have to contribute toward the cost of my support. Over the past 4 months, funding for my support has been cut back and I also have to pay increased charges so I am paying more for less support. If this continues it will increasingly cause me difficulties in meeting other everyday costs, due to my limited income. Equally importantly it also risks the PAs' livelihoods. If the worst comes to the worst I may have to make all of the PAs redundant.

My condition will not improve and in fact I am advised that my mobility will decrease over time. I do worry about what the future holds as I do not want to lose the independence, choice and control that Self-directed Support has given me.

Susanne, Heather and Gerry's Story



Heather (PA employer):

I was driving to one of my last shifts as a midwife before going on maternity leave when a young 'racer' lost control of his car and hit me head on.

I suffered severe injuries and life changed immeasurably from that moment. At that time our daughter Natasha was 14 months old and I subsequently gave birth to Zoe who has Cerebral Palsy.

□ Gerry (Husband, dad + PA employer): As I am sure you can imagine, life was very difficult following the accident and Zoe's birth. I called the council to ask what assistance might be available but we were informed that if we earned in excess of £16,000 per annum, we were not entitled to any assistance. As both Heather and I worked, this took us over the figure and so we just had to 'get on with it.'

Initially we had only family members to help us, but the closest lives in Blairgowrie and we live in Inverness. The distance coupled with having to make room in our house to accommodate them, just wasn't practical, grateful though we were for the offer of family assistance. When Heather had to go for spinal surgery 18 months after the car accident, Zoe's paediatrician asked us who was looking after the children while we were in Aberdeen. We explained that my mum



had travelled up from Fife to help us. It was only then that the local authority was contacted by health staff, concerned about the pressure we were under, and a support package was put in place for us.

Sadly the support provided was not appropriate. The support workers provided were agency staff from a care company. It was a case of sending 'who was available' rather than providing appropriately skilled and trained workers. This unfortunately caused a great deal of stress between the care workers and ourselves and we felt we had no option but to advertise for our own staff. We were put in touch with Highland Advocacy who took us step by step through the process of applying for a direct payment. At that point we began to realise that for the first time we had a say in who would be coming in to support us, which although daunting, was quite liberating. We were finally in a position where we could identify the

needs we had, and ensure they were being met, by employing PAs who had the skills required to work closely with my family.

☐ Susanne (PA): Before I became a PA I was a development worker for a charity supporting families affected by a brain injury. Part of my role as a development worker was to facilitate peer support. I first met Heather whilst working for the charity and encouraged her to attend one of the peer support groups. She told me that she was looking for someone to support her with planning and organising her day. I started working a few hours a week but now I work full time helping Heather to plan and organise her family's life!

☐ Gerry: Initially, I did most of the organisation myself, except PA interviews which Heather took charge of as she works so closely with the PAs. However due to the amount of work



involved we felt it would be easier if we created a 'senior PA' as a manager and Susanne has now successfully filled that role for the past 2 years. We honestly couldn't have chosen anyone better. She deals with all aspects of our service except for the financial side which is still my responsibility.

Susanne: I assist with domestic tasks, attend appointments and social activities with Heather and I coordinate and manage a team of 12 PAs who are employed to support Zoe. I deal with rotas, organising cover for sickness and holidays, training, instruction and supervision. Heather and I also work together on strategies and goals to help her own recovery.

Heather: Due to my brain injury which I sustained in the accident, I have difficulty retaining information and so this is a task Susanne assists with. For example she set up a white board in the kitchen which we use as a diary. All appointments, events etc, are written up and I can refer to it at any time as a reminder. We also set up alarms on my smartphone to remind me to take medications. Simple, often inexpensive strategies like this can be very effective.

Gerry: To some people having twelve PAs may seem excessive, but we have to balance having the support at the critical times we need seven days a week, with offering reasonable hours and fair working conditions for the PAs who are so valuable to us. Of course it is always difficult when you have



"I enjoy the flexibility and opportunity to help someone improve aspects of their life"

Susanne - PA

someone in your house constantly. However when that person is there to assist and help us to have as close to an ordinary family life as we can, then it's a sacrifice we are happy to make. Our children can enjoy days at the beach, going swimming, even going away on holiday as a family, something we just can't manage without their support.

For anyone thinking about applying to be a PA I would say "why are you waiting?" For us it's so empowering to be able to choose who we want to assist us rather than wondering who is going to be turning up at your door from an agency. You also receive more loyalty and understanding from someone you have employed yourself. Heather and I would never consider going back to using agency staff having experienced the freedom and

reassurance of having PAs working with our family, who we have chosen and employed ourselves.

Susanne: I enjoy the flexibility and opportunity to help someone improve aspects of their life. I also enjoy the variety of the work. No day is ever the same. It can be difficult for either party to not overstep boundaries as you become a big part of the family's life so you have to always be aware of that.

I'd say give it a go. It's very rewarding. You can make such a difference to people's lives.

Susan, Jack, Leslie and Eileen's Story

"She drives my car,
Both near and far, when
journeying I have to go

For, unlike mine, her
eyes see fine, in brilliant
sunshine, rain or snow.

She drives relaxed, her
skills untaxed by
cyclist, sheep, or
wayward weasel;

She doesn't race; her
steady pace saves
gallons of
expensive diesel!"

A verse from a
poem written by
Jack about Susan.

□ **Susan (PA):** I have been a full time PA for both Jack (dad) and Leslie (son) who has autism, since 2015. Eileen (Jack's daughter and Leslie's sister) is my employer and Power of Attorney for both her dad and brother.

The family all live next door to each other in a small township called Heylor consisting of 8 houses in the North Mainland of Shetland. Heylor is 35 miles away from Lerwick, the only town in Shetland. The area is typical of many others in Shetland and is served by single track roads. This can make it quite remote in the winter months. I live at Sandvoe which is 9 miles away.

I have known the family since I was at the Urafirth school with Eileen and Leslie; the school roll at the time being 36 pupils. My primary teacher from that time is also now the relief PA for Leslie and Jack, covering my leave periods and training.

Before being a PA I had many different jobs from chef work, care at home, to supporting young adults with disabilities. All my previous experiences and skills came into their own when I became a PA.



Jack and his family never felt the need to use service providers for Leslie when he was younger, but as Jack got older and began to experience health problems, he accepted that support was required. Jack and Leslie had been on their own for many years and they were used to their way of doing things. It was of the utmost importance therefore, that I carried out my role with sensitivity and with the set routines that worked well for them.

I feel that Leslie has adapted well to me being around. I have gradually introduced small changes for his own independence. We now have a number of things we enjoy doing: growing things in the greenhouse, craft, taking photos, and not forgetting walking, which we do twice daily. One of our favourite activities is making a picture diary of all the things we do together. Also, before Jack's sight deteriorated,

he had always kept a daily diary. This is now our job. We compare Leslie's to Jack's diary that he has kept since 1992. It is a window into the general activities and tasks that used to be carried out in and around the home, for example home improvements, which were large jobs which Jack did himself. Ruby (Jack's late wife), had a love of gardening and they gradually turned what was a 'kale yard' (vegetable plot) into a beautiful area that was "weel kent" all over Shetland. The diary also contains stories about family and friends that are no longer with us, the daily weather report which is always a favourite topic this far north and treasured memories of things like the CB Radio (Citizens Band Radio). This was used locally as an essential form of communication, long before the days of mobile phones! Leslie responds well to hearing these stories and it is very interesting for both of us.



PA work for me has been the best move I've made yet. The fact that it is tailored to suit the families involved gives total job satisfaction. Having known this family for most of my life, I feel I know what they would do in a situation. We have regular contact as well as a private Facebook page with all the family members involved. This has brought the family closer, as everyone can be involved and make suggestions. Jack's immediate family all work, so having this communication enables us to make adjustments to the package as they arise. Seeing Leslie looking relaxed and responding to our activities is very gratifying indeed. I feel like every "peerie" (small) thing I do makes a difference. We have fantastic cover for when I take holidays and this works well because the relief PA has different ideas, giving Leslie more things to occupy his time. Another familiar face gives us all reassurance and a smooth transition for Leslie.

There's nothing I don't enjoy about being a PA – apart from possibly the fact that I feel a little isolated. Shared experiences and advice from other folks that do PA work, I believe, could enhance our job and give us more confidence.

I would definitely recommend becoming a PA. The day to day running of the home, introducing interests and activities for myself and Leslie as well as liaising with professional bodies is such a great variety and makes my job very interesting.

Eileen: Before Susan came to help us I could never really go anywhere and was worried about the future. Mam (Ruby) did all the care for Leslie before she died, she was so supportive. After Mam died I really didn't know what to do and as dad's health declined this really got me down. I began to think that I might have to give up my work to look after them both, but I felt this wasn't the best solution for Dad and Leslie or what I wanted to do.



Leslie didn't have any contact with services as he is happiest at home and it was so important to have someone who he knows and trusts to help him out. Having people unknown to Leslie would make things worse.

I had no idea where to start and I panicked a lot. Susan was a good friend of the family and she approached us suggesting we looked into receiving direct payments. As soon as Susan mentioned how direct payments worked we all knew it was exactly what we needed, and it was the answer to our prayers.

A Citizens Advice Bureau (CAB) adviser became my mentor through the setting up of the direct payment. I felt overwhelmed and Advocacy Shetland advised us too. An accountant deals with the payroll, if it wasn't for this support I wouldn't be able to cope and the cost comes out of the budget we get.

Just 3 months into the job, Leslie had a fall, breaking his knee very badly. For the first time ever he had to go into hospital in Aberdeen. He had never been on a plane or even out of Shetland. Dad also had to undergo an operation the following spring so having Susan to support us was so important.

The support we now have is wonderful; a complete transformation in our lives, Susan feels like a family member. Susan and I did worry that it might change our friendship, but we agreed that communication was key and to talk about things as they came up.

I would definitely encourage people to think about employing a PA, but would suggest it is someone you trust. It also helps to speak to others who have already employed PAs.

Aileen and Barry's Story



Barry (PA Employer): I'm Barry and I live an independent life, in my own home with my cat Ruby and with the support of my PA, Aileen.

Before I applied for Self-directed Support I had agency staff coming into my home to support me, but I felt 'unseen.' The workers would ignore my views about how I wanted to be supported and largely ignored my suggestions about what I wanted to do. I have a significant physical impairment and they did things 'for and to' me rather than encouraging or supporting me to be more independent. I communicate with a Lightwriter using my feet and this takes time, but they just didn't have the time. Being unable to express myself to those workers became detrimental to my health and I had periods of feeling very low.

Aileen (PA): I had little experience of PA work before working for Barry. I had worked in quality assurance and as a cleaning supervisor so this was 'new territory' for me. I began to think more about the quality of support that people should have access to during a difficult time when my father was ill and my son was recovering from a road accident. I got a great deal of satisfaction helping them both to recover to full strength.

"Barry is
a published
author"

Aileen - PA

Barry
Smiths
Life Story
up to
5 years

Barry

Starvin
Marvine
and Family

BARRY SMITH



Barry's books are available
on Amazon Kindle.

□ Aileen (PA): Following that experience I joined an agency and initially began working with Barry through the agency and we got on really well, but I became dissatisfied with the work as there was never time to get to know the people I supported. It was 'complete the task and move on to the next person.' Barry was already unhappy with the agency's general response to his wishes.

□ Barry: I received advice from the person who manages my Self-directed Support budget that I could directly employ someone as a PA, so I gave up the agency, offered Aileen the PA job and we have never looked back! I think of Aileen as my 'hands' to do things that I can't do for myself. Aileen helps with housework, food shopping, meal preparation, and personal support. But it's also so much more than that. Aileen supports me to get out into the community. We go to a variety of activities including swimming and we go along to the local golf club – ok I admit it's for the social side only, but I really enjoy having a drink and 'chewing the fat' with the club members.



"It's great to see how much happier he is now"

Aileen - PA

Aileen: I think that I should also mention that Barry is a published author.

Barry: I had the ideas for the books in my head for a long time and had started with the first one, but things had stalled a bit. Aileen encouraged, or should I say cajoled me, to keep going! It was worth it: I have now completed and published two books, a novel and the first volume of my autobiography. It's a long story, so I am now working on the second volume.

Aileen: It's great to see how much happier he is now, but the job has also given me a great deal. I really enjoy Barry's company and feel I am

more forward-looking, open, and more confident. I know Barry well enough to do more than simply complete physical tasks. I can discuss my ideas with him and encourage him to try out new things, but the final decision is his. I don't forget that he's the boss.

I would say to anyone thinking about applying to be a PA to just do it. It's the best job ever!

Barry: There should be more coverage in the media about how disabled people can have so much more choice and say in their lives through having a PA. Life for me now is good and I feel back to my old self.

Personal Assistant

Frequently asked questions

What is the role of a personal assistant?

The Scottish Government defines a personal assistant (PA) as:

“An employee of a person needing support”

Independent living is not about ‘doing everything for oneself’; rather it’s about people having the choice and control over the support they require.

As a PA you will provide practical assistance and support to enable your employer to live a full, active and independent life in the way that they choose. No two roles will be the same as each job will be specific to the needs of the PA employer.

The 14 stories featured in this book illustrate the wide and varied role of a PA.

Who is my employer?

The employer of a PA is the person who is in receipt of a direct payment. This is normally the person requiring support or someone acting on their behalf if the person is under 16 or has an appointed decision maker. For children, this will normally be their parent or guardian.

Who can be a Personal Assistant?

There are no specific qualifications or skills needed to become a PA.

Employers often consider a number of factors when looking for a PA. It is not just about qualifications or past experience, PA employers often look for a PA who possesses the values, skills and personality that will best meet their needs.



What rights do I have as a PA?

PAs have the same statutory (legal) rights as any other employee in the UK, this includes the right to:

- ✓ Statutory holiday pay
- ✓ Statutory maternity/paternity/adoption leave (if applicable)
- ✓ Statutory sick pay
- ✓ Statutory redundancy pay
- ✓ A statement of main terms or contract of employment
- ✓ Access your employer's pension scheme
- ✓ Not be unfairly dismissed
- ✓ Join a trade union
- ✓ Work in a safe environment.

Your employer has a responsibility to work with you to identify any training needs and secure suitable training to ensure you are able to fulfil your duties.

For more information

Social workers, social work students and social service workers who work for agencies or organisations need to register with the Scottish Social Services Council (SSSC). The SSSC sets standards for their practice, conduct, training and education and supports professional development.

PAs are not 'regulated' i.e. they do not need to register with the SSSC. However the SSSC have produced information and guidance for people who are working or considering a career as a PA.

Find out more at:

<http://www.sssc.uk.com/workforce-development/our-current-work/self-directed-support>

Open Badges



Thousands of organisations around the world issue Open Badges and the SSSC are using them too. They are a digital record of learning tied to criteria and evidence.

You can use Open Badges to show you have not only completed some form of learning, but you understand what you learned and improved your practice as a result of it. Unlike traditional certificates, badges are information-rich, meaning each badge awarded to you includes important data about:

- What the badge is for
- What you had to do to earn the badge
- Who awarded you the badge
- Links to evidence of the work you did to get the badge
- The date you were awarded the badge and whether it will expire.



On the SSSC Open Badges webpage you will find badges about dementia, communications and relationships, health and safety, principles of care, maintaining your learning, digital skills and more. All you need to get started is an email address.

Find out more at <https://badges.sssc.uk.com>

PA Network Scotland



What support is available to PAs?

While the role of a PA is very rewarding and satisfying, it also has challenges. PAs may sometimes feel isolated, disconnected, on their own. It may be difficult to establish a professional relationship with an employer, especially if it's someone you know on a personal level.

Nobody can better understand the demands and challenges of being a PA than other PAs. This is why the Personal Assistants Network Scotland came to life. It is a joint initiative funded by the Scottish Government and run by the Workers Educational Association and Unison.

The PA Network Scotland is a place where PAs can talk about their concerns, get answers they need and have their voices heard.

We can offer:

- Networking events for PAs from all over Scotland to meet each other
- Training sessions based on learning needs identified by the PAs
- Space, both online and offline, for PAs to discuss their needs and share their experiences
- A fully accessible website offering information about meetings and training opportunities; links to sources of information relevant to SDS and PAs; a forum to exchange experiences and receive peer support and some online training

Join us if you would like to:

- Access a supportive network of other PAs
- Find out about training opportunities in your area
- Have your voice heard
- Meet and work with other PAs
- Learn about your rights at work
- Make new friends.

Find out more at www.panetworkscotland.org.uk

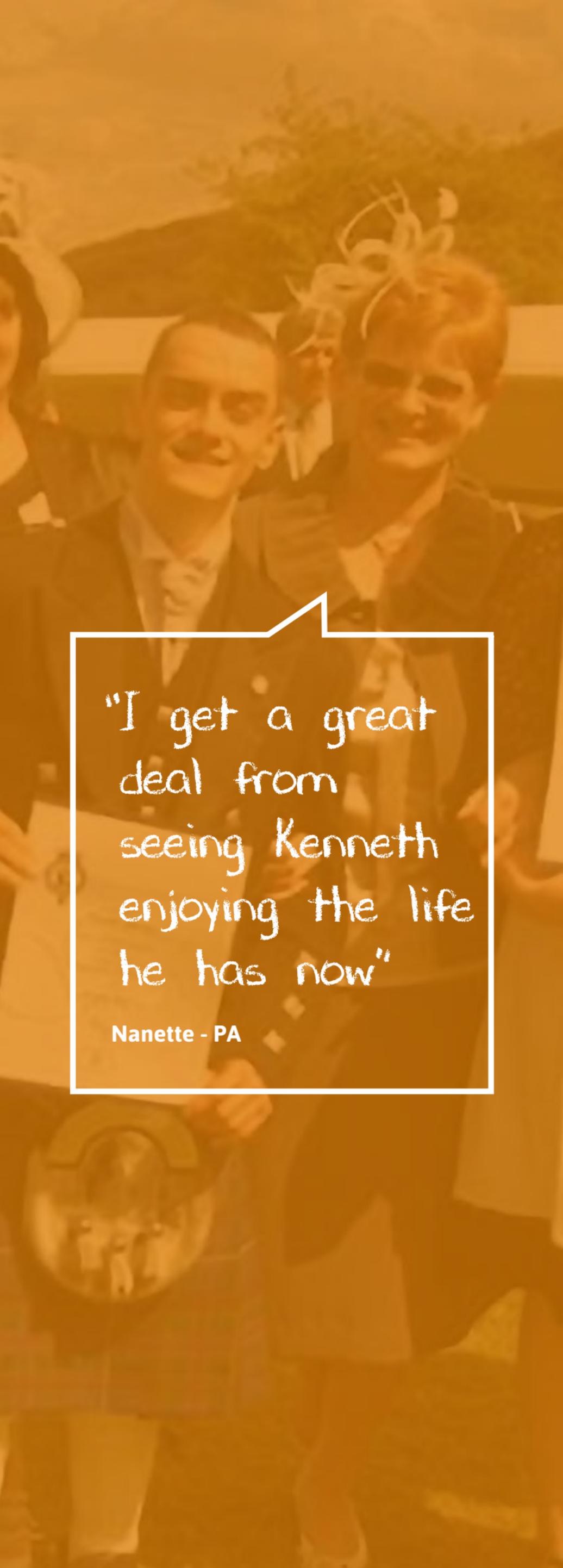
Nanette and Kenneth's Story



Nanette (PA):
I have worked as a
PA for Kenneth for
15 years, but I had
known him for many
years before that.

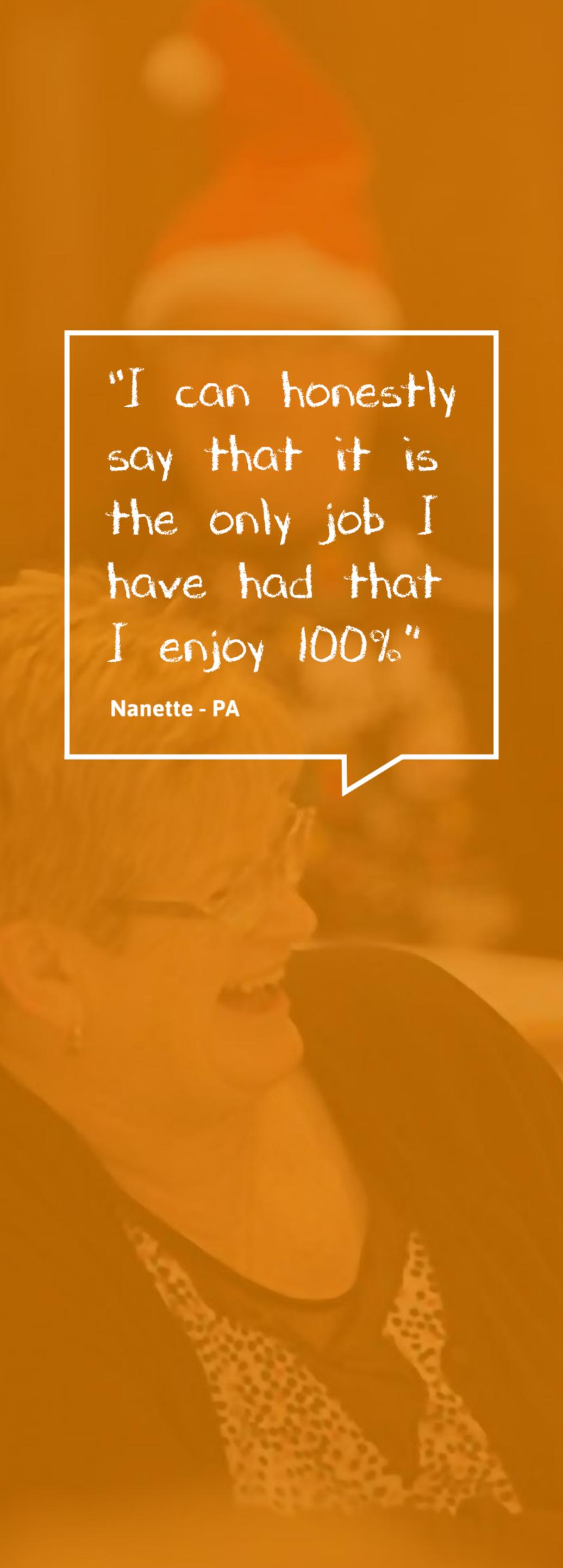
Nanette: Like Kenneth, my daughter Kerry has a hearing impairment and she was friendly with Kenneth and met up at the same clubs and activities. I used to volunteer at a local club, supporting young people to gain Duke of Edinburgh awards and I got to know Kenneth through that work. I didn't have any work experience in social care before becoming his PA. I did bar work, worked in a factory and later worked in a children's nursery. Despite living in Ayrshire, Kenneth had to travel to Glasgow to school and I was employed to escort him to and from school.

Kenneth: Before I applied for Self-directed Support I had very little help and depended a lot on my family. As I had a lot of health problems growing up, including having a tracheostomy fitted when I was two years of age, most of the support I received was for my health needs. However in 2006 I was able to have my tracheostomy removed and this made a huge difference to my life. Eventually I applied for Self-directed Support because although I have a great relationship with my family, I wanted to be more independent and live an active life.



"I get a great deal from seeing Kenneth enjoying the life he has now"

Nanette - PA



"I can honestly
say that it is
the only job I
have had that
I enjoy 100%"

Nanette - PA



Nanette: Over the years Kenneth and I got to know each other well and when the PA job came up I felt that I could offer the type of support he wanted. Although Kenneth lip reads he also uses British Sign Language (BSL). Due to my daughter's hearing impairment I can sign so this allows me to communicate well with him and interpret for him when required. I think that's a good example of the personal skills that you can bring to being a PA.

Kenneth: Nanette works with me several days a week. I put appointments and the things I want to do in my diary and we decide when Nanette will work based on my plans for the week. I chose a PA because I like the fact that I have one person working for me who gets to know me well rather than several different workers coming into my home. I learned to drive recently and Nanette supports me to go out to activities or day outings. We don't do everything together though! I also attend clubs or just enjoy time with my family. I trained

"I wanted to be more independent"

Kenneth - PA Employer

to be a BSL language assessor and I am now fully qualified. I travel to England and other places to assess students' BSL skills. This involves testing the standard of the students' sign language skills through having conversations with them. Unfortunately there is also a great deal of paperwork which is not so enjoyable! Nanette travels with me so some weeks we adjust her working hours to allow us to build up extra hours for travelling which can sometimes involve overnight stays.

Nanette: I also support Kenneth with day to day tasks such as general housework, shopping and cooking. Because Kenneth had the tracheostomy for so many years he needs to have food prepared in a certain way and I help with that also. I get a great deal from seeing Kenneth enjoying the life he has now. I can honestly say that it is the only job I have had that I enjoy 100%. I've never looked back.

Kenneth: I would say to anyone thinking about employing a PA that it can be difficult to begin with, but once you build a good working relationship with your PA, it's worth it!

Julia and Liz's Story



Liz (PA Employer):
My name is Liz and I live with my partner Jeremy on the beautiful island of Lismore, situated between Oban and Fort William, with a population of 190 people.

I was born with very short arms due to the drug Thalidomide which my mother took in early pregnancy to prevent morning sickness, when she was expecting me. No one at that time (early 1960s) knew the damage it was going to cause.

Until 11 years ago I had a good career in conservation at local, national and EU level. I loved my job and worked hard – too hard as it turns out. I admit that I ignored the early warning signs that my body was not keeping up with the demands I was placing on it and as a result I began experiencing severe pain in my back, neck and arms and was losing the function of my arms. I suffered a very low period of physical and mental ill health and it took some years for me to recover.

I had never liked the word 'help' and always felt that I could do everything I needed to do without help. However, I feel that the support I now receive from my PA Julia, which I control and manage, is actually quite a good thing! Read on to find out why.



Julia: (PA) I have lived on Lismore for over a year now and 3 years in Scotland, although I come from the Baltic region of Germany. I trained for three years in Hamburg to become a commercial photographer, but after I completed my apprenticeship I did not enjoy the nature of the industry, which is very much about just making rich people richer! My ambition was to use my skills more creatively and support smaller businesses. Once settled here on Lismore I wanted to contribute to the island community and I got to know Liz through our mutual interests. We are both members of the island choir and also the Lismore Community Trust Energy Group which explores ways of developing alternative sustainable energy sources for the island. Earlier this year Liz approached me and asked

if I would consider working for her as a PA. I had no background in this type of work, but I was really chuffed that she considered me to be skilled and trustworthy enough to work with her in her home and I was delighted to accept. As well as working for Liz I manage a holiday let on the island, photograph a local craft company's products for their online gift shop and make films, for example about community projects and sustainable farming. You have to do a bit of everything when living on an island and I am pleased to be able to do such varied work.

Liz: My period of illness hit me hard as I am so used to just 'getting on with things'. Once I recovered a bit I was bored. I had accepted that I would



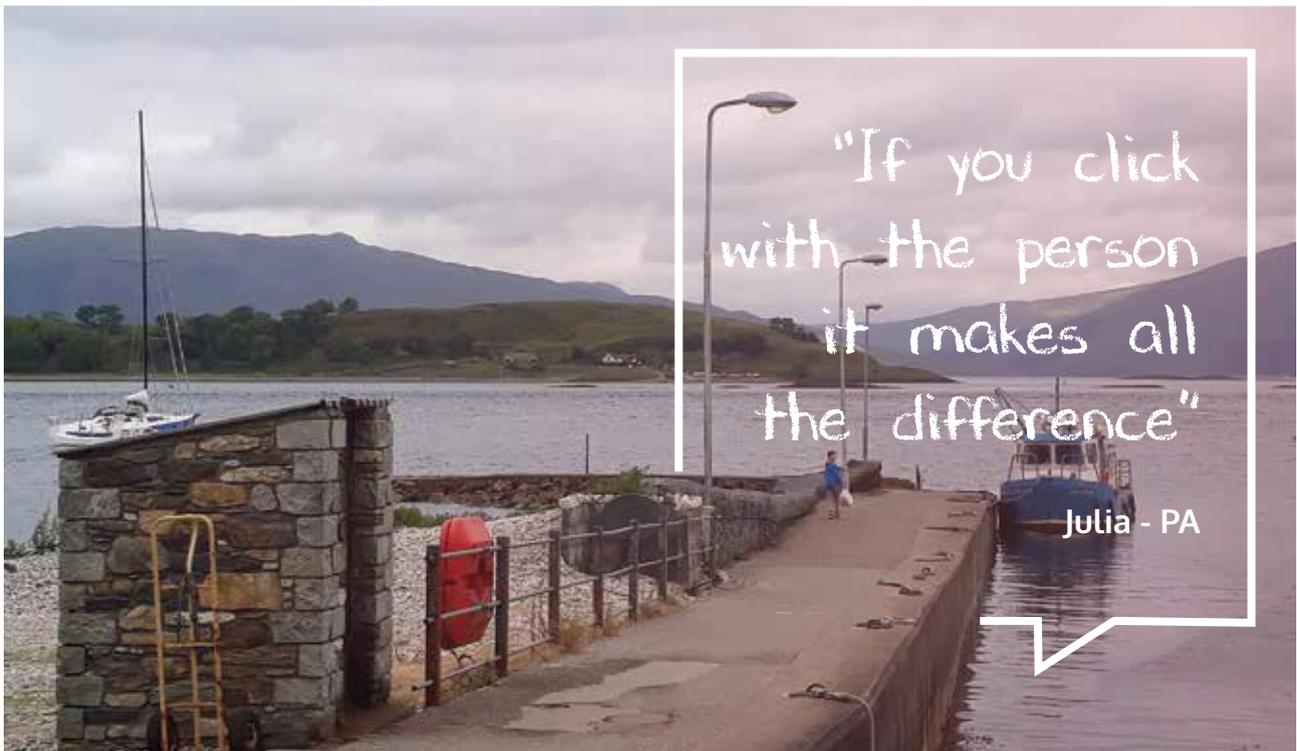
Photograph by Julia

not be able to return to work, but with support I could still manage around the house and pursue the activities that interest me. This is what led me to consider Self-directed Support. Despite my previous managerial experience I was very nervous about becoming an employer, but fortunately I had support with recruitment when employing my first PA. I was much more confident by the time I came to employ Julia.

Julia: I would say my work is a combination of undertaking some tasks for Liz and others with her. I do the day to day tasks around the house that Liz can't manage, prepare meals, bake and I enjoy organising the house to make things more accessible. Liz loves the garden and we tend it together. She

also likes making jams and chutneys so we go round the island collecting elderflowers and other natural ingredients. Sometimes I feel bad that I get paid because it feels more like just helping a friend and I share so many of Liz's interests, but perhaps it is this compatibility that makes it work. I also like the atmosphere in the house as Liz is such good company. My work is mainly on the island, but I would be happy to travel with Liz if required.

Liz: I will email or message Julia to let her know what I want to do the following week so that, for example, she can wear the appropriate clothes if we are going to work outside. We are also planning some longer term projects related to the seasons. Julia has other commitments that require



an occasional change of hours, but in turn she is happy to change her hours to suit me if I have something specific to do. I do enjoy having a young person around the house and hearing about her views and perspective on life. Julia contributes to my life, to this island community and to the Scottish economy as do so many young people from the EU and further afield who come to make their home here. I worry that in the future those valuable skills and talents might be lost.

I have one other PA, Andy, who I employ on an occasional basis so that I can go out to sea in my canoe. I have two single person canoes and one two person canoe which are all propelled using foot-pedals. Andy accompanies me as I have been strongly advised

by everyone not to go out on my own. I prefer the single canoe, partly for the independence it offers and partly because I am not always convinced that Andy works as hard as he should on the pedals when we are in the two person canoe – he thinks I don't notice!

I do still get a bit frustrated at times that I am not as active as I used to be. There was a long period where I felt my life had 'contracted', however, now I feel that it is expanding again. I really value the support that I receive and the fact that I am in control.

Julia: The human relationship is so important too. If you click with the person it makes all the difference.

Anne and Walter's Story



Walter (PA employer):
I'm a born and bred
'portonian.' That's
the local name for
those of us who hail
from Grangemouth.

I have lived on my own since 2006 and despite having no sight I initially only received four hours support a week via social services. After my new guide dog came along I asked for more support and received 20 minutes per week simply for hoovering to keep all the dog hairs in check! I just couldn't get things done with so little support.

Some people I chatted to on the internet told me about their experiences of Self-directed Support, but I thought it only applied to England. However I began to make enquiries and with the help of the Self-directed Support, Forth Valley help team, I applied for Self-directed Support and opted for a direct payment.

□ Anne (PA): Months after my husband died which ended a period of caring for him, I needed some purpose and structure. Family and friends were always there for me, but I soon realised that I had to get on with life and I felt I still had something to offer.

My past experience included working in various retail jobs, a bowling alley and petrol station, to



name a few. I had applied for a couple of shop jobs that I wasn't really keen on when I saw Walter's advert, but I wasn't sure about applying as I thought a PA was only for big companies. When I looked at the range of tasks required, after having a closer look at the advert, I thought "actually I can do this."

Walter: I had had PAs before Anne, some good and some not so good. One PA carried out the tasks I asked of her. but in-depth conversation was difficult since she had no opinion on any topic I raised. This experience made me realise how important it is to have someone not just to complete tasks, but who I can relate to, and who likes a conversation, as I depend so much on verbal communication. Being able to employ someone of my generation was also important as we would have more in common. At my request a member of staff from the Self-directed Support Forth Valley help desk sat in on the interviews with me. I wanted to hear how people answered my questions, but it was equally essential to receive feedback on their non verbal responses and how they presented.

Anne: When I first started it was a big learning curve. The cooking and household tasks required were not a problem, but I had never worked with a blind person before and I made so many basic mistakes like leaving doors half open, placing food in the fridge and cupboards without telling Walter where I had put them and not switching lights off when I left. I received so many phone calls from Walter after I got home asking "what have you done with so and so?" that I'm surprised I lasted beyond the probationary period! Once I bought plums and tomatoes which were the same size and in the same type of packaging and placed them in the fridge, but forgot to tell Walter which was which. I'm so glad he has a good sense of humour as he had to smell and taste them to figure it out. However Walter was so patient and understanding and over the years I have learned so much from him. We get on well, we have a lot in common and I can talk until the cows come home so we have some great conversations. The only problem now is making sure that Walter doesn't trip over the toys his guide dog Pepper leaves lying around the house. Walter is very active in the community. He gives talks about his experience of Self-directed Support, visual impairment and guide dog awareness. I go with Walter to support him and sometimes to 'prompt' him if he forgets something that I know he would want to cover. We have been to numerous community groups, schools and colleges.



"Being a PA can start off as 'just a job' but it soon becomes so much more"

Anne - PA

Walter: I opted for a direct payment because I wanted to be in control of my support and choose the person I wanted to support me. For me a direct payment is the 'a la carte' option on the Self-directed Support menu. I felt that in the past it was 'take it or leave it' when it came to the support that was provided. A direct payment allows me to employ the person that best suits my needs, it's all about choice. Anne now knows exactly what I need done and she will come in and just get on with things, even if I am out walking with Pepper. I also value her opinion, e.g. if I am buying clothes or something for the house.

Until Anne told me, I didn't know that my house was wall to wall pink,

furniture included! People had decorated without asking my opinions, so we worked together to redecorate. I am reliably informed that the house would now be much more to my liking. I particularly appreciate the flexibility of having a PA. If I need to change the hours to suit my commitments I just discuss this with Anne. It works both ways of course and we come and go with each other. Of course I could have engaged a care agency to meet my support needs, but one aspect of this is the agencies here require their employees to wear a uniform with the company logo emblazoned on it, plus a picture ID on a lanyard. This screams out that the person they are with has "a problem" and it isn't very discreet and I just don't like drawing that kind of



"I feel fitter
having lost 7 stone
in weight in the
last year"

Walter - PA Employer

attention to myself. I do use an agency to handle domestic cleaning needs and this is quite handy as I can increase the agency hours to cover Anne's holidays.

□ Anne: Being a PA can start off as 'just a job' but it soon becomes so much more. In the past I was always working to make money for someone else. Being a PA is not about money as much as about supporting someone to just get on with life in the ways that we often take for granted and I value being part of that. In turn I feel valued as Walter is very considerate and appreciative of my contribution to his life. There is friendship and mutual respect. Walter never takes me for granted, although I have had to say on the odd occasion "Walter I know I can

multitask but wait a minute!" Is there anything I don't enjoy? Yes: ironing, but Walter doesn't let me away with that!

□ Walter: I have choice and control over my support, I feel fitter having lost 7 stone in weight in the last year and as I prefer being a 'giver' rather than a 'receiver' I feel that the talks I give on behalf of various organisations about Guide Dogs and also Self-directed Support and Blind Awareness, help to give something back to the community. All in all, with the control I have over my support needs and the help of a good PA, it makes the effort of getting out of bed in the morning worthwhile.

Antonio and Ethan's Story

Antonio (PA):

Before meeting Ethan I had been a lawyer for 10 years in my home country of Portugal. We first got to know each other in Derry in 2009 when I was studying for a Masters degree in human rights, specialising in conflict resolution.

I was writing my thesis (The Democratic Transition in Northern Ireland - a study about the constitutional solutions adopted by the Good Friday Agreement) which was an analysis of the Northern Irish troubles and the constitutional legal framework (power sharing) that sustains the Good Friday agreement. Ethan and I were taking part in a peace building course at Ulster University. We are both passionate about being involved in human rights and peace work: e.g. I travelled to Pakistan as a short term observer to the EU Election Observation Mission covering the general elections in 2013.

Our friendship developed and from 2012, I travelled with Ethan as a volunteer support worker to a number of countries including Kenya where we spent some time involved in a human rights project called Peace by Piece.

After going home to Portugal for a period, I returned to Scotland in January 2017 and since then I have been Ethan's PA.



Ethan: I studied Film and Media Studies and Mathematics for a year at university, but left to play competitive pool representing Scotland – yes I know, but I was young! Realising that this was definitely not a long term option and as I always liked maths I returned to Stirling University as an employee in the Finance dept. However after a while I again got ‘itchy feet’ after a Sahara Desert Charity Trek and applied to Voluntary Service Overseas, completing six-month placements in Wales and India. Following that I travelled widely including to the Palestinian West Bank and Kenya.

Before receiving a direct payment, I had no support and relied on family and friends who were, and continue to be, very supportive. One of the reasons I left university was that I really needed more support, but was

not ready to admit it. After setting up my own charity, working both internationally and locally for several years, I was beginning to feel that I needed a more structured job with a clear brief and with appropriate support in place. I really wanted to find a post with a human rights perspective and so was delighted to secure a job with Inclusion Scotland. I started in September 2016 in the post of Civic Participation Officer with a remit to lead on the Access to Elected Office Fund Scotland, which was set up to provide finance to overcome the impairment related campaign barriers that disabled people face when running for party selection and as a candidate for elected office.

Antonio: My main role is to provide practical personal support to Ethan, e.g. in the morning to get ready



for work. I drive him to-and-from work and provide whatever support Ethan needs during working hours from assisting him with his job tasks to making the tea or coffee! Having this practical support helps Ethan to conserve his energy so that he can fully focus on the demands of the job. I accompany Ethan to any outside visits or events in relation to his job and I check out the accessibility and facilities to ensure they are suitable for his needs. I work to a set rota every week, but there is still flexibility. We discuss any changes in hours that might be needed depending on Ethan's commitments.

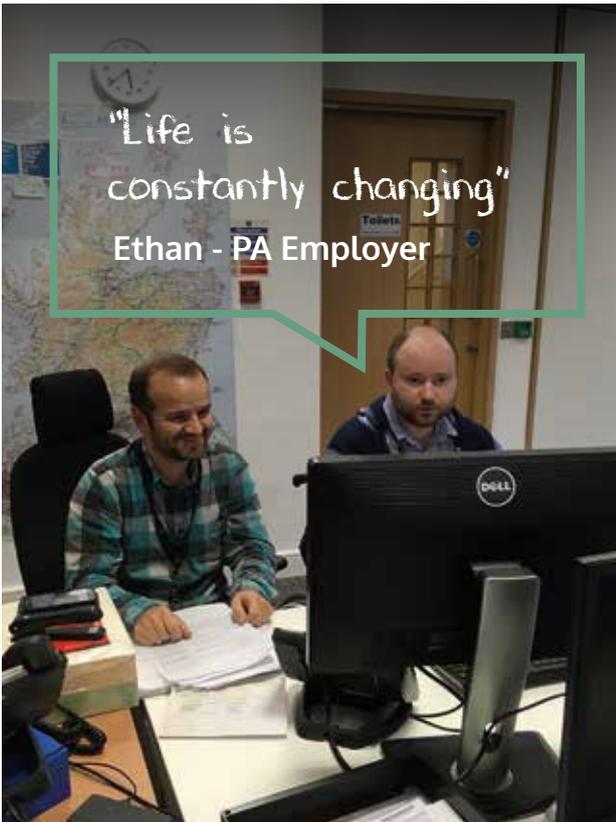
The quality of our relationship, the fact that we feel very comfortable with each other and the level of trust that has to exist between us is absolutely critical. Ethan says that it is almost like a marriage and to an extent the joys and pressures of spending so much time in each other's company are similar to that I think! Ethan does have another PA (Alasdair) and we provide cover for each other's holidays.

The type of support I provide has changed over the time I have known Ethan. In Kenya the environmental conditions were harsh which was a challenge whereas now Ethan's condition means he needs a greater degree of support, but knowing him for so long helps me to understand and appreciate his changing needs.

Ethan: I chose to have PAs because my dad had the same condition as me and he used agency workers, but there was no consistency. We all have people that are in our 'circle of trust' and I felt that those workers operated outwith that. Workers came and went and he was having to explain his needs to different people time and time again. I didn't want that.

My condition was deteriorating and I was forced to admit that I was able to do less and less. Having a PA has opened up a whole new world of opportunity for me and now with the support of PAs I am now able to do more than in some previous years. I also wanted to be able to offer secure employment to people and help them develop onto the next part of their journey. I employ Antonio using a combination of direct payments and Access to Work funding.

Of course you have to be clear about your responsibilities as an employer. It takes time to put everything in place and I would encourage people to use the support organisations that are there to help.

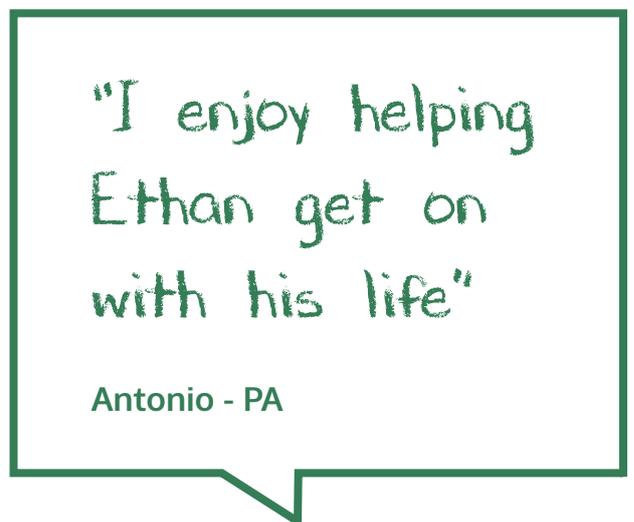


Antonio: I enjoy helping Ethan get on with his life in the way that he wants. I like to be busy and although there are some occasional quiet times it balances out on the days we go 100 miles an hour. I would say that you really have to love the job. If you don't enjoy this type of job it won't work.

Ethan: Life is constantly changing. My close friends and I all have busier lives so we don't see each other as often, however I am moving to Edinburgh soon and see that as the beginning of a new chapter. With the support of my PAs I am looking forward to getting involved in all the city has to offer.

And sometimes the unexpected happens. Travelling through to a meeting in Glasgow today we gave a lift to two hitchhikers from the Czech

Republic. They were travelling to the city and wanted to visit Celtic Park, which conveniently happened to be on my route. We were delighted to be able to assist them and welcome them to Scotland, but I would not have been able to do that without a PA. That just says it all!



Kirsty and Susan's Story

Kirsty (PA): My first contact with Susan was when I heard from a mutual friend that she was looking for someone to do a couple of hours cleaning. That was 3 years ago and I am still here, but I am now a PA doing a variety of tasks to assist her to live her life.

I had always worked full time until a back injury, coinciding with illness in the wider family, resulted in my having to stop work for a while as the situation took its toll. When I recovered I took a job in a hotel kitchen. I enjoyed the physical side of the job and I just wanted to get back into the world of work. When I started the cleaning work with Susan we got on from the beginning and we enjoyed each other's company. When Susan's health began to deteriorate more support was required and although she already had council carers, she asked me if I would be prepared to take on a wider PA role which I happily agreed to. I had supported my family through a difficult period of illness which had made me realise what I was capable of. Another important factor was that we had got to know each other well and had built a trusting relationship. In the past Susan had had some problems with one of the council carers who she felt had taken advantage of her and so having a trusting relationship with those who supported her was of the utmost importance.

"Having a PA
has made such
a positive
impact on
my life"

Susan - PA Employer



□ Susan (PA employer): I first moved to the East Neuk of Fife 20 years ago to take up a job in the hospitality industry, fell in love with the area and I have lived here ever since. I have a number of illnesses, but I was able to continue to work part time. However the Job Centre put undue pressure on me to increase my hours to full time and I found this impossible, so sadly I had to give up work 13 years ago. I started receiving support from council care workers, but they were not able to give me the support that I needed. I take a long time to get up in the morning and they simply did not have the time to support me with all the tasks required. Also I have very particular dietary requirements, yet microwave meals were the only option. Had I allowed this to continue it would have been significantly detrimental to my health.

□ Kirsty: I start the day with Susan by supporting her with personal tasks. Although a council carer comes in earlier in the morning to undertake some basic tasks, Susan tends to stay in bed until I arrive as I have the time to support her to get up and dressed in a relaxed atmosphere, with her favourite incense burning, at her pace and with a lot of chat in between! I then do some general household tasks, bill paying and meal preparation. Due to Susan's very specific dietary needs I make

sure that particular ingredients are bought and that all meals are freshly prepared.

Every so often I batch cook for the freezer so that Susan is never short of the meals she needs. I am very conscious of food hygiene requirements and as both Susan and I have worked in kitchens, we are pretty fussy in that regard! Some days we might go out shopping, a trip to one of the other villages or just down to the local harbour area.

□ Susan: Having a PA has made such a positive impact on my life. Kirsty is so considerate and thoughtful. She has reorganised the house to make everything I need so much easier for me to reach and there are so many things that she does that may seem insignificant to others, but are so helpful to me, e.g. I have a weak wrist and she never fills the kettle more than she knows I will be able to lift. She makes up salad in individual little tubs so that I can have a healthy snack any time I want. Before she leaves she makes sure that drinks, snacks, medications etc, are all at my bedside as I can't get up during the night and she lays out all the things, in order, that I will need for the evening and bedtime. She anticipates what I need because she knows me so well, but she never 'takes over.' In fact everyone should have a 'Kirsty'!

□ Kirsty: My favourite part of the job is being able to contribute positively to Susan's life and we genuinely enjoy each other's company.



We are similar in nature and I am sure that helps. I have some caring responsibilities for my new grandson and Susan is very considerate of that. The only down side of the job is the hour and a half journey to-and-from work, but that is a consequence of rural living and on the plus side it gives me some time to myself each day!

□ Susan: The local community here is very supportive too. I have good neighbours, the local shopkeepers are very helpful and the local pub down at the harbour has offered to cook meals to my specification and deliver them if I am ever stuck. I am a member of the board of the East Neuk Recovery Group Initiative (ENeRGI) which offers a range of supports to people in Fife and, health permitting, I hope to become more involved.

Having a PA has lifted a weight off my shoulders. I have a good life and it's important to me that I give something back.

□ Kirsty: To be effective you have to give something of yourself to the job so you need to think about how much you feel you can commit. However it can be worth it!

Marion's Story

Marion (PA): You may have heard of Fettercairn where I live. It is often mentioned on BBC Scotland's travel reports during the winter as the Banchory to Fettercairn road is regularly blocked by snow – such is the reality of rural living!

About two years ago, suddenly and unexpectedly I had to rethink what I would do for a living. I had worked for many years for a business based in the neighbouring town of Laurencekirk. The business ran a haberdashery shop and small factory which embroidered badges onto uniforms. Many of our customers were related to the oil industry and sadly, as a result of the downturn, the business folded and the staff were made redundant. I really enjoyed the job and I had great colleagues so this came as a bit of a shock. Living in such a rural community means that jobs are in short supply so this was a worrying time.

While I was searching for jobs I came across Cornerstone SDS Aberdeenshire who were advertising a number of PA jobs on behalf of people in the local area. I had not realised that such jobs existed, but having given it some thought I decided to give it a try. My first job was with a lady called Louise. We hit it off right away and she loved a bit of 'banter.'



"The key words are organisation, trust, communication, confidentiality and flexibility."

Marion - PA

Although my remit was primarily to provide personal support, over time, I was able to gently encourage her to do small things to rebuild her confidence. Sadly she died, but the experience of working for Louise made me realise what a rewarding job being a PA could be. Within weeks I had other work and I am now a very busy PA as I work for four different people, undertaking a wide variety of tasks.

I am one of four PAs working for Duncan who lives in a local sheltered housing complex a few minutes from my home. Due to Duncan's complex needs, two PAs work together on a rota basis and I do several shifts a week for him. To ensure that we are supporting Duncan at the critical times

he requires, I sometimes have to do split shifts, which I know is not everyone's cup of tea, but because I live so close to his home I don't find it to be a problem. My main tasks are personal support and some housework. Duncan does not really like going out, but he enjoys a conversation and like Louise, we enjoy the 'banter' and having a laugh.

I work once a fortnight for Brenda who lives in Catterline, supporting her to travel to Aberdeen to go shopping or for a social activity of her choice. Last week we ended up in Peterhead prison – no we weren't in trouble, Brenda just wanted to visit the museum there! She really enjoys the social side of having a coffee or lunch and a chat. Like all the people I work for, I enjoy her company.

With Brenda it doesn't seem like work. Another PA supports Brenda on alternate weeks and we cover for each other's holidays so that Brenda's weekly service is maintained.

I heard about Dorothy through a friend. She had just lost her husband and felt isolated. Because of what I have learned through working for all my employers, I actually told Dorothy about Self-directed Support. She applied and opted for a direct payment and I now work for her. I support her once a week to go shopping and I provide transport to and from a craft club which she really enjoys.

Jane* has Dementia and is my most recent employer. She requires 24 hour care with funding shared by the local authority and family. I work for Jane two days a week and will also

do occasional sleepovers if the PAs who provide the regular night cover are ill or on holiday. Jane has a senior PA who coordinates and organises the PA rotas. The shifts are long, from 9am – 7pm, but this best suits Jane's needs as she responds well to having that consistency. Building a relationship with Jane has been so important because now that trust has been established I am able to provide, in particular, the personal support that she was reticent to allow me and the other PAs to help her with before now. We have good conversations about memories of her life. I just take her lead in the things she wants to talk about.

As I am sure you can imagine, there are a number of issues related to working for a number of employers, particularly in a rural setting.



"With Brenda
it doesn't seem
like work"

Marion - PA

The key words are organisation, trust, communication, confidentiality and flexibility. My diary and mobile phone are a must for arranging work and for the regular discussions required between all the PAs.

Trust is also vital as our employers need to be reassured that the arrangements the PAs make genuinely ensure that all our employers are appropriately supported in the way and at the times they choose. Confidentiality must be respected particularly in such a small community where everyone knows everyone else. Anything said or shared in the employer's home stays there!

Being a car owner is absolutely essential. The only public transport in and out of Fettercairn is the school bus and nobody would wish to travel on that! I use my car constantly both to get to and from work and to carry out some of the tasks required.

Finally, working directly for four different people makes being paid a

bit complicated. Thankfully the payroll service used by each of my employers deals with all that!

Being a PA took a bit of getting used to as I had spent so long in a Monday to Friday 9am – 5pm work routine. However it has been a pleasure to meet and get to know people who I would not have known otherwise and I enjoy the variety of tasks required, except housework, but no job's perfect!

It's a privilege to be able to contribute to helping people to remain in their local community for as long as possible. If you are thinking about this type of work I'd say "give it a go," as you might be pleasantly surprised as to what everyone involved can gain from the relationships you can build. It's all about enabling people to live as normal a life as possible in their own homes where they are happiest.

**Employer's name has been changed to protect privacy*

"Building a
relationship
with Jane
has been so
important"

Marion - PA



Joanne and Christine's Story

Christine (Daughter and family carer): My mum (Margaret) died on the 8th June 2017 at the age of 96 years. Following a diagnosis of vascular dementia four years ago, we were concerned about how she would manage in her own home, where she'd lived alone since my dad died over thirty years ago.

We wanted her to move in with us as we had space and we had plans to extend the house, but she wouldn't agree to it. She wanted to stay in her own house for as long as possible, so for a while we managed around that, although it was quite stressful for me.

Mum had council homecare, but she didn't like it. She didn't like having people coming to the house and she complained about it. The workers were nice and our experience of council homecare was reasonably positive, but it was quite inflexible. In time, and as she deteriorated, we managed to persuade her that she'd be happier living with us, and we adapted our ground floor so that in the end she moved in with us for the final two years of her life.

When Mum did move in I was concerned that she wasn't going to be safe by herself while I was out at work. I leave the house at 9am and I'm not back until 6pm and that was too long, even with the council homecare workers coming in. I began looking for another solution and found out about Self-directed Support (SDS). Thanks to a local support organisation I applied for SDS and opted for a direct payment so that I could arrange and manage Mum's support myself.

Joanne (PA): My parents are Scottish, but until returning to Scotland sixteen years ago I had lived all my life in Zimbabwe. I have always worked in an office environment, but I began to volunteer with the local Credit Union here and this put me in contact with older people in particular who were benefiting from locally organised support. I began to feel that this was something I would like to do. The support for people here is so different from Zimbabwe where families are expected to provide all the care and support and if that is not possible then the only option is to pay privately. There's so much more choice here although I appreciate things are not perfect!

I initially worked for a care agency and when Christine used the direct payment to contract with the agency, I was identified to work with Margaret. Margaret and I got on well from the start and I enjoyed working for her, but I was unhappy working for the agency. There was little training or support for staff and we were moved around at short notice. This was very unsettling for Margaret as consistency was crucial. She would get upset and not let new workers assist her.

Christine: I was unhappy with the service, but I was delighted with the way that Joanne worked with mum. She understood mum's needs down to the finest detail like the correct temperature of her tea! And she was a dog lover. We have three dogs and although that may seem a minor issue

the dogs were part of mum's and our family's life. Most importantly I trusted Joanne implicitly. I could go to work and not worry – this was so important. I eventually asked Joanne if she would leave the agency and become a PA employed by me. I was so conscious that, given mum's deteriorating condition, it was unlikely that I could guarantee Joanne long term employment, but she agreed to take the risk.

Joanne: At first my main tasks were some personal support, meal preparation as Margaret loved her food, general supervision to keep her safe and to provide stimulation. Margaret had kept diaries and we spent many hours going through the diaries or looking at old photos with Margaret telling stories and reminiscing. I would also look for interesting news articles which we could talk about. The aspect of the job that I most enjoyed was doing my best to give Margaret quality time.





Joanne and Jennifer

Due to a fall Margaret broke her hip and was admitted to hospital. This was very difficult for her, but I, and her other PA Jennifer, continued to support her for the five weeks she was in hospital. The hospital staff tolerated us, but did display a rather cold 'why do you need to be here' attitude. Margaret was very frail by this time and we provided personal support, fed her with food Christine prepared, and just provided conversation and reassurance that someone was there with her.

Christine: Things were not great by this stage and I was determined mum would come home for her final days. I have to say that once the decision was made, health staff were hugely supportive. The hospital developed an end of life plan with me so we were clear about everyone's responsibilities whatever happened.

The GP and district nursing staff were very helpful and we received a high quality hospital bed and appropriate equipment from the local joint equipment loan service. Thanks to previous training and advice from health staff, Joanne and Jennifer were able to undertake the personal care tasks that were now required for mum.

Mum died on the 8th June – election day. It was unexpected but very peaceful, and she passed away just minutes before the exit poll announcement at 10pm, with me and two of her beloved grandchildren beside her. We kept her at home overnight and in the morning I phoned Joanne and Jennifer to let them know – two phone calls I was dreading.

Joanne: I came round and together with Christine we prepared Margaret for the arrival of the funeral directors.



I felt it was my final act of giving to Margaret's life. I'd really liked working for her and it was so rewarding to know that I had made a positive contribution to this final chapter. I can honestly say that I did not dwell on the fact that I would inevitably lose my job.

Now a few weeks down the road I have just accepted a job with an agency that offers the opportunity to work specifically with people who have dementia. However I would definitely work as a PA again if the right job came up.

Christine: The high quality of support mum received was the result of a combination of forward planning and having good people around her. I spent a lot of time planning the best possible support option before she moved into our home and again with health staff prior to her hospital discharge. Having Joanne and Jennifer,

who were so committed to her and understanding of her needs, was an immense comfort to all of us.

"The high quality of support mum received was the result of a combination of forward planning and having good people around her"

Christine - Daughter & family carer

Acknowledgements

The publication of “PAssport to Independent Living” would not have been possible without the support of a significant number of individuals and organisations.

GCIL would like to thank the following organisations who identified PAs and PA employers who were willing to share their stories:



Alzheimer Scotland



Ayrshire Independent Living Network



Community Contacts, A Carr Gomm Project



Cornerstone SDS Aberdeenshire



ENeRGI, East Neuk Recovery Group Initiative



Lothian Centre for Independent Living



Personal Assistants Network Scotland with 



Shetland Islands Council



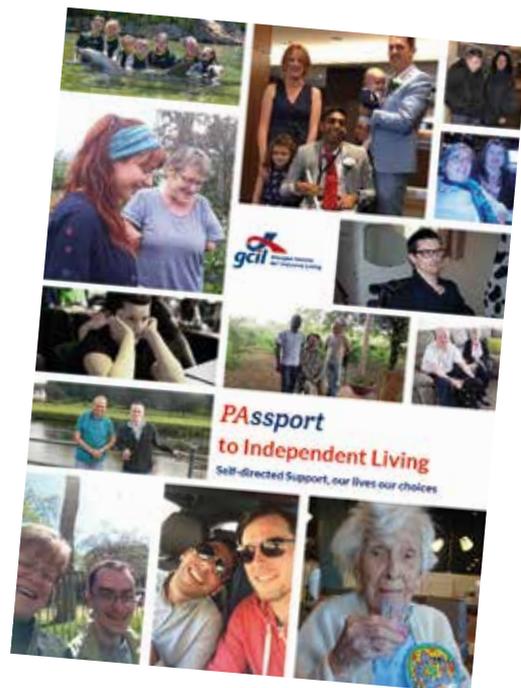
Self Directed Support, Forth Valley

In addition we would like to thank:

- Staff from the Personal Assistants Network Scotland and Shetland Islands Council for interviewing and drafting two of the stories on our behalf
- Aileen Campbell MSP, Minister for Public Health and Sport for providing the Foreword to the book
- The Scottish Social Services Council for their advice and assistance with the PA information pages
- The Scottish Government for funding the book
- Daniel and Simon at Cole AD for the book's exemplary standard of design and layout
- Leigh from GCIL's Support Team who proof read all the stories on more than one occasion!

Most of all we would like to thank the PAs, PA employers and their families, all of whom participated in this project with immense enthusiasm and commitment.

We thank them for trusting us with their stories.





Address: Glasgow Centre for Inclusive Living (GCIL),
117-127 Brook Street, Glasgow G40 3AP

Phone: 0141 550 4455

Textphone: 0141 554 6482

Fax: 0141 550 4858

Email: gci@gcil.org.uk

Website: www.gcil.org.uk

Design by: www.cole-ad.co.uk

Glasgow Centre for Inclusive Living (GCIL) is a registered Scottish Charity No: SCO2499 and
a Company Limited by Guarantee No: 161693

